

Report to the
Legislature



Washington State Traumatic Brain Injury Council

Recommendations for a Comprehensive Statewide Plan

RCW 74.31.030(3)
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Services Administration

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Traumatic Brain Injury Council
Final Report— Recommendations for a Comprehensive Statewide Plan

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Executive Summary

Traumatic Brain Injury (TBI) alters the lives of individuals living in Washington State. National estimates indicate that 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 TBI Council and the Department of Social and Health Services have collaborated to develop the following recommendations:

1. Continue with the foundational activities outlined in Chapter 74.31RCW: 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, the 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.

The comprehensive statewide plan was accomplished by volunteers who were willing to share their expertise in an effort to better the lives of Individuals living with TBI and their families. The hard work of these individuals and the ongoing funding of the TBI account by the Washington State Legislature has a significant and positive impact on individuals living with TBI.

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Eastern Washington Wheat

A TBI is caused by a bump, blow or jolt to the head or a penetrating head injury that disrupts the normal function of the brain.

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Background

In 2007 the Washington State Legislature established Chapter 74.31 RCW, also known as the Tommy Manning Act, to address 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 traumatic brain injuries.

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 traumatic brain injury account in the state treasury. Approximately three million dollars is deposited into the account each biennium. Revenue for the account is generated through a two 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 traumatic brain injury, information and referral services, and staff costs to support the council.

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A Long-term Vision of a Comprehensive Statewide TBI System

The Department and Council recognize that full system and resource development will not occur quickly. 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 service 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;
- Provide effective, supported, and coordinated program relationships for TBI survivors and their employers;
- Transitional supports for individuals with TBI and their family members; and
- Full community integration and participation for those living with TBI.



Skagit Valley Tulips

Who's at risk?

Males are about twice as likely to incur a TBI as females. The two age groups most at risk for TBI are persons between the ages of 15 to 24 and individuals over 75. In children ages 0 to 14, unintentional injury is the leading cause of death and TBI is the type of unintentional injury most often associated with death.

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Council Accomplishments in 2014

The Department and Council worked hard over this past year to accomplish foundational activities that support a multi-year strategy necessary to achieve the long-term vision for persons in Washington State impacted by TBI. As examples of foundational activities, in 2014, the Department and Council:

- Provided TBI-specific training to 45 support group facilitators both east and west of the mountains;
- Promoted the Brain Injury Alliance and Seattle BrainWorks 4th Annual Walk, Run, & Roll for Thought with 350 participants and the 1st ever Kitsap Walk, Run, & Roll with 100 attendees;
- Increased the number and geographic distribution of support groups by providing essential seed funding to create and maintain 44 support groups across the state;
- Worked with Seattle BrainWorks community-based Clubhouse to grow its membership to 82 members and be open approximately 201 days per year. Seattle Clubhouse also provided employment services such as; job development, job-site training, job supports, transition services and employment planning;
- Maintained an extensive resource database that provided 100% statewide resource management coverage. This service provides care coordination and outreach to individuals with TBI and their families who need more direct assistance to identify and access services. There have been more than 24,000 individuals and families served in 2014;
- Sponsored a successful TBI conferences in 2014 with over 400 attendees providing education and didactics for TBI survivors, family members and healthcare professionals;
- Maintained TBI website, www.tbiwashington.org, to provide education, advocacy, research, and support to TBI survivors and care givers;

The estimated economic cost of TBI in 2010, including direct and indirect medical costs, is estimated to be approximately \$76.5 billion.

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Westport, WA

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Apple Orchard

According to the Social Security Administration, vocational rehabilitation (VR) assistance to Social Security recipients with significant disabilities will result in a projected lifetime SSA recoupment rate of \$7.00 to every \$1.00 reimbursed to VR. These former SSA beneficiaries will generate \$828 million in savings to the Social Security Trust Fund and the federal treasury.

Council of State Administrators of Vocational Rehabilitation

Accomplishments continued

- The Brain Injury Alliance of Washington provided 154 days of outreach in 2012/2013 reaching 54,828 individuals and in 2013/2014 provided 143 days of outreach reaching 56,033 individuals;
- Leveraged public and private funding to increase public awareness of TBI;
- Partnered with Department of Veterans Affairs since 2010, which includes:
 - 80 Vet Corps sites that received training on TBI and were visited at least 3 times by the DVA outreach coordinator. The coordinator ensured that appropriate referrals and supports were 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 2014 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 attending trainings and receiving information on TBI and resources available throughout the state;
- Partnered with the Washington State Criminal Justice Training Center to provide Train-the-Trainer First Responder Training Program for Law Enforcement and Corrections personnel;
- Partnered with the University of Washington and Harborview to create a curriculum for First Responder Medical Personnel;
- Partnered with Department of Commerce and King County to build and open Terry Home II, a 12 bed facility in Auburn dedicated to individuals with TBI; and
- Partnered with Statewide Health Insurance Benefits Advisors (SHIBA) to provide 8 trainings for individuals with TBI, caregivers, and professionals on health insurance as it relates to TBI.

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From 2006-2010 falls were the leading cause of TBI, accounting for 40% of all TBIs in the United States.

Unintentional blunt trauma was the second leading cause of TBI, accounting for 15% of TBIs in the United States.

Motor vehicle crashes were the third overall leading cause of TBI at 14%.

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Foundations for the 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 are 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 Native.
- 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 traumatic brain injuries 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. Prior to passage of RCW 74.31.030, there had been no publically-funded program in the state whose specific role was to address the needs of this unique community.

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Washington Apples

***Prevalence of Traumatic
Brain Injury:***

The incidence rate of TBI in 2010 climbed to a rate of 823.7 per 100,000. TBI related deaths decreased slightly from 18.5 per 100,000 in 2001 to 17.1 per 100,000 in 2010.

*Center for Disease Control
and Prevention*

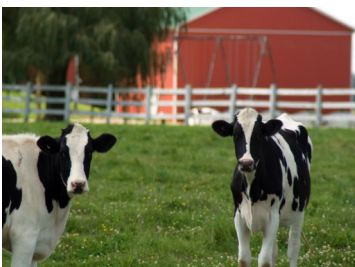
Foundations continued

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 specific needs of a broader population, including mental health, alcohol and substance abuse, developmental disabilities and long-term care. Targeted, specialized treatment and intervention provides a much more efficient use of resources and improves community integration of individuals who live with severe impacts from TBI.

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Effects of TBI can include impaired thinking or memory, movement, sensation (e.g. vision or hearing), emotional functioning (e.g. personality changes, depression). These issues not only affect individuals but can have lasting effects on families and communities.

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Washington Dairy Farming

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; and
- 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.

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Percival Landing, Olympia

Falls are the leading cause of TBI. Rates are highest for children aged 0-4 years and for adults aged 65 and older.

Falls result in the greatest number of TBI related emergency department visits and hospitalizations.

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Recommendations

To address the long-term vision for a comprehensive statewide TBI system, the Department and Council make the following recommendations to the Legislature. Full implementation of the recommendations will require TBI-specific funding, which may be a combination of federal and 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 the state and legislature about the need for TBI-specific Medicaid services;
 2. Educate the legislature 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 (e.g. Minnesota).
 - 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 practice for achieving fair employment for individuals with TBI.

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Each year, U.S. emergency departments (EDs) treat an estimated 173,285 sports- and recreation-related TBIs, including concussions, among children and adolescents, from birth to 19 years. During the last decade, ED visits for sports— and recreation-related TBIs, including concussions, among children and adolescents increased by 60%.

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Guemes Island, WA

Recommendations continued

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. Medicaid/Medicare access (lack of providers who accept low reimbursement rates);
 - b. Medically necessary services that are 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 expansion of the Division of Vocational Rehabilitation (DVR), Labor & Industries (L&I) return to work program to extend beyond the 60-day limit for individuals with TBI.
2. Create a system to improve transition from the hospital (or doctor) back to school and work after a TBI.
3. Develop partnerships with the business/employment community to include human resource, compliance, affirmative action, and disability coordinators.

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Washington Ferry

A concussion is a type of traumatic brain injury (TBI) caused by a bump, blow, or jolt to the head. Concussions can also occur from a fall or a blow to the body that causes the head and brain to move quickly back and forth. Doctors may describe a concussion as a “mild” brain injury because concussions are usually not life threatening. Even so, their effects can be serious.

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Recommendations continued

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. Development of 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.

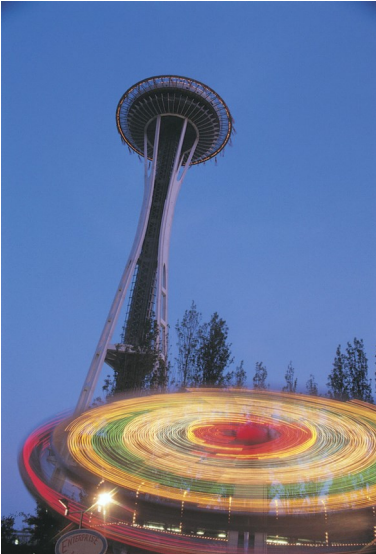
C. Housing

1. Identify key housing and service stakeholders and create and foster partnerships;
2. Implement a TBI housing plan;
3. Educate the legislature on cost savings of community-based TBI homes.

D. School – Work

1. Partner with 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.

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Seattle Space Needle

More than 300,000 service members have suffered from TBI since 2000. The injuries have been a grim signature of the wars in Iraq and Afghanistan.

The Department of Defense reported 27,187 medical diagnosis of TBI in 2013, that is a decrease from 30,615 reported diagnosis in 2012.

Defense Medical Surveillance System

Recommendations continued

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. 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. Know insurance benefits and rights;
 - b. Know Medicaid/Medicare benefits and rights.
3. School - Work
 - a. Train individuals on disclosure and requesting accommodations.

6. Develop a staffing plan for TBI Council support

Examples of this include, but are not limited to:

A. Additional Support Staffing

1. Hire one additional FTE to assume the administrative and logistical aspects of supporting council work and activities.

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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. Traumatic Brain Injury 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.



Aberdeen, WA

***Traumatic Brain
Injury
A Life Altering
Impact***

For more information go to:

www.TBIWashington.org

or

***Call the
TBI Resource Center
1-877-TBI-1766***

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Appendix B: Roster of TBI Council Members

Member	Board Position
Janet Masella	Represents the Department of Commerce Individual with TBI
Tom Gray	Represents Division of Behavioral Health and Recovery
Deborah Crawley	Executive Director of a Brain Injury Association of Washington
Lynn Siedenstrang	Rehabilitation Specialist with experience working with persons with TBI
Bruce Santy	Individual with TBI
Lynn Steckline	Family member of individual with TBI
Eric Dean	Represents the Department of Health
Betty Schwieterman	Represents Disability Rights of Washington
Jennifer Schonberger	Public member experienced in issues related to the causes of TBI
Jason Alves	Represents Washington Department of Veterans Affairs Clinical psychologist or social worker with experience working with TBI
Sheryl Lamberton	Represents the Department of Social and Health Services Family member of individual with TBI
Pete Stone	Represents the Washington National Guard
Sharon Ashman	Individual with expertise working with children with TBI
Andrew Phillips	Represents the Department of Corrections
Regina Smithrud	Member of public experienced with issues related to the causes of TBI
Taku Mineshita	Represents Children’s Administration
John Evans	Represents the Division of Vocational Rehabilitation
Mary Ellen Dawson	Represents Aging and Disability Services Administration
Tamara Cooper-Woodrich	Represents a Native American Tribe in Washington State
Jane Kucera Thompson	Neuropsychologist who has experience working with persons with TBI Represents a non-profit organization serving individuals with TBI Physician with experience working with individuals with TBI