

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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Washington State
Department of Social
& Health Services

ADSA Aging & Disability
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 135,000 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.

Centers for Disease Control and Prevention

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 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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Skagit Valley Tulips

In Washington State:

Children less than 1 year old, older adolescents and young adults 15 to 24 years old and adults 65 years old and older are most likely to be hospitalized from a TBI.

TBI is a contributing factor to a third of all injury related deaths.

WA State Department of Health

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

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Direct medical costs and indirect costs of TBI, such as lost productivity, totaled an estimated \$60 billion in the United States in 2000.

Centers for Disease Control and Prevention



Westport, WA

Council Accomplishments in 2012

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 2012, the Department and Council:

- Provided TBI-specific training to 45 support group facilitators both east and west of the mountains;
- Were recognized by the Health Resources and Services Administration as a Big Strides Award winner for its activities around 2007 TBI Legislation, TBI State Plan, TBI Clubhouse, First Responder Curriculum and public awareness work in Washington State;
- Increased the number and geographic distribution of support groups by providing essential seed funding to create and maintain 30 support groups across the state;
- Continued to assist the development of a TBI vocational skill development clubhouse located in Seattle. The TBI clubhouse membership has grown to 68 members and is open approximately 215 days per year. The clubhouse is in the process of developing an employment component for its members with the Division of Vocational Rehabilitation;
- Combined the Resource Line and Resource Management into one location which also increased the statewide resource management coverage from 54% to 100%. 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 2012;
- Sponsored a successful TBI conferences in 2012 with over 400 attendees providing education and didactics for TBI survivors, family members and healthcare professionals;
- Maintained a widely used TBI website;

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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

- Continued to distribute TBI Washington branding materials;
- Leveraged public and private funding to increase public awareness of TBI;
- Partnered with Department of Veterans Affairs since 2010, which includes:
 - 32 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;
 - 27 student and faculty/staff trainings conducted at colleges around the state with 15 of these trainings being given to students and 12 to faculty/staff;
 - 6 trainings for National Guard/Reserve members, and their families;
 - 2 TBI conferences held for Veterans and family members (one in Seattle and one in Spokane);
 - Approximately 1,204 people attending trainings and receiving information on TBI and resources available throughout the state;
- Partnered with the Washington State Criminal Justice Training Center to create a curriculum to establish a First Responder Training Program for Law Enforcement;
- 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 Terry Home II a 12 bed facility in Auburn dedicated to individuals with TBI. The completion of the facility is scheduled for January 2013; 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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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 135,000 people in Washington State live with a long-term disability as a result of TBI.

TBIs are caused by falls (35%); car crashes (17%); workplace accidents (16%); assaults (10%), and other causes (21%).

Brain Injury Association of America



San Juan Islands Great Horned Owl

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 35% of all traumatic brain injuries are caused by falls. Motor vehicle collisions account for 17%. 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 for TBI is 506 per every 100,000. This is higher than HIV/AIDS (21 per 100,000), Breast Cancer (68 per 100,000), and even all cancers combined (463 per 100,000).

“The Essential Brain Injury Guide” 2009. Brain Injury Association of America

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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TBI can cause a wide range of functional short or long-term changes affecting thinking, sensation, language, or emotions.

**Thinking (memory and reasoning)*

**Sensation (touch, taste, and smell)*

**Language (communication, expression, and understanding)*

**Emotion (depression, anxiety, personality changes, aggression, acting out, and social inappropriateness)*

Centers for Disease Control and Prevention



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 75 and older.

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

Centers for Disease Control and Prevention

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.

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.

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.

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Among all age groups, motor vehicle crashes and traffic-related incidents were the second leading cause of TBI (17.3%) and resulted in the largest percentage of TBI-related deaths (31.8%).

Centers for Disease Control and Prevention



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.
2. Identify current research on cost/benefit ratio of TBI specific evaluations and services such as neuropsychological evaluation and cognitive rehabilitation, vocational rehabilitation, and recreational therapy.

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.

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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.

Centers for Disease Control and Prevention

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 (or refine 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, private insurance, tribal health, military, L&I, and other payment systems.

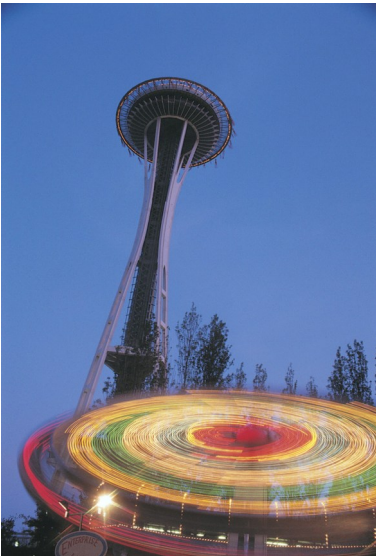
C. Housing

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, other disability organizations and the Office of the Superintendent of Public Instruction to create a program to improve school transitions for students with TBI;

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Seattle Space Needle

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.

Overall, the activities associated with the greatest number of TBI-related ED visits included bicycling, football, playground activities, basketball, and soccer.

Centers for Disease Control and Prevention

Recommendations continued

2. Partner with the Division of Vocational Rehabilitation, other disability organizations, 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 create ways 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. Fund research 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.

B. Self-advocacy

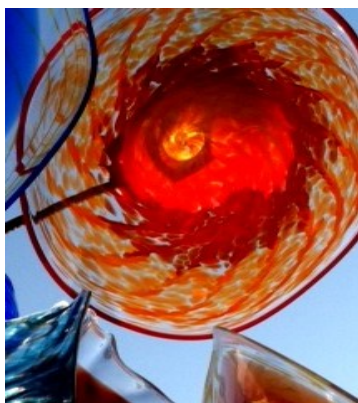
1. Awareness Education and Training
 - a. Increase scholarship opportunities for the TBI Conferences;
 - b. Provide advocacy training;
 - c. Encourage TBI survivors to tell their stories in a culturally competent manner.
2. Insurance
 - a. Know insurance benefits and rights;
 - b. Know Medicaid/Medicare benefits and rights.
3. School - Work
 - a. Train individuals on disclosure and requesting accommodations.

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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
Tommy Manning	Individual with TBI
Constance J. Miller	Represents a non-profit organization serving individuals with TBI
Kara Panek	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
Lois Thadei	Individual with TBI
Lynn Steckline	Family member of individual with TBI
Kathy Schmitt	Represents Department of Health
Betty Schwieterman	Represents Disability Rights of Washington
Andrea Okomski	Represents a public member experienced in issues related to the causes of TBI
Jason Alves	Represents Washington Department of Veterans Affairs
Jonathan W. Anderson	Clinical psychologist with experience working with persons who have sustained TBI
Sheryl Lamberton	Represents Department of Social and Health Services
Desiree Douglass	Family member of individual with TBI
Kurt Shevalier	Represents Washington National Guard
Sharon Ashman	Individual with expertise working with children with TBI
Jackie Shuey	Represents Department of Corrections
Bruce Santy	Member of public experienced with issues related to the causes of TBI
Michelle Bogart	Represents Children's Administration
John Evans	Represents 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
Janet Masella	Represents Department of Commerce