

Report to the
Legislature



Traumatic Brain Injury

Final Report - Recommendations for a Comprehensive Statewide Plan

RCW 74.31.030 (3)
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Recommendations for a Comprehensive Statewide Plan

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Recommendations for a Comprehensive Statewide Plan



Executive Summary

RCW 74.31, also known as the Tommy Manning Act, addresses issues related to Traumatic Brain Injury (TBI). The statute recognizes that current programs and services are 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 population.

This was carried out by creating the Washington Traumatic Brain Injury Strategic Partnership Advisory Council (TBI Council).

The council is made up of twenty-two members from the public and private sector and includes individuals with TBI, medical professionals serving individuals 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.

Revenues to the account are generated through a two dollar fee imposed for traffic violations governed under RCW 46.63.110 (7) (b) that must be deposited into the account.

The Office of Financial Management estimates the TBI account will generate approximately \$1.5 million annually. Monies in the account may be spent only after appropriation.

This report from the Department of Social and Health Services (DSHS) is submitted to meet the following requirements in RCW 74.31.030 (3):

(3) *By December 1, 2007, the department shall provide a preliminary report to the legislature and the governor, and shall provide a final report by December 1, 2008, containing recommendations for a comprehensive statewide plan to address the needs of individuals with traumatic brain injuries, including the use of public-private partnerships and a public awareness campaign. The comprehensive plan should be created in collaboration with the council and should consider the following:*

- a. Building provider capacity and provider training;
- b. Improving the coordination of services;
- c. The feasibility of establishing agreements with private sector agencies to develop services for individuals with traumatic brain injuries; and
- d. Other areas the council deems appropriate.

To achieve the long-term vision requires a multi-year approach to infrastructure and service design. The goal of the department and the council is for Washington to be a state that:

- a. Is aware of the life altering impact of traumatic brain injury;
- b. Understands and applies prevention strategies;
- c. Reduces the disparate impact of TBI on populations where it is most prevalent;
- d. Is educated about how to identify and deliver culturally competent services across the life span to survivors and their families; and
- e. Has TBI specific rehabilitation and long-term services and supports available across the state.

Recommendations for a Comprehensive Statewide Plan

In creating these recommendations, the department worked in collaboration with the TBI Council to identify gaps and needs and create a plan that reflects the expertise of survivors, family members, providers, and caregivers, representing private and public sectors. The following recommendations are offered to the Legislature as a product of that vision and collaboration. Full implementation of the recommendations will eventually require TBI-specific funding, which may include a combination of federal and state funding and private partnerships.

1. **Continue the foundational activities** delineated in RCW 74.31: Information & Referral, Public Awareness, TBI related Support Groups, and activities of the TBI council.
2. **Enhance the foundational activities delineated** in number 1 above to comprehensively address the needs of individuals impacted by TBI by providing on-going, flexible and adequate authority for use of the TBI account for this purpose.
3. **Create and improve access, coordination, and availability of essential services** for persons impacted by TBI by broadening authorized uses of the TBI account.
4. **Build upon existing data, screening, and reporting systems** to better understand the prevalence and impact of TBI in Washington State by authorizing the use of the TBI account for this purpose.
5. **Revise current statute to:**
 - a. Broaden the array of services and supports offered;
 - b. Increase revenues and flexibility by giving the council authority to fundraise, write grants, and create public/private partnerships;
 - c. Assure adequate staffing to continue current activities and recommended enhancements.

Foundation for the Recommendations

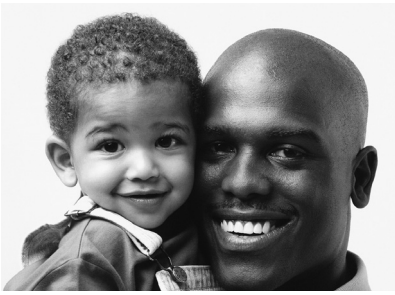
In making these recommendations for a comprehensive TBI plan, the department and the TBI Council acknowledge and consider the following underlying foundation:

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 occurs when a sudden trauma causes damage to the brain. According to the Federal Centers for Disease Control (CDC), approximately 1.4 million people sustain a traumatic brain injury each year in the



“It’s an incident that changes your life and family forever... I sometimes hardly recognize who I am.”

*—Allen House
age 62, sustained a TBI in 2004*



TBI hospitalization rates are highest among African Americans and American Indians/Alaska Natives (AI/AN). African Americans have the highest death rate from TBI (CDC).

Most traumatic brain injuries are preventable and early intervention increases long-term success for individuals and their families and community supports.

Conservative estimates are that 117,000 people in Washington State live with a long-term disability as a result of TBI (CDC).

United States from a variety of causes, including falls, motor vehicle collisions, being struck by an object, or as a result of a violent crime. TBI impacts all age groups, cultures and races. In Washington State every year, an estimated 25,763 individuals are treated in an emergency room for TBI related injuries; 4,147 individuals are hospitalized as a result of TBI; and 1,724 sustain long-term disabilities. Conservative estimates are that 117,000 people in Washington State live with a long-term disability as a result of TBI.

Some population groups are disproportionately impacted by TBI. Planning, coordination, and service delivery must emphasize culturally competent, ethnic and cultural diversity, and outreach to underserved populations. TBI hospitalization rates are highest among African Americans and American Indians/Alaska Natives (AI/AN). African Americans have the highest death rate from TBI. Currently due to international conflicts, veterans are also disproportionately impacted. The statewide TBI plan must address the needs of ethnically and culturally diverse populations. Services should have a culturally competent basis, including outreach to underserved groups.

Most traumatic brain injuries are preventable and early intervention increases long-term success for individuals and their families and community supports. TBI planning must address prevention and early intervention. According to the CDC, about 50% of all traumatic brain injuries are caused by motor vehicle crashes. Falls account for 21% and are the leading causes of traumatic brain injury in older adults. Assaults and violence account for 12% of traumatic brain injuries, and sports and recreation account for 10%. Potentially, any of these causes of TBI can in some measure be prevented. Also, long-term disability related to any of these causes of TBI can be greatly reduced by early and appropriate intervention. TBI planning should continue and expand public awareness, information & referral, and timely intervention and service activities.

TBI planning must address services and interventions that are specific to the needs of survivors and families. Currently people 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. TBI impacts schools at all levels and all sectors of the judicial system, from juvenile rehabilitation to adult prison and parole systems. Prior to the passage of RCW 74.31.030, there has been no publically funded program in the state whose sole purpose is to address the specialized needs related to TBI, even though virtually all human service and judicial programs are impacted. Providers in generic human service programs, schools, and the judicial system are not trained to recognize TBI, and services are not tailored to the unique needs of the population. Veterans may require assistance to bridge Federal and State services to meet their needs. Targeted, specialized treatment and intervention would provide a much more efficient use of resources and improve community integration of individuals who live with severe impacts from TBI.

A long-term vision of a comprehensive, statewide TBI system

The department and council recognize that full system and resource development will not occur over a single biennium. A multi-year strategy is necessary to achieve the long-term vision for persons in Washington State impacted by TBI. The recommendations to the Legislature in this report address immediate and urgent needs for prevention, public awareness activities, and a set of essential, 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
- Person centered planning for survivors
- Full community integration and participation for survivors

Process used to develop the recommendations

The Legislature directed the TBI Council to collaborate with DSHS in developing recommendations that will create a comprehensive system of care to help meet the needs of individuals impacted by TBI. The process employed to develop the recommendations followed a collaborative approach between DSHS and the TBI Council.

The TBI council created Technical Advisory Committees (TAC). Each committee focused on specific gaps and specialty areas to ensure the recommendations reflect the expertise of survivors, family members, providers, and caregivers, representing private and public sectors. TAC focus areas were:

- Improving Coordination and Capacity of Services and Providers;
- Addressing the Needs of Children and Youth;
- Increasing Services and Supports;
- Increasing Public Awareness;
- Increasing Ability to Identify and Understand the Prevalence and Impact of TBI;
- Supporting Veterans with TBI; and
- Developing Partnerships and Funding.

The TAC's each produced recommendations which were presented to the full council. The council came to consensus on five broad recommendations as the foundation for immediate system development, as well as long range planning.



“It sucks...you can’t do a lot of things you used to be able to do... like run, think, talk, walk. I had a lot going for me before I got injured, running competitively, and an “A” student, I had lots of friends. I was much more independent. Now I have to start all over again from age 14.... “

Joe Robinson— age 19



“If I could create one service or program for TBI survivors it would be... TBI Clubhouse is a place for survivors to be empowered in their new lives. To take charge of their lives and grow into their new selves.”
—Andrea Okomski

Recommendations

Full implementation of the recommendations will eventually require TBI-specific funding, which may include a combination of federal and state funding and private partnerships. To address immediate and urgent development needs and to support this long range vision of a comprehensive system, the department and council make the following recommendations to the Legislature:

1. Continue the foundational activities delineated in RCW 74.31:

- a. Information and Referral;
- b. Public Awareness;
- c. Support for TBI related support groups; and
- d. TBI Council activities and staff/Council FTE.

2. Broaden budget authority to include access, coordination, and availability of essential services.

Examples of this include, but are not limited to:

- a. Establishing a TBI Waiver that includes services targeted to the population, such as cognitive retraining and tailored vocational assistance;
- b. Increasing access to neuropsychological evaluations and other clinical assessments and therapies; and
- c. Funding a comprehensive feasibility study related to housing needs and services.

3. Establish ongoing, flexible and adequate budget authority to enhance and make comprehensive the foundational activities delineated in RCW 74.31.

Examples of this include, but are not limited to:

- a. Developing and implementing training curricula for caregivers, first responders, medical professionals, state agencies, the criminal justice system, and school personnel;
- b. Establishing an ongoing Public Awareness Campaign responsive to current needs;
- c. Establishing coordinated links between TBI Information and Referral services and services provided by tribal governments, Urban Indian programs, programs serving veterans, and programs serving children and youth.

4. Broaden budget authority to build upon existing data, screening, and reporting systems to better understand the prevalence and impact of TBI in Washington State.

Examples of this include, but are not limited to:

- a. Developing screening tools for institutional settings such as schools, correctional facilities, state hospitals; and
- b. Conducting a feasibility study for a statewide TBI registry.

5. Revise current statute to:

- a. Broaden authority of programs and services offered;
- b. Increase revenues by creating the authority for the council to fundraise, write grants, and create public/private partnerships; and
- c. Assure adequate staffing to continue current activities and recommended enhancements.

Conclusion

Traumatic brain injury can instantly and forever alter the life of the person injured, and often has a devastating, long-term impact on his or her family and community. Until recently, no cohesive support system existed in Washington State to specifically address the unique needs of people who have sustained a TBI or their families. The Legislature took an important step towards addressing these issues by establishing the TBI Council and the TBI account.

The recommendations in this report represent the work of volunteers from across the state who were willing to donate time, expertise, and effort because they understand the devastating impacts of TBI and the real potential in Washington to reduce the prevalence of TBI and significantly improve the lives of those impacted by TBI.

Appendices

Appendix A: Roster of TBI Council Members

Appendix B: Accomplishments/Activities in 2008



“... You have lost the person you loved, and must learn to grieve the loss without feeling like a traitor to your survivor. There is a loss of expectations, plans, security, and the burden is real.”

—Andrea Okomski

Appendix A: Roster of TBI Council

Name of Member	Board Position
Tommy Manning	Individual with TBI
Constance J. Miller	Represents a non-profit organization serving individuals with TBI
Kara M. Panek	Represents Mental Health Division
Gene van den Bosch	Executive Director of a Brain Injury Association
Peter C. Esselman	Rehabilitation Specialist with experience working with persons with TBI
Traci Adair	Represents Aging and Disability Services
Valerie Wootton	Family member of individual with TBI
Kathy Schmitt	Represents Department of Health
Mark Stroh	Executive Director of Disability Rights of Washington
Andrea Okomski	Represents a public member experienced in issues related to the causes of TBI
Marty Oroshiba	Represents an organization serving Veterans
Marylouise E. Jones	Clinical psychologist with experience working with persons who have sustained TBI
Bea-Alise Rector	Represents Department of Social and Health Services
Janice Navarre	Represents Community, Trade and Economic Development
Carol E. Munsey	Represents Washington National Guard
Laura Dahmer-White	Neuropsychologist with experience working with persons with TBI
Penny Condoll	Individual with TBI
Arlene West-House	Family member of individual with TBI
Barbara Curtis	Represents Department of Corrections
Maralisse Hood Quan	Member of public experienced with issues related to the causes of TBI
Michelle Bogart	Represents Children's Administration
Lynnae Ruttledge	Represents Division of Vocational Rehabilitation

Appendix B: Accomplishments/Activities in 2008

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. Those foundational activities include:

1. Establishing a Statewide Information and Referral Service

DSHS partnered with the TBI Council to develop criteria and expectations for a Request for Proposal process. DSHS contracted with Brain Injury Association of Washington in December of 2007, establishing the service by:

- a. Creating the statewide toll-free TBI Help Line (1-877-TBI-1766);
- b. Providing ongoing updates to the list of TBI specific resources available to consumers;
- c. Providing information and referrals and follow-up to consumers who request services; and
- d. Establishing reporting mechanisms.

2. Funding TBI-specific support groups throughout the state

Twenty-three unique TBI-specific support groups received funding statewide.

3. Increasing Public Awareness of TBI

- a. Launching a statewide Public Awareness Campaign including:
 - Producing Go-Mobile ads,
 - Creating and distributing TBI awareness brochures,
 - Utilizing print and news media;
- b. Governor Proclaiming March as “TBI Awareness Month”; and
- c. Creating the Washington TBI Website: www.TBIWashington.org.

4. Initiating a Pilot Resource Coordination Project

The department partnered with the TBI Council to develop criteria and expectations for a Request for Proposal process to establish a Pilot Resource Coordination project.

- a. Establishing a comprehensive and coordinated approach linking individuals with TBI to the appropriate resources; and
- b. Providing education to the individual with a brain injury and principal support/caregiver. Education includes information on:
 - Brain Injury;
 - Personal advocacy; and
 - Partnership development.

5. Developing a long-term plan for the TBI Strategic Partnership Council by:

- a. Establishing by-laws, policies and group standards;
- b. Creating Technical Advisory Committees to ensure recommendations reflect the expertise of private and public sectors;
- c. Collaboratively prioritizing the recommendations of the Technical Advisory committees; and
- d. Completing the final report with recommendations for a comprehensive statewide plan.



“Dylan has needed so much care, that for many years I had no time to take care of myself, ...I was constantly running to appointments and spending hours keeping him safe holding him when his behavior was out of control ...people like myself who take care of a loved one who has been brain injured. It is a full time job”

—Brandi Matros



Traumatic Brain Injury
A Life Altering Impact

For more information go to:

www.TBIWashington.org

Or

Call the TBI Help line

1-877-TBI-1766

(1-877-824-1766)