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Chair:	Senator Sara Gelser
Vice Chair:	Senator Art Robinson
Member:	Senator Floyd Prozanski
Member:	Senator Suzanne Weber

Thank you for the opportunity to testify on behalf of SB 420.

I have had a long career in providing health and social services In Oregon. I spent nearly 30 years at Central City Concern developing and managing a system of services including primary care, addiction treatment, special needs housing, and employment counseling. After retiring from CCC I served as Director of Addiction and Mental Health Services for the State of Oregon from 2008-2012. After retirement from this last position I was appointed to co-chair the Governor's Task Force on Traumatic Brain Injury along with Cameron Smith, then Director of the Oregon Department of Veterans' Affairs.

My work on the Governor's Task Force gave me a deeper understanding of the many issues connected to brain injury. This understanding, combined with my previous experience in providing needed health, housing, and rehabilitation services, has resulted in a strong and lasting commitment to seek to improve the system of care for people with brain injury. SB 420 will make an important improvement by helping people who suffer the effects of brain injury and their families get the <u>right services</u> at the <u>right time</u> – this essential safety-net is missing today.

I would like you to imagine getting a call that your wife, husband, partner, or child has been in an auto accident, has serious injuries, and is in the Emergency Department at your local hospital. As you drop everything you are doing and head to the E.D. you are imagining the worst. Your loved one has been admitted to the hospital for care for visible and internal injuries, including head trauma. The news that your loved one has a head injury that is moderate to severe raises many short- and long-term possibilities. The symptoms and the severity of the brain injury can vary, and short-term effects will be addressed in the hospital, but the longer term effects may require a variety of rehabilitation and support services. The average person with a brain injury of moderate to severe may need at least a dozen distinct services.

The person with a brain injury is in no position to navigate the complexity of services, so the burden falls on family or friends to negotiate insurance claims, determine eligibility for various rehabilitation services, manage waiting lists for services, identify transportation to connect to services, finding services close to home or locate housing with support services, and deal with employment and educational institutions. Just managing insurance claims amounts to a near fulltime job even assisted with spreadsheets and a computer, which many people with brain injury can no longer use.

During our meetings with people with brain injuries and family care givers, the Governor's Task Force heard over and over how difficult it is to navigate the various systems that swamp their lives. Family members lose jobs and income, housing, and communication with relatives and friends when they have to be care givers.

Now go one step further and imagine what happens to individuals who don't have supportive and stable relationships with others. How terrifying this must be to the victims of brain injury. At best, it is trial and error just to meet basic needs, let alone traverse the services that might be present in the community. It is truly relying on the kindness of strangers.

Although people in the homeless population, victims of domestic violence, and individuals in jails and prisons may have little in common, they do share a high incidence of brain injury.

S.B. 420 is a step toward providing the support to the brain injured and their families. On a larger scale, this type of support and direction is essential to tie together a hodge-podge of siloed and disconnected services that are required to deal effectively deal with brain injury.

ADDENDUM

The May, 2018 Governor's Task Force on Brain Injury and copy of the first 9 pages, including a list of Task Force members, table of contents, and executive summary.

Senate Bill 420 is based on Recommendation 4 of the Report which calls for the establishment of a system of care coordinators to assist people with brain injury and family members to navigate the complex array of services needed rehabilitation and support services. Governor's Task Force on Traumatic Brain Injury Recommendation #4: "Establish a statewide program of care coordinators specifically trained to serve individuals with brain injury and their families members and assist them in navigating resource services, supports and benefits, and maintain regular contact."

GOVERNOR'S TASK FORCE ON TRAUMATIC BRAIN INJURY: EXECUTIVE ORDER NO. 13-02, 2013

REPORT ON FINDINGS AND RECOMMENDATIONS

August 2016 - Updated May 2018

GTF MEMBERS AND EXPERT CONSULTANTS

GTF Co-Chairs:

- Richard Harris – Public member; Former Director of Oregon's Dept. of Addictions and Mental Health & Executive Director of Central City Concern
- Cameron Smith, Director – Oregon Dept. of Veterans Affairs

GTF Members:

- Bryan Andresen, MD – Physiatrist – Rehabilitation Medicine Associates, Eugene; Medical Director – Community Rehabilitation Services of Oregon & Oregon Rehabilitation Center, Sacred Heart Medical Center
- Curtis Brown – Survivor of traumatic brain injury
- James Chesnutt, MD – Sports Medicine, Oregon Health Sciences University; Co-Director OHSU TBI Initiative; OSAA Sports Medicine Advisory Committee
- Sarah Drinkwater, PhD – Assistant Superintendent, Office of Learning/Student Services-Oregon Dept. of Education
- Adrienne Greene – MPA, Injury & Violence Prevention Program Grants Manager, Oregon Public Health Division – Oregon Health Authority
- Cathy Hurowitz, MS ED – Parent of a child with traumatic brain injury; Educator
- Bob Joondeph, JD – Executive Director of Disability Rights Oregon
- Ginny Real – Spouse of a survivor with acquired brain injury
- Daryl Ruthven, MD – Chief of Psychiatry, Oregon Dept. of Corrections
- Sherry Stock, ED, MS, CBIST – Executive Director, Brain Injury Alliance of Oregon
- Jane-Ellen Weidanz – Aging and People with Disabilities, Oregon Dept. of Human Services
- Fern Wilgus – Survivor acquired brain injury; Veteran; Advocate

Expert consultants

- David Kracke, JD, Attorney – Nichols Law Group, Portland
- Ann Glang, PhD – Director, Center on Brain Injury Research and Training, University of Oregon
- Melissa McCart, PhD – Director, Oregon TBI Teams
- Carolyn Saraceno – Survivor of brain injury; Research Assistant, Center on Brain Injury Research and Training, University of Oregon

Report Production: Staff at the Center on Brain Injury Research and Training, University of Oregon, prepared this report in consultation with GTF members and consultants. We would like to extend a special thanks to Karen Menne for her work coordinating the GTF on TBI.

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GOVERNOR'S TASK FORCE ON TRAUMATIC BRAIN INJURY

EXECUTIVE SUMMARY

PURPOSE

The purpose of the Governor's Task Force (GTF) on Traumatic Brain Injury (TBI) (Executive Order No. 13-02, 2013) was to (1) identify the gaps in Oregon's public and private sector system of services for individuals with brain injury; and (2) make policy recommendations to address those gaps.

BACKGROUND

Traumatic brain injury (TBI) is a sudden bump, jolt, or blow to the head or penetrating injury that disrupts the normal function of the brain. TBI is a significant national public health problem, affecting people of all ages and cultural backgrounds. Non-traumatic causes of brain injury include stroke, heart attack, anoxia, toxicity, tumors, encephalitis, and meningitis. Individuals with brain injury experience a complex blend of physical, sensory, cognitive, behavioral, and psychological challenges that defy easy categorization, making it difficult for them to access coordinated, culturally sensitive services and staff trained to serve their unique needs on an ongoing basis.

TASK FORCE FINDINGS

For this report, stakeholders with brain injury, their families, and service providers identified areas of strengths in Oregon's brain injury-related services and programs. These include support and advocacy groups, legislation, and TBI prevention efforts. Several gaps were identified.

GAPS IN SERVICES AND RELATED CHALLENGES

1. Lack of culturally sensitive services and resources
2. Lack of adequate education and training about brain injury, including the lack of a standardized screening protocol
3. Complex, siloed service networks making it difficult to access services
4. Family members serving as unpaid caregivers
5. Financial hardships and difficulty accessing federal and state benefits
6. Difficulties dealing with private insurance and accessing appropriate treatment options
7. Lack of affordable, appropriate housing
8. Challenges with co-occurring mental health disorders and addictions
9. Lack of adequate vocational training and employment opportunities
10. Lack of TBI identification and appropriate supports in the schools
11. Challenges identifying and managing TBI in the corrections system

STATEWIDE RECOMMENDATIONS TO ADDRESS GAPS IN CARE

Recommendation 1. Increase **educational outreach** to:

- train professionals, administrators, and service providers across multiple fields and organizations, including medicine, rehabilitation, mental health, social work, education, and state agencies;
- promote a standardized approach to (a) screening for TBI in the medical and allied health communities and (b) identifying the need for services among individuals with brain injury across state agencies and private sector entities; and
- support community partners, emphasizing brain injury resource education and coordination of services.

Recommendation 2. Establish a **TBI Clinical Registry** based on the current TBI Data Registry that would:

- provide a history of traumatic events;
- be available for clinical purposes, including TBI screening/assessment to determine eligibility for services, treatment planning, and case management;
- be accessible, with patient consent, to designated medical, educational, and services providers; and
- establish a universally understood definition of TBI.

Recommendation 3. Establish a centralized, comprehensive, culturally sensitive, easy-to-navigate **statewide map of brain injury services and supports** (web-based and hard copy), framed around key stakeholder questions/needs and including a technical assistance program to support its use.

Recommendation 4. Establish a statewide program of **care coordinators** specifically trained to serve individuals with brain injury and their family members across cultures and age ranges, who will assist them in navigating resources, services, supports, and benefits and maintain regular contact.

Recommendation 5: Develop an **equitable system of care and services** that provides medical care, vocational training, affordable/appropriate housing options, and an array of long-term services and supports for those with severe injuries and behavior challenges and those with co-occurring mental health or addiction issues. This recommendation would meet the requirements of federal Home and Community Based Services standards and the ADA.

Recommendation 6. Develop and implement a **communication system** to improve coordination across agencies, including the medical community, social services, and schools. This coordination should support individuals transitioning between systems, especially children as they age out of the educational system and juvenile social service programs.

Recommendation 7. Establish **sustainable, equitable funding mechanisms** to support implementation of recommendations 1–6. These could include:

- establishing a TBI-specific program (e.g., targeted Medicaid funds to support community-based living);
- ensuring family caregivers receive compensation to help replace income lost while they cared for a family member with a brain injury;
- ensuring the same level of financial support and service, regardless of age of injury or severity of injury; and
- addressing the issue of insurance negotiated in bad faith regarding payment for necessary medical care and covered living expenses.

Program Note: Some stakeholders suggested that Oregon apply for and administer a TBI Waiver. TBI Waivers usually refer to a Medicaid funding authority (i.e., 1915(c)) that allows states to develop TBI specific services and supports. Oregon currently uses the 1915(k) Community First Choice funding authority. The 1915(k) allows Oregon the same flexibility as a 1915(c) provides. State agency representatives believe the state has the opportunity to develop a more comprehensive service array that takes advantage of all of the services and flexibility allowed in the 1915(k). The 1915(k) also provides more federal revenues than a 1915(c), stretching state resources further. See Appendix D, Department of Human Services, pg. 55.

Recommendation 8. Establish a high-level staff position in the Office of the Governor named the **Governor's Brain Injury (BI) Coordinator and Advocate**. This individual will (a) report to the governor and (b) be charged with implementing the recommendations of the GTF to ensure the State of Oregon improves its primary and secondary prevention of TBI and care for people living with brain injury. Funding for the position and support staff will be provided and shared by the Oregon Health Authority and the Oregon Departments of Veterans' Affairs, Education, Human Services, and Corrections. The Coordinator will work with state agency staff and private sector community partners to develop and improve the delivery of preventive actions and improve the coordination of effective care. Where legislation or administrative rule changes are needed, the Coordinator will advocate for the necessary changes. The BI Coordinator-Advocate will also work closely with the community of people with brain injury. The position will be limited to a five-year tenure.

(NOTE: Agency-specific recommendations are described in Appendix D, pg. 54 of this report.)