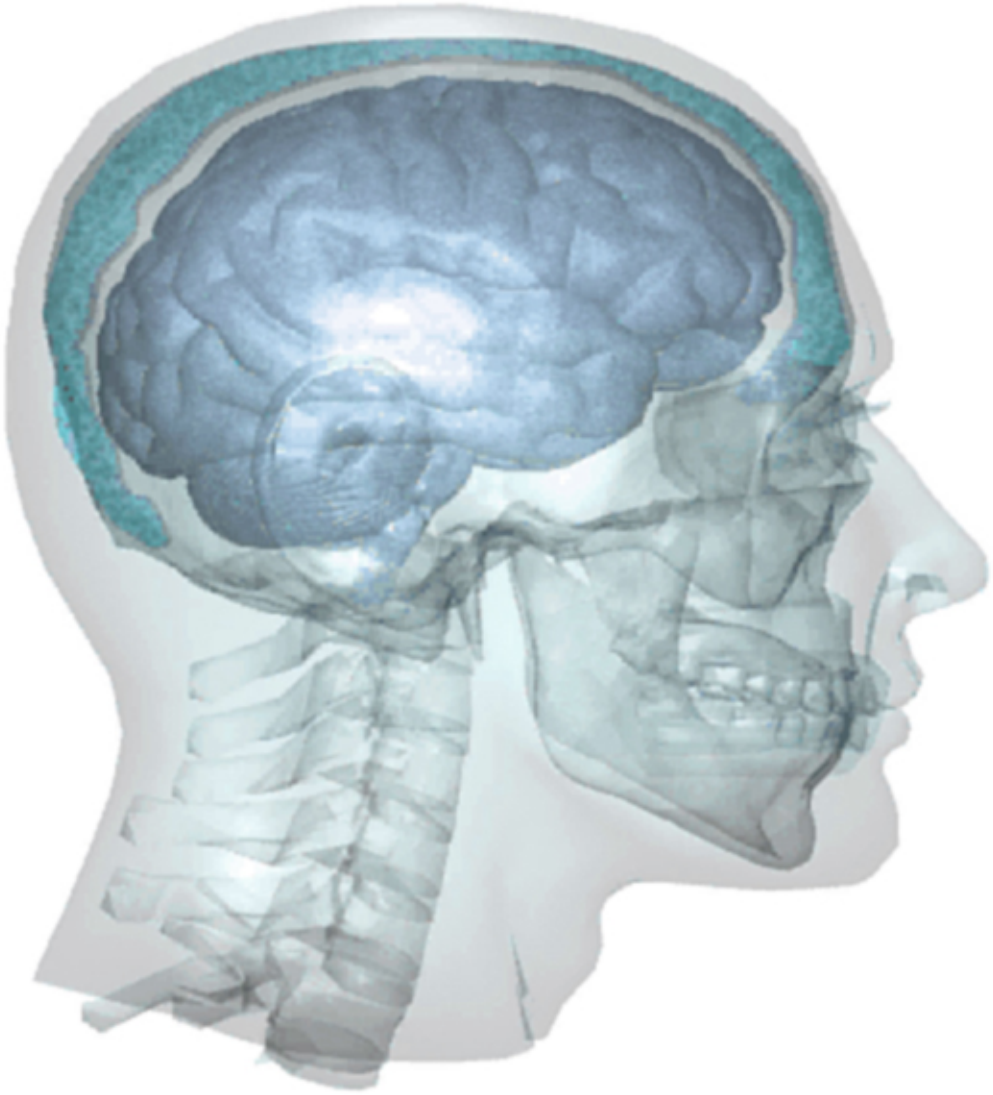

GOVERNOR'S TASK FORCE ON TRAUMATIC BRAIN INJURY: EXECUTIVE ORDER NO. 13-02, 2013

REPORT ON FINDINGS AND RECOMMENDATIONS

August 2016 - Updated May 2018

GTF MEMBERS AND EXPERT CONSULTANTS

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- 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

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- 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
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- 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
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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.

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.)