

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

**REPORT ON FINDINGS AND
RECOMMENDATIONS**

August 2016

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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-private sector system of services for individuals with brain injury; and (2) make policy recommendations to address these gaps.

BACKGROUND

Traumatic brain injury (TBI) is a sudden bump, jolt or blow to the head or penetrating injury disrupting 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/or psychological challenges that defy easy categorization, making it difficult 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 services providers described several helpful resources and programs including support and advocacy groups as well as laws to prevent TBI.

GAPS IN SERVICES AND RELATED CHALLENGES

1. Lack of culturally sensitive services and resources
 2. Lack of adequate education and training about brain injury - Lack of standardized screening protocol
 3. Lack of a “road map” for accessing services and ongoing case management
 4. Family members serving as unpaid caregivers
 5. Financial hardships; 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/or addictions
 9. Lack of adequate vocational training and employment opportunities
 10. Lack of TBI identification and appropriate supports in the schools
 11. Challenges with identification and management of TBI in the corrections system
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STATEWIDE RECOMMENDATIONS TO ADDRESS THESE GAPS

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 community 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, eligibility for service benefits, treatment planning, and case management;
- be accessible, with patient consent, to designated medical, educational and service providers; and
- establish a universally understood definition of TBI.

Recommendation 3. Establish a centralized, comprehensive, culturally sensitive, easy-to-navigate **“road map”** of brain injury services and resources (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, assisting them in navigating resources, services, supports and benefits with regular follow-ups.

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 more severe injuries and behavior challenges and those with co-occurring mental health and/or addiction issues. This meets the requirements of federal Home and Community Based Services standards and the ADA.

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

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

- establishing a TBI-specific program (i.e., targeted Medicaid funds to support community-based living);
- ensuring family caregivers receive compensation to help with loss of income when caring for their family member with a brain injury;
- ensuring the same level of financial support and service, regardless of age of injury and severity of injury; and
- addressing the issue of insurance bad faith regarding payment of 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 allow 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 opportunity is 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 additional federal revenues compared to a 1915(c) stretching state resources further. See Appendix D, Department of Human Services, pg. 55.

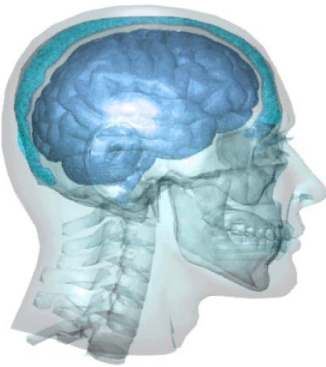
Recommendation 8. Establish a high-level staff position in the Office of the Governor. This position will be named the **Governor's Brain Injury (BI) Coordinator and Advocate**. This individual will (a) report to the governor and (b) be charged with implementing the recommendations of the GTF to ensure the State of Oregon improves the 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 prevention actions and improve the coordination of effective delivery of care. In the case where legislation or administrative rule change is 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. 53 of the report.)

GOVERNOR'S TASK FORCE ON TRAUMATIC BRAIN INJURY

REPORT ON FINDINGS AND RECOMMENDATIONS

OUR VISION



The vision of the Governor's Task Force on TBI is that Oregon will establish and maintain a comprehensive, public-private system of coordinated care and supports for individuals with brain injury of all ages, severity levels, and backgrounds that facilitates maximum community engagement and quality of life.

I. BACKGROUND

Traumatic brain injury (TBI) is a sudden bump, jolt or blow to the head or penetrating injury disrupting the normal function of the brain.¹ TBI is a significant national public health problem.

- Each year, an estimated 1.7 million people in the United States sustain TBIs through falls, unintentional blunt trauma, motor vehicle collisions, firearm incidents, and sports activities.^{1,2}
- Of particular concern is violence-related TBI, with at least 156,000 deaths, hospitalizations, and emergency department visits in the U.S. each year due to TBI-related assaults,³ including domestic partner violence.³

- Even though most TBIs are classified as “mild”, they can still have an extremely serious impact on everyday life; a concussion is a mild TBI.¹

Non-traumatic causes of brain injury include stroke, heart attack, anoxia, toxicity, tumors, encephalitis, and meningitis.

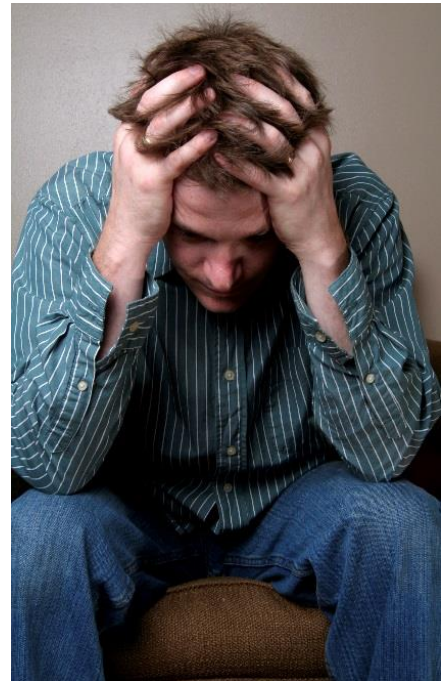
- Sports-related concussions have gained increased public attention in recent years, accounting for up to 5% of all emergency department visits.^{4,5} Chronic traumatic encephalopathy (CTE) is a degenerative condition and is potentially associated with repeated brain injuries,⁶ including repeated sports-related concussions.⁷
- Estimates suggest that almost 125,000 of those injured each year will experience permanent disability resulting from significant changes in social, behavioral, physical, and cognitive functioning.⁸
- The CDC estimates that the economic costs of TBIs in 2010 were \$76.5 billion, including \$11.5 billion in direct medical costs and \$64.8 billion in indirect costs (e.g., lost wages, lost productivity, and nonmedical expenditures).^{9,10}
- TBI is also the signature injury of the Afghanistan and Iraq wars.¹¹ Of the blast-exposed patients treated at Walter Reed Army Medical Center, 59% were diagnosed with TBI.¹²
- Up to 53% of individuals who are homeless have sustained a TBI.¹³ The rate of TBI in the general population is 8.5%.¹⁴

Added to these numbers are those who experience brain injury due to other causes. *Acquired brain injury* is the term used to describe damage to the brain resulting from traumatic causes, (i.e., TBI), and non-traumatic causes, including stroke, heart attack, anoxia, toxicity, tumors, encephalitis, and meningitis. The focus of this GTF was on TBI; however, individuals with brain injury, regardless

of the cause, have similar needs. Recommendations in this report will therefore have broad applicability to individuals with all types of brain injury.

A. TBI IN OREGON

We estimate that thousands of Oregonians are now living with the long-term consequences of TBI, and that thousands more have sustained TBIs for which they were not hospitalized, yet which caused life-altering changes (e.g., job loss), often due to a missed diagnosis or misdiagnosis.



- From 2004 to 2014, an annual average of 785 Oregonians died from TBI and 2800 were hospitalized.¹⁵
- There are currently 266 students with TBI on Individual Education Plans¹⁶ and approximately 5,000 students who need some other type of formalized support, including 504 plans.^A
- In Oregon, there are 1,071 veterans with combat-related TBIs from the wars in Iraq and Afghanistan. Of those, 85% have mild TBI, 7% moderate TBI, and 3% severe TBI. Veterans with non-combat related TBIs or those who served in other wars are not tracked.¹⁷
- State agency personnel reports indicate over 1,700 veterans, many of whom may have a brain injury, have received services through Oregon's Office of Aging and People with Disabilities.¹⁸
- The exact number of individuals with TBI in the Oregon corrections system is unknown because of challenges with self-reporting TBI and/or multiple co-occurring diagnoses (e.g., mental illness). Approximately 4,400 individuals - 30% of the total number of individuals currently incarcerated in Oregon - are suspected of having a TBI.^{19,20}

The numbers tell only part of the story. Individuals with brain injury often experience a complex blend of physical, sensory, cognitive, behavioral and/or psychological challenges that defy easy categorization, therefore precluding access to coordinated, culturally sensitive services and staff trained to serve their unique needs on an ongoing basis. In children, the challenges can be even more complex, as the effects of brain injury often emerge over time, when expectations for independence at school and home increase.

To illustrate:

Mother of a child with a TBI: *Our 9-year-old son survived being hit by a car. But is a new person. We are grieving for the child we lost while trying to learn to love this new child.*

Mother of a teenager with a TBI: *Finding appropriate supports following my child's hospitalization was extremely difficult. That was a very different challenge (than the TBI itself). I was lost and lonely never having had the experience of living with someone with a TBI.*

Mother of adult son with TBI: *After his brain injury, our son was so heavily medicated, resulting in such severe behavioral issues, that he was the only patient in the psych unit at the hospital for nearly ten months costing OHP over \$370,000 a month until the state finally agreed on a placement.*

Adult survivor of TBI: *After a brain injury you have an identity trauma. We slip through the cracks. Many in the medical community don't know about brain injury. What resources are available? I have no idea....that's a marketing and accessibility failure on the government's part. Ideally, we'd have a case manager assigned to us.*

Service provider: *We need beds. I get case managers crying to me. We need a place to graduate folks. We need people who are trained in the TBI population—We need to gear ourselves to assessments, that these are geared to what a TBI looks like.*

Family member: *It seems like we always have to FIGHT for anything we need.*

Adult survivor of TBI and her son (and caregiver): *Quality of life for people with TBI is horrible. We all need to work on this. We need halfway houses. We need to put people to work. Everybody has a skill. Hope is what we need.*

The above comments illuminate the complexity of life with a brain injury and the gaps in federal, state, and private sector services. These gaps can lead to serious consequences in the health and economic well-being of these individuals and their families. Resource allocation challenges amplify this situation. For those hospitalized following brain injury, the profusion of healthcare dollars spent during the acute stage of hospitalization to achieve medical stability is rarely matched during the post-acute/chronic stage when rehabilitation services and supports are of critical importance to achieving maximum quality of life.

To further understand and recommend policy-based solutions to address these gaps, Governor John Kitzhaber signed an Executive Order in 2013 to convene the Governor's Task Force (GTF) on TBI with the purpose of gathering information to inform policy recommendations within and across state agencies and private sector entities (see Appendix A, pg. 42).

The 14-member GTF was comprised of representatives from various stakeholder groups, including individuals with TBI, family members, medical professionals, advocacy groups, Disability Rights Oregon and state agency representatives from the departments of Corrections (DOC), Education (ODE), Human Services (DHS), Veterans Affairs (ODVA), and the Oregon Health Authority (OHA).

Individuals with specific expertise were also invited to contribute background information and policy recommendations (see Appendix B, pg. 48).

The purpose of this report is to summarize the GTF's findings and to make specific policy recommendations addressing (a) coordination of services; (b) prevention and awareness; and (c) education, employment, and housing as well as other domains that emerged as a part of the evaluation process (see Section III below, pg. 7).

II. OVERVIEW OF PROCESS

A. PARTICIPANTS

Stakeholder groups included: (a) individuals with different types of brain injury, but predominantly TBI; (b) their family members; (c) state agency representatives; (d) medical professionals; (e) service providers; (f) advocacy groups; and (g) legal professionals.

Each member of the GTF represented the perspectives of hundreds of individuals with brain injury, their families, and service providers. Additionally, over 100 stakeholders with brain injury, their family members, and professionals gave input directly to the GTF. Direct input was collected via oral testimony, focus groups, one-on-one interviews and/or written comments across 10 separate events from January 2014 to January 2016. Several of these participants were family caregivers representing a family member with a brain injury who was unable to attend the proceedings.

Taken together, all age ranges were represented. Individuals from Latino, Russian, and Native American backgrounds were also represented, as were veterans, those who are homeless, and those living in rural communities.

B. SUB-COMMITTEE PROCESS/ANALYSIS

The “Experiential” and “Policy” sub-committees of the GTF were formed to organize and evaluate themes emerging from the stakeholder groups.

The **Experiential Sub-Committee** focused on the review and analysis of input and perspectives provided by stakeholders who have direct experience with brain injury (i.e., individuals with brain injury, their family members/caregivers, and professionals who serve them).

The **Policy Sub-Committee** focused on state agency policies, administrative rules, and statutes on behalf of these stakeholder groups. Selected DHS staff members facilitated this process by conducting in-depth interviews with non-GTF member staff across selected state agencies (e.g., DHS, ODE, OHA, DOC).

Each committee conducted a “gaps analysis” process to organize and analyze stakeholder input for the presence or absence (gaps) of essential services and resources.

III. STRENGTHS & GAPS

Guidelines for selecting themes to include in this report include the *frequency* with which a topic or group of related topics were mentioned and the *long-term implications* regarding the safety, health, and well-being of individuals with brain injury and their families. Case examples/quotes are used to illustrate each of the strengths and gaps drawn from stakeholder input.

A. STRENGTHS

SUMMARY OF STRENGTHS

Areas of strength identified by the Governor's Task Force included:

1. Support and advocacy
2. Legislation
3. Federal-state agency services
4. State-private sector services
5. TBI prevention programs

1. Support and advocacy. Stakeholders reported that brain injury advocacy and support groups as well as the Centers for Independent Living are critically important resources for getting connected with peers, information, and activities. (Note: Several participants indicated that it took longer than it should have to get plugged into these groups and that there aren't nearly enough support groups statewide, particularly in rural communities, to meet the need.) Church groups were also cited as an important source of support. Disability Rights Oregon (DRO) provides legal advocacy for individuals with TBI through the federally-funded Protection and Advocacy for Traumatic Brain Injury (PATBI) program.

Survivor: *My "real" recovery started with my women's brain injury support group and continues today, now that I've been introduced to my new community, that of a brain injury survivor.*

Spouse: *I found help through the state brain injury association and support groups and have gained a lot of knowledge.*

Survivors & Parents: *Peer mentor groups are extremely beneficial in helping others in the same situation.*

Survivor: *I finally got SSD [Social Security Disability] after years of trying, thanks to the ILR [Independent Living Resources].*

2. Legislation. Oregon has been a leader in passing legislation aimed at raising awareness of and preventing TBI through:

- establishing March as Brain Injury Awareness Month;
- mandating bicycle helmets for anyone under the age of 16; and
- mandating helmets for anyone riding a motorcycle or moped.

In 2009, Oregon passed legislation requiring that health benefit plans provide coverage of medically necessary therapy and services for the treatment of traumatic brain injury. Increased public awareness concerning sports concussions has been extremely helpful in raising awareness about brain injury in our state.



The signing of Jenna's Law, 2014. Max's and Jenna's Laws mandate sports concussion education and implementation of concussion response protocols.

- In 2009 Oregon enacted Max's Law, named after high school quarterback Max Conradt. The landmark legislation requires mandatory concussion education and concussion response protocols for all Oregon high school athletic programs.
- Where Max's Law only covered high school athletes, Jenna's Law, enacted in 2014, covers all other young athletes (under the age of 18) in Oregon who participate in organized sports. The Oregon Concussion Awareness

and Management Program (OCAMP) is a consortium of educational, athletic, medical, legal and rehabilitation experts in sports concussion, charged with education and dissemination of resources concerning these two laws.

Note: See Appendix C, pg. 50 for more information about these laws.

3. Federal - State agency services. Stakeholders described specific examples of helpful state agency services, including care worker and case manager support, vocational re-training and ODVA medical services. The Oregon Traumatic Brain Injury Educational Consulting Team - funded by the Oregon Department of Education – provides training to educators serving students age 0–21 with TBI. Also, the Affordable Care Act includes a mandate for the provision of “habilitative” services in health policies.^B

Parent: *My son now has a care worker through DHS from the Home Healthcare registry. His case manager is helpful.*

Parent: *I was so used to being called to school to listen to all the problems my daughter has. This meeting [with the Oregon TBI team consultant] really gave my daughter and me an opportunity to think creatively and to focus on her strengths. It's only been three weeks since that meeting and we've already accomplished all the initial goals we came up with!*

Parent: *My son is now part of a Latino support group and has a great case manager.*

Parent: *My son's current Vocational Rehabilitation (VR) counselor is very helpful.*

Survivor: *The VA is great. I've gotten all the services I need. The smartest move I ever made was signing up for the Marine Corps.*

4. State – Private sector services. Few programs offer the integrated, case management-based services frequently cited as a critical gap in service-delivery for individuals with brain injury statewide. A few programs, however, do set an example of integrated services. Central City Concern serves the homeless community in Portland, OR, providing housing, case management, healthcare, mental health and addiction services using an integrated team approach. Selected university-based programs, private sector rehabilitation, and supported living programs each offer an integrated team approach to concussion/TBI management. Campus disability services programs provide college students with TBI much-needed support regarding academic accommodations and services.

Central City staff & two survivors of TBI, who are homeless with mental health and addiction histories: *These men relied on the case managers for help with arranging housing, treatment, rehabilitation and healthcare services. Both individuals were engaged with staff, dealing with their many issues. Although both men are coping on a limited basis, neither is engaged in TBI rehabilitation services.*

Parent: *The university-based TBI program was very helpful for being able to identify-label-understand symptoms.*

Parent: *She was able to get to disability services at a state university and, in time, she spoke at a disabilities class.*

5. TBI prevention programs. The prevention of TBI is a broad topic that can be framed according to the prevention of (a) TBI from occurring in the first place, (b) repeated TBIs following an initial injury, and (c) complications related to an undiagnosed or misdiagnosed TBI and/or lack of early intervention and ongoing supports. Leading causes of TBI in Oregon are suicide, unintentional falls, motor vehicle traffic collisions, and sports injuries.

Statewide prevention programs include:

- Oregon Department of Transportation's Transportation Safety Division;
- Oregon Health Sciences University's Think First Program;
- Legacy Emanuel's Trauma Nurses Talk Tough; and
- Oregon Safe Kids.

Dozens of other prevention programs have worked for more than 25 years to prevent motor vehicle-related TBIs through increasing seat belt use rates and use of helmets when cycling. In addition, programs to reduce falls by senior adults have been adopted by many of Oregon's health systems; a media campaign to address toddlers from falling from open windows has been in place for the past five years with some public awareness success; and several hospitals are implementing a firearm restriction program that targets youth who are high-risk for suicide.

TBI often impairs the cognitive skills needed to navigate a complex healthcare system.

Previously described legislative mandates targeting sports concussion training for coaches and families are specifically designed to reduce the risk of/prevent second impact syndrome. Diagnosis-related complications have been addressed across several of the previous sections. Specific campaigns, such as special education "Child Find," would be a helpful approach to finding students with TBI in the schools who may need services.^C

Discussion

The previously described strengths inform starting points for policy recommendations moving forward. However, those strengths also point to myriad gaps, particularly the extremely difficult process of learning about, let alone navigating, the complicated private-public system of services and supports. The

cognitive skills required to navigate such a system - memory, organization, planning, initiation, and follow through - are often impaired following brain injury, making it extremely difficult to independently navigate the system, apply for, and access these resources. Furthermore, family members caring for an individual with a brain injury are often overwhelmed and exhausted, leaving little room to navigate the system on their own. “Falling through the cracks” was expressed in many ways across all stakeholder groups.

B. GAPS

SUMMARY OF GAPS

- 1. Lack of culturally sensitive services and resources**
- 2. Lack of adequate education and training about TBI – lack of standardized screening protocol**
- 3. Lack of a “road map” for accessing services and ongoing case management**
- 4. Family members as unpaid caregivers**
- 5. Financial hardships; difficulty accessing federal and state benefits**
- 6. Difficulty with private insurance and accessing appropriate treatment options**
- 7. Lack of affordable, appropriate housing**
- 8. Challenges with co-occurring mental health disorders and/or addictions**
- 9. Lack of adequate vocational training and employment opportunities**
- 10. Lack of TBI identification and appropriate supports in the schools**
- 11. Challenges with identification and management of TBI in the corrections system**

1. Lack of culturally sensitive services and resources available statewide and across the lifespan. Stakeholders underscored the significant lack of resources, services, and trained professionals/paraprofessionals attuned to the needs of individuals with brain injury across the lifespan, particularly those representing culturally diverse groups, different ages (youth to elderly), and those living in rural communities. Stakeholders from culturally diverse backgrounds experience even greater challenges accessing services than the general population because of a lack of TBI educational materials in their own language and bilingually-trained medical and allied health service providers. Undocumented individuals with brain injury are at a particular disadvantage accessing services. TBI among seniors may be ignored or missed entirely with medical professionals assuming some other cause for changes in behavior (e.g., dementia), while those living in rural communities experience significantly reduced access to ongoing, high quality services.

Survivor: *There are not enough brain injury support organizations statewide to enable survivors, family and friends to obtain information, resources training and to socialize/decrease their isolation. Most brain injury support groups are non-profits relying on very limited budgets.*

Parent: *As a Latino family, it was difficult to ask for help and to find culturally appropriate education and services.*

Sister of Undocumented Survivor: *We live “in the shadows” with little to no medical insurance and do not trust the Federal government.*

Survivor: *I’m now getting older and the world is getting faster paced. I have no caregivers or managers of my affairs. I do it all on my own. Can’t afford technology or follow it.*

Professional: *People living in rural communities are isolated, further removed from services. They are less likely to get the gold standard of care, particularly for those with mild injuries. There is less familiarity with brain injury, therefore [professionals are] less likely to provide care or know to initiate care.*

2. Lack of education and training about brain injury – Lack of standardized screening protocol.

Several stakeholders reported that they did not receive an accurate, timely diagnosis of TBI and that TBI is often masked in the presence of



life threatening conditions or other physical impairments (e.g., respiratory distress, broken bones). For example, a TBI might go undetected in a child who is in a car crash and has a broken leg and internal injuries. Several stakeholders reported that they experienced dismissive

attitudes from some, not all, medical and rehabilitation providers. All of these concerns may be in part attributed to a lack of awareness and training about TBI

among medical and allied health professionals, educators, service providers, and state agency staff. Further, there is no standardized TBI screening protocol used across public-private entities to begin to

address this concern; an accurate diagnosis of TBI is the first, critically important step to receiving benefits.^D While it was acknowledged that there has been an increase in public awareness of TBI over the past several years, stakeholders reported there remains a huge void in public awareness regarding TBI - what is often referred to as the “invisible injury.” The lack of a *TBI Clinical Registry* that accurately documents and tracks the number of individuals with TBI adds to this concern.

Not all brain injuries show up on a CT scan or MRI.

Survivor: *Not all brain injuries show up on a CT scan or MRI. Not all brain injuries manifest until later on. That's when I was told I was lying about my brain injury.*

Survivor: *The proper diagnosis of TBI is an issue. My TBI was not properly diagnosed. I was over-medicated on psychiatric meds and pain killers.*

Survivor: *I was told by a physician that he didn't know what to do to help me. Much later I was told I had a TBI, even though I had previous neuropsychological testing. I was treated very poorly. Feels very blaming, that it's our fault.*

Family member: *Hospital didn't provide adequate information. Concussion was diagnosed then he was discharged after 4 hours.*

Advocate: *How do people work with individuals with TBI who have challenging behaviors without support and training? How do doctors and hospital staff recognize a TBI?*

3. Lack of a “road map” and ongoing case management. Once a brain injury is diagnosed, lack of timely follow up information and a “road map” to services was reported frequently. Also, lack of ongoing case management to navigate these services, particularly *after*



hospitalization and across the lifespan and severity range of brain injury was of great concern. Several individuals with brain injury and their families reported delays in receiving much needed services post-hospitalization or received no services at all. Only a few families were told that state monies are available to pay for care providers.

Parent: *Following my son's hospitalization, there was no one I could turn to on a regular basis for guidance on where to find help. I had to quit my job to care for him and figure everything out on my own. Community support groups were a life-saver, but it took months before anyone told me about these resources.*

Parent: *I didn't know that we were supposed to think about a neuropsychological evaluation for my daughter. I didn't know vocational rehabilitation existed. Getting the information notebook right as we were leaving the hospital was overwhelming and I didn't look at it for several months. When I was ready, there was no one to talk to that could relate this information to me in a meaningful way.*

Adult survivor of TBI: *Many in the medical community don't know about brain injury. What resources are available? I have no idea... that's a marketing and accessibility failure on the government's part. Ideally, we'd have a case manager assigned to us.*

4. Family members as unpaid caregivers. A clear pattern emerged showing the extent to which family members, when available and willing to help, served as both caregivers *and* untrained, unpaid resource navigators, often at great cost to themselves and other family members. Several family members reported having to quit their jobs to stay home and care for their family member with brain injury, while also reporting feeling depressed and isolated themselves.

Parent: *Our family is the main support for our son. However, as his mother, I don't have any support system of my own. My grown children help at times. We had more outlets/sources of support while living in Kansas; they have a waiver program... but here in Oregon, we're now at a loss.*

Sister: *I quit my job and now fill three roles for my brother-caregiver, navigator, advocate with different people-It's been overwhelming. Everyone disappears from your life. I've experienced depression.*

Spouse: *Nobody told me what to expect. After the injury, there was this impulsive/compulsive person. One nightmare after another. There was no relief for me.*

5. Financial hardship - Difficulty accessing federal & state benefits.

Stakeholders described an array of challenges in this domain, including:

- the overwhelming debt often associated with brain injury due to medical expenses, lost income, etc.;
- barriers to learning about, applying for and obtaining benefits, including workman's compensation, Social Security Disability (SSD), Supplemental Security Income (SSI); and
- accessing specific types of benefits such as food stamps and transportation support.



Even with medical documentation of their disability, stakeholders reported being routinely denied SSD benefits before these were finally awarded, if at all. Many gave up trying because of the difficult application process. Others described qualifying for SSD only to have these benefits taken away because they made just over the allowable income.

State-based services are available through the Department of Human Services (DHS).^E Those who sustained their TBI before the age of 22 may qualify for services through the DHS Office of Developmental Disabilities. Those who sustained their injury at age 22 or older may qualify through the DHS Office of Aging and People with Disabilities. Stakeholders may be confused concerning which of these two systems they need to access. Finally, on average only 3 out of 10 Oregon veterans access their earned benefits including broad healthcare support.²¹

Only 3 out of 10 Oregon veterans access their earned benefits.

Spouse: *I had to put things on credit cards. Prior to my husband's brain injury, we had excellent credit but then we lost our truck, motor home, and later home due to illegal foreclosure (bank-related). I don't get any financial support from the state because I'm married. We would have to divorce.*

Survivor: *Sometimes I do not take my meds because I cannot afford them. My food stamps were cut from \$200 per month to \$15.*

Survivor-Advocate: *Most do not even think of brain injury as being eligible for "disability" services and especially that I/we might be eligible for some caretaker training and funds.*

Professional-Rural Communities: *Workers in the logging and construction industries often sustain concussions, but are very hesitant to report these to their superiors. They are fearful of getting fired because the employer might fear an expensive workman's comp claim.*

Parent: *Our son is unable to get back on SSI because he makes a little too much as a clerk at a grocery store, but it is not enough to live on. He does get insurance through his work but the deductible is quite high. Now, we're trying to go through the developmental disability route. Waiting for a neuropsych test.*

6. Difficulty with private insurance – Difficulty accessing treatment options across the TBI severity continuum & lifespan. Stakeholders described an array of challenges working with private insurance companies and accessing ongoing, comprehensive services, particularly following hospitalization. Family members, already worried and anxious, are compelled to spend additional time and energy appealing insurance companies decisions regarding denied or severely limited healthcare and rehabilitation services. In addition, the need for greater breadth and depth of services in both urban and rural areas was underscored, particularly for individuals who are medically fragile or those with mild-moderate TBIs, who do not necessarily qualify for services as do those with more severe injuries.

Family member: *In many cases, the insurance companies are telling the medical folks HOW MANY and WHAT KIND of services the patient needs, not the other way around.*

Family member: *Has both TBI and is medically fragile. We know of no place like this, so he has to stay at home.*

Professional-Advocate: *Rehabilitation benefits are often orientated to orthopedic impairments, not neurological or specialty services, such as vision or hearing. Lack of a TBI waiver is problematic.*

Parent: *I'm old and live in a small house; I wish my daughter had some place else to go during the day...some club or something.*

Survivor: *Can't go anywhere because of very limited transportation (not affordable).*

7. Lack of affordable, appropriate housing. Housing emerged as a pivotal issue. Several stakeholders reported losing their homes because they could no longer afford their rents/mortgages, whether because of job loss, divorce and/or catastrophic medical bills. Some moved to a much less expensive and less desirable dwelling while others moved in with other family members to cut down on expenses. There are a few, but not nearly enough, Adult Foster Homes (AFH) or other care settings for individuals with severe TBI, particularly those with challenging behaviors that preclude their families from taking care of them. Further, some AFH's are changing over to private pay because the state does not pay enough to cover the costs of care. As a result, these individuals are more likely to be admitted to state or private hospital mental health wards. Those who are homeless experienced even greater hardship, with few programs available to meet their complex needs.

There are not nearly enough Adult Foster Homes for individuals with severe TBI, particularly those with challenging behaviors.

Survivor: *I lost my house because I couldn't manage the stairs. I had to do a short sale and I still owe the government. This is typical, that families like ours experience a downward spiral.*

Family member: *Rentals/housing (even section 8) is getting too expensive to live in—unless you want to live in a dump.*

Professional: *Without the security of safe, stable housing, people with TBI are at extreme risk (for homelessness), and have profound difficulties in managing their conditions and their lives. Social Security Disability (SSD) income is inadequate to afford even the cheapest Single Room Occupancy (SRO) housing.*

Survivor: *Brain injury folks who cannot live independently have no place to go except foster care where mostly older people live and/or those with severe disabilities. This does not lend itself to a positive living environment.*

Professional: *People with TBI who reside in the state hospital, nursing homes, Oregon Youth Authority facilities, or state-operated secure facilities for I/DD [Intellectual/Developmental Disabilities], experience high barriers to placement in more community integrated settings.*

8. Challenges with co-occurring mental health disorders and/or addictions.

Co-occurring mental health disorders and drug/alcohol addictions significantly complicate life with a TBI. These disorders can mask a pre-existing TBI or lead to a TBI, thereby compounding problems accessing services and increasing the risk of homelessness and/or trouble with law enforcement. Services are often provided in private and state institutions such as emergency rooms, homeless shelters, and correctional facilities, exacting an extremely high financial and personal toll when compared with the possibility of receiving well-coordinated, ongoing services initiated immediately following a TBI. Stakeholders described an array of challenges in this domain, including accurate diagnosis of TBI, accessing mental health support, housing services, proper medication and TBI-related rehabilitation services, and the risk of recurring TBIs.

Spouse: He tried to go back to work, but became suicidal. He went into a psych ward. Because of his depression, his health started deteriorating. It was hard to find mental health support.

Professionals: Both J. and S. were middle-aged males, who experienced years of homelessness, frequent incarcerations, were disaffiliated from family and friends and were not working. They had been chronically unemployed. Both had experienced multiple head traumas and were multi-diagnosed with addiction histories. Neither individual is actively engaged in TBI rehabilitation services.

Professionals: Psych medications that may be appropriate for mental illness treatment may be confused with and overpower symptoms of TBI.

Professionals: For someone with TBI, addictions and mental illness, living on the streets and shelters is truly frightening and puts the person at risk for further head trauma and other destabilizing events. Living on the streets is dangerous for anybody, but for the person with behavioral control issues, it is extremely dangerous and should be considered life threatening.

9. Lack of adequate vocational training and employment opportunities.

Stakeholders, while appreciative of vocational rehabilitation services, highlighted challenges within this system having to do with a lack of adequate staff training for working with individuals with TBI, jobs not appropriately matched to an individual's abilities and interests, and the need for ongoing vocational rehab support beyond what is currently available.

Family member: Most Voc Rehab employees do not know how to work with individuals with brain injury, their needs and potential capabilities. You don't need to stick someone with just low level work. They get tired of doing meaningless work.

Survivor-Advocate: Voc Rehab takes a "one size fits all" approach with disabilities and doesn't always customize its services to meet the needs of individuals with TBI.

Professional: TBI survivors need more long-term supports in vocational rehabilitation, similar to the developmental disability community and mental health.

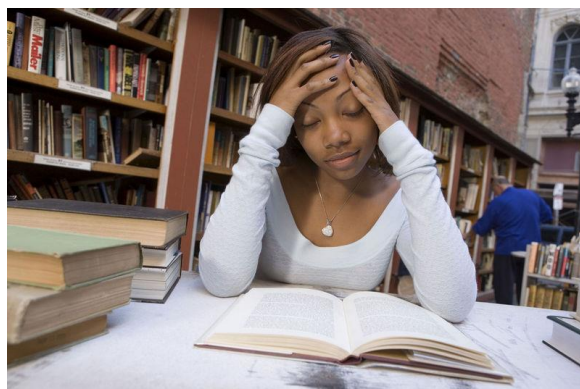
Parent: Voc Rehab recommended a trade for our son, so we helped him start a small business, then he got kicked off SSI and had to pay the money back.

Parent (same as above): Later, he got a job at grocery store as courtesy clerk—with his sister's help; however, store staff step into to compensate for certain tasks. Currently, he can't work the bottle room, he has difficulty with store "closing" tasks and staff don't have time to do both their and his tasks. Currently, the new manager--doesn't understand about brain injury and is cutting his hours; Current VR counselor ordered neuropsych test; has helped a great deal with focusing on goals that are doable.

10. Lack of TBI identification and appropriate supports in the schools.

Schools are often not informed if a student has sustained a TBI. And yet, schools have an obligation to identify students with disabilities who are eligible for special education services and to create an Individualized Education Plan (IEP). Also, once a student has been identified, schools are often not equipped to support the student. Students may potentially receive services under a disability category other than TBI (e.g., learning disabled, ADHD), thus impacting individualized

services to meet their unique needs. Further, pre-existing educational challenges make it difficult to access appropriate school services and eligibilities. If a student received services for other challenges such as a learning disability or ADHD prior to their TBI, schools often do not re-evaluate



for TBI and continue providing services under the student's prior eligibility category. This is problematic for the student as it limits the services they can access after they exit the school system and during the transition phase. Finally, students with less severe TBIs, who may not need an IEP, may not be identified as needing 504 plan^A accommodations or modifications within their school program, and as such, are not effectively supported (see Appendix C, pg. 51 regarding *Return to Learn*).

Parent: *His initial attempt to return to school...very unstable; he wasn't ready. Grades plummeted. He currently goes to a private school in Washington.*

Parent: *My child tried going back to school following his injury...didn't go well but later he completed his GED.*

Survivor: *I didn't know what else to do and so re-entered school my Senior year of high school- following my brain injury. After my first day in classes, I broke down in tears. One of my teachers brought in a school counselor and my mom. Other than that, there was no support.*

Professional: *Still need a medical statement from a physician, which is sometimes difficult to get if the (student's) TBI occurred a long time ago. In this case, they are often labeled differently (e.g., learning disabled; other health impaired), but they still get services.*

11. Challenges with identification and management of TBI in the corrections system.

Oregon Department of Correction's management of TBIs includes:

- a highly controlled and predictable environment;
- training of both custody and non-custody staff about the prevalence of TBI, recognizing general types of impairment, and how to interact with inmates who may be upset, slowed, or confused from a variety of causes;
- medications, when warranted, to help improve control of mood and affect; and
- providing specialized training in management of acute TBI for medical providers.

Challenges within this system include lack of a standardized approach to screening for TBI. Inmates often have a difficult time self-reporting if and when they may have sustained a TBI(s) because of past histories that may include multiple fights, drug use, and/or abuse. To determine whether a TBI pre-dated and therefore may be causally linked to the crime for which an individual is incarcerated is difficult at best. There are no neuropsychology services available within the corrections system to assist with answering these questions. Further, there are no specialized rehabilitation services for individuals with TBI within corrections facilities, nor are there comprehensive, individualized transition planning services specifically geared toward those with TBI. Difficulties with attention, memory, impulse control, initiation, and follow through, often associated with the TBI, can make it difficult to successfully adhere to probation or parole plans.

Chief Psychiatrist of Corrections:

Patients in any correctional system are unlikely to have a “pure”, discrete TBI history. The few examples of severe TBI we have are usually readily identified. TBIs usually serve to accentuate and worsen well-documented preexisting problems, such as impulse control problems and anger, rather than create new ones, but we are usually unable to document that there is a clear post-TBI change.

In addition to the various ways in which risky lifestyles increase the chances of accumulating repeat concussions, we also question how many of the folks we see have an undocumented history of TBI secondary to early childhood physical abuse or injury (that they don't recall) which impairs subsequent brain development and negatively affects learning, affect and impulse control, and behavior.

Many inmates report growing up in chaotic, violence-prone households. By the time they get to jail or prison they have often accumulated a variety of diagnoses (conduct disorder, oppositional defiant disorder, ADHD, learning disabilities, various mood disorders, etc.).

We can infer that some of the difficulties the inmate faces are ultimately secondary to the cumulative developmental effects of early TBIs, but we cannot prove it, certainly not to the extent of having them qualify for specialized TBI services in the community.

IV. SUMMARY

The focus of the GTF on TBI was to examine the policies, practices, and the prevention of TBI and the delivery of services to those living with brain injury and their families. Specifically, the GTF looked at policies, procedures, administrative rules, and statutes that guide and inform the delivery of services across selected state agencies (e.g., ODE, ODVA, DHS, DOC). The goal was to learn where there are strengths in services and policies, gaps in services, and duplication of effort. After analysis of the existing practices, a number of conclusions were reached by the GTF resulting in eight recommendations that will require cross-agency collaboration, both across state agencies and between state agencies and private sector entities.

The last of these recommendations, but potentially the most important, is establishing the position of the **Governor's Brain Injury (BI) Coordinator and Advocate**. This position is deemed necessary by the GTF as an action to ensure that identified improvements to various services will actually happen. The current systems of care being administered by the identified state agencies are uneven and "silo-ed." Some services are readily available to some people while other services are virtually nonexistent. Some services cross over different agencies and have different qualifying standards. Knowledge of brain injury and acceptance of treatment protocols varies from agency to agency.

There is no coordinated system pulling all the elements of brain injury diagnosis, acute care treatment, rehabilitation, coordination of insurance benefits, vocational support, and peer support together. Individuals with brain injury, their family members, and caregivers are confronted with understanding and navigating an extremely complex system. Ironically, the cognitive impairments frequently associated with brain injury, including memory loss and difficulty with organization and follow-through, compound the problem. These

recommendations have broad applicability for individuals who live with all types of brain injury (e.g., stroke, tumor, anoxia).

The BI Coordinator-Advocate will have the opportunity to address these concerns, working across state agencies and with individuals with brain injury, their family members, and care and advocacy groups throughout the state. Outreach to private sector care, advocacy groups and organizations is an important aspect of the BI Coordinator-Advocate's responsibilities as it is vital that the needs of all individuals with brain injury, their families and friends be recognized and addressed specifically with any recommended state action. As a result, it is important that the BI Coordinator-Advocate have knowledge of and an ability to work with the various survivor groups including private Veterans' associations, the Brain Injury Alliance of Oregon, Brain Injury Connections NW, private care facilities and the other brain injury advocacy, support and care groups throughout the state.

V. STATEWIDE RECOMMENDATIONS

RECOMMENDATIONS AT A GLANCE

- 1. Increase educational outreach**
- 2. Establish a TBI Clinical Registry**
- 3. Establish a centralized "road map" of services and resources**
- 4. Establish a statewide program of care coordinators**
- 5. Develop an equitable system of care and services**
- 6. Develop a communication system to improve coordination across agencies**
- 7. Establish sustainable, equitable funding mechanisms**
- 8. Establish the Governor's Traumatic Brain Injury Coordinator and Advocate in the Office of the Governor**

(Note: See Appendix D, pg. 53 for agency-specific recommendations.)

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 community 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, eligibility for service benefits, treatment planning, and case management;
- be accessible with patient consent to designated medical, educational and service providers; and
- establish a universally understood definition of TBI.

Recommendation 3: Establish a centralized, comprehensive, culturally sensitive, easy-to-navigate **“road map”** of brain injury services and resources (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, assisting them in navigating resources, services, supports and benefits with regular follow-ups.

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 more severe injuries and behavior challenges and those with co-occurring mental health and/or addiction issues. This meets the requirements of federal Home and Community Based Services standards and the ADA.

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

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

- establishing a TBI-specific program (i.e., targeted Medicaid funds to support community-based living);
- ensuring family caregivers receive compensation to help with loss of income when caring for their family member with a brain injury;
- ensuring the same level of financial support and service, regardless of age of injury and severity of injury; and
- addressing the issue of insurance bad faith regarding payment of 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 allow 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 opportunity is 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 additional federal revenues compared to 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. This position will be 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 the 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 prevention actions and improve the coordination of effective delivery of care. In the case where legislation or administrative rule change is 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.

Figures 1 and 2 below illustrate a service delivery system that addresses the gaps and recommendations outlined in this report.

FIGURE 1. OVERVIEW OF OREGONS PLAN TO IMPROVE SERVICES AND SUPPORTS FOR INDIVIDUALS WITH BRAIN INJURY AND THEIR FAMILIES

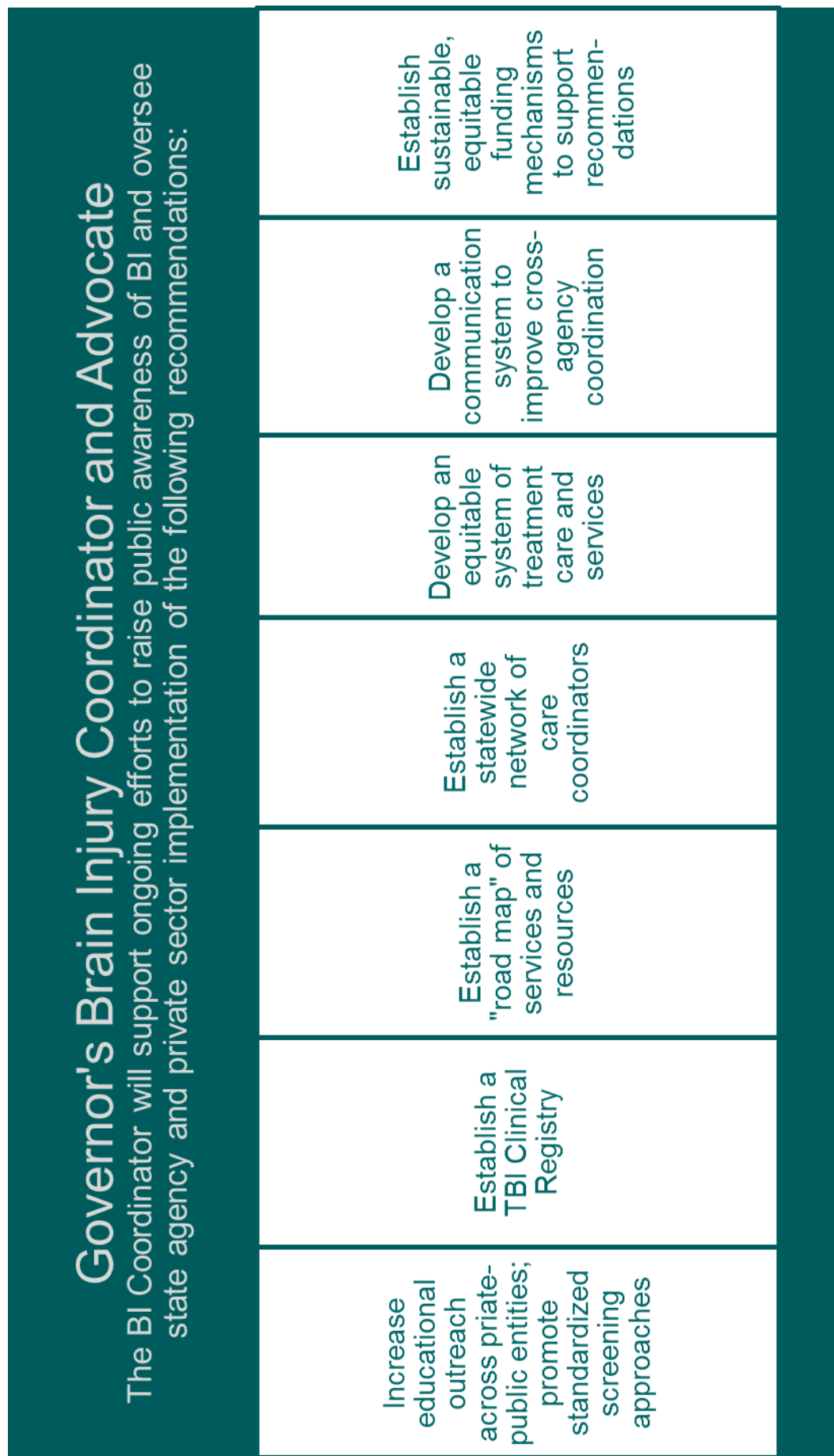
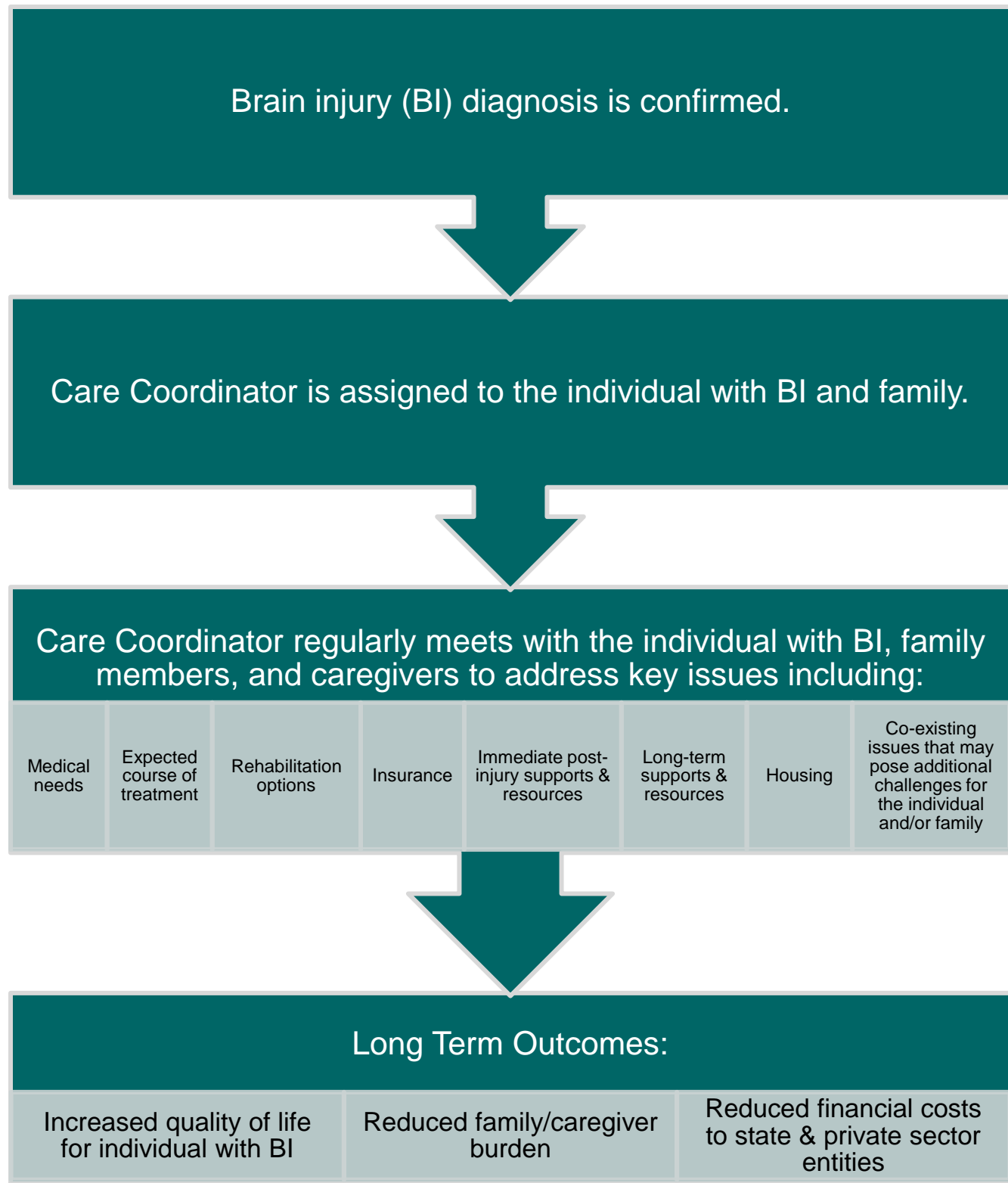


FIGURE 2. EXAMPLE OF SERVICES AND SUPPORTS SEQUENCE AND LONG TERM OUTCOMES



CONCLUSION & ACKNOWLEDGEMENTS

This report was informed by numerous stakeholder stories exposing gaps in a system of care that unnecessarily adds to the burdens of life with a brain injury. Yet stakeholders also described many helpful resources and programs that, if brought together in a coordinated public-private system of care, could minimize unnecessary challenges and instead emphasize proactive, ongoing access to coordinated systems and supports. This report serves as a reference for policy and legislative changes to achieve that end.

The GTF on TBI extends its untold thanks to the many stakeholders who offered their personal stories and experiences to help shape this report. Their invaluable contributions inform the work ahead in pursuit of our state's vision of improved public-private services and supports to maximize community engagement and quality of life for individuals with brain injury.

ENDNOTES

^A A 504 Plan is a plan of support developed to ensure that a child with a disability attending an elementary or secondary educational institution receives *accommodations* providing him/her access to the learning environment. A 504 plan is different than an Individualized Education Plan (IEP), which provides for *specialized instruction and related services* (i.e., special education) to access the learning environment. The Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973 mandate IEP and 504 plans, respectively.

^B Because the disabling effects of a brain injury may emerge months after the initial injury, an individual may become ineligible for health insurance coverage of “rehabilitative services” that help them recover functioning. Coverage for “habilitative services” is not dependent on their proximity to the injury. These are services that help a person who needs to keep, learn, or improve skills and functioning for daily living. They may include physical and occupational therapy, speech-language therapy and other services.

^C Child Find is a component of the Individuals with Disabilities Education Act (IDEA) requiring that States must have (a) policies and procedures to ensure that all children with disabilities are identified, located, and evaluated; and (b) a practical method for determining which children are currently receiving needed special education and related services, including those on 504 plans.

^D Medical facilities are allowed to destroy patient records, including chart notes and brain imaging studies, after several years making it difficult for those seeking disability benefits to provide documentation of their TBI. To mitigate this problem, survivors of brain injury need to have control of their medical file in hard copy or electronic form that the survivor can keep on a long-term basis.

^E Oregon's Department of Human Services administers long term services and supports through the 1915(k) Community First Choice.

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Brain Injury Alliance of Oregon

Brain Injury Connections – Northwest

Central City Concern, Portland, OR

Oregon Dept. of Corrections

Oregon Dept. of Education

Oregon Dept. of Human Services

Oregon Dept. of Veteran's Affairs

APPENDIX A: EXECUTIVE ORDER NO. 13-02

Establishing the Task Force on Traumatic Brain Injury



EXECUTIVE ORDER NO 13-02

ESTABLISHING THE TASK FORCE ON TRAUMATIC BRAIN INJURY

Traumatic Brain Injury (TBI) represents a significant public health problem. Each year, almost 1.7 million people in the United States sustain brain injuries due to motor vehicle collisions, assaults, falls, firearm incidents, and sports activities. Of the total number of individuals injured each year, more than 124,000 will be left with permanent disability in social, behavioral, physical, and cognitive functioning. Currently, approximately 3.17 million people in the United States need help with daily living due to a TBI.

There are approximately 45,000 Oregonians with TBI and more than 3,000 individuals are added to this number every year. Over 1000 students in Oregon are hospitalized for brain injury each year. Approximately 16% of these children will be left with significant alterations in functioning (based on national averages) indicating a cumulative total of nearly 2000 students who should be identified for special education services. However, Oregon's Special Education Child Count for 2010-11 identified only 284 students with TBI.

Traumatic brain injury has become the signature injury of the Afghanistan and Iraq wars. The incidence rate among combat-exposed military personnel is estimated at 15-20%. However, as in the civilian population, the true incidence of brain injury in the military is likely much higher due to significant under-reporting. To illustrate, congressional research reports indicate that there are over 700 veterans with brain injury living in Oregon. However, state agency personnel reports indicate over 1700 veterans, many of whom may have brain injury, are currently receiving services through Oregon's Office of Seniors and People with Disabilities alone.

Oregonians with TBI are a growing population attempting to navigate private, state, and federal agencies to address their complex medical, rehabilitation, and vocational needs. Lack of coordinated, on-going services following injury is common and can result in persons with brain injury being served in higher cost private and state institutions such as emergency rooms, homeless shelters, and correctional facilities. Coordinated services early post-injury are thus critical to maximizing independence and reducing long-term costs to the state. Recent health care transformation efforts have created an unprecedented opportunity for coordinated services for this and other populations with complex needs.

Three areas of concern underscore the need for coordinated services for all persons with TBI:



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PAGE TWO

- (a) **Disabilities and access to services:** The physical, cognitive, and psychological disabilities following brain injury often prevent access to services. For example, impairments in memory, organization, and problem solving—the very skills needed to navigate complex service delivery systems often preclude persons with TBI from independently accessing these services.
- (b) **Co-occurring disorders:** Brain injury can occur with other disorders including attention deficit disorder, mental illness, or drug/alcohol dependence. For example, many veterans with TBI also have post-traumatic stress disorder (PTSD). Treating these over-lapping conditions requires highly integrated care.
- (c) **Diverse needs:** Just as no two individuals are alike, no two brain injuries are alike. Hence, individuals with TBI do not all need the same type and intensity of services. For example, students with TBI need person-centered individualized education programs and transition plans to maximize success. Similarly, adults with brain injury benefit from individualized, coordinated care plans. What is common to all persons with brain injury and their families is the need for assistance navigating the complex service-delivery system.

In 2001, Executive Order (EO) 01-02 created a Task Force on Traumatic Brain Injury. The EO 01-02 report drafted in 2002 provided recommendations to state agencies and advocacy organizations to focus on legislation on behalf of persons with traumatic brain injury and their families.

Since 2002, the service-delivery landscape for persons with brain injury has changed dramatically. The return of Oregon soldiers with TBI and continued improvements in life-saving medical procedures for civilians and military personnel alike contribute to the need for sustained, coordinated services across public agencies and private sector groups. This executive order repeals EO 01-02 and focuses on policy formation across state agencies.

NOW THEREFORE, IT IS HEREBY DIRECTED AND ORDERED:

1. The Task Force on Traumatic Brain Injury (“Task Force”) is established. The purpose of this Task Force is to formulate policies with state agencies focusing on improved service delivery for this population.





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PAGE THREE

2. To ensure diversity of input, Task Force membership will include representation from the following categories:
 - a. Two brain injury survivors appointed by the Governor;
 - b. Two relatives of brain injury survivors appointed by the Governor;
 - c. Two medical professionals with experience in treating brain injury appointed by the Governor;
 - d. One member of the public appointed by the Governor;
 - e. One agency representative appointed by the director of the Brain Injury Alliance of Oregon;
 - f. One agency representative appointed by the director of Disability Rights Oregon;
 - g. One agency representative appointed by the director of the Oregon Department of Corrections;
 - h. One agency representative appointed by the director of the Oregon Department of Veterans' Affairs;
 - i. One agency representative appointed by the director of the Oregon Health Authority;
 - j. One agency representative appointed by the director of the Oregon Department of Human Services; and
 - k. One agency representative appointed by the director of the Oregon Department of Education.
3. The Task Force membership term for all members is three years. The 14 Task Force members may enlist others with specific expertise to develop the proposed policies. The Task Force members shall select the chair. Task force members will not be reimbursed for mileage or per diem.
4. At least seven members must be present for a quorum. The Task Force shall meet at least quarterly for three years after the EO takes effect.
5. The Task Force will take the lead on formulating policies in partnership with state agencies and groups that directly serve Oregonians with TBI, addressing the domains of (a) coordination of services, (b) prevention and awareness, and (c) employment, education, and housing.
6. The Task Force will address coordination of services by:
 - a. Developing joint policies with the state agencies that provide services to persons with TBI. These agencies include: Oregon





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- Department of Education; Oregon Department of Veterans' Affairs; Oregon Health Authority; Oregon Department of Corrections; Oregon Youth Authority; Office of Vocational Rehabilitation Services; Office of Developmental Disability Services; and Office of Seniors and People with Disabilities.
- b. Developing joint policies with healthcare delivery entities including coordinated care organizations for comprehensive, integrated services for people with TBI. Types of care considered will include medical, mental health, and cognitive rehabilitation services.
 - c. Developing joint policies with the Veterans' Administration and other military organizations, including the Oregon National Guard, to improve services delivered to veterans and returning military whether covered by service-related medical benefits or not.
7. The Task Force will address prevention and awareness by:
- a. Developing policy with the Oregon Health Authority to reduce the incidence of TBI through a program of identification (screening and registry), prevention, and public awareness.
 - b. Developing policy with Oregon Youth Authority and the Oregon Department of Education to implement wide-scale TBI screening programs to identify and recommend treatment for students with TBI.
8. The Task Force will address education, employment, and housing by:
- a. Developing policy with the Oregon Department of Education to improve quality of Individual Education Plans and Transition Plans for students with TBI.
 - b. Developing policy with the Office of Vocational Rehabilitation Services to improve employment outcomes of individuals with TBI.
 - c. Developing policy with the Office of Seniors and People with Disabilities, the Office of Developmental Disability Services, the Oregon Health Authority and Oregon Housing and Community Services to improve housing opportunities for people with TBI.
9. The Task Force will also advise on Oregon's Health Resources and Services Administration (HRSA) Traumatic Brain Injury Implementation grants, as needed.





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10. The term Acquired Brain Injury (ABI) is the term used to describe damage resulting from traumatic causes (e.g., TBIs due to car crashes, falls, assaults) and non-traumatic causes (e.g., stroke, tumor, anoxia, meningitis). Persons with ABI due to non-traumatic causes benefit from similar services to those with TBI. The current Task Force will focus on TBI. However, persons with ABI would benefit from a similar policy development effort. Therefore, the Task Force will develop a strategy for future inclusion of ABI in state agency policy and/or legislation.
11. Administrative support for the Task Force will be shared by the Oregon Health Authority, Department of Human Services and the Oregon Department of Education or its designee.
12. This Executive Order hereby supersedes and replaces in total Executive Order 01-02.
13. This order shall expire January 29, 2016.

Done at Salem, Oregon, this 31 day of January, 2013.

John A. Kitzhaber, M.D.
GOVERNOR

ATTEST:

Kate Brown
SECRETARY OF STATE



APPENDIX B: 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 – Psychiatrist – 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.

APPENDIX C: OVERVIEW OF OREGON'S TBI-RELATED LEGISLATION & INITIATIVES

Max's Law

In 2009 Oregon enacted what is now known as Max's Law, named after high school quarterback Max Conratt. The landmark legislation requires mandatory concussion education and concussion response protocols for all Oregon high school athletic programs. Max's Law requires all high school athletic coaches to obtain annual concussion education. This education is designed to ensure that if a high school athlete is suspected of sustaining a concussion, then the coach must respond in a way that will minimize the health impacts of that concussion including removing the athlete from the game or practice and not allowing the athlete to return to play until that athlete is cleared to do so by a qualified health care professional.

Jenna's Law

Where Max's Law only covered high school athletes, Jenna's Law covers all other young athletes (under the age of eighteen) in Oregon who are participating in organized sports. Named after the courageous Jenna Sneva, a skier who suffered multiple concussions during her skiing career, and an Oregon law since 2014, Jenna's Law requires all coaches, referees, players (over the age of twelve) and at least one parent of each player to receive annual concussion education training. The same concussion protocols of removal from the athletic activity, referral to a health care professional after the suspected concussion and return to play only after receiving a health care professional's authorization to do so apply. Jenna's law has been transformative in its effect and it is estimated that over one hundred and fifty thousand Oregonians are required to receive annual concussion education and training as a result of this landmark legislation.

More information on both Max and Jenna's Laws can be found at <http://cbirt.org/ocamp/>.

Return to Learn

Return to Learn (RTL) is the process of returning to school after a brain injury. Brain injury can directly impact a student's ability to learn. Therefore, students may need varying levels of supports and academic accommodations during the recovery process. This is especially true in the early stages of recovery but may be needed for several months as the student recovers. *Return to Learn* simply means addressing each individual student's needs as they come back to school after an injury and as they recover.

In Oregon, the Center on Brain Injury Research and Training (CBIRT) provides technical assistance to schools who want to develop and implement an effective RTL program. This work dovetails with that of the Oregon TBI Team, as a small percentage of students who experience mild TBI/concussion will need ongoing supports. Those students who qualify for IEPs or section 504 plans will be served by the Team, with ongoing oversight by the regional special education program.

TBI Health Care Mandate

In 2009 the legislature enacted SB 381 which required that a health benefit plan as defined in ORS 743.730, now ORS 743B.005, shall provide coverage of medically necessary therapy and services for the treatment of traumatic brain injury. The law is now codified in ORS 743A.175. This law requires that any covered health benefit plan now provide coverage for treatments associated with TBI that are deemed medically necessary.

Bicycle Helmet Laws

One of the first laws to recognize the need for prevention of TBI in Oregon's youth were the mandatory bike helmet laws passed in 1994. Those laws were updated and expanded in 2004 and again in 2015.

In 1994 the legislature mandated that if a person is under the age of 16, and if they are riding a bike (or a passenger on a bike) on a place intended to be used by vehicles, or a place that is open to the public, they must wear a helmet when riding a bike. In 2004 the law was expanded to include skateboards, scooters and in-line skates (ORS 814.485). Oregon law also requires that to meet the requirements of the mandatory helmet law, bicycle helmets must "conform, insofar as practicable, to national safety standards and specifications for such headgear."

Mandatory Motorcycle Helmet Laws

In 1988, the Oregon legislature required anyone riding a motorcycle or a moped (as a driver or a passenger) to wear an approved motorcycle helmet. Helmets must have a label on them saying they meet U.S. Department of Transportation (DOT) standards. Motorcycle crashes were recognized as a leading cause of TBI for motorcycle operators and this law was deemed necessary to reduce the incidence of TBI among this group.

APPENDIX D: AGENCY-SPECIFIC RECOMMENDATIONS

Oregon Health Authority-Public Health Division:

- Increase efforts to educate the public about TBI and how to prevent them;
- Support health-systems level policies that require TBI screening;
- Increase the dissemination and uptake of population-level TBI incidence data;
- Develop and implement strategies to increase recognition of TBI in clinical care; and
- Support the development and implementation of outcome measures (e.g., number of days before return-to-work following mild TBI).

Oregon Health Authority-Mental Health Programs:

- Increase identification of TBI as a co-occurring condition;
- Increase the number of skilled providers who can address co-occurring conditions; and
- Develop protocols for individuals transitioning from the state hospitals to create successful discharges.

Oregon Health Authority-Medical Assistance Programs:

- Work with Coordinated Care Organizations (CCOs), who have some level of discretion in services provided; and
- Increase coverage of post-acute rehabilitation services to incorporate individualized rehabilitation services without set caps and expectations of progress.

Oregon Department of Education:

- Address TBI deliverables and recommendations for support in regional program contracts;
- Develop and provide education for school districts, family members and teachers;
- Convene a work group on developing policies and disseminating best practices;
- Improve communication and coordinated service to youths across education, medical and social service systems; and
- Develop a tracking system for school-aged youth to monitor TBI, particularly students on 504 plans.

Oregon Department of Corrections:

- Improve the strength of community-based partnerships & relationships;
- Improve recognition and tracking of TBI and associated sequelae;
- Develop recovery focused treatment and skills training programs to support eventual release; and
- Develop protocols for individuals with significant TBI sequelae releasing from incarceration to create stable supports upon release.

Oregon Department of Veterans Affairs:

- Increase number of VA-community partnerships;
- Ensure veteran services offices are well staffed and resourced; and
- Increase education and awareness of available resources.

Department of Human Services – General:

- Increase number of providers willing and able to serve individuals with behaviors or other needs due to their brain injury;
- Enhance the availability of family support and respite services regardless of Medicaid eligibility;
- Consider modifying program eligibility between Aging and People with Disabilities (APD), Developmental Disabilities (DD) and OHA-Mental Health (MH) services; and
- Develop policies and procedures to maximize collaboration and successfully transitioning individuals between programs.

Department of Human Services – Aging & People with Disabilities (APD):

- Increase in-home services and supports;
- Maximize the availability, and knowledge, of services and supports that increase independence and well-being;
- Develop a full continuum of services and supports that maximize the individual's independence and expand options in the least-restrictive settings throughout the state; and
- Develop employment and education supports within the Medicaid Long Term Care System.

Department of Human Services – Office of Developmental Disability Services (ODDS):

- Develop processes and procedures for transitioning children who are moving from ODDS to the APD system to ensure the continuity of care;

- Provide outreach to families and partner with the education system to ensure that families are encouraged to apply for DD services in a timely manner; and
- Maximize the availability, and knowledge, services and supports that increase independence and well-being.

Department of Human Services - Vocational Rehabilitation:

- Work with young adults in transition to ensure the best start in work;
- Increase services to individuals who sustain their TBI after 22 years of age;
- Increase provision and training of assistive technology; and
- Examine why services for this population have decreased over the past five years.

Specific recommendations from stakeholders with BI and their family members:

- Develop and provide more respite care and opportunities for social activities;
- Create mechanisms to support families in the development of plans for the future when parents aren't around; and
- Remember to acknowledge PTSD for both survivors of TBI and their families.