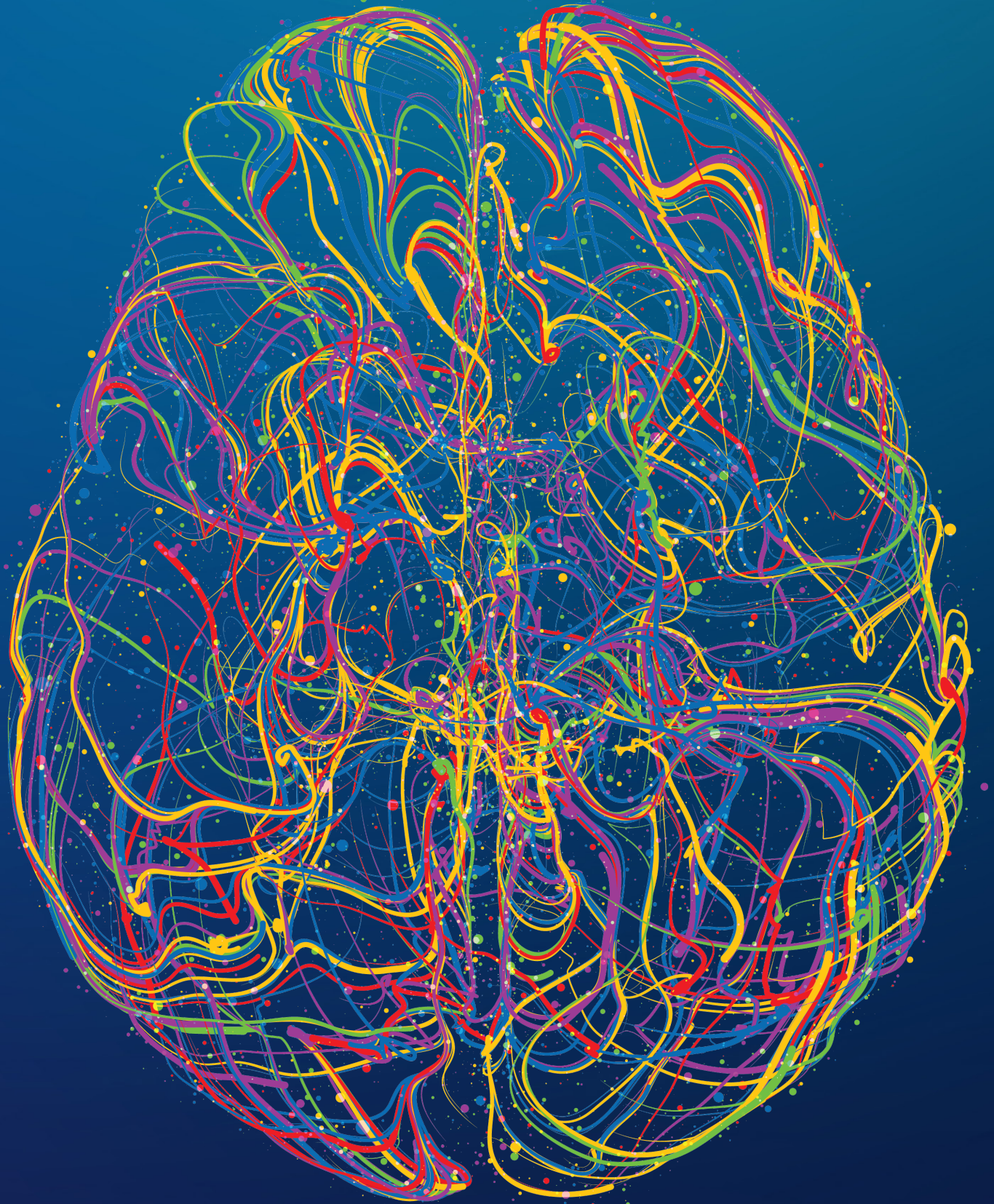


West Virginia State Plan for Traumatic Brain Injury



2023-2027

This product was supported, in part by grant number 90TBSG0069-02-02, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express their findings and conclusions freely. Points of view or opinions do not, therefore, necessarily represent official ACL policy.



Acknowledgments

The West Virginia State Plan for Traumatic Brain Injury 2023-2027 was developed by the West Virginia Traumatic Brain Injury Advisory Board along with its lead agency, the West Virginia University Center for Excellence in Disabilities. The plan represents a collaborative effort among members of the West Virginia Traumatic Brain Injury Advisory Board and other stakeholders from across the state.

We would also like to acknowledge contributions from the people with lived experience, caregivers and professionals in West Virginia who completed the Traumatic Brain Injury Needs Assessment survey. Thank you for providing guidance and content. Your contributions were integral to developing this plan.

Table of contents

- Purpose 1
- Traumatic Brain Injury Defined 1
- Traumatic Brain Injury in West Virginia 1
- Needs Assessment Summary 2
- West Virginia Traumatic Brain Injury Advisory Board 3
- Focus, Goals, & Activities 4
 - Focus Area 1: Service System Enhancement 4
 - Focus Area 2: Advocacy 6
 - Focus Area 3: Awareness & Education 7

Purpose

The West Virginia State Plan for Traumatic Brain Injury (TBI) intends to define measurable and achievable goals that address the needs of people with lived experience of TBI and their caregivers. The goals defined in this document are designed to be addressed within a five-year timeframe (2023-2027). This document offers advice for program planning, design, evaluation and implementation of state services to support people with lived experience and strengthen West Virginia's ability to serve those with TBI effectively.

Traumatic Brain Injury Defined

According to the West Virginia State Code §9-10-1, "Traumatic brain injury" means an acquired injury to the brain, including brain injuries caused by anoxia due to near drowning. "Traumatic brain injury" does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma.

Traumatic Brain Injury In West Virginia

Traumatic Brain Injury caused by falls, violence, accidents or sports is one of the main causes of death and disability in the United States. According to the Centers for Disease Control and Prevention (CDC), West Virginia has the highest age-adjusted unintentional injury fatality rate (Peterson et al., 2021). In 2015, 411 people died from sustaining a TBI in West Virginia. This number represents 20% of all injury-related deaths in the state. The annual TBI-related deaths in West Virginia were 2.4% for people between the ages of 0-24 months, and 40.95% for people over the age of 65 (West Virginia Violence & Injury Prevention Program).

TBI prevalence is particularly high in many underserved populations including individuals that use substances. West Virginia is one of the top ten states for the rate of opioid prescriptions at 69.3 per 100 people compared to 51.4 nationally.

There were over 700 deaths in West Virginia involving drug overdoses in 2018 (NIDA, 2020). Studies have suggested that those hospitalized with their first TBI before the age of six or between the ages of 16-21 are three times more likely to be diagnosed with a substance use disorder (SUD) by age 25 (McKinlay, Et al., 2008).

Domestic violence is also a major public health crisis, and victims/survivors of such assaults are at risk of sustaining a TBI due to the nature of the violence (Corrigan et al., 2003). According to a 2019 study, of the 3.2 million women who were victims/survivors of intimate partner violence (IPV), 1.6 million sustained a TBI. Someone in West Virginia calls a domestic violence hotline every nine minutes. **(con't)**

39.4% of West Virginia women and 36.3% of West Virginia men experience intimate partner physical violence, intimate partner sexual violence and/or intimate partner stalking in their lifetimes. Two out of three women in West Virginia who are murdered each year are the result of domestic violence (National Coalition Against Domestic Violence, 2021).

Another important health concern is the incidence of TBI in justice-involved populations, with reports of 25-87% of inmates experiencing a TBI (CDC, n.d.). People in correctional facilities may not be screened for a TBI or may face challenges with getting TBI-related care. The unsheltered community faces similar challenges. Compared to the general population, people who experience homelessness are two to four times more likely to have any type of TBI and up to 10 times more likely to have a history of a moderate or severe TBI (CDC, n.d.). There is also a relationship between substance use, violence and homelessness, however there is limited reporting of TBI in these populations. Information is lacking in West Virginia regarding the prevalence of such injuries despite a national trend for a connection between TBI and these at-risk populations.

TBI Needs Assessment Summary



Several factors influenced the direction of this West Virginia State Plan for TBI. One of these factors was the TBI Needs Assessment. This assessment, specifically designed for West Virginia, used surveys to inform the needs, gaps and barriers that must be addressed to improve access to services for individuals with TBI and their families. This was an opportunity to provide valuable, individualized feedback that can assist in steering TBI service efforts across West Virginia.

Participants from the following populations were recruited for this needs assessment:

- 1. West Virginia residents over the age of 18 who have either a medical record or self-report of a TBI in the last 10 years.**
- 2. Family members and caregivers of a person with a TBI.**
- 3. Professionals/providers for people with TBI.**

Collecting information from these three groups provided a comprehensive look at TBI in the state that accounts for a diverse set of experiences and perspectives. The goals specified in this document stem from the needs assessment responses.

Results

The two most cited barriers to service among those with lived experience of a TBI were “unaware of ways to get services” and “difficulty finding a provider who understands brain injury”. Caregivers echoed the sentiments of the latter, ranking “hard to find a provider who understands TBI” as their most common barrier to service.

This data suggests that removing barriers to appropriate services and furthering brain injury education are two priorities for the state. Due to the survey results, we created several goals directly related to the subject. These goals were then further categorized into several focus areas, grouping goals that interconnect and impact each other. For this report, access to services is addressed in focus area 1 (Service System Enhancement) and furthering provider and lived experience knowledge about brain injury is addressed in focus area 3 (Awareness & Education).

You can learn more about the contents and results of the needs assessment by using the following link: <https://acrobat.adobe.com/link/review?uri=urn:aaid:scds:US:fe3274cc-b689-38ab-9433-f4606fee24a8>

West Virginia Traumatic Brain Injury Advisory Board

In addition to the needs assessment, additional focus areas were determined through the careful deliberation of the West Virginia TBI Advisory Board. This board ensures a variety of stakeholders participate in determining the needs of individuals with TBI, their families and support systems. The board is composed of consumer and professional stakeholders including 29 voting members, 10 state agency representatives who serve as non-voting members, and staff to aid the committee. Voting members must be comprised of at least 50% people with lived experience, including those from diverse and underserved populations. The board works with the West Virginia University Center for Excellence in Disabilities TBI program to offer support, guidance and statewide decision-making on matters relating to persons with lived experience. This board serves in an advisory role and uses a collaborative approach to build West Virginia’s capacity to serve people with lived experience in the state.



Focus, Goals & Activities

Collectively, the needs assessment, board review, and additional data gathering from individuals with TBI produced three focus areas that guide the direction of system enhancements from 2023-2027. Accompanying each focus area are a series of goals that specify how to pursue improvements for each category of need. Through the insights of the needs assessment and advisory board, the following focus areas were identified:

1. Service System Enhancement

2. Advocacy

3. Awareness & Education

You can find more details about each focus area and their respective goals in the following pages of this document.

Focus Area 1: Service System Enhancement

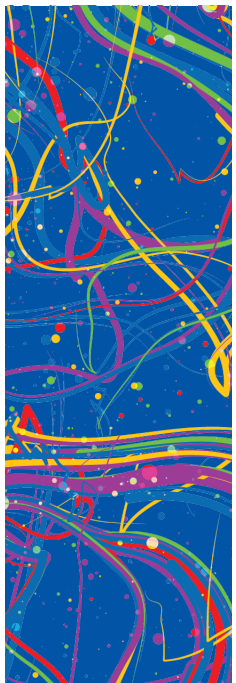
West Virginia will develop a person-centered traumatic brain injury system of care that identifies and addresses the needs and services across the lifespan of individuals with TBI and their families. According to the Administration for Community Living (ACL), “Person-centered planning (PCP) is a process for selecting and organizing the services and supports that an older adult or person with a disability may need to live in the community. Most important, it is a process that is directed by the person who receives the support” (2021).

Goal 1: Develop a system to capture the prevalence and incidence of people with lived experience in West Virginia.

- Increase the number of hospitals and the timeframes of those reporting to the TBI Registry.
- Explore systems such as the Behavioral Risk Factor Surveillance System to better capture the prevalence of TBI in West Virginia.
- Accurately identify the prevalence of TBI, including concussion, and establish data sharing relationships with those serving rural populations, at-risk populations (e.g., substance use disorder, those experiencing homelessness, survivors of domestic violence, incarcerated populations, economically disfranchised), military/veterans, athletes and those with co-occurring conditions.
- Design and implement a concussion surveillance system.



Goal 2: Identify the needs of people with TBI, their caregivers and professionals, and develop strategies based on those needs.



- Conduct a statewide needs assessment of the perceptions of people with TBI, their caregivers and professionals about the availability of current and needed services, and publicly report the findings including community reintegration and participation.
- Identify community and family needs in West Virginia and implement strategies such as using financial support in the state for unmet needs and customized employment opportunities to help overcome the impact of COVID-19.
- Identify the needs of people with TBI, their caregivers and professionals, and develop strategies based on those needs.
- Advocate to expand support services for people with TBI and their caregivers (e.g., inpatient rehabilitation facilities, day treatment facilities, and mentor programs).
- Develop an infrastructure for support groups throughout the state for people with TBI and caregivers.
- Create a collaborative resource hub/webpage containing information and West Virginia's TBI related resources.

Goal 3: Increase the number and types of partnerships to build capacity for those with TBI.

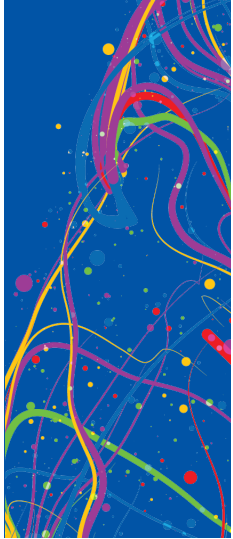


- Maintain a TBI advisory board for the state of West Virginia with at least 50% representative of those with TBI.
- Establish and maintain partnerships with West Virginia county state agencies, advocacy organizations and healthcare providers in all 55 counties with open lines of communication and cooperation.
- Develop and implement a patient navigation system with partners to connect the medical home with resource coordination services for people with TBI.
- Develop a methodology for monitoring progress of the state plan.

Focus Area 2: Advocacy

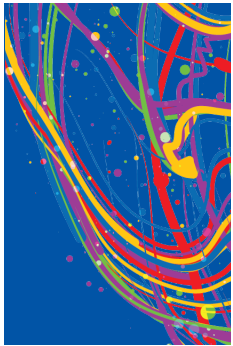
Empower individuals with TBI and their support system to improve independence, systemic advocacy (legislative and policy change), self-advocacy and reintegration into the community.

Goal 4: Explore opportunities for systemic advocacy.



- Advocate for the expansion of West Virginia's state definition of TBI to include anoxia due to near strangulation, carbon monoxide poisoning, drug overdose and smoke inhalation by examining incident rates and comparing definitions to other similar states.
- Develop standard protocols for point of care clinics (Urgent Care, etc.), emergency rooms and other additional providers on topics such as concussion diagnosis-symptom score, concussion vital signs and awareness of concussions in medical settings, and return to learn/play/work.
- Evaluate TBI screening tools and make a policy recommendation for a standardized tool to be used across the state.
- Identify and coordinate services with professional veterans' advocates related to TBI.

Goal 5: Explore opportunities for self-advocacy.



- Improve voting access including electronic absentee voting, disseminate information about steps to voting, ensuring proper access and accommodations in voting facilities.
- Provide tools and training for legislative advocacy to those with lived experience.
- Advocate for those with lived experience to have access to more public forums regarding TBI discourse.
- Disseminate information and training for those with lived experience on advocating for their needs when interacting with medical/service structures.

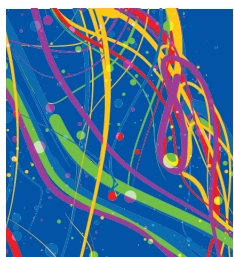


Focus Area 3: Awareness & Education

Educate and train community members and professionals to be responsive to the needs of people with TBI as they re-enter and/or participate in educational, employment and community opportunities.

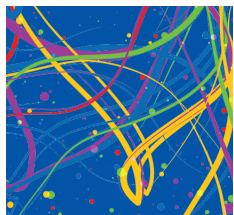


Goal 6: Increase awareness and knowledge of prevention and the consequences of TBI within the state for people with TBI, caregivers and professionals.



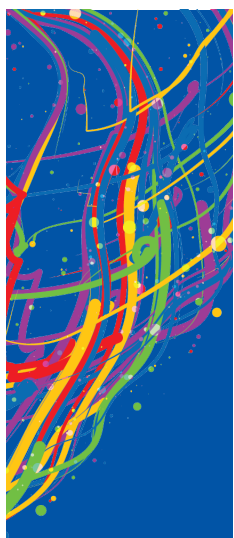
- Develop and coordinate a statewide TBI conference for people with TBI, family members, caregivers, stakeholders, professionals and educators.
- Develop a statewide quarterly virtual newsletter.
- Identify stakeholders and partners to provide trainings on TBI to their employees.
- Train regarding dual diagnosis between TBI and other co-occurring experiences.

Goal 7: Disseminate information and spread awareness of Acquired Brain Injury (ABI) and its impact.



- Gather information regarding the prevention and consequences of ABI.
- Develop a system to better capture and understand the needs of those with ABIs.
- Deliver educational materials regarding the impact of ABIs to relevant stakeholders.

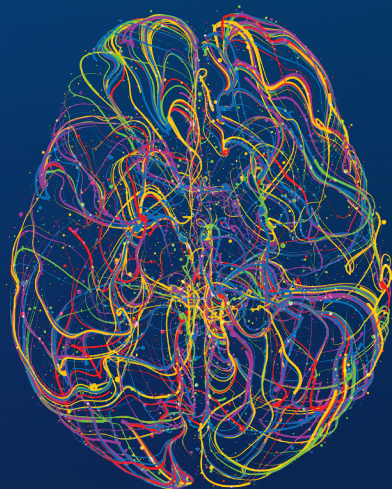
Goal 8: Develop a professional training infrastructure.



- Increase the number of Certified Brain Injury Specialist trainings across the state.
- Expand simulation labs for medical professional students within the state focusing on assessment and intervention plans for people with TBI and their caregivers.
- Provide specialized TBI trainings for providers throughout the state across multiple fields.
- Standardize implementation of concussion training/education in various settings (school personnel, emergency room services, West Virginia Athletic Training Association, etc.).
- Develop an online portal for virtual trainings to be used by programs throughout the state.
- Advocate for continuing education requirements for practitioners who work with TBI across different fields.

References

- Administration for Community Living (2021). Person Centered Planning. Retrieved from [https://acl.gov/programs/consumer-control/person-centered-planning#:~:text=Person%2Dcentered%20planning%20\(PCP\),person%20who%20receives%20the%20support](https://acl.gov/programs/consumer-control/person-centered-planning#:~:text=Person%2Dcentered%20planning%20(PCP),person%20who%20receives%20the%20support)
- Appalachian Regional Commission. (June 2020). County economic status and number of distressed areas in West Virginia, Fiscal Year 2021. Retrieved from <https://www.arc.gov/wp-content/uploads/2020/07/CountyEconomicStatusandDistressAreasFY2021WestVirginia.pdf>
- Centers for Disease Control and Prevention: Health Disparities and TBI (n.d.). Retrieved from <https://www.cdc.gov/traumaticbraininjury/health-disparities-tbi.html>
- Centers for Disease Control and Prevention: National Center for Health Statistics (2022). Drug Overdose Mortality by State. Retrieved from <https://www.cdc.gov/nchs/pressroom/states/westvirginia/wv.htm>
- Centers for Disease Control (n.d.). Traumatic Brain Injury in Prisons and Jails: An Unrecognized Problem. Retrieved from https://www.cdc.gov/traumaticbraininjury/pdf/prisoner_tbi_prof-a.pdf
- Corrigan, J. D., Wolfe, M., Mysiw, W. J., Jackson, R. D., & Bogner, J. A. (2003). Early identification of mild traumatic brain injury in female victims of domestic violence. *American journal of obstetrics and gynecology*, 188(5 Suppl), S71–S76. <https://doi.org/10.1067/mob.2003.404>
- Erickson, W., Lee, C., & von Schrader, S. (2019). 2017 Disability Status Report: West Virginia. Ithaca, NY: Cornell University Yang-Tan Institute on Employment and Disability (YTI). Retrieved from https://www.disabilitystatistics.org/StatusReports/2017-PDF/2017-StatusReport_WV.pdf?CFID=20534414&CFTOKEN=25b8a39669025425-8E7EB889-EC34-35BA-0723C7DF61C5B891
- McKinlay, Et al. (2008). Prevalence of traumatic brain injury among children, adolescents and young adults: prospective evidence from a birth cohort. DOI: 10.1080/02699050801888824
- National Coalition Against Domestic Violence. (2016). Domestic violence in West Virginia. Retrieved from https://assets.speakcdn.com/assets/2497/west_virginia.pdf
- NIDA. 2020, April 3. West Virginia: Opioid-Involved Deaths and Related Harms. Retrieved from <https://www.drugabuse.gov/drug-topics/opioids/opioid-summaries-by-state/west-virginia-opioid-involved-deaths-related-harms> on 2021, May 11.
- Peterson, C., Luo, F., & Florence, C. (2021). State-Level Economic Costs of Fatal Injuries – United States, 2019. *MMWR. Morbidity and mortality weekly report*, 70(48), 1660–1663. <https://doi.org/10.15585/mmwr.mm7048a2>
- United States Census Bureau (2022). Quick Facts West Virginia. Retrieved from <https://www.census.gov/quickfacts/WV>.
- Valera, M., Eve (2019). Correlates of Brain Injuries in Women Subjected to Intimate Partner Violence: Identifying the Dangers and Raising Awareness. Retrieved from <https://doi.org/10.1080/10926771.2019.1581864>



West Virginia University®

CENTER FOR EXCELLENCE IN DISABILITIES
TRAUMATIC BRAIN INJURY SERVICES