

Traumatic Brain Injury Surveillance and Program Report 2018-2019

Division of Family Health and
Wellness

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INTRODUCTION

In 1993, the Tennessee General Assembly passed legislation establishing the Traumatic Brain Injury (TBI) Program within the Department of Health to address the unique needs of persons with brain injury and their families. The legislation outlines the components of the program which includes the appointment of a program coordinator and the development of a TBI registry. The legislation also calls for the submission of this Annual Report summarizing the registry statistics, the administration of the program and recommendations for improving service delivery for persons with brain injury.

The TBI registry collects data on a calendar year while the Program operates on the fiscal year. Therefore this report contains data information from calendar year January - December 2018 and program information from fiscal year July 2018 – June 2019.

Since analysis of the data provides the foundation of program activities, in this report, the data is reviewed first and followed by the description of progress in other program components.

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Traumatic Brain Injury Surveillance Report

January 2018 – December 2018

EXECUTIVE SUMMARY

In 1993, the Tennessee General Assembly established the Tennessee Traumatic Brain Injury Program to address the needs of persons with brain injury and their families. Tennessee Code Annotated 68-55-203 mandates that the Department of Health maintain a registry of these patients. Data collection began in 1996 and an annual report summarizes the characteristics of patients submitted to the registry. Since inception, the registry has collected data on over 150,000 patients and has connected persons with brain injury in Tennessee with resources vital for their recovery. Data from the registry has been advantageous in detecting populations at risk for and prevalent mechanisms of TBI in order to improve and tailor prevention efforts, such as supporting the universal motorcycle helmet law and developing the Safe Stars initiative to reduce youth sports concussion. The findings in this report serve to continue and enhance these efforts.

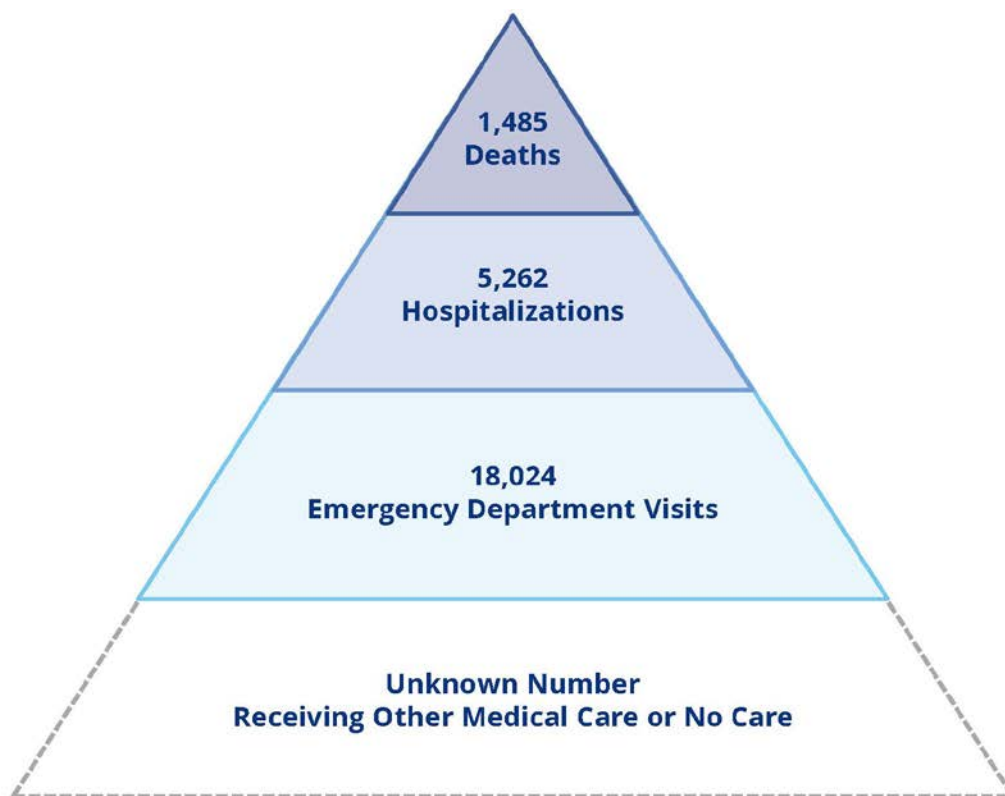
Key Findings

- **Overall:** During the 2018 calendar year, a total of 8,023 patients were reported to the TBI registry. Of these, 7,141 were discharged from the hospital alive and the remaining 882 were deceased.
- **Discharge status:** A substantial percentage of TBI patients required extended care following their injury: 35% of patients who were discharged from the hospital alive went on to rehabilitation, skilled nursing, or other long-term care facilities.
- **Age:** 58% of TBI patients reported to the registry were adults over 54 years of age. Females ages 75 to 84 comprised the largest proportion of registry patients.
- **Gender:** 60% of TBI patients were males. The number of male patients exceeded females in every age group less than 75 years. The gender difference varied within racial/ethnic groups: 57% of White non-Hispanic patients were male compared to 71% of Black non-Hispanic patients and 75% of Hispanic patients.
- **Type of Injury:** Intracranial injuries were by far the most common type of TBI, present in 94% of patients (sometimes in conjunction with other TBI diagnoses).
- **Causes:** Falls were the leading cause of TBI, followed by motor vehicle crashes. Especially wide gender disparities existed for injuries caused by assault and intentional self-harm, where males made up 81%, and 74% of patients respectively.
- **Annual Trend:** The total number of TBI registry patients increased by 8.4% from 2017 to 2018, a statistically significant change.

Introduction

A traumatic brain injury is a disruption in the normal function of the brain that can be caused by a bump, blow, or jolt to the head, or penetrating head injury¹. Because of their nature, TBIs are a major cause of death and disability, making these injuries a significant public health problem across the United States. In Tennessee, a total of 24,771 TBI-related ED visits, hospitalizations, and deaths occurred during 2017² (Figure 1).

Figure 1. TBI-related deaths, hospitalizations, and ED visits among Tennessee residents during calendar year 2017.



Data Source: Tennessee Department of Health, Office of Vital Records and Vital Statistics; Tennessee Department of Health, Office of Population Health Surveillance.

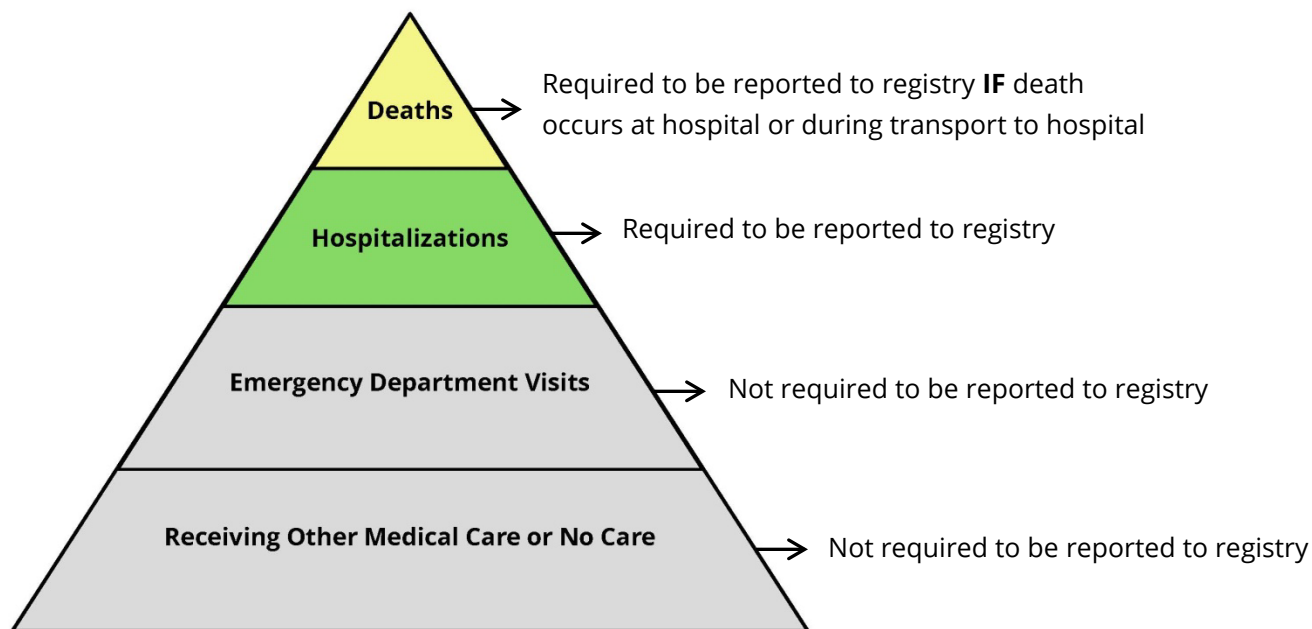
¹ Basic Information about Traumatic Brain Injury and Concussion. (2019, March 6) Retrieved from: <https://www.cdc.gov/traumaticbraininjury/basics.html>

²Note that data source is the state Vital Statistics and Hospital Discharge databases (not the TBI registry) in order to have complete counts of TBI-related deaths and emergency department visits, all of which are not reported to the registry (see Figure 2). Because these data sources take longer to finalize, this data is a full calendar year behind the registry data presented in this report for 2018.

In order to address the unique needs of Tennesseans who have sustained a TBI, the Tennessee General Assembly established the Tennessee Traumatic Brain Injury Program and registry in 1993. The Tennessee Traumatic Brain Injury registry began collecting brain injury data in 1996 with the core purpose of connecting persons with brain injury to resources available to them during the course of their recovery.

All non-federal hospitals are mandated to report any TBI that results in an inpatient hospitalization or death that occurs either at or during transport to the hospital (Figure 2). TBI-related deaths that occur outside the purview of the hospital (e.g., fatal gunshot wounds of the head that are declared dead at the scene) are not reported to the registry. TBI patients who are treated only in the emergency department or who receive other or no medical care are also not included in the registry.

Figure 2. Pyramid of traumatic brain injury showing which encounters meet criteria for required report to the registry.



Patients meeting these criteria must be reported regardless of residence, although only Tennessee residents receive a letter from the program regarding available services. TBI-related emergency department visits are increasingly reported, but are not compulsory.

The data within this report describe the causes of TBIs in Tennessee and support the planning and implementation of initiatives to reduce these injuries throughout the state. Information presented in this surveillance summary is based on final data collected by the Tennessee TBI registry for the calendar year of 2018.

Note on Coding Terminology

In the data hospitals submit to the registry, diagnoses are captured in the International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) coding system. Table 1 includes the ICD-10-CM diagnosis codes used for traumatic brain injury surveillance. If one or more of these diagnoses codes appears in a patient's record, the patient must be reported to the TBI registry.

Table 1. Surveillance case definition for traumatic brain injury³.

ICD-10-CM Code	Description
S02.0, S02.1-	Fracture of skull
S02.8, S02.91	Fracture of other specified skull and facial bones; Unspecified fracture of skull
S04.02, S04.03-, S04.04-	Injury of optic chiasm; injury of optic tract and pathways; injury of visual cortex
S06-	Intracranial injury
S07.1	Crushing injury of skull
T74.4	Shaken infant syndrome

"-" indicates any 4th, 5th or 6th character

7th character of A or B for S02.0, S02.1-, S02.8 and S02.91

7th character of A for S04.02, S04.03-, S04.04-, S06-, S07.1 and T74.4

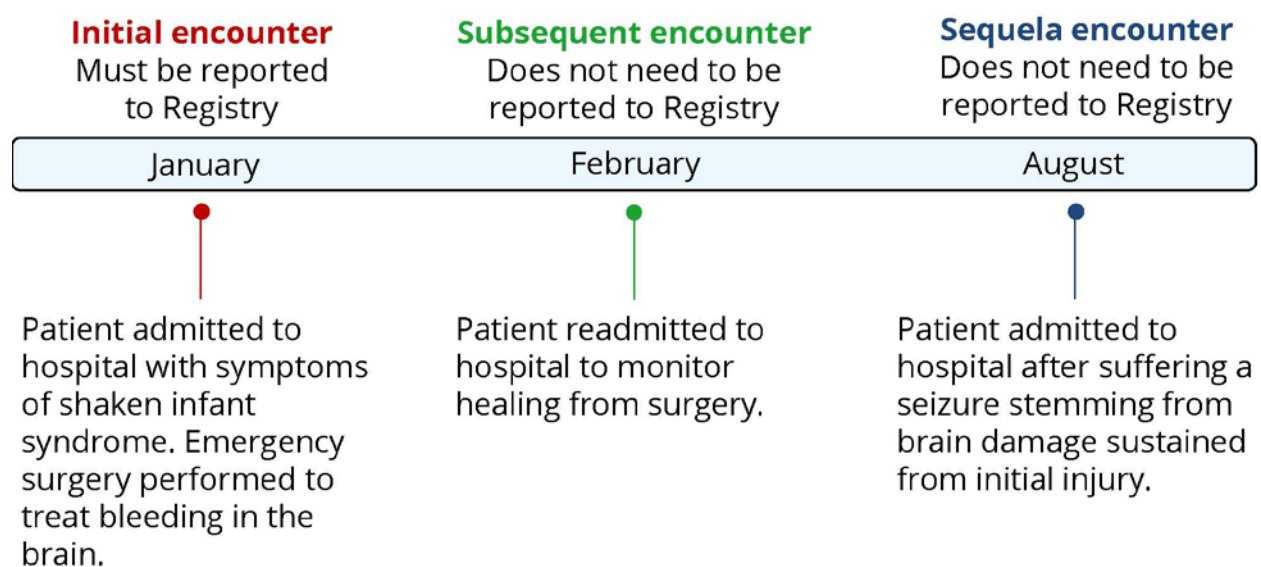
The notes below Table 1 state that the definition only includes diagnoses codes with a 7th character of 'A' or 'B', which indicate "initial encounters" for the injury. This means that the patient was receiving active treatment for the traumatic brain injury. ICD-10-CM also includes diagnoses codes for "subsequent encounters" (7th character of 'D' to 'R') and "sequelae" (7th character of 'S'). Subsequent encounters are defined as encounters after the patient has already received active treatment for the injury and is now receiving routine care during the healing or recovery phase. Examples of subsequent care for an injury include visits to change or remove a cast, remove an external or internal fixation device, adjust medication, and other types of routine follow-up⁴.

³ Hedegaard, H., Johnson, R. L., Warner, M., & Chen, L. (2016). Proposed Framework for Presenting Injury Data Using the International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) Diagnosis Codes. *National Health Statistics Reports*, 89, 1-20. Retrieved July 30, 2019, from <https://www.cdc.gov/nchs/data/nhsr/nhsr089.pdf>.

⁴ Mitchell, D. (2014, April 1). Initial, Subsequent, or Sequela Encounter? Retrieved July 30, 2019, from Advancing the Business of Healthcare: <https://www.aapc.com/blog/27096-initial-subsequent-sequela-encounter/>

Sequelae, on the other hand, are defined as complications or conditions that arise as a direct result of an injury, such as scar formation after a burn. These can be thought of as “late effects” of an injury. For the Program’s purposes, there is no need for hospitals to report multiple hospitalizations stemming from the same TBI. Hospitals are therefore only required to report initial encounters to the registry, and not subsequent encounters or sequelae. Figure 3 illustrates a hypothetical example of three hospital encounters for a patient diagnosed with shaken infant syndrome. Note that only the first hospitalization associated with active treatment for an acute traumatic brain injury needs to be reported to the registry.

Figure 3. Hypothetical example of different hospital encounter types that could result from one traumatic brain injury.



General

As stated in the Introduction, hospitals are mandated to report all TBIs that result in hospitalization and deaths that occur at or during transport to the hospital. TBI-related deaths that occur outside of the hospital are not included in the registry.

In 2018, 8,023 patients were reported to the registry with a traumatic brain injury

During calendar year 2018, a total of 8,023 patients met the criteria for mandated report to the registry. Of these patients, 7,141 were discharged from the hospital alive and the remaining 882 were deceased. The average length of hospital stay amongst all TBI registry patients was 6.6 days.

Table 2 describes the status of the 7,141 patients who were alive at discharge. Most patients (53%) had routine discharges to home, but a considerable percentage required extended care following their hospitalization. More than one-third (35%) of patients went from the hospital to a rehabilitation, skilled nursing, or other long-term care facility.

Table 2. Discharge status of registry patients who left the hospital alive.

Discharge status	Number	Percent
Alive at discharge	7141	–
Routine discharge to home	3803	53
Discharge to home under care of organized home health service organization	573	8
Discharged to another hospital for further care	156	2
Discharged to rehabilitation, skilled nursing, or other long-term care facility (includes hospice home care)	2471	35
Other (includes left against medical advice and discharged to jail, prison, or other detention facilities)	138	2

Demographics

The majority of traumatic brain injuries reported to the registry occurred in the older adult population: 58% (N=4,659) of patients were over 54 years of age. More males (60%, N=4784) sustained traumatic brain injuries than females, and this difference was seen within nearly all age groups. However, within the two oldest age groups, the trend changed and most patients were female. As demonstrated in Figure 4, of the age and sex groups examined, females between the ages of 75 and 84 made up the largest category. One out of every ten patients reported to the TBI registry was a woman between the ages of 75 and 84.

*58% of TBI patients
were older adults over
54 years of age*

Figure 4. Number of TBI registry patients by age group and sex, 2018.

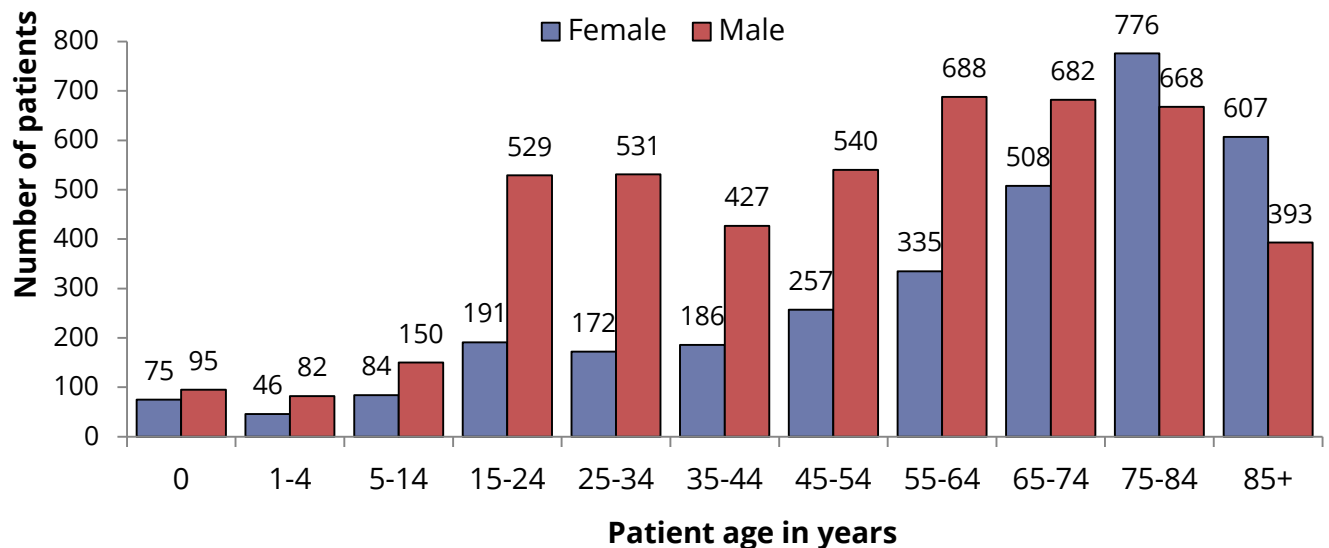
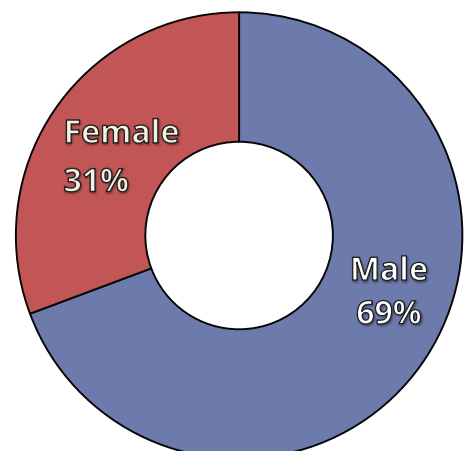


Figure 5. TBI registry patients under the age of 65 by sex, 2018.

Excluding the senior population, the gender difference widened (Figure 5). Amongst TBI patients less than 65 years of age (N=4388), 69% (N=3039) were male. The age group with the largest gender gap was from 25 to 34 years, where the number of male TBI patients was over three times that of female TBI patients.



The racial/ethnic demographics of the TBI patients reported to the registry reflect the demographics of Tennessee as a whole. Overall, 79% of patients were White non-Hispanic (Figure 6). Looking within the three main racial/ethnic groups, different patterns emerged. The male majority seen amongst TBI patients overall was much more pronounced for Black non-Hispanic and Hispanic patients (Figure 7). Over 70 percent of patients in these groups were male, compared to 57 percent of White non-Hispanic patients. The age distribution of TBI patients also differed greatly across the racial/ethnic groups. The average age of Black non-Hispanic and Hispanic patients was much younger than that of White non-Hispanic patients (Figure 8). Half (50%) of all non-Hispanic White patients were seniors 65 and older, but for non-Hispanic Black and Hispanic patients, the percentage of senior patients was 22% and 12% respectively.

Figure 6. Race/ethnicity of TBI registry patients, 2018.

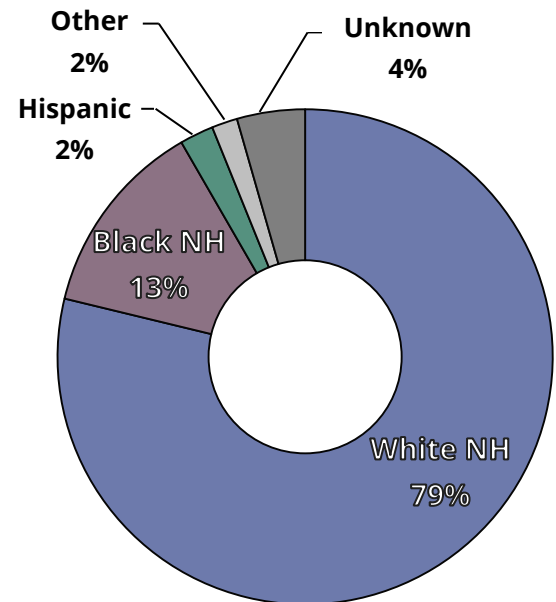


Figure 7. Percentage of male and female TBI registry patients by race/ethnicity, 2018.

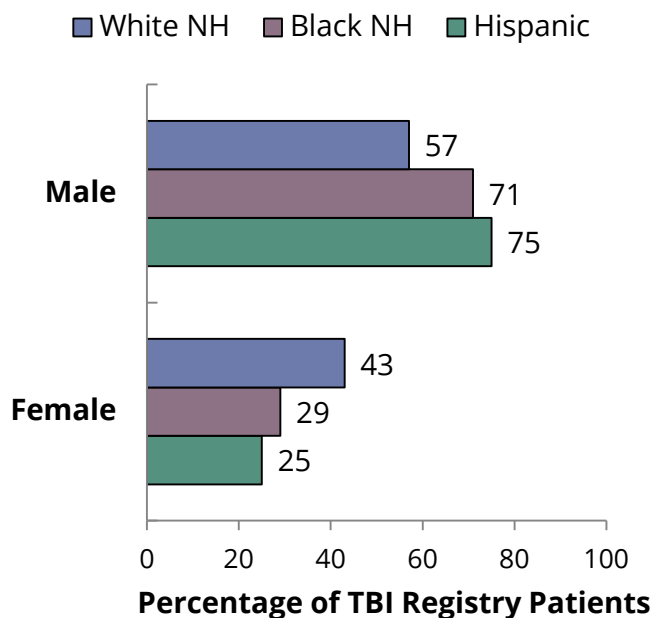
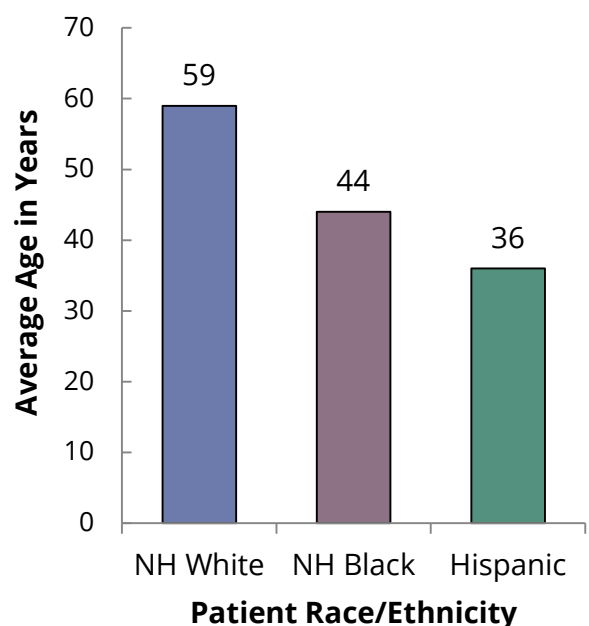


Figure 8. Average age of TBI registry patients by race/ethnicity, 2018.



Brain Injury Diagnoses

Every patient reported to the registry had at least one traumatic brain injury diagnosis, and many patients had multiple types of TBI. By far, the most common traumatic brain injuries reported were categorized as intracranial injuries (Figure 9). Although this may not have been the primary TBI diagnosis in each case, 94% (N=7,558) of registry patients were diagnosed with at least one intracranial injury. Skull fractures were the next most common type of TBI, diagnosed in 24% of registry patients. The other types of TBI were comparatively extremely uncommon amongst registry patients.

Figure 9. Number of traumatic brain injuries by diagnosis category amongst registry patients, 2018.

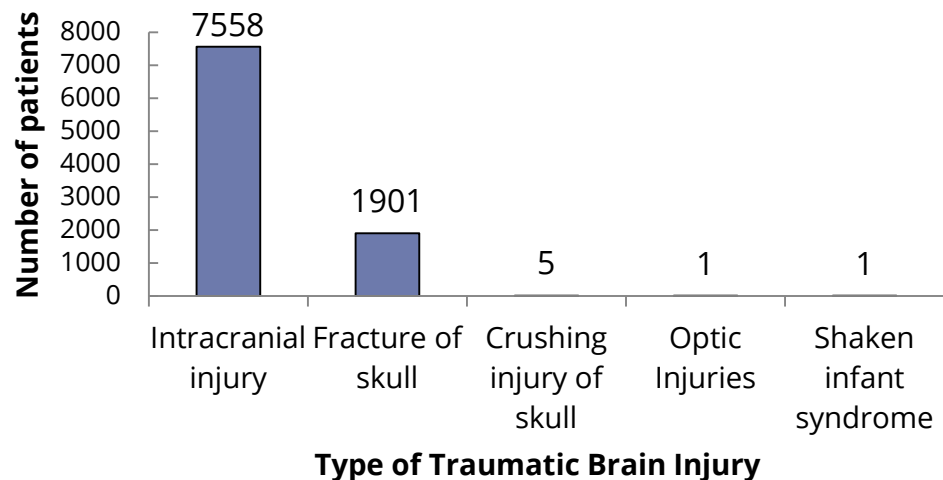
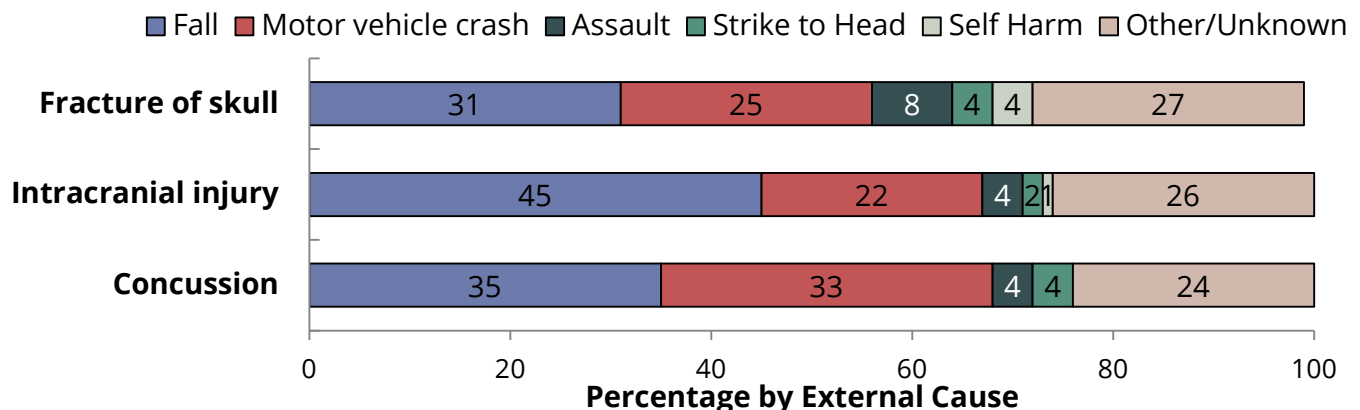


Figure 10 shows the cause of injury for patients with two main types of TBI diagnoses, intracranial injuries and skull fractures, and for patients with concussions, the least severe variety of intracranial injury. Accidental falls were the most common cause of injury for patients with each type of TBI, followed by motor vehicle crashes.

Figure 10. Cause of injury amongst registry patients diagnosed with skull fracture, intracranial injury, and concussion, 2018.



The traumatic brain injuries reported to the registry are classified as mild, moderate, severe or penetrating. The criteria for each severity level are listed in Table 3. For patients with multiple types of TBI, the highest level of severity was assigned. For example, a patient diagnosed with one type of 'mild' TBI and another type of 'moderate' TBI would be classified as 'moderate'.

Most registry patients (79%) sustained moderate TBIs, with smaller percentages diagnosed with mild (12%), severe (5%), and penetrating (5%) brain injuries (Figure 11).

Figure 11. TBI severity level for registry patients, 2018.

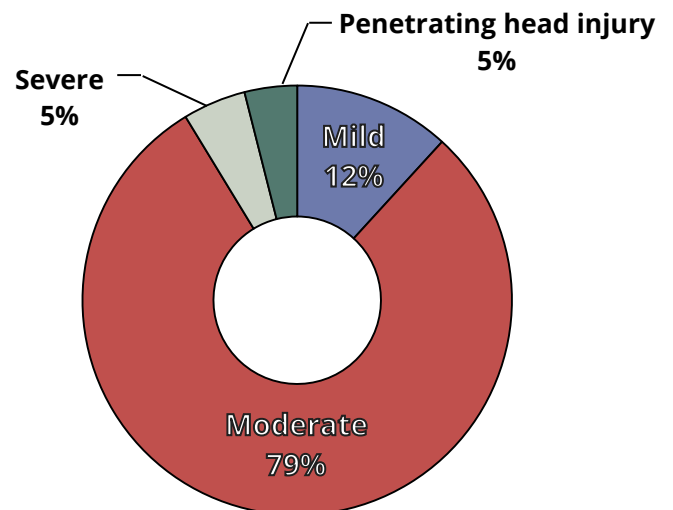


Table 3. Criteria for levels of TBI severity.

Mild TBI	Moderate TBI	Severe TBI	Penetrating TBI
➤ Confused or disoriented state which lasts less than 24 hours <i>or</i> ➤ Loss of consciousness for up to 30 minutes <i>or</i> ➤ Memory loss lasting less than 24 hours <i>Excludes penetrating TBI</i>	➤ Confused or disoriented state which lasts more than 24 hours <i>or</i> ➤ Loss of consciousness for more than 30 minutes, but less than 24 hours <i>or</i> ➤ Memory loss lasting more than 24 hours, but less than 7 days <i>or</i> ➤ Meets criteria for mild TBI, but with an abnormal CT scan <i>Excludes penetrating TBI</i>	➤ Confused or disoriented state which lasts more than 24 hours <i>or</i> ➤ Loss of consciousness for more than 24 hours <i>or</i> ➤ Memory loss lasting more than seven days <i>Excludes penetrating TBI</i>	➤ Head injury in which the scalp, skull, and dura mater (the outer layer of the meninges) are penetrated

External Cause

External cause refers to the mechanism by which the patient sustained their traumatic brain injury. Hospital reporters are not required to include this information, as the mechanism is often unknown, but they are encouraged to capture this whenever possible. For 2018, 83% of registry patients had information about the external cause of injury, a nine percentage point improvement from 2017.

Overall, falls were the most common cause of injury at 44% (N=3554) of registry patients followed by motor vehicle crashes at 22% (N=1748) (Figure 12). Cause of injury differed greatly across age groups (Figure 13). Amongst children less than five and seniors 65 and older, falls dominated all other external causes, accounting for 42% and 68% of patients respectively. Motor vehicle crashes made a relatively minor contribution: 12% of TBI patients less than five and 9% of patients 65 and older. This trend reversed amongst youth over five and younger adults. Here, motor vehicle crashes were the leading external cause of injury, representing 43% of TBIs to patients aged 5 to 24 and 38% of TBIs to patients aged 25 to 44. Falls caused just 12% and 15% of TBIs in these age groups, respectively.

Figure 12. Cause of injury amongst registry patients, 2018.

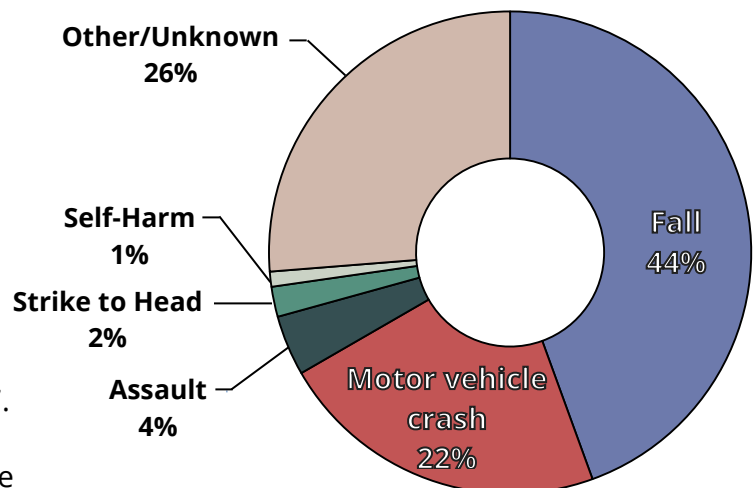
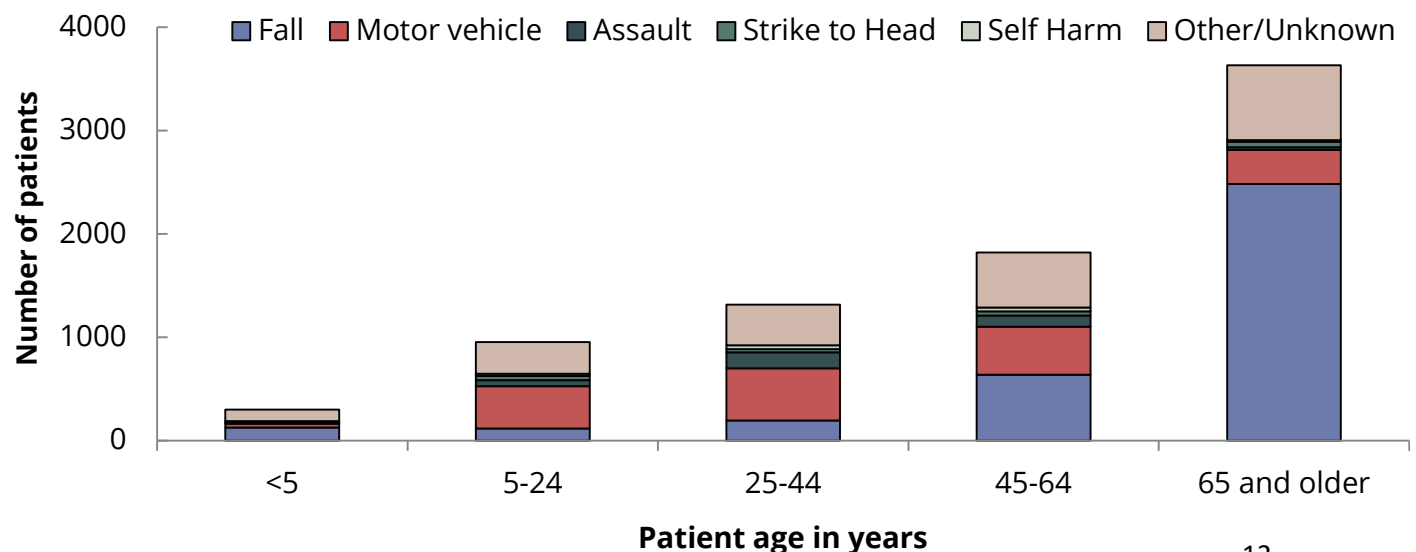
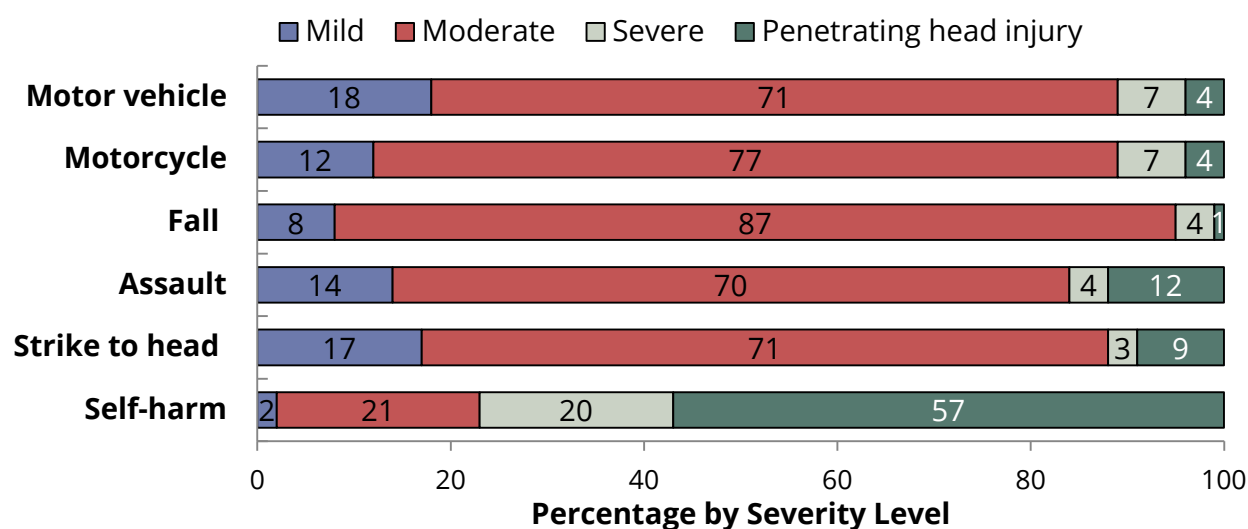


Figure 13. External cause of injury by patient age, 2018.



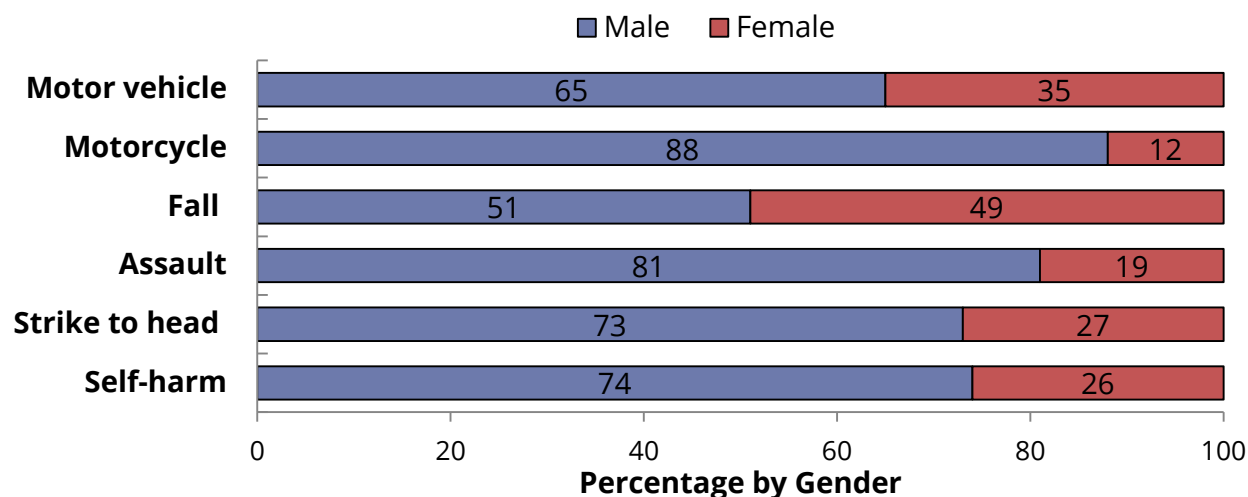
Severity of injury also varied by external cause. Figure 14 shows the percentage of TBIs assigned to each severity level for the five main external causes examined and for motorcycle-related injuries, a subset of motor vehicle. Although TBIs caused by self-harm represented just 1% (N=109) of TBIs overall, these injuries were most likely to be categorized as severe and as penetrating brain injuries. This increased lethality reflects the dominant method of self-harm amongst these cases: 81% involved a firearm.

Figure 14. Severity of injury by external cause, 2018.



The male majority amongst TBI cases overall increased substantially within injuries by certain causes. The only external cause of injury where males did not make up the majority of patients was falls (Figure 15). For injuries caused by assault and motorcycle crashes, males represented over 80% of cases.

Figure 15. Percentage of male and female TBI registry patients by external cause, 2018.



Patient Residence by State and County

Patient Residence by State

Approximately 75% (N=5,981) of TBI registry patients were Tennessee residents, while the remaining 25% (N=2,042) involved non-residents, primarily from bordering states (Table 4).

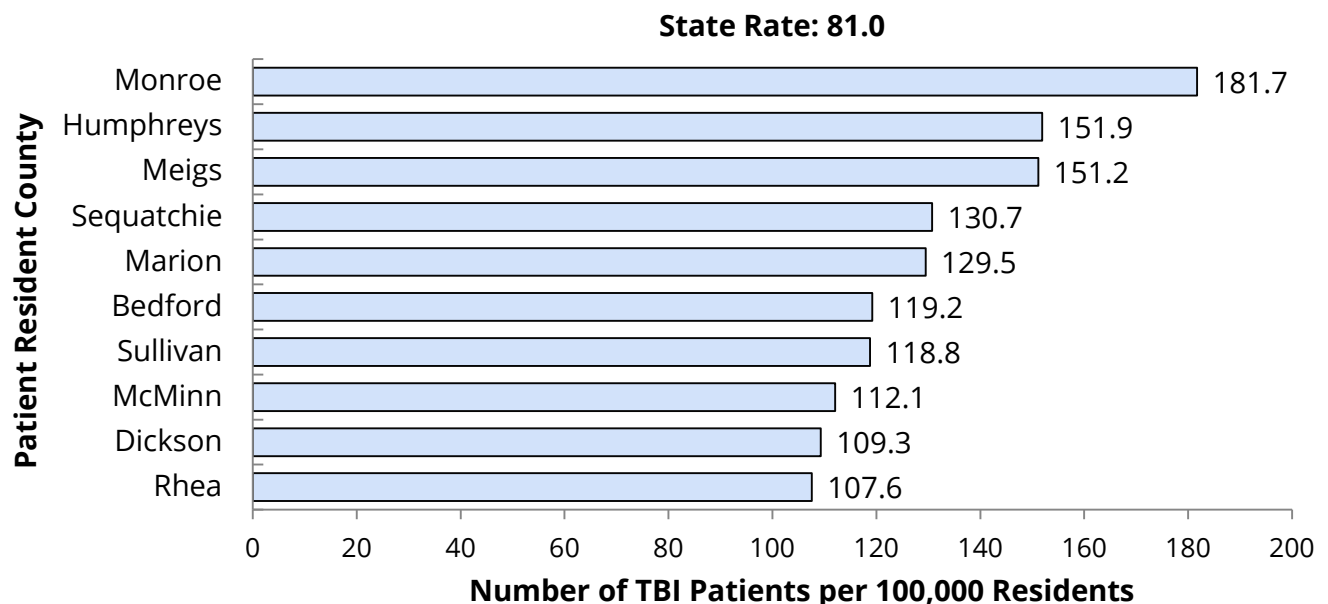
Table 4. State of residence of 8,023 TBI registry patients, 2018.

Patient State of Residence	Number of Patients	Percent of Patients
Tennessee	5981	74.5
Kentucky	416	5.2
Georgia	362	4.5
Mississippi	353	4.4
Virginia	226	2.8
Arkansas	188	2.3
Other States	497	6.3

Top Tennessee Counties

Figure 16 demonstrates the ten Tennessee counties with the highest number of TBI registry patients per 100,000 residents, after adjusting for the counties' age distribution to make for a more fair comparison. While this list fluctuates from year to year, two Tennessee counties, Meigs and Sequatchie, have consistently ranked amongst the top five counties in the state. A full listing of counties can be found in the Appendix on page 16.

Figure 16. Top ten Tennessee counties for number of TBI registry patients per 100,000 residents, 2018.

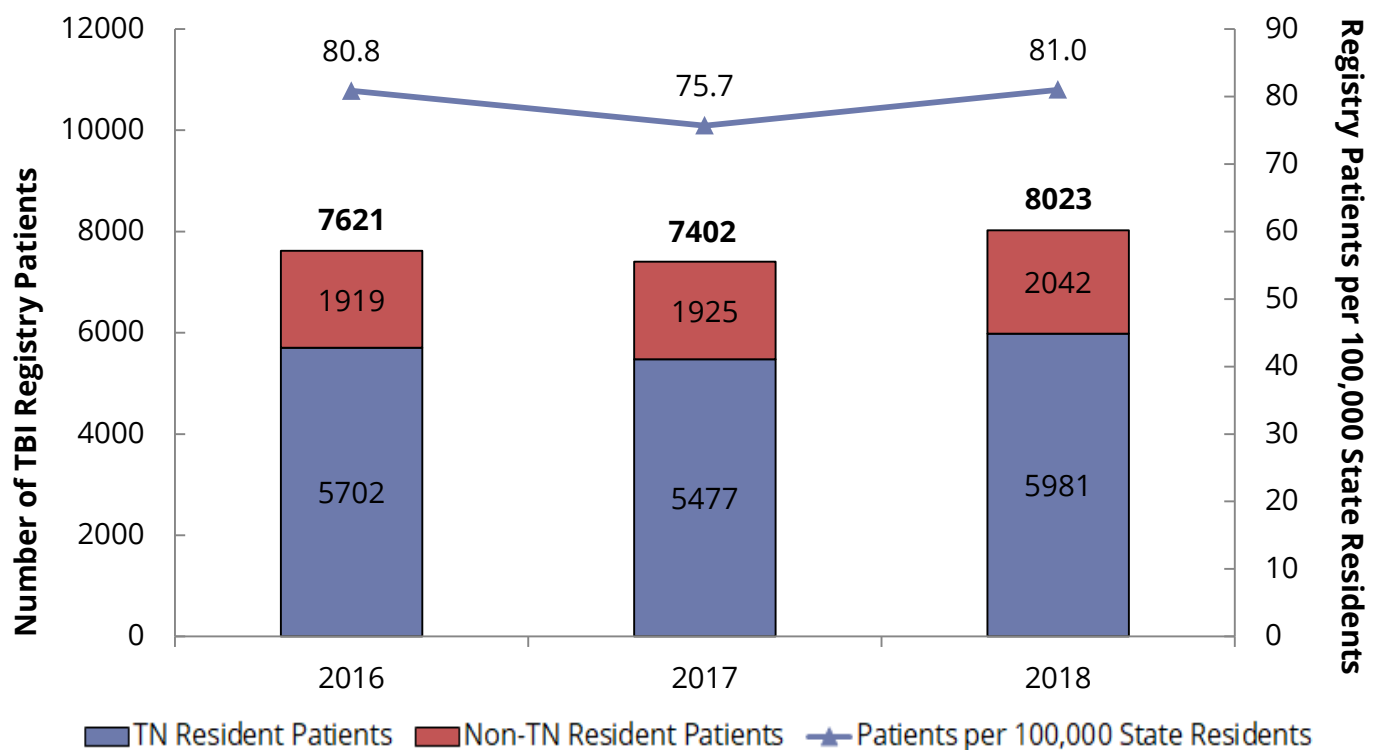


Annual Trend in TBI Registry Patients

Though the TBI registry has been collecting patient data since 1996, Figure 17 includes the total number of registry patients and the number of Tennessee resident patients per 100,000 state residents for 2016 to 2018. This is because the ICD-10-CM coding system described on page 4 was introduced at the end of 2015. The shift to this new coding system represented a change in the way TBI patients are captured, making it difficult to compare the trend across the transition. For this reason, the Program chooses to present annual data from 2016 and on whenever possible, though historical registry data are available upon request.

Over this most recent time frame, approximately 7,700 TBI patients on average have been reported to the registry each year. The total number of TBI registry patients for 2018 represented an 8.4% increase from the total number of patients for 2017. The percentage of total registry patients who were Tennessee residents was consistent at approximately 75%.

Figure 17. Annual trend in total number of TBI registry patients and number of TN patients per 100,000 state residents, 2016-2018.



Conclusion

Traumatic brain injury contributes to a significant proportion of death and disability in the State of Tennessee. Fortunately, T.C.A. 68-55-203 has enabled the TBI Program to offer assistance to over 80,000 Tennesseans with brain injury since this legislation came into effect. Continuous surveillance of TBI allows for targeted interventions that may alleviate this burden moving forward.

Advancements in neurological science and clinical care allow for improved intervention and better long-term outcomes for TBI patients. However, these injuries still occur at alarming rates and often, patients are still in need of long-term assistance. The findings in this report not only emphasize the continued need for these TBI patient resources in Tennessee, but also highlight the opportunity to enhance TBI prevention efforts such as supporting the universal motorcycle helmet law, implementing motor vehicle crash prevention programs including the Checkpoints program for teen drivers, and collaborating with Prevent Child Abuse Tennessee (PCAT) to reduce pediatric abusive head trauma.

Appendix

The following table includes the number of TBI registry patients and number of patients per 100,000 county residents for each county of Tennessee. For counties that had fewer than 20 TBI registry patients in 2018, the number of patients per 100,000 residents is suppressed (marked with a dash) because it is too unreliable to be useful for comparison. Counties are also ranked in descending order (i.e., the county with the highest number of TBI registry patients per 100,000 residents has a rank of 1). Ranks were only assigned for counties that had at least 20 TBI registry patients and therefore extend from 1 (highest prevalence of TBI) to 61 (lowest prevalence of TBI).

County	Number of TBI Registry Patients	Number of TBI Registry Patients per 100,000 County Residents (Age-Adjusted)	Rank
Anderson	65	67.3	56
Bedford	59	119.2	6
Benton	13	—	—
Bledsoe	15	—	—
Blount	148	94.3	18
Bradley	91	76.7	43
Campbell	46	97.7	13
Cannon	13	—	—
Carroll	24	74.7	47
Carter	46	69.7	53
Cheatham	33	90.1	25
Chester	17	—	—
Claiborne	27	74.6	48
Clay	<5	—	—
Cocke	29	73.0	50
Coffee	60	96.8	14
Crockett	11	—	—
Cumberland	66	77.7	41
Davidson	575	84.3	32
Decatur	19	—	—
DeKalb	23	94.2	19
Dickson	60	109.3	9
Dyer	38	96.4	15
Fayette	22	47.3	61
Fentress	13	—	—

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County	Number of TBI Registry Patients	Number of TBI Registry Patients per 100,000 County Residents (Age-Adjusted)	Rank
Franklin	43	94.1	20
Gibson	29	51.8	60
Giles	17	—	—
Grainger	24	96.0	16
Greene	82	98.2	12
Grundy	9	—	—
Hamblen	50	67.8	54
Hamilton	338	78.9	38
Hancock	9	—	—
Hardeman	18	—	—
Hardin	23	87.5	29
Hawkins	61	95.7	17
Haywood	11	—	—
Henderson	23	72.9	51
Henry	28	75.9	44
Hickman	25	89.2	27
Houston	9	—	—
Humphreys	32	151.9	2
Jackson	13	—	—
Jefferson	53	86.2	31
Johnson	13	—	—
Knox	385	75.1	46
Lake	7	—	—
Lauderdale	24	89.3	26
Lawrence	38	75.6	45
Lewis	11	—	—
Lincoln	22	55.7	59
Loudon	64	93.2	22
Macon	24	91.6	24
Madison	62	57.4	58
Marion	42	129.5	5
Marshall	35	93.9	21
Maury	78	78.7	39
McMinn	69	112.1	8
McNairy	14	—	—
Meigs	20	151.2	3
Monroe	103	181.7	1

Continued on next page

County	Number of TBI Registry Patients	Number of TBI Registry Patients per 100,000 County Residents (Age-Adjusted)	Rank
Montgomery	141	81.4	36
Moore	<5	—	—
Morgan	10	—	—
Obion	15	—	—
Overton	23	86.4	30
Perry	5	—	—
Pickett	<5	—	—
Polk	15	—	—
Putnam	70	79.0	37
Rhea	39	107.6	10
Roane	64	92.6	23
Robertson	57	77.6	42
Rutherford	187	67.5	55
Scott	17	—	—
Sequatchie	21	130.7	4
Sevier	89	78.6	40
Shelby	833	88.1	28
Smith	22	99.6	11
Stewart	14	—	—
Sullivan	225	118.8	7
Sumner	165	81.8	35
Tipton	48	70.6	52
Trousdale	10	—	—
Unicoi	16	—	—
Union	17	—	—
Van Buren	7	—	—
Warren	36	83.1	33
Washington	123	82.3	34
Wayne	11	—	—
Weakley	16	—	—
White	19	—	—
Williamson	132	60.4	57
Wilson	108	74.1	49

Traumatic Brain Injury Program Report

July 2018 – June 2019

EXECUTIVE SUMMARY

In 1993, the Tennessee General Assembly passed legislation establishing the Traumatic Brain Injury (TBI) Program within the Department of Health. The TBI Program staff, with guidance from a nine-member, Governor-appointed Advisory Council, is charged with expanding and revising existing state plans and services for persons with traumatic brain injuries. This report contains specific information concerning the progress made from July 2018 through June 2019 in each of the major components of the Traumatic Brain Injury Program.

Each year, approximately 6,000 Tennesseans are reported to the TBI registry with a traumatic brain injury-related hospitalization or death. Survivors of TBI may experience impairments that affect their physical, cognitive and behavioral functioning, which in turn impacts their ability to return to home, school and work. Regardless of the cause, persons with brain injury and families may experience emotional and economic stress. The enabling legislation charges the TBI Program with improving services for persons with brain injury and their families.

Key Accomplishments

- In FY19, there were 120 participants in the TBI Family Support Program which provides direct financial assist for persons with TBI.
- TBI Service coordinators provided case management services to TBI survivors and their families; each served an average case load of 60 survivors. They collectively provided information on TBI to over 11,000 callers.
- The TBI service coordinators collectively made 75 educational presentations to a total of 1,797 persons and provided 35 exhibits that were seen by 3,734 attendants.
- Supportive living services were available to nine survivors living in two affordable and accessible apartment facilities in Memphis.
- Personal care services were available to 24 residents of Crumley House Brain Injury Rehabilitation Center.
- Forty six adult and youth survivors of brain injury attended camp sessions.
- Brain links staff provided 14 trainings to 321 participants.

Introduction

In 1993, in response to testimony presented by persons with brain injury from across the state, the Tennessee General Assembly established the Traumatic Brain Injury (TBI) Program within the Department of Health to address the unique needs of survivors and their families.

In Tennessee, approximately 8,000 people per year are reported to the TBI Registry with a traumatic brain injury-related hospitalization or death. Of that number, approximately 6,000 are Tennessee residents, with the remaining number being residents of other states that are admitted to Tennessee hospitals. An additional 18,000 emergency department visits of Tennessee residents were related to a TBI during calendar year 2017 (the most recent data year). Survivors may experience impairments that affect their physical, cognitive and behavioral functioning, which in turn impacts their ability to return to home, school and work. Whether the injury is the result of a fall, motor vehicle accident, assault, or sports activity, these persons with brain injury and families may experience emotional and economic stress. The focus of the TBI Program is to improve services for persons with brain injury and their families.

This report contains specific information concerning progress made from July 2018 through June 2019 in each of the major components of the TBI Program, as well as pertinent historical information. The TBI Program is housed in the Department of Health, Division of Family Health and Wellness, Injury Prevention and Detection section. Currently, staff consists of a Program Director and an Epidemiologist that oversees the TBI registry.

The enabling legislation calls for the establishment of a state TBI registry and a TBI trust fund, and describes the duties of the Coordinator. Each of these areas is addressed by first citing the Tennessee Code Annotated (T.C.A.) followed by a description of activities and progress.

Part 1. T.C.A 68-55-102 & 103. Advisory Council Established – Duties

The TBI Advisory Council was organized in accordance with the legislation to provide advice and guidance to the TBI Program staff. The nine-member Council is appointed by the Governor and includes representatives from the Departments of Education, Mental Health and Substance Abuse Services, & Intellectual and Developmental Disabilities, and Human

Services. An additional member represents health care professionals. Five of the nine members represent the category of TBI survivor, family member or primary caregiver. The Council was organized in 1994 and has met quarterly since that time. During FY19, the TBI Advisory Council was comprised of the following members:

Council member	Representation category
Joanna Bivins	Department of Education
Amy Boulware	Survivor, Family member, Primary Care Giver
Pam Bryan	Survivor, Family member, Primary Care Giver
Avis Easley	Department of Mental Health and Substance Abuse Services, and Department of Intellectual and Development Disabilities
Alicia Fitts	Survivor, Family member, Primary Care Giver
Mark Heydt, Chair	Health Care Professional
Joanne Morris	Department of Human Services, Vocational Rehab
Brian Potter	Survivor, Family member, Primary Care Giver
Michelle Stanton	Survivor, Family member, Primary Care Giver

The duties of the council are to advise the TBI coordinator, make recommendations, and perform other duties as necessary for the implementation of a state-wide plan to assist persons with TBI and their families. The Advisory Council is comprised of individuals dedicated to improving the lives of TBI survivors in Tennessee. Their recommendations have been invaluable to the development of the TBI program.

In FY19, the TBI Advisory Council continued to utilize resources in the trust fund for the benefit of TBI survivors. The Council has developed a five-year plan to use these funds to directly assist persons with TBI and their families by implementing a TBI Family Support Program, modeled on the existing state Family support program in the Department of Intellectual and Developmental Disabilities. The program is designed to assist individuals with disability due to brain injury, allowing them along with their families to remain together in their homes and communities. Services are flexible and responsive to families and their needs. During the second year in FY19, there were 120 participants.

Part 2. T.C.A. 68-55-201. TBI Coordinator to be designated.

The commissioner shall create a full-time position within the department and designate a person as the TBI coordinator to supervise and coordinate the development,

implementation and enhancement of a registry and services system for persons with TBIs and provide sufficient staff to accomplish the effect and intent of this chapter. The TBI coordinator shall, to the fullest extent possible, utilize the services of the advisory council in fulfilling the duties and responsibilities required by this chapter.

The current full-time TBI coordinator (program director) has been in place since 1994, supervising and directing the program as described in this report. The TBI registry was established in 1994 along with the service system for persons with TBI. Staff includes the program director and the epidemiologist that oversees the TBI registry. The program director consults with Advisory Council members a minimum of quarterly to secure their advice and guidance.

T.C.A. 68-55-202. Duties.

(a) The TBI coordinator shall:

(1) Aggressively seek and obtain funding, on an ongoing basis, from all available sources, including but not limited to Medicaid waivers and for expansion of the Medicaid program, private and federal funds needed to implement new state plans and services, and to expand and revise existing state plans and services for persons with traumatic brain injuries, including case management;

The TBI Coordinator continuously seeks additional funding from all available sources.

Medicaid Waiver: The TBI community continues to promote the idea of a TBI-specific Medicaid waiver which some states have implemented. TennCare has existing home and community-based waivers to serve the elderly and disabled for which survivors of brain injury may be eligible.

Federal Grant award: Since 2000, the TDH Traumatic Brain Injury Program has been the recipient of grants from the U.S. Health Resources and Services Administration (HRSA) and the Administration for Community Living (ACL) that focus on educating the workforce that support persons with brain injury. In June 2018, the TDH TBI Program was awarded a new three-year grant by the Administration for Community Living to build on the foundation established by the previous grants. The new grant program, Brain Links, is focusing on training the workforce that serves persons with brain injury across the lifespan, including pediatricians and school professionals.

Expansion of services: The expansion of services for TBI survivors is accomplished

through the grants program as outlined in Section 68-55-402 below. In FY19, the TBI Program continued the TBI Targeted Family Support Program which provides funding directly to eligible families and survivors to cover costs not covered by other resources. In addition, program staff collaborates with other relevant agencies such as the Tennessee Disability Coalition, the Brain Injury Association of Tennessee and the Epilepsy Foundation to improve services for all persons with disabilities in the state.

Case management: Through the TBI Program's case management program, known as Service Coordination, eight service coordinators assist persons with brain injury and their families in all 95 counties through contract arrangements with non-profit agencies. Each agency has established a Brain Injury Support Center in its service area for the purpose of providing assistance to children and adults with TBI. These services include: providing information, referring consumers to appropriate services and agencies, assisting consumers in applying for and accessing services, advocacy, overseeing support groups, and the development of new programs and activities. The service coordinators also have a pivotal role in connecting survivors to the TBI Family Support Program. The role of the Service Coordinator is to work with the person with brain injury to assess needs and coordinate resources within the community on behalf of the client. The eight service coordinators are each serving an average case load of 60 survivors and families. During FY19, the service coordinators collectively provided information on TBI to over 11,000 callers.

(2) Seek funding, on an ongoing basis, and, in conjunction with other state agencies, prepare, coordinate, and advocate for state appropriations needed to fund and to develop services to implement the state plan:

The TBI Program Director and the Advisory Council seek funding on an ongoing basis. The Council includes representatives from the other state departments that also serve persons with brain injury -- Education, Mental Health and Substance Abuse Services, Human Services, and Intellectual and Developmental Disabilities -- and provides a mechanism for cooperation and collaboration.

(3) Identify available programs and services and compile a comprehensive directory of identified programs and services:

A comprehensive resource directory, *Traumatic Brain Injury Services Directory and Resource*

Information Guide, 2019-2020 was updated in 2019, distributed statewide and has served to increase awareness of the TBI program. The directory is also available on the program web site: <https://www.tn.gov/health/health-program-areas/fhw/vipp/tbi.html> In addition, all TBI service coordinators develop resource files for their local service areas.

(4) Provide technical assistance and define gaps in service delivery and spearhead the development of those services needed for a comprehensive system of service delivery;

The TBI office provides technical assistance as requested by consumers, families, and providers. Examples include providing information on services and programs, referrals to rehabilitation programs, and making connections to support groups. The TBI office also conducts annual technical assistance site visits with all TBI contractors.

The Service Coordination project described above [TCA 68-55-202 (a)(1)] is designed to assist survivors and their families in order to overcome the gaps in services within their communities.

(5) Implement, oversee and receive surveillance data from the Tennessee Brain Trauma Registry to use in developing and revising the state plan to meet the changing needs of this population:

The TBI registry data has been a valuable tool in documenting the need for TBI services and in program planning. Data from the TBI registry enabled successful application for the federal grant award that resulted in the new grant for Brain Links.

Registry data on sports concussions highlighted a problem in the state and, as a result, Tennessee became the 44th state to pass a sports concussion law designed to reduce youth sports concussions and increase awareness of traumatic brain injury. The Department of Health collaborated with Vanderbilt Medical Center and other professionals to develop *Return to Learn/Return to Play: Concussion Management Guidelines* which is available on the department website. The document is a resource for educators, coaches, health care providers, families and athletes. In FY19, 1,750 copies of the guidelines were printed and distributed statewide.

The TBI Program Director serves on the CDC grant-funded Commissioner's Council on Injury Prevention. The TBI registry data is one of the data sources being used to identify areas of

need.

(5) Evaluate surveillance data regarding the quality of services provided and outcome and impact on the quality of life of this population, including reintegration and productivity in the community;

Although the surveillance data in the registry does not capture the quality of services provided, the TBI Program conducts a satisfaction survey of the recipients of the TBI Family Support Program which provides insight into quality of life and productivity. For the 2019 report, there were 120 surveys mailed with 58 responses for a 48% response rate. Overall, the survey respondents indicated great satisfaction with the program and gratitude for the availability of the funds. Families and survivors used the funding to address a variety of needs including expenses related to respite, transportation and medical expenses not covered by other payers. At least half of the respondents noted that without the funds they would not have been able to pay for personal assistance, medications or get to medical appointments.

(7) Promote research on the causes, effects, prevention, treatment and rehabilitation of head trauma injuries;

The development of the state registry and the resulting availability of statistics are directed toward encouraging research on the causes, effects and treatment of brain injuries. As information on TBI is collected by the central office and the service coordinators, areas for research on causes, effects, and prevention can be identified.

(8) Serve as a clearinghouse for the collection and dissemination of information collected on available programs and services. A statewide, toll-free telephone line shall be established and operated during normal business hours for the express purpose of providing such information to callers.

The TBI clearinghouse has been operational since 1994 and is accessible via a toll-free number. Information is routinely updated on available programs and services across the state. A TBI Program brochure has been broadly distributed. The Program also has a web page on the Department of Health website:

(b) Utilizing the services and expertise of the advisory council to the greatest extent possible and in cooperation with the advisory council, the TBI coordinator shall:

(1) Develop a coordinated case management system, a short-term state plan, a long-term state plan, affordable and accessible home and community based services, and criteria to identify training needs and priorities for all persons serving TBI clients;

The case management system known as Service Coordination and described in TCA 68-55-202 (a)(1) covers all 95 counties in the state. The Advisory Council and TBI coordinator have developed short-term and long-term goals and objectives for the program following the mandates in the legislation. Efforts to provide affordable and accessible home and community-based services are on-going through the TennCare Choices program. Currently, the TBI Program has a contract to provide personal care services on a limited basis in select facilities in Memphis and Johnson City. Training needs of persons serving TBI clients are being identified and addressed in the new federal grant, Brain Links. The TBI service coordinators also provide training to health care professionals in their respective communities.

(2) Establish and provide for the centralized organization of a statewide family clearinghouse of information, including availability of services, education and referral to survivors, professionals, and family members during the early stages of injury in the acute hospital setting.

The TBI Program staff has made contacts in the hospitals where acute care is provided through the establishment of the TBI registry and the development of the TBI Resource Directory. The service coordinators have developed referral relationships with their local hospitals. Each year, copies of the updated Resource Directory are distributed to facilities statewide. These efforts serve to make assistance available to survivors and family members in the early stages of injury and across the lifespan.

(3) Assure statewide compliance with licensure, if any, and performance standards through regular service monitoring, site visitation, and self-appraisal;

(4) If licensure is required, monitor and update licensure requirements specific to this

population;

The Department of Health oversees certification and licensure of health care facilities in Tennessee. The TBI Program coordinator works with appropriate staff to ensure licensure compliance and to monitor and update licensure requirements specific to this population, as needed.

(5) Seek funding and other resources to assure that state personnel working with this disability group are properly trained and provided, at least annually, an opportunity to attend formal or informal education programs through colleges, workshops, seminars, or conferences;

In 2019, the TBI Program collaborated with the Brain Injury Association of Tennessee and Disability Rights Tennessee to plan and present an annual statewide conference. The *30th Annual TBI Survivor, Family and Caregiver Event* was attended by 90 people. Speakers addressed advocacy issues and law enforcement. The final panel presentation included speakers who provided impactful stories of their experiences as a survivor, a family member, and service provider. Being able to offer the event day at no charge to participants is very much appreciated by survivors and families.

The TBI Program Director regularly provides educational presentations on brain injury to the Commissioner's Council on Injury Prevention which is attended by key stakeholders that serve the TBI community. The TBI staff and service coordinators, as well as the Project BRAIN staff, regularly present at seminars and workshops, enhancing the ability of state personnel to meet the needs of survivors. During FY19, the TBI service coordinators collectively made 75 educational presentations to a total of 1,797 health care professionals and community members. They also provided 35 exhibits on brain injury that were seen by 3,734 participants. Brain Links staff have provided 14 trainings to a total of 321 attendees that include school personnel and pediatrician offices. Brain Links staff have also designed two comprehensive educational products on management of pediatric mild traumatic brain injury, the *Toolkit for School Nurses* and *Healthcare Provider Toolkit*. Both include their new product, *Concussion Management Protocol*.

(6) Ensure updates and compliance standards from the National Head Injury

Foundation's quality standards committee are made available to professionals and providers, on a timely basis, to help educate providers and professionals regarding the latest technology available to this disability group;

In addition to regularly scheduled trainings and the annual conference, the TBI program has developed a TBI Community Listserv to provide information on the latest technology available for the TBI community.

(7) Oversee efforts to better educate the general public concerning the need for head injury prevention programs and the need for early intervention, including but not limited to, developing plans and programs for affordable post-acute rehabilitation services, long-term care programs, respite services, and day treatment programs to deal with those who have lifelong disabilities, as well as developing plans and programs to deal effectively with TBI students in the educational system;

The TBI Program collaborates with the Brain Injury Association of Tennessee to present an annual conference focusing on current topics, including prevention and the need for early intervention. In addition, the TBI Service Coordinators provide prevention programs in their respective service areas. The TBI Program Director regularly provides educational presentations on brain injury to the Council on Injury Prevention. Information on post-acute rehabilitation services, respite services, and day programs are included in the TBI Clearinghouse and the TBI Resource Directory.

(8) Work with vocational rehabilitation and other state agencies to offer incentives and to obtain cooperation of private industries to initiate on-the-job training and supported employment for TBI persons;

The TBI program staff and service coordinators work with Vocational Rehabilitation counselors located throughout the state, helping to promote incentives and encourage private industry to initiate on-the-job training and supported employment opportunities for persons with traumatic brain injury. A representative of the Vocational Rehabilitation program serves on the TBI Advisory Council, which furthers collaborative opportunities. In May 2019, the Director of Programs and Services at Tennessee Rehabilitation Center in Smyrna provided an overview of the recent transformation of their program to a Career and Technical Model. In addition, TBI staff is available to provide technical assistance, as requested.

(9) Assist in obtaining grant funding and provide technical assistance for the Tennessee Head Injury Association (THIA) to develop policies and procedures to maximize self-determination and self-advocacy of a person suffering a TBI.

The TBI Program has established an excellent working relationship with the staff and board of the Brain Injury Association of Tennessee (BIAT) (formerly Tennessee Head Injury Association). In FY19, the TBI Program continued to support BIAT's work with survivors and their families. A grant from the TBI Program funded a full-time executive director who serves as an advocate to improve funding for services benefiting TBI survivors. In addition, the Nashville area service coordinator is housed at BIAT, an efficient and direct connection for BIAT callers. The TBI Service Coordinators facilitate brain injury support groups across the state. The monthly meetings of the support groups provide a way to meet the educational, social, and emotional needs of survivors and families.

T.C.A. 68-55-203. Brain Trauma Registry

The commissioner shall establish and maintain a central registry of persons who sustain traumatic brain injury. The purpose of the registry is to: (1) collect information to facilitate the development of injury prevention, treatment and rehabilitation programs; and (2) ensure the provision to persons with traumatic brain injury of information regarding appropriate public or private agencies that provide rehabilitation services so that injured person may obtain needed services to alleviate injuries and avoid secondary problems.

The TBI registry is a mechanism for collecting data on brain injury in the state. In calendar year 2018, 8,023 patients were reported to the TBI registry with at least one brain injury diagnosis; 7,141 of these patients were hospitalized and discharged alive while the remaining 882 patients died as a result of their injuries. Accidental falls were the leading cause of injury amongst patients included in the Registry at 44% of all causes.

The TBI registry is supported by an Epidemiologist housed in the Family Health and Wellness Division. Data collection officially began with patients discharged during 1996. Reporting hospitals submit data on inpatients or any deceased patients with TBI-specific ICD-10 diagnosis codes; patients seen in emergency rooms who were sent home the same day are not included in the registry. Hospitals are required to report within six weeks of the end of the quarter. All hospitals in the state are currently in compliance with this legislation.

The registry also serves to connect brain injury survivors with needed services. All

Tennessee residents listed on the registry receive a letter and program brochure to inform them of the services available through the TBI program. This year, 3,480 letters were mailed. For many, the letter is the first link to information regarding needed rehabilitation services and programs.

Part 3 & 4. T.C.A. 68-55-401. Traumatic Brain Injury Fund.

There is hereby established a general fund reserve to be allocated by the General Appropriations Act which shall be known as the “traumatic brain injury fund” hereafter referred to as the fund. Money from the fund may be expended to fund the registry, the TBI coordinator position, and additional staff requirements and other expenditures and grants under the provisions of this chapter.

The fund has been established in the Department of Health and revenues have been deposited into the fund as they have been received. The Fund Balance as of June 30, 2018 was \$1,174,000. Funds are used to cover staff positions and to fund grants. In FY17, the TBI Advisory Council was approved to utilize available resources in the TBI trust fund for the benefit of TBI survivors. The Council developed a five-year plan to use these funds to directly assist persons with TBI and their families by implementing a Targeted TBI Family Support Program, modeled on the existing state Family Support Program in the Department of Intellectual and Developmental Disabilities.

T.C.A. 68-55-402. Grant Programs.

From the revenues deposited in the traumatic brain injury fund, the Department of Health is authorized to provide grants to county and municipal governments and/or not for profit organizations for home and community based programs to serve the needs of TBI persons and their families. The department is authorized to establish such grant programs and to develop criteria for eligible applicants.

In accordance with the legislation, the TBI Program has awarded numerous grants for a variety of projects since 1995. In FY19, through competitively awarded grants the following services were provided:

- Tennessee Community Resource Agency provided personal care services for nine individuals with TBI who live in two accessible, affordable apartment buildings in Memphis.

- Crumley House Brain Injury Rehabilitation Center offered respite and personal care assistance to twenty-four residents with brain injury.
- TBI Service coordinators provided case management services to TBI survivors and their families; each served an average case load of 60 survivors. They collectively provided information on TBI to over 11,000 callers.
- The TBI service coordinators collectively made 75 educational presentations to a total of 1,797 persons and provided 35 exhibits that were seen by 3,734 attendants.
- Arc of Davidson County and Greater Nashville provided TBI Family Support Program services to 120 participants.
- Easter Seals Tennessee provided camp and recreational opportunities for 46 adults and youth with TBI.
- The Brain Injury Association of Tennessee employed a full-time executive director.
- The Tennessee Disability Coalition managed and implemented the federal grant, Brain Links.
- Brain Links staff provided 14 trainings to 321 participants.
- Grants for service coordination were awarded to:
 - Brain Injury Association of Tennessee
 - Chattanooga Area Brain Injury Association
 - Crumley House Brain Injury Rehab Center
 - Epilepsy Foundation of Middle and West Tennessee
 - Fort Sanders Regional Medical Center
 - Jackson Madison County General Hospital District
 - Regional One Health

Part 5 T.C.A. 68-55-501 to 503 Youth Sport-Related Injuries

Tennessee is one of 44 states that have passed legislation aimed at reducing youth sports concussion and increasing awareness of traumatic brain injury. Both public and private school sports and recreational leagues for children under age 18 that require a fee are affected by the law which covers all sports. The required educational materials are free of charge and readily available from the Tennessee Department of Health website:

<https://www.tn.gov/health/health-program-areas/fhw/vipp/tbi/tennessee-concussion.html>

In an effort to provide needed resources on concussion, the Department of Health

collaborated with Vanderbilt Medical Center and other professionals to develop *Return to Learn/Return to Play: Concussion Management Guidelines* which has been printed and distributed. It is also available on the department website. The document is a valuable resource for educators, coaches, health care providers, families and athletes.

The TBI Program Director also promotes the Safe Stars Initiative, a collaboration between the Tennessee Department of Health and the Program for Injury Prevention in Youth Sports at The Monroe Carell Jr. Children's Hospital at Vanderbilt.

The Safe Stars initiative recognizes youth sports leagues throughout Tennessee for providing the highest level of safety for their young athletes. Safe Stars involves implementation of policies on concussion education as well as topics such as weather safety and injury prevention. The goal of Safe Stars is to provide resources and opportunities for every youth sports league to enhance their safety standards.

<https://www.tn.gov/health/health-program-areas/fhw/vipp/safe-stars-initiative.html>

Conclusion and Recommendations

Although much has been accomplished, injuries persist. Work must continue to address the needs of all persons with brain injury in the state, particularly in the areas of residential services, day programs, long-term care and rehabilitation. The Council respectfully recommends that the legislature continue to support making home and community-based services available as an alternative to institutional care. The TBI Advisory Council commends the legislature for the passage of the sports concussion law which will improve the safety of sports statewide, and for maintaining the universal motorcycle helmet law that has resulted in lives saved and injuries avoided. The Council extends their gratitude for the opportunity to work to improve the lives of TBI survivors throughout Tennessee.