



# Traumatic Brain Injury Needs Assessment Report

July 2022

Tennessee Department of Health | Division of Family Health and Wellness



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## Introduction

In 1992, families of traumatic brain injury survivors from across the state petitioned the Tennessee General Assembly to create a brain injury program within state government. Thus, in 1993, Tennessee's Traumatic Brain Injury (TBI) Program was legislatively established. The TBI Program is mandated to define gaps in services and resources and to develop and implement strategies to address the needs for TBI survivors, family members, caregivers, and service providers. As an acknowledgement of that legislative establishment, this project was purposed to develop, administer, and analyze a statewide needs assessment.

The overall objective of this needs assessment is to describe services and support needs for people living with TBI and their family members and caregivers and examine availability and gaps in knowledge, practices, or skills of providers. Results from this needs assessment serve as a basis for developing and/or enhancing needed programs and services across Tennessee while facilitating the expansion of a comprehensive, multidisciplinary, and easily accessible system of care for individuals with TBI and their families.

The TBI Needs Assessment was administered using three survey instruments via REDCap®. The survey response cycle began on May 5th, 2022 and closed on June 17th, 2022.

### **For questions or further information, please contact:**

Traumatic Brain Injury Program  
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# Overview

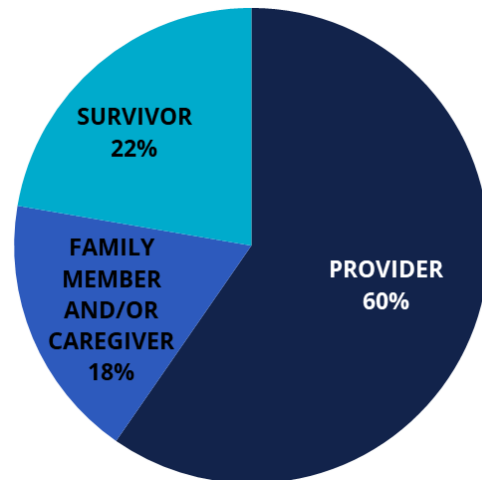
A combined 233 responses were captured via REDCap®

## Breakdown of the TBI Needs Assessment

The TBI Needs Assessment was administered electronically via REDCap® using three survey instruments. The target populations for this assessment were TBI survivors and providers, families, and/or caregivers who may provide supports and services to persons with TBI.

Of 233 responses, 139 (60%) were Providers, 52 (22%) were Survivors of a TBI, and 42 (18%) were a Family Member and/or Caregiver (FMC) of a person with TBI. Survey completion was highest among FMCs (64%), followed by survivors (62%), and providers (54%).

Figure 1. Breakdown of Responses



## Participant Characteristics



92%

Survivors and Family and/or caregiver participants were mostly **White**



61%

Survivors and Family and/or caregivers were primarily from **East Tennessee**



69%

Survivors and Family and/or caregivers were mostly **Female**



100%

All Caregiver participants were **family members** of a person with TBI



24%

About 1 in 4 provider respondents was a **Speech Therapist**



84%

Most providers worked at either a **Public** or **Non-Profit** facility/organization



92%

Most providers had **some general knowledge** about TBI



64%

Family members and/or caregivers had the **highest survey completion rate**

## **Key Findings**

**AGE:** Most TBI survivors (69%) were diagnosed with at least one TBI between ages 22-54 years.

**CAUSE:** The most common cause of TBI in survey participants was a motor vehicle crash (59%).

**SEVERITY:** About half of TBI survivors (52%) and two-thirds of care recipients (68%) were diagnosed with severe<sup>1</sup> TBIs.

**BARRIERS:** The most common barriers to care reported by persons living with TBI and their caregivers were related to the location of services (not located locally or conveniently, long distance travel, and difficulty accessing transportation), lack of support or advocacy (often feeling isolated) and, enrollment process (difficulty understanding paperwork and getting started with services and supports).

**SERVICES:** The most sought-after services needed by persons living with TBI and their caregivers include information and referral services, financial management assistance, TBI service coordination or case management, recreation services, legal or advocacy services, and TBI support groups.

**BEHAVIOR:** People living with TBI were concerned with the following behavioral and mental health issues: irritability, poor decision-making skills, impulsiveness, anxiety, and depression.

**COVID-19:** The top three concerns for **survivors** of TBI and **family members or caregivers** of persons with TBI during the COVID-19 pandemic were isolation<sup>2</sup>, mental health<sup>3</sup>, and financial stability.<sup>4</sup> These concerns were also echoed by providers who noted that the covid-19 pandemic affected limited survivors' access to care<sup>5</sup> and was associated with increased isolation, and mental health issues.

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<sup>1</sup> Severe: Confused or disoriented state which lasts more than 24 hours, or loss of consciousness for more than 24 hours, or memory loss lasting more than seven days

<sup>2</sup> Isolation (i.e., lack of social or emotional support, physical support)

<sup>3</sup> Mental health (i.e., increased depression, anxiety, suicidal thoughts, other mental health concerns)

<sup>4</sup> Financial stability (i.e., unable to pay monthly or day-to-day bills)

<sup>5</sup> Access to care (i.e., medical services, information, and resources)

## Survivors

The TBI survivor survey was designed to **assess** the knowledge and utilization of TBI services, **capture** the need for and demand of different services, and **address** barriers to care among TBI survivors in Tennessee. This assessment allowed TBI survivors to answer questions about their experiences with TBI—or someone close to the TBI survivor to answer on their behalf. Based on the data collected, most TBI survivor participants (85%) completed the survey themselves, leaving the remaining submissions (15%) completed by a family member or friend.

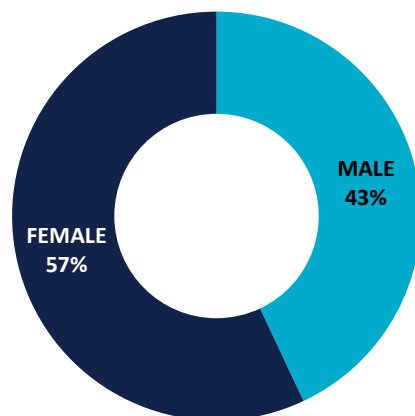
### Participant Characteristics

Over half (57%) of all survivor respondents were female. This is a contrast to the 2021 TBI Registry report data, where the male majority is seen across all TBI patients. When broken down further by race/ethnicity, most participants were female and non-Hispanic White (46%), and the second highest majority were Male and non-Hispanic White (43%).

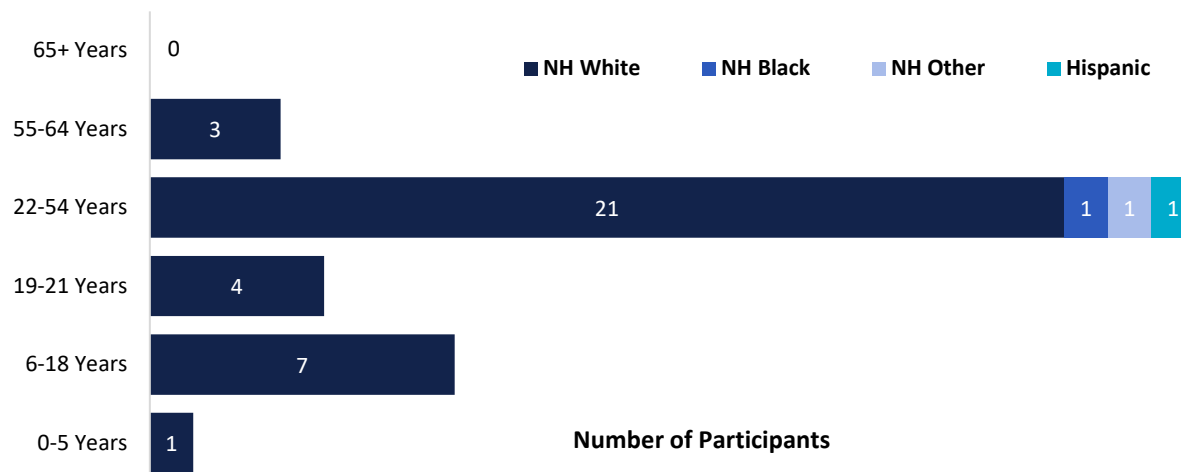
Most survivors were diagnosed between 22-54 years (67%). The average age of the participants was 49 years—the youngest was 28 and the oldest 73 years old.

TBI is more common among adults aged 55+, however only 8% of survivor respondents were 55 years and older.

**Figure 2. Survivor Participants by Sex (N=37)**

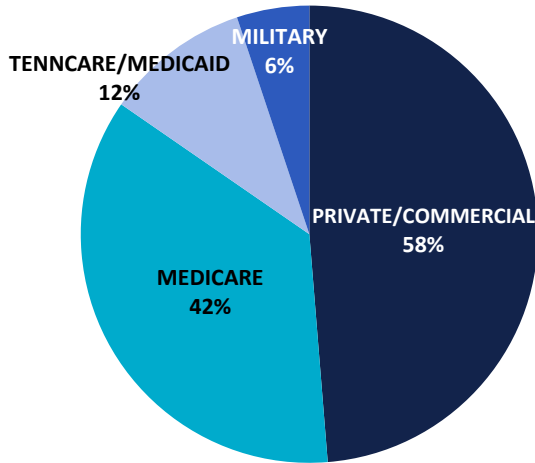


**Figure 3. Age of Diagnosis by Race/Ethnicity (N=37)**



Most survivors (68%) had at least an undergraduate education and were non-veterans (81%). About half of respondents were unemployed (49%) while only 41% reported having a full-time job. The leading contributors to unemployment among respondents were disability (50%) and inability to perform a previous job (33%).

**Figure 4. Most TBI Survivors are Privately Insured or Have Medicaid (N=37)**



Most participants had at least one form of health insurance coverage (89%). Of those that were covered:

- 58% were privately insured
- 42% had Medicare
- 12% had TennCare/Medicaid
- 6% had Military (Tricare or VA)

Participants who were not covered by health insurance reported prolonging an appointment, not purchasing medications, or skipping/canceling services altogether.

\*Health insurance was not mutually exclusive. Respondents were able to select more than one option if applicable.

To capture potential economic barriers, survivors were asked about their source(s) of income and whether their income covered their expenses.

- About three of five (62%) participants reported having enough income to cover monthly expenses while the remaining 38% reported never or rarely having enough income to cover monthly expenses.
- About one in two TBI survivors (51%) reported having income from a salary while approximately half (49%) reported income from other sources such as social security disability insurance, social security income, a family member, retirement, alimony, and military disability.
- Almost one in three (30%) participants reported living independently with no assistance
  - 73% were content with their current living arrangement.
  - Those that were not content, preferred to live in their own home with outside assistance (33%), independently (33%), with a family member (22%), or in group home with care (22%).
- The top three barriers preventing a desired living arrangement were: (1) insufficient financial resources; (2) lack of accessible and affordable housing; and (3) lack of conveniently located housing to facilitate care.

## Brain Injury Diagnosis

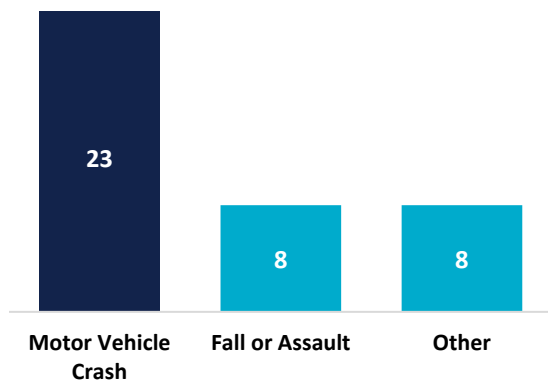
**Most (89%) of survivor participants were diagnosed with one TBI** while the remaining participants had at least two diagnoses. The most common cause for TBI among survey participants was a motor vehicle crash (e.g., car, ATV, motorcycle). Even so, it is important to recognize that some **survivors' TBIs were attributed to domestic violence or assault**.

In 2020, there were 69,646 domestic violence victims reported to Tennessee law enforcement agencies. Despite the high number of instances reported, it is estimated that only 56% of non-fatal domestic violence victimizations are reported or otherwise known to the police<sup>6</sup>.

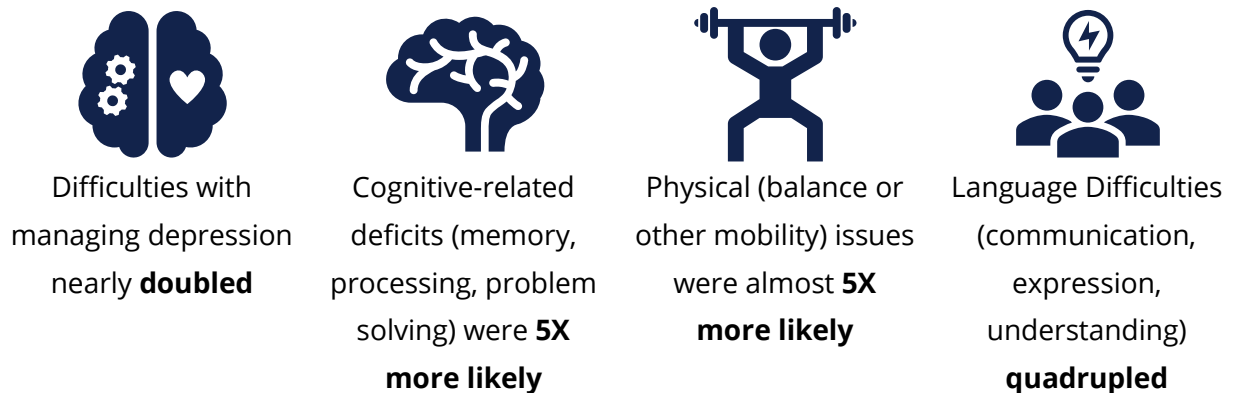
The most common diagnosis type among survey participants was severe TBI—defined as a confused or disoriented state which lasts more than 24 hours, or loss of consciousness for more than 24 hours, or memory loss lasting more than seven days.

Following a TBI, some survivors experienced changes in cognitive skills, behavior/personality, and mental health conditions (Figure 5). The changes that most interfered with survivors receiving services were difficulties managing irritability, anxiety, depression, and inappropriate social behavior. Reported disabilities or significant health conditions nearly tripled (2.8) following a TBI diagnosis.

**Figure 5. Motor Vehicle Crashes are the Leading Cause of Traumatic Brain Injury**



**Figure 6. Most common disabilities or significant health conditions AFTER a TBI diagnosis**



<sup>6</sup> Yi, I.Y., Stach, A.M. Domestic Violence -- Tennessee, 2020. Tennessee Department of Health, Division of Family Health, and Wellness. Nashville, Tennessee. February 2022.



## TBI Information



**73%** of participants did not receive or do not remember receiving a TBI Registry letter



**59%** did **NOT** receive information about TBI services following their diagnosis



**41%** received information about TBI services **before** leaving the hospital

Rehabilitation staff (46%), medical professionals (38%), TBI service coordinators (31%), Brain Injury Association (31%), and family/friends (23%) were responsible for providing information about services available for people with traumatic brain injury.

## Supports and Services

Overall, persons living with TBI had some knowledge and general awareness about TBI supports and services, as over half of all participants (**58%**) received at least one type of service or support. The average satisfaction score for all services provided was **86%**. Nonetheless, many individuals voiced concerns about access to adequate supports and services that are both flexible and relevant to their needs.



The **most utilized** services by TBI survivors were:

1. TBI support groups (58%)
2. Continuing education related to TBI-seminars, workshops, conferences, classes, or newsletter (52%)
3. Mental health treatment/counseling (45%).



The **least utilized** services by TBI survivors were:

1. Substance abuse treatment/counseling (3%)
2. Housing assistance/in-home services (6%)
3. Community living skills (6%).



The **most needed** services are:

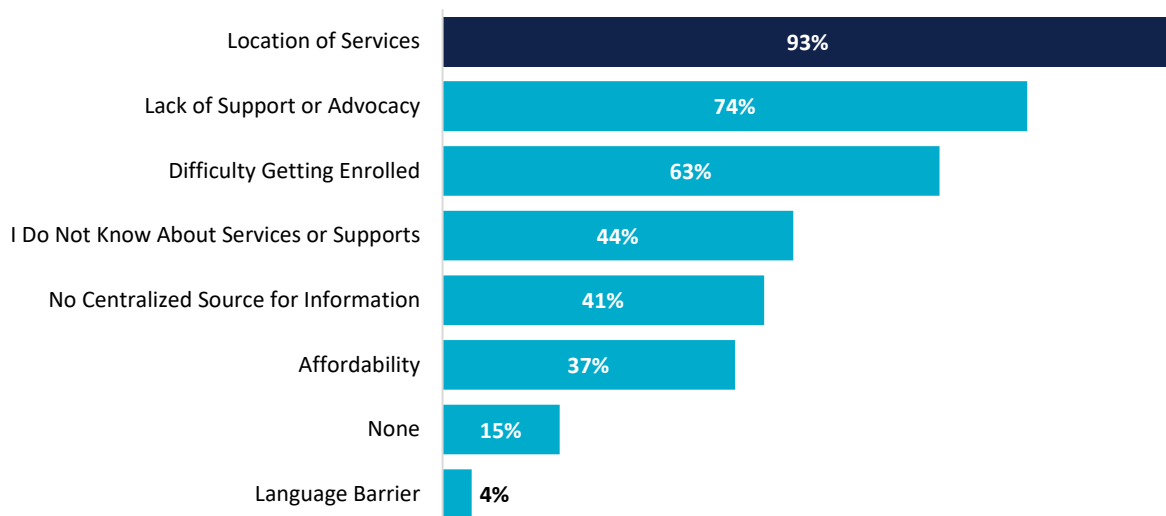
1. Information and referral services (52%)
2. Financial management assistance (42%)
3. TBI service coordination or case management (39%).

## Barriers

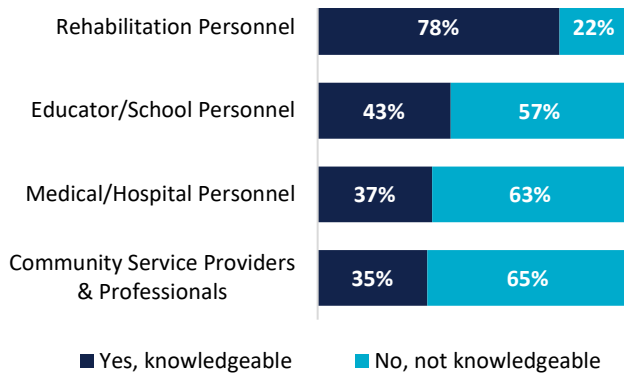
A common theme that stood out in the needs assessment was survivors' reflection on the challenges of moving forward and returning to the life they lived prior to their TBI event. Survivors specified barriers that make recovering or adapting extremely difficult and, in some instances, unattainable. Figure 7 illustrates barriers to care that were most prevalent for TBI survivors.

**Almost all (93%) participants reported difficulty getting to the location of service** as some had limited access to transportation and facilities were not located locally or conveniently or required long distance travel. About three quarters of survivors (74%) reported an inadequate support or advocacy from family and providers, making it a daunting task to seek treatment/care. Difficulty understanding paperwork and other enrollment requisites also made it challenging to access care. TBI survivors would benefit from having a clear and direct pathway to services aimed at addressing the lasting impact of their injuries, improved support or advocacy systems, and travel or transportation accommodations.

**Figure 7. Barriers to Care (N=27)**



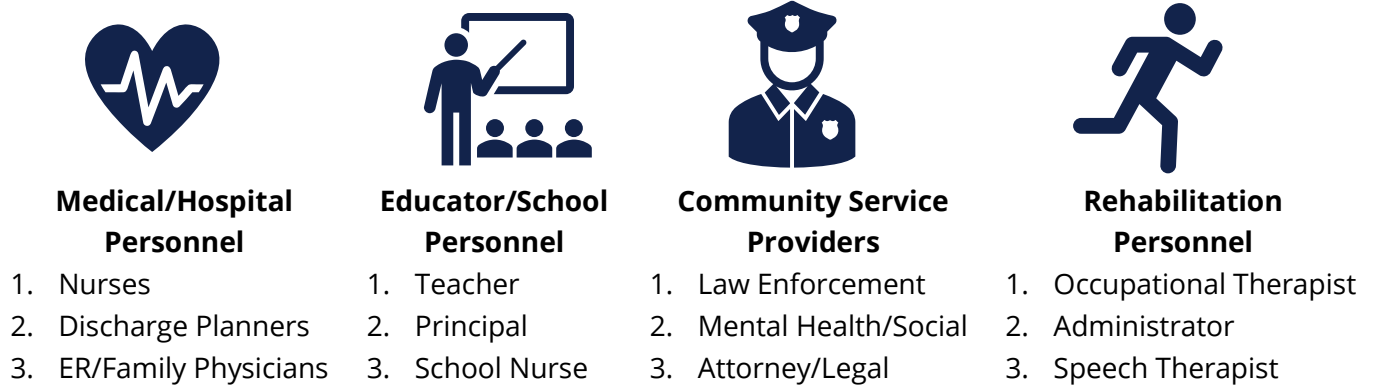
**Figure 8. Survivors' Experience with Professionals**



In addition to the socioeconomic challenges, survivors also experienced challenges meeting with professionals knowledgeable about TBI.

The professionals that were the most knowledgeable about TBI were rehabilitation personnel (78%) and the least knowledgeable were community service providers & professionals<sup>7</sup> (65%).

**Figure 9. Encounters with Professionals Not Knowledgeable about TBI (Most Frequent)**



**COVID-19 & TBI**



The top concerns among survivor participants during the COVID-19 pandemic was equal across mental health (61%), financial stability (61%), and isolation (61%). Participants also expressed concerns high about access to medical care (52%), and employment (48%).

<sup>7</sup> Law enforcement personnel, attorney's, adult brain injury program providers, first responders, in-home care providers, mental health professionals, social workers

# Family Members and/or Caregivers

TBIs not only affect individuals but can also have lasting effects on families and communities. The TBI family member and caregiver survey was designed to capture their **perspective** on caring for a person with TBI and **assess** their knowledge and utilization of TBI services, capture their need for and demand of different services, and **address** barriers that make providing care challenging.

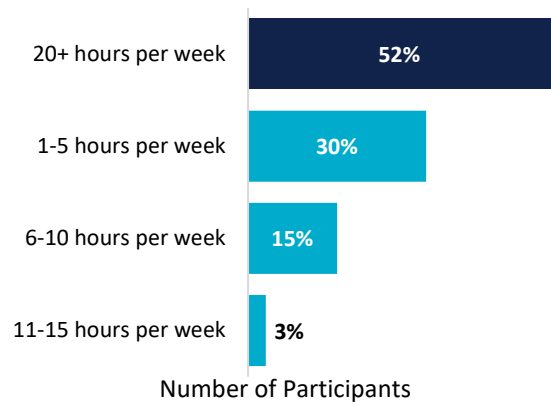
## Participant Characteristics

This needs assessment found that **all participants were family members of a person with TBI**, and the majority (94%) were not paid to provide care. Most participants were also non-Hispanic White (94%), female (83%), and a parent or spouse (66%). The majority reside in the same county (83%) as their care recipient and three quarters of them (75%) lived at home with their care recipients. About 40% of caregivers that do not reside in the same county provide care at their care recipient’s own home/apartment. The average age of the family member and/or caregiver was 54—the youngest was 31 and the oldest was 77.

## Key Findings from Caregivers for Persons Living with TBI

- 69% of family members and/or caregivers received no training or were self-taught in brain injury and/or caregiving.
- 94% of family members and/or caregivers are not paid to provide care.
- Most of family members and/or caregivers that travel to provide care, travel more than two hours (33%).
- Over half (52%) of family members and/or caregivers provide more than 20 hours of care per week.

**Figure 10. Provision of Care (N=33)**



## Brain Injury Diagnosis

Following a traumatic brain injury event, a person can become more susceptible to physical and emotional changes. Difficulties with impulsiveness, poor decision-making skills, and irritability were the most common behavioral concerns reported by family members and/or caregivers.

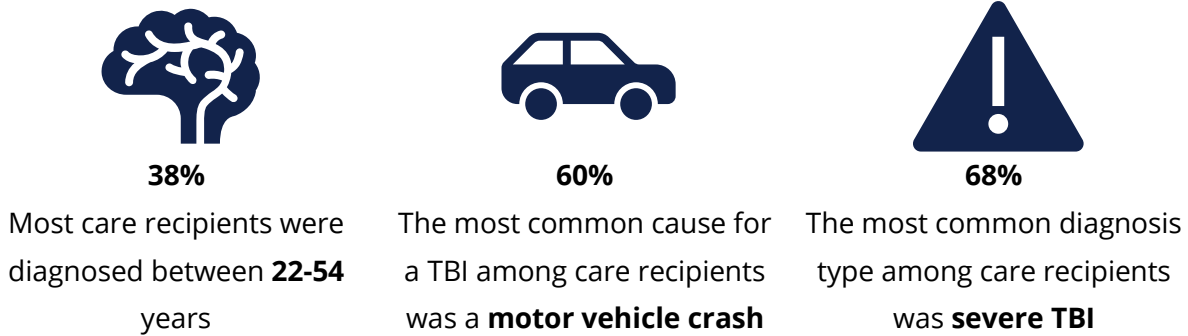


Poor decision-making skills, irritability, and sudden rapid mood changes were the top contributors for care recipients not receiving services.



The most common types of services provided by family members and/or caregivers are preparing meals (92%), managing money or budgets (76%), and shopping for personal items (73%).

**Figure 11. Brain Injury Characteristics**



### **Supports and Services**

Overall, family members and/or caregivers had some general awareness about TBI supports and services, as over three quarters (78%) reported their care recipients using at least one in the past. However, like the participants of the survivor survey, it appears there is a lack of awareness of services available for their care recipients.



The **most desired** improvements in services were:

1. Providers that specialize in brain injury (66%)
2. Access to community-based support and services (53%)
3. Availability of services provided (47%).



The **most needed** services are:

1. Recreation services (48%)
2. Legal or advocacy services (42%)
3. Financial management assistance (36%).

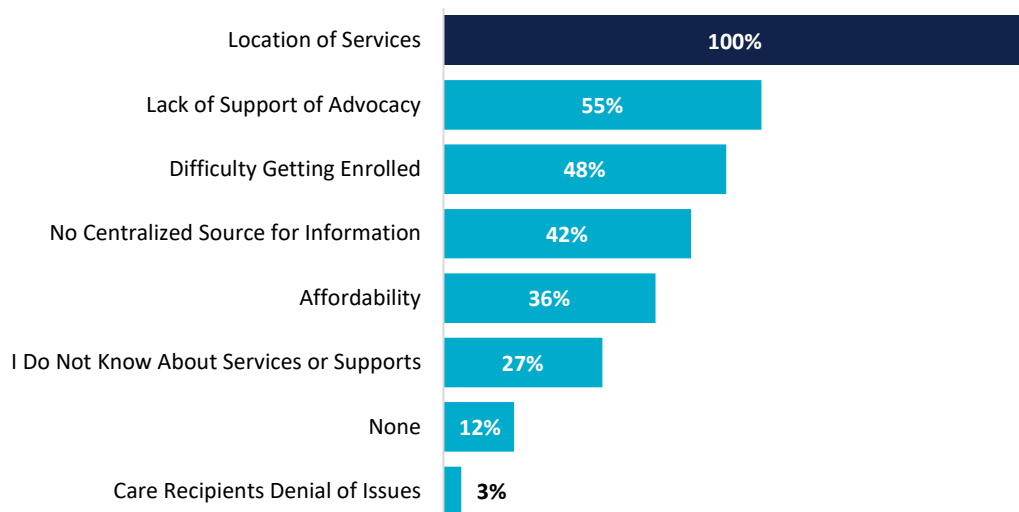
### **Barriers**

Family members and/or caregivers of persons with TBI oftentimes share the role of full-time employee and full-time caretaker. When asked directly to describe their roles these were some common themes and challenges.

- **Difficult finding balance** oftentimes feeling “tired”, “overwhelmed”, “stressed”, and sometimes “helpless” with the physical and financial demands.
- **Selfless** job that can be emotionally “exhausting,” “isolating,” and “discouraging,” particularly on days when needs are not being addressed.
- **Constantly learning** by “necessity” and with “little to no” support.
- **Competing priorities** and **limited resources** are amplified when the caregiver must care for other household member(s) with debilitating conditions.

**All participants reported difficulty getting to the location of service** as some had limited access to transportation and facilities were not located locally or conveniently or required long distance travel. Over half (55%) of the participants also reported having inadequate support or advocacy from family and providers, making it a daunting and isolating task to seek treatment/care for their loved ones. Difficulty understanding paperwork and other enrollment requisites also made it challenging to access care. An estimated 42% of caregivers also reported not having a central source for information about TBI frustrating, as many are not generally knowledgeable about TBI. Likewise, TBI survivors and their support systems would benefit from having a clear and direct pathway to services aimed at addressing the lasting impact of their injuries, improved support or advocacy systems, and travel or transportation accommodations. Figure 12 illustrates barriers to care that were most prevalent for TBI survivors.

**Figure 12. The location of services is the top barrier to care (N=33)**



## COVID-19 & TBI



The top three concerns among family member and/or caregiver participants during the COVID-19 pandemic were related to feelings of isolation (79%), mental health (62%), and financial stability (48%). Participants also expressed high concerns about access to medical care (45%) for their loved one, and not being able to afford such services.

# Providers

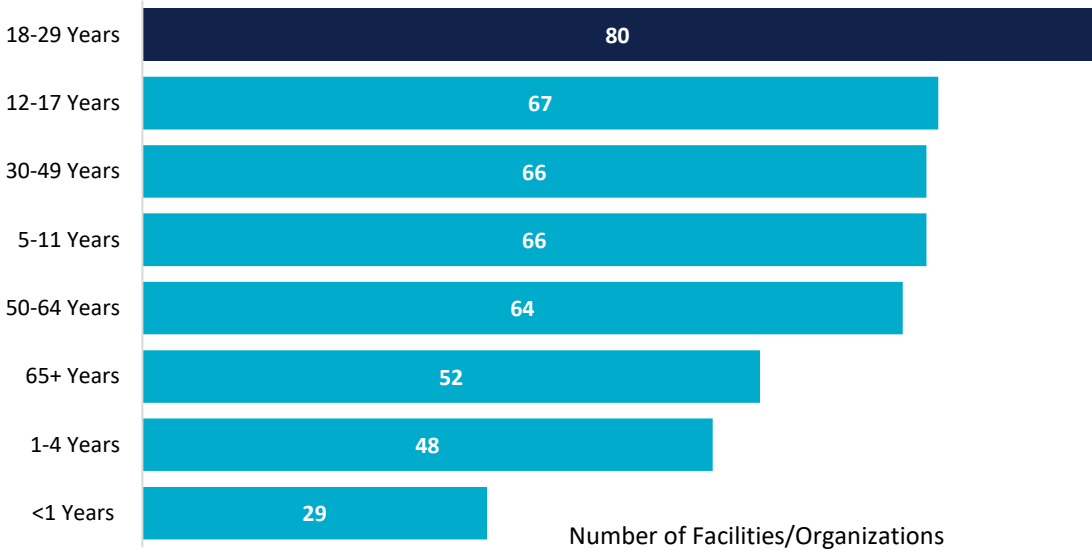
TBIs require a robust team of providers to diagnose, manage, rehabilitate, and link survivors to support and vocational services. Therefore, a provider survey was designed to gain insight on the knowledge and capacity of Tennessee providers, facilities, and organizations that provide services to persons with TBI. The assessment aims to **identify** existing **resources** for survivors of brain injury, **gaps** in TBI education/training among providers, and **challenges** with access to services.

## *Provider, Facility, and Organization Characteristics*

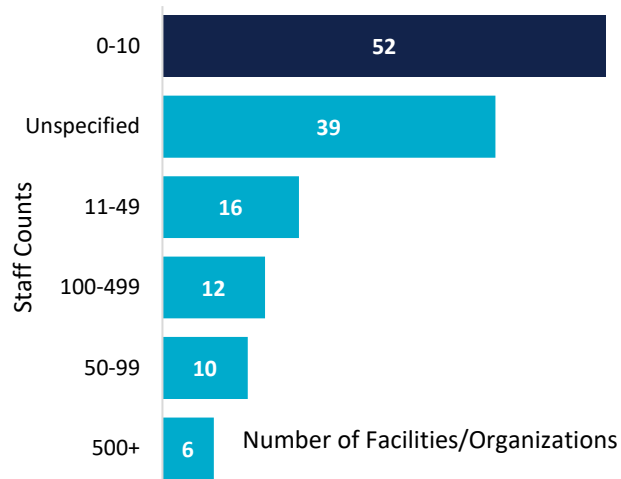
Most providers (84%) worked in a public or non-profit /organization. About half (51%) of providers who worked with public organizations served in schools—these providers were speech therapists (39%) or nurses (11%). Less than half (40%) of providers in non-profit organizations worked in acute-care hospitals; they were nurses (21%) or service coordinators/case managers (15%).

The most common population served by providers were young adults (18-29) (70%). The least common were families (22%) and infants (25%). Although non-Hispanic Black have the highest rate of TBI and Hispanics have the highest proportion of work-related TBI in Tennessee, less than two in five providers (37%) disclosed serving patients that were minorities. Similarly, less than half (40%) of providers saw low-income patients.

**Figure 13: Providers serve individuals across the life course**



**Figure 14. Most facilities have a workforce of less than 10 people providing care to persons with TBI**



A robust workforce is essential to the care and management of TBIs. **Most provider respondents worked in facilities with a workforce of less than 10 employees.**

Both survivors and their families/caregivers expressed that lack of financial resources limited their access to healthcare services. Given the need for financial resources, however, only 22% of facilities/organizations accept scholarship admission while most accept multiple methods for reimbursement. The top methods accepted for

reimbursement were self-pay (50%), private insurance (50%), Medicare (43%), workers comp (39%), and veteran’s benefits (33%).

## Services



The **most** available **medical/therapeutic** services for children and adults:

1. Physical Therapy
2. Medical Services
3. Nursing

The **least** available **medical/therapeutic** services for children and adults:

1. Dental Services
2. Orthodontics/Prosthetics
3. Alternative Therapies



The **most** available **rehabilitation services** for children and adults:

1. Speech Language Therapy
2. Case Management/Service Coordination/Social Work
3. Occupational therapy

The **least** available **rehabilitation services** for children and adults:

1. Driver Education
2. Therapeutic Recreation
3. Neurobehavioral Treatment



The **most** available **educational/employment services** for children and adults:

1. Advocacy
2. Pre-Vocational Services
3. Career Counseling/Guidance



The **least** available **educational/employment services** for children and adults:

1. Job Sampling
2. Vocational Evaluation
3. Volunteer Placement

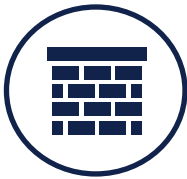


The **most** available **community living support** services provided to children and adults:

1. Information and Referral
2. Support Groups
3. Social Skills Training

The **least** available **community living support** services provided to children and adults:

1. Residential-Behavioral Issues
2. Housing Supported
3. Personal Assistance Services



The **most** perceived **barriers** to services in patients with TBI were:

1. Patient/Client is unaware of services/resources (80%)
2. Lack of transportation (80%)
3. Inadequate support from family/caregiver (78%)
4. Inability to pay for services (78%)
  - Lack of Insurance (72%)
  - Limited Insurance (71%)
5. Services not located locally or conveniently (76%).

## Staff



Most providers (59%) reported that employees in their organization were **moderately trained/educated** to serve persons with TBI.



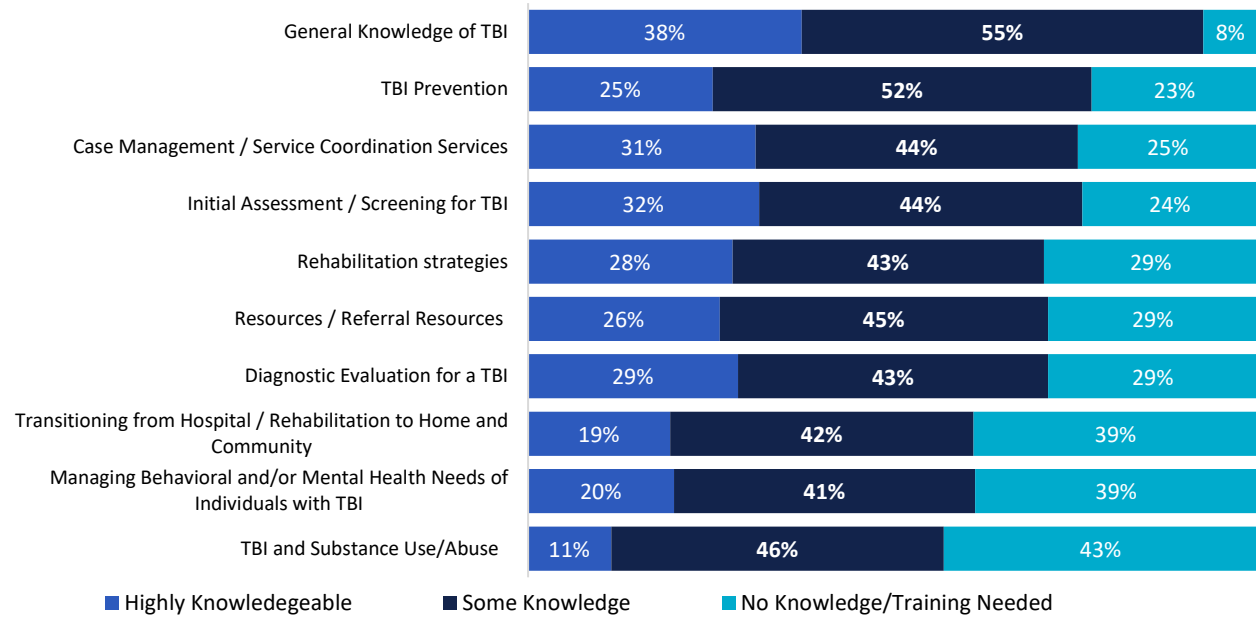
The top three approaches providers use to **train/educate** staff are:

1. Workshops or conferences outside the agency (48%)
2. Online/external training modules (not college) (41%)
3. Informal mentoring (35%).

## Training

Overall, providers had some knowledge about TBI, and most (79%) were interested in further training. Figure 15 illustrates the variation in topic knowledge among providers. Providers stated they needed additional training in TBI and substance use/abuse (43%), managing behavioral and/or mental health needs of individuals with a TBI (39%), and transitioning from hospital/rehabilitation to home and community (39%).

**Figure 15. Provider Knowledge on TBI (N=80)**



## COVID-19 & TBI



The top three concerns reported by providers in patients during the COVID-19 pandemic were related to reduced access to care, isolation, and mental health.



**62%** of providers reported their facilities/organizations are experiencing staff shortages due to COVID-19.



**55%** of providers reported their facilities have been able to continue contact with partners/stakeholders.



**26%** of providers reported an increased demand in services. Providers that were more able to provide services include:

- Mental Health Professionals
- Speech Therapists
- Service Coordinator/Case Managers.



**34%** of providers reported a decreased in services. Providers that we less able to provide services include:

- Nurses
- Speech Therapists
- Physical Therapists.

## Limitations

While valuable and insightful information was obtained from these responses, compared to the size of the population affected, the response rate was low. A low response rate may produce prevalence estimates that are biased by selective non-response or be non-representative of the populations affected. For example, in 2020, Hispanic Tennesseans had the highest rate of work-related TBI injuries, yet only one survey responder identified as Hispanic; Non-Hispanic Black Tennesseans were most affected by TBIs, yet only two survey responders identified as Non-Hispanic Black. Finally, male respondents outnumbered females in every age group except for the oldest category (81+), yet most survey responders were female (57%). Challenges brought on by low response rates can be further exacerbated when survey completion rates are also low.

When conducting a needs assessment, every response is vital for drawing precise and accurate conclusions. Therefore, when survey completion rates are low, the likelihood for data misinterpretation or bias becomes larger, as data consistency is reduced. Overall, 58% of survey responses were complete. While this provides a little over half of all available data, it is important to consider what factors may have influenced this outcome. For instance, competing priorities and limited resources can discourage participation altogether. This needs assessment was administered electronically, mandating access to technology capable of uploading the survey and continuous and reliable internet services. Although access to these kinds of resources has increased in recent years, it inevitably limits the sample population to people who have access to them in the first place. Working on how to improve these circumstances will improve future needs assessments.

## Recommendations

To maximize the efficacy of a needs assessment, it is essential that the target populations are being reached so that when interpretations are being made, they are generalizable, and representative of the population affected. Improving factors such as survey awareness, interest, and accessibility would be a step forward. Perhaps by taking on a more targeted approach to promote the needs assessment in the future will help increase overall survey awareness and therefore, reach and attract more of the target populations. Producing instruments and other program materials in languages beside English could potentially interest participants of different ethnic backgrounds and encourage more participation; and allocating resources to support multiple means to carry out the survey would also be more conducive towards more accurate and precise interpretations. For example, in rural areas, towns with older populations, and homes of lower socioeconomic status, a “pen and paper” survey may be more favorable and accessible than the technological demands of an electronic survey.

With increased participation from the populations of interest, the potential to modify and create programs and policies that can directly address specific needs as well as gaps in knowledge, practices, or skills grows. For example, not only did TBI survivors feel isolated and overwhelmed as they adapted to new physical, financial, social, and emotional demands brought on by their

TBI, so did their families and caretakers. Families and caretakers of persons with TBI repeatedly expressed a need for respite care and support groups, as they too, were being challenged by the onset of new demands brought on by their role as caretakers. By addressing those needs and others, the potential for benefits to cascade from caretaker to care recipient becomes possible.

## Implications

The results of this needs assessment provide insight to specific health disparities and inequities prevalent in the TBI community and invites a plan for the additional allocation of resources—with a special emphasis on better communication about the availability of those resources and improved access to those resources. Persons living with TBI, their families, and caregivers that found obtaining services/support the most difficult, reported location, lack of support, and difficulty getting enrolled as their top concerns. Furthermore, participants with no health insurance coverage were more likely to forgo or prolong medical care. Changes in cognitive skills, behavior/personality, and mental health conditions following a TBI were also common inhibitors to follow-up care, as the social and emotional changes increased demands. Overall, respondents felt their providers were knowledgeable about TBI, however, expressed the need for more specialized training. This aligns with most providers reporting being moderately trained/educated on providing services to persons with TBI but interested in further, more specialized training.