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Georgia Statewide Traumatic Brain Injury (TBI) Needs Assessment Report



**Brain & Spinal Injury
Trust Fund Commission**



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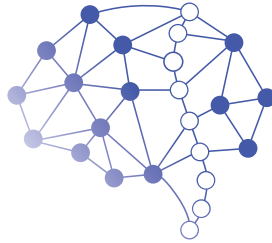
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About the Needs Assessment

The Brain and Spinal Injury Trust Fund Commission (BSITFC) enlisted the assistance of the Research and Evaluation Unit (REU) at the Institute on Human Development and Disability (IHDD) at the University of Georgia (UGA) in 2021 to conduct a statewide needs assessment for Georgia. The purpose of this assessment was to explore the needs of individuals with Traumatic Brain Injuries (TBI) living in Georgia, and to assess the availability of existing services and support in Georgia. Reviews of research and data were conducted to help identify gaps in TBI services across the state. Online surveys, focus groups and interviews were conducted with individuals with TBI, caregivers and professionals to review the extent to which Georgians with TBI are receiving sufficient services to support quality of life in the community. Results from the environmental scan and data collection from key stakeholders are presented in the sections below.

Background on Brain Injuries

What is a Brain Injury?

Acquired brain injuries (ABI) are brain injuries that occur after birth and can be classified as either traumatic or non-traumatic, depending on whether the injury occurred due to external trauma or internal trauma to the brain.¹ This study focuses on traumatic brain injuries, defined as a form of acquired brain injury, which occurs when a sudden trauma causes damage to the brain. TBI can result when the head suddenly and violently hits an object, or when an object pierces the skull and enters brain tissue. Symptoms of a TBI can be mild, moderate, or severe, depending on the extent of the damage to the brain.

The CDC defines a traumatic brain injury as “a disruption in the normal function of the brain that can be caused by a bump, blow, or jolt to the head or a penetrating head injury.”² The external trauma to the brain can cause the brain to bounce around or twist in the skull, chemical changes in the brain, or stretching and damaging of brain cells.³ TBIs may be categorized as mild, moderate, or severe with the Glasgow Coma Scale.⁴ In the U.S., approximately 58-73% of TBIs are mild, often referred to as concussions. Another 8-25% are moderate TBIs and 6-8% are severe.⁵

A TBI may result in a variety of short-term and long-term effects, and many people who sustain a TBI recover completely. However, the timeline to recovery may be days, weeks, months, or even longer. A significant portion of those who sustain a TBI have lingering symptoms and disability for the rest of their life.⁶ TBI can cause a period of unconsciousness, coma, or amnesia immediately after occurrence of the injury. TBI can also cause additional health problems after the injury, including physical symptoms, cognitive and learning issues, and changes in motor skills, hearing, vision, emotions and mood, and/or behavior.⁷

Prevalence of Traumatic Brain Injuries

National Prevalence

Annually in the U.S., 1,299 people per 100,000 population will incur a TBI based on a 2019 study. With the 2021 U.S. population estimate (n=331,893,745), it is estimated that 4,311,299 people

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in the U.S. incurred a TBI.⁸ The CDC estimates there were 223,135 TBI-related hospitalizations and 60,611 TBI-related deaths in the United States in 2019. These estimates do not include the many traumatic brain injuries that are only treated in the emergency department, urgent care, primary care, or not at all.⁹ Some CDC models estimate that 25% of all mild and moderate TBIs are medically untreated and thus, unreported.¹⁰ The CDC estimates that 5.3 million U.S. citizens (approximately 2% of the population) live with a disability as a result of a TBI. The incidence of known TBIs is greater than all incidents of spinal cord injury, HIV/AIDS, breast cancer, and multiple sclerosis combined in the U.S.¹¹

Georgia Prevalence

Using Dewan et al.'s estimate of 1,299 per 100,000 people incurring a TBI, we estimate that 140,286 Georgians incurred a TBI in 2021 (n=10,799,566).⁸ The Georgia Brain and Spinal Injury Registry recorded 29,924 traumatic brain injuries including 21,026 emergency department visits and 8,081 hospital admissions in 2019.¹² Georgia has a higher rate of TBI-related deaths than the overall U.S. rate (20.3 deaths per 100,000 vs. 17.3 deaths per 100,000).¹⁰ Based on the CDC estimate that 2% of the population in the United States live with a disability as a result of a TBI, we estimate that 215,991 (n=10,799,566) Georgians have a TBI-related disability.^{11,13}

Causes of Traumatic Brain Injuries

The main causes of a TBI-related emergency department visit, hospitalization, or death include falls, struck by/against, motor vehicle related, assaults/homicides, self-inflicted/suicides.¹⁴ Overall, falls are the leading mechanism of injury to cause a TBI-related emergency department visit, hospitalization, or death. However, motor vehicle related and self-inflicted, suicide TBIs have the highest rates of death of any mechanism of injury. Common causes of traumatic brain injuries include falls, assaults, motor vehicle accidents, sports and recreation injuries, abusive head trauma, gunshot wounds, workplace injuries, child abuse, intimate partner violence, and military related injuries.

Impact of Brain Injury

The impacts of a traumatic brain injury are dependent on what part of the brain is damaged during the injury. The brain has six distinct lobes, all with specific functions.¹⁵ Depending on which brain lobe(s) is damaged in the injury, people with TBIs will have different short and long-term impacts.

- » Frontal Lobe: Injury may impact ability to control emotions, impulses, and behavior, or may cause difficulty with memory or speaking.
- » Brain Stem: Injury to the brain stem may impact the body's involuntary functions (e.g. breathing, heart rate), which can impact ability to survive.
- » Temporal Lobe: Difficulty with communication or memory.
- » Parietal Lobe: Difficulty with the five primary senses (sight, smell, taste, touch, hearing).
- » Cerebellum: Difficulty with balance, movement, and coordination

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- » Occipital Lobe: Challenges with vision, depth perception.

Impacts of TBI also depend on which side of the brain is injured.¹⁵

- » Left Side: Difficulties understanding language and/or speaking; feelings of depression and/or anxiety; impaired logic; sequencing difficulties; decreased control of right-sided body movement.
- » Right Side: Visual-spatial impairment; visual memory deficits; decreased awareness of deficits; altered creativity; altered perception of music; unable to think “big picture”; decreased control of left-sided body movement.

The Traumatic Brain Injury Model Systems (TBIMS) Database looked at outcomes of persons 16 years of age and older who received inpatient rehabilitation services for a primary diagnosis of TBI, five years after injury.¹⁶ Of all individuals with moderate to severe TBI, 22% died, 30% became worse, 22% stayed the same and 26% improved.

Costs of Care for Brain Injuries

Traumatic brain injuries have both short-term and long-term effects and costs for the individuals who have suffered the injury, their families, and society as a whole. One estimate of TBI-related costs, including direct medical costs and indirect costs, is more than \$76 billion annually in the United States.¹⁷ In 2016, the direct healthcare costs attributable to TBI was \$40.6 billion.¹⁸ Estimated lifetime costs of treatment for a TBI run anywhere from \$85,000 to \$3 million, which does not include the indirect costs of lost wages. The indirect costs can be seen in the unemployment rate for people with TBI, two years after diagnosis of a TBI, which sits at an alarming 60%.¹⁹ The Brain and Spinal Injury Trust Fund Commission estimates that traumatic brain injuries cost Georgians more than \$1.5 billion annually in lost wages and medical costs. With these extremely high costs of traumatic brain injuries, it is imperative to have specific, well-funded financial support for those recovering from TBI.

Neurobehavioral Issues Associated with Brain Injuries

Traumatic brain injuries can cause chronic neurobehavioral issues for survivors, which may complicate the recovery processes. These neurobehavioral issues can be classified into the following categories: changes in cognition, changes in personality, and psychiatric disorders.

Changes in Cognition

The most common complaints after TBI are changes in cognition, which are major hindrances to a return to normalcy in independent living, social adaptation, family life and vocational endeavors. Attention, short-term memory and learning, information processing, and speech and language functioning are often negatively affected by TBI.²⁰

Changes in Personality

Changes in personality may occur as an exaggeration of pre-injury personality traits, or as a fundamental change in personality traits. Some key problem areas seen as a result of TBI are impulsivity, irritability, affective instability, and apathy. These key problem areas may be exacerbated by anosognosia, a lack of awareness that any personality change has occurred as a result

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of injury.²⁰ Additional changes seen in individuals with TBI are dysphoria, disinhibition, delusions, aggression, and euphoria.²¹

Psychiatric Disorders

TBI results in an increased risk of developing various psychiatric disorders. One study found that almost half of individuals with TBI developed a new psychiatric disorder after their injury. The most common diagnoses post-TBI are major depression and anxiety disorders, including post-traumatic stress disorder, obsessive-compulsive disorder, and panic disorder.²² There is also recent research showing a relationship between TBI and dementia and Alzheimer's disease.²⁰

How Does Brain Injury Affect Specific Vulnerable Populations?

Traumatic brain injury affects people across all age groups, races, socioeconomic statuses, backgrounds, and employment types. However, there are some groups that research has found to be at a greater risk of incurring TBI, dying from a TBI, and/or developing long-term health challenges due to the injury. These groups include: culturally and linguistically diverse populations, military service members and Veterans, people who are incarcerated, people who experience homelessness, survivors of intimate partner violence, people in rural areas, people who do not have health insurance, people with low-incomes, infants, children, and youth, and aging people. Below is more information on how some of these populations are affected by TBI including service members and Veterans, racial and ethnic minority groups, infants, children, and youth, again populations, and incarcerated populations.

Service Members and Veterans

The Traumatic Brain Injury Center of Excellence, formerly referred to as the Defense and Veterans Brain Injury Center, collects and reports on prevalence data of traumatic brain injury in service members. From 2000-2021, 453,919 service members were reported as having incurred one or more TBI. Of those traumatic brain injuries, 82.3% were classified as mild, 10.8% as moderate, 1% as severe, 1.2% as penetrating, and 4.6% as not classifiable. The majority of all reported TBI occurred in the Army (58.5%), with the Navy, Air Force, and Marines each reporting approximately 13-14% of TBI incidence.²³ From 2000-2011, the overall rate of TBI among active duty service members more than doubled from 720.3 per 100,000 to 1,811.4 per 100,000.²⁴ A large research study found that TBIs cause short and long term effects including physical and mental health effects, health, mental health, and rehabilitation needs, type and availability of long-term rehabilitation and other care services, and effects on the family.²⁵ Some of these effects are described below.

Physical and Mental Health Effects

The most important health factor related to long-term outcomes is the presence of mental health symptoms, especially post-traumatic stress symptoms. As compared to service members with no injury, service members and Veterans who sustained a TBI have the greatest rates of physical health risks. Other common problems associated with TBI include chronic pain sleep disturbance, orthopedic injuries, cardiovascular disease, sexual dysfunction, and gastrointestinal disease.

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Additionally, TBI has a great negative impact on cognitive health, and these cognitive problems such as memory deficits or difficulty problem-solving can persist for years.

Health, Mental Health, and Rehabilitation Needs

Hospital readmission for rehabilitation was common during the year post-TBI, especially for those with more severe injuries. Among those who received inpatient rehabilitation services for their TBI, it is common to see continued rehabilitation needs for five years or more after their injury. Common ongoing needs included cognitive health, managing physical symptoms, mental health, and service coordination needs. Black service members and Veterans report having greater unmet needs for help with managing emotions, community reintegration, employment, and at-home independence.

Effects on the Family

Much of the caregiving responsibilities for service members or Veterans with TBI fall on family caregivers. Caregivers who experience significant caregiving burden experience poor mental health, headaches, gastrointestinal issues, obesity, hypertension, and sleep problems. The impact of a family member with a TBI is also felt by their children. These children report many co-occurring medical problems, and in families where the Service member or Veteran shows anger, anxiety, and depression, the children have significant behavioral health problems. Those with both PTSD and a co-occurring mental health issue such as depression, anger, irritability, or aggression were more likely to have a negative impact on their family stability and cohesion.

Incarcerated Populations

People who are incarcerated or in the criminal justice system in the United States have extremely high prevalence rates of TBI. In male prisons, it is estimated that 40-60% of incarcerated individuals have sustained at least one TBI, compared to general population prevalence estimates of approximately 8-15%. Prison populations also tend to include more cases of moderate or severe TBI and repeated injuries.²⁶ The presence of a TBI is also associated with higher rates of recidivism and violent offending.²⁷

Children and Youth

Children under the age of 18 accounted for roughly 8% of all TBIs in the United States in 2016, with the majority being classified as mild.^{28,29} However, given that they are less likely to seek care for mild injuries, the prevalence of TBIs in children is underestimated. Further, TBIs that occur in young children are often misdiagnosed as a behavioral or learning disorder because they do not manifest until later into adolescence, far after the injury's occurrence.³⁰ The leading causes of injury for youth are falls and motorized vehicle accidents.

TBI in children can be additionally complex because the injury occurs during brain development, which can cause the injury to affect both previously-learned skills and the development of future skills, and problems related to the injury can continue surfacing for years after its incurrence. In fact, over half of children with moderate-to-severe TBI and about 14% with mild TBI develop long-term disabilities that require specialized care.³¹ Beyond physical impairment,

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children with TBI are likely to experience social and behavioral impairments, especially in the educational system. Children who have sustained a moderate-to-severe TBI tend to have persistent lower life satisfaction, reduced adaptive functioning, and lower rates of participation in activities.

Most children with moderate to severe TBI and many with mild TBI require academic support and accommodation after injury.³² While services including early intervention, special education, and academic support are technically legally available to children with TBI through a Section 504 plan, many patients and families experience challenges in obtaining this support.³³ It is common for teachers to hold misunderstandings about TBI and its effects on emotional, cognitive, and social development.³⁴ These misunderstandings lead to misdiagnosis of learning and behavioral disorders in children, causing stress and exacerbation of a child's symptoms.³⁵ Many patients and families find that educators lack training in how best to support children in the academic setting after injury.³⁶

Aging Population

Older adults have high rates of TBI incurrence and are more likely than any other age group to be hospitalized and die as a result of a TBI.³⁷ For older adults, falls are the leading cause of injury death. In 2019 falls caused 34,000 deaths in U.S. adults age 65 and older. Traumatic brain injury can be made more potentially dangerous if the patient is taking certain medicines such as blood thinners, which can increase the risk of a brain bleed after a TBI.³⁷ People age 75 and older in the U.S. are the largest age group to be hospitalized for a TBI and to have a TBI-related death.³⁸ This group of aging adults makes up 32% of all TBI-related hospitalizations and 28% of TBI-related deaths, despite making up only 7.8% of the U.S. population.^{38,39}

In addition to the increased risk of incurring a TBI, older adults who have a TBI experience higher morbidity and mortality, a longer recovery time, and overall worse outcomes than younger populations do.⁴⁰ Older adults also have a high rate of pre-existing medical conditions that are associated with worse outcomes in TBI recovery.⁴⁰ If an older adult is hospitalized after TBI, they are more likely to need extended hospitalization and are more likely to be severely disabled and functionally dependent upon their eventual discharge from the hospital.⁴⁰ Due to these high risk factors, high rates of TBI incurrence, and high morbidity and mortality rates, older adults are an extremely vulnerable population when it comes to traumatic brain injury.

Racial and Ethnic Disparities in TBI Outcomes & Care

Across age groups, there are disparities and inequities relating to TBI prevalence, outcomes, and access to care depending on racial and ethnic identity. Individuals of color experience some of the leading causes of TBI, such as car accidents and violent injury, more frequently than White individuals.³⁴ Statistics from CDC found that the emergency room admission rate for the White population was 66 per 1,000 as compared to 74 per 1,000 for populations of color.⁴¹ Post-TBI outcomes differ by race and ethnicity. Compared to their White peers, both Black and Hispanic individuals with TBI are less likely to receive post-TBI treatment, have worse functional outcomes, experience less community re-integration, and have lower employment rates. A 2019 study found that Black and Hispanic patients were less likely to be moved to inpatient rehabilitation after

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receiving acute care as compared to White patients.³⁴ Lack of ongoing care post-TBI may lead to worse functional and quality-of-life outcomes for patients of color because of the relationship between post-acute rehabilitation outcomes and functional status, community reintegration, and employment.³⁴ Children belonging to communities of color experienced differences in acute care post-TBI; a 2006 study found that Black children under 10 who experienced TBI after a car accident had significantly higher rates of death and hospitalization than their White peers.³⁴

It has also been observed that access to resources for Black and Hispanic individuals and families affected by TBI are more limited than for White individuals and families. There is limited cultural competence when it comes to professional outreach efforts toward these groups, and this may contribute to the ongoing gap in representation for Black and Hispanic individuals and families within the TBI community. Language barriers play an important role in restricting access to care.³⁴ Increased access to services after leaving acute care may result in more positive outcomes for populations of color. Hiring racially and ethnically diverse TBI professionals, as well as increasing cultural competency training for TBI professionals may serve to increase access to and interest in TBI services for individuals and families of color.

Georgia Traumatic Brain Injury Services Landscape

To accurately describe the state of TBI in Georgia, the extent of available resources for both individuals with TBI and their family members must be examined. The summary below highlights primary service areas for individuals with TBI. Information about current available services comes from the Georgia Board of Healthcare Workforce and Department of Community Health Active Provider Directory.^{42,43} Knowing the state of current services will help in future resource and services planning for individuals with TBI in Georgia.

The purpose of this summary is to create a snapshot of the current service system for individuals with TBI in the state of Georgia. This summary aims to quantify the resources available in each county. It is important to note here that the number of providers who serve people with TBI is based upon each provider's self-report about whether they have the capacity to provide such specialized services. It is not based upon licensing or certifications, which means there is no guarantee that a provider who reports that they are able to serve people with TBI really does have the training and specialized services necessary to do so effectively and appropriately. The Figures are presented at the end of this section.

Georgia Total Population

There are approximately 10.7 million people in the state of Georgia overall.⁴⁴ Roughly 79% of all people in Georgia live in non-rural counties ($n = 8,482,248$), which make up only 26% of all counties in Georgia ($n = 41$ non-rural counties). Fifty-seven percent of all Georgians live within the 29-county metro Atlanta area ($n = 6,089,815$). An overview of total population by county from the 2020 Census is presented in Appendix A, Figure 1.

Hospitals

As indicated in Appendix A (Figures 2 and 3), there are 258 hospitals across the state of Georgia.⁴³ There are 51 counties in Georgia without a hospital, and 108 with a hospital. 61 rural

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counties have at least one hospital (56% all rural counties). Of those without a hospital, 94% are rural counties (n = 48). The three non-rural counties without a hospital are Columbia County, Jackson County, and Walker County.

Physicians

There are currently 27,002 full time effort (FTE) physicians in the state of Georgia.⁴² 91% of FTE physicians are located in non-rural counties (n = 24,513). Of 118 rural counties, 110 have at least one FTE physician. The counties with no FTE physicians are: Chattahoochee County, Echols County, Montgomery County, Schley County, Talbot County, Taliaferro County, Treutlen County, Turner County, and Webster County. An overview of the total number of FTE physicians by county can be seen in Figure 4, while an overview of counties with no FTE physicians can be seen in Appendix A, Figure 5.

Physicians Assistants

There are currently 4,078 FTE physician assistants in the state of Georgia.⁴² Roughly 89% of all FTE physician assistants are located in non-rural counties (n = 3,638). Of 118 rural counties, 84 have at least one FTE physician assistant. Five counties in Georgia have no FTE physicians and no physician assistants. Those counties include: Schley County, Talbot County, Taliaferro County, Treutlen County, and Webster County. An overview of the total number of physician assistants by county can be seen in Appendix A, Figure 6.

Nurses

There are currently 143,288 nurses in the state of Georgia.⁴² Roughly 81% of all nurses are located in non-rural counties (n = 115,451). Of 118 rural counties, 115 have at least 9 nurses. Only one county has no physicians, physician assistants, or nurses (Schley County, Georgia). The counties with no nurses are Bleckley County and Glascock County. An overview of the total number of nurses by county can be seen in Appendix A, Figure 7.

Rehabilitation Facilities

Rehabilitation facilities included in this map comprise of rehabilitation hospitals (6), clinics (2), and home & community-based rehabilitation services (4).⁴³ The number of facilities for this map has been pulled from the Active Provider Directory from the Georgia Department of Community Health. Although the Shepherd Center is a Level I rehabilitation care facility in Georgia, it is not specifically listed as a rehabilitation hospital in this database.

There are currently 12 rehabilitation facilities in the state of Georgia.⁴³ Nine of those are located in non-rural counties. The three rural counties with rehabilitation facilities include Union, Meriwether, and Washington Counties. Besides the one facility in Chatham County, there are no rehabilitation facilities in southeastern Georgia. The majority of facilities are in central portions of the state. An overview of the total number of rehabilitation facilities by county can be seen in Appendix A, Figure 8.

Mental Health Professionals

There are 9,469 mental health professionals in the state of Georgia.⁴³ About 89% of all mental health professionals are located in non-rural counties (n = 8,436). Of 118 rural counties, 97 had at

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least one mental health professional, leaving the 21 remaining rural counties with no mental health professionals. Most of these counties are in the southern part of the state. An overview of the total number of mental health professionals by county can be seen in Appendix A, Figure 9.

Speech/Language Pathologists

There are 4,359 speech and language pathologists (SLPs) in the state of Georgia.⁴³ There are 58 counties without a SLP, one of which is a non-rural county (Walker County). Of 118 rural counties, 61 had at least one SLP in the county. An overview of the total number of speech and language pathologists by county can be seen in Appendix A, Figure 10.

Neuro Professionals: Neurosurgery Physicians, Neurosurgery Critical Care, Neurological Surgery Physicians, and Neurology Workers

There is a definitive shortage of availability for neurology professionals, especially in the field of neurological surgery.⁴² In the state of Georgia, there are only two neurosurgery physicians; however, there are 203 FTE physicians with neurological surgery listed as their specialty area. There is only one physician with neurosurgery critical care as their specialty. In the general area of neurology, there are about 529 FTE physicians who list their specialty area as neurology. The majority of these neuro professionals are located in urban areas, primarily the Metro-Atlanta counties, Richmond County, and Chatham County. An overview of the total number of neurology professionals by specialty area can be seen in Appendix A, Figures 11, 12, 13, and 14.

Child Neurology

There are 26.6 FTE child neurology physicians in the state of Georgia.⁴² All of these physicians are located in non-rural counties, with the majority of them being clustered within the Metro-Atlanta region. Further, 45% of child neurology physicians are located in DeKalb County alone. An overview of child neurology physicians by county can be seen in Appendix A, Figure 15.

Transportation

There are 19 transportation services in the state of Georgia across 16 counties (11% of all counties).⁴³ Of those 19 services, 68% are in non-rural counties ($n = 13$). The rural counties with transportation services include Burke County, Coffee County, Early County, Jeff Davis County, Laurens County, and Sumter County. An overview of the total number of transportation services by county can be seen in Appendix A, Figure 16.

Brain Injury Workers

Brain injury categories include providers who selected “Brain Injury” as one of their specialty areas. This may include any type of rehabilitation service providers, such as case managers, physicians, and others and is not exclusive to medical service providers. There are 30 professionals who specialize in brain injury in the state of Georgia.⁴³ Of those, only one was located in a rural county (Baldwin County). The majority of brain injury specialists were concentrated in the Atlanta metro area, as well as urbanized areas such as Chatham County and Richmond County. An overview of the total number of brain injury specialists by county can be seen in Appendix A, Figure 17.

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Physical Therapists

There are 3,898 physical therapists (PTs) in the state of Georgia.⁴³ There are 46 counties without a PT, all of which are rural counties. An overview of the total number of physical therapists by county can be seen in Appendix A, Figure 18.

Occupational Therapists

There are 2,510 occupational therapists (OTs) in the state of Georgia.⁴³ About 86% of all OTs are located in non-rural counties (n = 2,174). Of 118 rural counties, 85 had at least one OT, leaving the 33 remaining rural counties with no OTs. Most of these counties are in the southern part of the state. An overview of the total number of occupational therapists by county can be seen in Appendix A, Figure 19.

Rural Hospitals

As of 2017, there are 37 rural hospitals and 30 critical access hospitals across all 118 rural counties in the state of Georgia.⁴⁵ Fifty-four rural Georgia counties have no hospitals in them, contributing to the healthcare availability shortage in rural areas. The majority of counties without a hospital are located in the southern and southwestern parts of the state. An overview of rural hospitals by county can be seen in Appendix A, Figure 20.

Designated Trauma Centers

As of 2022, there are 31 designated trauma centers of varying levels and types in the state of Georgia.⁴⁶ As seen in Appendix A, Figure 21, there are four levels of trauma hospitals with Level 1 hospitals being able to handle the most severe injuries and Level 4 being able to handle the least serious injuries. There are also Level 1 and 2 pediatric trauma hospitals listed. It is important to note that there are no Level 1 trauma hospitals located in any rural counties. There is a distinct string of southwestern Georgia counties where there are no designated trauma hospitals.

Rural Counties Without a Rural Health Clinic

As of 2017, there are 10 rural Georgia counties with no Rural Health Clinics (RHC).⁴⁷ In contrast to other trends where most counties with no access to a particular resource are in the southern part of the state, 50% of the counties without a RHC are located in central Georgia just southeast of the Metro-Atlanta counties. One possible explanation is that individuals in these counties drive into the surrounding Metro-Atlanta area to take care of their medical needs. An overview of the counties without a RHC can be seen in Appendix A, Figure 22.

Support Groups for Individuals With Brain Injuries and Caregivers

Support groups for individuals with a TBI and their caregivers in Georgia are offered mostly in larger cities like Atlanta, Savannah, Columbus, and Augusta. Before the COVID pandemic in 2020, most support groups were in-person, however, many of them adapted and shifted to a virtual format to support TBI survivors and their caregivers. Currently, there are 23 support groups in Georgia offering services in a virtual format (Appendix A, Table 1). It is also important to note that many support groups had to shut down in Georgia due to the pandemic. While some are continuing their services in a virtual format, others are working towards restarting the support group services in person.

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Rural Healthcare Workforce Shortages (Georgia)

National data and trends show a clear pattern of disparities between rural and non-rural access to healthcare in the United States. Hospital consolidation and closure rates have grown across the country in recent decades, particularly resulting in more closures in rural areas, furthering the rural care access divide.⁴⁸ According to a recent Government Accountability Office (GAO) report, the median travel distance to a hospital increased by about 20 miles between 2012 and 2018 in areas that saw rural hospital closures.⁴⁹

Given the county level data on the Georgia healthcare workforce previously discussed in this report, it is clear that this trend is deeply affecting rural Georgia. As seen in Figure 2, a little over half of all rural Georgia counties do have at least one hospital.⁴³ However, 76% of all total hospitals (n = 268) in Georgia are concentrated in non-rural counties. When considering that rural counties account for 70% of all counties in the state, there is a clear dearth of rural healthcare workers.

Neurologist Shortage: Georgia, Southeast, and Nationally

There is evidence that a neurologist shortage is pertinent, both in Georgia and across the United States. According to a paper from Merritt Hawkins (2021), demand for neurologists is expected to grow faster than the current supply, with an expected deficit of 19% by 2025.⁵⁰ This trend is clear when looking at the current number of neurologists in Georgia. According to the American Academy of Neurology, there are currently 3.22 neurologists per 1,000 people in the state of Georgia.⁵¹ This equates to roughly 350 neurologists across the state. When compared with other southeastern states with a similar population size such as North Carolina (3.49 neurologists per 1,000 people) as well as the national average (3.52 per 1,000 people), it is clear that Georgia is already lagging behind current demands for neurology care.⁵¹ This trend continues when looking at other specialty areas within neurology, such as neuropsychology. The shortage of neurology professionals in the United States is currently being felt and is on track to only be exacerbated.⁵²

Shortage of TBI Professionals in Georgia

As discussed in relation to Figure 17, there is a clear shortage of brain injury professionals in the state of Georgia.⁴³ According to the Active Provider Directory put out by Georgia Department of Community Health, there are only 30 self-indicated brain injury professionals in the state of Georgia.⁴³ However, the number may actually be smaller given that some of these professionals may only specialize in certain kinds of brain or head injuries and not necessarily TBIs. While there are no specific numbers for TBI professionals in this directory, the membership directory for the National Academy of Neuropsychology indicates that there are 13 neuropsychologists in the state of Georgia who list traumatic brain injury as one of their areas of specialty.⁵³ This is out of a total 43 neuropsychologists in the Georgia membership directory. Further, none of those neuropsychologists specializing in TBI are located in rural counties.

Rehabilitative Resource Distribution (SLPs, PTs, Rehab Centers)

To evaluate the overall distribution of rehabilitative resources in Georgia, the total number of rehabilitation hospitals and clinics, speech and language pathologists (SLPs), physical therapists (PTs), and occupational therapists was collected for each Georgia county. Overall, there are 10,777

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rehabilitation resources in the state of Georgia.⁴³ Of this, over half of all rehabilitation resources are concentrated in seven Metro-Atlanta counties (Cobb, Cherokee, DeKalb, Fulton, Forsyth, Gwinnett, and Hall County). Of the 159 counties in Georgia, 12% of them have no rehabilitative resources, all of which are rural. Most of the counties with few or no access to resources are located in the southern and central-eastern parts of the state. An overview of the distribution of rehabilitation resources in Georgia can be seen in Appendix A, Figure 23.

Georgia Agencies and Services Landscape

This section focuses on agencies, services and waivers in Georgia that are designed to serve individuals with disabilities including those with TBI.

State Agencies With Programs for Others but Include People With TBI

- » Department of Community Health, Office of Medicaid
 - The Department of Community Health offers a number of resources for people with disabilities, including Home and Community-based Services waivers (HCBS), the Katie Beckett Program, and the Money Follows the Person (MFP) Demonstration Program. Further detail on the HCBS Waivers and the Katie Beckett Program can be found below, in the Waivers section of this report.
 - Money Follows the Person (MFP) Demonstration Program: MFP offers transition services to qualified Medicaid eligible adults. One may qualify for MFP if they have lived in an inpatient facility for at least 60 consecutive days. MFP uses home and community-based Medicaid waiver services if needed for ongoing support and one-time transition services to move from inpatient to community-based care.
- » Department of Labor, Georgia Vocational Rehabilitation Agency, Vocational Rehabilitation, Roosevelt Warm Springs
 - Vocational Rehabilitation services offered by GVRA include connection to a personal vocational rehabilitation counselor, obtaining assistive work technology, and referrals to additional services, including Roosevelt Warm Springs, noted above.
 - Roosevelt Warm Springs is a residential campus where students receive medical and vocational rehabilitation services. Students may work towards earning professional certifications and developing life skills with the final goal being employment for all students. It is the only program that the Department of Labor has developed to meet the specific needs of people with TBI.
 - The state has designated the GVRA to oversee federal funding for the Centers for Independent Living (CILs) and to work closely with the State Independent Living Council (SILC) and the nine participating CILs to execute the State Plan for Independent Living (SPIL). Georgia's Centers for Independent Living are designed and operated by people with disabilities to provide independent living services, tools, resources, and supports for people with disabilities. Their mission is to facilitate equal participation of people with disabilities within their communities. The foundation of these services is the peer-to-peer relationship,

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where people with disabilities act as mentors for other people with disabilities, showing them by example how to help themselves and to live independently. Georgia has 9 CILs; 26 counties are unserved by a CIL. Georgia's CILs core services include individual and systems advocacy, peer counseling and support, information and referrals, independent living skills training, and transition services. In Georgia, CILs and their service providers can be found in the cities listed in Appendix A, Table 2.

» Brain and Spinal Injury Trust Fund Commission

- The BSITFC provides direct grants to Georgians with traumatic brain and spinal injuries to assist in creating lives of independence and inclusion. The BSITFC is the lead agency for traumatic brain injury for the State of Georgia, which advises the legislature on relevant policy. The BSITFC also partners with the Brain Injury Association of Georgia (BIAG) to provide a free Resource Facilitation Program for Georgians who have a TBI.

» Georgia's Aging & Disability Resource Connection (ADRC)

- The Aging & Disability Resource Connection links seniors and adults with disabilities to resources that promote independence. Counselors use the Empower line database to connect individuals to resources that can help them stay in their homes.
- The formation of formal and informal partnerships is an essential element in the success of the ADRC model. The Aging and Disability Resource Connection relies on the collaborative nature of multiple agencies at both the state and local level.
- State and local level partnerships include: Division of Mental Health, Developmental Disabilities and Addictive Diseases; Division of Aging Services; Department of Labor-Tools for Life; Georgia Hospital Association; Governor's Council on Developmental Disabilities; Governor's Council on Aging; Governor's Office of Planning and Budget; Department of Community Health; Walton Options; Brain and Spinal Injury Trust Fund Commission; Shepherd Spinal Center; Alzheimer's Association of Georgia; Atlanta Alliance on Developmental Disabilities; Adult Protective Services and the Division of Family and Children Services; Service Providers and Consumers.

» Department of Human Services, Office of Facilities and Support Services, Transportation Services

- The DHS Transportation Services may be utilized by consumers of Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) and Georgia Vocational Rehabilitation Agency (GVRA).

» Department of Public Health, Injury Prevention Program

- Return to Play Initiative: The Return to Play law, passed in 2013, aims to adopt and implement a concussion management and return to play policy for youth athletes in Georgia.
- Intimate Partner Violence (IPV) and TBI: The IPV and TBI project partners with the Georgia Coalition against Domestic Violence to analyze the intersection of TBI and IPV.

» Department of Education, Division for Special Education Services and Supports: TBI Rules and Regulations

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- The TBI Rules and Regulations dictate the eligibility evaluation requirements for a child who has a TBI to receive appropriate placement and service delivery within the education system.

Private Providers

- » Rehabilitation hospitals specializing in treating people with TBI, including Children's Healthcare of Atlanta, Emory Center for Rehabilitation (Atlanta), Shepherd Center (Atlanta), Walton Rehabilitation Center (Augusta), and Memorial Hospital (Savannah).
- » The Brain Injury Association of Georgia (BIAG) is a non-profit organization which serves individuals with brain injuries, along with their support networks. BIAG provides support groups, education, advocacy, a Resource Facilitation program, and additional supports and resources to people with brain injuries.
- » The Georgia Advocacy Office is a private, non-profit organization aimed to protect and advocate for people with disabilities in Georgia. The Georgia Advocacy Office hosts a number of programs, including Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI). PATBI works to protect persons with TBI in Georgia from abuse and neglect, to respond to allegations of discrimination and violations of rights, and to promote the integration and self-determination of individuals with TBI in the community.
- » Side by Side Brain Injury Clubhouse is a work-oriented day program designed to support adults with brain injuries. Side by Side is a non-profit organization located in Stone Mountain, GA and is a community-based, voluntary, member-directed program. Their mission is to advance the long-term well-being of individuals with brain injury-related disabilities through social and work-related skills development, support, and advocacy.
- » Collage Rehabilitation Center is a for-profit program with service centers located across the country. In Georgia, Learning Services is located in Lilburn, Roswell, and Stone Mountain, GA. Collage provides post-acute rehabilitation services such as neurobehavioral rehabilitation and supported living. Learning Services is a 38-bed long-term residential treatment center and long-term supported living program for people with neurobehavioral issues in Georgia.
- » The Jimmy Simpson Foundation is a private non-profit organization dedicated to supporting people in Georgia with brain injuries.
- » Safe haven is a 24-hour, life-long living TBI facility, focused on providing individualized care for each resident with health, social, and related support services. The North Georgia Support Group for people with acquired brain injuries is hosted monthly at Safe haven and provides both education and social activities for attendees.

Georgia Agencies - Services Provided

This section includes data on the number of individuals served and services provided by various agencies to individuals with traumatic brain injuries in Georgia. Due to the public health emergency (COVID-19 pandemic) and resulting lock downs and health impacts, the number of individuals

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served by various state and private agencies were affected. Most state agencies experienced a drop in the number of people applying for and receiving services. Many schools were closed or switched to a virtual format for many semesters. This resulted in students dropping out of the school system or switching to virtual schools during that time. This report therefore includes counts of number of individuals served by various agencies for four years, starting from 2018 through 2022, whenever possible. This will enable us to understand the trends before, during and after the pandemic. The data presented below need to be interpreted within this context.

Georgia Department of Education

Georgia Students with TBI

The Georgia Department of Education (DOE) does yearly tracking of the number of students with disabilities in each school district.⁵⁴ Each district has been placed into their respective county for this data summarization. The total number of Georgia students reported to have a TBI in 2022 were 387, down 11% from 436 in 2018. However, the number of Georgia students with TBI differ in school districts across the state. More urban counties have students who have identified as having a TBI, compared to rural counties. DeKalb County, after combining the DeKalb County School District with Atlanta Public Schools and City of Decatur Schools (located in DeKalb), reported the highest number of students with TBI with 34 students. By contrast, many rural districts report few to no students with TBI. Sixty-six school districts in Georgia, all rural, reported zero students with TBI in 2022.

Georgia Students with TBI by Year: Fiscal Years 2018-2022

Table 1 below reflects the number of Georgia students identified as having a TBI according to the Georgia Department of Education (DOE) between fiscal years 2018-2022.⁵⁴ Due to the public health emergency (COVID-19 pandemic), most schools have switched to a virtual format for many semesters and many students had dropped out of the school system or switch to virtual schools during that time. This report therefore includes counts of number of students for four years, starting from 2018 through 2022, whenever possible. This will enable us to understand the trends before, during and after the pandemic. As shown, the recorded number of students with TBI has lowered yearly during this time period, particularly during the years 2020 and 2021 due to the pandemic.

Table 1. Number of Georgia Students with TBI: 2018-2022

Year	Number of Students with TBI
2018	436
2019	418
2020	406
2021	394
2022	387

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Georgia Students with TBI by School District: Fiscal Year 2022

Figure 24 in Appendix A reflects the distribution of Georgia students with TBI by county in fiscal year 2022.⁵⁴ As pictured, urban and Metro Atlanta counties report having more students with TBI. DeKalb County has the highest number of students with TBI in the state with 34 students.

Georgia TBI Students With 504 Plans

The Georgia Department of Education also does yearly tracking of the number of students with a 504 plan each year, categorized by disability.⁵⁴ A 504 plan is a specialized program that is developed to provide students who are identified as disabled under the law with accommodations to promote increased access to academic success.⁵⁵ Though there were 387 Georgia students reported to have a TBI in 2022, only 137 Georgia students with TBI were reported to have a 504 plan. 35% of Georgia students identified as having a TBI had a 504 plan in 2022. Additionally, students with 504 plans are primarily located in the Metro-Atlanta area. Figure 25 in Appendix A maps the distribution of Georgia TBI students by county.

Racial and Gender Representation of Georgia Students With TBI: 2018-2022

The racial representation of Georgia students identified as having a TBI changed between fiscal years 2018-2022, as shown in Table 2 and Table 3 below.⁵⁴ The total student count of Georgia students with TBI decreased by 11% from 436 in 2018 to 387 in 2022. Reductions in enrollment have been observed in all recorded racial categories. The number of Asian students decreased by 25%, the number of White students with TBI decreased by 17% from 2018-2022, the number of Hispanic students decreased by nearly 13%, and the number of Black students decreased by 11%. Significant reductions in enrollment are also present for male students; the number of male students with TBI decreased by almost 14%. This trend could be attributed partly to the pandemic and the shift to virtual schooling.

Table 2. Race Demographics of Georgia Students with TBI: 2018-2022

Fiscal Year	Total Student Count	Ethnicity: Hispanic	Race: American Indian	Race: Asian	Race: Black	Race: Pacific Islander	Race: White	Race: Two or More Races
2018	436	56	0	12	177	0	180	11
2019	418	46	0	13	178	0	170	11
2020	406	49	2	11	176	0	158	10
2021	394	45	2	9	171	0	153	14
2022	387	49	3	9	158	0	149	19

Table 3. Gender of Georgia Students with TBI: 2018-2022

Fiscal Year	Total Student Count	Female	Male
2018	436	167	269
2019	418	160	258
2020	406	150	256
2021	394	144	250
2022	387	154	233

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School Providers in Georgia

Students with TBI in Georgia may access services from a variety of providers within schools, including special education teachers, school counselors, school psychologists, and Georgia Network for Educational and Therapeutic Support (GNETS) psychologists.⁵⁴ The numbers of special education teachers (Table 4), school counselors (Table 5), and school psychologists (Table 6) have all risen steadily between the years of 2018-2022; the number of special education teachers increased by 6%, the number of school counselors increased by 9%, and the number of school psychologists increased by 6%. The number of GNETS psychologists declined by 60% from 15 to 6 between the years of 2018-2022.

Table 4. Number of Special Education Teachers in Georgia: 2018-2022

Year	Number of Special Education Teachers
2018	18466
2019	19548
2020	19731
2021	19920
2022	19586

Table 5. Number of School Counselors in Georgia: 2018-2022

Year	Number of School Counselors
2018	3905
2019	3992
2020	4127
2021	4169
2022	4275

Table 6. Number of School Psychologists in Georgia: 2018-2022

Year	Number of School Psychologists	Number of GNETS Psychologists
2018	737	15
2019	743	14
2020	755	11
2021	768	9
2022	783	6

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Distribution of School Providers in Georgia by County: 2022

As of 2022, the number and distribution of special education teachers, counselors, and psychologists in Georgia schools closely aligns with the number and distribution of Georgia students identified as having a TBI or having a 504 plan in place for TBI.⁵⁴ More providers are seen in urban and Metro-Atlanta schools, in alignment with a higher number of students with TBI being distributed in these areas. Rural counties see both lower numbers of students with TBI and lower numbers of providers in schools. Figures 26, 27, 28, and 29 in Appendix A map the distribution of school providers by county.

State Charter Schools

There were 387 students with TBI attending Georgia schools in 2022, including 10 at State Charter Schools (not pictured on maps).⁵⁴ Mountain Education Charter High School and the Georgia Cyber Academy both had the most enrolled students with TBI, each reporting three students with TBI. Both the Georgia Connections Academy & the Coweta Charter Academy reported two students with TBI. Out of the 40 total state charter schools in Georgia, 36 state charter schools reported zero students with TBI. However, the total numbers of special education teachers (229), school counselors (198), and school psychologists (6) in state charter schools align closely with those of mid-sized Georgia counties.

Georgia Vocational Rehabilitation Agency (GVRA)

GVRA Service Count of Individuals With TBI

Table 7 below reflects the number of individuals with TBI served by GVRA each year from 2018 through 2022.⁵⁶ These were non-distinct case counts, as some individuals may have been included in the count for multiple years. The GVRA served the most individuals in 2018, with a count of 369 individuals; this number has decreased by 44% to 207 as of 2021. The GVRA has served 154 individuals thus far in 2022. This trend could be attributed partly to the COVID pandemic, where most state agencies experienced a drop in the number of people applying for and receiving services.

Table 7. Number of Individuals with TBI served by GVRA by District: 2018-2022

District	2018	2019	2020	2021	2022
District 1	49	47	33	26	19
District 2	89	82	66	61	41
District 3	74	70	53	38	27
District 4	49	45	30	25	20
District 5	26	27	23	15	10
District 6	37	44	25	23	21
District 7	30	24	15	9	9
District 8	15	10	13	10	7
Total*	369	349	258	207	154

*Note: The yearly count of individuals served is not distinct. The yearly count includes individuals who may have been served by the GVRA for multiple years.

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The GVRA recorded 544 distinct individuals with TBI whose cases were closed between 2018-2022.⁵⁶ This number includes both successful as well as unsuccessful closures. Demographic data from these cases were used to observe potential trends regarding the gender, age, and race of individuals served during this time (Tables 8 & 9). GVRA typically closes a case if an individual has reached their work goal, if an individual cannot be contacted or locates, the individual no longer wants or needs services due to a variety of reasons.

With respect to age, the majority (26%) of case closures were from the 20-29 age group (144 out of 544 closures).⁵⁶ The 30-39 and 40-49 age groups each consisted of 18% of case closures. Majority of individuals with TBI whose cases were closed, were White (61%), followed by African American (38%). Hispanic individuals made up 6% of cases closed (Table 9). More cases were closed for men (69%, n=377) compared to women (31%, n=167).

Table 8. VR Case Closures by Age: 2018-2022

Age at VR Application	Number of Case Closures
14-19	121
20-29	144
30-39	97
40-49	99
50-59	69
60-69	12
70+	2
Total	544

Table 9. VR Case Closures by Race: 2018-2022

Ethnic Group Description	Distinct Count Case Closures 2018-current
White	331
Black or African American	205
Hispanic or Latino	31
Asian	9
American Indian or Alaskan Native	4
Native Hawaiian or Other Pacific Islander	2
Do not wish to self-identify	1
Total	544

Successful GVRA Case Closures

The GVRA currently marks cases as closed successfully once VR participants have obtained and maintained employment for 90 days. Between 2018-present, the GVRA marked the cases of 68 clients with TBI as complete (Table 10).⁵⁶ The majority of successful closures during this time for

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individuals with TBI were located in Metro-Atlanta counties. Figure 30 in Appendix A shows the county distribution of successful GVRA closures between 2018-2022.

Table 10. Successful GVRA Closures for TBI: 2018-2022

Closure Date	Number of Successful Closures
2018	13
2019	22
2020	12
2021	12
2022	9
Total	68

Brain and Spinal Trust Fund Commission (BSITFC)

The Brain and Spinal Injury Trust Fund Commission (BSITFC) was created by state legislation in 1998 to fill the financial gaps in the system for individuals with brain and spinal injuries. The BSITFC provides direct grants to Georgians with traumatic brain and spinal injuries to assist in creating lives of independence and inclusion. The BSITFC is the lead agency for traumatic brain injury for the State of Georgia, which makes the Commission responsible for advising the legislature on relevant policy. The BSITFC also partners with the Brain Injury Association of Georgia (BIAG) to provide a free Resource Facilitation Program for Georgians who have a TBI.

Georgia Central Registry Program

The Brain and Spinal Injury Trust Fund Commission (BSITFC) hosts the Georgia Central Registry program, which collects data and contact information for individuals with newly diagnosed traumatic brain and spinal injuries in Georgia, in order to support these individuals, identify trends in injury, and educate policy-makers and community stakeholders about the needs and incidence of those with TBI. The Commission leverages the Central Registry to reach out to those who have suffered a TBI or SCI with information about resources that may be available to assist them in their recovery. The Commission also utilizes the data collected to monitor the incidence rate of traumatic injuries in Georgia, both overall and within specific demographics.

The Central Registry was created in response to a need for public support for those with TBI and SCI to receive life-saving services. Each person in Georgia identified as having sustained a TBI or SCI receives a resource packet that provides information about resources and funding available to individuals with traumatic brain and spinal cord injuries. This includes information about waivers, grant funding through the BSITFC, and service providers.

Georgia is one of only fourteen states in the United States that have a Central Registry for TBI and SCI. In November 2021, eight organizations came together to form a National TBI Registry Coalition, which aims to work with the federal government to build a National TBI Registry. With so few state registries, there is a geographic inequity in the information shared about resources and support for those with TBI. The move towards a centralized, national registry indicates Georgia's

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ability to be at the forefront of the movement to support all individuals with traumatic brain injuries. With 40 years of experience operating a central TBI registry, Georgia is a leader in data collection and information distribution for those with TBI or SCI.

In 2021, the Trust Fund distributed 153 grants, totaling more than \$1 million. The majority of the grant funding went towards transportation services, followed by personal support services and durable medical equipment.¹² Individuals may apply for a grant through the Trust Fund, with a lifetime maximum distribution of \$10,000 per applicant except for certain vehicle modifications which may be funded up to \$15,000. These grants may be utilized to fund many services and goods, including housing, health care, personal assistance, assistive technology, transportation, respite, recreation, and rehabilitation. The number of Georgians who received trust fund services from the BSITFC declined slightly from 2018-2022, as presented in Table 11 below.^{12,57,58,59} This trend could be attributed, in part, to the COVID pandemic, where most state agencies experienced a drop in the number of people applying for and receiving services.

Table 11. Number of Trust Fund Grants Distributed by BSITFC

Year	Number of Trust Fund Grants Distributed
2018	161
2019	155
2020	143
2021	153

Central Registry and Department of Education Comparisons

One example of the effect of the pandemic is illustrated by a comparison between Central Registry and Department of Education (DOE) data. In 2019, the Central Registry identified a total of 10,433 youths between ages 0 and 24 who were either hospitalized or treated and released from emergency departments for TBI (Table 12). In the same year the DOE reported that only 418 children between ages 2 and 23 had been identified by the school systems as having a TBI.¹²

Table 12. Central Registry Youth TBI Data (2019)

Age in Years	Emergency TBI	Hospital TBI	Total
0-4	1115	281	1396
5-9	1045	107	1152
10-14	2175	121	2296
15-19	2912	321	3233
20-24	1981	375	2356
Total	9228	1205	10433

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Brain Injury Association of Georgia (BIAG)

BIAG Service Information: 2018-2021

BIAG served a total of 580 individuals with TBI between 2018-2021. The organization received 478 total requests for resources within the same time period.⁶⁰

Resources Provided by BIAG: 2018-2021

BIAG provides resources exclusively to individuals with brain injury in Georgia. Between 2018-2021, BIAG provided resources to clients in the areas of medical, financial, housing/assisted living, transportation, employment, and homecare assistance (Table 13).⁶⁰ During this time, a total of 755 resources were provided to Georgians with brain injury. Medical resources were provided to clients most often with 236 resources given (31%). Financial resources accounted for 24% of resources provided; 182 were given during this time. Homecare assistance resources, which include various home-based services, represented 18% of resources provided with 133 resources given.

Table 13. Number of Resources Provided by BIAG

Resources Provided	Number of Resources Provided
Medical	236
Financial	182
Housing/Assisted Living*	102
Transportation	46
Employment	56
Other - Homecare Assistance	133
Total	755

*Note: 6 of the housing/assisted living resources provided were homeless shelters.

BIAG Referrals to Outside Agencies: 2018-2021

When resource requests by individuals with brain injury cannot be fulfilled by BIAG, they provide referrals to outside agencies. Between 2018-2021, BIAG provided 1323 referrals to outside agencies (Table 14).⁶⁰ Referrals to Social Security, Medicaid, and Medicare were most common at 58% of total referrals. It must be noted that the reported total of 764 referrals is higher because some individuals seeking resources were referred to multiple agencies within this group. Twenty-six percent of referrals were made to BSITFC (344 referrals); 206 individuals were referred to BIAG, representing 16% of total referrals.

Table 14. Number of Referrals provided by BIAG

Referred to Outside Agencies	Number of Referrals
Social Security/Medicaid/Medicare*	764
BSITFC	344
ADRC	206
Crisis Line - DPHH	9
Total	1323

*Note: This total is higher because some callers were referred to multiple agencies.

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Georgia's Aging and Disability Resource Connection

ADRCs serve as entry points to long-term care supports and services. ADRC's are free, one-stop shops for information about services and programs for older adults and people with disabilities. Every county in GA (as well as the US) is covered by an ADRC. ADRCs provide information and referral counseling, intake and screening for Medicaid and non-Medicaid home and community-based services, Options Counseling, caregiver programs, and more. Georgia's ADRC is branded empowerline. Empowerline connects older people, adults with disabilities, and their caregivers with the support they need including meals, financial assistance, community programs and other things. Empowerline received 198 calls in 2019, 136 in 2020, 152 in 2021 and about 36 calls in 2022.

Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI) at Georgia Advocacy Office (GAO)

Key Issues Identified by PATBI Consumers

Key issues identified by consumers of the PATBI program included housing concerns, issues regarding payment for guardianships and representatives, and availability of TBI services and supports.⁶¹ Additionally, the PATBI program received calls about handling criminal issues, which is outside the PATBI program's scope of service.

Information and Referral Requests to the PATBI Program: 2018-2021

The Georgia Advocacy Office's PATBI program received 112 total information and referral requests between fiscal years 2018-2021 (Table 15).⁶¹ The number of requests doubled from 22 in 2018 to 44 in 2019, but lowered by almost 30% in 2020 to 31 requests. The PATBI program received the lowest number of requests in 2021 with a count of 15, a decrease of nearly 52% from 2020. This trend could be attributed, in part, to the COVID pandemic, where most state agencies experienced a drop in the number of people applying for and receiving services.

Table 15. Number of Information and Referral Requests received by PATBI: 2018-2021

Fiscal Year	Number of Information & Referral Requests
2018	22
2019	44
2020	31
2021	15
Total	112

PATBI Information & Referral Requests by County: 2018-2021

Figure 31 in Appendix A shows counties where information and referral requests came in between 2018-2021. Requests to the PATBI program came from counties across the state, but the majority were from counties in North Georgia and the metro-Atlanta area, with additional requests coming from urban locations in South Georgia such as Chatham & Lowndes counties.⁶¹

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Shepherd Center

The Shepherd Center does yearly tracking of their inpatient and outpatient client populations. This includes demographic tracking. The numbers of admitted inpatient clients and served outpatient clients are recorded (Table 16).⁶² The number of inpatient clients admitted to the Shepherd Center varied over the past few years; there was an overall increase of 9% in clients admitted between 2017-2021. Similar numbers of clients were seen in years 2017 (100 clients) and 2018 (104 clients), though it must be noted that roughly 10% of recorded clients during these years were referred to Shepherd from a facility outside of Georgia (see note in the chart below). There was a reported 35% drop in inpatient clients in 2019 to 68 inpatient clients (see note in the chart below). The number of inpatient clients rebounded the next year; numbers rose by 32% to 90 clients in 2020, and rose again in 2021 to 109 clients.

Table 16. Number of Inpatient TBI Clients admitted to the Shepherd Center: 2017-2021

	CY2017	CY2018	CY2019	CY2020	CY2021
TBI inpatients admitted*	100	104	68	90	109

*Note: CY2019 is understated because of challenges due to EHR conversion during the year. EHR data conversion, or data migration, is the process of taking data from an old health record system and transferring it into a new system. Also, CY2017-2018 are likely understated because this calculation uses the state of the referring facility, not necessarily the home state of the patient, and ~10% of patients are referred from a facility outside their home state. CY2020-2021 use the home state of the patient.

The number of Georgia-based outpatient clients served by the Shepherd Center has fluctuated between 2020-2022 (Table 17).⁶² While the number of clients served rose overall by 14% during this time, there was a decline in clients served between 2021-2022. In 2020, 158 clients were served in. In 2021, the number of outpatient clients served increased by 28% to 202 clients. However, the number of outpatient clients served in 2022 decreased by 10% to 181 clients.

Table 17. Number of Outpatient TBI Clients Served by Shepherd Center: 2020-2022

	FY2020	FY2021	FY2022
TBI outpatients served from GA	158	202	181

Department of Community Health (DCH)

Medicaid Members Diagnosed With TBI:

According to the Department of Community Health, the number of Medicaid members diagnosed with a TBI has been maintained at just over 8,000 members a year from 2018-2021, with slight declines in 2020 and 2021 (Table 18).⁶³

Table 18. Number of Medicaid Members with a TBI Diagnosis: 2018-2021

Year	2018	2019	2020	2021
TBI Patient Count	8,301	8,360	8,210	8,138

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Georgia Medicaid Waivers

Under Georgia's Medicaid waiver programs, some waivers are potentially available to people with traumatic brain injuries. Brief descriptions of each of the waivers and the number of clients with TBI in the waiver program are described below.

While each waiver program provides different specific services to distinct populations, all waiver programs provide the following core services:

- » Service coordination: assistance managing care needs and services
- » Personal support: assistance with daily living activities
- » Home health services: nursing, home health aide, outpatient therapies
- » Emergency response systems
- » Respite care for primary caregivers

ICWP (Independent Care Waiver Program)

Eligibility: Must be 21-64 years of age at time of application and when services begin; person must have a severe physical impairment and/or TBI that limits one or more activities of daily living and requires the assistance of another individual. Must not have a primary diagnosis of a mental disorder and must be medically stable but at risk of institutional placement if community-based support services are not available. Must currently be safely placed in a home or community setting. Must be Medicaid eligible.

Goal(s): ICWP aims to help individuals who are considering institutional care to obtain home- and community-based services as an alternative. Participants in ICWP work with their families, case managers, and providers to establish a plan of care individually tailored to their specific needs.

Levels of Services: ICWP provides two levels of services to those eligible. The nursing facility level has an annual waiver cap of \$62,000. Key informants in this needs assessment noted that this level of support is generally regarded as insufficient to enable individuals with TBI to live successfully in their homes and communities. Due to the high cost of medical care, supplies, and equipment, this budget does not leave much left over for personal care services. The hospital level of care has an annual cap of \$100,000. Key informants also noted this budget to not be sufficient in providing individuals with TBI the funding they need to successfully live in their homes and communities with the appropriate services they need.

Number of TBI Clients: The ICWP has seen a TBI client increase of 24% and a TBI-based service claim increase of 54% between 2018-2021. Client count and service claims have risen from 286 clients and 28,839 claims in 2018 to 354 clients and 44,389 claims in 2021 (Table 19 below).⁶³

NOW (New Options Waiver)

Eligibility: Someone with an intellectual or developmental disability (I/DD) or closely related condition, currently receiving the level of care provided in an intermediate care facility for people with intellectual disabilities (ICF-ID), for whom home- and community-based services are an appropriate alternative. Must be Medicaid eligible.

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Goal(s): NOW offers services and supports to individuals to enable them to be able to remain living in their own or family home and participate or live independently in their community. Goals for NOW program participants include increasing independence and quality of life, increasing flexibility of service planning and delivery to meet exact individual needs, provide an opportunity for participants to direct their services to the extent they choose, and ensure their health, safety, and welfare.

Number of TBI Clients: The NOW program has seen small changes in TBI client counts and an overall decrease in TBI-based service claims between 2018-2021.⁶³ Client counts increased by 13% between 2018 (46 clients) and 2019 (52 clients), but remained nearly the same in 2020 (51 clients) and declined by 11% in 2021 (45 clients). There was an overall decrease of 27% in claims between 2018-2021. The number of claims made stayed relatively similar from 2018 (3,736) to 2019 (3,823). However, there was a decrease of 23% in claims made from 2019 to 2020 (2,934), as well as a decrease of 7% in claims made from 2020 to 2021 (2,716) (Table 19 below).

COMP (Comprehensive Supports Waiver Program)

Eligibility: Someone with an I/DD or closely related condition, currently receiving the level of care provided in an intermediate care facility for people with intellectual disabilities (ICF-ID), for whom home- and community-based services are an appropriate alternative. Must be Medicaid eligible. COMP primarily provides services to individuals with more intensive needs than those in the NOW program.

Goal(s): The COMP program primarily provides residential care for individuals with I/DD by offering comprehensive and extensive waiver services to enable individuals with urgent and intense needs to avoid institutional placement. The COMP program's goals for participants are to increase independence and quality of life, to offer opportunities for participant direction, and to facilitate the transition of institutionalized individuals to community living while ensuring health, safety, and welfare.

Number of TBI Clients: COMP grew in TBI client count and TBI-based claim count yearly from 2018-2020, with a slight decline in client count in 2021.⁶³ While the client count increased by 21% from 2018 (175 clients) to 2020 (212 clients), it decreased slightly (by 5%) to 201 clients in 2021. The number of claims made increased overall from 2018-2021; there was an increase by 12% from 2018 (26,867) to 2019 (30,116), a 1% decrease in 2020 (29,813) and a slight increase (less than 1%) in 2021 (29,925) (Table 19 below).

CCSP (Community Care Services Program)

Eligibility: Someone who has a functional impairment caused by physical limitations who has approval by a physician of the need for an intermediate level of nursing home care and the development of a care plan. The client must choose to receive services in the home and community instead of a nursing home. Must be Medicaid eligible and can only participate in one waiver program at a time.

Goal(s): The CCSP aims to provide a home and community-based waiver services program that provides community-based social, health, and support services as an alternative to placement

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in a nursing home. Each participant receives a care coordinator who will create a consumer-focused comprehensive plan of care in collaboration with the participant's physician.

Number of TBI Clients: TBI client count and TBI-based service claims made in the CCSP waiver program have increased yearly between 2018-2021.⁶³ Numbers increased from 269 patients who made 22,601 claims in 2018 to 367 patients who made 39,739 claims in 2021, which is a client increase of 36% and claim increase of 76% (Table 19 below).

SOURCE (Service Options Using Resources in a Community Environment)

Eligibility: Someone who is eligible for full Medicaid and meets nursing home level of care requirements. Eligibility is determined through a comprehensive assessment.

Goal(s): SOURCE links primary medical care and case management with long-term health services in a person's home or community. Each participant will have an individual care path designed based on their specific needs, with family members, other caregivers, and staff from support agencies included in development of the care path.

Number of TBI Clients: The SOURCE waiver program contained the highest number of TBI clients and TBI-based service claims out of all programs detailed.⁶³ There was an overall increase of 6% for clients and 34% for claims between 2018-2021. The number of clients and service claims increased from 575 clients and 54,031 claims in 2018 to 607 clients and 72,373 claims in 2021. While this program has seen overall increases in TBI client count and service claims between 2018-2021, there were slight decreases to both client counts and service claims in 2020 (Table 19 below).

GAPP (Georgia Pediatric Program)

Eligibility: Those under age 21 determined to be medically fragile with multiple systems diagnoses who meet the same level of care necessary for institutional admission. Families must be Medicaid eligible.

Goal(s): GAPP is a fee-for-service program aimed at providing at-home nursing care and personal care to medically fragile children. It may provide assistance with daily living activities, monitoring vital signs, assistance with ambulation, IV therapies, wound care, and tube feedings, among other services and support.

Number of TBI Clients: The GAPP fee-for-service program saw general growth between 2018-2021.⁶³ During this period there was a 24% growth in number of TBI clients and a 37% increase in number of claims made by TBI clients. The numbers of TBI clients and service claims increased the most from 2018 (120 clients made 8,367 claims) to 2019 (141 clients made 10,906 requests); there was an 18% rise in clients and a 30% rise in claims. The numbers of TBI clients and claims made remained similar in 2020 and 2021, with a slight decrease in claims in 2020 and a small increase in clients in 2021 (Table 19 below).

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Katie Beckett Program (Deeming Waiver)

Eligibility: Someone age 18 years or younger who meets federal criteria for disability, is financially ineligible for SSI benefits, requires an institutional level of care and can be appropriately cared for at home, and whose estimated cost of care outside of an institution will not exceed estimated cost of care within an institution. Prior to the child's 18th birthday, the family should re-apply for SSI as the young adult will no longer be ineligible due to family income level.

Goal(s): The Katie Beckett Program waives standard Medicaid eligibility criteria to permit the state to only evaluate the child's income for provision of services when a child with disability meets an institutional level requirement of care.

Number of TBI Clients: The Katie Beckett waiver program holds the smallest number of TBI clients, as it is limited to youths under age 18 who require institutional levels of care.⁶³ Overall, both the number of TBI clients and the number of TBI-based claims saw general increases between 2018-2021; clients increased by 11% (37 in 2018 to 41 in 2021) and claims increased by 20% (5,922 in 2018 to 7106 in 2021) (Table 19 below).

Early and Periodic Screening Diagnosis and Treatment (EPSDT)

Eligibility: All children who are Medicaid eligible. Individuals may receive benefits from both EPSDT and the Katie Beckett Program (Deeming Waiver) to gain access to additional support and services.

Goal(s): EPSDT is a federally mandated program, which all states must provide regardless of whether they have expanded Medicaid. Thus, Georgia provides EPSDT. The purpose of EPSDT is “to ensure that all Medicaid eligible children receive comprehensive and preventive health care to the maximum extent that Medicaid allows.” The overarching goal of EPSDT is to prevent impeded growth and development of children through early identification and treatment of health conditions.

Services Provided: EPSDT provides services based on the child's needs “as determined by their doctor and not by predetermined limits or caps established in the state's plan or Medicaid policy.” These services may include: inpatient and outpatient services, rural clinic services, laboratory and x-ray services, family planning services and supplies, dental services, vision services, physical therapy, occupational therapy, speech therapy, and other related services, prescribed drugs, other diagnostic, screening, preventive, and rehabilitative services, ICF-MR, inpatient psychiatric hospital services, hospice care, case-management services, respiratory care services, personal care services, and any other medical care or remedial care recognized under state law. EPSDT also provides TB-related services. There is no waiting list for EPSDT services, nor is there a monetary cap, hours of services provided limit, or limit on the number of visits to providers under EPSDT. Prior authorization may be required for many EPSDT services.

Number of TBI Clients: The EPSDT program has seen pronounced growth in TBI client counts and TBI-based service claims made from 2018 (429 clients with 782 claims made) to 2021 (759 clients with 1,466 claims made).⁶³ The number of clients within this program increased 77%

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between 2018-2021, while the number of claims increased by 87%. There was a slight decrease of 4% in client counts from 2019 (715) to 2020 (687), but the number of claims made did not lower during those years (1,354 claims in 2019 and 1,437 claims in 2020) (Table 19 below).

The number of TBI clients in each of the Georgia Medicaid waiver programs have been summarized in the table below.

Table 19. Number of TBI Clients in Georgia Medicaid Waiver Programs: 2018-2021

Year	2018		2019		2020		2021	
Medicaid Waiver	Clients	Claims	Clients	Claims	Clients	Claims	Clients	Claims
590 CCSP	269	22,601	296	23,280	337	25,169	367	39,739
600 EPSDT	429	782	715	1,354	687	1,437	759	1,466
660 ICWP	286	28,839	319	31,342	330	34,595	354	44,389
680 NOW	46	3,736	52	3,823	51	2,934	45	2,716
681 COMP	175	26,867	206	30,116	212	29,813	201	29,925
930 SOURCE	575	54,031	576	54,379	571	52,689	607	72,373
971 GAPP	120	8,367	141	10,906	142	10,792	149	11,460
*Katie Beckett	37	5,922	36	6,209	37	6,230	41	7,106

-Report is based on service date incurred 1/1/2018 to 12/31/2021

-Report is based on diagnosis code Z87820 to identify TBI patient

-Report is based on Aid Category 250 for *Katie Beckett patient.

All other waiver programs are based on Category of Services

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Table 20. Summarization of Services Provided by Georgia Medicaid Waiver programs

	NOW	COMP	ICWP	CCSP	SOURCE	EPSDT
Services Offered						
Service coordination	X	X	X	X	X	X
Personal support services	X	X	X	X	X	X
Home health services (nursing, home health aide, OT, PT, Speech Therapy)	X	X	X	X	X	X
Emergency response systems	X	X	X	X	X	
Respite care	X		X	X	X	
Dental services	X	X				X
Vision & hearing services						X
Additional staffing services	X	X				
Behavioral supports	X	X				X
Community access	X	X				
Community guide	X	X				
Community living support	X	X				X
Environmental accessibility adaptation	X	X				
Financial support services	X	X				
Individual directed goods and services	X	X				X
Interpreter	X					X
Natural support training	X	X				
Pre-vocational services	X	X				
Specialized medical equipment services	X	X	X			X
Supported employment	X	X				
Transportation	X	X				X
Vehicle adaptation	X	X				
Community residential alternative services		X				
Adult day health			X	X	X	
Home modification			X			
Alternative living services			X	X	X	X
Home-delivered meals				X	X	
Additional support to family caregivers living with participant. Based on eligibility				X		

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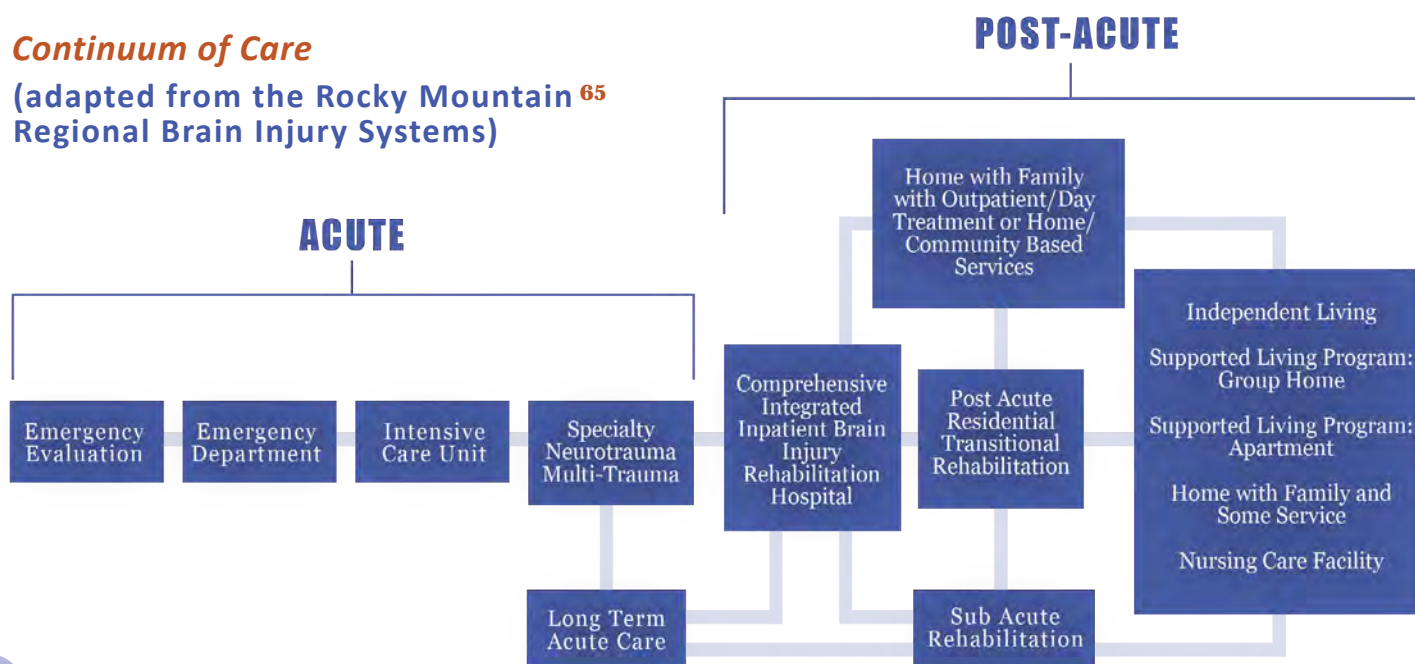
Continuum of Care

Traumatic brain injuries require a complex continuum of care, which if followed correctly can insure maximal recovery from the TBI. The continuum of care flows from acute to post-acute care, with many potential steps and care settings within that flow. It is imperative to keep in mind that healing is not linear, and this continuum of care is not a one-size-fits all plan of care. Many individuals with TBI move backwards and forwards along the continuum during their journey of healing and recovery, and may only access points on the continuum that maximize their chance of full recovery. Movement through the continuum should be guided by the functional level and needs of the individual with TBI.⁶⁴

Acute care is where diagnosis, stabilization, and the beginnings of analysis of prognostic indicators occur. In some cases, rehabilitation and therapies occur during acute care, but the goal is to prevent further complications while reaching medical stabilization. Sub-acute care begins when the patient is considered sufficiently stable but still in need of rehabilitative services and physiological monitoring. Sub-acute care may occur in a number of settings, including nursing homes or other institutions, in the home and community, or a rehabilitation center. Patients appropriate for post-acute or transitional facilities are generally higher functioning and require supervision. This is provided in a variety of settings including group homes, day programs, outpatient care and at home in community-based settings. Long-term care support can be provided by trained individuals who assist the patient with monitoring of ongoing issues of daily living. Case managers, personal managers or family members can monitor progress. A qualified physician should be available to assist with the long-term care issues as they might arise. They may be competitively employed but may have problems with money management and transportation. They may need assistance with proper nutrition, etc. Supported living can be anywhere from a group home to home and community-based settings including living with their loved ones in individual apartments or homes.

Continuum of Care

(adapted from the Rocky Mountain⁶⁵ Regional Brain Injury Systems)



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Resource Facilitation

Resource Facilitation has been defined as “a partnership that helps individuals and communities choose, get and keep information, services and supports to make informed choices and meet their goals.”⁶⁶ Resource Facilitation most closely resembles care coordination and case management services. Resource Facilitation operates on seven key principles: it is individualized, accessible, holistic, effective and valued, participant directed, creative and flexible, and builds community partnerships. At its most ideal, Resource Facilitation has ten key operations, outlined below:

- **Assessment** of the current status, needs, and resources of the participant and their personal support system.
- **Planning** out the goals and service and support needs of both the participant and their personal support system with specifically stated areas of responsibility and anticipated timelines.
- **Identify** the services and supports outlined in the agreed upon plan, evaluate effectiveness for the individual, and seek out additional resources to fill any gaps.
- **Negotiate** access to services, supports and resources through providing referrals and securing providers.
- **Monitor** the quality and appropriateness of services and supports used proactively.
- **Reassess** each component of the process, including the partnership itself, on at least a quarterly basis for all active participants.
- **Outreach** in the community to find new services, supports, resources, and program participants.
- **Educate and train** people in the participants’ personal support systems and community at large about brain injuries.
- **Emotionally support** participants by supportively and proactively listening to their needs. This flows through and is a key part of all components of Resource Facilitation.
- **Advocate** by helping participants assert their rights and needs on their own. This flows through and is a key part of all components of Resource Facilitation.

The goals of Resource Facilitation include supporting participants to make informed choices, providing helpful, personalized information to participants, providing education to the participants, their personal support systems, and their communities, increasing personal satisfaction of participants, and increasing community capacity to serve and support people with brain injuries. Resource Facilitation aims to improve return-to-work outcomes through facilitated, personalized connections with community agencies, funding resources, and other trainings and services.⁶⁷

Since Resource Facilitation first got its start in the field of brain injury in 1984, the efficacy of this type of programming has been shown in several randomized controlled studies, and the need for RF has grown exceedingly apparent. In one study, participants who received Resource Facilitation services returned-to-work at a rate of 87.5% within a 15-month treatment period, as compared to those who did not receive the services at the rate of 50%. Overall, Resource Facilitation participants were found to have 7x higher odds of returning to participation in a productive community based-work environment (e.g. school, volunteering, paid employment) than those who did not receive services.⁶⁸



NEEDS ASSESSMENT METHODOLOGY

NEEDS ASSESSMENT METHODOLOGY

For this needs assessment, input was obtained from 187 individuals who were either individuals with TBI, their caregivers or professionals working with them. A mixed method approach that included online surveys, interviews and focus groups was used. Input was obtained from 145 surveys (93 individuals with TBI, 52 professionals), 20 key informant interviews, and 22 individuals with TBI and caregivers through focus groups.

Surveys

Surveys were developed to collect input from the following target groups: 1) Individuals with a traumatic brain injury, and 2) Professional caregivers and/or service providers working with individuals with a traumatic brain injury. All surveys were developed using Qualtrics online survey. A webpage dedicated to the Needs Assessment was developed by Graphic designers at IHDD. The webpage had information about the study and links to complete they surveys. Information about the surveys was shared using flyers that were distributed widely in Georgia.

The surveys were developed by the research team at REU and reviewed by the BSITFC leadership. The surveys were pilot tested with some respondents. Surveys were piloted to test their validity, ease of understanding, relevance and length. Based on the feedback from the pilot testing and the BSITFC board, modifications were made to the surveys. The revised versions of the surveys were then used for data collection.

The surveys were available online for 11 weeks between March and June 2022. The links to the surveys and the webpage were widely distributed across a wide network including individuals, organizations and networks linked to individuals with a TBI in Georgia. Survey links were shared using social media like Facebook, Instagram, list-servs and Twitter. Recruitment efforts included sending introductory emails to the entities introducing the project, along with information that could be copied and pasted when forwarding to others. They were urged to post information about the needs assessment on their social media platform. The links were publicized on social media platforms of key disability agencies and entities across Georgia.

Information about the needs assessment and links to the surveys were shared with about 22 disability service organizations, providers, advocacy agencies and other entities working in the disability arena in Georgia. Information was shared with the eight rehabilitation hospitals in Georgia nine local Centers for Independent Living, the Aging and Disability Resource Network list-serv, more than 15 nursing homes, more than 14 hospitals including ones that focus on brain injuries, trauma centers, list-servs of rehabilitation personnel including physical therapists and occupational therapists, veteran's organizations and veteran's listservs, and disability service provider agencies including their administrative staff and direct support providers. We connected with almost all support groups hosted by BIAG to either conduct a focus group or share information so that participants could later connect with us to participate in a focus group or interview.

Our goal was also to capture the perspectives of a wide range of individuals, caregivers and professionals with TBI, including individuals having intersectional identities; those who experience significant behavioral problems as a result of their brain injury; those from unserved and underserved regions (rural areas); and those from culturally and linguistically diverse backgrounds (African American, Hispanic, American Indian, Asian). To that end, special attempts were made

NEEDS ASSESSMENT METHODOLOGY

to advertise and encourage individuals with diverse backgrounds to complete the survey. A total number of 145 valid surveys were completed by a variety of entities including individuals with a TBI, parents and family members, professional caregivers, service providers and representatives from state agencies. Valid surveys included 93 individuals with a TBI or their caregivers and 52 professionals. Valid surveys refer to surveys where the individual completed the survey, even if they did not answer all of the questions. Surveys that are not considered valid were those in which the respondent opened but did not start or complete the survey.

	Surveys started	Valid completed surveys
Individuals with TBI, caregivers	114	93
Professionals	57	52

Accessibility

All formats were accessible, readable at the 10th grade level or less, reliable and had face validity. The electronic survey was designed using an accessible, internet-based survey application (Qualtrics). Surveys were found to be accessible for individuals with vision impairments or who used screen readers. Respondents were provided with the name and contact information in order to place requests for alternate survey formats.

Efforts to Ensure Respondent Confidentiality

Respondents to the survey were not asked to identify themselves when completing the survey. Additionally, the survey responses were aggregated and summarized by the project team at REU prior to reporting the results. This step facilitated further obscuring the individual identities of the survey respondents.

Key Informant Interviews

Key informant interviews were conducted with experts who are particularly knowledgeable about the needs of individuals with TBI, their families, service providers and systems. The purpose of these interviews was to identify the needs of individuals with TBI, their families, the barriers they experience in receiving services, what is working and what needs to be improved as far as services and support for people with TBI in Georgia. Participants were asked to discuss the needs of individuals from underrepresented groups including cultural, ethnic and other groups. A total of 20 virtual key informant interviews were conducted using Zoom. On an average, each interview lasted for about 45 minutes and was audio recorded. Key informants were initially sent an e-mail message by the researchers at REU informing them of the interview effort and were asked to schedule a time for an interview. Key informants who did not respond to either the email message or telephone call were contacted once more by e-mail and offered an opportunity to participate. A semi-structured interview protocol (included in the appendices) was used to guide the interview to allow for tailoring based on the interviewee's experiences and expertise. Verbal informed consent was obtained before the interview started. Interviews were audio recorded with the participants' permission. Following the close of the interview, the interviewer saved audio recordings and transcriptions for each key informant. Verbatim transcriptions of audio recordings were then used for analysis.

NEEDS ASSESSMENT METHODOLOGY

Efforts to Ensure Respondent Confidentiality

The Zoom interviews were audio recorded with permission. Participants were informed that their participation was completely voluntary, they could stop the interview at any time, and they only had to answer the questions they wanted to answer. The responses were pooled together and results are reported in aggregate form.

Focus Groups

Focus groups were conducted with individuals with TBI and their caregivers. The purpose of these group was to identify the needs of individuals with TBI, their families, the barriers they experience in receiving services, what is working and what needs to be improved as far as services and support for people with TBI in Georgia. Participants were asked to discuss the needs of individuals from underrepresented groups including cultural, ethnic and other groups. A total of 22 individuals attended the four Zoom-based focus groups that were conducted. Each session lasted about an hour and was audio recorded. Two researchers facilitated each group; one served as moderator and the other served as a technological support person who also took notes. A semi-structured interview protocol was used to guide the interview to allow for tailoring based on the participant's experiences. Verbal informed consent was obtained before the focus group started. Focus group conversations were audio recorded with the participants' permission. Audio recordings and transcripts from the focus groups were saved. Verbatim transcriptions of audio recordings were used for analysis.

Efforts to Ensure Respondent Confidentiality

The Zoom interviews were audio recorded with permission. Participants were informed that their participation was completely voluntary, they could stop the session at any time, and they only had to answer the questions they wanted to answer. The responses were pooled together and results are reported in aggregate form.

Data Analysis

For quantitative data, analysis consisted of computing frequencies and descriptive statistics for the survey items with fixed response options. Data were analyzed using quantitative statistical software IBM SPSS Statistics v.26, Qualtrics and Excel 2016. Frequencies, percentages, means and other inferential statistics were used for analyzing quantitative data from surveys. Open-ended survey questions, which yielded narrative responses were analyzed using content analysis for themes or concepts that were expressed consistently by respondents.

Notes were transcribed and analyzed by the researchers at REU. Narratives were analyzed using content analysis for themes or concepts that were expressed consistently by respondents. Results were organized according to the prompts used to stimulate discussion of the needs of individuals with disabilities (e.g., barriers to obtaining services). Themes or concerns that surfaced with consistency across groups (within or across regions) were identified and reported as consensual themes in the report narrative.



RESULTS FROM DATA COLLECTION

RESULTS FROM DATA COLLECTION

SUMMARY OF SURVEY FINDINGS

SURVEYS FOR INDIVIDUALS WITH TBI AND PROFESSIONALS

For this needs assessment, input was obtained from 187 individuals in Georgia who were either individuals with Traumatic Brain Injuries (TBI), their caregivers or professionals working with them. A mixed method approach that included online surveys, interviews and focus groups was used. Input was obtained from 145 surveys (93 individuals with TBI, 52 professionals), 20 key informant interviews and 22 individuals with TBI and caregivers through focus groups.

The following paragraphs highlight findings of the survey portion of the needs assessment. More detailed data on each finding is presented in a subsequent section of this report.

TBI Services

Services Utilized by Individuals with Disabilities

- » While a wide range of services were utilized by individuals with TBI, the five most common ones were: in-home services, transportation services, service coordination and case management, general health management, and TBI support groups.

Services Needed but not yet Received

- » The top three services that were needed but not yet received were cognitive and memory training, TBI support groups, and behavioral supports.

Services Provided by Professionals

- » The three most common services provided by professionals and/or their organizations to persons with TBI were case management, supportive services, and advocacy services. The three least common services provided were neurobehavioral training, special education, and other services.

Knowledge of Available TBI Services

- » A little less than half of professionals indicated having a moderate level of knowledge about available TBI services in Georgia (43%). However, 39% reported having only minimal knowledge.

Adequacy of TBI Services

- » In terms of professionals' perception of the adequacy of TBI services, 52% of respondents rated the TBI services in Georgia as being very inadequate or somewhat inadequate. Twenty-two percent of respondents were not sure stating they didn't know much about Georgia's service system for individuals with TBI.
- » Professionals rated hospital discharge, home health, and housing assistance as the most inadequate services. The most adequate services were: emergency room care, inpatient rehab, and general health management.

RESULTS FROM DATA COLLECTION

Adequacy of Specific Services in Georgia		
Medical and Hospital Services	Acute rehabilitation services	Community support and services
Most inadequate: <ul style="list-style-type: none"> ◦ Hospital discharge planning Most adequate: <ul style="list-style-type: none"> ◦ Emergency room care 	Most inadequate: <ul style="list-style-type: none"> ◦ Home health Most adequate: <ul style="list-style-type: none"> ◦ Inpatient rehabilitation 	Most inadequate: <ul style="list-style-type: none"> ◦ Section 8 and other housing assistance Most adequate: <ul style="list-style-type: none"> ◦ General health management

Barriers to Accessing Services

- » **Individuals with TBI, Caregivers** - The most common barriers to accessing services were related to information availability, including not being aware of services and resources, and there being no centralized source for obtaining information. Concerns related to quality and accessibility of care were also mentioned, including that professionals are not trained for working with individuals with TBI and difficulty finding providers.
- » **Professionals** - Professional rated the most common barriers to persons with TBI accessing services were a lack of awareness of services and resources, inadequate support for family and caregivers, services located far from home, lack of transportation, lack of individualized services, inability to pay for services, and difficulty in finding providers.

Top Barriers to Obtaining Services	
Persons with TBI	Professionals
<ul style="list-style-type: none"> ◦ Not aware of services and resources ◦ No centralized source for TBI information ◦ Lack of patient support, advocacy ◦ Professionals are not trained for working with persons with TBI ◦ Difficulty finding providers 	<ul style="list-style-type: none"> ◦ Not aware of services and resources ◦ Inadequate support for family and caregivers ◦ Services are far from home, lack of transportation ◦ Lack of individualized services ◦ Inability to pay for services, ◦ Difficulty in finding providers

RESULTS FROM DATA COLLECTION

Desired Improvements to Georgia TBI Service System

- » **Individuals with TBI, Caregivers** - The most commonly desired improvements to the TBI system needed by persons with TBI included: increased awareness of brain injury across the state; a need to create and expand Medicaid waivers for brain injury; more trained providers specializing in brain injury; and better service coordination and referrals for TBI.
- » **Professionals** - The top five desired improvements as viewed by professionals were: access to more community-based supports and services; more services; training and education for family members and caregivers; a need to create and expand Medicaid waivers for brain injury; and training and education for professionals working with individuals with TBI.

Desired Improvements for Georgia TBI Service System	
Persons with TBI	Professionals
<ul style="list-style-type: none"> ◦ Increased awareness of brain injury across the state ◦ Create and expand Medicaid waivers for brain injury ◦ More trained providers specializing in brain injury ◦ Better service coordination and referrals for TBI. 	<ul style="list-style-type: none"> ◦ Access to more community-based supports and services ◦ More services ◦ Training and education for family members and caregivers ◦ Create and expand Medicaid waivers for brain injury ◦ Training and education for professionals working with individuals with TBI.

Employment

- » Most persons with TBI were not currently working (86%). Of the few (14%) who were currently working, half of them employed full-time. Of those working, close to half of them required accommodations in order to work successfully.
- » Of those who were not currently working, the top three reasons given were, being told by professionals that they are unable to work, being concerned that having a job would affect their benefits, and that they have tried but been unable to keep a job due to their disability.
- » Professionals indicated that the top three barriers to employment of persons with TBI were: access to dependable transportation; lack of long-term services and ongoing job coaching; and employer's concerns about risks associated with hiring individuals with TBI.

Housing, Current Living Situation

- » Most persons with TBI either had their own home or apartment (41%) or they lived with someone else (family, loved one, friend) who covers their housing expenses (41%). Nine percent of respondents lived in a group living facility of some form (9%). A small number of respondents reported that they were at risk of losing their residency (3%); 1% were currently living in temporary housing and seeking a more stable set up; another 1% were homeless.

RESULTS FROM DATA COLLECTION

- » Of those living in some form of group living facility (n=6), two-thirds of respondents were unsure whether they wanted to return to the community (66%), with the rest being evenly split between yes and no (both 17%). All the above individuals, even if they selected being unsure about returning to the community, mentioned that they would like to live in the community if sufficient resources were available to enable that. Key barriers that made people unsure about returning to community living include not getting the in-home supports they need, not getting the medical or rehabilitation care or having financial resources, that would make it possible for them to live in the community.

Transportation

- » While a wide variety of transportation means are used generally, the most common among respondents is either to ride with other family (31%) or drive themselves (25%), though some expressed concern with having to drive themselves due to cognitive or physical demands.
- » The majority of respondents noted their transportation means as reliable and accessible.

Financial Situation and Healthcare Coverage

- » The three most common ways healthcare was paid for were Medicare (31%), Medicaid (27%), and private insurance (27%). Other sources of funding included the Brain and Spinal Injury Trust Fund, Personal Injury Protection, or no coverage/out of pocket.
- » Most persons with TBI also had either SSI or SSDI. About a third of respondents had not applied to the Brain and Spinal Injury Trust Fund for assistance.

Training for Professionals

- » In general, the majority of professionals reported that they had received some form of training around TBI. Of those, the most common topic areas covered in training were: behavioral changes, general knowledge, and medical and physical changes.
- » The most common topic areas covered in within-organization training were: general knowledge, available services, and behavioral changes.
- » Most professionals had sought out additional TBI training outside of their organization. Of those who sought out additional training, the most common topic areas covered were: behavioral changes, medical and physical changes, and communication and cognitive changes.
- » The preferred method for additional trainings was online training, with the least preferred being regional training and state conference.
- » The most common topic areas covered in community training were: general knowledge, available services, and skills for independence.

What is Working Well

The top three things rated by professionals as working well were acute care, timely diagnosis and treatment, and medical care. The bottom three were access to information, resources, and referrals; support groups; and continued care.

RESULTS FROM DATA COLLECTION

SUMMARY OF SURVEY FINDINGS

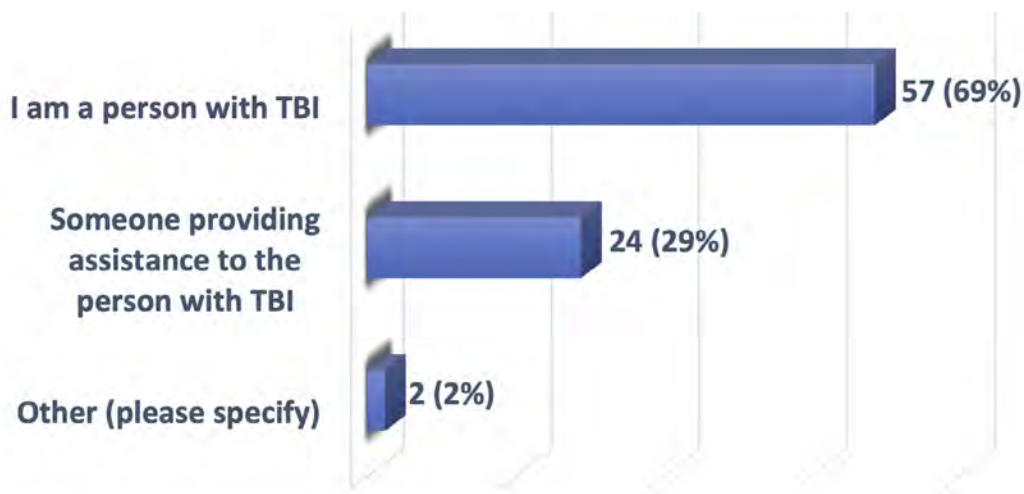
SURVEY FOR INDIVIDUALS WITH DISABILITIES

Demographics

Respondent Identity

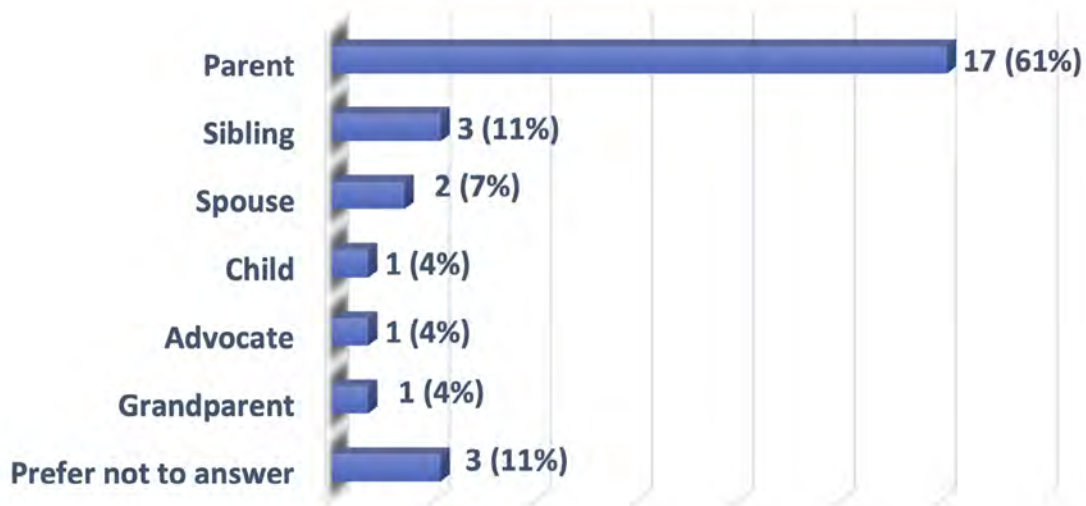
The majority of the respondents were persons with a TBI (69%). The rest were people providing assistance to persons with a TBI (29%) and responding on their behalf. Of those responding on someone else's behalf, the majority were parents (61%) or another household member such as a spouse (7%) or sibling (11%).

Survey Respondent Identity (n = 85)



If Assisting an Individual with TBI, their Identity

Identity of Those Answering for Person With TBI (n = 28)

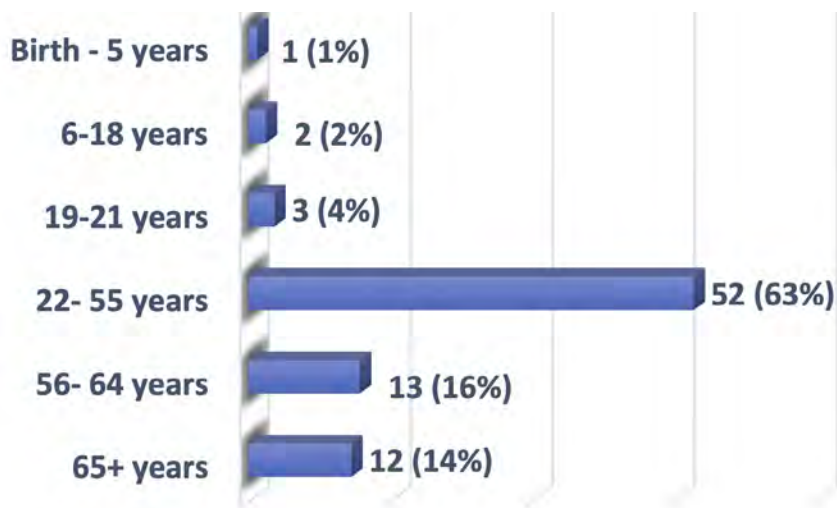


RESULTS FROM DATA COLLECTION

Age Group of Individuals with TBI

The age ranges of persons with a TBI are shown below. These data include people with TBI regardless of whether the person was responding for themselves or whether a family member was responding to the survey in their behalf. The sample was primarily made up of older adults with a TBI. Over 60% of individuals were between the ages of 22 to 55 (63%), followed by ages 56 to 64 (16%) and ages 65 and over (14%). Children with a TBI made up about 3% of the sample.

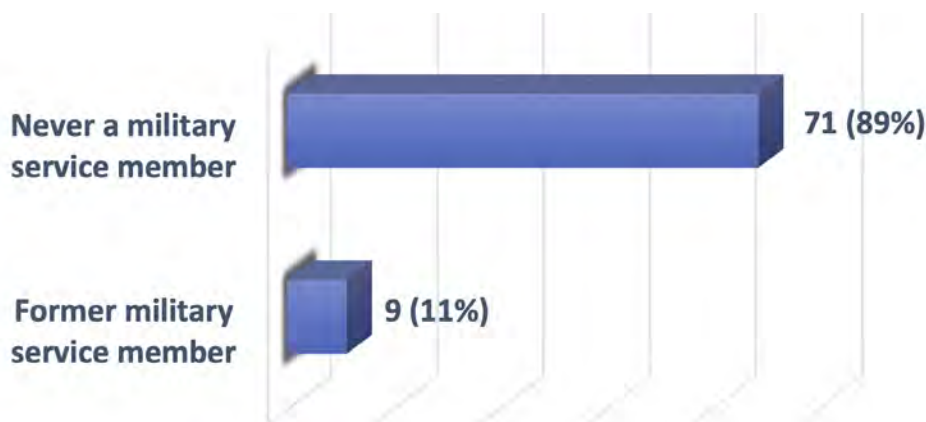
Age Range of Persons With TBI (n = 83)



Military Service Membership of Individuals With TBI

The graph below depicts the military status of survey respondents. About 11% of the sample were former military service members.

Military Status of Persons With TBI (n = 80)

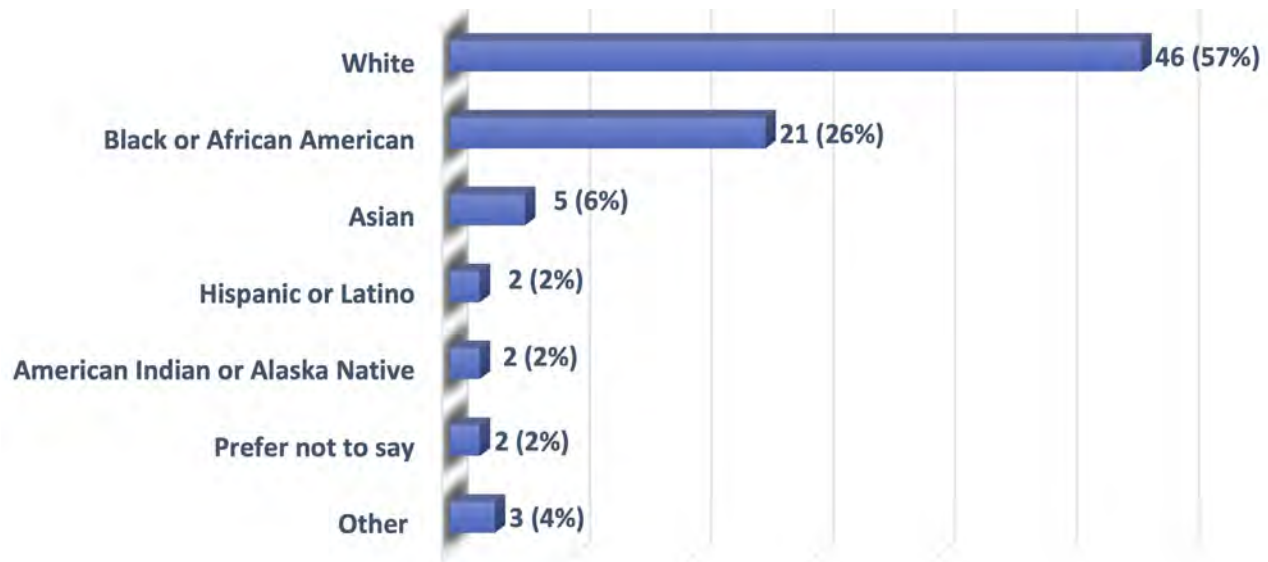


RESULTS FROM DATA COLLECTION

Race/Ethnicity of Individuals with TBI

Over half of the sample was White (57%), with Black or African American comprising nearly one-fourth of respondents (26%). Remaining racial/ethnic backgrounds represented in the sample include American Indian/Alaskan Native, Asian, and Hispanic/Latino. This is close to the U.S. Census statistics for Georgia where 58% were White, 32% were Black or African American.

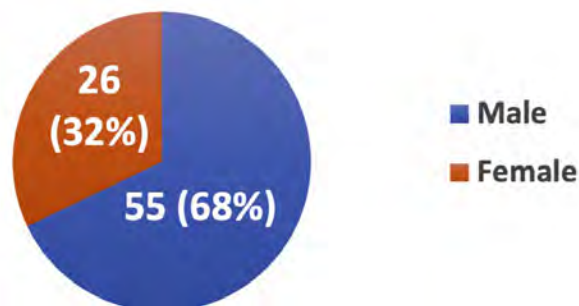
Race/Ethnicity of Person With TBI (n = 80)



Gender of Individuals with TBI

Two-thirds of the sample was male (68%); the rest was female (32%). CDC Statistics suggest that males are nearly two times more likely to be hospitalized and three times more likely to die from a TBI than females.⁶⁹

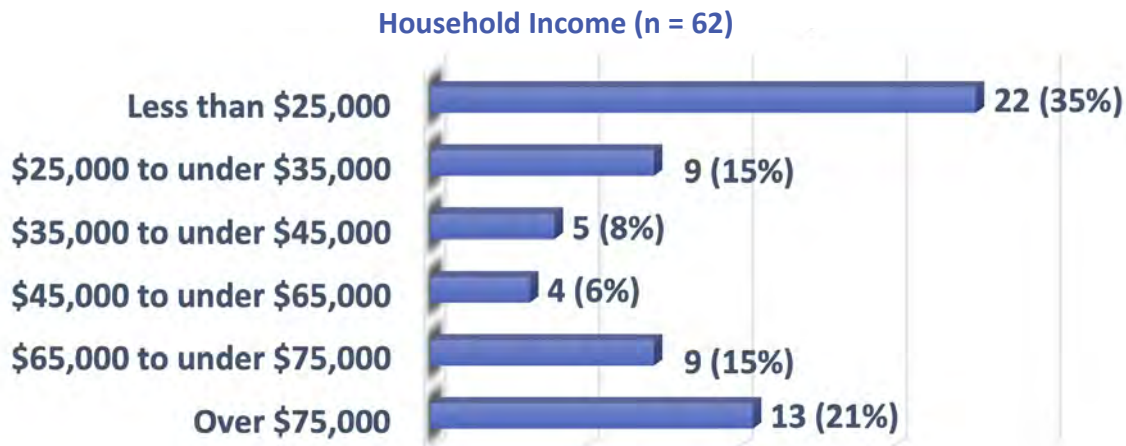
Gender of Persons With TBI (n = 80)



RESULTS FROM DATA COLLECTION

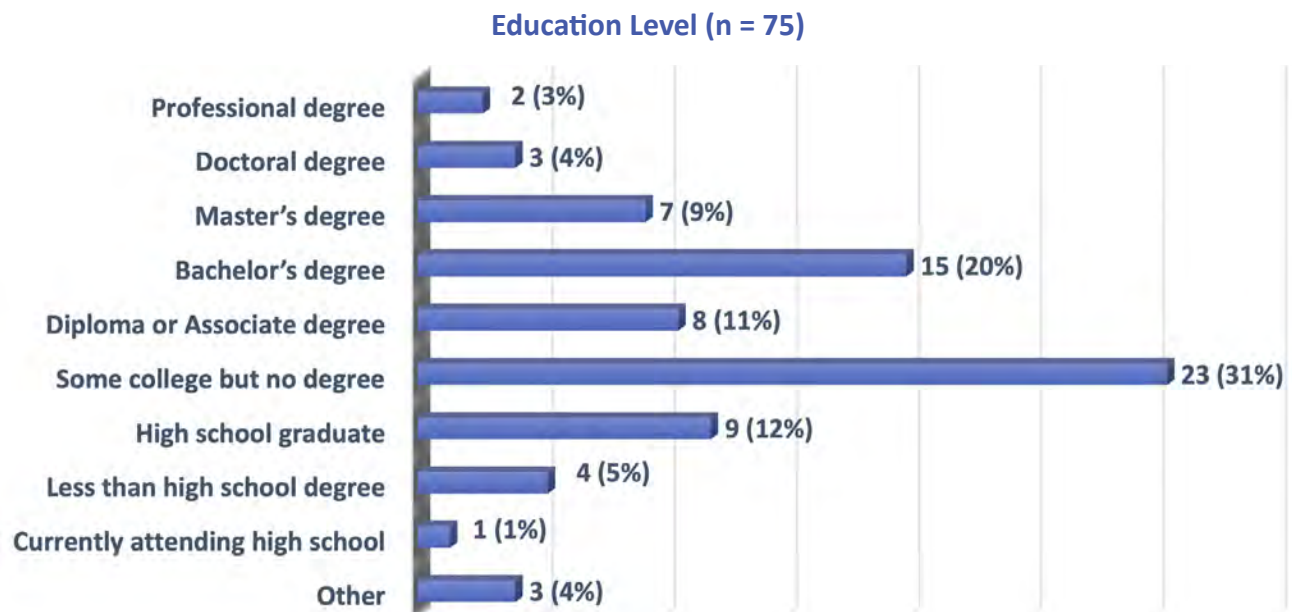
Total Household Income

The following chart details household income information of survey respondents. One-third of respondents had a household income of less than \$25,000 (35%). The next common income levels were over \$75,000 (21%) followed by \$25,000 to \$35,000, and \$65,000 to \$75,000 (both 15%).



Highest Level of School or Degree of Individuals with TBI

Most respondents either had some college but no degree (31%), had a Bachelor's degree (20%), or were a high school graduate (12%). About 16% of respondents had a degree beyond their Bachelors (Master's, Doctoral, or Professional degree). Less than 7% of respondents were either currently attending high school or had less than a high school degree.



RESULTS FROM DATA COLLECTION

County of Residence of Individuals with TBI

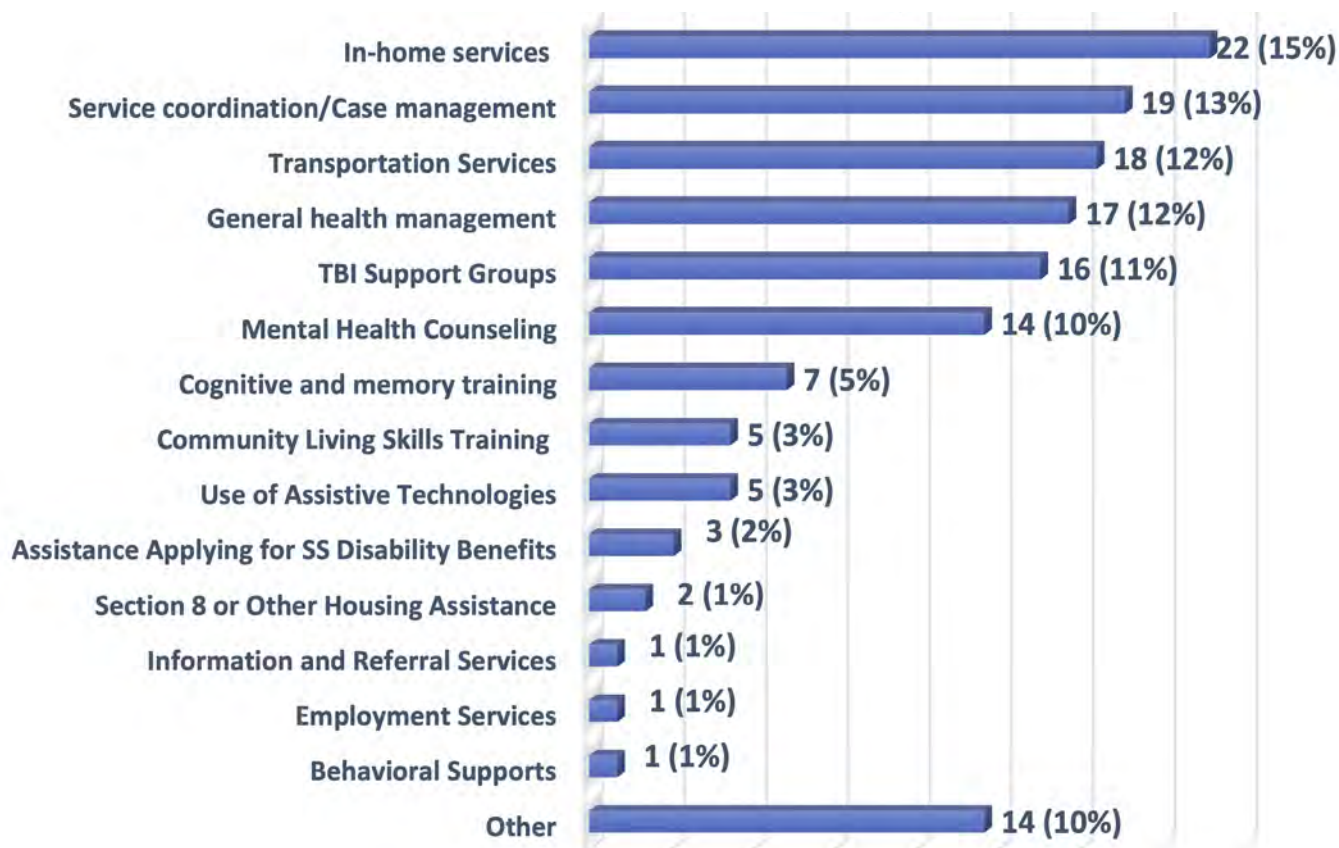
A little over three-fifths (67%) of individuals with TBI responding to the survey reside in or near Metro-Atlanta counties per the Atlanta Regional Commission. The Atlanta region includes Cherokee, Clayton, Cobb, DeKalb, Douglas, Fayette, Forsyth, Fulton, Gwinnett, Henry and Rockdale counties, and the city of Atlanta. The five counties with the highest representation include Cobb, Gwinnett, DeKalb, Fulton, and Cherokee. About 33% resided in other counties including Oconee, Paulding, Newton, Chatham, Catoosa, Glynn, Habersham and many other rural counties across the state.

TBI Services

Current Community-Based Services Being Received

The following chart depicts the community-based services used by survey respondents. While a wide range of services were utilized by respondents, the five most common ones were: in-home services (15%), transportation services (12%), service coordination and case management (13%), general health management (12%), and TBI support groups (11%). The least common ones were: assistance applying for Social Security benefits (2%), housing assistance (1%), information and referral services (1%), employment services (1%), and behavioral support (1%).

Current Services Being Received (n = 85)

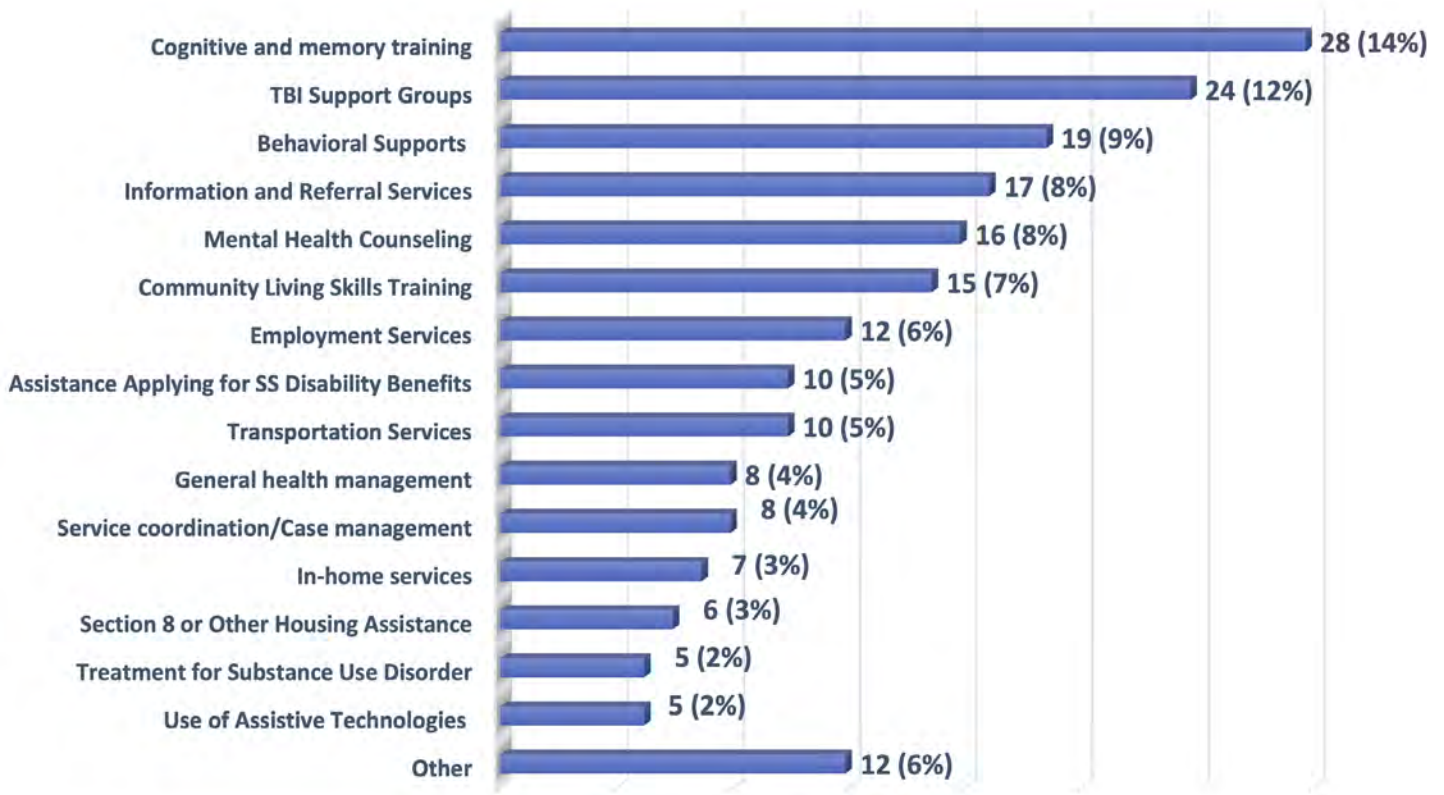


RESULTS FROM DATA COLLECTION

Community-Based Services Needed but Not Received

The following chart depicts the services survey respondents have needed but not yet received. All services listed were noted as being needed by at least five individuals. The top three services needed were: Cognitive and memory training (14%), TBI support groups (12%), and behavioral supports (9%).

Community-Based Services Needed But Not Yet Received (n = 85)

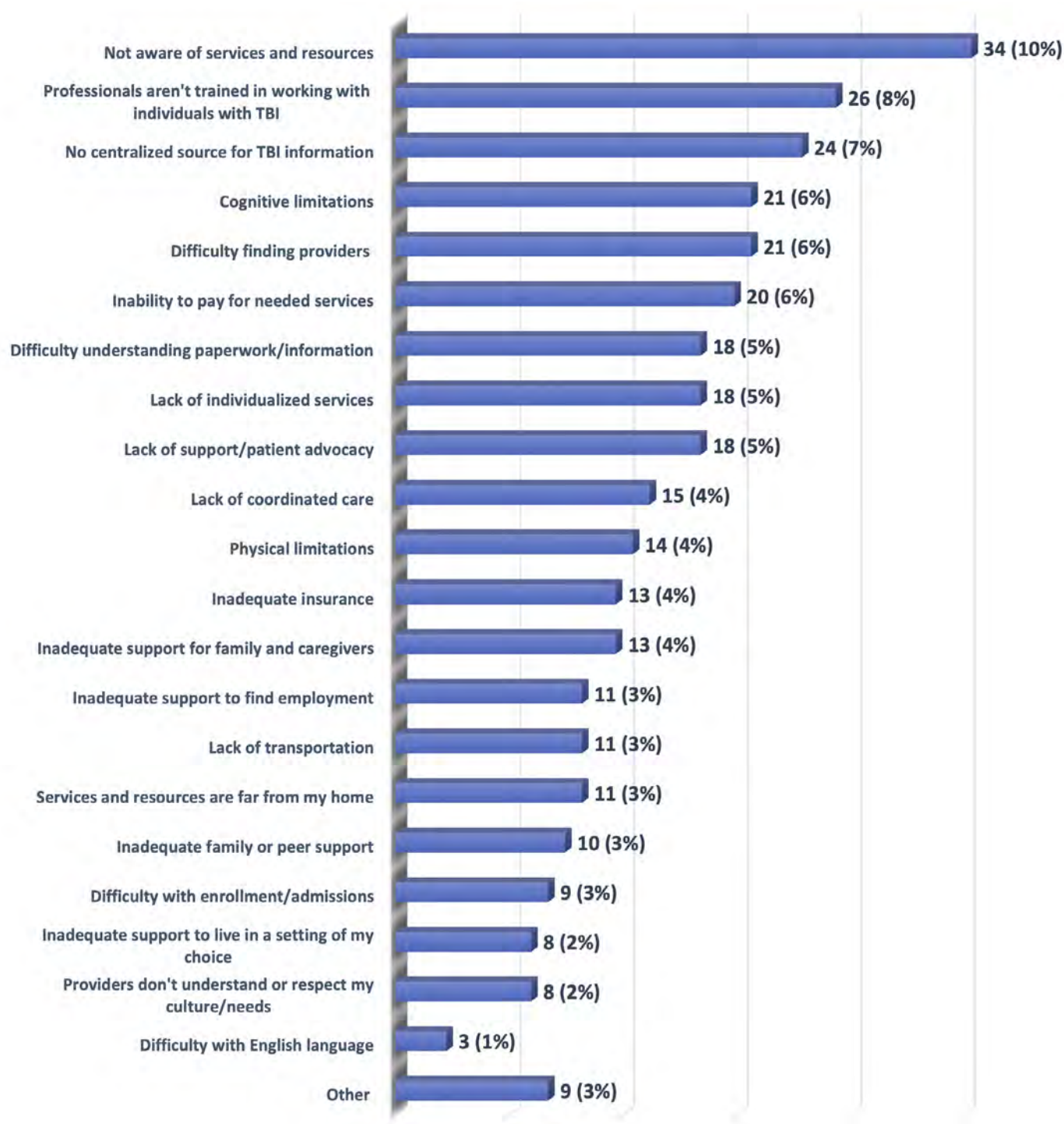


Barriers to Receiving Services

The following chart depicts barriers respondents face in getting services needed related to their TBI. The most common barriers reported were related to not having a centralized source of information or care coordination: respondents reported that they were either not aware of services and resources (10%), that there is no centralized source for acquiring TBI information (7%), and lack of support or patient advocacy (6%). Concerns related to quality and accessibility of care were also mentioned, including that professionals are not trained for working with individuals with TBI (8%) and difficulty finding providers (6%). Another top barrier listed was cognitive limitations (6%).

RESULTS FROM DATA COLLECTION

Barriers to Receiving Services (n = 85)

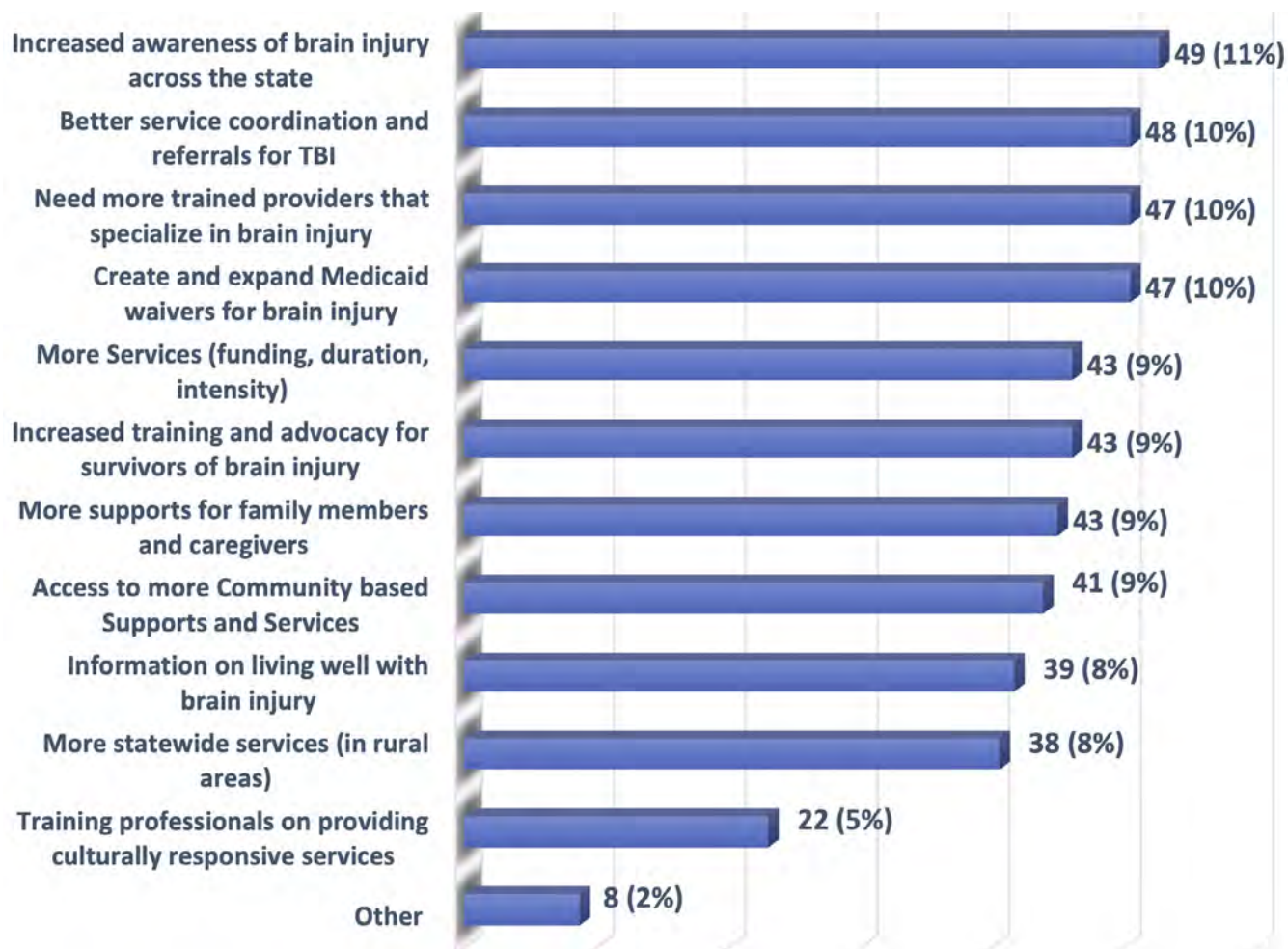


RESULTS FROM DATA COLLECTION

Desired Improvements to TBI Service System

The chart below details the improvements respondents would like to see to the TBI service system in Georgia. The top improvements mentioned were: Increased awareness of brain injury across the state (11%), need to create and expand Medicaid waivers for brain injury, need for more trained providers specializing in brain injury, and better service coordination and referrals for TBI (all 10%).

Desired Improvements to TBI Service System (n = 85)



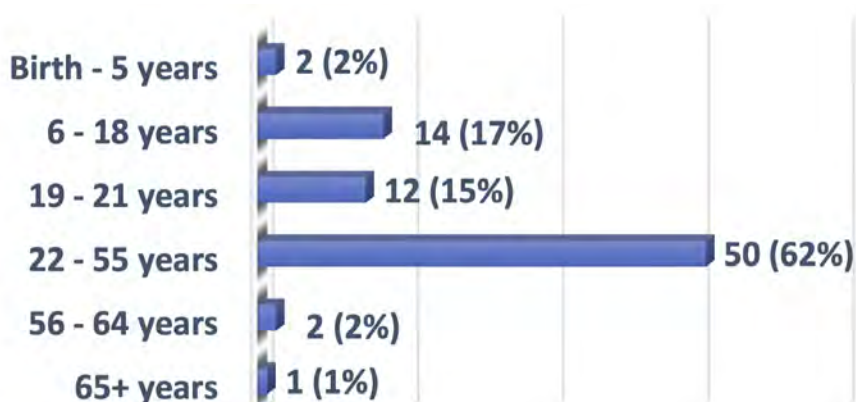
Injury Details

Age at the Time of Injury

The graph below shows the age range of individuals with TBI at the time of injury. Similar to the age of the respondents, the majority of injuries occurred between the ages of 22 to 55 (62%). However, even if the current age of respondents was higher, a large proportion of respondents were either injured during childhood (about 19%) or early adulthood (15%). Roughly 4% of respondents sustained their injury at age 56 or older.

RESULTS FROM DATA COLLECTION

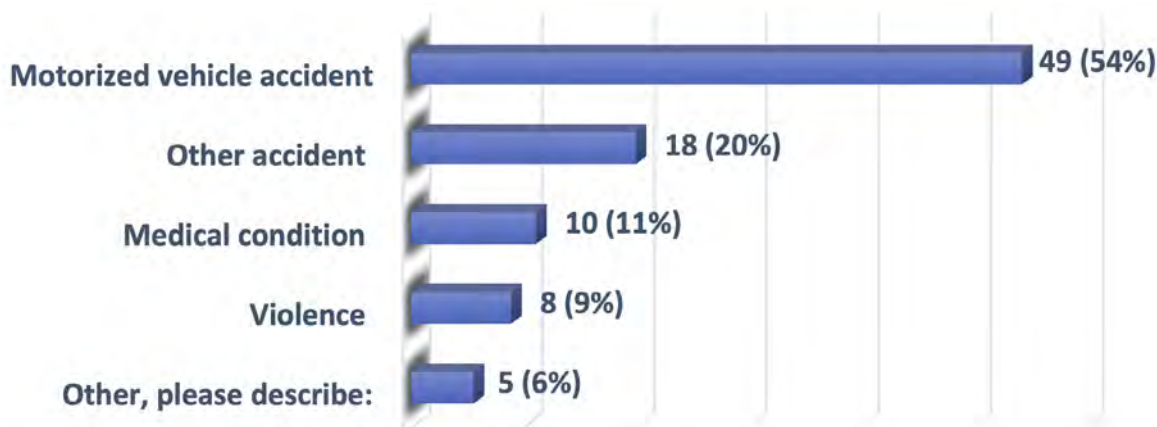
Age at Time of TBI Injury (n = 81)



Cause of TBI

The graph below depicts how person's TBI injury occurred. In over half of the cases reported, TBIs were sustained from a motorized vehicle accident (54%). Accidents of any kind made up the majority of responses, including other types of accidents such as falling or a sports injury (20%). Additional causes of TBI included a medical condition (11%), violence (9%), or other miscellaneous causes (6%).

Cause of TBI (n = 90)

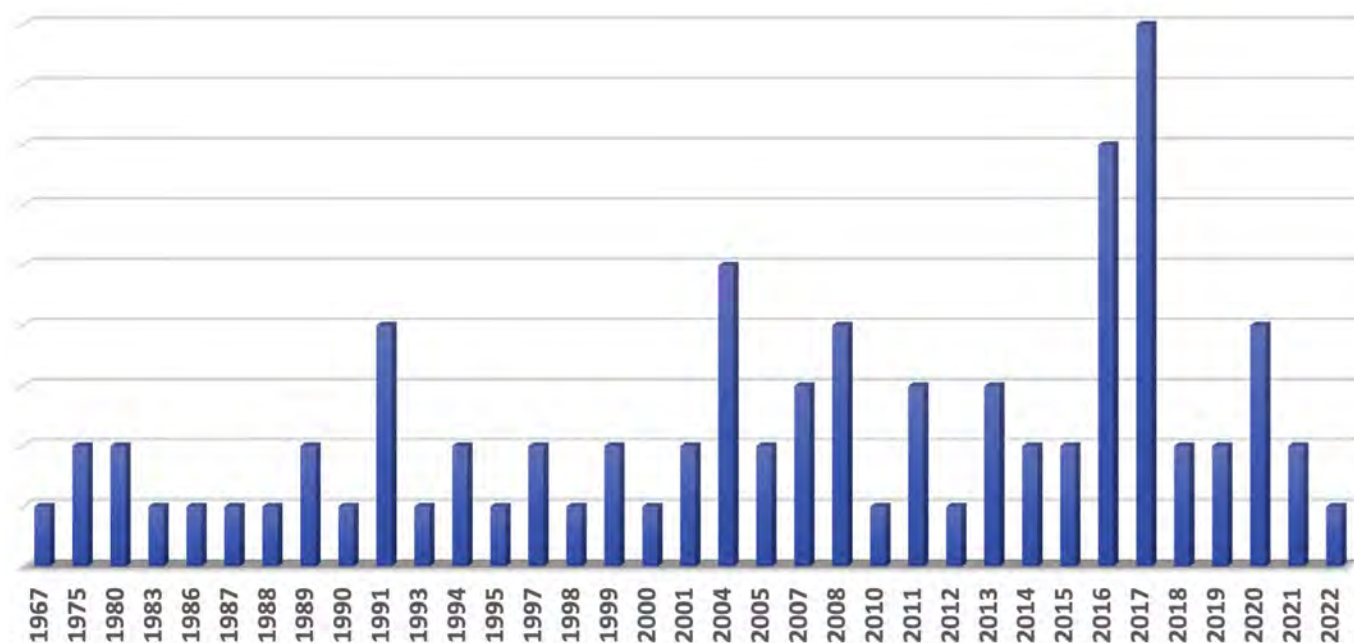


RESULTS FROM DATA COLLECTION

Year of Injury Occurrence

The graph below depicts the year(s) in which a person with a TBI was injured. The amount of time is very variable, with injuries ranging from 1967 to 2022. About two-thirds of injuries occurred in the past 20 years, and 44% in the past 10 years. Most respondents only reported one year for their injury; however, the maximum reported for a single person included four separate injuries. Of those who reported a second TBI injury, all of them had occurred since 2001, ranging up to 2019. The majority of second TBIs occurred between 2011-2019, with the most in one year being three in 2017.

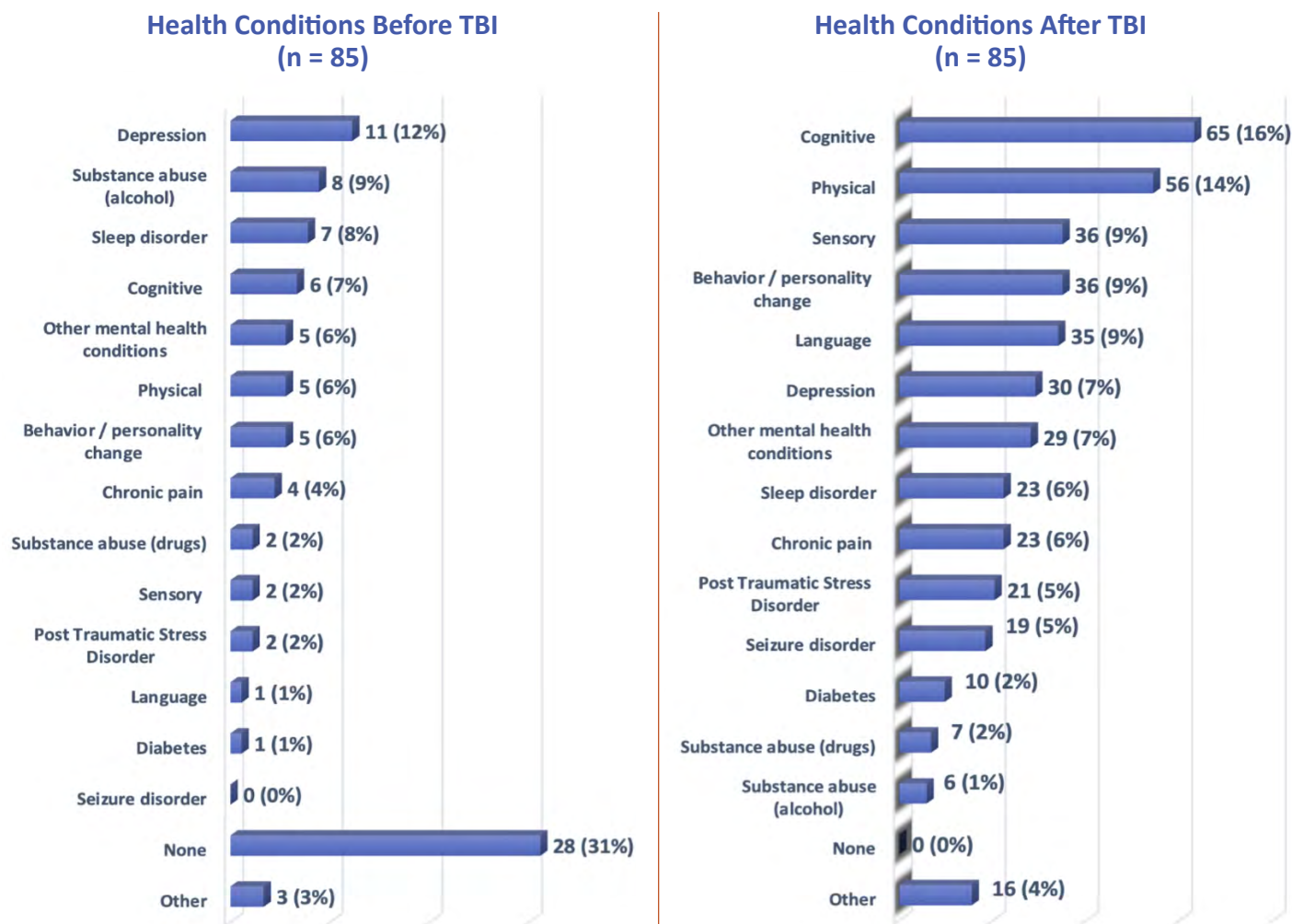
Year of TBI Injury (n = 81)



Disabilities or Significant Health Conditions Before and After TBI

The graph below compares the disabilities or significant health conditions of survey respondents before and after their TBI occurred. Before TBI, nearly one-third of respondents had no significant health conditions (31%). Of those with existing health conditions, the most common ones were depression (12%), substance abuse (alcohol; 9%), and sleep disorder (8%). However, after TBI, reporting and frequency of various health conditions increased by over 350%. The top three reported health conditions post-TBI injury were cognitive health issues (16%), physical health issues (14%), language and sensory issues (9% each), and behavior/personality change (9%). The least common reported conditions were substance abuse (1% for alcohol and 2% for drugs) and diabetes (2%).

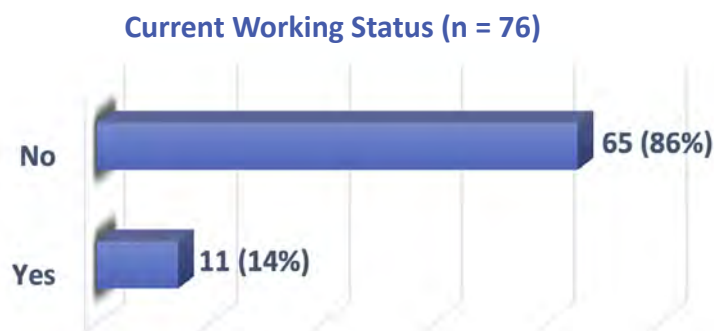
RESULTS FROM DATA COLLECTION



Employment

Current Employment Status of Individual with TBI

The following chart depicts information about survey respondents' employment status. Majority of respondents were not currently working or employed (86%).



RESULTS FROM DATA COLLECTION

Full, Part Time Employment Status of Individual With TBI

Of those survey respondents who were employed, (n=11) the majority are working full-time (55%), followed by part-time employment (18%) and volunteer employment (9%). The median hours worked per week was 35 (Range = 5 - 40+ hours). About 45% of employed individuals with TBI indicated that they did require accommodations. Of those needing them, 83% said they both had accommodations and are able to use them successfully in order to work. 27% said they did not need any accommodations and 18% of individuals did not know if they needed accommodations.

Reasons for Not Working

The chart below details reasons that unemployed survey respondents gave for not working. The top three reasons given were: being told by professionals that they are unable to work (22%), concern that having a job will affect their benefits (19%), and that they have tried but have been unable to keep a job due to their disability (16%).

Reasons for Not Working (n = 93)

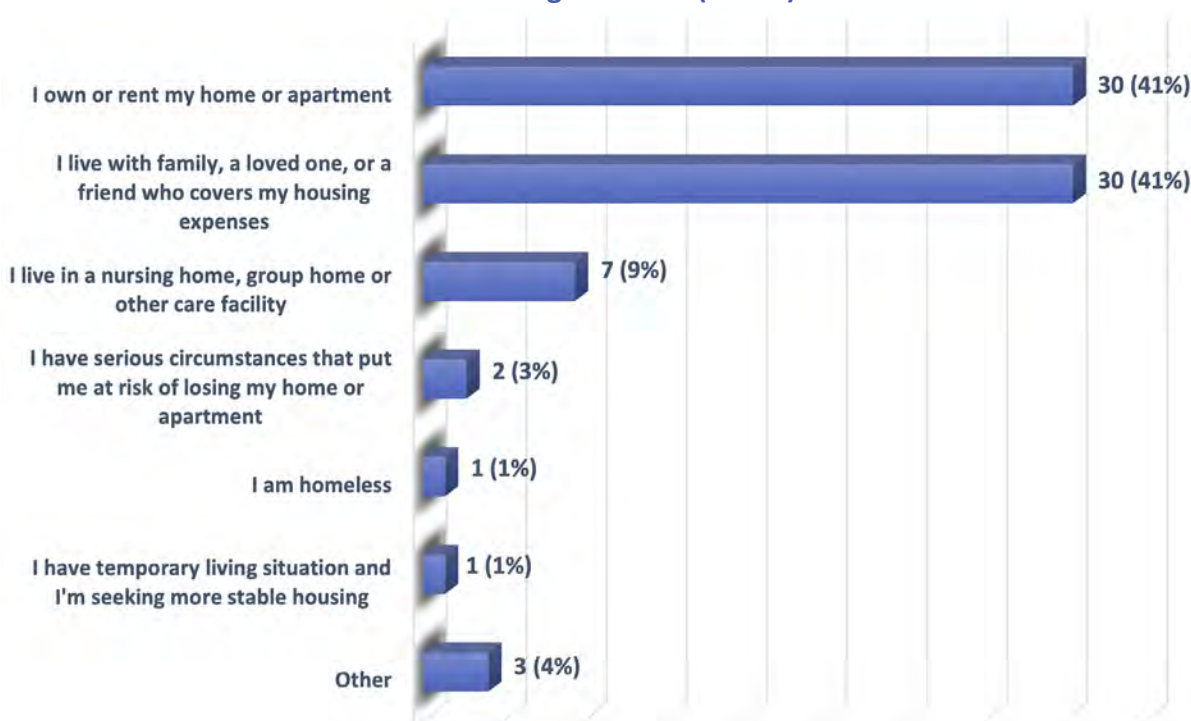


RESULTS FROM DATA COLLECTION

Current Living Situation

The table below depicts the current residency status of individuals with TBI. A little less than half of the respondents either owned or rented their own place (41%) with the other half who lived with someone else (family, loved one, friend) who covers their housing expenses (41%). Beyond those two categories, respondents noted either living in a group living facility of some form (9%), being at risk of losing their residency (3%), or currently being in temporary housing and seeking a more stable set up or homeless (both 1%).

Current Living Situation (n = 74)



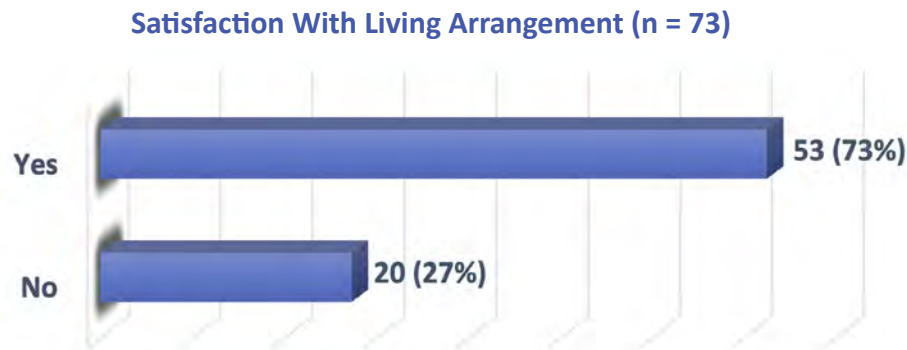
Desire to Return to Community From Nursing Facility

Of those living in some form of group living facility (n=6), two-thirds of respondents were unsure whether they wanted to return to the community (66%), with the rest being evenly split between yes and no (both 17%). All the above individuals, even if they selected being unsure about returning to the community, mentioned that they would like to live in the community if sufficient resources were available to enable that. Key barriers that made people unsure about returning to community living include not getting the in-home supports they need, not getting the medical or rehabilitation care or having financial resources, that would make it possible for them to live in the community. In *Olmstead v. L.C.*, the United States Supreme Court held that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when such services are appropriate and can be reasonably accommodated.⁷⁰

RESULTS FROM DATA COLLECTION

Satisfaction with Current Living Arrangement

The graph below depicts information about survey respondents' current satisfaction with their living arrangement. Nearly three-quarters of respondents indicated satisfaction with their current arrangement (73%).



Reasons for Satisfaction Towards Living Situation

"I think my son would like to live on his own, but he doesn't know how to go about it. He is a help to me and I don't mind him being here. I am concerned about where he will go when I die. He is mid-forties and I am over 75 years old."

"I am living in a house with lots of stairs that are a problem."

"I am not working and in jeopardy of being homeless again for to lack of resources (financial and beyond)."

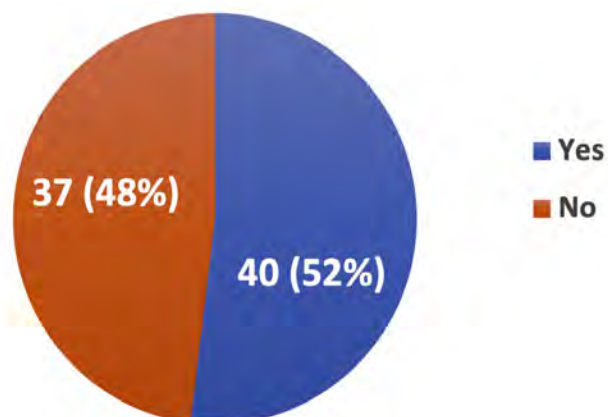
"My son would like to be living in a more accessible home. He is not unhappy or depressed, but given the opportunity, he would love to have a bedroom and bathroom that are on the main level, or even separate quarters attached to our home. We have the space, but not the funds to make that happen. We currently use a stair lift to the basement that he cannot manage without help. His bedroom is also not very accessible. His wheelchair cannot be moved easily on the carpet, and he cannot reach any of his own things due to his hands or because they are out of reach. I am with my son 24/7 to assist."

Information Shared With Individuals Post TBI Injury

The graphs below present an overview of the information shared with respondents after their TBI occurred. Most respondents noted that someone shared information with either them or their family about services for people with TBI (52%). Of those who received information, three-quarters received this information at the hospital or doctor's office (76%).

RESULTS FROM DATA COLLECTION

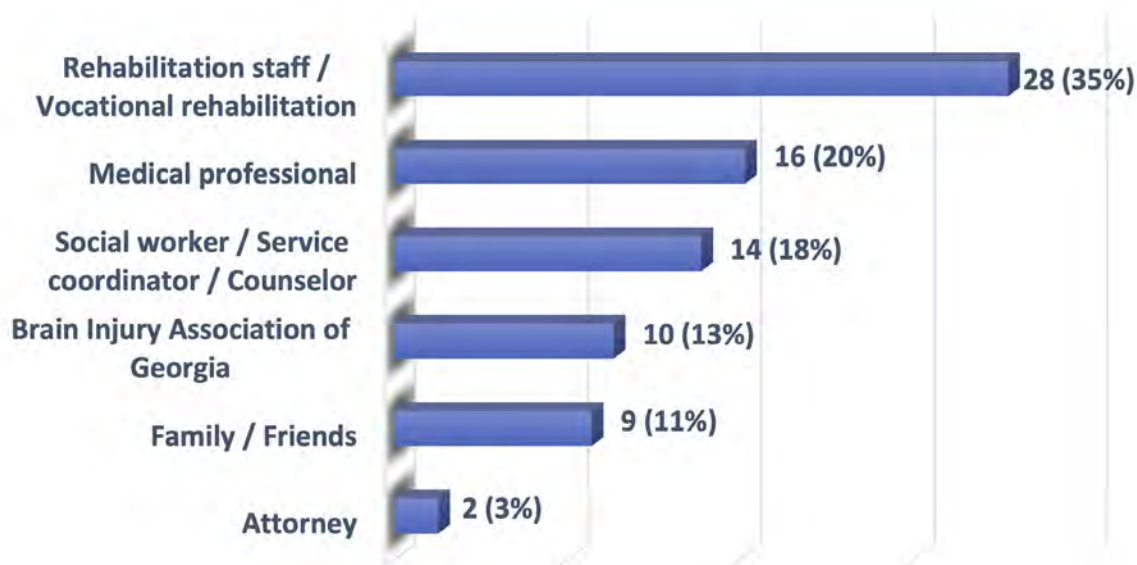
Information Shared With Individual Post-TBI Injury (n = 77)



Source of TBI Services Information

A majority of respondents had information provided by rehabilitation personnel (35%) or medical professionals (20%). Other points of information acquisition included social workers or counselors (18%), the Brain Injury Association of Georgia (13%), friends and family (11%), or an attorney (3%).

Who Provided You With TBI Services Information? (n = 79)

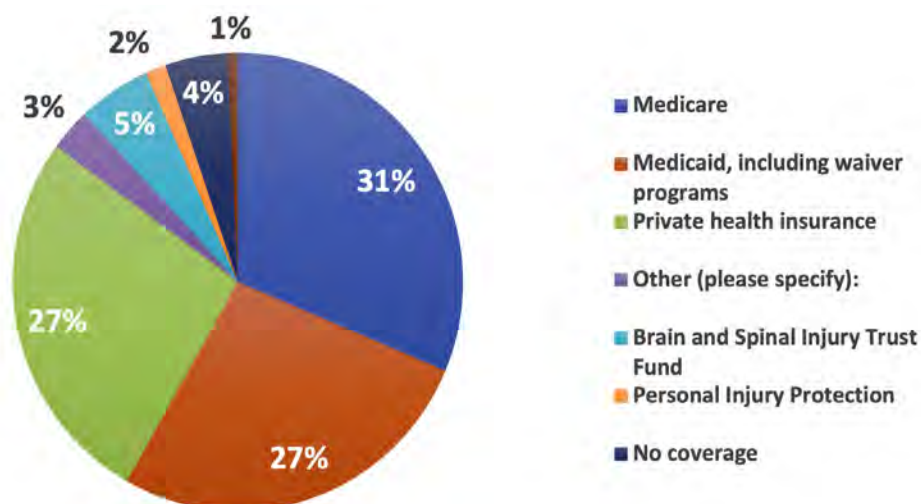


How Healthcare Costs Are Paid

The chart and table below depict how survey respondents paid for healthcare costs. Most respondents used Medicare (31%), Medicaid (27%), or private health insurance (27%). Other sources of funding included the Brain and Spinal Injury Trust Fund, Personal Injury Protection, or no coverage/out of pocket.

RESULTS FROM DATA COLLECTION

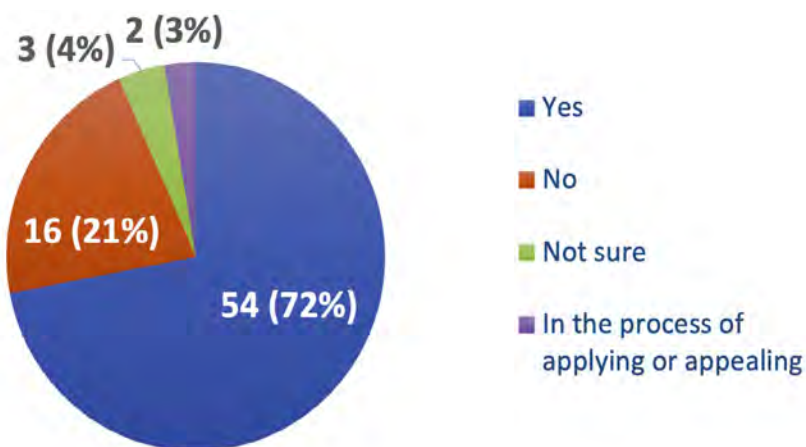
How Healthcare Costs are Paid (n = 85)



Respondents With SSI or SSDI

Nearly three-quarters of respondents either already had SSI/SSDI (72%) or were actively applying/appealing (3%). Other participants either did not have SSI/SSDI (21%) or were unsure (4%).

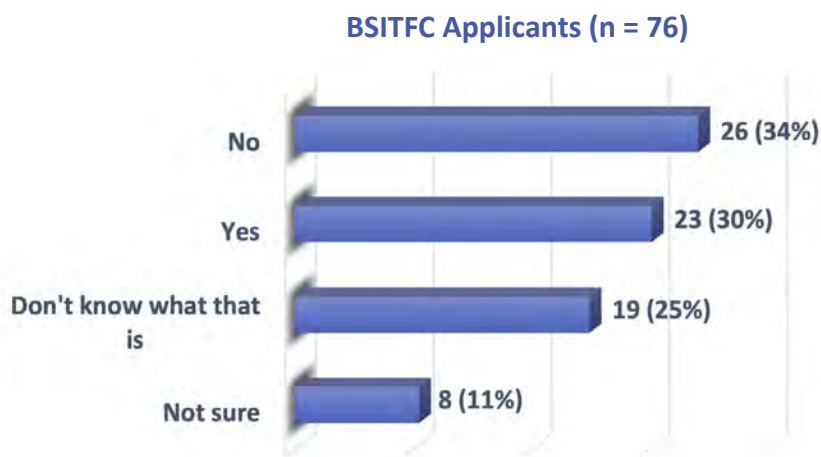
Respondents Who Have SSI/SSDI (n = 75)



Brain and Spinal Injury Trust Fund Applicants

The chart below highlights survey respondents' familiarity and involvement with the Brain and Spinal Injury Trust Fund Commission (BSITFC). About 30% of respondents had applied to the Brain and Spinal Injury Trust Fund (30%). The majority of respondents either had not applied to the fund (34%) or did not know what it was (25%).

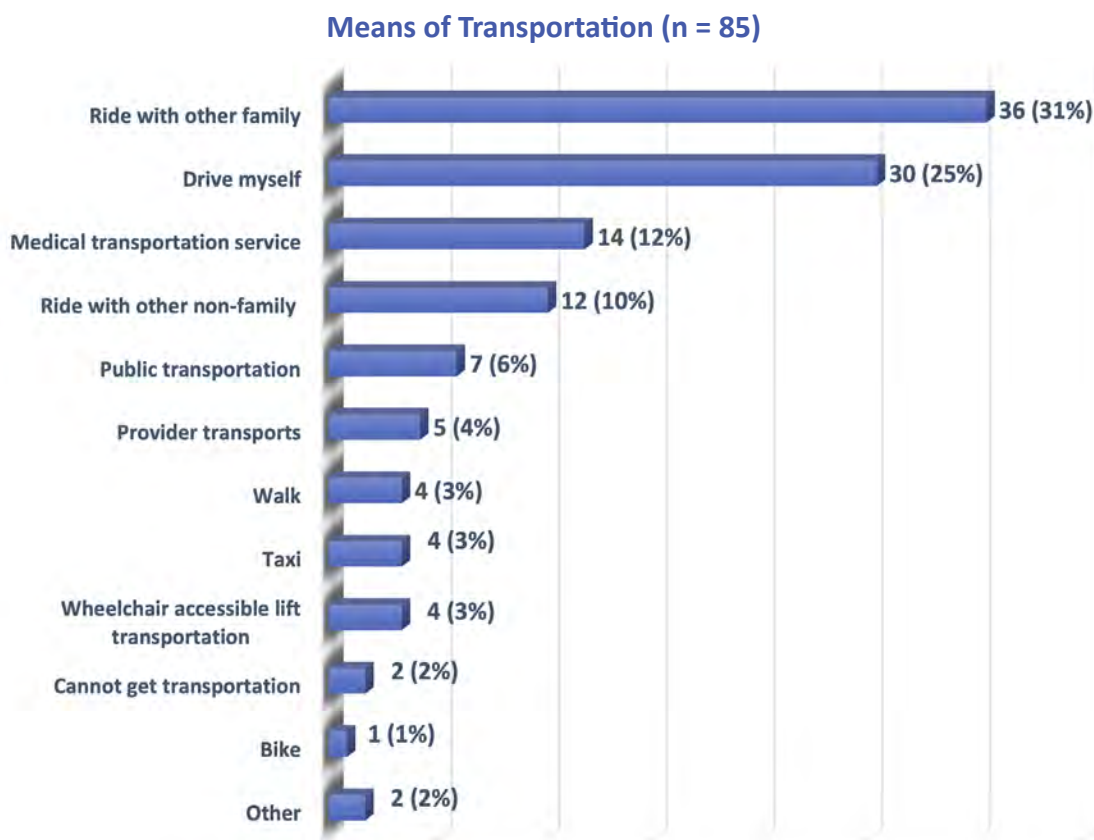
RESULTS FROM DATA COLLECTION



Transportation

Means of Transportation

The chart below depicts the current transportation usage of survey respondents. While a wide variety of transportation means are used generally, the most common among respondents is either to ride with other family (31%) or drive themselves (25%), though some expressed concern with having to drive themselves due to cognitive or physical demands. Other transportation modes include riding with non-family (10%), medical transportation service (12%), and public transportation (6%). About 87% of respondents noted their transportation means as reliable and accessible (85%).



RESULTS FROM DATA COLLECTION

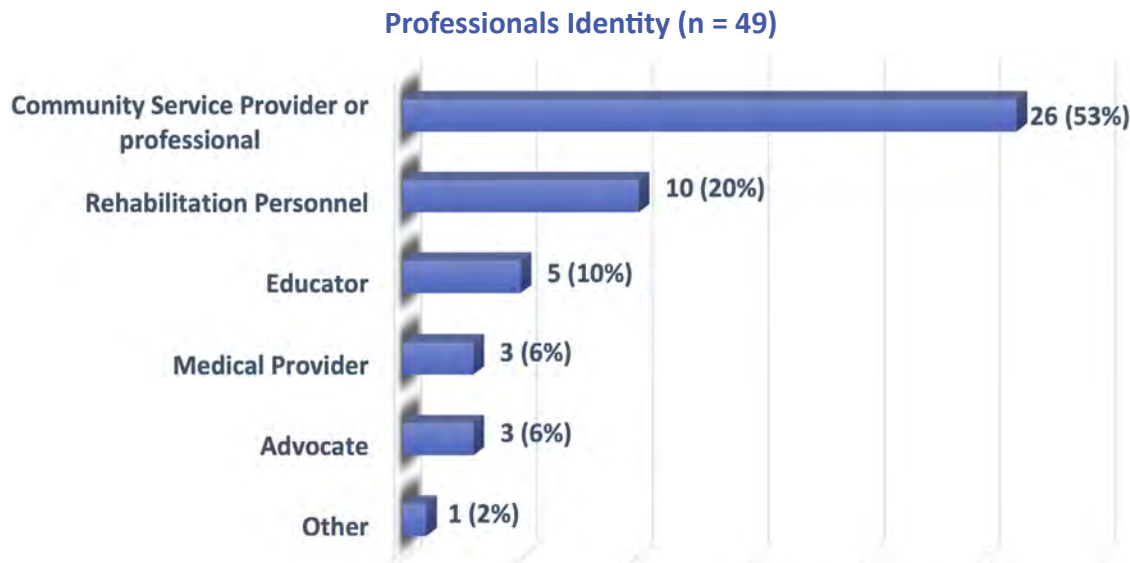
SUMMARY OF SURVEY FINDINGS

SURVEY FOR PROFESSIONALS

Demographics

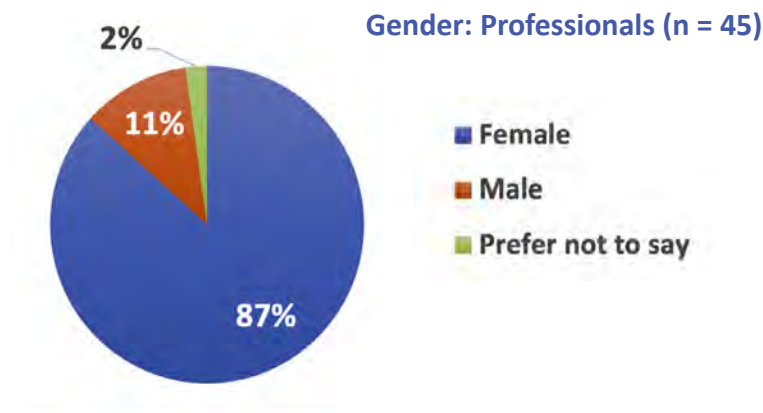
Professional Identity of Respondent

The graphs below depict the professional identity of survey respondents. Over half of respondents (53%) were community service providers or professionals, followed by rehabilitation personnel (20%) and educators (10%). Of the community service providers, represented job titles were case workers or managers, social workers, program providers, other advocates, and mental health professionals. One primary care physician was represented in the sample. Most rehabilitation personnel were either occupational therapists (40%) or other (30%). Sixty percent of educators were teachers. The remaining were transition specialists.



Gender

The graph below depicts the gender makeup of survey respondents. The vast majority of professionals were female (87%).

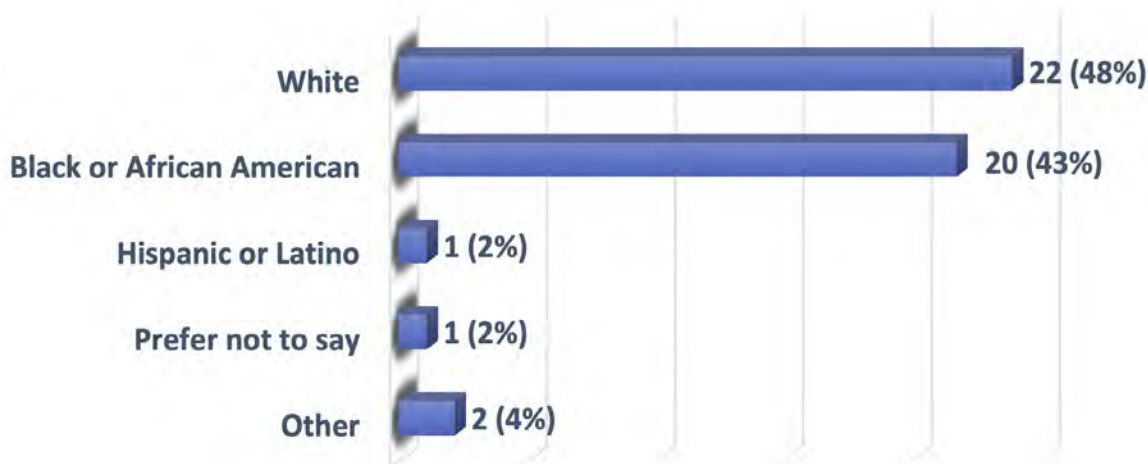


RESULTS FROM DATA COLLECTION

Race/Ethnicity

The graph below depicts the race/ethnicity. The most commonly reported race/ethnicity was White (48%), followed by Black or African American (43%). Compared to the estimated racial/ethnic makeup of Georgia (2020 US Census Data), these numbers are slightly under estimates for White individuals and slightly above estimates for Black or African American individuals.

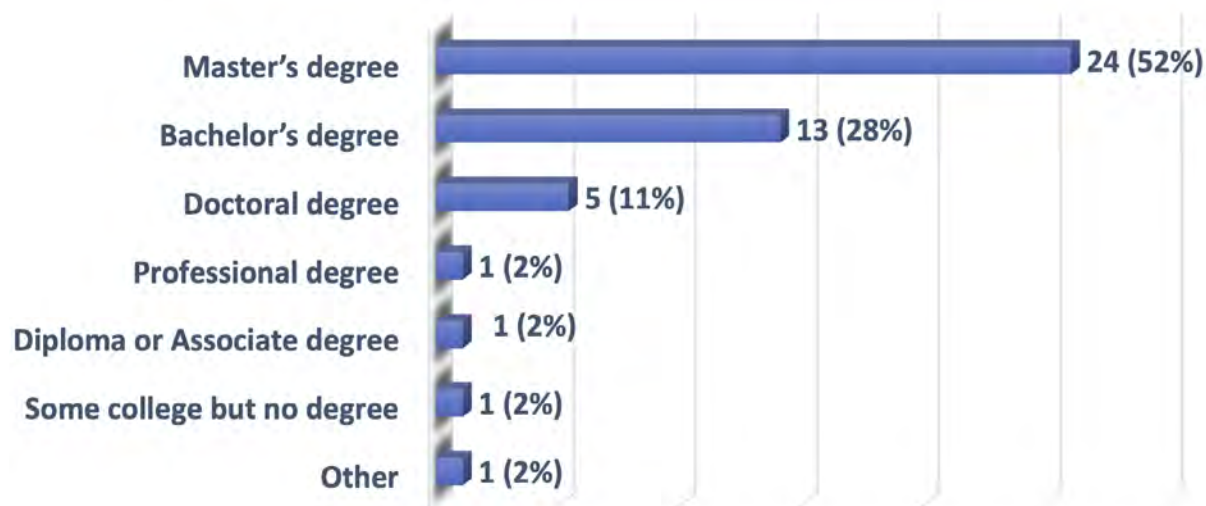
Race/Ethnicity: Professionals (n = 46)



Education Level

The graph below details the education level of survey respondents. About half of the professionals surveyed had a Master's degree (52%). This was followed by professionals having Bachelor's degree (28%) and Doctoral degree (11%).

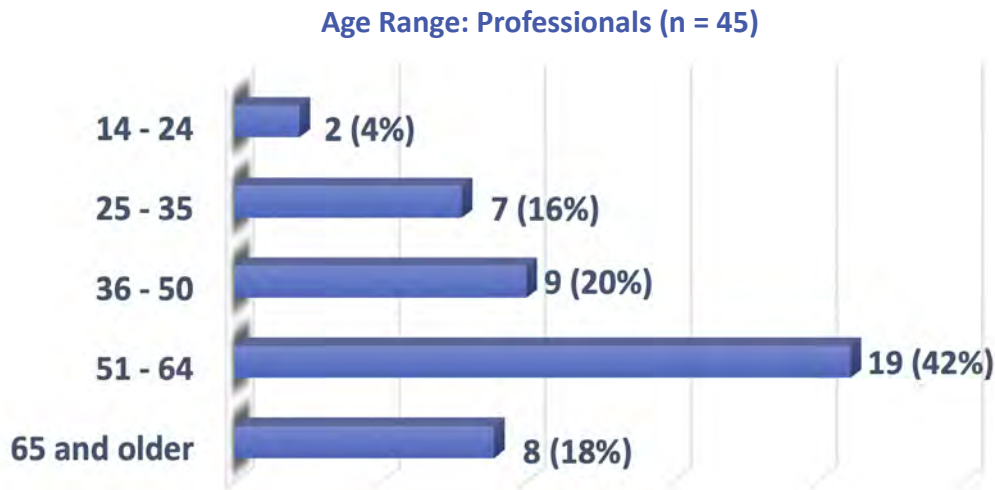
Education Level: Professionals (n = 46)



RESULTS FROM DATA COLLECTION

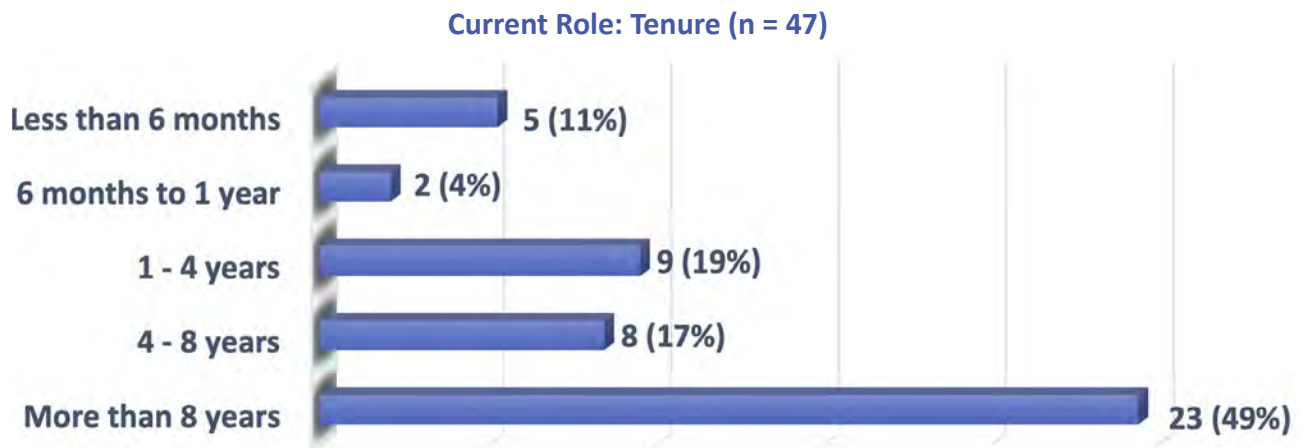
Age Range

The graph below shows the age ranges of surveyed professionals. Most of the sample fell into the 51 to 64 years old range (42%), or the 36 to 50 years old range (20%). Given that most respondents had some form of post-secondary degree, this older sample is in line with what would be expected.



Average Work Hours

The following graph displays the current job tenure of surveyed professionals. Nearly half of survey respondents have been in their current role for over 8 years (49%). The next most common range for tenure was people who have been in their current job for 1 to 4 years (19%). The median number of working hours per week was 40 (range: 5-50 hours).



RESULTS FROM DATA COLLECTION

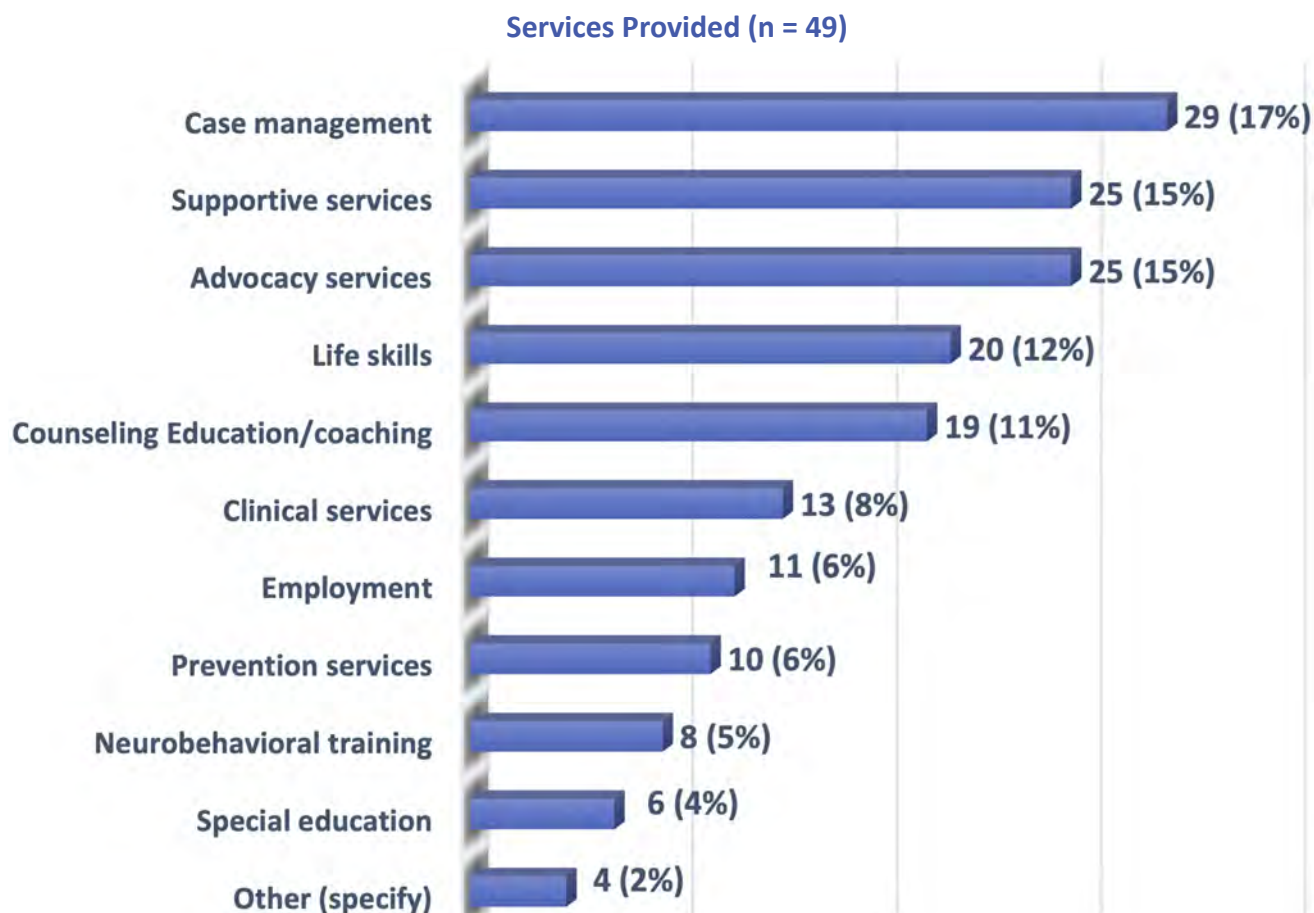
County of Residence

Three quarters (72%) of professionals working with individuals with TBI responding to the survey reside in or near Metro-Atlanta counties per the Atlanta Regional Commission. The Atlanta region includes Clayton, Cobb, DeKalb, Douglas, Fayette, Forsyth, Fulton, Gwinnett, Henry and Rockdale counties, and the city of Atlanta. The five counties with the highest representation include Cobb, Gwinnett, DeKalb, and Fulton. About 28% resided in other counties including Clarke, Banks, Bartow, Dooley, Terrell, Muscogee, Walton and many other rural counties across the state.

TBI Services

Services Provided

The graph below details the services provided by professionals and/or their organizations to persons with TBI. The three most common services provided were: case management (17%), supportive services (15%), and advocacy services (15%). The three least common services provided were: neurobehavioral training (5%), special education (4%), and other services (2%).

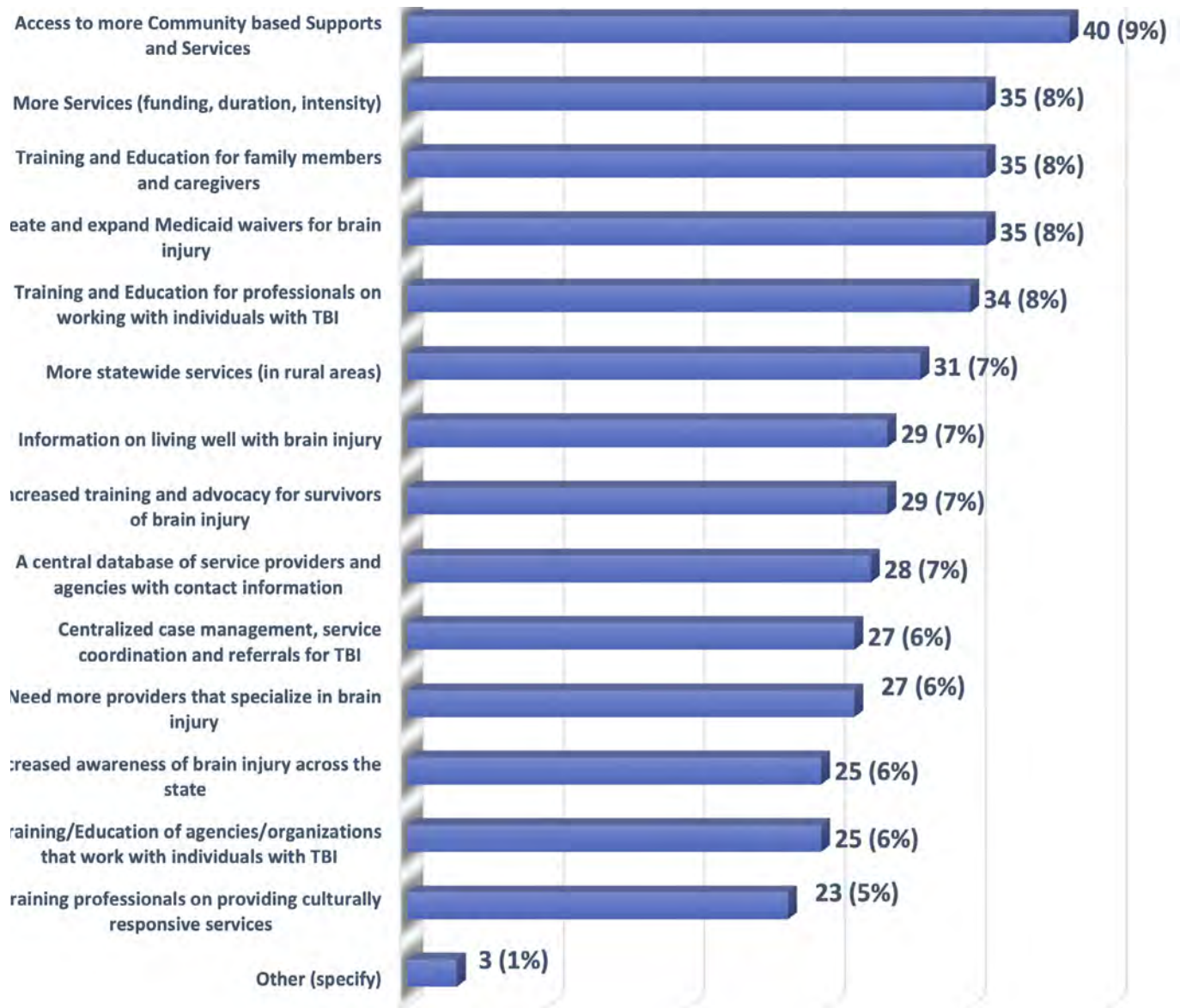


RESULTS FROM DATA COLLECTION

Desired Improvements: TBI Service System in Georgia

The graph below provides information about professionals' desired improvements to the Georgia TBI service system. The top five desired improvements were: access to more community-based supports and services (9%), more services (8%), training and education for family members and caregivers (8%), create and expand Medicaid waivers for brain injury (8%), and training and education for professionals working with individuals with TBI (8%).

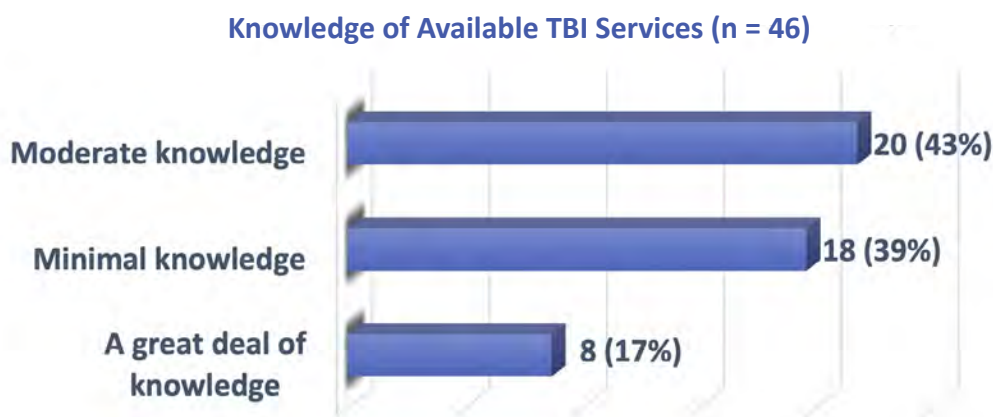
Desired Improvements to TBI Service System in Georgia (n = 49)



RESULTS FROM DATA COLLECTION

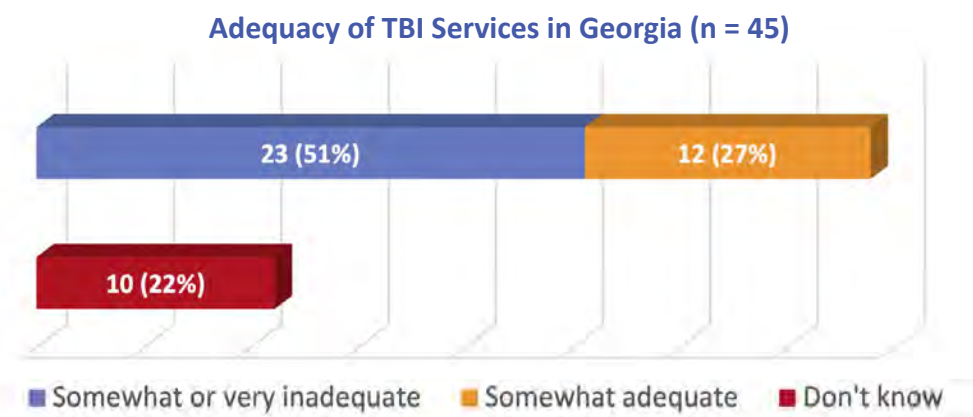
Knowledge of Available TBI Services

The following graphs depict surveyed professionals' extent of knowledge about TBI services in Georgia. Most respondents indicated having a moderate level of knowledge about available TBI services in Georgia (43%). However, 39% reported having only minimal knowledge.



Adequacy of TBI Services in Georgia

The chart below shows the professionals' perception of the adequacy of TBI services. In terms of adequacy, 51% of respondents rated the TBI services in Georgia as being very inadequate or somewhat inadequate and 27% rated the services as being somewhat or very adequate. Twenty-two percent of respondents said they did not know much about Georgia's service system for individuals with TBI.



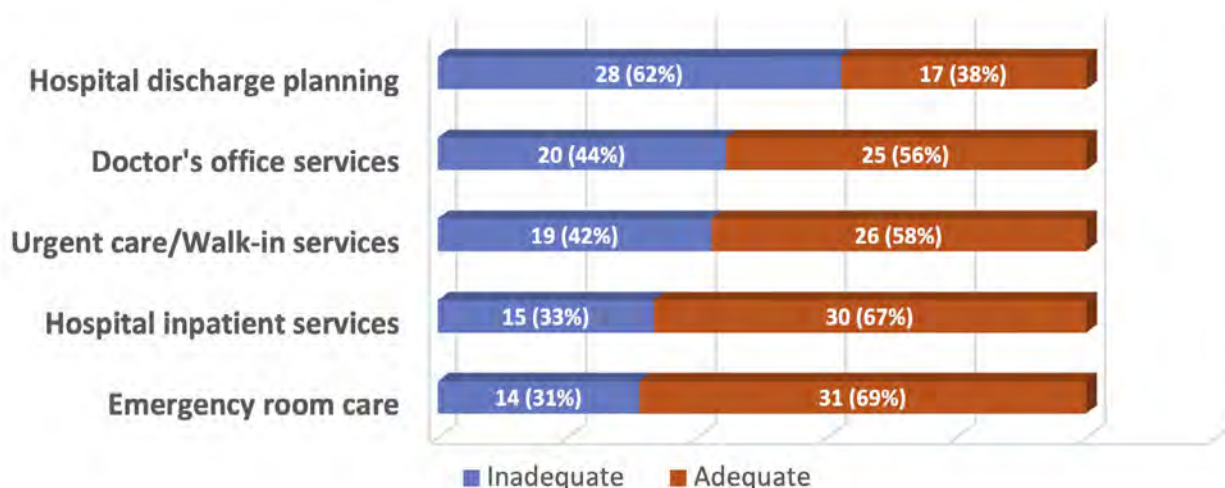
The following charts detail professionals' perceptions on the adequacy of various support and services within Georgia. These fall into three primary categories: medical/hospital services, acute rehabilitation services, and community support and services. Ratings were given on a scale of 1 to 4 (1 = very inadequate, 4 = very adequate).

RESULTS FROM DATA COLLECTION

Adequacy of Medical and Hospital Services

For medical and hospital services, the service with the lowest average rating was hospital discharge planning (2.13). Two-third (62%) of respondents rated hospital discharge planning as being very inadequate or somewhat inadequate. The emergency room care and hospital inpatient services received the highest average adequacy ratings (2.69), which majority (69%) of respondents rated as being very adequate or somewhat adequate.

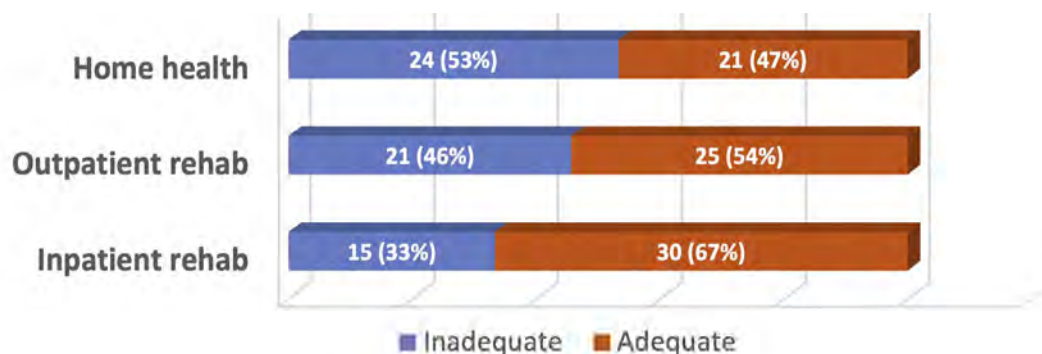
Adequacy of Medical and Hospital Services in Georgia (n = 45)



Adequacy of Acute Rehabilitation Services

For acute rehabilitation services, inpatient rehab received the highest average adequacy rating (2.62), where in 67% of respondents rated the services as either very or somewhat adequate. The service with the lowest average rating was home health (2.31)

Adequacy of Acute Rehabilitation Services in Georgia (n = 46)

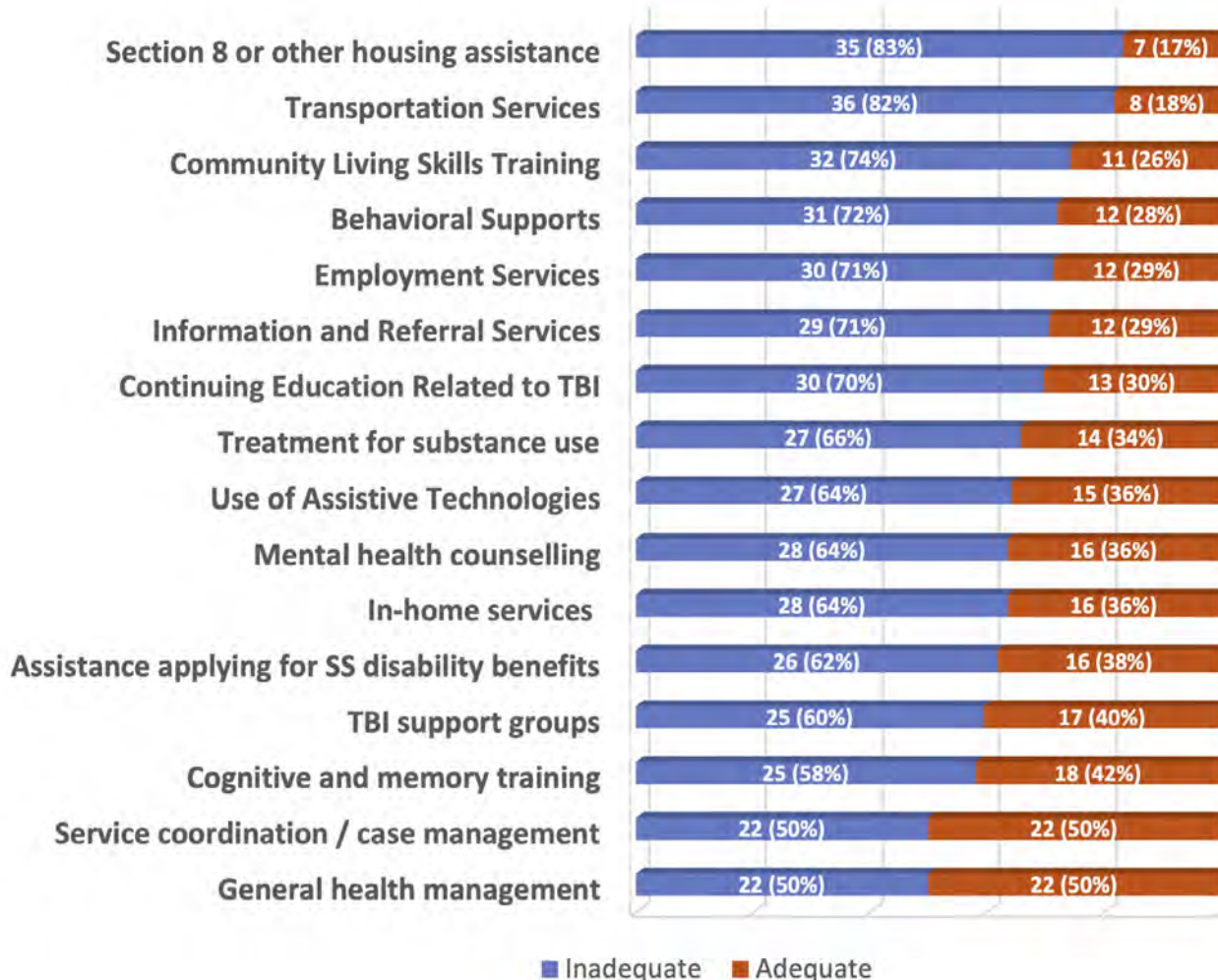


RESULTS FROM DATA COLLECTION

Adequacy of Community Support and Services

For community support and services, the services with the three lowest average adequacy ratings were: transportation services (82%), Section 8/other housing assistance (83%), and community living skills training (74%). The services with the three highest average adequacy ratings were: general health management (50%), service coordination and case management (50%) and cognitive and memory training (58%). One trend to note is that most ratings were range restricted and never exceeded a value of 3.0 or below 1.0. This means that most professionals rated services as either somewhat adequate or somewhat inadequate.

Adequacy of Community Support and Services in Georgia (n = 44)

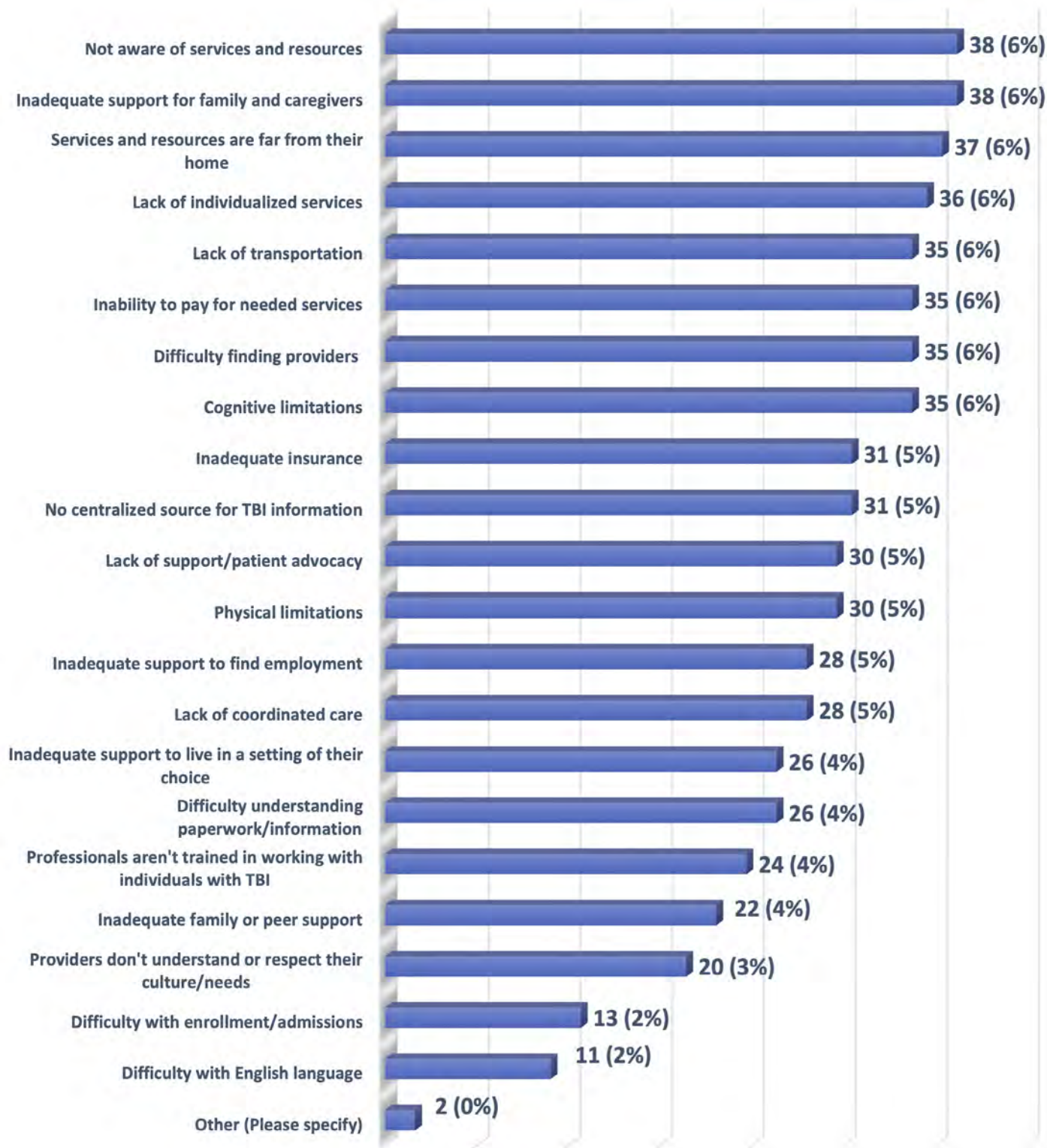


Barriers to Obtaining Services

There were many barriers to obtaining services identified by professionals as being important: not being aware of services and resources, inadequate support for family and caregivers, services are far from their home, lack of individualized services, lack of transportation, inability to pay for services, difficulty in finding providers and cognitive limitations of individuals with TBI (6% each).

RESULTS FROM DATA COLLECTION

Problems Persons with TBI Have in Obtaining Services (n = 49)

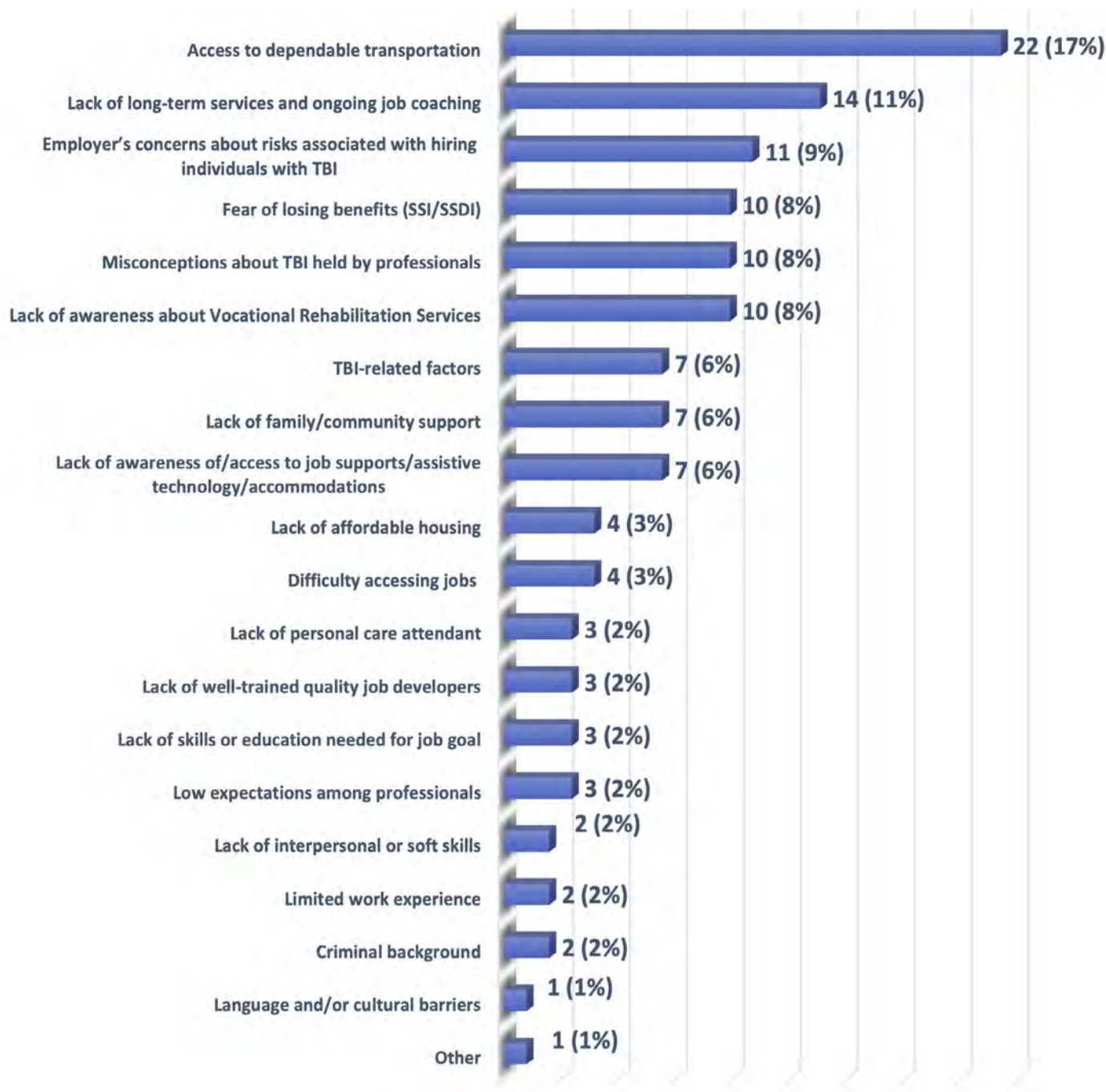


RESULTS FROM DATA COLLECTION

Top Three Barriers to Employment

The graph below depicts the top barriers to employment that professionals observed persons with TBI encountering. The top three barriers were: access to dependable transportation (17%), lack of long-term services and ongoing job coaching (11%), and employer's concerns about risks associated with hiring individuals with TBI (9%).

Top Three Barriers to Employment for Persons With TBI (n = 49)

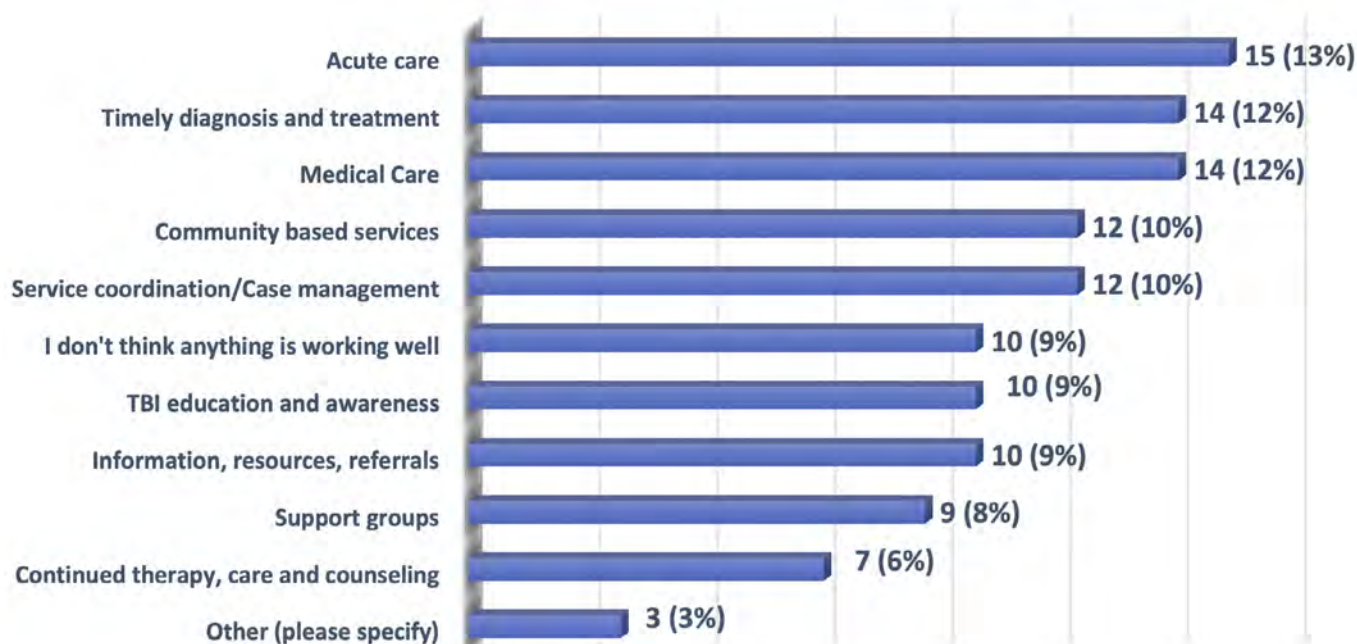


RESULTS FROM DATA COLLECTION

What is Working Well

The graph below details professionals' perceptions of what is working well for persons with TBI. The top three services and support mentioned were: acute care, timely diagnosis and treatment, and medical care. The bottom three were: information/resources/referrals (9%), support groups (8%), and continued therapy/care and counseling (6%). Notably, 9% of professionals indicated that they do not believe anything is working well.

Perceptions of What is Working Well for Persons With TBI (n = 49)

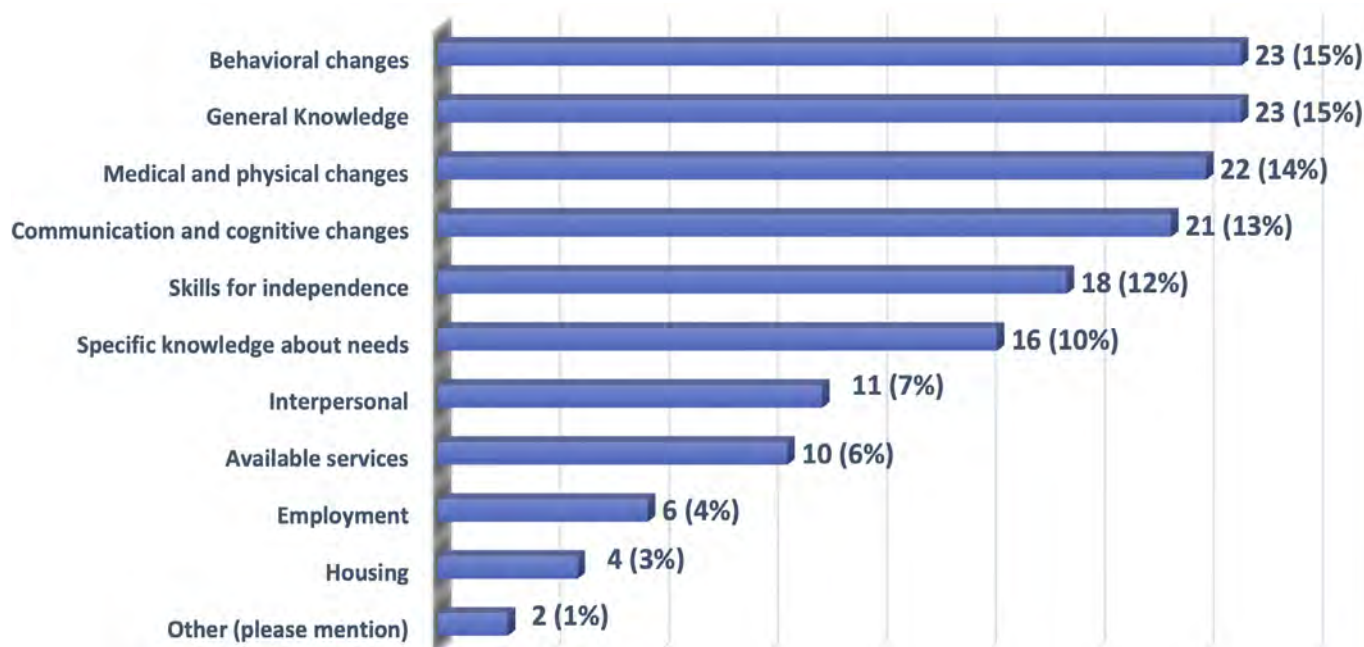


TBI Training

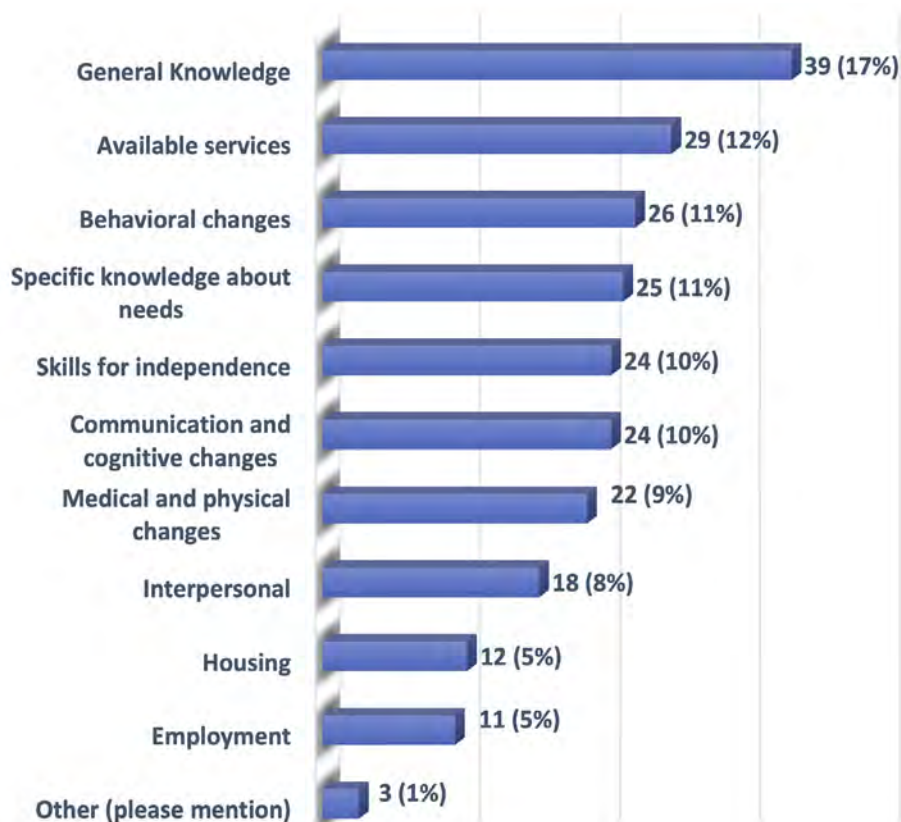
The following graphs detail information about the extent of TBI training professionals have received. In general, the majority of professionals had received some form of training around TBI (60%). Of those, the most common topic areas covered in training were: behavioral changes (15%), general knowledge (15%), and medical and physical changes (14%). Next, professionals were asked about the extent of TBI training received within their current organization. The most common topic areas covered in within-organization training were: general knowledge (17%), available services (12%), and behavioral changes (11%).

RESULTS FROM DATA COLLECTION

Extent of TBI Training (n = 49)



TBI Training Within Organization (n = 49)

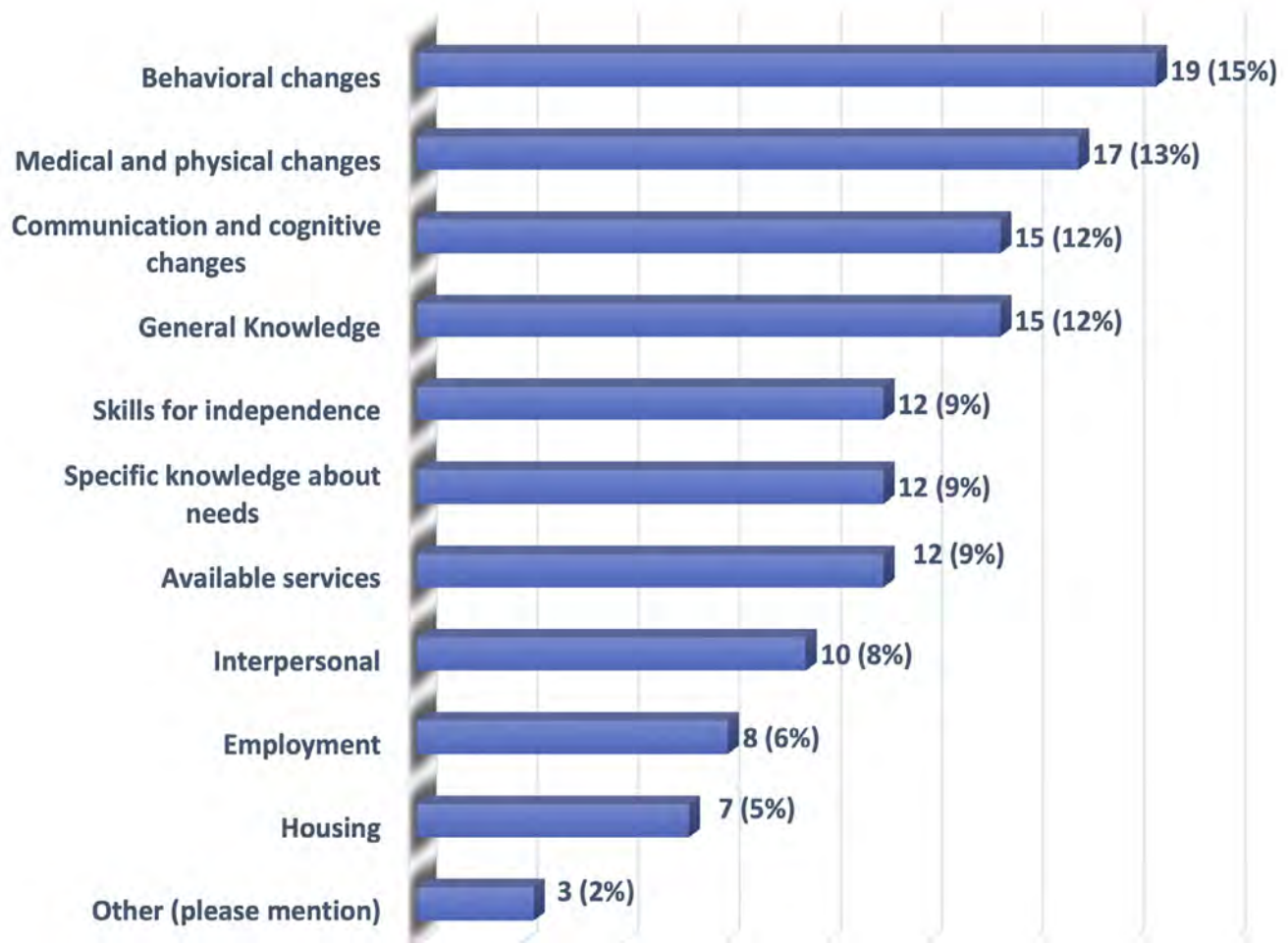


RESULTS FROM DATA COLLECTION

Additional TBI Training Outside the Organization

The following graphs provide information about additional TBI training for professionals. Sixty-five percent of survey respondents had sought out additional TBI training outside of their organization. Of those who sought out additional training, the most common topic areas covered were: behavioral changes (15%), medical and physical changes (13%), and communication and cognitive changes (12%).

Extent of External TBI Training (n = 46)

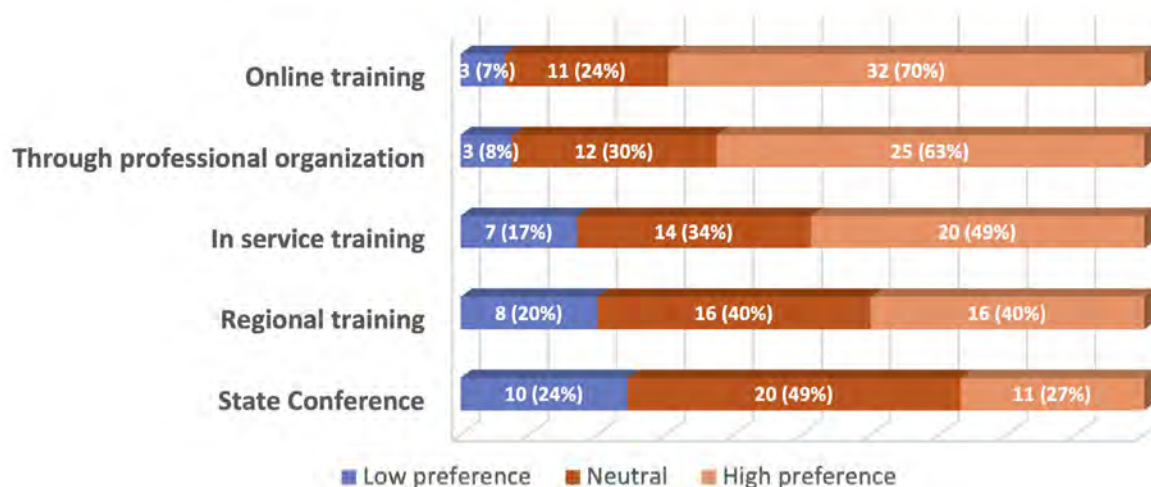


Preferred Method of Training

Survey respondents were also asked about the additional training they would like to receive, as well as their preferred modality. In terms of preferred training modalities, highest preference was given to either online training (70%) or through professional organization (63%). The least preferred modalities were state conference (24%) and regional training (20%).

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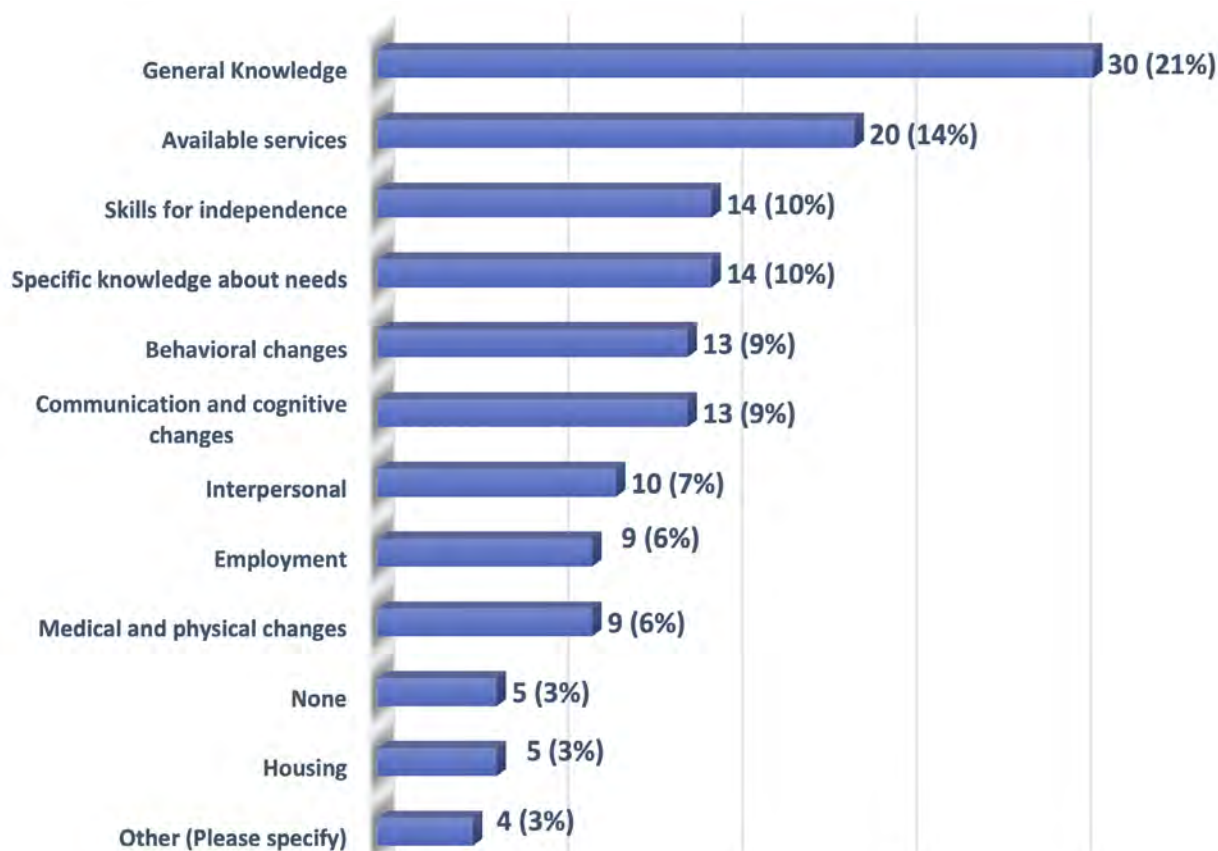
Preferred Method for Additional Training (n = 49)



TBI Training Provided to Community

The graph below details the extent of training provided to the community by professionals' organizations. The most common topic areas covered in community training were: general knowledge (21%), available services (14%), and skills for independence (10%).

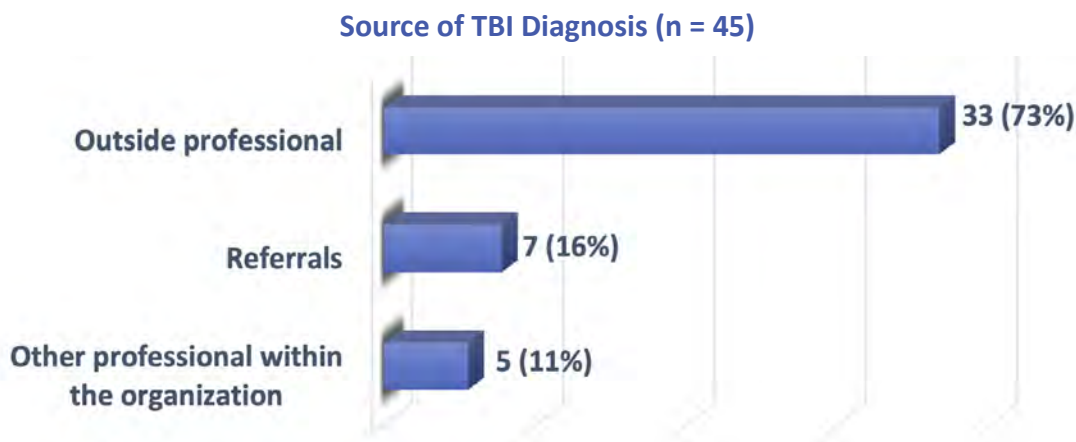
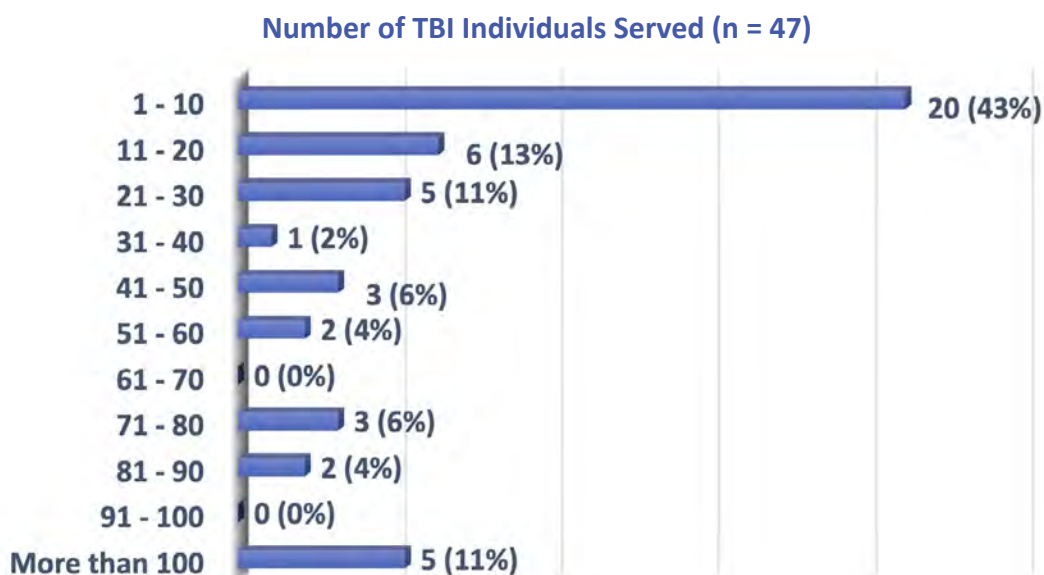
Extent of Training Provided to Community (n = 49)



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Client Information

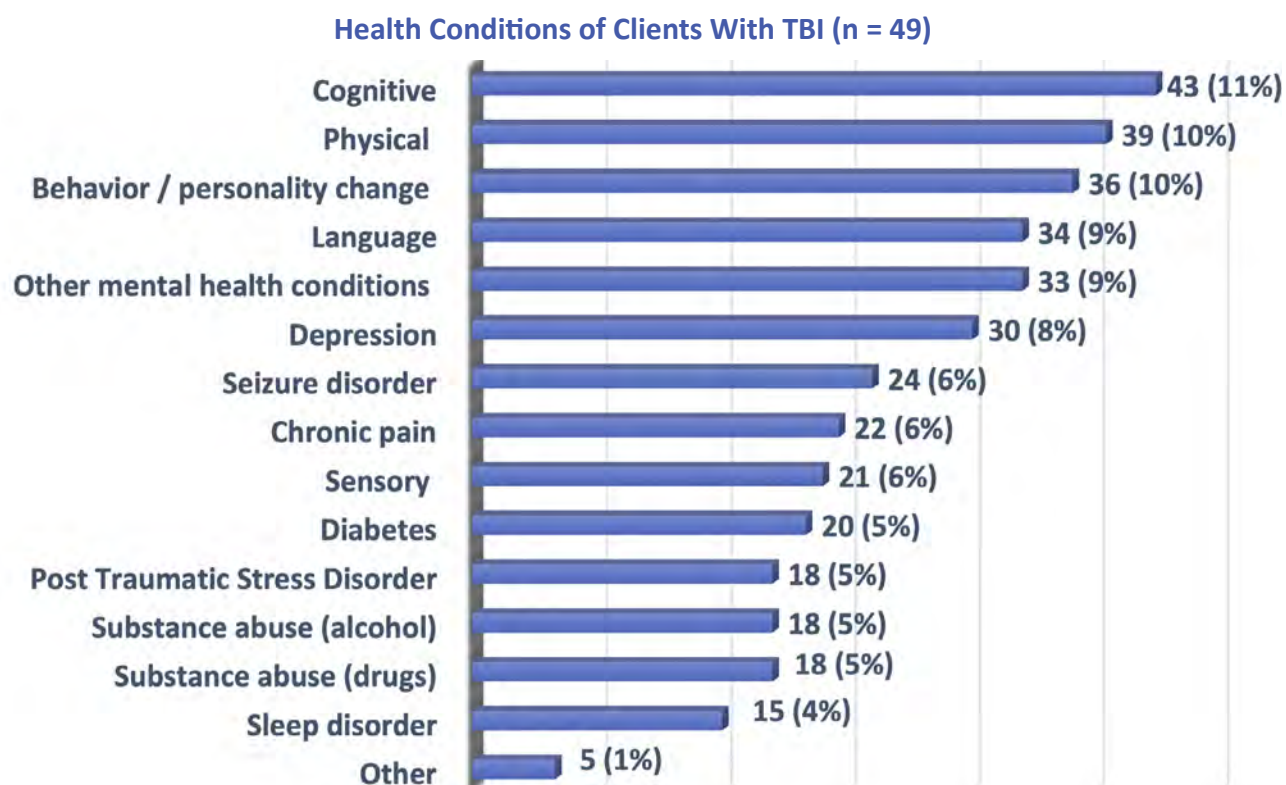
The following graphs provide information on the clients serviced by surveyed professionals. The majority of professionals worked with other clients in addition to working with people with TBI (86%), with the rest working only with people with TBI (14%). Most professionals had served or had contact with a range of 1 to 10 persons with TBI within the last five years (43%). The three most common number of clients with TBI beyond that were 11 to 20 (13%), more than 100 (11%), and 21 to 30 (11%). Professionals were also asked about the source of their clients TBI diagnosis. The majority of respondents noted that an outside professional had diagnosed the TBI (73%). None of the survey respondents had diagnosed the individual with TBI themselves.



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Health Conditions

The graph below provides information about the health conditions that surveyed professionals notice in their clients with TBI. The three most common conditions were: cognitive (11%), physical (10%), and behavior/personality change (10%). The least common conditions observed were: substance abuse of drugs and alcohol (both 5%) and sleep disorder (4%).



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QUALITATIVE DATA – KEY FINDINGS

Below are the key themes that emerged from qualitative data from focus groups, key informant interviews as well as open ended responses on surveys. The following key themes emerged from the qualitative data:

- » **Post-Acute Care for TBI;**
- » **Service Coordination and Resource Facilitation;**
- » **Financial Issues;**
- » **Training, Awareness and Advocacy;**
- » **Support for Caregivers;**
- » **Identification and Diagnosis.**

Post-Acute Care for TBI

Issues With Access to Home and Community-based Living Options

For a person with TBI to successfully live in the community, a range of community services and support are needed including community-based, in-home care, personal care/support, specialized counseling, and professional behavioral support, among other things. These services ensure that the person with TBI is appropriately supported to live in a home or community-based setting, which reduces the likelihood that they will be placed in congregate group settings that can be very costly for the state. In circumstances where an individual with TBI's behavior becomes too difficult to manage or too threatening to themselves or others, families need crisis management services. This would enable families to receive assistance from trained professionals to deescalate the situation or, if necessary, to provide a temporary, more secure environment until the risks associated with the person's behavior can be controlled. Unfortunately, one of the most glaring gaps in Georgia's TBI service delivery system documented in the qualitative data from the needs assessment is the lack of community support for people with TBI, especially people with neurobehavioral issues.

Respondents mentioned that there is a lack of understanding within hospitals in Georgia about the right for people with disabilities to continue living in communities, instead of institutional settings like, nursing homes. Hospitals prepare discharge papers ready to be sent out to nursing homes and provide no alternatives for the individuals and families affected by TBI. Nursing homes lack caregivers who are trained to work with individuals with TBI, and are unable to handle the behavior issues of these individuals. This lack of awareness leads to people with TBI sometimes being drugged unnecessarily and kept in nursing homes. The exit path for many TBI individuals is being admitted to a nursing home from the hospital, in spite of the fact that there are opportunities for them to continue living in their homes and communities. This needs assessment indicated that transition services for individuals with a severe to moderate TBI from outpatient living to community living and eventually employment, is a challenge for most individuals and families.

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Once an individual is stable and ready to be moved from an acute care setting or a nursing home, they could potentially have access to Medicaid funded waivers and other resources. Individuals and families need to know more about their rights and about these Medicaid funded waivers that could be used to deflect them away from nursing facilities and into community-based settings.

Preadmission Screening and Resident Review (PASRR) is a federal requirement to help ensure that individuals are not inappropriately placed in nursing homes for long term care. PASRR requires that Medicaid-certified nursing facilities:

- » Evaluate all applicants for serious mental illness (SMI) and/or intellectual disability (ID)
- » Offer all applicants the most appropriate setting for their needs (in the community, a nursing facility, or acute care settings)
- » Provide all applicants the services they need in those settings

PASRR is an important tool for states to use in rebalancing services away from institutions and towards supporting people in their homes. Per the Supreme Court decision, *Olmstead vs L.C.* (1999), under the Americans with Disabilities Act, individuals with disabilities cannot be required to be institutionalized to receive public benefits that could be furnished in community-based settings.⁷⁰ PASRR can also advance person-centered care planning by assuring that psychological, psychiatric, and functional needs are considered along with personal goals and preferences in planning long-term care. In short, the PASRR process requires that all applicants to Medicaid-certified nursing facilities be given a preliminary assessment to determine whether they might have SMI or ID. This is called a “Level I screen.” Those individuals who test positive at Level I are then evaluated in depth, called “Level II” PASRR. The results of this evaluation result in a determination of need, determination of appropriate setting, and a set of recommendations for services to inform the individual’s plan of care.

However, in Georgia hospitals, informants on the needs assessment indicated that the nurse case managers who do the discharge planning, have very little to no awareness or training on the PASRR tool requirements. They prepare discharge papers ready to be sent out to nursing homes and provide no information or alternatives to the individuals and families about their rights or the options available. Key informants highlighted the importance of educating the nurse case managers, medical social workers and others in hospitals about options for follow-up care including rehabilitative and long term-care, the various community living options in the state including the options that are available through waivers and other financial programs in Georgia. It is important to train the nurse case managers since they do the discharge planning at hospitals rather than the medical social workers.

When an individual has a brain injury before the age of 22 years and they meet certain functional criteria, then they may have access to Home and Community Based Waivers in Georgia. These waivers set an individual up differently compared to someone who has the brain injury after the age of 22 years of age since they would not have access to these HCBS waivers. Once an individual who is less than 22 years of age is stabilized and ready to be discharged from an acute

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care or rehabilitative care facility, they need to apply for Home and Community-based waivers through Medicaid. When young adults or families are not aware of these waivers, they get sent to a nursing home instead of a home or community-based setting. There is a lack of knowledge about and access to HCBS services, especially in rural areas of Georgia. Individuals, families and professionals need to know more about the Medicaid waivers so as to deflect individuals with TBI away from nursing facilities and into community-based settings.

Lifelong impact of a TBI for a child or youth under age 22 could include deficits to speech or language, mobility, learning, self-direction, capacity for independent decision making, and capacity for self-care. If a young adult has a traumatic brain injury before 22 years of age and has deficits in three of the six areas of functioning, that means the person has a developmental disability. This then provides the individual with access to Medicaid waivers (NOW, COMP waivers) for people with intellectual and developmental disabilities administered by the Department of Behavioral Health and Developmental Disabilities (DBHDD). When someone has a NOW/COMP waiver, they are also still covered under the federal Early and Periodic Screening Diagnosis and Treatment (EPSDT) benefits. The EPSDT does not supplant but supplements the benefits from Medicaid waivers. An individual can have NOW/COMP as well as EPSDT benefits simultaneously so that even if the state does not cover certain services, they should be able to get those services from the EPSDT federal waiver benefit. This is particularly helpful for children and youth with a lot of healthcare needs or an individual who has experienced a traumatic brain injury before the age of 22 years.

Children and Youth with TBI may also have access to another resource, the Katie Beckett Medicaid Program, often called the Deeming Waiver. This program provides Medicaid benefits to children under 18 years of age who qualify as disabled under §1614 of the Social Security Act and who live at home rather than in an institution. The Deeming Waiver focuses on the needs of the child, rather than family income/resources, so the child can remain at home with family & avoid institutionalization. The Deeming waiver only provides Medicaid and no other specialized services. However, a child or youth can have both the Deeming waiver as well as EPSDT federal benefit, at the same time making them eligible for more service. Prior to 18th birthday (about six months), the family should re-apply for SSI as the young adult is no longer ineligible due to family income.

If an individual experiences a TBI at age 23 years or later, they do not have the same access to the different HCBS waivers and they are set up differently compared to someone who has the brain injury before 22 years of age. Georgia offers several Home and Community-Based Services (HCBS) waivers, including the Community Care Services Program (CCSP), the New Options Waiver Program (NOWP), the Comprehensive Support Waiver Program (COMP) and the Independent Care Waiver Program (ICWP). Of these, ICWP is the only one designed to serve people with traumatic brain injuries. The others have limitations that prevent people with brain injuries from getting adequate and appropriate care.

The ICWP is available to people who experience a significant physical impairment or traumatic brain injury (TBI) that substantially limits one or more daily activities and requires the assistance of another individual. The person must be able to direct his/her own services, with the exception of people with a TBI (a person with a TBI can designate another individual to direct ICWP services). To be eligible, the individual must be Medicaid eligible or potentially Medicaid eligible; must

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be between 21 and 64 years of age at the time of application; must be at risk of nursing facility placement due to inadequate community services. The waiver can be used for individuals to enable them to move out of nursing homes or to avoid it completely. The waiver provides two levels of services. One is the nursing level of the facility that has an annual cap of \$62,000, which is not sufficient to enable most individuals to successfully live in the community with the appropriate services they need. If one factors in the cost of medical supplies, equipment, incontinence supplies or formula for G-tubes, then individuals are not left with much for personal attendant services. The other level of care within ICWP is hospital level of care, which has an annual cap of \$100,000. This is still not sufficient to enable many individuals to successfully live in the community with the appropriate services they need including trach or vent dependent support, medical services, equipment, recreation, personal care and support services among others.

Respondents indicated that here are various problems with Georgia's ICWP waiver that prevent people with TBI from receiving the care they need to live in the community. These include the way costs are calculated for the waiver, an annual cap that has been instituted, and low rates of reimbursement for critical services. These issues are discussed in detail in a White paper published by the Brain and Spinal Injury Trust Fund Commission in 2007.

Lack of sufficient coverage for services is an important reason why individuals with TBI in Georgia are not able to access adequate rehabilitative and community-based services. Medicaid and private insurance companies do not include adequate coverage for these services. With appropriate services and support, the majority of people with TBI will be able to live successfully in the community, which is why every effort should be made to provide sufficient funding, training, and other infrastructure necessary to provide the needed supports.

Key informants in this needs assessment expressed a desire to see the ICWP waiver expand its coverage of TBI services. The waiver needs to be expanded to cover more services for individuals with brain injuries including personal assistance services to enable them to live in community settings. The annual caps on this waiver should be increased or removed and rates of reimbursement for critical services need to be increased. Key informants also talked about the need for Georgia to apply for a TBI specific brain waiver, like in some other states, that provides funding for home and community-based services for children and adults who have an acquired or traumatic brain injury. As of 2018, 21 States administered brain injury HCBS waiver programs. A few States administered more than one brain injury waiver. Services offered generally include: adult day care, personal assistance, behavioral programming, case management, independent living skills training, cognitive rehabilitation, durable medical equipment, homemaker chore services, home accessibility modifications, therapies, respite, prevocational services, supported employment, and personal emergency response systems.

Access to Rehabilitation and Long-Term Care Services

For an individual with a traumatic brain injury (TBI), once the acute interventions have stabilized the condition of the person, the need for rehabilitation and follow-up services become paramount. This is necessary to optimize the person's day-to-day functioning, have an improved quality of life, and to increase their ability to live successfully in the community or in the least-restrictive setting possible. Appropriate services for individuals with brain injury may include

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cognitive and behavior therapy, as well as specialized counseling and psychotherapy; transition services, including organizing and/or arranging the home environment in such a way that functional skills are developed or facilitated; and pharmacological interventions.

Evidence indicates that rehabilitation is most effective if it is initiated early, soon after the injury. However, it is vital and can still be effective for people who may be identified with brain injury long after their injury occurred. While rehabilitation seems like a basic need, unfortunately, the qualitative needs assessment data suggests that many people with TBI are unable to receive sufficient rehabilitation because Medicaid and private insurance companies do not provide sufficient coverage for effective rehabilitation. This is often because brain injuries are “hidden” or “invisible” injuries, meaning there are no visible signs of injury. A person with a brain injury may look and appear to be perfectly fine, however the damage to their brain will become apparent in their speech, behaviors, emotions, thought processes, etc. Medicaid and private insurance companies generally do not provide sufficient funding for rehabilitation. In Georgia, it is important for the TBI advocates to educate Medicaid and private insurance companies about TBI and neurobehavioral issues in order to expand the types of covered services for care and rehabilitation of TBI.

Lack of access to Services and Trained Providers in Rural Areas

An important issue highlighted by respondents was the insufficient number of long-term rehabilitative support services in rural Georgia. Most services seem to be concentrated around metro or suburban areas with a dearth of acute rehabilitation and community-based services related to TBI in rural locations. Areas outside of metro Atlanta do not have adequate facilities or providers for services like medical care, rehabilitative care, mental health services, transportation, employment, internet and finances. There are fewer hospitals in rural Georgia. For most services, people in rural areas have to travel to Atlanta or Savannah or Columbus to get what they need. Many individuals with TBI are not able to drive and have to rely on others for their transportation needs. Individuals may or may not have access to reliable transportation options to get them to their appointments. Respondents highlighted the lack of education and training of physicians, nurses, and direct support professionals about the care of brain injured individuals, which in turn compromises the quality of services in rural areas of Georgia.

Lack of Specialized Support Like Neurobehavioral, Vision

Areas outside of metro Atlanta have a shortage of trained TBI professionals like neuropsychologists, cognitive therapists, neurobehavioral therapists, and vision therapists can assess or treat individuals with TBI. Key informants particularly emphasized the acute dearth of neurology professionals in Georgia (both in Atlanta and rural areas) and that there is not a good pipeline for them. Increasing the numbers of TBI facilities, TBI trained providers and services in rural Georgia is suggested. Respondents also talked about the lack of support for vision services. Vision therapists are expensive and often, individuals with TBI are forced to pay out of pocket because the specialized services for TBI are not covered by insurance.

Lack of Personal Support Providers

Some individuals with moderate to severe TBIs need personal support services including day to day personal care including toileting, bathing, and eating. Respondents talked about the lack

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of adequate direct support providers who are trained in caring for individuals with brain injuries, particularly those who also experience neurobehavioral issues. This was especially relevant for respondents in rural areas. There is a current crisis in Georgia related to lack of adequate personal care and support providers (direct support professionals). The workforce of direct support providers in Georgia has been on a decline, especially post pandemic and during the current workforce crisis. Another issue that affects service access for individuals with TBI is that most providers do not have staff that are trained to manage neurobehavioral issues, or funding is not available to cover the services. While there are many agencies that provide personal care support for individuals with cognitive disabilities, the majority of them do not have staff that are trained in neurobehavioral issues

Transportation

In the qualitative component of the needs assessment, transportation was one of the most significant challenges identified by individuals with TBI and their families in Georgia. Professionals identified lack of transportation as one of the top barriers that prevent individuals with TBI from working and accessing needed services. Specific issues associated with transportation include inadequate public transportation available in different geographical areas in the state (rural areas), challenges in accessing disability specific transportation and paratransit, the high costs of transportation, and barriers in accessing funds and waivers from agencies to finance the transportation needs.

Many individuals with TBI, particularly those who are unable to drive anymore due to their TBI or do not have a caregiver who can drive them around, depend on public transportation to go from one place to another. However, these services are sometimes not readily available, accessible, affordable, particularly for those residing in rural areas. Public transportation facilities like MARTA, bus services and other modes are mainly available in urban or suburban areas to the exclusion of rural areas. Even though Georgia has been doing well with services like dial-a-ride and ride shares in urban areas, rural areas are often neglected with minimal services. Respondents shared concerns related to the availability and timing of buses and taxis with them not being available on evenings or weekends. Respondents shared that most services like support groups and doctors' appointments with brain injury specialists are often far away in Metro areas or in the evenings. Taxis rides are expensive, they don't go far enough (sometimes not even outside their particular counties), and are not available in the evenings, which is when the support groups meet. Taxis also often arrive late or sometimes do not show up, causing huge delays for individuals. Medicaid and Medicare provide transportation services to individuals but are restricted to only for doctor's appointments. There are provider agencies that provide transportation, but are extremely expensive to use even with Medicaid.

Individuals with TBI talked about the drivers sometimes not understanding what they are saying due to aphasia. The pandemic has made accessing these services even more difficult for individuals and families. Caregivers shared that when the individual with TBI they care for, cannot find transportation to their appointments, they have to drop what they are doing to give the individual rides to their appointments. For individuals that can drive, respondents noted that the driving assessments conducted by occupational therapists are only available in a few places in Georgia.

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Making more transportation funding options available to individuals with a TBI in the form of waivers, vouchers or grants is needed. Medicaid or Medicare need to expand transportation support for individuals with TBI. It is important for advocates to work with local entities to increase and improve local transportation options for individuals with brain injuries, particularly in rural areas. For individuals and communities living far from rehabilitation services, organizations should consider providing transit services for the consumers. To help address this concern, the Brain and Spinal Cord Injury Trust Fund Commission has dedicated a large portion of their budget to meet the transportation needs of individuals with a TBI. Through the trust fund commission, individuals can apply for funds that would allow them to make modifications to their vehicles and meet their transportation needs.

Housing

Another challenge identified by individuals with a TBI and their families is access to affordable and accessible housing, especially in rural areas. Rents have increased considerably this year (2022) which puts additional financial strain on people. Even with Section 8 of housing assistance provided in the state of Georgia, finding affordable and accessible houses has been a challenge. There are very limited number of accessible apartments in Georgia. The newer apartment complexes are much costlier. One key informant shared that housing is one of the most requested services for the Georgia Aging and Disability Resource Connection (ADRC).

It was noted that there are some group homes available for people with brain injuries who live along with people with other kinds of disabilities. Some nursing homes allow individuals with a brain injury. In most of these congregate housing settings, the personal support providers do not have adequate training on how to work with individuals with TBI, particularly those who also experience behavioral issues. A big challenge related to assisting TBI individuals transfer out from nursing homes or other institutionalized care and back to their own homes is the access to licensed and available contractors to perform home modifications across all populations, particularly in rural areas. There are some programs that help with housing and home modification like building a ramp but most of these services are not targeted for adults with a TBI. It was highlighted that finding knowledgeable and competent contractors who know what they are doing with home modifications is a challenge. Despite State and federal housing subsidy programs, housing remains a major barrier to community-based care for individuals with TBI.

Advocacy for housing in Georgia is often focused more on individuals with intellectual disability or developmental disabilities and may not focus as much on individuals with brain injuries, since those are invisible disabilities. More advocacy for housing support for individuals with brain injuries is warranted. More options for subsidized housing and waivers available for individuals with a TBI apart from or in addition to section 8 are needed.

Employment

Another important challenge experienced by some individuals with TBI is related to finding community-based, competitive and meaningful employment. The invisible nature of TBI creates significant barriers to employment-related services and support. Because its effects are often psychological in nature rather than physical, caregivers, professionals and the general public lack

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awareness regarding the needs of persons living with TBI. Employers often lack awareness and understanding of brain injuries and the functional and work-related limitations that individuals experience. They are often not knowledgeable about, or unwilling to provide the accommodations and support needed for individuals with TBI to perform their work tasks successfully. Respondents mentioned that since each brain injury is very different and individuals have differing impacts from their injuries, it is a challenge to find or customize a job which is suitable to an individual's needs and expertise. It was noted that often, individuals who experience traumatic brain injuries have advanced educational degrees and were previously in high functioning careers and professions (like engineering) before the injury. However, post injury, they are sometimes assumed to have intellectual disabilities and are therefore provided with job options like sorting nuts and bolts which are not a match for their abilities, skills or interest, and may not be in their best interest.

The lead agency in Georgia that provides employment support for individuals with disabilities in Georgia is the Georgia Vocational Rehabilitation Agency (GVRA). The goal of GVRA is to help people with disabilities to become fully productive members of society by achieving independence and meaningful employment. Individuals who have developmental disabilities who are on Developmental Disabilities Waivers, are often able to get continued employment supports after Georgia Vocational Rehabilitation Agency (GVRA) services end because the payment for support shifts to their waiver. But individuals with TBI, are often on the Independent Care Waiver Program (ICWP) waiver, which does not offer employment support services. The ICWP waiver needs to be expanded to cover more services for individuals with brain injuries including long term employment support services to enable them to obtain and maintain meaningful employment.

Support Groups in Georgia

Support groups in Georgia have played a major role in acting as safe sharing spaces to connect with other individuals who have gone through the same situation. Support groups facilitate socialization and connection. They also serve as educational spaces that provide information about resources and services to individuals with TBI and caregivers. Respondents were generally satisfied with the presence and functionality of support groups and found them a very valuable resource. Many support groups had moved to virtual format during the pandemic. Those groups have increased access for individuals, especially those in rural areas or those who have transportation issues. So, the virtual format for the support groups needs to be retained.

Respondents shared that while there are some support groups available in larger urban areas like Atlanta, Savannah, Columbus, and Augusta, these services are unavailable in rural areas. There is a need for such supportive services in rural areas of Georgia. Respondents emphasized the need for targeted outreach to address barriers and encourage participation of people of color with TBI and caregivers in support groups. Most support groups cater to older individuals who have different needs (such as transitioning out of life) compared to the youth. Thus, focus groups targeted at youth survivors of TBI are needed.

Mild TBI or Concussions

A concussion is generally referred to as a mild traumatic brain injury or mTBI. In 2017, 2.5 million U.S. high school students reported experiencing at least one concussion.⁷¹ Not all concussion

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symptoms will be noticeable right after the injury, with some not appearing until days or weeks later. A year after injury, 53% of those experiencing a “mild TBI” report persistent symptoms and functional impairment. Early identification and follow-up with a TBI specialist, are associated with faster recovery and improved outcomes from concussion. Emergency room doctors or family physicians, who are usually their first point of contact, usually do not have enough knowledge or expertise to identify or diagnose traumatic brain injuries. As a result, a lot of TBIs in Georgia go undetected, due to their invisible nature. Individuals with mTBI therefore may not be connected to services that can assist them with the long-term symptoms that may arise months after the injury. More awareness and training on concussions for families, medical professionals and general public, is needed.

Issues Related to Children and Youth With TBI

Another important concern noted by respondents is the identification and diagnosis of TBI in children and youth. Key informants shared that families often do not understand the process of how to report their child’s TBI to the school, because of which children do not get special education services they need. Schools rely on parents to provide the medical diagnosis of TBI in order to obtain school supports under this category. Parents sometimes fail to notify the school system that their child has sustained a TBI because they do not understand the connection between the brain injury and the child’s performance level and academic support needs in school. Parents often fail to notify the school also because they are in denial about the extent of the child’s injury and potential impacts, or fear the stigma attached to special education services. This can be particularly true for individuals from racial, ethnic and other minority identities.

Parents who are interested in accessing special education services for their child sometimes experience difficulty in establishing eligibility. One way to establish eligibility is to provide medical documentation of the injury. If the injury has occurred when the child was very young, those hospital records may not be available anymore. A second option for families is to request a new neuropsychological evaluation. These services are not available in schools. The outside services are expensive and require medical insurance coverage or a referral by school in order to cover the costs. There is also a dearth of professionals that provide neuropsychological evaluations in Georgia, which presents a challenge. Due to all these issues around identification and diagnosis, many children with TBI, who display behavioral symptoms, are incorrectly diagnosed as having behavioral disorders, which leads to inappropriate placement and services that can exacerbate the student’s behavioral problems. Children may also experience other physical challenges like headaches, loss of hearing or vision due to their TBI. These challenges may have an impact on their functioning in the classroom and may need supports from the teacher.

Parents shared that teachers sometimes do not have adequate awareness and knowledge of brain injuries and their potential effects on children and are therefore ill-equipped to address the needs of students with TBI. In spite of the fact that, children are in one of the highest risk groups for TBI, majority of professionals in the school system receive no training in TBI. Parents were also concerned that there were not adequate services to support their children while they are at school. Given that children with TBI are likely to be misunderstood and at risk of misdiagnosis of

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TBI symptoms, it is clear that there is a need for attention on how educational, medical, and other pediatric professionals can best support children with TBI. Coordination between medical providers and schools is key to ensuring that children and adolescents with TBI receive educational and other supports to facilitate their learning. Both parents and the school system need to work together to ensure proper identification, diagnosis, placement and service provision for students with TBI. Parents can help by sharing medical information with school to ensure correct diagnosis and placement. Schools need to develop mechanisms for screening and identification of TBI and train their staff in identification, providing appropriate accommodations and tailoring the curriculum to address the learning needs of students with TBI.

Parents expressed a need for appropriate transition services, especially for children with TBI, who are entering and exiting the schooling system. Another theme that emerged from the data was parental concern about long-term care for their child with TBI. Many parents were very concerned about who would take care of and advocate for their children when they are not around to do so.

Many young children grow up with undiagnosed traumatic brain injuries. If a child or youth presents with challenging behaviors like aggression, they often get misdiagnosed as having psychiatric issues rather than brain injury. Key informants expressed an important concern related to children having traumatic brain injuries entering the foster care system. Many of the children enter foster care due to abuse, and therefore may have experienced head traumas or injuries. In one case, a key informant shared that a youth they were working with was in the foster system, was in jail and had various psychiatric labels due to behavioral issues. When the key informant dug into the medical history of the child, they found that the youth had hit their head on a ride in an amusement park when they were 8 years old. The child was mislabeled with psychiatric issues and was overly medicated with psychiatric drugs with no results, when in fact they needed neuropsychological evaluations for brain injuries. It is important that during the family assessment process, Georgia Division of Family and Children services personnel ask parents whether the child has ever had a fall or head injury.

Families having autistic children and youth need to be educated about what they should be looking for in terms of developmental milestones. The CDC has the Act Early program that has a developmental milestones booklet that parents can use. This could be a particularly helpful resource for parents of autistic children and youth who may have head banging or other self-injurious behaviors to monitor them for concussions or head injuries. Children with special healthcare needs are 9 times more likely to experience a TBI due to self-injurious behaviors, falls, etc.

Respondents highlighted the importance of sharing relevant information on concussions and other brain injuries with families of children and youth so that they can prevent, identify brain injuries and seek appropriate treatment as necessary. Babies Can't Wait and early intervention provide phenomenal opportunities to educate parents about brain injuries. Georgia has the Children's First that is mainly accessed by families having limited resources and lack of access to medical insurance or medical care. Information about brain injuries can be disseminated to families through Children's First, other children's hospitals and clinics in rural areas like Savannah Children's hospital, Grady hospital, and Putnam hospital.

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Issues Related to Culturally and Ethnically Diverse Populations

Individuals with TBI from cultural and ethnically diverse backgrounds seem to be less likely to receive proper diagnosis and identification and services. In general, a lack of awareness regarding available TBI services, a culture of mistrust toward medical professionals, fear of being misunderstood and a lack of culturally responsive services act as barriers for access to medical and rehabilitation care, especially for persons within Asian, Black, Native American, and Hispanic communities. Language barrier is another issue preventing access to services. When individuals with TBI or their caregivers cannot understand the language or communicate with providers, seeking services becomes difficult. Key informants highlighted the need for increased availability of Spanish-speaking TBI information and services. Respondents mentioned that individuals with undocumented status may be afraid to approach or interact with medical or government professionals. It is important to do targeted outreach to this population by building relationships with community brokers or leaders to increase access to medical and brain injury service access for these individuals. Some individuals and families may be hesitant to talk about their issues and seek support due to the stigma attached to disabilities within some cultures. Respondents shared that medical, rehabilitation and other support professionals need appropriate training to be able to provide culturally responsive services.

Service Coordination and Resource Facilitation

Individuals with TBI experience many challenges and barriers related to accessing the services and support they need to live in the community. One of the greatest needs that was identified by all key stakeholders in this needs assessment was the need for service coordination. Service coordination is absolutely critical to providing a seamless system of care. Respondents shared that currently, Georgia's system of services is fragmented. There is lack of information on available services; lack of coordinated services; no single point-of-entry to access services; eligibility criteria are confusing; there is a lack of a standardized application process. There are gaps in communication between agencies, application processes are redundant, eligibility criteria are complex and confusing, and there are often waiting lists, making it very difficult for people to get even the most basic services. Respondents in this needs assessment all emphasized the difficulty in locating and accessing the rehabilitation, services, and goods necessary to gain or return to a better quality of life following a traumatic injury in Georgia.

Not only is the service system complex, but the most common symptoms of brain injury (memory impairment executive functioning, the skills that allow us to organize and initiate actions) mean that individuals with brain injuries are likely to find actually accessing the system more difficult. For an individual with a brain injury, a once simple task might take two to three times as long to accomplish and the individual might need cues and reminders throughout the process to finish it. Brain injury survivors therefore have difficulty navigating systems of support due to the nature of the way their brain processes information post-injury.

Families are overwhelmed by their grief, loss of income or financial security, lack of knowledge of the needs of their loved one, and lack of familiarity with the services and funding available to

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address those needs. The world as they know it has changed dramatically overnight. Survivors and their families in Georgia therefore need help with their support needs. Those seeking services need to know where to go for assistance. In the current Georgia service system, individuals with a brain injury often leave the emergency room or acute rehabilitation with a prescription for the physical pain but not a prescription outlining next steps for their brain injury. Some never get connected with the necessary support as individuals get confused moving from one system of care to another.

The extent to which an individual with TBI is able to access services depends largely upon the severity of the injury and where the person receives initial treatment for the injury. Often people who sustain a concussion or other mild TBI will either seek treatment from their family physician or not at all, and as a result they may not be connected with services that can assist them with the long-term symptoms that may arise months after the injury. Even when a person sustains a severe brain injury he or she may not necessarily be connected with the appropriate and most effective rehabilitation and long-term support services because of the lack of service coordination and specialized training on brain injury. Respondents emphasized the need to move away from a medical model of service provision for TBI to a public health model where TBI is treated as a chronic illness due to an injury, rather than a once and done treatment model and then letting the individual or family figure things out on their own.

Key informants shared that individuals with TBI and families need services and support in the community, that respect and encourage their autonomy but with proper safeguards, as laid by the home and community-based services final rule. Currently, there are multiple points of entry for brain injury services, and depending which is used, a person may or may not find the services and support they need. While emergency rooms tend to provide resources for short-term treatment, individuals may forget to follow up and reach out to other doctors due to newly developed memory issues. Proactive outreach to survivors of brain injuries post-discharge would help better support individuals with a brain injury. Keeping a personal profile for each person with a brain injury will be a useful tool for caregivers to regularly update and keep track of the history of the survivor in case of any change in the caregiver. Many agencies and entities that provide services and support to individuals with TBI follow up with the individual only for a short span of time lasting ninety days to six months. However, individuals with a TBI have an ongoing need for support. There is a need for care coordination through a resource facilitation program. Some participants suggested the need for a one stop shop - a place that will have the answers to their questions and the information about options for individuals with TBI and their families.

Establishment of a Resource Facilitation Program

Georgia's service coordination gap has been well documented by the Brain and Spinal Injury Trust Fund Commission (BSITFC) for 15 years as outlined in a White paper developed in 2007. To address the lack of centralized information about resources in Georgia, establishment of a statewide resource facilitation (RF) program is important. The program would have dedicated resource facilitators, who would be specifically trained to serve individuals with brain injury and their family members across cultures and age ranges, who will assist them in navigating resources, services, supports, and benefits and maintain regular contact. This can be provided by dedicated

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full time or part-time employee(s) and/or case managers at the Brain Injury Association of Georgia. This will help address Georgia's gaps in service provision stemming from lack of awareness and underutilization of services by persons with TBI and their family members, particularly those from underrepresented backgrounds. The pilot program on resource facilitation, funded by Administration on Community Living (ACL), currently being implemented by BISTFC and BIAG is a great first step in this direction. The program eventually needs to be scaled and expanded across the state, particularly in rural areas of Georgia.

As discussed earlier in the Resource Facilitation sub-section of the environmental scan of this report, RF has been shown to be effective in improving community participation after TBI, including return to work. The relatively modest costs of its implementation are expected to be offset by long-term savings to the state through greater employability and decreased reliance on public assistance programs after TBI. In a couple of randomized control studies conducted to date, participants who receive resource facilitation were found to return to competitive work, school or volunteering significantly more than those who did not receive the services. Participants receiving services were also found to have a significant advantage in terms of resuming community-based productive roles and activities relative to control participants.⁷²

Increased Coordination and Collaboration Across Georgia's Service Systems

There is a need for continuation of, and concerted new efforts toward, development of new policies that support a coordinated system of care facilitated jointly by key agencies working with individuals with Brain injuries in Georgia. It is possible that the Brain & Spinal Injury Trust Fund Commission (BSITFC), which is the Lead Agency on Traumatic Brain & Spinal Injuries for the state of Georgia could take the lead in this effort. The Commission's Advisory Committee is already made up of representatives from key state agencies, people with TBI and their caregivers, service providers, advocates, and other stakeholders. Thus, many of the partners needed to be involved in creating a coordinated system are already present at the Commission's table. In its role as Lead Agency, the Commission could oversee the development of such a system, working with the community of stakeholders to develop appropriate services and funding. Respondents noted that agencies like the Brain Injury Association of Georgia (BIAG), Georgia Advocacy Office (GAO), Georgia Vocational Rehabilitation Agency, and others could be important collaborators in this effort. There is a need for increased communication and collaboration between Georgia's service systems and agencies to improve coordination, including between medical community, social services, and schools. This coordination should support individuals transitioning between systems, especially children as they age out of the education and juvenile social service programs.

Financial Issues

Individuals with TBI and their caregivers encounter issues related to healthcare coverage and the financial costs resulting from the injury, treatment and resulting lifestyle changes. Respondents expressed concerns related to the fact that health insurance in the United States is tied to employment. When someone experiences a traumatic brain injury and the person loses their job, and/or their spouse loses their job due to the caregiving responsibilities, the family loses their health insurance benefits. Respondents shared that the process of applying for SSDI, SSI or

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one of the waiver programs is a struggle emotionally and financially. Respondents highlighted a gap in awareness regarding health insurance coverage, particularly rehabilitative care. Increased awareness of cost-effective care and relevant cost-saving measures would allow increased access to medical care for a wider segment of the population living with TBI.

Another financial issue that was commonly mentioned was the sheer cost of TBI-related services. A vast majority of respondents shared the same concern that their health insurance (whether Medicare, Medicaid, or private insurance) does not cover all costs of TBI services and needs. Individuals shared that the health insurance only covers a set number of therapy visits per year and often they do not have the extra money to increase the number of days of occupational therapy. Individuals are left to pick and choose between necessary services. Respondents shared that health insurance doesn't adequately cover long term support services.

There is a need to ensure that insurance payments for post-acute and long term-care for TBI along with rehabilitation align better with best care practices. The current payment guidelines are restrictive, inadequate and poorly timed. Medicare needs to cover longer stays for inpatient rehabilitation and more resources to find doctors that specialize in TBIs. More providers who accept Medicaid for physiotherapy and neurology are needed. Educating Medicaid and private insurance companies about TBI and neurobehavioral issues is needed to expand the types of covered services for care and rehabilitation of TBI. Beyond just medical costs, individuals with TBI commonly talked about the long-term financial toll that the medical and rehabilitative costs have on the family's finances. Respondents shared about the difficulty in meeting general financial demands such as bills and other TBI-related services such as home and vehicle modifications. Provision of low-cost services and information about financial assistance options available to individuals with a TBI is needed.

Respondents shared that currently, funding is needed so that individuals with TBI in Georgia can have a safe and healthy life in the community with positive outcomes around health, community engagement and employment. Key informants in Georgia talked about the need for expansion of Medicare, Medicaid, and the Independent Care Waiver Program (ICWP). While these programs do provide some assistance to the costs accrued by persons with TBI, it is not enough funding for the person to have access to the type of support they would need, to not only live in the community, but most importantly, have access to a personal attendant to assist them. Establishing a sustainable and equitable funding mechanism to support individuals with TBI is needed. Key informants expressed a desire to see the ICWP specifically expand its coverage of TBI services. They talked about the need for Georgia to apply for a TBI specific brain waiver, like in some other states, which would cover services like adult day care, personal assistance, behavioral programming, case management, cognitive rehabilitation, durable medical equipment, homemaker chore services, home accessibility modifications, therapies, respite, prevocational services, supported employment, and personal emergency response systems.

Respondents shared that the Brain and Spinal Injury Trust Fund Commission is a great resource. BSITFC grant funding awards grants to individuals with TBI. The funding is capped per person at \$10,000. These funds are available for a variety of goods and services over any length of time until the balance is obligated or spent. Respondents noted the lack of advocacy resources

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for brain injuries at the state-level in Georgia. Respondents discussed a need for a state agency in Georgia that can specifically advocate for individuals with brain injuries.

Training, Awareness, and Advocacy

Professionals' Knowledge of TBI

Respondents indicated a divide between professional's knowledge and patient experiences. Doctor's familiarity with TBI (symptomatology, presentation, comorbidity) varies a great deal between settings. Emergency room doctors, who are usually the first point of contact for many individuals with TBI, do not have enough knowledge or expertise in TBI to identify or diagnose traumatic brain injuries. As a results, many individuals with TBI either remain undiagnosed or are misdiagnosed due to their invisible nature. Key informants shared that the actual number of individuals in Georgia living with brain injuries may be much higher than what is reported on official statistics. Emergency room doctors and family physicians, who are usually their first point of contact, need more training on how to identify or diagnose traumatic brain injuries including concussions. These training should help medical practitioners to think and reflect on issues around disability and what it means. It is suggested that medical practitioners understand patients from a holistic humanistic view instead of just a body that needs to be treated.

Medical providers are often not aware of resources available for individuals with TBI, and are thus unable to direct patients to the resources that might help them. Key informants shared that TBI survivors are sometimes unable to access the necessary resources (therapy, medication) not due to lack of existing services, but due to lack of understanding, information or referrals from professionals. It is important to educate medical professionals about the resources available for individuals with a TBI and their families.

TBI survivors shared that they felt unheard, misunderstood and invalidated when communicating their needs to medical professionals. They often expressed discomfort in speaking with medical professionals. Doctors sometimes lack sufficient knowledge of TBI and therefore either identify the cause of symptoms to be psychosomatic or psychiatric. Doctors sometimes have a presumption that all individuals with TBI have intellectual disabilities. Chronic dismissal of their symptoms or concerns from doctors led to mistrust of medical professionals, and resulted in individuals with TBI remaining untreated. Key informants shared that while some doctors may be knowledgeable about the medical impact of TBI on individuals, they often do not have an adequate understanding of the psychological, behavioral, social or functional impacts of brain injuries. Key informants shared the importance of using technological advances like Power of Patients (PofP), which is a patient-centric app that records patient symptoms and triggers and provides patients, caregivers and clinicians, health management support. Through individualized symptom and triggers tracking, PofP tool can be used by individuals, caregivers and medical and rehabilitative professionals to personalize care for individuals with TBI to expedite their recovery. Aggregated, de-identified data and reports of patients can be shared with professionals, used for advocacy and fundraising, and be used to provide guidance and referral for services for TBI patients in Georgia. (Please see Appendix).

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Lack of Information and Awareness – Individuals With TBI

Individuals with TBI and their caregivers identified the lack of information about resources to be a huge gap in Georgia. TBI survivors and caregivers expressed a need for information about rehabilitation options and long term supports such as insurance coverage, Medicaid waivers, therapy, mental health supports, and support groups. Respondents shared that even when the resources are available, they are sometimes unable to access them because of lack of adequate knowledge and information.

Respondents shared that individuals who end up in trauma centers, like Shepherd Center for example, are much more likely to receive rehabilitation care and get connected to long-term resources like therapies. Brain Injury Association of Georgia (BIAG) was also mentioned as an important source for information and referrals. Individuals who do not end up in a trauma center or get connected to BIAG including those living in rural areas or smaller towns are left disconnected with adequate information about resources.

Key informants emphasized the need for nurse case managers to be trained about the PASRR tool requirements since they do the discharge planning at hospitals. This would help ensure that upon exiting from acute care, individuals with TBI are deflected away from nursing homes and are given options to live in community settings with opportunities for a person-centered care planning. Nurse case managers need to share information and connect TBI survivors and families to long-term care when they patients exiting acute care. Individuals and families highlighted the need for sharing information with families about their rights and about the Home and Community Based Waivers so as to deflect people with TBI away from nursing facilities and into community-based settings. This would be particularly helpful for children and youth with a lot of healthcare needs or an individual who has experienced a traumatic brain injury before the age of 22 years. Also, sharing information about transition in care options for individuals after they turn 21 years of age would be beneficial.

Public Awareness of TBI

An important reason why the general public and professionals lack awareness of brain injuries is because of the “hidden” or “invisible” nature of brain injuries, as there are no visible signs of injury. A person with a brain injury may look and appear to be perfectly fine, however the damage to their brain will become apparent in their speech, behaviors, emotions, thought processes, etc. Because its effects are often psychological in nature rather than physical, caregivers, professionals and the general public lack awareness regarding the needs of persons living with TBI. Due to the invisible nature of brain injuries, they are not given priority nationally and at the state level, compared to other disabilities.

The invisible nature of TBI creates significant barriers to services and support for individuals with TBI and their caregivers, particularly as it relates to therapy and employment. Employers often lack awareness and understanding of brain injuries and the functional and work-related limitations that individuals experience. They are often not knowledgeable about, or unwilling to provide the accommodations and support needed by individuals with TBI to perform their work

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tasks successfully. Sharing information about brain injuries and the functional and work-related limitations that individuals experience with employers would be helpful. Educating employers on the potential benefits of hiring individuals with disabilities including brain injuries and how to make appropriate accommodations is needed.

Respondents emphasized the need for increased awareness, education and advocacy related to traumatic brain injuries and their impact. Many individuals in Georgia are living with a TBI without knowing about it due to lack of knowledge about identification and treatment options. General information on how to recognize the signs of TBI may be helpful to the general public. Professionals and the public alike would benefit from enhanced knowledge regarding who may be impacted by TBI, how TBI impacts lives, and what resources are needed to promote increased quality of life for those living with TBI. Increased awareness and education among the general public is suggested so that communities can support each other better to live in the community and advocate for equitable long-term support.

More awareness and training on concussions or mild TBI (mTBI) for families, medical professionals, and the general public is needed. Respondents highlighted the importance of sharing relevant information on concussions and other brain injuries with families of children and youth so that they can prevent, identify, and seek appropriate treatment as necessary. Babies Can't Wait (early intervention) and Georgia Children's First provide phenomenal opportunities to educate parents about brain injuries. Information about brain injuries can be disseminated to families through children's hospitals and clinics in rural areas like Savannah Children's hospital, Grady hospital, Putnam hospital.

Respondents emphasized the need to increase public awareness of TBI via increased advocacy efforts at the local, state, and federal levels. More advocacy for individuals with TBI, especially those from vulnerable populations like children, veterans, those from underrepresented racial and ethnic groups and incarcerated individuals is recommended. Increased public awareness and advocacy of TBI would increase the probability of the needs of individuals with TBI to be met. There is a need for increased funding for marketing and promotion for advocacy agencies so that they can increase public awareness about TBI.

Support for Caregivers

Moderate to severe brain injuries often affect an individuals' functional or cognitive abilities, so it becomes the responsibility of the family members to provide day-to-day support as the person recovers. Families can be overwhelmed and struggle with adjusting to the new changes. The world they knew changed overnight. They may experience grief, loss of old person they knew, loss of income or financial security from the person with TBI, loss of their own income due to having to take care of the loved one, lack of knowledge of the needs of their loved one, and lack of familiarity with the services and funding needed for services. Individuals with a brain injury often leave the emergency room or acute rehabilitation with a prescription for the physical pain, but not a prescription outlining next steps for their brain injury. Caregivers are left on their own to do the

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research and find support and resources at a time when they are overwhelmed and least equipped to do so. Some never get connected to the necessary long term supports as they get confused, moving from one system of care to another. Caregivers need more support in finding the information and resources they need to support their family member with TBI.

Because the caregiving role takes priority over other matters, caregivers endorsed that other domains in their life often get affected and take a backseat including their work, finances, emotional health, and personal fulfillment. Caregivers need physical as well as emotional and mental health support to help them avoid the potential social isolation that caregiving can create. Respondents mentioned respite care for caregivers being a very important need so as to give them breaks to focus on self-care. Caregivers endorsed the potential positive impact of respite care in being able to provide more competent care for persons with TBI. Caregivers mentioned entities like the Brain Injury Association of Georgia (BIAG) as well as the Shepherd Center as being important resources for caregiver support groups. Many of the face-to-face support groups are limited to metro or urban areas. Caregivers shared that having more virtual support groups for them at convenient times would help a lot of the emotional, social and mental health support that they need.

Issues related to balancing their work along with caregiving responsibilities was endorsed as a significant concern by many caregivers. Virtual work is a benefit to those who can, but those without this accommodation have limited options for engaging in both caregiving and professional work. A key informant shared about how a caregiver (that they work with) is trying to get back to a job but feels pulled between trying to help the individual with TBI and trying to devote her time towards her job, leading to guilt feelings. Caregivers reported the necessity of flexible work arrangements in order to meet the demands of caregiving. Sometimes, spouses or parents may have their own health issues that present special challenges in taking care of individuals with TBI. One caregiver shared that the rehabilitation center expected them to use a gait belt for their spouse which was difficult for them because they had balance and coordination issues themselves.

Caregivers acknowledged the challenges of adjustment to the role of caregiving for a person with TBI. Caregivers spoke about the personality changes in their spouses after the brain injury and the use of mood-altering medicines. Respondents endorsed difficulty coming to terms with the resultant personality changes of those in their care. It is often difficult for them as a caregiver, and also as a spouse, to understand the complexity of a brain injury. Respondents shared that often, the needs of caregivers get ignored in favor of those of individuals with TBI.

Caregivers talked about the impact of their family member's TBI on their own emotional wellbeing as well as their marital relationship. Experiencing a TBI comes with changes to the expectations initially set within a relationship. Both caregivers and persons with TBI endorsed challenges with setting reasonable expectations for life management as the person with TBI gradually gains autonomy post-TBI. Respondents indicated that expectation management negotiation can negatively impact persons with TBI as well as caregivers. Respondents shared how some issues they already had in their marital relationship got magnified because of the traumatic brain injury of one partner. Marital counseling or couples' therapy was identified as an important

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need for families. While respondents acknowledged that individual as well as marital counseling may serve to address some of their concerns, they found that mental health providers lacked expertise in TBI-related topics.

Identification and Diagnosis

Proper screening is a crucial step for individuals with a TBI to identify and treat any neurobehavioral issues as soon as possible. This step helps prevent neurobehavioral issues that may occur due to misdiagnosis or lack of appropriate medical service at that point of time. It also helps a person with a TBI learn about any risks associated with experiencing neurobehavioral issues later. Screening can be a great tool in cases where a person has forgotten about a sustained TBI in the past or may believe that they do not have residual effects from a TBI. The next step after screening for possible neurobehavioral issues is to get a formal identification and confirmation of behavioral issues through a neuropsychological evaluation. The evaluation consists of standardized testing that evaluate the different functions of the brain like attention, motor performance, perceptual coding, learning, memory among others.

Many respondents communicated about the lack of neuropsychologists and neurobehavioral therapists in Georgia and lack of a pipeline for new professionals to stay in Georgia. They're especially harder to locate in smaller, more rural communities. During one of the key informant interviews, the interviewee shared how they had a very difficult time getting a neuropsychology exam for their loved one. Insurances sometimes do not cover the costs so families end up paying for it themselves. They mentioned using the brain injury screening questionnaire from Mayo Clinic Portland to get a neuropsychology exam for their loved one who had sustained a TBI. The exam enabled them and their loved one to learn about the global impact of the TBI on the brain and its function. The exam gives a full comprehensive view which helps in deciding the next steps and therapies needed for rehabilitation. Doctors often do not recommend a neuropsychology exam unless an individual has a family or a good case management support.

The state of Georgia does not have a systematic way of screening and identifying people with neurobehavioral issues. These screening efforts currently reside with providers with specialization in TBI services like the rehabilitation hospitals, Side by Side Brain Injury Clubhouse, Restore Neurobehavioral Center, etc. However, the assumption is that the person with TBI has already been identified and referred by medical experts. Screening efforts in Georgia have been fragmented or nonexistent among providers working with diverse medical conditions, including TBI.

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What is Working Well

Outlined below are some things that respondents identified as working well for Georgia.

Acute Care

- » The majority of respondents reported being satisfied with the acute care services available for TBI in the state of Georgia. One person said, *“Georgia is lucky to have trauma centers and super specialized centers which are great.”* Individuals also stated that the reporting and triage system for seniors to trauma centers who sustain head injury is working well in Georgia.

Services in Urban Metro Area

- » Those located in urban and suburban areas (around Metro Atlanta) highlighted being satisfied with the availability and accessibility of services, information, and resources for persons with TBI and their families and caregivers. As one individual shared, *“If you have good insurance and you are in an urban area, you have access to more resources and get the best possible care.”* In particular, youth services in the Atlanta area for children and youths with TBI were endorsed by respondents as being satisfactory.

Children and Youth Services

- » Many highlighted that they were satisfied with the availability of services for children and youth with TBIs in the state of Georgia. Services highlighted include programs at facilities such as the Shepherd Center, and transition and care services provided by Children’s Healthcare of Atlanta (CHOA). As one person shared, *“... they are much better organized and equipped to provide very good services to children and youth with TBI as well as their families.”* Respondents shared that CHOA is able to see children for inpatient rehabilitation regardless of their ability to pay. Acute care services are also good in Atlanta. Key informants shared that children and youth committees are doing work in providing education about concussions and concussion management to youth, parents and families.

Support Groups

- » Respondents were generally satisfied with the presence and functionality of support groups, both for individuals with TBI and for families and caregivers. They found the groups to be a valuable resource. Many support groups had moved to virtual format during the pandemic. Those groups have increased access for individuals, especially those in rural areas or those who have transportation issues.

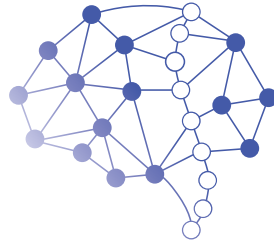
Non-profit and Private Agencies

- » Individuals with TBI and their caregivers were generally pleased with the private and nonprofit services within Georgia. Some of the organizations highlighted include Brain Injury Association of Georgia, Brain Injury Trust Fund Commission, the Shepherd Center, Side by Side Clubhouse among others.
- » **Brain Injury Association of Georgia:** One organization that was most commonly mentioned and praised by respondents was the Brain Injury Association of Georgia (BIAG). Beyond

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providing information and resources to families and people with brain injuries, people shared they loved their support groups and summer camp. As one respondent shared, *“BIAG is a great support group and platform for me. I wish the state of Georgia offered more for people with disabilities.”* Another respondent touted Camp BIAG as follows. *“Camp BIAG was an amazing resource for individuals to have some time away from their caregivers and feel some independence. We desperately want that in person camp option to return.”*

- » **Brain and Spinal Injury Trust Fund Commission:** Another commonly referenced organization was the Brain and Spinal Injury Trust Fund Commission (BSITFC). People were primarily pleased with the financial assistance they had been able to receive through the trust fund, as well as advocacy and information sharing services. *“Brain and Spinal Injury Trust Fund helped us get personal training for our son, and that made a world of difference in his recovery! It also is a good feeling to know that fines from drunk and reckless driving goes to this good cause.”* Another respondent shared, *“BSITFC provides funds for families that can be used for therapy or equipment or transportation.”*
- » **Shepherd Center:** The Shepherd Center was mentioned frequently, specifically their transition support program and the Shepherd Share program. While a variety of endorsements were given for their programs and services, some of the most commonly mentioned ones included case management, rehabilitation services, family-centered care management, and the recreational programs offered. One respondent shared, *“They really care about not only the patient, but the family.”*
- » **Side by Side Clubhouse:** Another organization that was highly appreciated by individuals with TBI and families was Side by Side and the clubhouse model that is available in areas across Georgia. Many people mentioned enjoying the opportunity to socialize, be actively engaged and learn new skills, as well as serving as a mechanism for giving respite to caregivers. As this person stated, *“...we have 15 clubhouses around the state of Georgia- it provides a place for people to learn new skills.”* *“If you live in an area which has groups like parent support network, survivor support network and you have access to such groups is essential for mental health like Side by Side clubhouse.”*



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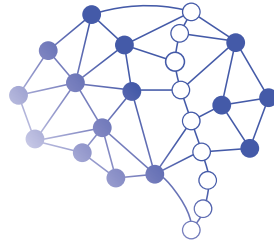
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APPENDICES

Figure 1.
Total Population by County



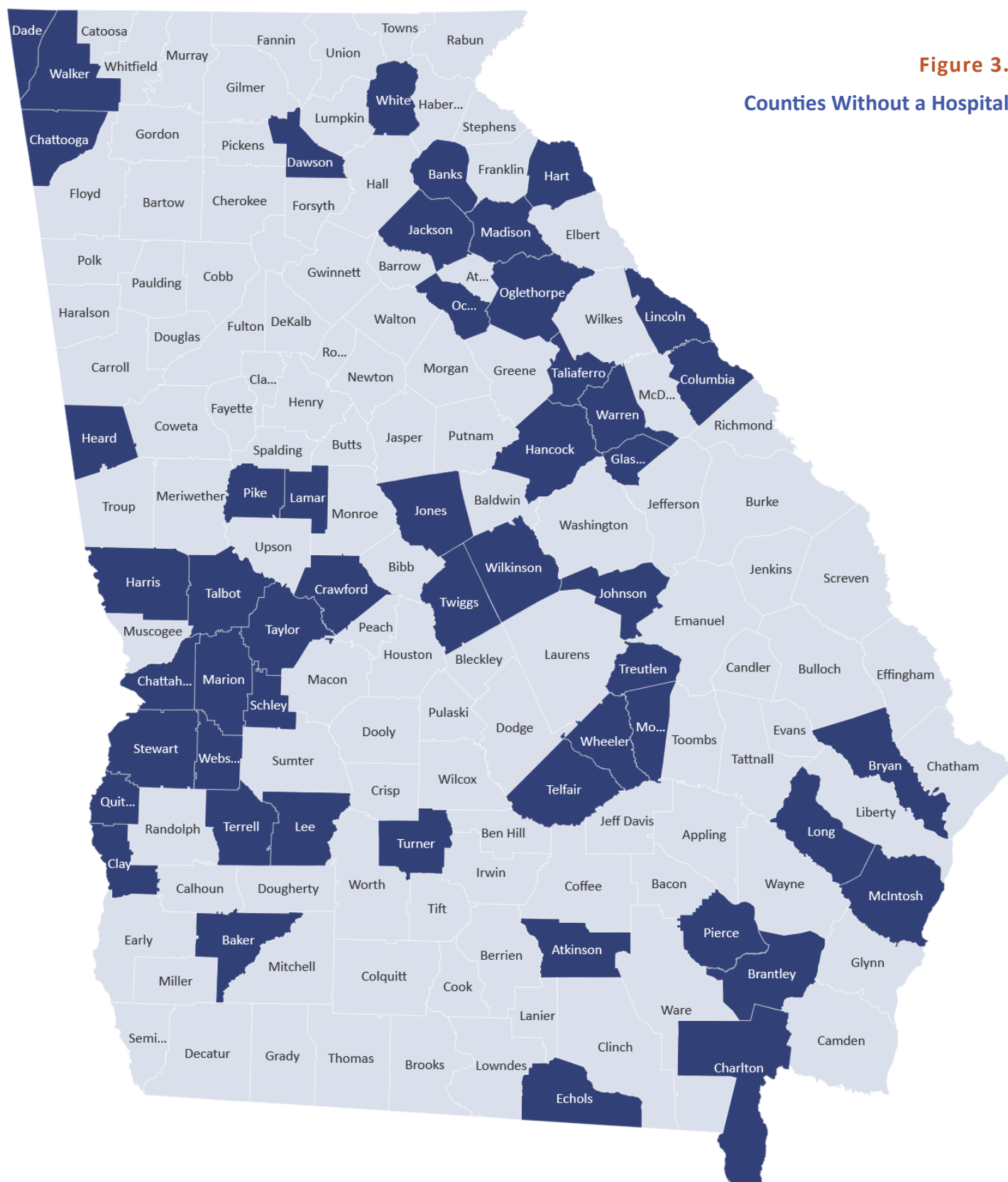
Figure 2.

Number of Hospitals by County

County	Hospitals
Dade	0
Catoosa	1
Fannin	1
Union	2
Towns	2
Rabun	2
Walker	0
Whitfield	1
Murray	1
Gilmer	1
Lumpkin	2
White	0
Habersham	1
Stephens	1
Franklin	1
Hart	0
Chattooga	0
Gordon	1
Pickens	1
Dawson	0
Forsyth	1
Hall	2
Banks	0
Jackson	0
Madison	0
Elbert	2
Floyd	2
Bartow	1
Cherokee	1
Polk	1
Paulding	1
Cobb	5
Gwinnett	4
Barrow	1
Atherstone	3
Oconee	0
Oglethorpe	0
Wilkes	2
Lincoln	0
Haralson	4
Douglas	2
Fulton	15
Walton	2
Newton	1
Morgan	2
Greene	2
Taliaferro	0
Warren	0
McIntosh	1
Columbia	0
Carroll	2
Clatsop	3
Henry	2
Fayette	1
Spalding	1
Butts	1
Jasper	1
Putnam	1
Hancock	0
Glascock	0
Richmond	6
Heard	0
Coweta	3
Meriwether	4
Pike	0
Lamar	0
Monroe	2
Jones	0
Baldwin	2
Washington	2
Jefferson	5
Burke	3
Jenkins	3
Screven	4
Troup	1
Harris	0
Talbot	0
Crawford	0
Bibb	6
Twigg	0
Wilkinson	0
Johnson	0
Emanuel	2
Bullock	1
Effingham	6
Chatham	7
Muscogee	4
Chattoah	0
Marion	0
Schley	0
Macon	2
Houston	4
Bleckley	4
Laurens	1
Treutlen	0
Candler	2
Bryan	0
Liberty	2
Long	0
McIntosh	0
Glynn	2
Camden	1
Charlton	0
Ware	1
Clinch	2
Echols	0
Brooks	2
Lowndes	3
Lanier	2
Atkinson	0
Berrien	1
Cook	4
Colquitt	5
Worth	5
Turner	0
Ben Hill	2
Irwin	1
Tift	2
Thomson	1
Grady	2
Decatur	2
Seminole	1
Miller	3
Baker	0
Mitchell	5
Stewart	0
Weber	0
Sumter	1
Dooly	1
Crisp	1
Wilcox	1
Pulaski	4
Dodge	2
Wheeler	0
Monroe	0
Toombs	1
Tattnell	3
Evans	2
Appling	5
Wayne	1
Pierce	0
Brantley	0
Glynn	2
Camden	1
Charlton	0
Early	3
Calhoun	1
Dougherty	2
Terrell	0
Lee	0
Quincy	0
Clay	0
Randolph	1

Source: Georgia Department of Community Health. (2021, November 2). *Active provider directory 20211102*. <https://dch.georgia.gov/providers/provider-directory>

APPENDIX - A



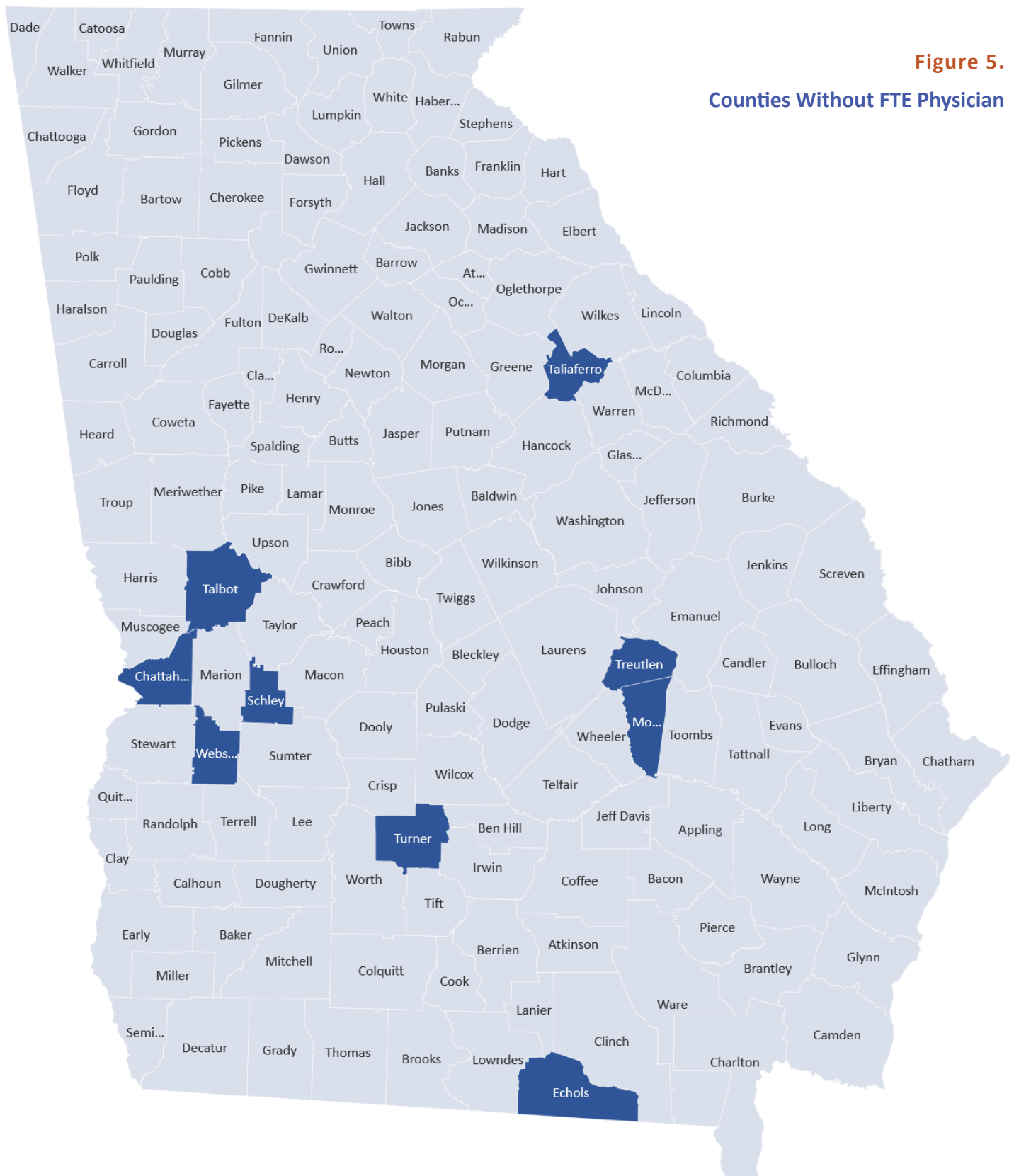
Source: Georgia Department of Community Health. (2021, November 2). *Active provider directory 20211102*.
<https://dch.georgia.gov/providers/provider-directory>

Figure 4.
Number of FTE Physicians by County



APPENDIX - A

Figure 5.
Counties Without FTE Physician



Source: Georgia Board of Health Care Workforce. *Health care workforce data.*
<https://healthcareworkforce.georgia.gov/health-care-workforce-data>

Figure 6.
FTE Physician Assistants by County



Figure 7.
Number of Nurses by County



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Figure 8.
Number of Rehabilitation Facilities by County

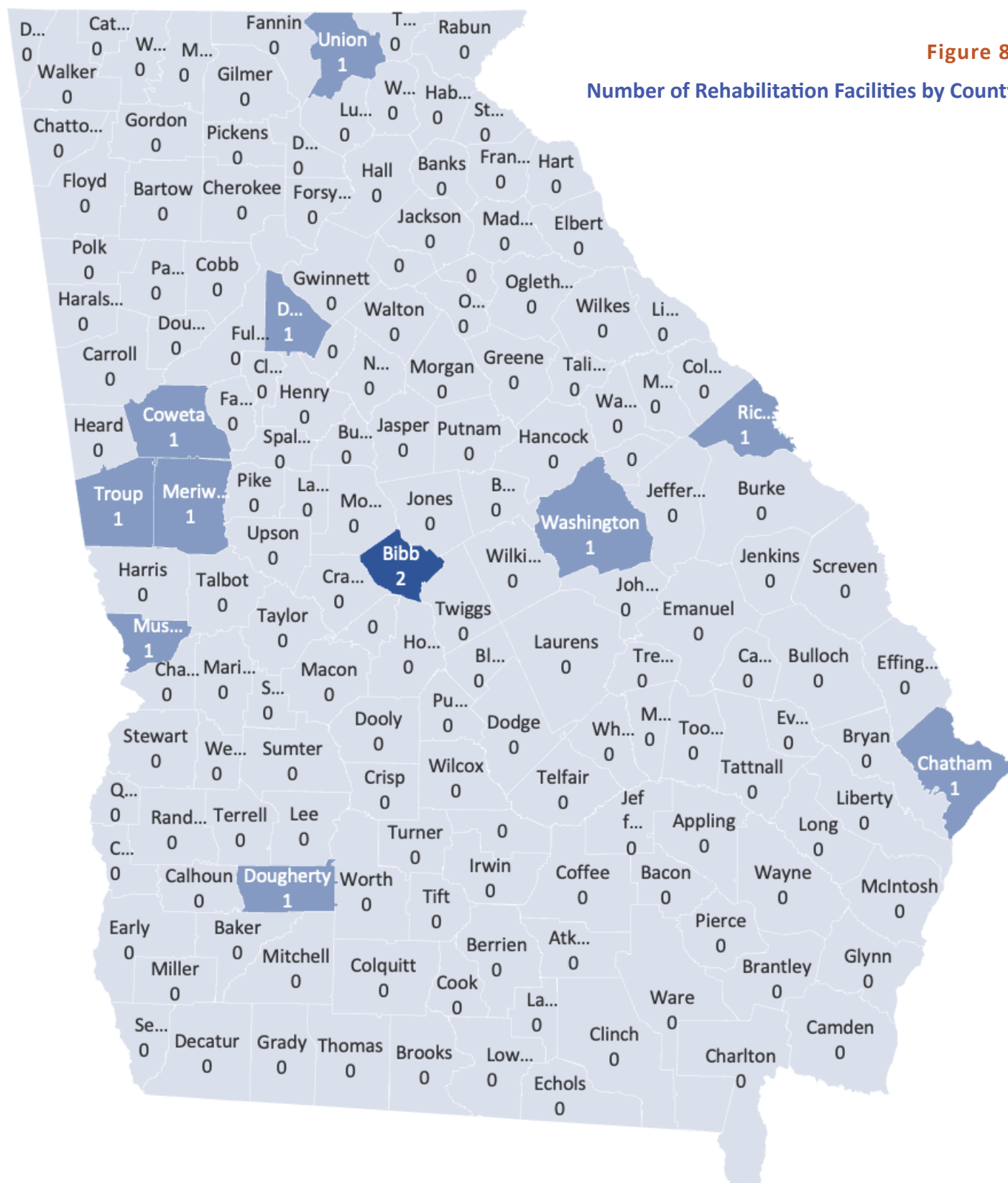


Figure 9.
Number of Mental Health Professionals by County



[illegible]

Source: Georgia Department of Community Health. (2021, November 2). *Active provider directory 20211102*. <https://dch.georgia.gov/providers/provider-directory>

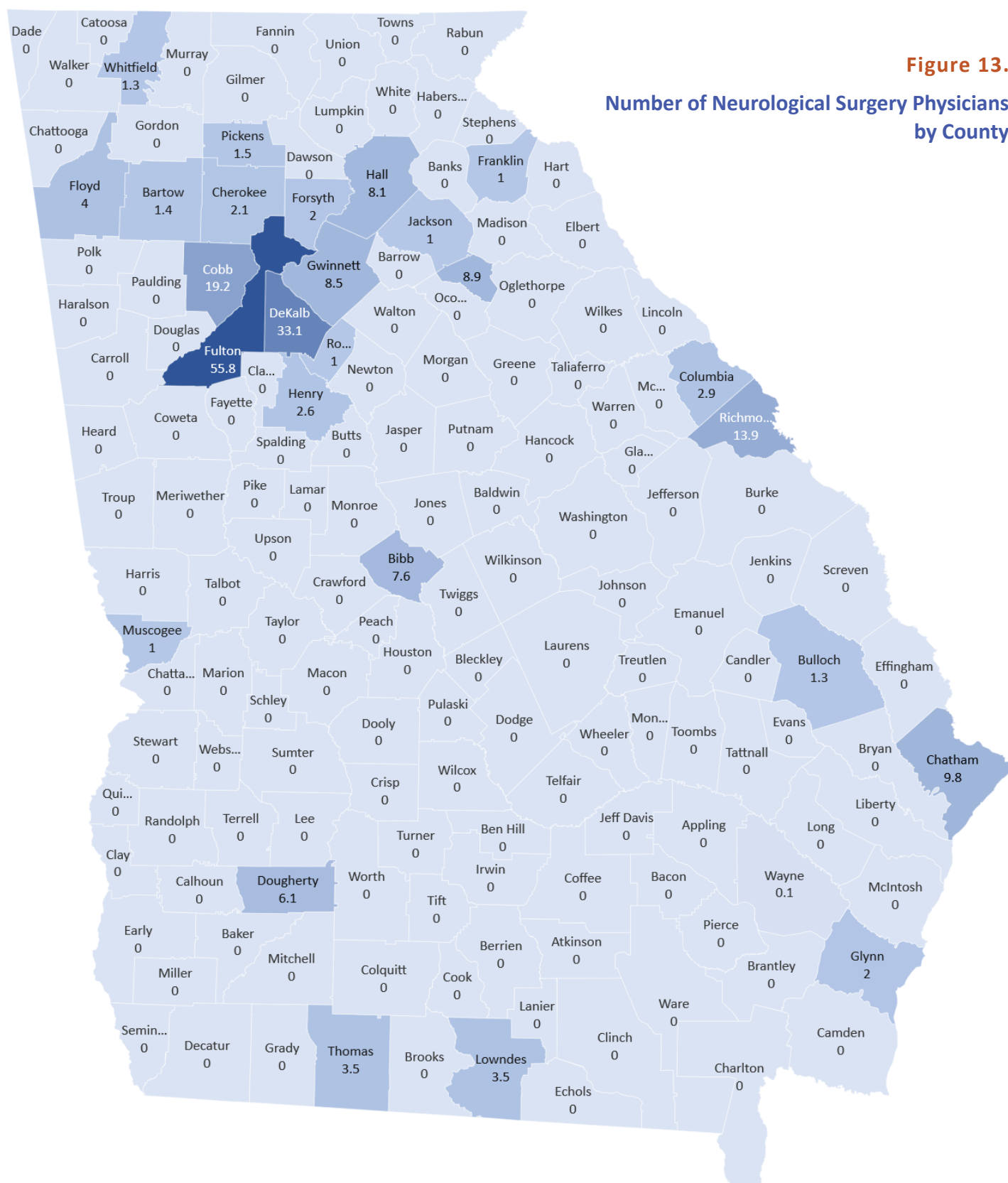
Figure 11.
Number of Neurosurgery Physicians
by County



Figure 12.
**Number of Neurosurgery Critical Care
by County**



APPENDIX - A



Source: Georgia Board of Health Care Workforce. *Health care workforce data.*
<https://healthcareworkforce.georgia.gov/health-care-workforce-data>

[illegible]

Source: Georgia Board of Health Care Workforce. *Health care workforce data*. <https://healthcareworkforce.georgia.gov/health-care-workforce-data>

Figure 15.
Child Neurologists by County



Source: Georgia Department of Community Health. (2021, November 2). *Active provider directory 20211102*. <https://dch.georgia.gov/providers/provider-directory>

Figure 17.
Number of Brain Injury Specialists
by County



[illegible]

Source: Georgia Department of Community Health. (2021, November 2). *Active provider directory 20211102*. <https://dch.georgia.gov/providers/provider-directory>

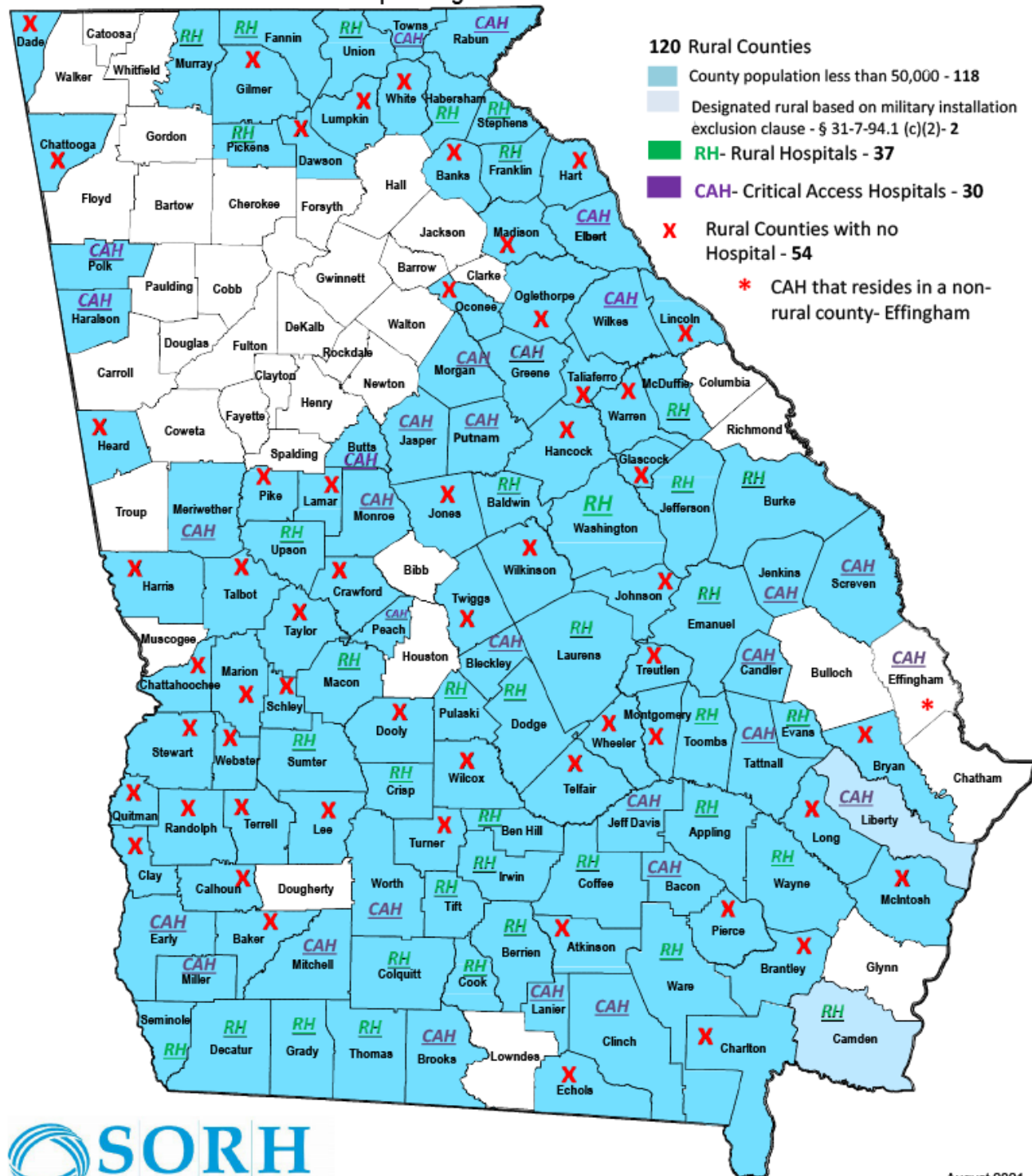
Figure 19.
Number of Occupational Therapists
by County



APPENDIX - A Figure 20. [external]

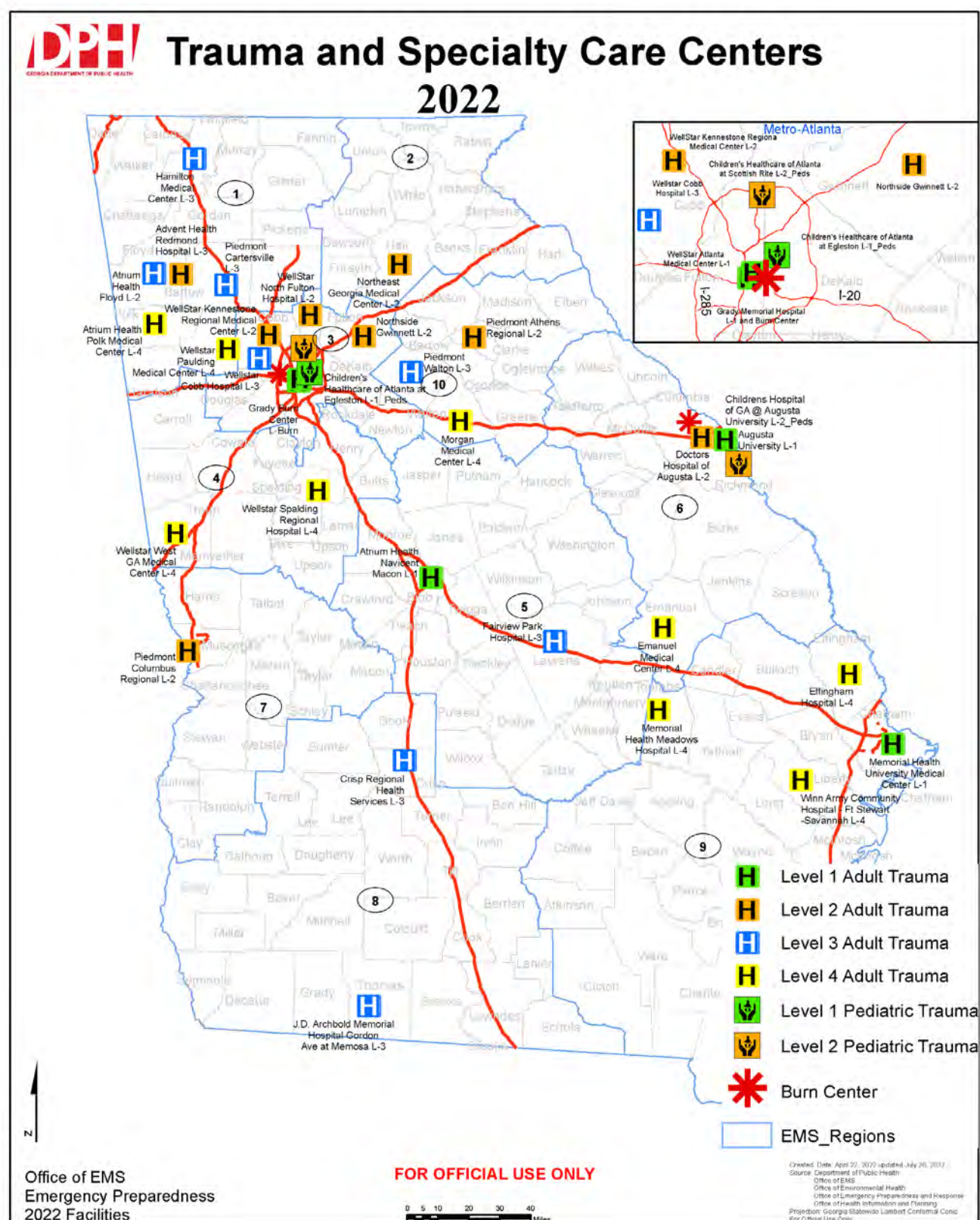
Georgia Rural Counties with Rural Hospitals, Critical Access Hospitals, and Rural Counties without a Hospital

Rural Hospital Organization Assistance Act of 2017



APPENDIX - A

Figure 21. [external]



Source: Office of EMS. (2022, July 26). *Trauma and specialty care centers 2022* [Map]. Georgia Department of Public Health. Retrieved from <https://dph.georgia.gov/EMS/specialty-care-centers-cardiac-trauma-stroke/designated-trauma-specialty-care-centers>

APPENDIX - A Figure 22. [external]

Georgia Rural Counties without a Rural Health Clinic

Rural Hospital Organization Assistance Act of 2017

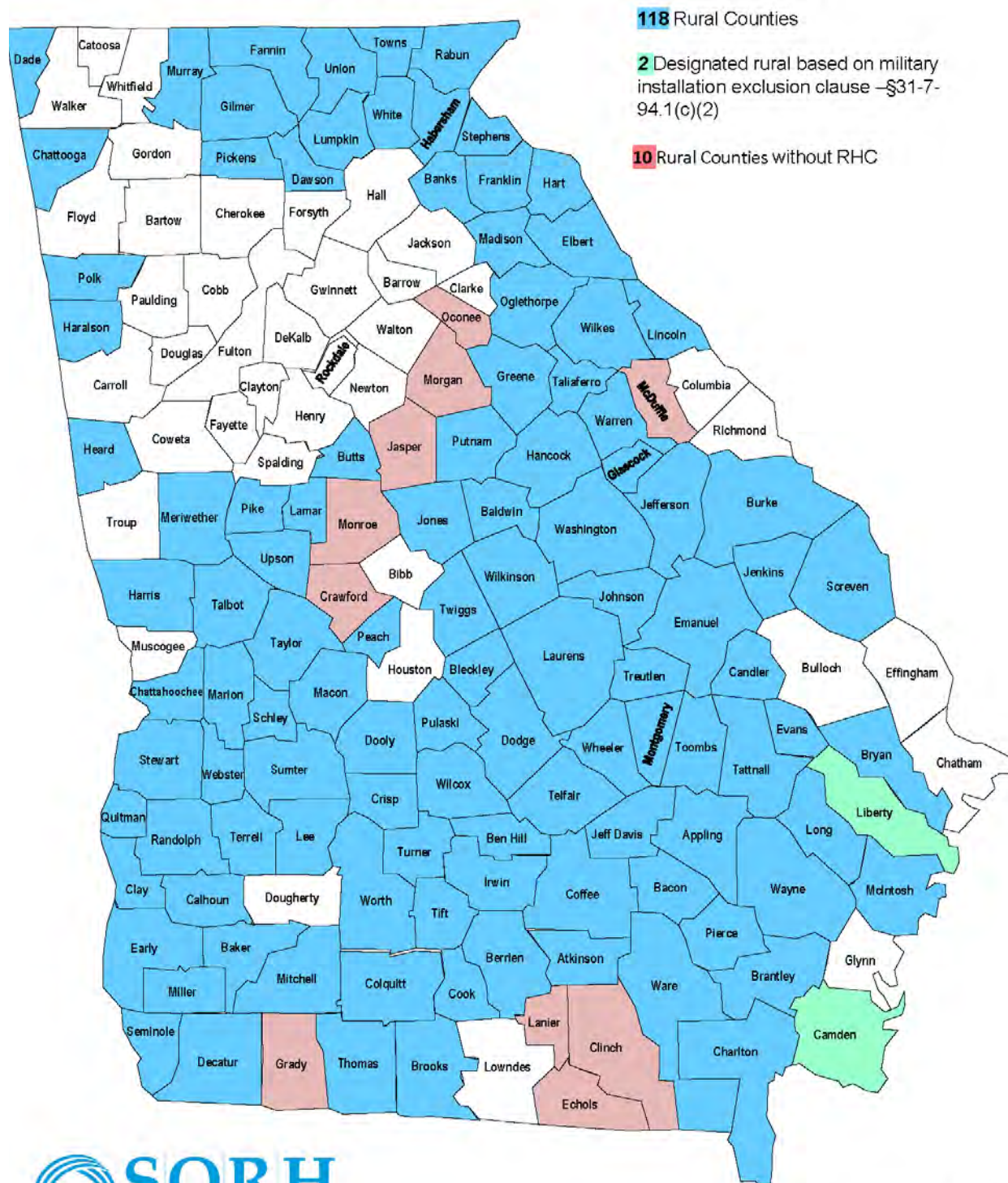


Figure 23.
Total Rehabilitative Services by County
(PTs, OTs, SLPs, and Rehab Centers)



APPENDIX - A

List of Support Groups in Georgia and Virtual

#	Name	County / Virtual	About
1	Savannah Grey Matters Memorial Medical Center	Chatham	3rd Thursday of each month @ 5:30-6:30 pm
2	Unlimited Possibilities Support Group For All Brain Injuries (TBI/ABI)	Cobb	Every 1st Tuesday @ 7 P.M. (excluding January); Breakfast social every Friday at 10 am
3	Emory Support Group	Dekalb	Meetings Held: Every 2nd Tuesday @ 6:30 pm
4	Veterans, Responders, Government Service Agents (VRGSA) Brain Injury Support Group	Virtual	Second Tuesday @ 7 pm: Veterans, Responders, Government Service Agents (VRGSA) Brain Injury Support Group. For Veterans, 1st Responders or Government Service Agents only!
5	Emory Rehabilitation Hospital Stroke Survivors' Club	Virtual	
6	Blue Ridge Support Group	Fannin	
7	Peace of Mind Brain Injury Support Group	Forsyth/N Fulton county	Meetings Held: 3rd Monday @ 7:00 pm. Virtual
8	Seminole Spirit, A Speech Language Improvement Group	Fulton	Meetings are three times a month, every other Friday, noon until 2 pm.
9	New Beginnings Brain Injury Support Group	Virtual-Gwinnett county	1st Friday of every month from 1:30-2:30 pm
10	Augusta Brain Injury Support Group	Richmond	Meetings Held: Every 2nd Thursday @ 6 pm
11	BIAG Caregivers Connect Support Group		Focused on care advocates of brain injured survivors. Virtual: Second Wednesday @ 7 pm (Caregivers only)
12	Brain Signal Peer Support Meetings	Virtual	Virtual: Every other Saturday 12:30-2:30 pm through Google Meet: meet.google.com/azz-rdpk-bbo
13	Side by Side Clubhouse	Virtual	First Thursday @ 5 pm (Caregivers only)
14	The Young and the Restless	Virtual	Young (at heart) Stroke/TBI Peer Engagement Group. 3rd Thursday at 6:30 pm
15	Georgia Southern University's "Different Strokes"	Bulloch	Thursdays at 9 am (both face to face and virtual)
16	Brain Signal Peer Support Meetings- Georgia State University	Virtual	2nd and 4th Saturday @ 12:30-2:30 pm through Google Meet
17	Emory Synapse	Virtual	
18	Brain Injury Association of Georgia Affiliated Support Groups	Fulton	1441 Clifton Road NE, Atlanta, GA 30322 (inside the Emory Center for Rehab)
19	Brain Injury Association of Georgia Affiliated Support Groups	Fulton	320 Parkway Dr. NE, S240, Atlanta, GA 30312
20	Tuesday Bus Station Committee	Virtual	This is a support group meeting with survivors from all over the nation. Every Tuesdays from 4-5 pm.
21	"Hope" Southwest Georgia Support Group		Phone help - one on one help for survivors
22	SMClark for Seniors	Virtual/Fulton	1st Monday each month from 7 pm-8 pm
23	WellStar Inpatient Rehab/ North Fulton Hospital	Fulton county	Last Wednesday every month. Support groups for stroke survivors

Figure 24.
Georgia Students with TBI
by County: FY 2022



[illegible]

Source: Georgia Department of Education (DOE). (2022). [Data for Georgia school demographics 2018-2022] [Unpublished raw data].

Figure 26.
Number of Special Education Teachers by County: 2022



[illegible]

Source: Georgia Department of Education (DOE). (2022). [Data for Georgia school demographics 2018-2022] [Unpublished raw data].

Figure 28.
Number of School Psychologists
by County: 2022



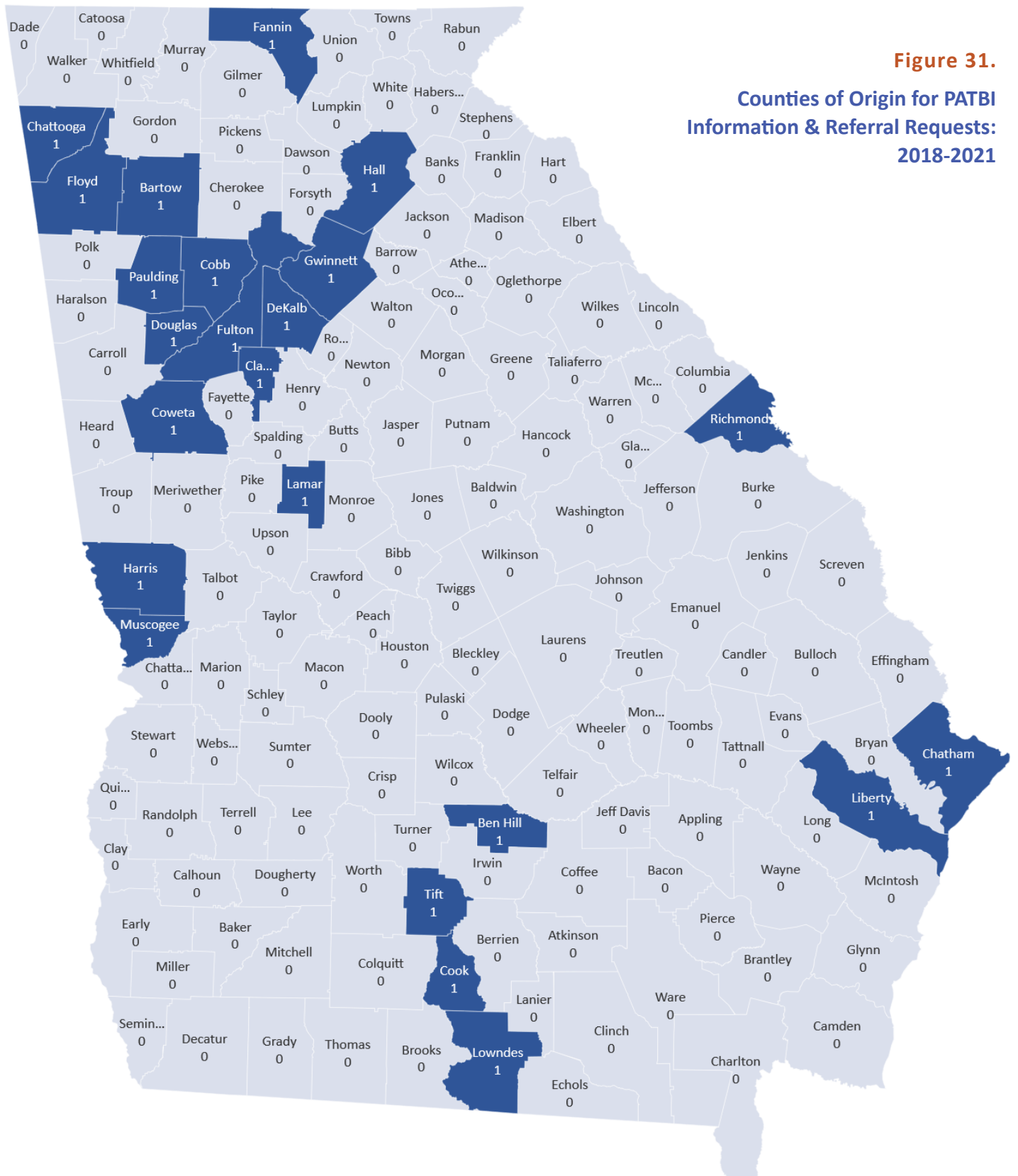
Figure 29.
Number of School GNETS Psychologists
by County: 2022



Figure 30.
Successful GVRA Closures for TBI
by County: 2018-2022



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Source: Georgia Advocacy Office (GAO). (2022). [Data for PATBI program participants 2018-2021] [Unpublished raw data].

APPENDIX - A

Table B. List of Centers for Independent living (CIL) in Georgia.

City	Resource
Athens	Multiple Choices
Atlanta	disABILITY Link
Augusta	Walton Options for Independent Living
Bainbridge	Bainbridge Individual Advocacy Network
Columbus	Access 2 Independence
Demorest	Disability Resource Center
Macon	Disability Connections
Rome	Northwest Georgia Center for Independent Living
Savannah	Living Independence for Everyone

APPENDIX - B

APPENDIX B

Survey - Individuals with TBI / Georgia Statewide TBI Needs Assessment

Survey for Georgians with Traumatic Brain Injury (TBI)

The Brain and Spinal Cord Injury Trust Fund Commission (BSITFC) through a grant funding from Administration on Community Living (ACL) is working with the Research and Evaluation Unit (REU) at IHDD to conduct a statewide needs assessment to understand the needs of people with Traumatic Brain Injury (TBI) for various services and support across systems and to help identify gaps and barriers to these services.

For the purpose of this study, Traumatic Brain Injury (TBI) is defined as a form of acquired brain injury, that occurs when a sudden trauma causes damage to the brain. TBI can result when the head suddenly and violently hits an object, or when an object pierces the skull and enters brain tissue. Symptoms of a TBI can be mild, moderate, or severe, depending on the extent of the damage to the brain.

Below are some guidelines for completing the survey.

This survey should take approximately 10-15 minutes to complete, and your participation is completely voluntary. None of the questions are mandatory, you can skip any of the questions and still continue with the survey. You may choose to finish the entire survey in one sitting or complete it in chunks and come back to it at your convenience. The survey will save your responses and begin from where you left off. You can also use the back button to go to previous questions and make changes as needed. There are no right or wrong answers, and you are free to answer only the questions you are comfortable with. Your responses will be kept confidential. Feedback gathered through this survey will be combined into a summary report along with other data collected for this project.

Should you need accommodations (large print, complete over the phone, answer questions) or would like this survey in an alternate format, please contact:

Brain Injury Association of Georgia (BIAG)

Research and Evaluation Unit (IHDD, UGA)

APPENDIX - B

Survey

Q1 Would you require assistance in filling out this survey (completing it over the phone)?

- ☐ Yes (1)
- ☐ No (2)

Skip To: Q2 If Would you require assistance in filling out this survey (completing it over the phone)? = Yes

Display This Question: If Would you require assistance in filling out this survey (completing it over the phone)? = Yes

Q2 Please leave your name, contact number and/or email address, where one of our trained interviewers can reach you.

Skip To: End of Survey If Condition: Please leave your name, con... Is Not Empty. Skip To: End of Survey.

Q3 Which best describes you (person completing the survey)?

- ☐ I am a person with TBI (1)
- ☐ Someone providing assistance to the person with TBI (responding on behalf of a person with TBI) (2)
- ☐ Other (please specify) (3) _____

Skip To: Q4 If Which best describes you (person completing the survey)? = Someone providing assistance to the person with TBI (responding on behalf of a person with TBI)

Skip To: Q5 If Which best describes you (person completing the survey)? = I am a person with TBI

Q4 If you are someone assisting an individual with TBI (responding on behalf of a person with TBI), please check who you are.

- ☐ Spouse (4)
- ☐ Sibling (3)
- ☐ Parent (2)
- ☐ Child (5)
- ☐ Significant other (6)

APPENDIX - B

- ☐ Grandparent (7)
- ☐ Family friend (8)
- ☐ Neighbor (9)
- ☐ Church member (1)
- ☐ Advocate (13)
- ☐ Other family member (10)
- ☐ Prefer not to answer (11)
- ☐ Other (specify): (12) _____

Note: If you are assisting with completing this survey, please answer the questions from the individual's viewpoint with a traumatic brain injury (TBI) whom you are helping.

Q5 What is your (survivor of TBI) age group?

- ☐ Birth - 5 years (1)
- ☐ 6-18 years (2)
- ☐ 19-21 years (3)
- ☐ 22- 55 years (4)
- ☐ 56- 64 years (5)
- ☐ 65+ years (6)

Q6 Are you (survivor of TBI) a military service member?

- ☐ Current military service member (1)
- ☐ Former military service member (2)
- ☐ Never a military service member (3)

Q7 What is your (survivor of TBI) gender?

- ☐ Male (1)
- ☐ Female (2)
- ☐ Non-binary / third gender (3)
- ☐ Prefer not to say (4)

Q8 What is your (survivor of TBI) race/ethnicity?

- ☐ White (1)
- ☐ Black or African American (2)

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- ☐ American Indian or Alaska Native (3)
- ☐ Native Hawaiian or Pacific Islander (4)
- ☐ Asian (5)
- ☐ Hispanic or Latino (6)
- ☐ Prefer not to say (8)
- ☐ Other (please specify) (7) _____

Q9 Which county do you (survivor of TBI) live in? Please select from the list.

▼ Appling County, GA (1) ... Worth County, GA (162)

Q10 What was your (survivor of TBI) age at the time of the injury?

- ☐ Birth - 5 years (1)
- ☐ 6 - 18 years (2)
- ☐ 19 - 21 years (3)
- ☐ 22 - 55 years (4)
- ☐ 56 - 64 years (5)
- ☐ 65+ years (6)

Q11 In what year did the injury occur? (e.g. 2015)

Q12 If you've had a second TBI injury, in what year did the second injury occur? (e.g. 2019)

Q13 How did your (survivor of TBI) TBI happen? If you have had more than one TBI, select all that apply

- ☐ Motorized vehicle accident (car, truck, motorcycle, ATV, etc) (1)
- ☐ Bicycle accident (2)
- ☐ Other accident (for example, falling, sports injury) (3)
- ☐ Violence (for example, fighting, assault, gunshot, explosion, combat, or suicide attempt) (4)
- ☐ Near drowning (5)

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- ☐ Medical condition (for example, stroke, brain tumor, infection, epilepsy) (6)
- ☐ Other, please describe: (7) _____

Q14 Please indicate any disabilities or significant health conditions that you (survivor of TBI) developed AFTER the TBI (Mark all that apply):

- ☐ Behavior / personality change (e.g. acting out, aggression, social inappropriateness) (1)
- ☐ Chronic pain (e.g. headaches) (2)
- ☐ Cognitive (memory, processing, problem solving) (3)
- ☐ Depression (4)
- ☐ Diabetes (5)
- ☐ Language (e.g. communication, expression, and understanding) (6)
- ☐ Physical (balance, other mobility) (7)
- ☐ Post Traumatic Stress Disorder (PTSD) (8)
- ☐ Seizure disorder (9)
- ☐ Sensory (vision, hearing, taste, smell) (10)
- ☐ Sleep disorder (11)
- ☐ Substance abuse (alcohol) (12)
- ☐ Substance abuse (drugs) (13)
- ☐ Other mental health conditions (e.g. anxiety) (14)
- ☐ Other (please specify) (15) _____

Q15 Please indicate any disabilities or significant health conditions that you (survivor of TBI) already had BEFORE the TBI (Mark all that apply):

- ☐ Behavior / personality change (e.g. acting out, aggression, social inappropriateness) (1)
- ☐ Chronic pain (e.g. headaches) (2)
- ☐ Cognitive (memory, processing, problem solving) (3)
- ☐ Depression (4)
- ☐ Diabetes (5)
- ☐ Language (e.g. communication, expression, and understanding) (6)
- ☐ Physical (balance, other mobility) (7)
- ☐ Post Traumatic Stress Disorder (PTSD) (8)

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- ☐ Seizure disorder (9)
- ☐ Sensory (vision, hearing, taste, smell) (10)
- ☐ Sleep disorder (11)
- ☐ Substance abuse (alcohol) (12)
- ☐ Substance abuse (drugs) (13)
- ☐ Other mental health conditions (e.g. anxiety) (14)
- ☐ None (16)
- ☐ Other (please specify) (15) _____

Q15 Please indicate any disabilities or significant health conditions that you (survivor of TBI) already had BEFORE the TBI (Mark all that apply):

- ☐ Behavior / personality change (e.g. acting out, aggression, social inappropriateness) (1)
- ☐ Chronic pain (e.g. headaches) (2)
- ☐ Cognitive (memory, processing, problem solving) (3)
- ☐ Depression (4)
- ☐ Diabetes (5)
- ☐ Language (e.g. communication, expression, and understanding) (6)
- ☐ Physical (balance, other mobility) (7)
- ☐ Post Traumatic Stress Disorder (PTSD) (8)
- ☐ Seizure disorder (9)
- ☐ Sensory (vision, hearing, taste, smell) (10)
- ☐ Sleep disorder (11)
- ☐ Substance abuse (alcohol) (12)
- ☐ Substance abuse (drugs) (13)
- ☐ Other mental health conditions (e.g. anxiety) (14)
- ☐ None (16)
- ☐ Other (please specify) (15) _____

Q16 What is the highest level of school you have completed or highest level of degree you have received?

- ☐ Currently attending High School (1)
- ☐ Less than high school degree (2)

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- ☐ High school graduate (high school diploma or equivalent including GED) (3)
- ☐ Some college but no degree (4)
- ☐ Diploma or Associate degree in college (5)
- ☐ Bachelor's degree (6)
- ☐ Master's degree (7)
- ☐ Doctoral degree (8)
- ☐ Professional degree (JD, MD) (9)
- ☐ Other, please describe: (10) _____

Q17 Following your injury, did anyone provide you (survivor of TBI) or your family with information or advise about services available for people with traumatic brain injury?

- ☐ Yes (1)
- ☐ No (3)

Display This Question: If Following your injury, did anyone provide you (survivor of TBI) or your family with information o... = Yes

Q18 Was this information provided before you (survivor of TBI) left the hospital or doctor's office?

- ☐ Yes (1)
- ☐ No (2)

Display This Question: If Following your injury, did anyone provide you (survivor of TBI) or your family with information o... = Yes

Q19 Who provided the information or advise you (survivor of TBI) or your family? (Select all that apply)

- ☐ Attorney (1)
- ☐ Brain Injury Association of Georgia (BIAG) (2)
- ☐ Family/friends (3)
- ☐ Medical professional (doctor/nurse/ PA) (4)
- ☐ Rehabilitation staff / vocational rehabilitation (5)
- ☐ Social worker / service coordinator / counselor (6)
- ☐ Other (Please specify) (7) _____

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Q20 Which of the following medical services are you (survivor of TBI) currently receiving. (Please select all that apply)

- ☐ None (12)
- ☐ Physical therapy (1)
- ☐ Occupational therapy (2)
- ☐ Speech therapy (3)
- ☐ Neuropsychological evaluation (4)
- ☐ Pain management (5)
- ☐ Cognitive therapy (6)
- ☐ Counseling (7)
- ☐ Behavior management (8)
- ☐ Dental (10)
- ☐ Vision (11)
- ☐ Other (please specify) (13) _____

Q21 Please list some names of the medical providers, hospitals, agencies that currently serve you or have served you (survivor of TBI) in the past?

Q22 Which of the following community-based services are you (survivor of TBI) currently receiving. (Please select all that apply)

- ☐ In-home services (e.g. personal care attendant) (1)
- ☐ Mental Health Counseling (3)
- ☐ TBI Support Groups (4)
- ☐ Information and Referral Services (information about how to find the services you need) (20)
- ☐ Service coordination / case management (6)
- ☐ Cognitive and memory training (memory, processing, problem solving) (9)
- ☐ General health management (10)

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- ☐ Community Living Skills Training (such as cooking or money management) (12)
- ☐ Behavioral Supports (such as anger management and social skills training) (11)
- ☐ Assistance Applying for Social Security Disability Benefits (7)
- ☐ Transportation Services (2)
- ☐ Section 8 or Other Housing Assistance (5)
- ☐ Employment Services (13)
- ☐ Use of Assistive Technologies (such as a communication board or wheelchair) (8)
- ☐ Treatment for Substance Use Disorder (15)
- ☐ Other (please specify) (21) _____

Q23 Which of the following community-based services have you (survivor of TBI) needed but not received. (Please select all that apply)

- ☐ In-home services (e.g. personal care attendant) (1)
- ☐ Mental Health Counseling (3)
- ☐ TBI Support Groups (4)
- ☐ Information and Referral Services (information about how to find the services you need) (20)
- ☐ Service coordination / case management (6)
- ☐ Cognitive and memory training (memory, processing, problem solving) (9)
- ☐ General health management (10)
- ☐ Community Living Skills Training (such as cooking or money management) (12)
- ☐ Behavioral Supports (such as anger management and social skills training) (11)
- ☐ Assistance Applying for Social Security Disability Benefits (7)
- ☐ Transportation Services (2)
- ☐ Section 8 or Other Housing Assistance (5)
- ☐ Employment Services (13)
- ☐ Use of Assistive Technologies (such as a communication board or wheelchair) (8)
- ☐ Treatment for Substance Use Disorder (15)
- ☐ Other (please specify) (21) _____

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Q24 What problems do you (survivor of TBI) have in getting the services you need related to TBI? (Select all that apply)

- ☐ Not aware of services and resources (13)
- ☐ No centralized source for TBI information (14)
- ☐ Services and resources are far from my home (12)
- ☐ Difficulty finding providers (e.g. medical, counselor) (18)
- ☐ Professionals are not trained in working with individuals with TBI (doctors, therapists) (19)
- ☐ Lack of individualized services (20)
- ☐ Providers do not understand or respect my culture and needs (32)
- ☐ Difficulty understanding paperwork/information (15)
- ☐ Difficulty with English language (16)
- ☐ Difficulty with enrollment/admissions (17)
- ☐ Inability to pay for needed services (21)
- ☐ Cognitive limitations (memory, processing, problem solving) (11)
- ☐ Physical limitations (33)
- ☐ Inadequate insurance (22)
- ☐ Lack of support/patient advocacy (24)
- ☐ Lack of coordinated care (25)
- ☐ Lack of transportation (26)
- ☐ Inadequate support to live in a setting of my choice (31)
- ☐ Inadequate support to find employment (30)
- ☐ Inadequate support for family and caregivers (28)
- ☐ Inadequate family or peer support (29)
- ☐ Other (please specify) (34) _____

Q25 What would you (survivor of TBI) like to see improved about TBI service system in Georgia? (Select all that apply)

- ☐ More statewide services (in rural areas) (11)
- ☐ Need more trained providers that specialize in brain injury (18)
- ☐ Training professionals on providing culturally responsive services (24)

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- ☐ Better service coordination and referrals for TBI (22)
- ☐ More supports for family members and caregivers (15)
- ☐ Access to more Community based Supports and Services (12)
- ☐ More Services (funding, duration, intensity) (17)
- ☐ Increased training and advocacy for survivors of brain injury (14)
- ☐ Information on living well with brain injury (19)
- ☐ Create and expand Medicaid waivers for brain injury (13)
- ☐ Increased awareness of brain injury across the state (16)
- ☐ Other (please specify) (21) _____

Q26 How are your health care costs paid? (Please select all that apply)

- ☐ Private health insurance (3)
- ☐ Medicaid, including waiver programs (15)
- ☐ Medicare (for those over age 65 or disabled) (16)
- ☐ Brain and Spinal Injury Trust Fund (17)
- ☐ Personal Injury Protection (i.e. automobile insurance) (18)
- ☐ Charity Care (19)
- ☐ No coverage (20)
- ☐ I don't know (21)
- ☐ Other (please specify): (22) _____

Q27 Do you (survivor of TBI) currently receive social security disability income (SSDI)/ Supplement security Income (SSI)?

- ☐ Yes (1)
- ☐ No (2)
- ☐ In the process of applying or appealing (3)
- ☐ Not sure (4)

Q28 Have you (survivor of TBI) ever applied to the Brain and Spinal Injury Trust Fund?

- ☐ Yes (2)
- ☐ No (3)
- ☐ Not sure (4)
- ☐ Don't know what that is (5)

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Q29 How do you (survivor of TBI) travel from place-to-place on a daily basis for medical or non-medical reasons? (Select all that apply)

- ☐ Drive myself (1)
- ☐ Ride with other family (4)
- ☐ Ride with other non-family (friend, neighbor etc) (5)
- ☐ Public transportation (8)
- ☐ Medical transportation service (6)
- ☐ Provider transports (7)
- ☐ Wheelchair accessible lift transportation (9)
- ☐ Taxi (10)
- ☐ Walk (11)
- ☐ Bike (12)
- ☐ Cannot get transportation (13)
- ☐ Other (please specify) (3) _____

Q30 Overall, is your (survivor of TBI) transportation reliable and accessible?

- ☐ Yes (1)
- ☐ No (2)

Display This Question: If Overall, is your (survivor of TBI) transportation reliable and accessible? = No

Q31 If transportation is not reliable or accessible, why not?

Q32 Are you currently working?

- ☐ Yes (1)
- ☐ No (4)

Display This Question: If Are you currently working? = Yes

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Q33 How will you (survivor of TBI) describe your current employment status?

- ☐ Employed full - time (1)
- ☐ Employed part-time (4)
- ☐ Supported employment (5)
- ☐ Volunteer (6)
- ☐ Homemaker (9)
- ☐ Student (11)
- ☐ Self Employed (13)
- ☐ Other (Specify): (12) _____

Display This Question: If Are you currently working? = Yes

Q34 How many hours per week do you work? (e.g. 20)

Display This Question: If Are you currently working? = Yes

Q35 Do you require accommodations for your injury in order to work? (Choose only ONE answer)

- ☐ I do not require any accommodations (1)
- ☐ I require accommodations and I'm able to use them successfully in order to work (4)
- ☐ I do not know if I need accommodations (13)
- ☐ Yes, I have accommodations but they are insufficient and outdated (14)
- ☐ Yes, I need accommodations but do not have them (15)

Display This Question: If Are you currently working? = No

Q36 I am not working because? (Please select all that apply)

- ☐ I am retired, a minor or I choose not to work (1)
- ☐ I have enough support and income that I do not have to work (4)
- ☐ I am concerned that having a job will affect my benefits (13)
- ☐ I need training for a new career because my injury prevents me from doing my previous job (14)
- ☐ I tried but have been unable to keep a job due to my disability (15)
- ☐ I interview but no one will hire me due to my disability (17)
- ☐ I have been told by professionals that I am unable to work (18)
- ☐ Other (please specify) (19) _____

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Q37 What is the total combined income per year for all persons in your (survivor of TBI) household? (This includes all sources such as jobs, Social Security, retirement income, and public assistance). Select one.

- ☐ Less than \$25,000 (1)
- ☐ \$25,000 to under \$35,000 (2)
- ☐ \$35,000 to under \$45,000 (3)
- ☐ \$45,000 to under \$65,000 (4)
- ☐ \$65,000 to under \$75,000 (5)
- ☐ Over \$75,000 (6)

Q38 Where do you (survivor of TBI) currently live? (Please select ONE response)

- ☐ I own or rent my home or apartment (1)
- ☐ I live with family, a loved one, or a friend who covers my housing expenses (2)
- ☐ I live in a nursing home, group home or other care facility (8)
- ☐ I have temporary living situation and I'm seeking more stable housing (11)
- ☐ I have serious circumstances that put me at risk of losing my home or apartment (12)
- ☐ I am homeless (13)
- ☐ Other (please specify) (19) _____

Display This Question: If Where do you (survivor of TBI) currently live? (Please select ONE response) = I live in a nursing home, group home or other care facility

Q39 Do you (survivor of TBI) wish to return to the community from the nursing facility?

- ☐ No (3)
- ☐ Not sure (4)
- ☐ Yes (5)

Display This Question: If Do you (survivor of TBI) wish to return to the community from the nursing facility? = Yes

Q40 If yes, what is preventing you (survivor of TBI) from moving ? (Select all that apply)

- ☐ Can't get the in-home services I need (e.g. personal care, homemaking services) (1)
- ☐ Can't get the medical care I need (2)
- ☐ Can't get the rehabilitation therapy I need (e.g. physical, speech, occupational) (3)
- ☐ Don't have access to transportation (4)

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- ☐ Insufficient financial resources (5)
- ☐ Lack of access to accessible and affordable housing (6)
- ☐ Lack of employment (7)
- ☐ Need help coordinating and planning for services (8)
- ☐ Need specialized training and services (e.g. cognitive training, behavioral supports, community living, skills training) (9)
- ☐ Other (Please specify) (10) _____

Display This Question: If Do you (survivor of TBI) wish to return to the community from the nursing facility? = No

Q41 If no, why not?

Q42 Are you happy with your (survivor of TBI) living arrangement?

- ☐ Yes (1)
- ☐ No (2)

Q43 Please explain the reason for the previous answer?

Q44 What is working well as far as services and supports for people with TBI and their families in Georgia?

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Q45 What do you (survivor of TBI) feel needs to be done to improve statewide services and supports for people with TBI and their families?

Q46 Is there anything else you (survivor of TBI) would like us to know?

Q47 Are you sure you want to submit your final responses to the survey? (Note: You can use the back button to go back to the previous questions and make changes.)

☐ Yes (1)

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APPENDIX C

Survey - Professionals Working with Individuals with TBI / Georgia Statewide TBI Needs Assessment

Survey for Professionals working with Individuals with a Traumatic Brain Injury (TBI)

The Brain and Spinal Cord Injury Trust Fund Commission (BSITFC) through a grant funding from Administration on Community Living (ACL) is working with the Research and Evaluation Unit (REU) at IHDD to conduct a statewide needs assessment to understand the needs of people with Traumatic Brain Injury (TBI) for various services and support across systems and to help identify gaps and barriers to these services.

For the purpose of this study, Traumatic Brain Injury (TBI) is defined as a form of acquired brain injury, that occurs when a sudden trauma causes damage to the brain. TBI can result when the head suddenly and violently hits an object, or when an object pierces the skull and enters brain tissue. Symptoms of a TBI can be mild, moderate, or severe, depending on the extent of the damage to the brain.

Below are some guidelines for completing the survey.

This survey should take approximately 10-15 minutes to complete, and your participation is completely voluntary. None of the questions are mandatory, you can skip any of the questions and still continue with the survey. You may choose to finish the entire survey in one sitting or complete it in chunks and come back to it at your convenience. The survey will save your responses and begin from where you left off. You can also use the back button to go to previous questions and make changes as needed. There are no right or wrong answers, and you are free to answer only the questions you are comfortable with. Your responses will be kept confidential. Feedback gathered through this survey will be combined into a summary report along with other data collected for this project.

Should you need accommodations (large print, complete over the phone, answer questions) or would like this survey in an alternate format, please contact:

Brain Injury Association of Georgia (BIAG)

Research and Evaluation Unit (IHDD, UGA)

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Survey

Q1 Which of the following best describes you? (Pick ONE)

- ☐ Medical Provider (30)
- ☐ Rehabilitation Personnel (31)
- ☐ Educator (32)
- ☐ Community Service Provider or professional (33)
- ☐ Advocate (53)
- ☐ Other (34) _____

Display This Question: If Which of the following best describes you? (Pick ONE) = Medical Provider

Q2 If you are a medical provider, which profile best describes you:

- ☐ Nurse (1)
- ☐ Primary Care physician (2)
- ☐ Emergency care physician (3)
- ☐ Physician assistant (4)
- ☐ Advanced nurse practitioner (5)
- ☐ Other physician (6)
- ☐ Psychologist (7)
- ☐ Licensed athletic trainer (8)
- ☐ Discharge Planner (9)
- ☐ Nurse practitioner (10)
- ☐ Other (please mention) (11) _____

Display This Question: If Which of the following best describes you? (Pick ONE) = Rehabilitation Personnel

Q3 If you are a rehabilitation personnel, which profile best describes you:

- ☐ Occupational therapist (1)
- ☐ Physical therapist (2)
- ☐ Speech therapist (3)
- ☐ Administrator (4)
- ☐ Other (please specify) (5) _____

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Display This Question: If Which of the following best describes you? (Pick ONE) = Educator

Q4 If you are an educator, which profile best describes you:

- ☐ Teacher (1)
- ☐ School nurse (2)
- ☐ Administrator (3)
- ☐ Coach/ director (4)
- ☐ Other (please specify) (5) _____

Display This Question: If Which of the following best describes you? (Pick ONE) = Community Service Provider or professional

Q5 If you are a community service provider or professional, which profile best describes you:

- ☐ Social worker (1)
- ☐ Adult brain injury program provider (2)
- ☐ Vocational rehab personnel (3)
- ☐ Caseworker (4)
- ☐ Mental health professional (5)
- ☐ Department of corrections personnel (6)
- ☐ In home care provider (7)
- ☐ Attorney (8)
- ☐ Other advocate (9)
- ☐ First responder (10)
- ☐ Law enforcement personnel (11)
- ☐ Youth Club coach (12)
- ☐ Other (please specify) (13) _____

Q6 What is your gender?

- ☐ Male (1)
- ☐ Female (2)
- ☐ Non-binary / third gender (3)
- ☐ Prefer not to say (4)

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Q7 What is your race/ethnicity?

- ☐ White (1)
- ☐ Black or African American (2)
- ☐ American Indian or Alaska Native (3)
- ☐ Native Hawaiian or Pacific Islander (4)
- ☐ Asian (5)
- ☐ Hispanic or Latino (6)
- ☐ Prefer not to say (8)
- ☐ Other (please specify) (7) _____

Q8 What is the highest level of school you have completed or highest level of degree you have received?

- ☐ Currently attending High School (1)
- ☐ Less than high school degree (2)
- ☐ High school graduate (high school diploma or equivalent including GED) (3)
- ☐ Some college but no degree (4)
- ☐ Diploma or Associate degree in college (5)
- ☐ Bachelor's degree (6)
- ☐ Master's degree (7)
- ☐ Doctoral degree (8)
- ☐ Professional degree (JD, MD) (9)
- ☐ Other, please describe: (10) _____

Q9 What is your current age range?

- ☐ 14 - 24 (1)
- ☐ 25 - 35 (2)
- ☐ 36 - 50 (3)
- ☐ 51 - 64 (4)
- ☐ 65 and older (5)

Q10 Which county do you live in? Please select from the list.

▼ Appling County, GA (1) ... Worth County, GA (162)

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Q11 How long have you been serving in your current role?

- ☐ Less than 6 months (1)
- ☐ 6 months to 1 year (2)
- ☐ 1 - 4 years (3)
- ☐ 4 - 8 years (4)
- ☐ More than 8 years (5)

Q12 Approximately how many individuals with TBI have YOU served or had contact with in the last five years (2017-2022)?

- ☐ 1 - 10 (1)
- ☐ 11 - 20 (2)
- ☐ 21 - 30 (3)
- ☐ 31 - 40 (4)
- ☐ 41 - 50 (5)
- ☐ 51 - 60 (6)
- ☐ 61 - 70 (7)
- ☐ 71 - 80 (8)
- ☐ 81 - 90 (9)
- ☐ 91 - 100 (10)
- ☐ More than 100 (11)

Q13 Please indicate who you serve.

- ☐ I serve only people with TBI (1)
- ☐ I serve others in addition to people with TBI (2)

Q14 In a typical work week, how many hours do you work? (e.g. 20)

☐ _____

Q15 Please indicate the type of services you and/or your organization provide to people with TBI ? (Check all that apply)

- ☐ Advocacy services (1)
- ☐ Case management (2)
- ☐ Clinical services (3)
- ☐ Counseling Education/coaching (4)

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- ☐ Employment (5)
- ☐ Life skills (6)
- ☐ Neurobehavioral training (7)
- ☐ Prevention services (8)
- ☐ Special education (9)
- ☐ Supportive services (10)
- ☐ Other (specify) (11) _____

Q16 Was Traumatic Brain Injury (TBI) part of your professional training?

- ☐ Yes (1)
- ☐ No (2)

Display This Question: If Was Traumatic Brain Injury (TBI) part of your professional training? = Yes

Q17 If yes, which were some of the areas of training related to TBI? (Check all that apply)

- ☐ General Knowledge (1)
- ☐ Available services (2)
- ☐ Medical and physical changes (3)
- ☐ Communication and cognitive changes (4)
- ☐ Behavioral changes (5)
- ☐ Specific knowledge about needs (6)
- ☐ Skills for independence (7)
- ☐ Employment (8)
- ☐ Interpersonal (9)
- ☐ Housing (10)
- ☐ Other (please mention) (11) _____

Q18 What type of training related to TBI did you receive within your organization (no external source training from outside the organization)? (Check all that apply)

- ☐ General Knowledge (1)
- ☐ Available services (2)
- ☐ Medical and physical changes (3)
- ☐ Communication and cognitive changes (4)

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- ☐ Behavioral changes (5)
- ☐ Specific knowledge about needs (6)
- ☐ Skills for independence (7)
- ☐ Employment (8)
- ☐ Interpersonal (9)
- ☐ Housing (10)
- ☐ Other (please mention) (11) _____

Q19 Have you accessed additional training related to TBI through external sources outside the organization?

- ☐ Yes (6)
- ☐ No (7)

Display This Question: If Have you accessed additional training related to TBI through external sources outside the organiz... = Yes

Q20 If yes, what were these additional trainings (related to TBI) about? (Check all that apply)

- ☐ General Knowledge (1)
- ☐ Available services (2)
- ☐ Medical and physical changes (3)
- ☐ Communication and cognitive changes (4)
- ☐ Behavioral changes (5)
- ☐ Specific knowledge about needs (6)
- ☐ Skills for independence (7)
- ☐ Employment (8)
- ☐ Interpersonal (9)
- ☐ Housing (10)
- ☐ Other (please mention) (11) _____

Q21 What training, education and/or workshops would you like to receive that will help you better serve/work with TBI clients?

APPENDIX - C

Q22 What is your preferred method through which to obtain additional training and information?

	Low preference (1)	Neutral (2)	High preference (3)
Online training (1)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In service training (2)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
State Conference (3)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Regional training (4)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Through professional organization (5)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q23 What type of TBI training was provided to the community by your organization? (Check all that apply)

- ☐ General Knowledge (1)
- ☐ Available services (2)
- ☐ Medical and physical changes (3)
- ☐ Communication and cognitive changes (4)
- ☐ Behavioral changes (5)
- ☐ Specific knowledge about needs (6)
- ☐ Skills for independence (7)
- ☐ Employment (8)
- ☐ Interpersonal (9)
- ☐ Housing (10)
- ☐ Other (Please specify) (11) _____

Q24 Who diagnosed the individual with TBI?

- ☐ I diagnosed the individual (1)
- ☐ Outside professional (2)
- ☐ Referrals (3)
- ☐ Other professional within the organization (4)
- ☐ Other, please specify: (5) _____

APPENDIX - C

Q25 What are some health conditions of the people with TBI that you serve? (Check all that apply)

- ☐ Behavior / personality change (e.g. acting out, aggression, social inappropriateness) (1)
- ☐ Chronic pain (e.g. headaches) (2)
- ☐ Cognitive (memory, processing, problem solving) (3)
- ☐ Depression (4)
- ☐ Diabetes (5)
- ☐ Language (e.g. communication, expression, and understanding) (6)
- ☐ Physical (balance, other mobility) (7)
- ☐ Post Traumatic Stress Disorder (PTSD) (8)
- ☐ Seizure disorder (9)
- ☐ Sensory (vision, hearing, taste, smell) (10)
- ☐ Sleep disorder (11)
- ☐ Substance abuse (alcohol) (12)
- ☐ Substance abuse (drugs) (13)
- ☐ Other mental health conditions (e.g. anxiety) (14)
- ☐ Other (please specify) (15) _____

Q26 Please rate your knowledge of available services and support for individuals with TBI and their families:

- ☐ A great deal of knowledge (1)
- ☐ Moderate knowledge (2)
- ☐ Minimal knowledge (3)
- ☐ No knowledge (4)

Q27 Please rate the adequacy of the services and support that currently exists in Georgia.

- ☐ Don't know (1)
- ☐ Very Inadequate (2)
- ☐ Somewhat Inadequate (3)
- ☐ Somewhat Adequate (4)
- ☐ Very Adequate (5)

APPENDIX - C

Q28 Please rate the adequacy of medical/ hospital services in Georgia.

	Very Inadequate (1)	Somewhat Inadequate (2)	Somewhat Adequate (3)	Very Adequate (4)
Emergency room care (1)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urgent care/Walk-in services (2)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doctor's office services (3)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital inpatient services (4)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital discharge planning (5)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q29 Please rate the adequacy of acute rehabilitation services in Georgia.

	Very Inadequate (1)	Somewhat Inadequate (2)	Somewhat Adequate (3)	Very Adequate (4)
Inpatient rehab (1)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home health (2)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Outpatient rehab (3)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q30 Please rate the adequacy of the community support and services in Georgia.

	Very Inadequate (1)	Somewhat Inadequate (2)	Somewhat Adequate (3)	Very Adequate (4)
In-home services (e.g. personal care attendant) (2)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental health counselling (9)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TBI support groups (12)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information and Referral Services (information about how to find the services you need) (20)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Service coordination / case management (7)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cognitive and memory training (memory, processing, problem solving) (3)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General health management (4)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community Living Skills Training (such as cooking or money management) (19)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behavioral Supports (such as anger management and social skills training) (5)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Assistance applying for social security disability benefits (17)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transportation Services (6)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Section 8 or other housing assistance (16)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employment Services (11)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use of Assistive Technologies (such as a communication board or wheelchair) (10)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment for substance use (8)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Continuing Education Related to TBI (seminars, workshops, conferences, classes, or newsletters) (18)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX - C

Q31 What problems do people with TBI have in getting the services they need related to TBI? (Check all that apply):

- ☐ Not aware of services and resources (13)
- ☐ No centralized source for TBI information (14)
- ☐ Services and resources are far from their home (12)
- ☐ Difficulty finding providers (e.g. medical, counselor) (18)
- ☐ Professionals are not trained in working with individuals with TBI (doctors, therapists) (19)
- ☐ Lack of individualized services (20)
- ☐ Providers do not understand or respect their culture and needs (32)
- ☐ Difficulty understanding paperwork/information (15)
- ☐ Difficulty with English language (16)
- ☐ Difficulty with enrollment/admissions (17)
- ☐ Inability to pay for needed services (21)
- ☐ Cognitive limitations (11)
- ☐ Physical limitations (33)
- ☐ Inadequate insurance (22)
- ☐ Lack of support/patient advocacy (24)
- ☐ Lack of coordinated care (25)
- ☐ Lack of transportation (26)
- ☐ Inadequate support to live in a setting of their choice (31)
- ☐ Inadequate support to find employment (30)
- ☐ Inadequate support for family and caregivers (28)
- ☐ Inadequate family or peer support (29)
- ☐ Other (Please specify) (34) _____

Q32 In regards to needed services and support, what do you think is working well for individuals with TBI and their families? (Check all that apply)

- ☐ TBI education and awareness (1)
- ☐ Acute care (2)
- ☐ Information, resources, referrals (3)

APPENDIX - C

- ☐ Service coordination/ Case management (4)
- ☐ Medical Care (5)
- ☐ Continued therapy, care and counselling (6)
- ☐ Support groups (7)
- ☐ Timely diagnosis and treatment (9)
- ☐ Community based services (13)
- ☐ I don't think anything is working well (12)
- ☐ Other (please specify) (11) _____

Q33 In your experience, what are the top three barriers to employment encountered by people with TBI? (Please select only THREE boxes)

- ☐ Access to dependable transportation (1)
- ☐ Lack of awareness about Vocational Rehabilitation Services (2)
- ☐ Low expectations among professionals (3)
- ☐ Misconceptions about TBI held by professionals (4)
- ☐ Employer's concerns about risks associated hiring individuals with TBI (e.g. worker's comp) (5)
- ☐ Lack of family/community support (6)
- ☐ TBI-related factors (severity, instability, etc.) (7)
- ☐ Fear of losing benefits (SSI/SSDI) (8)
- ☐ Criminal background (9)
- ☐ Lack of skills or education needed for job goal (10)
- ☐ Limited work experience (11)
- ☐ Slow job market (12)
- ☐ Lack of long-term services and ongoing job coaching (13)
- ☐ Language and/or cultural barriers (14)
- ☐ Difficulty accessing jobs (identifying openings, application process, interviewing, etc.) (15)
- ☐ Lack of well-trained quality job developers (16)
- ☐ Lack of interpersonal or soft skills (17)
- ☐ Lack of awareness of or access to job supports, assistive technology or accommodations (18)
- ☐ Lack of affordable housing (19)

APPENDIX - C

- ☐ Lack of physical accessibility (20)
- ☐ Lack of personal care attendant (21)
- ☐ Other: Please describe (22) _____

Q34 What would you like to see improved about TBI service system in Georgia? (Select all that apply):

- ☐ Create and expand Medicaid waivers for brain injury (1)
- ☐ Access to more Community based Supports and Services (2)
- ☐ More Services (funding, duration, intensity) (3)
- ☐ More statewide services (in rural areas) (4)
- ☐ Need more providers that specialize in brain injury (5)
- ☐ Training & Education for professionals (doctors, counselors) working with individuals with TBI (6)
- ☐ Training professionals on providing culturally responsive services (7)
- ☐ Training and Education of agencies and organizations that work with individuals with TBI (8)
- ☐ A central database of service providers and agencies with contact information (9)
- ☐ Centralized case management, service coordination and referrals for TBI (10)
- ☐ Increased training and advocacy for survivors of brain injury (11)
- ☐ Information on living well with brain injury (12)
- ☐ Training and Education for family members and caregivers (13)
- ☐ Increased awareness of brain injury across the state (14)
- ☐ Other (specify) (15) _____

Q35 What do YOU feel needs to be done to improve statewide services and supports for people with TBI and their families?

APPENDIX - C

Q36 What are the rewards of working with individuals with a TBI?

Q37 Are you sure you want to submit your final responses to the survey? (Note: You can use the back button to go back to the previous questions and make changes.)

☐ Yes I am sure (1)

APPENDIX - D

Focus Group Questions - Individuals with TBI

1. What services are most needed for individuals with TBI and their families? (Probe: medical, rehabilitation, community-based; Speech, PT, OT, Cognitive, mental health, neuropsychological therapies)
2. Talk more about your experience accessing services for your TBI. What challenges or barriers have you faced in accessing TBI services and support? (Probes: rehabilitation and therapies (Speech, PT, OT, Cognitive, mental health, neuropsychological therapies; benefits (SSDI, Medicaid); support groups, counseling; insurance pre-approvals, services are far, transportation, housing, lack of coordinated care, not culturally responsive; are services adequate?)
3. What are some gaps in services for individuals with TBI and their families from unserved and underserved regions and populations in Georgia?

How trained and competent are providers in providing culturally responsive care and services to individuals with TBI from underserved and unserved communities?
4. What would you say are some of the gaps in the TBI service delivery system in Georgia? (Probes: lack of coordinated care, geographical disparity in services, transportation, housing challenges, centralized source of TBI information, training of professionals, community on TBI)
5. What suggestions do you have for improving the services and supports for individuals with TBI and their families in Georgia? (Probes: more Community based Supports and Services, more services, more funding, more education, care coordination)
6. What are some things that are working well for the brain injury service delivery system in Georgia?
7. Is there anything else you would like to share?

APPENDIX - E

Focus Group Questions - Caregivers of Individuals with TBI

1. What services are most needed for individuals with TBI and their families? (Probe: medical, rehabilitation, community-based; Speech, PT, OT, Cognitive, mental health, neuropsychological therapies)
2. Talk more about your experience accessing services for the person with TBI. What challenges or barriers have you faced in accessing TBI services and support? (Probes: rehabilitation and therapies (Speech, PT, OT, Cognitive, mental health, neuropsychological therapies; benefits (SSDI, Medicaid); support groups, counseling; insurance pre-approvals, services are far, transportation, housing, lack of coordinated care, not culturally responsive; are services adequate?)
3. What are some challenges that you experience as you care for the person with TBI?
4. What are your needs related to support as you care for the individuals with TBI? Are you able to access the support and services needed?
5. What would you say are some of the gaps in the TBI service delivery system in Georgia? (Probes: lack of coordinated care, geographical disparity in services, transportation, housing challenges, centralized source of TBI information, training of professionals, community on TBI)
6. What are some gaps in services for individuals with TBI and their families from unserved and underserved regions and populations in Georgia?

How trained and competent are providers in providing culturally responsive care and services to individuals with TBI from underserved and unserved communities?
7. What suggestions do you have for improving the services and supports for individuals with TBI and their families in Georgia? (Probes: more Community based Supports and Services, more services, more funding, more education, care coordination)
8. What are some things that are working well for the brain injury service delivery system in Georgia?
9. Is there anything else you would like to share?

APPENDIX - F

Key Informant Interview Questions

Main Questions	Probes (If any)
Tell me a little more about your professional role and your experiences related to individuals with TBI	Job title, your role, experience related to TBI
What are the most needed services for individuals with TBI and their caregivers in Georgia?	Rehabilitation, therapies, mental health support, support groups, transportation, housing, employment.
What are some challenges or barriers that individuals with TBI face in accessing services and support in Georgia?	-transportation, housing, lack of services, lack of information, insurance issues, services are far, providers not trained, lack of caregiver support, legal services, lack of coordinated care, lack of individualization, not culturally responsive
What are your views about the current status as far as adequacy and accessibility of services and support for individuals with TBI and their families in Georgia?	-Talk about the adequacy of medical, hospital services -adequacy of acute rehabilitation services -adequacy of community services and support
With regard to services and support, what do you think is working well for individuals with TBI and their families in Georgia?	TBI education and awareness, acute care, Information, resources, referrals, Service coordination/ Case management, Medical Care, Continued therapy, care and counseling, support groups, timely diagnosis and treatment, community based services
What would you say are some of the gaps in the brain injury service delivery system in Georgia?	Probes: lack of coordinated care, geographical disparity in services, transportation, housing challenges, centralized source of TBI information, training and education of professionals, community on TBI
What are some gaps in services for individuals with TBI and their families from unserved and underserved regions and populations in Georgia?	
Can you think of any specific issues or concerns that should be considered and addressed related to services and support for individuals with TBI and their families in Georgia? Yes/No. If yes, what are they?	
What do YOU feel needs to be done to improve statewide services and supports for people with TBI and their families?	Create and expand Medicaid waivers for brain injury, Access to more Community based Services and support, need more providers that specialize in brain injury, training and Education for professionals (doctors, counselors), information and referral, case management.
Is there anything else you would like to share?	

APPENDIX - G

Power of Patients AI data tracking tool and Dashboard

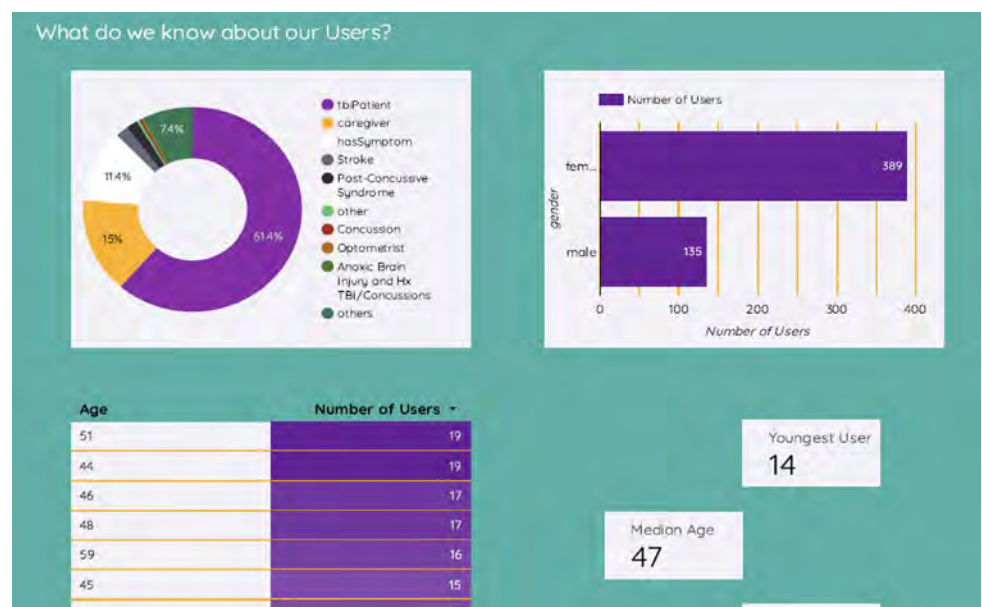
There is a pervasive knowledge gap that exists among researchers, the medical and patient communities as it pertains to Traumatic Brain Injuries (TBI). Power of Patients (PofP) is a patient-centric app that records patient symptoms and triggers, while providing patients, caregivers and clinicians health management support. Through individualized symptom and triggers tracking, PofP tool can be used to personalize care for individuals with TBI, accelerate their recovery.

Power of Patients (PofP) has entered in a strategic partnership with the Brain Injury Association of Georgia (BIAG). The primary purpose of this agreement is to mutually support each organization's mission. Recognizing that BIAG focuses on the outreach and education for persons suffering from and engaged with brain injuries and PofP offers education, advocacy and personalized data for each user, PofP and BIAG has discovered they have shared memberships. In order to boost engagement and increase outreach efforts and membership, PofP and BIAG now provide mutual referral efforts. Additionally, BIAG realizes that evidence [data] is necessary in order to provide appropriate services to their constituents, and through the MOA, PofP can supply BIAG with brain injury data specific to Georgia.

One example of the data reporting is provided below. This sample output is an example that demonstrates and highlights the brain injury symptom trends people are still experiencing, despite the extreme number of years they have been seeking help. Having access to this type of data, BIAG recognizes they will be able to appropriate proper funding to support individuals with necessary services and align providers with appropriate patients.

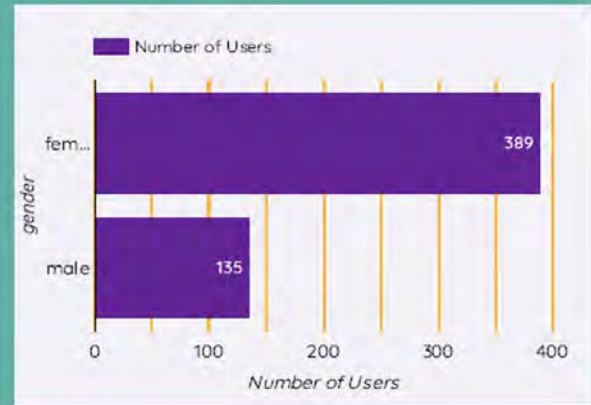
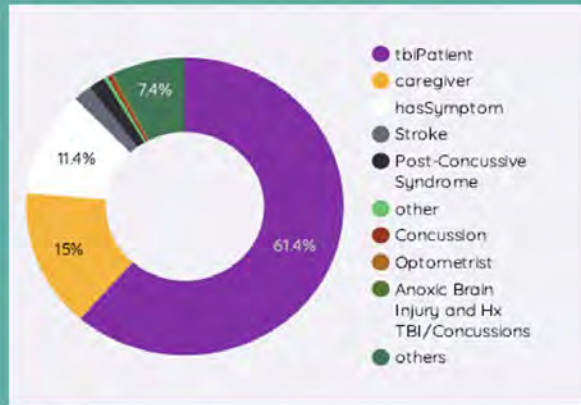
After a preliminary review of the existing PofP registered users, it has been identified that PofP data warehouse has nearly 50% more Georgia users than has been identified by BIAG. These PofP Georgia users are actively tracking their current symptoms and social determinants of health, which indicates they have not fully received appropriate rehabilitation and may be a fiscal burden to the Georgia healthcare system, disability and employment divisions. Appendix B shows the categories of the available data to track broken down by medical domains and SDOH.

Power of Patients has developed 1 solution, a proprietary AI augmented platform, that serves 3 constituents; patients, clinicians, and industry. We have the solution to personalize care for persons with brain injuries, accelerate their recovery and supply aggregated, deidentified data and reports to our partners so that services may be provided for the TBI patients in Georgia.



APPENDIX - G

What do we know about our Users?



Age	Number of Users
51	19
44	19
46	17
48	17
59	16
45	15
66	15
47	15

Youngest User
14

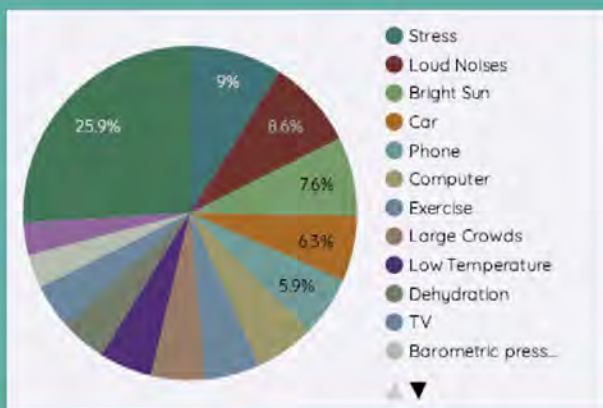
Median Age
47

Oldest User
110

User Analytics - Symptom Breakdown

POWER OF PATIENTS

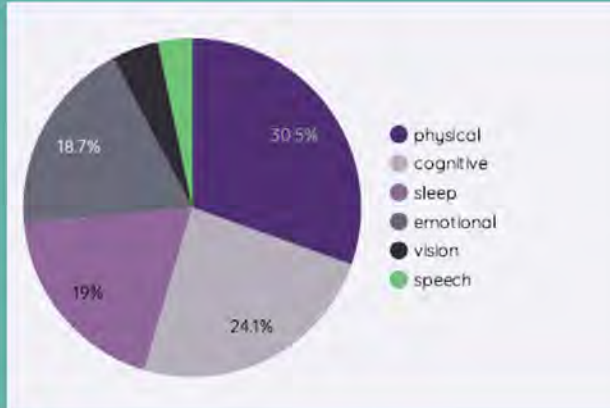
What SDOH Symptoms are they tracking?



factor	Percentage
1. Stress	9.02%
2. Loud Noises	8.6%
3. Bright Sun	7.64%
4. Car	6.33%
5. Phone	5.85%
6. Computer	5.8%
7. Exercise	5.34%
8. Large Crowds	5.17%

APPENDIX - G

What Medical Symptoms are they tracking?



factor	subcate...	Percentage
1. Headaches and/or ...	physical	7.98%
2. Fatigue	sleep	6.26%
3. Loss of Balance/Di...	physical	6.08%
4. Anxiety	emotional	4.87%
5. Short Term Memor...	cognitive	4.72%
6. Can't find the right ...	cognitive	4.61%
7. Brain Fog, Lack of F...	cognitive	4.38%
8. Slow Thinking or Pr...	cognitive	3.89%

1 - 100 / 227 < >

Summary report for Jan 12 - Feb 10, 2021



GOALS

1. I want to sleep better
2. walk 4 miles
- 3.



DETAILS

Date	Symptom	Severity	Description
01-12-2021	Caffeine		
01-12-2021	Feeling Today	100	

APPENDIX - G

