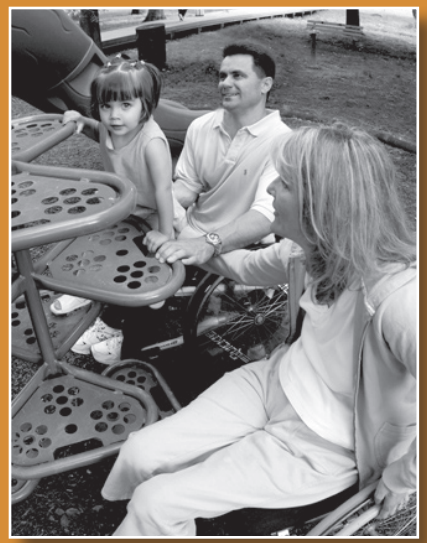
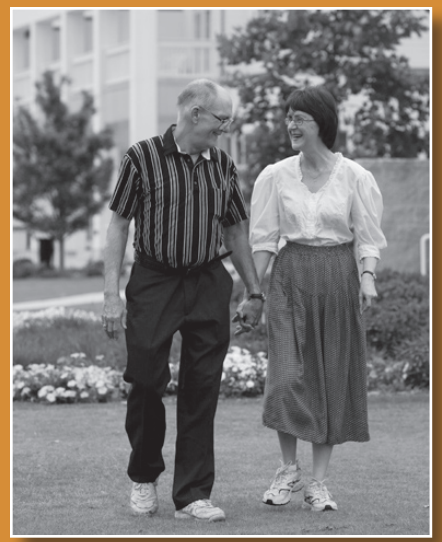
Brain and Spinal Injuries in Georgia: A Needs Assessment and State Action Plan

A report on the needs of Georgians with brain and spinal injuries and the opportunities to enhance quality of life and community living





Brain & Spinal Injury Trust Fund Commission

Sonny Perdue, Governor • State of Georgia • July 2008

MISSION

The Brain & Spinal Injury Trust Fund Commission enhances the lives of Georgians with traumatic brain and spinal cord injuries. Guided by the aspirations of people with traumatic injuries, the Commission supports lives of meaning, independence and inclusion. As the state's Lead Agency on Traumatic Injuries we:

- administer the Central Registry to identify those who are injured,
- distribute resources through the Trust Fund, and
- advocate for improvements in statewide services.

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ACKNOWLEDGEMENTS

The Needs Assessment and State Action Plan were developed by the Brain & Spinal Injury Trust Fund Commission, the Lead Agency on Traumatic Brain & Spinal Injuries for the state of Georgia. The Plan represents a collaborative effort among members of the Commission's Traumatic Injury Advisory Committee, the Brain Injury Task Force, the Children & Youth Subcommittee, and the Spinal Cord Injury Task Force, which include a broad representation of people with brain and spinal injuries, caregivers, advocates, clinicians, service providers, state agency representatives, and others from across the state. The members of these committees contributed an immeasurable amount of time and energy to the formation of this report in the hope that it will lead to a comprehensive system of services that promotes community-based, independent living for Georgians with brain and spinal injuries.

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EXECUTIVE SUMMARY

A Significant Public Health Problem

Brain and spinal injuries are a significant public health issue for the state of Georgia. These injuries affect more than 70,000 Georgians each year, resulting in substantial costs to the individual, the family, and the state in terms of decreased quality of life, lost wages, and need for services. While brain and spinal injuries can be devastating, it is possible for people with such injuries to live lives of independence and meaning within the community. To do so, however, requires a commitment at the local, state, and national level to develop a comprehensive, specialized, and coordinated system of care.

Evaluating the Needs

To determine whether such a system exists in Georgia, and whether Georgians with brain and spinal injuries are receiving sufficient services and funding to support quality of life in the community, the Brain & Spinal Injury Trust Fund Commission conducted a formal Needs Assessment. In its capacity as the Lead Agency on Traumatic Brain and Spinal Injuries for the state of Georgia the Commission invited stakeholders from across the state to participate in a series of focus groups, surveys, roundtable discussions, and reviews of data and research. The Assessment, which is detailed in this report, examines the wide range of needs of people with traumatic injuries and compares them to the existing level of services and funding provided in Georgia. The results of the Needs Assessment reveal that there are many gaps in services and funding that prevent Georgians with brain and spinal injuries from living as independently as possible and contributing to their communities. Specific areas of need that were identified include:

For people with brain injuries

- Screening & Identification
- Training & Awareness
- Rehabilitation & Wellness
- Service Coordination
- Long-term or Lifelong Supports

For people with spinal cord injuries

- Training & Awareness
- Rehabilitation & Wellness
- Service Coordination
- Tools for Independent & Integrated Living
- Community Participation

A Plan for Improvement

To address these areas of need and identify ways to create a high quality system of care the Commission also developed a State Action Plan. Again, the Commission included a variety of people with experience and expertise to serve on subcommittees that analyzed the results of the Needs Assessment, reviewed best practices both locally and throughout the country, and developed recommendations for ways to develop a system that will support independent living for Georgians with brain and spinal injuries. The resulting Plan contains numerous goals that have been organized into seven initiatives, including:

- Educating state agencies and elected officials of the incidence, needs, and specialized service models for Georgians with brain and spinal injuries;
- Securing adequate and specialized funding, and a single point-of-entry to the service system;
- Improving medical and rehabilitative care, health and wellness, and access to school services;
- Enhancing support for people with brain and spinal injuries, their families and caregivers;
- Identifying and screening additional people with brain injuries;
- Facilitating independent living and community participation; and
- Reducing the incidence of brain and spinal injuries among Georgians.

Helping Georgia's Children with Injuries

Because children and youth are at high risk of sustaining brain and spinal injuries the Commission included specific goals and initiatives to support them, including:

- Increasing funding for school re-entry services;
- Ensuring that schools are prepared to support children and youth with injuries;
- Increasing identification of children and youth with brain injuries;
- Enhancing the ability of children and youth with brain and spinal injuries and their families to become self-advocates; and

- Providing a seamless transition from youth to adulthood.

A Collaborative Effort

The Commission respectfully presents the results of the Needs Assessment and the recommendations of the State Action Plan to the Governor, General Assembly, state agency leaders, and the citizens of Georgia with the hope that it will prompt meaningful dialogue and the development of partnerships to accomplish the goals of the Plan. Although this multi-year Plan has been developed by the Commission it recognizes that successful completion of the Plan will require the involvement of many and hopes that agencies, organizations, and individuals across the state will take ownership of the Plan and identify ways in which they can assist in its completion.

Recommendations for FY09

The Commission will begin the process of implementing the recommended goals in the State Action Plan during FY 2009. To assist with this process the Commission requests the assistance of the Governor, the General Assembly, state agency leaders, and the citizens of Georgia during this next year to:

1. Learn more about the incidence, needs, and specialized service models for Georgians with brain and spinal injuries.

2. Modify the Medicaid waivers and allocate additional funds to improve services and support for Georgians with brain and spinal injuries who need:
    a. In-home and day programs
    b. Durable medical equipment, supplies, and assistive technology
    c. Attendant services
    d. Neurobehavioral services
    e. Respite

3. Support the Commission's request for additional surcharges on specific violations including disability parking violations, failure to wear a helmet while riding a motorcycle, boating under the influence, and reckless driving, in order to increase revenue for the Brain & Spinal Injury Trust Fund.

For a complete copy of the State Action Plan, including the objectives, timeline, partners, and outcome measures, please go to www.bsitf.state.ga.us or call 404/651-5112.

INTRODUCTION

The Brain and Spinal Injury Trust Fund was created by legislation in 1998 to provide funds to assist people with traumatic brain injuries (TBI) and spinal cord injuries (SCI) with the costs of receiving care and rehabilitative services. People with TBI and/or SCI can apply for funding for a range of services and goods, including home modifications, durable medical equipment, personal assistance, assistive technology, transportation, respite, and rehabilitation. The Commission also administers the Central Registry on Traumatic Brain and Spinal Injuries, the state's service registry that tracks the number of people with TBI and SCI who were treated in a hospital setting and provides information about available resources to them soon after injury.

In addition, the Commission is the state's Lead Agency on Traumatic Brain and Spinal Injuries. In this role the Commission is charged with assessing the needs of Georgians with traumatic brain and spinal injuries and making recommendations to the Governor and General Assembly for improvements to the state's system of care for them. To accomplish this, the Commission created the Traumatic Injury Advisory Committee, inviting representatives of state agencies, people with traumatic brain and spinal injuries, family members, service providers, and advocates to collaborate in this effort.

In 2005 the Commission was awarded a three-year Traumatic Brain Injury Implementation Partnership Grant from the Federal Health Resources and Services Administration, Maternal and Child Health Bureau, to conduct a formal needs assessment of people with TBI and their families, and to develop a set of comprehensive recommendations for improvements to the state's system of services for people with TBI. This report is the result of that effort.

(Given that the needs of people with acquired brain injuries (ABI) – those brain injuries that are caused by a non-traumatic event such as stroke, heart attack, anoxia, etc. – mirror the needs of people with TBI the Commission has broadened the Needs Assessment and State Action Plan to include the needs of people with ABI as well. Similarly, since the Commission distributes the Trust Fund to people with SCI the Commission has also included their needs in this report.)

The Advisory Committee began by conducting a formal Needs Assessment to identify the needs of Georgians with brain and spinal injuries and compare them to the current level of services and funding provided in Georgia. First, the Committee invited stakeholders from across the state - people with TBI and SCI, their family members, service providers, advocates, and other experts - to participate in a series of focus groups, roundtable discus-

What is a Lead Agency on Traumatic Brain & Spinal Injuries?

Title 42, Chapter 6A, Subchapter X of the 1996 Traumatic Brain Injury (TBI) Act (citation 42 USC Sec. 300d-52 01/22/02) requires each state to designate an agency to serve as the lead agency on traumatic brain injury. The lead agency is responsible for establishing an advisory board that makes recommendations to the State on ways to improve service coordination regarding traumatic brain injury.

In 2003, the Brain and Spinal Injury Trust Fund Commission was asked to take over the role of Lead Agency in Georgia since the Commission is the only state agency that is solely focused on the needs of people with traumatic brain and spinal injuries. The Commission agreed to take on the role and immediately established the Traumatic Injury Advisory Committee to fulfill the requirements of the federal TBI Act. Because the Commission is focused on the needs of both people with traumatic brain injury and people with traumatic spinal cord injury the Commission expanded the scope of the Lead Agency role, and subsequently the Advisory Committee, to include the needs of both populations.

The goal of the Traumatic Injury Advisory Committee is to improve the state system of services for Georgians with traumatic brain or spinal cord injuries and their families by providing ongoing evaluation of the needs for and delivery of services, developing collaborations among stakeholders, and making policy recommendations to improve coordination of and access to services.

sions, and surveys over a four-year period, including:

- 19 focus groups held in 9 cities across the state between January and April, 2003;
- 9 roundtable discussions held between November, 2005 and April, 2006; and
- 1 survey of children with TBI and SCI and their families, distributed between August and September, 2007, in partnership with Children's Healthcare of Atlanta.

The Committee also reviewed additional material including:

- A 1998 report on the needs of Georgians with TBI conducted by the State Health Planning Agency (the Lead Agency on TBI for the state of Georgia at the time);
- A 2005 survey of brain injury support group participants conducted by the Brain Injury Association of Georgia;
- A 2006 report on the most effective use of Brain & Spinal Injury Trust Fund dollars developed by the University of Georgia's Institute on Human Development and Disability;
- Feedback from the 2006 Brain Injury Support Group Leaders' Summit held by the Brain Injury Association of Georgia;
- Trust Fund distribution data, which includes the number and types of services and goods for which Trust Fund dollars are being requested; and
- Incidence and other data from the Central Registry on Traumatic Brain & Spinal Injuries.

Lastly, the Committee incorporated the findings from the Commission's White Paper titled "Georgia's Neurobehavioral Crisis: Lack of Coordinated Care, Inappropriate Institutionalizations." In the paper, which was released in October, 2007, the Commission described the needs of Georgians with brain injuries, particularly those who experience significant behavioral problems as a result of their brain injury, and called for the development of a specialized and coordinated system of care. The recommendations included in the White Paper are relevant to the Needs Assessment as they accurately describe the needs of Georgians with brain injury as well as gaps in services.

Once the needs were identified the Advisory Committee began the three-fold process of assessing the current level of services in order to identify existing services as well as any gaps in service. First, the Committee mailed surveys to 26 state agencies inquiring about the types of services provided to people with brain and spinal injuries. The Committee reviewed the responses to the survey and developed profiles of each agency to show the existing level of services for Georgians with these injuries (see Appendix B). Second, the Committee reviewed the listing of community-based services for people with disabilities from the ESP/Connect database maintained by the Atlanta Regional Commission's Area Agency on Aging. This listing, which contains over 17,000 resources that are available for older adults or people with disabilities in Georgia, helped the Committee to identify services that are provided locally across the state (see Appendix C). Third, the Commission compared the three primary Medicaid waiver programs to assess their level of support for Georgians with brain and spinal injuries (see Appendix D).

Findings from the Needs Assessment were then used to develop a State Action Plan. Again, the process of creating the State Action Plan was highly inclusive and involved stakeholders from across the state. Together, these stakeholders created a State Action Plan that contains 43 goals which, when accomplished, should address the identified needs and result in a comprehensive, specialized and coordinated system of care for Georgians with brain and spinal injuries. The Plan is respectfully presented with the goal of assisting state leaders and other stakeholders in developing partnerships to support its implementation.

What is a brain injury?

There are two types of brain injury:

A **traumatic brain injury (TBI)** is caused by a jolt, blow or penetrating injury to the brain. Georgia defines traumatic brain injury as "an injury to the brain, not of a degenerative or congenital nature, but arising from blunt or penetrating trauma from acceleration-deceleration forces, that is associated with any of these symptoms or signs attributed to the injury:

- *decreased level of consciousness*
- *amnesia*
- *other neurological or neuropsychological abnormalities*
- *skull fracture or*
- *diagnosed intracranial lesions.*

These impairments may be either temporary or permanent and can result in a partial or total functional disability."

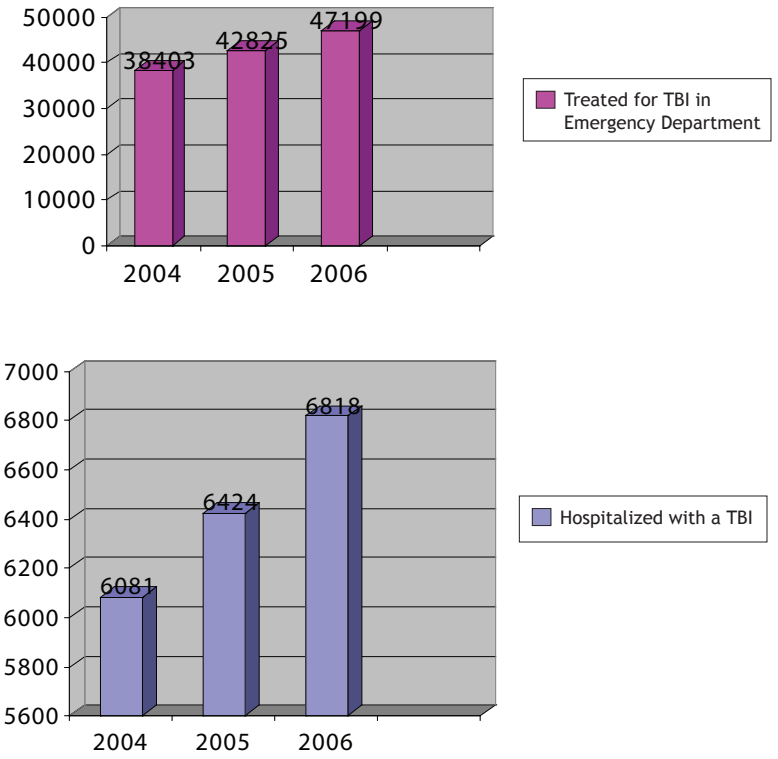
Whereas with TBI only specific areas of the brain can be affected (depending upon which parts of the brain were injured), **acquired brain injury (ABI)** is an injury that takes place at the cellular level, meaning that the injury can effect cells throughout the entire brain. According to the Brain Injury Association of America, "an acquired brain injury is an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. An acquired brain injury is an injury to the brain that has occurred after birth."

How many people have a brain injury?

Traumatic brain injury is the leading cause of death and disability for anyone age 45 or younger. According to the Centers for Disease Control and Prevention (CDC) there are 1.5 million new TBI's every year in the United States. In Georgia, the incidence of traumatic brain injury is increasing rapidly, up 21% from 2004 to 2006, as shown at right:

Incidence of Traumatic Brain Injury in Georgia, 2004-2006

Source: Central Registry for Traumatic Brain and Spinal Injuries



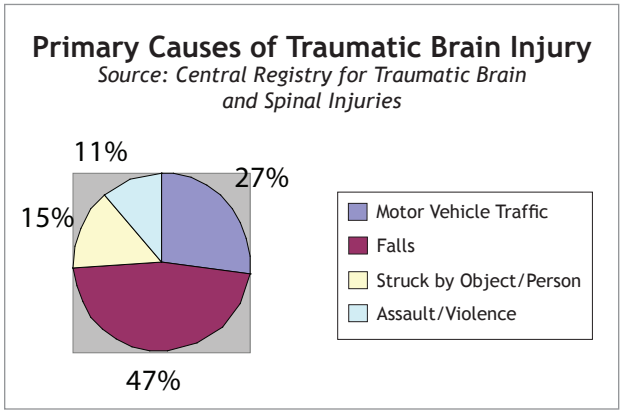
The CDC estimates that approximately 2% of the U.S. population, or at least 5.3 million Americans, currently have a long-term or life-long need for help to perform activities of daily living as the result of a traumatic brain injury. Accordingly, this could mean that approximately 187,000 Georgians have a long-term or lifelong disability relating to TBI.

It is important at this point in time to note that TBI is not just a civilian issue. Indeed, the Defense and Veterans Brain Injury Center has declared that TBI is the "signature wound" of the wars in Iraq and Afghanistan. This is because a significant number of soldiers are returning from these wars with brain injuries that were caused, in part, by explosive devices resulting in concussive shock blasts or "blast injuries" that are damaging to the brain. According to the *New York Times* (July 6, 2008), a study conducted in 2008 found that "nearly one in five service members, or about 320,000 people, were likely to have suffered a traumatic brain injury in Iraq or Afghanistan." Given the large number of military bases in the state it is likely that many of these veterans will require services and support from the state of Georgia to live as independently as possible.

While the incidence rate for acquired brain injury is not as high as that of TBI its impact is still significant on our society. According to the Georgia Hospital Association more than 15,000 Georgians sustained an ABI for 2005. As previously stated, people with ABI experience the majority of symptoms and issues, including behavioral issues, that people with TBI experience, leading to the same need for long-term or lifelong services and funding.

What are the causes of brain injury?

As shown below, the primary causes of TBI are motor vehicle crashes and falls. Other causes are gunshot wounds, violence and assaults, industrial or work-related injuries, and sports-related injuries.



Causes of ABI can include near-drowning, choking, electrical shock, heart attack, stroke, infectious disease, brain tumors, and exposure to toxic gases.

What are the costs of care for people with brain injuries?

Whether the injury is the result of a car crash, a slip and fall, a stroke, or a disease the economic consequences of brain injury can be enormous. In the United States, the average lifetime cost of care for a person with a brain injury ranges from $600,000 to $1,875,000, although studies have shown that the lifetime costs of care for someone with a severe brain injury can reach as high as $4,000,000. This does not include lost earnings of the injured person or family caregivers. The total cost of brain injury to the nation is estimated at $56.3 billion annually.

Source: Report of the NIH Consensus Development Conference on the Rehabilitation of Persons with Traumatic Brain Injury. National Institutes of Health, National Institutes of Child Health and Development, Bethesda, MD: 1999.

What are neurobehavioral problems associated with brain injuries?

In some cases brain injury can cause significant behavioral issues, often called neurobehavioral issues. According to the Brain Injury Association of America, the term neurobehavior refers to "an individual's ability to process thoughts or to think, behave socially, communicate, and control emotions." Thus, the term neurobehavioral is frequently used to describe the significant behavioral problems that often result from an injury to the brain. These cognitive and behavioral problems may relate to:

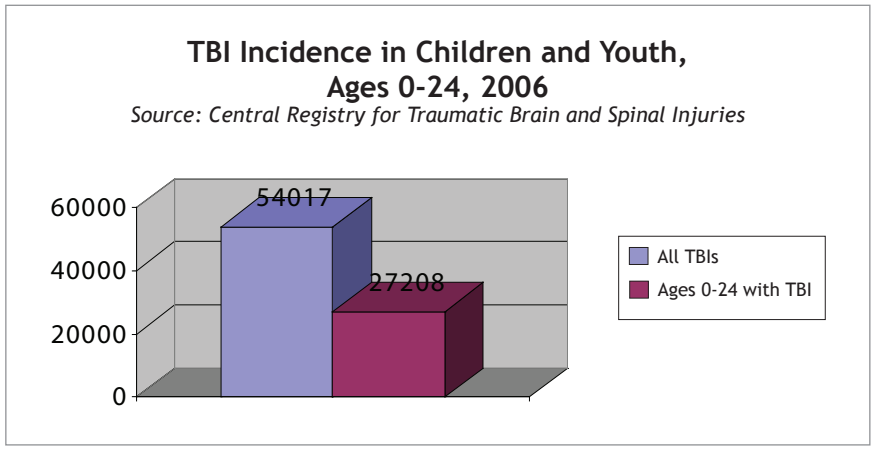
- concentration
- memory and attention
- impulsivity
- aggression
- irritability
- depression
- moodiness
- changes in personality

In layman's terms, a person with neurobehavioral issues may be verbally disruptive or threatening, destroy property, behave inappropriately sexually, resist assistance from others, or exhibit physical aggression. These cognitive and behavioral issues have the most significant impact in terms of an individual's ability to return to work and reside in the home and community. As a result, it is critical to address the particular needs of Georgians with neurobehavioral issues in designing a comprehensive, specialized, and coordinated system of care for people with brain injury.

Studies estimate that, of the 187,000 Georgians who have a long-term or lifelong disability as the result of a traumatic brain injury, between 3 and 10%, or anywhere from 5,600 – 18,700, of them will require ongoing, intensive services and supports due to the neurobehavioral issues they experience. In addition, many people with ABI will also require extensive services and supports as a result of their neurobehavioral issues.

How does brain injury affect children?

As previously stated, TBI is the leading cause of death and disability for anyone under age 45. This means that children and youth are particularly at risk for sustaining a brain injury. This is confirmed by the Central Registry, which identified 27,208 children and youth age 0 – 24 who were either treated in an emergency department or admitted to the hospital for a TBI in 2006. That means that 54% of all TBI's in Georgia in 2006 were sustained by someone under age 24, as shown below.



Falls are the leading cause of traumatic brain injury for children ages 0 to 4 years. This age group has the highest rate of TBI-related emergency department visits, followed by older adolescents ages 15-19 years. Other causes of TBI for children and youth include bicycles, skate boards, other sporting injuries and child abuse.

Children who sustain a brain injury are three times more likely to develop behavioral and emotional problems even if the child had no prior history of difficult behaviors. However, for children who receive a brain injury at an early age, neurobehavioral problems may not become apparent or identified until many years after their injury. Often, by the time difficult behavior becomes apparent, children are many years post-injury and the diagnosis of TBI is not available in their current medical or school records. This is because a child does not develop the capacity for higher reasoning until adolescence so any behavioral or cognitive problems may not manifest until that time. As a result, many children with TBI are often diagnosed or classified as having a learning disability, an emotional disability or mental retardation rather than neurobehavioral issues following a TBI. This can cause significant stress and exacerbate symptoms for the child, the family, and the school system when a child is improperly diagnosed.

What are the needs of Georgians with brain injuries?

In its October, 2007 White Paper on the needs of Georgians with brain injury, particularly those who experience significant behavioral problems as a result of their injury, the Commission identified the following needs, which have been confirmed by the results of the Advisory Committee's various data collection methods for this report:

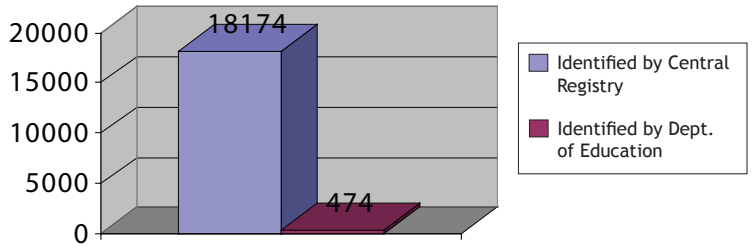
- **Screening and identification**
  It is very common for people to have an undiagnosed – and therefore unidentified – brain injury. This is particularly true for mild traumatic brain injuries that are often dismissed or minimized for being a "bump on the head" or "just a concussion." However, this is also true for more severe injuries if the person has, at the same time, sustained other significant or life-threatening physical injuries (such as in a car accident where the person may have also sustained a spinal cord injury, severed limb, or other severe injury) that may take precedent over diagnosis of head trauma. Proper screening for people with brain injury is critical in order to identify any subsequent problems, such as neurobehavioral issues, and arrange and provide appropriate supports.

  Presently, the state of Georgia does not have a systematic way of screening and identifying people with brain injuries. Screening efforts are primarily limited to service providers with expertise in brain injury, however, this assumes that a person with a brain injury has already been identified and referred to such experts. Generally, screening efforts are fragmented or nonexistent among other agencies and providers whose populations are more diverse,

but who may include people with TBI. One example of this is illustrated by a comparison between Central Registry and Department of Education (DOE) data. In 2006, the Central Registry identified a total of 18,174 children between ages 3 and 21 who were either hospitalized or treated and released from emergency departments for TBI. In the same year the DOE reported that only 474 children between ages 3 and 21 had been identified by the school systems as having a TBI, as shown below. This lack of identification means that thousands of children with TBI are not receiving the specialized supports that school systems could offer them. Thousands of adults with brain injury are suffering a similar fate because of the lack of formalized screening processes in other service systems throughout the state.

Comparison of Identified Children and Youth (ages 3-21) with TBI, 2006

Source: Central Registry for Traumatic Brain and Spinal Injuries and Georgia Department of Education



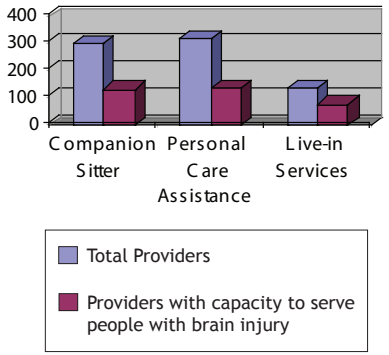
- **Training and awareness**

It can be challenging to provide support for people with brain injury, especially if they have neurobehavioral issues. This is particularly true for the people who are actually providing the support: rehabilitation professionals, family members, other caregivers, personal attendants, teachers, nurses, therapists, etc. Specialized training for care providers is critical and should be conducted in a variety of settings and across agencies in order to assist with screening and identification; provide adequate and appropriate rehabilitation and support services; reduce stress, high turnover, and burnout in families, caregivers, and support services staff; and reduce long-term costs of care and inappropriate placements.

Unfortunately, Georgia is facing many of these problems because of its lack of organized training programs. One of the most serious problems is that there are not enough service providers who can provide specialized services for people with brain injury in the state, especially if they have neurobehavioral issues. This is revealed in the results of an analysis of the ESP/Connect database, which shows that less than half of the private providers in Georgia have staff that is trained to serve people with TBI, as shown above and in Appendix C.

Service Providers with Capacity to Serve People with Brain Injury

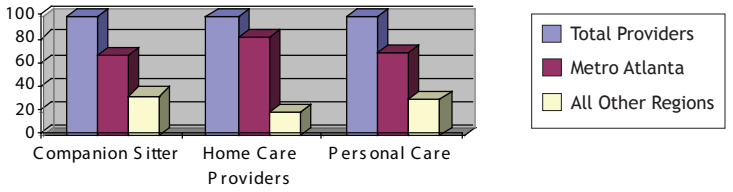
Source: Atlanta Regional Commission's Area Agency on Aging



Further analysis reveals that anywhere from 67% - 82% of the providers who do have the capacity to serve people with TBI are located in the metro-Atlanta area of the state, leaving families in all other areas of the state with very few options for community-based services, as shown below, and in Appendix C.

Location of Service Providers with Capacity to Serve People with Brain Injury, by Percentage

Source: Atlanta Regional Commission's Area Agency on Aging



(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.)

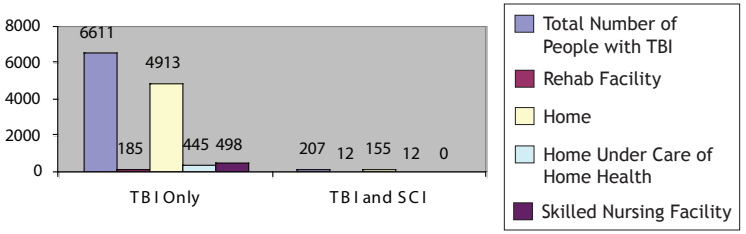
- **Rehabilitation and wellness**

Once a person has been identified as having a brain injury it is critical that he/she receives adequate and appropriate rehabilitation. This is necessary to increase his/her ability to live successfully in the community or in the least-restrictive setting possible. Obviously, rehabilitation is most effective if provided 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. Appropriate therapy for brain injury may include: a) cognitive and behavior therapy, as well as specialized counseling and psychotherapy; b) transition services, including organizing and/or arranging the home environment in such a way that functional skills are developed or facilitated; and c) pharmacological interventions.

Unfortunately, the majority of Georgians with brain injuries are not receiving the rehabilitation they need. According to the Central Registry, in 2006 only 185 (or 2.7%) of the 6,611 people who were hospitalized for a TBI, and only 12 (or 5.7%) of the 207 people who were hospitalized for both a TBI and SCI, were discharged to a rehabilitation facility, as shown below. The majority (4,913, or 74%) of people were instead sent home, only a few under the care of a home health agency. Others were discharged to skilled nursing facilities (nursing homes), most of which do not have the specialized training to care for a person with brain injury and are an inappropriate placement for them.

Destination Upon Discharge From Hospital: People with Traumatic Brain Injury, 2006

Source: Central Registry for Traumatic Brain and Spinal Injuries



The most common reason that people do not get rehabilitation following a traumatic injury is that 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 understand this about brain injury and will subsequently not provide sufficient funding for rehabilitation.

> *"Continued medication will stabilize my mental state to do ordinary tasks without delusions, fear, and/or hallucinations, etc. Eliminating my fear of social environments will allow me to be a more active participant in my community and in the lives of my family."*
>
> - P., person with TBI who needs specialized counseling and medication for brain injury

The problem is also caused by increasing problems with the Medicaid system. People who were on Medicaid at the time of their injury are often unable to get rehabilitation. This is because Medicaid's reimbursement rates are too low and, as a result, hospitals have limited the number of inpatient rehabilitation beds they offer to patients who will be using Medicaid to pay for services. The prospects are even worse for people who were not on Medicaid at the time of their injury. First, in order to qualify for Medicaid a person must first apply for social security, a process which takes anywhere from nine months to two years. Until they are approved for social security they are considered to be "Medicaid pending," which means that hospitals do not have a guarantee of payment and are reluctant to accept such patients. Second, by the time the person is approved for Medicaid (again, possibly 9 months to two years following their injury) he/she is ready for outpatient therapies and services. However, by that time Medicaid has determined the person's condition to be "chronic" and will not approve such services. Even for those few cases where there is the possibility of approval for outpatient services, Medicaid's process for preauthorizing outpatient services is so lengthy that many facilities are reluctant to invest the time to go through it when, again, the

"If I can continue my physical therapy they say I will be able to walk with a walker or crab crutches instead of being in a wheelchair. I will feel like a human being that can function more in my every day life."

- R., person with TBI who needs therapeutic and rehab services

reimbursement rate is so low.

As a result of these problems with Medicaid and private insurance people have requested funding for rehabilitation from the Brain & Spinal Injury Trust Fund, making it the second most requested item among people with TBI. Unfortunately, the Trust Fund has limited resources and insufficient funding to meet the need for brain injury rehabilitation in Georgia.

- **Service coordination**

Georgians with brain injuries face many challenges in getting the services and goods they need to live as independently as possible in the community or in the least restrictive setting, however, by far the greatest need that was identified consistently across all methods of the Needs Assessment, and which was highlighted in the White Paper, was the need for service coordination.

Service coordination is absolutely critical to providing a seamless system of care. Families are overwhelmed by their grief, loss of financial security, lack of knowledge of the needs of their loved one, and lack of familiarity with the services and funding available to address those needs. The world as they know it has changed dramatically overnight. At the same time, the state's system of services is fragmented: there is little or no communication between agencies, application processes are redundant, eligibility criteria is complex and confusing, and there are often waiting lists, making it very difficult for people to get even the most basic services and goods.

Participants in the focus groups, surveys, and roundtable discussions all emphasized the difficulty of locating and accessing the rehabilitation, services, and goods necessary to gain or return to a high quality of life following a traumatic injury in Georgia. Contributing to the difficulty is:

- the lack of a single point-of-entry to access services;
- the lack of a standardized application process;
- confusing eligibility criteria;
- the lack of coordinated services; and
- the lack of information on available services.

Where, when and if a person with a brain injury accesses 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. However, 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.

- **Long-term or lifelong supports**

In order to live successfully in the community people with brain injuries need a range of community services and supports, including professionally-designed behavioral supports, specialized counseling, community-based and in-home care, and personal care/support. These services are designed to treat behaviors in the home and community setting and reduce the likelihood of people being placed in more costly settings. In the event that a person's behavior becomes too difficult to manage or too threatening to themselves or others, families also need crisis management services. Such services 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.

"It will give my brother and his wife a chance to "rest up" so that I can continue to live with them and not be placed permanently in a facility. I want to continue living with my brother."

- H., person with TBI who needs personal support services and respite care

Unfortunately, one of the most glaring gaps in Georgia's service delivery system is the lack of community supports for people with brain injuries, especially people with neurobehavioral issues. Medicaid and private insurance companies do not understand the need for these services and do not include sufficient coverage for these services. This is

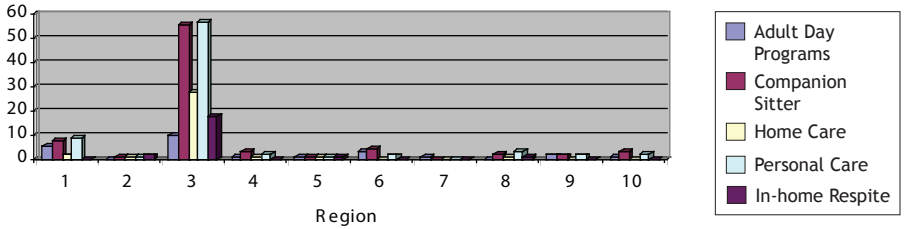
particularly true for Georgia's Medicaid waiver programs, which are designed to provide community-based – rather than institutional - support for people with disabilities.

Georgia offers several Home and Community-Based Services (HCBS) waivers, including the Community Care Services Program (CCSP), the Independent Care Waiver Program (ICWP), and the New Options Waiver Program (NOWP). Of these three programs, ICWP is the only one designed to serve people with traumatic brain injuries. The other two have limitations that prevent people with brain injuries from getting adequate and appropriate care. However, as the Commission revealed in its White Paper there are many serious problems with the ICWP that prevent people with TBI from receiving the care they need to live in the community. These problems include the way costs are calculated for the waiver, an annual cap that has been instituted, and low rates of reimbursement for critical services. (A brief comparison of the waivers is included in Appendix D. For additional information, please refer to the Commission's White Paper "Georgia's Neurobehavioral Crisis: Lack of Coordinated Care, Inappropriate Institutionalizations." For a copy of the paper, go to www.bsitf.state.ga.us or call 404/651-5112.)

In addition to the lack of funding, many people do not get community supports because these types of services do not exist in most areas of the state, and providers do not have staff that is trained to assist people with brain injuries. This is evidenced by an analysis of the Atlanta Regional Commission's ESP/Connect Database, which shows the low number of providers in each region of Georgia who are able to provide services for people with TBI, as shown below (for a regional map, see Appendix E).

Location (by Region) of Service Providers with Capacity to Serve People with TBI

Source: Atlanta Regional Commission's Area Agency on Aging



In addition to these community supports there are a number of other types of support that Georgians with brain injuries need to live in and contribute to their communities, including:

- accessible, available, affordable, and acceptable housing;
- accessible, available, affordable, and acceptable transportation, particularly in rural areas;
- support for securing appropriate and meaningful education;
- assistance in transitioning from school to employment;
- assistance with securing meaningful employment, including supported and customized employment options for people with neurobehavioral issues; and
- support and respite for caregivers.

With such services and supports the majority of people with brain injuries 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 them.

"Getting a van will change every aspect of my life. I will gain independence from my family, be an asset to society, possibly move out on my own and get a paycheck! Once I have transportation, there will be no restrictions to hold me back from living my every day life."

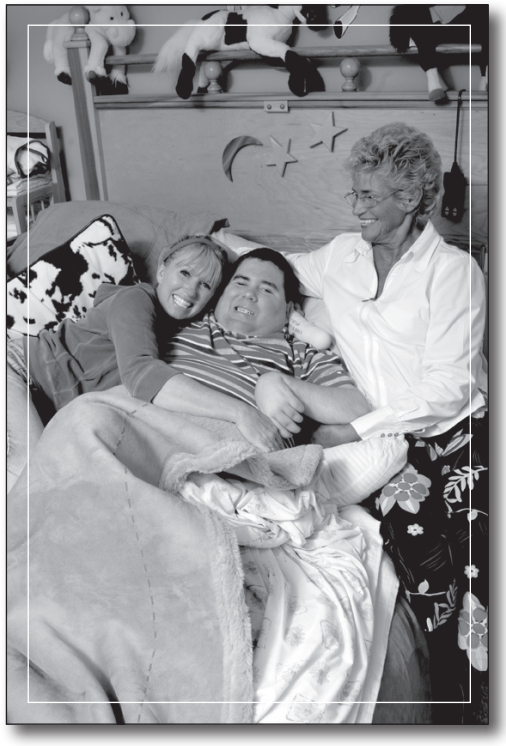
- A., person with TBI who needs an accessible van

However, even with sufficient community supports there are people who will require more structured residential treatment and care for their life-time. This is particularly true for individuals who sustain a severe brain injury and whose behaviors pose a significant and ongoing threat to themselves and others. For these people it is necessary to have residential settings in which the staff is specifically trained to provide support for people with neurobehavioral issues. Rather than nursing homes and other institutions, people with significant behavioral issues resulting from brain injury should be supported in specialized, community-based residential neurobehavioral programs that combine cognitive, behavioral, and pharmacological treatments. These programs should have the capacity to serve people on a long-term basis but should also have crisis beds available to allow someone to be removed from a home or other setting in an emergency situation.

Unfortunately, in Georgia all but a handful of people receive the benefit of this critical, specialized service. In its White Paper the Commission discussed the fact that there is only one option for specialized long-term residential treatment for people with neurobehavioral issues in Georgia (which has a limited number of beds), as well as the fact that Medicaid and private insurance place significant restrictions on funding for this type of service. As a result, the large majority of Georgians with severe neurobehavioral issues are not receiving the assistance they need and are needlessly ending up in the state's nursing homes, prisons, state hospitals, or homeless. Adding insult to injury is the fact that, according to the Commission's White Paper, such inappropriate institutionalization is extremely costly to the state: in one case study the Commission calculated that the cost of inappropriate care for one Georgian with neurobehavioral issues totaled more than $545,500. (For additional information, please refer to the Commission's White Paper.)

Conclusion

Georgians with brain injuries are currently not able to live as independently as possible and contribute to their communities because of a lack of comprehensive, specialized, and coordinated services in the state. While Georgia offers a few specialized services for its citizens with brain injuries, in general there are insufficient resources and funding for them. As a result of these gaps, many Georgians with brain injuries are not receiving services, causing significant problems and costs for them, their families, communities, and the state. In more severe cases, these gaps in services are causing people with brain injury to be inappropriately institutionalized in nursing homes, state hospitals, or prisons, or to become homeless. This is a disturbing reality for people who once led active lives and who could live successfully in the community with the proper supports.



What is spinal cord injury?

A **spinal cord injury (SCI)** is caused by a jolt, blow or penetrating injury to the spinal cord. Georgia defines spinal cord injury as "a traumatic injury to the spinal cord, not of a degenerative or congenital nature, but arising from blunt or penetrating trauma from acceleration-deceleration forces, resulting in paraplegia or quadriplegia, which can be a partial or total loss of physical function."

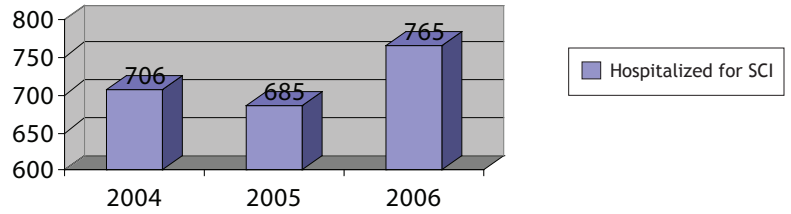
The severity of SCI depends upon the level of injury, or the area of the spinal cord that was damaged. Quadriplegia occurs when the cervical (neck) area of the spinal cord is injured anywhere between levels C1 and C8 of the spinal cord. People who are injured between C1 and C3 generally require a ventilator to breathe, while injuries between C4 and C8 will result in partial or total loss of control of shoulders, biceps, wrists or hands. Paraplegia occurs when either the thoracic area (T1 to T12) or the lumbar region (L1 to L5) of the spinal cord are injured. People who are injured between T1 and T7 generally have use of their hands and arms but may have poor control of their chest and abdominal muscles, while lower level injures (T9 – T12) may leave chest and abdominal control intact. Those who are injured between L1 and L5 will have paralysis in some parts of their feet and/or legs but may be able to walk with the use of assistive devices.

Spinal cord injuries can be complete or incomplete. A complete injury is one in which functioning below the level of injury is completely cut off, whereas in an incomplete injury a person may have some movement or feeling below the level of injury.

How many people have spinal cord injuries?

It is estimated that more than 12,000 Americans sustain a SCI each year, however, because there have been no overall incidence studies of SCI in the United States since the 1970's it is not known if this number has changed. A review of Georgia's Central Registry data may indicate that the incidence of SCI has risen, given that each year more than 650 Georgians sustain a SCI, including 765 in 2006 (207 of which also sustained a TBI). Like traumatic brain injury, the incidence of spinal cord injury in our state has increased significantly between 2004 and 2006, as shown below.

Incidence of Spinal Cord Injury in Georgia, 2004-2006
Source: Central Registry for Traumatic Brain and Spinal Injuries



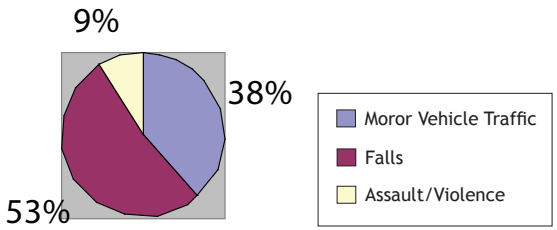
SCI is more frequent in males (75%) than in females (25%). While nationally SCI is most common among people age 16 – 30 years, in Georgia the highest incidence was among people age 35 – 54 years in 2006.

What are the causes of spinal cord injuries?

The primary causes of SCI are falls and motor vehicle accidents.

In Georgia, children age 21 and younger are more likely to sustain an SCI from a motor vehicle accident rather than falls while for adults the reverse is true. Other causes of SCI are gunshot wounds, violence and assaults, industrial or work-related injuries, and sports-related injuries.

Primary Causes of Spinal Cord Injuries
Source: Central Registry for Traumatic Brain and Spinal Injuries



What are the costs of care for people with spinal cord injuries?

The average lifetime cost of care for a person with SCI depends upon the severity of injury and the age at which the injury is sustained.

AVERAGE YEARLY EXPENSES		
Severity of Injury	**First Year**	**Each Subsequent Year**
High quadriplegia (C1 - C4)	$710,275	$127,227
Low quadriplegia (C5 - C8)	$458,666	$52,114
Paraplegia	$259,531	$26,410
Incomplete motor function at any level	$209,324	$14,670

ESTIMATED LIFETIME COSTS BY AGE OF INJURY		
Severity of Injury	**25 Years Old**	**50 Years Old**
High quadriplegia (C1 - C4)	$2,801,642	$1,649,342
Low quadriplegia (C5 - C8)	$1,584,132	$1,003,192
Paraplegia	$936,088	$638,472
Incomplete motor function at any level	$624,441	$452,545

Source: The University of Alabama National Spinal Cord Injury Statistical Center, Centers for Disease Control and Prevention

What about people with SCI who are dependent upon ventilators?

As the tables above show, people with high quadriplegia are faced with significant annual and lifetime costs of care. This is because people with high quadriplegia can lose voluntary functions such as breathing and may require mechanical ventilators to help them breathe. People who are dependent upon ventilators for breathing face unique challenges. Because ventilators are mechanical, and thus are at risk of malfunctioning when least expected, people with SCI who are dependent upon them require someone to be with them 24 hours every day to provide assistance in case of a problem with the machine. This need for round-the-clock care can be financially devastating for many people, yet Medicaid and private insurance do not always provide sufficient coverage for this service. As a result, family members are left in an exhausting and never-ending role of attending to their loved one, and many end up unemployed and in need of medical care themselves due to the physical and psychological toll of their situation.

What are the needs of Georgians with spinal cord injuries?

According to the responses from people with SCI and their caregivers, services providers, advocates, state agency representatives, and other experts, the primary needs of Georgians with SCI are:

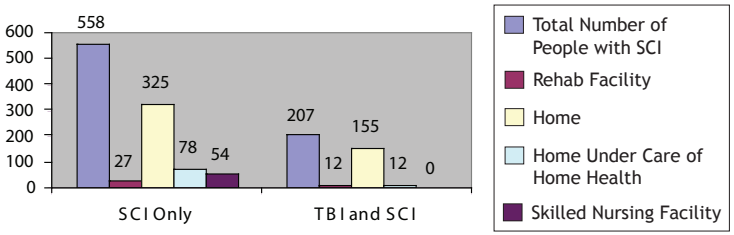
- **Training and awareness**
  Just as there is a need for training and awareness about brain injury among providers, caregivers, school personnel, state agencies, etc. there is also a need for training about SCI. In particular people with SCI and other experts pointed to the need for training on the special health care needs of people with SCI. Such training is needed not just for family members and other caregivers but also for medical (trauma, acute, and long-term) and rehabilitation providers who do not specialize in caring for people with spinal cord injuries and thus lack knowledge on appropriate and effective treatment. It is common for people with SCI to develop serious and unnecessary complications, including pressure sores, dysreflexia, and other life-threatening conditions in a hospital or rehabilitation center that does not have specially-trained staff.

- **Rehabilitation and wellness**
  Appropriate and effective rehabilitation is critical for people with SCI to help them improve remaining muscle strength, prevent complications, and foster the greatest amount of mobility and independence. The most effective SCI rehab programs are those that can provide specialized medical care, physical and occupational therapy, social work, counseling, and recreational opportunities. Rehabilitative therapy may begin in the hospital and continue in a rehabilitation facility, but at times therapy may continue on an outpatient basis following discharge from the rehabilitation facility.

Like people with brain injury, however, many Georgians with SCI are not being sent to a rehabilitation facility following their discharge from acute care hospitals. As shown below, in 2006 only 27 (or 4.8%) of the 558 people who were hospitalized for a spinal cord injury, and 12 of the 207 people with both injuries, were discharged to a rehabilitation facility. The large majority were sent home, while others were sent to a skilled nursing facility (nursing home), which generally lacks specialized training to care for people with SCI and is an inappropriate placement for most of them (particularly the 26% who were under age 50 at the time of their injury).

Destination Upon Discharge From Hospital: People with Spinal Cord Injury, 2006

Source: Central Registry for Traumatic Brain and Spinal Injuries



It is surprising that people with SCI do not get sufficient rehabilitation, given that their injury and its effects are very visible. However, as with brain injury, people with SCI generally do not receive rehabilitation because of a lack of funding from Medicaid and private insurance, and because of the lack of specialized rehabilitation centers for SCI in Georgia, particularly in the rural areas as well as for children with SCI. Unfortunately, this lack of funding and sufficient access to rehab costs the state and the nation a significant amount in terms of lost wages, higher healthcare, and other unnecessary expenses. Indeed, the University of Alabama National Spinal Cord Injury Statistical Center estimates that the United States would save as much as $400 billion on future direct and indirect lifetime costs by developing appropriate rehabilitative therapies for people with SCI and preventing new injuries.

- **Service coordination**

Similar to people with brain injury, the largest barrier to accessing and using services for people with SCI is the lack of service coordination. As a result of the lack of a single point-of-entry to the service system, or a navigator to assist in accessing the system, people with SCI and their family members often are unaware of existing services, are unable to find existing services, or are unable to access them.

"Having a child with a traumatic & permanent injury is like being dropped off on another planet. It would be so helpful to give parents a head start so they are not alone in trying to navigate through the new world that they have found themselves in. The feeling of isolation is enormous. Having a link to resources and others in similar situations would go a long way to help alleviate the feelings of desperation."

- Mother of C., age 12, who sustained an SCI at the age of 2

- **Tools for independent and integrated living**

People with SCI require a number of "tools" to live as independently as possible in the community, including:

  - **Durable medical equipment, medical and hygiene supplies, and assistive technology:** these tools are critical for people with SCI to complete their activities of daily living (feeding, bathing, toileting, dressing, and grooming) as well as communicate, work, go to school, raise families, and otherwise participate in the community.

"I was able to use the device for two days, and it tremendously helped with my walking. I am now walking with a cane and very possibly could walk without it with future use of the device."

- J., person with SCI who is using a walking aid

As important as these tools are, however, there are many limitations and restrictions placed on them by Medicaid and private insurance, making it unnecessarily difficult for people with SCI to get even the basics, such as shower chairs or power wheelchairs for people with quadriplegia. This problem is confirmed by the Commission's Trust Fund distribution data, which reveals that durable medical equipment and other supplies are one of the top three items

for which funding is requested by Georgians with SCI, as shown below right.

- **Personal support or attendant services:** attendants provide assistance to people with SCI in completing their activities of daily living, managing household tasks (cooking, cleaning, managing finances, caring for children, etc.), taking medications, and other important functions. In the case of people with quadriplegia who are dependent upon ventilators, attendants are especially needed to ensure that the machine is working properly 24 hours a day. This type of service allows people with SCI to live in the community and also enables family members to return to work, rest, and attend to the needs of themselves or other family members.

  The challenge that people with SCI face in securing attendant services is, like so many other things, funding. Because people with permanent paralysis require attendant services on a regular basis for the rest of their lives the costs of attendant services can add up quickly and become devastating for most families. As a result, family members often must give up their paid jobs so that they can serve in the role of full-time attendant, and end up developing sufficient skills and experience as an attendant over time. However, Medicaid and private insurance are reluctant to pay family members who are serving in this role, leaving many families destitute. The other challenge is that too few people are drawn to the field of attendant services because attendants are usually not paid well and receive little or no health benefits, standards, or training, resulting in a shortage of highly-skilled workers, particularly in rural areas.

- **Accessibility**: accessibility refers to buildings, vehicles, walkways, and other areas that are usable and/or easily accessed by people using wheelchairs or other mobile devices. The two most important areas of accessibility for people with SCI are housing and transportation. Sustaining a SCI means that suddenly a person's home and vehicle are no longer available for their use. Modifications must be made to both in order to make them wheelchair accessible.

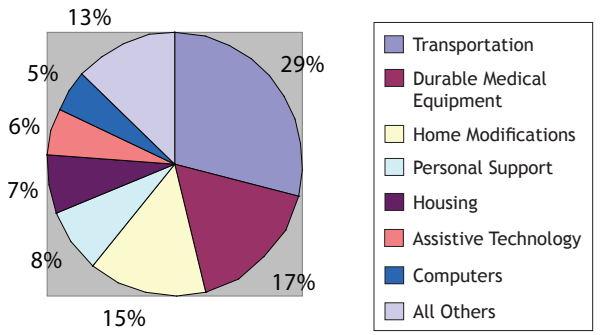
"I need repair and replacement of my severely worn flooring and subfloor (in order to) make my home safe for my very heavy wheelchair."
- B., person with SCI who needs home modifications

However, such modifications are expensive – a modified vehicle can cost as much as $50,000 - and there are few funding sources that can provide assistance with these costs. As a result, many people with SCI become "imprisoned:" they end up living their life in only one room because the rest of their house or apartment is inaccessible, and/or they cannot leave their home and go to work, the doctor's office, or other places in the community because their vehicle has not been modified. This greatly increases the risk for isolation, depression, unemployment, and increased medical complications.

The great need for assistance with transportation, and housing and home modifications, is borne out by the Commission's Distribution data that shows transportation as the most requested item, while home modifications is third and housing is fifth, as shown below.

Brain & Spinal Injury Trust Fund: Requests by People with SCI, by Percentage, 2002-2008

Source: Brain & Spinal Injury Trust Fund Commission



** Note: "All Others" refers to Advocacy, Dental Services, Health and Wellness, Medical Care, Psychology/Counseling, Recreation/Hobbies, Vision Services, and Vocational Support.*

Accessibility issues are not limited to housing and transportation. Repeatedly, and across time and geography, people with SCI expressed their frustration over the difficulty in accessing everything from parking spaces, sidewalks, public buildings, and public transportation to private homes and vacation destinations (including cruise ships and hotels). Even with passage of the Americans with Disabilities Act in 1990 many public areas and building remain inaccessible. This is not just a problem in the rural regions, where accessible transportation and buildings are particularly difficult to find, but also in the metro regions as well. The lack of accessibility prevents many people with SCI from returning to work, fully participating in school, handling medical issues, or living in the community altogether.

- **Community participation**

Community participation is any activity or living arrangement that allows people to be involved in and contribute to their communities, particularly education, employment and/or volunteer opportunities, and community-based residential living.

"The lift would . . . allow me to get into and out of my car much more easily and with less pain, and therefore I would be more able to participate in work and social activities.
-B., person with SCI who needs a vertical platform lift

In terms of education, schools must be prepared to receive a child with SCI as soon as the child is medically-stable enough to return to school. This means much more than just making sure that the building is accessible to wheelchairs. It also means providing training to the teachers, school nurses, and other staff, providing the appropriate assistive technology (if necessary), and arranging for accessible school buses that ensure the child will remain integrated with his/her peers and able to participate in extra-curricular activities and field trips. This is true for both public and private schools, as well as colleges, universities, and technical schools.

In some cases, however, schools are resistant to making the necessary preparations, whether it's because of a lack of funding or other resources, a lack of training, or an unwillingness to make accommodations for a student with a disability. In these cases it is critical that students with SCI and their families receive training and information to advocate for their needs and rights and assist schools in making the necessary preparations.

"This will decrease my dependence on my family members, as they have to load and unload my wheelchair into the vehicles I travel in. I will be more apt to freely travel, as I will neither have to transfer from my wheelchair to the seat in the car, nor will anyone have to lift me to seat me in the van."
- P., person with SCI who needs van modifications

In terms of employment it must be said that the large majority of adults with SCI want to work or volunteer. Indeed, a study conducted by the National Spinal Cord Injury Statistical Center revealed that more than half (54.7%) of the people with SCI reported being employed at the time of their injury. In order for them to return to work or gain new employment they must have the Tools for independent and integrated living listed above, and the employer must be prepared to accommodate the employee or volunteer in terms of accessible buildings and work spaces, assistive technology, etc. As has been previously stated, however, many people with SCI do not have the basic Tools, and in some cases employers are reluctant to make the necessary accommodations to support a person with SCI to work. But these are not the only barriers to employment for people with SCI. Many people with SCI are discouraged from returning to work because of the current laws governing Social Security benefits, which threaten to rescind the benefits when a person begins to earn more than $940 per month. In these cases, as with education, it is important for people with SCI to become educated in order to be effective self-advocates, and to find mentors in other people with SCI who have successfully gained employment.

Conclusion

Like Georgians with brain injury, Georgians with SCI can, with the appropriate supports, live in and contribute to the community. However, many of the most critical services and goods are not available for them in Georgia. As a result, many people with SCI, including children and youth, end up unemployed, develop serious medical problems, and/or become institutionalized in nursing homes at great cost to them, their families, their communities, and the state.

STATE ACTION PLAN

Based upon the needs that have been identified the Brain & Spinal Injury Trust Fund Commission has developed the following State Action Plan. These goals and objectives are designed to address the identified needs and enhance the quality of life of Georgians with brain and spinal injuries. They are significant and ambitious, and if completed will result in a comprehensive, specialized, and coordinated system of care for Georgians with brain and spinal injuries.

To develop these goals, the members of the Advisory Committee and its subcommittees spent innumerable hours reviewing the results of the Needs Assessment, assessing the state's current level of service provision, and researching successful models in other states. The committees developed goals for each of the Areas of Need before reorganizing them into specific initiatives. These initiatives include goals that address the particular needs of children and youth with brain and spinal injuries.

In developing the State Action Plan the Advisory Committee recognizes and acknowledges the need for services, training and educational materials, and interventions that are varied and individualized to meet the needs of Georgia's diverse cultural populations. Rather than develop separate goals to address a diversity of needs the Committee agreed to invite specific partners to collaborate and participate in the implementation stage to ensure the cultural competence of each goal.

It is important to note that the responsibility for completion of this Plan will not, and should not, be the sole responsibility of the Commission and its Advisory Committee. In fact, successful accomplishment of these goals will require the involvement and partnerships of many groups and individuals. Although the Plan has been developed by the Commission in its capacity as the Lead Agency on Traumatic Brain and Spinal Injuries for the state of Georgia, the Commission hopes that agencies, organizations, and individuals across the state will take ownership of the Plan and identify ways in which they can assist in its completion. Indeed, the Commission invites partners to assist in identifying activities, leaders, timelines, and outcome measures for each goal.

The Advisory Committee will use these timelines and outcome measures to monitor progress of the State Action Plan and make regular reports to the Brain & Spinal Injury Trust Fund Commission. The Committee will also monitor changes in the environment (social, economic, and political) and make revisions to the Plan as necessary to ensure continued relevance throughout the period of its implementation.

For a complete copy of the State Action Plan, including the objectives, timeline, partners, and outcome measures, please go to www.bsitf.state.ga.us or call 404/651-5112.

Initiative One

Increase awareness and education among state agencies and elected officials of the incidence, needs, and specialized service model for Georgians with brain and spinal injuries.

- Develop a data collection process to match incidence data with research on rehabilitation outcomes
- Develop a service model for people with brain injuries in Georgia
- Educate state agencies and elected officials about the needs of Georgians with brain and spinal injuries
- Educate school personnel regarding identification, assessment, strategies, interventions, and services for children and youth with brain and spinal injuries

Initiative Two

Secure adequate and specialized funding, and a single point-of-entry, to meet the needs of Georgians with brain and spinal injuries.

- Modify existing Medicaid medical services and waivers, private insurance, and other funding sources to provide adequate funding for:
    - o community-based care, including in-home and day programs
    - o post-acute rehab and community support services
    - o school re-entry services

  - durable medical equipment, supplies, and assistive technology
  - attendant services
  - specialized, community-based neurobehavioral programs
  - specialized, community-based residential programs for people with brain injuries who have complex medical needs
  - specialized, community-based residential programs for people with spinal cord injuries who must live in a residential setting
  - Develop a single point-of-entry to make it easier for people with brain and spinal injuries to access needed services and funding
  - Increase availability of service coordinators and case managers
  - Empower people with brain and spinal injuries and their families to navigate the system themselves
  - Provide a seamless transition from youth to adulthood

Initiative Three

Improve medical and rehabilitative care, health and wellness, and access to school services for Georgians with brain and spinal injuries.

- Provide training for medical and rehabilitation personnel on appropriate and effective treatment of people with brain and spinal injuries
- Increase access to high-quality, age-appropriate rehabilitation and care, particularly in rural areas
- Increase the number of service providers and caregivers with specialized training in caring for people with brain and spinal injuries
- Increase awareness of risk factors associated with brain and spinal injuries
- Promote positive physical, emotional, mental, and spiritual lifestyles and practices among people with brain and spinal injuries
- Increase school re-entry services and training to ensure that schools are prepared to support children and youth with brain and spinal injuries

Initiative Four

Enhance support for people with brain and spinal injuries, their families and caregivers.

- Provide families with training and education to address ongoing and recurring needs
- Increase number of support services and respite options for families and caregivers
- Provide crisis management services for people with brain injuries, their families and caregivers
- Increase opportunities for networking, communication, and peer support among people with brain and spinal injuries
- Enhance the ability of people with brain and spinal injuries, their families and caregivers to be self-advocates
- Provide training and support to children and youth with brain and spinal injuries, their families and caregivers, to become self-advocates in the school system

Initiative Five

Identify and screen additional people with brain injuries.

- Educate the public about the need for proper screening and identification of brain injuries
- Develop a statewide, multilevel system for effective identification of people with brain injuries
- Increase awareness of post-injury symptoms and problems and the need for proper identification and reporting for children and youth with brain injuries
- Develop ways to identify and provide community-based support for people with brain injuries who are in nursing homes, state hospitals or prisons, or who are homeless

Initiative Six

Facilitate independent living and community participation for people with brain and spinal injuries.

- Ensure that people with brain and spinal injuries have access to affordable, accessible, available, and acceptable:
  - Housing
  - Public transportation
  - Private transportation

- Ensure that children and youth with brain and spinal injuries have access to inclusive and integrated transportation
- Ensure that accessible parking is always available for people with brain and spinal injuries
- Ensure that all public buildings are accessible

Initiative Seven

Reduce the incidence of brain and spinal injuries among Georgians.

- Raise awareness of the causes and prevention strategies for brain and spinal injuries

APPENDICES

A. Commission Roster
B. Analysis of Available State-Sponsored Services
C. Analysis of Community-Based Services
D. Comparison of Medicaid Waiver Services
E. Regional Map

APPENDIX A: COMMISSION ROSTER

E. Culver "Rusty" Kidd, Chair
Governor's appointee
Person with SCI
Milledgeville, Georgia

Susan Johnson, Vice Chair
Governor's appointee
Family member of person with SCI
Alpharetta, Georgia

Annette Bowling
Governor's appointee
Albany ARC
Albany, Georgia

Mary Alice Bullock
Governor's appointee
Family member of person with TBI
Hull, Georgia

Lisa Dawson
Department of Human Resources appointee
Atlanta, Georgia

Joseph D. Frazier
Governor's appointee
Person with SCI
Marietta, Georgia

Griffin Garner
Governor's appointee
Person with TBI
Carrollton, Georgia

Gina Gelinas
Department of Education appointee
Atlanta, Georgia

Judy Hagebak
Department of Community Health appointee
Atlanta, Georgia

Steven K. Leibel
Governor's appointee
Attorney
Dahlonega, Georgia

Carl H. McRae
Department of Labor appointee
Atlanta, Georgia

Estelle Lee Miller
Governor's appointee
Family member of person with TBI
Columbus, Georgia

David W. Renz
Governor's appointee
Person with SCI
Rocky Face, Georgia

Dan Roach
Department of Public Safety appointee
Atlanta, Georgia

Bill Smith
Governor's appointee
Family member of person with TBI
Woodbine, Georgia

APPENDIX B: ANALYSIS OF AVAILABLE STATE-SPONSORED SERVICES

The following spreadsheet is a summary of the survey responses received from state agencies as well as the Commission's assessment of existing state services. The data is provided to show the range of state services offered that may benefit Georgians with brain or spinal cord injuries. The "Eligible" column indicates whether people with TBI, ABI, and SCI are eligible for the particular services. The "Specialized Services" column indicates whether the agency provides services that have been specially designed to meet the needs of people with TBI, ABI or SCI. Finally, recommendations (if applicable) are provided for ways to improve the delivery of services for Georgians with brain and spinal injuries.

PROGRAM DESCRIPTION	ELIGIBILITY CRITERIA	ELIGIBLE AGE GROUPS	ELIGIBLE			SERVICES OFFERED	SPECIALIZED SERVICES			FINANCIAL ASSISTANCE OFFERED	RECOMMENDATIONS (IF APPLICABLE)
			TBI	ABI	SCI		TBI	ABI	SCI		
ADDICTIVE DISEASES, OFFICE OF											
Division of Mental Health, Developmental Disabilities, and Addictive Diseases / Department of Human Resources											
The Office of Addictive Diseases offers a range of treatment and support services to promote integration into the community and recovery for people with serious substance abuse issues.	A person must be diagnosed with an approved diagnostic category for state-funded services for addictive diseases.	All ages	Yes	Yes	Yes	The Office of Addictive Diseases provides services through core providers and specialty providers, depending upon the needs of the person. Services vary by region but may include: crisis services, outpatient services, community support services, day and employment services, residential support and regional hospitals. The services a person receives depends on a professional determination of a level of need as well as the availability of services and other community supports.	No	No	No	Services are offered on a sliding scale, although services are free for people who meet Federal Poverty Level criteria. Services are reimbursed by Medicaid for people who are Medicaid-eligible.	People with brain injury are at an increased risk of developing substance abuse issues, however, to successfully address this problem they require specialized interventions and services that address both the brain injury and the substance abuse issues (1). Development of such interventions and services is recommended. In addition, several studies have discussed the relation between people with SCI and depression, particularly soon after the injury was sustained, and possible increased risk for substance abuse, particularly if there was a preexisting condition of substance abuse (2). This, too, would warrant specialized programs to screen for and address substance abuse in people with SCI.
ADOPTIONS, OFFICE OF											
Division of Family and Children Services / Department of Human Resources											
The Office of Adoptions assists Georgia's children who are in state custody with finding loving families in permanent homes.	Children who are in permanent state custody due to unresolved family crises. If a child is available for adoption the parents may have volunteered to give up their parental rights, but usually these rights were terminated by the court system due to abuse, neglect, or abandonment. Many of the children are in the adoptive category of Special Needs.	Age 0 - 18	Yes	Yes	Yes	The Office of Adoptions provides services that span a child's life, including Adoption Services to help a child find a loving family, Post Adoption Services to assist the child and their new family during the transition process, and Birth Family Search to help adoptive children and birth families find each other (once the child has become an adult).	No	No	No	There are no fees for a parent who requests to adopt a child through DHR. DHR has contracts with certain private agencies that do not charge fees under the agreement. However, fees are incurred during the qualification process, which includes services such as home safety inspections and legal fees. If the child is considered Special Needs up to $2,000 may be reimbursed through financial Adoption Assistance. In addition, some assistance is available to help meet the costs of caring for children with Special Needs. The amount of the assistance depends upon the child's needs.	Given the fact that many children are in state custody because of abuse, and brain or spinal injuries are often caused by abuse, it would be important to provide screening services to help identify and provide appropriate support for children with brain and spinal injuries who are being served by the Office of Adoptions.

PROGRAM DESCRIPTION	ELIGIBILITY CRITERIA	ELIGIBLE AGE GROUPS	ELIGIBLE			SERVICES OFFERED	SPECIALIZED SERVICES			FINANCIAL ASSISTANCE OFFERED	RECOMMENDATIONS (IF APPLICABLE)
			TBI	ABI	SCI		TBI	ABI	SCI		
AGING SERVICES, DIVISION OF											
Department of Human Resources											
The Division for Aging Services coordinates with the 12 Area Agencies on Aging to provide services to appropriately sustain older Georgians and people with chronic conditions or disabilities in their homes and communities. These services also provide support to family members and caregivers.	Generally, any person who is aging or has a disability or chronic condition, and their family members and caregivers. However, additional eligibility criteria varies by program.	Primarily adults	Yes	Yes	Yes	The Division administers several programs, including Adult Protective Services, Caregiving, the Community Care Services Program, the Elder Rights & Advocacy Program, Georgia Cares, the Long-term Care Ombudsmen Program, and the Senior Community Service Employment Program. However, all community-based services for older adults are coordinated through its 12 Area Agencies on Aging, located throughout the state.	No	No	No	The Division administers the Community Care Services Program (CCSP), a Medicaid waiver program, which is available for Medicaid-eligible, functionally impaired citizens, and is designed to support and assist older Georgians and those with chronic conditions and disabilities who require intensive health services to stay in their homes and communities.	Many services for older adults focus on dementia, however, while brain injury often mimics symptoms of dementia it requires a different, specialized approach. Given that older adults are at high risk for TBI caused by falls more specialized programs should be developed to address brain injury for this population.
BABIES CAN'T WAIT											
Children with Special Needs / Women's Health Branch / Division of Public Health / Department of Human Resources											
Babies Can't Wait (BCW) is Georgia's statewide interagency service delivery system for infants and toddlers with developmental delays or disabilities and their families. BCW is established by Part C of the Individuals with Disabilities Education Act (IDEA) which guarantees all eligible children, regardless of their disability, access to services that will enhance their development.	BCW serves children from birth up to their third birthday, regardless of income, who have a developmental delay. A listing of the complete list of diagnoses that result in automatic eligibility for Babies Can't Wait is available on their website. Traumatic brain injury is excluded from the list of eligible conditions.	0 - 3 years old	No	No	Yes	BCW offers the following two services at no cost: 1) a multidisciplinary evaluation and assessment to determine the child's eligibility and the scope of services needed for the child; and 2) service coordination that assists the family and other professionals in developing a plan to enhance the child's development. In addition, BCW offers access to early intervention services identified in the child's plan (although families may be required to pay for these services), which may include: assistive technology devices, audiology, family training and counseling, health services, medical diagnostic services, certain nursing services, nutrition services, occupational therapy, physical therapy, psychological services, social work, special instruction, speech-language pathology, vision services, and transportation to services.	No	No	No	State funds are available to help pay for the costs of early intervention services, based on a sliding fee scale, to assist families who are determined by the local BCW Program to be unable to pay for them.	Brain injury is not included in the list of eligible conditions. This is problematic, given that, according to the Centers for Disease Control and Prevention (CDC), children age 0 - 4 are among the two highest risk age groups for sustaining a TBI (3). Indeed, 18% of all TBI's in Georgia in 2006 were among children age 0 - 4. This data points to the need for revisions to the eligible conditions to include brain injury so that young children with brain injury can receive needed services.
BRAIN & SPINAL INJURY TRUST FUND											
Brain & Spinal Injury Trust Fund Commission											
The Brain & Spinal Injury Trust Fund Commission administers the Trust Fund, a source of funds to assist Georgians with traumatic brain and spinal injuries in paying for the costs of care and rehabilitation. Revenue for the Trust Fund is generated from surcharges on drunk driving convictions.	To be eligible to receive an award from the Trust Fund a person must have a traumatic brain or spinal cord injury and be a resident of the state of Georgia. Acquired brain injury is excluded.	All ages	Yes	No	Yes	The Commission accepts applications for distributions from the Brain & Spinal Injury Trust Fund. The goal of distributing the Trust Fund is to support independence, inclusion in the community, consumer choice, and self-determination. People can apply for a distribution to help pay for a range of services and goods, including (but not limited to): assistive technology, computer technology, dental service, durable medical equipment, health and wellness, home modifications, housing, medical care, personal support services, psychology/counseling, rehabilitative therapeutic services, recreation, speech services, vehicles/transportation, vision services, and vocational support. The Commission provides assistance in completing applications for the Trust Fund and may also provide assistance with referrals to other services.	Yes	No	Yes	Distributions from the Trust Fund are awarded based upon eligibility, payer of last resort status, appropriateness of request, availability of funds, and other conditions as defined by the Distribution Policies.	The Trust Fund is the only funding source in Georgia that is dedicated to addressing the needs of people with brain and spinal injuries, however, its average annual revenue is less than $2 million per year, which is insufficient to meet the needs of the population. It should also be noted that people with acquired brain injury are not eligible for distributions from the Trust Fund, and there is no comparable source of funding for people with ABI.

PROGRAM DESCRIPTION	ELIGIBILITY CRITERIA	ELIGIBLE AGE GROUPS	ELIGIBLE			SERVICES OFFERED	SPECIALIZED SERVICES			FINANCIAL ASSISTANCE OFFERED	RECOMMENDATIONS (IF APPLICABLE)
			TBI	ABI	SCI		TBI	ABI	SCI		
CHILD PROTECTIVE SERVICES											
Division of Family and Children Services / Department of Human Resources											
Child Protective Services (CPS) staff investigates reports of child abuse or neglect and provides services to protect the child and strengthen the family.	Families who are reported to CPS for suspected abuse or neglect.	Age 18 and under	Yes	Yes	Yes	CPS investigates reports of child abuse or neglect and provides services to protect the child and strengthen the family. CPS also has a Special Investigations Unit that investigates all child deaths and serious injuries.	No	No	No	None	Given the fact that many children sustain brain or spinal injuries as the result of abuse it would be important to provide screening services to help identify and provide appropriate support for children with brain and spinal injuries involved with CPS. In addition, brain injury can cause behavioral problems in children, which may increase strain on families and thus, the risk for abuse. Providing appropriate services, training and support for families of children with brain injuries may help to reduce the incidence of abuse.
CHILDREN'S MEDICAL SERVICES											
Children with Special Needs / Women's Health Branch / Division of Public Health / Department of Human Resources											
Children's Medical Services (CMS) provides comprehensive, coordinated specialty care for children from birth to age 21 who have chronic medical conditions. CMS is the state and federally funded Title V Children with Special Health Care Needs Program for the state of Georgia.	Eligibility for the program requires that children meet certain medical and financial requirements. The medical requirements are that children must have a chronic medical condition caused by a list of certain eligible conditions (for a list of all medical eligibility conditions go to the CMS website). The financial requirements are updated yearly and are based upon Federal Poverty Level guidelines and other condition (for a list of all financial eligibility conditions go to the CMS website). Brain injury is excluded from the list of eligible conditions.	0 - 21 years	No	No	Yes	CMS may provide or assist in paying for an array of services that include: comprehensive physical assessment, diagnostic testing, in-patient/out-patient hospital services, medications, medical treatments, therapy, durable and disposable medical equipment, hearing aids, dental care (if related to the CMS eligible condition), health education, care coordination for client and family (may include referrals to other providers such as schools, day care, social service programs, etc), and/or genetic consultations.	No	No	No	CMS may provide financial assistance for assistive technology, medical equipment or supplies, transportation, or other services. Financial assistance is restricted to the availability of funds in each region and is available only to families who meet certain guidelines.	Brain injury is not included in the list of eligible conditions. According to the CDC, the two age groups that are at highest risk for sustaining a TBI are children age 0 - 4 and children age 15 - 19 (3). Indeed, 53.5% of all TBI's in Georgia in 2006 were among children and youth age 24 and younger. This data points to the need for revisions to the eligible conditions to include brain injury so that children and youth with brain injuries can receive needed services.
CORRECTIONS, DEPARTMENT OF											
Department of Corrections											
The Georgia Department of Corrections (DOC) protects and serves the public as a professional organization by effectively managing offenders while helping to provide a safe and secure environment for the citizens of Georgia.	Anyone convicted of a crime and sentenced to prison, or any person on parole or probation.	Age 17 and over	Yes	Yes	Yes	DOC conducts a comprehensive assessment of the needs and security risks of every offender entering the prison system. DOC manages 37 state prisons, 3 private prisons by contract, 24 county prisons by contract, 12 transitional centers, 1 inmate boot camp, 1 probation boot camp, 49 probation circuit offices, 7 pre-release centers, and 5 day reporting centers. It provides risk reduction programs, including cognitive behavior programs, susbstance abuse education, GED and vocational classes, and faith- and character-based programs. It operates pre-release centers to assist offenders in transitioning back into the community, which include additional opportunities to develop work experience and/or cognitive skills, and to participate in AA/NA treatment programs prior to release. It manages all probation and parole services, including supervision of the offender in the community. DOC also operates Georgia Correctional Industries, which uses inmate labor to produce and sell goods and services.	No	No	No	None	According to jail and prison studies, 25-87% of inmates report having experienced a head injury or TBI as compared to 8.5% in a general population (4). Indeed, the CDC writes that "many people in prisons and jails are living with TBI-related problems that complicate their management and treatment while they are incarcerated. Because most of these prisoners will be released these problems will also pose challenges when they return to the community (4)." The Commission also discussed this problem in their white paper. However, DOC does not provide screening to identify inmates with TBI and thus does not provide specialized services for them that could improve their ability to live successfully in prison or in the community. It is critical to develop such screening and other specialized programs.

PROGRAM DESCRIPTION	ELIGIBILITY CRITERIA	ELIGIBLE AGE GROUPS	ELIGIBLE			SERVICES OFFERED	SPECIALIZED SERVICES			FINANCIAL ASSISTANCE OFFERED	RECOMMENDATIONS (IF APPLICABLE)
			TBI	ABI	SCI		TBI	ABI	SCI		
CRIME VICTIMS COMPENSATION PROGRAM											
Criminal Justice Coordinating Council											
The Crime Victims Compensation Program (CVCP) assists with crime-related expenses if someone is the victim of a violent crime.	To be eligible to receive an award from the Program a person must have been physically injured in a violent crime; report the crime to law enforcement within 72 hours; and file a claim within one year of the date of the crime.	All ages	Yes	Yes	Yes	CVCP provides funding to cover costs related to being victimized in a violent crime, including medical expenses, counseling bills, funeral expenses, and lost wages or support.	No	No	No	CVCP provides financial assistance to help cover costs of medical expenses (up to $15,000), counseling bills (up to $3,000), funeral expenses (up to $3,000), and lost wages or support (up to $10,000) that were incurred after being victimized in a violent crime. CVCP is a payer of last resort and does not cover expenses covered by a third party.	People who sustained a brain or spinal injury as the result of a violent crime may be eligible to receive assistance from the CVCP.
DEVELOPMENTAL DISABILITIES, OFFICE OF											
Division of Mental Health, Developmental Disabilities, and Addictive Diseases / Department of Human Resources											
The Office of Developmental Disabilities (ODD) exists to support Georgians with developmental disabilities to live meaningful lives in their communities. ODD offers state-supported services that are aimed at helping families care for their loved ones with developmental disabilities; serving people who do not live with their families in a home setting; and promoting independence and self-determination.	A person must have a diagnosis of mental retardation or a developmental disability and meet the criteria for "most in need." People who are "most in need" of services are those with social, emotional, developmental or physical disabilities resulting from mental retardation/developmental disabilities who without state-supported services would have significant difficulty or be unable to successfully live day to day. In addition, family support services are available for people with autism and certain other developmental disabilities.	All ages	Yes	Yes	Yes	The services a person receives depends on a professional determination of level of need, as well as the availability of services and other community resources. Services may include: family support, supported employment, respite services, community residential services or personal support, day supports, and regional hospitals. ODD also administers the New Options Waiver and Comprehensive Waiver Programs, which provide funding and services to support people with developmental disabilities in the community, rather than an institution.	No	No	No	Services are offered on a sliding scale, although services are free for people who meet Federal Poverty Level criteria. For people who are eligible for services under the DD waiver services the New Options Waiver and Comprehensive Waiver pay for most community-based DD services.	A person with brain injury may be eligible for services from the Office of Developmental Disabilities if they sustained their brain injury prior to age 22 and require services similar to those needed by people with mental retardation; live in an insitution for people with mental retardation or developmental disabilities or are at risk of being placed in such an institution. This may include eligibility for the two Waiver Programs. However, it is important to recognize that the services and interventions that are designed to support people with developmental disabilities are not always appropriate for people with brain injuries. For a person with brain injury to be supported under ODD services it is necessary to ensure that services offered are individualized and specialized to address the particular needs of people with brain injury. It should be said that, to date, this has been done on a limited basis under the Comprehensive Waiver Program with great success.
FAMILY VIOLENCE PROGRAM											
Division of Family and Children Services / Department of Human Resources											
The Family Violence Program (FVP) approves and administers funds to Georgia's family violence programs throughout the state, which are operated by private nonprofit organizations. These programs provide emergency shelter, Victim Assistance, and support to victims of domestic violence, and training and prevention education to local communities.	Technical assistance, support and funding services are for local family violence programs. These programs, in turn, serve victims of family violence, who are primarily women and children.	All ages	Yes	Yes	Yes	FVP provides training and technical assistance to Georgia's family violence programs. These programs provide emergency shelter, Victim Assistance, training, and prevention education services at the local level.	No	No	No	None	A number of studies have been conducted that indicate that victims of domestic violence are at risk for sustaining a brain injury (5). Since many women often return to abusive situations it is possible that they will sustain multiple brain injuries over time, which have a cumulative effect over time. TBI can affect whether the woman returns to the abuser, how well she functions in a shelter, and whether she will be successful in leaving the abuser (5). This raises the need for screening to identify victims of family violence who may have brain injuries, as well as the need for specialized services. The state of Alabama has developed an excellent model for a partnership between brain injury organizations and family violence programs.

PROGRAM DESCRIPTION	ELIGIBILITY CRITERIA	ELIGIBLE AGE GROUPS	ELIGIBLE			SERVICES OFFERED	SPECIALIZED SERVICES			FINANCIAL ASSISTANCE OFFERED	RECOMMENDATIONS (IF APPLICABLE)
			TBI	ABI	SCI		TBI	ABI	SCI		
JUVENILE JUSTICE, DEPARTMENT OF											
Department of Juvenile Justice											
The Georgia Department of Juvenile Justice (DJJ) holds youthful offenders accountable for their actions through the delivery of treatment services and sanctions in appropriate settings and by establishing youth in their communities as productive and law abiding citizens.	Any youth referred to by the Department of Juvenile Courts and at-risk youth identified by public, private, and community entities.	"Any individual who is under the age of 17 years; under the age of 21 years, who committed an act of delinquency before reaching the age of 17 years, and who has been placed under the supervision of the court or on probation to the court; or under the age of 18 years, if alleged to be a deprived child.	Yes	Yes	Yes	DJJ conducts a comprehensive assessment of the needs of every juvenile who has been referred to the DJJ system to determine the most appropriate placement and services for him/her. DJJ operates 22 Regional Youth Detention Centers (secure short-term centers for youths awaiting trial in Juvenile or Superior Court, or placement elsewhere within the DJJ system), and 8 Youth Detention Centers (6 long-term rehabilitation facilities for youth sentenced or committed to DJJ custody by the courts and 2 facilities exclusively for short-term youth placed in the custody of DJJ for 60 days or less). Youths in the DJJ system receive a comprehensive physical and mental health assessment, as well as educational and/or vocational training.	No	No	No	None	As stated above in the Recommendation for the Department of Corrections, studies reveal a high rate of TBI among jail and prison inmates. Given the high rate of TBI among youth, it is conceivable that there is also a high rate of TBI among youthful offenders. As such, the same need for specialized screening and interventions applies.
MEDICAID, OFFICE OF											
Division of Medical Assistance / Department of Community Health											
The Office of Medicaid administers the Medicaid program, which provides healthcare for children, pregnant women, and people who are aging, blind or disabled.	Eligibility is based on income criteria, which varies according to each program.	All ages	Yes	Yes	Yes	The Office of Medicaid offers several Medicaid programs including: SSI Recipients, Nursing Home, Community Care, Qualified Medical Beneficiaries, Right from the Start Medicaid for Pregnant Women and Their Children, Medically Needs, Low-Income Medicaid, and Hospice. The Office also administers the state's Home and Community-Based Services waiver programs, including the Independent Care Waiver Program. In addition, the Office administers two state plan programs: SOURCE and the Katie Beckett Program.	No	No	No	The Office provides low-cost health insurance and waiver programs for qualified individuals.	There are a number of issues that prevent people on Medicaid from receiving rehabilitation for brain and spinal injuries. For people who have Medicaid at the time of their injury Medicaid's reimbursement rates are too low and, as a result, hospitals have limited the number of inpatient rehabilitation beds they offer to patients who will be using Medicaid to pay for services. For people who were not on Medicaid at the time of their injury, they must wait anywhere from nine months to two years to get approved for Medicaid. During this waiting period they are considered to be "Medicaid pending," which means that hospitals do not have a guarantee of payment and are reluctant to accept such patients. By the time the person is approved for Medicaid people are ready for outpatient therapies and services, however, by that time Medicaid has determined the person's condition to be "chronic" and will not approve such services. In addition, Medicaid's process for preauthorizing outpatient services is so lengthy that many hospitals are reluctant to invest the time for such low reimbursement rates. Significant reforms are needed to make Medicaid relevant for Georgians with brain and spinal injuries.

PROGRAM DESCRIPTION	ELIGIBILITY CRITERIA	ELIGIBLE AGE GROUPS	ELIGIBLE			SERVICES OFFERED	SPECIALIZED SERVICES			FINANCIAL ASSISTANCE OFFERED	RECOMMENDATIONS (IF APPLICABLE)
			TBI	ABI	SCI		TBI	ABI	SCI		
MENTAL HEALTH, OFFICE OF											
Division of Mental Health, Developmental Disabilities, and Addictive Diseases / Department of Human Resources											
The Office of Mental Health offers a range of treatment and support services to promote integration into the community and recovery for people with serious mental illnesses.	A person must be diagnosed with an approved diagnostic category for state-funded services for mental illness.	All ages	Yes	Yes	Yes	The Office of Mental Health provides services through core providers and specialty providers, depending upon the needs of the person. Services vary by region but may include: crisis services, outpatient services, community support services, day and employment services, residential support and regional hospitals. The services a person receives depends on a professional determination of a level of need as well as the availability of services and other community supports.	No	No	No	Services are offered on a sliding scale, although services are free for people who meet Federal Poverty Level criteria. Services are reimbursed by Medicaid for people who are Medicaid-eligible.	People with brain injury or SCI are eligible for Mental Health services only if they are diagnosed with a mental illness. Otherwise, people with a primary diagnosis of TBI are specifically prohibited by statute from receiving Mental Health services. That being said, symptoms of brain injury often mimic those of mental illness and many people with brain injury often end up being misdiagnosed with mental illness and receiving services that are inappropriate, and possible harmful, for brain injury. It is critical to develop screening tools to help identify people with brain injuries who enter the Mental Health system and to provide appropriate services for them. Also, given the fact that people with severe neurobehavioral issues can at times pose a danger to themselves or others it is important to explore a possible partnership to provide crisis management services for people with brain injury.
PEACHCARE FOR KIDS™											
Division of Medical Assistance / Department of Community Health											
PeachCare of Kids™ is a comprehensive health care program for uninsured children living in Georgia.	Any child under the age of 18 and under (a child is eligible until their 19th birthday) who is a U.S. citizen, is uninsured, and whose family income is less than or equal to 235% of the Federal Poverty Level. A child may be ineligible if he/she is eligible for Medicaid, or if the child has access to health insurance through a parent's employment with the State of Georgia, even if the parent has not purchased the State coverage.	Age 18 and under	Yes	Yes	Yes	The health benefits include primary, preventive, specialist, dental care and vision care. PeachCare for Kids™ also covers hospitalization, emergency room services, prescription medications and mental health care. Each child in the program has a Georgia Healthy Families Care Management Organization (CMO) who is responsible for coordinating the child's care.	No	No	No	The program provides free health care for children under age 6. There is a cost per month for children over age 6 that is based upon the number of children in the program.	Children with brain and spinal injuries may be eligible for PeachCare of Kids™.
SPECIAL EDUCATION SERVICES & SUPPORTS, DIVISION FOR											
Department of Education											
The Georgia Department of Education, Divisions for Special Education Services and Supports strives to ensure that all children with disabilities in Georgia will participate in a challenging educational program designed to meet their unique needs that results in increased academic performance and prepares them for employment and independent living.	A child with a disability is a child evaluated and determined to be eligible for special education services for intellectual disabilities, a hearing impairment including deafness, a speech or language impairment, a visual impairment including blindness, emotional disturbance, an orthopedic impairment, autism, traumatic brain injury, other health impairment, a specific learning disability, or Deaf/blindness.	3 - 21 years	Yes	Yes	Yes	A wide range of services may be offered as determined by the student's Individualized Education Program (IEP) team. Services must be documented in the student's IEP. Services may include, but not be limited to, specialized instruction, speech therapy, physical therapy, occupational therapy, transportation, audiological services, adapted physical education, and vision services.	Yes	No	No	Students with disabilities are entitled to a "free, appropriate public education " (FAPE) under the Individuals with Disabilities Education Act (IDEA)	The DOE has a diagnostic category for TBI, although most teachers have not received training to support children with TBI. Children with ABI and SCI are provided services under the more generalized category of "Other Health Impairments."

PROGRAM DESCRIPTION	ELIGIBILITY CRITERIA	ELIGIBLE AGE GROUPS	ELIGIBLE			SERVICES OFFERED	SPECIALIZED SERVICES			FINANCIAL ASSISTANCE OFFERED	RECOMMENDATIONS (IF APPLICABLE)
			TBI	ABI	SCI		TBI	ABI	SCI		
VOCATIONAL REHABILITATION											
Rehabilitation Services / Department of Labor											
Vocational Rehabilitation (VR) provides services to help persons with disabilities prepare for, start, and maintain competitive employment. The VR program has 13 regional offices statewide, as well as 53 local offices with VR counselors who work in the community and have an in-depth knowledge of both the marketplace and support services available.	Any resident of the state of Georgia who has a permanent physical or mental disability that interferes with their ability to work; for whom VR services are necessary for the person to prepare for, enter, engage in, or keep gainful employment; and who can, will, and wants to work. Eligibility for Vocational Rehabilitation services is determined by a Certified Rehabilitation Counselor within 60 days of application for services.	16 and up	Yes	Yes	Yes	VR provides access to counseling and guidance; support for college and university education; supported employment; work readiness training; work adjustment training; vocational and technical training; on the job training; and job coaching.	No	No	No	VR provides funding for qualified applicants to assist with costs related to preparing for and obtaining employment, including: college and university education; supported employment; work readiness training; vocational and technical training; on the job training; job coaching; home modifications; and vehicle modifications.	In the 1990's VR recognized the particular needs of people with brain injury and developed specialized employment services for them. These services were discontinued because of a lack of funding in the late 1990's. Currently, VR uses a generalized service model to assist people with all types of disabilities. For people with brain injuries to be successful in employment it is recommended that specialized services be redeveloped.

References

1. "Substance Abuse Issues After Traumatic Brain Injury." Brain Injury Association of America Fact Sheet.
2. Dryden DM, Saunders LD, Rowe BH, et al. "Depression Following Traumatic Spinal Cord Injury." Neuroepidemiology. 2005;25(2):55-61. Epub 2005 Jun 8.
3. Langlois JA, Rutland-Brown W, Thomas KE. Traumatic brain injury in the United States:emergency department visits, hospitalizations, and deaths. Atlanta (GA): Centers for Disease Control and Prevention, National Center for Injury Prevention and Control; 2006.
4. "TBI in Prisons and Jails: An Unrecognized Problem." Centers for Disease Control and Prevention Fact Sheet.
5. "Linking Domestic Violence and Traumatic Brain Injury." Alabama Department of Rehabilitation PowerPoint presentation.

APPENDIX C:
ANALYSIS OF COMMUNITY-BASED SERVICES LISTED IN ESP/CONNECT DATABASE

The following spreadsheet is a summary of the Advisory Committee's analysis of the ESP/Connect Database, which is administered by the Atlanta Regional Commission's Area Agency on Aging. The Database contains listings of more than 17,000 resources for older adults and people with disabilities in Georgia. In 2005 the Advisory Committee partnered with the Atlanta Regional Commission to expand the Database to include resources for people with brain and spinal injuries.

For the purposes of the analysis the Advisory Committee reviewed the geographic locations of those services that are most critical for Georgians with brain and spinal injuries to live independently. The purpose of the analysis was to assess the number of services in each of the Commission's ten regions of the state and identify any gaps in services. The Advisory Committee noted many areas, particularly outside the Metro Atlanta region (region 3), where there is an insufficient number of available services for people with brain and/or spinal cord injuries. (Refer to Appendix E for a regional map.)

Where appropriate, categories are divided between providers who specialize in serving people with TBI and those who can serve people with SCI. It is important to note here that the number of providers listed who serve people with TBI or SCI 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 or SCI really does have the training and specialized services necessary to do so effectively and appropriately.

ESP/CONNECT DATABASE CATEGORY	DEFINITION	COMMISSION REGION									
		1	2	3	4	5	6	7	8	9	10
ADVOCACY SERVICES											
Advocacy Assistance: Disabilities	Organizations that provide information, training and support to assist people with disabilities to protect their rights, improve services, and remove barriers to independent living.	1	1	13	0	5	2	0	5	3	2
Legal Services: General	Organizations that provide free or low-cost legal aid to people with disabilities.	1	1	5	0	1	1	1	2	2	1
ANIMAL ASSISTANCE											
Pet Supportive Services	Community-based programs that assist older adults and people with disabilities in keeping, feeding, and caring for their pets.	0	0	1	0	0	0	0	2	1	0
Canine Assistance Programs	Organizations that provide service dogs to assist people with disabilities.	0	0	1	0	0	0	0	1	1	0
DAY PROGRAMS											
Adult Day Care (Self-Report): TBI	Community-based programs designed to meet the needs of adults with functional impairments. Through a structured and comprehensive program a variety of health, social and related support services are offered in a supervised protective setting during some portion of a twenty-four hour day.	6	0	10	1	1	4	1	0	2	1
Adult Day Care (Self-Report): SCI		5	0	9	1	1	4	1	0	1	1
EDUCATIONAL SERVICES											
Educational Services: TBI and SCI	Programs that provide support to children, youth, and adults who need assistance and support to pursue and complete their education, from primary education through college and university level education.	0	0	1	0	0	1	0	1	0	1
EQUIPMENT, TECHNOLOGY AND SUPPLIES											
Assistive Technology Devices	Products, devices, or equipment that are used to maintain, increase, or improve the functional capabilities of people with disabilities. Such devices can be used to help a person communicate, complete their activities of daily living, work, go to school, and otherwise live as independently as possible.	6	11	13	2	10	9	11	9	10	5

ESP/CONNECT DATABASE CATEGORY	DEFINITION	COMMISSION REGION									
		1	2	3	4	5	6	7	8	9	10
Daily Living Aides	Products, equipment, and supplies that help a person to complete their activities of daily living (eating, bathing, grooming, dressing, preparing meals, etc.).	35	15	10	9	8	7	11	18	14	1
Durable Medical Equipment	Certain types of medical equipment that are used to assist people with disabilities in their homes and communities. DME must be prescribed by a doctor. DME can include walkers, wheelchairs, canes, cognitive prostethetics, special supportive mattresses and pillows, shower chairs, etc.	29	24	29	21	14	11	11	11	22	10
Specialized Clothing	Clothing and footwear designed for use by older adults and people with disabilities including adult diapers, incontinence clothing, diabetic shoes and socks, side snap and back snap clothing, etc.	4	4	3	0	1	2	7	2	1	0
HEALTH CONDITIONS											
Health Conditions: TBI	Agencies that are organized at state, local or national levels and are engaged in programs of service, education, and research and/or the provision of information to the general public specifically about brain injury. Programs may also offer screening procedures.	1	0	6	1	0	2	1	2	1	0
Health Conditions: SCI	Agencies that are organized at state, local or national levels and are engaged in programs of service, education, and research and/or the provision of information to the general public specifically about spinal cord injury. Programs may also offer screening procedures.	1	0	4	0	0	1	0	1	1	0
HOME MODIFICATIONS											
Home Modifications	Programs that pay for or provide assistance in the form of labor and supplies for disabled people who need to install ramps, widen doorways, install grab bars in showers and bathrooms, lower kitchen and other cabinets, or make other modifications in their homes to make them accessible. Also included are programs that assess the accessibility of homes of people who have disabilities and make recommendations regarding necessary modifications.	5	8	5	3	7	5	2	6	5	10
INFORMATION AND REFERRAL											
Information and Referral: Disabilities	Organizations that provide information on and referrals for available resources.	2	2	20	0	4	6	9	4	5	11
MEDICAL SPECIALTIES											
Neuro/Psych/Counseling: TBI	Neuropsychological testing provides a comprehensive assessment of cognitive, behavioral and psychological issues associated with brain injury. Counseling provides treatment with emphasis on improving the psychological aspects by integrating the cognitive issues associated with the brain injury. It also may include counseling and education with the caregivers to better understand the brain behavior relationships	0	0	11	1	0	1	0	1	1	1
Physiatrist: TBI and SCI	Physicians who are board certified in physical medicine and rehabilitation. The physicians specialize in brain and spinal cord injury and other neuromuscular disorders. They diagnose, treat and make recommendations for services that will benefit an individual medically, clinically and behaviorally.	0	0	1	0	0	0	0	0	0	0
NEUROBEHAVIORAL PROGRAMS											
Neurobehavioral Programs	Programs that provide a safe and controlled environment for people who have significant behavior problems as a result of a brain injury. These programs focus on a combination of medication and behavioral structure with the goal of enabling the person to live successfully without posing a risk to others and/or themselves.	0	0	1	1	0	1	0	0	1	0
NURSING HOMES											
Nursing Homes (Self-Report): TBI	A residential facility that provides skilled nursing services for older adults and people with disabilities or chronic illnesses.	32	0	15	0	6	0	0	23	9	1
Nursing Homes (Self-Report): SCI		33	0	16	0	5	0	0	23	8	1

ESP/CONNECT DATABASE CATEGORY	DEFINITION	COMMISSION REGION									
		1	2	3	4	5	6	7	8	9	10
PERSONAL SUPPORT/ATTENDANT CARE											
Companion Sitter (Self-Report): TBI	Programs that offer the services of paraprofessionals who provide transportation and escort services, meal preparation and serving, as well as household tasks essential to cleanliness and safety.	8	1	56	4	1	5	0	3	2	4
Companion Sitter (Self-Report): SCI		9	1	57	4	0	5	0	3	2	4
Home Care Providers: TBI and SCI	Programs that provide nursing care, personal care assistance, companion/sitter services and therapy to people with brain and spinal cord injuries in their own private homes. A written service agreement must be executed before services are begun. Staffing, record keeping and supervision requirements are specified by law and applicable regulations. The Georgia Department of Human Resources licenses private home cares providers.	2	1	28	1	1	0	0	1	0	0
Personal Care Assistance (Self-Report): TBI	Programs that offer the services of trained personnel to provide assistance with bathing, toileting, grooming, shaving, dental care, dressing, and eating. Personal care assistance may also include proper nutrition, home management, housekeeping tasks, ambulation and transfer, and medically related activities under carefully specified conditions.	9	1	57	3	1	2	0	4	2	3
Personal Care Assistance (Self-Report): SCI		10	1	58	4	0	2	0	4	2	3
RECREATIONS											
Recreation Programs: TBI and SCI	Programs that provide recreational opportunities for people with brain or spinal cord injuries.	1	1	6	1	0	1	0	0	0	0
REHABILITATION											
Day Hospital Facilities	Day treatment programs intended to improve the functional ability of the person through comprehensive therapeutic and medical interventions and supervised activities. Programs are intensive and can be provided from 3x to 7x per week. Day treatment programs focus on community reintegration.	0	0	5	1	0	1	0	0	1	0
Rehab Acute Inpatient Care	Medical programs that are designed to improve the functional ability of people with brain or spinal cord injuries through a coordinated, comprehensive and integrative approach of medical care and intensive rehabilitation services. The program is generally provided on a specialized unit or in a free standing hospital with trained staff in rehabilitation	3	3	10	2	0	4	0	2	1	2
Rehab Coma Programs	Medical and rehabilitative programs that provide some rehabilitative services for people who are in a coma, semi-coma and minimally conscious state. These programs also provide extensive family education and training for the caregivers. These programs can be provided short term or long term.	0	0	1	0	0	1	0	0	0	0
Rehab Long-term Acute Care Facility	Health care facilities that specialize in treating patients who require extensive physiological monitoring, intravenous therapy or postoperative care, ventilatory care, pulmonary issues or other medically complex interventions, while still providing some rehabilitative services to prevent complications and improve function.	0	0	3	1	0	2	0	0	1	0
Rehab Neurobehavioral Outpatient	Programs that provide specialized outpatient services for people with neurobehavioral issues.	0	0	0	0	0	1	0	0	0	0
Rehab Outpatient Programs	1. Programs that provide coordinated and integrated evaluation and treatment with emphasis on improving functional abilities. At minimum they include medial direction, medical supports services and consultation, rehabilitation therapies and other services. These programs are generally designed for people who need ongoing treatment from an inpatient rehabilitation program or for whom an inpatient rehab program is not appropriate. May provide some transportation services. 2. Programs that offer a wide range of services from a private practitioner's office that offers fee for service to facilities that offer single service therapies. These are more for short-term non-catastrophic illnesses.	2	3	5	0	0	0	0	1	2	0
Rehab Subacute Care	Nursing Homes that provide short-term rehabilitative therapies in order to improve function and with the goal of discharging the patient back to their home setting.	2	0	0	0	0	0	0	1	0	0

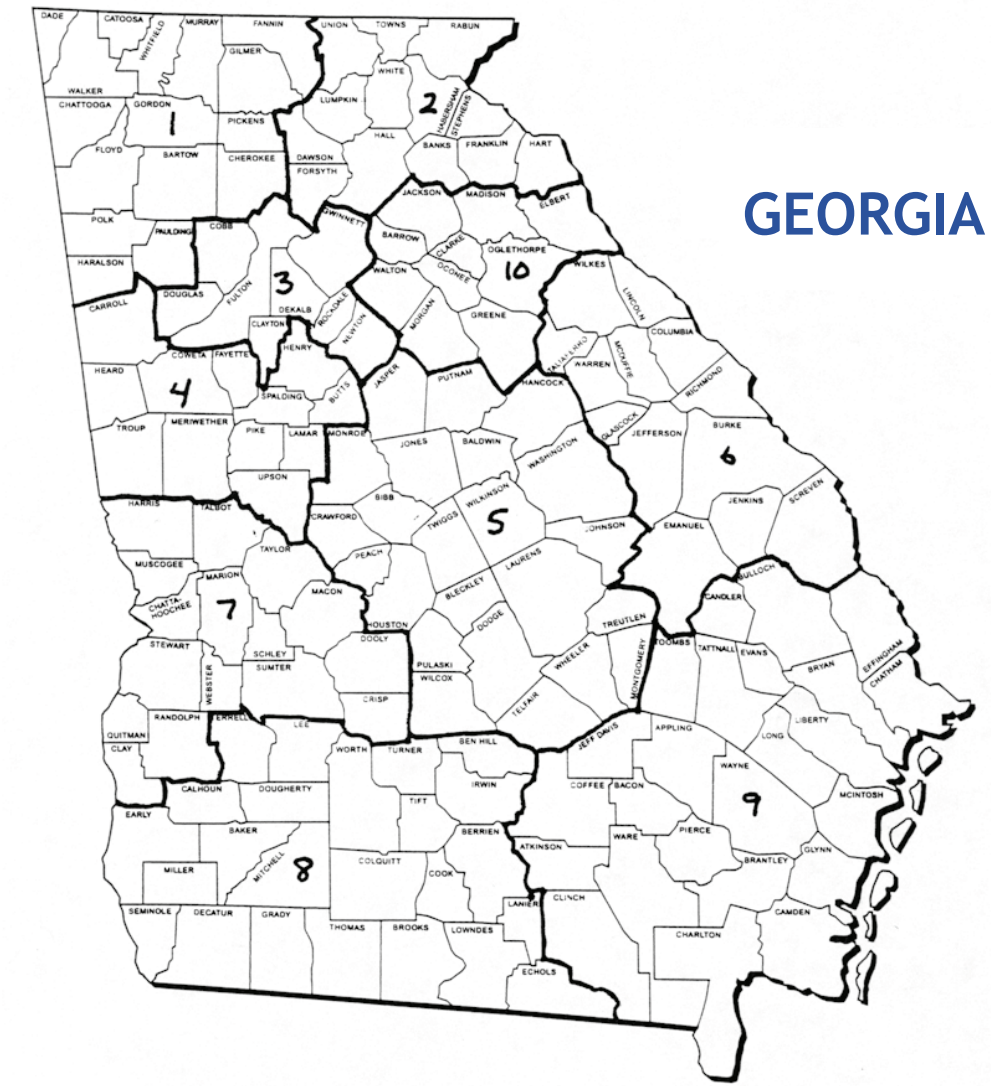
ESP/CONNECT DATABASE CATEGORY	DEFINITION	COMMISSION REGION									
		1	2	3	4	5	6	7	8	9	10
RESIDENTIAL SETTINGS											
Personal Care Home (Self-Report): TBI	A single home, building or group of buildings where personal care services (assistance with daily living activities such as bathing, toileting, grooming, dressing, eating, etc.) are provided to two or more non-family adults with brain or spinal cord injuries.	9	1	42	1	3	55	6	2	1	1
Personal Care Home (Self-Report): SCI		9	0	42	1	2	54	6	2	0	2
Residential Options: TBI	Facilities that provide 24-hour supervision and comprehensive medical and clinical services to people with brain injury in order to maximize functioning and the ability to return to home.	1	0	8	0	0	2	0	1	0	0
RESPITE											
Respite In Home: TBI and SCI	Programs that provide long-term or short-term relief or respite in one's home from caregiver responsibilities to individuals who are caring people with a brain or spinal cord injury.	0	2	18	0	1	0	0	1	0	0
Respite Out of Home: TBI and SCI	Programs that provide short-term relief or respite in a community based facility from caregiver responsibilities to individuals who are caring people with a brain or spinal cord injury.	0	0	6	0	0	3	1	0	2	0
SERVICE COORDINATION											
Care Management	Programs that assist people with disabilities or chronic conditions to coordinate medical, social, and/or mental health care and services in an effort to manage medical conditions more effectively.	1	1	30	5	4	2	4	7	6	4
SUPPORT GROUPS											
Support Groups: TBI	An organized group of people with brain and/or spinal injuries, and/or their family members or caregivers, who meet to provide each other with moral support, information, and advice.	3	2	12	1	1	2	1	1	2	1
Support Groups: SCI		0	0	3	0	1	0	1	0	1	0
VEHICLE CONVERSION											
Vehicle Conversion	Companies that make modifications to vehicles to enable them to be used by people with a disabilities.	1	0	4	1	1	0	0	0	3	1
VOCATIONAL SERVICES											
Vocational Services: TBI and SCI	Programs that provide vocational services, including supportive employment, vocational evaluation, job counseling, job skills training, job placement, community employment, and work adjustment to people with brain and spinal cord injury.	5	3	19	4	5	3	1	4	5	6
Total Services:		**236**	**87**	**644**	**74**	**84**	**202**	**75**	**148**	**121**	**77**

APPENDIX D: COMPARISON OF MEDICAID WAIVER SERVICES

PURPOSE	SERVICES OFFERED	ELIGIBLE			REVIEW AND RECOMMENDATIONS
		TBI	ABI	SCI	
COMMUNITY CARE SERVICES PROGRAM					
Division of Aging Services / Department of Human Resources					
CCSP was designed for people with limited incomes who are elderly and/or people who have functional impairments or other disabilities.	Core Services (service coordination, personal support, home health services, emergency response systems, respite care), adult day health care, alternative living services (such as a personal care home), or home-delivered meals.	Yes	Yes	Yes	CCSP is primarily designed to address medical issues through services such as home health services, attendant services, adult day health care, etc. This may make it appropriate for people with SCI. Most people with brain injuries do not need medical care but instead need behavioral support. However, the only behavioral support that is provided by CCSP is adult day programs for people with Alzheimer's disease or other types of dementia, but the environment, strategies, and interventions used in these programs are inappropriate and ineffective for people with brain injuries, particularly young people with brain injuries.
INDEPENDENT CARE WAIVER PROGRAM					
Office of Medicaid / Division of Medical Assistance / Department of Community Health					
ICWP was designed to meet the needs of people with significant physical disabilities, between the ages of 21 and 64, who needed 24 hour care, but eventually ICWP expanded its eligibility criteria to include services for people with TBI.	Core Services (service coordination, personal support, home health services, emergency response systems, respite care), behavior management services, specialized medical equipment and supplies, counseling, and home modifications.	Yes	Yes	Yes	ICWP is the waiver that is best designed to serve the needs of people with brain and spinal injuries. It has the capacity to provide the most appropriate types of services and supports and thus assist many people with brain and spinal injuries to live in the community. This is because it was designed to serve people with significant physical disabilities, including people with SCI who are dependent upon ventilators and need 24-hour care, and because it includes behavioral management services that are specifically designed for people with TBI in its list of covered services. However, as the Commission identified in its White Paper there are many major flaws with the ICWP. These flaws include the way in which costs are calculated for the waiver, a cap that has been instituted (and which thus prevents its use by the people for which it was designed), and very low reimbursement rates for the most critical services. The Commission strongly recommends revisions to the ICWP to enable it to be used to support Georgians with TBI and SCI in the community.
NEW OPTIONS WAIVER PROGRAM AND COMPREHENSIVE SUPPORTS WAIVER PROGRAM					
Office of Developmental Disabilities / Division on Mental Health, Developmental Disabilities, and Addictive Diseases / Department of Human Resources					
NOW and CSW were designed for people with mental retardation or who have another developmental disability. NOW is designed to support people who do not need 24 hour care, while CSW is designed for people who do need 24 hour care.	Core Services (service coordination, personal support, home health services, emergency response systems, respite care), consumer and family education, day habilitation and supported employment, family support, residential training and supervision, and specialized medical equipment and supplies.	Yes, if they meet eligibility criteria for mental retardation or developmental disability.			The Office of Developmental Disabilities recently introduced the NOW in an effort to give people more control over the ways in which their waiver dollars are spent and to provide greater options for services and supports. The design of the new waivers reflects the desire of the Office of Developmental Disabilities to ensure that people with developmental disabilities have the funding and support they need to live in the community. Budgets for the waivers are based upon the individual's needs and the family has the ability to choose innovative ways to support their loved one in the community. These two waivers offer an excellent model for redesign of the ICWP waiver, where the focus is on providing funding based upon the individualized and particular needs of the individual. NOW and CSW provide sufficient funding for a variety of services that are necessary to support people with behavioral issues, including behavioral supports, community living support (similar to personal support), natural supports training to train support personnel, and professional therapeutic services. All of these services are necessary to support people with brain injury and should be funded by the ICWP.

APPENDIX E: REGIONAL MAP

Brain & Spinal Injury Trust Fund Distribution Regions



Brain & Spinal Injury
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