Brain & Spinal Injury Trust Fund Commission

Georgia's Neurobehavioral Crisis:

Lack of Coordinated Care, Inappropriate Institutionalizations

Public Policy Report and Recommendations

FACT SHEET

What is Traumatic Brain Injury (TBI)?

A TBI is an injury to the brain caused by "blunt or penetrating trauma from acceleration-deceleration forces," such as a car accident, fall, gunshot wound, or sports injury.

How many people are affected by TBI?

TBI is the leading cause of death and disability for anyone age 45 or younger. Approximately 2% of the U.S. population is living with a long-term disability relating to a TBI, which means that **187,000 Georgians are impacted by this disability**—10% of whom may need ongoing, intensive supports because of behavioral issues.

What are the costs of care for people with TBI?

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 TBI 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 TBI to the nation is estimated at $56.3 billion annually. Research has shown that these costs can be reduced with appropriate and effective services and supports.

What significant behavioral issues are associated with TBI?

A person with neurobehavioral issues associated with TBI may be verbally disruptive or threatening, destroy property, behave in sexually inappropriate ways, resist assistance from others, or exhibit physical aggression. Additionally, people with neurobehavioral issues may have problems with:

- Concentration
- Memory and attention
- Impulsivity
- Aggression
- Irritability
- Depression
- Moodiness
- Changes in personality

People with TBI are also at a higher risk for psychiatric disorders: 20-50% of people with TBI may have at least one psychiatric disorder in the first year following injury.

These behavioral issues impede an individual's ability to return to work or school, to maintain relationships, and to resume community living. Those with more severe behaviors may hurt themselvers or others.

B.'s Story: *A Life Disrupted by an Inadequate System*

B., a father in his mid-20s, sustained a TBI in a car crash in October 2004. As a result of his injury, he developed significant neurobehavioral issues. He needed more help than a hospital could provide, but unfortunately, no money was available to pay for a program that would offer the necessary 24-hour behavioral, cognitive, and physical treatment in a community setting. The hospital instead contacted 117 nursing homes, all of which denied B. admission because they were not equipped to care for someone with significant behavioral problems. The regional medical center that was already treating B.'s injuries had no choice but to keep him in their facility. For 14 months, the medical center cared for B. at their expense—a total cost of $552,500.

Unfortunately, the hospital was not able to care appropriately for B., and as a result, he did not get the basic treatment he needed, like physical therapies and grooming. As a result, B.'s legs became severely contracted, requiring numerous surgeries, causing great physical pain, and intensifying his neurobehavioral problems.

Finally, a specialized brain injury rehabilitation hospital in Atlanta agreed to admit B. while the regional medical center assisted in finding his next placement. Though his neurobehavioral problems persisted, the appropriate treatment began to bear fruit. After only 70 days in the rehab hospital, B. was ready to be discharged for neurobehavioral rehabilitation.

But B. had nowhere to go. The only neurobehavioral program in the state refused to admit him because of his physical limitations, lack of places to go upon discharge, and lack of funding. His ICWP application was denied because the cost of the rehabilitation program would exceed the allowable amount for the waiver, and because ICWP believed that B.'s behaviors could not be managed in the community.

What are the appropriate supports for people with neurobehavioral issues?

A coordinated system of care for people with neurobehavioral issues resulting from TBI includes: *screening and identification, training and awareness, rehabilitation, and long-term or life-long supports.*

Unfortunately, this kind of coordinated system of care is not available in Georgia, largely due to lack of public and private funding.

Without appropriate supports, what happens to these people?

Without sufficient services and funding, people with TBI who have significant behavior problems generally end up in nursing homes, out-of-state programs, state hospitals, jail or prison, or become homeless.

How would the state benefit from providing appropriate supports for people with neurobehavioral issues?

The State of Georgia is losing a significant amount of money in terms of lost productivity, duplicated services, and out-of-state and/or inappropriate placements as a result of its lack of service coordination for people with neurobehavioral issues. See the charts below and column with B.'s story for a case study:

Costs of Actual, Inappropriate Services for B.		
Time spent	**Service**	**Cost**
425 days	Regional medical center: $1300/day	$552,500
70 days	Specialized brain injury rehab hospital: $1,100/day	$77,000
330 days	Out-of-state neurobehavioral program: $600/day	$198,000
Total costs of inappropriate care:		**$827,500**

Costs of Appropriate Services for B.		
Time needed	**Service**	**Cost**
90 days	Regional medical center: $1500/day*	$135,000
45 days	Specialized brain injury rehab hospital: $1100/day	$49,500
150 days	Out-of-state neurobehavioral program: $650/day*	$97,500
Total costs of appropriate care:		**$282,000**

Difference in costs to the state in dollars: $545,500
Difference in days of service to B. and his family: 540

**The costs listed illustrate the difference between the costs of actual services provided to B. and the estimated costs of providing appropriate services for him. Costs of care vary depending upon the needs of the individual person.*

Ultimately, the regional hospital where B. was first treated agreed to pay for 3 months of treatment in an out-of-state neurobehavioral program, rather than readmit him. However, because of few discharge options, B. ended up staying in the out-of-state program for 11 months, at a cost of $198,000. The treatment was very effective, however, and by the end of his stay, his improvements resulted in increased quality of life and decreased cost of care. He was even able to have visits with his son.

Because of his improved condition, B.'s parents felt up to the task of caring for him in their home, with the assistance of personal attendants. Though ICWP initially agreed to provide funding for B. to live with his parents, unfortunately, the available attendants did not have specialized training in neurobehavioral issues and were unable to manage and redirect his behavior. His parents became overwhelmed with the challenge of caring for B., and were left with no other choice but to admit him to a nursing home. As a result, ICWP discontinued funding for B.'s care.

Recently, B. was suddenly and prematurely discharged from the nursing home and placed back at the regional medical center where he was first admitted. It is unclear why the nursing home discharged him. The nursing home staff had received training in managing neurobehavioral issues, and reported that, as a result, it had become easy for them to manage B.'s behavior. There is some concern that the reason for discharge was the nursing home administrators' reluctance to keep B. in their facility. Attorneys for the regional medical center, where B. has had no behavioral problems, are suing the nursing home. B.'s parents have reapplied for the ICWP and are exploring other alternatives for his care. At this point, however, they have almost no options left.

Sufficient funding and services for rehabilitation and community supports would have:

- Prevented B. from developing severe physical and neurobehavioral issues that required costly rehabilitation;
- Prevented B. from being sent out-of-state for neurobehavioral treatment;
- Enabled B. to return home after months, rather than years;
- Saved hundreds of thousands of dollars in costs of care and staff time;
- Allowed B. to live in the community with his family and help raise his son.

What services are currently available?

Few services are available for Georgians with neurobehavioral issues resulting from TBI. They include:

Programs designed specifically for people with TBI:

- *Brain and Spinal Injury Trust Fund Commission*
  - Only state agency/funding source dedicated to meeting the needs of people with TBI.
- *Department of Labor, Rehabilitation Services, Roosevelt Warm Springs Institute for Rehabilitation*
  - Medical & vocational rehabilitation facility.
- *Private Providers*
  - High quality, but low capacity.

Programs for other disabilities that could include TBI:

- *Department of Community Health, Office of Medicaid*
  - ICWP, the only one of the four Home and Community-based Services waivers that is designed for people with TBI, is flawed.
- *Department of Education, Division for Exceptional Students*
  - Many children with TBI elude diagnosis and therefore do not receive available services.
- *Department of Human Resources*
  - Division of Mental Health, Developmental Disabilities, and Addictive Diseases
    - People with TBI specifically excluded.
  - Division of Public Health, Family Health Branch, Children's Medical Services
    - No category exists for TBI.
- *Department of Labor, Rehabilitation Services, Vocational Rehabilitation*
  - Head Injury Program cut in 1990s; though some elements remain, critical components are missing from currently available services.
- *Independent Living Centers*
  - Non-residential, community-based organizations staffed by people with disabilities; no specific TBI services.

What's the bottom line?

- Brain injury is a significant public health issue in Georgia.
- There is no service-delivery system for Georgians with TBI. Existing systems are inappropriate or inadequate.
- The only funding source designated for Georgians with TBI is the Brain & Spinal Injury Trust Fund, with an average annual revenue of $1.8 million—a grossly inadequate amount to address the long-term care needs of the more than 187,000 Georgians with TBI.
- ICWP is seriously flawed and causes many Georgians with brain injury to be institutionalized inappropriately.
- Many people whose income disqualifies them from Medicaid waiver programs cannot afford to pay for long-term care because private insurance doesn't cover support for neurobehavioral issues.

When ICWP Fails People with Neurobehavioral Issues

C. was a thriving high-school sophomore when he was severely injured in a car accident in 2001. He was life-flighted to a hospital, where he remained in a coma for three weeks. After being transferred to an Atlanta-based specialized brain injury rehabilitation hospital, C. eventually came out of the coma and began the arduous and painful task of relearning to walk, talk, eat, and perform other basic activities. C. had his first violent episode while participating in the hospital's outpatient program. His behavior continued to escalate, posing a significant risk to himself and others.

At first, C.'s private insurance paid for him to be admitted to the state's only inpatient rehab center for people with neurobehavioral issues. Unfortunately, the insurance coverage did not provide for the full time it took to address his issues, so C. was discharged to the care of his mother in August 2002. At that point, it became extremely difficult for her to get the necessary assistance for her son. It was clear that she could not manage C.'s behavior by herself and that he still needed additional rehabilitation.

C.'s mother spent nine months trying to get assistance from ICWP, the Office of Mental Health (MH), and others, but none of these agencies would agree to provide services or funding. Meanwhile C.'s mother often had to rely upon the police to ensure C.'s and her family's safety. During this time C. was in and out of both private- and state-funded mental health facilities as well as a residential setting for people with brain injury, where he was eventually discharged because of his aggressive behavior. Only when C.'s mother called Rep. Nathan Deal's office did ICWP finally agree to pay for C. to be re-admitted to the inpatient rehab center.

Throughout the time C. was at home and in the rehabilitation center, his local school system made efforts to serve him in the community, but eventually decided to pay for his placement in a residential facility rather than continue to try to manage his behaviors in the local school setting. Since the school system was providing the funding for placement, ICWP discharged C. from their program. Unfortunately, one of the few programs that was available and that would accept the funding source was an out-of-state

What does the Brain & Spinal Injury Trust Fund Commission recommend?

The Commission strongly recommends a coordinated system of care that supports people with TBI, their family members and primary caregivers, and which allows individuals to live as independently as possible. Such a system would:

- greatly improve quality of life for people with TBI,
- reduce the use of state funds for inappropriate and ineffective services, and
- create a model of care for the rest of the country.

To accomplish this goal, the Commission recommends the following:

Recommendation 1: Create a legislative study committee to identify legislation, funding, responsible entities, and other infrastructures to create and support a coordinated system of care for people with TBI.

Recommendation 2: Develop a coordinated system of care that addresses four key components:

I. Screening & Identification

- Expand capacity for behavior screening, assessment and evaluation for children and adults to identify people with TBI-related significant behavioral issues.

II. Training & Awareness

- Develop and provide training for direct care staff, providers, paraprofessionals, educators and other professionals to increase awareness and expertise in behavior associated with brain injury.
- Develop and maintain a centralized database of direct support staff, providers, paraprofessionals, educators and other professionals who have expertise in behavior associated with brain injury.

III. Rehabilitation

- Expand funding and opportunities for post-acute rehabilitation, community and school re-entry services.

IV. Long-term or life-long supports

- Expand capacity for service coordination and case management services.
- Expand capacity for short-term, long-term and intermittent support such as professionally-designed behavioral supports, counseling, community-based and in-home care, personal care/support, and crisis management services.
- Expand capacity for support services and respite options for caregivers.
- Develop capacity to provide for structured, community-based residential treatment and care for individuals who are a danger to themselves and others.

Recommendation 3: Provide oversight and policy development to support a coordinated system of care facilitated through the Brain & Spinal Injury Trust Fund Commission.

program that specialized in developmental disabilities rather than brain injury, which meant that C. would not get further assistance for his neurobehavioral issues. Therefore, since July 2004, C. has lived in an inappropriate setting far from his loved ones, a situation that has exacerbated his condition, not improved it.

C. will turn 22 and be discharged from the out-of-state program and returned to Georgia in October 2007. In an attempt to plan ahead for C.'s care, his mother began in August 2006 to secure funding and services for C. This meant repeating the laborious application processes for all of the state agencies with which she had previously dealt. This time, in addition to MH and ICWP, C.'s mother also requested assistance from the Office of Developmental Disabilities. However, she again faced a system in which no agency would agree to provide services for her son: DD said that C. does not quality for their services because his I.Q. is too high. MH denied services for C. because his behavioral problems are the result of a brain injury rather than mental illness. The only program whose eligibility criteria C. did meet was ICWP, but the program refused to provide services to him citing his violent behavior, the need for 24-hour care that would exceed their $49,016 cap on services, and their belief that C. could not be supported in the community.

With no other options for C.'s care, his mother was forced to make the difficult and painful decision not to apply for legal guardianship of her son. This means that the responsibility for his care will fall upon the state when he returns in October.

In Summary

Developing a coordinated system of care for people with brain injury may require redirecting existing funds (that currently support people in inappropriate placements), new funding, changes in state Medicaid program, and/or state legislation. The Brain and Spinal Injury Trust Fund Commission welcomes the opportunity to coordinate cooperation and planning among the stakeholders who, together, can achieve Georgia's coordinated system of care for people with TBI.