

TBI Project ACCESS

Fall Forums



Wednesday, October 11, 9 am – 2 pm
Clemmons, North Carolina

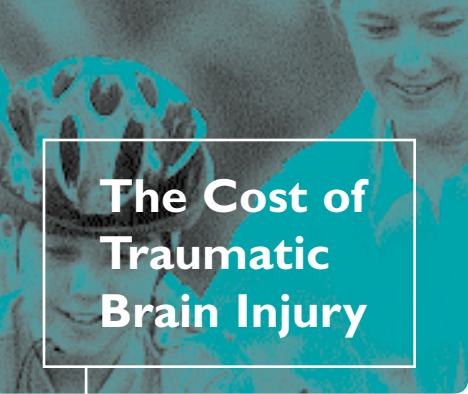
Thursday, October 12, 9 am – 2 pm
Greenville, North Carolina

Wednesday, October 25, 9 am – 2 pm
Chapel Hill, North Carolina

Tuesday, October 31, 9 am – 2 pm
Charlotte, North Carolina



TBI
TRAUMATIC BRAIN INJURY
STATE DEMONSTRATION GRANT PROGRAM



The Cost of Traumatic Brain Injury

The cost of traumatic brain injury in the United States is estimated to be **\$48.3**

billion annually.

Hospitalization accounts for \$31.7 billion, and fatal brain injuries cost the nation \$16.6 billion each year. Traumatic brain injury can also result in enormous loss of income or earning potential and large expenses for medical care and other services over a lifetime.

TRAUMATIC BRAIN INJURY

- Traumatic brain injury is the most frequent cause of disability and death among children and adolescents in the United States.
- Each year, more than one million children sustain brain injuries, ranging from minor concussions to severe trauma.
- More than 30,000 children have permanent disabilities as a result of brain injury annually.
- Of all pediatric injury cases in the United States, about one third are related to brain injury.

“Even professionals like myself who work with children with developmental delays on a daily basis have underestimated how frequently brain injury occurs and how often it’s missed.”

Dr. Joshua Alexander, principal investigator, UNC Hospitals

impairment. Many milder cases of TBI often go undiagnosed because there may have been no loss of consciousness, medical treatment was not sought, or because the injury could not be detected on a CT Scan. But these injuries can still result in long-term disability. Symptoms of TBI may be immediate or not surface for days, weeks or even months after sustaining the trauma.

While TBI may result in physical impairment, the more significant—and often less obvious—consequences involve an individual’s cognitive and social functioning. These can impact interpersonal relationships. Families are disrupted. Behavior problems may surface. Children with TBI may struggle with schoolwork.

Traumatic brain injury (TBI) is broadly defined as a brain injury from externally inflicted trauma. The primary causes of TBI include incidents involving motor vehicles, falls, acts of violence and sports injuries.

TBI can range from mild (concussions) to severe, with outcomes ranging from a few symptoms to lifelong



The Effects of Brain Injury

Brain injury can affect how a person thinks, acts and behaves.

For some children with TBI, their lives are altered forever. Each year, approximately 30,000 children in the U.S. incur a TBI resulting in a long-term, substantial loss of functioning. They may need costly services for the rest of their lives. Their employment and education options may be limited, resulting in loss of earning potential.

So what can be done to minimize the effects of traumatic brain injury? Project A.C.C.E.S.S., a federally funded, demonstration grant program, has laid the groundwork for significantly changing the current system to assure coordinated care, education and support for survivors of brain injury.



“One of the barriers that we have encountered is people’s misunderstanding about the effects of TBI. Just because a child can walk after a brain injury, people assume the child is okay. The child doesn’t ‘look’ sick. However, cognitive and other problems may remain or surface later.”

Dr. Dan Moore,
principal investigator,
ECU Brody School of Medicine

Cognitive consequences can include:

- short- or long-term memory loss
- slowed ability to process information
- trouble concentrating or paying attention
- difficulty keeping up with a conversation; other communication difficulties such as word finding problems
- taking things too literally
- trouble remembering things
- thinks and reacts slowly
- spatial disorientation
- organizational problems and impaired judgment
- inability to do more than one thing at a time

Physical consequences can include:

- seizures
- muscle spasticity
- vision problems
- loss of smell or taste
- speech impairments
- headaches
- fatigue, sleep disturbances
- decreased endurance
- balance problems

Behavioral consequences can include:

- lack of ability to initiate activities; difficulty in completing tasks without reminders
- increased anxiety
- depression, mood swings
- decreased self-awareness
- denial of deficits
- impulsive behavior
- agitation
- difficulty seeing how behaviors can affect others

PROJECT A.C.C.E.S.S.

Project A.C.C.E.S.S.—Assuring Coordinated Care, Education and Support for Survivors—is a three-year, federally supported, state-managed demonstration project awarded to the N. C. Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services by the Health Resources and Services Administration, Maternal and Child Health Bureau. Three level-one trauma centers in North Carolina are participating in Project A.C.C.E.S.S.: UNC Health Care System in Chapel Hill, the Carolinas Healthcare System including the Carolinas Medical Center and the Charlotte Institute of Rehabilitation in Charlotte, and the University Health Systems of Eastern Carolina in collaboration with East Carolina University, Brody School of Medicine in Greenville.

The R. Stuart Dickson Institute for Health Studies serves as a repository for all data collected by the project and will analyze the data and evaluate the efficacy of the project. The Brain Injury Association of North Carolina is conducting the Family Satisfaction Survey.

A direct product of the Traumatic Brain Injury (TBI) Act of 1996, Project A.C.C.E.S.S. addresses many of the problems inherent in the current system of providing appropriate information, access to services and follow up for children with TBI.

Scope of the Problem

The major problems confronting children with TBI include:

- Lack of appropriate screening or recognition of the potential problems associated with TBI
- Insufficient education for parents to help them identify future problems and connect them back to the head injury as the source of the problem
- Poor communication between the hospital providing initial treatment for TBI and a child's primary care provider and school
- Difficult reintegration back into their communities and lack of linkages to appropriate services

If these challenges are not addressed, they can contribute to decreased success at school, lack of community resources, poor outcomes and unnecessary frustrations.



Mary Hill
CTC
Community
Transition
Coordinator

Dr. Kat Kolaski
PI
Principal
Investigator

Sheri Bartel
CTC
Community
Transition
Coordinator

Implementation

To address these and other problems, Project A.C.C.E.S.S. established a community transition coordinator (CTC) position at each site. In collaboration with the site's principal investigator, the CTC identifies children and adolescents who may have sustained a TBI, provides information to their parents, places follow-up calls at regular intervals, helps secure services as needed and works with the family to make the transition back into the community more streamlined.

To identify children with brain injury for Project A.C.C.E.S.S., CTCs screen medical records from the emergency department and inpatient units for head injuries or other diagnoses which might be associated with a brain injury. For example, if a child falls off a horse and breaks a limb, the CTC might follow up to make sure there was no loss of consciousness or other indicators of head injury. When possible, the CTC meets with the parents of inpatients to provide them information about TBI and to enroll the child in Project A.C.C.E.S.S. For children who are seen in the emergency department but are not admitted, the CTC calls families, mails information and may refer them to the TBI clinic to determine if they are having symptoms of TBI.

The CTC follows up on each child participating in Project A.C.C.E.S.S. at one-, four- and ten-month intervals. Phone calls are placed to each child's family and data is collected. This data is then compiled from the three sites and evaluated.

If a child is experiencing symptoms at any follow-up call, the CTC refers the child to the on-site pediatric brain injury clinic to be screened for cognitive dysfunction and other TBI-related problems. The pediatric brain injury clinic at each site can provide a full range of pediatric therapy services including physical therapy, occupational therapy, speech therapy, psychology, social services and cognitive education. Upon recommendation of the project physician, the CTC helps arrange additional appointments at the pediatric brain injury clinic or other departments and facilities as necessary.



Dr. Kat Kolaski with 11 year patient struck in head by object resulting in severe brain injury

Project A.C.C.E.S.S. Participant Description

From May 1998 through December 1999, 1,251 children and adolescents, from birth through age 17, were followed as part of Project A.C.C.E.S.S. at the three North Carolina sites. Characteristics of this group are:

Average age:
8.5 years

Race:
51% Caucasian,
35% African-American

Gender: 59% male

Hospitalized:
36.6%

Departments:
63.4%

Nature of TBI:
43% motor vehicles,
28% falls

Through Project A.C.C.E.S.S., resource materials about TBI have been developed and/or purchased and are available for distribution within the hospital setting and to families, primary care physicians, schools and community service agencies. Project A.C.C.E.S.S. personnel have also worked with hospital staff to raise awareness of brain injury, associated symptoms and issues children may face after leaving the hospital or emergency department.

To help ensure the appropriate continuum of medical care, CTCs work with families to notify their primary care physicians of the injury and to provide needed information.

“Working with Project Access has been so helpful in understanding how brain injuries impact children and their families. A representative of the project came to school and met with our school-based team in order to formulate the best plan for our injured student. They provided brochures, booklets, and other educational materials. We really appreciate all the time and energy.”

Lisa DeCesaris, school social worker
Roberta Brown school nurse

(Most hospitals do not have a system in place to automatically notify primary care physicians of emergency-related treatment.) CTCs attempt to impress upon the families the importance and necessity of follow-up care with their primary care providers.

A key role of the CTC is to help children with TBI transition back into school. CTCs provide information to school personnel about TBI and how it is affecting or may affect the child in the classroom. As an advocate for the child, the CTC works with the school system to have children identified as TBI in order to receive services through the Exceptional Children’s Program or to make modifications to regular classrooms to enhance the child’s success at school.

The CTC also helps the family identify and secure other services in the community. CTCs serve as valuable resources of information and single points of contact for families looking for assistance obtaining services and medical care for their children with TBI.

“The brain injury information that I received from Project A.C.C.E.S.S. was so helpful and described my son’s condition so well. Before I met the community transition coordinator, I had been looking at the health science library for information my family could understand and couldn’t find anything that wasn’t a medical textbook.”

Mother of an 11-year-old pedestrian who was hit by a car

Accomplishments

The primary goal of Project A.C.C.E.S.S. is to provide an organized structure for supporting children with TBI and their families from point of injury, through acute and rehabilitation care, to successful reintegration into schools and their community. The Project A.C.C.E.S.S. staff has developed a system to provide a continuum of support and care to the project participants that can be modeled throughout the state.

“Facilitation of services through coordinated care efforts like Project A.C.C.E.S.S. can hopefully improve the recovery process of a child who has sustained a brain injury and make the process less stressful for the family”

Dr. Kat Kolaski
principal investigator,
Carolinas Healthcare System

Because of Project A.C.C.E.S.S., there have also been significant improvements in communications and relations both within the hospitals and between the hospitals and the community, especially the school systems and primary care physicians. More information is being disseminated and there is a

better understanding of the consequences of TBI by family members, hospital personnel, family doctors, school administrators, teachers and service providers.

Through regular contact with the participating Project A.C.C.E.S.S. families, the CTCs became valuable sources for information about TBI as well as about services that might be available and how to access them. The follow-up calls helped prevent children from "falling through the cracks" of the current system and gave CTCs the opportunity to provide continuing education about TBI to family members. Not only did the families benefit but the regular follow ups reflected positively on the hospitals as part of a caring medical community.



Beth Callahan
CTC at UNC.

Recommendations

Project A.C.C.E.S.S. is not the conclusion but merely the beginning of potential system changes that will ensure that the thousands of North Carolina children with TBI and their families receive the appropriate information, follow up, care and services.

Once the project has been completed and the data analyzed, Project A.C.C.E.S.S. staff will present their findings and formal recommendations for systems change. Some initial recommendations from Project A.C.C.E.S.S. staff that merit further study include:

- Be alert to the possibility of a brain injury even when this is not the presenting complaint.
- Provide written information about symptoms of TBI and possible changes in behavior and personality to families every time a child receives an injury to the head including minor abrasions.
- Assure that the child's primary care physician and school know about the child's injury.

“Project A.C.C.E.S.S. has been a nice bridge to help kids with more severe head injuries get back into the community. It has been a great safety net (for the hospital) to know that the community transition coordinators are following the families of injured children to assist with the ongoing issues that often result from head injuries.”

Nora Smith, RN, MSN, pediatric
trauma nurse coordinator

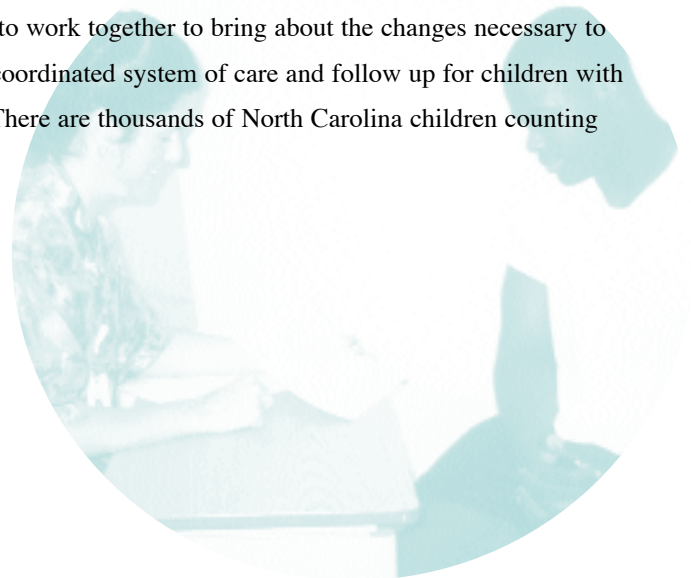


Funding Project A.C.C.E.S.S.

The three-year grant was awarded by Health Resources and Services Administration, Maternal & Child Health Bureau. Project A.C.C.E.S.S. received \$200,000 in federal funding each year for three years beginning in the Fall of 1997. Cash matching funds of \$100,000 each year, for a total of \$300,000, was provided by UNC Memorial Hospital, the Carolinas Healthcare System, the University Health Systems of Eastern Carolina, the Division of Mental Health, Developmental Disabilities and Substance Abuse Services, the Division of Public Health and the Brain Injury Association of N.C.

- Identify one person who can assist with the coordination of care for the child throughout the acute care/rehabilitation and transition to community process.
- Involve Physical Medicine and Rehabilitation and Speech and Occupational Therapy services early on following trauma.
- Set up an outpatient clinic for TBI at each major trauma hospital and make services available to patients from other outlying community hospitals.
- Link families with the Brain Injury Association as a primary source of information, support, and referral to services.
- Further study how best to establish a safety net of support for families who are either not ready to pursue services through the Developmental Disabilities Single Portal of Entry system or whose children do not meet developmental disabilities eligibility criteria.
- Utilize neuropsychological evaluations within the school setting as a tool for understanding the needs of children with TBI and to assist in the development of an Individualized Education Plan.

It's time for the medical community, the school systems, health and human service agencies, and legislators to work together to bring about the changes necessary to implement an effective, coordinated system of care and follow up for children with TBI and their families. There are thousands of North Carolina children counting on you.



University Health Systems of Eastern Carolina

Site: University Health Systems of Eastern Carolina in collaboration with the ECU Brody School of Medicine

Location: Greenville

Facilities: Level I trauma center, inpatient pediatric rehabilitation center affiliated with Children's Hospital of Eastern North Carolina, pediatric brain injury clinic

Population served: Eastern North Carolina covering 29 counties; primarily rural population. Large percentage of participants do not live in Pitt County.

Number of Project A.C.C.E.S.S. participants: 724 screened of which 459 participated

Project A.C.C.E.S.S. personnel:

Daniel Moore, M.D., principal investigator

Jennifer King, community transition coordinator

Kristin King, speech/language pathologist

Goals include: Help secure the services needed so that the majority of children with TBI can get back into the school system and succeed; get more consistent information to all the hospital emergency departments in the eastern region of the state.

Unique Site Features

This site is a collaborative effort between the University Health Systems of Eastern Carolina and East Carolina University, Brody School of Medicine. Collaboration with the ECU School of Social Work and Criminal Justice was also a highlight of the program.

While the University Health Systems of Eastern Carolina has one of two pediatric inpatient rehabilitation units in the state, it did not have a pediatric brain injury clinic until Project A.C.C.E.S.S.

The Project A.C.C.E.S.S. staff worked closely with the East Carolina Injury Prevention Program. In addition, this site worked with the Safe Kids Coalition in helping prevent TBI through activities such as distributing bike helmets and educating parents to properly install and use car seats.



UNC Healthcare System

Site: UNC Hospitals

Location: Chapel Hill

Facilities: Level I trauma center, pediatric transitional care team, pediatric brain injury clinic

Population served: North- and south-central regions of North Carolina, primarily rural and suburban areas

Number of Project A.C.C.E.S.S. participants: 543 screened of which 272 participated

Project A.C.C.E.S.S. personnel:

Josh Alexander, M.D., principal investigator

Beth Callahan, CBIS, community transition coordinator

Connie McDonald-Bell, MS/CCC-SLP

Goals include: Create a system of care for children with TBI with seamless transitions from the healthcare setting to the community that can be emulated throughout North Carolina and in other states; have a CTC at every major trauma center in the state.

Unique Site Features

Prior to Project A.C.C.E.S.S., the only brain injury clinic available at UNC Memorial Hospital was for adults. Shortly after the project started, UNC Memorial Hospital established a pediatric head injury clinic for all levels of severity with the leadership of Project A.C.C.E.S.S. staff.

Another major accomplishment of Project A.C.C.E.S.S. at this site was increased awareness of brain injury and improved communications within the hospital. This is most evident through the inclusion of the site's CTC on the hospital's Transitional Care Team. This interdisciplinary group of professionals addresses the needs of children with acquired or congenital disabilities.

To help prevent further head injuries, Project A.C.C.E.S.S. staff at UNC Hospitals distributed approximately 100 bike and all-sports helmets to children in the clinic and to patients being discharged from the hospital.



Kristen King Speech Language Pathologist
Dr. Daniel Moore Director of Pediatric Rehabilitation
Jennifer King Community Transition Coordinator

Carolinas Healthcare System

Site: Carolinas Healthcare System including the Carolinas Medical Center and the Charlotte Institute of Rehabilitation

Location: Charlotte

Facilities: Level I trauma center, inpatient pediatric rehabilitation center, pediatric brain injury clinic

Population served: Mecklenburg and other western N.C. counties

Project A.C.C.E.S.S. personnel:

Kat Kolaski, M.D., principal investigator

Mary Hill, community transition coordinator

Sheri Bartel, community transition coordinator

Susan Fewell, M.S., CVE, site manager

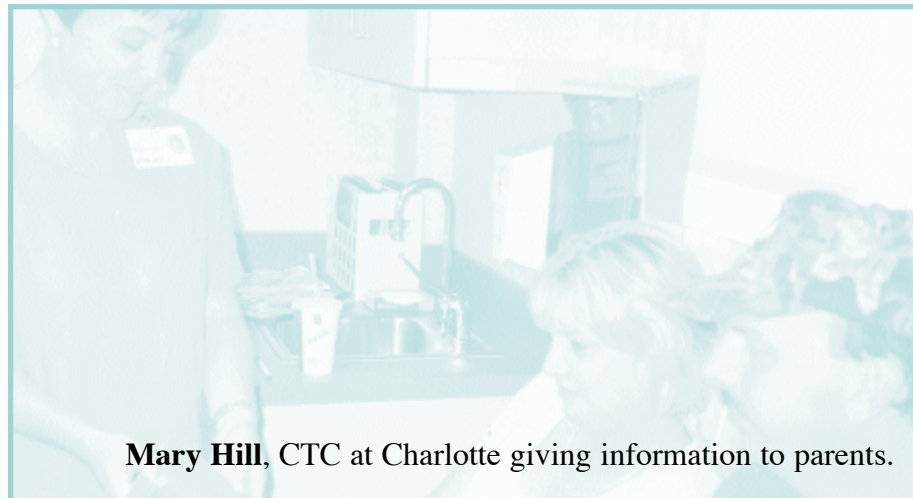
Goals include: Making sure the kids get the attention they deserve and the treatment they need because of their brain injury; creating awareness and providing education for parents, teachers, school systems and the community of the possible effects of brain injury and how to deal with them.

Unique Site Features

The Carolinas Medical Center has the largest volume of emergency department and hospitalized children and adolescents with brain injury in North Carolina, and the Charlotte Institute of Rehabilitation has the largest inpatient pediatric rehabilitation unit in the Carolinas. Of the three sites, the Carolinas Health Healthcare System has the largest Project A.C.C.E.S.S. staff.

The Project A.C.C.E.S.S. staff is supported by the system's permanent staff and departments. For example, the Carolinas Medical Center's pediatric trauma nurse coordinator assists with providing information and setting up clinic appointments—CTC responsibilities at the other sites. The project's principal investigator also serves on the multidisciplinary Pediatric Trauma Outcomes Committee that reviews all aspects of care for pediatric patients with brain injury for quality assurance and systems improvement for all hospitals within the Carolinas Healthcare System.

Project A.C.C.E.S.S. staff formed the Pediatric Brain Injury Community Task Force to educate the community about the special needs of pediatric brain injury survivors and their families and to strengthen the relationship between the medical community and school personnel.



Mary Hill, CTC at Charlotte giving information to parents.

A special thank you to the following persons for their contributions to Project A.C.C.E.S.S.

Project A.C.C.E.S.S. Staff:

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Susan Fewell, site manager, Carolinas Healthcare System

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Nancy Washburn, communications specialist, Brain Injury Association of North Carolina
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Mike Wolff, family support specialist, Brain Injury Association of North Carolina

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Elsie Siebelink, Regional Rehabilitation Center, Pitt County Memorial Hospital



**East Carolina Dr. Moore
with Veronica Pollard**



UNC



**Charlotte Healthcare
System**