

Tennessee Department of Health  
Traumatic Brain Injury Program

# Annual Report

July 2012 – June 2013



Winner, Bicycle Safety poster contest

## **Traumatic Brain Injury Program 2012-2013 Annual Report EXECUTIVE SUMMARY**

In 1993, the Tennessee General Assembly passed legislation establishing the Traumatic Brain Injury (TBI) Program in the Department of Health. The TBI Program staff, with guidance from a nine-member, governor-appointed Advisory Council, is charged with expanding and revising existing state plans and services for persons with traumatic brain injuries. The program has achieved many accomplishments since its inception. This report contains specific information concerning the progress made from July 2012 through June 2013 in each of the major components of the Traumatic Brain Injury Program.

In Tennessee, approximately 8,000 people per year are injured and admitted to the hospital with traumatic brain injury, a rate of 125 injuries per 100,000 people. TBI survivors can experience impairments that affect their physical, cognitive and behavioral functioning which in turn impacts their ability to return to home, school, and work. Whether the injury is the result of a car crash, a slip and fall, assault or sports activity, there can be an economic and emotional toll on the survivor and the family. The focus of the TBI Program is to improve services available to survivors of TBI and their families.

### **Traumatic Brain Injury Advisory Council**

The nine-member governor appointed Advisory Council has met quarterly since 1994. The Council is composed of individuals dedicated to improving the lives of TBI survivors in Tennessee. Their guidance and recommendations have been invaluable to the development of the TBI program.

### **Federal Grant**

Fiscal Year 2013 was the fourth year of a four year, \$375,000 per year HRSA grant awarded in March 2009 to continue the work of Project Brain. The Department of Education is providing the match money, currently \$100,000 per year. Since the original grant award in 2000, the TBI Program has received a total of \$2,100,000 in federal funding, and \$700,000 from the Tennessee Department of Education for matching funds.

### **Case Management**

Service Coordinators are established in eight locations and cover all 95 counties, providing case management services to TBI survivors and their families. Through a contract arrangement, each non-profit agency has established a Family Support Center in their respective area for the purpose of providing the following services for children and adults with TBI: providing information; making referrals to services and agencies; assisting consumers in applying for and accessing services; advocacy; support group development; and the development of new programs and activities. The role of the Service Coordinator is to assess an individual survivor and to coordinate available resources within the community

### **Directory of Program and Services**

A comprehensive resource directory, "*The Traumatic Brain Injury Services Directory and Resource Information Guide*" has been developed and distributed statewide. The first edition was produced in December 1995 and has been updated each year. These directories are distributed to health care facilities and TBI professionals across the state and have served to increase awareness of the TBI program.

### **Traumatic Brain Injury Registry**

Hospitals are mandated to provide information to the department and all are in compliance. Data is available starting from the first quarter of 1996. Analysis of the data allows staff to pinpoint where and how injuries are occurring, what age groups are affected, and enables the development of programs to prevent injuries. During 2012, the number of persons in Tennessee admitted to the hospital with at least one brain injury diagnostic code was 7,864 (provisional data). All Tennessee residents listed on the registry receive a letter and program brochure to inform them of the services available through the TBI program.

### **Clearinghouse**

The Clearinghouse with the toll-free 800 number has been operational since 1994. Information is constantly updated on available programs and services across the state. A TBI brochure has been broadly distributed. The TBI newsletter, *TBI Headlines*, is printed and distributed biannually. The Program has a web page on the department website: <http://health.tn.gov/TBI/Index.htm>

### **Education and Prevention**

The TBI program collaborates each year with the Brain Injury Association of Tennessee to present their annual statewide conference. The target audience is brain injury survivors, their families and caregivers, and the professionals who work with them. Program staff also participate on the Injury Control and Prevention committee.

### **Traumatic Brain Injury trust fund**

The fund has been established by the Department's Bureau of Administrative Services and revenues have been deposited into the fund as they have been received.

### **Grant Programs**

The TBI program is authorized to provide grants to county and municipal governments and/or not-for-profit organizations for home and community based programs to serve the needs of TBI persons and their families. Since 1995, the TBI Program has awarded numerous grants for a variety of projects.

### **Conclusion**

Although much has been accomplished, injuries persist. Work must continue to address the needs of all survivors in the state. The TBI Advisory Council extends their gratitude to the General Assembly for the opportunity to improve the lives of TBI survivors statewide.

**Tennessee Department of Health  
Traumatic Brain Injury Program  
ANNUAL REPORT  
July 2012– June 2013**

In 1992, survivors of traumatic brain injury from across the state petitioned the Tennessee General Assembly to create a brain injury program within state government. The Traumatic Brain Injury (TBI) Program was legislatively established in 1993 to address the special needs of survivors of brain injuries and their families.

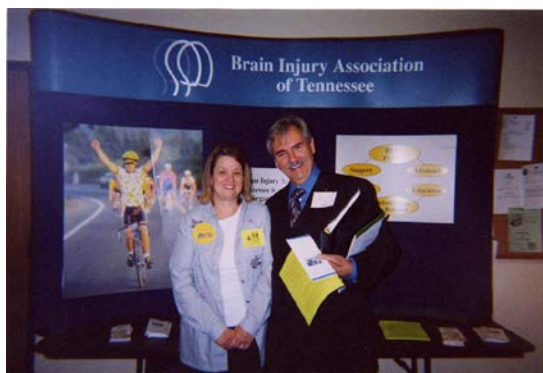
In Tennessee, approximately 8,000 people per year are injured and admitted to the hospital with traumatic brain injury, a rate of 125 injuries per 100,000 people. TBI survivors can experience impairments that affect their physical, cognitive and behavioral functioning which in turn impacts their ability to return to home, school, and work. Whether the injury is the result of a car crash, a slip and fall, assault or sports activity, there can be an economic and emotional toll on the survivor and the family. The focus of the TBI Program is to improve services available to survivors of TBI and their families.

This report contains specific information concerning the progress made from July 2012 through June 2013 in each of the major components of the TBI Program as well as pertinent historical information. The TBI Program is housed in the Department of Health, Division of Community Health Services. Currently staff is comprised of a Program Director. A Statistical Analyst, housed in Policy Planning and Assessment, oversees the TBI registry.

The enabling legislation calls for the establishment of a state TBI registry, a TBI trust fund, and describes a number of duties for the Coordinator. Each of these areas is addressed by first citing the Tennessee Code Annotated (T.C.A.) followed by a description of activities and progress.

**T.C.A. 68-55-102 & 103. Advisory Council established – Duties**

**TBI Advisory Council members**



The Traumatic Brain Injury Advisory Council was organized in accordance with the legislation to provide advice and guidance to the TBI program staff. The nine-member Council is appointed by the Governor and includes representatives from the Departments of Education, Human Services, Mental Health and Intellectual and Developmental Disabilities. An additional member represents the Tennessee Hospital Association. Five of the nine members represent the category of TBI survivor, family member or

primary care giver. The Council was organized in 1994 and has met quarterly since that time.

The duties of the advisory council are to advise the TBI coordinator, to make recommendations and perform other duties as necessary for the implementation of a state-wide plan to assist TBI persons and their families. The Advisory Council is composed of individuals dedicated to improving the lives of TBI survivors in Tennessee. Their advice and recommendations have been invaluable to the development of the TBI program. Council members have assisted in identifying the needs of survivors and designing grant programs to meet those needs. They recognized the benefit of providing education and awareness on brain injury issues and approved funding for a statewide brain injury conference.

**T.C.A. 68-55-201. TBI Coordinator to be designated.**

**The commissioner shall create a full-time position within the department and designate a person as the TBI coordinator to supervise and coordinate the development, implementation and enhancement of a registry and services system for persons with TBIs and provide sufficient staff to accomplish the effect and intent of this chapter. The TBI coordinator shall, to the fullest extent possible, utilize the services of the advisory council in fulfilling the duties and responsibilities required by this chapter.**

The current TBI coordinator (program director) has been in place since 1994, supervising and directing the program as described in this report. The TBI registry is supported by a Statistical Programming Specialist in the Policy Planning and Assessment section. All persons listed on the registry receive a letter and program brochure to inform them of the services available through the TBI program.

**T.C.A. 68-55-202. Duties. –**

**(a) The TBI coordinator shall:**

**(1) Aggressively seek and obtain funding, on an ongoing basis, from all available sources, including but not limited to Medicaid waivers and for expansion of the Medicaid program, private and federal funds needed to implement new state plans and services, and to expand and revise existing state plans and services for persons with traumatic brain injuries, including case management;**

The TBI Program Director continuously seeks additional funding from all available sources.

**Medicaid Waiver:** The TBI Advisory Council members continue to promote the idea of a TBI specific Medicaid waiver. The administration has indicated that TBI survivors may be eligible to participate in existing waivers for the elderly and disabled or through the TennCare Choices program.

**Federal Grant award:** Beginning in 2000, the Traumatic Brain Injury Program was awarded a grant from the U.S. Health Resources and Services Administration (HRSA). The original three-year grant had as its focus the provision of education and training for educators, families, and health professionals who support students with TBI. The overall goal of Project BRAIN is to improve educational outcomes for children with brain injuries in Tennessee.

### Project BRAIN staff at conference



Fiscal Year 2013 was the fourth year of a four year, \$375,000 per year HRSA grant awarded in March 2009 to continue the work of Project Brain. The Tennessee Department of Education is providing the match money, currently \$100,000 per year. In February 2013, HRSA extended the existing cohort of H21 grants originally scheduled to end in March 2013. The grant was continued for one year with current level funding. Since the original grant award

in 2000, the TBI Program has received a total of \$2,100,000 in federal funding, and \$700,000 from the Department of Education for matching funds.

Project BRAIN seeks to link hospital and community health providers with school professionals for identifying and addressing the needs of students with brain injuries.

A specially designed TBI curriculum, *Brain Injury 101*, is used to train educators, health professionals and families. Community-based TBI Resource Teams have been recruited and trained to provide expertise and sustain educational support for students with brain injury. In FY13, Staff provided 52 trainings to approximately 1,109 educators and related professionals. Project BRAIN provides training in any school system in the state upon request.

**Case management:** There are currently eight Service Coordinators assisting TBI survivors and their families in all 95 counties through contract arrangements with various non-profit agencies. Each agency has established a Family Support Center in their respective area for the purpose of providing service coordination for children and adults with TBI. These services include: providing information; referring consumers to appropriate services and agencies; assisting consumers in applying for and accessing services; advocacy; support group development; and the development of new programs and activities. The role of the Service Coordinator is to work with the individual survivor to assess needs and to collaborate and coordinate resources within the community on behalf of the client. The eight service coordinators are serving an average case load of fifty survivors and families.

**Expansion of services:** The expansion of services for TBI survivors is accomplished through the grants program, outlined in Section 68-55-402 below. In addition, program staff collaborate with other relevant agencies to improve services for all persons with disabilities in the state.

Project BRAIN funds a transition liaison program in three children's hospitals across the state. The Brain Injury Transition Liaisons (BITLs) work in Monroe Carell Jr. Children's Hospital at Vanderbilt in Nashville, LeBonheur Children's Hospital in Memphis and T.C. Thompson in Chattanooga.



TC Thompson BITL with hospital staff

A BITL follows up with families after they leave the hospital emergency department when their child has been treated for TBI. When families consent to receive follow up calls, they can also be supported by the Department of Education. Since the inception of the BITL process in May 2011, they have served 1,694 families.



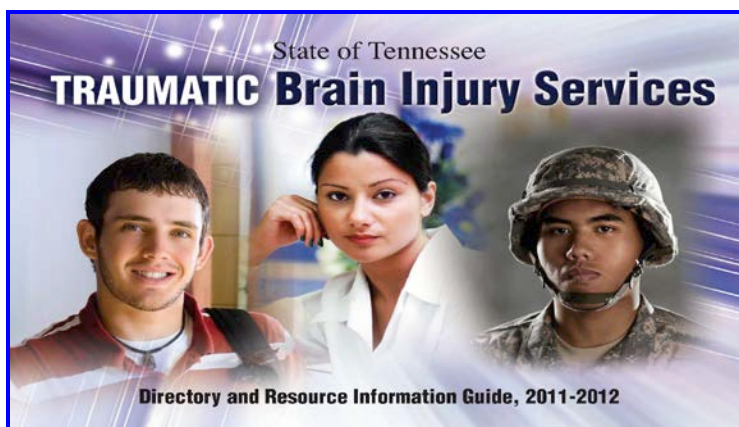
**Coordinator duties (continued)**

**(2) Seek funding, on an ongoing basis, and, in conjunction with other state agencies, prepare, coordinate, and advocate for state appropriations needed to fund and to develop services to implement the state plan:**

The TBI Program Director and the Advisory Council seek funding on an ongoing basis. The composition of the Council, which includes representatives from the three state departments that also serve persons with brain injury - Education, Human Services, Mental Health and Intellectual and Developmental Disabilities, provides an opportunity for cooperation and collaboration.

**(3) Identify available programs and services and compile a comprehensive directory of identified programs and services:**

A comprehensive resource directory, "*The Traumatic Brain Injury Services Directory and Resource Information Guide*" has been developed and distributed statewide. The first edition was produced in December 1995 and has been updated each year. These directories have been distributed to health care facilities and TBI professionals across the state and have served to increase awareness of the TBI program. The directory is also available on the program web site: <http://health.tn.gov/TBI/Index.htm>



**(4) Provide technical assistance and define gaps in service delivery and spearhead the development of those services needed for a comprehensive system of service delivery;**

Needs Assessment surveys were used to identify gaps in the service delivery system. The results served as the basis for the Request for Grant Proposal document which listed examples of services that could be developed by applicants. The grants allow for the development of programs that address those gaps in services.

The TBI office provides technical assistance as requested by consumers, families, and providers. Examples include providing information on services and programs, referrals to rehabilitation programs and other types of facilities, and making connections to support groups. The TBI office also conducts annual technical assistance site visits with all TBI contractors.

The Service Coordination project described above [68-55-202 (a)(1)] is designed to assist survivors and their families overcome the gaps in services in their communities.

**(5) Implement, oversee and receive surveillance data from the Tennessee Brain Trauma Registry to use in developing and revising the state plan to meet the changing needs of this population:**

The TBI registry data has been a valuable tool in documenting the need for TBI services and in program planning. Using data from the TBI registry made the critical difference in securing the federal grant award that resulted in Project BRAIN. According to the registry, in 1998, there were 1,592 children and youth ages 3-21 in Tennessee who were admitted to the hospital as a result of a TBI. That same year, the Department of Education classified 338 students in the category of TBI. The discrepancy in the number of children identified through the TBI Registry in comparison to the number of children classified by DOE indicated a need for correct identification of students with TBI. Project BRAIN was developed to address that need.

The TBI Coordinator serves on the Department's Council on Injury Prevention and Control and participated in the development of a state plan for injury control. The project is funded by a grant from the CDC. The TBI registry data is one of the major data sources being used to develop the plan.

**(6) Evaluate surveillance data regarding the quality of services provided and outcome and impact on the quality of life of this population, including reintegration and productivity in the community;**

As noted in 68-55-202(a)(5) above, surveillance data is limited. The type of information being collected in the registry does not include the quality of services provided. The TBI program at the Tennessee Rehabilitation Center provides reports on the outcome and impact of the quality of life of this population, particularly in community reintegration and productivity.



**(7) Promote research on the causes, effects, prevention, treatment and rehabilitation of head trauma injuries;**

**Safe Kids mascot**



The development of the state registry and the resulting availability of statistics are directed toward encouraging research on the causes, effects and treatment of brain trauma injuries. The collection of all types of information on TBI through the Clearinghouse will further identify areas for research development. Education and injury prevention activities for health care providers and the public provide baseline data for pursuing further investigations.

**(8) Serve as a clearinghouse for the collection and dissemination of information collected on available programs and services. A statewide, toll-free telephone line shall be established and operated during normal business hours for the express purpose of providing such information to callers.**

The Clearinghouse with the toll-free 800 number has been operational since 1994. Information is constantly updated on available programs and services across the state. A log system has been developed and the types of calls are categorized. Information is provided on service coordination, rehabilitation facilities, day programs, respite care, transportation and financial issues. To publicize the Clearinghouse, TBI staff designed and developed a TBI brochure which has been broadly distributed. The TBI newsletter, *TBI Headlines*, is printed and distributed biannually. The Program has a web page on the department website: <http://health.tn.gov/TBI/Index.htm>

**(b) Utilizing the services and expertise of the advisory council to the greatest extent possible and in cooperation with the advisory council, the TBI coordinator shall:**

**(1) Develop a coordinated case management system, a short-term state plan, a long-term state plan, affordable and accessible home and community based services, and criteria to identify training needs and priorities for all persons serving TBI clients;**

The case management system, known as Service Coordination and described in 68-55-202 (a)(1), now covers all 95 counties in the state. The Advisory Council and TBI coordinator have developed short term and long term goals and objectives for the program following the outline of the legislation. Efforts to provide affordable and accessible home and community-based services are on-going through the TennCare Choices program. Currently, the TBI program is providing personal care services on a limited basis through a contract arrangement in select facilities in Memphis and Johnson City.

**(2) Establish and provide for the centralized organization of a statewide family clearinghouse of information, including availability of services, education and referral to survivors, professionals, and family members during the early stages of injury in the acute hospital setting.**

In the process of developing a resource guide and in establishing the TBI registry, contacts have been made in the hospitals where acute care is provided. Copies of the updated Resource Directory are distributed to facilities statewide and awareness of the TBI Clearinghouse is increasing. With the improved system of reporting to the registry and letters being sent to survivors, coupled with service coordinators in place across the state, information and assistance is available to survivors and family members in the early stages of injury.

**(3) Assure statewide compliance with licensure, if any, and performance standards through regular service monitoring, site visitation, and self-appraisal;**  
**(4) If licensure is required, monitor and update licensure requirements specific to this population;**

The Department of Health oversees certification and licensure of health care facilities in Tennessee. The TBI Program coordinator works with appropriate staff to ensure licensure compliance and to monitor and update licensure requirements specific to this population.

**(5) Seek funding and other resources to assure that state personnel working with this disability group are properly trained and provided, at least annually, an opportunity to attend formal or informal education programs through colleges, workshops, seminars, or conferences;**

TBI staff participate on the Council on Injury Prevention and have planned and presented at the annual Injury Prevention Symposium. The TBI program collaborates with the Brain Injury Association of Tennessee in the planning and presentation of an annual statewide conference. The TBI staff regularly present at seminars and workshops, enhancing the ability of state personnel to meet the needs of survivors.

**(6) Ensure updates and compliance standards from the National Head Injury Foundation's quality standards committee are made available to professionals and providers, on a timely basis, to help educate providers and professionals regarding the latest technology available to this disability group;**

In addition to regularly scheduled trainings and the biannual newsletter, the TBI program has developed a TBI Community Listserv to provide information on the latest technology available for the TBI community.

**(7) Oversee efforts to better educate the general public concerning the need for head injury prevention programs and the need for early intervention, including but not limited to, developing plans and programs for affordable post-acute rehabilitation services, long-term care programs, respite services, and day treatment programs to deal with those who have lifelong disabilities, as well as**

**developing plans and programs to deal effectively with TBI students in the educational system;**

The TBI Program collaborates with the Brain Injury Association of Tennessee to present an annual conference focusing on current topics including prevention and the need for early intervention. In addition, the TBI Service Coordinators provide prevention programs in their service area. Project BRAIN, the HRSA funded grant project, is a program designed specifically to deal effectively with TBI students in the educational system.

**Service Coordinator and helmet promotion**



Information on post-acute rehabilitation services, respite services, and day programs are included in the TBI clearinghouse.

**(8) Work with vocational rehabilitation and other state agencies to offer incentives and to obtain cooperation of private industries to initiate on-the-job training and supported employment for TBI persons;**

The TBI staff maintains a close working relationship with Voc-Rehab counselors and the TBI program at the Tennessee Rehabilitation Center in Smyrna. The comprehensive program provides job skills training and placement for approximately 45 students a year. The Voc-Rehab TBI program staff work with VR counselors located throughout the state. This helps promote incentives and obtain cooperation of private industry to initiate on-the-job training and supported employment opportunities for persons with traumatic brain injury. TBI staff are available to provide technical assistance as requested.

**(9) Assist in obtaining grant funding and provide technical assistance for the Tennessee Head Injury Association (THIA) to develop policies and procedures to maximize self-determination and self-advocacy of a person suffering a TBI.**

The TBI program is fortunate to have established an excellent working relationship with the staff and board of the Brain Injury Association of Tennessee (BIAT)( formerly THIA).

#### BIAT Global Picnic



The TBI Service Coordinators facilitate BIAT support groups across the state. These monthly meetings of the support groups provide a way to meet educational, social and emotional needs of survivors and families.

In FY13 the TBI Program continued to support BIAT's work with survivors and their families. The Executive Director acts as an advocate to improve funding for services benefiting TBI survivors. In addition, the Nashville Area Service coordinator is housed at BIAT. The service coordinator works with the individual survivor to assess needs and to identify resources within the community on behalf of the client. Having the service coordinator at the BIAT office allows a direct connection for BIAT callers, resulting in the survivors receiving services in a more efficient manner.

**T.C.A. 68-55-203. Brain Trauma Registry -- The commissioner shall establish and maintain a central registry of persons who sustain traumatic brain injury. The purpose of the registry is to: (1) collect information to facilitate the development of injury prevention, treatment and rehabilitation programs; and (2) ensure the provision to persons with traumatic brain injury of information regarding appropriate public or private agencies that provide rehabilitation services so that injured person may obtain needed services to alleviate injuries and avoid secondary problems.**

TBI registry data collection officially began with patients discharged during 1996. The hospitals complete a questionnaire for inpatients, with specific ICD-9 diagnosis codes, whose admission and discharge dates are different, and for those individuals who died. Hospitals are required to report within six weeks of the end of the quarter. Patients seen in emergency rooms who were sent home the same day are not included in the registry. All hospitals in the state are currently in compliance with this legislation. The data enables staff to pinpoint the population being affected by brain injury and are used for injury prevention and health care planning. [See also 68-55-202(a)(5)]

All Tennessee residents listed on the registry receive a letter and program brochure to inform them of the services available through the TBI program. Approximately 4,400 letters are sent each year. For many, the letter is the first link to information regarding needed rehabilitation services and programs. During FY13, revisions were made to the letter which included adding a date, a signature of a staff person, an email address and link to the program website. These differences have improved the number of responses to the registry letter.

During 2013, the number of persons in Tennessee admitted to the hospital with at least one head injury diagnostic code was 7,864 (provisional data).

**T.C.A. 68-55-401. Traumatic Brain Injury fund. -- There is hereby established a general fund reserve to be allocated by the General Appropriations Act which shall be known as the “traumatic brain injury fund” hereafter referred to as the fund. Money from the fund may be expended to fund the registry, the TBI coordinator position, and additional staff requirements and other expenditures and grants under the provisions of this chapter.**

The fund has been established by the Department’s Bureau of Administrative Services and revenues have been deposited into the fund as they have been received. The Fund Balance as of June 30, 2012 was \$397,311.73. Although revenues declined between FY08 and FY11, since then they have leveled off. In FY13, the total revenues were \$1,110,452. Funds are used appropriate to pay staff positions and grants.

**T.C.A. 68-55-402. Grant Programs. -- From the revenues deposited in the traumatic brain injury fund, the Department of Health is authorized to provide grants to county and municipal governments and/or not for profit organizations for home and community based programs to serve the needs of TBI persons and their families. The department is authorized to establish such grant programs and to develop criteria for eligible applicants.**

In accordance with the legislation, the TBI program has awarded numerous grants for a variety of projects since 1995. Examples include:

- Crumley House Brain Injury Rehabilitation Program in Johnson City expanded their day program to provide recreation; transportation and respite care to TBI survivors and their families.
- Mid-South Head Injury Association in Memphis and Brain Injury Association of Tennessee used grant funds to develop a comprehensive proposal to build affordable, accessible, supportive housing for forty-eight TBI survivors using HUD Section 811 grant dollars in Memphis and Nashville.
- The Division of Rehabilitation Services, Tennessee Rehabilitation Center in Smyrna created a specialized rehabilitation program for TBI persons.
- The Tennessee Emergency Services for Children Project received funds to improve the capability of 54 rural hospitals in the early management of acutely injured children.
- Centerstone Community Mental Health Centers, Inc. provided intensive in-home counseling and behavioral intervention for TBI students in 24 counties of middle Tennessee.
- The “Danger Dog and Cautious Cat Prevention Program” was presented to 10,000 children and parents in the Mid-Cumberland region.

In FY13, grant awards provided the following services:

- Meritan provides personal care services for individuals with TBI who live in two accessible, affordable apartment buildings in Memphis.
- Crumley House Brain Injury Rehab Center offers respite and personal care assistance to TBI survivors.

- Grants for service coordination have been awarded to:
  - Fort Sanders Regional Medical Center
  - Brain Injury Association of Tennessee
  - Regional Medical Center at Memphis
  - Epilepsy Foundation of Middle Tennessee
  - Crumley House Brain Injury Rehab Center
  - Chattanooga Area Brain Injury Association
  - Jackson Madison County General Hospital District

### **Conclusion**

The TBI Program is authorized to award grants for home and community based programs to address the needs of TBI survivors in Tennessee. The majority of the program revenues of \$1 million are allocated for grants. In FY13, services provided through grants included:

- Eight service coordinators served an average case load of fifty survivors, assisting them with accessing local resources and programs.
- Supportive living services were available to nine survivors living in two affordable and accessible apartment facilities in Memphis. In addition, personal care services were available to 14 residents of Crumley House Brain Injury Rehab Center.
- Project BRAIN transition liaisons in three children's hospitals have assisted 564 families in their transition from hospital to home to school.

### **Recommendations**

Although much has been accomplished, injuries persist. Work must continue to address the needs of all survivors in the state, particularly in the areas of day programs, housing, long-term care, and rehabilitation. The TBI Advisory Council recommends that the legislature continue to support making home and community-based services available as an alternative to institutional care.

In April 2013, Tennessee became the 44<sup>th</sup> state to pass a sports concussion law aimed at reducing youth sports concussion and increasing awareness of traumatic brain injury. Both public and private school sports and recreational leagues for children under 18 that require a fee will be affected by the new law. The law covers all sports. The required educational materials will be free of charge and readily available from the Tennessee Department of Health website. The TBI Program staff convened a team to review materials and make recommendations.

The TBI Advisory Council extends their gratitude to the General Assembly for the opportunity to work to improve the lives of TBI survivors statewide.