

Brain Injury Association of North Carolina
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House Bill 950, Session Law 2012-142 Report

1. The Brain Injury Association of NC (BIANC) is the single statewide organization whose goal is to create a better future for individuals with brain injury through prevention, research, education and advocacy. An official affiliate of the Brain Injury Association of America, BIANC's mission is to offer help, hope and a voice to people with brain injuries and their families. Brain injury is a leading cause of death and disability in North Carolina according to discharge data from hospitals and trauma centers, with traumatic brain injury (TBI) being the most prevalent. The direct cost of medical and rehabilitation treatment, long term care, and the indirect cost of loss of income for individuals and families is enormous. The CDC estimates that the annual national cost is over \$76 billion dollars. North Carolina's acute medical and rehabilitation resources provide excellent care but the full impact of TBI is experienced by the families and survivors over time and in local communities. TBI has been termed the "silent epidemic" as well as and the signature wound of the war in Iraq and Afghanistan. Military service members with brain injuries who are returning to their home communities in NC are increasing the demands for information support, care and services.

The Brain Injury Association of North Carolina is a 501 (c) 3 non-profit organization which was founded in 1982 by a group of families who recognized that they needed more support and information to better care for their loved ones with brain injuries. The Association has grown over the years to include four Brain Injury Resource Centers, one volunteer resource site and over 30 support groups with membership ranging from 10 to 50 people. BIANC provides educational opportunities, retreats and training programs for families and persons with brain injury, access to information and referral sources, community education, prevention activities and linkages with networks of medical centers, rehabilitation facilities and public agencies, non-profit organizations and long term care providers.

BIANC is directed and managed by an Executive Director, CEO from the central office at the Raleigh Brain Injury Resource Center. The Executive Director reports to the Board of Directors which is composed of 17 to 20 volunteer members who are professionals, family members and persons with brain injuries from across the state. The BOD holds quarterly meetings, develops the strategic plan, and oversees the budget and financial development for the Association. Brain Injury Resource Centers are also located in Greenville, Asheville, Charlotte and a volunteer center is in Winston Salem. Regional Resource coordinators from each of the statewide Centers report to the Executive Director. BIANC collaborates with Project STAR for management of the Charlotte Resource Center at Carolinas Rehabilitation. Because of limited staff resources, there is significant dependence on volunteers and student interns to supplement outreach and support activities.

2. The regional Brain Injury Resource Centers are the cornerstone for a) early intervention by providing information and referral and support to families and persons with brain injuries, b) educating caregivers and providers, c) supporting primary and secondary prevention efforts, d) building linkages between hospital/rehabilitation providers and community services/resources, and e) helping families navigate a complex array of public and private agencies and programs with varying funding sources and eligibility requirements.

Analysis of calls and recommendations of focus groups of families, persons with brain injury and providers of services held within the last several years, as well as the State Plan on Brain Injury Services, consistently identify needs for a) information about the causes and consequences of brain injury, b) improved awareness of and access to North Carolina's service delivery systems with emphasis on early intervention, d) strengthening regional centers and support groups across the state: f) greater public awareness of the scope of the problem g) prevention of brain injury to reduce the economic and societal costs.

The contract between the Brain Injury Association of NC and the NC Division of Mental Health/ Developmental Disabilities/Substance Abuse Services (DMH/DD/SAS) addresses each of these needs through a) providing a comprehensive program of information and referral as well as dissemination of information and education, b) collaboration with the Division and its Local Management Entities (LMEs) c) support groups recruitment, training and leadership development, d) public education initiatives and e) dissemination of morbidity and mortality data to support prevention initiatives.

The DMH/DD/SAS contract with the Brain Injury Association of North Carolina includes requirements that BIANC:

A) Maintain staff supervision and resources for four Brain injury Resource Centers to provide information and referrals to individuals with TBI, their families, and professionals via telephone, mail, email and social networking sites,
Contract deliverables include:

- a) Provide information and referral upon request about traumatic brain injury (TBI), prevention, and awareness to at least 2,00 individuals with TBI, their families, and professionals via phone, mail, email and social networking sites.
- b) Maintain a statewide 1-800 helpline for people seeking information about brain injury including resources and support services.
- c) Provide specialized TBI information to 8 acute care and rehabilitation hospital case manager/ discharge planners, LME points of contact, and 3 Alcohol and Drug Abuse Treatment Centers (ADATCs) across the state including referral resources and support group information.
- d) Maintain and report dissemination data of products/projects developed and implemented under the auspices of DMH/DD/SAS.
- e) Maintain a statewide TBI resource book and TBI Education Resource manual on the BIANC website.
- f) Coordinate a Professional Provider Council for education on relevant clinical issues; organize at least two regional meetings.
- g) Write and disseminate an annual report.
- h) Provide staff support for statewide Brain Injury Advisory Council.

B) Provide training and education about brain injury and promote prevention of TBI among the public as well as consumers, professionals and service providers statewide.
Contract deliverables include:

- a) With DMH/DD/SAS, review and update all informational products developed/disseminated by BIANC under DMH/DD/SAS auspices.

- b) Exhibit/present at 8 clinical conferences (such as the NC Council) at least one per quarter, to reach at least 500 people.
- c) Collaborate with AHEC on one statewide conference on brain injury for professionals with minimum attendance of 100.
- d) Publish *Starting Point* newsletter, quarterly in electronic and print format with special columns to address identified needs of families and persons with brain injuries. Disseminate to a minimum of 1,000 consumers, family members and professionals per quarter, including information on upcoming events, BIANC updates and information for caregivers and support group leaders.
- e) Provide a minimum of 8 regional TBI trainings throughout the state for LME staff, service providers and/or professionals.
- f) Provide at least 2 specialized TBI trainings to meet the needs of the LMEs and other service providers requesting individualized training.
- g) Develop and implement education plan for schools/coaches around sports concussion across the state.
- h) Coordinate health and wellness activities for individuals who have sustained brain injury.

C) Maintain, expand and strengthen the network of brain injury support groups for statewide availability and accessibility to meet the needs of people with brain injury and their families.

Contract deliverables include:

- a) Provide three regional trainings to support group leaders in skills such as communication, leadership, group process and social skills to facilitate effective meetings and activities.
- b) Maintain ongoing communication with acute care and rehabilitation providers regarding availability and benefits of support groups for early referral of families and persons with brain injuries.
- c) Communicate with support group facilitators and members via email and other appropriate means regarding support group meetings, events and activities.
- d) Assist support group leaders with developing networks of community based natural supports to help those with brain injuries to better integrate in their home communities.

3) The Brain Injury Association of North Carolina serves all people in our state who are living with the effects of brain injury. This includes people of all ages, ethnicities, and social/economic backgrounds. The Brain Injury Association of America notes that brain injury may affect anyone, anytime and anyplace and BIANC provides outreach and support to children, youth, young adults and older adults. However, young adult males are the demographic most likely to sustain a serve brain injury with lifelong needs for care and support. It is estimated that the cost of long term care for a young person with a brain injury will be over \$4 million dollars.

The four regional BIANC offices cover all areas of the state and handled call inquiry calls from the state's 100 counties. More than 30 brain injury support groups across the state provide support to families in all regions. Also, BIANC coordinated regional information and training programs with Mountain Area AHEC, Southeastern Area AHEC and Wake AHEC

4) The Brain Injury Association of NC met and exceeded all of our DMH/DD/SAS contract goals for information and support, training, and support groups assistance for 2011-2012

A) Resource Center deliverables:

- BIANC provided information and resource support to 2,054 people who called the 1-800 Helpline or sent emails requesting information.
- BIANC also mailed 715 informational packets, disseminated 7,000 newsletters, sent monthly information updates via email to 1,811 contacts, and communicated with 2,484 Facebook friends and 889 Twitter followers.
- BIANC developed two specialized Skill Packets, one for family members and one for professionals at rehabilitation hospitals, to educate families about brain injury and provide guidelines for transitioning from the hospital to home or community placement. BIANC staff met regularly with case managers/discharge planners at each of the eight regional rehabilitation hospitals to verify that families were receiving the information and support that they needed to help with their discharge planning. BIANC also participated in trainings at the regional Alcohol and Drug Abuse Treatment Centers (ADATCs) to educate the treatment staff about the most effective treatment models for people with brain injuries who have substance use/abuse issues.
- BIANC received regular updates from the North Carolina Department of Public Health with new data on brain injury incidence, prevalence and impact which we included in our monthly email reports and newsletter editions. We also provided regular updates on the re-structuring of the MH/DD/SAS system to help families and professionals navigate the service delivery system
- BIANC developed a comprehensive directory of resources for people with brain injuries including information on treatment facilities, healthcare professionals, long term care options, state agencies and community resources. The resource directory is available on our website and copies are disseminated to rehabilitation hospitals, Local Management Entities and other professional groups.
- BIANC coordinated four Professional Provider Council meetings for residential and day program providers across the state. We provided education and information about clinical issues and changes in the state MH/DD/SAS system and encouraged service providers to share information about best practice procedures
- BIANC developed an annual report documenting our accomplishments and goals for 2011. The annual report was added to our website and disseminated to the public.
- BIANC staff provided administrative/technical support for quarterly meetings of the Brain Injury Advisory Council

Outcome measures for the Brain Injury Resource Centers included two caller satisfaction surveys, one at the time of the original call and a follow up questionnaire utilizing an on-line survey program. The first survey indicated that 92% of callers responded that the call met their needs and 97 % in the second survey indicated that they agreed or strongly agreed that the call was helpful.

B) Training and education deliverables:

- BIANC reviewed and updated all informational products developed/disseminated by BIANC under DMH/DD/SAS including Skill Packs for families and professionals and our statewide resource directory
- BIANC staff exhibited and or presented at 13 clinical conferences including presentations at the NC Conference on Aging, the Department of Public Instruction's Exceptional Children's Conference, the National Black Speech Association Conference and the NC TIDE Conference. BIANC provided information and education to over 1,700 participants at the 13 conferences.
- BIANC collaborated with WakeAHEC to provide an annual statewide professional symposium "Traumatic Brain Injury 2011: After the Big Bang, Managing Your New Universe" on Oct. 27 -28 in Raleigh. The conference had 130 attendees.

- BIANC published a quarterly newsletter, *Starting Point*, with specialized columns which addressed the needs of families and persons with brain injuries. Editions covered the themes of research, caregivers, sport injuries and military families. Each edition was disseminated to over 1,200 people including persons with brain injuries, family members, rehabilitation hospitals and professionals.
- BIANC provided Brain Injury 101 training programs to 19 groups including LME staff, service providers and professionals from OPC, Mecklenburg, ECBH, Wake and Western Highlands LMEs. BIANC training programs also included four certified brain injury specialist (CBIS) trainings which offered CBIS certification from the Brain Injury Association of America for direct care staff and professionals.
- BIANC provided 11 individualized training programs for LMEs and service providers who requested help to better serve specific individuals with traumatic brain injuries. These trainings included programs for a military support group in Fayetteville, adult care or assisted living facilities and the Analenisgi Mental Health Center in Cherokee, NC
- BIANC developed a training program to help prevent, evaluate and manage sport concussions for youth sport groups. The program was presented to local high schools and youth sport groups in the Raleigh, Greenville, Asheville and Charlotte areas.
- BIANC coordinated a statewide weekend wellness retreat for over 100 survivors and support group leaders which was funded by donations from corporate sponsors, members of the NC Pilot club and individuals. BIANC also coordinated three regional wellness day events which focused on good health management including exercise programs, eating and diet regimens and socialization. The goal of the wellness events was to improve the quality of the lives of people living with brain injury and to prevent secondary illness like obesity, hypertension, and depression.
- Outcome measure included completing 53 training programs across the state reaching over 2,763 individuals. The training sessions were well attended and evaluations of the programs demonstrated an average of 85% ratings as either satisfied or very satisfied.

C) Support Group deliverables:

- BIANC provided three regional training programs to support group leaders across the state. The training programs included information on leadership, communications, group process and developing skills to ensure that the support groups are effective and sustainable.
- BIANC staff had regular meetings with acute care and rehabilitation hospital staff and provided information on the availability and benefits of support groups for early referral of families and persons with brain injuries. Many of the regional support groups are affiliated with and meet at rehabilitation hospitals including WakeMed in Raleigh, UNC Hospital in Chapel Hill, Moses Cone in Greensboro and Coastal Rehab in Wilmington.
- BIANC communicated with the support groups leaders and members via monthly email updates, quarterly newsletters, and support group presentations to provide information on events, activities and important developments in brain injury service delivery and care.
- BIANC sponsored an annual family conference "Building Community from the Inside Out" which targeted people with brain injuries, their families, caregivers, military/veterans, and service providers and provided information on ways that families can help a person with a disability become involved in community activities.

Outcome measures included providing four regional support group leader training programs and six support group in-services. BIANC surveyed the regional Support Group Leaders and determined that 80% found our programs and services to be either helpful or very helpful.

5) Below is BIANC's total budget for NC State fiscal year July 2011-June 2012. The budget included:

Expenses 2011-12

Personnel	Total	MH/DD/SAS	HRSA	Gen Fund
Salaries				
Executive director 1 FTE	\$52,000.00	\$34,320.00	\$13,000.00	
Community support coordinator (Triangle) .75 FTE	\$33,000.00	\$16,800.00		
Community support coordinator (Eastern) .33 FTE	\$13,200.00	\$10,000.00		\$3,200.00
Community support coordinator (Western) 1 FTE	\$40,000.00	\$16,800.00	\$19,318.00	
Business manager .75 FTE	\$33,000.00	\$16,800.00	\$8,925.00	
Assistant support coordinator 1 FTE	\$38,000.00	\$10,400.00	\$19,318.00	
Training Coordinator 1 FTE	\$42,000.00	\$0.00	\$42,000.00	
Benefits	\$42,704.00	\$17,870.00	\$17,417.00	
Total	\$293,904.00	\$122,990.00	\$119,978.00	\$3,200.00
Supplies and Materials				
Office supplies	\$12,758.00	\$8,540.00	\$4,218.00	
Education/Community outreach materials	\$10,000.00	\$9,500.00	\$500.00	
Total	\$22,758.00	\$18,040.00	\$4,718.00	\$0.00
Program Support				
Travel (auto mileage & overnight stay)	\$15,000.00	\$6,500.00	\$8,500.00	
Telephone and Internet	\$12,500.00	\$6,279.00	\$6,221.00	
Printing	\$19,000.00	\$10,900.00	\$5,200.00	\$2,900.00
Payroll and accounting services	\$8,800.00			\$9,341.00
Professional development	\$2,000.00	\$500.00		\$1,500.00
Advertising/marketing	\$1,000.00			
Board member expenses	\$500.00			
Website support	\$1,000.00			\$1,000.00
Consultant fees/ honorariums	\$6,000.00			\$614.00
Event expenses (camp & training events)	\$19,000.00		\$10,274.00	\$8,726.00
Total	\$84,800.00	\$24,179.00	\$30,195.00	\$24,081.00
Fixed Charges and Expenses				
Rent	\$11,588.00	\$11,400.00		\$343.00
Dues (BIAA)	\$13,994.00			\$6,427.00
Insurance and bond	\$5,000.00	\$3,000.00		\$2,000.00
Total	\$30,582.00	\$14,400.00		\$8,770.00
Project STAR subcontract	\$45,614.00	\$45,614.00		
Total expenditures	\$477,658.00	\$225,223.00	\$154,891.00	\$36,051.00
Income 2011-12				
MH/DD/SAS Contract	\$225,000.00			
HRSA Grant	\$167,000.00			
Vidant Foundation Grant	\$8,000.00			
Carolina Panthers Charities Grant	\$10,000.00			
Total	\$410,000.00			
Fundraising Income				
Membership/donations	\$20,000.00			
Memorials	\$4,000.00			
Walk and Roll-athon	\$45,000.00			
Ride for the Rock (bike race)	\$5,000.00			
Fall Fund Raising Events	\$15,000.00			
Corporate Sponsors	\$40,000.00			
Conference/trainings	\$5,000.00			
Total	\$134,000.00			
Total income	\$544,000.00			

- 6) The BIANC budget includes revenue from contracts with the NC Division of Mental Health/Developmental Disabilities/Substance Abuse Services from state funds, a MH/DD/SAS contract funded through the federal Health Resources Service Administration (HRSA), a grant with the Vidant Hospital Foundation, a grant with the Carolina Panthers Charities, membership fees, donations and memorials, and fundraising events.

The HRSA contract provides \$167,000.00 per year for five years from 2010 through 2014. BIANC provides \$90,000 per year in-kind match from donated time from volunteers and rental space. BIANC has used the HRSA funds to provide technical assistance to develop two new clubhouse day programs for people with brain injuries, including military service members, developed an ombudsman program with volunteers who have a brain injury or are family members and offered a yearly statewide family conference.

The Vidant Hospital Foundation Grant is in its 9th year and provides \$8,000 which helps support the BIANC office in Greenville, NC. The office is located at the National Guard's Family Readiness Centers and provides support to civilian and military families in eastern NC.

The Carolina Panthers Charities grant is for \$10,000 and provides funds to disseminate smart phone applications donated by the Gfeller Sport Medicine Center which help athletic personnel evaluate and manage concussions on the sports field. BIANC's training coordinator educates the staff of youth sports organizations and middle schools about the concussions and the appropriate use of the phone application.

BIANC received \$134,000 in funding from donations, memorials, membership fees and fundraising events that is used to support our work across the state. We also receive in-kind donation of office space from CarePartners in Asheville, Carolinas Rehabilitation in Charlotte, Wake Forest Baptist Medical Center in Winston-Salem and the National Guard Family Readiness Center in Greenville.