North Carolina Traumatic Brain Injury Advisory Council

Created 2003 by NC Session Law 2003-114

Department of Health and Human Services

Division of Mental Health/ Developmental Disabilities/ Substance Abuse Services

2009-2010

Annual Report

Executive Summary of Report on 2010 of the Brain Injury Advisory Council for North Carolina

Legislatively Established Statewide Brain Injury Advisory Council

- Council strengthened by passage of Bill 1309 with expanded membership
- Council developed and implemented system to monitor and refine the membership process
- Expanded membership almost complete

Committed Lead Agency with Adequate Funding

- Funding for brain injury services continue to be maintained despite state fiscal crisis.
- Significant progress in Division's fiscal management of brain injury services and requirements for documentation and reporting by LMEs.
- The Council has identified a critical need for more accurate and data
  Brain injury services continue to be severely underfunded ; MHDDSAS was unable to fund **Unable to fund $1,984,856** in requests from LMEs in 2010.

Community-Based Waiver for Brain Injury

- The Council worked extensively, conducting a survey of 22 states and developing preliminary criteria for services under a waiver
- House Bill 77 and Senate Bill 335 would direct the Division to apply to the Centers for Medicare and Medicaid Services for a Waiver which would allow people who sustain traumatic brain injury after age 22 to access home and community-based Medicaid services only if matching dollars are identified.
- Without a $500,000 match from NC, it is unlikely that services will be available for those Medicaid-qualified North Carolinians with TBI above the age of 22.
- Successful application would provide an additional $1,000,000 of federal dollars for those services.

Licensing of Residential Services

- House Bill # 1309 required the Division of Mental Health/Developmental Disabilities/Substance Abuse to "adopt rules providing for the licensure and accreditation of residential treatment facilities for persons with traumatic brain injury." (2010 Session of the General Assembly)
- The Council formed a task force to investigate current licensure rules and regulations to determine needs but under the current economic exigencies, there was concern that new regulations might make service delivery more difficult.
- There are currently no TBI specific rules for residential facilities in North Carolina to accommodate the unique and varied management needs of this population
- Through the Division of State Operated Health Care, training is being developed as a stop gap measure but is not a requirement

Fulltime Program Coordinator in the Lead Agency

- The Brain Injury Program remains understaffed and over worked due to hiring freeze and budget cutbacks making it difficult to address the complex scope of work and the unmet needs of the brain injury community.
- The Council applauds the yeoman efforts of staff despite these stressful circumstances.

Federal Grant

- A 4 year federal grant was awarded to strengthen the statewide system of community TBI services in three priority areas of social support, family advocacy and substance abuse screening.
- The Ombudsman Program is now in operation across the state providing help to families
- The Gateway Program has begun providing day programming to persons with TBI
- Training has been implemented for families and for substance abuse providers regarding TBI

The Institute of Medicine Task Force

- The Council Chair and BIANC Director, participated in the Task Force with attendance and contributions from MH/DD/SAS staff .
- ***Honoring Their Service: Behavioral Health Services for the Military and Their Families*** has been completed and published.
- The need for a comprehensive and integrated system of services was recognized and stressed.

Prevention

- The Council reviewed the Sports Concussion initiatives through the Matthew Gfeller Sports Related TBI Research Center, the State Board of Education initiative, and NC High School Athletic organizations
- The Council reviewed the Prevention of Underage Drinking Initiative and a presentation on forensic testing for alcohol

North Carolina Traumatic Brain Injury Advisory Council

Carol Ornitz	Chair, family member of persons with a brain injury
James Amos	Designee, American Heart Association, Stroke Survivor
Hurshell Baggett	Designee, NC Medical Society
Dale Beatty	survivor of a brain injury and military veteran
Cindy Boyd	nurse with expertise in brain injury treatment (
Christine Craig	Designee, NC Hospital Association
Sandra Farmer	Executive Director, Brain Injury Association of NC
Martin Foil, III.	Designee, Division of Insurance
David W. Forsythe	brain injury service provider
Travis Glass	survivor of a brain injury (Western NC)
Linda Herbert	family member of a person with a brain injury
Stephen Hooper	educational provider
Marilyn Lash	family member of a person with a brain injury
LaToya Lucas	survivor of a brain injury and military veteran (Eastern NC) (pending)
Ken Jones	LME Director
Stephanie McAdams	Chairman, Brain Injury Association of NC
Charles Monnett III	Designee, NC Academy of Trial Lawyers
Maureen Nelson, MD	physician with expertise in rehabilitation
Elizabeth Newlin	nurse with expertise in trauma
Peggy Philbrick	family member of a person with brain injury
Maureen Nelson, MD	physician with expertise brain injury treatment
Dick Seidenspinner	survivor of a brain injury (Central NC)
Vickie Smith	Disability Rights, NC

Candice Britt	representative NC Division of Social Services
Spencer Clark	representative NC Division of MH/DD/SAS
Alan Dellapenna	representative NC Office of Emergency Medical Services
Michiele Elliott	representative NC Division of Health Services Regulation
Gloria Hale	representative NC Office of Emergency Medical Services
Susan Johnson	representative NC Division of Medical Assistance
Holly Riddle	representative NC Council on Developmental Disabilities
Sharon Rhyne	Past Chair, representative Division of Public Health
James Swain	representative NC Division of Vocational Rehabilitation
Tom Winton	representative NC Exceptional Children's Division, Dept of Public Instruction
(On Hold)	representative NC Dept of Veteran Affairs

Joan Kaye	Staff Support from Div of MH/DD/SAS
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Executive Summary of Report on 2009 of the Brain Injury Advisory Council for North Carolina

Legislatively Established Statewide Brain Injury Advisory Council

- Council strengthened by passage of Bill 1309 with expanded membership.
- State budget cuts resulted in inability to secure Council funding under Bill 1642.

State Plan for Development of Full Continuum of Brain Injury Services

- Statewide plan for brain injury developed, approved and disseminated.

Committed Lead Agency with Adequate Funding

- Funding for brain injury services maintained despite state fiscal crisis.
- Significant progress in Division's fiscal management of brain injury services and requirements for documentation and reporting by LMEs.
- Overreliance on state budget due to lack of diverse funding streams.
- Brain injury services continue to be severely underfunded.

Community-Based Waiver for Brain Injury

- House Bill 737 directed the Division to apply to the Centers for Medicare and Medicaid Services for a Waiver which would allow people who sustain traumatic brain injury after age 22 to access home and community-based Medicaid services.

Special or Dedicated Fund with Recurring Revenue

- While extensive study of dedicated brain injury trust funds established in other states has been conducted, the Council has been unable to identify a revenue source for a Brain Injury Trust Fund.

Licensing of Residential Services

- House Bill # 1309 requires the Division of Mental Health/Developmental Disabilities/Substance Abuse to "adopt rules providing for the licensure and accreditation of residential treatment facilities for persons with traumatic brain injury."

Fulltime Program Coordinator in the Lead Agency

- The Brain Injury Program remains understaffed due to hiring freeze and budget cutbacks making it difficult to address the complex scope of work and the unmet needs of the brain injury community.

Prevention

- The Division and the Department of Public Health have collaborated on a statewide prevention survey and analysis of data.

Federal Grant

- A 4 year federal grant was awarded to strengthen the statewide system of community TBI services in three priority areas of social support, family advocacy and substance abuse screening.

Introduction

The Brain Injury Advisory Council for North Carolina has worked closely with the Traumatic Brain Injury (TBI) Program within the Division of Mental Health/Developmental Disabilities/Substance Abuse Services, throughout 2009. During this period, the TBI Program has made major advancements in policy development, financial management, reporting systems, and communication with key stakeholders including the local management entities (LMEs) and the provider community for brain injury services. These advances and accomplishments are remarkable because they occurred while:

- The State of North Carolina faced major budget deficits due to the declining economy yet legislative support for brain injury funds was sustained in the final state budget.
- Increasing numbers of service members are returning from Iraq and Afghanistan with traumatic brain injuries with an uncertain financial and programmatic impact on state agencies and their local communities.

A person who survives a severe traumatic brain injury
Will survive an average of 50 years post injury.
Source: NC Center for Health Statistics, 2007

The most persistent needs over the lifetime of a person with brain injury are help with cognitive changes (difficulties with attention, memory, judgment and reasoning) and assistance with behavioral challenges (impulsivity, agitation and a variety of emotions). Many individuals also require personal care/assistance to remain in their communities. A statewide needs assessment identified the following unmet needs for brain injury neurobehavioral services:

- crisis assessment and intervention
- family support
- caregiver training and
- a continuum of residential services and day programs.

Without these services, individuals with brain injuries are at greater risk for admission to psychiatric hospitals, criminal charges, incarceration, and/or homelessness.

State funding for brain injury services has historically been minimal. There is a very limited number of providers who are trained and experienced in providing services to individuals with brain injury. Those providers who have this expertise are scattered around the state resulting in geographic pockets of services, but no statewide network readily accessible to all individuals. Despite a significant increase in fiscal year 2008 for the TBI program under the Division to $2.3 million, the TBI program remains underfunded and statewide community capacity is minimal.

- ***A comprehensive continuum of brain injury services simply does not exist in North Carolina***.

While considerable progress has been made by the Division with the support and collaboration of the Council over the past year, brain injury services continue to be fragmented, underfunded and inadequate to meet the needs of survivors and their families. Building community capacity for brain injury services continues to be thwarted by administrative and financial disincentives and barriers for new and existing providers.

Despite the Council and Lead Agency's progress over the past year, North Carolina remains significantly behind other states in the development of a comprehensive brain injury service system. In 2005, the National Association of State Head Injury Administrators identified five essential components for a statewide comprehensive brain injury service system. They are identified below with progress and challenges discussed for North Carolina.

1) Legislatively Established Statewide Brain Injury Advisory Council

Background:

The NC Traumatic Brain Injury Advisory Council was established in the 2003 Legislative Session and became operational in July, 2004. No funds have been allocated for the operation of the Council.

Progress in 2009:

- ✓ The Council was strengthened by passage of Bill 1309 with the following changes:
  - New name of Brain Injury Advisory Council for NC in recognition of Council's original mandate to examine issues of both acquired and traumatic brain injuries.
  - Change of state employees to ex-officio members with no voting status to avoid conflicts of interest.
  - Increased membership from 29 to 33 (23 voting and 10 non-voting), including new positions for an additional family member, stroke survivor, and veteran or family member.
- ✓ Increased leadership by Chairs and members of the Council's Legislative Committee, Health Services Committee, and Prevention Committee.
- ✓ Stronger collaboration and communication with the TBI Program within DMM/DD/SAS.

Barriers in 2009:

Bill 1642 was submitted with the request of $50,000 to fund work of the Council including technical assistance and consultation on critical issues of waiver development and trust fund exploration. The Council has been operating on a voluntary basis for all members; however, due to the scope of work and the limited staff resources available at the Division, funds to support the Council's work are needed and will be requested again in 2010. Due to the freeze in state hiring, assistance by the Council is even more critical for the TBI program in order to provide the needed expertise and assistance for policy development and sustainable programs.

2) State Plan for Development of Full Continuum of Brain Injury Services

Background:

A State Plan for TBI is required in order to apply for federal funds under the TBI Act through the Health Resources Service Administration (HRSA). An initial plan was developed in 1996 In order to remain current and relevant, HRSA recommends that the Plan be updated every five years.

Progress in 2009:

The TBI Program completed its most recent update of the Plan in collaboration with the Council. It was developed with input from:

- ✓ Needs assessment conducted by the Center for Development and Learning at UNC
- ✓ Focus groups of providers, families, survivors and advocates conducted statewide
- ✓ Public and provider stakeholders

The statewide plan provides a "blueprint" for the further development of brain injury services with the following goals:

- Increase service capacity
- Improve coordination of data collection/dissemination
- Maintain and enhance training/educational opportunities
- Maintain diversity and independence of advisory council
- Update definition and eligibility guidelines for brain injury
- Develop statewide prevention plan

The State of North Carolina needs to expand, develop and coordinate services for individuals, and coordinate education and prevention efforts. This State Plan provides the structure for those activities.

3) Committed Lead Agency with Adequate Funding

Progress in 2009:

Major progress was achieved when funding for brain injury services was increased from $1.3 million to $2.3 million in the 2008 legislative session. Legislative support and the work of the Council's Legislative Committee were crucial for maintaining this level of funding in the 2009 session given the state budget's shortfall. While funding cuts were made to state contracts for brain injury services and LMEs made budgetary determinations locally for brain injury funds, overall funding levels for brain injury services remained relatively intact.

The Council has addressed two financial concerns regarding brain injury funding. First is the level of annual funding for this population, and second, the management of those funds. In 2009, the Council worked closely with the Division to improve the fiscal reporting and management of brain injury funds. This was considered critical as the allocation and disbursement of TBI funds moved from the overall control of the TBI Program Director at the Division to local LMEs. In prior years, the fiscal analysis, management and accountability for the TBI program was very weak with little administrative oversight and fiscal controls. There was little data reporting and program analysis for TBI services making it difficult for the Council to determine the costs, services, and outcomes for clients and providers.

During 2009, the Division made major advances in fiscal reporting, management and accountability for brain injury funds. This was critical with the conversion to single stream funding and LME allocations as directed by the Legislature. The TBI Program has worked very diligently to develop fiscal reporting systems and tools to track the expenditure of brain injury funds and these were implemented in 2009 with the LMEs and computerized data reporting. In addition to fiscal information, systems have been developed to gather information on the demographics and clinical needs of the TBI population being served and information on the services provided. LMEs have been responsive to increasing reporting requirements for TBI funds which have been complemented and reinforced with improved communication and collaboration with TBI Program staff. These steps and procedures were major advances in fiscal management and the Council applauds the diligent work of the TBI Program staff to design and implement these changes.

Barriers:

Funding for brain injury services in NC remains woefully inadequate and contrasts with the fact the traumatic brain injury is a leading cause of disability. The Centers for Disease Control estimates that 160,000 North Carolinians are living with impairments and disabilities due to traumatic brain injury. The long-term funding needs of this population require a more comprehensive approach with diverse funding streams that are not reliant on the yearly state budget and variances of the state's economy. These are addressed next.

An additional barrier is the complexity of the contracting and funding process for private providers to access state funds. This can be a lengthy and complex process and many providers report significant delays between the provision of services and payment by the local LME. This makes it difficult for providers to operate efficiently, manage overhead expenses, and maintain adequate staffing.

4) Community-Based Waiver for Brain Injury

Background:

A Home and Community Based Services (HCBS) waiver gives the Secretary of Health and Human Services the authority to waive Medicaid provisions in order to allow long-term care services to be delivered in community settings rather than in institutional settings. While the need for a HCBS Waiver for Brain Injury has been discussed by the Division as far back as the early 1990s, an application has never been filed. In fact, it became more difficult to secure support and a commitment from the Division in recent years given the massive reorganization and reallocation of resources required for Mental Health Reform.

Progress in 2009:

The Council has examined how 21 other states developed and sustain long-term funding for brain injury services via a Brain Injury Waiver. Because the federal Medicaid program provides approximately $.64 for every $.36 that the state/county contributes in matching funds, the Advisory Council believes that a Waiver is one of the most cost-effective ways to serve individuals who have significant long-term needs in a non-institutional setting.

- ✓ The Council supported House Bill 737 which "directs the Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (Department) to apply to the Centers for Medicare and Medicaid Services for a 1915© waiver to allow people who sustain traumatic brain injury after age 22 to access home and community-based Medicaid services." Additional language provides that if the waiver is approved, the Department cannot implement it without an act by the General Assembly authorizing appropriation of funds required for the match.
- ✓ The Council fully supports the Department's development and application for a HCBS Brain Injury Waiver.
- ✓ Brain Injury Licensure and Waiver Work Groups have been established by the Division of MH/DD/SAS. Under the leadership of the Division's TBI staff, these groups are providing consultation and technical assistance for the development of the brain injury waiver and for the development of licensing regulations for residential programs for persons with TBI. They are collaborating closely with the Division of Medical Assistance (DMA), the Division of Health Service Regulation, and selected Advisory Council members and volunteers.

5) Special or Dedicated Fund with Recurring Revenue

Background:

A Brain Injury Trust Fund is an account established by law and dedicated for activities that benefit individuals who have sustained a brain injury and/or for activities that prevent brain injuries. Trust Funds are typically supported by revenues from a fee, fine, surcharge, or excise tax. Revenue is placed in an interest-bearing, non-reverting account. The first Brain Injury Trust Fund was established in 1985 in the State of Pennsylvania and 22 states now have Trust Funds that benefit persons with brain injury. Estimated revenues vary widely among states ranging from less than $1 million to up to $25 million per year. Fines from speeding tickets and driving while intoxicated are the most common source of revenue for brain injury trust funds. Such fines have been used as speeding and DWI are directly related to motor vehicle collisions resulting in brain injuries to drivers, passengers and pedestrians.

Progress in 2009:

Brain Injury Trust Funds are the second mechanism that states have used widely to sustain brain injury services in the community and to decrease reliance on state budgets. The Council has collected and reviewed extensive information on Brain Injury Trust Funds in other states to determine potential revenue sources, to identify the most cost effective services, and to determine efficient management practices. The challenge for NC is to identify a revenue source for a Brain Injury Trust Fund.

Barriers:

Virtually no progress has been made on establishing a Brain Injury Trust Fund for North Carolina despite widespread support by the Council and the TBI Program. The major barrier repeatedly cited is the provision that monies collected via fines must go to the Department of Public Instruction (DPI) and distributed to local schools according to the NC Constitution. While the Council has explored other possible sources such as a tax on alcohol or tobacco use, no plan has been developed. The requested funds for the Council (item 1) are needed to explore and examine how to develop such a Trust Fund.

Additional Issues, Barriers and Accomplishments

Licensing of Residential Services

Background:

Individuals with brain injuries requiring residential services have very limited access to such programs within NC. Individuals needing residential care due to traumatic brain injury may have a wide range of physical, cognitive, behavioral and/or communicative impairments and disabilities.

LMEs currently authorize expenditure of TBI funds for residential care among 8 residential programs. Seven of these programs serve 2 to 6 individuals with TBI and are licensed as 122C-Supervised Living within Section (.5600C) under homes licensed for individuals with developmental disability. The exception to this is a residential program licensed as 131D as an Adult Care Home with the largest licensed capacity of 37 individuals (currently operating with 24 residents with TBI due to staffing and financial constraints).

In each of these facilities, the monthly rental rate is set by the State and currently is $1,182 per month. Also in each of these facilities State funds (IPRS and TBI Non-UCR) can not be utilized for an individual if that individual receives CAP-MR/DD services according to SB202, Section 10.21B and CAP-MR/DD Update dated 07/22/09. This rule would also apply to the current TBI waiver being developed.

This rule makes it particularly difficult to serve individuals with multiple disabilities and meet their service support needs. The General Assembly authorized under Section 10.15(u) The Division of Health and Human Services to "review the State-County Special Assistance rates to develop an appropriate rate for special care units for persons with a mental health disability, including individuals with Traumatic Brain Injury (TBI), and shall review current rules pertaining to special care units for persons with a mental health disability to determine if additional standards are necessary….." Although findings were to be reported no later than January 1, 2009, the Council has been unable to determine the status of this report and its recommendations.

Progress in 2009:

House Bill # 1309 requires the Division of Mental Health/Developmental Disabilities/Substance Abuse to "adopt rules providing for the licensure and accreditation of residential treatment facilities for persons with traumatic brain injury."

A small task force organized by the Council conducted a survey of TBI residential programs in 7 states to gather information on licensing categories, regulations, training requirements, and rates for this population. This information has been shared with the Division of MH/DD/SAS which has now established a Licensure/Waiver Work Group to address the need for licensing rules that will be specific and responsive to the needs of individuals with traumatic brain injury. The Division of Health Service Regulation is represented on this workgroup and provides expertise on licensing regulations.

Barriers:

Providers are supportive of the development of new rules for licensure of residential programs for persons with TBI. The length of time required for the complex process of developing and implementing new rules is a continuing barrier for the fiscal operation of current programs. It is also a significant barrier for attracting new residential providers to the state for this population. Without appropriate and adequate services within the state, it is possible that there may be an increase in requests for out-of-state placements and services as has been evident in other states.

Fulltime Program Coordinator in the Lead Agency

Background:

Currently the Lead Agency has one fulltime equivalent position assigned among two staff members: a part-time program manager and a part-time program coordinator. A full-time TBI program manager and a full-time program coordinator are needed to adequately address the scope of work for a statewide TBI program. Awards under the federal TBI Act state that a full-time manager is needed in recognition of the challenges for systems development to better serve this population.

Progress in 2009:

The Council continues to support the need for increased staffing of the TBI program by the Lead Agency. Staff reorganization in 2009 strengthened the management and leadership of the program but it remains severely understaffed given the significant challenges and gaps identified in this report.

Barriers:

A hiring freeze and budget cutbacks in 2009 negatively impacted efforts to expand staffing. Given the likelihood that this will continue in 2010, it is even more critical for the Council to have financial support to supplement to work of the TBI Program staff.

Limited staffing has also delayed the fiscal and programmatic analysis required to determine the impact of broadening the definition of brain injury used by the Division. It currently uses the narrow definition of traumatic brain injury, i.e injuries caused by an external blow to the head or skull. The Council has conducted a thorough review of brain injury definitions used by other states. It has also reviewed the public health data on traumatic and acquired brain injuries in North Carolina. The Council recommended that the Division consider a broader definition of acquired brain injury in 2009. This would expand the population to include persons with traumatic injuries plus those caused by internal causes, i.e. brain tumors, brain infections, etc. However, because of the state's fiscal crisis and limited staffing within the Division's TBI program, the Council suspended this discussion until the required analysis of its impact can be performed.

Prevention

Background:

While clearly the only real *deterrent* for brain injuries is prevention, the reality is that we can only hope to reduce or minimize the impact of these injuries. Prevention of brain injuries and early intervention following brain injury saves lives and reduces long term costs. An aggressive statewide prevention/early intervention plan is needed.

Progress:

The Council's Prevention Committee has conducted an extensive survey and analysis of injury prevention programs, including those specific to TBI, in NC and compiled results. Because of limited staffing and resources in the Division, the Council supports efforts for interagency collaboration and planning with public and private agencies and organizations interested in and conducting injury prevention programs. The Department of Public Health is a key collaborator for this initiative as they provide data for ongoing analysis of brain injuries across the state.

HRSA Grant

Background:

The federal TBI Act supports competitive grants to TBI Lead Agencies in 14 states for the purpose of strengthening statewide service systems on brain injury. Awards are given for 4 years with $250,000 in federal funds per year requiring a state match of $125,000 that may include in-kind donations.

Progress:

The Division received approval for a 4 year award to commence 4-1-2009 with work to be completed by 3/31/2012. The overall goal of the project is to strengthen the statewide system of community TBI services in three priority areas of social support, family advocacy and substance abuse screening. The multi year project will: 1) Increase access to community based services for social support, cognitive retraining, and prevocational services; 2) Prepare families with knowledge and strategies to successfully address barriers in accessing community help and related services; and 3) Increase competence of substance abuse providers in the community for improved identification, assessment and treatment of individuals with TBI. The goals are consistent with those identified in the State Plan approved by the Council. The Council applauds the work of the TBI Program staff who developed an exceptional application which was competitively reviewed and awarded.

Conclusion

The Council and the TBI Program have made major strides in 2009 toward addressing the immediate needs for improved financial and administrative oversight of brain injury funds. At the same time, the Council and TBI Program are now working more closely than ever to address the long-term systemic issues of sustainable funding, increasing community capacity, strengthening provider networks, and improving competency via training. The major initiatives of licensing, a brain injury waiver, and brain injury trust fund are high priorities for the Council and TBI Program over this next year as these are the fundamental building blocks and foundation for a comprehensive brain injury service system in NC.