In the 1980s, following passage of the Trauma Services Act of the late 1970s, selected hospitals began to be designated as trauma centers. Their primary function was to save lives, which meant that persons who had sustained traumatic brain injury (TBI) had an increased chance of surviving past the acute care period. Increased survival, however, meant increased morbidity and a greater need for long-term care. Consequently, the number of rehabilitation centers increased, from seven designated brain injury programs in the country in the early 1980s to over 700 a decade later. These centers offered multi/interdisciplinary services; lengths of stay were quite long (months to years); insurance companies and many state Medicaid offices generally paid for their services. With growth and expansion also came regulatory oversight, which pared down the number of programs over time.

This national trend was mirrored in North Carolina. Indeed, our state has a long history of serving victims of TBI and, as illustrated by many of the articles in this issue, has provided the training and facilities to serve children, adolescents, and adults affected by TBI. With state-of-the-art biomedical procedures like MRI increasingly available even in rural areas, and with five Level I Trauma Centers, North Carolina clearly is in a position to be a national leader in the treatment of TBI. With this history in mind, we assembled a range of articles for this special issue of the North Carolina Medical Journal that address three major goals.

The first goal was to summarize current information about TBI-related issues across the life span. The paper by Smith et al on page 328 provides an overview of current definitional issues, epidemiological findings, and other evidenced-based aspects of TBI. Other articles look at TBI in infancy (Keenan and Runyan, page 340), in adolescence and young adulthood (Mueller, page 368), and in the elderly (Sasser et al, page 364). Several papers address a variety of medical and rehabilitation issues ranging from acute care for children with TBI (Alexander and Moore, page 344) to post-acute services (Evans, page 373) and community integration (Hodges et al, page 355). Alexander et al (page 359) describe a model program designed to provide the beginnings of a relatively seamless system of care, Project ACCESS, for children who sustain TBI. Hooper et al (page 350) outline a training model designed to educate school-based personnel about TBI. Finally, a critical article by Thompson et al (page 376) examines the costs of TBI to individuals and to society.

A second goal was to showcase several innovative programs pertaining to TBI services and training in this state. The papers on Project ACCESS, on community integration, and on the school-based training model developed by the North Carolina Department of Public Instruction are noteworthy examples, but the evidenced-based activities described in nearly every paper highlight North Carolina’s ongoing research into the various nuances of TBI.

Taken together, the topics in this issue offer a rich sampling of the wide range of efforts on behalf of TBI-affected individuals and families that are currently under way in North Carolina. However, as we move into the twenty-first century, a number of challenges remain, and the state’s services still show room for improvement. Our third goal was to identify the specific areas where improvement is needed. We have made progress in this regard, but much work remains. Of the many needs that could be discussed in this article, we have chosen to focus on six: diagnostic concerns, service delivery models, family needs, support groups, prevention activities, and public policy.
Key Issues for TBI Services

Diagnostic Concerns. Most professionals working in the field have little difficulty diagnosing moderate to severe brain injury; mild injury, on the other hand, can pose a major diagnostic challenge, particularly when the primary complaint does not involve the head (for example, in a child with an arm injury from a bicycle accident). The fact is that most TBIs are mild injuries, and an increased understanding of mild TBI and its subsequent effects would improve the medical guidance and treatment we could provide to those who sustain it. For example, sports-related injuries have been getting increased attention over the past 5-10 years. As a result, high school and college athletic trainers and coaches are better prepared to identify and deal with the effects of concussion and mild TBI. For another example, a Standardized Assessment of Concussion protocol has been developed and is now recommended for use by ambulance teams and emergency department personnel. The Office of Emergency Medical Services is revising its guidelines to accommodate the long-recognized need for an improved assessment protocol for head injuries. The state’s Project ACCESS has been helpful in providing appropriate educational material to persons discharged from emergency rooms, and other hospital settings. These educational materials inform brain-injured patients and families what to do if symptoms arise, worsen, or persist. This should lessen frustration and aid in finding appropriate assistance.

Service Delivery Model. The number and quality of services available to persons with TBI have improved over the past decade. What has been lacking is recognition of appropriate community-based resources, adequate training of selected professionals in the area of TBI, and a state-wide linkage of these services. Even the sequence of services from the time of injury has been inconsistent across state communities.

Over the past five years, TBI grants from the Health Resource Services Administration (HRSA) have allowed the state to begin addressing service delivery issues. One of the key efforts has been to create a “seamless system of care” for persons following a TBI, regardless of its severity. The Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, in the Department of Health and Human Services, has made some progress in meeting this challenge. Figure 1 shows a suggested flow of services from the time of injury through hospitalization to community-based services. This suggested pattern will need to be made applicable to rural and urban areas, but it should facilitate a “catalog” of services available in various regions of the state. Identifying specific services (or the lack thereof), and improving linkages between services will increase the efficiency of care for individuals and families.

Family Needs. Following TBI, family members of the victim experience a variety of responses—disbelief, shock, anger, hopelessness. These feelings can be compounded by lack of empathy or knowledge on the part of medical staff, insufficient education about the nature of the injury and subsequent recovery issues, and lack of discussion of possible outcomes in the context of family needs and wants. These shortcomings can be further compounded if there is no “quarterback,” a service coordinator who can provide a consistent point of contact. Unfortunately, even many professionals do not fully understand what services and agencies are available for the victims, or when and how services like social security, disability, or vocational rehabilitation should be pursued.

Attempts to make service delivery systems more responsive to individual needs still leave families of TBI survivors at risk of feeling misunderstood at each point of service. We must get better at communicating information to families, and with families. We must be sensitive to their emotional needs. For example, during the acute phase of recovery, some families need to be given options and recommendations about rehabilitation services, but they should still be encouraged to have a strong, decisive voice in the process. Professional awareness of resources in the community is important; all case coordinators should be well acquainted with them. But we must help families recognize and communicate their needs (which can change significantly over time). In particular, family members of a TBI survivor are at risk for medical and mental health problems of their own, and their financial burden can be considerable as well. Recognizing and supporting those family needs is important and should be part of a larger system of care for TBI.

Support Groups. A core concept of support groups is the bringing together of people with common experiences. The Brain Injury Association of North Carolina (BIANC) provides approximately 20 active support groups. In addition, several agencies, including BIANC, help individuals start their own groups. Agencies like the Family Support Network and the Exceptional Children’s Assistance Center can match families of children with similar disabilities.

Despite these positive efforts, we need more circles of support in North Carolina. We can help identify natural supports (leisure activities, recreation, religion), can merge disability-specific and other support groups and activities, and can learn from the experience of groups like Arc (formerly the Association for Retarded Citizens). Doctors and other professionals need to know where these support groups are located, how to make referrals and, when feasible, should make themselves available as a resource. The state of New Jersey has begun training clergy in TBI, and these professionals have been an active part of the circle of support for families and survivors of TBI.

Prevention Activities. North Carolina has many efforts focused on TBI prevention. They include bicycle rodeos, programs to increase use of child safety restraints and seatbelts, teaching sports coaches about TBI, and recognizing RiskWatch...
Figure. The movement of clients following a TBI through a proposed system of care.
Communities and Headsmart Schools (schools where the TBI training curriculum has been conducted with all staff). Public policy supports these efforts by providing stricter laws about seat belt use, drunken driving, and teenage driving practices. A state law enacted on October 1, 2001, mandates the use of bicycle helmets by children 16 years old and under. The Injury Prevention Research Center (IPRC) has published a TBI Prevention Handbook (now in need of revision), which catalogs and critiques prevention programs in the state. The Governor’s Highway Traffic Safety Administration has awarded grants to help three North Carolina communities develop safe communities. It is hoped that, as part of the larger initiatives, these communities will increase education about TBI and thereby lessen the frequency of injuries leading to TBI.

These prevention efforts are noteworthy, but the state clearly needs to make prevention activities better known to members of the general and professional community. A statewide clearinghouse for ongoing prevention activities, perhaps overseen by and updated on the BIANC website, might address this need. Public health promotions about preventing TBI should also be considered.

**Public Policy.** Public policy is closely related to prevention efforts, especially in regard to funding. Current legislation does reflect increased sensitivity to the issue of TBI, but initiatives in prevention and service delivery have not always been financially sustained. Indeed, one could argue that TBI so increases the needs of individuals and families for services and long-term support that TBI deserves to be a line item in the state budget. The availability of state funds would lessen dependence on discretionary monies and grants, and increase the stability of the overall system of care. Members of nearly every disability group could make similar arguments, but the financial burden of treatment, management, and long-term support of brain-injured persons can be extraordinary, and some state-based support, such as Medicaid waiver, would be a big help.

The state implementation grant from HRSA has made some headway in establishing a registry of persons with TBI, but a legislatively mandated survivor registry would be better because it would document the need for services in the state’s respective regions. Accurate epidemiological data would target available state-based funds to regions of the state with the most needs.

Professionals who deal with brain-injured individuals and their families need more and better training and education. Specifically, since there is only one portal of entry to mental health services in this state, it is imperative that Case Managers in Developmental Disabilities have core competency regarding TBI. The North Carolina Department of Public Instruction has an innovative model for training school psychologists; it could expand this training to include other school personnel (regular and special educators), and link to other community-based services.

It would seem important from a public policy perspective to make TBI a primary public health concern in the state. It truly is a silent epidemic, and TBI-related issues should be aggressively addressed from a public health perspective. A disability-specific focus on TBI may go against policy trends in this state and across the country, but the unique needs presented by this population across the life span argue for active consideration.

Finally, the role of the BIANC has grown over the past several years, and its role in policy making should be considered. This nonprofit organization is supported by membership fees and voluntary donations (web site: www.bianc.org). Currently, amid an array of other activities, BIANC provides information and resources to families; helps coordinate several regional support centers; provides advocacy for TBI survivors and their families; conducts an annual state-wide conference for survivors, families, and professionals; and conducts an annual retreat and camp for survivors and families. Strengthening the linkage of BIANC to other TBI-related activities in the state will strengthen the orchestration of state public policy initiatives.

**Conclusions: The State of the State**

The state of North Carolina has seen significant growth in the field of traumatic brain injury. As the contents of this special issue illustrate, we have made much progress in understanding many of the issues related to TBI, and a wide variety of hospital- and community-based professionals have become aware of the issues surrounding TBI. The state has embarked on several training initiatives, and several models have been developed to increase the state’s capabilities to deal with TBI. From these perspectives, the state of the state is clearly positive, and there is a dynamic vision for how services will be coordinated and implemented throughout the state and how we can increase collaboration in TBI education and training activities, sustain interest in public policy endeavors—including key legislative mandates—and improve the involvement of families in these processes. The future for survivors of TBI and their families in the state of North Carolina continues to be positive.

**Acknowledgment.** This project was supported by funding from the Health Resources Services Administration (#SH21MC00006-03) to the North Carolina Department of Health and Human Services Division of Mental Health, Developmental Disabilities, and Substance Abuse, and by grants awarded to the Center for Development and Learning by the Administration on Developmental Disabilities (#90DD043003) and the Maternal Child Health Bureau (#MCJ379154A).