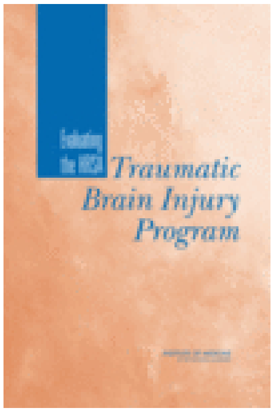

Evaluating the HRSA Traumatic Brain Injury Program

Committee on Traumatic Brain Injury

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THE NATIONAL ACADEMIES
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Evaluating the HRSA
Traumatic Brain Injury Program

Committee on Traumatic Brain Injury
Board on Health Care Services

Jill Eden and Rosemary Stevens, Editors

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> *Willing is not enough; we must do."*
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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the NRC's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **Paul D. Cleary**, Harvard Medical School, and **Dennis W. Choi**, Merck Research Laboratories. Appointed by the National Research Council and Institute of Medicine, they were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

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Preface

Bumps or blows to the head are commonplace events in ordinary life. Fortunately they are often of small importance: an "ouch," bruises, brief pain, or transient tears rather than something intractable and life changing. There are many instances, though, where traumatic brain injury (TBI) has lasting effects. Every day 4,000 individuals, on average, sustain an externally inflicted head injury in the United States. Among this very varied group—the child injured in the playground, passenger flung off motorcycle, driver of car hurled into windshield, someone slipping on ice or in the bath tub or falling downstairs, another surviving a ski accident, mugging, or gunshot wound, and many, many more—the injury may come to define their life: how it was before, and how it is afterward. More than five million people in the United States live with a disability as a result of brain injury. This report evaluates what is being done to improve services to this population and their families through a dedicated federal program of grants to states for traumatic brain injury.

Coping with the effects of brain injury presents unique opportunities and problems for public and private initiative, as this report shows. TBI also presents a stark example of more general challenges to medicine and health care in the twenty-first century; notably, how to optimize rehabilitation, encourage care, achieve the best quality of life, and (not least) keep family members functioning in the face of long-term effects of injury or disease. Those effects may be behavioral, cognitive, social and economic, and include personality changes, memory problems, and loss of income, jobs, or ability to learn. Much, if not all, of the responsibility and the costs fall on individuals and their families.

The central organizational and policy questions in the federal-state programs addressed here involve consumer-centered and systems improvement approaches to change. How, for example, can individuals be helped to navigate their way through an otherwise disconnected array of possible services—which for an individual TBI survivor, family, and friends might include finding appropriate and affordable rehabilitation, neuropsychological and psychological testing, job and disability advice, behavioral training, advocacy and legal services, family and community support services, or applying for a Medicaid waiver? How can available federal and state programs relevant to TBI, which are scattered among different government agencies, be used more effectively? How can coordination be improved between public and private organizations?

Congress authorized the federal TBI program under the TBI Act of 1996 (P.L. 104-166). Administration of the program resides in the Health Resources and Services Administration (HRSA), part of the U.S. Department of Health and Human Services. HRSA's Maternal and Child Health Bureau has responsibility for the TBI program (though it applies to all members of the population, not just mothers and children); and the program was reauthorized under the Children's Health Act of 2000 (P.L. 106-310). The Bureau's objective for the program, as stated on its website, is: "Ensure that the estimated 5.3 million individuals and their families who live with the effects of TBI in the United States have access to comprehensive, coordinated systems of care that are person-centered and attend to their changing needs from the moment of injury throughout the rest of their lives." Ringing words. In March 2005, HRSA asked the Institute of Medicine (IOM) to conduct an evaluation of the program. This is the report of the IOM committee set up to undertake the evaluation.

To understand the scope and purposes of the program—and thus this report—it is useful to begin with a caveat or two. The committee was not charged with examining the diagnosis and treatment of individuals with acute brain injury in hospitals, emergency rooms, and other clinical settings, nor with evaluating the current state of clinical and basic neuroscience as these affect TBI, nor with considering prospects for acute treatment of head injury in the future. We were not charged to examine questions of head injury prevention. Such issues fall outside the responsibility of the HRSA TBI program. The committee is aware, for example, that exciting and important advances in diagnosis and treatment may result from current research in neuroscience that might decrease the extent of permanent injury and long-term disability for at least some individuals. Let us hope that better pharmacological and behavioral (or mixed) approaches to the acute phase of traumatic brain injury will become available through encouragement of basic, clinical, and behavioral research—and eventually made readily accessible to patients. But now is now. This report deals with the realities of patients and their families in the light of the knowledge, practices, and experiences of today.

Three other observations about the program should be made here as preface to the report. The first, if perhaps most mundane aspect of the federal TBI program is that it is, in dollar terms, quite small. Its budget was approximately $9 million in fiscal 2005. This includes grants to states, awarded on a competitive basis; a contract for technical assistance to the states, including information about innovative state programs; and grants for protection and advocacy (P&A) services in the states along the lines of other forms of legal advocacy on behalf of disabled individuals. When divvied up, a particular state or P&A may (or may not) receive an amount in federal funds that is sufficient to cover the cost of one full-time employee. Acceptance of such funds signifies a duty—and a willingness—to improve TBI services beyond the capacity of the federal funds alone.

A second characteristic of the TBI program is its focus on the states. The federal government provides seed money for organizational and systems change in, by, and through the states. Indeed there is only one professional director of the program with no other staff at the federal level. Federal requirements for grants to the states include four core components, which we describe in the report. Suffice it to say here that states have to (1) set up a statewide TBI advisory board representing public interests and private organizations (such as the state brain injury association, typically an affiliate of the Brain Injury Association of America, the major organization representing TBI patients and their families); (2) designate a single state agency (their choice of which agency) as the lead agency for TBI activities under the grant; (3) conduct a needs and resources assessment for the state (approaches may vary); and (4) write a state action plan (again in a format chosen by the state). Apart from these core components, states are relatively free to develop programs as they think fit, in the light of the specific historical, economic, and political contexts of each state, and the presence or absence of strong program leadership. While not specifically stated this way, the Federal TBI Program challenged each state to be entrepreneurial, each in its own way. A member of our committee put the goal succinctly: "To make something out of nothing."

A third observation, common to traumatic brain injury in general but of great interest to the committee in making its evaluation, is the degree to which there are few standardized measures of TBI status, recovery trajectories, actual use of services (and which services) by individuals, or long-term outcomes. Basic statistics are incomplete on how many individuals there are across the states who suffer at any given time from the effects of a brain injury. Assessing patient or client data was not part of the committee's charge, which was to evaluate and recommend improvement in the federal TBI program. We do point out, though, that there is a need, outside of this study, for federal, state, and private research agencies to encourage scientific research studies, establish scientific consensus on standards, and provide better data systems for TBI than now exist.

Assessing the impact of the program on how states are working or failing to work in support of individuals with TBI was, however, part of our charge. In an ideal world we might present statistical data showing utilization and service trends in the states, based on scientifically grounded patient or client data, both before and after the implementation of the federal TBI program. Even if such data were generally available, though, they might be difficult to interpret as part of our evaluation. In order to address HRSA's goals for the TBI program we would need to know which services these were, who received them (and who not), whether they did any good or were appropriate to need, who paid for them and whether they were cost effective, and whether services as a whole were coordinated so as to provide the best possible care to the individual.

HRSA's goals are not about volume but organization. They include improving state and local capability; using existing research-based knowledge, state-of-the-art systems development approaches, and drawing on promising program innovations; and generating support from local and private sources, as well as legislative, regulatory, and policy changes in the states, so as to achieve sustainable support for services for individuals with TBI and their families, and the incorporation of such services into state service delivery systems.

These are organizational and systems goals. To address our evaluation of the Federal TBI Program—modest in expenditures, large in purpose and practical in its goals—the IOM committee thus focused on organized responses to the program by the states. What have the states actually done? How and how well does the program work as implemented in different states? How far and in what ways has the program succeeded so far, or failed? Our conclusions are based on multiple sources, including a special study of experiences in seven states.

I would like to extend my thanks to members of the committee. The committee has worked hard and diligently on a concentrated basis through face-to-face meetings and conference calls. The committee gives hearty thanks to Jill Eden, director of the study, and her staff at the Institute of Medicine, and to Holly Korda, the project's consultant.

This study is of a small federal program that has huge implications for individuals with traumatic brain injury and their families. It is in some ways a study of hope: that the disparate collection of resources in the public and private sector (including for TBI the significant enterprise of volunteers) can be harnessed for the good of neighbors, families, friends, or ourselves if any of us suffers a traumatic brain injury, maybe by just crossing the wrong street. There is remarkable commitment to this hope across the states. In contrast, systems change is difficult and slow, hobbled by the dead weight of inertia or the clash of bureaucratic cultures. TBI agendas can easily be ignored without the efforts of energetic, effective leaders in the public and/or private sector. Nevertheless, making systems work, town by town and state by state, is a necessary, commonsense key to service innovation and improvement. In the case of TBI this requires government agencies to work together and as partners with private individuals, organizations, and communities.

Rosemary A. Stevens
Chair

Executive Summary

A traumatic brain injury (TBI)—a brain injury caused by a sudden jolt, blow, or penetrating head trauma that disrupts the function of the brain—can happen to anyone. A high school quarterback collides with a running back and lies unconscious on the playing field. A young mother suffers a fractured skull and concussion when her minivan is blindsided by a drunk driver. A bicyclist loses control of his bicycle when it hits a rut in the pavement, flips over the handlebars, and lands head first in the street, losing consciousness. A 5-year-old child loses consciousness after darting into traffic and being struck by a car. A soldier survives a roadside blast in Iraq, but the explosion causes his brain to move violently inside the skull.

The effects of a TBI vary from person to person, depending on the force dynamics of injury and the patient's anatomy and physiology. When a TBI occurs, the brain may be injured in a specific location or the injury may be diffuse and located in many different parts of the brain. The potential effects include a broad range of physical, cognitive, and behavioral impairments that may be temporary or permanent. People with TBI-related disabilities and their family members and caregivers need comprehensive, coordinated, person-centered systems of care that attend to their changing needs long after their acute injury has been treated medically. At least 5.3 million Americans are estimated to have a TBI-related disability.

The Health Resources and Services Administration's (HRSA) TBI Program, initially authorized by the Traumatic Brain Injury Act of 1996 (P.L. 104-106) and reauthorized by the Children's Health Act of 2000

(P.L. 106-310), is a modest federal program with broad ambitions: a $9 million grants program aimed at motivating states to create systems improvement on behalf of persons with TBI with disabilities and their families. As explained further below, the HRSA TBI Program encompasses two grant programs: (1) the TBI State Grants Program; and (2) the Protection and Advocacy for TBI (PATBI) Grants Program. The program was designed with the underlying premise that distributing small grants to states that meet certain requirements will be sufficient to initiate the creation of sustainable infrastructure and increased capacity for comprehensive, coordinated, and integrated services systems to meet the post-acute needs of persons with TBI and their families.

In 2004, the federal Office of Management and Budget (OMB) questioned the effectiveness of the HRSA TBI Program, noting that there had been no regular independent evaluations of the program's effects on TBI patients and their families. To address these concerns, HRSA contracted with the Institute of Medicine (IOM) in the spring of 2005 to conduct a study: (1) to assess the impact of the HRSA Program on how state systems are working or failing to work in support of individuals with TBI; and (2) to advise HRSA on how it could improve the program to best serve individuals with TBI and their families. The IOM appointed an 11-member Committee on Traumatic Brain Injury to perform the study.

This report presents the IOM Committee on Traumatic Brain Injury's assessment of the HRSA TBI Program's impact and recommendations for improving the program. The committee's key findings and recommendations are summarized in Box ES-1 through Box ES-4.

APPROACH TO THE STUDY

This study is not intended as a technical evaluation of the HRSA TBI Program's impact on either the delivery of TBI-related services or on person-level outcomes—such an analysis is not feasible given currently available data. Rather, the study's focus is on whether the TBI Program has led to an expansion in state systems infrastructure as a precondition for better serving persons with TBI and their families.

The committee used a qualitative method to assess the program's impact. Qualitative methods are often used to investigate developing institutions and systems as well as to assess the impact of government programs. Data were gathered from a variety of sources and were analyzed for key themes and recurring issues. Primary sources of data included semi-structured interviews with TBI stakeholders in seven states and representatives of selected national organizations, research literature and TBI program materials, and relevant survey data.

Clearly, HRSA should develop a more complete evaluation strategy to

BOX ES-1
The Quality and Coordination of Post-Acute TBI Service Systems

Many people with TBI experience persistent, lifelong disabilities. For these individuals, and their caregivers, finding needed services is, far too often, an overwhelming logistical, financial, and psychological challenge. **The committee finds that the quality and coordination of post-acute TBI service systems remains inadequate, although progress has been made in some states.**

- Persons with TBI, their family members, and caregivers report substantial problems in getting basic services, including housing, vocational services, neurobehavioral services, transportation, and respite for caregivers. Yet efforts to address these issues are stymied by inadequate data systems, insufficient resources, and lack of coordination.
- TBI services are rarely coordinated across programs except in some service sites. Furthermore, in most states, there is no single entry point into TBI systems of care. Access to service systems and financial support is typically driven by non-clinical variables, such as family income, health coverage, geography, and other socioeconomic factors that may change over time.
- Little is known about how persons with persistent TBI-related impairments fare in today's fragmented and disparate service systems. Persons without health insurance, racial and ethnic minorities, non-English speakers, rural residents, children, and individuals in prolonged coma are especially underserved. Persons with TBI-related neurobehavioral problems, but no obvious physical impairments, face unique obstacles to getting needed services.
- While health care data collection is outside the committee's charge and HRSA's purview, the committee notes that the establishment of relevant data systems is integral to "impact evaluation" as strictly interpreted and prescribed by OMB.

assess whether individuals with TBI have benefited from the HRSA Program. Many federal agencies require significant improvements in their evaluation information and capacity, according to OMB and the U.S. General Accountability Office (GAO). The committee suggests that HRSA follow GAO's approach to building evaluation capacity in government agencies. GAO recommends four essential elements for a government-based evaluation infrastructure: (1) a culture of evaluation made evident through routine evaluations of how well programs are working to achieve agency goals; (2) quality data that are credible, reliable, and consistent; (3) analytic expertise in both technical methods and the relevant program field; and (4) collaborative partnerships with program partners or sister agencies to leverage resources and expertise.

BOX ES-2
The Impact of HRSA's TBI State Grants Program

FINDING:

The committee finds that the HRSA's TBI State Grants Program has produced demonstrable, beneficial change in organizational infrastructure and increased the visibility of TBI—essential conditions for improving TBI service systems. There is considerable value in providing small-scale federal funding to motivate state action on behalf of individuals with TBI. Whether state programs can be sustained without HRSA grants remains an open question.

- In some states, TBI State Program Grants have led to substantial growth in basic state-level infrastructure for addressing TBI. The necessary TBI infrastructure is beginning to take root in most states. The next stage will be critical. Substantial work is needed to ensure that the infrastructure is effective and TBI service systems improved, expanded, and sustained.
- Although HRSA's four mandatory components of a state's TBI infrastructure—a statewide TBI advisory board, a lead state agency for TBI, a statewide assessment of TBI needs and resources, and a statewide TBI action plan—are essential, they are not enough to effect lasting improvement in services for individuals with TBI and their families. Sustainable progress requires reliable, long-term data collection and monitoring; interagency collaboration on both federal and state levels; and effective funding mechanisms (e.g., state trust funds, special revenues, expansions in health coverage)
- HRSA's 1-year TBI State Program Grants required states to engage in projects with unrealistically short time periods. The committee supports the new program grants that extend funding for up to 3 years to improve program continuity. A minimum 3-year grant period would facilitate recruitment and retention of personnel, program continuity, and reduce the expense and time that states invest in obtaining grant support.

OVERVIEW OF THE HRSA TBI PROGRAM

The organizational home of the program is HRSA's Maternal and Child Health Bureau (currently in the Division of Services for Children with Special Health Care Needs). Since FY 2003, the annual federal appropriation for the HRSA TBI Program has been in the range of \$9.3 to \$9.5 million. The program is dwarfed within its parent agency HRSA, which had a \$7.37 billion budget in FY 2005 and operates five different bureaus and 11 special offices.

- HRSA is the sole federal agency charged with improving state TBI service systems. HRSA cannot succeed, however, without its sister federal programs—particularly the National Center for Injury Prevention and Control, Centers for Disease Control and Prevention (CDC); the TBI Model Systems Program and the Interagency Subcommittee on Disability Statistics, the National Institute on Disability and Rehabilitation Research (NIDRR); the National Center for Medical Rehabilitation Research (NCMRR), the National Institutes of Health; and the Defense and Veterans Brain Injury Center (DVBIC), a combined effort of the Departments of Defense and Veterans Affairs.

RECOMMENDATION:

The committee recommends that HRSA continue to support and nurture the program.

- HRSA should continue to mandate the four infrastructure components. It should also encourage states to regularly revisit their TBI action plans, updating them as appropriate.
- TBI Program Grants should be awarded for a minimum 3-year time period.
- HRSA should require states to assess and report on progress in achieving specific goals set in their statewide TBI action plan. This would be made easier if HRSA developed a simple and straightforward format for the action plans, and advised states on establishing strategic goals and setting realistic timeframes. Other federal programs, in HRSA or elsewhere, might offer useful models.
- HRSA should take the lead in establishing a TBI interagency group to ensure active collaboration among the relevant agencies noted above. An alternative lead federal TBI agency could also be considered. The Substance Abuse and Mental Health Services Administration (SAMHSA) should be invited to participate. SAMHSA has had little involvement in TBI to date; yet it is a federal agency with extensive resources in substance abuse and mental illness—two conditions that often co-occur with TBI.

Grants Provided Under the HRSA TBI Program

As noted earlier, the HRSA TBI Program encompasses two grant programs: (1) the TBI State Grants Program; and (2) the Protection and Advocacy for TBI (PATBI) Grants Program.

TBI State Grants Program. HRSA's mandate under the Traumatic Brain Injury Act of 1996 was to implement a program of federal grants to states, U.S. territories, and the District of Columbia to help them improve their

BOX ES-3
The Impact of HRSA's Protection and Advocacy for TBI (PATBI) Grants Program

FINDING:

The committee finds that it is too soon to know whether HRSA's 3-year-old PATBI Grants Program has meaningfully improved circumstances for people with TBI-related disabilities.

Nevertheless, PATBI Grants have led to new and much-needed attention to the protection and advocacy (P&A) concerns of people with TBI-related disabilities and their families.

- There is widespread sentiment among TBI stakeholders in the states that PATBI Grants have led state-based P&A systems to focus on TBI for the first time.
- Many stakeholders believe that PATBI Grants are too small to catalyze measurable improvements for persons with TBI.
- Currently available data are insufficient to assess the impact of HRSA's PATBI Grants Program. Furthermore, the extent to which persons with TBI are aware of P&A services in their communities is not known.

RECOMMENDATION:

The committee recommends that HRSA continue to fund the PATBI Grants Program.

- HRSA should contract with an evaluation expert (or obtain in-house expertise) to develop a rigorous but practical design for evaluating the PATBI Program, including recommendations for how data should be collect and analyzed. The data must be credible, reliable, and consistent to ensure that evaluation findings are valid.
- HRSA should implement the PATBI evaluation plan as soon as is feasible.
- HRSA should encourage P&A systems in the states to increase public awareness of their services, particularly persons with TBI and their caregivers, health care providers, and others offering TBI-related services.

TBI infrastructure and service systems for meeting the post-acute needs of individuals with TBI and their families. Since FY 1997, HRSA has competitively awarded three types of TBI State Program Grants to states, territories, and the District of Columbia: Planning Grants, Implementation Grants, and Post-Demonstration Grants.

In FY 1997 and FY 1998, the first 2 years of the TBI State Grants Program, grants were available as 1-year demonstration project awards. Depending on its existing TBI infrastructure, a state could apply for either a Planning Grant to help build the necessary infrastructure for a coordi-

BOX ES-4
Adequacy of the Management and Oversight of the HRSA TBI Program

FINDING:

The committee finds that the management of the TBI Program is inadequate to assure public accountability at the federal level and to provide strong leadership to help states continue their progress toward improving systems for persons with TBI and their families.

- From its beginning in 1997, only one full-time individual—the program director—has staffed the TBI Program. The HRSA program director position has turned over four times.
- The program between 1997 and 2005 was a grant program designed to stimulate public-private entrepreneurship in the states as a relatively open-ended process, with little feedback built in. The program demands more formal accountability, particularly at its present level of maturity.
- HRSA should be commended for funding the TBI Technical Assistance Center (TBI TAC), which has become an essential resource for both federal and state agencies. TBI TAC is widely praised for facilitating the work of and providing technical assistance to state agencies, Brain Injury Associations, protection and advocacy organizations, and other stakeholders.
- HRSA has shown only token attention to evaluating its TBI Program. Program rules require that state grantees conduct evaluations, but the rules have not been enforced and states are ill equipped to conduct technical evaluations.

RECOMMENDATION:

The committee recommends that HRSA lead by example—that it instill rigor in the management of the HRSA TBI Program and build an appropriate infrastructure to ensure program evaluation and accountability.

Thus, the committee recommends that HRSA do the following:

- Ensure that the TBI Program develops an "evaluation culture," including a strategy for collecting and maintaining program data that are credible, reliable, and consistent; analytic expertise in evaluation methods and TBI (either in-house or via contract); and collaborative partnerships with program partners or sister agencies to leverage resources and expertise.
- Appoint a national HRSA TBI Program Advisory Board as soon as possible. The board's initial tasks should include articulating a vision for the program; developing an action plan for HRSA that includes a blueprint for ongoing data collection and program evaluation; and ensuring adequate program resources.
- Advocate for and support TBI grantees by pressing relevant federal agencies to furnish needed data and to address TBI in eligibility rules for other federal programs; keep track of emerging issues in state TBI programs; serve as a national information resource on the special needs of individuals with TBI; and disseminate information on best practices.
- Oversee the TBI TAC contract, including reassessing which HRSA TBI Program activities are optimally performed by TBI TAC.

nated TBI service system or an Implementation Grant to execute various program implementation activities.

Planning Grants of $75,000 per year for states to establish the four core capacity components of a TBI infrastructure were available for up to 2 years. A state was eligible for a Planning Grant if it had an established plan for developing the four core capacity components of a TBI infrastructure (Box ES-5).

Implementation Grants of up to $200,000 per year were available for up to 3 years. States were eligible to apply for such grants if they had evidence that the four core capacity components of a TBI infrastructure were already in place. These grants were designed to encourage states to execute various program implementation activities, including carrying out the state's TBI action plan, programs to address identified needs, and initiatives to improve access.

Post-Demonstration Grants were established by HRSA following the reauthorization of the HRSA TBI Program in the Children's Health Act of

BOX ES-5
Four Core Capacity Components of a State TBI Infrastructure

While the terms and available funding for TBI State Program Grants have evolved, the four core components of a state TBI infrastructure required by HRSA have not changed:

1. **Statewide TBI advisory board.** The state must agree to establish an advisory board (or council) charged with advising and making recommendations on ways to improve coordination of TBI services. The advisory board must hold public hearings and other community outreach efforts to encourage citizen participation in the TBI program. Members of the advisory board must include representatives specified by HRSA.
2. **Lead state agency for TBI.** The state must designate a state agency and a staff position responsible for coordination of state TBI activities.
3. **Statewide TBI needs/resources assessment.** The state must have a statewide TBI needs and resources assessment, with an emphasis on resources, completed or updated within the last 5 years. It should cover the full spectrum of care and services from initial acute treatment through community reintegration for individuals of all ages having TBI.
4. **Statewide TBI action plan.** The state must develop a TBI action plan to provide a culturally competent, comprehensive community-based system of care that encompasses physical, psychological, educational, vocational, and social aspects of TBI services and addresses the needs of individuals with TBI as well as family members.

SOURCE: HRSA Program Guidance, 1997–2005.

2000. These are 1-year grants of up to $100,000 intended to advance states' efforts to build state-level TBI service capacity. A state must have satisfactorily completed an Implementation Grant to be eligible for a Post-Demonstration Grant.

Protection and Advocacy for TBI (PATBI) Grants Program. In the Children's Health Act of 2000, Congress reauthorized the HRSA TBI Program and broadened HRSA's mandate under the program. The 2000 act directed HRSA to implement a program of federal grants to protection and advocacy (P&A) systems in states, U.S. territories, and the District of Columbia to provide information, referrals, and advice; individual and family advocacy; legal representation; and specific assistance in self-advocacy for individuals with TBI and their families.

In FY 2002, the first year of the PATBI Grant Program, HRSA competitively awarded $1.5 million in grants to federally mandated P&A systems for people with disabilities. P&A systems in states and the District of Columbia were eligible for $50,000 PATBI Grants; those in U.S. territories and the American Indian Consortium were eligible for $20,000 grants.

In FY 2003, Congress doubled federal appropriations for the PATBI Grants Program to $3 million, and the grants became formula-based. Currently, therefore, all states, territories, and the District of Columbia receive PATBI Grants, with annual allotments ranging from $50,000 to $117,000 (California).

Administration of the HRSA TBI Program

The HRSA TBI Program has just one full-time staff position (program director), and four different people have held the position since 1997. Many of the administrative duties of the HRSA TBI Program are the responsibility of the TBI Technical Assistance Center (TBI TAC).

TBI TAC is in essence HRSA's *de facto* TBI program staff. Its activities include general technical assistance to program grantees and applicants; an e-mail listserv that allows grantees and other participants to post inquiries, disseminate funding announcements, share best practices, and other program materials; a voluntary benchmark initiative; an online database, the "TBI Collaboration Space," for grantees and others affiliated with the TBI Program; as well as national meetings and webcasts.

Since 2002, TBI TAC has been operated under a contract between HRSA and the National Association of State Head Injury Administrators (NASHIA).[1] NASHIA is the national membership association for state TBI

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[1] The Children's National Medical Center (Washington, D.C.) held the TBI TAC contract from 1997 to 2002.

program officials and other individuals concerned with state and federal brain injury policy.

EPIDEMIOLOGY AND CONSEQUENCES OF TRAUMATIC BRAIN INJURY—AN INVISIBLE DISABILITY

Data on the epidemiology of TBI have limitations because they draw primarily from hospital and emergency department records and do not include individuals who sustain TBIs and are seen in doctor's offices or not treated for their injuries. It is known, however, that TBI is a leading cause of death and disability in the United States.

The Centers for Disease Control and Prevention (CDC) estimates that at least 1.4 million TBIs occur in the United States annually, and 80,000 to 90,000 individuals per year sustain a TBI with long-term, often lifelong implications. At a minimum, CDC estimates, 5.3 million Americans have a TBI-related disability.

Individuals who sustain a TBI are a heterogeneous group, including the very young, the very elderly, as well as adolescents and young adults. Although many individuals with TBI were robust and healthy prior to their injury, others may have had one or more preexisting conditions that put them at risk.

From 1995–2001 the leading causes of TBI were falls (28 percent), motor vehicle accidents (20 percent), struck by/against (19 percent), and assaults (11 percent); these accounted for three-fourths of TBI-related emergency department visits, hospital stays, and deaths. TBI often goes undetected among high school, college, and professional athletes.

TBI has become a signature wound of the current Iraq war, largely because soldiers are increasingly exposed to improvised explosive devices and protected by improved military armor. Helmets cannot prevent the internal bleeding, bruising, and tearing of brain tissue that result from exposure to blasts.

The majority of people who sustain a TBI are mobile and able to care for themselves after a TBI, but physical health problems are common. Such problems include balance and motor coordination, fatigue, headache, sleep disturbance, seizures, sensory impairments, slurred speech, spasticity and tremors, problems in urinary control, dizziness and vestibular dysfunction, and weakness.

Typically, TBI-related cognitive problems and behavioral impairments have more impact on a person's recovery and outcome than physical limitations. Cognitively impaired persons with TBI may experience problems in concentrating, remembering, organizing their thoughts, making good decisions, solving everyday problems, and planning and foresight. They may be easily confused or forgetful. Their language skills, both written and spoken, may also be impaired. Some individuals with TBI may find it hard to learn new information or interpret the subtle cues and actions of others. As a result, they may act or speak inappropriately.

Furthermore, a substantial literature documents that TBI increases the risk of major depression, general anxiety disorder, obsessive-compulsive disorder, panic disorder, post-traumatic stress disorder, anti-social behavior such as criminality and substance abuse, and suicide. Individuals with TBI with preexisting behavioral and psychiatric problems may find that the brain injury exacerbates their condition and makes the management of day-to-day function all the more complex and difficult.

It is difficult to capture the impact of TBI on an individual's every day existence. Data collection and analysis are daunting challenges given the fragmented nature of TBI services and the inflexibility of their disparate data systems, lack of standardized definitions, and multiple public and private service systems.

Nevertheless, substantial proportions of individuals with TBI report persistent limitations in activities of daily living, ability to return to work, social skills, relationships, and community participation.

Family caregivers of individuals with TBI-related disabilities may have to radically change their lives to meet their loved ones' long-term needs and financial burdens. Most families are not equipped to care for someone with the cognitive deficits and behavioral and emotional changes that are characteristic of severe TBI and often suffer substantial stress. As a result, the emotional and physical health status of family caregivers can be as compromised as that of the person with the TBI. In addition, there is evidence that TBI places a substantial burden on an array of social institutions and systems such as psychiatric facilities, courts and correctional facilities, schools, and disability and welfare programs.

SERVICE NEEDS AND SOURCES OF FUNDING AND OTHER SUPPORTS FOR PEOPLE WITH TBI-RELATED DISABILITIES

For TBI survivors with disabilities, insurance coverage of acute and post-acute services may be limited both by the type of services and by the intensity and duration of services. Coverage of behavioral health services and cognitive and physical rehabilitation is often restricted or not available at all. Focused surveys and qualitative research show that some TBI survivors have persistent unmet needs long after the acute crisis of their injury.

Finding needed services is typically a logistical, financial, and psychological challenge for family members and other caregivers, because few coordinated systems of care exist for individuals with TBI. People with TBI-related disabilities often require access to diverse services including case management, health care services, cognitive and physical rehabilitative therapies, behavioral health care services, family and caregiver supports, vocational rehabilitation, housing, and transportation services. Eligibility criteria for services and supports are often confusing and exclusionary—access to funding and supports is often driven by nonclinical variables, such as family income, health coverage, geography, and other socioeconomic factors that may change over time. Many families may not even know what is available.

Given the array of services that may be necessary for a given individual with TBI-related disabilities, the absence of coordinated systems of care for individuals with TBI-related disabilities is a major problem for many persons with TBI and their families. It is easy for them to get lost, depressed, or desperate. Guidance of persons with TBI and their families through multiple potential sources of care through public and private agencies and system coordination is a *prima facie* essential condition for adequate service.

The principal sources of funding and support for TBI services are Social Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, and Medicare. Eligibility for SSI and SSDI is often the critical path to Medicaid- or Medicare-sponsored health coverage. For low-income persons, eligibility for a Medicaid long-term home and community-based waiver may be the only means to essential services such as personal care, homemaker services, and transportation. Several programs administered by the Office of Special Education and Rehabilitation Services in the U.S. Department of Education also provide critical supports: Independent Living Services, Vocational Rehabilitation, and Protection and Advocacy for Assistive Technology. Although there is only limited information documenting how well these programs cover the post-acute needs of persons with TBI, it is well established that there is a substantial discrepancy between needs and adequacy of funding for essential services.

ASSESSING THE HRSA TBI PROGRAM

Since the implementation of the HRSA TBI Program in 1997, there has been demonstrable improvement in two essential preconditions for improving TBI service systems—state-level TBI systems infrastructure and the overall visibility of TBI have grown considerably.

Almost all states have demonstrated interest in expanding their capacity to serve individuals with TBI (Table ES-1). All but two states (Louisiana and South Dakota) have applied for and received at least one TBI State Program Grant from HRSA (Figure ES-1). Many states have successfully completed Planning and Implementation Grants. As of 2005, 37 states had received Planning Grants; 40, Implementation Grants; and 23, Post-

TABLE ES-1 Number of States Participating in HRSA's TBI State Grants Program, by Type of Grant, 2005*

Type of TBI State Program Grant Received from HRSA	Number of States
Never funded	2
Ever funded	
Planning Grant	37
Implementation Grant	40
Post-Demonstration Grant	23
Any Type of Grant	49
Currently funded	
Planning Grant	2
Implementation Grant	10
Post-Demonstration Grant	0
Any Type of Grant	12

*Includes 50 states plus the District of Columbia.

SOURCE: NASHIA/TBI TAC, 2005.

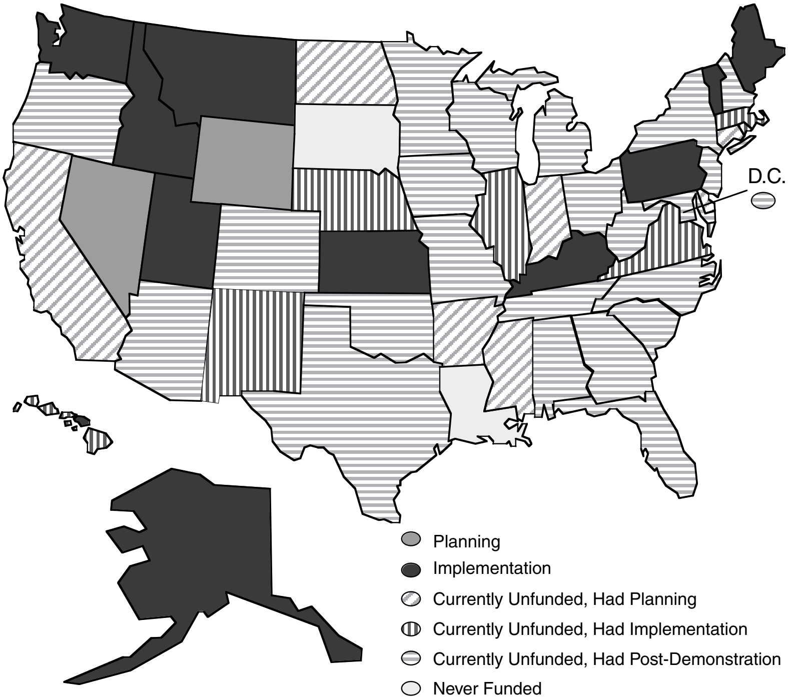

FIGURE ES-1 Traumatic brain injury program grants by state, 2005.
SOURCE: TBI TAC, 2005.

Demonstration Grants.[2] Twelve states were in the midst of a Planning or Implementation Grant.

The committee is impressed with what has been done and rates the HRSA TBI Program overall a success. There is considerable value in providing small-scale federal funding to catalyze state action. Nevertheless, substantial work remains to be done at both national and state levels.

So far, the HRSA experience shows that no two state TBI programs have evolved in the same way. Not surprisingly, states with established leadership, interagency cooperation, and/or CDC-sponsored TBI data collection have been better positioned to use the TBI grants from HRSA more quickly and effectively than other states. Yet serendipity also plays a part; there is no substitute for having an influential policy maker who champions the TBI cause.

The committee believes that the management and oversight of the HRSA TBI Program have been inadequate. To date, perhaps because of insufficient resources, HRSA has not built the infrastructure necessary for a systematic review of the TBI Program's strengths and weaknesses or the state grantee evaluations and final reports that HRSA requires. HRSA has shown only token attention to evaluation of the state grantees or the TBI Program itself. The states are ill equipped to conduct technical evaluations and require constructive guidance in this area.

Thus far, the HRSA TBI State Grants Program has been handled as a grant program designed to establish four core organizational and strategic components in each state but to allow considerable state variation. This approach was realistic in two ways: (1) by recognizing the different bases on which improvement might take place in different states (some already organized for TBI, others not); and (2) by encouraging entrepreneurship and innovation. TBI TAC has provided valuable assistance as an information base and a spur for diffusion of innovation across the states.

The committee concludes that it is too soon to know whether the 3-year-old PATBI Grants Program has meaningfully improved circumstances for persons with TBI. State P&A systems have begun to focus on TBI, significantly for the first time. HRSA should collect data on P&A TBI-related activities in order to evaluate the impact of the PATBI Grants. HRSA should also ensure that persons with TBI and their families are aware of P&A services in their communities.

The committee urges HRSA to exercise strong leadership on behalf of the state grantees. Indeed, the program should embody many of the characteristics it demands of the grantees. It should serve as a national information resource on the special needs of individuals with TBI, keep track of

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[2] Note that tallies of state participation include the District of Columbia.

emerging issues in state TBI programs, and disseminate information on best practices. It should also advocate for the TBI grantees, by, for example, pressing sister federal agencies to furnish needed data and to address TBI in eligibility rules for other federal programs.

Further progress in TBI systems and services will be elusive if HRSA does not address the program's fundamental need for greater leadership, data systems, additional resources, and improved coordination among federal agencies. It is worrisome that the modestly budgeted HRSA TBI Program continues to be vulnerable to budget cuts. The states are now at a critical stage and will need continued federal support if they are to build an effective, durable service system for meeting the needs of individuals with TBI and their families. The HRSA TBI Program should be a priority for HRSA.

1

Overview of the HRSA Traumatic Brain Injury Program

A traumatic brain injury (TBI) is a brain injury caused by a sudden jolt, blow, or penetrating head trauma that disrupts the function of the brain. A 5-year-old child darts into traffic and is struck by a car. A high school quarterback collides with a running back and lies unconscious on the playing field. A young mother suffers a fractured skull and concussion when her minivan is blindsided by a drunk driver. On a summer evening, a man loses control of his bicycle when it hits a rut in the pavement; he flips over the handlebars and lands head first in the street. A soldier survives a roadside blast in Iraq, but the explosion causes his brain to move violently inside the skull.

The effects of a TBI vary from person to person, depending on the force dynamics of injury and the patient's anatomy and physiology. When a TBI occurs, the brain may be injured in a specific location or the injury may be diffuse and located in many different parts of the brain. The effects may be temporary or permanent and include a broad range of physical, cognitive, and behavioral impairments that result from externally inflicted trauma to the brain (NIH, 1998). TBI survivors with persistent impairments may require ongoing services, such as case management, cognitive and physical rehabilitation, medical and behavioral health care, financial assistance, vocational training, housing, transportation, and other services, long after their acute injuries are treated medically. The parents, spouses, other caregivers, and especially young children in the injured person's family may also experience intense, long-term social, psychological, and physical health effects and need services as well.

This report presents the analysis, findings, and recommendations of the Institute of Medicine's (IOM) Committee on Traumatic Brain Injury with regard to the Federal TBI Program administered by the Health Resources and Services Administration (HRSA). The HRSA TBI Program is a congressionally mandated program intended to facilitate the development of state-level infrastructure and service delivery systems for individuals with TBI and their families, particularly with respect to family or consumer support, return to work, housing or supportive living personal assistance services, assistive technology and devices, behavioral health services, substance abuse services, and traumatic brain injury treatment and rehabilitation (Title 42 *U.S. Code*, Ch. 6A, 2003). The effectiveness of the HRSA TBI Program was recently called into question in a federal Office of Management and Budget (OMB) Program Assessment Rating Tool (PART) review report (OMB, 2005). In its critique, OMB found fault with the TBI Program, citing that it had neither long-term health outcomes measures nor regular independent evaluations of the program's effects on TBI patients and their families.

To address these criticisms, HRSA contracted with the IOM in the spring of 2005 to conduct a study: (1) to assess the impact of the HRSA Program on how state systems are working or failing to work in support of individuals with a TBI; and (2) to advise HRSA on how it could improve the program to best serve individuals with TBI and their families (Box 1-1). The IOM appointed an 11-member Committee on Traumatic Brain Injury to assess the impact of the HRSA TBI Program and make recommendations to HRSA. Committee members were selected for their expertise in neurology, neuropsychology, cognitive and physical rehabilitation, clinical medicine and nursing, epidemiology, program evaluation, behavioral health, social work, and personal TBI experience.

APPROACH TO THE STUDY

The underlying premise of the HRSA TBI Program is that grants to states that meet certain requirements will facilitate the creation of infrastructure and increased capacity for serving individuals with TBI. This study is not intended as a technical evaluation of the HRSA TBI Program's impact on either the delivery of TBI-related services or on person-level outcomes—such an analysis is not feasible given currently available data. Rather, the study's focus is on whether the TBI Program has led to an expansion in state systems infrastructure as a precondition for better serving persons with TBI and their families.

The committee used a qualitative study method to assess the program's impact. Qualitative methods are often used to investigate developing institutions and systems as well as to assess the impact of government programs (Caudle, 1994; Sofaer, 1999; Newcomer and Scheirer, 2001; World Bank

BOX 1-1
Charge to the Committee on Traumatic Brain Injury

The objective of this study is to evaluate and recommend improvements to the Health Resources and Services Administration (HRSA) Federal Traumatic Brain Injury (TBI) Program. TBIs are brain injuries that result from sudden jolts, blows, or penetrating trauma to the brain.

The TBI Program was created by the Traumatic Brain Injury Act of 1996 (P.L. 104-166) and later reauthorized as Title XIII of the Children's Health Act of 2000 (P.L. 106-310). The legislation provides for state-based grant programs charged with improving service delivery, establishing policy, and securing the financial support to bring about lasting systems change in the care of persons with TBI. The focus is on a particular subset of the TBI population—those individuals with TBI (and their families) who require the services of complex public and private service systems.

Since 2002, the HRSA Program has also included formula-based Protection and Advocacy (P&A) grants to states, territories, and the Native American Protection and Advocacy Project to bolster advocacy support for individuals with TBI and their families.

The charge to the IOM Committee on Traumatic Brain Injury is twofold:

1. To assess the impact of the HRSA Program on how state systems are working or failing to work in support of individuals with a TBI.
2. To advise HRSA on how it could improve the program to best serve individuals with TBI and their families.

Group, 2005). Qualitative data were gathered from a variety of sources and were analyzed for key themes and recurring issues. Primary sources of data included semi-structured interviews with TBI stakeholders in seven sample states and representatives of selected national organizations (a requirement of the IOM/HRSA agreement), research literature and TBI program materials, and relevant survey data. Appendix A, *Method of the Study*, presents a complete description of the study methods.

Clearly, HRSA should develop a more complete evaluation strategy to assess whether individuals with TBI have benefited from the HRSA Program. Many federal agencies require significant improvements in their evaluation information and capacity, according to OMB and the U.S. General Accountability Office (GAO) (GAO, 2003; OMB, 2004). The committee suggests that HRSA follow GAO's approach to building evaluation capacity in government agencies. GAO recommends four essential elements for a government-based evaluation infrastructure: (1) a culture of evaluation made evident through routine evaluations of how well programs are working to achieve agency goals; (2) quality data that are credible, reliable, and consistent; (3) analytic expertise in both technical methods and the relevant program field; and (4) collaborative partnerships with program partners or sister agencies to leverage resources and expertise.

ORGANIZATION OF THE REPORT

This report presents the Committee on Traumatic Brain Injury's assessment of the impact of the HRSA TBI Program. The report is organized as follows:

- This chapter, Chapter 1, *Overview of the HRSA Traumatic Brain Injury Program*, introduces the report and establishes the context for the committee's assessment of the HRSA TBI Program's impact by describing the program's legislative history, program administration, and grants design.
- Chapter 2, *Epidemiology and Consequences of Traumatic Brain Injury—An Invisible Disability*, provides further background by describing the epidemiology and consequences of TBI, focusing on the subset of the TBI population (and their families) who require post-acute TBI services because of persistent impairments.
- Chapter 3, *Service Needs and Sources of Funding and Supports for People with TBI-Related Disabilities*, provides additional background by describing the post-acute service needs and available sources of funding and support for TBI survivors with TBI-related disabilities.
- Chapter 4, *Assessment of the HRSA TBI Program*, presents the committee's findings regarding the impact of the HRSA TBI Program, along with the committee's recommendations.

Additional research and background materials prepared as part of the committee's evaluation are presented in the report's appendixes:

- Appendix A, *Methods of the Study*, describes the committee's approach to the evaluation, including a public workshop, site visits, and stakeholder interviews in seven states.
- Appendix B, *Interview Guide Developed by the IOM Committee on Traumatic Brain Injury*, is a discussion guide that was developed and used for semi-structured interviews with TBI stakeholders in seven states.
- Appendix C, *State TBI Programs and Protection and Advocacy Systems: Characteristics and Accomplishments, by State*, includes three detailed tables summarizing for each state: (1) the characteristics of the state's TBI program, (2) the reported accomplishments of the state TBI program, and (3) the reported goals and accomplishments of protection and advo-

cacy (P&A) systems for people with disabilities with respect to P&A for people with TBI.

- Appendix D, *Profiles of TBI Initiatives in Seven States*, describes the TBI programs in Alabama, California, Colorado, Georgia, New Jersey, Ohio, and Washington. The profiles summarize each state's HRSA TBI Program grant history; resources; services for people with TBI and their families; interorganizational collaboration and coordination; TBI-related data, monitoring, and evaluation; and successes and challenges of the HRSA grant experience.
- Appendix E, *Stakeholders Assess the HRSA TBI Program: A Report on National Interviews and Interviews in Seven States*, is a specially commissioned report on a series of semi-structured interviews with stakeholders in the seven states (referenced above).
- Finally, Appendix F presents the glossary, abbreviations, and acronyms.

The remaining pages of this chapter give an overview of the HRSA TBI Program, including the program's legislative mandate, administration by HRSA, and the two major components of the grant program.

Legislative Mandate for the HRSA TBI Program

The HRSA TBI Program was initially authorized by the Traumatic Brain Injury Act of 1996 (P.L. 104-166, 1996). That act marked the beginning of a multipronged federal endeavor to address the needs of persons with TBI. It authorized three federal agencies within the U.S. Department of Health and Human Services—HRSA, the Centers for Disease Control and Prevention, and the National Institutes of Health—to implement several first-time, federal TBI initiatives and to coordinate their activities as appropriate (Box 1-2).

Congress clearly intended the HRSA TBI Program to be a federal-state partnership.[1] The focus of the HRSA TBI Program is on meeting the needs of a particular subset of the TBI population—namely, individuals with TBI (and their families) with post-acute impairments who require the services of complex public and private service systems. HRSA's role was envisioned as spurring state action to bring about improvements and lasting change in state-level service systems for TBI survivors and their families. Under the HRSA TBI Program, HRSA competitively awards federal grants to states, territories, and the District of Columbia to improve their infrastructure and

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[1] The District of Columbia and U.S. territories are also eligible to participate in the TBI Program.

BOX 1-2
Federal Initiatives Mandated by the Traumatic Brain Injury Act of 1996

The Traumatic Brain Injury Act of 1996 (P.L. 104-166) directed three agencies of the U.S. Department of Health and Human Services—the Health Resources and Services Administration, the Centers for Disease Control and Prevention, and the National Institutes of Health—to implement several first-time programs related to TBI and to coordinate their activities as appropriate.

Health Resources and Services Administration (HRSA). HRSA was mandated to implement a program of grants to states and territories to help them improve their TBI infrastructure and service systems for meeting the post-acute needs of individuals with TBI and their families.

Centers for Disease Control and Prevention (CDC). CDC was directed to address prevention of TBI by (1) tracking its incidence and prevalence; (2) conducting research to identify effective prevention strategies; and (3) implementing public information and education programs to increase public awareness of the consequences of brain injury.

National Institutes of Health (NIH). NIH was given the responsibility for (1) conducting a consensus conference; (2) developing programs that expand participation of academic centers of excellence in TBI treatment and rehabilitation research and training; and (3) conducting basic and applied research on more effective diagnosis and prognosis, therapies that retard, prevent, or reverse brain damage after TBI, and the continuum of care from acute care through rehabilitation.

SOURCE: P.L. 104-166.

services to better meet the post-acute needs of individuals with TBI and their families.

When it reauthorized the HRSA TBI Program in the Children's Health Act of 2000 (P.L. 106-310, 2000), Congress expanded HRSA's mandate. Specifically, it authorized HRSA to provide federal grants to federally mandated P&A systems for the disabled—commonly referred to as P&A systems—in the states, territories, and District of Columbia to help ensure their provision of P&A services for individuals with TBI and their families (Box 1-3).

Apart from the HRSA TBI Program and other TBI-related programs identified in Box 1-2, several federal programs provide cash support, health coverage, or other supports to eligible persons with TBI (discussed in Chapter 3). In addition, the National Institute on Disability and Rehabilitation Research (NIDRR) within the U.S. Department of Education funds the TBI Model Systems of Care program—the locus of federal research on the

BOX 1-3
State-Based Protection and Advocacy (P&A) Systems for Individuals with Disabilities

In 1975, Congress enacted the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 103-230). That act established the federal Protection and Advocacy for Developmental Disabilities Program and laid the groundwork for a comprehensive nationwide network of protection and advocacy (P&A) organizations for people with developmental disabilities.

The Protection and Advocacy for Persons with Developmental Disabilities (PADD) Program, administered by the Administration for Children, Youth, and Families within the U.S. Department of Health and Human Services, is mandated to do the following for people with developmental disabilities:

- Provide information and referral services.
- Exercise legal, administrative, and other remedies to resolve problems for individuals or groups of individuals with developmental disabilities.
- Reach out to members of minority groups that historically have been underserved.
- Investigate and follow up incidents of abuse and neglect.
- Have access to all client records—when granted permission by the client or the client's representative—or when there is probable cause that abuse or neglect is involved.

The 1975 act conditioned a state or territory's receipt of federal funds under the PADD program on the existence of "a system to protect and advocate the rights of individuals with developmental disabilities" and led to the establishment of federally funded, state-administered P&A systems in all 50 states, U.S. territories, and the District of Columbia. P&A systems are required by law to be independent of public and private service providers. Since 1975, Congress has expanded the responsibilities of P&A systems in the states and territories to include P&A for individuals with mental illness and other severe disabilities, including individuals with TBI.

SOURCE: Administration on Developmental Disabilities, 2005.

course of brain injury recovery and outcomes following the delivery of a coordinated system of emergency care, acute neurotrauma management, comprehensive inpatient rehabilitation, and long-term interdisciplinary follow-up services. There are 16 TBI Model Systems of Care sites throughout the country.[2] These sites provide comprehensive systems of brain injury

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[2] The sites are Birmingham (Alabama), San Jose (California), Englewood (Colorado), Boston, Detroit, Rochester (Minnesota), Jackson (Mississippi), Edison (New Jersey), New York City; Charlotte, Columbus, Philadelphia, Pittsburgh, Dallas, Richmond, and Seattle.

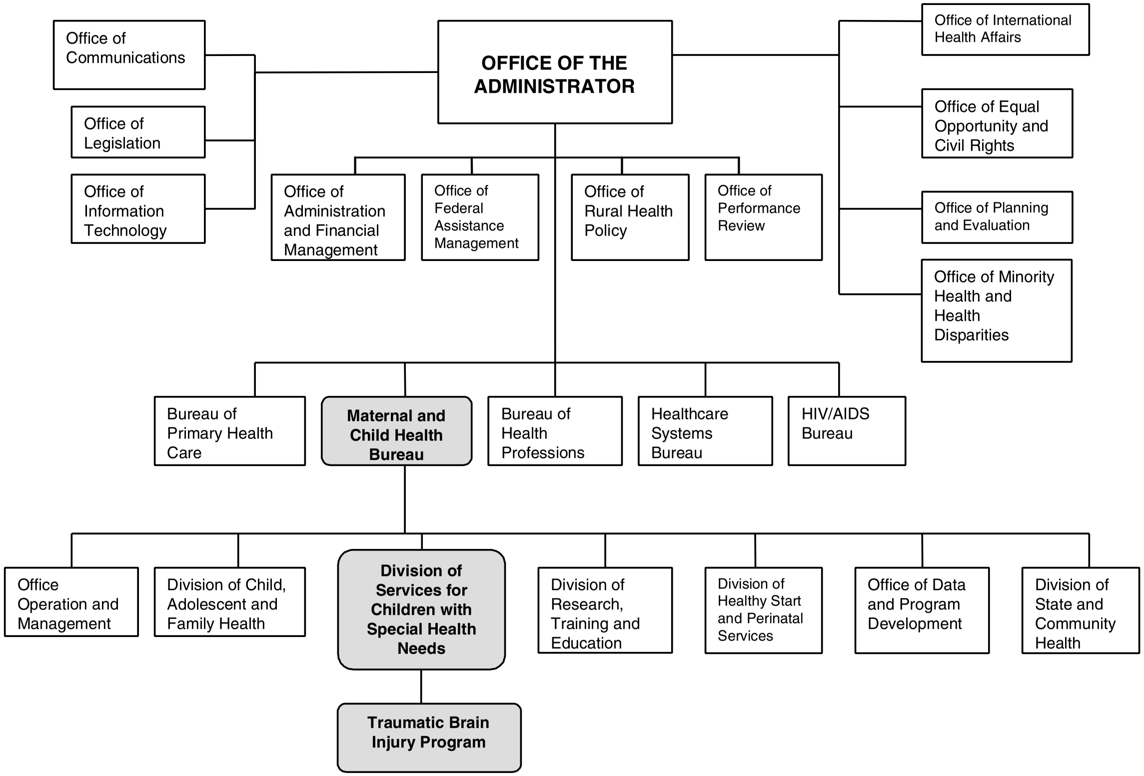

FIGURE 1-1 The HRSA TBI Program's place in the HRSA bureaucracy, 2005.
SOURCE: Adapted from U.S. Department of Health and Human Services, 2005: http://www.hrsa.gov/orgchart.htm and http://www.hrsa.gov/org/mchb.html.

care to individuals, from acute care through community reentry. The NIDRR TBI Model Systems of Care program includes a national, longitudinal dataset that is designed to provide information about best practices and the short- and long-term consequences of TBI.

The HRSA TBI Program's Place in the HRSA Bureaucracy

The HRSA TBI Program is dwarfed within its parent agency (Figure 1-1). HRSA, an agency with a budget of nearly $7.4 billion in FY 2005, has broad national responsibilities for helping improve the health of uninsured, underserved, and special needs populations; preparing for public health emergencies; and strengthening the health care workforce (DHHS, 2005).

HRSA operates five bureaus (the Maternal and Child Health Bureau, Bureau of Primary Health Care, Bureau of Health Professions, Healthcare Systems Bureau, and HIV/AIDS Bureau). It also operates 11 special offices charged with either programmatic duties such as rural health policy and minority health disparities or administrative tasks such as financial management and information technology. The organizational home of the HRSA TBI Program, which is intended to help persons of all ages, is the Maternal and Child Health Bureau of HRSA; originally, in the Division of Child, Family, and Adolescent Health and, more recently, in the Division of Services for Children with Special Health Care Needs.

Budget for the HRSA TBI Program

The history of federal appropriations for the HRSA TBI Program from FY 1997 to FY 2005 is shown in Table 1-1. Federal appropriations for the HRSA TBI Program are essentially "seed monies" that states can leverage to develop more substantial sources of support for TBI services. In FY 1997 and FY 1998, Congress appropriated from $2.9 million to $3.0 million for the HRSA TBI Program. This amount covered spending on personnel and other administrative costs, TBI-related technical assistance, and TBI Program Grants to the 50 states, 5 territories,[3] and the District of Columbia (Martin-Heppel, 2005). By FY 2001, the appropriation for the program had risen to $5.0 million.

In FY 2002, when the HRSA TBI Program was expanded to include separate state grants to state P&A systems, the appropriation was increased

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[3] U.S. territories are Puerto Rico, U.S. Virgin Islands, Guam, American Samoa, and the Northern Mariana Islands. These territories are not included in the IOM committee's evaluation of the Federal TBI Program in Chapter 4.

TABLE 1-1 HRSA TBI Program Appropriations and Spending, FY 1997 to FY 2005 ($ in millions)

	2005	2004	2003	2002	2001	2000	1999	1998	1997
Appropriation[a]	$9.30	$9.50	$9.50	$7.50	$5.00	$5.00	$5.00	$3.00	$2.90
Spending									
TBI Program Grants	2.03	4.78	4.19	4.16	4.80	4.33	3.89	2.75	2.20
PATBI Grants to P&A Systems	3.00	3.00	3.00	1.50	—	—	—	—	—
TBI Technical Assistance Center[b]	3.47	0.77	1.45	0.97	0.15	0.59	0.93	NA	0.58
NDRN	0.05	0.05	0.07	—	—	—	—	—	—
Other	0.42	0.49	0.48	0.71	0.01	0.04	0.14	NA	.05
Total Spending	$8.97	$9.09	$9.19	$7.34	$4.96	$4.96	$4.96	NA	$2.83

NOTE: Dollars are rounded to the nearest thousand. PATBI = Protection and Advocacy for TBI; P&A = protection and advocacy; NDRN = National Disability Rights Network (formerly known as the National Association of Protection and Advocacy); NA = not available.

[a] Total appropriations are not available to the TBI Program; each year HRSA "taps" the appropriation to help cover the agency's overall administrative, evaluation, and other costs.

[b] Funds distributed to the TBI Technical Assistance Center (TBI TAC) in FY 2005 are intended to cover expenses for FY 2005 through early FY 2007.

SOURCE: Martin-Heppel, 2005.

to $7.5 million. Since FY 2003, the federal appropriation for the HRSA TBI Program has been in the range of $9.3 to $9.5 million.

States that receive TBI State Program Grants must provide matching funds of $1 for each $2 of federal grant funds they receive. In the early years of the HRSA TBI Program, FY 1997 to FY 2000, the match was required to be in cash. Since FY 2001, states have been permitted to use in-kind contributions including plant, equipment, or services.

In January 2005 and January 2006, the Administration has recommended zeroing out the TBI Program budget in the subsequent fiscal years (DHHS, 2005; DHHS, 2006). As of 2005, Congress was planning to continue funding at or near current levels, around $9 million (NASHIA, 2005).

Staffing for the HRSA TBI Program

The HRSA TBI Program has been operating with minimal staff—one full-time program director. The program director's position has turned over four times since 1997. The current program director, a commissioned officer of the Public Health Service, has been running the HRSA TBI Program since October 2004.

A TBI Technical Assistance Center (TBI TAC), operated under contract to HRSA by the National Association of State Head Injury Administrators (NASHIA),[4,5] supplements the skeletal staff for the HRSA TBI Program. TBI TAC is responsible for encouraging information and resource exchange, supporting the development of promising practices, and providing individualized assistance to state TBI programs and state-based protection and advocacy systems. It employs staff specialists who develop and disseminate special materials, plan annual grantee meetings, maintain a grantee listserv, and conduct site visits to state agencies.

Two TBI TAC activities are particularly notable. First, TBI TAC operates a web-based collaborative space (www.tbitac.nashia.org/tbics/), called TBICS. TBICS is available to all HRSA TBI Program grantees; other interested organizations and individuals may access TBICS, with permission. Second, TBI TAC has developed a set of performance benchmarks that state grantees may use to assess their progress in establishing an infrastructure (HRSA, 2005). HRSA's payments to TBI TAC have fluctuated over the

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[4] NASHIA is a membership organization for state employees who interact with individuals with brain injury and also TBI advocates, professionals, and other organizations with an interest in state and local policy and service delivery.

[5] The Children's National Medical Center (Washington, D.C.) held the TBI TAC contract from 1997 to 2002.

years along with fluctuations in the availability of funds (Currier and Zeltinger, 2005). In recent years, TBI TAC's operating budget has averaged around $1million.

GRANTS PROVIDED UNDER THE HRSA TBI PROGRAM

As noted earlier, the HRSA TBI Program encompasses two major programs: (1) the TBI State Grants Program, which awards grants to states, U.S. territories, and the District of Columbia to help them improve their infrastructure and capacity to provide post-acute services for persons with TBI and their families; and (2) the Protection and Advocacy for TBI (PATBI) Program, which awards grants to federally mandated P&A systems in states, U.S. territories, and the District of Columbia to help ensure their provision of P&A services for individuals with TBI and their families. Additional information about both is provided below.

TBI State Grants Program

HRSA has awarded grants to states and other entities to help them improve their TBI infrastructure and capacity on a competitive basis since the first grant cycle in FY 1997. Grants awarded under the TBI State Grants Program fall into three categories: Planning Grants, Implementation Grants, and Post-Demonstration Grants (Box 1-4).

During the first 2 years of the HRSA TBI Program's existence, states and territories were able to compete for 1-year demonstration project awards (NASHIA, 2005). Under the TBI State Grants Program, the grants for which states were eligible depended on their status with respect to their progress in developing the four core components of a state's TBI infrastructure. The four core components of a state's TBI infrastructure are the following:

- ***Statewide TBI advisory board.*** An advisory board charged with advising and making recommendations on ways to improve coordination of TBI services must be established. The board is obligated to hold public hearings and other community outreach efforts to encourage citizen participation in the TBI Program. Members of the advisory board must include representatives of the involved state agencies, public and nonprofit private health-related organizations, state disability advisory or planning groups, members of a state or local organization representing persons with TBI, local injury control programs (if such programs exist), and individuals who are TBI survivors or the family members of such individuals.
- ***Lead state agency for TBI.*** A state agency and a staff position responsible for coordination of state TBI activities must be designated.

BOX 1-4

TBI State Program Grants Awarded by HRSA on a Competitive Basis, 1997–2005

Planning Grants

Planning Grants to states are intended to help states build the necessary infrastructure for a coordinated TBI service system. States must use the Planning Grants to establish four mandatory components of a TBI system infrastructure—namely, a statewide TBI advisory board, a lead state agency for TBI, a statewide TBI needs/resources assessment, and a statewide TBI action plan. Planning Grants of $75,000 per year were available for up to 2 years.

Implementation Grants

Implementation Grants to states are designed to encourage states to execute various program implementation activities, including carrying out the state's TBI action plan, programs to address identified needs, and initiatives to improve access. Implementation Grants of $200,000 per year were available for up to 3 years.

Post-Demonstration Grants

Post-Demonstration Grants to states of $100,000 for 1 year were intended to further state efforts to build TBI service capacity and are available to states after their satisfactory completion of an Implementation Grant. These grants were first established when the HRSA TBI Program was reauthorized in the Children's Health Act of 2000.

SOURCE: HRSA, 1997.

- ***Statewide TBI needs/resources assessment.*** A statewide assessment of TBI needs and resources, with an emphasis on resources, must be completed or updated within the last 5 years and include the full spectrum of care and services from initial acute treatment through community reintegration for individuals of all ages having TBI.
- ***Statewide TBI action plan.*** A statewide "action plan" to provide a culturally competent, comprehensive community-based system of care that encompasses physical, psychological, educational, vocational, and social aspects of TBI services and addresses the needs of individuals with TBI, as well as family members, must be developed.

Under the TBI State Grants Program, states that had an established plan for developing the four core components of a TBI infrastructure were eligible to compete for a Planning Grant. States that had evidence that the four components were already in place were eligible to compete for an Implementation Grant. Post-Demonstration Grants intended to further efforts to build state-level TBI service capacity were established following the reauthorization of the HRSA TBI Program in the Children's Health Act of 2000. In order to compete for these grants, states must have satisfactorily completed an Implementation Grant.

Federal statute circumscribes the services that states can fund with TBI State Program Grants (Box 1-5). Eligible services include interventions with the assumed potential to empower patients and families, to improve coordination of care, and to expedite access for underserved persons. HRSA prohibits grantees from using TBI State Program Grants to support primary injury prevention, research, or the provision of direct services (although the authorizing legislation is silent on this point) (HRSA, 2003; Martin-Heppel, 2005).

Protection and Advocacy for TBI (PATBI) Program

P&A systems for people with disabilities in the states, territories, and the District of Columbia, initially required as a condition of receiving federal P&A funds under the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (P.L. 103-230, 1975), currently exist in all 50 states and U.S. territories. Federal law requires that the P&A agency in a state or territory be independent of public and private service providers.

HRSA has distributed PATBI Grants to P&A systems in states, territories, the District of Columbia, and the Native American Protection and Advocacy Project to bolster advocacy support for individuals with TBI and their families since FY 2002. As noted earlier, the PATBI Grants Program was authorized as a component of the HRSA TBI Program in the Children's Health Act of 2000.

To be eligible for a PATBI Grant, the P&A system in a state or territory must have local authority to pursue legal, administrative, and other appropriate means to, for example, help persons with TBI establish their eligibility for treatment, community-based services, or change in living arrangements (HRSA, 2003). A P&A system may use the PATBI Grant to provide information, referrals, and advice; individual and family advocacy; legal representation; and specific assistance in self-advocacy for persons with TBI and their families.

In FY 2002, HRSA distributed $1.5 million in PATBI Grants on a competitive basis (Table 1-1 above) (NAPAS, 2005). P&A systems in the states were eligible for $50,000 grants; P&A systems in U.S. territories and the American Indian Consortium were eligible for $20,000 grants. Appro-

BOX 1-5
Federal Statutory Guidance on the Use of TBI State Program Grants

States may use their TBI State Program Grants to do the following:

- Develop or enhance community-based service delivery systems to ensure children's and adults' timely access to comprehensive appropriate services and supports
- Focus outreach to underserved and inappropriately served individuals, such as persons who live in institutional settings, have low socioeconomic resources, reside in rural communities, or belong to culturally and linguistically diverse communities
- Award contracts to nonprofit entities for consumer or family service access training, consumer support, peer mentoring, and parent-to-parent programs
- Develop individual and family service coordination or case management systems
- Support other identified needs

States may also use their TBI State Program Grant funds to build state-level capacity for the following:

- Educating consumers and families
- Training professionals in public/private sector financing of TBI services
- Developing or improving case management or service coordination systems
- Developing best practices in family/consumer support, return to work, housing or supportive living personal assistance services, assistive technology and devices, behavioral health services, substance abuse services, and traumatic brain injury treatment and rehabilitation
- Tailoring current systems to accommodate needs of individuals with TBI, including state agencies responsible for health, mental health, labor and employment, education, mental retardation and developmental disorders, transportation, and correctional facilities
- Improving datasets coordinated across systems

SOURCE: P.L. 106-310, 2000.

priations for the PATBI Program were doubled to $3.0 million in FY 2003. Since then, PATBI Grants to P&A systems have been formula-based, so all states and territories have received the grants, with annual allotments ranging from a minimum of $50,000 up to $117,000 (California).

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2

Epidemiology and Consequences of Traumatic Brain Injury—An Invisible Disability

Traumatic brain injury (TBI)—a brain injury caused by a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain—is a leading cause of death and disability in the United States, particularly among very young children, adolescents, young adults, and elderly persons (NIH, 1998; Thurman et al., 1999; Coronado et al., 2005). Yet for many people who sustain a TBI, the effects of the injury are not obviously evident. The injury may not even be evident on neuroimaging in some cases (Gordon et al., 1998).

Because the damage to the brain from a TBI is hidden from view and the consequences are often not obvious to the casual observer, epidemiologists and other researchers often portray TBI as a "hidden" or "silent" epidemic (Box 2-1). The long-term consequences of TBI may manifest themselves in the form of altered cognition, personality, and behavior and, to a lesser extent, sensory and motor impairments (NIH, 1998; Thurman et al., 1999; Flashman and McAllister, 2002). Yet many health care professionals, community service workers, and the public are unaware of these consequences (Reynolds, 1993; Harris Interactive, 2000).

As background for the committee's assessment of the impact of the TBI Program administered by the Health Resources and Services Administration (HRSA), this chapter provides basic information on the epidemiology and consequences of TBI. The focus here is on a particular subset of the TBI population—namely, individuals (and their families) with a TBI with post-acute impairments who require the services of myriad public and private service systems. Those individuals and the complex systems of care that

BOX 2-1
TBI—The Invisible Disability

Mark is an attorney who does accounting. When you see him in his suit behind his desk punching numbers into his calculator you can't tell that he needs cueing for such things as bathing, dressing, and other tasks of daily living.

Lindsey is beautiful, charming, and lost. Injured as a college sophomore, she has returned 2 years later to audit her first class. She pretends to follow along, but she has yet to pass a test.

Joey looks tough with his well-developed muscles as he struts along wearing his dark glasses to hide his feelings about his wife working and his inability to understand so much of what is happening around him. He is unable to accept his new less important and unpaid job in the photocopying department and depressed that he can no longer support his wife and four children.

Anne's first job, post-injury, was that of ticket taker at the movie theater, but she did not fit in. In addition to her frequent errors, she couldn't recognize faces so she failed to acknowledge her coworkers. They were offended and considered her aloof. She could no longer drive and often was late for her job because she got lost while walking to work. She cried and angered easily and inappropriately. She was fired after 2 weeks.

serve them constitute the group of individuals whose needs Congress addressed when it initially authorized the HRSA TBI Program in 1996 (P.L. 104-166) and then reauthorized it in 2000 (P.L. 106-310, 2000).[1]

EPIDEMIOLOGY OF TBI

TBI Incidence and Prevalence Estimates

In the immediate aftermath of TBI, a person may have a skull fracture, intracranial lesion, decreased level of consciousness for a period of time, or limited memory for events immediately preceding or following the onset of the brain injury, and other neurological or neuropsychological abnormalities. Initially, temporary swelling and bruising of the brain can produce a number of impairments such as confusion and loss of consciousness. When the initial swelling and bruising abates, the affected areas of the brain may return to normal functioning. In severe cases, the swelling may cause pres-

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[1] See Chapter 1 for an overview of the HRSA TBI Program and its legislative history.

sure on the area of the brain that controls consciousness and wakefulness—the brainstem—thus causing coma or death.

TBI is known to affect millions of Americans, but experts widely acknowledge that precise estimates of the incidence and prevalence of TBI in the United States are elusive (NIH, 1998; Langlois et al., 2004). Available estimates of the incidence and prevalence of TBI are undercounts because most TBI surveillance systems draw only from hospital and emergency department records;[2] however, people who have sustained a TBI may not be immediately evaluated at an emergency department, may not be hospitalized, or may not receive medical attention at all (Sosin et al., 1996; NIH, 1998; Schootman and Fuortes, 2000).

Furthermore, little is known about persons who sustain a TBI and are seen in doctor's offices or other nonhospital settings. In individuals who sustain severe body injuries, or painful soft tissue injuries to the neck and shoulders, TBI may not be diagnosed until cognitive problems become evident. Some persons with a TBI may not seek care because they believe a "bump on the head" does not require medical attention or because they face barriers to care such as lack of health insurance (Reynolds et al., 2001). And in some cases, individuals who have sustained a TBI are not even recognized. Individuals with TBI who go uncounted are most likely persons with mild TBI or concussions (NIH, 1998).

Estimates of the number of people living with TBI-related disabilities in the United States are similarly imprecise. The number of people with long-term TBI-related disabilities has not been documented, because available surveillance data fail to differentiate between persons with TBI who have good recoveries and persons with TBI who experience persistent post-TBI symptoms and disability (NCIPC, 2003).

The Centers for Disease Control and Prevention (CDC), with a clear caveat that its estimates of the number of people living with a TBI-related disability in the United States are low, reports that *at least* 1.4 million TBIs occur in the United States annually (Figure 2-1) (Langlois, 2004). Of the 1.4 million people who sustain TBIs, approximately 50,000 die from their injuries and an estimated 80,000 to 90,000 incur a long-term, often permanent disability (Thurman et al., 1999). At a minimum, 5.3 million Americans are estimated to be living with a TBI-related disability (Thurman et al., 1999).

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[2] Until recently only TBIs resulting in overnight hospital stays were reported. Thus, it is difficult to discern whether observed declines in TBI incidence are due to improvements in injury protection, for example, or an artifact of a coincident decline in hospital-based care (Thurman et al., 1999).

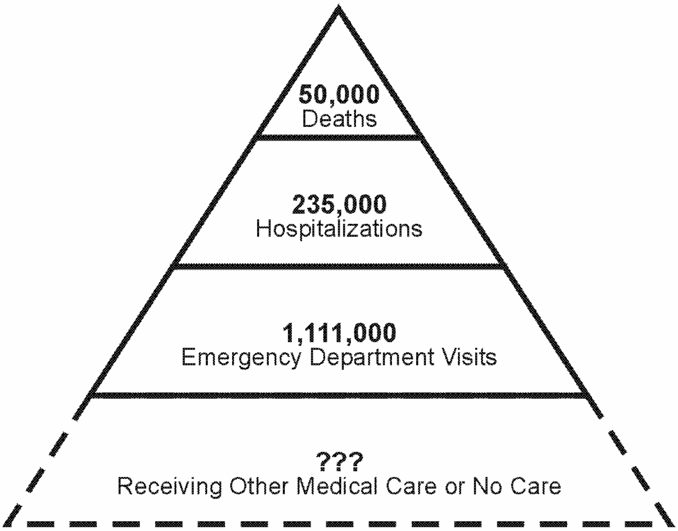

FIGURE 2-1 Average annual number of TBI-related emergency department visits, hospitalizations, and deaths, U.S., 1995–2001.
NOTE: Emergency department visits exclude persons who were hospitalized, died, transferred to another facility, or who had an unknown disposition. Hospitalizations exclude persons who died while being hospitalized.
SOURCE: Langlois et al., 2004.

Causes of TBI

The causes of TBI are varied. A TBI may result from a bullet entering brain tissue, forces due to extreme acceleration and deceleration produced by a motor vehicle crash or exposure to a bomb blast, or the sudden impact of falls, violent punches, construction accidents, or collisions on the playing field (NIH, 1998; Gondusky and Reiter, 2005; DVBIC, 2005).

During the period 1995–2001, the leading causes of TBI were falls (28 percent), motor vehicle accidents (20 percent), struck by/against[3] (19 percent), and assaults (11 percent); these accounted for three-fourths of TBI-related emergency department visits, hospital stays, and deaths (Figure 2-2) (Langlois et al., 2004). Firearms are a major cause of TBI-related deaths (Thurman, 2001).

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[3] Struck by/against is an ICD-9-CM coding category that includes trauma caused when someone is struck by an object (e.g., falling debris, a ball in sports) or someone collides with an object (e.g., wall or post).

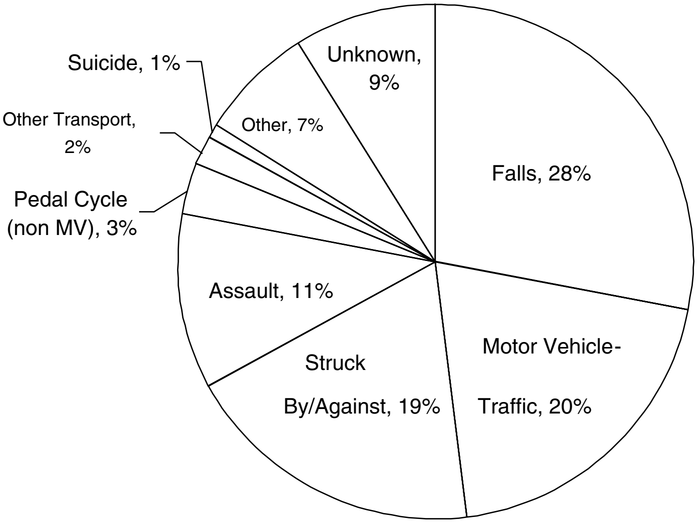

FIGURE 2-2 Average annual TBI-related emergency department visits, hospitalizations, and deaths, percent by external cause, U.S., 1995–2001.
SOURCE: Adapted from Langlois et al., 2004.

Risk Factors for TBI

Individuals who sustain a TBI are a heterogeneous group (NIH, 1998). Available TBI surveillance data related to TBI-related hospitalizations, emergency department visits, and deaths suggest that the population of individuals who sustain a TBI includes substantial numbers of the very young, the very elderly, as well as adolescents and young adults (Table 2-1).

Although many individuals who sustain a TBI were robust and healthy prior to their injury, others may have had one or more preexisting conditions that put them at risk (Corrigan, 1995; Guskiewicz et al., 2000; Coronado et al., 2005). The leading factors associated with risk for TBI-related hospitalization, emergency department visit, or death—age, gender, athletic activity, and military duty—are reviewed below.[4]

Age

The risk for TBI is age-related (Table 2-2). TBIs affect the very young (under age 5) at an alarming rate (1,120.7 TBIs per 100,000) that is 38 per-

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[4] Unless otherwise noted, the data presented in this section are drawn from Langlois et al. 2004.

TABLE 2-1 TBI-Related Emergency Department Visits, Hospitalizations, and Deaths, Number and Percent by Age Group, U.S., 1995–2001

Age Group	Number	Percent of Total	Cumulative Percent
0–4	216,000	15.5	15.5
5–9	133,000	9.5	25.0
10–14	125,000	9.0	34.0
15–19	160,000	11.5	45.4
20–24	103,000	7.4	52.8
25–34	184,000	13.2	66.0
35–44	166,000	11.9	77.9
45–54	101,000	7.2	85.1
55–64	53,000	3.8	88.9
65–74[a]	50,000	3.6	92.5
Over 74	105,000	7.5	100.0
All ages	1,396,000	[b]	100.0

[a] Sample size is small so estimate may not be stable.
[b] Total percent does not add to 100 due to rounding.

SOURCE: Adapted from Langlois et al., 2004.

cent greater than that for the age group with the next highest TBI rate, 15- to 19-year-olds (814.4 TBIs per 100,000).

As shown in Figure 2-3, accidental falls are the predominant cause of TBIs in young children. Motor vehicle traffic crashes are the predominant

TABLE 2-2 Rate of TBI-Related Hospitalizations, Emergency Department Visits, and Death, by Age, U.S., 1995–2001[a]

Age Group	Rate per 100,000
0–4	1120.7
5–9	659.3
10–14	628.6
15–19	814.4
20–24	555.5
25–34	450.2
35–44	374.7
45–54	285.2
55–64	229.5
65–74[b]	267.4
Over 74	659.1
All ages	506.4

[a] Age-adjusted to the 2000 U.S. standard population.
[b] Sample size is small so estimate may not be stable.

SOURCE: Adapted from Langlois, 2004.

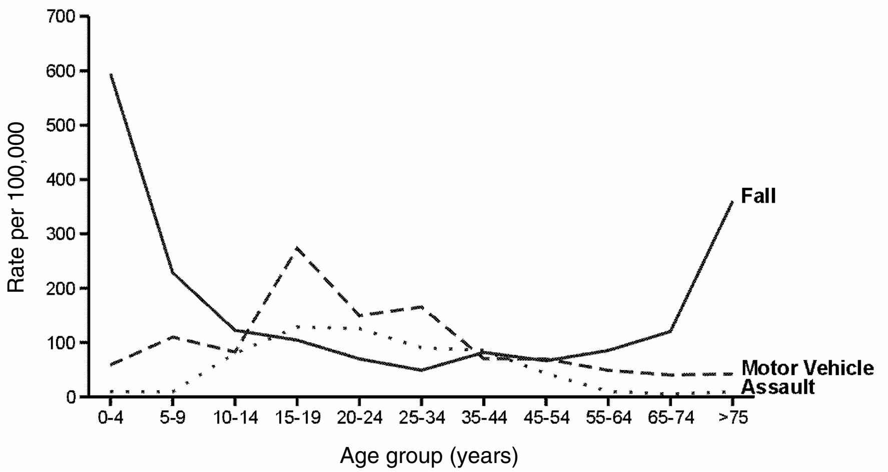

FIGURE 2-3 Average annual TBI-related rates for emergency department visits, hospitalizations, and deaths, by age group and external cause, U.S., 1995–2001.
SOURCE: Langlois et al., 2004.

cause of TBI among teenagers. The rate of TBI among adults tends to increase with age beginning at about age 65. Falls are by far the leading cause of TBI in this age group, accounting for more than half. Falls are the principal cause of TBI-related hospitalizations in older persons, especially among those with multiple, comorbid conditions (Coronado et al., 2005).

Gender

Males are far more likely than females to have a TBI (Figure 2-4). Fifteen- to 19-year-old males, for example, experience 174.5 TBI-related hospitalizations per 100,000 population compared with 81.1 TBI-related hospitalizations per 100,000 for similarly aged females.

Athletic Activity

The rate of sport-related TBI is not known. However, there is an extensive literature suggesting that TBI often goes undetected among high school, college, and professional athletes (Powell and Barber-Foss, 1999; Guskiewicz et al., 2000). Several studies also suggest that a history of concussion significantly increases the risk of sustaining another, more severe brain injury (Guskiewicz et al., 2000, 2003; Schulz et al., 2004).

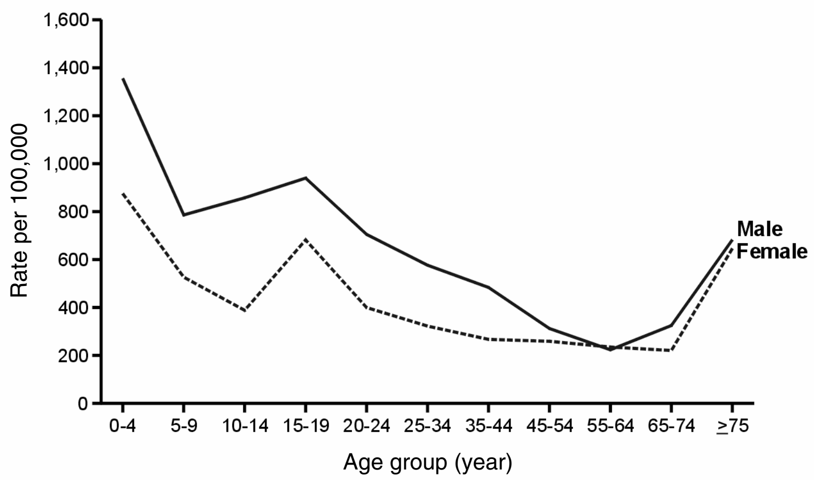

FIGURE 2-4 Average annual TBI-related rates for emergency department visits, hospitalizations, and deaths, by age group and sex, U.S., 1995–2001.
SOURCE: Langlois et al., 2004.

Military Duty

Military personnel in both noncombat and combat posts are at high risk for sustaining a TBI (Ommaya et al., 1996; DVBIC, 2005; Okie, 2005). One study, for example, found that 23 percent of noncombat, active-duty soldiers at Fort Bragg (n = 2,276) sustained a TBI during their military service (Ivins et al., 2003). The risk of TBI was highest among those soldiers with a prior TBI.

Furthermore, TBI has become a signature wound of the current war in Iraq (Box 2-2). Recent studies have found alarming rates of TBI among veterans injured by exposure to improvised explosive devices.

Native Americans

American Indians/Alaskan Natives have high rates of TBI-related hospitalizations compared with other races. Rutland-Brown and colleagues analyzed 1997–1999 hospital discharge data for persons in 13 states who were discharged alive after a TBI-related hospitalization (Rutland-Brown et al., 2005). The researchers found that among all adults, aged 20 to 44 years, American Indians/Alaskan Natives (78.5 per 100,000 persons) had the highest rate of TBI—almost 30 percent greater than that for whites (54.7 per 100,000 persons).

BOX 2-2
TBI Among Veterans of the War in Iraq

TBI has become a signature injury of the Iraq war. The high incidence of penetrating and closed-brain injuries is in part a result of U.S. soldiers' increasing exposure to improvised explosive devices and improved military armor. Kevlar helmets, for example, often save lives but cannot prevent the internal bleeding, bruising, and tearing of brain tissue that result from exposure to blasts.

The Defense and Veterans Brain Injury Center has studied the incidence of TBI at military health facilities. The center's research and other recent studies find alarming rates of TBI among soldiers injured in Iraq. For example:

- Walter Reed Medical Center routinely screens for TBI among soldiers injured as a result of blasts, motor vehicle crashes, falls, and gunshot wounds to the head. TBI was diagnosed in 96 of 155 soldiers (62 percent) during a 3-month period in 2003.
- Almost all (97 percent) of the 125 members of the First Light Armored Reconnaissance U.S. Military Battalion who were wounded or killed from March to August 2004, were injured by an improvised explosive device or mine. More than half (53 percent) of the group sustained an injury to the head and/or neck.

There is anecdotal evidence that soldiers who sustain TBIs may face unique barriers to both diagnosis and recovery. Some soldiers may return to their jobs and families without realizing the severity or consequences of their injury. Access to information and appropriate care appears to be a particular problem for veterans returning to rural areas.

SOURCE: Peota, 2005; Okie, 2005; Gondusky and Reiter, 2005; DVBIC, 2005.

Range in Severity

As discussed below, the terms commonly used for describing the severity of an acute TBI are *mild*, *moderate*, and *severe*; however, the severity of the initial brain injury is not sufficient to predict long-term consequences (Povlishock and Katz, 2005). It is important to recognize that some individuals in all severity groups experience a high rate of persistent symptoms.

The Glasgow Coma Scale is commonly used to determine the initial severity of TBI.[5] A score of 13–15 is described as a mild TBI, 9–12 as a

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[5] The Glasgow Coma Scale (GCS) is one of several approaches for gauging and documenting the severity of a TBI. The Abbreviated Injury Scale (AIS), for example, is a computerized algorithm that can be used to classify injury severity using ICD-9-CM data in the medical record (MacKenzie, 1984; MacKenzie et al., 1989; Durbin et al., 2001).

BOX 2-3
"Mild" TBI—Its Impact May Be Far From "Mild"

Jane Woods was a 39-year-old senior economist working 55 hours a week for a think tank when she sustained a TBI. She is a graduate of Yale University, holds a Ph.D. in economics from Duke University, and is a former varsity athlete.

Her "mild" TBI of 8 years ago has had a marked impact on her life. Today, she manages with effort to work 2 hours at a time in her volunteer job, and she can drive only 10 minutes at 10 mph before nausea forces her to stop. She continues to have auditory, visual, vestibular, and language deficits.

Her summary: "Current criteria define my injury as mild; the changes in my life are radical."

moderate TBI, and ≤ 8 as a severe TBI.[6] The variables typically considered in determining the initial severity of an acute TBI include decreased level of consciousness, duration of post-traumatic amnesia, skull fracture, bruises or blood clots in the brain, and neurological or neuropsychological dysfunction (Kay et al., 1993). In one study of hospital discharge data in 14 states, the CDC used the Glasgow Coma Scale to analyze severity of injury among persons hospitalized for TBI in 1997 (Langlois et al., 2003). The analysis found that approximately 10 percent of the hospitalized patients sustained severe TBIs; 10 percent, moderate; 75 percent, mild; and 6 percent, were of unknown severity.

The CDC further defines a mild TBI as an injury with any period of observed or self-reported transient confusion, disorientation or impaired consciousness; any amnesia with post-traumatic amnesia less than 24 hours; a loss of consciousness of 30 minutes or less; or observed signs of neurologic or neuropsychological dysfunction (NCIPC, 2003).

The majority (85 percent) of TBIs are considered "mild" (NIH, 1998; NCIPC, 2003; Bazarian et al., 2005). The signs and symptoms of mild TBI are often subtle and may be undetected by the patient, family members, and physicians in the period immediately following injury; the signs and symptoms may become apparent only when the individual attempts to resume his or her normal life activities.

The label "mild" TBI can also be misleading, because an estimated 10 to 20 percent of so-called "mild" TBI cases have significant persistent impairments (Box 2-3). Many individuals with mild TBI have significant

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[6] The GCS is scored between 3 and 15, 3 being the worst, and 15 the best. It is composed of three parameters : (1) best eye response, (2) best verbal response, and (3) best motor response.

cognitive, physical, psychological, and social problems that lead to substantial disability and unemployment (Binder et al., 2005; Bazarian et al., 2005; Ruff, 2005); they are sometimes referred to as the "miserable minority." Perhaps for this reason, the literature on identifying and treating the long-term consequences of "mild" TBI is growing (Kushner, 1998; Dikmen, 2001; NCIPC, 2003; Vanderploeg et al., 2003; Carroll et al., 2004; Peloso et al., 2004; Bazarian et al., 2005; Ruff, 2005).

CONSEQUENCES OF TBI FOR INDIVIDUALS, FAMILY MEMBERS, AND SOCIETY

The committee believes that for persons with TBI and the systems that serve them, it is far more important to identify and address the *consequences* of TBI than to characterize acute TBIs as mild, moderate, or severe. Despite the shortcomings in available research, a picture of the potential long-term impact of TBI has emerged. As discussed below, substantial proportions of persons with TBI report persistent limitations in activities of daily living; ability to return to work; social skills, relationships, and community participation. Family members trying to meet the needs of the injured person may experience declines in their own emotional and physical health status. There is also evidence that TBI has worrisome and significant costs for society at large—with particular burdens on an array of public and private systems including physical and behavioral health care delivery systems, schools, disability and welfare programs, and courts and correctional facilities.

Consequences of TBI for Individuals

For the majority of individuals with TBI, there are few, if any, long-term obvious effects (however, research is being conducted to better understand whether TBI creates vulnerability to future neurologic compromise). Yet some persons with TBI are likely to experience multiple signs and symptoms that appear in unique, unpredictable ways throughout their lifetime (Corrigan and Bogner, 2004). For these individuals, TBI brings a constellation of potential physical, cognitive, and behavioral consequences that may be temporary or permanent (Table 2-3) (NIH, 1998; NINDS, 2002). The consequences of TBI for individuals who suffer post-acute impairments are discussed below.[7]

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[7] Although it is beyond the scope of this study to review the scientific literature in detail; numerous informative literature reviews are available (see, e.g., Gordon, in press; van Baalen et al., 2003; Foster and Tilse, 2003; Taylor, 2004; Ownsworth and McKenna, 2004; Dijkers, 2004; Elovic et al., 2004; Sherer, 2005; Callahan, 2005).

TABLE 2-3 Constellation of Physical, Cognitive, and Behavior Changes After TBI

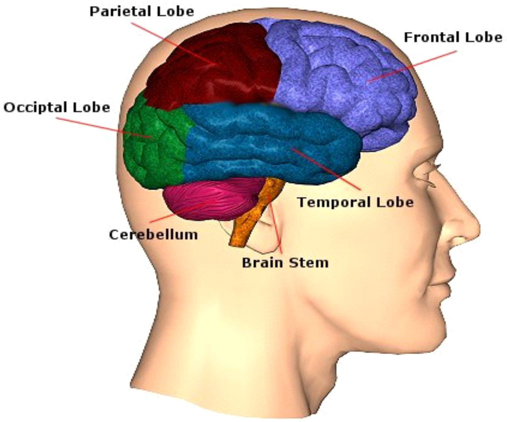
Physical Changes	Cognitive Changes	Behavioral Changes
• Fatigue and/or weakness • Gastrointestinal problems • Dizziness • Headache • Vision impairment • Pulmonary and metabolic problems • Sleep disorders • Seizures • Movement disorders	• Attention • Concentration • Memory • Perception • Speech/Language • Problem solving • Judgment • Self-perception • Information processing	• Depression • Irritability • Disinhibition • Emotional lability • Altered sexual functioning • Problems with emotional control • Anxiety • Frustration

SOURCE: NIH, 1998.

The direct consequences of TBI depend, in part, on which areas of the brain are injured (Figure 2-5). Injury to the frontal lobes of the brain, for example, can lead to an unusually broad range of symptoms, because this area of the brain is involved in many functions including fine motor skills, problem solving, spontaneity, memory, speech and language, initiation, judgment, impulse control, and social and sexual behavior (Thurman et al., 1999; Brown and Levin, 2001). Many TBIs involve the frontal lobes because they reside in a vulnerable location—directly behind the forehead and in a section of the skull with space for the brain to move around (NIDCD, 1998).

Recent research suggests that diffuse damage to brain tissue also significantly contributes to disturbances in concentration, attention, ability to handle multiple stimuli, and mood disorders (Smith et al., 2003; Buki and Povlishock, 2006). Diffuse injury occurs when a sudden jolt to the head causes the brain to move back and forth against the skull, leading to swelling and contusions in multiple areas of the brain. It is often produced by motor vehicle crashes and, sometimes, falls and assaults (Smith et al., 2003).

The sequence and nature of a TBI's emerging symptoms depends on a range of critical factors including the site and severity of the injury; preexisting conditions, such as prior TBIs; behavioral, psychiatric, substance abuse, and learning problems; and a number of mediating variables including age, family income, health insurance, access to appropriate services; and social supports (Gordon et al., in press; Hibbard et al., 1998; Novack et al., 2001; Forducey et al., 2003; Dikmen et al., 2003; Mellick et al., 2003; Breed et al., 2004; Whiteneck et al., 2004a, 2004b). Diagnosing and under-



Frontal Lobe
- Speech
- Problem solving
- Planning and organization
- Impulse control

Occipital Lobe
- Visual processing

Cerebellum
- Balance and coordination
- Skilled motor function

Parietal Lobe
- Sensory perception

Temporal Lobe
- Auditory processing
- Integration of sensory information and memories

Brain Stem
- Vital functioning (respiration, heart rate)

FIGURE 2-5 Architecture of the brain.
NOTE: This figure provides a superficial guide to major brain areas and is not meant to imply that specific functions mentioned are exclusively located in the areas shown; rather, related functions affect and are affected by other functions and brain regions in complex interactions to produce fully effective expression.
SOURCE: NINDS, 2005; Centre for Neuroskills, 2005.

standing TBI in infants, children, and adolescents can be particularly challenging because the effects of the injury may not become apparent until the child ages and fails to attain developmental milestones (Box 2-4).

Physical Health

The majority of individuals with TBI are mobile and able to care for themselves (Novack, 2000). Nevertheless, there are numerous physical

BOX 2-4
Children with Traumatic Brain Injury

The complex physical, cognitive, and behavioral impairments associated with TBI have profound implications for children. In contrast to adults, pediatric TBI alters a developing brain. Furthermore, a child's recovery occurs in the context of ongoing developmental processes. The TBI may not only affect previously learned skills, but also the capacity to gain new skills.

As time passes and the child grows, the long-term impact of a child's TBI may be misinterpreted or undetected altogether. Children injured early in life may appear to resume school activities successfully until they move on to middle school or high school and are expected to be increasingly competent and independent. Psychosocial disorders may not become obvious until the child moves into a more emotionally and socially challenging environment.

SOURCES: NIH, 1998; Glang, 2004; Ylvisaker et al., 2005; Savage et al., 2005.

health problems that are common after a TBI (Table 2-3) (Hibbard et al., 1998; NINDS, 2002; Breed, 2004).

Cognitive Abilities and Communication

Cognitive problems related to TBI typically have more impact on a patient's recovery and outcome than physical limitations. Individuals with TBI with cognitive impairments often have difficulties concentrating, remembering, organizing their thoughts, making good decisions, solving everyday problems, and planning and foresight. They may be easily confused or forgetful. Language skills, both written and spoken, may also be impaired. Some people with TBI find it hard to learn new information or interpret the subtle cues and actions of others. As a result, they may act or speak inappropriately. Such deficits can impede one's ability to communicate with others, to seek and obtain necessary services, and to maintain or develop all types of human relationships. Getting necessary care is also difficult because patients often forget appointments and struggle to articulate effectively and present their problems to providers.

Behavioral Competence

A substantial literature documents that TBI increases the risk of major depression, general anxiety disorder, obsessive-compulsive disorder, panic disorder, post-traumatic stress disorder, anti-social behavior such as criminality and substance abuse, and suicide (Gordon et al., in press; Brown and Levin, 2001; Fann et al., 2004; Oquendo et al., 2004). The occurrence of these disorders appears to be independent of injury, age, severity of injury, and gender.

Individuals with TBI frequently report emotional problems related to impaired social relations, feelings of estrangement and isolation, difficulty accepting physical and lifestyle changes and difficulty accepting loss of control or competence in day-to-day decision making (Jordan et al., 2003). Individuals with TBI with preexisting behavioral and psychiatric problems may find that the brain injury exacerbates their condition and makes the management of day-to-day function all the more complex and difficult.

Depression is particularly prevalent post-TBI and is correlated with other problems including perceived impact of TBI, social support, cognitive symptoms, physical complaints and activity limitations, sexual dysfunction, and satisfaction with health and income (Granger et al., 1995; CDC, 1999; Hibbard et al., 2004).

It is important for health care professionals to recognize and treat psychological problems in individuals with TBI. Unfortunately, the potential for focusing on the psychological consequences of TBI can result in an inappropriate primary diagnosis of a psychiatric illness, ignoring the TBI diagnosis (McGuire et al., 1998; Torsney, 2004).

Daily Lives

It is difficult to capture the impact of TBI on an individual's every day existence. Data collection and analysis are daunting challenges given the fragmented nature of TBI services and the inflexibility of their disparate data systems, lack of standardized definitions, and multiple public and private service systems.

Most of the available research draws from convenience samples, such as persons hospitalized for TBI, medical record reviews, and follow-up interviews with persons with TBI to document levels of impairment and need for assistance (Novack et al., 2001; Whiteneck et al., 2004b). Findings from such studies cannot be generalized to the overall TBI population and are limited by a variety of inconsistent outcome measures and other methodological details. A "better accounting" of the long-term consequences of TBI in a comprehensive sample of individuals with TBI is clearly needed (Dawson and Chipman, 1995). Advancing the research will be critical if federal, state, and private TBI programs are to meet the needs of individuals with TBI and their families.

Ability to Perform Activities of Daily Living (ADLs). An individual's ability to perform ADLs is a well-established indicator of the person's level of disability and dependence on others. ADLs are basic, personal activities such as bathing, eating, dressing, mobility, transferring from bed to chair, and using the toilet (DHHS, 2003). ADLs also include higher level activities such as shopping, cooking, and managing personal finances.

The percentages of persons with TBI who are unable to perform specific ADLs are not known. The available studies report a wide range of estimates. Whiteneck and colleagues, for example, followed 1,591 Colorado adults who were hospitalized for TBI from 1996–1999. At 1 year post-TBI, 37 percent of the interviewees reported requiring assistance in either eating, bathing, dressing, toileting, walking, and/or using a wheelchair (Whiteneck et al., 2004b). In a study of 454 Canadian adults with TBI living in the community, Dawson and Chipman documented long-term rates of various indicators of disability. After an average 13 years post-injury, 15 percent of the sample needed assistance in personal care, and more than 30 percent reported needing help with basic activities such as shopping and managing personal finances (Dawson and Chipman, 1995).

Ability to Return to Work, School, and Productive Activity. The ability to be a productive member of society, whether in employment, school, or other settings, is associated with perceived quality of life after TBI (O'Neill et al., 1998; Steadman-Pare et al., 2001). There are no definitive estimates of employment and school attendance post-TBI, and little is known about how productive activity after TBI changes over time. The available research suggests, however, that psychosocial, cognitive, and physical impairments dramatically limit some individuals' ability to return to productive activity, whether it is work, school, or other endeavors (Buffington and Malec, 1997). It also appears that successful employment after TBI is related to severity of injury, preinjury occupation or education, and age at injury (Wehman et al., 2005).

In the Colorado study, described above, return to work varied significantly by severity of injury and gender: 1 year after injury, less than half (47 percent) of the 207 individuals with severe injuries had returned to work, compared with 80.5 percent of the 1,273 persons with mild injuries (Whiteneck et al., 2004b). Regardless of severity, return to work was not necessarily with the same employer or in the same position as before injury.

Kreutzer and colleagues followed 186 previously employed adults who had been admitted to an acute care hospital within 24 hours of a mild, moderate, or severe brain injury (Kreutzer et al., 2003). Each subject received an individualized, comprehensive program of inpatient rehabilitation, including occupational therapy, physiatry and related medical services, psychology and neuropsychology, therapeutic recreation, social services, and speech and language therapy. The patients were interviewed annually over a 4-year, period and their medical records were reviewed. At 3 or 4 years after injury, just 42 percent of the subjects were employed.

Ability to Develop and Maintain Relationships. Sound physical health, cognition, and behavior are intrinsic to one's social skills and ability to develop and maintain relationships. Impairments in these critical human abilities have profound implications for an individual's sense of independence, perception of well-being, and overall quality of life (Jordan et al., 2003). Persons with brain injury are often susceptible to overstimulation and thus some traditional mental health group treatments may be overwhelming. Additionally, some housing options have a high degree of visual and acoustic stimuli, which may agitate the person with a brain injury and lead to a behavioral outburst (Torsney, 2004).

Consequences of TBI for Family Members

The emotional and physical health status of the family caregiver can be as compromised as that of the person with TBI (Thomsen, 1984; Hall et al., 1994). Many individuals with severe brain injury require ongoing care and supervision and are thus dependent on their families to meet their daily needs. Most families are not equipped to care for someone with the cognitive deficits and behavioral and emotional changes that are characteristic of TBI (Lezak, 1988). Families generally have little knowledge about the effects of brain injury, how to manage the associated problems, or how to care for individuals with brain injury.

The consequence is substantial stress for family caregivers who must radically change their lives to meet their loved ones' long-term needs and financial burdens. In addition, dealing with the brain injured person's "former self" and feeling trapped and isolated can contribute to high stress levels and compromised mental health. Family members experience not only the loss of income, but the loss of the relationship before the injury (Vandiver et al., 2003).

In general, family stress following brain injury revolves around three areas: isolation, quality of life, and health status (Lezak, 1988). With regard to isolation, studies have shown that friends and relatives may rally around the family in the early stages of recovery but tend to withdraw support and contact over time (Jordan et al., 2003). Clinical experience suggests that outpatient psychological care may be offered to people in the early stages of recovery, but family members may not be ready to receive this form of support at that time. Several years after injury, when problems are finally recognized, relatives may not know how to request services or may be ineligible for them because of insurance or other financial restraints (Gervasio and Kreutzer, 1997).

Consequences of TBI for Society

TBI appears to place a substantial burden on an array of social institutions and systems such as psychiatric facilities, courts and correctional facilities, schools, and disability and welfare programs. Definitive estimates of the prevalence of TBI among users of these institutions do not exist. Nevertheless, available research suggests that TBI definitely has an impact. Several studies of various convenience samples, for example, have found that half or more of individuals charged with a criminal offense or in prison have a history of TBI (Lewis et al., 1986; Sarapata et al., 1998; Slaughter et al., 2003).

Co-occurrence of TBI and substance abuse is well documented (Silver et al., 2001; Fann et al., 2002; Bombardier et al., 2002; Walker et al., 2003; Horner et al., 2005). A literature review of 11 studies of patients admitted to brain injury rehabilitation centers found that 50 to 66 percent of the patients had a history of alcohol or other drug abuse (Corrigan, 1995).

Murrey and colleagues reviewed the clinical and legal records of 3,133 adult inpatients in seven U.S. state-operated psychiatric hospitals (Murrey et al., 2004). The researchers found that 16.7 percent of the inpatients had a documented history of TBI, and 6.4 percent had dysfunction of thinking considered secondary to TBI. Silver and colleagues interviewed a probability sample of 5,034 adults in the New Haven metropolitan area for a National Institute of Mental Health epidemiologic study. They found that 43 percent of persons with a history of severe brain trauma had a diagnosed psychiatric disorder, twice the rate of persons (20 percent) with no TBI.

SUMMARY

This chapter has described the epidemiology and consequences of TBI for individuals, family members, and society. The immediate aftermath of a TBI may be a skull fracture, intracranial lesion, decreased level of consciousness or limited memory for events immediately preceding or following the injury, and other neurological or neuropsychological abnormalities. The immediate effects of a TBI are not necessarily predictive of longer term outcomes.

The repercussions of brain injury may be temporary or may result in profound disability. Individuals with TBI are likely to experience multiple signs and symptoms that appear in unique, unpredictable ways throughout their lifetime. The sequence and nature of a TBI's emerging symptoms depends on the site and severity of the injury; preexisting conditions, such as prior TBIs; behavioral, psychiatric, substance abuse, and learning problems; and a number of mediating variables including age, family income, health insurance, access to appropriate services, and social supports.

Data on the epidemiology of TBI have limitations because they are drawn primarily from hospital and emergency department records, so they do not capture individuals with TBI who are seen in doctors' offices or who do not seek medical care. In the United States, it is estimated that 80,000 to 90,000 individuals per year sustain a TBI with long-term, often lifelong implications. At a minimum, 5.3 million people in the United States live with a TBI-related disability.

Individuals with TBI are a heterogeneous group, including the very young, the very elderly, as well as adolescents and young adults. Although many individuals with TBI were robust and healthy prior to their injury, others may have had one or more preexisting conditions that put them at risk. Persons in the military are at heightened risk—TBI is the signature injury of the conflict in Iraq.

The majority of individuals with TBI are mobile and able to care for themselves. Nevertheless, various physical health problems are common after a TBI, including difficulties in balance and motor coordination, fatigue, headache, sleep disturbances, seizures, sensory impairments, slurred speech, spasticity and tremors, difficulties in urinary control, dizziness and vestibular dysfunction, and weakness.

Cognitive problems related to TBI typically have more impact on a patient's recovery and outcome than physical limitations. Cognitively impaired persons with TBI are easily confused or forgetful; their language skills may also be impaired. Some people with TBI find it hard to learn new information or interpret the subtle cues and actions of others.

A substantial literature documents that TBI increases the risk of major depression, general anxiety disorder, panic disorder, post-traumatic stress disorder, antisocial behavior such as criminality and substance abuse, and suicide. Individuals with TBI with preexisting behavioral and psychiatric problems may find that the brain injury exacerbates their condition and makes the management of day-to-day function all the more complex and difficult.

It is difficult to capture the impact of TBI on an individual's every day existence. Data collection and analysis are daunting challenges given the fragmented nature of TBI services and the inflexibility of their disparate data systems, lack of standardized definitions, and multiple public and private service systems. Nevertheless, substantial proportions of individuals with TBI report persistent limitations in activities of daily living, ability to return to work, social skills, relationships, and community participation.

The emotional and physical health status of the family caregiver can be as compromised as that of the individual with TBI. Most families are not equipped to care for someone with the cognitive deficits and behavioral and emotional changes that are characteristic of severe TBI. The consequence is substantial stress for family caregivers who must radically change their lives to meet their loved ones' long-term needs and financial burdens. There is also evidence that TBI has worrisome and significant costs for society at large, placing burdens on physical and behavioral health care delivery systems, schools, disability and welfare programs, and courts and correctional facilities.

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3

Service Needs and Sources of Funding and Supports for People with TBI-Related Disabilities

People with disabilities related to traumatic brain injury (TBI) need coordinated, long-term services if they are to return to productive activity, learn to compensate for their impairments, or achieve an optimal quality of life. When Congress authorized the Health Resources and Services Administration's (HRSA) Traumatic Brain Injury Program in 1996 (P.L. 104-166, 1996) and reauthorized it in 2000 (P.L. 106-310, 2000), it specifically addressed the need for these longer term services by directing HRSA to encourage states to improve and facilitate coordinated post-acute service delivery for people with TBI and their families.[1]

As background for the assessment of the HRSA TBI Program's impact, this chapter provides an overview of the post-acute service needs and sources of funding and other supports for individuals with TBI and their families. The services required by people with TBI-related disabilities are complex and involve numerous areas of technical expertise, both clinical and nonclinical. Case management; continuing availability of medical care; cognitive and physical therapies; family education, counseling, and respite; emotional support; financial assistance; vocational training; housing; and transportation services are essential to achieving a successful outcome (NIH, 1998).

Because there are few coordinated systems of care for persons with TBI-related disabilities, these individuals may not obtain the post-acute

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[1] See Chapter 1 for an overview of the HRSA TBI program and its legislative history.

BOX 3-1
One TBI Survivor's Challenges in Obtaining Needed Services

Scott suffered a severe TBI at age 17 and continues to have many language, motor, behavioral, and cognitive deficits. Now, at age 33, he still uses a wheelchair and has marked disinhibition that caused him a recent arrest for public lewdness. He needs constant supervision.

Despite his problems, Scott received SIB-R testing scores[a] that made him ineligible for his state's Medicaid development disabilities waiver. Scott's receipt of a social security death benefit from his father made him ineligible for Medicaid due to his total income exceeding a limitation. Scott is ineligible for the TBI Medicaid waiver in his state because he was younger than 22 when he sustained his injury.

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[a] The SIB-R (Scale of Independent Behavior-Revised) is a widely used assessment tool. SIB-R is used to evaluate persons' behaviors to determine the type and amount of special assistance they may need including, for example, home-based support services for infants and children and their families, special education and vocational training for young people, and supported work or special living arrangements such as personal care attendants, group homes, or nursing homes for adults. Go to *http://www.cpinternet.com/~bhill/sibr/* for further information.

services they need. At best, their access to services may be circumscribed by nonclinical variables such as health, disability, or accident insurance; family income; health coverage; geography; primary language for communication; and other cultural and socioeconomic factors (NIH, 1998) (Box 3-1). Over time, as persons with TBI-related impairments grow older and their personal circumstances evolve, their eligibility for services may change and they may encounter new obstacles to care.

A lucky few individuals with TBI-related impairments may obtain some needed services in a serendipitous way (Box 3-2).

WHAT SERVICES DO PEOPLE WITH TBI-RELATED DISABILITIES NEED?

As noted in Chapter 2, TBI usually begins as an acute medical problem. If the individual with the injury is covered by health insurance, initial treatment for the injury may be obtained in a hospital, physician's office, or other acute health care setting. If the injury is severe enough to require prolonged hospitalization, individuals with no insurance or limited insurance are often covered by Medicaid.

If a person with a TBI survives, however, much of the person's improvement is likely to occur after the acute crisis ends when health benefits may be limited. Some individuals with severe disabilities must have ongoing

BOX 3-2
One TBI Survivor's Journey from a Nursing Home to the Community

John lacked private insurance or a family to care for his needs, so following his severe TBI, John was placed in a nursing home. He was in his early twenties, trapped in a facility of elderly patients, with little intellectual or social stimulation and no rehabilitation.

Fortunately, a creative director of the institution put John to work in a supervised position washing dishes in the kitchen. Slowly over time, John learned more and more skills and began earning money. Eventually he became a member of the nursing home staff with full health benefits and moved into his own apartment.

care and supervision in a community-based or residential care setting. Others with TBI-related disabilities may require access to a broad range of nonmedical and medical services and support (NIH, 1998) (Figure 3-1).

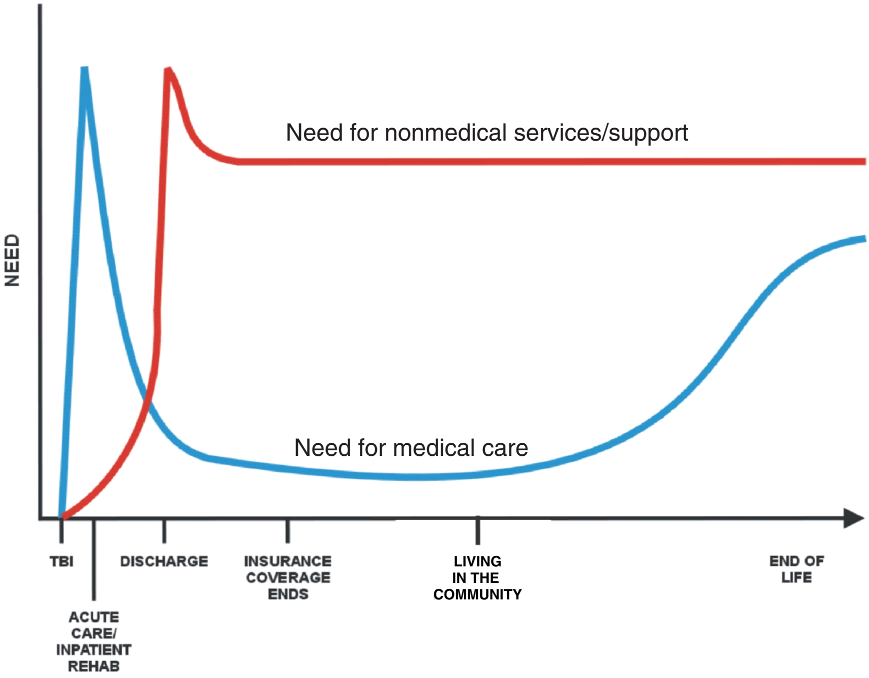

FIGURE 3-1 Continuum of needs post-traumatic brain injury.
SOURCE: Langlois, 2005.

In 1998, a National Institutes of Health (NIH) consensus conference on rehabilitation of persons with TBI highlighted an urgent need for research on the optimal mix, duration, and intensity of post-acute services for TBI (NIH, 1998; Chesnut et al., 1999). There is now substantial evidence supporting selected TBI therapies, such as cognitive rehabilitation (Colantonio et al., 2004; Cicerone et al., 2005). However, little is known about the therapeutic factors and patient characteristics that might optimize clinical outcomes (Cappa et al., 2005; Yasuda et al., 2001; Labi et al., 2003; Peloso et al., 2004).[2]

As discussed in Chapter 2, months, sometimes years, may pass before the full extent of a TBI survivor's needs becomes evident (Langlois, 2005). This observation holds especially true for children with a TBI, whose deficits may become noticeable and whose handicaps may become increasingly apparent as expectations for social effectiveness and independent behaviors increase during the high school years.

For TBI-related disabilities, insurance coverage of acute and post-acute services may be limited both by what services will be paid for and by what intensity and the duration of services will be paid for (Leith et al., 2004). Coverage of behavioral health services and cognitive and physical rehabilitation is often restricted or not available at all (GAO, 1998; Chan, 2001; Technology Evaluation Center, 2002; Barry et al., 2003; CIGNA, 2005). Focused surveys and qualitative research show that some persons with TBI have persistent unmet needs long after the acute crisis of their injury.

Brown and Vandergoot, for example, studied 430 individuals with TBI and found that they reported significantly more unmet needs than individuals with spinal cord injury (Brown and Vandergoot, 1998).

In another study, Corrigan and colleagues conducted a telephone survey of 1,802 persons (or their proxies), aged 15 and older, who were hospitalized for TBI in Colorado in 2000 (Corrigan et al., 2004). One year after being discharged from the hospital, 40.2 percent of the Colorado respondents reported at least one persistent, unmet need for services related to self-care and instrumental activities of daily living, cognitive and emotional functioning, or employment (Figure 3-2). Continuing needs for employment-related, cognitive, and behavioral supports were most prevalent in the Colorado study. The vast majority of respondents with persistent, unmet needs reported requiring help finding work (95.9 percent), job skills (83.6 percent), improving cognition (79.8 per-

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[2] The locus for federal research on neurotrauma and rehabilitation care is the Traumatic Brain Injury Model Systems (TBIMS) program in the National Institute on Disability and Rehabilitation Research (NIDRR). TBIMS research activities focus on all aspects of care for persons with TBI. Go to http://www.tbindc.org/registry/center.php for further information.

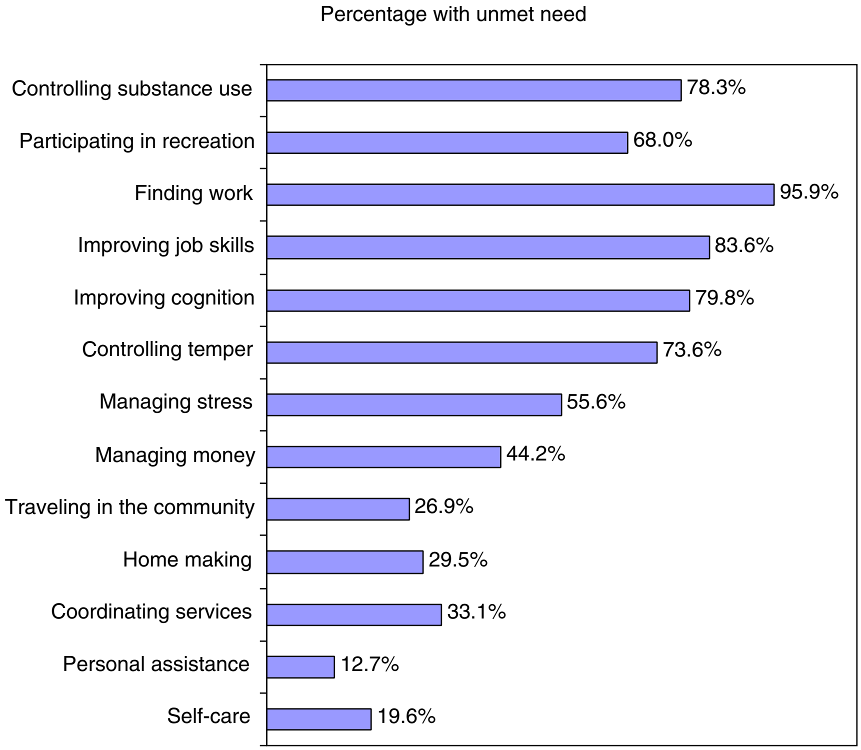

FIGURE 3-2 Persistent need for services 1 year post-traumatic brain injury hospitalization.
SOURCE: Corrigan et al., 2004.

cent), controlling substance use (78.3 percent), and controlling temper (73.6 percent). Yet, a substantial proportion of the study group also had ongoing, unmet needs for such basic assistance as self-care (19.6 percent), transportation (26.9 percent), home making (29.5 percent), and help with coordinating services (33.1 percent).

Findings from other surveys of persons with TBI, family members, and providers, as well as reports based on focus groups, regional town meetings, and stakeholder conferences, underscore the prevalence of persistent, unmet needs in the TBI population (Farmer et al., 1996; Corrigan, 2001; Heinemann et al., 2002; Mellick et al., 2003; Leith et al., 2004; Whiteneck et al., 2004; Selassie et al., 2005).

Public and private systems serving persons with TBI are shown in Figure 3-3. For family members and other caregivers, figuring out which

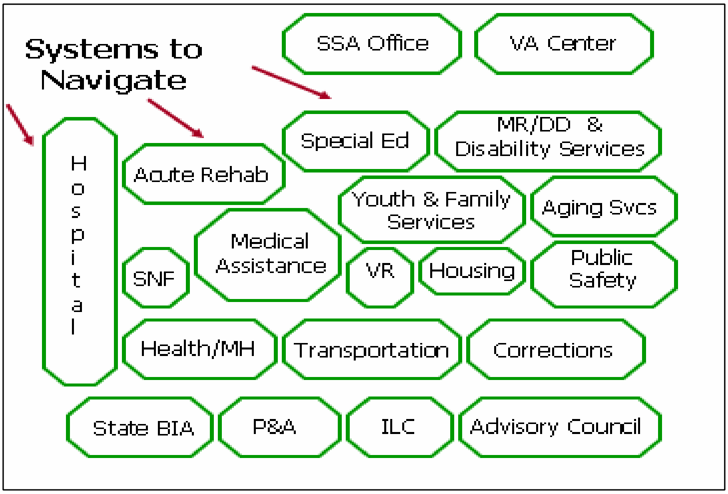

FIGURE 3-3 Public and private systems serving persons with traumatic brain injury.
SOURCE: Connors, 2005.

services are necessary, how to find financial support for needed services, and how to access needed services for a person with TBI may pose a series of daunting logistical, financial, and psychological challenges (Gervasio and Kreutzer, 1997; Leith et al., 2004; Rocchio, 2005; Sample and Langlois, 2005).

A number of surveys suggest that health providers, teachers and other school officials, and police and judicial officers are often poorly informed about the needs of persons with TBI (Corrigan, 2001). Furthermore, every brain injury is different and has unique clinical manifestations requiring a unique array of services for each patient. In an award-winning review of the pathophysiology of TBI, Bigler describes this succinctly (Bigler, 2001):

> At the time of injury, every patient brings to that accident a unique set of circumstances and anatomy. The force dynamics of injury will be distinctive to each accident, as will the patient's anatomy and physiology along with genetic endowment. Each patient's response to injury also will be unique, particularly in terms of metabolic and vascular reactions. Thus, two patients, of similar age and sex, can be in the same accident (i.e., both seat-belted in the back seat of a vehicle that is hit dead-center, head-on) and come away with very different injuries and sequelae. (p. 101)

Individuals with TBI and their families may ultimately need services from a very broad range of experts which may include primary care and

TABLE 3-1 Types of Services Needed by Persons with TBI and Their Families

- Alternative residence
- Assessment/evaluation
- Behavioral services
- Case management
- Cognitive therapy
- Community/family education
- Durable medical equipment
- Emotional support
- Financial assistance
- Housing
- Individual/family counseling
- Legal advice
- Life skills training
- Medical services
- Personal care
- Prescription drugs
- Recreation/socialization
- Rehabilitative therapies
- Respite (families)
- Special education
- Substance abuse treatment
- Supported employment
- Transportation
- Vocational training

SOURCES: GAO, 1998; Heinemann et al., 2002; Corrigan et al., 2004; Sample and Langlois, 2005; Connors, 2005.

specialist physicians, rehabilitation nurses, respiratory care providers, rehabilitation technicians and behavior attendants, neuropsychologists, speech and language pathologists, physical therapists, occupational therapists, therapeutic recreation specialists, school tutors, driving evaluators, dieticians, community reintegration specialists, clinical psychologists, social workers, patient and family service counselors, and insurance experts (Table 3-1). These services are discussed in further detail below.

Case Management

The myriad service systems that provide services that people with TBI-related disabilities and their families need may or may not overlap, may or may not be financed through the same program, and may be available only to certain subgroups of persons with TBI (e.g., children, veterans, or persons residing in certain geographic areas). Case managers can help persons with TBI and their families navigate through the myriad service systems they require. Case management services for persons with TBI and their families may include assessing individual needs, creating service plans, giving referrals to services, helping to obtain financial support for services, coordinating and monitoring service delivery, arranging transportation, identifying alternative living arrangements, and providing assistance on an ongoing basis.

Medical Health Care Services

As noted in Chapter 2, various health problems are common in the wake of a TBI (NINDS, 2002). As a consequence, some individuals with TBI have ongoing or episodic needs for medical management of ongoing problems such as seizures, pain, and psychological issues. They may require ongoing diagnostic testing, treatment, and prescription medications. Neuropsychological evaluation is a critical diagnostic component in identifying the integrity of cognitive functions, such as attention and memory, which impact medical management, rehabilitation, and behavioral therapies. They may also have an ongoing need for various types of durable medical equipment (e.g., wheelchairs and assistive medical equipment).

Cognitive and Physical Rehabilitation Services

Persons with TBI-related disabilities typically need cognitive and physical assessment and rehabilitative services to optimize their ability to process and interpret information, to help ensure their functioning in family and community life, and to enable them to live in the least restrictive setting (NIH, 1998; Ylvisaker et al., 2003, 2005). The objective of the rehabilitation may be “restorative” (that is, to improve specific functions) or “compensatory” (to adapt to a deficit), or both.

TBI rehabilitation services may be provided in a number of different settings, including the home, hospital outpatient units, inpatient rehabilitation centers, comprehensive day programs at rehabilitation centers, supportive living programs, independent living centers, club-house programs, school-based programs for children, and others (NINDS, 2002). Although a person with TBI may initiate rehabilitation services in an inpatient rehabilitation setting, ideally the person will continue rehabilitation services on an outpatient basis for an extended period. As the individual achieves certain therapeutic goals, or as clinical conditions change, some therapies may be discontinued and other therapies may be intensified or added.

Cognitive Rehabilitation Services

Cognitive rehabilitation is a critical component of post-acute TBI care. The objective of cognitive rehabilitation is to improve cognitive functioning and to increase levels of self-management and independence (NIH, 1998). Although the specific tasks are individualized to patients’ needs, cognitive rehabilitation generally emphasizes restoring lost functions, teaching compensatory strategies to circumvent impaired cognitive functions, and improving competence in performing instrumental activities of daily living such as managing medications, using the telephone, and handling finances

(Cicerone et al., 2000, 2005; Miller et al., 2003; Ylvisaker et al., 2003, 2005). The particular focus of the therapy may be on improving specific deficits whether in memory, attention, perception, learning, planning, and/or judgment.

Physical Rehabilitation Services

Physical rehabilitation is also a critical component of post-acute TBI care. People with TBI-related impairments often need an organized program of physical, occupational, speech, and other therapies to regain former abilities or develop new skills to compensate for their impairments. It may also involve modifications to home and work environments.

Behavioral Health Care

People who sustain a TBI are at risk for significant behavioral health problems, including major depression, general anxiety disorder, obsessive-compulsive disorder, panic disorder, post-traumatic stress disorder, anti-social behavior such as criminality and substance abuse, and suicide (Gordon et al., in press; Brown and Levin, 2001; Fann et al., 2004; Oquendo et al., 2004). For persons with TBI who are affected by such problems, access to neurobehavioral and substance abuse counseling and other behavioral remediation services is often fundamental to basic functioning and sound health, to living with family and in the community, and to overall quality of life.

Family and Caregiver Supports

Having access to health information and education, training, social, and psychological services can help TBI caregivers cope and, in turn, potentially improve outcomes for the individual with TBI (Armstrong and Kerns, 2002). As noted earlier, TBI can have intense, long-term social, psychological, and physical health implications for parents, spouses, and other caregivers (Kreutzer et al., 1994; Hall et al., 1994; Ergh et al., 2002; Carnes and Quinn, 2005; Boschen et al., 2005; NASHIA, 2005). Families generally have little knowledge about how to care for individuals with brain injury and are rarely prepared to care for someone with the cognitive deficits and behavioral and emotional changes that may follow a TBI (Lezak, 1986). The related stress is heightened when the TBI leads to dramatic change in the caregiver's daily routines, employment, housing, financial status, and social life.

BOX 3-3
A TBI Survivor's Return to Work

Prior to sustaining a TBI, Peter had a career as a surgical scrub nurse and was known for his people skills. He could keep everyone serene and happy during stressful situations.

After 8 weeks of post-TBI rehab, Peter was given a new job as a doctor's office receptionist at one-fourth the pay. He performed adequately on the computer and on the phone and was often warm and friendly. At times, however, he would snap at complaining patients. When they yelled in protest, he would yell back, inflaming the situation, and he sometimes shouted curses at them. Because of this behavior, he was fired on his 4th day at work as a receptionist.

Fortunately, Peter's wife Rita sought out a rehabilitation program that helped address his disinhibition. Today Peter still earns a modest income, but he has kept his job as an office assistant in a dental office for 7 months, and his wife is no longer contemplating divorce.

Vocational Rehabilitation Services

Vocational rehabilitation services include a range of services organized to help individuals to cope emotionally, psychologically, and physically with the changing circumstances of their lives (Vandiver et al., 2003; DHHS, 2003). Vocational rehabilitation may involve skills training, job coaching, and supported employment[3] to facilitate return to work or, if return to a preinjury job is not an option, alternative employment or other productive activity.

Although there are no definitive estimates of the rate of return to work after brain injury, numerous studies suggest unemployment is high among persons with severe TBI (Wehman et al., 2000; Yasuda et al., 2001; Kreutzer et al., 2003; Wehman et al., 2005). The psychosocial, cognitive, and physical impairments associated with TBI often interfere with an individual's ability to return to work (Machamer et al., 2005) (Box 3-3). Doctor and colleagues analyzed a group of persons with TBI who had been employed prior to their injury and compared them with the general population's

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[3] Supported employment refers to programs that subsidize paid employment in community settings for persons with severe disabilities who need ongoing support to perform their work. Support can include on-the-job training, ongoing external job coaching, transportation or supervision. Go to http://www.partnersinpolicymaking.com/employment/glossary.html for further information.

unemployment risk, calculated from transition probabilities; they found that the individuals with TBI were 4.5 times more likely to be unemployed 1 year post-injury than was predicted by the expected relative risk of unemployment in the general population (Doctor et al., 2005).

Legal and Advocacy Services

Legal assistance and advocacy is a critical service for persons with cognitive impairments, psychiatric disorders, or behavioral health problems. Persons with TBI who are cognitively impaired without physical disabilities are particularly likely to be denied needed services—even if they lack the executive skills, such as planning and problem solving, to live independently in the community (GAO, 1998). They are also at risk for ending up homeless or in a nursing home, psychiatric institution, or prison. These people benefit from a legal advocate who can help maximize their potential and their quality of life by finding a suitable place to live, accessing attendant care and/or assistive technology, and obtaining physical, behavioral, and rehabilitation services as needed.

SOURCES OF FUNDING AND SUPPORTS FOR PEOPLE WITH TBI-RELATED DISABILITIES

There is only limited information documenting how well private or public sources of funding cover the post-acute service needs of people with TBI-related disabilities. Eligibility criteria are often confusing and exclusionary (and families may not know what is available). Nonetheless, reviews of eligibility rules for health and disability programs, population surveys on unmet needs (described above), and anecdotal evidence show that there is a substantial discrepancy between needs and availability of funding (GAO, 1998; NIH, 1998; Banja, 1999; Vaughn and King, 2001; Starr, 2001; Drew et al., 2001; GAO, 2005; West, 2000; Technology Evaluation Center, 2002; CIGNA, 2005).

Table 3-2 provides selected details on coverage and eligibility of the principal sources of federal and state funding for TBI services. The Social Security Administration administers two programs of cash benefits: Social Security Income (SSI) and Social Security Disability Insurance (SSDI). Eligibility for SSI or SSDI is often the critical path to Medicaid- or Medicare-sponsored health insurance coverage. For low-income persons, eligibility for a Medicaid long-term home and community-based waiver may be the only means to essential services such as personal care, homemaker services, and transportation.

TABLE 3-2 Selected Government Programs Supporting Acute and Post-Acute Service Needs of People with TBI-Related Disabilities

Federal Agency and Program	Covered Services	Eligibility Criteria
Social Security Administration (SSA)		
Social Security Income (SSI)	Cash benefits	Eligibility is restricted to individuals with resources below the SSI threshold and with a disability that prevents them from working. SSA uses a strict definition of disability that limits adult eligibility to individuals who cannot engage in any "substantial gainful activity" because of a physical or mental impairment that is expected to result in death or to continue for at least 12 months. There are different SSI rules for children. A child with a TBI disability may quality for SSI if he/she has a "medically determinable physical or mental impairment which results in marked and severe functional limitations, and which can be expected to result in death, or which has lasted or can be expected to last for a continuous period of not less than 12 months."
Social Security Disability Insurance (SSDI)	Cash benefits	For persons under age 65 who are unable to work for a year or more because of a disability. Must be disabled under the SSA definition, and have worked long enough and recently enough. SSDI benefits are based on how much the individual has "paid into the system" by paying income taxes. The required length of employment increases with age group (younger than age 24, 24–31 years old, and age 31 or older). Benefits usually continue until a person is able to work again on a regular basis. Special

continues

TABLE 3-2 Continued

Federal Agency and Program	Covered Services	Eligibility Criteria
		"work incentives" provide continued benefits and health care coverage to help with the transition back to work.
		At age 65, SSDI benefits automatically convert to Social Security retirement benefits.
Center for Medicare and Medicaid Services (CMS)		
Medicaid	Joint federal/state program. At the state level, Medicaid functions as a health insurance plan covering a core set of mandatory benefits including inpatient and outpatient hospital care, physician services, and nursing facility care. States have the option to cover rehabilitative services and prescription drugs.	TBI-related disability may qualify persons for Medicaid coverage under several criteria related to the disability, income and resource standards, immigration status, and residency in the state where Medicaid benefits are requested. Eligibility for receiving SSI cash benefits (see above) is the primary pathway to Medicaid coverage: in 39 states and the District of Columbia, Medicaid coverage is automatic for persons eligible for SSI. In 11 states, Medicaid eligibility is separate from SSI participation.
	Medicaid's long-term home and community-based waivers give states the option of providing services such as personal care, homemaker services, and non-medical transportation, to adults who are disabled by TBI. The specific services covered by a waiver vary by state.	In some states, individuals with TBI disability may be eligible for Medicaid if they are "medically needy," i.e., they meet the SSI disability standard and their income, less medical expenses, falls below a state-established threshold. This route to Medicaid coverage is especially relevant to persons who are hospitalized or institutionalized at considerable expense.
	Medicaid also provides supplemental coverage to low-income Medicare beneficiaries for services not covered by Medicare Part A (e.g., outpatient or prescriptions) and Medicare premium, deductibles, and cost sharing.	Eligibility for services under a TBI Medicaid waiver is at each state's discretion. In 2002, 22 states had a Medicaid waiver program for persons with TBI. Half of these waivers limited eligibility to persons with income up to 300 percent of SSI. Other

		states capped eligibility at or below 100 percent of SSI. Access to waiver services is often.
Medicare	Part A: Hospital stays, skilled nursing facility care (after a 3-day hospital stay and not custodial care), home health care, hospice care. Prescription medications. Part B: Optional medical insurance for physicians' services and other outpatient services including physical, occupational and speech therapies; some durable medical equipment and home health care, and clinical laboratory. Optional prescription drug coverage as of January 1, 2006.	Persons who qualify for SSDI payments are automatically eligible for Medicare after a 24-month waiting period (i.e., because they meet the SSA standard for long-term, serious disability). Disabled adult children of Medicare beneficiaries are also eligible even after the parent's death.
Department of Education		
Vocational Rehabilitation (VR)	Joint federal/state program. States have the option to provide services to adults who are disabled by TBI so that they can reenter the community. Covered services may include rehabilitative therapies and supported employment. Federal support for the program is limited to 18 months.	Must have a physical or mental impairment that is a substantial impediment to employment; be able to benefit from VR services in terms of employment; and require vocational rehabilitation services to prepare for, enter, engage in, or retain employment.
Independent Living Services (ILS)	ILS provides training, peer support, advocacy, and referral through a decentralized system of federally funded programs to help people with disabilities live independently. ILS centers are	Individuals with significant physical, mental cognitive, or sensor impairments whose ability to function independently in the family or community or whose ability to obtain, maintain, or advance in employment is substantially limited.

continues

TABLE 3-2 Continued

Federal Agency and Program	Covered Services	Eligibility Criteria
	required to provide four core services: independent living skills training, peer support, advocacy, and referral on a continuing basis. States have the option to purchase additional services, such as personal assistant services or home modifications.	
State Protection and Advocacy for Assistive Technology	Advocacy assistance in obtaining funding for a wide range of assistive technology devices, including shower chairs, adapter computer equipment, access ramps and lifts for the home, and custom, power wheelchairs. Also covers training for using the devices.	Eligibility is granted to any individual with a disability who seeks funding for an assistive device or service. Funding, however, is very limited. States receive federal grants of $50,000 to $100,000 per year to furnish the assistive technology needs of all disabled individuals (including persons with TBI).

SOURCES: GAO, 1998; Sheldon and Ronald, 2001; Drew et al., 2001; Crowley and Elias, 2003; Kitchener et al., 2005; NASHIA, 2005a; Catalog of federal domestic assistance.

SUMMARY

This chapter has described the post-acute service needs and sources of funding and other supports for persons with TBI, providing background for the IOM committee's assessment of the HRSA TBI Program. Although the research literature has limitations, there is convincing evidence that individuals with TBI have persistent impairments in activities of daily living, ability to return to work, social skills, relationships, and community participation.

Finding needed services is typically a logistical, financial, and psychological challenge for family members and other caregivers. People with TBI require access to diverse services including case management, health care services, cognitive and physical rehabilitative therapies, behavioral health care services, family and caregiver supports, vocational rehabilitation, housing, and transportation services. Eligibility criteria for services and supports are often confusing and exclusionary (and families may not know what is available). Few coordinated systems of care exist so that access to funding is typically driven by nonclinical variables, such as family income, health coverage, geography, and other socioeconomic factors that may change over time.

Given the array of services that may be necessary for a given individual, it is a major problem for that person and family when services are not coordinated. It is easy to get lost, depressed, or desperate. Guidance through multiple potential sources of care through public and private agencies, and system coordination are *prima facie* essential conditions for adequate service.

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4

Assessment of the HRSA TBI Program

> *There are no words to express the fear, anguish, and despair of TBI victims and their families. The problems resulting from severe impairment of a family member are compounded by the frustrations of trying to work within medical, legal, and social systems that for the most part are not equipped to deal with either the immediate or long-term consequences of TBI. Indeed, many patients and their families find that the present system discourages efforts toward self-sufficiency and provides no support for the family as a unit.*
>
> —U.S. Interagency Head Injury Task Force Report, 1989

Just 16 years ago, a newly established federal interagency task force reported to the nation that there were serious gaps in post-acute clinical care and rehabilitation for traumatic brain injury (TBI) (NINDS, 1989). The task force concluded that optimal post-acute care was largely unavailable or inaccessible. It also found an urgent need for a federal agency to take lead responsibility for coordinating federal, state, and private sector TBI activities.

Eight years later in the Traumatic Brain Injury Act of 1996, Congress directed the Health Resources and Services Administration (HRSA) to take on a share of the responsibility for advancing state-based TBI service systems. The HRSA TBI Program established in 1997 is a modest federal initiative with broad ambitions; a $9 million grants program aimed at motivating states to create systems improvement on behalf of persons with TBI and their families. The program was designed with the underlying premise—characteristic of other federal infrastructure grant programs—that distributing small grants to states that meet certain requirements will be sufficient to initiate the creation of a sustainable infrastructure and increased capacity for comprehensive, coordinated, and integrated service systems for individuals with TBI.

In Chapter 2 and Chapter 3, the committee concluded that, despite a limited research literature and body of evidence, it is clear that the quality and coordination of post-acute TBI service systems remains inadequate (Box 4-1). This chapter presents the committee's findings and recommen-

BOX 4-1
The Quality and Coordination of Post-Acute TBI Service Systems

The quality and coordination of post-acute TBI service systems remains inadequate, although progress has been made in some states. Many people with TBI experience persistent, lifelong disabilities. For these individuals, and their caregivers, finding needed services is, far too often, an overwhelming logistical, financial, and psychological challenge.

- Individuals with TBI-related disabilities, their family members, and caregivers report substantial problems in getting basic services, including housing, vocational services, neurobehavioral services, transportation, and respite for caregivers. Yet efforts to address these issues are stymied by inadequate data systems, insufficient resources, and lack of coordination.
- TBI services are rarely coordinated across programs except in some service sites. Furthermore, in most states, there is no single entry point into TBI systems of care. Access to service systems and financial support is typically driven by nonclinical variables, such as family income, health coverage, geography, and other socioeconomic factors that may change over time.
- Little is known about how persons with persistent TBI-related impairments fare in today's fragmented and disparate service systems. Persons without health insurance, racial and ethnic minorities, non-English speakers, rural residents, children, and individuals in prolonged coma are especially underserved. Persons with TBI-related neurobehavioral problems, but no obvious physical impairments, face unique obstacles getting needed services.
- Although the collection of health care data is outside the committee's charge and HRSA's purview, the committee notes that the establishment of relevant data systems is integral to "impact evaluation" as strictly interpreted and prescribed by the federal Office of Management and Budget.

dations regarding the impact of the HRSA TBI Program. Each set of findings and recommendations is accompanied by a summary of evidence drawn from the committee's review of the HRSA TBI Program. The committee's findings and recommendations pertain to three major topics:

1. The impact of HRSA's TBI State Grants Program on state infrastructure and capacity for improving TBI-related service systems (Box 4-2)
2. The impact of HRSA's Protection and Advocacy for TBI (PATBI) Grants Program on circumstances for people with TBI-related disabilities
3. The adequacy of the management and oversight of the HRSA TBI Program

BOX 4-2
The Impact of HRSA's State Grants Program

FINDING:

The committee finds that the HRSA's TBI State Grants Program has produced demonstrable, beneficial change in organizational infrastructure and increased the visibility of TBI—essential conditions for improving TBI service systems. There is considerable value in providing small-scale federal funding to motivate state action on behalf of individuals with TBI. Whether state programs can be sustained without HRSA grants remains an open question.

- In some states, TBI State Program Grants have led to substantial growth in basic state-level infrastructure for addressing TBI. The necessary TBI infrastructure is beginning to take root in most states. Many TBI Program Grantees believe that HRSA funding has increased the visibility of TBI and related issues among state agencies, providers, and the public.
- The next stage is critical. Substantial work is needed to ensure that the infrastructure is effective and TBI service systems are improved, expanded, and sustained.
- Although HRSA's four mandatory components of a state's TBI infrastructure—a statewide TBI advisory board, a lead state agency for TBI, a statewide assessment of TBI needs and resources, and a statewide TBI action plan—are essential, they are not enough to effect lasting improvement in services for individuals with TBI and their families. Sustainable progress requires reliable, long-term data collection and monitoring; interagency collaboration on both federal and state levels; and effective funding mechanisms (e.g., state trust funds, special revenues, expansions in health coverage).
- HRSA's 1-year TBI State Post-Demonstration Grants required states to engage in projects with unrealistically short time periods. The committee supports the new program grants that extend funding for up to 3 years to improve program continuity. A minimum 3-year grant period would facilitate recruitment and retention of personnel, program continuity, and reduce the expense and time that states invest in obtaining grant support.
- HRSA is the sole federal agency charged with improving state TBI service systems. HRSA cannot succeed, however, without its sister federal programs—particularly the National Center for Injury Prevention and Control, Centers for Disease Control and Prevention (CDC); the TBI Model Systems program and the Interagency Subcommittee on Disability Statistics, National Institute on Disability and Rehabilitation Research (NIDRR); the National Center for Medical Rehabilitation Research (NCMRR), National Institutes of Health; the Substance and Mental Health Services Administration (SAMHSA), and the Defense and Veterans Brain Injury Center (DVBIC), a combined effort of the Department of Defense and Veterans Affairs.

continues

BOX 4-2 CONTINUED

RECOMMENDATION:

The committee recommends that HRSA continue to support and nurture the program.

- HRSA should continue to mandate the four infrastructure components. It should also encourage states to regularly revisit their TBI action plans, updating them as appropriate.
- TBI Program grants should be awarded for a minimum 3-year time period.
- HRSA should require states to assess and report on progress in achieving specific goals set in their statewide TBI action plan. This would be made easier if HRSA developed a simple and straightforward format for the action plans, and advised states on establishing strategic goals and setting realistic timeframes. Other federal programs, in HRSA or elsewhere, might offer useful models.
- HRSA should take the lead in establishing a TBI interagency group to ensure active collaboration among the relevant agencies noted above. An alternative lead federal TBI agency could also be considered. SAMHSA should be invited to participate. SAMHSA has had little involvement in TBI to date; yet it is a federal agency with extensive resources in substance abuse and mental illness—two conditions that often co-occur with TBI.

THE IMPACT OF HRSA'S TBI STATE GRANTS PROGRAM[1]

Effect of the TBI State Grants Program on States' TBI Infrastructure

Almost all states have demonstrated interest in expanding their capacity to serve individuals with TBI. All but two states (Louisiana and South Dakota) have applied for and received at least one TBI State Program Grant from HRSA (Figure 4-1). Many states have successfully completed Planning and Implementation Grants. As of 2005, 37 states had received Planning Grants; 40, Implementation Grants; and 23, Post-Demonstration

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[1] Unless noted otherwise, this chapter's findings are drawn from the committee's commissioned interviews with TBI stakeholders in seven states (Alabama, California, Colorado, Georgia, New Jersey, Ohio, Washington State) (Korda, 2005) and a recent National Association of State Head Injury Administrators/Brain Injury Association (NASHIA/BIAA) survey of TBI stakeholders (Robinson, 2005). Additional information about the committee's commissioned survey is presented in Appendix B (the interview guide); Appendix D (profiles of TBI initiatives in the seven states); and Appendix E (consultant's report on the interviews). See Appendix C, Table C-2 for details on the characteristics and self-reported accomplishments of state TBI systems in each state.

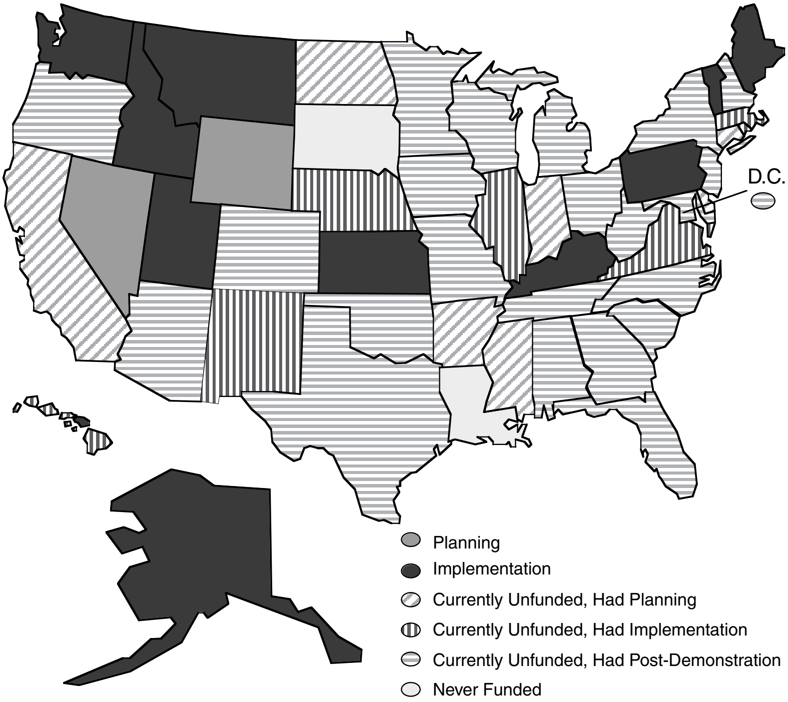

FIGURE 4-1 TBI Program grants by state, 2005.
SOURCE: TBI TAC, 2005.

Grants.[2] Twelve states were in the midst of a Planning or Implementation Grant (Table 4-1).

As noted in Chapter 1, HRSA requires all states seeking a federal grant under its TBI State Grants Program to establish or show proof that they have the four mandatory components of a TBI infrastructure—a statewide TBI advisory board, a lead state agency for TBI, a statewide assessment of TBI needs and resources, and a statewide TBI action plan. From 1997 through 2005, many states adopted these basic elements of statewide capacity for creating and coordinating TBI service systems (Table 4-2). As of 2005, 47 states had a lead agency for TBI, 43 states had an approved TBI action plan and an operational TBI advisory board, and 39 states had conducted a TBI needs and resources assessment. Although 12 states[3]

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[2] Note that tallies of state participation include the District of Columbia.

[3] The 12 states are Alabama, Arizona, Florida, Massachusetts, Minnesota, Missouri, New Jersey, New Mexico, New York, North Carolina, Ohio, and Tennessee.

TABLE 4-1 Number of States Participating in HRSA's TBI State Grants Program, by Type of Grant, 2005*

Type of TBI State Program Grant Received from HRSA	Number of States
Never funded	2
Ever funded	
Planning Grant	37
Implementation Grant	40
Post-Demonstration Grant	23
Any Type of Grant	49
Currently funded	
Planning Grant	2
Implementation Grant	10
Post-Demonstration Grant	0
Any Type of Grant	12

*Includes 50 states plus the District of Columbia.

SOURCE: NASHIA/TBI TAC, 2005.

achieved these accomplishments on their own, it is likely that most other states would not have progressed to this stage in the absence of the TBI State Program Grants.

The vast majority of states have embraced HRSA's mandatory TBI infrastructure (Box 4-3), although some have found that incorporating the structure in a way suited to their own political, socioeconomic, and geographic circumstances is challenging. Many states have had to create a wholly new governmental enterprise, requiring the collaboration of numerous state and private agencies.

Lead state agencies for TBI have been designated in at least nine different state agencies, including departments of public health, health, or community health (12 states); human or social services (12 states); rehabilitation services (4 states); education (4 states); and mental health (2 states) (TBI TAC, 2005). There is no evidence to suggest that bureaucratic placement of the lead TBI agency has a significant impact on a state's capacity for mobilizing effective services. In fact, the labels that states give agencies are not particularly meaningful. The names of state agencies do not reveal their functions and, in many states, the lead TBI agency has multiple roles such as health and social services, social and rehabilitative services, or health and mental hygiene.

In some cases, finding the right administrative home for a lead state agency for TBI has been a process of trial and error. In Georgia, for example, the first two lead agencies for TBI, the State Health Planning Agency

TABLE 4-2 Summary of the Four Core Components of TBI Infrastructure, by State, 2005

State	TBI Advisory Board	Statewide TBI Action Plan	TBI Needs & Resources Assessment	Lead State Agency for TBI
Total all states*	43	43	48	47
Alabama**	√	√	√	√
Alaska	√	√	√	√
Arizona**	√	√	√	√
Arkansas		√	√	√
California		√	√	√
Colorado	√	√	√	√
Connecticut	√		√	√
Delaware		√	√	√
D.C.		√	√	√
Florida**	√	√	√	√
Georgia	√	√	√	√
Hawaii	√	√	√	√
Idaho	√	√	√	√
Illinois	√	√	√	√
Indiana			√	
Iowa	√	√	√	√
Kansas	√	√	√	√
Kentucky	√	√	√	√
Louisiana				
Maine	√	√	√	√
Maryland	√	√	√	√
Massachusetts**	√	√	√	√
Michigan	√	√	√	√
Minnesota**	√		√	√
Mississippi			√	√
Missouri**	√	√	√	√
Montana	√	√	√	√
Nebraska	√	√	√	√
Nevada	√		√	√
New Hampshire	√	√	√	√
New Jersey*	√	√	√	√
New Mexico**	√	√	√	√
New York**	√	√	√	√
North Carolina**	√	√	√	√
North Dakota	√		√	
Ohio**	√	√	√	√
Oklahoma	√	√	√	√
Oregon	√	√	√	√
Pennsylvania	√	√	√	√
Rhode Island	√	√	√	√
South Carolina	√	√	√	√
South Dakota				
Tennessee**	√	√	√	√

continues

TABLE 4-2 Continued

State	TBI Advisory Board	Statewide TBI Action Plan	TBI Needs & Resources Assessment	Lead State Agency for TBI
Texas	√	√	√	√
Utah	√	√	√	√
Vermont	√	√	√	√
Virginia	√	√	√	√
Washington	√	√	√	√
West Virginia	√	√	√	√
Wisconsin	√	√	√	√
Wyoming	√			√

*Totals include 12 states which established all four infrastructure components before participating in the HRSA TBI State Grants Program.

**This state established all four core TBI infrastructure components before participating in the HRSA TBI State Grants Program.

SOURCE: NASHIA/TBI TAC, 2005.

BOX 4-3
Selected Comments from TBI Stakeholders in the Seven Study States on Their State's TBI Infrastructure

Successes

"We successfully achieved the goals identified in our Planning Grant and for the first time, Virginia had a written 'plan' for developing services for people with brain injury. I also believe that the Planning Grant activities and process raised awareness about the needs of people with brain injury in Virginia, but also helped link people with existing services. It also helped to bring together the lead agency, the Brain Injury Association state affiliate, and the state advisory council—we all became focused on moving forward in a more organized, focused manner. This ultimately led to the formation of the Virginia Alliance of Brain Injury Services Providers, which has done an amazing job educating members of the General Assembly and successfully obtaining funding for brain injury services. I would say that the Planning Grant definitely served as a 'catalyst' in our state to bring the TBI community together in a more cohesive fashion."

"The HRSA TBI funding has been responsible for brain injury awareness in the state of Colorado. Up until the Planning Grant, there was no relationship with the state or the legislature. Since HRSA's funding, we have an established Statewide Brain Injury Advisory Board, a designated state agency dedicated to brain injury, a Brain Injury Trust Fund established by the state legislature, energy assistance and Section 8 housing designated specifically for survivors of brain injury, and education for schools through the Brain Stars Program as well as education for rural and the Georgia Department of Community Health, had little success in advancing the state's TBI program; however, Georgia's current lead agency for TBI, the Brain and Spinal Injury Trust Fund Commission, appears quite promising. In Washington State, the Division of Rehabilitation served as the lead state agency for TBI for the first 2 years of the HRSA grant program, then determined that TBI was not its mission; currently, the Home and Community Services Division of the state's Aging and Disability Adult Services Administration is at the helm.

Some states have grappled with determining the appropriate size and membership of their statewide TBI advisory board. Colorado, for example, found that too large a group was unwieldy. At first, California's TBI advisory board was burdened by discord and the challenge of the state's vast size. Eventually the group worked through its differences and reached consensus on a state action plan. Washington State's TBI advisory board had difficulty in defining and agreeing on its mission; in order to focus the TBI advisory board, the membership of the board was pared down and planning activities were used to develop a list of goals.

areas from the Center for Community Participation. We have the Colorado Information, Resource Coordination, Linkage & Education (CIRCLE) program in the following areas: Denver, Ft. Collins, Greeley, Pueblo, and Grand Junction. All this can be attributed to the HRSA TBI funding. If future funding does not continue, I am afraid that in a decade, we can be back to where we were in 1999. This would be a tragedy."

Frustrations

"The need to have a 'project' to fund is sometimes less than helpful—if we could fund a staff member on a continuing basis, or if we could add funding to existing state programs to encourage increasing expertise in TBI, it would be far more helpful to us. At some point, too, we need to recognize that we have done all the planning we can do, we have reorganized the system over and over again—we need money for direct services."

"So far, the state has refused to allow the state BIA [Brain Injury Association] affiliate to partner on any aspect of the action plan. The affiliate is represented on the advisory committee, and has offered to take responsibility for key components. All efforts have been met with a negative response."

"Given the lack of services and the defending by the legislature of what did exist on a state level during the grant period I cannot identify any positive outcomes, except for the development of a good plan (albeit unused)."

SOURCE: Robinson, 2005; Korda, 2005.

Of the four required TBI infrastructure components, the tasks of assessing statewide TBI needs and resources and a subsequent TBI action plan have presented the greatest challenge for states. States were often ill equipped to take on the technical task of measuring and documenting TBI needs. Their lead state agencies for TBI conducted or commissioned mail, telephone, and web-based surveys of persons with TBI, families, and providers; held focus groups, town hall meetings, and stakeholder conferences; interviewed providers and state officials; and analyzed secondary data (Corrigan, 2001; Korda, 2005). Their methods, however, were of variable quality. Some state surveys, for example, used nonrepresentative samples and had poor response rates. Analytic data were developed with nonstandard definitions and lacked key clinical variables such as age, time post injury, and severity of injury. Many states also lacked state-specific data, which some researchers regard as essential. Some states' assessments overemphasized "need" and gave little attention to documenting available resources (Corrigan, 2001).

Most states now have a statewide TBI action plan in place. The action plans are quite variable. In some states, the action plans are brief, one-page lists of key issues and activities; in other states, the action plans are ambitious, highly detailed documents. Most states' TBI action plans draw from the state's TBI needs and resources assessment, along with other information sources.

California developed a comprehensive TBI action plan with the input of many constituents, but according to one observer, "the bottom has dropped out without resources." Georgia's TBI action plan identified the need to increase access to transportation; neurobehavioral; and cognitive rehabilitation services; lifelong services; and supports that include rehabilitation and housing.

This experience suggests that states might benefit from more prescriptive, practical guidance from HRSA on their TBI action plans, including scope, structure, and setting of realistic goals to be accomplished within specific timeframes. Such practical guidance from HRSA would be useful both for states and HRSA in evaluating success and failure in achieving state-specified goals. Standard reporting would also allow comparisons to be made more readily across states. Specifications for the statewide TBI plans should be simple and straightforward. The committee notes that the underlying presumptions for this suggestion are a continuing role for HRSA and sustainable funding for TBI at the state level.

Effect of the TBI State Grants Program on States' TBI Service Systems

Building the *capacity* for systems improvement has been a principal objective of the HRSA TBI State Grants Program's Planning Grants awarded to states. The focus of the program's Implementation and Post-Demonstration Grants—catalyzing systems improvement—is especially bold. Many states have initiated projects—often in collaboration with community groups—to educate TBI caregivers, the public, schools, prisons and judicial system, physicians, behavioral health care providers; to outreach to underserved persons in schools, institutional settings, and inner-city neighborhoods; to raise awareness among state legislators and other policy makers; and data collection and research (Table 4-3).[4]

In New Jersey, for example, there was close collaboration between the state TBI program and the state Brain Injury Association to expand outreach and education for faith-based communities and inner-city minority neighborhoods. In Colorado, collaboration between the state TBI program and the Brain Injury Association was also fruitful; together they developed regional community networks, called CIRCLE (Colorado Information, Resource Coordination, Linkage, and Education) Networks, for promoting information dissemination, resource coordination, linkage, and education throughout the state (Colorado Department of Human Services and Brain Injury Association of Colorado, 2005). The networks continue to operate without additional HRSA funding because of dedicated community interest and volunteer support (see Table 4-4, Appendix C, and Appendix D for other examples).

Gauging whether sustainable TBI-related systems improvement has occurred and if it is attributable to HRSA's TBI State Grants Program is difficult, but it is certain that stakeholders credit the program with motivating states to develop programs and projects that otherwise would have received scant if any attention. Many stakeholders associate favorable systems' improvements—both direct and indirect—with the TBI State Grants Program. Some observers even question whether states can sustain and capitalize on these improvements without continued federal support (Box 4-4).

Participants in the committee's commissioned TBI stakeholder interviews in seven states noted that HRSA's TBI State Grants Program heightened awareness of TBI in multiple spheres of state government, the nonprofit and private sectors, and the advocacy community. They also pointed to "spillover" impacts that occurred as a consequence of the HRSA TBI State Program Grants, including program expansions, trust fund develop-

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[4] Appendix C presents a summary of state TBI program characteristics and self-reported accomplishments in all 50 states for 1997–2005. Appendix D presents detailed profiles of TBI initiatives in seven states (Alabama, California, Colorado, Georgia, New Jersey, Ohio, and Washington State). Appendix E presents the original consultant's report on interviews with TBI stakeholders in the seven states.

TABLE 4-3 Dedicated TBI Funding by State, 2005

State	Trust Fund	Medicaid Waiver*	Special Revenue Funding
Alabama	√	√	
Alaska		√	
Arizona	√	√	
Arkansas		√	
California	√		
Colorado	√	√*	
Connecticut		√*	
Delaware		√*	
D.C.		√	
Florida	√	√*	
Georgia	√	√	
Hawaii		√	√
Idaho		√*	
Illinois		√*	
Indiana		√*	
Iowa		√*	
Kansas		√*	
Kentucky	√	√*	
Louisiana	√	√	
Maine		√	
Maryland		√*	
Massachusetts	√	√*	√
Michigan		√	
Minnesota	√	√*	
Mississippi	√	√*	
Missouri	√	√	
Montana		√	
Nebraska		√*	
Nevada		√	
New Hampshire		√*	
New Jersey	√	√*	
New Mexico	√	√	
New York		√*	
North Carolina		√	
North Dakota		√*	
Ohio		√	
Oklahoma		√	√
Oregon		√	
Pennsylvania	√	√*	
Rhode Island		√	
South Carolina		√*	√
South Dakota		√	
Tennessee	√		
Texas	√	√	
Utah		√*	
Vermont		√*	
Virginia	√	√	

TABLE 4-3 Continued

State	Trust Fund	Medicaid Waiver*	Special Revenue Funding
Washington		√	
West Virginia		√	
Wisconsin		√*	
Wyoming		√*	

*Indicates that the Medicaid waiver specifically targets persons with TBI.

SOURCE: TBI TAC, 2005.

ment, and other activities. New Jersey, for example, developed the core components of its TBI program in *anticipation* of the state's receiving a HRSA TBI State Program Grant. New Jersey's TBI trust fund and TBI research fund, though also initiated without HRSA TBI State Program Grant funding, were reportedly developed as TBI gained new visibility as a result of New Jersey's activities related to the HRSA grant.

Several examples of "spillover" effects from the HRSA TBI State Grants Program are apparent in Colorado. According to local observers, TBI's new visibility contributed to the state legislature's creating a TBI trust fund and also to increasing participation in the state's Medicaid TBI waiver program.

The committee observed that a number of mediating factors can influence how HRSA grants influence local TBI systems development. Overall, it appears that no two state TBI service systems have evolved in the same way. Simple serendipity is often an important determinant. A state may have an influential government official or charismatic advocate who champions the TBI cause because of a personal family experience. In Alabama, for example, the crippling assassination attempt on former Governor George Wallace was an early impetus for the state's widely admired community-based service system that predated but set the context for the state's HRSA TBI Program. The state's "homebound" program that serves severely disabled individuals with TBI (or spinal cord injury) was started by Governor Wallace after he experienced problems obtaining basic services (Weiner and Goldenson, 2001).

Success breeds success. It takes time to build effective public and private, state and local systems. Thus, states with already established leadership, interagency cooperation, and/or Centers for Disease Control and Prevention (CDC)-sponsored TBI data collection, are better positioned to use the grants more quickly and effectively than other states, which must labor to create "something from nothing."

TABLE 4-4 Examples of State TBI Program Accomplishments Reported by the Seven Study States, 1997–2005

Alabama
- Developed a "Service Linkage Program" that identifies and refers adolescents in schools.
- Implemented education and outreach programs to raise awareness about the links between TBI and psychiatric disorders and TBI and domestic violence.
- Created and implemented the PASSAGES Model, a community-based system for children and youth with TBI.
- Trained vocational rehabilitation counselors to screen individuals for TBI.

California
- Limited resources currently preclude implementation of the state's TBI action plan; however, there are ongoing volunteer efforts to increase awareness, improve access to existing services through statewide training, and launch a new website and a toll-free information hotline.
- Legislation was introduced to extend the sunset date for the state's TBI trust fund.

Colorado
- Created the Colorado Information, Resource Coordination, Linkage, and Education (CIRCLE) community support networks.
- Initiated a cross-training program with the state's Disability Determination Service to reduce the high disability denial rate for people with TBI.

Georgia
- Substantially improved the states' TBI registry to include data from hospital discharges, emergency departments, and ambulatory surgical clinics.
- Developed a statewide TBI resource database to help individuals and families find local resources and services.
- Convened a workshop on TBI data, reporting, surveillance, and analysis.

New Jersey
- Implemented an outreach program to inner-city neighborhoods.
- Developed education programs for state staff on One-Stop vocational support centers.

Ohio
- Established TBI resource facilitation programs at three hospitals.
- Updated information on TBI resources, system utilization, and gaps in service.
- Increased referrals, especially from emergency departments and outpatient services, by distributing relevant information.

Washington
- Created a TBI tool kit for consumers.
- Developed a framework for public and professional education through product development and dissemination.
- Developed an interactive TBI educational series for rural and urban communities (in collaboration with the University of Washington's TBI Model System and the Idaho TBI program).

NOTE: See Appendix C, Table C-2 for information on the self-reported accomplishments of state TBI programs, by state.

SOURCE: Korda, 2005.

BOX 4-4
Selected Comments from TBI Stakeholders in the Seven Study States on Their State's TBI Resources

Successes

"Without the TBI Implementation HRSA grant providing funding to 'empower' persons with brain injury through our leadership training, New Mexico would not have had a chance of getting the New Mexico legislature to pass a bill to provide brain injury waiver services. Nor would the governor have been so influenced to sign the bill that became law."

"The HRSA grant stimulated the state to look at the whole system. The benefit was having money for an unrecognized population."

Frustrations

"What has turned states off are limited competitive 1-year grants. They're not worth the trouble."

"As state budgets continue to shrink there are few resources to focus on improving systems (data, developing outcomes, training, setting provider competencies) or expanding capacity. Federal funding needs to be available consistently so states may continue their work and maintain stability."

"The past and current funding level are just enough to whet the appetite, but insufficient for large states to make a significant impact. Equity in funding (per capita formula +) should be considered, plus performance of states and outcomes. Also the variation of needs and complexity of states MUST be taken into consideration, i.e. trust funds or TBI waivers may not be a panacea for every state. Active cooperation among state BIA [Brain Injury Association] and lead agency should be a must for continued funding."

"Sustainability and having to write a new grant every year is difficult and time consuming. Also, it was difficult to come up with new projects for 1 year at $100,000."

SOURCE: Robinson, 2005; Korda, 2005.

States that cultivate durable sources of TBI funding, such as trust funds, are more likely to sustain the service innovations that are initially developed with HRSA's grant support (Box 4-5).

In the absence of predictable, long-term funding, it is difficult to maintain the momentum of a grant-funded activity when the funds run out. Holding on to a project staff position, for example, is especially problematic in the context of irregular funding cycles and the uncertainty of competitive grant awards (Box 4-6).

BOX 4-5
Special TBI Trust Funds in the States

Eighteen states raise revenues for people with TBI through special trust funds. The revenues are generated by surcharges on traffic violations or fees related to motor vehicle or firearm registrations. The funds are used to pay for direct patient services, outpatient rehabilitation, transitional living services, adaptive equipment and home modifications; family supports such as respite services and psychotherapy groups; research and education; and awareness and prevention initiatives. In some states, trust funds have provided key financing for initiatives first developed through a HRSA TBI State Program Grant.

States' TBI trust fund revenues can be substantial. In 2004, annual trust fund revenues ranged from an estimated $500,000 in Missouri to $15 million in Florida. Alabama's trust fund, for example, is funded through $100 fines on each "driving under the influence" conviction; the fund generates an estimated $1.2 million annually and, in 2003, subsidized services for more than 1,300 individuals. California's trust fund receives 0.66 percent of state penalty fund revenues from vehicle code violations; this has been generating approximately $1 million annually.

In New Jersey, mentor and training programs first developed with HRSA TBI State Program Grant funding have been sustained by trust fund dollars. Alabama uses trust fund dollars for care coordination for children with TBI, a program that was created with a HRSA TBI State Program Grant. Georgia's trust fund supports the enhancement of the state's central TBI registry; it also makes direct payments up to $5,000 annually per recipient to eligible individuals.

Some states' trust funds serve people with spinal cord or other severe injuries, as well as people with TBI.

SOURCE: Korda, 2005; NASHIA, 2005.

Leveraging Medicaid coverage can help facilitate community-based TBI services. In fact, most states have either TBI-specific or generic home and community-based Medicaid waiver programs in place (Table 4-4). Yet in many states, it appears that budgetary concerns limit the number of slots for persons with TBI. Recent evidence suggests that resources might be freed up with increased use of waiver funds. Kitchener and colleagues analyzed national participation and expenditure trends for all TBI/spinal cord waivers during the period from 1995 to 2002. The researchers concluded that average Medicaid expenditures per waiver participant were two-fifths the average cost of institutional care (Kitchener et al., 2005).

HRSA's New Design for TBI State Program Grants in FY 2006

In August 2005, HRSA announced a new approach to its TBI State Grants Program for FY 2006 (HRSA, 2005). All future TBI State Program

BOX 4-6
Selected Comments from TBI Stakeholders in the Seven Study States on Their State's TBI Systems Improvement

Successes

"This grant funding was absolutely critical in moving Virginia forward regarding the development of a system of care to serve people with TBI. The information developed through the planning grant has been the justification for a number of initiatives, including the state legislature's approval of over $1 million of annual funding for community-based services. The project has also demonstrated (to many skeptics) the value to unserved areas of the Regional Resource Center concept."

"We are just now, after several years of HRSA funding, starting to see improved services and supports for families with TBI. The HRSA funding has been critical to linking families to necessary services, training service providers, and increasing brain injury awareness of policy makers. Systems change takes time and moving the program to more long-term funding will be beneficial."

Frustrations

"Because there was no funding source for continuing the outcomes of the grant no progress has occurred as a result, even though the grant resulted in an excellent plan for the future, with the exception of an 800 information line which the West Virginia Center of Excellence for Disabilities maintains out of their own budget now that the TBI funds are no longer available."

"The programs and infrastructure developed under our state's HRSA grant were amazingly effective in effecting systems change. However, as funding draws to a close, we are losing one of the 'change agents'—Regional Resource Coordinator—located throughout the state, as well as the central resource expertise located at Brain Injury of Virginia office . . . It has also been a challenge to keep the focus on systems change and not move toward service provision which is SO badly needed! It is also difficult to explain to survivors and families why the funds cannot be used to support programs and services."

SOURCE: Robinson, 2005; Korda, 2005.

Grants will be $100,000 annual Implementation Grants available for project periods up to 3 years; the requirement for states to implement the four core TBI infrastructure components—a statewide TBI advisory board, a lead state agency for TBI, a statewide assessment of TBI needs and resources, and a statewide TBI action plan—remains (Box 4-7). HRSA reports that there are sufficient funds for every state to qualify for a grant.

The committee believes that this change is a step in the right direction. Every grantee operates under unique political, socioeconomic, and geographic circumstances. Every state has a different historical context for

BOX 4-7
HRSA's Review Criteria for Implementation Grants Under the TBI State Grants Program, 2006

1 **Need** (15% of score)—The extent to which the application describes the problem and associated contributing factors to the problem.

2 **Response** (30% of score)—The extent to which the proposed project responds to the "Purpose and Goals" included in the program description. The clarity of the proposed goals and objectives and their relationship to the identified project. The extent to which the activities (scientific or other) described in the application are capable of addressing the problem and attaining the project objectives.
   (a) The extent to which the project will address the need for improved access, availability, appropriateness and or acceptability of services for individuals with TBI and their families including special populations.
   (b) The extent to which the project will incorporate the best practices and products in the field.
   (c) The extent to which the project will contribute to sustainable change.

3 **Evaluative Measures** (10% of score)—The effectiveness of the method proposed to monitor and evaluate the project results. Evaluative measures must be able to assess (1) to what extent the program objectives have been met, and (2) to what extent these can be attributed to the project.

4 **Impact** (10% of score)—The extent to which this project expands and improves state and local capability which, in turn, would enhance access to comprehensive and coordinated services for individuals with TBI and their families.
   (a) The extent to which the Lead Agency is able to make change across state systems.
   (b) The extent to which the Advisory Board is able to make policy change across state systems.

addressing TBI issues. Moreover, most states are beyond the initial stages of infrastructure building and planning. By essentially meeting grantees "where they are," the 2006 Implementation Grants will allow states to leverage HRSA funds for their specific situations.

THE IMPACT OF HRSA'S PROTECTION AND ADVOCACY FOR TBI (PATBI) GRANTS PROGRAM

Protection and advocacy (P&A) systems for people with disabilities in the states, territories, and the District of Columbia were initially required by Congress as a condition of receiving federal P&A funds under the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (P.L. 103-230, 1975). Thus, when Congress reauthorized HRSA's TBI Program in the Children's Health Act of 2000 and directed HRSA to implement the PATBI

5 **Resources/Capabilities** (25% of score)—The extent to which project personnel are qualified by training and/or experience to implement and carry out the project. The capabilities of the applicant organization, and quality and availability of facilities and personnel to fulfill the needs and requirements of the proposed project.
   (a) Qualifications and experience of the project director and other key personnel, including any proposed consultants and subcontractors.
   (b) Degree of commitment of proposed partners.
   (c) Clarity of proposed project's organizational structure.
   (d) Adequacy and availability of resources for conducting proposed project (for example, staffing, facilities, equipment and information technology).
   (e) Adequacy of proposed project's plan for managing personnel and resources.
   (f) Adequacy of proposed project's plan for monitoring and tracking project activities.

6 **Support Requested** (10% of score)—The reasonableness of the proposed budget in relation to the objectives, the complexity of the activities, and the anticipated results.
   (a) Degree of conformity of the budget request to the funding level stated in the Application Guidance
   (b) Degree to which the budget justification logically documents (in adequate detail), how and why the line item requests support the objectives and activities of the proposed project.
   (c) A detailed budget request, including a justification, is provided for each year of the 3-year project period.

SOURCE: HRSA, 2005.

Grants Program, there already existed an infrastructure of P&A systems to receive the new grants. Moreover, people with TBI-related disabilities, along with many other disabled persons, had long been eligible for P&A services before the PATBI Grants were distributed by HRSA.

It is difficult to discern whether any recent improvements in states' TBI systems and services can be attributed directly to HRSA's PATBI Grants Program (Box 4-8). Many TBI stakeholders in the seven states who were interviewed for this study agreed that the PATBI Grants have led their P&A systems to focus on TBI significantly for the first time. Unfortunately, comprehensive and objective data on the TBI-related activities of P&A systems in the states are not available.

The committee's commissioned interviews with PATBI grantees in seven states (Alabama, California, Colorado, Georgia, New Jersey, Ohio, and Washington State) revealed that P&A systems in the states are variable;

BOX 4-8
The Impact of HRSA's Protection and Advocacy for TBI (PATBI) Grants Program

FINDING:

The committee finds that it is too soon to know whether HRSA's 3-year-old PATBI Grants Program has meaningfully improved circumstances for people with TBI-related disabilities.

Nevertheless, PATBI Grants have led to new and much-needed attention to the protection and advocacy (P&A) concerns of people with TBI-related disabilities and their families.

- There is widespread sentiment among TBI stakeholders in the states that PATBI Grants have led state-based P&A systems to focus on TBI for the first time.
- Many stakeholders believe that PATBI Grants are too small to catalyze measurable improvements for persons with TBI.
- Currently available data are insufficient to assess the impact of HRSA's PATBI Grants Program. Furthermore, the extent to which persons with TBI are aware of P&A services in their communities is not known.

RECOMMENDATION:

The committee recommends that HRSA continue to fund the PATBI Grants Program.

- HRSA should contract with an evaluation expert (or obtain in-house expertise) to develop a rigorous but practical design for evaluating the PATBI program, including recommendations for how data should be collect and analyzed. The data must be credible, reliable, and consistent to ensure that evaluation findings are valid.
- HRSA should implement the PATBI evaluation plan as soon as is feasible.
- HRSA should encourage P&A systems in the states to increase public awareness of their services, particularly persons with TBI and their caregivers, health care providers, and others offering TBI-related services.

there is a wide range in their resources and service capacity. Most often, the PATBI Grants have been used in the states to provide information and referrals, to advocate for the special education needs of children with TBI, and to identify persons with TBI who may be inappropriately placed in nursing homes, mental health facilities, prisons, or other residential settings (Table 4-5).[5]

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[5] Additional information about the committee's commissioned survey of TBI stakeholders in the seven study states is presented in Appendix B (the interview used in the survey); Appendix D (profiles of TBI initiatives in the seven states); and Appendix E (consultant's report on TBI stakeholder interviews in the seven states). See Appendix C, Table C-3 for details on TBI-related goals and self-reported accomplishments of P&A systems in each of the 50 states.

TABLE 4-5 PATBI Grant Activities Reported by the Seven Study States, 2005

Alabama

- Alabama Disabilities Advocacy Program serves persons with TBI and other disabilities. Stakeholders say that before receiving the annual PATBI Grants, the program had limited capacity to serve persons with TBI.
- PATBI Grants have been used to locate inappropriately institutionalized persons with TBI in psychiatric or mental retardation settings, identify school children with TBI, develop community-based services for individuals with both mental illness and TBI, and training of law enforcement officers and clinical staff in mental health centers.

California

- California Protection and Advocacy, Inc. did not focus on TBI until receiving a PATBI Grant, although it has always served individuals with TBI within its general disability programs.
- PATBI Grants have been used to support a TBI Community Living Project to increase community living options.
- PATBI Grants have also been used to increase awareness of TBI activities in the community and that California's response to the Olmstead decision incorporates TBI-specific concerns.

Colorado

- Colorado Center for Legal Advocacy has three principal priorities for its PATBI Grant: training staff and recruiting a staff person with TBI, conducting a TBI needs and resources assessment to identify available services, and advocating for individuals with TBI.

Georgia

- Georgia Advocacy Office, Inc. provides support for all persons with disabilities; it did not focus on TBI until receiving a PATBI Grant.
- PATBI Grants have been used to fund a half-time TBI/Olmstead advocate who is responsible for identifying and helping persons who are inappropriately housed in nursing homes. The Georgia Advocacy Office is also developing TBI-specific special information and outreach.

New Jersey

- New Jersey Protection and Advocacy, Inc. did not focus on TBI until receiving a PATBI Grant, although it has always served individuals with TBI within its general disability programs.
- PATBI Grants have been used for planning and assessment; information and referral services; legal representation; outreach, training, and technical assistance (especially in communities of color); and promoting self-advocacy of persons.

Ohio

- Ohio Legal Rights Service has historically served persons with TBI, including participating in Ohio's Brain Injury Advisory Committee before the era of PATBI Grants.
- PATBI Grants have been used to identify and advocate for children with TBI; to educate parents, educators, and other professionals; and other activities.

continues

TABLE 4-5 Continued

Washington
- Washington Protection and Advocacy System serves all individuals with disabilities but did not focus on TBI until its first PATBI Grant from HRSA. The P&A system collaborates closely with the state TBI advisory board.
- Washington Protection and Advocacy System has used PATBI Grants to tailor its services to people with TBI, outreach to community providers, and collaborate with state and other agencies including the Washington TBI Model System.

SOURCE: Korda, 2005.

Many TBI stakeholders interviewed in the seven study states reported that the PATBI Grants have had the greatest impact in the areas of self-advocacy, consumer education, and training of parents and other caregivers (Box 4-9). They also agreed that most P&A systems collaborate closely with their corresponding state TBI program. In one state, P&A advocacy on behalf of children led to new legislation mandating expanded TBI screening of school children.

Nevertheless, a common perception among TBI stakeholders in the seven study states is that the PATBI Grants have not ameliorated the circumstances of persons with TBI, particularly with respect to improving access to community-based services, vocational training, housing, long-term supports, or protection in the judicial and correctional systems. That this perception exists is not surprising given that HRSA's PATBI Grants are quite modest, and the 3-year-old PATBI Grants Program has not had enough time to tackle such thorny and entrenched social problems.

ADEQUACY OF THE MANAGEMENT AND OVERSIGHT OF THE HRSA TBI PROGRAM

Administration of the HRSA TBI Program

The HRSA TBI Program has been administered by a less-than-skeletal staff—just one full-time individual—since its creation. The program has been shuttled from one division in HRSA's Maternal and Child Health Bureau to another—including the Division of Child, Family, and Adolescent Health, Special Projects of Regional and National Significance, and most recently, the Division of Services for Children with Special Health Care Needs (Martin-Heppel, 2005). It also has been threatened with debilitating cutbacks, most recently in January 2006 (DHHS, 2006).

Although the committee agrees that in the face of these significant challenges, the HRSA TBI Program contributed to improvements in state-

BOX 4-9
Selected Comments from TBI Stakeholders in the Seven Study States on Their State's P&A for TBI

Successes

"HRSA TBI funding has allowed the P&A to increase and focus more individuals and policy advocacy work on TBI issues and has played a CRITICAL role in supporting consumer/family involvement in public policy development."

"As a result of the grant, the agency was able to significantly increase the number of outreach and educational activities provided. The number of referrals and cases has increased as a result of the activity. Since the outreaches include information on all P&A activities, the number of inquiries, referrals, and cases has increased with the awareness of the agency's existence."

Frustrations

"Due to the very small size of the [HRSA PATBI] Grant, it has done little to increase our capacity to actually provide effective advocacy services except for a small handful of individuals, and in a sense, has possibly done harm by raising expectations in the community that we are not in a position to meet. The budget is inadequate for the P&A to even think about major litigation."

"Funding currently enables us to do some but not all of the work that is required on behalf of the TBI population of California. Our P&A is the only California entity that is working to protect and advance the rights of individuals with TBI in our state and therefore greater support in the future for our efforts is warranted if improvements in access to services and enforcement of the civil rights of individuals with TBI are to be realized."

"The amount of money is small for P&As, not enough for a dedicated staff member. I'd love a TBI specialist who also provides advocacy. That's one thing that has held us back. But it also means we all have to learn about TBI in the P&A—we can't say it is someone else's responsibility."

SOURCE: Robinson, 2005; Korda, 2005.

level TBI infrastructure and public awareness of TBI, it finds that HRSA's management and oversight of the program has been inadequate (Box 4-10). To date, perhaps because of insufficient resources, HRSA has not built a management infrastructure to allow for systematic review of either the HRSA TBI Program's strengths and weaknesses or the state grantee evaluations and final reports that HRSA requires. There is no evidence that HRSA has ever enforced its mandate that TBI grantees in the states conduct program evaluations. However, the TBI Technical Assistance Center (TAC) has developed a self-assessment tool and benchmarks to help states gauge

BOX 4-10
Adequacy of the Management and Oversight of the HRSA TBI Program

FINDING:

The committee finds that the management of the TBI Program is inadequate to assure public accountability at the federal level and to provide strong leadership to help states continue their progress toward improving systems for persons with TBI and their families.

- From its beginning in 1997, only one full-time individual—the program director—has staffed the TBI Program. The HRSA program director position has turned over four times.
- The program has been designed to stimulate public-private entrepreneurship in the states as a relatively open-ended process, with little feedback built in. The program demands more formal accountability, particularly at its present level of maturity.
- HRSA should be commended for funding the TBI Technical Assistance Center (TBI TAC), which has become an essential resource for both federal and state agencies. TBI TAC is widely praised for facilitating the work of and providing technical assistance to state agencies, Brain Injury Associations, protection and advocacy organizations, and other stakeholders.
- HRSA has shown only token attention to evaluating its TBI Program. Program rules require that state grantees conduct evaluations, but the rules have not been enforced and states are ill equipped to conduct technical evaluations.

RECOMMENDATION:

The committee recommends that HRSA lead by example—that it instill rigor in the management of the HRSA TBI Program and build an appropriate infrastructure to ensure program evaluation and accountability. Thus, the committee recommends that HRSA do the following:

- Ensure that the TBI Program develops an "evaluation culture," including a strategy for collecting and maintaining program data that are credible, reliable, and consistent; analytic expertise in evaluation methods and TBI (either in-house or via contract); and collaborative partnerships with program partners or sister agencies to leverage resources and expertise.
- Appoint a national HRSA TBI Program Advisory Board as soon as possible. The board's initial tasks should include articulating a vision for the program; developing an action plan for HRSA that includes a blueprint for ongoing data collection and program evaluation; and ensuring adequate program resources.
- Advocate for and support TBI grantees by pressing relevant federal agencies to furnish needed data and to address TBI in eligibility rules for other federal programs; keep track of emerging issues in state TBI programs; serve as a national information resource on the special needs of individuals with TBI; and disseminate information on best practices.
- Oversee the TBI TAC contract, including reassessing which HRSA TBI Program activities are optimally performed by TBI TAC.

their progress *vis a vis* infrastructure development—these provide a useful starting point for program monitoring.[6]

HRSA should plan and implement—for both grantees and itself—a standardized reporting system to ensure basic accountability and program evaluation. The committee recognizes that doing this may require additional funds and a modest expansion in the HRSA TBI Program's administrative capacity.

The committee urges the HRSA TBI Program to exercise strong leadership on behalf of the state grantees. Indeed, the program should embody many of the characteristics it demands of the grantees. It should serve as a national information resource on the special needs of individuals with TBI, keep track of emerging issues in state TBI programs, and disseminate information on best practices. It should also advocate for the TBI grantees, by, for example, pressing sister federal agencies to furnish needed data and to address TBI in eligibility rules for other federal programs.

Just as the state TBI programs do, the HRSA TBI Program needs the guidance of an actively engaged advisory board to help garner resources and to develop a vision and action plan for the future. There should be a formal process for appointing the advisory body, and the appointees should represent the relevant federal agencies, state and national brain injury associations, professional groups, TBI protection and advocacy systems, persons with TBI, and family members or other caregivers.

The HRSA TBI Program's collaboration with other federal agencies involved in TBI-related activities is paramount. The 1988 Interagency Head Injury Task Force has apparently been defunct for years. Although there is some evidence of interagency activity regarding TBI, such as the Federal Interagency Conference on Traumatic Brain Injury, it appears to be *ad hoc* and irregular. It is not enough to stimulate true collaboration that builds on the unique strengths and resources of the various federal agencies.

The committee urges HRSA to issue and lead a formal call for active, interagency action including at a minimum the Centers for Disease Control and Prevention, National Institute on Disability and Rehabilitation Research, National Center for Medical Rehabilitation Research, Defense and Veterans Brain Injury Center, and Substance Abuse and Mental Health Services Administration. The Interagency Committee on Disability Research may be a model worth emulating.[7]

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[6] The TBI TAC benchmarks are available at http://www.nashia.org/grantee/tote/TBI%20Program%20Benchmarks.pdf. The self-assessment tool is at http://www.nashia.org/grantee/tote/Self%20Assessment%20Tool%20-%20State%20TBI%20Program.pdf.

[7] For information on the Interagency Committee for Disability Research, go to http://www.icdr.us.

TBI Technical Assistance Center (TBI TAC)

Many of the HRSA TBI Program's administrative duties are the responsibility of its Technical Assistance Center, called TBI TAC.[8] TBI TAC is in essence HRSA's *de facto* TBI program staff. Since 2002, TBI TAC has been operated under a contract between HRSA and the National Association of State Head Injury Administrators (NASHIA).[9] TBI TAC's activities include the following:

- *Providing general technical assistance* to HRSA TBI Program grantees.
- *Maintaining an e-mail listserv* that allows HRSA TBI Program grantees and other participants to post inquiries, disseminate funding announcements, share best practices, and other program materials. In 2005, listserv messages covered a wide range of topics including Medicaid TBI waiver design, nursing home transitions, return to work, grants watch and other funding ideas, program assessment tools, training and education, services for special populations (e.g., young adults, students), domestic violence, policy development, and protection and advocacy.
- *Providing TBI program benchmarks* for states to assess their progress in establishing the core components of a TBI infrastructure; state participation is optional (TBI TAC, 2005).
- *Maintaining the TBI Collaboration Space or TBICS* (http://www.tbitac.nashia.org/tbics/), an online database for grantees and others affiliated with the HRSA TBI Program. The regularly updated database includes recent and archived documents related to action plans, advisory boards, lead agencies, needs and resources assessment methods, program evaluation, funding strategies for sustainability (e.g., trust funds, Medicaid waivers), data issues, product and policy development, public education and training, collaboration and coalition building, and service coordination.
- *Sponsoring national meetings and webcasts related to TBI.*

TBI TAC is highly regarded by state grantees and other stakeholders. It has clearly become an essential resource and information forum. Contracting out technical assistance to NASHIA has the advantage of utilizing cross-state experience and knowledge about TBI by an organization representing individuals working in the field at the state level. Currently, however, the lines of responsibility between the HRSA program office and TBI TAC are blurred; many individuals interviewed for this study remarked that they were confused about the respective roles of HRSA and TBI TAC. Further-

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[8] See Chapter 1 for additional information on TBI TAC.

[9] The Children's National Medical Center (Washington, D.C.) held the TBI TAC contract from 1997 to 2002.

more, the committee questions the extent to which the TBI TAC assumes delegated administrative and oversight functions for the federal government. As an entity of NASHIA, the national membership association for state TBI program officials and other individuals concerned with state and federal brain injury policy, it represents the very agencies that seek HRSA funding.

The committee urges HRSA to evaluate the TBI TAC in order to learn how it might best serve the TBI program and its grantees. HRSA should also carefully assess which of its TBI Program activities are optimally performed by TBI TAC (versus the HRSA program office).

SUMMARY

In the years since the HRSA TBI Program's implementation in 1997, there has been demonstrable improvement in two essential preconditions for improving TBI service systems—state-level TBI systems infrastructure and the overall visibility of TBI have grown considerably. The committee is impressed with what has been done and rates the HRSA TBI Program overall a success. There is considerable value in providing small-scale federal funding to catalyze state action. Nevertheless, substantial work remains to be done at both national and state levels.

So far, the HRSA experience shows that no two state TBI programs have evolved in the same way. Not surprisingly, states with established leadership, interagency cooperation, and/or a CDC-sponsored TBI data collection, have been better positioned to use the TBI grants more quickly and effectively than other states. Yet serendipity also plays a part; there is no substitute for having an influential policy maker who champions the TBI cause.

The committee also believes that management and oversight of the HRSA TBI Program has been inadequate. HRSA has shown only token attention to evaluation of the state grantees or the HRSA TBI Program itself. The states are ill equipped to conduct technical evaluations and require constructive guidance in this area.

Since its implementation, the HRSA TBI State Grants Program has been handled as a grant program designed to establish four core TBI organizational and strategic components in each state but to allow considerable state variation. This approach was realistic in two ways: (1) by recognizing the different bases on which improvement might take place in different states (some already organized for TBI, others not); and (2) by encouraging entrepreneurship and innovation. TBI TAC has provided valuable assistance as an information base and a spur for diffusion of innovation across the states.

The committee concludes that it is too soon to know whether HRSA's 3-year-old PATBI Grants Program has meaningfully improved circumstances for persons with TBI. It appears that P&A systems for people with disabilities in the states have begun to focus on TBI significantly for the first time. To evaluate the impact of the PATBI Grants, HRSA should collect data on P&A systems TBI-related activities. In addition, HRSA should ensure that people with TBI-related disabilities and their families are aware of P&A services in their communities.

Further progress in the development of TBI systems and services in the states will be elusive if HRSA does not address the program's fundamental need for greater leadership, data systems, additional resources, and improved coordination among federal agencies. It is worrisome that the modestly budgeted HRSA TBI Program has been vulnerable to budget cuts. The states are now at a critical stage and will need continue federal support if they are to build an effective, durable service system for meeting the needs of individuals with TBI and their families. The state TBI programs will find it difficult to maintain the momentum of HRSA grant-funded TBI activities when the HRSA funds run out. The HRSA TBI Program should be a priority for HRSA.

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APPENDIX A

Methods of the Study

In the spring of 2005, the Institute of Medicine (IOM) was asked by the Health Resources and Services Administration (HRSA) to perform an assessment of the impact of the HRSA Traumatic Brain Injury (TBI) Program focusing on (1) how state systems are working or failing to work in support of individuals with TBI; and (2) how HRSA could improve the program to best serve individuals with TBI and their families. The study focuses on whether the TBI Program has led to an expansion in state systems infrastructure as a *precondition* for better serving persons with TBI and their families. It is not a technical evaluation of the HRSA TBI Program's impact on either the delivery of TBI-related services or on person-level outcomes—such an analysis is not feasible given currently available data (as noted in chapters 2 and 3 of this report).

The committee used a qualitative study method to assess the TBI Program's impact. Qualitative methods are often used in health services research to investigate developing institutions and systems as well as to assess the impact of government programs (Caudle, 1994; Sofaer, 1999; Newcomer and Scheirer, 2001; World Bank Group, 2005). Qualitative data were gathered from a variety of sources and were analyzed for key themes and recurring issues. Primary sources of data included semi-structured interviews with TBI stakeholders in seven states and representatives of selected national organizations (a requirement of the IOM/HRSA agreement), research literature and TBI program materials, and relevant survey data.

The committee's approach to the selection of the states and stakeholder interviews in those states is described in this appendix, along with other methods used in the study, including the literature review, committee meetings, and a public workshop.

DATA LIMITATIONS

The data used in this study had important limitations. Comprehensive, standardized analytic information on the Federal TBI Program is not available. The National Association of State Head Injury Administrators (NASHIA) *Guide to State Government Brain Injury Policies, Funding and Services* is the only source of comprehensive information on the characteristics and activities of state TBI programs (NASHIA, 2005). The guide, although informative, draws primarily from self-reported data from state TBI programs. The data are neither standardized nor audited. States do not use a standard diagnostic definition of TBI nor is there a standard terminology for describing TBI services. One state, for example, may define "personal care" as a single service, while another state uses the same term to describe a range of assisted living or residential supports. Eligibility for state TBI services also varies; for example, some programs target adults only, while other programs also serve children.

As described below, the study used information gathered in interviews with TBI stakeholders in seven states and representatives of selected national organizations. The state-based interview informants were not disinterested participants; they were either state officials of the respective state TBI programs or other individuals identified by the state agencies. These individuals could be motivated by an interest in perpetuating federal funding.

LITERATURE REVIEW

Staff searched the primary scientific literature via Medline and collected TBI program data and relevant materials from HRSA, other federal agencies, and state TBI programs; the TBI Technical Assistance Center (TBI TAC), NASHIA, Brain Injury Associations, federally mandated protection and advocacy (P&A) systems in the states, and others.

COMMITTEE MEETINGS AND PUBLIC WORKSHOP

The committee met eight times by telephone conference and held two in-person meetings to formulate its approach to the study, review the data collected, and develop the report. The first in-person meeting included a 1-day public workshop to gain the perspectives and assessments of experts and key stakeholders. Box A-1 presents the workshop agenda, which included presentations from researchers, state TBI program directors, representatives of federal agencies and nonprofit organizations, and individuals with family members with TBI.

IN-DEPTH LOOK AT TBI INITIATIVES IN SEVEN STATES

The committee agreed to study seven state TBI programs to collect qualitative (interview) data and additional data, where it existed, on states' experiences with the HRSA TBI Program. Over the course of several meetings, as discussed below, the committee formulated a conceptual framework, developed selection criteria and picked the seven states, developed an interview guide for use in the seven states, and identified the respondent pool. It accomplished these activities with the full-time support of a staff consultant, Holly Korda, Ph.D., Principal, Health Systems Research Associates, Chevy Chase, Maryland, whose final report is presented in Appendix E.

Conceptual Framework

The basic premise of the HRSA TBI Program is that with the modest investment of federal funds, states will build necessary infrastructure, create channels of communication between relevant agencies, and integrate the disparate systems that serve the TBI population—while also finding the means to sustain these efforts. Figure A-1 illustrates the linkages between the HRSA TBI Program and the myriad state, federal, local, public, and private organizations that relate to persons with TBI and their families.

Although the intended long-term outcome of the HRSA TBI Program is improved health and quality of life for persons with TBI and their families, the committee recognized, as had the federal Office of Management and Budget's Program Assessment Rating Tool study before it in 2004, that it was impossible to evaluate the HRSA program on the basis of clinical outcomes data, which were nonstandardized, inadequate, and/or nonexistent. For that reason, the committee focused instead on demonstrable organizational and strategic change associated with the program, such as infrastructure development, education and training of relevant personnel, planning and implementation of new services, and the development of outreach services to persons with TBI and their families.

Selection of the Seven States for an In-Depth Look

A series of tables detailing the characteristics and self-reported accomplishments of the 50 state TBI programs and federally mandated P&A systems in the states appears in Appendix C. The data in these tables were

BOX A-1
Agenda for IOM Workshop on Traumatic Brain Injury
July 18, 2005

8:30 **Welcome and Introduction**—*Rosemary Stevens, Chair, IOM Committee on Traumatic Brain Injury*

8:40 **The Epidemiology of TBI**—*Jean Langlois, Senior Epidemiologist, National Center for Injury Prevention and Control, Centers for Disease Control and Prevention*

9:15 **Background and History of the HRSA TBI Program**
- Legislative History and Challenges for the States—*Susan Vaughn, Director of Public Policy, National Association of State Head Injury Administrators (NASHIA)*
- History of the HRSA TBI Program—*Jane Martin-Heppel, Director, HRSA TBI Program*

10:00 **Break**

10:15 **Video**

10:30 **TBI Resource Facilitation: Clinical, Psycho-Social, Services Challenges**
- Many Services, Many Types of Care—*Susan Connors, CEO and President, Brain Injury Association (BIA) of America*
- TBI Needs and Challenges among Native Americans—*Alta Bruce, President, Indigenous People's BIA and Injury Prevention Specialist, Indian Health Service*

11:15 **TBI Model Systems Program**—*Ruth Brannon, Associate Director, Division of Research, National Institute on Disability and Rehabilitation Research*

drawn from materials provided to the committee by state and federal TBI programs, the TBI Technical Assistance Center (TBI TAC), and NASHIA.

The committee found the national data to be very helpful in indicating activities as reported for grant purposes by different states, but it concluded that the data were not sufficiently standardized to form a study population from which statistically representative states could be drawn. The committee noted, in addition, that each state's experience with the HRSA program was contingent on the prior history and organizational context of TBI services in that state.

After reviewing this information, the committee concluded that the state programs were too diverse, and the study's resources too limited, to

11:45 Lunch

12:30 HRSA TBI Technical Assistance Center (TBI TAC)
- Role of TBI TAC and State Technical Assistance—*Ken Currier, Acting Executive Director, NASHIA, and Director, TBI TAC*
- Demonstration of TBI Collaborative Space, Benchmarks, Other Tools—*Rebecca Zeltinger, TBITAC Director of Knowledge Exchange*

1:15 TBI State Grantees and Stakeholders Speak on the Program
- History of the Disability Legal Advocacy Network—*Curt Decker, Executive Director, National Association of Protection and Advocacy*
- Consumer Perspectives—*Jan Brown, Member, TBI Technical Assistance Center Steering Committee and Carolyn Rocchio, Family member, Florida Brain Injury Association*

2:00 Break

2:15 Leveraging HRSA Funds to Improve Access to TBI Services and Systems
- National Overview—*Bill Ditto, Director, New Jersey Division of Disability Services*
- Empowering People with TBI and Legislative Change—*Bil Schmidt, New Mexico TBI Program Director and Beverly James, Participant, NM "Empowerment" Program*
- Using State Data for TBI Systems Change—*Manfred Tatzmann, Director, Michigan TBI Program*
- Moving from HRSA Program Funding to Sustainability—*Augusta Cash, Alabama TBI Program Director*

4:15 Discussion: What Have We Learned? Where Do We Go from Here?—*Rosemary Stevens*

4:45 Adjourn

identify a group of seven states that would represent the full range of TBI experiences. Because the number of states was limited by budget considerations, the committee's criteria for selection focused on identifying seven states with diverse state experiences that would signal major successes and failures, as well as common themes.

Several criteria were used to select the seven states for in-depth study—for example, participation in the HRSA TBI Program, state TBI funding, locus of the lead state agency for TBI, geographical diversity, etc. (For the rationale for each selection criterion, see Table A-1).

Ultimately, the committee asked seven states—Alabama, California, Colorado, Georgia, New Jersey, Ohio, and Washington State—to partici-

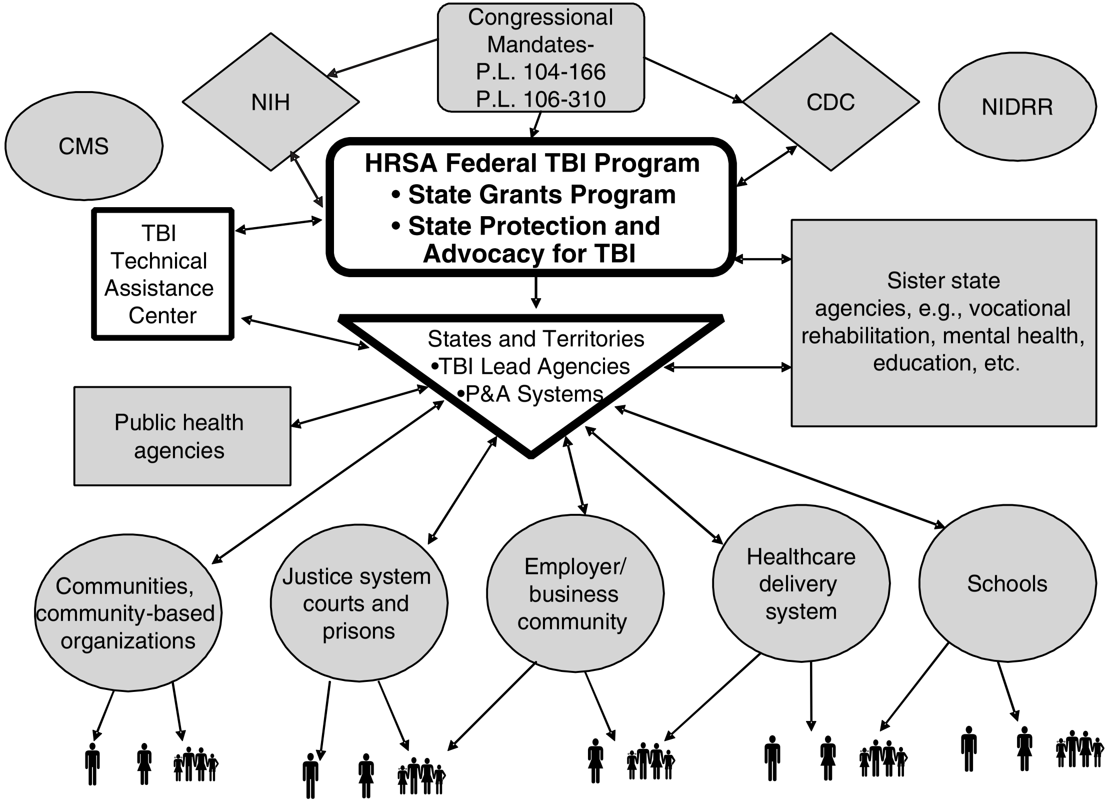

FIGURE A-1 Linkages between the Federal TBI Program and other entities.

TABLE A-1 The Committee's Criteria for Selecting Seven States for an In-Depth Look

Criterion	Description	Rationale
Participation in the Federal TBI Program	Type of TBI Program Grant received by the state from the Health Resources and Services Administration (HRSA)—TBI Planning Grant, TBI Implementation Grant, and/or TBI Post-Demonstration Grant)—and duration of the grant received.	In 2005, 2 states had a TBI Planning Grant; 10, a TBI Implementation Grant; and 0, a Post-Demonstration Grant. Past history: 37 states had previous Planning Grants; 40, Implementation Grants; and 23, Post-Demonstration Grants. Some states appear to have moved swiftly and effectively after receiving TBI Program Grant funding from HRSA; other states had not moved beyond modest planning activities.
State TBI funding	TBI trust fund, Medicaid waiver, or dedicated state TBI funding.	The relative importance of Federal TBI Program Grants to states depends on other state funding sources. States with highly developed TBI programs often have TBI trust funds, TBI-specific or other Medicaid waivers, or other dedicated state funding. Less developed TBI programs draw from general state funds.
Locus of the lead state agency for TBI	State agency with lead authority for TBI (appointed by the governor)	The state agency with lead authority for TBI programs varies considerably and may affect the program's effectiveness, especially as the need for integration of TBI services becomes increasingly complex.
Other	Region, urban/rural, cultural diversity, data systems, and participation in the TBI Model Systems Program.*	The potential impact of a Federal TBI Program Grant to a state may be compromised or enhanced by any of these factors.

*The National Institute on Disability and Rehabilitation Research (NIDRR) provides grants to 16 state TBI Model Systems, programs that develop and conduct research on TBI service delivery systems.

TABLE A-2 Dedicated State Funding for TBI in the Seven States

	Dedicated State Funding (in $ millions)		
State	Trust Fund	Medicaid Waiver	General Funds
Alabama	$1.2		
California	$1.1		
Colorado	$2.5	$5.2	
Georgia	$2.3		
New Jersey	$3.4	$14.6	
Ohio			$.346
Washington			

SOURCE: TBI TAC, 2005.

TABLE A-3 Participation in the Federal TBI Program by the Seven States

	Federal TBI Program Grant Received			
State	TBI Planning Grant	Implementation Grant	Post-Demonstration Grant	Protection and Advocacy for TBI (PATBI) Grant*
Alabama	—	√	√	√
California	√	—	—	√
Colorado	√	√	√	√
Georgia	√	√	√	√
New Jersey	—	√	√	√
Ohio	—	√	√	√
Washington	√	√	—	√

*All 50 states receive PATBI Grants.

SOURCE: TBI TAC, 2005.

pate in the interviews (and all agreed).[1] These states were selected as the likely best representatives of the considerable state-to-state differences in their preparedness for applying for and using these grants. Tables A-2 to A-5 provide details on selected features of the TBI programs in the seven states.

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[1] See Appendix D for detailed profiles of TBI initiatives in each of the seven sample states, including the states' HRSA grant histories; resources; services for people with TBI and their families; interorganizational collaboration and coordination; TBI-related data, monitoring, and evaluation; and successes and challenges of the HRSA grant experience.

TABLE A-4 Locus of the Lead State Agency for TBI in the Seven States

State	Lead Agency
Alabama	Department of Rehabilitative Services
California	Department of Mental Health
Colorado	Office of Behavioral Health & Housing, Department of Human Services
Georgia	Brain and Spinal Injury Trust Fund Commission
New Jersey	Division of Disability Services, Department of Human Services
Ohio	Rehabilitation Services Commission
Washington	Aging and Disability Services Administration, Department of Social and Health Services

SOURCE: TBI TAC, 2005.

Interview Guide Developed by the Committee

Appendix B presents the interview guide developed by the committee for the interviews with TBI stakeholders in the seven states. The committee structured the guide so that it could be used for a 45-minute, in-person, or telephone interview. The interview questions were formulated

TABLE A-5 Other Pertinent Characteristics of the Seven States

	TBI Data Systems				
State	Percent Rural Population	TBI Registry	Trauma Registry	CDC TBI Surveillance[a]	TBI Model System[b]
Alabama	44.6	√	√	√	√
California	5.6	—	—	√	√
Colorado	15.5	—	√	√	√
Georgia	28.4	√	√	—	—
New Jersey	5.6	—	√	√	√
Ohio	22.6	—	√	—	√
Washington	18.0	—	√	—	√

[a] Alabama, California, Colorado, and New Jersey have received Centers for Disease Control and Prevention (CDC) grants for TBI surveillance. Alabama and Colorado participate in other CDC TBI data projects, medical records studies, and a TBI follow-up registry (Colorado only).

[b] The National Institute on Disability and Rehabilitation Research (NIDRR) provides grants to 16 state TBI Model Systems, programs that develop and conduct research on TBI service delivery systems.

SOURCE: TBI TAC, 2005; U.S. 2000 Census Data.

to learn respondents' perceptions in eight areas: (1) the background and context for state TBI activities; (2) HRSA Grant Program participation; (3) TBI services and the impact of the grants; (4) TBI program monitoring and evaluation; (5) state TBI data sources and uses; (6) experience with the TBI TAC; (7) experience as a HRSA TBI Program grantee; and (8) expectations for the future. The committee structured the interview guide to be flexible and open-ended, recognizing that there was wide variation in TBI programs, interview participants, and strategies used to develop TBI infrastructure in different states.

Selection of Interview Respondents

For reasons of efficiency, the committee asked the TBI lead agencies in the states to help identify potential respondents representing TBI interests in the state, including the lead state agency for TBI, the independent P&A system, the Brain Injury Association, the state agency responsible for injury prevention, TBI trust funds, Medicaid waiver programs, and persons with TBI or family members.

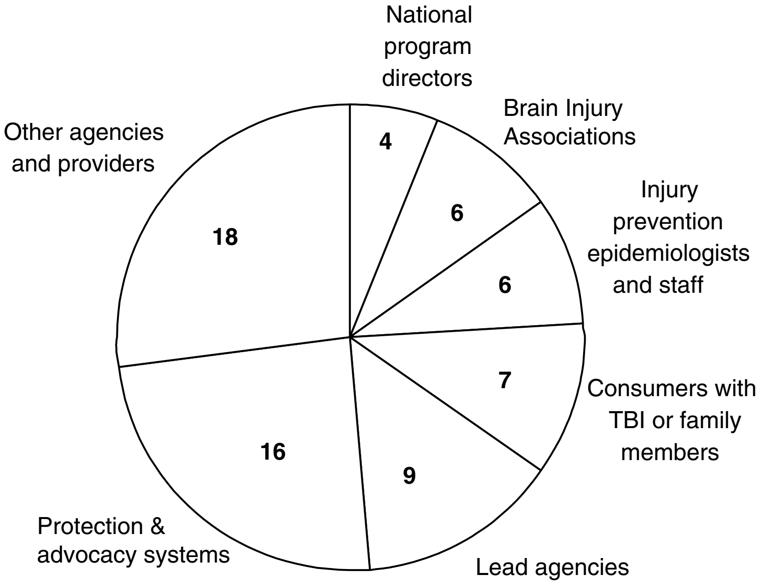

FIGURE A-2 Interview respondent pool by organizational affiliation.

Telephone or in-person interviews were conducted with one or more representatives from the various state agencies and organizations. In two states, Georgia and Colorado, the interviews were conducted in person and held as part of 2-day site visits by consultant Holly Korda, committee chair Rosemary Stevens, and study director Jill Eden. In addition to conducting the interviews, the IOM group toured and met with officials of two state-of-the-art rehabilitation facilities: the Shepherd Center in Atlanta and Craig Hospital outside of Denver. Figure A-2 shows the final makeup of the respondent pool by organizational affiliation.

Interviews were also conducted with the leaders of the following national organizations: HRSA TBI Program, NASHIA, TBI TAC,[2] Brain Injury Association of America, and National Disability Rights Network.[3] During the study period, the Brain Injury Association of America and NASHIA conducted an independent, online survey of stakeholders in all 50 states and the District of Columbia; those results too were made available to the committee.

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[2] NASHIA and TBI TAC are led by the same individual.

[3] Formerly the National Association of Protection and Advocacy Systems, Inc.

APPENDIX B

Interview Guide Developed by the IOM Committee on Traumatic Brain Injury with the Assistance of Holly Korda, Ph.D.

TBI Interview Guide
Institute of Medicine (IOM) Study on the Health Resources and Services Administration (HRSA) TBI Program

Thank you for participating in this phone interview on your state's experience with the HRSA TBI Program. Your interview is one of many conducted in seven states for an IOM study on TBI. The purpose of the study is to evaluate and recommend improvements to the Program. The purpose of this interview is to learn how the Program has helped states meet the many complex needs of individuals with TBI and their families. Learn more about the IOM study at www.iom.edu/project.asp?id=27723.

The telephone interview will be about 40-50 minutes. This guide will facilitate the discussion. Not all questions pertain to all respondents. All responses are confidential; your name will not be revealed.

Please contact Holly Korda, consultant to the IOM study, with questions about the interview at: hkorda@aol.com, or Jill Eden, IOM Study Director, with questions about the study at: jeden@nas.edu.

Respondent Name: ____

Job title/position: ____

Organization: ____

City/State: ____

History of TBI Grant Awards:

Grant Type	Years Awarded
Planning	__________
Implementation	__________
Post Demonstration	__________

I. Background/Context of State TBI Activities

1. Please describe TBI service delivery and coordination in your state <u>at the time you first applied for a HRSA TBI grant</u>.

1.a. Did your state/organization already have a TBI-specific program in place?

Yes __ No __ Don't know __

Please explain: ____
____

1.b. What did your state/organization expect to gain from the Program? *(Check all that apply)*

- __ Funding for TBI-related activities not paid by the state
- __ Catalyst for attention to TBI in my state/organization
- __ Information sharing/networking with other state TBI programs
- __ Technical assistance from HRSA re: TBI service coordination, best practices
- __ Technical assistance from the TBI Technical Assistance Center
- __ Other (specify): ____

1.c. Did your state perceive any drawbacks to participating? (*check all that apply*)

- __ Potential amount of grant funding too limited
- __ Requirement for state matching funds
- __ Concern about challenges of coordinating state agencies and other services
- __ HRSA TBI Program directives were not relevant or priorities
- __ Other (specify): ____

II. Grant Program Participation

2. Describe your state's experience with each type of HRSA TBI grant *(see below).*

2.a. ***Planning grants*** *allow states to build infrastructure through the TBI Program's four core components—1) establishing a TBI Statewide Advisory Board, 2) identifying a Lead Agency, 3) conducting a Needs and Resources Assessment, and 4) developing a TBI State Action Plan.*

2.a.1. When your state applied for a Planning Grant, how were grant priorities established? *(Check all that apply)*

- __ Lead agency determined the grant priorities
- __ State agencies that provide TBI-related services decided jointly
- __ State agencies, advocates, and other stakeholders decided jointly
- __ Other (specify): ______________________________________
- __ Don't know
- __ Not applicable—state did not have a Planning Grant (skip to 2.b)

2.a.2. What were the greatest challenges and successes in developing or expanding the four required core components of a TBI Planning Grant *(see below)?*

Statewide TBI Advisory Board: *Development of a Statewide TBI Advisory Board within the appropriate health department of the state or within another department as designated by the chief executive officer of the state. The Board's composition must include representatives of the involved state agencies; public and nonprofit private health-related organizations; disability advisory or planning groups; members of an organization or foundation representing individuals with TBI; state and local injury control programs if they exist, and a substantial number of individuals with TBI or their family members.*

i. Successes: ____
____

ii. Challenges: ____
____

Lead Agency: *Designation of a state agency and a designated staff position responsible for coordination of state TBI activities.*

i. Successes: ____
____

ii. Challenges: ____
____

Needs & Resources Assessment: *Statewide needs and resources assessment, with an emphasis on resources, completed or updated within the last five years, of the full spectrum of care and services from initial acute treatment through community reintegration for individuals of all ages having TBI.*

i. Successes: ____
____

ii. Challenges: ____
____

TBI State Action Plan: *Development of a Statewide Action Plan to develop a culturally competent comprehensive community-based system of care that encompasses physical, psychological, educational, vocational, and social aspects of TBI services and addresses the needs of individuals with TBI as well as family members.*

i. Successes: ____
____

ii. Challenges: ____
____

2.a.3. Did the HRSA Planning Grant yield particular benefits that your state could not have obtained without the grant?

Yes __ No __ Don't know __ Not applicable __

Please explain: ____
____

2.b. ***Implementation Grants** allow states to undertake activities, e.g., implementation of the State Action plan or activities to address identified needs, to improve access for individuals with TBI and their families.*

2.b.1. When your state applied for an Implementation Grant, how were grant priorities established? If the state did not apply for an Implementation Grant, why not?

Please explain: ____
____

2.b.2. What were the greatest challenges and successes in carrying out the Implementation Grant? *(see below.)*

i. Successes: ____
____

ii. Challenges: ____
____

2.b.3. Did the HRSA Implementation Grant yield particular benefits that your state could not have obtained without the grant?

__ Yes __ No __ Don't know __ Not applicable

Please explain: ____
____

2.c. ***Post-Demonstration Grants** authorized by the Children's Health Act of 2000 have been available to allow states that have completed three years of implementation to support specific activities that will help States build TBI capacity.*

2.c.1. When your state applied for a Post-Demonstration Grant, how were grant priorities established? If your state did not apply, why not?

Please explain: ____
____

2.c.2. What were your state's greatest challenges and successes in applying its TBI Post-Demonstration Grant(s)? *(see below.)*

i. Successes: ____
____

ii. Challenges: ____
____

2.c.3. Did the HRSA Post Demonstration Grant(s) yield particular benefits that your state could not have obtained without the grant(s)?

Yes __ No __ Don't know __ Not applicable ___

Please explain: ____
____

III. State TBI Services and Program Impact

3.1. Coordination of TBI-related services (e.g., education, vocational rehabilitation, justice system, employment, housing, transportation, and behavioral health)

3.1.a. How are TBI-related services coordinated across agencies in your state?

__ There is neither formal nor informal coordination of TBI services.
__ Services are coordinated informally, based on interpersonal referral.
__ Case management and referral services have been developed.
__ There is an established network linking multiple agencies, e.g., education, vocational rehabilitation, SSI, disability, others.
__ Other (specify): ____

Please describe: ____
____

3.1.b. What are the greatest challenges to effective service coordination in your state? *(specify)*
____
____

3.1.c. What are your state's greatest successes in improving services for persons and families with TBI? *(specify)*
____
____

3.1.d. What changes or improvements in service coordination in your state, if any, would you attribute to participation in the HRSA TBI Program? *(Provide examples.)*
____
____

3.2. Which TBI-related services do people with TBI and their families find hardest to access? *(Provide examples.)*

____
____

IV. TBI Program Monitoring and Evaluation

4.1. Program impact on persons with TBI and families

4.1.a. Does your agency/organization monitor or evaluate the impact of TBI-related services on persons with TBI and their families? (*Distinguish between activities of inter-organizational/ statewide efforts by Lead Agency and other agencies/organizations with specific TBI interests.)*

Yes __ No__ Don't know __ Not applicable __

If yes, please describe: ____
____

4.1.b. Please provide a case example of an individual with a TBI and/or family member who has benefited from activities funded by your HRSA grant(s)? *(Specify which type of grant.)*

____
____

4.1.c. Describe the hard-to-reach groups in your state's TBI population *(e.g., urban/rural, racial or ethnic minorities, etc.)*

____
____

4.1.d. Describe your state's efforts (if any) to address cultural competence issues in serving persons with TBI.

____
____

4.1.e. How is your state addressing Olmstead decision requirements for states to provide community-based alternatives to institutional placements?

____
____

4.1.f. How, if at all, does your HRSA TBI program interact with other federal/state programs that address TBI? *(Please explain.)*

- CDC TBI programs: ____
- Medicaid (including waiver programs): __________________________________
- NIDRR TBI Model Systems: ____
- NIH TBI Clinical Trials Network: ____
- Protection and Advocacy System: _______________________________________
- Other (specify): ____

4.1.g. Please describe how your state's Protection and Advocacy System has addressed the needs of persons and families with TBI.

____
____

4.2. Program Impact on State Service Coordination for Persons with TBI and their Families

4.2.a. Does your agency/organization monitor or evaluate its grant or non-grant-supported TBI services for persons with TBI and their families? (*Distinguish activities of inter-organizational/statewide efforts by Lead Agency and other agencies/organizations with specific TBI interests)*

Yes __ No__ Don't know__ Not applicable __

If yes, please describe: ____
____

4.2.b. Please provide an example of how your state used HRSA grant funds to improve service coordination for individuals with TBI and their families.

____
____

4.2.c. If there was a time when your state's HRSA grant funds were insufficient to address an important TBI program need, please describe.

____
____

4.2.d. Can you provide an example of a *sustained* improvement to your state's TBI system that originated from a HRSA grant?

Yes __ No __ Don't know __ Not applicable __

How was sustainability achieved? *(Please explain.)* ______________________________
____

V. State TBI Data Sources and Uses

5.1.a. Describe how the following data sources been used to monitor or improve TBI services.

Data Sources	Data uses (e.g., program monitoring, evaluation, service improvements)	Comment
TBI surveillance system		
State TBI Registry		
Consumer satisfaction surveys		
Medicaid data		
Protection & Advocacy system		
Evaluation of grant activities		
State agencies (e.g., welfare, family services, substance abuse, vocational rehab, etc.)		
Other (specify)		

5.1.b. Please describe past, ongoing, or planned research on TBI-related issues in your state.

____

____

5.1.c. Can you suggest an approach to evaluating TBI services in your state? What resources might be required for such evaluation?

____

____

VI. Experience with the TBI Technical Assistance Center (TBI TAC)

6.1.a. Which TBI TAC services have you used? *(Check all that apply)*

__ Attended an annual grantee meeting

__ TBI TAC Collaborative Space

__ TBI TAC Grantee Listserv

__ TBI Program Benchmarks

__ TBI TAC staff site visit

__ TBI Program info request

__ Publications & reports

__ Other (specify): _______________

__ No experience with TBI TAC

6.1.b. Please rate TBI TAC's services and products. (C*heck one)*

__ Poor __ Fair __ Average __ Good __ Excellent

Please explain: ____
____

6.1.c. Are there other services the TBI TAC could offer to help improve TBI service coordination and access in your state? If yes, please specify.

____
____

6.1.d. Please provide one or more examples of how your state has adapted or used TBI–related materials from other states.

____
____

Did the TBI TAC play a role in facilitating these efforts?

Yes __ No __ Don't know __ Not applicable __

Please explain: ____
____

VII. Experience as a HRSA TBI Program Grantee

How has the HRSA TBI Program helped or hindered TBI service delivery and coordination in your state? (*see below)*

7.1.a. In your opinion, what has been the most significant benefit of the HRSA TBI Program in your state?

____
____

7.1.b. What has been the most significant drawback to the HRSA TBI Program in your state?

____
____

7.1.c. What (if any) changes are needed in the HRSA TBI Program to better support your state's efforts to provide coordinated, accessible services to all persons and families with TBI?

____
____

7.1.d. How would persons and families with TBI be affected if HRSA TBI funding were no longer available in your state?

____
____

VIII. Looking to the Future

8.1.a. If you could implement one change to improve coordination of TBI services in your state, what would that be?

____
____

8.1.b. What changes are likely in your state's TBI services system over the next 5 years?

____
____

8.1.c. Other comments or suggestions?

____
____

Thank you for your participation in this important study.

APPENDIX C

State TBI Programs and Protection and Advocacy Systems: Characteristics and Accomplishments, by State

TABLE C-1 Characteristics of State Traumatic Brain Injury (TBI) Programs by State, 2005

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Alabama *Alabama Department of Rehabilitation Services* Population: 4,447,100 2,780 hospitalized with TBI 24,351 emergency department (ED) visits for TBI 1,630 TBI disabled	Implementation: 1997, 1998, 1999, 2000 Post-Demonstration: 2001, 2002, 2004	Alabama's statewide TBI advisory board was established within the Department of Rehabilitation Services in 1986. Its 35 members are appointed by the commissioner of the Department of Rehabilitation Services. Board members consist of 85% agency staff; 15% consumers/family. The board meets quarterly. It engages in advocacy, collaboration, education, planning, and the development and monitoring of the implementation of a statewide TBI action plan.
Alaska *Alaska Department of Health and Social Services* Population: 626,932 459 hospitalized with TBI 2,953 ED visits for TBI 177 TBI disabled	Planning: 2000, 2002 Implementation: 2003, 2004, 2005	Alaska's statewide TBI advisory board was established within the Division of Mental Health/Developmental Disabilities in 2000. The 20–24 board members consist of 21% agency staff; 50% consumers/family; 29% elected other members. The board has monthly teleconferences and meets quarterly. It engages in advocacy, collaboration, information/referral, planning in addition to overseeing the statewide TBI resource/needs assessment, and eventual development of a statewide TBI action plan.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
State TBI funding source(s): Trust fund State agency: Rehabilitation Services Year funding source established: 1993 Annual amount(s): $1.2 million Number served: 678 (information and referral); 1,359 (services) (2001–2002) Alabama's trust fund is supported through fines on impaired drivers with driving under the influence (DUI) convictions at $100 per conviction. A portion of revenue is used to support a TBI registry; remaining funds provide direct or purchased services.	Alabama has a trauma registry, TBI registry, and surveillance system. The TBI registry is mandated in statute, and data are reported to Alabama's Department of Public Health. Consumers are contacted 3 months post injury and provided with information and linkage to resources.	—Alabama's Interactive Community-Based Model (ICBM) pairs survivors with a care coordinator to address preemployment issues, is a model for other states. —Alabama enacted graduated drivers' license legislation in 2001–02. —Alabama's expanded ICBM model to children in 2001 has served 518 children through Children's Rehabilitation Services Division. —Alabama developed a screening tool, training for domestic violence providers in 2004 (five referrals made to vocational rehabilitation for employment services); implemented TBI screening for children in public schools, materials for educators.
State TBI funding source(s): General revenue State agencies: Public Health; Mental Health/Developmental Disabilities Year funding source(s) established: 2001, 2001 Annual amount(s): $106,000, $105,000 (2001–2002) Number served: Not available, unknown Funding to Alaska's Division of Mental Health/Developmental Disabilities serves as match for HRSA grant.	Alaska has a trauma registry and surveillance system funded by the federal Centers for Disease Control and Prevention (CDC).	—Alaska's statewide TBI advisory board has 50% consumer/family representation in an extremely rural area. —Alaska is developing a Medicaid rehabilitation services pilot for persons with TBI who have mental illness and functional limitations.

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Arizona *Arizona Department of Economic Security* State population: 5,130,632 4,114 hospitalized with TBI 25,229 ED visits for TBI 1,689 TBI disabled	Implementation: 1997, 1998, 1999 Post-Demonstration: 2001	Arizona's statewide TBI advisory board was established by statute within the Department of Economic Security, Rehabilitation Services Administration in 1992. The 18-member board is appointed by Arizona's governor. It consists of 11% nonvoting agency staff; 39% consumers/family; 44% others. The board meets at least quarterly and addresses both brain and spinal cord injury issues, and engages in collaboration, education, funding decisions, information/referral, planning, and policy development. The board has produced curricula and resources for personal care assistants, other health care providers, families, teachers, and administrators.
Arkansas *Arkansas Department of Education* State population: 2,673,400 1,263 hospitalized with TBI 15,225 ED visits for TBI 1,019 TBI disabled	Planning: 2001, 2002	Arkansas' statewide TBI advisory board was established within the University of Arkansas Medical School System in 2001. Of its 24 members, 46% are agency staff; 50% are consumers/family; 4% are other. The advisory board was established jointly by the Arkansas Department of Health and the Partners Program to conduct a statewide TBI resource/needs assessment and develop a statewide TBI action plan. It meets on an as-needed basis.
California *California Department of Mental Health*	Planning: 1999, 2001	California's statewide TBI advisory board was established within the Department of Mental Health in 1999. Its 20 members are appointed by the director of the Department of Mental Health. They consist of 70%

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
State TBI funding source(s): Trust fund, Title V State agencies: Rehabilitation Services, Health Year funding source(s) established: 1992, 2001 Annual amount(s): $1.8–2.4 million, $200,000 Number served: Not available A trust fund was established by statute, and is supported by surcharges on civil and criminal fines, penalties, forfeitures. The trust fund pays for prevention activities, case support, match against federal funding for vocational rehabilitation services, HRSA grant, staff positions, training, information, and referral. Title V funds augment service coordination, training/education, and prevention activities of service coordinators.	Arizona has a trauma registry and surveillance system.	—Arizona's HRSA-funded resource cards have been replicated in other states. —Continuum of care teams in Arizona have built referral protocols, which link children and families with resources. —Arizona's trust fund provided a one-time appropriation of $3 million to sustain operation of two trauma centers in 2001–02.
		Arkansas has been nationally recognized for instituting a model Olmstead plan,[b] which provides community long-term care support services for individuals with mental disabilities and brain injuries.
State TBI funding source(s): Trust fund State agency: Mental Health Year funding source established: 1988	California has a TBI surveillance system.	—California has caregiver resource centers for caregivers of adults with onset of cognitive and neurological impairments.

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
California *continued*		
State population: 33,871,648 22,413 hospitalized with TBI 108,698 ED visits for TBI 7,274 TBI disabled		agency staff; 30% consumers/families. The board meets quarterly and is engaged in advocacy, collaboration, and planning, and will produce the statewide TBI resource/needs assessment and statewide TBI action plan.
Colorado *Colorado Department of Human Services* State population: 4,301,261 3,206 hospitalized with TBI 21,054 ED visits for TBI 1,214 TBI disabled	Planning: 1999 Implementation: 2001, 2002, 2003 Post-Demonstration: 2004 *TBI-specific Medicaid waiver (1995)	Colorado's statewide TBI advisory board, initially established in 1998 in Colorado's Department of Human Services, Office of Behavioral Health and Housing, was designated lead coordinating agency for TBI by executive order in 2000. Its 32 members are elected by membership, and consist of 38% agency staff; 43% consumers/family; 19% others. The board meets quarterly and engages in advocacy, collaboration, education, information/referral, planning, and statewide TBI action plan development and implementation.
Connecticut *Connecticut Department of Social Services*	Planning: 2003, 2004 *TBI-specific Medicaid waiver (1999)	Connecticut's statewide TBI advisory board is no longer active.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
Annual amount(s): $1.1 million Number served: 622 A trust fund is supported by 66% of State Penalty Fund revenues from vehicle code violations. Approximately $950,000 was used to provide services to 622 persons in FY 2001; a portion was used for personnel costs and evaluations. Another portion wa used to draw down $620,000 in federal vocational rehabilitation funds, serving 30 persons.		—Attempts to repeal California's safety helmet law in 2001–02 were defeated.
State TBI funding source(s): Trust fund, TBI-specific Medicaid waiver State agencies: Human Services, Health Care Policy Year funding source(s) established: 2002, 1995 Annual amount(s): $2.5 million (est.); $5,202,549 Number served: TBD, 284 (2001–2002) Trust fund legislation imposes $10 and $15 surcharges for certain traffic convictions, requires 5% of funds be used to educate parents, educators, and nonmedical professionals in identifying TBI and assisting persons to seek proper medical care; 65% for services; 30% for research to promote understanding and treatment of TBI.	Colorado has a trauma registry and surveillance system.	—Colorado has a CDC-funded Craig Hospital Data Collection Project. —Colorado established a TBI trust fund in 2002; created 13-member board.
State TBI funding source(s): General revenue, TBI-specific Medicaid waiver State agencies: Social Services, Social Services Year funding source(s) established:	Connecticut has a trauma registry.	—A person-centered plan is required for all Medicaid TBI waiver recipients in Connecticut. —Connecticut legislature asked Department of

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Connecticut *continued* State population: 3,405,565 1,518 hospitalized with TBI 8,494 ED visits for TBI 568 TBI disabled		
Delaware *Delaware Department of Health and Social Services* State population: 783,600 1,294 hospitalized with TBI 2,731 ED visits for TBI 483 TBI disabled	Planning: 1997, 1998 *TBI-specific Medicaid waiver (2002)	Delaware does not have a distinct statewide TBI advisory board; however, the Governor's Advisory Council on Aging and Adults with Physical Disabilities formed in 1997 does have a TBI steering committee. The TBI steering committee has 28 members, appointed by the division director, including 30% agency staff; 50% consumers/family; 20% others. It meets as needed when directed by the division director, is engaged in advocacy, collaboration, education, and funding decisions. It prepared a report on Delaware's statewide TBI resource/needs assessment and developed a coma guide.
District of Columbia *D.C. Department of Health* State population: 572,059 651 hospitalized with TBI 3,268 ED visits for TBI 219 TBI disabled	Planning: 1997, 1998 Implementation: 1999, 2000, 2001 Post-Demonstration: 2002, 2003	The District of Columbia established a TBI advisory board within the D.C. Department of Health in 1997. The advisory board has 25 members appointed by the director of the Department of Health or a bureau chief. They include 50% agency staff; 20% consumers/family; 30% others. The board meets quarterly and engages in advocacy, collaboration, education, and planning. It played a role in development of Healthy People 2010 plan, has provided testimony on registry bill, provides technical assistance in planning and implementing grant activities, and was

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
1985, 1999 Annual amount(s): $2,027,330; $5,034,853 Number served: 2,240 (dup), 158 (2001–2002) General revenue is used for direct services. Some funds are used for services to class-action lawsuit members. Medicaid TBI waiver has 500 slots; 158 persons had been served as of April 2002.		Public Health to study how a TBI registry could be developed and report back. —Connecticut legislature passed legislation establishing group home pilot for older adults with TBI/acquired brain injury in 2005.
State TBI funding source(s): General revenues, TBI-specific Medicaid waiver State agencies: Health and Social Services, Health and Social Services Year funding source(s) established: 2001, 2002 Annual amount(s): $209,000, not yet implemented (2003) Number served: Unknown, unknown	Delaware has a trauma registry and surveillance system.	—Delaware received Olmstead Systems Change and Assistive Technology grants from the Centers for Medicare and Medicaid Services (CMS) to improve their community long-term care support services for individuals with brain injury and mental illness. —Disability Commission was created in the state in 2001–02.
The District of Columbia has no TBI-specific state funding at this time.	The District of Columbia has no data collection system in place but is working toward an Intentional and Unintentional Injury registry, which will include TBI. There are also plans for mandatory injury reporting for	—Collaboration with faith communities aims to improve education and care regarding TBI in community settings. —Collaboration between the TBI advisory board and other stakeholders is reportedly moving D.C. to mandatory injury reporting.

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
District of Columbia *continued*		
		involved in an injury reporting bill for 2002.
Florida *Florida Department of Health* State population: 15,982,378 12,719 hospitalized with TBI 65,345 ED visits for TBI 4,373 TBI disabled	Implementation: 1997, 1998, 1999, 2000 Post-Demonstration: 2001, 2003, 2004 *TBI-specific Medicaid waiver (1999)	Florida has an advisory board that addresses needs of both TBI and spinal cord injury that was established by statute in 1985. The board's 16 members are appointed by the secretary of Florida's Department of Health. They include 50% consumers/family; 50% others such as physicians, advocacy organizations, etc. The board meets quarterly and is engaged in developing and maintaining standards for designation in acute and sub-acute care, inpatient and outpatient rehabilitation, and transitional living facilities. It also participates in advocacy, collaboration, education, funding, information/referral, and planning; approves product development; recommends legislative changes as needed, and produces an annual performance report.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
	hospitals, ambulatory clinics, Metropolitan Police Departments, D.C. Fire Department and Emergency Medical Services, and the Office of the Chief Medical Examiner.	
State TBI funding source(s): Tobacco settlement, Medicaid TBI waiver, trust fund State agencies: Health, Health, Health Year funding source(s) established: 2000, 1999, 1988 Annual amount(s): $270,000; $4,300,000; $15,000,000 Number served: Approximately 850; up to 300; 3,167 (case management)/1,183 (other) A trust fund derives revenue from a percentage of fees levied from traffic-related fines, surcharges for diving and boating under the influence convictions, and temporary license tags. A portion of the proceeds provides matching funds for the state's Medicaid TBI waiver and supports research, case management and other staffing components for operating the registry, and various contracts.	Florida has a trauma registry and TBI registry. All hospitals, attending physicians, public, private, and social agencies are required to report all new moderate-to-severe brain injuries to the central registry. A case manager is required to contact the individual within 10 working days to determine eligibility for Brain and Spinal Cord Injury Program services, and to assist coordinating all state, federal, and community resources.	—Florida has a Nursing Home Deinstitutionalization and Diversion Project. —Florida has specialty motorcycle tag in which 25% of funds collected annually go to the Brain and Spinal Cord Injury Program. —State appropriations increased for TBI-specific Medicaid waiver slots in 2005.

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Georgia *Brain and Spinal Injury Trust Fund Commission* State population: 8,186,453 5,581 hospitalized 40,787 ED visits for TBI 2,729 TBI disabled	Planning: 1997 Implementation: 1998, 1999, 2000 Post-Demonstration: 2004	Georgia's statewide TBI advisory board was created in 1994. It is located within the Brain and Spinal Cord Injury Trust Fund Commission. Its 21 members include 33% agency staff; 33% consumers/family members; 33% others as appointed by the Advisory Board chairperson. The TBI advisory board meets bimonthly and is engaged in collaboration, education, funding decisions, information/referral, and planning.
Hawaii *Hawaii Department of Health* State population: 1,211,537 339 hospitalized with TBI 3,460 ED visits for TBI 232 TBI disabled	Planning: 1999, 2000 Implementation: 2002, 2003, 2004	Hawaii's statewide TBI advisory board was established by state statute in 1997. Its nine members are appointed by the director of the Department of Health. The board consists of 44% consumers/family members and 56% others (trauma centers, rehabilitation facilities, private providers, maternal and child health representatives, neuropsychiatric institute). The board meets monthly. It engages in advocacy, collaboration, education, planning, and legislative advocacy, and produces the statewide TBI action plan.
Idaho *Idaho Department of Health and Welfare* State population:	Planning: 2000, 2001 Implementation: 2003, 2004, 2005 *TBI-specific	Idaho's statewide TBI advisory board was established in 2000 and is located within the Department of Health and Welfare/ Medicaid. Its 35 members are appointed by the director of that agency. They include representatives from three regional councils: 31% agency staff, 68% consumers/family,

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
State TBI funding source(s): Trust fund State agency: Brain and Spinal Injury Trust Fund Commission Year funding source established: 1998 Annual amount(s): $2,339,708 Number served: 1,883 The Commission distributes just over $2 million per year to individuals with TBI. Georgia does not have a Medicaid waiver specific to persons with TBI, but 30 slots in its Independent Care Medicaid waiver have been set aside for persons with TBI.	Georgia has a trauma registry, TBI registry, and surveillance system.	SB582 moved operation of the state's TBI registry from the Division of Rehabilitation Services to the Brain and Spinal Injury Trust Fund Commission.
State TBI funding source(s): Special fund State agencies: Developmental Disabilities/Health Year funding source established: 2002 Annual amount: $600,000 (est.) Number served: Not available Hawaii passed legislation in 2002 creating a special TBI fund supported by fines from traffic violations. The state is developing criteria to access funds, anticipated for a TBI-specific Medicaid waiver match, registry, case management, and other direct services.	Hawaii does not have systems for collecting TBI-related data. The state hopes to establish a registry with special funds.	—Hawaii has person-centered Planning and Circle of Supports. —Hawaii passed legislation creating a special TBI fund in 2002.
State TBI funding source(s): TBI-specific Medicaid waiver State agency: Medicaid Year funding source established: 1998 Annual amount(s): $546,674 Number served: 23	Idaho has a trauma registry.	—Idaho has been awarded a CMS Real Choices Systems Change Grant and a HRSA Telehealth Grant. —Idaho passed trauma registry legislation in

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Idaho *continued* 1,293,953 599 hospitalized with TBI 7,330 ED visits for TBI 490 TBI disabled	Medicaid waiver (1998)	37% private providers. The TBI advisory board meets quarterly and engages in advocacy, collaboration, education, information/referral, and planning.
Illinois *Illinois Department of Human Services* State population: 12,419,293 7,896 hospitalized with TBI 37,257 ED visits for TBI 2,493 TBI disabled	Planning: 1997, 1998 Implementation: 2000, 2001, 2002 *TBI-specific Medicaid waiver (1999)	Illinois' statewide TBI advisory board, located within the Hawaii Department of Human Services, was established by statute in 1994. Its 29 members are appointed by the governor. They include 28% agency staff; 28% consumers/family; 44% others. The statute specifies that the TBI advisory board, in addition to including agency staff and consumers/family, is to include neurosurgeons, orthopedic surgeons, and rehabilitation specialists. The board meets quarterly and is engaged in collaboration, education, funding, decision, information, referral, planning, and development of a statewide TBI action plan for both TBI and spinal cord injury survivors.
Indiana No lead state agency for TBI State population: 6,080,485 3,702 hospitalized with TBI 25,527 ED visits for TBI 1,708 TBI disabled	Planning: 1999 *TBI-specific Medicaid waiver (2001)	None.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
		2002.
State TBI funding source(s): General revenue, TBI-specific Medicaid waiver State agencies: Rehabilitation Services, Rehabilitation Services Year funding source(s) established: 1999, 1999 Annual amount(s): $300,000; $5,823,376 Number served: 1,200; 1,400	Illinois has a trauma registry and a TBI registry. A general statute mandates reporting to the Department of Public Health, but trauma centers are most likely to comply. The Department of Public Health provides data, without identifiers, to the statewide TBI advisory board to use for planning. There is no formal followup with families/consumers.	Medicaid waiver case managers use a holistic approach to helping consumers address their needs.
State TBI funding source(s): TBI-specific Medicaid State agency: Bureau of Aging and In-Home Services Year funding source established: 2001 Annual amount(s): $1,523,948 Number served: 150	There is currently no registry for TBI data in Indiana.	The Indiana Protection and Advocacy system is funded with an HRSA federal TBI P&A grant and is in the process of collaborating with state agencies to identify a suitable lead agency.

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Iowa *Iowa Department of Public Health* State population: 2,926,324 2,160 hospitalized with TBI 11,019 ED visits for TBI 737 TBI disabled	Planning: 1997 Implementation: 1998, 1999, 2000 Post-Demonstration: 2001, 2002, 2003 *TBI-specific Medicaid waiver (1996)	Iowa's statewide TBI advisory board was established by statute in 1989. The board is located within the Bureau of Health Promotion and Disability in the Iowa Department of Public Health. Its 20 members are appointed by the governor. The board consists of 50% consumers/family member and 50% professionals, advocates, etc. Agency staff serve as ex officio members. The board meets quarterly and engages in advocacy, collaboration, information and referral, planning, and is responsible for developing and publishing the statewide TBI resource/needs assessment and statewide TBI action plan.
Kansas *Kansas Department of Social and Rehabilitation Services*	Planning: 2001, 2002 Implementation: 2003, 2004, 2005 *TBI-specific	Kansas' statewide TBI advisory board was established in 2001 and is located within the Department of Social and Rehabilitation Services. Its 21 members evolved from the TBI-specific Medicaid waiver steering committee and include 38% agency staff; 29% consumers/family; 33% others. The

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
State TBI funding source(s): General revenue, TBI-specific Medicaid waiver State agencies: Public Health, Public Health Year funding source(s) established: 1989, 1996 Annual amount(s): $68,885; $2,057,722 (match) Number served: 1,000 (information and referral), 50 (Peer); 150 $68,885 is used to leverage additional funding.	Iowa has a trauma registry and a TBI registry. The TBI registry is established in statute. Data are reported to Department of Public Health, Bureau of Emergency Medical Services, but followup contact is not conducted.	—As part of HRSA grant activities, Iowa developed a discharge planner model and peer support network to meet information, support, and service linkage needs of families experiencing brain injury—known as the Iowa Brain Injury Resource Network functioning in 18 locations with 22 peer mentor volunteers. —Brain Injury Association of Iowa and Iowa's statewide TBI advisory board pushed to get a seat on new Mental Health/Developmental Disabilities Commission, 2002. —Iowa passed legislation redesigning Department of Mental Health, Developmental Disabilities, and TBI (includes TBI in name and services, 2004. —Iowa passed legislation designating Department of Public Health as lead state agency for TBI, $6.0 million appropriated to eliminate Medicaid waiver waiting lists, 2005.
State TBI funding source(s): TBI-specific Medicaid waiver, no-fault insurance State agency: Department Social and Rehabilitation Services Year funding source established: 1991	Department of Health and Environment is developing a trauma registry.	—Kansas implemented the first TBI-specific Medicaid waiver. It focuses on rehab and independent living and incorporates self-directed supports. Kansas was also

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Kansas *continued* State population: 2,926,324 1,460 hospitalized with TBI 10,932 ED visits for TBI 732 TBI disabled	Medicaid waiver (1991)	TBI advisory board meets at least quarterly and is conducting a statewide TBI resource/needs assessment that will guide its future activities.
Kentucky *Kentucky Cabinet for Health Services/ Department of Mental Health and Mental Retardation* State population: 4,041,769 1,857 hospitalized with TBI 18,274 ED visits for TBI 1,223 TBI disabled	Planning: 1999 Implementation: 2003, 2004, 2005 *TBI-specific Medicaid waiver (1999)	Kentucky's statewide TBI advisory board, located in the Cabinet for Health Services, was established BY statute in 1998 in conjunction with the passage of Kentucky's trust fund legislation. The board's nine members include three positions mandated by legislation and six appointed by Kentucky's governor: 22% agency staff; 33% consumers/Family; 45% others (secretary of cabinet of health services, state epidemiologist, Brain Injury Association of Kentucky, neurosurgeon, neuropsychologist, rehabilitation specialist, social worker, three consumers/family). It has an ad hoc committee to address issues broader than trust fund management and meets as needed but not less frequently than quarterly.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
Annual amount(s): $7.5 million Number served: 118 —The TBI-specific Medicaid waiver has a rehabilitation focus with individuals typically remaining in service for 3–5 years, after which they may move to a different Medicaid waiver if they need lifelong support. —No-fault insurance pays 85% of lost wages up to $900/month for 12 months; at least $4,500 medical and $4,500 rehab costs; $25/day for 1 year in substitution benefits; $2,000 funeral costs; AND $900/month survivor benefits. Law covers pedestrians hit by a car as well as persons injured in a car.		one of the first states to develop a teacher training/technical assistance project using a mini-team approach—the Neurological Disabilities Support Project. —$2.5 million additional dollars were appropriated in Kansas to increase Medicaid match in 2002.
State TBI funding source(s): Trust fund, TBI-specific Medicaid waiver State agencies: Mental Health/Mental Retardation; Mental Health/Mental Retardation Year funding source(s) established: 1998, 1999 Annual amount(s): $2.2 million Number served: 500, 95 of 110 A trust fund was established by statute and is funded with surcharges onfines for moving violations, DUI violations, overweight trucks, etc. A trust fund provides $125,000 for the registry, $2.75 million for direct services, and $60,000 for administrative costs. Fines/revenue were increased in 2004.	Kentucky has a TBI registry established in statute. The TBI registry is not population based, reporting is not mandatory, and there is no followup.	—A legislative task force was established in Kentucky 2002 to address need for long-term residential care, decriminalization of brain injury, and long-term case management. Legislation expanded trust fund capabilities by including court costs. —Legislation passed adding TBI as eligibility category for Department of Mental Health & Mental Retardation and Developmental Disabilities services, 2005.

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Louisiana *Louisiana Department of Social Services/ Louisiana Rehabilitation Services* State population: 4,468,976 2,816 hospitalized with TBI 26,214 ED visits for TBI 965 TBI disabled	No Federal TBI Program grants received.	In Louisiana, an advisory board within the Department of Rehabilitation Services serves as the trust fund board for TBI and spinal cord injury. Its 13 members are appointed by the governor. They include 8% agency staff; 30% consumers/family; 62% mandatory others (director of Rehabilitation Services; executive director of the Brain Injury Association of Louisiana; the executive director of the Spinal Cord Injury Association; nominated psychologist; survivor of TBI and spinal cord injury; family member of each; presidents of medical society, hospital association, dental association, House, Senate). The board meets quarterly.
Maine *Maine Department of Human Services* State population: 1,274,923 519 hospitalized with TBI 4,534 ED visits for TBI 303 TBI disabled	Planning: 2003, 2004 Implementation: 2005	Maine's statewide TBI advisory board, located within the Department of Human Services, was established in April 2002. The 25-member board was formed by joint invitation of the department director and the executive director of the Brain Injury Association of Maine. Activities of this new group focus on establishing a lead state agency for TBI; creating a mission statement, bylaws, and common definition for brain injury; and positioning itself to obtain a federal TBI Program grant from HRSA. The board meets bimonthly.
Maryland *Maryland Department of Health and Mental Hygiene* State population: 5,296,486 4,614 hospitalized with TBI 15,383 ED visits for TBI	Planning: 1998 Implementation: 1999, 2000, 2001 Post-Demonstration: 2003, 2004 *TBI-specific Medicaid waiver (2003)	Maryland's statewide TBI advisory board, located within the Department of Health and Mental Hygiene, was established in 1998. State legislation passed in 2005 established the board statutorily. Target membership is 31 members. In 2003, Maryland reported 18 voting and 3 ex officio members appointed by the Mental Hygiene Administration. The board included 46% agency staff; 18% consumers/family; 36% others. The board meets six times per year. It is responsible for Maryland's statewide TBI action plan,

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
State TBI funding source(s): Trust fund State agency: Rehabilitation Services Year funding source established: 1993 Annual amount(s): $1.3 million Number served: 259 A trust fund was established by statute in 1993. It is funded by fees attached to fines for speeding, reckless operation, and DUI convictions. Trust fund spent $2.7 million in 2001–2002 because of a prior year surplus.	Louisiana has a trauma registry that is not population based, a TBI registry, and a surveillance system. The TBI registry is established in statute. Reporting is mandatory but does not include followup contact.	Louisiana's governor issued an executive order directing state agencies to develop short- and long-term plans to provide community-based services to individuals with disabilities and elderly who need long-term care, 2004.
Maine's Medicaid state plan specifically targets persons with TBI in its rehab services package. Persons with TBI also benefit from a higher reimbursement rate for nursing facility services. Contingent upon eligibility criteria, they may also access Medicaid adults with developmental disabilities waivers. The number of persons benefiting from these services or expenditures is not available.		Maine's Medicaid state plan rehabilitation package.
State TBI funding source(s): General revenues, TBI-specific Medicaid waiver State agencies: Mental Hygiene, Mental Hygiene Year funding source(s) established: 1996, 2002 Annual amount(s): $1.2 million Number served: 14 The TBI-specific Medicaid waiver was implemented in 2003, when results were reported, so there is no	Maryland has a trauma registry, TBI registry, and surveillance system. TBI registry is established in statute. Reporting to the Office of Injury Prevention, Department of Health and Mental Hygiene is	—Maryland's "all-payer system" established equitable rates for Maryland hospitals and ensures that individuals are able to obtain acute-care services regardless of income or insurance benefits. It is the only state in the United States with this system. —Maryland developed a TBI pilot case

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Maryland *continued* 1,856 TBI disabled		and is involved in collaboration, education, information/referral, and planning.
Massachusetts *Massachusetts Executive Office of Health and Human Services/ Massachusetts Rehabilitation Commission* State population: 6,349,097 2,835 hospitalized with TBI 10,200 ED visits for TBI 683 TBI disabled	Implementation: 2000, 2001, 2002 *TBI-specific Medicaid waiver (2002)	Massachusetts' statewide TBI advisory board, established in 1985, is located within the Rehabilitation Commission. Its 18 members are nominated by the membership and appointed by the chair. They include 22% agency staff; 65% consumers/family; 11% others. The board meets quarterly and engages in advocacy, collaboration, education, funding decisions, and planning.
Michigan *Michigan Department of Community Health* State population: 9,938,444 5,893 hospitalized with TBI 34,054 ED visits for TBI 2,279 TBI disabled	Planning: 1998 Implementation: 2001, 2002, 2003 Post-Demonstration: 2004	Michigan's statewide TBI advisory board, located in the Department of Community Health, was established in 1999. Its 54 members are appointed by the lead state agency for TBI. They include 33% agency staff; 13% consumers/family; 54% others. The board has five committees that meet monthly, and the full board meets twice per year. The board has produced brochures for consumers and professionals, and a resource guide, and a website.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
history yet.	mandatory but does not include followup contact.	management project within the mental health system. —Maryland awarded an Independence Plus waiver[c] to assist individuals with disabilities to reside in their own homes, 2004.
State TBI funding source(s): General revenues, trust funds (2), TBI-specific Medicaid waiver State agencies: Rehabilitation Commission, Rehabilitation Commission, Rehabilitation Commission Year funding source(s) established: 1985, 1991, 2002 Annual amount(s): $6.1 million, $750,000 Number served: 520; 720 (information and referral), 40 (services); 250 slots	Massachusetts has a trauma registry.	—Massachusetts was one of the first states to develop a state TBI program using general revenue funds to pay for a range of services. —Massachusetts worked with three culturally diverse communities to improve outreach and referral to state services.
State TBI funding source(s): General revenues, no-fault insurance State agencies: Community Health, Office of Financial and Insurance Services Year funding source(s) established: 2000, 1972 Annual amount(s): $1.0 million Number served: Not available $100,000 in general revenue is matched for the HRSA grant and not available for services to individuals. In Michigan, persons with Diagnostic and Statistical Manual–IV diagnosis	Michigan has a trauma registry; legislation authorizing it sunsetted in 1995. The state's HRSA grant focuses on developing an integrated data collection system. Analysis of data from Medicaid, hospital discharge, ED visits, vital statistics, and	Michigan's self-determination movement and Medicaid choice waiver.[d]

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Michigan *continued*		
Minnesota *Minnesota Department of Human Services* State population: 4,919,479 2,796 hospitalized with TBI 15,467 ED visits for TBI 1,470 TBI disabled	Implementation: 1997, 1998, 1999 Post-Demonstration: 2002, 2003 *TBI-specific Medicaid waiver (1992)	Minnesota's statewide TBI advisory board, established in 1990 by statute, is located within the Department of Human Services. The board must have no fewer than 10 and no more than 30 members appointed by the commissioner of the Department of Human Services. It includes 50% consumers/family; 50% providers or advocates. State staff are ex officio. The board meets bimonthly, engages in advocacy, collaboration, education, funding decisions, information/referral, and planning.
Mississippi *Mississippi Department of Rehabilitation Services* State population: 2,844,658	Planning: 1997 *TBI/spinal cord injury (SCI) Medicaid waiver (2001)	Mississippi has an advisory board that serves both TBI and SCI. It was established by statute in 1996 and is located within Mississippi's Department of Rehabilitative Services. Its 10 members are appointed by the director of Department of Rehabilitation Services. The board consists of 60% consumers/family; 40% others. The board meets bimonthly and is engaged

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
are eligible for mental health/developmental disabilities services. HRSA-funded data project shows 80,000 persons with TBI diagnosis who are receiving Medicaid-funded services. No-fault insurance pays all medical costs up to 85% of an individual's income to a ceiling of $4,027/month, $20/day replacement services (e.g., yard work), and $1 million property maximum.	insurance companies is being conducted to determine TBI incidence and costs since 1997. 23 hospitals are participating in collection of ED statistics.	
State TBI funding source(s): Trust fund, TBI-specific Medicaid waiver State agencies: Health, Human Services Year funding source(s) established: 1991, 1992 Annual amount(s): $350,000; $17,017,589 Number served: Not available, 495 Persons whose driver's license has been revoked must pay a surcharge to the revocation fee. As of July 2003, surcharge was increased from $145 to $380. 5% is credited to a TBI/spinal cord injury account to be disbursed as follows: 35% for contracted services to help persons with TBI access supports, and 65% to maintain the registry.	Minnesota has a trauma registry, TBI registry, and surveillance system. The TBI registry is established in statute, requires mandatory reporting, and includes followup contact at 3 months post injury.	—In 1993, state hospitals for the mentally ill in Minnesota began screening new admissions for TBI. Personal care services under the Medicaid state plan include cognitive and behavioral supports. —Crisis support became available as a rehabilitation option to persons with TBI in the state in 2002.
State TBI funding source(s): Trust fund, TBI/SCI Medicaid waiver State agencies: Rehabilitation Services, Rehabilitation Services Year established: 1996, 2001 Annual amount(s): $1.3–$2.0 million, unavailable Number served: 436; 400 slots/41 served	Mississippi has a trauma registry, TBI registry, and surveillance system. The TBI registry is mandated by statute. Data are reported to the Department of	

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Mississippi *continued* 1,533 hospitalized with TBI 16,432 ED visits for TBI 1,100 TBI disabled		in advocacy, collaboration, education, funding decisions, and planning, and monitors the trust fund.
Missouri Missouri Department of Health and Senior Services State population: 5,595,211 4,575 hospitalized with TBI 28,797 ED visits for TBI 1,129 TBI disabled	Implementation: 1997, 1998, 1999, 2000 Post-Demonstration: 2001, 2002, 2004	Missouri's statewide TBI advisory board was initially established by executive order in 1985 and, statute in 1986 and is housed in the Office of Administration. In 2005, it was transferred by executive order to the Missouri Department of Health and Senior Services. The board's members are appointed: 21 members by the governor and 4 by the state legislature. They include 32% agency staff; 27% consumers/family; 41% others. The board meets bimonthly and has initiated the registry, funding for services, and a trauma center; sponsors conferences; and functions as an internal advocate for several agencies and departments within the state. It has produced reports, training modules, and educational booklets; maintains a web page; and has developed a playground safety program.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
A trust fund was established by state statute and is supported by a $25 surcharge on DUI violations and a $4 surcharge on other moving vehicle violations. It funds prevention, the registry, and direct services.	Health, which contracts with the Department of Rehabilitation Services to maintain the registry. Resource information sent to families; no further followup.	
State TBI funding source(s): General revenue, Trust fund State agencies: Health and Senior Services, Health and Senior Services Year funding source(s) established: General revenue funding for the TBI advisory board, 1985; general revenue for state-contracted services and for Missouri's Rehabilitation Center, FY 1986; Trust fund, 2002 Annual amount(s): $106,000 (planning/policy/council prior to 2000 was general revenue, shifted to trust fund in 2001); $41,750 (prevention); $1,724,298 (general revenue direct contractual services/service coordination); $10,907,435 Missouri (rehabilitation center, but not broken out for specific TBI services) Number served: 443 (rehabilitation), not available	Missouri has a trauma registry, TBI registry, and surveillance system. The TBI registry was established by statute (1986). Reporting of surveillance data to the Missouri Head Injury Advisory Council is required, but there is not a followup contact system. Data are used for injury control and prevention program as well.	—Division of Special Education developed four training modules for educators. Missouri has provided training to case managers on person-centered planning. —Trust fund legislation was passed in 2002. —Developed data linkages project across all state agencies that has continued through Office of Administration; early information and referral protocols with trauma centers/rehab centers; core competences for direct-care providers and service coordinators that are being adopted across special health care needs programs. —Legislation repealed comprehensive day rehab and other Medicaid optional services for adults, 2005 —Head Injury Program (GR) was cut by ~$800,000, 2005 for FY 2006.

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Montana *Montana Department of Public Health and Human Services* State population: 902,195 452 hospitalized with TBI 5,578 ED visits for TBI 373 TBI disabled	Planning: 2001, 2002 Implementation: 2003, 2004, 2005	Montana's statewide TBI advisory board, located within the Department of Public Health and Human Services, was established in 2001. Its 14 members are appointed by the Department of Public Health and Human Services. They include 21% agency staff; 29% consumers/family; 50% others. There is a broad-based interagency task force that addresses a wide range of issues and reports to the official TBI advisory board, which meets three times each year.
Nebraska *Nebraska Department of Education* State population: 1,711,263 824 hospitalized with TBI 6,799 ED visits for TBI 339 TBI disabled	Planning: 2000, 2001 Implementation: 2002, 2003, 2004 *TBI-specific Medicaid waiver (2002)	Nebraska's statewide TBI advisory board, located within the Department of Education, was established by statute in 1999. Its 15 members are appointed by the commissioner of education. They include 20% agency staff; 47% consumers/family; 33% others. The board meets quarterly and is engaged in collaboration and planning activities. It also produces a report to the state legislature.
Nevada *Nevada Office of Community-Based Services* State population: 1,998,257 1,342 hospitalized with TBI 11,652 ED visits 780 TBI disabled	Planning: 1997, 2005	Nevada's statewide TBI advisory board was created in 1993, but it had difficulty continuing to meet on a formal basis. Former board members continue to collaborate informally and have provided input to a 10-year strategic plan that includes persons with TBI.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
State TBI funding source(s): Medicaid Home and Community-based Waiver Program State agency: Public Health Year funding source established: Unknown Annual amount(s): Not available Number served: 97 Montana does not have a TBI-specific Medicaid waiver, but special services in the state's Medicaid Home and Community-based waiver for the elderly and disabled may be used by persons with TBI.		Montana's ability to piggyback on an existing Medicaid home and community-based waiver program is cost-effective. Post-acute rehabilitation services are reported to be exceptional.
State TBI funding source(s): TBI-specific Medicaid waiver State agency: Not available Year funding source established: 2002 Annual amount(s): Not available Number served: 35 TBI-specific Medicaid waiver is a model waiver focusing on adult residential/supported living, ages 18–64.	Nebraska has a trauma registry and TBI/SCI registry that is population based and established in statute. Data are reported to the Nebraska Department of Public Health and Human services but the registry does not include followup contact.	Nebraska's registry was reauthorized by the state legislature in 2002.
State TBI funding source(s): General revenus, tobacco settlement State agencies: Community-Based Services, Community Enrichment Year funding source(s) established: 1992, 2000 Annual amount(s): $300,000; $5.0 million Number served: 10, Not available General revenue used for direct services. Tobacco settlement used to	Nevada has a trauma registry.	—Nevada's incorporation of alternative medicine into rehabilitation services. —In 2002, Nevada received increases in personal care assistance, independent living service,s and equipment loans and defeated efforts to eliminate helmet law.

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Nevada *continued*		
New Hampshire *New Hampshire Department of Health and Human Services/ Division of Developmental Services* State population: 1,235,786 466 hospitalized with TBI 3,980 ED visits for TBI 240 TBI disabled	Planning: 1997, 1998 Implementation: 2000, 2001, 2002 Post-Demonstration: 2003, 2004 *TBI-specific Medicaid waiver (1993)	New Hampshire has an advisory board that addresses TBI and spinal cord injury that was created by statute in 1998. The board's composition is mandated in statute. The board includes 11 members designated by the governor, heads of the legislature, and department heads. It includes 11% agency staff; 33% consumers/family; 56% others (legislators, Brain Injury Association appointees, injury prevention center representative). The board meets quarterly and engages in advocacy, education, and planning.
New Jersey *New Jersey Department of Human Services* State population: 8,414,350 4,630 hospitalized with TBI	Implementation: 1999, 2000, 2001 Post-Demonstration: 2002, 2003, 2004 *TBI-specific Medicaid waiver (1993)	New Jersey's TBI advisory board, located within the Department of Human Services, was established in 1998 by executive order and by statute. The board's 26 members include 31% agency staff; 27% consumers/family; 42% others. The board meets quarterly and actively engages in advocacy, collaboration, education, and planning. New Jersey's Federal TBI Program grant from HRSA focused on children's

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
build a rehabilitation center at a college with therapist training programs.		
State TBI funding source(s): General revenue, general revenue, general revenue, TBI-specific Medicaid waiver State agencies: Brain Injury Association of New Hampshire, Developmental Services, Developmental Services, Developmental Services, Medicaid Year funding source(s) established: 1993, 1993, 2002, 1993 Annual amount(s): $50,000; $50,000; $200,000; $5,657,499 Number served: Not available; 720; not avalable; 85 The Brain Injury Association of New Hampshire contract funds support New Hampshire's TBI registry. Other general revenue supports information and referral, case management, and some direct services. New Hampshire's Division of Developmental Services provides match for Medicaid state plan services. Medicaid TBI waiver spending authorized at $7.6 million; unused funds support services for non-waiver-covered persons.	New Hampshire has a TBI registry. The TBI registry is population based and is established in statute. Reporting to the TBI registry is mandatory; data are reported to New Hampshire Hospital Association. A followup/outreach mechanism, which begins with initial contact in the acute hospital setting, is being piloted.	—Focus of HRSA Implementation Grant in New Hampshire is to build neurobehavioral service capacity. —Additional general revenues was received in 2002 in New Hampshire and will be used to establish a statewide case management system. Any excess will be used for prevention, respite, home modifications, and family support.
State TBI funding source(s): Trust fund, TBI-specific Medicaid waiver State agencies: Human Services, Human Services Year funding source(s) established: 2002, 1993 Annual amount(s): $3.4 million; $14,557,615 Number served: Not available, 250	New Jersey has a trauma registry and a surveillance system.	—New Jersey offers cash and counseling; Medicaid buy-in for employed individuals; and mentoring program for persons with TBI (HRSA grant). —New Jersey passed legislation establishing Brain Injury Research

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TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
New Jersey *continued* 18,953 ED visits for TBI 1,268 TBI disabled		sports injuries, and developing guides for public school staff.
New Mexico *New Mexico Department of Health* State population: 1,819,046 954 hospitalized with TBI 9,233 ED visits for TBI 618 TBI disabled	Implementation: 2001, 2002, 2003	New Mexico's TBI advisory board, located within the state's Developmental Disabilities Planning Council, was established by statute in 1997. Its 18 members are appointed by the governor. They include 17% agency staff; 40% consumers/family; 43% others. The board meets quarterly and is engaged in a broad range of activities, including advising the Department of Health on funding recommendations. The board anticipates forming a subcommittee to suggest a drug formulary.
New York *New York Department of Health* State population: 18,976,457 12,840 hospitalized with TBI 51,185 ED visits 5,159 TBI disabled	Implementation: 1997, 1998, 1999, 2000 Post-Demonstration: 2001, 2002, 2004 *TBI-specific Medicaid waiver (1995)	New York's TBI advisory board, located in the Department of Health, was established by statute in 1994. The statute mandates the participation of representatives from state agencies and others appointed by the governor or leaders of the New York legislature. The board's 19 members include 42% agency staff; 31% consumers/family; 26% others. The board meets quarterly and engages in advocacy, collaboration, education, planning, and analysis.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
A trust fund was established by statute and is funded by surcharges on motor vehicle registrations.		Act, making New Jersey the first state with dedicated funding for research on TBI, 2004. —New Jersey developed a TBI family and peer support program involving clergy and the faith community, as well as families and consumers.
State TBI funding source(s): Trust fund State agency: Health Year funding source(s) established: 1997 Annual amount(s): $2.0 million Number served: 572 A trust fund was established by statute by a combination of $600,000 in general revenue and $5 from each traffic violation fee. $100,000 has been used for HRSA grant match; remaining funds have been allocated to direct services.	New Mexico has a trauma registry.	—Crisis services and life skills training are available statewide in New Mexico. —New Mexico's governor signed legislation authorizing a Medicaid home and community-based waiver that could be used for individuals with TBI, 2005.
State TBI funding source(s): General revenue, general revenue, TBI-specific Medicaid waiver State agencies: Various, Health, Medicaid Year funding source(s) established: 1995, 1995, 1995 Annual amount(s): $2.0 million, $4.0 million, Not available Number served: Not available; 750; 1,000 The $2.0 million appropriation supports various planning and policy activities. The $4.0 million pays for rent subsidies and housing support to waiver recipients.	New York has a trauma registry and a surveillance system.	—New York's TBI program provides rent subsidies and housing supports to waiver participants. A Neurobehavioral Resource Project trains staff; and service providers; consults on crises; and provides technical and clinical support to TBI providers. —Participated in CMS pilot of participant evaluation survey for individuals served by Medicaid TBI waiver.

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TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
North Carolina *North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services* State population: 8,049,313 4,485 hospitalized with TBI 36,883 ED visits for TBI 2,468 TBI disabled	Implementation: 1997, 1998, 1999 Post-Demonstration: 2001	North Carolina's TBI advisory board evolved from a task force established in 1995 to write North Carolina's statewide TBI action plan. The current advisory board has been in effect since 1998 but is not mandated. It has 30 members invited by a TBI specialist. It includes 43% agency staff; 15% consumers/family; 42% others. The board uses subcommittees and meets monthly.
North Dakota *North Dakota Department of Human Services* State population: 642,200 267 hospitalized with TBI 2,281 ED visits for TBI 153 TBI disabled	Planning: 2003, 2004 *TBI-specific Medicaid waiver (1994)	North Dakota's TBI advisory board, located within the Department of Human Services, was established in 2001. Its 20 members are appointed by the director of the Division of Aging. They include 50% agency staff; 10% consumer/family; 40% others. The board meets quarterly and is involved in advocacy, planning, collaboration, education, and funding activities.
Ohio *Ohio Rehabilitation Services Commission*	Implementation: 1998, 1999, 2000 Post-Demonstration: 2002, 2003, 2004	Ohio's TBI advisory board, located in the Ohio Rehabilitation Services Commission, was established by state statute in 1990. The 1990 statute mandates the involvement on the TBI advisory board of agency directors/designees and others appointed

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
State TBI funding source(s): General revenue, general revenue State agency: Mental Health/ Developmental Disabilities/ Substance Abuse Services; Vocational Rehabilitation Independent Living Year funding source(s) established: 1993, 1999 Annual amount(s): $1,596,702; $251,627 Number served: 1,519,446 $400,000 will be appropriated as a Medicaid TBI waiver match. Wide range of consumer supports provided case by case. The Division of Vocational Rehabilitation Services supports two positions and case service for independent living.	North Carolina has a trauma registry which captures information on persons treated at 21 of its 115 hospitals. North Carolina attempted to establish a TBI registry, but efforts were ineffective due to no mandatory requirement to report.	—North Carolina's inclusion of TBI within developmental disabilities definition enables people of all ages with TBI to use developmental disabilities agency service coordination and broad developmental disabilities funding. —North Carolina's General Assembly authorized a Medicaid TBI waiver and a bike helmet law for ages 0–16.
State TBI funding source(s): TBI-specific Medicaid waiver State agency: Human Services Year funding source established: 1994 Annual amount(s): $580,982 Number served: 32 (37 slots) Persons with TBI in North Dakota may also be served under programs designed for those not eligible for Medicaid waiver but who need personal and homemaker services through Aging Services.	North Dakota has a trauma registry.	
State TBI funding source(s): General revenue State agency: Rehabilitation Services Commission Year funding source established: 1990	Ohio has a trauma registry and is a Model Systems site.	—Ohio has collaborated with the Ohio Legal Rights on housing initiative and on a Medicaid guide. It is contracting with a development specialist to

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Ohio *continued* State population: 11,353,140 7,607 hospitalized with TBI 38,624 ED visits for TBI 2,585 TBI disabled		by the executive director of Ohio's Rehabilitation Services Commission. The board's 21 members include 47% agency staff; 33% consumers/family; 25% others. The board meets six times per year and engages in a wide range of activities; it has produced guides and an incidence report.
Oklahoma *Oklahoma Department of Health* State population: 3,450,654 2,560 hospitalized with TBI 18,398 ED visits for TBI 817 TBI disabled	Planning: 1997, 1998 Implementation: 1999, 2000, 2001 Post-Demonstration: 2003, 2004	Oklahoma's TBI advisory board was established in 1991 and was appointed by the governor. A revised TBI advisory board was established in 1997 in the Oklahoma Department of Health to better address Federal TBI Program mandates. The board has 26 members of whom 68% are agency staff and 32% are consumers/family. The board engages in activities that include reviewing and approving grant project products and curricula. The full board meets quarterly; task forces meet six to eight times a year.
Oregon *Oregon Department of Education* State population: 3,421,399 2,828 hospitalized with TBI 17,964 ED visits for TBI 1,202 TBI disabled	Planning: 1997 Implementation: 1998, 1999, 2000 Post-Demonstration: 2001, 2002, 2004	Oregon's TBI advisory board was established in 1997 with the state's federal TBI Program Planning grant from HRSA. The TBI advisory board's 42 members are invited by the state Department of Education or nominated by their agencies. They include 21% agency staff; 38% consumers/family; 64% others. The board's executive committee has met often. The board focuses on federal TBI Program grants from HRSA and sustainability. The full board meets as needed.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
Annual amount(s): $346,000 Number served: Not available General revenue provides funding for planning, prevention, research, services, and development. Persons with TBI who meet eligibility requirements may access one of six Medicaid waivers (three nursing facility level of care and three intermediate level of care facilities for people with mental retardation).		educate public policy makers. —Medicaid waivers may be used for individuals with TBI. —The Ohio legislature awarded an additional $50,000 for TBI-related services in tight budget times, 2002.
Oklahoma is in the process of developing a Medicaid waiver. Individuals who meet eligibility criteria can currently access one of four other waivers.	Oklahoma has a trauma registry and a surveillance system.	—Oklahoma has improved discharge planning practices. —Oklahoma has increased funding for a trauma system approved by the legislature in 2002. —Oklahoma passed legislation establishing Consumer-Directed Personal Assistance and Support Services for adults with disabilities, 2004.
Adults with TBI in Oregon can access the Medicaid aging and disabled waiver if they meet eligibility requirements.	Oregon has a trauma registry.	Oregon's TBI Consult Team funded by the Department of Education provides support to local educators; the Oregon Brain Injury Research Network provides information. An executive order created the governor's TBI task force and recommended a TBI trust fund, 2002.

continues

TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Pennsylvania *Pennsylvania Department of Health* State population: 12,281,054 8,550 hospitalized with TBI 41,282 ED visits for TBI 2,762 TBI disabled	Planning: 2001, 2002 Implementation: 2003, 2004, 2005 *TBI-specific Medicaid waiver (2002)	Pennsylvania's TBI advisory board, located within the Department of Health, was established in 2001. Its 18 members are appointed by the secretary of the Department of Health. They include 44% agency staff; 34% consumers/family; 22% others. The board meets monthly, and its current focus is on statewide TBI resource/needs assessment and developing a statewide TBI action plan.
Rhode Island *Rhode Island Department of Human Services* State population: 1,048,319 531 hospitalized with TBI 2,500 ED visits for TBI 214 TBI disabled	Planning: 1999, 2000 Implementation: 2002, 2003, 2004	Rhode Island's TBI advisory board was established by state statute in 1986. Its 13 members are appointed by the governor and include 31% agency staff; 31% consumers/family; 38% others. The board meets monthly and engages in advocacy, education, and planning, and makes funding recommendations to the governor.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
State TBI funding source(s): Trust fund, TBI-specific Medicaid waiver State agencies: Health, Public Welfare, Insurance Year funding source(s) established: 1985, 2002, 1980s Annual amount(s): $3.0 million; not available; not applicable Number served: 175; 50 slots; unknown A trust fund was established by statute It is funded by DUI and moving violations and provides services and coordination to adults with incomes at or below 300% of the federal poverty level. A catastrophic loss fund was available 1984–1989 to auto accident victims, but it is almost exhausted as claimants have hit the $1.0 million lifetime limit.	Pennsylvania has a trauma registry and surveillance system.	
State TBI funding source(s): General revenue State agency: Human Services Year funding source established: 1986 Annual amount(s): $2,000 Number served: Not available The Department of Human Services provides funding from general revenue to the Brain Injury Association of Rhode Island to provide informationand referrals. Rhode Island does not have a TBI-specific Medicaid waiver, but more than 700 persons with TBI access services from five other Medicaid waivers.	Rhode Island has a TBI registry, mandated in statute and population based. Data are reported to the Department of Health, which sends out resource information to individuals with brain injury and families within 3–6 months.	Rhode Island's new habilitation waiver is expected to serve as many as 25 persons with TBI.

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TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
South Carolina *South Carolina Department of Disabilities and Special Needs* State population: 4,012,012 2,203 hospitalized with TBI 20,551 ED visits for TBI 908 TBI disabled	Planning: 1997, 1998 Implementation: 2000, 2001, 2002 Post-Demonstration: 2004 *TBI-specific head and spinal cord injury (HASC) Medicaid waiver (1995)[e]	South Carolina's TBI advisory board was established in 1997. Initial membership on the board was by invitation of the South Carolina Department of Disabilities and Special Needs, the lead state agency for TBI. The TBI advisory board is becoming an independent entity, and new members are selected by the board. Of its 40 members, 35% are agency staff; 38% are consumers/family members; 27% are others. The board meets quarterly and engages in range of activities, including statewide TBI action plan development, data collection and reporting on comprehensive rehabilitation, employment and residential services.
South Dakota State population: 754,844 341 hospitalized with TBI 3,845 ED visits for TBI 257 TBI disabled	No Federal TBI Program grants received	Profile not available
Tennessee *Tennessee Department of Health* State population: 5,689,283 3,575 hospitalized with TBI	Implementation: 2000, 2001, 2002 Post-Demonstration: 2003, 2004	Tennessee's TBI advisory board, located within the Department of Health, was established by state statute in 1993. Its nine members are appointed by the governor. The board consists of 33% agency staff; 55% consumers/family members; 11% others. The board meets quarterly and engages in advocacy, collaboration, funding decisions, planning activities, and developing program policies.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
State TBI funding source(s): General revenue, TBI-specific Medicaid waiver State agencies: Department of Disabilities and Special Needs, Medicaid Year funding source(s) established: 1994, 1995 Annual amount(s): $6.0 million, not available Number served: 600, 50 General revenue in the state includes appropriations, Medicaid match for TBI/SCI waiver, and money collected from a surcharge on DUI fines. The Medicaid waiver has 440 slots, most occupied by individuals with spinal cord injury. Approximately 100 persons with TBI use the state's Medicaid mental retardation and developmental disabilities waiver.	South Carolina has a surveillance system and a CDC-funded followup project that may lead to development of a TBI registry.	South Carolina has an individuals rehabilitation support project to prepare persons for return to work for greater independence.
State TBI funding source(s): General revenue, trust fund State agencies: Vocational Rehabilitation, Health Year funding source(s) established: 1998, 1993 Annual amount(s): $108,000; $750,000 Number served: 40; 2,603	Tennessee has a trauma registry and a TBI registry. The TBI registry was established by statute and is population based. Reporting to the Department of Health is	—Beginning in 1999, the Tennessee TBI program developed distance learning to train TBI providers. To date, 754 professionals have attended sessions. —The Tennessee legislature defeated repeal of the helmet law in 2002.

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TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Tennessee *continued* 27,860 ED visits for TBI 1,864 TBI disabled		
Texas *Texas Department of Health and Human Services* State population: 20,851,820 14,229 hospitalized with TBI 85,593 ED visits for TBI 5,728 TBI disabled	Planning: 1997, 1998 Implementation: 2000, 2001, 2002 Post-Demonstration: 2004	Texas' TBI advisory board, located in the Texas Health and Human Services Commission, was established in 1997. Its 21 members are appointed by the commission and include 38% agency staff; 38% consumers/family; 24% others. The board meets quarterly and addresses long-term services and systems coordination, engages in advocacy, collaboration, education, information and referral, and planning. It has produced concussion cards and "First Steps" brochures.
Utah *Utah Department of Human Services* State population: 2,233,169 1,410 hospitalized with TBI 10,065 ED visits for TBI 549 TBI disabled	Planning: 2001, 2002 Implementation: 2003, 2004 *TBI-specific Medicaid waiver (1996)	Utah's TBI advisory board, located within the Department of Health, was established in 2001. Its 28 members are appointed by the bureau director. The board composition is as follows: 35% agency staff, 22% consumers/family; 22% health care providers; 21% advocacy or research groups. The board meets quarterly. It has focused on statewide TBI resource/needs assessment and statewide TBI action plan development.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
General revenue supports TBI at the Tennessee Rehabilitation Center, which also receives $98,000 from trust fund. Remaining trust funds are used for planning, registry, services, information, and referral. A trust fund was established by legislation and is supported by fines on motor vehicle violations.	mandatory. Follow up occurs within 6 months post injury with information brochure.	—Tennessee increased fines/revenue for trust fund, 2004.
State TBI funding source(s): Trust fund State agency: Rehabilitation Commission Year funding source established: 1991 Annual amount(s): $10.0–10.5 million Number served: 450 A trust fund, established by statute, serves TBI and spinal cord injury and pays for eligible inpatient medical rehabilitation, outpatient rehabilitation-focused, post-acute cognitive. The trust fund is payer of last resort, and recipients must be Rancho IV or higher and at least 16 years old upon completion of rehabilitation.	Texas has a trauma registry, surveillance system, and TBI registry. The TBI registry was established by statute and is population based. Reporting to the Department of Health, Injury Epidemiology and the surveillance program is mandatory. The registry does not include followup contact.	Eight legislative issues related to TBI were addressed by Texas in 2002. Most of them involved including or directing services or amending laws to benefit TBI survivorship.
State TBI funding source(s): TBI-specific Medicaid waiver State agency: Health Services Year funding source established: 1996 Annual amount(s): $1,391,570 Number served: 68 Children receive services through Utah's mental retardation/developmental disabilities waiver and the public school system.	Utah has a trauma registry and a surveillance system.	Utah's governor signed legislation that adds/defines acquired brain injury as an eligible diagnosis for the state's Division of People with Disabilities.

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TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Vermont *Vermont Division of Vocational Rehabilitation* State population: 608,827 228 hospitalized with TBI 2,385 ED visits for TBI 160 TBI disabled	Planning: 2001, 2002 Implementation: 2004, 2005 *TBI-specific Medicaid waiver (1994)	Vermont's TBI advisory board, located within the Vermont Division of Vocational Rehabilitation, was established in September 2002. Its 24 members are appointed by the Division of Vocational Rehabilitation. They include one-third each of agency staff, consumers/family, others. In 2003, outside consultants were chairing meetings every 2–3 months until the board could be fully established. The steering committee met every 2–3 weeks. The board undertakes broad activities, but its initial focus was on the HRSA grant.
Virginia *Virginia Department of Rehabilitation Services* State population: 7,078,515 4,586 hospitalized with TBI 28,711 ED visits for TBI 1,921 TBI disabled	Planning: 1998, 1999 Implementation: 2002, 2003, 2004	Virginia's TBI advisory board, located within the state Department of Rehabilitation Services, was established in 1986 by executive order. Its 31 members were appointed initially and sustained by election. They include 52% agency staff; 23% consumers/family; 25% others. The board, which meets at least quarterly, advises the commissioner of the Department of Rehabilitation Services and is involved with development and implementation of strategic plan.
Washington *Washington Department of Social and Health Services*	Planning: 2000, 2001 Implementation: 2003, 2004, 2005	Washington's TBI advisory board was established in Washington in 2000 and is located within the Department of Social and Health Services. Its 25 members are appointed by the division director. The board includes 40% agency staff; 50% consumers/family; 10% others.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
State TBI funding source(s): TBI-specific Medicaid waiver State agency: Vocational Rehabilitation Year funding source established: 1994 Annual amount(s): $2,151,635 Number served: 50	Vermont has a trauma registry.	Vermont's person-centered Medicaid TBI waiver.
State TBI funding source(s): General revenues, Trust fund State agencies: Rehabilitation Services, Rehabilitation Services Year funding source(s) established: 1984, 1998 Annual amount(s): $1,801,000; $1.1 to 1.5 million Number served: Unknown General revenues support registry (also federal vocational rehabilitation funds), direct services, long-term rehabilitation case management. Virginia's trust fund was established in statute and is supported by drivers' license reinstatement fees. It is used to fund research and grants to community rehabilitation providers. Persons with TBI in Virginia can access one of six Medicaid waivers if eligible.	Virginia has a trauma registry and TBI registry.	—Virginia's Department of Rehabilitation Services developed and annually sponsors a Life Skills Trainer Program for individuals and organizations interested in obtaining more training working with persons with TBI. —Virginia's general assembly approved using some trust fund money to hire a staff person to manage the trust fund.
Washington does not have any dedicated TBI-specific funding sources, but for people with disabilities housing supplements are provided up to 6 months from the Civil Penalties Fund to assist transition from nursing homes.	Washington has a trauma registry.	

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TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Washington *continued* State population: 5,894,121 4,147 hospitalized with TBI 25,763 ED visits for TBI 1,724 TBI disabled		The board meets monthly and is engaged in collaboration and planning and in producing the statewide TBI action plan.
West Virginia *West Virginia Division of Rehabilitation Services* State population: 1,808,344 770 hospitalized with TBI 8,033 ED visits for TBI 538 TBI disabled	Planning: 1997 Implementation: 1999, 2000, 2001 Post-Demonstration: 2002, 2004	West Virginia has an advisory board, located in West Virginia's Division of Rehabilitation Services, that serves both TBI and spinal cord injury. The board was established by statute in 1996. Its has 23 members, of whom 39% are agency staff and 61% are consumers/family. State agency representatives serve as ex officio members; consumers/family are appointed by the governor. The board meets quarterly and addresses broad issues.
Wisconsin *Wisconsin Department of Health and Family Services* State population: 5,363,675 2,728 hospitalized with TBI 20,067 ED visits for TBI 1,343 TBI disabled	Planning Grant: 1997, 1998 Implementation: 1999, 2000, 2001 Post-Demonstration: 2002, 2004 *TBI-specific Medicaid waiver (1995)	Wisconsin's statewide TBI advisory board, created in 1998, is an ad hoc committee of the Developmental Disabilities Council. The 17-member committee includes 31% agency staff; 38% consumers/family; 31% others. The lead state agency for TBI, the Wisconsin Department of Health and Family Services, recommends appointments to the ad hoc committee. The committee meets five times per year. It addresses a wide range of issues and engages in collaboration, education, and planning.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
A medical institution income exemption allows persons to have money to maintain their home. Persons with TBI may use the Medicaid aging and disabled waiver,[f] based on functional abilities rather than diagnosis.		
State TBI funding source(s): General revenue State agencies: Division of Rehabilitation Services Year funding source established: 1998 Annual amount(s): $250,000 Number served: 7,551 7,551 persons received information and referral services; 80 also received case management and direct services. Persons may also use Medicaid mental retardation and developmental disabilities[g] or aging and disabled waivers if eligible.	West Virginia has a trauma registry, TBI registry, and CDC-funded surveillance system. The TBI registry is established in statute. The Division of Rehabilitation Services contracts data collection. It currently does not include followup contact.	—West Virginia has developed a transportation guidebook, accreditation standards, and a resource coordination model. —A resolution was passed to study dedicated funding for TBI/spinal cord injury, 2002. —Medicaid mental retardation and developmental disabilities and aging and disabled waivers may be used by TBI eligibles.
State TBI funding source(s): TBI-specific Medicaid waiver State agency: Department of Health and Family Services Year funding source established: 1995 Annual amount(s): $14,397,750 Number served: 225 522 persons with TBI are also served via other Medicaid waivers in Wisconsin. The state's lead agency for TBI provides matching funds to support the Medicaid TBI waiver.	Wisconsin does not have any formal reporting mechanisms but is in the process of developing a TBI registry. Current HRSA grant activities include development of an annual report based on hospital discharge information.	Wisconsin uses personal futures planning for all programs and has developed a short screening tool to identify persons with TBI in the Federal Temporary Assistance for Needy Families Program who have barriers to employability.

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TABLE C-1 Continued

State, Lead State Agency for TBI, and Other Information[a]	Federal TBI Program Grant(s) Received from HRSA	Statewide TBI Advisory Board
Wyoming *Wyoming Department of Health* State population: 493,782 281 hospitalized with TBI 3,426 ED visits for TBI 229 TBI disabled	Planning: 2005 *TBI-specific Medicaid home and community-based waiver (2001)	A task force of Wyoming's Developmental Disabilities Advisory Board serves as Wyoming's statewide TBI advisory board. This task force is located in the Wyoming's Division of Developmental Disabilities within the Department of Health. Its eight members are appointed by the director of the Division of Developmental Disabilities. They include 5% agency staff; 70% consumers/family; 25% providers. The task force meets periodically. It engages in a wide range of activities, including advocacy for and approval of a Medicaid home and community-based waiver for individuals with acquired brain injury.

NOTE: Data displayed in this table are compiled from state self-reports collected by the National Association of Head Injury Administrators (NASHIA). Programs or accomplishments reported in this table may be unique to an individual state.

[a] State population numbers are from the 2000 U.S. Census. Estimated data on the number of individuals with TBI hospitalization, emergency department (ED) visits, and number of individuals disabled as a result of TBI are from the most recent Centers for Disease Control and Prevention (CDC) TBI Surveillance Program and National Center for Health Statistics data as of May 20, 2005.

[b] On June 22, 1999, the U.S. Supreme Court held in *Olmstead v. L.C.* that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The court ruled that the Americans with Disabilities Act may require states to provide community-based services rather than institutional placements for individuals with disabilities.

[c] The goal of the Independence Plus Grant, initiated in 2001 by the Centers for Medicare & Medicaid Services (CMS), is to develop a federal waiver that will allow individuals with disabilities to direct their own individual budget and choose the services and supports that best meet their needs in the community.

[d] A Medicaid choice waiver allows states to implement managed care delivery systems, or otherwise limit individuals' choice of provider under Medicaid.

TBI-Specific State Funding	Availability of TBI-Related Data	Promising Practices and Recent Legislation Related to TBI
State TBI funding source(s): General revenues, TBI-specific Medicaid waiver State agencies: Health/Developmental Disabilities; Health/Developmental Disabilities Year funding source(s) established: 1999, 2001 Annual amount(s): $1.9 million, $4.5 million Number served: 12, 80 General revenue supports the Visions Program, a residential program for persons with TBI.		—Wyoming refined eligibility for its TBI-specific Medicaid waiver and will be able to determine individual budgeted amounts for each person. —Medicaid waiver implementation, funding through 2004 approved 2002.

[e] South Carolina's Medicaid head and spinal cord injury (HASC) waiver is a type of Medicaid home and community-based services waiver, which allows states to waive Medicaid provisions in order to allow long-term care services to be delivered in community settings; it is the Medicaid alternative to providing comprehensive long-term services in institutional settings. Individuals served by the HASC waiver must have TBI, spinal cord injury (SCI), or a similar disability and must apply for the waiver before their 60th birthday.

[f] The Medicaid aging and disabled waiver provides an alternative to nursing home care. The program includes services that allow a person to continue living in his or her home (e.g., adult day care, an emergency response system, orthotics and prosthetics, personal care and respite services).

[g] The Medicaid mental retardation and developmental disabilities waiver is part of the Medicaid home and community-based waiver program, and provides services to individuals with developmental disabilities, including TBI, incurred before the age of 22.

SOURCE: Connors S, King A, Vaughn S. *Guide to State Government Brain Injury Policies, Funding and Services*. 1st ed. Bethesda, MD: NASHIA, 2003; King A, Vaughn SL. *Guide to State Government Brain Injury Policies, Funding and Services*. 2nd edition. Bethesda, MD: NASHIA, 2005.

TABLE C-2 Accomplishments of State Traumatic Brain Injury (TBI) Programs by State, 1997–2005

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Alabama	Implementation: 1997, 1998, 1999, 2000
Alabama Department of Rehabilitation Services	Post-Demonstration: 2001, 2002, 2004
Alaska	Planning: 2000, 2002
Alaska Department of Health and Social Services	Implementation: 2003, 2004, 2005
Arizona	Implementation: 1997, 1998, 1999
Arizona Department of Economic Security	Post-Demonstration: 2001

Accomplishments of the State TBI Program	Continuing Efforts by the State
• Improved Alabama's communication and interagency linkages to maximize services and supports for individuals with brain injuries and their families. • Developed and implemented the PASSAGES Model—a sustainable, community-based system of care for children and youth with TBI that is individual and family centered. • Trained vocational rehabilitation transition counselors to screen individuals for TBI.	Though Alabama had initiated and sustained significant TBI systems changes previously, Alabama's Federal TBI Program grants from HRSA have led the state to identify other important issues to be addressed—for example, the need to address catastrophic insurance coverage, the potential for a TBI-specific Medicaid home and community-based services waiver, and the addition of personal care and targeted case management as optional services under Medicaid.
• Established Alaska's Department of Health and Social Services, Division of Behavioral Health as the lead state agency for coordinating TBI grant activities. • Established Alaska's statewide TBI advisory board with members from different communities, cities, and villages, which is in the process of applying for 501(c)(3) nonprofit status. • Completed a statewide TBI needs/resources assessment and a statewide TBI action plan for Alaska. • Integrated TBI into Alaska's existing screening tool, which is used by all community mental health and substance abuse grantees.	Alaska continues to incorporate TBI into existing systems. The state is working to raise awareness of TBI issues in the school setting so as to improve educational outcomes for students with TBI. The state is also incorporating TBI issues in other complementary federal grant projects, such as the federal Substance Abuse and Mental Health Services Administration's jail diversion program, as well as the compacting process with the federal Indian Health Service.
• Developed new TBI-related educational materials for Arizona and purchased and disseminated existing educational materials to consumers and providers. • Developed and provided professionals (e.g., educators, nurses, agency personnel) with TBI-related training on the service and support needs of children with TBI. • Convened an interactive TBI symposium with policy makers to discuss multiagency systems change issues. • Developed Arizona's statewide TBI service coordination program within the Maternal	Despite Arizona's many sustained accomplishments and systems changes, the Federal TBI Program grants from HRSA have helped the state identify the need for additional systems changes—for example, coordination among systems serving children, development of TBI service standards, identification of children with TBI, and mitigating policy and program eligibility differences among service programs that limit the delivery of services.

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Arizona *continued*	
Arkansas *Arkansas Department of Education*	Planning: 2001, 2002
California *California Department of Mental Health*	Planning: 1999, 2001
Colorado *Colorado Department of Human Services*	Planning: 1999 Implementation: 2001, 2002, 2003 Post-Demonstration: 2004

Accomplishments of the State TBI Program	Continuing Efforts by the State
and Child Health Bureau, Office for Children with Special Health Care Needs.	
• Identified Arkansas' Department of Education as the lead state agency for coordinating TBI grant activities. • Established a culturally and geographically diverse statewide TBI advisory board for Arkansas. • Conducted a statewide TBI needs/resources assessment and created a statewide TBI action plan for Arkansas.	With additional funding, Arkansas plans to improve educational services to students with TBI; implement hospital discharge and school re-entry procedures; and develop an infrastructure to facilitate leadership and advocacy skills among the brain injury community. Another important area of need, according to the statewide TBI needs/resources assessment, is development and coordination of community long-term supports, including housing and employment services.
• Established California's Department of Mental Health as the lead state agency for TBI for coordinating TBI activities. • Established a statewide TBI advisory board • Completed a statewide TBI needs/resources assessment and developed a statewide TBI action plan.	Although limited resources have temporarily precluded active implementation of California's statewide TBI action plan, efforts continue at the grassroots level to increase awareness of TBI and improve access to existing services through statewide training, a new website, and the nationwide toll-free information hotline. Legislation has been introduced to extend the sunset date of California's TBI Fund, and advocates continue to promote permanent establishment of the fund.
• Developed methods for providing individuals with TBI and their families in Colorado with accessible and appropriate information and referrals. • Initiated a cross-training program with the state's Disability Determination Service to reduce the high disability denial rate for people with TBI.	Although Colorado's TBI trust fund will be able to support some of the activities initiated under the Federal TBI Program grants from HRSA, there remain other issues, as identified by Colorado's TBI action plan, that require focus—for example, development and integration of additional service coordination networks; training of professionals who serve and educate

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Colorado *continued*	
Connecticut	Planning: 2003, 2004
Connecticut Department of Social Services	
Delaware	Planning: 1997, 1998
Delaware Department of Health and Social Services	
District of Columbia	Planning: 1997, 1998
D.C. Department of Health	Implementation: 1999, 2000, 2001
	Post-Demonstration: 2002, 2003

Accomplishments of the State TBI Program	Continuing Efforts by the State
	children and youth with TBI; and training of state agency personnel. As professionals in California become more aware of TBI-related issues, they will be better prepared to identify and coordinate state program and policy changes.
• Appointed members of Connecticut's diverse and representative statewide TBI advisory board (appointment by the commissioner of the Connecticut Department of Social Services). • Had members of Connecticut's statewide TBI advisory board participate in several trainings on TBI 101 and TBI among Southeast Asians. • Conducted seven forums on services and resources for persons with TBI throughout the state. • Hired a project coordinator.	Connecticut's TBI advisory board members have drafted a bill to have the board legislatively mandated. Connecticut continues to develop the members of the advisory board and complete Connecticut's TBI needs/resources assessment in order to create a statewide TBI action plan that will define the optimal coordination system of services and supports for individuals with TBI and their families in the state.
• Completed Delaware's statewide TBI needs/resources assessment. • Developed a statewide TBI action plan. • Identified barriers individuals with TBI and their families face in trying to access appropriate services and supports. • Developed educational resources for caregivers, families of individuals with TBI.	Delaware has received approval for a TBI-specific Medicaid TBI waiver and is currently in the process of implementation. Other issues identified in the statewide TBI action plan may be addressed in the future with additional funding.
• Produced culturally sensitive educational materials related to TBI. • Collaborated with the faith-based community to promote TBI awareness • Established a TBI registry for D.C.	D.C. continues to work with appropriate stakeholders to ensure the sustainability of the D.C. TBI registry. D.C. is also addressing the transition process to daycare, preschool, middle and high school, as well as the transition to post-secondary options for infants, children, youth, and young adults with TBI.

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Florida	Implementation: 1997, 1998, 1999, 2000
Florida Department of Health	Post-Demonstration: 2001, 2003, 2004
Georgia	Planning: 1997
Brain and Spinal Injury Trust Fund Commission	Implementation: 1998, 1999, 2000
	Post-Demonstration: 2004
Hawaii	Planning: 1999, 2000
Hawaii Department of Health	Implementation: 2002, 2003, 2004

Accomplishments of the State TBI Program	Continuing Efforts by the State
• Adapted the Partners in Policymaking model of leadership training for individuals with TBI in Florida. • Increased awareness of TBI-related issues and available resources for individuals with TBI and their families in Florida through public awareness campaigns with the copyrighted slogan: "Brain Injury, It's the last thing on your mind, until it's the ONLY thing."®.	With each additional Federal TBI Program grant, Florida addresses yet another area in its statewide TBI action plan. Currently, state resources are being leveraged to improve the employment outcomes for individuals with TBI and their families. Florida has also been successful in integrating TBI issues in its Olmstead planning[a] and its Real Choice Systems Change Grant from the Centers for Medicare & Medicaid Services (CMS).
• Transitioned the lead state agency role to the Brain and Spinal Injury Trust Fund Commission. • Worked with the Brain Injury Resource Foundation to expand access to family resources. • Enhanced the state's TBI registry by changing methods for data collection.	As the new lead state agency for TBI, Georgia's Brain and Spinal Injury Trust Fund Commission is redeveloping the former statewide TBI advisory board as a permanent body to lead systems change. Additionally, efforts are underway to update the statewide TBI needs/ resources assessment. The statewide TBI action plan has identified the need to increase access to transportation, neurobehavioral, and cognitive rehabilitation services; lifelong services; and supports that include rehabilitation and housing.
• Completed Hawaii's statewide TBI needs/ resources assessment and developed a statewide TBI action plan. • Developed and maintained a toll-free help line for information and referral that receives an average of 25 calls per month. • Implemented a distance learning program in brain injury with George Washington University. • Produced a website and resource directory. • Disseminated a TBI information packet for acute care and rehabilitation hospitals.	Hawaii continues to educate the community about TBI through a speakers bureau and other mechanisms and develop the capacity of the statewide TBI advisory board members to lead systems change efforts. Among the priorities identified in the statewide TBI action plan are the need to gather and utilize reliable information from program evaluations, increase TBI awareness, and improve access to coordinated TBI services throughout the state.

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Idaho *Idaho Department of Health and Welfare*	Planning: 2000, 2001 Implementation: 2003, 2004, 2005
Illinois *Illinois Department of Human Services*	Planning: 1997, 1998 Implementation: 2000, 2001, 2002
Indiana *Indiana Department of Health*	Planning: 1999
Iowa *Iowa Department of Public Health*	Planning: 1997 Implementation: 1998, 1999, 2000 Post-Demonstration: 2001, 2002, 2003

Accomplishments of the State TBI Program	Continuing Efforts by the State
• Presented a Virtual Program Center prototype at a congressional fair for the U.S. Senate in June 2002. • Developed and produced the Virtual Grand Rounds semester-long series, attended to date by 350 individuals. • Downsized tripartite advisory councils to maximize efficiency and effectiveness. • Finalized charter for Idaho's lead state agency for TBI signatures. • Assisted with passage of trauma legislation • Completed Idaho's annual statewide TBI needs/resources assessment of providers, agency personnel, persons with TBI, and family members. • Completed a policy analysis of payment systems and a review for cost neutrality.	Idaho's fall 2004 Virtual Grand Rounds were being coordinated with Washington State. Idaho also expected to continue its economic analysis in collaboration with the Real Choice Systems Change Grant from CMS; the development of the TBI Virtual Program Center; its continued coordination with state and federal community integration and self-determination efforts (e.g., Commission on Aging, Consortium of Idahoans with Disabilities, and Telehealth Idaho).
• Completed Illinois' statewide TBI needs/resources assessment and developed a statewide TBI action plan. • Improved the state's infrastructure for providing appropriate information and resources to individuals with TBI, families, and service professionals. • Conducted TBI training programs in the state. • Developed a satisfactory survey instrument.	Illinois is working to implement elements of the statewide TBI action plan. For example, efforts continue to improve access to transportation, improve vocational rehabilitation services and employment outcomes, and increase access to educational services and institutions.
• Established Indiana's lead state agency to coordinate TBI grant activities. • Established a statewide TBI advisory board. • Completed a statewide TBI needs/resources assessment. • Developed a statewide TBI action plan.	Indiana has utilized a TBI Planning Grant to identify and begin to organize state resources. The state's planning activities have provided valuable information that will help establish priorities for future TBI systems change activities.
• Established the Iowa Brain Injury Resource Network as part of the Brain Injury. Association of Iowa's coordinated discharge planning program at more than 50 trauma, rehabilitation, and service/support locations. • Implemented the Iowa Family Support Network—a peer-to-peer mentoring network of 26 families—within the Iowa Brain Injury	A priority for Iowa's TBI program is to identify and secure alternative sources of financial support to ensure the long-term sustainability of projects initiated during the grant. Additionally, Iowa continues to work on developing and implementing standards of care to ensure service

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Iowa *continued*	
Kansas	Planning: 2001, 2002
Kansas Department of Social and Rehabilitation Services	Implementation: 2003, 2004, 2005
Kentucky	Planning: 1999
Kentucky Cabinet for Health Services/Department of Mental Health and Mental Retardation	Implementation: 2003, 2004, 2005
Louisiana	No Federal TBI Program grants received
Louisiana Department of Social Services/ Rehabilitation Services	
Maine	Planning: 2003, 2004
Maine Department of Human Services	Implementation: 2005

Accomplishments of the State TBI Program	Continuing Efforts by the State
Resource Network. • Increased access to educational materials, services, and supports for individuals with TBI and their families, including development of a website, *www.biaia.org*.	quality and cost effectiveness, make case management available to all individuals with TBI, and ensure that the Brain Injury Association of Iowa is recognized as the single point of contact for statewide information and referral services.
• Established Kansas' statewide TBI advisory board. • Conducted a statewide TBI needs/resources assessment and developed a statewide TBI action plan. • Collaborated with a local Veterans Administration Center on the development of a statewide TBI conference. • Planned statewide forums on TBI for professionals from various disciplines.	Kansas continues to address areas of need as identified by its statewide TBI action plan by promoting awareness of TBI within various professional communities; developing a screening tool and licensure process for substance abuse counselors; and further developing the statewide TBI advisory board.
• Completed Kentucky's TBI needs/resources assessment and developed a statewide TBI action plan. • Hired staff and signed agreements to implement the natural support networks. • Established a mechanism for the permanent, required inclusion of brain injury in Division of Mental Retardation training. • Drafted a brain injury training model under a memorandum of agreement with the Division of Mental Health.	Kentucky is also working to address other issues as identified by the statewide TBI action plan: maximizing the ability of individuals with TBI and their families to plan for and support themselves in their homes and communities and establishing sustainable funding for needed services.
• Established Maine's statewide TBI advisory board. • Conducted 12 focus groups and 13 personal interviews with and distributed 550 surveys to individuals with TBI and their families; also conducted five focus groups with and distributed 200 surveys to providers as part	Maine will address some of the issues identified in its statewide TBI action plan to improve the lives of individuals with TBI.

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Maine *continued*	
Maryland *Maryland Department of Health and Mental Hygiene*	Planning: 1998 Implementation: 1999, 2000, 2001 Post-Demonstration: 2003, 2004
Massachusetts *Massachusetts Executive Office of Health and Human Services/ Rehabilitation Commission*	Implementation: 2000, 2001, 2002

Accomplishments of the State TBI Program	Continuing Efforts by the State
of the statewide TBI needs/resources assessment process.	
• Completed Maryland's statewide TBI needs/resources assessment, developed a statewide TBI action plan, and established a statewide TBI advisory board. • Established a workgroup to identify and assess state agency data on brain injury services and supports. • Developed a directory of resources for people with TBI, families, professionals. • Conducted TBI training program for state agency personnel. • Created training modules for self-advocacy for individuals with TBI and their families • Implemented a TBI-specific Medicaid waiver.	Maryland is continuing its efforts to increase statewide awareness of TBI and to ensure individuals with TBI and their families have access to the information they need to access appropriate services.
• Developed, translated, and now has available TBI information in multiple languages for Massachusetts residents. • Conducted TBI training programs, including train-the-trainer programs, for providers from diverse communities. • Recruiting case managers and clinical consultants within organizations of underserved populations and establishing support groups within these communities. • Presently working with the Chinese, Vietnamese, Cambodian, and Latino communities as an integral part of the state's system. • Hired a consultant who is both African American and Native American and has a brain injury to assist in multicultural outreach. • Has ensured that the state staff now includes individuals whose cultural backgrounds and primary language are Chinese, Vietnamese, and Cambodian.	Other needed systems change priorities identified in the Massachusetts statewide TBI action plan include the need to increase access to community-based services, family support services, school capacity to serve children with TBI, and the need for improved funding, among others.

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Michigan *Michigan Department of Community Health*	Planning: 1998 Implementation: 2001, 2002, 2003 Post-Demonstration: 2004
Minnesota *Minnesota Department of Human Services*	Implementation: 1997, 1998, 1999 Post-Demonstration: 2002, 2003
Mississippi *Mississippi Department of Rehabilitation Services*	Planning: 1997

Accomplishments of the State TBI Program	Continuing Efforts by the State
• Designated Michigan's Department of Community Health as the lead state agency for TBI. • Established a statewide TBI advisory board. • Completed a statewide TBI needs/resources assessment. • Developed a statewide TBI action plan. • Developed and distributed a resource guide for persons with TBI and their families. • Initiated TBI training for service and support consumers and providers. • Developed a diary, a training manual, and access guidelines for persons with TBI.	Michigan is developing strategies to maximize the effective and efficient use of public funds, promote public-private partnerships, improve service coordination, and ensure TBI services and supports are comprehensive and support individually determined outcomes to the extent possible.
• Established Minnesota's statewide TBI advisory board, completed a statewide TBI needs/resources assessment, and developed a statewide TBI action plan, which continues to be updated. • Formalized the preexisting strong partnership between five state agencies and the Brain Injury Association of Minnesota with an Interagency Agreement to address agency gaps and overlaps in policy, funding, and services, creating the Minnesota TBI Interagency Leadership Council. • Expanded the Interagency Leadership Council to include Minnesota's Department of Corrections, the TBI Protection and Advocacy Program, and the TBI Program at the VA Medical Center, Minneapolis. • Implemented the "Hospital Discharge Model" (now "resource facilitation"), which wa developed and enhanced by the federal TBI Program grants statewide. The 2003 Minnesota state legislature funded a special surcharge, part of the TBI-dedicated funds.	Minnesota's statewide TBI action plan identifies systems change needs in addition to work begun and sustained by the state's Federal TBI Program grants from HRSA. These additional needs include improved access to pertinent information; better linkage to resources in various systems (e.g., education, work, behavioral health, etc.); coordinating with "border hospitals" in neighboring states; and outreach to the underserved.
• Identified Mississippi's Department of Rehabilitation Services as the lead state agency for TBI.	With an additional Federal TBI Program Planning Grant from HRSA, Mississippi plans to convene a statewide TBI advisory board, which will conduct a statewide TBI needs/resources assessment and formulate a statewide TBI action plan. As a

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Mississippi *continued*	
Missouri	Implementation: 1997, 1998, 1999, 2000
Missouri Department of Health and Senior Services	Post-Demonstration: 2001, 2002, 2004
Montana	Planning: 2001, 2002
Montana Department of Public Health and Human Services	Implementation: 2003, 2004, 2005
Nebraska	Planning: 2000, 2001
Nebraska Department of Education	Implementation: 2002, 2003, 2004

Accomplishments of the State TBI Program	Continuing Efforts by the State
	result of the initial planning phase, several significant systems change needs were identified. For example, it was learned that individuals with TBI and their families are often unaware of existing TBI services and supports and have difficulty accessing appropriate services and supports, or services and resources are unavailable in some communities.
• Developed and trained rural service providers in Missouri, expanding the rural provider base • Developed and initiated a service coordinator training program and evaluation system that focuses on outcomes (e.g., community inclusion, competitive employment) for Missouri's Head Injury Program • Developed and initiated an outreach and education initiative to ensure that underserved communities have access to TBI information	Missouri is working to implement a service coordination and Futures Planning model statewide, and to ensure that reliable, person-centered outcome data are utilized to evaluate programs. Other priorities identified in its statewide TBI action plan include: addressing the needs of individuals with behavioral issues; improving employment outcomes; addressing the unique needs of children with TBI.
• Completed Montana's statewide TBI needs/ resources assessment • Montana legislation created a special revenue fund for public information and education on TBI and established a governor-appointed statewide TBI advisory board	Montana continues to develop its information and referral program; create coordinated services within two Indian Reservations; and create training modules for providers and individuals with TBI and their families. Cultural competence is infused in the project via the Native American representation on the statewide TBI advisory board.
• Completed Nebraska's statewide TBI needs/ resources assessment and developed a statewide TBI action plan • Designed and established a coordinated service structure with a designated "point of entry"—NEBrainstorm, the state's brain injury resource network	Nebraska's priorities, as identified by its statewide TBI action plan, are to increase awareness of the service and support needs of individuals with TBI and their families, increase the local availability of services and supports, and improve the

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Nebraska *continued*	
Nevada *Nevada Office of Community-Based Services*	Planning: 1997, 2005
New Hampshire *New Hampshire Department of Health and Human Services/ Division of Developmental Services*	Planning: 1997, 1998 Implementation: 2000, 2001, 2002 Post-Demonstration: 2003, 2004

Accomplishments of the State TBI Program	Continuing Efforts by the State
• Initiated a brain injury network focused on community awareness and education. • Established new services, including a service collaborative of vocational rehabilitation, health, and education agencies.	coordination of services and funding sources.
• Identified Nevada's lead state agency for TBI. • Conducted a statewide TBI needs/resources assessment.	Nevada has completed a number of important statewide planning and organizational activities. These efforts have identified the need to develop a coordinated approach to services and supports delivery, increase access to information and referral services, increase access to services and supports, and increase public awareness of TBI-related issues.
• Completed New Hampshire's statewide TBI needs/resources assessment and a statewide TBI action plan. • Developed an acquired brain disorders training curriculum and an education program for individuals with TBI and families. • Trained providers in evaluating and treating neurobehavioral consequences of TBI via mobile resource teams. Team sustainability is pending legislative authorization. • Developed a peer mentoring program to train mentors (both individuals with TBI and family members) and match mentor to mentee. • The New Hampshire Legislature has appropriated $200,000 that, in part, funds the Brain Injury Association of New Hampshire's resource facilitation program. • Established agreements with four rehabilitation facilities throughout New Hampshire to support monthly family trainings.	New Hampshire is also working to address other issues as identified by the statewide TBI action plan: increasing the knowledge base and skills of professionals; developing statewide capacity to provide responsive service coordination and referral; and continuing to strengthen the statewide TBI advisory board.

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TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
New Jersey	Implementation: 1999, 2000, 2001
New Jersey Department of Human Services	Post-Demonstration: 2002, 2003, 2004
New Mexico	Implementation: 2001, 2002, 2003
New Mexico Department of Health	
New York	Implementation: 1997, 1998, 1999, 2000
New York Department of Health	Post-Demonstration: 2001, 2002, 2004

Accomplishments of the State TBI Program	Continuing Efforts by the State
• Developed a mentor training program for family members and individuals with TBI in New Jersey. • Expanded the capacity of hospital chaplains and community clergy to support individuals with TBI and their families. • Produced print and electronic materials for individuals with TBI, families, service providers, and education system professionals in multiple languages and alternate formats. • Developed an urban pilot for outreach and support for persons with TBI in underserved populations with a community agency.	New Jersey continues to develop and disseminate educational materials for various audiences. New Jersey also integrates TBI in other disability initiatives, including Olmstead planning initiatives and its Real Choice Systems Change Grant from CMS. With the establishment of the New Jersey TBI Fund and a Brain Injury Research Fund, New Jersey has gained a significant boost ($3.4 million annually) toward the sustainability of its systems change efforts initiated with the Federal TBI Program.
• Required all TBI program providers in New Mexico to provide customer satisfaction surveys. • Developed a TBI education/resource manual in English and Spanish, Navajo audio, CD, and website formats. • Increased the number of telephone calls to the information and referral line by disseminating a TBI wallet information card. • Conducted advocacy training sessions for 50 individuals. • Achieved TBI-favorable policy changes improving TBI awareness. • New Mexico legislature appropriated $100,000 yearly for continuation of awareness and education projects, including billboards, public service announcements, a TV special, posters, and bumper stickers.	New Mexico is working with several contractors to conduct program evaluations of existing state TBI service and support systems. The results of these evaluations will help to guide future systems change activities. A refresher advocacy training course will be given to the 50 advocacy graduates in preparation for passage of the TBI-specific Medicaid waiver in the 2005 legislative session.
• Established a collaborative partnership among New York state agencies, service providers, consumers of services, and advocacy organizations. • Developed culturally competent educational materials and tools, discharge planning models, and training modules for the African-American/Caribbean, Chinese American, and Latino communities. • Completed analyses of TBI-specific Medicaid waiver participant satisfaction and submitted report to HRSA with recommendations.	New York continues to evaluate the efficacy and cost effectiveness of service and community reintegration. Other ongoing activities include increased service coordination, and collaboration with insurance companies and health maintenance organizations.

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
North Carolina *North Carolina Division of Mental, Developmental Disabilities, and Substance Abuse Services*	Implementation: 1997, 1998, 1999 Post-Demonstration: 2001
North Dakota *North Dakota Department of Human Services*	Planning: 2003, 2004
Ohio *Ohio Rehabilitation Services Commission*	Implementation: 1998, 1999, 2000 Post-Demonstration: 2002, 2003, 2004

Accomplishments of the State TBI Program	Continuing Efforts by the State
• Graduated North Carolina's TBI action plan from an informally updated document to a proactive tool for policy development, legislative initiatives, and program expansion. • Developed or modified existing TBI educational materials for distribution to service professionals and individuals with TBI as well as their families. • Worked with North Carolina trauma centers to ensure key hospital support staff members have the information and training necessary to assist individuals with TBI and their families as they prepare to leave the hospital. • Developed a skill pack for hospital staff to improve the outcomes of the discharge process.	In North Carolina, in addition to the systems changes addressed by Federal TBI Program grants, the statewide TBI action plan has identified a need to increase public awareness about TBI-related issues, develop rehabilitation programs that include prevocational and vocational rehabilitation with therapies, secure financing to support local service and support programs, and develop a regional information and resources infrastructure.
• Established North Dakota's statewide TBI advisory board with representation from the Native American community and service providers. • Initiated North Dakota's statewide TBI needs/resources assessment process. • Conducted a focus group process in five Native American communities and five urban communities. • Began the survey process of TBI service (medical and program) providers.	North Dakota is working to establish a lead state agency for TBI and complete its statewide TBI needs/resources assessment. The results of this process will provide the information needed to develop a comprehensive statewide TBI action plan, which will provide the foundation and direction for future systems change activities in North Dakota.
• Further developed a state blueprint—The Ohio Plan—for a comprehensive, resource coordination system that includes a statewide toll-free helpline; regional community support network (CSN) offices; and individual services coordination. • Added four CSN offices (two in Appalachia, two in metro areas). • Developed communication and accountability infrastructure supports for The Ohio Plan including website and Internet access, interoffice network, and databases documenting numbers served, customer satisfaction, and programs and services. • Promoted community capacity-building initiatives through involvement of CSN	Ohio is updating its joint Brain Injury Advisory Committee—Brain Injury Association of Ohio statewide TBI action plan and working with policy makers to ensure access to services and supports for persons with brain injury and their families.

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Ohio *continued*	
Oklahoma *Oklahoma Department of Health*	Planning: 1997, 1998 Implementation: 1999, 2000, 2001 Post-Demonstration: 2003, 2004
Oregon *Oregon Department of Education*	Planning: 1997 Implementation: 1998, 1999, 2000 Post-Demonstration: 2001, 2002, 2004

Accomplishments of the State TBI Program	Continuing Efforts by the State
personnel, TBI Collaborative Groups, support groups, and individuals with TBI and their families. • Conducted "town hall" meetings providing forums for citizens with brain injury and their families to voice their needs and to generate greater awareness about TBI.	
• Implemented a pilot hospital pre-discharge planning model in three hospitals in Oklahoma. • Developed, implemented, and evaluated TBI training curricula for vocational rehabilitation counselors, allied health students, and law enforcement. • Developed, distributed, and evaluated four TBI brochures for emergency departments, hospitals, vocational rehabilitation, and the Brain Injury Association of Oklahoma in English and Spanish. • Assisted in marketing, client base expansion, and service evaluation of the Brain Injury Association of Oklahoma. • Conducted a TBI Practice and Research Symposium in 2003 with high attendance and excellent evaluation results.	Oklahoma is sharing its discharge planning model improvement recommendations with hospitals and other groups. Oklahoma's statewide TBI action plan has also identified a need to improve prevention of common secondary effects of TBI.
• Implemented the Oregon TBI Resource Team to provide TBI-related information and assistance to local school systems. • Established the Oregon Brain Injury Resource Network to provide timely, appropriate TBI information to individuals with TBI, families, and service providers. • Developed a family-advocacy training curriculum. • Established the Oregon Brain Injury Council, a state-level coordinating group. • Established a Governor's Brain Injury Task Force to inform state-level infrastructure decisions. • Established a Curry County Collaborative to build regional capacity to improve access to community-based services.	Oregon continues to develop a single point of contact where individuals with TBI, families, and service and support providers can access information about TBI services and supports and to expand the Cadre Model to work with larger communities around the state. The state's partners continue the legislative efforts begun under the grant.

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Pennsylvania *Pennsylvania Department of Health*	Planning: 2001, 2002 Implementation: 2003, 2004, 2005
Rhode Island *Rhode Island Department of Human Services*	Planning: 1999, 2000 Implementation: 2002, 2003, 2004
South Carolina *South Carolina Department of Disabilities and Special Needs*	Planning: 1997, 1998 Implementation: 2000, 2001, 2002 Post-Demonstration: 2004

Accomplishments of the State TBI Program	Continuing Efforts by the State
• Established Pennsylvania's statewide TBI advisory board. • Conducted a statewide TBI needs/resources assessment and developed a statewide TBI action plan. • Reviewing materials for the information and referral clearinghouse, library, and trainings.	Pennsylvania continues to strengthen its interagency collaborations to address issues identified in its statewide TBI action plan, including the need for greater public awareness of TBI and the improvement in the quality of care and services for those with TBI and their families.
• Completed Rhode Island's statewide TBI needs/resources assessment and developed a statewide TBI action plan. • Increased communication and collaboration with stakeholders, individuals with TBI, and their families. • Established a TBI resource center in an accessible storefront location. • Increased telephone queries and walk-ins to the TBI Resource Center by 300 percent—most likely due to the more than 8,000 fact sheets (in English, Portuguese, Spanish, and Cambodian) and emergency medical technician cards (in English and Spanish) distributed statewide, plus radio broadcasts and a television news story.	Future activities include increasing public awareness of the causes and consequences of TBI, improving the TBI knowledge and skills of health and service professionals, improving access to information and resources on TBI for individuals with TBI and families, improving service coordination statewide, and increasing the focus on person-centered services and supports, among other issues. Also, Rhode Island continues to develop its Needs and Resource Directory as well as training videos. Legislation has been introduced to expand the Governor's Permanent Advisory Council and to establish a trust fund to pay for expanded services for people with TBI and their families.
• The Brain Injury Alliance of South Carolina is developing as a unified statewide consumer organization affiliated with the Brain Injury Association of America. • The South Carolina Brain Injury Leadership Council is becoming more active and effective as the statewide TBI advisory board. • Initiated the "Community Opportunities" model (which includes a resource/drop-in center, individual rehabilitation supports, and a vocational interests and productivity program) into four areas of South Carolina. • Increased the number of people with TBI served by the program and increased the number of people with TBI employed.	Although South Carolina has a basic service structure in place and some dedicated funding for TBI, implementation of specialized employment preparation for individuals with TBI and TBI training for state agency staff and professionals remain important areas of need.

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
South Carolina *continued*	
South Dakota	No Federal TBI Program grants received
Tennessee	Implementation: 2000, 2001, 2002
Tennessee Department of Health	Post-Demonstration: 2003, 2004
Texas	Planning: 1997, 1998
Texas Department of Health and Human Services	Implementation: 2000, 2001, 2002 Post-Demonstration: 2004
Utah	Planning: 2001, 2002
Utah Department of Human Services	Implementation: 2003, 2004

Accomplishments of the State TBI Program	Continuing Efforts by the State
• Established the TBI Training Institute within the University of South Carolina School of Medicine, Center for Disability Resources.	
• Developed a TBI curriculum entitled "Brain Injury 101: Supporting Students with Brain Injury in the Classroom" to raise awareness of TBI and to provide information to those serving students with TBI. • Produced an educational video entitled "Take Two: Life After TBI" to illustrate the effects of brain injury on three Tennessee families. • Trained over 1,000 with the "Brain Injury 101" curriculum. • Established the Project BRAIN Summer Institute, an intensive training for BRAIN ResourceTeams. • Established 17 multidisciplinary Resource Teams of education professionals.	Tennessee's statewide TBI action plan has identified the need to secure sustainable financial support for TBI services and supports, improve access to the information and services individuals with TBI and their families need, and to improve service coordination.
• Reviewed and commented on TBI-related Texas legislation and reports. • Informed the Texas state legislative process during enactment of legislation prohibiting insurers from excluding cognitive rehabilitation coverage for individuals with TBI; worked with the state Department of Insurance to draft implementing regulations. • Provided training on TBI to case managers. • Developed and disseminated concussion cards to emergency medical service providers and family packets to trauma centers.	The Texas TBI program continues to participate with state agencies to ensure that barriers to coordinated and comprehensive TBI services and supports are eliminated, and to ensure that individuals with TBI and their families are appropriately served across the state.
• Designated Utah's Department of Human Services as the lead state agency for TBI. • Increased the diversity of the statewide TBI advisory board by 20 percent. • Completed a statewide TBI needs/resources assessment. • Developed and promoted the statewide TBI action plan.	With its Implementation Grant, Utah began its analysis of current state policies for functionality and as a basis for promoting TBI-favorable systems change. Utah will also continue its efforts to develop a comprehensive information and referral system and improve the case

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
Utah *continued*	
Vermont	Planning: 2001, 2002
Vermont Division of Vocational Rehabilitation	Implementation: 2004, 2005
Virginia	Planning: 1998, 1999
Virginia Department of Rehabilitation Services	Implementation: 2002, 2003, 2004
Washington	Planning: 2000, 2001
Washington Department of Social and Health Services	Implementation: 2003, 2004, 2005

Accomplishments of the State TBI Program	Continuing Efforts by the State
• Initiated a rural pilot to improve the case management and education services provided to those with TBI and their families.	management and education services, among others, for those with TBI and their families.
• Established Vermont's statewide TBI advisory board. • Conducted a statewide TBI needs/resources assessment. • Developed a statewide TBI action plan.	With its Planning Grant, Vermont made great strides in identifying the next steps in achieving systems change for those with TBI and their families. The Implementation Grant will allow Vermont to address a subset of the needs identified by the statewide TBI action plan.
• Played a significant role in garnering $1 million in new state funding for brain injury services in Virginia. • Involved in local group that successfully established the Center for Independent Living services in underserved areas. • Developed three TBI documentaries, two of which aired on public access; also, public service announcements aired in two areas. • Developed best practice manual for primary and secondary education, as well as a policy maker's manual on TBI. • Developed an "Advocacy Academy" for consumers and family members. • Developed and disseminated 500 "TBI and Domestic Violence" tip cards.	Virginia will continue to address needs identified by its statewide TBI action plan: regional resource centers, a central registry, neurobehavioral treatment, case management, personal assistance, improved employment outcomes, transportation, and individual/family support.
• Completed Washington's statewide TBI needs/resources assessment and developed a statewide TBI action plan. • Incorporated existing Federal TBI Program products and others into a TBI Tool Kit using a consumer-directed process. • Developed a framework to enhance public and professional education through product development and dissemination. • Developed an interactive TBI educational series targeting the needs of rural and urban communities in collaboration with the University of Washington's TBI Model Systems and Idaho's Federal TBI Program grants.	Washington continues to further strengthen its various interagency collaborations and its statewide TBI advisory board to achieve the priorities as identified in the statewide TBI action plan, including the development of support for a housing option specifically for those with TBI.

continues

TABLE C-2 Continued

State and Lead State Agency for TBI	Federal TBI Program Grant(s) Received from HRSA
West Virginia *West Virginia Division of Rehabilitation Services*	Planning: 1997 Implementation: 1999, 2000, 2001 Post-Demonstration: 2002, 2004
Wisconsin *Wisconsin Department of Health and Family Services*	Planning: 1997, 1998 Implementation: 1999, 2000, 2001 Post-Demonstration: 2002, 2004
Wyoming *Wyoming Department of Health*	Planning: 2005

NOTE: Data displayed in this table are compiled from state self-reports collected by the National Association of Head Injury Administrators (NASHIA). Programs or accomplishments reported in this table may be unique to an individual state.

[a] On June 22, 1999, the U.S. Supreme Court held in *Olmstead v. L.C.* that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The court ruled that the Americans with Disabilities Act may require states to

Accomplishments of the State TBI Program	Continuing Efforts by the State
• Surveyed 10,000 service providers across West Virginia to identify local service and support capacity • Conducted TBI and service coordination training for service and support professionals across the state • Developed, implemented, and disseminated a TBI training curriculum and the "Road Map to the Future" (resource coordination organizational tool) to increase state agencies' capacity to provide appropriate, person-centered TBI services	West Virginia will continue to collaborate with other state projects including the Real Choice Systems Change Grant from CMS and the Nursing Home Transition Project to address other issues prioritized by the statewide TBI action plan: improved self advocacy training for individuals with TBI; and comprehensive and coordinated systems of services and supports, from hospital discharge to community integration, among others.
• Established the Brain Injury Association of Wisconsin as a central point of contact for information and referral services • Established a data system to record and analyze data on service needs, individual outcomes, program evaluation, and customer satisfaction	Wisconsin is incorporating the TBI service delivery system into existing state and county services. The emphasis at this time is to develop further the statewide TBI advisory board; address the various needs of the Native American and other underserved populations; and explore sustainability options for activities initiated under Federal TBI Program grants. A partnership between the Brain Injury Association of Wisconsin and the Association for Retarded Citizens of Wisconsin continues as the organizations work to increase disability service capacity in rural areas.
As of March 2005, Wyoming did not have results to report from its 2005 TBI Planning Grant from HRSA.	

provide community-based services rather than institutional placements for individuals with disabilities.

SOURCE: Connors S, King A, Vaughn S. *Guide to State Government Brain Injury Policies, Funding and Services*. 1st ed. Bethesda, MD: NASHIA, 2003; King A, Vaughn SL. *Guide to State Government Brain Injury Policies, Funding and Services*. 2nd ed. Bethesda, MD: NASHIA, 2005.

TABLE C-3 State-Based Protection and Advocacy (P&A) Systems for Individuals with Developmental Disabilities: Goals and Accomplishments Related to P&A for Individuals with Traumatic Brain Injury (PATBI) by State, 2005

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Alabama *Alabama Disabilities Advocacy Program*	PATBI Grant: $150,000	1. Increase outreach and advocacy services to adults and children with TBI and their families residing in Alabama's rural areas. 2. Advocate for appropriate treatment or rehabilitation for persons with TBI residing in state-funded institutions or participating in state-funded community programs. 3. Advocate for proper treatment of people with TBI in the criminal justice system. 4. Advocate for the reduction of seclusion and restraint practices for adults and children with TBI residing in state-funded institutions and community programs. 5. Assist and represent people with TBI in their right to access services and programs free of discrimination by providing technical assistance, training, developing materials, and/or assisting with complaints.
Alaska *Disability Law Center of Alaska*	PATBI Grant: $150,000	1. Conduct self-advocacy trainings for individuals with TBI and their families. 2. Produce a TBI addendum to the Disability Law Center's *Special Education and the Law* handbook. 3. Provide direct legal assistance to students with TBI from rural areas to obtain a free appropriate public education. 4. Increase outreach and services to the homeless and veterans groups. 5. Collaborate with Alaska's statewide TBI advisory board and support groups.
Arizona *Arizona Center for Disability Law*	PATBI Grant: $150,931	1. Develop outreach materials describing P&A services for the TBI community. 2. Provide information on the project and P&A services to organizations throughout the state. 3. Provide information about P&A services to individuals with TBI via the Center's website. 4. Perform a series of outreach and training events

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Involved in Alabama's TBI planning process. • Involved with University of Alabama TBI research project. • Reviewed 89 TBI Wyatt class cases for best practices. • Attended two statewide TBI conferences; held eight focus groups. • Collaborated on parent training and a train-the-trainer model for youth. • Advocated for 17 individuals with TBI in special education classes. • Published an article on assistive technology and TBI. • Involved in TBI training initiatives for law enforcement. • Developed and distributed TBI brochures and posters.	The Alabama Disabilities Advocacy Program will continue to provide case advocacy for individuals with TBI, education and training regarding rights of those with TBI, and outreach to individuals with TBI residing in rural areas.
• Project staff members serve on subcommittees of Alaska's statewide TBI advisory board. • Providing training to TBI support groups through the Independent Living Council. • Partnering with the special education service agency to develop a special education publication. • Conducting outreach to homeless and veterans shelters.	The Disability Law Center of Alaska will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.
• Collaborating with Arizona's TBI lead agency on several initiatives, including a conference in June 2003. • Participated in trainings for service provider staff, e.g., case managers and special education personnel. • Increased number of TBI calls.	The Arizona Center for Disability Law will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Alabama *continued*		around the state targeting individuals with TBI, their families, and caregivers. 5. Co-sponsor a half-day conference on TBI in collaboration with the Arizona Governor's Council on Spinal and Head Injury. 6. Provide direct representation of those with TBI who experience barriers in applying for publicly funded services and obtaining employment.
Arkansas *Disability Rights Center, Inc.*	PATBI Grant: $100,000	1. Monitor the implementation of Arkansas' Olmstead plan[b] by attending meetings of the governor's housing taskforce and publish information gained on the Disability Rights Center website. 2. Collaborate with the state Department of Education and other agencies important to individuals with TBI in order to support Arkansas in its effort to receive a Federal TBI Program Implementation Grant from HRSA. 3. Assist in developing Arkansas' statewide TBI advisory board consisting of over 50 percent TBI survivors and family members and advise on TBI advocacy needs, outreach strategies, and service priorities. 4. Produce and distribute two informational flyers and a public service announcement as recommended by the statewide TBI advisory board; contribute to updated general Disability Rights Center materials and newsletters; and publish in English and Spanish. 5. Identify future legislative and public policy needs for improved access to and coordination of TBI services and supports for individuals with TBI and families. 6. Collaborate with other organizations to share information and post proposed bills to the 2005 Arkansas General Assembly Forum on the Disability Rights Center website message board.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Over 100 individuals with TBI, their families, and service providers attended June conference. Participants requested an annual event. • Created an internal resource book that contains general information about TBI for the staff as well as callers. • Participated with Arizona's TBI lead agency and the Brain Injury Association to identify gaps in the continuum of services and to close those gaps and develop a speakers bureau.	
• Conducted one TBI staff training session for the Disability Rights Center and took part in training at the University of Arkansas at Little Rock for staff teaching students with TBI. • Collaborated with the Brain Injury Association of Arkansas to present the TBI conference at the University of Central Arkansas.	The Disability Rights Center is planning advocacy and outreach strategies for training medical technicians, first responders, and coaches and a public relations project utilizing Arkansas' statewide TBI advisory board members' stories in a press release.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
California *Protection & Advocacy, Inc.*	PATBI Grant: $241,487	1. Increase awareness in the TBI community about Protection & Advocacy, Inc.'s advocacy services and the rights of individuals with TBI in California to community-living services and supports. 2. Develop or modify existing materials outlining available services and supports from Protection & Advocacy, Inc. 3. Translate these materials into Spanish and one Asian language. 4. Provide training and presentations to individuals with TBI and providers as part of the outreach effort. 5. Provide training on disability rights to individuals with TBI who are Native American. 6. Increase the understanding and capacity of Protection & Advocacy, Inc., to serve the TBI community. 7. Prepare and disseminate information to Protection & Advocacy, Inc. staff and board about the TBI project. 8. Increase the number of TBI clients served by Protection & Advocacy, Inc. 9. Ensure participation of the TBI community in the California Olmstead planning process.
Colorado *The Legal Center for People with Disabilities and Older People*	PATBI Grant: $150,000	1. Plan, assess, and expand the Colorado P&A system's capacity to serve people with TBI. 2. Develop a process to prioritize issues to be addressed by Colorado's program for P&A for individuals with TBI and their families. 3. Enhance the Colorado P&A system's process of information and referral, and provide to people with TBI and families. 4. Provide self-advocacy assistance and direct legal representation to those with TBI and family members to access appropriate supports and services. 5. Implement collaborative activities to research and address systemic issues regarding access to services.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
Not available.	Protection & Advocacy, Inc. in California will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.
• Participates on Colorado's statewide TBI advisory board. Still working with the Colorado TBI lead agencyand the Brain Injury Association affiliate to clarifywhere service systems are lacking. • Attempting to clarify priority issues: vocational rehabilitation; health/insurance/medical; mental health counseling. • Currently serving 14 individuals under the Federal PATBI Grant. • Coordinating with the Brain Injury Association of Colorado to develop a CIRCLE group in western Colorado to network service providers.	The Legal Center will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Connecticut *Connecticut Protection & Advocacy for Persons with Disabilities*	PATBI Grant: $100,000	1. Increase the Connecticut P&A system's capacity and competence to provide protection and advocacy services for individuals with brain injuries. 2. Develop an effective coalition of allied advocacy groups to promote relevant, accessible, consumer-responsive systems of service; sound public policy; and community support for people with brain injuries. 3. Increase participation by members of racial and ethnic minority communities in organized advocacy efforts on behalf of people with brain injuries in Connecticut. 4. Complete a resource guide and a comprehensive assessment of unmet service and advocacy needs. 5. Co-host consumer focus groups with the Brain Injury Association of Connecticut, including groups representing minority communities. 6. Develop and present information regarding needs to policy makers. 7. Develop an interagency case referral protocol between Connecticut P&A and the Brain Injury Association of Connecticut. 8. Co-host a 1-day statewide conference for consumers and families. 9. Secure representation from the brain injury community on the Connecticut P&A system's governor-appointed advisory board. 10. Develop the Connecticut P&A system's service priorities that reflect the needs of people with brain injury.
Delaware		
Community Legal Aid Society, Inc.	PATBI Grant: $150,000	1. Collaborate with the brain injury and policy and law committees of the State Council for Persons with Disabilities in analyzing state legislation, regulations, Medicaid waivers, and selected policies with significant effect on TBI prevention and recourse options as well as access to "safety-net" health and financial benefits. 2. Collaborate with the State Council for Persons with Disabilities and the Governor's Advisory Council for

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Developed relationships with the key stakeholders in brain injury in the state. • Membership on Connecticut's TBI statewide advisory board. • Actively representing individuals with TBI.	Connecticut Protection & Advocacy for Persons with Disabilities will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.
• Drafted and secured enactment of an airbag safety bill to deter fraud and reduce incidence of TBI due to vehicular accidents. • Identified TBI special education resource materials and successfully promoted $5,000 Developmental Disabilities Council grant to purchase and distribute to special educators to improve identification and programming for students with TBI.	The Community Legal Aid Society is researching a bill to raise the mandatory bicycle helmet age in Delaware from under 16 to under 18.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Delaware *continued*		
		Exceptional Citizens to promote the timely and valid identification of students with TBI in implementation of Senate Bill 105. 3. Provide advocacy services to individuals with TBI facing program eligibility or significant service denials/terminations in "safety-net" health and financial public benefits contexts (e.g., Supplemental Security Income, Medicaid, and Food Stamps). 4. Provide technical assistance to persons with TBI, families, and professionals in response to inquiries concerning service needs.
District of Columbia *University Legal Services*	PATBI Grant: $100,000	1. Promote expansion and responsiveness of the TBI service delivery systems. 2. Inform the general public and disability community of the TBI project including its purpose and priorities. 3. Provide systemic and individual advocacy to clients with TBI. 4. Provide information and referral, short-term services, and legal representation. 5. Collaborate with the Brain Injury Association of D.C. 6. Evaluate the overall effectiveness of the TBI project through an annual Public Input Survey and Client Satisfaction Survey; gather individual client data and statistics.
Florida *Advocacy Center for Persons with Disabilities, Inc.*	PATBI Grant: $154,458	1. Provide direct advocacy to assist individuals with TBI with issues related to employment and related services and supports. 2. Provide systemic advocacy on employment and related services and supports. 3. Provide outreach to the TBI community (including previously underserved populations) regarding the programs and services of the Advocacy Center for Persons with Disabilities, especially in the area of employment. 4. Conduct research and planning for future activities and initiatives regarding employment and related

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Sponsored a training session for 36 advocates, case managers, and interested persons in issues related to acquired brain injury and long-term care. • Successfully advocated for the state Department of Health and the Mental Retardation and Developmental Disabilities Administration to change their positions and commit to serving people with developmental disabilities (with or without mental retardation) under the Medicaid home and community-based waiver.	University Legal Services in D.C. will continue to provide outreach and education on TBI and advocate on behalf of people with TBI.
• Completed 40 information and referral requests and worked on 16 cases involving employment and government benefits issues. • Conducted outreach with TBI support groups and service providers; and attended the Brain Injury Association of Florida's annual conference. • Conducted initial research on the provision of mental health services to persons with TBI.	The Advocacy Center for Persons with Disabilities, Inc., in Florida continues to work in the focus areas of its Federal PATBI Grant from HRSA, as well as respond to other requests for individual advocacy as they arise.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Florida *continued*		
		services and supports; special education for children and youth with TBI; access to health care services; and mental health services.
Georgia *Georgia Advocacy Office, Inc.*	PATBI Grant: $116,532	1. Ensure that individuals with TBI will be safe from abuse and neglect and will be guaranteed basic personal rights in a culturally competent manner. 2. Ensure that individuals with TBI reside in integrated community settings. 3. Ensure that individuals with TBI and their families have increased access to advocacy skills to enable themto effectively seek and secure adequate and appropriate treatment and support.
Hawaii *Hawaii Disability Rights Center*	PATBI Grant: $150,000	1. Provide information and referral. 2. Provide education and outreach. 3. Provide individual and family advocacy. 4. Provide individual and/or systemic legal representation. 5. Provide self-advocacy coaching and assistance.
Idaho *Comprehensive Advocacy, Inc. (Co-Ad, Inc.)*	PATBI Grant: $150,000	1. Increase Co-Ad expertise in advocacy for people with TBI in Idaho. 2. Increase Co-Ad capacity for advocacy services by expanding staff to include another full-time equivalent employee. 3. Reserve staff time from specially trained staff in the regional office exclusively for TBI advocacy. 4. Establish the involvement of people with TBI and their families in the development of annual priorities, objectives, and case acceptance criteria. 5. Increase and improve information and referral materials related to TBI advocacy issues.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Hired a full-time TBI Olmstead advocate who is integrated into the Georgia Advocacy Office's existing organizational structure. • Opened numerous cases this past year. One of the most complex involves a young woman with a TBI who was thought to be mute and incoherent. The project obtained equipment so that her voice might be heard, reintroduced visitation with her children, prevented termination of her parental rights in court, and helped develop a plan for her to live in the community.	The Georgia Advocacy Office will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.
• Provided individual case advocacy for 43 individuals with TBI. • Provided information and referral to 72 individuals. • Provided training, education, and outreach to 213 groups. • Distributed 6,000 TBI brochures.	The Hawaii Disability Rights Center anticipates providing the following services in the upcoming year: individual case advocacy for 45 individuals with TBI; information and referral to 180 individuals; training, education, and outreach to 197 groups; and the distribution of 6,600 TBI brochures.
• Collaborating with the Brain Injury Association of Idaho and Idaho State University's Institute on Rural Health. • Developed a PATBI program brochure and informational material. • Integrated all aspects of the PATBI Grant into the P&A disability advocacy program.	Co-Ad will continue its collaboration with the Brain Injury Association of Idaho and Idaho State University's Institute on Rural Health. It will monitor and refine home and community-based services provided through Medicaid waivers; develop position statements and strategies on public policy issues affecting people with TBI; and influence

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Idaho *continued*		
		6. Include specific TBI issues in systemic advocacy with state agencies, the legislature, and in Olmstead compliance activities.
Illinois *Equip for Equality, Inc.*	PATBI Grant: $187,123	1. Identify some of the systemic issues uniquely affecting the Illinois community at large. 2. Provide one-on-one advice and assistance in self-advocacy to eligible individuals with TBI through the Training Institute. 3. Provide legal services to those who fall within the priorities of employment discrimination, guardianship rights, and abuse and neglect. 4. Develop resource information and training in disability rights to individuals with TBI and their families.
Indiana *Indiana Protection and Advocacy Services*	PATBI Grant: $106,286	1. Assess Indiana Protection and Advocacy Services' responsiveness to disability rights issues affecting individuals with TBI. 2. Provide information and referral services to individuals with TBI and their families. 3. Provide advocacy services to individuals with TBI and families to protect their rights and assist them in accessing appropriate services and supports in their communities. 4. Increase the quality, availability, and effectiveness of educational and community-based programs designed to prevent disease and improve health and quality of life.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
	system change through direct and systemic advocacy.
• Developed a needs assessment tool in English & Spanish to better understand the needs of people with TBI in Illinois. The tool has been distributed to advisory board members and to attendees at outreach activities and trainings. • Developed training materials in English & Spanish for outreach activities and educational seminars to people with TBI, family members, and service providers. • Presented training on the Americans with Disabilities Act and TBI to numerous centers for independent living, brain injury support groups, and brain injury case management agencies across Illinois. • Developed a TBI webpage on Equip for Equality's website in English and Spanish. • Developed a TBI project brochure. • Conducted research to determine the status of various TBI programs and resources in Illinois, including a previously unknown teacher's manual from the Illinois board of education relevant to students with TBI.	Equip for Equality will continue to implement its grant objectives nd provide aadvocacy for individuals with TBI and their families in accessing services and supports to meet their needs.
• Serving individuals with TBI in regards to assistive technology and education issues. • Developed a brochure outlining the goals of the TBI program and is also in the process of developing an informational packet to be provided to parents of school-aged individuals with TBI as their children exit from rehabilitation units and services. • Continue to support the Brain Injury Association of Indiana's efforts to reorganize and solidify themselves as a legitimate, functioning agency.	Indiana continues to attempt to identify a lead state agency for procurement of additional Federal TBI Program grant monies to fund P&A activities.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Indiana *continued*		
		5. Develop and implement outreach strategies to assure that Indiana P&A services will be delivered appropriately for individuals with TBI and their families. 6. Collaborate with appropriate partners to identify and utilize relevant research-based information about service needs of individuals with TBI and “state of the art” systems development approaches to enhance TBI-related services.
Iowa *Iowa Protection and Advocacy Services, Inc.*	PATBI Grant: $100,000	1. Enhance family and provider access to information about services and supports necessary for individuals with TBI and their families. 2. Improve the capability of Iowa’s service providers to serve children and adults with TBI, inappropriately placed in public and private residential facilities, working to ensure that they receive appropriate programming and treatment and are free from abuse and neglect. 3. Ensure that children diagnosed with TBI shall receive a free, appropriate public education within Iowa’s public school system and be free from abuse and neglect. 4. Ensure adults and children with TBI who are unserved/underserved experience appropriate placement, treatment, therapy, and programming.
Kansas *Kansas Advocacy & Protective Services*	PATBI Grant: $100,000	1. Advocate for rights of individuals with TBI to have adequate numbers of safe, affordable, decent, and accessible housing. 2. Strive toward eliminating abuse, neglect, and exploitation by decreasing the use of seclusion, restraints, life-threatening injury, or deaths of persons with TBI. 3. Promote the rights of persons with TBI by ensuring that they have knowledge of and access to appropriate community services of their choice. 4. Promote and advocate for access to free and appropriate education under the Individuals with Disabilities Education Act.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Participated in the TBI grant-funded Iowa Brain Injury Resource Network and have gained knowledge and skill in working with individuals with TBI.	As Iowa moves toward a community-based service system, Iowa Protection and Advocacy Services will diligently and systemically advocate that persons with TBI be placed where they can receive habilitative and rehabilitative services as well as work with individuals with TBI in realizing and selecting appropriate placement and program service opportunities within community programs.
• As a result of advocacy provided by Kansas Advocacy & Protective Services and other collaborating disability partners, the 2004 Kansas legislature increased TBI services funding by $500,000.	Kansas Advocacy & Protective Services will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Kansas *continued*		
		5. Promote options to and the appropriate use of guardianship or conservatorship. 6. Promote positive systems and policy changes that will increase the independence of Kansans with TBI and enable them to live with dignity, independence, and respect in the most integrated setting possible. 7. Promote appropriate diversion, treatment, and discharge planning for persons with TBI who are in or entering the criminal justice system. 8. Provide disability rights advocacy to individuals experiencing barriers in eligibility and application processes because of TBI. 9. Educate policy makers when proposed laws or regulations impact the rights of individuals with TBI.
Kentucky *Kentucky Protection & Advocacy*	PATBI Grant: $150,000	1. Educate and provide information to legislators regarding the high incidence of TBI in Kentucky. 2. Work with the TBI consumer advocacy committee and other advocacy and education organizations to develop advocacy strategies regarding issues and policies impacting lives of people with TBI. 3. Provide training and outreach to un/underserved, minority and refugee populations regarding rights of persons with TBI. 4. Represent two to three persons with TBI unnecessarily institutionalized or at risk of institutionalization to ensure the most integrated setting possible for their services and living arrangements. 5. Represent five persons whose Medicaid waiver services have been denied, reduced, changed, or terminated. 6. Provide short-term assistance and information and referral to persons with TBI who do not meet priority for representation.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Met with consumer advocacy group. (The meeting was arranged by the Office of Family Leadership.) This group now serves as the project advisory group. • Working closely with the Kentucky Brain Injury Association affiliate and the Office of Family Leadership in areas such as legislative initiatives. • Representing seven individuals in hearings on special education, assistive technology, and Medicaid waivers. • Conducted self-advocacy training. • Presented an advocacy workshop at the state Brain Injury Association affiliate's sponsored brain injury summit.	Kentucky Protection and Advocacy will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Louisiana *Advocacy Center*	PATBI Grant: $150,000	1. Ensure that P&A services are known to individuals with TBI and their families. 2. Assess the needs of the TBI population and to modify P&A priorities if indicated. 3. Identify and begin work on systems advocacy priorities for the TBI population. 4. Foster the reactivation of a state association for TBI and foster the submission of a proposal for a state grant by Louisiana. 5. Represent individuals with TBI in the areas of special education, abuse and neglect, and community access. 6. Initiate outreach program to key persons in the TBI community. 7. Design a needs assessment instrument that will be used with the outreach activities.
Maine *Disability Rights Center*	PATBI Grant: $150,000	1. Conduct outreach to Maine citizens in at least four facilities. 2. Implement training and necessary policy, procedure, and practice changes in facilities where abuse, neglect, or personal rights violations are found. 3. Train the staff on consumer perspectives on treatment and on rights in at least one facility. 4. Include people with TBI in Olmstead planning to assure that individuals with TBI receive necessary supports in integrated settings. 5. Obtain housing in an inclusive setting in the community of choice for those who are forced to enter or remain in a living situation more restrictive than what the client wants and needs. 6. Develop sustainable, interactive workshop to train people with TBI, families, and guardians on self-advocacy skills and rights. 7. Develop and collect state-of-the-art training materials, resource information, and information on best practices to be made available to individuals with TBI and their families.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Established a Brain Injury Alliance of Louisiana that will apply for Brain Injury Association affiliation in 2005. Toll free number operational, spring, 2005. • Conducted town meetings and delivered presentations on findings of the Federal TBI Program needs assessment at injury prevention and rehabilitation conferences. • Conducted outreach and self-advocacy trainings to underserved communities via health clinics and TBI support groups. • Ongoing analysis of TBI needs assessment and communication of needs to service delivery systems for improved access. • Expanded the numbers of persons with TBI and their families who are aware of the resources available through the P&A. • Developed TBI-specific information and referral resource manual.	The Advocacy Center in Louisiana will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.
• Working on Medicaid waivers and other funding streams to expand capacity. • Completed several trainings for multiple audiences, including support groups, in-home service providers, hospital emergency room staff and social workers, and the long-term ombudsman program. • Started an Acquired Brain Injury Council (Corrections and Transportation representation) last year. • Currently handling several abuse and neglect cases.	The Disability Rights Center in Maine will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Maryland *Maryland Disability Law Center*	PATBI Grant: $102,472	1. Advocate for people with TBI in state psychiatric facilities and nursing facilities to promote community-based alternatives to institutionalization. 2. Provide information and training to individuals with TBI and advocates regarding home and community-based options. 3. Advocate for public policy changes needed to expand community options for individuals with TBI.
Massachusetts *Disability Law Center, Inc.*	PATBI Grant: $104,038	1. Establish a PATBI advisory board including seven members with TBI or family. 2. Develop and conduct a comprehensive statewide needs assessment to update the last assessment conducted in 1998. 3. Develop a mini-resource guide that will be mailed to every individual and agency receiving the needs assessment. 4. Conduct, in collaboration with other organizations, six regional trainings on available services and the importance of the needs assessment for individuals with TBI and their families. 5. Continue to provide information and referrals to individuals with TBI and their family members and to develop a mechanism for capturing information from callers. 6. Continue to provide direct representation for individuals needing legal representation under the current system until the needs assessment is complete. 7. Begin to explore with advisory board ways to develop a self-advocacy/peer-advocacy curriculum for the TBI community.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Helped several persons with TBI, who were charged with minor criminal offenses, found incompetent to stand trial, and kept in institutions for years without being tried (in violation of constitutional rights) obtain release and community services, and sued on behalf of similarly situated persons, while seeking necessary changes in law. • Succeeded in changing policies that prevented nursing facility residents with TBI (and others) from accessing needed waivers and community services. • Helped individuals with TBI resolve forced medication, discharge, waivers, community services, and other issues.	The Maryland Disability Law Center will continue efforts (through legislative advocacy, litigation, and otherwise) to eliminate unconstitutional confinement of persons with TBI found incompetent to stand trial but not promptly restored to competency or tried. The Maryland Disability Law Center will continue to provide community services access for those with TBI to avoid/eliminate unnecessary institutionalization.
• Conducted five statewide needs assessments trainings for more than 500 participants in collaboration with the Massachusetts Brain Injury Association and three regional special education trainings with more than 50 participants. • Provided information and referral to 100+ individuals and their families in FY 2004. • Provided legal representation for 36 individuals. • Spent an additional $16,000 in unrestricted funds serving individuals with TBI.	The Disability Law Center will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Michigan *Michigan Protection and Advocacy Service, Inc.*	PATBI Grant: $175,055	1. Represent referrals when lack of services jeopardize the health and safety of the individual; person is at risk of placement in a more restrictive setting; eligibility for services is denied; and lack of person-centered discharge planning. 2. Provide information and referral services to individuals with TBI. 3. Provide self-advocacy training to people with TBI and families. 4. Develop a TBI advocacy network in conjunction with the Brain Injury Association of America. 5. Focus on the following two systemic issues: increased access to disability-related public services and discharge from congregate care facilities, both through the use of a person-centered planning process.
Minnesota *Minnesota Disability Law Center*	PATBI Grant: $150,638	1. Ensure that advocates for persons with TBI in Minnesota counties know about TBI waivers and how to access them. 2. Work with counties, providers to foster development of services in rural, and other areas with limited or no services. 3. Facilitate client access to appropriate services. 4. Monitor and ensure institutional and agency compliance with the Olmstead decision. 5. Investigate abuse and neglect issues for TBI clients, in particular inappropriate treatment plans and treatment settings. 6. Provide outreach to communities of color about the TBI waiver and how to access services. 7. Conduct presentations to service providers on the TBI waiver. 8. Address specific legal issues for persons with TBI through referrals received from the Brain Injury Association of Minnesota. 9. Work with providers, including TBI hospitals, to negotiate appropriate individual service plans. 10. Advocate for and represent clients with TBI and families at fair hearings when TBI-waiver services are denied or delayed.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Participated in Michigan's statewide TBI advisory board meetings. • Coordinated training with the Michigan lead agency for TBI. The P&A conducted several self-advocacy trainings throughout Michigan, and the lead agency for TBI has continued conducting training for select providers. • Increased outreach efforts throughout state. • Conducted training at the Michigan Brain Injury Association's conference. • Developed a brochure. • Increased direct client representation to more than three times the number from the previous year.	The Michigan Protection and Advocacy Service will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.
• Project staff members attend meetings of Minnesota's statewide TBI advisory board. • Participate in meetings with lead state agency for TBI and regional Brain Injury Association affiliates. • Partnered with legal services and brain injury groups on outreach within the Latino community. • Served 75 clients in FY 2004; 67 new cases were opened, and 56 cases were closed.	The Minnesota Disability Law Center will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Mississippi *Mississippi Protection and Advocacy System for Developmental Disabilities, Inc.*	PATBI Grant: $100,000	1. Provide information and referral services to persons with TBI. 2. Provide training concerning best-practices treatment and assistive technology to persons with TBI, their parents/guardians, and service providers. 3. Handle all TBI cases for individuals within the agency's priority areas. 4. Identify and correct at least one systemic problem. 5. Engage in extensive outreach efforts in order to advise persons with TBI and their family members/guardians of the services of this agency.
Missouri *Missouri Protection and Advocacy Services, Inc.*	PATBI Grant: $153,925	1. Provide information and referral services to 50 individuals with TBI and their family members and service providers per year. 2. Provide legal-based advocacy and litigation services to 18 persons with TBI per year in the areas of special education, employment accommodations, housing, benefits, guardianship, access to community services, and other legal issues. 3. Provide four sessions of education and training in self-advocacy to individuals with TBI and their families per year and three sessions for other professionals per year. 4. Work collaboratively with other entities in this field to produce two manuals and one brochure during the course of this grant.
Montana *Montana Advocacy Program*	PATBI Grant: $100,000	1. Provide information, referral, and advice. 2. Develop an informational brochure regarding the TBI P&A program. 3. Provide individual and family advocacy. 4. Provide legal representation. 5. Develop self-advocacy training for individuals with TBI and their families.
Nebraska *Nebraska Advocacy Services, Inc.*	PATBI Grant: $150,000	1. Create an internal advisory structure that collaborates with Nebraska's statewide TBI advisory board. 2. Conduct staff and board training. 3. Conduct information and referral on legal and

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Provided information or referral to other federal, state, or private agencies or organizations serving 33 individuals with TBI and/or their families. • Provided advocacy for 10 individual TBI cases. • Identified and addressed one systemic issue around Medicaid and power wheelchairs. • Trained TBI family members and service providers in at least three conferences. • Provided outreach to the Methodist Rehabilitation Center and other service providers for persons with TBI.	The Mississippi Protection and Advocacy System for Developmental Disabilities will continue to identify persons with TBI who are being served by this office and provide outreach services.
• Completed training for Missouri P&A staff. • Provided legal and advocacy services to consumers and families. • Provided presentations to consumers, family members, and service providers on aspects of legal advocacy and P&A services. • Produced a brochure on Missouri's PATBI Grant Program. • Developed a productive working relationship with all of the Federal TBI Program grantees and service providers in the state.	Missouri Protection and Advocacy Services will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.
Not available	The Montana Advocacy Program will continue to implement its grant objectives and advocate for individuals with TBI and their families in accessing services and supports to meet their needs.
• Participating on Nebraska's statewide TBI advisory board. • Participating on state interagency information and referral committee convened to develop a single point of referral.	Nebraska Advocacy Services will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Nebraska *continued*		financial issues. 4. Provide legal advocacy planning by developing the capacity of attorneys and case advocates to be able to respond to the most significant issues for those with TBI and their families. 5. Complete comprehensive analysis of existing state and federal laws and regulations regarding TBI together with other entities. 6. Strengthen existing network of peer and family support groups.
Nevada *Nevada Disability Advocacy and Law Center*	PATBI Grant: $100,000	1. Increase Nevada P&A system's capacity for advocacy services. 2. Increase Nevada P&A system's expertise in advocacy for people with TBI. 3. Develop outreach materials describing P&A services for the TBI community. 4. Provide information and referral to individuals with TBI and families. 5. Provide assistance with self-advocacy or direct advocacy to individuals with TBI and their families. 6. Perform a series of training events around the state targeting individuals with TBI, their families, and caregivers. 7. Provide targeted outreach to minority and underserved populations in Nevada.
New Hampshire *Disability Rights Center, Inc.*	PATBI Grant: $150,000	1. Right to choice, self-determination, and freedom from coercion and other harm such as undue control, abuse/neglect, and inappropriate restraint/seclusion. 2. Discrimination in public services, public accommodations, and government funded services.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Hired dedicated TBI staff in March of 2005. • Met with representatives from various state agencies to coordinate projects. • Developed an in-service training on TBI for staff to increase internal capacity; is revising the training based on evaluations.	accessing services and supports to meet their needs.
Not available.	The Nevada Disability Advocacy and Law Center will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.
• Conducted approximately 60 trainings for 500 individuals and their families. • Developed and implemented 5-year diversity plan. • Represented a class of individuals with TBI in a lawsuit against the state challenging the waitlist under the Medicaid waiver program. • Took the lead in collaboration with 20 organizations to reduce exclusionary practices of schools and ensure equal educational opportunities for students with disabilities.	The Disabilities Rights Center will continue to implement its grant objective and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
New Jersey *New Jersey Protection & Advocacy, Inc.*	PATBI Grant: $167,640	1. Create a blueprint for enhancing current protection and advocacy services for individuals with TBI and their families in New Jersey through a consumer-driven planning and assessment process. 2. Identify and include individuals with TBI, their family members, and other key stakeholders for inclusion in the assessment and planning activities, such as surveys and focus groups. 3. Conduct focus groups with individuals with TBI and their families as part of a needs assessment. 4. Survey the brain injury community to identify additionally needed P&A services and barriers to accessing such services.
New Mexico *Protection & Advocacy System*	PATBI Grant: $150,000	1. Provide information and referral to individuals with TBI and their families. 2. Provide assistance in or self-advocacy or direct advocacy to individuals with TBI and their families. 3. Provide legal representation to individuals with TBI and their families. 4. Conduct public policy advocacy to expand and improve service systems.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Provided services to 41 individuals to several more information and referral/technical assistance. • Completed numerous outreach/trainings for providers and Brain Injury Association New Jersey family support staff; and self-advocacy training for individuals with TBI. • Prepared revisions to th 1995 TBI guide/advocacy handbook; developed brochure and separate website page for TBI. Published a newsletter article on TBI and TBI Bulletin. • Established an advisory council for New Jersey's Federal PATBI Grant.; working toward TBI-specific program internally. • Served as liaison to New Jersey's statewide TBI advisory board. • Met with staff members of two state representatives in Washington, D.C., to advocate for the needs of individuals with TBI.	New Jersey Protection & Advocacy, Inc., will continue and expand outreach, education, and promotion of self-advocacy to individuals with TBI, their families, providers, and service organizations.
• Assisted state partners with their "empowerment project" by providing training for individuals with TBI and their families. • Worked with the Brain Injury Association affiliate in New Mexico and New Mexico's statewide TBI advisory board to develop and pass state legislation in 2004 to establish and fund a Medicaid home and community-based services waiver[c] applicable to persons with TBI. The bill was pocket vetoed by the governor in 2004. The P&A system continues to work with TBI partners to pass TBI legislation in 2005 that will meet the governor's concerns. • Provided input to New Mexico's TBI lead agency to develop a new self-directed Medicaid waiver program for TBI to assure adequacy and appropriateness to the needs of individuals with TBI. • Successfully resolved the majority of individual cases in which advocacy and representation were provided to individuals with TBI.	New Mexico's Protection & Advocacy System will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
New York *New York State Commission on Quality Care for Persons with Disabilities*	PATBI Grant: $169,023	1. Ensure that individuals with TBI are afforded due process under all Medicaid home and community-based services (HCBS) waivers. 2. Ensure that individuals with TBI receive access to comprehensive, high-quality health care services. 3. Ensure that children with TBI receive appropriate post-rehabilitation special education services. 4. Assist the state Department of Health in developing a comprehensive quality assurance program.
North Carolina *Governor's Advocacy Council for Persons with Disabilities*	PATBI Grant: $115,864	1. Conduct systemic analysis and policy implementation. 2. Inform general public and the disability community about the TBI project. 3. Collaborate with individuals, organizations, P&A Ad hoc Subcommittee, and others to identify and develop multi-faceted solutions to the educational and community integration barriers encountered by persons with TBI by the end of the first year. 4. Develop outreach materials for those with TBI that describe services offered by the P&A system and the legal rights of persons with TBI. 5. Coordinate with the Brain Injury Association of North Carolina to hold focus groups with the existing 23 support groups. 6. Implement appropriate legal and regulatory changes. 7. Protect individuals with disabilities through age 21 with TBI and ensure a free appropriate public education in the least restrictive environment. 8. Provide individual assistance to a minimum of 50 individuals with TBI through information and referral, advocacy, and legal services for those who fall within the project's priorities. 9. Enforce, monitor, and promote the rights of persons with TBI to live in an integrated community setting.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Assisted with individual appeals and has been working with the state agency that sponsors HCBS waivers to institute better due process notices. • Moving toward a more systemic approach to insurance problems given the number of complaints involving health insurers. • Distributing special education cases within the Commission's P&A network. The Federal PATBI Program worked with the Developmental Disabilities Planning Council to fund a special education intervention program for students with TBI. • Assisted in the development of quality assurance measures for the Department of Health TBI waiver.	The PATBI Program will join the Brain Injury Association of New York State in training judges and attorneys regarding the needs of individuals with TBI; help people with TBI overcome barriers that interfere with access to benefits and services to which they are entitled; and continue working with the major state agencies to provide coordinated services for individuals with TBI and other correlated disabilities.
The Governor's Advocacy Council for Persons with Disabilities (GACPD), in collaboration with the Brain Injury Association of North Carolina, has held meetings throughout North Carolina to inform citizens about the work being done through the PATBI Grant. As a result, TBI-related calls and cases coming into GACPD have increased dramatically. The statewide meetings have also given GACPD insight into the needs of North Carolina's TBI population.	The Governor's Advocacy Council for Persons with Disabilities is working with North Carolina's TBI Advisory Council to shape the service delivery system for North Carolina's TBI population.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
North Dakota *Protection and Advocacy Project*	PATBI Grant: $150,000	1. Provide information and referral services to individuals with TBI and their families. 2. Train all disability advocates on TBI and develop a training packet for presentation at TBI support group meetings. 3. Participate in ongoing education of TBI issues through North Dakota's statewide TBI advisory board activities, staff meetings with stakeholders. 4. Develop a minimum of eight additional TBI support groups in North Dakota, including one on each of the four American Indian reservations. 5. Provide training to the TBI support groups. 6. Present session on "advocacy" at each of the annual conferences sponsored by the Brain Injury Association North Dakota and the Indigenous Peoples Brain Injury Association. 7. Visit the American Indian reservations. 8. Access information on individuals with TBI who reside in long-term care facilities. 9. Advocate for and legally represent individuals with TBI. 10. Advocate for the state of North Dakota to pursue and implement Planning and Implementation Grants from the Federal TBI Program. 11. Develop a plan and successfully advocate for financial support of TBI-related services.
Ohio *Ohio Legal Rights Service*	PATBI Grant: $181,937	1. Provide protection and advocacy services to students with TBI regarding identification, assessments, and individualized education plans. 2. Investigate and review complaints of inadequate special education services provided to students with TBI and provide representation or other levels of service as appropriate. 3. Provide information and referral about special education services and assistance available to students during the course of case management. 4. Increase the knowledge and skills of parents, educators, other professionals, and advocates and expand planning activities with Ohio's TBI stakeholders.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Made contact with three of the four reservations/ tribal governments; have outreach activities in two. • Provided training/information to providers and several support groups (one advocacy case opened as a result of the latter). • Opened six cases under the project. • Was invited to attend a rehabilitation hospital discharge planning meeting. • Provided assistance to North Dakota's Department of Human Services in its application to HRSA for North Dakota's TBI Planning Grant and secured private funding to ensure match funds. • One staff attorney serves as member at-large on the Brain Injury Association of North Dakota Board of Directors.	The Protection and Advocacy Project in North Dakota will continue to implement the grant objectives and advocate for individuals with TBI and their families in accessing services and supports to meet their needs.
• Sitting on Ohio's Housing Committee and working to reactivate the Special Education Committee. • Conducting seven regional meetings (three in collaboration with the Brain Injury Association affiliate) for parents on barriers and getting through them. • Handled 16 special education cases. • Assembled a statewide advisory committee to provide guidance in developing a self-advocacy document for parents of children with TBI to help guide them through the special education system. Membership includes parents and family members.	The Ohio Legal Rights Service will continue to represent students with TBI on issues specific to the receipt of an appropriate education.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Ohio *continued*		5. Develop a self-advocacy document for parents of students with TBI that will describe student and parent rights, self-advocacy tools, and information germane to students with brain injuries.
Oklahoma *Oklahoma Disability Law Center, Inc.*	PATBI Grant: $100,000	1. Provide information and referral. 2. Provide education and outreach. 3. Provide individual and family advocacy. 4. Provide individual and/or systemic legal representation. 5. Provide self-advocacy coaching and assistance.
Oregon *Oregon Advocacy Center*	PATBI Grant: $100,000	1. Provide person- and family-directed P&A services that are responsive to TBI issues, culturally competent, and planned and implemented with involvement of persons with TBI and families. 2. Create the internal infrastructure and staffing for the program and provide information and referral services. 3. Advocate for preservation and restoration for state-funded health care, in-home supports, and other services. 4. Continue litigation challenging service cuts and educate policy makers about impact of cuts to TBI-related services and supports. 5. Develop TBI specific outreach materials and information. 6. Conduct advocacy training for community groups and Hispanic parents group. 7. Meet with native tribal leaders to identify TBI needs and provide effective, culturally competent P&A services to individuals with TBI and their families. 8. Provide case advocacy for benefits, health care, in-home supports, and education matters. 9. Collect service data and submit data and reports to HRSA as required. 10. Evaluate program effectiveness and report results.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
Communicated with the Oklahoma Department of Health to establish a working relationship on issues related to traumatic brain injuries.	The Oklahoma Disability Law Center will continue to implement its grant objectives and provide advocacy for individuals with TBI and families in accessing services and supports to meet their needs.
Not available.	The Oregon Advocacy Center will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Oregon *continued*		
		11. Collect and evaluate all program satisfaction indicators. 12. Evaluate progress of systems advocacy initiatives.
Pennsylvania *Pennsylvania P&A, Inc.*	PATBI Grant: $186,451	1. Increase the availability of and timely access to services for Pennsylvanians with TBI within their own communities. 2. Provide technical assistance and case services to individuals with TBI and, as appropriate, to their families. 3. Provide information on rights, resources, and self-advocacy to individuals with TBI and their family members. 4. Collaborate with other stakeholders serving the TBI population in Pennsylvania. 5. Conduct program evaluation and report on outcomes.
Rhode Island *Rhode Island Disability Law Center, Inc.*	PATBI Grant: $150,000	1. Improve individual and family coping skills and knowledge in order to better access culturally competent and appropriate services. 2. Improve existing provider quality and competency. 3. Build in-state capacity for TBI-competent services not currently available. 4. Increase the reports of ease of access to information and quality of services by at least 20 percent by the middle of the project and 50 percent by the end. 5. Increase provider test scores on TBI training by at least 20 percent from pre- to post-test administration. 6. Have at least one new residential and one new day habilitation service provider accredited in TBI establish practices in Rhode Island. 7. Increase overall state funding for TBI by at least 10 percent. 8. Demonstrate at least 80 percent of followup interviews with information-line callers resulted in appropriate information and referral.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Developed simpler language document called "Seven Steps to Success" with Community Skills Program as an aid to people who want to strengthen or start a brain injury support group. • Continued working with TBI stakeholders to increase awareness of TBI issues. • Collaborated with Dauphin County staff to support the Dauphin County Brain Injury Panel, now a vibrant gathering. • Recorded 92 TBI callers in the intake system this year and 14 callers the last year. Reviewed almost 50 intakes; handled 30 individual cases this year and two cases last year.	Pennsylvania P&A will continue to provide information on rights, resources, and self-advocacy to individuals with TBI, family members, and interested professionals where appropriate. Pennsylvania P&A will also collaborate with other stakeholders and external advocacy organizations to ensure inclusion of TBI service issues in all planning processes and program designs.
• The executive director sits on Rhode Island's statewide TBI advisory board. • Developing a video for individuals with TBI and their caregivers. • A TBI staff attorney started at .50 FTE in April. • Participated in the Rhode Island Brain Injury Association's second annual conference.	The Rhode Island Disability Law Center will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
South Carolina *Protection and Advocacy for People with Disabilities*	PATBI Grant: $150,000	1. Recruit and train staff who will be managing TBI priorities. 2. Publicize the TBI program at the P&A system through public news media, newsletters of disability organizations and agencies, and the P&A system's own newsletter and outreach radio broadcasts. 3. Conduct consumer focus groups within Brain Injury Association of South Carolina's support network to identify the topics for systemic advocacy. 4. Provide information, referral, and technical assistance services on self-advocacy to individuals with TBI. 5. Provide advocacy and legal services related to community integration and equal access to individuals with TBI. 6. Identify procedures and policies related to significant barriers for individuals with TBI and modify these procedures or policies through systemic advocacy.
South Dakota *South Dakota Advocacy Services*	PATBI Grant: $150,000	1. Provide information and referral services on disability-related issues as appropriate to eligible individuals and their families. 2. Provide advice, consultation, and self-advocacy and skill development training including Partners in Policymaking to eligible individuals and their families. 3. Provide personal and legal representation as necessary to protect the rights of eligible individuals and their families. 4. Investigate and review disability-based complaints of inadequate service being provided to eligible individuals. 5. Provide education, training, and outreach on the purpose and goals of the Federal PATBI Program to potential clients, collaborating entities, interested groups, and public and private providers.
Tennessee *Tennessee P&A, Inc.*	PATBI Grant: $154,383	1. Educate individuals with TBI, staff at facilities, and the general public about the rights of individuals with disabilities to be free from abuse and neglect by conducting three trainings on abuse and neglect,

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Participated in the activities of South Carolina's leadership council and systems development committee. • Prevented a significant decrease in the amount of funds available to the Medicaid head and spinal cord (HASC) injury waiver[d] participants for home and vehicle modifications. • Conducted outreach, focus groups, and self-advocacy trainings at brain injury support groups, community opportunity centers, hospitals, nursing homes, and at statewide brain injury conferences. • Publicized the P&A system's TBI program by publishing articles in newsletters of several disability and service provider groups and through radio broadcasts.	Protection and Advocacy for People with Disabilities in South Carolina will continue to provide advocacy and legal services related to community integration, employment, housing, and education.
• Participated in a coalition of TBI stakeholders in developing awareness to increase and enhance state TBI services and supports. • Linked with the revitalized Brain Injury Association of South Dakota, rehabilitation centers, Indian reservations, brain injury support groups, and state agencies. • Provided information and referral services to approximately 46 people; served 10 individuals in areas such as housing, education, employment, Social Security, and guardianship. • Provided testimony to support a bill that would create a statewide TBI advisory board for South Dakota/TBI rehabilitation and research. • Disseminated ~2,300 brochures related to P&A for individuals with TBI and their families.	South Dakota Advocacy Services will continue to implement its grant objectives and advocate for individuals with TBI and their families in accessing services and supports to meet their needs.
• Created information on specific goals and objectives of this grant that is provided to the TBI community. Created an article for the Tennessee P&A newsletter.	Tennessee P&A will continue efforts to have a P&A representative on Tennessee's statewide TBI advisory board.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Tennessee *continued*		by providing informational materials to 200 persons in institutional settings, and by authoring four articles on abuse and neglect on any website and/or in any newsletter. 2. Advocate for students with TBI with the goal of effecting systemic impact in two of the cases. 3. Inform and empower persons with TBI regarding self-advocacy and the Tennessee P&A system's services with 18 presentations, focus groups, listening sessions, information fairs, outreach, trainings, and/or collaborations; develop and and disseminate 130 family-needs surveys and resource packets of information to persons with TBI. 4. Develop a TBI community coalition to share information and collaborate on projects concerning persons with TBI.
Texas *Advocacy, Inc.*	PATBI Grant: $178,147	1. Increase direct casework to people with TBI above the 2004 target by at least 10 percent. 2. Focus policy efforts on informing state officials about impact of legislation and continue systemic advocacy for rehabilitative services covered under Medicaid and other state-funded services. 3. Continue relationship with state and local organizations representing survivors of TBI, families, and brain-injury professionals. 4. Develop relationships across the states and support education and advocacy efforts of the Texas TBI advisory board.
Utah *Disability Law Center*	PATBI Grant: $150,000	1. Receive continuous feedback from the TBI community in the needs assessment and planning process through focus groups and collaboration with the Federal TBI State Program Grant to Utah. 2. Invite participation of individuals with TBI in the governance of the Disability Law Center. 3. Provide high-quality information, referral, and short-term assistance services to persons with brain injury. 4. Design a low-literacy brochure for the TBI community explaining P&A services.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Contacted all TBI service coordinators statewide and provided information on the project and services. • Conducted presentations for local chapters of Brain Injury Association of Tennessee to inform them of the TBI program and other Tennessee P&A programs. • Developed collaborative relationships with the Department of Health and the Division of Vocational Rehabilitation on TBI issues.	
Advocacy, Inc., served 97 individuals with TBI P&A funds in fiscal year 2004.	Advocacy, Inc., will continue to advocate for the development and availability of additional community support services for individuals with TBI in Texas.
• Increased TBI-related calls by over 350% (since the inception of the program). • The Brain Injury Association of Utah did a brown-bag sensitivity training for staff. • The director of the Brain Injury Association of Utah and a member of the Disability Law Center's board of trustees conducted a Disability Law Center board training on TBI issues. • Conducted two legal rights trainings at Utah's Brain Injury Association affiliate. • Participated at the 2004 Brain Injury Association	The Disability Law Center was a member of the planning committee for the conference of the Utah Trial Lawyers/Brain Injury Association of Utah planned for March 2005 and a member of Utah's TBI program. The Disability Law Center was expected to conduct a focus group on March 17, 2005, with a TBI

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Utah *continued*		5. Provide high-quality legal services using issue team structure. 6. Conduct case finding activities at the Utah State Hospital. 7. Conduct legislative advocacy. 8. Increase awareness of the Disability Law Center's services and legal rights among persons with brain injury, their families, and the legal profession.
Vermont *Vermont Protection and Advocacy, Inc.*	PATBI Grant: $150,000	1. Provide individual advocacy to obtain access to community-based services and supports for people with TBI living in residential facilities. 2. Enhance access to comprehensive and coordinated supports and services for people with TBI and their families through system advocacy with partner agencies. 3. Collaborate with Vermont's State Implementation Grant awarded by HRSA from the Federal TBI Program in attainment of goals and objectives of the statewide TBI action plan, specifically by improving access to TBI services and increasing TBI expertise of vocational counselors through educational trainings. 4. Work with state government agencies and legislature to expand services, supports, and funding available to persons with TBI. 5. Enhance the knowledge base of individuals with TBI and their family members, service providers, and legislators about resources and provision of TBI services and supports.
Virginia *Virginia Office for Protection and Advocacy*	PATBI Grant: $111,141	1. Develop outreach materials for TBI community that describe available P&A services and legal rights of persons with TBI. 2. Provide information on the project and available P&A services to individuals with TBI to organizations that serve this community throughout the state. 3. Provide information about P&A services available to individuals with TBI on the website.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
of Utah's Family and Professional Conference. • Conducted five focus groups. • Developed a new and improved TBI brochure.	support group at a local hospital.
• Project staff members attend all meetings of Vermont's statewide TBI advisory board and steering committee. • Developed a training program for individuals with TBI, their families, and a service providers. • Developed and published a legal resource manual.	Vermont Protection and Advocacy is scheduling trainings for individuals with TBI, family members, and service providers on legal resources for all areas of Vermont and working with the Vermont legislature and state agencies to expand services, supports, and funding available to individuals with TBI.
The Virginia Office for Protection and Advocacy has developed a partnership with the Brain Injury Association of Virginia.	The Virginia Office for Protection and Advocacy will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Virginia *continued*		
		4. Perform a series of outreach and training events around the state that target individuals with TBI, families, and caregivers. 5. Direct representation of 10 people with TBI who are experiencing barriers in accessing appropriate services. These cases will include those with dual diagnosis: TBI and bipolar disorder or TBI and mental retardation. 6. Provide ongoing direct representation of persons with TBI and families in health care, mental health care, employment, abuse and neglect, access to community services, and education.
Washington *Washington Protection and Advocacy*	PATBI Grant: $155,191	1. Increase the number of people with TBI who have information and referrals regarding their rights and increase the number of people with TBI who receive short-term advocacy services. 2. Increase the number of systemic or policy issues that affect people with TBI being addressed by policy makers. 3. Increase the number of people with TBI who receive adequate mental health services in large city jail and psychiatric hospitals. 4. Increase the number of people with TBI who receive appropriate discharge planning from a large city jail and decrease the number of people with TBI who have unnecessarily extended stays in psychiatric hospitals. 5. Increase the number of people with TBI who receive adequate housing, mental health, and other supports in the community.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• Conducted investigation of conditions in a city jail for prisoners with developmental disabilities, mental illness, and TBI, which resulted in changes in several policies. • Lawsuit against state of Washington regarding inadequate discharge and funding of services for people with developmental disabilities, mental illness, and TBI. • Provided hundreds of people with TBI and family with information, referral and short-term advocacy services. • Provided People First and Self-Determination input to the statewide TBI advisory board as it created the TBI Toolkit. • Handled special education legal cases and conducted outreach to the special education community, and attorneys. • Conducted employment trainings that reached 540 people. • Advanced Mental Health Parity legislation. • Preserved funding for Healthcare for Workers with Disabilities (Medicaid Buy-In).	Washington Protection and Advocacy will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

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TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
West Virginia *West Virginia Advocates, Inc.*	PATBI Grant: $100,000	1. Establish collaborative relationships through written memorandums of understanding with other key stakeholders. 2. Advocate and assist with the exploration, development, and implementation of an array of services that meet the culturally diverse needs for individuals with TBI. 3. Provide direct-advocacy services/legal representation for at least 25 individuals with TBI in accordance with established priorities and objectives. 4. Include individuals with TBI and/or family members on the Program Advisory Council. 5. Provide assistance in self-advocacy to persons with TBI and families. 6. Provide outreach and education to citizens of West Virginia to increase awareness of individuals with TBI. 7. Develop and/or adapt outreach and TBI educational tools. 8. Conduct TBI forums in at least four geographic areas in West Virginia. 9. Provide outreach to health care providers, social workers, individuals with TBI, and family members in rehabilitation hospitals and the two existing trauma centers in West Virginia.
Wisconsin *Wisconsin Coalition for Advocacy*	PATBI Grant: $152,799	1. Conduct effective outreach and provide high-quality information and referral and individual advocacy assistance to people with TBI and their families throughout Wisconsin. 2. Increase the self-advocacy skills of people with TBI and their families throughout Wisconsin. 3. Improve Wisconsin's TBI service delivery system through legislation, policy and and impact litigation strategies. 4. Elevate the TBI competencies of the Wisconsin Coalition for Advocacy staff, county and state employees, and others through a combination of training and materials development/dissemination.

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
• West Virginia Advocates has actively recruited individuals with TBI for membership on the West Virginia Advocates Program Advisory Council. • Provided direct advocacy services, community education, and referral to individuals with TBI and their guardians and/or family members.	West Virginia Advocates will continue to provide a TBI P&A program that is responsive to the needs of individuals with TBI and their families.
• Appointed to Wisconsin's statewide TBI advisory board. • Established a memorandum of understanding with the State Brain Injury Association affiliate to collaborate on conferences and referrals. • Conducted outreach to 21 Brain Injury Association support groups. • Published TBI information on the website. • Beginning to work with criminal justice system; also doing outreach to women's shelters under another contract, but including information on TBI. • Increase in referrals—35 between January and March 2005, and 47 total in 2004.	The Wisconsin Coalition for Advocacy will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

continues

TABLE C-3 Continued

State and State-Based P&A System for Individuals with Developmental Disabilities[a]	Federal PATBI Grant Received from HRSA Period: 9/01/2004–8/31/2006	Goals Under the Federal PATBI Grant
Wyoming *Wyoming P&A*	PATBI Grant: $100,000	1. Develop an outreach brochure describing P&A services for the TBI community. 2. Provide information on the TBI Program to organizations statewide. 3. Provide a series of training and outreach events around Wyoming targeting individuals with TBI, their families, and caregivers. 4. Provide information and referral services on disability-related issues as appropriate to eligible individuals and their families who are seeking TBI program services. 5. Provide advice, consultation, self-advocacy assistance, and legal representation as necessary to protect the rights of eligible individuals and their families to assist them in addressing disability-related issues.

NOTE: Data displayed in this table are compiled from state self-reports collected by the National Association of Head Injury Administrators (NASHIA). Programs or accomplishments reported in this table may be unique to an individual state.

[a] Under the Developmental Disabilities Assistance and Bill of Rights Act (42 *U.S.Code* 6012), each state seeking a federal grant for protection and advocacy (P&A) services for individuals with developmental disabilities must establish a protection and advocacy system independent of service-providing agencies, to empower, protect, and advocate on behalf of persons with developmental disabilities. The Children's Health Act of 2000 (P.L. 106-310) directed the Health Resources and Services Administration (HRSA) to make grants to state-based P&A systems to provide information, referral, and self-advocacy to individuals with TBI and their families.

[b] On June 22, 1999, the U.S. Supreme Court held in *Olmstead v. L.C.* that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The court ruled that the Americans with Disabilities Act may require states to

Accomplishments of the State-Based P&A System Under the Federal PATBI Grant	Continuing Efforts Related to P&A for Individuals with TBI and Their Families
Prepared an annual report that details all of the Wyoming's P&A system's accomplishments of goals 1–5.	Wyoming P&A will continue to implement its grant objectives and provide advocacy for individuals with TBI and their families in accessing services and supports to meet their needs.

provide community-based services rather than institutional placements for individuals with disabilities.

[c] The Medicaid home and community-based services waiver allows states to waive Medicaid provisions in order to allow long-term care services to be delivered in community settings; it is the Medicaid alternative to providing comprehensive long-term services in institutional settings.

[d] The Medicaid head and spinal cord injury (HASC) waiver is a type of Medicaid home and community-based services waiver. Individuals served by the HASC waiver must have TBI, SCI, or a similar disability and must apply for the waiver before their 60th birthday.

SOURCE: Connors S, King A, Vaughn S. *Guide to State Government Brain Injury Policies, Funding and Services*. 1st ed. Bethesda, MD: NASHIA 2003; King A, Vaughn SL. *Guide to State Government Brain Injury Policies, Funding and Services*. 2nd edition. Bethesda, MD: NASHIA, 2005.

APPENDIX D

Profiles of TBI Initiatives in Seven States

As noted in Appendix A, the Institute of Medicine (IOM) Committee on Traumatic Brain Injury agreed to take an in-depth look at traumatic brain injury (TBI) initiatives in seven states that would illustrate major successes and failures, as well as common themes, related to Federal TBI Program Grants. TBI initiatives in Alabama, California, Colorado, Georgia, New Jersey, Ohio, and Washington State are profiled in some detail below.[1] The information presented here was obtained during the summer of 2005 via telephone or in-person stakeholder interviews with one or more representatives of various state organizations using the semi-structured interview guide presented in Appendix B.[2]

ALABAMA STATE TBI PROFILE

Background

Alabama has had a special focus on brain and spinal cord injury since 1979, after the shooting of former Governor George Wallace heightened

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[1] These states were thought to be representative of the considerable state-to-state differences in their preparedness for applying for TBI Program Grants. The criteria used to select the seven states are identified in Table A-1 of Appendix A.

[2] Additional information on the interviews and findings in the seven states is presented in the consultant's report in Appendix E.

public awareness of such injuries. The Alabama State Head Injury Program was created in 1981 to provide vocational and rehabilitation services for individuals with TBI.

In 1989, the Alabama Department of Rehabilitation Services established the Alabama Head Injury Task Force and designated a statewide coordinator. A TBI work team made up of individuals with a TBI, family members, rehabilitation professionals, and medical and social services providers was also established to develop a service delivery model to address problems with traditional vocational rehabilitation services for people with brain injury.

This group developed the Interactive Community-Based Model (ICBM) to decentralize and provide community integration services for people with TBI in local communities. The ICBM was piloted in three locations in Alabama from 1990 to 1992. In 1992–1993, the Alabama legislature created the Impaired Drivers Trust Fund. This trust fund allowed the expansion of the ICBM model and serves as the basis for the state's activities related to grants from the Federal TBI Program. In 1997, the Alabama legislature enacted the Alabama Head Injury and Spinal Cord Injury Registry Act, designating the Alabama Department of Public Health the lead state agency for data and registry activities.

Alabama's Department of Rehabilitation Services was designated the lead state agency for TBI for Federal TBI Program Grants from the Health Resources and Services Administration (HRSA) in 1997. This department has established relationships and works closely with several state agencies and organizations, including the Alabama Head Injury Foundation, founded in 1983; TBI programs for adults and children within the Alabama Department of Rehabilitation Services; and the University of Alabama's TBI Model System of Care, funded in 1998 by the National Institute for Disability and Rehabilitation Research (NIDRR), among others.

Alabama has received funding for TBI-related surveillance from the federal Centers for Disease Control and Prevention (CDC), although it was reported in the summer of 2005 that funding for the current cycle had not been approved. As of the summer of 2005, Alabama had not developed a Medicaid TBI waiver.

The federally mandated protection and advocacy (P&A) system for adults and children with developmental disabilities in Alabama is the Alabama Disabilities Advocacy Program. Since 1976, this program, at the direction of Alabama's governor, has been administered by the clinical program of the University of Alabama School of Law. The Alabama Disabilities Advocacy Program is also the entity in Alabama designated to receive Protection and Advocacy for TBI (PATBI) Grants from HRSA. At the time it applied for a PATBI Grant, the Alabama Disabilities Advocacy Program had already operated several programs that served persons with

TBI and individuals with other disabilities, but it had limited capacity to serve persons with TBI (Table D-1).

TBI Planning Grants. None.

TBI Implementation Grants. To address the lack of service coordination for children with TBI, Alabama's Department of Rehabilitation Services, in collaboration with the Alabama Head Injury Foundation, applied for and received a TBI Implementation Grant from HRSA for a statewide pediatric service delivery model known as PASSAGES. The PASSAGES model, an expansion of Alabama's ICBM for adults with TBI, was designed to increase interagency collaboration, offer education/training opportunities for families and service providers, and provide coordinated intervention activities to strengthen the existing continuum of care for children with TBI. The Implementation Grant also supported Alabama's efforts to build the capacity to link individuals of all ages who experience TBI to needed community-based services and supports through the Alabama Head and Spinal Cord Injury Registry, established in 1998.

TBI Post-Demonstration Grants. Alabama received three TBI Post-Demonstration Grants from HRSA. The focus of the first grant was on the identification, accommodation, and referral of adolescents in schools to the Alabama's Department of Rehabilitation Services' Service Linkage Program; and educating family members about TBI. The second grant was used to address education and outreach to providers and the public about psychiatric disorders and TBI. The third grant was used to provide education and outreach about domestic violence and TBI, including providing outreach at women's shelters.

Protection and Advocacy for TBI Grants. The Alabama Disability Advocacy Program's first P&A Grant from HRSA focused on mental illness and mental retardation. Newly available data were used to identify TBI cases in populations with mental illness and mental retardation and expand work related to the state's *Wyatt v. Sawyer* case to end warehousing of individuals with mental illness and mental retardation, as well as to conduct outreach with TBI-serving agencies in the state to let them know about the Alabama Disabilities Advocacy Program.

TABLE D-1 Federal TBI Grants Received by Alabama

Federal TBI Grant Received from HRSA	Years Awarded
Planning	
Implementation	1997, 1998, 1999, 2000
Post-Demonstration	2002, 2003, 2004
Protection and Advocacy	2002, 2003, 2004, 2005

The Alabama Disabilities Advocacy Program's subsequent PATBI Grants from HRSA supported identifying and advocating for school children with TBI; improving services in the community for individuals dually diagnosed with mental illness and TBI; and providing training for law enforcement officers, mental health center directors, and mental health center clinical staff.

TBI-Specific State Funding: Trust Fund, Waiver, Other

In 1993, the Alabama legislature passed a law creating the Impaired Drivers Trust Fund to benefit individuals with brain and spinal cord injury. This trust fund is funded via fines on "driving under the influence" convictions, with assessments of $100 per conviction, and is the principal funding source for TBI (and spinal cord injury). A portion of trust fund revenues is used to support Alabama's TBI registry; the remaining funds provide direct or purchased services.

Alabama's Impaired Drivers Trust Fund supports the following types of services: Alabama Head Injury Foundation's toll-free help line, resource coordination, the ICBM, State of Alabama Independent Living Service, extended job support, respite care for families, housing assistance, and recreation. An advisory board oversees the use of the state's Impaired Drivers Trust Fund. Trust fund revenues are estimated at $1.2 million. Money from the trust fund was used to provide 678 individuals with information and referral services and 1,359 individuals with other services in 2003. Although Alabama serves individuals with TBI through several state programs, it does not report dedicated funding for TBI. The state has not developed a TBI-specific Medicaid waiver, but it does have several Medicaid waivers that could be accessed by individuals with TBI.

Services for People with TBI and Their Families

To help individuals with TBI and their families to gain access to needed services and supports across state agencies and organizations, Alabama's current established core service delivery network—the Interactive Community-Based Model—uses care coordinators, PASSAGES (pediatric) care coordinators, Alabama Head Injury Foundation family resource coordinators, and the TBI registry service linkage system. The state TBI registry, which is part of this system, allows for the identification and followup of individuals who sustain a TBI through hospital discharge data. The ICBM for adults was first piloted in the early 1990s. Alabama identified expansion of the ICBM to serve children and providing education and referral outreach for specific TBI populations for its Post-Demonstration Grants from HRSA.

Interorganizational Collaborations and Coordination Related to TBI

The coordination and delivery of services and supports for persons with TBI and their families in Alabama is facilitated by a history of established relationships among key individuals and organizations involved with TBI throughout the state, as well as by more than two decades of state government leadership and commitment to addressing TBI. The lead state agency for TBI, the Alabama Department of Rehabilitation Services, collaborates closely with the Alabama Head Injury Foundation, the Alabama Disability Advocacy Program, the Alabama Department of Public Health, the University of Alabama, and others.

TBI-Related Data Monitoring and Evaluation

The Alabama Head Injury and Spinal Cord Injury Registry Act of 1998 mandated development of a TBI registry that has become an important component of Alabama's core service delivery for individuals with TBI. Hospital discharge data are reported to the Alabama Department of Public Health, which works closely with the TBI registry coordinator of the Alabama Department of Rehabilitation Services. Consumers are contacted 3 months post-injury and provided with information and linkage to resources.

In the summer of 2005, Alabama had recently completed a 3-year cycle of funding from CDC for TBI surveillance; however, the state did not receive continuing support. The TBI surveillance data have been sent to the state legislature and are used to support injury education programs. The Alabama Department of Public Health is represented on the board of Alabama's Impaired Drivers Trust Fund. Alabama has access to more and better TBI data than many states, but the state has done little evaluation of its TBI programs.

HRSA Grant Experience: Alabama's Successes and Challenges

With its Federal TBI Program Grants, Alabama has been successful in implementing its community-based PASSAGES model for children with TBI and has been able to obtain some state support to sustain the program (i.e., maintaining care coordinator positions). Communication and interagency linkages to maximize services and supports for individuals with brain injuries and their families were reported to have improved in the state. Outreach efforts to train providers, individuals with TBI and their families, and others in Alabama—especially outreach efforts involving schools and domestic violence programs—were reported to be successful. Efforts to bridge gaps in the mental health sector have been more difficult and require continued focus. P&A efforts on behalf of persons with TBI in Alabama also were reported to have increased.

CALIFORNIA STATE TBI PROFILE

Background

California has faced the obstacles of large geographic size and diverse population in seeking to develop and coordinate services and supports for persons with TBI and their families throughout the state, but the state has nevertheless managed to undertake several initiatives for this population.

Early programs for persons with TBI and their families in the state included the following: (1) caregiver resource centers, developed in 1985 by the California Department of Mental Health to provide family support and service coordination for caregivers of brain-injured adults; (2) the Traumatic Brain Injury Project (now called Traumatic Brain Injury Services of California), established in 1990 as a result of action passed in 1988 to develop and pilot a post-acute continuum of care for persons with acquired TBI; (3) a TBI trust fund established in 1988 to support service programs; (4) a program of 28 independent living centers funded by the California Department of Rehabilitation to serve persons with a variety of disabilities; and (5) other programs.

Injury surveillance has been undertaken by the California Department of Health Services. This department received a 7-year surveillance grant from CDC and was part of CDC's national surveillance effort. In addition, California has an NIDRR-funded TBI Model System of Care;[3] however, this does not participate substantially with California's efforts to serve individuals with TBI and their families.

When California applied for its TBI Planning Grant from HRSA, it designated the California Department of Mental Health as California's lead state agency for TBI; however, California had no clearly defined responsibility vested in any single state agency, no statewide TBI advisory committee, no strategic plan, and no statewide needs survey for the TBI population.

The California Department of Mental Health successfully brought together diverse stakeholder groups under the Planning Grant from HRSA. The statewide TBI advisory council's activities ended soon after California was denied an Implementation Grant. A stakeholder workgroup to advise the California Department of Mental Health on TBI services is provided for in a state statute, however, and this group continued after the grant. The California government has undergone budgetary crises and reorganizations in recent years.

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[3] The NIDRR TBI Model System of Care Program provides grants to 16 state TBI Model System of Care to study the course of brain injury recovery and outcomes following the delivery of a coordinated system of emergency care, acute neurotrauma management, comprehensive in-patient rehabilitation, and long-term interdisciplinary followup services.

The Brain Injury Association of California established in 1993 was involved with California's early HRSA grant efforts, but this organization was not operational as of the summer of 2005. A brain injury hotline sponsored by a state-supported TBI program to facilitate information and referral was forced to close in July 2005 because of a lack of funding. The California Department of Mental Health has worked closely with the California Department of Rehabilitation, Collaborative Services Section, for several years and continues to do so.

The California Department of Health Services' application to CDC for TBI surveillance funding was not approved. As of the summer of 2005, although California's statewide TBI advisory board was no longer meeting, the California Department of Mental Health's TBI coordinator continued as coordinator as part of her broader responsibilities.

California's federally mandated statewide P&A system for adults and children with developmental disabilities is Protection and Advocacy, Inc. This organization has served people with disabilities, including individuals with TBI, since 1978. It has 200 employees at four locations throughout California. Protection and Advocacy, Inc., is also the recipient of California's PATBI Grants from HRSA. The organization also operates the Office of Clients' Rights Advocacy under a contract with the California Department of Developmental Services; it also operates the Office of Patients' Rights under contract with the California Department of Mental Health. Protection and Advocacy, Inc., served individuals with TBI within its general disability programs prior to receiving PATBI Grant funding from HRSA, but the organization's programming did not have a TBI-specific focus (Table D-2).

TBI Planning Grants. At the time of California's application for a TBI Planning Grant from HRSA, the state had designated the California Department of Mental Health as the lead state agency for TBI activities, but it had no TBI service infrastructure. The Planning Grant focused on development of three of the four core capacity components of a TBI service system: a statewide TBI advisory board, a statewide TBI needs and resources assessment, and a statewide TBI action plan.[4] The state applied for two 1-year Planning Grants from HRSA to complete these tasks.

TBI Implementation Grants. California submitted an application for a TBI Implementation Grant from HRSA, but the application was denied.

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[4] The four core capacity components of a TBI service system are the following: (1) a lead state agency and state staff person responsible for state TBI activities; (2) a statewide TBI advisory board (or council); (3) a statewide TBI needs/resources assessment; and (4) a statewide TBI action plan that is a comprehensive, community-based system of care that addresses the need of individuals with TBI and their families.

TABLE D-2 Federal TBI Grants Received by California

Federal TBI Grant Received from HRSA	Years Awarded
Planning	1999, 2001
Implementation	
Post-Demonstration	
Protection and Advocacy	2003, 2004, 2005

TBI Post-Demonstration Grants. None.

Protection and Advocacy for TBI Grants. California Protection and Advocacy, Inc. has focused its PATBI Grant from HRSA on the TBI Community Living Project to increase community living options for TBI survivors. The PATBI Grant funds were directed to do the following: (1) increase awareness of TBI activities in the community; (2) increase the understanding and capability of the Protection and Advocacy, Inc. to serve the TBI community; and (3) ensure participation of the TBI community as California redesigns its long-term care system in response to the Olmstead decision.[5]

TBI-Specific State Funding: Trust Fund, Medicaid Waiver, Other

California established a TBI trust fund in 1988 to provide services to individuals and TBI program support. The trust fund receives 0.66 percent of State Penalty Fund revenues from vehicle code violations, and has been generating approximately $1 million annually. In FY 2004, money from California's TBI trust fund was used to provide services for 1,204 individuals, as well as to cover personnel and evaluation costs. Another portion was used to draw down federal vocational rehabilitation funds, serving 30 individuals. State respondents report that trust fund resources have been quickly spent down for services as California's budgetary crisis continues. There are no Medicaid waivers or sources of dedicated funding for TBI other than the trust fund in California.

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[5] On June 22, 1999, the U.S. Supreme Court held in *Olmstead v. L.C.* that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The court ruled that the Americans with Disabilities Act may require states to provide community-based services rather than institutional placements for individuals with disabilities.

Services for People with TBI and Their Families

Services for people with TBI and their families in California are formally coordinated through seven California Department of Mental Health sites that serve limited numbers of clients, and beyond these sites, coordination of services does not occur. The seven California Department of Mental Health sites offer an umbrella of services and are listed on a state-sponsored website. These sites—two of which are hospital-based and five of which are community-based—demonstrate diverse approaches to service delivery and coordination. Services and coordination available through these sites is reportedly good, but little is known about the independent services used by individuals served outside these sites. The TBI-related services provided in California do not focus on children.

Interorganizational Collaborations Related to TBI

California's Department of Mental Health, as designated lead state agency for TBI, developed and facilitated coordination of the TBI advisory board during the period of California's TBI Planning Grant activities. Obtaining representation from all regions of California was challenging, and the group struggled to find common goals. With professional facilitation, however, the group was able to come to consensus on a statewide action plan for a comprehensive, community-based system of care for TBI.

After the California's TBI grant support from HRSA ended and the state experienced continuing fiscal crisis, the state's TBI advisory board disbanded and many state offices were reorganized. As of the summer of 2005, the Brain Injury Association of California was no longer operational. A brain injury hotline operated in its place for a while but had to close in July 2005 because of a lack of funding. California's TBI coordinator continues to collaborate informally with the California Department of Vocational Rehabilitation and serves as a TBI contact as needed, in addition to performing other official duties. Injury surveillance in California has been undertaken by the California Department of Health Services, but funding from CDC for TBI surveillance has ended and will not be continued.

TBI-Related Data Monitoring and Evaluation

During the period of California's TBI Planning Grant from HRSA, the California Department of Health Services, Injury and Epidemiology Section, developed TBI incidence data and attended statewide TBI advisory board meetings. California received CDC funding for TBI surveillance for a 7-year period but was not subsequently refunded. As of the summer of 2005, California did not have a TBI registry; however, the state does mandate the submission of hospital data to the state and has electronic data from hospitals, including both discharge and emergency room data, which could be linked with death records from Vital Statistics for a comprehensive view of TBI in the state.

HRSA Grant Experience: California's Successes and Challenges

California succeeded in developing the core TBI program components under its TBI Planning Grant from HRSA. California's statewide TBI advisory board experienced an initial lack of focus and difficulty coming together as a group, but it was able to come to consensus in identifying priorities for the statewide TBI action plan.

California did not receive funding from HRSA for a TBI Implementation Grant. Fiscal crisis in the state further contributed to reorganizations and placed activities of the state's TBI-related infrastructure on hold. The lack of strong community-based organizations, including the Brain Injury Association of California, also contributed to difficulties sustaining this basic infrastructure.

Protection and Advocacy, Inc., has reportedly made progress moving forward its focus on TBI at the organizational and case levels and maintains contact with the California Department of Mental Health's TBI coordinator, who continues to serve as the state TBI contact. The California Department of Rehabilitation, Collaborative Services Section, continues to work together with the California Department of Mental Health's TBI coordinator.

COLORADO STATE TBI PROFILE

Background

Colorado had a long history of grassroots activity involving persons with brain injury and their family members, state agencies, and other stakeholders prior to its involvement with the Federal TBI Program administered by HRSA. The Brain Injury Association of Colorado formed in 1980, has long been an active force behind brain injury advocacy and systems and services development. The Rocky Mountain Regional Brain Injury Center, established in 1989, has played an important role in developing TBI services and systems in Colorado. Developed as a 4-year federally funded regionwide project from the Rehabilitation Services Administration to Colorado Rehabilitation Services (now the Colorado Division of Vocational Rehabilitation), the Rocky Mountain Regional Brain Injury Center facilitated the beginning development of a statewide infrastructure to support persons with TBI and their families.

In 1992, the Brain Injury Association of Colorado and the Rocky

Mountain Regional Brain Injury Center established the Brain Injury Task Force, a broad-based coalition of state agency representatives, persons with TBI and their family members, Craig Hospital, and other providers and stakeholders formed to influence public policy and legislation in areas relating to brain injury. The Brain Injury Association of Colorado and the Brain Injury Task Force have successfully advocated for legislation in areas of brain injury prevention, automobile insurance, Medicaid managed care, attendant care, and other issues.

In 1997, the Brain Injury Legislative Coalition was established to merge the efforts of the Brain Injury Association of Colorado, the Brain Injury Task Force, the Pikes Peak Challenge Committee for Long-Term Funding for Persons with Brain Injury, and other stakeholders to make recommendations to establish a catastrophic fund for Coloradoans with brain injury. Soon thereafter, representatives from the Brain Injury Association of Colorado and the Brain Injury Task Force approached the manager of the Colorado Department of Human Services' Office of Behavioral Health and Housing (CDHS-OBHH) (formally the Colorado Office of Rehabilitation Services) to lead Colorado's TBI-related activities. CDHS-OBHH is responsible for Colorado's Alcohol and Drug Abuse Division, Division of Mental Health, Developmental Disabilities Services, and Supportive Housing and Homeless Programs.

CDHS-OBHH led efforts to form Colorado's TBI State Planning Group, a subgroup of which prepared the state's first application to HRSA for a TBI Planning Grant. Colorado reapplied for a Planning Grant from HRSA in 1999 and was funded, following a year of CDHS-OBHH support, to begin development of Colorado's Brain Injury Planning Initiative to establish the four core capacity components of a TBI service system. Colorado is home of Craig Hospital's NIDRR-funded TBI Model System of Care, and has conducted CDC-funded TBI surveillance. Colorado developed a Medicaid TBI waiver in 1995 and established a TBI trust fund in 2002.

Colorado's federally mandated statewide P&A system for adults and children with developmental disabilities is the Center for Legal Advocacy, established in 1976. This organization provides legal representation, advocacy, education, and legislative analysis to protect and promote the rights of people with disabilities and older people in Colorado. It is also the state recipient of PATBI Grants from HRSA. The Center for Legal Advocacy has offices in Denver and Grand Junction, and served persons with TBI within its disability programs, but did not address TBI as a specific programmatic focus at the time of its PATBI Grant application. The Center for Legal Advocacy met with Colorado's TBI program director as it prepared its PATBI Grant application to identify program priorities. The Center for Legal Advocacy became part of Colorado's statewide TBI advisory board at that time (Table D-3).

TABLE D-3 Federal TBI Grants Received by Colorado

Federal TBI Grant Received from HRSA	Years Awarded
Planning	1999
Implementation	2001, 2002, 2003
Post-Demonstration	2004
Protection and Advocacy	2002, 2003, 2004, 2005

TBI Planning Grants. Colorado completed a statewide TBI needs/resources assessment and a statewide TBI action plan during the period of its TBI Planning Grant from HRSA. It also continued to develop its Brain Injury Planning Initiative with the CDHS-OHRS as designated lead state agency and a statewide TBI advisory board in place when its Planning Grant was awarded.

TBI Implementation Grants. Colorado's TBI Implementation Grant was developed to enhance and expand on resources, services, and supports available to persons with TBI and their families, as well to the providers who serve them. The grant focused on the following objectives: (1) increasing statewide availability of information and resources; (2) continuing Colorado Information, Resource Coordination, Linkage and Education (CIRCLE) programs that convened providers and stakeholders for information sharing and referral in the Denver and Northeast regions; (3) addressing needs of children with TBI through development of a BrainSTARS manual and training for parents and school personnel; and (4) increasing awareness of state agency personnel about brain injury and identify and change barriers to effective service coordination.

TBI Post-Demonstration Grants. Colorado did not initially receive funding for its Post-Demonstration Grant application in 2004, and the result was nearly a year of downtime before the application was funded by HRSA later in the year. Meanwhile, participants kept the project alive through volunteer efforts. Colorado's TBI Post-Demonstration Grant from HRSA expanded the CIRCLE networks to two new communities (Pueblo and Grand Junction), provided additional training sessions for parents and school personnel regarding children with TBI, and continued efforts to increase TBI awareness among state agency personnel.

Protection and Advocacy for TBI Grants. The Center for Legal Advocacy in Colorado identified three priorities for its PATBI Grant from HRSA: (1) training staff and recruiting a person with TBI; (2) conducting a statewide TBI needs/resources assessment to identify available services; and (3) individual advocacy. The Center for Legal Advocacy developed a TBI-specific focus to its programs to increase services to individuals with TBI.

TBI-Specific State Funding: Trust Fund, Medicaid Waiver, Other

Colorado created a Medicaid TBI/acquired brain injury (ABI) waiver in 1995. This waiver has two levels of care: (1) rehabilitation-level care; and (2) nursing facility-level care. Individuals can access the waiver as a three-step process: (1) through a case manager at one of 26 single entry points in the state, based on a functional assessment tool to evaluate level of care, with a prognosis of improvement; (2) through financial application that allows participation for individuals up to 300 percent of their social security income; and (3) through meeting social security disability requirements. The waiver caseload in Colorado has increased from 143 clients in 1997–1998 to 366 clients in 2003–2004, with Medicaid outlays of $1.46 million and $8.89 million in these years, respectively. Medicaid is seeking to further increase these waiver slots.

In 2002, Colorado established a TBI trust fund and a 13-member trust fund board. Colorado's TBI trust fund legislation imposes surcharges for certain traffic convictions, and requires that 5 percent of funds be used to educate TBI survivors, parents, educators, and nonmedical professionals in identifying TBI and assisting persons to seek proper medical care; 65 percent be used for services; and 30 percent be used for research related to the treatment and understanding of TBI. The TBI trust fund provides an estimated $1.5 million annually.

Services for People with TBI and Their Families

Colorado has an array of services and supports for persons with TBI and their families, especially in the Denver area. The state has established CIRCLE networks with the Brain Injury Association of Colorado. CIRCLE networks operate regionally and allow local areas to identify and collaborate as participants find appropriate given their needs and resources. Colorado provides TBI-related information and training throughout the state on issues including children and TBI. The state also provides some housing slots for persons with TBI. Colorado has a large Medicaid TBI/aquired brain injury (ABI) waiver and a TBI trust fund that can be used for services support.

Interorganizational Collaborations Related to TBI

Colorado has a history of collaboration involving key individuals, organizations, and state agencies that serve individuals with brain injury. These relationships provide a foundation for their HRSA grant collaboration, as well as other activity relating to TBI in the state, including activities relating to the state's trust fund. Colorado's statewide TBI advisory board and TBI trust fund include several members in common.

Colorado's Federal TBI Program Grants from HRSA involved partnerships between CDHS-OHRS and the Brain Injury Association of Colorado to establish the CIRCLE programs in different areas of the state. The focus on children with TBI involved collaboration involving the Health Care Program for Children with Special Needs, the BrainSTARS Program located at Children's Hospital, and the Center for Community Participation at Colorado State University. The CIRCLE programs in Colorado appear to be popular as a regional opportunity for collaboration involving TBI providers and other stakeholders and are likely to continue independent of HRSA funding.

TBI-Related Data Monitoring and Evaluation

Colorado has had TBI data systems since 1991, including a state trauma registry and, more recently, CDC-funded TBI surveillance. Both data systems are maintained by the Colorado Department of Public Health and Environment, which is represented on Colorado's statewide TBI advisory board. Colorado's data on TBI are obtained from hospital discharges and death certificates; the state does not have electronic emergency department data. Colorado will receive continued funding from CDC for TBI surveillance.

Colorado's TBI Implementation Grant from HRSA has been evaluated by two professional researchers through the University of Denver. The evaluation used multiple methods, including interorganizational surveys and other approaches to measure systems change. The researchers also provided consultation in program and systems development to Colorado's statewide TBI advisory board.

Colorado's TBI trust fund legislation specifies that 30 percent of trust fund monies be directed to support research. As of the summer of 2005, five studies were underway that were receiving TBI trust fund support.

HRSA Grant Experience: Colorado's Challenges and Successes

Colorado has successfully leveraged established relationships and resources with Federal TBI Program grants from HRSA. It has made impressive progress in improving the coordination of services for individuals with TBI and their families through its CIRCLE networks. The BrainSTARS manual and trainings have been provided throughout Colorado to raise awareness and understanding of TBI and its effects in children. Furthermore, Colorado's Center for Legal Advocacy identified its PATBI Grant priorities from the state's TBI needs/resources assessment and participates on Colorado's statewide TBI advisory board.

There are several examples of spillover effects where change was a consequence but not a direct result of HRSA funding in Colorado. Colorado established a TBI trust fund independent of the HRSA grant and has provided resources that help support and sustain the state's emphasis on TBI. Increased awareness about TBI appears to have resulted in increased utilization of Colorado's Medicaid TBI/ABI waiver. Respondents noted that the impact of the HRSA grant and Colorado's TBI trust fund are sometimes blurred. Their boards share several members, and the trust fund is able to provide substantial resources to support TBI-related efforts in Colorado.

GEORGIA STATE TBI PROFILE

Background

Georgia has a history of TBI services dating to the 1980s, including legislative efforts and programs established through the Georgia Department of Labor's Division of Rehabilitation Services programs, including the Roosevelt Warm Springs Institute for Rehabilitation and its vocational rehabilitation program.

In 1981, Georgia established a central registry for spinal cord injury (SCI), mandated by the Georgia legislature to be maintained by the Division of Rehabilitation Services. The SCI registry was expanded to include TBI in 1985. The Roosevelt Warm Springs Institute for Rehabilitation developed a number of programs for individuals with TBI, including the Head Injury Rehabilitation Program, the Head Injury Transitional Program, and the Georgia Traumatic Brain Injury Rehabilitation Center, which opened its doors in 1988. Georgia's vocational rehabilitation program established a program of rehabilitation counselors throughout the state to assist individuals with TBI in gaining and maintaining employment opportunities. As a result of the changes in data collection, the Commission identified 44,484 people who sustained a TBI in 2004.

Recently, the principal services available to individuals with TBI and their families have been provided by the Georgia Department of Community Health, which is responsible for administration of Georgia's various Medicaid waivers; the Georgia Department of Human Resources, which is responsible for provision of direct services; and Department of Labor programs through the Roosevelt Warm Springs Institute for Rehabilitation and vocational rehabilitation programs.

In 1998, in a separate effort spearheaded by a TBI survivor, Georgia established a brain and spinal injury trust fund to help offset the high costs of needed services for persons with TBI and SCI. In addition to state programs in Georgia, there are several nonprofit and provider organizations active in service delivery for individuals with TBI and their families—the

Brain Injury Resource Foundation, the Shepherd Center for rehabilitation of individuals with SCI and TBI, and others.

Georgia's Department of Human Resources applied for Georgia's first two Federal TBI Program Grants from HRSA. The members of Georgia's large TBI advisory board had difficulty working together, placement of the lead state agency for TBI was reportedly not an appropriate fit, and only limited success toward project goals was achieved. The state's HRSA grant was moved to the Department of Community Health, and with encouragement of the Brain Injury Association of Georgia (now, the Brain Injury Resource Foundation), Georgia applied for a Post-Demonstration Grant from HRSA. This application was denied, and Georgia's statewide TBI advisory board disbanded soon thereafter.

In 2003, Georgia's Brain and Spinal Injury Trust Fund Commission, with new leadership, was designated Georgia's lead state agency for TBI. It applied for and received a Post-Demonstration Grant that focused on enhancement of the central registry that was established in 1981.

Georgia's federally mandated statewide P&A system for adults and children with developmental disabilities is Georgia Advocacy Office, Inc. It operates several federally funded programs to serve individuals with disabilities, and coordinates citizen advocacy offices to facilitate volunteer mentors to support individuals with disabilities. At the time of its first PATBI Grant application to HRSA, Georgia Advocacy Office provided support for persons with disabilities through its programs and through eight citizen advocacy programs but did not have a TBI-specific focus in these programs (Table D-4).

TBI Planning Grants. Georgia had none of the four core capacity components of its TBI service system in place at the time of application for its first TBI Planning Grant from HRSA. Georgia's TBI Planning Grant sought to develop the four core components of a service system: a lead state agency for TBI, a statewide TBI advisory committee, a statewide TBI needs/resources assessment, and a statewide TBI action plan.

TABLE D-4 Federal TBI Grants Received by Georgia

Federal TBI Grant Received from HRSA	Years Awarded
Planning	1997
Implementation	1998, 1999, 2000
Post-Demonstration	2004
Protection and Advocacy	2003, 2004, 2005

TBI Implementation Grants. Georgia's TBI Implementation Grant from HRSA focused on expanding the state's service delivery system to include children with TBI. The project focused on: (1) increasing interagency collaboration and linkages to improve access to a continuum of care for children with TBI and their families, with a special focus on minorities; (2) developing materials directed at TBI survivors and their family members; (3) improving services, support, and culturally competent information for minority populations; (4) providing immediate access to TBI resource information to survivors, families, and providers; (5) improving data reporting, collection, and surveillance relating to TBI; (6) developing and implementing a plan to increase the number of public and private payers, including managed care plans in the state, to cover TBI-related services; and (7) increasing public awareness of TBI-related issues.

TBI Post-Demonstration Grants. Georgia applied to HRSA for its TBI Post-Demonstration Grant with a new lead agency, the Brain and Spinal Injury Trust Fund Commission, and a new focus. This grant was intended to be used for the following: (1) to enhance the infrastructure for the central registry; (2) to provide accurate data on TBI for use in policy development for all state agencies; and (3) to ensure individuals with TBI and their families have improved access to resources. A statewide resource database has been developed in Georgia using this grant.

Protection and Advocacy for TBI Grants. The Georgia Advocacy Office's PATBI Grants from HRSA addressed ways to develop a TBI-related focus in its programming through a series of information and outreach efforts, and to increase TBI-specific advocacy. As of the summer of 2005, the TBI/Olmstead advocate at the Georgia Advocacy Office was being funded half time through the HRSA grant to seek out inappropriately institutionalized individuals in nursing homes and assist efforts for community placement.

TBI-Specific State Funding: Trust Fund, Medicaid Waiver, Other

Georgia established a TBI/SCI trust fund in 1998. The trust fund provides up to $2.3 million annually for services to individuals. Awards are made to improve services to individuals based on the following criteria: (1) independence, (2) inclusion, and (3) sustainability. Acuity of injury is not considered. In FY 2005, Georgia's Brain and Spinal Injury Trust Fund Commission disbursed all but $50,000 of available funds.

Georgia does not have a Medicaid waiver specific to persons with TBI, but the state does have a Medicaid independent care waiver that includes 30 slots for individuals with TBI. The state also has a Medicaid-funded community care services program and a model waiver program.

Services for People with TBI and Their Families

As of the summer of 2005, services for people with TBI and their families in Georgia were not coordinated across programs or agencies, and information about service availability in the state was lacking. Georgia was updating its statewide TBI needs/resources assessment and its statewide TBI action plan to identify agencies and services needed and available to serve persons with TBI and their families, as well as opportunities that might exist for coordination.

Interorganizational Collaborations Related to TBI

Georgia experienced a lack of stability and continuity of leadership in the early years of the state's involvement in the Federal TBI Program administered by HRSA. The Georgia Department of Human Resources first served as Georgia's lead state agency for TBI, and this responsibility later shifted to the Georgia Department of Community Health.

Georgia's original statewide TBI advisory board, which was reported to have included more than 50 members, disbanded following the completion of Georgia's TBI Implementation Grant from HRSA. The Brain Injury and Spinal Trust Fund Commission was the lead state agency for TBI for Georgia's Post-Demonstration Grant from HRSA, and this placement appears to be a good fit. Many of the state's original participants in the Federal TBI Program are no longer involved. Georgia's TBI/SCI advisory board and Georgia Advocacy Office have a joint board for the Federal TBI Program, including 22 members; this board is a subcommittee of the Brain Injury and Spinal Trust Fund Commission.

TBI-Related Data Monitoring and Evaluation

Georgia has operated a central registry for SCI since 1981; the registry was expanded to include TBI in 1985. The state has used Federal TBI Program Grants from HRSA to expand its central SCI/TBI registry through the Brain and Spinal Injury Trust Fund Commission. With help from 2004 legislation transferring operation of the central registry to the commission, the Brain and Spinal Injury Trust Fund Commission increased participation from 30 percent prior to the commission's oversight to 100 percent as of the summer of 2005. Data collected by the central SCI/TBI registry in Georgia include hospital discharge data, emergency department, and ambulatory surgical clinic data. As of the summer of 2005, the Brain and Spinal Injury Trust Fund Commission was analyzing 2004 data from the SCI/TBI registry.

HRSA Grant Experience: Georgia's Challenges and Successes

Georgia experienced instability and difficulties achieving the goals and objectives of its TBI Planning and Implementation Grants from HRSA and apparently achieved little success in improving the coordination of services to individuals with TBI during these grant cycles.

The Brain and Spinal Injury Trust Fund and Commission were created by the Georgia legislature in 1998, and the Brain and Spinal Injury Commission became Georgia's lead state agency for TBI in 2003. This appears to be a more appropriate home for Georgia's TBI-related efforts. Georgia has now redirected the focus of its grant from HRSA to building up the central SCI/TBI registry to provide needed data. This new direction is more focused than earlier grant projects in the state, and useful data can now be obtained.

NEW JERSEY STATE TBI PROFILE

Background

New Jersey applied to HRSA for 3 years in a row for a grant before receiving a TBI Implementation Grant in 1999. At the time, the state had a newly designated lead state agency for TBI, New Jersey Department of Human Services, Division of Disability Services, and a statewide TBI advisory board designated by the governor.

New Jersey's application for an Implementation Grant was developed on the basis of strong collaboration between the state and the Brain Injury Association of New Jersey. In anticipation of applying for the grant, New Jersey updated its statewide TBI needs/resources assessment. Needs identified through review of the following sources were prioritized in New Jersey's statewide TBI action plan: the 1997 Commissioner's Technical Assistance Group on TBI, with addressed needs and resources in multiple human services agencies; 1993 TBI (and SCI) Surveillance System findings; Update of 1988 Needs Assessment of individuals discharged from rehabilitation facilities; 1988 Needs Assessment based on a state-mandated study of needs of individuals with brain injury; and 1985 Governor's Council on Prevention of Mental Retardation and Developmental Disabilities, which noted a growing prevalence of TBI among children.

TBI surveillance has been undertaken by the New Jersey Department of Health and Senior Services through a grant from CDC, but it was reported in the summer of 2005 that the grant would not be renewed the next funding cycle. New Jersey is home to an NIDRR-funded TBI Model System of Care; however, the model system does not participate substantially with the state's TBI services and systems efforts.

In 1993, New Jersey created a Medicaid TBI waiver, which was expanded during the HRSA grant period. The New Jersey state legislature established a TBI trust fund via legislation in 2002.

New Jersey's federally mandated statewide P&A system for adults and children with developmental disabilities is New Jersey Protection and Advocacy, Inc. This organization has been in operation over 10 years and provides many programs for persons with disabilities. New Jersey Protection and Advocacy, Inc., is also the state's recipient of PATBI Grants from HRSA. Although the organization served individuals with TBI prior to receiving PATBI Grant funds from HRSA, it did not have a specific focus on TBI. New Jersey Protection and Advocacy, Inc.'s history and experience working with individuals with TBI includes a 1994 grant from the federal Rehabilitation Services Administration to provide P&A services for individuals with TBI and their families (Table D-5).

TBI Planning Grants. None.

TBI Implementation Grants. The TBI Implementation Grant New Jersey received from HRSA was used to develop the Supporting Families in Crisis program. This involved collaboration with the Brain Injury Association of New Jersey, which developed and implemented substantial program activities under contract to the state. The University Affiliated Program New Jersey also participated as a training site for Supporting Families in Crisis program's family mentor program. The Supporting Families in Crisis program was developed with four objectives: (1) to increase families' knowledge of TBI through education about resources and outcomes; (2) to increase trauma center staff knowledge about community resources for discharge planning of persons with TBI; (3) to increase the numbers of minority and non-English speakers with TBI who access services; and (4) to increase identification of children with mild or moderate TBI in the school and youth services systems.

TBI Post-Demonstration Grants. New Jersey received three TBI Post-Demonstration Grants from HRSA. The first provided outreach to minority neighborhoods in inner city Camden. The second grant followed up first-year activities by establishing social and recreational supports in these

TABLE D-5 Federal TBI Grants Received by New Jersey

Federal TBI Grant Received from HRSA	Years Awarded
Planning	
Implementation	1999, 2000, 2001
Post-Demonstration	2002, 2003, 2004
Protection and Advocacy	2002, 2003, 2004, 2005

neighborhoods, often through partnerships with faith-based organizations. Family and peer support programs involving local clergy were successfully implemented. The third grant provided education and outreach to staff at the state's "one-stop" centers, available in each county to provide vocational support, employment, and workforce development services.

Protection and Advocacy for TBI Grants. New Jersey Protection and Advocacy, Inc. has focused efforts on outreach and education strategies to leverage the limited PATBI Grant funds available from HRSA. The organization's PATBI Grants from HRSA are directed to the following: (1) planning and assessment of P&A services with community partners, including state agencies, the Brain Injury Association of New Jersey, and consumer groups; (2) providing information and referral, legal advocacy and representation, and systemic and legislative advocacy; (3) providing outreach, training, and technical assistance, especially in communities of color; (4) promoting and supporting self-advocacy of persons with TBI and their families; and (5) establishing a distinct but integrated TBI P&A program in New Jersey.

TBI-Specific State Funding: Trust Fund, Medicaid Waiver, Other

A Medicaid 1915(c) home and community-based waiver for individuals with ABI was created by New Jersey in 1993. During the period that New Jersey was operating with Federal TBI Program Grants from HRSA, New Jersey's Division of Disability Services was able to secure additional state appropriations to increase the available waiver slots by 100. As of the summer of 2005, 350 individuals were being served under New Jersey's Medicaid waiver.

In 2002, New Jersey passed legislation creating a TBI trust fund. The TBI trust fund in New Jersey provides flexible funding support for services to individuals and program development activities, which are contracted to the Brain Injury Association of New Jersey. Administered by the New Jersey Division of Disability Services (formerly, State Office on Disability Services), the TBI trust fund has been used to sustain programs and activities initiated with Federal TBI Program Grant funding from HRSA and shown to be successful (e.g., training and outreach). The TBI trust fund generates approximately $3.4 million per year and is funded by a $.50 surcharge on motor vehicle registrations. As of the summer of 2005, New Jersey's TBI trust fund had provided direct financial support to approximately 450 individuals.

In 2004, the New Jersey legislature established a TBI research fund, making New Jersey the first state with dedicated funding for research on TBI. The TBI research fund, which was spearheaded by the father of a son with a brain injury, is funded by a surcharge on motor vehicle accidents.

Services for People with TBI and Their Families

New Jersey's TBI-related services are provided through informal collaboration and are not formally coordinated. When TBI-related services are coordinated, the coordination occurs through a specific program, such as Medicaid, that includes case management as part of New Jersey's Medicaid TBI waiver. State services in New Jersey are available through generic disability programs rather than TBI-specific services. Respondents identified the justice system as an area where collaboration and linkages need further development. Meetings between the justice system and the New Jersey Division of Disability Services were initiated in fall 2005.

Interorganizational Collaborations Related to TBI

New Jersey's TBI services involve multiple agencies and offices of state government, and close collaboration with the Brain Injury Association of New Jersey. Both the state program and New Jersey Protection and Advocacy, Inc., have expanded outreach and education to involve new TBI partnerships, including efforts with faith-based communities and inner-city minority neighborhoods. There is interest in improving communications and collaboration between advisory board organizations and the justice system.

TBI-Related Data Monitoring and Evaluation

The New Jersey Department of Health and Senior Services, Center for Health Statistics, serves as the TBI data resource for New Jersey's statewide TBI advisory board. The major data source used by the TBI advisory board has been CDC-funded TBI surveillance data; however, CDC surveillance funding has not been continued in this funding cycle. Respondents noted they have no good data on mild and moderate TBI. New Jersey's Center for Health Statistics has been working since 2001 with two groups in the state on development of TBI and SCI registries that will provide patient-level data. The TBI and SCI registries were "brought to life" by the Christopher Reeve Foundation and the father of a TBI survivor and are viewed as an important avenue to pursue for TBI prevention and service planning. New Jersey's TBI research fund, established in 2002 and funded through a surcharge on motor vehicle accidents, has supported some minimal evaluation to date.

HRSA Grant Experience: New Jersey's Challenges and Successes

New Jersey used its TBI Program Grants from HRSA as seed money, thereby drawing a focus to TBI in state government, with providers, and in communities. Funding levels and short time frames for 1-year grants in the state were reported to be frustrating. Nonetheless, there were reported improvements in direct TBI program activities, such as the mentor program and building partnerships in underserved, minority communities. New Jersey's TBI advisory board was developed as a result of HRSA's requirements under the Federal TBI Program. Spillover effects where change was a consequence but not a direct result of HRSA funding were also apparent in New Jersey. Such effects include an increased number of Medicaid TBI waiver slots, the establishment of a TBI trust fund, and the establishment of a TBI research fund in New Jersey. Through TBI trust fund disbursements, New Jersey has been able to sustain successful components initiated through the HRSA grant, such as training and education efforts. New Jersey Protection and Advocacy, Inc., has engaged in several activities in tandem with the state program, addressing similar areas of need.

OHIO STATE TBI PROFILE

Background

Ohio has a history of community advocacy for children and adults with brain injury and their families beginning in 1983, with the incorporation of the Ohio Brain Injury Association (now known as the Brain Injury Association of Ohio). In 1990, Ohio legislation created the Ohio Head Injury Advisory Council (now known as the Brain Injury Advisory Committee) as the state-level, intergovernmental planning and coordinating body. The mission of the new organization was complementary to the mission of the Brain Injury Association of Ohio—to improve services to persons with brain injury through development of a comprehensive, coordinated delivery system and through prevention efforts.

Ohio's Brain Injury Advisory Committee and its affiliated Head Injury Program (now Brain Injury Program) were originally located within the Ohio Department of Health, but were both transferred to the Ohio Rehabilitation Services Commission in 1991 to maximize federal matching funds through the Vocational Rehabilitation Act. The Ohio's Brain Injury Advisory Committee and the Brain Injury Association of Ohio have worked closely through the years. Ohio's first statewide TBI needs/resources assessment was completed in 1992, and joint action (strategic) plans were developed for 1995–1999, with plans for 1999–2004, and 2005 to follow.

The ongoing partnership between Ohio's Brain Injury Advisory Committee and the Brain Injury Association of Ohio led to development of "The Ohio Plan: Building Ramps to the Human Service System for People with Brain Injury"—with a vision for a comprehensive model service coordination continuum and a strategy to further develop the model continuum. The system's three components are as follows: (1) help line and information clearinghouse; (2) community support network; and (3) individualized resource facilitation services. Ohio's TBI Implementation Grant from HRSA focused on developing Operation MAPS, the community support network component, by adding four community support networks to the two already developed by the Brain Injury Association of Ohio. A total of 15 community support networks were envisioned statewide. "The Ohio Plan" also drew expertise and support from Ohio State University's NIDRR-funded TBI Model System of Care project, the Ohio Valley Center for Brain Injury Rehabilitation and Prevention, other state agencies, and community organizations. Ohio does not have a TBI trust fund. The state has eight Medicaid home and community-based waivers, but none are specific to TBI.

Ohio's federally mandated statewide P&A system for adults and children with developmental disabilities is the Ohio Legal Rights Service, an organization with a history of working with persons with TBI. This organization is also the recipient of PATBI Grants from HRSA. The Ohio Legal Rights Service has served on Ohio's Rehabilitation Services Commission Brain Injury Advisory Committee since well before the HRSA grant. The organization has worked on creating a model Medicaid waiver, housing issues, and other TBI-related issues (Table D-6).

TBI Planning Grants. None.

TBI Implementation Grants. Ohio's first TBI Implementation Grant application to HRSA did not get funded, but the state did receive funding for an Implementation Grant in 1998. The Implementation Grant was viewed as a way to add four additional community support networks to Ohio's network of two community support networks. Subcontracts to the Brain Injury Association of Ohio were developed to establish sites in the new service areas. Securing additional funding to sustain all the sites proved to be a challenge, and Ohio has not been able to fund two community support networks of the six total community support networks established statewide.

TABLE D-6 Federal TBI Grants Received by Ohio

Federal TBI Grant Received from HRSA	Years Awarded
Planning	
Implementation	1998, 1999, 2000
Post-Demonstration	2002, 2003, 2004
Protection and Advocacy	2002, 2003, 2004, 2005

TBI Post-Demonstration Grants. Ohio received three TBI Post-Demonstration Grants from HRSA. The first was to enhance collaboration between Ohio's statewide TBI advisory board and the Brain Injury Association of Ohio in order to increase buy-in of participants. Ohio's second and third Post-Demonstration Grants had a different focus and involved working with a partner in Akron to conduct hospital-based education and work with families of individuals with TBI.

Protection and Advocacy for TBI Grants. The Ohio Legal Rights Service directed its PATBI Grants from HRSA to the following: (1) adding, identifying, and providing protection and advocacy to children with TBI in special education to its agency priorities; (2) increasing the knowledge and skills of parents, educators, other professionals ,and advocates and expanding planning activities with TBI stakeholders; and (3) expanding the capacity of the Brain Injury Association of Ohio's community support networks and education advocates.

TBI-Specific State Funding: Trust Fund, Medicaid Waiver, Other

Ohio does not have a TBI trust fund or a TBI-specific waiver, although persons with TBI can access one of six Medicaid home and community-based services waivers (three nursing facility level, three intermediate-care facilities for people with mental retardation) if eligible. The Ohio Rehabilitation Services Commission receives $226,012 in general revenue that provides funding for planning, prevention, research, services, and development relating to TBI.

Services for People with TBI and Their Families

Ohio uses the community support network model outlined in "The Ohio Plan" to coordinate services for persons with TBI and their families in the four service areas where community support networks have been established. Other areas of the state are not served by the community support networks. A statewide database for information and referral is also available to facilitate access to TBI-related services. As of the summer of 2005, nine agencies were represented on Ohio's TBI advisory board, some of which serve persons with TBI and some of which do not. There was no single point of entry. Service coordination in Ohio is reportedly "haphazard," depending on which agency provides service, what benefits are provided, which door one comes through. Generic Medicaid waivers are available for individuals with TBI who meet eligibility requirements.

Interorganizational Collaborations Related to TBI

Ohio involves nine TBI agencies and other stakeholder organizations on its statewide TBI advisory board for the Federal TBI Program Grants from HRSA. Brain injury and other organizations, including the Ohio Legal Rights Service, had been collaborating for many years prior to the grants and continue to do so. Until recently, the Brain Injury Association of Ohio and Ohio's TBI advisory board conducted joint strategic planning. Ohio State University's TBI Model System of Care funded by NIDRR has provided strong technical and information analytic assistance to support development of services coordination.

Many organizations have "intertwined" membership and share board representatives. Ohio recently conducted a planning retreat to refocus the statewide TBI advisory board to its "advisory" mission and clarify relationships with service-directed organizations such as the Brain Injury Association of Ohio.

TBI-Related Data Monitoring and Evaluation

Ohio has a legally mandated trauma registry, which is not used for followup or service assistance. Confidentiality issues reportedly pose challenges to the state's use of patient-level data. The state relies on CDC information about TBI and does not have a CDC-funded surveillance program.

With assistance from the Ohio State University TBI Model System of Care funded by NIDRR, Ohio has developed a comprehensive information and referral database of services available statewide. The TBI Model System has provided data and information analysis in support of TBI services delivery in the state.

HRSA Grant Experience: Ohio's Challenges and Successes

Ohio has successfully used grants from the Federal TBI Grant Program administered by HRSA to develop community support networks to advance Ohio's TBI plan. Still, sustainability after HRSA funding has ended has been a problem. The state has not been able to fund two community support networks of the six total community support networks established statewide (including four HRSA-funded).

Ohio's TBI plan was initiated prior to the HRSA grant on the basis of a close collaboration involving the Ohio Brain Injury Advisory Committee and the Brain Injury Association of Ohio. The Ohio Legal Rights Service has participated in these efforts and has directed its PATBI Grant funding from HRSA to support state activities. Ohio has many brain injury committees and advisory boards. As the state's TBI-related efforts have matured and increased in complexity, some confusion has emerged regarding organizational missions and direction. Attempts were being made in the summer of 2005 to clarify roles and relationships.

WASHINGTON STATE TBI PROFILE

Background

Washington State has addressed issues associated with TBI through programs and initiatives within the Washington Department of Social and Health Services since the 1980s. A multiagency task force convened in Washington State at that time resulted in a study and training of individuals with TBI and their families through a contract with the Brain Injury Association of Washington (then the Washington State Head Injury Foundation) and sponsored by the Washington State Division of Vocational Rehabilitation. In addition, the multiagency task force recommended designating a TBI coordinator within each division of the Washington Department of Social and Health Services.

In 1994, the Washington Department of Social and Health Services' Aging and Adult Services Administration developed a Medicaid demonstration waiver to provide community or residential services to individuals with TBI. The waiver was not renewed, but the department's Medicaid elderly and disabled waiver was modified and expanded to meet the needs of individuals with TBI.

The University of Washington has a TBI Model System of Care funded by NIDRR and an Injury Prevention Center funded by CDC. The state-initiated partnership with the TBI Model System has worked closely with researchers at the University of Washington and the TBI Model System through its HRSA grant. As of the summer of 2005, TBI-related studies were continuing at Harborview Hospital and included research addressing TBI and substance abuse.

When Washington applied for a TBI Planning Grant from HRSA, individuals had been identified as TBI coordinators for Washington Department of Social and Health Services divisions, but no overall responsibility had been assigned for coordination of these and other services in a comprehensive, statewide manner, and services remained fragmented.

The Washington State legislature has passed primary prevention key head injury legislation—including mandatory use of car seats and seat belts, motorcycle helmets, and stronger drunk driving laws—but the state has been unable to establish a TBI trust fund. The Brain Injury Association of Washington discontinued operation following fiscal and other difficulties after 2001; as of the summer of 2005, efforts were underway to rebuild the organization.

Washington State does not have a Medicaid TBI waiver or other dedicated funding for TBI, but includes individuals with TBI in its numerous home and community-based waivers.

The federally mandated statewide P&A system for adults and children with developmental disabilities in Washington State is Washington Protection and Advocacy, which has provided advocacy and legal representation to individuals with disabilities for more than 30 years. This organization is also the recipient in the state of PATBI Grants from HRSA. Washington Protection and Advocacy had provided services for individuals with TBI as part of its general disabilities programming, but it did not have a specific TBI focus at the time it applied for its first PATBI Grant from HRSA. Washington Protection and Advocacy has worked with Washington's statewide TBI advisory board and works closely with the Washington State TBI program (Table D-7).

TBI Planning Grants. When Washington State applied for its TBI Planning Grants from HRSA, the Division of Rehabilitation served as lead state agency for TBI. Washington's first Planning Grant focused on developing a statewide TBI advisory board; the second Planning Grant focused on developing a statewide TBI needs/resources assessment and a statewide TBI action plan.

Washington State experienced initial difficulties searching for and retaining a project director. A number of TBI advisory board processes reportedly posed challenges to effective collaboration and development of core TBI components. It was reported that (1) large, diverse membership made consensus difficult; and (2) attendance at monthly meetings was difficult for members from regions separated by geographic distance. Nevertheless, all of the state's Planning Grant goals were addressed. A University of Washington researcher under contract to the advisory board provided data and analytic support for the statewide TBI needs/resource assessment.

TABLE D-7 Federal TBI Grants Received by Washington State

Federal TBI Grant Received from HRSA	Years Awarded
Planning	2000, 2001
Implementation	2003, 2004, 2005
Post-Demonstration	
Protection and Advocacy	2002, 2003, 2004, 2005

TBI Implementation Grants. For its TBI Implementation Grant applications to HRSA, Washington State changed its lead state agency for TBI to the Disabilities and Long-Term Care Administration (now Aging and Disability Adult Services Administration, Home and Community Services Division). The new lead agency has been considered a better fit for the program given its broader array of services for persons with TBI. The Brain Injury Association of Washington was not a viable partner at the time, but the state developed and maintained strong collaboration with the TBI Model System of Care funded by NIDRR, Washington Protection and Advocacy, and other state agencies.

Washington State's TBI Implementation Grants were developed from Washington's statewide TBI action plan, refined with assistance from the TBI Technical Assistance Center, and addressed the following goals: (1) create a strong statewide information and resources system that would increase appropriate referral and services for persons with TBI; (2) increase capacity for appropriately identifying and serving persons with TBI within state and other systems that build upon the needs assessment; (3) collaborate with state and other agencies that administer services for persons with brain injury and their families in developing programs to address housing/service needs of persons with TBI; and (4) strengthen Washington's statewide TBI advisory board. Washington State, with the NIDRR-funded TBI Model System of Care, developed toolkits and educational materials and videoconferences as part of the Implementation Grant. The TBI Model System in the state had established capabilities in these areas, and the partnership resulted in several sustainable products.

TBI Post-Demonstration Grants. None.

Protection and Advocacy for TBI Grants. Washington Protection and Advocacy directed its PATBI Grant from HRSA to enhance and add focus to the services of its resource systems advocacy teams for the needs of people with TBI, and the provision of new legal advocacy team services. The organization also conducted outreach with its own organization and with community providers and has been an active collaborator with state agencies, other agencies, and the University of Washington's TBI Model Systemsof Care.

TBI-Specific State Funding: Trust Fund, Medicaid Waiver, Other

Washington State has no dedicated funding sources for TBI. The state does not have a Medicaid TBI waiver or a TBI trust fund. On the other hand, the state does have a medical institution income exemption that allows persons to have money to maintain their homes, a community transition service, and a residential care discharge allowance. Persons with TBI in the state may use the Medicaid aging and disabled waiver on the basis of a multifactorial assessment, including psychosocial factors, and other eligibility requirements.

Services for People with TBI and Their Families

Many people are reported to receive in-home services throughout Washington State. The Seattle area is location to a cluster of facilities with services for persons with TBI, including University of Washington's Harborview Hospital, but Seattle-based services are not readily accessible to the state's more rural residents. More limited hospital services are available in other parts of the state. Community-based services are difficult to access in urban and rural areas. There is limited coordination of services unless an individual is enrolled as a participant in a specific program that offers case management or related services.

Interorganizational Collaborations Related to TBI

Interorganizational collaboration in Washington State is complicated by geography, with services located in metropolitan Seattle, state offices in Olympia, and a large rural population in the eastern part of the state. Pulling together diverse organizations for Washington's statewide TBI advisory board was an early challenge to the state's HRSA grant efforts. With the shift of the lead state agency for TBI after the state received a Planning Grant from HRSA, the statewide TBI advisory board was downsized and has since achieved more effective results. Interlocking directorates on advisory boards of TBI-collaborating organizations is common and is viewed as an effective method of interorganizational communication. The Washington State TBI program and Washington Protection and Advocacy have separate advisory boards. The Washington State TBI advisory board meets in the offices of Washington Protection and Advocacy.

TBI-Related Data Monitoring and Evaluation

The Washington State Aging and Disability Adult Services Administration is using several sources to collect data on persons with TBI served by state services. The University of Washington's TBI Model System of Care funded by NIDRR and university-affiliated researchers have provided support to the HRSA grant's information and evaluation activities from the beginning. Washington Protection and Advocacy and other groups have also provided evaluation input. However, the lack of, and need for data about TBI was identified as an ongoing issue of particular importance when approaching the legislature.

HRSA Grant Experience: Washington State's Challenges and Successes

Washington State experienced difficulties in coordinating agencies and organizations on its statewide TBI advisory board and in finding an appropriate lead state agency "home" for the state TBI program in the initial stages of its Planning Grant from HRSA. The loss of the Brain Injury Association of Washington as an organization and statewide TBI advisory board participant also challenged the state's TBI-related efforts.

Nonetheless, Washington State was able to complete numerous products and trainings with the help of committed participants and collaborations with other community-based organizations. The state has produced products and educational materials through the implementation grant and is currently working on a TBI waiver to address the specialized housing and service needs of persons with TBI that are in or likely to be placed in state hospitals. The state's grants from HRSA succeeded in leveraging resources with close collaborators, Washington Protection and Advocacy, and the University of Washington's TBI Model System funded by NIDRR. As of the summer of 2005, new leadership was rebuilding and reinvigorating the Brain Injury Association of Washington.

Washington Protection and Advocacy has been and continues to be an active collaborator with community-based TBI organizations in Washington State. It identified three legislative victories in rehabilitation: (1) a 7-year effort involving 125 organizations leading to passage of a mental health parity law; (2) legislative successes in the area of guardianship and the right to vote; and (3) a bill on court accommodations relating to abuse among people with disabilities.

As of the summer of 2005, there was interest in Washington State in pursuing development of a TBI trust fund. The state's TBI advisory board was also working on a Medicaid waiver request.

APPENDIX E

Stakeholders Assess the HRSA TBI Program: A Report on National Interviews and Interviews in Seven States

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Stakeholder interviews were conducted during the summer of 2005 in a sample of seven states: Alabama, California, Colorado, Georgia, New Jersey, Ohio, and Washington State. These states were selected to provide a cross section of state and program characteristics including: length of participation in the Health Resources and Services Administration (HRSA) Grant Program; maturity of the state's Traumatic Brain Injury (TBI) program infrastructure; state funding levels and mechanisms such as Medicaid waivers and TBI trust funds; lead agency location in state government; program accomplishments; data availability; presence or absence of other programs, e.g., TBI Model Systems, TBI surveillance, and others; and geographic and cultural diversity. The Institute of Medicine (IOM) staff consultant conducted telephone interviews in Alabama, California, New Jersey, Ohio, and Washington State. The committee chair, study director, and staff consultant participated in 2-day site visits to conduct in-person interviews with stakeholders in Georgia and Colorado.

Study respondents in each state were selected based on criteria developed by the IOM Committee, and include: TBI lead agency representative, protection and advocacy (P&A) system representative, state brain injury association representative, consumer or family member of an individual with TBI, lead injury prevention representative, and other stakeholder rep-

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resentatives of key state agencies, TBI trust funds, Medicaid waivers, and related interests. State TBI lead agency representatives helped to identify appropriate representatives to be contacted in their states. National program stakeholders involved with the HRSA TBI Program were also contacted for interviews, including the HRSA TBI Program Director; Executive Director of the National Association of State Head Injury Administrators/Director of the TBI Technical Assistance Center (TBI TAC); President/CEO of the Brain Injury Association of America; and Executive Director of the National Disability Rights Network (formerly the National Association of Protection and Advocacy Systems, Inc.).

Interviews were conducted using a semi-structured interview guide developed by the IOM Committee to address areas of importance relating to state program implementation; program impact on persons with TBI and their caregivers; and coordination of TBI-related services, including education, vocational rehabilitation, employment, housing, transportation, and mental and behavioral health care. The interview guide includes questions about each state's history of TBI service delivery, and their experiences with each of the HRSA TBI Program grants:

Planning grants allow states to build infrastructure through the TBI Program's four core components—(1) establishing a TBI Statewide Advisory Board, (2) identifying a Lead Agency, (3) conducting a Needs and Resources Assessment, and 4) developing a TBI State Action Plan.

Implementation Grants allow states to undertake activities, e.g., implementation of the State Action Plan or activities to address identified needs, to improve access for individuals with TBI and their families.

Post-Demonstration Grants authorized by the Children's Health Act of 2000 have been available to allow states that have completed 3 years of implementation to support specific activities that will help states build TBI capacity.

Protection and Advocacy Systems Grants allow 57 states, territories, and the Native American Protection and Advocacy Project to assess their state P&A Systems' responsiveness to TBI issues and provide advocacy support to individuals with TBI and their families.

The interview guide also includes questions about states' experiences with the TBI Technical Assistance Center and with the HRSA TBI Program grant structure and processes. Each interview was approximately 40–50 minutes in length.

Stakeholders of the HRSA TBI Program interviewed for this study are represented by category in Figure E-1. Interviews were conducted with a total of 66 TBI stakeholders, including: national program directors (n=4), state brain injury associations (n=6), state injury prevention epidemiolo-

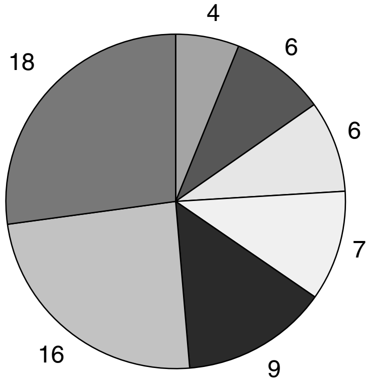

FIGURE E-1 TBI study respondents.

gists and staff (n=6), consumers with TBI or family members (n=7), state lead agency representatives (n=9), protection and advocacy systems staff (n=16), and others, including state agency and provider representatives (n=18).

STAKEHOLDER INTERVIEW SUMMARY AND KEY FINDINGS

I. TBI Grant History and Program Background

State TBI grantees differ widely with regard to availability of human and organizational resources, historical context, and political leadership and commitment to TBI—all factors that appear to be related to their abilities to leverage HRSA TBI Program funding for TBI services and systems coordination.

States with established, well-supported services and supports have been more successful leveraging HRSA funding than states with limited or no resources. States submitted grant applications to the HRSA TBI Program with different histories and resources for TBI services coordination and systems development. The HRSA grants to states have been competitively awarded since the first grant cycle in 1997. During the first 2 years of the HRSA TBI Program, Planning and Implementation grants were available as 1-year demonstration project awards. During these start-up years, as states and the HRSA Program gained experience with these grants, it became clear that longer funding cycles were needed to accomplish grant expectations. Funding availability for Planning grants was subsequently expanded to 2 years, and Implementation grant funding was expanded to 3 years. After reauthorization of the Federal TBI Program in 2000, Post-Demonstration grants were introduced and became available, as 1-year awards. The HRSA TBI grants to P&As were added and awarded as 1-year competitive grants in 2002. The following year, the P&A grants were changed to formula-based awards. In August 2005, the HRSA TBI Program introduced new, 3-year Partnership Implementation grants that replace HRSA's other TBI grant programs to states. Planning grants were $75,000 for up to 2 years, Implementation grants have averaged $250,000 over 3 years, and Post Demonstration grants have averaged $100,000 over 1 year. The P&A grants start at a base average of $50,000 per year. The new Partnership Implementation grants are limited to $100,000 per year for a 3-year period.

Grant histories for the seven study states are summarized in Table E-1, below.

California, Colorado, Georgia, and Washington State had none of HRSA's four core TBI Program components in place when they received their first grant awards. Colorado and Georgia reported previous, established programs for individuals with TBI in their states dating to the 1980s: Colorado's federally-funded Rocky Mountain Regional Brain Injury Center (RMRBIC) and the Georgia Department of Labor's comprehensive programs developed at Roosevelt Warm Springs Institute for Rehabilitation

TABLE E-1 HRSA TBI Grants Program History: State Award Years

Grant Type	Alabama	California	Colorado	Georgia	New Jersey	Ohio	Washington
Planning	—	1999, 2001	1999	1997	—	—	2000, 2001
Implementation	1997, 1998, 1999, 2000	—	2001, 2002, 2003	1998, 1999, 2000	1999, 2000, 2001	1998, 1999, 2000	2003, 2004, 2005
Post-Demonstration	2001, 2002, 2004	—	2004	2004	2002, 2003, 2004	2002, 2003, 2004	—
Protection and Advocacy	2002, 2003, 2004, 2005	2003, 2004, 2005	2002, 2003, 2004, 2005	2003, 2004, 2005	2002, 2003, 2004, 2005	2002, 2003, 2004, 2005	2002, 2003, 2004, 2005

and its Vocational Rehabilitation programs. California and Washington State also noted early efforts to address TBI through their states. California's Department of Mental Health established Caregiver Resource Centers and a TBI trust fund, in the 1980s. Washington State developed demonstration projects addressing the needs of individuals with TBI. Each of these states has also hosted TBI Model Systems,[1] funded by the National Institute on Disability and Rehabilitation Research (NIDRR). Colorado, Georgia and Washington State hosted Centers for Disease Control and Prevention (CDC) Core Injury Programs. Still, none of the four states had developed a sustainable TBI infrastructure.

Each of these states applied for Planning grants to develop the HRSA TBI Program's four core TBI program components. California applied for, but was not awarded, an Implementation grant. Washington is in its third year of its Implementation grant, and Colorado continued on to receive a Post-Demonstration grant after completing a 3-year Implementation grant.

Alabama, Ohio, and New Jersey were well under way with state efforts to coordinate services to individuals with TBI and their families when these states applied for HRSA grant funding. Alabama, which established its State Head Injury Program for adults in 1989 and designated its State Head Injury Task Force and a coordinator in 1990, applied for HRSA funding to expand its Interactive Community-Based Model for adults with TBI to create a children's system. Ohio applied to the HRSA TBI Program with an established Advisory Council in place. The state's collaboration with the Ohio Brain Injury Association led to development of a strategy to develop a comprehensive model service coordination continuum that would be expanded with HRSA funding. New Jersey had services with several state agencies, but did not have a coordinating group in state government. Preparing for its next grant application after two rejected attempts, the state moved to designate the Department of Human Services, Office of Disabilities as lead agency, as well as an interagency advisory board. New Jersey's first grant involved collaboration with an established partner, the Brain Injury Association of New Jersey. Alabama and Ohio had established CDC Core Injury Programs, and all three states hosted NIDRR-funded TBI Model Systems. All three states were served by Rehabilitation Services Administration grants for TBI Regional Centers, with those centers actually awarded to programs in Alabama and Ohio. The Rocky Mountain Regional Brain Injury Center mentioned above was also a TBI Regional Center.

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[1] Georgia's TBI Model System involving The Shepherd Center and Emory University is no longer operational.

II. HRSA TBI Grant Experience

The seven study states used diverse approaches and met with varied results implementing their HRSA TBI Program grants. Key findings are summarized below.

Planning Grants

> **HRSA's four core TBI program components—Lead Agency, Statewide TBI Advisory Board, Needs Assessment, and State Action Plan—have been embraced as helpful elements for coordination and collaboration around TBI at the state level.**

Although some states have shifted agency placement and contacts since their start-up Planning grants, there is general agreement that these four components are helpful for moving TBI services and systems change forward. States have conducted Needs and Resources Assessments and developed State Action Plans, and have used this information to guide TBI efforts for the HRSA grant, as required by the HRSA TBI Program.

1. Statewide TBI Advisory Board: *Requirement to develop or demonstrate the existence of a Statewide TBI Advisory Board within the appropriate health department of the state or within another department as designated by the state's chief executive officer. The Board's composition must include representatives of the involved state agencies; public and private nonprofit health-related organizations; disability advisory or planning groups; members of an organization or foundation representing individuals with TBI; state and local injury control programs if they exist; and a substantial number of individuals with TBI or their family members.*

The requirements for, and states' experiences developing, the four core components of the HRSA TBI Program are described in the following section.

The four states that established TBI statewide Advisory Boards after receiving HRSA grants—California, Colorado, Georgia, and Washington State—identified two critical elements to this activity: having membership of a manageable size and including the right people as representatives. Stakeholders in each state struggled with these elements in building and, in some cases, rebuilding a board.

One respondent who served as a member of Georgia's early Advisory

Board described it as *"unwieldy, with 50–60 members."* Another added, *"It's hard to work with a group that large . . . They tried to do too much."*

Georgia's Advisory Board held together through the state's Planning and Implementation grants, but disbanded after its Post-Demonstration grant request was denied. The state established a Brain and Spinal Cord Injury Trust Fund and Commission in 1998. The Commission has 14–15 members, including some members of the re-established TBI Advisory Board. The new board is much smaller and is reported to be more focused.

Washington State also started with a large Advisory Board that has since been pared down. One respondent describes the challenges as *"participation and coordination. People come and go. Forming a sustainable board was a challenge."* Defining its mission in the state was challenging, but important to the Board's coming together as a group.

"We were also asking ourselves, were we here for the Planning grant or another, broader mission? The planning group, our planning activities, gave the Advisory Board a focus."

In Colorado, where many key participants had established working relationships in the brain injury community predating the HRSA TBI Program, there were so many people who wanted to serve on the Advisory Board that people were turned away. This Board limited the number of participants from the start, facing the challenge of *"making sure we had the right people at the table."*

Establishing an Advisory Board in California was complicated by the diversity of members as well as the state's vast geography. One respondent described the Board as *"initially very divisive, there was no common goal. People came to the table with different agendas, the community was divided."* With help from a skilled consultant the group did come to consensus on a State Action Plan, working through its differences. However, the Advisory Board disbanded after the state's application for an Implementation grant was denied.

2. Lead Agency: *Designation of a state agency and a staff position responsible for coordination of state TBI activities.*

Finding the most appropriate fit for a state lead agency is a key issue for states in the early stages of developing their state TBI programs. The TBI Technical Assistance Center (TAC) reports that throughout the history of the HRSA TBI Program, lead agencies have been located in at least nine different state agencies, including Public Health, Human Services, Social Services, Medicaid, Rehabilitation Services, Mental Health, Developmental Disabilities, and Education.

States often change lead agencies in search of an appropriate "home" for TBI in state government. Placement of the lead agency is closely tied to the political and programmatic leadership, commitment, and focus of the state's TBI activities. Three of the four states that received Planning grants—California, Georgia, and Washington—changed lead agencies as they moved forward with their HRSA grants. California shifted its lead agency from Vocational Rehabilitation to the Department of Mental Health, although respondents in this state remain unclear why the agency remains in this location given the service needs of the state's TBI clients and families. In Washington State the Vocational Rehabilitation agency served as the lead agency for the first two HRSA grant years, then determined that TBI was not its mission. Aging and Adult Services *"agreed to take us on,"* recalled one respondent. The state TBI program is now with Aging and Disability Services, which state respondents observe is a better fit.

Georgia designated the State Health Planning Agency (SHPA) as the lead agency for its Planning and Implementation grants, but the agency did not have the capacity or commitment to move the program forward. Georgia's brain injury association urged the state to apply for a Post-Demonstration grant in 2002, and approached the Department of Community Health (DCH) to serve as lead agency. The application was denied. The DCH, which addressed numerous programs not related to TBI, approached the Brain and Spinal Injury Trust Fund Commission, a relatively young agency with a focus on TBI and asked the Commission to take over its role as lead agency in applying for a new Post-Demonstration grant. The Commission currently serves as Georgia's lead agency and has made considerable progress building a Central Registry with its HRSA grant.

3. Needs and Resources Assessment: *Statewide needs and resources assessment, with an emphasis on resources, completed or updated within the last five years, of the full spectrum of care and services from initial acute treatment through community reintegration for individuals of all ages having TBI.*

The four states that conducted Needs and Resources Assessments with their HRSA Planning grants did not have state-specific data about their states' TBI population and needs, and used different approaches to identify needs and resources to inform their programs. The HRSA TBI Program, through TBI TAC, provides a forum for states to share information about the methods they use, and allows states to select and develop their own approaches. Information from the assessments provides the basis for states to develop the State Action Plan required as part of the TBI Program core.

Approaches used by the four sample states that developed Needs and Resources Assessments for their Planning grants are included below.

- California used multiple methods to obtain information for their Needs and Resources Assessment, including provider and public assessments, public meetings, and extensive networking throughout the state.
- Washington State conducted two assessments: one for providers, and an Internet-based assessment for families. One stakeholder recalls, *"When DVR had this, there weren't clear parameters about how to do a Needs Assessment,"* suggesting that approved parameters for collecting information might help future grantees.
- Colorado's Needs and Resources Assessment included interviews with state agencies to determine their awareness of and involvement in TBI issues, and their perceptions of TBI needs and resources; in-depth interviews with providers; community forums; and printed questionnaires distributed to members of brain injury support groups.
- Georgia developed and distributed surveys, conducted regional town hall meetings, surveyed case managers, and hosted a statewide Stakeholders' Conference to determine concerns and service needs of TBI survivors and families.

4. TBI Statewide Action Plan: *Development of a Statewide Action Plan to develop a culturally competent, comprehensive, community-based system of care that encompasses physical, psychological, educational, vocational, and social aspects of TBI services and addresses the needs of individuals with TBI as well as family members.*

TBI State Action Plans required by the HRSA TBI Program reportedly vary in both format and length. A TBI TAC respondent noted that the plans are difficult to compare state by state: some plans are brief, one-page lists of key issues and activities; others are lengthy, detailed documents. Most State Action Plans draw on information obtained in the Needs and Resources Assessment, but states also use other sources of information and Advisory Board deliberations to target priority areas for TBI services and systems development.

The TBI TAC has worked with several states to help them achieve more focus in their State Action Plans. As a technical assistance activity, the most difficult aspect of the State Action Plan is *"getting grantees to understand the Action Plan is a living, breathing document,"* as a TBI TAC respondent observed.

Often, states must refine or revisit their planning as resources and conditions in the state change. California reportedly made great strides pulling together different constituents in developing its State Action Plan, resulting in *"a very democratic process . . . a very sensitive, comprehensive plan,"* but *"the bottom has dropped out without resources."* Washington State worked with TBI TAC after the state changed its lead agency, in an effort to refine the plan to a more manageable effort that was subsequently developed through the state's Implementation grant.

Implementation Grants

> **Implementation grants are sometimes seen as a vehicle to maintain a state's TBI infrastructure, and have been used to expand existing programs and initiate new projects, often by leveraging the state's resources with partner organizations.**

State respondents credit the HRSA TBI Program with providing the funding and political motivation to continue the focus on TBI through program and project development in areas not likely to be initially funded by the state. Partnerships with Brain Injury Associations, universities, and other organizations helped states leverage grant resources and professional expertise.

Six of the seven sample states received Implementation grants. These grants allow states to implement activities identified in their State Action Plans or other activities that address identified needs, to improve access for individuals with TBI and their families. Implementation grants were awarded for 1 year during the early years of the HRSA TBI Program. Following reauthorization of the TBI Act in 2000, these grants were extended to 3-year awards, a time frame seen as more appropriate to the scope of activities states addressed than the 1-year grants. One national respondent observed that states often *"struggled deciding what to choose"* as a focus of their Implementation grants, facing the need to maintain infrastructure as well as select from among many identified needs.

The sample states reported different experiences with their Implementation grants. California applied but was denied an award. A state respondent explained, *"HRSA felt we were biting off too much. One of the problems we had was, we had priorities identified and picked out . . . [Federal requirements] didn't fit well with the state's priorities. [The application] wasn't well put together when we tried to add on these requirements."*

Georgia applied for and received an Implementation grant after completing the four core components under its Planning grant. The state reportedly achieved only modest success completing tasks proposed under the grant, with an ambitious agenda, changes in states government, and difficulties pulling together the Lead Agency and Advisory Board. Georgia's TBI Advisory Board disbanded after the Implementation grant was completed. State respondents noted, "*there's not much to show*" for the grant.

New Jersey and Washington State involved strong partner organizations that enabled these states to leverage partners' resources to address grant objectives. New Jersey entered the HRSA TBI Program after two applications had been denied, establishing its core TBI Program components during this downtime. The state received HRSA funding for its third application, an Implementation grant to develop the Supporting Families in Crisis (SFC) program in close partnership with the state brain injury association. The SFC focused on educating families and providers about TBI-related resources, increasing the numbers of minorities and non-English speakers who access services, and increasing the identification of children with TBI in schools. Washington State developed a strong collaboration with its TBI Model System, which worked with the P&A and other state agencies to develop TBI Tool Kits, videoconferences, and other materials. The TBI Model System shared board membership with the state's TBI Advisory Board and was seen as *"a natural partner . . . The Model System was doing good work with telehealth [videoconferences and distance learning], so there were good opportunities to get involved."*

Alabama, Ohio, and Colorado used their grants to build on and expand existing plans for TBI services development. Alabama received Implementation grant funding to develop a statewide pediatric service delivery model, PASSAGES, as an expansion of the state's Interactive Community-Based Model for adults with TBI. Ohio did not receive funding for its first application, but was awarded funding for an Implementation grant the following year. Ohio's grant focused on developing four Community Support Networks (CSNs) to add to two CSNs already established as part of the state's comprehensive "Ohio Plan: Building Ramps to the Human Service System for People with Brain Injury." Colorado worked closely with its state brain injury association and other stakeholders to continue Colorado Information, Resource, Coordination, Linkage, and Education (CIRCLE) programs that convened providers and stakeholders for information sharing and referral. Other grant activities included increasing availability of information statewide, addressing the needs of children with TBI through development of a training manual (BrainSTARS) and training materials for parents and school personnel, and increasing awareness of state agency personnel about brain injury and to identify and change barriers to effective service coordination.

Post-Demonstration Grants

> **States found the 1-year award cycle and the $100,000 funding cap on Post-Demonstration grants to be too short a time, and too limited in support for meaningful TBI projects.** While some states were able to pilot projects that otherwise would not have been funded through the program, most respondents noted that these grants were difficult to develop and implement.

Post-Demonstration grants were added to the HRSA TBI Program following their authorization as part of the Children's Health Act of 2000. These grants have been available to allow states that have completed three years of implementation funding to support specific activities that will help build state TBI capacity. Of the seven sample states, Alabama, New Jersey, and Ohio received three Post-Demonstration grants; Colorado and Georgia received one Post-Demonstration grant; and California and Washington State have not received the grants. Table E-2 shows Post-Demonstration grant projects funded in these states.

TABLE E-2 Post-Demonstration Grant Projects Funded in Sample States

Alabama	2001: Identification, accommodation, referral of adolescents in schools to AL's Service Linkage Program 2002: Education and outreach to providers and the public about psychiatric disorders and TBI 2004: Education and outreach about domestic violence and TBI
New Jersey	2002: Outreach to inner-city minority neighborhoods 2003: Development of social, recreational supports for individuals with TBI, in partnership with faith-based, other community organizations 2004: Education and outreach to state staff of One-Stop vocational support centers
Ohio	2002: Enhancement of collaboration between Advisory Board and Brain Injury Association of OH, to increase participant buy-in 2003: Hospital-based education and work with families of individuals with TBI 2004: Hospital-based education and work with families of individuals with TBI
Colorado	2004: Expansion of CIRCLE networks, training for parents and school personnel regarding children and TBI, continued efforts to increase TBI awareness among state personnel
Georgia	2004: Development of a Central Registry infrastructure, provision of accurate data on TBI for use in state policy development, development of statewide resource database to improve resource access for individuals with TBI and families

Respondents in the five states that received Post-Demonstration grants noted that the grants had helped them develop TBI projects in new and underdeveloped areas—but most found it difficult to work within the grant's time frames and funding limits. Respondents commented,

> *"The Post-Demonstration grants we've seen as helpful but also frustrating. One hundred thousand dollars is not much. There's lots of preparation, paperwork putting together the application. It's very labor intensive, for not much in funding."*
>
> *"The biggest challenge is that the grant period is too short. Make them longer than 1 year, or make the grants so you can build on past efforts, not just develop new ones. In one year you can barely establish the right contacts. Many communities see projects come and go, and you need to build trust in approaching and working with them. It takes more than a year. Two year grants, even if less money, would be better."*
>
> *"We appreciate the one year monies, but it takes more than a year to do [a project]. You need to link with people and at the same time identify what the grant was about. The year passed quickly."*

Protection and Advocacy System Grants

> **All Protection and Advocacy Systems provided legal advocacy for individuals with TBI before initiation of the HRSA P&A grants, and all reported increased attention to this population with receipt of HRSA funding.** The P&As, like state grantees, vary in sophistication, capability, and capacity to serve individuals with TBI, and have directed their grant funding in different ways. The P&A stakeholders noted the importance of finding a balance between education and training within their own organization and in the community, and conducting individual advocacy to effect systems change. All P&As noted the challenges of addressing TBI with limited HRSA funding.

Protection and Advocacy system grants have been offered since 2002 to support states, territories, and the Native American Protection and Advocacy Project to assess their P&A systems' responsiveness to TBI issues and provide advocacy to support individuals with TBI and their families. While states' P&As are charged to keep watch over states' policies and programs affecting individuals with TBI and other disabilities, all seven P&As in the sample states reported working closely with the state TBI grant program. Georgia's P&A and state TBI program share an Advisory Board, and in Washington State, the state's TBI Advisory Board meetings are held at the P&A offices.

P&A respondents used their HRSA grants to *"raise the visibility of the P&A"* as a provider of advocacy for persons with TBI, and looked for ways to leverage limited funding, starting at $50,000, to achieve this goal. Respondents reported providing education, outreach, and training about TBI within their own organizations, in the provider community and the public. A Washington State respondent explained

> *"Systemically, TBI was a new focus for us. We had no TBI focus before, although the P&A, like all P&As, has served people with TBI. The grant allowed us this focus . . . We receive a small amount of funding from HRSA at the P&A, so we asked ourselves, how could we get the biggest bang for the buck? We decided to fold a TBI focus into our other work. I am also on many community councils, and I bring a TBI focus to these as well. We leverage the money to get the most out of it."*

Respondents at Ohio's P&A explained that, unlike most states' P&As, their organization came to the HRSA Program with a long history working with TBI, and has served on the Ohio Brain Injury Committee since before the HRSA grant. This P&A was able to move quickly, without a learning curve, when HRSA P&A grants became available.

> *"When we got P&A dollars, had we not already developed a focus on systems through the HRSA state grants, we couldn't have focused on children in special education . . . I can't imagine HRSA sending funding to a state that didn't have this background work in place, established. It takes years to understand the TBI population. We had the background, relationships, special education skills—so we were able to make things happen quickly, without having to learn the basics."*

The P&As in Colorado and Georgia used state assessments, planning documents, and other materials to help focus their P&A grants. Alabama's P&A also notes they have been *"involved from the outset"* with the state's TBI initiatives.

In California, where the state's TBI Advisory Board is currently inactive, the P&A's presence is of particular importance keeping some state attention on TBI. However, the P&A struggles to stretch funding with one dedicated TBI staff coordinating efforts for a 200-person organization across four regional offices.

> *"It's great that California got the Planning grant, but there was and is no infrastructure to sustain it. There was no one with 'juice' in the administration to keep it going . . .*
>
> *Successful states have high-level people in key positions to support TBI activity. It didn't happen in California . . . What we [P&A] are trying to do is take what we have—we have eight members on our TBI Board, including five TBI survivors/family. The P&A is also asking why California doesn't have a Medicaid waiver for TBI, to provide home and community care."*

III. TBI Service and Systems Coordination

> **States described a spectrum of service system coordination, collaboration, and fragmentation. Service coordination for individuals with TBI and their families often depends on program eligibility.** States recognize the need to coordinate TBI-related services at both the individual and the systems level—as well as the need to develop basic services to coordinate.

States in the study sample described various service delivery arrangements for individuals with TBI and their families. States described varying levels of service coordination to help people navigate service systems, system coordination, and interagency collaboration. States that entered the HRSA TBI Program with a history of collaboration and efforts to coordinate services prior to their involvement with HRSA were able to build on this foundation with their HRSA grants. Alabama described a statewide network for individuals with TBI that built on the state's Interactive Community-Based Model, a decentralized approach to provide community services integration in local communities first piloted in the early 1990s. Ohio also developed its TBI services networks from efforts in the 1990s to develop "The Ohio Plan," a model envisioning Community Support Networks in local areas, a statewide Helpline and Information Clearinghouse, and individualized resource facilitation services. Washington State, which used its HRSA funds to begin establishing a basic infrastructure for TBI, described fewer resources, services coordination limited to individual programs, and little or no systems coordination. State descriptions of TBI service and systems coordination are shown in Table E-3, below.

Medicaid Waivers

> **Medicaid programs in several states provide substantial support for individuals with TBI and their families through TBI-specific and generic waivers for home and community-based services.** As TBI becomes more visible among providers and communities, demand for waiver slots is reportedly increasing. Eligibility and availability of slots are common barriers to access.

Several states use Medicaid waivers to provide community-based services, rehabilitation, or long-term support for individuals with TBI. Colorado and New Jersey have established Medicaid waivers specifically for individuals with TBI. Georgia, Washington State, and Ohio provide services to individuals with TBI through Medicaid waivers for aged or disabled individuals for which they may qualify. *"Many states think waivers solve the problem,"* a national respondent stated, noting that *"Medicaid*

TABLE E-3 TBI Services and Systems Coordination in Study States

Alabama	AL has an established core service delivery network—the Interactive Community-Based Model (ICBM)—that uses care coordinators to help individuals with TBI and their families access services and supports across state agencies and organizations. The TBI registry is part of this system, allowing identification and followup of individuals who sustain TBI. The adult ICBM was first piloted in the early 1990s.
California	Services are formally coordinated through seven sites administered by the CA Department of Mental Health. The sites offer an umbrella of services and are listed on a state-sponsored web site. The sites serve limited numbers of clients; coordination does not occur outside these sites. Services are not provided for children. Little is known about the independent services used by individuals served outside these sites. The sites demonstrate diverse approaches to service delivery and coordination; two are hospital-based, while the other five are community-based.
Colorado	CO has an array of services for persons with TBI and their families, especially in the Denver area. CIRCLE networks established with the brain injury association operate regionally and allow local areas to identify and collaborate regarding needs and resources. Information and training statewide is conducted on issues including children and TBI. The state also provides some housing slots for persons with TBI. CO has a large Medicaid TBI/Acquired Brain Injury (ABI) waiver and a TBI Trust Fund that can be used for services support.
Georgia	Services are not currently coordinated across programs or agencies, and information about service availability in the state is lacking. Georgia is currently updating its Needs and Resources Assessment and State Action Plan to identify agencies and services needed and available to serve persons with TBI and their families, and opportunities that may exist for coordination.
New Jersey	NJ's TBI-related services operate through informal collaboration and are not formally coordinated. When services are coordinated, it is through a specific program, e.g., Medicaid, which includes case management as part of the Medicaid TBI waiver. State services are available through generic disability programs.
Ohio	OH uses the Community Services Network (CSN) model outlined in "The Ohio Plan" to coordinate services for persons with TBI and their families in four service areas where CSNs have been established. Other areas of the state are not served by the CSNs. A statewide database for information and referral is available to facilitate service access. There is no single point of entry. Service coordination is reportedly "haphazard," depending on which agency provides service, what benefits are provided, which door one comes through. Generic Medicaid waivers are available for individuals with TBI who meet eligibility requirements.

TABLE E-3 Continued

Washington	Many people reportedly receive in-home services in WA. The Seattle area is location to a cluster of facilities with services for persons with TBI, including University of Washington's Harborview Hospital, but Seattle-based services are not readily accessible to the state's rural residents. Community-based services are difficult to access in urban and rural areas. There is no coordination of services unless an individual is enrolled as a participant in a specific program that offers case management or related services.

waivers serve small numbers." A summary of Medicaid waiver programs in study states in shown in Table E-4, below.

Colorado respondents noted increased demand for TBI waiver slots as TBI has increased its visibility as an issue. Whether and to what extent the HRSA grant may contribute to this increase is not clear. One state respondent reported, *"In FY1997/98, at the beginning of the waiver, we had 143 clients. For FY 2003/04 we have 366 clients reported. Waiver costs increased from $1.46 million to $8.89 million [from FY1997/98 to FY2003/04] . . . I don't really know why. I can't say one way or the other if it is related to the HRSA grant."*

The P&As in states with Medicaid waivers reported that their cases involving persons with TBI often addressed availability and access to state

TABLE E-4 Medicaid Waivers Serving Individuals with TBI in Study States

State	Year Established	Amount	Description
Colorado	1995	$5.2 million	
Georgia			GA does not have a TBI-specific waiver, but 30 slots in the Independent Care waiver are set aside for persons with TBI.
New Jersey	1993	$14.6 million	
Ohio			Medicaid waivers can be used for eligible persons with TBI.
Washington			Persons with TBI can use the state's Aging and Disabilities waiver, based on functional abilities rather than diagnosis.

waivers. In Ohio, the P&A developed a model waiver and has played a key role advising the state on related issues.

TBI Trust Funds

> **Trust Funds are seen as an effective way for states to access funds for TBI services. The substantial resources marshaled through these vehicles can provide strong leverage for TBI services and systems.** Study states have TBI trust funds that direct funding for individuals, program support, or both. Stakeholders in trust fund states emphasized the importance of these funds for supporting their TBI-related efforts.

Five of the sample states—Alabama, California, Colorado, Georgia, and New Jersey—have established TBI trust funds using penalties or surcharges on traffic violations. These trust funds generate annual funds ranging from $1.1 million in California to $3.4 million in New Jersey. Three of the funds predate the state's involvement with the HRSA Program. Colorado and New Jersey established their funds during participation in the HRSA Program. A summary of TBI trust funds in sample states is shown in Table E-5, below.

Some states used trust fund dollars to expand or sustain initiatives identified and implemented with HRSA grant funding; others targeted funds to support services for individuals. In New Jersey, trust fund dollars administered by the Division of Disability Services were used to continue mentor and training programs developed with HRSA funding. Alabama also used trust fund dollars to continue care coordination activities developed for its HRSA-funded children's program. Georgia's trust fund is administered by the Brain and Spinal Cord Injury Trust Fund Commission, which oversees development of the state's Central Registry and provides support for services to individuals, to a cap of $5,000 annually per recipient.

Trust funds can be a powerful tool to help states support their TBI programs and services, but not all states are able to establish them. *"Many stars need to align"* for a state to establish a trust fund, observed a national respondent, *"and the politics are complex."*

TBI "Special" Populations

> **Respondents in every state named TBI populations that were difficult to reach and serve.** These populations include cultural and ethnic minorities, non-English speakers, rural residents, and individuals with coma or neurobehavioral conditions.

TABLE E-5 TBI Trust Funds in Study States

State	Year Established	Amount	Description
Alabama	1993	$1.2 million	The Impaired Driver's Trust Fund is supported through fines on DUI convictions @ $100 per conviction. A portion of the revenues is used to support the TBI registry; remaining funds provide direct or purchased services. The fund supported information and referral for 678 individuals, and services for 1,359 individuals.
California	1988	$1.1 million	The TBI Trust Fund is supported by 66% of State Penalty Fund revenues from vehicle code violations. Approximately $950,000 was used to provide services to 622 persons in FY2001; a portion was used for personnel costs and evaluations. Another portion was used to draw down $620,000 in federal vocational rehabilitation funds, serving 30 persons.
Colorado	2002	$2.5 million	The TBI trust fund legislation imposes $10 and $15 surcharges for certain traffic convictions, requires 5% of funds be used to educate parents, educators, non-medical professionals in identifying TBI and assisting persons to seek proper medical care; 65% for services; 30% for research to promote understanding and treatment of TBI.
Georgia	1998	$2.3 million	The Brain and Spinal Cord Injury Trust Fund is supported by a 10% surcharge on fines for driving under the influence (DUI). The commission distributes just over $2 million per year to individuals with TBI in awards of up to $5,000 per person.
New Jersey	2002	$3.4 million	The TBI Trust Fund was established by statute and is funded by a $.50 surcharge on motor vehicle registrations. Funds can be used for services or program support.

States and P&A respondents identified several subgroups of the TBI population as difficult to reach and serve. Cultural and ethnic minorities of all backgrounds, non-English speakers, and rural residents were named most frequently, followed by individuals with coma or neurobehavioral conditions, who typically reside in institutions. Respondents in Washington

State and Colorado also identified Native Americans in their states among those difficult to reach and serve.

Both states and P&As have initiated activities to reach out to these populations, with varying success. All respondents agreed that the needs are great and often unknown in these under-represented groups.

New Jersey undertook efforts to develop social and recreational supports in minority neighborhoods in the Camden area as a followup to its first Post-Demonstration grant. Respondents from the state and its partner brain injury association soon agreed that establishing community relationships in these neighborhoods involved more time—and trust—than they anticipated. One respondent recalled, *"We found recreation was not a priority for the partners, the churches in Camden . . . programs like food pantries, shelters . . . were important to them."* The project re-designed its objectives, working through local churches.

In Alabama, a state respondent identified Spanish speakers from Mexico as a population in need of special outreach, but also recognized the challenges of reaching out to this group. This respondent commented that efforts to increase consumer involvement in the state's minority communities have been difficult, even among native English speakers, noting that *"[the state program] has not had as much consumer involvement from the African American population"* as they'd like.

Services Difficult to Access for Individuals and Families with TBI

> **Despite differences in states' TBI infrastructure and resources, respondents in every state named services that are difficult for individuals with TBI and their families to access.** Respondents named housing, vocational services, and services for individuals with neurobehavioral disorders most frequently as difficult to access services.

Services not covered by public and private insurance, including non-medical social and post-rehabilitation community support, were mentioned most frequently as services difficult for individuals and families with TBI to access. In addition to housing, vocational services, and neurobehavioral healthcare, respondents listed transportation, service coordination, and access to waiver slots as difficult to access services. One family member spoke to the needs of family caregivers, and placed hiring adult sitters and day care at the top of her list:

"Hiring sitters is the hardest thing. It is not covered by insurance. All of us who are caregivers need help with this. [My son] goes to Adult Day Care at the YMCA, and he's there with people who are developmentally

disabled . . . his dad and I both work . . . He's never alone, I can't leave him by himself."

Another consumer respondent emphasized the importance of insurance coverage in providing service access for persons with TBI and their family members, noting, *"Medicaid provides options, private pay does . . . but others have a hard time."*

IV. TBI Data, Monitoring, and Evaluation

> **Data about TBI and TBI-related services in the study states are limited. Some state agencies collect data and track service utilization among individuals with TBI, but none of the study states reported comprehensive, cross-agency data monitoring. Several study states have established registries, which vary in scope and application, and some have conducted TBI surveillance with grant support from CDC.** Respondents named lack of funding and expertise for data activities, as well as the challenges of how to monitor services and outcomes as obstacles to data-related activities.

TBI Data Collection in Study States

Registries and surveillance systems are the primary sources of TBI data in most states. Typically, injury prevention professionals in state health departments maintain and report these data, and report summary findings to state TBI Advisory Boards. States that do not conduct TBI surveillance rely on national estimates prepared by CDC.

Registries and surveillance systems vary widely across states. According to an injury prevention specialist in one sample state, there is much confusion in the field about *"what constitutes a 'Registry' and a 'Surveillance System,'"* and the terms are often used interchangeably. This respondent explained, *"Registries usually have contact information . . . Surveillance is usually a data system without contact information, and is used to identify risk factors."*

In practice, not all registries are used to contact individuals, and the quality and comprehensiveness of state survey data are not uniform across states.

Registries. Three of the seven study states—Alabama, Georgia, and Washington State—have established TBI registries, and a fourth state, New Jersey, is involved in efforts to create a combined TBI/Spinal Cord Injury

(SCI) registry. These registries were developed using different approaches and are used in various ways.

- Alabama's registry was established with the passage of the Alabama Head Injury and Spinal Cord Injury Registry Act in 1998, which requires hospitals to submit their data to the state. While respondents provided differing assessments about the comprehensiveness of the registry data, state TBI program staff report having successfully integrated the registry as part of Alabama's TBI services system, enabling followup of newly identified TBI cases.
- Georgia established its Central Registry for spinal cord injury in 1981, and expanded the Registry to include TBI in 1985. Expansion of the Central Registry has been the focus of the state's 2004 Post-Demonstration grant under the leadership of Georgia's Brain and Spinal Cord Injury Trust Fund Commission.
- Washington State maintains a TBI registry but does not conduct follow up of individuals.
- New Jersey stakeholders have been working for the past two years with the state's Center for Health Statistics to develop registries for TBI and spinal cord injury. The registries were brought to life by the Christopher Reeve Foundation and the father of a TBI survivor.

Surveillance. Four of the study states—Alabama, California, Colorado, and New Jersey—have conducted TBI surveillance with funding from the CDC; of these, only Colorado has received CDC funding for the current grant cycle. States use TBI surveillance data, which typically combines death certificate and hospital discharge data, to monitor trends and target prevention efforts. While this information can provide a basis for prevention-related public health monitoring, its utility is limited for services planning. One respondent explained, "*[The TBI surveillance system] captures incidence, or new injuries, which makes sense when the purpose is primary prevention. What service providers really want is point prevalence, that is, how many people live in the state who have had a TBI ever, and currently have a need for services?*"

There are a couple of ways to estimate prevalence, this respondent noted: "*Some use incidence data as the starting point . . . However, to use incidence data one needs to know the life expectancy of people with TBI at various ages and gender and the probability of ongoing disability related to the TBI—or some other measure or definition of 'need for services' for various age groups and gender . . .*"

Other data collection. Several issues complicate states' TBI data collection, monitoring, and evaluation efforts. Lack of knowledge about TBI outcomes and service use and difficulties obtaining funding to sustaining data collection efforts are among respondents' top concerns. Respondents commented:

> *"We don't know a lot about outcomes regarding TBI. Do outcomes vary by ICD-9 code? Who are we designing services for? Different outcomes occur across the severity of TBI."*
>
> *"We're not good at measuring outcomes, mild TBIs, or projecting who will need what types of services. We don't have good ways to measure information regarding TBI."*
>
> *"Funding [for data collection and analysis] from several [federal] sources is drying up . . . we are constantly looking for grants."*
>
> *"We scramble to get money together [for data collection and analysis] from wherever we can. They [federal and state government] keep cutting us."*
>
> *"I'm not certain of the role of epidemiology in TBI systems change. Data alone do not create change . . . individuals make change. Data don't take into account of values or politics."*

TBI Data Activities in Protection and Advocacy Organizations

> **The P&As reported variable capabilities for data collection to document and track their TBI activities.** Some organizations have licensed a data system developed by their national association; others use in-house tracking systems.

The P&As in the study sample recognized the challenges associated with identifying and tracking their TBI cases, as individuals with TBI approaching the P&As may be advised by phone, or seen in different established programs of their organizations. Anecdotally, all of the seven state P&As stated that individuals with TBI were now more visible as a result of the HRSA P&A grants.

Colorado's P&A, visited during a study site visit, was able to produce data demonstrating an increase in identified TBI cases addressed at the organization. The Colorado P&A uses an in-house tracking system, but plans to join the more than 40 state P&As that use the Disability Advocacy Database (DAD) operated and maintained by the National Disability Rights Network (NDRN, formerly the National Association of Protection and Advocacy Systems).

Alabama's P&A currently uses DAD. A P&A respondent explained, *"I can ask for information on projects and cases easily. DAD is our whole record-keeping system. It includes information obtained at the phone in-*

take, demographics, and the type of inquiry. It also includes the attorney notes."

National leaders including the Executive Director of the P&A association are working to identify measures for TBI and disability advocacy that can be used by P&As nationwide through DAD.

TBI Program and Systems Evaluation

> **Few states are conducting evaluation of their TBI programs or efforts to achieve systems change.** Several stakeholders called for information on "what works and what doesn't" and suggested that HRSA establish measures against which they could assess progress achieving systems change. Stakeholders requested technical support for evaluation. Also, interest was expressed in obtaining clinical information about service needs and outcomes throughout the lifecycle of individuals with TBI.

The HRSA TBI Program guidance includes a requirement that grantees evaluate their efforts. All grantees conduct some form of evaluation, but states' capabilities and resources for evaluation differ widely. States' evaluation activities range from basic monitoring of project task completion; to conducting process evaluations of conferences, training sessions, and products; to program impact and effectiveness studies. Both state and P&A respondents expressed interest in understanding "what works and what doesn't" as they develop their programs, but most states have not conducted this type of evaluation. Only one of the sample states, Colorado, included a developed evaluation component that examines the systemic effects of the grant-funded projects.

State respondents expressed frustration at their inability to evaluate and assess their TBI programs, citing lack of staff with skills in data analysis and evaluation, and problems understanding what and how to measure changes. A respondent in a state with mature infrastructure in place stated that, even with available data, their evaluation efforts were lacking. This respondent commented, *"Evaluation is the area I'm least satisfied with and feel we need improvement. We need personnel. We have a great data system, but we don't have anyone to pull it together. I'd love to have a data person, even if just 6 months to a year, to do this."*

New Jersey and Colorado have placed a greater focus on research and evaluation than have other study states. New Jersey established a TBI Research Fund in 2004, spearheaded by the father of a son with a head injury. The Fund is supported by a surcharge on motor vehicle registrations. Colorado directs a portion of its TBI trust fund, initiated by a university-based researcher with interest in TBI, to research, including evaluation. Colorado has also engaged two evaluators to assess the state's Implementation grant activities. The evaluators also serve as program consultants, sharing results with the state and its TBI Advisory Board.

A national respondent reported that a subgroup of grantees and the federal program have started meeting to discuss evaluation issues and possible measures. The group is exploring the question, "*What do you need to evaluate to tell you what you need to know?*" The group expects to identify key system outcomes for the TBI Program.

V. TBI Technical Assistance Center

> **The TBI Technical Assistance Center (TBI TAC) plays a major role facilitating information sharing among state grantees and, to a lesser extent, P&As.** State grantees and P&As provided strong praise for the assistance, support, and information across states available through TBI TAC. All states provided examples of how they were able to avoid "reinventing the wheel" by contacting the TBI TAC or other grantees of the program for brochures, training materials, and general advice. The annual grantee meeting and the list serv received high marks. The P&As also rated TBI TAC highly, but noted they receive information primarily through the national P&A association.

The HRSA TBI Program supports TBI TAC through a contract with the National Association of State Head Injury Administrators (NASHIA). TBI TAC was established to help states in the planning and development of effective programs that improve access to health and other services for individuals with TBI and their families. TBI TAC staff specialists provide states with a range of technical assistance offerings, including: annual grantee meetings, a web-based Collaborative Space to share documents and other information, a grantee list serv, individualized site visits, and others. TBI TAC also develops and disseminates a variety of specialized documents and initiatives for HRSA's TBI Program. TBI TAC serves all HRSA TBI Program grantees. Brain injury organizations and individuals with interests in TBI services can request access to the TBI TAC web site.

Twenty-five respondents provided information about their use of TBI TAC. Respondents' use of specific services by type is shown in Figure E-2, below. The most frequently used services include the TBI TAC grantee list serv and the Annual Grantee meeting, named by 21 and 20 respondents, respectively.

TBI TAC services received above average ratings from these users. Twelve of 24 respondents rated the TBI TAC offerings as "excellent," five

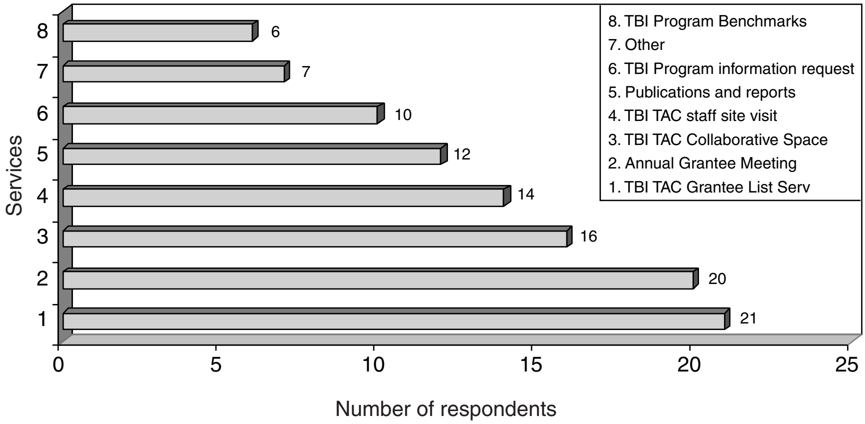

FIGURE E-2 Respondents' use of specific services, by type.

respondents rated TBI TAC as "very good," and seven rated it as "good." No respondents rated the services as average, fair, or poor. (See Figure E-3.)

> **Two stakeholders representing national organizations questioned the appropriateness of the amount of funding directed to the TBI TAC in the context of overall HRSA TBI Program funding, and whether or to what extent the TBI TAC should provide non-technical assistance program administrative support to the HRSA TBI Program.** State respondents were not always clear about roles and relationships between HRSA and TBI TAC for program administration.

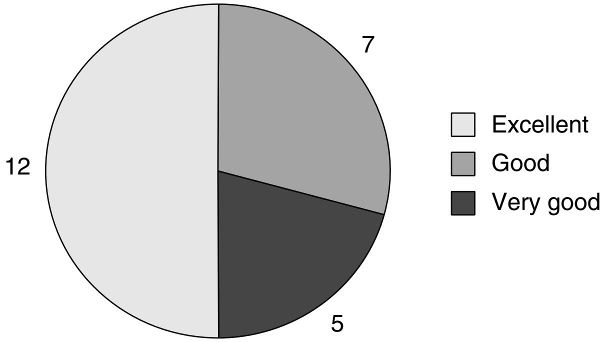

FIGURE E-3 TBI TAC user ratings.

While states praised the services provided by the TBI TAC, one national stakeholder raised concerns about the level of resources provided to the TBI TAC. This respondent noted that the TBI TAC receives a generous portion of HRSA's TBI Program appropriation[2] compared with the limited funding provided to states and the P&As, stating . . . *"It's the elephant in the living room. Do we really need to be spending this much on the TBI TAC?"*

Another respondent raised questions about role clarity and potential conflicts of interest involving the TBI TAC and the HRSA TBI Program, commenting: *"The TBI TAC is in a difficult position. They are the TA Center, but also grant staff for HRSA. It is a conflicting role. It creates a situation where people in states can feel they're being spied on . . . The same people there to help them are the ones asking for their grantee reports. It's too much to expect, it leads to a conflict. Some people resent it."*

The HRSA TBI Program Director as well as the TBI TAC Director both recognized and appreciated the dilemma and the necessity of this close relationship—and the importance of drawing a clear line between official government responsibilities that remain with HRSA, and administrative responsibilities that can be delegated to the TBI TAC. The relationship is especially significant given program staffing and resource limitations at HRSA. One respondent suggested that dedicated staff could be housed at NASHIA or another organization outside government, maintaining a separation of the technical assistance and program administration functions of the TBI TAC.

VI. HRSA TBI Program Grantee Experience

The HRSA TBI Program is administered by HRSA's Bureau of Maternal and Child Health, with program oversight provided by a Public Health Services Commission Corps Program Director. The TBI Program has had four Program Directors since it was established in the Bureau in 1997. The current TBI Program Director does not have staff, and noted the challenges of overseeing several types of state grants and P&A grants, as well as providing contract oversight of the TBI TAC and other administrative activities relating to the TBI Program. The TBI Program Director currently delegates some program support activities to the TBI TAC, but retains program authority and responsibility on behalf of the government.

State and P&A stakeholders were asked to comment on their experiences with the HRSA TBI Program. Respondents were asked to name ben-

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[2] HRSA's TBI Program funding (FY2005) was distributed in the following approximate amounts: State Infrastructure grants, $5 million; Protection and Advocacy grants, $3 million; TBI TAC, $1 million.

efits and drawbacks of their states' participation. Respondents were also asked to provide comments and suggestions for program improvement. Stakeholders' responses are summarized below.

Benefits of the HRSA Grant Program

> **Stakeholders credited the HRSA TBI Program with several types of benefits in their states.** State grantees and P&As noted that HRSA funding has increased the visibility of TBI and related issues among state agencies, providers, and the public as a valuable benefit of the HRSA grant funding. These respondents also named TBI-specific funding for inter-organizational activities and funding for TBI-specific projects and materials as benefits.

Both state grantees and P&As reported that HRSA funding, while limited, was valuable to "jump start" TBI-related activities in their states. The ability to focus on TBI and increased visibility of TBI as an issue were mentioned most frequently as benefits, followed by specific activities and materials developed with HRSA funding. Stakeholders in states with TBI trust funds noted that the HRSA Program helped the state prioritize fund expenditures. Respondents commented

> *"The HRSA grant stimulated the state to look at the whole system. The benefit was having money for an unrecognized population."*
>
> *"The biggest thing the grant has done is to bring attention to TBI. The grant helped to identify issues, the Trust Fund paid for services."*
>
> *"TBI-specific funding, products. In state government we have a real lot on our plates. This allows us to focus on TBI."*

Drawbacks of the HRSA Grant Program

> **State grantees were appreciative of the funding obtained through the HRSA Federal TBI Program, and noted that even small amounts of funding could be effectively leveraged to raise visibility and awareness of TBI. However, many reported that 1-year grants, e.g., Post-Demonstration grants at the $100,000 level, provided insufficient time and resources to impact systems change goals.** Stakeholders frequently shared their frustrations at the time consuming preparation required for limited funding, and problems sustaining funding. Stakeholders also commented that building relationships and trust at the community level is required for real systems change, and often requires more than a 1-year time-

> commitment. Many called out for formula funding, on a regular schedule to allow program continuity.

Study respondents named issues related to the structure of the HRSA grant program—lack of sustainable funding, competitive grant applications, limited and restricted funding—as the top drawbacks to participation in the HRSA TBI Program. Respondents commented,

> *"What has turned states off are limited competitive one-year grants. They're not worth the trouble."*
>
> *"Sustainability and having to write a new grant every year is difficult and time consuming. Also, it was difficult to come up with new projects for one year at $100,000."*
>
> *"Limited funding. The amount of money is small for P&As, not enough for a dedicated staff member. I'd love a TBI specialist who also provides advocacy. That's one thing that has held us back. But it also means we all have to learn about TBI in the P&A—we can't say it's someone else's responsibility."*
>
> *"One of the things that kept limiting us was we couldn't do anything about services. If there could be a pilot for service delivery it would be great!"*

Other HRSA TBI Program Considerations

> **The HRSA TBI Program has served as a catalyst for a host of TBI-related activities in the study states, including programs and projects funded by HRSA and others funded independently. However, sustaining state infrastructure and project activities in the absence of HRSA or other funding continues to challenge grantees.** Many states reported direct and spillover impacts—and many question how they can continue to support these efforts.

Spillover effects. The HRSA grants have demonstrated both direct and spillover impacts, especially when funding is skillfully leveraged. State and P&A respondents were able to point to direct impacts of the HRSA grant funding, including increased visibility and awareness of TBI, as well as spillover impacts that occurred "as a consequence but not as a direct result" of grant funding.

Respondents provided many examples of TBI-related activities and initiatives undertaken in their states that occurred because awareness of TBI was heightened in multiple spheres of state government, the non-profit and private sectors, and the advocacy community. These include program expansions, trust fund development, and other activities. Some examples include:

- New Jersey developed the core components of its state TBI program *in anticipation of* the state's receiving their first HRSA grant award. New Jersey's TBI Trust Fund and TBI Research Fund were developed through efforts initiated without HRSA funding, but were reportedly developed as TBI gained new visibility as a result of HRSA-funded grant activities.
- Colorado's CIRCLE programs, established to facilitate information sharing about TBI service needs and availability at the community level, were continued through volunteer efforts when HRSA funding was no longer available. State respondents noted that these successful meetings have been embraced by local stakeholders, and have developed a momentum of their own.

Sustaining program components and infrastructure. Respondents named sustainability of program components as a significant challenge to maintaining program infrastructure established under the HRSA TBI Program. Stakeholders in nearly every state named sustainability of TBI programs developed under the HRSA grant program as a great challenge. States with access to trust fund dollars were sometimes able to continue successful programs and trainings. However, states with limited resources may be unable to continue the momentum of program activity beyond the grant period. Additionally, irregular funding cycles and the uncertainty of competitive grant awards create difficulties for staff retention as well as program sustainability in general.

Looking to the Future

Stakeholders commented on program improvements and reforms in several areas, revealing consistent themes across respondents in the seven study states. Respondents gave positive marks to the flexibility of the HRSA TBI Program in allowing grantees to address issues relevant to their state TBI programs. At the same time, respondents called for more structure and information about state program and service effectiveness in improving outcomes for individuals with TBI and their families. One stakeholder stated, "*We'd love to see the program go to a more mature level . . . How to promote the best outcomes . . .*"

Respondents also directed comments to changes in the grant program application process, funding levels, and time frames. The P&As currently receive formula funding for their TBI applications, and states are calling for the same, including discretionary support and mechanisms to help sustain their TBI programs.

Some example comments include:

> *"We are glad the TBI program is there, grateful for funding and support. Would like more discussion on focused issues. And more sophisticated, targeted advice."*
>
> *"There should be less emphasis on processes, work more on something universally acceptable. Take the best that works and package it. Share these with other states, hospitals. There MUST be common practices that work! Evaluate them and package them."*
>
> *"Continue the system as it is, with more centralized control in the Lead Agency. We need more support for statistics, research, to more accurately target dollars . . . number crunching capabilities . . . and more money!"*
>
> *"Being able to integrate state efforts to a basic level would help . . ."*
>
> *"Somehow, local work has to be integrated with state policy change. They need to be pulled together. There needs to be articulation of how the state system overlays [and how the trust fund fits in]."*
>
> *"We need to educate people . . . Could HRSA develop things about services, needs across the lifespan of people with TBI? Different strategies as the person ages? So people know what comes with TBI . . ."*
>
> *"The main thing is time for the grants and the irregularity of funding. It impacts our ability to get and keep staff."*
>
> *"When it's time to do the grant proposals, the HRSA proposals require more narrative than others we typically do. I'd suggest simplified paperwork for the formula funds."*

States' suggestions to move to a new structure for state grants have already been addressed. In August 2005 HRSA released its new program guidance, which provides support for 3-year "Partnership Implementation" grants. Seen as a step closer to the formula grant approach, which must be legislatively authorized, the Partnership Implementation grants "meet states where they are." The new grants replace the Planning, Implementation, and Post-Demonstration grants previously available and, while the new grants will be competitively awarded, they are available to all states and territories.

APPENDIX F

Glossary, Abbreviations, and Acronyms

GLOSSARY OF TERMS

Activities of Daily Living (ADLs): Basic personal activities such as bathing, eating, dressing, mobility, transferring from bed to chair, and using the toilet.

Brain Injury Association of America: A nonprofit organization working on behalf of individuals with brain injury and their families.

Children's Health Act of 2000 (P.L. 106-310): A federal law passed by Congress that included several provisions related to children's health, as well as Title XIII, which reauthorized the grant programs established under the Traumatic Brain Injury Act of 1996 (P.L. 104-166). In addition, the act authorized HRSA to award Protection and Advocacy Grants for TBI to federally mandated protection and advocacy (P&A) systems in the states, territories, and the District of Columbia to bolster their P&A services for individuals with TBI and their families.

Core components of a state's TBI infrastructure: Under the HRSA TBI Program, the four core components of a TBI infrastructure are the following: (1) a *statewide TBI advisory board* charged with advising and making recommendations on ways to improve coordination of TBI services; (2) a *lead state agency for TBI* responsible for coordination of state TBI activities; (3) a *statewide assessment of TBI needs and resources* completed or updated within the last 5 years and including the full spectrum of care and services from initial acute treatment through community reintegration for individuals of all ages having TBI; and

(4) a *statewide TBI action plan* to provide a culturally competent, comprehensive, community-based system of care that encompasses physical, psychological, educational, vocational, and social aspects of TBI services and addresses the needs of individuals with TBI, as well as family members.

Defense and Veterans Brain Injury Center (DVBIC): A partnership of the Department of Defense, the Department of Veterans Affairs health care system, and a civilian partner that includes seven clinical care and surgery sites and conducts clinical research on brain injury. When founded in 1992, it was known as the Defense and Veterans Brain Injury Program.

Health Resources and Services Administration (HRSA): A federal agency, within the U.S. Department of Health and Human Resources, that is charged with providing access to health care for the medically underserved. HRSA operates five bureaus including the Maternal and Child Health Bureau, Bureau of Primary Health Care, Bureau of Health Professions, Healthcare Systems Bureau, and HIV/AIDS Bureau, as well as 11 special offices. HRSA's Maternal and Child Health Bureau administers the HRSA TBI Program.

HRSA TBI Program: A federal grant program administered by HRSA's Maternal and Child Health Bureau. The HRSA TBI Program includes two state-based grant programs intended to improve access to health care and other services for individuals with TBI and their families: (1) ***the TBI State Grants Program***, and (2) ***the Protection and Advocacy for TBI (PATBI) Program*** (see below).

Implementation Grants: One of three types of state grants that have been awarded to states, territories, and the District of Columbia under the HRSA TBI State Grants Program. Implementation Grants funded various TBI program implementation activities, including the implementation of a state's TBI action plan, programs to address identified needs of TBI survivors and their families, and initiatives to improve access to services for TBI survivors and their families.

Medicaid head and spinal cord (HASC) injury waiver: A type of Medicaid home and community-based services waiver to provide services to individuals with TBI, spinal cord injury, or a similar disability.

Medicaid home and community-based services (HCBS) waiver: A Medicaid waiver that allows a state to waive Medicaid provisions in order to allow long-term care services to be delivered in community settings; it is the Medicaid alternative to providing comprehensive long-term services in institutional settings. This allows a state to provide additional services to Medicaid beneficiaries with TBI (e.g., case management, respite care, life-skills training) through a waiver program.

Medicaid mental retardation and developmental disabilities waiver: A Medicaid waiver that is part of the Medicaid home and community-based waiver program; this waiver allows a state to waive Medicaid provisions in order to provide services to individuals with developmental disabilities, including TBI, incurred before the age of 22.

National Association of State Head Injury Administrators (NASHIA): The national membership association for state TBI program officials and other individuals concerned with state and federal brain injury policy.

National Disability Rights Network (NDRN): A voluntary national membership association of protection and advocacy systems and client assistance programs. NDRN is formally known as the National Association of Protection and Advocacy Systems (NAPAS).

Olmstead decision: On June 22, 1999, the U.S. Supreme Court held in *Olmstead v. L.C.* that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The court ruled that the Americans with Disabilities Act may require states to provide community-based services rather than institutional placements for individuals with disabilities. Many states now implement Olmstead plans, which provide community-based services for individuals with disabilities in accordance with the Olmstead ruling.

P&A system: Under the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. 6012), each state seeking a federal grant for P&A services for individuals with developmental disabilities must establish a P&A system independent of service-providing agencies to empower, protect, and advocate on behalf of persons with developmental disabilities.

PATBI Grant Program: A grant program authorized by the Children's Health Act of 2000 that is one of two grant programs that make up the HRSA TBI Program (see above). Under this program, HRSA awards PATBI Grants to federally mandated P&A systems in states, territories, and the District of Columbia to bolster their P&A services for people with TBI and their families.

Planning Grants: One of three types of grants that have been awarded to states, territories, and the District of Columbia under the TBI State Grants Program. Planning Grants were used to establish the four core components of a TBI system infrastructure—namely, a statewide TBI advisory board, a lead state agency for TBI, a needs/resources assessment, and a statewide TBI action plan.

Post-Demonstration Grants: One of three types of grants that have been awarded to states, territories, and the District of Columbia under the TBI State Grants Program. Post-Demonstration Grants were awarded to help states or other entities that have satisfactorily completed an

Implementation Grant further their efforts to build TBI service capacity.

Supported employment: The provision of ongoing support from an external source (e.g., a community rehabilitation provider or state agency) to an individual in a paid, community-based employment setting where the majority of workers do not have disabilities.

TBI Model Systems: A research initiative, administered by the National Institute on Disability and Rehabilitation Research (NIDDR), with the objective of studying the course of brain injury recovery and outcomes following the delivery of a coordinated system of emergency care, acute neurotrauma management, comprehensive inpatient rehabilitation, and long-term interdisciplinary followup services. The 16 TBI Model Systems of Care sites throughout the country are Birmingham (Alabama), San Jose (California), Englewood (Colorado), Boston, Detroit, Rochester (Minnesota), Jackson (Mississippi), Edison (New Jersey), New York City, Charlotte, Columbus, Philadelphia, Pittsburgh, Dallas, Richmond, and Seattle.

TBI State Grants Program: A program authorized by the Federal Traumatic Brain Injury Act of 1996, and later reauthorized in the Children's Health Act of 2000, that is one of two programs in the HRSA TBI Program (see above). Under this program, HRSA awards grants to states, territories, and the District of Columbia to help them improve their TBI infrastructure and state-level capacity for meeting the post-acute needs of persons with TBI.

TBI State Program Grants: Federal grants awarded by HRSA under the TBI State Grants Program (see TBI State Grants Program).

TBI Trust Funds: Funds that are established in a state from fines or other fees imposed from a variety of sources that provide a funding stream for services and supports for individuals with TBI.

Traumatic brain injury (TBI): A brain injury caused by a sudden jolt, blow, or penetrating head trauma that disrupts the function of the brain. The effects of TBI vary from person to person, depending on the force dynamics of injury and the patient's anatomy and physiology. When TBI occurs, the brain may be injured in a specific location or the injury may be diffuse and located in many different parts of the brain. The effects of TBI may be temporary or permanent and include a broad range of physical, cognitive, and behavioral impairments that result from externally inflicted trauma to the brain.

Traumatic Brain Injury Act of 1996 (P.L. 104-166): A 1996 federal law that directed three agencies of the U.S. Department of Health and Human Services—HRSA, the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH)—to implement several first-time programs related to TBI. HRSA was mandated to implement a grants program to foster state-based TBI infrastructure and service systems for meeting the post-acute needs of individuals with TBI and their families. CDC was directed to address prevention of TBI through surveillance, research on prevention, and public information and education programs. NIH was charged with conducting a consensus conference; expanding participation of academic centers of excellence in TBI treatment and rehabilitation research and training; and conducting research on diagnosis, prognosis, and treatment from acute care through rehabilitation.

ACRONYMS AND ABBREVIATIONS

ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
BIAA	Brain Injury Association of America
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare & Medicaid Services
DHHS	Department of Health and Human Services
DVBIC	Defense and Veterans Brain Injury Center
FY	fiscal year
HRSA	Health Resources and Services Administration
IOM	Institute of Medicine
MCHB	Maternal and Child Health Bureau
NAPAS	National Association of Protection and Advocacy Systems
NASHIA	National Association of State Head Injury Administrators
NIDRR	National Institute on Disability and Rehabilitation Research
NIH	National Institutes of Health
OMB	Office of Management and Budget
OSEP	Office of Special Education Programs
OSERS	Office of Special Education and Rehabilitation Services
P&A	protection and advocacy
PART	Program Assessment Rating Tool
PATBI	Protection and Advocacy for TBI
RSA	Rehabilitation Services Administration
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
TBI TAC	Traumatic Brian Injury Technical Assistance Center
TBI	traumatic brain injury
TBICS	Traumatic Brain Injury Collaborative Space
VR	Vocational rehabilitation