

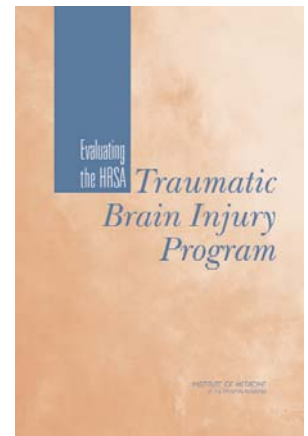
EVALUATING THE HRSA TRAUMATIC BRAIN INJURY PROGRAM

At least 5.3 million Americans are estimated to have a disability related to a traumatic brain injury (TBI), an injury caused by a sudden jolt, blow, or penetrating head trauma that disrupts brain function. TBI is a leading cause of death and disability in the U.S., with the Centers for Disease Control and Prevention (CDC) estimating that at least 1.4 million such injuries occur annually. Of those, as many as 90,000 individuals each year sustain a TBI with long-term consequences that may include altered cognition, personality, and behavior, as well as sensory and motor impairments. Because these conditions are often out of sight, researchers describe TBI as a “hidden” or “silent” epidemic and many health care professionals, community service workers, and the general public are unaware of TBI’s impact

Many people with TBI experience persistent, lifelong disabilities, and finding the help and resources needed to support these individuals, their family members and caregivers is often fraught with frustration. Problems getting basic services such as rehabilitation, housing, vocational services, neurobehavioral services, transportation, and respite for caregivers, are commonplace.

In 1996, the Traumatic Brain Injury Act directed three agencies of the U.S. Department of Health and Human Services—the Health Resources and Services Administration (HRSA), the CDC, and the National Institutes of Health—to create first-time programs related to TBI. HRSA was charged with developing a TBI state-based grants program to improve service delivery, establish policy, and secure the financial support for lasting systems change for persons with TBI. Since 2002, the HRSA Program has included grants to state Protection and Advocacy (P&A) systems to bolster advocacy support for individuals with TBI.

In *Evaluating the HRSA Traumatic Brain Injury Program*, the Institute of Medicine (IOM) assesses the impact of and recommends improvements to the modest \$9 million HRSA TBI Program. The IOM Committee on Traumatic Brain Injury found that improvements have been made in state-level TBI systems infrastructure and the overall visibility of TBI has grown considerably; however, overall quality and coordination of post-acute TBI services systems remain inadequate.



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SMALL FEDERAL PROGRAM IS MAKING A DIFFERENCE

The HRSA TBI Program was designed on the premise that distributing small grants to states would spark the creation of sustainable infrastructure and improved capacity for comprehensive, coordinated, and integrated services systems to meet the post-acute needs of persons with TBI and their families.

The committee found considerable value in this approach. Since the TBI Program was first established in 1997, many states have created new TBI service systems infrastructure through the collaboration of state and private agencies.

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 achieved these accomplishments on their own, it is likely that most other states would not have progressed to this stage without the TBI State Program Grants. No two state TBI programs have evolved in the same way, and not surprisingly, states with established leadership, interagency cooperation, and/or a CDC-sponsored TBI data system have been better positioned to use the TBI grants from HRSA more quickly and effectively than other states. Almost all states have demonstrated interest in expanding their capacity to serve individuals with TBI and all but two states (Louisiana and South Dakota) have applied for and received at least one TBI State Program Grant from HRSA (Figure 1).

It is too soon to determine the impact of HRSA's 3-year-old P&A for TBI Grant Program, although it is clear that the grants have led state P&A systems to focus on people with TBI for the first time. Whether these people and/or their caregivers are aware of the P&A services in their communities is not known.

To date...HRSA has not built a management infrastructure to allow for systematic review of either the TBI Program's strengths and weaknesses or the state grantee evaluations and final reports that HRSA requires.

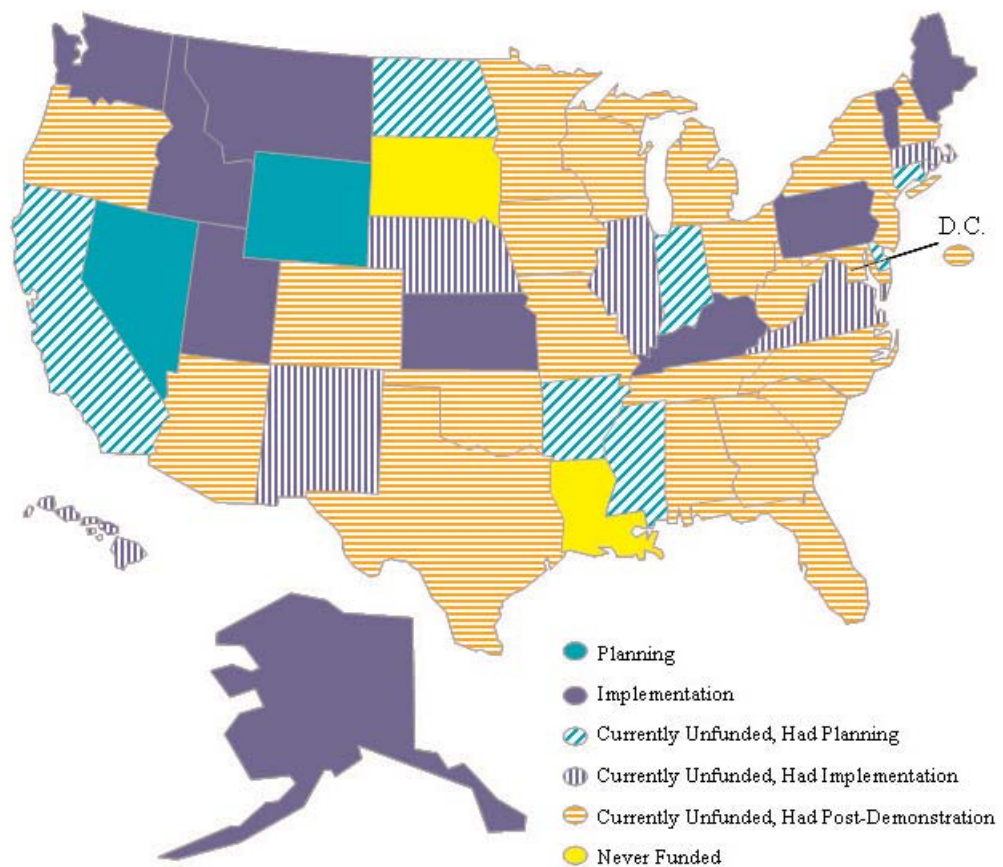


FIGURE 1. States that applied for and received at least one TBI State Program Grant from HRSA

CRITICAL SHORTCOMINGS

Although improvements have been made in TBI systems infrastructure, overall management of the TBI Program is inadequate. Since its beginning, the program has been run by less than a skeletal staff and 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 the Division of Services for Children with Special Health Care Needs—and has been threatened with debilitating cutbacks.

The TBI program demands more formal accountability. To date, perhaps because of insufficient resources, HRSA has not built a management infrastructure to allow for systematic review of either the 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.

ESSENTIAL NEXT STEPS

The committee urged HRSA to exercise strong leadership on behalf of the state TBI 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.

The committee recommended that HRSA lead by example, instilling rigor in the management of the TBI Program. HRSA should plan and implement—for both state grantees and itself—a standardized reporting system to ensure basic accountability and program evaluation. A national HRSA TBI Program Advisory Board should be appointed 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. The committee recognized that taking these steps may require additional funds and a modest expansion in the HRSA TBI Program's administrative capacity, but feels they are important steps to improve the program.

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. The committee urged that HRSA or another federal agency lead a formal call for active, interagency action regarding TBI—including the CDC, 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. Future collaboration should build upon each agency's unique strengths and resources.

HRSA SHOULD MAKE THE TBI PROGRAM A TOP PRIORITY

State TBI programs are now at a critical stage and need continued federal support to effectively meet the needs of individuals with TBI and their families. HRSA should continue to support and nurture the TBI Program while focusing on the substantial work that remains. Whether state TBI programs can be sustained without HRSA grants remains an open question. But further progress will become elusive if HRSA does not address the program's fundamental need for leadership, data systems, additional resources, and greater interagency collaboration.

HRSA should continue to support and nurture the TBI Program while focusing on the substantial work that remains.

FOR MORE INFORMATION...

Copies of *Evaluating the HRSA Traumatic Brain Injury Program* are available from the National Academies Press, 500 Fifth Street, N.W., Lockbox 285, Washington, DC 20055; (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area); Internet, <http://www.nap.edu>. The full text of this report is available at <http://www.nap.edu>.

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