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Building Up TBI Systems

Tools for Successful TBI State Programs

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Note: Throughout these pages, we use the term “state” to stand for state, territory, and tribe.

Since 1997, grantees have worked to increase access to brain injury services and to bolster the systems that advocate on behalf of people seeking services. The considerations and strategies laid out here are based on these grantees’ experiences. Broken out by program stage, they are useful for states at all levels of program and system development—from those that are just beginning to develop infrastructure to those with developed infrastructure in place.

Much of the content presented here was drawn from “Pathways for Systems Change: Benchmarks” and the “Self-Assessment Tool for State TBI Programs,” both of which were developed by the Federal Traumatic Brain Injury Technical Assistance Center which was under the Health Resources & Services Administration and revised in 2008.

This document covers four elements of a successful TBI state program, listed below and detailed on the following pages.

➤ [Self-advocate led advisory board or council](#)

Grantees receiving funds through the TBI State Partnership Grant program are required to have a state advisory board within the appropriate health department—or in another department as designated by the chief executive officer (for states, the governor).

The goal of the state advisory board is to ensure that a diversity of voices participate in determining the needs of people with brain injury, their families, and caregivers and in recommending actions to address those needs. The board also creates a structure for statewide cross-system collaboration, which is essential for systems change work.

➤ [Commitment and investment from lead state agency](#)

For the grant program, the chief executive officer (for states, the governor) designates a “lead state agency” to seek grant funding and oversee grant activities. Commitment by the lead state

agency is vital to ensure that services, supports, and resources are developed and available to people with brain injury and their families. The lead agency should also support the state advisory board's efforts to plan and to make recommendations for improving services and supports.

➤ [State plan based on assessment of needs and resources](#)

One step in planning for services and supports is to conduct a needs and resources assessment for the state. This type of assessment determines the gaps and barriers that prevent people from accessing needed services and supports. Once needs are identified, a state can develop the goals, objectives, and strategies for addressing gaps in services—the state plan.

➤ [Data to connect people to and evaluate services](#)

Navigating services offered by multiple agencies can be daunting for people with brain injury and their families. Agencies may differ in their eligibility requirements and service packages, and some may not be what a person needs at the time (such as vocational rehabilitation when post-acute rehabilitation or other supports are needed instead). Service coordinators or resource facilitators can assist by helping people transition post-injury—from trauma centers, emergency departments, or other healthcare providers—to needed services.

Many states maintain a brain injury registry to help connect people to services: Healthcare facilities (usually hospitals) report the names and contact information of people treated for brain injury to a state agency to ensure that follow-up can occur. A brain injury registry can also help states to gauge incidence and prevalence of brain injury.

Self-Advocate Led Advisory Board or Council



ACL encourages grantees to establish boards that are composed largely of members with brain injury and that engage people with brain injury throughout the process of state planning and service delivery. Some states have advisory bodies with more than 30 years of experience whereas other states are still in the process of developing or rebuilding their advisory boards.

Considerations

Establishing a board

- Is there a commitment within state government to establish the board?
- How many members does the board need to be effective and efficient in carrying out the mission? How is that determined (e.g., state legislation, executive order, and/or budget)?
- How will members be appointed/selected (e.g., state agency, executive order, law)?
- Does board composition reflect federal law and ACL requirements and guidance for:
 - People with brain injury from across the state?
 - ACL urges boards to have at least half of the members be people with TBI.
 - Families of people with brain injury from across the state?
 - Member of an organization representing brain injury in the state?
 - The TBI Act specifies a member of an organization representing individuals with TBI.
 - Key state agencies?
 - The TBI Act specifies that the membership should include injury control programs at the state or local level, if such programs exist. The Centers for Disease Control and Prevention (CDC) funds Core State Violence and Injury Prevention Programs, formerly referred to as injury control programs.
 - Rehabilitation professionals?
 - Healthcare and community providers?
 - Underserved populations, including members of ethnic/racial/cultural minority groups?

- The disability community at large?
 - ACL recommends including Protection & Advocacy; Center for Independent Living/State Independent Living Council; Aging and Disability Resource Center representation; long-term care ombudsman; and National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) funded TBI Model Systems representation, if one exists in the state.
- Other potential collaborators?
 - Are paid staff available to assist with meeting planning, minutes, copying materials, assisting with meeting agendas and other board activities?

Becoming a functioning board

- Do members understand the role of the advisory board and its members?
- Have members agreed on a shared vision and mission statement, and do board meetings and all board decisions reflect the vision and mission?
- Is there a regular meeting schedule and yearly calendar of meetings?
- Did the board elect a chairperson and other officers as allowed by its governing structure?
- Do members follow Robert's Rules of Order or other parliamentary procedures with regard to the agenda and meeting deliberations?
- Is a meeting agenda circulated in advance and does it reflect the purpose and objectives of the board (which may be necessary to meet the state's open meetings law)?
- Are meeting minutes taken and available to the public?
- Is there a process for learning about the state's service delivery and for obtaining input with regard to needs and resources?
- Is there a process for engaging individuals with brain injury and their families, both with regard to membership and the community at large (e.g., public forums, questionnaires)?
- Have costs for meeting accommodations been allocated to ensure access to the venue and meeting materials?
- Is there a process for people to request reasonable accommodations so they may attend meetings and access materials?

Operating a functioning board

- Are there established operational procedures (e.g., bylaws or other mechanisms for board governance)?
- Is there a process for member orientation and does it include clearly defined membership roles and responsibilities?
- Is there a process for creating a state plan that reflects an overall mission, vision, goals, and objectives to address service delivery gaps?
- Are meeting objectives routinely reviewed to ensure they reflect the mission statement, goals, and progress?
- Is there a formal planning process for board development?
- Are there work groups, committees, or other working bodies within the board to share the work, to build broader involvement, and to increase visibility of issues?
- Are there members who can serve as liaisons to relevant stakeholder groups?
- Do board members routinely participate in a self-assessment process to ensure the board is meeting expectations; the board is making progress toward attaining goals; and that members believe there are opportunities for participation by all members?
- Are the state agency representatives who serve on the board active participants?

Operating a high-performing board

- Does the board have statutory authority (has legislation been enacted to establish the board by law)?
- Are members working as both a group and as individual liaisons to and from their respective agencies, associations, or advocacy groups to assist in carrying out the mission of the board?
- Does membership include state agency representatives who have authority to carry out proposed objectives/activities as described in the state plan or to report to supervisors to obtain state agency support?
- Is there an ongoing process to identify and address policy issues, including those derived from the state plan?
- Is the board engaged in moving the state plan forward, in collaboration with the lead state agency, by regularly reviewing progress and assisting with carrying out strategies to achieve the state's goals?
- Is staffing and funding adequate to support the work of the advisory board?
- Is there a process for members to review and provide input into other federal plans developed by state agencies, such as its behavioral health plan, Title V (Special Health Care Needs), aging plan, and developmental disabilities plan?

- Are data provided through presentations and reports from state agencies, such as vocational rehabilitation data, special education data, public safety/highway patrol data (e.g., crash reports), and health statistics (e.g., trauma registry, TBI registry, hospital discharge, Emergency Medical Services [EMS], death certificate) to assess issues relating to brain injury?
- Is there a website that provides links to meeting agenda, minutes, documents, and resources?
- Is there a newsletter or other communication effort to keep stakeholders and the public informed of the board's activities?
- Is information on brain injury made available at other disability-, education-, and health-related conferences and meetings?
- Does the board take advantage of opportunities to co-sponsor conferences or training opportunities with other brain injury and disability organizations?
- Does the board take advantage of opportunities to participate in disability and healthcare coalitions to advance policies?
- Does the board produce an annual report or other reporting mechanism to note progress in meeting state plan goals and objectives?

Resources

- [A Complete Guide to Board Meeting Agendas — with Templates!](#)
- [How to Have an Effective Disability Advisory Committee](#)
- [Robert's Rules of Order](#)
- Instructional videos on Robert's Rules of Order, available on YouTube: [How to conduct a meeting according to Robert's Rules of Order](#) and [How to make a motion according to Robert's Rules of Order](#)
- [10 Habits of Highly-Effective Governing Bodies](#)
- [Self-Assessments for Nonprofit Boards](#), National Council of Nonprofits
- [Evaluating the HRSA Traumatic Brain Injury Program, 2006](#)

Commitment and Investment From Lead State Agency



The designated lead state agency, which is responsible for applying for grant funding and administering grant activities, generally has demonstrated a commitment to assisting people with brain injury and their families and is supportive of the advisory board; willing to administer services, either by expanding their own capacity or administering services and resources designed specifically for individuals with brain injury; and is willing to apply for federal funding to assist with increasing access to service delivery.

To apply for federal funding from the TBI State Partnership Program grant, federal law requires the state to provide a 2:1 state match (cash or non-federal in-kind). Non-federal contributions may be use of office space and supplies, equipment, other personnel, including volunteer hours, and/or services not otherwise funded by the grant. These non-federal contributions may also be provided by other organizations involved in the grant activities.

Basic Level

- A lead agency has been designated, and the agency designates or contracts for staff and other resources to assist with carrying out the grant activities.
- The lead agency assists with communication and collaboration with other state agencies to develop an awareness of the need for resources, services, and supports.
- The lead agency supports the full participation of people with brain injury, family members, and diverse representation in planning, policy formulation, and program development for services and supports.

Intermediate Level

- A lead agency has been recognized by multiple constituencies as having expertise and access to resources for brain injury and for collaborating with other agencies and organizations.
- The lead agency collaborates on the development of a systems approach to the coordination of the state's TBI services and supports.
- The lead agency has built collaborative relationships to gain assistance as needed for data collection/analysis, strategic planning, program development, and implementation of the state plan and/or assistance with the grant proposal development with other states, programs or state/national organizations (listed at the bottom of this page).

- The lead agency participates in the development of resources/products and helps to facilitate their dissemination.

Advanced Level

- The lead agency is proactive in maintaining or seeking funding and resources delineated in the state plan.
- The lead agency works with broader disability or healthcare coalitions on issues related to brain injury and/or invites people with brain injury to participate in activities such as Medicaid Home and Community-based Services (HCBS) transition plans, Olmstead Plans, and changes in Medicaid systems.
- The lead agency staff have opportunities to receive training with regard to brain injury.
- The lead agency includes information on brain injury and resources in state agency training designed for programs and services *other* than specific services for people with brain injury—such as juvenile justice, education, older adults, substance use, and behavioral health.
- The lead agency offers opportunities for screening and identification for likelihood of brain injury for populations served who may not have brain injury as a primary diagnosis, such as people receiving substance use and behavioral health treatment services.
- The lead agency enters into memoranda of understanding (MOUs) with regard to shared client information or funding, such as Medicaid reimbursement for a Medicaid state plan service provided by a brain injury state program.
- The lead agency is established in state legislation to be eligible for services, resources, and funding (e.g., trust fund, state and/or Medicaid).

Resources

- The [National Conference of State Legislatures](#) tracks state legislation on brain injury and provides materials and resources featuring brain injury initiatives, such as juvenile justice and brain injury
- The [Council of State Governments](#), a national organization serving all three branches of state government to foster the exchange of insights and ideas to help state officials shape public policy
- [Evaluating the HRSA Traumatic Brain Injury Program, 2006](#)

National Organizations

- [Brain Injury Association of America](#) (BIAA)
- [National Association of State Head Injury Administrators](#) (NASHIA)
- [National Disability Rights Network](#) (NDRN)
- [TBI Technical Assistance and Resource Center](#) (TBI TARC)
- [U.S. Brain Injury Alliance](#)

State Plan Based on Assessment of Needs and Resources



To create a fully informed state plan, it is essential to know the problems that need to be addressed—whether there are limited providers, who is most at risk, whether there are funding gaps, etc.—and the resources that are available.

A needs assessment is the process of gathering information about the barriers to service delivery or the underlying need for a program or services. A resource assessment is the process of gathering information about the resources available to address a particular need or those who are at risk or who are underserved. Together, these assessments provide the foundation for developing a state plan with a roadmap for improving service delivery.

This process may be primarily the responsibility of the advisory board/council or the lead agency, or in partnership, depending on the state. The state plan may be the product of the advisory board/council or the lead agency, depending on the state.

Needs and Resources Assessment

Basic Approaches

- The advisory board/council and/or lead agency knows how to assess needs—whether through an assessment tool, questionnaire, facilitated public forum, open forum with no facilitator, or a combination of these methods.
- If using a questionnaire or some other method for soliciting written information, the advisory board/council and/or lead agency has determined how it will be disseminated (e.g., on a website, mailing by multiple agencies, mailing by advisory board).
- People with brain injury and their family members have helped to develop the assessment tool.
- The assessment tool is user-friendly, easy to understand, and provided in alternate formats as needed.
- The advisory board/council and/or lead agency have developed and implemented a variety of culturally appropriate methods for disseminating the assessment tool.
- The data collected in the assessment help the advisory board/council or lead agency to determine the incidence and prevalence of brain injury and resulting needs.
- The assessment tool identifies existing services, gaps, or barriers to services in both the private and public sectors.

- The advisory board/council and/or lead agency have a process for reviewing the results of the assessment and available data used for making state plan recommendations.
- The advisory board/council and/or lead agency have a method for disseminating the results of the needs and resources assessment.

Intermediate Approaches

- The needs and resources assessment is thorough and representative of the state as it incorporates the cultural needs of underserved populations with brain injury and their families.
- People with brain injury and family members are involved in evaluating the tool to improve it the next time it is used.

Advanced Approaches

- The lead agency commits resources to fund an ongoing needs and resources assessment process (3-5 year cycle) that will reflect current needs and the state of services, including a process for data analysis and a mechanism for disseminating results.
- The lead agency, along with other state agencies as appropriate, provides information about the costs of existing services and supports in the private and public sectors in order to assist with state plan development.

TBI State Action Plan

Basic Elements

- The plan defines the period of time for which it applies—for example, a one-year or three-year plan.
- The needs and resources assessment results, along with other available data, are reflected in the priorities, goals, and objectives defined in the plan.
- Strategic partners, including people with brain injury and their family members, are involved in developing the plan.
- The plan reflects the needs prioritized by people with brain injury and their family members.
- The plan describes a person-centered, person- and family-directed, and culturally competent framework with regard to desired service delivery.

Intermediate Elements

- The plan describes a process for measuring and documenting actions that build collaboration and sustainability of acceptable, accessible, appropriate and available services and supports for people with brain injury and their family members.
- The objectives contained in the plan are SMART (Specific, Measurable, Attainable, Relevant, and Time-based).
- The plan provides strategies to support collaboration among relevant state and local partners and agencies.
- The recommendations described in the plan include sufficient history and justification to present before state leadership in order to serve as the basis for policy development, changes, or expansion.
- The review process for the plan includes focused discussions with state leadership and a mechanism for structured feedback that facilitates engagement, provides guidance, and increases the likelihood for continued dialogue and the promotion of an evaluation process.
- The plan includes recommendations for policy development that would lead to coordinated systems of services and supports for people with brain injury and their family members.
- The plan incorporates available data on numbers of people served in nursing facilities, by other state agencies' programs, and in out-of-state placements in the assessment of needs and resources.

Advanced Elements

- The plan promotes and reflects interagency buy-in or sign-off through MOUs or MOAs, letters of commitment, and/or mandated involvement from agencies and entities who may be responsible for carrying out activities specified in the plan.
- The plan identifies a collaborative interagency structure for building and maintaining interagency support, planning, and problem-solving.
- The plan functions as a living document to be reviewed and staff revises it on a regular basis to capture current practices, initiatives, and resources, and it becomes a vehicle to assess potential feasibility, relevance, and evaluation.

Resources

- [Assess Needs and Resources](#), CDC
- [Needs and Resources Assessment](#), Rand Corporation
- [Setting Goals and Developing Specific, Measurable, Achievable, Relevant, and Time-bound Objectives](#), SAMHSA

- [Strategic Planning](#), Municipal Research and Services Center
- [Strategic Planning Guide: Guidance and Resources to Assist State and Territorial Health Agencies](#) in Developing a Strategic Plan, Association of State and Territorial Health Officials
- [Evaluating the HRSA Traumatic Brain Injury Program, 2006](#)

Data to Connect People to and Evaluate Services



Offering the *right services at the right time* is often challenging, especially at the time of injury when a person is transitioning from a trauma center, emergency department or other healthcare provider to post-injury services and over time, once the person is living in his or her home and community. A brain injury registry can help in connecting people at the time of injury to services. It can also help when it comes to collecting data on incidence and prevalence of brain injury.

Another challenge is providing outreach and assistance to people with brain injury who may not have been identified and reported through a registry or who may be several years past their initial diagnosis/treatment and have ongoing and changing needs. States have developed resource facilitation or service coordination systems to conduct awareness and to help link people with brain injury to resources, services, and supports. States may also use Money Follows the Person Demonstration grant funding to identify people with brain injury in nursing facilities and to transition them to home and community-based services and supports.

Basic considerations

- Assess data needs for surveillance, service planning, and/or linking individuals to services.
- Determine data available in the state (e.g., brain injury and/or trauma registry, hospital discharge data, EMS data).
- Determine if additional data is needed for identified goals and purpose, and how it would be obtained (e.g., state legislation to mandate a registry requiring reporting by all hospitals or emergency departments or by adding capacity to existing systems, such as the Behavioral Risk Factor Surveillance System).
- Determine which state agency, and any other pertinent organizations, such as the state hospital association, would be involved in collecting data and administering a registry or other means for obtaining data.
- Determine if state legislation or other regulatory procedures would be needed for new data or if existing data systems could be augmented, such as a state nursing home reporting system or Special Health Care Needs survey, to capture persons with brain injury.
- Define the purpose or intended use for the information: who would report, who would collect, and who would receive the information.
- Determine what information is needed or what questions need to be answered.

- Obtain buy-in and collaboration from agencies or organizations that collect or would benefit from brain injury–related data.

Intermediate considerations

- Ensure a process for confidentiality through MOUs, MOAs, or some other formal process.
- Identify who can receive information and how they will use that information.
- Develop a process to collect and analyze data, and a process for follow-up.
- Develop a budget needed to collect and analyze data and to conduct follow-up.
- Develop a pilot linkage implementation plan based on the feasibility study findings.
- Develop information on resources and assistance that may be available to provide to people with brain injury and their families at the time of injury and that can also be available via a website or other method for awareness in order to assist people long after initial treatment and rehabilitation.
- Expand existing service coordination systems that may be in place for people with intellectual/developmental disabilities and/or for participants in the Title V Children with Special Health Care Needs program to include people with brain injury to assist in locating and coordinating resources and services.
- Develop a plan for resource facilitation or service coordination for people with brain injury in order to link people to services who may have been identified by a registry, other state and community programs, or as the result of public awareness.

Advanced considerations

- Ensure there is authority in place (for example, legislation) to implement the registry and to require healthcare providers (such as trauma centers, all hospitals, emergency departments, and/or rehabilitation facilities) to report. It should define the state agency responsible for the data, how the agency uses that data, and how the people identified will receive follow-up services (and the responsible parties for this) to connect with resources.
- Use data to link people with brain injury to appropriate services and supports via information, such as a letter that provides information and a contact, 800-number, and/or service coordination.
- Institute a surveillance system for service delivery issues that examines the magnitude of the problem, identifies the causes, and identifies high-risk groups.
- Implement a resource facilitation or service coordination system for people with brain injury to facilitate linking to resources, services, and supports.
- Include people with brain injury in the Money Follows the Person Demonstration grant program, should the state Medicaid agency be implementing one, which would identify

people with brain injury in nursing facilities who would be eligible for home and community-based services.

Resources

- [Getting Better at Getting Them Better: Enhancing the Minnesota Traumatic Brain & Spinal Cord Injury Registry and Connecting Survivors to Resources](#), Minnesota Department of Health
- [Florida Brain and Spinal Cord Injury Program's Central Registry](#)
- [Missouri Electronic Surveillance System for the Early Notification of Community-based Epidemics](#) (ESSENCE), which provides names to the Missouri Adult Brain Injury Program for follow up
- [Money Follows the Person Program](#), Centers for Medicare and Medicaid Services
- [Traumatic Brain Injury in the United States: The Future of Registries and Data Systems](#), CDC, 2002