ACL TBI: As-Is Assessment

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INTRODUCTION

EVALUATION PROCESS

Coray Gurnitz Consulting (CGC) began working with the Administration for Community Living (ACL) on the transition of the traumatic brain injury (TBI) grants program in November 2015, shortly after ACL assumed full control of the program on October 1, 2015.

Given that the TBI Grants program had almost 20 years' worth of history and a variety of stakeholders with sometimes diverging opinions, CGC recommended that ACL use a deliberate process to clearly understand the strengths and weaknesses of the program before making substantive changes.

ACL program officials agreed with this approach, and after initial discussions with high-level stakeholders, presented a recommendation to ACL Administrator Kathy Greenlee, who approved a comprehensive analysis of the grants program on February 29, 2016. The purpose of this assessment is to understand the current, or "As-Is", state of the TBI Grants program. CGC focused on producing a data-driven, stakeholder-informed assessment of the TBI Grants program that will enable ACL Program Managers to make decisions about the program's design, structure, and future. This report will also act as the foundation of a future state, or "To-Be" Assessment, which CGC will co-create with ACL and deliver in early 2017.

CGC's analysis of the As-Is state of the program formally commenced in March 2016, focusing on the following four phases, each of which is described in greater detail on pages 1-3.

- Phase 1: Discovery
- Phase 2: Exploration
- Phase 3: Assessment
- Phase 4: Recommendations

Phase I: Discovery

CGC conducted a comprehensive review of program literature shortly after its work with ACL began. An initial review of TBI literature led to CGC's recommendation to conduct a comprehensive review of the TBI Grants program. CGC presented ACL with initial findings in January 2016.

Key documents included in CGC's initial literature review are listed below:

- Public Law 104–166. 1996 Legislation authorizing the State TBI Grants program.
- Public Law 106–310. 2000 Legislation authorizing the Protection and Advocacy Traumatic Brain Injury (PATBI) Grants Program.
- Public Law 110–206. Traumatic Brain Injury Act of 2008.
- Public Law 113–196. Traumatic Brain Injury Reauthorization Act of 2014.
- "Evaluating the HRSA Traumatic Brain Injury Program". 2006 report completed by the Institute of Medicine (IOM).

- National Research Action Plan (NRAP). 2013 Report developed in response to the 2012 White House Executive Order entitled "Improving Access to Mental Health Services for Veterans, Service Members, and Military Families".

Phase II: Exploration

After Administrator Kathy Greenlee authorized ACL and CGC to complete a more in-depth analysis of the program, CGC conducted a series of planning sessions with ACL staff members to understand the legislative intent of the TBI Grants program.

Understanding legislative intent is a first step in program evaluation, and it led to the creation of a program logic model (see page 4), a series of high level research questions, and an initial list of possible resources that could supply answers to some of the research questions.

Phase III: Assessment

After completing the Exploration phase in June of 2016, CGC began its assessment of the TBI Grants program. Initial work included historical analysis of the program's budget and grant distribution processes, as well as identification of ongoing grant activities and program output information.

CGC then began its stakeholder interview process. Interviews were conducted with three sets of stakeholders, which are outlined below..

- Federal partners – Coordination Interviews
  - Department of Defense (DoD)
  - Department of Veterans Affairs (VA)
  - Centers for Disease Control and Prevention (CDC)
  - National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
  - Substance Abuse and Mental Health Services Administration (SAMHSA)
  - The Model Systems Knowledge Translation Center (MSKTC)
- National stakeholders and historic program staff
  - Health Resources and Services Administration (HRSA, former lead agency for the TBI Grants program)
  - National Opinion Research Center (NORC) at the University of Chicago (former TBI State Grants contractor)
  - Grant Thornton (current TBI State Grants contractor)
  - National Disability Rights Network (NDRN, PATBI Technical Assistance Contractor)
  - National Association of State Head Injury Administrators (NASHIA)
  - The Brain Injury association of America (BIAA)
  - The Arc

- State officials[1]
  - Current state TBI grantees – Missouri, Alabama, Nebraska
  - Former state TBI grantees – Georgia, Utah
  - PATBI grantees – New Jersey, Oregon, Louisiana, Pennsylvania

Phase IV: Recommendation

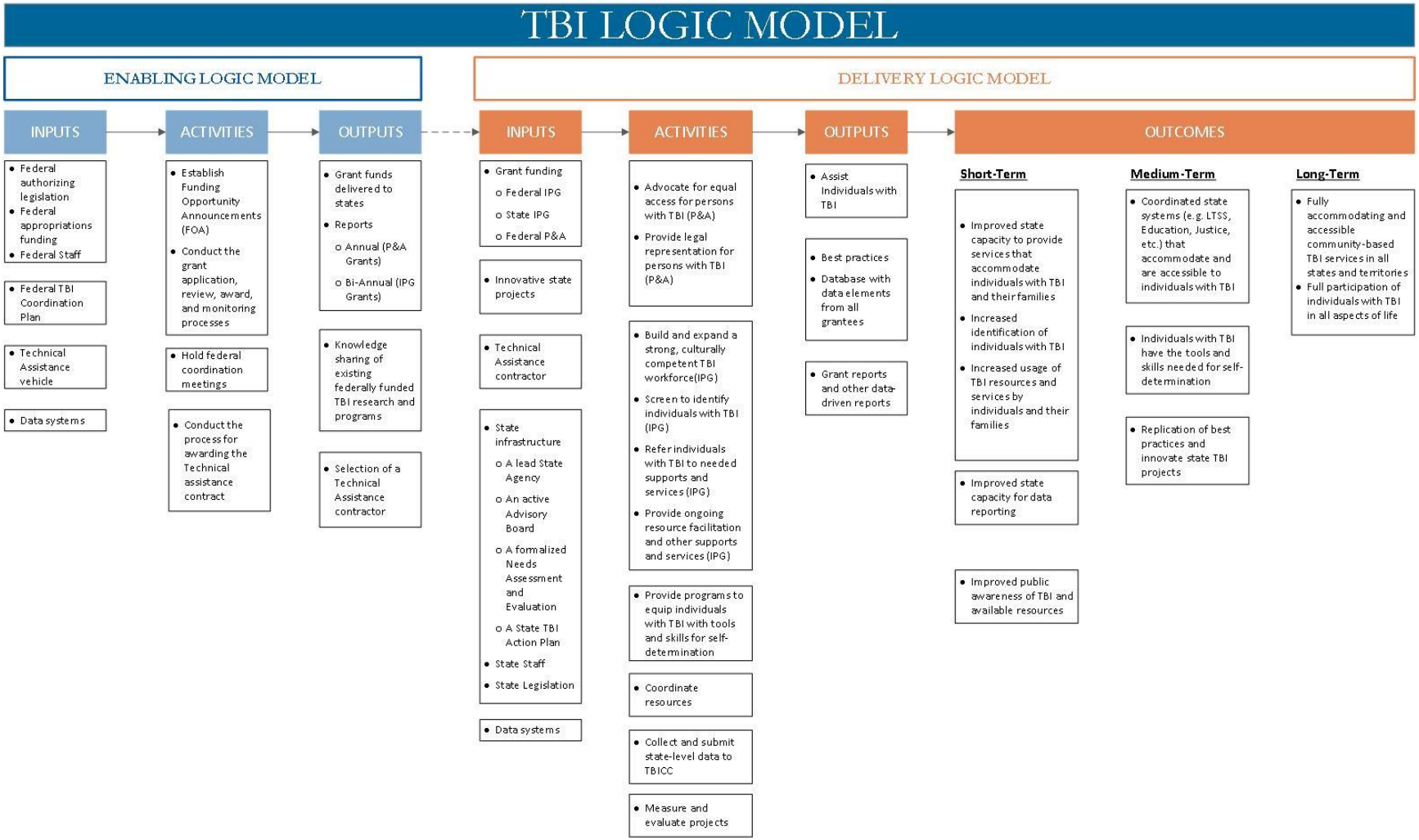
After analyzing interview responses and program data, CGC has developed an initial set of recommendations, which are summarized on pages 6-8

These recommendations are not intended to be clear mandates for specific actions, but rather a list of options to consider in FY17 as the program further transitions from the current HRSA-developed model to ACL's future state.

[1]The Paperwork Reduction Act (PRA) of 1995 requires approval from the Office of Management and Budget (OMB) for data collection requests of 10 or more individuals. As a result, CGC identified nine states through a random process that considered geography and historical levels of TBI grant participation. CGC's initial list was presented to and approved by ACL prior to formal data collection.

LOGIC MODEL

The Logic Model the ACL TBI team developed identifies the different components of the ACL program and their relationships to one another. The Logic Model illustrates the program's enabling components, which are housed at ACL headquarters, and those elements delivered by state grantees.



SUMMARY

GRANT COMPARISON

The Traumatic Brain Injury (TBI) Grants Program currently run by the Administration for Community Living (ACL) includes two types of grants: Protection and Advocacy (PATBI) and State TBI Grants. The below chart compares these two grant types.

TABLE 1: Grant Comparison

	STATE TBI GRANTS[2]	PATBI GRANTS
Authorizing Legislation	Public Law 104–166 (1996)	Public Law 106–310 (2000)
Total Annual Funding	$5.25m	$3.1m
Largest Annual Funding	$5.4m (2007)	$3.3m (2009-12)
# of Current Grantees[3]	20	57
Funding Type	Competitive	Formula
# of Current Grant Types	1	1
# of Historical Grant Types	3	1
Current Technical Assistance Contractor (TAC)	Grant Thornton	NDRN
Previous TACs	3	0
Data Collection Tool?	None	Proposed NDRN Tool

SOURCE OF CHART DATA: http://datawarehouse.hrsa.gov/Tools/FindGrants.aspx

SUPPORT SYSTEMS

In addition to the grant funding directed to states, the program is supported by Technical Assistance Contractors (TACs)[4] and coordination efforts at the state and federal levels.

This report focuses on **four elements** of the TBI Grants program.

1. State TBI Grants
2. PATBI Grants
3. Technical Assistance Contractors:
    a. State TBI: Grant Thornton
    b. PATBI: National Disability Rights Network (NDRN)
4. Coordination

[2] As seen above, there have been various types of State TBI Grants, including Planning, Implementation, and Post-Demonstration. Within this report these grants are referred to as State TBI Grants, which is a reference to the 1996 legislation that created this funding stream (SEC. 1252. STATE GRANTS FOR DEMONSTRATION PROJECTS REGARDING TRAUMATIC BRAIN INJURY).

[3] Over the life of the State TBI Grant program, seven states and territories have never received a grant. They are: Louisiana, Mississippi, South Dakota, American Samoa, Puerto Rico, the US Virgin Island, and the Native American Disability Law Center

[4] The program's primary Technical Assistance Contractor, Grant Thornton, is often referred to as the TBI Coordinating Center, or TBICC. Given the number of contractors discussed in this report and the focus on contractor support generally, CGC uses the term TAC to refer to grant program contractual support throughout this document.

REPORT SUMMARY

This report was developed during a six-month process that included the creation of a Logic Model, identification of research topics and data sources, and report findings and recommendations.

The chart below aligns the research topics, findings and recommendations of this report. Each recommendation is described in greater detail on pages 6 and 7.

TABLE 2: REPORT SUMMARY

LOGIC MODEL	HOW DO ENABLING SYSTEMS (FEDERAL) IMPACT DELIVERY SYSTEMS (STATES)?			HOW DO ACTIVITIES LEAD TO OUTPUTS?			HOW TO MEASURE ACTIVITIES, OUTPUTS, AND OUTCOMES?				
RESEARCH TOPICS	Grant Operations	Program Support	TAC	Coordination			Grant Metrics				
				Federal	State	Individual					
FINDING	A. The State TBI Grants disbursement process requires definition	B. Staff roles and responsibilities require definition		C. There is a gap in federal coordination meetings	D. There is a desire for an annual TBI conference	E. Stakeholders would like frequent access to information	F. The PATBI Grants have effective infrastructure	G. Flat funding has led to decreased services	H. Improved data collection is possible	I. Flat funding has led to decreased services	J. There is a desire for a registry of state resources
DECISION POINTS & RECOMMENDATIONS	1. Define State TBI grant disbursement process	2. Define roles and responsibilities		3. Resume Federal Interagency Committee (FIC) meetings	4. Resume the annual TBI conference	5. Create a single, fully transparent web portal for all stakeholders	6. Adopt the NDRN data collection tool for the PATBI grants			7. Define and collect TBI metrics	

Decision Points and Recommendations

The following list of seven items summarizes the specific Decision Points and Recommendations put forward by CGC. These items can be traced back to the chart on Page 6 above, along with corresponding findings. The individual findings are further described in the detailed PATBI, State TBI, and Coordination sections below.

1. **Define State TBI grant disbursement process.** There have been three separate phases of grant disbursement for the State TBI program. In short, Phase 1 focused on building state infrastructure, Phase 2 provided grant funding to 90% of states and territories, and Phase 3 has focused on a competitive process. Each approach is justifiable, but ACL must identify the approach they feel best meets the goals of the program. Stakeholders interviewed for this analysis generally felt that more states should receive grants, but that decreased funding levels, even for the states who were awarded a grant, would be a sub-optimal outcome. One approach is to return to a multi-grant award structure, where every state and territory would be eligible for some small amount of funding.
2. **Define roles and responsibilities.** HRSA's selection of Technical Assistance Contractors (TACs) was based in part on its internal capability. Interviewees indicated that a certain level of subject matter expertise is required within the program nationally and that expertise should be located either within federal staff or the TAC. If ACL determines that more staff with TBI backgrounds should be hired, then that will likely influence the scope of the contractor's duties. If, however, ACL expects the contractor to deliver subject matter expertise to the grantees, including TBI research and state systems information, then that will result in a different scope for the TAC.
3. **Resume Federal Interagency Committee (FIC) meetings.** The FIC meetings initially run by HRSA were well-intentioned and met a key programmatic need. These meetings were suspended due to the transition of the program, and the corresponding gap in federal coordination has yet to be filled. These meetings should resume, although ACL should develop pre- and post-meeting communication strategies. For example, states and stakeholder groups should have an ability to identify areas of interest or concern before meetings occur, and ACL should use that information to define topics and leverage research partners.
4. **Resume the annual TBI conference.** While there are a variety of technological solutions to improve and/or facilitate coordination, in-person interactions were consistently listed as a high point experience during stakeholder interviews. Resuming an annual TBI conference for all states (PATBI or State TBI grantees, funded or unfunded), would increase knowledge sharing at all programmatic levels.
5. **Create a single, fully transparent web portal for all stakeholders.** Based on feedback obtained during interviews, ACL should maintain a web presence where all stakeholders – federal agencies, state representatives, contractors, non-profits, and individuals – can understand the work being done within the program. The primary focus of this site should be on projects and resources related to the PATBI and State TBI grants, but the site should also connect to emerging research, whether it occurs through the DoD, VA, or the CDC.
6. **Adopt the NDRN data collection tool for the PATBI grants.** The PATBI grant program benefits from strong infrastructure at the federal, state, and contractor levels. Those factors contribute to an ability to generate quality data at the national level, which could help the PATBI grantees

articulate a need for increased funding. CGC recommends the adoption of the data collection tool developed by NDRN.

7. **Define and collect TBI metrics.** Because both State TBI grantees and PATBI grantees struggle with flat funding CGC recommends improving data collection processes for both programs, which will allow ACL to demonstrate the value of and results from its TBI grants. Unlike the PATBI program, the State TBI grants do not have an existing data collection tool that has been vetted with the state grantees. While instruments like the Balanced Scorecard currently exist, ACL should work with stakeholders and grantees to ensure any new data collection efforts are acceptable to program stakeholders at the federal and state levels. ACL should also ensure that there is a minimum collection effort for all 57 states and territories, even if a separate, more robust collection exists for the State TBI grantees.

PATBI GRANTS

PATBI PROGRAM REVIEW

The TBI Protection and Advocacy grants, or PATBI grants, were legislatively added to the TBI Grants program in October 2000. These grants are defined by their population-based formula funding, as well as their connection to a well-established and well-connected Protection and Advocacy system at the federal and state levels. There has been a great deal of consistency in the PATBI program, including predictable funding, a stable contractor, and established contacts in all 57 states and territories.

The purpose of these grants, as defined by Public Law 106–310 (October 17, 2000), is to enable Protection and Advocacy systems "…to provide services to individuals with traumatic brain injury".

Services provided may include information, referrals, and advice; individual and family advocacy; legal representation; and specific assistance in self-advocacy.

BACKGROUND

While the PATBI grants are a unique program, they are tied to the broader Protection and Advocacy (P&A) Systems that exists within 57 states and U.S. territories.

In 1975, the federal government established a national P&A system with specific contacts in all states and territories. This system was established by the Developmental Disabilities Assistance and Bill of Rights (DD) Act of 1975, which required the governor of each state to designate a P&A agency that was independent of any service provider.

Today, most entities designated as P&As are private, non-profit organizations that are created specifically for the purpose of conducting the P&A programs. In addition, in the 40 years since the initial passage of the DD Act, the federal government has authorized seven additional P&A programs, including the TBI program. At present, there are eight P&A programs:

- Individuals with Developmental Disabilities (PADD)
- Voting Accessibility (PAVA)
- Assistive Technology (PAAT)
- Traumatic Brain Injury (PATBI)
- Client Assistance Program (CAP)[5]
- Individuals with Mental Illness (PAIMI)
- Individual Rights (PAIR)
- Beneficiaries of Social Security (PABSS)

ACL Relocation

With the TBI Grants program moving from HRSA to ACL in 2015, the PATBI grants became one of four P&A programs located within ACL, each of which works with the same Technical Assistance Contractor (TAC), the National Disability Rights Network (NDRN). Since the initial authorization of the PATBI grants in 2000, NDRN has served as the TAC for this program.

[5] CAP is the only program that does not require its funds to go to the entity designated as the state P&A. As a result, CAP offices and P&A offices are separate in 20 of the 56 states and territories with a CAP office.

NDRN is the nonprofit membership organization for all P&A systems, which gives them direct contact to, and a meaningful working history with, the state P&A Offices and the eight programs.

The chart below outlines the P&A programs and funding currently housed within ACL.

TABLE 3: ACL'S P&A PROGRAMS

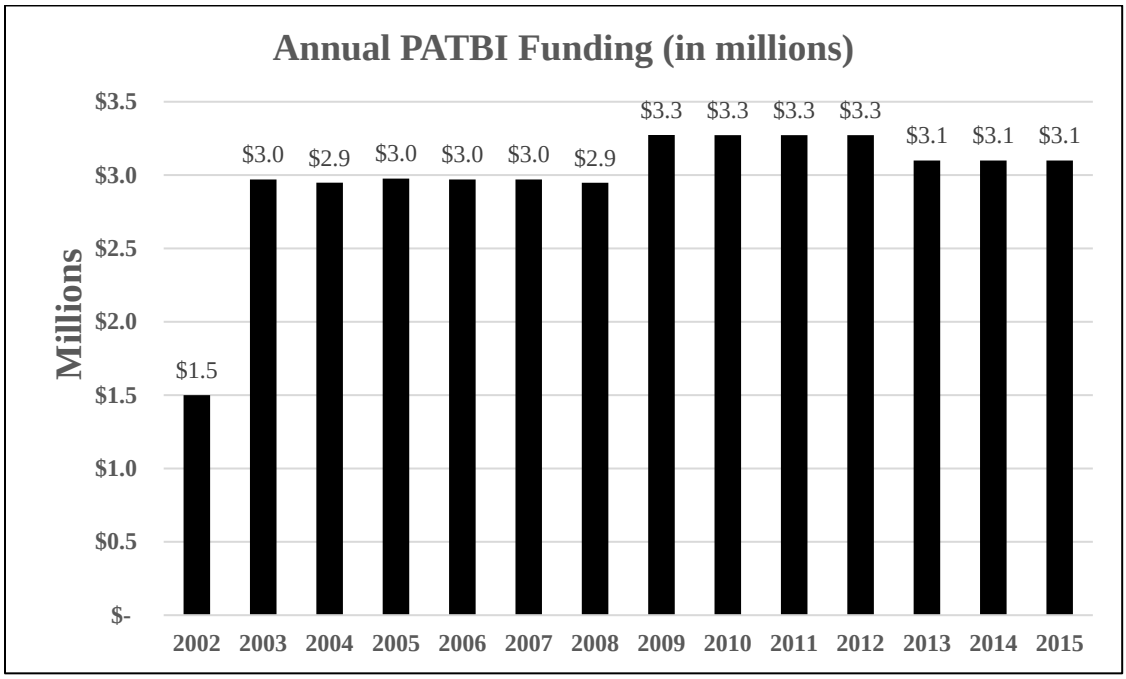
PROGRAM	FEDERAL AGENCY	TA CONTRACTOR	FY16 FUNDING	FY2016 TA
PATBI	ACL	NDRN	$ 3,100,000	$ 35,000
PAVA	ACL	NDRN	$ 4,900,000	$ 347,410
PAAT	ACL	NDRN	$ 4,300,000	$ 100,000
PADD	ACL	NDRN	$ 38,700,000	$ 748,483
		TOTAL	**$ 51,000,000**	**$ 1,230,893**

SOURCES: Data in this chart was gathered from HHS websites and confirmed by ACL staff.

Budget

Relative to other P&A programs, funding for the PATBI grants is small, as total grantee funding is only $3.1m per year. 75% of all states and territories receive less than $55,000 per year.

CHART 1: ANNUAL PATBI FUNDING



SOURCE: http://datawarehouse.hrsa.gov/Tools/FindGrants.aspx

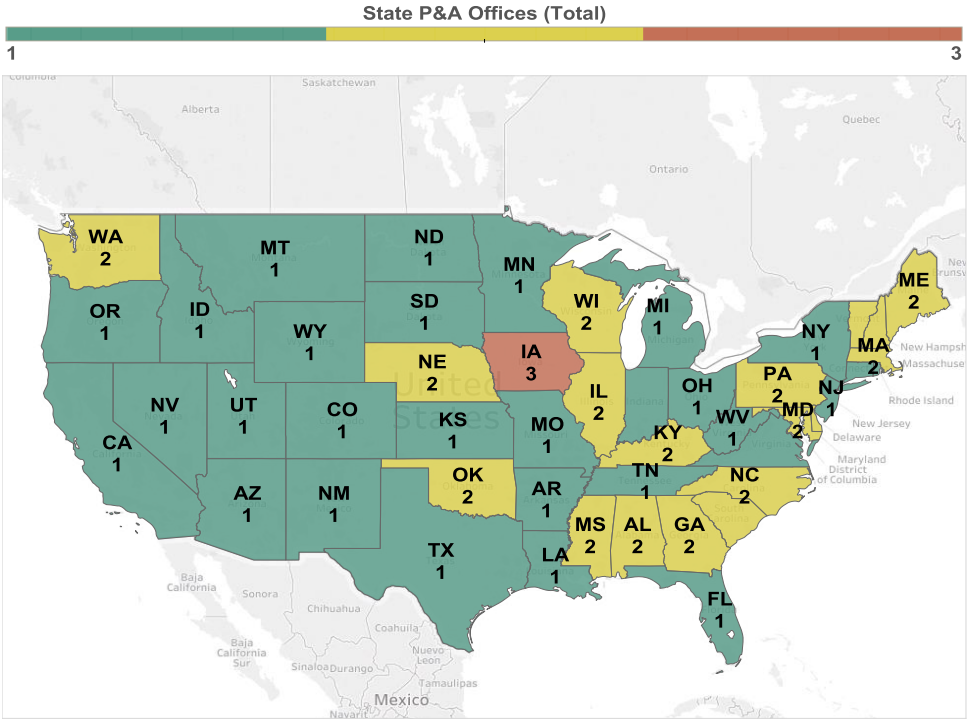
While funding has remained flat in real dollars, increased business and administrative costs have resulted in decreased services to the TBI population. As a result, co-locating this program with other, larger P&A programs in ACL has benefits to the PATBI grants, including lower administrative costs and established reporting requirements.

State Support

As noted on page 9, the DD Act of 1975 required the governor of each state to designate a P&A agency. Even as the number of state P&A programs has increased, most states have maintained a single office for all eight programs.

- 54 of the 57 states and territories (95%) have the seven principal P&A programs (non-CAP) located in one office.
- 35 states and territories (61%) have all eight programs located in one office. These states are represented in green in the map below.

CHART 2: STATE P&A OFFICES



SOURCE: http://ndrn.org/en/ndrn-member-agencies.html

Data Collection and Availability

Data collection for the TBI Grants program has always been limited, and while preliminary steps have been taken to improve data collection and availability, ultimately there is very little reliable data to analyze.

There is, however, some level of ongoing data collection for the P&A systems generally. ACL currently has publicly available state-level data for the following metrics[6]:

[6] All of the P&A data is accumulated across each state's entire Protection and Advocacy system, and it is not analyzed by topic area. Therefore, of the 17,000 clients served in 2014, it is not apparent how many were served for TBI-related issues vs. Social Security or Voting Accessibility issues.

SOURCE: http://www.acl.gov/programs/aidd/Programs/PA/index.aspx#data

- **Clients Served:** 17,00 clients served across all 57 P&A systems in 2014
- **Clients by Age:** 60% of 2014 clients were between the ages of 5 and 22
- **Clients by Race and Ethnicity:** Racial and ethnic breakdown largely coincides with national demographic trends (58% White, 18% Hispanic/Latino, 13% African-American)
- **Clients' Living Conditions:** 75% of clients served either live at home (66%) or in an independent living facility (9%)
- **Outcomes by Areas of Emphasis:** No data currently available
- **Reasons for Closing Cases:** 74% of cases were resolved in favor of the client
- **Intervention Strategies:** 64% of clients requested either technical assistance in self-advocacy (33%) or short-term assistance (31%)
- **Problem Areas/Complaints of Clients Served:** 67% of service areas related either to Neglect and Abuse (36%) or Education (31%)

Future Data Collection

One of the most commonly cited issues for PATBI states has been the amount of time and money devoted to reporting. Given the low funding totals available through these grants, states have wanted to streamline reporting requirements for some time. In addition, the PATBI program, and in particular the TAC (NDRN), has taken steps to improve overall data collection.

Both goals might be achievable. ACL already has an existing data collection infrastructure for all P&A programs, and NDRN has created a data collection instrument that was previously sent to P&A states for voluntary completion. Based on discussions with NDRN, there is optimism that this voluntary instrument will become the sole (mandatory) data requirement for PATBI grantees. State feedback on this form during interviews was also positive.

A data collection tool that does not burden the state grantees and provides meaningful objective data will reduce state administrative costs while also improving overall messaging about the program and its impact.

PATBI KEY FINDINGS

CGC discovered the following three findings through analysis of PATBI programmatic information and state interviews (see the chart on Page 6 for additional information, including links to Recommendations).

Finding F: The PATBI Grants have effective infrastructure

The PATBI grants currently have three benefits in terms of infrastructure:

1. A shared point of contact with three other P&A programs at the ***federal level***.
2. A shared point of contact with at least five other P&A programs at the ***state level***.
3. A longstanding relationship with the TAC (NDRN), who has decades of experience working with state P&A systems.

Findings G & I: Flat funding has led to decreased services

Because PATBI grant funding is distributed by a legislatively mandated formula, and because total funding has remained flat for the last 13 years, states have not been able to advance TBI programmatic goals as much as they would like. While the cost of doing business has increased in the last decade, the level of PATBI resources has remained unchanged, which results in fewer services to individuals.

Finding H: Improved data collection is possible

The PATBI grants are well positioned to implement a new data collection process, which should benefit both state grantees and the program as a whole. One way for the PATBI program to receive more funding is to illustrate that it is a good steward of existing funding. Improved data collection, which includes not only basic counting statistics (such as clients served), but also includes outcomes and improvements, would allow the PATBI program to demonstrate the benefits it supplies to its clients.

STATE TBI GRANTS[7]

PROGRAM REVIEW

Legislative Overview

The State TBI program was established within HRSA in 1996 to "[carry] out demonstration projects to improve access to health and other services regarding [TBI]"[8]. This legislation mandated that all grantees possess a State Advisory Board and match federal funds at a $1:$2 ratio.

The 2000 legislation struck "demonstration" from the language and clarified that grant dollars were to be used for community services and supports and for state capacity building. HRSA began focusing on state capacity building, specifically encouraging states to develop the following four components of state infrastructure:

- Statewide TBI Advisory Board (mandated by the 1996 legislation)
- Lead State Agency
- Statewide needs/resources assessment
- Statewide action plan

In 2014, the legislation removed HRSA references, eventually leading to the transition of the program from HRSA to ACL.

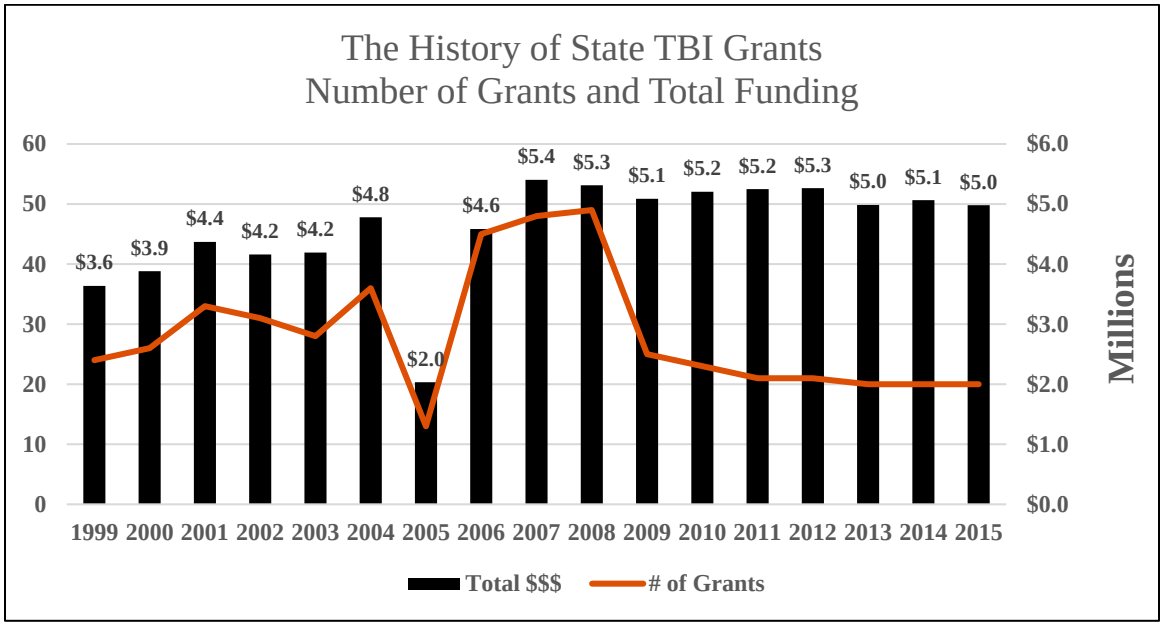
Budget

During the 20 years of the program's existence, both the number of grants and the total dollars have changed. Total funding has been relatively stable over the last 10 years, but the number of grants has not, ranging from 40+ state grants in 2006-08, to 20-25 grants in 2009–present (see Chart 3 on the following page).

[7] There have been various types of State TBI Grants, including Planning, Implementation, and Post-Demonstration grants. Within this section of the report these grants are referred to as State TBI Grants, which is a reference to the 1996 legislation that created this funding stream.

[8] Public Law 104-166 (July 29, 1996

CHART 3: STATE TBI GRANTS HISTORY



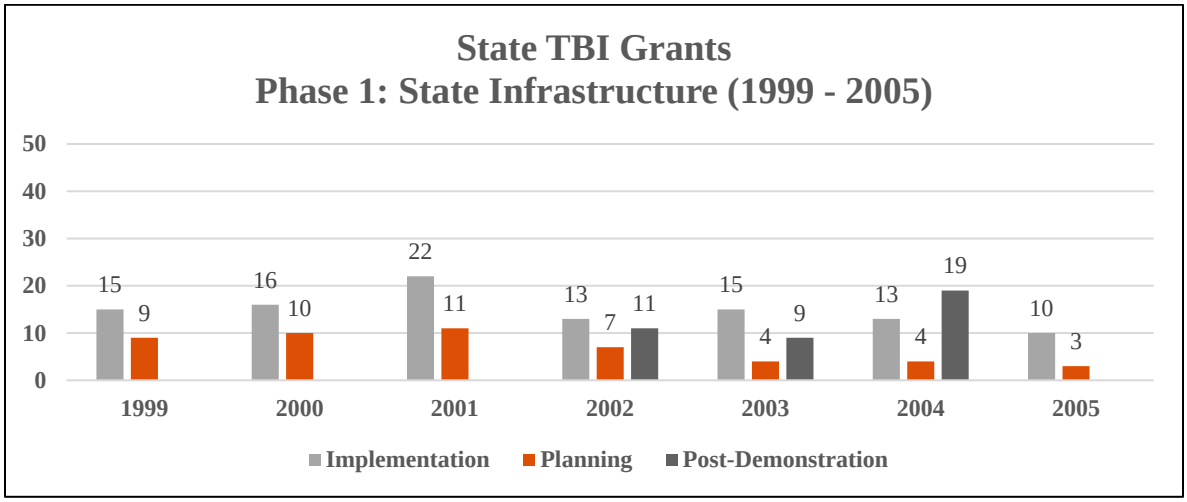
SOURCE: http://datawarehouse.hrsa.gov/Tools/FindGrants.aspx

Background: Phase 1

In the initial years of the State TBI Grants program, HRSA offered three types of grants, with a general focus on building and maintaining state infrastructure (see Chart 4 on the following page).

- **Planning:** Two year grants with funding of $75,000 per year. These grants were designed to improve state infrastructure.
- **Implementation:** Three year grants with annual funding of $200,000. States were required to exhibit the four components of state infrastructure when applying for these grants, which focused on program implementation.
- **Post-Demonstration:** One year grants worth $100,000. These grants were designed to build overall service capacity. Only states that had completed an Implementation grant were eligible for Post-Demonstration grants.

CHART 4: STATE TBI GRANTS PHASE 1



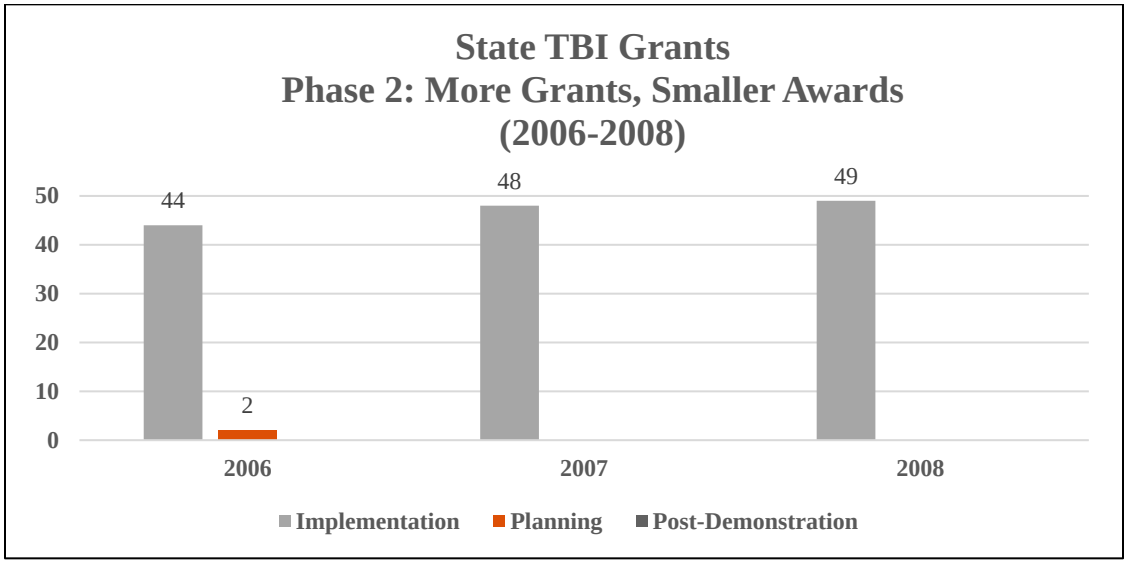
SOURCE: http://datawarehouse.hrsa.gov/Tools/FindGrants.aspx

Background: Phase 2

Beginning in 2006, HRSA focused on giving virtually every state and territory a grant. According to the Funding Opportunity Announcement released on August 5, 2005, the "major funding emphasis (was) on activities which will…improve access to comprehensive and coordinated TBI services". This language, along with the change in grant distribution, suggests that the program was moving away from state infrastructure building and towards demonstration projects.

In 2008, 49 out of 57 states and territories had State TBI Grants (see Chart 5 below), and each of those states and territories received over $100,000 in combined PATBI/State TBI Funding. South Dakota, Mississippi, and Louisiana were the only continental U.S. states to not receive a State TBI Grant in 2008.

CHART 5: STATE TBI GRANTS PHASE 2

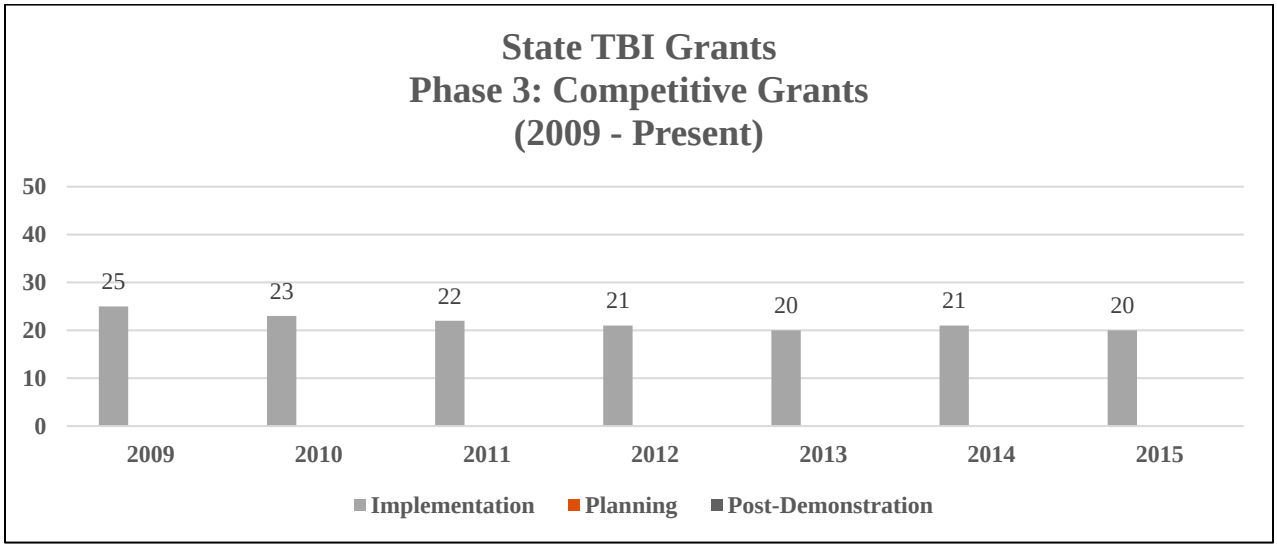


SOURCE: http://datawarehouse.hrsa.gov/Tools/FindGrants.aspx

Background: Phase 3

In recent years, HRSA made the decision to deliver fewer grants to the states (see Chart 6 below). The benefit of this model is that states who receive grants are eligible for larger awards ($250,000). Aside from funding reductions, the drawback to the states who do not receive these grants is that they become disconnected from the larger TBI community. They are unable to participate in conferences calls, webinars, or discuss best practices with other states.

CHART 6: STATE TBI GRANTS PHASE 3

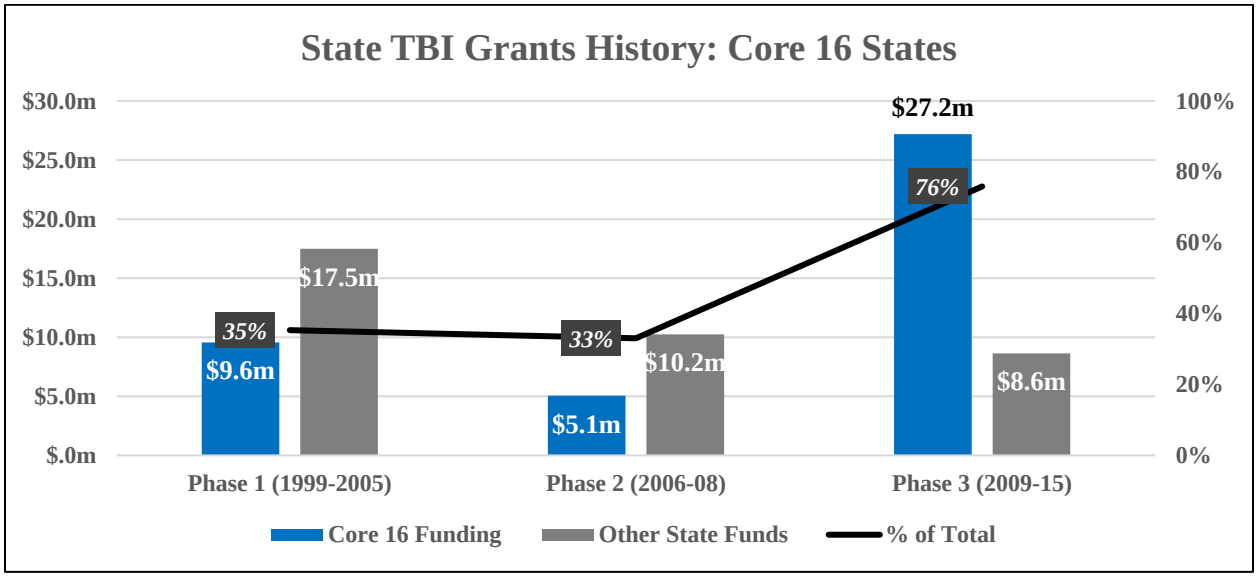


SOURCE: http://datawarehouse.hrsa.gov/Tools/FindGrants.aspx

The "Core 16"

A secondary result of the 2009 change in grant distribution was the creation of a core group of 16 states. As described in Chart 7 below, between 2009 and 2015 these 16 states received $27m of the roughly $36m that was available to the 57 states and territories (76%). Prior to 2009, these same states received only 35% of the available funds, which is consistent with the population level of these states.

CHART 7: CORE 16 STATES



SOURCE: http://datawarehouse.hrsa.gov/Tools/FindGrants.aspx

These 16 states are currently active in the TBI Model Systems program (an additional funding source available through NIDILRR), receiving 10 of the 16 available Model Systems grants (see Table 4 on the following page). As a result, these states are currently receiving a disproportionately large share of available TBI resources.

That these 16 states have benefitted from the competitive nature of the current State TBI grants should not be seen as an indictment of these states, but rather as a starting point for exploring the overarching goal of the program.

TABLE 4: CORE 16 STATES – TOTAL FUNDING, INCLUDING TBI MODEL SYSTEMS

State	Population	Current Funding	# of State TBI Grants Received	Total Dollars Received	Model Systems Projects
Alabama	4,817,678	$ 249,841	15	$ 2,653,240	1
Arizona	6,561,516	$ 249,791	12	$ 2,359,614	
Colorado	5,197,580	$ 250,000	16	$ 2,600,515	1
Idaho	1,599,464	$ 250,000	16	$ 2,840,389	
Indiana	6,542,411	$ 249,008	11	$ 2,091,834	1
Iowa	3,078,116	$ 250,000	15	$ 2,760,218	
Massachusetts	6,657,291	$ 249,315	13	$ 2,684,604	1
Missouri	6,028,076	$ 250,000	15	$ 2,665,657	
Nebraska	1,855,617	$ 250,000	15	$ 2,791,630	
New York	19,594,330	$ 250,000	15	$ 2,720,079	2
North Carolina	9,750,405	$ 250,000	12	$ 2,341,629	
Ohio	11,560,380	$ 245,485	14	$ 2,518,565	1
Pennsylvania	12,758,729	$ 250,000	14	$ 2,372,397	2
Tennessee	6,451,365	$ 250,000	15	$ 2,841,630	
Virginia	8,185,131	$ 250,000	14	$ 2,745,515	1
West Virginia	1,853,881	$ 250,000	15	$ 2,830,720	

SOURCES: http://datawarehouse.hrsa.gov/Tools/FindGrants.aspx; http://www.msktc.org/tbi/model-system-centers; http://www.census.gov/data.html

Developing State Infrastructure

In the initial years of the State TBI Grants program, HRSA focused on the four components of state infrastructure:

1. Statewide TBI Advisory Board (mandated by the 1996 legislation)
2. Lead State Agency
3. Statewide Needs/Resources Assessment
4. Statewide Action Plan

This focus on infrastructure enabled HRSA to understand each state's ability to develop a system of care for individuals with TBI. In particular, the creation of a State TBI Advisory Board and Lead State Agency allowed HRSA to gauge state capacity and identify points of contact within each state.

During CGC's stakeholder interviews, NASHIA mentioned that while acting as the TAC for the State TBI Grants they maintained a state registry of resources, with each state's points of contact and the status of their infrastructure components listed. As the program has transitioned to a focus on competitive projects, it no longer maintains a state resource registry. Yet given the limited number of states who currently receive grants, the program could benefit from the creation of a state registry, which would supply ACL with more knowledge about state capability and better

data to illustrate the impact of initial infrastructure efforts. The registry could also inform decision making around the disbursement of the State TBI Grants.

Contractor Support

Since the inception of the TBI Grants Program, four contractors have provided primary technical assistance to the State TBI grantees. These four contractors are described below:

- Children's National Medical Center (1997-2002) & NASHIA (2002-2009): In the program's initial years, HRSA relied heavily on industry experts, which included staff at NASHIA. According to the 2006 Institute of Medicine (IOM) report, "many of the administrative duties of the HRSA TBI Program are the responsibility of the TBI Technical Assistance Center".
- NORC (2009-2014): Eventually HRSA decided to hire a contractor who did not possess a specific TBI focus, yet NORC continued to employ subject matter experts and provide administrative support to the program, including meeting facilitation and website maintenance.
- Grant Thornton (2014 – Present): In 2014 HRSA decided to award the TBI TAC to Grant Thornton, in part because of a desire for greater technological expertise, and in part because of HRSA's increased confidence in its ability to handle many of the administrative details that had typically been supplied by the TAC. The decision to change the contract was made prior to the 2014 legislation which allowed HHS to move the program from HRSA to ACL.

KEY FINDINGS

CGC discovered the following three findings through analysis of State TBI Grants information and state interviews (see the chart on Page 6 for additional information, including links to Recommendations).

Finding A: There is a desire for a grant disbursement process that rewards states with established infrastructure while retaining connections to all 57 states and territories.

Many stakeholders interviewed for this analysis believed that there is a need for (a) all states and territories to receive a grant, and (b) increased funding for established states. This goal can be accomplished, but only if the minimum funding amount for states who do not receive a competitive grant is limited - $5,000-$10,000. ACL might think creatively about using this small amount of funding to maintain connections with those states who do not receive competitive grants.

Finding B: The role of ACL's programmatic staff and the corresponding role of the TBI TAC require definition.

As the new managers of this program, ACL must determine what level of support they expect to provide to the state grantees, and what corresponding level of support they need from a Technical Assistance Contractor (TAC). Specifically, ACL must decide how much technical support, administrative assistance, and subject matter expertise it requires from the TAC and what it will accomplish apart from the TAC. Decisions in these three areas will help determine the scope of TAC work and the type of contractor to accomplish that scope.

Finding J: There is a desire for a registry of state resources

Given that there are only 20 current State TBI grantees, information about state TBI capability is limited in the majority of states and territories. While stakeholder groups like NASHIA and BIAA have access to certain information, there is not a single source of general TBI information for each state. As a Federal program, ACL can benefit from a collection of national resources, even if funding disbursement remains focused on a portion of the total population. A comprehensive state registry might include a list of traditional TBI infrastructure components (e.g. Advisory Board, Action Plan, etc.), as well as a list of state programs and resources, like trust funds, hospital registries, and state funding streams.

COORDINATION

OVERVIEW

Given the limited funding streams available to both grant programs, coordination of resources is an important component of the PATBI and State TBI grant programs. While coordination of resources within states and between states is an important feature of this program, so too is federal coordination.

REVIEW

At the state level the Technical Assistance Contractors (TACs) for both programs (NDRN for the PATBI grants; Grant Thornton for the State TBI grants) have historically provided a host of coordination activities, including webinars, conference calls, in-person conferences, and online resources (i.e. listserve and central website).

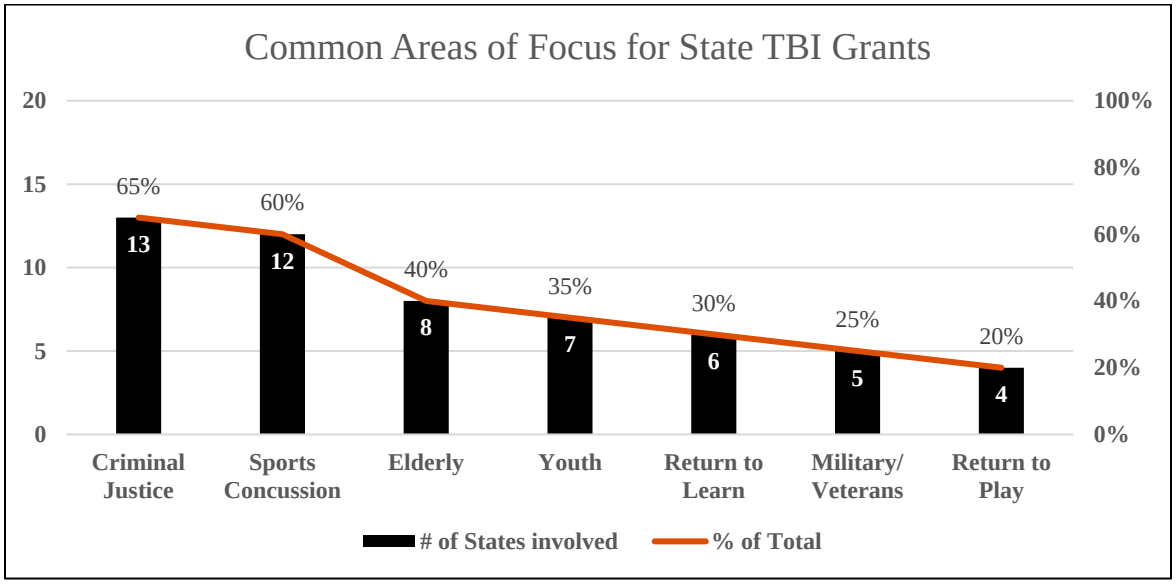
Grant Thornton conducted an assessment of the 20 State TBI grantees in February and March of 2016, and of the five "Grantee Expectations" listed on Slide 2 of the "*Assessment of Individualized Technical Assistance Needed*", the most widely cited were:

- Connect Grantees with Each Other to Share TBI Resources and Best Practices
- Introduce a user-friendly TBICS[9] and Listserv

These expectations were consistent with what has been traditionally provided to states and what the nine states interviewed by CGC described as areas of need or interest.

There is a specific need for state-to-state coordination because of overlapping interest in specific TBI sub-populations. As seen below, the State TBI grantees focus on a small list of sub-populations, including individuals in the criminal justice system and youth involved in sports.

CHART 8: COMMON FOCUS AREAS



SOURCES: http://datawarehouse.hrsa.gov/Tools/FindGrants.aspx; Grant Thornton Program Issue Summaries (2015)

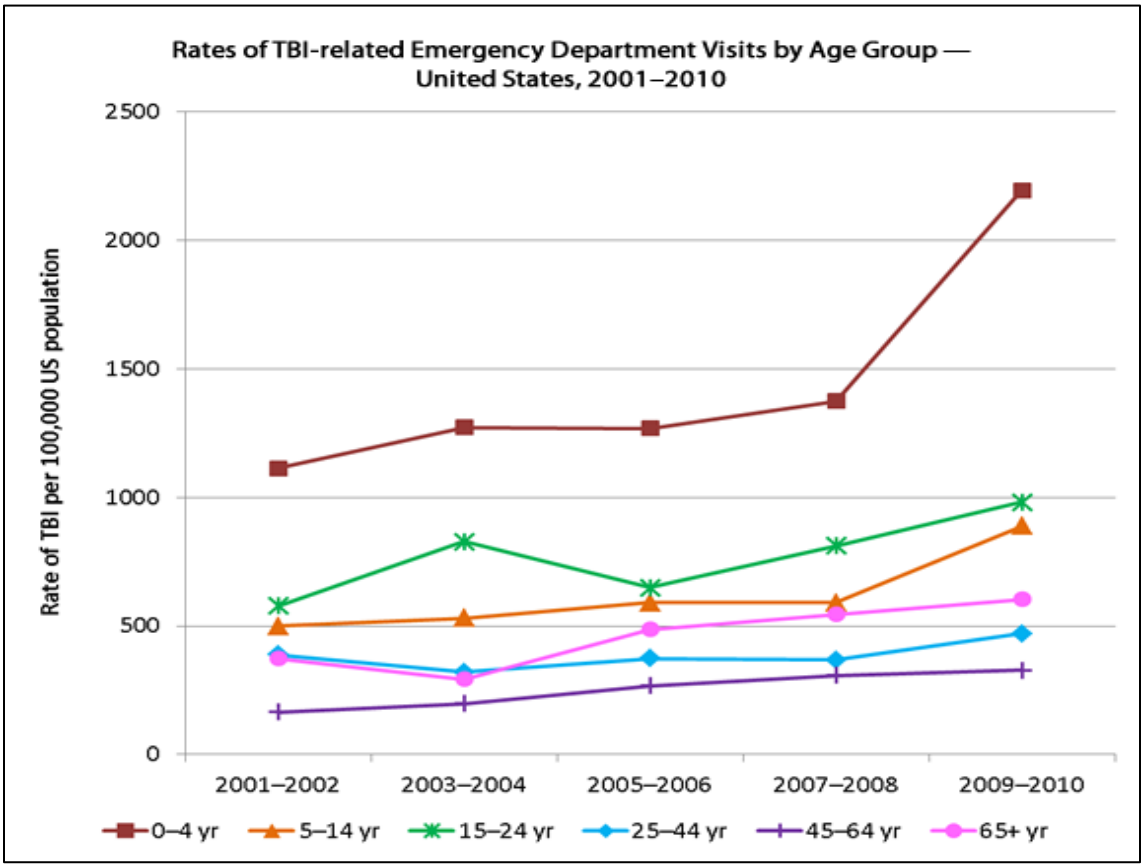
[9] TBICS: Traumatic Brain Injury Coordination Space, the web portal traditionally available to State TBI Grantees

It is also worth exploring if the populations that state grantees currently work with fulfill the program's goals. For example:

- Which population(s) are the most affected by TBI?
- Which systems are the most prepared to positively impact certain populations?

Data from the Center for Disease Control and Prevention (CDC)'s website linked to the National Hospital Ambulatory Medical Care Survey indicate that the very young (ages 0 to 4) are at the greatest risk of a TBI-related emergency department (ED) visit[10]. Moreover, the same survey indicates that 73% of all ED visits for those between the ages of 0 and 4 occur due to falls[11]. This type of information should impact grantee awards and funding criteria.

CHART 9: EMERGENCY DEPARTMENT VISITS BY AGE GROUP



One way to link grantee actions with emerging research is to improve federal coordination. The idea of improving coordination at the federal level was highlighted in the 2006 Institute of Medicine (IOM) report entitled, "Evaluating the HRSA Traumatic Brain Injury Program".

In the Executive Summary of that report, IOM made the following recommendations:

[10] SOURCE: http://www.cdc.gov/traumaticbraininjury/data/rates_ed_byage.html

[11] SOURCE: http://www.cdc.gov/traumaticbraininjury/data/dist_ed.html

> "[The TBI Grants program]…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.
>
> "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***". (emphasis added)

In response to the IOM report, HRSA formed a Federal Interagency Committee (FIC) on TBI in 2011. In their initial invitation to potential partners, HRSA referenced the IOM report's recommendation to "issue and lead a formal call to action". The invitation also noted HRSA's intention "…to maximize collaboration and coordination of programs relevant to families affected by traumatic brain injury at the Federal level". The committee's plan was to have two annual all-day meetings and two annual conference calls. As the TBI Grants program transitioned from HRSA to ACL, the Federal Interagency Committee (FIC) meetings were suspended.

While there are other federal coordination activities currently in place, none of them adequately address the initial goals of the FIC meetings, which included:

- Promoting greater visibility of federal TBI programs;
- Communicating research findings to clinical practitioners;
- Encouraging communication at the highest levels of each agency involved with TBI, to maximize resources and identify opportunities for collaboration;
- Developing action plans for associated Federal TBI programs that include blueprints for ongoing data collection, program evaluation, and communication of information across agencies;
- Promoting best practices in screening for TBI; and
- Disseminating best practices for ensuring access to services following TBI, including systems infrastructure development.

KEY FINDINGS

CGC discovered the following three findings through an analysis of past and current coordination activities, which included stakeholder interviews (see the chart on Page 6 for additional information, including links to Recommendations).

Finding C: There is a gap in federal coordination meetings

While the actual FIC meetings did not produce the tangible products some stakeholders had expected, the goal(s) of those meetings were supported by the 2006 IOM report, and they remain valid today. In particular, one or more stakeholder groups mentioned all of the following FIC interests in interviews:

- Sharing research with practitioners;
- Communicating best practices; and
- Maximizing federal resources and encouraging collaboration

Finding D: There is a desire for an annual TBI conference, with an open invitation to all stakeholders

During stakeholder interviews, representative from multiple groups – including states, federal agencies, and non-profit groups – mentioned annual in-person conferences as a preferred way to increase knowledge and connect with other stakeholders. At one time HRSA ran an annual conference that was open to all states and territories, but that conference ceased to exist after federal guidance restricted the availability of conference funding.[12]

Finding E: Stakeholders at all levels would like frequent access to information

Historically, the TBI Grants program has had a number of coordination efforts, particularly at the state level. Yet many of those efforts were targeted to specific groups. For example, conference calls or webinars about projects related to youth sports only involve (a) current state TBI grantees who (b) run projects focused on the youth sports population. While limiting participation in certain meetings or conferences is sometimes necessary, it is also important to create mechanisms to share the work being done with the broader TBI community. This applies to project work, research work, and data collection. While not all TBI stakeholders can attend every conference or participate in every webinar, increasing access to and transparency of information will improve coordination at all levels.

[12] https://www.whitehouse.gov/sites/default/files/omb/memoranda/2012/m-12-12.pdf

NEXT STEPS

In summary, the seven recommendations identified through the As-Is assessment are listed below. Most of these recommendations require additional definition and a process for implementation. CGC intends to validate these recommendations with core ACL staff members, and then define the process for taking action through a future state, or "To-Be", assessment. The To-Be assessment is scheduled to begin in October 2016 and be completed by January 2017.

- Define State TBI grant disbursement process.
- Define roles and responsibilities.
- Resume Federal Interagency Committee (FIC) meetings.
- Resume the annual TBI conference.
- Create a single, fully transparent web portal for all stakeholders.
- Adopt the NDRN data collection tool for the PATBI grants.
- Define and collect TBI metrics.