# PERFORMANCE MEASURES FOR THE TRAUMATIC BRAIN INJURY STATE PARTNERSHIP GRANT PROGRAM

Supporting Statement for Paperwork Reduction Act Information Collection Request

#### A. JUSTIFICATION

#### 1. Circumstances Making the Collection of Information Necessary

The Administration for Community Living (ACL) is requesting approval from the Office of Management and Budget (OMB) for data collection associated with the management of its Traumatic Brain Injury State Partnership Program. The purpose of the federal Traumatic Brain Injury (TBI) State Partnership Program is to create and strengthen a system of services and supports that maximizes the independence, well-being, and health of people with TBIs across the lifespan and all other demographics, their family members, and support networks. The TBI State Partnership Program funds the development and implementation of statewide systems that ensure access to TBI related services, including transitional services, rehabilitation, education and employment, and long-term community support. To best monitor, guide, and support TBI State Partnership Program grantees, ACL needs regular information about the grantees' activities and outcomes. The simplest, least burdensome, and most useful way to accomplish this goal is to require grantees to submit information as part of their required semiannual reports via the proposed electronic data submission instrument (Appendix A).

In 1996, the Public Health Service Act was amended "to provide for the conduct of expanded studies and the establishment of innovative programs with respect to traumatic brain injury, and for other purposes" (Public Law 104–166). This legislation allowed for the implementation of "grants to States for the purpose of carrying out demonstration projects to improve access to health and other services regarding traumatic brain injury." The TBI Reauthorization Act of 2014 (P.L. 113-196) allowed the Department of Health and Human Services Secretary to review oversight of the federal TBI programs (TBI State Partnership Grant program and the TBI Protection and Advocacy program) and reconsider which operating division should lead them. With avid support from TBI stakeholders, the Secretary found that the goals of the federal TBI programs closely align with ACL's mission to advance policy and implement programs that support the rights of older Americans and people with disabilities to live in their communities. As a result, on Oct. 1, 2015, the federal TBI programs moved from the Health Resources and Services Administration to ACL. These programs were reauthorized again by the Traumatic Brain Injury Reauthorization Act of 2018 (P.L. 115-377).

The proposed performance measures are consistent with both the TBI State Partnership Program's purpose and also ACL's mission.

The 2010 Government Performance Results Modernization Act<sup>1</sup> requires federal agencies to develop annual and long-term performance outcome measures and to report on these measures annually. ACL sees the GPRA Modernization Act as an opportunity to document annually the results that are produced through the programs it administers under the authority for the TBI State Partnership Program. It is the intent and commitment of ACL, in concert with grantees, to use the performance measurement tools of GPRAMA to continuously improve its programs and services.

## 2. Purpose and Use of the Information Collection

Through regular performance reports, federal agencies provide detailed information on their progress in meeting program performance objectives. Congress and OMB use performance information to inform budget decisions. Many state and local governments are requiring similar systems of accountability to document results and justify funding. Performance measures allow ACL to monitor and assess grantees' progress and to ensure grantees are making progress toward these agency and the grant program goals:

- Research-based Practices: Use existing research-based knowledge, state-ofthe-art systems development approaches, and the experience of previous TBI grantees in meeting program goals.
- Funding: Implement management and workforce practices that support the
  integrity and efficient operations of programs serving people with disabilities and
  older adults and ensure stewardship of taxpayers' dollars.
- **Health & Well-being:** Advance the health, safety, and well-being of all Americans including people with disabilities and older adults.
- Interagency Collaboration: Coordinate between relevant federal agencies and programs to identify, strengthen, and enhance cross-agency collaborations that focus on serving individuals with disabilities and their families.
- Access to Services and Supports: Empower individuals with TBI and their families to access home and community-based services and supports that ensure opportunity for full and meaningful community participation.
- Social Integration: Maximize the integration and full inclusion, including employment, of older adult individuals with disabilities into society.
- Advocacy/Public Awareness: Ensure individuals and their support systems engage and participate in their communities, make informed decisions, and exercise self-determination and control about their independence, well-being, and health.
- Consumer Satisfaction: Ensure individuals and their caregivers feel services
  are accessible, of a high quality, and essential to assist them with remaining in
  the community or preventing unnecessary institutionalization.

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<sup>&</sup>lt;sup>1</sup> http://www.gao.gov/key issues/managing for results in government/issue summary

 Services: Assist states to develop high quality, person-centered, and integrated systems that seamlessly address the health and long-term services and supports needs of people with disabilities and older adults.

## 3. Use of Improved Information Technology and Burden Reduction

ACL plans to collect this information using a web-based data collection system. Skip patterns and data validation checks will be programmed into the system so ACL grantees are only responsible for answering those questions relevant to their program and do not have to reenter unchanged data. In addition, the data entry portal will include guidance, definitions of terms, and other information to support data collection and submission. The portal will be available at all times, with the exception of when maintenance is required, so that grantees can submit their data at their convenience in advance of the semi-annual reports.

## 4. Efforts to Identify Duplication and Use of Similar Information

There is no other governmental or nongovernmental ongoing program to collect systematic data on the performance of TBI State Partnership Program grantees over the course of their funding cycles.

## 5. Impact upon Small Businesses or Other Small Entities

The proposed data collection does not involve small businesses or other small entities. Data will be submitted only by state-level TBI grantee organizations.

## 6. Consequences of Collecting the Information Less Frequently

Semiannual data collection is the minimal frequency that permits meaningful program and policy activities. Administrative and legislative decisions regarding TBI programs require the semiannual collection of data. Semiannual data collection is supported by the state grantees for the following reasons:

- Once the state grantees receive training to submit the performance measures data, semiannual reporting is a minimal burden.
- Semiannual data collection enables grantee states to maintain the interest, commitment, and expertise necessary for participation. The selected performance measures will help the grantees to maximize their success and make needed adjustments over the course of their funding cycles, and after federal funding ends. Less frequent collection may result in increased burden due to the need to retrain staff.

#### 7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

This data collection request is fully consistent with the guidelines in 5 CFR 1320.8(d). There are no special circumstances required for the collection of

information in this data collection.

- Report Information More Often than Quarterly. There are no circumstances
  that could result in the data needing to be collected more frequently than
  quarterly. The proposed schedule of data submission is twice per year.
- Requiring Response in Less than 30 Days. There are no circumstances that could result in a state needing to respond in less than 30 days. States will be formally notified of their reporting responsibilities when their grant cycle begins; therefore, grantees will have more than 6 months to respond.
- Requiring Respondents to Submit More than One Original and Two Copies. ACL plans to have grantees submit the Semiannual Performance Measures Report using a web-based data collection system.
- Requiring Respondents to Maintain Records for More than 3 Years. Only data
  for a given funding year are required. Because states extract data from their
  administrative databases, their source data are maintained for state
  purposes. ACL will archive each state's submission and will provide the state
  with prior data submissions, as needed. States will not need to retain their
  submissions.
- In Connection with a Statistical Survey. These data are not collected as part of a statistical survey.
- Use of a Statistical Data Classification that Has Not Been Approved by OMB. This data collection does not require the use of statistical data collection.
- Pledge of Confidentiality. No actual case or individual identifiers will be submitted. No identifying data (e.g., name, address, Social Security number) will be collected.
- Requiring Respondents to Submit Trade Secrets or Other Confidential Information. The Semiannual Performance Measures Report will not collect any data related to trade secrets. No identifying data on any individual will be collected.

A Privacy Act "system of records" is defined as "a group of any records under the control of any agency from which information is retrieved by the name of the individual or by some identifying number, symbol, or other identifying particular assigned to the individual" (The Privacy Act of 1974, 5 U.S.C. § 552a). The TBI Semiannual Performance Measures Report does not fall under Privacy Act system of records requirements. No identifiable data will be collected or maintained.

# 8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency

ACL published a 60-day Federal Register Notice from 11/13/2017-01/12/2018 (Vol. 82, No.217 pp. 52305-52306). ACL received a large volume of substantive stakeholder comments, causing revisions to the IC based on those public comments. The period in publication between the 60-day FRN and 30-day FRN, allowed ACL to thoughtfully review and apply the significant number of substantive public comments to the proposed new TBI IC.

In response to the original federal register notice in 2018, twenty-three (23) individuals provided written comments in response to the federal register notice containing the original proposed TBI Performance Measures, presented in the form of a reporting instrument for future TBI grantees. Commenters provided feedback on specific reporting instrument questions as well as general suggestions and recommendations for ACL about what grantees should report.

- 268 separate comments were made about one or more specific survey questions.
- 102 separate comments asked for a definition, further guidance, or clarification with regard to terminology used.
- 81 comments made a general recommendation, not specific to a particular question

ACL also received feedback in 2018 through multiple face-to-face interactions with a majority of the current TBI grantees regarding the proposed measures.

ACL revised the instrument in 2019, in order to remain compliant with PRA 5 CFR 1320.8(d), ACL published an abbreviated public comment period prior to publishing the 30-day FRN and submitting to OMB. ACL solicited comments during the abbreviated public comment period regarding: (1) the accuracy of ACL's revised estimate of the burden for the proposed collection of information performance reporting data elements and (2) whether the proposed revisions to the collection of information enhance the quality, utility, and clarity of the information to be collected.

During the abbreviated public comment period published in the 83 FR 53738 received 14 additional comments. These comments have been addressed largely through the addition of definitions and guidance. The tool has been simplified, some questions have been eliminated or simplified because of concern about the burden, and three open-ended narrative questions added.

The most prevalent comments and themes emerging from the public comments are summarized below:

Intended scope of the questions: The suggestion that occurred most across all commenters was for ACL to better define the scope of the questions. Many commenters asked whether ACL expected grantees to limit their reporting to their own grant activities, the staff they train with the grant funds, and the people with TBI they interact with using grant funds or if they would be expected to report about activities going on in the state beyond their grant activities. Commenters raised the issue of intended scope in general and specifically about almost all the questions in the instrument. Several commenters noted that the grants were awarded to different types of state agencies in different states a nd the reporting instrument did not make clear what ACL meant by the term "TBI System," which could be interpreted to mean different things such as: the Medicaid system, the criminal justice system, the educational system, the vocational rehabilitation system, the broader medical system, or all of these together. Many indicated that grantees would have limited or no access to data about activities or people supported outside the grant activities being conducted by their own partnering organizations.

**Response and Changes to Instrument:** ACL intends for TBI grantees to report only about their own grant activities, the staff they train using grant funds, the partners they work with, and the people affected by TBI they interact with using grant funds. Additional guidance and definitions will be added to the online version of the instrument to clarify this intent and provide more guidance for grantees operating in different systems. For example:

- If a grantee is using grant funds to serve people with TBI within the criminal justice system statewide, the scope of their reporting will be limited to the statewide criminal justice system.
- If a grantee is using their grant funds to assist people interacting with the vocational rehabilitation system in one region of the state, the scope of their reporting will be limited to that region's vocational rehabilitation system.
- If grant funds are going to several partnering organizations to work with people with TBI, the scope of that grantee's reporting will include the grant-funded activities of all of those partnering organizations (to the extent possible).

In addition, ACL added some new structured and open-ended questions to the instrument to allow grantees to identify their main areas of focus and describe report full or partial data from across their partners depending on what they can access.

Purpose of performance measures and accounting for state and grantee differences: Several commenters indicated they thought the instrument did not adequately account for the differences in how state systems are structured and the different focus areas of different grantees. Several commenters expressed concern

that individual grantees would be negatively evaluated. Specific questions were edited to allow for grantees that are not able to provide data about activities and people outside of the scope of their grants or are otherwise not able to respond to every question.

Response and Changes to Instrument: ACL does not intend to use this reporting instrument to score grantees' individual performance or to compare grantees' performance with one another. ACL's intent is to gather a standard set of information from all grantee states, so that it can be aggregated to provide a better picture of the national impact of the grant program. However, ACL understands that states are working within different systems and focusing on different activities and that states' current capacity to collect and report data varies. ACL anticipates that some grantees will not be able to respond to every question on the instrument and this will not negatively affect those grantees. ACL hopes that every question will be applicable and feasible to answer for at least a subset of grantees, therefore providing a more complete (although not perfect) picture of grant activities than is currently available.

ACL revised the instrument questions to account more for state and grantee differences. For example, new structured and open-ended questions have been added at the beginning of the instrument to allow grantees to identify their main areas of focus and describe where the data they report are coming from so that ACL can interpret it appropriately. Using skip patterns programmed into the online tool, additional questions related to these areas of focus will only appear to grantees who indicate they are working in those areas. ACL will program the instrument into the online system so that some grantees may be directed to answer or not to answer some questions depending on how they answer initial questions about their grant activities and scope. Finally, an additional field has been added to most questions to allow grantees who do not respond or who can only respond partially to provide some descriptive notes about the data they submit.

Estimating prevalence and unmet need: Several commenters noted that reporting the prevalence of TBI and estimating the needs of people living with a TBI and their families would be very challenging for many grantees. Some noted that many states do not have registries or good/recent epidemiology data. Others indicated grantees would have no way of estimating the number of people who might need supports but are not accessing them. Several suggested that grantees might be able to respond to these questions if additional funding and/or technical assistance to carry out further study are provided.

**Response and Changes to Instrument:** These questions have been eliminated from the proposed instrument.

**Defining services and supports:** Several commenters expressed concern that the instrument asked questions about "services and supports" and wondered what ACL means by that term. Noting that grantees are currently focusing on system change work and are not allowed to use grant funds to provide direct in-home hands-on services and supports, some asked whether the funding announcement for new grants will include a different set of objectives and scope than they have in the past. Finally, several commenters interpreted the term to mean Medicaid home and community-based services and noted that not all states have a TBI Medicaid waiver. Those that do not are not likely to be able to access information about participants in other Medicaid waivers who are living with a TBI, so they would not be able to report about people with TBI receiving Medicaid services and supports.

Response and Changes to Instrument: ACL does not intend for grantees to use grant funds to provide direct in-home hands-on services and supports, such as those provided through Medicaid HCBS programs. The instrument's questions were revised to ask more clearly about the specific types of ways grantees may be assisting or supporting people with TBI and their families, such as with information and referral, screening, resource facilitation, service coordination/case management, outreach and education, building stronger partnerships, and other systems change work.

The remaining questions about utilization of home and community-based services and supports are intended to capture information about the extent to which people with TBI who are eligible for these types of services are accessing them, which may be an indicator of long-term systems change that grantees are working towards. These questions will only be applicable to grantees specifically working to increase access to and utilization of home and community-based services in their states.

*Medically oriented questions:* Several commenters expressed confusion about the instrument including questions they interpreted to be medically oriented, such as questions about technological tools, diagnosis, and treatment. They noted that grant activities might include screening people to identify a history of TBI and/or to better support people with TBI to live more fully in the community – but not diagnosis or medical treatment. They noted these questions would not be applicable to many grantees nor would grantees have access to data about diagnoses and treatment.

**Response and Changes to Instrument:** The instrument questions have been revised to ask more clearly about the specific ways grantees may be assisting people with TBI and their families, such as by screening for a lifetime history of TBI and facilitating access to community-based services. Questions about diagnosis and treatment are removed.

A 30-day Federal Register Notice published in the FR 85 6198 on February 4, 2020.

## 9. Explanation of Any Payment or Gift to Respondents

No payment to respondents is required as part of this data collection.

## 10. Assurance of Confidentiality Provided to Respondents

As no individuals are identified in the data collection process and all data are group-level, no assurance of confidentiality will be needed.

## 11. Justification for Sensitive Questions

The data collection instruments will not collect any data of a sensitive nature.

#### 12. Estimates of Annualized Burden Hours and Costs

The annual burden estimates are shown below.

Instrument	Number of Respndents	Number of Responses (per respondent)	Average Burden Hours (per response)	Total Burden Hours
Semiannual Performance Measures Report	27	2	8	432
Estimated Tota	432			

States will likely expend varying amounts of time completing data submissions. The estimate above is based upon states that invest considerable attention to submitting comprehensive, accurate data.

The estimate of future levels of effort assumes the following:

- The length of the grant funding is three years, except for the three grants awarded in FY19 that will only have funding for two years.
- The annual burden may decrease after the first entry of data into the system by the grantees. Once the data for the first report has been entered, subsequent reports will only require updated data and, therefore, less effort.
- The annual burden may decrease if the same individuals compile the required data, because they will become more adept at finding the information and submitting the report.

The estimated Performance Measures Report annual burden is based upon an average hourly salary of \$46.00 for state programmatic staff. Across all respondents,

assuming a group of 27 grantees, the programmatic staff total average annual burden is estimated at 432 hours at \$46 per hour for a total of \$19,872.

# 13. Estimates of Other Total Annual Cost Burden to Respondents and Record Keepers

Because the Semiannual Performance Measures Report data collection effort depends upon the existing state grantee administrative information systems, states will not incur special data collection costs. Most of the data collected are standard data used by the grantee agency. Operating costs of the information systems are part of state agency operations and are not maintained solely for the purpose of submitting the Semiannual Performance Measures Report.

#### 14. Annualized Cost to the Federal Government

The annual cost to the federal government is shown in the following table.

AGENCY	YEAR 1	YEAR 2	YEAR 3	AVERAGE
ACL	\$7,108	\$7,108	\$7,108	\$7,108
Contractor Staff	\$150,000	\$150,000	\$150,000	\$150,000
Total	\$157,108	\$157,108	\$157,108	\$157,108

The above costs are based upon:

- 1. ACL staff oversight of 5% time for a GS 12 and
- 2. The use of contractor staff to compile, process, and analyze the Semiannual Performance Measures Report. Contractor staff may also provide TA to states to help them submit quality data in the Semiannual Performance Measures Report. Federal staff direct and monitor all efforts. Contractor costs are based on a review of existing contracts for similar services.

## 15. Explanation for Program Changes or Adjustments

The burden estimates presented here represent a significant reduction in estimated burden compared to the initial proposed IC in January 2018. At that time, ACL estimated there would could be as many as 45 grantees and each report would require 16 hours of grantee time to complete or 32 hours per year total. This submission to OMB includes our revised burden estimates based on how the proposed instrument has been shortened in length, narrowed in scope, and simplified in terms of the data requested. The specific changes to the data collection instrument that produce these reductions in burden are described under Question 8 above. This is a new information collection with a program change increase of 432 annual burden hours.

## 16. Plans for Tabulation and Publication and Project Time Schedule

The highlights of the semiannual data collection schedule are as follows:

- June 1 Funds are awarded to grantees
- December 1 Semiannual grant period closes
- December 31 Semiannual Performance Measures Reports are due
- January 1-February 28 Data extraction, compilation, and analyses
- May 30 Annual grant period closes
- June 30 Semiannual Performance Measures Reports are due
- July 1-August 30 Data extraction, compilation, and analyses

## 17. Reason(s) Display of OMB Expiration Date is Inappropriate

The expiration dates will be displayed on the data collection instructions and instruments.

## 18. Exceptions to Certification for Paperwork Reduction Act Submissions

No exceptions to the above certification are being sought.