

September 10, 2019

RE: Request to publish abbreviated public comment period prior to 30-day FRN and OMB submittal for the Traumatic Brain Injury (TBI) State Partnership Program 0985-New

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. ACL believes this gap in publication was necessary to enhance the quality, utility, clarity, and minimize respondent reporting burden to the TBI data collection elements. ACL used this time for review of all the feedback from stakeholders and the public applying substantive revisions to the IC published in November. In previous collection cycles the TBI gathered information from the FOA 0985-0006 a generic IC, which is significantly different from the proposed new program specific TBI IC. The proposed new TBI IC is required for usage in December 2019, publishing a second 60-day FRN for public comment on the substantive IC revisions since the January 2018 60-day FRN would cause significant delay in meeting the December statutory deadline. In order to remain compliant with PRA 5 CFR 1320.8(d) and meet the December 2019 statutory deadline, ACL requests approval to publish an abbreviated public comment period prior to publishing a 30-day FRN and submittal to OMB. An abbreviated public comment period will allow stakeholders and the public to review the substantive revisions based on the previous public comment period and ACL submittal to OMB for review, comment and approval prior to December 2019. ACL proposes the publication of a two or four week public comment period for review of the substantive revisions allowing any possible additional comments be submitted to ACL prior to submittal to OMB on publication of the 30-day FRN. Although, ACL does not believe there will be any further substantive comments from stakeholders; in order to adhere to the PRA this option serves as an ideal work around. If this option is, allowable ACL will publish an abbreviated comment period with a preamble in the notice informing the public of the purpose. At close of the abbreviated comment period, ACL will publish the 30-day FRN and submit to OMB for review, comment and approval. Below is a summary of the comments and changes to the estimates in annual reporting burden for your determination review.

Comments in Response to the 60-day Federal Register Notice

Federal Register November 13, 2017 vol. 82, Number 217; pp. 52305-52306

Summary of comments

- Twenty-three (23) individuals provided written comments in response to the proposed new TBI Performance Measures instrument.
- 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.

Most prevalent themes and responses

Intended scope of the questions: The most frequently repeated suggestion 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 noted that the grants were awarded to different types of state agencies in different states and 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: 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 a TBI they interact with using grant funds. Additional guidance and definitions will be added to 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 impact people with TBI within the criminal justice system statewide, the scope of their reporting should be 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 should be 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 should be the grant-funded activities of all of those partnering organizations (to the extent possible).

ACL added some new structured and open-ended questions at the beginning of the instrument to allow grantees to identify their main areas of focus and describe the basis of the data they are reporting; this will better allow ACL to interpret respondent information. ACL edited specific questions to allow grantees to report full or partial data from across their partners depending on their access level(s).

Purpose of performance measures and accounting for state and grantee differences: Several commenters indicated thoughts on the instrument adequately accounting for the differences in State systems structure and the different focus areas for different grantees. Several commenters expressed concern that individual grantees would be negatively evaluated and/or the impact of their work would be misunderstood if grantees are asked 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: ACL does not intend to use this reporting instrument to evaluate grantees' individual performance or to compare grantees' performance with one another ACL's intent is to gather a standard set of information from across as many states as possible, 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 that is fine. 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 also revised the instrument questions to account more for state and grantee differences. For example, some new structured and open-ended questions may be 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. ACL will also consider ways to revise the instrument 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, additional multiple choice answer options will be added to each question that will allow grantees who do not respond or who can only respond partially to indicate why (e.g., this question does not apply to our grant activities, this question applies but no data are available, this question applies but only some of the data are available).

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: ACL has heard from many stakeholders that they would like more information about people living with TBI and to what extent they are receiving formal services and supports if they need them, because there are not adequate state or federal data sources. ACL understands that some states have already carried out studies or conducted needs assessments that may allow them to respond to some of these questions, while others have not. By asking grantees to report information if they have it, ACL hopes to be able to provide the field with more information than is available now.

The instrument will also be revised to include a place for grantees who can respond to these questions to describe what (if any) surveillance work or needs assessment they conducted, what data sources they used, and how they developed estimates of need so this information might be used to inform other grantees.

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: ACL does not intend for future grantees to use grant funds to provide direct in-home hands-on services and supports, such as those provided through Medicaid HCBS programs. Some questions will be 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. These may also ask for information about the grantees’ ability to provide these types of supports for everyone who requests them.

Other 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 system changes that grantees are working towards. These questions would 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 may 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: The instrument questions were 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 will be revised or removed.

Selected Representative Comments

- We recommend that the program **establish overall grant goals**, such as increased identification, increased employment, community living and integration; expanded services, improved quality; etc., and then, the state should identify the strategies that are necessary to obtain the goal (e.g., screening, training, certification, core competencies, data, policy, funding). The outcome measures may relate to number of individuals screened, identified and referred; number of trained professionals and providers; increased numbers receiving specified services and supports; and increased system's capacity for services (e.g., increased or new funding, increased number of providers).
- We feel that the amount of funding available to individual states is not adequate to support projects that would provide substantive and sustainable direct services. We would be opposed to ACL reducing the overall number of grant awards in an effort to assure the viability of direct service initiatives. Virginia maintains – and many other states agree – that we have been able to introduce and implement significant systems change projects through the use of ACL funds. **We believe strongly that ACL's TBI State Grant Program should remain focused solely on "systems change" initiatives**, which allow the states to target high risk, high need areas with the federal funds. For example, many states have identified the intersection of brain injury and the correctional system as a particular unmet issue. While we cannot directly provide services to juveniles residing in a facility, we have been able to make much progress with our professional training efforts, development of relevant written materials, moving legislative discussions toward better solutions, advocating for state dollars to provide direct services, etc. In our opinion, these efforts are much better supported with our ACL funds than a small number of individuals who might be fortunate to receive limited (short-term) direct services – grant funding is, after all, time-limited: the needs of individuals in our state systems are not.
- Although the performance measures are well written they do not provide any benchmarks to measure progress for the program. **Are states responsible for developing their own benchmarks or will ACL develop these?** My concern is that without bench marks these performance measures are really just a survey within a state. The second concern is that these measures are very generic. If this was done to recognize the uniqueness of each state, will states have the ability to report "not applicable or a "zero" in a particular field within all questions? Without some definition of what success is across all state program's we will have a very difficult time competing for limited resources with other federally funded programs.
- **Please define "TBI system"** - does this mean a TBI medical treatment system or community-based service system or a combination of the two? Does this mean the TBI

grant-funded activities or larger TBI service system? Is there any flexibility in these categories? Can we revise these or add other categories that have already been in place for data collection?

- Overall, many of the proposed measures appear **very medically oriented**. For example, the word "treatment" is used in several proposed survey questions, which implies medical treatment. Historically, the state TBI Grant Program has been focused on community-based and system-change activities, not the provision of direct medical services.
- **What treatment?** In general, when I think treatment I think clinical or medical which is not typically the focus of these grants. Maybe support would be a better term but still would need to be defined.
- Many people have sustained a TBI but do not have a resulting disability. Is this really intended to capture the number **living with a disability as a result of a TBI?**
- The performance measures include questions that are medically oriented, e.g., Survey Question 7, which asks for **technological tools used for screening**, such as, CT, MRI, EEG, etc. It is not clear how these questions are relevant to the state grant programs, which have a long-term community-based focus. Additionally, these data are not available to community service coordinators/state grant programs.
- Some of this is **well beyond the scope of what the grant** has focused on. Grant staff and contractors are not medically oriented professionals. There is no way to track what, if any, tools are used for diagnosing TBI. Even if this was attempted, many individuals don't follow thru to get the additional tests done, can't afford to pay for them, wouldn't always follow up to report outcomes, etc. There could be liabilities associated with this that would prevent states from applying for the grant if this was a requirement.
- The measures proposed would not necessarily reflect how well a particular project performed overall. I think it will be very difficult to create a standard set of performance measures that adequately demonstrate the return on investment since **the needs identified and projects proposed are specific to each state** and their unique systems.
- I agree that increasing our knowledge of the incidence of TBI state by state would support the need for the grant program as well as help states have useful data when advocating for additional resources, however I am not aware of a data source for this information that is available to all states.
- (Related to Question 4) **Medicaid, Medicare, SSI and SSDI -these sources are both eligibility and entitlement programs that are available to the individual**. Some provide a monthly benefit amount for an individual while others provide health insurance coverage. Some individuals are dual eligible, receiving both Medicare and Medicaid. At least for Medicaid different states have different match requirements. It appears as if states are being asked to track individual recipient benefit amounts in addition to program costs, is this accurate? This could be very labor intensive and intrusive for a state to collect.

- For many states where the lead agency does not have responsibility for providing home and community based services **this data would have to come from the agency with responsibility** for providing home and community based services. For this reason, it may be difficult for some states to acquire this information since it is outside their authority.
- State/projects would not have access to any treatment data from **hospitals, private providers, rehab facilities**. Also, as a rural state with no level one trauma center and limited specialty care many individuals access treatment **out of state**. How would those numbers be tracked and reported?

ESTIMATED PROGRAM BURDEN:

These revisions based on public comments caused a change in the annual reporting burden estimates; there is a program change decrease of -1,008 annual burden hours from the 60-day FRN. In addition, the 60-day FRN respondent estimate was based on the highest number of possible awards anticipated; there is an adjustment decrease of -18 respondents.

Adjusted Number of Respondents	Number of Responses (per respondent)	Average Burden Hours (per response)	Total Burden Hours
27	2	8	432

60-day FRN Number of Respondents	Number of Responses (per respondent)	Average Burden Hours (per response)	Total Burden Hours
45	2	16	1,440

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.