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8/22/2016

Greg Link
Administration for Community Living
U.S. Department of Health and Human Services
330 C St SW
Washington, DC 20201

Re: Agency Information Collection Activities; Proposed Collection; Comment Request; Request for New Information Collection for a Program Instruction on Guidance for the Development and Submission of State Plans on Aging, State Plan Amendments and the Intrastate Funding Formula

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Dear Mr. Link:

On behalf of the National Association of States United for Aging and Disabilities (NASUAD), I am writing in response to the notice of information collection activities issued by the Administration for Community Living (ACL) at 81 C.F.R 40312 on June 21, 2016. NASUAD represents the 56 officially designated state and territorial agencies on aging and disabilities. Each of our members oversees the implementation of the Older Americans Act (OAA), and many also serve as the operating agency in their state for Medicaid waivers that serve older adults and individuals with disabilities. Together with our members, we work to design, improve, and sustain state systems delivering home and community based services and supports for people who are older or have a disability and for their caregivers.

In the notice, ACL requested comment on proposed changes to the State Plan on Aging (the Plan) that states are required to develop when administering the OAA. Specifically, ACL requested feedback on a proposed template that would expand the populations designated as "greatest social need." In the template, there is an emphasis on individuals who are lesbian, gay, bisexual and transgender (LGBT), American Indian (regardless of membership in a Federal or state-recognized tribe); being a Holocaust survivor; status as a refugee; or discrimination and/or persecution (past or present) based on religious/social/political beliefs.

NASUAD appreciates ACL's interest in ensuring the maximum inclusion of all individuals within the aging network and its services. However, we have some specific concerns about the potential ramifications of the expansion of the definition of greatest social need on state funding decisions and the services provided at the local level. Due to the lack of available information regarding the prevalence of some

of these populations, coupled with the need to ensure that resources are adequately allocated to network providers within the states, we believe that it would be preferable to retain prior definitions and policies regarding “greatest social need.” Instead, we recommend that ACL engage with states, area agencies on aging (AAAs), and the advocacy and consumer organizations that represent the different populations receiving services in order to increase training, outreach, and awareness building regarding universally inclusive services.

Data Collection Creates Challenges

In order to determine the scope of need for state plan development, adequate information is needed regarding individuals who fall into the different categories. In some of the populations discussed, there are distinct challenges with identifying individuals who would be included in these targeting criteria. For example, when local entities have included questions to better understand the prevalence of LGBT individuals there has been very low response rates. This may be due to a number of factors, including a lack of training for individuals collecting the information; an unwillingness of beneficiaries to disclose their sexual orientation and/or gender identity; or questions that do not solicit this information in a sensitive or meaningful fashion. Other identified groups with a history of trauma and/or exclusion, including Holocaust survivors and those with a refugee status, may be uninclined to identify as a member of such population or to provide other information about their status.

These challenges with data collection and potential low response rates could lead to decisions based on skewed information. For example, if one Area Agency on Aging is able to collect better information from a larger number of people, then it could appear that there is a higher concentration of individuals with the greatest social need in one region of the state. Similarly, low response rates could ultimately understate the number of individuals within a group.

NASUAD recommends that ACL work with states and AAAs to examine best practices for data collection in order to better understand the scope of services required by different populations within the network.

Burdens on State Systems and Participants

As noted above, many of the individuals identified in this notice may not be inclined to disclose their personal information. However, states would still need to make significant changes to their data collection tools, including intake and assessment forms, as well as to their information technology systems. Additionally, employees of state agencies as well as AAAs will be responsible for determining whether the targeting activities are resulting in services to the newly identified populations. Collecting this new information on whether services have had adequate reach into specific communities and populations would significantly add to the state and AAA administrative oversight burden as well as to the state plan preparation time.

These changes will also create further burdens on OAA program participants. Many states solely collect federally mandated data from consumers of service. States will need to require

significant additional information from those program participants so that they can assess whether a beneficiary falls into one of the identified populations, collect appropriate information for development of the state plan, and evaluate the effectiveness of their targeting activities. All OAA participants will be subjected to additional assessments and questioning in order to meet this mandate.

Implications for Funding

Section 305(a) of the Older Americans Act requires that a state's development of its intrastate funding formula must take into account, "the distribution among planning and service areas of older individuals with greatest economic need and older individuals with greatest social need." While the proposed changes in this notice do not explicitly require states to change the funding allocations to different AAAs across the state, the implications of the new definition will clearly lead to new expectations regarding the distribution of funding within each state.

This type of change is especially concerning when coupled with the challenges of collecting valid and reliable data about the personal status and background of individuals seeking services. The potential for inadequate and inequitable data collection informing key funding allocation decisions is concerning, and issues with the collection and quality of information should be addressed prior to mandating substantial changes to the state plan requirements. The OAA requires states to use the best available data, which is uncollected and unreliable at this time.

Such a change in requirements must also be accompanied by increased resources to meet the needs of individuals that require services. Many of the changes under consideration will require new processes, policies, and additional staff work to perform targeted outreach as well as information collection. Upgrades to existing information technology systems would also increase costs on state agency budgets. This would place additional strain on a system that is already stretched to capacity and underfunded. Since 10,000 individuals are estimated to turn 65 each day, states are prioritizing service delivery over administrative costs. Any new requirements on the system that would require more resources for program administration must be accompanied by additional funding that prevents service reductions from occurring as a result.

Opportunities for Collaboration

NASUAD and our members strongly believe that all components of the aging network should be operated in a way that is welcoming and accessible for individuals who wish to receive services. We also recognize that histories of trauma, isolation, discrimination, or exclusion could lead to some individuals choosing not to seek supports and services for which they are eligible, and we agree that additional work is needed to ensure that people with these experiences are comfortable and able to access OAA supports.

The 2016 Older Americans Act Reauthorization includes instructions for ACL to release guidance regarding promising practices for outreach and services to Holocaust providers. Similarly, the National Resource Center on LGBT Aging, led by Services and Advocacy for GLBT Elders (SAGE), has a mission to provide training, technical assistance and educational resources to aging providers, LGBT organizations and LGBT older adults. There is ample opportunity to leverage the ACL resource centers and to promote the collaborative development of additional promising practices in order to increase the inclusiveness of OAA services. However, these efforts can occur without an overly burdensome Federal mandate on state systems.

As such, NASUAD believes that ACL, states, and AAAs should continue to work towards universal inclusion within their networks. This effort must be done with the ACL resource centers, advocacy organizations, consumer groups, beneficiaries, and other organizations that represent the needs of different populations eligible for OAA services. We recognize that there is a need to continue and strengthen existing efforts regarding inclusion and we encourage ACL to provide leadership towards this end.

Conclusion

NASUAD and our members appreciate ACL's efforts to ensure that the needs of participants can be met within the aging network. However, we strongly oppose this new mandate on states as they develop their Plan. We do not believe that it is necessary for the proper administration of the state plan, we believe that it will require additional burdensome intake processes and information technology upgrades, and we believe that it could have detrimental impacts and unintended consequences. Therefore, we recommend that these new requirements for data collection and changes to greatest social need be removed from the ACL program instructions. Instead, we recommend ongoing partnerships to strengthen existing efforts that foster the inclusiveness of OAA services.

Please contact Damon Terzaghi of my staff at dterzaghi@nasuad.org if you have any questions or concerns.

Sincerely,



Martha A. Roherty
Executive Director
NASUAD

