June 2, 2022

The Honorable Alison Barkoff  
Acting Assistant Secretary for Aging and Administrator  
Administration for Community Living  
Department of Health and Human Services  
330 C Street SW  
Washington, DC 20201

Re: Request for Information: Older Americans Act Regulations

Submitted via: OAAregulations@acl.hhs.gov

Dear Acting Assistant Secretary for Aging and Administrator Barkoff:

AARP, on behalf of our nearly 38 million members and all older Americans nationwide, appreciates the opportunity to provide input on recommended changes to Older Americans Act (OAA) regulations in response to the Administration for Community Living’s request for information.

The Older American Act has a powerful legacy. Since 1965, it has provided older Americans with the support they need to live at home with independence and dignity, deferring or eliminating more costly institutional services and hospitalizations. OAA programs include home care, congregate and home-delivered meals, case management, family caregiver support, transportation, adult day care, legal service, elder abuse prevention, and job training and employment opportunities for low-income older adults. In a typical year, OAA programs provide services for 11 million older adults. As noted in the request for information, with some exceptions, current regulations for programs authorized under OAA date from 1988 and have not been substantively revised. There are currently no regulations to support the implementation of the National Family Caregiver Support Program (NFCSP), which was created in 2000 to support a range of services that assist family and other unpaid caregivers. Our following comments apply to 45 CFR part 1321—Grants to State and Community Programs on Aging.

Support for Caregivers

Most of us are, have been, or will be a family caregiver or will need help with some tasks as we age. Family caregivers are the backbone of America’s care system. We estimate that America’s 41 million family caregivers provide a staggering $470 billion annually in unpaid care—ranging from bathing and dressing to managing finances and transportation.¹ Additionally, family caregivers are increasingly performing skilled activities that nurses typically perform—such as

injections, tube feedings, and catheter care—often with little preparation or training. Family caregivers often serve as care coordinators, navigating systems of care and different providers. By supporting family caregivers, we can help people stay at home—where most people prefer to remain as they age—helping to delay or prevent more costly nursing home care and unnecessary hospitalizations.

While caregiving spans across age groups, those caring for older adults make up the vast majority of caregivers—79 percent of all unpaid caregivers in the U.S. provide care for someone 50 years of age or older. One in 6 Americans now provide care to someone age 50 or older. As Boomers continue to age—one of the largest demographic groups—family caregivers will likely face greater strains as the number of family caregivers is not expected to keep up with the large number of older adults needing care. This underscores the importance of regulations that further strengthen the implementation of the National Family Caregiver Support Program (NFCSP). Collecting data that are accurate, comprehensive, and actionable is fundamental to making sound policy and programmatic decisions. Therefore, we encourage ACL to consider adding specificity around what impacts to monitor and publicly report annually as it relates to section 218 of the Supporting Older Americans Act of 2020, such as the following:

- the number of family caregivers and older relative caregivers receiving support services within the service area of each individual area agency on aging nationwide at the program level and disaggregated by each NFCSP support service;
- percent of total federal and total non-federal funding used to serve each caregiver population by service area;
- unmet need for support services of family caregivers and older relative caregivers;
- disaggregated data broken down into multiple demographic categories such as race, ethnicity, age, socioeconomic status, sexual orientation, gender identity, spoken/written language, and disability; and
- reporting on the volume of missing data (e.g., percent unknown or otherwise absent data points or responses).

**Caregiver Assessments**

The Supporting Older Americans Act of 2020 included language to encourage the use of caregiver assessments under NFCSP and provide technical assistance to support grantees in carrying out the assessments. Understanding the family caregiving situation is a critical step in the process for linking the family caregiver to the most appropriate support services (e.g., counseling, respite care, etc.), as the circumstances of each caregiver are varied. Questions regarding the skills, abilities and knowledge of family caregivers can help to identify the tasks that are most problematic and stressful for the caregiver. This information, in turn, can lead to targeting support services more effectively and efficiently. Better targeting of support services can also help maintain the health and well-being of the caregiver, sustain their ability to provide care, produce better outcomes for the care recipient, and prevent or delay nursing home placement.

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2 https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf
The 2021 Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act Initial Report to Congress included caregiver assessments as a key recommendation to contribute to the national caregiving strategy. Recommendation 2.2 called for engaging family caregivers through the use of evidence supported and culturally sensitive family caregiver assessments to determine the willingness, ability, and needs of family caregivers to provide support. A similar recommendation was made by the Supporting Grandparents Raising Grandchildren Act Initial Report to Congress. Both reports will help inform the national caregiving strategy expected in fall 2022. Assessing the needs of caregivers provides opportunities for a more person- and family-centered approach.

As ACL considers updating OAA regulations, we recommend adding language that supports the use of person- and family-centered caregiver assessments under NFCSP.

**Advancing Equity**

For more than 60 years, AARP has fought to build a more equitable society—advocating for policies and programs that empower people to live longer, healthier, more productive lives. The older population is projected to become more racially and ethnically diverse as our society ages, which has enormous implications for meeting diverse individual and family caregiver needs. Evidence shows that family caregivers from communities of color often report feeling “invisible” or left out of the decision-making process and not included in discussions and decisions around care and support. “For caregivers of color, the ability to care and advocate for their family member is often impeded by the larger context of institutional racism, implicit bias and inequities that affect people of color in every aspect of their lives.” This is also true for other groups that experience discrimination. As ACL responds to Executive Order 13985, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government, we suggest adding the following elements throughout OAA regulations, as appropriate, to help build equitable longevity:

- collect disaggregated demographic data such as by race, ethnicity, age, socioeconomic status, sexual orientation, gender identity, spoken/written language, disability, and geography;
- encourage states to leverage the demographic data to identify and provide support to those in greatest social and economic need;
- reduce bias in the aging network through staff training (e.g., person- and family-centered training, unconscious bias training);
- encourage diversity in state agency staffing—45 CFR part 1321.9; and
- ensure grants to state and community programs on aging account for the diverse needs, preferences, and cultures of older adults and caregivers served.

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6 [https://www.nextavenue.org/recognizing-diverse-caregiver-experiences/](https://www.nextavenue.org/recognizing-diverse-caregiver-experiences/)
Public Participation—45 CFR part 1321.27 and 1321.37

AARP urges ACL to review the requirements for state agencies around public participation to ensure transparency and opportunity for robust review and comment from the public when developing, changing, and administering the state plan and its intrastate funding formula (IFF). Ensuring a process that encourages public feedback can be informational and provide on-the-ground experiences, data, and other considerations relevant to a state agency’s decisions. This process can offer insights into the needs and challenges of people receiving and delivering OAA services. Changes to a state’s intrastate funding formula may shift OAA funding between service areas depending on how factors are weighted and result in certain communities losing funding, which may not align with OAA’s longstanding commitment to advancing equity. Stakeholders should be informed of any planned IFF changes, allowed ample time to review the proposed changes, and afforded the opportunity to share their comments through multiple avenues. We therefore recommend adding specificity around mechanisms a state agency must have in place to ensure public notification and encourage public engagement, including a minimum time period for the public review and comment process.

We appreciate the opportunity to offer comments on updating regulations to support older adults and their caregivers in receiving services under OAA. If you have questions, please contact me or Nicole Burda on our Government Affairs team at 202-826-8641 or nburda@aarp.org.

Sincerely,

David Certner
Legislative Counsel and Legislative Policy Director
Government Affairs