



August 15, 2023

Alison Barkoff
Acting Assistant Secretary for Aging and ACL Administrator
Administration for Community Living
Department of Health and Human Services
Attention: ACL-AA17-P
330 C Street, SW

Re: Re: Older Americans Act: Grants to State and Community Programs on Aging; Grants to Indian Tribes for Support and Nutrition Services; Grants for Supportive and Nutritional Services to Older Hawaiian Natives; and Allotments for Vulnerable Elder Rights Protection Activities (ACL- RIN Number 0985-AA17)

Submitted electronically via www.regulations.gov

Dear Ms. Barkoff,

On behalf of the Coalition to Transform Advanced Care (C-TAC), we appreciate the opportunity to provide comments on this proposed rule regarding its effect on those living with serious illness.

C-TAC is a national non-partisan, not-for-profit coalition dedicated to ensuring that all those living with serious illness, especially the sickest and most vulnerable, receive comprehensive, high- quality, person- and family-centered care that is consistent with their goals and values and honors their dignity. C-TAC is made up of over 200 national and regional organizations including patient and consumer advocacy groups, practitioners, health plans, faith-based and community organizations, and others who share a common vision of improving care for serious illness in the U.S.

C-TAC [defines serious illness](#) as a health condition that carries a high risk of mortality and either negatively impacts a person’s daily function, or quality of life, or excessively strains their family caregivers. This definition has been widely adopted, including by the National Committee for Quality Assurance (NCQA) and the National Quality Forum (NQF).

A history of disenfranchisement has led to healthcare gaps across the country. Per a [2021 Commonwealth report](#) on racial and ethnic health equity, communities of color live fewer years, on average, than white people, are more likely to die from treatable conditions, and are also at higher risk for many chronic health conditions. For serious illness, the lack of access to health

insurance and primary care mean many are diagnosed only at a late or end-stage of illness, when disease-modifying treatment is typically no longer effective. The COVID-19 pandemic has only made things worse, with average life expectancies among these groups falling more sharply compared to white people. Those from historically under-resourced communities who also have serious illness experience poorer care and access, making improving their care a health equity opportunity.

C-TAC and the Older Americans Act's (OAA)

C-TAC is a long-standing and strong supporter of the OAA's critically important supports and services and the Aging Network which brings it to our communities. We work closely with many of the OAA's stakeholders and have shared our knowledge and resources about serious illness with them. Supporting the nation's Area Agencies on Aging (AAAs) and others in the Aging Network to develop programmatic, regulatory, and legislative solutions to strengthen community-based organizations (CBOs) and their ability to deliver community-based care and support to those living with advanced or serious illness and their families is a C-TAC priority.

For many years, we have been working together with other key health care, social service, and policymaking stakeholder groups, including the Administration for Community Living (ACL) and the CMS Center for Medicare and Medicaid Innovation (CMMI), to develop avenues for reimbursement and integration of AAAs and other CBOs into new payment and delivery models. In addition, during the last OAA reauthorization process, we supported a range of additions to the Act to support the Aging Network in addressing the needs of older individuals with serious illness and their caregivers. Included in the last reauthorization (at our request) was direction to the Administration to broadly disseminate and collect feedback on the Administration for Community Living's *Principles for Person-directed Services and Supports during Serious Illness*. More recently, we have partnered with USAgeing to expand access to advance care planning (ACP) through a project funded by The John A. Hartford Foundation to identify community-based models that are currently providing or accessing ACP services for older adults; increase the community's implementation of these models, and improving the community's knowledge and advocacy around Medicare codes for ACP; and creating a tool kit for AAAs and other CBOs to use to expand the support of older adults who would benefit from ACP discussions.

Proposed OAA rule

C-TAC supports the modernization of the OAA regulations to conform to many years of statutory changes. We will focus our comments on several areas that relate to older adults with serious illness and their family caregivers, including the Long-Term Care Ombudsman Program (LTCOP), legal services, caregivers, social isolation, and AAA contracting:

Long-Term Care Ombudsman Program

For many older adults with serious illnesses, it can become necessary to spend time in a long-term care facility such as a nursing home or assisted living facility. As a resident in such a facility, the individual and their family frequently need the assistance, protection, and problem-solving abilities of a long-term care ombudsman. The ombudsman is available to support them

and advocate on their behalf. Ombudsmen work to ensure they are treated as individuals with autonomy, choice, independence, and access to quality health care; these are key principles in the work of C-TAC, as well. This program is an unsung champion of the OAA and is focused on the resident and at the direction of resident, while ensuring strict confidentiality. The following are specific comments regarding the LTCOP section of the proposed regulations:

- *1324.11(e)(1)(v) – Prompt response to complaints-* C-TAC supports the goal of providing more clarity to what a prompt response to time-sensitive situations for residents, particularly those with a serious illness. Standards to ensure a prompt response to complaints or potentially harmful situations can be extremely important near the end of life for both the resident and their family.
- *1324.11(e)(2)(iv)(C) – Procedures for access-* Similarly, we support the new language that would provide ombudsmen access to resident records in situations where the resident is unable to communicate consent and has no legal representative. This enables ombudsmen to access what might be critical information regarding residents and to assist in ensuring that their care preferences are followed regardless of a resident’s ability to consent or status of a legal representative.
- 1321.7 – Organization and staffing of the State agency- We support the additional language which recognizes the State Ombudsman as the head of the Office and requires adequate additional staff to carry out the duties of the program as required by the Act. Suffice it to say, the LTCOP is woefully underfunded, and that additional staff equates to further protection of the rights of long-term care facility residents. Section 1321.7(e), which provides needed support and oversight for the development of legal services programs for older individuals, is also very helpful. At times residents need legal support to secure their care preferences, so making access to necessary legal services for residents, who often have severe financial constraints, should be a priority. Such legal services may help with ACP issues, surrogate decision making, and other quality of life concerns.

Legal Services

C-TAC supports the OAA’s prioritizing older adults with the greatest economic and social needs. In the legal services space, the proposed regulation requires that legal assistance providers demonstrate the capacity to prioritize representation and advice that focus on the specific areas of law that give rise to problems that are experienced by older adults with economic or social need. In addition, the programs must do outreach to help ensure that older adults with the greatest economic and social needs, including older adults of color, underserved communities (e.g., limited-English proficiency, severe disabilities, rural residents, those at risk for institutional placement, and those with neurological and organic brain dysfunction and their caregivers) are aware of the availability of legal assistance.

- *1321.93 – Legal assistance-* Under 1321.93(c), we are told by colleagues, who serve as ombudsmen that they struggle to meet the needs of residents facing a variety of legal

issues. We understand the need to focus resources on situations where older adults are at grave risk of being deprived of the basic human right to make their own decisions. Resources should also be focused on educating and assisting older adults in completing advance directives to avoid guardianship through powers of attorney and surrogate or supportive decision making, where state law or statute provides for such options. We also agree with aging advocates that believe the regulations should require the Legal Assistance Developer to be an individual dedicated full-time to the position.

Caregivers

C-TAC is acutely aware of the tremendous value of family caregivers to individuals with serious illnesses, to the healthcare system, and to society at large. We also recognize the importance of the OAA in providing a support infrastructure for informal/unpaid family caregivers through the National Family Caregiver Support Program (NFCSP). We therefore support the following:

- ACL's inclusion of guidance for the NFCSP and the Native American Caregiver Support Program. Further, we believe that the final rules should be in alignment with the National Strategy to Support Family Caregivers.
- Prioritizing and requiring adequate demographic and service provision data collection and sharing. This will help ensure awareness of the vital role played by caregivers and will provide much needed information for policy development and implementation.
- *1321.71 – Purpose of services allotments under Title III-* C-TAC supports that this section would expressly include the NFCSP and family caregivers as a designated service population. We also endorse the inclusion of the core services and supports offered through the programs.
- *Section 1321.91 – Family caregiver support services-* C-TAC agrees that by specifying the types of services that must be available statewide, including individual information or assistance, case management or care coordination, individual counseling, caregiver trainings, and the organization of support groups for caregivers, would help to facilitate the equitable provision of family caregiver support services. Further, ACL could use this regulation to encourage social isolation and loneliness interventions within the NFCSP to support caregivers at risk of experiencing social isolation and loneliness.

Social Isolation and Loneliness

Individuals with serious illness and their caregivers are at risk of becoming socially isolated. C-TAC understands that the Coalition to End Social Isolation and Loneliness (CESIL) has offered comments and recommendations to the Administration for Community Living's proposed rule on the OAA. C-TAC is a long-time advocate for the work of CESIL and supports its goals to ensure that people are empowered to and supplied with the means to forge social connections and prevent the health risks that accrue from social isolation and loneliness. CESIL relies on OAA programs to foster its goals within the Aging Network. They have identified points in the proposed regulation that could strengthen ways to combat social isolation and

loneliness. C-TAC agrees with CESIL's following recommendations:

- *Include social isolation in ACL's definition of "greatest social need" to better address and respond to the substantial social needs faced by older adults;*
- *Revise the regulation to define social isolation;*
- *Revise the regulation to include and define loneliness;*
- *Incorporate social isolation and social connection in State Plans on Aging; and*
- *Recommend that the ACL provides guidance and technical assistance to help State agencies incorporate screening tools or measures directly related to social isolation, loneliness, and social connection in their state aging plans.*

Contracting

C-TAC has worked extensively with many community-based organizations, including AAAs and faith-based organizations, and their membership organizations to help expand their resources to provide supports and services to individuals with serious illness. As mentioned previously, some of that work has been to secure support from stakeholder groups, including the Administration for Community Living (ACL) and the CMS Center for Medicare and Medicaid Innovation (CMMI), to develop avenues for reimbursement and integration of AAAs and other CBOs into new payment and delivery models. Currently, we are also working to expand access to advance care planning (ACP) via the Aging Network and to secure health care dollars to support community-based organizations (CBOs) in that access effort.

- *1321.9(c)(2)(xiv) – Contracts and Commercial Relationships-* Regarding the proposed regulation on contracts and commercial relationships, C-TAC understands the concerns raised by USAging on elements of the proposed rule. *USAging does not agree that the statute requires state approval for contracts and commercial relationships that are outside of OAA and where no OAA funds are used.* C-TAC supports USAging's position of needing to protect the ability of AAAs to make contracts and commercial relationships. The strength and viability of CBOs is critical to C-TAC's priority of ensuring that a full range of community-based supports and services are available for older adults with serious illness. These services save the health care system billions of dollars by helping individuals stay in their homes and communities and out of emergency rooms, hospitals, and nursing homes. Please take these concerns into consideration when you review the proposed rule and work to ensure that nothing would restrict or negatively impact this critical work of the AAAs.

Thank you for the opportunity to comment on this proposed rule. If you have any questions, please contact Marian Grant, Senior Regulatory Advisor, C-TAC, at mgrant@thectac.org.

Sincerely,

Marian Grant

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