TEMPLATE LANGUAGE FOR CAREGIVER ADVOCATES TO RESPOND TO SENATE HELP COMMITTEE RFI

*\*\*Note: The following letter includes content from the comment letter that the National Alliance for Caregiving is compiling to submit to the Senate Health, Education, Labor, and Pensions Committee in response to their* [*Request for Information (RFI)*](https://www.sanders.senate.gov/wp-content/uploads/HELP-OAA-RFI-2024.pdf) *issued in advance of Older Americans Act reauthorization negotiations.* ***Comments are due to the Committee by EOD on Thursday, March 21****. Please feel free to use any of the below information to inform your own comment letter. Advocates should feel free to answer any/all of the questions included in the RFI, but responses are not required to address every question. The most effective letters will also reflect personal/professional experiences and perspective\*\**

March 21, 2024

Senator Bernard Sanders, Chair

Senator Bill Cassidy, M.D., Ranking Member

Committee on Health, Education, Labor, and Pensions

United States Senate

428 Dirksen Senate Office Building

Washington, DC 20510

*Submitted electronically via* [*OAA@help.senate.gov*](mailto:OAA@help.senate.gov)

Dear Chairman Sanders and Ranking Member Cassidy:

On behalf of the *[INSERT YOUR NAME/ORGANIZATION]* we are writing in response to the Request for Information issued by the Senate Health, Education, Labor, and Pensions (HELP) Committee in advance of Older Americans Act (OAA) reauthorization discussions. We appreciate the opportunity to weigh in on critical considerations as HELP Committee Members and colleagues in the Senate advance OAA reauthorization.

*[Include information about you/your organization and why you care about family caregivers and older adults. Feel free to reference NAC’s letter for an example.]*

**General Questions:**

* *What are the biggest challenges currently facing the older adult population? How have OAA programs performed historically in addressing these challenges? How can OAA programs be improved upon to better address these challenges?*

The intent of the OAA to enable older adults to live and age with dignity in their homes and communities has remained consistent since the Act was first signed into law in 1965. However, the environmental, financial, and demographic realities and challenges facing older adults and caregivers have significantly intensified.

One of the most significant challenges facing older adults—and their caregivers—is demographics. The population of older adults is growing at an historic rate, necessitating the support of increasing numbers of family caregivers. In fact, between 2015 and 2020, the number of unpaid family caregivers increased by more than ten million, to fifty-three million family caregivers according to research from NAC and AARP.[[1]](#footnote-1) However, the ratio of available caregivers to those who need care is declining.[[2]](#footnote-2)

Since the inception of the National Family Caregiver Support Program in 2000, the OAA has funded various supports that help family and unpaid caregivers care for older adults where they want to be for as long as possible. With the growing number of older adults and the shrinking ratio of available family caregivers, the supports offered through OAA Title III-E, National Family Caregiver Support Program, are increasingly important.

***Funding Older Americans Act programs at a level sufficient to meet the vast and growing needs is the primary—and most effective—improvement to Older Americans Act programs that legislators can make***.

*[ADD ANY OTHER CHALLENGES THAT YOU WOULD LIKE TO IDENTIFY AND/OR OPPORTUNITIES FOR IMPROVEMENT]*

* *What are your top priorities for OAA reauthorization? Please explain why.*

*[INCLUDE YOUR/YOUR ORGANIZATION’S TOP PRIORITIES FOR OAA REAUTHORIZATION. PLEASE PULL FROM ANY/ALL OF NAC’S PRIORITIES BELOW THAT ARE RELEVANT TO YOUR EXPERIENCES/WORK]*

1. **Increasing authorization levels for the entirety of the OAA—including the National Family Caregiver Support Program—is *[ORGANIZATION’S]* top priority for reauthorization.** *[IF YOU AGREE, YOU CAN ALIGN YOUR REQUEST WITH NAC’S LANGUAGE: “We join our peers from other national advocacy organizations and a significant number of policymakers to request that lawmakers—at a minimum—double the authorization amounts for Older Americans Act programs from current appropriations.”]*
2. **Specifically, we urge the Senate to, at a minimum, increase the authorized funding level for the National Family Caregiver Support Program (Title III-E) to $410,000,000**.

*[ADD ANY PERSONAL/PROFESSIONAL INSIGHT ABOUT WHY THE NFCSP IS IMPORTANT TO CAREGIVERS YOU KNOW/WORK WITH. FEEL FREE TO USE ANY OF NAC’S LANGUAGE: “The National Family Caregiver Support Program has improved the ability of millions of family caregivers to care for the older adults in their families. As of 2021, the unpaid work that family caregivers provide holds an economic value of nearly $600 billion[[3]](#footnote-3)—savings that reduce the overall cost of federal health care and social support dollars. The program provides grants to states and territories to create innovative programs to empower caregivers to care for their families at home for as long as possible. By providing information, counseling, training, respite care and services, the program reduces caregiver depression, anxiety, and stress, enables caregivers to provide care longer and thereby avoiding or delaying the need for costly hospital and institutional care. Currently the NFCSP reaches only a fraction of eligible caregivers needing support. While we realize that appropriators must follow through to fully fund authorization levels, we urge authorizers to establish an important precedent by doubling recommended funding levels for these critical programs.]*

1. **Require the HHS Secretary to carry out the duties of the RAISE Family Caregivers Act (P.L. 115-119) and extend the sunset date of the Recognize, Assist, Include, Support, Engage (RAISE) Family Caregivers Act through the OAA to align with the OAA reauthorization. This will ensure that the National Strategy is updated on a biennial basis to reflect changes in the caregiver landscape.**

*[ADD LANGUAGE ABOUT WHY YOU THINK IT IS IMPORTANT TO EXTEND RAISE FAMILY CAREGIVERS ACT. FEEL FREE TO PULL FROM NAC’S LANGUAGE: “Since the 2020 reauthorization, significant public and private investments have been made to promote a national framework through which to advance supports for family caregivers. The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act, first passed in 2018 and extended in the 2020 OAA reauthorization, served as a catalyst to advance comprehensive strategies to support the broad cross section of the country’s fifty-three million caregivers. The RAISE Family Caregivers Act supported efforts to develop the milestone 2022 National Strategy to Support Family Caregivers, which reflects a whole-of-government approach to:*

* *Achieve greater awareness of and enhance outreach to family caregivers;*
* *Advance partnerships and engagement with family caregivers;*
* *Strengthen services and supports for family caregivers;*
* *Improve financial and workplace security for family caregivers; and*
* *Develop more data, research, and evidence-based practices to support family caregivers.*

*Modest federal investments in the RAISE Family Caregivers Act and resulting national planning activities have paved the way for significant advancements in national efforts to improve supports for family caregivers.* *As such, 15 federal agencies have begun to implement over 350 actions that they can take under existing authority to strengthen support and outreach to family caregivers. Substantial private sector investment has been made—more than 370 grants totaling over $100 million in 2021 and 2022 alone directly aligned with each of the goals of the Strategy. Additionally, over 100 organizations from across the country have joined NAC to ensure the National Strategy is implemented and strengthened over time.]*

1. ***Additionally, to advance the goals identified in the National Strategy to Support Family Caregivers, the Administration for Community Living has made critical investments in Activities of National Significance to support family caregivers, which are funded through the OAA. We urge policymakers to guarantee the continuation of funding for Activities of National Significance.***
2. ***We also join colleagues to call for an increase in funding to Title VI Native American Aging Programs, including an increase for Part C Caregiver Supports.***

*[ADD ANY INFORMATION ABOUT WHY YOU ARE SUPPORTING INCREASES FOR CAREGIVER SUPPORTS FOR NATIVE AMERICAN AGING PROGRAMS. AS AN EXAMPLE, NAC INCLUDED: “While increasing funding and extending programs included in the National Family Caregiver Support Program represents the most significant opportunity to support family caregivers through the Older Americans Act, we also urge lawmakers to ensure that additional critical programs within the Act receive necessary and long-overdue funding boosts. OAA Title VI Native American Programs provide essential nutrition, supportive, and caregiver services to American Indian, Alaskan Native, and Native Hawaiian older adults and caregivers. Title VI authorizes grants eligible tribal organizations and Title VI Part C supports focus on assisting families in caring for older relatives with chronic illness or disability, and grandparents caring for grandchildren.”]*

1. **Double authorized funding levels for Older Americans Act Title III B Supportive Services, which provide flexible home and community-based services (HCBS) that allow older adults to stay in their homes and communities for as long as possible and offer value to family caregivers.**

*[OAA TITLE III B SUPPORTIVE SERVICES PROVIDE HCBS TO OLDER ADULTS, WHICH CAN OFTEN SERVE AS A RELIEF FOR CAREGIVERS STRUGGLING TO PROVIDE THESE SERVICES. INCLUDE PERSPECTIVE ON THE IMPORTANCE OF PROVIDING HCBS TO OLDER ADULTS AND THE VALUE TO CAREGIVERS]*

**Targeted Questions:**

* *Congress made several changes to OAA through the Supporting Older Americans Act of 2020, including adding caregiver assessments to the National Family Caregiver Support Program as well as efforts to improve social isolation.* 
  + *Have these policies better informed resources needed by caregivers or older Americans? Please explain why or why not, and if yes, how.*
  + *How can Congress improve these efforts?*
  + *What changes made in the Supporting Older Americans Act of 2020 but not mentioned above should Congress examine for this reauthorization?*

*[BACKGROUND: THE 2020 OAA REAUTHORIZATION INCLUDED ADDITIONAL LANGUAGE ALLOWING CAREGIVER ASSESSMENTS AS AN ALLOWED SERVICE UNDER NFCSP. DO YOU HAVE EXPERIENCES TO SHARE REGARDING CAREGIVER ASSESSMENTS? NAC’S LANGUAGE: It is well documented that the majority of caregivers of adults are not having conversations with health professionals and service providers about their needs, though many would like to have these conversations. Caregivers are looking for information not only about how to keep the person they care for safe, but also how to address self-care needs. Fewer than 3 in 10 caregivers say a health care provider, such as a doctor, nurse, or social worker, has asked about what was needed to care for their recipient and just 13 percent say a health care provider has asked what they need to care for themselves. We appreciate that the 2020 OAA reauthorization added caregiver assessments as a covered service under OAA Title III E. NAC was supportive of this change in 2020, and we look forward to the opportunity to work with lawmakers and other advocates to continue to advance opportunities to improve understanding and awareness of caregiver needs and circumstances.*

*NAC also supports sentiment from Aging Network advocates to ensure that policy changes that would expand or encourage the use of evidence-based caregiver assessments consider both existing assessment activities and funding realities. The 2020 OAA reauthorization included directives for the Assistant Secretary of Aging to:*

* *Identify and make publicly available best practices associated with the use of caregiver assessments;*
* *Require technical assistance to promote the use of family caregiver assessments; and*
* *Evaluate and report on the use of caregiver assessments by Aging Network stakeholders.*

*These requirements were intended to ensure that any progress toward increasing evidence-based caregiver assessments in OAA reflected current practice. NAC recognizes that the COVID-19 pandemic delayed or prevented many of these—and other—activities from moving forward according to the specified deadlines.* ***Therefore, we urge lawmakers to renew these requirements and ensure that funding reflects the capacity needed to conduct these important activities. We look forward to working with policymakers and federal agency partners to ensure that we can advance these evaluation and technical assistance efforts.****”]*

* *ACL recently finalized regulations regarding OAA. Should Congress consider any changes in response to the new rule?*

*[BACKGROUND: THE FOLLOWING RECOMMENDATIONS WERE NOT ADDRESSED IN THE FINAL OAA REGULATIONS. IF YOU/YOUR ORGANIZATION ECHOED THESE RECOMMENDATIONS, FEEL FREE TO INCLUDE THEM IN YOUR RESPONSE TO THE HELP COMMITTEE RFI. NAC LANGUAGE: “In comments to ACL on the proposed OAA rule, NAC urged ACL to prioritize and require adequate demographic and service provision data collection and sharing to enhance the understanding of a changing world for caregivers, and to track the impact of National Strategy implementation efforts.*

*Awareness and identification of caregivers is a vital component to ensuring that they receive the support that they need at both the macro and individual level. Developing and implementing effective policies and specific services to support caregivers requires an accurate understanding of caregiver populations. Data about caregivers served through the OAA is an important—albeit limited—opportunity to gain better local, state, and national understanding about caregiver populations, who are too often overlooked.* ***As such, we urge policy makers to increase research efforts (potentially through the Title IV research, demonstration and evaluation center) to identify the return on investment (ROI) of caregiver support for unpaid family caregivers****, including evaluating the ROI of family caregiver services and supports, which could support expanded investment in these vital programs.*

*We appreciate that ACL codified the state agency’s responsibility to establish and maintain policies and procedures to ensure state, AAA, and Title VI policies and procedures are aligned with the agency data collection and reporting requirements. We encourage lawmakers to identify opportunities to encourage states and AAAs to collect—and share—anonymized, aggregated, data—particularly regarding family caregivers.*

*While client assessment and data collection are required annually, broader evaluations and needs assessments are required through the state and area planning processes, which can occur on a two, three, or four-year cycle. We recognize that data gathering activities can be cost-prohibitive to engage in annually, however, we believe that caregivers, service providers, planning entities, and policy makers at all levels would be well-served to have more frequently available data about local, state, and national caregiver populations.*

*We are eager to work with lawmakers to explore opportunities to ensure that states and area agencies on aging facilitate access to data in a timely fashion, which is critical to identifying and meeting service needs.*

*Facilitating increased data collection and improved access is consistent with goal five in the National Strategy which highlights the need for a national infrastructure to support the collection of population-based data, using standardized wording of the definition of family caregiving, and standardized wording of questions that address the core characteristics of the family caregiving experience.*

***Additionally, we encourage lawmakers to explore opportunities to reinforce the importance of state, area agency on aging (AAA), and service provider coordination with public health entities.*** *We appreciate that the final rule included several provisions requiring state and AAA disaster planning emergency preparedness and response efforts to reflect lessons learned from the COVID-19 pandemic regarding vital flexibility to coordinate with and respond to public health crises.*

*However, we encourage policymakers to identify opportunities in the OAA reauthorization to boost coordination with state and local public health entities beyond disaster planning and emergency response efforts. Specifically, recognizing that caregiving is a significant public health issue that affects the quality of life of millions of individuals, we support opportunities to foster strong local, state, and national coordination with public health officials with the aim of:*

1. *Strengthening population health data collection among family caregivers and those in their care;*
2. *Increasing access to literature and information among service providers about the vital role of family caregivers in maintaining population health; and*
3. *Improving entry-point service coordination for family caregivers across sectors that influence various social determinants of health for both the caregiver and the person receiving care.*

*These goals align with the calls-to-action identified in a 2022 brief from the Centers for Disease Control and Prevention and others that identifies caregiving as an important public health issue.[[4]](#footnote-4) We believe that encouraging ongoing coordination among states, AAAs, service providers, and public health officials has the potential to catalyze core changes to systems that promote the health and well-being of both caregivers and their care recipients.”]*

**Conclusion**

Thank you for your consideration of *[NAME/ORGANIZATION]* comments. We appreciate the Senate HELP Committee’s commitment to supporting and expanding the comprehensive and coordinated community-based continuums of services and supports inherent in the mission of the Older Americans Act. We look forward to continuing to work with you and other stakeholders to ensure family caregivers are valued and supported in their vital role as Older Americans Act reauthorization conversations progress. If you have any questions about this submission, please contact *[NAME/CONTACT INFORMATION]*.

Sincerely,

*[SIGNATURE]*

1. *Supra* at 1. [↑](#footnote-ref-1)
2. Centers for Disease Control and Prevention and the National Association of Chronic Disease Directors, Caregiving for Family and Friends — A Public Health Issue (Last Reviewed: August 7, 2019). Available at: <https://www.cdc.gov/aging/caregiving/caregiver-brief.html#:~:text=The%20need%20for%20caregivers%20is,family%20caregivers%20per%20older%20adult>. [↑](#footnote-ref-2)
3. <https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-the-invaluable-2023-update.doi.10.26419-2Fppi.00082.006.pdf> [↑](#footnote-ref-3)
4. *Supra* at 5. [↑](#footnote-ref-4)