



Policy Brief: The Older Americans Act and Supporting Family Caregivers

Older Americans Act Reauthorization is Critical to Family Caregivers in Every Community

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Introduction

For nearly six decades, the Older Americans Act (OAA or the Act) has provided services to older adults and their caregivers to live with dignity in their homes and communities as they age. The OAA was first passed and signed into law in 1965, and since then lawmakers have advanced many bipartisan updates to this legislation that enables people to age at home and in the community where they overwhelmingly want to be. Supporting close to 12 million older adults and caregivers annually, the OAA funds states and local agencies to deliver critical services including, but not limited to, nutrition, transportation, in-home supports, health promotion and disease prevention, and caregiver supports. Funds covered under the OAA also enable the U.S. Department of Health and Human Services to develop, update, and improve the National Strategy to Support Family Caregivers, which was released in 2022.

As the OAA faces reauthorization, lawmakers have the opportunity to strengthen support for millions of family caregivers by increasing funding and better centering the needs of caregivers across the OAA's programs. This policy brief outlines recommendations to achieve this goal.

Background

The National Family Caregiver Support Program (NFCSP or OAA Title III-E) was added to the Older Americans Act nearly 25 years ago to provide respite care, caregiver training, information and referral assistance, counseling, and other services to caregivers of older adults and kinship caregivers. The NFCSP is a foundational program recognizing the important roles that family caregivers serve in our nation's long-term services and supports system. OAA programs serving family caregivers are more important than ever as the population of older adults is growing rapidly, and the ratio of available family caregivers to those needing support is decreasing.

The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (Pub.L. 115-119) passed by Congress in 2018 authorized the Department of Health and Human Services to develop a National Strategy to Support Family Caregivers (National Strategy). The National Strategy, released in 2022, is a first-of-its-kind, multi-stakeholder call to action that identified programmatic and systemic opportunities for every level of society to bolster support for family caregivers in communities and across the country—caregivers across ages, conditions, racial/ethnic, geography, socio-economic status and other demographics across individual characteristics. This historic achievement reflects decades of cross-sector research, engagement, advocacy, and robust and enthusiastic public-private investment. The RAISE Family Caregivers Act called for the National Strategy to be updated and strengthened every two years to reflect changes in the care landscape.

With the OAA expiring in 2024, it will be up to federal lawmakers to reauthorize these essential programs and to ensure that this support can meet the growing demand. Because OAA programs serve older adults and caregivers in every state, congressional district, and community in the country, the National Alliance for Caregiving and the ACT on RAISE Campaign have identified policy priorities for lawmakers to consider as they reauthorize OAA, focused on strengthening and expanding supports for family caregivers.

We are urging lawmakers to:

1. Double authorized funding levels for all Older Americans Act Programs, with particular attention to those that support family caregivers.

- a. Increase authorized funding for the National Family Caregiver Support Program (Title III-E) to at least \$410 million.
- b. Increase authorized funding for OAA Supportive Services & Centers (Title III-B) to at least \$820 million, reflecting the value that these programs provide to family caregivers.
- c. Increase authorized funding for Native American Aging Programs (Title VI), including an increase for Part C Caregiver Supports to at least \$24 million.

2. Ensure that Older Americans Act reauthorization extends authorities and funding for the RAISE Family Caregivers Act and the National Strategy to Support Family Caregivers to advance cross-cutting, national efforts to improve supports for family caregivers.

- a. Reauthorize and extend the sunset date of the Recognize, Assist, Include, Support, Engage (RAISE) Family Caregivers Act through the OAA to ensure that national leaders continue to update and improve the National Strategy to Support Family Caregivers on a biennial basis.
- b. Guarantee the continuation of funding for Activities of National Significance and at least double the current \$20 million federal investment in activities that support implementation of the National Strategy to Support Family Caregivers.

3. Ensure that the Older Americans Act includes opportunities to expand and enhance data collection efforts about the needs of family caregivers and their care recipients to inform program improvements for a growing population.

- a. Renew requirements to advance adoption of evidence-based caregiver assessments in OAA service delivery.
- b. Increase investments in 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.
- c. Explore policy opportunities to strengthen state, area agency on aging (AAA), and service provider coordination with public health entities.



Priority 1. Double authorized funding levels for all Older Americans Act Programs, with particular attention to those that support family caregivers.

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 changed. 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 10 million, to 53 million family caregivers. However, the ratio of available caregivers to those who need care is declining.

This means that caregiver support is increasingly important. We urge lawmakers to double funding for all vital OAA programs with a particular focus on that that support family caregivers including Title III-E National Family Caregivers Support Program, Title III B Supportive Services, and Title VI Native American Aging Programs Caregiver Supports.

“If I didn’t have my network of people I ended up relying on so much I would have needed help managing my wife’s care”

– Tom, Family Caregiver, MN

Tom’s wife was diagnosed with early onset Alzheimer’s disease when she was 57—five years after she first started experiencing symptoms. Over the years, Tom struggled to ensure she had adequate care options given her younger age and found navigating the health care system very challenging and inaccessible to caregivers. Tom says what would be very helpful to him is a care manager to help him navigate the system for his wife and even address some of his own needs. The OAA Title III-E National Family Caregiver Support and OAA Title III-B Supportive Services can provide access to both these essential services, but funding is inadequate to meet the growing needs. Tom’s story demonstrates the importance of increasing investments in these vital OAA Title III Programs.

Increase authorized funding for the National Family Caregiver Support Program (Title III-E) to at least \$410 million.

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 family caregivers provide an estimated \$610 billion in unpaid work, which reduces the overall cost of federal health care and social support dollars. The NFCSP 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.

Increase authorized funding for OAA Supportive Services & Centers (Title III-B) to at least \$820 million, reflecting the value that these programs provide to family caregivers.

Older Americans Act Title III B Supportive Services provides flexible home and community-based services (HCBS) that allow older adults to stay in their homes and communities for as long as possible. There are more than twenty-five authorized services that local agencies can fund through Title III B, allowing agencies to develop programming to reflect community needs and provide tailored supports for older adults. Because many of the services funded through OAA Title III B reflect the individual needs of older adults—they can include many of the activities that family caregivers often undertake. As such, OAA III B services not only address the needs of individual older adults and can serve as an essential lifeline to family caregivers.

“My values as a Native American are that you care for your elders”

– Zuzette, Family Caregiver, AZ

A member of the Gila River Indian Community, Zuzette is a primary caregiver for her mother and father. Zuzette’s responsibilities include helping with transportation, medication management, and all household needs, and often feels overwhelmed. Because she felt that caring for older family members is a valued part of Native American culture, Zuzette didn’t realize she was a ‘caregiver’, and not just a daughter helping her parents, until she attended an Older Americans Title VI, which changed her perspective. She realized that money had been delegated to support caregivers like herself, and it made her want to share that information with other people in a similar situation. Zuzette’s story demonstrates the importance of increasing funding for Title VI Caregiver Programs.

Increase authorized funding for Native American Aging Programs (Title VI), including an increase for Part C Caregiver Supports to at least \$24 million.

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. Caregiver supports provided through OAA Title VI do not replace the tradition of families caring for their elders, but rather strengthens a family’s capacity to care for older relatives with chronic illness or disability, and grandparents caring for grandchildren.

Unfortunately, these programs have been historically underfunded and native elders are among the populations face the highest rates of poverty of any racial group in the United States. Doubling funding for Title VI Part C Caregiver Support programs would require a relatively modest increase in dollars, but would represent an important commitment to ameliorating long-standing inequities in tribal communities.



Priority 2. Ensure that OAA reauthorization extends authorities and funding for the RAISE Family Caregivers Act and the National Strategy to Support Family Caregivers to advance cross-cutting, national efforts to improve supports for family caregivers.

Since the 2020 OAA reauthorization, significant public and private investments have been made to promote a national framework to advance supports for family caregivers. National initiatives such as the Recognize, Assist, Include, Support, Engage (RAISE) Family Caregivers Act and the 2022 National Strategy to Support Family Caregivers have spurred awareness of and commitment to improving the landscape of available services and support for caregivers. The 2024

OAA reauthorization should maintain this momentum and preserve progress by extending the RAISE Family Caregivers Act and expanding programs authorized under Activities of National Significance.

Reauthorize and extend the sunset date of the Recognize, Assist, Include, Support, Engage (RAISE) Family Caregivers Act through the OAA to ensure that national leaders continue to update and improve the National Strategy to Support Family Caregivers on a biennial basis.

The RAISE Family Caregivers Act first passed in 2018 and was extended in the 2020 OAA reauthorization. RAISE has served as a catalyst to advance comprehensive strategies to support the broad cross section of the country's 53 million 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.

Lawmakers should ensure that OAA reauthorization also extends the RAISE Family Caregivers Act. Extending the RAISE Family Caregiver Act will ensure that leaders and advocates at every level can continue to work toward the National Strategy goals 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.

To continue this significant momentum, we urge lawmakers to extend the sunset date of the 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.

Guarantee the continuation of funding for Activities of National Significance and at least double the current \$20 million federal investment in activities that support implementation of the National Strategy to Support Family Caregivers.

The 2020 OAA reauthorization included funding for national projects to advance efforts to support family caregivers. In 2023, the Administration for Community Living (ACL) announced that this funding would support implementation of the goals of the 2022 National Strategy to Support Family Caregivers within the National Family Caregiver Support Program and the Native American Caregiver Support program.

Using the National Strategy as a roadmap, these projects aim to develop, test, and disseminate new approaches to supporting family caregivers and fosters an unprecedented opportunity for the aging and disability networks to build new partnerships with organizations in other fields that can help drive innovation to meet caregiver needs. We urge lawmakers to leverage the momentum and progress made to-date by continuing and increasing funding for these efforts.



Priority 3. Ensure that the Older Americans Act includes opportunities to expand and enhance data collection efforts about the needs of family caregivers and their care recipients to inform program improvements for a growing population.

Developing and implementing effective policies and specific services to support caregivers requires an accurate understanding of caregiver needs and populations. Adequate assessment, demographic, and service provision data collection and sharing will allow policy leaders and advocates to better understand individual caregiver needs among a changing world for caregivers. Additionally, awareness and identification of caregivers is essential to ensuring that they receive the support that they need at both the macro and individual level.

“[Health care providers] haven’t been trained about how to ask the ‘right’ questions of the caregiver...”

– Leslie, Family Caregiver, WA

Les and his wife Julie, now in their 80’s, have been together since they were 16. In 2015 Les’s wife told him that she was having concerning problems with her memory. He tried to respect her independence while maintaining her safety, but often struggled. He shared that healthcare providers weren’t necessarily asking the “right” questions to help him find the right services as a caregiver. While he was eventually able to get help from the local Alzheimer’s Association, Les’s story illustrates the value of effective caregiver assessments to help caregivers balance their responsibilities as caregivers and meet their own needs. The Older Americans Act reauthorization should advance efforts toward ensuring that evidence-informed caregiver assessments help to ease access to appropriate services and supports for all caregivers.

Renew requirements to advance adoption of evidence-based caregiver assessments in OAA service delivery.

Aimed at advancing opportunities to improve understanding and awareness of caregiver needs and circumstances, the 2020 OAA reauthorization highlighted caregiver assessments as a covered service under the National Family Caregiver Support Program. An important component of improving this understanding includes expanding and encouraging the use of evidence-based caregiver assessments to align with existing caregiver assessment activities and funding realities.

To encourage progress toward enhancing the landscape of available data about family caregivers, the 2020 OAA reauthorization also 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.

However, 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.

Increase investments in 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.

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 (including through the Title IV Research, Demonstration and Evaluation Center) to identify the return on investment (ROI) of family caregivers and services and supports provided to unpaid family caregivers.

Enhanced understanding about this critical population could support additional investment in vital caregiver support programs. We encourage lawmakers to identify opportunities to encourage states and AAAs to collect—and share— anonymized, aggregated, data—particularly regarding family caregivers.

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.

Explore policy opportunities to strengthen state, area agency on aging (AAA), and service provider coordination with public health entities.

The 2020 OAA reauthorization and subsequent regulations include provisions requiring state and AAA disaster planning emergency preparedness and response efforts including coordination public health agencies. 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 aims of strengthening population health data collection among family caregivers and those in their care; increasing access to literature and information among service providers about the vital role of family caregivers in maintaining population health; and improving entry-point service coordination for family caregivers across sectors that influence various social determinants of health for both the caregiver and care recipient.

These goals align with various federal agency the calls-to-action that identify caregiving as an important public health issue. 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

The Older Americans Act (OAA) embodies a longstanding national commitment to empowering older adults and their caregivers, providing essential services that enable dignified living at home and within their communities—where most individuals prefer to age. The upcoming 2024 OAA reauthorization presents lawmakers with a crucial opportunity to champion a comprehensive approach that bolsters support for both family caregivers and the older adults they care for. By strengthening caregiver provisions in the OAA, policymakers can foster caregiver-friendly communities and an inclusive economy that benefits millions of Americans shouldering caregiving responsibilities.

Acknowledgements

The Act on RAISE campaign – powered by the National Alliance for Caregiving – is focused on driving implementation of the actions outlined in the National Strategy to Support Family Caregivers (National Strategy). The campaign brings together stakeholders across aging, patient advocacy, disability, and caregiving to strengthen our nation’s first-ever National Strategy to support America’s 53 million family caregivers. The Act on RAISE campaign is supported by a cornerstone investment from The John A. Hartford Foundation.



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