

Raising Support for Our Nation's Caregivers

A Roadmap for Area Agencies on Aging and Title VI Programs

Family caregivers are the backbone of the long-term care system — providing critical care to support older adults and people with disabilities to live well at home and in the community. And as such, supporting family caregivers is foundational to the mission of the Aging Network.

Area Agencies on Aging (AAAs) and Title VI Native American Aging Programs have been committed to supporting family caregivers long before the passage of the National Family Caregiver Support Program (NFCSP). The NFCSP, included in the 2000 reauthorization of the Older Americans Act, embodied in statute what AAAs and Title VI programs had been doing in whatever way they could in the absence of dedicated funding to help family caregivers provide care and support.

With the passage of the NFCSP, AAAs and Title VI programs received funding to expand and enhance their outreach and services to support caregivers with a focus on those who were most economically and socially in need. AAAs and Title VI programs were able to formalize caregiver training programs to help adult children, friends, and others learn the best ways to provide needed help and support. These programs established caregiver support programs to enable caregivers to meet and share their stories, their successes, and lessons learned with each other while building a community of caring peers. They established emergency funds that caregivers could tap into to pay for services that were needed to support their loved ones or themselves so they could continue to care. And they launched respite programs to give caregivers a needed break, a chance to take a breath, and a recharge so they could continue to provide the much-needed care. Importantly, family caregivers receiving services funded with NFCSP dollars may be able to support the care recipient for longer and help them avoid impoverishment to qualify for Medicaid, another frequent payer of services and supports.

Since 2000 the number of caregivers has grown, far outpacing the funding for the NFCSP. Today, it is estimated there are 42 million caregivers of older adults and approximately 53 million caregivers of care recipients of all ages (National Alliance for Caregiving, 2020). By 2030, 1 in every 5 Americans will be over the age of 65. And by 2034, for the first time in the nation's history, there will be more Americans over the age of 65 than under the age of 18 – impacting the caregiver balance in future years.

Along with the growth in people needing care is the complexity of the care they need and that which caregivers are called upon to provide. The caregiver journey is often unexpected, long, and filled with surprises and obstacles as the care recipient's needs change over time. The changing needs often require caregivers to provide a range of supports, as well as increasingly medical and other health care interventions formerly done by health care professionals. Supporting family caregivers can often be the critical lynchpin to helping an older adult or someone with disabilities remain safely in the community. And, given the complexity of the care they provide, overburdened caregivers risk their own health and well-being as a result of taking on their caregiver duties.

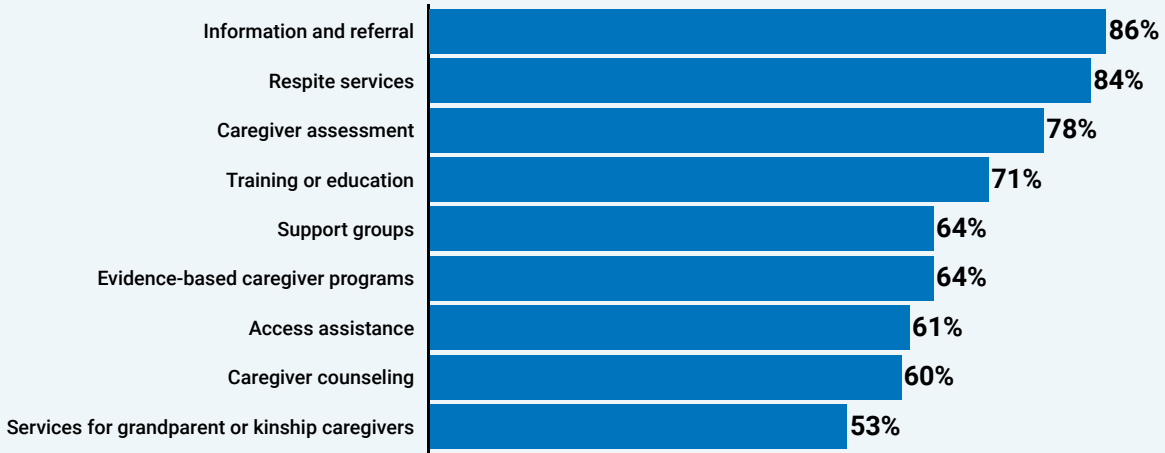
The recognition of the growing number of caregivers, including grandparents raising grandchildren and other kinship caregivers, along with the intensity of the care they are providing, led policymakers to pass the RAISE Family Caregivers (Recognize, Access, Inform, Support, and Engage) Act. The goal of RAISE is to give national focus to what this nation must do to address the needs of family caregivers. The result of the legislation and work done by the RAISE Advisory Council, in collaboration with the Advisory Council to Support Grandparents Raising Grandchildren, was the release of the **“National Strategy to Support Family Caregivers”** in September 2022. The National Strategy contains over 350 recommendations for federal actions involving a range of federal agencies, but it also includes recommendations for states, local governments, and communities to champion and move forward.

To assist AAAs and Title VI programs with implementing recommendations from the National Strategy, this roadmap outlines specific actions they can take directly or in collaboration with partners.

The time to raise up and address the needs of family caregivers is now! AAAs and Title VI programs are critical players in making that happen. To help AAAs and Title VI programs create momentum and action in their communities, we have included steps and actions that agencies can take to raise the awareness and visibility of caregiving, as well as best practice examples from AAAs and Title VI programs that can easily be adapted or replicated. This information is designed to spur ideas and actions that AAAs and Title VI programs can take and encourage agencies to share those with us. We are all in this together to support our nation's caregivers. We must ACT on RAISE!

Data Indicator: AAAs provide a variety of services for family caregivers.

Figure 1. Percentage of AAAs Providing Specific Caregiver Services, 2022



Source: USAging's 2022 National Survey of Area Agencies on Aging

Data Indicator: Title VI Programs Reaching Family Caregivers

- **90 percent** of Title VI programs provide family caregiver services.
- **73 percent** of Title VI programs provide respite services.
- **73 percent** of Title VI programs provide supportive services for grandparents raising grandchildren.

Source: USAging's 2020 Title VI Program Survey

Section 1: Increase Awareness of and Outreach to Family Caregivers

Many people who are caring for others don't identify themselves as caregivers, instead they are just being a helping spouse/partner, adult child, friend, or neighbor. AAAs and Title VI programs are perfectly positioned as the trusted community resource to conduct outreach to caregivers before they even label themselves as one.

To help caregivers self-identify and to seek services and support to assist them in their caregiver duties, AAAs and Title VI programs can:

- Launch or expand an existing community-wide outreach program for family caregivers involving traditional as well as non-traditional aging partner groups, including physicians, hospitals, emergency medical staff, employers, hair stylists and barbers, grocery stores, and pharmacies
- Create or expand an existing community caregiver task force to get input on needed services and supports and to serve as ambassadors in the community to promote AAA and Title VI caregiver services
- Ensure that outreach efforts are targeted to all sectors and populations in the community with culturally appropriate language, images, and messages

Program Example: Fairfax Caregiver Alert Notifications (Fairfax, Virginia)

In Fairfax County, Virginia, Caregiver Alert Notifications enable family caregivers to remain informed, obtain education, and easily access programs and services offered by the Fairfax AAA and other county departments via text messages, emails, and/or voice communication. Caregivers subscribe to the AAA/Caregivers option through Fairfax Office of Emergency Management's Fairfax Alerts System and receive weekly notifications with information about workshops, webinars, support groups, and other supportive services. The program contributes to family caregivers' quality of life and well-being by promoting meaningful community engagement, connection, and awareness of caregiver resources. As caregivers have signed up for alerts, there has been a 73 percent increase in attendance at caregiver webinars, a 621 percent increase in views of archived recordings of caregiver webinars and panel conversations, and a 45 percent increase in caregivers accessing the caregiver telephone support call center, as well as increased incoming calls and referrals to the Aging Disability and Resource line.

Section 2: Advance Partnerships and Engagement with Family Caregivers

Caregivers are an integral part of the care team of the person they are caring for, and their involvement ensures better care and support for the care recipient, as well as better care and support for the caregiver. However, oftentimes the role of the caregiver, nor the physical and mental burden of caregiving, is not recognized by health systems. AAAs and Title VI programs can play an important role in promoting the role of caregivers within the health system by:

- Providing information to physician practices and hospitals to help them ask questions that both identify the caregiver and engage them as appropriate in medical and health care discussions
- Providing education, counseling, or an assessment of caregivers to help identify and address their own needs for services and supports
- Promoting the services their agency provides to support caregivers and their care recipients to a broad range of health care providers in the community; encouraging providers to make referrals or even write a caregiver prescription to reach out to their agency and develop partnerships and contracts with health care entities to fund the referred services

Program Example: CareAware (Indianapolis, Indiana)

In Indianapolis, the six-part video series “CareAware: Help and Hope for Family Caregivers,” developed by CICOA Aging & In-Home Solutions, features interviews with local subject matter experts and caregivers, who provide insights and practical advice for caregivers. Topics covered in the series include the journey of caregiving; key legal documents and advance directives for end-of-life care; dealing with negative emotions; preventing caregiver burnout; physical, emotional, and financial abuse; and community resources. The video series is accompanied by a workbook and promotional resources for support group leaders, which are available at www.careawarejourney.org. The videos are free for private, non-commercial use. Caregivers and caregiver support groups can access the resources online.

Section 3: Strengthen Services and Supports for Family Caregivers

Through the National Family Caregiver Support Program, AAAs and Title VI programs assist older caregivers and family members caring for older adults, as well as older adults caring for younger relatives, by offering supports and services that include caregiver training, respite, support groups, and emergency assistance. As the needs of caregivers continue to intensify, AAAs and Title VI programs can enhance and expand caregiver support by:

- Infusing person- and family-centered, trauma-informed, and culturally appropriate approaches throughout caregiver services and supports
- Developing or expanding innovative respite opportunities for caregivers by, for example, partnering with AmeriCorps’s RSVP to use volunteers for respite or offering tutoring to youth in grandfamilies, which provides time off for the kinship caregivers
- Ensuring caregivers have the training and education they need in their caregiving role, which can be particularly important for caregivers of people living with dementia, who may experience behavioral changes and challenges

Program Example: Volunteer Caregiver Respite Program (Toledo, Ohio)

The Area Office on Aging of Northwestern Ohio Inc.’s Volunteer Caregiver Respite Program helps family members caring for aging loved ones alleviate stress by providing them with a temporary break. Each week, an RSVP member visits with the aging loved one at home for two to four hours so the caregiver has some time off. The new relationships formed benefit the volunteer and care recipient at the same time that the caregiver gets a much-needed break. The Volunteer Caregiver Respite Program merges two existing programs – the National Family Caregiver Support Program and RSVP – to provide evidence-based training through respite education and support tools and coordination for caregivers. Respite has been shown to not only improve the health and well-being of family caregivers but delay nursing home placements, hospital readmissions, and emergency room expenditures for older adults and people with disabilities (NASHP, 2023).

Section 4: Ensure Financial and Workplace Security for Family Caregivers

AARP estimates that each year family caregivers provide \$600 billion worth of supports to their family and friends. In addition to having out-of-pocket expenses, caregivers jeopardize their own economic security by turning down job promotions that would require more hours or provide less flexibility, reducing their hours and subsequently their pay/benefits, and/or leaving the workforce altogether based on their caregiving demands. In addition to the impact of caregiving on family caregivers, paid caregivers also are affected by the lack of adequate pay, benefits, training, and professional recognition. To help address the economic burden on family and paid caregivers AAAs and Title VI programs can:

- Establish partnerships with banks, financial planners, or other knowledgeable community leaders to offer training and education on financial and workplace security for family caregivers
- Offer training to banks, financial planners, elder law attorneys, and employers in the community to ensure they are aware of supports for caregivers offered through the Aging Network, as well as the prevalence of family caregivers in the workplace
- Offer flexibility and security for agency staff who are family caregivers by offering options such as remote work, flexible work hours, and job sharing and encouraging agencies and organizations to do the same

Program Example: Respite Tutoring Services (Chattanooga, Tennessee)

The Southeast Tennessee Area Agency on Aging & Disability NFCSP expanded its services to relative caregivers age 55 or older caring for a minor child by partnering with a local tutoring program to provide respite services during the COVID-19 pandemic. The kin caregiver is provided a short break while the child participates in in-person or virtual tutoring sessions. In fiscal year 2021, 30 kin caregivers were served through 1,400 hours of tutoring to 42 students. Caregivers reported decreased levels of stress, time to do things for themselves, relief at children's improvement at school, and improved relationships.

Section 5: Data, Outcomes, and Evaluation

Data, outcomes, and evaluation drive change. They measure and target need. And they provide indicators of impact and success, as well as opportunities for growth and improvement. As more AAAs and Title VI programs establish agreements with health care payers, outcome data also solidify the important role and impact of AAA and Title VI program services. According to the 2022 AAA National Survey, 37 percent of AAAs collect outcome data on caregiver health/quality of life. However, there are opportunities to enhance outcome-based data collection of caregiver services. The NFCSP has reporting measures, but to expand on the need for and success of caregiver services and supports, AAAs and Title VI programs need to:

- Ensure the use of broader and more inclusive definitions of family caregivers
- Conduct an assessment of family caregiver needs and track/monitor their experience as they receive NFCSP or their care recipient receives other AAA or Title VI services
- Implement and develop collective impact reports on the delivery of evidence-based caregiver support programs

Program Example: MyPlan by Sourcewise (Santa Clara, California)

Sourcewise, a AAA in Santa Clara, California, through a partnership with Stanford University, created MyPlan, a web-based application that enables caregivers to enroll anytime and gain access to resources instantly through a personalized resource library. MyPlan diversifies how care managers can connect with caregivers, enabling communication in real time via a two-way chat and making meeting scheduling easy. Caregivers can opt to receive text messages related to self-care, satisfaction, and mental health. MyPlan allows Sourcewise to serve more caregivers, without sacrificing quality, and to measure health-related outcomes for caregivers and their loved ones. Caregivers who completed baseline and conclusion questionnaires report decreases in depression of 26 percent, stress of 10 percent, and feelings of isolation of 73 percent. Informal caregivers experienced improvements with the social determinants of health, with a 22 percent increase in transportation access, a 10 percent reduction in food insecurity, a 44 percent reduction in caregiver emergency department visits, a 58 percent reduction in caregiver overnight stays, and a 57 percent increase in caregivers reporting their loved one had not fallen in the past three months.

Acknowledgment

This action guide was made possible by a grant from [The John A. Hartford Foundation](#) to the [National Academy for State Health Policy](#) in collaboration with the [U.S. Administration for Community Living](#).

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