

## Article

# The Older Americans Act and Family Caregiving: Perspectives from Federal and State Levels

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Informal caregivers, including family, friends, or neighbors, are typically the first line of support to an older adult in need and are major providers of long-term care for older adults. In 2013, about 40 million caregivers in the United States provided 37 billion hours of care to an adult with limitations in daily activities (National Alliance for Caregiving & AARP Public Policy Institute, 2015). Although caregiving is not a new phenomenon, the ways in which the caregiving role is carried out have shifted significantly with the demographic trends of increased lifespans and the aging of the notably large Baby Boomer generation. Caregiving is often a group effort, wherein family members and friends collaborate as primary and secondary caregivers to support their care recipient. Moreover, caregiving is not an activity with an active role and a passive role, but rather one that entails the active engagement of the care recipient. Caregiving is a demanding and complex undertaking that has demonstrated extensive physical, emotional, relational, and financial burdens on families. Given the multifaceted role of caregiving and the shift from long-term care institutions toward community-based services, a wide range of supports and services are needed for caregivers to maintain their health and well-being, build their skills, and sustain their roles. As part of the reauthorization of the Older Americans Act (OAA) in 2000, the National Family Caregiver Support Program (NFCSP) was established in an effort to support family caregivers. NFCSP funds a range of supports that assist families

in caring for dependent older adults. This paper examines the process and outcome evaluations of NFCSP, identifying areas of strength and improvement. Utilizing New York State as an example, we examine the way the NFCSP interfaces with caregiving policies and programs at the state level, offering further insight into the OAA's value to caregiver support services and into future directions of this work.

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The OAA, originally enacted in 1965, supports a range of home- and community-based services to help older adults live independently in their homes and communities. OAA provided the policy foundation for a nationwide infrastructure of state and local agencies dedicated to advocacy, planning, program design, and implementation on behalf of older Americans, many of whom have heightened economic,

health, and social needs (Takamura, 1999). Since its conception, OAA has expanded to add evidence-informed and judicious programs that are reflective of issues, concerns, and needs of older adults and their families. The expansion of OAA provides the necessary opportunity to modernize the OAA to better serve current and future older Americans.

With Title III-E, the NFCSP was established through the reauthorization and expansion of the OAA in 2000. The NFCSP was based on a successful state caregiver support program. Under the leadership of Rick Greene, former Director of the NFCSP at the Administration on Aging, NFCSP became the first comprehensive federal program designed to support the needs of caregivers for older family members, as well as grandparent and older relative caregivers with minor children under their care (Table 1). The NFCSP strengthens the ability of OAA to address the pressing challenges that threaten the independence, health, and economic security of older adults who rely on the support of family caregivers. States and tribes are allocated proportional grants to work in partnership with Area Agencies on Aging (AAA) and local service providers (LSP), in order to provide a flexible base of caregiver services. For fiscal years 2013–2019, funding for the NFCSP ranged from \$145,586,000–181,186,000 (Administration for Community Living, 2019). In fiscal year 2015, over 700,000 caregivers were served by NFCSP in their efforts to keep their care recipient in the settings of their choice for as long as possible (Administration for Community Living, 2019).

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## Overview of the National Family Caregiver Support Program Process Evaluation

In 2016, the Administration for Community Living collaborated with the University of Connecticut Health Center on Aging, The Scripps Gerontology Center, and the Lewin Group to conduct a process evaluation of NFCSP (Lewin Group, 2016). The goals of the process evaluation were to (a) provide information to support program planning; (b) develop information about the program's efficiency; and (c) assess the program's effectiveness. A 77-question online survey was administered to State Units on Aging (SUA) in all 54 states and territories that operate NFCSP (100% response rate). A 111-question survey was administered to all 619 AAAs active at the time of the survey (73% response rate). A 32-question survey was administered to a sample of LSPs from the responding AAAs (67% response rate). The comprehensive surveys sought to answer a series of organizational, programmatic, and process questions, with the goal of understanding differences in service delivery in different communities, while also highlighting common practices. The evaluation also allowed for the documentation of the benefits that caregivers and communities receive because of the program.

The process evaluation found that volunteers play an essential role in the NFCSP, with nearly half of AAAs and LSPs reporting roles for volunteers, including administrative program support (40%) and caregiver training and education (40%). In accordance with the OAA, the majority of SUAs (69%) and AAAs (82%) reported targeting outreach efforts to special caregiver populations, including caregivers of people with Alzheimer's disease, grandparents raising grandchildren and other relative caregivers, rural caregivers, and caregivers over the age of 70. Less than half of SUAs and AAAs reported targeting racially/ethnically diverse caregivers, caregivers of veterans, employed caregivers, and younger caregivers (age 18–25).

**Table 1.** Core Services and Eligible Program Participants

### NFCSP Core Services

Information to caregivers about available services.

Assistance to caregivers in accessing supportive services.

Individual counseling, support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their roles.

Respite care to temporarily relieve caregivers from their responsibilities.

Supplemental services, on a limited basis, to complement the care provided by caregivers.

### Eligible Program Participants

Adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older.

Adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer's disease and related disorders.

Older relatives (not parents) age 55 and older providing care to children under the age of 18.

Older relatives, including parents, age 55 and older providing care to adults ages 18–59 with disabilities.

For AAAs, partnerships were essential for organizational activities (e.g., program outreach, developing a community needs assessment) and service activities (e.g., coordinating caregiver conferences and caregiver coalitions). Nearly half of AAAs (47%) utilize partnerships for community fundraising for caregiver support. For AAAs, the most important partnerships for administering services were the local/state chapters of national organizations, Aging and Disability Resource Centers/Aging Resource Centers, and health-care providers. At the state level, 17% of SUAs reported working with other state agencies to implement caregiver programs.

Caregiver needs assessments play an important role in identifying the needs, priorities, values, capacities, and resources of caregivers (Bangerter, Griffin, Zarit, & Havyer, 2017). The NFCSP process evaluation suggested that caregiver assessments are prevalent, though there are variations in the assessment processes and instruments used by states and local organizations. Notably, 41% of responding SUAs answered that they have no standardized process for assessing caregivers. The majority of SUAs and AAAs reported assessing both the caregiver and the care recipient. Although 81% of SUAs and 69% of AAAs assess both caregivers and care recipients, 15% of AAAs assess only the care recipients.

After the enactment of the NFCSP in 2000, there were significant increases in SUA support groups (247% increase), training and education (227% increase), information about available services (47% increase), caregiver counseling (563% increase), and respite care (93% increase). Likewise, over half of AAAs did not have a caregiver program before NFCSP, indicating that NFCSP brought needed services to this population. Overall, it is evident that the NFCSP proved to be a facilitator for either providing or formalizing caregiver support services.

## Overview of the National Family Caregiver Support Program Outcome Evaluation

To support ongoing program planning efforts and determine the efficacy of the NFCSP, the Administration for Community Living and the Administration on Aging contracted with Westat to conduct an outcome evaluation of the program (Westat, 2018). The outcome evaluation focused on the collection of survey response data from a nationally representative sample of NFCSP client caregivers, a comparison group of caregivers who do not receive NFCSP services, and a sample of care recipients of caregivers in the two groups. The objectives of the outcome evaluation were to: (a) understand which kinds of services are most helpful for caregivers and identify any unmet needs of caregivers and gaps in caregiver support; (b) identify NFCSP resources that contribute to positive outcomes for caregivers; (c) assess the impact of services on the ability of caregivers to continue providing care; and (d) examine the

relationship between NFCSP client outcomes and AAAs providing NFCSP services.

The outcome evaluation found that 43% of NFCSP client caregivers said they received respite care from their AAA in the past 6 months (median = 6 hours per week). Caregivers who received  $\geq 4$  hours of respite per week had a decrease in their self-reported burden over time, while the comparison caregivers experienced an increase in their self-reported burden. A caregiver's socioeconomic status was not associated with the amount of NFCSP respite hours or the amount of educational services received. The analysis indicates that older caregivers, those with more care tasks, spousal caregivers, and caregivers of persons with Alzheimer's disease or dementia were more likely to use respite. Notably, one-third of NFCSP client caregivers who said they did not use respite care did not do so because they did not know about the service.

Among NFCSP client caregivers, 24% said they had received caregiver education or training, individual counseling, or support group services in the past 6 months. Support group services (52%) had the most utilization, followed by caregiver education or training, such as classroom or online courses (36%), and individual counseling (24%).

## National Family Caregiver Support Program at the State Level: Spotlight on New York State

OAA programs are in every state and almost every Congressional district in the United States, and stress local decision-making on best practices and the most-needed services for older adults. New York State, for example, has taken a multi-level and multi-agency approach to addressing caregiver needs; the success of this approach can help inform the national picture and serve as a model for other states. As one of only a handful of states to pass such legislation, beginning in 2018, New York State's Paid Family Leave Act began providing New Yorkers with job-protected, paid leave that covers caring for a person with a serious health condition. Starting in 2019, eligible individuals may receive up to 10 weeks of paid family leave and can receive 55% of their average weekly wage (New York State Department of Health, 2019). This legislation marks a growing recognition of the high percentage of employed caregivers, the unique burden of care when balanced with work, as well as the significant economic risk that often accompanies the caregiving role (Chen, 2016).

Another caregiver-focused policy in New York aims to enhance care transitions from acute and long-term settings into the community. The Caregiver Advise, Record, Enable (CARE) Act was signed into law in 2015 in New York State. The Act requires hospitals to allow patients to formally designate a caregiver and to educate and support caregivers to provide post-discharge care at home, with an

aim toward better outcomes for the caregiver and the person they support (Coleman, 2016).

NFCSP services in New York function in the context of various program efforts to support caregivers. One program targeting caregivers via a public health lens, the New York State Department of Health Alzheimer's Disease Caregiver Support Initiative, represents an expansion of preexisting caregiver support to a 5 year initiative distributing \$27.5 million annually through a series of grant projects for people with dementia and their caregivers. This effort recognizes the growing prevalence of dementia and, consequently, the increase in the number of family members and friends impacted by the disease as well, with over 1 million estimated caregivers of people with dementia in New York State (Alzheimers Association, 2018). The Alzheimer's Disease Caregiver Support Initiative provides disease-specific, community-based education and support, as well as clinical diagnostics, care management, and professional training. The program structure is based on an array of evidence that these services help improve caregiver health outcomes, reduce unnecessary hospitalizations, and delay nursing home placements. A comprehensive, statewide evaluation of the program is underway, with findings indicating an enhanced capacity of the state to serve people with dementia and their caregivers (Gallant, Riley-Jacome, and Fadel, 2018). By infusing and expanding dementia-specific programs and supports into the mix of services available in the state, the program allows for cross-referrals and both formal and informal collaborations with agencies administering NFCSP services, among others.

There are many additional efforts to provide caregiver support in New York, including the Respite Education and Support Tools (REST) program, which aims to enhance the sustainability of respite options through training opportunities. In 2017, New York State received the REST Vision Award, which is given to the state that has trained the highest number of individuals or organizations to provide respite support for caregivers. Also of note is the release of the 2018 pilot edition of the New York State Department of Health Caregiver Guide, offering a valuable source of information to help caregivers plan for care while also taking care of themselves. The guide was developed by caregiving experts at the State Department of Health, in collaboration with the New York State Office for the Aging.

## Future Direction

The NFCSP has strengthened the ability of the OAA to address the challenges that threaten the independence, health, and well-being of older adults who rely on family caregivers. The process and outcome evaluations of the NFCSP, as well as state-level caregiver programs and policies, demonstrate the value of caregiver services seeded in the OAA. Process and outcome evaluations of the NFCSP also shed light on directions for the future expansion of the OAA and NFCSP, including optimizing caregiver assessments and targeting vulnerable caregiver populations,

particularly minority and employed caregivers. Recent estimates suggest that caregivers provide an economic value of approximately \$470 billion in care (Reinhard, Feinberg, Choula, & Houser, 2015). Thus, funding for the NFCSP supports a mere fraction of the unpaid care that caregivers provide. An imbalance of funding is indicated by the nearly half of AAAs engaging in community fundraising efforts for caregiver support. A comprehensive cost analysis of the NCFSP is a logical next step towards establishing a need for additional funding for caregiver programs and OAA as a whole. Greater monetary investments in the OAA and NFCSP contribute to the ability of older adults to age in place and reduce the likelihood that older adults will require more costly health-care options, such as hospitals and nursing homes. Moreover, by proactively supporting aging adults and their caregivers, the OAA reduces the financial burden on the Medicare and Medicaid systems.

In 2016, the National Academies of Sciences, Engineering, and Medicine convened an ad hoc committee to develop a report with recommendations for public and private sector policies to support family caregivers. The committee called for a transformation in the policies and practices affecting the care of older adults, including payment reform to motivate providers to engage family caregivers effectively (National Academies of Sciences, Engineering, and Medicine, 2016). As the population of older adults grows, so does the demand for person- and family-centered long-term care options. Increasing attention is being paid to the role of Medicaid programs, which pay for the vast majority of long-term services and supports. These have shifted from institutional care settings to include home- or community-based settings (HCBS) that allow older adults to reside in their own homes, often with the support of a caregiver. Family caregivers may receive payment for part or all the HCBS care that the beneficiary receives and, therefore, need to play an active role in establishing bundled payments for HCBS. Likewise, policymakers and stakeholders must weigh crucial factors that will affect the implementation of bundled payments in health-care organizations, and determine where/how family caregivers fit within bundled payment models. One approach is to include caregiver training as a part of a bundled payment model. This approach could reduce health-care costs by preventing skilled nursing facility use and rehospitalization through post-discharge caregiver training. Because health-care organizations reported more bundled payment-related savings from post-discharge care, another approach is for hospitals to reinvest these savings into establishing, testing, and implementing evidence-based training for caregivers.

Findings from NFCSP, as well as lessons learned at the state level, should support the implementation of a national strategy to support caregivers, mandated by the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act. Authorized within the RAISE Act is the formation of an advisory council, tasked with preparing

recommendations to the Secretary of Health and Human Services on evidence-based practices and innovative models for support of family caregivers and for improving coordination across federal government programs. The national strategy resulting from the RAISE Act must encompass both short- and long-term actions to address the needs of caregivers (Feinberg, 2014). The most beneficial strategy will enable caregivers to comprehensively partner with providers, communities, employers, and families to create a sustainable network of support and care for the growing population of aging adults.

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