Background

The Administration for Community Living (ACL) was formed in 2012, combining the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the HHS Office on Disability to ensure a more comprehensive approach to aging and disability across the lifespan. ACL’s mission is to maximize the independence and well-being of older adults, individuals with disabilities, and their families and caregivers. To support this mission, ACL funds a broad spectrum of services and supports delivered through state agencies and community-based programs, providing assistance on health and wellness, protecting rights, and funding research to improve our understanding of the health issues faced by an aging America (ACL, 2017a).

The following brief serves as an introduction to the National Family Caregiver Support Program and related programs administered by ACL that provide support to family caregivers of older adults. While this brief approaches these programs from the perspective of aging services and supports, they are not exclusive to caregivers of older Americans and reach a broad population.

An Overview of Informal Caregiving

As individuals age and begin to experience declines in their health, family members and friends commonly assume greater roles in making treatment decisions and providing other supports to the care recipient. In many cases, these family and friends take on the role of caregiver, performing tasks such as assisting with activities of daily living (ADLs) and instrumental
activities of daily living (IADLs) (Institute of Medicine [IoM], 2008). As defined by the reauthorized Older Americans Act (OAA), a family caregiver is:

An adult family member, or another individual, who is an informal provider of in-home and community care to an older individual or to an individual with Alzheimer’s disease or a related disorder with neurological and organic brain dysfunction (2016, 2018).

Informal caregiving occurs across a broad variety of settings in which the person receives care, and often requires caregivers to coordinate between multiple specialty providers; assist in transition in and out of hospitals, homes, and rehabilitation centers; and frequently continues up to placement of the recipient in a nursing home or in end-of-life care (Liu, Kim, & Zarit, 2015; Health and Medicine Division [HMD], 2016).

The National Family Caregiver Support Program (NFCSP)
The National Family Caregiver Support Program (NFCSP) was established in 2000 to provide grants to states and territories to fund support programs to assist informal caregivers in caring for a recipient in the home (ACL, 2017d). The NFCSP provides grants for five types of services: (i) informational resources to caregivers about available services; (ii) assistance to caregivers in accessing services; (iii) individual counseling, support groups, and caregiver training; (iv) respite care; and (v) supplemental services on a limited basis (ACL, 2017d). Figure 1 illustrates the percentage of caregivers who reported accessing the services provided through the NFCSP.

**Figure 1. Services Accessed by Caregivers as Self-Reported in the 2017 National Survey of Older Americans Act Participants (NSOAAP)**
Like other funding streams under the Older Americans Act (OAA), funding for NFCSP services flows from the ACL to states via a formula based on the age demographics of each state. ACL funds for state NFCSP services are apportioned based on the population of adults age 70 and older. Based on an intrastate funding formula (IFF), each state then allocates funds to local area agencies on aging (AAAs) who, in turn, work with a network of local service providers (LSPs) to design and deliver the range of services and supports required by the program. At the federal level, the ACL serves as the primary advocate for older adults and their family caregivers, ensuring that the Aging Services Network provides programs and supports grounded in person-centered principles and delivered on a flexible basis to meet the needs of older adults and their families.

State Units on Aging (SUAs) are state-level agencies responsible for designing and executing multi-year state plans for delivering assistance to older residents and their families. Most states are further divided into planning and service areas (PSAs) so that programs can be tailored to meet the specific needs of residents at a local level. Through the NFCSP, ACL directs SUAs to work in partnership with Area Agencies on Aging (AAAs) to provide comprehensive information on the array of services provided through NFCSP funding, as well as those state programs that fall outside of its scope (ACL, 2017f).

AAAs are public or private nonprofits designated by a state to address the needs of older persons at the regional and local levels. AAAs are accountable for a planning and service area (PSA), which is either a city, a single county, or a multi-county district (P.L. 89-73, 2016). AAAs coordinate and offer services that enable older adults who desire to remain in their homes do so, aided by services designed to maintain independent living as a viable option. With a range of supports available, AAAs empower and support older individuals and their family caregivers to choose the services and living arrangements right for them (ACL 2017c).

In 2016, with a budget of slightly over $150 million, NFCSP provided support services to over 212,000 individual caregivers. This included 61,989 caregivers who received respite services, as well as 120,100 individuals who received counseling. The ACL also reached over 20 million caregivers with their informational services (ACL, AGID, 2017). In 2016, an evaluation by the ACL of NFCSP implementation found that NFCSP is the primary or only source of caregiver support provided through AAAs in nearly 75 percent of service areas. Results also indicated that, in states which had established caregiver programs prior to the NFCSP, the number of caregivers served increased substantially after implementation (The Lewin Group, 2016).

Individual counseling and support group programs funded through the NFCSP vary by state, in part because the ACL does not impose programmatic requirements. Not all support groups or counseling programs provided through AAAs receive funding through the NFCSP, as AAAs may incorporate existing local services instead of creating new programs from the ground up. Some

What services do caregivers find most helpful?
Based on responses to the 2017 NSOAAP, fifty percent (50%) of caregivers report that respite services (including adult day care) are the most beneficial to them.
AAA programs may provide grief management or end-of-life counseling, and family counseling. The NFCSP also funds trainings, including evidence-base interventions to help caregivers attend to the stress of caregiving (Link, 2015/2016). Respite care programs provide trained caregivers to attend to a recipient’s needs and perform care activities, in either a planned or emergency capacity, providing temporary relief for the primary caregiver to attend to their own needs. These services are primarily provided in a home setting, but can also occur through adult day care centers and overnight residential facilities (ARCH National Respite Network and Resource Center, 2018).

**NFCSP Evaluation**

Given the extensive reach of NFCSP programs and the complex, multi-tiered structure through which caregivers can access assistance, the Administration for Community Living (ACL) sought to gauge the impact of its investment in NFCSP by conducting a comprehensive evaluation to assess program efficiencies, gauge progress towards outcomes, and better understand how services and supports are targeted and delivered to family caregivers and those for whom they provide care. ACL is applying the findings in its ongoing efforts to improve OAA programs.

The recent NFCSP Evaluation is the first full-scale assessment of the NFCSP. ACL recognizes the differences in service delivery in different communities. The NFCSP process and outcomes evaluations allow for a broader understanding of these differences while also highlighting common practices. The evaluations also allow for more comprehensive documentation of the benefits that clients and communities receive because of the program (The Lewin Group, 2016).

The process evaluation completed by the Lewin Group in 2016 has already yielded insights into the function and organizational performance at every level of NFCSP. Key findings are summarized below:

- Approximately one third of local service providers (LSPs) contacted during study recruitment were unfamiliar with the NFCSP or were unaware that it funded all or part of their caregiving services. Although AAAs are the organizations that receive the funding and contract with LSPs, the latter require targeted trainings to effectively deliver NFCSP services.

- The process evaluation also indicated a lack of cohesion between the SUAs and the AAAs on implementation of the NFCSP. A clarification of stakeholder roles in service delivery and a restructuring of how information is shared between them.

- Few AAAs reported comprehensive monitoring of caregiver outcomes. Of the AAAs included in the process evaluation, the following monitoring procedures were reported:
  - Satisfaction Survey of Program Participants (75%);
  - Feedback Mechanism (e.g., complaint mechanism, comment box) (39%);
  - Monitoring of Client ADL/IADL Functioning (24%); and
  - AAA Does Not Conduct Program Participants Assessment of Services (11%).
More standardized assessment of caregivers’ experiences is needed to monitor the impact of services. An expansion of data collection by SUAs and AAAs would enable them to monitor their programs’ impacts on caregivers and identify areas for improvement.

The NFCSP process evaluation findings further supported the need for additional funding for the NFCSP. The program is often the only source of formalized caregiver supports that many SUAs and AAAs can provide. Additionally, SUAs, AAAs, and LSPs all noted the need for continued funding of this program, with SUAs reporting a concern regarding decreased funding accompanied by increased demand for caregiver supports in the near future (The Lewin Group, 2016).

**Additional Programs Supporting Caregivers**

In addition to the NFCSP, there is a broad array of programs and supports coordinated by the ACL to serve older Americans and family caregivers; among these, informational resources and individual daily supports are among the most visible and directly impactful in the lives of individuals and their caregivers. The following sections outline a few those programs that directly support family caregivers of older adults as well as individuals across the life span.

**Aging and Disability Resource Centers (ADRCs)**

Among other activities, Aging and Disability Resource Centers (ADRCs) across the country facilitate access to information about long-term services and supports to create a “one-stop shop” for individuals looking to understand the range of program options available to them, regardless of their age or disability. ADRCs provide objective information, advice, and counseling to empower individuals and their families to make informed decisions about the LTSS they receive from both public and private programs. ADRCs provide unbiased, reliable information and counseling to people with all levels of income (ACL, 2017b).

ADRCs are also an integral component of the No Wrong Door (NWD) initiative. A collaboration between ACL, the Centers for Medicare & Medicaid Services (CMS), and the Veterans Health Administration (VHA), the NWD initiative streamlines access to LTSS for older adults, people with disabilities, and their families. The NWD system coordinates between agencies and stakeholders, bypassing duplicative eligibility and enrollment criteria, and directing individuals and their caregivers to the programs that best fit their needs (ACL, 2017e).

Data released from the last comprehensive review of ADRC service delivery highlight the needs of older Americans and their caregivers in accessing OAA services:

- The five most frequently requested supports were Transportation (82%); Medicaid (79%); Medicare (74%); Personal/Attendant Care (71%); and Affordable Housing (70%);
- The most reported barriers to service access were a lack of transportation (95%); non-availability of required services (94%); and a lack of health insurance (88%);
- Over 82% of service recipients reported being satisfied by the completeness of information received from ADRCs; nearly 80% reported being satisfied by the degree to which services
met their specific needs; and over 91% were satisfied with the accuracy of information (Barretto et al., 2014).

**Alzheimer’s Disease Programs Initiative (ADPI)**

Establishing dementia capable home and community based service systems designed to meet the needs of formal and informal caregivers of individuals with Alzheimer's disease and related disorders (ADRD) is critical to helping these caregivers continue to provide care (ACL, 2017g). The Alzheimer’s Disease Programs Initiative provides funding for the development and implementation of these person-centered services and supports partnerships with public and private entities to identify and address the unique needs of persons with ADRD and their caregivers (ACL, 2018a). In an effort to fill some identified gaps in existing systems that support caregivers and people with ADRD, the Alzheimer’s Disease program dedicates resources for States and community-based organizations with proven capability in the provision of both services and training to targeted special populations. Through the Alzheimer’s Disease program, grants from ACL aim to:

- Create state-wide, person-centered, dementia-capable home and community-based service systems;
- Translate and implement evidence-based supportive services for persons with ADRD and their caregivers at the community level;
- Work with public and private entities to identify and address the special needs of persons with ADRD and their caregivers; and
- Offer direct services and supports to thousands of persons with ADRD and their caregivers (ACL, 2017g).

Created in 1992 by Section 3698 of the Public Health Services Act, the grant program to support Alzheimer’s Disease has moved from innovative practices and evidence-based grants to its current focus on building dementia capability within state systems. In 2018, thirty-three states and Puerto Rico have active grants, and there are sixty-one active programs.

**Lifespan Respite Care Program**

The Lifespan Respite Care Program was authorized by Congress in 2006 under Title XXIX of the Public Health Service Act (42 U.S.C 201). Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs. Such programs reduce duplication of effort and assist in the development of respite care infrastructures at the state and local levels (ACL, 2018b).

Lifespan Respite Care programs work to improve the delivery and quality of respite services available through the following objectives:

- Expand and enhance respite services in the states;
- Improve coordination and dissemination of respite services;
Streamline access to programs;
Fill gaps in service where necessary; and
Improve the overall quality of the respite services currently available.

Since 2009, Congress has appropriated $2-4 million per year to implement Lifespan Respite Programs. As of 2018, competitive grants have been awarded in 37 states and the District of Columbia (ACL, 2018b).

Conclusion

Through its network of NFCSP-funded services and additional supports for older adults and persons with disabilities, the ACL delivers daily on its mission to maximize the independence and well-being of older adults, as well as their families and caregivers. Through its broad array of services and supports, the ACL works to meet the variety of complex needs faced by its beneficiaries, while recognizing the unique circumstances of each individual’s experience with the aging network and allowing for flexibility and person-centered planning.

Through the Aging and Disability Services Network, the ACL is able to tailor support strategies to various populations and levels of need, while investing in coordination of information delivery and standardization of eligibility requirements through the No Wrong Door initiative facilitates service access through a single point of entry. The extensive data collection and comprehensive program reviews undertaken by the ACL serve to further strengthen the quality of services provided by the Administration, and to identify and eliminate barriers to effective utilization of program offerings.

In coordination with agencies at every level, family caregivers, service providers, and the individuals they support, the Administration for Community Living is positioned to define new standards of programs for the elderly, and to shape the way we think about care delivery for an aging America.

References


