Process Evaluation of the Older Americans Act Title III-E National Family Caregiver Support Program: Final Report

HEALTH CARE AND HUMAN SERVICES POLICY, RESEARCH, AND CONSULTING—WITH REAL-WORLD PERSPECTIVE.

DATE:	PREPARED FOR:	SUBMITTED BY:
March 2016	The Administration for Community Living	The Lewin Group, Inc.

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I. National Family Caregiver Support Program Process Evaluation

The National Family Caregiver Support Program (NFCSP) represents a significant Federal investment in supporting caregivers who provide care and assistance to aging adults and to grandparents raising grandchildren. Through this program, the Aging Network helps meet the immediate needs of caregivers and care recipients while also being the catalyst for broadening the long-term care (LTC) service systems at State, Territory, local, and Tribal levels to better support families. Its ultimate goal is to support individuals who prefer to age in their own homes and communities—as opposed to institutional settings—through lower-cost, nonmedical services and supports. The Administration for Community Living (ACL) sought to gauge the impact of its investment in NFCSP by conducting a comprehensive evaluation, thereby improving program efficiency, client outcomes, and effective targeting of vulnerable elders and their caregivers. Further, the evaluation will provide guidance to ACL as it takes the necessary steps to improve Older Americans Act (OAA) programs, ensuring that the vision of consumer choice and direction is met.

Established via the reauthorization of OAA by the 106th Congress in 2000, the Title III-E NFCSP became the first comprehensive Federal program designed to support the needs of family caregivers as they lend assistance to their older family members as well as grandparent and older relative caregivers with minor children under their care. Each state and territory receives varying funding levels depending on the proportion of its population age 70 and older. Since FY 2008, the program's annual appropriation has remained relatively constant at approximately $154 million.[1]

NFCSP calls for all states and tribes, working in partnership with Area Agencies on Aging (AAA) and local service providers (LSP) in the community, to offer the following five core services for family caregivers[2]:

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

ACL included these core services based on research evidence that they would best meet the range of caregivers' needs while affording flexibility through the provision of supplemental services.

More broadly, ACL envisioned that each service component would eventually become available to caregivers nationwide by stimulating development of a multifaceted system that integrates NFCSP core services, other OAA services, and other home and community-based service (HCBS) programs across the U.S. Department of Health and Human Services and other Federal, State, and local entities. States were also advised to build sustainable systems of support across all recommended services; ultimately, the program will help family caregivers experience a

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[1] http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/
[2] http://www.aoa.gov/AOA_programs/OAA/oaa_full.asp#_Toc153957627

seamless process for connecting to information that best meets their needs and enhances caregiving to the greatest extent possible.

The NFCSP provides these supports and services to four primary groups of individuals:

- Adult family members or other informal caregivers age 18 and older providing care to individuals age 60 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;
- Grandparents and other relatives (excluding parents) age 55 and older providing care to children under age 18; and,
- Grandparents and other relatives (excluding parents) age 55 and older providing care to adults ages 18 to 59 with disabilities.

This evaluation focused on the first two primary groups of individuals.

Existing program performance data suggests that caregivers are benefitting from the program. More than three-quarters of caregivers say that services provided through the NFCSP have allowed them to provide care for a longer period than otherwise possible. Additionally, 89 percent of caregivers reported that these services help them be better caregivers.

The current project is the first full-scale evaluation of the NFCSP. ACL recognizes the differences in service delivery in different communities. The NFCSP process evaluation allows for a broader understanding of these differences while also highlighting common practices. The evaluation also allows for fuller documentation of the benefits that clients and communities receive because of the program.

II. Evaluation Objectives

The overall purpose of this process evaluation is to understand and document the strategies used to meet NFCSP goals. The methodology aligns with the research questions identified below, with an emphasis on understanding the program's contribution to LTC system reform and identifying effective program models. The evaluation will promote a better understanding of program impacts at multiple levels—i.e., on LTC policy and HCBS systems and programs (State and local levels). It also identifies opportunities for change.

Information gained from the evaluation greatly enhances efforts to improve the quality of Aging Network caregiver programs. As discussed in the literature review, supporting family caregivers becomes even more critical as certain sociodemographic changes unfold—a growing older adult population with LTC needs (Freedman et al., 2013; Spillman et al., 2014), smaller family sizes (Roth et al., 2015), and the amount of female caregivers who are also in the workforce (Feinberg & Choula, 2012). Supporting family caregivers is an important part of ACL's goal of furthering HCBS options, independence, choice, and consumer-directed care.

This process evaluation described in this report is part of a two-phase approach to evaluating the NFCSP with a specific focus on assessing services provided to caregivers of older adults. The Lewin Group (Lewin) was contracted to complete the process evaluation at the State Unit on Aging (SUA), AAA, and LSP levels. Under a separate contract, ACL is completing the NFCSP outcomes evaluation to examine the program's impact on caregivers receiving services and the care recipients that they serve.

The process evaluation focuses on two broad research questions:

- **How does the program meet its goals?** Do caregivers have easy access to a high-quality, multifaceted system of support and services that meets caregivers' diverse and changing needs and preferences? What systems must be in place to achieve this access?
- **Has the program contributed to LTC system efficiency?** How is the NFCSP integrated or coordinated with other LTC programs, and what is the effect?

The NFCSP process evaluation has three primary objectives:

1. Provide information to support program planning, including an analysis of program operations;
2. Develop information about program efficiency; and,
3. Assess program effectiveness in determining community and client needs, targeting and prioritizing, and providing services to family caregivers.

The NFCSP Survey results offer meaningful insights into operations that support family caregivers daily. The questions being answered focus on how organizations and agencies provide this support, what this support consists of, and what systemic challenges face institutions providing support, among others.

III. Literature Review

Caregivers have often been called “the backbone of America’s long-term care system” (U.S. Administration on Aging, 2012, p.5). They are found in every community, gender, age group, and socioeconomic status. Their work, concerns, personal needs, and the outcomes of programs to assist them have been the subject of both academic study and policy deliberations for many decades, and what we know about caregivers has evolved greatly since the first significant caregiver research in the 1970s.

The NFCSP describes family caregivers as adult family members or other informal caregivers age 18 and older providing care to individuals age 60 and older, or to individuals with Alzheimer’s disease and related disorders.[3] “Informal” (also called “family”) caregivers who are served by the NFCSP, are not paid for their services (Applebaum & Breitbart, 2013; Chari, Engberg, Ray, & Mehrotra, 2015; Freedman, Cornman, & Carr, 2014). By contrast, so-called “formal” caregivers are “paid care providers associated with a service system” (Family Caregiver Alliance: National Center on Caregiving, 2015).

Informal caregiving was first researched with a focus on the hidden costs of caregiving to individuals providing care for a family member (Montgomery & Holzhausen, 2003–2004). Over subsequent years, as researchers contributed to the scientific discourse on informal caregiving, fuller views of its impacts emerged, including awareness of the personal costs (Chappell & Reid, 2002; Pinquart & Sörensen, 2003; Roth, Perkins, Wadley, Temple, & Haley, 2009) and benefits to the caregiver (Brown et al. 2009; Fredman et al. 2008; O’Reilly, Connolly, Rosato, & Patterson, 2008; Roth et al. 2013) as well as benefits and costs to society as a whole (Chari et al. 2015). Attention has been drawn to the hidden contributions informal caregivers make to society by enabling care recipients to remain in the community; moreover, advocates for these caregivers contend that if society wants to minimize nursing home costs, more should be done to support caregivers and to help alleviate the burdens they experience in their role (Lipson, 2015).

Currently, informal caregiving is one of the most significant supports available to older adults despite the potential associated risks of stress, competing demands, and financial hardship (Chappell & Reid, 2002; Feinberg et al. 2011; Pinquart & Sörensen, 2003; Roth, Perkins, Wadley, Temple, & Haley, 2009). Caregivers not only improve quality of care but also contribute to reducing the use of nursing home and inpatient hospital care (Chari, Engberg, Ray, & Mehrotra, 2015; Lipson, 2015).

This literature review focuses on informal caregiving in the United States, including the policy implications of informal caregiving, the interface with formal caregiving services, and best practices in supporting informal caregivers.

Methodology

A review of the literature on informal caregiving was conducted to identify the policy context, the impacts of informal caregiving, and concerns as they relate to the growth and increasing dependence on informal caregiving in the American long-term services and supports (LTSS) system.

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[3] The NFCSP also defines caregivers to include grandparent and other relative caregivers who are providing care to children under 18 or to adults age 18-59 with disabilities. As these two groups are not the focus of this study, this literature review does not include research on them.

The search was performed using research databases, particularly Google Scholar, Academic Search Premier, CINAHL with Full Text (EBSCO), PubMed, Scopus, and iCONN (Connecticut Digital Library). Searches were conducted, as well, on the Oxford Journals website, a trusted gateway to scholarly research and resources that has more than 25 percent of journals ranked in the top 10 percent of their subject category. The review was limited to papers written in the English language and with full text availability. Preference was given to peer-reviewed articles and articles published within the past 5 years. Older articles were included to better understand the historical nature of informal caregiving.

Literature Review Outline

The review is structured in sections as follows:

I. *Nature and Extent of Informal Caregiving:* The meaning of informal caregiving, caregivers and care recipients' characteristics, prevalence of caregivers, the work they do, and pathways into caregiving are explored.
II. *Impacts of Informal Caregiving:* Impacts associated with informal caregiving include positive and negative effects on caregivers' health, employment, and relationships.
III. *Supports for Informal Caregivers:* Formal care services, respite care, support of extended family and friends, education, support groups, information, referral and access services, and supplemental services are explored.
IV. *Special Issues in Informal Caregiving:* Informal caregivers represent many subpopulations, including racial and ethnic minority groups, impoverished caregivers, and female caregivers, and caregivers or care recipients who are members of the lesbian, gay, bisexual and transgender community. Characteristics of care recipients that might add challenges include dementia and mental illness.
V. *Policy Context:* Historically, informal caregivers have been largely invisible; however, demographic and social changes have placed increasing emphasis on the value of caregiver contributions, and provided a sociological perspective within which caregiver policy is framed.

Section I: Nature and Extent of Informal Caregiving

Informal caregivers are unpaid persons, generally family and friends, who assist persons with a chronic disease or disability. The assistance provided typically involves helping with activities of daily living (ADL)[4], instrumental activities of daily living (IADL)[5], or both (Family Caregiver Alliance: National Center on Caregiving, 2015; Roth, Fredman, & Haley, 2015).

Characteristics of Caregivers and Care Recipients

The majority of caregivers are white females, usually middle-age daughters or wives of the care recipients, who care for one person (National Alliance for Caregiving & AARP, 2015; Horrell,

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[4] Activities of daily living include basic self-care tasks such as bathing, dressing, eating, personal hygiene, using the toilet, and mobility.

[5] Instrumental activities of daily living include activities associated with independent living such as meal preparation, housework, managing medications, managing finances, using the telephone, shopping and transportation.

Stephens, & Breheny, 2014; Spillman, Wolff, Freedman, & Kasper, 2014). Seven percent of caregivers are age 75 or older (National Alliance for Caregiving & AARP, 2015).

Formal caregivers who are also informal caregivers for dependent children or adult family members are referred to as providing "double-duty caregiving," and formal caregivers caring informally for both dependent children and older adults are referred to as "triple-duty caregivers" (DePasquale, Bangerter, Williams, & Almeida, 2015). This distinction is important because many formal caregivers also provide unpaid care to family members needing help and are at greater risk for health-related problems than persons who are not double- or triple-duty caregivers (DePasquale et al. 2015; National Research Council, 2010).

Caregivers differ in the relationships they have with care recipients, their living arrangements, the type of care provided (i.e., primary or supplemental support), and the care recipients' clinical conditions (e.g., dementia, frailty, mental illness, stroke) (Roth et al. 2015). Most caregivers report caring for a relative (85 percent), most commonly an adult child caring for a parent (49 percent) (National Alliance for Caregiving & AARP, 2015). Approximately 10 percent of caregivers provide care to a spouse (National Alliance for Caregiving & AARP, 2015). While spouses typically provide more hours of care than other types of caregivers, many have their own health problems and could benefit from caregivers themselves (Freedman et al. 2014). Some studies show that older caregivers sometimes perceive themselves primarily as a spouse, partner, or parent instead of a caregiver, and that differentiating between caregiver and recipient can be difficult because roles are unclear, with both members of the dyad giving and receiving care (Argyle, 2001).

With respect to care recipients, 59 percent report a chronic physical condition, 35 percent report a short-term physical condition, and 26 percent report memory problems. Unsurprisingly, 37 percent report comorbidities (National Alliance for Caregiving & AARP, 2015). Most older people receiving informal care (80 percent) live in the community rather than in skilled nursing facilities (Congressional Budget Office, 2013; Horrell et al. 2014). More than one-half of care recipients (58 percent) live in their own home, and slightly fewer than one-quarter (20 percent) live in their caregiver's home (Family Caregiver Alliance: National Center on Caregiving, 2012).

Although living arrangements vary, a Gallup Poll of caregivers shows that most (66 percent) live within 10 miles of the person for whom they provide care (Family Caregiver Alliance: National Center on Caregiving, 2012).

Numbers of Informal Caregivers

Estimates for the prevalence of informal caregiving in the United States vary depending on the definitions for both caregiver and care recipient, the population studied (e.g., caregivers of people with dementia; specific age groups of care recipients, such as adults over age 50 or 70), and the study methodology (e.g., use of landline telephones versus online data collection). For example, a 2009 study conducted by the National Alliance for Caregiving and AARP estimates that as many as 65.7 million informal caregivers in the United States are caring for an individual who has an ongoing illness or disability. A study using data from the 2010 Health and Retirement Study estimated that 5.5 million informal caregivers provide care to adults age 70 and older, while a 2011 study using data from the National Survey of Caregiving estimated that 18 million informal caregivers are providing care to 9 million adults (Friedman, Shih, Langa, & Hurd, 2015). Another study estimated 44 million caregivers age 18 and older provide informal care to a person age 18 or older (National Alliance for Caregiving & AARP, 2015). The same study, using online data collection methods, notes that an estimated 34.2 million informal caregivers provided unpaid care to a person age 50 or older in the past year (National Alliance for Caregiving & AARP, 2015).

The estimates of the prevalence of informal caregiving make clear that there is a great deal of reliance on family members to provide care to people living in the community. This care may become unsustainable as family sizes decrease and large numbers of women, who have traditionally served in the role of informal caregivers, seek paid employment to support themselves and their families (Friedman et al. 2015). There are estimates of a decrease in the caregiver support ratio from 7:1 in 2010 to 4:1 by 2030 and 3:1 by 2050 (Redfoot, Feinberg, & Houser, 2013).

Work of Informal Caregivers

The work of informal caregivers varies depending on the care recipient's age, type of illness, and degree of impairment. Typically, informal caregivers interact with providers, agencies, and other professionals and carry out the directives of health care providers, but do so without the training and support of the formal caregiving system (Family Caregiver Alliance: National Center on Caregiving, 2009; Pezzin, Pollak, & Schone, 2015). They sometimes provide assistance with medication management and function both as care coordinators and personal advocates for the care recipient (National Research Council, 2010). Other informal caregiving tasks may include transporting the care recipient to appointments; providing emotional support, social stimulation, or both; helping with finances (e.g., paying bills); and, ensuring a healthy diet and safe environment (Arksey & Hirst, 2005; Spillman et al. 2014).

Caregivers commonly report helping a care recipient with a broad range of health-related activities, including ADLs such as getting in and out of bed as well as with more challenging ADLs, including dealing with incontinence and bathing or showering (National Alliance for Caregiving & AARP, 2015). In addition, caregivers provide IADL assistance (e.g., housework, transportation, grocery shopping, managing finances) and might also carry out medical or nursing tasks (e.g., tube feedings, catheter and colostomy care) when trained to do so (Administration on Aging, 2011; National Research Council, 2010; Spillman et al. 2014).

While much variability exists in informal caregiving situations, caregivers report providing an average of 24 hours per week in caring for their family member, with 23 percent providing upward of 41 hours per week (National Alliance for Caregiving & AARP, 2015). Recent data also indicate that as hours of care increase, the likelihood of the caregiver and care recipient co-residing increases (National Alliance for Caregiving & AARP, 2015). Recent literature reports that caregivers have been in their role for about 4 years on average, with 24 percent providing care for 5 years or more (National Alliance for Caregiving & AARP, 2015). The more hours caregivers provide care, the more likely it is they have been in their role for more than 10 years (National Alliance for Caregiving & AARP, 2015).

Eighty percent of older adults receiving help in the community reported a range of functional limitations as a reason for caregiver assistance (Family Caregiver Alliance: National Center on Caregiving, 2015). These care recipients reported receiving an average of 9 hours daily for help with three or more ADLs, and care recipients age 85 and older reported needing an estimated 11 hours of help daily for ADLs (Congressional Budget Office, 2013; Family Caregiver Alliance:

National Center on Caregiving, 2015).

Pathways into Caregiving

Pathways into caregiving are as varied as the caregivers and recipients themselves. Family members assume many caregiving responsibilities and report a wide range of reasons for becoming caregivers, including feeling more useful or giving back to someone who provided for them in the past (Roth et al. 2009).

Recent data show that "old age," Alzheimer's disease or other dementia, and surgery or wound care were the top three reasons care is needed, but other conditions (e.g., cancer, mobility issues, recent hospitalizations, and emotional or mental health conditions) were also noted. People might assume caregiving responsibilities because formal care is unaffordable, as almost 15 percent of adults age 65 and older were near or below the poverty level (Administration on Aging, 2014). Others assume these responsibilities because an older friend or relative wants to remain at home while receiving care (National Alliance for Caregiving, 2010). Across the range of pathways to informal caregiving, nearly one-half of caregivers (49 percent) reported they feel they had no choice in assuming the role of caregiver (National Alliance for Caregiving & AARP, 2015).

Section II: Impacts of Informal Caregiving

More than 35 years ago, Zarit, Reever, and Bach-Peterson (1980) described the impacts perceived by informal caregivers during the caregiving process. Since then, these impacts have been explored as an outcome of informal caregiving and as a predictor for health problems (Savundranayagam, Montgomery, & Kosloski, 2011). The literature demonstrates that although the economic value of informal caregiving may be estimated, with one recent estimate amounting to $234 billion annually (Congressional Budget Office, 2013), caregivers also experience a personal cost with the potential to adversely impact them physically, psychologically, socially, or financially or any combination of the foregoing (Applebaum & Breitbart, 2013; Horrell et al. 2014; Pinquart & Sörensen, 2003; National Research Council, 2010; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009; Vitaliano, Zhang, & Scanlon, 2003).

While caregiving burden dominates the informal caregiving literature, some studies have explored the psychological benefits of caregiving and attribute an improvement in caregiver health to the caregiving role (Bertrand et al. 2012; Brown et al. 2009; Carbonneau, Caron, & Desrosiers, 2010; Van Durme, Macq, Jeanmart, & Gobert, 2012). In studies examining a broad range of caregiving aspects, both negative and positive experiences emerge and demonstrate a more balanced picture of the burden and benefits that caregivers encounter in their role (Beach, Schulz, Yee, & Jackson, 2000; Harmell, Chattillion, Roepke, & Mausbach, 2011; Robison, et al. 2009; Spillman et al. 2014).

Impacts on Mental and Physical Health

Ample literature shows that informal caregivers are at risk for mental (e.g., depression) and physical health problems (Bauer & Sousa-Poza, 2015; National Research Council, 2010; Pinquart & Sörensen, 2003; Robison et al. 2009; Roth et al. 2015; Saban, Sherwood, DeVon, & Hynes, 2010; Vitaliano et al. 2003), yet evidence also exists that many caregivers experience no seemingly unhealthy levels of strain as a result of their role. For example, Schulz and Beach (1999) reported that 44 percent of spouse caregivers experienced no strain in caregiving. A decade later, Roth et al. (2009) reported that 33 percent of caregivers surveyed indicated no strain in their role, and recent data demonstrate that 54 percent of caregivers experience little or no strain in caregiving (National Alliance for Caregiving & AARP, 2015). Outcomes from another survey show that 83 percent of informal caregivers viewed caregiving as a positive experience (National Opinion Research Center, 2014). Differences in mental and physical health impacts appear to depend largely on the populations studied, whether they were a representative sample, the sample size, and the different types of caregiving relationships explored. As a result, outcomes remain mixed regarding the negative effects on objective indicators of health.

Perceived caregiver burden associated with mental and physical health were most often reported by caregivers involved in highly stressful caregiving situations, such as longer hours of caregiving, caring for multiple persons or persons with challenging behaviors, and taking on tasks beyond the caregiver’s abilities (Bauer & Souza-Poza, 2015; Chappell & Reid, 2002; Leggett, Zarit, Kim, Almeida, & Klein, 2015; Miller & Wolinsky, 2007; National Alliance for Caregiving & AARP, 2015; Perkins et al. 2013; Pinquart & Sörensen, 2003; Roth et al. 2009; Williams, Dilworth-Anderson, & Goodwin, 2003). According to one study, nearly 70 percent of respondents reported that caring for a family member is their primary source of stress (Feinberg, Reinhard, Houser, and Choula, 2011). Deterioration in physical health, including increased risk of disability and mobility limitations, was noted mostly in older adult and female caregivers (Rosso et al. 2014). The literature suggests that this decline might result from elevated stress hormones, risky health behaviors (e.g., poor diet, substance abuse), or both, triggered by the strain of caregiving (Vitaliano et al. 2003). Providing care for a spouse or other close relative is more emotionally stressful than caring for a nonrelative, and providing care to someone with chronic conditions or dementia increases the level of emotional stress experienced (Alliance for Caregiving & AARP, 2015; Leggett et al. 2015). Although studies of mental health outcomes generally focus on the risks of anxiety and depression (Pinquart & Sörensen, 2003), recent caregiving literature has explored anger as an emotion that can affect the relationship between anxiety, depression, and potentially detrimental behaviors (Crespo & Fernández-Lansac, 2014; Leggett et al. 2015).

Some studies show that caregivers reporting mental and emotional strain as a result of their caregiving role are at higher risk for mortality (Perkins et al. 2013; Roth et al. 2013; Roth et al. 2015). Other literature indicates that increased mortality occurs primarily among spousal caregivers and women whose caregiving exceeds 9 hours weekly (Fredman et al. 2008). Although some research demonstrates an association between certain caregiver groups and mortality, other studies show that caregiving might actually reduce mortality and extend life (Brown et al. 2009; Fredman et al. 2008; Roth et al; 2013; Roth et al. 2015). These ambivalent outcomes indicate that more rigorous research is needed to explore the impact of caregiving on mental and physical health and that future studies should embrace more scientifically designed approaches to better inform research, practice, and policy (Roth et al. 2015).

Numerous studies also raise concerns about caregivers’ use of health care services for themselves. Some caregivers might visit their own physicians less frequently partly because of the stress and time consumption their caregiving responsibilities impose. For example, one small study found that caregivers of persons with cognitive impairment scored lower than demographically matched non-caregiver counterparts on nearly every measure of health promoting self-care behavior and reported significantly more barriers to self-care (Acton, 2002). Another study of caregivers for persons with dementia found that one-third failed to take their own medications frequently or occasionally, and one-half were unable to fully keep their own appointments with health care providers (Wang, Robinson, & Hardin, 2015).

By contrast, one statewide study of caregivers and non-caregivers found that caregivers were more likely to have had a dental cleaning in the last year than non-caregivers (although that finding was reversed for caregivers who live with their family member or have inadequate income) and were just as likely to have had a wellness checkup in the last two years (Robison et al. 2009). Although more research is needed, these findings might indicate a greater need for training and awareness for caregivers in maintaining and enhancing their own use of health services.

Impacts on Family Life and Relationships

Informal caregivers are typically the first line of support to an older adult in need. The stress of caregiving, the need for making decisions, and conflicts that arise within the caregiving dyad have the potential to affect the relationships of all individuals involved. Factors that impact family life and relationships include the nature of the care recipient's illness or disability and associated health conditions (National Research Council, 2010; Roth et al. 2009), the caregiving tasks involved and the number of hours caregiving is required (Zarit, Femia, Kim, & Whitlatch, 2010), the type of familial or other relationship experienced by the caregiver-care recipient dyad (Spillman et al. 2014), the physician-caregiver relationship and perceived support available to the caregiver (Mitnick, Leffler, & Hood, 2010), and competing employment responsibilities (Pinquart & Sörensen, 2011). Older caregivers, in general, are considered a vulnerable group, especially if they do not self-identify as a caregiver and are, therefore, less likely to seek support from others (Montgomery & Kwak, 2011).

The impacts on family life and relationships tend to be greater for individuals who are the sole caregiver, higher-hour caregivers (generally defined as individuals who provide 21 or more hours of care per week), and caregivers providing care for a spouse (National Alliance for Caregiving & AARP, 2015). The potential for impacts on family life and relationships is also greater among informal caregivers and their siblings, who jointly provide care for an older adult, because of the need to negotiate and settle disagreements associated with care provision (National Research Council, 2010). Although the impacts on family life in general have received minimal attention in research, it is evident that caregiving responsibilities compete with leisure time and limit opportunities important in maintaining healthy family relationships (Bauer & Sousa-Poza, 2015).

Impacts on Employment and Finances

Although informal caregivers are less likely to hold a paid job while caregiving (Carmichael, Charles, & Hulme, 2010; Lilly, Laporte, & Coyte, 2010; Nguyen & Connelly, 2014), similar to non-caregivers, a majority of informal caregivers have been in the workforce at some point in their lives and for some length of time (Feinberg & Choula, 2012). About one-half of informal caregivers work for pay, with rates of employment typically higher among adult children caregivers than caregiving spouses (Pinquart & Sörensen, 2011; Spillman et al. 2014) and among caregivers who provide lower levels of care to family members (Spillman et al. 2014). Recent estimates show that 6 in 10 caregivers worked in the past year while also providing informal care and that 6 in 10 of caregivers who were working needed to request some kind of workplace accommodation because of caregiving (National Alliance for Caregiving & AARP, 2015).

Accommodations include flexible work hours (e.g., arriving late for work or leaving work early), and reducing the number of hours worked per week (Feinberg & Choula, 2012). Accommodations were more likely to be requested by caregivers providing more than 21 hours of caregiving per week (Feinberg & Choula, 2012). A recent national survey indicates that 19 percent of people who retired did so earlier than anticipated because of informal caregiving responsibilities (Hellman, Copeland, & Van Derhei, 2012). Recent literature indicates that fewer than one-quarter of informal caregivers have employers that offer help through employee assistance programs or telecommuting (National Alliance for Caregiving & AARP, 2015). Informal caregivers who out of necessity have to leave the workforce early suffer lost wages and other reduced benefits (e.g., health insurance, retirement contributions, and Social Security income) and, individually as well as cumulatively, these losses impact the financial well-being of many caregivers (Feinberg & Choula, 2012).

Recent data show that one in five caregivers experience financial burden as a result of providing informal care and that higher-hour caregivers typically experience greater financial burden than lower-hour caregivers (National Alliance for Caregiving & AARP, 2015). Other caregivers who experience high levels of financial burden include higher-hour caregivers who live more than an hour's travel away from the people for whom they care, caregivers who provide longer-term care, primary caregivers, and caregivers of a person with a mental health condition (National Alliance for Caregiving & AARP, 2015).

As well as impacting caregivers in multiple ways, caregiving costs also affect employers who lose as much as $33.6 billion annually in decreased productivity from caregivers employed full time; such costs are related to high rates of absenteeism, distractions while on the job, diminished hours of employment, and expense of hiring new employees subsequent to caregivers' leaving the workforce (Feinberg & Choula, 2012; Gautun & Hagen, 2010). Although some studies suggest a weak informal care-work association (Bauer & Sousa-Poza, 2015), more employed people currently have caregiving responsibilities than their counterparts did a decade ago (Feinberg & Choula, 2012). This trend suggests the importance of better understanding the effect of informal caregiving on employment as well as what employers can do to support this important but largely hidden population of workers.

Positive Impacts

An expanding body of literature focuses on the positive impacts of informal caregiving and underscores the satisfaction, rewards, and gains associated with unpaid caregiving (Roff, Burgio, Gitlin, Nichols, Chaplin, & Hardin, 2004; Roth, Dilworth-Anderson, Huang, Gross, & Gitlin, 2015; Spillman et al. 2014). Some literature suggests that higher-hour caregivers have higher levels of both positive and negative caregiving experiences (Spillman et al. 2014). Positive experiences mentioned in association with informal caregiving include learning new skills, personal growth, development of deeper family relationships, enhanced sense of wellbeing, satisfaction with life, and confidence that the care recipient is receiving good care (Bertrand et al. 2012; Brown et al. 2009; Carbonneau et al. 2010; Spillman et al. 2014; Van Durme et al. 2012).

Because most research is cross-sectional, no causal relationships can be inferred to explain why some caregivers experience more of the positive aspects of caregiving and others experience the more burdensome aspects. Clearly though, the complex relationships between the number of caregiving hours provided, caregiver and care recipient health, caregiving limitations, and perceptions of the burden involved in caregiving contribute to the experience. Whether caregivers have primarily positive or negative perceptions about their caregiving, the literature demonstrates that many caregivers are overwhelmed by their responsibilities, are fatigued from their caregiving responsibilities, and have minimal time for themselves (Spillman et al. 2014). The impacts of caregiving indicate a critical need to support informal caregivers in their roles so the caregiving needs and preferences of a growing older adult population can be effectively met (Freedman et al. 2013; Spillman et al. 2014).

Section III: Supports for Informal Caregivers

The OAA specifies five areas of caregiver support services to be provided by the states under the NFCSP (Older Americans Act Amendments of 2006, Section 373(b)). These include:

- Respite care
- Counseling, education, and establishment of support groups
- Information and referral
- Access assistance
- Supplemental services

The ability to remain at home and receive care in the community often depends on the provision of such supports to caregivers and any additional support informal caregivers can access (Benefield & Holtzclaw, 2014; Link, 2015; Martinez, 2015). Informal caregivers have long been known as “the bedrock of long-term care” (Levine, Halper, Peist, & Gould, 2010). Given the multifaceted role informal caregivers play, and the rebalancing of long-term care away from institutions and toward community-based services, a wide range of supports is needed to enable caregivers to maintain their health and wellbeing, to improve their caregiving skills, and to be sustained in their role (Brazil, Bainbridge, & Rodriguez, 2010; Levine et al. 2010; Schulz & Martire, 2004).

Support services analyzed in the literature often fall into one of the categories described in the OAA. These include but are not limited to caregiver education, assistance with information and referral (I&R), counseling, support groups, in-home services, home modifications, and respite (Brazil et al. 2013; Kwak, Montgomery, Kosloski, & Lang, 2011; Schulz & Martire, 2004; Stevens & Thorud, 2015). Although caregiver support services are available through local government agencies, service organizations, faith-based organizations, and employers’ programs, they are not always well used (Di Rosa et al. 2011; Iris, Berman, & Stein, 2014; Montgomery & Kosloski, 2013). For example, one in four caregivers reports difficulty finding services in the community because of lack of affordability, more common among higher-hour caregivers (National Alliance for Caregiving & AARP, 2015). Other reasons include limited information about services or difficulty accessing them; and, in some cases, caregivers are reluctant to seek or accept assistance even when it is available (Hooyman & Kiyak, 2011). Recent data indicate that three in five informal caregivers received one support service, with home modifications and financial assistance being the most common, followed by transportation and respite care services (National Alliance for Caregiving & AARP, 2015). Other data show that 78 percent of caregivers report needing more help with at least 14 different caregiving topics (Martinez, 2015).

Given the impact of caregiving on caregivers’ physical and emotional health and other related costs (e.g., lost wages and retirement benefits, higher health care expenditures) and the rapid demographic changes, including aging baby boomers and decreasing caregiver support ratios, the need for support services to informal caregivers will continue to grow (Kwak & Polivka, 2014).

Respite Care Services

Respite care as envisioned by the OAA is designed to enable caregivers to be temporarily relieved from their caregiving responsibilities (Older Americans Act Amendments of 2006). It may be planned or emergency care to help provide temporary relief to alleviate caregiver stress and to reduce the demands of caregiving (Petrovic, 2013). For certain caregiver groups, such as those providing care to people with dementia, it is a "cornerstone service" (Neville, Beattie, Fielding, & MacAndrew, 2015) intended to lessen the risk of physical and psychological health problems among caregivers (Neville et al. 2015). Providing respite allows time for an often homebound caregiver to rest and take time for herself, whether in the home or in a community setting (Evans, 2013; Neville et al. 2015). Delivered regularly or as needed by in-home care services (e.g., companion services, skilled care services, homemaker services) or by friends and other volunteers, respite care is crucial for informal caregivers providing care to people with chronic conditions or who need long-term care (Petrovic, 2013). Adult day programs, short-term nursing home care, and residential facilities also offer respite services for caregivers (Brown, Friedemann, & Mauro, 2014; Family Caregiver Alliance: National Center on Caregiving, 2014; Gaugler, 2014).

Given the burden of caregiving and its impact on the caregiver (e.g., physical and psychological health, financial burdens), respite provides a temporary break and enables caregivers to continue in their important role (Collins & Swartz, 2011; Musil, Morris, Warner, & Saeid, 2003; Neville et al. 2015). In one study, caregivers reported that they regard respite as the most needed of services to continue in their role (Utz, Lund, Caserta, & Wright, 2012). For caregivers employed outside the home and whose formal employment adds to their existing burden, respite services are all the more important (Utz, et al. 2012).

Informal caregivers who perform 21 or more hours of caregiving per week and live with the care recipient report that respite services would be helpful (National Alliance for Caregiving & AARP, 2015). Caregivers also indicate that respite has improved their quality of life and left them feeling more invigorated (Salin, Kaunonen, & Astedt-Kurki, 2009). For the care recipients, respite allows them an opportunity to meet with others, spend time in a safe environment, and participate in activities designed to match their abilities and needs (Alzheimer's Association, 2016). Research indicates that although respite can be beneficial, particularly for higher-hour caregivers, some, such as caregivers providing dementia care, reported they were less likely to avail themselves of this support (Neville et al. 2015). Barriers to accessing respite services include misinformation, inability to recognize the need for respite, and inability to permit oneself to temporarily leave caregiving responsibilities (Neville et al. 2015).

Policymakers are becoming increasingly aware of the importance of supporting the millions of Americans who provide informal care through respite and other such services. One State legislator from Hawaii succinctly summarized the immediacy of the issue for some policymakers: "If we do not make this a top priority, there will be a crisis" (Martinez, 2015).

Counseling, Education, and Establishment of Support Groups

A second major category of support services encompasses caregiver training, individual counseling, and support group organization, which the OAA specifies should "assist caregivers in the areas of health, nutrition, and financial literacy" and help them develop strategies in role-related decision-making and problem-solving (Generations United, 2003). Although earlier research focused primarily on interventions involving counseling and education, more recent research has targeted programs to strengthen individual or family counseling, case management, skills training, and behavior management strategies (Applebaum & Breitbart, 2013; Brodaty, Green, & Koschera, 2003; Sörensen, Pinquart, & Duberstein, 2002). Studies in which interventions targeted some of these topics have demonstrated significant improvement in caregiver burden, depression, sense of wellbeing, and satisfaction with caregiving skills (Brodaty et al. 2003; Schulz et al. 2002). For example, a recent study shows that 84 percent of caregivers reported a need for more information and training on caregiving topics, such as how to keep their loved ones safe and recommendations on stress management (National Alliance for Caregiving & AARP, 2015). Higher-hour caregivers were more likely to ask for information on reducing stress, managing loved one’s challenging behaviors, incontinence and toileting problems, and end-of-life decisions (National Alliance for Caregiving & AARP, 2015).

Some research has found that web-based training for providers might be an effective tool that benefits adults with dementia and their caregivers (Mittelman & Bartels, 2014). In one state, individualized services in the form of care consultants assisted dementia caregivers, with outcomes showing caregivers felt more empowered in their role (Klug, Halaas, & Peterson, 2014). Support groups, which may be general or specific to a particular diagnosis or characteristic, also empower caregivers in their role. One example is Caring Together, Living Better (CTLB), a partnership of nonprofit and faith-based organizations in an Illinois suburban county that aims to develop a regional support network for African American caregivers (Iris et al. 2014). The CTLB partnership takes a culturally sensitive approach while recognizing spirituality and prayer as an important support, resulting in improved caregiver quality of life (Iris et al. 2014). As demands for informal care increase, addressing training, education and support groups in caregiver policy will be critical in supporting caregivers and in ensuring their family members experience dignity and wellbeing in the face of chronic or progressive disability, illness, or both.

Information, Referral and Access Assistance

The complex task of assisting older adults to age in place often requires caregivers to acquire extensive knowledge within the health, social, financial, housing, and technology arenas, which in turn requires assistance to those caregivers as they make crucial decisions and solve problems related to caregiving (Generations United, 2003). The OAA specifies that states make available to caregivers not only information about and referral to available services (I&R), but also assistance in gaining access to them. I&R and access assistance (sometimes collectively referred to as I&R/A) are the most foundational support services to caregivers, who are among the most frequent seekers and users of such services (National Association of States United for Aging and Disabilities, 2013).

Nevertheless, a common problem noted in the literature is that many caregivers are unaware of existing services and unable, therefore, to access them (Maslow & Selstad, 2001). Early research underscores the importance of information sharing, and reports that information about available supports is the most necessary of caregiver services (Friss, 1990). More recent research explores the benefits of interventions to increase caregiver knowledge but cautions that information alone is less useful than information and a link to accessing the service (Kennet, Burgio, & Schulz, 2000).

Caregivers may obtain information and receive referrals to programs from nearby resources, such as social services departments and local senior centers. AAAs often host outreach education sessions at these local centers and offer materials on aging issues for caregivers in the form of books and videos (Smith, 2010). Support services within AAAs include information, assistance, outreach, transportation, and disease prevention and health promotion activities (Smith, 2010). In addition, AAAs provide I&R to nutrition services and congregate meals, including home-delivered meals (Smith, 2010). Research shows that telephone support programs are potentially more useful than other services in diminishing burden and depression and in increasing knowledge and use of services in the community (Smith & Toseland, 2006).

Caregivers also benefit from information about new technologies that support aging in place (Andruszkiewicz & Fike, 2015, The Lewin Group, 2012). As an example, the Center for Technology and Aging in California helps consumers learn about and leverage technology that can potentially improve a care recipient's life while supporting the caregiver (Andruszkiewicz & Fike, 2015). The Internet is a means for linking caregivers to resources that can potentially support them and the people for whom they care (Petrovic, 2013).

Despite the wide variety of resources that can aid caregivers with I&R to services, a barrier remains when caregivers do not know where to seek that help and when the information sources themselves might be widely scattered and topic-specific. The expanding network of aging and disability resource centers (ADRCs), sponsored in nearly every state by ACL and the Centers for Medicare and Medicaid Services, is creating a more streamlined "single entry point" or "no wrong door" experience that should help caregivers find assistance in one place with one request (Alecxih & Blakeway, 2012).

Supplemental Services

The OAA requires states to provide caregivers access to supplemental services, on a limited basis, to complement the care provided by caregivers. States have some leeway to determine the breadth of supplemental services to provide, but all complement the care provided by the caregiver and most often include one-time health-related items such as medical equipment, home modifications, and assistive technology, or consumables such as continence supplies. In the literature, supplemental services may also encompass care management, legal assistance, financial consultation, home safety interventions, and transportation (Feinberg, Newman, Gray, & Kolb, 2004; Generations United, 2003; The Lewin Group, 2012). New technologies help caregivers and care recipients by delivering products that support monitoring and managing care recipients' health and home environment (Andruszkiewicz & Fike, 2015).

Enhanced support services for caregivers of people with dementia have been found to increase caregivers' abilities and wellbeing and, at the same time, to delay institutionalization for care recipients (Long, Moriarity, Mittelman, & Foldes, 2013). When supplemental services are widely implemented, they can prove cost effective (Fox-Grage & Walls, 2013; Long et al. 2013). Supplemental services that address caregivers' psychosocial needs have been shown to diminish burden, including depression and distress (Mittelman & Bartels, 2014.) Benefits of a State-funded Dementia Care Services Program included the use of fewer potentially avoidable medical services (e.g., hospitalizations) and possible savings of $39 million to payers of long term care from delayed nursing home placement (Klug et al. 2014).

Section IV: Special Issues in Informal Caregiving

Caregiving within certain populations and for persons with certain conditions can create special challenges. Factors such as race, ethnicity, income level, gender, marital status, and a host of others can affect caregiving outcomes. For example, higher-income caregivers can avoid some of the caregiver stressors with which lower-income caregivers must struggle. On the other hand, the burdens of caring for persons with dementia or mental illness can leave caregivers across the economic spectrum facing the same negative effects on their own health.

Caregiving among Members of Racial and Ethnic Minority Groups

The numbers and proportions of older people who are members of racial and ethnic minority groups is projected to grow rapidly from nearly 2 million in 2000 to an estimated 8.6 million in 2030, with the majority of growth occurring in the Hispanic and Asian populations (Brown, 2014; Feng, Fennell, Tyler, Clark, & Mor, 2011; National Research Council, 2010). Pinquart & Sörensen (2005, p. 90) defined ethnic groups as follows: Ethnic or ethnocultural groups are distinguished on the basis of a common history, a unique language or communications system, group-held values and beliefs as well as normative expectations and attendant customs and practices, the intergenerational transmission of these shared values, and a common locale or country of origin.

Outcomes from the Pinquart & Sörensen (2005) meta-analysis show that compared with non-Hispanic White caregivers, ethnic and racial minority caregivers are more likely to be younger and to have lower incomes and lower educational attainment. Although they tended to have better psychological outcomes, physical health was worse among ethnic and racial minority caregivers than non-Hispanic White caregivers (Pinquart & Sörensen, 2005). The literature suggests that higher levels of burden in racial and ethnic minority caregivers might exist because minority elders are at increased risk of the cumulative outcomes of economic disadvantage and discrimination (Pinquart & Sörensen, 2005). Additional literature shows that racial and ethnic minority older adults tend to have poorer health outcomes and are less likely to seek formal LTSS than non-Hispanic Whites and therefore rely more heavily on informal care (Botsford, Clarke, & Gibb, 2011; Kirby & Lau, 2010).

The prevalence of caregiving varies by racial and ethnic group. For example, it is highest among Hispanics and lowest among non-Hispanic Whites (National Alliance for Caregiving & AARP, 2015). African American caregivers are more likely to care for a nonrelative than caregivers from other racial and ethnic groups (23 percent versus 13 percent), and Asian Americans provide care for the oldest recipients (72.8 years old, on average), followed by Whites (71.1 years), African Americans (66.3 years), and Hispanics (65.3 years) (National Alliance for Caregiving & AARP, 2015).

While the number of non-Hispanic Whites entering nursing homes has declined, the number of older Hispanics and Asians entering nursing homes has increased by about 54 percent for each group (Feng, Fennell, Tyler, Clark, & Mor, 2011). These percentages might reflect the rapidly occurring demographic shifts, but they could also indicate unequal minority access to care in the community, which is typically preferred (Dilworth-Anderson, Williams, & Gibson, 2002). The preference for informal care among racial and ethnic minorities might be fostered by psychosocial factors, such as cultural values and beliefs associated with caregiving for older adults, economic factors (e.g., lower income available for formal health care services), and availability of family and friends to help (Dilworth-Anderson, Pierre, & Hillard, 2012; Goins, Garroutte, Fox, Dee Geiger, & Manson, 2011; Knight & Sayegh, 2010; National Research

Council, 2010). Some literature suggests that social capital (i.e., interpersonal trust and norms of reciprocity) is stronger in certain racial and ethnic communities leading to a preference for informal care over formal services, but there may also not be enough informal caregivers among racial and ethnic minorities to meet the growing need (Kirby & Lau, 2010). Further, culturally-based attitudes might make acknowledging the need for help or accepting formal support in the home more challenging, but language gaps and communication barriers also make seeking help and support difficult for some racial and ethnic caregivers (Pinquart & Sörensen, 2005). The lack of formal minority health care workers might further dishearten caregivers trying to find additional assistance for themselves and the care recipient (Hepworth, 2005).

Some literature warns that it is important not to attribute differences in racial and ethnic patterns of caregiving to psychosocial factors, as has been the tendency in the past (Kirby & Lau, 2010). Other literature suggests that erroneous assumptions about caregiving among racial and ethnic minority groups may lead to a lack of recognition of needs, and looking beyond racial and ethnic labels when considering caregiving might be more fruitful (Botsford et al. 2011). Socioeconomic differences among racial and ethnic groups, including education, employment, physical health, and psychological health, may be compounding variables in the experience of particular communities (Botsford et al. 2011). For example, although the achievement gap between White, Black, and Hispanic students receiving high school diplomas narrowed between 2011 and 2013, differences remain when comparing minority education attainment to that of White students (U.S. Department of Education, 2015). For over 40 years, unemployment rates for Blacks have been higher than unemployment for Whites and have recently been more than twice as high (11.4 percent and 5.3 percent, respectively) (Bump, 2014).

Since the release of the Institute of Medicine’s 2003 ground-breaking report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health*, racial and ethnic minorities continue to experience disparities related to physical and psychological health (Holden et al. 2014; U.S. Department of Health and Human Services, 2012). Although health indicators (e.g., life expectancy) have improved for many Americans, members of minority groups are more likely to be impacted by systemic disparities that result in higher rates of preventable illness and disability (Centers for Disease Control and Prevention, 2015; Fiscella, Franks, Gold, & Clancy, 2008; Smedley, Stith, & Nelson, 2003).

Given the rapid changes in population demographics and the LTSS landscape, better understanding of how different racial and ethnic subgroups of caregivers experience various aspects of caregiving continues to be crucial, including use of formal caregiving, as an important supplement to informal caregiving. As underscored in the literature, policy should include the goal of reducing disparities while ensuring sufficient access to formal caregiver resources, including respite care, to help educate, support, and relieve informal caregivers (Kirby & Lau, 2010; Feng et al. 2011; Neville et al. 2015).

Caregiving and Socioeconomic Status

Widely documented throughout the life course (Adler et al. 1994; Case, Lubotsky, & Paxson, 2002; Marmot, 2002), the impact of socioeconomic status is known to exert both short- and long-term effects on individuals’ physical health (Haas, 2008). Further, research shows that a caregiver in a lower socioeconomic group likely has the same lifestyle as the care recipient and might, therefore, have a greater potential for some of the same disabilities his or her care recipient has (e.g., cognitive decline, decrease in strength and mobility) (National Research

Council, 2010). As the pool of informal caregivers shrinks and the need for care and associated costs increase, many middle class and lower class families might be unable to afford care for family members who have chronic illnesses (Bruhn & Rebach, 2014) and might be forced to take on even more of the informal care burden.

Few studies focus solely on the impact of socioeconomic status on informal caregiver outcomes. However, many studies include income as a potential confounding factor in the analysis. Although informal caregivers are diverse and represent every socioeconomic group, overall, they are more likely to have a lower socioeconomic status (National Research Council, 2010; Pinquart & Sörensen, 2005). This status might make providing care to a loved one more difficult for several reasons. For example, lower socioeconomic status might limit the ability of informal caregivers to address the impacts of caregiving, whereas caregivers with higher socioeconomic status potentially have greater ability to make a wider range of choices and access the services they seek (Argyle, 2001). A 2007 study with a statewide random sample of both baby boomers and older adults found that inadequate income for caregivers (defined as not having enough money to make ends meet) was a strong predictor of several negative health and psychosocial outcomes, including a much higher likelihood of symptoms of depression (Robison et al. 2009). Lower socioeconomic status might also decrease choices for social contact and in so doing increase the social isolation of caregivers (Argyle, 2001).

Caregivers in lower socioeconomic groups might have less ability to mediate the burdens associated with caregiving, and caregivers who demonstrate more resilience and self-efficacy are better able to cope with the stresses of caregiving (Gallagher et al. 2011; Löckenhoff, Duberstein, Friedman, & Costa, 2011; Merluzzi, Philip, Vachon, & Heitzmann, 2011). Stress process models have described the relationship between the caregiving experience, the associated burdens, and caregiving outcomes (Au et al. 2010; Pearlin, Mullan, Semple, & Skaff, 1990). Consistent with Pearlin et al.'s (1990) approach, contextual variables appear to influence level of burden and ability to cope. Earlier literature shows that when exploring the association between caregiving and depression, socioeconomic status might be related to depression because informal caregivers with lower annual incomes reported significantly higher depression symptoms (Cameron, Cheung, Streiner, Coyte, & Stewart, 2006).

Female Caregivers

Sixty percent of informal caregivers are women, most of whom are higher-hour caregivers (generally defined at 21 or more hours of care per week) who provide care to spouses, parents, in-laws, friends, and neighbors (National Alliance for Caregiving & AARP, 2015). Forty-nine years old, married, and employed, the average female caregiver cares for a parent who does not live with her (Feinberg, Reinhard, Houser, & Choula, 2011).

Pinquart and Sörensen (2006) conducted a meta-analysis assimilating the outcomes of 229 studies to explore gender differences in caregiver stressors, social resources, and health and found that, compared with men, women reported higher levels of caregiver burden and depression and lower levels of physical health and subjective wellbeing. Other studies have reported more negative physical effects of caregiving for women (e.g., sleep problems, elevated blood pressure, poorer immune system) (Gibson, Gander, & Jones, 2014; Lee, Colditz, Berkman, & Kawachi, 2003; National Alliance for Caregiving & AARP, 2015; Rosso et al. 2014; Spencer, Goins, Henderson, Wen, & Goldberg, 2013).

As well as experiencing more stressors from caregiving, women often bear more financial burden than do male caregivers by providing monetary assistance to the care recipient (MetLife Mature Market Institute, 2011). The literature suggests that women, especially unmarried women, might have fewer options when trying to balance the responsibilities of personal life, caregiving, and work (Feinberg & Choula, 2012). Workplace compromises are more common among women engaged in informal caregiving and include decreasing working hours; arriving late, leaving early, or both; and retiring early (Feinberg & Choula, 2012). Costs associated with caregiving for women often include lost wages and reduced retirement and Social Security benefits (MetLife Mature Market Institute, 2011). Estimates show that 20 percent of women in the United States who work for pay are also informal caregivers (Feinberg & Choula, 2012). Minority and low income female caregivers might face additional difficulties. The poverty rate, for example, among single Black women and Hispanic women age 65 and older is 31 percent and 41 percent, respectively, suggesting that accessing any paid caregiving supportive services might not be an alternative (Administration on Aging, 2011).

Research demonstrates that support services make a difference in the daily lives of female caregivers and exert a positive impact on their health and wellbeing (Corry, While, Neenan, & Smith, 2014; Lopez-Hartmann, Wens, Verhoven, & Remmen, 2012; Van Houtven, Voils, & Weinberger, 2011).

LGBT Caregiving

There is increasing diversity among older adults by sexual and gender identity. Approximately 2.4 million Americans today identify as lesbian, gay, bisexual, or transgender (LGBT) (Fredriksen-Goldstein, 2014). Given the rapid demographic changes in the U.S. population, it is estimated that by 2030 there will be approximately 5 million LGBT adults age 50 and older (Fredriksen-Goldstein, 2014). These individuals often find themselves in the role of caregiver, care recipient, or both.

Older LGBT adults often experience significant health disparities and may experience greater difficulty remaining in the community and receiving informal caregiving in that setting (Centers for Disease Control and Prevention, 2011; Fredriksen-Goldstein, Kim, & Barkan, 2012; Grossman, d'Augelli, & Hershberger, 2000). For example, compared to same-age heterosexuals, LGBT older adults are at greater risk of poor physical health, depression, and disability (Croghan, Moone, & Olson, 2014). Outcomes of a 2010 study show that same-sex older adult couples are more likely to experience poverty than their heterosexual peers, a conclusion even more pronounced among LGBT people of color (Wiger, 2015).

Historically, informal caregiving has reflected traditional family patterns with women providing informal care when needed, but LGBT older adults are not as likely to have children and often lack support from extended biological families due to various reason including discrimination (de Vries, 2006; Croghan et al. 2014; Fredriksen-Goldstein, 2014; MetLife 2010a). According to some research, LGBT individuals are more likely to depend on a "chosen family" instead of a biological family and one study indicated that as many as 64 percent of LGBT baby boomers have a "chosen family" (Croghan et al. 2014).

Even when LGBT individuals do have caregiving support from a biological family or a "chosen family," health care providers participating in local and local and regional studies often indicate they feel inadequate to address the specific caregiving needs of people who identify as LGBT

(Croghan et al. 2014). Because there has often been a high level of discrimination based on sexual orientation among providers toward LGBT individuals, caregivers may be reticent to seek provider services and supports (Brotman et al. 2007). Additionally, access to quality services may be limited by reluctance to disclose sexual orientation by LGBT caregivers or the people they care for to service providers (Croghan et al. 2014). Given the likelihood of reliance on more limited social networks and the experience of discrimination from providers, people identifying as LGBT may experience more social isolation than their heterosexual counterparts and may also underutilize health and social services to help them live in the community and maintain quality of life (Brennan-Ing, Seidel, Larson, & Karpiak, 2014).

While all informal caregivers need support to avoid burnout and to protect themselves against chronic health problems arising from self-neglect (Hunt & Reinhard, 2015-2016), progress remains slow in reducing discrimination and health disparities for LGBT caregivers (Takamura, 2014-2015). Expansion of the definition of family to include a variety of family and care structures of all racial, ethnic, and LGBT communities, including partners and families of choice as well as spouses and biological families, is still on the horizon (National Alliance for caregiving, 2012). The goals remain clear, however, for the need to develop cultural competence to help providers interact sensitively with people in all cultural groups, including LGBT older adults and their caregivers (Takamura, 2014-2015). Addressing the specific health concerns of LBGT populations and increasing available, adequate, and affordable caregiving resources is also necessary to reduce disparities related to LBGT caregivers and the people they care for (Takamura, 2014-2015).

Informal Caregiving and Dementia

In the literature, dementia is defined as “a cognitive decline severe enough to require help with daily activities” (Friedman et al. 2015, p. 1,637). The impact of Alzheimer’s disease or other dementia, a chronic, progressive condition, is considerable, and the lack of disease-modifying treatments and the intense care required have the potential to increase caregiver burden (Corcoran, 2011; de Oliveira, Vass, & Aubeeluck, 2015; World Health Organization, 2012). Care associated with dementia for some 5.5 million American adults ages 70 and older is estimated to cost $159 billion to $215 billion annually, with $109 billion of that figure representing the cost of care purchased in the market, and the rest the estimated value of informal care (Friedman et al. 2015; Hurd, Martorell, Delavande, Mullen, & Langa, 2013). People with dementia most often are cared for by family members, and as the number of older adults living with dementia continues to increase, grave concern exists about the burdens placed on informal caregivers (Kasper, Freedman, Spillman, & Wolff, 2015). Dementia is more prevalent among some ethnic groups, especially where higher risks of hypertension and strokes are evident (Botsford et al. 2011). For example, Asian American caregivers are more likely to report caring for someone with Alzheimer’s disease or other dementia (National Alliance for Caregiving & AARP, 2015).

Nearly all the dementia caregiving literature underscores the importance of interventions and supports. Without the appropriate support, informal caregivers providing care for someone with dementia might be more likely to develop sleep problems (Gibson et al. 2014), “compassion fatigue” (Day, Anderson, & Davis, 2014, p. 796), major depression, anxiety disorders, and additional physical health problems that might lead to higher mortality rates than generally expected in the broader population (Judge, Menne, & Whitlatch, 2009; Mausbach et al. 2012;

Moon & Dilworth-Anderson, 2015; World Health Organization, 2012). One-half of Alzheimer's or other dementia caregivers (50 percent) report feeling emotional stress (National Alliance for Caregiving & AARP, 2015).

Given certain characteristics of baby boomers (e.g., lower marriage rates, higher divorce rates, fewer children), some research suggests that baby boomer caregivers providing care for someone with dementia might benefit from interventions specifically designed to help them manage caregiving burdens and improve their physical and mental health (Moon & Dilworth-Anderson, 2015). For example, research demonstrates that physical activity, as an intervention, reduces dementia caregivers' emotional burden (Orgeta & Miranda-Castillo, 2014). Other research explores the importance of obtaining insight into the challenges of providing care to persons with dementia through networks of multiple caregivers within families, rather than the more limited "single informant" approach through the primary caregiver. This broader approach yields greater understanding of how families share caregiving responsibilities and the impact this sharing has on the care recipient (Koehly, Ashida, Schafer, & Ludden, 2014). Additional research explores strength-based skills training for dementia caregiving dyads in an effort to develop support for caregivers coping with the challenges and burden of dementia caregiving (Judge et al. 2009).

Behaviors common to dementia are stressful and threaten caregiver health. Learning to manage these behaviors without pharmacological interventions is thought to be helpful and to minimize negative impacts on caregiver health (Kales, Gitlin, & Lyketsos, 2014). Even though a large number of individuals are affected by dementia, current systems of care for people with dementia and their caregivers are disorganized. Kales et al. (2014) focuses on addressing the behavioral symptoms of dementia and on encouraging better prevention, assessment, and behavior management through specific steps (i.e., describe, investigate, create, and evaluate) based on patient, caregiver, and environmental considerations. Reducing stress by addressing behavioral symptoms and by identifying factors influencing quality of life is another psychosocial intervention proving useful for people with dementia and their caregivers. In one study, lower caregiver stress was associated with better quality of life for the person with dementia, and higher caregiver quality of life was associated with lower caregiver stress and better caregiver health (Ortega, Orrell, Hounsome, & Woods, 2014).

Additional research posits the importance of understanding the dementia diagnosis and how it impacts the caregiving experience. Caregivers emphasized the need for more information, particularly in regard to better understanding behavioral, physical, and psychological changes in the care recipient (Stokes, Combes, & Stokes, 2014). Finally, although much of the literature focuses on dementia caregiving's negative aspects, other research focuses on the positive aspects (Carbonneau et al. 2010; Roff et al. 2004; Roth et al. 2015). In particular, Carbonneau et al. (2010) suggest a conceptual framework of positive aspects, noting that they have the potential to spawn useful support programs based more on the positive than the negative aspects of caregiving. Given that respite services are especially appealing to caregivers of people with dementia (46 percent of dementia caregivers would like respite versus 30 percent of non-dementia caregivers) (National Alliance for Caregiving & AARP, 2015), strengthening caregivers by providing access to respite care as well as other supports (e.g., information, resources, training, financial support) is critical (de Labra et al. 2015; World Health Organization, 2012).

Informal Caregiving and Mental Illness

Similar to dementia caregiving literature, extensive research has been conducted on informal caregiving for people with a mental illness (Beach et al. 2000; Lindenbaum, Stroka, & Linder, 2014; National Alliance for Caregiving & National Alliance for Mental Illness, 2016; Ohaeri, 2002; Pearlin et al. 1990; Zegwaard, Aartsen, Grypdonck, & Cuijpers, 2013). . An estimated 43 million American adults (18 percent) suffer from a mental illness, 19.7 million (8 percent) have a substance use problem, and 8.8 million (4 percent) report serious thoughts of suicide (Insel, 2015; Mental Health America, 2015). Approximately 8.4 million Americans provide care to an adult with a mental illness; although 58 percent of these care recipients are age 18-39, about 20 percent are age 65 or older (National Alliance for Caregiving & National Alliance for Mental Illness, 2016).

The earliest literature, more than 60 years ago, focused on the burden of caring for someone with a mental illness (Yarrow, Schwartz, & Murphy, 1955). With a shift from institutionalization to community care, the role of family members caring for someone with a mental illness has grown, and the burden associated with such care has expanded (Anderson et al. 2013; Muhlbauer, 2002; National Alliance for Caregiving & National Alliance for Mental Illness, 2016; Ohaeri, 2002; Rose, Mallinson, & Walton-Moss, 2002; Wolthaus et al. 2002; Yesufu-Udechuku et al. 2015).

Requiring effort, energy, and compassion, caring for people with a mental illness has the potential to significantly impact caregivers' daily lives physically, emotionally, socially, and financially (Cummings & Kropf, 2015; Lindenbaum et al. 2014; World Federation for Mental Health, 2014; Yesufu-Udechuku et al. 2015). According to a recent study, nearly three-quarters of adults providing care for a family member with a mental illness report high emotional stress and about half of caregivers (49%) report that their family member is financially dependent on them (National Alliance for Caregiving & National Alliance for Mental Illness, 2016). Almost half of caregivers in the same study report it is difficult to talk with anyone about their caregiving experience because of the stigma associated with a mental illness, and four in ten caregivers report that the combination of stigma and isolation make it challenging for them to take care of their own physical and emotional health (National Alliance for Caregiving & National Alliance for Mental Illness, 2016).

As the baby boomer cohort ages, mental health needs are increasing in the older population and will challenge the existing pool of informal caregivers (Bartels, Pepin, & Gill, 2014; Eden, Maslow, Le, & Blazer, 2012). Although many people with a mental illness need help to function, some of them have alienated family and friends, making it more difficult to receive the support they need in a community setting (Cummings & Kropf, 2015). Caring for someone with a mental illness is often challenging because of its progressive nature and, in some cases, the adverse effects of medication (Zegwaard et al. 2013). In addition, people with a mental illness are more likely to have addiction disorders or multiple chronic illnesses than people without a mental illness (Cummings & Kropf, 2015).

Informal caregivers of people with a mental illness continue to have difficulty locating providers and programs to support them. In one study 51 percent were dissatisfied with the number of available and affordable services and 46 percent were concerned about the quality of services (National Alliance for Caregiving & National Alliance for Mental Illness, 2016). Current research underscores the strong need for interventions that meet the individual support requirements of informal caregivers of individuals with a mental illness (Lindenbaum et al. 2014;

Zegwaard et al. 2013). In addition, caregivers who report high levels of stress from caring for someone with a mental illness seek information about managing both their stress and the care recipient's behaviors (National Alliance for Caregiving & AARP, 2015). Given that respite services are particularly appealing to high- and medium-burden caregivers who care for a person with a mental illness, such services should be considered a priority for this population (National Alliance for Caregiving & AARP, 2015).

Playing a large role in the health and wellbeing of older adults with mental health and substance use conditions, informal caregivers need the empowering support that education and interventions provide (National Alliance for Caregiving & AARP, 2015). To better support informal caregivers of people with a mental illness, Eden et al. (2012) suggest the importance of more fully evaluating educational and support initiatives while developing and implementing culturally sensitive interventions and making sure they are accessible to all, including minority populations. In addition, a recent study suggests that what caregivers want most is policy support to enable them to better navigate and access the services and supports they seek (National Alliance for Caregiving & National Alliance for Mental Illness, 2016).

Section V: Policy Context

The status quo in the U.S. health and long term care systems has long been of growing concern to American consumers, health care providers, public policymakers, and employers. Now, rapidly changing demographics and ever rising health and long term care costs threaten to increase the burden on informal caregivers and on older adults and persons with chronic disease or disability for whom they provide care, creating a policy challenge.

Impact of Demographic Changes

Although informal caregiving has always been a part of family and community life, recent trends toward significantly longer life have dramatically increased the number of older adults living in the community with physical and cognitive impairments, creating increased challenges for both family members and society to ensure the availability of appropriate care resources (Roth et al. 2015). At a time when the older population and the need for informal care are experiencing dramatic growth, the availability of close family members to provide care has been strained by other demographic trends, such as smaller family size, greater prevalence of divorce, and increased geographic mobility (Roth et al. 2015). Recent studies have noted cohort differences in informal caregivers' availability, with aging baby boomers less likely to receive care from either spouses or children than prior generations (Robison, Shugrue, Fortinsky, & Gruman, 2014).

Importance of Caregiver Contributions

Policymakers who wish to avoid or delay the potential fiscal strain of government responsibility for the increasing number of vulnerable older adults are highly motivated to recognize informal caregiver contributions and support them in their roles. To make informed decisions that balance incentives for informal caregiving against the possible opportunity costs of reduced employment and higher health care costs for caregivers, policymakers must understand both the prevalence and the value of informal caregiving (Bauer & Sousa-Posa, 2015; Chari et al. 2015).

As described earlier, although there are varying estimates of the prevalence of informal caregiving, there is agreement that it is substantial. Estimates of the value of such caregiving also vary. By definition, informal caregiving cannot be directly valued by the market through price, so researchers have used a variety of techniques to estimate its value. One recent study used data from the 2011 and 2012 American Time Use Survey to estimate informal caregiving's value for elders in the United States as a function of opportunity cost (Chari et al. 2015). It concluded that the value (opportunity cost) of such care in the United States was $522 billion annually and that the cost of replacing such care would be $221 billion for unskilled paid workers and $642 billion for skilled home health aide care. AARP recently updated its periodic analysis of informal caregiving's economic value, pegging the value of 40 million caregivers providing 37 billion hours of care annually at $470 billion in 2013, up from $450 billion in 2009 (Reinhard, Feinberg, Chouler, & Houser, 2015). The Congressional Budget Office, using data from the Health and Retirement Study, valued 11.2 billion hours of informal care in 2011 at $234 billion (Congressional Budget Office, 2013). Whichever methodology is used, clearly the economic value of informal caregiving is enormous and difficult to replace.

Caregiver Policies

Caregiver policies and programs in the United States currently lag behind their counterparts in most other developed countries (Lipson, 2015; Bauer & Sousa-Posa, 2015), in part because informal caregiving has been viewed historically as a private responsibility, rather than a public policy concern (Levine et al. 2010; Feinberg, 2014; Feinberg & Levine, 2015). Indeed, the United States is the only developed country that lacks a paid family and medical leave policy for all workers and their families (Chen, 2014). Lipson (2015) has described the slow, incremental development of federal caregiver policy, beginning with the Family Medical Leave Act (FMLA) of 1993, which requires some employers to provide at least 12 weeks of unpaid leave per year for certain defined caregiving situations. At present, however, fewer than 60 percent of workers are covered by FMLA, which applies only to employers of 50 or more and only to caregivers of certain designated relatives (Sabatino, 2015).

The NFCSP, added to the OAA in 2000, spends approximately $150 million per year on grants to states for I&R, counseling, support, training, and respite for caregivers. The Lifespan Respite Care Act, added in 2006, awards approximately $2.5 million annually to help states develop coordinated systems of accessible higher quality respite programs (Lipson, 2015).[6] In addition to these two programs, limited Federal tax incentives for caregivers exist, although efforts to credit Social Security earnings to caregivers for missed work time have failed. Proposals to provide federal paid leave for caregiving have also failed, but three states (California, New Jersey, and Rhode Island) have paid family leave insurance allowing 4 weeks to 6 weeks' paid caregiving (Lipson, 2015; Shabo, 2015). By contrast, many European countries provide significantly greater levels of both paid and unpaid leave, direct payments to caregivers or care recipients, services in kind, or a combination of two more of such benefits. Such generous caregiver benefits can, however, lead to a "substitution effect," wherein public support can make families less willing to provide informal care (Bauer & Sousa-Posa, 2015).

In addition to the Federal Government, states and private entities, including employers, make caregiver policies. According to a recent 50-state AARP survey of informal caregiver assessment practices in Medicaid HCBS programs, approximately 30 percent of states assess informal caregivers as part of the client assessment process (Kelly, Wolfe, Gibson, & Feinberg, 2013). In addition to assessing caregiver needs, some state HCBS programs provide respite services, and

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[6] Both the NFCSP and LRCA operated for some time under lower budgets due to sequestration cuts (Hunt & Reinhard, 2015).

some allow family or friends to be paid (Lipson, 2015; Kelly et al. 2013). Many states (17 as of mid-2015) have adopted the model CARE (Caregiver Advise, Record, Enable) legislation, which allows caregivers to be care team members in acute care settings, participate in discharge planning, and receive education and instruction on post-discharge duties (Hunt & Reinhard, 2015).

Some private employers, in addition to complying with mandated responsibilities under FMLA and other legislation, sponsor a range of voluntary benefits and options such as elder care referral, employee assistance programs, paid time off, and flexible work options (MetLife Mature Market Institute, 2010b) that may help employees with caregiving responsibilities. Available more often in larger companies, such policies are primarily designed to help companies to retain employees. Job flexibility is still rare for many employees, who have little input about their schedules, their work hours, or the availability of telecommuting (Shabo, 2015). The most costly benefits (e.g., services of a geriatric care manager, access to backup elder care), however, are offered by only about 1 percent of employers (MetLife Mature Market Institute, 2010b).

Employers that fail to treat employees who are caregivers fairly might be subject to claims under an expanding theory of "family responsibility discrimination," generally defined as bias against an employee based on caregiving duties, whether for children, aging parents, or others with illness or disability. Although discrimination on that basis is generally not expressly prohibited, claims might succeed if defined as unlawful disparate treatment under laws concerning gender discrimination, hostile work environment, or association with a person with a disability (Sabatino, 2015).

A positive development is the growing movement among some employers to view their employees' caregiving responsibilities as a business issue and to put the full force of their creativity into solving it. By investing appropriately in caregiver resources, employers can benefit through employee retention, reduced turnover, and increased productivity (Holzapfel, Adelson, & McUlsky, 2015). One prominent example is ReACT (Respect a Caregiver's Time), a coalition of employers, academic institutions, and nonprofits established at the World Economic Forum attempting to change workplace culture to better support caregivers (Holzapfel, Adelson, & McUlsky, 2015; Hunt & Reinhard, 2015).

Recent developments have focused increased attention on caregiver issues on the policy front. The so-called CLASS Act (Community Living Assistance Services and Supports) of 2010 would have created a voluntary LTSS financing program of great assistance to informal caregivers. Although ultimately repealed in 2013 for failure to meet actuarial requirements for fiscal solvency, it led to the creation of the Federal Commission on Long-Term Care (Hunt & Reinhard, 2015). Among other extensive recommendations concerning informal caregivers, the Commission recommended that the Centers for Medicare and Medicaid Services "require assessment of family caregiver needs in a care plan or discharge plan that is dependent on them" (Commission on Long-Term Care, 2013, p. 51). The March 2015 establishment of the ACT (Assisting Caregivers Today) Congressional Caucus was a bipartisan attempt to promote community living and informal caregiving through education and policy solutions and should, at a minimum, foster a national dialogue on caregiving topics (Hunt & Reinhard, 2015; Reinhard et al. 2015). In addition, a committee of the prestigious Institute of Medicine is preparing a "Study on Family Caregiving for Older Adults" that will develop recommendations on Federal programs and policies as well as private and public health, workplace rules, and additional considerations.

One promising model of caregiver policy is the Department of Veterans Affairs (VA) Caregiver Support Program, which provides a variety of supports to caregivers of Veterans, including caregiver assessments, training, respite, and stipends (Hunt & Reinhard, 2015).

Other public policies not targeting caregivers directly might, nevertheless, have profound consequences for them. One prominent example is the major policy shift to “rebalance” the LTSS system by promoting community living and aging in place through expansion of home- and community-based services and reduction of institutional care (Levine et al. 2010). Although this trend requires substantial changes for professional caregiving, it also provides increased challenges for family support and community programs (Zarit & Reamy, 2013), with increasing risk that informal caregivers will be unable to sustain the care of formerly institutionalized individuals without increased supports (Levine et al. 2010).

As greater policy attention is paid to assisting informal caregivers, focus is trained on comprehensively assessing need, defining eligibility criteria for services, evaluating effectiveness of a variety of interventions, and determining costs and benefits of each.

IV. Data and Methodology

The NFCSP process evaluation has assessed the way SUAs, AAAs, and LSPs planned for and operated their programs. This section describes the NFCSP sampling design, survey instrument development, response rates, data collection, and analysis.

The research staff conducting this project included Lewin, which led the overall evaluation and the SUA Survey; the Scripps Gerontology Center (Scripps), which led the AAA survey; and the University of Connecticut Center on Aging (UConn), which led the LSP survey.

In the planning stages of this process evaluation, ACL and Lewin engaged a technical advisory group (TAG) to provide expert advice and guidance on the study design. The list of these attendees can be found in Appendix A. The TAG also offered input on the specification of the study objectives and research questions, the evaluation design, and other issues relevant to the evaluation planning.

NFCSP Sampling Design

The SUA survey was administered to all 54 states and territories that operate an NFCSP[7]. The evaluation team surveyed all 619 AAAs active at the time of the survey.

In addition, the survey was administered to a sample of LSPs from the responding AAAs. Scripps followed up with all responding AAAs to request their lists of providers of training and education, respite care services, or both. From the data on the 457 AAA respondents (74 percent of the universe, with no evidence of nonresponse bias), the average number of total LSPs per AAA was 10, and the median was 6. The distance between these two measures of central tendency was based in part on the number of sole-proprietor providers, consumer-directed providers, or both in some AAAs; these figures excluded two AAAs that reported more than 1,000 providers and were considered outliers. Using an average of 10 LSPs per each of the 619 AAAs, the universe of LSPs was 6,190. These figures were based on the AAAs responses to the question “Indicate the number of providers of contracted NFCSP services in your Planning and

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[7] The Virgin Islands and Commonwealth of the Northern Mariana Islands, which do not operate an NFCSP

Service Area (PSA).” Applying sampling parameters (confidence interval half-width of .05, 50 percent population distribution on dichotomous questions, 95 percent confidence level) to the estimated population of 6,190 yielded a required sample size of 362 LSPs. Adjusting for an assumed 60 percent response rate, the evaluation team needed to contact a sample of at least 603 LSPs.

Survey Instrument Development

SUAs, AAAs, and LSPs each completed a different survey. Although questions varied among the three surveys, all focused on the services available for caregivers as well as on the ways in which caregivers could use these services. The SUA survey consisted of 77 questions, the AAA survey consisted of 111 questions, and the LSP survey consisted of 32 questions. Common topics (e.g., funding sources, wait lists, prioritization of services, assessment policies, program administration) were included across the three surveys.

To determine whether the language in these three survey instruments was clear, the evaluation team conducted pilot testing, consisting of two SUA representatives, nine AAA representatives, and five LSP representatives taking pilot surveys and providing feedback on time burden, question wording, and question ordering. Researchers made the necessary changes before survey dissemination to the larger sample.

Under Paperwork Reduction Act (PRA) guidelines, ACL and the evaluation team submitted a PRA package to the Office of Management and Budget (OMB), receiving OMB clearance for the SUA and AAA surveys in December 2014 and for the LSP survey in July 2015.

The surveys disseminated to the SUAs, AAAs, and LSPs are available in Appendix B.

Survey Response Rates

The evaluation team fielded the SUA survey online from January 2015 to May 2015, with the option of an editable PDF format. Because 10 of the 54 SUAs have a single PSA, they function as an AAA and, therefore, received the AAA survey and an additional list of SUA questions. The SUAs were emailed a unique survey link and PDF attachment, with the option to submit the survey in either format. All 54 SUAs completed the survey for a 100.0 percent response rate.

The AAA survey was fielded to the universe of AAAs (n=619) via an online option from January 2015 to July 2015. All AAAs received an email message with their link to the survey, which was prefilled with basic AAA contact information that they were asked to verify before completing the rest of the survey. A total of 457 AAAs completed the survey either fully (n=423) or partially (n=34), yielding a 73.8 percent response rate.

Of the AAAs that completed the survey, slightly fewer than one-half (n=219) responded to the request for LSP lists. Taking the full sample of LSPs in the list (if fewer than 5) or a random sample of 4 LSPs from a longer list, we surveyed 642 LSPs. These surveys were fielded from August 2015 to December 2015. Thirty-seven LSPs were ineligible because they no longer provided NFCSP services, and 26 were ineligible because they did not provide support for caregivers of older adults, resulting in a valid sample of 579. Of this valid sample, 393 LSPs fully (n=384) or partially (n=9) completed the survey for a 67.9 percent response rate. Table 1 summarizes the NFCSP Survey response rates. Table 2 showcases the percentage of AAAs responding by region.

Table 1: NFCSP Survey Response Rates

Survey	Sample	Ineligible	Refusal/ Nonresponse	Complete	Partial	Percent
SUA	54	0	0	56	0	100.0%
AAA	619	0	162	423	34	73.8%
LSP	642	63	186	384	9	67.9%

Table 2: AAA Response Rates by Region

Region	Number Responding	Percent
Northeast	115	25.3%
Midwest	72	15.9%
South	179	39.4%
West	88	19.4%
Total	**454***	**100.0%**

*The three AAAs representing Guam and Puerto Rico are excluded because they do not fit into U.S. Regional breakdowns provided by the U.S. Census Bureau.

Data Collection

The SUA survey was available through Research.net, a widely used survey development and dissemination resource. Lewin extracted collected data and converted it from a Microsoft Excel format to one usable by the statistical software suite SAS. Conversion of “dummy” values, such as “0” to “No” and “1” to “Yes,” among others, took place to allow more intuitive interpretation of results. Identification of outlier values also took place, and follow-up verification with survey participants was conducted to ensure that all data provided were correct.

The AAA survey was available through SNAP, a survey software package. Scripps led the data collection and cleaning identical to the process employed for the SUA survey. Outlier values (e.g., more than 1,000 LSPs) were verified by contacting the AAAs and changes were made as necessary. On completion, Scripps provided an SPSS Statistics file to Lewin, which was converted to SAS for further analysis. Lewin also performed further cleaning to ensure that units were standardized across responses to certain quantitative-focused survey items (e.g., converting all wait list times to days).

The LSP survey was available through a software package designed for UConn. The same data preparation process was applied, and on completion, UConn provided an SPSS Statistics file to Lewin, which was converted to SAS for additional analysis.

Data Analysis

Initial analyses for the surveys focused on descriptive results, allowing computation of frequencies, percentages, means, and ranges as necessary across a wide range of question types (i.e., frequencies and percentages were provided for categorical variables, and means and ranges were provided for continuous variables). As noted earlier, Microsoft Excel, SAS, and SPSS were the software packages used to conduct these analyses. These descriptive tables can be found in Appendix C.

Descriptive analyses were also conducted on select SUA variables stratified by region (Northeast, Midwest, South, and West) and on select AAA and LSP variables stratified by budget size (small, medium, and large) and geographic area (urban and suburban, rural and frontier, and mixed). For the AAA budget, the AAAs were split into tertiles based on their budget ranges. We defined the AAA budget ranges accordingly:

- Small AAAs have a budget of less than $2,185,058.
- Medium AAAs have a budget of $2,185,059 to $5,703,224.
- Large AAAs have a budget of more than $5,703,224.

A full list of selected stratification tables for the SUA, AAA, and LSPs is available in Appendix D. These tables were selected based on the structure of this final report and the categories discussed in more detail herein.

Lewin also conducted qualitative analyses on survey items that include a written element, most often in the form of responses that extend beyond the provided multiple-choice options (e.g., an "Other" option). To ensure that results were both valid and reliable, several iterations of analysis took place. Two researchers analyzed these items individually, creating counts of common responses, and later compared results. Once researchers had resolved discrepancies, a third Lewin researcher spot-checked selected survey items.

Study Limitations

Given the census of SUAs and AAAs for sampling, sampling errors for these populations was not a concern. The LSP sample is primarily of mixed geography and represents the range of budget sizes.

Item Nonresponse

When reviewing this report, noting that some stem questions received a response rate of less than 80 percent across the SUA, AAA, and LSP surveys is important. These results should be interpreted cautiously.

All questions in the SUA survey were not asked of all SUA respondents – 10 of the SUAs represented were from single-PSA states. These states were not asked questions about AAA oversight. Of the questions that were asked of all SUAs, there was one question with less than an 80 percent response rate, which was:

- Please indicate the typical minimum wait for services by caregiver service.

The AAA survey questions with a response rate of less than 80 percent are listed below. For questions on total budget, AAA respondents might have no budget for these services or might receive no funding from these sources. The survey had no mechanism for respondents to note such information, so blanks (nonresponses) might be inapplicable.

- Over the last three years how has the provider pool changed?
- How many unduplicated volunteers worked on the OAA NFCSP at your AAA in the most completed fiscal year? (NOTE: Respondents were instructed to report "Zero" if they employee no volunteers, but they might have skipped this question instead.)

- In total, how many volunteer hours did the OAA NFCSP at your AAA receive in the most recently completed fiscal year? (NOTE: Respondents were instructed to report “Zero” if they employee no volunteers, but they might have skipped this question instead.)
- Have you used OAA NFCSP supplemental service category to fund in whole or in part any of the following services?
- During the most recently completed fiscal year, what was the total, unduplicated count of caregivers supported in whole or in part by your OAA NFCSP (Title III-E) {NFCSP Program Name}?
- We’re interested in the organizations that your AAA uses to provide family caregiver support services. Please indicate the number of providers of contracted National Family Caregiver Support Program (NFCSP) services in your PSA.
- What was the total budget for the grandparent/relative caregiver portion of the NFCSP?*
- What was the total budget for supplemental services?*
- What was the total budget for access/assistance services?*
- What was the total budget for information services?*
- What was the total budget for counseling, support groups, and caregiver training?
- In the last fiscal year, how much did your AAA expend from any of the following sources to support the caregivers served in [INSERT NAME OF OAA NFCSP PROGRAM]?*
    - Total Federal Funding: 309
    - Older Americans Act funds: 298
    - Other federal agency: 107
    - Total State Funding: 264
    - General Revenue: 193
    - State funded caregiver program: 218
    - Other Sources of Funding (e.g., local funding, non-profit, private for-profit, contributions, foundation): 230
- Please mark which of the following funding sources are used to serve OAA NFCSP Title III-E caregiver clients.

For the LSP survey, one stem question received a response rate less than 80 percent:

- How likely are you to continue providing caregiver services one year from now?

LSP Recruitment Barriers

When fielding the LSP survey, UConn researchers experienced several recruitment barriers. AAAs provided contact information for LSPs that then received an email invitation to complete the survey. Weekly reminder messages were sent, followed by phone calls from UConn research team members until the LSP completed the survey, refused, was found ineligible, or failed to respond after numerous contacts. The barriers and solutions employed are discussed in more detail in Appendix E. For example, approximately one-third of LSPs contacted by phone were completely unfamiliar with the NFCSP or were unaware that it funded all or a portion of their respite caregiving services or caregiver education and training services. The evaluation team changed the recruitment calling script to provide more education regarding the program when follow-up phone calls with the LSPs were conducted.

V. Results

This section examines results, organized into topical categories, from all three surveys. Discussions of SUAs refer to the 54 SUAs that operate a NFCSP and that responded to the survey. Discussions concerning AAAs and LSPs refer to the 457 AAAs and 393 LSPs responding to the NFCSP Survey.

Organization Background

SUAs, AAAs, and LSPs were asked to provide background on their organizations.

SUA Background

SUAs reported on the number of AAAs in their state. The 44 SUAs that were comprised of multiple PSAs reported a mean of 14.6 AAAs for a range of 3 to 59 AAAs in their states. The other 10 SUAs are single PSA states that operate as AAAs themselves.

AAA Background

AAAs provided additional background information, including on the governance of their organizations. The largest share of AAAs reported their governance structure as an independent, not-for-profit agency (40.4 percent), with other common responses being a division of a city or county government (29.6 percent) or a part of a council of governments or regional planning and development agency (24.1 percent). Table 3 tallies the answers regarding governance, displaying the frequency and the percentage for responding AAAs.

Table 3: AAA Governance

Answer	Frequency	Percent
An independent, not-for-profit agency	183	40.4%
A division of a city or county government	134	29.6%
Part of a council of governments or regional planning and development agency	109	24.1%
Other	21	4.6%
Educational institution	4	0.9%
A Tribal Government entity	1	0.2%
Don’t know	1	0.2%
Total (n=453)	**453**	**100.0%**

When asked to identify what best describes their PSA boundaries, the majority of AAAs responded that their PSA is multicounty (55.9 percent), followed by single county (34.6 percent).

LSP Background

Similarly to AAAs, LSPs were asked about their organization's governance. The largest share of LSPs reported being a not-for-profit agency (55.0 percent), followed by a for-profit agency (23.5 percent). Table 4 shows the answers regarding governance, displaying the frequency and the percentage for responding LSPs.

Table 4: LSP Governance

Answer	Frequency	Percent
A not-for-profit agency	213	55.0%
A for-profit agency	91	23.5%
A division of a city or county government	50	12.9%
Part of a council of governments or regional planning and development agency	14	3.6%
Educational institution	9	2.3%
Other	5	1.3%
Don't know	4	1.0%
A Tribal Government entity	1	0.3%
Total (n=387)	**387**	**100.0%**

When asked to report on the number of years their organization has been operating, the majority of LSPs responded "More than 20 years" (64.0 percent), with no respondents operating for less than 1 year. Table 5 tallies the answers regarding years of operation, displaying the frequency and the percentage for responding LSPs.

Table 5: LSP Years of Operation

Answer	Frequency	Percent
More than 20 years	249	64.0%
11 to 20 years	73	18.8%
6 to 10 years	38	9.8%
1 to 5 years	29	7.5%
Less than 1 year	0	0.0%
Total (n=389)	**389**	**100.0%**

Similarly, the majority of LSPs have been serving caregivers of older adults for more than 10 years (58.7 percent) with only one-fifth of respondents serving caregivers for 5 years or fewer (20.7 percent), as shown in Table 6.

Table 6: LSP Years of Serving Caregivers

Answer	Frequency	Percent
More than 10 years	227	58.7%
6 to 10 years	80	20.7%
1 to 5 years	70	18.1%
Less than 1 year	10	2.6%
Total (n=387)	**387**	**100.0%**

When asked to report the number of AAAs with which they have a relationship for the purpose of providing NFCSP services, the majority of LSPs (69.8 percent) responded only "1," as shown in Table 7. Approximately 10 percent of LSPs do not know with how many AAAs they have a relationship. Additionally, nearly one-tenth of LSPs (8.8 percent) have a relationship with two AAAs to provide NFCSP services. This data includes LSPs that are also AAAs (5 percent of LSPs (n=20) are also AAAs).

Table 7: Number of AAAs With Which LSPs Partner to Provide NFCSP Services

Answer	Frequency	Percent
1	270	69.8%
Don't know	39	10.1%
2	34	8.8%
3	17	4.4%
4	14	3.6%
5+	8	2.1%
0	3	0.8%
Other	2	0.5%
Total (n=387)	**387**	**100.0%**

History of Caregiver Services Availability

More than one-half (53.6 percent) of SUAs that currently administer a separate caregiver program funded outside the NFCSP (n=28) began their effort before the inception of NFCSP services.

Examined, as well, were regional differences in offering caregiver support programs before and after the start of the NFCSP. As shown in Table 8, of the 15 SUAs that launched their state's caregiver support program before the inception of NFCSP services, six were in Northeast states.

Table 8: Regional Differences in SUA Caregiver Services

	Before NFCSP	After NFCSP	At the Same Time as the NFCSP	Don't Know	Other	Didn't Answer
Northeast (n= 9)	6 (66.7%)	1 (11.1%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (22.2%)
Midwest (n=12)	4 (33.3%)	1 (8.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	7 (58.3%)
South (n=17)	2 (11.8%)	7 (41.2%)	1 (5.9%)	0 (0.0%)	0 (0.0%)	7 (41.2%)
West (n=13)	3 (23.1%)	1 (7.7%)	0 (0.0%)	1 (7.7%)	0 (0.0%)	8 (61.5%)
Total (n=51)	**15 (29.4%)**	**10 (19.6%)**	**1 (2.0%)**	**1 (2.0%)**	**0 (0.0%)**	**24 (47.1%)**

An analysis of services available to caregivers before and after the NFCSP started, as reported by SUAs, found a 247 percent increase in support group services, a 227 percent increase in training and education services, a 47 percent increase in I&R services, a 563 percent increase in caregiver counseling, and a 93 percent increase in respite care services.

AAAs were asked as to whether they had established a caregiver program, defined as a set of services specifically for caregivers, before the NFCSP started. One hundred twenty-three AAAs (27.6 percent) responded that they did operate a caregiver program before 2000, while 231 AAAs (51.8 percent) reported no such program during that time period. The remaining AAAs (20.6 percent) responded "Don't know."

When asked to document how the NFCSP impacts caregiver services their organization is providing, many AAAs noted that the program enables them to deliver new services (79.1 percent), that it increases the number of caregivers served (74.8 percent), and that it increases the amount of services provided to most caregivers (67.0 percent). "Other" responses include increased awareness of services and information access, increased financial resources, and establishment of services specific to caregivers.

AAAs were also asked to report on the caregiver services their organization provided before the NFCSP started. Nearly three-quarters (74.3 percent) of AAAs provide I&R, while almost one-half (48.5 percent) offer supplemental services, including home-delivered meals, home modification, and emergency response; 40.7 percent provide respite care. Table 9 lists these answers and others, displaying the frequency and the percentage for responding AAAs.

Table 9: AAA Reported Caregiver Services Before Inception of NFCSP Services

Answer	Frequency	Percent
I&R	332	74.3%
Supplemental services (e.g., home-delivered meals, home modification, emergency response)	217	48.5%
Respite care	182	40.7%
Care coordination	128	28.6%

Answer	Frequency	Percent
Training/Education	125	28.0%
Support groups	98	21.9%
Don't know	74	16.6%
Caregiver support coordination	64	14.3%
Counseling	62	13.9%
Other	18	4.0%
Total (n=447)	**-**	**NA**

Before the NFCSP started, 45.5 percent of large AAAs and 43.3 percent of medium AAAs provided respite care compared with 29.3 percent of small AAAs, a noteworthy data point. Approximately one-half (50.8 percent) of urban and suburban AAAs provided respite care compared with 39.7 percent of mixed-geography AAAs and 36.6 percent of rural and frontier AAAs. Additionally, 21.3 percent of urban and suburban AAAs offered caregiver support coordination previously compared with 13.9 percent of mixed-geography AAAs and 11.9 percent of rural and frontier AAAs. Please see Appendix D for more information.

An analysis of services available to caregivers before and after the NFCSP started, as reported by AAAs, found that there was a 208 percent increase in support group services, 206 percent increase in training and education services, 32 percent increase in I&R services, 445 percent increase in caregiver counseling, and 130 percent increase in respite services. Table 10 summarizes these findings.

Table 10: AAA Reported Caregiver Services Before and After Inception of NFCSP Services

Caregiver Services	Yes/ No	Before NFCSP	After NFCSP	Percent increase in AAAs offering services
Support groups	Yes No	98 (21.9%) 349 (78.1%)	302 (67.7%) 144 (32.3%)	208%
Training / Education	Yes No	125 (28.0%) 322 (72.0%)	382 (85.8%) 63 (14.2%)	206%
Information (labeled I&R before)	Yes No	332 (74.3%) 115 (25.7%)	439 (98.4%) 7 (1.6%)	32%
Caregiver counseling	Yes No	62 (13.9%) 385 (86.1%)	338 (76.1%) 106 (23.9%)	445%
Respite services	Yes No	182 (40.7%) 265 (59.3%)	418 (93.93%) 27 (6.1%)	130%
Access assistance	Yes No	(Do not ask about access assistance prior to NFCSP)	410 (92.3%) 34 (7.7%)	N/A
Total (n=447)	-	-	-	-

NFCSP Staffing and Training

The means by which SUAs, AAAs, and LSPs administer their programs were examined by posing questions to them about NFCSP staff, volunteers, and training.

SUA Staff and Training

Forty SUAs (78.4 percent) responded that they currently employ a caregiver program manager or coordinator who plans, develops, administers, implements, or evaluates their NFCSP or performs any combination of the foregoing tasks. One-half of the SUAs require training for AAA staff or volunteers who work with informal caregivers.

SUAs that require training (n=27) were asked which staff or volunteers must complete this instruction. As shown in Table 11, a variety of staff members and volunteers must do so. Nearly one-half of these SUAs indicated that the decision to require training is made at the AAA level (44.4 percent) or at the provider level (18.5 percent).

Table 11: SUA Required Staff Training

Answer	Frequency	Percent
Information and referral staff	19	70.4%
Direct Service Workers (e.g., social workers, counselors, care managers)	17	66.7%
Decided at AAA level	12	44.4%
Supervisory Staff	10	37.0%
Other Program Administrative Staff	9	33.3%
Volunteers	8	29.6%
Decided at provider level	5	18.5%
Other	5	18.5%
Total (n=27)	**-**	**NA**

SUAs reported the frequency of the training as more than once a year or on a regular basis (52.0 percent), annually (20.0 percent), or occasionally or when a new hire employee is hired (28.0 percent).

In addition, SUAs were queried regarding topics on which their staff were trained during the most recently completed fiscal year. As shown in Table 12, the training topics most commonly reported were data collection and reporting (54.9 percent), Alzheimer's disease or a related disorder with neurological and organic brain dysfunction (47.1 percent), caregiver assessment (45.1 percent), and caregiver intake and screening (39.2 percent).

Table 12: SUA Staff Training Topics

Answer	Frequency	Percent
Program data collection and reporting	28	54.9%
Alzheimer's disease or a related disorder with neurological and organic brain dysfunction	24	47.1%
Caregiver assessment	23	45.1%
Caregiver intake and screening	20	39.2%
Service delivery specifications (e.g., protocols, referrals)	19	37.3%
Conducting outreach/public awareness activities	17	33.3%
Specific evidence-based caregiver education programs (e.g., Powerful Tools; Savvy Caregiver)	17	33.3%
Grandparents raising grandchildren	16	31.4%
Care coordination/care management	15	29.4%
Caregiver health and well-being	14	27.5%
Technical aspects of administering consumer-directed options (e.g., vouchers, cash payments or fiscal intermediaries)	12	23.5%
Cultural/ethnic competency	10	19.6%
Facilitating family meetings/mediation/conflict resolution	7	13.7%
Employed caregivers	6	11.8%
Not applicable	6	11.8%
Care recipient diseases/chronic conditions	5	9.8%
Don't know	1	2.0%
Total (n=51)	**-**	**NA**

AAA Staff

AAAs reported a mean of 2.6 full-time equivalent (FTE) employees at their agency who work on the caregiver program in a typical week. They were advised to include full- and part-time employees assigned to some aspect of caregiver programming and services and to exclude staff who routinely provide information to caregivers but who have no specific caregiver program responsibilities (e.g., I&R personnel).

As shown in Table 13, when stratified by AAA budget size, large AAAs have a mean of 4.3 FTE employees at their agency who work on their caregiver programs, with small and medium AAAs averaging slightly fewer than 2.0 FTE employees.

Table 13: AAA Full-Time Equivalent Employees by Budget Size

	Mean	Range	Don’t Know or Didn’t Answer
Large AAAs: >$5,703,224 (n=134)	4.3	0.05–60.0	17
Medium AAAs: $2,185,059 to $5,703,224 (n=134)	1.9	0.04–13.0	22
Small AAAs: <$2,185,058 (n=133)	1.7	0.1–9.3	22
Total AAAs with budget data (n=401)	**2.7**	**0.04–60.0**	**61**

To acknowledge the myriad services AAAs provide, they were asked whether caregiver program staff work on programs or provider services outside the NFCSP. The majority of AAAs responded that all caregiver program staff do so (63.6 percent).

Similarly, a significant number of AAAs (85.4 percent) indicated that the staff position directing or managing caregiver programs and services includes other duties or program focus areas, as well. Most AAAs (82.7 percent) reported having a paid staff position responsible for directing or managing their NFCSP.

AAA Volunteers

When AAAs were queried concerning the types of tasks that volunteers perform for their NFCSP, the majority (54.6 percent) answered that they employ no volunteers. AAAs who do engage volunteers responded that such workers commonly provide administrative program support (40.9 percent) and caregiver training and education (40.4 percent), as shown in Table 14. Other types of tasks volunteers perform include organizing caregiver events, serving on advisory councils, and completing minor home modifications and repairs.

Table 14: AAA Volunteer Tasks

Answer	Frequency	Percent
Administrative program support	81	40.9%
Caregiver training/education	80	40.4%
Phone reassurance	60	30.3%
Information and assistance	56	28.3%
Support group leader(s)	54	27.3%
Respite services	46	23.2%
Other	36	18.2%
Transportation	32	16.2%
Financial services (e.g., tax preparation, bill paying, budgeting, pension counseling)	24	12.1%
Legal services (e.g., assistance completing powers of attorney or advance directives)	18	9.1%
Don’t know	9	4.5%
Total (n=198)	**-**	**NA**

AAAs reported a mean of 8.8 unduplicated volunteers working on the NFCSP at their agency in the most recently completed fiscal year. Volunteer allocation was examined by budget size and geography. Unsurprisingly, large AAAs use the greatest number of volunteers (n=16). More interestingly, however, medium-size AAAs work with the smallest mean number of volunteers (n=3). AAAs providing services in a mixed geography area reported the highest number of unduplicated volunteers in their NFCSP while AAAs serving urban and suburban areas reported the lowest number of volunteers, as shown in Tables 15 and 16.

Table 15: AAA Average Number of Volunteers by Budget Size

	Mean	Range	Don't Know or Didn't Answer
Large AAAs: >$5,703,224 (n=134)	16	0–567	32
Small AAAs: <$2,185,058 (n=133)	8	0–499	21
Medium AAAs: $2,185,059 to $5,703,224 (n=134)	3	0–110	24
Total AAAs with budget data (n=401)	**9**	**0–567**	**77**

Table 16: AAA Average Number of Volunteers by Geography

	Mean	Range	Don't Know or Didn't Answer
Mixed AAAs (n=194)	14	0–567	46
Rural & Frontier AAAs (n=202)	6	0–499	45
Urban & Suburban AAAs (n=61)	3	0–40	16
Total (n=457)	**9**	**0–567**	**107**

AAA Staff and Volunteer Training

When asked whether they require training for different groups or individuals *outside* the NFCSP on topics associated with supporting caregivers, nearly one-third of AAAs (32.3 percent, n=142) reported that they require no such training for non-caregiver program staff and volunteers. Among AAAs that do require training, 82.5 percent require training for I&R staff, with another 72.4 percent requiring it for direct service workers. Table 17 lists the answers regarding staff and volunteers requiring training, displaying the frequency and the percentage for responding AAAs.

Table 17: AAA Staff and Volunteers Requiring Training

Answer	Frequency	Percent
Information and referral staff	245	82.5%
Direct Service Workers (e.g., social workers, counselors, care managers, caregiver specialists)	215	72.4%
Supervisory staff	173	58.2%
Other Program Administrative staff	127	42.8%

Answer	Frequency	Percent
Volunteers	86	29.0%
Don’t know	15	5.1%
Total (n=297)	**-**	**NA**

AAAs, as well, were asked about the caregiver training topics for NFCSP staff and volunteers at their agency during the most recently completed fiscal year. Responding AAAs most commonly reported that Alzheimer’s disease or a related disorder (74.9 percent), caregiver assessment (52.4 percent), and program data collection and reporting (50.4 percent) were training topics required for staff or volunteers. Table 18 lists the answers regarding training topics required for staff or volunteers, displaying the frequency and the percentage for responding AAAs.

Table 18: AAA Caregiver Training Topics

Answer	Frequency	Percent
Alzheimer’s disease or a related disorder	296	74.9%
Caregiver assessment	207	52.4%
Program data collection and reporting	199	50.4%
Caregiver intake and screening	190	48.1%
Care coordination/care management	189	47.8%
Caregiver health and well-being	184	46.6%
Conducting outreach/public awareness activities	183	46.3%
Service delivery specifications (e.g., protocols)	167	42.3%
Care recipient diseases/chronic conditions	149	37.7%
Cultural/ethnic competency	138	34.9%
Grandparents raising grandchildren	125	31.6%
Specific evidence-based caregiver education programs (e.g., Powerful Tools; Savvy Caregiver)	112	28.4%
Facilitating family meetings/mediation/conflict resolution	91	23.0%
Technical aspects of administering consumer directed options (e.g., vouchers, cash payments or fiscal intermediaries)	75	19.0%
Employed caregivers	51	12.9%
Other	19	4.8%
Don’t know	13	3.3%
Total (n=395)	**-**	**NA**

Among the 19 AAAs that indicated they offer “Other” caregiver training/education topics, 15 provided more detail. Sixteen of the topics concern specific issues and skills, such as advanced directives (n=3), hospice (n=3), suicide prevention (n=2), fraud and abuse prevention (n=2), chronic disease and diabetes self-management programs (n=2), hoarding issues and interventions (n=1), first aid (n=1), bed bugs (n=1), and working with couples with divergent needs (n=1). Ten of these responses focus on background education topics, such as mental health advocacy, HIPAA, person-centered planning, and ethics. The remaining responses relate to information, assistance, and referral topics (n=9), such as financial planning (n=2), legal assistance (n=2), Federal and State benefits (n=2), housing and living options (n=1), physical therapy options (n=1), and local resources (n=1).

LSP Staff and Volunteers

To gauge organization size, LSPs were asked how many FTE employees (including the respondent) they had in the most recently completed fiscal year. LSPs reported an average of 48.1 FTE employees and 33.8 part-time employees on staff.

An examination of the number of full- and part-time LSP employees by categories found that more than 50 percent of LSPs are operating with 15 or fewer FTE employees, and more than 65 percent have 15 or fewer part-time employees. Table 19 breaks down the LSP employee counts by full-time and part-time employees, listing the percentages of each for six spans of numbers of persons employed, from 1–5 to 251+.

Table 19: LSP Employee Count

Answer	Full-Time Employees	Percent	Part-Time Employees	Percent
1–5	102	29.9%	154	46.0%
6–15	92	27.0%	64	19.1%
16–50	75	22.0%	63	18.8%
51–100	37	10.9%	26	7.8%
101–250	18	5.3%	20	6.0%
251+	17	5.0%	8	2.4%
-	**Total = 341**	**-**	**Total = 335**	**-**

LSPs also were asked about volunteer duties. Nearly one-third of LSPs (32.1 percent) do not work with volunteers. However, LSPs that do have active volunteers indicated their duties most commonly involve administrative program support and information and assistance.

Many LSPs expanded on “Other” volunteer duties, mentioning meal and grocery assistance or delivery, activities (e.g., exercise, art classes, gardening), and clerical or janitorial tasks.

Fifty-eight LSPs reported on the number of volunteers working on respite services, for an average of 38.3 respite volunteers. Forty-eight LSPs reported receiving an average of 4,734.7 volunteer hours for their organization’s respite program during the most recently completed fiscal year.

Seventy LSPs reported on the number of volunteers who work in caregiver training and education programs at their organization, for an average of 12.1 volunteers. Sixty LSPs reported receiving an average of 343.2 volunteer hours for their organization's caregiver training and education program during the most recently completed fiscal year.

Table 20 lists the answers regarding volunteer activities, displaying the frequency and the percentage for responding LSPs.

Table 20: LSP Volunteer Duties

Answer	Frequency	Percent
Administrative program support	118	44.2%
Other	96	36.0%
Information and assistance	85	31.8%
Phone reassurance	80	30.0%
Support group leader(s)	76	28.5%
Caregiver training/education	72	27.0%
Respite services	62	23.2%
Transportation	58	21.7%
Financial services (e.g., tax preparation, bill paying, pension counseling)	41	15.4%
Legal services (e.g., assistance completing powers of attorney or advance directives)	23	8.6%
Don't know	9	3.4%
Total (n=267)	-	-

Targeting Caregiver Populations

To elicit more information about individuals whom the Aging Network makes a specific effort to serve, AAAs and SUAs were asked about their targeted outreach to caregiver populations.

SUA Targeting

More than 80 percent of SUAs that reported targeting have made a specific effort to serve caregivers of persons with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction. A similar percentage of SUAs (81.6 percent) target grandparents raising grandchildren and other relative caregivers for the NFCSP. Two-thirds of SUAs (67.3 percent) work to support rural caregivers and more than one-half (63.3 percent) work to support racially and ethnically diverse caregivers. Table 21 demonstrates the frequency with which SUAs support a range of informal caregivers and the percentage doing so.

Table 21: SUA Target Group Populations

Answer	Frequency	Percent
Caregivers of persons with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction	41	83.7%

Answer	Frequency	Percent
Grandparents raising grandchildren and other relative caregivers	40	81.6%
Rural caregivers	33	67.3%
Racially and ethnically diverse caregivers	31	63.3%
Caregivers, Older (age 70+)	24	49.0%
Caregivers of veterans	15	30.6%
Employed family caregivers	15	30.6%
Other (please specify)	12	24.5%
Caregivers, Younger (age 18–25)	7	14.3%
Don't know	1	2.0%
Total (n=49)	**-**	**-**

When asked about activities they undertake to address the needs of special populations of caregivers, nearly 70 percent (69.6 percent) of SUAs reported using targeted marketing and outreach campaigns to establish contact with such populations. More than one-half (54.4 percent) translate or adapt their agency's materials in a language other than English to reach specific caregivers. Although some SUAs (41.3 percent) hire staff or recruit volunteers with specialized knowledge of, or skills for working with, special caregiver populations, others have developed partnerships with VA systems (37.0 percent), schools (26.1 percent), and employers (19.6 percent). Table 22 lists these approaches and others that SUAs pursue to engage special populations of caregivers.

Table 22: SUA Targeting Activities

Answer	Frequency	Percent
Targeted marketing and outreach campaigns	32	69.6%
Translated or adapted materials in languages other than English	25	54.4%
Other (please specify)	20	43.5%
Hired staff or obtained volunteers with specialized knowledge of or skills working with special populations of caregivers	19	41.3%
Developed partnerships with VA systems	17	37.0%
Developed services to meet specialized needs (e.g., mobile adult day services and mobile I&R units for rural caregivers)	16	34.8%
Produced culturally specific and appropriate materials	15	32.6%
Developed partnerships with schools	12	26.1%
Developed partnerships with employers	9	19.6%
Don't know	1	2.2%
Total (n=46)	**-**	**-**

SUAs were asked about the criteria they use to determine NFCSP service priority. Among 44 SUAs that reported using criteria for service prioritization, 30 indicated a diagnosis of Alzheimer's disease or a related disorder with neurological and organic brain dysfunction, 25 indicated an ADL or IADL impairment minimum or both, and 22 indicated low income level. Fewer responding SUAs use homebound status, recipient's social isolation, limited English proficiency, geographic isolation, or the presence of a chronic health disease (e.g., diabetes) to determine NFCSP service priority. Some SUAs use a caregiver's referral from Adult Protective Services, mental health or emotional status, or both when determining NFCSP service priority. Table 23 lists a wide range of SUA reported criteria for determining service priority for both care recipients and caregivers, displaying the frequency and the percentage for responding SUAs.

Table 23: SUA Criteria for Determining NFCSP Service Priority

Answer	Care Recipient Frequency	Care Recipient Percent	Caregiver Frequency	Caregiver Percent
Diagnosis of Alzheimer's disease or a related disorder with neurological and organic brain dysfunction	30	68.2%	5	11.4%
ADL and/or IADL impairment minimum (e.g., 3+ ADL impairments)	25	56.8%	2	4.5%
Low income (e.g., % of federal poverty level)	22	50.0%	16	36.4%
Geographic isolation (e.g., rural)	18	40.9%	15	34.1%
Social isolation (e.g., lives alone)	17	38.6%	7	15.9%
Homebound status	14	31.8%	3	6.8%
Racial/ethnic minority	13	29.5%	11	25.0%
Limited English proficiency	12	27.3%	9	20.5%
Lack of informal/family support	11	25.0%	10	22.7%
Advanced age (e.g., 75+, 85+)	10	22.7%	7	15.9%
Chronic health condition (e.g., diabetes)	10	22.7%	6	13.6%
Long-term care need for service	10	22.7%	4	9.1%
Perceived potential for abuse, neglect or exploitation	10	22.7%	8	18.2%
Mental Health/Emotional Status	7	15.9%	11	25.0%
Adult Protective Services referral	6	13.6%	6	13.6%
Criteria are not set by the SUA	6	13.6%	6	13.6%
Short-term care need for service	5	11.4%	5	11.4%
Poor housing	4	9.1%	3	6.8%
Adult Day Program Participation	3	6.8%	4	9.1%
Other (please specify below)	10	22.7%	14	31.8%
Total (n=44)	-	-	-	-

AAA Targeting

AAAs also reported on targeting. One in five AAAs (17.8 percent) makes no specific effort to address special populations. However, among AAAs that do make a concerted effort, populations most commonly targeted are caregivers of persons with Alzheimer's disease or a related disorder, grandparents raising grandchildren and other relative caregivers, and rural caregivers, as shown in Table 24. Other special populations of caregivers are targeted by fewer AAAs.

Table 24: AAA Target Group Populations

Answer	Frequency	Percent
Caregivers of persons with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction	278	76.4%
Grandparents raising grandchildren and other relative caregivers	215	59.1%
Rural caregivers	204	56.0%
Caregivers, Older (age 70+)	189	51.9%
Racially and ethnically diverse caregivers	154	42.3%
Caregivers of veterans	129	35.4%
Employed family caregivers	126	34.6%
Caregivers, Younger (under age 25)	30	8.2%
Other	21	5.8%
Do not know	2	0.5%
Total (n=364)	**-**	**NA**

When asked about activities undertaken to address the needs of special populations of caregivers, AAAs that do respond to such needs mentioned, as their most frequent approaches, targeted marketing and outreach campaigns (69.8 percent) and provision of materials in languages other than English (36.4 percent). Other approaches are less common. Approximately one-fifth (20.1 percent) hire staff or recruit volunteers with specialized knowledge of, or skills working with, special populations of caregivers, and 18.4 percent produce culturally specific and appropriate materials. A small proportion has developed partnerships with VA systems (28.8 percent), schools (16.9 percent), and employers (15.8 percent). Table 25 lists a range of activities AAAs undertake to target special populations of caregivers, displaying the frequency and the percentage for responding AAAs.

Table 25: AAA Targeting Activities

Answer	Frequency	Percent
Targeted marketing and outreach campaigns	247	69.8%
Translated or adopted materials in languages other than English	129	36.4%
Developed partnerships with VA systems	102	28.8%

Answer	Frequency	Percent
Hired staff or obtained volunteers with specialized knowledge of, or skills working with, special populations of caregivers	71	20.1%
Produced culturally specific and appropriate materials	65	18.4%
Developed partnerships with schools	60	16.9%
Developed partnerships with employers	56	15.8%
Developed services to meet specialized needs (e.g., mobile adult day services and mobile I&R unit for rural caregivers)	55	15.5%
Don't know	37	10.5%
Other	35	9.9%
Developed mobile mechanisms to address needs of rural caregivers	26	7.3%
Total (n=354)	**-**	**NA**

Partnerships

To gauge the types of partnerships the respondents cultivate to improve service offerings, SUAs, AAAs, and LSPs were asked about current working relationships they have formed.

SUA Partnerships

Nine SUAs reported working with other State agencies to implement the NFCSP; these SUAs were asked to list the agencies and to describe their relationship.

- Three SUAs are working with departments of social services in areas that include universal assessment tool development, using the other agency for referrals, and providing staff training about programs available under the NFCSP.
- Four SUAs are working with departments of health services that include developing health education resources.
- Three SUAs are working with Medicaid departments in areas that include universal assessment tool development, referrals, and staff training about programs available under the NFCSP.
- Two SUAs are coordinating and collaborating with departments of family services, especially for services to grandparents caring for grandchildren.

Other partners include Lifespan Respite (n=2), State Councils on Developmental Disabilities (n=2), university extension services (n=1), Veterans Affairs (n=1), mental health departments (n=1), and Centers for Independent Living (n=1). Collaborations with these partners include referrals, staff trainings, advisory board participation, and program development.

AAA Partnerships

AAAs were asked to describe their involvement in organizational activities with or without partners. A partnership was defined as a "well-defined relationship with another organization." Almost one in five AAAs (17.6 percent) that have a website are involved in partnerships supporting website operations. Four in ten (40.1 percent) of AAAs engaging in program planning and development did so with a partner, as did 43.8 percent of AAAs engaged in developing strategies to contact hard-to-reach caregivers. Table 26 lists organizational activities in which AAAs reported participating, with or without a partner.

Table 26: AAA NFCSP Partnerships for Organizational Activities

Answer	Involved without Partnership	Involved with Partnership	NA/Not Involved in This Activity*
Website (n=318)	262 (82.4%)	56 (17.6%)	82
Program planning/development (n=379)	227 (59.9%)	152 (40.1%)	47
Program outreach (n=396)	209 (52.8%)	187 (47.2%)	40
Marketing plan (n=259)	185 (71.4%)	74 (28.6%)	121
Developing strategies to reach hard-to-reach caregivers (n=272)	153 (56.3%)	119 (43.8%)	124
Developing a community needs assessment of family caregiver support and service (n=256)	141 (55.1%)	115 (44.9%)	127
Developing/enhancing a web-based informational database of caregiver support options (n=219)	112 (51.1%)	107 (48.9%)	160
Promoting changes to improve family caregiver support within Medicaid-funded HCBS programs (n=173)	84 (48.6%)	89 (41.1%)	198
Developing a uniform caregiver assessment instrument (n=194)	79 (40.7%)	115 (59.3%)	185
Other (n=3)	1 (33.3%)	2 (66.7%)	111

*Respondents who selected "NA/Not Involved in This Activity" are excluded from the percent or total N.

AAAs also were queried about partnership involvement in service activities. Almost one-half (47.5 percent) of AAAs that engage in community fundraising for informal caregiver support do so in partnership with another organization. More than one-half (54.8 percent) of AAAs that reported engaging in activities to enhance support for working caregivers do so in a partnership, as do 64.1 percent of AAAs conducting work to enhance kinship care. Table 27 lists service activities in which AAAs reported participating, with or without a partner.

Table 27: AAA NFCSP Partnerships for Service Activities

Answer	Involved without Partnership	Involved with Partnership	NA/Not Involved in This Activity*
Coordinating information fair(s) (n=394)	136 (34.5%)	258 (65.5%)	54
Enhancing support to working caregivers (n=208)	94 (45.2%)	114 (54.8%)	173
Coordinating caregiver conference(s) (n=289)	71 (24.6%)	218 (75.4%)	129

Answer	Involved without Partnership	Involved with Partnership	NA/Not Involved in This Activity*
Enhancing kinship care (n=167)	60 (35.9%)	107 (64.1%)	222
Forming a caregiver coalition or community collaborative (n=213)	42 (19.7%)	171 (80.3%)	179
Community fundraising for family caregiver support (n=80)	42 (52.5%)	38 (47.5%)	277
Other (n=1)	0 (0.0%)	1 (100.0%)	121

*Respondents who selected "NA/Not Involved in This Activity" are excluded from the percent or total N.

AAAs named as many as three of their most important partners for administering their NFCSP. Nearly two-thirds (61.1 percent) of AAAs identified the state and local chapters of the Alzheimer's Association and other such organizations. Approximately one-half (51.8 percent) indicated that ADRCs or Aging Resource Centers are a key partner, as well. More than 40 percent of AAAs (41.6 percent) also responded that health care providers—including community health centers, hospitals, and physicians' offices—are among the three most important partners for administering their program. Table 28 lists the partners AAAs name most frequently for administering their NFCSP.

Table 28: AAA Reported Most Important Partners for Administering NFCSP Services

Answer	Frequency	Percent
Local/state chapter of national organizations (e.g. Alzheimer's Association, AARP, American Health Care Association)	250	61.1%
Aging and Disability Resource Center or Aging Resource Center	212	51.8%
Health care providers including community health centers, hospitals and physicians' offices	170	41.6%
Elder Abuse Prevention programs, Adult Protective Services (APS), or TRIAD	144	35.2%
Caregiver coalitions/respite coalitions	109	26.7%
Faith-based organizations	77	18.8%
Long-term care facilities (nursing homes, assisted living)	56	13.7%
Other	35	8.6%
Public housing and related services, including senior housing	18	4.4%
Local business	15	3.7%
Title VI (Native American) program	8	2.0%
Total (n=409)	**-**	**NA**

AAA Coalition Involvement

The majority (53.8%) of AAAs do not participate in a coalition. Approximately one-third (31.7 percent) reported being part of a caregiver coalition, followed by 18.5 percent in a respite coalition, and 11.3 percent in a kinship care coalition. Table 29 displays the breakdown of AAA coalition involvement.

Table 29: AAA Involvement in Coalitions

Answer	Frequency	Percent
No Coalitions	229	53.8%
Caregiver coalition	135	31.7%
Respite coalition	79	18.5%
Kinship care coalition	48	11.3%
Total (n=426)	**-**	**NA**

Variation exists in respite coalition membership between different sizes of AAAs (stratified by budget size) with the highest proportion (21.8 percent), small AAAs, being coalition members followed by medium AAAs (17.2 percent) and large AAAs (14.9 percent). Additionally, nearly 42.6 percent of urban and suburban AAAs are members of caregiver coalitions compared with 23.8 percent of rural and frontier AAAs and 31.4 percent of mixed-geography AAAs. Please see Appendix D for more information.

NFCSP Intake and Screening

Intake and screening techniques differ within and between AAAs and SUAs. LSPs were not queried concerning intake and screening, except to inquire whether AAAs share intake and screening results with them.

SUA Intake and Screening

To learn more about common strategies, SUAs were asked for information about their agency's intake practices for caregiver support services. Nearly one-half (48.8 percent) of responding SUAs indicated that their state requires them to complete a standardized set of questions, but the AAA or individual providers may develop their own intake process. More than 40 percent (44.2 percent) of SUA caregiver support programs share relevant caregiver intake data with other programs in which the caregiver might be eligible for support (either verbally or electronically), although 34.9 percent reported that they receive this information from other programs. Table 30 summarizes the requirements and policies (including data sharing) associated with caregiver admittance to NFCSP services, displaying the frequency and the percentage for responding SUAs.

Table 30: SUA Policies for NFCSP Intake

Answer	Frequency	Percent
The state requires a standardized data set but the AAA or individual providers can develop their own intake process.	21	48.8%
Our family caregiver support program shares relevant caregiver intake data with other programs in which the caregiver might be eligible for support (either verbally or electronically)	19	44.2%
We require a standardized intake process for caregiver support in our state	17	39.5%

Answer	Frequency	Percent
Our family caregiver support program receives relevant caregiver intake data from other programs (either verbally or electronically)	15	34.9%
We have, but do not require, a standardized intake process for caregiver support in our state	6	14%
Other (please specify)	5	11.6%
Does not apply	1	2.3%
Total (n=43)	**-**	**NA**

Further examination of SUA intake processes revealed that nearly one-half (47.1 percent) of SUAs in the South reported a standardized intake process for caregiver support compared with smaller proportions in other regions. More than one-half of SUAs in the South (52.9 percent) indicated NFCSPs share relevant caregiver intake data with other programs in which the caregiver might be eligible for support compared with only 25.0 percent of Midwestern SUAs and 23.1 percent of Western SUAs. Please see Appendix D for additional information.

SUAs were asked, too, about State policies around screening activities for caregiver support services. Many SUAs (41.9 percent) responded that their NFCSP shares relevant screening data with other programs for which the caregiver might qualify. An identical number of SUAs reported that they require a standardized data set, but the AAA or the individual providers develop their own screening processes. Table 31 summarizes the requirements and policies (including data sharing) associated with caregiver screening for NFCSP services, displaying the frequency and the percentage for responding SUAs. SUAs could select all that apply.

Table 31: SUA Policies for NFCSP Screening

Answer	Frequency	Percent
Our family caregiver support program shares relevant screening data with other programs in which the caregiver might be eligible for support (either verbally or electronically)	18	41.9%
The state requires a standardized data set but the AAA or individual providers can develop their own screening process.	18	41.9%
We require a standardized screening process for caregiver support in our state	15	34.9%
Our family caregiver support program receives relevant caregiver screening data from other programs (either verbally or electronically)	14	32.6%
We have, but do not require, a standardized screening process for caregiver support in our state	4	9.3%
Does not apply	4	9.3%
Other (please specify)	4	9.3%
Total (n=43)	**-**	**NA**

AAA Intake and Screening

AAAs were asked about their intake and screening processes, including whether they have a standard set of questions or steps to determine whether a caregiver is present when a consumer calls. Among the more than two-thirds (68.3 percent) of AAAs that have these tools, almost all (90.2 percent) have a standard process for following up with the caregiver.

Only 61.9 percent of medium-size AAAs reported having a standard set of questions or steps to determine whether a caregiver is present compared with 70.9 percent of large AAAs and 69.9 percent of small AAAs, a noteworthy data point. Additionally, 65.7 percent of large AAAs responded that they have a standard process for following up with the caregiver compared with 61.7 percent of small AAAs and 54.5 percent of medium AAAs. Please see Appendix D for more information.

When AAAs were asked whether intake and screening are separate activities for caregiver support services, fewer than one-half (42.4 percent) responded affirmatively; 54.8 percent noted that intake and screening are not separate activities for caregiver support.

Queries were posed concerning activities that apply to intake and screening for caregiver support in an AAA's PSA, too. This process evaluation is reporting on the AAAs' responses for which intake and screening are *not* separate activities. Tables displaying responses from the AAAs that maintain intake and screening as separate activities appear in Appendix C.

AAAs described who conducts the initial intake and screening for their NFCSP services. At most AAAs (62.0 percent), general I&R staff manage these initial processes, although a specific caregiver unit performs this work at 30.4 percent of AAAs. Local service providers are responsible for these tasks at 26.6 percent of AAAs.

Table 32 lists the entities that conduct intake and screening for the NFCSP at the AAA level, displaying the frequency and the percentage for responding AAAs.

Table 32: Entities Conducting NFCSP Intake and Screening at AAA Level

Answer	Frequency	Percent
General I&R at AAA	147	62.0%
Specific caregiver unit at AAA	72	30.4%
Local service providers	63	26.6%
ADRC (if entity other than the AAA)	38	16.0%
Other	8	3.4%
Don't know	1	0.4%
Total (n=237)	**-**	**NA**

Forty-four percent of AAAs reported that intake and screening came about as a result of the NFCSP under which the process includes information about the care recipient for the majority of AAAs (97.5 percent).

Assessment and Reassessment

Assessment and reassessment activities in which SUAs, AAAs, and LSPs engage are critical for determining how clients receive services. To further understand these strategies, agencies and other organizations were asked for information about the policies guiding these processes.

SUA Caregiver Assessment Policies and Procedures

SUAs gave a range of answers when queried as to how they define caregiver assessment. Definitions covered the following aspects of assessment: goals and outcomes, structure, information collected about caregivers, and information collected about care recipients. Goals and outcomes included eligibility determination, identification of needed services and care plan development, service coordination, and defining of the relationship between caregiver and care recipient. These outcomes help connect caregivers to the services they need to deliver high-quality care themselves to their care recipient and to prevent burnout. Additional assessment after program participation helps measure program effectiveness.

SUAs reported that they conduct their assessments in multiple ways, including through face-to-face and phone interviews, home visits, screenings, and intake processing. Conducted as a written evaluation or as series of questions, these assessments emphasize listening to caregivers.

Information collected about caregivers could include demographics, willingness and ability to provide support, current formal and informal supports, physical and mental health, risk areas and stress triggers, training needs, financial resources, and hours of service they are providing. Information collected about care recipients could include demographics, current formal and informal supports, physical and mental health, risk areas, home environment, and number of ADLs with which they require assistance.

When asked to select the policies, regulations, or guidance their state has on individual-level caregiver assessments, most SUAs reported that the states have policies, regulations, or guidance on individual-level caregiver assessments for the NFCSP as it relates to who is to be assessed (82.0 percent), the content of the assessments (66.0 percent), how often the assessments are conducted (58.0 percent), and who can perform assessments (52.0 percent). Table 33 lists the frequency and percentages of these answers as reported by the SUAs.

Table 33: SUA NFCSP Policy on Caregiver Assessment

Answer	Frequency	Percent
Who is to be assessed	41	82.0%
Content of assessments	33	66.0%
How often the assessment is conducted	29	58.0%
Who can perform assessments	26	52.0%
Other (please specify)	14	28.0%
Total (n=50)	**-**	**NA**

SUAs in the South have a higher proportion of policies, regulations, or guidance for determining who is to be assessed (94.1 percent), assessment content (70.6 percent), and who can perform assessments (52.9 percent) than do their counterparts in the Northeast, the Midwest, and the West. Please see Appendix D for more information.

Most SUAs (58.8 percent) reported having a standardized process for assessing caregiver needs. Twenty-one of the 30 respondents (70.0 percent) uses this process for all informal caregiver program clients, and the remaining 9 (30.0 percent) reported using the process for only specific services. Slightly more than 40 percent of SUAs (41.2 percent) reported having no standardized process for assessing caregivers. Table 34 lists the frequency and percentages of these answers as reported by the SUAs.

Table 34: SUA NFCSP Standardized Processes for Assessing Caregiver Needs

Answer	Frequency	Percent
Yes, for all family caregiver program clients	21	41.2%
No, we don't have a standardized process for assessing caregivers	21	41.2%
Yes, for specific services only	9	17.6%
Results (n=51)	**51**	**100.0%**

Furthermore, a higher proportion of SUAs in the South also reported having a standardized process for all informal caregiver program clients (52.9 percent) and for specific services only (29.4 percent) than their counterparts in the Northeast, the Midwest, and the West. Please see Appendix D for more information.

SUAs also responded to questions about the individual being assessed. A majority of them (81.1 percent) reported assessing both the caregiver and the care recipient for their caregiver support program. A small proportion assess either *only* the caregiver (7.6 percent) *or* the care recipient (7.6 percent), while 3.8 percent conduct no assessment.

When asked whether their state has a standardized caregiver assessment, more SUAs responded affirmatively (56.9 percent) than negatively (43.2 percent). SUAs that reported having a standardized assessment for caregivers noted the most frequently included domains: care recipient's background, such as demographic information and financial status (86.2 percent); care recipient's health and wellbeing, including their functional and cognitive status (82.8 percent); and impact of caregiving on the caregiver (79.3 percent). Table 35 lists these most frequently reported domains as well as others only slightly less frequently reported.

Table 35: Domains in SUA NFCSP Standardized Caregiver Assessment

Answer	Frequency	Percent
Care recipient background (demographics, financial status)	25	86.2%
Care recipient's health and well-being (functional and cognitive status)	24	82.8%
Impact of caregiving on the caregiver	23	79.3%
Caregiver's background and the caregiving situation	22	75.9%
Caregiver's perception of care recipient health and functional status	22	75.9%
Resources available to support the caregiver	22	75.9%
Resources available to support the care recipient	22	75.9%
Caregiver's health and well-being	21	72.4%
Caregiver's skills, ability, knowledge or other requirements to provide care	17	58.6%

Answer	Frequency	Percent
Caregiver's values and preferences with respect to everyday living and care provision	12	41.4%
Other (please specify)	4	13.18%
Total (n=29)	**-**	**NA**

To queries regarding their policy on frequency of reassessments, half of SUAs (50.0 percent) reported conducting annual informal caregiver reassessments for services. More than 40 percent (44.0 percent) of SUAs reported conducting such assessments when change in caregiver status occurs, and a similar proportion (42.0 percent) reported doing so when a change in care recipient status occurs. Table 36 lists SUAs' most frequently reported reasons for conducting informal caregiver reassessments for NFCSP services.

Table 36: SUA NFCSP Policy on Frequency of Caregiver Reassessments

Answer	Frequency	Percent
Annually	25	50.0%
Prompted by change in caregiver status	22	44.0%
Prompted by change in care recipient status	21	42.0%
We do not have a policy for conducting reassessments	10	20.0%
Left up to the AAA	8	16.0%
Semi-annually	7	14.0%
Other (please specify)	5	10.0%
Total (n=50)	**-**	**NA**

To queries concerning how caregiver assessments and reassessments are used, approximately two-thirds (63.3 percent) of SUAs responded that they use these tools to develop a care plan for the caregiver. More than 40 percent (44.9 percent) of SUAs reported that their organization uses them to prioritize who receives services. The decision on how to use these tools and their results is made at the AAA level for 36.7 percent of SUAs. Table 37 lists the answers regarding assessment and reassessment use, displaying the frequency and the percentage for responding SUAs.

Table 37: SUA NFCSP Policy on Caregiver Assessment and Reassessment Use

Answer	Frequency	Percent
Care plan development for the caregiver	31	63.3%
To prioritize who receives services	22	44.9%
Decided at the AAA level	18	36.7%
Strategic planning/forecasting and/or program development	11	22.5%

Answer	Frequency	Percent
Measuring caregiver program outcomes	9	18.4%
Other (please specify)	7	14.3%
Total (n=49)	**-**	**NA**

SUAs in the South are more likely than their counterparts in the Northeast, the Midwest, and the West to have a policy of using caregiver assessments and reassessments to prioritize service recipients (58.8 percent) and to develop a care plan for the caregiver (76.5 percent). Please see Appendix D for more information.

AAA Caregiver Assessment Policies and Procedures

AAAs reported on assessment recipients in their caregiver support program. A majority of AAAs (69.7 percent) assess both care recipients and caregivers in their caregiver support programs. A smaller proportion reported that they assess *only* caregivers (11.7 percent) *or* care recipients (15.4 percent). Few AAAs (3.2 percent) conduct no assessment. Table 38 tallies the answers regarding assessment recipients, displaying the frequency and the percentage for responding AAAs.

Table 38: AAA NFCSP Policy on Assessment Recipients

Answer	Frequency	Percent
Both	303	69.7%
Care Recipient	67	15.4%
Family caregiver	51	11.7%
No assessment is conducted	14	3.2%
Total (n=435)	**435**	**100.0%**

AAAs were also asked whether they use a standardized assessment tool. Most AAAs (71.2 percent) use a standardized assessment tool, 21.4 percent use no standardized assessment tool, and 7.4 percent do not know whether they use such a tool. The most frequent explanations for not employing such tools are the fact that assessments are conducted by an outside provider or office and the AAA provides no caregiver services.

Reporting on the areas included in their caregiver assessments, AAAs responded that almost all (84.4 percent) of their individual-level needs assessments pose questions on the care recipient's health and wellbeing, including their functional and cognitive status. Approximately three-quarters of assessments include questions on caregiver health and wellbeing (76.9 percent) and on resources available to support the caregiver (76.2 percent). Table 39 lists the domains reported most frequently by AAAs as well as others less frequently reported.

Table 39: Domains in AAA NFCSP Standardized Caregiver Assessments

Answer	Frequency	Percent
Care recipient's health and well-being (functional and cognitive status)	347	84.4%
Caregiver's health and well-being	316	76.9%
Resources available to support the caregiver	313	76.2%
Caregiver's background and the caregiving situation	311	75.7%
Care recipient background (demographics, financial status)	308	74.9%
Impact of caregiving on the caregiver	306	74.5%
Resources available to support the care recipient	300	73.0%
Caregiver's perception of care recipient health and functional status	276	67.2%
Caregiver's skills, ability, knowledge or other requirements to provide care	232	56.4%
Caregiver's values and preferences with respect to everyday living and care provision	200	48.7%
Other	10	2.4%
Total (n=411)	**-**	**NA**

When asked about their policy on frequency of conducting informal caregiver reassessments for services, almost one-half (49.6 percent) of AAAs reported conducting annual informal caregiver reassessments for services. Nearly 4 in 10 (37.9 percent) responded that they conduct reassessments when a change in caregiver status occurs, and 36.0 percent do so when a change in care recipient status occurs. Table 40 lists AAAs' most frequently reported reasons for conducting informal caregiver reassessments for NFCSP services.

Table 40: AAA NFCSP Policy on Frequency of Caregiver Reassessments

Answer	Frequency	Percent
Annually	208	49.6%
Prompted by a change in caregiver status	159	37.9%
Prompted by change in care recipient status	151	36.0%
Semi-annually	102	24.3%
We do not have a policy for conducting reassessments	56	13.4%
Other	21	5.0%
Don't know	6	1.4%
Total (n=419)	**-**	**NA**

Although 54.9 percent of small AAAs and 50.7 percent of medium AAAs conduct informal caregiver reassessments for services annually, only 39.6 percent of large AAAs do so—a noteworthy point to consider. Additionally, 26.2 percent of urban and suburban AAAs have no policy for conducting reassessments, while only 9.4 percent of rural and frontier AAAs and 10.8 percent of mixed-size AAAs have no such policy. Also noteworthy is the fact that

24.2 percent of mixed-size AAAs and 22.8 percent of rural and frontier AAAs conduct these reassessments semiannually compared with only 14.8 percent of urban and suburban AAAs. Please see Appendix D for more information.

AAAs reported, as well, on the purposes for which caregiver assessments or reassessments are used. More than three-quarters of AAAs (78.5 percent) use them to develop a care plan for the caregiver. Fewer than one-half (45.5 percent) use these tools to prioritize who receives services, while approximately one-quarter (23.9 percent) use them for strategic planning, forecasting, program development, or any combination of these functions. Table 41 lists the answers regarding assessment and reassessment use, displaying the frequency and the percentage for responding AAAs.

Table 41: AAA NFCSP Policy on Caregiver Assessment and Reassessment Use

Answer	Frequency	Percent
Care plan development for the caregiver	328	78.5%
To prioritize who receives services	190	45.5%
Strategic planning/forecasting and/or program development	100	23.9%
Measuring caregiver program outcomes	64	15.3%
Don’t know	18	4.3%
Other	16	3.8%
Total (n=418)	**-**	**NA**

Stratification analyses also reveal that approximately one-half of small AAAs (49.6 percent) and medium AAAs (47.0 percent) use caregiver assessments and reassessments to prioritize service recipients compared with only 33.6 percent of large AAAs. Additionally, 45.5 percent of rural and frontier AAAs and 41.8 percent of mixed-geography AAAs use the assessments and reassessments for this purpose compared with only 27.9 percent of urban and suburban AAAs. Please see Appendix D for more information.

AAAs that reported measuring caregiver program outcomes with their caregiver assessments and reassessments were asked to indicate the outcomes they measure. Seventy-five percent of these AAAs measure caregiver burden, 60.9 percent measure extent of caregiver load/demand, and 56.3 percent measured emotional or mental health or both. Other common outcomes measured include caregiver depression (53.1 percent) and physical health (50.0 percent). Table 42 lists the answers regarding outcomes measured, displaying the frequency and the percentage for responding AAAs.

Table 42: AAA Caregiver Outcomes Measured

Answer	Frequency	Percent
Monitor caregiver burden	48	75.0%
Extent of caregiver load/demand	39	60.9%
Emotional/mental health	36	56.3%

Answer	Frequency	Percent
Monitor caregiver depression	34	53.1%
Physical health	32	50.0%
Balance among caregiving, work, or other life domains	30	46.9%
Financial/employment	22	34.4%
Other	7	10.9%
Total (n=64)	**-**	**NA**

LSP Caregiver Assessment Policies and Procedures

A similar set of questions was posed to LSPs about caregiver assessments, including whether they conduct an initial comprehensive needs assessment for their NFCSP caregiver clients. Approximately one-half (52.2 percent) of LSPs do so, while the remainder do not.

When asked how often their organization conducts NFCSP caregiver client assessments, more than four-fifths (80.7 percent) of LSPs responded that they do conduct the assessments all or most of the time, while just fewer than one-fifth (18.7 percent) reported conducting the assessment some of the time. One LSP reported that it rarely assesses caregivers. Table 43 tallies these answers regarding policy on conducting caregiver assessments, displaying the frequency and the percentage for responding LSPs.

Table 43: LSP NFCSP Policy on Conducting Caregiver Assessments

Answer	Frequency	Percent
All or most of the time	151	80.7%
Some of the time	35	18.7%
Hardly ever	1	0.5%
Total (n=187)	**187**	**100.0%**

LSPs also reported on the elements contained in their caregiver assessment. More than 80 percent of assessments contain items pertaining to the caregiver's health and wellbeing (83.5 percent), the caregiver's background and the caregiving situation (82.5 percent), and the impact of caregiving on the caregiver (80.4 percent). Other items most assessments include are determining the care recipient's health and wellbeing (79.4 percent) and resources available to support the caregiver (77.3 percent). Table 44 lists these most frequently reported domains as well as others less frequently reported.

Table 44: Domains in LSP NFCSP Caregiver Assessment

Answer	Frequency	Percent
Caregiver's health and well-being	162	83.5%
Caregiver's background and the caregiving situation	160	82.5%

Answer	Frequency	Percent
Impact of caregiving on the caregiver	156	80.4%
Care recipient's health and well-being (functional and cognitive status)	154	79.4%
Resources available to support the caregiver	150	77.3%
Caregiver's perception of care recipient health and functional status	145	74.7%
Care recipient background (demographics, financial status)	142	73.2%
Resources available to support the care recipient	141	72.7%
Caregiver's values and preferences with respect to everyday living and care provision	117	60.3%
Caregiver's skills, ability, knowledge or other requirements to provide care	113	58.2%
Other	9	4.6%
Total (n=194)	**-**	**NA**

Reporting on the frequency of sharing assessment findings with AAAs, the majority (61.8 percent) of LSPs indicated that they share this information all or most of the time, while 23.1 percent share these findings only some of the time. Fifteen percent of LSPs hardly ever or never share caregiver assessment findings with their AAA. Table 45 tallies these answers regarding the sharing of assessment findings with AAAs, displaying the frequency and the percentage for responding LSPs.

Table 45: LSP Frequency of Sharing Caregiver Assessment Findings With AAAs

Answer	Frequency	Percent
All or most of the time	115	61.8%
Some of the time	43	23.1%
Hardly ever	14	7.5%
Never	14	7.5%
Total (n=186)	**186**	**100.0%**

LSPs also reported on the origin of their assessment form. More than one-third (38.5 percent) of LSPs create their own assessment form compared with 31.0 percent using a statewide assessment form. Slightly less than one-quarter (23.5 percent) use a form provided by their AAA.

When asked to quantify the frequency with which their organization receives results from a caregiver screening or an assessment from a AAA for their NFCSP caregiver clients, more than one-half (52.4 percent) of LSPs responded that they never or hardly ever receive such results or assessments. Fewer than one-third (29.5 percent) receive this information all or most of the time, and 18.1 percent receive it some of the time. Table 46 tallies these answers regarding frequency of receiving caregiver screen and assessment result from AAAs, displaying the percentage for responding LSPs.

Table 46: LSP Frequency of Receiving NFCSP Caregiver Client Screening Results and Assessments From AAAs

Answer	Frequency	Percent
Never	130	36.2%
All or most of the time	106	29.5%
Some of the time	65	18.1%
Hardly ever	58	16.2%
Total (n=359)	**359**	**100.0%**

Wait Lists and Service Caps

SUAs, AAAs, and LSPs were asked for background information on their wait lists and service caps as well as for information about policies surrounding their usage.

SUA Wait Lists

SUAs reported on whether they currently have policies, guidance, or regulations for creating and managing wait lists for NFCSP services. More than one-half (58.8 percent) of SUAs responded that they currently have *no* such policies, guidance, or regulations.

Slightly more than one-half of SUAs (53.7 percent) have no wait list for any NFCSP services, while 38.9 percent do have a wait list and 7.4 percent do not know whether they have such a list. Worth mentioning is the fact that 58.8 percent of SUAs in the South have wait lists for NFCSP services compared with 33.3 percent in the Northeast, 30.8 percent in the West, and 25.0 percent in the Midwest. Please see Appendix D for more information.

SUAs also reported on the organization of their wait lists. Approximately one-quarter (24.4 percent) of SUAs have multiple wait lists maintained for NFCSP specific caregiver support services, such as respite care and caregiver counseling. A smaller proportion (13.3 percent) maintains a single wait list for the NFCSP overall, and 8.9 percent do not know how their wait lists are organized. Table 47 tallies these answers regarding wait list organization, displaying the frequency and the percentage for responding SUAs.

Table 47: SUA Policy on Wait List Organization

Answer	Frequency	Percent
Other (specified below)	24	53.3%
Multiple waitlists are maintained for NFCSP specific caregiver support services (e.g., respite care, caregiver counseling)	11	24.4%
A single waitlist is maintained for the NFCSP overall	6	13.3%
Don’t know	4	8.9%
Total (n=45)	**45**	**100.0%**

The majority of SUAs selecting the "Other" answer for this question added that wait lists are populated and maintained at the local level.

AAA Wait Lists

When asked whether a wait list exists for NFCSP services, more than one-half (55.3 percent) of AAAs reported that they have no wait list for such services. A wait list does exist, however, in 40.3 percent of AAAs, and 4.4 percent of AAAs do not know whether there is a wait list. Table 48 tallies these answers regarding the existence of wait lists for NFCSP services, displaying the frequency and the percentage for responding AAAs.

Table 48: AAA NFCSP Wait Lists

Answer	Frequency	Percent
No	240	55.3%
Yes	175	40.3%
Don't know	19	4.4%
Total (n=433)	**434**	**100.0%**

More than 4 in 10 (44.3 percent) mixed-geography AAAs and 37.1 percent of rural and frontier AAAs have a wait list for NFCSP services compared with only 23.0 percent of urban and suburban AAAs. Please see Appendix D for more information.

AAAs, as well, reported on the organization of their wait lists. The majority of AAAs (56.4 percent) have a single wait list maintained for the National Family Caregiver System Program overall, while 27.5 percent maintain multiple wait lists for NFCSP specific caregiver support services including, respite care and caregiver counseling. Fewer than 10 percent of responding AAAs (7.2 percent) do not know how wait lists are organized. Table 49 presents these answers regarding wait list organization, displaying the frequency and the percentage for responding AAAs.

Table 49: AAA Policy on NFCSP Wait Lists

Answer	Frequency	Percent
A single waiting list is maintained for the OAA NFCSP overall	203	56.4%
Multiple waiting lists are maintained for OAA NFCSP specific caregiver support services (e.g., respite care, caregiver counseling)	99	27.5%
Other	32	8.9%
Don't know	26	7.2%
Total (n=360)	**360**	**100.0%**

Most small-budget AAAs (57.1 percent) have a single wait list maintained for NFCSP services overall compared with only 41.0 percent of medium-budget AAAs and 41.8 percent of large-budget AAAs. Additionally, 48.5 percent of rural and frontier AAAs and 45.4 percent of mixed-geography AAAs have a single wait list compared with only 27.9 percent of urban and suburban

AAAs. Please see Appendix D for more information.

AAAs reported on the number of individuals on wait lists for services, if such a list exists. Among AAAs having a wait list, the average list size for respite care was 35.3 individuals, 34.9 individuals when a single list for NFCSP services overall was used, and 32.2 individuals for supplemental services. Table 50 lists these answers and others regarding wait list amounts, displaying the frequency and the percentage for responding AAAs.

Table 50: AAA Reported NFCSP Wait List Amounts

Answer	Mean Response	Answer Range	Number of Responses
Respite care	35.3	0–484	59
Single waiting list for the NFCSP overall	34.9	0–500	35
Supplemental Services	32.2	0–800	46
Access assistance/case management/care coordination	20.1	0–484	35
Caregiver counseling, training and education	0.3	0–6	34
Caregiver support groups	0.0	0–0	29

Most AAAs have no wait list for nearly all services. However, when AAAs *do* have a wait list, the maximum waiting period most often is greater than 6 months. Respite care is the service for which AAAs were most likely to report having a wait list. Of the 79 AAAs reporting, 22.8 percent have individuals on a respite wait list for a maximum waiting period of more than 6 months.

AAAs were queried as to who maintains the wait lists for their NFCSP services. Because wait lists can be maintained in multiple locations, respondents were asked to select all that apply. Approximately 78 percent of AAAs (78.1) reported that they maintain their own wait lists for their NFCSP services. Other service providers maintain the wait lists for 26.7 percent of AAAs, while 3.1 percent of AAAs have their lists maintained by SUAs. Table 51 lists these answers regarding wait list maintenance, displaying the percentage for responding AAAs.

Table 51: AAA Policy on NFCSP Wait List Maintenance

Answer	Frequency	Percent
AAA	275	78.1%
Service Provider(s)	94	26.7%
Other	13	3.7%
SUA	11	3.1%
Total (n=352)	**-**	**NA**

Reporting on their wait list policies and practices for prioritization, AAAs were asked to select all applicable answers. Most AAAs (58.1 percent) prioritize their wait lists using a needs measurement based on caregiver and care recipient circumstances (e.g., caregiver’s age, caregiver’s health status, whether the caregiver lives with the care recipient). One-third

(33.3 percent) of AAAs use a first come, first served policy after eligibility determination, while 26.4 percent prioritize by needs measurement based on care recipient functioning alone. Table 52 lists these answers regarding wait list policies for prioritizing caregiver services, displaying the frequency and the percentage for responding AAAs.

Table 52: AAA NFCSP Wait List Policies on Prioritizing Services

Answer	Frequency	Percent
Prioritized by a needs measurement, based on care recipient and caregiver circumstances (i.e., caregiver's age, health status, if living with the care recipient)	211	58.1%
First come, first served after eligibility determination	121	33.3%
Prioritized by a needs measurement, based on care recipient functioning	96	26.4%
First come, first served prior to establishing eligibility determination	33	9.1%
Other	19	5.2%
Total (n=363)	**-**	**NA**

When asked whether caregivers receive services, in addition to I&R, while on wait lists for NFCSP services, just more than three-quarters (75.1 percent) of AAAs responded that caregivers do, indeed, receive some other services. Among this group of respondents, 41.8 percent reported that caregivers receive available Title III-E services, while 33.3 percent reported that caregivers receive non-Title III-E services.

Nearly two-thirds of AAAs monitor their wait list for NFCSP services regularly, checking for duplicates and to identify individuals no longer eligible or in need. About 30 percent update the wait list monthly. Nearly one-fifth (18.0 percent) do so quarterly, and 10.7 percent conduct weekly checks. Approximately one in six (16.1 percent) AAAs does not know the frequency at which these checks are completed. Table 53 tallies these answers and others regarding wait list monitoring, displaying the frequency and the percentage for responding AAAs.

Table 53: AAA Frequency of Monitoring NFCSP Wait Lists for Duplicates

Answer	Frequency	Percent
Monthly	108	30.4%
Quarterly	64	18.0%
Don't know	57	16.1%
Weekly	38	10.7%
Other	32	9.0%
Semi-annually	27	7.6%
Yearly	15	4.2%
Never	14	3.9%
Total (n=355)	**355**	**100.0%**

AAA Service Caps

More than 7 in 10 AAAs (74.4 percent) have a policy that limits or caps the amount or cost of service a caregiver may receive. The majority (60.8 percent) of AAAs set their own policies regarding service caps, as shown in Table 54. For nearly one-third (31.5 percent) of AAAs, the SUA sets the policies. A State entity other than the SUA sets service cap policies for 12.1 percent of AAAs.

Table 54: AAA Policies on Entity That Sets NFCSP Service Caps

Answer	Frequency	Percent
AAA	191	60.8%
SUA	99	31.5%
State entity other than SUA	38	12.1%
Service provider	34	10.8%
Don't know	14	4.5%
Other	11	3.5%
Total (n=314)	**-**	**NA**

The majority (63.1 percent) of AAAs do not have NFCSP service caps. However, when caps exist, AAAs reported, the average

- Hourly cap for all services is 311.3 hours, with a range that falls between 0 hours and 2,750 hours; and,
- Monetary cap for all services is $1,305.63, with a range that falls between $100 and $6,000.

AAAs also reported on the time period for all service caps, as displayed in Table 55. More than two-thirds (67.9 percent) of AAAs establish a yearly time period for all service caps; approximately one-quarter (25.9 percent) fix a monthly time period for all service caps.

Table 55: AAA NFCSP All Services Cap Time Period

Answer	Frequency	Percent
Yearly	76	67.9%
Monthly	29	25.9%
Other	5	4.5%
Lifetime	1	0.9%
Quarterly	1	0.9%
Total (n=112)	**112**	**100.0%**

Focusing heavily on respite services, this process evaluation sought to determine whether respite services are capped. The majority (78.2 percent) of AAAs responded that their respite services *are* capped, while the remainder (21.8 percent) reported that they are not capped. AAAs reported that the average

- Hourly cap for the amount of respite services is 135.2 hours, with a range between 3 hours and 3,000 hours; and,
- Monetary cap for respite services is $1,382, with a range between $1.00 and $13,027.00.

As shown in Table 56, the majority (70.5 percent) of AAAs establish a yearly time period for respite service caps, while a smaller proportion (17.3 percent) fix a monthly time period.

Table 56: AAA NFCSP Respite Service Cap Time Period

Answer	Frequency	Percent
Yearly	167	70.5%
Monthly	41	17.3%
Other	19	8.0%
Lifetime	5	2.1%
Quarterly	5	2.1%
Total (n=237)	**237**	**100.0%**

NFCSP Services

To share more about the range of services offered through their NFCSP, AAAs, SUAs, and LSPs were asked to respond to questions about them.

SUA NFCSP Services

All SUAs (n=53) reporting on the services they deliver through their NFCSP indicated that they offer I&R, and 94.3 percent offer outreach presentations.

When asked about assistance services, SUAs (n=54) highlighted their work with caregivers in care and case management (79.6 percent) and options counseling (72.2 percent). All except one SUA (52 of 53) reported that they facilitate caregiver support groups, and 45 SUAs (84.9 percent) make individual counseling available. Forty-nine (92.5 percent) offer training on various aspects of caregiving.

SUAs also reported on the types of respite made available through their NFCSP. All SUAs provide some form of respite, with the majority (98.2 percent) delivering in-home respite during normal business hours. Of note is the fact that 68.5 percent of SUAs offer emergency respite services. Table 57 lists various types of respite services provided, with the frequency and the percentage of SUAs offering them.

Table 57: SUA NFCSP Types of Caregiver Respite Services Provided

Answer	Frequency	Percent
In-home respite during normal business hours	53	98.2%
In-home respite during evenings	47	87.0%

Answer	Frequency	Percent
Adult day program respite	45	83.3%
Overnight in a facility or extended respite (extended respite = 24 hours)	41	75.9%
In-home respite overnight	39	72.2%
Emergency respite services	37	68.5%
Respite weekend, including camps	35	64.8%
Other (please specify)	10	18.5%
Total (n=54)	**-**	**NA**

Fifty-one SUAs reported on the supplemental services they provide through their NFCSP. More than three-quarters (78.4 percent) of SUAs make home modifications and repairs. Almost three-quarters (72.6 percent) offer homemaker and chore services, followed by transportation and consumable supplies (both 62.8 percent) and assistive technology (60.8 percent). Table 58 lists supplemental services provided, with the frequency and the percentage of SUAs offering them.

Table 58: SUA NFCSP Supplemental Services Provided

Answer	Frequency	Percent
Home Modification/Repairs	40	78.4%
Homemaker/Chore Services	37	72.6%
Consumable Supplies	32	62.8%
Transportation	32	62.8%
Assistive Technology	31	60.8%
Emergency Response	26	51.0%
Legal and/or Financial Consultation	26	51.0%
In-Home Assessment	24	47.1%
Cash Grant	13	25.5%
Other (please specify)	8	17.7%
Total (n=51)	**-**	**NA**

AAA NFCSP Services

AAAs reported on the three types of services or information most requested, listed in descending order of frequency in Table 59. According to nearly three-quarters (74.7 percent) of AAAs, caregivers apply for respite care services—including services provided in institutional settings, in the home, and through day services—far more often than for any other service. Additionally, approximately one-quarter of AAAs responded that information on Federal and State financial assistance programs (26.5 percent) and general information about caregiving (25.6 percent) and home health care (25.6 percent) are commonly requested.

Table 59: AAA Reported Frequent Caregiver Service Requests

Answer	Frequency	Percent
Respite care (institutional, in-home, day services)	324	74.7%
Federal/State financial assistance programs	115	26.5%
General information about caregiving	111	25.6%
Home health care	111	25.6%
Emotional support	102	23.5%
Care coordination	86	19.8%
Self-directed services (e.g., paid family caregiving)	68	15.7%
Crisis	57	13.1%
Transportation	57	13.1%
Home modifications	55	12.7%
Nutrition/Food	48	11.1%
Medical supplies	41	9.4%
Energy assistance	24	5.5%
Housing options	24	5.5%
Legal services	24	5.5%
Disease-specific information	23	5.3%
Other	15	3.5%
Don’t know	3	0.7%
Total (n=434)	**-**	**NA**

Reporting on how they provide each of their services, AAAs were asked to select all applicable answers. Most support groups, training and education, information, caregiver counseling, and access assistance are provided directly by AAAs. Respite services, responded one-half (50.1 percent) of AAAs, are delivered through a contract between the AAA and another organization. Table 60 breaks down, by service category, the method of service delivery, displaying the frequency and the percentage of each for responding AAAs.

Table 60: AAA Reported Entity That Provides NFCSP Services

Answer	Direct Service Provided by AAA	Through Grant between AAA and Another Organization	Through Contract between AAA and Another Organization	Other Entity
Information	386 (84.8%)	42 (9.2%)	86 (18.9%)	37 (8.1%)
Access assistance	340 (74.9%)	48 (10.6%)	90 (19.8%)	51 (11.2%)

Answer	Direct Service Provided by AAA	Through Grant between AAA and Another Organization	Through Contract between AAA and Another Organization	Other Entity
Training/Education	271 (59.6%)	60 (13.2%)	122 (26.8%)	110 (24.2%)
Caregiver counseling	212 (46.7%)	54 (11.9%)	117 (25.8%)	131 (28.9%)
Respite services	178 (39.1%)	70 (15.4%)	228 (50.1%)	52 (11.4%)
Support groups	178 (39.0%)	57 (12.5%)	109 (23.9%)	184 (40.4%)
Total (n=448)	-	-	-	-

Additional details were provided on caregiver training and education. When asked about their policy on frequency of caregiver training and education offerings, AAAs answered with a similar distribution across the response options: frequency determined by local service provider (31.4 percent), regularly scheduled (30.7 percent), and programming provided on an as-needed basis (30.3 percent). Only 4.7 percent of AAAs reported that education benefits are unavailable to caregivers in their NFCSP. Table 61 tallies these answers regarding frequency of caregiver training and education, displaying the percentage for responding AAAs.

Table 61: AAA NFCSP Policy on Frequency of Caregiver Training and Education

Answer	Frequency	Percent
Frequency determined by local service provider	140	31.4%
Regularly scheduled	137	30.7%
Programming provided on an as-needed basis	135	30.3%
Caregiver education is not available for participants	21	4.7%
Don’t know	13	2.9%
Total (n=446)	**446**	**100.0%**

AAAs reported on a variety of evidence-based caregiver training and education interventions. Slightly more than one-half (51.5 percent) of AAAs offer no evidenced-based caregiver training and education interventions. When evidence-based interventions are used, however, the answer selected most often was Savvy Caregiver (9.0 percent). “Other” types used, responded many AAAs, include Powerful Tools for Caregivers (n=79), making that program the most frequently used. Table 62 lists several evidence-based caregiver training and education interventions offered, displaying the frequency and the percentage for responding AAAs.

Table 62: AAA Reported Offering of Evidence-Based Caregiver Training and Education Interventions

Answer	Frequency	Percent
None	228	51.5%

Answer	Frequency	Percent
Other	126	28.4%
Don’t know	56	12.6%
Savvy Caregiver (Ostwald/Hepburn)	40	9.0%
REACH II Interventions (Schultz et al)	16	3.6%
STAR-C Intervention (Teri)	6	1.4%
Coordinated system of care intervention (Vickery)	3	0.7%
COPE for Cancer Caregivers (McMillan)	1	0.2%
Total (n=443)	**-**	**NA**

Responding to queries concerning how they support caregivers with care transitions of loved ones between different settings, AAAs were asked to select all applicable answers. As shown in Table 63, care transitions support reported includes hospital discharge to home (59.2 percent), nursing home or assisted living discharge to the community (47.8 percent), placement of the care recipient into a nursing facility or assisted living (46.0 percent), and hospital discharge to a nursing home or assisted living (34.2 percent). Almost one-third (30.6 percent) of AAAs selected none of the care transitions answers listed.

Table 63: AAA Support of Care Transitions

Answer	Frequency	Percent
Hospital discharge to home	261	59.2%
Nursing home or assisted living discharge to the community	211	47.8%
Placement of the care recipient into a nursing facility or assisted living	203	46.0%
Hospital discharge to nursing home or assisted living	151	34.2%
None of the above	135	30.6%
Total (n=441)	**-**	**NA**

AAAs reported, as well, on the types of caregiver respite services they deliver, either directly by their agency or via a contracted provider. The vast majority of responding AAAs deliver in-home respite during normal business hours (95.2 percent). As well as day program respite (67.6 percent), many provide in-home respite during evenings (71.2 percent), too. Table 64 lists an array of caregiver respite services delivered, displaying the frequency and the percentage for responding AAAs.

Table 64: AAA NFCSP Types of Caregiver Respite Services Provided

Answer	Frequency	Percent
In-home respite during normal business hours	420	95.2%
In-home respite during evenings	314	71.2%

Answer	Frequency	Percent
Day program respite	298	67.6%
In-home respite overnight	230	52.2%
Overnight in a facility or extended respite (extended respite = 24 hours)	208	47.2%
Emergency respite services	184	41.7%
Respite weekend, including camps	183	41.5%
Other	26	5.9%
Total (n=441)	**-**	**NA**

When asked to estimate how often caregivers' minimum respite needs are met, about one-half (52.4 percent) of AAAs reported "some of the time," with another 41.3 percent reporting "all or most of the time." A small number (6.1 percent) of AAAs responded "hardly ever."

AAAs could select all applicable answers when queried as to common reasons caregiver respite needs are unmet. As shown in Table 65, the majority (86.5 percent) chose "funding," distantly followed by "not enough provider agencies" (24.9 percent).

Table 65: AAA Reported Reasons for Being Unable to Meet Caregiver Respite Needs

Answer	Frequency	Percent
Funding	371	86.5%
Not enough provider agencies	107	24.9%
Lack of trained providers	75	17.5%
Transportation for consumer	71	16.6%
Other	45	10.5%
Total (n=429)	**-**	**-**

LSP NFCSP Services

Nearly three-quarters (74.2 percent) of LSPs maintained that they can distinguish NFCSP funds, and the caregivers supported by those funds, from other caregiver services funding. Almost one-fifth (17.4 percent) of LSPs do not know whether they can make this distinction, while 8.4 percent of LSPs know that they are unable to do so.

The majority of LSPs provide caregiver respite services (79.1 percent), I&R (68.7 percent), and training and education (51.4 percent). In descending order of frequency, Table 66 lists these services and others that LSPs offer to caregivers.

Table 66: LSP NFCSP Services Offered to Caregivers

Answer	Frequency	Percent
Respite care	311	79.1%

Answer	Frequency	Percent
Information & Referral	270	68.7%
Training/Education	202	51.4%
Support Groups	178	45.3%
Case Management	170	43.3%
Counseling	166	42.2%
Supplemental services	124	31.6%
Don’t know	6	1.5%
Total (n=393)	**-**	**-**

Among LSPs delivering caregiver respite services, 80.4 percent offer in-home respite care during normal business hours, and 55.6 percent offer in-home respite care during evenings. Fewer than one-half (44.1 percent) provide adult day program respite services. Table 67 lists an array of caregiver respite services delivered, displaying the frequency and the percentage for responding LSPs.

Table 67: LSP NFCSP Types of Respite Services Provided to Caregivers

Answer	Frequency	Percent
In-home respite during normal business hours	250	80.4%
In-home respite during evenings	173	55.6%
Adult day program respite	137	44.1%
In-home respite overnight	104	33.4%
Respite weekend, including camps	67	21.5%
Emergency respite services	67	21.5%
Overnight in a facility or extended respite (extended respite = 24 hours)	66	21.2%
Other	19	6.1%
Total (n=311)	**-**	**NA**

From LSPs reporting on the number of unduplicated clients their organization serves, the mean response was 4,178 clients, with a range of 0 to 92,000. Looking at clients by category, shown in Table 68, 35.2 percent of LSPs responded that they serve between 501 and 5,000 clients, by far the most frequently reported range.

Table 68: LSP Reported Number of Unduplicated Caregiver Clients

Answer	Frequency	Percent
1–25 clients	24	6.8%

Answer	Frequency	Percent
26–100 clients	57	16.2%
101–250 clients	59	16.8%
251–500 clients	36	10.2%
501–5,000 clients	124	35.2%
5,001–10,000 clients	22	6.3%
10,001+ clients	30	8.5%
Total (n=352)	**-**	**NA**

LSPs were asked to report the total number of unduplicated NFCSP caregiver clients who receive respite services. An average of 82 NFCSP caregiver clients received respite services from each LSP during the most recently completed fiscal year, with the number of clients receiving respite services ranging from 0 to 3,600. For this question, LSPs most frequently reported 50 or fewer unduplicated NFCSP caregiver clients who receive respite services (72.7 percent reported either 1–10 or 11–50 clients).

LSPs also responded concerning the number of unduplicated NFCSP caregiver clients receiving training and education. An average of 287 received caregiver training and education from each LSP during the most recently completed fiscal year, with the number of clients given caregiver training and education ranging from 0 to 11,495. For this question, more than 50 percent of LSPs reported delivering such instruction to 50 or fewer unduplicated NFCSP caregiver clients.

To queries regarding evidence-based caregiving training and education interventions for NFCSP caregiver clients, approximately one-third (33.2 percent) of LSPs responded that they offer Powerful Tools for Caregivers. Savvy Caregiver (Ostwald/Hepburn) is offered by 7.4 percent of LSPs and REACH II (Shultz et al.) by 5.9 percent. “Other” types of such instruction include in-person trainings from experts. Almost one-third (31.2 percent) of LSPs provide no evidence-based caregiving training and education interventions at all. Table 69 lists several evidence-based caregiver training and education interventions offered, displaying the frequency and the percentage for responding LSPs.

Table 69: LSP Reported Offering of Evidence-Based Caregiver Trainings and Education Interventions

Answer	Frequency	Percent
Powerful Tools for Caregivers	67	33.2%
None	63	31.2%
Other	42	20.8%
Don’t know	23	11.4%
Savvy Caregiver (Ostwald/Hepburn)	15	7.4%
REACH II Interventions (Shultz et al.)	12	5.9%

Answer	Frequency	Percent
STAR-C Intervention (Teri)	1	0.5%
Coordinated system of care intervention (Vickery)	1	0.5%
COPE for Cancer Caregivers (McMillan)	1	0.5%
Total (n=202)	**-**	**NA**

LSPs, as well, support caregivers with care transitions between settings for loved ones. As shown in Table 70, more than one-half (50.4 percent) of LSPs help caregivers transition care recipients to their home on hospital discharge. Forty-two percent support care transitions between a nursing home or assisted living facility on discharge to the community, and 39.7 percent assist with placement of care recipients into a nursing or assisted living facility.

Table 70: LSP Support for Care Transitions

Answer	Frequency	Percent
Hospital discharge to home	198	50.4%
Nursing home or assisted living discharge to the community	165	42.0%
Placement of the care recipient into a nursing facility or assisted living	156	39.7%
None of the above	132	33.6%
Hospital discharge to nursing home or assisted living	113	28.8%
Total (n=393)	**-**	**NA**

LSP Service Plans

When reporting on entities that develop the individual service plan for NFCSP caregiver clients, more than one-half (62.3 percent) of LSPs indicated that their own organization develops the service plans, and another 36.1 percent answered that the AAA creates the plans. Table 71 lists the answers regarding service plan development, displaying the frequency and the percentage for responding LSPs.

Table 71: NFCSP Service Plan Development

Answer	Frequency	Percent
Your own organization	245	62.3%
Area Agency on Aging	142	36.1%
Caregiver	42	10.7%
Another service provider	39	9.9%
Other	21	5.3%
State Unit on Aging	19	4.8%
Total (n=393)	**-**	**-**

LSPs were asked how often they can meet the elements of their service plans. As shown in Table

72, nearly three-quarters (71.3 percent) of LSPs answered that all or most of the time they can meet all the service plan elements (e.g., frequency of visits, days requested) for NFCSP caregiver clients. Slightly more than one-fifth (21.4 percent), however, can do so only some of the time, while 7.2 percent can hardly ever or never do so.

Table 72: LSP Reported Ability to Meet Service Plan Elements

Answer	Frequency	Percent
All or most of the time	256	71.3%
Some of the time	77	21.4%
Never	17	4.7%
Hardly ever	9	2.5%
Total (n=359)	**359**	**100.0%**

LSPs unable to meet all service plan elements for NFCSP caregiver clients all or most of the time selected common barriers, listed in Table 73. The reasons most frequently cited for being unable to meet service plan elements include insufficient funding (67.0 percent) and workers (28.2 percent) as well as inadequately trained workers (12.6 percent). LSPs also mentioned that some client requests, such as 24/7 care or care at specific times, are outside the scope of their organization's services. "Other" common explanations include LSPs not offering service plans, care plans being too complex, client requests for specific staff, and lack of volunteers.

Table 73: LSP Reported Barriers to Meeting Service Plan Elements

Answer	Frequency	Percent
Funding	69	67.0%
Not enough workers	29	28.2%
Other	21	20.4%
Lack of adequately trained workers	13	12.6%
Transportation for consumer	9	8.7%
Transportation for workers	3	2.9%
Total (n=103)	**-**	**-**

When asked about what happens when an LSP is unable to accept an NFCSP caregiver client or to fulfill the entire service plan, a significant number (69.7 percent) of LSPs explained that they **refer these clients elsewhere** all, most, or some of the time, although nearly one-third (30.3 percent) hardly ever or never refer such clients.

More than one-half (52.7 percent) of LSPs, when unable to accept an NFCSP caregiver client or to fulfill the entire service plan, never or hardly ever **put the client on a wait list within their organization**. Slightly fewer than one-half (47.4 percent) put such clients on a wait list all, most, or some of the time.

A large proportion (68.0 percent) of LSPs, when unable to accept an NFCSP caregiver client or to fulfill the entire service plan, **provide partial services to the client** all, most, or some of the time. Nearly one-third (32.0 percent) hardly ever or never offer partial services to such clients.

Asked to disclose how often NFCSP caregiver clients pay privately for their organization's services, almost three-quarters (72.7 percent) of LSPs responded that NFCSP caregiver clients never or hardly ever access additional support by paying for it. Private payment for additional support occurs some of the time with 22.9 percent of LSPs and most of the time with 4.4 percent of LSPs.

NFCSP Performance Monitoring

To evaluate the role performance monitoring plays in NFCSP administration and the potential insights it yields, SUAs, AAAs, and LSPs were questioned about levels of program monitoring, types of data collected, use and sharing of monitoring results, performance reviews, use of caregiver client satisfaction surveys, and other relevant issues.

SUA Program Monitoring

SUAs reported on how they monitor NFCSP performance, shown in Table 74. Two-thirds (66.7 percent) of SUAs conduct routine program monitoring at the AAA level. Nearly one-quarter conduct routine program monitoring at either the LSP level (17.7 percent) or both the LSP level and the AAA level (5.9 percent). The remainder (9.8 percent) reported no routine program monitoring.

Table 74: SUA Policy on Conducting Routine NFCSP Monitoring

Answer	Frequency	Percent
Yes, at the AAA level	34	66.7%
Yes, at the local/provider level	9	17.7%
No, the SUA does not conduct routine programmatic monitoring	5	9.8%
Yes, at the AAA level and the local/provider level	3	5.9%
Total (n=51)	**51**	**100.0%**

Nine in 10 SUAs (90.5 percent) reported using the results of their program monitoring to ensure compliance with Title III E. The next most frequent answers given to the question of results use were "Planning purposes" (66.7 percent), "Ongoing implementation purposes" (54.8 percent), and "Program changes" (54.8 percent). Expanding on an "Other" answer, some SUAs wrote in training and technical assistance (n=3) and best practice development and review (n=2). Table 75 lists these answers and others, displaying the frequency and the percentage for responding SUAs.

Table 75: SUA Use of NFCSP Monitoring Results

Answer	Frequency	Percent
Ensure compliance to Title III E	38	90.5%
Planning purposes	28	66.7%
Ongoing implementation purposes	23	54.8%

Answer	Frequency	Percent
Program changes	23	54.8%
Budget justification	14	33.3%
Funding requests	8	19.1%
Advocate for program funding	7	16.7%
Other (please specify)	7	16.7%
Public Relations	4	9.5%
Fundraising	-	-
Total (n=42)	**-**	**NA**

Almost all SUAs (91.8 percent) expect to share their program monitoring results internally. Many planned to share results with their AAAs (79.6 percent), too, and some with the legislature (36.7 percent) and with their provider network (22.5 percent). Table 76 lists these answers and others, displaying the frequency percentage for responding SUAs.

Table 76: SUA Reported Entities That Receive NFCSP Monitoring Results

Answer	Frequency	Percent
Internal SUA	45	91.8%
AAAs	39	79.6%
Legislature	18	36.7%
Provider network	11	22.5%
Advocacy organizations	10	20.4%
Other state agencies	8	16.3%
Other (please specify)	3	6.1%
Total (n=49)	**-**	**NA**

Forty-three SUAs reported on the elements they include as a part of monitoring the AAAs' implementation of the NFCSP Approximately three-quarters of SUAs include assessments on data reporting (76.7 percent) and fiscal management (72.1 percent). More than one-third (39.5 percent) include assessments on service targeting. And, nearly one-third indicated that outreach activities (30.2 percent) and client satisfaction (27.9 percent) are part of assessments. Table 77 lists, in descending order of frequency, these monitoring elements and others, displaying the percentage for responding SUAs.

Table 77: SUA Reported Elements of AAA NFCSP Monitoring

Answer	Frequency	Percent
Reporting of data	33	76.7%

Answer	Frequency	Percent
Fiscal management	31	72.1%
Targeting of service	17	39.5%
Outreach activities	13	30.2%
Client satisfaction	12	27.9%
Access to service	7	16.3%
Other (please specify)	7	16.3%
Don’t know	2	4.7%
Total (n=43)	**-**	**NA**

When asked about specific data collected beyond Administration on Aging (AoA) State Program Report (SPR) requirements, more than one-half (58.5 percent) of SUAs reported collecting fiscal management data, as well, and approximately one-half answered NFCSP reports and program performance data (50.9 percent). Moreover, quality assurance findings are gathered by about one-quarter (24.5 percent) of SUAs. Twenty-eight percent of SUAs require no data collection beyond AoA SPR requirements. Table 78 lists these types of data collected, displaying the frequency and the percentage for responding SUAs.

Table 78: SUA Data Collected Beyond SPR Requirements

Answer	Frequency	Percent
Fiscal management reports	31	58.5%
NFCSP reports/program performance data	27	50.9%
We don’t require data beyond what is required in the AoA State Program Report	15	28.3%
Quality assurance findings	13	24.5%
Other (please specify)	6	11.3%
Don’t know	1	1.9%
Total (n=53)	**-**	**NA**

SUAs were queried as to whether they or the AAAs establish NFCSP performance measures at the AAA level. Approximately one-half of SUAs (52.3 percent) responded that NFCSP performance measures are not established by the SUA or AAA at the AAA level. Eighteen percent of SUAs answered that their organization establishes the NFCSP performance measures at the AAA level, 11.0 percent answered that the AAAs establish the performance measures, and just fewer than 14.0 percent answered that both their organization and the AAAs establish them.

SUA NFCSP Caregiver Client Satisfaction

Reporting on satisfaction assessments for NFCSP caregiver clients, the majority (59.1 percent) of SUAs indicated that the AAAs assume this responsibility. More than one-quarter of SUAs reported that their organization assesses client satisfaction (27.3 percent), while the remainder (13.6 percent) reported that client satisfaction is not assessed. Table 79 shows that usually the AAA, rather than the SUA, assesses client satisfaction. When client satisfaction *is* assessed at the State level, 11 SUAs reported annual assessments (64.7 percent).

Table 79: SUA NFCSP Client Satisfaction Data Collection and Assessment

Answer	Frequency	Percent
AAA assesses client satisfaction	26	59.1%
Yes	12	27.3%
No	6	13.6%
Total (n=44)	**44**	**100.0%**

SUAs were asked to report on use of uniform caregiver client satisfaction surveys across all AAAs. Among the 12 SUAs that reported assessing client satisfaction, three-quarters indicated that they use a uniform caregiver satisfaction survey across all AAAs. The remaining one-quarter do not.

AAA Program Monitoring

When questioned about the frequency of SUA performance reviews for their NFCSP, roughly one-half (52.2 percent) of AAAs reported undergoing a formal, SUA-administered onsite or desk program review once a year. More than one-third of AAAs responded that they receive a program review less often than once a year (34.2 percent), and 6.3 percent reported receiving a review more frequently. The remainder (7.2 percent) had never been reviewed by their SUA. Table 80 tallies the answers regarding frequency of SUA-administered performance reviews, displaying the percentage for responding AAAs.

Table 80: AAA NFCSP Frequency of Undergoing SUA Performance Review

Answer	Frequency	Percent
Once a year	224	52.2%
Every three years or less frequently	86	20.0%
Every two years	61	14.2%
Never been reviewed	31	7.2%
More than once a year	27	6.3%
Total (n=429)	**429**	**100.0%**

Most often, AAAs use the results from these formal, onsite or desk program reviews to ensure compliance with Title III-E (87.2 percent). Other common uses reported are planning (63.8 percent), program changes (56.9 percent), and ongoing implementation (53.1 percent). More than one-fourth of AAAs reported budget justification (31.4 percent) and advocating for program funding (27.6 percent) as other uses for the review results. Table 81 lists, in descending order of frequency, these uses and others, displaying the percentage for responding AAAs.

Table 81: AAA Uses for NFCSP Performance Review Results

Answer	Frequency	Percent
Ensure compliance to Title III-E	342	87.2%
Planning purposes	250	63.8%
Program changes	223	56.9%
Ongoing implementation purposes	208	53.1%
Budget justification	123	31.4%
Advocate for program funding	108	27.6%
Funding requests	67	17.1%
Public relations	35	8.9%
Fundraising	12	3.1%
Other	3	0.8%
Total (n=392)	**-**	**NA**

AAAs also reported on what their agency formally monitors or reviews at the provider level or both. Compliance with OAA requirements (79.8 percent) and with state rules, regulations, or guidance (76.9 percent) are the most frequently monitored specifications for NFCSP services provision at the provider level. The majority of AAAs also reported client record maintenance (76.7 percent), fiscal management (73.4 percent), and subcontract monitoring (53.2 percent). Table 82 lists the monitored specifications for NFCSP services provision at the provider level, displaying the percentage for responding AAAs.

Table 82: AAA Monitoring at NFCSP Provider Level

Answer	Frequency	Percent
Compliance with requirements in the Older Americans Act	339	79.8%
Compliance with state rules, regulations or guidance	327	76.9%
Client record maintenance	326	76.7%
Fiscal management	312	73.4%
Subcontract monitoring	226	53.2%
Compliance with licensing of the organization or its staff	200	47.1%
Standards of practice for Social Workers/Care Managers	121	28.5%
None	25	5.9%
Other	7	1.6%
Total (n=425)	**-**	**-**

When asked about the frequency of formal, onsite or desk program reviews at the provider level, nearly two-thirds (63.4 percent) of AAAs answered that such reviews take place annually. Fourteen percent of AAAs reported LSP reviews occurring more frequently than once a year, while about 15 percent reported LSP reviews occurring every 2 or 3 years (15.7 percent). Seven percent of AAAs reported no formal reviews for LSPs taking place. Table 83 tallies the answers regarding frequency AAA conducted LSP performance reviews, displaying the percentage for responding AAAs.

Table 83: AAA Reported Frequency of Reviewing LSPs

Answer	Frequency	Percent
Once a year	263	63.4%
More than once a year	58	14.0%
Every two years	38	9.2%
Never been reviewed	29	7.0%
Every three years or less	27	6.5%
Total (n=415)	**415**	**100.0%**

AAAs were asked to report on strategies used to assess outcomes for NFCSP services. A satisfaction survey of program participants was the most commonly reported strategy to assess service outcomes (75.3 percent). AAAs mentioned, as well, feedback mechanisms (38.5 percent), changes in caregiver assessments over time (24.7 percent), and monitoring of client ADL and IADL functioning (24.2 percent). Table 84 lists these strategies for assessing outcomes for NFCSP services, displaying the frequency and the percentage for responding AAAs.

Table 84: AAA Strategies to Assess NFCSP Services Outcomes

Answer	Frequency	Percent
Satisfaction survey of program participants	323	75.3%
Feedback mechanism (e.g., complaint mechanism, comment box/card)	165	38.5%
Changes in caregiver assessments over time	106	24.7%
Monitor client ADL/IADL functioning	104	24.2%
AAA does not conduct program participants assessment of NFCSP services	45	10.5%
Don’t know	14	3.3%
Other	6	1.4%
Total (n=429)	**-**	**NA**

AAA NFCSP Caregiver Client Satisfaction

Reporting on the frequency with which they assess NFCSP caregiver client satisfaction, more than one-half (56.0 percent) of the AAAs that assess program satisfaction survey participants annually. Fewer than 14 percent reported assessing participants more frequently—semiannually, quarterly, or monthly. Almost 15 percent responded that assessment frequency varies by service, and approximately 13 percent reported that assessment is ongoing. Table 85 lists these answers regarding satisfaction assessment timing, displaying the frequency and the percentage for responding AAAs.

Table 85: AAA Frequency of Assessing NFCSP Caregiver Client Satisfaction

Answer	Frequency	Percent
Annually	181	56.0%
Varies by service	48	14.9%
Ongoing	41	12.7%
Semi-annually	24	7.4%
Quarterly	17	5.3%
Other	8	2.5%
Monthly	4	1.2%
Total (n=323)	**323**	**100.0%**

LSP NFCSP Caregiver Client Satisfaction

LSPs, as well, reported on how often they conduct NFCSP caregiver client satisfaction surveys to assess service quality. At the LSP level, a wide range of timeframes for conducting these surveys exists. Although almost one-half reported annual surveys (45.6 percent), more than one-tenth (12.6 percent) reported never conducting these surveys. Additional responses include more frequently than once a year (i.e., semiannually, quarterly, or monthly) (18.7 percent), surveys that vary by service (11.5 percent), and ongoing surveys (7.2 percent). Moreover, 16 LSPs (4.3 percent) mentioned other intervals, not included as answer options, that depend on session occurrence (e.g., at the end of each educational session, at the conclusion of legal representation, after every six sessions). Table 86 lists these answers regarding client satisfaction assessment frequency, displaying the percentage for responding LSPs.

Table 86: LSP Reported Frequency of Assessing NFCSP Caregiver Client Satisfaction

Answer	Frequency	Percent
Annually	170	45.6%
Never	47	12.6%
Varies by service	43	11.5%
Semi-annually	37	9.9%
Quarterly	27	7.2%
Ongoing	27	7.2%

Answer	Frequency	Percent
Other interval	16	4.3%
Monthly	6	1.6%
Total (n=373)	**373**	**100.0%**

When asked what purposes caregiver client survey data serve, LSPs responded that managing caregiver services (60.1 percent) and program planning (54.9 percent) are their most frequent uses for this information. Other uses selected by more than 40 percent of LSPs include providing information to stakeholders (43.9 percent) and contract or grant reporting (43.6 percent). Approximately 17 percent of LSPs answered either that they do not know how the caregiver client survey data are used or that the use was not included in the answer options ("None of the above"). Table 87 lists these answers related to LSP use of their client satisfaction data.

Table 87: LSP Use of NFCSP Caregiver Client Satisfaction Data

Answer	Frequency	Percent
Managing the caregiver services	196	60.1%
Program planning	179	54.9%
Providing information to stakeholders (governing board, local/state government, advocacy organizations, etc.)	143	43.9%
Contract/grant reporting	142	43.6%
Don't know	31	9.5%
None of the above	24	7.4%
Total (n=326)	**-**	**NA**

Almost one-half of LSPs reported sharing the results of their caregiver client surveys with the AAA all of the time (49.2 percent). One-quarter reported either sharing the results most of the time (10.3 percent) or some of the time (15.1 percent). The other one-quarter reported hardly ever (10.6 percent) or never (14.8 percent) sharing results with the AAA. Table 88 tallies these answers regarding the LSP sharing of caregiver client survey results with AAAs, displaying the frequency and the percentage for responding LSPs.

Table 88: LSP Frequency of Sharing NFCSP Caregiver Client Satisfaction Survey Data With AAAs

Answer	Frequency	Percent
All of the time	153	49.2%
Some of the time	47	15.1%
Never	46	14.8%
Hardly ever	33	10.6%

Answer	Frequency	Percent
Most of the time	32	10.3%
Total (n=311)	**311**	**100.0%**

Other Caregiver Programs and HCBS Integration

Aging Network participants offered feedback on other caregiver programs and integration of the caregiver support program with other HCBS programs.

SUA HCBS Integration

More than two-thirds (68.6 percent) of SUAs indicated that no effort has been made at the State level to use the same caregiver and care recipient assessment tools across all HCBS programs. Among the 31.4 percent (n=16) of SUAs reporting that such an effort *has* been made, three-quarters indicated that those programs involved are Medicaid HCBS for the elderly and Medicaid HCBS for adults with disabilities. More than two-thirds (68.8 percent) include State-funded caregiver programs or services, and one-quarter include kinship care programs. Table 89 provides state responses on HCBS integration.

Table 89: SUA Reported State-Level Efforts to Integrate NFCSP Assessment Tools With Other HCBS Programs

Answer	Frequency	Percent
Medicaid HCBS for elderly	12	75.0%
Medicaid HCBS for adults with disabilities	12	75.0%
State-funded caregiver program/services	11	68.8%
Kinship care program	4	25.0%
Other (please specify)	2	12.5%
Total (n=16)	**-**	**NA**

SUAs reporting on barriers to integrating with HCBS programs selected common ones among the answer options, listed in Table 90. Different eligibility requirements (72.0 percent), different reporting requirements (54.0 percent), and different client populations (52.0 percent)—the top three—were cited as major barriers to integration.

Table 90: SUA Reported Barriers to Integrating HCBS Programs

Answer	Frequency	Percent
Different eligibility requirements	36	72.0%
Different reporting requirements	27	54.0%
Different client population than in other programs	26	52.0%
Federal regulatory or statutory requirements	17	34.0%

Answer	Frequency	Percent
Organizational cultural and administrative differences	16	32.0%
Complexity of accessing and arranging services	13	26.0%
Lack of access to adequate computer technology and support	13	26.0%
State regulatory or statutory requirements	12	24.0%
Staff has too many responsibilities	11	22.0%
Lack of knowledge of opportunities for integration	8	16.0%
Other (please specify)	8	16.0%
Low priority given to caregiver support services	6	12.0%
No barriers to integration	4	8.0%
Total (n=50)	**-**	**NA**

Asked specifically how they coordinate with ADRCs, more than one-half of SUAs answered that the NFCSP coordinates with ADRCs to develop or to implement referral and assessment processes (62.0 percent) and to deliver options counseling (62.0 percent). In addition, one-half of SUAs reported coordination with ADRCs to develop or to implement screening protocols. Forty-six percent reported coordination with ADRCs to develop or to implement intake tools; 44.0 percent, to develop or to review policies, guidance, or regulations regarding inclusion of caregiver services; and 38.0 percent, to provide training. Fewer than one-quarter mentioned NFCSP coordination with ADRCs to facilitate care transitions (24.0 percent). Table 91 lists these answers regarding coordination between SUAs and ADRCs, displaying the frequency and the percentage for responding SUAs.

Table 91: SUA Reported Coordination With ADRCs

Answer	Frequency	Percent
Development or implementation of referral/assessment processes	31	62.0%
Provision of Options Counseling	31	62.0%
Development or implementation of screening protocols	25	50.0%
Development or implementation of intake tools	23	46.0%
Development or review of policies, guidance or regulations regarding the inclusion of caregiver services	22	44.0%
Provision of training	19	38.0%
Provision of Care Transitions	12	24.0%
Other (please specify)	11	22.0%
NFCSP does not coordinate with the ADRC	6	12.0%
Total (n=50)	**-**	**NA**

Other responses SUAs submitted include the ADRC and the SUA being operated by a single organization (n=4) and coordination being decided on a local level (n=3). Twelve percent of SUAs responded that no coordination occurs between the NFCSP and the ADRCs.

SUA Non-OAA Caregiver Programs

More than one-half (54.7 percent) of SUAs reported that their state administers a separate caregiver program funded outside the NFCSP. In the Northeast region, 88.9 percent of SUAs reported a separate caregiver program as compared with only 38.5 percent in the West. See Appendix D for full results stratified by region.

SUAs serve a range of enrolled caregivers, from 64 to 14,000 in their non-OAA, caregiver programs. Twenty-nine SUAs reported administering a non-OAA caregiver program, but only 17 provided data on the number of caregivers enrolled. The average number of enrolled caregivers across these non-OAA programs is 2,904.

The majority of SUAs with a non-OAA program reported that their state's non-OAA caregiver program began before the NFCSP (53.6 percent). More than one-third (35.7 percent) of SUAs reported that their non-OAA program began after the NFCSP and only one SUA (3.6 percent) reported that the non-OAA program began at the same time as the NFCSP.

When a state's non-OAA program began before the NFCSP, most SUA respondents described improvements as a result of its enactment. Nine respondents indicated that additional caregivers were served, with two of them responding that the definitions of eligible caregivers expanded. Other improvements include addition of new services (n=8); more services for most caregivers (n=6); improved coordination of services (n=2); increased flexibility for AAAs to maximize funding based on local needs (n=1), and improvements to reporting and policies (n=1). Four respondents reported no change. Only one response indicated a negative change, which was a decrease in State funding.

When asked how NFCSP affected implementation of non-OAA caregiver programs that started afterwards, two SUAs responded that the non-OAA caregiver programs benefited from having the NFCSP in place by building on NFCSP practices. One respondent indicated that the two exist in partnership and use Lifespan Respite when AAAs have exhausted their respite funding. One respondent indicated that the non-OAA program targets a population ineligible for NFCSP. Three indicated that the non-OAA programs were unaffected, with two emphasizing their separate nature.

SUAs responded to a question concerning the relationship between the NFCSP and pre-existing caregiver programs and services. More than 40 percent of SUAs with separate non-OAA programs answered that their non-OAA and OAA programs are integrated into one program with multiple funding streams (41.2 percent). Approximately one-third (35.3 percent) answered that their non-OAA and OAA programs are separate with coordinated operations, and 17.7 percent answered that the programs are distinct and operate separately. Selecting "Other," one SUA added that the relationship varies on the AAA level with some AAAs contracting with preexisting caregiver programs. Table 92 tallies these answers, displaying the percentage for responding SUAs.

Table 92: SUA NFCSP Relationship With Preexisting Caregiver Programs and Services

Answer	Frequency	Percent
Programs are integrated into one program with multiple funding streams	7	41.2%
Programs are separate with coordinated operations	6	35.3%
Programs are distinct and operate separately	3	17.7%
Other (please specify)	1	5.9%
Total (n=17)	**17**	**100.0%**

SUAs described how they integrate or coordinate their NFCSP and non-OAA caregiver programs. Five SUAs indicated that their programs are integrated into one program with multiple funding streams. The respondents indicated that the multiple funding streams are combined and used to serve all caregivers (n=2) or that the programs function similarly but specific funding streams pay for services for individuals based on eligibility (n=3).

Separate programs with coordinated operations showed more variety across six responses. Coordination techniques include case managers (n=1), shared staff and applications (n=1), administration by the same agency (n=1), and joint training (n=1). Additionally, two respondents indicated that coordination is encouraged. Two other respondents indicated that AAAs determine program coordination, and a respondent that selected “Other” added local coordination decisions.

AAA Non-OAA Caregiver Programs

About one-quarter of AAAs reported that they administer a separate caregiver program funded outside the OAA NFCSP.

Of those 24.1 percent (n=105), almost one-half (47.6 percent) reported that their separate caregiver program has an income or asset eligibility requirement—either on the part of the caregiver or the care recipient. Similarly, approximately one-half (47.1 percent) of AAAs administering a separate non-NFCSP-funded caregiver program reported that caregivers or care recipients who meet certain criteria receive priority for services in the separate program.

Among the AAAs administering a separate caregiver program, fewer than one-quarter (23.1 percent) indicated that their non-NFCSP-funded program is more flexible regarding services, eligibility, types of consumers served, and hours and days of operation than the NFCSP. Seventeen percent reported, in fact, that their separate caregiver program is less flexible, but the majority (59.6 percent) reported that the programs are about the same in terms of flexibility.

Future of the National Family Caregiver Support Program

In response to a request for written feedback, SUAs offered their thoughts on issues they expect their caregiver programs to face in the coming years, obstacles to be overcome, and improvements they would like to see, while AAAs responded with ideas to enhance program planning and administration, services provision, outreach materials development, staff training, and more. LSPs proposed improvements, but amid ever present concerns about insufficient funding, did address the question of their continued operation beyond 2016. The considered input of all three groups reflects an enthusiasm for their work and a strong commitment to both informal caregivers and their care recipients.

SUA Perspectives on NFCSP Challenges and Planned Improvements

SUAs were asked to describe the most significant issues their informal caregiver program will face over the next year, to which an array of answers emerged, including obstacles and planned improvements, increasing demand from a growing population (n=10), limited or decreasing funding (n=19), and limited provider availability (n=3). SUAs also reported on state- and policy-level improvements and AAA-or service area-level improvements, which are described in more detail in Appendix C.

Next, SUAs responded to what they see as the most significant issues for their informal caregiver program over the next 3 years to 5 years. Their thoughts include obstacles and planned improvements. Many answers are similar to others for the previous questions. Increasing demand from a growing population (n=22), limited or decreasing funding (n=20), and sustainability (n=3) are issues raised. SUAs also reported on service-related improvements, such as resources and efforts focused on working caregivers.

SUAs were asked, as well, to suggest ways to improve the NFCSP program, other than allocating additional funding. Their responses include improvements for the Federal, State, and local levels. At the Federal level, eight respondents express a wish for more guidance, specifically in the areas of program implementation, caregiver assessments, requiring evidence-based caregiver support programs, monitoring and evaluation tools, clarification and consistency in services, funding, and requiring plans for individual services. However, at the same time, other respondents appreciate the flexibility SUAs are permitted in managing their NFCSP or they request more flexibility, specifically in the areas of eligibility requirements (n=3), sliding fee scales (n=2), and the supplemental services cap (n=1).

At the State and local levels, recommendations include supplying additional training to providers, building awareness of caregiver programs, developing or updating consumer resource databases, developing closer connections with partner organizations, and better use of waivers and vouchers.

AAA Suggestions for the National Family Caregiver Support Program

One hundred nine AAAs responded to a request for suggestions to improve the way the NFCSP program works. Their comments cover a range of areas and perspectives. Respondents would like more guidance in some areas, including increased direction on, and standardization in, program implementation; forms and use of funds, and caregiver assessments.

Just the same, however, other respondents request more flexibility in general (n=2) as well as in how to designate funds and decide services (n=8). Specific requests for more flexibility also relate to expanding services, including expanding respite services (n=9), allowing more hours (service unspecified) per client (n=4), allowing more spending on supplemental services (n=3), making eligibility guidelines more flexible (n=8), and increasing training offerings (n=9).

Despite the question specifying non-funding improvements, 10 respondents emphasize a need for additional funding in addition to others that mention funding integrated with their other recommendations. More detail on these responses is provided in Appendix C.

LSP Continued Service Provision

Asked specifically about providing caregiver services 1 year from now, an overwhelming majority of LSPs responded that they "very likely" will continue. An additional 5.6 percent of LSPs reported that they are "somewhat likely" to continue providing services. Only 1.6 percent indicated that they are "not very likely" or "not at all likely" to continue providing caregiver services 1 year from now. Table 93 tallies these answers, displaying the frequency and the percentage for responding LSPs.

Table 93: LSP Reported Likelihood of Providing Caregiver Services 1 Year From Now

Answer	Frequency	Percent
Very likely	280	92.7%
Somewhat likely	17	5.6%
Not very likely	4	1.3%
Not at all likely	1	0.3%
Total (n=302)	**302**	**100.0%**

Expanding on what could impact their likelihood of providing caregiver services 1 year from now, the majority of LSPs noted that funding availability is a factor (n=30). Related to funding, they also noted that their continued provision of services depends on whether they are contracted to do so (n=27). Many LSPs added that they are committed to providing services, and that this service provision is part of their organization's mission (n=33). Another potential impact on service provision is level of demand for caregiver services (n= 27).

Similarly to SUAs and AAAs, LSPs responded with suggestions for improvements to the NFCSP program, with the exception of additional funding. Many LSPs noted that they have no suggestions and that they feel the program is working well (n=38). They did suggest types of caregiver services that could be added (n=26), however, including broadening the provision of culturally-based caregiver services and increasing flexibility in caregiver service plans to adjust to their changing needs.

VI. Discussion and Conclusion

Examining the history of caregiver services available before and after the NFCSP's enactment in 2000, we recognize clearly that this effort has proven to be a catalyst for supports and services designed specifically for caregivers. Previously, half of SUAs and AAAs had no caregiver program.

A review of the types of caregiver services available before and after 2000 confirms the substantial increase that has occurred. As noted in the Results section, twice as many AAAs deliver respite care now as did earlier. More than three times as many AAAs now offer caregiver support groups and caregiver training and education. And, today, more than nine times as many AAAs provide caregiver counseling.

At the State level, only half of SUAs reported delivering respite care—one of the most sought-after caregiver support services—before the NFCSP existed. In the NFCSP Survey, *all* SUAs reported providing some form of respite, such as in-home respite during normal business hours, overnight respite in a facility, or emergency respite services.

Additionally, more than two-thirds (68 percent) of SUAs responded that the NFCSP has resulted in the creation of standardized eligibility criteria for caregiver services.

These achievements speak for themselves and for the success of the NFCSP over the past decade and a half. Nevertheless, work remains to be done and improvements can be made. Here, we summarize the program's weaknesses as well as some of its most significant strengths.

NFCSP Staffing, Training, and Education

Dedicated staff demonstrate a commitment to caregivers and, by extension, to care recipients. Almost 80 percent of SUAs reported currently employing a caregiver program manager or coordinator who plans, develops, administers, implements, or evaluates the NFCSP or performs any combination of the foregoing tasks. At the AAA level, NFCSP staff are integrated into other programs and projects, as well, outside the NFCSP.

More than half of LSPs are relatively small, employing fewer than 15 FTE staff. LSPs noted a variety of tasks completed by volunteers, suggesting that smaller organizations might be better able to complete the range of activities by routinely tapping volunteers.

Also important to note is the commitment to training and educating staff on the variety of caregiver topics, with Alzheimer's disease or a related disorder being a training topic to which SUAs and AAAs are especially committed. Caregiver assessments are another function for which the Aging Network is providing staff education.

Targeting Caregiver Populations

In line with OAA guidance, the majority of SUAs and AAAs are making an effort at outreach to special caregiver populations—primarily caregivers of people with Alzheimer's disease, grandparents raising grandchildren and other relative caregivers, and rural caregivers. To address the specific needs of these populations, both SUAs and AAAs employ targeted marketing and outreach campaigns, informed by caregiver and care recipient criteria such as socioeconomic status and geographic location. We also observed efforts at partnership development (e.g., with VA systems) to better serve these populations.

Partnerships

Partnerships constitute an important part of local implementation of the NFCSP. At the State level, a small number of SUAs reported working with other State agencies to implement the program (17.3 percent). However, at the AAA level, partnerships are a critical component of operating NFCSP services. AAAs reported involvement in partnerships for planning and developing programs, conducting program outreach, contacting hard-to-reach caregivers, developing a community needs assessment, and other such activities.

In ranking important partnerships, we found that AAAs frequently reported relationships with local and state chapters of national organizations, ADRCs, and health care providers. The proportion of health-related partnerships (41.6 percent of AAAs) might point to enhanced caregiver outreach through health channels (e.g., primary care physicians, hospitals), increased involvement in transitions among a variety of health care settings, and understanding of the increasingly medical roles that caregivers assume (e.g., wound care, transferring and lifting care recipients).

Assessment and Reassessment

Another critical component of the NFCSP, caregiver assessments have become an area of increasing focus in the Aging Network community. The majority of SUAs and AAAs reported assessing both the caregiver and the care recipient, with a little more than half of SUAs reporting that they use a standardized caregiver assessment. Notably, although 81.1 percent of SUAs assess both caregiver and care recipient, 69.7 percent of AAAs do so. A smaller proportion of AAAs assess *only* the care recipient (15.4 percent).

Despite the large proportion of SUAs reporting that they assess at the caregiver level, almost half (41.2 percent) of responding SUAs answered that they have *no* standardized process for assessing caregivers. Room for growth in standardization exists at the State and local levels, for both their processes and their assessment instruments.

At the local level, only about half (52.2 percent) of LSPs reported performing an initial comprehensive needs assessment, possibly indicating that most are contracted for only particular services after another entity (likely the AAA) has completed the assessment.

SUAs, AAAs, and LSPs were asked what information their caregiver assessment contains. For almost three-fourths of each responding group, the impact of caregiving on the caregiver is an element of the caregiver assessment.

Wait Lists and Service Caps

At the State level, information on wait lists and service caps was minimal. More than one half of SUAs (58.8 percent) reported that they currently have no policies, guidelines, or regulations for creating and managing wait lists for NFCSP services. Additionally, more than half of SUAs responded that they have no wait list. Most SUAs took the opportunity to add that wait lists are maintained at the local and provider levels.

Similarly to the SUA response, more than half of AAAs indicated that they have no wait list for NFCSP services. For AAAs that do keep a wait list, a single list for all services (not a specific service) is most commonly maintained. Although AAAs reported that wait lists exist, only a small percentage reported information about the number of individuals on their wait list. When wait lists exist for specific NFCSP services, AAAs most likely reported a list for respite care, suggesting the demand for, and importance of, this service.

The majority of AAAs impose service caps to limit caregivers' use of at least some NFCSP services. Only about a third of AAAs cap all services, and most cap annual service use, more commonly based on service cost than on the number of units or hours provided. Respite care is the most commonly capped service, followed by supplemental services.

At the local level, rates for inability to accept NFCSP clients are low. When LSPs note that they are unable to accept a client, usually the potential client has more needs than can be met. This circumstance might suggest that the program is failing to reach highest-needs caregivers, that AAAs must identify multiple provider organizations to meet a caregiver's complex needs, or both.

NFCSP Services

Among NFCSP services, respite care continues to be one of the most in demand and, therefore, essential. AAAs reported that the type of information caregivers request most often concerns respite care (74.7 percent). Because respite care is also more complicated to deliver and administer than other services, more AAAs are contracting with another organization to address this particular need.

Despite the majority of SUAs and AAAs reporting that they offer respite care, LSPs reported a relative lack of overnight and weekend respite. In fact, when reviewing the response to this question across the Aging Network, the proportion of organizations reporting that they provide this type of respite care decreased at each level (up to 75 percent of SUAs, 42 percent of AAAs, and 21 percent of LSPs).

When examining provision of evidence-based caregiver training and education interventions, we noticed that a small proportion of AAAs and LSPs reported using the programs listed in the survey. Selecting the "Other" answer, AAAs added that they use Powerful Tools for Caregivers, making it the most frequently selected LSP evidence-based program (33.2 percent). More than half of AAAs responded that they offer no evidence-based caregiver training and education interventions.

Program Performance Monitoring

The majority of SUAs and AAAs reported regular program monitoring. Few SUAs noted that they conduct no program monitoring (9.8 percent), with the remaining conducting their monitoring primarily at the AAA level (66.7 percent). The SUAs reported less sharing of program monitoring results with entities outside of their own organization (e.g., Legislature, provider network, advocacy organizations). SUAs do share this data more frequently with their AAAs, which might be in line with the primary purpose reported for using program results to ensure compliance with NFCSP requirements (90.5 percent).

Another commonly reported use of program monitoring results at both the SUA and AAA levels is program change assessment, which might indicate a commitment to program improvements through data monitoring.

Few SUAs conduct caregiver client satisfaction surveys; however, more than half reported that the AAA conducts this assessment (59.1 percent). This finding is consistent with more than three-quarters of AAAs' reporting that they use a satisfaction survey of program participants to assess outcomes related to NFCSP services.

LSPs also conduct caregiver client satisfaction surveys, with only 12.6 percent noting that they never conduct a caregiver satisfaction survey. These organizations most frequently reported using the results for managing caregiver services and for program planning. The NFCSP process evaluation results indicate a need for increased communication between the AAAs and LSPs, with a quarter of LSPs reporting that they hardly ever or never share their results with the AAAs.

Few organizations indicated that they monitor caregiver outcomes beyond caregiver satisfaction. Although many organizations conduct satisfaction surveys annually, additional caregiver outcomes—burden, depression, unmet needs, and positive caregiver experiences, to name a few—could be tracked over time, yielding much richer data bout NFCSP impacts.

Other Caregiver Programs and HCBS Integration

The NFCSP process evaluation results indicate an opportunity for the NFCSP to become better integrated with other HCBS programs. More than two-thirds of SUAs reported that no effort has been made to integrate the programs at the State level. Where progress *has* been made, SUAs reported integration of the NFCSP with Medicaid HCBS programs. Barriers to HCBS integration include more frequently reported issues with different eligibility requirements, different client populations, and different reporting requirements as well as organizational, cultural, and administrative differences.

An interesting finding is the number of non-OAA caregiver programs. More than half of states administer a separate caregiver program, funded outside the NFCSP. At the local level, just a quarter of AAAs reported administering a separate caregiver program.

Funding for the National Family Caregiver Support Program

At both the SUA and AAA levels, a commonly stated concern for NFCSP challenges is limited or decreased funding. This concern corresponds directly to a concern over increasing demand from a growing population. Some SUAs specifically highlighted concerns over provider availability in rural areas.

At the local level, 93 percent of LSPs believe they still will be providing services 1 year from now. However, their major concern for ceasing service provision is the same concern of SUAs and AAAs—that funding will be decreased, limited or eliminated.

Conclusion and Recommendations

A key finding from the NFCSP process evaluation is that this program, enacted in 2000, proved to be a catalyst for either providing or formalizing caregiver support services. For some states, the NFCSP might be the only means through which caregivers can receive much needed services.

This process evaluation has examined the policies and procedures through which SUAs, AAAs, and LSPs meet NFCSP goals. Given the breadth of services that programs reported offering, the Aging Network has succeeded in developing a system through which caregivers can access supports. The number of SUAs reporting on a standardized caregiver assessment suggests that states are aiming to meet caregivers' diverse needs and preferences. Both SUAs and AAAs employ targeting methods to reach vulnerable caregiver populations. Additionally, AAAs indicate specifically the use of partners in their NFCSP implementation, including outreach to vulnerable populations through partnerships (e.g., with schools, employers, VA systems).

The process evaluation has been unable to fully answer the question of whether the NFCSP has contributed to the LTC system's efficiency. Although we now understand better the ways in which the Aging Network coordinates with other programs (e.g., Medicaid HCBS, ADRCs), we recognize, too, that several barriers to this coordination exist. SUAs reported that these barriers include different eligibility requirements, different reporting requirements, and different target populations. As noted earlier, the NFCSP might be the only formalized program for caregiver supports in many states and localities. Therefore, aging entities should engage in improving coordination across different LTSS programs as a way to ensure that caregivers receive services through this program.

Multiple recommendations arise from reviewing the NFCSP process evaluation data and from lessons learned in fielding the surveys to SUAs, AAAs, and LSPs.

Ongoing NFCSP Communications Across the Aging Network

- **Federal Guidance with NFCSP Management Flexibility for SUAs:** Qualitative analysis yielded SUA recommendations for more NFCSP policy and procedure guidance, which includes suggestions on program implementation, caregiver assessments, requiring evidence-based caregiver support programs, monitoring and evaluation tools, clarification and consistency in services, funding, and requiring plans for individual services. Nevertheless, the point should be made that some SUAs appreciate the flexibility they have been permitted in managing their NFCSP.
- **LSPs Knowledge About the National Family Caregiver Support Program:** Findings from the process of fielding the survey should be noted, as well. Many LSPs were unfamiliar with the NFCSP, as described in Appendix E. Although AAAs are the organizations that receive the funding and contract with LSPs, the latter might be better able to serve NFCSP caregiver clients if they know more about the program. It would also bolster support for additional funding requests from Congress for NFCSP/OAA programs.
- **SUA and AAA Alignment on NFCSP Implementation:** Responses to the same questions varied between the SUA and AAA surveys. (A comparison of select questions is available in Appendix F.) No pattern emerged in comparing these responses; however, the response variations might relate to a communication gap between the SUAs and the AAAs on implementation of the NFCSP. Variations might also represent the SUAs' response to the survey, answering for what some AAAs are doing in the state, even if it is not a statewide policy or practice.

Research

- **Examining Partnerships in Implementing the NFCSP:** SUA and AAA data illustrate a variety of partners for implementing the NFCSP, especially at the AAA level. The SUAs reported limited partnerships with other State agencies to implement the program, and approximately two-thirds of SUAs reported partnering with ADRCs for this effort. About half of AAAs reported partnering with ADRCs, and 250 AAAs reported partnering with local or state chapters of national organizations for the program. As noted in the Results discussion, another important partnership for AAAs is health centers, with more than 40 percent of AAAs reporting this collaboration. This partnership is a key one, with literature supporting the fact that caregivers often perform medical or nursing tasks. Health center partnerships might help NFCSPs target and educate caregivers about some of these more medical caregiver tasks. Research might focus on the ways that State and local agencies cooperate to implement the NFCSP.
- **Understanding Wait List Policies and Procedures:** Although the process evaluation has yielded information on who sets the policies and procedures for NFCSP services wait lists, little data were forthcoming from the SUAs and AAAs on their wait list numbers. For example, 203 AAAs reported that a single wait list is maintained for the NFCSP overall, but only 35 AAAs reported on the numbers. Responding to all questions was optional; notwithstanding, the small response left a substantial gap in the knowledge that might have been gained. About 30 percent of the AAAs indicated that either providers or others actually maintain the lists, which likely accounts for some of the nonresponse. Research efforts might focus on these challenges to better understand the ways in which SUAs and AAAs maintain wait lists.

- **Examination of NFCSP Targeting Methods:** SUAs reported that they prioritize services for low-income caregivers. The literature suggests the need to better target 1) low income caregivers, 2) employed caregivers, and 3) higher-hour caregivers, defined as individuals providing 21 or more hours per week of assistance. In the NFCSP process evaluation, organizations were asked who they target and what methods they employ to target special caregiver populations. The evidence base supports the need for this type of caregiver targeting, and further research could focus on methods for targeting these caregivers as well as on the effectiveness and impact of targeting high-need caregivers.

Caregiver Assessment and Outcomes

- **Development of Standardized Caregiver Assessment Instruments:** SUAs, AAAs, and LSPs were asked many questions about caregiver assessments. More than half of the SUAs reported using a standardized caregiver assessment tool. The SUAs also largely answered (81.1 percent) that they assess both the care recipient and the caregiver. A notable finding is that 15.4 percent of AAAs reported assessing *only* the care recipient. Considering state and local policies on caregiver assessments is vital for the NFCSP. Recommendations from caregiver literature include making caregiver assessments more universal and ensuring that assessments include questions on the caregiver. This approach is especially important for the NFCSP, which focuses on the caregiver. As part of the NFCSP process evaluation, we asked SUAs, AAAs, and LSPs that reported using standardized caregiver assessments to send their tools to Lewin. Having compiled these tools, a thorough review could be used for designing a nationally accepted caregiver assessment tool.
- **Increased Monitoring of Caregiver Outcomes:** Few organizations reported that they monitor caregiver outcomes beyond caregiver satisfaction. The standardized assessment of caregivers recommended above could help SUAs, AAAs, and LSPs in better monitoring the impact of their services on caregivers. A benefit of SUAs' and AAAs' expanding on their data collection would be the ability to monitor their program's impact on caregivers and to determine whether modifications should be made based on these outcomes. These organizations also could consider examining their own caregiver outcomes compared with the findings from other studies, including the upcoming NFCSP Outcomes Evaluation.

Funding for the National Family Caregiver Support Program

- **NFCSP Program Funding**: The NFCSP process evaluation findings support the need for additional funding for the NFCSP. Serving as a catalyst for caregiver services, 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. AAAs reported that insufficient funding is the most common reason for unmet respite needs, and LSPs reported that when providers are unable to meet the elements of an NFCSP caregiver service plan, insufficient funding is the most common reason for being unable to do so. Per our literature review, caregivers face significant burden; respite, education, and other caregiver services available under the NFCSP are critical to supporting their role as the primary providers of LTSS for older adults and people with disabilities.

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