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Final
Report

Outcome Evaluation of the National Family Caregiver Support Program

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Introduction by the Administration for Community Living

In 2000, Congress established the National Family Caregiver Support Program (NFCSP) as part of the reauthorization of the Older Americans Act (OAA). At the time, this new program marked the first federal recognition of the critical role families play in the nation's system of long-term services and supports. As well, it was the first federal program to make it possible for every state and community to provide family caregivers with a flexible base of services and supports to assist them in their efforts to keep their loved ones in the settings of their choice for as long as possible. Today, the NFCSP is an integral component of our nation's fabric of long-term services and supports and is a trusted and reliable source of information and support for family and older relative caregivers.

The results of the 2018 Outcome Evaluation of the NFCSP report presented here are the culmination of a multi-year effort by the Administration for Community Living (ACL) to evaluate the program's design and operation at the state, local, and provider levels, and to assess its impacts on the family caregivers it serves. The Outcome Evaluation was undertaken with the following key objectives in mind:

- To help ACL understand which kinds of services are most helpful for caregivers and identify any unmet needs of caregivers and gaps in support for them;
- To assess the impact of services on caregivers' ability to continue to provide home-based caregiving as needed; and
- To examine the relationship between caregiver outcomes and key processes and characteristics of the Area Agencies on Aging managing and/or providing NFCSP services.

Key among the evaluation's findings are important insights into the value of respite in reducing caregiver burden and that education and training services can lead to greater caregiver confidence over time. Additionally, the evaluation demonstrates that caregiver use of the services made available by the NFCSP helped them continue in their role for longer periods, an important factor in delaying or preventing the institutionalization of the care recipient. Finally, the results show the connections between certain processes (e.g., targeting and caregiver assessment) and caregiver outcomes that may help the aging services network better design and shape local programs to meet the needs of family caregivers.

ACL believes that the results of this evaluation, when combined with the Process Evaluation results published in 2016,[1] will provide the aging services network, advocates, and policymakers with information that will be instrumental in shaping the future of family caregiver supports in the U.S. ACL plans to use the results of this evaluation to continue to shape its efforts to better support families and family caregivers, and to provide targeted training and technical assistance to the aging services network to ensure optimal responsiveness to the needs of family caregivers.

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[1] The Process Evaluation Final Report is publicly available at https://acl.gov/sites/default/files/programs/2017-02/NFCSP_Final_Report-update.pdf

Executive Summary

Background

Established via the reauthorization of the Older Americans Act (OAA) by the 106th U.S. Congress in 2000, the Title III-E National Family Caregiver Support Program (NFCSP) is a Federal program designed to support the needs of family or other informal caregivers as they lend assistance to aging adults, as well as grandparents and older relatives caring for minor children or adults with disabilities. The Administration on Aging (AoA) within the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services (DHHS) administers the NFCSP, which aims to help individuals remain in their homes and communities as long as possible.

Through the NFCSP, states and territories offer the following five core services for caregivers, in partnership with Area Agencies on Aging (AAAs) and local service providers:

- **Information for Caregivers about Available Services.** Caregivers can learn about a range of supports, resources, and services available.
- **Assistance to Caregivers in Gaining Access to Services.** Access assistance helps connect caregivers with services offered by private and voluntary agencies.
- **Caregiver Education/Training, Individual Counseling, and Support Groups.** These services help caregivers better manage their responsibilities and cope with the stress of caregiving.
- **Respite Care.** Trained caregivers provide care for individuals, either at home or at adult day care facilities, so that caregivers can rest or attend to their own needs.
- **Supplemental Services.** Additional services may include transportation, home modifications, and medical equipment.

The NFCSP assists caregivers in the following groups:

- 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;

- Older relative caregivers (excluding parents) age 55 and older providing care to children under age 18; and
- Older relative caregivers (including parents) age 55 and older providing care to adults ages 18 to 59 with disabilities.

The outcome evaluation described in this report focused on the first two groups of caregivers.

NFCSP Evaluation

The mission of ACL is to maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers. To support ongoing program planning efforts and determine the efficacy of the Title III-E NFCSP, ACL/AoA contracted with Westat to conduct an outcome evaluation of the program. The outcome evaluation represents the second phase of a two-part evaluation of the NFCSP. The first phase, the process evaluation, was completed in 2016.[2] The purpose of the two-phase evaluation was to generate information about the NFCSP and its clients for policymakers, funders, and program developers, and to measure the efficacy of those services in improving caregiver outcomes. This report is the second of two reports about the program's evaluation, and summarizes findings from the NFCSP outcome evaluation.

The outcome evaluation focused on the collection of survey response data from a nationally representative sample of NFCSP client caregivers, a Comparison group of caregivers who do not receive NFCSP services, and a sample of care recipients (CRs) of caregivers in the two groups. This was the first national longitudinal survey of caregivers designed for the purpose of evaluating the NFCSP. Survey data collected in the outcome evaluation coupled with the AAA-level data collected during the process evaluation allow for the investigation into what types of organizational structures, approaches, and strategies for delivering NFCSP services are associated with optimal caregiver-level outcomes. Furthermore, the evaluation's findings should be of assistance to the Secretary of Health and Human Services in developing a national strategy to support family caregivers (RAISE Family Caregivers Act, 2017).

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[2] The Process Evaluation Final Report is publicly available at https://www.acl.gov/sites/default/files/programs/2017-02/NFCSP_Final_Report-update.pdf.

Outcome Evaluation Objectives

The objectives of the outcome evaluation were to:

- Help ACL understand which kinds of services are most helpful for caregivers and identify any unmet needs of caregivers and gaps in the support for them;

- Identify any NFCSP resources, organizational characteristics, and implementation practices that appear to contribute to positive outcomes for caregivers receiving the key NFCSP caregiver services of respite care and/or education/training, individual counseling, and support groups;

- Assess the impact of services on the ability of caregivers to continue providing home-based caregiving as needed; for example, by examining the relationship between self-reported caregiver measures of mental health, physical health and well-being and the amount of caregiver services received; and

- Examine the relationship between NFCSP client outcomes and key processes and characteristics of the AAAs managing and/or providing NFCSP services.

The outcome evaluation was designed to address the following four key evaluation questions:

- **Evaluation Question #1 (EQ1).** In conjunction with information from the process evaluation (conducted in Phase 1), what types of organizational structures and/or approaches for NFCSP services are associated with the best participant-level outcomes?

- **Evaluation Question #2 (EQ2).** Are services reaching the groups targeted by the OAA, including caregivers serving older adults with greatest social or economic need?

- **Evaluation Question #3 (EQ3).** To what extent do NFCSP service participants also receive other home- and community-based long-term support and services, and what is the relationship among these services?

- **Evaluation Question #4 (EQ4).** To what extent do NFCSP program participants' outcomes differ from those of caregivers who do not receive support and services from the NFCSP?

Methodology

The NFCSP outcome evaluation draws on information obtained from comprehensive telephone-based surveys of NFCSP client caregivers and a Comparison group of caregivers who were not clients of NFCSP. A survey was administered to random samples of participants, based on probability samples of AAAs that were surveyed as part of the ACL's 11th National Survey of Older Americans Act Participants (NSOAAP). The nonparticipant Comparison group was formed by identifying clients of Older Americans Act services who indicated during the NSOAAP that they had someone who assisted them with activities of daily living (ADLs) and who were not recipients of NFCSP caregiver services. These clients were called and asked if they had a family caregiver.

The Westat evaluation team attempted phone interviews with each caregiver three times: (1) baseline in Winter 2016, (2) 6-month follow-up in Summer 2017, and (3) 12-month follow-up in Winter 2017.

Caregiver Outcome Measures

The caregiver survey collected information about caregivers' health and well-being, referred to as outcome measures in this evaluation. The measures are self-reported; thus they are subjective and not clinical assessments. However, for the longitudinal analysis, the self-reported measures are adequate to measure person-level change. Three of the five measures are composite measures, which means several items are grouped to make one score. The items comprising the composite measures come from instruments that are nationally known and have been tested for validity, meaning they adequately measure the construct being measured. The five key outcome measures used in this evaluation are reported in the next subsections.

PROMIS Mental Health and Physical Health Measures

To measure mental and physical health, the survey included the 4-item PROMIS Global Mental Health items and the PROMIS Global Physical Health score collected by the Adult PROMIS SF v1.1 Global Short Form (Hays et al., 2009). For the PROMIS measures, higher scores indicate better health.

The **PROMIS Mental health** score is the sum of four items measuring different aspects of caregiver's mental health, each with a scale of 1 to 5. The items include:

1. Perception of quality of life;
2. General rating of self-perceived mental health, including mood and ability to think;
3. Satisfaction with social activities and relationships and
4. Frequency of being bothered by emotional problems such as feeling anxious, depressed, or irritable.

The **PROMIS Physical health** score is the sum of four items assessing different aspects of caregiver's physical health on a scale of 1 to 5. The items include:

1. General rating of physical health;
2. Perceived ability to carry everyday physical activities such as walking, climbing stairs; carrying groceries, or moving a chair;
3. Average fatigue rating; and
4. Average pain rating.

Zarit Caregiver Burden

To measure burden, the evaluation used the Zarit Burden Inventory (ZBI) with four items that are summarized into one score. In 1980, Dr. Steven Zarit developed ZBI to measure caregiver subjective perceptions of burden (Zarit et al., 1980). ZBI items are assessed on a 5-point Likert scale, with higher scores indicating greater burden.

The items that make up the **Zarit Caregiver burden** score are:

1. Having sufficient time for self;
2. Feeling stressed between caregiving and other responsibilities;
3. Feeling strained when around the CR; and
4. Feeling uncertain about what to do about the CR.

Caregiver Satisfaction and Caregiver Confidence

Caregiver satisfaction was a single item measuring the caregiver's level of agreement with the following statement: "*I get a great deal of satisfaction from being a caregiver.*" Responses ranged from 1 to 5 with higher scores indicating stronger agreement.

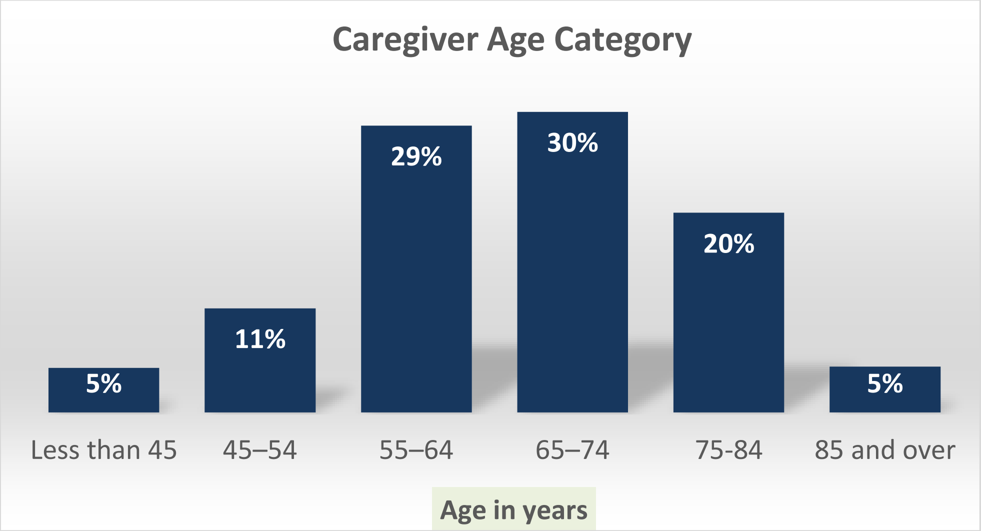
Caregiver confidence was also a single item that asked "*Overall, how would you rate your confidence as a caregiver? Would you say very confident, somewhat confident, a little confident, not very confident, or not at all confident?*" Responses ranged from 1 to 5 with higher scores indicating more confidence.

Results and Key Findings

A. Participant Characteristics

Analysis of the baseline responses among 1,568 caregivers was used to characterize the evaluation's caregivers and CRs. The mean age of the caregivers was 66. Figure ES-1 shows the breakdown of caregivers by age category.

Figure ES-1. Distribution of age category among caregivers



Other characteristics among the 1,568 baseline caregivers in the evaluation include:

- 79 percent White and non-Hispanic
- 2 percent Spanish-speaking

- 73 percent female
- 44 percent were children of the CRs (including in-laws); 43 percent were spouses
- The average number of years that the caregivers have been caregiving is 7 years
- The average number of hours a day that the caregivers "help the CR" is 9 hours
- 16 percent responded that caregiving was "very difficult" emotionally
- 7 percent responded that caregiving was "very difficult" physically
- 34 percent worked for pay in the past year
- 70 percent responded that they get a great deal of satisfaction from caregiving
- 83 percent receive caregiving help from family members, friends, or neighbors
- 48 percent receive caregiving help from an agency (including NFCSP) or a private provider

B. Caregiver Use of NFCSP Services

At baseline, 43 percent (N = 522) of NFCSP client caregivers said they received respite care from their AAA in the past 6 months—mainly in their home. Among those, the median number of NFCSP respite hours used each week was six. Twenty-four percent (N = 298) of NFCSP client caregivers said they received caregiver education/training, individual counseling, or support group services[3] in the past 6 months. Among them, support group services (52%) had the most utilization, followed by caregiver education or training such as classroom or online courses (36%), and individual counseling (24%).

Among NFCSP client caregivers who said they did not use NFCSP respite care in the past six months, approximately one-third said they did not use respite because they did not know about the service from the agency. The next most common reason for not obtaining needed respite care was that the caregiver did not qualify for the service. The third most common reason was that the caregiver did not need the service. Among NFCSP client caregivers who said they did not use NFCSP educational services, approximately half said they did not know about the service from the agency. The next most common reason for not obtaining educational services was that they were unable to attend.

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[3] Education/training, individual counseling, and support group services are hereafter referred to as "educational services" in this report.

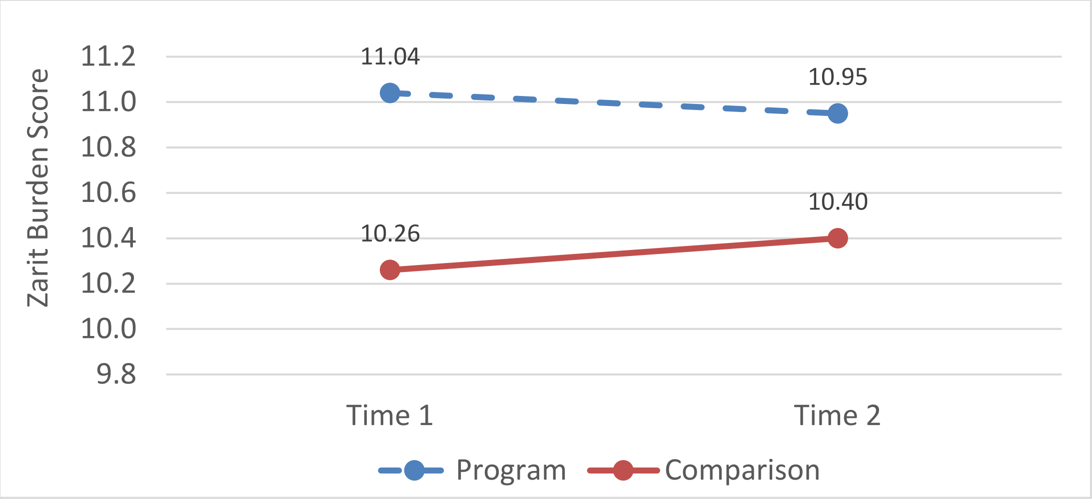
C. Effect of NFCSP Services on Caregiver Outcomes

To examine the effect of NFCSP services on the five caregiver outcomes, Westat conducted a series of difference-in-differences (D-i-D) analyses. This type of analysis looks at the change in outcomes across time for the Program caregivers (N = 491) versus the Comparison caregivers (N = 417).[4]

Caregivers who received 4 or more NFCSP respite care hours per week reported a decline in caregiver burden over time.

One key finding from the longitudinal D-i-D was that, on average, Program caregivers who received 4 or more hours of respite care per week had a decrease in self-reported burden over time, while the Comparison caregivers experienced an increase in self-reported burden. As shown in Figure ES-2, while caregiver self-reported burden became greater for the Comparison caregivers from Time 1 to Time 2 (+ 0.145 points), the burden for the Program group decreased (- 0.095 points).

Figure ES-2. Changes in adjusted mean Zarit Caregiver Burden scores for Program and Comparison caregiver groups



Previous studies have found that both respite care and caregiver emotional support can reduce burden among caregivers (Griffin et al., 2013). This finding suggests that caregiver burden may be particularly sensitive to the amount of respite care received and that there may be a certain minimum amount of respite care needed to reduce caregiver burden (Brock et al., 2011).

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[4] For detailed information regarding comparison group matching and the D-i-D analysis, refer to Appendix C: Evaluation Methodology.

Caregivers who utilized NFCSP educational services showed increased confidence with caregiving over time.

The second key finding of the D-i-D evaluation was an increase in Caregiver confidence among Program caregivers who used NFCSP educational services. More specifically, Program caregivers who attended at least one education/training, counseling, or support group session during the course of the evaluation experienced an increase in self-reported caregiver confidence over time. In contrast, Comparison caregivers who did not receive any NFCSP educational services showed a decrease in their mean confidence scores. This finding is consistent with evidence from previous studies that found education and supportive therapy to be effective in increasing caregiver confidence (Vandepitte et al., 2016). Caregivers confident in their capability to provide care may be more likely to engage in caring for CRs with complex medical needs (Vellone et al., 2015) and may have a positive effect on CR ADL performance (Li & McLaughlin, 2011), thus underscoring the importance of programs that successfully increase caregiver confidence.

While the evaluation found improvements in Caregiver burden and Caregiver confidence for Program caregivers, there was no such effect found for NFCSP services on caregiver mental health, physical health, or satisfaction. One interpretation could be that NFCSP services are not designed to address the caregiver's physical health, including chronic conditions and pain (Ivey et al., 2017; Polenick et al., 2017). Another possibility is that the evaluation duration may not have been sufficient to capture changes in mental and physical health. Unlike the Zarit Caregiver burden score, the PROMIS Mental health and Physical health measures were not developed to be caregiver specific, but rather as more general assessment instruments. Therefore, Zarit Caregiver burden scores may have been more sensitive than, for example PROMIS Mental health scores, in capturing the effects of NFCSP services such as respite hours. Finally, Caregiver satisfaction is a complex concept that could be affected by a myriad of factors unrelated to the use of support services.

D. Caregiver Perceptions of the Usefulness of NFCSP Services

When caregivers who used NFCSP respite were asked *"How helpful are the respite services from {Agency} to you as a caregiver?"* 98 percent of the caregivers said the service was either "very helpful" (86%) or "somewhat helpful" (12%). Similarly, among those caregivers who received educational services, 99 percent said the service was either "very helpful" (74%) or "somewhat helpful" (25%).

More use of NFCSP services was associated with caregivers' perception that the services definitely helped them continue caregiving.

In a more global question, caregivers were asked at baseline *"Have the services you received from {Agency} enabled you to provide care longer than would have been possible without these services?"* (referred to as **Continued caregiving**). The evaluation team found that, among caregivers who used NFCSP respite care, as the respite hours per week increased so did the probability of a more favorable response to the Continued caregiving item. The same relationship was found for educational services amount. These findings were the results of multivariable regression models that controlled for caregiver and CR characteristics.

E. The Intersection Between NFCSP Process and Outcomes

The Westat team investigated the relationship between program processes of the NFCSP and client-reported effectiveness of caregiver services using survey data collected in a previous evaluation from 43 AAAs combined with this evaluation's caregiver survey responses. The sample includes responses from 364 caregivers who received NFCSP caregiver services in the preceding 6 months from 43 AAAs. A multivariable regression model that controlled for daily intensity of caregiving and other caregiver characteristics was used to estimate the association between an AAA's frequency of assessing client satisfaction and the frequency of caregivers responding "Definitely yes" when asked if NFCSP services have enabled them to continue caregiving longer. Findings show that the percentage of caregivers who responded "Definitely yes" was higher within AAAs that assessed client satisfaction more often than annually than for AAAs with less frequent assessments (65.7% versus 45.0%, respectively; p = 0.0085). This finding suggests that agencies with a process to assess caregiver/client satisfaction more often than annually have, on average, NFCSP clients who have a more favorable perception of the benefits of NFCSP caregiver services for Continued caregiving.

The association between assessment and reassessment by the AAAs and Caregiver burden was also investigated. This analysis included response data from 54 AAAs combined with outcome scores from 458 caregivers who received NFCSP respite care and/or educational services from those AAAs. Significantly higher Caregiver burden scores were found among the caregivers from AAAs that include the *impact of caregiving* in their needs assessment, in comparison to AAAs that do not include such evaluation (p = 0.02). This result suggests that agencies that focus on individual caregiver strain when assessing for need for services may better understand their clients' needs than agencies that do not have these processes.

F. Caregiver NFCSP Use and Socioeconomic Need

One of the key evaluation questions was to examine whether caregivers with more social or economic need were receiving the same amount of NFCSP services as those with less need. To accomplish this, the evaluation team created a Socioeconomic (SES) Need index as the sum of five caregiver characteristics selected to be as similar as possible to the greatest economic and social need indicators described in the Older Americans Act of 1965: older caregiver age, low income, minority status, limited English proficiency, and social isolation. The two NFCSP services of interest included the number of respite hours the caregiver received per week (range 0-60 hours), and the number of educational services the caregiver received or attended in the past 6 months (range 2-33 times).

The analysis found that caregiver SES Need index was not associated with the amount of NFCSP respite hours received nor the amount of educational services received. However, when exploring individual items related to Caregiver burden, the analysis revealed that NFCSP services were reaching the caregivers with more burden. For example, the following caregiver characteristics were significantly associated with the receipt of NFCSP respite care: older age, greater caregiving intensity, living with CR, CR being a spouse, CR having Alzheimer's disease or dementia diagnosis, and CR resisting aid.

G. Caregiver and Care Recipient Use of Home and Community-Based Support and Services

Another key evaluation question was to determine if caregivers using NFCSP services also receive other home and community-based support (HCBS) and services (e.g., home delivered meals, homemaker services, home modifications, legal assistance). There were no differences in receipt of the majority of HCBS between NFCSP and non-NFCSP caregivers. The evaluation team found that caregivers receiving other HCBS may become aware of and initiate NFCSP respite or educational services subsequently, either through discovery on their own or through introduction to the NFCSP caregiver services by the organization providing the other HCBS. By comparison, there is no clear suggestion that clients may receive other HCBS as a result of initiating NFCSP respite/educational services, although in this small sample the data appears to indicate that direction.

Conclusion

The outcome evaluation shows that NFCSP caregiver services are effective in reducing caregiver burden and in assisting caregivers to continue caregiving longer. The evaluation also found that the NFCSP is targeting caregivers with more caregiver burden. Consistent with other studies focused on caregiver services, the findings from this evaluation suggest that the amount of service matters and there may be certain amounts of respite care and educational services required to reduce caregiver burden. More research is needed to better understand how to determine the ideal amount of NFCSP support that makes a difference to improve caregiver outcomes and to increase their longevity as a caregiver.

1. Introduction

1.1 The National Family Caregiver Support Program

Established via the reauthorization of the OAA by the 106th U.S. Congress in 2000, the Title III-E National Family Caregiver Support Program (NFCSP) is a Federal program designed to support the needs of family or other informal caregivers as they lend assistance to aging adults, as well as grandparents and older relatives caring for minor children or adults with disabilities. The overarching goal of the NFCSP is to assist family and informal caregivers to help their loved ones remain in their homes and communities as long as possible.

The NFCSP is administered by the Administration on Aging (AoA) within the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services (DHHS). The annual appropriation for the program was approximately $180 million in 2018 (Dept. of Health and Human Services, 2018). States and territories receive funding based on the proportion of their population age 70 and older, and are required to offer the following five core services in partnership with Area Agencies on Aging (AAA) and local service providers:

- **Information for Caregivers about Available Services.** Caregivers can learn about a range of supports, resources, and services available.
- **Assistance to Caregivers in Gaining Access to Services.** Access assistance helps connect caregivers with services offered by private and voluntary agencies.
- **Individual Counseling, Support Groups, and Caregiver Training.** These services help caregivers better manage their responsibilities and cope with the stress of caregiving.
- **Respite Care.** Trained caregivers provide care for individuals, either at home or at adult day care facilities, so that caregivers can rest or attend to their own needs.
- **Supplemental Services.** Additional services may include transportation, home modifications, and medical equipment.

The NFCSP assists more than 700,000 caregivers annually (Administration for Community Living, 2018) in the following groups:

- 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;
- Older relative caregivers (not parents) age 55 and older providing care to children under age 18; and
- Older relative caregivers (including parents) age 55 and older providing care to adults ages 18 to 59 with disabilities.

The outcome evaluation described in this report focuses on the first two groups of caregivers.

1.2 NFCSP Evaluation

The outcome evaluation represents the second phase of a two-part evaluation of the NFCSP, with a specific focus on assessing the program's impact on caregivers receiving services and the CRs that they serve. The first evaluation phase (to finalize the overall evaluation methodology and conduct the process evaluation data collection, analysis, and reporting) was completed by The Lewin Group in 2016. The process evaluation focused on assessing services provided to caregivers of older adults by State Units on Aging, AAAs, and local service providers, and addressed these 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 meet caregivers' diverse and changing needs and preferences? What system must be in place to achieve this access?
- Has the program contributed to long-term care system efficiency? How is the NFCSP integrated or coordinated with other LTC programs and what is the effect?

The process evaluation found wide variations in caregiver assessment policies and practices across all levels of the NFCSP. The evaluation also found that fewer than half of AAAs use assessment data to prioritize who receives services, and concluded that there is room for improvement and for standardization among NFCSP AAAs and providers in assessing and reassessing the impact of caregiving on the caregiver's health and well-being (Shugrue et al. 2017). The Process Evaluation Final Report is publicly available on the ACL website (The Lewin Group, 2016).

The second evaluation phase, the outcome evaluation, was conducted by Westat from 2014-2018 and is the focus of this report. The outcome evaluation focuses on the collection of survey response data from a nationally representative sample of NFCSP client caregivers, a matched Comparison group of caregivers who did not receive NFCSP services, and a sample of CRs. Survey data collected in the outcome evaluation coupled with the data collected during the process evaluation allowed the investigation to determine what types of organizational structures, approaches, and strategies to deliver NFCSP services are associated with optimal participant-level outcomes. Together, the two phases result in an integrated evaluation that combines process and outcome evaluation information, and represent the first evaluation of the NFCSP since the program's inception.

1.3 Outcome Evaluation Objectives

The outcome evaluation provides an understanding of the NFCSP client service outcomes associated with a comprehensive and coordinated caregiver services and support system, including (but not limited to) stress reduction and maintenance of the care recipient (CR) in the community. The primary objective was to assess a series of target outcomes by comparing NFCSP participants to non-participants, to determine whether NFCSP caregiver service recipients:

- Cope better with the emotional, physical, and financial challenges of caregiving;
- Feel less depressed, anxious, and stressed due to their caregiving; and
- Report providing care longer than non-NFCSP caregivers, thus delaying or avoiding the need for their CRs to be placed in a nursing home or other institutional care setting.

The outcome evaluation also seeks to:

- Help ACL understand which kinds of services are most helpful for caregivers and identify any unmet needs of caregivers and gaps in support for them;
- Identify any NFCSP resources, organizational characteristics, and implementation practices that appear to contribute to positive outcomes for caregivers receiving the key NFCSP services of respite care and/or caregiver education/training, individual counseling, or support groups;[5] and

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[5] Education/training, individual counseling, and support group services are hereafter referred to as "educational services" in this report.

- Assess the impact of services on the ability of caregivers to continue providing home-based caregiving as needed; for example, by examining the relationship between self-reported caregiver measures of mental and physical well-being and the amount of caregiver services received.

To achieve these objectives, 1,250 NFCSP client caregivers and a matched Comparison group of caregivers not receiving NFCSP services were participated in the evaluation. Survey instruments were administered to members of the Program and Comparison groups via telephone interviews at three time points: baseline, 6 months after the initial interview, and 12 months after the initial interview. While the outcome evaluation focused primarily on the NFCSP's impact on caregivers, the evaluation also included a short survey of the CRs to ascertain awareness and perceived impact of NFCSP services on their caregivers.

An additional objective of the outcome evaluation was to examine the relationship between NFCSP client outcomes and key processes and characteristics of the AAAs managing and/or providing NFCSP services.

1.4 Evaluation Questions

The outcome evaluation was designed to help ACL answer the following four key evaluation questions:

- **Evaluation Question #1 (EQ1).** In conjunction with information from the process evaluation (conducted in Phase 1), what types of organizational structures and/or approaches for NFCSP services are associated with the best participant-level outcomes?
- **Evaluation Question #2 (EQ2).** Are services reaching the groups targeted by the OAA, including caregivers serving older adults with greatest social or economic need?
- **Evaluation Question #3 (EQ3).** To what extent do NFCSP services participants also receive other home- and community-based long-term support and services, and what is the relationship among these services?
- **Evaluation Question #4 (EQ4).** To what extent do NFCSP program participants' outcomes differ from those of caregivers who do not receive support and services from the NFCSP?

1.5 Organization of the Report

The chapters that follow describe the methods used for the data collection and analysis and present the results of the outcome evaluation. Chapters 2 and 3 discuss the survey methodology, including the survey instrument, sampling, and participant recruitment. Chapter 4 gives an overview of analysis methods. Chapter 5 provides descriptive statistics about caregivers' demographics, service use, and other characteristics from the caregiver survey, as well as detailed information about the caregivers' CRs. Chapter 6 explores organizational-level characteristics of AAAs that are associated with optimal caregiver outcomes (EQ1). Chapter 7 presents findings about service utilization as it relates to the targeted need of specific populations (EQ2), barriers to receiving services, and caregivers' utilization of other non-NFCSP services in addition to NFCSP services (EQ3). Chapter 8 presents detailed tables describing findings of the comparative analysis of outcomes between caregivers receiving NFCSP services and caregivers not receiving NFCSP services (EQ4). Chapter 9 presents results of the care recipient (CR) survey, and Chapter 10 summarizes the overall findings of the outcome evaluation. Throughout the report, there are sections that present results from a detailed analysis. These sections end with "What Do These Results Mean?"

The appendices present the survey instruments, methodology, and detailed data tables. Appendix A contains the caregiver survey instrument and Appendix B contains the care recipient survey instrument. Appendix C includes the detailed methods behind the sampling, recruitment, data collection, and analysis. Appendix C also includes lessons learned by the evaluation team during the outcome evaluation that may have utility for future evaluation and data collection efforts. The remaining appendices present data frequency tables for the caregiver baseline survey (Appendix D), additional items in the caregiver 6-month survey (Appendix E), and the care recipient survey (Appendix F).

2. Survey Methodology

2.1 Survey Instrument Design

The telephone interview surveys used in the evaluation received clearance from the U.S. Office of Management and Budget (OMB) in March 2016 (OMB Control Number 0985-0052). Westat's Institutional Review Board (IRB) provided approval of the Caregiver Outcome Evaluation on August 3, 2016. As part of the initial IRB submission, Westat agreed to comply with all necessary precautions to ensure the privacy and anonymity of all data collected as a condition of OMB clearance and IRB approval. Non-substantive revisions to the survey before the 6-month follow-up received clearance from OMB in May 2017.[6]

2.1.1 Caregiver Survey Instrument

The caregiver survey instrument was initially developed in 2013 by The Lewin Group, based on questions from the following sources:

- National Survey of Older Americans Act Participants (NSOAAP);[7]
- National Health and Aging Trends Study (NHATS)/National Study of Caregiving (NSOC); and[8]
- National Survey of Older Americans Act Participants Performance Outcomes Measurement Project (POMP).[9]

Initial input for survey development was received from several State Units on Aging and, in 2013, a draft of the instrument was submitted to the Federal Register for public comment. A 60-day Federal Register Notice was published in the Federal Register Volume 78, No. 224, pages 69683-69684, on November 20, 2013. ACL received six sets of comments between November 20, 2013, and January 23, 2014, on topics including length and ease of the survey, participants' privacy, and terminology.

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[6] More detailed information about survey revisions is provided in Appendix C: Evaluation Methodology.
[7] Information available at Information available at https://agid.acl.gov/DataFiles/NPS/.
[8] Information available at https://www.nhats.org/scripts/QuickLinkNSOC.htm.
[9] Information available at https://www.acl.gov/programs/pomp.

In 2014, Westat enhanced the survey instrument by using a framework for detailing the components of caregiving activities and caregiver and CR outcomes (Van Houtven et al., 2011). The caregiver survey instrument is in Appendix A. The following briefly describes the sections of the caregiver survey instrument.

Survey Section A: Use of NFCSP Services for Respite and Educational Services

The section starts with a screener question; if the person is no longer the primary caregiver, additional questions attempt to learn why. Caregivers were asked how long they have been a caregiver for the CR. The caregivers were asked about caregiver support service use to understand which respite services and educational services a caregiver received from NFCSP in the past 6 months, from other organizations, or informally. Additional items ask about the helpfulness of services through NFCSP and other organizations.

Survey Section B: Caregiving Tasks, Frequency, and Intensity

This section asks about caregiving activities as listed in the NSOAAP. Caregiving intensity is an important element of the caregiver experience (Wolff et al., 2016) and scaled response levels make it easier to detect change in intensity of caregivers' activities over time. Therefore, to better measure change in outcomes longitudinally, Westat replaced "yes"/"no" responses with a scale. For example, responses related to the frequency of caregiving activities are: "daily," "several times a week," "once a week," "several times a month," "once a month," and "do not provide this help."

Survey Section C: Knowledge and Use of Formal Services Available

This section includes questions about caregivers' receipt of support services from any paid agency, caregivers' need for services, and caregivers' perceptions about whether services help. The items in this section, as well as those in Survey Section A, help gauge (1) the extent of caregivers' receipt of NFCSP services and other services and (2) the association between receipt of NFCSP services and receipt of other services. This section includes a global question about getting help with caregiving and a question about the most helpful caregiver service.

Survey Section D: Caregiver Satisfaction and Other Aspects

This section includes items that measure caregiver burden, satisfaction from being a caregiver, and confidence in being a caregiver. These are three of the five key outcomes for the evaluation. For example, the NSOAAP found that 88 percent of NFCSP participants reported that receiving caregiver services help make them a better caregiver (Administration for Community Living, 2017). Thus, satisfaction and confidence can be considered measurable outcomes associated with a "better" caregiving experience. Lastly, this section includes an item about the caregiver's family beliefs with respect to caregiving as mentioned in previous studies (Rozario and DeRienzis, 2008; Aranda and Knight, 1997).

Survey Section E: Impact of Caregiving (Health, Social, and Financial)

The items in this section ask about the caregiver's mental and physical health—two of the five outcomes for this evaluation. Stress experienced by caregivers can lead to decline in mental or physical health, which in turn can result in the relinquishment of caregiver activities or institutional placement of the CR (Pearlin et al., 1990). This section also includes questions about caregiver employment and financial status.

Survey Section F: Delayed Institutionalization and Continued Caregiving

This section asks the caregiver whether (1) the services that he/she has received from NFCSP have enabled him/her to provide care to the CR for a longer amount of time than if the caregiver had not received those services, and (2) the services have influenced whether the CR has been able to remain home longer than if they had not been provided.

Survey Section G: Caregiver and Household Demographics

This section includes basic demographic questions about the caregiver. In addition to being descriptive of the participants, the data collected about race, ethnicity, income, and years of education are also important as covariates for propensity score matching and subpopulation analysis.

Survey Section H: Caregiver Health Status and Healthcare Utilization

This section asks the caregiver about their hospitalizations, emergency department visits, nursing facility use, and services from a hospital outpatient department or ambulatory surgical center during the past 6 months. One item asks the caregiver about his/her overall health status.

Survey Section I: Caregiver Report of Care Recipient's Demographics, Health, and Function

In this section, the caregiver is asked about the CR's demographics, behaviors, activities of daily living (ADLs), chronic disease conditions, and healthcare utilization. This section employs the same list of ADLs and instrumental ADLs found in NSOAAP and in NSOC's chronic disease list.

2.1.2 Care Recipient Survey Instrument

Westat developed a brief survey instrument containing a set of questions for the CRs of the caregivers. The survey included questions about the CR's well-being (4 items); their perception of the importance of having a caregiver, which allows him/her to live at home; and their perception of whether his/her caregiver is receiving all the help he/she needs from family, friends, or an organization.

Interviewers asked permission from the NFCSP client caregivers to contact interview their CRs; however, 49 percent declined. When the initial call was placed to the CR for the Comparison group, the priority of the interview was to collect the information to further contact their caregiver. (See Appendix C: Evaluation Methodology for more detail about Comparison group recruitment.) The care recipient survey instrument is in Appendix B; baseline frequencies for all care recipient survey variables are in Appendix F; and results are reported and discussed in Chapter 9.

2.2 Telephone Interviewing for Data Collection

Westat utilized computer-assisted telephone interviewing (CATI) technology to conduct the surveys and to collect the response data. To reduce the burden for the respondents, Westat scheduled appointments for calls at times that were convenient for respondents. The use of the CATI system in combination with Westat's highly structured telephone interviewer training and procedures ensured that interviewers conducted the surveys in a professional, controlled, and consistent manner. (More details about Interviewer Training is in Appendix C: Evaluation Methodology.)

3. Evaluation Participants and Survey Implementation

3.1 Sampling and Recruitment

To identify a sample of NFCSP clients, the sample design for the evaluation was based on a two-stage stratified probability sample of AAA clients who were listed as recipients of NFCSP services. The first stage was a stratified sample of AAAs across the nation selected for the 11th NSOAAP that took place only months before this evaluation's first baseline interview.

Table 3-1 shows the agency distribution in the frame and the originally selected sample by Census Region.

Table 3-1. Distributions of agencies in the sample frame and final sample

Census region	Number of AAAs in the frame	Number of AAAs in the sample
Northeast	171	85
Midwest	104	62
South	229	108
West	124	61
Total	**628**	**316**

The second stage consisted of a systematic random sampling of NFCSP clients within the 316 sampled AAAs. The target sample size was set to 22 clients for AAAs that had details about the services received by the clients and 27 for AAAs that did not have that detail. In addition, for the 41 largest AAAs (sampled with probability 1), the targets were adjusted by a function of the measure of size of the AAA. To reduce interview burden on individuals, the sampled caregivers from AAAs in the 11th NSOAAP were deleted from the evaluation client list so that they could not be sampled again as a participant for this evaluation.

To best measure the effect of NFCSP services on caregiver outcomes, a "Comparison group" of caregivers was needed. The Comparison caregivers were identified through their CRs. More specifically, response data were used from AAA clients in the 11th NSOAAP who did not receive caregiver services (but received the OAA services of case management, homemaker, transportation, congregate nutrition, or home-delivered nutrition), and who reported that they needed help with ADLs (eating, bathing, dressing, toileting, walking, continence), suggesting that they may have a family caregiver.

Figure 3-1 depicts how caregivers and CRs were included as participants in the evaluation.

Figure 3-1. Flow chart of evaluation participants

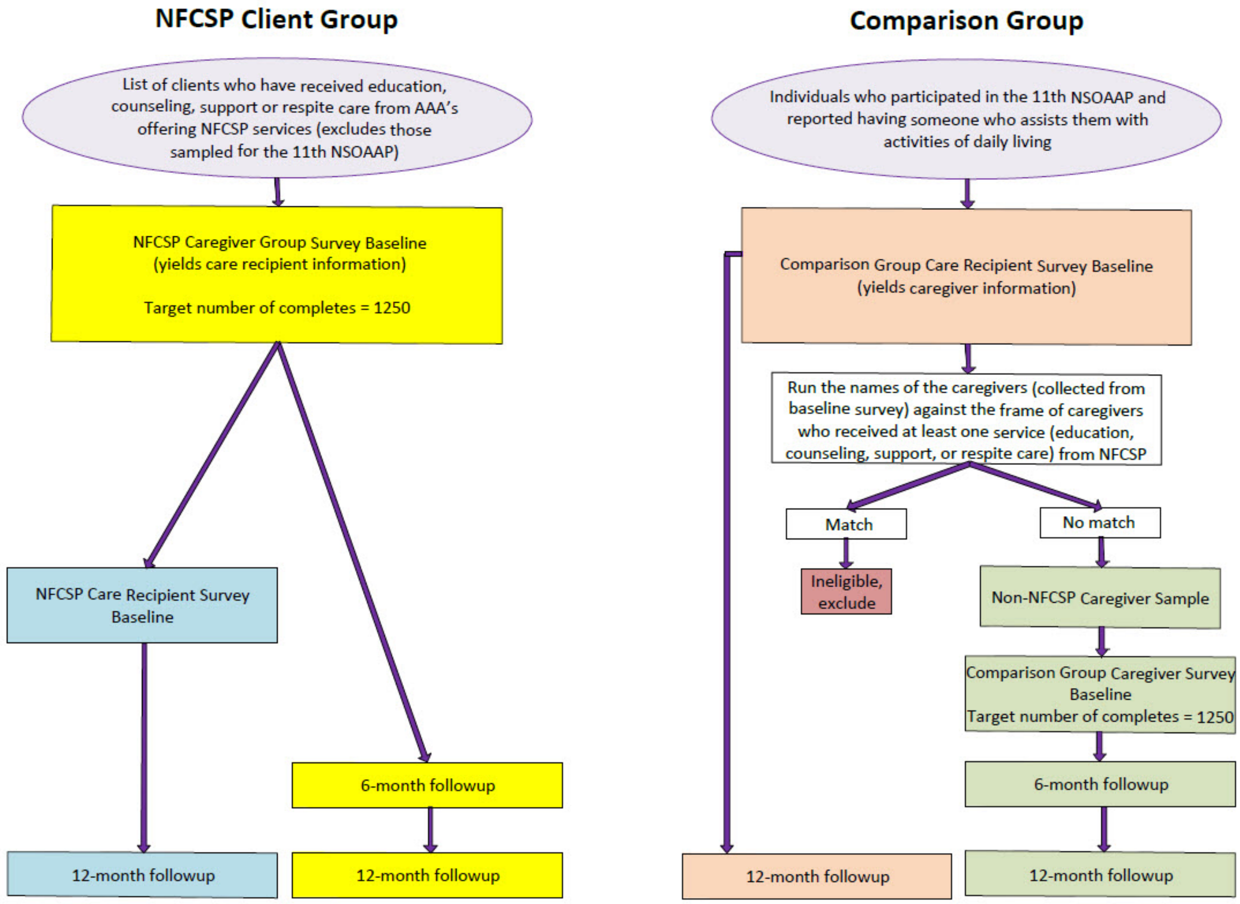

Table 3-2 shows the three interview timeframes for the evaluation. Westat attempted to interview the caregivers three times and the CRs twice. If a caregiver dropped out of the evaluation/study or became ineligible, the CR was also removed as an active participant.

Table 3-2. Interview timeframes and brief description of interview process

	Start and end dates	Who was called for interview from the list of AAA NFCSP clients	Who was called for interview from the Comparison group
Baseline	November 21, 2016 – January 5, 2017	All listed clients/caregivers. Asked permission to interview CR.	CRs interviewed (if possible) and caregiver information obtained for caregiver interview.
6-month follow-up	May 22, 2017 – July 3, 2017	Caregivers who completed baseline.	Caregivers who completed baseline.
12-month follow-up	November 27, 2017 – January 5, 2018	Caregivers and their consented CRs who completed baseline and were still eligible.	Caregivers and their consented CRs who completed baseline and were still eligible.

3.2 Survey Response Rates and Evaluation of Participant Retention

For baseline interviews that took place from November 2016 to early January 2017, the sample frame of caregivers called was 6,749. Twenty-five percent (N = 1,659) of the caregiver sample frame was ineligible because they told the interviewer that they were not a caregiver. This includes persons who may have been a caregiver but the CR was deceased or institutionalized or, in some cases with the Comparison group, the called caregiver was a formal "paid" caregiver or home health aide. The target number of completed caregiver interviews at baseline was 2,500. The actual number of completed caregiver interviews was 1,568, resulting in a completion rate of 63 percent. This was due to difficulties in identifying Comparison group caregivers. Table 3-3 provides information about baseline response rates and the percentage of caregivers who did not want to participate in the evaluation.

Description of Statistics in Table 3-3

- In-scope sample frame = the number of individuals in the sample frame minus those who were ineligible (i.e., not caregivers).
- In-scope response rate is the number of completed surveys divided by the in-scope sample frame. For Comparison CRs, the in-scope response rate is the number of individuals who provided caregiver contact information divided by the in-scope sample frame of eligible CRs.
- Opt-out rate = the number of individuals who responded during the baseline interview period that they did not want to be in the study, divided by the sample frame. This does not include individuals who called Westat to opt out after receiving the recruitment letter but before the start of the interview period.

Table 3-3. Baseline in-scope response rates and opt-out rates

Statistic	AAA-provided NFCSP clients		Comparison group	
	Caregivers	CRs	Caregivers	CRs
In-Scope Sample Frame	4,355	532	735	1,626
In-Scope Response Rate	28.8%	61.7%	44.4%	55.0%
Opt-Out Rate	6.7%	5.5%	7.4%	3.6%

In total, 1,152 caregivers participated in interviews two or more times. During the 6-month interview timeframe, Westat interviewed a total of 1,005 caregivers of the 1,553 who were called. During the 12-month interview timeframe, Westat interviewed 794 caregivers, of the 1,231 who were called. At either follow-up timeframe, there were 379 caregivers who became ineligible and could not take the full survey.

A pre-notification letter and an information brochure were mailed to potential evaluation participants before each interview timeframe. Before the 12-month follow-up interviews, Westat conducted aggressive tracing efforts to obtain contact information on caregivers who were not reached at 6 months. Each remaining caregiver participant was mailed a notification letter and a glossy newsletter with feedback on preliminary statistics from the baseline interviews. Also included in the letter was a "thank you" magnet for each caregiver.

More detailed information about sampling, recruitment, response rates, and retention efforts can be found in Appendix C: Evaluation Methodology.

4. Analysis Methods

4.1 Quantifying the Use of NFCSP Services and Group Assignment of Caregivers

To understand the use of NFCSP services, caregivers were asked the following questions with a "yes"/"no" response:

- *In the past 6 months, have you received caregiver education, training, counseling, or support group services from the provider agency?*
- *In the past 6 months, have you received respite care from the provider agency?*

Each question led with "in the past 6 months" because the two follow-up interviews were done approximately 6 months apart and the aim was to capture only the service use after the previous interview. When a caregiver said "yes" to one of these questions, the interviewer asked follow-up questions about the type of service and how often they received the service. At baseline, the above two questions were only asked of NFCSP client caregivers; however, they were asked of all caregivers at the 6-month and 12-month interviews.

At baseline, only 709 of the 1,242 NFCSP client caregivers (57%) said they used NFCSP respite or educational services in the past 6 months. Therefore, this evaluation, which required the use of a Comparison group, could not use *a priori* group assignments because the expectation was that NFCSP clients would have 100 percent service use. ACL and Westat decided to use responses to baseline and 6-month NFCSP service use questions to determine the grouping of caregivers as either a "Program" group or a "Comparison" group caregiver. Caregiver responses to these items were compared over time and any cases with responses that varied over time were investigated, including looking at the last time they received their "most helpful service" and closely reviewing their reported respite hours per week or the number of times they used educational services.

Among the caregivers who completed at least two surveys, 47 percent were assigned to the Comparison group because they did not use either service, were unsure about their use of these services, or they reported small amounts of service use at only one interview timeframe. About one-third of the original NFCSP client list caregivers were "switched" to the Comparison group. For example, at either baseline or 6 months, only 43 percent of the NFCSP client group said "yes" to receiving an educational service at either baseline or 6 months; 76 percent said “yes” to respite. The remaining caregivers who reported NFCSP service use were assigned to the Program group (N = 607). Two caregivers did not fit into either the Program or Comparison group as these two caregivers did not use any services at baseline or at 6 months, but had high utilization at the 12-month interview.

The caregiver grouping was necessary to perform the key evaluation analysis that estimates the effect of receiving NFCSP caregiver services on caregiver outcomes. The analysis used a technique called difference-in-difference modeling or D-i-D. The first step of the analysis was to match each Program caregiver with one or more Comparison caregivers who shared similar characteristics related to the propensity of receiving caregiving support, using a technique called propensity score matching. The D-i-D analysis included all caregivers who were called at follow-up and remained eligible to complete the full survey (Program group = 491 and Comparison group = 417). The D-i-D results are described in Chapter 8 of this report.

This evaluation also measured the amount of NFCSP caregiver services received. More specifically, information on respite care hours per week was collected with this question: *“How many hours per week of respite care do you usually receive through this program?”* Information on the amount of NFCSP educational services received in the past 6 months was collected with these questions:

1. *“In the past 6 months, how many times did you attend an individual caregiver education or training session?”*
2. *“In the past 6 months, how many individual counseling sessions did you receive?”*
3. *“In the past 6 months, how many caregiver support group sessions have you attended?”*

More detail about the service amount calculation can be found in Appendix C: Evaluation Methodology.

4.2 Constructing Key Caregiver Characteristic Variables

Throughout the evaluation, and especially for the D-i-D analysis (where Program and Comparison groups were matched by the propensity to receive caregiver services), the following variables were constructed:

a. **Caregiving Intensity.** The sum of five ADLs with which the caregiver provided assistance daily (eating, dressing, toileting, and mobility), or daily/several times a week (bathing), with greater values indicating greater intensity. This measure could also be represented as a percentage of the aforementioned five activities.

b. **Caregiver Race.** Categorical variable capturing whether the caregiver was White, Black/African American, or other. Caregivers who reported their race as only White and did not select other races were classified as White. Caregivers who reported being African American and no other race were classified as Black/African Americans. All other caregivers were classified as belonging to "other" racial group, which included all other races and individuals who selected multiple racial categories.

c. **Caregiver Annual Income.** Categorical variable assessing the caregiver's annual income (1 = 11,500 dollars or less; 8 = More than 70,000 dollars). If the annual income was missing but monthly income was available, the annual income was supplemented with appropriately converted monthly income.

d. **Caregiver Education Level.** Binary variable assessing caregiver's education level (0 = Less than HS graduate, 1 = HS graduate or above).

4.3 Description of Caregiver Outcome Measures

The caregiver survey collected information about caregivers' health and well-being, referred to as outcome measures in this evaluation. These outcomes were collected at all three data collection points: baseline, 6-month follow-up, and 12-month follow-up. Collecting these outcomes at three points in time made it possible to observe changes in the outcomes for Program caregivers and Comparison caregivers over time. The five outcome measures are self-reported; thus, they are subjective and not clinical assessments. Three of the five measures are composite measures, which means several items were grouped to make one score. The items comprising the composite measures come from nationally known and tested instruments.

The mental and physical health items are drawn from the Adult Patient Reported Outcomes Measurement Information System (PROMIS®) Global Short Form (SF) v1.1 (Hays et al., 2009). Funded by the National Institutes of Health, PROMIS is a system of valid and reliable self-reported measures of health and well-being.[10] PROMIS measure sets are feasible and reliable for tracking change in caregiver outcomes (Shin et al, 2018; Carlozzi et al., 2018). The PROMIS Global SF uses a 5-response scale (from excellent to poor) and provides standardized scoring for mental and physical health.

The PROMIS **Mental health** score is the sum of four items measuring different aspects of caregiver's mental health on a scale of 1 to 5, with higher scores indicating better mental health. The four items include:

1. Perception of quality of life;
2. General rating of self-perceived mental health, including mood and ability to think;
3. Satisfaction with social activities and relationships; and
4. Frequency of being bothered by emotional problems such as feeling anxious, depressed, or irritable.

As shown in Table 4-1, the average composite PROMIS Mental health score was 12.54. The item with the lowest mean score was Satisfaction with social activities and relationships.

Table 4-1. Baseline means for PROMIS Mental health score and individual components

Measure	Mean (SD) (N = 1,568)
PROMIS Mental health score	12.54 (3.34)
Mental health rating	3.26 (0.98)
Quality of life rating	3.01 (1.04)
Social activities rating	2.82 (1.10)
Frequency of emotional problems	3.45 (1.07)

The PROMIS **Physical health** score is the sum of four items assessing different aspects of caregiver's physical health on a scale of 1 to 5, with higher scores indicating better physical health. Items include:

1. General rating of physical health;
2. Perceived ability to carry out everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair;
3. Average fatigue rating; and

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[10] Surveys available at http://www.healthmeasures.net/explore-measurement-systems/promis.

4. Average pain rating.

Table 4-2 shows that the average composite PROMIS Physical health score was 14.13. The lowest scoring item was the General rating for physical health.

Table 4-2. Baseline means for PROMIS Physical health score and individual components

Measure	Mean (SD) (N = 1,568)
PROMIS Physical health score	14.13 (3.15)
Physical health rating	2.99 (1.04)
Physical activities rating	4.02 (1.07)
Pain rating	3.66 (1.07)
Fatigue rating	3.44 (0.92)

To measure **Caregiver burden,** the evaluation used a 4-item version of the Zarit Burden Inventory (ZBI). In 1980, Dr. Steven Zarit developed the ZBI to measure caregiver subjective perceptions of burden among ethnically diverse populations (Zarit et al., 1980). ZBI items are assessed on a 5-point Likert scale, with higher scores indicating greater burden. In 2001, a 4-item version of ZBI was found to correlate well with the full 22-item version. The widely used, simple, 4-item screen has proven to be valid and reliable (Bedard et al., 2001).

For this measure, a lower score is better and the score can range from 4 to 20. The questions include:

1. Do you feel that because of the time you spend with the care recipient, you don't have enough time for yourself?
2. Do you feel stressed between caring for the care recipient and trying to meet other responsibilities (work/family)?
3. Do you feel strained when you are around the care recipient?
4. Do you feel uncertain about what to do about the care recipient?

As shown in Table 4-3, the average self-reported Caregiver burden was 10.70. The item with the highest mean score associated with more burden was Feeling stressed between caregiving and meeting other responsibilities.

Table 4-3. Baseline means for Zarit Caregiver Burden score and individual Zarit Burden Inventory components

Measure	Mean (SD) (N = 1,568)
Zarit Burden score	10.70 (3.48)
Time for self	2.98 (1.18)
Feeling stressed	3.07 (1.18)
Feeling strained	2.40 (1.12)
Feeling uncertain	2.24 (1.06)

Caregiver satisfaction was collected through a single item measuring the caregiver's level of agreement with the following statement: "*I get a great deal of satisfaction from being a caregiver.*" Responses ranged from 1 for "strongly disagree" to 5 for "strongly agree." The baseline mean Caregiver satisfaction score was 3.86.

Caregiver confidence was also collected through a single item that asked *"Overall, how would you rate your confidence as a caregiver?"* Responses ranged from 1 for "not at all confident" to 5 for "very confident". The baseline mean Caregiver confidence score was 4.45. This high level of confidence may stem from the fact that only 4 percent of the caregivers had less than 1 year of caregiving experience.

5. Descriptive Statistics from the Caregiver Survey

5.1 Caregivers

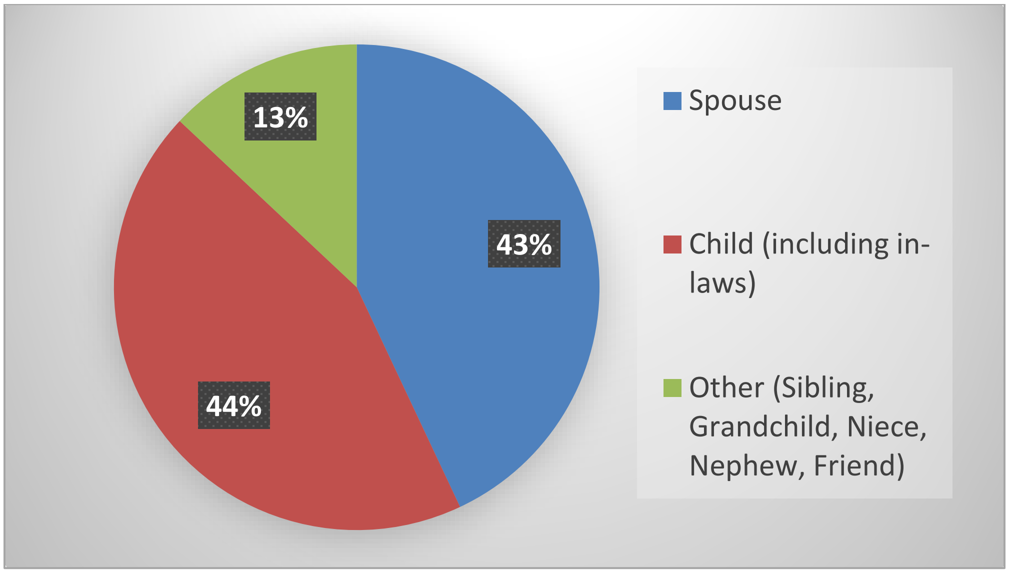
Baseline frequency tables of all items asked in the Caregiver Survey can be found in Appendix D. The sections that follow present descriptive statistics about the caregivers who participated in the evaluation.

5.1.1 Baseline Caregiver Demographics

A total of 1,568 caregivers participated in this evaluation. The caregivers resided in 43 different states in the U.S. The seven states with the most representation are Florida (130 caregivers), Massachusetts (102), Ohio (100), California (84), Georgia (74), Washington (73), and Texas (70). The distribution of states is in Appendix D. Only 11 percent of the caregivers lived in a zip code categorized as rural.

As shown in Figure 5-1, most of the caregivers were either the spouse or an adult child of the CR. Among the 689 child caregivers, the majority (79%) were a daughter or a daughter-in-law.

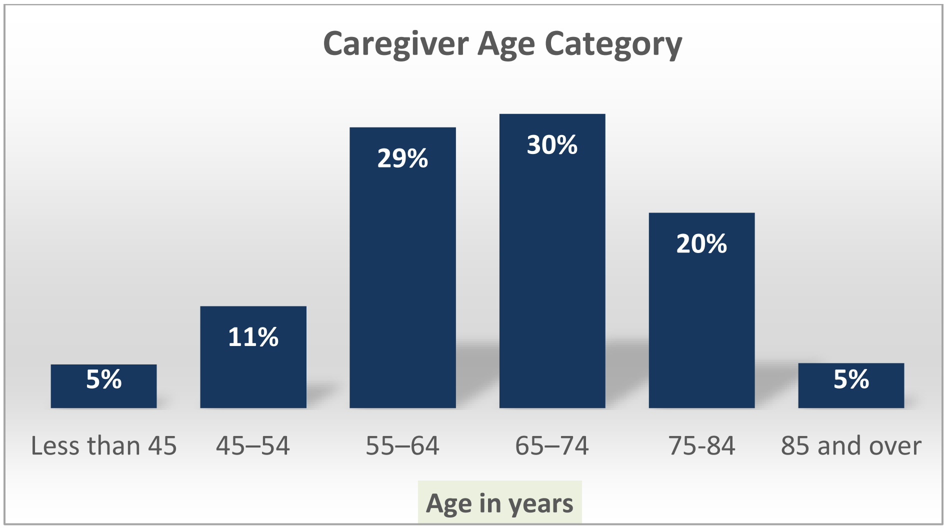
Figure 5-1. **Caregiver relationship with CR**



Adult child caregivers were asked *"Does this statement fit your belief: 'You were chosen by your family as a child to provide care for all your family members'?"* Twenty-nine percent said "definitely true," 25 percent answered "somewhat true," 10 percent answered "somewhat false," and 37 percent answered "definitely false."

As shown in Figure 5-2, the majority of the caregivers were between the ages of 55 and 74. The mean age was 66, and 55 percent were age 65 or older.

Figure 5-2. Distribution of caregiver age (N = 1,568)



Seventy-nine percent of caregivers were White, 17 percent Black, and 4 percent other. At baseline, the interview was conducted in Spanish for 37 caregivers (2.4%).

5.1.2 Caregiving Tasks, Frequency, and Intensity

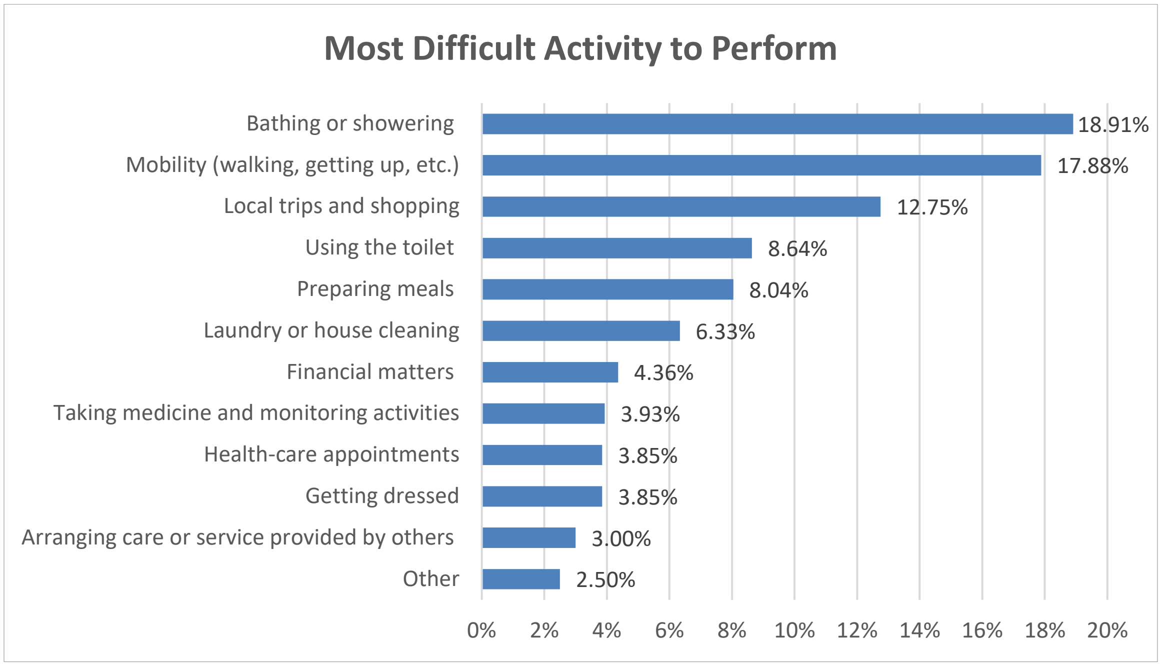
Table 5-1 shows the tasks that the caregivers perform to help the CRs. At least half of the caregivers helped CRs on a daily basis with activities, such as preparing meals (74%); taking medicine (64%); doing laundry or cleaning the house (54%); and keeping track of bills, insurance issues, or other financial matters (50%). Many of the caregivers helped with getting dressed (45%) and mobility (44%) on a daily basis. Thirty-six percent of the caregivers helped with eating on a daily basis.

Table 5-1. Frequency of caregivers' help with care recipients' activities

Activities	Daily	Several times a week	Once a week	Several times a month	Once a month	None of the time
Medical or Health Care						
Taking medicine, giving shots, using monitors or meters	64.2%	3.5%	4.4%	2.4%	1.3%	24.2%
Wound care, including ostomy care and changing bandages	14.7%	3.4%	2.1%	2.5%	4.0%	73.3%
Medical equipment such as dialysis or ventilators	9.2%	2.1%	0.5%	0.5%	0.7%	87.0%
Setting up health care appointments and speaking with doctors or other providers	26.3%	10.6%	7.3%	23.0%	19.5%	13.4%
Personal Care						
Dressing	45.0%	13.1%	3.2%	3.7%	2.7%	32.0%
Eating	36.3%	5.4%	1.1%	1.1%	0.5%	55.6%
Toileting	32.7%	4.8%	0.8%	1.4%	1.0%	59.2%
Bathing or Showering	21.5%	19.4%	7.9%	2.9%	1.5%	46.8%
Mobility						
Mobility, such as walking, getting out of bed, or standing up from a sitting position	43.9%	15.1%	3.7%	6.0%	3.7%	27.6%
Transportation						
Local trips, such as going shopping or to the doctor's office	21.0%	29.0%	15.0%	8.0%	10%	8.0%
Other						
Preparing meals	74.0%	8.5%	2.2%	2.8%	1.2%	11.0%
Doing laundry or cleaning the house	54.0%	20.0%	9.4%	3.6%	1.7%	11.6%
Keeping track of bills, insurance issues, or other financial matters	49.9%	11.2%	5.2%	9.9%	9.5%	14.3%
Arranging for care or services provided by others	22.0%	14.0%	10.0%	12.4%	10.7%	31.1%

Following the questions about activities, the caregivers were then asked *"Which one activity do you consider to be the most difficult for you to perform?"* Figure 5-3 shows the frequency of the top twelve responses to the most difficult activity to perform. The caregiving activities deemed most difficult were bathing/showering and helping the CR with mobility.

Figure 5-3. Response frequencies to most difficult caregiving activity to perform



5.1.3 Caregiving Hours and Perceived Difficulty

Caregivers were asked about the hours that they spend helping their CR on a daily basis. The mean was 8.6 hours on a typical weekday, and 9.0 hours on a typical weekend. Caregivers were asked "*In the last month, how often did helping care recipient cause your sleep to be interrupted?"* Frequencies were: 13.2 percent "every day," 9.9 percent "most days," 28.2 percent "some days," 26.5 percent "rarely," and 22.2 percent "never."

Caregivers were asked two items about their perceived difficulty of caregiving. Each of these items had a 4-item response option scale, where 1 was "not at all difficult," 2 was "a little," 3 was "somewhat," and 4 was "very difficult." The mean responses are shown in Table 5-2.

Table 5-2. Perceived difficulty of caregiving

	Mean	% Very difficult
How physically difficult would you say that caring for care recipient is for you?	2.2	7.3
How emotionally difficult would you say that caring for care recipient is for you?	2.4	15.7

5.1.4 Impact of Caregiving on Employment Situation

Caregivers were asked questions about their employment status and out-of-pocket financial demands associated with caregiving. The first question asked of all caregivers was *"Are you currently working for pay either full time or part time?"* At baseline, among the 1,568 caregivers, 468 (30%) said "yes." On average, this group of 468 working caregivers worked 33 hours per week. Of the 1,100 caregivers who said "no" to currently working, 2.3 percent said they never work and 97.3 percent said they stopped working (of which 6.5 percent said they stopped working within the past year and 90.8 percent said they stopped working over a year ago).

Of the 1,066 caregivers who stopped working within the past year or over a year ago, 27 percent said they stopped because of caregiving. Among caregivers who worked in the past year, three follow-up questions were asked about how caregiving impacted their employment. The responses to these follow-up questions are shown in Table 5-3. Two-thirds of working caregivers responded that caregiving caused them to go to work late, leave early, or take time off during their workday.

Table 5-3. Follow-up caregiver employment questions

Question	Who was asked	Number asked	% Yes
Did you stop working because of caring for care recipient?	Those who answered that they stopped working at any time.	1,066	27.1
As a result of your caregiving responsibilities, did you have to go in late, leave early, or take time off during the day to provide care?	Those who said they were working for pay in the past year or stopped working in the past year.	539	63.7
As a result of your caregiving responsibilities, did you have to take a leave of absence?	Those who said they were working for pay in the past year or stopped working in the past year.	539	16.0
As a result of your caregiving responsibilities, did you have to reduce your regular work hours, or take a less demanding job?	Those who said they were working for pay in the past year or stopped working in the past year.	539	24.9

Ninety-two caregivers also indicated that there was "other" impact on their employment. The two most common text responses for "other" impacts to employment were lower income and a negative impact on their work performance.

5.1.5 Caregiving Financial Impact

Caregivers who were not a spouse were asked about money they spent for the CR in the last year. As shown in Table 5-4, almost one-third of non-spousal caregivers spent their own money to purchase medications or pay for health care services for their CR. About one-fourth of caregivers had to pay for home improvements, and one-fifth paid to obtain an in-home helper.

Table 5-4. Non-spouse caregiver questions about money spent

Question asked of non-spouse caregivers (N = 890)	% Yes
Have you used your own money to pay for CR's medications or medical care?	32.4
Have you used your own money to pay for CR's Medicare premiums or copayments, or other insurance premiums and copayments?	13.0
Have you used your own money to pay for mobility devices for CR such as a walker, cane, or wheelchair?	14.1
Have you used your own money to pay for things that made CR's home safer, such as a railing or a ramp, grab bars in the bathroom, a seat for the shower or tub, or an emergency call system?	30.9
Have you used your own money to pay for any other assistive devices for CR that make it easier or safer for him/her to do activities on his/her own?	18.3
Have you used your own money to pay for an in-home helper for CR?	19.6

Lastly, all 1,568 caregivers, including spouses, were asked the following question *"How financially difficult would you say that caring for the care recipient is for you?"* Response options were "not very difficult" (1), "a little difficult" (2), "somewhat difficult" (3), and "very difficult" (4). The mean response was 1.86, indicating that, on average, caregivers felt that caring for the CR was "not very difficult" to "a little difficult." Only 9 percent said it was "very difficult."

5.1.6 Caregiver Healthcare Utilization

Maintaining healthy caregivers is critical in supporting CRs in the community. To determine their use of healthcare facilities potentially involving an extended time away from caregiving, caregivers responded to four questions about their use of healthcare facilities in the past 6 months. For example: *"During the past six months did you have to go to the emergency department?"* As shown in Table 5-5, at baseline, relatively few caregivers stayed in a hospital (10%) or skilled nursing facility (1%). Twenty percent of the 1,568 caregivers said they had to go to the emergency department and another 20 percent said they had to go to an outpatient hospital department or an ambulatory surgical center.

Table 5-5. Caregivers' use of healthcare facilities during the past 6 months

Facility	Number	Percent
Hospital	161	10.3
Skilled Nursing Facility	16	1.0
Emergency Department	307	19.6
Hospital Outpatient or Ambulatory Surgical Center	317	20.2

5.1.7 Why Caregivers Stopped Caregiving

Caregivers may stop caregiving for various reasons. At the start of each follow-up interview, if a caregiver said they were no longer the caregiver for the stated CR, the interviewer attempted to learn why. There were 1,154 caregivers who had a follow-up interview at 6 months and/or 12 months.

As shown in Table 5-6, 67 percent of the caregivers were still caregiving at the time of their last survey response (either 6 month or 12 month). Of those caregivers who were no longer caregiving and who provided a reason for stopping, one-third stopped caregiving mainly because of the CR's death or the CR's placement in a long-term care facility (also called "institutionalization").

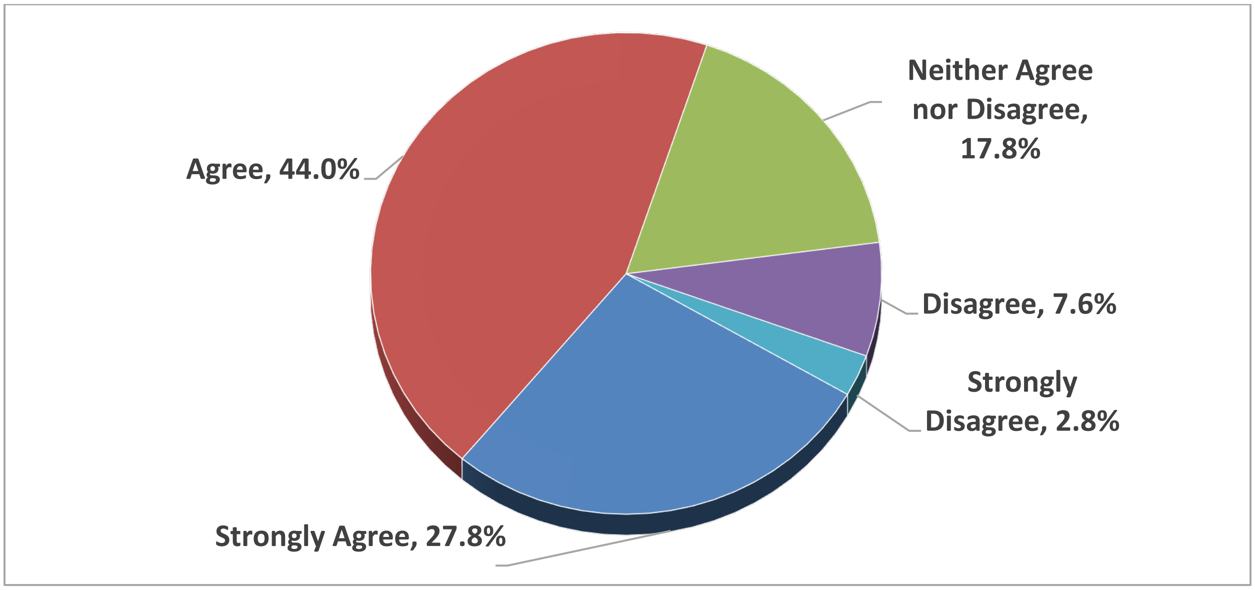
Table 5-6. Follow-up caregiving status and reasons for not still caregiving

	Number	Percent
Still Caregiving	775	67.2
No Longer Caregiving		
CR's death	149	12.9
Institutionalization	91	7.8
No longer care needed	9	0.8
Someone else caregiver	23	2.0
Other reason/Don't Know/Refused	19	1.6
Unknown/Non-response	88	7.6

5.1.8 Caregiver Satisfaction and Enjoyment

The survey instrument included a series of items on satisfaction with caregiving and the caregivers' perceptions of the extent to which CRs appreciated the care provided. Figure 5-4 shows the results of responses to the statement: *"I get a great deal of satisfaction from being a caregiver."* Slightly over 70 percent of the respondents "strongly agreed" (28%) or "agreed" (44%) with the statement.

Figure 5-4. Response frequencies to getting a great deal of satisfaction from caregiving



Caregivers also reported that helping CRs gave them satisfaction that the CR was well cared for. Eighty-four percent responded "very much," 15 percent responded "somewhat," and only 1 percent responded "not so much." As shown in Table 5-7, over 70 percent of the caregivers enjoyed being with the CR, and over 70 percent also reported that, from their perspective, their CR appreciated what was done for him/her.

Table 5-7. Enjoyment of caregiving and perspective of care recipients' appreciation

Question	A lot	Some	A little	Not at all
How much do you enjoy being with the care recipient?	72.3%	21.7%	4.6%	1.4%
How much does the care recipient appreciate what you do for him/her?	75.0%	15.7%	6.1%	3.6%

5.1.9 Caregivers' Use of Caregiver Support – All Sources

This section shows the results of survey questions about caregiver use of support services and the help they get for caregiving activities from members of the community, family, and private-pay home health aides. At baseline, all 1,568 caregivers were asked "*Do you have anyone who helps you with your caregiving activities for care recipient? This help could be paid assistance or help from a family member or friend.* Sixty-eight percent (1,065) said "yes."

As shown in Table 5-8, of those 1,065 caregivers, 88 percent said they receive the help from family members, friends, or neighbors, 49 percent said they receive help from an agency, private provider or housekeeper, and 13 percent received help from volunteers from a place of worship. These responses are not mutually exclusive, meaning that a person could have said "yes" to more than one source type.

Table 5-8. Help with caregiving activities by source type

Source type	Number	Percent
Family members, friends, or neighbors	936	88.0
Agency, private provider, or housekeeper	523	49.4
Volunteers from a house of worship	142	13.4

These results show that the majority of caregivers rely on their family members, friends, or neighbors for help with caregiving activities. The 12-month evaluation was too short to allow for examining patterns or exploring the trajectory of support sources among caregivers.

5.1.10 Caregivers' Use and Perceived Helpfulness of NFCSP Respite Care

Early in the telephone interview with the caregivers, the following statement was read to all NFCSP client caregivers, with {Agency} being the name of their specific AAA and with the name of their CR replacing {care recipient}.

"I'd like to ask you some questions about the Family Caregiver services that you receive from {Agency}. These are services that help you provide care at home for {care recipient}. For example, caregiver services can be:

- *Information about available services;*
- *Assistance in accessing supportive services;*
- *Individual counseling, support groups, and education/training to assist you in making decisions and solving problems relating to your caregiving role;*
- *Respite care to temporarily relieve you from your caregiving responsibilities; and*
- *Supplemental services such as home modifications; nutritional supplements; assistive devices such as walkers, canes or crutches; emergency response systems; specialized equipment, such as CPAP, apnea machines, hospital bed, WanderGuard, or receiving a voucher, money, or stipend.*

The caregivers were asked *"For how long have you been receiving caregiver support services from {NFCSP Agency}?"* In the question, *{NFCSP Agency}* was customized with the name of the caregiver's AAA and also a provider, if known. The mean number of years receiving NFCSP support was 2.6 years with a minimum of 1 week to a maximum of 12 years. At baseline, this question and those that followed in this section were only asked among NFCSP client caregivers; comparison caregivers were not asked these questions.

Next, the NFCSP client caregivers were asked if they received respite care from their AAA. The percent of the caregivers who said "yes" to using respite was 42.5 percent and the percent who said "don't know" was 14 percent. When a caregiver responded "yes," he/she was asked what type of respite care he/she received. Table 5-9 shows the percentage of the 522 caregivers who received each type of NFCSP respite care service at baseline. Most caregivers received respite care in their homes.

Table 5-9. Frequency of caregivers' use of NFCSP respite care

Question	% Yes
In-home respite, where someone comes into the home to care for the CR*	82.8
Adult daycare, where the CR goes to a facility for care during the day*	20.7
Overnight respite care in a facility*	2.6
Overnight respite care in the home*	8.8

*Item only asked among the 522 caregivers (42.5%) who said "yes" to using respite care from the Agency.

Caregivers who answered "yes" to receiving respite care were asked *"How many hours per week of respite care do you usually receive through this program?"* Unfortunately, among the 522 caregivers who were asked this question at baseline, only 475 provided their hours. Among the responders, the mean number of NFCSP respite hours was 9.2 hours per week.

After the question about the number of hours of respite received, the caregivers were asked *"How helpful are the respite services from {Agency} to you as a caregiver?"* and were provided four response options. Among the 522 asked, 449 (86%) said "very helpful," 64 (12%) said "somewhat helpful," five (1%) said "somewhat unhelpful," one said "not at all helpful," and three replied "don't know." Those who used NFCSP respite care perceived the service to be helpful, as 98 percent said the service was helpful.

5.1.11 Caregivers' Use and Perceived Helpfulness of NFCSP Educational Services

Caregivers were also asked about their use of NFCSP educational services. At baseline, the percentage of NFCSP client caregivers who said "yes" to using educational services was 24.1 percent and less than 1 percent said "don't know." When the caregivers responded "yes," they were asked which type of service they received. Table 5-10 shows the percentage of the 297 caregivers who utilized each service type. The most used service type was support groups followed by education/training.

Table 5-10. Type of NFCSP educational service in the past 6 months

Question*	% Yes
Caregiver education or training such as classroom or online courses from {Agency}	36.1
Individual counseling sessions at the {Agency} to assist with your specific caregiving situation	23.6
Any caregiver support groups at the {Agency}	51.5

* Items only asked among the 297 caregivers (24.1%) who said "yes" to using educational services from Agency.

Caregivers who answered "yes" to receiving one of the educational services were asked how many times they attended a session in the past 6 months. Table 5-11 shows the reported amount of educational services used by NFCSP client caregivers at baseline.

Table 5-11. Amount of use of NFCSP educational services

	Times attended among those who said they used the service in the past 6 months			
Type of Educational Service (# asked)	1-3	4-6	7-9	10 or more
Caregiver education or training (107)	51.9%	30.2%	7.6%	10.4%
Individual counseling (70)	64.7%	19.1%	2.9%	13.2%
Support group (153)	29.6%	46.7%	7.9%	15.8%

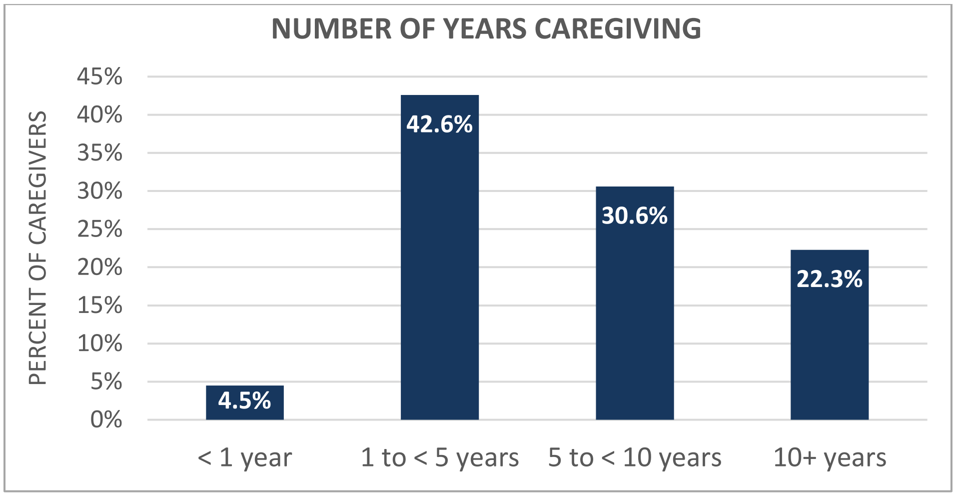
The majority of those who attended a support group went more than 3 times. In contrast, education and counseling were more likely to be attended only 1-3 times.

After the questions about the amount of use of NFCSP educational services, caregivers were asked *"How helpful are these services from {Agency} to you as a caregiver?"* Among those who provided an amount of use response, 164 (74%) said "very helpful," 55 (25%) said "somewhat helpful," two (1%) said "somewhat unhelpful," one said "not at all helpful," and three replied "don't know." Caregivers who used NFCSP educational services perceived them to be helpful, as 99 percent said these services were helpful.

5.1.12 Length of Caregiving by Caregiver Characteristics

The evaluation team analyzed the relationship between caregiver characteristics and the length of time that they said they had been a caregiver. In the beginning of the survey, after a caregiver said "yes" to still being a caregiver, the interviewer asked: *"How long have you been the caregiver for {care recipient}?"* At baseline, the average was 7 years. Figure 5-5 displays the frequency of caregiving years in four categories.

Figure 5-5. Prior caregiving years by four categories

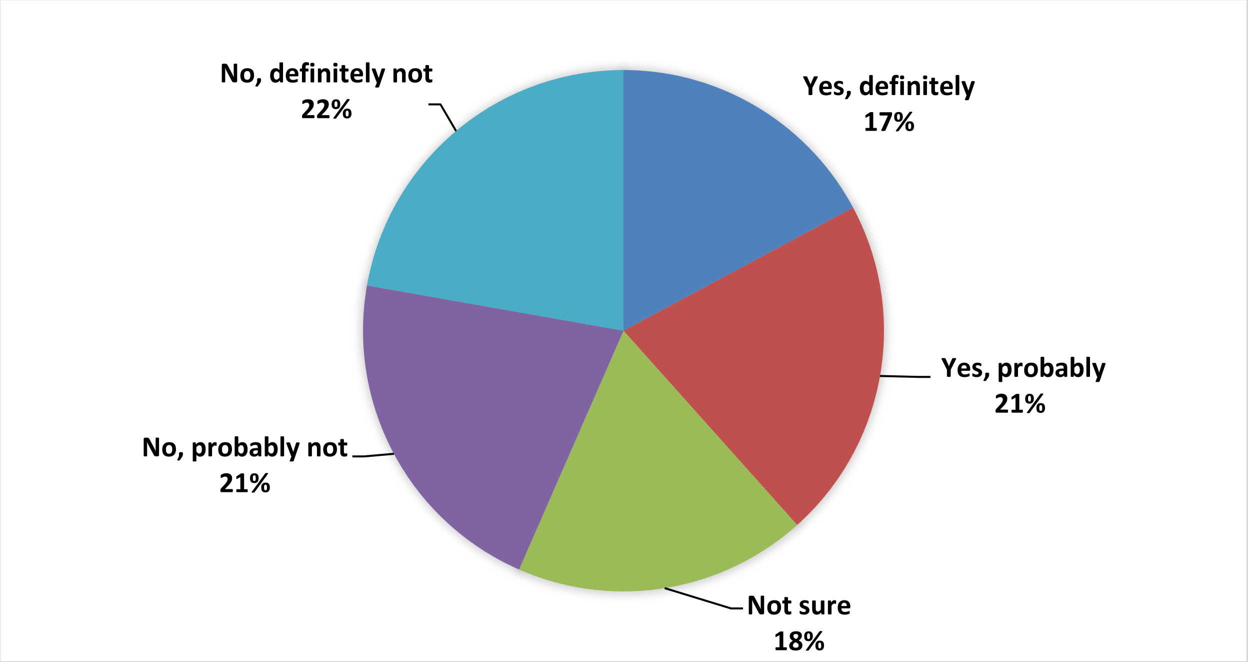


At baseline, 55 percent of the Program caregivers (who said they used NFCSP services) reported that they had been a caregiver for 5 or more years. In comparison, 50 percent of the Comparison caregivers reported 5 or more years. Not surprisingly, older caregivers and spouse caregivers reported longer years of caregiving than younger caregivers and non-spouse caregivers, respectively.

5.1.13 Caregiver Need for Help

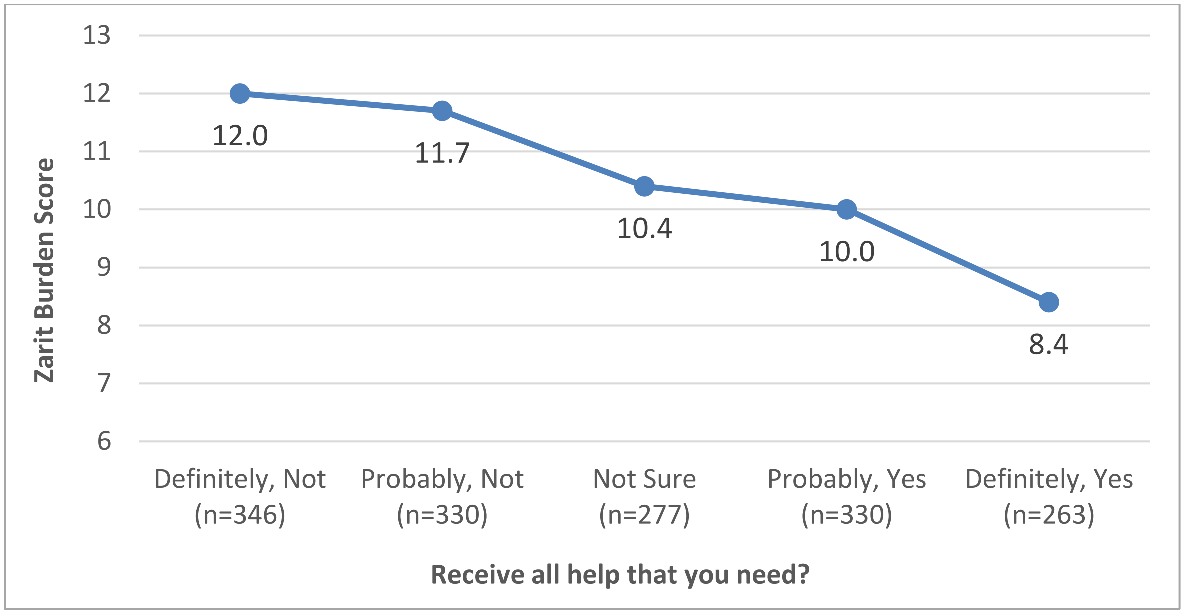
Regardless to the source of support, all caregivers were asked: *As {care recipient}'s caregiver, are you receiving all the help that you need?* This question was also asked of each care recipient. As displayed in Figure 5-6, the caregivers' responses at baseline were: 22 percent "no, definitely not," 21 percent "no, probably not," 18 percent "not sure," 21 percent "yes, probably," and 17 percent "yes, definitely."

Figure 5-6. Caregiver responses to “Are you receiving all the help that you need?” (N = 1,568)



The evaluation team examined the relationship between these response categories and Caregiver burden. As shown in Figure 5-7, the mean Zarit Caregiver burden score is highest/worst among caregivers that said “no, definitely not” and lowest/best among the caregivers who said “yes, definitely” to receiving all the help that he/she needs.

Figure 5-7. Mean Zarit Caregiver burden score plotted by receiving all the help response



The figure above shows a trend between Caregiver burden and the perception of receiving all the help a caregiver needs. However, since other factors can be associated with a caregiver's response to having all the help they need, the evaluation team analyzed the relationship between Caregiver burden and having all they help they need using a multivariable model to control for other factors that may influence the response. Those factors include CR age and the following caregiver characteristics: urban/rural, age, gender, race/ethnicity, relationship with CR, caregiving years, caregiving intensity of five ADLs, employment status, annual income, education level, caring for any children under 18 years of age, caring for any other adults age 60 and older, and lives with CR.

As shown in Table 5-12, the adjusted mean burden score for those who responded "Definitely not" when asked if they were receiving all the help they needed was significantly different from those who had other responses. For example, caregivers with a "Definitely yes" response reported a lower burden score by 3.44 than the caregivers who responded "definitely not," holding other characteristics in the model constant ($p < 0.001$).[11]

Table 5-12. The effect of perception of receiving all the help needed on Caregiver burden score

	Regression estimates for Caregiver burden		
Received all help?	**Effect Estimate (B)**	**Standard error**	**P-value**
Definitely not (reference category)			
Probably not	-0.51	0.240	0.034
Not sure	-1.33	0.252	< 0.001
Probably yes	-2.08	0.244	< 0.001
Definitely yes	-3.44	0.260	< 0.001

What Do These Results Mean?

Self-reported Caregiver burden is higher among caregivers who feel as though they are not receiving all the help they need. Unfortunately, this evaluation was unable to measure causation. For example, does more burden make a caregiver feel as though they need more help, or does not having all the help they need increase their burden? Is the burden highest when a caregiver first starts caregiving or does the burden increase as both the caregiver and CR age? This highlights the need to better understand the relationship between caregiver burden trajectory and caregiver need for help.

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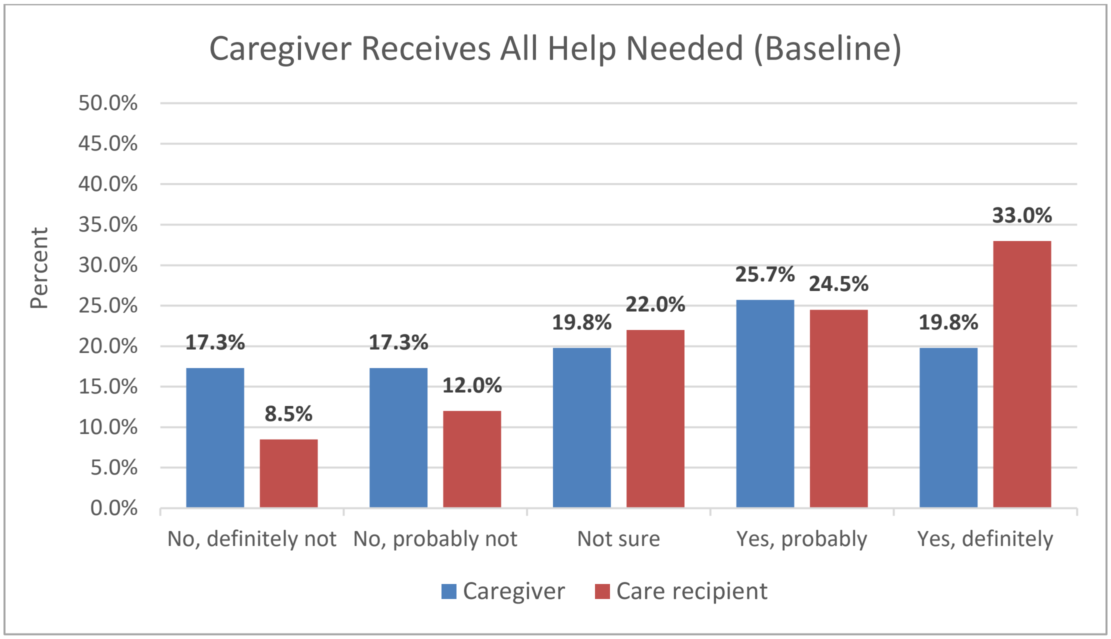
[11] In this report, statistical significance level is set at 0.05. This means that any statistical test results with p-values less than 0.05 are considered to be statistically significant. Throughout the report, a single asterisk (*) indicates $p < 0.05$, a double asterisk (**) indicates $p < 0.01$, and triple asterisk (***) indicates $p < 0.001$. More detail is available in Appendix C: Evaluation Methodology.

Nevertheless, this analysis shows that these two measures—the 4-item ZBI and a question about receiving needed help—are related and can be used to understand the support needs of caregivers.

Caregiver and Care Recipient Responses

For those CRs who had both baseline and 12-month data (N = 206), the evaluation team compared the CR and the caregiver responses to the question about if the caregiver is receiving all the help he/she needs. As shown in Figure 5-8, at baseline, more caregivers than CRs said that the caregiver's support needs are not being met (17.3% versus 8.5% for "no, definitely not," and 17.3% versus 12.0% for "no, probably not"). Conversely, only 19.8 percent of caregivers said their support needs are definitely being met versus 33.0 percent of CRs who said the same about the caregivers. The differences for the "not sure" category and the "yes, probably" category were relatively small. These differences in responses were statistically significant between the caregivers and their CRs (chi-squared statistic = 29.36, p = 0.0216). The results for 12-month responses were similar (not shown).

Figure 5-8. Comparison of responses for caregiver receives all help needed response between caregivers and care recipients at baseline



What Do These Results Mean?

Based on these findings, the CRs and caregivers view caregiver needs differently. Within the dyads, 17 percent of the caregivers perceived that they were "definitely not" receiving all the help they need, but only 8.5 percent of the CRs responded that way.

5.2 Care Recipients

This section reports the information collected *from caregivers* about their CRs.

5.2.1 Care Recipient Demographics and Functioning

Caregivers provided basic demographics about their CRs as shown in Table 5-13. During the interview, the CR's first name was used within the questions. The mean CR age was 81 years old, ranging from a minimum age of 58 to a maximum age of 105.

Table 5-13. Care recipient characteristics

Characteristic	% Yes
Female Gender	61.2
Marital Status	
Married	49.6
Widowed	37.2
Divorced	8.1
Never Married or Separated	4.2
Race	
White	78.3
Black or African American	16.7
Other	3.1
American Indian or Alaska Native	2.9
Asian	2.2
Pacific Islander	0.3
Hispanic or Latino Origin	8.8
Veteran	19.8

Early in the interview, all caregivers were asked about the activities they performed to help their CRs. Later in the interview, if a caregiver did not say that they helped the CR with an activity, they were asked about the CR's need for assistance in performing some common activities of everyday life. Table 5-14 shows responses to questions about CR's difficulties in performing ADLs and if the caregiver provided help with each activity.

Table 5-14. Care recipient activities that require help

CR Activity	Caregiver provides help (%)	Caregiver does not provide help, but CR has difficulty with the activity (%)
Getting around inside the home	71.6	5.7
Going outside home (examples: to shop or visit a doctor's office)	71.6	2.0
Getting in or out of bed or a chair	71.6	5.0
Taking a bath or shower	52.9	19.1
Getting dressed	67.4	5.3
Walking (help beyond using a walker or cane)	71.6	5.3
Eating	44.2	2.0
Using the toilet or getting to the toilet	40.4	7.6
Keeping track of money or bills	84.1	4.5
Preparing meals	89.0	3.8
Taking prescribed medicines	75.7	6.6

As shown in Table 5-14, helping the CR bathe or shower seems to be a caregiving activity that may be too difficult or too private for the family caregiver, as almost 20 percent of the caregivers responded that help was needed but they do not provide the assistance.

5.2.2 Care Recipient Health Conditions, Behaviors, and Hospitalizations

All caregivers were asked about diseases that the CR may have. The interviewer said *"Has a doctor ever told you or CR that he (or she) had…"* and then read a list of diseases or conditions. Table 5-15 lists the reported conditions in descending frequency.

Table 5-15. Diseases or conditions of care recipients at baseline

Conditions told by a doctor	% Yes*	% Don't know
Arthritis	67.4	1.5
Any other disease or condition such as liver disease, kidney disease, high blood pressure, or a mini-stroke	66.6	0.8
Alzheimer's disease, dementia, or other type of memory problem	52.2	0.4
Serious difficulty hearing	39.2	0.5
Serious difficulty seeing	34.2	0.7
Osteoporosis or thinning of the bones	34.1	3.6
Other heart disease, including angina or congestive heart failure	33.9	1.8
Diabetes	33.0	0.6
Lung disease such as emphysema, asthma, COPD, or chronic bronchitis	24.7	0.7
Cancer	26.4	0.8
Heart attack or myocardial infarction	24.0	1.5

* This is the percent of valid "yes" or "no" responses. "Don't know" is not considered a valid response.

The table above shows the percentages of "don't know" responses because more than 1 percent of caregivers seemed to have difficulty in reporting if their CR had arthritis, osteoporosis, or a heart condition. Over half of the caregivers had a CR with Alzheimer's or dementia. Similar to national caregiver statistics (e.g., Reinhard at al., 2014), the majority of the CRs had multiple chronic physical and cognitive conditions that required complex care by the caregivers.

All caregivers were asked questions about their CR's behavior that could impact the complexity of the caregiving situation. The interviewer led with *"Does CR display any of the following behaviors?"* Table 5-16 shows the five behaviors and the baseline "yes" percentages. These behavior questions were asked of all caregivers, not just those who had a CR with Alzheimer's disease or dementia. As shown in Table 5-16, almost one-third of the 1,568 caregivers said they had a CR who resists aid.

Table 5-16. Items about care recipient behavior

Question	% Yes
Does he/she yell?	29.7
Does he/she moan frequently?	25.5
Does he/she resist your attempts to provide aid?	30.4
Does he/she hit or bite you?	8.1
Does he/she wander or get lost?	17.1

Lastly, caregivers were asked if the CR had been hospitalized in the past 6 months, and twenty-seven percent (414) said "yes." The most common reasons were injury from a fall or accident (17%), respiratory condition (16%), infection of organ or body part (13%), cardiac condition (13%), cardiovascular condition (9%), digestive or gastrointestinal (7%), cancer or tumor (3%), or orthopedic condition (3%). Post-hospitalization of the CR is a time when caregiving can become relatively more complex for a caregiver (Moon, 2017; National Academies of Sciences, Engineering, and Medicine, 2016; National Alliance for Caregiving & AARP, 2015).

5.2.3 Care Recipient Institutionalization

An analysis was performed to measure rates of CR institutionalization to a nursing home or other long-term care facility during the evaluation timeframe. For this analysis it was decided to focus on the sample of 1,010 caregivers with a CR age of 65 or older who did not die during the 12-month evaluation timeframe. At follow-up interviews, caregivers were asked if they were still the CR's caregiver. Unfortunately, there were 88 caregivers who either left a phone message that they were no longer a caregiver after receiving a pre-notification letter, or who did not stay on the phone long enough to tell the interviewer why they stopped caregiving. (See Section 5.1.7 of this report for the reasons why caregivers stopped caregiving.)

At baseline, caregivers reported how long they had been a caregiver for their CR. The years ranged from 0 to 20 years. Each caregiver's length of caregiving was used to estimate a beginning (or origin) date by subtracting the reported number of caregiving years from the follow-up interview date. Using this retrospective origin date, an analysis called survival analysis was performed to calculate the event rate of CR institutionalization across the number years of caregiving. This analysis method computes and graphically displays the survival probability of not having an event. As expected, the probability of "surviving" the event decreases or declines with longer caregiving years. In other words, the probability of CR institutionalization increases with longer caregiving years because the CRs are aging.

The evaluation team compared the survival probabilities trended by caregiving years—and the converse event rate of institutionalization—by caregiver race and if the CR had been recently hospitalized. More details about this analysis can be found in Appendix C: Evaluation Methodology.

In Figure 5-9a, the lowest survival probability (steepest downward trend line) was for the CRs of White caregivers. For example, among White caregivers who had been caregiving for 10 years, about 80 percent of the CRs had not been institutionalized and 20 percent had been institutionalized. In comparison, among the non-Hispanic Black caregivers who had been caregiving for 10 years, about 97 percent had not been institutionalized and 3 percent had been institutionalized. There were no CRs institutionalized among the Hispanic caregivers. For the second comparison, Figure 5-9b shows a steeper decline in survival probability for CRs who had been recently hospitalized in comparison to those who had not been recently hospitalized.

Figure 5-9a. Comparison of care recipient institutionalization trends by caregiver race/ethnicity

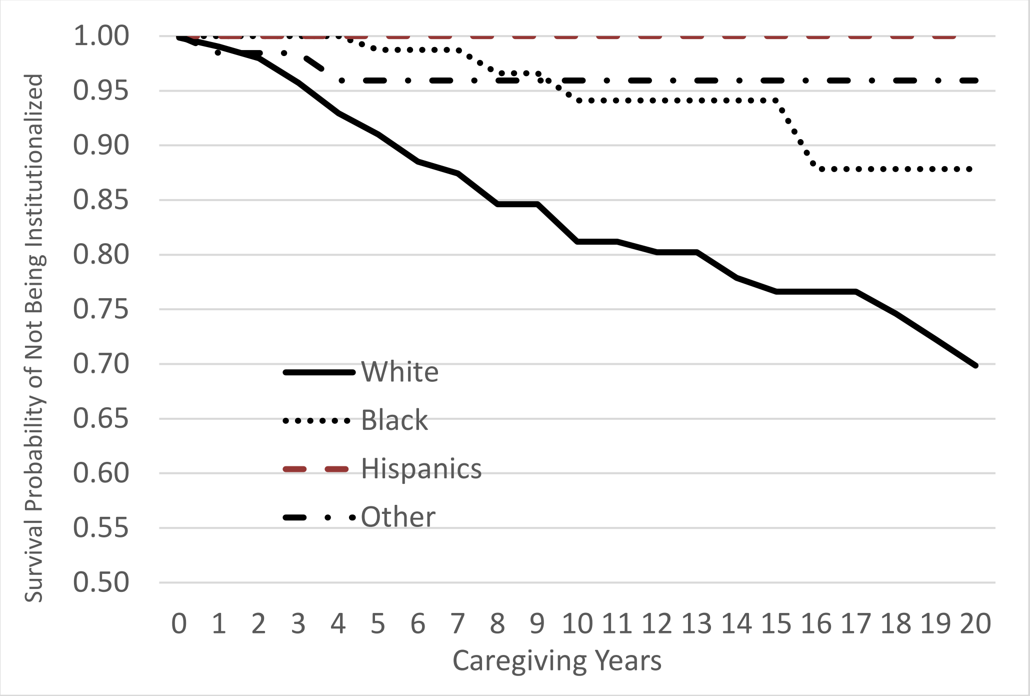
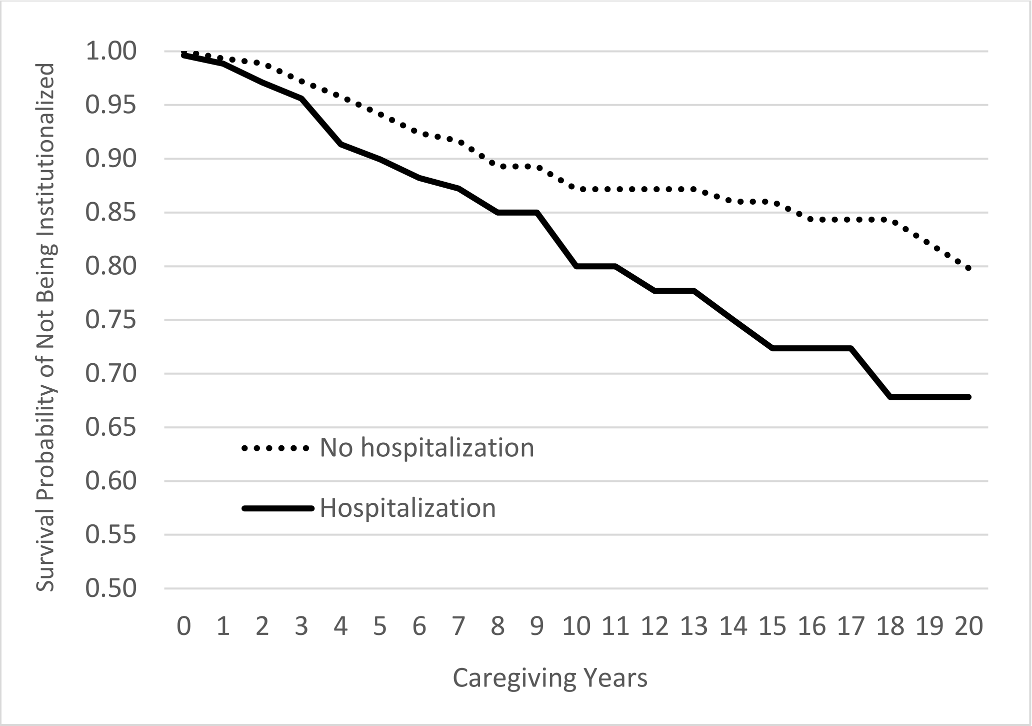


Figure 5-9b. **Comparison of care recipient institutionalization trends by prior hospitalization of care recipient**



What Do These Results Mean?

The rate of CR institutionalization across caregiving years was highest among White caregivers, suggesting that White caregivers may choose to institutionalize the CR sooner and/or at a higher rate than caregivers that are non-White. This differential of institutionalization rates among race/ethnicity groups may be related to differentials in socioeconomic status among the groups. However, previous research has shown that African American caregivers report significantly less burden than White caregivers (e.g., Clay et al., 2008; Lee et al., 2010; Dilworth-Anderson et al., 2012), which may lead to longer caregiving. The rate of CR institutionalization was higher when the CR had a prior hospitalization, regardless to how many years the caregiver had been caregiving. These results should be reviewed with caution because there were 88 caregivers for whom the evaluation team was unable to collect the reason why they stopped caregiving. Additionally, this evaluation was unequipped and unable to determine if NFCSP service use was associated with CR institutionalization because: (1) the timeframe was too short for this outcome, (2) the interview instrument and the data collected focused mainly on caregiver characteristics and caregiver well-being and did not collect enough information on the family's situation, caregiver experience and expectations, the CR's living situation, or the CR's current state of health for proper analysis, and (3) the complexity of this event and end of life care may best be researched qualitatively through interviews that allow for the collection of more in-depth information (Ornstein et al., 2017).

5.3 Caregiver Perceptions of the Usefulness of NFCSP Services for Continuing Caregiving and Delaying Institutionalization of the Care Recipient

This analysis explored the relationship between the receipt of NFCSP agency services on caregivers' perceived usefulness of services in supporting the caregiver to continue taking care of the CR at home.

All NFCSP client caregivers were asked these first two questions:

1. Continued caregiving

Have the services you received from {Agency} enabled you to provide care longer than would have been possible without these services? Would you say. . . (1)"Definitely yes," (2)"Probably yes," (3)"No, probably not," or (4)"No, definitely not"? The "Definitely yes" response is favorable.

2. Continued staying at home

Would {care recipient} have been able to continue to live at home if caregiver services from {Agency} had not been provided? The response options were (1) "Definitely yes," (2) "Probably yes," (3) "No, probably not," or (4) "No, definitely not." The "no" responses (3 and 4) are favorable as they indicate that the caregiver feels as though the services help the CR to live at home. When a caregiver responded "no," they were asked this third item:

3. Delayed institutionalization

Where do you think CR would be living without AGENCY services? The response options were: "in my home," "in the home of another family member or friend," "in an assisted living unit," "in a nursing home," "CR would have died," or "other, specify." For analysis purposes, "in an assisted living unit," "in a nursing home," and certain "other specify" responses were grouped as a favorable "yes" response to the perception that the NFCSP services help delay institutionalization.[12]

Receipt of NFCSP services and caregivers' perceived usefulness of services

As shown in Table 5-17, there were 51 percent of caregivers who received respite services and responded favorably to the Continued caregiving item, in comparison to 37 percent of caregivers who did not receive respite services.

Table 5-17. The percentage of favorable responses by recent NFCSP service use at baseline

	Service helps with Continued caregiving		Service helps continue staying at home of CR		Service helps delay institutionalization of CR	
	Definitely yes	Chi square p-value	Yes	Chi square p-value	Yes	Chi square p-value
Received respite care in last 6 months						
Yes	50.8%	<0.001	39.7%	0.039	25.4%	0.022
No	36.8%		33.6%		19.6%	
Received educational services in last 6 months						
Yes	46.7%	0.152	37.3%	0.742	21.1%	0.718
No	41.6%		35.9%		22.4%	

To measure the association between service use and the favorable responses to these survey items, the evaluation team performed a logistic regression that controlled for 13 covariates.[13] These are potential influencing factors that could confound the relationship between service use and perception of usefulness. Including these factors as control variables in the model helps to distinguish better and separate out the independent relationship between NFCSP service use and the amount of use on the probability of responding favorably to these questions.

Table 5-18 shows the results from three multivariable logistic regression models—one per survey question. Only the covariates with a significant association are listed. (See Appendix C: Evaluation Methodology for more details about the modeling.) After the 13 covariates were taken into account, the probability of the favorable "Definitely yes" response for Continued caregiving remained significantly higher for caregivers who said "yes" to receiving respite services in the past 6 months.

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[12] "Other, specify" items: "Care center," "continuing care community," "group home," "state-run facility," "VA Hospital," "adult foster care," "convalescent," "rehab center," "senior building."

[13] The following covariates were used: (1) caregiver geographical area type (urban center, urban area, rural area), (2) caregiver age, (3) caregiver gender, (4) CR age, (5) caregiver race, (6) if the caregiver is spouse to CR, (7) how long the caregiver has been caregiving, (8) caregiving intensity, (9) if the caregiver is employed, (10) caregiver annual income category, (11) if the caregiver takes care of any children under age 18, (12) if the caregiver cares for any other adults age 60 years or older, and (13) if the caregiver lives with the CR.

For example, the 0.168 marginal effect means that the probability of responding "Definitely yes" was 17 percent higher for a caregiver receiving respite care in comparison to a caregiver who did not receive respite care. This is a significant association with p-value < 0.001. The probability of responding "Definitely yes" to Continued caregiving was higher by 7 percent for those who received NFCSP educational services in the past 6 months, although the association was not significant. The probability of a favorable response for the Continued staying at home and Delayed institutionalization questions were 5 percent higher for caregivers who received respite care in the past 6 months in comparison to those who did not, yet not statistically significant. There was no association between receipt of educational services and the probability of the most favorable responses to these questions.

Table 5-18. Regression model results to predict favorable responses of service usefulness

	Continued caregiving		Continued staying at home		Delayed institutionalization	
Variables (reference category)	Marginal effect	P-value	Marginal effect	P-value	Marginal effect	P-value
Received respite care	0.168	0.000	0.054	0.074	0.049	0.054
Received educational services	0.070	0.055	0.019	0.581	-0.014	0.613
Caregiver Race (ref = Non-Hispanic White)						
Non-Hispanic Black	0.126	0.012	0.012	0.805	0.004	0.919
Hispanic	0.069	0.225	-0.023	0.655	-0.046	0.239
Non-Hispanic Other	-0.021	0.746	-0.043	0.475	-0.017	0.731
Care for another adult age 60+	-0.048	0.337	-0.143	0.001	-0.057	0.096
Living with CR	-0.167	0.001	-0.056	0.249	-0.029	0.485
Caregiver Annual Income (ref =< $11,500)						
11,500 to <20,000	0.001	0.994	0.204	0.014	0.254	0.019
20,000 to <30,000	0.004	0.956	0.134	0.096	0.199	0.048
30,000 to <40,000	-0.039	0.593	0.161	0.049	0.210	0.043
40,000 to <50,000	-0.058	0.457	0.143	0.109	0.210	0.065
50,000 to <60,000	-0.029	0.722	0.251	0.004	0.344	0.004
60,000 to <70,000	-0.007	0.940	0.081	0.414	0.152	0.218
70,000+	-0.050	0.499	0.172	0.040	0.210	0.048

Note: A marginal effect with respect to a variable represents the partial effect for the average observation. For dichotomous ("yes" or "no") variables, the comparison is with caregivers who do not have the characteristic. For categorical variables, changes are expressed moving from the reference category to a particular category.

Only the covariates that were significantly related to at least one of the outcome variables are shown.

What Do These Results Mean?

The caregivers who responded at baseline that they had used services in the past 6 months compared to the caregivers who said they did not, were more likely to say that “Definitely yes,” the NFCSP services were enabling them to be a caregiver longer.

Amount of NFCSP Respite Care and Continued Caregiving

For a deeper analysis, the evaluation team looked to see if the probability of a more favorable response for the Continued caregiving question increased for caregivers who had higher amounts of respite care. The modeling technique called ordinal regression was used to see if respite hours were a significant factor for predicting each of the response categories in order: (1) “Definitely no,” (2) “No,” (3) “Yes,” and (4) “Definitely yes.”

The analysis included a sample of 447 caregivers who said “yes” to receiving NFCSP respite care in the past 6 months and were followed up with a question asking how many hours of respite care they usually received each week. The average number of respite care hours per week among the 447 caregivers was 9.5.

Table 5-19 shows the results of the regression model, with respite hours as the main factor of interest. Because the sample size used in the analysis was smaller, the number of covariates in the model was reduced to only four: CR age, caregiver race, if the caregiver lives with the CR, and caregiving intensity. The reported 1.047 odds ratio for respite care hours means that the probability of a caregiver responding more favorably to Continued caregiving increases 4.7 percent for each hour increase in respite hours ($p < 0.001$). In other words, caregivers in our sample with the fewest amount of respite hours were more likely to say “definitely no” to the Continued caregiving question, and caregivers with the most respite hours were more likely to say “Definitely yes.”

Table 5-19. Respite care hours and the odds ratio of a more favorable response to Continued caregiving (N = 447 caregivers)

Variables (reference category)	Odds ratio	P-value	Lower CI	Upper CI
Respite care hours per week	**1.047**	**0.000**	**1.024**	**1.073**
Control Variables:				
CR Age (< 65 years old)				
65 to <75	0.607	0.359	0.195	1.699
75 to <80	0.476	0.180	0.151	1.357
80 to <85	0.486	0.182	0.157	1.348
85 to <90	0.840	0.749	0.271	2.347
90+	0.374	0.068	0.121	1.034
Caregiver Race (Non-Hispanic White)				
Non-Hispanic Black	1.518	0.168	0.847	2.787
Hispanic	1.382	0.404	0.655	3.024
Non-Hispanic Other	1.394	0.364	0.689	2.910
Living with CR	0.455	0.014	0.238	0.844
Count of ADL's Needing Help Daily (No ADLs)				
1	1.571	0.175	0.819	3.032
2	1.995	0.039	1.038	3.865
3	2.592	0.005	1.340	5.069
4	1.505	0.199	0.807	2.817
5	1.428	0.276	0.753	2.719

What Do These Results Mean?

Among caregivers who used NFCSP respite in the past 6 months, as the number of hours increased, so did the probability of a more favorable response to *"Have the services you received from {Agency} enabled you to provide care longer than would have been possible without these services?"*

Amount of NFCSP Educational Services and Continued Caregiving

The same analysis was performed to see if the probability of a more favorable response to the Continued caregiving question increased for caregivers who had higher amounts of educational services. This analysis included a sample of only 216 caregivers because only caregivers who said "yes" to receiving NFCSP educational services in the past 6 months were followed up with a question about how many times they attended a class or session in the past 6 months. The average number of times that caregivers used an educational service in the past 6 months was 7 times. Again, because the sample size was smaller, the number of covariates in the model was reduced to four. See Appendix C: Evaluation Methodology for more details about the construction of the educational services amount. As shown in Table 5-20, the reported odds ratio for educational services amount for a more favorable response to the Continued caregiving question was 1.064 (p = 0.023). This means that the probability of a caregiver responding more favorably to Continued caregiving increases 6.4 percent for each additional time that a caregiver used an educational service.

Table 5-20. Educational services amount and the odds ratio of a more favorable response to Continued caregiving (N = 212 caregivers)

Variables (reference category)	Odds ratio	P-value	Lower CI	Upper CI
Total Educational Services	1.064	0.023	1.010	1.124
Control Variables:				
CR Age (ref = < 65 years old)				
65 to <75	0.722	0.636	0.178	2.732
75 to <80	1.421	0.616	0.343	5.545
80 to <85	0.787	0.728	0.193	2.998
85 to <90	1.283	0.727	0.301	5.138
90+	0.826	0.790	0.193	3.333
Caregiver Race (ref = Non-Hispanic White)				
Non-Hispanic Black	1.522	0.391	0.594	4.117
Hispanic	1.664	0.288	0.663	4.406
Non-Hispanic Other	1.982	0.229	0.670	6.433
Living with CR	0.536	0.168	0.214	1.282
Count of CRs' ADL's Needing Help Daily (*ref = No ADLs*)				
1	1.993	0.091	0.905	4.508
2	2.646	0.040	1.057	6.845
3	2.350	0.084	0.903	6.333
4	2.561	0.044	1.041	6.559
5	1.678	0.242	0.710	4.042

What Do These Results Mean?

Among caregivers who used NFCSP educational services in the past 6 months, as the amount of service use increased, so did the probability of a more favorable response to *"Have the services you received from {Agency} enabled you to provide care longer than would have been possible without these services?"*

5.4 Most Helpful Caregiver Service from AAA

At baseline, NFCSP client caregivers were asked "*Now, thinking back to all the caregiver services that you received only from the agency, which service was most helpful for you?"* This question was not asked of the 326 initial Comparison caregivers. Table 5-21 shows the response frequencies for the most helpful caregiver service.

Table 5-21. Caregiver response frequencies to most helpful AAA service

Response category	Frequency	Percent
Information about available services	47	4.1
Assistance accessing supportive services	71	6.2
Caregiver education and training, individual counseling, support groups	159	13.8
Respite care	480	41.6
Supplemental services, on a limited basis	113	9.8
None of the above (“other”)	284	24.6
Total	**1,154**	**100**

Respite was deemed the most helpful service by 42 percent of the respondents. Second most helpful, at 25 percent were “other” services, which caregivers said were mainly home health aide, physical therapist, homemaker services/house cleaning, and meals. The third most helpful at 14 percent was caregiver education and training, individual counseling, and support groups.

6. Association Between Processes for Delivering NFCSP Services and Caregiver Outcomes

6.1 NFCSP Process Evaluation

In 2015, the NFCSP process evaluation assessed how AAAs planned for and operated their programs. Using cross-sectional survey data collected as part of the 2015 NFCSP Process Evaluation, Lewin analyzed caregiver assessment policies and practices in 54 State Units on Aging (SUA), 619 AAA, and 642 local service providers (LSPs).

The Lewin process evaluation examined the policies and procedures through which SUAs, AAAs, and LSPs meet NFCSP goals. Key findings regarding organizational structure, policies, and procedures at the AAA level were:

- There were 231 AAAs (51.8%) who reported that they did not operate a caregiver program before year 2000.
- Large AAAs have a mean of 4.3 full-time employees (FTEs) at their agency who work on their caregiver programs, with small and medium AAAs averaging slightly fewer than 2.0 FTEs.
- Caregiver populations that AAAs most commonly target are caregivers of persons with Alzheimer's disease or a related disorder, grandparents raising grandchildren and other relative caregivers, and rural caregivers.
- The majority of AAAs (69.7%) assess both CRs and caregivers in their caregiver support programs. Fifteen percent only assess CRs.
- Among those with a wait list for NFCSP services, the majority of AAAs (56.4%) have a single wait list maintained for the NFCSP overall, while 27.5 percent maintain multiple wait lists by NFCSP specific caregiver support services.
- More than 7 in 10 AAAs (74.4%) have a policy that limits or caps the amount or cost of service a caregiver may receive.
- AAAs reported that caregivers apply for respite care services far more often than for any other service.

- Thirty-one percent of AAAs said that the frequency of caregiver training and offerings was determined by LSP, 31 percent said they were regularly scheduled, and 30 percent said programming was provided on an as-needed basis.

- Approximately 25 percent of AAAs reported that they administer a separate caregiver program funded outside the NFCSP.

6.2 Processes and Structure at the AAA-Level Associated with Optimal Caregiver Outcomes

Evaluation Question #1: In conjunction with information from the process evaluation (conducted in Phase 1), what types of organizational structures and/or approaches for NFCSP services are associated with the best participant-level outcomes?

To identify the organizational characteristics, policies, and procedures that are associated with caregiver outcomes, the Westat evaluation team merged the AAA-level process survey data with the caregiver outcome data for Program caregivers (i.e., those who received NFCSP respite care or educational services). Each caregiver was associated with an agency and the two datasets was merged on the AAA id number. The two datasets coincided on 105 AAAs. AAAs were excluded if they had fewer than five caregiver respondents (N = 51 AAAs) in the post-merge sample. The final sample for this analysis included 458 caregivers among 54 AAAs within 29 states. The states included 19 percent in the Midwest region, 17 percent in the Northeast region, 30 percent in the South region, and 34 percent in the West region. The mean number of clients per AAA was 8.5 with a range of 5 to 22 caregivers. An exploratory analysis for significant differences using correlations and frequency tables was performed on all AAA-level items collected in the process evaluation with caregiver outcomes. Associations were found with AAA assessment policies. The following two analyses were pursued.

The relationship between AAA assessment and reassessment policies and caregiver outcomes.

Assessment and reassessment activities are critical for determining how clients receive services. From the merged process evaluation data, Table 6-1 shows the AAA-level response frequencies to the questions asked of the AAAs about their assessment process.

Table 6-1. AAA caregiver assessment policies: Items from the process evaluation

Question	AAAs with a response	% Yes
Does your agency use a standardized assessment tool?	51	69
Does your agency's needs assessment include assessing the impact of caregiving on the caregiver?	50	70
Does your agency have a policy for client reassessment?	51	75
Does your agency use caregiver assessment and reassessment to prioritize who receives services?	51	35
Does your agency use needs assessment to determine the type and amount of caregiver service?	53	68

An analysis was performed to compare the mean burden, mental health, and physical health scores between caregivers with agencies who responded "yes" to caregivers with agencies who responded "no" to the implementation of each of these processes. The outcome measures used in this analysis were the PROMIS Mental health and Physical health scores and the Zarit Caregiver burden collected at baseline. Table 6-2 shows the results of t-tests, which were used to determine if the means were significantly different. Significantly higher mean Caregiver burden scores were found among the caregivers from AAAs that include the impact of caregiving in their needs assessment, in comparison to AAAs that do not include such evaluation (p = 0.02).

Table 6-2. Comparison of mean caregiver outcome scores among AAA groups: t-test results

	Caregiver burden			Mental health			Physical health		
	AAA response			AAA response			AAA response		
Process item	Yes	No	P-value	Yes	No	P-value	Yes	No	P-value
Uses a standardized assessment tool	11.4	10.7	0.09	12.1	12.9	0.04	14.1	14.7	0.09
Needs assessment includes assessing the impact of caregiving	11.5	10.5	0.02	12.0	12.8	0.04	14.1	14.6	0.15
Has policy for client reassessment	11.2	11.1	0.78	12.2	12.7	0.28	14.1	14.9	0.04
Uses caregiver assessment and reassessment to prioritize who receives services	10.8	11.3	0.19	12.1	12.4	0.35	14.0	14.4	0.17
Uses needs assessment to determine the type and amount of caregiver service	11.2	11.2	0.99	12.4	12.3	0.86	14.3	14.2	0.94

The evaluation team also explored possible covariates that may have confounded the associations and/or were not balanced between the two AAA groups for each process item; there were no differences in mean caregiver age (68 years), caregiver gender (male = 30%), and "my care recipient has dementia, memory problem, or Alzheimer's" (mean = 65%).

What Do These Results Mean?

The AAA process of including the impact of caregiving in the needs assessment was associated with clients reporting higher caregiver burden. These results suggest that agencies assessing the impact of caregiving may have more opportunities to understand their clients' needs than agencies that do not have these processes. Having a standardized assessment tool may help target caregivers with poor mental health for service receipt. One could argue that a clear understanding of client needs may enable AAAs to better educate their clients about the impacts of caregiving and provide a more customized caregiver support plan. More research is needed to understand the organizational characteristics that enable effective assessment for the determination of services that meet the caregivers' needs.

The association between AAA frequency of measuring client program satisfaction and caregivers' perceived benefits of NFCSP for Continued caregiving.

The AAA process and caregiver outcome survey datasets were merged at the AAA level for 105 AAAs. AAAs that had less than five caregiver respondents (N = 51) in the sample, and were missing responses to the question about the frequency of measuring client satisfaction (N = 11), were excluded. The final sample for this analysis included 364 caregivers among 43 AAAs within 31 states. The mean number of clients per AAA was 8.5 with a range of 5 to 22 caregivers.

Agencies were asked the following question:

> *How frequently does your AAA assess {NFCSP} program participant satisfaction?*

The responses (and frequencies) were "ongoing" (9.3%), "semi-annually" (2.3%), "quarterly" (0%), "monthly" (2.3%), "annually" (62.8%), "varies by service" (20.9%), and "other" (2.3%). The first four were categorized as a frequency of "more often than annually" (14%).

The analysis used caregiver responses to the Continued caregiving question:

> *"Have the services you received from {Agency} enabled you to provide care longer than would have been possible without these services?"*

The percentage of caregivers who responded "Definitely yes" was calculated per AAA. Across the 43 AAAs, the average percentage of "Definitely yes" responses among the caregivers was 48 percent. AAAs that said they assess client satisfaction more often than annually had a higher percentage of caregivers who responded "Definitely yes" for Continued caregiving (unadjusted mean = 66.5% versus 44.9%, p = 0.0073).

However, it is better to analyze this relationship while controlling for measured factors that can influence the caregivers' "Definitely yes" response. Therefore, a multivariable regression model was performed to estimate the association between the frequency of client satisfaction assessment with aggregated AAA-level percent of caregivers who responded "Definitely yes" to the Continued caregiving question. Table 6-3 lists the four control variables in the model and their mean values aggregated at the AAA-level.

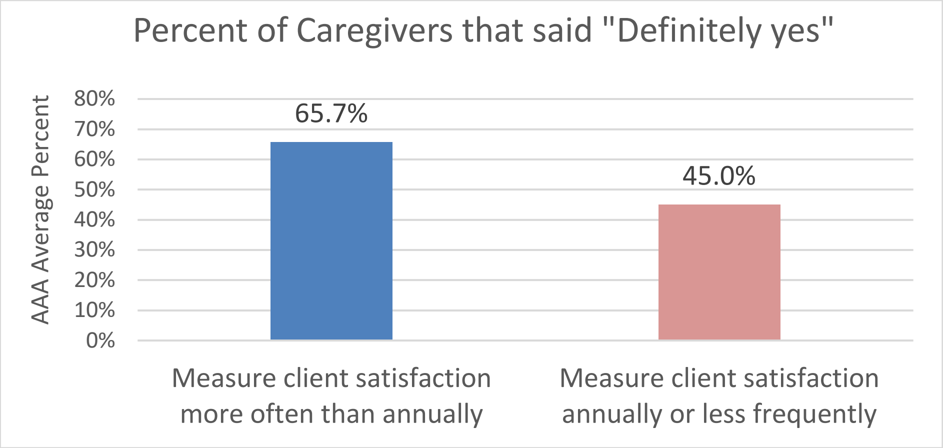
Table 6-3. Mean value of model control variables

AAA-level measure	Mean percent
% Caregivers with CRs with dementia or Alzheimer's	63.1
% Of five ADLs that caregivers help daily*	45.9
% Caregivers who get help from family/friends	36.1
# Of caregivers per AAA in sample	8.5

* The five ADLs include bathing, eating, dressing, toileting, and mobility. A 100 percent represents that a caregiver responded that they help with all 5 ADLs on a daily basis. (Bathing includes daily or several times a week.)

Figure 6-1 displays the adjusted mean "Definitely yes" percent between the two groups of AAAs.

Figure 6-1. Comparison of AAA adjusted means for Continued caregiving (N = 43 AAAs)



Note: Mean response scores adjusted for these AAA-level variables: % of CRs with Alzheimer/dementia, help with ADLs daily, informal help with caregiving, and # of caregivers surveyed. Significantly different means (p = 0.0085).

Table 6-4 shows the results from the multivariable linear regression model. The regression coefficient estimate of 0.206 means that in comparison to AAAs that do not assess more often than annually, the AAAs that do measure satisfaction more often than annually have a significantly higher percentage of caregivers who responded "Definitely yes" to the Continued caregiving item (p = 0.009). The percentage of caregivers with more daily caregiving responsibility was significantly associated with more "Definitely yes" responses to the Continued caregiving question, suggesting that caregivers with more intense caregiving perceive more benefit/helpfulness from NFCSP respite care and/or educational services.

Table 6-4. Regression estimates for AAA-level means of "Definitely yes" to NFCSP services enabling the caregiver to Continued caregiving

	Linear model results		
Variable	Estimate (B)	SE B	P-value
AAA measures satisfaction more often than annually	0.206	0.074	0.009
– vs AAA measures <= annually (reference group)	0	–	–
% Caregivers with CRs with dementia or Alzheimer's	-0.059	0.135	0.686
% of five ADLs that caregivers help with daily	0.482	0.173	0.008
% Caregivers who get help from family/friends	-0.152	0.127	0.238
# of caregivers per AAA	-0.000	0.007	0.977

What Do These Results Mean?

These findings suggest that agencies with a process to measure caregiver/client satisfaction more often than annually have, on average, a higher percentage of caregiver clients with the most favorable perception that NFCSP enables them to be caregivers longer. It is possible that AAA measurement of satisfaction that is more frequent provides better monitoring and management of what each client needs to support him/her in taking care of his/her CR in the community. Because this analysis was cross-sectional, the results only show an association and not causation. More research is needed to understand the organizational structure and goals of the AAAs that measure client satisfaction more often, and to determine if those AAAs are providing NFCSP caregiver services in a more effective manner.

7. Caregiver Targeted Need and Overall Support

7.1 Targeting NFCSP Service to Those with the Greatest Need

Evaluation Question #2: Are services reaching the groups targeted by the OAA, including caregivers (serving older adults), with greatest social or economic need?

The objective of this analysis was to measure if caregivers with more social or economic need were receiving as much NFCSP services as those with less need. This analysis stacked the survey data to allow for more responses. For example, we used 1 to 3 survey responses per caregiver, depending on if they took only the baseline, the 6-month follow-up, the 12-month follow-up, or any combination of the three.

The evaluation team developed an SES Need Index, as the sum of five factors/components. The factors were selected to be as similar as possible to the greatest economic and social need indicators described in the Older American Act of 1965. The Act defined the individuals in greatest economic and social need as older, low income, minority, with limited English language proficiency, and socially isolated.

SES Need Index Components and Criteria:

Older Caregiver. Caregiver is 60 years of age or older.

Low Income. Caregiver's annual household income from all sources was less than or equal to $30,000. If the annual income was missing but monthly income was available, the annual income was supplemented with appropriately converted monthly income. The above cutoff was based on the definition of low income as being approximately 200 percent of the federal poverty level (O'Brien, Wu, & Baer, 2010) and using the 2018 federal poverty guidelines for a two-person household (U.S. Department of Health and Human Services, 2018).

Minority Status. Caregiver's race and ethnicity were anything other than White and non-Hispanic.

Limited English Proficiency. Caregiver took the survey in Spanish.

Social Isolation. Caregiver who (1) resided in a rural location based on their zip code, (2) reported being nearly always stressed between caring for the CR and trying to meet other responsibilities, such as work or family, and (3) provided poor rating for satisfaction with social activities. This variable was a proxy for the Older American Act-defined isolation-related need. Social isolation—culturally, socially, or geographically—can lead to "negative social interaction" which has been found to be a stronger risk factor for poorer caregiver well-being than the level of recipient impairment or the amount of care provided (Haley et al., 2003; Smith, 2011).

NFCSP Respite Care Hours

To analyze the relationship between the SES Need Index and NFCSP respite hours, the sample only included caregivers who said that they used respite care in the past 6 months and answered the question about how many hours of respite care they usually received each week. The sample included 637 unique caregivers and 987 survey responses; an average of 1.5 surveys per caregiver. For this "repeated data" sample, caregivers reported receiving an average of 9.03 hours of NFCSP respite care per week.

NFCSP Educational Services

The NFCSP educational services sample included any caregivers who said "yes" to using education/training, individual counseling or support group services and answered the question about how many times they attended or received each service in the past 6 months. The amount of services was summed across all three types of services. The sample included 257 unique caregivers and 431 survey responses; an average of 1.7 surveys per caregiver. For this "repeated data" sample, on average, the caregivers reported receiving these services 6.95 times during the past 6 months.

SES Need Index Among NFCSP Respite Care Users

On average across the three timeframes, 82 percent of the caregivers were older, 42 percent were low income, 27 percent were racial/ethnic minorities, 1.5 percent had limited English proficiency, and 36 percent were considered to be socially isolated. Table 7-1 reports the percentage of caregivers who met the criteria for each of the SES Need Index indicator by timeframe.

Table 7-1. SES Need Index indicators among caregivers who used NFCSP respite care

Indicator	Percent of caregivers with indicator		
	Baseline (N = 474)	6 months (N = 286)	12 months (N = 227)
Older caregiver age	80.4	83.2	82.4
Low income	42.4	43.7	40.1
Minority status	27.6	25.5	27.3
Limited English	1.9	0.7	1.8
Social isolation	35.4	38.5	35.2

Association Between SES Need Index and Respite Hours at Baseline

At baseline, 5 percent of 474 respite-using caregivers had an index = 0; 31 percent had an index = 1; 40 percent had an index = 2; 20 percent had an index = 3; and 4 percent had an index = 4. The index's six-level range (0-5) was transformed into 0-4 by collapsing the two highest categories (4 and 5) to improve the distribution of this variable because there were very few caregivers with an index = 5.

Figure 7-1 shows the mean agency respite hours for each SES Need Index value; the overall pattern suggests that caregivers with more social and economic needs received fewer hours of respite each week. However, the differences were not statistically significant.

Figure 7-1. Mean NFCSP respite hours per week at each SES Need Index value at baseline (N = 474 caregivers)

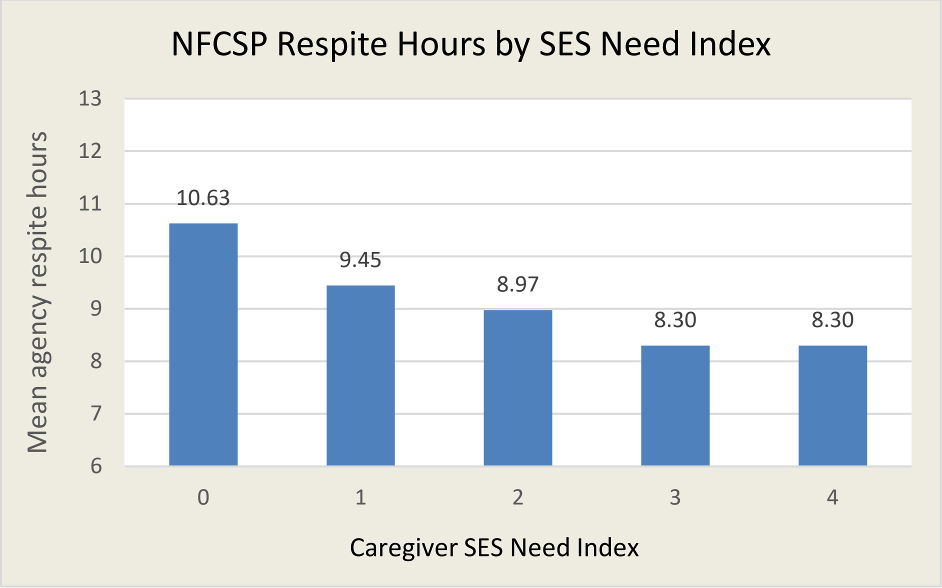


Table 7-2 shows the mean agency respite hours for caregivers with and without each of the SES Need index indicators. The only statistically significant finding in this table is that minority status caregivers received more respite than non-minority caregivers at 6 months (11.6 versus 8.6, p = 0.0400).

Table 7-2. Comparison of mean weekly respite hours by each indicator of the SES Need Index

Index indicator	Respite hours at baseline (N = 747)	Respite hours at 6-months (N = 286)	Respite hours at 12-months (N = 227)
Index: Older Age (≥ 60)	**8.6**	**9.0**	**8.3**
Age < 60	10.7	10.8	10.3
Index: Low Income (≤ 30K)	**8.2**	**10.0**	**8.9**
Income > 30K	9.7	8.8	8.4
Index: Minority Status	**10.4**	**11.6**	**9.6**
Not Minority Status	8.5	8.6*	8.3
Index: Limited English	**12.1**	**10.0**	**16.3**
No Limited English	9.0	9.3	8.5
Index: Social Isolation	**8.2**	**8.6**	**7.2**
No Social Isolation	9.5	9.8	9.4

* p < 0.05, ** p < 0.01, *** p < 0.001

Association Between Respite Hours and SES Need Index

Findings from the repeated measures regression model with respite hours as the dependent variable and the SES Need Index as the independent variable showed no association between the index and hours. However, when the SES Need Index was replaced with the five index indicators, the model showed that older age (60+) was associated with fewer hours (regression coefficient B = – 1.92, p = 0.034) and minority status was associated with more respite hours (B = 1.79, p = 0.031). (Regression results not shown.)

SES Need Index Among NFCSP Educational Service Users

Among the subset of caregivers who used NFCSP educational services, 82 percent of the caregivers were older, 28 percent were low income, 22 percent were racial/ethnic minorities, 1 percent had limited English proficiency, and 30 percent were considered to be socially isolated. (See Table 7-3.) In comparison to the respite care sample displayed in Table 7-1, fewer of these caregivers were low income or socially isolated.

Table 7-3. **Frequency of SES Need Index indicators among caregivers who used NFCSP educational services**

Indicator	Educational services sample Baseline (N = 222) (%)	6 months (N = 117) (%)	12 months (N = 92) (%)
Older caregiver age	77.9	86.3	81.5
Low income	27.0	30.8	27.2
Minority status	22.5	18.0	25.0
Limited English	1.4	0.0	1.1
Social isolation	26.1	29.9	34.8

Association between SES Need Index and Educational Services

At baseline, 8 percent of 222 caregivers who used NFCSP educational services had an index = 0; 42 percent had an index = 1; 40 percent had an index = 2; 9 percent had an index = 3; and 2 percent had an index = 4. Figure 7-2 shows a graph of the mean agency educational services amount for each SES Need index value in the NFCSP educational services sample at baseline. The pattern suggests that an increase in the number of social and economic needs corresponds to a decrease in mean educational services amount received, with the exception of the 2 percent of caregivers with an index = 4. The differences were not statistically significant.

Figure 7-2. **Mean NFCSP educational services amount at each SES Need Index value at baseline (N = 222 caregivers)**

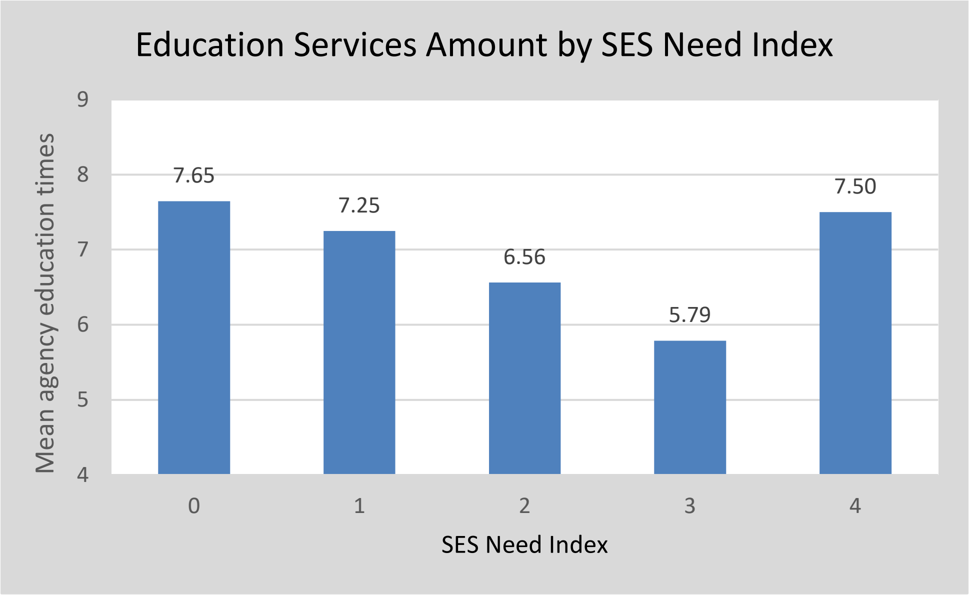


Table 7-4 shows the mean NFCSP educational services amount for caregivers with and without each of the SES Need indicators. There were no significant differences in the means.

Table 7-4. Comparison of mean educational services amount by each indicator of the SES Need Index

Index indicator	Baseline amount (N = 222)	6 months amount (N = 117)	12 months amount (N = 92)
Index: Older Age (≥ 60)	6.9	6.2	7.6
Age < 60	6.8	8.1	8.2
Index: Low Income (≤ 30K)	6.0	5.9	7.1
Income > 30K	7.2	6.7	8.0
Index: Minority Status	5.6	7.2	7.6
Not Minority Status	7.0	6.3	7.8
Index: Limited English	5.0	–	–
No Limited English	6.9	–	–
Index: Social Isolation	6.9	5.9	7.1
No Social Isolation	6.9	6.7	8.1

Association Between Educational Services Amount and SES Need Index: Regression Model Results

Findings from the repeated measures regression model with educational services amount as the dependent variable and the SES Need index as the independent variable showed no association between the index and hours. The model was also performed with the five indicators as independent variables replacing the index. There were no associations found from the multivariable model; however, significant associations are more difficult to detect with a smaller sample size. (Regression results not shown.)

What Do These Results Mean?

This analysis examined the association between NFCSP service amount and SES need. Because the focus of the analysis was on social and economic needs based on the OAA, the analysis did not include other important aspects of caregiver needs assessment and targeting, such as care recipient frailty, care recipient diagnosis of Alzheimer's disease or dementia, or caregiver burden. Results indicate that, at baseline, over 90 percent of the caregivers receiving NFCSP services had at least one of the socioeconomic need factors. Although caregiver SES Need index was not associated with the amount of NFCSP respite hours received, significant associations emerged for two of its components: caregiver age and minority status. Among this caregiver sample, the caregivers under age 60 reported significantly more respite hours per week (on average) than caregivers age 60+. One could hypothesize that younger caregivers may have more competing responsibilities such as childcare and employment, aspects that may necessitate the need for longer respite care hours. Additionally, racial/ethnic minority caregivers reported receiving more respite hours per week (on average) than non-minority caregivers.

For educational services, neither the SES Need index nor any of its components were significantly associated with more service use. Because educational services can be provided in a group setting and are often less costly to provide than respite care, there is less necessity for SES-based targeting for these services.

7.2 Barriers to Receiving Services from Any Organization

The survey included several items about barriers to receiving caregiver services. The first question was *"Have you tried to obtain any formal caregiving support services from a community organization such as a business or agency but were not able to receive them?"*

Of the baseline caregivers who responded to this question, only 12 percent (N = 190) replied "yes" and 88 percent replied "no." The caregivers who answered "yes" were then asked questions about reasons for not obtaining services (shown in Table 7-5).

Table 7-5. Reasons caregivers were unable to obtain caregiver support services from any organization

Question	% Yes
Were you on a waiting list?	24.7
Did the services cost too much?	46.0
Did your local agency not have the service you need?	3.8
Was there some other reason?	63.0

The top specified response was that the services cost too much (46 percent); however, 63 percent of the respondents also indicated "other reasons" they could not obtain services. Table 7-6 shows the top "other reasons" as reported by 116 caregivers.

Table 7-6. Other reasons caregivers were unable to obtain caregiver support services from any organization

Specified "other" reasons	Frequency
Ineligible: income or assets too high	48
Did not qualify/ineligible not because of income	20
Agency underfunded or short staffed	7
Never heard from agency	6
Insurance not accepted/couldn't afford	5

When determining respite care eligibility, an organization may give priority to older persons with low incomes (as compared to the Federal Poverty Level) when choosing their clients. For example, most AAAs will assess the income and sometimes the assets of the CR. Eligibility requirements for respite care differ with each administering AAA. Most commonly, respite care from the AAA is offered free of charge. However, some agencies might require a co-payment based on income. For example, they may grant $500 of respite care, but the family has to pay $100 (20% co-pay).

7.3 Why Caregivers Do Not Seek Services

To better understand why caregivers listed as NFCSP clients were not receiving services, new items were asked during the 6-month interview. More specifically, during the 6-month interview, 323 NFCSP client caregivers who responded "no" to receiving respite care or respite vouchers were subsequently asked for the reasons why they did not receive the service. The responses are shown in Table 7-7.

Table 7-7. Reasons caregivers responded "no" to receiving NFCSP respite care or vouchers

Did you not receive respite care from {Agency} during the past 6 months because	% Yes (among 323)
You didn't know about this service from this agency?	39.3
You didn't need the service from this agency?	3.7
You were previously not satisfied with the service and did not request again from this agency?	0.9
Prior to 6 months ago, you used all your allotted respite hours for the year from this agency?	4.3
You wanted to receive respite care from this agency, but they didn't have the staff or resources to provide during the past 6 months?	5.6
Because of some other reason?	10.8

More than one-third of those who were on the NFCSP client list but did not use respite care services said that they did not know about the service from the agency. The two most common "other reasons" for not obtaining respite services were: (1) does not qualify and (2) the CR does not want anybody to come over.

During the 6-month interview, 472 NFCSP client caregivers who responded "no" to receiving educational services were asked about specific reasons they did not receive the service. The responses are shown in Table 7-8.

Table 7-8. Reasons caregivers responded "no" to receiving NFCSP educational services

Did you not receive caregiver education, training, counseling, or support group services from {Agency} during the past 6 months because ….	% Yes (among 472)
You didn't know about this service from this agency?	56.4
You didn't need the service from this agency during the past 6 months?	28.2
You have not been satisfied with the service and did not request again from this agency?	0.0
You wanted these services, but there were no classes, courses, or sessions offered from this agency?	2.5
You wanted individual counseling, but were unable to get an appointment through this agency?	0.8
Because of some other reason?	8.3

More than half of those who were on the NFCSP client list but did not use educational services said that they did not know about the services from the agency. The two most common "other reasons" for not obtaining educational services were: (1) unable to attend and (2) ineligible.

7.4 The Extent to Which NFCSP Clients Receive Other Services

The analyses in this section used the responses from caregiver survey results collected at baseline only. The Program/Comparison group assignments that used 6-month responses for caregiver group determination were not applicable for this baseline-only analysis (See Appendix C: Evaluation Methodology for details about group assignment). For this analysis, an NFCSP caregiver is defined as a caregiver who reported:

- Receipt of at least 1 hour per week of NFCSP respite care, or
- Attending an NFCSP educational service one or more times in the past 6 months.

Respite Care and Educational Services

The survey asked the caregivers detailed questions about caregiver respite care and educational services that were obtained from NFCSP and other sources. The first two tables (Tables 7-9 and

7-10) show caregivers' reported use of these two services within the past 6 months at the baseline interview.

As shown in Table 7-9, 54 percent of NFCSP caregivers received respite care from family and friends. A lower percentage (36%) of the non-NFCSP caregivers received respite care from family and friends, yet they reported more hours per week. The two groups reported the same amount educational services although, again, more NFCSP caregivers (19%) reported receiving this service in comparison to the non-NFCSP caregivers.

Table 7-9. Comparison of receipt of respite care or educational services provided by family, friends, or neighbors

	NFCSP caregivers (N = 617)		Non-NFCSP caregivers (N = 951)	
Services by family/friend	% Yes	Mean amount	% Yes	Mean amount
Respite care	54.0	9.77 hrs./week	35.8	13.42 hrs./week
Educational	18.6	5.11 sessions	10.7	5.13 sessions

Table 7-10 shows that, at baseline, the percentage of NFCSP caregivers who received respite care from a non-NFCSP organization was slightly higher than the percentage of non-NFCSP caregivers (20% versus 16%, respectively). Similar to the respite care received from family and friends, the NFCSP caregivers received fewer hours, on average, than non-NFCSP caregivers (14.5 versus 15 hours per week, respectively).

Table 7-10. Comparison of receipt of respite and educational services provided by different sources: NFCSP versus non-NFCSP caregivers

	NFCSP caregivers (N = 617)		Non-NFCSP caregivers (N = 951)	
Services by non-NFCSP organization	% Yes	Mean amount	% Yes	Mean amount
Respite care	20.0	14.51 hrs./week	16.1	15.47 hrs./week
Educational services	21.7	6.99 sessions	16.7	5.62 sessions

Less than one-fourth of all the caregivers were receiving respite care from another paid agency/organization that was not an NFCSP agency.

Use of Home and Community-Based Services (HCBS)[14] for Caregiver or Care Recipient

To address Evaluation Question #3, an analysis was performed to understand the extent to which the NFCSP caregivers also receive other HCBS. Caregivers were asked the following questions about other services that they or the CR received from a non-NFCSP paid agency: *"In the last 6 months, have you, as the caregiver, or CR received any of the following services offered by another organization with paid staff? This includes services paid for by Medicaid or Medicare."* Comparison caregivers were asked *"In the last 6 months, have you, as the caregiver, or CR received any of the following services offered by any organization with paid staff? This includes services paid for by Medicaid or Medicare."*

The results for NFCSP caregivers and non-NFCSP caregivers are shown in Table 7-11. Incontinence supplies, home health aides, home delivered meals, and case management were the most reported services. For the majority of services, there was little difference between the two types of caregivers. However, there were exceptions for two types of services. NFCSP caregivers were significantly more likely to have received legal assistance (9.4% versus 5.3%; p = 0.010). By contrast, NFCSP caregivers were significantly less likely to have received home-delivered meal services (16.7% versus 30.2%; p < 0.001).

Table 7-11. Receipt of home and community-based services: NFCSP versus non-NFCSP caregivers

	NFCSP caregivers (N = 709)	Non-NFCSP caregivers (N = 859)	
Service	% Received	% Received	P-value
Help applying for services	24.17	22.37	0.40
Case management	23.64	23.54	0.96
Training on attending to recipient's medical needs	13.21	11.02	0.19
Legal assistance	9.39	5.26	<0.01*
Incontinence supplies	25.53	23.92	0.46
Home modification such as grab bars or ramps	12.31	10.50	0.26
Nutritional supplements such as Ensure or Boost	11.91	9.37	0.10
Transportation	18.56	21.59	0.14
Home delivered meals	16.67	30.22	<0.01*
Congregate meals	12.02	13.79	0.30
Mental health services	9.65	8.24	0.33
Homemaker services	20.85	24.50	0.09
Home health aide that was not respite care	23.90	25.12	0.58
Other services	8.91	8.18	0.61

Note: P-values shown are for two-tailed chi square tests; physical and occupational therapist were the most common "other" services.

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[14] HCBS includes the following 14 categories: Help with applying; Case management; Training on attending to recipient's medical needs; Legal assistance; Incontinence supplies, home modification such as grab bars, ramps; Nutritional supplements such as Ensure or Boost; Transportation; Home delivery meals; Congregate meals; Mental health services; Homemaker services; Home health aide that was not respite care; Any other services.

Relationship Between Use of HCBS and NFCSP: A Look at the Initiation of Services

For this analysis, the evaluation team used survey data from baseline and follow-up for caregivers in the Program group (N = 747 caregivers). The evaluation team performed an analysis to best answer these two questions:

1. Do clients receive other HCBS as a result of initiating NFCSP caregiver services?
2. Do clients of other HCBS become aware of and initiate NFCSP services?

To answer the first question, the evaluation team identified 163 Program caregivers who used NFCSP caregiver services at baseline but *did not* receive any HCBS at baseline. For the second question, the sample was limited to 330 caregivers who received HCBS at baseline, but not NFCSP caregiver services at baseline.

Logistic regression models were performed to determine whether the use of one service at baseline increased the likelihood of starting the use of the other service at follow-up. The hypothesis for the first question was that receiving NFCSP respite/educational services would help caregiver clients and their CRs receive other HCBS as well. The odds ratio of 1.2 means that receiving NFCSP service at baseline increased the likelihood of HCBS at follow-up (an OR > 1.0 is an increased likelihood), but the finding was not statistically significant. (See Table 7-12, Model 1). The hypothesis for the second question was that initiating HCBS for either the caregiver or the CR would initiate the use of NFCSP services. The odds ratio of 1.9 indicates that receiving HCBS at baseline increased the likelihood of receiving NFCSP services at follow-up. This finding was statistically significant (p = 0.04) (Table 7-12, Model 2.)

Table 7-12. Results of logistic regression predicting use of a service at follow-up

	Model 1 (N = 163 who did not use other HCBS at baseline)		Model 2 (N = 330 who did not use respite/ education at baseline)	
	Using other HCBS at follow-up		Using respite/ educational services at follow-up	
Variables (reference category)	Odds ratio	P-value	Odds ratio	P-value
Received respite/education offered by NFCSP agencies at baseline (*not received*)	1.23	0.52	–	–
Received other HCBS at baseline (*not creceived*)	–	–	1.90	0.04

What Do These Results Mean?

There is no clear suggestion that NFCSP is serving as a gateway to receiving HCBS. Thus, these findings suggest that NFCSP could be more integrated with HCBS providers. The caregivers and CRs receiving other HCBS from their local AAA or another paid organization did appear to initiate NFCSP services subsequently, either through discovery of their own or through introduction to the NFCSP services by the organization providing the other HCBS.

A higher percentage of NFCSP caregivers are receiving respite care and educational services from family and friends than non-NFCSP caregivers. The same was found for respite care and educational services from other paid organizations. However, when comparing the amount of support received from other sources, the NFCSP caregivers receive fewer respite hours, especially from family and friends.

Results also suggest that the caregiver's connection with NFCSP increased the likelihood of a referral for legal assistance. In contrast, the non-NFCSP caregivers reported more use of home delivered meals and homemaker services. This is not surprising considering that the evaluation's sample frame for Comparison caregivers came from finding CRs who were AAA clients for OAA services such as home-delivered meals and homemaker services.

8. Caregiver Outcome Evaluation

Evaluation Question #4: To what extent do NFCSP program participants' outcomes differ from those of caregivers who do not receive support and services from the NFCSP?

To compare outcomes between NFCSP caregivers and Comparison group caregivers, the evaluation team used caregivers' longitudinal survey response data to measure change in outcomes such as Mental health, Physical health, Caregiver burden, Caregiver satisfaction, and Caregiver confidence.

8.1 Propensity Score Matching

To evaluate the effectiveness of NFCSP services across time, the first step was to create a longitudinal dataset of caregivers interviewed at baseline and who remained eligible (i.e., "still a caregiver") for a follow-up interview (N = 908). Each of these caregivers was assigned a caregiver group based on the actual use of NFCSP services as described in Section 4.1 of this report. The full longitudinal sample included 908 caregivers: 491 Program caregivers and 417 Comparison caregivers.

A linear regression analysis was conducted for each of the five outcome measures as described in Section 4.3 of this report: PROMIS Mental health, PROMIS Physical health, Zarit Caregiver Burden, Caregiver satisfaction, and Caregiver confidence.

Each regression model's main variables of interest to evaluate the effectiveness of NFCSP services across time were:

- **Time.** Single item indicating data collection time (Time 1 = 0, Time 2 = 1). Whereas Time 1 indicated baseline measurement, Time 2 indicated either 6-month or 12-month measurement, specific to each caregiver's latest completed survey.
- **Caregiver Group.** (Program = 1; Comparison = 0).
- **Time x Group.** An interaction term that is the product of the two variables above. This value = 0 for all interactions except Time 2 for the Program group.

An ideal way of evaluating the effectiveness of NFCSP services would be to compare outcomes for caregivers who are alike in all aspects except if they received the services. In a randomized controlled trial, this is done by randomization of treatment or intervention that minimizes the differences between treatment and control groups. However, such designs are often not feasible in real-world situations. An alternative approach is to use data from an observational study to isolate caregivers receiving NFCSP services and compare them to caregivers who are not receiving those services on selected outcomes. Statistical methods such as propensity score matching can then be used to make the two groups as similar as possible on known characteristics.

The evaluation team took the latter approach and used propensity score matching to improve the balance of key baseline characteristics that can influence the probability of receiving caregiver support services between the Program group and the Comparison group. After exploration of several caregiver characteristics, the following variables were selected for matching based on their conceptual relevance to the receipt of NFCSP services and their correlation with the caregiver outcomes:

1. **Caregiving Intensity.** The percentage of five ADLs with which the caregiver provided assistance daily (eating, dressing, toileting, and mobility) or daily/several times a week (bathing), with greater values indicating greater intensity (range 0 to 100%).
2. **Other Respite Care.** Binary variable assessing whether caregiver received respite services from sources other than the selected agency in the past 6 months (0=No, 1=Yes).
3. **CR Dementia Diagnosis.** Binary measure capturing whether CR was diagnosed with dementia (0=No, 1=Yes).
4. **Spouse Relationship to CR.** Binary variable assessing whether CR was a spouse of the caregiver (0=No, 1=Yes).
5. **Caregiver Race (Black/African American).** Binary measure capturing whether caregiver was Black/African American (0=No, 1=Yes).
6. **Caregiver Education.** Binary variable assessing caregiver's education level (0=Less than HS graduate, 1=HS graduate or above).
7. **Caregiver Employment.** Binary variable measuring whether caregiver was working for pay either full or part time (0=No, 1=Yes).
8. **Caregiver Child Care.** Binary measure capturing whether caregiver also cared for children under 18 years old (0=No, 1=Yes).

9. **CR Resists Aid.** Binary variable assessing whether CR resisted caregiver's attempts to provide aid (0=No, 1=Yes).

10. **Caregiver Lives with CR.** Binary variable assessing whether caregiver lives with CR (0=No, 1=Yes).

11. **Other Education.** Single item capturing whether caregiver received educational services from sources other than the selected agency in the past 6 months (0=No, 1=Yes).

12. **Caregiver Age.** Continuous variable assessing caregiver's age (range 21 to 95).

13. **Caregiver Income.** Categorical variable assessing caregiver's annual income (range 1=11,500 dollars or less to 8=More than 70,000 dollars). If the annual income was missing but monthly income was available, the annual income was supplemented with appropriately converted monthly income.

Table 8-1 compares the values of covariates used in matching the full sample of Program and Comparison caregivers (N = 908). Program and Comparison caregivers differed significantly on 11 of the 13 baseline characteristics.

Table 8-1. Comparison of Program and Comparison caregivers before and after propensity score matching: Covariate means or percentages (N = 908)

Baseline covariates	Program caregivers (N = 491)	Comparison caregivers (N = 417)
Caregiver age	68.04	65.27**
Caregiver Black/African American	13.03%	17.27%
Caregiver HS graduate or above	92.06%	88.01%*
Caregiver employed	24.44%	29.26%
Caregiver income category	4.53	3.97**
Caregiving high intensity	45.00%	32.92%***
Caregiver cares for children under 18 years old	7.13%	11.27%*
Caregiver lives with CR	87.98%	75.78%***
Caregiver received other respite services	60.49%	38.85%***
Caregiver received other educational services	34.22%	23.26%**
CR is a spouse	53.16%	43.41%*
CR diagnosed with dementia	62.93%	39.09%***
CR resists aid	34.83%	25.90%**

*p < 0.05, **p < 0.01, ***p < 0.001

Note: Differences in means were calculated on variables with imputed values.

On average, the Program caregivers were older, had higher incomes, and greater caregiving intensity. They were also more likely to be high school graduates, live with CRs, receive other respite and educational services, and less likely to care for children under 18 years of age. Program caregivers' CRs were more likely to be spouses, have a dementia diagnosis, and resist aid.

For each caregiver, the 13 characteristics were included in a logistic regression model to estimate the probability of being in the Program group. The propensity scores obtained with this method were used to create matches between caregivers in the Program and Comparison groups for the sample of caregivers used to analyze the effect of NFCSP respite care services on mental health, physical health, and burden. Matches were also created on the sample of caregivers used to analyze the effect of NFCSP educational services on satisfaction and confidence. After matching, the differences between Program and Comparison caregivers on the 13 baseline characteristics decreased substantially. (See Appendix C: Evaluation Methodology for details about propensity score matching and imputation for missing data.)

8.2 Comparison of Outcomes Between Program Caregivers and Comparison Caregivers

To examine the effect of the NFCSP services on the five caregiver outcomes, the evaluation team conducted a series of D-i-D analyses. This type of analysis looks at the change in outcomes across time for Program caregivers versus Comparison caregivers. For each outcome, the regression model included (1) the outcome score as the dependent variable, (2) the three variables of interest—caregiver group, time (outcome score Time 1 and outcome score Time 2), group by time interaction, and (3) all 13 covariates used in matching for double-robustness (Stuart, 2010). Each model also included *outcome timing*, a binary variable assessing whether the caregiver's latest outcome used in the analysis was collected at 6 months or 12 months (0=6 months, 1=12 months) to adjust for any effect of outcome timing.

8.2.1 Weighted Regression Results – Full Longitudinal Sample

Table 8-2 presents the results of multiple linear regression using the full longitudinal sample (491 Program; 417 Comparison) and predicting outcome scores from Time 1 to Time 2 after propensity score matching (weighted). The table includes unstandardized coefficients (B) for each predictor. The unstandardized coefficients are interpreted as the amount of change in the dependent variable for one unit increase in the independent variable, while controlling for the effect of all other variables in the model.

Table 8-2. Regression results: Effects on outcomes among 908 caregivers

Variable	Coefficient estimates (B) for: Mental health	Physical health	Burden$^+$	Satisfaction	Confidence
Time (reference is baseline)	-0.06	-0.05	0.05	-0.05	0.03
Group (reference is Comparison)	-0.78**	-0.07	0.83***	-0.11	0.07
Time x Group	**0.05**	**-0.07**	**0.05**	**0.00**	**-0.01**
Caregiver age	0.00	-0.02*	0.00	-0.01**	-0.01*
Caregiver Black/African American	0.10	-0.09	-0.74**	0.04	-0.03
Caregiver HS graduate or above	-0.08	0.13	0.76*	-0.19	0.04
Caregiver employed	0.67**	0.87***	-0.01	-0.21*	-0.08
Caregiver income	0.07	0.23***	0.16***	-0.04**	0.00
Caregiving high intensity	0.11	-0.13	0.01	0.25*	0.22**
Cares for children <18 years old	-0.33	-0.31	0.65**	-0.17	0.01
Caregiver lives with CR	-0.43	0.17	0.08	-0.14	0.05
Received other respite services	0.36	0.23	0.23	0.00	0.04
Received other educ services	-0.17	-0.34	0.65	-0.01	-0.13*
CR is spouse	-0.46	-0.42	0.02	-0.05	-0.02
CR diagnosed with dementia	-0.30	0.12	0.81***	-0.06	-0.07
CR resists aid	-1.42***	-0.84***	1.53**	-0.24**	-0.12*
Outcome timing	-0.42*	-0.09	0.27	0.01	-0.06

*p < 0.05, **p < 0.01, ***p < 0.001

Note: Burden is the only outcome score where lower is better.

The first row (for time) shows that time alone did not have a significant effect on caregiver outcomes, meaning that for both groups, the scores did not change significantly from Time 1 to Time 2. The second row (for caregiver group) shows that the Program caregivers have significantly worse scores for Mental health and Caregiver burden. The third row (time x group) shows that the change in the outcome scores was not significantly different for Program and Comparison group from Time 1 to Time 2.

What Do The Results Mean?

The propensity score matched regression models results on the full longitudinal sample of 908 caregivers did not show a significant effect of NFCSP on outcomes (see Table 8-2). The model results show that higher income caregivers had better physical health but higher burden and lower caregiver satisfaction. As expected, caregivers with a CR diagnosed with Alzheimer's disease or dementia had more caregiver burden. Findings on the full longitudinal sample show that caregivers with a CR who resists aid had worse mental health, worse physical health, more caregiver burden, and were less satisfied in caregiving. NFCSP may want to provide more caregiver education and training to help caregivers cope with difficult behaviors from their CRs.

8.2.2 Effect of NFCSP Respite Care on Mental Health, Physical Health, and Caregiver Burden

Caregivers often said "yes" to using NFCSP respite care, but did not provide respite hours that quantifiably supported service use. For this analysis, it was important to have a clear and clean distinction between Program caregivers who used NFCSP respite care and Comparison caregivers who did not use NFCSP respite care.

Studies have found that respite care is an effective intervention for caregiver well-being (Sorrell 2014; Jeon et al. 2005; Hughes et al. 2014, Vandepitte et al., 2016). For example, Richardson et al. (2013), found that lack of time to devote to personal needs contributes to poor caregiver physical and mental health outcomes. For this analysis, the evaluation team wanted a group of Program caregivers who had clearly used NFCSP respite services. Therefore, the Program group caregivers included in the D-i-D analyses had to have reported an average (across interviews) of 4 or more hours of NFCSP respite care per week as their responses to "*How many hours per week of respite care do you usually receive through this program*?" Furthermore, Comparison caregivers who had conflicting use responses across the evaluation period were removed.

Table 8-3 shows the adjusted mean PROMIS Mental health scores for the Comparison group and the Program groups. Time 1 is subtracted from Time 2 to quantify the change in the score. Results indicate that the Comparison group had better Mental health scores. Both groups saw an improvement in Mental health scores from Time 1 to Time 2. The D-i-D (calculations: 0.342 minus 0.325 and 0.024 minus 0.007) is very small at 0.017 and not statistically significant.

Table 8-3. Differences in mean PROMIS Mental health scores for Program and Comparison groups over time

	Mental health		
	Comparison (N = 370)	Program (N = 307)	Difference (C-P)
Time 2	12.636	12.294	0.342
Time 1	12.612	12.287	0.325
Difference (T2-T1)	0.024	0.007	0.017 (D-i-D)

Table 8-4 shows the adjusted mean PROMIS Physical health scores for the Comparison group and the Program groups. Time 1 is subtracted from Time 2 to quantify the change in the score. Both groups saw a decline in Physical health scores from Time 1 to Time 2, with the Program group having more decline. The D-i-D was 0.160 and not statistically significant.

Table 8-4. Differences in mean PROMIS Physical health scores for Program and Comparison groups over time

	Physical health		
	Comparison (N = 370)	Program (N = 307)	Difference (C-P)
Time 2	14.056	13.711	0.345
Time 1	14.085	13.900	0.186
Difference (T2-T1)	-0.029	-0.189	0.160 (D-i-D)

Table 8-5 shows the adjusted mean Zarit Caregiver burden scores for the Comparison group and the Program group. Time 1 is subtracted from Time 2 to quantify the change in the score. The Program group had significantly more Caregiver burden and the Program group also had a (favorable) decrease in their Zarit Caregiver burden mean score from Time 1 to Time 2. More specifically, the results in Table 8-5 indicate that while the Caregiver burden increased for the Comparison caregivers from Time 1 to Time 2 (by 0.145 points), the burden for the Program group decreased by 0.095 points, resulting in the overall adjusted D-i-D of 0.239 points. This difference, however, was not statistically significant.

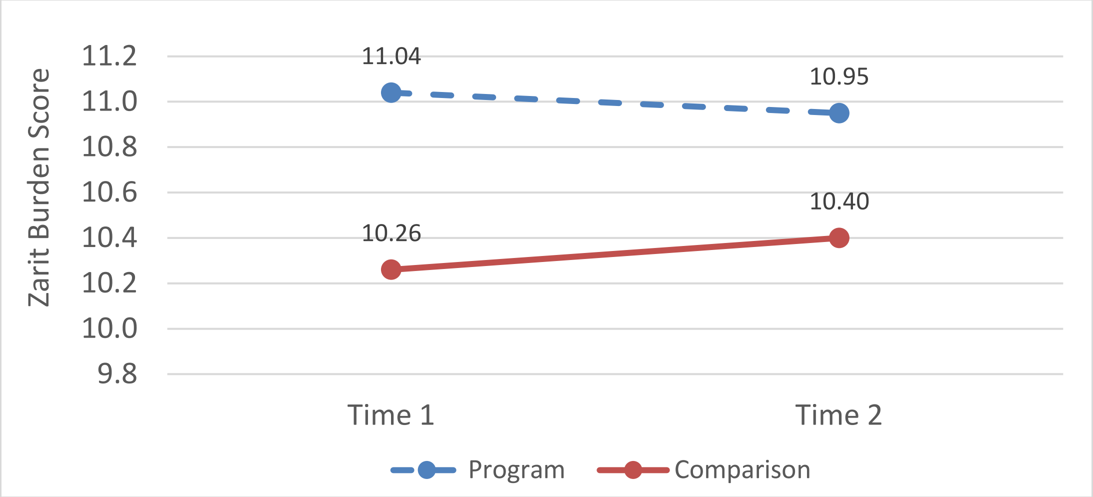
Table 8-5. Differences in mean Zarit Caregiver Burden scores for Program and Comparison groups over time after propensity score adjustment

	Caregiver Burden		
	Comparison (N = 370)	Program (N = 307)	Difference (C-P)
Time 2	10.403	10.947	-0.544*
Time 1	10.258	11.041	-0.784**
Difference (T2-T1)	0.145	-0.095	0.239 (D-i-D)

*p < 0.05, **p < 0.01, ***p < 0.001

Figure 8-1 illustrates the change in mean Caregiver burden scores over time for the two caregiver groups. The Program group's burden (dashed line) decreased, while the Comparison group's burden increased (became worse).

Figure 8-1. **Changes in adjusted mean Zarit Caregiver burden scores for Program and Comparison groups between Time 1 and Time 2**



What Do These Results Mean?

Although the result was not statistically significant, the D-i-D analysis that controlled for thirteen covariates, such as respite care from other sources and caregiving intensity, did find a reduction in caregiver burden among the Program caregivers but not among the Comparison caregivers. Because the sample of Program caregivers was restricted to only those receiving 4 or more hours of respite per week, this finding suggests that there may be a certain minimum amount of respite care needed to reduce caregiver burden. It is worth noting that Program caregivers reported experiencing more burden than the Comparison caregivers at both Time 1 and Time 2, implying that the caregivers who received NFCSP respite care were in greater need of support to reduce burden.

The D-i-D analysis did not find any significant differences in the change in the mental health or physical health between the Program caregivers and the Comparisons caregivers. Both groups of caregivers had small improvements in mental health over time and both had declines in physical health.

8.2.3 Effect of NFCSP Educational Services on Satisfaction and Confidence

Because the goal of providing caregiver educational services is to increase caregivers' ability to provide care, to cope, and to handle CRs' challenging behaviors (Graff et al., 2006), it was hypothesized that education amount would be most relevant to improve Caregiver satisfaction and confidence. In analyzing the effect of NFCSP services on Caregiver satisfaction and confidence, the evaluation team wanted a group of Program caregivers who had clearly used NFCSP educational services. Therefore, the Program group caregivers included in the D-i-D analyses had to have reported using an educational service at least once during the evaluation timeframe. Note that more NFCSP Program caregivers used respite than educational services, so this inclusion criteria greatly reduced the number of Program caregivers in the D-i-D analysis.

The amount of NFCSP educational services was calculated by using the responses to "how many times" questions described in Chapter 4.1 of this report. The number of times a caregiver used educational services was averaged across time for each caregiver. (See Appendix C: Evaluation Methodology for more details.) The aforementioned restrictions reduced the Program group by 86 percent (from 491 to 71) and the Comparison group by 16 percent (from 417 to 352).

Table 8-6 shows the adjusted mean Caregiver satisfaction scores for the Comparison group and the Program group. Time 1 is subtracted from Time 2 to quantify the change in the score. Both groups experienced an increase in satisfaction across time. The Comparison group had higher caregiver satisfaction; the differences were not significant, but this could be due to the smaller sample size. The overall D-i-D of 0.021 is very small and not statistically significant.

Table 8-6. Differences in mean Caregiver satisfaction scores for Program and Comparison groups over time

	Caregiver satisfaction		
	Comparison (N = 352)	Program (N = 71)	Difference (C-P)
Time 2	4.014	3.812	0.202
Time 1	3.965	3.784	0.182
Difference (T2-T1)	0.049	0.028	0.021 (D-i-D)

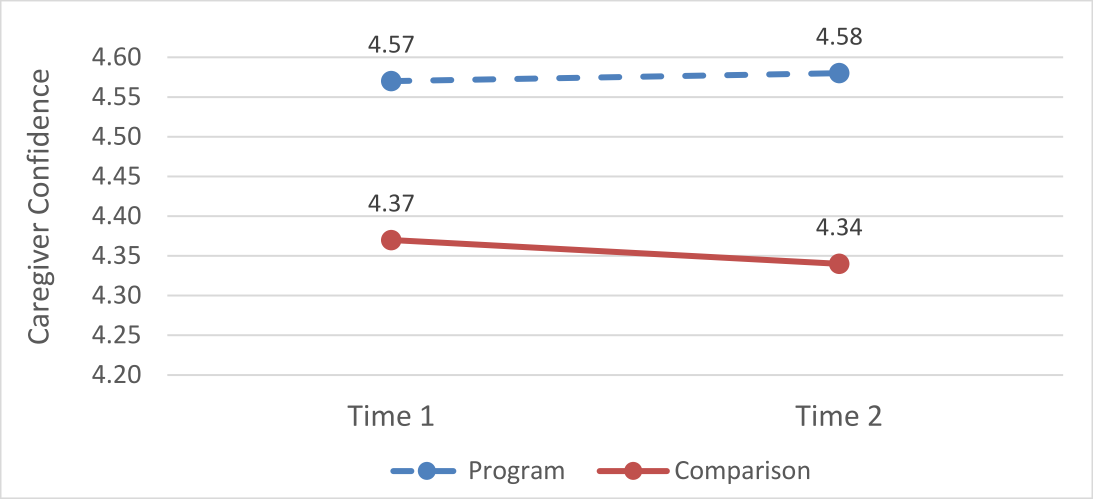
Table 8-7 shows the adjusted mean Caregiver confidence scores for the Comparison group and the Program group. Time 1 is subtracted from Time 2 to quantify the change in the score. The Comparison caregivers' confidence decreased from Time 1 to Time 2, while the mean score increased for the Program caregivers. The overall D-i-D was -0.05, but not statistically significant.

Table 8-7. **Differences in mean Caregiver confidence scores for Program and Comparison groups over time**

	Caregiver confidence		
	Comparison (N = 352)	**Program (N = 71)**	**Difference (C-P)**
Time 2	4.339	4.583	-0.245
Time 1	4.374	4.569	-0.195
Difference (T2-T1)	-0.036	0.014	-0.050 (D-i-D)

Figure 8-2 depicts the change in adjusted mean Caregiver confidence scores over time.

Figure 8-2. **Changes in mean Caregiver confidence scores for Program and Comparison groups between Time 1 and Time 2**



What Do These Results Mean?

Both groups of caregivers had small improvements in caregiver satisfaction over time. Although not statistically significant, the D-i-D analysis found an increase in caregiver confidence among the Program caregivers but not among the Comparison caregivers.

9. Results from the Care Recipient Survey

CRs were interviewed at baseline (N = 1,338) and 12 months (N = 212). There were 206 dyads of caregivers with CRs who were interviewed at both baseline and 12-months.

9.1 Survey Items

In addition to "Caregiver Receives Needed Help" (see Section 5.1.13), below are the five questions from the CR survey:

1. **Quality of Life Rating.** CR's rating of his/her quality of life (1=Poor to 5=Excellent).
2. **Mental Health Rating.** CR's rating of his/her mental health, including mood and ability to think (1=Poor to 5=Excellent).
3. **Social Activities Satisfaction Rating.** CR's rating of his/her satisfaction with social activities and relationships (1=Poor to 5=Excellent).
4. **Frequency of Emotional Problems.** CR's frequency of being bothered by emotional problems such as feeling anxious, depressed, or irritable in the past 7 days (1=Never to 5=Always).
5. **Remain at Home.** CR's perceived importance of having a caregiver in helping him/her remain living at home (1=Not at all important to 3=Very important).

The baseline frequencies for all of the above variables are provided in Appendix F.

9.2 Care Recipient and Caregiver Well-Being

For those CRs who were part of a caregiver-CR dyad and had both baseline and 12-month data (N = 206), the evaluation team compared the CR responses to the quality of life and well-being items by caregiver group assignment (Program, N = 91 versus Comparison, N = 115) at baseline and at 12 months. Results, presented in Table 9-1, indicate that, on average, caregivers and CRs did not differ significantly on any of the quality of life and well-being measures at baseline.

Table 9-1. Comparison of care recipients' responses and caregivers' responses on the quality of life and well-being measures at baseline and at 12 months

Measure	Baseline		12 months	
	CRs	Caregivers	CRs	Caregivers
Quality of life rating	3.01	3.13	3.12	3.11
Mental health rating	3.26	3.30	3.35	3.35
Social activities satisfaction rating	2.99	2.93	2.87	3.07
Frequency of emotional problems	2.52	2.44	2.44	2.43

As shown in Table 9-2, at baseline, a higher CR mental health rating was associated with a higher caregiver mental health rating (Spearman's correlation coefficient, $r_s = 0.18$, $p = 0.0095$). There was also a positive association between CR and caregiver rating of satisfaction with social activities ($r_s = 0.19$, $p = 0.0065$).

Table 9-2. Correlations between care recipients' responses and caregivers' responses on the quality of life and well-being measures at baseline (N = 206 dyads)

Measure	CG quality of life rating	CG mental health rating	CG social activities satisfaction rating	CG frequency of emotional problems
CR quality of life rating	0.10	0.02	0.00	-0.01
CR mental health rating	0.10	0.18**	0.11	-0.14
CR social activities satisfaction rating	0.11	0.07	0.19**	-0.08
CR frequency of emotional problems	-0.07	-0.06	-0.07	0.15*

*p < 0.05, **p < 0.01, ***p < 0.001

Notes: CG=Caregiver.

Table 9-3 presents correlations at 12 months. Greater CR satisfaction with social activities was related to greater caregiver quality of life rating ($r_s = 0.20$, $p= 0.0053$).

Table 9-3. Correlations between care recipients' responses and caregivers' responses on the quality of life and well-being measures at 12 months (N = 206 dyads)

Measure	CG quality of life rating	CG mental health rating	CG social activities satisfaction rating	CG frequency of emotional problems
CR quality of life rating	0.13	0.11	0.09	-0.08
CR mental health rating	0.12	0.25***	0.12	-0.08
CR social activities satisfaction rating	0.20**	0.13	0.13	-0.11
CR frequency of emotional problems	-0.05	-0.14*	-0.04	0.13

*p < 0.05, **p < 0.01, ***p < 0.001

Note: CG=Caregiver.

What Do These Results Mean?

Among 206 caregiver-CR dyads, the comparison of responses showed that mental health was correlated; CRs with better mental health had caregivers with better mental health and fewer emotional problems. Interestingly, greater CR satisfaction with social activities was related to higher caregiver quality of life rating. These findings suggest that some aspects of mental health and well-being may not be independent, but instead shared between CRs and caregivers who may be influencing each other in dynamic, bidirectional ways (Wolff et al., 2016). Furthermore, interventions or programs targeting CR social activities may have a positive effect on both the caregiver and the CR.

10. Summary

10.1 Profile of Caregivers and Care Recipients

The mean age of caregivers who took the survey at baseline was 66 years, and 55 percent were age 65 or older. However, this is an older group of caregivers than the nationally reported mean age of 49 years among all informal caregivers (National Alliance for Caregiving & AARP, 2015) or the reported mean age of 59 among caregivers of Medicare recipients surveyed as part of the National Health and Aging Trends Study (Riffin et al., 2017). This is because the evaluation only included informal caregivers of CRs who were age 60 and older and caregivers of CRs of any age diagnosed with Alzheimer's disease and/or related memory disorders. Forty-three percent of the caregivers in the evaluation were a spouse of the CR, a statistic higher than the nationally reported 10 percent of caregivers (National Alliance for Caregiving & AARP, 2015).

Similar to national statistics, 61 percent of caregivers were female and 44 percent were children of the CR (National Alliance for Caregiving & AARP, 2015). Among caregivers taking care of their parents, 54 percent said it was true that they were chosen by their family as a child to provide care for all family members. From 43 different states, 78 percent of the caregivers were White, 17 percent Black or African American, and 5 percent reported other race. Almost one-fourth of caregivers said that they had to stop working because of their caregiving responsibilities, a common situation among informal caregivers (Feinberg, 2013).

The mean age of CRs was 81 years. Two-thirds of the CRs were diagnosed with arthritis, and half of the CRs were diagnosed with Alzheimer's disease, dementia, or a memory problem. Almost one-third of caregivers said they had a CR who resisted aid.

The activities performed by the highest percentage of caregivers at any time were keeping track of money or bills, helping to prepare meals, and helping with housework. On a daily basis, however, the most common type of assistance was with medications and preparing meals. On a weekly basis, three-fourths of caregivers helped with the CR's medications including administering intravenous fluids and injections, activities that become more difficult if the CR has a complex chronic condition or has recently been hospitalized (Moon et al., 2017).

The caregiving activity deemed the most difficult was bathing or showering. Interestingly, 71 percent of CRs needed assistance with this ADL, but among those with bathing assistance needs, 21 percent of the caregivers were not providing that help. This is an important area for further research to learn whether the CR is receiving other assistance with bathing or showering, or is struggling to perform this activity himself or herself.

With the exception of caregiver confidence, the NFCSP Program caregivers had worse outcomes at baseline than the Comparison caregivers. There was a decline, or worsening, in caregiver self-reported physical health during the evaluation period. The caregiver burden worsened slightly over time. A drill-down into the individual items suggest that the caregivers were feeling stressed between caring for the CR and trying to meet other responsibilities, and feeling as though they did not have enough time for themselves. Similar to study findings by Hughes et al. (2014), caregivers who responded that they were "definitely not" receiving all they help they need had a significantly higher mean caregiver burden score than those who did not respond with "definitely not".

10.2 NFCSP Service Use, Effectiveness, Targeting, and Perceived Helpfulness

More caregivers used NFCSP respite care than education/training, individual counseling, and support group services combined. Among the caregivers who used respite at baseline, 86 percent said the service was very helpful and 42 percent deemed respite care the most helpful service received from their AAA. However, among those on the NFCSP client list who did not use respite care at baseline, one-third reported that they did not know that the agency offered the service. Among the caregivers who used an educational service, 75 percent said the service was very helpful. Among those on the NFCSP client list who did not use educational services, 56 percent of caregivers reported that they did not know that the agency offered these services.

This evaluation found that Program caregivers who received four or more hours of respite per week experienced a decrease in self-reported caregiver burden over time while the Comparison caregivers without NFCSP respite experienced an increase in caregiver burden. The second key finding of the evaluation was that Program caregivers who used education, counseling, or support group services experienced an increase in caregiver confidence while Comparison caregivers' confidence decreased during the evaluation timeframe.

Among the caregivers receiving NFCSP respite care, higher respite hours were associated with a significantly higher likelihood of responding "Definitely yes" when asked if the services they received from their AAA enabled them to continue caregiving. The evaluation team found similar results with the number of times a caregiver used educational services, but the strength of the educational times association with service enabling continued caregiving was not as high as the respite amount. At the AAA level, the "Definitely yes" frequency of responses to the Continued caregiving question was higher for caregivers who were clients of AAAs that assessed client satisfaction more often than annually, in comparison to the caregivers with AAAs with less frequent assessments.

The evaluation did find evidence that NFCSP services are reaching one of the five groups of caregivers with greatest social or economic need. More specifically, the caregivers who were Hispanic, Black, or other (approximately 25% of the sample) used more respite care hours than White caregivers. However, when caregivers were categorized by a summary of socioeconomic indicators (with an SES need index), the index was not associated with the NFCSP respite hours. The evaluation also found that caregivers younger than 60 years old were receiving more respite hours. One could hypothesize that younger caregivers have more competing responsibilities that necessitate the need for longer hours of respite.

In contrast to the SES need, the evaluation did find that NFCSP services are reaching the caregivers with more caregiver burden. First, in propensity matching for the D-i-D analysis (Chapter 8, Table 8-1), the following caregiver characteristics were associated with the receipt of NFCSP respite care: older age, greater caregiving intensity, living with CR, CR being a spouse, CR having Alzheimer's disease or dementia diagnosis, and CR resisting aid. Second, the analysis with AAA process data found that caregivers of the AAAs that included the impact of caregiving in their needs assessment had significantly higher mean burden scores in comparison to caregivers in the AAAs that did not include such evaluation. These findings suggest that agency procedures and policies are targeting the caregivers with the most caregiving burden. Yet, are agencies equipped with the right tools to gauge change in burden across the caregiving continuum and provide caregiver services and support in a timely and efficient manner? NFCSP caregiver services are helping our nation's informal caregivers, but more research is needed to better understand how to determine the ideal amount of NFCSP support for each caregiver to make a difference in their outcomes and longevity as a caregiver.

10.3 Evaluation Strengths and Limitations

This was the first national longitudinal survey of caregivers designed to evaluate the NFCSP. The strengths of the evaluation include the use of a comparison group of caregivers and standardized outcome measures to measure change in caregiver burden and well-being. Furthermore, the survey instrument items were designed to parse out caregivers' use of NFCSP respite care and educational services separately. Lastly, the caregiver data collected in the evaluation coupled with the AAA-level data collected during the process evaluation allowed for the investigation into what types of organizational structures, approaches, and strategies for delivering NFCSP services are associated with optimal participant-level outcomes.

Although the evaluation used sophisticated techniques to randomly select a nationally representative sample of caregivers, the non-response bias of caregivers who chose not to participate is unknown, and thus, a limitation to the evaluation. At baseline, 45 percent of caregivers who received recruitment letters and phone calls either never responded to outreach attempts or opted out of participation. Most likely, there are non-random differences between caregivers who participated in the evaluation and caregivers who did not (i.e., non-response bias). Lastly, one drawback of the 12-month timeframe, as opposed to a 24-month or longer timeframe, is that a longer timeframe may have resulted in a greater amount of measureable change in caregiver outcomes. However, the shorter timeframe likely lent itself to greater retention of caregivers for follow-up data collection.

Conclusion

The outcome evaluation shows that the caregiver services provided by the NFCSP are effective in reducing caregiver burden, increasing caregiver confidence and increasing the caregivers' perception that the services are helping them continue caregiving. The evaluation found that NFCSP does successfully target caregivers with the most caregiving burden. Consistent with other studies focused on caregiver services, the findings from this evaluation suggest that the amount of caregiver services provided by NFCSP matters and that there may be an ideal amount of respite care needed to reduce burden and an ideal amount of education/training, counseling and support group services to improve confidence.

References

Administration for Community Living. (2018). Results from 12th National Survey of Older Americans Act Participants (NSOAAP): Caregiver. Retrieved from https://agid.acl.gov/Resources/DataSources/.

Administration for Community Living. (2017). Aging Integrated Database: National Survey of OAA Participants. Retrieved from https://agid.acl.gov/CustomTables/NPS/Data/.

Aranda, M.P., and Knight, B.G. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: a sociocultural review and analysis. *The Gerontologist, 37*(3):342-54.

Bedard, M., Molloy, D.W., Squire, L., Dubois, S., Lever, J.A., and O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist, 41*, 652-657.

Brock, D., Rabinovich, B., Severynse, J., and Ficke, R. (2011). Risk factors for nursing home placement among Older Americans Act service recipients. Washington, DC: Administration on Aging, U.S. Department of Health and Human Services.

Carlozzi, N.E., Ianni, P.A., et al. (2018).Understanding health-related quality of life of caregivers of civilians and service members/veterans with traumatic brain injury: Establishing the reliability and validity of PROMIS social health measures. *Arch Phys Med Rehabil,* Jul 31.

Clay, O.J., Roth, D.L., Wadley, V.G., and Haley, W.E. (2008). Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and White dementia caregivers. *Int J Geriatr Psychiatry, 23*(8):857-62.

Dept. of Health and Human Services. Administration for Community Living. (2018). Fiscal Year 2019 Justification of Estimates for Appropriations Committees. Accessible at https://www.acl.gov/sites/default/files/about-acl/2018-05/FY2019ACL-CJ3.pdf.

Dilworth-Anderson, P., William, I.C., and Gibson, F.E. (2012). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *The Gerontologist,* 42:237-272.

Feinberg, L. (2013). Keeping up with the times: supporting family caregivers with workplace leave policies (Washington, DC: AARP Public Policy Institute). Retrieved from https://www.aarp.org/home-family/caregiving/info-06-2013/supporting-family-caregivers-with-workplace-leave-policies-AARP-ppi-ltc.html.

Graff, M.J.L., Vernooij-Dassen, M.J.M, et al. (2006). Community based occupational therapy for patients with dementia and their caregivers: Randomized controlled trial. *BMJ 333*, 1196-1199.

Griffin, J.M., Meis, L., Greer, N., et al. (2013). *Effectiveness of family and caregiver interventions on patient outcomes among adults with cancer or memory-related disorders: A systematic review* (VA-ESP Project #09-009). Washington, DC: U.S. Government Printing Office.

Haley, W., LaMonde, L., Han, B., Burton, A., and Schonwetter, R. (2003). Predictors of depression and life satisfaction among spousal caregivers in hospice: Application of a stress process model. *J Palliat Med, 6*(2):215-24.

Hays, R.D., Bjorner, J.B., Revicki, D.A., Spritzer, K.L., and Cella, D. (2009). Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. *Quality of Life Research, 18*(7):873-880.

Hughes, T.B., Black, B.S., and Albert, M. (2014). Correlates of objective and subjective measures of caregiver burden among dementia caregivers: Influence of unmet patient and caregiver dementia-related care needs. *Int Psychogeriatr, 26*(11):1875-83.

Ivey, K., Allen, R.S., Liu, Y., Parmelee, P.A., and Zarit, S.H. (2017). Immediate and lagged effects of daily stress and affect on caregivers' daily pain experience. *The Gerontologist,* [epub] https://doi.org/10.1093/geront/gnx099.

Jeon, Y.H., Brodaty, H., and Chesterson, J. (2005). Respite care for caregivers and people with severe mental illness: Literature review. *J Adv Nurs, 49,* 297-306.

Lee, C.C., Czaja, S.J., and Schulz, R.S. (2010). The moderating influence of demographic characteristics, social support, and religious coping on the effectiveness of a multicomponent psychosocial caregiver intervention in three racial ethnic groups. *J Gerontol B Psychol Sci Soc Sci, 65B*(2):185-194.

Li, L.W., and McLaughlin, S.J. (2011). Caregiver confidence: Does it predict changes in disability among elderly home care recipients? *The Gerentologist, 52*(1), 79-88.

Moon, M. (2017). The unprepared caregiver. *The Gerontologist, 57(1):*26–31.

National Academies of Sciences, Engineering, and Medicine. (2016). Families caring for an aging America. Washington, DC: The National Academies. Press. doi: 10.17226/23606.

National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S. Washington, D.C.: AARP Public Policy Institute. Retrieved from http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf.

O'Brien, E., Wu, K.B., and Baer, D. (2010). Older Americans in poverty: a snapshot. AARP Public Policy Institute. Retrieved from https://assets.aarp.org/rgcenter/ppi/econ-sec/2010-03-poverty.pdf.

Ornstein, K.A., Kelley, A.S., Bollens-Lund, E., and Wolff J.L. (2017). A national profile of end-of-life caregiving in the United States. *Health Aff, 36*(7), 1184-1192.

Pearlin, L.I., Mullan, J.T., Semple, S.J., and Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30,* 583-594.

Polenick, C.A., Leggett, A.N., Webster, N.J., Han, B.H., Zarit, S.H., and Piette, J.D. (2017). Multiple chronic conditions in spousal caregivers of older adults with functional disability: Associations with caregiving difficulties and gains. *J Gerontol B Psychol Sci Soc Sci.* doi: 10.1093/geronb/gbx118. [Epub ahead of print].

Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2017. Public Law No: 115-119.

Reinhard, S.C., Levine, C., and Samis, S. (2014). Family caregivers providing complex chronic care to their spouses. Washington, DC: AARP Public Policy Institute, Retrievable at https://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/2014/family-caregivers-providing-complex-chronic-care-spouses-AARP-ppi-health.pdf.

Richardson, T.J., Lee, S.J., Berg-Weger, M., and Grossberg, G.T. (2013). Caregiver health: Health of caregivers of Alzheimer's and other dementia patients. *Current Psychiatry Reports, 15*:367.

Riffin, C., Van Ness, P.H., Wolff, J.L., Fried, T. (2017) Family and Other Unpaid Caregivers and Older Adults with and without Dementia and Disability. *Journal of the American Geriatrics Society, 65*, 1821-1828.

Rozario, P.A., and DeRienzis, D. (2008). Familism beliefs and psychological distress among African American women caregivers. *The Gerontologist, 48*(6):772-780.

Shin, J.Y., Pohlig, R.T., Habermann, B. (2018). Feasibility of Using PROMIS in Individuals With Advanced Parkinson's Disease and Their Caregivers. *Res Gerontol Nurs.* 2018 May 1;*11*(3):129-136.

Shugrue, N., Kellett, K., Gruman, C., Tomisek, A., Straker, J., Kunkel, S., and Robison, J. (2017). Progress and policy opportunities in family caregiver assessment: Results from a national survey. *J Appl Gerontol.* doi: 10.1177/0733464817733104. [Epub ahead of print].

Smith, G., Williamson, G., Miller, L., and Schulz, R. (2011). Depression and quality of informal care: A longitudinal investigation of caregiving stressors. *Psychol Aging, 26*(3):584-91.

Sorrell, J.M. (2014). Moving beyond caregiver burden: identifying helpful interventions for family caregivers. *Journal of Psychosocial Nursing and Mental Health Services, 52*(3):15-18.

Stuart, E.A. (2010). Matching methods for causal inference: A review and a look forward. *Statistical Science,* 25(1), 1-21.

The Lewin Group. (2016). Process Evaluation of the Older Americans Act Title III-E National Family Caregiver Support Program: Final Report. Prepared for the Administration for Community Living. Retrieved from https://www.acl.gov/sites/default/files/programs/2017-02/NFCSP_Final_Report-update.pdf.

U.S. Department of Health and Human Services. (2018). *Poverty guidelines.* Retrieved from https://aspe.hhs.gov/poverty-guidelines.

Vandepitte, S., Van Den Noortgate, N. et al. (2016). Effectiveness of respite care in supporting informal caregivers of persons with dementia: A systematic review. *Int J Geriatr Psychiatry*, *31*(12):1277-1288.

Van Houtven, C., Voils, C., and Weinberger, M. (2011). An organizing framework for informal caregiver interventions: detailing caregiving activities and caregiver and care recipient outcomes to optimize evaluation efforts. *BMC Geriatrics, 11*, 77.

Vellone, E., D'Agostino, F., Buck, H.G., Frida, R., Spatola, C.F., Petruzzo, A.,…Riege., B. (2015). The key role of caregiver confidence in the caregiver's contribution to self-care in adults with heart failure. *European Journal of Cardiovascular Nursing, 14(5)*, 372-81.

Wolff, J.L., Spillman, B.C., Freedman, V.A., and Kasper, J.D. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine, 176*(3):372-379.

Zarit, S.H., Reever, K.E., and Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20,* 649–655.