

Understanding the NFCSP

Evaluating Caregiver Supports and Services

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Background

The National Family Caregiver Support Program (NFCSP) was established in 2000 to fund support programs to assist informal caregivers in caring for a recipient in the home (Administration for Community Living [ACL], 2019). The NFCSP provides grants to states and territories for five types of services: (i) informational resources to caregivers about available services; (ii) assistance to caregivers in accessing services; (iii) individual counseling, support groups, and caregiver training; (iv) respite care; and (v) supplemental services on a limited basis (ACL, 2019b).

Given the extensive reach of NFCSP and the multi-layered structure through which caregivers access assistance, ACL sought to gauge the impact of its investment in NFCSP. ACL has embarked on a comprehensive evaluation of program efficiencies, progress towards outcomes, and how the program delivers services and supports to family caregivers and those for whom they provide care.

This brief serves as a summary review of the three NFCSP evaluations coordinated by ACL. For a more detailed discussion of the history of the NFCSP, and family caregiving in general, please refer to the companion to this brief: *ACL Supports for Family Caregivers across the Lifespan*.

Evaluation of the NFCSP

The recent NFCSP Evaluation is its first full-scale assessment. The results presented here are the culmination of a multi-year effort by ACL to evaluate the program's design and operation at the state, local, and provider levels, and to assess its impact on the family caregivers it serves.

Table 1 below summarizes the two-part evaluation.

The following specific populations of caregivers are eligible to receive services under the NFCSP:

- Adult family members or other informal caregivers age 18 and older providing care to individuals 60 years of age and older
- Adult family members or other informal caregivers age 18 and older providing care to individuals of any age with Alzheimer's disease and related disorders
- Older relatives (not parents) age 55 and older providing care to children under the age of 18; and
- Older relatives, including parents, age 55 and older providing care to adults ages 18-59 with disabilities



In addition to the two evaluations, ACL conducted a study to expand on findings through phone-based retrospective interviews with caregiver participants whose care recipient passed away. This special study was completed in 2018 and findings are included in this report where applicable.

Table 1: Summaries of NFCSP Evaluations Funded by ACL

	Process Evaluation	Outcome Evaluation
Population	State Units on Aging (SUAs), Area Agencies on Aging (AAAs), and Local Service Providers (LSPs)	Nationally representative sample of NFCSP caregivers, non-NFCSP caregivers, and care recipients from both groups
Methodology	Survey of network agencies and providers	Longitudinal survey of three survey groups
Dates Active	2015 - 2016	2014 - 2018
Evaluation Team	The Lewin Group	Westat
Final Report	https://acl.gov/sites/default/files/programs/2017-02/NFCSP_Final_Report-update.pdf	https://acl.gov/sites/default/files/programs/2018-12/Caregiver_Outcome_Evaluation_Final_Report.pdf

Process Evaluation

The process evaluation is part of a two-phase approach to the NFCSP evaluation with a specific focus on assessing service delivery to caregivers of older adults through the Aging Services Network. Research questions include:

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

A survey was administered to all 54 states and territories that operate an NFCSP, all 619 AAAs active at the time of the survey, and a sample of LSPs from the responding AAAs.

Outcome Evaluation

This was the first national longitudinal survey of caregivers designed to evaluate the NFCSP. The four key evaluation questions include:



- In conjunction with information from the process evaluation, what types of organizational structures and/or approaches for NFCSP services are associated with the best participant-level outcomes?
- Are services reaching the groups targeted by the Older Americans Act (OAA), including caregivers serving older adults with greatest social or economic need?
- To what extent do NFCSP service participants also receive other home- and community-based (HCBS) long-term support and services (LTSS), and what is the relationship among these services?
- To what extent do NFCSP program participants' outcomes differ from those of caregivers who do not receive support and services from the NFCSP?

The NFCSP outcome evaluation draws on information obtained from telephone-based surveys of a random sample 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).

Survey data collected in the outcome evaluation coupled with the AAA-level data collected during the process evaluation allow for investigation into what types of organizational structures, approaches, and strategies for delivering NFCSP services are associated with optimal caregiver-level outcomes.

Bereaved Caregiver Supplementary Study

Data at a Glance

- Among NFCSP caregivers, 24% (n = 298) said they received caregiver education/training, individual counseling, or support group services in the past six months.
 - Support group services (52%) had the most utilization, followed by caregiver education or training such as classroom or online courses (36%), and individual counseling (24%).
 - Three quarters of the caregivers (75%) said the service was very helpful.
- Caregivers who attended at least one education/training, counseling, or support group session saw an increase in self-reported confidence over time. In contrast, comparison caregivers showed a decrease in their mean confidence scores.

In the course of the outcome evaluation, some caregivers participating became ineligible to complete the final interview because the care recipient had passed away. Recognizing the unique opportunity to gain insight into how caregivers' need for support changes during the end-of-life phase of care, ACL funded a small retrospective study of these bereaved caregivers as a supplement to the process and outcome evaluations.

Key questions for this study include the following:

- What were the circumstances that directed/led caregivers to services?
- What supports, either formal or informal, were caregivers receiving?

- How did the caregiver’s support needs evolve over the course of the caregiving experience?
- What supports were caregivers offered or did they need after their care recipients passed away? If none were offered, what did they need?

Telephone interviews were conducted with caregivers who were previously engaged in the outcome evaluation, and who self-selected to take part in the study. A qualitative analysis of interview transcripts identified overarching themes, as exemplified in the call-out box above.

Evaluation Results

Caregiver Education and Emotional Support

The outcome evaluation found that there was an increase in caregiver confidence among caregivers who used NFCSP educational services. This finding is consistent with previous studies that found that education and emotional support services are effective in increasing caregiver confidence (Vandepitte et al., 2016). Confident caregivers are more likely to engage in caring for family members with complex medical needs (Vellone et al., 2015) leading to more positive outcomes (Li & McLaughlin, 2011).

Among bereaved caregivers, over half (63%) accessed support group services through the NFCSP. Individual counseling saw an identical rate of usage, but it is interesting to note that all caregivers who accessed individual counseling did so through their hospice program, after a significant decline in their care recipient’s condition. This suggests that, while caregivers may actively seek emotional supports from other caregivers, more formal supports may not result in a need until the end-of-life phase of care (Lewin, 2019).

Among caregivers who had lost their care recipient, caregivers who had accessed emotional support services were less likely to report depression, significant stress, or complicated grief than those who did not make use of emotional support services. This may suggest support for the theory of anticipatory grief, where providing care to a loved one during the end-of-life phase, coupled with sufficient emotional supports, can help a caregiver cope with the impending loss and may lessen the severity of the bereavement period (Nielsen et al., 2016; Lewin, 2019).

Caregivers who utilized NFCSP educational services showed increased confidence with caregiving over time (Westat, 2018).

Strengthening Long-Term Care (LTC) Integration and Efficiency

Data at a Glance

- Prior to the enactment of the NFCSP in 2000, half of the SUAs and AAAs had no caregiver program. Since the program began
 - Twice as many AAAs deliver respite care now as did before 2000.
 - More than three times as many AAAs now offer caregiver support groups and caregiver training and education.
 - More than nine times as many AAAs now provide caregiver counseling.
- More than two thirds of SUAs reported a lack of integration at the State level
 - SUAs cite barriers such as: (1) different eligibility requirements, (2) different populations, (3) different reporting requirements, and (4) organizational, cultural, and administrative differences.

While not the main goal of the NFCSP, the process evaluation examined the partnership involvement of SUAs and AAAs within the broader LTC system. Although AAA data illustrate a variety of partners for implementing the NFCSP, the SUAs reported limited partnerships with other state agencies to implement the program, and the NFCSP process evaluation results indicate an opportunity for the NFCSP to become better integrated with other HCBS programs (Lewin, 2016).

This is reflected in the extent to which caregivers using NFCSP services also receive other HCBS (e.g., home delivered meals, homemaker services, home modifications, legal assistance). The outcome evaluation found no differences in HCBS access between NFCSP and non-NFCSP caregivers. Caregivers receiving other HCBS may subsequently become aware of and initiate NFCSP respite or educational services, either on their own or through introduction to the NFCSP caregiver services by the organization providing HCBS (Westat, 2018).

Monitoring and Assessment

Data at a Glance

- More than half of the SUAs reported using a standardized caregiver assessment tool.
- Among SUAs, 81% responded that they assessed both the care recipient and the caregiver.
- Of the AAAs included in the process evaluation, the following monitoring procedures were reported:
 - Satisfaction Survey of Program Participants (75%);
 - Feedback Mechanism (e.g., complaint mechanism, comment box) (39%);
 - Monitoring of Client ADL/IADL Functioning (24%); and
 - AAA Does Not Conduct Program Participants Assessment of Services (11%).
- 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.

SUAs, AAAs, and LSPs were asked many questions about caregiver assessments. The number of SUAs reporting on a standardized caregiver assessment suggests that states are aiming to meet caregivers' diverse needs and preferences. However, few AAAs reported comprehensive monitoring of caregiver outcomes.

These organizations most frequently reported using the results for managing caregiver services and for program planning. Although many organizations conduct satisfaction surveys annually, tracking additional caregiver outcomes over time—burden, depression, unmet needs, and positive caregiver experiences, to name a few—could facilitate the monitoring of program impacts and lead to the identification of areas for improvement (Lewin, 2016).

Additionally, SUAs and AAAs currently employ targeting methods to reach vulnerable caregiver populations, with AAAs highlighting outreach to vulnerable populations through partnerships (e.g., with schools, employers, VA systems) (Lewin, 2016). This is supported by data from the outcome evaluation indicating that AAAs who capture the impact of caregiving in needs assessments have higher mean burden scores than those that do not. These findings suggest that agencies not only have procedures and policies in place to identify high need caregivers, but that they are successfully targeting the caregivers with the most burden.

The following caregiver characteristics are associated with increased burden:

- Older age;
- Cohabitation with CR;
- CR being a spouse;
- CR having Alzheimer's disease or dementia diagnosis; and
- CR resisting aid.

(Schulz & Sherwood, 2008)

Respite Care

Data at a Glance

- AAAs reported that the type of information caregivers request most often concerns respite care (75%).
- At baseline, 43% (n = 522) of NFCSP caregivers said they received respite care from their AAA in the past six months—mainly in their home.
 - Among those, the median number of NFCSP respite hours used each week was six.
 - Among the caregivers who used respite at baseline, 86% said the service was very helpful.
 - Respite care was deemed the most helpful service received from their AAA's by 42% of caregivers.
- NFCSP caregivers who received four or more hours of respite care per week had a decrease in self-reported burden over time, while the comparison group experienced an increase in self-reported burden.
- Increased respite hours per week correlated with the probability of a more favorable response from caregivers when asked if the services they received made caregiving possible for longer.

Of all NFCSP services, respite care is the most essential and noted as consistently in high demand by caregivers, particularly those whose care recipient is in the end-of-life phase of care. Among bereaved caregivers, respite care was the most commonly accessed service (88%) and was frequently cited as the most valuable service received (75%). When asked about the need for additional service capacity, the most popular caregiver responses included having access to respite on a more frequent basis (63%), for longer periods of time (63%), and on an overnight basis (38%) (Lewin, 2019).

While previous studies have found that respite care can reduce burden among caregivers, the

Respite care is shown to significantly reduce caregiver burden, explaining why it is the service most often requested and most highly valued by caregivers (Lewin, 2016; Westat 2018; Lewin, 2019).

outcome evaluation found that NFCSP caregivers receiving four or more hours of respite each week experienced a significant decrease in burden. This suggests that caregiver burden is likely particularly sensitive to the amount of respite care received. This research suggests that a minimum amount of respite care needed to reduce caregiver burden is worth further exploration (Brock et al., 2011; Griffin et al., 2013; Westat, 2018). This finding is particularly relevant for caregivers experiencing increasing burden such as those who are caring for family members nearing the end-of-life.

Coordination of NFCSP Services

Data at a Glance

- Among NFCSP 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.
- Among those on the NFCSP recipient list who did not use educational services, 56% of caregivers reported that they did not know that the agency offered these services.
- Approximately one third of local service providers (LSPs) contacted during study recruitment were unfamiliar with the NFCSP or were unaware that it funded all or part of their caregiving services.

Reports from participants in the outcome evaluation indicate a substantial gap in the information caregivers are receiving about the availability of supports and services. This conclusion is further supported by the study of bereaved caregivers, among whom the most common reason for not accessing any service was being unaware that the service was available to them under the NFCSP (75%). Bereaved caregivers further reported that they did not feel they had received enough information about available supports (63%), and that the information they received frequently came too late in the caregiving experience to have impact (50%) (Lewin, 2019).

Although AAAs are the organizations that receive the funding and contract with LSPs, the latter require targeted trainings to effectively deliver NFCSP services. (Lewin, 2016). This suggests that the gap in the dissemination of information about NFCSP supports may result in a disconnect between the providers, with whom the caregivers interface most often, and the agencies coordinating services in that region. The process evaluation also indicated a lack of cohesion between the SUAs and the AAAs on implementation of the NFCSP, with SUA and AAA responses to the same questions varying. Caregivers are often too busy providing care to perform adequate research into the support options available to them, and would benefit from streamlined access to NFCSP services. Bringing SUAs and AAAs into alignment by increasing the information shared between them, and clarifying the role of each organization in communicating information on services and supports to caregivers, would help close the information gap experienced by caregivers (Lewin, 2016).

The need for improvements in the dissemination of information and helping caregivers identify their own needs as they develop is evidenced in the literature, and is particularly important in helping caregivers avoid negative health outcomes (Garrido & Prigerson, 2014; Aoun et al., 2015; Nielsen et al., 2016).

Caregiver Health and Wellbeing

While the outcome evaluation found improvements in caregiver burden and caregiver confidence for NFCSP caregivers, the researchers did not identify a statistically significant impact of



NFCSP services on caregiver mental health, physical health, or satisfaction (Westat, 2018). In contrast, in the study of bereaved caregivers, researchers found a moderate correlation between the early and frequent use of NFCSP services and more positive self-reports of caregiver physical and mental health, compared with those caregivers who delayed or made infrequent use of NFCSP services (Lewin, 2019).

The physical and mental health of caregivers are affected by many variables, including caregiver burden and their relationship to the care recipient. Further research is needed before drawing conclusions about the NFCSP's impact on health and wellbeing (Schulz & Sherwood, 2008; Liu et al., 2015). Future research in this area would benefit from the use of matched pairs for a better direct comparison between caregivers accessing services and control, as well as a longer study duration to capture longitudinal impacts of service use and overcome any period of latency before health impacts become evident.

Future Directions

For many states, the NFCSP is the only means through which caregivers can receive much needed services. Given the breadth of services that programs reported offering, the Aging Services Network has succeeded in developing a system through which caregivers can access supports. Furthermore, 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. Because family caregiving is a key element in delaying or preventing institutionalization, which is often more expensive and less integrated into the community than HCBS, the NFCSP is an important pillar in the drive toward lower-cost, higher-quality, and person-centered care (Miller & Weissert, 2000; Liu et al., 2015; Westat, 2018). The following recommendations are made to researchers, program staff, and policymakers who are positioned to apply their unique perspectives and the results of the evaluation in considering the program's future direction and how to build upon its successes.

Researchers

Based on the results of this evaluation, future evaluation efforts and research should focus on two areas: (1) investigating the impact of respite care, assessing the minimum threshold for effectiveness in reducing caregiver burden, and determining the system's capacity to expand respite services; and (2) investigating the impact of NFCSP services on caregiver health and wellbeing, in particular, understanding the role that caregiving and emotional support services may play in easing bereavement through anticipatory grief, and the role of NFCSP services in helping caregivers continue to provide effective care for longer.

For researchers to fully understand the impacts of respite care and other support options on caregiver burden, physical and mental health, and the returns on services provided through the LTSS network, better data are needed. An integral first step is to engage the LTSS network in

improving data collection pertaining to caregiver and recipient outcomes, and to apply longitudinal data on caregiver burden, emotional wellbeing, and unmet needs in refining service delivery.

Program Staff

The multi-phase evaluation found that SUAs and AAAs do work to identify caregivers with the highest need, and successfully prioritize delivery of services to caregivers with the most caregiving burden. Understanding these processes and the associated caregiver outcomes that may help the Aging Services Network refine programs to meet the needs of family caregivers and reduce burden for those at greatest risk (Lewin, 2016; Westat, 2018).

However, further work is needed to ensure that caregivers are receiving the supports that they need to provide continued, effective care to their loved ones. Chief among these opportunities for improvement is a review of how information about service options and availability reaches caregivers. Due to the extensive demands on a caregiver's time, caregivers may find it difficult to think and act proactively in identifying support options available to them, which may impede access to services such as caregiver training and education, and emotional support services. In particular, caregivers and their loved ones would benefit from greater communication between SUAs and AAAs, and clarification of the roles of each organization in disseminating information on service opportunities and provider options to caregivers.

Finally, improvements to data collection practices would further support the enhanced targeting of high-burden caregivers, and would also assist in the deeper integration of the NFCSP with other HCBS programs, by identifying caregivers and recipients who would benefit from the expanded suite of service options.

Policymakers

As the NFCSP comes up on its 20th year, it is clear that the program has met with substantial success. Recipients of LTSS are receiving more individualized care in comfortable settings, their caregivers are better supported to provide quality care for longer, and there is potential for substantial savings to accrue given the diversion from costly and otherwise unnecessary institutionalizations. Through constant efforts by ACL to identify opportunities for growth and service improvement, there is a bright future for caregivers and their loved ones. However, this is contingent on the continued buy-in and investment by policymakers.

Gaps remain in the information pipeline, creating a barrier to service access for some caregivers, particularly those experiencing high-burden who are least equipped to explore their options and are most in need of support. Single-point entry systems such as the No Wrong Door (NWD) model hold tremendous promise for streamlining service access by consolidating information and expert assistance, and facilitating enhanced communication across stakeholder agencies. Adoption of a NWD System would require legislation authorizing and allocating funding for



system transformation, and requires policymakers to recognize the substantial returns promised by single-point access.

Caregivers continue to report respite care as a primary need, and would benefit both from expanded capacity to provide respite and from more variety and flexibility in the delivery of respite to better mesh with the challenging and irregular schedules common to caring for a loved one with age- or disability-related health concerns. Additionally, policymakers should consider the expansion of services areas to cover the needs of caregivers living in rural areas.

Conclusion

Family caregivers close the gaps in LTSS systems facing a direct service workforce crisis, and help return tremendous savings to the system through delayed institutionalization and reduced home health care utilization. In 2011, the Congressional Budget Office (CBO) estimated that family caregiving accounted for almost \$234 billion in savings (CBO, 2013; HMD, 2016). With the number of people 65 years or older expected to double by 2030, and the number of potential family caregivers projected to drop from seven to four per adult aged 65 or older, laying the groundwork for a strong network of caregiver supports to combat burnout and ensure sustainable and high quality care becomes paramount (IoM, 2008; Centers for Disease Control and Prevention [CDC], 2018).

In 2016, with a budget of slightly over \$150 million, NFCSP provided support services to over 212,000 individual caregivers. This included 61,989 caregivers who received respite services, as well as 120,100 caregivers who received counseling. The ACL further reached nearly 20 million caregivers with their informational services, and provided nearly 1.2 million contacts to caregivers seeking services through its access assistance program (ACL, 2019a). For caregivers in nearly 75% of service areas, the NFCSP is the primary or only source of caregiver support services, and is credited as the primary driver behind the expansion of services to reach millions of caregivers who went unserved prior to the program's inception in 2000 (The Lewin Group, 2016).

Caregivers are on the forefront of long-term care, furthering the goals of high-quality care, community integration, and cost reductions; the NFCSP is the critical component in providing the emotional, educational, and respite supports that empower caregivers to care for their loved ones on their terms. In the 19 years since the NFCSP became operational, it has become more than just a program of services and supports to family caregivers. It is a recognizable and valued investment in the future of long-term care and is a critical lynchpin of LTSS in a rapidly aging society.



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