

# Users of National Family Caregiver Support Program (NFCSP) Services

A comparison of caregivers who used NFCSP educational services or respite care with caregivers who did not use the services

## PURPOSE

The National Family Caregiver Support Program (NFCSP) was established in 2000 by the Older Americans Act Title III-E to support the needs of informal caregivers. Through NFCSP funding, states and territories offer services to caregivers in partnership with Area Agencies on Aging (AAAs).

This profile examines the differences in caregiver demographics and the dynamics at play between caregivers who used NFCSP education services or respite care and caregivers who did not use these services.

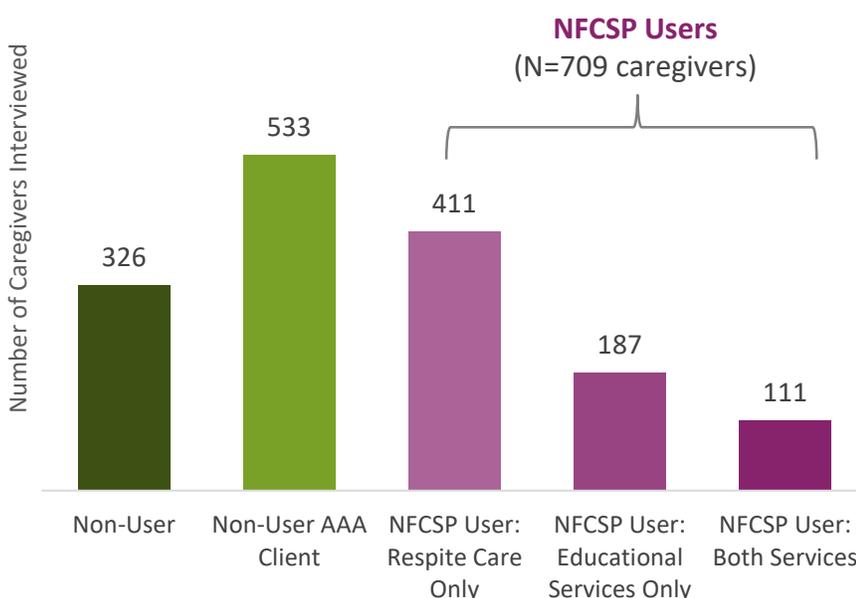
These comparisons can help organizations in the National Aging Network, an informal network of home- and community-based care providers, understand the needs and the characteristics of caregivers who used NFCSP services.

 **NFCSP Users** are AAA client caregivers who used NFCSP educational services or respite care in the past 6 months

 **Non-User AAA Clients** are caregivers who did not use NFCSP services in the past 6 months, but are AAA clients

 **Non-Users** are caregivers who did not use NFCSP services in the past 6 months and are *not* AAA clients

## NFCSP SERVICE USE: ANALYSIS CATEGORIES



### Definition of services:

- 1) *Educational services* – caregiver education, training, individual counseling, and support groups to help caregivers better manage their responsibilities and cope with the stress of caregiving
- 2) *Respite care* - care provided at home by trained individuals so that informal caregivers can rest or attend to their own needs

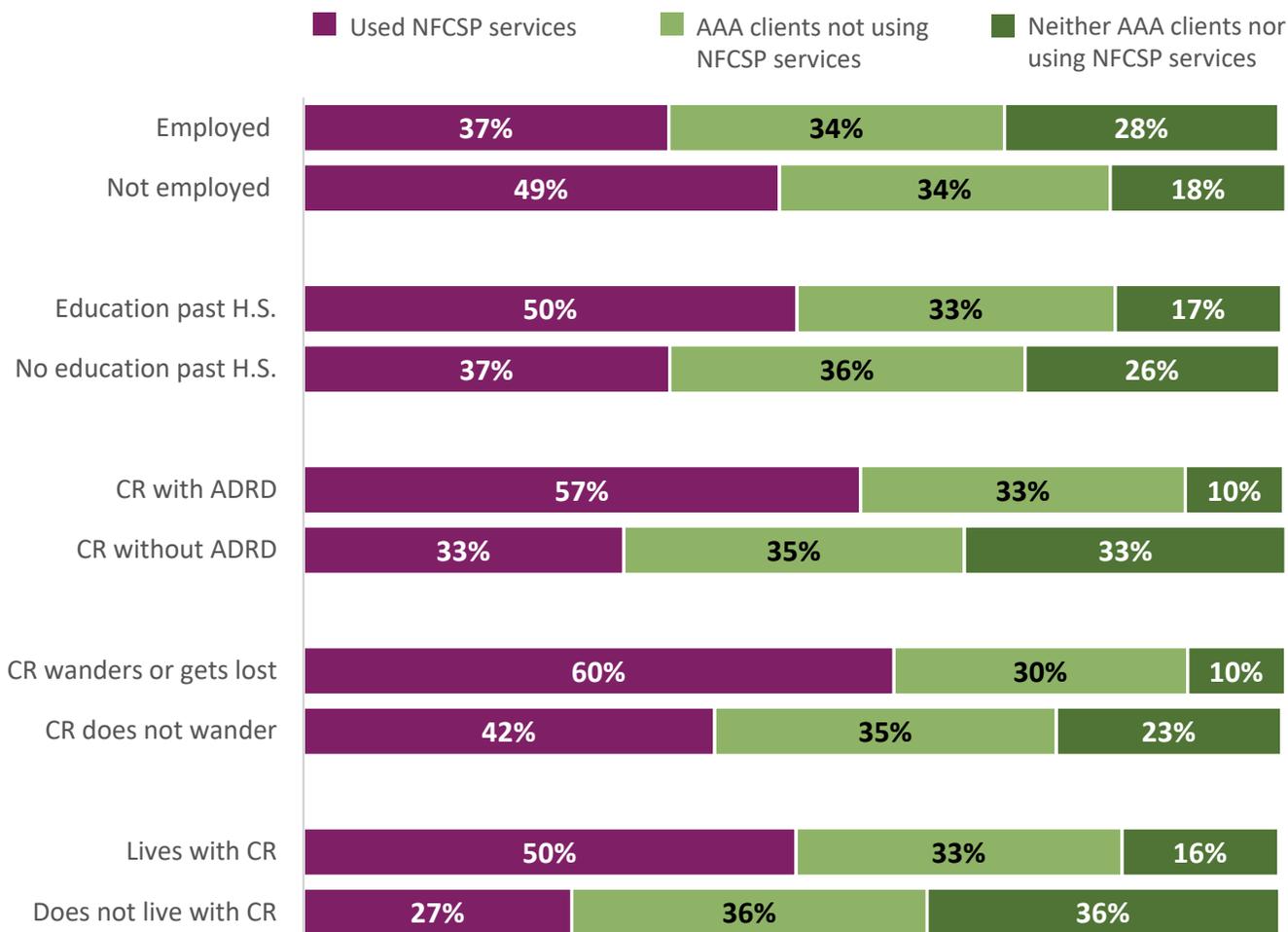
### Average age of caregivers:

- 68 for NFCSP Users
- 67 for Non-User AAA Clients
- 64 for Non-Users

The data used in this profile were collected by interview in December 2016 for the Administration for Community Living's outcome evaluation of the NFCSP.

## WHAT TYPE OF CAREGIVER USES NFCSP SERVICES?

The bar graphs below show the percentage of caregivers among a characteristic-based subgroup that are in each of the three user groups. For example, the top bar shows that among caregivers who are employed part-time or full-time, 37% used NFCSP services, 34% are AAA clients who did not use NFCSP services in the past 6 months, and 28% are not AAA clients and did not use NFCSP services.



CR = Care Recipient  
 ADRD = Alzheimer's Disease or Related Dementias

### SIGNIFICANT DIFFERENCES IN THE PERCENTAGE OF CAREGIVERS WHO ARE NFCSP USERS\*

- 49% among those not employed part-time or full-time compared to 37% of those employed
- 50% among those with an education past high school compared to 37% of those without education past high school
- 57% among those who care for a care recipient (CR) with Alzheimer's Disease or Related Dementias (ADRD) compared to 33% of those caring for a CR without ADRD.
- 60% among those with a CR who wanders or gets lost compared to 42% among those with a CR who does not wander or get lost
- 50% among those who live with their CR compared to 27% among those that do not live with their CR.

\* Significantly different at  $p$ -value  $< 0.001$  using a Chi-square statistic.

## RELATIONSHIP TO CARE RECIPIENT

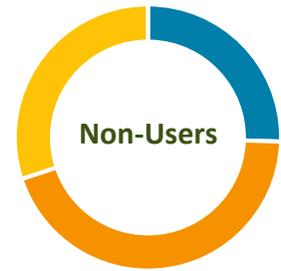
More NFCSP Users are the care recipient's **spouse (51%)** compared with Non-User AAA Clients (44%) and Non-Users (26%).



- 51% Spouse
- 43% Child including in-laws
- 6% Other (sibling, friend, etc.)



- 44% Spouse
- 45% Child including in-laws
- 11% Other (sibling, friend, etc.)

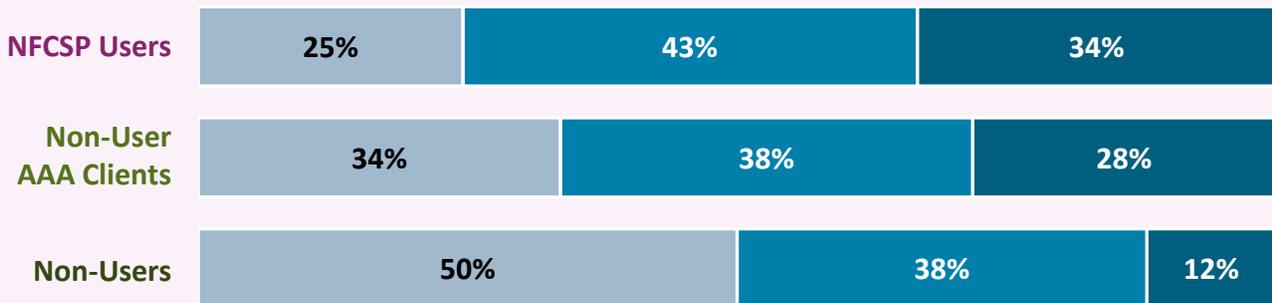


- 26% Spouse
- 44% Child including in-laws
- 30% Other (sibling, friend, etc.)

## CAREGIVING INTENSITY

Caregiving intensity was measured as the percentage of five activities of daily living (ADLs) with which the caregiver provided assistance daily (eating, dressing, toileting, and mobility), or daily/several times a week (bathing), with greater percentages indicating greater intensity. **Thirty-four percent of NFCSP Users** provided assistance with four or five (≥ 80%) of the five ADLs daily compared with **28%** of Non-User AAA Clients and **12%** of Non-Users.

### Caregiving Intensity as a Percentage of Five ADLs Provided Daily



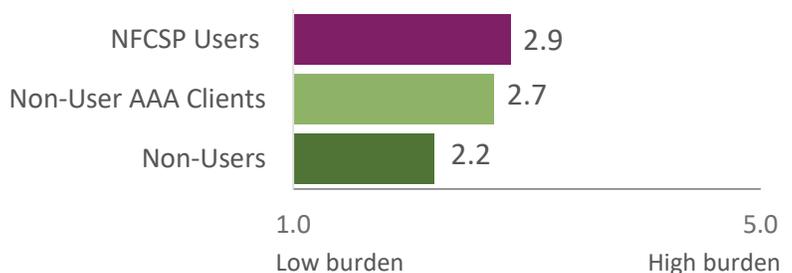
Percent of caregivers

- 0% of ADLs (low intensity)
- 0.1% to < 80% of ADLs
- 80+% of ADLs (high intensity)

## CAREGIVER BURDEN

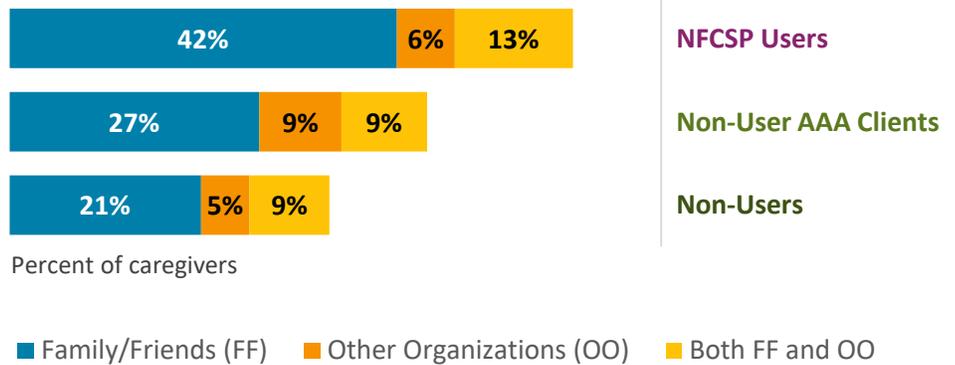
Using the Zarit Burden Inventory, which measures self-reported caregiver burden, **NFCSP Users reported more burden** than Non-User AAA Clients and Non-Users.

### Zarit Burden Score (Mean)



## RESPIRE CARE FROM OTHER SOURCES OUTSIDE OF NFCSP

Caregivers also receive respite care from family or friends and from other organizations, including Medicare or private home health care. **More NFCSP Users received respite care from family and friends** compared with Non-User AAA Clients and Non-Users.



## Key Differences Between the NFCSP Users Group and the Non-Users Group\*

- The mean age of NFCSP Users (68 years) was significantly higher than the mean age of Non-Users (64 years).
- Fifty-one percent of NFCSP Users were spouses to the CR compared to 26% of Non-Users.
- NFCSP Users were more likely to report daily caregiving intensity of 80% or higher in comparison to Non-Users (34% vs 12%, respectively).
- NFCSP Users reported higher caregiver burden than Non-Users (2.9 mean Zarit burden score vs 2.2 mean Zarit burden score, respectively).
- NFCSP Users were more likely to receive respite care from family and friends than Non-Users (42% vs 21%, respectively).

## DATA SOURCE

This profile utilized the data collected by Westat during baseline interviews for the NFCSP outcome evaluation. The sample of 1,568 caregivers reside in 43 states in the U.S. For this analysis, the definition of a NFCSP User is a caregiver who answered “Yes” when asked if he/she used NFCSP education services or NFCSP respite care in the past 6 months. Information about NFCSP, evaluation sample design, and the evaluation findings are publicly available at [https://acl.gov/sites/default/files/programs/2018-12/Caregiver\\_Outcome\\_Evaluation\\_Final\\_Report.pdf](https://acl.gov/sites/default/files/programs/2018-12/Caregiver_Outcome_Evaluation_Final_Report.pdf).

\* Excluding Non-User AAA Clients, significantly different at p-value < 0.001

Group means and frequencies are calculated for each characteristic. T-test, Chi-square, and Mantel-Haenszel chi-square statistics are used to test significant differences between NFCSP Users and caregivers who did not use the services. Percentages are rounded to the nearest whole number.