



National Family Caregiver Support Program Outcome Evaluation

November 28, 2018

Presentation Outline

NFCSP Outcome Evaluation Objectives

Study Design and Methodology

Caregiver Outcome Measures

Key Findings:

1. Relationship between NFCSP service use and other HCBS services
2. Difference in outcomes: NFCSP Caregivers vs. Comparison caregivers
3. AAA-level processes associated with the caregiver outcomes and perception of program effectiveness
4. Association between NFCSP service amount and caregiver perception of program effectiveness

NFCSP Outcome Evaluation Objectives

- To assess the impact of NFCSP services on caregivers' well-being and their ability to continue to provide home-based caregiving.
- To examine the relationship between caregiver outcomes and key processes and characteristics of the Area Agencies on Aging (AAAs) managing and/or providing NFCSP services.
- To provide the aging services network, advocates, and policymakers with information that will be instrumental in shaping future strategies for supporting family caregivers in the U.S.

Participants: NFCSP Client Group

1. Stratified sample of AAAs selected for the 11th National Survey of Older Americans Act Participants (NSOAAP).
 - Client lists from AAAs
 - Removed clients interviewed for NSOAAP and those listed as only receiving supplemental services
2. Systematic random sampling of NFCSP clients within the sample of 176 AAAs
3. Estimated response rates were used to set the size of the sampling frames. For example, the baseline sampling frame for Client caregivers was 6,024 with a target of 1,250 complete interviews.

Evaluation Participants with Completed Surveys by Interview Cycle

	Caregivers	Care Recipients
Baseline (Winter '16-17)	1,578	1,222
6-month Follow (Summer 2017)	1,005 (20.5% ineligible*)	n/a
12-month Follow (Winter '17-18)	794 (19% ineligible*)	212

** Ineligible because they were no longer a caregiver.*

Surveys were completed two or more times by 908 caregivers.

Caregiver Groups

Group assignment was based on the actual reported use of NFCSP services at baseline and 6-months.

In the past 6 months, have you received...

1. Respite care from the provider agency?
 - If yes “How many hours per week of respite care do you usually receive through this program?”
2. Caregiver education, training, counseling, or support group services from the provider agency?
 - If yes “What was the number of the sessions attended in the past 6 months?”

**607 Program Caregivers
(53%)**

**545 Comparison Caregivers
(47%)**

Caregiver Outcome Measures

Mental Health score

Caregiver Satisfaction

Physical Health score

Caregiver Confidence

Caregiver Burden

Perception of the effectiveness of NFCSP services for Continued caregiving:

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

The NIH Adult PROMIS Health Measures

Short Form v1.1 Global Mental Health score (range 4-20)

Composite and Individual Components	Baseline Mean N=1,568
PROMIS Mental health score	12.54
Mental health rating	3.26
Quality of life rating	3.01
Social activities rating	2.82
Frequency of emotional problems	3.45

Short Form v1.1 Global Physical Health score (range 4-20)

Composite and Individual Components	Baseline Mean N=1,568
PROMIS Physical health score	14.13
Physical health rating	2.99
Physical activities rating	4.02
Fatigue rating	3.66
Pain rating	3.44

Values for the individual components range from 1 to 5.

The Zarit Burden Score

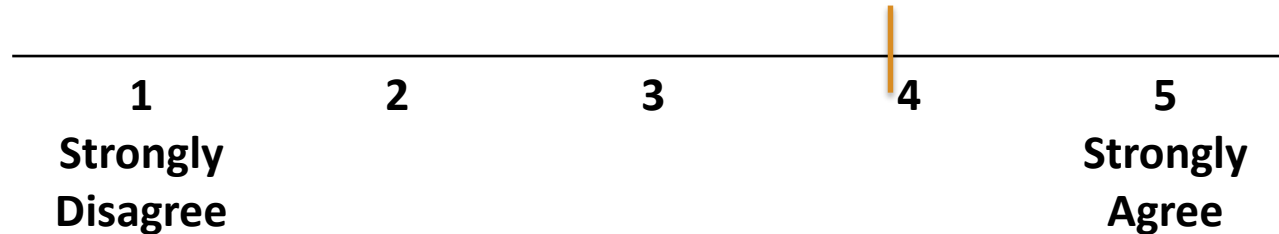
In 1980, Dr. Steven Zarit developed the 22-item Zarit Burden Inventory to measure caregiver subjective perceptions of burden among ethnically diverse populations. A shortened 4-item version was developed and validated in 2001.* The composite score ranges from 4-20.

Composite and Individual Components	Baseline Mean N=1,568
Zarit Burden score	10.70
Time for self	2.98
Feeling stressed	3.07
Feeling strained	2.40
Feeling uncertain	2.24

* Bedard M, Molloy DW, Squire L, Dubois S, Lever JA, & O'Donnell M. The Zarit Burden Interview: A new short version and screening version. *The Gerontologist*. 2001;41, 652-657.

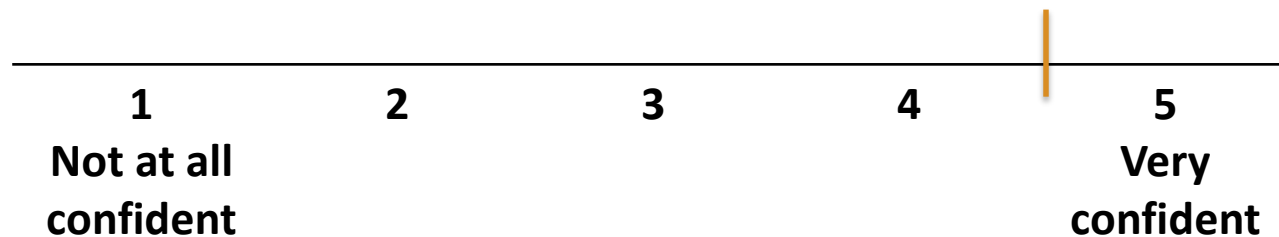
*I get a great deal of
satisfaction from being a caregiver.*

BASELINE MEAN: **3.86**



*Overall, how would you rate your
confidence as a caregiver?*

BASELINE MEAN: **4.45**



Analysis #1: To what extent do NFCSP service participants and care recipients also receive other home- and community-based services (HCBS)?

- Caregivers were asked if they or their care recipients received HCBS from any organization **outside of NFCSP** (including services paid by Medicaid and Medicare).
 - Incontinence supplies, home health aides, home delivered meals and case management were the most reported non-NFCSP services.
- Model 1 included 163 Program caregivers who, at baseline, used NFCSP caregiver services but did not receive any HCBS.
- Model 2 included 330 caregivers who received HCBS at baseline, but not NFCSP caregiver services.

Logistic Regression Results

- Receiving NFCSP caregiver services at baseline only slightly increased the likelihood of receiving non-NFCSP HCBS at follow-up (Odds ratio = 1.2; not statistically significant - Model 1).
- Receiving HCBS at baseline significantly increased the likelihood of receiving NFCSP services at follow-up (Table below - Model 2):

Effect of using HCBS at baseline on receiving NFCSP services at follow-up:		
	Odds ratio	P-value
Caregivers who received other HCBS at baseline vs. those who did not receive HCBS at baseline	1.90	0.04

Analysis #1 Conclusion

There is no clear suggestion that NFCSP is serving as a gateway to receiving other home- and community-based services (HCBS).

However, 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.

AAAs have an opportunity to increase the awareness of HCBS to NFCSP caregiver clients.

Analysis #2: To what extent do program participants' outcomes differ from those of caregivers who do not receive services from the NFCSP?

- The difference-in-difference (D-i-D) analysis included those caregivers who completed surveys at baseline and 6 or 12-month follow-up.

Caregivers with Longitudinal Results	Program	Comparison	Total
Full Sample (Any NFCSP service)	491	417	908
Restricted Sample (Respite Care)	370	307	677
Restricted Sample (Educational Services)	71	352	423

- Each Program caregiver was matched with one or more Comparison caregivers who shared similar characteristics as related to the likelihood of receiving NFCSP services, using a technique called *propensity score matching*.

Characteristics before Propensity Matching

Matching covariates (baseline)	Program Mean or %	Comparison Mean or %
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 (1-8)	4.53	3.97**
Caregiving intensity	45.00%	32.92%***
Also cares for children under 18 years old	7.13%	11.27%*
Caregiver lives with care recipient	87.98%	75.78%***
Caregiver received other respite services	60.49%	38.85%***
Caregiver received other education services	34.22%	23.26%**
Care recipient is a spouse	53.16%	43.41%*
Care recipient diagnosed with dementia	62.93%	39.09%***
Care recipient resists aid	34.83%	25.90%**

*p<.05; ** p<.01;*** p<.001

Example of Balancing a Characteristic with Matching

Propensity score matching substantially reduced average differences between Program and Comparison caregivers on the selected baseline characteristics.

Example for *Care recipient diagnosed with dementia*:

	Program %	Comparison %	
		Before matching	After matching
CR diagnosed with dementia	62.93%	39.09%***	62.63%

*** $p < .001$

The Effect of NFCSP Respite or Educational Services on Outcomes: Full Sample Results

- Among the full sample of caregivers, results did not show a significant effect of NFCSP on the five outcomes.
- The difference in differences was less than 0.1 for each outcome.

Covariate findings:

- The model results show that higher income caregivers had significantly better physical health but higher burden and lower caregiver satisfaction.
- Caregivers with a CR diagnosed with Alzheimer's disease or dementia had significantly more caregiver burden.
- Caregivers with a CR who resists aid had significantly worse mental health, worse physical health, more caregiver burden, and were less satisfied in caregiving.

NFCSP Respite Care Effect on Outcomes

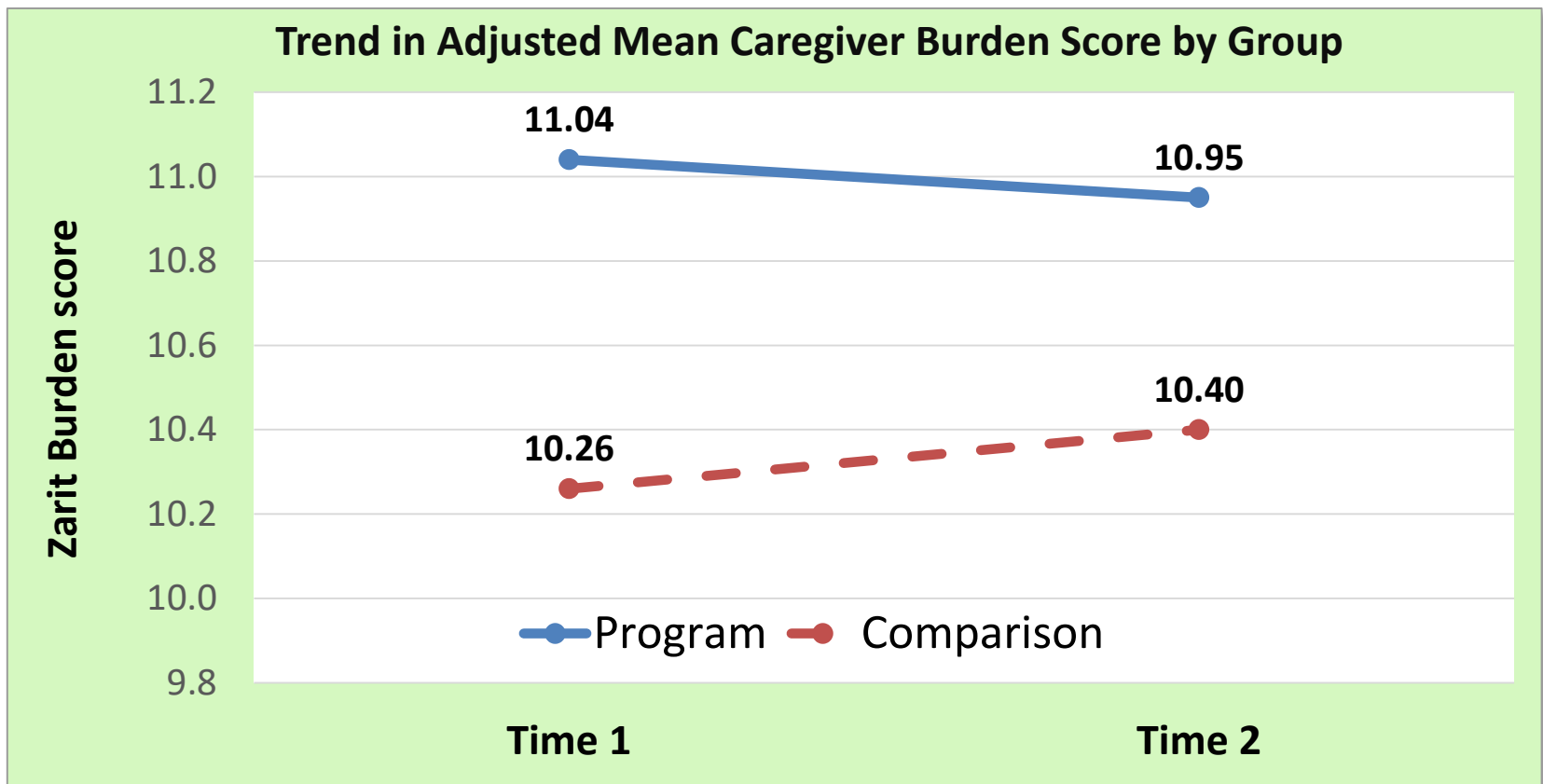
Program Sample: 370 caregivers who reported 4 or more average NFCSP respite hours per week.

It was hypothesized that respite hours would be most relevant to improving Caregiver mental health, physical health, and burden.

Both groups of caregivers had small improvements in mental health over time and both had declines in physical health, but the difference in differences between the Program and Comparison caregivers was not statistically significant for either outcome.

Burden Results Refined by Respite Hours

Caregivers who received more than 4 hours of NFCSP respite per week reported a decrease in their burden scores, while Comparison caregivers reported an increase in burden.



Time x Group (DiD)=0.24

NFCSP Educational Services Effect

Program Sample: 71 caregivers who reported using a NFCSP educational service at least once in the past 6 months.

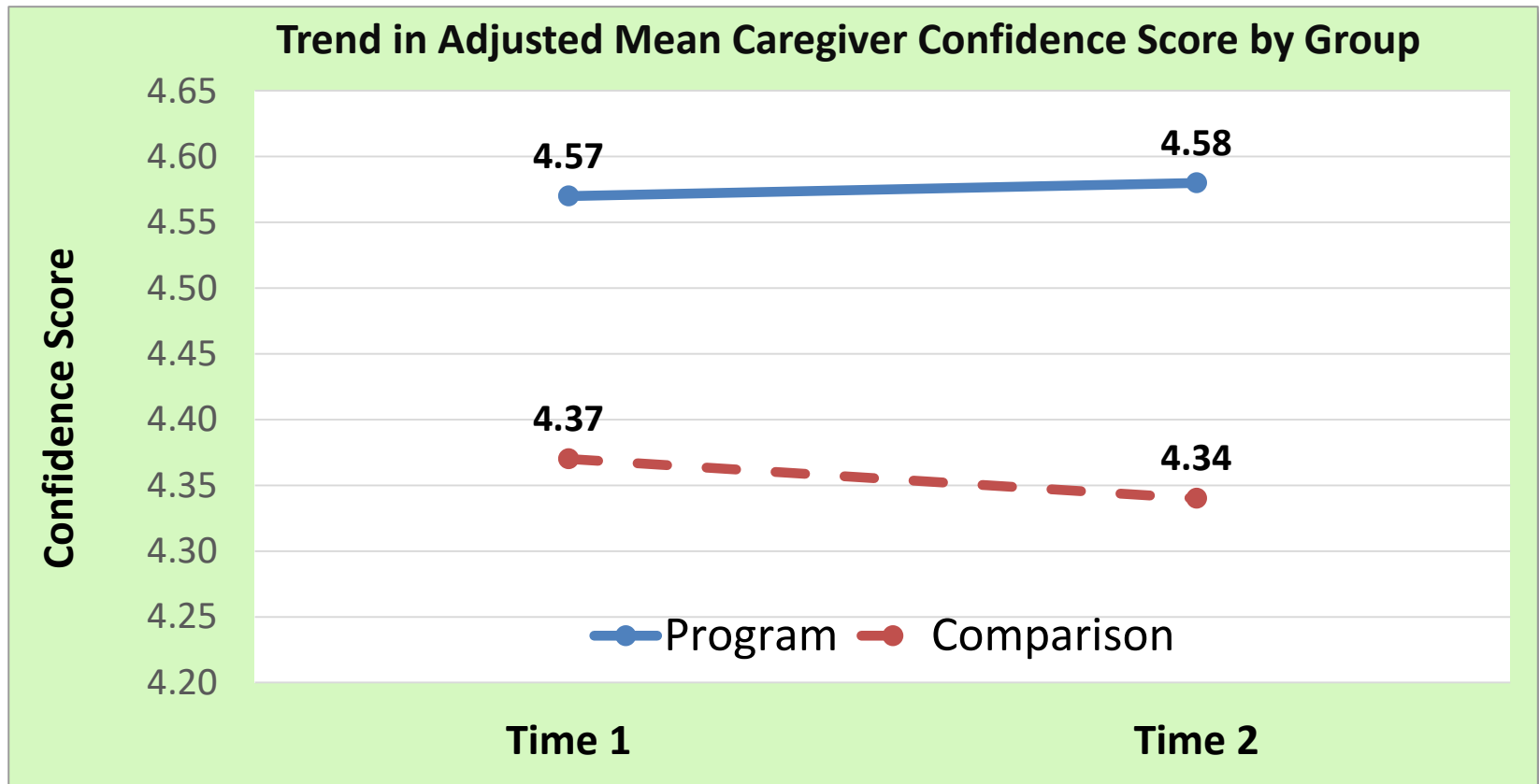
It was hypothesized that educational services amount would be most relevant to improving Caregiver satisfaction and confidence.

Both groups experienced a small increase in mean caregiver satisfaction scores across time.

Although not statistically significant, the D-i-D analysis found that caregiver confidence declined among the Comparison caregivers, but not among the Program caregivers.

Results Refined by Educational Services Amount

Even though Program caregivers had higher confidence scores at baseline than the Comparison group, they did not experience a decline in Caregiver confidence.



Time x Group (DiD)= -0.05

Analysis #2 Conclusion

- The DiD evaluation findings suggest that NFCSP caregiver services are effective in reducing caregiver burden and improving caregiver confidence.
- While caregiver burden increased over time for the Comparison group, it decreased slightly for the Program caregivers who received 4 or more hours a week of respite care from the NFCSP.
- These findings suggest that there may be a certain minimum amount of respite care needed to reduce caregiver burden.

Analysis #3: What types of organizational structures and/or approaches for NFCSP services are associated with the best participant-level outcomes?

- A. To examine the association between AAA assessment and reassessment processes with measures of caregiver outcomes.
- B. To examine the association between frequency of measuring client satisfaction and caregiver perception that services help the caregiver continue caregiving longer.

Two datasets linked together:

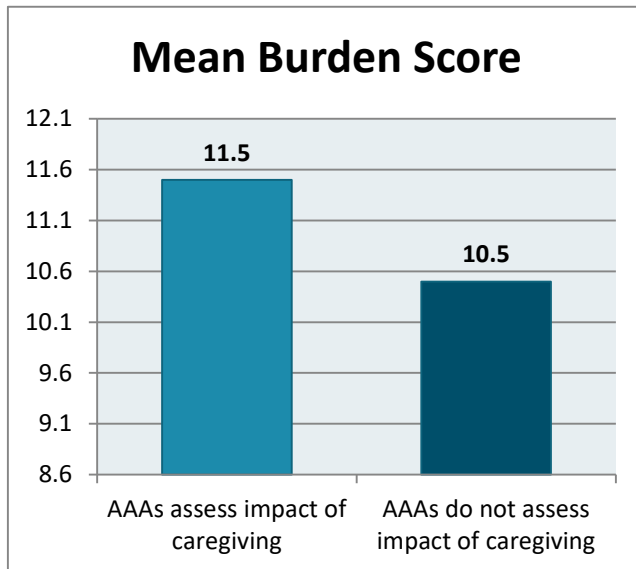
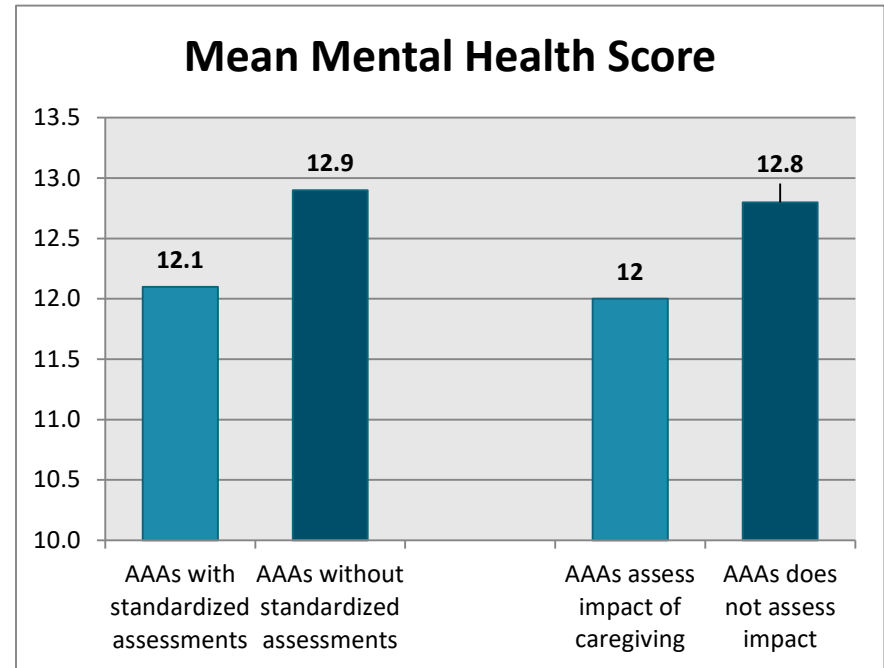
- AAA-level process survey data
- Survey response data among caregivers who said they received NFCSP services in the past 6 months

A. Assessment Policies

PROCESS QUESTIONS	Percent Yes
➤ Does your agency use a standardized assessment tool?	69%
➤ Does your needs assessment include assessing the impact of caregiving?	70%
➤ Does your agency have a policy for client reassessment?	75%
➤ Does your agency use caregiver assessment and reassessment to prioritize who receives services?	35%
➤ Does your agency use needs assessment to determine the type and amount of caregiver service?	68%

Caregiver Outcomes by AAA Process Type

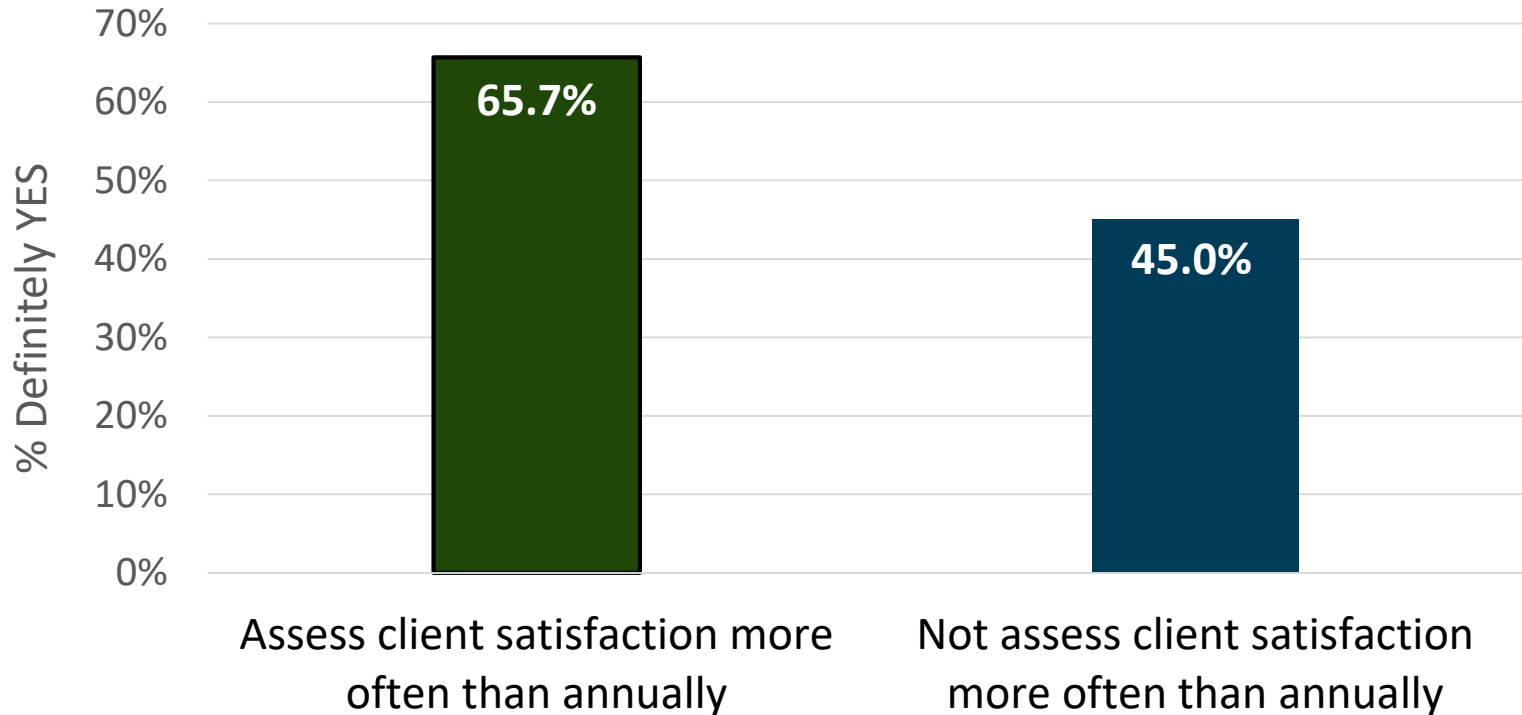
Compared to AAAs without the policy, significantly lower (worse) *mental health* scores were found among the caregivers from AAAs that have **standardized assessment tools** and include **the impact of caregiving in their needs assessment** ($p = 0.04$ for both).



Significantly higher (worse) mean *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 ($p = 0.02$).

B. Frequency in Measuring Client Satisfaction

AAAs that assess client satisfaction more often than annually had a higher % of caregivers that responded “definitely YES” to “Have the services you received from {Agency} **enabled you to provide care longer** than would have been possible without these services?”



Sample: 364 caregivers among **43 Area Agencies on Aging (AAAs)** within 31 states.

Analysis #3 Conclusion

- Assessing the impact of caregiving may be enabling AAAs to target caregivers with emotional stress and/or experiencing more burden.
- More frequent AAA measurement of satisfaction may offer more opportunity for client feedback to assist with customizing support for the purpose of enabling the caregiver to care longer.
- Opportunities exist for ACL and NFCSP to discover and share best practices for using client satisfaction feedback and assessments to improve the quality of caregiver services.

Analysis #4: Service Use Amount and Continued Caregiving

Using a modeling technique called ordinal regression, the goal was to determine if the amount of NFCSP services received was a significant factor in predicting a higher level response category to the Continued caregiving item.

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

Response	Baseline Percent
Definitely Yes	42.9%
Probably Yes	29.8%
No, Probably Not	13.5%
No, Definitely Not	13.8%

Four control variables:

1. Care recipient age
2. Caregiver race
3. If the caregiver lives with the CR or not
4. Caregiving intensity (% of ADLs - assistance daily)

Model Results

- As the NFCSP service amount increased so did the probability of a more favorable response to the Continued caregiving item.
- The probability of a caregiver responding more favorably to Continued caregiving increased 4.7 percent for each hour increase in respite hours (Odds ratio = 1.047; $p < 0.001$).
- The probability increased 6.4 percent for each additional time that a caregiver used an educational service (Odds ratio = 1.064; $p < 0.023$).

Analysis #4 Conclusion

- Results suggest that caregiver services provided by the NFCSP are effective for increasing the caregivers' perception that the services are helping them continue caregiving.
- More research is needed to understand the optimal amount of service needed to enable caregivers to care longer, thus delaying or avoiding the need for their care recipients to be placed in a nursing home or other institutional care setting.

Evaluation Summary

- ❑ Findings suggest that NFCSP could be more integrated with HCBS providers.
- ❑ A minimum amount of NFCSP respite care (4 average weekly hours) was effective in reducing caregiver burden.
- ❑ Education and training services can lead to greater caregiver confidence over time.
- ❑ The connections between certain processes and caregiver outcomes may help the aging services network better design and shape local programs to meet the needs of family caregivers.
- ❑ Caregiver use of the services made available by the NFCSP helped them continue caregiving

Thank you!

Westat Evaluation Team:

Joanne Campione, Project Director
Katarzyna Zebrak, Lead Researcher
Dwight Brock, Senior Statistician
Susan Hassell, Report Manager
Beth Rabinovich, Analyst
Robin Ritter, Recruitment Director
Cecilia Avison, Project Manager
Duck-Hye Yang, Data Analyst
Jackie Severynse, Statistician

