

National Family Caregiver Support Program (NFCSP) Evaluation

Provider Survey

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0985 xxxx. The time required to complete this information collection is estimated to average 30 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and

review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: U.S. Department of Health & Human Services, Administration for Community Living, 1 Massachusetts Ave., N.W., Room 5203, Washington D.C. 20201, Attention: PRA Reports Clearance Officer

Evaluation of the National Family Caregiver Support Program: Survey of Providers

E-mail Invitation (to be sent with a link to the survey)

Dear NFCSP Provider,

We are inviting you to participate in an important new study of caregiver support funded by the Administration on Aging (AoA) in the US Administration for Community Living (ACL). Your organization was selected to participate in the study as part of our random sample, and we hope to hear from you. As part of ACL's continuing commitment to evaluate the effectiveness of programs and services in the Aging Network, we are seeking information to help us learn more about National Family Caregiver Support Program (NFCSP) providers and the important work they do for older adults and those who care for them. We are reaching out to you because we received your contact information through the _____ Area Agency on Aging (AAA). We would greatly appreciate your participation in this brief survey.

ACL has partnered with The Lewin Group who has enlisted the University of Connecticut Health Center (UConn), Center on Aging to collect information about the range of services you provide to caregivers in general and about the NFCSP in particular. The efforts of the Aging Network to support caregivers have a significant impact on older adults, their families, employers, and entire communities. Supporting caregivers is essential to maintaining older adults' independence in their own homes. This evaluation is vital to documenting the effectiveness of the NFCSP. These results will be used to better understand what works, identify areas for improvement, and plan for the future.

The survey will take about twenty minutes to complete. Your responses will remain confidential among ACL, and the Lewin and UConn research teams and your answers will not be reported in a way that can identify your organization. Your participation is voluntary and you may skip any question you do not want to answer. We highly encourage all NFCSP providers to join us in this important effort. The principal investigator for this study is Dr. Julie Robison, and she can be reached at 860-679-4278 if you have any questions.

The survey will ask you to provide some specific information about your organization. Before you start the survey, you may want to collect the following information. You can also save the survey at any point and return to it if you need to look something up.

Each of the items below is for the last fiscal year:

1. Your organization's approximate total operating budget
2. The number of full time *equivalent* employees at your organization
3. The number of part time employees at your organization
4. The number of volunteers who worked on respite services (& how many volunteer hours, if available)
5. The number of volunteers who worked on caregiver training and education (& how many volunteer hours, if available)
6. Unduplicated number of all clients served by your organization
7. Unduplicated number of NFCSP caregiver clients who received respite services
8. Unduplicated number of NFCSP caregiver clients who received education & training
9. An electronic copy of your caregiver assessment form, if applicable.

Simply click on the link provided at the bottom of this email and use the log in below to access the survey online. Further instructions for completing the survey will be provided after you log in. You can save your answers and return later using this same link. Feel free to forward this survey to the person in your organization most familiar with your caregiving programs and services.

Please complete this survey by [DATE]. If you have questions about completing the survey or would like to complete it by telephone, please contact a UConn Research Associate toll free at [insert UConn number] or send an email to: [insert UConn survey email address].

We recognize that all of you are very busy. Thank you for taking a few minutes to complete this very important survey.

Sincerely,

NAME

Administration for Community Living

Click here to begin the survey: [Insert UCHC survey link]

Your log in access code is: _____

If you have any trouble connecting to the survey please copy and paste the link directly into your browser.

E-Mail Reminder

Sent every two weeks or as needed

Dear NFCSP Provider,

We are writing to remind you about the Administration for Community Living's (ACL) Family Caregiver Survey which is part of the first national

evaluation of Title III-E family support programs (please see below for log-in information). **The survey is only available until [DATE] so we hope to hear from your organization as soon as possible.**

ACL has partnered with The Lewin Group who has enlisted the University of Connecticut Health Center (UConn), Center on Aging to gather and analyze information about the range of services you provide to caregivers in general, and about the National Family Caregiver Support Program in particular. The efforts of the Aging Network to support caregivers have a significant impact on older adults, their families, employers, and entire communities. Supporting caregivers is essential to maintaining older adults' independence in their own homes. This evaluation is vital to documenting the effectiveness of the NFCSP. These results will be used to better understand what works, identify areas for improvement, and plan for the future.

The survey will take about twenty minutes to complete. Your responses will remain confidential among ACL, and the Lewin and UConn research teams and your answers will not be reported in a way that can identify your organization. Your participation is voluntary and you may skip any question you do not want to answer. We highly encourage all NFCSP providers to join us in this important effort. The principal investigator for this study is Dr. Julie Robison, and she can be reached at 860-679-4278 if you have any questions.

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3. The number of part time employees at your organization
4. The number of volunteers who worked on respite services (& how many volunteer hours, if available)
5. The number of volunteers who worked on caregiver training and education (& how many volunteer hours, if available)
6. Unduplicated number of all clients served by your organization
7. Unduplicated number of NFCSP caregiver clients who received respite services
8. Unduplicated number of NFCSP caregiver clients who received education & training
9. An electronic copy of your caregiver assessment form, if applicable.

Simply click on the link provided at the bottom of this email and use the log in below to access the survey online. Further instructions for completing the survey will be provided after you log in. You can save your answers and return later using this same link. Feel free to forward this survey to the person in your organization most familiar with your caregiving programs and services.

Please complete this survey by [DATE]. If you have questions about completing the survey or would like to complete it by telephone, please contact a

UConn Research Associate toll free at [insert UConn number] or send an email to: [insert UConn survey email address].

We recognize that all of you are very busy. Thank you for taking a few minutes to complete this very important survey.

Here is the password you will need to log in:
Click here to begin the survey: [Insert UCHC survey link]
Your log in access code is: _____

If you have any trouble connecting to the survey please copy and paste the link directly into your browser.

Sincerely,

NAME
Administration for Community Living

On log in page of the survey:

The survey will ask you to provide some specific information about your organization. Before you start the survey, you may want to collect the following information. You can also save the survey at any point and return to it if you need to look something up.

Each of the items below is for the last fiscal year:

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Evaluation of the Older Americans Act National Family Caregiver Support Program (OAA NFCSP): Survey of Providers

1) Which groups of caregivers do you provide services to? (check all that apply)

- Caregivers of older adults
- Caregivers of adults of any age with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction
- Grandparents and other relatives raising grandchildren
- Grandparents and other relatives caring for adults ages 18-59 with a disability

From now on, we are going to focus our questions on caregivers of older adults.

2) Which of the following services do you provide to NFCSP caregiver clients? (Check all that apply) For this survey, "NFCSP caregiver client" means any caregiver client who is referred by and/or whose services are paid for by any AAA under the NFCSP.

- Information & Referral** (Providing information on services available and linking individuals to the services)
- Training/Education** (Delivery of information to caregivers in a variety of settings about specific caregiving roles or issues)
- Support Groups** (Organized gatherings of caregivers to help them cope with the emotional, financial, or physical strain of caregiving)
- Counseling** (Assisting caregivers to make decisions and solve problems relating to their caregiver roles)
- Respite care** [ask Q2a] (Allows a brief period of rest or relief for caregivers while care is provided by someone else for the care recipient in the home or outside of the home)
- Supplemental services** (Complements the care provided by caregivers, including home modifications, assistive technologies, emergency response systems, and incontinence supplies)
- Case Management** (Assessing needs, developing care plans, authorizing and coordinating services among providers, and providing follow-up and reassessment, as required)
- Don't know**

2a) What kind of respite care does your organization provide? (check all that apply)

- In-home respite during normal business hours
- In-home respite during evenings
- In-home respite overnight
- Adult day program respite
- Respite weekend, including camps
- Overnight in a facility or extended respite (extended respite = 24 hours)

- Emergency respite services
- Other (please specify)

3) How long has your organization been in operation?

- Less than 1 year
- 1 to 5 years
- 6 to 10 years
- 11 to 20 years
- More than 20 years

4) How long has your organization been serving NFCSP caregiver clients?

- Less than 1 year
- 1 to 5 years
- 6 to 10 years
- More than 10 years

5) When did your most recently completed fiscal year end?

MM/DD/YYYY (Fill in the blank)

- Don't know

6) For your most recently completed fiscal year, please give us the range of your organization's total operating budget.

- Less than \$100,000
- \$100,000-\$499,999
- \$500,000-\$999,999
- \$1,000,000-\$4,999,999
- \$5,000,000-\$9,999,999
- \$10,000,000-\$49,999,999
- Over \$50,000,000

7) Which of the following best describes the governance of your organization?

- A not-for-profit agency
- A for-profit agency
- A division of a city or county government
- Part of a council of governments or regional planning and development agency
- A Tribal Government entity
- Educational institution
- Other (please specify): _____
- Don't know

8) How many AAAs do you have a relationship with to provide NFCSP caregiver services? Note, if you work with multiple branch offices of the same AAA, count them as 1.

- 1
- 2
- 3
- 4
- Other (*please specify*): _____
- Don't Know

9) During your most recently completed fiscal year, including yourself, how many full-time equivalent employees did your organization have?

____|____|____|____| *Number of full-time equivalent employees*

Don't know

10) During your most recently completed fiscal year, how many of your organization's employees were part-time employees?

____|____|____|____| *Number of part-time employees*

Don't know

11) Please indicate the types of tasks volunteers provide at your organization: (Check all that apply)

- Phone reassurance
- Respite services
- Support group leader(s)
- Caregiver training/education
- Transportation
- Legal services (e.g. assistance completing powers of attorney or advance directives)
- Financial services (e.g. tax preparation, bill paying, budgeting, pension counseling)
- Information and assistance
- Administrative program support
- Other (*please specify*): _____
- Don't use volunteers
- Don't know

12) During your most recently completed fiscal year, how many volunteers worked on respite services at your organization? [Web programming note: only ask this question if "respite services" checked in question 11]

____|____|____|____| *Number of volunteers*

Don't know

13) During your most recently completed fiscal year, how many volunteers worked on caregiver training and education at your organization? [Web programming note: only ask this question if "caregiver training/education" checked in question 11]

|_|_|_|_|_|_|_| *Number of volunteers*

Don't know

14) In total, how many volunteer hours did the respite program at your organization receive in the most recently completed fiscal year? [Web programming note: only ask this question if "respite services" checked in question 11]

|_|_|_|_|_|_|_|_|_|_| *Number of volunteer hours*

Don't track volunteer hours

15) In total, how many volunteer hours did the caregiver education and training program at your organization receive in the most recently completed fiscal year? [Web programming note: only ask this question if "caregiver training/education" checked in question 11]

|_|_|_|_|_|_|_|_|_|_| *Number of volunteer hours*

Don't track volunteer hours

Now we will be asking about unduplicated clients served by your organization. An unduplicated number is the number of unique clients who receive services. An individual is counted only once regardless of how many services they received. Your best estimate is fine.

16) During your most recently completed fiscal year, what was the total, unduplicated number of people who received any service through your organization?

|_|_|_|_|_|_|_|_|_|_| *People received any service (ALLOW FOR 7 DIGITS)*

17) Is your organization able to distinguish NFCSP funds, and the caregivers supported by those funds, from other caregiver services funding?

- Yes
- No
- Don't know

18) During your most recently completed fiscal year, what was the total unduplicated number of NFCSP caregiver clients who received respite services? [Web programming note: only ask this question if “respite care” checked in Question #2 / If more than the first box is checked in question 1, add the following language to the question: “Remember that these questions focus only on caregivers of older adults.”]

|_|_|_|_|_|_|_|_| Unduplicated caregivers who received
respite services (ALLOW FOR 7 DIGITS)

Cannot Distinguish
 Don't Know

19) During your most recently completed fiscal year, what was the total unduplicated number of NFCSP caregiver clients who received caregiver education and training? [Web programming note: only ask this question if “training/education” checked in Question #2 / If more than the first box is checked in question 1, add the following language to the question: “Remember that these questions focus only on caregivers of older adults.”]

|_|_|_|_|_|_|_|_| Unduplicated caregivers who received
caregiver education and training (ALLOW FOR 7 DIGITS)

Cannot Distinguish
 Don't Know

20) Which of the following evidence-based caregiving training/education interventions does your organization provide to NFCSP caregiver clients? (Check all that apply.) [Web programming note: only ask this question if “training/education” checked in Question #2]]

- REACH II Interventions (Shultz et al.)
- Savvy Caregiver (Ostwald/Hepburn)
- STAR-C Intervention (Teri)
- Coordinated system of care intervention (Vickery)
- COPE for Cancer Caregivers (McMillan)
- Powerful Tools for Caregivers
- Other (*Please describe*) _____
- None
- Do not know

21) Does your program support caregivers with care transitions of their loved ones between any of the following settings? Include informal support as well as formalized care transition programs. (Check all that apply.)

- Hospital discharge to nursing home or assisted living
- Hospital discharge to home
- Nursing home or assisted living discharge to the community

- Placement of the care recipient into a nursing facility or assisted living
- None of the above

22) Does your organization ever conduct an initial comprehensive assessment of need for your NFCSP caregiver clients?

- Yes
- No (Skip to question 23)

22a) Which of the following elements does your caregiver assessment contain? (check all that apply):

- Caregiver's background and the caregiving situation
- Caregiver's perception of care recipient health and functional status
- Caregiver's values and preferences with respect to everyday living and care provision
- Caregiver's health and well-being
- Impact of caregiving on the caregiver
- Caregiver's skills, ability, knowledge or other requirements to provide care
- Resources available to support the caregiver
- Care recipient background (demographics, financial status)
- Care recipient's health and well-being (functional and cognitive status)
- Resources available to support the care recipient
- Other (please specify): _____

22b) How often does your organization conduct the caregiver assessment for your NFCSP caregiver clients?

- All or most of the time
- Some of the time
- Hardly ever

22c) How often does your organization share the findings of these assessments with the Area Agency on Aging?

- All or most of the time
- Some of the time
- Hardly ever
- Never

22d) What is the origin of your assessment form?

- Our assessment is a state-wide assessment
- Our assessment is from the AAA
- Our assessment is created by our agency
- Other (please specify): _____

22e) Please upload a copy of your caregiver assessment. [web programming note: Allow user to upload files.]

23) How often does your organization receive results from a caregiver screen and/or assessment from any AAA for your NFCSP caregiver clients?

- All or most of the time
- Some of the time
- Hardly ever
- Never

24) Which entity develops the individual service plan of a NFCSP caregiver client? (Check all that apply.)

- Your own organization
- Another service provider
- Area Agency on Aging
- State Unit on Aging
- Caregiver
- Other (Please describe) _____

25) How often does your organization not accept a NFCSP caregiver client?

- All or most of the time
- Some of the time
- Hardly ever
- Never (skip to Q26)

25a) Which of the following are common reasons your organization ever cannot accept a client? (check all that apply)

- Not enough workers
- Lack of bilingual workers
- Transportation for workers
- Safety concerns for workers
- Client has more needs than you can meet
- Client lives out of range of your transportation services
- Other (Please describe) _____

26) How often is your organization able to meet all the elements of the service plan for NFCSP caregiver clients (e.g., frequency of visits, days requested)?

- All or most of the time (skip to Q27)
- Some of the time
- Hardly ever
- Never

26a) Which of the following are common reasons your organization is unable to meet all the elements of a service plan? (check all that apply)

- Not enough workers
- Lack of adequately trained workers
- Transportation for workers
- Transportation for consumer
- Funding
- Other (Please describe) _____

27) If your organization ever is unable to accept NFCSP caregiver clients or is unable to fulfill the entire service plan, how often do each of the following occur?

	All or most of the Time	Some of the Time	Hardly Ever	Never
(a) AAA or your organization refers client elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Client is put on a wait list at your organization	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Client receives partial services, or what your organization is able to provide at the time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Other (Please describe) _____ _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

28) During the most recent fiscal year, how often did your NFCSP caregiver clients pay privately for additional service support from your organization (e.g. for additional hours or days to augment the service schedule under the caregiver program)?

- Most of the time
- Some of the time
- Hardly ever
- Never

29) How often do you conduct a survey of NFCSP caregiver clients that includes clients' ratings of the quality of services?

- Annually
- Semi-annually
- Quarterly
- Monthly
- Ongoing
- Varies by service
- Other (Please specify) _____

**29a) [web programming: show 29a and 29b unless answered never to Q29]
Does your organization currently use caregiver client survey data for: (check all that apply)**

- Managing the caregiver services
- Providing information to stakeholders (governing board, local/state government, advocacy organizations, etc)
- Program planning
- Contract/grant reporting
- None of the above
- Don't know

29b) How often do you share the results of those surveys with the Area Agency on Aging?

- All of the time
- Most of the time
- Some of the time
- Hardly ever
- Never

30) How likely are you to continue providing caregiver services 1 year from now?

- Very likely → please explain _____
- Somewhat likely → please explain _____
- Not very likely → please explain _____
- Not at all likely → please explain _____

31) Other than additional funding, what suggestions would you make to improve the way the NFCSP caregiver services program works?

32) Optional: If you have one, please share either (1) a best practice you have used in providing caregiver services or (2) a way your services really helped an NFCSP caregiver client.

This concludes the survey. Thank you again for your participation. The information you have provided will be a valuable contribution to our evaluation of the National Family Caregiver Service Program, and ultimately to the improved delivery of services to older adults and their caregivers across the nation.