National Family Caregiver Support Program Evaluation

2014 SUA Survey

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

National Evaluation of the Title III-E National Family Caregiver Support Program State Unit on Aging Survey

Dear SUA Director,

As part of the Administration for Community Living's (ACL) continuing commitment to evaluate the effectiveness of programs and services in the Aging Network, we seek information about your State Unit on Aging (SUA) and the important work you do for older adults and those who care for them.

ACL has partnered with The Lewin Group to gather and analyze information about the range of services SUAs provide to caregivers in general and about the National Family Caregiver Support Program (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. Demonstrating the effectiveness of these programs provides necessary evidence for advocacy efforts and funding at the federal, state, and local levels.

Completing the survey should take about 90 minutes. Your responses will remain confidential among ACL and the Lewin research team and your answers will not be reported in a way that can identify your agency. We highly encourage all SUAs to join us in this important effort. Please forward this email survey invitation to the person(s) in your organization most familiar with your caregiving programs and services.

The deadline for completion of the surveys is [DATE]. A series of reminders will be sent if you have not completed the survey. If you have questions about completing the survey please contact Dr. Cindy Gruman (703-269-5506 or cindy.gruman@lewin.com) or Ashley Tomisek (703-269-5632 or ashley.tomisek@lewin.com).

We recognize that all of you are very busy. Thank you for taking the time to complete this very important survey.

Insert Unique SUA survey link.

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

E-Mail Reminder
Send every two weeks or as needed

We are writing to remind you about the Administration for Community Living's (ACL) National Family Caregiver Support Program Survey which is part of the first national evaluation of Title III-E National Family Caregiver Support Program. Please see the link below. **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 to gather and analyze information about the range of services State Units on Aging provide to caregivers in general and about the National Family Caregiver Support Program (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. Demonstrating the effectiveness of these programs provides necessary evidence for advocacy efforts and funding at the federal, state, and local levels.

Completing the survey should take about 90 minutes.   We highly encourage all SUAs to join us in this important effort. Please feel free to forward this survey to the person(s) in your organization most familiar with your caregiving programs and services. The link is unique to your state.

The deadline for completion of the surveys is [DATE]. One more reminder will be sent out to your SUA if you have not completed the survey. If you have questions about completing the survey please contact Dr. Cindy Gruman (703-269-5506 or cindy.gruman@lewin.com) or Ashley Tomisek (703-269-5632 or ashley.tomisek@lewin.com).

We recognize that all of you are very busy. Thank you for taking the time to complete this very important survey.

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Sincerely,

NAME
Administration for Community Living

Before You Begin/SURVEY Introduction Page—Initial Screen of Web Version

Thank you for taking the time to complete this very important survey on caregiving. The information you provide is an essential part of the Administration for Community Living's (ACLs) first national evaluation of the Title III-E National Family Caregiver Support Program (NFCSP). State Units on Aging (SUAs) play a vital role in overseeing programs and services provided to caregivers in their local areas. It is the goal of this survey to:

- Obtain a broad understanding of the services SUAs provide to caregivers
- Understand the variety of ways caregiver programs are implemented and monitored by SUAs nationwide
- Examine the features of caregiver programs such as consumer direction, caregiver assessments and case/care management

Your responses to this survey will provide important information to document the scope, effectiveness and impact of caregiver programs in your state and community.

The survey asks a few questions about the characteristics of your caregiver programs and your SUA. Before you begin it may be helpful to gather the following information:

1) Estimated number of unduplicated consumers who received caregiver services from your SUA in your most recent fiscal year.
2) Estimated number of unduplicated grandparents 55+ caring for grandchildren and receiving caregiver services in your most recent fiscal year.
3) Total amount of expenditures in your SUA in the most recent fiscal year.
4) Amount of expenditures on Title III-E (National Family Caregiver Support Program in the most recent fiscal year.
5) NFCSP Waiting List information (number of people on the waiting list for each NFCSP service, as applicable).
6) NFCSP Services cap information.
7) Top three supplemental services for caregivers of older adults and grandparent caregivers who care for grandchildren.

If you are using HIPAA-compliant internet access, your server may log you off after a period of inactivity. Save your work periodically, especially if you step away from your computer, by clicking "next" to get to the next page. Otherwise, your work may be lost.

If you have questions about completing the survey, please contact Cindy Gruman (703-269-5506 or cindy.gruman@lewin.com) or Ashley Tomisek (703-269-5632 or ashley.tomisek@lewin.com).

Contents

National Evaluation of the Title III-E National Family Caregiver Support Program State Unit on Aging Survey

This survey is to be administered in a web-based format to state-level Title III-E coordinators/ NFCSP specialists in all states. There will also be the option of a paper format to be faxed, scanned or returned through mail.

All questions pertain to the State's Title III-E/OAA NFCSP program, which will be referred to as NFCSP throughout the survey.

What is the name of your NFCSP/family caregiver support program?
_____

1) **How many Area Agencies on Aging (AAA) are there currently in your state? |_|_|_| AAAs**

2) **Of the total number of AAAs in your state, please record the number of AAAs that are characterized by each of the various types of planning and service area boundaries.**

Planning and Service Area Boundaries	Number of AAAs	Don't Know
a. Single-county	|_|_|_|	☐
b. Multi-county	|_|_|_|	☐
c. Single city/metro area	|_|_|_|	☐
d. Multiple city/metro area	|_|_|_|	☐
e. Other (*Specify*) _____	|_|_|_|	☐

3) **Does the SUA currently employ a caregiver program manager/coordinator who plans, develops, administers, implements, and/or evaluates the NFCSP?**
   ☐ Yes
   ☐ No
   ☐ Don't know

4) **Currently, does your SUA have a policy or standardized eligibility criteria that defines caregivers as clients?**

   ☐ Yes
   ☐ No
   ☐ Don't know

5) **Does your SUA have a statewide identity for the NFCSP? (Check all that apply)**
   ☐ Consistent logo
   ☐ Tagline

- [ ] Statewide toll-free number
- [ ] Statewide web-based caregiver resource database
- [ ] Dedicated website
- [ ] Link within another website
- [ ] No statewide identity (***Programmer note: If a respondent selects this answer, they cannot select any other option***)

Staff/Volunteer Training

The next set of questions will ask about staff and volunteer training.

6) **Does the SUA require training for AAA or other staff or volunteers who work with family caregivers?**
   - [ ] Yes
   - [ ] No policy on training (Skip to Q7)

   6a) If yes, which of the following staff members or volunteers are required to take training?
   - [ ] Information and referral staff
   - [ ] Other Program Administrative Staff
   - [ ] Supervisory Staff
   - [ ] Direct Service Workers (e.g., social workers, counselors, care managers)
   - [ ] Volunteers
   - [ ] Decided at AAA level
   - [ ] Decided at provider level
   - [ ] Other (*please specify)*: _____
   - [ ] Don't know
   - [ ] None of the above

   6b) How often is training provided? (Check one)
   - [ ] More than once a year/on a regular basis (e.g., quarterly)
   - [ ] Once a year
   - [ ] Occasionally, when the opportunity presents itself
   - [ ] Whenever there's a new hire, s/he gets one-on-one training
   - [ ] Once every couple of years
   - [ ] Once at time of hire
   - [ ] Never
   - [ ] Don't know

7) **During your most recently completed fiscal year, which of the following topics did the SUA provide training to staff or volunteers who work with family caregivers? (Check all that apply)**
   - [ ] Alzheimer's disease or a related disorder with neurological and organic brain dysfunction
   - [ ] Caregiver assessment
   - [ ] Care coordination/care management
   - [ ] Caregiver health and well-being
   - [ ] Caregiver intake and screening
   - [ ] Conducting outreach/public awareness activities
   - [ ] Care recipient diseases/chronic conditions

☐ Cultural/ethnic competency
☐ Employed caregivers
☐ Facilitating family meetings/mediation/conflict resolution
☐ Program data collection and reporting
☐ Service delivery specifications (e.g., protocols, referrals)
☐ Specific evidence-based caregiver education programs (e.g., Powerful Tools; SAVVY Caregiver)
☐ Technical aspects of administering consumer directed options (e.g., vouchers, cash payments or fiscal intermediaries)
☐ Grandparents Raising Grandchildren
☐ Other (please specify): _____
☐ Not applicable
☐ Don't know

Funding Sources

8) Please mark which of the following funding sources are used to serve NFCSP caregiver clients. (Check all that apply)

☐ Aging and Disability Resources Center initiative (ADRC)
☐ Alzheimer's Disease Demonstration Grants to States (ADDGS)
☐ Lottery funds
☐ Money Follows the Person (MFP)
☐ Medicaid Aged/Disabled HCBS waiver (A/D Waiver)
☐ Medicaid State Plan
☐ Private foundation
☐ Social Services Block Grant (Title XX)
☐ Tobacco settlement funds
☐ Veterans Directed Home and Community Based Services (VD-HCBS)
☐ Other (please specify): _____
☐ Don't know

Targeting

The next questions are about targeting. Targeting is defined as modifying or adapting services and outreach to attract and meet the needs of identified groups who may be under-represented or are considered in special need of services. Target populations are defined by the Older Americans Act as… "*Older individuals with greatest economic need and older individuals with greatest social need (with particular attention to low-income older individuals, including low-income minority older individuals, older individuals with limited English proficiency, and older individuals residing in rural areas)*."

9) Since program implementation, which special populations of caregivers, if any, has your program made a specific effort to serve? (Check all that apply)

☐ Caregivers, Older (age 70+)
☐ Caregivers, Younger (age 18-25)
☐ Caregivers of persons with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction
☐ Caregivers of veterans
☐ Employed family caregivers
☐ Grandparents raising grandchildren and other relative caregivers
☐ Rural caregivers
☐ Racially and ethnically diverse caregivers

☐ Other (please specify): _____
☐ No specific efforts have been made to address special populations (Skip to Q11)
☐ Don't know

10) **Since program implementation began, which of the following activities has your program undertaken to address those special populations of caregivers? (Check all that apply)**
☐ Targeted marketing and outreach campaigns
☐ Translated or adopted materials in languages other than English
☐ Produced culturally specific and appropriate materials
☐ Developed services to meet specialized needs (e.g. mobile adult day services and mobile I&A unit for rural caregivers)
☐ Hired staff or obtained volunteers with specialized knowledge of or skills working with special populations of caregivers
☐ Developed mobile mechanisms to address needs of rural caregivers
☐ Developed partnerships with employers
☐ Developed partnerships with schools
☐ Developed partnerships with VA systems
☐ Other (Please specify)
☐ Don't know

11) **Do you have a statewide task force, commission or coalition specifically to examine family caregiver issues?**
☐ Yes
☐ No

11a) If yes, what is the name and contact information for this entity?
Name: _____
Contact information (e.g., e-mail; phone):_____

11b) Please e-mail a copy of the task force's, coalition's, or commission's report if it was completed in the last five years to Cindy Gruman (cindy.gruman@lewin.com). This report can include a summary of the group's activities, research, recommendations, etc. You will receive a reminder at the end of this survey.

Community Needs Assessment

The next set of questions will ask about your state's Community Needs Assessment protocol.

12) **Have community needs assessments for caregiver support services been conducted?**
☐ Yes, a state-wide community needs assessment that includes caregiver support services has been done (skip to 12b)
☐ Yes, one or more local level (PSA-level) community needs assessments that include caregiver support services have been done (go to 12a)
☐ No assessment has been done (Skip to Q14)
☐ Don't know (Skip to Q14)

12a) Did the local level community needs assessment(s) follow a consistent protocol (e.g., standard methodology and/or timeframes for community assessment) that included caregiver services?

☐ Yes
☐ No (Skip to Q13)
☐ Don't know

12b) If yes, how many years ago? If you do not know, enter DK

_____

12c) Please e-mail a copy of your state's assessment protocol to Cindy Gruman (cindy.gruman@lewin.com). You will receive a reminder at the end of this survey.

13) **Were results from the community needs assessment(s) pertaining to caregiver support services utilized or incorporated into the state plan?**

☐ Yes
☐ No
☐ Don't know

Caregiver Intake, Screening, and Assessment

The next set of questions will ask about Caregiver Intake, Screening, and Assessment.

14) **What are your state policies around <u>intake</u> activities for caregiver support services? (Check all that apply)**

☐ We require a standardized intake process for caregiver support in our state (Programmer note: If this first answer option is selected, the second answer option cannot be selected)
☐ We have, but do not require, a standardized intake process for caregiver support in our state (Programmer note: If this second answer option is selected, the first answer option cannot be selected)
☐ Our family caregiver support program shares relevant caregiver intake data with other programs in which the caregiver might be eligible for support (either verbally or electronically)
☐ Our family caregiver support program receives relevant caregiver intake data from other programs (either verbally or electronically)
☐ The state requires a standardized data set but the AAA or individual providers can develop their own intake process.
☐ Does not apply
☐ Other (please specify): _____

15) **What are your state policies around <u>screening</u> activities for caregiver support services? (Check all that apply)**

☐ We require a standardized screening process for caregiver support in our state (Programmer note: If this first answer option is selected, the second answer option cannot be selected)

☐ We have, but do not require, a standardized screening process for caregiver support in our state (Programmer note: If this second answer option is selected, the first answer option cannot be selected)

☐ Our family caregiver support program shares relevant screening data with other programs in which the caregiver might be eligible for support (either verbally or electronically)

☐ Our family caregiver support program receives relevant caregiver screening data from other programs (either verbally or electronically)

☐ The state requires a standardized data set but the AAA or individual providers can develop their own screening process.

☐ Does not apply

☐ Other (please specify): _____

The next few questions will be about your state's practices for assessing caregiver needs.

16) How does your SUA define caregiver assessment?

_____
_____

17) Which policies, regulations, or guidance does your state have on <u>individual level caregiver assessments</u> for the NFCSP?

☐ Who is to be assessed
☐ Content of assessments
☐ Who can perform assessments
☐ How often the assessment is conducted
☐ Other (*please specify*): _____

18) Does your SUA have a standardized process (e.g., assessment instrument, policies) for assessing caregiver needs? (Check all that apply)

☐ Yes, for all family caregiver program clients
☐ Yes, for specific services only:
  ☐ Access assistance
  ☐ Respite services
  ☐ Education/Training
  ☐ Support groups
  ☐ Counseling
  ☐ Supplemental services
  ☐ Other (please specify): _____
☐ No, we don't have a standardized process for assessing caregiver needs
☐ Don't know

19) In your caregiver support program, who is assessed?

☐ Care Recipient (Skip to 20)
☐ Family caregiver (Skip to 20)
☐ Both (Skip to 20)
☐ No assessment is conducted (Go to 19a)

19a) Can you describe the reasons why you do not conduct assessments? (Open ended): _____ (Skip to 23)

20) Does your state have a standardized caregiver assessment?

☐ Yes
☐ No (Skip to Q21)
☐ Don't know

20a)   Which of the following domains are included in your standardized caregiver assessment? (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): _____

20b) Please e-mail a copy of your state's standardized assessment instrument to Cindy Gruman (cindy.gruman@lewin.com). You will receive a reminder at the end of this survey.

21) What is your SUA's policy on the frequency of conducting family caregiver reassessments for services? (Check all that apply)

☐ We do not have a policy for conducting reassessments
☐ Annually
☐ Semi-annually
☐ Prompted by change in caregiver status
☐ Prompted by change in care recipient status
☐ Left up to the AAA
☐ Other (please specify) _____
☐ Don't know

22) Does the SUA set the policy for how the caregiver assessments and reassessments are used?

☐ To prioritize who receives services (Skip to Q23)
☐ Care plan development for the caregiver (Skip to Q23)
☐ Measuring caregiver program outcomes (Go to Q22a)
☐ Strategic planning/forecasting and/ or program development (Skip to Q23)
☐ Decided at the AAA level (Skip to Q23)
☐ Other (please specify): _____ (Skip to Q23)
☐ Don't know (Skip to Q23)

22a) You indicated that you measure caregiver outcomes. Which of the following outcomes do you measure (Check all that apply)

☐ Monitor caregiver burden
☐ Monitor caregiver depression
☐ Emotional/mental health
☐ Financial/employment
☐ Extent of caregiving load/demand
☐ Balance among caregiving, work, or other life domains
☐ Physical health
☐ Other (please specify): _____

Program Integration

23) Has there been an effort at the state level to use the same caregiver and care recipient assessment tools across all home and community-based (HCBS) programs?

☐ Yes
☐ No (Skip to 24)

23a) If yes, indicate which HCBS programs? (Check all that apply)

☐ Medicaid HCBS for elderly
☐ Medicaid HCBS for adults with disabilities
☐ State-funded caregiver program/services
☐ Kinship care program
☐ Other (please specify):_____

24) What is the level of integration of the following components of your state's home and community-based service system for the elderly and adults with physical disabilities? [Check one for each row]

Level of Integration	Fully Integrated	Partially Integrated	Not Integrated	Don't Know
Intake	☐	☐	☐	☐
Assessment	☐	☐	☐	☐
Care Planning	☐	☐	☐	☐
Data Collection	☐	☐	☐	☐

25) What are the major barriers limiting/preventing integration of NFCSP with other home and community-based programs in your state. (Check all that apply)

☐ Complexity of accessing and arranging services
☐ Different client population than in other programs
☐ Different eligibility requirements
☐ Different reporting requirements
☐ Federal regulatory or statutory requirements
☐ Lack of access to adequate computer technology and support
☐ Lack of knowledge of opportunities for integration
☐ Low priority given to caregiver support services

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☐ Organizational cultural and administrative differences
☐ Staff has too many responsibilities
☐ State regulatory or statutory requirements
☐ Other (please specify): _____
☐ No barriers to integration

25a) Does your NFCSP have a method for identifying caregivers for referral to other publicly funded services?

☐ Yes
☐ No
☐ Don't Know

25b) Does your state have a protocol on referral of caregivers between programs?

☐ Yes
☐ No
☐ Don't Know

26) Does the Aging and Disability Resource Center site(s) currently use client intake and assessments for caregiver services that are consistent across the state?

☐ Yes, they are consistent
☐ No, they are not consistent
☐ Only one site in state
☐ ADRC does not conduct client intake or assessments
☐ Don't know

State and Area Plans

27) Does the OAA required State Plan on Aging currently include a caregiver supports and services component?

☐ Yes
☐ No
☐ Don't Know

28) Does the Area Plan for Aging format currently include a caregiver services component?

☐ Yes
☐ No
☐ Don't Know

Waiting Lists

The next set of questions asks about waiting lists for NFCSP services.

29) Does the SUA currently have policies, guidance or regulations pertaining to the creation and management of waiting lists for NFCSP services?

☐ Yes
☐ No

☐ Don't know

30) In your SUA, is there a waiting list for any NFCSP service?

☐ Yes
☐ No
☐ Don't know

31) How are waiting lists organized?

☐ A single waitlist is maintained for the NFCSP overall
☐ Multiple waitlists are maintained for NFCSP specific caregiver support services (e.g., respite care, caregiver counseling)
☐ Other (*Please specify*):_____
☐ Don't know

32) Please indicate how many caregivers are on the lists, and what the typical waiting period is?

Caregiver Service	# of caregivers on the waitlist	Typical minimum wait for services	Typical Maximum wait for services
Single waitlist for the NFCSP overall	_____ ☐ None ☐ Don't know	___ yrs ___months ___days ☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know	___ yrs ___months ___days ☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know
Caregiver counseling, training and education	_____ ☐ None ☐ Don't know	___ yrs ___months ___days ☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know	___ yrs ___months ___days ☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know
Caregiver support groups	_____ ☐ None ☐ Don't know	___ yrs ___months ___days ☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know	___ yrs ___months ___days ☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know
Respite care	_____ ☐ None	___ yrs ___months ___days	___ yrs ___months ___days

Caregiver Service	# of caregivers on the waitlist	Typical minimum wait for services	Typical Maximum wait for services
	☐ Don't know	☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know	☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know
Supplemental Services	_____ ☐ None ☐ Don't know	___ yrs ___months ___days ☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know	___ yrs ___months ___days ☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know
Access assistance/case management/care coordination	_____ ☐ None ☐ Don't know	___ yrs ___months ___days ☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know	___ yrs ___months ___days ☐ No wait ☐ SUA does not keep that data at the state level ☐ Don't know

Prioritization of Services

The next section asks about how services are prioritized in your state.

33) Which of the following best describes how the SUA's current prioritization policy was set for the NFCSP?

☐ Prioritization policy is set by the SUA
☐ Prioritization policy is set by the SUA with input from AAAs
☐ Prioritization policy is set by the AAAs with input from SUA
☐ Prioritization policy is set by the AAAs
☐ Prioritization policy is set by the local service providers
☐ No prioritization policy exists
☐ Don't know

34) Are prioritization criteria statewide or do they vary by AAA?

☐ Prioritization criteria are statewide
☐ Prioritization criteria are AAA specific
☐ Prioritization criteria are local service provider specific
☐ Don't know

35) Which of the following criteria are used to determine NFCSP service priority according to SUA policy? (check all that apply)

Criteria	check all that apply
a. ADL and/or IADL impairment minimum (e.g., 3+ ADL impairments)	☐
b. Adult Day Program Participation	☐
c. Adult Protective Services referral	☐
d. Advanced age (e.g., 75+, 85+)	☐
e. Chronic health condition (e.g., diabetes)	☐
f. Combined score on Intake/Risk Screening and/or Stress Inventory Score	☐
g. Alzheimer's disease or a related disorder with neurological and organic brain dysfunction	☐
h. Geographic isolation (e.g., rural)	☐
i. Homebound	☐
j. Lack of informal/family support	☐
k. Limited English proficiency	☐
l. Long-term care need for service	☐
m. Low income (e.g., % of federal poverty level)	☐
n. Nutrition risk assessment	☐
o. Poor housing or lack of kitchen access	☐
p. Racial/ethnic minority	☐
q. Short-term care need for service	☐
r. Social isolation (e.g., lives alone)	☐
s. Other (Specify) _____	☐
t. No prioritization criteria	☐
u. Criteria are not set by the SUA	☐

Caregiver Service Operation and Quality Assurance

The next section asks about protocols for caregiver services and quality assurance in your state.

36) Please check all of the following services that your family caregiver support program provides specifically to family caregivers (directly through the AAA or local service providers).

Information
    ☐ Information & Referral
    ☐ Outreach Presentations
    ☐ Other (Please specify): _____
Assistance
    ☐ Options Counseling
    ☐ Care/case management (e.g., assessment, developing care plans, arranging services)
    ☐ Follow-up and/or reassessments

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☐ Other (Please specify): _____

Counseling/Education & Training
☐ Support Groups
☐ Individual Counseling
☐ Family Consultation, Counseling, Meetings
☐ Training on various aspects related to caregiving
☐ Other (Please specify): _____

Respite Services
☐ 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): _____

Supplemental Services
☐ Assistive Technology
☐ Cash Grant
☐ Consumable Supplies
☐ Emergency Response
☐ In-Home Assessment
☐ Home Modification/Repairs
☐ Legal and/or Financial Consultation
☐ Homemaker/Chore Services
☐ Transportation
☐ Other (Please specify): _____

37) Must the caregiver live with the care recipient to be eligible for respite assistance?

☐ Yes
☐ No

38) Are eligible family caregivers offered the same package of NFCSP services in every PSA in your state?

☐ Yes
☐ No, please explain _____
☐ Don't know

39) Does your NFCSP caregiver program have a policy that limits or caps the amount or cost of service an individual may receive?

☐ Yes, annual limit
☐ Yes, lifetime limit
☐ Limits vary by service
☐ No limits on the amount of services (Skip to Q40)

39a) Who sets the policy regarding NFCSP service caps? (Check all that apply)

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☐ SUA
☐ AAA
☐ Local service provider
☐ SUA sets funding cap for the AAA; the AAA can set additional funding caps for local service providers
☐ Other state-level agencies or policies
☐ Other (please specify) _____
☐ Not applicable

39b) Is the cap uniform across each Planning and Service Area?

☐ Yes
☐ No
☐ Not applicable

39c) Please complete the following to describe the service caps in your NFCSP program (Check all that apply):

WEB PROGRAMMER: IF QUESTION 39b = NO, SKIP TO Q40

Services	Capped	Type & Amount of Cap	Cap time period
All NFSCP services treated the same	☐ Yes ☐ No ☐ Don't know	☐ Hours: _____hrs ☐ Dollars: $_____	☐ Lifetime ☐ Monthly ☐ Quarterly ☐ Yearly ☐ Other: _____
Respite	☐ Yes ☐ No ☐ Don't know	☐ Hours: _____hrs ☐ Dollars: $_____	☐ Lifetime ☐ Monthly ☐ Quarterly ☐ Yearly ☐ Other: _____
Training and Education	☐ Yes ☐ No ☐ Don't know	☐ Hours: _____hrs ☐ Dollars: $_____	☐ Lifetime ☐ Monthly ☐ Quarterly ☐ Yearly ☐ Other: _____
Supplemental Services	☐ Yes ☐ No ☐ Don't know	☐ Hours: _____hrs ☐ Dollars: $_____	☐ Lifetime ☐ Monthly ☐ Quarterly ☐ Yearly ☐ Other: _____
Care/case management/ Care coordination	☐ Yes ☐ No ☐ Don't know	☐ Hours: _____hrs ☐ Dollars: $_____	☐ Lifetime ☐ Monthly ☐ Quarterly ☐ Yearly ☐ Other: _____

Monitoring and Evaluation

The next section asks about programmatic monitoring activities in your state.

40) Does your SUA conduct routine programmatic monitoring of the NFCSP program? (Check all that apply)

☐ Yes, at the AAA level
☐ Yes, at the local/provider level
☐ No, the SUA does not conduct routine programmatic monitoring (Skip to Q41)

40a) How does your program use the results?

☐ Advocate for program funding
☐ Budget justification
☐ Ensure compliance to Title III-E
☐ Funding requests
☐ Fundraising
☐ Ongoing implementation purposes
☐ Planning purposes
☐ Program changes
☐ Public Relations
☐ Other (please specify):_____

40b) With whom did you/plan to share the results? (Check all that apply)

☐ Internal SUA
☐ AAAs
☐ Provider network
☐ Other state agencies
☐ Advocacy organizations
☐ Legislature
☐ Other (please specify):_____

40c) Please e-mail a copy of your state's programmatic monitoring results to Cindy Gruman (cindy.gruman@lewin.com). You will receive a reminder at the end of this survey.

41) Does your SUA assess client satisfaction?
☐ Yes
☐ No (Skip to Q43)
☐ AAA assesses client satisfaction (Skip to Q43)

42) How frequently does your SUA assess program participant satisfaction?

☐ Annually
☐ Semi-annually
☐ Quarterly
☐ Monthly
☐ Ongoing
☐ Varies by service

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☐ Other (Please specify):_____

☐ Periodic (no schedule)

42a) Do you use a uniform caregiver satisfaction survey across all AAAs?

☐ Yes
☐ No

42b) Please e-mail a copy of your caregiver satisfaction survey to Cindy Gruman (cindy.gruman@lewin.com). You will receive a reminder at the end of this survey.

43) Which of the following requirements are included in your contracts with AAAs pertaining to the NFCSP? (Check all that apply)

☐ Adherence to the Title III-E
☐ Staff certification requirements for staff who work directly with caregivers
☐ Staff training requirements for all staff
☐ Staff training requirements for staff who work directly with caregivers
☐ Delivery of evidence-based interventions and/or practices
☐ IT/MIS infrastructure
☐ Performance-based outcomes
☐ Mode of caregiver contact (Communication – in person, phone, online)
☐ Other (*please specify*): _____

44) Does the SUA currently include assessments in any of the following areas to monitor the AAAs' implementation of the NFCSP?
☐ Client satisfaction
☐ Targeting of service
☐ Outreach activities
☐ Access to service
☐ Reporting of data
☐ Fiscal management
☐ None of the above
☐ Don't know
☐ Other (please specify): _____

45) How do AAAs currently report NFCSP data to the SUA?
☐ Software/computer system
☐ Email (Skip to Q46)
☐ Phone (Skip to Q46)
☐ Mail (Skip to Q46)
☐ Other (please specify): _____ (Skip to Q46)
☐ Don't know (Skip to Q46)

45a) Are all AAAs in your state currently required to use the same software for reporting NFCSP data?
☐ Yes
☐ No
☐ Don't Know

46) What specific data are currently collected beyond what is required for the State Program Report?

☐ NFCSP reports /program performance data
☐ Quality assurance findings
☐ Fiscal management reports
☐ Other (*please specify*): _____
☐ We don't require data beyond what is required in the AoA State Program Report
☐ Don't know

47) Does the SUA or AAA establish NFCSP performance measures at the AAA level?

☐ Yes, the SUA
☐ Yes, the AAA
☐ Yes, both the SUA and AAA
☐ No, not established
☐ Don't Know

Systems Development

48) Has your SUA designed a website or webpage for family caregivers? (Check all that apply)

☐ Yes, as a separate website
☐ Yes, as a separate webpage
☐ Yes, as part of the ADRC initiative
☐ Yes, as part of a community database unrelated to/as a separate effort from the ADRC initiative
☐ No website or webpage but there are plans to do so
☐ No website or webpage

49) Does your SUA work with other state agencies to implement the NFCSP?

☐ Yes
☐ No (Skip to Q50)

49a) If yes, please list these state agencies and describe your relationship in implementing the NFCSP:
_____

Supplemental Services

The next set of questions ask about provision of supplemental services in your state.

50) Which entity determines which supplemental services may be purchased under the NFCSP? (Check all that apply)

☐ SUA
☐ AAA
☐ Local service providers
☐ Other (please describe): _____

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51) Please list your top three supplemental services for NFCSP caregivers of older adults.

1) _____

2) _____

3) _____

☐ Don't know

52) Please list your top three supplemental services for NFCSP grandparent caregivers who care for grandchildren.

1) _____

2) _____

3) _____

☐ Don't know

Self-directed Care/Consumer Direction

The next questions are about self-directed care. Self-directed care is defined as programs and services, in which clients can choose to select, manage and dismiss their workers. This may also be referred to as "consumer-directed" care.

53) Does the SUA currently have policies that permit self-directed home and community-based services for caregivers?

☐ Yes

☐ No

☐ Don't know

54) What kinds of choice and control over services does your NFCSP provide for family caregivers? (Check all that apply)

☐ Caregivers can choose the services that best fit their needs from a menu of services

☐ Caregivers can choose who they want to provide respite care (e.g. choosing between contract agencies and independent providers)

☐ Caregivers receive a voucher or budget to use for respite care

☐ Caregivers receive a voucher or budget to use for supplemental services (e.g., consumable supplies, home modifications, etc.)

☐ Caregivers receive a budget for the purchase of goods or services

☐ Other (please describe): _____

☐ None of the above

55) Can family members other than the primary caregiver be paid through your NFCSP to provide care?

☐ Yes

☐ No (Skip to Q56)

55a) What types of services can they be paid to provide? (Check all that apply)

☐ Respite care

☐ Personal care

☐ Other (please describe): _____

55b) Are there any family members who cannot be paid? (Check all that apply)
☐ Spouses
☐ Parents/guardians of minors
☐ Adult children
☐ Other (please describe): _____
☐ Any family member can be paid

55c) What types of special requirements are there for family members who are paid to provide services? (Check all that apply)
☐ Criminal background checks
☐ Minimum training requirements
☐ Other (please describe): _____
☐ No special requirements

Program Administration

The next set of questions asks about state and federal financing, and single point-of-entry systems.

56) If your state operates a single point-of-entry system for all home and community-based care programs, does the single point-of-entry include or exclude access to the NFCSP? (Check one)
☐ Include
☐ Exclude
☐ Varies at the local level
☐ No single point-of-entry

57) In your opinion, how difficult is it for the state to meet the federal match requirements for the NFCSP?

☐ Not at all difficult
☐ Somewhat difficult
☐ Quite a bit difficult
☐ Extremely difficult
☐ I don't know

58) How is the federal match requirement for the NFCSP met in your state (check all that apply)

☐ The state provides the match
☐ The AAA provides the match
☐ The service provider provides the match

59) What effect has your state's current state fiscal status had on services to support family caregivers and/or state initiatives to explicitly assist family caregivers? Would you say:

☐ A strong negative effect
☐ A moderate negative effect
☐ A little negative effect
☐ No effect at all
☐ A little positive effect
☐ A moderate positive effect
☐ A strong positive effect

59a) Please explain your answer: _____

Program Funding and Resources

The next questions are about your state's budget during the most recently completed fiscal year.

60) How does the state make funding allocation decisions for each of the NFCSP services?

☐ SUA alone determines amount
☐ SUA determines amounts with consultation with AAAs or local providers
☐ SUA and AAAs make a joint decision
☐ SUA determines the amounts based solely on the amounts requested by the AAAs
☐ SUA gives total allocation and AAA determines how much goes to each Title III-E service
☐ Other (please specify): _____
☐ Don't know

61) In your most recently completed fiscal year, how much did your state expend from the following sources to support the caregivers served in the NFCSP? Please provide category totals (i.e., shaded lines below), even if you cannot provide expenditures within each category.

	Expenditures	Don't know
Total Federal Funding	$_____	☐
a.　Older Americans Act funds	$_____	☐
b.　Other federal	$_____	☐
(Please specify)	_____	
Total State Funding	$_____	☐
c. General Revenue	$_____	☐

| d. State funded caregiver program | $_____ | ☐ |
| **Other Sources of Funding** (e.g., local funding, non-profit, private for-profit, contributions, foundation) | $_____ | ☐ |

62) **During the most recently completed fiscal year, what were the total expenditures for your SUA, including expenditures for the NFCSP?**

$|_|,|_|_|_|,|_|_|_|,|_|_|_|

☐ **Don't know**

63) **Does the SUA have policy, guidance, or regulations related to AAA and local service provider offering private pay/fee-for-service caregiver services?**
☐ Yes
☐ No
☐ Don't know

64) **Please indicate how much your SUA encourages or discourages AAAs or service providers to operate private pay/fee-for-service NFCSP for older adults?**
☐ Strongly encourages
☐ Encourages
☐ Allows private pay but neither encourages nor discourages the activity
☐ Discourages
☐ Prohibits
☐ Don't know

Non-OAA Caregiver Program

The next questions are about caregiver programs in your state that are not funded by the OAA.

65) **Prior to the establishment of OAA NFCSP in your SUA, which of the following services did your SUA offer (either directly or via contract with another provider) to caregivers? (Check all that apply)**
☐ I&R
☐ Training/Education
☐ Support Groups
☐ Counseling
☐ Respite care
☐ Supplemental service (e.g. home-delivered meals, home modification, emergency response)
☐ Care Coordination
☐ Caregiver Support Coordination
☐ Access assistance
☐ Cash and counseling
☐ Other (please specify): _____
☐ Don't know

66) Did the establishment of the NFCSP result in the creation of standardized eligibility criteria for caregiver services and supports?

☐ Yes
☐ No
☐ Don't know

67) Does your state currently administer a separate caregiver program funded outside of the NFCSP?

☐ Yes
☐ No (Skip to Q71)

67a) If yes, what is the caregiver minimum age eligibility requirement?

☐ 18+
☐ 55+
☐ 60+
☐ 65+
☐ Other minimum caregiver age. What age?_____
☐ No age requirement if care recipient meets age requirement
☐ No age requirement for caregiver

67b) If yes, what is the care recipient minimum age eligibility requirement?

☐ Under 18
☐ 18+
☐ 55+
☐ 60+
☐ 65+
☐ Other minimum care recipient age. What age? _____
☐ No age requirement if caregiver meets age requirement

67c) If yes, what are the care recipient functional status (e.g. ADL limitation) eligibility requirements? (Check all that apply)

☐ Unable to complete at least 1 Activity of Daily Living (ADL)
☐ Unable to complete at least 2 ADLs
☐ Unable to complete 3 or more ADLs
☐ Unable to complete at least 1 Instrumental Activity of Daily Living (IADL)
☐ Unable to complete at least 2 IADLs
☐ Unable to complete 3 or more IADLs
☐ Nursing home eligible
☐ Diagnosed with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction
☐ Requires 24-hour monitoring or supervision due to cognitive impairment
☐ Judged to have severe disability
☐ No functional status requirement
☐ Other (please describe)

68) During the last fiscal year, approximately how many caregivers were in your non-OAA caregiver programs?

_____

69) When did your non-OAA caregiver program begin?

☐ Before the NFCSP (Go to Q69a, then skip to Q70)
☐ After the NFCSP program (Skip to Q69b)
☐ At the same time as the NFCSP (Skip to Q69b)
☐ Don't Know (Skip to Q71)
☐ Other [Please specify]:_____

69a) How did your non-OAA caregiver program(s) change as a result of the NFCSP implementation?

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[Skip to Q70]

69b) How did the NFCSP affect implementation of your state's non-OAA caregiver program?

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[Skip to Q71]

70) Which best describes the current relationship between the OAA NFCSP and pre-existing caregiver programs and services?

☐ Programs are distinct and operate separately (Skip to 71)
☐ Programs are separate with coordinated operations
☐ Programs are integrated into one program with multiple funding streams
☐ Other (please specify): _____
☐ Don't know

70a)   Please describe how your SUA integrated or coordinated these programs.

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Integration with Non-Caregiver Programs

The next questions address state efforts to integrate the NFCSP with non-caregiver programs.

71) Has the NFCSP coordinated with ADRCs in any of the following ways? (check all that apply)

☐ Development or review of policies, guidance or regulations regarding the inclusion of caregiver services

☐ Development or implementation of screening protocols
☐ Development or implementation of intake tools
☐ Development or implementation of referral/assessment processes
☐ Provision of training
☐ Provision of Care Transitions
☐ Provision of Options Counseling
☐ Other (*please specify*): _____
☐ NFCSP does not coordinate with the ADRC

Other Issues

Now we are going to ask you questions about additional long-term care issues in your state.

72) What is the current status of the following long-term issues in your SUA?

	Fully Operationalized	Currently working on this	Plan to do this in the future	Not a priority	Don't know
a. Expanding Medicaid home and community-based waivers for the elderly and people with disabilities	☐	☐	☐	☐	☐
b. Expanding state-funded home and community-based care services for the elderly and people with disabilities	☐	☐	☐	☐	☐
c. Developing policies to address the needs of family caregivers of Medicare-Medicaid eligible populations	☐	☐	☐	☐	☐
d. Expanding state-funded family caregiver support programs	☐	☐	☐	☐	☐
e. Establishing family leave and/ or workplace accommodation policies for family caregivers	☐	☐	☐	☐	☐
f. Establishing tax credits for caregiving	☐	☐	☐	☐	☐
g. Reducing direct service worker shortages	☐	☐	☐	☐	☐
h. Implementing an Olmstead plan	☐	☐	☐	☐	☐
i. Developing a centralized intake, screening and assessment for family caregivers	☐	☐	☐	☐	☐
j. Implementing or expanding consumer directed options	☐	☐	☐	☐	☐
k. Establishing a single point-of-entry for all home and community-based programs, including caregiver support	☐	☐	☐	☐	☐
l. Reducing nursing home beds	☐	☐	☐	☐	☐
m. Other (please explain)	☐	☐	☐	☐	☐

73) **What do you see as the most significant issues your family caregiver program will face over the next year?**

74) **What do you see as the most significant issues your family caregiver program will face over the next three to five years?**

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

76) **Give one example of an NFCSP activity in your state that you would nominate as a "best practice" for caregiver support. Provide the name of the activity/practice and a description and how outcomes were evaluated, if they were.**

Contact Information

Your Name: [Type text]

Title: [Type text]

State Department/Division: [Type text]

Mailing Address: [Type text]

Telephone: [Type text]

Fax: [Type text]

Email address: [Type text]

 Program contact (if different from person completing survey)

Name: [Type text]

Title: [Type text]

Telephone: [Type text]

Email Address: [Type text]

Thank you for your timely response!