

# National Family Caregiver Support Program Evaluation- 2015 State Unit

## Introduction

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). Your State Unit on Aging (SUA) plays a vital role in overseeing and/or providing programs and services to caregivers in their local areas. It is the goal of this survey to:

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

The survey includes 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.

Given the length of this survey and diversity of questions, we encourage you to draw upon the experiences and knowledge of others to accurately complete the requested information. You can start and stop the survey an unlimited number of times. 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](mailto:cindy.gruman@lewin.com) or Ashley Tomisek (703)269-5632 or [ashley.tomisek@lewin.com](mailto:ashley.tomisek@lewin.com).

Acknowledgment and Disclaimer: This evaluation is made possible by a contract from the U.S. Department of Health and Human Services' Administration for Community Living: Contract Number HHSP23320095639WC).

## Introduction

### 1. What is the name of your NFCSP/family caregiver support program?

### 2. How many Area Agencies on Aging (AAA) are there currently in your state?

### 3. 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.

**If you don't know the number of AAAs by type, please leave blank.**

Single-county	<input type="text"/>
Multi-county	<input type="text"/>
Single city/metro area	<input type="text"/>
Multiple city/metro area	<input type="text"/>
Other entity (name/type of entity)	<input type="text"/>
Other entity (number of AAAs)	<input type="text"/>

### 4. 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

### 5. Currently, does your SUA have a policy or standardized eligibility criteria that defines caregivers as clients?

- ☐ Yes
- ☐ No
- ☐ Don't Know

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### 6. 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

## Staff/Volunteer Training

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

### **7. Does the SUA require training for AAA or other staff or volunteers who work with family caregivers?**

- ☐ Yes
- ☐ No policy on training



## Staff/Volunteer Training

### 7a. If yes, which of the following staff members or volunteers are required to take training? (Check all that apply)

- ☐ 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
- ☐ Don't know
- ☐ None of the above
- ☐ Other (please specify)

### 7b. How often is training provided?

- ☐ 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

## Staff/Volunteer Training

**8. 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
- ☐ Not applicable
- ☐ Don't know
- ☐ Other (please specify)

## Funding Sources

### 9. Please mark which of the following additional 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)
- ☐ Don't know
- ☐ Other (please specify)

## 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)."

### **10. 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
- ☐ No specific efforts have been made to address special populations
- ☐ Don't know
- ☐ Other (please specify)

## Targeting

**11. 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 adapted 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 partnerships with employers
- ☐ Developed partnerships with schools
- ☐ Developed partnerships with VA systems
- ☐ Don't know
- ☐ Other (please specify)

## Targeting

**12. Do you have a statewide task force, commission or coalition specifically to examine family caregiver issues?**

☐ Yes

☐ No

## Targeting

### 12a. If yes, what is the name and contact information for this entity?

Name

Contact Information (e.g. e-mail, phone number)

## Targeting

12b. 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.

### **13. 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
- ☐ Yes, one or more local level (PSA-level) community needs assessments that include caregiver support services have been done
- ☐ No assessment has been done
- ☐ Don't know

**Community Needs Assessment**

**13a. 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
- ☐ Don't know

**Community Needs Assessment**

**13b. If yes, how many years ago was the community needs assessment for caregiver support services conducted?**

## Community Needs Assessment

13c. Please e-mail a copy of your state's assessment protocol to Cindy Gruman ([cindy.gruman@lewin.com](mailto:cindy.gruman@lewin.com)). You will receive a reminder at the end of this survey.

**Community Needs Assessment**

**14. 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

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## Caregiver Intake, Screening, and Assessment

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

### 15. What are your state policies around intake activities for caregiver support services? (Check all that apply)

- ☐ We require a standardized intake process for caregiver support in our state
- ☐ We have, but do not require, a standardized intake process for caregiver support in our state
- ☐ 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)

### 16. What are your state policies around screening activities for caregiver support services? (Check all that apply)

- ☐ We require a standardized screening process for caregiver support in our state
- ☐ We have, but do not require, a standardized screening process for caregiver support in our state
- ☐ 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)

# National Family Caregiver Support Program Evaluation- 2015 State Unit on

## Caregiver Intake, Screening, and Assessment

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

**17. How does your SUA define caregiver assessment? You can use a definition of caregiver assessment from a training manual or describe your SUA's definition in your own words.**

**18. Which policies, regulations, or guidance does your state have on individual level caregiver assessments for the NFCSP? (Check all that apply)**

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

**19. Does your SUA have a standardized process (e.g., assessment instrument, policies) for assessing caregiver needs?**

- ☐ Yes, for all family caregiver program clients
- ☐ Yes, for specific services only
- ☐ No, we don't have a standardized process for assessing caregiver needs
- ☐ Don't know

## Caregiver Intake, Screening, and Assessment

**19a. If your SUA has a standardized process (e.g., assessment instrument, policies) for assessing caregiver needs for specific services only, please indicate which services the process applies to. (Check all that apply)**

- ☐ Access assistance
- ☐ Respite services
- ☐ Education/Training
- ☐ Support groups
- ☐ Counseling
- ☐ Supplemental services
- ☐ Other (please specify)



**Caregiver Intake, Screening, and Assessment**

**20. In your caregiver support program, who is assessed?**

- ☐ Care Recipient
- ☐ Family caregiver
- ☐ Both
- ☐ No assessment is conducted

**Caregiver Intake, Screening, and Assessment**

**20a. If no, can you describe the reasons why you do not conduct assessments?**

**Caregiver Intake, Screening, and Assessment**

**21. Does your state have a standardized caregiver assessment?**

- ☐ Yes
- ☐ No
- ☐ Don't Know

## Program Integration

### 21a. 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)

## Caregiver Intake, Screening, and Assessment

21b. Please e-mail a copy of your state's standardized assessment instrument to Cindy Gruman ([cindy.gruman@lewin.com](mailto:cindy.gruman@lewin.com)). You will receive a reminder at the end of this survey.

## Caregiver Intake, Screening, and Assessment

### 22. 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
- ☐ Don't know
- ☐ Other (please specify)

### 23. What is the policy for how the caregiver assessments and reassessments are used? (Check all that apply)

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

## Caregiver Intake, Screening, and Assessment

**23a. 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**

**24. 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



## Program Integration

### 24a. 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)

## Program Integration

**25. 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]**

	Fully Integrated	Partially Integrated	Not Integrated	Don't Know
Intake	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assessment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care Planning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Data Collection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**26. 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
- ☐ Organizational cultural and administrative differences
- ☐ Staff has too many responsibilities
- ☐ State regulatory or statutory requirements
- ☐ No barriers to integration
- ☐ Other (please specify)

## Program Integration

**26a. Does your NFCSP have a method for identifying caregivers for referral to other publicly funded services?**

- ☐ Yes
- ☐ No
- ☐ Don't Know

**26b. Does your state have a protocol on referral of caregivers between programs?**

- ☐ Yes
- ☐ No
- ☐ Don't Know

## Program Integration

**27. 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

**28. Does the OAA required State Plan on Aging currently include a caregiver supports and services component?**

- ☐ Yes
- ☐ No
- ☐ Don't Know

**29. 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 ask about waiting lists for NFCSP services.

**30. 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

**31. In your SUA, is there a waiting list for any NFCSP service?**

- ☐ Yes
- ☐ No
- ☐ Don't Know

## Waiting Lists

### 32. 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)
- ☐ Don't know
- ☐ Other (please specify)

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## Waiting Lists

**33. Please indicate how many caregivers are on the waitlists by caregiver service.**

**If there is no one on a particular waitlist, please enter '0'.**

**If you do not know how many are on a waitlist, please leave blank.**

Single waitlist for the NFCSP overall	<input type="text"/>
Caregiver counseling, training and education	<input type="text"/>
Caregiver support groups	<input type="text"/>
Respite care	<input type="text"/>
Supplemental Services	<input type="text"/>
Access assistance/case management/care coordination	<input type="text"/>

**33a. Please indicate the typical minimum wait for services by caregiver service.**

**If there is no wait for a service, please select "No wait list" under the "Other" category.**

**If the SUA does not keep that data at the state level, please select "SUA does not keep that data at the state level" under the "Other" category.**

**If you do not know how long the wait for a particular service is, please select "Don't know" under the "Other" category.**

	Days	Months	Years	Other
Single waitlist for the NFCSP overall	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Caregiver counseling, training and education	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Caregiver support groups	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Respite care	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Supplemental Services	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Access assistance/case management/care coordination	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>



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**33b. Please indicate the typical maximum wait for services by caregiver service.**

**If there is no wait for a service, please select "No wait list" under the "Other" category.**

**If the SUA does not keep that data at the state level, please select "SUA does not keep that data at the state level" under the "Other" category.**

**If you do not know how long the wait for a particular service is, please select "Don't know" under the "Other" category.**

	Days	Months	Years	Other
Single waitlist for the NFCSP overall	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Caregiver counseling, training and education	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Caregiver support groups	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Respite care	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Supplemental Services	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Access assistance/case management/care coordination	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

## Prioritization of Services

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

### **34. 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
- ☐ SUA with input from AAAs
- ☐ AAAs with input from SUA
- ☐ AAAs
- ☐ Local service providers
- ☐ No prioritization policy exists
- ☐ Don't know

### **35. 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

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

	Care Recipient	Caregiver
ADL and/or IADL impairment minimum (e.g., 3+ ADL impairments)	<input type="checkbox"/>	<input type="checkbox"/>
Adult Day Program Participation	<input type="checkbox"/>	<input type="checkbox"/>
Adult Protective Services referral	<input type="checkbox"/>	<input type="checkbox"/>
Advanced age (e.g., 75+, 85+)	<input type="checkbox"/>	<input type="checkbox"/>
Chronic health condition (e.g., diabetes)	<input type="checkbox"/>	<input type="checkbox"/>
Diagnosis of Alzheimer's disease or a related disorder with neurological and organic brain dysfunction	<input type="checkbox"/>	<input type="checkbox"/>
Geographic isolation (e.g., rural)	<input type="checkbox"/>	<input type="checkbox"/>
Homebound status	<input type="checkbox"/>	<input type="checkbox"/>
Lack of informal/family support	<input type="checkbox"/>	<input type="checkbox"/>
Limited English proficiency	<input type="checkbox"/>	<input type="checkbox"/>
Long-term care need for service	<input type="checkbox"/>	<input type="checkbox"/>
Low income (e.g., % of federal poverty level)	<input type="checkbox"/>	<input type="checkbox"/>
Mental Health / Emotional Status	<input type="checkbox"/>	<input type="checkbox"/>
Perceived potential for abuse, neglect or exploitation	<input type="checkbox"/>	<input type="checkbox"/>
Poor housing	<input type="checkbox"/>	<input type="checkbox"/>
Racial/ethnic minority	<input type="checkbox"/>	<input type="checkbox"/>
Short-term care need for service	<input type="checkbox"/>	<input type="checkbox"/>
Social isolation (e.g., lives alone)	<input type="checkbox"/>	<input type="checkbox"/>
No prioritization criteria	<input type="checkbox"/>	<input type="checkbox"/>
Criteria are not set by the SUA	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify below)	<input type="checkbox"/>	<input type="checkbox"/>

Please specify "other" here:

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## Caregiver Service Operation and Quality Assurance

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

**37. 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) regarding information.**

- ☐ Information & Referral
- ☐ Outreach Presentations
- ☐ Other (please specify)

**37a. 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) regarding assistance.**

- ☐ Options Counseling
- ☐ Care/case management (e.g., assessment, developing care plans, arranging services)
- ☐ Follow-up and/or reassessments
- ☐ Other (please specify)

**37b. 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) regarding counseling, education and training**

- ☐ Support Groups
- ☐ Individual Counseling
- ☐ Family Consultation, Counseling, Meetings
- ☐ Training on various aspects related to caregiving
- ☐ Other (please specify)

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**37c. 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) regarding 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)

**37d. 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) regarding 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)

## Caregiver Service Operation and Quality Assurance

**38. Must the caregiver live with the care recipient to be eligible for respite services?**

☐ Yes

☐ No

**39. Are eligible family caregivers offered the same package of NFCSP services in every PSA in your state?**

☐ Yes

☐ No (please explain below)

☐ Don't Know

If you responded that eligible family caregivers are not offered the same package of NFCSP services in every PSA in your state, please explain further here:

**40. 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

## Caregiver Service Operation and Quality Assurance

### 40a. Who sets the policy regarding NFCSP service caps? (Check all that apply)

- ☐ 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
- ☐ Not Applicable
- ☐ Other (please specify)

### 40b. Is the service cap the same for all Planning and Service Areas in the state?

- ☐ Yes
- ☐ No
- ☐ Not applicable



## Caregiver Service Operation and Quality Assurance

**40c. If all NFCSP services are treated the same, please specify the amount of dollars and hours at which services are capped.**

Dollar Value

Number of Hours

**40d. If all NFCSP services are treated the same, please specify the cap time period for services.**

☐ Lifetime

☐ Monthly

☐ Quarterly

☐ Yearly

☐ Other (please specify)

# National Family Caregiver Support Program Evaluation- 2015 State Unit on

## Caregiver Service Operation and Quality Assurance

### 40e. If services are capped separately, please specify which services are capped.

	Capped?
Respite	<input type="text"/>
Training and Education	<input type="text"/>
Supplemental Services	<input type="text"/>
Care/case management/Care coordination	<input type="text"/>

### 40f. Please specify the dollar amount at which services are capped. If there is no cap, please enter '0'.

Respite	<input type="text"/>
Training and Education	<input type="text"/>
Supplemental Services	<input type="text"/>
Care/case management/Care coordination	<input type="text"/>

### 40g. Please specify the number of hours at which services are capped. If there is no cap, please enter '0'.

Respite	<input type="text"/>
Training and Education	<input type="text"/>
Supplemental Services	<input type="text"/>
Care/case management/Care coordination	<input type="text"/>

### 40h. Please specify the cap time period for each service.

	Cap time period
Respite	<input type="text"/>
Training and Education	<input type="text"/>
Supplemental Services	<input type="text"/>
Care/case management/Care coordination	<input type="text"/>

If applicable, please explain "Other" answer selections

## Monitoring and Evaluation

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

**41. 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

## Monitoring and Evaluation

### 41a. 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)

### 41b. 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)

41c. Please e-mail a copy of your state's programmatic monitoring results to Cindy Gruman ([cindy.gruman@lewin.com](mailto:cindy.gruman@lewin.com)). You will receive a reminder at the end of this survey.

## Monitoring and Evaluation

### 42. Does your SUA assess client satisfaction?

- ☐ Yes
- ☐ No
- ☐ AAA assesses client satisfaction

## Monitoring and Evaluation

### 43. How frequently does your SUA assess client satisfaction?

- ☐ Annually
- ☐ Semi-annually
- ☐ Quarterly
- ☐ Monthly
- ☐ Periodic (no schedule)
- ☐ Other (please specify)

### 43a. Do you use a uniform caregiver satisfaction survey across all AAAs?

- ☐ Yes
- ☐ No

## Monitoring and Evaluation

43b. Please e-mail a copy of your caregiver satisfaction survey to Cindy Gruman ([cindy.gruman@lewin.com](mailto:cindy.gruman@lewin.com)). You will receive a reminder at the end of this survey.

## Monitoring and Evaluation

### 44. 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)

### 45. Does the SUA currently include assessments in any of the following areas to monitor the AAAs' implementation of the NFCSP? (Check all that apply)

- ☐ 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)



## 46. How do AAAs currently report NFCSP data to the SUA?

- ☐ Software/computer system
- ☐ Email
- ☐ Phone
- ☐ Mail
- ☐ Don't know
- ☐ Other (please specify)

## Monitoring and Evaluation

**46a. Are all AAAs in your state currently required to use the same software for reporting NFCSP data?**

- ☐ Yes
- ☐ No
- ☐ Don't Know

## Monitoring and Evaluation

### 47. What specific data are currently collected beyond what is required for the State Program Report? (Check all that apply)

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

### 48. 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

### **49. Has your SUA designed a website or webpage for family caregivers? (Check all that apply)**

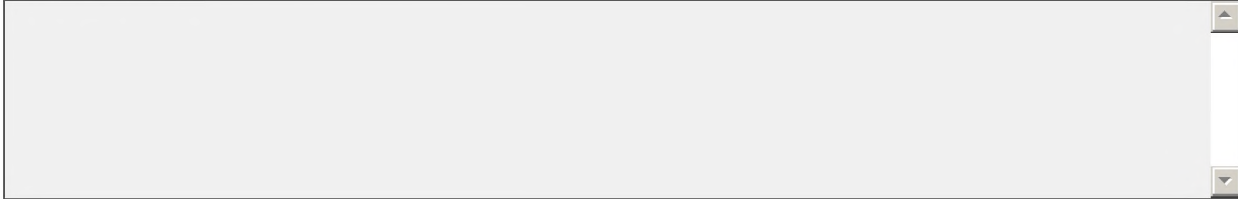
- ☐ Yes, as a separate website
- ☐ Yes, as a separate webpage
- ☐ Yes, as part of the ADRC initiative
- ☐ Yes, as part of a community database unrelated to/as a separate effort from the ADRC initiative
- ☐ No website or webpage but there are plans to do so
- ☐ No website or webpage

### **50. Does your SUA work with other state agencies to implement the NFCSP?**

- ☐ Yes
- ☐ No

**Systems Development**

**50a. 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.

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

- ☐ SUA
- ☐ AAA
- ☐ Local service providers
- ☐ Other (please specify)

**52. Please list your top three supplemental services for NFCSP caregivers of older adults. If you don't know, please leave blank.**

1	<input type="text"/>
2	<input type="text"/>
3	<input type="text"/>

**53. Please list your top three supplemental services for NFCSP grandparent caregivers who care for grandchildren. If you don't know, please leave blank.**

1	<input type="text"/>
2	<input type="text"/>
3	<input type="text"/>

## 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.

### 54. Does the SUA currently have policies that permit self-directed home and community-based services for caregivers?

- ☐ Yes
- ☐ No
- ☐ Don't Know

### 55. 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
- ☐ None of the above
- ☐ Other (please specify)

### 56. Can family members other than the primary caregiver be paid through your NFCSP to provide care?

- ☐ Yes
- ☐ No

## Self-directed Care/Consumer Direction

### 56a. What types of services can they be paid to provide? (Check all that apply)

- ☐ Respite care
- ☐ Personal care
- ☐ Other (please specify)

### 56b. Are there any family members who cannot be paid? (Check all that apply)

- ☐ Spouses
- ☐ Parents/guardians of minors
- ☐ Adult children
- ☐ Any family member can be paid
- ☐ Other (please specify)

### 56c. 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
- ☐ No special requirements
- ☐ Other (please specify)



## Program Administration

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

**57. 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

**58. 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

**59. 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

**60. 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

60a. Please explain your answer

# National Family Caregiver Support Program Evaluation- 2015 State Unit on

## Program Funding and Resources

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

### 61. 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
- ☐ Don't know
- ☐ Other (please specify)

### 62. 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, even if you cannot provide expenditures within each category. If you do not know the expenditures for any given category, please leave that category field blank.

Total Federal Funding	<input type="text"/>
Older Americans Act funds	<input type="text"/>
Other federal funds (please specify below)	<input type="text"/>
Total State Funding	<input type="text"/>
General Revenue	<input type="text"/>
State funded caregiver program	<input type="text"/>
Other Sources of Funding (e.g., local funding, non-profit, private for-profit, contributions, foundation)	<input type="text"/>

#### 62a. Please explain "Other Federal Funds" and "Other Sources of Funding", if applicable

## Program Funding and Resources

**63. During the most recently completed fiscal year, what were the total expenditures for your SUA, including expenditures for the NFCSP? If you do not know, please leave blank.**

**64. 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

**65. 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

# National Family Caregiver Support Program Evaluation- 2015 State Unit on

## Non-OAA Caregiver Program

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

**66. Prior to the establishment of 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
- ☐ Don't know
- ☐ Other (please specify)

**67. Did the establishment of the NFCSP result in the creation of standardized eligibility criteria for caregiver services and supports?**

- ☐ Yes
- ☐ No
- ☐ Don't Know

**68. Does your state currently administer a separate caregiver program funded outside of the NFCSP?**

- ☐ Yes
- ☐ No

## Non-OAA Caregiver Program

### 68a. If yes, what is the caregiver minimum age eligibility requirement?

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

### 68b. If yes, what is the care recipient minimum age eligibility requirement?

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

## National Family Caregiver Support Program Evaluation- 2015 State Unit on

### 68c. 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)

**Non-OAA Caregiver Program**

**69. During the last fiscal year, approximately how many caregivers were in your non-OAA caregiver programs?**

**70. When did your non-OAA caregiver program begin?**

- ☐ Before the NFCSP
- ☐ After the NFSCP program
- ☐ At the same time as the NFCSP
- ☐ Don't know
- ☐ Other (please specify)



**Non-OAA Caregiver Program**

**70a. If your non-OAA caregiver program(s) began before NFCSP, how did your non-OAA caregiver program(s) change as a result of the NFCSP implementation?**

## Non-OAA Caregiver Program

**70b. If your non-OAA caregiver program(s) began after, or at the same time, as the NFCSP, how did the NFCSP affect implementation of your state's non-OAA caregiver program(s)?**

## Non-OAA Caregiver Program

### 71. Which best describes the current relationship between the OAA NFCSP and pre-existing caregiver programs and services?

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

**Non-OAA Caregiver Program**

**71a. Please describe how your SUA integrated or coordinated these programs.**



## Integration with Non-Caregiver Programs

The next question addresses state efforts to integrate the NFCSP with non-caregiver programs.

**72. 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
- ☐ NFCSP does not coordinate with the ADRC
- ☐ Other (please specify)

# National Family Caregiver Support Program Evaluation- 2015 State Unit on

## Other Issues

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

### 73. 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
Expanding Medicaid home and community-based waivers for the elderly and people with disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Expanding state-funded home and community-based care services for the elderly and people with disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Developing policies to address the needs of family caregivers of Medicare-Medicaid eligible populations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Expanding state-funded family caregiver support programs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Establishing family leave and/ or workplace accommodation policies for family caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Establishing tax credits for caregiving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reducing direct service worker shortages	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Implementing an Olmstead plan	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Developing a centralized intake, screening and assessment for family caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Implementing or expanding consumer directed options	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Establishing a single point-of-entry for all home and community-based programs, including caregiver support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reducing nursing home beds	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Specify "other" here

## Other Issues

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

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

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

**77. 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

### 78. Please enter your contact information below

Your Name:	<input type="text"/>
Title:	<input type="text"/>
State Department/Division:	<input type="text"/>
Main Address:	<input type="text"/>
City:	<input type="text"/>
State:	<input type="text"/>
Zip Code:	<input type="text"/>
Telephone:	<input type="text"/>
Fax:	<input type="text"/>
Email address:	<input type="text"/>

### 79. Please enter the contact information for the NFCSP program contact, if different from person completing survey. If you are the NFCSP program contact, leave this question blank.

Name:	<input type="text"/>
Title:	<input type="text"/>
Telephone:	<input type="text"/>
Email Address:	<input type="text"/>



# National Family Caregiver Support Program Evaluation- 2015 State Unit on

Thank you for your timely response!

You have completed the National Family Caregiver Support Program Evaluation SUA survey.

If you have any questions, please contact Ashley Tomisek ([ashley.tomisek@lewin.com](mailto:ashley.tomisek@lewin.com)) or Cindy Gruman ([cindy.gruman@lewin.com](mailto:cindy.gruman@lewin.com)).

As a reminder, if you have copies of the following documents, please send them to [cindy.gruman@lewin.com](mailto:cindy.gruman@lewin.com):

- Your statewide task force, commission, or coalition report;
- Your state's assessment protocol;
- Your state's standardized assessment instrument;
- Your state's programmatic monitoring results; and/or,
- Your state's caregiver satisfaction survey.

Thank you, again, for your time!