**National Family Caregiver Support Program (NFCSP) Evaluation**

**AAA Survey**

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information

unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0985 xxxx

. The time required to complete this information collection is estimated to average two hours per response,

including the time to review instructions, search existing data resources, gather the data needed, and complete and

review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions

for improving this form, please write to: U.S. Department of Health & Human Services, Administration for Community Living , 1 Massachusetts Ave., N.W., Room 5203,Washington D.C. 20201, Attention: PRA Reports Clearance Officer

National Evaluation of the Title III-E NFCSP Area Agency on Aging (AAA) Survey

Dear AAA Director,

As part of the Administration for Community Living’s continuing commitment to evaluate the effectiveness of programs and services in the Aging Network, we seek information about the AAAs and the important work they do for older adults and those who care for them.

ACL has partnered with The Lewin Group and the Scripps Gerontology Center in Oxford, Ohio to gather and analyze information about the range of services AAAs 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 our programs provides necessary evidence for advocacy efforts and funding at the federal, state, and local levels.

 Completing the survey should take about 45 to 90 minutes. You can work on it in several sessions by saving your work and returning later using the link and login provided at the bottom of this e-mail. Your responses will remain confidential among ACL, and the Lewin and Scripps research teams and your answers will not be reported in a way that can identify your agency. You may choose not to participate and you may skip any question you do not want to answer, but we highly encourage all AAAs to join us in this important effort. Please feel free to forward this survey to the person in your organization most familiar with your caregiving programs and services and the person who can provide the information requested on the list of information asked for in the survey.

The deadline for completion of the surveys is [DATE]. If you have questions about completing the survey please contact [Research Associate] at the Scripps Gerontology Center, toll free 1-855-359-3033 or the survey helpline at AAAsurvey@muohio.edu.

Before you begin, you may want to gather the following information that will be asked for in the survey. This information will be provided in the instructions. We recognize that all of you are very busy. Thank you for taking the time to complete this very important survey.

Here is the password you will need to log in:

<http://survey.muohio.edu/snaponline/surveylogin.asp?k=125268374340>

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**

Sent every two weeks or as needed

We are writing to remind you about ACL’s Family Caregiver Survey which is part of the first national evaluation of Title III-E family support programs. Please see below for log-in information. **The survey is only available until [DATE] so we hope to hear from your organization as soon as possible.**

The Administration for Community Living has partnered with The Lewin Group and the Scripps Gerontology Center in Oxford, Ohio to gather and analyze information about the range of services AAAs 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 our programs provides necessary evidence for advocacy efforts and funding at the federal, state, and local levels.

 Completing the survey should take about 1 to 2 hours. You can work on it in several sessions by saving your work and returning later using the link and login provided at the bottom of this e-mail. Your responses will remain confidential among ACL, and the Lewin and Scripps research teams and your answers will not be reported in a way that can identify your agency. You may choose not to participate and you may skip any question you do not want to answer, but we highly encourage all AAAs to join us in this important effort. Please feel free to forward this survey to the person in your organization most familiar with your caregiving programs and services and the person who can provide the information requested on the list of information asked for in the survey.

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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

**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 ACL’s first national evaluation of the Title III-E National Family Caregiver Support Program (NFCSP). Area Agencies on Aging (AAAs) play a vital role in providing programs and services to caregivers in their local areas. It is the goal of this survey to:

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

You will also be asked for information about your service providers. That information will assist us in selecting AAAs from whom local service providers will also be surveyed.

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

The survey asks a few questions about the characteristics of your caregiver programs and your AAA. Before you begin it may be helpful to gather the following information about your most recently completed fiscal year.

Before you begin, you may want to gather the following information that will be asked for in the survey.

* Number of contracted providers that provided NFCSP services in total
* Number of providers that provide each type of NFCSP service.
* Number of full-time equivalent employees working on the NFCSP
* Number of unduplicated caregivers served by the NFCSP (Title III-E) services
* Number of unduplicated caregivers that receive:
  + Training, counseling & support services
  + Respite services
  + Caregiver supplemental services
  + Caregiver access assistance services
  + Caregiver consumer-directed services
* Number of unduplicated grandparents or other relatives 55 and over caring for children
* Total number of unduplicated volunteers on the NFCSP
* Total number of volunteer hours on the NFCSP
* Your AAA’s total operating budget for last completed fiscal year
* Total operating budget for OAA NFCSP
* Total budget for grandparent/relative portion of NFCSP
* Total budget for respite care services
* Total budget for caregiver supplemental services
* Total budget for access/assistance services
* Total budget for information services
* Total budget for counseling, support groups and caregiver training
* Total budget spent on caregiver services from your NFCSP from each of these sources:
  + Total federal funds
  + Total OAA funds
  + Other federal funds (e.g. HUD, VA)
  + Total state funding
  + State general revenue funds
  + State-funded caregiver program
  + Other state funds spent on caregivers
  + Other funding sources providing caregiver funding
  + Sources of referrals, if you track referral sources
* If your agency has one, a copy — either in electronic form or hard copy — of the standardized caregiver assessment form

You may save your partially completed survey and return to it another time by choosing “save” at the bottom of the page where you end your work. Return to your survey from the link in your e-mail invitation. Use the “back” and “next” buttons at the bottom of the page to move through the survey, not the buttons on your browser. 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. Otherwise, your work may be lost.

You can print a blank PDF version of the survey before you begin by clicking here: [link to PDF on website].

You can print your completed survey by choosing the “print” button on the final screen. Do not choose “submit” on the final screen until you have completed all work on your survey, printed a copy (if desired) and are ready to leave the survey. If you submit before you are finished we will have to reset your survey and your work will be lost.

A glossary has been provided for your reference. You will be taken to the glossary once you click “yes” and “next” below. Please use the print icon on your toolbar if you want to print the glossary.

If you have questions, please contact our survey helpline at [AAAsurvey@muohio.edu](mailto:AAAsurvey@muohio.edu) or by calling [Research Associate] at 1-855-359-3033.

Do you want to see the glossary?  
\_\_\_\_Yes [PROGRAMMER—link to glossary included at end of survey]

\_\_\_\_No

# Program Background

1. **What is the name of your OAA Family Caregiver Support Program in your Planning and Service Area (PSA) funded in whole or in part by the OAA Title III-E NFCSP? If your programs have several different names, please write Family Caregiver Program in the space below.**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of Agency PREFILL

Agency Address PREFILL

Agency Telephone PREFILL

Agency e-mail address

If the information above has changed, please overwrite the information provided in the boxes.

1. **Which of the following best describes the governance of your AAA?**

An independent, not-for-profit agency

A division of a city or county government

Part of a council of governments or regional planning and development agency

A Tribal Government entity

Educational institution

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

**NOTE: All questions regarding Older Americans Act programs and services should be based on all funding sources and not restricted to the federal share of the program or service unless otherwise specified.**

1. **Does your AAA serve populations under 60 years of age through non-OAA programs and services?**

Yes

No

Don’t know

1. **Is the area served by your organization:**

Predominantly urban

Predominantly suburban

A mix of urban and suburban

A mix of urban and rural

Predominantly rural

Predominantly remote or frontier

A mix of suburban and rural

A mix of urban, suburban and rural

1. **Which of the following best describes the boundaries of your PSA? (Check all that apply)**

Single state

Single county

Multi-county

Single city/Metro area

Multiple city/Metro area

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

1. **Is your AAA leading, or part of, an Aging and Disability Resource Center (ADRC or ARC)?**

Yes, we are the lead organization

Yes, we are part of an ADRC or ARC but are not the lead organization

No

Don’t know

1. **Does a Title VI [Native American] program operate within your PSA?**

Yes

No (Skip to Q8)

Don’t know (Skip to Q8)

**7a) What are the major areas in which you collaborate with Title VI programs within your PSA related to caregiver programs and services? (Check all that apply)**

Fundraising

Shared resources

Advocacy

Strategic Planning

Public education

Referrals

Service delivery

Shared outreach

Targeting special populations

Training/technical assistance

Volunteer recruitment or retention

Other

Don’t collaborate with Title VI programs

Don’t know

# Program History

**The OAA NFCSP was established in 2000, but ACL is interested in your AAA’s caregiver program history prior to the establishment of NFCSP, if and how the NFCSP has since been integrated with other programs, and the ways the NFCSP has impacted your AAA’s services for caregivers.**

1. **Prior to the OAA NFCSP, did your AAA have a policy that defined caregivers as clients?**

Yes

No

Don’t know

1. **Did your AAA have a caregiver program (a set of services specifically for caregivers) prior to the enactment of the OAA NFCSP in 2000?**

Yes

No (Skip to Q10)

Don’t know (Skip to Q10)

**9a) If yes, in what year was that caregiver program (set of caregiver services) first established? If you do not know, enter “DK”.**

\_\_\_\_\_\_\_\_\_

1. **Prior to the establishment of OAA NFCSP in your AAA, which of the following services did your AAA 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 services (e.g. home-delivered meals, home modification, emergency response)

Care Coordination

Caregiver Support Coordination

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

1. **How did the OAA NFSCP impact the caregiver services provided by your agency? (Check all that apply)**

Provided additional new services

Increased the number of caregivers served

Increased the amount of services provided to most caregivers

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

1. **Which best describes the current relationship between the OAA NFCSP and pre-existing caregiver programs and services? [PROGRAMMING: SKIP IF NO TO QUESTION 9]**

Programs are distinct and operate separately (Skip to Q13)

Programs are separate with coordinated operations (Skip to Q13)

Programs are integrated into one program with multiple funding streams

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

**12a) Please describe how your AAA integrated or coordinated these programs.**

1. **Did you offer consumer direction/self-direction prior to NFCSP?**

Yes

No

Don’t know

# Community Needs Assessment

1. **In addition to the Area Plan, did you complete a needs assessment for caregiver services as a component of a general community assessment or a standalone assessment?**

Yes, as part of a community assessment

Yes, as a standalone assessment

No

Don’t know

**14a) If yes, how many years ago? If you do not know, enter DK**

**\_\_\_\_\_\_\_\_\_\_\_\_\_**

1. **Who has primary responsibility for conducting community needs assessments for caregiver services? [PROGRAMMING: If answer to 14 is no, or don’t know, skip #16.]**

SUA

AAA

Caregiver Coalition

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

1. **Has the community needs assessment of caregivers been used in the following ways? (Check all that apply)**

Development of area plan

Program planning

Program development

Advocacy activities

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

# Services Provided

1. **Currently, does your AAA have a policy or standardized eligibility criteria that defines caregivers as clients?**

Yes

No

Don’t know

1. **Can a caregiver being served under [INSERT NAME OF OAA NFCSP PROGRAM] also be eligible to receive caregiver support from other state- and locally-funded programs, such as a state respite program?**

Yes

No

Don’t know

1. **[Programmer Note: This question requires a response]. For each service under NFCSP, how many local service providers (LSPs) provide this type of service? If there are none, put “0”.**

|  |  |
| --- | --- |
| Service Type | Number of LSPs providing this service type |
| a. Support Groups | | | | | |
| b. Training/Education | | | | | |
| c. Information | | | | | |
| d. Caregiver Counseling | | | | | |
| e. Respite Services | | | | | |

**19a) For each of the following services under NFCSP, how are these services provided? [Programmer Note: This question requires a response]**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Service Type | Direct service provided by  AAA | Through a **grant** between the AAA and another organization | Through a **contract** between the AAA and another organization | Other entity |
| a. Support Groups |  |  |  |  |
| b. Training/Education |  |  |  |  |
| c. Information |  |  |  |  |
| d. Caregiver Counseling |  |  |  |  |
| e. Respite Services |  |  |  |  |
| e. Access Assistance |  |  |  |  |

1. **Over the last three years, how has the provider pool changed?**

Same pool

Changed significantly (50% or more turnover)

Changed a little (less than 50% turnover)

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

# CAREGIVER EDUCATION AND TRAINING

1. **What is your policy regarding the frequency of caregiver education offerings?**

Frequency determined by local service provider

Regularly scheduled

Programming provided on an as-needed basis

Caregiver education is not available for participants

Don’t know

1. **Which of the following evidence-based caregiver training/education interventions for caregiver clients were provided by your AAA [either directly or under contract] during your most recently completed fiscal year, funded in whole or in part by OAA NFCSP Title III-E funds?**

REACH II Interventions (Shultz et al.)

Savvy Caregiver (Ostwald/Hepburn)

STAR-C Intervention (Teri)

Coordinated system of care intervention (Vickery)

COPE for Cancer Caregivers (McMillan)

Powerful Tools for Caregivers

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

None

1. **Does the [program name] support caregivers with care transitions of their loved ones between any of the following settings? Include informal support as well as formalized care transition programs. Check all that apply.**

Hospital discharge to nursing home or assisted living

Hospital discharge to home

Nursing home or assisted living discharge to the community

Placement of the care recipient into a nursing facility or assisted living

None of the above

# Caregiver Respite Services

1. **What respite services are provided to support caregivers, either directly by your AAA or by a grant or contract with a provider?  Check all that apply.**

In-home respite during normal business hours

In-home respite during evenings

In-home respite overnight

Day program respite

Respite weekend, including camps

Overnight in a facility or extended respite (extended respite = 24 hours)

Emergency respite services

Other (please specify)

1. **How often are caregivers’ minimum respite needs met?**

All or most of the time

Some of the time

Hardly ever

Never

1. **Which of the following are common reasons caregiver respite needs are unmet? (check all that apply.)**

Not enough provider agencies

Lack of trained providers

Transportation for consumer

Funding

Other

**26a) You indicated other reason your organization is unable to meet respite needs. Please describe: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

1. **Must the caregiver live with the care recipient to be eligible for respite assistance?**

Yes

No

1. **Do you give priority for respite assistance to caregivers who live with care recipients?**

Yes, living together is a priority

No

# Staff and Volunteers

## Staff

1. **How many full-time equivalents at your AAA work on your caregiver programs in a typical week? Include full and part-time employees who are assigned to some aspect of caregiver programming and services. Do not include staff such as I&A who routinely provide information to caregivers but who do not have specific caregiver program responsibilities. One full-time caregiver staff person working 40 hours per week or 10 staff members each assigned to caregiver programs 4 hours per week provide 1 full-time equivalent staff person. If you do not know the answer, enter “DK”.**

| | | | | |

Don’t know

1. **Does the caregiver program staff work on other programs or provide services outside of the OAA NFCSP?**

Yes, all do

Yes, some do

No, all are solely dedicated to the OAA NFCSP

Don’t know

1. **Does the staff position that directs or manages caregiver services and programs include other duties or program focus areas in addition to caregiver programs and services?**

Yes

No

Don’t know

1. **Does your AAA have a paid staff position that is responsible for directing or managing [INSERT NAME OF OAA NFCSP PROGRAM]?**

Yes

No (skip to Q33)

Don’t know

**32a) If yes, when was the paid staff position that is responsible for directing or managing caregiver services and programs in [INSERT NAME OF OAA NFCSP PROGRAM] established?**

YYYY

Don’t know

1. **What minimum qualifications are required for entry into the following positions that serve family caregivers at your AAA?**

|  |  |  |
| --- | --- | --- |
| **Staff Positions** | **Education Requirement (Check all that apply)** | **Do you require years of relevant experience?** |
| 1. Information and Referral/Assistance | □ Master’s  □ Bachelor’s  □ AIRS certified  □ No specific degree or certification requirement  □ Don’t know | □ Yes  □ No  □ Can substitute education for experience  □ Can substitute experience for education  □ Don’t know |
| 1. Care/case managers/specialists | □ Master’s  □ Bachelor’s  □ Licensed Social Worker (LSW, LCSW)  □ RN or LPN  □ No specific degree or license requirement  □ Don’ have care managers  □ Don’t know | □ Yes  □ No  □ Can substitute education for experience  □ Can substitute experience for education  □ Don’t know |
| 1. Program Director | □ Master’s  □ Bachelor’s  □ License or certification  □ No specific degree or license requirement  □ Don’t have a caregiver program director  □ Don’t know | □ Yes  □ No  □ Can substitute education for experience  □ Don’t know |

## Volunteers

1. **Please indicate the types of tasks volunteers provide for the OAA NFCSP at your AAA: (Check all that apply)**

Administrative program support

Caregiver training/education

Financial services, (e.g. tax preparation, bill paying, budgeting, pension counseling)

Information and assistance

Legal services, (e.g. assistance completing powers of attorney or advance directives)

Phone reassurance

Respite services

Support group leader(s)

Transportation

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t use volunteers in our NFSCP

Don’t know

1. **How many unduplicated volunteers worked on the OAA NFCSP at your AAA in the most recently completed fiscal year? [Please do not include volunteers for the Local Service Providers]. If you do not use volunteers, please report “0”.**

| | | | | *Number of unduplicated volunteers*

Don’t know

1. **In total, how many volunteer hours did the OAA NFCSP at your AAA receive in the most recently completed fiscal year? [Please do not include volunteers for the Local Service Providers].**

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

Don’t track volunteer hours

## Staff/Volunteer Training:

1. **Does your AAA require training for any of the following groups or individuals outside the NFCSP to receive training on topics associated with supporting caregivers? (Check all groups that are required to receive training)**

Information and referral staff

Other Program Administrative Staff

Supervisory Staff

Direct Service Workers (e.g., social workers, counselors, care managers,)

Volunteers

No. Caregiver training is not required for non-caregiver program staff or volunteers

Don’t know

1. **Which of the following caregiver education/training topics were provided to OAA NFCSP staff or volunteers at your AAA during your most recently completed fiscal year? (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)

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

# Program Funding and Resources

1. **In the last 3 years, has your AAA experienced any of the following changes to the NFCSP? (check all that apply)**

Increased sharing of physical and staff resources (e.g., co-locating staff, co-sponsoring programming, etc)

Increased staff caseloads or responsibilities

Increased use of volunteers

Increased use of technology to reach out to and support clients (e.g. e-mail and phone)

Reduced overall program budget

Reduced the number of caregivers served

Reduced or eliminated certain types of respite care services

Reduced or eliminated certain supplemental services

Reduced the frequency of service delivery

Reduced hours or days of service

Reduced staff hours

Reduced staff salaries, froze staff salaries or eliminated staff salary increases

Refined targeting of program participants

Established a waiting list

Established or refined program or service caps

Changes in a service provider contracts or RFP requirements or specifics to reduce costs

Obtained or secured new or additional funding sources to add to or match NFCSP funds

No changes

Don’t know

# Targeting

1. **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 (under age 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 Q42)

Don’t know

1. **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

1. **Please indicate the approximate number of your caregiver program participants in the most recently completed fiscal year that fall into each racial or ethnic category for the [INSERT NAME OF OAA NFCSP PROGRAM].**

|  |  |  |
| --- | --- | --- |
|  | Number of Caregivers in Program | Don’t Know |
|  |  |
| a. American Indian or Alaska Native (alone) | | | | | | | □ |
| b. Asian (alone) | | | | | | | □ |
| c. Black or African American (alone) | | | | | | | □ |
| d. Native Hawaiian or other Pacific Islander (alone) | | | | | | | □ |
| e. White, non-Hispanic- | | | | | | | □ |
| f. Person reporting 2 or more races | | | | | | | □ |
| g. Hispanic | | | | | | | □ |
| h. Unknown | | | | | | | □ |
| g. Other (Specify) | | | | | | | □ |

# Caregiver I&R, Intake, Screening, and Assessment

1. **For every call that you get from a consumer for services, do you have a standard set of questions or steps to determine if a caregiver is present?**

Yes

No (Skip to Q44)

Don’t know

**43a) If yes, is there a standard process for following up with the caregiver?**

Yes

No

Don’t know

1. **In your estimation, what are the three types of services or information most frequently requested on the part of caregivers? Check three of the following: PROGRAMMER—LIMIT TO 3 CHOICES**

Care coordination

Crisis

Disease-specific information

Emotional support

Energy assistance

Federal/State financial assistance programs

General information about caregiving

Home health care

Home modifications

Housing options

Legal services

Medical supplies

Nutrition/Food

Respite care (institutional, in-home, day services)

Self-directed services, e.g. paid family caregiving

Transportation

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

**Referrals**

1. **Does your AAA or the I&A provider have a referral tracking system for caregiver services? (Check all that apply)**

Yes, referrals to AAA are tracked

Yes, AAA referrals to other providers for caregiver services not provided by AAA are tracked

No

Other (please specify)

Don’t know

1. **Do you track the source of referrals to the [INSERT NAME OF OAA NFCSP PROGRAM]?**

Yes

No (Skip to Q47)

Don’t know (Skip to Q47)

**46a) Since you track the source of referrals to the [INSERT NAME OF OAA NFCSP PROGRAM] please rank the top three sources generating the most referrals to the OAA NFCSP based on estimates from your most recently completed fiscal year. Rank 1 should be the most referrals, followed by 2 and 3. PROGRAMMER—limit ranks to 1, 2, and 3—no ties.**

|  |  |
| --- | --- |
| **Referral Source** | **Rank** |
| a. Family/Friends | \_\_\_\_\_ |
| b. Tertiary health care (e.g. hospital, health care facility) | \_\_\_\_\_ |
| c. Discharge planner or primary health care (e.g. physician, clinic, other health care provider) | \_\_\_\_\_ |
| d. Case/care management program | \_\_\_\_\_ |
| e. Aging and Disability Resource Center | \_\_\_\_\_ |
| f. Information and Assistance system | \_\_\_\_\_ |
| g. Medicaid Waiver | \_\_\_\_\_ |
| h. Faith-based organizations  i. Self  j. Nursing home  k. Assisted Living Facility/other residential facility  l. Health and/or advocacy organization (e.g., MS Society, Alzheimer’s Association, Easter Seals, United Cerebral Palsy, etc.)  m. Other social service program (e.g. home-delivered nutrition program)  n.. Other: please specify \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_ |
| \_\_\_\_\_ |
| \_\_\_\_\_ |
| \_\_\_\_\_ |
| \_\_\_\_\_ |
| o. Don’t know | □ |

**Screening**

1. **At your AAA, are screening and intake separate activities for caregiver support services?**

Yes (skip to 48)

No (ask 47a – 47c; skip to 50)

Don’t Know

**47a) Please check all that apply to screening and intake activities for caregiver support in your PSA. (Check all that apply)**

Standardized screening process for caregiver support in our PSA

Standardized intake process for caregiver support in our PSA

Screening and intake varies by service provider

PSA shares relevant caregiver intake and/or screening data with other programs in which the caregiver might be eligible for support (either verbally or electronically)

PSA receives relevant caregiver intake and/or screening data from other programs (either verbally or electronically)

Don’t know

None of the above

**47b) Who conducts the initial caregiver intake and screening for the [INSERT NAME OF OAA NFCSP PROGRAM]? (Check all that apply)**

General I&A at AAA

Specific caregiver unit at AAA

ADRC (if entity other than the AAA)

Local service providers

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

**47b.1) Has this process come about as a result of the OAA NFCSP Title III-E?**

Yes

No

Don’t know

**47c) Under the [INSERT NAME OF OAA NFCSP PROGRAM], does intake and caregiver screening include information about the care recipient?**

Yes

No

Don’t know

[Skip to Q50]

1. **Please check all that apply to intake activities for caregiver support in your PSA. (Check all that apply)**

Standardized intake process for caregiver support in our PSA

Intake varies by service provider

PSA shares relevant caregiver intake data with other programs in which the caregiver might be eligible for support (either verbally or electronically)

PSA receives relevant caregiver intake data from other programs (either verbally or electronically)

Don’t know

None of the above

**48a) Who conducts the initial caregiver intake for the [INSERT NAME OF OAA NFCSP PROGRAM]? (Check all that apply)**

General I&A at AAA

Specific caregiver unit at AAA

ADRC (if entity other than the AAA)

Local service providers

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

**48a.1) Has this process come about as a result of the OAA NFCSP Title III-E?**

Yes

No

Don’t know

**48c) Under the [INSERT NAME OF OAA NFCSP PROGRAM], does caregiver intake include information about the care recipient?**

Yes

No

Don’t know

1. **Please check all that apply to screening activities for caregiver support in your PSA. (Check all that apply)**

Standardized screening process for caregiver support in our PSA

Screening varies by service provider

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

PSA receives relevant caregiver screening data from other programs (either verbally or electronically)

Don’t know

None of the above

**49a) Who conducts the initial caregiver screening for the [INSERT NAME OF OAA NFCSP PROGRAM]? (Check all that apply)**

General I&A at AAA

Specific caregiver unit at AAA

ADRC (if entity other than the AAA)

Local service providers

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

**49a.1) Has this process come about as a result of the OAA NFCSP Title III-E?**

Yes

No

Don’t know

**49b) Under the [INSERT NAME OF OAA NFCSP PROGRAM], does caregiver screening include information about the care recipient?**

Yes

No

Don’t know

# Assessment

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

Care Recipient (ask 50a, then skip to 51)

Family caregiver (asks 50a, then skip to 51)

Both (ask 50a, then skip to 51)

No assessment is conducted (skip to 50b)

**50a) Do you use a standardized assessment tool?**

Yes

No (Skip to Q51)

Don’t Know (Skip to Q51)

**50a.1)** You indicated that you do use a standardized assessment tool to conduct caregiver assessments. Please fax [(513) 529-1476](tel:%28513%29%20529-1476) or email [aaasurvey@miamioh.edu](mailto:aaasurvey@miamioh.edu) a copy of this tool to Scripps Gerontology Center.

**50b) If no, can you describe the reasons why you don’t conduct assessments? (Skip to Q54)**

1. **Which of the following areas are included in your AAA’s individual-level caregiver needs 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): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. **What is your AAA’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

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

1. **How are the caregiver assessments and reassessments used? (Check all that apply)**

To prioritize who receives services (Skip to Q54)

Care plan development for the caregiver (Skip to Q54)

Measuring caregiver program outcomes (Go to Q53a)

Strategic planning/forecasting and/ or program development (Skip to Q54)

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_ (Skip to Q54)

Don’t know (Skip to Q54)

**53a) You indicated that you measure caregiver program outcomes. Which of the following out comes 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): \_\_\_\_\_\_\_\_\_\_\_

# Service Access

**OAA Caregiver Program**

1. **Do you prioritize who gets caregiver services based on the following characteristics?**

|  |  |  |
| --- | --- | --- |
|  | **MARK ALL THAT APPLY** | |
| **Characteristic** | **Caregiver criteria** | **Care Recipient criteria** |
| 1. Geographic isolation |  |  |
| b. Lack of social support |  |  |
| 1. Homebound status |  |  |
| 1. Diagnosis of Alzheimer’s disease or a related disorder with neurological and organic brain dysfunction 2. Other Specific health diagnosis |  |  |
| f. Age older than 60 |  |  |
| 1. Mental health/emotional status 2. ADL or IADL impairment level |  |  |
| 1. Potential for abuse, neglect or exploitation |  |  |

1. **Who established this prioritization mechanism? Check all that apply.**

SUA

AAA (skip to Q57)

Local Service Provider

Other State-level entity

Other (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

1. **How much influence does your AAA have on modifying these criteria?**

A lot

Some

A little

None

Don’t know

1. **How is the type and amount of caregiver service determined? (Check all that apply)**

Program participant/family request

Caregiver needs assessment

Prioritization criteria other than caregiver needs (e.g. targeted group, care recipient diagnosis, etc).

Standardized service amount

Availability of program resources

Availability of services

Other (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

1. **Who is involved in the care planning process? (Check all that apply)**

Supervisory staff

Other AAA clinical staff (e.g. nurse, social worker)

Case/care manager

Service provider

Caregiver(s)

Care recipient

Other (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Non OAA Caregiver Program**

**The following questions refer to caregiver programs funded outside of the OAA NFCSP that your AAA may be administering.**

1. **Does your AAA administer a separate caregiver program funded outside of the NFCSP?**

Yes

No (Skip to Q63)

**59a) 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

**59b) 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

**59c) 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)

1. **Does your non-NFCSP caregiver program have any income or asset eligibility requirements, either on the part of the caregiver or care recipient, for any services?**

Yes

No (skip to Q61)

**60a) If yes, indicate any income or asset eligibility requirements for the non-NFCSP caregiver program. (Check all that apply)**

Care recipient must meet same income or asset eligibility requirements as Medicaid or SSI

Care recipient must meet income or asset requirements, which are higher than Medicaid or SSI requirements

Care recipient does not need to meet any income or asset requirements

Caregiver must meet income and/ or asset eligibility requirement

Caregiver does not need to meet any income or asset requirement

1. **Do caregivers or care recipients who meet certain criteria get priority for services in the non-NFCSP program?**

Yes

No

1. **In general, are these programs more flexible, less flexible or the same compared to Title III-E in regards to services, eligibility, types of consumers served, hours and days of operation?**

More flexible

Less flexible

About the same

# Waiting Lists

1. **In your PSA, is there a waiting list for any OAA NFCSP service?**

Yes

No

Don’t know

1. **Even if you do not have a list now, are you aware of polices or practice for how waiting lists are supposed to work?**

Yes

No—skip to Q70.

1. **How are waiting lists organized?**

A single waitlist is maintained for the OAA NFCSP overall

Multiple waitlists are maintained for OAA NFCSP specific caregiver support services (e.g., respite care, caregiver counseling)

Other (Please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

**65a) If “multiple waitlists are maintained for OAA NFCSP specific services”, do waiting lists exist for any of the following services listed below? If so, how many are on the lists, and what is a typical waiting period?**

|  |  |  |  |
| --- | --- | --- | --- |
| **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  Don’t know | \_\_\_ yrs \_\_\_months \_\_\_days  No wait  Don’t know |
| Caregiver counseling, training and education | \_\_\_\_\_\_\_\_\_\_  None  Don’t know | \_\_\_ yrs \_\_\_months \_\_\_days  No wait  Don’t know | \_\_\_ yrs \_\_\_months \_\_\_days  No wait  Don’t know |
| Caregiver support groups | \_\_\_\_\_\_\_\_\_\_  None  Don’t know | \_\_\_ yrs \_\_\_months \_\_\_days  No wait  Don’t know | \_\_\_ yrs \_\_\_months \_\_\_days  No wait  Don’t know |
| Respite care | \_\_\_\_\_\_\_\_\_\_  None  Don’t know | \_\_\_ yrs \_\_\_months \_\_\_days  No wait  Don’t know | \_\_\_ yrs \_\_\_months \_\_\_days  No wait  Don’t know |
| Supplemental Services | \_\_\_\_\_\_\_\_\_\_  None  Don’t know | \_\_\_ yrs \_\_\_months \_\_\_days  No wait  Don’t know | \_\_\_ yrs \_\_\_months \_\_\_days  No wait  Don’t know |
| Access assistance/case management/care coordination | \_\_\_\_\_\_\_\_\_\_  None  Don’t know | \_\_\_ yrs \_\_\_months \_\_\_days  No wait  Don’t know | \_\_\_ yrs \_\_\_months \_\_\_days  No wait  Don’t know |

1. **Who maintains the waiting list(s) for [INSERT NAME OF OAA NFCSP PROGRAM] services? Check all that apply.**

SUA

AAA

Service Provider(s)

Other (Please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_

1. **What best describes your waitlist policies and practices? (Check all that apply)**

First come, first serve, prior to establishing eligibility determination

First come, first serve after eligibility determination

Prioritized by a needs measurement, based on care recipient functioning

Prioritized by a needs measurement, based on care recipient and caregiver circumstances (i.e., caregiver’s age, health status, if living with the care recipient)

Other (please describe)

1. **Do caregivers receive any services in addition to I&R/A while on a waiting list for OAA NFCSP services?**

No

Yes, available Title III-E services

Yes, available non- Title III-E services

1. **On average, how often is the waiting list for the family caregiver support program checked for duplicates and those no longer eligible or in need, and then updated?**

Weekly

Monthly

Quarterly

Semi-annually

Yearly

Never

Other (Please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t know

# Access Assistance

1. **Do you, or one of your contracted organizations, provide care/case management?**

Yes

No (SKIP to Question 74)

1. **Under what circumstances is care/case management provided? (check all that apply)**

All caregivers are care/case managed

Care/case management is provided only for specific service needs (respite, counseling, supplemental services, etc.)

Emergency/crisis situations

When abuse, neglect or exploitation is suspected

Caregivers who are transitioning care recipient from one setting to another

Other (please specify):\_\_\_\_\_\_\_\_\_

1. **In your AAA, are some care/case managers assigned caseloads that include only caregivers?**

Yes

No

Does not apply—we do not have care/case managers. (Skip to Q74)

1. **Caregiver care/case management is provided: (Check all that apply)**

By telephone

Face-to-face - office or community setting

Face-to-face - home setting

Web-based application

E-mail

Other (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**73a) How frequently must a care/case manager conduct an in-person visit with the caregiver?**

Monthly

Every 6 months

Yearly

Schedule differs by care recipient or caregiver level of need

As needed for all clients

No in-person visit requirement

1. **Does [INSERT NAME OF OAA NFCSP 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 76)

**74a) If yes, who sets the policy regarding service caps? (Check all that apply.)**

AAA

SUA

Service provider

State entity other than SUA

Other (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Don’t Know

1. **Please complete the following to describe the service caps in your NFCSP program. (Check all that apply)**

|  |  |  |  |
| --- | --- | --- | --- |
| Services | Capped | Type & Amount of Cap | Cap time period |
| All NFCSP services treated the same | 􀂉 Yes  􀂉 No | 􀂉 Hours: \_\_\_\_\_\_\_\_\_hrs  􀂉 Dollars: $\_\_\_\_\_\_\_\_\_ | 􀂉 Lifetime  􀂉 Monthly  􀂉 Quarterly  􀂉 Yearly􀂉 Other: \_\_\_\_\_\_\_\_\_\_\_ |
| Respite | 􀂉 Yes  􀂉 No | 􀂉 Hours: \_\_\_\_\_\_\_\_\_hrs  􀂉 Dollars: $\_\_\_\_\_\_\_\_\_ | 􀂉 Lifetime  􀂉 Monthly  􀂉 Quarterly  􀂉 Yearly  􀂉 Other: \_\_\_\_\_\_\_\_\_\_\_ |
| Training and Education | 􀂉 Yes  􀂉 No | 􀂉 Hours: \_\_\_\_\_\_\_\_\_hrs  􀂉 Dollars: $\_\_\_\_\_\_\_\_\_ | 􀂉 Lifetime  􀂉 Monthly  􀂉 Quarterly  􀂉 Yearly  􀂉 Other: \_\_\_\_\_\_\_\_\_\_\_ |
| Supplemental Services | 􀂉 Yes  􀂉 No | 􀂉 Hours: \_\_\_\_\_\_\_\_\_hrs  􀂉 Dollars: $\_\_\_\_\_\_\_\_\_ | 􀂉 Lifetime  􀂉 Monthly  􀂉 Quarterly  􀂉 Yearly  􀂉 Other: \_\_\_\_\_\_\_\_\_\_\_ |
| Care/case management/  Care coordination | 􀂉 Yes  􀂉 No | 􀂉 Hours: \_\_\_\_\_\_\_\_\_hrs  􀂉 Dollars: $\_\_\_\_\_\_\_\_\_ | 􀂉 Lifetime  􀂉 Monthly  􀂉 Quarterly  􀂉 Yearly  􀂉 Other: \_\_\_\_\_\_\_\_\_\_\_ |

# Program Quality Assurance

1. **How frequently does your program undergo a formal, on-site or desk program review by the SUA?**

More than once a year

Once a year

Every 2 Years

Every 3 Years or less frequently

Never been reviewed

**76a) How has your program used the results of the formal, on-site or desk program review? Check all that apply.**

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):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

1. **Which of the following specifications for NFCSP service provision does your AAA formally monitor or review (either on-site or desk review) at the provider level? (Check all that apply.)**

Compliance with licensing of the organization or its staff

Client record maintenance

Standards of practice for Social Workers/Care Managers

Subcontract monitoring

Compliance with requirements in the Older Americans Act

Compliance with state rules, regulations or guidance

Fiscal management

None

Other (Please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**77a) How often does a formal, on-site or desk program review take place?**

More than once a year

Once a year

Every 2 Years

Every 3 Years or less

Never been reviewed

1. **Does your AAA use any of the following strategies to assess program outcomes related to NFCSP service receipt? (Check all that apply)**

Satisfaction survey of program participants (ask Q78a)

Feedback mechanism (e.g. complaint mechanism, comment box/card)

Changes in caregiver assessments over time

Monitor client ADL/IADL functioning

Other (*please specify*): \_\_\_\_\_\_\_\_\_\_\_\_\_

AAA does not conduct program participant assessment of NFCSP services

Don’t know

**78a) How frequently does your AAA assess program participant satisfaction?**

Annually

Semi-annually

Quarterly

Monthly

Ongoing

Varies by service

Other (Please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

# Disaster/Emergency Preparedness Planning

1. **Does the disaster/emergency preparedness plan used by your AAA (either your own or another entity’s plan) address the needs of family caregivers?**

Yes

No

We do not have and are not part of an emergency plan

Don’t know

# Program Integration

1. **Does your AAA have a website or webpage for family caregivers? (Check all that apply) (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 design one

No website or webpage

1. **Please indicate if the AAA is involved in any of the activities below without or without partners. By partners, we mean a well-defined relationship with another organization. Please do not include partners with whom your relationship is strictly based on referrals.**

|  |  |  |  |
| --- | --- | --- | --- |
| **Organizational Activities** | Involved **without** a partnership | Involved **with** a partnership | Not applicable/ not involved in this activity |
| Program planning/development |  |  |  |
| Program outreach |  |  |  |
| Marketing plan |  |  |  |
| Website |  |  |  |
| Developing a community needs assessment of family caregiver support and service |  |  |  |
| Developing/enhancing a web-based informational database of caregiver support options |  |  |  |
| Promoting changes to improve family caregiver support within Medicaid-funded HCBS programs |  |  |  |
| Developing a uniform caregiver assessment instrument |  |  |  |
| Developing strategies to reach hard-to-reach caregivers |  |  |  |
| Other (Please describe) |  |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **Service Activities** | Involved without a partnership | Involved with a partnership | Not applicable/ not involved in this activity |
| Coordinating information fair(s) |  |  |  |
| Coordinating caregiver conference(s) |  |  |  |
| Forming a caregiver coalition or community collaborative |  |  |  |
| Enhancing support to working caregivers |  |  |  |
| Enhancing kinship care |  |  |  |
| Community fundraising for family caregiver support |  |  |  |
| Other (Please describe) |  |  |  |

1. **Is your AAA a member of any of the following coalitions? (Check all that apply)**

Caregiver coalition

Respite coalition

Kinship care coalition

None of the above

1. **Please mark up to three of your most important partners specifically for administering [INSERT NAME OF OAA NFCSP PROGRAM]. By partners, we mean a well-defined relationship with another organization. Please do not include partners with whom your relationship is strictly based on referrals.**

Caregiver coalitions/respite coalitions

Local/state chapter of national organizations (e.g. Alzheimer’s Association, AARP, American Health Care Association)

Faith-based organizations

Aging and Disability Resource Center or Aging Resource Center

Long-term care facilities (nursing homes, assisted living)

Local business (please specify type):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Health care providers including community health centers, hospitals and physicians’ offices

Public housing and related services, including senior housing

Title VI (Native American) program

Elder Abuse Prevention programs, Adult Protective Services (APS), or TRIAD

Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**83a) For each partnership listed, please indicate which activities you jointly engaged in for the Family Caregiver Support Program during your most recently completed fiscal year.**

(PARTNERSHIP NAMES WILL AUTOMATICALLY FILL BASED ON RESPONSES TO 83)

|  |  |  |  |
| --- | --- | --- | --- |
|  | Partnership 1 Name | Partnership 2 Name | Partnership 3 Name |
| a. Fundraising |  |  |  |
| b. Shared resources/staff |  |  |  |
| c. Advocacy |  |  |  |
| d. Strategic planning/needs assessment |  |  |  |
| e. Public education |  |  |  |
| f. Referrals |  |  |  |
| g. Service delivery |  |  |  |
| h. Shared outreach |  |  |  |
| i. Targeting special populations |  |  |  |
| j. Training/technical assistance |  |  |  |
| k. Volunteer recruitment or retention |  |  |  |
| l. Other |  |  |  |
| m. Don’t know |  |  |  |

# Medicaid Waiver Programs for the Elderly

1. **Check each of the following caregiver services that are included in the Medicaid Waiver program for the elderly in your PSA.**

Respite Care

Caregiver Counseling

Caregiver Education and Training

Other

Don’t know

1. **Did the establishment of the OAA NFCSP prompt any of the following changes within the Medicaid Waiver Program for Elderly in your PSA? Check all that apply.**

Increased awareness and knowledge of caregiving issues among Medicaid waiver staff

Refined intake and screening process within Medicaid waiver program to identify caregiver issues/ potential need

Enhancement or creation of caregiver component in comprehensive assessment

Greater coordination of services between family caregiver programs and the Elderly Waiver

None of the above

Don’t know

Assistive Technology

1. **During the past year, did your AAA provide caregivers with information & referral for assistive technology and/or home modification (AT/HM) through the OAA NFCSP?**

Yes

No

1. **Have you used OAA NFCSP funding in whole or in part to fund any AT/HM services?**

Yes

No

1. **Does your AAA have plans to expand the dissemination of information about AT/HM to caregivers?**

Yes

No

1. **Have you used OAA NFCSP supplemental service category to fund in whole or in part any of the following services? (Check all that apply)**

Grab bars

Lift chair

Stair lift

Gait belts

Lift vests

Wheelchair ramp or mechanical lift

Doorway expansion

Lighting improvements

Elevated/raised toilets

Vehicle retrofitting

Other AT/HM

**This next section asks for data on clients and budget. If another person in your organization is best suited to provide these answers, please save your work and forward your e-mail invitation with the survey link to the person in your organization who can best provide these answers.**

Program Participation

**ACL is interested in learning more about your AAA’s program participation.**

1. **When did your most recently completed fiscal year end?**

MM/DD/YYYY (DROPDOWN)

1. **During the most recently completed fiscal year, what was the total, unduplicated count of caregivers supported in whole or in part by your OAA NFCSP (Title III-E) [INSERT NAME OF OAA NFCSP PROGRAM]?**

| | | | | | | | Caregivers *received OAA NFCSP service in the most recently completed fiscal year* ***(ALLOW FOR 7 DIGITS)***

Don’t know

1. **During the most recently completed fiscal year, what data did you report to your state for their state program report on the total, unduplicated number of caregivers (serving older adults and grandparents caring for grandchildren) who received each of the following services through the [INSERT NAME OF OAA NFCSP PROGRAM]?.**

**92a) Counseling/ Support Groups, Caregiver Training?**

| | | | | | | | *Caregivers received training/education, counseling, or support group* ***(ALLOW FOR 7 DIGITS)***

Don’t know

**92b) Respite care? [either in-home or institutional respite]**

| | | | | | | | *Caregivers received respite care services* ***(ALLOW FOR 7 DIGITS)***

Don’t know

**92c) Supplemental services? [e.g. home modification, transportation, assistive devices]**

| | | | | | | | *Caregivers received supplemental services* ***(ALLOW FOR 7 DIGITS)***

Don’t know

**92d) Self-Directed Care**

| | | | | | | | *Caregivers received access assistance* ***(ALLOW FOR 7 DIGITS)***

Don’t know

1. **During the most recently completed fiscal year, what was the total, unduplicated count of grandparents or other relative caregivers 55 years and older who are raising children served by the [INSERT NAME OF OAA NFCSP PROGRAM], supported in whole or in part by OAA NFCSP, Title III-E?**

| | | | | | | | *Grandparents or relative caregivers 55+ who received OAA NFCSP services in the most recently completed fiscal year* ***(ALLOW FOR 7 DIGITS)***

Don’t know

Local Service Providers

1. **We’re interested in the organizations that your AAA uses to provide family caregiver support services. Please indicate the number of providers of contracted National Family Caregiver Support Program (NFCSP) services in your PSA. Include a provider only once even if they have multiple contracts to provide multiple services. If your AAA also provides service, count your organization as well.\_\_\_\_\_\_\_\_\_\_\_**
2. **How does your AAA maintain information about your NFCSP providers?**

On paper

Electronically

Combination of paper and electronic

**95a. You indicated that your AAA electronically maintains provider information. Please check which program(s) you use to maintain this information. Check all that apply.**

Excel or Access

Self- or custom-designed software

Commercial database product (e.g. Synergy or Harmony)

Other database program

1. **What information do you collect and/or generate about providers?**

Contact information

Contract period

All services contracted by each provider

Owner name

Type of ownership (e.g. for-profit, not-for-profit)

Consumer satisfaction with the individual provider

Annual number of unduplicated clients in programs/services funded by your AAA

1. **Of the [PROGRAMMER NOTE: Pre-fill with number provided in Q94] providers of NFCSP services, how many are paid through each of the following fund allocation models? Please provide your best estimate for each category.**

|  |  |
| --- | --- |
| **Fund Allocation Models** | **Estimated number of providers** |
| Paid only through lump sum grant distribution model (sub-recipient or sub-grantee) only | \_\_\_\_\_\_\_ |
| Paid only through fee-for-service agreement model (cost-per-unit reimbursement) only | \_\_\_\_\_\_\_ |
| Paid through both lump sum grant distribution and fee-for-service agreement models | \_\_\_\_\_\_\_ |
| Other (please specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_ |

1. **Do you require your NFCSP providers to secure matching funds for NFCSP services?**

Yes

No

Don’t Know

1. **What proportion of your NFCSP providers are not-for-profit (including government)? Choose the range below that reflects your best estimate.**

0-25%

26-50%

51-75%

76-100%

## Program Funding and Resources

**The next questions are about your AAA budget during the most recently completed fiscal year.**

1. **For your most recently completed fiscal year, please give us the range of your AAA’s total operating budget**

Less than $499,000

$500,000-$999,999

$1,000,000-$4,999,999

$5,000,000-$9,999,999

$10,000,000-$49,999,999

$50,000,000-$99,999,999

Over $100,000,000

100a) You indicated that your budget was less than $499,000, what is your organization’s total operating budget?  Please enter only numbers; no commas, dollar signs, etc. (EXAMPLE: 660778) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

100b) You indicated that your budget was between $500,000-$999,999, what is your organization’s total operating budget?  Please enter only numbers; no commas, dollar signs, etc. (EXAMPLE: 660778)   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

100c) You indicated that your budget was between $1,000,000-$4,999,999, what is your organization’s total operating budget?  Please enter only numbers; no commas, dollar signs, etc. (EXAMPLE: 2660778)   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

100d) You indicated that your budget was between $5,000,000-$9,999,999, what is your organization’s total operating budget?  Please enter only numbers; no commas, dollar signs, etc. (EXAMPLE: 2660778)   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

100e) You indicated that your budget was between $10,000,000-$49,999,999, what is your organization’s total operating budget?  Please enter only numbers; no commas, dollar signs, etc. (EXAMPLE: 27660778)   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

100f) You indicated that your budget was between $50,000,000-$99,999,999, what is your organization’s total operating budget?  Please enter only numbers; no commas, dollar signs, etc. (EXAMPLE: 26670778)   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

100g) You indicated that your budget was over $100,000,000, what is your organization’s total operating budget?  Please enter only numbers; no commas, dollar signs, etc. (EXAMPLE: 266080778)   \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**The items below cover budgeted amounts for caregiver services. Use amounts you reported to your state unit on aging for the state performance report for the most recent year.**

1. **What was the total operating budget for the OAA NFCSP? This includes expenditures from funds received from the OAA plus any additional sources of funds.**

$ | | |**,**| | | |**,**| | | |**,**| | | | ***(ALLOW FOR 11 DIGITS)***

1. **What was the total budget for the grandparent/relative caregiver portion of the NFCSP? This includes expenditures from funds received from the OAA plus any additional sources of funds.**

$ | | |**,**| | | |**,**| | | |**,**| | | | ***(ALLOW FOR 11 DIGITS)***

1. **What was the total budget for respite care services?**

$ | | |**,**| | | |**,**| | | |**,**| | | | ***(ALLOW FOR 11 DIGITS)***

1. **What was the total budget for supplemental services?**

$ | | |**,**| | | |**,**| | | |**,**| | | | ***(ALLOW FOR 11 DIGITS)***

1. **What was the total budget for access/assistance services?**

$ | | |**,**| | | |**,**| | | |**,**| | | | ***(ALLOW FOR 11 DIGITS)***

1. **What was the total budget for information services?**

$ | | |**,**| | | |**,**| | | |**,**| | | | ***(ALLOW FOR 11 DIGITS)***

1. **What was the total budget for counseling, support groups, and caregiver training?**

$ | | |**,**| | | |**,**| | | |**,**| | | | ***(ALLOW FOR 11 DIGITS)***

1. **In the last fiscal year, how much did your AAA expend from any of the following sources to support the caregivers served in [INSERT NAME OF OAA NFCSP PROGRAM]? Please provide category totals, even if you cannot provide expenditures within each category.**

|  |  |  |
| --- | --- | --- |
|  | **Expenditures** | **Don’t know** |
| **Total Federal Funding** | $\_\_\_\_\_\_\_\_\_\_ | □ |
| a. Older Americans Act funds | $\_\_\_\_\_\_\_\_\_\_ | □ |
| b. Other federal agency  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)** | $\_\_\_\_\_\_\_\_\_\_ | □ |

1. **Please mark which of the following funding sources are used to serve OAA NFCSP Title III-E caregiver clients. (Check all that apply)**

Aging and Disability Resources Center initiative (ADRC)

Alzheimer’s Disease Demonstration Grants to States (ADDGS)

Lottery funds

Medicaid Aged/Disabled HCBS waiver (A/D Waiver)

Medicaid State Plan

Money Follows the Person (MFP)

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

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

**We are interested in locating caregivers who may receive services funded in other ways besides the OAA or NFCSP, provided by organizations outside your AAA.**

1. Are you aware of organizations or individuals in your PSA that provide caregiver services such as respite, counseling and support, information and assistance or supplemental services with funds other than the OAA/NFCSP? For example, these may be organizations that your AAA refers caregivers to when services are not immediately available (e.g. NFCSP waiting lists) or when they need assistance beyond the scope of what the NFCSP provides. They may include churches, private geriatric care managers, private home care providers or other social service organizations that are not funded by NFCSP.

Yes

No

If yes--

Please provide contact information for up to 5 top organizations or individuals--those that provide the most non-NFCSP caregiver services or are likely to be serving the largest numbers of caregivers.

Organization Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Organization Street Address: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

City: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

State: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Zip: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Telephone: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Contact person for caregiver services, if known: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**If we have questions about your survey responses who should we contact?**

Contact Name:

Title or Role in AAA:

Email Address:

Telephone Number: | | | | | | | | | | | | |

**Thank you very much for completing this survey!**

1. **SUPPLEMENTAL SERVICES:** Services provided on a limited basis to complement care provided by caregivers. Examples of supplemental services include, but are not limited to, the following:

**• Home modifications** (necessary repair, modifications and/or adaptive alterations to improve the older person’s mobility, safety and accessibility);

**• Assistive technologies** (assistive technology products and/or services including cognitive/learning devices, control and signaling aids, daily living aids, hearing augmentation aids, mobility aids, prosthetic/orthotic/seating devices, recreational aids, speech aids and visual/reading aids, as prescribed by a medical doctor or equivalent health professional);

**• Emergency response systems** (systems that ensure that elderly individuals, or people who have medical problems or potential allergic reactions to specific drugs, and other isolated or vulnerable individuals who are at risk of health-related crises receive the medical attention they need during an emergency; includes programs that offer a means of identifying or locating individuals who may wander away from those responsible for their care and becoming lost);

**• Incontinence supplies** (adult diapers and other garments, bedding protection, control devices and alarm systems to help people who have bowel or urination control problems deal with their situation);

**• Home-delivered meals** (home delivered meals are provided to caregivers and/or care recipients in their place of residence. Supplemental Services should be used only when the caterer, meal, or caregiver do not meet the requirements of the Older Americans Act, as described under Section 331, 336, 337, and 339 or C2 Home- Delivered Meals Program. These meals are not eligible for the NSIP count);

**• Legal assistance** (legal advice, counseling and representation by an attorney or other person acting under the supervision of an attorney);

**• Nutritional supplement** (food supplements to ensure that the nutritional needs of low-income and indigent individuals and families are met. This includes liquid dietary supplements needed by cancer patients and others who have difficulty swallowing, digesting or keeping solid food down);

**• Transportation** (transportation from one location to another; does not include any other activity, and is not available through Title IIIB); and

**• Other supplemental services** (other than those mentioned above).

**• Supplemental respite services**

1. **ACTIVITIES**

**Respite care** allows a brief period of rest or relief while temporary care is provided in the home or someplace else.

**Home modifications** (such as a wheelchair ramp, stair glide, handrails, walk-in shower, hand-held shower head, grab bars, lowered or widened doors, lowered shelves, first floor bathroom, additional lighting, moving appliances to more accessible locations, easier to operate door handles, sliding shelves, etc.)

**Assistive technology** is any piece of equipment, training or intervention that promotes greater independence. It may directly or indirectly benefit you.

(assistive technology products and/or services)