

**NATIONAL
FAMILY
CAREGIVER
SUPPORT
PROGRAM**

HOW TO ADMINISTER THE PROGRAM

DECEMBER 12, 2019

LEARNING OBJECTIVES

- Program intent
- Caregiver Needs Assessment
- Who program serves - Eligibility
- Minimum service requirements
- Paperwork
- Data collection
- Caregiver Coalitions

SUPPORTING DOCUMENTS

- Everything referenced today is housed on the GWAAR website: www.gwaar.org
 - > Technical Assistance > Family Caregiver Support > National Family Caregiver Support Program
 - Enrollment Forms
 - Data Collection – SAMS & REDCap
 - Policy Information
 - Program Information
 - Caregiver Resources
 - Program Management Resources
- Always get forms directly from the website to ensure you are getting updated forms



**PROGRAM
INTENT**

WHAT THE PROGRAM IS ALL ABOUT

FOCUS ON THE CAREGIVER



- Informal or Family Caregivers
- Caregiver definition:
“A person who is helping care for another individual, enabling them to remain living in the community.”
- Not focused on the person who is unable to care for themselves
- Most people who come to your agency have a caregiver or are a caregiver
- Train all staff to seek out caregivers who could utilize NFCSP

MAINTAIN CAREGIVER HEALTH

- Caregivers have higher stress levels and are more likely to suffer health problems.
- Helping the caregiver improves their ability to provide better care for their loved one, and for a longer time.
- It is easy to focus on the person receiving care instead of the caregiver, but that is not the purpose of the NFCSP.
- The purpose of NFCSP is to **support the caregiver** which in turn will support the care recipient.



SERVING THE CAREGIVER

Neighbor looking for help paying for friend's hearing aids.
First things to address:

- The neighbor is a “caregiver” - do they identify as on?
- What else is the neighbor doing for the neighbor?
- What other needs does the *caregiver/neighbor* have?

And finally,

- What programs that can pay for hearing aids?

* Use the Needs Assessment to determine caregiver's greatest need(s)



**CAREGIVER
NEEDS
ASSESSMENT**

DETERMINING CAREGIVER NEEDS

CAREGIVER NEEDS ASSESSMENT

- Complete to help determine most urgent needs of the *caregiver* are being addressed
- More than just more paperwork – a TOOL to help you
- Ensures full scope of services are being offered
- Complete for all who are being enrolled in any caregiving program
- See [Building Interviewing Skills for a Successful Needs Assessment](#) for help with interviewing techniques

CAREGIVER NEEDS ASSESSMENT

- Include all areas in your discussion with the family
 - Unmet needs of Care Recipient
 - Unmet Caregiver Respite Needs
 - Unmet Caregiver Physical Health Needs
 - Unmet Caregiver Emotional Health Needs
 - Education and Resource Needs
 - Conversation Starters
- Do not ask each question, but address each section

CAREGIVER NEEDS ASSESSMENT

- Find the Needs Assessment under Enrollment Forms
- Refer to Supplement and Best Practices documents for help (under Program Management Resources)
- See [Building Interviewing Skills for a Successful Needs Assessment](#) for help with interviewing techniques
- Enter information into REDCap system
 - See Webinar and User Guide for help (under Data Collection – SAMS & REDCap)

CAREGIVER PROGRAM EVALUATION

- Rates how the caregiver feels about their caregiving role – before and after resources/services are in place
- Completed by program participants before services begin and again after one year of participation or upon leaving the program.
- Enter data into REDCap
- Find the Program Evaluation form under Enrollment Forms

CUSTOMER SATISFACTION SURVEY

- Rates how well agency staff handled their situation
- Give survey to participant after resources/services are set up
- Include a self-addressed, stamped envelope (request envelopes from [Lynn Gall](#) at DHS)
- They will complete and mail survey to DHS in Madison

**WHO DOES THE
PROGRAM
SERVE?**

ELIGIBILITY REQUIREMENTS

3 TYPES OF CAREGIVERS

1. Family members and informal caregivers, including friends and neighbors



2. Grandparents and other older adults who are taking care of a child who is 18 years old or younger



3. Grandparents and other older adults who are caring for an adult who is disabled



FAMILY, FRIEND, NEIGHBOR

- The caregiver can be any age.
- The person being cared for must be:
 - Age 60+ OR have a dementia diagnosis (any age).
 - “Frail” – need assistance with 2 ADLs or IADLs
- The caregiver may be a friend or neighbor – they do not have to be “family.”
- The caregiver does not have to live with the person.



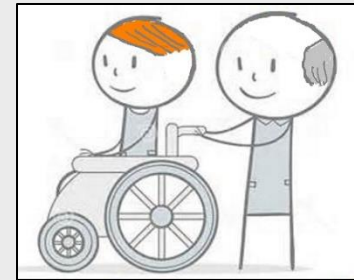
GRANDPARENT OR RELATIVE CARING FOR A CHILD

- Must be age 55+
- Must be the child's primary caregiver
- Must live with the child
- May have legal custody, but it is not required
- Must be related to the child, not the parent
- Child must be age 18 or under



OLDER ADULT CARING FOR DISABLED ADULT CHILD

- Must be age 55+
- Must be the primary caregiver
- May have legal custody, but it is not required
- Must be related to the child – CAN be the parent
- The disability must substantially limit the ability to care for themselves



ELIGIBILITY REQUIREMENTS

- Must meet definition of one of the three types of caregivers
- No financial eligibility criteria
 - Different from any non-OAA services
 - Different concept from working with means-tested programs
 - Participants should have an opportunity to donate for services

Priority should be given to:

- Caregivers of people with dementia
- Caregivers at risk of being admitted to a skilled care facility
- Older caregivers with the greatest social and economic need



**MINIMUM
SERVICE
REQUIREMENTS**

SERVICES THAT MUST BE AVAILABLE

FIVE SERVICE REQUIREMENTS

1. Information to caregivers about available services
2. Assistance to caregivers in gaining access to services
3. Individual counseling, support groups and training
4. Respite care to temporarily relieve caregivers from their responsibilities
5. Supplemental services that complement care provided

INFORMATION ABOUT AVAILABLE SERVICES

- Educational presentations at various community sites
 - Caregiving Awareness and Resources
 - Managing Stress
 - Dementia/Memory Loss



- Marketing materials

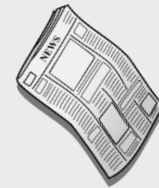
- Brochures and Flyers
- Resource Guides
- Support Group or Caregiving Class Information



* *In SAMS is referred to as Public Information or Information Services*

INFORMATION ABOUT AVAILABLE SERVICES

- Stories or articles about caregiving-related topics
 - Newsletters – yours and partner agencies
 - Local newspapers
 - Radio and Television
- Vendor tables or exhibits
 - Conferences
 - Community events
- Website and Facebook



ASSISTANCE IN GAINING ACCESS TO SERVICES

- *Information to Caregivers* = broad spectrum
- *Helping Caregivers Gain Access to Services* = personal connection
- Listen to their story – needs assessment
- Help them understand their options and form a plan
- Visits may be in the office, on the phone or in their home
- Follow up is important!

COUNSELING, SUPPORT GROUPS AND TRAINING

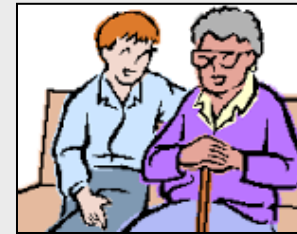
- Individual Counseling = 1:1 Professional Counseling
- Support Groups including Caregiver Café's and Telephone support groups
- Caregiver Training
 - Powerful Tools for Caregivers
 - Books and DVDs
 - Caregiver Conferences
 - Any other type of education that benefits the caregiver



RESPITE CARE

Temporarily relieves caregivers from their responsibilities

- Adult day care
- In home visits
- Short-term institutional stay



Services that are considered Respite:

- House cleaning
- Shopping
- Meal preparation
- Raking and snow shoveling



**No more than 112 hours of respite per caregiver per year*

SUPPLEMENTAL SERVICES

Things that make a caregiver's job easier and less stressful; and "complement" the care provided:

- Emergency Response Systems
 - Safe Return and Project Lifesaver
 - Transportation
 - Adaptive equipment/assistive technology
 - Activities to keep the care recipient engaged
 - Activities for the caregiver
 - Caregiving supplies
- Use needs assessment to determine greatest needs



**Max of 20% of allocation can be used for Supplemental Services*

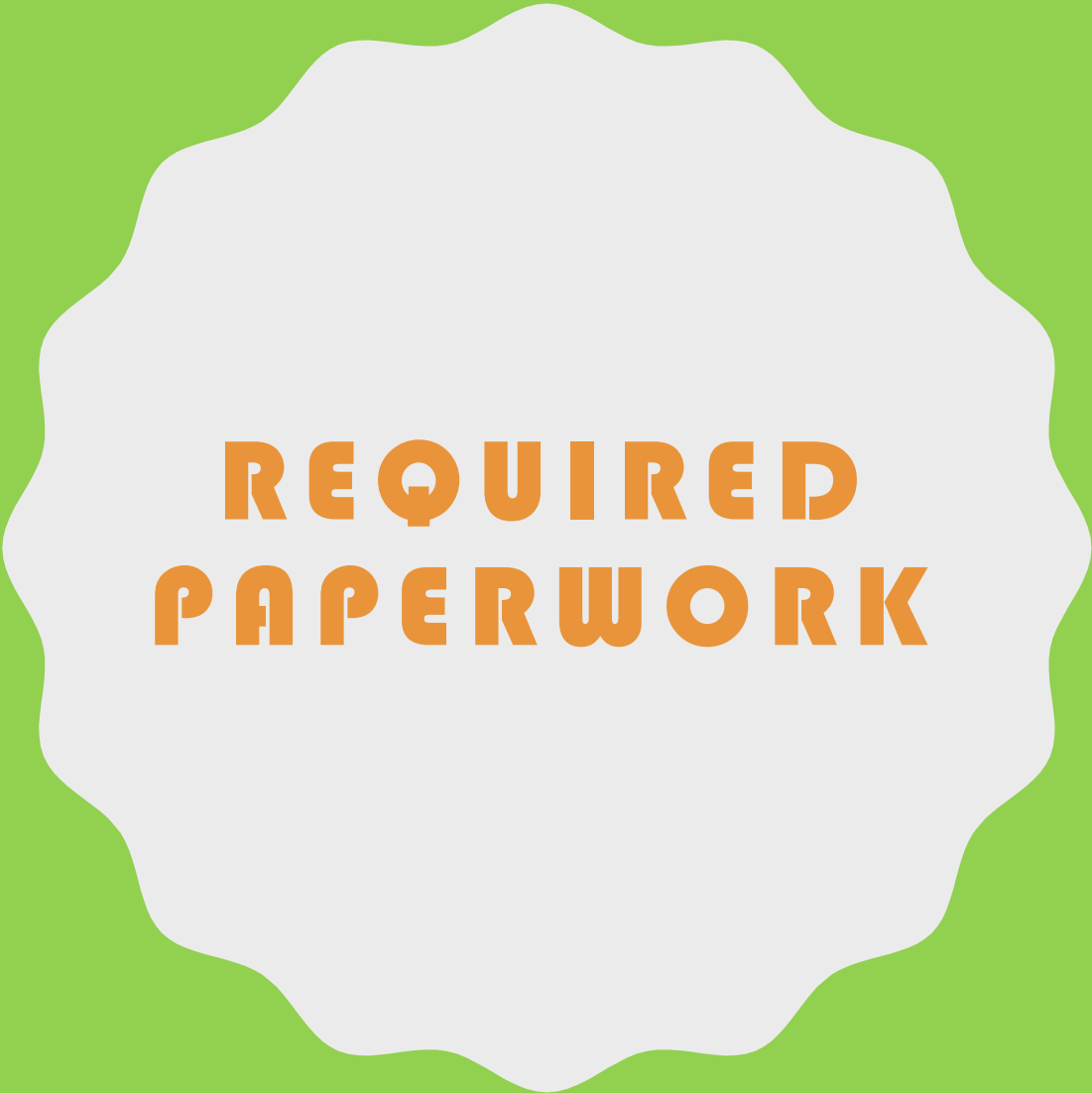


**PROGRAM
RESTRICTIONS**

THINGS TO WATCH OUT FOR

PROGRAM RESTRICTIONS

1. A caregiver cannot receive more than 112 hours of respite care in a calendar year
2. No more than 20% of total expenditures can be spent on Supplemental Services



**REQUIRED
PAPERWORK**

DO NOT OMIT THIS STEP!

PAPERWORK

Caregiver Registration Form* – two sided

- Caregiver information
- Care Recipient Information
- Under Enrollment Forms
[on website](#)



CAREGIVER INFORMATION

- Must be completed when providing:
 - Respite
 - Supplemental Services
 - Support Groups
 - Training (Powerful Tools, etc.)
 - Case Management
 - Counseling
- Gathers required data for reporting

| NFCSP Caregiver Registration Form | |
|--|---|
| Name (First, MI, Last): | Date of Registration: |
| Residential Address (Fire No. & Street): | Date of Birth (month/day/year): |
| City/State/Zip: | Gender: <input type="checkbox"/> Male <input type="checkbox"/> Female |
| Telephone Number: | Income Status: |
| Race: | Ethnicity: |
| <input type="checkbox"/> American Indian or Native Alaskan <input type="checkbox"/> Asian or Asian American <input type="checkbox"/> Black or African American <input type="checkbox"/> Native Hawaiian or Pacific Islander <input type="checkbox"/> White (non-Hispanic) <input type="checkbox"/> White-Hispanic <input type="checkbox"/> Other | <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Not Hispanic or Latino |
| Is your income below the following Federal Income Guidelines? | |
| <input type="checkbox"/> Yes <input type="checkbox"/> No | |
| # in Home | Month Year |
| 1 | \$1,083 \$12,790 |
| 2 | \$1,437 \$17,240 |
| 3 | \$1,810 \$21,720 |
| 4 | \$2,183 \$28,200 |
| Name of the person you are caring for (First, MI, Last) | |
| What is the person's Date of Birth (mm/dd/yyyy): | |
| If the person you care for is 60 years of age or older what is your relationship to him or her? <input type="checkbox"/> Husband <input type="checkbox"/> Wife <input type="checkbox"/> Son/Son-in-Law <input type="checkbox"/> Daughter/Daughter-in-Law <input type="checkbox"/> Other Relative <input type="checkbox"/> Non-Relative | Choose only one option: If the person you care for is between 19 and 59 years of age AND has Early Onset Dementia - what is your relationship to him or her? <input type="checkbox"/> Husband <input type="checkbox"/> Wife <input type="checkbox"/> Son/Son-in-Law <input type="checkbox"/> Daughter/Daughter-in-Law <input type="checkbox"/> Other Relative <input type="checkbox"/> Non-Relative |
| If the person you care for is under 19 years old what is your relationship to him or her? <input type="checkbox"/> Grandparent (55 years of age or older) <input type="checkbox"/> Other Elderly Relative (55 years of age or older) (related by blood, marriage or adoption) | If the person you care for is between 19 and 59 years of age AND is disabled - what is your relationship to him or her? <input type="checkbox"/> Grandparent (55 years of age or older) <input type="checkbox"/> Other Elderly Relative (55 years of age or older) (related by blood, marriage or adoption) |
| Privacy Statement: "The information you are being asked to provide is needed to determine if you are eligible to receive Older Americans Act Services and to comply with federal reporting requirements. This information will be stored in a secure electronic database and will not be used for any other purpose. Your information will not be shared with another agency without your permission. This information will not be sold to anyone. You have the right to review your electronic record and request changes to insure accuracy. You will not be denied most services if you refuse to provide this information. If you have questions regarding this, please ask the aging unit staff." | |
| Rev. 10-01-20 CK | |

CARE RECIPIENT INFORMATION

- Must be completed when providing Respite and Supplemental Services
 - Assesses care recipient for being frail
 - Gathers required data for reporting
- ** Always collect receipts/invoices

Care Recipient Only – if receiving Respite Care or Supplemental Services:

| ACTIVITIES OF DAILY LIVING (ADLs) and INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLs) | | |
|--|-------|-------|
| Check each ADL that you/the client have/has difficulty in completing or need help with: | | |
| Getting in and out of the bath or shower or preparing the bath, washing and drying | No | Yes |
| Dressing and undressing | | |
| Completing toilet activities and personal care | | |
| Getting in and out of bed or a chair | | |
| Using utensils and eating without help | | |
| Walking up and down a flight of stairs or walking without assistance | | |
| TOTAL Number of Yes ADLs | | |
| Check each IADL that you/the client have/has difficulty in completing or need help with: | | |
| Preparing own meals | No | Yes |
| Medication management | | |
| Handling bill paying, banking, etc. | | |
| Doing heavy housework and outside chores | | |
| Doing light housework | | |
| Shopping for personal items and/or groceries | | |
| Traveling in a van, taxi, bus, or car | | |
| Answering the telephone or calling out on the telephone | | |
| TOTAL Number of Yes IADLs | | |

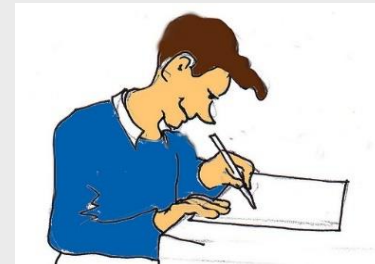
Additional Care Recipient information (optional):

| | | |
|--|-------------------------------|---------------------------------|
| Gender: | <input type="checkbox"/> Male | <input type="checkbox"/> Female |
| Telephone Number: | | |
| Residential Address (Fire No. & Street): | | |
| City/State/Zip: | | |

Rev. 10-01-20 CK

OTHER PAPERWORK MUSTS

- For Respite and Supplemental Services – collect receipts/invoices
- For Support Groups and Trainings - must keep attendance log
- For Case Management and Counseling – must track number of contacts/sessions



PROGRAM EVALUATION

- Use for all caregivers receiving services
- Complete before services begin
- Re-evaluate after one year or when they are no longer utilizing services
- Gathers important information for advocacy and local programming

ID # _____

Program Evaluation

This assessment should be completed by program participants before services begin, and again after one year of participation or upon leaving the program.

Name: _____

Today's Date: _____

| | Circle Response |
|---|---------------------------------|
| 1. How would you rate your ability provide for the person in your care? | Good Fair Poor Neutral |
| 2. How would you rate your energy to do what is needed? | Good Fair Poor Neutral |
| 3. How would you rate your mood/morale about performing caregiving tasks? | Good Fair Poor Neutral |
| 4. How would you rate your physical health at this time? | Good Fair Poor Neutral |
| 5. How would you rate your mental or emotional health at this time? | Good Fair Poor Neutral |
| 6. How would you rate your knowledge about community resources available to help? | Good Fair Poor Neutral |

| For Office Use Only | | | | |
|---------------------|----------|-----------------|-------------|---------------------|
| Program | Enrolled | Enrollment Date | Survey Date | Pre or Post Survey? |
| AFCSF | | | | |
| NFCSP | | | | |
| Both | | | | |

Women's Family Caregiver Support Programs

Publish Date: January 2018

REDCAP DATA ENTRY

- Three entries into REDCap for each caregiver
 - Caregiver Needs Assessment
 - Pre-Program Evaluation
 - Post-Program Evaluation
- See DHS REDCap Registration & User Guide and DHS REDCap Training Webinar (under Data Collection)
- Customer Satisfaction Survey – give to caregiver for them to complete and mail in self-addressed, stamped envelope



**DATA
COLLECTION**

SAMS REQUIREMENTS

DATA COLLECTION AND SAMS

- Data must be collected and reported on all activities funded with NFCSP
- Data is entered into the Social Assistance Management System (SAMS)
- Data reported into SAMS must match fiscal reports
- *Even if you don't do the actual SAMS data input, it is still important that you understand the information needed*

WHY SAMS IS IMPORTANT

- Data in SAMS shows how NFCSP grant money was used
- Statewide reports are generated from SAMS and submitted to the federal government
- Shows what services were provided and how many people were served
- This data is increasingly important for advocacy efforts

SAMS DATA COLLECTION TOOLS*

1. SAMS Reference Sheet - explains how and where to report services for all five service requirements.
2. NFCSP Data Collection Sheet - optional tool to collect data for Information Services (Public Information).
3. SAMS Service Definitions – gives detailed description of all SAMS categories

* Found on the [GWAAR Website](#) under Data Collection

DATA COLLECTION FOR RESPITE

- Indicate what type of respite
 - **#66a Respite Care** - In Home
 - **#66b Respite Care** – Facility Based Day
 - **#66c Respite Care** – Facility Based Overnight
- Must choose a subservice – general, chore, homemaker, etc
- Report number of hours in 15-minute increments

DATA COLLECTION FOR SUPPLEMENTAL SERVICES

- Report under **#67 Supplemental Services**
 - Subservice is not required
- Anything that “complements the care provided” by the caregiver
 - transportation, supplies, adaptive equipment, etc.
- Record the number of occurrences each month

DATA COLLECTION FOR CAREGIVER SUPPORT GROUPS

#6503s Caregiver Support Groups

- Attendees should complete the Caregiver Registration Form at the first meeting they attend
- Use a sign in sheet at every meeting
- Record under each caregiver the number of sessions attended each month

**Memory Café's reported under Information Services as a Public Presentation*

**Caregiver Café's – if reported as a support group, need CG Registration form, if reported as Information Services, just need number of attendees*

MEMORY & CAREGIVER CAFÉS

- Memory Café's are reported under Information Services as a Public Presentation
- Caregiver Café's
 - If reported as a support group, need Caregiver Registration form
 - If reported as Information Services, just need number of attendees

DATA COLLECTION FOR CAREGIVER TRAINING

#6502s Caregiver Training

- Powerful Tools for Caregivers
- Small presentations or classes
- Sending caregiver(s) to a conference
- Complete the Caregiver Registration Form at the first meeting or class they attend
- Use a sign in sheet at every meeting
- Record the number of sessions attended each month
- Report under each caregiver

DATA COLLECTION FOR CASE MANAGEMENT



64-Caregiver Case Management

- Not the traditional definition of Case Management
- Can be used for Coordinator Salary for time spent working with caregivers
- Complete Caregiver Registration Form
- Record the number of contacts made – not actual time spent
- Suggest to enter all caregivers that are enrolled in NFCSP

DATA COLLECTION FOR CAREGIVER COUNSELING

#650 Is-Caregiver Counseling

- Refers to actual counseling provided by a professionally trained person
- Complete Caregiver Registration Form
- Record the number of contacts made, not actual time spent



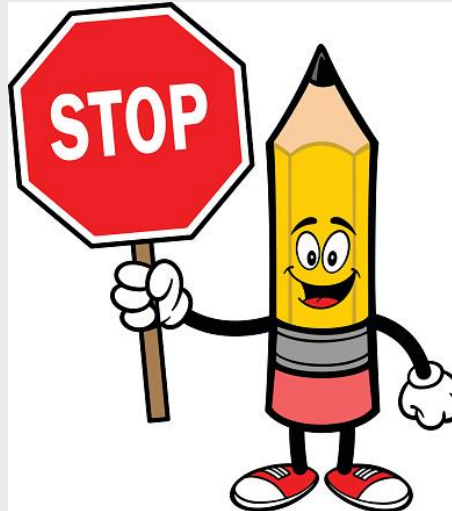
DATA COLLECTION FOR INFORMATION TO CAREGIVERS

#68 Information Services (Public Information)

- Presentations, vendor fairs, mailings, articles, ads, etc.
- No intake forms needed
- Use NFCSP Data Collection sheet to keep track of the number of occurrences AND the number of consumers reached
- Number of occurrences will be smaller than the number of consumers reached (1 health fair = 350 people reached)

INFORMATION AND ASSISTANCE

- At this time, you are not able to report Information and Assistance for caregivers into SAMS – STAY TUNED!





**CAREGIVER
COALITIONS**

COMMUNITY PARTNERSHIPS

CAREGIVER COALITIONS

- NFCSP policy requires each Aging Unit to be a member of a coalition with other agencies who work with family caregivers
- Can utilize an existing coalition with similar membership
- Aging Unit representative needs to attend meetings
- Caregiver issues must be discussed
- Ideally work on a project that benefits caregivers
- Caregiver Coalition page on GWAAR Website



QUESTIONS?



Contact Jane Mahoney or Lynn Gall any time with questions:

Jane – Jane.Mahoney@gwaar.org

Lynn - Lynn.Gall@dhs.wisconsin.gov