

Caregiver Support

Aging Operations Manual

I. Introduction

Wisconsin administers two family caregiver support programs:

- Title III-E of the Older Americans Act (OAA), also known as the National Family Caregiver Support Program (NFCSP)
- The Wisconsin Alzheimer’s Family Caregiver Support Program (AFCSP)

Caregiver support programs are typically administered at the local level by area agencies on aging (AAAs), county aging units (CAUs), tribal aging units (TAUs), aging and disability resource centers (ADRCs), and other service providers, **hereafter referred to collectively as “agencies.”** Agencies coordinate services to provide supports and services to family members, friends, and others who provide in-home care for older adults; older relative caregivers of children; and caregivers of adults with severe disabilities. The federal and state programs are similar, but there are differences that program coordinators and all agency staff must understand and adhere to when serving customers.

Title III-E of the Older Americans Act provides federal funding to states for the provision of caregiver support services to family members and friends caring for older adults with any health condition, grandparents and older relative caregivers who are primary caregivers for children under 18, and older adults who are primary caregivers for disabled adults between the ages of 19 and 59. The Wisconsin Department of Health Services (DHS) Bureau of Aging and Disability Resources (BADR) distributes funding to every county in the state, and tribes receive family caregiver support services funding directly from the Administration for Community Living (ACL) as part of Title VI of the OAA.

Congress added caregiver support services to the OAA in 2000, 35 years after the original Older Americans Act was adopted, in recognition of the important role that family members and friends play in enabling older adults to remain living at home for as long as possible. The addition of family caregiver supports also recognizes the financial hardships, emotional stressors,

employment challenges, and other conflicts experienced by caregivers who provide around-the-clock care at home. Caregiver support services are designed to help alleviate these daily pressures.

The Wisconsin AFCSP was established by the state legislature in 1985 and is funded by state tax dollars. Designed specifically to support caregivers of people living in the community with Alzheimer’s disease and other irreversible dementias, the AFCSP was the model for what eventually became the federal Title III-E/NFCSP. As a result, the Wisconsin AFCSP and federal NFCSP are similar in their intent, but there are a few differences that agency staff must understand.

Close coordination of the two programs is required to deliver high-quality caregiver support services.

II. Requirements for provision of caregiver support

A. National Family Caregiver Support Program (NFCSP)

1. Eligibility for services

The NFCSP provides for multifaceted systems of caregiver support services to the following groups:

a. Caregivers of older adults

This is defined as family members and friends aged 18 and older who are caring for individuals aged 60 or older, or who are caring for a person of any age diagnosed with irreversible dementia.

Priority is given to the following:

- Caregivers of individuals living at home who are at risk of being admitted to a nursing home or skilled care facility
- Caregivers and care recipients with greatest social and economic needs

"Family caregiver" means an adult family member (age 18 or older), friend, or other individual who is an informal provider of in-home care to a person age 60 or older or to an individual with Alzheimer's disease or other untreatable disorder with irreversible neurological and organic brain dysfunction.

b. Older relative caregivers

(1) Grandparents or older relatives aged 55 and older who are caring for children younger than 18

Note: There is no longer a limit on the amount of an agency's NFCSP that may be used for serving this population.

"Grandparent or other relative caregiver" means a grandparent; step-grandparent; or other relative by blood, marriage, or adoption, of a child who is younger than 18 years old and for whom all the following are true:

- The caregiver lives with the child.
- The grandparent or other relative is the primary caregiver for the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver.
- The caregiver has legal guardianship of the child or is raising the child informally.

(2) Relative caregivers providing care for adults with a disability who are between 19 and 59 years old

Relative caregivers must be aged 55 and older and live with the disabled adult. This may include the parent of the disabled adult. Priority is given to caregivers of adult children with severe disabilities.

"Disability" means a disability attributable to cognitive or physical impairment or a combination of cognitive and physical impairments that result in substantial functional limitations in one or more of the following areas of major life activities:

- Self-care
- Receptive and expressive language
- Learning
- Mobility
- Self-direction
- Capacity for independent living
- Economic self-sufficiency
- Cognitive functioning
- Emotional adjustment

"**Severe disability**" means a severe chronic disability attributable to cognitive or physical impairment or a combination of cognitive and physical impairments, which is likely to continue indefinitely, and which results in substantial functional limitation in three or more of the major life activities specified under the definition of "disability."

c. Caregivers of Family Care participants receiving the non-nursing home level of care benefit, which does not provide respite or other family caregiver supports.

"**Non-nursing home level of care**" is a limited Family Care benefit to help coordinate services through an interdisciplinary management team for individuals who meet Family Care functional eligibility. It does not provide the full Family Care benefit. Because the non-nursing home level of Family Care does not provide family caregiver support services, caregivers may receive those supports through AFCSP or NFCSP.

d. Family caregivers of individuals enrolled in IRIS, Family Care, or other programs.

Note: This group is provided **limited support** only if the individual receiving care is enrolled in a program that specifically prohibits providing a good or service deemed necessary to support the caregiver.

To be eligible to receive respite, in-home care, or supplemental services, family caregivers must be providing in-home care to older individuals who meet one of the following criteria:

- Is unable to perform at least two activities of daily living or independent activities of daily living without substantial human assistance, including verbal reminding, physical cueing, or supervision.
- Due to cognitive impairment, requires substantial supervision to manage behavior that poses a serious health or safety hazard to the individual or another person.

2. Level of service (minimum requirements)

Agencies are required to use the following instruments to meet minimum service requirements for the AFCSP and NFCSP. Technical assistance on the use of each instrument and required data reporting is available from the Office on Aging and GWAAR staff.

- Eligibility and enrollment forms
- Caregiver needs assessment for each AFCSP and NFCSP participant
- Initial and post-program evaluation survey that measures participant outcomes over time
- DHS customer satisfaction survey

All AFCSP and NFCSP forms and instruments are available on BADR's [SharePoint Aging Forms page](#).

The caregiver needs assessment, initial and post-program evaluation surveys, and DHS customer satisfaction survey are also available in English and Spanish in the [DHS Forms Library](#) and on the [Greater Wisconsin Agency for Aging Resources technical assistance page](#). Self-addressed stamped envelopes to return paper customer satisfaction surveys are available from the BADR office in Madison.

AFCSP and NFCSP participants are encouraged to complete the [DHS customer satisfaction survey](#) online.

Five required services must be provided directly by the aging unit or purchased through a contract. Per the OAA, AAAs are not allowed to provide direct services. The following are the five minimum service requirements for NFCSP:

a. Information to caregivers about available services

“Information” means a public and media activity that conveys information to caregivers about available services, which can include an in-person interactive presentation to the public; a booth or exhibit at a fair, conference, or other public event; and a radio, TV, or website event. Unlike "information and assistance," this service is not tailored to the needs of the individual.

b. Assistance to caregivers in gaining access to services

(1) Assistance

“Assistance” means one-to-one contact that:

- Provides individuals with current information on opportunities and services available within their communities, including information relating to assistive technology.
- Assesses the needs and capacities of the individuals.
- Links the individuals to the opportunities and services that are available.
- Ensures, to the maximum extent practicable, that family caregivers receive the services needed and individuals are aware of the opportunities available.
- Establishes adequate follow-up procedures.
- Serves the entire community of family caregivers, particularly individuals caring for:
 - Older individuals with greatest economic need.
 - Family caregivers who provide care for individuals with Alzheimer’s disease and other irreversible disorders with neurological and organic brain dysfunction.

(2) Case management

"Case management" means service coordination provided to a caregiver:

- By an individual who is trained or experienced in the case-management skills that are required to deliver caregiver support services.
- To assess the caregiver's needs and to approve, arrange, coordinate, and monitor an optimum package of services to meet those needs.

Case management routinely includes the following:

- A comprehensive assessment of the caregiver (including physical, emotional, education, and social needs).
- Development and implementation of a service plan in coordination with the caregiver to mobilize formal and informal resources and services identified through the needs assessment, including coordination of goods and services.
- Coordination with any other services currently being received.
- Information and assistance services provided under the OAA.
- Observation of formal and informal service delivery to ensure that services specified in the service plan are being provided.
- Periodic reassessment of the caregiver's needs.
- Advocacy on behalf of the caregiver for needed services or resources, in accordance with the wishes of the caregiver.

c. Individual counseling, organization of support groups, and training to assist caregivers in making decisions and solving problems relating to their caregiver roles

(1) Individual counseling

“**Counseling**” means a service designed to support caregivers and assist them in their decision making and problem solving. Counselors are service providers that are degreed and/or credentialed as required by state policy and trained to work with older adults and families specifically to address the complex physical, behavioral, and emotional problems related to their caregiver roles. This includes counseling in individual or group sessions. Counseling is a separate function apart from support group activities or caregiver training (see definitions for these services).

(2) Organization of support groups

“**Support groups**” means a service that is led by a trained individual, moderator, or professional, as required by state policy, to facilitate caregivers to discuss common experiences and concerns, and to develop a mutual support system. Support groups are typically held on a regularly scheduled basis and may be conducted in person, over the telephone, or online. For the purposes of Title III-E funding, caregiver support groups would not include “caregiver education groups,” “peer-to-peer support groups,” or other groups primarily aimed at teaching skills or meeting on an informal basis without a facilitator who possesses training and/or credentials as required by state policy.

(3) Caregiver training

“**Training**” means a service that provides family caregivers with instruction to improve knowledge and performance of specific skills relating to their caregiving roles and responsibilities. Training may include education related to health, nutrition, and financial management; providing personal care; communicating with health care providers and other family members; learning through Wisconsin’s online training portal, [Trualta](#); or the use of evidence-based programs. Training may be conducted in-person or online to individuals or in group settings.

d. Respite services to enable caregivers to be temporarily relieved from their caregiving responsibilities

"**Respite**" means services which offer temporary substitute supports or living arrangements for persons in need of care to provide a brief period of relief or rest for the family caregiver.

"**Temporary**" means occasional or intermittent care or supports that is not intended to be permanent.

Respite includes any of the following:

- "**General in-home respite**" means a respite service provided in the home of the caregiver or care receiver that allows the caregiver time away to engage in other activities. During such respite, other respite activities can occur, which offer additional support to either the caregiver or care receiver, including homemaker or personal care services. (Source: ACT committee)
- "**Personal care in-home respite**" means an in-home service that includes an appropriately skilled provider or volunteer providing personal assistance, stand-by assistance, supervision, or cues for a care recipient having difficulties with one or more activities of daily living such as bathing, dressing, toileting, getting in or out of a bed or chair, eating, or walking.
- "**Homemaker in-home respite**" means an in-home service that includes an appropriately skilled provider or volunteer assisting with routine household tasks. Homemaker tasks may include, but are not limited to, laundry, ironing, meal preparation, shopping for necessities (including groceries), and light housekeeping (for example, dusting, vacuuming, mopping floors, cleaning bathroom and kitchen, making beds, or maintaining a safe environment).
- "**Chore in-home respite**" means an in-home service that includes an appropriately skilled provider or volunteer assisting a caregiver with non-continual household tasks. Chore activities may include, but are not limited to, installing screens and storm windows, cleaning appliances, cleaning and securing carpets and rugs, washing walls and windows, scrubbing floors, cleaning attics and basements to remove fire and health hazards, providing pest control, cutting grass, raking leaves, clearing walkways, trimming overhanging tree branches, chopping wood, and moving heavy furniture.

- **“Facility-based day respite”** means a respite service provided in settings other than the caregiver or care receiver’s home, including adult day care, a senior center, or other non-residential setting (in the case of older relatives raising children, day camps), where an overnight stay does not occur but allows the caregiver time away to do other activities. (Source: ACT committee)
- **“Facility-based overnight respite”** means a respite service provided in residential settings, such as nursing homes, assisted living facilities, and adult foster homes (or, in the case of older relatives raising children, summer camps), in which the care receiver resides in the facility on a temporary basis for a full 24-hour period, allowing the caregiver time away to do other activities. (Source: ACT committee)

NFCSP funding cannot be used to cover the day-to-day operating expenses of adult day facilities. All NFCSP respite payments must be associated with a specific care recipient and caregiver. The only exception is when an agency has pre-planned for the limited-time expansion or development of new community programming or services.

e. Supplemental services, on a limited basis, to complement the care provided by caregivers

"Supplemental services" means services provided on a limited basis to complement the care provided by family caregivers. Supplemental services may include:

- Home-delivered meals (provided through the Older Americans Act, a restaurant, or other meal service).
- Congregate meals.
- Nutrition counseling, which means the provision of individualized advice and guidance to individuals or family caregivers who are at nutritional risk because of their health or nutritional history, dietary intake, medication use, or chronic illness. Counseling must be performed by a health professional in accordance with state policy and may include options and methods for improving nutritional status.
- Assisted transportation, which means the provision of assistance, including escort, to a person who has physical or cognitive difficulties that limit their ability to use personal or public transportation on their own.
- Transportation, which is defined as the provision of a means of transport for a person from one location to another. This does not include any other activity.

- Legal or financial services.
- Nutrition education.
- Medication management.
- Health promotion (non-evidence-based).
- Assistive devices and technology.
- Consumable supplies.
- Home repair and modifications (cannot exceed \$5,000 per calendar year).
- Home security and safety.
- Professional visits by nurses, occupational therapists, and physical therapists.
- Other goods and services that enable older adults to remain living safely at home. Approvable goods and services may include, but are not limited to, minor home modifications, adaptive aids, assistive technologies, emergency response systems, incontinence supplies, over-the-counter medications, and communication and technology devices or equipment.

Agencies providing either respite or supplemental services will assess and record the functional limitations of the person receiving care to determine if they meet the ADL or IADL functional limitations to receive services under the NFCSP.

NOTE: Family caregiver support programs **do not use** the long-term care functional screen that assesses eligibility for Medicaid long-term care programs. Instead, use the [Family Caregiver Needs Assessment, F-02519](#) located in the [DHS Forms Library](#).

When there is a concern about the use of limited resources for respite and supplemental services, agencies may, with the advice and consultation of their governing body and/or coordinating committee, limit the level of services provided to caregivers. Such local policy decisions must be in writing and must be applied uniformly to all participants to ensure equity.

f. Waivers

In an emergency, an administering agency may request a waiver to exceed respite limits defined as "temporary." A waiver request explaining the special circumstances must be submitted in writing to BADR or to GWAAR, for agencies served by the GWAAR AAA.

In requesting a waiver, the administering agency will demonstrate that the situation is an emergency threatening the health or safety of an individual, and that no other source of funding is available to provide necessary services. BADR or GWAAR may grant a waiver to exceed established policy limitations on a case-by-case basis.

B. Wisconsin Alzheimer's Family Caregiver Support Program (AFCSP)

1. Eligibility for services

Eligibility and service provision requirements for the Wisconsin Alzheimer's Family Caregiver Support Program are established by [Wis. Admin. Code ch. DHS 68](#), "Support for Persons with Dementia and Their Caregivers." The administrative code is promulgated pursuant to ss. 46.87 and 227.11 (2)(a), Stats., section 3023 (28m) of 1985 Wis. Act 29, and 2015 Wis. Act 273 to establish procedures and criteria for distributing funding. All payments for goods and services must be provided in accordance with this chapter.

The AFCSP is intended to provide a diverse array of community services directed at preventing or delaying the institutionalization of people who have dementia, enhancing quality of life, and providing assistance to family members and others who provide in-home care without compensation.

Individuals may not be enrolled in the Wisconsin AFCSP and federal NFCSP at the same time. However, caregivers of individuals diagnosed with dementia who financially qualify for the AFCSP are allowed to utilize both the AFCSP and NFCSP during the same calendar year when it is determined their needs exceed the \$4,000 annual AFCSP services limit. Agencies will use the [Caregiver Needs Assessment, F-02519](#) to determine the level of each

individual's need and coordinate with their county or tribal NFCSP/Title VI program to ensure that supports and services are maintained.

As of February 1, 2019, any person who meets the AFCSP income requirements and has a medical diagnosis of Alzheimer's disease or other dementia, or a non-reversible condition meeting the definitions in Wis. Admin. Code ch. DHS 68 may choose to enroll in the Wisconsin AFCSP.

2. Level of service

At least 40% of county AFCSP expenditures must be spent on providing respite to caregivers. Respite may include transportation required to participate in respite, adaptive equipment and technology, expenses related to keeping caregivers socially engaged with others, or any other item or service requested by the caregiver to provide them with respite.

Tribes are exempt from the 40% respite spending requirement but are encouraged to prioritize using AFCSP funding to provide respite to caregivers.

When there is a concern about the use of limited resources, agencies may, with the advice and consultation of their governing body and/or coordinating committee, limit the level of services provided to caregivers (refer to [Wis. Admin. Code ch. DHS 68](#)). Local policy decisions must be in writing and must be applied uniformly to all participants to ensure equity.

III. Collaborating family caregiver supports with other aging and disability programs

Caregiver support is a function of both aging units and ADRCs, especially related to the provision of information and assistance to caregivers. It is critical that the aging unit and the ADRC collaborate to provide caregiver support services to community members.

A. Title III and Title VI programs

Older Americans Act funding allows aging units an opportunity to advocate with other provider agencies about expanding and enhancing existing services to better meet the needs of family caregivers. Every effort must be made to integrate and closely coordinate the NFCSP and the Wisconsin AFCSP with other Title III and Tribal Title VI programs.

B. Dementia care specialists (DCS)

At a minimum, close coordination of the two caregiver programs with local dementia care specialists is required to maximize the dollars available to serve family caregivers and to avoid duplication of services.

C. Kinship programs

Programs are expected to coordinate with county and tribal kinship programs to avoid duplication of services to grandparents and relative caregivers and maximize supports.

D. Community-based long-term care programs

AFCSP and NFCSP funding cannot be used to provide respite or caregiver support services for individuals enrolled in home and community-based waiver programs such as Family Care, IRIS, or Partnership, which can pay for respite, adult day care and some other caregiver support services. The only exception is for individuals enrolled in the Family Care non-nursing home level of care benefit, which does not provide caregiver supports as part of the benefit.

E. Residential facilities

Funding cannot be used to pay residential fees or provide caregiver respite for people permanently residing in an assisted living facility, community-based residential facility, residential care apartment complex, or other non-home setting. However, NFCSP and AFCSP may be used to help the caregivers of such people provide additional care, goods or services that are not included in residential fees. Examples could include transporting the older adult to medical appointments if not covered by Medicare or private insurance, purchasing incontinence supplies, or participating in caregiver counseling and education.

F. Other community requirements—caregiver coalitions

To ensure coordination of services within the county and ADRC service areas and tribes, agencies will convene or be a member of a local family caregiver coalition or coordinating committee with other local providers who support family caregivers. Coalitions will set goals and coordinate activities with other community agencies and volunteer organizations providing services to caregivers.

IV. Operational policies and procedures

A. Statutory references

- Caregiver support is a requirement under the federal [Older Americans Act of 1965, 2020 Reauthorization, Section 316](#).
- Wisconsin Alzheimer's Family Caregiver Support Program policy is established by [Wis. Admin. Code ch. DHS 68](#), "Support for Persons with Dementia and Their Caregivers," promulgated pursuant to Wis. Stat. §§ 46.87 and 227.11 (2)(a); 1985 Wis. Act 29, Section 3023, § (28m); and 2015 Wis. Act 273.

B. Agency requirements

- Title III-E (NFCSP) services are to be provided by or contracted through the local aging unit. AAAs are not allowed to be direct service providers.
- The Wisconsin AFCSP is contracted to every county and tribe.

1. Tribal aging units

TAUs are eligible to receive family caregiver program funding under Part C of Title VI of the Native American Caregiver Support Program. Tribal Title VI funds are awarded and administered by the U.S. Administration for Community Living. Therefore, tribes do not receive a state allocation for NFCSP.

Tribes receive an AFCSP allocation from DHS based on the state's population-based formula.

2. Coordination of services

It is the intent of the OAA for information and services to be provided to family caregivers in a direct and helpful manner. It is, therefore, in the best interest of family caregivers that Title III-E of the OAA (NFCSP) and the Wisconsin AFCSP be administered by the same agency.

C. Supervision

Agency supervisors are expected to maintain expertise in the requirements for providing caregiver support services, administering the AFCSP and NFCSP, and incorporating best practice approaches into their agency's staff training.

D. Allowable funding source(s) and expenses

Aging units and Tribes may use AFCSP funding to hire agency staff serving families enrolled in the AFCSP.

Aging units cannot use NFCSP to hire agency staff. Title III-B should be used.

Staff or subcontractors funded with Title III-E or AFCSP will work on behalf of family caregivers.

1. OAA Title III-E and AFCSP

Distribution of state and federal funds will be determined using the Title III intrastate funding formula included in the current State Aging Plan.

2. Local funding—NFCSP required match

NFCSP requires a 25% [local match](#) of non-federal dollars. This match may also be in-kind. State and local funding not currently used to match other programs may be used. Caregiver support services provided using local match

funding must be reported in SAMS under Title III-E along with services provided using federal funds. Wisconsin AFCSP funding, which is state general purpose revenue (GPR), may be used to meet the federal match requirement.

3. Program income—participant contributions

There will be no cost-share requirement or fees charged to any caregiver program participant. However, participants must be given the opportunity to [voluntarily contribute](#) toward the cost of services if they choose. OAA requirements for [program income](#) apply to Title III-E (NFCSP) contributions.

If a state-funded AFCSP participant chooses to make a voluntary contribution to the Older Americans Act Title III-C [Elder Nutrition Program](#) for dining or home-delivered meals, a [Wisconsin AFCSP Home-Delivered Meals Contribution Authorization, F-02425](#), signed by the AFCSP participant, allows the program to transfer funds toward the cost of meals on the participant's behalf. AFCSP participants must be made aware that their meal program contribution will be deducted from the amount of AFCSP available for other caregiver support services. A copy of all communications related to Older Americans Act Title III-C contributions must be provided to the AFCSP participant and/or caregiver to avoid miscommunication or confusion.

AFCSP participants and caregivers who are not eligible for the federal Title III-C senior dining or home-delivered meal program may still receive meals, but they must pay the full cost. AFCSP may be used to reimburse the full cost of meals, and program participants must be made aware that meal program purchases will reduce the amount of AFCSP available for other caregiver support services.

E. Policy requirements

Agencies may contract for all or part of the services required under the AFCSP and NFCSP. If the agency contracts for caregiver support services, formal legal contracts must be used to meet the contract requirements found in the [contract administration](#) and [fiscal management](#) chapters of this manual and must ensure all of the following:

- The contract agency can demonstrate interagency coordination.

- The contract agency has in place a mechanism for identifying and prioritizing individuals with the greatest social and economic need.
- The contract agency has the capacity to collect and report necessary data to demonstrate that people receiving direct services meet the [eligibility criteria](#).
- The contract agency has a procedure in place to record, report, and manage generated program income.

In instances where the agency contracts for all or part of the services, the county or tribal agency remains responsible for ensuring that all five of the federal minimum requirements for services are met. This can be achieved by maintaining oversight using a single contract or through a combination of direct-service provision and contracts.

F. Reporting requirements

AFCSP reporting requirements are set by the state aging unit and include the submission of an annual budget and annual fiscal report of expenditures.

[Federal reporting requirements](#) for the NFCSP are the same as for other Title III-funded services.

G. Planning requirements

Family caregiver support services will be a priority in AAA and local [aging unit plans](#) and will include a detailed explanation for the proposed use of Title III-E and AFCSP funds.

AAAs will provide technical assistance to local and tribal aging units on how to develop caregiver support program plans and establish program goals.

H. Training and certification requirements

No person with a known history of physical, sexual, emotional, or financial abuse may be hired as a respite or in-home provider of any kind for AFCSP and NFCSP participants. Agencies should encourage participants to order background

checks for all individuals seeking to be hired as respite or in-home service providers if they are not hired through an agency that conducts its own background checks. Each participant's service plan may include payment approval for as many background checks as needed to ensure a safe service plan.

Local agencies are responsible for training their caregiver program staff. Staff training and development associated with the duties of NFCSP and AFCSP administration is an allowable cost. This may include training registration fees and associated mileage, meals, and lodging, as well as the purchase of training materials and resources.

OAA consultants at GWAAR and the family caregiver support programs manager at BADR are available to provide technical assistance and supplemental training as needed. GWAAR offers online training modules and professional development for Older Americans Act program staff through [GWAAR ED](#).

Links to additional training resources can be accessed through the [Aging SharePoint site](#).