Chapter 11. National Family Caregiver Support Program (NFCSP) and Wisconsin Alzheimer’s Family Caregiver Support Program (AFCSP)

11.1 Title III-E (NFCSP) Purpose and Legislation

Title III, Section 316 of the Older Americans Act creates the National Family Caregiver Support Program (NFCSP). In Wisconsin, Title III-E services are to be provided by or contracted through the local aging unit. Area Agencies on Aging are not allowed to be direct service providers.

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

(1) **Family caregivers of individuals age 60 or older, or who are caring for a person of any age diagnosed with dementia**

 Priority is to be given to the following:

* Family caregivers of individuals living at home who are at risk of being admitted to a nursing home or skilled care facility
* Family caregivers with greatest social and economic needs

 (2) **Grandparents or older relatives age 55 or older caring for children younger than 18 years of age.** There is no longer a limit on the amount of NFCSP that may be used for serving this population.

(3) **Relative caregivers providing care for adults with a disability who are between 18 and 59 years of age.** Relative caregivers must be 55 years of age and older, live with the disabled adult, and may include the child’s parent. Priority is to be given to caregivers of adult children with severe disabilities.

(4) **Caregivers of** **Family Care participants receiving the non-nursing home level of care** **benefit** and who do not receive respite or other family caregiver support services as part of their limited Family Care benefit.

(5) **Limited support to family caregivers of individuals enrolled in IRIS, Family Care** or other programs if the program specifically prohibits providing a good or service deemed necessary for the caregiver.

11.2 Definitions

(1) "**Assistance**" means one-to-one contact to provide one of the following:

 (A) "**Information and Assistance**" means a service that provides current information on opportunities and services available; assesses the problems and capacities of the individuals; links people to the opportunities and services available; and to the maximum extent practicable, ensures by establishing adequate follow-up procedures that the individuals receive the services needed and are aware of caregiver supports available to them.

 (B) "**Case Management**" means assistance either in the form of access or care coordination in circumstances where the older person or caregiver is experiencing diminished functioning capacities, personal conditions or other characteristics which require the provision of services by formal service providers. Activities of case management may include the following: assessing needs, developing care plans, authorizing services, arranging services, coordinating the provision of services among providers, follow-up contacts and reassessment.

(2) "**Child**" means an individual who is younger than 18 years of age.

(3) "**Counseling / Support Groups / Training**" means the provision of advice, guidance and instruction about options and methods for providing support to caregivers in an individual or group setting.

(4) "**Disability**"means a disability attributable to mental or physical impairment or a combination of mental and physical impairments that result in substantial functional limitations in one or more of the following areas of major life activity:

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

(5) "**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 an individual age 60 or older, or to an individual with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction.

(6) "**Grandparent or Other Relative Caregiver**" means a grandparent or step-grandparent of a child, or a relative of a child by blood, marriage or adoption who is younger than19 years of age and for whom all of the following are true:

 (A) Lives with the child

 (B) Is the primary caregiver for the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver

 (C) Has a legal guardianship of the child or is raising the child informally

 (7) "**Information**" means group services, including public education and provision of
 information at health fairs, expositions and other similar events.

(8) “**Outreach**" means interventions for the purpose of identifying potential caregivers and encouraging their use of existing services and benefits.

(9) "**Respite**" means services which offer temporary, substitute supports or living arrangements for persons in need of care in order to provide a brief period of relief or rest for caregivers. Respite care includes the following:

 (A) In-home respite (personal care, homemaker and other in-home services)

 (B) Respite provided at an adult day center or other non-residential program

 (C) Institutional respite provided by placing the care recipient in an institutional setting for an overnight stay on an intermittent, occasional or emergency basis and includes participation in educational events and sports or summer camps for the children of grandparents and other relative caregivers. Respite services may include any of the following:

 (i) "**Personal Care**" means providing personal assistance, stand-by assistance, supervision or cues for people having difficulties with one or more of the following activities of daily living: eating, dressing, bathing, toileting and transferring in and out of bed.

 (ii) "**Homemaker**" means providing assistance to people having difficulty with one or more of the following instrumental activities of daily living: preparing meals, shopping for personal items, managing money, using the telephone or doing light housework.

 (iii) "**Chore**" means providing assistance to people having difficulty with one or more of the following instrumental activities of daily living: heavy housework, yard work or sidewalk maintenance.

 (iv) "**Adult Day Care/Adult Day Health**" means the provision of care for dependent adults in a supervised, protective, congregate setting during some portion of a 24-hour day. Services offered in conjunction with adult day care / adult day health typically include social and recreational activities, training, counseling, meals, and services such as rehabilitation, medications assistance and home health-aide services for adult day health.

(10) "**Severe Disability**"means a severe, chronic disability attributable to mental or physical impairment; or a combination of mental 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” (4)

(11) "**Temporary**" means up to 112 hours of respite in a calendar year. *(This provision is
 waived until the end of 2022 in response to increased needs related to the COVID-19
 pandemic.)*

(12) **“Non-Nursing Home Level of Care”** means functional eligibility for the limited Family Care benefit provided to help coordinate services through an interdisciplinary management team, but which does not offer the full Family Care benefit. (Because the non-nursing home level of care does not provide family caregiver support services, caregivers may receive those supports by enrolling in the AFCSP or the NFCSP.)

(13) "**Supplemental Services**" means services provided on a limited basis to complement the care provided by caregivers. Supplemental Services may include:

 (A) "**Assisted Transportation:**" The provision of assistance, including escort, to a person who has physical or cognitive difficulties using personal or public transportation on their own.

 (B) "**Nutrition Counseling:**" 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 may include options and methods for improving nutritional status performed by a health professional in accordance with state policy.

 (C) "**Transportation:**" The provision of a means of transport for a person from one location to another. This does not include any other activity.

 (D) "**Other:**" Goods and services, other than those listed above, which enable older adults to remain living safely at home. Goods and services may include, but are not limited to, minor home modifications, adaptive aids, assistive technologies, emergency response systems, incontinence supplies and professional visits by a registered nurse, physical therapist or occupational therapist.

11.3 Minimum Service Requirements

There are five required services that must be provided directly by the aging unit or may be purchased through a contract, but Area Agencies on Aging are not allowed to provide direct services. The five minimum service requirements are:

(1) Information to caregivers about available services

(2) Assistance to caregivers in gaining access to services

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

(4) Respite services to enable caregivers to be temporarily relieved from their caregiving responsibilities

(5) Supplemental services, on a limited basis, to complement the care provided by caregivers

 Aging units may use funds for hiring staff to provide the five required services. Staff or subcontractors funded with Title III-E shall work on behalf of family caregivers.

Agencies providing either respite or supplemental services shall assess and record the functional limitations of the person receiving care to determine if they meet the definition of "frail" as outlined in subparagraph (A)(I) or (B) of Section 102(28) of the Older Americans Act. (See Section **11.**(3) of this chapter.)

The Long Term Care Functional Screen, which is used to assess eligibility for publicly funded long-term care programs such as Family Care and IRIS, should not be used to assess or record functional limitations for NFCSP. Instead, use the Caregiver Registration Form located on GWAAR’s [NFCSP technical assistance webpage](https://gwaar.org/national-family-caregiver-support-program).

* 1. Assessment and Reporting Requirements

Federal reporting requirements will be the same as for other Title III-funded services.

The Wisconsin Office on Aging additionally requires agencies that administer the NFCSP and the AFCSP to implement quality control safeguards, which include the following:

1. Conducting a uniform caregiver needs assessment for each program participant

2. Administering a program evaluation that measures participant outcomes over time

3. Distributing and encouraging participation in a state-level customer satisfaction survey

* The caregiver needs assessment is available in English and Spanish on the [Wisconsin Department of Health Services website](https://www.dhs.wisconsin.gov/library/f-02519.htm) and on the [Greater Wisconsin Agency for Aging Resources technical assistance page](https://gwaar.org/national-family-caregiver-support-program).
* The program evaluation survey tool is available in English and Spanish from the DHS Forms Library or on the [Greater Wisconsin Agency for Aging Resources technical assistance page](https://gwaar.org/national-family-caregiver-support-program).
* The DHS customer satisfaction survey may be completed online using [this link](https://www.surveygizmo.com/s3/4129124/AFCSP-2018-Customer-Satisfcation-Survey) or printable surveys can be downloaded in English and Spanish from the [DHS Forms Library](https://www.dhs.wisconsin.gov/library/f-02331.htm). Self-addressed stamped envelopes to return paper surveys are available from the Bureau of Aging and Disability Resources office in Madison.
	1. Coordination of Services
1. It is the intent of the Older Americans Act 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 Older Americans Act (NFCSP) and the Wisconsin Alzheimer’s Family Caregiver Support Program (AFCSP) be administered by the same agency. At a minimum, close coordination of these two programs and coordination with local Dementia Care Specialists are essential to maximize the dollars available to serve family caregivers and to avoid duplication of services.

Additional information about the Wisconsin Alzheimer’s Family Caregiver Support Program can be found under Section 11.15 of this chapter.

1. To ensure coordination of caregiver services in the county and with tribes, the aging unit shall convene or be a member of a local family-caregiver coalition or coordinating committee with other local providers who currently provide support services to family caregivers. The aging unit shall coordinate the activities under this program with other community agencies and voluntary organizations providing services to caregivers.
2. Funding under this program allows aging units an opportunity to advocate with other provider agencies about expanding and enhancing existing services in order to better meet the needs of family caregivers. Every effort must be made to integrate or closely coordinate the National Family Caregiver Support Program and the Wisconsin Alzheimer's Family and Caregiver Support Program, preferably with other Title III and Tribal Title VI programs.
3. When there is a concern about the use of limited resources for respite and supplemental services, aging units 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 should be in writing and applied uniformly for all program participants.
4. Aging units may contract for all or part of the services required under the AFCSP or NFCSP. If the aging unit contracts for caregiver support services, formal contracts should 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:
5. The contract agency can demonstrate interagency coordination.
6. The contract agency has in place a mechanism for identifying and prioritizing individuals with the greatest social and economic need.
7. The contract agency has the capacity to collect necessary data to demonstrate that persons receiving direct services under Section **11.3**(4) and Section **11.3**(5) meet the eligibility criteria in Section **11.**(3).
8. The contract agency has a procedure in place to record, report and manage generated program income.

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

11.6 Maintenance-of-Effort: Non-Supplanting

The intent of the maintenance-of-effort provision under Section 374 of the Older Americans Act is for Title‑III E funds to be spent in addition to, and not supplant, any other federal, state or local government funds (including an area agency on aging) currently being used to provide services to caregivers as described in OAA Section 373. Maintenance-of-effort provision shall be met with monetary funding, not in-kind contributions.

The maintenance-of-effort date, for purposes of this program, is any funding used to support caregivers as of November 12, 2000, for services described under "Minimum Requirements for Services," Section **11.3** of this policy manual.

11.7 Restrictions on Use of Funding

(1) To be eligible to receive respite care and supplemental services, family caregivers must be providing in-home care to older individuals who meet the definition of "frail" as outlined in subparagraph (A)(I) or (B) of Section 102(28) of the Older Americans Act, as follows:

"The term "frail" means that the older individual is determined to be functionally impaired because:

 a) he/she is unable to perform at least two Activities of Daily Living (ADLs) or Independent Activities of Daily Living (IADLs) without substantial human assistance, including verbal reminding, physical cueing or supervision; or

 b) due to cognitive or mental impairment, the individual requires substantial supervision due to behavior that poses a serious health or safety hazard to the individual or another.

(2) Caregivers may not be enrolled in the AFCSP and NFCSP at the same time. However, caregivers of individuals with dementia who qualify for the AFCSP are allowed to utilize both programs at different times during a calendar year if a needs assessment determines that the caregiver has exhausted supports available to them through the program in which they initially enrolled.

(3) Funding shall not be used to cover day-to-day operating expenses of adult day facilities.
All NFCSP service payments must be associated with a caregiver’s individual respite, except for payments allowed to support the limited-time expansion or development of new community programming or services.

(4) Funding shall not 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 receiving Family Care’s non-nursing home level of care benefit who do not have access to caregiver supports as part of their benefit.

(5) Funding shall not be used to pay residential fees or provide caregiver respite for persons residing in an assisted living facility, CBRF, RCAC or other non-home setting. However, NFCSP and AFCSP may be used to help the caregivers of such persons provide needed 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 caregiver counseling and education.

(6) Home modifications and repairs cannot exceed $5,000 per calendar year.

11.8 Distribution of Funds

Distribution of these funds will be under the current Title III intrastate funding formula.

11.9 Waivers

In an emergency situation, an administering agency may request a waiver to exceed respite limits defined as "temporary" and "on a limited basis." This waiver request must be in writing to the Area Agency on Aging or State Aging Unit. In requesting a waiver, the administering agency shall demonstrate that the situation is an emergency threatening the health or safety of an individual, and that no other source of funds is available to provide necessary services. The Area Agency on Aging or State Aging Unit may grant a waiver to exceed established limitations on a case-by-case basis.

11.10 Required Match

NFCSP requires a 25 percent local match of non-federal dollars. 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 match funding must be reported in SAMS under Title III-E along with services provided using federal funds. Wisconsin Alzheimer's Family and Caregiver Support Program (AFCSP) funding, which is state general purpose revenue (GPR), may be used to meet the federal match requirement.

11.11 Fees and Donations

There will be no cost-share requirement or fee charged to caregiver program participants. Participants may voluntarily donate toward the cost of services provided if they choose. Older-Americans-Act requirements for program income shall apply to Title‑III E (NFCSP) donations.

If a state-funded AFCSP participant chooses to make a voluntary donation to the Older Americans Act Title III-C Elder Nutrition Program for dining or home-delivered meals, a [Form-02425](https://www.dhs.wisconsin.gov/forms/f02425.docx) signed by the AFCSP participant allows the program to reimburse for funds donated toward the cost of meals on the participant’s behalf. AFCSP participants must be made aware that their meal program donation 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 and meal donations should be provided to the AFCSP participant’s 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.

11.12 Staff Training and Development

Staff training and development associated with the duties of NFCSP 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.

11.13 Plan Requirements

Family caregiver support services shall be a priority in local aging unit plans and include a detailed explanation for the proposed use of Title III-E funds.

Area Agencies on Aging will provide technical assistance to local and tribal aging units on how to develop caregiver support programs and establish program goals.

11.14 Tribal Aging Units

Tribal Aging Units 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 of Community Living. Therefore. tribes do not receive a state allocation for NFCSP.

Tribes do receive a state allocation for the AFCSP based upon the state’s population-based formula.

11.15 Wisconsin Alzheimer’s Family Caregiver Support Program
 (AFCSP)

(1) Wisconsin Chapter DHS 68 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 funds for the provision of service payments, goods and services to persons with dementia and to their caregivers. The payments, goods and services provided in accordance with this chapter are intended to help make available a diverse array of community services directed at preventing or delaying institutionalization of persons who have dementia and enhancing the quality of their lives, and to provide assistance to family members and others who take care of persons with dementia without compensation.

Policies and procedures for administering the AFCSP are outlined in [Chapter DHS 68 Support for Persons with Dementia and Their Caregivers.](https://docs.legis.wisconsin.gov/code/admin_code/dhs/030/68)

**(2)** As of February 1, 2019, Medicaid-eligible individuals are no longer required to access caregiver supports through a long term care program. Any person who meets the AFCSP income requirements and has received a diagnosis of Alzheimer’s disease, other dementia or a non-reversible condition meeting the definitions in DHS 68 may choose to enroll in the Wisconsin AFCSP.

**(3)** At least 40 percent of county AFCSP expenditures must be spent providing respite to caregivers. AFCSP respite may include transportation costs, adaptive equipment and technology, and expenses related to keeping caregivers socially engaged with others during periods of temporary respite.

Tribes are exempt from the 40% respite requirement.

 **(3) Reporting Requirements**

Agencies administering the Wisconsin Alzheimer’s and Family Caregiver Support Program (AFCSP) are required to submit an annual budget and an annual fiscal report to the DHS Office on Aging in order to receive funding. In addition, agencies are required to implement quality control safeguards, which include the following:

1. Conducting a uniform caregiver needs assessment for each program participant

2. Administering a program evaluation that measures participant outcomes over time

3. Distributing and encouraging participation in a state-level customer satisfaction survey

* The caregiver needs assessment is available in English and Spanish on the [Wisconsin Department of Health Services website](https://www.dhs.wisconsin.gov/library/f-02519.htm) and on the [Greater Wisconsin Agency for Aging Resources technical assistance page](https://gwaar.org/alzheimers-family-caregiver-support-program).
* The program evaluation survey tool is available in English and Spanish from the DHS Forms Library or on the [Greater Wisconsin Agency for Aging Resources technical assistance page](https://gwaar.org/alzheimers-family-caregiver-support-program).
* AFCSP and NFCSP participants may complete the DHS customer satisfaction survey online using [this link](https://www.surveygizmo.com/s3/4129124/AFCSP-2018-Customer-Satisfcation-Survey) or paper versions can be downloaded from the [DHS Forms Library](https://www.dhs.wisconsin.gov/library/f-02331.htm). Self-addressed stamped envelopes to return paper surveys are available from the Bureau of Aging and Disability Resources office in Madison.