

National Family Caregiver Support Program (NFCSP) Aging Policy Manual

I. Purpose and Legislation

Title III, Section 316 of the Older Americans Act creates the National Family Caregiver Support Program (NFCSP) (Title III-E). In Wisconsin, services are to be provided by or contracted through the local aging unit. The program provides for multifaceted systems of support services for the following:

(1) Family Caregivers

Priority is to be given to the following:

- family caregivers of people who have been diagnosed with Alzheimer's disease and other dementia, including persons below 60 years of age with Alzheimer's disease
- family caregivers who are older individuals caring for people, including children with severe disabilities
- family caregivers who are older individuals with greatest social and economic needs

(2) Grandparents or older individuals that are relative caregivers of children under 19 years of age

(3) Grandparent or relative caregivers providing care for adult children with a disability who are between 19 and 59 years of age

These caregivers must be age 55 years of age and older and cannot be the child's parent(s). Services provided to these caregivers shall not be counted against the 10 percent ceiling for grandparents and other caregivers.

Priority is to be given to family caregivers providing care for an adult child with severe disabilities.

The intent of the program is to provide information, support and assistance to family caregivers. No more than 20 percent of this funding may be used to provide supplemental direct services to the individual needing care. Temporary respite is not included in the 20 percent for direct services. By definition, temporary respite cannot be provided on an ongoing basis.

Wisconsin's Alzheimer's Family and Caregiver Support Program (AFCSP) is one of the programs used as a model for the NFCSP. It is the intent of the Older Americans Act that information and services are provided to family caregivers in a direct and helpful manner. It is, therefore, in the best interest of family caregivers that Title III-E and

AFCSP both be administered by the same agency. At a minimum, coordination of these two programs is essential to maximize the dollars available for family caregivers and to avoid duplication of services.

II. Definitions

- (1) "Child" means an individual who is not more than 18 years of age or who is an individual with a disability.
- (2) "Family Caregiver" means an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual or to an individual with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction. (A minimum of 90 percent of the county's NFCSP allocation shall be spent serving family caregivers.)
- (3) "Grandparent or Older Individual who is a Relative Caregiver" means a grandparent or step-grandparent of a child, or a relative of a child by blood, marriage, or adoption who is 55 years of age or older and for whom all of the following are true:
 - (A) lives with the child
 - (B) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child
 - (C) has a legal relationship to the child, as such legal custody or guardianship, or is raising the child informally
 (A maximum of 10 percent of the county's NFCSP allocation may be spent serving older relative caregivers.)
- (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) "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 above.

- (6) "Information" means group services, including public education, provision of information at health fairs, expositions and other similar events.
- (7) "Outreach" means interventions for the purpose of identifying potential caregivers and encouraging their use of existing services and benefits.
- (8) "Assistance" means one-on-one contact to provide one of the following:
 - "Information and Assistance" means a service that provides current information on opportunities and services available; assesses the problems and capacities of the individuals; links the individuals 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 the opportunities available to them.
 - (A) "Case Management" means assistance either in the form of access or care coordination in circumstances where the older person or their caregivers are experiencing diminished functioning capacities, personal conditions or other characteristics which require the provision of services by formal service providers. Activities of case management include the following as required: assessing needs, developing care plans, authorizing services, arranging services, coordinating the provision of services among providers, follow-up, and reassessment.
- (9) "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.
- (10) "Respite" means services which offer temporary, substitute supports or living arrangements for care recipients 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 respite)
 - (B) respite provided by attendance of the care recipient at an adult day center or other nonresidential 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, including summer camps for grandparents/relatives caring for children, including 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, and counseling, meals for adult day care, and services such as rehabilitation, medications assistance and home health-aide services for adult day health.

Agencies providing either respite or supportive services shall use a functional screen document that is able to capture the required information.

- (1) "Temporary" means up to 112 hours (14 days x 8 hours) for any and all respite services provided in a calendar year.
- (2) "Limited Basis" means not more than once per week (or a total of eight hours per week).
- (3) "Supplemental Services" means services provided on a limited basis to complement the care provided by caregivers, as follows:
 - (A) "Nutrition Counseling" 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 may include options and methods for improving nutritional status performed by a health professional in accordance with state policy.
 - (B) "Assisted Transportation" means the provision of assistance, including escort, to a person who has difficulties (physical or cognitive) using regular vehicular transportation.
 - (C) "Transportation" means the provision of a means of transportation for a person from one location to another. This does not include any other activity.
 - (D) "Other" means all services other than those listed above, but not limited to, home modifications, adaptive aids, assistive technologies, emergency response systems, incontinence supplies or professional visits by an RN, PT or OT.

Agencies providing either respite or supportive services shall use a functional screen document that is able to capture

the required information.

III. Minimum Service Requirements

The services may be provided directly by the aging unit or may be purchased through a contract and shall include all five of the minimum requirements for services, as follows:

- (1) information to caregivers about available services
- (2) assistance to caregivers in gaining access to the services
- (3) individual counseling, organization of support groups, and training to caregivers to assist in making decisions and solving problems relating to their caregiver roles
- (4) respite care 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. *These services are not to exceed 20 percent of the county expenditure.* Aging units may use funds for hiring staff to provide the five services to caregivers. Staff or subcontractors funded with these resources shall work on behalf of family caregivers.

IV. Coordination of Services

To ensure coordination of caregiver services in the county, 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. Funding under this program gives 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 Alzheimer's Family and Caregiver Support Program, preferably with other Title-III programs.

When there is a concern over the use of limited resources for respite care and supplemental services, aging units may, with the advice and consultation of their controlling committee and/or a coordinating committee or coalition of family caregivers, further limit the amount of services provided to an individual caregiver. This local policy decision should be in writing and applied uniformly for all caregivers.

Aging units may contract for all or part of the services required under the NFCSP. If the aging unit contracts for caregiver-support services, formal contracts should be used which meet the contract requirements found in Contract Administration and Fiscal Management of this manual, which ensure all of the following:

- (1) The contract agency can demonstrate interagency coordination.
- (2) The contract agency has in place a mechanism for targeting individuals in the greatest social and economic need.
- (3) The contract agency has the capacity to collect necessary data to demonstrate that persons receiving direct services.
- (4) The contract agency has a procedure in place to report and manage generated program income.

In instances where the aging unit contracts for all or part of the services, they must still ensure that all five of the minimum requirements for services are met, either by a single contract or a combination of direct-service provision and contracts.

V. 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 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 by money, not in-kind.)

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".

VI. Restrictions on Use of Funding

- (1) No more than 10 percent of this funding may be used to support grandparents (55+) and older individuals who are relative caregivers providing care for their grandchildren/children (under 19 years of age).
- (2) No more than 20 percent of this funding may be used for supplemental services.
- (3) To be eligible to receive respite care and supplemental services, family caregivers must be providing in-home

and community care to older individuals who meet the following 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 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."

Agencies providing either respite or supportive services shall use a functional screen document that is able to capture the required information.

NOTE: The functional screen provision does not apply to grandparents or other older individuals who are relative caregivers of children not more than 19 years of age and who are requesting respite care and/or supplemental services.

- (4) Priority shall be given to individuals who are currently *not* receiving caregiver- support services under the Wisconsin Alzheimer's Family and Caregiver Support Program (AFCSP).
- (5) Funding shall not be used to provide adult day care on a regular, ongoing basis.
- (6) Funding shall not be used to provide respite or day-care services for individuals currently receiving other home and community-based services funding (COP, Family Care, etc.) which can pay for respite and day care.

VII. Distribution of Funds

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

VIII. Waiver

In an emergency situation, an aging unit may request a waiver to exceed the timelimits as defined by "temporary" and "limited basis." This waiver request must be in writing to the area agency on aging. In requesting a waiver, the aging unit shall demonstrate that no other source of funds is available to provide the necessary services. The area

agency on aging may grant a waiver to an aging unit to exceed the limitations of temporary or limited services on a case-by-case basis.

IX. Outcomes Measures/Reporting Requirements

Reporting requirements will be the same as for other Title III funded services and reporting formats.

X. Required Match

This program requires a match of 25 percent non-federal dollars. State and local funding not currently used to match other programs may be used as match. The state Alzheimer's Family and Caregiver Support Program (AFCSP) money may be used as match to this program. Match may also be in the form of in-kind.

XI. Cost Share/Program Income

There will be no cost-share provision for caregiver programs; participants may donate toward the cost of services provided. Older-Americans-Act requirements for program income shall apply to Title-III-E donations.

XII. Staff Training and Development

Staff training and development is an allowable cost. This may include the cost of training (registration, mileage, meals and lodging), purchase of training materials and resources.

XIII. Plan Requirements

Aging units will be required to include caregiver services in their county plan indicating the proposed use of Title III-E funds. Area agencies on aging will be expected to provide technical assistance to aging units on how to develop caregiver- support programs. Aging units will be expected to demonstrate how they coordinate their efforts with other provider agencies that also serve family caregivers.

This will be a program priority in aging plans. Area agencies on aging and aging units should plan accordingly.

XIV. Tribal Aging Units

Tribal Aging Units will be eligible to receive caregiver program money under Part C of Title VI the Native American Caregiver Support Program.