

COMMONWEALTH OF PENNSYLVANIA
Department of Aging

DATE: March 4, 2010

TO: Area Agency on Aging Directors
Executive Staff of Aging/OLTL

FROM: John Michael Hall
Secretary



SUBJECT: Summary of changes to APD #10-01-02 Family Caregiver Support Program

The purpose of this memo is to transmit the revised APD #10-01-02, Family Caregiver Support Program. Changes to the APD were made based on changes contained in the reauthorization of the Older Americans Act and input received from the Area Agencies on Aging.

For your convenience, we have summarized the major changes contained in the APD. They are:

- A new group of caregivers may now be considered for eligibility to the program. Caregivers age 55 or older providing care to adult relatives with disabilities who are between 19 and 59 years of age can now be served. The caregiver cannot be the care receiver's parent. The caregiver and care receiver must live together. To determine eligibility for the new group of caregivers, complete the LOCA and CMI for the care receiver and indicate that the care receiver has a score of 3 or more in at least 2 activities of daily living. (Refer to Section 20.1 – Significant requirements and provisions in the Federal FCSP Act: Section 20.21 – Eligibility for Program Benefits; and Section 20.32 – Assessment and Care Management.)
- The age for caregivers in the Grand parenting Program has been reduced from Age 60 to 55. (Refer to Section 20.1 – Significant requirements and provisions in the Federal FCSP Act and Section 20.51 – Grand Parenting Program - General Provisions.)

- Priority for service should be given to:
 - Caregivers of older individuals with dementia;
 - Older caregivers with greatest economic and social need;
 - Older caregivers providing care for an adult with severe disabilities; and
 - In the Grandparenting Program, priority must be given to caregivers providing care to children with severe disabilities and to older caregivers with greatest social and economic need

(Refer to Section 20.1 – Significant requirements and provisions in the Federal FCSP Act; Section 20.32 – Assessment and Care Management; and Section 20.51 – Grandparenting Program – General Provisions.)

Note: Care Managers should continue to use the Functional Needs Measurement (FNM) score to determine priority for service.

Additional APD Changes Impacting the State and Federal Programs:

- The paragraph on mandatory enrollment has been deleted. The policy on mandatory enrollment will be clarified in an upcoming Office of Long-Term Living Bulletin. (Refer to Section 20.21 – Eligibility for Program Benefits.)
- In the definitions section, the policy clarification on FCSP date March 2, 2009 has been added to the definition of functionally dependent. (Refer to Section 20.2 – Definitions.)

Thank you for your continued cooperation and support. If you have any questions or comments please contact me or Patricia Clark at (717) 425-5115 or patrclark@state.pa.us

Attachment

this chapter, and caregivers and carereceivers who receive benefits of the Program.

The FCSP is designed to assist family and other unpaid adult primary caregivers caring for functionally dependent older persons and adult relatives with chronic dementia. The program's goal is to reduce caregiver stress and burden through benefits and resource counseling, access to support groups, care giving skills training and education, support and financial reimbursement for expenses incurred in purchasing caregiving related services (including respite), supplies, durable goods, home modifications and assistive technology. Reimbursement benefits are subject to cost sharing. A standardized scale, based on household income and household size where the carereceiver resides, is used to determine the amount of the consumer cost sharing. **(See Appendix – FCSP Cost Sharing Guide).**

The FCSP, consumer-driven and flexible, is meant to support the primary caregiver and family in ways that are specific to their individual needs and preferences. An expense can be approved for reimbursement if it is clearly justified in the case record as a legitimate caregiving supply, good and/or service that is needed in the particular case in question. It allows a range of options for respite care to meet the individual needs of each consumer (i.e. hiring a neighbor or friend rather than a staff person from an agency to provide the service).

In addition to the Regulations, the FCSP is governed by both the Pennsylvania Statute (62 P.S. 3061-3068) and Federal Law (Older Americans Act, As Amended in 2006: Title III (E), (National Family Caregiver Support Act, Subpart 1, Caregiver Support Program, Sections 371-374). **(See Appendix – FCSP – Part E – National FCSP).**

Significant requirements and provisions in the Pennsylvania FCSP statute:

- Functionally dependent older carereceiver must be 60 years of age or older and have one (1) or more activities of daily living (ADL) deficiencies (score of three or higher on the Level of Care Assessment (LOCA), meaning at least needing supervision, set-up, cueing or coaxing to perform the ADL).
- The statute is silent on the age of primary caregiver. Since there is no reference to children as caregivers and the responsibilities assigned to the primary caregiver clearly require the judgment of an adult, PDA has established a minimum age of 18 for primary caregivers.
- Primary caregiver and carereceiver must be related and live in the same household.
- Serves adult carereceivers with chronic dementia such as Alzheimer's disease regardless of age, in addition to over age 60 functionally dependent persons.

Significant requirements and provisions in the Federal FCSP Act

- Functionally dependent older carereceiver must be 60 years of age or older and have two (2) or more ADL deficiencies (score of 3 or higher on LOCA, meaning at least needing supervision, set-up curing or coaxing to perform the ADL).
- Statute requires that the primary caregiver be an adult and PDA has defined an adult as a person age 18 or older.
- No requirement for primary caregiver and older carereceiver (age 60 and older) to be related or live in the same household.
- Effective with the October 2006 re-authorization of the Older American Act, grandparents or relative caregivers, providing care for adult relatives with disabilities, who are between 19 and 59 years of age, can now be served under the NFCSP. These caregivers must be age 55 years and older and cannot be the carereceiver's parent. Priority shall be given to those older caregivers providing care for an adult with severe disabilities. Services provided to these caregivers shall not be counted against the 10% ceiling for services to support grandparents and other caregivers of children age 18 or younger.
- Under the provisions of the Grandparenting Program, up to 10% of Federal FCSP funds may be spent on services for older (age 55 and above) related primary caregivers of children age 18 or younger, living in the same household. Priority must be given to those older related primary caregivers of children with severe disabilities.
- Effective with the 2006 re-authorization of the Older American Act, caregivers of older individuals with dementia or related disorders are to receive priority for service, as are older caregivers with greatest economic and social need, and older individuals who care for persons of any age with severe disabilities.
- The 2006 re-authorization also mandates that AAAs make use of trained volunteers to expand the provision of available services, including:
 - 1) information to caregivers about available services;
 - 2) assistance to caregivers in gaining access to services;
 - 3) individual counseling, organization of support groups, and caregiver training to assist the caregivers in the areas of health, nutrition, and financial literacy, and in making decisions and solving problems relating to their caregiving roles;
 - 4) respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
 - 5) supplemental services, on a limited basis, to complement the care provided by caregivers.

It further encourages AAAs to work with established volunteer organizations such as organizations carrying out Federal service programs administered by the Corporation for National and Community Service.

(See Appendix for a FCSP Comparison Chart, which provides a side-by-side view of the State, Federal and Combined FCSP Programs.)

SECTION 20.2 DEFINITIONS

Family Caregiver Support Program (FCSP): Unless otherwise specified in this directive, the term FCSP includes both the State and Federal programs.

All definitions contained in Section 20.2 of the Regulations apply to the Federal and State FCSP **with the exception of the last sentence of the definition of “OPTIONS”, which is obsolete.** Updated terminology can be found in Section 20.22 of this directive.

Act – *The Family Caregiver Support Act (62 P.S. §§3061-3068)*

Area Agency on Aging – *the local agency designated by the Department within each planning and service area to administer the delivery of a comprehensive and coordinated plan of social and other services and activities in the planning and service area.*

Assistive devices – *Nondisposable personal devices, as distinguished from modification to a home, that are usable to assist the carereceiver, or the caregiver on the carereceiver’s behalf, to carry out an activity of daily living and, thereby, reduce the caregiver’s burden.*

Benefits counseling – *A service that provides family caregivers with an individual, comprehensive review of their caregiving situations to identify appropriate resources available and to assist caregivers to access these resources.*

Caregiver education or caregiver training – *Services that provide instruction or training to family caregivers, in groups or individually, in general and specific information or skills required in the care of functionally impaired older persons.*

Carereceiver – *A functionally dependent older adult or other adult with chronic dementia such as Alzheimer’s Disease who is being cared for by a relative who lives in the same residence.*

Clarification: Under the Federal FCSP adults below the age of 60 are eligible to be carereceivers if they have a disability, with priority given to carereceivers with severe disabilities. Additionally, under the provisions of the Federal FCSP’s Grandparenting Program, carereceivers are defined as relatives age 18 or under, with priority given to those children with

severe disabilities. Among older carereceivers, priority is to be given to carereceivers with Alzheimer's disease and related disorders.

Under Federal FCSP, "disability" is defined as a disability attributable to mental or physical impairment, or a combination of mental and physical impairments, that results in substantial functional limitations in 1 or more of the following areas of major life activity: A) self care, B) receptive and expressive language, C) learning, D) mobility, E) self-direction, F) capacity for independent living, G) economic self-sufficiency, H) cognitive functioning, and I) emotional adjustment.

Under Federal FCSP, "severe disability" is defined as a severe, chronic disability attributable to mental or physical impairment, or a combination of mental and physical impairments, that is likely to continue indefinitely; and results in substantial functional limitation in 3 or more of the major life activities A) through I) specified in the definition of disability.

Chronic dementia – *An irreversible global loss of cognitive function causing evident intellectual impairment which always includes memory loss, without alteration to state of consciousness as diagnosed by a physician and which is severe enough to interfere with work or social activities, or both, and to require continuous care or supervision.*

Consumable supplies – *Expendable items needed on an ongoing basis to provide care to a carereceiver. Consumable supplies do not include prescription drugs.*

Clarification: In response to numerous questions regarding this definition, the Department has adopted the following elaboration upon the regulatory definition of consumable supplies: Supplies that are routine consumable household supplies, such as tissues or toilet paper, are not included in this definition unless a medical condition warrants abnormally high use of such a product. In such a case, the additional supplies required by the medical condition may be paid for by the FCSP.

Continuous supervision - *Uninterrupted care which does not preclude brief periods when the carereceiver may be left alone, if appropriate and consistent with the care plan*

Department - *The Department of Aging of the Commonwealth*

Functionally dependent - *Requiring enough assistance with one or more activities of daily living to be deemed by the area agency on aging, under this chapter, to require continuous care or supervision. Limitations contributing to the functional dependency may include physical or cognitive impairments.*

Clarification: Implied in the definition is "requiring enough assistance with one or more activities of daily living to be deemed by the area agency on aging, under this chapter, to require continuous care or supervision..." **to perform the activities of daily living.** This is consistent with Section

20.1 of the APD under Significant Requirements and Provisions where supervision relates to performance of the activity of daily living.

The definition sets the requirement of continuous care or supervision. It does not; however, set the requirement for continuous care and supervision, nor does it imply that the individual must be in need of constant 24-hour supervision in order to be considered functionally dependent. Applying the criteria of constant 24-hour supervision would be too restrictive and as such would severely limit participation in the program.

Home modifications - *Reasonable modifications, approved under this chapter, to the structure of a home for the purpose of reducing caregiver burden. The term does not include repairs.*

Clarification: In response to numerous questions regarding this definition, the exclusion of home repairs from the definition of home modifications, has the effect of precluding the use of FCSP funds for home repairs, because nowhere else in the law or regulations are such expenditures authorized. It should be emphasized that a repair or enhancement to a home modification is considered a home modification, not a home repair, and is therefore allowable.

Household – *Persons who occupy the same residence.*

Household income – *The income of all members of a household with the exception of a minor or dependent student.*

Income – *Income, from whatever source derived, as specified in §20.23 (relating to income).*

OPTIONS - *A program operated by the Department for persons who need long term care because they are functionally disabled. The program provides a continuum of assessment, care management and services, which may make it possible for a functionally disabled person to be maintained in the community as an alternative to institutional placement. [Each of these three functions under OPTIONS—assessment, care management and services—is divided into Level I or Level II based on the intensity and complexity of need.]*

Clarification: As explained in the preamble of this section, the last sentence in the above definition is obsolete.

Older Adult or older person or older relative – *A person who is 60 years of age or older, and who is a relative of the caregiver.*

Ongoing caregiving expenses – *The costs of respite care and other supportive services or consumable supplies, which are directly related to the provision of care to the older relative.*

Clarification: In the case of the Grandparenting provisions for the Federal FCSP, the care is to the relative in the same household who is 18 years of age or younger.

Other adult – *A person 18 years of age or older residing within this Commonwealth who is suffering from a chronic dementia such as Alzheimer's Disease.*

Other supportive services - *Services other than respite care services that are directly related and necessary to the care being provided to the carereceiver and which are noted in the client's care plan. These services may include the following:*

- (i) *Personal care skills training and other caregiver education services not available directly from the Program.*
- (ii) *Counseling under a certified counseling or mental health agency.*
- (iii) *Legal and financial counseling necessary to manage the affairs of the carereceiver.*
- (iv) *Specialized transportation services.*

Planning and service area - *The geographic unit within this Commonwealth, as designated by the Secretary, for the allocation of funds for the delivery of social services to older persons residing in that unit.*

Poverty level - *The income level indicated in the Federal Poverty Income Guidelines developed, annually updated and published in the Federal Register by the United States Department of Health and Human Services.*

Primary caregiver - *The one identified relative who has assumed the primary responsibility for the provision of care needed to maintain the physical or mental health of a functionally dependent older adult or other adult suffering from chronic dementia such as Alzheimer's Disease, who lives in the same residence with the individual on a continuous basis and does not receive financial compensation for the care provided.*

Clarification: The Federal FCSP does not require the caregiver to live with, or be related to, the carereceiver if the carereceiver is 60 years of age or older. The minimum age for caregivers of children or related adults below the age of 60 with disabilities is 55. In addition to the Federal FCSP priorities clarified under the definition of "Carereceiver" above, priority is to be given to older caregivers with greatest social and economic need (with particular attention to low-income older individual). Additionally, older individuals providing care to individuals (including children) with severe disabilities are to receive priority.

Program – *The FCSP*

Relative - A spouse or parent; child; stepparent; stepchild; grandparent; grandchild; brother; sister; half-brother; half-sister; aunt; great aunt; uncle; great uncle; niece; or nephew, by blood, marriage or adoption.

Respite care service - A regular, intermittent or emergency service which provides the primary caregiver of a functionally dependent older adult or other adult suffering from a chronic dementia such as Alzheimer's Disease with relief from normal caregiving duties and responsibilities.

Same residence – A house, apartment, mobile home, group of rooms, or single room, occupied as separate living quarters.

Clarification: People who live in separate, unconnected apartments in the same building are not considered to be living in the same residence.

Secretary – The Secretary of the Department.

SECTION 20.3 BACKGROUND

The Family Caregiver Support Program was established in 1987 as a demonstration program to provide support to unpaid primary caregivers of family members who lived with them. In 1991, the program was expanded statewide, financed through Pennsylvania's General Fund.

The program proved to be very beneficial and popular. However, it was learned that intense caregiving relationships exist where the caregiver and carereceiver do not live together, and/or are not related by blood, marriage or adoption. It also became clear that while the \$200 monthly benefit ceiling was just enough to ease the caregiving burden in many cases, some caregivers needed additional assistance.

In the year 2000, the National Family Caregiver Support Program was established, using Federal Older Americans Act funds, and subsequently amended in October of 2006. This program contained clear program eligibility guidelines, but the development of program structure was left to the individual states. In Pennsylvania, it was decided to use the state program rules for the Federal program as well, with three significant changes:

- 1) The Caregiver did not have to live with the carereceiver.
- 2) The Caregiver did not have to be related to the carereceiver.
- 3) In individual cases where the need is specifically documented, the maximum FCSP benefit could be as high as \$500, as long as the Area Agency on Aging's average benefit did not exceed \$300 across its entire FCSP caseload.

Changes #1 and #2 above were never intended to dilute the caregiving relationship required for participation in the program. The program was never intended to support "long-distance caregivers" or people whose role was limited

to occasional care or informal care management. The intent of the program has always been and still remains to support people who are providing the majority of the hands-on care, even after the FCSP has been introduced into the relationship.

Change #3 above was never intended to raise the standard FCSP benefit from \$200 to \$300 or \$500. The standard benefit remains \$200. In individual cases it can go as high as \$500 with appropriate documentation. The \$300 cap has no application to individual cases. It was established to ensure that introduction of the Federal FCSP funds resulted in more people receiving service, in addition to certain individuals receiving more service.

PROGRAM ADMINISTRATION

SECTION 20.11 Administrative Functions and Responsibilities of the Department

The Language contained in Section 20.11 of the Regulations applies to both the State and Federal FCSP.

(a) The Department will administer the Program under contract with area agencies on aging.

(b) In the administration of the Program, the Department's functions and responsibilities include the following:

(1) The review and approval of annual Program plans submitted by area agencies on aging under §20.12 (relating to administrative functions and responsibilities of area agencies on aging).

(2) The allocation to area agencies on aging of funds appropriated for the provision of services and benefits under this chapter.

(3) The establishment and maintenance of minimum standards for the operation of the Program and the provision of services and benefits under this chapter.

(4) The development and maintenance of fiscal and service data collection forms and procedures for collecting information on families served and services and benefits provided.

(5) The monitoring of local Programs for compliance with this chapter and approved area agency on aging Program plans.

SECTION 20.12 Administrative functions and responsibilities of area agencies on aging

The Language contained in Section 20.12 of the Regulations applies to both the State and Federal FCSP.

a) General.

- (1) *Each area agency on aging shall administer a Program under this chapter in its planning and service area.*
 - (2) *In the administration of the Program, the functions and responsibilities of the area agency on aging shall include the following:*
 - (i) *The development and submission of a Program plan under subsection (b).*
 - (ii) *The coordination of service development and delivery under this chapter with other appropriate agencies and organizations in the community, with special efforts to develop and maintain an effective network of local support for family caregivers.*
 - (iii) *The collection and submission to the Department of Program and fiscal information on families served, and services and benefits provided, on forms provided by the Department.*
- b) Program plans. Each area agency on aging shall submit annually a plan, which includes the following information:*
- (1) *An organizational chart, which illustrates the staffing, and flow of decision making for the Program.*
 - (2) *A discussion of how the agency will assign casework staff to the Program to achieve and maintain the consistency required under §20.32 (relating to assessment and care management).*
 - (3) *A training plan, which describes special training for staff persons to be assigned to the project.*
 - (4) *A description of the procedures to be used for reimbursing caregivers.*
 - (5) *A description of area agency on aging strategies for the strengthening or developing of a local network of family caregiver resources. At a minimum, an area agency on aging shall form and utilize an inter-organizational advisory or oversight committee to establish or enhance a local network of caregiver resources. This committee may be an adjunct of the area agency on aging advisory council. The use of network models that involve local voluntary groups, churches, health care organizations active in the areas of Alzheimer's Disease, support groups for family caregivers and other similar organizations is strongly encouraged.*
 - (6) *An explanation of how the area agency on aging will assure that all ethnic groups and economic levels of the community are effectively reached by the Program.*

(7) A description of strategies for carrying out caregiver education so that different kinds of caregiver education needs are effectively met. Caregiver education shall involve, to the extent possible, the participation of existing community resources. These efforts may include support groups if appropriate.

(8) A 12-month operating budget on a form provided by the Department.

(c) Program compliance. Failure of an area agency on aging to comply with corrective action requirements resulting from the Department's compliance monitoring shall lead to sanctions imposed by the Department when, after discussion, the area agency on aging and the Department are unable to reach a mutually satisfactory resolution of the noncompliance issue.

CAREGIVER PARTICIPATION

SECTION 20.21 Eligibility for Program Benefits

For the purposes of the FCSP, primary caregiver is defined as the one identified person who has assumed the primary responsibility for the provision of continuous care needed to maintain the physical and mental health of the carereceiver. In addition, the primary caregiver provides daily, hands-on personal assistance and supervision (even after FCSP services begin) and receives no personal financial compensation for care provided.

The Federal FCSP does not require that the carereceiver and caregiver live together or be related, except in cases where the carereceiver is below the age of sixty. Otherwise, there can be no dilution of the required intensity of the caregiving relationship, as described in the above paragraph, when using Federal FCSP funds. Specifically, "long distance" caregivers and people whose roles are limited to arranging or managing care are not permitted to be primary caregivers in either the State or Federal FCSP.

The provisions of §20.21 of the Regulations allowing services to persons under the age of 60 with chronic dementia do not apply to the Federal FCSP as stated in the Regulations. Instead, the Federal FCSP allows services to caregivers of persons below the age of 60 if they have a disability (which could be caused by Alzheimer's disease or related disorders or any other cause), with priority given to older caregivers of persons with severe disabilities.

As stated in paragraph two of this section, the requirements in the Regulations that the primary caregiver and carereceiver be relatives and live together in the same residence, do not apply to the Federal FCSP if the carereceiver is age 60 or older. However, in the Federal FCSP, if the carereceiver is below the age of 60, the caregiver must live with the carereceiver and must be related to the carereceiver, but must not be his or her parent. The remaining provisions of that section apply to both the State and Federal FCSP. Again, it must be emphasized, that the standards for a primary caregiver outlined above in

paragraphs one and two of this section must be met, and that neither the State nor Federal FCSP provides support to long distance caregivers.

(a) *General. The services and benefits of the Program are available to the primary caregiver of a functionally dependent older adult relative, or other adult relative suffering from a chronic dementia such as Alzheimer's Disease, who lives in the same residence and whose household income does not exceed 380% of the poverty level. In addition to a thorough family assessment, these services include benefits counseling, caregiver education and financial benefits. The financial benefits are available, as provided under §§20.41—20.45 (relating to reimbursement benefits), to reimburse caregivers for expenses directly related to the provision of care. Subject to the availability of appropriated funds allocated to a planning and service area, these benefits are available on a cost-sharing basis up to specified maximum amount according to the caregiver family's household income and documented expenditures.*

(b) *Criteria for the determination of eligibility. For a caregiver to be determined eligible for the services and benefits available under this chapter, the following criteria shall be met:*

(1) *The caregiver shall be the primary caregiver as defined under §20.2 (relating to definitions).*

(2) *The primary caregiver and the carereceiver shall be relatives and live together in the same residence as defined under §20.2.*

(3) *The caregiver family (carereceiver included) shall cooperate with the area agency on aging in the completion of a comprehensive assessment of the caregiver, the carereceiver and the caregiving environment as required under §20.32 (relating to assessment and care management).*

(4) *The carereceiver shall be a functionally dependent older adult or other adult with a chronic dementia such as Alzheimer's Disease as diagnosed under §20.32.*

(5) *The household income of the caregiver family, as provided under §20.23 (relating to income), may not exceed 380% of the poverty level.*

SECTION 20.22 Conditions of Participation

Sub-section D of §20.22 of the regulations contains obsolete language regarding OPTIONS Level II and OPTIONS Level I. To apply the regulations in the current context, "OPTIONS Level II" in the Regulations should be read as "a Medicaid Waiver" and "OPTIONS Level I" should be read as simply "OPTIONS." The effect of this update is that FCSP services may be combined with OPTIONS services, but FCSP services may not be combined with Medicaid Waiver services, including the Aging Waiver. Otherwise, the provisions of §20.22 apply to both the State and Federal FCSP.

- (a) *Certification of accountability: As a condition of participation in the Program, an eligible primary caregiver shall sign a certification of accountability as provided under §20.32 (relating to assessment and care management). The primary caregiver's signature on the certification will attest to the truth of information provided during the assessment and will indicate the caregiver's understanding of responsibility for compliance with Program requirements, especially those under §§20.41—20.45 (relating to reimbursement benefits) which relate to the reimbursement of caregiver expenses and the penalties for violation of this chapter.*
- (b) *Change of status. It is the responsibility of the primary caregiver to report to the area agency on aging any change of status in the caregiving situation, which might affect eligibility for the Program or the service plan developed under §20.32. Reportable changes include significant changes in the health status of the carereceiver, living arrangements or household income, the ability of the caregiver to provide the necessary care and the availability of informal supports to the care being provided.*
- (c) *Documentation of information. The area agency on aging shall require a primary caregiver to document household income with a copy of Federal income tax returns from the previous calendar year. If the required tax return is unavailable, examples of other documentation, which may be provided, are listed under §20.23 (relating to income). The area agency on aging may require a primary caregiver to document other eligibility-related information provided during assessment.*
- (d) *Choice of available services.*
 - (1) *Individual carereceivers and their caregiver families may not receive the services of the Program and Level II Services of the OPTIONS Program simultaneously. The caregivers of carereceivers who are on a waiting list for OPTIONS Level II Services may be accepted into the Program until the carereceiver is admitted to Level II Services. When a place becomes available in Level II Services, the area agency on aging, in full consultation with a family which has been in the Program while on the waiting list for Level II Services, shall review the relative benefits and the appropriateness of the two*

programs and choose the one which is most appropriate. This provision does not preclude the possibility of an OPTIONS Level II care recipient living in the same residence as a separate carereceiver and caregiver who are eligible to receive benefits and services under this chapter.

(2) Carereceivers who are assessed under the OPTIONS Program and referred to Level I Services may receive these services, when appropriate, in addition to their primary caregiver receiving benefits and services from the Program.

(e) Protection from abuse: A substantiated case of abuse, neglect, exploitation, abandonment as defined in The Older Adults Protective Services Act (35 P. S. §§10211—10224) or under another civil or criminal statute regarding an older adult, shall prohibit a caregiver from receiving benefits and services under this chapter unless authorized by the Department to prevent further abuse. The caregiver is required to certify on the certification of accountability under §20.32 whether one or more of the following apply:

(1) The caregiver has been convicted of a crime relating to abuse, neglect, exploitation or abandonment of an older adult.

(2) The caregiver has been found civilly liable for abuse, neglect, exploitation or abandonment of an older adult.

(3) The caregiver has been notified that the caregiver is an alleged perpetrator in a substantiated report of need for protective services under The Older Adults Protective Services Act.

SECTION 20.23 Income

Eligibility for the FCSP reimbursement is based on the total **household** income of the **carereceiver**. The provisions of §20.23 of the Regulations apply to both the State and Federal FCSP with the following exceptions: In the State FCSP, if income is above 380% of poverty, the family is ineligible for the program. In Federal FCSP, if income is above 380% of poverty, the family is eligible to participate in the FCSP, but 100% cost sharing for reimbursement benefits will be incurred, effectively eliminating reimbursement benefits.

For both the Federal and State FCSP, core services such as assessment, care management, benefits counseling and caregiver education and training will be provided at no cost for eligible families, regardless of income. In both the State and Federal FCSP, families with household income at or below 200% of Poverty receive full reimbursement benefits. Families with household income above 200% and at or below 380% are subject to a sliding reimbursement scale. (**See Appendix – FCSP Cost Sharing Guide**).

(a) Income limits:

- (1) Caregivers whose household income exceeds 380% of poverty level are not eligible for the benefits and services under this chapter.
- (2) Caregivers whose income exceeds 200% of poverty level and does not exceed 380% of poverty level are required to share in the costs of reimbursable items and services under this chapter as provided under §20.41 (relating to general reimbursement).

(b) *Income inclusions. Income includes the following:*

- (1) *Salaries.*
- (2) *Wages.*
- (3) *Bonuses.*
- (4) *Commissions.*
- (5) *Net income from self-employment or partnership income.*
- (6) *Alimony.*
- (7) *Support money.*
- (8) *Cash Public Assistance and relief.*
- (9) *The gross amount of pensions or annuities, including Railroad Retirement benefits.*
- (10) *The gross amount of cash benefits received under the Social Security Act (42 U.S.C.A. §§301—1397e), except Medicare benefits.*
- (11) *Benefits received under State unemployment insurance laws.*
- (12) *Veteran's disability payments.*
- (13) *Interest, including interest received from the Federal government, State government or an instrumentality or political subdivision thereof.*
- (14) *Realized capital gains except as provided in subsection (c).*
- (15) *Rental income.*
- (16) *Workmen's compensation benefits and the gross amount of loss of time insurance benefits, except those benefits granted under section 306(c) of the Workmen's Compensation Act (77 P. S. §513).*

- (17) *Life insurance benefits and proceeds, except as provided in subsection (c).*
- (18) *Gifts or bequests of cash or property converted to cash, other than transfers by gift between members of a household, in excess of \$300.*
- (19) *Any amount of money or the net cash realized from the sale of a prize, such as an automobile or a trip won in a lottery, contest or by a form of gambling.*
- (20) *Royalties.*
- (21) *Dividends.*

(c) Income exclusions. Income does not include the following:

- (1) *Surplus food or other noncash relief, including food stamps, supplied by a government agency.*
- (2) *Property tax rebate payments and rent rebate payments, received under the Senior Citizens Rebate and Assistance Act (72 P. S. §§4751-1—4751-12).*
- (3) *Medicare benefits.*
- (4) *The first \$5,000 of the total of death benefit payments received upon the death of each person from whom the benefits may be due.*
- (5) *The difference between the purchase price of a person's residence and its selling price, to the extent that the person uses the proceeds from the sale of the residence to purchase a different residence within 2 years of the sale of the former residence.*
- (6) *The amount of damages received, whether by civil suit or settlement agreement, due to personal injuries. Damages received means an amount received through prosecution of a legal suit, action or other claim based on tort or tort type rights, or through a settlement agreement entered into in lieu of litigation, except to the extent that the amount duplicates reimbursements previously received. Damages include black lung benefits and benefits granted under section 306(c) of the Workmen's Compensation Act.*
- (7) *Payments provided to eligible low income households under the Low Income Home Energy Assistance Program.*

- (8) *That portion of client payments received by home providers in the Domiciliary Care Program administered by the Department under Chapter 21 (relating to domiciliary care services for adults), which, for any specific income year, does not exceed the actual expenses of providing domiciliary care services.*

(d) Documentation of income.

- (1) *Except as provided in paragraph (2), a primary caregiver seeking benefits under this chapter shall document through copies of the applicable Federal income tax returns, or other acceptable documentation, the total annual household income for the calendar year immediately preceding the year in which the caregiver is assessed or reassessed for participation in the Program.*

Example—A primary caregiver applies to participate in the Program on August 16, 1992. The caregiver shall provide copies of the tax returns, which reflect the total annual household income for the previous year, which is calendar year 1991. Accordingly, the caregiver shall provide tax returns, which document household income received from January 1, 1991, up to, and including December 31, 1991.

- (2) *If the caregiver believes that recent changes in income have resulted in a lower household income, which would affect the caregiver's eligibility, or the level of cost sharing required, the caregiver may provide the area agency on aging with documentation of current annual income. The area agency on aging will determine what documentation is necessary and the period of time for which the documentation is needed in order for the agency to determine an accurate calculation of current annual household income.*

- (3) *The failure to provide truthful information with respect to this section will subject the caregiver to the penalties provided under §20.45 (relating to Program violations and penalties).*

(e) Acceptable documentation of income. The following are examples of documents, photocopies of which may be provided as acceptable documentation of income under subsection (d):

- (1) *Federal, State or local income tax returns.*
- (2) *Pension checks, annuity checks or checks from other sources of income. When the checks are issued monthly, or on some other less-than-annual basis, a photocopy of the check for a single month, or other applicable period, will suffice. United States Treasury checks may not be photocopied.*
- (3) *Statements from a financial institution where direct deposit is made for the applicant or claimant or statements from a*

government agency, such as the Social Security Administration or the Railroad Retirement Board.

- (4) *Documents that clearly verify the type and amount of income or a recent change in previous annual income.*

The AAA must maintain documents in the case file that are the current basis for verification of income.

SECTION 20.24 Appeals

The language contained in §20.24 of the Regulations applies to both the State and Federal FCSP.

Primary caregivers have the right to appeal an adverse decision by an area agency on aging regarding eligibility or the level of cost sharing determined by the agency. Appeals shall be filed under Chapter 3 (relating to fair hearings and appeals).

CORE PROGRAM SERVICES

SECTION 20.31 General

The language contained in §20.31 of the Regulations applies to both the State and Federal FCSP.

The core services of the Program include the assessment of the caregiver, carereceiver and caregiving environment; the development of a careplan responsive to the caregiver's needs and burdens; ongoing casework services as needs may arise; benefits counseling; and caregiver education and training.

SECTION 20.32 Assessment and Care Management

The provisions of §20.32.c.4 of the Regulations, related to services to carereceivers under the age of 60 with chronic dementia, do not apply to the Federal FCSP. When serving an adult carereceiver below the age of 60 in the Federal FCSP, it is sufficient to complete the LOCA and CMI and indicate that the individual has a score of 3 or more in at least two activities of daily living, establishing that the carereceiver has sufficient disabilities to participate in the Federal FCSP. Otherwise, the language contained in §20.32 of the Regulations applies to both the State and Federal FCSP.

Special instructions and sections for assessment of the caregiver are contained in the Care Management Instrument (CMI). An assessment supplement is not required. A full LOCA or CMI is not required for the caregiver. The full LOCA and CMI are to be completed for the carereceiver. The information gathered through completion of the LOCA and CMI will be the basis for the decision that the consumer's needs can best be met through the FCSP. FCSP priority will be based on the Functional Needs Measurement (FNM) scores (**See FNM Chapter 2**).

(a) *Activities.* Assessment and care management services include the following activities:

(1) *The assessment of the status and needs of the caregiver, the carereceiver and the caregiving environment.*

(2) *The development and management of a care plan.*

(3) *The reassessment of status and needs every 6 months. Reassessment includes ongoing casework as problems arise.*

Clarification: In accordance with current practices, this means that a Care Management Instrument (CMI) must be completed every six months and that a Level of Care Assessment (LOCA) must be completed whenever there is a significant change in the condition of the carereceiver.

(b) *Certification.* In addition to the activities provided for under subsection (a), the area agency on aging staff person who carries out the assessment shall secure, at the time of assessment, the signature of the primary caregiver on the certification of accountability required under §20.22 (relating to conditions of participation). This certification shall make reference to the caregiver's responsibilities, including compliance with restrictions on the reimbursement of expenses, under the Program and attest to the truth of the information provided by the caregiver. As a witness, the area agency on aging staff person completing the assessment shall also sign it. This certification will serve as the contractual basis for the area agency on aging's reimbursements for the caregiver's expenses. It may also be used as a basis for the recovery of reimbursements subsequently determined to be inappropriate under §20.45 (relating to program violations and penalties).

(c) *Standards and procedures.* Assessment and care management activities shall be carried out under the following standards and procedures:

(1) *In addition to the requirements of this chapter, the activities of assessment and care management under the Program shall be carried out in conformity with the general care management procedures currently in practice with services under Department contracts with area agencies on aging. This includes efforts by area agencies on aging to conserve resources by developing and utilizing screening instruments to target appropriate families for assessment and subsequent services or placement on a waiting list. Waiting list procedures for the Program will establish the priority of service and position on the waiting list by rating factors relating to the status of the carereceiver, the family and the total caregiving situation to determine the situations of greatest need for agency intervention.*

- (2) *An assessment shall be completed on each caregiver family using the current form established by the Department. The assessment provides for the collection of information concerning the caregiver, the caregiver's burden, the carereceiver and the caregiving environment.*

Clarification: In accordance with current practices, completion of the LOCA and CMI meets the above requirement.

- (3) *When the carereceiver is an older adult, a clinical determination of the functional dependency of the carereceiver shall be made by the caseworker on the basis of information obtained on the assessment instrument. Special reference shall be made to the carereceiver's limitations in carrying out the activities of daily living, including mobility; the cognitive limitations of the carereceiver; and the conditions of the caregiving environment that may contribute to the need for the continuous care or supervision of the carereceiver or increase the caregiver's burden, or both. If the functional dependency of the carereceiver cannot be established, the area agency on aging may not serve the caregiver under the Program.*

- (4) *When the carereceiver is an adult 59 years of age or younger, the area agency on aging shall establish the categorical need for the Program by applying the following provisions:*

- (i) *Through the assessment process, the area agency on aging shall determine that the history of the onset of the carereceiver's condition indicates an identifiable decline in intellectual function resulting in a cognitive impairment that is severe enough to interfere with work or social activities, or both, and requires the continuous care or supervision of the caregiver.*

- (ii) *The area agency on aging shall require the presentation of written documentation from a physician, or team of physicians, that a medical diagnosis which meets the following minimum criteria indicates that the carereceiver has a chronic dementia such as Alzheimer's Disease:*

(A) *It shall document, to the extent possible, that the carereceiver has suffered a decline in intellectual function.*

(B) *It shall document through the use of a mental status examination or a neuropsychological examination that there is a global loss of cognitive function. Global loss of cognitive function includes memory impairment, the impairment of visio-constructive abilities and at least one of the following:*

- (I) *Impairment of abstract thinking.*
- (II) *Impairment of judgment.*
- (III) *Impairment of other complex capabilities, such as language use, the ability to perform complex physical tasks, the ability to recognize objects or people or the ability to construct objects.*
- (IV) *A personality change.*

(C) *It shall document testing to establish that the carereceiver was, at the time of diagnosis, in a state of clear consciousness and that other mental states such as acute or subacute delirium, sleep, coma, stupor and intoxication were considered and ruled out. It shall document clinical tests that were administered to insure that the patient's cognitive impairment is not due to delirium alone and is not due to a reversible loss of cognitive function.*

(d) *Staff resources.*

- (1) *Assessments and care management shall be carried out by staff persons who meet or exceed the minimum experience and training qualifications for the caseworker classification of the Pennsylvania State Civil Service System.*
- (2) *Consistency in the assignment of casework staff to the Program is required. While this consistency may be achieved with different combinations of shared or dedicated staff, at a minimum, assignments shall provide for the development over time of special staff expertise in the unique aspects of the Program. How the area agency on aging intends to achieve and maintain this staff expertise shall be discussed in the plan required under §20.12 (relating to administrative functions and responsibilities of area agencies on aging).*
- (3) *Each area agency on aging is required to secure the consultation services of a person experienced in rehabilitation technology to provide consultation, as appropriate, on the agency's home environment assessments, to help determine if special expertise is needed to assess specific situations (for example, from a rehabilitation engineer), to identify all available resources for responding to the carereceiver's need for home modifications and assistive devices and how project resources should be utilized for this purpose; and to provide technical assistance to case managers for assessing home environments.*

- (4) *Area agencies on aging shall take special precaution and require disclosure of potential conflicts of interest when using the services of consultants; for example, a consultant who owns, or is employed by, a medical supply company. If a consultant who has a potential conflict of interest is used as a consultant for a specific caregiver case, the area agency on aging shall insure that the arrangement for the consultation precludes the purchase of a recommended item from the consultant.*

SECTION 20.33 Benefits Counseling

The language contained in §20.33 of the Regulations applies to both the State and Federal FCSP.

(a) General:

- (1) *The family-centered assessment of caregiving needs and stresses required under §20.32 (relating to assessments and care management) forms the basis for the provision of comprehensive counseling about resources and benefits appropriate to meet the specific needs of each caregiving family. This includes Federal, State and local, formal and informal resources and assistance in gaining access to these resources.*
- (2) *Caregivers may be people from a wide range of family circumstances. The benefit and resource information relevant to a caregiver's needs may be different from that which is relevant to traditional area agency on aging clients. Benefits counseling may need to assist caregivers in securing resources to address a wide variety of problems in areas ranging from day care for young children to mental health, drug and alcohol abuse or vocational rehabilitation.*

(b) Service activities. Benefits counseling services include the following activities:

- (1) *Review of existing assessment documentation, and intensive exploration of additional resources or entitlements, or both.*
- (2) *Providing comprehensive relevant information regarding resources or making referrals to resources, or both. This may be through caseworker/client discussion, the provision of telephone contacts, pamphlets or direct referral.*
- (3) *Exploring resources and benefits, including the following:*
 - (i) *MH/MR Programs.*
 - (ii) *Drug and alcohol programs.*

- (iii) *Insurance programs/policies.*
- (iv) *Specific disease related organizations—cancer, Alzheimer's Disease, and the like.*
- (v) *Support groups.*
- (vi) *Veterans Administration programs.*
- (vii) *Healthy Horizons.*

- (viii) *Social Security.*
- (ix) *SSI.*
- (x) *Food Stamps.*
- (xi) *PACE.*
- (xii) *Property Tax/Rent Rebate.*
- (xiii) *LIHEAP (energy assistance).*
- (xiv) *Medical Assistance.*
- (xv) *Housing programs.*
- (xvi) *Weatherization programs.*
- (xvii) *Community based soc/rec programs.*
- (xviii) *Local city mission services.*
- (xix) *Red Cross.*
- (xx) *Lions Club.*
- (xxi) *Blind Association.*
- (xxii) *Transportation programs.*
- (xxiii) *Food banks.*
- (xxiv) *Community action programs.*
- (xxv) *VISTA.*

- (4) *Reviewing of medical supply needs and, in the absence of alternative sources, attempting to obtain supplies and equipment on behalf of the caregiver.*
- (5) *Assisting with the completion of applications for public benefits programs, such as PACE, Property Tax and Rent Rebate, Veterans Administration benefits, housing programs, and the like.*
- (6) *Following-up as appropriate.*

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- (c) *Exclusions. While benefits counseling may include the exploration of options, resources and services, as well as the potential consequences of either the use or lack of use of them, it may not include recommendations or advice to caregivers on specific providers of purchased services and supplies when there are specific choices available to them.*
 - (e) *In-service training. Staff assigned to the benefits counseling functions shall receive special in-service training in caregiving needs and available resources.*

SECTION 20.34 Caregiver Education and Training

The language contained in §20.34 of the Regulations applies to both the State and Federal FCSP.

- (a) *General. The purpose of caregiver education and training is to strengthen caregiving skills and ease the burden of caregiving, with special attention to health problems of care receivers, coping skills for caregivers and the performance of appropriate personal care tasks. For the purpose of this Program, caregiver education shall be carried out on a face-to-face basis or, at a minimum, through videotape instruction. Printed educational materials may be used to supplement these activities.*
- (b) *Service activities. The service activities of caregiver education may consist of a variety of approaches designed to reach the general caregiver population in the community. Area agencies on aging shall take steps to ensure that opportunities for caregiver education are readily accessible to caregivers under the Program. Activities include the following:*
 - (1) *The review of existing assessment documentation, and intensive exploration of the educational needs of individual caregivers.*
 - (2) *The development of programming to meet the educational needs of individual Program caregivers and groups of Program caregivers.*

- (3) *Hands-on training to develop a caregiver's skill in performing an essential task of caregiving such as bathing.*
 - (4) *The development of an educational library. An educational library may contain either written or videotaped material, and shall promote both individual or group Program caregiver utilization of this material.*
 - (5) *Special "caregiver days," such as events held in recognition of National Caregivers Week or Older Americans Month. These "Caregiver Days" may consist of educational programs, group interaction or group review of educational videotapes.*
 - (6) *Support group activities, including educational programming.*
 - (7) *The review of educational videotapes by individual caregivers in their homes.*
 - (8) *The facilitation of caregiver access to educational services not available directly from the Program.*
- (c) *Funding caregiver education. The area agency on aging is not required to fund as a core service all caregiver education services available. In developing caregiver education services, area agencies on aging shall rely heavily upon other resources of the area agency on aging and local resources available elsewhere in the community. Program plans shall contain minimal reliance upon funding appropriated under this chapter to fund caregiver education activities.*

REIMBURSEMENT BENEFITS

SECTION 20.41 General Reimbursement

The expenditure parameters outlined in §20.41.a of the Regulations apply to the State FCSP but do not apply to the Federal FCSP. Comparable parameters for the Federal FCSP are that no more than 10% of the federal dollars may be spent on administration and no more than 20% of the dollars may be spent on supplies, assistive devices and home modifications. Consistent with standard practice, the Department also limits expenditures on administration in the State FCSP to 10% of the total dollars.

Likewise, the provisions related to cost-shared benefits and maximum amounts in §20.41.b and c.1 of the Regulations only apply to the State FCSP. For Federal FCSP consumers, it is recommended that the \$200/month cap be maintained. However, recognizing that there are some families who would benefit from a higher cap, families in the Federal FCSP can receive up to (but no more than) \$500/month, with the provision that each AAA's aggregate average cost per case across both the State and Federal FCSP caseload must not exceed \$300/month. When authorizing service costs above \$200, there must be clear documentation justifying services that exceed the recommended cap.

Both Federal and State FCSP funds may be used for one case, as long as eligibility criteria for both programs are met, but the AAA may not exceed \$200 of State FCSP funds per case, per month. Additionally, the combined State and Federal FCSP benefit may not exceed \$500 per month. Rules for the State FCSP apply to State Dollars and Federal Match, and those for the Federal FCSP apply to the Federal Dollars. This means that each AAA must spend at least as much money on dual eligibles to account for the state match.

If Federal and/or State FCSP funds are used in combination with OPTIONS dollars, the cost of the total, combined benefit must not exceed the OPTIONS cap per month, per case. Such cases must be seen as primarily FCSP cases requiring supplementary OPTIONS benefits. Funds can be combined in any proportion as long as the State FCSP contribution does not exceed \$200 per case month, the Federal FCSP contribution does not exceed \$500 per case per month and the combined FCSP portion does not exceed \$500 per month. Cost sharing for combined cases must follow the funding streams, i.e. FCSP dollars are cost shared using the FCSP cost sharing scale and OPTIONS dollars are cost shared using the OPTIONS cost sharing scale.

Also, only one reimbursement per exclusive primary caregiver/carereceiver dyad, or match, is allowed, i.e. one primary caregiver, one carereceiver and one reimbursement to a family or household. The only exception is if there are different primary caregivers, each having a different and exclusive primary caregiving relationship with a different carereceiver that meets the requirements in §20.21 in this directive. If there are multiple carereceivers and one primary caregiver in a family, only one of the carereceivers can be a carereceiver in the FCSP. The other carereceivers could only be served by the AAA using the Aging Waiver (if eligible) or OPTIONS dollars.

The provisions in §20.41.c.2 regarding the maximum \$2,000 reimbursement over the life of the case for the combination of assistive devices and home modifications apply to all consumers receiving FCSP funds (Federal, State or combination of both). Cost sharing rules for these dollars are the same as those for the monthly benefit for services and supplies. In general the FCSP dollars for home modifications and assistive devices should not be supplemented with OPTIONS dollars, unless such supplementation is determined, through a rigorous local exceptions process, to be necessary to prevent inappropriate institutionalization.

The provisions in §20.41.c.3 of the Regulations apply to both the State and Federal FCSP. The provisions of §20.41.d also apply, with the exception that the language regarding the \$200 per month maximum in §20.41.d.7 may be disregarded for the Federal FCSP.

(a) Expenditure parameters. When an area agency on aging has annualized its Program and the ongoing caseload level has stabilized at, or around, the level projected in the approved Program plan, the following parameters on expenditures shall be observed:

- (1) *At least 55% of the allocated funding shall be budgeted and expended for the reimbursement of caregivers.*
- (2) *No more than 20% of the amount budgeted and expended for the reimbursement of caregivers may be budgeted and expended for home modifications and assistive devices.*

Clarification: AAAs must monitor their budgets on an ongoing basis to ensure compliance with this requirement.

(b) Cost-shared benefits. Funding to reimburse primary caregivers for caregiving expenses as provided in this chapter is available on a cost-sharing basis as follows:

- (1) *Up to 100% of the maximum amounts provided in subsection (c), depending on expenditures and availability of funds, may be used to reimburse primary caregivers whose household income does not exceed 200% of the current poverty level.*
- (2) *As household income increases in 20% brackets, the available reimbursement benefit decreases by 10%. Thus, a primary caregiver whose household income is between 280% and 300% of the poverty level may be reimbursed for up to 50% of the maximum benefit available, or up to \$100 per month for ongoing expenses for \$1,000 for home modifications or assistive devices as provided under subsection (c).*
- (3) *The Department will maintain a cost-sharing table indicating the current dollar amounts of household income ranges at he different cost-sharing levels and household sizes. This table will be updated annually on the basis of revised Federal poverty guidelines published in the Federal Register. Interested parties may obtain a copy of the current cost-sharing table from the local area agency on aging or from the Pennsylvania Department of Aging.*
- (4) *To determine the amount, which may be reimbursable, by the area agency on aging, the appropriate percentage of the maximum benefit available is applied to the amount the caregiver expended up to that maximum. When caregiver expenditures exceed the maximum amounts available, the percentage is applied only to the maximum amount. Thus, if a primary caregiver is eligible for 50% of the maximum benefit and incurs monthly caregiving expenditures of \$400, the most the caregiver may be reimbursed is \$100, that is, 50% of the \$200 maximum benefit available.*

(c) Maximum amounts.

- (1) *To reimburse for ongoing expenses of respite care services, other related services and consumable supplies needed to*

provide the necessary care, up to \$200 per month may be made available depending upon actual expenditures, household income and the availability of funds.

- (2) To reimburse for expenses incurred for home modifications and assistive devices purchased under this chapter, up to \$2,000, depending upon actual expenditures, household income and the availability of funds may be made available during the full time that a case is active.*
- (3) Caregivers are not entitled to the maximum amounts under paragraphs (1) and (2). Reimbursements are made on the basis of need, income, actual expenditures and the availability of funds. Although area agencies on aging retain the discretion to control caregiver reimbursements to prevent the depletion of available funds by projected utilization patterns, an area agency on aging does not have authority to set different maximum amounts in its planning and service area.*

(d) Other general controls:

- (1) An area agency on aging may control the utilization of reimbursement funding through the use of waiting lists for new families, delay in accepting families from waiting lists to permit attrition to decrease funding demands, delay in preapprovals of home modifications and assistive devices until additional funds are available. Primary caregivers shall be made aware at intake that reimbursements are not entitlements and are contingent upon the availability of funds under the Program appropriation.*
- (2) An area agency on aging may require a primary caregiver to provide additional documentation of the income information provided during assessment when there is clear justification to question the validity of the documentation provided previously.*
- (3) Some form of direct reimbursement of documented caregiving expenses shall be instituted. If explained in an approved Program plan as provided under §20.12 (relating to administrative functions and responsibilities of area agencies on aging), an area agency on aging may also use one or more other methods, such as a voucher system, to get the reimbursement benefits to primary caregivers.*
- (4) Funding available for the reimbursement of caregivers is not intended to displace other resources available to the caregiver family. Area agencies on aging may not knowingly use the resources and shall take steps through benefits counseling to promote the utilization of other available resources to assure that displacement of other resources does not occur.*

- (5) *To provide an adequate audit trail for reimbursements, that area agency on aging shall obtain from primary caregivers and retain in agency files documentation of caregiver expenditures for which reimbursements are made.*
- (6) *Funding available for the reimbursement of care giving expenses may not be used to cover caregiver payments for the services of relatives. Area agencies on aging shall make primary caregivers aware of this restriction at the time they are admitted into the Program by including it in the certification of accountability required under §20.22 (relating to conditions or participation).*
- (7) *Categories for reimbursed purchases shall remain distinct when maximum amounts are applied. Costs of ongoing expenses and consumable supplies are subject to the \$200 per month maximum. Costs of home modifications and assistive device purchases are subject to the \$2,000 maximum during the full time the case is active. Since the costs of leasing an assistive device are also ongoing "out-of-pocket" expense, an area agency may have some discretion in determining which category is to be charged if the caregiver's needs for other respite care are not jeopardized.*
- (8) *Area agencies on aging are expected to promote the concept that the reimbursement for ongoing expenses is available to empower caregivers to make their own decisions and choices. While it is important to work with caregivers in planning appropriate responses to their needs, the emphasis should be on expanding the awareness of the various options, which may be open to them.*

SECTION 20.42 Ongoing Caregiving Expenses

The language contained in Section 20.42 of the Regulations applies to both the State and Federal FCSP.

- (a) *Reimbursable expenses. To qualify for reimbursement under this chapter, ongoing expenses shall be for services or consumable supplies directly related and necessary to the care being provided to the care receiver. To the extent that they are consistent with the developed care plan, the services may include all forms of respite care, other supportive services and consumable supplies as defined in this chapter.*
- (b) *Accumulated benefits. To facilitate the purchase of more expensive respite care and other supportive services for a period of time that would afford a primary caregiver the opportunity to be away from several days of vacation, hospitalization or special emergency absences, an area agency on aging may permit caregivers to accumulate unused financial benefits under the following provisions:*

- (1) *Unused reimbursement benefits may only be accumulated for the purposes described under this subsection when an area agency on aging has included its intent and procedures for allowing accumulated benefits in its approved Program plan as provided under §20.12 (relating to administrative functions and responsibilities of area agencies on aging).*
- (2) *Reimbursement benefits available for home modifications and assistive devices may not be used for the special circumstances provided under this subsection.*
- (3) *Accumulated reimbursement benefits may not be anticipated. They shall have been earned on a monthly basis prior to use.*
- (4) *Unused reimbursement benefits may be accumulated over a period of time and not to exceed six months.*
- (5) *Accumulated reimbursement benefits may not be carried over from one contract year to another unless the Department has waived this requirement. The Department will consider waiving this requirement only if an area agency on aging submits a written request for a waiver which adequately explains how the area agency on aging proposes to provide accumulated benefits across contract years without charging expenditures in one contract year to the budget for a different contract year. This paragraph is not subject to §20.62 (relating to Waivers).*

Clarification: While the Regulations offer flexibility to AAAs on whether to allow accumulated benefits in the FCSP, the Department encourages AAAs to do so, consistent with the program's philosophy of offering flexibility to consumers.

SECTION 20.43 Home Modifications

The language contained in Section 20.43 of the Regulations applies to both the State and Federal FCSP.

- (a) *Preapproval. Area agencies on aging shall develop a system for the preapproval of home modifications to be authorized for reimbursement benefits. The system shall require all approved home modifications to be in response to specific details noted in the caregiver's assessment and care plan. The system may include standards for controlling the expenditure of available funding for this purpose in a way that optimizes the distribution of these funds to the most caregivers with the greatest need for home modifications.*
- (b) *Property ownership:*
 - (1) *The area agency on aging may approve reimbursement for a home modification of a property owned by the caregiver family without regard for whether the caregiver or the carereceiver is the owner of the property.*

- (2) *An area agency on aging may approve reimbursement of a home modification of rented property at the agency's discretion if the following minimum standards are observed:*
- (i) *The area agency on aging shall determine that there is a reasonable expectation that the family, including the caregiver, will continue to live in the home in the foreseeable future.*
 - (ii) *The caregiver shall secure the permission of the owner before the area agency on aging grants preapproval for the home modifications.*
 - (iii) *The permission obtained from the owner shall indicate whether the owner will or will not require the home to be returned to its original state when the caregiver family moves out. In some cases, this indication may be a major factor related to area agency on aging approval of the requested home modification. Program funds may not be used for restoring the home to its original state if the owner requires it. In some cases, restoration by the caregiver may be possible without additional funding.*
 - (iv) *Major modifications shall only be approved with the highest discretion with regard to caregiver need and the availability of funding.*
 - (v) *The documentation maintained by the area agency on aging of an approval of a modification of rented property shall indicate that the minimum standards of this paragraph have been observed and shall state the area agency's rationale for approving the reimbursement.*

SECTION 20.44 Assistive Devices

The language contained in §20.44 of the Regulations applies to both the State and Federal FCSP.

- (a) *Preapprovals. Area agencies on aging shall develop a system of preapproval of reimbursable purchases of assistive devices. An area agency on aging shall take appropriate steps to determine the availability of other funding – such as Medicare or Medical Assistance, or local charitable organizations – before authorizing the purchase of assistive devices.*
- (b) *Leased Equipment. If the area agency on aging determines that a caregiver – requested assistive device may be leased or at a potential saving to the Program, the area agency on aging shall limit*

reimbursement to the costs of leasing rather than the purchase of the equipment.

- (c) Return of assistive devices. When an assistive device purchased under the Program is no longer needed in the care giving situation, the area agency on aging shall encourage the family to return it to the area agency on aging for use with future clients of the Program.*

SECTION 20.45 Program Violations and Penalties

The language contained in §20.45 of the Regulations applies to both the State and Federal FCSP.

(a) Violations. Caregivers who receive services under the Program are subject to the administrative actions and penalties under this section if they commit one or more of the following acts:

- (1) Making or causing to be made a false statement or representation of a material fact relating to information affecting eligibility for the benefits of the Program.*
- (2) Submitting false or fraudulent documentation of caregiving expenses for which reimbursement is sought or received.*
- (3) Violating this chapter, including a provision which affects the eligibility status of the primary caregiver, the payment of reimbursement benefits under this chapter or the refusal to provide requested documentation of eligibility – related information as provided under §20.22 (relating to conditions of participation).*

(b) Administrative actions and penalties.

- (1) If the area agency on aging determines that a primary caregiver has violated the act or this chapter, the area agency on aging has the authority to suspend or terminate services to the caregiver under this chapter.*
- (2) If the area agency on aging determines that a primary caregiver has knowingly received financial reimbursement for which the caregiver is not eligible as a result of violations under this section, the area agency on aging may recover twice the amount of the reimbursements determined to be inappropriate plus interest.*
- (3) If the area agency on aging determines that a primary caregiver has knowingly received reimbursement monies from the Program by false or fraudulent documentation of eligibility for that reimbursement, the area agency on aging shall request the appropriate district attorney to initiate proceedings against the caregiver.*

(c) Caregiver right to appeal. Actions by an area agency on aging against a primary caregiver for violations under subsection (b)(1) and (2) are subject to the right of appeal under Chapter 3 (relating to hearings and appeals).

GRANDPARENTING PROGRAM

SECTION 20.51 General Provisions

All AAAs must offer a grandparenting/intergenerational care giving type program, which meets the federal guidelines (Title III (e) of the Older Americans Act). No more than 10% of the AAAs Federal FCSP allocation may be spent on the grandparenting program unless a Waiver is obtained from the Department of Aging, through a written request to the Bureau of Program Integrity. No State FCSP money may be spent on the Grandparenting Program. AAAs must monitor their budgets on an ongoing basis to ensure that the 10% limit is not exceeded without Departmental approval.

With the following four exceptions, the provisions of the Regulations and other sections of this directive apply to the Grandparenting Program:

- (1) The demographic eligibility criteria in §20.21 for the Regulations and this directive do not apply. The Demographic Eligibility Criteria for the Grandparenting Program are as follows:
 - Primary caregiver must be age 55 and above.
 - Caregiver must be “primary” caregiver.
 - Carereceiver must be age 18 or younger.
 - Primary caregiver and carereceiver must be related (grandparent or older relative, but not the parent) and must reside in the same household.
 - Priority must be given to those older relative caregivers providing care to children with severe disabilities.
 - Priority must also be given to those older caregivers with greatest social and economic need, with particular attention to low-income individuals.
- (2) Due to the prevalence of siblings and the importance of keeping families together and the lack of alternative program options at the disposal of the AAA, the requirement of a one-to-one dyad, or match, of a primary caregiver and carereceiver does not apply to the Grandparenting Program. While program benefits may be shared among carereceivers, only one program benefit is permitted per

household. The benefit limits and cost sharing rules applicable to the Federal FCSP apply to the Grandparenting Program.

- (3) Due to the developmental needs of children and adolescents, reimbursement benefits needed in the Grandparenting Program may or may not be similar to those offered in the regular FCSP. Some care plans may heavily involve traditional respite for the caregiver and accommodations to address the physical needs of the carereceiver. Other, however, may focus on services, equipment and supplies to address the developmental needs of the carereceivers.
- (4) While the caregiver section of the CMI may be valuable in some cases, the bulk of the LOCA and CMI are often inapplicable to these cases, and therefore the use of the LOCA and CMI is not required for the Grandparenting Program. However, information and results regarding needs assessments, and what the AAA deems appropriate to address needs, must be clearly documented in the case record. Where possible, appropriate professional expertise should be utilized in the needs assessment and care planning processes. Alternative funding sources and less expensive appropriate alternatives must be explored and exhausted before any services, supplies, devices and equipment may be purchased using FCSP Grandparenting Funds.

For those that would like assistance with the development of a Grandparenting Program, it is recommended that local MH/MR, ARC and/or UCP office be contacted for information and ideas for programs as well as information on local needs in the area. It is also recommended that AAAs partner with these and other similar local agencies in the development and implementation of the programs.

OTHER PROVISIONS

SECTION 20.61 Entitlement

The language contained in §20.61 of the Regulations applies to both the State and Federal FCSP.

The act does not create or provide an individual with an entitlement to services or benefits under this chapter. As provided in section 6 of the act (62 P.S. §3066), it is the intent of the General Assembly that services under the act shall be made available only to the extent of the availability and level of appropriations made by the General Assembly.

SECTION 20.62 Waivers

The language contained in §20.62 of the Regulations applies to both the State and Federal FCSP.

- (a) *The Department may for justifiable reasons, grant exceptions to and departures from this chapter to an area agency on aging when the area agency on aging can, by clear and convincing evidence,*

demonstrate that compliance would cause an unreasonable and undue hardship upon the area agency on aging and that an exception would not create a negative impact upon the participation of a caregiver family in the Program or otherwise compromise the intent of this chapter. The Department will not waive requirements in the act.

- (b) A waiver request shall be made in writing to the Secretary. A request shall specifically identify and explain the burden created by the requirement for which the exception is being sought, the alternative method for fulfilling the basic intent of the requirement and evidence of the steps to be taken to prevent a negative impact upon the participation of caregiver families in the Program.*
- (c) An exception granted under this chapter may be revoked by the Department for a justifiable reason. Notice of revocation will be in writing and will include the reason for the action of the Department and a specific date upon which the exception will be terminated.*
- (d) In revoking an exception, the Department will provide for a reasonable time between the date of the written notice of revocation and the date of termination of an exception for the agency to come into compliance with the applicable provision of this chapter.*
- (e) If an agency wishes to request a reconsideration of a denial or revocation of an exception, it shall do so in writing to the Secretary within 15 days of receipt of the notification of adverse action.*

Family Caregiver Support Program Cost Sharing Guide

Using The Cost Sharing Chart

The **maximum** benefit available to help with the purchase of caregiving services and supplies is \$200/month.

AND

The **maximum** benefit available to help with the purchase of home adaptations and assistive devices is \$2,000 during the life of the case.

The **allowable** benefit (the amount to be provided to the family) is determined as follows:

- When the amount actually spent equals or exceeds the maximum benefit available, apply the percentage indicated on the chart for a specific income level and household size to the maximum benefit available (i.e. \$200/month for caregiving expenses or \$2,000 during the life of the case for home adaptations and assistive devices);
- When the amount actually spent is less than the maximum benefit available, apply the appropriate percentage to the amount actually spent. Please note that in cases such as this, the amounts of \$200 or \$2,000 have no relevance to the calculation of the allowable benefit.

In all cases the calculation of the benefit is based upon the caregiver's out-of-pocket expenses. Costs covered by other available resources are not considered an expense to the caregiver.

FCSP Comparison Chart

	State FCSP	Federal FCSP	Combined State & Federal FCSP	FCSP & OPTIONS	Federal Grandparenting	Federal Caregiver of Indiv w/ Disability
Eligibility						
Caregiver	PCG 18+	PCG 18+	PCG 18+		PCG 55+	PCG 55+
Care Receiver	CR 60+ or has chronic dementia (regardless of age)	CR 60+	CR 60+	CR 60+	CR 18 or Younger	CR 19 - 59
Functional Need	CR has at least 1 ADL deficit (3+)	CR has at least 2 ADL deficits (3+)	CR has at least 2 ADL deficits (3+)	Other eligibility rules apply for FCSP funds utilized (i.e. State, Federal or Combined)	N/A	CR has at least 2 ADL deficits (3+); CR has disability
Financial Need	Household income less than 380% of poverty to qualify for reimbursement benefits.	Household income of CR less than 380% of poverty to qualify for reimbursement benefits.	Household income less than 380% of poverty to qualify for reimbursement benefits.	""	Household income less than 380% of poverty to qualify for reimbursement benefits.	Household income less than 380% of poverty to qualify for reimbursement benefits.
Caregiving Relationship	PCG & CR related		PCG & CR related	""	PCG & CR related	PCG & CR related but PGC cannot be parent
	PCG & CR cohabitate		PCG & CR cohabitate	""	PCG & CR cohabitate	PCG & CR cohabitate
	PCG must provide majority of hands-on care	PCG must provide majority of hands-on care	PCG must provide majority of hands-on care	""	PCG must provide majority of care/supervision when crisis at home	PCG must provide majority of hands-on care
	Exclusive one-on-one PGC-CR DYAD required	Exclusive one-on-one PGC-CR DYAD required	Exclusive one-on-one PGC-CR DYAD required	""		Exclusive one-on-one PGC-CR DYAD required

FCSP Comparison Chart

	State FCSP	Federal FCSP	Combined State & Federal FCSP	FCSP & OPTIONS	Federal Grandparenting	Federal Caregiver of Indiv w/ Disability
Reimbursement: Benefit Maximums	\$200/month for services & supplies	Standard benefit maximum of \$200 per month for services & supplies With clear justification documented in the care plan, the monetary benefit may increase, but no higher than \$500 per month	Same reimbursement maximums apply as for federal FCSP, with the condition that no more than \$200 per month in state FCSP funds can be reimbursed for services & supplies. The combined State and Federal FCSP benefit may in no case exceed \$500 per month for services & supplies.	Total monthly reimbursement max for services & supplies may not exceed the OPTIONS cap/month. Funding streams charged in proportion with no more than \$200/month charged to the State FCSP & no more than \$500/month charged to the State and Fed FCSP combined.	Reimbursement benefit maximums are the same as for the Federal FCSP. Maximum one program benefit per household	Reimbursement benefit maximums are the same as for the Federal FCSP
		An AAA's average monthly reimburs. benefit may not exceed \$300 across its entire FCSP caseload			An AAA can spend a maximum of 10% of Federal FCSP funds on Grandparenting Program.	
	\$2,000 over the life of the case for home mods and assistive devices	\$2,000 over the life of the case for home mods and assistive devices	The combined State and Federal FCSP benefit may in no case exceed \$2,000 over the life of the case for home mods and assistive devices	\$2,000 over the life of the case for home mods and assistive devices may not be supplemented with OPTIONS dollars except through a strict local exception process	\$2,000 over the life of the case for home mods and assistive devices	\$2,000 over the life of the case for home mods and assistive devices
Cost Sharing	FCSP Cost Sharing Scale Applies. Cost sharing applies to reimbursements for services, supplies, home mods and assistive devices	Same as for State FCSP	Same as for State FCSP	For FCSP dollars - use FCSP cost sharing scale. For OPTIONS dollars - use OPTIONS cost sharing scale. Cost sharing applies to reimburs. for services, supplies, home mods and assistive devices.	Same as for State FCSP	Same as for State FCSP

PART E—NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

Section. 371. SHORT TITLE.

This part may be cited as the "National Family Caregiver Support Act".
(42 U.S.C. 3030s)

Subpart 1—Caregiver Support Program

Section. 372. DEFINITIONS.

(a) In General. -

In this subpart:

- (1) **CHILD.**—The term "child" means an individual who is not more than 18 years of age **or who is an individual with a disability.**
- (2) **GRANDPARENT OR OLDER INDIVIDUAL WHO IS A RELATIVE CAREGIVER.**—The term "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—
 - (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; and
 - (C) has a legal relationship to the child, as such legal custody or guardianship, or is raising the child informally.

(b) RULE.—In providing services under this subpart—

- (1) **for family caregivers who provide care for individuals with Alzheimer's disease and related disorders with neurological and organic brain dysfunction, the State involved shall give priority to caregivers who provide care for older individuals with such disease or disorder; and**
- (2) **for grandparents or older individuals who are relative caregivers, the State involved shall give priority to caregivers who provide care for children with severe disabilities.**

(42 U.S.C. 3030s)

Section. 373. PROGRAM AUTHORIZED.

(a) **IN GENERAL.**—The Assistant Secretary shall carry out a program for making grants to States with State plans approved under section 307, to pay for the Federal share of the cost of carrying out State programs, to enable area agencies on aging, or entities that such area agencies on aging contract with, to provide multifaceted systems of support services—

- (1) for family caregivers; and
- (2) for grandparents or older individuals who are relative caregivers.

(b) **SUPPORT SERVICES.**—The services provided, in a State program under subsection (a), by an area agency on aging, or entity that such agency has contracted with, shall include—

- (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 caregiver training to **assist the caregivers in the areas of health, nutrition, and financial literacy, and in making decisions and solving problems relating to their caregiving roles;**
- (4) respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- (5) supplemental services, on a limited basis, to complement the care provided by caregivers.

(c) **POPULATION SERVED; PRIORITY.—**

(1) **POPULATION SERVED.**—Services under a State program under this subpart shall be provided to family caregivers, and grandparents and older individuals who are relative caregivers, and who—

- (A) are described in paragraph (1) or (2) of subsection (a); and
- (B) with regard to the services specified in paragraphs (4) and (5) of subsection (b), in the case of a caregiver described in paragraph (1), is providing care to an older individual who meets the condition specified in **subparagraph (A)(i) or (B) of section 102(22).**

(2) **PRIORITY.**—**In providing services under this subpart, the State, in addition to giving the priority described in section 372(b), shall give priority—**

- (A) **to caregivers who are older individuals with greatest social need, and older individuals with greatest economic need (with particular attention to low-income older individuals); and**
- (B) **to older individuals providing care to individuals with severe disabilities, including children with severe disabilities.**

(d) **USE OF VOLUNTEERS.**—**In carrying out this subpart, each area agency on aging shall make use of trained volunteers to expand the provision of the available services described in subsection (b) and, if possible, work in coordination with organizations that have experience in providing training, placement, and stipends for volunteers or participants (such as organizations carrying out Federal service programs administered by the Corporation for National and Community Service), in community service settings.**

(e) **QUALITY STANDARDS AND MECHANISMS AND ACCOUNTABILITY.—**

(1) **QUALITY STANDARDS AND MECHANISMS.**—The State shall establish standards and mechanisms designed to assure the quality of services provided with assistance made available under this subpart.

(2) **DATA AND RECORDS.**—The State shall collect data and maintain records relating to the State program in a standardized format specified by the Assistant Secretary. The State shall furnish the records to the Assistant Secretary, at such time as the Assistant Secretary may require, in order to

enable the Assistant Secretary to monitor State program administration and compliance, and to evaluate and compare the effectiveness of the State programs.

(3) **REPORTS.**—The State shall prepare and submit to the Assistant Secretary reports on the data and records required under paragraph (2), including information on the services funded under this subpart, and standards and mechanisms by which the quality of the services shall be assured. **The reports shall describe any mechanisms used in the State to provide to persons who are family caregivers, or grandparents or older individuals who are relative caregivers, information about and access to various services so that the persons can better carry out their care responsibilities.**

(f) **CAREGIVER ALLOTMENT.**—

(1) **IN GENERAL.**—

(A) From sums appropriated under section 303(e) for fiscal years **2007, 2008, 2009, 2010, and 2011** the Assistant Secretary shall allot amounts among the States proportionately based on the population of individuals 70 years of age or older in the States.

(B) In determining the amounts allotted to States from the sums appropriated under section 303 for a fiscal year, the Assistant Secretary shall first determine the amount allotted to each State under subparagraph (A) and then proportionately adjust such amounts, if necessary, to meet the requirements of paragraph (2).

(C) The number of individuals 70 years of age or older in any State and in all States shall be determined by the Assistant Secretary on the basis of the most recent data available from the Bureau of the Census and other reliable demographic data satisfactory to the Assistant Secretary.

(2) **MINIMUM ALLOTMENT.**—

(A) The amounts allotted under paragraph (1) shall be reduced proportionately to the extent necessary to increase other allotments under such paragraph to achieve the amounts described in subparagraph (B).

(B)(i) Each State shall be allotted 1/2 of 1 percent of the amount appropriated for the fiscal year for which the determination is made.

(ii) Guam and the Virgin Islands of the United States shall each be allotted 1/4 of 1 percent of the amount appropriated for the fiscal year for which the determination is made.

(iii) American Samoa and the Commonwealth of the Northern Mariana Islands shall each be allotted 1/16 of 1 percent of the amount appropriated for the fiscal year for which the determination is made.

(C) For the purposes of subparagraph (B)(i), the term "State" does not include Guam, American Samoa, the Virgin Islands of the United States, and the Commonwealth of the Northern Mariana Islands.

(g) **AVAILABILITY OF FUNDS.**—

(1) **USE OF FUNDS FOR ADMINISTRATION OF AREA PLANS.**—

Amounts made available to a State to carry out the State program under this subpart may be used, in addition to amounts available in accordance with section 303(c)(1), for costs of administration of area plans.

(2) **FEDERAL SHARE.**—

(A) **IN GENERAL.**—Notwithstanding section 304(d)(1)(D), the Federal share of the cost of carrying out a State program under this subpart shall be 75 percent.

(B) **NON-FEDERAL SHARE.**—The non-Federal share of the cost shall be provided from State and local sources.

(C) **LIMITATION.**—A State may use not more than 10 percent of the total Federal and non-Federal share available to the State to provide support services to grandparents and older individuals who are relative caregivers **of a child who is not more than 18 years of age.**

(42 U.S.C. 3030s-1)

Section. 374. MAINTENANCE OF EFFORT.

Funds made available under this subpart shall supplement, and not supplant, any Federal, State, or local funds expended by a State or unit of general purpose local government (including an area agency on aging) to provide services described in section 373.

(42 U.S.C. 3030s-2)