No. 1990-204

AN ACT

HB 698

Establishing a program to assist persons who bear primary responsibility for the at-home care of functionally dependent older adults and victims of chronic dementia.

The General Assembly recognizes that:

- (1) There is an enormous need in this Commonwealth for services to assist families that provide at-home care to functionally dependent older adults and other adults who are victims of chronic dementia such as Alzheimer's disease.
- (2) Most care provided for such individuals is delivered by family members. Family involvement is a critical element for avoiding or post-poning institutionalization of functionally dependent older adults or those adults who are victims of a chronic dementia such as Alzheimer's disease.
- (3) Primary caregivers who provide continuous care in the home are frequently under substantial physical, psychological and financial stress. Respite care and other supportive services for the caregiver could relieve some of the stress while maintaining and strengthening the family structure.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. Short title.

This act shall be known and may be cited as the Family Caregiver Support Act.

Section 2. Intent.

It is the intent of this act to ease the strain of caregiving and to assist relatives who bear primary responsibility for the at-home care of functionally dependent older adults and other adults who are victims of chronic dementia by providing resources for services such as the following:

- (1) Assistance to the caregiver to assure that supports to the functionally dependent older adult or adult suffering from a chronic dementia are adequate and appropriate to maintain these individuals in the bome.
 - (2) Intermittent, planned or emergency relief to the caregiver.
 - (3) Restoration or maintenance of the caregiver's well-being.
- (4) Preservation of the caregiver's informal supports such as family and friends.
 - (5) Supportive social services to the caregiver.
- (6) Affordable services through a cost-sharing mechanism developed by the department for those families whose household incomes do not exceed 380% of the poverty level.

Section 3. Definitions.

The following words and phrases when used in this act shall have the meanings given to them in this section unless the context clearly indicates otherwise:

"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.

"Area agency on aging." The single 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.

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

"Department." The Department of Aging of the Commonwealth.

"Functionally dependent older adult." A person 60 years of age or older residing within this Commonwealth who, because of his or her inability to perform tasks required for daily living as defined through regulation and as assessed by the area agency on aging, needs continuous care or supervision.

"Home modification." Reasonable modifications to the structure of a home for the purpose of reducing the caregiving burden of the caregiver, as approved by the department. Modifications do not include repairs, and payment for such repairs is prohibited.

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

"Income." All income, from whatever source derived, including, but not limited to, wages, salaries, Social Security or railroad retirement income, public assistance income, realized capital gains and workmen's compensation. The department shall determine income amounts and inclusions for purposes of this act through regulation.

"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, who lives in the same residence with such individual on a continuous basis and does not receive financial compensation for the care provided. A substantiated case of abuse, neglect, exploitation, abandonment as defined in the act of November 6, 1987 (P.L.381, No.79), known as the Older Adults Protective Services Act, or pursuant to any other civil or criminal statute regarding an older adult, shall prohibit a caregiver from receiving benefits under this act unless authorized by the department to prevent further abuse.

"Relative." A spouse or parent, child, stepparent, stepchild, grandparent, grandchild, brother, sister, half-brother, half-sister, aunt, great aunt, uncle, great uncle, niece, 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 with relief from normal caregiving duties and responsibilities.

Section 4. Caregiver support program.

- (a) Description.—The persons to be served under this act are primary, unpaid caregivers who live with and provide continuous care to a functionally dependent older adult or other adult suffering from a chronic dementia such as Alzheimer's disease.
- (b) Authority.—The department shall develop operating procedures and guidelines and shall contract with area agencies on aging to provide the benefits set forth in this act. The department shall have the authority to develop criteria through regulation relating to eligibility for caregivers to receive assistance pursuant to this act.
- (c) Supportive services.—The department shall identify by regulation supportive services which are directly related to the provision of care to the functionally dependent older adult or other adult suffering from chronic dementia. Supportive services include, but are not limited to:
 - (1) Benefits counseling and caregiver counseling, education and training.
 - (2) Reimbursement to primary caregivers whose households financially qualify for assistance pursuant to section 5 and as set forth through regulation for expenses incurred in obtaining day or night respite care services, transportation to respite care service locations or other supportive services defined by regulation, and consumable supplies such as incontinence pads.
 - (3) Reimbursement to primary caregivers whose households financially qualify for assistance pursuant to section 5 and as developed through regulation for expenses incurred in obtaining home modifications or assistive devices as approved by the department which help the functionally dependent older adult or adult suffering from chronic dementia to carry out tasks required for daily living such as grab bars, safety devices and wheelchair ramps.

Section 5. Reimbursements.

- (a) General rule.—The department through contracts with area agencies on aging shall provide the services described in section 4(c)(1) and shall reimburse qualified primary caregivers for purchase of approved services described in section 4(c)(2) and (3).
 - (b) Maximum amounts.—
 - (1) The maximum amount available to a qualified caregiver whose household income is under 200% of poverty level shall be established by regulation, but shall not exceed \$200 per month, for out-of-pocket expenses incurred for services described in section 4(c)(2).
 - (2) The maximum amount available to a qualified caregiver whose household income is under 200% of poverty level shall be established by regulation, but shall not exceed \$2,000 for the entire duration of the case, for expenses incurred for home modifications or assistive devices as described in section 4(c)(3).

(c) Scale of benefits.—A sliding benefits scale shall be established by the department by regulation to ensure that caregivers who qualify under this act and whose household income exceeds 200% of poverty level shall pay some portion of the out-of-pocket expenses for services described in section 4(c). In no event will caregivers whose household income exceeds 380% of the poverty level be considered eligible for benefits under this act.

Section 6. Entitlement not created.

Nothing in this act creates or provides any individual with an entitlement to services or benefits. It is the intent of the General Assembly that services under this act shall be made available only to the extent of the availability and level of appropriations made by the General Assembly.

Section 7. Other benefits.

Funding authorized under this act shall not be used to displace benefits, entitlements or resources available under other programs.

Section 8. Enforcement.

The department shall have authority to establish penalties, by regulation, associated with the violation of this act or departmental rules or regulations promulgated under this act.

Section 9. Effective date.

This act shall take effect in 60 days.

APPROVED—The 19th day of December, A. D. 1990.

ROBERT P. CASEY