

# ACT 20 of 2021

## FAMILY CAREGIVER SUPPORT ACT

Act of Dec. 19, 1990, P.L. 1234, No. 204

Cl. 67

AN ACT

Establishing a program to assist persons who bear primary responsibility for the at-home care of functionally dependent older adults, individuals with Alzheimer's disease or a related disorder, children with parents who are unable to care for them and individuals with disabilities. (Title amended June 11, 2021, P.L.52, No.20)

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 postponing 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 Pennsylvania Caregiver Support Act.

(1 amended Dec. 22, 2011, P.L.526, No.112)

### **Section 2. Intent.**

It is the intent of this act to ease the strain of caregiving and to assist adult family members and other individuals who bear primary responsibility for the at-home care of functionally dependent older adults and other adults who are living with Alzheimer's disease or a related disorder by providing resources for services such as the following: (Intro. par. amended June 11, 2021, P.L.52, No.20)

(1) Assistance to the primary caregiver to assure that supports to the care receiver are adequate and appropriate to maintain these individuals in the home.

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(2) Intermittent, planned or emergency relief to the primary caregiver.

(3) Restoration or maintenance of the primary caregiver's well-being.

(4) Preservation of the primary caregiver's informal supports such as family and friends.

(5) Supportive social services to the primary 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 Federal poverty guidelines.

(2 amended Dec. 22, 2011, P.L.526, No.112)

### 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." (Def. deleted by amendment)

"Adult with chronic dementia." (Def. deleted by amendment June 11, 2021, P.L.52, No.20)

"Alzheimer's disease or a related disorder." An irreversible and progressive neurological disorder diagnosed by a physician that:

(1) causes cognitive and memory impairment, behavioral and psychiatric problems and the loss of the ability to care for oneself;

(2) is severe enough to interfere with work or social activities; and

(3) requires continuous care or supervision.

(Def. added June 11, 2021, P.L.52, No.20)

"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.

"Care receiver." Any of the following:

(1) A functionally dependent older adult who is 60 years of age or older and cared for by a primary caregiver who is 18 years of age or older.

(2) An individual with Alzheimer's disease or a related disorder who is cared for by a caregiver 18 years of age or older.

(3) A child who is younger than 18 years of age who is cared for and resides with an older relative caregiver for a child.

(4) An individual who is between 18 and 59 years of age, has a non-dementia-related disability and is cared for and

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resides with an older relative caregiver for an individual with a disability.

(Def. amended June 11, 2021, P.L.52, No.20)

"Chronic dementia." (Def. deleted by amendment)

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

"Federal poverty guidelines." The poverty guidelines updated periodically in the Federal Register by the Department of Health and Human Services under the authority of section 673 of the Omnibus Budget Reconciliation Act of 1981 (Public Law 97-35, 42 U.S.C. § 9902(2)).

"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 primary 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 care receiver's household with the exception of a minor or dependent student. (Def. amended June 11, 2021, P.L.52, No.20)

"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.

"Older relative caregiver for a child." An individual who satisfies all of the following criteria:

(1) The individual is 55 years of age or older and resides with a child who is younger than 18 years of age.

(2) The individual is the grandparent, step-grandparent or other relative, not including the biological or adoptive parent related by blood, marriage or adoption.

(3) The individual is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to act as the primary caregiver of the child.

(4) The individual has a legal relationship to the child, including legal custody, adoption or guardianship of the child, or is caring for the child in an informal manner.

(Def. added June 11, 2021, P.L.52, No.20)

"Older relative caregiver for an individual with a disability." An individual who satisfies all of the following criteria:

(1) The individual is 55 years of age or older.

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(2) The individual cares for and resides with an individual with a disability who is no younger than 18 years of age and no older than 59 years of age.

(3) The individual is the primary caregiver for the individual with a disability.

(4) The individual is the parent, grandparent or other relative of the individual with a disability by blood, marriage or adoption.

(Def. added June 11, 2021, P.L.52, No.20)

"Primary caregiver." The one identified family member or other responsible individual who has primary responsibility for the provision of care, including the coordination of care and services needed to maintain the physical and mental health of the care receiver and who does not receive financial compensation for the care provided. (Def. amended June 11, 2021, P.L.52, No.20)

"Relative." (Def. deleted by amendment)

"Respite care service." A regular, intermittent or emergency service which provides the primary caregiver of a care receiver with relief from normal caregiving duties and responsibilities.

(3 amended Dec. 22, 2011, P.L.526, No.112)

### **Section 4. Primary caregiver support program.**

(a) Description.--The persons to be served under this act are unpaid, primary caregivers who provide continuous care to a care receiver.

(b) Authority.--

(1) 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.

(2) The department shall have the authority to develop criteria through regulation relating to eligibility for primary caregivers to receive assistance pursuant to this act.

(3) After all eligibility criteria have been met, the department shall give priority in awarding assistance paid for by the State Lottery Fund to primary caregivers who provide care for a functionally dependent older adult and an older adult with Alzheimer's disease or a related disorder.

((3) amended June 11, 2021, P.L.52, No.20)

(c) Supportive services.--The department shall identify by regulation supportive services which are directly related to the provision of care to the care receiver. Supportive services include, but are not limited to:

(1) Benefits counseling and primary caregiver counseling, education and training.

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(2) Reimbursement to primary caregivers whose care receivers' households financially qualify for assistance under 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 care receivers' households financially qualify for assistance under 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 care receiver to carry out tasks required for daily living such as grab bars, safety devices and wheelchair ramps.

(4 amended Dec. 22, 2011, P.L.526, No.112)

### **Section 5. Reimbursements.**

(a) General rule.--The department through contracts with area agencies on aging shall provide the services described under section 4(c)(1) and shall reimburse qualified primary caregivers for purchase of approved services described under section 4(c)(2) and (3).

(b) Maximum amounts.--

(1) The maximum amount available to a qualified primary caregiver whose care receivers' household income is under 200% of the Federal poverty guidelines shall be established by the department for out-of-pocket expenses incurred for services.

(i) (Deleted by amendment).

(ii) (Deleted by amendment).

(2) The maximum amount available to a qualified primary caregiver whose care receivers' household income is under 200% of the Federal poverty guidelines shall be established by the department for the entire duration of the case, for expenses incurred for home modifications or assistive devices as described under section 4(c)(3). Prior to making a change to the maximum amount available to a qualified primary caregiver for out-of-pocket expenses incurred for services or for home modifications or assistive devices, the department shall transmit notice to the Legislative Reference Bureau for publication in the Pennsylvania Bulletin and provide notification to the chairperson and minority chairperson of the Aging and Youth Committee of the Senate and the chairperson and minority chairperson of the Aging and Older Adult Services Committee of the House of Representatives.

(b) amended June 11, 2021, P.L.52, No.20)

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(c) Scale of benefits.--A sliding benefits scale shall be established by the department by regulation to ensure that primary caregivers whose care receivers qualify under this act and whose household incomes exceed 200% of the Federal poverty guidelines shall pay some portion of the out-of-pocket expenses for services described under section 4(c). In no event will primary caregivers whose care receivers' household incomes exceed 380% of the Federal poverty guidelines be considered eligible for benefits under this act.

(5 amended Dec. 22, 2011, P.L.526, No.112)

### **Section 6. Entitlement not created and prohibition.**

(a) Entitlement not created.--Nothing in this act creates or provides any individual with an entitlement to services or benefits. Services under this act shall be made available only to the extent of the availability and level of appropriations made by the General Assembly.

(b) Prohibition.--A primary caregiver shall be prohibited from receiving benefits under this act under the following circumstances:

(1) the primary caregiver is a perpetrator in a substantiated case of abuse, neglect, exploitation or abandonment as defined in the act of November 6, 1987 (P.L.381, No.79), known as the Older Adults Protective Services Act;

(2) the primary caregiver is a perpetrator in a substantiated case of abuse, neglect, exploitation or abandonment as defined in the act of October 7, 2010 (P.L.484, No.70), known as the Adult Protective Services Act;  
or

(3) the primary caregiver is a perpetrator in a substantiated case of child abuse as defined in 23 Pa.C.S. Ch. 63 (relating to child protective services).

(6 amended June 11, 2021, P.L.52, No.20)

### **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. The department may not promulgate a regulation under this section that interferes with any privileges or rights provided under Federal law.

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(8 amended June 11, 2021, P.L.52, No.20)

Section 9. Effective date.

This act shall take effect in 60 days.