

AN ACT in relation to aging.

**Be it enacted by the People of the State of Illinois,  
represented in the General Assembly:**

Section 1. Short title. This Act may be cited as the Family Caregiver Act.

Section 5. Legislative findings. The General Assembly recognizes the following:

(1) Family caregivers, serving without compensation, have been the mainstay of the long-term care system in this country. Care provided by these informal caregivers is the most crucial factor in avoiding or postponing institutionalization of the State's residents.

(2) Among non-institutionalized persons needing assistance with personal care needs, two-thirds depend solely on family and friends for assistance. Another 25% supplement family care with services from paid providers. Only a little more than 5% rely exclusively on paid services.

(3) Family caregivers are frequently under substantial physical, psychological, and financial stress. Unrelieved by support services available to the caregiver, this stress may lead to premature or unnecessary institutionalization of the care recipient or deterioration in the health condition and family circumstances of the caregiver.

(4) Two out of 3 family caregivers, due to being employed outside the home, experience additional stress. Two-thirds of working caregivers report conflicts between work and caregiving, requiring them to rearrange their work schedules, work fewer than normal hours, or take an unpaid leave of absence. For this population, caregiver support services have the added benefit of allowing family caregivers to remain active members of our State's

workforce.

Section 10. Legislative intent. It is the intent of the General Assembly to establish a multi-faceted family caregiver support program to assist unpaid family caregivers and grandparents or other older individuals who are relative caregivers, who are informal providers of in-home and community care to older individuals or children.

Services provided under this program shall do the following:

(1) Provide information, relief, and support to family and other unpaid caregivers of older individuals and children.

(2) Encourage family members to provide care for their family members who are older individuals and children.

(3) Provide temporary substitute support services or living arrangements to allow a period of relief or rest for caregivers.

(4) Be provided in the least restrictive setting available consistent with the individually assessed needs of older individuals and children.

(5) Include services appropriate to the needs of family members caring for older individuals and children, including older individuals with dementia.

(6) Provide family caregivers with services that enable them to make informed decisions about current and future care plans, solve day-to-day caregiving problems, learn essential care giving skills, and locate services that may strengthen their capacity to provide care.

Section 15. Definitions. In this Act:

"Caregiver" or "family caregiver" means an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual, or a grandparent or older individual who is a relative caregiver.

"Child" or "children" means an individual or individuals 18

years of age or under.

"Department" means the Department on Aging.

"Eligible participant" means a family caregiver or a grandparent or older individual who is a relative caregiver.

"Family caregiver support services" includes, but is not limited to, the following:

(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 for caregivers to assist the caregivers 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.

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

(6) Other services as identified by the Department and defined by rule.

"Frail individual" means an older individual who is determined to be functionally impaired because the individual (i) is unable to perform from at least 2 activities of daily living without substantial human assistance, including verbal reminding, physical cueing, or supervision or (ii) due to a cognitive or other mental impairment, requires substantial supervision because the individual behaves in a manner that poses a serious health or safety hazard to the individual or to another individual.

"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 or marriage, who:

(1) lives with the child;

(2) is the primary caregiver for the child because the child's biological or adoptive parents are unable or unwilling to serve as the primary caregiver for the child;

and

(3) has a legal relationship to the child, such as legal custody or guardianship, or is raising the child informally.

"Informal provider" means an individual who is not compensated for the care he or she provides.

"Older individual" means an individual who is 60 years of age or older, except for a grandparent or older individual who is a relative caregiver.

"Respite care" means substitute supports or living arrangements provided on an intermittent, occasional basis. The term includes, but is not limited to, in-home respite care, adult day care, child care, and institutional care. The term also includes respite care as defined in Section 2 of the Respite Program Act to the extent that such services are allowable and participants are eligible under the National Family Caregiver Support Program.

Section 16. Family caregiver demonstration grant. The Department shall seek federal funding for the establishment and assessment of a Family Caregiver Training and Support Demonstration Project. The Department is authorized to fund 2 sites, one in a rural community and one in a more urban area. The Department shall adopt rules governing participation and oversight of the program. The Department shall seek technical assistance from the Department of Public Aid and the Department of Human Services. The Department shall advise the Governor and the General Assembly regarding the effectiveness of the program within 6 months after the conclusion of the demonstration period.

Section 20. Powers and duties of the Department. The Department shall administer this Act and shall adopt rules and standards the Department deems necessary for that purpose. At a minimum, those rules and standards shall address the following:

(1) Standards and mechanisms designed to ensure the

quality of services provided with assistance made available under this Act.

(2) Data collection and record maintenance.

The Department shall administer this Act in coordination with Section 4.02 and related provisions of the Illinois Act on the Aging.

Section 25. Provision of services. The Department shall contract with area agencies on aging and other appropriate agencies to conduct family caregiver support services to the extent of available State and federal funding. Services provided under this Act must be provided according to the requirements of federal law and rules, except for the provision of services to grandparents or older individuals who are relative caregivers when State funding is utilized to provide those services.

Section 30. Eligibility for respite and supplemental services. When a family caregiver is providing in-home and community care to an older individual, the older individual must be a frail individual as defined in this Act in order for the family caregiver to be eligible to receive respite and supplemental services.

Section 35. Health care practitioners and facilities not impaired. Nothing in this Act shall impair the practice of any licensed health care practitioner or licensed health care facility.

Section 40. Entitlement not created; funding; waivers.

(a) Nothing in this Act creates or provides any individual with an entitlement to services or benefits. It is the General Assembly's intent 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.

(b) The Director may seek and obtain State and federal

funds that may be available to finance services under this Act, and may also seek and obtain other non-State resources for which the State may be eligible.

(c) The Department may seek appropriate waivers of federal requirements from the U.S. Department of Health and Human Services.

Section 90. The Respite Program Act is amended by changing Sections 1.5, 2, 3, 4, 5, 6, 8, 11, and 12 as follows:

(320 ILCS 10/1.5) (from Ch. 23, par. 6201.5)

Sec. 1.5. Purpose. It is hereby found and determined by the General Assembly that respite care provides relief and support to the primary care-giver of a frail ~~or abused~~ or ~~functionally~~ disabled ~~or cognitively impaired older~~ adult and provides by providing a break for the caregiver from the continuous responsibilities of care-giving. Without this support, the primary care-giver's ability to continue in his or her role would be jeopardized; thereby increasing the risk of institutionalization of the frail ~~or abused~~ or ~~functionally~~ disabled ~~or cognitively impaired older~~ adult.

By providing ~~improving and expanding the in-home~~ respite care ~~services currently available~~ through intermittent planned or emergency relief to the care-giver during the regular week-day, evening, and weekend hours, both the special physical and psychological needs of the primary care-giver and the frail ~~or abused~~ or ~~functionally~~ disabled, ~~or cognitively impaired older~~ adult, who is the recipient of continuous care, shall be met reducing or preventing the need for institutionalization.

Furthermore, the primary care-giver providing continuous care is frequently under substantial financial stress. Respite care and other supportive services sustain and preserve the primary care-giver and family caregiving unit. It is the intent of the General Assembly that this ~~amendatory Act of 1992~~ ensure that Illinois primary care-givers of frail ~~or abused~~ or ~~functionally~~ disabled ~~or cognitively impaired older~~ adults

have access to affordable, appropriate in-home respite care services.

(Source: P.A. 87-974.)

(320 ILCS 10/2) (from Ch. 23, par. 6202)

Sec. 2. Definitions. As used in this Act:

(1) "Respite care" means the provision of intermittent and temporary substitute care or supervision of frail ~~or abused~~ or ~~functionally disabled or cognitively impaired~~ older adults on behalf of and in the absence of the primary care-giver, for the purpose of providing relief from the stress or responsibilities concomitant with providing constant care, so as to enable the care-giver to continue the provision of care in the home. Respite care should be available to sustain the ~~primary~~ care-giver throughout the period of care-giving, which can vary from several months to a number of years. Respite care can be provided in the home, in a ~~community-based~~ day care setting during the day, overnight, in a substitute residential setting such as a long-term care facility required to be licensed under the Nursing Home Care Act or the Assisted Living and Shared Housing Act, or for more extended periods of time on a temporary basis.

(1.5) "In-home respite care" means care provided by an appropriately trained paid worker providing short-term intermittent care, supervision, or companionship to the frail or disabled adult in the home while relieving the care-giver, by permitting a short-term break from the care-giver's care-giving role. This support may contribute to the delay, reduction, and prevention of institutionalization by enabling the care-giver to continue in his or her care-giving role. In-home respite care should be flexible and available in a manner that is responsive to the needs of the care-giver. This may consist of evening respite care services that are available from 6:00 p.m. to 8:00 a.m. Monday through Friday and weekend respite care services from 6:00 p.m. Friday to 8:00 a.m. Monday.

(2) "Care-giver" shall mean the family member or other natural person who normally provides the daily care or supervision of a frail, ~~abused~~ or disabled ~~elderly~~ adult. Such care-giver may, but need not, reside in the same household as the frail or disabled adult.

(3) (Blank). ~~"Provider" shall mean any entity enumerated in paragraph (1) of this Section which is the supplier of services providing respite.~~

(4) (Blank). ~~"Sponsor" shall mean the provider, public agency or community group approved by the Director which establishes a contractual relationship with the Department for the purposes of providing services to persons under this Act, and which is responsible for the recruitment of providers, the coordination and arrangement of provider services in a manner which meets client needs, the general supervision of the local program, and the submission of such information or reports as may be required by the Director.~~

(5) (Blank). ~~"Director" shall mean the Director of Aging.~~

(6) "Department" shall mean the Department on Aging.

(7) (Blank). ~~"Abused" shall have the same meaning ascribed to it in Section 103 of the Illinois Domestic Violence Act of 1986.~~

(8) "Frail or disabled adult" shall mean any person ~~suffering from Alzheimer's disease~~ who is 60 ~~55~~ years of age or older ~~and or any adult 60 years of age or older,~~ who either (i) suffers from Alzheimer's disease or a related disorder or (ii) is unable to attend to his or her daily needs without the assistance or regular supervision of a care-giver due to mental or physical impairment and who is otherwise eligible for services on the basis of his or her level of impairment.

(9) "Emergency respite care" means the immediate placement of a trained, in-home respite care worker in the home during an emergency or unplanned event, or during a temporary placement outside the home, to substitute for the ~~primary~~ care-giver. Emergency respite care may be provided ~~in the home~~ on one or more occasions unless an extension is deemed necessary by the



case coordination unit or by another agency designated by the Department and area agencies on aging to conduct needs assessments for respite care services. When there is an urgent need for emergency respite care, procedures to accommodate this need must be determined. An emergency is:

(a) An unplanned event that results in the immediate and unavoidable absence of the ~~primary~~ care-giver from the home in an excess of 4 hours at a time when no other qualified care-giver is available.

(b) An unplanned situation that prevents the ~~primary~~ care-giver from providing the care required by a frail or ~~abused or functionally disabled or cognitively impaired~~ adult living at home.

(c) An unplanned event that threatens the health and safety of the frail or disabled adult.

(d) An unplanned event that threatens the health and safety of the ~~primary~~ care-giver thereby placing the frail or ~~abused or functionally disabled or cognitively impaired~~ ~~older~~ adult in danger.

(10) (Blank). ~~"Primary care giver" means the spouse, relative, or friend, 18 years of age or older, who provides the daily in home care and supervision of a frail or abused or functionally disabled or cognitively impaired older adult. A primary care giver may, but does not need to, reside in the same household as the frail or abused or functionally disabled or cognitively impaired adult. A primary care giver requires intermittent relief from his or her caregiving duties to continue to function as the primary care giver.~~

(Source: P.A. 91-357, eff. 7-29-99; 92-16, eff. 6-28-01.)

(320 ILCS 10/3) (from Ch. 23, par. 6203)

Sec. 3. Respite Program. The Director is hereby authorized to administer a program of ~~establish respite projects for the purposes of providing care and assistance to persons in need and to deter the institutionalization of frail or disabled or functionally disabled or cognitively impaired adults.~~

(Source: P.A. 87-974.)

(320 ILCS 10/4) (from Ch. 23, par. 6204)

Sec. 4. No Limit to Care. Nothing contained in this Act shall be construed so as to limit, modify or otherwise affect the provisions, ~~for long-term~~ in-home services being provided under, ~~of~~ Section 4.02 of the Illinois Act on the Aging.

(Source: P.A. 87-974.)

(320 ILCS 10/5) (from Ch. 23, par. 6205)

Sec. 5. Eligibility. The Department may establish eligibility standards for respite services taking into consideration the unique economic and social needs of the population for whom they are to be provided. The population identified for the purposes of this Act includes persons suffering from Alzheimer's disease or a related disorder and persons who are 60 ~~55~~ years of age or older, ~~or persons age 60 and older~~ with an identified service need. Priority shall be given in all cases to frail, ~~abused~~ or ~~functionally~~ disabled ~~or cognitively impaired~~ adults.

(Source: P.A. 87-974.)

(320 ILCS 10/6) (from Ch. 23, par. 6206)

Sec. 6. Responsibilities. ~~The following requirements shall apply for any projects authorized under Section 3 of this Act:~~

(a) The Department Director shall administer this Act and shall adopt rules and standards the Department deems necessary for that purpose ~~establish target areas needing respite care services.~~

(b) The Department Director shall make grants to or contract with Area Agencies on Aging and other appropriate community-based organizations to provide respite care under this Act ~~publicize the existence of, and make available, application forms for sponsors seeking to establish a respite program.~~

(c) (Blank). ~~The application forms shall require the following information and any other information the Director deems necessary.~~

~~(1) Identity and qualifications of a sponsor.~~

~~(2) Identity and qualifications of a provider and a plan for the coordination of services.~~

~~(3) An assessment of the community need, support and participation for respite services. The assessment shall include documentation.~~

~~(4) Plans for the coordination and arrangement of provider services in a manner that meets client needs.~~

~~(5) A fiscal plan, including specific provisions for the utilization of existing reimbursement and funding sources and the development of local financial support.~~

~~(6) Plans for publicizing the purpose of the project and the services to be provided.~~

~~(7) Certification of licensure or certification of any individual, agency or family providing a service subject to licensure, or certification under State law.~~

(d) (Blank). ~~The Director shall review and evaluate each application and present each application for review and evaluation by the Council on Aging established under Section 7 of the Illinois Act on the Aging. The Council and the Department shall approve a number of applications and, within the amounts appropriated, award grants for the operation of respite programs.~~

(e) (Blank). ~~The application approved by the Director and the Council on Aging shall be the service plan of the provider. The Director shall ensure that each service plan is coordinated with the designated area agency provided for in Sections 3.07 and 3.08 of the Illinois Act on the Aging, the local public health authority, and any other public or private service provider to ensure that every effort will be made to utilize existing funding sources and service providers and to avoid unnecessary duplication of services.~~

(f) Nothing in this Act shall be construed to limit,

modify, or otherwise affect the provision of long-term in-home services under Section 4.02 of the Illinois Act on the Aging.

(Source: P.A. 87-974.)

(320 ILCS 10/8) (from Ch. 23, par. 6208)

Sec. 8. Funding. Services ~~Respite projects~~ authorized under this Act shall be funded only to the extent of available appropriations for such purposes. The Director may ~~shall~~ seek and obtain State and federal funds that may be available to finance respite care ~~grants awarded~~ under ~~Section 6~~ of this Act, and may ~~shall~~ also seek and obtain other non-state resources for which the State may be eligible. ~~Implementation of projects under this Act shall be contingent upon the availability of federal financial participation. To the extent necessary for implementation of this Act,~~ The Department may ~~shall~~ seek appropriate waivers of federal requirements from the U.S. Department of Health and Human Services.

(Source: P.A. 87-974.)

(320 ILCS 10/11) (from Ch. 23, par. 6211)

Sec. 11. Respite Care Worker Training.

(a) A respite care worker shall be an appropriately trained individual whose duty it is to provide in-home supervision and assistance to a frail ~~or abused~~ or ~~functionally~~ disabled ~~or cognitively impaired~~ older adult in order to allow the ~~primary~~ care-giver a break from his or her continuous care-giving responsibilities.

(b) The Director may prescribe minimum training guidelines ~~standards~~ for respite care workers to ensure that the special needs of persons receiving services under this Act and their ~~primary~~ caregivers will be met. The Director may designate Alzheimer's disease associations and community agencies to conduct such training. Nothing in this Act should be construed to exempt any individual providing a service subject to licensure or certification under State law from these requirements.

(Source: P.A. 87-974.)

(320 ILCS 10/12) (from Ch. 23, par. 6212)

Sec. 12. Annual Report. The Director shall submit a report each year to the Governor and the General Assembly detailing the progress of the respite care services provided ~~programs established~~ under this Act. ~~The report shall include:~~

- ~~(a) a financial report for each program;~~
- ~~(b) a qualitative and quantitative profile of sponsors, providers, care givers and recipients participating in the program;~~
- ~~(c) a comparative assessment of the costs and effectiveness of each service or combination of services provided;~~
- ~~(d) an assessment of the nature and extent of the demand for services; and~~
- ~~(e) an evaluation of the success of programs receiving grants for services.~~

(Source: P.A. 87-974.)

(320 ILCS 10/7 rep.)

(320 ILCS 10/9 rep.)

(320 ILCS 10/10 rep.)

Section 91. The Respite Program Act is amended by repealing Sections 7, 9, and 10.

Section 99. Effective date. This Act takes effect on July 1, 2004.