

1 AN ACT in relation to aging.

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

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

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

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

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

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

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

1 workforce.

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

8 Services provided under this program shall do the
9 following:

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

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

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

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

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

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

29 Section 15. Definitions. In this Act:

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

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

1 years of age or under.

2 "Department" means the Department on Aging.

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

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

7 (1) Information to caregivers about available
8 services.

9 (2) Assistance to caregivers in gaining access to the
10 services.

11 (3) Individual counseling, organization of support
12 groups, and caregiver training for caregivers to assist the
13 caregivers in making decisions and solving problems
14 relating to their caregiving roles.

15 (4) Respite care to enable caregivers to be temporarily
16 relieved from their caregiving responsibilities.

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

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

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

30 "Grandparent or older individual who is a relative
31 caregiver" means a grandparent or step-grandparent of a child,
32 or a relative of a child by blood or marriage, who:

33 (1) lives with the child;

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

1 and

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

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

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

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

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

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

34 (1) Standards and mechanisms designed to ensure the

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

3 (2) Data collection and record maintenance.

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

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

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

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

26 Section 40. Entitlement not created; funding; waivers.

27 (a) Nothing in this Act creates or provides any individual
28 with an entitlement to services or benefits. It is the General
29 Assembly's intent that services under this Act shall be made
30 available only to the extent of the availability and level of
31 appropriations made by the General Assembly.

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

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

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

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

9 (320 ILCS 10/1.5) (from Ch. 23, par. 6201.5)

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

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

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

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

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

4 (320 ILCS 10/2) (from Ch. 23, par. 6202)

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

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

22 (1.5) "In-home respite care" means care provided by an
23 appropriately trained paid worker providing short-term
24 intermittent care, supervision, or companionship to the frail
25 or disabled adult in the home while relieving the care-giver,
26 by permitting a short-term break from the care-giver's
27 care-giving role. This support may contribute to the delay,
28 reduction, and prevention of institutionalization by enabling
29 the care-giver to continue in his or her care-giving role.
30 In-home respite care should be flexible and available in a
31 manner that is responsive to the needs of the care-giver. This
32 may consist of evening respite care services that are available
33 from 6:00 p.m. to 8:00 a.m. Monday through Friday and weekend
34 respite care services from 6:00 p.m. Friday to 8:00 a.m.
35 Monday.

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

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

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

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

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

20 (7) (Blank). ~~"Abused" shall have the same meaning ascribed~~
21 ~~to it in Section 103 of the Illinois Domestic Violence Act of~~
22 ~~1986.~~

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

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

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

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

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

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

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

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

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

30 (320 ILCS 10/3) (from Ch. 23, par. 6203)

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

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

2 (320 ILCS 10/4) (from Ch. 23, par. 6204)

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

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

8 (320 ILCS 10/5) (from Ch. 23, par. 6205)

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

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

20 (320 ILCS 10/6) (from Ch. 23, par. 6206)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

4 (320 ILCS 10/8) (from Ch. 23, par. 6208)

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

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

18 (320 ILCS 10/11) (from Ch. 23, par. 6211)

19 Sec. 11. Respite Care Worker Training.

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

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

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

2 (320 ILCS 10/12) (from Ch. 23, par. 6212)

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

7 ~~(a) a financial report for each program;~~

8 ~~(b) a qualitative and quantitative profile of sponsors,~~
9 ~~providers, care givers and recipients participating in the~~
10 ~~program;~~

11 ~~(c) a comparative assessment of the costs and effectiveness~~
12 ~~of each service or combination of services provided;~~

13 ~~(d) an assessment of the nature and extent of the demand~~
14 ~~for services; and~~

15 ~~(e) an evaluation of the success of programs receiving~~
16 ~~grants for services.~~

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

18 (320 ILCS 10/7 rep.)

19 (320 ILCS 10/9 rep.)

20 (320 ILCS 10/10 rep.)

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

23 Section 99. Effective date. This Act takes effect on July
24 1, 2004.