

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
9 compensation, have been the mainstay of the long-term
10 care system in this country. Care provided by these
11 informal caregivers is the most crucial factor in
12 avoiding or postponing institutionalization of the
13 State's residents.

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

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

27 (4) Two out of 3 family caregivers, due to being
28 employed outside the home, experience additional stress.
29 Two-thirds of working caregivers report conflicts between
30 work and caregiving, requiring them to rearrange their
31 work schedules, work fewer than normal hours, or take an

1 unpaid leave of absence. For this population, caregiver
2 support services have the added benefit of allowing
3 family caregivers to remain active members of our State's
4 workforce.

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

11 Services provided under this program shall do the
12 following:

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

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

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

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

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

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

1 Section 15. Definitions. In this Act:

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

6 "Child" or "children" means an individual or individuals
7 18 years of age or under.

8 "Department" means the Department on Aging.

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

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

13 (1) Information to caregivers about available
14 services.

15 (2) Assistance to caregivers in gaining access to
16 the services.

17 (3) Individual counseling, organization of support
18 groups, and caregiver training for caregivers to assist
19 the caregivers in making decisions and solving problems
20 relating to their caregiving roles.

21 (4) Respite care to enable caregivers to be
22 temporarily relieved from their caregiving
23 responsibilities.

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

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

28 "Frail individual" means an older individual who is
29 determined to be functionally impaired because the individual
30 (i) is unable to perform from at least 2 activities of daily
31 living without substantial human assistance, including verbal
32 reminding, physical cueing, or supervision or (ii) due to a
33 cognitive or other mental impairment, requires substantial
34 supervision because the individual behaves in a manner that

1 poses a serious health or safety hazard to the individual or
2 to another individual.

3 "Grandparent or older individual who is a relative
4 caregiver" means a grandparent or step-grandparent of a
5 child, or a relative of a child by blood or marriage, who:

6 (1) lives with the child;

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

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

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

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

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

27 Section 16. Family caregiver demonstration grant. The
28 Department shall seek federal funding for the establishment
29 and assessment of a Family Caregiver Training and Support
30 Demonstration Project. The Department is authorized to fund 2
31 sites, one in a rural community and one in a more urban area.
32 The Department shall adopt rules governing participation and
33 oversight of the program. The Department shall seek

1 technical assistance from the Department of Public Aid and
2 the Department of Human Services. The Department shall
3 advise the Governor and the General Assembly regarding the
4 effectiveness of the program within 6 months after the
5 conclusion of the demonstration period.

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

11 (1) Standards and mechanisms designed to ensure the
12 quality of services provided with assistance made
13 available under this Act.

14 (2) Data collection and record maintenance.

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

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

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

1 and supplemental services.

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

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

7 (a) Nothing in this Act creates or provides any
8 individual with an entitlement to services or benefits. It is
9 the General Assembly's intent that services under this Act
10 shall be made available only to the extent of the
11 availability and level of appropriations made by the General
12 Assembly.

13 (b) The Director may seek and obtain State and federal
14 funds that may be available to finance services under this
15 Act, and may also seek and obtain other non-State resources
16 for which the State may be eligible.

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

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

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

24 Sec. 1.5. Purpose. It is hereby found and determined by
25 the General Assembly that respite care provides relief and
26 support to the primary care-giver of a frail ~~or-abused~~ or
27 ~~functionally disabled or-cognitively-impaired-elder~~ adult and
28 provides by-providing a break for the caregiver from the
29 continuous responsibilities of care-giving. Without this
30 support, the primary care-giver's ability to continue in his

1 or her role would be jeopardized; thereby increasing the risk
2 of institutionalization of the frail ~~or--abused~~ or
3 ~~functionally disabled or cognitively-impaired-elder~~ adult.

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

13 Furthermore, the primary care-giver providing continuous
14 care is frequently under substantial financial stress.
15 Respite care and other supportive services sustain and
16 preserve the primary care-giver and family caregiving unit.
17 It is the intent of the General Assembly that this amendatory
18 Act ~~of-1992~~ ensure that Illinois primary care-givers of frail
19 ~~or--abused~~ or ~~functionally disabled or cognitively-impaired~~
20 ~~elder~~ adults have access to affordable, appropriate in-home
21 respite care services.

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

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

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

25 (1) "Respite care" means the provision of intermittent
26 and temporary substitute care or supervision of frail ~~or~~
27 ~~abused~~ or ~~functionally disabled or cognitively-impaired-elder~~
28 adults on behalf of and in the absence of the primary
29 care-giver, for the purpose of providing relief from the
30 stress or responsibilities concomitant with providing
31 constant care, so as to enable the care-giver to continue the
32 provision of care in the home. Respite care should be
33 available to sustain the ~~primary~~ care-giver throughout the

1 period of care-giving, which can vary from several months to
 2 a number of years. Respite care can be provided in the home,
 3 in a community--based day care setting during the day,
 4 overnight, in a substitute residential setting such as a
 5 long-term care facility required to be licensed under the
 6 Nursing Home Care Act or the Assisted Living and Shared
 7 Housing Act, or for more extended periods of time on a
 8 temporary basis.

9 (1.5) "In-home respite care" means care provided by an
 10 appropriately trained paid worker providing short-term
 11 intermittent care, supervision, or companionship to the frail
 12 or disabled adult in the home while relieving the care-giver,
 13 by permitting a short-term break from the care-giver's
 14 care-giving role. This support may contribute to the delay,
 15 reduction, and prevention of institutionalization by enabling
 16 the care-giver to continue in his or her care-giving role.
 17 In-home respite care should be flexible and available in a
 18 manner that is responsive to the needs of the care-giver.
 19 This may consist of evening respite care services that are
 20 available from 6:00 p.m. to 8:00 a.m. Monday through Friday
 21 and weekend respite care services from 6:00 p.m. Friday to
 22 8:00 a.m. Monday.

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

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

31 (4) (Blank). "Spensor"--shall-mean-the-provider,-public
 32 agency-or-community-group--approved--by--the--Director--which
 33 establishes--a--contractual--relationship-with-the-Department
 34 for-the-purposes-of-providing-services-to-persons-under--this

1 Act, and which is responsible for the recruitment of
2 providers, the coordination and arrangement of provider
3 services in a manner which meets client needs, the general
4 supervision of the local program, and the submission of such
5 information or reports as may be required by the Director.

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

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

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

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

21 (9) "Emergency respite care" means the immediate
22 placement of a trained, in-home respite care worker in the
23 home during an emergency or unplanned event, or during a
24 temporary placement outside the home, to substitute for the
25 primary care-giver. Emergency respite care may be provided
26 in the home on one or more occasions unless an extension is
27 deemed necessary by the case coordination unit. When there
28 is an urgent need for emergency respite care, procedures to
29 accommodate this need must be determined. An emergency is:

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

34 (b) An unplanned situation that prevents the

1 primary care-giver from providing the care required by a
2 frail or abused-or-functionally disabled or-cognitively
3 impaired adult living at home.

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

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

10 (10) (Blank). "Primary--care-giver"--means--the--spouse,
11 relative,--or--friend, 18-years-of-age-or-older, who-provides
12 the-daily-in-home-care-and-supervision-of-a-frail--or--abused
13 or-functionally-disabled-or-cognitively-impaired-elder-adult.
14 A-primary-care-giver-may, but-does-not-need-to, reside-in-the
15 same--household--as--the--frail--or--abused--or--functionally
16 disabled--or-cognitively-impaired-adult.-A-primary-care-giver
17 requires-intermittent--relief--from--his--or--her--caregiving
18 duties-to-continue-to-function-as-the-primary-care-giver.
19 (Source: P.A. 91-357, eff. 7-29-99; 92-16, eff. 6-28-01.)

20 (320 ILCS 10/3) (from Ch. 23, par. 6203)
21 Sec. 3. Respite Program. The Director is hereby
22 authorized to administer a program of establish--respite
23 projects-for-the-purposes-of-providing-care-and assistance to
24 persons in need and to deter the institutionalization of
25 frail or disabled or--functionally--disabled--or--cognitively
26 impaired adults.
27 (Source: P.A. 87-974.)

28 (320 ILCS 10/4) (from Ch. 23, par. 6204)
29 Sec. 4. No Limit to Care. Nothing contained in this Act
30 shall be construed so as to limit, modify or otherwise affect
31 the provisions, for long-term in-home services being provided
32 under, of Section 4.02 of the Illinois Act on the Aging.

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

2 (320 ILCS 10/5) (from Ch. 23, par. 6205)

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

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

14 (320 ILCS 10/6) (from Ch. 23, par. 6206)

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

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

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

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

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

32 (2) ~~Identity and qualifications of a provider and a~~

1 plan-for-the-coordination-of-services.

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

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

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

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

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

15 (d) (Blank). The-Director-shall-review-and-evaluate-each
16 application--and--present--each--application--for--review-and
17 evaluation-by-the-Council-on-Aging-established-under--Section
18 7--of--the--Illinois--Act--on-the-Aging.--The-Council-and-the
19 Department-shall-approve-a-number-of-applications-and,--within
20 the-amounts-appropriated,--award-grants-for-the--operation--of
21 respite-programs.

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

31 (f) Nothing in this Act shall be construed to limit,
32 modify, or otherwise affect the provision of long-term
33 in-home services under Section 4.02 of the Illinois Act on
34 the Aging.

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

2 (320 ILCS 10/8) (from Ch. 23, par. 6208)

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

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

17 (320 ILCS 10/11) (from Ch. 23, par. 6211)

18 Sec. 11. Respite Care Worker Training.

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

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

1 from these requirements.

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

3 (320 ILCS 10/12) (from Ch. 23, par. 6212)

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

9 ~~(a)--a-financial-report-for-each-program;~~

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

13 ~~(c)--a-comparative---assessment---of---the---costs---and~~
14 ~~effectiveness--of--each--service--or--combination-of-services~~
15 ~~provided;~~

16 ~~(d)--an-assessment-of-the-nature-and-extent-of-the-demand~~
17 ~~for-services;-and~~

18 ~~(e)--an-evaluation-of-the-success-of--programs--receiving~~
19 ~~grants-for-services.~~

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

21 (320 ILCS 10/7 rep.)

22 (320 ILCS 10/9 rep.)

23 (320 ILCS 10/10 rep.)

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

26 Section 99. Effective date. This Act takes effect upon
27 becoming law.