

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 who are informal providers of in-home and community care to  
9 frail individuals or children.

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

12 (1) Provide information, relief, and support to  
13 family and other unpaid caregivers of frail individuals.

14 (2) Encourage family members to provide care for  
15 their family members who are frail individuals.

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

19 (4) Be provided in the least restrictive setting  
20 available consistent with the individually assessed needs  
21 of the frail individual.

22 (5) Include services appropriate to the needs of  
23 family members caring for the frail individual, including  
24 a frail individual with dementia.

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

30 Section 15. Definitions. In this Act:

31 "Child" or "children" means an individual or individuals  
32 18 years of age or under.

1 "Department" means the Department on Aging.

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

4 "Family caregiver" means an adult family member, or  
5 another individual, who is an informal provider of in-home  
6 and community care to a frail individual.

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

9 (1) Information to caregivers about available  
10 services.

11 (2) Assistance to caregivers in gaining access to  
12 the services.

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

17 (4) Respite care provided to a frail individual  
18 that will enable caregivers to be temporarily relieved  
19 from their caregiving responsibilities.

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

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

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

33 "Grandparent or older individual who is a relative  
34 caregiver" means a grandparent or step-grandparent of a

1 child, or a relative of a child by blood or marriage, who is  
2 60 years of age or older and who:

- 3 (1) lives with the child;
- 4 (2) is the caregiver for the child because the  
5 child's biological or adoptive parents are unable or  
6 unwilling to serve as the primary caregiver for the  
7 child; and
- 8 (3) has a legal relationship to the child, such as  
9 legal custody or guardianship, or is raising the child  
10 informally.

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

13 "Older individual" means an individual who is 60 years of  
14 age or older.

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

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

- 28 (1) Standards and mechanisms designed to ensure the  
29 quality of services provided with assistance made  
30 available under this Act.
- 31 (2) Data collection and record maintenance.

32 The Department shall administer this Act in coordination  
33 with Section 4.02 and related provisions of the Illinois Act

1 on the Aging.

2 Section 25. Provision of services. The Department shall  
3 contract with area agencies on aging and other appropriate  
4 agencies to conduct family caregiver support services to the  
5 extent of available State and federal funding. Services  
6 provided under this Act must be provided according to the  
7 requirements of federal law and rules.

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

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

13 (a) Nothing in this Act creates or provides any  
14 individual with an entitlement to services or benefits. It is  
15 the General Assembly's intent that services under this Act  
16 shall be made available only to the extent of the  
17 availability and level of appropriations made by the General  
18 Assembly.

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

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

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

29 (320 ILCS 10/1.5) (from Ch. 23, par. 6201.5)

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

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

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

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

30 (320 ILCS 10/2) (from Ch. 23, par. 6202)

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

32 (1) "Respite care" means the provision of intermittent  
 33 and temporary substitute care or supervision of frail ~~or~~

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

16 (1.5) "In-home respite care" means care provided by an  
17 appropriately trained paid worker providing short-term  
18 intermittent care, supervision, or companionship to the frail  
19 or disabled adult in the home while relieving the care-giver,  
20 by permitting a short-term break from the care-giver's  
21 care-giving role. This support may contribute to the delay,  
22 reduction, and prevention of institutionalization by enabling  
23 the care-giver to continue in his or her care-giving role.  
24 In-home respite care should be flexible and available in a  
25 manner that is responsive to the needs of the care-giver.  
26 This may consist of evening respite care services that are  
27 available from 6:00 p.m. to 8:00 a.m. Monday through Friday  
28 and weekend respite care services from 6:00 p.m. Friday to  
29 8:00 a.m. Monday.

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

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

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

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

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

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

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

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



1 is an urgent need for emergency respite care, procedures to  
2 accommodate this need must be determined. An emergency is:

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

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

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

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

17 (10) (Blank). "Primary--care-giver"--means--the--spouse,  
18 relative,  
19 --or--friend,  
20 --18-years-of-age-or-older,  
21 --who-provides  
22 the-daily-in-home-care-and-supervision-of-a-frail--or--abused  
23 or-functionally-disabled-or-cognitively-impaired-elder-adult.  
24 A-primary-care-giver-may,  
25 but-does-not-need-to,  
26 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.)

27 (320 ILCS 10/3) (from Ch. 23, par. 6203)  
28 Sec. 3. Respite Program. The Director is hereby  
29 authorized to administer a program of establish--respite  
30 projects-for-the-purposes-of-providing-care-and assistance to  
31 persons in need and to deter the institutionalization of  
32 frail or disabled or--functionally--disabled--or--cognitively  
33 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~~  
16 ~~60 and older~~ with an identified service need. Priority shall  
17 be given in all cases to frail, ~~abused~~ or ~~functionally~~  
18 ~~disabled or 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~~  
23 ~~this Act:~~

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

1 application-forms-for-sponsors-seeking-to-establish-a-respite  
2 program.

3 (c) (Blank). The-application--forms--shall--require--the  
4 following--information-and-any-other-information-the-Director  
5 deems-necessary.

6 (1)--Identity-and-qualifications-of-a-sponsor.

7 (2)--Identity-and-qualifications-of-a-provider-and-a  
8 plan-for-the-coordination-of-services.

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

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

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

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

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

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

29 (e) (Blank). The--application-approved-by-the-Director  
30 and-the-Council-on-Aging-shall-be-the--service--plan--of--the  
31 provider.--The--Director-shall-ensure-that-each-service-plan  
32 is-coordinated-with-the-designated-area-agency--provided--for  
33 in--Sections--3.07-and-3.08-of-the-Illinois-Act-on-the-Aging,  
34 the-local-public-health-authority,--and-any--other--public--or

1 private--service-provider-to-ensure-that-every-effort-will-be  
2 made--to--utilize--existing--funding--sources---and---service  
3 providers-and-to-avoid-unnecessary-duplication-of-services.

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

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

9 (320 ILCS 10/8) (from Ch. 23, par. 6208)

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

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

24 (320 ILCS 10/11) (from Ch. 23, par. 6211)

25 Sec. 11. Respite Care Worker Training.

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

32 (b) The Director may prescribe minimum training

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

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

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

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

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

17 ~~(b)--a-qualitative-and-quantitative-profile-of--sponsors,~~  
 18 ~~providers,~~~~care-givers--and--recipients-participating-in-the~~  
 19 ~~program;~~

20 ~~(c)--a-comparative--assessment--of--the--costs--and~~  
 21 ~~effectiveness--of--each--service--or--combination-of-services~~  
 22 ~~provided;~~

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

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

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

28 (320 ILCS 10/7 rep.)

29 (320 ILCS 10/9 rep.)

30 (320 ILCS 10/10 rep.)

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

1           Section 99. Effective date. This Act takes effect upon  
2 becoming law.