

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 Illinois Income Tax Act is amended by  
27 adding Section 210.10 as follows:

28 (35 ILCS 5/210.10 new)

29 Sec. 210.10. Family caregiver tax credit.

1       (a) In this Section, unless the context clearly requires  
2 otherwise:

3       "Family caregiver" means the individual who normally  
4 provides the daily care or supervision of a family member who  
5 is a frail or disabled adult. The family caregiver may, but  
6 need not, reside in the same household as the frail or  
7 disabled adult.

8       "Family member" means the family caregiver's spouse or a  
9 parent, grandparent, brother, or sister of the family  
10 caregiver or of the family caregiver's spouse.

11       "Frail or disabled adult" means a person who is 60 years  
12 of age or older and who either (i) suffers from Alzheimer's  
13 disease or a related disorder or (ii) is unable to attend to  
14 his or her daily needs without the assistance or regular  
15 supervision of a caregiver due to mental or physical  
16 impairment.

17       (b) For taxable years ending on or after December 31,  
18 2003, a taxpayer who is a family caregiver is entitled to a  
19 credit against the tax imposed by subsections (a) and (b) of  
20 Section 201 in an amount equal to \$10 for each day in the  
21 taxable year on which the taxpayer provides the care or  
22 supervision of a family member who is a frail or disabled  
23 adult. The amount of the tax credit for a taxable year may  
24 not exceed \$3,000, however.

25       (c) The tax credit may not reduce the taxpayer's  
26 liability to less than zero. If the amount of the tax credit  
27 exceeds the tax liability for the year, the excess may be  
28 carried forward and applied to the tax liability of the  
29 taxable year following the excess credit year.

30       (d) A taxpayer claiming the tax credit provided by this  
31 Section must maintain and record the information required by  
32 the Department by rule regarding the care or supervision  
33 provided to the taxpayer's family member. The Department's  
34 rules must include a requirement that the Department on Aging

1 confirm that the taxpayer has provided the daily care or  
2 supervision for which the tax credit is claimed.

3 (e) The provisions of Section 250 do not apply to the  
4 family caregiver tax credit under this Section.

5 Section 95. The Respite Program Act is amended by  
6 changing Sections 1.5, 2, 3, 4, 5, 6, 8, 11, and 12 as  
7 follows:

8 (320 ILCS 10/1.5) (from Ch. 23, par. 6201.5)

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

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

28 Furthermore, the primary care-giver providing continuous  
29 care is frequently under substantial financial stress.  
30 Respite care and other supportive services sustain and  
31 preserve the primary care-giver and family caregiving unit.  
32 It is the intent of the General Assembly that this amendatory

1 Act of 1992 ensure that Illinois primary care-givers of frail  
2 or--abused or functionally disabled or-cognitively-impaired  
3 elder adults have access to affordable, appropriate in-home  
4 respite care services.

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

6 (320 ILCS 10/2) (from Ch. 23, par. 6202)

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

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

25 (1.5) "In-home respite care" means care provided by an  
26 appropriately trained paid worker providing short-term  
27 intermittent care, supervision, or companionship to the frail  
28 or disabled adult in the home while relieving the care-giver,  
29 by permitting a short-term break from the care-giver's  
30 care-giving role. This support may contribute to the delay,  
31 reduction, and prevention of institutionalization by enabling  
32 the care-giver to continue in his or her care-giving role.  
33 In-home respite care should be flexible and available in a



1 manner that is responsive to the needs of the care-giver.  
 2 This may consist of evening respite care services that are  
 3 available from 6:00 p.m. to 8:00 a.m. Monday through Friday  
 4 and weekend respite care services from 6:00 p.m. Friday to  
 5 8:00 a.m. Monday.

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

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

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

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

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

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

29 (8) "Frail or disabled adult" shall mean any person  
 30 suffering from Alzheimer's disease who is 60 55 years of age  
 31 or older and or any adult 60 years of age or older, who  
 32 either (i) suffers from Alzheimer's disease or a related  
 33 disorder or (ii) is unable to attend to his or her daily  
 34 needs without the assistance or regular supervision of a

1 care-giver due to mental or physical impairment and who is  
2 otherwise eligible for services on the basis of his or her  
3 level of impairment.

4 (9) "Emergency respite care" means the immediate  
5 placement of a trained, in-home respite care worker in the  
6 home during an emergency or unplanned event, or during a  
7 temporary placement outside the home, to substitute for the  
8 ~~primary~~ care-giver. Emergency respite care may be provided  
9 ~~in--the--home~~ on one or more occasions unless an extension is  
10 deemed necessary by the case coordination unit. When there  
11 is an urgent need for emergency respite care, procedures to  
12 accommodate this need must be determined. An emergency is:

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

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

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

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

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

1 ~~duties-to-continue-to-function-as-the-primary-care-giver-~~  
2 (Source: P.A. 91-357, eff. 7-29-99; 92-16, eff. 6-28-01.)

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

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

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

11 (320 ILCS 10/4) (from Ch. 23, par. 6204)

12 Sec. 4. No Limit to Care. Nothing contained in this Act  
13 shall be construed so as to limit, modify or otherwise affect  
14 the provisions<sub>7</sub> for ~~long-term~~ in-home services being provided  
15 under<sub>7</sub> ~~of~~ Section 4.02 of the Illinois Act on the Aging.

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

17 (320 ILCS 10/5) (from Ch. 23, par. 6205)

18 Sec. 5. Eligibility. The Department may establish  
19 eligibility standards for respite services taking into  
20 consideration the unique economic and social needs of the  
21 population for whom they are to be provided. The population  
22 identified for the purposes of this Act includes persons  
23 suffering from Alzheimer's disease or a related disorder and  
24 persons who are 60 55 years of age or older<sub>7</sub> ~~or persons age~~  
25 ~~60-and-older~~ with an identified service need. Priority shall  
26 be given in all cases to frail<sub>7</sub> ~~abused~~ or functionally  
27 disabled ~~or cognitively-impaired~~ adults.

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

29 (320 ILCS 10/6) (from Ch. 23, par. 6206)

30 Sec. 6. Responsibilities. ~~The--following-requirements~~

1 shall-apply-for-any-projects-authorized-under--Section--3--of  
2 this-Act:

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

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

13 (c) (Blank). The-application--forms--shall--require--the  
14 following--information-and-any-other-information-the-Director  
15 deems-necessary.

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

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

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

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

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

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

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

32 (d) (Blank). The-Director-shall-review-and-evaluate-each  
33 application--and--present--each--application--for--review-and  
34 evaluation-by-the-Council-on-Aging-established-under--Section

1 7--of--the--Illinois--Act--on--the--Aging--The-Council-and-the  
 2 Department-shall-approve-a-number-of-applications-and, within  
 3 the-amounts-appropriated, award-grants-for-the--operation--of  
 4 respite-programs.

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

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

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

19 (320 ILCS 10/8) (from Ch. 23, par. 6208)

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

33 (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--elder~~ 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

1           ~~(e)--an-evaluation-of-the-success-of--programs--receiving~~  
2           ~~grants-for-services-~~

3           (Source: P.A. 87-974.)

4           (320 ILCS 10/7 rep.)

5           (320 ILCS 10/9 rep.)

6           (320 ILCS 10/10 rep.)

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

9           Section 99. Effective date. This Act takes effect upon  
10          becoming law.