

1                                    AMENDMENT TO HOUSE BILL 16

2            AMENDMENT NO. \_\_\_\_\_. Amend House Bill 16 by replacing the  
3 title with the following:

4            "AN ACT in relation to aging."; and

5 by replacing everything after the enacting clause with the  
6 following:

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

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

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

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

1 services.

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

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

18 Section 10. Legislative intent. It is the intent of the  
19 General Assembly to establish a multi-faceted family  
20 caregiver support program to assist unpaid family caregivers,  
21 who are informal providers of in-home and community care to  
22 frail individuals or children.

23 Services provided under this program shall do the  
24 following:

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

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

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

32 (4) Be provided in the least restrictive setting  
33 available consistent with the individually assessed needs

1 of the frail individual.

2 (5) Include services appropriate to the needs of  
3 family members caring for the frail individual, including  
4 a frail individual with dementia.

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

10 Section 15. Definitions. In this Act:

11 "Child" or "children" means an individual or individuals  
12 18 years of age or under.

13 "Department" means the Department on Aging.

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

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

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

21 (1) Information to caregivers about available  
22 services.

23 (2) Assistance to caregivers in gaining access to  
24 the services.

25 (3) Individual counseling, organization of support  
26 groups, and caregiver training for caregivers to assist  
27 the caregivers in making decisions and solving problems  
28 relating to their caregiving roles.

29 (4) Respite care provided to a frail individual  
30 that will enable caregivers to be temporarily relieved  
31 from their caregiving responsibilities.

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

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

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

12          "Grandparent or older individual who is a relative  
13          caregiver" means a grandparent or step-grandparent of a  
14          child, or a relative of a child by blood or marriage, who is  
15          60 years of age or older and who:

- 16                 (1) lives with the child;  
17                 (2) is the caregiver for the child because the  
18                 child's biological or adoptive parents are unable or  
19                 unwilling to serve as the primary caregiver for the  
20                 child; and  
21                 (3) has a legal relationship to the child, such as  
22                 legal custody or guardianship, or is raising the child  
23                 informally.

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

26          "Older individual" means an individual who is 60 years of  
27          age or older.

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

1 Family Caregiver Support Program.

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

7 (1) Standards and mechanisms designed to ensure the  
8 quality of services provided with assistance made  
9 available under this Act.

10 (2) Data collection and record maintenance.

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

14 Section 25. Provision of services. The Department shall  
15 contract with area agencies on aging and other appropriate  
16 agencies to conduct family caregiver support services to the  
17 extent of available State and federal funding. Services  
18 provided under this Act must be provided according to the  
19 requirements of federal law and rules.

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

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

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

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

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

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

11           (320 ILCS 10/1.5) (from Ch. 23, par. 6201.5)

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

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

31           Furthermore, the primary care-giver providing continuous  
 32 care is frequently under substantial financial stress.

1 Respite care and other supportive services sustain and  
 2 preserve the primary care-giver and family caregiving unit.  
 3 It is the intent of the General Assembly that this amendatory  
 4 Act of 1992 ensure that Illinois primary care-givers of frail  
 5 or abused or functionally disabled or cognitively-impaired  
 6 elder adults have access to affordable, appropriate in-home  
 7 respite care services.

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

9 (320 ILCS 10/2) (from Ch. 23, par. 6202)

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

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

28 (1.5) "In-home respite care" means care provided by an  
 29 appropriately trained paid worker providing short-term  
 30 intermittent care, supervision, or companionship to the frail  
 31 or disabled adult in the home while relieving the care-giver,  
 32 by permitting a short-term break from the care-giver's  
 33 care-giving role. This support may contribute to the delay,

1 reduction, and prevention of institutionalization by enabling  
 2 the care-giver to continue in his or her care-giving role.  
 3 In-home respite care should be flexible and available in a  
 4 manner that is responsive to the needs of the care-giver.  
 5 This may consist of evening respite care services that are  
 6 available from 6:00 p.m. to 8:00 a.m. Monday through Friday  
 7 and weekend respite care services from 6:00 p.m. Friday to  
 8 8:00 a.m. Monday.

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

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

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

26 (5) (Blank). "Director" shall mean the Director on  
 27 Aging.

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

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

32 (8) "Frail or disabled adult" shall mean any person  
 33 suffering from Alzheimer's disease and who is 60 55 years of  
 34 age or older and or any adult 60 years of age or older, who

1 either (i) suffers from Alzheimer's disease or a related  
 2 disorder or (ii) is unable to attend to his or her daily  
 3 needs without the assistance or regular supervision of a  
 4 care-giver due to mental or physical impairment and who is  
 5 otherwise eligible for services on the basis of his or her  
 6 level of impairment.

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

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

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

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

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

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

1 same--household--as--the--frail--or--abused--or--functionally  
 2 disabled--or--cognitively-impaired-adult.-A-primary-care-giver  
 3 requires-intermittent-relief-from-their-caregiving-duties--to  
 4 continue-to-function-as-the-primary-care-giver.

5 (Source: P.A. 91-357, eff. 7-29-99; revised 2-23-00.)

6 (320 ILCS 10/3) (from Ch. 23, par. 6203)

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

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

14 (320 ILCS 10/4) (from Ch. 23, par. 6204)

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

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

20 (320 ILCS 10/5) (from Ch. 23, par. 6205)

21 Sec. 5. Eligibility. The Department may establish  
 22 eligibility standards for respite services taking into  
 23 consideration the unique economic and social needs of the  
 24 population for whom they are to be provided. The population  
 25 identified for the purposes of this Act includes persons  
 26 suffering from Alzheimer's disease or a related disorder and  
 27 persons who are 60 55 years of age or older<sub>7</sub>--or--persons-age  
 28 60--and--older with an identified service need. Priority shall  
 29 be given in all cases to frail<sub>7</sub>--abused or functionally  
 30 disabled or--cognitively-impaired adults.

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

1 (320 ILCS 10/6) (from Ch. 23, par. 6206)

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

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

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

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

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

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

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

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

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

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

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

34 (d) (Blank). The-Director-shall-review-and-evaluate-each

1 application--and--present--each--application--for--review-and  
 2 evaluation-by-the-Council-on-Aging-established-under--Section  
 3 7--of--the--Illinois--Act--on-the-Aging.--The-Council-and-the  
 4 Department-shall-approve-a-number-of-applications-and, within  
 5 the-amounts-appropriated, award-grants-for-the--operation--of  
 6 respite-programs.

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

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

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

21 (320 ILCS 10/8) (from Ch. 23, par. 6208)

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

1 and Human Services.

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

3 (320 ILCS 10/11) (from Ch. 23, par. 6211)

4 Sec. 11. Respite Care Worker Training.

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

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

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

21 (320 ILCS 10/12) (from Ch. 23, par. 6212)

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

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

28 (b) ~~--a--qualitative--and--quantitative--profile--of--sponsors,~~  
29 ~~providers,~~ ~~--care-givers--and--recipients--participating--in--the~~  
30 ~~program;~~

31 (c) ~~--a--comparative--assessment--of--the--costs--and~~  
32 ~~effectiveness--of--each--service--or--combination--of--services~~

1 provided;

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

4 ~~(e)--an-evaluation-of-the-success-of--programs--receiving~~  
5 ~~grants-for-services-~~

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

7 (320 ILCS 10/7 rep.)

8 (320 ILCS 10/9 rep.)

9 (320 ILCS 10/10 rep.)

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

12 Section 99. Effective date. This Act takes effect upon  
13 becoming law."