

1 AMENDMENT TO HOUSE BILL 1102

2 AMENDMENT NO. _____. Amend House Bill 1102 by replacing
3 everything after the enacting clause with the following:

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

1 caregiver, this stress may lead to premature or
2 unnecessary institutionalization of the care recipient or
3 deterioration in the health condition and family
4 circumstances of the caregiver.

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

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

19 Services provided under this program shall do the
20 following:

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

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

25 (3) Provide temporary substitute support services
26 or living arrangements to allow a period of relief or
27 rest for caregivers.

28 (4) Be provided in the least restrictive setting
29 available consistent with the individually assessed needs
30 of the frail individual.

31 (5) Include services appropriate to the needs of
32 family members caring for the frail individual, including
33 a frail individual with dementia.

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

6 Section 15. Definitions. In this Act:

7 "Child" or "children" means an individual or individuals
8 18 years of age or under.

9 "Department" means the Department on Aging.

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

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

15 "Family caregiver support services" includes, but is not
16 limited to, the following:

17 (1) Information to caregivers about available
18 services.

19 (2) Assistance to caregivers in gaining access to
20 the services.

21 (3) Individual counseling, organization of support
22 groups, and caregiver training for caregivers to assist
23 the caregivers in making decisions and solving problems
24 relating to their caregiving roles.

25 (4) Respite care provided to a frail individual
26 that will enable caregivers to be temporarily relieved
27 from their caregiving responsibilities.

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

30 (6) Other services as identified by the Department
31 and defined by rule.

32 "Frail individual" means an older individual who is
33 determined to be functionally impaired because the individual

1 (i) is unable to perform from at least 2 activities of daily
2 living without substantial human assistance, including verbal
3 reminding, physical cueing, or supervision or (ii) due to a
4 cognitive or other mental impairment, requires substantial
5 supervision because the individual behaves in a manner that
6 poses a serious health or safety hazard to the individual or
7 to another individual.

8 "Grandparent or older individual who is a relative
9 caregiver" means a grandparent or step-grandparent of a
10 child, or a relative of a child by blood or marriage, who is
11 60 years of age or older and who:

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

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

22 "Older individual" means an individual who is 60 years of
23 age or older.

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

32 Section 16. Family caregiver demonstration grant. The
33 Department shall seek federal funding for the establishment

1 and assessment of a Family Caregiver Training and Support
2 Demonstration Project using residential facilities licensed
3 under the Nursing Home Care Act. The Department is
4 authorized to fund 2 sites, one in a rural community and one
5 in a more urban area. The Department shall adopt rules
6 governing participation and oversight of the program. The
7 Department shall seek technical assistance from the
8 Department of Public Aid. The Department shall advise the
9 Governor and the General Assembly regarding the effectiveness
10 of the program within 6 months after the conclusion of the
11 demonstration period.

12 Section 20. Powers and duties of the Department. The
13 Department shall administer this Act and shall adopt rules
14 and standards the Department deems necessary for that
15 purpose. At a minimum, those rules and standards shall
16 address the following:

17 (1) Standards and mechanisms designed to ensure the
18 quality of services provided with assistance made
19 available under this Act.

20 (2) Data collection and record maintenance.

21 The Department shall administer this Act in coordination
22 with Section 4.02 and related provisions of the Illinois Act
23 on the Aging.

24 Section 25. Provision of services. The Department shall
25 contract with area agencies on aging and other appropriate
26 agencies to conduct family caregiver support services to the
27 extent of available State and federal funding. Services
28 provided under this Act must be provided according to the
29 requirements of federal law and rules.

30 Section 35. Health care practitioners and facilities not
31 impaired. Nothing in this Act shall impair the practice of

1 any licensed health care practitioner or licensed health care
2 facility.

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

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

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

14 (c) The Department may seek appropriate waivers of
15 federal requirements from the U.S. Department of Health and
16 Human Services.

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

20 (320 ILCS 10/1.5) (from Ch. 23, par. 6201.5)

21 Sec. 1.5. Purpose. It is hereby found and determined by
22 the General Assembly that respite care provides relief and
23 support to the primary care-giver of a frail ~~or--abused~~ or
24 ~~functionally disabled or-cognitively-impaired-older~~ adult and
25 provides ~~by--providing~~ a break for the caregiver from the
26 continuous responsibilities of care-giving. Without this
27 support, the primary care-giver's ability to continue in his
28 or her role would be jeopardized; thereby increasing the risk
29 of institutionalization of the frail ~~or---abused~~ or
30 ~~functionally disabled or-cognitively-impaired-older~~ adult.

31 By providing ~~improving-and-expanding-the-in-home~~ respite

1 care services--currently--available through intermittent
 2 planned or emergency relief to the care-giver during the
 3 regular week-day, evening, and weekend hours, both the
 4 special physical and psychological needs of the primary
 5 care-giver and the frail or-abused or functionally disabled,
 6 or-cognitively-impaired-elder adult, who is the recipient of
 7 continuous care, shall be met reducing or preventing the need
 8 for institutionalization.

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

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

19 (320 ILCS 10/2) (from Ch. 23, par. 6202)

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

21 (1) "Respite care" means the provision of intermittent
 22 and temporary substitute care or supervision of frail or
 23 abused or functionally disabled or-cognitively-impaired-elder
 24 adults on behalf of and in the absence of the primary
 25 care-giver, for the purpose of providing relief from the
 26 stress or responsibilities concomitant with providing
 27 constant care, so as to enable the care-giver to continue the
 28 provision of care in the home. Respite care should be
 29 available to sustain the primary care-giver throughout the
 30 period of care-giving, which can vary from several months to
 31 a number of years. Respite care can be provided in the home,
 32 in a community--based day care setting during the day,
 33 overnight, in a substitute residential setting such as a

1 long-term care facility required to be licensed under the
 2 Nursing Home Care Act or the Assisted Living and Shared
 3 Housing Act, or for more extended periods of time on a
 4 temporary basis.

5 (1.5) "In-home respite care" means care provided by an
 6 appropriately trained paid worker providing short-term
 7 intermittent care, supervision, or companionship to the frail
 8 or disabled adult in the home while relieving the care-giver,
 9 by permitting a short-term break from the care-giver's
 10 care-giving role. This support may contribute to the delay,
 11 reduction, and prevention of institutionalization by enabling
 12 the care-giver to continue in his or her care-giving role.
 13 In-home respite care should be flexible and available in a
 14 manner that is responsive to the needs of the care-giver.
 15 This may consist of evening respite care services that are
 16 available from 6:00 p.m. to 8:00 a.m. Monday through Friday
 17 and weekend respite care services from 6:00 p.m. Friday to
 18 8:00 a.m. Monday.

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

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

27 (4) (Blank). "Sponsor"-shall-mean-the--provider,--public
 28 agency--or--community--group--approved--by-the-Director-which
 29 establishes-a-contractual-relationship--with--the--Department
 30 for--the-purposes-of-providing-services-to-persons-under-this
 31 Act,--and--which--is--responsible--for--the--recruitment---of
 32 providers,--the--coordination--and--arrangement--of--provider
 33 services--in--a--manner-which-meets-client-needs,--the-general
 34 supervision-of-the-local-program,--and-the-submission-of--such

1 information-or-reports-as-may-be-required-by-the-Director.

2 (5) (Blank). "Director"--shall--mean--the--Director--of
3 Aging.

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

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

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

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

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

30 (b) An unplanned situation that prevents the
31 primary care-giver from providing the care required by a
32 frail or abused-or-functionally disabled or--cognitively
33 impaired adult living at home.

34 (c) An unplanned event that threatens the health

1 and safety of the frail or disabled adult.

2 (d) An unplanned event that threatens the health
3 and safety of the primary care-giver thereby placing the
4 frail or abused-or-functionally disabled or--cognitively
5 impaired-elder adult in danger.

6 (10) (Blank). "Primary--care-giver"--means--the-spouse,
7 relative,-or-friend,-18-years-of-age-or-elder,-who--provides
8 the--daily--in-home-care-and-supervision-of-a-frail-or-abused
9 or-functionally-disabled-or-cognitively-impaired-elder-adult.
10 A-primary-care-giver-may,-but-does-not-need-to,-reside-in-the
11 same--household--as--the--frail--or--abused--or--functionally
12 disabled-or-cognitively-impaired-adult.-A-primary--care-giver
13 requires--intermittent--relief--from--his--or--her-caregiving
14 duties-to-continue-to-function-as-the-primary-care-giver-

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

16 (320 ILCS 10/3) (from Ch. 23, par. 6203)

17 Sec. 3. Respite Program. The Director is hereby
18 authorized to administer a program of establish-respite
19 projects-for-the-purposes-of-providing-care-and assistance to
20 persons in need and to deter the institutionalization of
21 frail or disabled or--functionally-disabled-or-cognitively
22 impaired adults.

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

24 (320 ILCS 10/4) (from Ch. 23, par. 6204)

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

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

30 (320 ILCS 10/5) (from Ch. 23, par. 6205)

31 Sec. 5. Eligibility. The Department may establish

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

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

11 (320 ILCS 10/6) (from Ch. 23, par. 6206)

12 Sec. 6. Responsibilities. ~~The following requirements~~
13 ~~shall apply for any projects authorized under Section 3 of~~
14 ~~this Act:~~

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

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

25 (c) (Blank). ~~The application forms shall require the~~
26 ~~following information and any other information the Director~~
27 ~~deems necessary:~~

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

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

31 (3) ~~An assessment of the community need, support~~
32 ~~and participation for respite services. The assessment~~
33 ~~shall include documentation.~~

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

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

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

8 (7) Certification of licensure or certification of
9 any individual, agency or family providing a service
10 subject to licensure, or certification under State law.

11 (d) (Blank). The Director shall review and evaluate each
12 application and present each application for review and
13 evaluation by the Council on Aging established under Section
14 7 of the Illinois Act on the Aging. The Council and the
15 Department shall approve a number of applications and, within
16 the amounts appropriated, award grants for the operation of
17 respite programs.

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

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

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

32 (320 ILCS 10/8) (from Ch. 23, par. 6208)

33 Sec. 8. Funding. Services Respite projects authorized

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

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

14 (320 ILCS 10/11) (from Ch. 23, par. 6211)

15 Sec. 11. Respite Care Worker Training.

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

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

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

32 (320 ILCS 10/12) (from Ch. 23, par. 6212)

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

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

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

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

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

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

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

18 (320 ILCS 10/7 rep.)

19 (320 ILCS 10/9 rep.)

20 (320 ILCS 10/10 rep.)

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

23 Section 99. Effective date. This Act takes effect upon
 24 becoming law."