

1 AMENDMENT TO SENATE BILL 1620

2 AMENDMENT NO. _____. Amend Senate Bill 1620 by replacing
3 the 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 and grandparents or other older individuals who are relative
22 caregivers, who are informal providers of in-home and
23 community care to older individuals or children.

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

26 (1) Provide information, relief, and support to
27 family and other unpaid caregivers of older individuals
28 and children.

29 (2) Encourage family members to provide care for
30 their family members who are older individuals and
31 children.

32 (3) Provide temporary substitute support services
33 or living arrangements to allow a period of relief or

1 rest for caregivers.

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

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

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

13 Section 15. Definitions. In this Act:

14 "Caregiver" or "family caregiver" means an adult family
15 member, or another individual, who is an informal provider of
16 in-home and community care to an older individual, or a
17 grandparent or older individual who is a relative caregiver.

18 "Child" or "children" means an individual or individuals
19 18 years of age or under.

20 "Department" means the Department on Aging.

21 "Eligible participant" means a family caregiver or a
22 grandparent or older individual who is a relative caregiver.

23 "Family caregiver support services" includes, but is not
24 limited to, the following:

25 (1) Information to caregivers about available
26 services.

27 (2) Assistance to caregivers in gaining access to
28 the services.

29 (3) Individual counseling, organization of support
30 groups, and caregiver training for caregivers to assist
31 the caregivers in making decisions and solving problems
32 relating to their caregiving roles.

33 (4) Respite care to enable caregivers to be

1 temporarily relieved from their caregiving
2 responsibilities.

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

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

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

16 "Grandparent or older individual who is a relative
17 caregiver" means a grandparent or step-grandparent of a
18 child, or a relative of a child by blood or marriage, who:

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

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

29 "Older individual" means an individual who is 60 years of
30 age or older, except for a grandparent or older individual
31 who is a relative caregiver.

32 "Respite care" means substitute supports or living
33 arrangements provided on an intermittent, occasional basis.
34 The term includes, but is not limited to, in-home respite

1 care, adult day care, child care, and institutional care. The
2 term also includes respite care as defined in Section 2 of
3 the Respite Program Act to the extent that such services are
4 allowable and participants are eligible under the National
5 Family Caregiver Support Program.

6 Section 16. Family caregiver demonstration grant. The
7 Department shall seek federal funding for the establishment
8 and assessment of a Family Caregiver Training and Support
9 Demonstration Project in collaboration with providers of
10 long-term care licensed under the Nursing Home Care Act. The
11 Department is authorized to fund 2 sites, one in a rural
12 community and one in a more urban area. The Department shall
13 adopt rules governing participation and oversight of the
14 program. The Department shall seek technical assistance from
15 the Department of Public Aid and the Department of Human
16 Services. The Department shall advise the Governor and the
17 General Assembly regarding the effectiveness of the program
18 within 6 months after the conclusion of the demonstration
19 period.

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

25 (1) Standards and mechanisms designed to ensure the
26 quality of services provided with assistance made
27 available under this Act.

28 (2) Data collection and record maintenance.

29 The Department shall administer this Act in coordination
30 with Section 4.02 and related provisions of the Illinois Act
31 on the Aging.

1 Section 25. Provision of services. The Department shall
2 contract with area agencies on aging and other appropriate
3 agencies to conduct family caregiver support services to the
4 extent of available State and federal funding. Services
5 provided under this Act must be provided according to the
6 requirements of federal law and rules, except for the
7 provision of services to grandparents or older individuals
8 who are relative caregivers when State funding is utilized to
9 provide those services.

10 Section 30. Eligibility for respite and supplemental
11 services. When a family caregiver is providing in-home and
12 community care to an older individual, the older individual
13 must be a frail individual as defined in this Act in order
14 for the family caregiver to be eligible to receive respite
15 and supplemental services.

16 Section 35. Health care practitioners and facilities not
17 impaired. Nothing in this Act shall impair the practice of
18 any licensed health care practitioner or licensed health care
19 facility.

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

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

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

31 (c) The Department may seek appropriate waivers of

1 federal requirements from the U.S. Department of Health and
2 Human Services.

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

6 (320 ILCS 10/1.5) (from Ch. 23, par. 6201.5)

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

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

26 Furthermore, the primary care-giver providing continuous
27 care is frequently under substantial financial stress.
28 Respite care and other supportive services sustain and
29 preserve the primary care-giver and family caregiving unit.
30 It is the intent of the General Assembly that this amendatory
31 Act ~~of-1992~~ ensure that Illinois primary care-givers of frail
32 ~~or--abused~~ or ~~functionally disabled or-cognitively-impaired~~

1 elder adults have access to affordable, appropriate in-home
2 respite care services.

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

4 (320 ILCS 10/2) (from Ch. 23, par. 6202)

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

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

23 (1.5) "In-home respite care" means care provided by an
24 appropriately trained paid worker providing short-term
25 intermittent care, supervision, or companionship to the frail
26 or disabled adult in the home while relieving the care-giver,
27 by permitting a short-term break from the care-giver's
28 care-giving role. This support may contribute to the delay,
29 reduction, and prevention of institutionalization by enabling
30 the care-giver to continue in his or her care-giving role.
31 In-home respite care should be flexible and available in a
32 manner that is responsive to the needs of the care-giver.
33 This may consist of evening respite care services that are

1 available from 6:00 p.m. to 8:00 a.m. Monday through Friday
2 and weekend respite care services from 6:00 p.m. Friday to
3 8:00 a.m. Monday.

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

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

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

21 (5) (Blank). "Director" shall mean the Director of
22 Aging.

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

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

27 (8) "Frail or disabled adult" shall mean any person
28 suffering from Alzheimer's disease who is 60 55 years of age
29 or older and or any adult 60 years of age or older, who
30 either (i) suffers from Alzheimer's disease or a related
31 disorder or (ii) is unable to attend to his or her daily
32 needs without the assistance or regular supervision of a
33 care-giver due to mental or physical impairment and who is
34 otherwise eligible for services on the basis of his or her

1 level of impairment.

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

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

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

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

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

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

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

1 (320 ILCS 10/3) (from Ch. 23, par. 6203)

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

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

9 (320 ILCS 10/4) (from Ch. 23, par. 6204)

10 Sec. 4. No Limit to Care. Nothing contained in this Act
11 shall be construed so as to limit, modify or otherwise affect
12 the provisions₇ for ~~long-term~~ in-home services being provided
13 under₇ ~~of~~ Section 4.02 of the Illinois Act on the Aging.

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

15 (320 ILCS 10/5) (from Ch. 23, par. 6205)

16 Sec. 5. Eligibility. The Department may establish
17 eligibility standards for respite services taking into
18 consideration the unique economic and social needs of the
19 population for whom they are to be provided. The population
20 identified for the purposes of this Act includes persons
21 suffering from Alzheimer's disease or a related disorder and
22 persons who are 60 55 years of age or older₇ ~~or persons age~~
23 ~~60-and-older~~ with an identified service need. Priority shall
24 be given in all cases to frail₇ ~~--abused~~ or ~~functionally~~
25 ~~disabled or cognitively-impaired~~ adults.

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

27 (320 ILCS 10/6) (from Ch. 23, par. 6206)

28 Sec. 6. Responsibilities. ~~The--following-requirements~~
29 ~~shall-apply-for-any-projects-authorized-under--Section--3--of~~
30 ~~this-Act:~~

31 (a) The Department ~~Director~~ shall administer this Act

1 and shall adopt rules and standards the Department deems
2 necessary for that purpose establish target areas needing
3 respite care services.

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

10 (c) (Blank). The application forms shall require the
11 following information and any other information the Director
12 deems necessary:

13 (1) Identity and qualifications of a sponsor.

14 (2) Identity and qualifications of a provider and a
15 plan for the coordination of services.

16 (3) An assessment of the community need, support
17 and participation for respite services. The assessment
18 shall include documentation.

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

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

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

26 (7) Certification of licensure or certification of
27 any individual, agency or family providing a service
28 subject to licensure, or certification under State law.

29 (d) (Blank). The Director shall review and evaluate each
30 application and present each application for review and
31 evaluation by the Council on Aging established under Section
32 7 of the Illinois Act on the Aging. The Council and the
33 Department shall approve a number of applications and, within
34 the amounts appropriated, award grants for the operation of

1 respite-programs.

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

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

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

16 (320 ILCS 10/8) (from Ch. 23, par. 6208)

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

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

31 (320 ILCS 10/11) (from Ch. 23, par. 6211)

32 Sec. 11. Respite Care Worker Training.

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

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

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

17 (320 ILCS 10/12) (from Ch. 23, par. 6212)

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

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

24 ~~(b)--a--qualitative--and--quantitative--profile--of--sponsors,~~
 25 ~~providers,~~~~--care-givers--and--recipients--participating--in--the~~
 26 ~~program;~~

27 ~~(c)--a--comparative--assessment--of--the--costs--and~~
 28 ~~effectiveness--of--each--service--or--combination--of--services~~
 29 ~~provided;~~

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

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

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

2 (320 ILCS 10/7 rep.)

3 (320 ILCS 10/9 rep.)

4 (320 ILCS 10/10 rep.)

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

7 Section 99. Effective date. This Act takes effect upon
8 becoming law."