

107TH CONGRESS
2^D SESSION

S. 2489

To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.

IN THE SENATE OF THE UNITED STATES

MAY 9, 2002

Mrs. CLINTON (for herself, Ms. SNOWE, Ms. MIKULSKI, and Mr. BREAU) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Lifespan Respite Care
5 Act of 2002”.

6 **SEC. 2. LIFESPAN RESPITE CARE.**

7 The Public Health Service Act (42 U.S.C. 201 et
8 seq.) is amended by adding at the end the following:

1 **“TITLE XXVIII—LIFESPAN**
2 **RESPITE CARE**

3 **“SEC. 2801. FINDINGS AND PURPOSES.**

4 “(a) FINDINGS.—Congress finds that—

5 “(1) an estimated 26,000,000 individuals in the
6 United States care each year for 1 or more adult
7 family members or friends who are chronically ill,
8 disabled, or terminally ill;

9 “(2) an estimated 18,000,000 children in the
10 United States have chronic physical, developmental,
11 behavioral, or emotional conditions that demand
12 caregiver monitoring, management, supervision, or
13 treatment beyond that required of children generally;

14 “(3) approximately 6,000,000 children in the
15 United States live with a grandparent or other rel-
16 ative because their parents are unable or unwilling
17 to care for them;

18 “(4) an estimated 165,000 children with dis-
19 abilities in the United States live with a foster care
20 parent;

21 “(5) nearly 4,000,000 individuals in the United
22 States of all ages who have mental retardation or
23 another developmental disability live with their fami-
24 lies;

1 “(6) almost 25 percent of the Nation’s elders
2 experience multiple chronic disabling conditions that
3 make it necessary to rely on others for help in meet-
4 ing their daily needs;

5 “(7) every year, approximately 600,000 Ameri-
6 cans die at home and many of these individuals rely
7 on extensive family caregiving before their death;

8 “(8) of all individuals in the United States
9 needing assistance in daily living, 42 percent are
10 under age 65;

11 “(9) there are insufficient resources to replace
12 family caregivers with paid workers;

13 “(10) if services provided by family caregivers
14 had to be replaced with paid services, it would cost
15 approximately \$200,000,000,000 annually;

16 “(11) the family caregiver role is personally re-
17 warding but can result in substantial emotional,
18 physical, and financial hardship;

19 “(12) approximately 75 percent of family care-
20 givers are women;

21 “(13) family caregivers often do not know
22 where to find information about available respite
23 care or how to access it;

24 “(14) available respite care programs are insuf-
25 ficient to meet the need and are directed at pri-

1 marily lower income populations and family care-
2 givers of the elderly, leaving large numbers of family
3 caregivers without adequate support; and

4 “(15) the limited number of available respite
5 care programs find it difficult to recruit appro-
6 priately trained respite workers.

7 “(b) PURPOSES.—The purposes of this title are—

8 “(1) to encourage States to establish State and
9 local lifespan respite care programs;

10 “(2) to improve and coordinate the dissemina-
11 tion of respite care information and resources to
12 family caregivers;

13 “(3) to provide, supplement, or improve respite
14 care services to family caregivers;

15 “(4) to promote innovative, flexible, and com-
16 prehensive approaches to—

17 “(A) the delivery of respite care;

18 “(B) respite care worker and volunteer re-
19 cruitment and training programs; and

20 “(C) training programs for family care-
21 givers to assist such family caregivers in mak-
22 ing informed decisions about respite care serv-
23 ices;

24 “(5) to support evaluative research to identify
25 effective respite care services that alleviate, reduce,

1 or minimize any negative consequences of caregiving;
2 and

3 “(6) to promote the dissemination of results,
4 findings, and information from programs and re-
5 search projects relating to respite care delivery, fam-
6 ily caregiver strain, respite care worker and volun-
7 teer recruitment and training, and training pro-
8 grams for family caregivers that assist such family
9 caregivers in making informed decisions about res-
10 pite care services.

11 **“SEC. 2802. DEFINITIONS.**

12 “In this title:

13 “(1) ASSOCIATE ADMINISTRATOR.—The term
14 ‘Associate Administrator’ means the Associate Ad-
15 ministrator of the Maternal and Child Health Bu-
16 reau of the Health Resources and Services Adminis-
17 tration.

18 “(2) CONDITION.—The term ‘condition’
19 includes—

20 “(A) Alzheimer’s disease and related dis-
21 orders;

22 “(B) developmental disabilities;

23 “(C) mental retardation;

24 “(D) physical disabilities;

25 “(E) chronic illness, including cancer;

1 “(F) behavioral, mental, and emotional
2 conditions;

3 “(G) cognitive impairments;

4 “(H) situations in which there exists a
5 high risk of abuse or neglect or of being placed
6 in the foster care system due to abuse and ne-
7 glect;

8 “(I) situations in which a child’s parent is
9 unavailable due to the parent’s death, incapaci-
10 tation, or incarceration; or

11 “(J) any other conditions as the Associate
12 Administrator may establish by regulation.

13 “(3) ELIGIBLE RECIPIENT.—The term ‘eligible
14 recipient’ means—

15 “(A) a State agency;

16 “(B) any other public entity that is capa-
17 ble of operating on a statewide basis;

18 “(C) a private, nonprofit organization that
19 is capable of operating on a statewide basis;

20 “(D) a political subdivision of a State that
21 has a population of not less than 3,000,000 in-
22 dividuals; or

23 “(E) any recognized State respite coordi-
24 nating agency that has—

1 “(i) a demonstrated ability to work
2 with other State and community-based
3 agencies;

4 “(ii) an understanding of respite care
5 and family caregiver issues; and

6 “(iii) the capacity to ensure meaning-
7 ful involvement of family members, family
8 caregivers, and care recipients.

9 “(4) FAMILY CAREGIVER.—The term ‘family
10 caregiver’ means an unpaid family member, a foster
11 parent, or another unpaid adult, who provides in-
12 home monitoring, management, supervision, or
13 treatment of a child or adult with a special need.

14 “(5) LIFESPAN RESPITE CARE.—The term ‘life-
15 span respite care’ means a coordinated system of ac-
16 cessible, community-based respite care services for
17 family caregivers of individuals regardless of the in-
18 dividual’s age, race, ethnicity, or special need.

19 “(6) RESPITE CARE.—The term ‘respite care’
20 means planned or emergency care provided to an in-
21 dividual with a special need—

22 “(A) in order to provide temporary relief
23 to the family caregiver of that individual; or

24 “(B) when the family caregiver of that in-
25 dividual is unable to provide care.

1 “(7) SPECIAL NEED.—The term ‘special need’
 2 means the particular needs of an individual of any
 3 age who requires care or supervision because of a
 4 condition in order to meet the individual’s basic
 5 needs or to prevent harm to the individual.

6 **“SEC. 2803. LIFESPAN RESPITE CARE GRANTS AND COOP-**
 7 **ERATIVE AGREEMENTS.**

8 “(a) PURPOSES.—The purposes of this section are—

9 “(1) to expand and enhance respite care serv-
 10 ices to family caregivers;

11 “(2) to improve the statewide dissemination and
 12 coordination of respite care; and

13 “(3) to provide, supplement, or improve access
 14 and quality of respite care services to family care-
 15 givers, thereby reducing family caregiver strain.

16 “(b) AUTHORIZATION.—Subject to subsection (f), the
 17 Associate Administrator is authorized to award grants or
 18 cooperative agreements to eligible recipients who submit
 19 an application pursuant to subsection (d).

20 “(c) FEDERAL LIFESPAN APPROACH.—In carrying
 21 out this section, the Associate Administrator shall work
 22 in cooperation with the National Family Caregiver Sup-
 23 port Program Officer of the Administration on Aging, and
 24 respite care program officers in the Administration for
 25 Children and Families, the Administration on Develop-

1 mental Disabilities, and the Substance Abuse and Mental
2 Health Services Administration, to ensure coordination of
3 respite care services for family caregivers of individuals
4 of all ages with special needs.

5 “(d) APPLICATION.—

6 “(1) SUBMISSION.—Each eligible recipient de-
7 siring to receive a grant or cooperative agreement
8 under this section shall submit an application to the
9 Associate Administrator at such time, in such man-
10 ner, and containing such information as the Asso-
11 ciate Administrator shall require.

12 “(2) CONTENTS.—Each application submitted
13 under this section shall include—

14 “(A) a description of the applicant’s—

15 “(i) understanding of respite care and
16 family caregiver issues;

17 “(ii) capacity to ensure meaningful in-
18 volvement of family members, family care-
19 givers, and care recipients; and

20 “(iii) collaboration with other State
21 and community-based public, nonprofit, or
22 private agencies;

23 “(B) with respect to the population of fam-
24 ily caregivers to whom respite care information
25 or services will be provided or for whom respite

1 care workers and volunteers will be recruited
2 and trained, a description of—

3 “(i) the population;

4 “(ii) the extent and nature of the res-
5 pite care needs of the population;

6 “(iii) existing respite care services for
7 the population, including numbers of fam-
8 ily caregivers being served and extent of
9 unmet need;

10 “(iv) existing methods or systems to
11 coordinate respite care information and
12 services to the population at the State and
13 local level and extent of unmet need;

14 “(v) how respite care information dis-
15 semination and coordination, respite care
16 services, respite care worker and volunteer
17 recruitment and training programs, or
18 training programs for family caregivers
19 that assist such family caregivers in mak-
20 ing informed decisions about respite care
21 services will be provided using grant or co-
22 operative agreement funds;

23 “(vi) a plan for collaboration and co-
24 ordination of the proposed respite care ac-
25 tivities with other related services or pro-

1 grams offered by public or private, non-
2 profit entities, including area agencies on
3 aging;

4 “(vii) how the population, including
5 family caregivers, care recipients, and rel-
6 evant public or private agencies, will par-
7 ticipate in the planning and implementa-
8 tion of the proposed respite care activities;

9 “(viii) how the proposed respite care
10 activities will make use, to the maximum
11 extent feasible, of other Federal, State,
12 and local funds, programs, contributions,
13 other forms of reimbursements, personnel,
14 and facilities;

15 “(ix) respite care services available to
16 family caregivers in the applicant’s State
17 or locality, including unmet needs and how
18 the applicant’s plan for use of funds will
19 improve the coordination and distribution
20 of respite care services for family care-
21 givers of individuals of all ages with special
22 needs;

23 “(x) the criteria used to identify fam-
24 ily caregivers eligible for respite care serv-
25 ices;

1 “(xi) how the quality and safety of
2 any respite care services provided will be
3 monitored, including methods to ensure
4 that respite care workers and volunteers
5 are appropriately screened and possess the
6 necessary skills to care for the needs of the
7 care recipient in the absence of the family
8 caregiver; and

9 “(xii) the results expected from pro-
10 posed respite care activities and the proce-
11 dures to be used for evaluating those re-
12 sults; and

13 “(C) assurances that, where appropriate,
14 the applicant shall have a system for maintain-
15 ing the confidentiality of care recipient and
16 family caregiver records.

17 “(e) REVIEW OF APPLICATIONS.—

18 “(1) ESTABLISHMENT OF REVIEW PANEL.—
19 The Associate Administrator shall establish a panel
20 to review applications submitted under this section.

21 “(2) MEETINGS.—The panel shall meet as often
22 as may be necessary to facilitate the expeditious re-
23 view of applications.

24 “(3) FUNCTION OF PANEL.—The panel shall—

1 “(A) review and evaluate each application
2 submitted under this section; and

3 “(B) make recommendations to the Asso-
4 ciate Administrator concerning whether the ap-
5 plication should be approved.

6 “(f) AWARDING OF GRANTS OR COOPERATIVE
7 AGREEMENTS.—

8 “(1) IN GENERAL.—The Associate Adminis-
9 trator shall award grants or cooperative agreements
10 from among the applications approved by the panel
11 under subsection (e)(3).

12 “(2) PRIORITY.—When awarding grants or co-
13 operative agreements under this subsection, the As-
14 sociate Administrator shall give priority to appli-
15 cants that show the greatest likelihood of imple-
16 menting or enhancing lifespan respite care statewide.

17 “(g) USE OF GRANT OR COOPERATIVE AGREEMENT
18 FUNDS.—

19 “(1) IN GENERAL.—

20 “(A) MANDATORY USES OF FUNDS.—Each
21 eligible recipient that is awarded a grant or co-
22 operative agreement under this section shall use
23 the funds for, unless such a program is in
24 existence—

1 “(i) the development of lifespan res-
2 pite care at the State and local levels; and

3 “(ii) an evaluation of the effectiveness
4 of such care.

5 “(B) DISCRETIONARY USES OF FUNDS.—

6 Each eligible recipient that is awarded a grant
7 or cooperative agreement under this section
8 may use the funds for—

9 “(i) respite care services;

10 “(ii) respite care worker and volunteer
11 training programs; or

12 “(iii) training programs for family
13 caregivers to assist such family caregivers
14 in making informed decisions about respite
15 care services.

16 “(C) EVALUATION.—If an eligible recipient
17 uses funds awarded under this section for an
18 activity described in subparagraph (B), the eli-
19 gible recipient shall use funds for an evaluation
20 of the effectiveness of the activity.

21 “(2) SUBCONTRACTS.—Each eligible recipient
22 that is awarded a grant or cooperative agreement
23 under this section may use the funds to subcontract
24 with a public or nonprofit agency to carry out the
25 activities described in paragraph (1).

1 “(h) TERM OF GRANTS OR COOPERATIVE AGREE-
2 MENTS.—

3 “(1) IN GENERAL.—The Associate Adminis-
4 trator shall award grants or cooperative agreements
5 under this section for terms that do not exceed 5
6 years.

7 “(2) RENEWAL.—The Associate Administrator
8 may renew a grant or cooperative agreement under
9 this section at the end of the term of the grant or
10 cooperative agreement determined under paragraph
11 (1).

12 “(i) SUPPLEMENT, NOT SUPPLANT.—Funds made
13 available under this section shall be used to supplement
14 and not supplant other Federal, State, and local funds
15 available for respite care services.

16 “(j) AUTHORIZATION OF APPROPRIATIONS.—There
17 are authorized to be appropriated to carry out this
18 section—

19 “(1) \$90,500,000 for fiscal year 2003;

20 “(2) \$118,000,000 for fiscal year 2004;

21 “(3) \$145,500,000 for fiscal year 2005;

22 “(4) \$173,000,000 for fiscal year 2006; and

23 “(5) \$200,000,000 for fiscal year 2007.

1 **“SEC. 2804. NATIONAL LIFESPAN RESPITE RESOURCE CEN-**
2 **TER.**

3 “(a) ESTABLISHMENT.—From funds appropriated
4 under subsection (c), the Associate Administrator shall
5 award a grant or cooperative agreement to a public or pri-
6 vate nonprofit entity to establish a National Resource
7 Center on Lifespan Respite Care (referred to in this sec-
8 tion as the ‘center’).

9 “(b) PURPOSES OF THE CENTER.—The center
10 shall—

11 “(1) maintain a national database on lifespan
12 respite care;

13 “(2) provide training and technical assistance
14 to State, community, and nonprofit respite care pro-
15 grams; and

16 “(3) provide information, referral, and edu-
17 cational programs to the public on lifespan respite
18 care.

19 “(c) AUTHORIZATION OF APPROPRIATIONS.—There
20 are authorized to be appropriated to carry out this section
21 \$500,000 for each of fiscal years 2003 through 2007.”.

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