

Calendar No. 511107TH 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, Mr. BREAUX, Mr. INOUE, Mr. SMITH of Oregon, Mr. HOLLINGS, Mrs. MURRAY, Mr. WARNER, Ms. COLLINS, and Mr. WELLSTONE) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

JULY 23, 2002

Reported by Mr. KENNEDY, with an amendment

[Strike out all after the enacting clause and insert the part printed in *italic*]

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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Lifespan Respite Care
3 Act of 2002”.

4 **SEC. 2. LIFESPAN RESPITE CARE.**

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

7 **“TITLE XXVIII—LIFESPAN**
8 **RESPITE CARE**

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

10 “(a) FINDINGS.—Congress finds that—

11 “(1) an estimated 26,000,000 individuals in the
12 United States care each year for 1 or more adult
13 family members or friends who are chronically ill,
14 disabled, or terminally ill;

15 “(2) an estimated 18,000,000 children in the
16 United States have chronic physical, developmental,
17 behavioral, or emotional conditions that demand
18 caregiver monitoring, management, supervision, or
19 treatment beyond that required of children generally;

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

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

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

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

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

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

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

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

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

23 “(12) approximately 75 percent of family care-
24 givers are women;

1 “(13) family caregivers often do not know
2 where to find information about available respite
3 care or how to access it;

4 “(14) available respite care programs are insuf-
5 ficient to meet the need and are directed at pri-
6 marily lower income populations and family care-
7 givers of the elderly, leaving large numbers of family
8 caregivers without adequate support; and

9 “(15) the limited number of available respite
10 care programs find it difficult to recruit appro-
11 priately trained respite workers.

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

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

15 “(2) to improve and coordinate the dissemina-
16 tion of respite care information and resources to
17 family caregivers;

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

20 “(4) to promote innovative, flexible, and com-
21 prehensive approaches to—

22 “(A) the delivery of respite care;

23 “(B) respite care worker and volunteer re-
24 cruitment and training programs; and

1 “(C) training programs for family care-
 2 givers to assist such family caregivers in mak-
 3 ing informed decisions about respite care serv-
 4 ices;

5 “(5) to support evaluative research to identify
 6 effective respite care services that alleviate, reduce,
 7 or minimize any negative consequences of caregiving;
 8 and

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

17 **“SEC. 2802. DEFINITIONS.**

18 “In this title:

19 “(1) ASSOCIATE ADMINISTRATOR.—The term
 20 ‘Associate Administrator’ means the Associate Ad-
 21 ministrator of the Maternal and Child Health Bu-
 22 reau of the Health Resources and Services Adminis-
 23 tration.

24 “(2) CONDITION.—The term ‘condition’
 25 includes—

1 “(A) Alzheimer’s disease and related dis-
2 orders;

3 “(B) developmental disabilities;

4 “(C) mental retardation;

5 “(D) physical disabilities;

6 “(E) chronic illness, including cancer;

7 “(F) behavioral, mental, and emotional
8 conditions;

9 “(G) cognitive impairments;

10 “(H) situations in which there exists a
11 high risk of abuse or neglect or of being placed
12 in the foster care system due to abuse and ne-
13 glect;

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

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

19 “(3) ELIGIBLE RECIPIENT.—The term ‘eligible
20 recipient’ means—

21 “(A) a State agency;

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

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

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

4 “(E) any recognized State respite coordi-
5 nating agency that has—

6 “(i) a demonstrated ability to work
7 with other State and community-based
8 agencies;

9 “(ii) an understanding of respite care
10 and family caregiver issues; and

11 “(iii) the capacity to ensure meaning-
12 ful involvement of family members, family
13 caregivers, and care recipients.

14 “(4) FAMILY CAREGIVER.—The term ‘family
15 caregiver’ means an unpaid family member, a foster
16 parent, or another unpaid adult, who provides in-
17 home monitoring, management, supervision, or
18 treatment of a child or adult with a special need.

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

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

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

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

8 “(7) SPECIAL NEED.—The term ‘special need’
9 means the particular needs of an individual of any
10 age who requires care or supervision because of a
11 condition in order to meet the individual’s basic
12 needs or to prevent harm to the individual.

13 **“SEC. 2803. LIFESPAN RESPITE CARE GRANTS AND COOP-**
14 **ERATIVE AGREEMENTS.**

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

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

18 “(2) to improve the statewide dissemination and
19 coordination of respite care; and

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

23 “(b) AUTHORIZATION.—Subject to subsection (f), the
24 Associate Administrator is authorized to award grants or

1 cooperative agreements to eligible recipients who submit
 2 an application pursuant to subsection (d).

3 “(e) ~~FEDERAL LIFESPAN APPROACH.~~—In carrying
 4 out this section, the Associate Administrator shall work
 5 in cooperation with the National Family Caregiver Sup-
 6 port Program Officer of the Administration on Aging, and
 7 respite care program officers in the Administration for
 8 Children and Families, the Administration on Develop-
 9 mental Disabilities, and the Substance Abuse and Mental
 10 Health Services Administration, to ensure coordination of
 11 respite care services for family caregivers of individuals
 12 of all ages with special needs.

13 “(d) ~~APPLICATION.~~—

14 “(1) ~~SUBMISSION.~~—Each eligible recipient de-
 15 siring to receive a grant or cooperative agreement
 16 under this section shall submit an application to the
 17 Associate Administrator at such time, in such man-
 18 ner, and containing such information as the Asso-
 19 ciate Administrator shall require.

20 “(2) ~~CONTENTS.~~—Each application submitted
 21 under this section shall include—

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

23 “(i) understanding of respite care and
 24 family caregiver issues;

1 “(ii) capacity to ensure meaningful in-
2 volvement of family members, family care-
3 givers, and care recipients; and

4 “(iii) collaboration with other State
5 and community-based public, nonprofit, or
6 private agencies;

7 “(B) with respect to the population of fam-
8 ily caregivers to whom respite care information
9 or services will be provided or for whom respite
10 care workers and volunteers will be recruited
11 and trained, a description of—

12 “(i) the population;

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

15 “(iii) existing respite care services for
16 the population, including numbers of fam-
17 ily caregivers being served and extent of
18 unmet need;

19 “(iv) existing methods or systems to
20 coordinate respite care information and
21 services to the population at the State and
22 local level and extent of unmet need;

23 “(v) how respite care information dis-
24 semination and coordination, respite care
25 services, respite care worker and volunteer

1 recruitment and training programs, or
2 training programs for family caregivers
3 that assist such family caregivers in mak-
4 ing informed decisions about respite care
5 services will be provided using grant or co-
6 operative agreement funds;

7 “(vi) a plan for collaboration and co-
8 ordination of the proposed respite care ac-
9 tivities with other related services or pro-
10 grams offered by public or private, non-
11 profit entities, including area agencies on
12 aging;

13 “(vii) how the population, including
14 family caregivers, care recipients, and rel-
15 evant public or private agencies, will par-
16 ticipate in the planning and implementa-
17 tion of the proposed respite care activities;

18 “(viii) how the proposed respite care
19 activities will make use, to the maximum
20 extent feasible, of other Federal, State,
21 and local funds, programs, contributions,
22 other forms of reimbursements, personnel,
23 and facilities;

24 “(ix) respite care services available to
25 family caregivers in the applicant’s State

1 or locality, including unmet needs and how
2 the applicant's plan for use of funds will
3 improve the coordination and distribution
4 of respite care services for family care-
5 givers of individuals of all ages with special
6 needs;

7 “(x) the criteria used to identify fam-
8 ily caregivers eligible for respite care serv-
9 ices;

10 “(xi) how the quality and safety of
11 any respite care services provided will be
12 monitored, including methods to ensure
13 that respite care workers and volunteers
14 are appropriately screened and possess the
15 necessary skills to care for the needs of the
16 care recipient in the absence of the family
17 caregiver; and

18 “(xii) the results expected from pro-
19 posed respite care activities and the proce-
20 dures to be used for evaluating those re-
21 sults; and

22 “(C) assurances that, where appropriate,
23 the applicant shall have a system for maintain-
24 ing the confidentiality of care recipient and
25 family caregiver records.

1 “(e) REVIEW OF APPLICATIONS.—

2 “(1) ESTABLISHMENT OF REVIEW PANEL.—

3 The Associate Administrator shall establish a panel
4 to review applications submitted under this section.

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

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

9 “(A) review and evaluate each application
10 submitted under this section; and

11 “(B) make recommendations to the Asso-
12 ciate Administrator concerning whether the ap-
13 plication should be approved.

14 “(f) AWARDING OF GRANTS OR COOPERATIVE
15 AGREEMENTS.—

16 “(1) IN GENERAL.—The Associate Adminis-
17 trator shall award grants or cooperative agreements
18 from among the applications approved by the panel
19 under subsection (e)(3).

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

1 “(g) USE OF GRANT OR COOPERATIVE AGREEMENT
2 FUNDS.—

3 “(1) IN GENERAL.—

4 “(A) MANDATORY USES OF FUNDS.—Each
5 eligible recipient that is awarded a grant or co-
6 operative agreement under this section shall use
7 the funds for, unless such a program is in
8 existence—

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

11 “(ii) an evaluation of the effectiveness
12 of such care.

13 “(B) DISCRETIONARY USES OF FUNDS.—
14 Each eligible recipient that is awarded a grant
15 or cooperative agreement under this section
16 may use the funds for—

17 “(i) respite care services;

18 “(ii) respite care worker and volunteer
19 training programs; or

20 “(iii) training programs for family
21 caregivers to assist such family caregivers
22 in making informed decisions about respite
23 care services.

24 “(C) EVALUATION.—If an eligible recipient
25 uses funds awarded under this section for an

1 activity described in subparagraph (B), the eli-
2 gible recipient shall use funds for an evaluation
3 of the effectiveness of the activity.

4 “(2) SUBCONTRACTS.—Each eligible recipient
5 that is awarded a grant or cooperative agreement
6 under this section may use the funds to subcontract
7 with a public or nonprofit agency to carry out the
8 activities described in paragraph (1).

9 “(h) TERM OF GRANTS OR COOPERATIVE AGREE-
10 MENTS.—

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

15 “(2) RENEWAL.—The Associate Administrator
16 may renew a grant or cooperative agreement under
17 this section at the end of the term of the grant or
18 cooperative agreement determined under paragraph
19 (1).

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

1 “(j) **AUTHORIZATION OF APPROPRIATIONS.**—There
2 are authorized to be appropriated to carry out this
3 section—

4 “(1) \$90,500,000 for fiscal year 2003;

5 “(2) \$118,000,000 for fiscal year 2004;

6 “(3) \$145,500,000 for fiscal year 2005;

7 “(4) \$173,000,000 for fiscal year 2006; and

8 “(5) \$200,000,000 for fiscal year 2007.

9 **“SEC. 2804. NATIONAL LIFESPAN RESPITE RESOURCE CEN-**
10 **TER.**

11 “(a) **ESTABLISHMENT.**—From funds appropriated
12 under subsection (e), the Associate Administrator shall
13 award a grant or cooperative agreement to a public or pri-
14 vate nonprofit entity to establish a National Resource
15 Center on Lifespan Respite Care (referred to in this sec-
16 tion as the ‘center’).

17 “(b) **PURPOSES OF THE CENTER.**—The center
18 shall—

19 “(1) maintain a national database on lifespan
20 respite care;

21 “(2) provide training and technical assistance
22 to State, community, and nonprofit respite care pro-
23 grams; and

1 ~~“(3) provide information, referral, and edu-~~
 2 ~~ational programs to the public on lifespan respite~~
 3 ~~care.~~

4 ~~“(e) AUTHORIZATION OF APPROPRIATIONS.—There~~
 5 ~~are authorized to be appropriated to carry out this section~~
 6 ~~\$500,000 for each of fiscal years 2003 through 2007.”.~~

7 **SECTION 1. SHORT TITLE.**

8 *This Act may be cited as the “Lifespan Respite Care*
 9 *Act of 2002”.*

10 **SEC. 2. LIFESPAN RESPITE CARE.**

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

13 **“TITLE XXVIII—LIFESPAN**
 14 **RESPITE CARE**

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

16 ~~“(a) FINDINGS.—Congress finds that—~~

17 ~~“(1) an estimated 26,000,000 individuals in the~~
 18 ~~United States care each year for 1 or more adult fam-~~
 19 ~~ily members or friends who are chronically ill, dis-~~
 20 ~~abled, or terminally ill;~~

21 ~~“(2) an estimated 18,000,000 children in the~~
 22 ~~United States have chronic physical, developmental,~~
 23 ~~behavioral, or emotional conditions that demand care-~~
 24 ~~giver monitoring, management, supervision, or treat-~~
 25 ~~ment beyond that required of children generally;~~

1 “(3) nearly 4,000,000 individuals in the United
2 States of all ages who have mental retardation or an-
3 other developmental disability live with their families;

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

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

11 “(6) of all individuals in the United States need-
12 ing assistance in daily living, 42 percent are under
13 age 65;

14 “(7) there are insufficient resources to replace
15 family caregivers with paid workers;

16 “(8) if services provided by family caregivers
17 had to be replaced with paid services, it would cost
18 approximately \$200,000,000,000 annually;

19 “(9) the family caregiver role is personally re-
20 warding but can result in substantial emotional,
21 physical, and financial hardship;

22 “(10) approximately 75 percent of family care-
23 givers are women;

1 “(11) family caregivers often do not know where
2 to find information about available respite care or
3 how to access it;

4 “(12) available respite care programs are insuffi-
5 cient to meet the need and are directed at primarily
6 lower income populations and family caregivers of the
7 elderly, leaving large numbers of family caregivers
8 without adequate support; and

9 “(13) the limited number of available respite
10 care programs find it difficult to recruit appro-
11 priately trained respite workers.

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

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

15 “(2) to improve and coordinate the dissemina-
16 tion of respite care information and resources to fam-
17 ily caregivers;

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

20 “(4) to promote innovative, flexible, and com-
21 prehensive approaches to—

22 “(A) the delivery of respite care;

23 “(B) respite care worker and volunteer re-
24 cruitment and training programs; and

1 “(C) training programs for family care-
2 givers to assist such family caregivers in making
3 informed decisions about respite care services;

4 “(5) to support evaluative research to identify ef-
5 fective respite care services that alleviate, reduce, or
6 minimize any negative consequences of caregiving;
7 and

8 “(6) to promote the dissemination of results,
9 findings, and information from programs and re-
10 search projects relating to respite care delivery, fam-
11 ily caregiver strain, respite care worker and volunteer
12 recruitment and training, and training programs for
13 family caregivers that assist such family caregivers in
14 making informed decisions about respite care services.

15 **“SEC. 2802. DEFINITIONS.**

16 *“In this title:*

17 “(1) *ELIGIBLE RECIPIENT.*—*The term ‘eligible*
18 *recipient’ means—*

19 “(A) *a State agency;*

20 “(B) *any other public entity that is capable*
21 *of operating on a statewide basis;*

22 “(C) *a private, nonprofit organization that*
23 *is capable of operating on a statewide basis;*

1 “(D) a political subdivision of a State that
2 has a population of not less than 3,000,000 indi-
3 viduals; or

4 “(E) any recognized State respite coordi-
5 nating agency that has—

6 “(i) a demonstrated ability to work
7 with other State and community-based
8 agencies;

9 “(ii) an understanding of respite care
10 and family caregiver issues; and

11 “(iii) the capacity to ensure meaning-
12 ful involvement of family members, family
13 caregivers, and care recipients.

14 “(2) ADULT WITH A SPECIAL NEED.—The term
15 ‘adult with a special need’ means a person 18 years
16 of age or older who requires care or supervision to—

17 “(A) meet the person’s basic needs; or

18 “(B) prevent physical self-injury or injury
19 to others.

20 “(3) CHILD WITH A SPECIAL NEED.—The term
21 ‘child with a special need’ means a person less than
22 18 years of age who requires care or supervision be-
23 yond that required of children generally to—

24 “(A) meet the child’s basic needs; or

1 “(B) prevent physical self-injury or injury
2 to others.

3 “(4) FAMILY CAREGIVER.—The term ‘family
4 caregiver’ means an unpaid family member, a foster
5 parent, or another unpaid adult, who provides in-
6 home monitoring, management, supervision, or treat-
7 ment of a child or adult with a special need.

8 “(5) RESPITE CARE.—The term ‘respite care’
9 means planned or emergency care provided to a child
10 or adult with a special need in order to provide tem-
11 porary relief to the family caregiver of that child or
12 adult.

13 “(6) LIFESPAN RESPITE CARE.—The term ‘life-
14 span respite care’ means a coordinated system of ac-
15 cessible, community-based respite care services for
16 family caregivers of children or adults with special
17 needs.

18 **“SEC. 2803. LIFESPAN RESPITE CARE GRANTS AND COOPER-**

19 **ATIVE AGREEMENTS.**

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

21 “(1) to expand and enhance respite care services
22 to family caregivers;

23 “(2) to improve the statewide dissemination and
24 coordination of respite care; and

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

4 “(b) *AUTHORIZATION*.—Subject to subsection (f), the
5 Secretary is authorized to award grants or cooperative
6 agreements to eligible recipients who submit an application
7 pursuant to subsection (d).

8 “(c) *FEDERAL LIFESPAN APPROACH*.—In carrying out
9 this section, the Secretary shall work in cooperation with
10 the National Family Caregiver Support Program Officer
11 of the Administration on Aging, and respite care program
12 officers in the Administration for Children and Families,
13 the Administration on Developmental Disabilities, the Ma-
14 ternal and Child Health Bureau of the Health Resources
15 and Services Administration, and the Substance Abuse and
16 Mental Health Services Administration, to ensure coordina-
17 tion of respite care services for family caregivers of children
18 and adults with special needs.

19 “(d) *APPLICATION*.—

20 “(1) *SUBMISSION*.—Each eligible recipient desir-
21 ing to receive a grant or cooperative agreement under
22 this section shall submit an application to the Sec-
23 retary at such time, in such manner, and containing
24 such information as the Secretary shall require.

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

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

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

6 “(ii) capacity to ensure meaningful in-
7 volvement of family members, family care-
8 givers, and care recipients; and

9 “(iii) collaboration with other State
10 and community-based public, nonprofit, or
11 private agencies;

12 “(B) with respect to the population of fam-
13 ily caregivers to whom respite care information
14 or services will be provided or for whom respite
15 care workers and volunteers will be recruited and
16 trained, a description of—

17 “(i) the population of family care-
18 givers;

19 “(ii) the extent and nature of the res-
20 pite care needs of that population;

21 “(iii) existing respite care services for
22 that population, including numbers of fam-
23 ily caregivers being served and extent of
24 unmet need;

1 “(iv) existing methods or systems to co-
2 ordinate respite care information and serv-
3 ices to the population at the State and local
4 level and extent of unmet need;

5 “(v) how respite care information dis-
6 semination and coordination, respite care
7 services, respite care worker and volunteer
8 recruitment and training programs, or
9 training programs for family caregivers
10 that assist such family caregivers in making
11 informed decisions about respite care serv-
12 ices will be provided using grant or cooper-
13 ative agreement funds;

14 “(vi) a plan for collaboration and co-
15 ordination of the proposed respite care ac-
16 >tivities with other related services or pro-
17 grams offered by public or private, non-
18 profit entities, including area agencies on
19 aging;

20 “(vii) how the population, including
21 family caregivers, care recipients, and rel-
22 evant public or private agencies, will par-
23 >ticipate in the planning and implementa-
24 tion of the proposed respite care activities;

1 “(viii) how the proposed respite care
2 activities will make use, to the maximum
3 extent feasible, of other Federal, State, and
4 local funds, programs, contributions, other
5 forms of reimbursements, personnel, and fa-
6 cilities;

7 “(ix) respite care services available to
8 family caregivers in the applicant’s State or
9 locality, including unmet needs and how the
10 applicant’s plan for use of funds will im-
11 prove the coordination and distribution of
12 respite care services for family caregivers of
13 children and adults with special needs;

14 “(x) the criteria used to identify fam-
15 ily caregivers eligible for respite care serv-
16 ices;

17 “(xi) how the quality and safety of any
18 respite care services provided will be mon-
19 itored, including methods to ensure that res-
20 pite care workers and volunteers are appro-
21 priately screened and possess the necessary
22 skills to care for the needs of the care recipi-
23 ent in the absence of the family caregiver;
24 and

1 “(xii) the results expected from pro-
 2 posed respite care activities and the proce-
 3 dures to be used for evaluating those results;
 4 and

5 “(C) assurances that, where appropriate,
 6 the applicant shall have a system for maintain-
 7 ing the confidentiality of care recipient and fam-
 8 ily caregiver records.

9 “(e) REVIEW OF APPLICATIONS.—

10 “(1) ESTABLISHMENT OF REVIEW PANEL.—The
 11 Secretary shall establish a panel to review applica-
 12 tions submitted under this section.

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

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

17 “(A) review and evaluate each application
 18 submitted under this section; and

19 “(B) make recommendations to the Sec-
 20 retary concerning whether the application should
 21 be approved.

22 “(f) AWARDING OF GRANTS OR COOPERATIVE AGREE-
 23 MENTS.—

24 “(1) IN GENERAL.—The Secretary shall award
 25 grants or cooperative agreements from among the ap-

1 *plications approved by the panel under subsection*
 2 *(e)(3).*

3 *“(2) PRIORITY.—When awarding grants or coop-*
 4 *erative agreements under this subsection, the Sec-*
 5 *retary shall give priority to applicants that show the*
 6 *greatest likelihood of implementing or enhancing life-*
 7 *span respite care statewide.*

8 *“(g) USE OF GRANT OR COOPERATIVE AGREEMENT*
 9 *FUNDS.—*

10 *“(1) IN GENERAL.—*

11 *“(A) MANDATORY USES OF FUNDS.—Each*
 12 *eligible recipient that is awarded a grant or co-*
 13 *operative agreement under this section shall use*
 14 *the funds for, unless such a program is in*
 15 *existence—*

16 *“(i) the development of lifespan respite*
 17 *care at the State and local levels; and*

18 *“(ii) an evaluation of the effectiveness*
 19 *of such care.*

20 *“(B) DISCRETIONARY USES OF FUNDS.—*
 21 *Each eligible recipient that is awarded a grant*
 22 *or cooperative agreement under this section may*
 23 *use the funds for—*

1 “(i) respite care services for family
2 caregivers of children and adults with spe-
3 cial needs;

4 “(ii) respite care worker and volunteer
5 training programs; or

6 “(iii) training programs for family
7 caregivers to assist such family caregivers
8 in making informed decisions about respite
9 care services.

10 “(C) EVALUATION.—If an eligible recipient
11 uses funds awarded under this section for an ac-
12 tivity described in subparagraph (B), the eligible
13 recipient shall use funds for an evaluation of the
14 effectiveness of the activity.

15 “(2) SUBCONTRACTS.—Each eligible recipient
16 that is awarded a grant or cooperative agreement
17 under this section may use the funds to subcontract
18 with a public or nonprofit agency to carry out the ac-
19 tivities described in paragraph (1).

20 “(h) TERM OF GRANTS OR COOPERATIVE AGREE-
21 MENTS.—

22 “(1) IN GENERAL.—The Secretary shall award
23 grants or cooperative agreements under this section
24 for terms that do not exceed 5 years.

1 “(2) *RENEWAL.*—*The Secretary may renew a*
 2 *grant or cooperative agreement under this section at*
 3 *the end of the term of the grant or cooperative agree-*
 4 *ment determined under paragraph (1).*

5 “(i) *SUPPLEMENT, NOT SUPPLANT.*—*Funds made*
 6 *available under this section shall be used to supplement and*
 7 *not supplant other Federal, State, and local funds available*
 8 *for respite care services.*

9 “(j) *AUTHORIZATION OF APPROPRIATIONS.*—*There are*
 10 *authorized to be appropriated to carry out this section—*

11 “(1) *\$90,500,000 for fiscal year 2003; and*

12 “(2) *such sums as are necessary for fiscal years*
 13 *2004 through 2007.*

14 **“SEC. 2804. NATIONAL LIFESPAN RESPITE RESOURCE CEN-**
 15 **TER.**

16 “(a) *ESTABLISHMENT.*—*From funds appropriated*
 17 *under subsection (c), the Secretary shall award a grant or*
 18 *cooperative agreement to a public or private nonprofit enti-*
 19 *ty to establish a National Resource Center on Lifespan Res-*
 20 *pite Care (referred to in this section as the ‘center’).*

21 “(b) *PURPOSES OF THE CENTER.*—*The center shall—*

22 “(1) *maintain a national database on lifespan*
 23 *respite care;*

1 “(2) *provide training and technical assistance to*
2 *State, community, and nonprofit respite care pro-*
3 *grams; and*

4 “(3) *provide information, referral, and edu-*
5 *cational programs to the public on lifespan respite*
6 *care.*

7 “(c) *AUTHORIZATION OF APPROPRIATIONS.—There are*
8 *authorized to be appropriated to carry out this section*
9 *\$500,000 for each of fiscal years 2003 through 2007.”.*

Calendar No. 511

107TH CONGRESS
2D SESSION

S. 2489

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.

JULY 23, 2002

Reported with an amendment