

**Calendar No. 511**107<sup>TH</sup> CONGRESS  
2<sup>D</sup> 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.

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**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*]

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**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           ministrato**r 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           ~~“(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**

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**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.

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JULY 23, 2002

Reported with an amendment