

108TH CONGRESS  
1ST SESSION

# H. R. 1083

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 HOUSE OF REPRESENTATIVES

MARCH 5, 2003

Mr. LANGEVIN (for himself, Mr. ABERCROMBIE, Mr. ACKERMAN, Mr. ALLEN, Mr. BRADY of Pennsylvania, Ms. CORRINE BROWN of Florida, Mr. BROWN of Ohio, Mrs. CHRISTENSEN, Ms. DELAURO, Mr. DOYLE, Mr. ENGEL, Mr. EVANS, Mr. FOLEY, Mr. FORD, Mr. FRANK of Massachusetts, Mr. FROST, Mr. GREEN of Texas, Mr. GREENWOOD, Mr. GUTIERREZ, Mr. HOEFFEL, Mrs. JOHNSON of Connecticut, Mrs. JONES of Ohio, Mr. KILDEE, Mr. KENNEDY of Rhode Island, Mr. LANTOS, Mr. MATSUI, Mr. McDERMOTT, Mr. MCHUGH, Mr. McNULTY, Ms. MILLENDER-MCDONALD, Mr. GEORGE MILLER of California, Mr. NADLER, Mrs. NAPOLITANO, Ms. NORTON, Mr. OBERSTAR, Mr. OWENS, Mr. PASCRELL, Mr. PAYNE, Mr. SERRANO, Mr. SIMMONS, Mr. SKELTON, Mr. STENHOLM, Mr. TOWNS, Mr. WAXMAN, Ms. WOOLSEY, Ms. BERKLEY, Mr. DAVIS of Illinois, Ms. GINNY BROWN-WAITE of Florida, Mr. CLYBURN, Ms. JACKSON-LEE of Texas, Mr. CROWLEY, and Mr. MARKEY) introduced the following bill; which was referred to the Committee on Energy and Commerce

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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 2003”.

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 XXIX—LIFESPAN**  
8 **RESPITE CARE**

9 **“SEC. 2901. 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 deaths;

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 primarily directed  
6 at lower income populations and family caregivers of  
7 the elderly, leaving large numbers of family care-  
8 givers without adequate support; and

9           “(15) there are a limited number of available  
10 respite care programs, and these programs have dif-  
11 ficulty recruiting appropriately trained respite work-  
12 ers.

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

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

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

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

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

23                   “(A) the delivery of respite care;

24                   “(B) respite care worker and volunteer re-  
25 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. 2902. DEFINITIONS.**

18          “In this title:

19                 “(1) **CONDITION.**—The term ‘condition’ in-  
20                 cludes—

21                         “(A) Alzheimer’s disease and other neuro-  
22                         logical disorders;

23                         “(B) developmental disabilities;

24                         “(C) mental retardation;

25                         “(D) physical disabilities;

1           “(E) chronic illness, including cancer;

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

4           “(G) cognitive impairments;

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

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

12           “(J) traumatic brain injury; and

13           “(K) such conditions as the Secretary may  
14 designate by regulation.

15           “(2) ELIGIBLE RECIPIENT.—The term ‘eligible  
16 recipient’ means—

17           “(A) a State agency;

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

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

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

1           “(E) any recognized State respite coordi-  
2           nating agency that has—

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

6                   “(ii) an understanding of respite care  
7                   and family caregiver issues; and

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

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

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

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

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

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

3           “(6) SECRETARY.—The term ‘Secretary’ means  
4           the Secretary of Health and Human Services.

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

10 **“SEC. 2903. LIFESPAN RESPITE CARE GRANTS AND COOP-**  
11 **ERATIVE AGREEMENTS.**

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

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

15                   “(2) to improve the statewide dissemination and  
16           coordination of respite care; and

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

20           “(b) AUTHORIZATION.—Subject to subsection (f), the  
21           Secretary may award grants or cooperative agreements to  
22           eligible recipients who submit an application pursuant to  
23           subsection (d).

24           “(c) FEDERAL LIFESPAN APPROACH.—In carrying  
25           out this section, the Secretary, acting through the Mater-

1 nal and Child Health Bureau of the Health Resources and  
2 Services Administration, and in cooperation with the Na-  
3 tional Family Caregiver Support Program in the Adminis-  
4 tration on Aging, the Administration for Children and  
5 Families, the Administration on Developmental Disabil-  
6 ities, and the Substance Abuse and Mental Health Serv-  
7 ices Administration, shall ensure coordination of respite  
8 care services for family caregivers of individuals of all ages  
9 with special needs.

10 “(d) APPLICATION.—

11 “(1) SUBMISSION.—Each eligible recipient de-  
12 siring to receive a grant or cooperative agreement  
13 under this section shall submit an application to the  
14 Secretary at such time, in such manner, and con-  
15 taining such information as the Secretary shall re-  
16 quire.

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

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

20 “(i) understanding of respite care and  
21 family caregiver issues;

22 “(ii) capacity to ensure meaningful in-  
23 volvement of family members, family care-  
24 givers, and care recipients; and

1           “(iii) collaboration with other State  
2           and community-based public, nonprofit, or  
3           private agencies;

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

9                   “(i) the population;

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

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

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

20                   “(v) how respite care information dis-  
21           semination and coordination, respite care  
22           services, respite care worker and volunteer  
23           recruitment and training programs, or  
24           training programs for family caregivers  
25           that assist such family caregivers in mak-

1 ing informed decisions about respite care  
2 services, will be provided using grant or co-  
3 operative agreement funds;

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

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

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

21 “(ix) respite care services available to  
22 family caregivers in the applicant’s State  
23 or locality, including unmet needs and how  
24 the applicant’s plan for use of funds will  
25 improve the coordination and distribution

1 of respite care services for family care-  
2 givers of individuals of all ages with special  
3 needs;

4 “(x) the criteria used to identify fam-  
5 ily caregivers eligible for respite care serv-  
6 ices;

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

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

19 “(C) assurances that, where appropriate,  
20 the applicant will have a system for maintaining  
21 the confidentiality of care recipient and family  
22 caregiver records.

23 “(e) REVIEW OF APPLICATIONS.—

1           “(1) ESTABLISHMENT OF REVIEW PANEL.—  
2           The Secretary shall establish a panel to review appli-  
3           cations submitted under this section.

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

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

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

10                   “(B) make recommendations to the Sec-  
11                   retary concerning whether the application  
12                   should be approved.

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

15                   “(1) IN GENERAL.—The Secretary shall award  
16                   grants or cooperative agreements from among the  
17                   applications recommended for approval by the panel  
18                   under subsection (e)(3).

19                   “(2) PRIORITY.—When awarding grants or co-  
20                   operative agreements under this subsection, the Sec-  
21                   retary shall give priority to applicants that show the  
22                   greatest likelihood of implementing or enhancing  
23                   lifespan respite care statewide.

24           “(g) USE OF GRANT OR COOPERATIVE AGREEMENT  
25           FUNDS.—

1           “(1) IN GENERAL.—The Secretary may not  
2           award a grant or cooperative agreement to an eligi-  
3           ble recipient under this section unless the recipient  
4           agrees to use the funds for—

5                   “(A) the development of lifespan respite  
6                   care at the State and local levels, taking into  
7                   consideration models and best practices in res-  
8                   pite care delivery and coordination;

9                   “(B) respite care services to meet unmet  
10                  needs and provide worker, volunteer, and family  
11                  training programs; and

12                  “(C) an evaluation of the effectiveness of  
13                  such development and services.

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

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

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

24                   “(2) RENEWAL.—The Secretary may renew a  
25                   grant or cooperative agreement under this section at

1 the end of the term of the grant or cooperative  
2 agreement determined under paragraph (1).

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

7 **“SEC. 2904. NATIONAL LIFESPAN RESPITE RESOURCE CEN-**  
8 **TER.**

9 “(a) ESTABLISHMENT.—The Secretary shall award a  
10 grant or cooperative agreement to a public or private non-  
11 profit entity to establish a National Resource Center on  
12 Lifespan Respite Care (referred to in this section as the  
13 ‘Center’).

14 “(b) DUTIES.—The Center shall—

15 “(1) maintain a national database on lifespan  
16 respite care;

17 “(2) provide training and technical assistance  
18 to State, community, and nonprofit respite care pro-  
19 grams; and

20 “(3) provide information, referral, and edu-  
21 cational programs to the public on lifespan respite  
22 care.

1 **“SEC. 2905. AUTHORIZATION OF APPROPRIATIONS.**

2       “There are authorized to be appropriated to carry out

3 this title such sums as may be necessary.”.

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