

108TH CONGRESS
1ST SESSION

S. 538

AN ACT

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 2003”.

1 **SEC. 2. LIFESPAN RESPITE CARE.**

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

4 **“TITLE XXIX—LIFESPAN**
5 **RESPITE CARE**

6 **“SEC. 2901. FINDINGS AND PURPOSES.**

7 “(a) FINDINGS.—Congress finds that—

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

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

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

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

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

4 “(6) of all individuals in the United States
5 needing assistance in daily living, 42 percent are
6 under age 65;

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

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

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

15 “(10) approximately 75 percent of family care-
16 givers are women;

17 “(11) family caregivers often do not know
18 where to find information about available respite
19 care or how to access it;

20 “(12) available respite care programs are insuf-
21 ficient to meet the need and are directed at pri-
22 marily lower income populations and family care-
23 givers of the elderly, leaving large numbers of family
24 caregivers without adequate support; and

1 “(13) the limited number of available respite
2 care programs find it difficult to recruit appro-
3 priately trained respite workers.

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

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

7 “(2) to improve and coordinate the dissemina-
8 tion of respite care information and resources to
9 family caregivers;

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

12 “(4) to promote innovative, flexible, and com-
13 prehensive approaches to—

14 “(A) the delivery of respite care;

15 “(B) respite care worker and volunteer re-
16 cruitment and training programs; and

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

21 “(5) to support evaluative research to identify
22 effective respite care services that alleviate, reduce,
23 or minimize any negative consequences of caregiving;
24 and

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

9 **“SEC. 2902. DEFINITIONS.**

10 “In this title:

11 “(1) ELIGIBLE RECIPIENT.—The term ‘eligible
12 recipient’ means—

13 “(A) a State agency;

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

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

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

21 “(E) any recognized State respite coordi-
22 nating agency that has—

23 “(i) a demonstrated ability to work
24 with other State and community-based
25 agencies;

1 “(ii) an understanding of respite care
2 and family caregiver issues; and

3 “(iii) the capacity to ensure meaning-
4 ful involvement of family members, family
5 caregivers, and care recipients.

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

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

10 “(B) prevent physical self-injury or injury
11 to others.

12 “(3) CHILD WITH A SPECIAL NEED.—The term
13 ‘child with a special need’ means a person less than
14 18 years of age who requires care or supervision be-
15 yond that required of children generally to—

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

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

19 “(4) FAMILY CAREGIVER.—The term ‘family
20 caregiver’ means an unpaid family member, a foster
21 parent, or another unpaid adult, who provides in-
22 home monitoring, management, supervision, or
23 treatment of a child or adult with a special need.

24 “(5) RESPITE CARE.—The term ‘respite care’
25 means planned or emergency care provided to a

1 child or adult with a special need in order to provide
 2 temporary relief to the family caregiver of that child
 3 or adult.

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

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

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

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

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

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

19 “(b) AUTHORIZATION.—Subject to subsection (f), the
 20 Secretary is authorized to award grants or cooperative
 21 agreements to eligible recipients who submit an applica-
 22 tion pursuant to subsection (d).

23 “(c) FEDERAL LIFESPAN APPROACH.—In carrying
 24 out this section, the Secretary shall work in cooperation
 25 with the National Family Caregiver Support Program Of-

1 ficer of the Administration on Aging, and respite care pro-
2 gram officers in the Administration for Children and Fam-
3 ilies, the Administration on Developmental Disabilities,
4 the Maternal and Child Health Bureau of the Health Re-
5 sources and Services Administration, and the Substance
6 Abuse and Mental Health Services Administration, to en-
7 sure coordination of respite care services for family care-
8 givers of children and adults with special needs.

9 “(d) APPLICATION.—

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

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

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

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

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

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

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

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

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

1 that assist such family caregivers in mak-
2 ing informed decisions about respite care
3 services will be provided using grant or co-
4 operative agreement funds;

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

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

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

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

1 improve the coordination and distribution
2 of respite care services for family care-
3 givers of children and adults with special
4 needs;

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

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

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

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

24 “(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 approved by the panel under subsection
 18 (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.—

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

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

9 “(ii) an evaluation of the effectiveness
10 of such care.

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

15 “(i) respite care services for family
16 caregivers of children and adults with spe-
17 cial needs;

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 Secretary shall award
12 grants or cooperative agreements under this section
13 for terms that do not exceed 5 years.

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

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

22 “(j) AUTHORIZATION OF APPROPRIATIONS.—There
23 are authorized to be appropriated to carry out this
24 section—

25 “(1) \$90,500,000 for fiscal year 2004; and

1 “(2) such sums as are necessary for fiscal years
2 2005 through 2008.

3 **“SEC. 2904. NATIONAL LIFESPAN RESPITE RESOURCE CEN-**
4 **TER.**

5 “(a) ESTABLISHMENT.—From funds appropriated
6 under subsection (c), the Secretary shall award a grant
7 or cooperative agreement to a public or private nonprofit
8 entity to establish a National Resource Center on Lifespan
9 Respite Care (referred to in this section as the ‘center’).

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

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

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

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

1 “(c) AUTHORIZATION OF APPROPRIATIONS.—There
2 are authorized to be appropriated to carry out this section
3 \$500,000 for each of fiscal years 2004 through 2008.”.

Passed the Senate April 10, 2003.

Attest:

Secretary.

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AN ACT

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.