

109TH CONGRESS  
1ST SESSION

# H. R. 1262

To amend the Public Health Service Act to fund breakthroughs in Alzheimer’s disease research while providing more help to caregivers and increasing public education about prevention.

---

## IN THE HOUSE OF REPRESENTATIVES

MARCH 10, 2005

Mr. SMITH of New Jersey (for himself, Mr. MARKEY, and Mr. BURGESS) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committee on Education and the Workforce, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

---

## A BILL

To amend the Public Health Service Act to fund breakthroughs in Alzheimer’s disease research while providing more help to caregivers and increasing public education about prevention.

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; TABLE OF CONTENTS.**

4 (a) SHORT TITLE.—This Act may be cited as the  
5 “Ronald Reagan Alzheimer’s Breakthrough Act of 2005”.

1 (b) TABLE OF CONTENTS.—The table of contents of  
 2 this Act is as follows:

Sec. 1. Short title; table of contents.  
 Sec. 2. Findings.

#### TITLE I—INCREASING THE FEDERAL COMMITMENT TO ALZHEIMER'S RESEARCH

Sec. 101. Doubling NIH funding for Alzheimer's disease research.  
 Sec. 102. Priority to Alzheimer's disease research.  
 Sec. 103. Alzheimer's disease prevention initiative.  
 Sec. 104. Alzheimer's disease clinical research.  
 Sec. 105. Research on Alzheimer's disease caregiving.  
 Sec. 106. National summit on Alzheimer's disease.

#### TITLE II—PUBLIC EDUCATION ABOUT ALZHEIMER'S DISEASE

Sec. 201. Public education campaign.

#### TITLE III—ASSISTANCE FOR CAREGIVERS

Sec. 301. Increased funding for National Family Caregiver Support Program.  
 Sec. 302. Alzheimer's disease demonstration grants.  
 Sec. 303. Safe return program.  
 Sec. 304. Lifespan respite care.

### 3 **SEC. 2. FINDINGS.**

4 Congress makes the following findings:

5 (1) Alzheimer's disease is a disorder that de-  
 6 stroys cells in the brain. The disease is the leading  
 7 cause of dementia, a condition that involves gradual  
 8 memory loss, decline in the ability to perform rou-  
 9 tine tasks, disorientation, difficulty in learning, loss  
 10 of language skills, impairment of judgment, and per-  
 11 sonality changes. As the disease progresses, people  
 12 with Alzheimer's disease become unable to care for  
 13 themselves. The loss of brain cells eventually leads  
 14 to the failure of other systems in the body.

1           (2) An estimated 4,500,000 Americans have  
2 Alzheimer's disease and 1 in 10 people have a family  
3 member with the disease. By 2050, the number of  
4 individuals with the disease could range from  
5 13,200,000 to 16,000,000 unless science finds a way  
6 to prevent or cure the disease.

7           (3) One in 10 people over the age of 65, and  
8 nearly half of those over the age of 85 have Alz-  
9 heimer's disease. Younger people also get the dis-  
10 ease.

11          (4) The Alzheimer's disease process may begin  
12 in the brain as many as 20 years before the symp-  
13 toms of Alzheimer's disease appear. A person will  
14 live an average of 8 years and as many as 20 once  
15 the symptoms of Alzheimer's disease appear.

16          (5) The average lifetime cost of care for an in-  
17 dividual with Alzheimer's disease is \$174,000.

18          (6) In 2000, medicare alone spent  
19 \$62,000,000,000 for the care of individuals with  
20 Alzheimer's disease and this amount is projected to  
21 increase to \$160,000,000,000 in 2010.

22          (7) Forty-nine percent of medicare beneficiaries  
23 who have Alzheimer's disease also receive medicaid.  
24 Of the total population dually eligible for medicare  
25 and medicaid, 22 percent have Alzheimer's disease.

1           (8) Seven in 10 people with Alzheimer's disease  
2       live at home. While almost 75 percent of home care  
3       is provided by family and friends, the average an-  
4       nual cost of paid care for people with Alzheimer's  
5       disease at home is \$12,500 per year. Almost all fam-  
6       ilies pay this cost out of pocket.

7           (9) Nearly 60 percent of all nursing home resi-  
8       dents have Alzheimer's disease or a related disorder.  
9       The average annual cost of Alzheimer's disease nurs-  
10      ing home care is nearly \$64,000. Medicaid pays half  
11      of the total nursing home bill and helps 2 out of 3  
12      residents pay for their care. Medicaid expenditures  
13      for nursing home care for people with Alzheimer's  
14      disease are estimated to increase from  
15      \$19,000,000,000 in 2000 to \$24,000,000,000 in  
16      2010.

17          (10) In fiscal year 2004, the Federal Govern-  
18      ment will spend an estimated \$680,000,000 on Alz-  
19      heimer's disease research. If our Nation achieves its  
20      research goals (preventing the onset of Alzheimer's  
21      disease in those at risk and treating and delaying  
22      progression of the disease in those who have symp-  
23      toms), the projected number of cases of Alzheimer's  
24      disease can be reduced by approximately 40 percent  
25      by the middle of the century. The number of baby

1 boomers with moderate to severe Alzheimer's disease  
2 can be reduced by 60 percent.

3 (11) A study commissioned by the United Hos-  
4 pital Fund estimated that the annual value of this  
5 informal care system is \$257,000,000,000. Family  
6 caregiving comes at enormous physical, emotional,  
7 and financial sacrifice, putting the whole system at  
8 risk.

9 (12) One in 8 Alzheimer's disease caregivers be-  
10 comes ill or injured as a direct result of caregiving.  
11 One in 3 uses medication for problems related to  
12 caregiving. Older caregivers are 3 times more likely  
13 to become clinically depressed than others in their  
14 age group.

15 (13) Elderly spouses strained by caregiving are  
16 63 percent more likely to die during a given 4-year  
17 period than other spouses their age.

18 (14) Almost 3 of 4 caregivers are women. One  
19 in 3 has children or grandchildren under the age of  
20 18 living at home. Caregiving leaves them less time  
21 for other family members and they are much more  
22 likely to report family conflicts because of their  
23 caregiving role.

24 (15) Most Alzheimer's disease caregivers work  
25 outside the home before beginning their caregiving

1 careers, but caregiving forces them to miss work, cut  
2 back to part-time, take less demanding jobs, choose  
3 early retirement, or give up work altogether. As a  
4 result, in 2002, Alzheimer's disease cost American  
5 business an estimated \$36,500,000,000 in lost pro-  
6 ductivity, as well as an additional \$24,600,000,000  
7 in business contributions to the total cost of care.

8 **TITLE I—INCREASING THE FED-**  
9 **ERAL COMMITMENT TO ALZ-**  
10 **HEIMER'S RESEARCH**

11 **SEC. 101. DOUBLING NIH FUNDING FOR ALZHEIMER'S DIS-**  
12 **EASE RESEARCH.**

13 (a) IN GENERAL.—For the purpose of conducting  
14 and supporting research on Alzheimer's disease (including  
15 related activities under subpart 5 of part C of title IV of  
16 the Public Health Service Act (42 U.S.C. 285e et seq.)  
17 there is authorized to be appropriated \$1,400,000,000 for  
18 fiscal year 2006, and such sums as may be necessary for  
19 each of fiscal years 2007 through 2010.

20 (b) AGING PROCESS REGARDING WOMEN.—Section  
21 445H(b) of the Public Health Service Act (42 U.S.C.  
22 285e–10(b)) is amended by striking “2003” and inserting  
23 “2010”.

24 (c) CLINICAL RESEARCH AND TRAINING AWARDS.—  
25 Section 445I(d) of the Public Health Service Act (42

1 U.S.C. 285e–10a(d)) is amended by striking “2005” and  
2 inserting “2010”.

3 **SEC. 102. PRIORITY TO ALZHEIMER’S DISEASE RESEARCH.**

4 Section 443 of the Public Health Service Act (42  
5 U.S.C. 285e) is amended—

6 (1) by striking “The general” and inserting  
7 “(a) In General.—The general”; and

8 (2) by adding at the end the following:

9 “(b) PRIORITIES.—The Director of the Institute  
10 shall, in expending amounts appropriated under this sub-  
11 part, give priority to conducting and supporting Alz-  
12 heimer’s disease research.”.

13 **SEC. 103. ALZHEIMER’S DISEASE PREVENTION INITIATIVE.**

14 Section 444 of the Public Health Service Act (42  
15 U.S.C. 285e–1) is amended—

16 (1) in subsection (d), by inserting “and train-  
17 ing” after “conduct research”; and

18 (2) by adding at the end the following:

19 “(e) The Director of the National Institutes of  
20 Health shall, in collaboration with the Director of the In-  
21 stitute, the directors of other relevant institutes, and with  
22 volunteer organizations and other stakeholders, undertake  
23 an Alzheimer’s Disease Prevention Initiative to—

24 “(1) accelerate the discovery of new risk and  
25 protective factors for Alzheimer’s disease;

1           “(2) rapidly identify candidate diagnostics,  
2           therapies, or preventive interventions or agents for  
3           clinical investigation and trials relating to Alz-  
4           heimer’s disease;

5           “(3) support or undertake such investigations  
6           and trials; and

7           “(4) implement effective prevention and treat-  
8           ment strategies, including strategies to improve pa-  
9           tient care and alleviate caregiver burdens relating to  
10          Alzheimer’s disease.”.

11 **SEC. 104. ALZHEIMER’S DISEASE CLINICAL RESEARCH.**

12          (a) CLINICAL RESEARCH.—Section 445F of the Pub-  
13          lic Health Service Act (42 U.S.C. 285e–8) is amended to  
14          read as follows:

15 **“SEC. 445F. ALZHEIMER’S DISEASE CLINICAL RESEARCH.**

16          “(a) IN GENERAL.—The Director of the Institute,  
17          pursuant to subsections (d) and (e) of section 444, shall  
18          conduct and support cooperative clinical research regard-  
19          ing Alzheimer’s disease. Such research shall include—

20               “(1) investigating therapies, interventions, and  
21               agents to detect, treat, slow the progression of, or  
22               prevent Alzheimer’s disease;

23               “(2) enhancing the national infrastructure for  
24               the conduct of clinical trials;



1           “(3) developing and testing novel approaches to  
2           the design and analysis of such trials;

3           “(4) facilitating the enrollment of patients for  
4           such trials, including patients from diverse popu-  
5           lations;

6           “(5) developing improved diagnostics and  
7           means of patient assessment for Alzheimer’s disease;  
8           and

9           “(6) as determined appropriate by the Director  
10          of the Institute, the Alzheimer’s Disease Centers  
11          and Alzheimer’s Disease Research Centers estab-  
12          lished under section 445.

13          “(b) EARLY DIAGNOSIS AND DETECTION RE-  
14          SEARCH.—

15               “(1) IN GENERAL.—The Director of the Insti-  
16               tute, in consultation with the directors of other rel-  
17               evant institutes and centers of the National Insti-  
18               tutes of Health, shall conduct, or make grants for  
19               the conduct of, research related to the early detec-  
20               tion and diagnosis of Alzheimer’s disease and of  
21               mild cognitive impairment or other potential precu-  
22               sors to Alzheimer’s disease.

23               “(2) EVALUATION.—The research described in  
24               paragraph (1) may include the evaluation of diag-  
25               nostic tests and imaging techniques.

1       “(c) VASCULAR DISEASE.—The Director of the Insti-  
2       tute, in consultation with the directors of other relevant  
3       institutes and centers of the National Institutes of Health,  
4       shall conduct, or make grants for the conduct of, research  
5       related to the relationship of vascular disease and Alz-  
6       heimer’s disease, including clinical trials to determine  
7       whether drugs developed to prevent cerebrovascular dis-  
8       ease can prevent the onset or progression of Alzheimer’s  
9       disease.

10       “(d) NATIONAL ALZHEIMER’S COORDINATING CEN-  
11       TER.—The Director of the Institute may establish a Na-  
12       tional Alzheimer’s Coordinating Center to facilitate col-  
13       laborative research among the Alzheimer’s Disease Cen-  
14       ters and Alzheimer’s Disease Research Centers established  
15       under section 445.”.

16       (b) ALZHEIMER’S DISEASE CENTERS.—Section  
17       445(a)(1) of the Public Health Service Act (42 U.S.C.  
18       285e–2(a)(1)) is amended by inserting “, and outcome  
19       measures and disease management” after “treatment  
20       methods”.

21       **SEC. 105. RESEARCH ON ALZHEIMER’S DISEASE**  
22       **CAREGIVING.**

23       Section 445C of the Public Health Service Act (42  
24       U.S.C. 285e–5) is amended—

1 (1) by striking “Sec. 445C. (a)” and inserting  
2 the following:

3 **“SEC. 445C. RESEARCH ON ALZHEIMER’S DISEASE SERV-**  
4 **ICES AND CAREGIVING.**

5 “(a) SERVICES RESEARCH.—”;

6 (2) by striking subsections (b), (c), and (e);

7 (3) by inserting after subsection (a) the fol-  
8 lowing:

9 “(b) INTERVENTIONS RESEARCH.—The Director  
10 shall, in collaboration with the directors of the other rel-  
11 evant institutes and centers of the National Institutes of  
12 Health, conduct, or make grants for the conduct of, clin-  
13 ical, social, and behavioral research related to interven-  
14 tions designed to help caregivers of patients with Alz-  
15 heimer’s disease and related disorders and improve patient  
16 outcomes.”; and

17 (4) in subsection (d) by striking “(d) the Direc-  
18 tor” and inserting “(c) Model Curricula and Tech-  
19 niques. —The Director”.

20 **SEC. 106. NATIONAL SUMMIT ON ALZHEIMER’S DISEASE.**

21 (a) IN GENERAL.—Not later than 1 year after the  
22 date of enactment of this Act, the Secretary of Health and  
23 Human Services (referred to in this section as the “Sec-  
24 retary”) shall convene a summit of researchers, represent-  
25 atives of academic institutions, Federal and State policy-

1 makers, public health professionals, and representatives of  
2 voluntary health agencies to provide a detailed overview  
3 of current research activities at the National Institutes of  
4 Health, as well as to discuss and solicit input related to  
5 potential areas of collaboration between the National In-  
6 stitutes of Health and other Federal health agencies, in-  
7 cluding the Centers for Disease Control and Prevention,  
8 the Administration on Aging, the Agency for Healthcare  
9 Research and Quality, and the Health Resources and  
10 Services Administration, related to research, prevention,  
11 and treatment of Alzheimer's disease.

12 (b) FOCUS AREAS.—The summit convened under  
13 subsection (a) shall focus on—

14 (1) a broad range of Alzheimer's disease re-  
15 search activities relating to biomedical research, pre-  
16 vention research, and caregiving issues;

17 (2) clinical research for the development and  
18 evaluation of new treatments for the disease;

19 (3) translational research on evidence-based and  
20 cost-effective best practices in the treatment and  
21 prevention of the disease;

22 (4) information and education programs for  
23 health care professionals and the public relating to  
24 the disease;

1           (5) priorities among the programs and activities  
2       of the various Federal agencies regarding such dis-  
3       eases; and

4           (6) challenges and opportunities for scientists,  
5       clinicians, patients, and voluntary organizations re-  
6       lating to the disease.

7       (c) REPORT.—Not later than 180 days after the date  
8       on which the National Summit on Alzheimer’s Disease is  
9       convened under subsection (a), the Director of National  
10      Institutes of Health shall prepare and submit to the ap-  
11      propriate committees of Congress a report that includes  
12      a summary of the proceedings of the summit and a de-  
13      scription of Alzheimer’s research, education, and other ac-  
14      tivities that are conducted or supported through the na-  
15      tional research institutes.

16      (d) PUBLIC INFORMATION.—The Secretary shall  
17      make readily available to the public information about the  
18      research, education, and other activities relating to Alz-  
19      heimer’s disease and other related dementias, conducted  
20      or supported by the National Institutes of Health.

21      (e) AUTHORIZATION OF APPROPRIATIONS.—There  
22      are authorized to be appropriated to carry out this section,  
23      such sums as may be necessary for each of fiscal years  
24      2006 through 2010.

1     **TITLE II—PUBLIC EDUCATION**  
2     **ABOUT ALZHEIMER’S DISEASE**

3     **SEC. 201. PUBLIC EDUCATION CAMPAIGN.**

4         Part P of title III of the Public Health Service Act  
5     (42 U.S.C. 280g et seq.) is amended by adding at the end  
6     the following:

7     **“SEC. 3990. ALZHEIMER’S DISEASE PUBLIC EDUCATION**  
8                 **CAMPAIGN.**

9         “(a) IN GENERAL.—The Secretary, acting through  
10     the Director of the Centers for Disease Control and Pre-  
11     vention, shall carry out a program to educate the public  
12     and public health community regarding—

13                 “(1) diagnosis and early warning signs of Alz-  
14     heimer’s disease; and

15                 “(2) how healthy lifestyles could maintain cog-  
16     nitive function and brain health.

17         “(b) EDUCATION OF HEALTH PROFESSIONALS AND  
18     PARTNERSHIPS.—The program carried out under sub-  
19     section (a) shall include activities to educate health profes-  
20     sionals about the diagnosis, care, and management of Alz-  
21     heimer’s disease and dementia, and the development of  
22     partnerships between State health departments, area  
23     agencies on aging, and local organizations serving people  
24     with Alzheimer’s disease.

1 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the  
 2 purpose of carrying out this section, there are authorized  
 3 to be appropriated \$7,000,000 for fiscal year 2006, and  
 4 such sums as may be necessary for each of fiscal years  
 5 2007 through 2010.”.

## 6 **TITLE III—ASSISTANCE FOR** 7 **CAREGIVERS**

### 8 **SEC. 301. INCREASED FUNDING FOR NATIONAL FAMILY** 9 **CAREGIVER SUPPORT PROGRAM.**

10 (a) IN GENERAL.—Section 303(e)(1) of the Older  
 11 Americans Act of 1965 (42 U.S.C. 3023(e)(1)) is amend-  
 12 ed by striking “\$125,000,000 for fiscal year 2001” and  
 13 inserting “\$250,000,000 for fiscal year 2006”.

14 (b) NATIVE AMERICANS.—Section 643(2) of the  
 15 Older Americans Act of 1965 (42 U.S.C. 3057n(2)) is  
 16 amended by striking “\$5,000,000 for fiscal year 2001”  
 17 and inserting “\$10,000,000 for fiscal year 2006”.

### 18 **SEC. 302. ALZHEIMER’S DISEASE DEMONSTRATION** 19 **GRANTS.**

20 Section 398B(e) of the Public Health Service Act (42  
 21 U.S.C. 280c–5(e)) is amended—

22 (1) by striking “and such” and inserting  
 23 “such”; and

24 (2) by inserting before the period “,  
 25 \$25,000,000 for fiscal year 2006, and such sums as

1        may be necessary for each of the fiscal years 2007  
2        through 2010”.

3    **SEC. 303. SAFE RETURN PROGRAM.**

4        Section 240001(d) of the Violent Crime Control and  
5    Law Enforcement Act of 1994 (42 U.S.C. 14181(d)) is  
6    amended to read as follows:

7        “(d) AUTHORIZATION OF APPROPRIATIONS.—There  
8    are authorized to be appropriated to carry out this section,  
9    \$1,000,000 for fiscal year 2006.”.

10   **SEC. 304. LIFESPAN RESPITE CARE.**

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

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

15   **“SEC. 2901. 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  
19        family members or friends who are chronically ill,  
20        disabled, 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  
24        caregiver monitoring, management, supervision, or  
25        treatment 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  
3       another developmental disability live with their fami-  
4       lies;

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

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

17          “(8) 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          “(9) the family caregiver role is personally re-  
21      warding but can result in substantial emotional,  
22      physical, and financial hardship;

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

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

4           “(12) 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           “(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  
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. 2902. DEFINITIONS.**

18        “In this title:

19           “(1) 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           “(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  
7                   treatment 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  
10                  child or adult with a special need in order to provide  
11                  temporary relief to the family caregiver of that child  
12                  or 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. 2903. LIFESPAN RESPITE CARE GRANTS AND COOP-**  
19                   **ERATIVE AGREEMENTS.**

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

21                   “(1) to expand and enhance respite care serv-  
22                   ices 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 applica-  
7           tion pursuant to subsection (d).

8           “(c) FEDERAL LIFESPAN APPROACH.—In carrying  
9           out this section, the Secretary shall work in cooperation  
10          with the National Family Caregiver Support Program Of-  
11          ficer of the Administration on Aging, and respite care pro-  
12          gram officers in the Administration for Children and Fam-  
13          ilies, the Administration on Developmental Disabilities,  
14          the Maternal and Child Health Bureau of the Health Re-  
15          sources and Services Administration, and the Substance  
16          Abuse and Mental Health Services Administration, to en-  
17          sure coordination of respite care services for family care-  
18          givers of children and adults with special needs.

19          “(d) APPLICATION.—

20                 “(1) SUBMISSION.—Each eligible recipient de-  
21                 siring to receive a grant or cooperative agreement  
22                 under this section shall submit an application to the  
23                 Secretary at such time, in such manner, and con-  
24                 taining such information as the Secretary shall re-  
25                 quire.

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  
16           and 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  
2           coordinate respite care information and  
3           services to the population at the State and  
4           local 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 mak-  
11          ing informed decisions about respite care  
12          services will be provided using grant or co-  
13          operative 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,  
4           and local funds, programs, contributions,  
5           other forms of reimbursements, personnel,  
6           and facilities;

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

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

18          “(xi) how the quality and safety of  
19          any respite care services provided will be  
20          monitored, including methods to ensure  
21          that respite care workers and volunteers  
22          are appropriately screened and possess the  
23          necessary skills to care for the needs of the  
24          care recipient in the absence of the family  
25          caregiver; and

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

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

9                   “(e) REVIEW OF APPLICATIONS.—

10                  “(1) ESTABLISHMENT OF REVIEW PANEL.—  
11                  The Secretary shall establish a panel to review appli-  
12                  cations 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  
21                          should be approved.

22                  “(f) AWARDING OF GRANTS OR COOPERATIVE  
23                  AGREEMENTS.—

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

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

3 “(2) PRIORITY.—When awarding grants or co-  
4 operative agreements under this subsection, the Sec-  
5 retary shall give priority to applicants that show the  
6 greatest likelihood of implementing or enhancing  
7 lifespan 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 exist-  
15 ence—

16 “(i) the development of lifespan res-  
17 pite 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  
23 may 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  
12                  activity described in subparagraph (B), the eli-  
13                  gible recipient shall use funds for an evaluation  
14                  of the 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  
19                  activities 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  
 4           agreement determined under paragraph (1).

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

9           “(j) AUTHORIZATION OF APPROPRIATIONS.—There  
 10          are authorized to be appropriated to carry out this sec-  
 11          tion—

12                   “(1) \$90,500,000 for fiscal year 2006; and

13                   “(2) such sums as are necessary for fiscal years  
 14          2007 through 2010.

15   **“SEC. 2904. NATIONAL LIFESPAN RESPITE RESOURCE CEN-**  
 16                   **TER.**

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

22           “(b) PURPOSES OF THE CENTER.—The center  
 23          shall—

24                   “(1) maintain a national database on lifespan  
 25          respite care;

1           “(2) provide training and technical assistance  
2           to 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  
8           are authorized to be appropriated to carry out this section  
9           \$500,000 for each of fiscal years 2006 through 2010.”.

○