

**AMENDMENT IN THE NATURE OF A SUBSTITUTE
TO H.R. 3248
OFFERED BY MR. FERGUSON OF NEW JERSEY**

Strike all after the enacting clause and insert the following:

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Lifespan Respite Care
3 Act of 2006”.

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. DEFINITIONS.**

10 “In this title:

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

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

15 “(B) prevent physical self-injury or injury
16 to others; or

17 “(C) avoid placement in an institutional
18 facility.

1 “(2) AGING AND DISABILITY RESOURCE CEN-
2 TER.—The term ‘aging and disability resource cen-
3 ter’ means an entity administering a program estab-
4 lished by the State, as part of the State’s system of
5 long-term care, to provide a coordinated system for
6 providing—

7 “(A) comprehensive information on avail-
8 able public and private long-term care pro-
9 grams, options, and resources;

10 “(B) personal counseling to assist individ-
11 uals in assessing their existing or anticipated
12 long-term care needs, and developing and imple-
13 menting a plan for long-term care designed to
14 meet their specific needs and circumstances;
15 and

16 “(C) consumer access to the range of pub-
17 licly-supported long-term care programs for
18 which consumers may be eligible, by serving as
19 a convenient point of entry for such programs.

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

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

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

3 “(4) ELIGIBLE STATE AGENCY.—The term ‘eli-
4 gible State agency’ means a State agency that—

5 “(A) administers the State’s program
6 under the Older Americans Act of 1965, admin-
7 isters the State’s program under title XIX of
8 the Social Security Act, or is designated by the
9 Governor of such State to administer the
10 State’s programs under this title;

11 “(B) is an aging and disability resource
12 center;

13 “(C) works in collaboration with a public
14 or private non-profit statewide respite care coa-
15 lition or organization; and

16 “(D) demonstrates—

17 “(i) an ability to work with other
18 State and community-based agencies;

19 “(ii) an understanding of respite care
20 and family caregiver issues across all age
21 groups, disabilities, and chronic conditions;
22 and

23 “(iii) the capacity to ensure meaning-
24 ful involvement of family members, family
25 caregivers, and care recipients.

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

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

11 “(7) RESPITE CARE.—The term ‘respite care’
12 means planned or emergency care provided to a
13 child or adult with a special need in order to provide
14 temporary relief to the family caregiver of that child
15 or adult.

16 “(8) STATE.—The term ‘State’ means any of
17 the several States, the District of Columbia, the Vir-
18 gin Islands of the United States, the Commonwealth
19 of Puerto Rico, Guam, American Samoa, and the
20 Commonwealth of the Northern Mariana Islands.

21 **“SEC. 2902. LIFESPAN RESPITE CARE GRANTS AND COOP-
22 ERATIVE AGREEMENTS.**

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

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

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

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

6 “(b) AUTHORIZATION.—Subject to subsection (e), the
7 Secretary is authorized to award grants or cooperative
8 agreements for the purposes described in subsection (a)
9 to eligible State agencies for which an application is sub-
10 mitted pursuant to subsection (d).

11 “(c) FEDERAL LIFESPAN APPROACH.—In carrying
12 out this section, the Secretary shall work in cooperation
13 with the National Family Caregiver Support Program of
14 the Administration on Aging and other respite care pro-
15 grams within the Department of Health and Human Serv-
16 ices to ensure coordination of respite care services for fam-
17 ily caregivers of children and adults with special needs.

18 “(d) APPLICATION.—

19 “(1) SUBMISSION.—Each Governor desiring the
20 eligible State agency of his or her State to receive
21 a grant or cooperative agreement under this section
22 shall submit an application on behalf of such agency
23 to the Secretary at such time, in such manner, and
24 containing such information as the Secretary shall
25 require.

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

3 “(A) a description of the eligible State
4 agency’s—

5 “(i) ability to work with other State
6 and community-based agencies;

7 “(ii) understanding of respite care
8 and family caregiver issues across all age
9 groups, disabilities, and chronic conditions;
10 and

11 “(iii) capacity to ensure meaningful
12 involvement of family members, family
13 caregivers, and care recipients;

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

19 “(i) the population of family care-
20 givers;

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

23 “(iii) existing respite care services for
24 that population, including numbers of fam-

1 ily caregivers being served and extent of
2 unmet need;

3 “(iv) existing methods or systems to
4 coordinate respite care information and
5 services to the population at the State and
6 local level and extent of unmet need;

7 “(v) how respite care information dis-
8 semination and coordination, respite care
9 services, respite care worker and volunteer
10 recruitment and training programs, or
11 training programs for family caregivers
12 that assist such family caregivers in mak-
13 ing informed decisions about respite care
14 services will be provided using grant or co-
15 operative agreement funds;

16 “(vi) a plan for administration, col-
17 laboration, and coordination of the pro-
18 posed respite care activities with other re-
19 lated services or programs offered by pub-
20 lic or private, nonprofit entities, including
21 area agencies on aging;

22 “(vii) how the population, including
23 family caregivers, care recipients, and rel-
24 evant public or private agencies, will par-

1 participate in the planning and implementa-
2 tion of the proposed respite care activities;

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

9 “(ix) respite care services available to
10 family caregivers in the eligible State agen-
11 cy’s State or locality, including unmet
12 needs and how the eligible State agency’s
13 plan for use of funds will improve the co-
14 ordination and distribution of respite care
15 services for family caregivers of children
16 and adults with special needs;

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

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

1 care recipient in the absence of the family
2 caregiver; and

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

7 “(C) assurances that, where appropriate,
8 the eligible State agency will have a system for
9 maintaining the confidentiality of care recipient
10 and family caregiver records; and

11 “(D) a memorandum of agreement regard-
12 ing the joint responsibility for the eligible State
13 agency’s lifespan respite program between—

14 “(i) the eligible State agency; and

15 “(ii) a public or private non-profit
16 statewide respite coalition or organization.

17 “(e) PRIORITY; CONSIDERATIONS.—When awarding
18 grants or cooperative agreements under this section, the
19 Secretary shall—

20 “(1) give priority to eligible State agencies that
21 the Secretary determines show the greatest likeli-
22 hood of implementing or enhancing lifespan respite
23 care statewide; and

24 “(2) give consideration to eligible State agencies
25 that are building or enhancing the capacity of their

1 long-term care systems to respond to the comprehen-
2 sive needs, including respite care needs, of their resi-
3 dents.

4 “(f) USE OF GRANT OR COOPERATIVE AGREEMENT
5 FUNDS.—

6 “(1) IN GENERAL.—

7 “(A) REQUIRED USES OF FUNDS.—Each
8 eligible State agency awarded a grant or coop-
9 erative agreement under this section shall use
10 all or part of the funds—

11 “(i) to develop or enhance lifespan
12 respite care at the State and local levels;

13 “(ii) to provide respite care services
14 for family caregivers caring for children or
15 adults;

16 “(iii) to train and recruit respite care
17 workers and volunteers;

18 “(iv) to provide information to care-
19 givers about available respite and support
20 services; and

21 “(v) to assist caregivers in gaining ac-
22 cess to such services.

23 “(B) OPTIONAL USES OF FUNDS.—Each
24 eligible State agency awarded a grant or coop-

1 erative agreement under this section may use
2 part of the funds for—

3 “(i) training programs for family
4 caregivers to assist such family caregivers
5 in making informed decisions about respite
6 care services;

7 “(ii) other services essential to the
8 provision of respite care as the Secretary
9 may specify; or

10 “(iii) training and education for new
11 caregivers.

12 “(2) SUBCONTRACTS.—Each eligible State
13 agency awarded a grant or cooperative agreement
14 under this section may carry out the activities de-
15 scribed in paragraph (1) directly or by grant to, or
16 contract with, public or private entities.

17 “(3) MATCHING FUNDS.—

18 “(A) IN GENERAL.—With respect to the
19 costs of the activities to be carried out under
20 paragraph (1), a condition for the receipt of a
21 grant or cooperative agreement under this sec-
22 tion is that the eligible State agency agree to
23 make available (directly or through donations
24 from public or private entities) non-Federal

1 contributions towards such costs in an amount
2 that is not less than 25 percent of such costs.

3 “(B) DETERMINATION OF AMOUNT CON-
4 TRIBUTED.—Non-Federal contributions re-
5 quired by subparagraph (A) may be in cash or
6 in kind, fairly evaluated, including plant, equip-
7 ment, or services. Amounts provided by the
8 Federal Government, or services assisted or
9 subsidized to any significant extent by the Fed-
10 eral Government, may not be included in deter-
11 mining the amount of such non-Federal con-
12 tributions.

13 “(g) TERM OF GRANTS OR COOPERATIVE AGREE-
14 MENTS.—

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

18 “(2) RENEWAL.—The Secretary may renew a
19 grant or cooperative agreement under this section at
20 the end of the term of the grant or cooperative
21 agreement determined under paragraph (1).

22 “(h) MAINTENANCE OF EFFORT.—Funds made
23 available under this section shall be used to supplement
24 and not supplant other Federal, State, and local funds
25 available for respite care services.

1 **“SEC. 2903. NATIONAL LIFESPAN RESPITE RESOURCE CEN-**
2 **TER.**

3 “(a) ESTABLISHMENT.—The Secretary may award a
4 grant or cooperative agreement to a public or private non-
5 profit entity to establish a National Resource Center on
6 Lifespan Respite Care (referred to in this section as the
7 ‘center’).

8 “(b) PURPOSES OF THE CENTER.—The center
9 shall—

10 “(1) maintain a national database on lifespan
11 respite care;

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

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

18 **“SEC. 2904. REPORT.**

19 “Not later than January 1, 2009, the Secretary shall
20 report to the Congress on the activities undertaken under
21 this title. Such report shall evaluate—

22 “(1) the number of States that have lifespan
23 respite care programs;

24 “(2) the demographics of the caregivers receiv-
25 ing respite care services through grants or coopera-
26 tive agreements under this title; and

1 “(3) the effectiveness of entities receiving
2 grants or cooperative agreements under this title.

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

4 “There are authorized to be appropriated to carry out
5 this title—

6 “(1) \$30,000,000 for fiscal year 2007;

7 “(2) \$40,000,000 for fiscal year 2008;

8 “(3) \$53,330,000 for fiscal year 2009;

9 “(4) \$71,110,000 for fiscal year 2010; and

10 “(5) \$94,810,000 for fiscal year 2011.”.