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# LIFESPAN RESPITE CARE ACT OF 2006

DECEMBER 5, 2006.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

Mr. Barton of Texas, from the Committee on Energy and Commerce, submitted the following

# REPORT

[To accompany H.R. 3248]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 3248) 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, having considered the same, report favorably thereon with an amendment and recommend that the bill as amended do pass.

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### **AMENDMENT**

The amendment is as follows: Strike all after the enacting clause and insert the following: 59-006

#### SECTION 1. SHORT TITLE.

This Act may be cited as the "Lifespan Respite Care Act of 2006".

### SEC. 2. LIFESPAN RESPITE CARE.

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

## "TITLE XXIX—LIFESPAN RESPITE CARE

### "SEC. 2901. DEFINITIONS.

"In this title:

"(1) ADULT WITH A SPECIAL NEED.—The term 'adult with a special need' means a person 18 years of age or older who requires care or supervision to-

"(A) meet the person's basic needs;
"(B) prevent physical self-injury or injury to others; or
"(C) avoid placement in an institutional facility.

"(2) AGING AND DISABILITY RESOURCE CENTER.—The term 'aging and disability resource center' means an entity administering a program established by the State, as part of the State's system of long-term care, to provide a coordinated system for providing—

"(A) comprehensive information on available public and private long-term

care programs, options, and resources;
"(B) personal counseling to assist individuals in assessing their existing or anticipated long-term care needs, and developing and implementing a plan for long-term care designed to meet their specific needs and circumstances; and

(C) consumer access to the range of publicly supported long-term care programs for which consumers may be eligible, by serving as a convenient

point of entry for such programs.

"(3) CHILD WITH A SPECIAL NEED.—The term 'child with a special need' means an individual less than 18 years of age who requires care or supervision beyond that required of children generally to-

(A) meet the child's basic needs; or

"(B) prevent physical injury, self-injury, or injury to others.
"(4) ELIGIBLE STATE AGENCY.—The term 'eligible State agency' means a State

agency that-

'(A) administers the State's program under the Older Americans Act of 1965, administers the State's program under title XIX of the Social Security Act, or is designated by the Governor of such State to administer the State's programs under this title;

(B) is an aging and disability resource center;

"(C) works in collaboration with a public or private nonprofit statewide respite care coalition or organization; and

"(D) demonstrates-

- "(i) an ability to work with other State and community-based agencies:
- "(ii) an understanding of respite care and family caregiver issues across all age groups, disabilities, and chronic conditions; and

"(iii) the capacity to ensure meaningful involvement of family mem-

- bers, family caregivers, and care recipients.

  "(5) FAMILY CAREGIVER.—The term 'family caregiver' means an unpaid family member, a foster parent, or another unpaid adult, who provides in-home monitoring, management, supervision, or treatment of a child or adult with a special
- "(6) LIFESPAN RESPITE CARE.—The term 'lifespan respite care' means a coordinated system of accessible, community-based respite care services for family caregivers of children or adults with special needs.

"(7) RESPITE CARE.—The term 'respite care' means planned or emergency care provided to a child or adult with a special need in order to provide temporary

relief to the family caregiver of that child or adult.

"(8) STATE.—The term 'State' means any of the several States, the District of Columbia, the Virgin Islands of the United States, the Commonwealth of Puerto Rico, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

### "SEC. 2902. LIFESPAN RESPITE CARE GRANTS AND COOPERATIVE AGREEMENTS.

"(a) Purposes.—The purposes of this section are-

"(1) to expand and enhance respite care services to family caregivers;

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

"(3) to provide, supplement, or improve access and quality of respite care serv-

ices to family caregivers, thereby reducing family caregiver strain.

"(b) AUTHORIZATION.—Subject to subsection (e), the Secretary is authorized to award grants or cooperative agreements for the purposes described in subsection (a) to eligible State agencies for which an application is submitted pursuant to subsection (d).

"(c) FEDERAL LIFESPAN APPROACH.—In carrying out this section, the Secretary shall work in cooperation with the National Family Caregiver Support Program of the Administration on Aging and other respite care programs within the Department of Health and Human Services to ensure coordination of respite care services for family caregivers of children and adults with special needs.

"(d) APPLICATION.—

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

"(2) CONTENTS.—Each application submitted under this section shall in-

clude-

"(A) a description of the eligible State agency's—

"(i) ability to work with other State and community-based agencies; "(ii) understanding of respite care and family caregiver issues across all age groups, disabilities, and chronic conditions; and

"(iii) capacity to ensure meaningful involvement of family members,

family caregivers, and care recipients;

"(B) with respect to the population of family caregivers to whom respite care information or services will be provided or for whom respite care workers and volunteers will be recruited and trained, a description of—

"(i) the population of family caregivers;

"(ii) the extent and nature of the respite care needs of that population;

"(iii) existing respite care services for that population, including numbers of family caregivers being served and extent of unmet need;

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

"(v) how respite care information dissemination and coordination, respite care services, respite care worker and volunteer recruitment and training programs, or training programs for family caregivers that assist such family caregivers in making informed decisions about respite care services will be provided using grant or cooperative agreement funds;

funds;
"(vi) a plan for administration, collaboration, and coordination of the proposed respite care activities with other related services or programs offered by public or private, nonprofit entities, including area agencies on aging;

"(vii) how the population, including family caregivers, care recipients, and relevant public or private agencies, will participate in the planning

and implementation of the proposed respite care activities;

"(viii) how the proposed respite care activities will make use, to the maximum extent feasible, of other Federal, State, and local funds, programs, contributions, other forms of reimbursements, personnel, and facilities;

"(ix) respite care services available to family caregivers in the eligible State agency's State or locality, including unmet needs and how the eligible State agency's plan for use of funds will improve the coordination and distribution of respite care services for family caregivers of children and adults with special needs;

"(x) the criteria used to identify family caregivers eligible for respite

care services;

"(xi) how the quality and safety of any respite care services provided will be monitored, including methods to ensure that respite care workers and volunteers are appropriately screened and possess the necessary skills to care for the needs of the care recipient in the absence of the family caregiver; and

"(xii) the results expected from proposed respite care activities and

the procedures to be used for evaluating those results;

"(C) assurances that, where appropriate, the eligible State agency will have a system for maintaining the confidentiality of care recipient and family caregiver records; and "(D) a memorandum of agreement regarding the joint responsibility for

the eligible State agency's lifespan respite program between-

(i) the eligible State agency; and

"(ii) a public or private nonprofit statewide respite coalition or organi-

"(e) PRIORITY; CONSIDERATIONS.—When awarding grants or cooperative agreements under this section, the Secretary shall-

"(1) give priority to eligible State agencies that the Secretary determines show the greatest likelihood of implementing or enhancing lifespan respite care statewide: and

"(2) give consideration to eligible State agencies that are building or enhancing the capacity of their long-term care systems to respond to the comprehensive needs, including respite care needs, of their residents. "(f) USE OF GRANT OR COOPERATIVE AGREEMENT FUNDS.

"(1) In general.-

"(A) REQUIRED USES OF FUNDS.—Each eligible State agency awarded a grant or cooperative agreement under this section shall use all or part of the funds-

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

"(ii) to provide respite care services for family caregivers caring for children or adults;

"(iii) to train and recruit respite care workers and volunteers;

"(iv) to provide information to caregivers about available respite and support services; and

(v) to assist caregivers in gaining access to such services.

"(B) OPTIONAL USES OF FUNDS.—Each eligible State agency awarded a grant or cooperative agreement under this section may use part of the funds for—

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

"(ii) other services essential to the provision of respite care as the Secretary may specify; or

"(iii) training and education for new caregivers.

"(2) SUBCONTRACTS.—Each eligible State agency awarded a grant or cooperative agreement under this section may carry out the activities described in paragraph (1) directly or by grant to, or contract with, public or private entities. "(3) MATCHING FUNDS.

"(A) IN GENERAL.—With respect to the costs of the activities to be carried out under paragraph (1), a condition for the receipt of a grant or cooperative agreement under this section is that the eligible State agency agrees to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs.

"(B) DETERMINATION OF AMOUNT CONTRIBUTED.—Non-Federal contributions required by subparagraph (A) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

"(g) TERM OF GRANTS OR COOPERATIVE AGREEMENTS.—
"(1) IN GENERAL.—The Secretary shall award grants or cooperative agreements under this section for terms that do not exceed 5 years.

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

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

### "SEC. 2903. NATIONAL LIFESPAN RESPITE RESOURCE CENTER.

"(a) ESTABLISHMENT.—The Secretary may award a grant or cooperative agreement to a public or private nonprofit entity to establish a National Resource Center on Lifespan Respite Care (referred to in this section as the 'center').

"(b) PURPOSES OF THE CENTER.—The center shall—

"(1) maintain a national database on lifespan respite care;

"(2) provide training and technical assistance to State, community, and non-profit respite care programs; and

"(3) provide information, referral, and educational programs to the public on lifespan respite care.

### "SEC. 2904. REPORT.

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

"(1) the number of States that have lifespan respite care programs;

"(2) the demographics of the caregivers receiving respite care services through grants or cooperative agreements under this title; and

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

### "SEC. 2905. AUTHORIZATION OF APPROPRIATIONS.

"There are authorized to be appropriated to carry out this title—

"(1) \$30,000,000 for fiscal year 2007; "(2) \$40,000,000 for fiscal year 2008; "(3) \$53,330,000 for fiscal year 2009; "(4) \$71,110,000 for fiscal year 2010; and "(5) \$94,810,000 for fiscal year 2011.".

### PURPOSE AND SUMMARY

H.R. 3248, the Lifespan Respite Care Act of 2006, amends the Public Health Service Act to authorize the Secretary of the Department of Health and Human Services (HHS) to award grants to State-designated Aging and Disability Resource Centers (ADRCs). Grants are to be awarded for the purposes of developing lifespan respite care programs at the State and local levels; providing planned or emergency respite care services for family caregivers of children and adults; training and recruiting respite workers and volunteers; providing information to caregivers about available respite and support services; and assisting caregivers in gaining access to such services.

### BACKGROUND AND NEED FOR LEGISLATION

It is estimated that 25 million Americans currently care for a sick, aged, or disabled loved one at home. For family caregivers, the time, stress, effort, and physical toil involved with caring for a loved one is compounded with the numerous responsibilities of daily life. The physical, emotional, and financial problems that result impede caregivers' ability to continue in their role as caregiver and may have an adverse impact on other aspects of their lives. Respite care is intended to give caregivers a break from caring for their loved ones, usually for a short period of time. Respite care affords caregivers the opportunity to go to the store, meet health care appointments, and perform necessary tasks of daily living outside of their caregiver roles. Respite care services can be delivered on either a planned or emergency basis. For example, emergency respite care may be required when a caregiver must leave the home for scheduled or unscheduled surgery. The term "respite care" refers to a broad array of in-home and out-of-home services, from home health and adult day care services to volunteer respite services. What distinguishes respite care from other forms of long term care support is that the focus is primarily on the needs of the caregiver.

Evidence suggests that the availability of respite care presents significant benefits to the caregiver, the sick, elderly, or disabled individual, and the rest of society. In a 1985 study, researchers

Cohen and Warren concluded that respite care could improve family functioning, improve satisfaction with life, enhance the caregiver's capacity to cope with stress, and improve attitudes toward the family member with an illness or disability. A more recent study conducted at Oklahoma State University found that the number of hospitalizations as well as the number of medical care claims decreased as the number of respite days increased. A 1996 evaluation of the Iowa Respite Child Care Project, which offers respite care for families parenting a child with developmental disabilities, found that when respite care is available, there is a statistically significant decrease in foster care placements. Other evidence suggests that respite care is equally beneficial to those caring for the elderly. A survey conducted by Theit et al. in 1994 found that over half of caregivers for the elderly receiving only four hours of respite a week for one year reported improved physical and emotional health. The Their survey also found that half of caregivers reported improved health for the sick or disabled elderly person.

The benefits of respite care can extend to third-party payers for long term care services. This is because the availability of effective respite care has shown the possibility of delaying or preventing entry into more expensive institutional long-term care facilities. The Theit survey found that 40 percent of caregivers were less likely to institutionalize the care recipient because of the respite they had received.

The trend toward greater spending on long-term care is likely to continue. National spending for long-term care was almost \$160 billion in 2002, representing about 12 percent of all personal health care expenditures. Almost half of this spending was through the Federal-State Medicaid program, primarily paying for care in nursing homes. On average, a year's nursing home charges can range from \$60,000 to \$70,000. The Government Accountability Office estimates that by 2020 the number of adults requiring assistance with daily living will increase to almost 40 million and the number of elderly persons requiring long-term care will double. Respite care, offered as part of a comprehensive range of in home and community-based care, can present sick, elderly, and disabled individuals and their families with less expensive alternatives to nursing home care. No estimates of the actual savings for public programs such as Medicaid were available.

In recent years, both Congress and the Executive Branch have ascribed greater importance to respite care in the assortment of long-term care support options. The Older Americans Act Amendments of 2000 created the National Family Caregiver Support Program (NFCSP). NFCSP provides assistance and services to families who care for the frail elderly. Services are targeted to Americans age 60 and older and include information and assistance to caregivers, counseling services, support groups, respite services, and other home and community-based services to provide families temporary caregiver relief. Other Federal initiatives involving or providing respite care include Section 1915(c) and Section 1115 Medicaid waivers that allow States to include respite care services in their home and community-based programs; Real Choice Systems Grants launched in 2003 that include respite care feasibility studies and development grants; and several demonstration projects

and model grants tied to respite care for families of children with developmental disabilities authorized under the Developmental Disabilities Act. Other initiatives such as the administration's New Freedom Initiative, Money Follows the Person, and Choices for Independence recognize the crucial role of respite care in allowing

families to provide care at home.

States have also begun to take the lead with innovative respite care programs. States including Oregon, Nebraska, and Wisconsin have enacted so-called "lifespan respite care acts," that establish State and local infrastructures for developing, providing, coordinating, and improving access to respite care services for eligible residents across the lifespan, encompassing people of many different ages, disabilities, and special needs. Oklahoma implemented such a lifespan respite care program without legislation. Several other States are actively considering or piloting similar programs or legislation.

Volunteer, non-profit, and faith-based organizations have also begun to build the capacity and infrastructure necessary to meet the Nation's respite care needs. The online National Respite Locator Service (see http://www.respitelocator.org/index.htm), lists hundreds of organizations around the country providing respite care referrals and services as a free public service by the ARCH National

Respite Network.

Rather than attempting to supplant, replace, or duplicate other Federal, State, local, and private respite care development efforts, the Lifespan Respite Care Act is intended to facilitate coordination between programs and reduce duplication of effort. It is also intended to assist in the development of respite care infrastructure at the state and local levels.

In carrying out the Act, the Committee urges the Secretary to ensure that State agencies and ADRCs use the funds provided by this Act to serve all age groups and disability categories without preference. In addition, assurances should be made that ADRCs will reach and serve family caregivers who remain at greatest risk of having no respite services, especially caregivers caring for individuals with Multiple Sclerosis, ALS, autism, spinal cord injury, traumatic brain injury, adults with developmental and cognitive disabilities, individuals—including children—with emotional or mental health conditions, and children with all other types of developmental disabilities and chronic conditions.

When considering a Federal agency to take the lead in implementation of this program, the Committee urges the Secretary of HHS to select an agency that is not limited in scope or mission by any age or disability category, has experience in serving all populations across disability and age groups, and will ensure that the ADRC is collaborating fully and sharing joint responsibility with a private or public nonprofit State respite coalition or organization in implementing a State lifespan respite program. In addition, current respite programs across Federal agencies shall be consulted in the ongoing implementation of the Lifespan Respite Care program, including programs administered by HRSA, MCHB, ACF, SAMSHA, CMS, and ADD.

Some Federal, State, and private programs currently support, or have the potential to support, planned and emergency or crisis respite care for caregivers of individuals who may not meet the bill's definition of special needs. There are also caregivers who are in continuously stressful situations due to extenuating circumstances or their own physical or mental health conditions, or who are in emergency situations that might put themselves or the person they are caring for in harm's way and rely on emergency respite services that might be provided by the State. Since the intent of the Committee in approving the bill is to reduce duplication and fragmentation of services and maximize existing resources, the Committee would like to emphasize that there is nothing in this bill that would preclude a grantee, in implementing State or local respite programs, from coordinating with these existing public or private

programs.

The intent of this legislation is to improve the delivery and quality of respite services available to families across age and disability groups by establishing coordinated lifespan respite systems. At a minimum, all family caregivers, regardless of the age, disability, or chronic condition of their loved ones, should be able to access a lifespan respite program for information on how and where to find a respite provider that meets their needs, and on how to pay for services. It is the responsibility of the Lifespan Respite Care program to have first identified all the current respite funding streams in the State and assist a family in determining for which existing private, State, or federally funded respite program they might be eligible. If that family does not qualify for any existing services, the Lifespan Respite Care program may use its funds to help families pay for respite care.

Within 24 months of receiving an ADRC grant, ADRC grantees must describe how they will institute eligibility screening and programmatic eligibility determinations for all individuals who may be eligible for publicly funded programs. In view of the limited resources available and existing requirements for ADRCs description of eligibility determinations, it is anticipated that ADRCs will provide information in their grant applications or as otherwise specified by the Secretary on how they will determine which families are eligible for financial assistance. However, no family should be turned away from seeking information on how or where to find or

pay for respite care.

The Committee would like to clarify that the definition of family caregivers includes grandparents of any age who are the primary caretakers of children or adults with special needs. Also, "unpaid family caregivers" means family caregivers who do not receive funds to provide care as their primary means of income (i.e., non-professional family caregivers). The language is not meant to exclude family caregivers who receive minimal payments from State or Federal sources from receiving lifespan respite information or services. Such sources include funds received under Home and Community Based Services (HCBS) Waiver developmental disability programs, Independence Plus and 1115 Waivers (Cash and Counseling programs included), and other State or Federal family support programs, to help assist with the person in their care, but this source of income is not what they rely on as primary income.

Finally, in the definition of children up to age 18 with special needs, the Committee intends the phrase "beyond that required of children generally" to mean care beyond that typically required of children of the same age. Clarification is necessary since "care re-

quired by children generally" is dependent on age. It would be typical to provide total 24-hour care, including feeding, dressing, toileting, safety, mobility, supervision, etc., to an infant; however, such care may not be typical for a seventeen-year old.

### **HEARINGS**

The Committee on Energy and Commerce has not held hearings on the legislation.

### COMMITTEE CONSIDERATION

On Wednesday, September 20, 2006, the Committee on Energy and Commerce met in open markup session and ordered H.R. 3248 favorably reported to the House, amended, by a voice vote, a quorum being present.

### COMMITTEE VOTES

Clause 3(b) of rule XIII of the Rules of the House of Representatives requires the Committee to list the record votes on the motion to report legislation and amendments thereto. There were no record votes taken in connection with ordering H.R. 3248 reported. A motion by Mr. Barton to order H.R. 3248 favorably reported to the House, amended, was agreed to by a voice vote.

### COMMITTEE OVERSIGHT FINDINGS

Pursuant to clause 3(c)(1) of rule XIII of the Rules of the House of Representatives, the Committee has not held oversight or legislative hearings on this legislation.

# STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

The goals and objectives of the Lifespan Respite Care Act are to promote respite care programs at the State and local levels; provide planned or emergency respite services for family caregivers of children and adults; train and recruit respite workers and volunteers; provide information to caregivers about available respite and support services; and assist caregivers in gaining access to such services.

# NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

In compliance with clause 3(c)(2) of rule XIII of the Rules of the House of Representatives, the Committee finds that H.R. 3248, the Lifespan Respite Care Act of 2006, would result in no new or increased budget authority, entitlement authority, or tax expenditures or revenues.

### EARMARK

In compliance with H. Res. 1000 as passed the House of Representatives on September 14, 2006, the Committee finds that H.R. 3248, the Lifespan Respite Care Act of 2006, contains no earmarks.

### COMMITTEE COST ESTIMATE

The Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

### CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII of the Rules of the House of Representatives, the following is the cost estimate provided by the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974:

U.S. Congress, Congressional Budget Office, Washington, DC, September 27, 2006.

Hon. Joe Barton, Chairman, Committee on Energy and Commerce, House of Representatives, Washington, DC.

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed cost estimate for H.R. 3248, the Lifespan Respite Care Act of 2005.

If you wish further details on this estimate, we will be pleased to provide them. The CBO staff contact is Camile Williams.

Sincerely,

ROBERT A. SUNSHINE (for Donald B. Marron, Acting Director).

Enclosure.

### H.R. 3248—Lifespan Respite Care Act of 2005

Summary: H.R. 3248 would amend the Public Health Service Act to authorize the Secretary of Health and Human Services to award grants and enter into cooperative agreements with states to expand and enhance services for lifespan respite care. Lifespan respite care is a coordinated system of community-based services that provide temporary relief from caregiving obligations to family members who normally provide care to a relative with special needs.

CBO estimates that implementing the H.R. 3248 would cost \$9 million in fiscal year 2007 and \$191 million over the 2007–2011 period, assuming appropriation of the specified amounts. Enacting H.R. 3248 would not affect direct spending of revenues.

H.R. 3248 contains no private-sector or intergovernmental mandates as defined in the Unfunded Mandates Reform Act (UMRA).

Estimated Cost to the Federal Government: The estimated budgetary impact of H.R. 3248 is shown in the following table. The costs of this legislation fall within budget function 550 (health).

	By fiscal year, in millions of dollars—					
	2007	2008	2009	2010	2011	
SPENDING SUBJECT TO APPROPRIATION						
Estimated Authorization Level	30 9	40 25	53 39	71 54	95 64	

Basis of estimate: H.R. 3248 would amend the Public Health Service Act to authorize the Secretary of Health and Human Services to make grants to states to expand the availability of respite care to caregivers, recruit and train individuals who provide respite care, and disseminate information about the availability of respite care services.

The bill also would direct the Secretary to award grants or enter into cooperative agreements with public or private nonprofit entities to establish the National Resource Center on Lifespan Respite Care. The National Resource Center would maintain a national database on lifespan respite care, provide training and technical assistance to state, community, and nonprofit programs involving respite care, and provide referral and educational programs to the public on respite care.

The bill would authorize the appropriation of \$30 million for fiscal year 2007 and \$289 million over the 2007–2011 period. Based on historical patterns of spending for similar activities, CBO estimates that implementing the bill would cost \$9 million in the fiscal year 2007 and \$191 million over the 2007–2011 period, assuming the appropriation of the specified amounts.

Intergovernmental and Private-Sector Impact: H.R. 3248 contains no private-sector or intergovernmental mandates as defined in UMRA. State governments would benefit from grant funding authorized by the bill as long as they agree to provide a 25 percent match, either in cash or in kind. Any costs incurred by states to qualify for such grants would be incurred voluntarily as conditions of federal assistance.

Estimate Prepared by: Federal Costs: Camile Williams. Impact on State, Local, and Tribal Governments: Leo Lex. Impact on the Private Sector: Paige Shelvin.

Estimate approved by: Robert A. Sunshine, Assistant Director for Budget Analysis.

### FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

### ADVISORY COMMITTEE STATEMENT

No advisory committees within the meaning of section 5(b) of the Federal Advisory Committee Act were created by this legislation.

### CONSTITUTIONAL AUTHORITY STATEMENT

Pursuant to clause 3(d)(1) of rule XIII of the Rules of the House of Representatives, the Committee finds that the Constitutional authority for this legislation is provided in Article I, section 8, clause 3, which grants Congress the power to regulate commerce with foreign nations, among the several States, and with the Indian tribes.

### APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

### SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

Section 1. Short title

Section 1 establishes the short title as the "Lifespan Respite Care Act of 2006".

Section 2. Amendments to the Public Health Service Act

Section 2 would establish a new Title XXIX in the Public Health Service Act to create a grant program for the development of respite care programs in the states.

Section 2901. Definitions

New Section 2901 would identify and define the elements of a new respite care grant program, including the terms "adult with a special need," "aging and disability resource center," "child with a special need," "eligible state agency," "family caregiver," "lifespan respite care," "respite care," and "State."

The definition of the term "adult with a special need" contains several parts. Persons may meet this definition if they are 18 years of age or older and require care or supervision to meet their basic needs (such as food, clothing, shelter, etc.), to prevent them from physically injuring themselves or others, or to avoid placement in an institutional facility.

Avoiding placement in an institutional facility may encompass many factors, including whether or not the individual's needs, financial assets and income, or health insurance status place that individual at high risk for being placed in an institutional facility.

The definition of the term "aging and disability resource center"

The definition of the term "aging and disability resource center" (ADRC) also has several parts. ADRCs are envisioned as State-based entities tasked with providing comprehensive information on the array of long-term support services available, including both public and private options. ADRCs will serve as a resource for individuals who need long-term support, their family caregivers, and those planning for future long-term support needs. Functions performed by the ADRCs include eligibility screening for public assistance, assistance in gaining access to long-term support services that may be paid for with private funds, and referral to other programs and benefits that can help people to provide for their long-term support needs.

Section 2902. Lifespan Respite Care grants and cooperative agreements

New Section 2902 authorizes the Secretary of HHS to award Lifespan Respite Care grants and cooperative agreements. It defines a "Federal lifespan approach," which is intended to ensure cooperation and coordination between existing federal respite programs.

Section 2903. National Lifespan Respite Resource Center

New Section 2903 of the Public Health Service Act authorizing the creation of the National Lifespan Respite Resource Center to maintain a database of respite care information and provide training, technical assistance, and information on respite care programs. Section 2904. Report

New Section 2904 requires the Secretary of HHS to report to Congress on the activities undertaken under this legislation, including information on State-level respite care programs and demographic information on caregivers receiving respite care services under the legislation.

Section 2905. Authorization of appropriations

New Section 2905 of the Public Health Service Act, authorizing appropriations to carry out program activities.

CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (new matter is printed in italics and existing law in which no change is proposed is shown in roman):

### PUBLIC HEALTH SERVICE ACT

# TITLE XXIX—LIFESPAN RESPITE CARE

### SEC. 2901. DEFINITIONS.

In this title:

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

(A) meet the person's basic needs;

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

(C) avoid placement in an institutional facility.

(2) AGING AND DISABILITY RESOURCE CENTER.—The term "aging and disability resource center" means an entity administering a program established by the State, as part of the State's system of long-term care, to provide a coordinated system for providing—

(A) comprehensive information on available public and private long-term care programs, options, and resources;

(B) personal counseling to assist individuals in assessing their existing or anticipated long-term care needs, and developing and implementing a plan for long-term care designed to meet their specific needs and circumstances; and

(C) consumer access to the range of publicly supported long-term care programs for which consumers may be eligible, by serving as a convenient point of entry for such programs.

(3) CHILD WITH A SPECIAL NEED.—The term "child with a special need" means an individual less than 18 years of age who requires care or supervision beyond that required of children generally to—

(Å) meet the child's basic needs; or

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

(4) Eligible State agentus and Eligible State agen-

cy" means a State agency that—

(A) administers the State's program under the Older Americans Act of 1965, administers the State's program under title XIX of the Social Security Act, or is designated by the Governor of such State to administer the State's programs under this title;

(B) is an aging and disability resource center;

(C) works in collaboration with a public or private nonprofit statewide respite care coalition or organization; and (D) demonstrates—

(i) an ability to work with other State and commu-

*nity-based agencies;* 

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

(iii) the capacity to ensure meaningful involvement of family members, family caregivers, and care recipients.

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

(6) LIFESPAN RESPITE CARE.—The term "lifespan respite care" means a coordinated system of accessible, community-based respite care services for family caregivers of children or adults

with special needs.

(7) Respite care.—The term "respite care" means planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult.

(8) State.—The term "State" means any of the several States, the District of Columbia, the Virgin Islands of the United States, the Commonwealth of Puerto Rico, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

# SEC. 2902. LIFESPAN RESPITE CARE GRANTS AND COOPERATIVE AGREEMENTS.

(a) Purposes.—The purposes of this section are—

(1) to expand and enhance respite care services to family caregivers;

(2) to improve the statewide dissemination and coordination

of respite care; and

(3) to provide, supplement, or improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain.

(b) AUTHORIZATION.—Subject to subsection (e), the Secretary is authorized to award grants or cooperative agreements for the purposes described in subsection (a) to eligible State agencies for which

an application is submitted pursuant to subsection (d).

(c) FEDERAL LIFESPAN APPROACH.—In carrying out this section, the Secretary shall work in cooperation with the National Family Caregiver Support Program of the Administration on Aging and other respite care programs within the Department of Health and

Human Services to ensure coordination of respite care services for family caregivers of children and adults with special needs.

(d) APPLICATION.—

- (1) Submission.—Each Governor desiring the eligible State agency of his or her State to receive a grant or cooperative agreement under this section shall submit an application on behalf of such agency to the Secretary at such time, in such manner, and containing such information as the Secretary shall require.
- (2) Contents.—Each application submitted under this section shall include—

(A) a description of the eligible State agency's—

(i) ability to work with other State and communitybased agencies:

(ii) understanding of respite care and family caregiver issues across all age groups, disabilities, and

chronic conditions; and

(iii) capacity to ensure meaningful involvement of family members, family caregivers, and care recipients; (B) with respect to the population of family caregivers to whom respite care information or services will be provided or for whom respite care workers and volunteers will be recruited and trained, a description of—

(i) the population of family caregivers;

(ii) the extent and nature of the respite care needs of

that population;

(iii) existing respite care services for that population, including numbers of family caregivers being served and extent of unmet need;

(iv) existing methods or systems to coordinate respite care information and services to the population at the

State and local level and extent of unmet need;

(v) how respite care information dissemination and coordination, respite care services, respite care worker and volunteer recruitment and training programs, or training programs for family caregivers that assist such family caregivers in making informed decisions about respite care services will be provided using grant or cooperative agreement funds;

(vi) a plan for administration, collaboration, and coordination of the proposed respite care activities with other related services or programs offered by public or private, nonprofit entities, including area agencies on

aging;

(vii) how the population, including family caregivers, care recipients, and relevant public or private agencies, will participate in the planning and implementation of

the proposed respite care activities;

(viii) how the proposed respite care activities will make use, to the maximum extent feasible, of other Federal, State, and local funds, programs, contributions, other forms of reimbursements, personnel, and facilities:

(ix) respite care services available to family caregivers in the eligible State agency's State or locality, including unmet needs and how the eligible State agency's plan for use of funds will improve the coordination and distribution of respite care services for family caregivers of children and adults with special needs;

(x) the criteria used to identify family caregivers eli-

gible for respite care services;

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

(xii) the results expected from proposed respite care activities and the procedures to be used for evaluating

those results;

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

(D) a memorandum of agreement regarding the joint responsibility for the eligible State agency's lifespan respite

program between—

(i) the eligible State agency; and

(ii) a public or private nonprofit statewide respite coalition or organization.

(e) PRIORITY; CONSIDERATIONS.—When awarding grants or coop-

erative agreements under this section, the Secretary shall—

(1) give priority to eligible State agencies that the Secretary determines show the greatest likelihood of implementing or en-

hancing lifespan respite care statewide; and

(2) give consideration to eligible State agencies that are building or enhancing the capacity of their long-term care systems to respond to the comprehensive needs, including respite care needs, of their residents.

(f) Use of Grant or Cooperative Agreement Funds.—

(1) In general.—

(A) REQUIRED USES OF FUNDS.—Each eligible State agency awarded a grant or cooperative agreement under this section shall use all or part of the funds—

(i) to develop or enhance lifespan respite care at the

State and local levels;

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

(iii) to train and recruit respite care workers and vol-

unteers:

- (iv) to provide information to caregivers about available respite and support services; and
- (v) to assist caregivers in gaining access to such services.

(B) Optional uses of funds.—Each eligible State agency awarded a grant or cooperative agreement under this section may use part of the funds for—

(i) training programs for family caregivers to assist such family caregivers in making informed decisions

about respite care services;

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

(iii) training and education for new caregivers.

(2) SUBCONTRACTS.—Each eligible State agency awarded a grant or cooperative agreement under this section may carry out the activities described in paragraph (1) directly or by grant to, or contract with, public or private entities.

(3) MATCHING FUNDS.—

(A) In General.—With respect to the costs of the activities to be carried out under paragraph (1), a condition for the receipt of a grant or cooperative agreement under this section is that the eligible State agency agrees to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs.

(B) DETERMINATION OF AMOUNT CONTRIBUTED.—Non-Federal contributions required by subparagraph (A) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.

(g) TERM OF GRANTS OR COOPERATIVE AGREEMENTS.—

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

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

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

### SEC. 2903. NATIONAL LIFESPAN RESPITE RESOURCE CENTER.

- (a) ESTABLISHMENT.—The Secretary may award a grant or cooperative agreement to a public or private nonprofit entity to establish a National Resource Center on Lifespan Respite Care (referred to in this section as the "center").
  - (b) Purposes of the Center.—The center shall—
    - (1) maintain a national database on lifespan respite care;
    - (2) provide training and technical assistance to State, community, and nonprofit respite care programs; and
    - (3) provide information, referral, and educational programs to the public on lifespan respite care.

### SEC. 2904. REPORT.

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

- (1) the number of States that have lifespan respite care programs:
- (2) the demographics of the caregivers receiving respite care services through grants or cooperative agreements under this title; and

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

# SEC. 2905. AUTHORIZATION OF APPROPRIATIONS.

There are authorized to be appropriated to carry out this title—
(1) \$30,000,000 for fiscal year 2007;
(2) \$40,000,000 for fiscal year 2008;
(3) \$53,330,000 for fiscal year 2009;
(4) \$71,110,000 for fiscal year 2010; and
(5) \$94,810,000 for fiscal year 2011.

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