

112TH CONGRESS
1ST SESSION

H. R. 883

To expand and enhance existing adult day programs for people with neurological diseases or conditions (such as multiple sclerosis, Parkinson's disease, traumatic brain injury, or other similar diseases or conditions) to support and improve access to respite services for family caregivers who are taking care of such people, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MARCH 2, 2011

Ms. LEE of California introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To expand and enhance existing adult day programs for people with neurological diseases or conditions (such as multiple sclerosis, Parkinson's disease, traumatic brain injury, or other similar diseases or conditions) to support and improve access to respite services for family caregivers who are taking care of such people, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the "Adult Day Achieve-
5 ment Center Enhancement Act".

1 **SEC. 2. FINDINGS.**

2 The Congress finds the following:

3 (1) One in 6 people in the United States lives
4 with a neurological disease or condition that can
5 often result in disability, and which may require the
6 individual to seek assistance in carrying out the ac-
7 tivities of daily living. Neurological diseases or condi-
8 tions such as multiple sclerosis (MS), early-onset
9 Parkinson's disease, and traumatic brain injury
10 (TBI) can also typically affect younger adults in the
11 middle of their lives.

12 (2) Multiple sclerosis is a chronic, often dis-
13 abling disease that attacks the central nervous sys-
14 tem with symptoms ranging from numbness in limbs
15 to paralysis and loss of vision. Most people with MS
16 are diagnosed between the ages of 20 and 50 years
17 of age. It is estimated that over 400,000 people in
18 the United States are living with MS. Persons living
19 with MS who experience more severe forms of the
20 disease are likely to require either home care or
21 nursing home placement, though the vast majority
22 would prefer to remain at home to receive the care
23 they need. Where home care is concerned, approxi-
24 mately 80 percent of such care is provided by infor-
25 mal, unpaid caregivers who are generally family
26 members.

1 (3) Parkinson’s disease is a chronic, progressive
2 neurological disease. The 4 primary symptoms of
3 Parkinson’s disease are tremor, or trembling in
4 hands, arms, legs, jaw, and face; rigidity, or stiffness
5 of the limbs and trunk; bradykinesia, or slowness of
6 movement; and postural instability, or impaired bal-
7 ance and coordination. It is estimated that nearly
8 1,000,000 people live with Parkinson’s and of those
9 5 to 10 percent are diagnosed younger than 60 and
10 deemed “early-onset”.

11 (4) Traumatic brain injury is a neurological
12 condition that typically results from a blow or jolt to
13 the head or a penetrating head injury and that can
14 impact one or more parts of the brain, thereby tem-
15 porarily or permanently disrupting normal brain
16 function. The Centers for Disease Control and Pre-
17 vention estimates that 1,400,000 TBIs occur annu-
18 ally, resulting in disabilities affecting up to 90,000
19 people among a broad range of age groups. Trau-
20 matic brain injury is also a serious issue that affects
21 military service members. Estimates in prior military
22 conflicts indicate that TBI was present in 14–20
23 percent of surviving casualties.

24 (5) Family caregivers are a crucial source of
25 support and assistance for individuals suffering with

1 disabilities. Family caregivers, the majority of whom
2 are women, provide an estimated \$306,000,000,000
3 in “free” services annually. The current pool of po-
4 tential family caregivers is dwindling, from 11 po-
5 tential caregivers for each person needing care today
6 to a projected 4 to 1 ratio by 2050.

7 (6) Recent studies indicate that the total esti-
8 mated cost to employers for full-time employees with
9 intensive caregiving responsibilities is
10 \$17,100,000,000. The total estimated cost to em-
11 ployers for all full-time, employed caregivers is
12 \$33,600,000,000 annually.

13 (7) Adult day programs can offer services, in-
14 cluding medical care, rehabilitation therapies, dig-
15 nified assistance with the activities of daily living,
16 nutrition therapy, health monitoring, social inter-
17 action, stimulating activities, and transportation to
18 seniors, people with disabilities, and younger adults
19 with chronic diseases.

20 (8) Adult day programs geared toward people
21 living with neurological diseases or conditions such
22 as MS, Parkinson’s disease, TBI, or other similar
23 diseases or conditions provide an important response
24 to the needs of people with living with these condi-
25 tions and their caregivers. Adult day programs can

1 help to ameliorate symptoms, reduce dependency,
2 provide important socialization opportunities, and
3 maintain quality of life.

4 (9) Adult day programs have been shown to
5 provide a range of documented benefits including
6 improvements in functional status, social support,
7 and reductions in fatigue, depression and pain.
8 Adult day programs also reduce ongoing medical
9 care and hospital costs and decrease admissions to
10 nursing home facilities, which can be costly for many
11 families, by allowing individuals to receive health
12 and social services while continuing to live at home.

13 (10) There are currently few adult day pro-
14 grams focused on younger adult populations in the
15 United States. As a result, the majority of people
16 living with neurological diseases are unable to access
17 this important opportunity for maximizing their
18 health and wellness. Although people living with neu-
19 rological diseases or conditions may be able to access
20 other existing adult day programs, such programs
21 are not typically intended for younger adults living
22 with chronic diseases or conditions, and may not
23 provide the appropriate services to meet the age-re-
24 lated or disability status of these individuals.

1 **SEC. 3. ESTABLISHMENT OF ADULT DAY PROGRAMS.**

2 (a) SURVEY OF EXISTING ADULT DAY PROGRAMS.—

3 (1) IN GENERAL.—Not later than 90 days after
4 the date of the enactment of this section, the Assist-
5 ant Secretary for Aging shall initiate a comprehen-
6 sive survey of current adult day programs that pro-
7 vide care and support to individuals living with neu-
8 rological diseases or conditions such as multiple scle-
9 rosis, Parkinson’s disease, or traumatic brain injury,
10 including any other similar diseases or conditions.

11 (2) SURVEY ELEMENTS.—In carrying out the
12 survey under paragraph (1), the Assistant Secretary
13 for Aging may utilize existing publicly available re-
14 search on adult day programs, and shall—

15 (A) identify ongoing successful adult day
16 programs, including by providing a brief de-
17 scription of how such programs were initially
18 established and funded;

19 (B) develop a set of best practices to help
20 guide the establishment and replication of addi-
21 tional successful adult day programs, includ-
22 ing—

23 (i) program guidelines;

24 (ii) recommendations on the scope of
25 services that should be provided (which
26 may include rehabilitation therapy, psycho-

1 social support, social stimulation and inter-
2 action, and spiritual, educational, or other
3 such services); and

4 (iii) performance goals and indicators
5 to measure and analyze the outcomes gen-
6 erated by the services provided and to
7 evaluate the overall success of the pro-
8 gram; and

9 (C) evaluate the extent to which the Ad-
10 ministration on Aging supports adult day pro-
11 grams, either directly or indirectly, through cur-
12 rent Federal grant programs.

13 (3) REPORT.—Not later than 180 days after
14 initiating the survey under paragraph (1), the As-
15 sistant Secretary for Aging shall produce and make
16 publicly available a summary report on the results of
17 the survey. Such report shall include each of the ele-
18 ments described in paragraph (2).

19 (b) ESTABLISHMENT OF GRANT PROGRAM.—

20 (1) IN GENERAL.—Not later than 90 days after
21 producing the report required by subsection (a)(3),
22 the Assistant Secretary for Aging shall establish
23 within the Administration on Aging a competitive
24 grant program for awarding grants annually to eligi-

1 ble entities, based on the best practices developed
2 under subsection (a), to fund adult day programs.

3 (2) ELIGIBLE ENTITIES.—In order to be eligi-
4 ble for a grant under this subsection, an entity shall
5 demonstrate the following:

6 (A) Understanding of the special needs of
7 people living with neurological diseases or con-
8 ditions such as multiple sclerosis, Parkinson’s
9 disease, traumatic brain injury, or other similar
10 diseases or conditions, including their functional
11 abilities and the potential complications across
12 all types of cases and stages of such diseases or
13 conditions.

14 (B) Understanding of the issues experi-
15 enced by family caregivers who assist a family
16 member with neurological diseases or conditions
17 such as multiple sclerosis, Parkinson’s disease,
18 traumatic brain injury, or other similar diseases
19 or conditions.

20 (C) A capacity to provide the services rec-
21 ommended by the best practices developed
22 under subsection (a).

23 (3) ADDITIONAL SELECTION REQUIREMENT.—
24 The Assistant Secretary for Aging shall not award
25 a grant to an entity under this subsection if the

1 amount of the award would constitute more than 40
2 percent of the operating budget of the entity in the
3 fiscal year for which funds for the grant are author-
4 ized to be expended. For purposes of this subsection,
5 the fair market value of annual in-kind contributions
6 of equipment or services shall be considered as part
7 of the operating budget of the entity.

8 (4) SELECTION OF GRANT RECIPIENTS.—Not
9 later than 90 days after establishing the grant pro-
10 gram under this subsection, the Assistant Secretary
11 for Aging shall award the first annual series of
12 grants under the program. In awarding grants under
13 this subsection, the Assistant Secretary should en-
14 sure, to the extent practicable, a diverse geographic
15 representation among grant recipients and that, sub-
16 ject to the availability of appropriations—

17 (A) a minimum of 5 entities are selected as
18 grant recipients for the first fiscal year for
19 which such grants are awarded;

20 (B) a minimum of 10 entities are selected
21 as grant recipients for the second such fiscal
22 year;

23 (C) a minimum of 12 entities are selected
24 as grant recipients for the third such fiscal
25 year; and

1 (D) a minimum of 15 entities are selected
2 as grant recipients for the fourth such fiscal
3 year.

4 (5) REPORT.—No later than 1 year after the
5 initial award of grants under this subsection, and
6 annually thereafter, the Assistant Secretary for
7 Aging shall produce and make publicly available a
8 brief summary report on the grant program under
9 this section. Each such report shall include the fol-
10 lowing:

11 (A) A description of the adult day pro-
12 grams receiving funding under this section, in-
13 cluding the amount of Federal funding awarded
14 and the expected outcomes of each program.

15 (B) A description of performance goals and
16 indicators to monitor the progress of grant re-
17 cipients in—

18 (i) responding to the needs of individ-
19 uals living with neurological diseases or
20 conditions such as multiple sclerosis, Par-
21 kinson’s disease, traumatic brain injury, or
22 other similar diseases or conditions; and

23 (ii) assisting the family caregivers of
24 such individuals.

1 (C) Any plans for improving oversight and
2 management of the grant program.

3 (c) DEFINITIONS.—In this Act:

4 (1) The term “adult day program” means a
5 program that provides comprehensive and effective
6 care and support services to individuals living with
7 neurological diseases or conditions such as multiple
8 sclerosis, Parkinson’s disease, traumatic brain in-
9 jury, or other similar diseases or conditions that
10 may result in a functional or degenerative disability
11 and to their family caregivers and that may assist
12 participants in ways that—

13 (A) maintain or improve their functional
14 abilities, or otherwise help them adjust to their
15 changing functional abilities;

16 (B) prevent the onset of complications as-
17 sociated with severe forms of the disease or con-
18 dition;

19 (C) promote alternatives to placement in
20 nursing homes;

21 (D) reduce the strain on family caregivers
22 taking care of a family member living with such
23 diseases or conditions;

1 (E) focus on supporting the emotional, so-
2 cial, and intellectual needs of a younger adult
3 population; or

4 (F) address the needs of veterans living
5 with such diseases or conditions.

6 (2) The term “family caregiver” means a family
7 member or foster parent who provides unpaid assist-
8 ance (which may include in-home monitoring, man-
9 agement, supervision, care and treatment, or other
10 similar assistance) to another adult family member
11 with a special need.

12 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
13 out this section, in addition to amounts otherwise made
14 available for such purpose, there are authorized to be ap-
15 propriated, and to remain available until expended, the fol-
16 lowing:

17 (1) \$1,000,000 for fiscal year 2012.

18 (2) \$3,000,000 for fiscal year 2013.

19 (3) \$6,000,000 for fiscal year 2014.

20 (4) \$8,000,000 for fiscal year 2015.

21 (5) \$10,000,000 for fiscal year 2016.

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