

113TH CONGRESS
1ST SESSION

H. R. 3221

To expand and enhance existing adult day programs for younger 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

SEPTEMBER 30, 2013

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 younger 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 Center En-
5 hancement 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. MS is a leading cause of disability in young
18 adults. Persons living with MS who experience more
19 severe forms of the disease are likely to require ei-
20 ther home care or nursing home placement, though
21 the vast majority would prefer to remain at home to
22 receive the care they need. Where home care is con-
23 cerned, approximately 80 percent of such care is
24 provided by informal, unpaid caregivers who are gen-
25 erally family members.

1 (3) Parkinson’s disease is a chronic, progressive
2 neurological disease. The four 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. Other symptoms may include
8 cognitive changes; difficulty in swallowing, chewing,
9 and speaking; urinary problems or constipation; skin
10 problems; and sleep disruptions. As these symptoms
11 become more pronounced, patients may have dif-
12 ficulty walking, talking, or completing other simple
13 tasks. It is estimated that nearly 500,000 to
14 1,500,000 people live with Parkinson’s and of those
15 5 to 10 percent are diagnosed younger than 60 and
16 deemed “early-onset”.

17 (4) Traumatic brain injury is a neurological
18 condition that typically results from a blow or jolt to
19 the head or a penetrating head injury and that can
20 impact one or more parts of the brain, thereby tem-
21 porarily or permanently disrupting normal brain
22 function. The Centers for Disease Control and Pre-
23 vention estimates that 1,400,000 TBIs occur annu-
24 ally, resulting in disabilities affecting up to 90,000
25 people among a broad range of age groups. Trau-

1 matic brain injury is also a serious issue that affects
2 military servicemembers. Estimates in prior military
3 conflicts indicate that TBI was present in 14–20
4 percent of surviving casualties.

5 (5) Family caregivers are a crucial source of
6 support and assistance for individuals suffering with
7 disabilities. Family caregivers, the majority of whom
8 are women, provide an estimated \$450,000,000,000
9 in “free” services annually. The current pool of po-
10 tential family caregivers is dwindling, from 11 po-
11 tential caregivers for each person needing care today
12 to a projected 4 to 1 ratio by 2050.

13 (6) Recent studies indicate that the total esti-
14 mated cost to employers for full-time employees with
15 intensive caregiving responsibilities is
16 \$17,100,000,000. The total estimated cost to em-
17 ployers for all full-time, employed caregivers is
18 \$33,600,000,000 annually.

19 (7) Currently more than half of care recipients
20 (56 percent) are under age 75, and almost one-third
21 (28 percent) are under age 50 reflecting the need to
22 offer age-appropriate services.

23 (8) Adult day programs can offer services, in-
24 cluding medical care, rehabilitation therapies, dig-
25 nified assistance with the activities of daily living,

1 nutrition therapy, health monitoring, social inter-
2 action, stimulating activities, and transportation to
3 seniors, people with disabilities, and younger adults
4 with chronic diseases.

5 (9) Adult day programs geared toward people
6 living with neurological diseases or conditions such
7 as MS, Parkinson’s disease, TBI, or other similar
8 diseases or conditions provide an important response
9 to the needs of people living with these conditions
10 and their caregivers. Adult day programs can help to
11 ameliorate symptoms, reduce dependency, provide
12 important socialization opportunities, and maintain
13 quality of life.

14 (10) Adult day programs have been shown to
15 provide a range of documented benefits including
16 improvements in functional status, social support,
17 and reductions in fatigue, depression and pain.
18 Adult day programs also reduce ongoing medical
19 care and hospital costs and decrease admissions to
20 nursing home facilities, which can be costly for many
21 families, by allowing individuals to receive health
22 and social services while continuing to live at home.

23 (11) There are currently few adult day pro-
24 grams focused on younger adult populations in the
25 United States. Although young people living with

1 neurological diseases or conditions may be able to
2 access existing adult day programs, such programs
3 are not typically intended for younger adults living
4 with chronic diseases or conditions, and may not
5 provide the appropriate services to meet the age-re-
6 lated or disability status of these individuals.

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

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

9 (1) IN GENERAL.—Not later than 90 days after
10 the date of the enactment of this section, the Assist-
11 ant Secretary for Aging shall initiate a comprehen-
12 sive survey of current adult day programs that pro-
13 vide care and support to individuals including young
14 adults living with neurological diseases or conditions
15 such as multiple sclerosis, Parkinson’s disease, trau-
16 matic brain injury, or any similar disease or condi-
17 tion.

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

22 (A) identify ongoing successful adult day
23 programs, including by providing a brief de-
24 scription of how such programs were initially
25 established and funded;

1 (B) identify which adult day programs are
2 serving young adults living with neurological
3 diseases or conditions;

4 (C) develop a set of best practices to help
5 guide the establishment and replication of addi-
6 tional successful adult day programs, includ-
7 ing—

8 (i) program guidelines;

9 (ii) recommendations on the scope of
10 services that should be provided to individ-
11 uals with neurological diseases or condi-
12 tions including young adults (which may
13 include rehabilitation therapy, psychosocial
14 support, social stimulation and interaction,
15 and spiritual, educational, or other such
16 services); and

17 (iii) performance goals and indicators
18 to measure and analyze the outcomes gen-
19 erated by the services provided and to
20 evaluate the overall success of the pro-
21 gram; and

22 (D) evaluate the extent to which the Ad-
23 ministration for Community Living supports
24 adult day programs, either directly or indi-
25 rectly, through current Federal grant programs.

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

7 (b) ESTABLISHMENT OF GRANT PROGRAM.—

8 (1) IN GENERAL.—Not later than 90 days after
9 producing the report required by subsection (a)(3),
10 the Assistant Secretary for Aging shall establish
11 within the Administration for Community Living a
12 competitive grant program for awarding grants an-
13 nually to eligible entities, based on the best practices
14 developed under subsection (a), to fund adult day
15 programs serving younger people with neurological
16 diseases or conditions.

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

20 (A) Understanding of the special needs of
21 younger people living with neurological diseases
22 or conditions such as multiple sclerosis, Parkin-
23 son's disease, traumatic brain injury, or other
24 similar diseases or conditions, including their
25 functional abilities and the potential complica-

1 tions across all types of cases and stages of
2 such diseases or conditions.

3 (B) Understanding of the issues experi-
4 enced by family caregivers who assist a family
5 member with neurological diseases or conditions
6 such as multiple sclerosis, Parkinson's disease,
7 traumatic brain injury, or other similar diseases
8 or conditions.

9 (C) A capacity to provide the services rec-
10 ommended by the best practices developed
11 under subsection (a).

12 (3) ADDITIONAL SELECTION REQUIREMENT.—
13 The Assistant Secretary for Aging shall not award
14 a grant to an entity under this subsection if the
15 amount of the award would constitute more than 40
16 percent of the operating budget of the entity in the
17 fiscal year for which funds for the grant are author-
18 ized to be expended. For purposes of this subsection,
19 the fair market value of annual in-kind contributions
20 of equipment or services shall be considered as part
21 of the operating budget of the entity.

22 (4) SELECTION OF GRANT RECIPIENTS.—Not
23 later than 90 days after establishing the grant pro-
24 gram under this subsection, the Assistant Secretary
25 for Aging shall award the first annual series of

1 grants under the program. In awarding grants under
2 this subsection, the Assistant Secretary should en-
3 sure, to the extent practicable, a diverse geographic
4 representation among grant recipients and that, sub-
5 ject to the availability of appropriations—

6 (A) a minimum of 5 entities are selected as
7 grant recipients for the first fiscal year for
8 which such grants are awarded;

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

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

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

18 (5) REPORT.—No later than 1 year after the
19 initial award of grants under this subsection, and
20 annually thereafter, the Assistant Secretary for
21 Aging shall produce and make publicly available a
22 brief summary report on the grant program under
23 this section. Each such report shall include the fol-
24 lowing:

1 (A) A description of the adult day pro-
2 grams receiving funding under this section, in-
3 cluding the amount of Federal funding awarded
4 and the expected outcomes of each program.

5 (B) A description of performance goals and
6 indicators to monitor the progress of grant re-
7 cipients in—

8 (i) responding to the needs of younger
9 individuals living with neurological diseases
10 or conditions such as multiple sclerosis,
11 Parkinson’s disease, traumatic brain in-
12 jury, or other similar diseases or condi-
13 tions; and

14 (ii) assisting the family caregivers of
15 such individuals.

16 (C) Any plans for improving oversight and
17 management of the grant program.

18 (c) DEFINITIONS.—In this Act:

19 (1) The term “adult day program” means a
20 program that provides comprehensive and effective
21 care and support services to individuals living with
22 neurological diseases or conditions such as multiple
23 sclerosis, Parkinson’s disease, traumatic brain in-
24 jury, or other similar diseases or conditions that
25 may result in a functional or degenerative disability

1 and to their family caregivers and that may assist
2 participants in ways that—

3 (A) maintain or improve their functional
4 abilities, or otherwise help them adjust to their
5 changing functional abilities;

6 (B) prevent the onset of complications as-
7 sociated with severe forms of the disease or con-
8 dition;

9 (C) promote alternatives to placement in
10 nursing homes;

11 (D) reduce the strain on family caregivers
12 taking care of a family member living with such
13 diseases or conditions;

14 (E) focus on supporting the emotional, so-
15 cial, and intellectual needs of a younger adult
16 population; or

17 (F) address the needs of veterans living
18 with such diseases or conditions.

19 (2) The term “family caregiver” means a family
20 member or foster parent who provides unpaid assist-
21 ance (which may include in-home monitoring, man-
22 agement, supervision, care and treatment, or other
23 similar assistance) to another adult family member
24 with a special need.

1 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
2 out this section, in addition to amounts otherwise made
3 available for such purpose, there are authorized to be ap-
4 propriated, and to remain available until expended, the fol-
5 lowing:

- 6 (1) \$1,000,000 for fiscal year 2014.
7 (2) \$3,000,000 for fiscal year 2015.
8 (3) \$6,000,000 for fiscal year 2016.
9 (4) \$8,000,000 for fiscal year 2017.
10 (5) \$10,000,000 for fiscal year 2018.

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