

116TH CONGRESS
1ST SESSION

H. R. 320

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

JANUARY 8, 2019

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 unpaid caregivers who are generally
25 family members.

(3) Parkinson's disease is a chronic, progressive neurological disease. The four primary symptoms of Parkinson's disease are tremor, or trembling in hands, arms, legs, jaw, and face; rigidity, or stiffness of the limbs and trunk; bradykinesia, or slowness of movement; and postural instability, or impaired balance and coordination. Other symptoms may include cognitive changes; difficulty in swallowing, chewing, and speaking; urinary problems or constipation; skin problems; and sleep disruptions. As these symptoms become more pronounced, patients may have difficulty walking, talking, or completing other simple tasks. It is estimated that nearly 1,000,0000,000 Americans will be living with Parkinson's by 2020 and of those 5 to 10 percent are diagnosed younger than 50 and deemed "early-onset".

1 brain injury is also a serious issue that affects mili-
2 tary 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 \$470,000,000,000
9 in “free” services annually. The supply of family
10 caregivers is unlikely to keep pace with future de-
11 mand. The caregiver support ratio of potential care-
12 givers aged 45 to 64 for each person aged 80 and
13 older, for instance, is 7 to 1 in 2010, 4 to 1 in 2030,
14 and 3 to 1 in 2050.

15 (6) The majority of family caregivers (or 53
16 percent) are caring for someone ages 18 to 74.
17 Forty-seven percent of family caregivers are caring
18 for someone 75 or older.

19 (7) Adult day programs can offer services, in-
20 cluding medical care, rehabilitation therapies, digni-
21 fied assistance with the activities of daily living,
22 nutrition therapy, health monitoring, social inter-
23 action, stimulating activities, and transportation to
24 seniors, people with disabilities, and younger adults
25 with chronic diseases.

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

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

19 (10) There are currently few adult day pro-
20 grams focused on younger adult populations in the
21 United States. Although young people living with
22 neurological diseases or conditions may be able to
23 access existing adult day programs, such programs
24 are not typically intended for younger adults living
25 with chronic diseases or conditions, and may not

1 provide the appropriate services to meet the age-re-
2 lated or disability status of these individuals.

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

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

5 (1) IN GENERAL.—Not later than 90 days after
6 the date of the enactment of this section, the Assis-
7 tant Secretary for Aging shall initiate a compre-
8 hensive survey of current adult day programs that pro-
9 vide care and support to individuals including young
10 adults living with neurological diseases or conditions
11 such as multiple sclerosis, Parkinson's disease, trau-
12 matic brain injury, or any similar disease or condi-
13 tion.

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

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

22 (B) identify which adult day programs are
23 serving young adults living with neurological
24 diseases or conditions;

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

5 (i) program guidelines;

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

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

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

1 publicly available a summary report on the results of
2 the survey. Such report shall include each of the ele-
3 ments described in paragraph (2).

4 (b) ESTABLISHMENT OF GRANT PROGRAM.—

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

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

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

1 sure, to the extent practicable, a diverse geographic
2 representation among grant recipients and that, sub-
3 ject to the availability of appropriations—

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

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

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

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

23 (A) A description of the adult day pro-
24 grams receiving funding under this section, in-

1 cluding the amount of Federal funding awarded
2 and the expected outcomes of each program.

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

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

12 (ii) assisting the family caregivers of
13 such individuals.

14 (C) Any plans for improving oversight and
15 management of the grant program.

16 (c) DEFINITIONS.—In this Act:

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

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

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

7 (C) promote alternatives to placement in
8 nursing homes;

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

(E) focus on supporting the emotional, social, and intellectual needs of a younger adult population; or

15 (F) address the needs of veterans living
16 with such diseases or conditions.

23 (d) AUTHORIZATION OF APPROPRIATIONS.—To carry
24 out this section, in addition to amounts otherwise made
25 available for such purpose, there are authorized to be ap-

1 appropriated, and to remain available until expended, the fol-
2 lowing:

3 (1) \$1,000,000 for fiscal year 2019.
4 (2) \$3,000,000 for fiscal year 2020.
5 (3) \$6,000,000 for fiscal year 2021.
6 (4) \$8,000,000 for fiscal year 2022.
7 (5) \$10,000,000 for fiscal year 2023.

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