114TH CONGRESS
1ST SESSION

H. R. 263

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 9, 2015

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

A BILL

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1 Be it enacted by the Senate and House of Representa-
2 tives of the United States of America in Congress assembled,
3
4 SECTION 1. SHORT TITLE.
5 This Act may be cited as the “Adult Day Center En-
6 hancement Act”.

SEC. 2. FINDINGS.

The Congress finds the following:

(1) One in 6 people in the United States lives with a neurological disease or condition that can often result in disability, and which may require the individual to seek assistance in carrying out the activities of daily living. Neurological diseases or conditions such as multiple sclerosis (MS), early-onset Parkinson’s disease, and traumatic brain injury (TBI) can also typically affect younger adults in the middle of their lives.

(2) Multiple sclerosis is a chronic, often disabling disease that attacks the central nervous system with symptoms ranging from numbness in limbs to paralysis and loss of vision. Most people with MS are diagnosed between the ages of 20 and 50 years of age. MS is a leading cause of disability in young adults. Persons living with MS who experience more severe forms of the disease are likely to require either home care or nursing home placement, though the vast majority would prefer to remain at home to receive the care they need. Where home care is concerned, approximately 80 percent of such care is provided by informal, unpaid caregivers who are generally 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 500,000 to 1,500,000 people live with Parkinson’s and of those 5 to 10 percent are diagnosed younger than 60 and deemed “early-onset”.

(4) Traumatic brain injury is a neurological condition that typically results from a blow or jolt to the head or a penetrating head injury and that can impact one or more parts of the brain, thereby temporarily or permanently disrupting normal brain function. The Centers for Disease Control and Prevention estimates that 1,400,000 TBIs occur annually, resulting in disabilities affecting up to 90,000 people among a broad range of age groups. Trau-
matic brain injury is also a serious issue that affects military servicemembers. Estimates in prior military conflicts indicate that TBI was present in 14–20 percent of surviving casualties.

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

(6) Recent studies indicate that the total estimated cost to employers for full-time employees with intensive caregiving responsibilities is $17,100,000,000. The total estimated cost to employers for all full-time, employed caregivers is $33,600,000,000 annually.

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

(8) Adult day programs can offer services, including medical care, rehabilitation therapies, dignified assistance with the activities of daily living,
nutrition therapy, health monitoring, social interaction, stimulating activities, and transportation to seniors, people with disabilities, and younger adults with chronic diseases.

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

(10) 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.

(11) There are currently few adult day programs focused on younger adult populations in the United States. Although young people living with
neurological diseases or conditions may be able to access existing adult day programs, such programs are not typically intended for younger adults living with chronic diseases or conditions, and may not provide the appropriate services to meet the age-related or disability status of these individuals.

SEC. 3. ESTABLISHMENT OF ADULT DAY PROGRAMS.

(a) Survey of Existing Adult Day Programs.—

(1) In general.—Not later than 90 days after the date of the enactment of this section, the Assistant Secretary for Aging shall initiate a comprehensive survey of current adult day programs that provide care and support to individuals including young adults living with neurological diseases or conditions such as multiple sclerosis, Parkinson’s disease, traumatic brain injury, or any similar disease or condition.

(2) Survey elements.—In carrying out the survey under paragraph (1), the Assistant Secretary for Aging may utilize existing publicly available research on adult day programs, and shall—

(A) identify ongoing successful adult day programs, including by providing a brief description of how such programs were initially established and funded;
(B) identify which adult day programs are serving young adults living with neurological diseases or conditions;

(C) develop a set of best practices to help guide the establishment and replication of additional successful adult day programs, including—

(i) program guidelines;

(ii) recommendations on the scope of services that should be provided to individuals with neurological diseases or conditions including young adults (which may include rehabilitation therapy, psychosocial support, social stimulation and interaction, and spiritual, educational, or other such services); and

(iii) performance goals and indicators to measure and analyze the outcomes generated by the services provided and to evaluate the overall success of the program; and

(D) evaluate the extent to which the Administration for Community Living supports adult day programs, either directly or indirectly, through current Federal grant programs.
(3) Report.—Not later than 180 days after
initiating the survey under paragraph (1), the As-
sistant Secretary for Aging shall produce and make
publicly available a summary report on the results of
the survey. Such report shall include each of the ele-
ments described in paragraph (2).

(b) Establishment of Grant Program.—

(1) In general.—Not later than 90 days after
producing the report required by subsection (a)(3),
the Assistant Secretary for Aging shall establish
within the Administration for Community Living a
competitive grant program for awarding grants an-
ually to eligible entities, based on the best practices
developed under subsection (a), to fund adult day
programs serving younger people with neurological
diseases or conditions.

(2) Eligible entities.—In order to be eligi-
ble for a grant under this subsection, an entity shall
demonstrate the following:

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

(B) Understanding of the issues experienced by family caregivers who assist a family member with neurological diseases or conditions such as multiple sclerosis, Parkinson’s disease, traumatic brain injury, or other similar diseases or conditions.

(C) A capacity to provide the services recommended by the best practices developed under subsection (a).

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

(4) SELECTION OF GRANT RECIPIENTS.—Not later than 90 days after establishing the grant program under this subsection, the Assistant Secretary for Aging shall award the first annual series of
grants under the program. In awarding grants under this subsection, the Assistant Secretary should ensure, to the extent practicable, a diverse geographic representation among grant recipients and that, subject to the availability of appropriations—

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

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

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

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

(5) REPORT.—No later than 1 year after the initial award of grants under this subsection, and annually thereafter, the Assistant Secretary for Aging shall produce and make publicly available a brief summary report on the grant program under this section. Each such report shall include the following:
(A) A description of the adult day programs receiving funding under this section, including the amount of Federal funding awarded and the expected outcomes of each program.

(B) A description of performance goals and indicators to monitor the progress of grant recipients in—

(i) responding to the needs of younger individuals living with neurological diseases or conditions such as multiple sclerosis, Parkinson’s disease, traumatic brain injury, or other similar diseases or conditions; and

(ii) assisting the family caregivers of such individuals.

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

(c) DEFINITIONS.—In this Act:

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

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

(B) prevent the onset of complications asso-
ciated with severe forms of the disease or con-
dition;

(C) promote alternatives to placement in
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, so-
cial, and intellectual needs of a younger adult
population; or

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

(2) The term “family caregiver” means a family
member or foster parent who provides unpaid assist-
ance (which may include in-home monitoring, man-
agement, supervision, care and treatment, or other
similar assistance) to another adult family member
with a special need.
(d) Authorization of Appropriations.—To carry out this section, in addition to amounts otherwise made available for such purpose, there are authorized to be appropriated, and to remain available until expended, the following:

(1) $1,000,000 for fiscal year 2016.
(2) $3,000,000 for fiscal year 2017.
(3) $6,000,000 for fiscal year 2018.
(4) $8,000,000 for fiscal year 2019.
(5) $10,000,000 for fiscal year 2020.