

112TH CONGRESS  
1ST SESSION

# S. 495

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

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IN THE SENATE OF THE UNITED STATES

MARCH 7, 2011

Mr. CASEY introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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## A BILL

To expand and enhance existing adult day programs for individuals with neurological diseases or conditions, including multiple sclerosis, Parkinson’s disease, traumatic brain injury, and other similar diseases or conditions, to support and improve access to respite services for family caregivers who are taking care of such individuals, 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 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) often affect younger adults in the middle of  
11 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 individuals with  
16 MS are diagnosed between the ages of 20 and 50.  
17 It is estimated that more than 400,000 individuals  
18 in the United States are living with MS. Individuals  
19 living with MS who experience more severe forms of  
20 the 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 individuals live with Parkinson’s disease  
9 and, of those individuals, 5 to 10 percent are diag-  
10 nosed with the disease before age 60 and deemed  
11 “early-onset”.

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

1           (5) Family caregivers are a crucial source of  
2 support and assistance for individuals suffering with  
3 disabilities. Family caregivers, the majority of whom  
4 are women, provide an estimated \$306,000,000,000  
5 in unpaid services annually. The current pool of po-  
6 tential family caregivers is dwindling, from 11 po-  
7 tential caregivers for each individual needing care  
8 today to a projected ratio of 4 potential caregivers  
9 for each such individual by 2050.

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

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

23           (8) Adult day programs geared toward individ-  
24 uals living with neurological diseases or conditions  
25 such as MS, Parkinson's disease, TBI, or other

1 similar diseases or conditions, provide an important  
2 response to the needs of individuals living with these  
3 conditions and the caregivers of such individuals.  
4 Adult day programs can help to ameliorate symp-  
5 toms, reduce dependency, provide important social-  
6 ization opportunities, and maintain quality of life.

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

16 (10) There are currently few adult day pro-  
17 grams focused on younger adult populations in the  
18 United States. As a result, the majority of individ-  
19 uals living with neurological diseases are unable to  
20 access this important opportunity for maximizing  
21 their health and wellness. Although individuals living  
22 with neurological diseases or conditions may be able  
23 to access other existing adult day programs, such  
24 programs are not typically intended for younger  
25 adults living with chronic diseases or conditions, and

1 may not provide the appropriate services to meet the  
2 age-related 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 Assist-  
7 ant Secretary for Aging shall initiate a comprehen-  
8 sive survey of current adult day programs that pro-  
9 vide care and support to individuals living with neu-  
10 rological diseases or conditions, including multiple  
11 sclerosis, Parkinson’s disease, traumatic brain in-  
12 jury, and any other similar disease or condition.

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

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

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

25 (i) program guidelines;

1 (ii) recommendations on the scope of  
2 services that should be provided (which  
3 may include rehabilitation therapy, psycho-  
4 social support, social stimulation and inter-  
5 action, and spiritual, educational, or other  
6 such services); and

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

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

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

22 (b) ESTABLISHMENT OF GRANT PROGRAM.—

23 (1) IN GENERAL.—Not later than 90 days after  
24 producing the report required by subsection (a)(3),  
25 the Assistant Secretary for Aging shall establish

1 within the Administration on Aging a competitive  
2 grant program for awarding grants annually to eligi-  
3 ble entities, based on the best practices developed  
4 under subsection (a), to fund adult day programs.

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

8 (A) Understanding of the special needs of  
9 individuals living with neurological diseases or  
10 conditions such as multiple sclerosis, Parkin-  
11 son’s disease, traumatic brain injury, or other  
12 similar diseases or conditions, including the  
13 functional abilities of such individuals and the  
14 potential complications across all types of cases  
15 and stages of such diseases or conditions.

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

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



1           (3) ADDITIONAL SELECTION REQUIREMENT.—

2           The Assistant Secretary for Aging shall not award  
3           a grant to an entity under this subsection if the  
4           amount of the award would constitute more than 40  
5           percent of the operating budget of the entity in the  
6           fiscal year for which funds for the grant are author-  
7           ized to be expended. For purposes of this subsection,  
8           the fair market value of annual in-kind contributions  
9           of equipment or services shall be considered as part  
10          of the operating budget of the entity.

11          (4) SELECTION OF GRANT RECIPIENTS.—Not  
12          later than 90 days after establishing the grant pro-  
13          gram under this subsection, the Assistant Secretary  
14          for Aging shall award the first annual series of  
15          grants under the program. In awarding grants under  
16          this subsection, the Assistant Secretary shall ensure,  
17          to the extent practicable, a diverse geographic rep-  
18          resentation among grant recipients and that, subject  
19          to the availability of appropriations—

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

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

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

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

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

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

18 (B) A description of performance goals and  
19 indicators to monitor the progress of grant re-  
20 cipients in—

21 (i) responding to the needs of individ-  
22 uals living with neurological diseases or  
23 conditions such as multiple sclerosis, Par-  
24 kinson's disease, traumatic brain injury,

1 and other similar diseases or conditions;

2 and

3 (ii) assisting the family caregivers of

4 such individuals.

5 (C) Any plans for improving oversight and

6 management of the grant program.

7 (c) DEFINITIONS.—In this Act:

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

18 (A) maintain or improve the functional  
19 abilities of such individuals, or otherwise help  
20 such individuals adjust to changing functional  
21 abilities;

22 (B) prevent the onset of complications as-  
23 sociated with severe forms of the disease or con-  
24 dition;

1 (C) promote alternatives to placement in  
2 nursing homes;

3 (D) reduce the strain on family caregivers  
4 taking care of a family member living with such  
5 a disease or condition;

6 (E) focus on supporting the emotional, so-  
7 cial, and intellectual needs of a younger adult  
8 population; or

9 (F) address the needs of veterans living  
10 with such a disease or condition.

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

17 (d) AUTHORIZATION OF APPROPRIATIONS.—There  
18 are authorized to be appropriated, in addition to amounts  
19 otherwise made available for such purpose, such sums as  
20 may be necessary to carry out this section.

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