

111<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 6208

To expand and enhance existing adult day programs for people with multiple sclerosis or other similar diseases, to support and improve access to respite services for family caregivers who are taking care of such people, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 23, 2010

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

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## A BILL

To expand and enhance existing adult day programs for people with multiple sclerosis or other similar diseases, 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”.

6        **SEC. 2. FINDINGS.**

7        The Congress finds the following:

1           (1) Multiple sclerosis (or MS) is a chronic,  
2 often disabling disease that attacks the central nerv-  
3 ous system, which is made up of the brain, spinal  
4 cord, and optic nerves. Most people with multiple  
5 sclerosis are diagnosed between the ages of 20 and  
6 50 years of age.

7           (2) The symptoms of MS may be mild, such as  
8 numbness in the limbs, or severe, such as paralysis  
9 or loss of vision. The progress, severity, and specific  
10 symptoms of MS are unpredictable and vary from  
11 one person to another.

12           (3) Persons living with MS who experience  
13 more severe forms of MS are likely to require either  
14 home care or nursing home placement, though the  
15 vast majority would prefer to remain at home to re-  
16 ceive the care they need. Where home care is con-  
17 cerned, approximately 80 percent of such care is  
18 provided by informal, unpaid, caregivers who are  
19 generally family members.

20           (4) Family caregivers of people with MS gen-  
21 erally average 60 years of age. Almost half spend  
22 more than 20 hours per week providing care for  
23 their family member living with MS and have been  
24 fulfilling this role on average for over 13 years.

1           (5) In general, family caregivers, the majority  
2 of whom are women, provide an estimated  
3 \$306,000,000,000 in “free” services annually. The  
4 pool of potential family caregivers is dwindling, from  
5 11 potential caregivers for each person needing care  
6 today 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 activities of daily living, nutri-  
16 tion therapy, health monitoring, social interaction,  
17 stimulating activities, and transportation, to seniors,  
18 people with disabilities, and younger adults with  
19 chronic diseases.

20           (8) Adult day programs geared toward people  
21 living with MS, or other similar diseases, provide an  
22 important response to the needs of people with se-  
23 vere MS and their caregivers. These MS Adult Day  
24 Programs (MSADPs) can help to ameliorate MS  
25 symptoms, reduce dependency, provide important so-

1 cialization opportunities, and maintain quality of  
2 life.

3 (9) MSADP programs have been shown to pro-  
4 vide a range of documented benefits to people living  
5 with MS including improvements in functional sta-  
6 tus, fatigue, depression, pain and social support.  
7 MSADPs also reduce ongoing medical care and hos-  
8 pital costs and decrease admissions to nursing home  
9 facilities, which can be costly for many families, by  
10 allowing individuals to receive health and social serv-  
11 ices while continuing to live at home.

12 (10) There are less than a dozen MSADPs in  
13 the United States at present and as a result the ma-  
14 jority of people living with MS are unable to access  
15 this important opportunity for maximizing their  
16 health and wellness. Although people living with MS  
17 may be able to access other existing adult day pro-  
18 grams, such programs are not typically intended for  
19 younger adults living with chronic diseases like MS,  
20 and may not provide the appropriate services to  
21 meet the age-related or disability status of these in-  
22 dividuals.

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

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

1           (1) IN GENERAL.—Not later than 90 days after  
2 the date of the enactment of this section, the Assist-  
3 ant Secretary for Aging shall initiate a comprehen-  
4 sive survey of current adult day programs that pro-  
5 vide care and support to individuals living with mul-  
6 tiple sclerosis, including any multiple sclerosis adult  
7 day programs and other similar adult day programs  
8 as defined in this Act.

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

13                   (A) identify ongoing successful MSADPs  
14 and other similar adult day programs, including  
15 by providing a brief description of how such  
16 programs were initially established and funded;

17                   (B) develop a set of best practices to help  
18 guide the establishment and replication of addi-  
19 tional successful MSADPs and other similar  
20 adult day programs, including—

21                           (i) program guidelines;

22                           (ii) recommendations on the scope of  
23 services that should be provided (which  
24 may include rehabilitation therapy, psycho-  
25 social support, social stimulation and inter-

1           action, and spiritual, educational, or other  
2           such services); and

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

8           (C) evaluate the extent to which the Ad-  
9           ministration on Aging supports MSADPs and  
10          other similar adult day programs, either di-  
11          rectly or indirectly, through current Federal  
12          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-  
25          ble entities, based on the best practices developed

1 under subsection (a), to fund MSADPs and other  
2 similar 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 multiple sclerosis or other  
8 similar diseases, including their functional abili-  
9 ties and the potential complications across all  
10 types of cases and stages of multiple sclerosis  
11 or other such similar diseases.

12 (B) Understanding of the issues experi-  
13 enced by family caregivers who assist a family  
14 member with multiple sclerosis or another such  
15 similar disease.

16 (C) A capacity to provide the services rec-  
17 ommended by the best practices developed  
18 under subsection (a).

19 (3) ADDITIONAL SELECTION REQUIREMENT.—  
20 The Assistant Secretary for Aging shall not award  
21 a grant to an entity under this subsection if the  
22 amount of the award would constitute more than 40  
23 percent of the operating budget of the entity in the  
24 fiscal year for which funds for the grant are author-  
25 ized to be expended. For purposes of this subsection,

1 the fair market value of annual in-kind contributions  
2 of equipment or services shall be considered as part  
3 of the operating budget of the entity.

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

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

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

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

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



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

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

12                  (B) A description of performance goals and  
13                  indicators to monitor the progress of grant re-  
14                  cipients in—

15                          (i) responding to the needs of individ-  
16                          uals living with multiple sclerosis or other  
17                          such similar chronic diseases; and

18                          (ii) assisting the family caregivers of  
19                          such individuals.

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

22       (c) DEFINITIONS.—In this Act:

23           (1) The term “multiple sclerosis adult day pro-  
24           gram” or “MSADP” means an adult day program  
25           that provides comprehensive and effective care and

1 support services to individuals living with multiple  
2 sclerosis and their family caregivers and that may  
3 assist participants in ways that—

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

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

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 with multiple  
13 sclerosis; or

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

17 (2) The term “other similar adult day pro-  
18 gram” means an adult day program that provides a  
19 set of services similar to those of an MSADP, but  
20 for individuals living with other chronic diseases  
21 similar to multiple sclerosis that affect an individ-  
22 ual’s central nervous system, and that may result in  
23 a functional or degenerative disability.

24 (3) The term “family caregiver” means a family  
25 member or foster parent who provides unpaid assist-

1       ance (which may include in-home monitoring, man-  
2       agement, supervision, care and treatment, or other  
3       similar assistance) to another adult family member  
4       with a special need.

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

- 10           (1) \$1,000,000 for fiscal year 2011.  
11           (2) \$3,000,000 for fiscal year 2012.  
12           (3) \$6,000,000 for fiscal year 2013.  
13           (4) \$8,000,000 for fiscal year 2014.  
14           (5) \$10,000,000 for fiscal year 2015.

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