

113TH CONGRESS  
2D SESSION

# H. R. 5633

To authorize grants for the support of caregivers.

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IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 18, 2014

Mr. PASCRELL introduced the following bill; which was referred to the  
Committee on Energy and Commerce

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## A BILL

To authorize grants for the support of caregivers.

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 “In-Home Caregiver  
5 Assessment Resources and Education Act” or the “In-  
6 Home CARE Act”.

7 **SEC. 2. FINDINGS.**

8 Congress finds the following:

9 (1) More than 65,000,000 unpaid caregivers  
10 provide care for a chronically ill, disabled, or aged  
11 family member or friend during any given year.

1           (2) Sixty-six percent of unpaid caregivers are  
2 women. More than 37 percent of caregivers live with  
3 children or grandchildren who are under 18 years  
4 old.

5           (3) Unpaid family caregivers spend an average  
6 of 20 hours per week caring for their loved ones,  
7 and 13 percent of family caregivers provide 40 or  
8 more hours of care per week.

9           (4) Thirty-six percent of caregivers care for a  
10 parent.

11          (5) Fourteen percent of caregivers care for a  
12 special needs child, including an estimated  
13 16,800,000 caregivers who care for special needs  
14 children who are under 18 years old.

15          (6) In 2007, the average caregiver for someone  
16 50 years or older spent \$5,531 per year on out-of-  
17 pocket caregiving expenses, which is more than 10  
18 percent of the median income for a family caregiver  
19 for that year. Forty-seven percent of working care-  
20 givers have used up all or most of their savings due  
21 to caregiving expenses.

22          (7) Seventy-three percent of caregivers who pro-  
23 vide care for an individual over the age of 18 are  
24 currently working or have worked while providing  
25 care. Sixty-six percent of such caregivers have had

1 to make some modifications to their work schedule,  
2 from arriving late to work to leaving their job en-  
3 tirely. One in 5 caregivers have had to take time off  
4 from work.

5 (8) Fifty-three percent of caregivers have experi-  
6 enced a decline in their health as a result of  
7 caregiving, which has affected their ability to provide  
8 care.

9 (9) Forty-six percent of caregivers perform  
10 medical or nursing tasks for patients with multiple  
11 physical and chronic conditions. Of these caregivers,  
12 78 percent were in charge of managing a patient's  
13 medications, administering fluids, or administering  
14 injections.

15 (10) Nearly 20 percent of caregivers who as-  
16 sisted with medication management and 33 percent  
17 who assisted with changing dressings or bandages  
18 received no training about how to perform these  
19 tasks.

20 (11) The vast majority (78 percent) of care-  
21 givers indicated they need more support related to  
22 caregiving.

23 (12) Home visiting programs are cost-effective  
24 and have been proven to improve outcomes for chil-

1       dren and parents in different domains ranging from  
2       child development to family violence.

3 **SEC. 3. PURPOSES.**

4       The purposes of this Act are—

5           (1) to improve the ability of unpaid caregivers  
6       to care for individuals in the home; and

7           (2) to increase opportunities for individuals who  
8       are in need of care to remain at home and reduce  
9       or postpone the need for such individuals to receive  
10      care at an institution.

11 **SEC. 4. CAREGIVER GRANTS.**

12       Subpart IV of part D of title III of the Public Health  
13      Service Act (42 U.S.C. 255 et seq.) is amended by adding  
14      at the end the following:

15 **“SEC. 339A. CAREGIVER GRANTS.**

16       “(a) IN GENERAL.—The Secretary, acting through  
17      the Administrator of the Administration for Community  
18      Living, shall award 3-year grants, on a competitive basis,  
19      to eligible organizations to carry out home visiting pro-  
20      grams for unpaid caregivers.

21       “(b) DEFINITIONS.—In this section:

22           “(1) CAREGIVER.—The term ‘caregiver’ means  
23      an unpaid family member, foster parent, or other  
24      unpaid adult who provides in-home monitoring, man-  
25      agement, supervision, or treatment of a child or

1 adult with a special need, such as a disease, dis-  
2 ability, or the frailties of old age.

3 “(2) CAREGIVER ASSESSMENT.—The term  
4 ‘caregiver assessment’ means an assessment that in-  
5 cludes talking directly to caregivers to better under-  
6 stand their needs, problems, resources, and  
7 strengths.

8 “(3) CHILD OR ADULT WITH A SPECIAL  
9 NEED.—The term ‘child or adult with a special need’  
10 means an individual for whom care or supervision is  
11 required to—

12 “(A) meet the basic needs of the indi-  
13 vidual;

14 “(B) prevent physical self-injury or injury  
15 to others; or

16 “(C) avoid placement in an institutional  
17 facility.

18 “(4) ELIGIBLE ORGANIZATION.—The term ‘eli-  
19 gible organization’ means—

20 “(A) a local government agency;

21 “(B) a health care entity; or

22 “(C) any other nonprofit or community or-  
23 ganization,

24 that can provide the services described in subsection  
25 (f).

1       “(c) COORDINATION.—In carrying out this section,  
2 the Secretary shall coordinate—

3           “(1) with the heads of the National Family  
4 Caregiver Support Program of the Administration  
5 on Aging and other programs within the Depart-  
6 ment of Health and Human Services (such as the  
7 Lifespan Respite Care Program), to ensure coordi-  
8 nation of caregiver services for caregivers of children  
9 or adults with special needs; and

10          “(2) with the Director of the Centers for Medi-  
11 care & Medicaid Services to avoid duplicative serv-  
12 ices and payments.

13       “(d) APPLICATION.—An eligible organization that de-  
14 sires a grant under this section shall submit an application  
15 at such time, in such manner, and containing such infor-  
16 mation as the Secretary may require, including, at a min-  
17 imum—

18           “(1) an outreach plan that identifies how the el-  
19 igible organization will ascertain which caregivers in  
20 the community—

21           “(A) are most in need of support and edu-  
22 cation, particularly caregivers who have had no  
23 training and provide complex chronic care ac-  
24 tivities or perform medical or nursing tasks in

1 addition to assisting with activities of daily liv-  
2 ing;

3 “(B) are caring for individuals who are at  
4 the greatest risk of needing institutional care;  
5 and

6 “(C) desire to participate in the caregiver  
7 home visiting program;

8 “(2) a description of the services that the eligi-  
9 ble organization will provide directly using grant  
10 funds, and a description of the services that the eli-  
11 gible organization will use grant funds to provide  
12 through contracts or referrals;

13 “(3) a description of how the eligible organiza-  
14 tion will identify gaps in the services that caregivers  
15 and children or adults with a special need who re-  
16 ceive care from a caregiver in the community are re-  
17 ceiving;

18 “(4) a description of how the eligible organiza-  
19 tion can provide—

20 “(A) an initial visit to caregivers in order  
21 to complete a caregiver assessment, including a  
22 description of the eligible organization’s exper-  
23 tise in conducting caregiver assessments;

24 “(B) education and training to help the  
25 caregiver learn how to best care for a child or

1 adult with a special need, by an individual with  
2 expertise in the tasks for which the caregiver  
3 requires education and training, including edu-  
4 cation and training regarding, as applicable—

5 “(i) medication management;

6 “(ii) wound care;

7 “(iii) nutrition and food preparation  
8 for special diets;

9 “(iv) falls prevention;

10 “(v) management of depression, anx-  
11 iety, stress, and other behavioral health  
12 conditions, including ways to minimize  
13 negative mental health effects;

14 “(vi) assistance with activities of daily  
15 living;

16 “(vii) ways to engage other family  
17 members in providing care;

18 “(viii) ways to identify and utilize  
19 available community resources; and

20 “(ix) abuse and neglect prevention;

21 and

22 “(C) recommendations for home modifica-  
23 tions or physical environmental changes that  
24 will improve the health or quality of life of a



1 child or adult with a special need who is receiv-  
2 ing care from a caregiver;

3 “(5) a description of the eligible organization’s  
4 ability to provide, or refer caregivers to local re-  
5 sources or programs of the Department of Health  
6 and Human Services that will provide—

7 “(A) physical and mental health care, in-  
8 cluding home health care and long-term support  
9 services;

10 “(B) transportation;

11 “(C) home modification services;

12 “(D) respite care;

13 “(E) adult day care;

14 “(F) support groups; and

15 “(G) legal assistance;

16 “(6) a description of the eligible organization’s  
17 ability to coordinate with other State and commu-  
18 nity-based agencies;

19 “(7) a description of the eligible organization’s  
20 understanding of caregiver issues—

21 “(A) across age groups; and

22 “(B) including disabilities and chronic con-  
23 ditions that affect the populations that the eli-  
24 gible organization will serve;

1           “(8) a description of the capacity of the eligible  
2 organization to engage caregivers, family members,  
3 and children or adults with a special need who re-  
4 ceive care from a caregiver; and

5           “(9) with respect to the population of caregivers  
6 to whom caregiver visits or services will be provided,  
7 or for whom workers and volunteers will be recruited  
8 and trained, a description of—

9                   “(A) the population of caregivers;

10                   “(B) the extent and nature of the needs of  
11 that population; and

12                   “(C) existing caregiver services for that  
13 population, including the number of caregivers  
14 served and the extent of unmet need.

15           “(e) PRIORITY.—In awarding grants under this sec-  
16 tion, the Secretary shall give priority to eligible organiza-  
17 tions that—

18                   “(1) the Secretary determines show the greatest  
19 likelihood of implementing or enhancing caregiver  
20 home visiting services for the greatest number of  
21 people;

22                   “(2) will allow caregivers to contact the eligible  
23 organization by phone, email, or two-way interactive  
24 video after home visits have ended or if a caregiver  
25 has questions or concerns;

1 “(3) have a proven record of caregiver support;

2 “(4) will use evidence-based programs; or

3 “(5) will provide matching funds or can dem-  
4 onstrate that the program funded by a grant under  
5 this section will be sustainable after grant funds are  
6 no longer provided.

7 “(f) AUTHORIZED ACTIVITIES.—An eligible organiza-  
8 tion receiving a grant under this section shall use grant  
9 funds to—

10 “(1) conduct an initial home visit for each care-  
11 giver participating in the program, during which a  
12 representative from the eligible organization who has  
13 expertise in care management and caregiving will  
14 perform a caregiver assessment and determine what  
15 follow-up services may benefit the caregiver and the  
16 child or adult with a special need who receives care  
17 from the caregiver;

18 “(2) conduct home visits for the purpose of  
19 caregiver education and training;

20 “(3) provide, or provide referrals for, the serv-  
21 ices described in subsection (d)(5);

22 “(4) provide an assessment and referral for  
23 physical and mental health services for the caregiver  
24 and for the child or adult with a special need who  
25 receives care from the caregiver, as needed; and

1           “(5) carry out any other activities that are de-  
2           scribed in the grant application submitted under  
3           subsection (d).

4           “(g) TECHNICAL ASSISTANCE CENTER.—The Sec-  
5           retary shall establish or contract to establish a technical  
6           assistance center through which the Secretary shall—

7           “(1) provide models for programs funded by  
8           grants under this section;

9           “(2) provide training for grantees;

10          “(3) answer questions from grantees; and

11          “(4) facilitate an exchange of information  
12          among grantees, and between grantees and other  
13          programs within the Department of Health and  
14          Human Services, including through use of the Tech-  
15          nical Assistance Exchange of the Administration for  
16          Community Living, in order to maximize the use of  
17          existing resources and services for caregivers and to  
18          avoid the duplication of such services.

19          “(h) EVALUATION.—

20          “(1) IN GENERAL.—Not later than 1 year after  
21          the date of enactment of this section, and annually  
22          thereafter, the Secretary shall evaluate the success  
23          of the grant program carried out under this section,  
24          based on criteria that the Secretary may develop for  
25          such evaluation.

1           “(2) OPTIONAL CONTENTS OF EVALUATION.—

2           The evaluation described in paragraph (1) may in-  
3           clude an evaluation of—

4                   “(A) the extent to which children or adults  
5                   with a special need who are cared for by a par-  
6                   ticipating caregiver have—

7                           “(i) a reduction in the potential num-  
8                           ber of hospitalizations;

9                           “(ii) a reduction in the potential num-  
10                          ber of institutionalizations;

11                          “(iii) cost reductions across the health  
12                          care system;

13                          “(iv) improved care; and

14                          “(v) improved quality of life (includ-  
15                          ing a reduction of stress and anxiety and  
16                          improved relationships and mood); and

17                          “(B) the extent to which participating  
18                          caregivers have improved quality of life (includ-  
19                          ing a reduction of stress and anxiety and im-  
20                          proved health, relationships, and mood).

21           “(i) REPORTS AND RECOMMENDATIONS.—Not later  
22           than 1 year before the expiration of the grants awarded  
23           under this section, the Secretary shall prepare and submit  
24           a report to Congress that includes recommendations,

1 based on the evaluation described in subsection (h),  
2 about—

3           “(1) changes to the grant program under this  
4 section;

5           “(2) the potential for expanding the number  
6 and scope of caregiver home visiting program grants  
7 distributed by the Secretary; and

8           “(3) extending the length of the grant program.

9           “(j) AUTHORIZATION OF APPROPRIATIONS.—There  
10 are authorized to be appropriated to carry out this section  
11 such sums as may be necessary.”.

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