

113TH CONGRESS
2D SESSION

S. 2866

To authorize grants for the support of caregivers.

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 18, 2014

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

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

adult with a special need, by an individual with expertise in the tasks for which the caregiver requires education and training, including education and training regarding, as applicable—

“(i) medication management;

“(ii) wound care;

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

“(iv) falls prevention;

“(v) management of depression, anxiety, stress, and other behavioral health conditions, including ways to minimize negative mental health effects;

“(vi) assistance with activities of daily living;

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

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

“(ix) abuse and neglect prevention; and

“(C) recommendations for home modifications or physical environmental changes that 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.”.

