

115TH CONGRESS
1ST SESSION

S. 1606

To authorize grants for the support of caregivers.

IN THE SENATE OF THE UNITED STATES

JULY 20, 2017

Mr. BOOKER (for himself and Mr. FRANKEN) introduced the following bill;
which was read twice and referred to the Committee on Health, Edu-
cation, 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 43,000,000 unpaid caregivers
10 provide care for a chronically ill, disabled, or aged
11 family member or friend during any given year.

1 (2) Sixty 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) Ethnic minority caregivers, particularly Af-
6 rican-American and Hispanic-American caregivers,
7 experience greater strain and worse physical health
8 than their counterparts. More than 50 percent of Af-
9 rican Americans are “sandwiched” between caring
10 for an older person and a younger person under age
11 18.

12 (4) The needs of caregivers and care recipients
13 vary by several factors such as race and ethnicity,
14 age, social class, sexual orientation, geographical lo-
15 cation, gender, military or veteran status, relation-
16 ship between caregiver and care recipient, health
17 status, and other factors.

18 (5) Unpaid family caregivers spend an average
19 of 24 hours per week caring for their loved ones,
20 and about 23 percent of family caregivers provide 41
21 or more hours of care per week.

22 (6) Forty-nine percent of caregivers care for a
23 parent.

24 (7) Fourteen percent of caregivers provide care
25 for a special needs child, including an estimated

1 16,800,000 caregivers who care for a special needs
2 child under 18 years of age.

3 (8) In 2016, the average caregiver for someone
4 18 years or older spent \$6,954 per year on out-of-
5 pocket caregiving expenses, which is nearly 20 per-
6 cent of the average annual income of caregivers.

7 (9) Sixty percent of caregivers who provide care
8 for an individual over the age of 18 are currently
9 working or have worked while providing care. Three
10 in five caregivers have had to make some modifica-
11 tions to their work schedule, from arriving late to
12 work to leaving their job entirely. Almost half of em-
13 ployed caregivers have had to take time off from
14 work.

15 (10) Fifty-three percent of caregivers have ex-
16perienced a decline in their health as a result of
17 caregiving, which has affected their ability to provide
18 care. Thirty-five percent of caregivers report having
19 difficulty finding time for oneself, and 29 percent re-
20 port difficulty managing emotional and physical
21 stress or balancing work and family responsibilities.

22 (11) Forty-six percent of caregivers of adults
23 perform medical or nursing tasks for patients with
24 multiple physical and chronic conditions. Of these
25 caregivers, 78 percent were in charge of managing

1 a patient's medications, administering fluids, or ad-
2 ministering injections.

3 (12) Nearly 20 percent of caregivers of adults
4 who assisted with medication management and 33
5 percent who assisted with changing dressings or
6 bandages received no training about how to perform
7 these tasks.

8 (13) The vast majority of caregivers (84 per-
9 cent) indicated they need more support related to
10 caregiving.

11 (14) Home visiting programs are cost-effective
12 and have been proven to improve outcomes for chil-
13 dren and parents in different domains ranging from
14 child development to family violence.

15 **SEC. 3. PURPOSES.**

16 The purposes of this Act are—

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

19 (2) to increase opportunities for individuals who
20 are in need of care to remain at home and reduce
21 or postpone the need for such individuals to receive
22 care at an institution or hospital.

1 **SEC. 4. CAREGIVER GRANTS.**

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

5 **“SEC. 339A. CAREGIVER GRANTS.**

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

11 “(b) DEFINITIONS.—In this section:

12 “(1) CAREGIVER.—The term ‘caregiver’ means
13 an unpaid family member, foster parent, or other
14 unpaid adult who provides consistent in-home moni-
15 toring, management, supervision, or treatment of a
16 child or adult with a special need, such as a disease,
17 disability, or the frailties of old age.

18 “(2) CAREGIVER ASSESSMENT.—The term
19 ‘caregiver assessment’ means an assessment that in-
20 cludes talking directly to caregivers to better under-
21 stand their needs, problems, resources, and
22 strengths.

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

1 “(A) meet the basic needs of the indi-
2 vidual;

3 “(B) prevent physical self-injury or injury
4 to others; or

5 “(C) avoid placement in an institutional
6 facility.

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

9 “(A) a local government agency;

10 “(B) a health care entity; or

11 “(C) any other nonprofit or community or-
12 ganization,

13 that has experience providing the services described
14 in subsection (f).

15 “(c) COORDINATION.—In carrying out this section,
16 the Secretary shall coordinate with—

17 “(1) the heads of the National Family Care-
18 giver Support Program of the Administration on
19 Aging and other programs within the Department of
20 Health and Human Services (such as the Lifespan
21 Respite Care Program) and the Secretary of Vet-
22 erans Affairs, to ensure coordination of caregiver
23 services for caregivers of children or adults with spe-
24 cial needs; and

1 “(2) the Administrator of the Centers for Medi-
2 care & Medicaid Services, to avoid duplicative serv-
3 ices and payments.

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

9 “(1) an outreach plan that identifies how the el-
10 igible organization will ascertain which caregivers in
11 the community—

12 “(A) are most in need of support and edu-
13 cation, particularly caregivers who have had no
14 training and provide complex chronic care ac-
15 tivities or perform medical or nursing tasks in
16 addition to assisting with activities of daily liv-
17 ing;

18 “(B) are caring for individuals who are at
19 the greatest risk of needing institutional care;
20 and

21 “(C) desire to participate in the caregiver
22 home visiting program;

23 “(2) a description of the services that the eligi-
24 ble organization will provide directly using grant
25 funds, and a description of the services that the eli-

1 gible organization will use grant funds to provide
2 through contracts or referrals;

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

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

10 “(A) an initial visit to caregivers in order
11 to complete a caregiver assessment, including a
12 description of the eligible organization’s exper-
13 tise in conducting caregiver assessments;

14 “(B) education and training, based on evi-
15 dence-based models, to help the caregiver learn
16 how to best care for a child or adult with a spe-
17 cial need, by an individual with expertise in the
18 tasks for which the caregiver requires education
19 and training, including education and training
20 regarding, as applicable—

21 “(i) medication management;

22 “(ii) wound care;

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

25 “(iv) fall prevention;

1 “(v) management of depression, anx-
2 iety, stress, trauma, and other behavioral
3 health conditions, including ways to mini-
4 mize negative mental health effects;

5 “(vi) assistance with activities of daily
6 living;

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

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

11 “(ix) abuse and neglect prevention;
12 and

13 “(C) recommendations for home modifica-
14 tions or physical environmental changes that
15 could improve the health or quality of life of a
16 child or adult with a special need who is receiv-
17 ing care from a caregiver;

18 “(5) a description of the eligible organization’s
19 ability to provide, or refer caregivers to local re-
20 sources or appropriate programs of the Department
21 of Health and Human Services or the Department
22 of Veterans Affairs that will provide—

23 “(A) physical and mental health care, in-
24 cluding home health care and long-term support
25 services;

1 “(B) transportation;

2 “(C) home modification services;

3 “(D) respite care;

4 “(E) adult day care;

5 “(F) support groups; and

6 “(G) legal assistance;

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

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

12 “(A) across demographic groups, including
13 age, gender, race and ethnicity, socioeconomic
14 status, sexual orientation, military status, and
15 geographical region; and

16 “(B) including disabilities and chronic con-
17 ditions that affect the populations that the eli-
18 gible organization will serve;

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

23 “(9) with respect to the population of caregivers
24 to whom caregiver visits or services will be provided,

1 or for whom workers and volunteers will be recruited
2 and trained, a description of—

3 “(A) the population of caregivers;

4 “(B) the extent and nature of the needs of
5 that population; and

6 “(C) existing caregiver services for that
7 population, including the number of caregivers
8 served and the extent of unmet need.

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

12 “(1) the Secretary determines show the greatest
13 likelihood of implementing or enhancing caregiver
14 home visiting services that best meet the needs of
15 the community;

16 “(2) will allow caregivers to contact the eligible
17 organization by phone, email, or 2-way interactive
18 video for up to 6 months after home visits have
19 ended, or to otherwise contact the organization at
20 any time if a caregiver has questions or concerns;

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

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

23 “(5) will provide matching funds or can dem-
24 onstrate that the program funded by a grant under

1 this section will be sustainable after grant funds are
2 no longer provided.

3 “(f) AUTHORIZED ACTIVITIES.—An eligible organiza-
4 tion receiving a grant under this section shall use grant
5 funds to—

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

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

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

18 “(4) provide an assessment and referral for
19 physical and mental health services for the caregiver
20 and for the child or adult with a special need who
21 receives care from the caregiver, as needed; and

22 “(5) carry out any other activities that are de-
23 scribed in the grant application submitted under
24 subsection (d).

1 “(g) TECHNICAL ASSISTANCE CENTER.—The Sec-
2 retary shall establish, or contract to establish, a technical
3 assistance center through which the Secretary shall—

4 “(1) provide evidence-based models for pro-
5 grams funded by grants under this section;

6 “(2) provide training for grantees;

7 “(3) answer questions from grantees; and

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

16 “(h) EVALUATION.—

17 “(1) IN GENERAL.—Not later than 2 years
18 after the date of enactment of this section, and an-
19 nually thereafter, the Secretary shall evaluate the
20 success of the grant program carried out under this
21 section, based on criteria that the Secretary may de-
22 velop for such evaluation.

23 “(2) OPTIONAL CONTENTS OF EVALUATION.—

24 The evaluation described in paragraph (1) may in-
25 clude an evaluation of—

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

4 “(i) a reduction in the potential num-
5 ber of hospitalizations;

6 “(ii) a reduction in the potential num-
7 ber of institutionalizations;

8 “(iii) cost reductions across the health
9 care system;

10 “(iv) improved connection to commu-
11 nity resources;

12 “(v) improved care; and

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

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

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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