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113TH CONGRESS
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H. R. 5633

To authorize grants for the support of caregivers.

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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''In-Home Caregiver Assessment Resources and Education Act'' or the ''In-Home CARE Act''.

SEC. 2. FINDINGS.

Congress finds the following:

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

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

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

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

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

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

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

to make some modifications to their work schedule, from arriving late to work to leaving their job entirely. One in 5 caregivers have had to take time off from work.

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

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

(10) Nearly 20 percent of caregivers who assisted with medication management and 33 percent who assisted with changing dressings or bandages received no training about how to perform these tasks.

(11) The vast majority (78 percent) of caregivers indicated they need more support related to caregiving.

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

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

SEC. 3. PURPOSES.

The purposes of this Act are—

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

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

SEC. 4. CAREGIVER GRANTS.

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

"SEC. 339A. CAREGIVER GRANTS.

"(a) IN GENERAL.—The Secretary, acting through the Administrator of the Administration for Community Living, shall award 3-year grants, on a competitive basis, to eligible organizations to carry out home visiting programs for unpaid caregivers.

"(b) DEFINITIONS.—In this section:

"(1) CAREGIVER.—The term 'caregiver' means an unpaid family member, foster parent, or other unpaid adult who provides in-home monitoring, management, supervision, or treatment of a child or

adult with a special need, such as a disease, disability, or the frailties of old age.

"(2) CAREGIVER ASSESSMENT.—The term 'caregiver assessment' means an assessment that includes talking directly to caregivers to better understand their needs, problems, resources, and strengths.

"(3) CHILD OR ADULT WITH A SPECIAL NEED.—The term 'child or adult with a special need' means an individual for whom care or supervision is required to—

"(A) meet the basic needs of the individual;

"(B) prevent physical self-injury or injury to others; or

"(C) avoid placement in an institutional facility.

"(4) ELIGIBLE ORGANIZATION.—The term 'eligible organization' means—

"(A) a local government agency;

"(B) a health care entity; or

"(C) any other nonprofit or community organization,

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

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

"(1) with the heads of the National Family Caregiver Support Program of the Administration on Aging and other programs within the Department of Health and Human Services (such as the Lifespan Respite Care Program), to ensure coordination of caregiver services for caregivers of children or adults with special needs; and

"(2) with the Director of the Centers for Medicare & Medicaid Services to avoid duplicative services and payments.

"(d) APPLICATION.—An eligible organization that desires a grant under this section shall submit an application at such time, in such manner, and containing such information as the Secretary may require, including, at a minimum—

"(1) an outreach plan that identifies how the eligible organization will ascertain which caregivers in the community—

"(A) are most in need of support and education, particularly caregivers who have had no training and provide complex chronic care activities or perform medical or nursing tasks in

addition to assisting with activities of daily living;

"(B) are caring for individuals who are at the greatest risk of needing institutional care; and

"(C) desire to participate in the caregiver home visiting program;

"(2) a description of the services that the eligible organization will provide directly using grant funds, and a description of the services that the eligible organization will use grant funds to provide through contracts or referrals;

"(3) a description of how the eligible organization will identify gaps in the services that caregivers and children or adults with a special need who receive care from a caregiver in the community are receiving;

"(4) a description of how the eligible organization can provide—

"(A) an initial visit to caregivers in order to complete a caregiver assessment, including a description of the eligible organization's expertise in conducting caregiver assessments;

"(B) education and training to help the 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

child or adult with a special need who is receiving care from a caregiver;

"(5) a description of the eligible organization's ability to provide, or refer caregivers to local resources or programs of the Department of Health and Human Services that will provide—

"(A) physical and mental health care, including home health care and long-term support services;

"(B) transportation;

"(C) home modification services;

"(D) respite care;

"(E) adult day care;

"(F) support groups; and

"(G) legal assistance;

"(6) a description of the eligible organization's ability to coordinate with other State and community-based agencies;

"(7) a description of the eligible organization's understanding of caregiver issues—

"(A) across age groups; and

"(B) including disabilities and chronic conditions that affect the populations that the eligible organization will serve;

"(8) a description of the capacity of the eligible organization to engage caregivers, family members, and children or adults with a special need who receive care from a caregiver; and

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

"(A) the population of caregivers;

"(B) the extent and nature of the needs of that population; and

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

"(e) PRIORITY.—In awarding grants under this section, the Secretary shall give priority to eligible organizations that—

"(1) the Secretary determines show the greatest likelihood of implementing or enhancing caregiver home visiting services for the greatest number of people;

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

"(3) have a proven record of caregiver support;

"(4) will use evidence-based programs; or

"(5) will provide matching funds or can demonstrate that the program funded by a grant under this section will be sustainable after grant funds are no longer provided.

"(f) AUTHORIZED ACTIVITIES.—An eligible organization receiving a grant under this section shall use grant funds to—

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

"(2) conduct home visits for the purpose of caregiver education and training;

"(3) provide, or provide referrals for, the services described in subsection (d)(5);

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

"(5) carry out any other activities that are described in the grant application submitted under subsection (d).

"(g) TECHNICAL ASSISTANCE CENTER.—The Secretary shall establish or contract to establish a technical assistance center through which the Secretary shall—

"(1) provide models for programs funded by grants under this section;

"(2) provide training for grantees;

"(3) answer questions from grantees; and

"(4) facilitate an exchange of information among grantees, and between grantees and other programs within the Department of Health and Human Services, including through use of the Technical Assistance Exchange of the Administration for Community Living, in order to maximize the use of existing resources and services for caregivers and to avoid the duplication of such services.

"(h) EVALUATION.—

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

"(2) OPTIONAL CONTENTS OF EVALUATION.—The evaluation described in paragraph (1) may include an evaluation of—

"(A) the extent to which children or adults with a special need who are cared for by a participating caregiver have—

"(i) a reduction in the potential number of hospitalizations;

"(ii) a reduction in the potential number of institutionalizations;

"(iii) cost reductions across the health care system;

"(iv) improved care; and

"(v) improved quality of life (including a reduction of stress and anxiety and improved relationships and mood); and

"(B) the extent to which participating caregivers have improved quality of life (including a reduction of stress and anxiety and improved health, relationships, and mood).

"(i) REPORTS AND RECOMMENDATIONS.—Not later than 1 year before the expiration of the grants awarded under this section, the Secretary shall prepare and submit 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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