S. 1333

To authorize the Secretary of Health and Human Services, acting through the Administrator of the Health Resources and Services Administration, to award grants for providing evidence-based caregiver skills training to family caregivers of children with autism spectrum disorder or other developmental disabilities or delays, and for other purposes.

IN THE SENATE OF THE UNITED STATES

APRIL 27, 2023

Mr. MENENDEZ (for himself and Ms. COLLINS) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To authorize the Secretary of Health and Human Services, acting through the Administrator of the Health Resources and Services Administration, to award grants for providing evidence-based caregiver skills training to family caregivers of children with autism spectrum disorder or other developmental disabilities or delays, and for other purposes.

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 “Autism Family Caregivers Act of 2023”.

SEC. 2. CAREGIVER SKILLS TRAINING PILOT PROGRAM.

(a) AUTHORIZATION.—The Secretary shall carry out a program, to be known as the Caregiver Skills Training Pilot Program, under which the Secretary shall award grants to eligible entities to provide evidence-based caregiver skills training to family caregivers of children with autism spectrum disorder or other developmental disabilities or delays, for the purposes of—

(1) improving the well-being of children and their caregivers; and

(2) teaching caregivers of such children evidenced-based intervention strategies to promote—

(A) improvement in the well-being of such children and their caregivers; and

(B) the greater inclusion of such children in family and community life.

(b) ELIGIBILITY.—To be eligible to receive a grant under subsection (a), an entity shall be—

(1) a nonprofit or other community-based organization;

(2) a Federally qualified health center;

(3) an academic health center;

(4) a health system; or
(5) a collaboration or consortium of 2 or more entities listed in paragraphs (1) through (4).

(c) APPLICATION.—To seek a grant under this section, an eligible entity shall submit to the Secretary an application that includes—

(1) a description of—

(A) the applicant’s experience delivering evidence-based caregiver skills training to family caregivers of children with autism spectrum disorder or other developmental disabilities or delays;

(B) the activities that the applicant proposes to carry out through the grant; and

(C) how such activities will achieve the purposes described in subsection (a); and

(2) a plan for—

(A) coordination with community-based organizations, State and local early intervention providers, State Medicaid systems, schools, and other providers of early intervening services;

(B) collaboration with health care payors (including public and private insurance), State departments of insurance, health plans, and other relevant payors;
(C) expanding the skills training program proposed to be carried out through the grant;

(D) achieving sustainability of such program; and

(E) establishing and maintaining a stakeholder implementation committee under subsection (f).

(d) SELECTION OF GRANTEES.—

(1) SELECTION CRITERIA.—In awarding a grant to an eligible entity or a collaboration or consortium of 2 or more entities described in subsection (b), the Secretary shall require at least one of the recipients to—

(A) have at least 3 years of demonstrated experience—

(i) delivering culturally competent services for children with autism spectrum disorder or other developmental delays or disabilities, as well as collaborating directly with their families, including in medically underserved communities;

(ii) providing services to children with autism spectrum disorder or other developmental delays or disabilities, as well as collaborating directly with their families;
(iii) providing individual caregiver coaching to caregivers of children with autism spectrum disorder or other developmental delays or disabilities; and

(iv) working with self-advocates or adults with autism spectrum disorder or other developmental delays or disabilities; and

(B) demonstrate the ability to access resources from and collaborate with—

(i) health care providers;

(ii) allied health professionals;

(iii) educators;

(iv) social workers; and

(v) nonprofessional family caregivers who assist with daily living and developmental activities, including for children with autism spectrum disorder or other developmental delays or disabilities.

(2) Reducing Disparities.—In awarding grants under this section, the Secretary may consider, as appropriate, the extent to which an eligible entity can deliver evidence-based, culturally competent caregiver skills training programs for children with autism spectrum disorder or other develop-
mental delays or disabilities from diverse racial, ethnic, geographic, or linguistic backgrounds.

(c) Use of Funds.—The recipient of a grant under this section shall use the grant—

(1) to provide, at no or minimal cost to participants—

(A) evidence-based caregiver skills training to family caregivers of children with autism spectrum disorder or other developmental delays or disabilities; and

(B) such training in areas related to children’s learning and development, including—

(i) communication skills;

(ii) social engagement;

(iii) daily living skills; and

(iv) caregiver response strategies to severe and challenging behaviors; and

(2) to establish and maintain a stakeholder implementation committee under subsection (f).

(f) Stakeholder Implementation Committee.—

(1) In General.—As a condition on receipt of a grant under this section, an eligible entity shall agree to use the grant to establish and maintain a stakeholder implementation committee to advise on
ensuring that the training provided pursuant to the 
grant is accessible and culturally relevant.

(2) COMPOSITION.—The members of the stake-
holder implementation committee shall all be from 
the local community served pursuant to the grant 
(or the relevant metropolitan statistical area) and 
shall include, at a minimum, the following:

(A) Family caregivers of children with au-
tism or other developmental disabilities, includ-
ing autistic caregivers and other caregivers with 
disabilities.

(B) Pediatric health care and early inter-
vention providers with experience providing 
services to children with autism or other devel-
opmenta delays or disabilities.

(C) Educators with experience working 
with children with autism or other develop-
mental delays or disabilities.

(D) Representatives of local organizations 
familiar with the cultural values and priorities 
of individuals in the local community.

(E) Local government officials.

(g) REQUIREMENTS.—

(1) NUMBER OF RECIPIENTS AND STATES.—
The Secretary shall award grants under subsection
(a) to not fewer than 25 eligible entities in not fewer
than 15 States.

(2) AMOUNT.—The total amount of each grant
awarded under subsection (a) shall be not less than
$500,000 over a 5-year period.

(h) SUPPLEMENT NOT SUPPLANT.—Amounts re-
ceived through a grant under this section shall be used
to supplement, not supplant, other amounts received to
provide—

(1) behavioral, medical, habilitative, and other
services covered by the Medicaid program or private
health insurance;

(2) services provided under the Individuals with
Disabilities Education Act (20 U.S.C. 1400 et seq.);
or

(3) adaptations of a training program using evi-
dence-based approaches to serve children of different
ages, communities, and underrepresented groups.

(i) ACTIVITIES OF THE SECRETARY.—The Secretary
shall—

(1) assist recipients of grants under subsection
(a) in—

(A) the implementation of caregiver skills
training programs using lessons learned from
other evidenced-based activities or caregiver
programs conducted or supported by the Health Resources and Services Administration;

(B) ensuring the programs of the recipients assist medically underserved communities, when possible; and

(C) developing plans for achieving sustainability of the programs of the recipients;

(2) conduct an annual evaluation of activities funded through grants under subsection (a), in consultation with the grant recipients, including evaluation of the effectiveness of such grants at improving health outcomes and quality of life for children with autism spectrum disorder or other developmental delays or disabilities and their family caregivers; and

(3) convene at least one national or regional meeting of such grant recipients to discuss best practices.

(j) Reports.—

(1) Initial report.—Not later than 6 months after awarding the first grant under subsection (a), the Secretary shall submit to the Committees on Appropriations of the House of Representatives and the Senate, and to other appropriate congressional committees, a report on the implementation of this section. Such report shall include—
(A) how many grants have been awarded;
(B) the name and location of the grant recipients;
(C) the communities impacted by the grants;
(D) a description of the kind of activities to be carried out with the grants;
(E) an analysis, conducted by the Secretary, based on the evaluation under subsection (i)(2), of the effectiveness of such grants at improving health outcomes and quality of life for children with autism or other developmental delays or disabilities and their family caregivers; and
(F) best practices to increase access to caregiver skills training programs described in subsection (a) in medically underserved communities.

(2) Final Report.—Not later than the end of fiscal year 2027, the Secretary shall submit to the Committees on Appropriations of the House of Representatives and the Senate, and to other appropriate congressional committees, a final report on the implementation of this section, including—
(A) the information, analysis, and best practices listed in subparagraphs (A) through (F) of paragraph (1); and

(B) recommendations on how to expand and extend the program under this section.

(k) Definitions.—In this section:

(1) The term “family caregiver” means an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, a child between the ages of 0 and 9 diagnosed with autism spectrum disorder or other developmental disabilities or delays.

(2) The term “Federally qualified health center” has the meaning given the term in section 1861(aa) of the Social Security Act (42 U.S.C. 1395x(aa)).

(3) The term “Secretary” means the Secretary of Health and Human Services, acting through the Administrator of the Health Resources and Services Administration.

(l) Authorization of Appropriations.—To carry out this section, there is authorized to be appropriated $10,000,000 for each of fiscal years 2024 through 2028.