

118TH CONGRESS  
1ST SESSION

# 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.

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## 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

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## 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.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Autism Family Care-  
3 givers Act of 2023”.

4 **SEC. 2. CAREGIVER SKILLS TRAINING PILOT PROGRAM.**

5 (a) **AUTHORIZATION.**—The Secretary shall carry out  
6 a program, to be known as the Caregiver Skills Training  
7 Pilot Program, under which the Secretary shall award  
8 grants to eligible entities to provide evidence-based care-  
9 giver skills training to family caregivers of children with  
10 autism spectrum disorder or other developmental disabil-  
11 ities or delays, for the purposes of—

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

14 (2) teaching caregivers of such children evi-  
15 denced-based intervention strategies to promote—

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

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

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

22 (1) a nonprofit or other community-based orga-  
23 nization;

24 (2) a Federally qualified health center;

25 (3) an academic health center;

26 (4) a health system; or

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

3           (c) APPLICATION.—To seek a grant under this sec-  
4 tion, an eligible entity shall submit to the Secretary an  
5 application that includes—

6           (1) a description of—

7               (A) the applicant’s experience delivering  
8 evidence-based caregiver skills training to fam-  
9 ily caregivers of children with autism spectrum  
10 disorder or other developmental disabilities or  
11 delays;

12               (B) the activities that the applicant pro-  
13 poses to carry out through the grant; and

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

16           (2) a plan for—

17               (A) coordination with community-based or-  
18 ganizations, State and local early intervention  
19 providers, State Medicaid systems, schools, and  
20 other providers of early intervening services;

21               (B) collaboration with health care payors  
22 (including public and private insurance), State  
23 departments of insurance, health plans, and  
24 other relevant payors;

1 (C) expanding the skills training program  
2 proposed to be carried out through the grant;

3 (D) achieving sustainability of such pro-  
4 gram; and

5 (E) establishing and maintaining a stake-  
6 holder implementation committee under sub-  
7 section (f).

8 (d) SELECTION OF GRANTEES.—

9 (1) SELECTION CRITERIA.—In awarding a  
10 grant to an eligible entity or a collaboration or con-  
11 sortium of 2 or more entities described in subsection  
12 (b), the Secretary shall require at least one of the  
13 recipients to—

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

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

22 (ii) providing services to children with  
23 autism spectrum disorder or other develop-  
24 mental delays or disabilities, as well as col-  
25 laborating directly with their families;

1 (iii) providing individual caregiver  
2 coaching to caregivers of children with au-  
3 tism spectrum disorder or other develop-  
4 mental delays or disabilities; and

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

9 (B) demonstrate the ability to access re-  
10 sources from and collaborate with—

11 (i) health care providers;

12 (ii) allied health professionals;

13 (iii) educators;

14 (iv) social workers; and

15 (v) nonprofessional family caregivers  
16 who assist with daily living and develop-  
17 mental activities, including for children  
18 with autism spectrum disorder or other de-  
19 velopmental delays or disabilities.

20 (2) REDUCING DISPARITIES.—In awarding  
21 grants under this section, the Secretary may con-  
22 sider, as appropriate, the extent to which an eligible  
23 entity can deliver evidence-based, culturally com-  
24 petent caregiver skills training programs for children  
25 with autism spectrum disorder or other develop-

1 mental delays or disabilities from diverse racial, eth-  
2 nic, geographic, or linguistic backgrounds.

3 (e) USE OF FUNDS.—The recipient of a grant under  
4 this section shall use the grant—

5 (1) to provide, at no or minimal cost to partici-  
6 pants—

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

11 (B) such training in areas related to chil-  
12 dren’s learning and development, including—

13 (i) communication skills;

14 (ii) social engagement;

15 (iii) daily living skills; and

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

18 (2) to establish and maintain a stakeholder im-  
19 plementation committee under subsection (f).

20 (f) STAKEHOLDER IMPLEMENTATION COMMITTEE.—

21 (1) IN GENERAL.—As a condition on receipt of  
22 a grant under this section, an eligible entity shall  
23 agree to use the grant to establish and maintain a  
24 stakeholder implementation committee to advise on

1 ensuring that the training provided pursuant to the  
2 grant is accessible and culturally relevant.

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

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

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

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

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

22 (E) Local government officials.

23 (g) REQUIREMENTS.—

24 (1) NUMBER OF RECIPIENTS AND STATES.—

25 The Secretary shall award grants under subsection

1 (a) to not fewer than 25 eligible entities in not fewer  
2 than 15 States.

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

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

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

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

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

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

21 (1) assist recipients of grants under subsection

22 (a) in—

23 (A) the implementation of caregiver skills  
24 training programs using lessons learned from  
25 other evidenced-based activities or caregiver

1 programs conducted or supported by the Health  
2 Resources and Services Administration;

3 (B) ensuring the programs of the recipi-  
4 ents assist medically underserved communities,  
5 when possible; and

6 (C) developing plans for achieving sustain-  
7 ability of the programs of the recipients;

8 (2) conduct an annual evaluation of activities  
9 funded through grants under subsection (a), in con-  
10 sultation with the grant recipients, including evalua-  
11 tion of the effectiveness of such grants at improving  
12 health outcomes and quality of life for children with  
13 autism spectrum disorder or other developmental  
14 delays or disabilities and their family caregivers; and

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

18 (j) REPORTS.—

19 (1) INITIAL REPORT.—Not later than 6 months  
20 after awarding the first grant under subsection (a),  
21 the Secretary shall submit to the Committees on Ap-  
22 propriations of the House of Representatives and the  
23 Senate, and to other appropriate congressional com-  
24 mittees, a report on the implementation of this sec-  
25 tion. Such report shall include—

1 (A) how many grants have been awarded;

2 (B) the name and location of the grant re-  
3 cipients;

4 (C) the communities impacted by the  
5 grants;

6 (D) a description of the kind of activities  
7 to be carried out with the grants;

8 (E) an analysis, conducted by the Sec-  
9 retary, based on the evaluation under sub-  
10 section (i)(2), of the effectiveness of such  
11 grants at improving health outcomes and qual-  
12 ity of life for children with autism or other de-  
13 velopmental delays or disabilities and their fam-  
14 ily caregivers; and

15 (F) best practices to increase access to  
16 caregiver skills training programs described in  
17 subsection (a) in medically underserved commu-  
18 nities.

19 (2) FINAL REPORT.—Not later than the end of  
20 fiscal year 2027, the Secretary shall submit to the  
21 Committees on Appropriations of the House of Rep-  
22 resentatives and the Senate, and to other appro-  
23 priate congressional committees, a final report on  
24 the implementation of this section, including—

1 (A) the information, analysis, and best  
2 practices listed in subparagraphs (A) through  
3 (F) of paragraph (1); and

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

6 (k) DEFINITIONS.—In this section:

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

13 (2) The term “Federally qualified health cen-  
14 ter” has the meaning given the term in section  
15 1861(aa) of the Social Security Act (42 U.S.C.  
16 1395x(aa)).

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

21 (l) AUTHORIZATION OF APPROPRIATIONS.—To carry  
22 out this section, there is authorized to be appropriated  
23 \$10,000,000 for each of fiscal years 2024 through 2028.

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