

118TH CONGRESS
1ST SESSION

H. R. 2965

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 HOUSE OF REPRESENTATIVES

APRIL 27, 2023

Ms. MENG (for herself, Mr. FITZPATRICK, Mr. CUELLAR, and Mr. MOLINARO) introduced the following bill; which was referred to the Committee on Energy and Commerce

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 of Health and
6 Human Services, acting through the Administrator of the
7 Health Resources and Services Administration, shall carry
8 out a program, to be known as the Caregiver Skills Train-
9 ing Pilot Program, under which the Secretary shall award
10 grants to eligible entities to provide evidence-based care-
11 giver skills training to family caregivers of children with
12 autism spectrum disorder or other developmental disabil-
13 ities or delays, for the purposes of—

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

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

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

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

22 (b) **ELIGIBILITY.**—To be eligible to receive an award
23 under subsection (a), an entity shall be—

24 (1) a nonprofit or other community-based orga-
25 nization;

26 (2) a Federally qualified health center;

1 (3) an academic health center;

2 (4) a health system; or

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

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

8 (1) a description of—

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

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

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

18 (2) a plan for—

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

23 (B) collaboration with health care payors
24 (including public and private insurance), State

1 departments of insurance, health plans, and
2 other relevant payors;

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

5 (D) achieving sustainability of such pro-
6 gram; and

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

10 (d) SELECTION OF GRANTEES.—

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

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

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

24 (ii) providing services to children with
25 autism spectrum disorder or other develop-

1 mental delays and disabilities, as well as
2 collaborating directly with their families;

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

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

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

13 (i) health care providers;

14 (ii) allied health professionals;

15 (iii) educators;

16 (iv) social workers; and

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

22 (2) REDUCING DISPARITIES.—In awarding
23 grants under this section, the Secretary may con-
24 sider, as appropriate, the extent to which an eligible
25 entity can deliver evidence-based, culturally com-

1 petent caregiver skills training programs for children
2 with autism spectrum disorder or other develop-
3 mental delays and disabilities from diverse racial,
4 ethnic, geographic, or linguistic backgrounds.

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

7 (1) to provide, at no or minimal cost to partici-
8 pants—

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

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

15 (i) communication skills;

16 (ii) social engagement;

17 (iii) daily living skills; and

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

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

22 (f) STAKEHOLDER IMPLEMENTATION COMMITTEE.—

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

1 stakeholder implementation committee to advise on
2 ensuring that the training provided pursuant to the
3 grant is accessible and culturally relevant.

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

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

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

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

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

23 (E) Local government officials.

24 (g) REQUIREMENTS.—

1 (1) NUMBER OF RECIPIENTS AND STATES.—

2 The Secretary shall award grants under subsection
3 (a) to not fewer than 25 eligible entities in not fewer
4 than 15 States.

5 (2) AMOUNT.—The total amount of each grant
6 awarded under subsection (a) shall be not less than
7 \$500,000 over a 5-year period.

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

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

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

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

21 (i) ACTIVITIES OF THE SECRETARY.—The Secretary,
22 acting through the Administrator of the Health Resources
23 and Services Administration, shall—

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

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

6 (B) ensuring the programs of the recipi-
7 ents assist medically underserved communities,
8 when possible; and

9 (C) developing plans for achieving sustain-
10 ability of the programs of the recipients;

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

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

22 (j) REPORTS.—

23 (1) INITIAL REPORT.—Not later than 6 months
24 after awarding the first grant under subsection (a),
25 the Secretary shall submit to the Committees on Ap-

1 appropriations of the House of Representatives and the
2 Senate, and to other appropriate congressional com-
3 mittees, a report on the implementation of this sec-
4 tion. Such report shall include—

5 (A) how many grants have been awarded;

6 (B) the name and location of the grant re-
7 cipients;

8 (C) the communities impacted by the
9 grants;

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

12 (E) an analysis, conducted by the Adminis-
13 trator of the Health Resources and Services Ad-
14 ministration, based on the evaluation under
15 subsection (h)(2), of the effectiveness of such
16 grants at improving health outcomes and qual-
17 ity of life for children with autism or other de-
18 velopmental disabilities or delays and their fam-
19 ily caregivers; and

20 (F) best practices to increase access to
21 caregiver skills training programs described in
22 subsection (a) in medically underserved commu-
23 nities.

24 (2) FINAL REPORT.—Not later than the end of
25 fiscal year 2027, the Secretary shall submit to the

1 Committees on Appropriations of the House of Rep-
2 resentatives and the Senate, and to other appro-
3 priate congressional committees, a final report on
4 the implementation of this section, including—

5 (A) the information, analysis, and best
6 practices listed in subparagraphs (A) through
7 (F) of paragraph (1); and

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

10 (k) DEFINITIONS.—In this section:

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

17 (2) The term “Federally qualified health cen-
18 ter” has the meaning given the term in section
19 1861(aa) of the Social Security Act (42 U.S.C.
20 1395x(aa)).

21 (3) The term “Secretary” means the Secretary
22 of Health and Human Services.

1 (l) AUTHORIZATION OF APPROPRIATIONS.—To carry
2 out this section, there is authorized to be appropriated
3 \$10,000,000 for each of fiscal years 2024 through 2028.

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