

116TH CONGRESS
1ST SESSION

S. 427

To amend the Public Health Service Act to enhance activities of the National Institutes of Health with respect to research on autism spectrum disorder and enhance programs relating to autism, and for other purposes.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 7, 2019

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

A BILL

To amend the Public Health Service Act to enhance activities of the National Institutes of Health with respect to research on autism spectrum disorder and enhance programs relating to autism, 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,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Autism Collaboration,
5 Accountability, Research, Education, and Support Act of
6 2019” or the “Autism CARES Act of 2019”.

1 **SEC. 2. EXPANSION, INTENSIFICATION, AND COORDINA-**
2 **TION OF ACTIVITIES OF THE NIH WITH RE-**
3 **SPECT TO RESEARCH ON AUTISM SPECTRUM**
4 **DISORDER.**

5 Section 409C of the Public Health Service Act (42
6 U.S.C. 284g) is amended—

7 (1) in subsection (a)(1)—

8 (A) in the first sentence, by striking “and
9 toxicology” and inserting “toxicology, and inter-
10 ventions to maximize outcomes for persons with
11 autism spectrum disorder”; and

12 (B) by striking the second sentence and in-
13 serting the following: “Such research shall in-
14 vestigate the causes (including possible environ-
15 mental causes), diagnosis or rule out, early and
16 ongoing detection, prevention, services across
17 the lifespan, supports, intervention, and treat-
18 ment of autism spectrum disorder, including
19 dissemination and implementation of clinical
20 care, supports, interventions, and treatments.”;

21 (2) in subsection (b)—

22 (A) in paragraph (2)—

23 (i) in the second sentence, by striking
24 “cause” and all that follows through “dis-
25 order” and inserting “causes, diagnosis,
26 early and ongoing detection, prevention,

1 and treatment of autism spectrum disorder
2 across the lifespan”; and

3 (ii) in the third sentence, by striking
4 “neurobiology” and all that follows
5 through the period and inserting “neurobi-
6 ology, genetics, genomics, psychopharma-
7 cology, developmental psychology, behav-
8 ioral psychology, and clinical psychology.”;
9 and

10 (B) in paragraph (3), by adding at the end
11 the following:

12 “(D) REDUCING DISPARITIES.—The Direc-
13 tor may consider, as appropriate, the extent to
14 which a center can demonstrate availability and
15 access to clinical services for youth and adults
16 from diverse racial, ethnic, geographic, or lin-
17 guistic backgrounds in decisions about awarding
18 grants to applicants which meet the scientific
19 criteria for funding under this section.”.

20 **SEC. 3. PROGRAMS RELATING TO AUTISM.**

21 (a) DEVELOPMENTAL DISABILITIES SURVEILLANCE
22 AND RESEARCH PROGRAM.—Section 399AA(e) of the
23 Public Health Service Act (42 U.S.C. 280i(e)) is amended
24 by striking “2019” and inserting “2024”.

1 (b) AUTISM EDUCATION, EARLY DETECTION, AND
2 INTERVENTION.—Section 399BB of the Public Health
3 Service Act (42 U.S.C. 280i–1) is amended—

4 (1) in subsection (a)(1), by striking “children
5 with autism spectrum disorder” and all that follows
6 through “disabilities;” and inserting “individuals
7 with autism spectrum disorder and other develop-
8 mental disabilities across their lifespan;”;

9 (2) in subsection (b)—

10 (A) in paragraph (2), by inserting “indi-
11 viduals with” before “autism spectrum dis-
12 order”;

13 (B) by redesignating paragraphs (4)
14 through (6) as paragraphs (5) through (7), re-
15 spectively; and

16 (C) by inserting after paragraph (3) the
17 following:

18 “(4) promote evidence-based screening tech-
19 niques and interventions for individuals with autism
20 spectrum disorder and other developmental disabil-
21 ities across their lifespan;”;

22 (3) in subsection (c)(1), in the matter preceding
23 subparagraph (A), by inserting “across their life-
24 span” before “and their families”;

25 (4) in subsection (e)—

1 (A) in paragraph (1)—

2 (i) in the matter preceding subpara-
3 graph (A), by inserting “across their life-
4 span” before “and ensure”; and

5 (ii) in subparagraph (B)(iv), by in-
6 serting “across their lifespan” after “other
7 developmental disabilities”;

8 (B) by redesignating paragraphs (2) and
9 (3) as paragraphs (3) and (4), respectively; and

10 (C) by inserting after paragraph (1) the
11 following:

12 “(2) DEVELOPMENTAL-BEHAVIORAL PEDIATRI-
13 CIAN TRAINING PROGRAMS.—

14 “(A) IN GENERAL.—In making awards
15 under this subsection, the Secretary may
16 prioritize awards to applicants that are develop-
17 mental-behavioral pediatrician training pro-
18 grams located in rural or underserved areas.

19 “(B) DEFINITION OF UNDERSERVED
20 AREA.—In this paragraph, the term ‘under-
21 served area’ means—

22 “(i) a health professional shortage
23 area (as defined in section 332(a)(1)(A));
24 and

1 “(ii) an urban or rural area des-
2 ignated by the Secretary as an area with
3 a shortage of personal health services as
4 described in section 330(b)(3)(A).”;

5 (5) in subsection (f), by inserting “across the
6 lifespan of such individuals” after “other develop-
7 mental disabilities”; and

8 (6) in subsection (g), by striking “2019” and
9 inserting “2024”.

10 (c) INTERAGENCY AUTISM COORDINATING COM-
11 MITTEE.—Section 399CC of the Public Health Service Act
12 (42 U.S.C. 280i–2) is amended—

13 (1) in subsection (b)—

14 (A) in paragraph (2), by inserting “across
15 the lifespan of such individuals” before the
16 semicolon; and

17 (B) in paragraph (5), by inserting “across
18 the lifespan of such individuals” before “and
19 the families”;

20 (2) in subsection (c)—

21 (A) in paragraph (1)(D), by inserting “,
22 the Department of Labor, the Department of
23 Justice, the Department of Housing and Urban
24 Development,” after “Department of Edu-
25 cation”; and

1 (B) in paragraph (3)(A), by striking “one
2 or more additional 4-year terms” and inserting
3 “one additional 4-year term”; and
4 (3) in subsection (f), by striking “2019” and
5 inserting “2024”.

6 (d) REPORTS TO CONGRESS.—Section 399DD of the
7 Public Health Service Act (42 U.S.C. 280i–3) is amend-
8 ed—

9 (1) in subsection (a)—

10 (A) in paragraph (1), by striking “Autism
11 CARES Act of 2014” and inserting “Autism
12 CARES Act of 2019”; and

13 (B) in paragraph (2)—

14 (i) in subparagraphs (A), (B), (D),
15 and (E), by striking “Autism CARES Act
16 of 2014” each place it appears and insert-
17 ing “Autism CARES Act of 2019”;

18 (ii) in subparagraph (G), by striking
19 “age of the child” and inserting “age of
20 the individual”;

21 (iii) in subparagraph (H), by striking
22 “; and” and inserting “;”;

23 (iv) in subparagraph (I), by striking
24 the period and inserting “; and”; and

25 (v) by adding at the end the following:

1 “(J) information on how States use home-
2 and community-based services and other sup-
3 ports to ensure that individuals with autism
4 spectrum disorder and other developmental dis-
5 abilities are living, working, and participating in
6 their community.”; and

7 (2) in subsection (b)—

8 (A) in the heading, by striking “YOUNG
9 ADULTS AND TRANSITIONING YOUTH” and in-
10 serting “THE HEALTH AND WELL-BEING OF
11 INDIVIDUALS WITH AUTISM SPECTRUM DIS-
12 ORDER ACROSS THEIR LIFESPAN”;

13 (B) by amending paragraph (1) to read as
14 follows:

15 “(1) IN GENERAL.—Not later than 2 years
16 after the date of enactment of the Autism CARES
17 Act of 2019, the Secretary shall prepare and submit,
18 to the Committee on Health, Education, Labor, and
19 Pensions of the Senate and the Committee on En-
20 ergy and Commerce of the House of Representa-
21 tives, a report concerning the health and well-being
22 of individuals with autism spectrum disorder.”; and

23 (C) in paragraph (2)—

24 (i) by amending subparagraph (A) to
25 read as follows:

1 “(A) demographic factors associated with
2 the health and well-being of individuals with au-
3 tism spectrum disorder;”;

4 (ii) in subparagraph (B), by striking
5 “young adults” and all that follows
6 through the semicolon and inserting “the
7 health and well-being of individuals with
8 autism spectrum disorder, including an
9 identification of existing Federal laws, reg-
10 ulations, policies, research, and pro-
11 grams;”;

12 (iii) by amending subparagraphs (C),
13 (D), and (E) to read as follows:

14 “(C) recommendations on establishing best
15 practices guidelines to ensure interdisciplinary
16 coordination between all relevant service pro-
17 viders receiving Federal funding;

18 “(D) comprehensive approaches to improv-
19 ing health outcomes and well-being for individ-
20 uals with autism spectrum disorder, including—

21 “(i) community-based behavioral sup-
22 ports and interventions;

23 “(ii) nutrition, recreational, and social
24 activities; and

1 “(iii) personal safety services related
2 to public safety agencies or the criminal
3 justice system for such individuals; and

4 “(E) recommendations that seek to im-
5 prove health outcomes for such individuals, in-
6 cluding across their lifespan, by addressing—

7 “(i) screening and diagnosis of chil-
8 dren and adults;

9 “(ii) behavioral and other therapeutic
10 approaches;

11 “(iii) primary and preventative care;

12 “(iv) communication challenges;

13 “(v) aggression, self-injury, elope-
14 ment, and other behavioral issues;

15 “(vi) emergency room visits and acute
16 care hospitalization;

17 “(vii) treatment for co-occurring phys-
18 ical and mental health conditions;

19 “(viii) premature mortality;

20 “(ix) medical practitioner training;

21 and

22 “(x) caregiver mental health.”.

23 (e) AUTHORIZATION OF APPROPRIATIONS.—Section
24 399EE of the Public Health Service Act (42 U.S.C. 280i-
25 4) is amended—

1 (1) in subsection (a), by striking “\$22,000,000
2 for each of fiscal years 2015 through 2019” and in-
3 serting “\$23,100,000 for each of fiscal years 2020
4 through 2024”;

5 (2) in subsection (b), by striking “\$48,000,000
6 for each of fiscal years 2015 through 2019” and in-
7 serting “\$50,599,000 for each of fiscal years 2020
8 through 2024”; and

9 (3) in subsection (c), by striking “there is au-
10 thorized to be appropriated \$190,000,000 for each
11 of fiscal years 2015 through 2019” and inserting
12 “there are authorized to be appropriated such sums
13 as may be necessary for each of fiscal years 2020
14 through 2024”.

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