

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.

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## 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

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## 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:

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

(2) in subsection (b)—

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

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

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

(C) in paragraph (2)—

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



“(A) demographic factors associated with the health and well-being of individuals with autism spectrum disorder;”;

(ii) in subparagraph (B), by striking “young adults” and all that follows through the semicolon and inserting “the health and well-being of individuals with autism spectrum disorder, including an identification of existing Federal laws, regulations, policies, research, and programs;”;

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

“(C) recommendations on establishing best practices guidelines to ensure interdisciplinary coordination between all relevant service providers receiving Federal funding;

“(D) comprehensive approaches to improving health outcomes and well-being for individuals with autism spectrum disorder, including—

“(i) community-based behavioral supports and interventions;

“(ii) nutrition, recreational, and social 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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