

116TH CONGRESS
1ST SESSION

H. R. 1058

IN THE SENATE OF THE UNITED STATES

JULY 25, 2019

Received

AN ACT

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,*

1 **SECTION 1. SHORT TITLE.**

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

5 **SEC. 2. EXPANSION, INTENSIFICATION, AND COORDINA-**
6 **TION OF ACTIVITIES OF THE NIH WITH RE-**
7 **SPECT TO RESEARCH ON AUTISM SPECTRUM**
8 **DISORDER.**

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

11 (1) in subsection (a)(1)—

12 (A) in the first sentence, by striking “and
13 toxicology” and inserting “toxicology, and inter-
14 ventions to maximize outcomes for individuals
15 with autism spectrum disorder”; and

16 (B) by striking the second sentence and in-
17 serting the following: “Such research shall in-
18 vestigate the causes (including possible environ-
19 mental causes), diagnosis or ruling out, early
20 and ongoing detection, prevention, services
21 across the lifespan, supports, intervention, and
22 treatment of autism spectrum disorder, includ-
23 ing dissemination and implementation of clin-
24 ical care, supports, interventions, and treat-
25 ments.”;

26 (2) in subsection (b)—

1 (A) in paragraph (2)—

2 (i) in the second sentence, by striking
3 “cause” and all that follows through “dis-
4 order” and inserting “causes, diagnosis,
5 early and ongoing detection, prevention,
6 and treatment of autism spectrum disorder
7 across the lifespan”; and

8 (ii) in the third sentence, by striking
9 “neurobiology” and all that follows
10 through the period and inserting
11 “neurobiology, genetics, genomics,
12 psychopharmacology, developmental psy-
13 chology, behavioral psychology, and clinical
14 psychology.”; and

15 (B) in paragraph (3), by adding at the end
16 the following:

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

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

2 (a) DEVELOPMENTAL DISABILITIES SURVEILLANCE
3 AND RESEARCH PROGRAM.—Section 399AA of the Public
4 Health Service Act (42 U.S.C. 280i) is amended—

5 (1) in subsection (a)(1), by striking “adults on
6 autism spectrum disorder” and inserting “adults
7 with autism spectrum disorder”;

8 (2) in subsection (a)(2)—

9 (A) by striking “State and local public
10 health officials” and inserting “State, local, and
11 Tribal public health officials”;

12 (B) by striking “or other developmental
13 disabilities” and inserting “and other develop-
14 mental disabilities”;

15 (3) in subsection (a)(3), by striking “a univer-
16 sity, or any other educational institution” and in-
17 sserting “a university, any other educational institu-
18 tion, an Indian tribe, or a tribal organization”;

19 (4) in subsection (b)(2)(A), by striking “rel-
20 evant State and local public health officials, private
21 sector developmental disability researchers, and ad-
22 vocates for individuals with developmental disabili-
23 ties” and inserting “State, local, and Tribal public
24 health officials, private sector developmental dis-
25 ability researchers, advocates for individuals with

1 autism spectrum disorder, and advocates for individ-
2 uals with other developmental disabilities”;

3 (5) in subsection (d)—

4 (A) by redesignating paragraphs (1) and
5 (2) as paragraphs (2) and (3), respectively; and

6 (B) by inserting before paragraph (2), as
7 so redesignated, the following new paragraph:

8 “(1) INDIAN TRIBE; TRIBAL ORGANIZATION.—

9 The terms ‘Indian tribe’ and ‘tribal organization’
10 have the meanings given such terms in section 4 of
11 the Indian Health Care Improvement Act.”; and

12 (6) in subsection (e), by striking “2019” and
13 inserting “2024”.

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

17 (1) in subsection (a)(1)—

18 (A) by striking “individuals with autism
19 spectrum disorder or other developmental dis-
20 abilities” and inserting “individuals with autism
21 spectrum disorder and other developmental dis-
22 abilities”; and

23 (B) by striking “children with autism spec-
24 trum disorder” and all that follows through
25 “disabilities;” and inserting “individuals with

1 autism spectrum disorder and other develop-
2 mental disabilities across their lifespan;”;

3 (2) in subsection (b)—

4 (A) in paragraph (2), by inserting “indi-
5 viduals with” before “autism spectrum dis-
6 order”;

7 (B) by redesignating paragraphs (4)
8 through (6) as paragraphs (5) through (7), re-
9 spectively; and

10 (C) by inserting after paragraph (3) the
11 following:

12 “(4) promote evidence-based screening tech-
13 niques and interventions for individuals with autism
14 spectrum disorder and other developmental disabil-
15 ities across their lifespan;”;

16 (3) in subsection (c)—

17 (A) in paragraph (1), in the matter pre-
18 ceding subparagraph (A), by striking “the
19 needs of individuals with autism spectrum dis-
20 order or other developmental disabilities and
21 their families” and inserting “the needs of indi-
22 viduals with autism spectrum disorder and
23 other developmental disabilities across their life-
24 span and the needs of their families”; and

25 (B) in paragraph (2)—

1 (i) in subparagraph (A)(ii), by strik-
2 ing “caregivers of individuals with an au-
3 tism spectrum disorder” and inserting
4 “caregivers of individuals with autism
5 spectrum disorder or other developmental
6 disabilities”;

7 (ii) in subparagraph (B)(i)(II), by in-
8 serting “autism spectrum disorder and”
9 after “individuals with”; and

10 (iii) in subparagraph (B)(ii), by in-
11 serting “autism spectrum disorder and”
12 after “individuals with”;

13 (4) in subsection (e)—

14 (A) in paragraph (1)—

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

18 (ii) in subparagraph (B)(iv), by in-
19 serting “across their lifespan” after “other
20 developmental disabilities”;

21 (B) by redesignating paragraphs (2) and
22 (3) as paragraphs (3) and (4), respectively; and

23 (C) by inserting after paragraph (1) the
24 following:

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

3 “(A) IN GENERAL.—In making awards
4 under this subsection, the Secretary may
5 prioritize awards to applicants that are develop-
6 mental-behavioral pediatrician training pro-
7 grams located in rural or underserved areas.

8 “(B) DEFINITION OF UNDERSERVED
9 AREA.—In this paragraph, the term ‘under-
10 served area’ means—

11 “(i) a health professional shortage
12 area (as defined in section 332(a)(1)(A));
13 and

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

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

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

23 (c) INTERAGENCY AUTISM COORDINATING COM-
24 MITTEE.—Section 399CC of the Public Health Service Act
25 (42 U.S.C. 280i-2) is amended—

1 (1) in subsection (b)—

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

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

8 (2) in subsection (c)—

9 (A) in paragraph (1)(D), by inserting “,
10 the Department of Labor, the Department of
11 Justice, the Department of Veterans Affairs,
12 the Department of Housing and Urban Devel-
13 opment,” after “Department of Education”;

14 (B) in subparagraphs (A), (B), and (C) of
15 paragraph (2), by striking “at least two such
16 members” each place it appears and inserting
17 “at least three such members”;

18 (C) in paragraph (3)(A), by striking “one
19 or more additional 4-year terms” and inserting
20 “one additional 4-year term”; and

21 (3) in subsection (f), by striking “2019” and
22 inserting “2024”.

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

1 (1) in subsection (a)—

2 (A) in paragraph (1), by striking “Autism
3 CARES Act of 2014” and inserting “Autism
4 CARES Act of 2019”; and

5 (B) in paragraph (2)—

6 (i) in subparagraphs (A), (B), (D),
7 and (E), by striking “Autism CARES Act
8 of 2014” each place it appears and insert-
9 ing “Autism CARES Act of 2019”;

10 (ii) in subparagraph (G), by striking
11 “age of the child” and inserting “age of
12 the individual”;

13 (iii) in subparagraph (H), by striking
14 “; and” and inserting “;”;

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

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

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

24 (2) in subsection (b)—

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

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

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

16 (C) in paragraph (2)—

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

19 “(A) demographic factors associated with
20 the health and well-being of individuals with au-
21 tism spectrum disorder;”;

22 (ii) in subparagraph (B), by striking
23 “young adults” and all that follows
24 through the semicolon and inserting “the
25 health and well-being of individuals with

1 autism spectrum disorder, including an
2 identification of existing Federal laws, reg-
3 ulations, policies, research, and pro-
4 grams;” and

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

7 “(C) recommendations on establishing best
8 practices guidelines to ensure interdisciplinary
9 coordination between all relevant service pro-
10 viders receiving Federal funding;

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

14 “(i) community-based behavioral sup-
15 ports and interventions;

16 “(ii) nutrition, recreational, and social
17 activities; and

18 “(iii) personal safety services related
19 to public safety agencies or the criminal
20 justice system for such individuals; and

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

24 “(i) screening and diagnosis of chil-
25 dren and adults;

1 “(ii) behavioral and other therapeutic
2 approaches;
3 “(iii) primary and preventative care;
4 “(iv) communication challenges;
5 “(v) aggression, self-injury, elope-
6 ment, and other behavioral issues;
7 “(vi) emergency room visits and acute
8 care hospitalization;
9 “(vii) treatment for co-occurring phys-
10 ical and mental health conditions;
11 “(viii) premature mortality;
12 “(ix) medical practitioner training;
13 and
14 “(x) caregiver mental health.”
15 (c) AUTHORIZATION OF APPROPRIATIONS.—Section
16 399EE of the Public Health Service Act (42 U.S.C. 280i-
17 4) is amended—
18 (1) in subsection (a), by striking “\$22,000,000
19 for each of fiscal years 2015 through 2019” and in-
20 serting “\$23,100,000 for each of fiscal years 2020
21 through 2024”;
22 (2) in subsection (b), by striking “\$48,000,000
23 for each of fiscal years 2015 through 2019” and in-
24 serting “\$50,599,000 for each of fiscal years 2020
25 through 2024”; and

