

Union Calendar No. 137

116TH CONGRESS
1ST SESSION

H. R. 1058

[Report No. 116–177]

To reauthorize certain provisions of the Public Health Service Act relating to autism, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 7, 2019

Mr. SMITH of New Jersey (for himself and Mr. MICHAEL F. DOYLE of Pennsylvania) introduced the following bill; which was referred to the Committee on Energy and Commerce

JULY 23, 2019

Additional sponsors: Mr. FITZPATRICK, Mr. BRENDAN F. BOYLE of Pennsylvania, Mr. SEAN PATRICK MALONEY of New York, Mr. PETERSON, Mr. SAN NICOLAS, Mr. PAYNE, Mr. SERRANO, Mr. DEUTCH, Mr. CARSON of Indiana, Mr. KING of New York, Mr. GOTTHEIMER, Mr. LIPINSKI, Ms. NORTON, Mr. YARMUTH, Mr. MCGOVERN, Mr. HASTINGS, Mr. BRINDISI, Mr. MOULTON, Ms. SLOTKIN, Mr. MEEKS, Mr. KIM, Mr. WELCH, Mrs. WALORSKI, Mr. SCHIFF, Ms. LOFGREN, Mr. RYAN, Ms. MATSUI, Ms. WATERS, Mr. KENNEDY, Ms. KUSTER of New Hampshire, Mrs. DAVIS of California, Mr. ROSE of New York, Mr. POCAN, Mr. RUPPERSBERGER, Mrs. HAYES, Mr. MARCHANT, Mr. STIVERS, Mr. KELLY of Pennsylvania, Mr. STAUBER, Mr. SIRES, Ms. SPANBERGER, Mr. YOUNG, Mr. COX of California, Mr. GARCÍA of Illinois, Mr. GOLDEN, Mr. RESCHENTHALER, Mr. RASKIN, Ms. BROWNLEY of California, Ms. SHERRILL, Ms. WILD, Ms. JUDY CHU of California, Mr. DAVID P. ROE of Tennessee, Mr. BROWN of Maryland, Mr. MCKINLEY, Mr. COLE, Mr. LEVIN of Michigan, Mr. CLAY, Ms. MUCARSEL-POWELL, Mr. COURTNEY, Mr. LAMBORN, Ms. HAALAND, Mr. CORREA, Mr. COOPER, Ms. CLARKE of New York, Mrs. RODGERS of Washington, Mr. DEFazio, Mr. GRIJALVA, Mrs. WATSON COLEMAN, Ms. CASTOR of Florida, Mr. BLUMENAUER, Mr. CONNOLLY, Ms. SCANLON, Mr. MORELLE, Miss RICE of New York, Ms. JOHNSON of Texas, Ms. OCASIO-CORTEZ, Mr. STEWART, Mr. HORSFORD, Mr. BOST, Ms. STEFANIK, Mr. COSTA, Ms. PINGREE, Mr. MALINOWSKI, Mrs. BEATTY, Mr. SWALWELL of California, Mrs. LEE of Nevada, Mrs. AXNE,

Mr. LAMB, Mr. THOMPSON of Mississippi, Mr. LOEBSACK, Ms. DELAURO, Mr. RODNEY DAVIS of Illinois, Mr. GALLEG0, Mr. SHIMKUS, Ms. PRESSLEY, Ms. TITUS, Mr. JOYCE of Ohio, Mr. CHABOT, Miss GONZÁLEZ-COLÓN of Puerto Rico, Mr. LARSON of Connecticut, Mr. JOYCE of Pennsylvania, Ms. JACKSON LEE, Ms. CRAIG, Mr. HURD of Texas, Ms. FINKENAUER, Ms. CLARK of Massachusetts, Mrs. DINGELL, Mrs. KIRKPATRICK, Mr. LUJÁN, Ms. BLUNT ROCHESTER, Mr. BUTTERFIELD, Mrs. MILLER, Mr. HECK, Mr. HARDER of California, Mr. ROUDA, Mrs. LAWRENCE, Mr. GREEN of Texas, Mr. COLLINS of New York, Mr. SCHWEIKERT, Mr. GIANFORTE, Mr. ENGEL, Mr. CÁRDENAS, Mr. TRONE, Mr. POSEY, Ms. LEE of California, Mrs. TRAHAN, Mr. RUSH, Mr. LATTÀ, Mr. UPTON, Mr. MCEACHIN, Mr. SOTO, Mr. SUOZZI, Mr. CARTER of Georgia, Mr. SPANO, Mr. TONKO, Mr. EMMER, Mr. LAWSON of Florida, Mr. CISNEROS, Mr. CARBAJAL, Mr. O'HALLERAN, Ms. OMAR, Mrs. BROOKS of Indiana, Mr. STEUBE, Mr. TED LIEU of California, Ms. ROYBAL-ALLARD, Mr. PHILLIPS, Ms. FUDGE, Ms. MCCOLLUM, Mr. GUTHRIE, Mr. PAPPAS, Mr. THOMPSON of Pennsylvania, Ms. UNDERWOOD, Mr. HUFFMAN, Ms. KAPTUR, Mr. MARSHALL, Mr. BARR, Ms. WEXTON, Ms. WASSERMAN SCHULTZ, Ms. SCHAKOWSKY, Mr. WALDEN, Mr. JOHNSON of South Dakota, Mr. HIMES, Mrs. LOWEY, Mr. ZELDIN, Mr. VAN DREW, Mr. NEGUSE, Mr. HAGEDORN, Ms. HERRERA BEUTLER, Mr. QUIGLEY, Mr. SABLÀN, Mr. GONZALEZ of Ohio, and Ms. KENDRA S. HORN of Oklahoma

JULY 23, 2019

Reported with amendments, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in italic]

[For text of introduced bill, see copy of bill as introduced on February 7, 2019]

A BILL

To reauthorize certain provisions of the Public Health Service Act 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”.*

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

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

13 *(1) in subsection (a)(1)—*

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

18 *(B) by striking the second sentence and in-*
 19 *serting the following: “Such research shall inves-*
 20 *tigate the causes (including possible environ-*
 21 *mental causes), diagnosis or ruling out, early*
 22 *and ongoing detection, prevention, services across*
 23 *the lifespan, supports, intervention, and treat-*
 24 *ment of autism spectrum disorder, including dis-*

1 *semination and implementation of clinical care,*
2 *supports, interventions, and treatments.”;*

3 *(2) in subsection (b)—*

4 *(A) in paragraph (2)—*

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

11 *(ii) in the third sentence, by striking*
12 *“neurobiology” and all that follows through*
13 *the period and inserting “neurobiology, ge-*
14 *netics, genomics, psychopharmacology, de-*
15 *velopmental psychology, behavioral psy-*
16 *chology, and clinical psychology.”; and*

17 *(B) in paragraph (3), by adding at the end*
18 *the following:*

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

1 *grants to applicants which meet the scientific*
 2 *criteria for funding under this section.”.*

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

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

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

10 *(2) in subsection (a)(2)—*

11 *(A) by striking “State and local public*
 12 *health officials” and inserting “State, local, and*
 13 *Tribal public health officials”;*

14 *(B) by striking “or other developmental dis-*
 15 *abilities” and inserting “and other develop-*
 16 *mental disabilities”;*

17 *(3) in subsection (a)(3), by striking “a univer-*
 18 *sity, or any other educational institution” and insert-*
 19 *ing “a university, any other educational institution,*
 20 *an Indian tribe, or a tribal organization”;*

21 *(4) in subsection (b)(2)(A), by striking “relevant*
 22 *State and local public health officials, private sector*
 23 *developmental disability researchers, and advocates*
 24 *for individuals with developmental disabilities” and*
 25 *inserting “State, local, and Tribal public health offi-*

cials, private sector developmental disability researchers, advocates for individuals with autism spectrum disorder, and advocates for individuals with other developmental disabilities”;

(5) in subsection (d)—

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

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

“(1) INDIAN TRIBE; TRIBAL ORGANIZATION.—The terms ‘Indian tribe’ and ‘tribal organization’ have the meanings given such terms in section 4 of the Indian Health Care Improvement Act.”; and

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

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

(1) in subsection (a)(1)—

(A) by striking “individuals with autism spectrum disorder or other developmental disabilities” and inserting “individuals with autism spectrum disorder and other developmental disabilities”; and

(B) by striking “children with autism spectrum disorder” and all that follows through “disabilities;” and inserting “individuals with autism spectrum disorder and other developmental disabilities across their lifespan;”;

(2) in subsection (b)—

(A) in paragraph (2), by inserting “individuals with” before “autism spectrum disorder”;

(B) by redesignating paragraphs (4) through (6) as paragraphs (5) through (7), respectively; and

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

“(4) promote evidence-based screening techniques and interventions for individuals with autism spectrum disorder and other developmental disabilities across their lifespan;”;

(3) in subsection (c)—

(A) in paragraph (1), in the matter preceding subparagraph (A), by striking “the needs of individuals with autism spectrum disorder or other developmental disabilities and their families” and inserting “the needs of individuals with autism spectrum disorder and other devel-

opmental disabilities across their lifespan and
the needs of their families”; and

(B) in paragraph (2)—

(i) in subparagraph (A)(ii), by striking “caregivers of individuals with an autism spectrum disorder” and inserting “caregivers of individuals with autism spectrum disorder or other developmental disabilities”;

(ii) in subparagraph (B)(i)(II), by inserting “autism spectrum disorder and” after “individuals with”; and

(iii) in subparagraph (B)(ii), by inserting “autism spectrum disorder and” after “individuals with”;

(4) in subsection (e)—

(A) in paragraph (1)—

(i) in the matter preceding subparagraph (A), by inserting “across their lifespan” before “and ensure”; and

(ii) in subparagraph (B)(iv), by inserting “across their lifespan” after “other developmental disabilities”;

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

1 (C) by inserting after paragraph (1) the fol-
 2 lowing:

3 “(2) *DEVELOPMENTAL-BEHAVIORAL PEDIATRI-*
 4 *CIAN TRAINING PROGRAMS.*—

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

10 “(B) *DEFINITION OF UNDERSERVED*
 11 *AREA.*—*In this paragraph, the term ‘underserved*
 12 *area’ means—*

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

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

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

22 (6) *in subsection (g), by striking “2019” and in-*
 23 *serting “2024”.*

1 (c) *INTERAGENCY AUTISM COORDINATING COM-*
2 *MITTEE.—Section 399CC of the Public Health Service Act*
3 *(42 U.S.C. 280i–2) is amended—*

4 (1) *in subsection (b)—*

5 (A) *in paragraph (2), by inserting “across*
6 *the lifespan of such individuals” before the semi-*
7 *colon; and*

8 (B) *in paragraph (5), by inserting “across*
9 *the lifespan of such individuals” before “and the*
10 *families”;*

11 (2) *in subsection (c)—*

12 (A) *in paragraph (1)(D), by inserting “, the*
13 *Department of Labor, the Department of Justice,*
14 *the Department of Veterans Affairs, the Depart-*
15 *ment of Housing and Urban Development,” after*
16 *“Department of Education”;*

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

21 (C) *in paragraph (3)(A), by striking “one*
22 *or more additional 4-year terms” and inserting*
23 *“one additional 4-year term”; and*

24 (3) *in subsection (f), by striking “2019” and in-*
25 *serting “2024”.*

1 (d) *REPORTS TO CONGRESS*.—Section 399DD of the
2 *Public Health Service Act* (42 U.S.C. 280i–3) is amended—

3 (1) in subsection (a)—

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

7 (B) in paragraph (2)—

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

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

15 (iii) in subparagraph (H), by striking
16 “; and” and inserting “;”;

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

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

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

1 (2) in subsection (b)—

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

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

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

17 (C) in paragraph (2)—

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

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

23 (ii) in subparagraph (B), by striking
24 “young adults” and all that follows through
25 the semicolon and inserting “the health and

1 *well-being of individuals with autism spec-*
2 *trum disorder, including an identification*
3 *of existing Federal laws, regulations, poli-*
4 *cies, research, and programs;” 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 to*
19 *public safety agencies or the criminal jus-*
20 *tice system for such individuals; and*

21 *“(E) recommendations that seek to improve*
22 *health outcomes for such individuals, including*
23 *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, elopement,
 6 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 (e) *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

1 (3) in subsection (c), by striking “there is au-
2 thorized to be appropriated \$190,000,000 for each of
3 fiscal years 2015 through 2019” and inserting “there
4 are authorized to be appropriated \$296,000,000 for
5 each of fiscal years 2020 through 2024”.

Amend the title so as to read: “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.”.

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