

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 (e)(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	(Λ) 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 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;"; and
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) in subsection (a), by striking "\$22,000,000
for each of fiscal years 2015 through 2019" and in-
serting "\$23,100,000 for each of fiscal years 2020
through 2024";

- (2) in subsection (b), by striking "\$48,000,000 for each of fiscal years 2015 through 2019" and inserting "\$50,599,000 for each of fiscal years 2020 through 2024"; and
- (3) in subsection (c), by striking "there is authorized to be appropriated \$190,000,000 for each of fiscal years 2015 through 2019" and inserting "there are authorized to be appropriated such sums as may be necessary for each of fiscal years 2020 through 2024".