118TH CONGRESS
2d Session
HOUSE OF REPRESENTATIVES
REPORT
118–620

AUTISM COLLABORATION, ACCOUNTABILITY, RESEARCH, EDUCATION, AND SUPPORT ACT OF 2024

JULY 30, 2024.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

Mrs. RODGERS of Washington, from the Committee on Energy and Commerce, submitted the following

REPORT

[To accompany H.R. 7213]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 7213) 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/reauthorize certain programs with respect to autism spectrum disorder?❳, and for other purposes, having considered the same, reports favorably thereon with amendments and recommends that the bill as amended do pass.

CONTENTS

The amendments are as follows:

Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

This Act may be cited as the "Autism Collaboration, Accountability, Research, Education, and Support Act of 2024" or the "Autism CARES Act of 2024".

SEC. 2. NATIONAL INSTITUTES OF HEALTH ACTIVITIES.

(a) EXPANSION OF ACTIVITIES.—Paragraph (1) of section 409C(a) of the Public Health Service Act (42 U.S.C. 284g(a)) is amended to read as follows:

"(1) EXPANSION OF ACTIVITIES.—The Director of NIH (in this section referred to as the 'Director'), in coordination and consultation with the Administrator of the Administration for Community Living, and other agencies as appropriate, shall—

"(A) subject to the availability of appropriations, expand, intensify, and coordinate the activities of the National Institutes of Health with respect to research on autism spectrum disorder, including—

"(i) basic and clinical research in fields including pathology, developmental neurobiology, genetics, epigenetics, pharmacology, nutrition, immunology, neuroimmunology, neurobehavioral development, endocrinology, gastroenterology, toxicology, speech, language and hearing science, psychiatry, psychology, developmental behavioral pediatrics, and gerontology; and

"(ii) research on interventions to maximize outcomes for individuals with autism spectrum disorder; and

"(B) ensure that research referred to in subparagraph (A)—

"(i) investigates the causes (including possible environmental causes), diagnosis or ruling out, early and ongoing detection, prevention, intervention, services, supports across the lifespan for autistic individuals and caregivers, and treatment for autism spectrum disorder and co-occurring conditions, including dissemination and implementation of clinical care, supports, interventions, and treatments; and

"(ii) reflects the entire population of individuals with autism spectrum disorder, including the full range of cognitive, communicative, behavioral, and adaptive functioning, as well as co-occurring conditions and needs for support and services, including care necessary for physical safety.".

(b) CENTERS OF EXCELLENCE.—Section 409C(b) of the Public Health Service Act (42 U.S.C. 284g(b)) is amended—

(1) in paragraph (2)—

(A) by striking "prevention, and treatment" and inserting "prevention, services, and treatment";

(B) by striking "including the fields" and inserting "including in the fields"; and

(C) by striking "behavioral psychology, and clinical psychology" and inserting "behavioral psychology, clinical psychology, and gerontology";

(2) in paragraph (5)(A), by striking "not less than five centers" and inserting "not fewer than six centers"; and

(3) in paragraph (5)(B), by striking "period of not to exceed" and inserting "period not to exceed".

(c) PUBLIC INPUT.—Section 409C(d) of the Public Health Service Act (42 U.S.C. 284g(d)) is amended to read as follows:

"(d) PUBLIC INPUT.—

"(1) IN GENERAL.—The Director shall under subsection (a)(1) provide for means through which the public can obtain information on the existing and planned programs and activities of the National Institutes of Health with respect to autism spectrum disorder and through which the Director can receive comments from the public regarding such programs and activities.

"(2) OPPORTUNITIES.—Such public input opportunities may include encouraging the centers under subsection (b)(1) to establish an external advisory board or adopting a comprehensive plan to ensure individuals with various backgrounds and perspectives are represented, among other activities. Such opportunities should consider including, as appropriate, individuals, family members, and caregivers of individuals with autism spectrum disorder who represent the entire population of individuals with autism spectrum disorder, including the full range of cognitive, communicative, behavioral, and adaptive functioning, to better inform research findings and future studies.".

SEC. 3. PROGRAMS RELATING TO AUTISM.

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

(1) in subsection (b)(1), by striking "and causes" and inserting "causes, and life course"; and

(2) in subsection (e), by striking “2024” and inserting “2029”.

(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)(2), by striking “subsequent interventions” and inserting “subsequent interventions and services”;

(2) in subsection (b)(1), by striking “culturally competent information” and inserting “culturally and linguistically responsive information”;

(3) in subsection (b)(2)—

(A) by striking “promote research” and inserting “promote research, which may include community-based participatory research,”; and

(B) by striking “screening tools” each place it appears and inserting “screening and diagnostic tools”;

(4) in subsection (b)(3), by striking “at higher risk” and inserting “at increased likelihood”;

(5) in subsection (b)(4), by inserting “, which may include such individuals utilizing parents and guardians trained to provide interventions, services, and supports” before the semicolon at the end;

(6) in subsection (c)(1), by striking “culturally competent information” and inserting “culturally and linguistically responsive information”;

(7) in subsection (c)(2)(A)(ii)—

(A) by striking “advocates,” and inserting “advocates, self-advocates,”; and

(B) by striking “culturally competent information” and inserting “culturally and linguistically responsive information”;

(8) by amending paragraph (1) of subsection (e) to read as follows:

“(1) TRAINING.—The Secretary, in coordination with activities conducted under title V of the Social Security Act, shall, subject to the availability of appropriations, strengthen the capacity of existing training programs and expand existing interdisciplinary training opportunities or opportunities to increase the number of programs that address the health and well-being of individuals who have or are at increased likelihood for autism spectrum disorder and other neurodevelopmental disabilities across their lifespan. Activities under the preceding sentence shall include—

“(A) awarding competitive grants or cooperative agreements to public or nonprofit agencies, including institutions of higher education, to expand existing or develop new maternal and child health interdisciplinary leadership education in neurodevelopmental and related disabilities programs (similar to the programs developed under section 501(a)(2) of the Social Security Act) in States that do not have such a program;

“(B) ensuring that trainees under such training programs—

“(i) receive an appropriate balance of academic, clinical, and community opportunities;

“(ii) are culturally and linguistically responsive;

“(iii) are from various backgrounds;

“(iv) demonstrate a capacity to evaluate, diagnose or rule out, develop, and provide evidence-based interventions and programs to individuals with autism spectrum disorder and other developmental disabilities across their lifespan; and

“(v) demonstrate an ability to use a person- and family-centered approach, which may include collaborating with research centers or networks to provide training for providers of respite care (as defined in section 2901);

“(C) ensuring that program sites provide culturally and linguistically responsive services; and

“(D) encouraging training programs to partner with appropriate entities to build community capacity.”;

(9) in subsection (e)(2), by adding at the end the following new subparagraph:

“(C) REPORT.—Not later than 2 years after September 30, 2024, the Comptroller General of the United States shall prepare and submit to the Committee on Energy and Commerce of the House of Representatives and the Committee on Health, Education, Labor, and Pensions of the Senate a report examining how to increase the number of developmental-behavioral pediatricians, including through the developmental behavioral pediatrician training program.”;

(10) in subsection (f)—

(A) by striking “promote research” and inserting “promote research, including community-based participatory research,”;

(B) by striking “physical and behavioral health of individuals” and inserting “physical and behavioral health, and communication needs, of individuals”; and

(C) by striking “disseminate information related to such research and guidelines” and inserting “disseminate information relating to such research and guidelines to improve the quality of life and long-term outcomes”; and

(11) in subsection (g), by striking “2024” and inserting “2029”.

(c) INTERAGENCY AUTISM COORDINATING COMMITTEE.—Section 399CC of the Public Health Service Act (42 U.S.C. 280i–2) is amended—

(1) in subsection (b)—

(A) in paragraph (2), by striking “develop a summary” and inserting “develop and update a summary”;

(B) in paragraphs (3) and (4), by striking “make recommendations” and inserting “make and update recommendations”; and

(C) by striking paragraphs (5) and (6) and inserting the following:

“(5) develop and update a strategic plan for the conduct of, and support for, autism spectrum disorder research, including as practicable for services and supports, for individuals with an autism spectrum disorder across the lifespan of such individuals and the families of such individuals, and across the entire population of individuals with autism spectrum disorder, including the full range of cognitive, communicative, behavioral, and adaptive functioning, as well as co-occurring conditions and needs for support and services, including care necessary for physical safety, which such plan shall include proposed budgetary requirements and recommendations to ensure that autism spectrum disorder research, and services and support activities to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies are not unnecessarily duplicative; and

“(6) submit to the Congress and President—

“(A) an annual update on the summary of advances described in paragraph (2); and

“(B) each update to the strategic plan described in paragraph (5), including any steps that have already been taken to implement the recommendations in such updated strategic plan and progress made in achieving the goals outlined in such updated strategic plan.”; and

(2) in subsection (f), by striking “2024” and inserting “2029”.

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

(1) by striking “Autism CARES Act of 2019” each place it appears and inserting “Autism CARES Act of 2024”;

(2) in subsection (a), by amending paragraph (1) to read as follows:

“(1) IN GENERAL.—Not later than 4 years after September 30, 2024, the Secretary, in consultation and coordination with other Federal departments and agencies that serve individuals with autism spectrum disorder, shall prepare and submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives, and make publicly available, including through posting on the internet website of the Department of Health and Human Services, a progress report on activities related to autism spectrum disorder and other developmental disabilities. Such report shall include activities and research related to the entire population of individuals with autism spectrum disorder, including the full range of cognitive, communicative, behavioral, and adaptive functioning, as well as co-occurring conditions and needs for support and services, including care necessary for physical safety.”; and

(3) by adding at the end the following:

“(c) UPDATE ON YOUNG ADULTS AND YOUTH TRANSITIONING TO ADULTHOOD.—Not later than 2 years after the date of enactment of the Autism CARES Act of 2024, the Secretary, in coordination with other Federal departments and agencies that serve individuals with autism spectrum disorder, shall prepare and submit to the Committee on Energy and Commerce of the House of Representatives and the Committee on Health, Education, Labor, and Pensions of the Senate an update to the report required pursuant to section 6 of the Autism Cares Act of 2014 (Public Law 113–157) concerning young adults with autism spectrum disorder and the challenges related to the transition from existing school-based services to those services available during adulthood.

“(d) PROFESSIONAL JUDGMENT BUDGET.—For each fiscal year through fiscal year 2029, the Director of the National Institutes of Health, in coordination with other relevant agencies, as appropriate, shall prepare and submit, directly to the President for review and transmittal to Congress, after reasonable opportunity for comment, but without change, by the Secretary and the Interagency Autism Coordinating Committee established under section 399CC(a), an annual budget estimate for carrying out the strategic plan developed and updated under section 399CC(b)(5).".

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

(1) in subsection (a), by striking "$23,100,000 for each of fiscal years 2020 through 2024" and inserting "$28,100,000 for each of fiscal years 2025 through 2029";

(2) in subsection (b), by striking "$50,599,000 for each of fiscal years 2020 through 2024" and inserting "$56,344,000 for each of fiscal years 2025 through 2029"; and

(3) in subsection (c), by striking "there are authorized to be appropriated $296,000,000 for each of fiscal years 2020 through 2024" and inserting "there is authorized to be appropriated $341,000,000 for each of fiscal years 2025 through 2029".

Amend the title so as to read:

A bill to amend the Public Health Service Act to enhance and reauthorize activities and programs relating to autism spectrum disorder, and for other purposes.

PURPOSE AND SUMMARY

The Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024 reauthorizes and makes improvements to certain programs related to autism spectrum disorder, including the Developmental Disabilities Surveillance and Research Program; Autism education, early detection, and intervention; and the Interagency Autism Coordination Committee at currently appropriated levels for fiscal years 2025 through 2029.

BACKGROUND AND NEED FOR LEGISLATION

Autism affects an estimated 1 in 36 children in the United States.[1] Behavioral signs of autism usually appear early in development, often as early as 12 to 18 months of age or earlier.[2] Research shows that early intervention and therapies lead to positive outcomes later in life for individuals with autism.[3]

First signed into law in 2006, the CARES Act funds programs to directly improve the quality of lives of individuals with Autism, their families, and their caregivers. The current authorization for these programs expires September 30, 2024.

H.R. 7213 would support and enhance existing programs related to autism spectrum disorder, including improving research coordination and research into evidence-based interventions, ensuring research is reflective of the entire population of individuals with autism spectrum disorder, continuing surveillance and early identification programs, and facilitating increased and robust opportunities for public input. The legislation also strengthens existing education and training programs for providers, and requires updated strategic plans and progress reports, as well as an annual budget plan to carry out such strategic planning.

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[1] Maenner MJ, Warren Z, Williams AR, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. MMWR Surveill Summ 2023;72 (No. SS–2):1–14. DOI:http://dx.doi.org/10.15585/mmwr.ss7202a1.

[2] "When do children usually show symptoms of autism?," *National Institutes of Health, Eunice Kennedy Shriver National Institute of Child Health and Human Development*, January 31, 2017, https://www.nichd.nih.gov/health/topics/autism/conditioninfo/symptoms-appear.

[3] "Autism spectrum disorder (ASD), What is autism?," *Autism Speaks*, https://www.autismspeaks.org/what-is-autism.

COMMITTEE ACTION

On February 14, 2024, the Subcommittee on Health held a hearing on H.R. 7213. The title of the hearing was "Legislative Proposals to Support Patients and Caregivers." The Subcommittee received testimony from:

- Andy Shih, PhD, Chief Science Officer, Autism Speaks;
- Corey Feist, JD, MBA, Co-Founder and CEO, Dr. Lorna Breen Heroes' Foundation;
- Joanne Pike, DrPH, President and CEO, Alzheimer's Association;
- Gordon Tomaselli, MD, Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emeritus and Professor of Medicine, Albert Einstein College of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine;
- Michelle Whitten, President, CEO, and Co-Founder, Global Down Syndrome Foundation;
- Randy Strozyk, President, American Ambulance Association; and
- Christina Annunziata, MD, PhD, Senior Vice President of Extramural Discovery Science, American Cancer Society.

On May 16, 2024, the Subcommittee on Health met in open markup session and forwarded H.R. 7213, as amended, to the full Committee by a record vote of 22 yeas to 0 nays.

On June 12, 2024, the full Committee on Energy and Commerce met in open markup session and ordered H.R. 7213, as amended, favorably reported to the House by a record vote of 42 yeas and 0 nays.

COMMITTEE VOTES

Clause 3(b) of rule XIII requires the Committee to list the record votes on the motion to report legislation and amendments thereto. The following reflects the record votes taken during the Committee consideration:

COMMITTEE ON ENERGY AND COMMERCE
118TH CONGRESS
ROLL CALL VOTE # 5

BILL: H.R. 7213, Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024

AMENDMENT: A motion by Chair Rodgers to order H.R. 7213 favorably reported to the House, as amended (Final Passage).

DISPOSITION: AGREED TO, by a recorded vote of 42 Yeas to 0 Nays.

REPRESENTATIVE	YEAS	NAYS	PRESENT	REPRESENTATIVE	YEAS	NAYS	PRESENT
Rep. Rodgers	X			Rep. Pallone	X		
Rep. Burgess	X			Rep. Eshoo	X		
Rep. Latta	X			Rep. DeGette	X		
Rep. Guthrie	X			Rep. Schakowsky	X		
Rep. Griffith	X			Rep. Matsui	X		
Rep. Bilirakis	X			Rep. Castor	X		
Rep. Bucshon	X			Rep. Sarbanes	X		
Rep. Hudson				Rep. Tonko	X		
Rep. Walberg	X			Rep. Clarke	X		
Rep. Carter	X			Rep. Cárdenas	X		
Rep. Duncan	X			Rep. Ruiz	X		
Rep. Palmer	X			Rep. Peters	X		
Rep. Dunn	X			Rep. Dingell	X		
Rep. Curtis				Rep. Veasey	X		
Rep. Lesko	X			Rep. Kuster	X		
Rep. Pence	X			Rep. Kelly	X		
Rep. Crenshaw				Rep. Barragán			
Rep. Joyce	X			Rep. Blunt Rochester			
Rep. Armstrong				Rep. Soto	X		
Rep. Weber	X			Rep. Craig			
Rep. Allen	X			Rep. Schrier	X		
Rep. Balderson	X			Rep. Trahan	X		
Rep. Fulcher				Rep. Fletcher	X		
Rep. Pfluger							
Rep. Harshbarger	X						
Rep. Miller-Meeks							
Rep. Cammack	X						
Rep. Obernolte	X						
Rep. James	X						

06/12/2024

OVERSIGHT FINDINGS AND RECOMMENDATIONS

Pursuant to clause 2(b)(1) of rule X and clause 3(c)(1) of rule XIII, the Committee held a hearing and made findings that are reflected in this report.

NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

Pursuant to clause 3(c)(2) of rule XIII, the Committee finds that H.R. 7213 would result in no new or increased budget authority, entitlement authority, or tax expenditures or revenues.

CONGRESSIONAL BUDGET OFFICE ESTIMATE

Pursuant to clause 3(c)(3) of rule XIII, at the time this report was filed, the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974 was not available.

FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

Pursuant to clause 3(c)(4) of rule XIII, the general performance goal or objective of this legislation is to reauthorize and make improvements to activities and programs relating to autism spectrum disorder.

DUPLICATION OF FEDERAL PROGRAMS

Pursuant to clause 3(c)(5) of rule XIII, no provision of H.R. 7213 is known to be duplicative of another Federal program, including any program that was included in a report to Congress pursuant to section 21 of Public Law 111–139 or the most recent Catalog of Federal Domestic Assistance.

RELATED COMMITTEE AND SUBCOMMITTEE HEARINGS

Pursuant to clause 3(c)(6) of rule XIII, the following related hearing was used to develop or consider H.R. 7213:

- On February 14, 2024, the Subcommittee on Health held a hearing on H.R. 7213. The title of the hearing was "Legislative Proposals to Support Patients and Caregivers." The Subcommittee received testimony from:
    - ○ Andy Shih, PhD, Chief Science Officer, Autism Speaks;
    - ○ Corey Feist, JD, MBA, Co-Founder and CEO, Dr. Lorna Breen Heroes' Foundation;
    - ○ Joanne Pike, DrPH, President and CEO, Alzheimer's Association;
    - ○ Gordon Tomaselli, MD, Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emeritus and Professor of Medicine, Albert Einstein Col-

lege of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine;

- ○ Michelle Whitten, President, CEO, and Co-Founder, Global Down Syndrome Foundation;
- ○ Randy Strozyk, President, American Ambulance Association; and
- ○ Christina Annunziata, MD, PhD, Senior Vice President of Extramural Discovery Science, American Cancer Society.

COMMITTEE COST ESTIMATE

Pursuant to clause 3(d)(1) of rule XIII, the Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974. At the time this report was filed, the estimate was not available.

EARMARK, LIMITED TAX BENEFITS, AND LIMITED TARIFF BENEFITS

Pursuant to clause 9(e), 9(f), and 9(g) of rule XXI, the Committee finds that H.R. 7213 contains no earmarks, limited tax benefits, or limited tariff benefits.

ADVISORY COMMITTEE STATEMENT

No advisory committees within the meaning of section 5(b) of the Federal Advisory Committee Act were created by this legislation.

APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

Section 1. Short title

Section 1 provides that the Act may be cited as the "Autism Collaboration, Accountability, Research, Education, and Support Act of 2024," or the "Autism CARES Act of 2024".

Section 2. National Institutes of Health activities

Section 2 expands and improves coordination of research related to autism spectrum disorder within the National Institutes of Health (NIH), including by ensuring such research reflects the entire population of individuals with autism spectrum disorder, and is informed by opportunities for public input. This section also increases the minimum number of currently existing centers of excellence from five to six.

Section 3. Programs relating to autism

Section 3 enhances existing education, early detection, and intervention training efforts by including parents and guardians as eligible participants and ensuring such efforts will appropriately serve patients with autism spectrum disorder. This section also requires the Interagency Autism Coordinating Committee (IACC) to develop updated strategic plans and reports, including progress made to implement the recommendations and strategies. In addition, this section requires a professional judgment budget for carrying out the strategic plan.

CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italics, and existing law in which no change is proposed is shown in roman):

PUBLIC HEALTH SERVICE ACT

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TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE

* * * * * * *

PART R—PROGRAMS RELATING TO AUTISM

SEC. 399AA. DEVELOPMENTAL DISABILITIES SURVEILLANCE AND RESEARCH PROGRAM.

(a) AUTISM SPECTRUM DISORDER AND OTHER DEVELOPMENTAL DISABILITIES.—

(1) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, may award grants or cooperative agreements to eligible entities for the collection, analysis, and reporting of State epidemiological data for children and adults with autism spectrum disorder and other developmental disabilities. An eligible entity shall assist with the development and coordination of State autism spectrum disorder and other developmental disability surveillance efforts within a region. In making such awards, the Secretary may provide direct technical assistance in lieu of cash.

(2) DATA STANDARDS.—In submitting epidemiological data to the Secretary pursuant to paragraph (1), an eligible entity shall report data according to guidelines prescribed by the Director of the Centers for Disease Control and Prevention, after consultation with relevant State, local, and Tribal public health officials, private sector developmental disability researchers, and advocates for individuals with autism spectrum disorder and other developmental disabilities.

(3) ELIGIBILITY.—To be eligible to receive an award under paragraph (1), an entity shall be a public or nonprofit private entity (including a health department of a State or a political subdivision of a State, a university, any other educational institution, an Indian tribe, or a tribal organization), and submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require.

(b) CENTERS OF EXCELLENCE IN AUTISM SPECTRUM DISORDER EPIDEMIOLOGY.—

(1) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall, subject to the availability of appropriations, award grants or cooperative agreements for the establishment or support of regional centers of excellence in autism spectrum disorder and other developmental disabilities epidemiology for the purpose of collecting and analyzing information on the number, incidence, correlates, ⟦and causes⟧ *causes, and life course* of autism spectrum disorder and other developmental disabilities for children and adults.

(2) REQUIREMENTS.—To be eligible to receive a grant or cooperative agreement under paragraph (1), an entity shall submit to the Secretary an application containing such agreements and information as the Secretary may require, including an agreement that the center to be established or supported under the grant or cooperative agreement shall operate in accordance with the following:

(A) The center will collect, analyze, and report autism spectrum disorder and other developmental disability data according to guidelines prescribed by the Director of the Centers for Disease Control and Prevention, after consultation with State, local, and Tribal public health officials, private sector developmental disability researchers, advocates for individuals with autism spectrum disorder, and advocates for individuals with other developmental disabilities.

(B) The center will develop or extend an area of special research expertise (including genetics, epigenetics, and epidemiological research related to environmental exposures), immunology, and other relevant research specialty areas.

(C) The center will identify eligible cases and controls through its surveillance system and conduct research into factors which may cause or increase the risk of autism spectrum disorder and other developmental disabilities.

(c) FEDERAL RESPONSE.—The Secretary shall coordinate the Federal response to requests for assistance from State health, mental health, and education department officials regarding potential or alleged autism spectrum disorder or developmental disability clusters.

(d) DEFINITIONS.—In this part:

(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.

(2) OTHER DEVELOPMENTAL DISABILITIES.—The term “other developmental disabilities” has the meaning given the term “developmental disability” in section 102(8) of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 U.S.C. 15002(8)).

(3) STATE.—The term “State” means each of the several States, the District of Columbia, the Commonwealth of Puerto Rico, American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, the Virgin Islands, and the Trust Territory of the Pacific Islands.

(e) SUNSET.—This section shall not apply after September 30, ⟦2024⟧ *2029*.

SEC. 399BB. AUTISM EDUCATION, EARLY DETECTION, AND INTERVENTION.

(a) PURPOSE.—It is the purpose of this section—

(1) to increase awareness, reduce barriers to screening and diagnosis, promote evidence-based interventions for individuals with autism spectrum disorder and other developmental disabilities, and train professionals to utilize valid and reliable screening tools to diagnose or rule out and provide evidence-based interventions for individuals with autism spectrum disorder and other developmental disabilities across their lifespan; and

(2) to conduct activities under this section with a focus on an interdisciplinary approach (as defined in programs developed under section 501(a)(2) of the Social Security Act) that will also focus on specific issues for children who are not receiving an early diagnosis and ❲subsequent interventions❳ *subsequent interventions and services*.

(b) IN GENERAL.—The Secretary shall, subject to the availability of appropriations, establish and evaluate activities to—

(1) provide ❲culturally competent information❳ *culturally and linguistically responsive information* and education on autism spectrum disorder and other developmental disabilities to increase public awareness of developmental milestones;

(2) ❲promote research❳ *promote research, which may include community-based participatory research,* into the development and validation of reliable ❲screening tools❳ *screening and diagnostic tools* for individuals with autism spectrum disorder and other developmental disabilities and disseminate information regarding those ❲screening tools❳ *screening and diagnostic tools*;

(3) promote early screening of individuals ❲at higher risk❳ *at increased likelihood* for autism spectrum disorder and other developmental disabilities as early as practicable, given evidence-based screening techniques and interventions;

(4) promote evidence-based screening techniques and interventions for individuals with autism spectrum disorder and other developmental disabilities across their lifespan*, which may include such individuals utilizing parents and guardians trained to provide interventions, services, and supports*;

(5) increase the number of individuals who are able to confirm or rule out a diagnosis of autism spectrum disorder and other developmental disabilities;

(6) increase the number of individuals able to provide evidence-based interventions for individuals diagnosed with autism spectrum disorder or other developmental disabilities; and

(7) promote the use of evidence-based interventions for individuals at higher risk for autism spectrum disorder and other developmental disabilities as early as practicable.

(c) INFORMATION AND EDUCATION.—

(1) IN GENERAL.—In carrying out subsection (b)(1), the Secretary, in collaboration with the Secretary of Education and the Secretary of Agriculture, shall, subject to the availability of appropriations, provide ❲culturally competent information❳ *culturally and linguistically responsive information* regarding autism spectrum disorder and other developmental disabilities,

risk factors, characteristics, identification, diagnosis or rule out, and evidence-based interventions to meet the needs of individuals with autism spectrum disorder and other developmental disabilities across their lifespan and the needs of their families through—

(A) Federal programs, including—

(i) the Head Start program;

(ii) the Early Start program;

(iii) the Healthy Start program;

(iv) programs under the Child Care and Development Block Grant Act of 1990;

(v) programs under title XIX of the Social Security Act (particularly the Medicaid Early and Periodic Screening, Diagnosis and Treatment Program);

(vi) the program under title XXI of the Social Security Act (the State Children's Health Insurance Program);

(vii) the program under title V of the Social Security Act (the Maternal and Child Health Block Grant Program);

(viii) the program under parts B and C of the Individuals with Disabilities Education Act;

(ix) the special supplemental nutrition program for women, infants, and children established under section 17 of the Child Nutrition Act of 1966 (42 U.S.C. 1786); and

(x) the State grant program under the Rehabilitation Act of 1973.

(B) State licensed child care facilities; and

(C) other community-based organizations or points of entry for individuals with autism spectrum disorder and other developmental disabilities to receive services.

(2) LEAD AGENCY.—

(A) DESIGNATION.—As a condition on the provision of assistance or the conduct of activities under this section with respect to a State, the Secretary may require the Governor of the State—

(i) to designate a public agency as a lead agency to coordinate the activities provided for under paragraph (1) in the State at the State level; and

(ii) acting through such lead agency, to make available to individuals and their family members, guardians, ⟦advocates,⟧ *advocates, self-advocates,* or authorized representatives; providers; and other appropriate individuals in the State, comprehensive ⟦culturally competent information⟧ *culturally and linguistically responsive information* about State and local resources regarding autism spectrum disorder and other developmental disabilities, risk factors, characteristics, identification, diagnosis or rule out, available services and supports (which may include respite care for caregivers of individuals with autism spectrum disorder or other developmental disabilities), and evidence-based interventions.

(B) REQUIREMENTS OF AGENCY.—In designating the lead agency under subparagraph (A)(i), the Governor shall—

(i) select an agency that has demonstrated experience and expertise in—

(I) autism spectrum disorder and other developmental disability issues; and

(II) developing, implementing, conducting, and administering programs and delivering education, information, and referral services (including technology-based curriculum-development services) to individuals with autism spectrum disorder and developmental disabilities and their family members, guardians, advocates or authorized representatives, providers, and other appropriate individuals locally and across the State; and

(ii) consider input from individuals with autism spectrum disorder and developmental disabilities and their family members, guardians, advocates or authorized representatives, providers, and other appropriate individuals.

(C) INFORMATION.—Information under subparagraph (A)(ii) shall be provided through—

(i) toll-free telephone numbers;

(ii) Internet websites;

(iii) mailings; or

(iv) such other means as the Governor may require.

(d) TOOLS.—

(1) IN GENERAL.—To promote the use of valid and reliable screening tools for autism spectrum disorder and other developmental disabilities, the Secretary shall develop a curriculum for continuing education to assist individuals in recognizing the need for valid and reliable screening tools and the use of such tools.

(2) COLLECTION, STORAGE, COORDINATION, AND AVAILABILITY.—The Secretary, in collaboration with the Secretary of Education, shall provide for the collection, storage, coordination, and public availability of tools described in paragraph (1), educational materials and other products that are used by the Federal programs referred to in subsection (c)(1)(A), as well as—

(A) programs authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000;

(B) early intervention programs or interagency coordinating councils authorized under part C of the Individuals with Disabilities Education Act; and

(C) children with special health care needs programs authorized under title V of the Social Security Act.

(3) REQUIRED SHARING.—In establishing mechanisms and entities under this subsection, the Secretary, and the Secretary of Education, shall ensure the sharing of tools, materials, and products developed under this subsection among entities receiving funding under this section.

(e) DIAGNOSIS.—

[(1) TRAINING.—The Secretary, in coordination with activities conducted under title V of the Social Security Act, shall, subject to the availability of appropriations, expand existing interdisciplinary training opportunities or opportunities to increase the number of sites able to diagnose or rule out individuals with autism spectrum disorder or other developmental disabilities across their lifespan and ensure that—

[(A) competitive grants or cooperative agreements are awarded to public or nonprofit agencies, including institutions of higher education, to expand existing or develop new maternal and child health interdisciplinary leadership education in neurodevelopmental and related disabilities programs (similar to the programs developed under section 501(a)(2) of the Social Security Act) in States that do not have such a program;

[(B) trainees under such training programs—

[(i) receive an appropriate balance of academic, clinical, and community opportunities;

[(ii) are culturally competent;

[(iii) are ethnically diverse;

[(iv) demonstrate a capacity to evaluate, diagnose or rule out, develop, and provide evidence-based interventions to individuals with autism spectrum disorder and other developmental disabilities across their lifespan; and

[(v) demonstrate an ability to use a family-centered approach, which may include collaborating with research centers or networks to provide training for providers of respite care (as defined in section 2901); and

[(C) program sites provide culturally competent services.]

(1) TRAINING.—The Secretary, in coordination with activities conducted under title V of the Social Security Act, shall, subject to the availability of appropriations, strengthen the capacity of existing training programs and expand existing interdisciplinary training opportunities or opportunities to increase the number of programs that address the health and well-being of individuals who have or are at increased likelihood for autism spectrum disorder and other neurodevelopmental disabilities across their lifespan. Activities under the preceding sentence shall include—

(A) awarding competitive grants or cooperative agreements to public or nonprofit agencies, including institutions of higher education, to expand existing or develop new maternal and child health interdisciplinary leadership education in neurodevelopmental and related disabilities programs (similar to the programs developed under section 501(a)(2) of the Social Security Act) in States that do not have such a program;

(B) ensuring that trainees under such training programs—

(i) receive an appropriate balance of academic, clinical, and community opportunities;

(ii) are culturally and linguistically responsive;

(iii) are from various backgrounds;

(iv) demonstrate a capacity to evaluate, diagnose or rule out, develop, and provide evidence-based interven-

tions and programs to individuals with autism spectrum disorder and other developmental disabilities across their lifespan; and

(v) demonstrate an ability to use a person- and family-centered approach, which may include collaborating with research centers or networks to provide training for providers of respite care (as defined in section 2901);

(C) ensuring that program sites provide culturally and linguistically responsive services; and

(D) encouraging training programs to partner with appropriate entities to build community capacity.

(2) DEVELOPMENTAL-BEHAVIORAL PEDIATRICIAN TRAINING PROGRAMS.—

(A) IN GENERAL.—In making awards under this subsection, the Secretary may prioritize awards to applicants that are developmental-behavioral pediatrician training programs located in rural or underserved areas.

(B) DEFINITION OF UNDERSERVED AREA.—In this paragraph, the term “underserved area” means—

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

(ii) an urban or rural area designated by the Secretary as an area with a shortage of personal health services (as described in section 330(b)(3)(A)).

(C) REPORT.—Not later than 2 years after September 30, 2024, the Comptroller General of the United States shall prepare and submit to the Committee on Energy and Commerce of the House of Representatives and the Committee on Health, Education, Labor, and Pensions of the Senate a report examining how to increase the number of developmental-behavioral pediatricians, including through the developmental behavioral pediatrician training program.

(3) TECHNICAL ASSISTANCE.—The Secretary may award one or more grants under this section to provide technical assistance to the network of interdisciplinary training programs.

(4) BEST PRACTICES.—The Secretary shall promote research into additional valid and reliable tools for shortening the time required to confirm or rule out a diagnosis of autism spectrum disorder or other developmental disabilities and detecting individuals with autism spectrum disorder or other developmental disabilities at an earlier age.

(f) INTERVENTION.—The Secretary shall [promote research] *promote research, including community-based participatory research,*, through grants or contracts, which may include grants or contracts to research centers or networks, to determine the evidence-based practices for interventions to improve the [physical and behavioral health of individuals] *physical and behavioral health, and communication needs, of individuals* with autism spectrum disorder or other developmental disabilities across the lifespan of such individuals, develop guidelines for those interventions, and [disseminate information related to such research and guidelines] *disseminate information relating to such research and guidelines to improve the quality of life and long-term outcomes*.

(g) SUNSET.—This section shall not apply after September 30, [2024] *2029*.

SEC. 399CC. INTERAGENCY AUTISM COORDINATING COMMITTEE.

(a) ESTABLISHMENT.—The Secretary shall establish a committee, to be known as the “Interagency Autism Coordinating Committee” (in this section referred to as the “Committee”), to coordinate all efforts within the Department of Health and Human Services concerning autism spectrum disorder.

(b) RESPONSIBILITIES.—In carrying out its duties under this section, the Committee shall—

(1) monitor autism spectrum disorder research, and to the extent practicable services and support activities, across all relevant Federal departments and agencies, including coordination of Federal activities with respect to autism spectrum disorder;

(2) [develop a summary] *develop and update a summary* of advances in autism spectrum disorder research related to causes, prevention, treatment, early screening, diagnosis or rule out, interventions, including school and community-based interventions, and access to services and supports for individuals with autism spectrum disorder across the lifespan of such individuals;

(3) [make recommendations] *make and update recommendations* to the Secretary regarding any appropriate changes to such activities, including with respect to the strategic plan developed under paragraph (5);

(4) [make recommendations] *make and update recommendations* to the Secretary regarding public participation in decisions relating to autism spectrum disorder, and the process by which public feedback can be better integrated into such decisions;

[(5) develop a strategic plan for the conduct of, and support for, autism spectrum disorder research, including as practicable for services and supports, for individuals with an autism spectrum disorder across the lifespan of such individuals and the families of such individuals, which shall include—

[(A) proposed budgetary requirements; and

[(B) recommendations to ensure that autism spectrum disorder research, and services and support activities to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies are not unnecessarily duplicative; and

[(6) submit to Congress and the President—

[(A) an annual update on the summary of advances described in paragraph (2); and

[(B) an annual update to the strategic plan described in paragraph (5), including any progress made in achieving the goals outlined in such strategic plan.]

(5) develop and update a strategic plan for the conduct of, and support for, autism spectrum disorder research, including as practicable for services and supports, for individuals with an autism spectrum disorder across the lifespan of such individuals and the families of such individuals, and across the entire population of individuals with autism spectrum disorder, including the full range of cognitive, communicative, behavioral,

and adaptive functioning, as well as co-occurring conditions and needs for support and services, including care necessary for physical safety, which such plan shall include proposed budgetary requirements and recommendations to ensure that autism spectrum disorder research, and services and support activities to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies are not unnecessarily duplicative; and

(6) submit to the Congress and President—

(A) an annual update on the summary of advances described in paragraph (2); and

(B) each update to the strategic plan described in paragraph (5), including any steps that have already been taken to implement the recommendations in such updated strategic plan and progress made in achieving the goals outlined in such updated strategic plan.

(c) MEMBERSHIP.—

(1) FEDERAL MEMBERSHIP.—The Committee shall be composed of the following Federal members—

(A) the Director of the Centers for Disease Control and Prevention;

(B) the Director of the National Institutes of Health, and the Directors of such national research institutes of the National Institutes of Health as the Secretary determines appropriate;

(C) the heads of such other agencies as the Secretary determines appropriate, such as the Administration for Community Living, Administration for Children and Families, the Centers for Medicare & Medicaid Services, the Food and Drug Administration, and the Health Resources and Services Administration; and

(D) representatives of other Federal Governmental agencies that serve individuals with autism spectrum disorder such as the Department of Education, the Department of Labor, the Department of Justice, the Department of Veterans Affairs, the Department of Housing and Urban Development, and the Department of Defense.

(2) NON-FEDERAL MEMBERS.—Not more than ½, but not fewer than ⅓, of the total membership of the Committee, shall be composed of non-Federal public members to be appointed by the Secretary, of which—

(A) at least three such members shall be individuals with a diagnosis of autism spectrum disorder;

(B) at least three such members shall be parents or legal guardians of an individual with an autism spectrum disorder; and

(C) at least three such members shall be representatives of leading research, advocacy, and service organizations for individuals with autism spectrum disorder.

(3) PERIOD OF APPOINTMENT; VACANCIES.—

(A) PERIOD OF APPOINTMENT FOR NON-FEDERAL MEMBERS.—Non-Federal members shall serve for a term of 4 years, and may be reappointed for one additional 4-year term.

(B) VACANCIES.—A vacancy on the Committee shall be filled in the manner in which the original appointment was made and shall not affect the powers or duties of the Committee. Any member appointed to fill a vacancy for an unexpired term shall be appointed for the remainder of such term. A member may serve after the expiration of the member's term until a successor has been appointed.

(d) ADMINISTRATIVE SUPPORT; TERMS OF SERVICE; OTHER PROVISIONS.—The following provisions shall apply with respect to the Committee:

(1) The Committee shall receive necessary and appropriate administrative support from the Secretary.

(2) The Committee shall meet at the call of the chairperson or upon the request of the Secretary. The Committee shall meet not fewer than 2 times each year.

(3) All meetings of the Committee shall be public and shall include appropriate time periods for questions and presentations by the public.

(e) SUBCOMMITTEES; ESTABLISHMENT AND MEMBERSHIP.—In carrying out its functions, the Committee may establish subcommittees and convene workshops and conferences. Such subcommittees shall be composed of Committee members and may hold such meetings as are necessary to enable the subcommittees to carry out their duties.

(f) SUNSET.—This section shall not apply after September 30, ⟦2024⟧ *2029*, and the Committee shall be terminated on such date.

SEC. 399DD. REPORTS TO CONGRESS.

(a) PROGRESS REPORT.—

⟦(1) IN GENERAL.—Not later than 4 years after the date of enactment of the Autism CARES Act of 2019, the Secretary, in coordination with the Secretary of Education and the Secretary of Defense, shall prepare and submit to the Health, Education, Labor, and Pensions Committee of the Senate and the Energy and Commerce Committee of the House of Representatives, and make publicly available, including through posting on the Internet Web site of the Department of Health and Human Services, a progress report on activities related to autism spectrum disorder and other developmental disabilities.⟧

(1) IN GENERAL.—Not later than 4 years after September 30, 2024, the Secretary, in consultation and coordination with other Federal departments and agencies that serve individuals with autism spectrum disorder, shall prepare and submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives, and make publicly available, including through posting on the internet website of the Department of Health and Human Services, a progress report on activities related to autism spectrum disorder and other developmental disabilities. Such report shall include activities and research related to the entire population of individuals with autism spectrum disorder, including the full range of cognitive, communicative, behavioral, and adaptive functioning, as well as co-occurring conditions and needs for support and services, including care necessary for physical safety.

(2) CONTENTS.—The report submitted under subsection (a) shall contain—

(A) a description of the progress made in implementing the provisions of the [Autism CARES Act of 2019] *Autism CARES Act of 2024*;

(B) a description of the amounts expended on the implementation of the amendments made by the [Autism CARES Act of 2019] *Autism CARES Act of 2024*;

(C) information on the incidence and prevalence of autism spectrum disorder, including available information on the prevalence of autism spectrum disorder among children and adults, and identification of any changes over time with respect to the incidence and prevalence of autism spectrum disorder;

(D) information on the average age of diagnosis for children with autism spectrum disorder and other disabilities, including how that age may have changed over the 4-year period beginning on the date of enactment of the [Autism CARES Act of 2019] *Autism CARES Act of 2024* and, as appropriate, how this age varies across population subgroups;

(E) information on the average age for intervention for individuals diagnosed with autism spectrum disorder and other developmental disabilities, including how that age may have changed over the 4-year period beginning on the date of enactment of the [Autism CARES Act of 2019] *Autism CARES Act of 2024* and, as appropriate, how this age varies across population subgroups;

(F) information on the average time between initial screening and then diagnosis or rule out for individuals with autism spectrum disorder or other developmental disabilities, as well as information on the average time between diagnosis and evidence-based intervention for individuals with autism spectrum disorder or other developmental disabilities and, as appropriate, on how such average time varies across population subgroups;

(G) information on the effectiveness and outcomes of interventions for individuals diagnosed with autism spectrum disorder, including by severity level as practicable, and other developmental disabilities and how the age of the individual or other factors, such as demographic characteristics, may affect such effectiveness;

(H) information on the effectiveness and outcomes of innovative and newly developed intervention strategies for individuals with autism spectrum disorder or other developmental disabilities;

(I) a description of the actions taken to implement and the progress made on implementation of the strategic plan developed by the Interagency Autism Coordinating Committee under section 399CC(b); and

(J) information on how States use home- and community-based services and other supports to ensure that individuals with autism spectrum disorder and other developmental disabilities are living, working, and participating in their community.

(b) REPORT ON THE HEALTH AND WELL-BEING OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDER ACROSS THEIR LIFESPAN.—

(1) IN GENERAL.—Not later than 2 years after the date of enactment of the [Autism CARES Act of 2019] *Autism CARES Act of 2024*, the Secretary shall prepare and submit, to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives, a report concerning the health and well-being of individuals with autism spectrum disorder.

(2) CONTENTS.—The report submitted under paragraph (1) shall contain—

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

(B) an overview of policies and programs relevant to the health and well-being of individuals with autism spectrum disorder, including an identification of existing Federal laws, regulations, policies, research, and programs;

(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

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

(E) recommendations that seek to improve health outcomes for such individuals, including across their lifespan, by addressing—

(i) screening and diagnosis of children and adults;

(ii) behavioral and other therapeutic approaches;

(iii) primary and preventative care;

(iv) communication challenges;

(v) aggression, self-injury, elopement, and other behavioral issues;

(vi) emergency room visits and acute care hospitalization;

(vii) treatment for co-occurring physical and mental health conditions;

(viii) premature mortality;

(ix) medical practitioner training; and

(x) caregiver mental health.

(c) UPDATE ON YOUNG ADULTS AND YOUTH TRANSITIONING TO ADULTHOOD.—Not later than 2 years after the date of enactment of the Autism CARES Act of 2024, the Secretary, in coordination with other Federal departments and agencies that serve individuals with autism spectrum disorder, shall prepare and submit to the Committee on Energy and Commerce of the House of Representatives and the Committee on Health, Education, Labor, and Pensions of the Senate an update to the report required pursuant to section 6 of the Autism Cares Act of 2014 (Public Law 113–157) concerning young adults with autism spectrum disorder and the challenges re-

lated to the transition from existing school-based services to those services available during adulthood.

(d) PROFESSIONAL JUDGMENT BUDGET.—For each fiscal year through fiscal year 2029, the Director of the National Institutes of Health, in coordination with other relevant agencies, as appropriate, shall prepare and submit, directly to the President for review and transmittal to Congress, after reasonable opportunity for comment, but without change, by the Secretary and the Interagency Autism Coordinating Committee established under section 399CC(a), an annual budget estimate for carrying out the strategic plan developed and updated under section 399CC(b)(5).

SEC. 399EE. AUTHORIZATION OF APPROPRIATIONS.

(a) DEVELOPMENTAL DISABILITIES SURVEILLANCE AND RESEARCH PROGRAM.—To carry out section 399AA, there is authorized to be appropriated ⟦$23,100,000 for each of fiscal years 2020 through 2024⟧ *$28,100,000 for each of fiscal years 2025 through 2029.*

(b) AUTISM EDUCATION, EARLY DETECTION, AND INTERVENTION.—To carry out section 399BB, there is authorized to be appropriated ⟦$50,599,000 for each of fiscal years 2020 through 2024⟧ *$56,344,000 for each of fiscal years 2025 through 2029.*

(c) INTERAGENCY AUTISM COORDINATING COMMITTEE; CERTAIN OTHER PROGRAMS.—To carry out sections 399CC and 409C, ⟦there are authorized to be appropriated $296,000,000 for each of fiscal years 2020 through 2024⟧ *there is authorized to be appropriated $341,000,000 for each of fiscal years 2025 through 2029.*

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TITLE IV—NATIONAL RESEARCH INSTITUTES

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PART B—GENERAL PROVISIONS RESPECTING NATIONAL RESEARCH INSTITUTES

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SEC. 409C. (a) IN GENERAL.—

⟦(1) EXPANSION OF ACTIVITIES.—The Director of NIH (in this section referred to as the "Director") shall, subject to the availability of appropriations, expand, intensify, and coordinate the activities of the National Institutes of Health with respect to research on autism spectrum disorder, including basic and clinical research in fields including pathology, developmental neurobiology, genetics, epigenetics, pharmacology, nutrition, immunology, neuroimmunology, neurobehavioral development, endocrinology, gastroenterology, toxicology, and interventions to maximize outcomes for individuals with autism spectrum disorder. Such research shall investigate the causes (including possible environmental causes), diagnosis or ruling out, early and ongoing detection, prevention, services across the lifespan, supports, intervention, and treatment of autism spectrum disorder, including dissemination and implementation of clinical care, supports, interventions, and treatments.⟧

(1) EXPANSION OF ACTIVITIES.—The Director of NIH (in this section referred to as the "Director"), in coordination and con-

sultation with the Administrator of the Administration for Community Living, and other agencies as appropriate, shall—

(A) subject to the availability of appropriations, expand, intensify, and coordinate the activities of the National Institutes of Health with respect to research on autism spectrum disorder, including—

(i) basic and clinical research in fields including pathology, developmental neurobiology, genetics, epigenetics, pharmacology, nutrition, immunology, neuroimmunology, neurobehavioral development, endocrinology, gastroenterology, toxicology, speech, language and hearing science, psychiatry, psychology, developmental behavioral pediatrics, and gerontology; and

(ii) research on interventions to maximize outcomes for individuals with autism spectrum disorder; and

(B) ensure that research referred to in subparagraph (A)—

(i) investigates the causes (including possible environmental causes), diagnosis or ruling out, early and ongoing detection, prevention, intervention, services, supports across the lifespan for autistic individuals and caregivers, and treatment for autism spectrum disorder and co-occurring conditions, including dissemination and implementation of clinical care, supports, interventions, and treatments; and

(ii) reflects the entire population of individuals with autism spectrum disorder, including the full range of cognitive, communicative, behavioral, and adaptive functioning, as well as co-occurring conditions and needs for support and services, including care necessary for physical safety.

(2) CONSOLIDATION.—The Director may consolidate program activities under this section if such consolidation would improve program efficiencies and outcomes.

(3) ADMINISTRATION OF PROGRAM; COLLABORATION AMONG AGENCIES.—The Director shall carry out this section acting through the Director of the National Institute of Mental Health and in collaboration with any other agencies that the Director determines appropriate.

(b) CENTERS OF EXCELLENCE.—

(1) IN GENERAL.—The Director shall under subsection (a)(1) make awards of grants and contracts to public or nonprofit private entities to pay all or part of the cost of planning, establishing, improving, and providing basic operating support for centers of excellence regarding research on autism spectrum disorder.

(2) RESEARCH.—Each center under paragraph (1) shall conduct basic and clinical research into autism spectrum disorder. Such research should include investigations into the causes, diagnosis, early and ongoing detection, [prevention, and treatment] *prevention, services, and treatment* of autism spectrum disorder across the lifespan. The centers, as a group, shall conduct research [including the fields] *including in the fields* of developmental neurobiology, genetics, genomics,

psychopharmacology, developmental psychology, [behavioral psychology, and clinical psychology] *behavioral psychology, clinical psychology, and gerontology*.

(3) SERVICES FOR PATIENTS.—

(A) IN GENERAL.—A center under paragraph (1) may expend amounts provided under such paragraph to carry out a program to make individuals aware of opportunities to participate as subjects in research conducted by the centers.

(B) REFERRALS AND COSTS.—A program under subparagraph (A) may, in accordance with such criteria as the Director may establish, provide to the subjects described in such subparagraph, referrals for health and other services, and such patient care costs as are required for research.

(C) AVAILABILITY AND ACCESS.—The extent to which a center can demonstrate availability and access to clinical services shall be considered by the Director in decisions about awarding grants to applicants which meet the scientific criteria for funding under this section.

(D) REDUCING DISPARITIES.—The Director may consider, as appropriate, the extent to which a center can demonstrate availability and access to clinical services for youth and adults from diverse racial, ethnic, geographic, or linguistic backgrounds in decisions about awarding grants to applicants which meet the scientific criteria for funding under this section.

(4) ORGANIZATION OF CENTERS.—Each center under paragraph (1) shall use the facilities of a single institution, or be formed from a consortium of cooperating institutions, meeting such requirements as may be prescribed by the Director.

(5) NUMBER OF CENTERS; DURATION OF SUPPORT.—

(A) IN GENERAL.—The Director shall provide for the establishment of [not less than five centers] *not fewer than six centers* under paragraph (1).

(B) DURATION.—Support for a center established under paragraph (1) may be provided under this section for a [period of not to exceed] *period not to exceed* 5 years. Such period may be extended for one or more additional periods not exceeding 5 years if the operations of such center have been reviewed by an appropriate technical and scientific peer review group established by the Director and if such group has recommended to the Director that such period should be extended.

(c) FACILITATION OF RESEARCH.—The Director shall under subsection (a)(1) provide for a program under which samples of tissues and genetic materials that are of use in research on autism spectrum disorder are donated, collected, preserved, and made available for such research. The program shall be carried out in accordance with accepted scientific and medical standards for the donation, collection, and preservation of such samples.

[(d) PUBLIC INPUT.—The Director shall under subsection (a)(1) provide for means through which the public can obtain information on the existing and planned programs and activities of the National Institutes of Health with respect to autism spectrum disorder and through which the Director can receive comments from the public regarding such programs and activities.]

(d) PUBLIC INPUT.—

(1) IN GENERAL.—The Director shall under subsection (a)(1) provide for means through which the public can obtain information on the existing and planned programs and activities of the National Institutes of Health with respect to autism spectrum disorder and through which the Director can receive comments from the public regarding such programs and activities.

(2) OPPORTUNITIES.—Such public input opportunities may include encouraging the centers under subsection (b)(1) to establish an external advisory board or adopting a comprehensive plan to ensure individuals with various backgrounds and perspectives are represented, among other activities. Such opportunities should consider including, as appropriate, individuals, family members, and caregivers of individuals with autism spectrum disorder who represent the entire population of individuals with autism spectrum disorder, including the full range of cognitive, communicative, behavioral, and adaptive functioning, to better inform research findings and future studies.

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