

One Hundred Ninth Congress
of the
United States of America

AT THE SECOND SESSION

*Begun and held at the City of Washington on Tuesday,
the third day of January, two thousand and six*

An Act

To amend the Public Health Service Act to combat autism through research, screening, intervention and education.

*Be it enacted by the Senate and House of Representatives of
the United States of America in Congress assembled,*

SECTION 1. SHORT TITLE.

This Act may be cited as the “Combating Autism Act of 2006”.

SEC. 2. CENTERS OF EXCELLENCE; IMPROVING AUTISM-RELATED RESEARCH.

(a) CENTERS OF EXCELLENCE REGARDING RESEARCH ON AUTISM.—Section 409C of the Public Health Service Act (42 U.S.C.284g) is amended—

(1) in the section heading, by striking “AUTISM” and inserting “AUTISM SPECTRUM DISORDER”;

(2) by striking the term “autism” each place such term appears (other than the section heading) and inserting “autism spectrum disorder”; and

(3) in subsection (a)—

(A) by redesignating paragraph (2) as paragraph (3);

and

(B) by striking paragraph (1) and inserting the following:

“(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, and toxicology. Such research shall investigate the cause (including possible environmental causes), diagnosis or rule out, early detection, prevention, services, supports, intervention, and treatment of autism spectrum disorder.

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

(b) CENTERS OF EXCELLENCE GENERALLY.—Part A of title IV of the Public Health Service Act (42 U.S.C. 281 et seq.) is amended by adding at the end the following:

“SEC. 404H. REVIEW OF CENTERS OF EXCELLENCE.

“(a) IN GENERAL.—Not later than April 1, 2008, and periodically thereafter, the Secretary, acting through the Director of NIH, shall conduct a review and submit a report to the appropriate committees of the Congress on the centers of excellence.

“(b) REPORT CONTENTS.—Each report under subsection (a) shall include the following:

“(1) Evaluation of the performance and research outcomes of each center of excellence.

“(2) Recommendations for promoting coordination of information among centers of excellence.

“(3) Recommendations for improving the effectiveness, efficiency, and outcomes of the centers of excellence.

“(c) DEFINITION.—In this section, the term ‘center of excellence’ means an entity receiving funding under this title in its capacity as a center of excellence.”.

SEC. 3. DEVELOPMENTAL DISABILITIES SURVEILLANCE AND RESEARCH PROGRAM.

(a) IN GENERAL.—Title III of the Public Health Service Act (42 U.S.C. 241 et seq.) is amended by adding at the end the following:

“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 on 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 and local public health officials, private sector developmental disability researchers, and advocates for individuals with autism spectrum disorder or 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, or any other educational institution), 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 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 of autism spectrum disorder and other developmental disabilities.

“(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 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 relevant State and local public health officials, private sector developmental disability researchers, and advocates for individuals with 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) 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)).

“(2) 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, 2011.

“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 or other developmental

disabilities, and train professionals to utilize valid and reliable screening tools to diagnose or rule out and provide evidence-based interventions for children with autism spectrum disorder and other developmental disabilities; 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.

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

“(1) provide information and education on autism spectrum disorder and other developmental disabilities to increase public awareness of developmental milestones;

“(2) promote research into the development and validation of reliable screening tools for autism spectrum disorder and other developmental disabilities and disseminate information regarding those screening tools;

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

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

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

“(6) 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 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 or other developmental disabilities and 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, or authorized representatives; providers; and other appropriate individuals in the State, comprehensive culturally competent 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, 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 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 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 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; and

“(v) demonstrate an ability to use a family-centered approach; and

“(C) program sites provide culturally competent services.

“(2) TECHNICAL ASSISTANCE.—The Secretary may award one or more grants under this section to provide technical

assistance to the network of interdisciplinary training programs.

“(3) 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, through grants or contracts, to determine the evidence-based practices for interventions for individuals with autism spectrum disorder or other developmental disabilities, develop guidelines for those interventions, and disseminate information related to such research and guidelines.

“(g) SUNSET.—This section shall not apply after September 30, 2011.

“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) develop and annually update a summary of advances in autism spectrum disorder research related to causes, prevention, treatment, early screening, diagnosis or rule out, intervention, and access to services and supports for individuals with autism spectrum disorder;

“(2) monitor Federal activities with respect to autism spectrum disorder;

“(3) make recommendations to the Secretary regarding any appropriate changes to such activities, including recommendations to the Director of NIH with respect to the strategic plan developed under paragraph (5);

“(4) make recommendations to the Secretary regarding public participation in decisions relating to autism spectrum disorder;

“(5) develop and annually update a strategic plan for the conduct of, and support for, autism spectrum disorder research, including proposed budgetary requirements; and

“(6) submit to the Congress such strategic plan and any updates to such plan.

“(c) MEMBERSHIP.—

“(1) IN GENERAL.—The Committee shall be composed of—

“(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;

“(D) representatives of other Federal Governmental agencies that serve individuals with autism spectrum disorder such as the Department of Education; and

“(E) the additional members appointed under paragraph (2).

“(2) ADDITIONAL MEMBERS.—Not fewer than 6 members of the Committee, or 1/3 of the total membership of the Committee, whichever is greater, shall be composed of non-Federal public members to be appointed by the Secretary, of which—

“(A) at least one such member shall be an individual with a diagnosis of autism spectrum disorder;

“(B) at least one such member shall be a parent or legal guardian of an individual with an autism spectrum disorder; and

“(C) at least one such member shall be a representative of leading research, advocacy, and service organizations for individuals with autism spectrum disorder.

“(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) Members of the Committee appointed under subsection (c)(2) shall serve for a term of 4 years, and may be reappointed for one or more additional 4 year term. 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 taken office.

“(3) 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.

“(4) 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, 2011, and the Committee shall be terminated on such date.

“SEC. 399DD. REPORT TO CONGRESS.

“(a) IN GENERAL.—Not later than 4 years after the date of enactment of the Combating Autism Act of 2006, the Secretary, in coordination with the Secretary of Education, 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 a progress report on activities related to autism spectrum disorder and other developmental disabilities.

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

“(1) a description of the progress made in implementing the provisions of the Combating Autism Act of 2006;

“(2) a description of the amounts expended on the implementation of the particular provisions of Combating Autism Act of 2006;

“(3) information on the incidence of autism spectrum disorder and trend data of such incidence since the date of enactment of the Combating Autism Act of 2006;

“(4) 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 this Act;

“(5) 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 this Act;

“(6) 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;

“(7) information on the effectiveness and outcomes of interventions for individuals diagnosed with autism spectrum disorder, including by various subtypes, and other developmental disabilities and how the age of the child may affect such effectiveness;

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

“(9) information on services and supports provided to individuals with autism spectrum disorder and other developmental disabilities who have reached the age of majority (as defined for purposes of section 615(m) of the Individuals with Disabilities Education Act (20 U.S.C. 1415(m))).”.

(b) REPEALS.—The following sections of the Children’s Health Act of 2000 (Public Law 106–310) are repealed:

(1) Section 102 (42 U.S.C. 247b–4b), relating to the Developmental Disabilities Surveillance and Research Program.

(2) Section 103 (42 U.S.C. 247b–4c), relating to information and education.

(3) Section 104 (42 U.S.C. 247b–4d), relating to the Inter-Agency Autism Coordinating Committee.

(4) Section 105 (42 U.S.C. 247b–4e), relating to reports.

SEC. 4. AUTHORIZATION OF APPROPRIATIONS.

(a) IN GENERAL.—Part R of title III of the Public Health Service Act, as added by section 3, is amended by adding at the end the following:

“SEC. 399EE. AUTHORIZATION OF APPROPRIATIONS.

“(a) DEVELOPMENTAL DISABILITIES SURVEILLANCE AND RESEARCH PROGRAM.—To carry out section 399AA, there are authorized to be appropriated the following:

“(1) For fiscal year 2007, \$15,000,000.

“(2) For fiscal year 2008, \$16,500,000.

“(3) For fiscal year 2009, \$18,000,000.

“(4) For fiscal year 2010, \$19,500,000.

“(5) For fiscal year 2011, \$21,000,000.

“(b) AUTISM EDUCATION, EARLY DETECTION, AND INTERVENTION.—To carry out section 399BB, there are authorized to be appropriated the following:

“(1) For fiscal year 2007, \$32,000,000.

“(2) For fiscal year 2008, \$37,000,000.

“(3) For fiscal year 2009, \$42,000,000.

“(4) For fiscal year 2010, \$47,000,000.

“(5) For fiscal year 2011, \$52,000,000.

“(c) INTERAGENCY AUTISM COORDINATING COMMITTEE; CERTAIN OTHER PROGRAMS.—To carry out section 399CC, 409C, and section 404H, there are authorized to be appropriated the following:

“(1) For fiscal year 2007, \$100,000,000.

“(2) For fiscal year 2008, \$114,500,000.

“(3) For fiscal year 2009, \$129,000,000.

“(4) For fiscal year 2010, \$143,500,000.

“(5) For fiscal year 2011, \$158,000,000.”.

(b) CONFORMING AMENDMENT.—Section 409C of the Public Health Service Act (42 U.S.C. 284g) is amended by striking subsection (e) (relating to funding).

Speaker of the House of Representatives.

*Vice President of the United States and
President of the Senate.*