

Calendar No. 578109TH CONGRESS
2^D SESSION**S. 843****[Report No. 109-318]**

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

IN THE SENATE OF THE UNITED STATES

APRIL 19, 2005

Mr. SANTORUM (for himself, Mr. DODD, Mr. CORZINE, Mr. LIEBERMAN, Mr. LAUTENBERG, Ms. CANTWELL, Mr. PRYOR, Mr. JEFFORDS, Mr. KERRY, Mr. COLEMAN, Ms. COLLINS, Mr. COCHRAN, Mr. AKAKA, Mr. LEAHY, Mrs. CLINTON, Mr. DAYTON, Ms. LANDRIEU, Mr. JOHNSON, Mr. ISAKSON, Mr. DEWINE, Ms. MIKULSKI, Mr. SARBANES, Mr. INOUE, Mr. BIDEN, Mrs. BOXER, Mr. SCHUMER, Mr. MENENDEZ, Mr. HATCH, Mr. DOMENICI, Mr. BINGAMAN, Mr. REED, Mrs. MURRAY, Mr. SUNUNU, Mr. VITTER, Mr. MCCAIN, Mr. BENNETT, Mr. TALENT, Mr. NELSON of Florida, Mr. CHAFEE, Mr. SALAZAR, Mr. HARKIN, Mrs. HUTCHISON, Mr. CORNYN, Mr. ENZI, Mr. BURR, Mr. FRIST, Mr. DURBIN, Mr. CHAMBLISS, and Mr. THUNE) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

AUGUST 3, 2006

Reported by Mr. ENZI, with an amendment

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

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

1 *Be it enacted by the Senate and House of Representa-*
 2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Combating Autism Act
 5 of 2005”.

6 **SEC. 2. ACTIVITIES TO IMPROVE AUTISM-RELATED RE-**
 7 **SEARCH AND FUNDING.**

8 Title IV of the Public Health Service Act (42 U.S.C.
 9 281 et seq.) is amended by adding at the end the fol-
 10 lowing:

11 **“PART J—AUTISM-RELATED ACTIVITIES**

12 **“SEC. 499A. AUTHORITY OF THE DIRECTOR OF THE NA-**
 13 **TIONAL INSTITUTES OF HEALTH RELATING**
 14 **TO AUTISM.**

15 “(a) **IDENTIFYING TOTAL EXPENDITURES ON AU-**
 16 **TISM SPECTRUM DISORDERS.**—The Director of NIH, in
 17 coordination with the National Institute of Mental Health
 18 and other institutes of the National Institutes of Health,
 19 shall identify the total amount of expenditures, both intra-
 20 mural and extramural, by the National Institutes of
 21 Health for autism spectrum disorders for fiscal year 2005.

22 “(b) **BUDGET FOR AUTISM RESEARCH AND COORDI-**
 23 **NATION OF ACTIVITIES AND PROGRAMS.**—The Director of
 24 NIH, based on the strategic plan developed under sub-
 25 section (c), shall—

1 “(1) develop and oversee the implementation of
2 a scientifically justified budget for research on au-
3 tism spectrum disorders at the National Institutes of
4 Health;

5 “(2) coordinate all research activities and pro-
6 grams on autism spectrum disorders at the insti-
7 tutes, centers, and divisions of the National Insti-
8 tutes of Health; and

9 “(3) evaluate all such activities and programs.

10 “(c) STRATEGIC PLAN FOR AUTISM RESEARCH.—

11 “(1) IN GENERAL.—The Director of NIH shall
12 develop and oversee the implementation of a com-
13 prehensive, long-range plan for the conduct and sup-
14 port of research on autism spectrum disorders by
15 the institutes, centers, and divisions of the National
16 Institutes of Health.

17 “(2) REQUIREMENTS.—The plan developed
18 under paragraph (1) shall—

19 “(A) be updated on an annual basis;

20 “(B) be based on the research rec-
21 ommendations contained in the Autism Re-
22 search Roadmap and Matrix of the Interagency
23 Autism Coordinating Committee;

1 “(C) determine and establish priorities
2 among critical scientific questions related to au-
3 tism spectrum disorders;

4 “(D) based on the priorities established
5 under subparagraph (C), specify the short and
6 long-range objectives to be achieved, and esti-
7 mate the resources needed to achieve these ob-
8 jectives;

9 “(E) evaluate the sufficiency of existing re-
10 search programs on autism spectrum disorders
11 to meet the objectives specified under subpara-
12 graph (D); and establish objectives, timelines,
13 and criteria for evaluating future research pro-
14 grams; and

15 “(F) make recommendations for changes
16 to existing research programs on autism spec-
17 trum disorders.

18 “(d) BUDGETARY AUTHORITY.—

19 “(1) IN GENERAL.—The Director of NIH
20 shall—

21 “(A) in accordance with the strategic plan
22 developed under subsection (c), annually pre-
23 pare and submit to Congress a scientifically jus-
24 tified budget estimate for research on autism
25 spectrum disorders to be conducted within the

1 agencies of the National Institutes of Health,
2 which shall include the amount of funds that
3 will be required for—

4 “(i) the continued funding of ongoing
5 discretionary program initiatives at the in-
6 stitutes, centers, and divisions of the Na-
7 tional Institutes of Health; and

8 “(ii) the funding of new and com-
9 plementary program initiatives.

10 “(B) receive all research funds for autism
11 spectrum disorders described in subparagraph
12 (A), and allocate those funds to the institutes,
13 centers, and divisions of the National Institutes
14 of Health.

15 “(2) EFFECTIVE DATE.—Paragraph (1)(B)
16 shall become effective in the fiscal year following the
17 submission of the autism budget described in para-
18 graph (1)(A).

19 “(c) EVALUATION AND REPORT.—

20 “(1) EVALUATION.—The Director of NIH shall
21 evaluate the effect of this section on the planning
22 and coordination of research programs on autism
23 spectrum disorders at the institutes, centers, and di-
24 visions of the National Institutes of Health, and the
25 extent to which funding mandated under this section

1 has followed the recommendation of the strategic
2 plan developed under subsection (e).

3 “(2) REPORT.—Not later than 1 year after the
4 date of enactment of this section, the Director of
5 NIH shall prepare and submit to the Committee on
6 Energy and Commerce and the Committee on Ap-
7 propriations of the House of Representatives, and
8 the Committee on Health, Education, Labor, and
9 Pensions and the Committee on Appropriations of
10 the Senate, a report based on the evaluation de-
11 scribed in paragraph (1).

12 **“SEC. 499B. EXPANSION, INTENSIFICATION, AND COORDI-**
13 **NATION OF ACTIVITIES OF NATIONAL INSTI-**
14 **TUTES OF HEALTH WITH RESPECT TO RE-**
15 **SEARCH ON AUTISM.**

16 “(a) IN GENERAL.—

17 “(1) EXPANSION OF ACTIVITIES.—The Director
18 of NIH shall expand, intensify, and coordinate the
19 activities of the National Institutes of Health with
20 respect to research on autism.

21 “(2) ADMINISTRATION OF PROGRAM; COORDI-
22 NATION AMONG AGENCIES.—The Director of NIH
23 shall carry out this section acting through the Direc-
24 tor of the National Institute of Mental Health and
25 in collaboration with the National Institute of Child

1 Health and Human Development, the National In-
 2 stitute of Neurological Disorders and Stroke, the
 3 National Institute of Environmental Health
 4 Sciences, the National Institute on Deafness and
 5 Other Communication Disorders, and any other
 6 agencies that the Director determines appropriate.

7 “(b) CENTERS OF EXCELLENCE.—

8 “(1) IN GENERAL.—In carrying out subsection
 9 (a)(1), the Director of NIH shall award grants and
 10 contracts to public or nonprofit private entities to
 11 pay all or part of the cost of planning, establishing,
 12 improving, and providing basic operating support for
 13 centers of excellence regarding research on autism.

14 “(2) RESEARCH.—Each center of excellence
 15 that receives funding under paragraph (1) shall con-
 16 duct basic and clinical research into autism. Such
 17 research—

18 “(A) shall be conducted in the fields of de-
 19 velopmental neurobiology, genetics, and
 20 psychopharmacology, and, beginning on July 1,
 21 2008, immunology, endocrinology, gastro-
 22 enterology, and toxicology, and

23 “(B) should include—

1 “(i) investigations into the cause, di-
2 agnosis, early detection, prevention, con-
3 trol, treatment, and cure of autism; and

4 “(ii) research on high-risk infant sib-
5 lings.

6 “(3) SERVICES FOR PATIENTS.—

7 “(A) IN GENERAL.—A center of excellence
8 that receives funding under paragraph (1) may
9 expend amounts provided under a grant or con-
10 tract under such paragraph to carry out a pro-
11 gram to make individuals aware of opportuni-
12 ties to participate as subjects in research con-
13 ducted by the centers.

14 “(B) REFERRALS AND COSTS.—A program
15 carried out under subparagraph (A) may, in ac-
16 cordance with such criteria as the Director of
17 NIH may establish, provide to the subjects de-
18 scribed in such subparagraph, referrals for
19 health and other services, and such patient care
20 costs as are required for research.

21 “(C) AVAILABILITY AND ACCESS.—The ex-
22 tent to which a center of excellence that re-
23 ceives funding under paragraph (1) can dem-
24 onstrate availability and access to clinical serv-
25 ices shall be considered by the Director of NIH

1 in decisions about awarding grants or contracts
2 to applicants that meet the scientific criteria for
3 funding under this section.

4 “(4) COORDINATION OF CENTERS OF EXCEL-
5 LENCE.—

6 “(A) IN GENERAL.—The Director of NIH
7 shall, as appropriate, provide for the coordina-
8 tion of information among centers of excellence
9 that receive funding under paragraph (1) and
10 centers of excellence that receive funding under
11 section 463C, and ensure regular communica-
12 tion between such centers.

13 “(B) PERIODIC REPORTS.—The Director
14 of NIH may require the periodic preparation of
15 reports on the activities of the centers described
16 in subparagraph (A) and the submission of
17 such reports to the Director.

18 “(C) COLLECTION AND STORAGE OF
19 DATA.—The Director of NIH shall establish
20 and fund mechanisms and entities for col-
21 lecting, storing, and coordinating data collected
22 by the centers referred to in subparagraph (A)
23 and data generated from public and private re-
24 search partnerships.

1 “(5) ORGANIZATION.—Each center of excellence
2 that receives funding under paragraph (1) shall use
3 the facilities of a single institution, or be formed
4 from a consortium of cooperating institutions, meet-
5 ing such requirements as may be prescribed by the
6 Director of NIH.

7 “(6) NUMBER AND DURATION.—

8 “(A) IN GENERAL.—The Director shall
9 provide for the establishment of not less than
10 10 centers under paragraph (1).

11 “(B) DURATION.—A grant or contract
12 awarded under paragraph (1) shall not exceed
13 a period of 5 years. Such period may be ex-
14 tended for 1 or more additional periods not ex-
15 ceeding 5 years if the operations of the center
16 of excellence involved have been reviewed by an
17 appropriate technical and scientific peer review
18 group established by the Director of NIH and
19 the group has recommended to the Director
20 that such period should be extended.

21 “(C) FACILITATION OF RESEARCH.—

22 “(i) ESTABLISHMENT OF PROGRAM.—

23 The Director of NIH shall establish a pro-
24 gram under which samples of tissues and
25 genetic and other biological materials that

1 are of use in research on autism are do-
2 nated, collected, preserved, and made avail-
3 able for such research.

4 “(ii) ACCEPTED SCIENTIFIC STAND-
5 ARDS.—The program established under
6 clause (i) shall be carried out in accord-
7 ance with accepted scientific and medical
8 standards for the donation, collection, and
9 preservation of such samples, and shall be
10 conducted so that the tissues and other
11 materials saved, as well as any database
12 compiled from such tissues and materials,
13 are available to researchers at a reasonable
14 cost.

15 “(D) PUBLIC INPUT.—In carrying out this
16 section, the Director of NIH shall provide for a
17 means through which the public can obtain in-
18 formation on the existing and planned pro-
19 grams and activities of the National Institutes
20 of Health with respect to autism and through
21 which the Director can receive comments from
22 the public regarding such programs and activi-
23 ties.

24 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
25 is authorized to be appropriated to carry out this section,

1 \$30,000,000 for each of fiscal years 2007 through 2011.
 2 Amounts appropriated under this subsection shall be in
 3 addition to any other amounts appropriated for such pur-
 4 pose.

5 **“SEC. 499C. COLLABORATIVE PROGRAMS OF EXCELLENCE**
 6 **IN AUTISM.**

7 “(a) IN GENERAL.—The Director of NIH, acting
 8 through the Director of the National Institute of Child
 9 Health and Human Development and the Director of the
 10 National Institute on Deafness and Other Disorders, shall
 11 award grants and contracts to public or nonprofit private
 12 entities to pay all or part of the cost of planning, estab-
 13 lishing, improving, and providing basic operating support
 14 for the Collaborative Programs of Excellence in Autism.

15 “(b) RESEARCH.—Each program established under
 16 subsection (a) shall conduct basic and clinical research
 17 into autism. Such program—

18 “(1) shall conduct research in the fields of de-
 19 velopmental neurobiology, genetics, and
 20 psychopharmacology, and, beginning July 1, 2008,
 21 in the fields of immunology, endocrinology, gastro-
 22 enterology, and toxicology; and

23 “(2) should conduct—

1 “(A) investigations into the cause, diag-
2 nosis, early detection, prevention, control, treat-
3 ment, and cure of autism; and

4 “(B) research on high-risk infant siblings.

5 “(c) COORDINATION OF PROGRAMS.—

6 “(1) IN GENERAL.—The Director of NIH shall,
7 as appropriate, provide for the coordination of infor-
8 mation among programs established under sub-
9 section (a), and centers of excellence that receive
10 funding under section 463C and 499B, and ensure
11 regular communication between such centers.

12 “(2) PERIODIC REPORTS.—The Director of
13 NIH may require the periodic preparation of reports
14 on the activities of the programs described in para-
15 graph (1) and the submission of such reports to the
16 Director.

17 “(3) COLLECTION AND STORAGE OF DATA.—
18 The Director of NIH shall establish and fund mech-
19 anisms and entities for collecting, storing, and co-
20 ordinating data collected by the programs referred
21 to in paragraph (1) and data generated from public
22 and private research partnerships.

23 “(d) ORGANIZATION.—Each program that receives
24 funding under subsection (a) shall use the facilities of a
25 single institution, or be formed from a consortium of co-

1 operating institutions, meeting such requirements as may
2 be prescribed by the Director of NIH.

3 “(e) NUMBER AND DURATION.—

4 “(1) IN GENERAL.—The Director shall provide
5 for the establishment of not less than 10 programs
6 under paragraph (1).

7 “(2) DURATION.—A grant or contract awarded
8 under subsection (a) shall not exceed a period of 5
9 years. Such period may be extended for 1 or more
10 additional periods not exceeding 5 years if the oper-
11 ations of the program involved have been reviewed
12 by an appropriate technical and scientific peer re-
13 view group established by the Director of NIH and
14 the group has recommended to the Director that
15 such period should be extended.

16 “(f) AUTHORIZATION OF APPROPRIATIONS.—There
17 is authorized to be appropriated to carry out this section,
18 \$14,000,000 for each of fiscal years 2007 through 2011.
19 Amounts appropriated under this subsection shall be in
20 addition to any other amounts appropriated for such pur-
21 pose.”.

1 **SEC. 3. DEVELOPMENTAL DISABILITIES SURVEILLANCE**
 2 **AND RESEARCH PROGRAM.**

3 Title III of the Public Health Service Act (42 U.S.C.
 4 241 et seq.) is amended by adding at the end thereof the
 5 following:

6 **“PART R—PROGRAMS RELATING TO AUTISM**

7 **“SEC. 399AA. DEVELOPMENTAL DISABILITIES SURVEIL-**
 8 **LANCE AND RESEARCH PROGRAM.**

9 **“(a) NATIONAL AUTISM AND PERVASIVE DEVELOP-**
 10 **MENTAL DISABILITIES SURVEILLANCE PROGRAM.—**

11 **“(1) IN GENERAL.—**The Secretary, acting
 12 through the Director of the Centers for Disease
 13 Control and Prevention, may award grants and co-
 14 operative agreements to eligible entities for the col-
 15 lection, analysis, and reporting of epidemiological
 16 data on autism and pervasive developmental disabil-
 17 ities. In making such awards, the Secretary may
 18 provide direct technical assistance in lieu of cash.

19 **“(2) ELIGIBILITY.—**To be eligible to receive a
 20 grant or cooperative agreement under paragraph (1),
 21 an entity shall be a public or nonprofit private entity
 22 (including a health department of a State or political
 23 subdivisions of a State, a university, or any other
 24 educational institution), and submit to the Secretary
 25 an application at such time, in such manner, and

1 containing such information as the Secretary may
2 require.

3 “(b) CENTERS OF EXCELLENCE IN AUTISM AND
4 PERVASIVE DEVELOPMENTAL DISABILITIES EPIDEMI-
5 OLOGY.—

6 “(1) IN GENERAL.—The Secretary, acting
7 through the Director of the Centers for Disease
8 Control and Prevention, shall establish not less than
9 6 regional centers of excellence in autism and perva-
10 sive developmental disabilities epidemiology for the
11 purpose of collecting and analyzing information on
12 the number, incidence, incidence trend over time,
13 correlates, and causes of autism and related develop-
14 mental disabilities.

15 “(2) RECIPIENTS OF AWARDS.—Each center of
16 excellence under paragraph (1) shall be established
17 and operated through the awarding of grants or co-
18 operative agreements to public or nonprofit private
19 entities that conduct research, including health de-
20 partments of States and political subdivisions of
21 States, and universities and other educational enti-
22 ties.

23 “(3) REQUIREMENTS.—To be eligible to receive
24 a grant or cooperative agreement under paragraph
25 (2), an entity shall submit to the Secretary an appli-

1 eation containing such agreements and information
2 as the Secretary may require, including an agree-
3 ment that the center to be established shall operate
4 in accordance with the following:

5 “(A) The center will collect, analyze, and
6 report autism and pervasive developmental dis-
7 abilities data according to guidelines prescribed
8 by the Director of the Centers for Disease Con-
9 trol and Prevention, after consultation with rel-
10 evant State and local public health officials, pri-
11 vate sector developmental disability researchers,
12 and advocates for those with developmental dis-
13 abilities.

14 “(B) The center will assist with the devel-
15 opment and coordination of State autism and
16 pervasive developmental disabilities surveillance
17 efforts within a region.

18 “(C) The center will identify eligible cases
19 and controls through its surveillance systems
20 and conduct research into factors which may
21 cause or increase the risk of autism and related
22 developmental disabilities.

23 “(D) The center will develop or extend an
24 area of special research expertise (including ge-
25 netics, environmental exposure to contaminants,

1 immunology, and other relevant research spe-
2 cialty areas).

3 “(e) CLEARINGHOUSE.—The Secretary, acting
4 through the Director of the Centers for Disease Control
5 and Prevention, shall carry out the following:

6 “(1) ESTABLISHMENT.—The Secretary shall es-
7 tablish a clearinghouse within the Centers for Dis-
8 ease Control and Prevention for the collection and
9 storage of data generated from the monitoring pro-
10 grams established under this part and part J of title
11 IV. Through the clearinghouse, such Centers shall
12 serve as the coordinating agency for autism and per-
13 vasive developmental disabilities surveillance activi-
14 ties. The functions of such clearinghouse shall in-
15 clude facilitating the coordination of research and
16 policy development relating to the epidemiology of
17 autism and other pervasive developmental disabili-
18 ties.

19 “(2) FEDERAL RESPONSE.—The Secretary shall
20 coordinate the Federal response to requests for as-
21 sistance from State health department officials re-
22 garding potential or alleged autism or developmental
23 disability clusters.

24 “(3) FACILITATION OF RESEARCH.—The Sec-
25 retary shall provide for the establishment of a pro-

1 gram under which samples of tissues and genetic
2 and other biological materials that are of use in re-
3 search on autism are donated, collected, preserved,
4 and made available for such research. Such program
5 shall be carried out in accordance with accepted sci-
6 entific and medical standards for the donation, col-
7 lection, and preservation of such samples, and shall
8 be conducted so that the tissues and other materials
9 saved, as well as any database compiled from such
10 tissues and materials, are available to researchers at
11 a reasonable cost.

12 “(4) COORDINATION.—The Centers for Disease
13 Control and Prevention shall coordinate research
14 and surveillance activities of such Centers with the
15 National Institutes of Health, other appropriate
16 Federal agencies, and interested nonprofit private
17 entities, in a manner consistent with the research
18 recommendations contained in the Autism Research
19 Roadmap and Matrix of the Interagency Autism Co-
20 ordinating Committee, which shall be updated as de-
21 termined appropriate by the Secretary.

22 “(d) STATE.—In this part, the term ‘State’ means
23 each of the several States, the District of Columbia, the
24 Commonwealth of Puerto Rico, American Samoa, Guam,
25 the Commonwealth of the Northern Mariana Islands, the

1 Virgin Islands, and the Trust Territory of the Pacific Is-
2 lands.

3 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
4 is authorized to be appropriated to carry out this section,
5 \$12,000,000 for each of fiscal years 2007 through 2011.

6 **“SEC. 399BB. INFORMATION AND EDUCATION RELATING TO**
7 **AUTISM.**

8 “(a) IN GENERAL.—The Secretary shall establish
9 and implement a program to provide information and edu-
10 cation on autism and its risk factors to health profes-
11 sionals and the general public, including information and
12 education on advances in the diagnosis and treatment of
13 autism and training and continuing education through
14 programs for scientists, physicians, and other health pro-
15 fessionals who provide care for patients with autism. The
16 program shall place special emphasis on early identifica-
17 tion of autism and those at risk for autism and prompt
18 referral for appropriate services.

19 “(b) STIPENDS.—The Secretary may use amounts
20 made available under this section to provide stipends for
21 health professionals who are enrolled in training programs
22 under this section.

23 “(c) AUTHORIZATION OF APPROPRIATIONS.—There
24 is authorized to be appropriated to carry out this section,
25 \$10,000,000 for each of fiscal years 2007 through 2011.

1 **“SEC. 399CC. INTERAGENCY AUTISM COORDINATING COM-**
 2 **MITTEE.**

3 “(a) **ESTABLISHMENT.**—The Secretary shall estab-
 4 lish a committee to be known as the ‘Autism Coordinating
 5 Committee’ (in this section referred to as the ‘Committee’)
 6 to coordinate all efforts within the Department of Health
 7 and Human Services concerning autism, including activi-
 8 ties carried out through the National Institutes of Health
 9 and the Centers for Disease Control and Prevention under
 10 the amendments made by the National Autism Research
 11 Act.

12 “(b) **MEMBERSHIP.**—

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

15 “(A) the Director of the Centers for Dis-
 16 ease Control and Prevention;

17 “(B) the Directors of such national re-
 18 search institutes of the National Institutes of
 19 Health as the Secretary determines appropriate;

20 “(C) the heads of such other agencies as
 21 the Secretary determines appropriate; and

22 “(D) the additional members appointed
 23 under paragraph (2) (if any).

24 “(2) **ADDITIONAL MEMBERS.**—If determined
 25 appropriate by the Secretary, the Secretary may ap-
 26 point to the Committee—

1 “(A) individuals with autism or other per-
2 vasive developmental disorders;

3 “(B) parents or legal guardians of individ-
4 uals with autism or other pervasive develop-
5 mental disorders;

6 “(C) representatives of leading autism re-
7 search and service organizations; and

8 “(D) representatives of other governmental
9 agencies that serve children with autism such
10 as the Department of Education.

11 “(e) ADMINISTRATIVE SUPPORT; TERMS OF SERV-
12 ICES; OTHER PROVISIONS.—The following shall apply
13 with respect to the Committee:

14 “(1) The Committee shall receive necessary and
15 appropriate administrative support from the Sec-
16 retary.

17 “(2) Members of the Committee appointed
18 under subsection (b)(2)(A) shall serve for a term of
19 3 years, and may serve for an unlimited number of
20 terms if reappointed.

21 “(3) The Committee shall meet not less than 2
22 times each year.

1 **“SEC. 399DD. SCREENING, DIAGNOSIS, AND TREATMENT OF**
2 **AUTISM; MEDICAL CARE FOR INDIVIDUALS**
3 **WITH AUTISM.**

4 **“(a) STATEWIDE AUTISM SCREENING, DIAGNOSIS,**
5 **AND INTERVENTION PROGRAMS AND SYSTEMS.—**

6 **“(1) IN GENERAL.—**The Secretary, acting
7 through the Administrator of the Health Resources
8 and Services Administration, shall award grants or
9 cooperative agreements to eligible entities to develop
10 statewide autism screening, diagnosis, and interven-
11 tion programs and systems for the purposes de-
12 scribed in paragraph (2).

13 **“(2) PURPOSES.—**The purposes described in
14 this paragraph are the following:

15 **“(A)** To develop and monitor the efficacy
16 of statewide autism screening, diagnosis, and
17 intervention programs and systems, ensuring
18 that all children are screened for autism before
19 their second birthday, and that children at risk
20 for autism receive appropriate services as early
21 as possible. Intervention includes referral to
22 schools and agencies, including community, con-
23 sumer, and parent-based agencies, and organi-
24 zations and other programs mandated by part
25 C of the Individuals with Disabilities Education
26 Act, which offer programs specifically designed

1 to meet the unique needs of children with au-
2 tism.

3 “(B) To collect data on statewide autism
4 screening, diagnosis, and intervention programs
5 and systems that can be used for applied re-
6 search, program evaluation, and policy develop-
7 ment.

8 “(C) To provide comprehensive medical
9 care for individuals with autism through evi-
10 dence-based practices, with specific attention to
11 medical conditions that may be associated with
12 autism, and to disseminate information on the
13 medical care of individuals with autism to
14 health professionals and the general public. In
15 carrying out the program under this paragraph,
16 a grant shall be awarded to a national organiza-
17 tion that will establish and support regional
18 centers of clinical excellence to provide medical
19 care to individuals with autism and promote re-
20 search aimed at improving the treatment of
21 such individuals, and that will build a shared
22 national medical database to record the results
23 of treatments and studies at the regional cen-
24 ters.

1 “(3) SET ASIDE OF FUNDS.—From amounts
2 appropriated under subsection (e), the Secretary
3 shall set aside not less than \$4,000,000 for each of
4 fiscal years 2007 through 2011 to carry out activi-
5 ties described in paragraph (2)(C).

6 “(b) TECHNICAL ASSISTANCE, DATA MANAGEMENT,
7 AND APPLIED RESEARCH.—The Secretary, acting
8 through the Director of the Centers for Disease Control
9 and Prevention, shall award grants or cooperative agree-
10 ments to provide technical assistance to State agencies to
11 conduct applied research related to autism screening, diag-
12 nosis, and intervention programs and systems. In carrying
13 out this section the Secretary shall develop standardized
14 procedures for data management and program effective-
15 ness and costs, including procedures—

16 “(1) to ensure quality monitoring of autism
17 screening, diagnosis, and intervention programs and
18 systems;

19 “(2) to provide technical assistance on data col-
20 lection and management;

21 “(3) to study the costs and effectiveness of au-
22 tism screening, diagnosis, and intervention programs
23 and systems conducted by State-based programs in
24 order to address issues of importance to State and
25 national policymakers;

1 “(4) to identify the causes and risk factors for
2 autism;

3 “(5) to study the effectiveness of autism screen-
4 ing, diagnosis, and intervention programs and sys-
5 tems by assessing the intellectual and social develop-
6 ment, cognitive status, and language skills of chil-
7 dren with autism at school age; and

8 “(6) to promote the sharing of data regarding
9 autism with State-based birth defects and develop-
10 mental disabilities monitoring programs and environ-
11 mental discharge monitoring programs of the Envi-
12 ronmental Protection Agency for the purpose of
13 identifying previously unknown causes of and risk
14 factors for autism.

15 “(e) COORDINATION AND COLLABORATION.—

16 “(1) IN GENERAL.—In carrying out programs
17 under this section, the Administrator of the Health
18 Resources and Services Administration, the Director
19 of the Centers for Disease Control and Prevention,
20 and the Director of the National Institutes of Health
21 shall collaborate and consult with—

22 “(A) other Federal, State and local agen-
23 cies, including those responsible for early inter-
24 vention services pursuant to title XIX of the
25 Social Security Act (particularly the Medicaid

1 Early and Periodic Screening, Diagnosis and
2 Treatment Program); title XXI of the Social
3 Security Act (State Children's Health Insur-
4 ance Program); title V of the Social Security
5 Act (Maternal and Child Health Block Grant
6 Program); and part C of the Individuals with
7 Disabilities Education Act;

8 “(B) consumer groups of, and that serve,
9 individuals with autism and their families;

10 “(C) appropriate national medical and
11 other health and education specialty organiza-
12 tions;

13 “(D) individuals with autism and their
14 families;

15 “(E) other qualified personnel who possess
16 the specialized knowledge, skills, and attributes
17 needed to serve autistic children and their fami-
18 lies; and

19 “(F) related commercial industries.

20 “(2) POLICY DEVELOPMENT.—The Adminis-
21 trator of the Health Resources and Services Admin-
22 istration, the Director of the Centers for Disease
23 Control and Prevention, and the Director of the Na-
24 tional Institutes of Health shall coordinate and col-
25 laborate on recommendations for policy development

1 at the Federal and State levels and with the private
2 sector, including consumer, medical, and other
3 health and education professional-based organiza-
4 tions, with respect to autism screening, diagnosis,
5 and intervention programs and systems.

6 “(3) STATE EARLY DETECTION, DIAGNOSIS,
7 AND INTERVENTION PROGRAMS AND SYSTEMS.—The
8 Administrator of the Health Resources and Services
9 Administration and the Director of the Centers for
10 Disease Control and Prevention shall coordinate and
11 collaborate in assisting States to establish autism
12 screening, diagnosis, and intervention programs and
13 systems under subsection (a) and to develop a data
14 collection system under subsection (b).

15 “(d) PHYSICIAN REIMBURSEMENT FOR DEVELOP-
16 MENT SCREENING.—To make developmental screening
17 more readily available, the Secretary, acting through the
18 Administrator of the Centers for Medicare & Medicaid
19 Services, shall assign a relative value unit to the diagnostic
20 code for developmental screening.

21 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
22 is authorized to be appropriated—

23 “(1) to carry out subsection (a), \$75,000,000
24 for each of fiscal years 2007 through 2011; and

1 “(2) to carry out subsection (b), \$25,000,000
2 for each of fiscal years 2007 through 2011.

3 **“SEC. 399EE. ANNUAL REPORT ON AUTISM.**

4 “(a) IN GENERAL.—Not later than January 1, 2006,
5 and each January 1 thereafter, the Secretary shall prepare
6 and submit to the appropriate committees of Congress, a
7 report concerning the implementation of this part and part
8 J of title IV.

9 “(b) CONTENTS.—The report, utilizing uniform re-
10 porting methods and procedures, shall—

11 “(1) provide the dollar amount that each insti-
12 tute of the National Institutes of Health expended
13 on autism research in the year for which the report
14 was prepared; and

15 “(2) detail the progress and success of the Na-
16 tional Institutes of Health in implementing and
17 funding the recommendations contained in the Au-
18 tism Research Roadmap and Matrix of the Inter-
19 agency Autism Coordinating Committee.”.

20 **SEC. 4. ENVIRONMENTAL HEALTH RESEARCH PROGRAMS.**

21 Subpart 12 of part C of title IV of the Public Health
22 Service Act (42 U.S.C. 2851 et seq.) is amended by adding
23 at the end the following:

1 **“SEC. 463C. ENVIRONMENTAL HEALTH RESEARCH PRO-**
2 **GRAMS.**

3 “(a) **CENTERS OF EXCELLENCE.**—The Director of
4 NIH, acting through the Director of the Institute, shall
5 awards grants and contracts to public or nonprofit private
6 entities to pay all or part of the cost of planning, estab-
7 lishing, improving, and providing basic operating support
8 for centers of excellence regarding environmental health
9 and autism.

10 “(b) **RESEARCH.**—Each center of excellence under
11 subsection (a) shall conduct basic and clinical research
12 into possible environmental causes of and risk factors for
13 autism and the mechanisms by which they may lead to
14 autism, and the developmental effects of environmental
15 agents that may be associated with autism.

16 “(c) **COORDINATION; REPORTS.**—The Director of
17 NIH shall, as appropriate, provide for the coordination of
18 information among centers of excellence established under
19 subsection (a) and section 499B and ensure regular com-
20 munication between such centers. The Director may re-
21 quire the periodic preparation of reports on the activities
22 of the centers and the submission of such reports to the
23 Director. The Director shall establish and fund mecha-
24 nisms and entities for collecting, storing, and coordinating
25 data collected by the centers established under this section

1 and data generated from public and private research part-
2 nerships.

3 “(d) ORGANIZATION.—Each center of excellence
4 under subsection (a) shall use the facilities of a single in-
5 stitution, or be formed from a consortium of cooperating
6 institutions, meeting such requirements as may be pre-
7 scribed by the Director of NIH.

8 “(e) NUMBER OF CENTERS; DURATION.—

9 “(1) IN GENERAL.—The Director shall provide
10 for the establishment of not less than 3 centers
11 under subsection (a).

12 “(A) DURATION.—A grant or contract
13 awarded under subsection (a) shall not exceed
14 a period of 5 years. Such period may be ex-
15 tended for 1 or more additional periods not ex-
16 ceeding 5 years if the operations of the center
17 of excellence involved have been reviewed by an
18 appropriate technical and scientific peer review
19 group established by the Director of NIH and
20 the group has recommended to the Director
21 that such period should be extended.

22 “(f) AUTHORIZATION OF APPROPRIATIONS.—There
23 is authorized to be appropriated to carry out this section,
24 \$6,000,000 for each of fiscal years 2007 through 2011.”.

1 **SECTION 1. SHORT TITLE.**

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

4 **SEC. 2. ACTIVITIES TO IMPROVE AUTISM-RELATED RE-**
 5 **SEARCH.**

6 *Section 409C of the Public Health Service Act (42*
 7 *U.S.C. 284g) is amended to read as follows:*

8 **“SEC. 409C. AUTHORITY OF THE DIRECTOR OF THE NA-**
 9 **TIONAL INSTITUTES OF HEALTH RELATING**
 10 **TO AUTISM.**

11 *“(a) STRATEGIC PLAN FOR AUTISM RESEARCH.—*

12 *“(1) IN GENERAL.—The Secretary, acting*
 13 *through the Director, shall develop and implement a*
 14 *strategic plan for the conduct and support of research*
 15 *related to autism spectrum disorder.*

16 *“(2) REQUIREMENTS.—The strategic plan devel-*
 17 *oped under paragraph (1)—*

18 *“(A) shall—*

19 *“(i) be updated annually;*

20 *“(ii) take into account the research rec-*
 21 *ommendations of the Interagency Autism*
 22 *Coordinating Committee under section*
 23 *399CC; and*

24 *“(iii) using professional judgment, out-*
 25 *line the proposed budgetary requirements of*
 26 *the strategic plan, including specific fund-*

1 *ing expectations for continued multi-year*
2 *program activities, as well as new and com-*
3 *plementary program activities, subject to*
4 *the availability of appropriations; and*

5 *“(B) may include investigator-initiated re-*
6 *search.*

7 *“(3) REPORT.—Not later than April 1, 2008,*
8 *and annually thereafter, the Secretary, acting through*
9 *the Director, shall prepare and submit to the appro-*
10 *priate committees of Congress a report that con-*
11 *tains—*

12 *“(A) the strategic plan under paragraph (1)*
13 *that will be applicable to the upcoming fiscal*
14 *year; and*

15 *“(B) a description of the actual dollar ex-*
16 *penditures for autism spectrum disorder during*
17 *the previous fiscal year.*

18 *“(b) EXPANSION, INTENSIFICATION, AND COORDINA-*
19 *TION OF ACTIVITIES.—The Secretary, acting through the*
20 *Director, shall, subject to the availability of appropriations,*
21 *expand, intensify, and coordinate the activities of the Na-*
22 *tional Institutes of Health with respect to autism spectrum*
23 *disorder.*

24 *“(c) CENTERS OF EXCELLENCE.—*

25 *“(1) AUTISM CENTERS OF EXCELLENCE.—*

1 “(A) *IN GENERAL.*—*The Secretary, acting*
2 *through the Director, shall, subject to the avail-*
3 *ability of appropriations, award grants or con-*
4 *tracts to public or nonprofit private entities to*
5 *assist such entities in paying all or part of the*
6 *costs of planning, establishing, improving, and*
7 *providing basic operating support for centers of*
8 *excellence concerning research on autism spec-*
9 *trum disorder.*

10 “(B) *RESEARCH ACTIVITIES.*—*A center of*
11 *excellence that receives funding under this para-*
12 *graph shall conduct basic and clinical research*
13 *into autism spectrum disorder. Such research*
14 *shall—*

15 “(i) *be conducted in the fields of devel-*
16 *opmental neurobiology, genetics, epigenetics,*
17 *pharmacology, nutrition, immunology,*
18 *neuroimmunology, neurobehavioral develop-*
19 *ment, endocrinology, gastroenterology,*
20 *psychopharmacology, or toxicology; and*

21 “(ii) *include investigations into the*
22 *causation, diagnosis or rule out, early detec-*
23 *tion, prevention, services, supports, or inter-*
24 *vention of autism spectrum disorder.*

25 “(C) *SERVICES.*—

1 “(i) *IN GENERAL.*—A center of excel-
2 lence that receives funding under this para-
3 graph may expend amounts provided under
4 a grant or contract under such paragraph
5 to carry out a program to make individuals
6 aware of opportunities to participate as
7 subjects in research conducted by the center.

8 “(ii) *REFERRALS AND COSTS.*—A pro-
9 gram carried out under clause (i) may, in
10 accordance with such criteria as the Direc-
11 tor may establish, provide to the subjects de-
12 scribed in such clause, referrals for health
13 and other services and reimbursement of
14 care for individuals as are required for such
15 research.

16 “(iii) *AVAILABILITY AND ACCESS.*—The
17 extent to which a center of excellence that
18 receives funding under this paragraph can
19 demonstrate the availability of and access to
20 clinical services shall be considered by the
21 Director in making decisions concerning the
22 awarding of grants or contracts to appli-
23 cants that meet the scientific criteria for
24 funding under this section.

1 “(D) *COORDINATION OF CENTERS OF EX-*
2 *CELLENCE.—The Director shall provide for the*
3 *appropriate coordination of information among*
4 *centers of excellence that receive funding under*
5 *this paragraph and ensure regular communica-*
6 *tion between such centers.*

7 “(E) *ORGANIZATION.—A center of excellence*
8 *that receives funding under this paragraph shall*
9 *use the facilities of a single institution, or be*
10 *formed through a consortium of cooperating in-*
11 *stitutions, that meets such requirements as may*
12 *be required by the Director.*

13 “(F) *DURATION.—The term of a grant or*
14 *contract awarded under this paragraph shall not*
15 *exceed a period of 5 years. Such period may be*
16 *extended for 1 or more additional periods not ex-*
17 *ceeding 5 years if the operations of the center of*
18 *excellence involved have been reviewed by an ap-*
19 *propriate technical and scientific peer review*
20 *group established by the Director and the group*
21 *has recommended to the Director the extension of*
22 *such period.*

23 “(G) *GEOGRAPHIC DIVERSITY.—The Direc-*
24 *tor shall consider geographic diversity in award-*
25 *ing centers of excellence.*

1 “(2) *CENTERS OF EXCELLENCE IN ENVIRON-*
2 *MENTAL HEALTH AND AUTISM.—*

3 “(A) *IN GENERAL.—The Director shall, sub-*
4 *ject to the availability of appropriations, award*
5 *grants or contracts to public or nonprofit private*
6 *entities to pay all or part of the cost of plan-*
7 *ning, establishing, improving, and providing*
8 *basic operating support for centers of excellence*
9 *regarding environmental health and autism spec-*
10 *trum disorder.*

11 “(B) *RESEARCH.—A center of excellence es-*
12 *tablished under this paragraph shall conduct*
13 *basic and clinical research of a broad array of*
14 *environmental factors that may have a possible*
15 *role in autism spectrum disorder.*

16 “(C) *COORDINATION AND ORGANIZATION.—*
17 *The Secretary, acting through the Director of*
18 *NIH, shall apply to the centers under this para-*
19 *graph the same requirements concerning coordi-*
20 *nation, reporting, and organization as the re-*
21 *quirements applied to the centers of excellence*
22 *under subparagraphs (D), (E), (F), and (G) of*
23 *paragraph (1).*

24 “(d) *COLLECTION AND STORAGE OF DATA.—*

1 “(1) *IN GENERAL.*—*The Secretary, acting*
2 *through the Director and in coordination with the Di-*
3 *rector of the Centers for Disease Control and Preven-*
4 *tion, shall, subject to the availability of appropria-*
5 *tions, establish and provide funding for mechanisms*
6 *and entities that provide for the collection, storage,*
7 *coordination, and public availability of data that is*
8 *collected by the centers of excellence under this section,*
9 *under section 399AA(b), and under section 409C(c)*
10 *and, to the extent possible, data generated from public*
11 *and private research partnerships. In establishing*
12 *such mechanisms and entities, the Secretary—*

13 “(A) *shall ensure that there is data sharing*
14 *among autism spectrum disorder researchers;*
15 *and*

16 “(B) *may utilize existing facilities.*

17 “(2) *FACILITATION OF RESEARCH.*—

18 “(A) *ESTABLISHMENT OF PROGRAM.*—*The*
19 *Secretary shall establish a program under which*
20 *samples of tissues and genetic and other biologi-*
21 *cal materials that are of use in research on au-*
22 *tism spectrum disorder are donated, collected,*
23 *preserved, and made available for such research.*

1 “(B) *ACCEPTED SCIENTIFIC STANDARDS.*—
2 *The program established under paragraph (1)*
3 *shall be—*

4 “(i) *carried out in accordance with ac-*
5 *cepted scientific and medical standards for*
6 *the donation, collection, and preservation of*
7 *such samples; and*

8 “(ii) *conducted so that the tissues and*
9 *other materials saved, as well as any data-*
10 *base compiled from such tissues and mate-*
11 *rials, are available to researchers at a rea-*
12 *sonable cost and on an expedited basis.*

13 “(e) *CONSOLIDATION.*—*The Secretary, acting through*
14 *the Director, may consolidate program activities under this*
15 *section if such consolidation would improve program effi-*
16 *ciencies and outcomes.*

17 “(f) *AUTHORIZATION OF APPROPRIATIONS.*—

18 “(1) *IN GENERAL.*—*There is authorized to be ap-*
19 *propriated—*

20 “(A) *\$68,000,000 for fiscal year 2007,*
21 *\$82,000,000 for fiscal year 2008, \$96,000,000 for*
22 *fiscal year 2009, \$120,000,000 for fiscal year*
23 *2010, and \$134,000,000 for fiscal year 2011, to*
24 *carry out subsections (a), (b), and (d);*

1 **“PART R—PROGRAMS RELATING TO AUTISM**

2 **“SEC. 399AA. DEVELOPMENTAL DISABILITIES SURVEIL-**
3 **LANCE AND RESEARCH PROGRAM.**

4 “(a) *AUTISM SPECTRUM DISORDER AND OTHER DE-*
5 *VELOPMENTAL DISABILITIES.*—

6 “(1) *IN GENERAL.*—*The Secretary, acting*
7 *through the Director of the Centers for Disease Con-*
8 *trol and Prevention, may award grants or cooperative*
9 *agreements to eligible entities for the collection, anal-*
10 *ysis, and reporting of State epidemiological data on*
11 *autism spectrum disorder and other developmental*
12 *disabilities. An eligible entity shall assist with the de-*
13 *velopment and coordination of State autism spectrum*
14 *disorder and other developmental disability surveil-*
15 *lance efforts within a region. In making such awards,*
16 *the Secretary may provide direct technical assistance*
17 *in lieu of cash.*

18 “(2) *DATA STANDARDS.*—*In submitting epi-*
19 *demiological data to the Secretary pursuant to sub-*
20 *section (a), an eligible entity shall report data accord-*
21 *ing to guidelines prescribed by the Director of the*
22 *Centers for Disease Control and Prevention, after con-*
23 *sultation with relevant State and local public health*
24 *officials, private sector developmental disability re-*
25 *searchers, and advocates for individuals with autism*
26 *spectrum disorder or other developmental disabilities.*

1 “(3) *ELIGIBILITY.*—*To be eligible to receive an*
2 *award under paragraph (1), an entity shall be a pub-*
3 *lic or nonprofit private entity (including a health de-*
4 *partment of a State or a political subdivision of a*
5 *State, a university, or any other educational institu-*
6 *tion), and submit to the Secretary an application at*
7 *such time, in such manner, and containing such in-*
8 *formation as the Secretary may require.*

9 “(b) *CENTERS OF EXCELLENCE IN AUTISM SPECTRUM*
10 *DISORDER EPIDEMIOLOGY.*—

11 “(1) *IN GENERAL.*—*The Secretary, acting*
12 *through the Director of the Centers for Disease Con-*
13 *trol and Prevention, shall, subject to the availability*
14 *of appropriations, award grants or cooperative agree-*
15 *ments for the establishment of regional centers of ex-*
16 *cellence in autism spectrum disorder and other devel-*
17 *opmental disabilities epidemiology for the purpose of*
18 *collecting and analyzing information on the number,*
19 *incidence, correlates and causes of autism spectrum*
20 *disorder and other developmental disabilities.*

21 “(2) *REQUIREMENTS.*—*To be eligible to receive a*
22 *grant or cooperative agreement under paragraph (1),*
23 *an entity shall submit to the Secretary an applica-*
24 *tion containing such agreements and information as*
25 *the Secretary may require, including an agreement*

1 *that the center to be established under the grant or co-*
2 *operative agreement shall operate in accordance with*
3 *the following:*

4 “(A) *The center will collect, analyze, and*
5 *report autism spectrum disorder and other devel-*
6 *opmental disability data according to guidelines*
7 *prescribed by the Director of the Centers for Dis-*
8 *ease Control and Prevention, after consultation*
9 *with relevant State and local public health offi-*
10 *cial, private sector developmental disability re-*
11 *searchers, and advocates for individuals with de-*
12 *velopmental disabilities.*

13 “(B) *The center will develop or extend an*
14 *area of special research expertise (including ge-*
15 *netics, epigenetics, epidemiological research re-*
16 *lated to environmental exposures), immunology,*
17 *and other relevant research specialty areas.*

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

23 “(c) *FEDERAL RESPONSE.—The Secretary shall co-*
24 *ordinate the Federal response to requests for assistance from*
25 *State health, mental health, and education department offi-*

1 cials regarding potential or alleged autism spectrum dis-
 2 order or developmental disability clusters.

3 “(d) *DEFINITIONS.*—*In this part:*

4 “(1) *OTHER DEVELOPMENTAL DISABILITIES.*—
 5 *The term ‘other developmental disabilities’ has the*
 6 *meaning given the term ‘developmental disability’ in*
 7 *section 102(8) of the Developmental Disabilities As-*
 8 *sistance and Bill of Rights Act of 2000 (42 U.S.C.*
 9 *15002(8)).*

10 “(2) *STATE.*—*The term ‘State’ means each of the*
 11 *several States, the District of Columbia, the Common-*
 12 *wealth of Puerto Rico, American Samoa, Guam, the*
 13 *Commonwealth of the Northern Mariana Islands, the*
 14 *Virgin Islands, and the Trust Territory of the Pacific*
 15 *Islands.*

16 “(e) *AUTHORIZATION OF APPROPRIATIONS.*—*To carry*
 17 *out this section, there is authorized to be appropriated,*
 18 *\$15,000,000 for fiscal year 2007, and such sums as may*
 19 *be necessary for each of fiscal years 2008 through 2011.*

20 “(f) *SUNSET.*—*This section shall not apply after Sep-*
 21 *tember 30, 2011.*

22 **“SEC. 399BB. AUTISM EDUCATION, EARLY DETECTION, AND**
 23 **INTERVENTION .**

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

1 “(1) to increase awareness, reduce barriers to
2 screening and diagnosis, promote evidence-based
3 interventions for individuals with autism spectrum
4 disorder or other developmental disabilities, and train
5 professionals to utilize valid and reliable screening
6 tools to diagnose or rule out and provide evidence-
7 based interventions for children with autism spectrum
8 disorder and other developmental disabilities; and

9 “(2) to conduct activities under this section with
10 a focus on an interdisciplinary approach (as defined
11 in programs developed under section 501(a)(2) of the
12 Social Security Act) that will also focus on specific
13 issues for children who are not receiving an early di-
14 agnosis and subsequent interventions.

15 “(b) *IN GENERAL.*—The Secretary shall, subject to the
16 availability of appropriations, establish and evaluate ac-
17 tivities to—

18 “(1) provide information and education on au-
19 tism spectrum disorder and other developmental dis-
20 abilities to increase public awareness of developmental
21 milestones;

22 “(2) promote research into the development and
23 validation of reliable screening tools for autism spec-
24 trum disorder and other developmental disabilities

1 *and disseminate information regarding those screen-*
2 *ing tools;*

3 “(3) *promote early screening of individuals at*
4 *higher risk for autism spectrum disorder and other*
5 *developmental disabilities as early as practicable,*
6 *given evidence-based screening techniques and inter-*
7 *ventions;*

8 “(4) *increase the number of individuals who are*
9 *able to confirm or rule out a diagnosis of autism*
10 *spectrum disorder and other developmental disabil-*
11 *ities;*

12 “(5) *increase the number of individuals able to*
13 *provide evidence-based interventions for individuals*
14 *diagnosed with autism spectrum disorder or other de-*
15 *velopmental disabilities; and*

16 “(6) *promote the use of evidence-based interven-*
17 *tions for individuals at higher risk for autism spec-*
18 *trum disorder and other developmental disabilities as*
19 *early as practicable.*

20 “(c) *INFORMATION AND EDUCATION.—*

21 “(1) *IN GENERAL.—In carrying out subsection*
22 *(b)(1), the Secretary, in collaboration with the Sec-*
23 *retary of Education and the Secretary of Agriculture,*
24 *shall, subject to the availability of appropriations,*
25 *provide culturally competent information regarding*

1 *autism spectrum disorder and other developmental*
2 *disabilities, risk factors, characteristics, identifica-*
3 *tion, diagnosis or rule out, and evidence-based inter-*
4 *ventions to meet the needs of individuals with autism*
5 *spectrum disorder or other developmental disabilities*
6 *and their families through—*

7 *“(A) Federal programs, including—*

8 *“(i) the Head Start program;*

9 *“(ii) the Early Start program;*

10 *“(iii) the Healthy Start program;*

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

13 *“(v) programs under title XIX of the*
14 *Social Security Act (particularly the Med-*
15 *icaid Early and Periodic Screening, Diag-*
16 *nosis and Treatment Program);*

17 *“(vi) the program under title XXI of*
18 *the Social Security Act (the State Chil-*
19 *dren’s Health Insurance Program);*

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

23 *“(viii) the program under parts B and*
24 *C of the Individuals with Disabilities Edu-*
25 *cation Act;*

1 “(ix) the special supplemental nutri-
2 tion program for women, infants, and chil-
3 dren established under section 17 of the
4 Child Nutrition Act of 1966 (42 U.S.C.
5 1786); and

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

8 “(B) State licensed child care facilities; and

9 “(C) other community-based organizations
10 or points of entry for individuals with autism
11 spectrum disorder and other developmental dis-
12 abilities to receive services.

13 “(2) LEAD AGENCY.—

14 “(A) DESIGNATION.—The governor of a
15 State shall designate a public agency as a lead
16 agency to coordinate the activities provided for
17 under paragraph (1) in the State at the State
18 level.

19 “(B) INFORMATION.—The Governor or a
20 State, acting through the lead agency under sub-
21 paragraph (A), shall make available to individ-
22 uals and their family members, guardians, advo-
23 cates, or authorized representatives, providers,
24 and other appropriate individuals in the State,
25 comprehensive culturally competent information

1 *about State and local resources regarding autism*
 2 *spectrum disorder and other developmental dis-*
 3 *abilities, risk factors, characteristics, identifica-*
 4 *tion, diagnosis or rule out, available services and*
 5 *supports, and evidence-based interventions. Such*
 6 *information shall be provided through—*

7 *“(i) toll-free telephone numbers;*

8 *“(ii) Internet websites;*

9 *“(iii) mailings; or*

10 *“(iv) other means as the Governor may*
 11 *require.*

12 *“(C) REQUIREMENTS OF AGENCY.—In des-*
 13 *ignating the lead agency under subparagraph*
 14 *(A), the Governor shall—*

15 *“(i) select an agency that has dem-*
 16 *onstrated experience and expertise in—*

17 *“(I) autism spectrum disorder*
 18 *and other developmental disability*
 19 *issues; and*

20 *“(II) developing, implementing,*
 21 *conducting, and administering pro-*
 22 *grams and delivering education, infor-*
 23 *mation, and referral services (includ-*
 24 *ing technology-based curriculum-devel-*
 25 *opment services) to individuals with*

1 *developmental disabilities and their*
2 *family members, guardians, advocates*
3 *or authorized representatives, pro-*
4 *viders, and other appropriate individ-*
5 *uals locally and across the State; and*
6 *“(ii) consider input from individuals*
7 *with developmental disabilities and their*
8 *family members, guardians, advocates or*
9 *authorized representatives, providers, and*
10 *other appropriate individuals.*

11 *“(d) TOOLS.—*

12 *“(1) IN GENERAL.—To promote the use of valid*
13 *and reliable screening tools for autism spectrum dis-*
14 *order and other developmental disabilities, the Sec-*
15 *retary shall develop a curriculum for continuing edu-*
16 *cation to assist individuals in recognizing the need*
17 *for valid and reliable screening tools and the use of*
18 *such tools.*

19 *“(2) COLLECTION, STORAGE, COORDINATION, AND*
20 *AVAILABILITY.—The Secretary, in collaboration with*
21 *the Secretary of Education, shall provide for the col-*
22 *lection, storage, coordination, and public availability*
23 *of tools described in paragraph (1), educational mate-*
24 *rials and other products that are used by the Federal*

1 *programs referred to in subsection (c)(1)(A), as well*
2 *as—*

3 *“(A) programs authorized under the Devel-*
4 *opmental Disabilities Assistance and Bill of*
5 *Rights Act of 2000;*

6 *“(B) early intervention programs or inter-*
7 *agency coordinating council’s authorized under*
8 *part C of the Individuals with Disabilities Edu-*
9 *cation Act; and*

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

13 *“(3) REQUIRED SHARING.—In establishing*
14 *mechanisms and entities under this subsection, the*
15 *Secretary, and the Secretary of Education, shall en-*
16 *sure the sharing of tools, materials, and products de-*
17 *veloped under this subsection among entities receiving*
18 *funding under this section.*

19 *“(e) DIAGNOSIS.—*

20 *“(1) TRAINING.—The Secretary, in coordination*
21 *with activities conducted under title V of the Social*
22 *Security Act, shall, subject to the availability of ap-*
23 *propriations, expand existing interdisciplinary train-*
24 *ing opportunities or opportunities to increase the*
25 *number of sites able to diagnose or rule out individ-*

1 *uals with autism spectrum disorder or other develop-*
2 *mental disabilities and ensure that—*

3 *“(A) competitive grants or cooperative*
4 *agreements are awarded to public or non-profit*
5 *agencies, including institutions of higher edu-*
6 *cation, to expanding existing or develop new ma-*
7 *ternal and child health interdisciplinary leader-*
8 *ship education in neurodevelopmental and re-*
9 *lated disabilities programs (similar to the pro-*
10 *grams developed under section 501(a)(2) of the*
11 *Social Security Act) in States that do not have*
12 *such a program;*

13 *“(B) trainees under such training pro-*
14 *grams—*

15 *“(i) receive an appropriate balance of*
16 *academic, clinical, and community oppor-*
17 *tunities;*

18 *“(ii) are culturally competent;*

19 *“(iii) are ethnically diverse;*

20 *“(iv) demonstrate a capacity to evalu-*
21 *ate, diagnose or rule out, develop, and pro-*
22 *vide evidence-based interventions to individ-*
23 *uals with autism spectrum disorder and*
24 *other developmental disabilities; and*

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

3 “(C) *program sites provide culturally com-*
4 *petent services.*

5 “(2) *TECHNICAL ASSISTANCE.—The Secretary*
6 *may award one or more grants under this section to*
7 *provide technical assistance to the network of inter-*
8 *disciplinary training programs.*

9 “(3) *BEST PRACTICES.—The Secretary shall pro-*
10 *mote research into additional valid and reliable tools*
11 *for shortening the time required to confirm or rule*
12 *out a diagnosis of autism spectrum disorder or other*
13 *developmental disabilities and detecting individuals*
14 *with autism spectrum disorder or other developmental*
15 *disabilities at an earlier age.*

16 “(f) *INTERVENTION.—The Secretary shall promote re-*
17 *search, through grants or contracts, to determine the evi-*
18 *dence-based practices for interventions for individuals with*
19 *autism spectrum disorder or other developmental disabil-*
20 *ities, develop guidelines for those interventions, and dis-*
21 *seminate information related to such research and guide-*
22 *lines.*

23 “(g) *AUTHORIZATION OF APPROPRIATIONS.—To carry*
24 *out this section, there is authorized to be appropriated,*
25 *\$32,000,000 for fiscal year 2007, \$37,000,000 for fiscal year*

1 2008, \$42,000,000 for fiscal year 2009, \$47,000,000 for fis-
 2 cal year 2010, and \$52,000,000 for fiscal year 2011, of
 3 which—

4 “(1) \$5,000,000 shall be made available in each
 5 fiscal year for activities described in subsection (c);
 6 and

7 “(2) \$3,000,000 shall be made available in fiscal
 8 year 2007, \$6,000,000 in fiscal year 2008, \$9,000,000
 9 in fiscal year 2009, \$12,000,000 in fiscal year 2010,
 10 and \$15,000,000 in fiscal year 2011, for activities de-
 11 scribed in subsection (f).

12 “(h) *SUNSET*.—This section shall not apply after Sep-
 13 tember 30, 2011.

14 **“SEC. 399CC. INTERAGENCY AUTISM COORDINATING COM-
 15 MITTEE.**

16 “(a) *ESTABLISHMENT*.—The Secretary shall establish
 17 a committee, to be known as the ‘Interagency Autism Co-
 18 ordinating Committee’ (in this section referred to as the
 19 ‘Committee’), to coordinate all efforts within the Depart-
 20 ment of Health and Human Services concerning autism
 21 spectrum disorder.

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

24 “(1) make recommendations concerning the stra-
 25 tegic plan described in section 409C(a);

1 “(2) *develop and annually update advances in*
2 *autism spectrum disorder research related to causes,*
3 *early screening, diagnosis or rule out, intervention,*
4 *and access to services and supports for individuals*
5 *with autism spectrum disorder; and*

6 “(3) *make recommendations to the Secretary re-*
7 *garding the public participation in decisions relating*
8 *to autism spectrum disorder.*

9 “(c) *MEMBERSHIP.—*

10 “(1) *IN GENERAL.—The Committee shall be com-*
11 *posed of—*

12 “(A) *the Director of the Centers for Disease*
13 *Control and Prevention;*

14 “(B) *the Director of the National Institutes*
15 *of Health, and the Directors of such national re-*
16 *search institutes of the National Institutes of*
17 *Health as the Secretary determines appropriate;*

18 “(C) *the heads of such other agencies as the*
19 *Secretary determines appropriate;*

20 “(D) *representatives of other Federal Gov-*
21 *ernmental agencies that serve individuals with*
22 *autism spectrum disorder such as the Depart-*
23 *ment of Education; and*

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

1 “(2) *ADDITIONAL MEMBERS.*—Not fewer than 6
2 *members of the Committee, or 1/3 of the total member-*
3 *ship of the Committee, whichever is greater, shall be*
4 *composed of non-federal public members to be ap-*
5 *pointed by the Secretary, of which—*

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

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

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

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

19 “(1) *The Committee shall receive necessary and*
20 *appropriate administrative support from the Sec-*
21 *retary.*

22 “(2) *Members of the Committee appointed under*
23 *subsection (c)(2) shall serve for a term of 4 years, and*
24 *may be reappointed for one or more additional 4 year*
25 *term. Any member appointed to fill a vacancy for an*

1 *unexpired term shall be appointed for the remainder*
2 *of such term. A member may serve after the expira-*
3 *tion of the member's term until a successor has taken*
4 *office.*

5 *“(3) The Committee shall meet at the call of the*
6 *chairperson or upon the request of the Secretary. The*
7 *Committee shall meet not fewer than 2 times each*
8 *year.*

9 *“(4) All meetings of the Committee shall be pub-*
10 *lic and shall include appropriate time periods for*
11 *questions and presentations by the public.*

12 *“(e) COMPENSATION AND EXPENSES.—Members of the*
13 *Committee who are officers or employees of the Federal Gov-*
14 *ernment shall serve as members of the Committee without*
15 *compensation in addition to that received in their regular*
16 *government employment. Other members of the Committee*
17 *shall receive compensation at rates not to exceed the daily*
18 *equivalent of the annual rate in effect for grade GS-18 of*
19 *the General Schedule for each day (including travel time)*
20 *they are engaged in the performance of their duties as mem-*
21 *bers of the Committee.*

22 *“(f) SUBCOMMITTEES; ESTABLISHMENT AND MEMBER-*
23 *SHIP.—In carrying out its functions, the Committee may*
24 *establish subcommittees and convene workshops and con-*
25 *ferences. Such subcommittees shall be composed of Com-*

1 *mittee members and may hold such meetings as are nec-*
2 *essary to enable the subcommittees to carry out their duties.*

3 “(g) *AUTHORIZATION OF APPROPRIATIONS.—To carry*
4 *out this section, there is authorized to be appropriated, such*
5 *sums as may be necessary for each of fiscal years 2007*
6 *through 2011.*

7 “(h) *SUNSET.—This section shall not apply after Sep-*
8 *tember 30, 2011 and the Committee shall be terminated on*
9 *such date.*

10 **“SEC. 399DD. REPORT TO CONGRESS.**

11 “(a) *IN GENERAL.—Not later than 4 years after the*
12 *date of enactment of the Combating Autism Act of 2006,*
13 *the Secretary, in coordination with the Secretary of Edu-*
14 *cation, shall prepare and submit to the Health, Education,*
15 *Labor, and Pensions Committee of the Senate and the En-*
16 *ergy and Commerce Committee of the House of Representa-*
17 *tives a progress report on activities related to autism spec-*
18 *trum disorder and other developmental disabilities.*

19 “(b) *CONTENTS.—The report submitted under sub-*
20 *section (a) shall contain—*

21 “(1) *a description of the progress made in imple-*
22 *menting the provisions of the Combating Autism Act*
23 *of 2006;*

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

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

8 “(4) information on the average age of diagnosis
9 for children with autism spectrum disorder and other
10 disabilities, including how that age may have
11 changed over the 4-year period beginning on the date
12 of enactment of this Act;

13 “(5) information on the average age for interven-
14 tion for individuals diagnosed with autism spectrum
15 disorder and other developmental disabilities, includ-
16 ing how that age may have changed over the 4-year
17 period beginning on the date of enactment of this Act;

18 “(6) information on the average time between
19 initial screening and then diagnosis or rule out for
20 individuals with autism spectrum disorder or other
21 developmental disabilities, as well as information on
22 the average time between diagnosis and evidence-
23 based intervention for individuals with autism spec-
24 trum disorder or other developmental disabilities;

1 “(7) information on the effectiveness and out-
2 comes of interventions for individuals diagnosed with
3 autism spectrum disorder, including by various
4 subtypes, and other developmental disabilities and
5 how the age of the child may affect such effectiveness;

6 “(8) information on the effectiveness and out-
7 comes of innovative and newly developed intervention
8 strategies for individuals with autism spectrum dis-
9 order or other developmental disabilities; and

10 “(9) information on services and supports pro-
11 vided to individuals with autism spectrum disorder
12 and other developmental disabilities who have reached
13 the age of majority (as defined for purposes of section
14 615(m) of the Individuals with Disabilities Education
15 Act (20 U.S.C. 1415(m)).”.

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

18 (1) *Section 101 (42 U.S.C. 247b–4a) relating to*
19 *research activities at the National Institutes of*
20 *Health.*

21 (2) *Section 102 (42 U.S.C. 247b–4b) relating to*
22 *the Developmental Disabilities Surveillance and Re-*
23 *search Program.*

24 (3) *Section 103 (42 U.S.C. 247b–4c) relating to*
25 *information and education.*

1 (4) *Section 104 (42 U.S.C. 247b-4d) relating to*
2 *the Inter-Agency Autism Coordinating Committee.*

3 (5) *Section 105 (42 U.S.C. 247b-4e) relating to*
4 *reports.*

Calendar No. 578

109TH CONGRESS
2^D SESSION

S. 843

[Report No. 109-318]

A BILL

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

August 3, 2006

Reported with an amendment