

109TH CONGRESS  
1ST SESSION

# S. 843

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 and Mr. DODD) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

---

## A BILL

To amend the Public Health Service Act to 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:

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

2   **“SEC. 499A. AUTHORITY OF THE DIRECTOR OF THE NA-**  
3                   **TIONAL INSTITUTES OF HEALTH RELATING**  
4                   **TO AUTISM.**

5           “(a) IDENTIFYING TOTAL EXPENDITURES ON AU-  
6 TISM SPECTRUM DISORDERS.—The Director of NIH, in  
7 coordination with the National Institute of Mental Health  
8 and other institutes of the National Institutes of Health,  
9 shall identify the total amount of expenditures, both intra-  
10 mural and extramural, by the National Institutes of  
11 Health for autism spectrum disorders for fiscal year 2005.

12           “(b) BUDGET FOR AUTISM RESEARCH AND COORDI-  
13 NATION OF ACTIVITIES AND PROGRAMS.—The Director of  
14 NIH, based on the strategic plan developed under sub-  
15 section (c), shall—

16                   “(1) develop and oversee the implementation of  
17 a scientifically justified budget for research on au-  
18 tism spectrum disorders at the National Institutes of  
19 Health;

20                   “(2) coordinate all research activities and pro-  
21 grams on autism spectrum disorders at the insti-  
22 tutes, centers, and divisions of the National Insti-  
23 tutes of Health; and

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

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

1           “(1) IN GENERAL.—The Director of NIH shall  
2           develop and oversee the implementation of a com-  
3           prehensive, long-range plan for the conduct and sup-  
4           port of research on autism spectrum disorders by  
5           the institutes, centers, and divisions of the National  
6           Institutes of Health.

7           “(2) REQUIREMENTS.—The plan developed  
8           under paragraph (1) shall—

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

10                   “(B) be based on the research rec-  
11                   ommendations contained in the Autism Re-  
12                   search Roadmap and Matrix of the Interagency  
13                   Autism Coordinating Committee;

14                   “(C) determine and establish priorities  
15                   among critical scientific questions related to au-  
16                   tism spectrum disorders;

17                   “(D) based on the priorities established  
18                   under subparagraph (C), specify the short and  
19                   long-range objectives to be achieved, and esti-  
20                   mate the resources needed to achieve these ob-  
21                   jectives;

22                   “(E) evaluate the sufficiency of existing re-  
23                   search programs on autism spectrum disorders  
24                   to meet the objectives specified under subpara-  
25                   graph (D), and establish objectives, timelines,

1 and criteria for evaluating future research pro-  
2 grams; and

3 “(F) make recommendations for changes  
4 to existing research programs on autism spec-  
5 trum disorders.

6 “(d) BUDGETARY AUTHORITY.—

7 “(1) IN GENERAL.—The Director of NIH  
8 shall—

9 “(A) in accordance with the strategic plan  
10 developed under subsection (c), annually pre-  
11 pare and submit to Congress a scientifically jus-  
12 tified budget estimate for research on autism  
13 spectrum disorders to be conducted within the  
14 agencies of the National Institutes of Health,  
15 which shall include the amount of funds that  
16 will be required for—

17 “(i) the continued funding of ongoing  
18 discretionary program initiatives at the in-  
19 stitutes, centers, and divisions of the Na-  
20 tional Institutes of Health; and

21 “(ii) the funding of new and com-  
22 plementary program initiatives.

23 “(B) receive all research funds for autism  
24 spectrum disorders described in subparagraph  
25 (A), and allocate those funds to the institutes,

1 centers, and divisions of the National Institutes  
2 of Health.

3 “(2) EFFECTIVE DATE.—Paragraph (1)(B)  
4 shall become effective in the fiscal year following the  
5 submission of the autism budget described in para-  
6 graph (1)(A).

7 “(e) EVALUATION AND REPORT.—

8 “(1) EVALUATION.—The Director of NIH shall  
9 evaluate the effect of this section on the planning  
10 and coordination of research programs on autism  
11 spectrum disorders at the institutes, centers, and di-  
12 visions of the National Institutes of Health, and the  
13 extent to which funding mandated under this section  
14 has followed the recommendation of the strategic  
15 plan developed under subsection (c).

16 “(2) REPORT.—Not later than 1 year after the  
17 date of enactment of this section, the Director of  
18 NIH shall prepare and submit to the Committee on  
19 Energy and Commerce and the Committee on Ap-  
20 propriations of the House of Representatives, and  
21 the Committee on Health, Education, Labor, and  
22 Pensions and the Committee on Appropriations of  
23 the Senate, a report based on the evaluation de-  
24 scribed in paragraph (1).

1 **“SEC. 499B. EXPANSION, INTENSIFICATION, AND COORDI-**  
2 **NATION OF ACTIVITIES OF NATIONAL INSTI-**  
3 **TUTES OF HEALTH WITH RESPECT TO RE-**  
4 **SEARCH ON AUTISM.**

5 “(a) IN GENERAL.—

6 “(1) EXPANSION OF ACTIVITIES.—The Director  
7 of NIH shall expand, intensify, and coordinate the  
8 activities of the National Institutes of Health with  
9 respect to research on autism.

10 “(2) ADMINISTRATION OF PROGRAM; COORDI-  
11 NATION AMONG AGENCIES.—The Director of NIH  
12 shall carry out this section acting through the Direc-  
13 tor of the National Institute of Mental Health and  
14 in collaboration with the National Institute of Child  
15 Health and Human Development, the National In-  
16 stitute of Neurological Disorders and Stroke, the  
17 National Institute of Environmental Health  
18 Sciences, the National Institute on Deafness and  
19 Other Communication Disorders, and any other  
20 agencies that the Director determines appropriate.

21 “(b) CENTERS OF EXCELLENCE.—

22 “(1) IN GENERAL.—In carrying out subsection  
23 (a)(1), the Director of NIH shall award grants and  
24 contracts to public or nonprofit private entities to  
25 pay all or part of the cost of planning, establishing,

1 improving, and providing basic operating support for  
2 centers of excellence regarding research on autism.

3 “(2) RESEARCH.—Each center of excellence  
4 that receives funding under paragraph (1) shall con-  
5 duct basic and clinical research into autism. Such  
6 research—

7 “(A) shall be conducted in the fields of de-  
8 velopmental neurobiology, genetics, and  
9 psychopharmacology, and, beginning on July 1,  
10 2008, immunology, endocrinology, gastro-  
11 enterology, and toxicology; and

12 “(B) should include—

13 “(i) investigations into the cause, di-  
14 agnosis, early detection, prevention, con-  
15 trol, treatment, and cure of autism; and

16 “(ii) research on high-risk infant sib-  
17 lings.

18 “(3) SERVICES FOR PATIENTS.—

19 “(A) IN GENERAL.—A center of excellence  
20 that receives funding under paragraph (1) may  
21 expend amounts provided under a grant or con-  
22 tract under such paragraph to carry out a pro-  
23 gram to make individuals aware of opportuni-  
24 ties to participate as subjects in research con-  
25 ducted by the centers.

1           “(B) REFERRALS AND COSTS.—A program  
2 carried out under subparagraph (A) may, in ac-  
3 cordance with such criteria as the Director of  
4 NIH may establish, provide to the subjects de-  
5 scribed in such subparagraph, referrals for  
6 health and other services, and such patient care  
7 costs as are required for research.

8           “(C) AVAILABILITY AND ACCESS.—The ex-  
9 tent to which a center of excellence that re-  
10 ceives funding under paragraph (1) can dem-  
11 onstrate availability and access to clinical serv-  
12 ices shall be considered by the Director of NIH  
13 in decisions about awarding grants or contracts  
14 to applicants that meet the scientific criteria for  
15 funding under this section.

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

18           “(A) IN GENERAL.—The Director of NIH  
19 shall, as appropriate, provide for the coordina-  
20 tion of information among centers of excellence  
21 that receive funding under paragraph (1) and  
22 centers of excellence that receive funding under  
23 section 463C, and ensure regular communica-  
24 tion between such centers.



1           “(B) PERIODIC REPORTS.—The Director  
2 of NIH may require the periodic preparation of  
3 reports on the activities of the centers described  
4 in subparagraph (A) and the submission of  
5 such reports to the Director.

6           “(C) COLLECTION AND STORAGE OF  
7 DATA.—The Director of NIH shall establish  
8 and fund mechanisms and entities for col-  
9 lecting, storing, and coordinating data collected  
10 by the centers referred to in subparagraph (A)  
11 and data generated from public and private re-  
12 search partnerships.

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

19           “(6) NUMBER AND DURATION.—

20           “(A) IN GENERAL.—The Director shall  
21 provide for the establishment of not less than  
22 10 centers under paragraph (1).

23           “(B) DURATION.—A grant or contract  
24 awarded under paragraph (1) shall not exceed  
25 a period of 5 years. Such period may be ex-

1 tended for 1 or more additional periods not ex-  
2 ceeding 5 years if the operations of the center  
3 of excellence involved have been reviewed by an  
4 appropriate technical and scientific peer review  
5 group established by the Director of NIH and  
6 the group has recommended to the Director  
7 that such period should be extended.

8 “(C) FACILITATION OF RESEARCH.—

9 “(i) ESTABLISHMENT OF PROGRAM.—

10 The Director of NIH shall establish a pro-  
11 gram under which samples of tissues and  
12 genetic and other biological materials that  
13 are of use in research on autism are do-  
14 nated, collected, preserved, and made avail-  
15 able for such research.

16 “(ii) ACCEPTED SCIENTIFIC STAND-  
17 ARDS.—The program established under  
18 clause (i) shall be carried out in accord-  
19 ance with accepted scientific and medical  
20 standards for the donation, collection, and  
21 preservation of such samples, and shall be  
22 conducted so that the tissues and other  
23 materials saved, as well as any database  
24 compiled from such tissues and materials,

1 are available to researchers at a reasonable  
2 cost.

3 “(D) PUBLIC INPUT.—In carrying out this  
4 section, the Director of NIH shall provide for a  
5 means through which the public can obtain in-  
6 formation on the existing and planned pro-  
7 grams and activities of the National Institutes  
8 of Health with respect to autism and through  
9 which the Director can receive comments from  
10 the public regarding such programs and activi-  
11 ties.

12 “(c) AUTHORIZATION OF APPROPRIATIONS.—There  
13 is authorized to be appropriated to carry out this section,  
14 \$30,000,000 for each of fiscal years 2007 through 2011.  
15 Amounts appropriated under this subsection shall be in  
16 addition to any other amounts appropriated for such pur-  
17 pose.

18 **“SEC. 499C. COLLABORATIVE PROGRAMS OF EXCELLENCE**  
19 **IN AUTISM.**

20 “(a) IN GENERAL.—The Director of NIH, acting  
21 through the Director of the National Institute of Child  
22 Health and Human Development and the Director of the  
23 National Institute on Deafness and Other Disorders, shall  
24 award grants and contracts to public or nonprofit private  
25 entities to pay all or part of the cost of planning, estab-

1 lishing, improving, and providing basic operating support  
 2 for the Collaborative Programs of Excellence in Autism.

3 “(b) RESEARCH.—Each program established under  
 4 subsection (a) shall conduct basic and clinical research  
 5 into autism. Such program—

6 “(1) shall conduct research in the fields of de-  
 7 velopmental neurobiology, genetics, and  
 8 psychopharmacology, and, beginning July 1, 2008,  
 9 in the fields of immunology, endocrinology, gastro-  
 10 enterology, and toxicology; and

11 “(2) should conduct—

12 “(A) investigations into the cause, diag-  
 13 nosis, early detection, prevention, control, treat-  
 14 ment, and cure of autism; and

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

16 “(c) COORDINATION OF PROGRAMS.—

17 “(1) IN GENERAL.—The Director of NIH shall,  
 18 as appropriate, provide for the coordination of infor-  
 19 mation among programs established under sub-  
 20 section (a), and centers of excellence that receive  
 21 funding under section 463C and 499B, and ensure  
 22 regular communication between such centers.

23 “(2) PERIODIC REPORTS.—The Director of  
 24 NIH may require the periodic preparation of reports  
 25 on the activities of the programs described in para-

1 graph (1) and the submission of such reports to the  
2 Director.

3 “(3) COLLECTION AND STORAGE OF DATA.—

4 The Director of NIH shall establish and fund mech-  
5 anisms and entities for collecting, storing, and co-  
6 ordinating data collected by the programs referred  
7 to in paragraph (1) and data generated from public  
8 and private research partnerships.

9 “(d) ORGANIZATION.—Each program that receives  
10 funding under subsection (a) shall use the facilities of a  
11 single institution, or be formed from a consortium of co-  
12 operating institutions, meeting such requirements as may  
13 be prescribed by the Director of NIH.

14 “(e) NUMBER AND DURATION.—

15 “(1) IN GENERAL.—The Director shall provide  
16 for the establishment of not less than 10 programs  
17 under paragraph (1).

18 “(2) DURATION.—A grant or contract awarded  
19 under subsection (a) shall not exceed a period of 5  
20 years. Such period may be extended for 1 or more  
21 additional periods not exceeding 5 years if the oper-  
22 ations of the program involved have been reviewed  
23 by an appropriate technical and scientific peer re-  
24 view group established by the Director of NIH and

1 the group has recommended to the Director that  
2 such period should be extended.

3 “(f) AUTHORIZATION OF APPROPRIATIONS.—There  
4 is authorized to be appropriated to carry out this section,  
5 \$14,000,000 for each of fiscal years 2007 through 2011.  
6 Amounts appropriated under this subsection shall be in  
7 addition to any other amounts appropriated for such pur-  
8 pose.”.

9 **SEC. 3. DEVELOPMENTAL DISABILITIES SURVEILLANCE**  
10 **AND RESEARCH PROGRAM.**

11 Title III of the Public Health Service Act (42 U.S.C.  
12 241 et seq.) is amended by adding at the end thereof the  
13 following:

14 **“PART R—PROGRAMS RELATING TO AUTISM**  
15 **“SEC. 399AA. DEVELOPMENTAL DISABILITIES SURVEIL-**  
16 **LANCE AND RESEARCH PROGRAM.**

17 “(a) NATIONAL AUTISM AND PERVASIVE DEVELOP-  
18 MENTAL DISABILITIES SURVEILLANCE PROGRAM.—

19 “(1) IN GENERAL.—The Secretary, acting  
20 through the Director of the Centers for Disease  
21 Control and Prevention, may award grants and co-  
22 operative agreements to eligible entities for the col-  
23 lection, analysis, and reporting of epidemiological  
24 data on autism and pervasive developmental disabil-

1 ities. In making such awards, the Secretary may  
2 provide direct technical assistance in lieu of cash.

3 “(2) ELIGIBILITY.—To be eligible to receive a  
4 grant or cooperative agreement under paragraph (1),  
5 an entity shall be a public or nonprofit private entity  
6 (including a health department of a State or political  
7 subdivisions of a State, a university, or any other  
8 educational institution), and submit to the Secretary  
9 an application at such time, in such manner, and  
10 containing such information as the Secretary may  
11 require.

12 “(b) CENTERS OF EXCELLENCE IN AUTISM AND  
13 PERVASIVE DEVELOPMENTAL DISABILITIES EPIDEMI-  
14 OLOGY.—

15 “(1) IN GENERAL.—The Secretary, acting  
16 through the Director of the Centers for Disease  
17 Control and Prevention, shall establish not less than  
18 6 regional centers of excellence in autism and perva-  
19 sive developmental disabilities epidemiology for the  
20 purpose of collecting and analyzing information on  
21 the number, incidence, incidence trend over time,  
22 correlates, and causes of autism and related develop-  
23 mental disabilities.

24 “(2) RECIPIENTS OF AWARDS.—Each center of  
25 excellence under paragraph (1) shall be established

1 and operated through the awarding of grants or co-  
2 operative agreements to public or nonprofit private  
3 entities that conduct research, including health de-  
4 partments of States and political subdivisions of  
5 States, and universities and other educational enti-  
6 ties.

7 “(3) REQUIREMENTS.—To be eligible to receive  
8 a grant or cooperative agreement under paragraph  
9 (2), an entity shall submit to the Secretary an appli-  
10 cation containing such agreements and information  
11 as the Secretary may require, including an agree-  
12 ment that the center to be established shall operate  
13 in accordance with the following:

14 “(A) The center will collect, analyze, and  
15 report autism and pervasive developmental dis-  
16 abilities data according to guidelines prescribed  
17 by the Director of the Centers for Disease Con-  
18 trol and Prevention, after consultation with rel-  
19 evant State and local public health officials, pri-  
20 vate sector developmental disability researchers,  
21 and advocates for those with developmental dis-  
22 abilities.

23 “(B) The center will assist with the devel-  
24 opment and coordination of State autism and



1 pervasive developmental disabilities surveillance  
2 efforts within a region.

3 “(C) The center will identify eligible cases  
4 and controls through its surveillance systems  
5 and conduct research into factors which may  
6 cause or increase the risk of autism and related  
7 developmental disabilities.

8 “(D) The center will develop or extend an  
9 area of special research expertise (including ge-  
10 netics, environmental exposure to contaminants,  
11 immunology, and other relevant research spe-  
12 cialty areas).

13 “(c) CLEARINGHOUSE.—The Secretary, acting  
14 through the Director of the Centers for Disease Control  
15 and Prevention, shall carry out the following:

16 “(1) ESTABLISHMENT.—The Secretary shall es-  
17 tablish a clearinghouse within the Centers for Dis-  
18 ease Control and Prevention for the collection and  
19 storage of data generated from the monitoring pro-  
20 grams established under this part and part J of title  
21 IV. Through the clearinghouse, such Centers shall  
22 serve as the coordinating agency for autism and per-  
23 vasive developmental disabilities surveillance activi-  
24 ties. The functions of such clearinghouse shall in-  
25 clude facilitating the coordination of research and

1 policy development relating to the epidemiology of  
2 autism and other pervasive developmental disabili-  
3 ties.

4 “(2) FEDERAL RESPONSE.—The Secretary shall  
5 coordinate the Federal response to requests for as-  
6 sistance from State health department officials re-  
7 garding potential or alleged autism or developmental  
8 disability clusters.

9 “(3) FACILITATION OF RESEARCH.—The Sec-  
10 retary shall provide for the establishment of a pro-  
11 gram under which samples of tissues and genetic  
12 and other biological materials that are of use in re-  
13 search on autism are donated, collected, preserved,  
14 and made available for such research. Such program  
15 shall be carried out in accordance with accepted sci-  
16 entific and medical standards for the donation, col-  
17 lection, and preservation of such samples, and shall  
18 be conducted so that the tissues and other materials  
19 saved, as well as any database compiled from such  
20 tissues and materials, are available to researchers at  
21 a reasonable cost.

22 “(4) COORDINATION.—The Centers for Disease  
23 Control and Prevention shall coordinate research  
24 and surveillance activities of such Centers with the  
25 National Institutes of Health, other appropriate

1 Federal agencies, and interested nonprofit private  
2 entities, in a manner consistent with the research  
3 recommendations contained in the Autism Research  
4 Roadmap and Matrix of the Interagency Autism Co-  
5 ordinating Committee, which shall be updated as de-  
6 termined appropriate by the Secretary.

7 “(d) STATE.—In this part, the term ‘State’ means  
8 each of the several States, the District of Columbia, the  
9 Commonwealth of Puerto Rico, American Samoa, Guam,  
10 the Commonwealth of the Northern Mariana Islands, the  
11 Virgin Islands, and the Trust Territory of the Pacific Is-  
12 lands.

13 “(e) AUTHORIZATION OF APPROPRIATIONS.—There  
14 is authorized to be appropriated to carry out this section,  
15 \$12,000,000 for each of fiscal years 2007 through 2011.

16 **“SEC. 399BB. INFORMATION AND EDUCATION RELATING TO**  
17 **AUTISM.**

18 “(a) IN GENERAL.—The Secretary shall establish  
19 and implement a program to provide information and edu-  
20 cation on autism and its risk factors to health profes-  
21 sionals and the general public, including information and  
22 education on advances in the diagnosis and treatment of  
23 autism and training and continuing education through  
24 programs for scientists, physicians, and other health pro-  
25 fessionals who provide care for patients with autism. The

1 program shall place special emphasis on early identifica-  
2 tion of autism and those at risk for autism and prompt  
3 referral for appropriate services.

4 “(b) STIPENDS.—The Secretary may use amounts  
5 made available under this section to provide stipends for  
6 health professionals who are enrolled in training programs  
7 under this section.

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

11 **“SEC. 399CC. INTERAGENCY AUTISM COORDINATING COM-  
12 MITTEE.**

13 “(a) ESTABLISHMENT.—The Secretary shall estab-  
14 lish a committee to be known as the ‘Autism Coordinating  
15 Committee’ (in this section referred to as the ‘Committee’)  
16 to coordinate all efforts within the Department of Health  
17 and Human Services concerning autism, including activi-  
18 ties carried out through the National Institutes of Health  
19 and the Centers for Disease Control and Prevention under  
20 the amendments made by the National Autism Research  
21 Act.

22 “(b) MEMBERSHIP.—

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

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

3           “(B) the Directors of such national re-  
4           search institutes of the National Institutes of  
5           Health as the Secretary determines appropriate;

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

8           “(D) the additional members appointed  
9           under paragraph (2) (if any).

10          “(2) ADDITIONAL MEMBERS.—If determined  
11          appropriate by the Secretary, the Secretary may ap-  
12          point to the Committee—

13               “(A) individuals with autism or other per-  
14               vasive developmental disorders;

15               “(B) parents or legal guardians of individ-  
16               uals with autism or other pervasive develop-  
17               mental disorders;

18               “(C) representatives of leading autism re-  
19               search and service organizations; and

20               “(D) representatives of other governmental  
21               agencies that serve children with autism such  
22               as the Department of Education.

23          “(c) ADMINISTRATIVE SUPPORT; TERMS OF SERV-  
24          ICES; OTHER PROVISIONS.—The following shall apply  
25          with respect to the Committee:

1           “(1) The Committee shall receive necessary and  
2 appropriate administrative support from the Sec-  
3 retary.

4           “(2) Members of the Committee appointed  
5 under subsection (b)(2)(A) shall serve for a term of  
6 3 years, and may serve for an unlimited number of  
7 terms if reappointed.

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

10 **“SEC. 399DD. SCREENING, DIAGNOSIS, AND TREATMENT OF**  
11 **AUTISM; MEDICAL CARE FOR INDIVIDUALS**  
12 **WITH AUTISM.**

13           “(a) STATEWIDE AUTISM SCREENING, DIAGNOSIS,  
14 AND INTERVENTION PROGRAMS AND SYSTEMS.—

15           “(1) IN GENERAL.—The Secretary, acting  
16 through the Administrator of the Health Resources  
17 and Services Administration, shall award grants or  
18 cooperative agreements to eligible entities to develop  
19 statewide autism screening, diagnosis, and interven-  
20 tion programs and systems for the purposes de-  
21 scribed in paragraph (2).

22           “(2) PURPOSES.—The purposes described in  
23 this paragraph are the following:

24           “(A) To develop and monitor the efficacy  
25 of statewide autism screening, diagnosis, and

1 intervention programs and systems, ensuring  
2 that all children are screened for autism before  
3 their second birthday, and that children at risk  
4 for autism receive appropriate services as early  
5 as possible. Intervention includes referral to  
6 schools and agencies, including community, con-  
7 sumer, and parent-based agencies, and organi-  
8 zations and other programs mandated by part  
9 C of the Individuals with Disabilities Education  
10 Act, which offer programs specifically designed  
11 to meet the unique needs of children with au-  
12 tism.

13 “(B) To collect data on statewide autism  
14 screening, diagnosis, and intervention programs  
15 and systems that can be used for applied re-  
16 search, program evaluation, and policy develop-  
17 ment.

18 “(C) To provide comprehensive medical  
19 care for individuals with autism through evi-  
20 dence-based practices, with specific attention to  
21 medical conditions that may be associated with  
22 autism, and to disseminate information on the  
23 medical care of individuals with autism to  
24 health professionals and the general public. In  
25 carrying out the program under this paragraph,

1 a grant shall be awarded to a national organiza-  
2 tion that will establish and support regional  
3 centers of clinical excellence to provide medical  
4 care to individuals with autism and promote re-  
5 search aimed at improving the treatment of  
6 such individuals, and that will build a shared  
7 national medical database to record the results  
8 of treatments and studies at the regional cen-  
9 ters.

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

15 “(b) TECHNICAL ASSISTANCE, DATA MANAGEMENT,  
16 AND APPLIED RESEARCH.—The Secretary, acting  
17 through the Director of the Centers for Disease Control  
18 and Prevention, shall award grants or cooperative agree-  
19 ments to provide technical assistance to State agencies to  
20 conduct applied research related to autism screening, diag-  
21 nosis, and intervention programs and systems. In carrying  
22 out this section the Secretary shall develop standardized  
23 procedures for data management and program effective-  
24 ness and costs, including procedures—



1           “(1) to ensure quality monitoring of autism  
2 screening, diagnosis, and intervention programs and  
3 systems;

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

6           “(3) to study the costs and effectiveness of au-  
7 tism screening, diagnosis, and intervention programs  
8 and systems conducted by State-based programs in  
9 order to address issues of importance to State and  
10 national policymakers;

11          “(4) to identify the causes and risk factors for  
12 autism;

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

18          “(6) to promote the sharing of data regarding  
19 autism with State-based birth defects and develop-  
20 mental disabilities monitoring programs and environ-  
21 mental discharge monitoring programs of the Envi-  
22 ronmental Protection Agency for the purpose of  
23 identifying previously unknown causes of and risk  
24 factors for autism.

25          “(c) COORDINATION AND COLLABORATION.—

1           “(1) IN GENERAL.—In carrying out programs  
2 under this section, the Administrator of the Health  
3 Resources and Services Administration, the Director  
4 of the Centers for Disease Control and Prevention,  
5 and the Director of the National Institutes of Health  
6 shall collaborate and consult with—

7           “(A) other Federal, State and local agen-  
8 cies, including those responsible for early inter-  
9 vention services pursuant to title XIX of the  
10 Social Security Act (particularly the Medicaid  
11 Early and Periodic Screening, Diagnosis and  
12 Treatment Program), title XXI of the Social  
13 Security Act (State Children’s Health Insur-  
14 ance Program), title V of the Social Security  
15 Act (Maternal and Child Health Block Grant  
16 Program), and part C of the Individuals with  
17 Disabilities Education Act;

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

20           “(C) appropriate national medical and  
21 other health and education specialty organiza-  
22 tions;

23           “(D) individuals with autism and their  
24 families;

1           “(E) other qualified personnel who possess  
2           the specialized knowledge, skills, and attributes  
3           needed to serve autistic children and their fami-  
4           lies; and

5           “(F) related commercial industries.

6           “(2) POLICY DEVELOPMENT.—The Adminis-  
7           trator of the Health Resources and Services Adminis-  
8           tration, the Director of the Centers for Disease  
9           Control and Prevention, and the Director of the Na-  
10          tional Institutes of Health shall coordinate and col-  
11          laborate on recommendations for policy development  
12          at the Federal and State levels and with the private  
13          sector, including consumer, medical, and other  
14          health and education professional-based organiza-  
15          tions, with respect to autism screening, diagnosis,  
16          and intervention programs and systems.

17          “(3) STATE EARLY DETECTION, DIAGNOSIS,  
18          AND INTERVENTION PROGRAMS AND SYSTEMS.—The  
19          Administrator of the Health Resources and Services  
20          Administration and the Director of the Centers for  
21          Disease Control and Prevention shall coordinate and  
22          collaborate in assisting States to establish autism  
23          screening, diagnosis, and intervention programs and  
24          systems under subsection (a) and to develop a data  
25          collection system under subsection (b).

1       “(d) PHYSICIAN REIMBURSEMENT FOR DEVELOP-  
2 MENT SCREENING.—To make developmental screening  
3 more readily available, the Secretary, acting through the  
4 Administrator of the Centers for Medicare & Medicaid  
5 Services, shall assign a relative value unit to the diagnostic  
6 code for developmental screening.

7       “(e) AUTHORIZATION OF APPROPRIATIONS.—There  
8 is authorized to be appropriated—

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

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

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

14       “(a) IN GENERAL.—Not later than January 1, 2006,  
15 and each January 1 thereafter, the Secretary shall prepare  
16 and submit to the appropriate committees of Congress, a  
17 report concerning the implementation of this part and part  
18 J of title IV.

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

21               “(1) provide the dollar amount that each insti-  
22 tute of the National Institutes of Health expended  
23 on autism research in the year for which the report  
24 was prepared; and

1           “(2) detail the progress and success of the Na-  
2           tional Institutes of Health in implementing and  
3           funding the recommendations contained in the Au-  
4           tism Research Roadmap and Matrix of the Inter-  
5           agency Autism Coordinating Committee.”.

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

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

10 **“SEC. 463C. ENVIRONMENTAL HEALTH RESEARCH PRO-**  
11 **GRAMS.**

12           “(a) **CENTERS OF EXCELLENCE.**—The Director of  
13           NIH, acting through the Director of the Institute, shall  
14           awards grants and contracts to public or nonprofit private  
15           entities to pay all or part of the cost of planning, estab-  
16           lishing, improving, and providing basic operating support  
17           for centers of excellence regarding environmental health  
18           and autism.

19           “(b) **RESEARCH.**—Each center of excellence under  
20           subsection (a) shall conduct basic and clinical research  
21           into possible environmental causes of and risk factors for  
22           autism and the mechanisms by which they may lead to  
23           autism, and the developmental effects of environmental  
24           agents that may be associated with autism.

1       “(c) COORDINATION; REPORTS.—The Director of  
2 NIH shall, as appropriate, provide for the coordination of  
3 information among centers of excellence established under  
4 subsection (a) and section 499B and ensure regular com-  
5 munication between such centers. The Director may re-  
6 quire the periodic preparation of reports on the activities  
7 of the centers and the submission of such reports to the  
8 Director. The Director shall establish and fund mecha-  
9 nisms and entities for collecting, storing, and coordinating  
10 data collected by the centers established under this section  
11 and data generated from public and private research part-  
12 nerships.

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

18       “(e) NUMBER OF CENTERS; DURATION.—

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

22                       “(A) DURATION.—A grant or contract  
23 awarded under subsection (a) shall not exceed  
24 a period of 5 years. Such period may be ex-  
25 tended for 1 or more additional periods not ex-

1           ceeding 5 years if the operations of the center  
2           of excellence involved have been reviewed by an  
3           appropriate technical and scientific peer review  
4           group established by the Director of NIH and  
5           the group has recommended to the Director  
6           that such period should be extended.

7           “(f) AUTHORIZATION OF APPROPRIATIONS.—There  
8           is authorized to be appropriated to carry out this section,  
9           \$6,000,000 for each of fiscal years 2007 through 2011.”.

○