

106TH CONGRESS
1ST SESSION

S. 512

To amend the Public Health Service Act to provide for the expansion, intensification, and coordination of the activities of the Department of Health and Human Services with respect to research on autism.

IN THE SENATE OF THE UNITED STATES

MARCH 2, 1999

Mr. GORTON (for himself, Mrs. FEINSTEIN, Mr. LAUTENBERG, Mr. TORRICELLI, Mr. LIEBERMAN, and Mr. EDWARDS) 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 provide for the expansion, intensification, and coordination of the activities of the Department of Health and Human Services with respect to research on autism.

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 “Advancement in Pedi-
5 atric Autism Research Act”.

6 **SEC. 2. FINDINGS.**

7 The Congress finds as follows:

1 (1) Infantile autism and autism spectrum dis-
2 orders are biologically-based neurodevelopmental dis-
3 eases that cause severe impairments in language and
4 communication and generally manifest in young chil-
5 dren sometime during the first two years of life.

6 (2) Best estimates indicate that 1 in 500 chil-
7 dren born today will be diagnosed with an autism
8 spectrum disorder and that 400,000 Americans have
9 autism or an autism spectrum disorder.

10 (3) There is little information on the prevalence
11 of autism and other pervasive developmental disabili-
12 ties in the United States. There have never been
13 any national prevalence studies in the United States,
14 and the two studies that were conducted in the
15 1980s examined only selected areas of the country.
16 Recent studies in Canada, Europe, and Japan sug-
17 gest that the prevalence of classic autism alone may
18 be 300 percent to 400 percent higher than pre-
19 viously estimated.

20 (4) Three quarters of those with infantile au-
21 tism spend their adult lives in institutions or group
22 homes, and usually enter institutions by the age of
23 13.

24 (5) The cost of caring for individuals with au-
25 tism and autism spectrum disorder is great, and is

1 estimated to be \$13.3 billion per year solely for di-
2 rect costs.

3 (6) The rapid advancements in biomedical
4 science suggest that effective treatments and a cure
5 for autism are attainable if—

6 (A) there is appropriate coordination of the
7 efforts of the various agencies of the Federal
8 Government involved in biomedical research on
9 autism and autism spectrum disorders;

10 (B) there is an increased understanding of
11 autism and autism spectrum disorders by the
12 scientific and medical communities involved in
13 autism research and treatment; and

14 (C) sufficient funds are allocated to re-
15 search.

16 (7) The discovery of effective treatments and a
17 cure for autism will be greatly enhanced when sci-
18 entists and epidemiologists have an accurate under-
19 standing of the prevalence and incidence of autism.

20 (8) Recent research suggests that environ-
21 mental factors may contribute to autism. As a re-
22 sult, contributing causes of autism, if identified, may
23 be preventable.

24 (9) Finding the answers to the causes of autism
25 and related developmental disabilities may help re-

1 searchers to understand other disorders, ranging
2 from learning problems, to hyperactivity, to commu-
3 nications deficits that affect millions of Americans.

4 (10) Specifically, more knowledge is needed
5 concerning—

6 (A) the underlying causes of autism and
7 autism spectrum disorders, how to treat the un-
8 derlying abnormality or abnormalities causing
9 the severe symptoms of autism, and how to pre-
10 vent these abnormalities from occurring in the
11 future;

12 (B) the epidemiology of, and the identifica-
13 tion of risk factors for, infantile autism and au-
14 tism spectrum disorders;

15 (C) the development of methods for early
16 medical diagnosis and functional assessment of
17 individuals with autism and autism spectrum
18 disorders, including identification and assess-
19 ment of the subtypes within the autism spec-
20 trum disorders, for the purpose of monitoring
21 the course of the disease and developing medi-
22 cally sound strategies for improving the out-
23 comes of such individuals;

24 (D) existing biomedical and diagnostic
25 data that are relevant to autism and autism

1 spectrum disorders for dissemination to medical
 2 personnel, particularly pediatricians, to aid in
 3 the early diagnosis and treatment of this dis-
 4 ease; and

5 (E) the costs incurred in educating and
 6 caring for individuals with autism and autism
 7 spectrum disorders.

8 (11) In 1998, the National Institutes of Health
 9 announced a program of research on autism and au-
 10 tism spectrum disorders. A sufficient level of fund-
 11 ing should be made available for carrying out the
 12 program.

13 **SEC. 3. EXPANSION, INTENSIFICATION, AND COORDINA-**
 14 **TION OF ACTIVITIES OF NATIONAL INSTI-**
 15 **TUTES OF HEALTH WITH RESPECT TO RE-**
 16 **SEARCH ON AUTISM.**

17 Part B of title IV of the Public Health Service Act
 18 (42 U.S.C. 284 et seq.) is amended by adding at the end
 19 the following section:

20 "AUTISM

21 "SEC. 409C. (a) IN GENERAL.—

22 "(1) EXPANSION OF ACTIVITIES.—The Director
 23 of NIH (in this section referred to as the 'Director')
 24 shall expand, intensify, and coordinate the activities
 25 of the National Institutes of Health with respect to
 26 research on autism.

1 “(2) ADMINISTRATION OF PROGRAM; COLLABO-
2 RATION AMONG AGENCIES.—The Director shall carry
3 out this section acting through the Director of the
4 National Institute of Mental Health and in collabo-
5 ration with any other agencies that the Director de-
6 termines appropriate.

7 “(b) CENTERS OF EXCELLENCE.—

8 “(1) IN GENERAL.—The Director shall under
9 subsection (a)(1) make awards of grants and con-
10 tracts to public or nonprofit private entities to pay
11 all or part of the cost of planning, establishing, im-
12 proving, and providing basic operating support for
13 centers of excellence regarding research on autism.

14 “(2) RESEARCH.—Each center under para-
15 graph (1) shall conduct basic and clinical research
16 into the cause, diagnosis, early detection, prevention,
17 control, and treatment of autism, including research
18 in the fields of developmental neurobiology, genetics,
19 and psychopharmacology.

20 “(3) SERVICES FOR PATIENTS.—A center under
21 paragraph (1) may expend amounts provided under
22 such paragraph to carry out a program to make in-
23 dividuals aware of opportunities to participate as
24 subjects in research conducted by the centers. The
25 program may provide fees to such subjects. The pro-

1 gram may, in accordance with such criteria as the
2 Director may establish, provide to such subjects
3 health care, referrals for health and other services,
4 and such incidental services as will facilitate the par-
5 ticipation of individuals as such subjects.

6 “(4) COORDINATION OF CENTERS; REPORTS.—
7 The Director shall, as appropriate, provide for the
8 coordination of information among centers under
9 paragraph (1) and ensure regular communication
10 between such centers, and may require the periodic
11 preparation of reports on the activities of the centers
12 and the submission of the reports to the Director.

13 “(5) ORGANIZATION OF CENTERS.—Each cen-
14 ter under paragraph (1) shall use the facilities of a
15 single institution, or be formed from a consortium of
16 cooperating institutions, meeting such requirements
17 as may be prescribed by the Director.

18 “(6) NUMBER OF CENTERS; DURATION OF SUP-
19 PORT.—The Director shall, subject to the extent of
20 amounts made available in appropriations Acts, pro-
21 vide for the establishment of not less than five cen-
22 ters under paragraph (1). Support of such a center
23 may be for a period not exceeding 5 years. Such pe-
24 riod may be extended for one or more additional pe-
25 riods not exceeding 5 years if the operations of such

1 center have been reviewed by an appropriate tech-
2 nical and scientific peer review group established by
3 the Director and if such group has recommended to
4 the Director that such period should be extended.

5 “(c) FACILITATION OF RESEARCH.—The Director
6 shall under subsection (a)(1) provide for a program under
7 which samples of tissues and genetic materials that are
8 of use in research on autism are donated, collected, pre-
9 served, and made available for such research. The pro-
10 gram shall be carried out in accordance with accepted sci-
11 entific and medical standards for the donation, collection,
12 and preservation of such samples.

13 “(d) PUBLIC INPUT.—The Director shall under sub-
14 section (a)(1) provide for means through which the public
15 can obtain information on the existing and planned pro-
16 grams and activities of the National Institutes of Health
17 with respect to autism and through which the Director can
18 receive comments from the public regarding such pro-
19 grams and activities.

20 “(e) FUNDING.—For the purpose of carrying out this
21 section, there are authorized to be appropriated
22 \$33,000,000 for fiscal year 2000, and such sums as may
23 be necessary for each of the fiscal years 2001 through
24 2004. Such authorizations of appropriations are in addi-

1 tion to any other authorization of appropriations that is
2 available for such purpose.”.

3 **SEC. 4. DEVELOPMENTAL DISABILITIES SURVEILLANCE**
4 **AND RESEARCH PROGRAMS.**

5 (a) NATIONAL AUTISM AND PERVASIVE DEVELOP-
6 MENTAL DISABILITIES SURVEILLANCE PROGRAM.—The
7 Secretary of Health and Human Services (in this Act re-
8 ferred to as the “Secretary”), acting through the Director
9 of the Centers for Disease Control and Prevention, may
10 make awards of grants and cooperative agreements for the
11 collection, analysis, and reporting of data on autism and
12 pervasive developmental disabilities. An entity may receive
13 such an award only if the entity is a public or nonprofit
14 private entity (including health departments of States and
15 political subdivisions of States, and including universities
16 and other educational entities). In making such awards,
17 the Secretary may provide direct technical assistance in
18 lieu of cash.

19 (b) CENTERS OF EXCELLENCE IN AUTISM AND PER-
20 VASIVE DEVELOPMENTAL DISABILITIES EPIDEMIOLOG-
21 OGY.—

22 (1) IN GENERAL.—The Secretary, acting
23 through the Director of the Centers for Disease
24 Control and Prevention, shall (subject to the extent
25 of amounts made available in appropriations Acts)

1 establish not less than 3, and not more than 5, re-
2 gional centers of excellence in autism and pervasive
3 developmental disabilities epidemiology for the pur-
4 pose of collecting and analyzing information on the
5 number, incidence, correlates, and causes of autism
6 and related developmental disabilities.

7 (2) RECIPIENTS OF AWARDS FOR ESTABLISH-
8 MENT OF CENTERS.—Centers under paragraph (1)
9 shall be established and operated through the award-
10 ing of grants or cooperative agreements to public or
11 nonprofit private entities that conduct research, in-
12 cluding health departments of States and political
13 subdivisions of States, and including universities and
14 other educational entities.

15 (3) CERTAIN REQUIREMENTS.—An award for a
16 center under paragraph (1) may be made only if the
17 entity involved submits to the Secretary an applica-
18 tion containing such agreements and information as
19 the Secretary may require, including an agreement
20 that the center involved will operate in accordance
21 with the following:

22 (A) The center will collect, analyze, and re-
23 port autism and pervasive developmental dis-
24 abilities data according to guidelines prescribed
25 by the Director, after consultation with relevant

1 State and local public health officials, private
2 sector developmental disability researchers, and
3 advocates for those with developmental disabili-
4 ties.

5 (B) The center will assist with the develop-
6 ment and coordination of State autism and per-
7 vasive developmental disabilities surveillance ef-
8 forts within a region.

9 (C) The center will provide education,
10 training, and clinical skills improvement for
11 health professionals aimed at better under-
12 standing and treatment of autism and related
13 developmental disabilities.

14 (D) The center will identify eligible cases
15 and controls through its surveillance systems
16 and conduct research into factors which may
17 cause autism and related developmental disabili-
18 ties. Each program will develop or extend an
19 area of special research expertise (including ge-
20 netics, environmental exposure to contaminants,
21 immunology, and other relevant research spe-
22 cialty areas).

23 (e) CLEARINGHOUSE.—The Secretary, acting
24 through the Director of the Centers for Disease Control
25 and Prevention, shall carry out the following:

1 (1) The Secretary shall establish a clearing-
2 house within the Centers for Disease Control and
3 Prevention for the collection and storage of data
4 generated from the monitoring programs created by
5 this Act. Through the clearinghouse, such Centers
6 shall serve as the coordinating agency for autism
7 and pervasive developmental disabilities surveillance
8 activities. The functions of such a clearinghouse
9 shall include facilitating the coordination of research
10 and policy development relating to the epidemiology
11 of autism and other pervasive developmental disabili-
12 ties.

13 (2) The Secretary, acting through the Centers
14 for Disease Control and Prevention, shall coordinate
15 the Federal response to requests for assistance from
16 State health department officials regarding potential
17 or alleged autism or developmental disability clus-
18 ters.

19 (d) DEFINITION.—In this Act, the term “State”
20 means each of the several States, the District of Columbia,
21 the Commonwealth of Puerto Rico, American Samoa,
22 Guam, the Commonwealth of the Northern Mariana Is-
23 lands, the Virgin Islands, and the Trust Territory of the
24 Pacific Islands.

1 (e) AUTHORIZATION OF APPROPRIATIONS.—To carry
2 out this section, there is authorized to be appropriated
3 \$7,500,000 for each of the fiscal years 2000 through
4 2004.

5 **SEC. 5. INFORMATION AND EDUCATION.**

6 (a) IN GENERAL.—The Secretary shall establish and
7 implement a program to provide information and edu-
8 cation on autism to health professionals and the general
9 public, including information and education on advances
10 in the diagnosis and treatment of autism and training and
11 continuing education through programs for scientists, phy-
12 sicians, and other health professionals who provide care
13 for patients with autism.

14 (b) STIPENDS.—The Secretary may use amounts
15 made available under this section to provide stipends for
16 health professionals who are enrolled in training programs
17 under this section.

18 (c) AUTHORIZATION OF APPROPRIATIONS.—To carry
19 out this section, there is authorized to be appropriated
20 \$6,000,000 for each of the fiscal years 2000 through
21 2004.

22 **SEC. 6. INTER-AGENCY AUTISM COORDINATING COMMIT-**
23 **TEE.**

24 (a) ESTABLISHMENT.—The Secretary shall establish
25 a committee to be known as the “Autism Coordinating

1 Committee” (in this section referred to as the “Commit-
2 tee”) to coordinate all efforts within the Department of
3 Health and Human Services concerning autism, including
4 activities carried out through the National Institutes of
5 Health and the Centers for Disease Control and Preven-
6 tion under this Act (and the amendment made by this
7 Act).

8 (b) MEMBERSHIP.—

9 (1) IN GENERAL.—The Committee shall be
10 composed of the Directors of such national research
11 institutes, of the Centers for Disease Control and
12 Prevention, and of such other agencies and such
13 other officials as the Secretary determines appro-
14 priate.

15 (2) ADDITIONAL MEMBERS.—If determined ap-
16 propriate by the Secretary, the Secretary may ap-
17 point to the Committee—

18 (A) parents or legal guardians of individ-
19 uals with autism or other pervasive develop-
20 mental disorders; and

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

1 (c) ADMINISTRATIVE SUPPORT; TERMS OF SERVICE;
2 OTHER PROVISIONS.—The following shall apply with re-
3 spect to the Committee:

4 (1) The Committee shall receive necessary and
5 appropriate administrative support from the Depart-
6 ment of Health and Human Services.

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

11 (3) The Committee shall meet not less than 2
12 times per year.

13 (4) Members of the Committee shall not receive
14 additional compensation for their service. Such
15 members may receive reimbursement for appropriate
16 and additional expenses that are incurred through
17 service on the Committee which would not have in-
18 curred had they not been a member of the Commit-
19 tee.

20 **SEC. 7. REPORT TO CONGRESS.**

21 Not later than January 1, 2000, and each January
22 1 thereafter, the Secretary shall prepare and submit to
23 the appropriate committees of Congress, a report concern-

- 1 ing the implementation of this Act and the amendments
- 2 made by this Act.

