

106TH CONGRESS  
1ST SESSION

# H. R. 997

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

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## IN THE HOUSE OF REPRESENTATIVES

MARCH 4, 1999

Mr. GREENWOOD (for himself, Mr. SMITH of New Jersey, Mr. ACKERMAN, Mr. BALDACCI, Mr. BORSKI, Mr. BOUCHER, Mr. COSTELLO, Mr. FROST, Mr. GREEN of Texas, Mr. HINCHEY, Ms. KILPATRICK, Mr. LaFALCE, Mr. LoBiondo, Mr. McNulty, Mr. PAYNE, Ms. Ros-Lehtinen, Mr. ROTHMAN, Mr. SHAYS, Mr. SHOWS, Mrs. TAUSCHER, and Ms. VELÁZQUEZ) introduced the following bill; which was referred to the Committee on Commerce

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## A BILL

To amend the Public Health Service Act to provide for the expansion, intensification, and coordination of the activities of the National Institutes of Health 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”.

1 **SEC. 2. FINDINGS.**

2 The Congress finds as follows:

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

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

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

22 (4) Three-quarters of those with infantile au-  
23 tism spend their adult lives in institutions or group  
24 homes, and usually enter institutions by the age of  
25 13.

1           (5) The cost of caring for individuals with au-  
2           tism and autism spectrum disorder is great, and is  
3           estimated to be \$13.3 billion per year solely for di-  
4           rect costs.

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

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

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

16                   (C) sufficient funds are allocated to re-  
17                  search.

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

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

1           (9) Finding the answers to the causes of autism  
2           and related developmental disabilities may help re-  
3           searchers to understand other disorders, ranging  
4           from learning problems, to hyperactivity, to commu-  
5           nications deficits that affect millions of Americans.

6           (10) Specifically, more knowledge is needed  
7           concerning—

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

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

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

1 (D) existing biomedical and diagnostic  
 2 data that are relevant to autism and autism  
 3 spectrum disorders for dissemination to medical  
 4 personnel, particularly pediatricians, to aid in  
 5 the early diagnosis and treatment of this dis-  
 6 ease; and

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

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

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

19 Part B of title IV of the Public Health Service Act  
 20 (42 U.S.C. 284 et seq.) is amended by adding at the end  
 21 the following section:

22 “AUTISM

23 “SEC. 409C. (a) IN GENERAL.—

24 “(1) EXPANSION OF ACTIVITIES.—The Director  
 25 of NIH (in this section referred to as the ‘Director’)  
 26 shall expand, intensify, and coordinate the activities

1 of the National Institutes of Health with respect to  
2 research on autism.

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

9 “(b) CENTERS OF EXCELLENCE.—

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

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

22 “(3) SERVICES FOR PATIENTS.—A center under  
23 paragraph (1) may expend amounts provided under  
24 such paragraph to carry out a program to make in-  
25 dividuals aware of opportunities to participate as

1 subjects in research conducted by the centers. The  
2 program may provide fees to such subjects. The pro-  
3 gram may, in accordance with such criteria as the  
4 Director may establish, provide to such subjects  
5 health care, referrals for health and other services,  
6 and such incidental services as will facilitate the par-  
7 ticipation of individuals as such subjects.

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

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

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

1       riod may be extended for one or more additional pe-  
2       riods not exceeding 5 years if the operations of such  
3       center have been reviewed by an appropriate tech-  
4       nical and scientific peer review group established by  
5       the Director and if such group has recommended to  
6       the Director that such period should be extended.

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

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

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



1 2004. Such authorizations of appropriations are in addi-  
2 tion to any other authorization of appropriations that is  
3 available for such purpose.”.

4 **SEC. 4. INFORMATION AND EDUCATION.**

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

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

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

21 **SEC. 5. AUTISM COORDINATING COMMITTEE.**

22 (a) ESTABLISHMENT.—The Secretary shall establish  
23 a committee to be known as the “Autism Coordinating  
24 Committee” (in this section referred to as the “Commit-  
25 tee”) to coordinate all efforts within the Department of

1 Health and Human Services concerning autism, including  
2 activities carried out through the National Institutes of  
3 Health and the Centers for Disease Control and Preven-  
4 tion under this Act (and the amendment made by this  
5 Act).

6 (b) MEMBERSHIP.—

7 (1) IN GENERAL.—The Committee shall be  
8 composed of ex officio members in accordance with  
9 paragraph (2) and 11 appointed members in accord-  
10 ance with paragraph (3).

11 (2) EX OFFICIO MEMBERS.—The following offi-  
12 cials shall serve as ex officio members of the Com-  
13 mittee:

14 (A) The Director of the National Institutes  
15 of Health.

16 (B) The Director of the National Institute  
17 on Mental Health.

18 (C) The Director of the Centers for Dis-  
19 ease Control and Prevention.

20 (D) The Administrator of the Health Re-  
21 sources and Services Administration.

22 (3) APPOINTED MEMBERS.—Appointments to  
23 the Committee shall be made in accordance with the  
24 following:

1 (A) Two members shall be research sci-  
2 entists with demonstrated achievements in re-  
3 search related to autism and related develop-  
4 mental disabilities. The scientists shall be ap-  
5 pointed by the Secretary in consultation with  
6 the National Academy of Sciences.

7 (B) Five members shall be representatives  
8 of the 5 national organizations whose primary  
9 emphasis is on research into autism and other  
10 pervasive developmental disabilities. One rep-  
11 resentative from each of such organizations  
12 shall be appointed by the Secretary in consulta-  
13 tion with the National Academy of Sciences.

14 (C) Two members shall be clinicians whose  
15 practice is primarily devoted to the treatment of  
16 individuals with autism and other pervasive de-  
17 velopmental disabilities. The clinicians shall be  
18 appointed by the Secretary in consultation with  
19 the Institute of Medicine and the National  
20 Academy of Sciences.

21 (D) Two members shall be individuals who  
22 are the parents or legal guardians of a person  
23 or persons with autism or other pervasive devel-  
24 opmental disabilities. The individuals shall be  
25 appointed by the Secretary in consultation with

1 the ex officio members under paragraph (1) and  
2 the 5 national organizations referred to in sub-  
3 paragraph (B).

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

7 (1) The Committee shall receive necessary and  
8 appropriate administrative support from the Depart-  
9 ment of Health and Human Services.

10 (2) Members of the Committee shall be ap-  
11 pointed for a term of 3 years, and may serve for an  
12 unlimited number of terms if reappointed.

13 (3) The Committee shall meet not less than 2  
14 times per year.

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

22 **SEC. 6. REPORT TO CONGRESS.**

23 Not later than January 1, 2000, and each January  
24 1 thereafter, the Secretary shall prepare and submit to  
25 the appropriate committees of Congress, a report concern-

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

