

105TH CONGRESS  
2D SESSION

# S. 2263

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 SENATE OF THE UNITED STATES

JULY 6, 1998

Mr. GORTON (for himself, Mr. LIEBERMAN, Mr. FAIRCLOTH, Mr. HARKIN, and Mrs. BOXER) introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

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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”.

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) Three quarters of those with infantile au-  
11 tism spend their adult lives in institutions or group  
12 homes, and usually enter institutions by the age of  
13 13.

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

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

21               (A) there is appropriate coordination of the  
22 efforts of the various agencies of the Federal  
23 Government involved in biomedical research on  
24 autism and autism spectrum disorders;

1 (B) there is an increased understanding of  
2 autism and autism spectrum disorders by the  
3 scientific and medical communities involved in  
4 autism research and treatment; and

5 (C) sufficient funds are allocated to re-  
6 search.

7 (6) Specifically, more knowledge is needed con-  
8 cerning—

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

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

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

1 cally sound strategies for improving the out-  
 2 comes of such individuals;

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

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

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

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

21 Part B of title IV of the Public Health Service Act  
 22 (42 U.S.C. 284 et seq.) is amended by adding at the end  
 23 the following section:

24 “AUTISM  
 25 “SEC. 409C. (a) IN GENERAL.—

1           “(1) EXPANSION OF ACTIVITIES.—The Director  
2 of NIH (in this section referred to as the ‘Director’)  
3 shall expand, intensify, and coordinate the activities  
4 of the National Institutes of Health with respect to  
5 research on autism.

6           “(2) ADMINISTRATION OF PROGRAM; COLLABO-  
7 RATION AMONG AGENCIES.—The Director shall carry  
8 out this section acting through the Director of the  
9 National Institute of Mental Health and in collabo-  
10 ration with the Director of the National Institute of  
11 Child Health and Human Development, the Director  
12 of the National Institute of Neurological Disorders  
13 and Stroke, and the Director of the National Insti-  
14 tute on Deafness and Other Communication Dis-  
15 orders.

16           “(3) AUTISM COORDINATING COMMITTEE.—The  
17 Director shall ensure that—

18           “(A) there is in operation at the National  
19 Institutes of Health a committee to coordinate,  
20 with respect to research on autism, the activi-  
21 ties of the national research institutes specified  
22 in paragraph (2); and

23           “(B) the coordinating committee is com-  
24 posed of the directors of such national research  
25 institutes and such other officials of the Na-

1           tional Institutes of Health as the Director de-  
2           termines to be appropriate.

3           “(b) CENTERS OF EXCELLENCE.—

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

10           “(2) RESEARCH, TRAINING, AND INFORMATION  
11           AND EDUCATION.—Each center under paragraph (1)  
12           shall conduct—

13           “(A) basic and clinical research into the  
14           cause, diagnosis, early detection, prevention,  
15           control, and treatment of autism, including re-  
16           search in the fields of developmental  
17           neurobiology,                   genetics,                   and  
18           psychopharmacology;

19           “(B) training programs for physicians, sci-  
20           entists, and other health and allied health pro-  
21           fessionals; and

22           “(C) information and continuing education  
23           programs for physicians and other health and  
24           allied health professionals who provide care for  
25           patients with autism.

1           “(3) SERVICES FOR PATIENTS.—A center under  
2 paragraph (1) may expend amounts provided under  
3 such paragraph to carry out a program to make in-  
4 dividuals aware of opportunities to participate as  
5 subjects in research conducted by the centers. The  
6 program may provide fees to such subjects. The pro-  
7 gram may, in accordance with such criteria as the  
8 Director may establish, provide to such subjects  
9 health care, referrals for health and other services,  
10 and such incidental services as will facilitate the par-  
11 ticipation of individuals as such subjects.

12           “(4) STIPENDS FOR TRAINING OF HEALTH PRO-  
13 FESSIONALS.—A center under paragraph (1) may  
14 expend amounts provided under such paragraph to  
15 provide stipends for health professionals enrolled in  
16 training programs under paragraph (2)(B).

17           “(5) COORDINATION OF CENTERS; REPORTS.—  
18 The Director shall, as appropriate, provide for the  
19 coordination of information among centers under  
20 paragraph (1) and ensure regular communication  
21 between such centers, and may require the periodic  
22 preparation of reports on the activities of the centers  
23 and the submission of the reports to the Director  
24 and the coordinating committee under subsection  
25 (a)(3).

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

6           “(7) NUMBER OF CENTERS; DURATION OF SUP-  
7           PORT.—The Director shall, subject to the extent of  
8           amounts made available in appropriations Acts, pro-  
9           vide for the establishment of not less than five cen-  
10          ters under paragraph (1). Support of such a center  
11          may be for a period not exceeding 5 years. Such pe-  
12          riod may be extended for one or more additional pe-  
13          riods not exceeding 5 years if the operations of such  
14          center have been reviewed by an appropriate tech-  
15          nical and scientific peer review group established by  
16          the Director and if such group has recommended to  
17          the Director that such period should be extended.

18          “(c) INFORMATION AND EDUCATION.—The Director  
19          shall under subsection (a)(1) carry out a program to pro-  
20          vide information and education on autism to health profes-  
21          sionals and the general public, including information and  
22          education on advances in the diagnosis and treatment of  
23          autism.

24          “(d) FACILITATION OF RESEARCH.—The Director  
25          shall under subsection (a)(1) provide by contract for a pro-



1 gram under which samples of tissues and genetic materials  
2 that are of use in research on autism are donated, col-  
3 lected, preserved, and made available for such research.  
4 The program shall be carried out in accordance with ac-  
5 cepted scientific and medical standards for the donation,  
6 collection, and preservation of such samples.

7 “(e) PUBLIC INPUT.—The Director shall under sub-  
8 section (a)(1) provide for means through which the public  
9 can obtain information on the existing and planned pro-  
10 grams and activities of the National Institutes of Health  
11 with respect to autism and through which the Director can  
12 receive comments from the public regarding such pro-  
13 grams and activities.

14 “(f) AUTISM SPECTRUM DISORDERS.—For purposes  
15 of this section, the term ‘autism’ includes autism spectrum  
16 disorders to the extent determined by the Director to be  
17 appropriate.

18 “(g) FUNDING.—

19 “(1) AUTHORIZATION OF APPROPRIATIONS.—  
20 For the purpose of carrying out this section, there  
21 are authorized to be appropriated \$40,000,000 for  
22 fiscal year 1999, and such sums as may be nec-  
23 essary for each of the fiscal years 2000 through  
24 2003. Such authorizations of appropriations are in

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

3 “(2) ALLOCATIONS.—Of the amounts appro-  
4 priated under paragraph (1) for a fiscal year, the  
5 Director shall make available not less than 75 per-  
6 cent for carrying out subsection (b), not less than 6  
7 percent for carrying out subsection (c), and not less  
8 than 4 percent for carrying out subsection (d).”.

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