

105<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 4725

To provide surveillance and research to better understand the prevalence and pattern of autism and other pervasive developmental disabilities so that effective treatment and prevention strategies can be implemented.

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## IN THE HOUSE OF REPRESENTATIVES

OCTOBER 7, 1998

Mr. SMITH of New Jersey introduced the following bill; which was referred to the Committee on Commerce

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## A BILL

To provide surveillance and research to better understand the prevalence and pattern of autism and other pervasive developmental disabilities so that effective treatment and prevention strategies can be implemented.

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 “Autism Statistics, Sur-  
5        veillance, Research, and Epidemiology Act of 1998 (AS-  
6        SURE)”.

7        **SEC. 2. FINDINGS.**

8        The Congress makes the following findings:

1           (1) Autism and other pervasive developmental  
2           disabilities (fragile X syndrome, Rett's syndrome,  
3           childhood disintegrative disorder, Landau-Kleffner  
4           syndrome, and pervasive developmental disorders not  
5           otherwise specified) are biologically based  
6           neurodevelopmental diseases which cause severe im-  
7           pairment in cognition, language, and affective abili-  
8           ties.

9           (2) Autism and pervasive developmental disabil-  
10          ities are not rare; they may affect as many as one  
11          in every 500 children, and more than 500,000 Amer-  
12          icans.

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

23          (4) The cost of caring for individuals with au-  
24          tism and pervasive developmental disabilities is esti-

1 mated at more than \$13,000,000,000 per year for  
2 direct costs only.

3 (5) Autism is considered by many scientists to  
4 be one of the most heritable of all the developmental  
5 disorders, and the most likely to yield to the latest  
6 scientific advancements in genetics and neurology.

7 (6) The discovery of effective treatments and a  
8 cure for autism will be greatly enhanced when sci-  
9 entists and epidemiologists have an accurate under-  
10 standing of the prevalence and incidence of autism.

11 (7) Recent research suggests that environ-  
12 mental factors may contribute to autism. As a re-  
13 sult, contributing causes of autism, if identified, may  
14 be preventable.

15 (8) Finding the answers to the causes of autism  
16 and related developmental disabilities may help re-  
17 searchers to understand other disorders, ranging  
18 from learning problems, to hyperactivity, to commu-  
19 nications deficits that affect millions of Americans.

20 **SEC. 3. DEVELOPMENTAL DISABILITIES SURVEILLANCE**  
21 **AND RESEARCH PROGRAMS.**

22 (a) NATIONAL AUTISM AND PERVASIVE DEVELOP-  
23 MENTAL DISABILITIES SURVEILLANCE PROGRAM.—The  
24 Secretary of Health and Human Services (in this Act re-  
25 ferred to as the “Secretary”), acting through the Director

1 of the Centers for Disease Control and Prevention, may  
2 make awards of grants and cooperative agreements for the  
3 collection, analysis, and reporting of data on autism and  
4 pervasive developmental disabilities. An entity may receive  
5 such an award only if the entity is a public or nonprofit  
6 private entity (including health departments of States and  
7 political subdivisions of States, and including universities  
8 and other educational entities). In making such awards,  
9 the Secretary may provide direct technical assistance in  
10 lieu of cash.

11 (b) CENTERS OF EXCELLENCE IN AUTISM AND PER-  
12 VASIVE DEVELOPMENTAL DISABILITIES EPIDEMIOLO-  
13 GY.—

14 (1) IN GENERAL.—The Secretary, acting  
15 through the Director of the Centers for Disease  
16 Control and Prevention, shall (subject to the extent  
17 of amounts made available in appropriations Acts)  
18 establish not less than three, and not more than five,  
19 regional centers of excellence in autism and perva-  
20 sive developmental disabilities epidemiology for the  
21 purpose of collecting and analyzing information on  
22 the number, incidence, correlates, and causes of au-  
23 tism and related developmental disabilities.

24 (2) RECIPIENTS OF AWARDS FOR ESTABLISH-  
25 MENT OF CENTERS.—Centers under paragraph (1)

1 shall be established and operated through the award  
2 of grants or cooperative agreements to public or  
3 nonprofit private entities that conduct research, in-  
4 cluding health departments of States and political  
5 subdivisions of States, and including universities and  
6 other educational entities.

7 (3) CERTAIN REQUIREMENTS.—An award for a  
8 center under paragraph (1) may be made only if the  
9 entity involved submits to the Secretary an applica-  
10 tion containing such agreements and information as  
11 the Secretary may require, including an agreement  
12 that the center involved will operate in accordance  
13 with the following:

14 (A) The center will collect, analyze, and re-  
15 port autism and pervasive developmental dis-  
16 abilities data according to guidelines prescribed  
17 the Director, after consultation with relevant  
18 State and local public health officials, private  
19 sector developmental disability researchers, and  
20 advocates for those with developmental disabili-  
21 ties;

22 (B) The center will assist with the develop-  
23 ment and coordination of State autism and per-  
24 vasive developmental disabilities surveillance ef-  
25 forts within a region;

1           (C) The center will provide education,  
2           training, and clinical skills improvement for  
3           health professionals aimed at better under-  
4           standing and treatment of autism and related  
5           developmental disabilities; and

6           (D) The center will identify eligible cases  
7           and controls through its surveillance systems  
8           and conduct research into factors which may  
9           cause autism and related developmental disabil-  
10          ities; each program will develop or extend an  
11          area of special research expertise (including,  
12          but not limited to, genetics, environmental ex-  
13          posure to contaminants, immunology, and other  
14          relevant research specialty areas).

15 **SEC. 4. CLEARINGHOUSE.**

16          The Secretary, acting through the Director of the  
17          Centers for Disease Control and Prevention, shall carry  
18          out the following:

19               (1) The Centers for Disease Control and Pre-  
20          vention shall serve as the coordinating agency for  
21          autism and pervasive developmental disabilities sur-  
22          veillance activities through the establishment of a  
23          clearinghouse for the collection and storage of data  
24          generated from the monitoring programs created by  
25          this Act. The functions of such a clearinghouse shall

1 include facilitating the coordination of research and  
2 policy development relating to the epidemiology of  
3 autism and other pervasive developmental disabili-  
4 ties.

5 (2) The Secretary, acting through the Centers  
6 for Disease Control and Prevention, shall coordinate  
7 the Federal response to requests for assistance from  
8 State health department officials regarding potential  
9 or alleged autism or developmental disability clus-  
10 ters.

11 **SEC. 5. ADVISORY COMMITTEE.**

12 (a) IN GENERAL.—The Secretary shall establish an  
13 Advisory Committee for Autism and Pervasive Develop-  
14 mental Disabilities Epidemiology Research (in this section  
15 referred to as the “Committee”). The Committee shall  
16 provide advice and recommendations to the Director of the  
17 Centers for Disease Control and Prevention on—

18 (1) the establishment of a national autism and  
19 pervasive developmental disabilities surveillance pro-  
20 gram;

21 (2) the establishment of centers of excellence in  
22 autism and pervasive developmental disabilities epi-  
23 demiology;

24 (3) methods and procedures to more effectively  
25 coordinate government and non-government pro-

1       grams and research on autism and pervasive devel-  
2       opmental disabilities epidemiology; and

3               (4) the effective operation of autism and perva-  
4       sive developmental disabilities epidemiology research  
5       activities.

6       (b) COMPOSITION.—

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 Center  
15                      for Environmental Health.

16                      (B) The Assistant Administrator of the  
17                      Agency for Toxic Substances and Disease Reg-  
18                      istry.

19                      (C) The Director of the National Institute  
20                      of Child Health and Human Development.

21                      (D) The Director of the National Institute  
22                      of Neurological Disorders and Stroke.

23              (3) APPOINTED MEMBERS.—Appointments to  
24      the Committee shall be made in accordance with the  
25      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 five 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 five national organizations referred to in  
3 subparagraph (B).

4 (c) ADMINISTRATIVE SUPPORT; TERMS OF SERVICE;  
5 OTHER PROVISIONS.—The following apply with respect to  
6 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 three years, and may serve for  
12 an unlimited number of terms if reappointed.

13 (3) The Committee shall meet no less than two  
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 The Secretary shall prepare and submit to the Con-  
24 gress, after consultation and comment by the Advisory  
25 Committee, an annual report regarding the prevalence and

1 incidence of autism and other pervasive developmental dis-  
2 orders, the results of research into the etiology of autism  
3 and other pervasive developmental disorders, public health  
4 responses to known or preventable causes of autism and  
5 other pervasive developmental disorders, and the need for  
6 additional research into promising lines of scientific in-  
7 quiry.

8 **SEC. 7. DEFINITION.**

9 For purposes of this Act, the term “State” means  
10 each of the several States, the District of Columbia, the  
11 Commonwealth of Puerto Rico, American Samoa, Guam,  
12 the Commonwealth of the Northern Mariana Islands, the  
13 Virgin Islands, and the Trust Territory of the Pacific Is-  
14 lands.

15 **SEC. 8. AUTHORIZATION OF APPROPRIATIONS.**

16 For the purpose of carrying out this Act, there is au-  
17 thorized to be appropriated \$7,500,000 for each of the fis-  
18 cal years 1999 through 2003.

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