

109TH CONGRESS
1ST SESSION

H. R. 2421

To amend the Public Health Service Act to combat autism through research, screening, intervention and education.

IN THE HOUSE OF REPRESENTATIVES

MAY 18, 2005

Mrs. BONO (for herself and Ms. DEGETTE) introduced the following bill;
which was referred to the Committee on Energy and Commerce

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. DEVELOPMENTAL DISABILITIES SURVEILLANCE**
7 **AND RESEARCH PROGRAM.**

8 (a) SURVEILLANCE PROGRAM; CENTERS OF EXCEL-
9 LENCE; CLEARINGHOUSE.—Section 102(e) of the Chil-
10 dren’s Health Act of 2000 (42 U.S.C. 247b–4b) is amend-

1 ed by striking “There are authorized” and all that follows
2 and inserting the following: “For the purpose of carrying
3 out this section, there are authorized to be appropriated
4 such sums as may be necessary for fiscal year 2006 and
5 each subsequent fiscal year.”.

6 (b) ADDITIONAL PROGRAMS.—Title III of the Public
7 Health Service Act (42 U.S.C. 241 et seq.) is amended
8 by adding at the end thereof the following:

9 **“PART R—PROGRAMS RELATING TO AUTISM**
10 **“SEC. 399AA. INFORMATION AND EDUCATION RELATING TO**
11 **AUTISM.**

12 “(a) IN GENERAL.—The Secretary shall establish
13 and implement a program to provide information and edu-
14 cation on autism and its risk factors to health profes-
15 sionals and the general public, including information and
16 education on advances in the diagnosis and treatment of
17 autism and training and continuing education through
18 programs for scientists, physicians, and other health pro-
19 fessionals who provide care for patients with autism. The
20 program shall place special emphasis on early identifica-
21 tion of autism and those at risk for autism and prompt
22 referral for appropriate services.

23 “(b) STIPENDS.—The Secretary may use amounts
24 made available under this section to provide stipends for

1 health professionals who are enrolled in training programs
2 under this section.

3 “(c) AUTHORIZATION OF APPROPRIATIONS.—There
4 is authorized to be appropriated to carry out this section,
5 \$10,000,000 for each of fiscal years 2007 through 2011.

6 **“SEC. 399BB. INTERAGENCY AUTISM COORDINATING COM-
7 MITTEE.**

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

17 “(b) MEMBERSHIP.—

18 “(1) IN GENERAL.—The Committee shall be
19 composed of—

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

22 “(B) the Directors of such national re-
23 search institutes of the National Institutes of
24 Health as the Secretary determines appropriate;

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

3 “(D) the additional members appointed
4 under paragraph (2) (if any).

5 “(2) ADDITIONAL MEMBERS.—If determined
6 appropriate by the Secretary, the Secretary may ap-
7 point to the Committee—

8 “(A) individuals with autism or other per-
9 vasive developmental disorders;

10 “(B) parents or legal guardians of individ-
11 uals with autism or other pervasive develop-
12 mental disorders;

13 “(C) representatives of leading autism re-
14 search and service organizations; and

15 “(D) representatives of other governmental
16 agencies that serve children with autism such
17 as the Department of Education.

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

21 “(1) The Committee shall receive necessary and
22 appropriate administrative support from the Sec-
23 retary.

24 “(2) Members of the Committee appointed
25 under subsection (b)(2)(A) shall serve for a term of

1 3 years, and may serve for an unlimited number of
2 terms if reappointed.

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

5 **“SEC. 399CC. SCREENING, DIAGNOSIS, AND TREATMENT OF**
6 **AUTISM; MEDICAL CARE FOR INDIVIDUALS**
7 **WITH AUTISM.**

8 “(a) STATEWIDE AUTISM SCREENING, DIAGNOSIS,
9 AND INTERVENTION PROGRAMS AND SYSTEMS.—

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

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

19 “(A) To develop and monitor the efficacy
20 of statewide autism screening, diagnosis, and
21 intervention programs and systems, ensuring
22 that all children are screened for autism before
23 their second birthday, and that children at risk
24 for autism receive appropriate services as early
25 as possible. Intervention includes referral to

1 schools and agencies, including community, con-
2 sumer, and parent-based agencies, and organi-
3 zations and other programs mandated by part
4 C of the Individuals with Disabilities Education
5 Act, which offer programs specifically designed
6 to meet the unique needs of children with au-
7 tism.

8 “(B) To collect data on statewide autism
9 screening, diagnosis, and intervention programs
10 and systems that can be used for applied re-
11 search, program evaluation, and policy develop-
12 ment.

13 “(C) To provide comprehensive medical
14 care for individuals with autism through evi-
15 dence-based practices, with specific attention to
16 medical conditions that may be associated with
17 autism, and to disseminate information on the
18 medical care of individuals with autism to
19 health professionals and the general public. In
20 carrying out the program under this paragraph,
21 a grant shall be awarded to a national organiza-
22 tion that will establish and support regional
23 centers of clinical excellence to provide medical
24 care to individuals with autism and promote re-
25 search aimed at improving the treatment of

1 such individuals, and that will build a shared
2 national medical database to record the results
3 of treatments and studies at the regional cen-
4 ters.

5 “(3) PARENTAL CONSENT.—Screenings and
6 other services available under this section for a child
7 may not be provided without the consent of a parent
8 or legal guardian of the child.

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

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

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

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

7 **“SEC. 399DD. ANNUAL REPORT ON AUTISM.**

8 “(a) IN GENERAL.—Not later than January 1, 2006,
9 and each January 1 thereafter, the Secretary shall prepare
10 and submit to the appropriate committees of Congress, a
11 report concerning the implementation of this part.

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

14 “(1) provide the dollar amount that each insti-
15 tute of the National Institutes of Health expended
16 on autism research in the year for which the report
17 was prepared; and

18 “(2) detail the progress and success of the Na-
19 tional Institutes of Health in implementing and
20 funding the recommendations contained in the Au-
21 tism Research Roadmap and Matrix of the Inter-
22 agency Autism Coordinating Committee.”.

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