

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

# H. R. 4365

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IN THE SENATE OF THE UNITED STATES

MAY 10, 2000

Received; read twice and referred to the Committee on Health, Education,  
Labor, and Pensions

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## AN ACT

To amend the Public Health Service Act with respect to  
children's health.

1       *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

1 **SECTION 1. SHORT TITLE.**

2       This Act may be cited as the “Children’s Health Act  
3 of 2000”.

4 **SEC. 2. TABLE OF CONTENTS.**

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- Sec. 111. Short title.
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TRANSPLANTATION

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garding needs of children.

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1                   **TITLE I—AUTISM**  
2   **Subtitle A—Surveillance and Re-**  
3   **search Regarding Prevalence**  
4   **and Pattern of Autism**

5   **SEC. 101. SHORT TITLE.**

6           This subtitle may be cited as the “Autism Statistics,  
7 Surveillance, Research, and Epidemiology Act of 2000  
8 (ASSURE)”.

9   **SEC. 102. SURVEILLANCE AND RESEARCH PROGRAMS;**  
10                   **CLEARINGHOUSE; ADVISORY COMMITTEE.**

11           Part B of title III of the Public Health Service Act  
12 (42 U.S.C. 243 et seq.) is amended by inserting after sec-  
13 tion 317G the following section:

14           “SURVEILLANCE AND RESEARCH REGARDING AUTISM  
15                   AND PERVASIVE DEVELOPMENTAL DISORDERS

16           “SEC. 317H. (a) IN GENERAL.—The Secretary , act-  
17 ing through the Director of the Centers for Disease Con-

1 trol and Prevention, may make awards of grants and coop-  
2 erative agreements for the collection, analysis, and report-  
3 ing of data on autism and pervasive developmental dis-  
4 orders. An entity may receive such an award only if the  
5 entity is a public or nonprofit private entity “(including  
6 health departments of States and political subdivisions of  
7 States, and including universities and other educational  
8 entities). In making such awards, the Secretary may pro-  
9 vide direct technical assistance in lieu of cash.

10 “(b) CENTERS OF EXCELLENCE IN AUTISM AND  
11 PERVASIVE DEVELOPMENTAL DISORDERS EPIDEMI-  
12 OLOGY.—

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

23 “(2) RECIPIENTS OF AWARDS FOR ESTABLISH-  
24 MENT OF CENTERS.—Centers under paragraph (1)  
25 shall be established and operated through the award

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

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

13 “(A) The center will collect, analyze, and  
14 report autism and pervasive developmental dis-  
15 orders data according to guidelines prescribed  
16 by the Director, after consultation with relevant  
17 State and local public health officials, private  
18 sector developmental disorder researchers, and  
19 advocates for those with developmental dis-  
20 orders;

21 “(B) The center will assist with the devel-  
22 opment and coordination of State autism and  
23 pervasive developmental disorders surveillance  
24 efforts 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 disorders; 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 dis-  
10          orders; 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          “(e) CLEARINGHOUSE.—The Secretary, acting  
16 through the Director of the Centers for Disease Control  
17 and Prevention, shall carry out the following:

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



1 and policy development relating to the epidemiology  
2 of autism and other pervasive developmental dis-  
3 orders.

4 “(2) The Secretary shall coordinate the Federal  
5 response to requests for assistance from State health  
6 department officials regarding potential or alleged  
7 autism or developmental disorder clusters.

8 “(d) ADVISORY COMMITTEE.—

9 “(1) IN GENERAL.—The Secretary shall estab-  
10 lish an Advisory Committee for Autism and Perva-  
11 sive developmental disorders Epidemiology Research  
12 (in this section referred to as the ‘Committee’). The  
13 Committee shall provide advice and recommenda-  
14 tions to the Director of the Centers for Disease Con-  
15 trol and Prevention on—

16 “(A) the establishment of a national au-  
17 tism and pervasive developmental disorders sur-  
18 veillance program;

19 “(B) the establishment of centers of excel-  
20 lence in autism and pervasive developmental  
21 disorders epidemiology;

22 “(C) methods and procedures to more ef-  
23 fectively coordinate government and non-gov-  
24 ernment programs and research on autism and

1 pervasive developmental disorders epidemiology;  
2 and

3 “(D) the effective operation of autism and  
4 pervasive developmental disorders epidemiology  
5 research activities.

6 “(2) COMPOSITION.—

7 “(A) IN GENERAL.—The Committee shall  
8 be composed of ex officio members in accord-  
9 ance with subparagraph (B) and 11 appointed  
10 members in accordance with subparagraph (C).

11 “(B) EX OFFICIO MEMBERS.—The fol-  
12 lowing officials shall serve as ex officio members  
13 of the Committee:

14 “(i) The Director of the National  
15 Center for Environmental Health.

16 “(ii) The Assistant Administrator of  
17 the Agency for Toxic Substances and Dis-  
18 ease Registry.

19 “(iii) The Director of the National In-  
20 stitute of Child Health and Human Devel-  
21 opment.

22 “(iv) The Director of the National In-  
23 stitute of Neurological Disorders and  
24 Stroke.

1           “(C) APPOINTED MEMBERS.—Appoint-  
2           ments to the Committee shall be made in ac-  
3           cordance with the following:

4                   “(i) Two members shall be research  
5                   scientists with demonstrated achievements  
6                   in research related to autism and related  
7                   developmental disorders. The scientists  
8                   shall be appointed by the Secretary in con-  
9                   sultation with the National Academy of  
10                  Sciences.

11                   “(ii) Five members shall be represent-  
12                   atives of the five national organizations  
13                   whose primary emphasis is on research  
14                   into autism and other pervasive develop-  
15                   mental disorders. One representative from  
16                   each of such organizations shall be ap-  
17                   pointed by the Secretary in consultation  
18                   with the National Academy of Sciences.

19                   “(iii) Two members shall be clinicians  
20                   whose practice is primarily devoted to the  
21                   treatment of individuals with autism and  
22                   other pervasive developmental disorders.  
23                   The clinicians shall be appointed by the  
24                   Secretary in consultation with the Institute

1 of Medicine and the National Academy of  
2 Sciences.

3 “(iv) Two members shall be individ-  
4 uals who are the parents or legal guardians  
5 of a person or persons with autism or  
6 other pervasive developmental disorders.  
7 The individuals shall be appointed by the  
8 Secretary in consultation with the ex offi-  
9 cio members under subparagraph (B) and  
10 the five national organizations referred to  
11 in clause (ii).

12 “(3) ADMINISTRATIVE SUPPORT; TERMS OF  
13 SERVICE; OTHER PROVISIONS.—The following apply  
14 with respect to the Committee:

15 “(A) The Committee shall receive nec-  
16 essary and appropriate administrative support  
17 from the Department of Health and Human  
18 Services.

19 “(B) Members of the Committee shall be  
20 appointed for a term of three years, and may  
21 serve for an unlimited number of terms if re-  
22 appointed.

23 “(C) The Committee shall meet no less  
24 than two times per year.

1           “(D) Members of the Committee shall not  
2           receive additional compensation for their serv-  
3           ice. Such members may receive reimbursement  
4           for appropriate and additional expenses that are  
5           incurred through service on the Committee  
6           which would not have incurred had they not  
7           been a member of the Committee.

8           “(e) REPORT TO CONGRESS.—The Secretary shall  
9           prepare and submit to the Congress, after consultation  
10          with and comment by the advisory committee under sub-  
11          section (d), an annual report regarding the prevalence and  
12          incidence of autism and other pervasive developmental dis-  
13          orders, the results of research into the etiology of autism  
14          and other pervasive developmental disorders, public health  
15          responses to known or preventable causes of autism and  
16          other pervasive developmental disorders, and the need for  
17          additional research into promising lines of scientific in-  
18          quiry.

19          “(f) AUTHORIZATION OF APPROPRIATIONS.—For the  
20          purpose of carrying out this section, there are authorized  
21          to be appropriated such sums as may be necessary for  
22          each of the fiscal years 2001 through 2005.”.

1 **Subtitle B—Expansion, Intensifica-**  
2 **tion, and Coordination of Au-**  
3 **tism Activities of National Insti-**  
4 **tutes of Health With Respect to**  
5 **Autism**

6 **SEC. 111. SHORT TITLE.**

7 This subtitle may be cited as the “Advancement in  
8 Pediatric Autism Research Act of 2000”.

9 **SEC. 112. EXPANSION, INTENSIFICATION, AND COORDINA-**  
10 **TION; INFORMATION AND EDUCATION;**  
11 **INTERAGENCY COORDINATING COMMITTEE.**

12 Part B of title IV of the Public Health Service Act  
13 (42 U.S.C. 284 et seq.) is amended by adding at the end  
14 the following section:

15 “AUTISM

16 “SEC. 409C. (a) IN GENERAL.—

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

22 “(2) ADMINISTRATION OF PROGRAM; COLLABO-  
23 RATION AMONG AGENCIES.—The Director shall carry  
24 out this section (other than subsection (b)) acting  
25 through the Director of the National Institute of

1 Mental Health and in collaboration with any other  
2 agencies that the Director determines appropriate.

3 “(b) INTERAGENCY COORDINATING COMMITTEE.—

4 “(1) IN GENERAL.—The Secretary shall ensure  
5 that there is in operation an interagency committee  
6 to be known as the ‘Autism Coordinating Com-  
7 mittee’ (referred to in this subsection as the ‘Com-  
8 mittee’) to coordinate all efforts within the Depart-  
9 ment of Health and Human Services concerning au-  
10 tism, including activities carried out through the Na-  
11 tional Institutes of Health under this section and ac-  
12 tivities carried out through the Centers for Disease  
13 Control and Prevention under section 317H.

14 “(2) MEMBERSHIP.—The Committee shall be  
15 composed of such directors of the national research  
16 institutes, such directors of centers within the Cen-  
17 ters for Disease Control and Prevention, and such  
18 other officials within the Department of Health and  
19 Human Services as the Secretary determines to be  
20 appropriate. The Committee may include representa-  
21 tives of other Federal agencies that serve children  
22 with autism, such as the Department of Education.

23 “(3) MEETINGS.—The Committee shall meet  
24 not less than twice per year.

25 “(c) CENTERS OF EXCELLENCE.—

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

7           “(2) RESEARCH.—Each center under para-  
8 graph (1) shall conduct basic and clinical research  
9 into autism. Such research should include investiga-  
10 tions into the cause, diagnosis, early detection, pre-  
11 vention, control, and treatment of autism. These  
12 centers, as a group, shall conduct research including  
13 but not limited to the fields of developmental  
14 neurobiology, genetics, and psychopharmacology.

15           “(3) SERVICES FOR PATIENTS.—A center under  
16 paragraph (1) may expend amounts provided under  
17 such paragraph to carry out a program to make in-  
18 dividuals aware of opportunities to participate as  
19 subjects in research conducted by the centers. The  
20 program may, in accordance with such criteria as  
21 the Director may establish, provide to such subjects  
22 referrals for health and other services, and such pa-  
23 tient care costs as are required for research. The ex-  
24 tent to which the center can demonstrate availability  
25 and access to clinical services shall be considered by



1 the Director in decisions about awarding the grants  
2 to applicants which meet the scientific criteria for  
3 funding.

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

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

16 “(6) NUMBER OF CENTERS; DURATION OF SUP-  
17 PORT.—The Director shall provide for the establish-  
18 ment of not less than five centers under paragraph  
19 (1), subject to the extent of amounts made available  
20 in appropriations Acts. Support of such a center  
21 may be for a period not exceeding 5 years. Such pe-  
22 riod may be extended for one or more additional pe-  
23 riods not exceeding 5 years if the operations of such  
24 center have been reviewed by an appropriate tech-  
25 nical and scientific peer review group established by

1 the Director and if such group has recommended to  
2 the Director that such period should be extended.

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

11 “(e) INFORMATION AND EDUCATION.—

12 “(1) IN GENERAL.—The Director shall establish  
13 and implement a program to provide information  
14 and education on autism to health professionals and  
15 the general public, including information and edu-  
16 cation on advances in the diagnosis and treatment of  
17 autism and training and continuing education  
18 through programs for scientists, physicians, and  
19 other health professionals who provide care for pa-  
20 tients with autism.

21 “(2) STIPENDS.—The Director may use  
22 amounts made available under this section to pro-  
23 vide stipends for health professionals who are en-  
24 rolled in training programs under this section.

1       “(f) PUBLIC INPUT.—The Director shall under sub-  
2 section (a)(1) provide for means through which the public  
3 can obtain information on the existing and planned pro-  
4 grams and activities of the National Institutes of Health  
5 with respect to autism and through which the Director can  
6 receive comments from the public regarding such pro-  
7 grams and activities.

8       “(g) ANNUAL REPORT TO CONGRESS.—The Director  
9 shall prepare and submit to the appropriate committees  
10 of the Congress reports regarding the activities carried out  
11 under this section. The first report shall be submitted not  
12 later than January 10, 2002, and subsequent reports shall  
13 be submitted annually thereafter.

14       “(h) FUNDING.—For the purpose of carrying out this  
15 section, there are authorized to be appropriated such sums  
16 as may be necessary for each of the fiscal years 2001  
17 through 2005. Such authorizations of appropriations are  
18 in addition to any other authorizations of appropriations  
19 that are available for such purpose.”.

20 **TITLE II—RESEARCH AND DE-**  
21 **VELOPMENT                   REGARDING**  
22 **FRAGILE X**

23 **SEC. 201. SHORT TITLE.**

24       This title may be cited as the “Fragile X Research  
25 Breakthrough Act of 2000”.

1 **SEC. 202. NATIONAL INSTITUTE OF CHILD HEALTH AND**  
2 **HUMAN DEVELOPMENT; RESEARCH ON FRAG-**  
3 **ILE X.**

4 Subpart 7 of part C of title IV of the Public Health  
5 Service Act is amended by adding at the end the following  
6 section:

7 “FRAGILE X

8 “SEC. 452E. (a) EXPANSION AND COORDINATION OF  
9 RESEARCH ACTIVITIES.—The Director of the Institute,  
10 after consultation with the advisory council for the Insti-  
11 tute, shall expand, intensify, and coordinate the activities  
12 of the Institute with respect to research on the disease  
13 known as fragile X.

14 “(b) RESEARCH CENTERS.—

15 “(1) IN GENERAL.—The Director of the Insti-  
16 tute, after consultation with the advisory council for  
17 the Institute, shall make grants to, or enter into  
18 contracts with, public or nonprofit private entities  
19 for the development and operation of centers to con-  
20 duct research for the purposes of improving the di-  
21 agnosis and treatment of, and finding the cure for,  
22 fragile X.

23 “(2) NUMBER OF CENTERS.—In carrying out  
24 paragraph (1), the Director of the Institute shall, to  
25 the extent that amounts are appropriated, provide

1 for the establishment of at least three fragile X re-  
2 search centers.

3 “(3) ACTIVITIES.—

4 “(A) IN GENERAL.—Each center assisted  
5 under paragraph (1) shall, with respect to frag-  
6 ile X—

7 “(i) conduct basic and clinical re-  
8 search, which may include clinical trials  
9 of—

10 “(I) new or improved diagnostic  
11 methods; and

12 “(II) drugs or other treatment  
13 approaches; and

14 “(ii) conduct research to find a cure.

15 “(B) FEES.—A center may use funds pro-  
16 vided under paragraph (1) to provide fees to in-  
17 dividuals serving as subjects in clinical trials  
18 conducted under subparagraph (A).

19 “(4) COORDINATION AMONG CENTERS.—The  
20 Director of the Institute shall, as appropriate, pro-  
21 vide for the coordination of the activities of the cen-  
22 ters assisted under this section, including providing  
23 for the exchange of information among the centers.

24 “(5) CERTAIN ADMINISTRATIVE REQUIRE-  
25 MENTS.—Each center assisted under paragraph (1)

1 shall use the facilities of a single institution, or be  
2 formed from a consortium of cooperating institu-  
3 tions, meeting such requirements as may be pre-  
4 scribed by the Director of the Institute.

5 “(6) DURATION OF SUPPORT.—Support may be  
6 provided to a center under paragraph (1) for a pe-  
7 riod not exceeding 5 years. Such period may be ex-  
8 tended for one or more additional periods, each of  
9 which may not exceed 5 years, if the operations of  
10 such center have been reviewed by an appropriate  
11 technical and scientific peer review group established  
12 by the Director and if such group has recommended  
13 to the Director that such period be extended.

14 “(7) AUTHORIZATION OF APPROPRIATIONS.—  
15 For the purpose of carrying out this subsection,  
16 there are authorized to be appropriated such sums  
17 as may be necessary for each of the fiscal years  
18 2001 through 2005.”.

19 **SEC. 203. NATIONAL INSTITUTE OF CHILD HEALTH AND**  
20 **HUMAN DEVELOPMENT; LOAN REPAYMENT**  
21 **PROGRAM REGARDING RESEARCH ON FRAG-**  
22 **ILE X.**

23 Part G of title IV of the Public Health Service Act  
24 (42 U.S.C. 288 et seq.) is amended by inserting after sec-  
25 tion 487E the following section:

1 “LOAN REPAYMENT PROGRAM REGARDING RESEARCH ON  
2 FRAGILE X

3 “SEC. 487F. (a) IN GENERAL.—The Secretary, in  
4 consultation with the Director of the National Institute  
5 of Child Health and Human Development, shall establish  
6 a program under which the Federal Government enters  
7 into contracts with qualified health professionals (includ-  
8 ing graduate students) who agree to conduct research re-  
9 garding fragile X in consideration of the Federal Govern-  
10 ment’s agreement to repay, for each year of such service,  
11 not more than \$35,000 of the principal and interest of  
12 the educational loans owed by such health professionals.

13 “(b) APPLICABILITY OF CERTAIN PROVISIONS.—  
14 With respect to the National Health Service Corps Loan  
15 Repayment Program established in subpart III of part D  
16 of title III, the provisions of such subpart (including sec-  
17 tion 338B(g)(3)) shall, except as inconsistent with sub-  
18 section (a) of this section, apply to the program estab-  
19 lished in such subsection in the same manner and to the  
20 same extent as such provisions apply to the National  
21 Health Service Corps Loan Repayment Program estab-  
22 lished in such subpart.

23 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the  
24 purpose of carrying out this section, there are authorized

1 to be appropriated such sums as may be necessary for  
2 each of the fiscal years 2001 through 2005.”.

3 **TITLE III—JUVENILE ARTHRITIS**  
4 **AND RELATED CONDITIONS**

5 **SEC. 301. NATIONAL INSTITUTE OF ARTHRITIS AND MUS-**  
6 **CULOSKELETAL AND SKIN DISEASES; RE-**  
7 **SEARCH ON JUVENILE ARTHRITIS AND RE-**  
8 **LATED CONDITIONS.**

9 Subpart 4 of part C of title IV of the Public Health  
10 Service Act (42 U.S.C. 285d et seq.) is amended by insert-  
11 ing after section 442 the following section:

12 “JUVENILE ARTHRITIS AND RELATED CONDITIONS

13 “SEC. 442A. (a) EXPANSION AND COORDINATION OF  
14 ACTIVITIES.—The Director of the Institute, in coordina-  
15 tion with the Director of the National Institute of Allergy  
16 and Infectious Diseases, shall expand and intensify the  
17 programs of such Institutes with respect to research and  
18 related activities concerning juvenile arthritis and related  
19 conditions.

20 “(b) COORDINATION.—The Directors referred to in  
21 subsection (a) shall jointly coordinate the programs re-  
22 ferred to in such subsection and consult with the Arthritis  
23 and Musculoskeletal Diseases Interagency Coordinating  
24 Committee.

25 “(c) PEDIATRIC RHEUMATOLOGY.—The Secretary,  
26 acting through the appropriate agencies of the Public



1 Health Service, shall develop a coordinated effort to help  
2 ensure that a national infrastructure is in place to train  
3 and develop pediatric rheumatologists to address the  
4 health care services requirements of children with arthritis  
5 and related conditions.

6 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the  
7 purpose of carrying out this section, there are authorized  
8 to be appropriated such sums as may be necessary for  
9 each of the fiscal years 2001 through 2005.”.

10 **SEC. 302. INFORMATION CLEARINGHOUSE.**

11 Section 438(b) of the Public Health Service Act (42  
12 U.S.C. 285d–3(b)) is amended by inserting “, including  
13 juvenile arthritis and related conditions,” after “diseases”.

14 **TITLE IV—REDUCING BURDEN**  
15 **OF DIABETES AMONG CHIL-**  
16 **DREN AND YOUTH**

17 **SEC. 401. PROGRAMS OF CENTERS FOR DISEASE CONTROL**  
18 **AND PREVENTION.**

19 Part B of title III of the Public Health Service Act,  
20 as amended by section 102 of this Act, is amended by in-  
21 serting after section 317H the following section:

22 “DIABETES IN CHILDREN AND YOUTH

23 “SEC. 317I. (a) NATIONAL REGISTRY ON JUVENILE  
24 DIABETES.—The Secretary , acting through the Director  
25 of the Centers for Disease Control and Prevention, shall  
26 develop a system to collect data on juvenile diabetes, in-

1 cluding with respect to incidence and prevalence, and shall  
2 establish a national database for such data.

3 “(b) TYPE 2 DIABETES IN YOUTH.—The Secretary,  
4 acting through the Director of the Centers for Disease  
5 Control and Prevention and in consultation with the Ad-  
6 ministrator of the Health Resources and Services Admin-  
7 istration, shall implement a national public health effort  
8 to address type 2 diabetes in youth, including—

9 “(1) enhancing surveillance systems and ex-  
10 panding research to better assess the prevalence of  
11 type 2 diabetes in youth and determine the extent to  
12 which type 2 diabetes is incorrectly diagnosed as  
13 type 1 diabetes among children;

14 “(2) assisting States in establishing coordinated  
15 school health programs and physical activity and nu-  
16 trition demonstration programs to control weight  
17 and increase physical activity among youth; and

18 “(3) developing and improving laboratory meth-  
19 ods to assist in diagnosis, treatment, and prevention  
20 of diabetes including, but not limited to, developing  
21 noninvasive ways to monitor blood glucose to prevent  
22 hypoglycemia and improving existing glucometers  
23 that measure blood glucose.

24 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the  
25 purpose of carrying out this section, there are authorized

1 to be appropriated such sums as may be necessary for  
2 each of the fiscal years 2001 through 2005.”.

3 **SEC. 402. PROGRAMS OF NATIONAL INSTITUTES OF**  
4 **HEALTH.**

5 Subpart 3 of part C of title IV of the Public Health  
6 Service Act (42 U.S.C. 285c et seq.) is amended by insert-  
7 ing after section 434 the following section:

8 “JUVENILE DIABETES

9 “SEC. 434A. (a) LONG-TERM EPIDEMIOLOGY STUD-  
10 IES.—

11 “(1) IN GENERAL.—The Director of the Insti-  
12 tute shall conduct or support long-term epidemiology  
13 studies in which individuals with type 1, or juvenile,  
14 diabetes are followed for 10 years or more. Such  
15 studies shall, in order to provide a valuable resource  
16 for the purposes specified in paragraph (2), provide  
17 for complete characterization of disease manifesta-  
18 tions, appropriate medical history, elucidation of en-  
19 vironmental factors, delineation of complications, re-  
20 sults of usual medical treatment and a variety of  
21 other potential valuable (such as samples of blood).

22 “(2) PURPOSES.—The purposes referred to in  
23 paragraph (1) with respect to type 1 diabetes are  
24 the following:

1           “(A) Delineation of potential environ-  
2           mental triggers thought precipitating or causing  
3           type 1 diabetes.

4           “(B) Delineation of those clinical charac-  
5           teristics or lab measures associated with com-  
6           plications of the disease.

7           “(C) Potential study population to enter  
8           into clinical trials for prevention and treatment,  
9           as well as genetic studies.

10       “(b) CLINICAL TRIAL INFRASTRUCTURE/INNOVATIVE  
11       TREATMENTS FOR JUVENILE DIABETES.—The Secretary,  
12       acting through the Director of the National Institutes of  
13       Health, shall support regional clinical centers for the cure  
14       of juvenile diabetes and shall through such centers provide  
15       for—

16           “(1) well-characterized population of children  
17           appropriate for study;

18           “(2) well-trained clinical scientists able to con-  
19           duct such trials;

20           “(3) appropriate clinical settings able to house  
21           such studies; and

22           “(4) appropriate statistical capability, data,  
23           safety and other monitoring capacity.

24       “(c) DEVELOPMENT OF VACCINE.—The Secretary,  
25       acting through the appropriate agencies of the Public

1 Health Service, shall provide for a national effort to de-  
 2 velop a vaccine for type 1 diabetes. Such effort shall pro-  
 3 vide for a combination of increased efforts in research and  
 4 development of candidate vaccines, coupled with appro-  
 5 priate ability to conduct large clinical trials in children.

6 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the  
 7 purpose of carrying out this section, there are authorized  
 8 to be appropriated such sums as may be necessary for  
 9 each of the fiscal years 2001 through 2005.”

10 **TITLE V—ASTHMA TREATMENT**  
 11 **SERVICES FOR CHILDREN**

12 **SEC. 501. SHORT TITLE.**

13 This title may be cited as the “Children’s Asthma Re-  
 14 lief Act of 2000”.

15 **Subtitle A—Treatment**

16 **SEC. 511. GRANTS FOR CHILDREN’S ASTHMA RELIEF.**

17 Title III of the Public Health Service Act (42 U.S.C.  
 18 241 et seq.) is amended by adding at the end the following  
 19 part:

20 **“PART P—ADDITIONAL PROGRAMS**

21 **“SEC. 399L. CHILDREN’S ASTHMA TREATMENT GRANTS**  
 22 **PROGRAM.**

23 “(a) AUTHORITY TO MAKE GRANTS.—

24 “(1) IN GENERAL.—In addition to any other  
 25 payments made under this Act or title V of the So-

1        cial Security Act, the Secretary shall award grants  
2        to eligible entities to carry out the following pur-  
3        poses:

4                “(A) To provide access to quality medical  
5                care for children who live in areas that have a  
6                high prevalence of asthma and who lack access  
7                to medical care.

8                “(B) To provide on-site education to par-  
9                ents, children, health care providers, and med-  
10              ical teams to recognize the signs and symptoms  
11              of asthma, and to train them in the use of  
12              medications to treat asthma and prevent its ex-  
13              acerbations.

14              “(C) To decrease preventable trips to the  
15              emergency room by making medication available  
16              to individuals who have not previously had ac-  
17              cess to treatment or education in the manage-  
18              ment of asthma.

19              “(D) To provide other services, such as  
20              smoking cessation programs, home modifica-  
21              tion, and other direct and support services that  
22              ameliorate conditions that exacerbate or induce  
23              asthma.

24              “(2) CERTAIN PROJECTS.—In making grants  
25              under paragraph (1), the Secretary may make

1 grants designed to develop and expand the following  
2 projects:

3 “(A) Projects to provide comprehensive  
4 asthma services to children in accordance with  
5 the guidelines of the National Asthma Edu-  
6 cation and Prevention Program (through the  
7 National Heart, Lung and Blood Institute), in-  
8 cluding access to care and treatment for asth-  
9 ma in a community-based setting;

10 “(B) Projects to demonstrate mobile health  
11 care clinics that in accordance with such guide-  
12 lines provide preventive asthma care. Such  
13 projects shall be evaluated and reports describ-  
14 ing the findings of the evaluations shall be sub-  
15 mitted to the Congress.

16 “(C) Projects to conduct validated asthma  
17 management education programs for patients  
18 with asthma and their families, including pa-  
19 tient education regarding asthma management,  
20 family education on asthma management, and  
21 the distribution of materials, including displays  
22 and videos, to reinforce concepts presented by  
23 medical teams.

24 “(2) AWARD OF GRANTS.—

25 “(A) APPLICATION.—

1           “(i) IN GENERAL.—An eligible entity  
2           shall submit an application to the Sec-  
3           retary for a grant under this section in  
4           such form and manner as the Secretary  
5           may require.

6           “(ii) REQUIRED INFORMATION.—An  
7           application submitted under this subpara-  
8           graph shall include a plan for the use of  
9           funds awarded under the grant and such  
10          other information as the Secretary may re-  
11          quire.

12          “(B) REQUIREMENT.—In awarding grants  
13          under this section, the Secretary shall give pref-  
14          erence to eligible entities that demonstrate that  
15          the activities to be carried out under this sec-  
16          tion shall be in localities within areas of known  
17          or suspected high prevalence of childhood asth-  
18          ma or high asthma-related mortality (relative to  
19          the average asthma prevalence rates and associ-  
20          ated mortality rates in the United States). Ac-  
21          ceptable data sets to demonstrate a high preva-  
22          lence of childhood asthma or high asthma-re-  
23          lated mortality may include data from Federal,  
24          State, or local vital statistics, claims data under  
25          title XIX or XXI of the Social Security Act,



1 other public health statistics or surveys, or  
2 other data that the Secretary, in consultation  
3 with the Director of the Centers for Disease  
4 Control and Prevention, deems appropriate.

5 “(3) DEFINITION OF ELIGIBLE ENTITY.—For  
6 purposes of this section, the term ‘eligible entity’  
7 means a State agency or other entity receiving funds  
8 under title V of the Social Security Act, a local com-  
9 munity, a nonprofit children’s hospital or founda-  
10 tion, or a nonprofit community-based organization.

11 “(b) COORDINATION WITH OTHER CHILDREN’S PRO-  
12 GRAMS.—An eligible entity shall identify in the plan sub-  
13 mitted as part of an application for a grant under this  
14 section how the entity will coordinate operations and ac-  
15 tivities under the grant with—

16 “(1) other programs operated in the State that  
17 serve children with asthma, including any such pro-  
18 grams operated under titles V, XIX, or XXI of the  
19 Social Security Act; and

20 “(2) one or more of the following—

21 “(A) the child welfare and foster care and  
22 adoption assistance programs under parts B  
23 and E of title IV of such Act;

1           “(B) the head start program established  
2           under the Head Start Act (42 U.S.C. 9831 et  
3           seq.);

4           “(C) the program of assistance under the  
5           special supplemental nutrition program for  
6           women, infants and children (WIC) under sec-  
7           tion 17 of the Child Nutrition Act of 1966 (42  
8           U.S.C. 1786);

9           “(D) local public and private elementary or  
10          secondary schools; or

11          “(E) public housing agencies, as defined in  
12          section 3 of the United States Housing Act of  
13          1937 (42 U.S.C. 1437a).

14          “(c) EVALUATION.—An eligible entity that receives a  
15          grant under this section shall submit to the Secretary an  
16          evaluation of the operations and activities carried out  
17          under the grant that includes—

18                 “(1) a description of the health status outcomes  
19                 of children assisted under the grant;

20                 “(2) an assessment of the utilization of asthma-  
21                 related health care services as a result of activities  
22                 carried out under the grant;

23                 “(3) the collection, analysis, and reporting of  
24                 asthma data according to guidelines prescribed by

1 the Director of the Centers for Disease Control and  
2 Prevention; and

3 “(4) such other information as the Secretary  
4 may require.

5 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the  
6 purpose of carrying out this section, there are authorized  
7 to be appropriated such sums as may be necessary for  
8 each of the fiscal years 2001 through 2005.”.

9 **SEC. 512. TECHNICAL AND CONFORMING AMENDMENTS.**

10 Title III of the Public Health Service Act (42 U.S.C.  
11 241 et seq.) is amended—

12 (1) in part L, by redesignating section 399D as  
13 section 399A;

14 (2) in part M—

15 (A) by redesignating sections 399H  
16 through 399L as sections 399B through 399F,  
17 respectively;

18 (B) in section 399B (as so redesignated),  
19 in subsection (e)—

20 (i) by striking “section 399K(b)” and  
21 inserting “subsection (b) of section 399E”;  
22 and

23 (ii) by striking “section 399C” and in-  
24 serting “such section”;

- 1 (C) in section 399E (as so redesignated),  
2 in subsection (e), by striking “section 399H(a)”  
3 and inserting “section 399B(a)”; and
- 4 (D) in section 399F (as so redesignated)—
- 5 (i) in subsection (a), by striking “sec-  
6 tion 399I” and inserting “section 399C”;
- 7 (ii) in subsection (a), by striking  
8 “subsection 399J” and inserting “section  
9 399D”; and
- 10 (iii) in subsection (b), by striking  
11 “subsection 399K” and inserting “section  
12 399E”;
- 13 (3) in part N, by redesignating section 399F as  
14 section 399G; and
- 15 (4) in part O—
- 16 (A) by redesignating sections 399G  
17 through 399J as sections 399H through 399K,  
18 respectively;
- 19 (B) in section 399H (as so redesignated),  
20 in subsection (b), by striking “section 399H”  
21 and inserting “section 399I”;
- 22 (C) in section 399J (as so redesignated),  
23 in subsection (b), by striking “section 399G(d)”  
24 and inserting “section 399H(d)”; and

1 (D) in section 399K (as so redesignated),  
2 by striking “section 399G(d)(1)” and inserting  
3 “section 399H(d)(1)”.

## 4 **Subtitle B—Prevention Activities**

### 5 **SEC. 521. PREVENTIVE HEALTH AND HEALTH SERVICES**

#### 6 **BLOCK GRANT; SYSTEMS FOR REDUCING** 7 **ASTHMA-RELATED ILLNESSES THROUGH** 8 **URBAN COCKROACH MANAGEMENT.**

9 Section 1904(a)(1) of the Public Health Service Act  
10 (42 U.S.C. 300w–3(a)(1)) is amended—

11 (1) by redesignating subparagraphs (E) and  
12 (F) as subparagraphs (F) and (G), respectively;

13 (2) by adding a period at the end of subpara-  
14 graph (G) (as so redesignated);

15 (3) by inserting after subparagraph (D), the  
16 following:

17 “(E) The establishment, operation, and coordi-  
18 nation of effective and cost-efficient systems to re-  
19 duce the prevalence of asthma and asthma-related  
20 illnesses among urban populations, especially chil-  
21 dren, by reducing the level of exposure to cockroach  
22 allergen through the use of integrated pest manage-  
23 ment, as applied to cockroaches. Amounts expended  
24 for such systems may include the costs of building  
25 maintenance and the costs of programs to promote

1 community participation in the carrying out at such  
 2 sites of integrated pest management, as applied to  
 3 cockroaches. For purposes of this subparagraph, the  
 4 term ‘integrated pest management’ means an ap-  
 5 proach to the management of pests in public facili-  
 6 ties that combines biological, cultural, physical, and  
 7 chemical tools in a way that minimizes economic,  
 8 health, and environmental risks.”;

9 (4) in subparagraph (F) (as so redesignated),  
 10 by striking “subparagraphs (A) through (D)” and  
 11 inserting “subparagraphs (A) through (E)”; and

12 (5) in subparagraph (G) (as so redesignated),  
 13 by striking “subparagraphs (A) through (E)” and  
 14 inserting “subparagraphs (A) through (F)”.

## 15 **Subtitle C—Coordination of** 16 **Federal Activities**

### 17 **SEC. 531. COORDINATION THROUGH NATIONAL INSTITUTES** 18 **OF HEALTH.**

19 Subpart 2 of part C of title IV of the Public Health  
 20 Service Act (42 U.S.C. 285b et seq.) is amended by insert-  
 21 ing after section 424A the following section:

22 “COORDINATION OF FEDERAL ASTHMA ACTIVITIES

23 “SEC. 424B (a) IN GENERAL.—The Director of In-  
 24 stitute shall, through the National Asthma Education Pre-  
 25 vention Program Coordinating Committee—

1           “(1) identify all Federal programs that carry  
2           out asthma-related activities;

3           “(2) develop, in consultation with appropriate  
4           Federal agencies and professional and voluntary  
5           health organizations, a Federal plan for responding  
6           to asthma; and

7           “(3) not later than 12 months after the date of  
8           the enactment of the Children’s Health Act of 2000,  
9           submit recommendations to the appropriate commit-  
10          tees of the Congress on ways to strengthen and im-  
11          prove the coordination of asthma-related activities of  
12          the Federal Government.

13          “(b) REPRESENTATION OF THE DEPARTMENT OF  
14          HOUSING AND URBAN DEVELOPMENT.—A representative  
15          of the Department of Housing and Urban Development  
16          shall be included on the National Asthma Education Pre-  
17          vention Program Coordinating Committee for the purpose  
18          of performing the tasks described in subsection (a).

19          “(c) AUTHORIZATION OF APPROPRIATIONS.—For the  
20          purpose of carrying out this section, there are authorized  
21          to be appropriated such sums as may be necessary for  
22          each of the fiscal years 2001 through 2005.”.

## 1     **Subtitle D—Compilation of Data**

### 2     **SEC. 541. COMPILATION OF DATA BY CENTERS FOR DIS-** 3                   **EASE CONTROL AND PREVENTION.**

4           Part B of title III of the Public Health Service Act,  
5 as amended by section 401 of this Act, is amended by in-  
6 serting after section 317I the following section:

7                   “COMPILATION OF DATA ON ASTHMA

8           “SEC. 317J. (a) IN GENERAL.—The Secretary, act-  
9 ing through the Director of the Centers for Disease Con-  
10 trol and Prevention and in consultation with the Director  
11 of the National Heart, Lung, and Blood Institute, shall—

12                   “(1) conduct local asthma surveillance activities  
13 to collect data on the prevalence and severity of  
14 asthma and the quality of asthma management;

15                   “(2) compile and annually publish data on the  
16 prevalence of children suffering from asthma in each  
17 State; and

18                   “(3) to the extent practicable, compile and pub-  
19 lish data on the childhood mortality rate associated  
20 with asthma nationally.

21           “(b) NATIONAL COORDINATING COMMITTEE.—The  
22 Director of the National Heart, Lung, and Blood Institute  
23 shall in carrying out subsection (a) consult with the Na-  
24 tional Asthma Education Prevention Program Coordi-  
25 nating Committee.



1 “(c) COLLABORATIVE EFFORTS.—The activities de-  
2 scribed in subsection (a)(1) may be conducted in collabo-  
3 ration with eligible entities awarded a grant under section  
4 399L.”.

5 **TITLE VI—BIRTH DEFECTS**  
6 **PREVENTION ACTIVITIES**

7 **Subtitle A—Folic Acid**

8 **SEC. 601. SHORT TITLE.**

9 This subtitle may be cited as the “Folic Acid Pro-  
10 motion and Birth Defects Prevention Act of 2000”.

11 **SEC. 602. PROGRAM REGARDING EFFECTS OF FOLIC ACID**  
12 **IN PREVENTION OF BIRTH DEFECTS.**

13 Part B of title III of the Public Health Service Act,  
14 as amended by section 541 of this Act, is amended by in-  
15 serting after section 317J the following section:

16 “EFFECTS OF FOLIC ACID IN PREVENTION OF BIRTH  
17 DEFECTS

18 “SEC. 317K. (a) IN GENERAL.—The Secretary, act-  
19 ing through the Director of the Centers for Disease Con-  
20 trol and Prevention, shall carry out a program (directly  
21 or through grants or contracts) for the following purposes:

22 “(1) To provide education and training for  
23 health professionals and the general public for pur-  
24 poses of explaining the effects of folic acid in pre-  
25 venting birth defects and for purposes of encour-  
26 aging each woman of reproductive capacity (whether

1 or not planning a pregnancy) to consume on a daily  
2 basis a dietary supplement that provides an appro-  
3 priate level of folic acid.

4 “(2) To conduct research with respect to such  
5 education and training, including identifying effec-  
6 tive strategies for increasing the rate of consumption  
7 of folic acid by women of reproductive capacity.

8 “(3) To conduct research to increase the under-  
9 standing of the effects of folic acid in preventing  
10 birth defects, including understanding with respect  
11 to cleft lip, cleft palate, and heart defects.

12 “(4) To provide for appropriate epidemiological  
13 activities regarding folic acid and birth defects, in-  
14 cluding epidemiological activities regarding neural  
15 tube defects.

16 “(b) CONSULTATIONS WITH STATES AND PRIVATE  
17 ENTITIES.—In carrying out subsection (a), the Secretary  
18 shall consult with the States and with other appropriate  
19 public or private entities, including national nonprofit pri-  
20 vate organizations, health professionals, and providers of  
21 health insurance and health plans.

22 “(c) TECHNICAL ASSISTANCE.—The Secretary may  
23 (directly or through grants or contracts) provide technical  
24 assistance to public and nonprofit private entities in car-  
25 rying out the activities described in subsection (a).

1       “(d) EVALUATIONS.—The Secretary shall (directly or  
2 through grants or contracts) provide for the evaluation of  
3 activities under subsection (a) in order to determine the  
4 extent to which such activities have been effective in car-  
5 rying out the purposes of the program under such sub-  
6 section, including the effects on various demographic pop-  
7 ulations. Methods of evaluation under the preceding sen-  
8 tence may include surveys of knowledge and attitudes on  
9 the consumption of folic acid and on blood folate levels.  
10 Such methods may include complete and timely moni-  
11 toring of infants who are born with neural tube defects.

12       “(e) AUTHORIZATION OF APPROPRIATIONS.—For the  
13 purpose of carrying out this section, there are authorized  
14 to be appropriated such sums as may be necessary for  
15 each of the fiscal years 2001 through 2005.”.

16 **Subtitle B—National Center on**  
17 **Birth Defects and Develop-**  
18 **mental Disabilities**

19 **SEC. 611. NATIONAL CENTER ON BIRTH DEFECTS AND**  
20 **DEVELOPMENTAL DISABILITIES.**

21       Section 317C of the Public Health Service Act (42  
22 U.S.C. 247b–4) is amended—

23               (1) by striking the heading for the section and  
24       inserting the following:

1           “NATIONAL CENTER ON BIRTH DEFECTS AND  
2                           DEVELOPMENTAL DISABILITIES”;

3           (2) by striking “SEC. 317C. (a)” and all that  
4 follows through the end of subsection (a) and insert-  
5 ing the following:

6           “SEC. 317C. (a) IN GENERAL.—

7                   “(1) NATIONAL CENTER.—There is established  
8 within the Centers for Disease Control and Preven-  
9 tion a center to be known as the National Center on  
10 Birth Defects and Developmental Disabilities (re-  
11 ferred to in this section as the ‘Center’), which shall  
12 be headed by a director appointed by the Director of  
13 the Centers for Disease Control and Prevention.

14                   “(2) GENERAL DUTIES.—The Secretary shall  
15 carry out programs—

16                           (A) to collect, analyze, and make available  
17 data on birth defects (in a manner that facili-  
18 tates compliance with subsection (d)(2)), includ-  
19 ing data on the causes of such defects and on  
20 the incidence and prevalence of such defects;

21                           (B) to operate regional centers for the con-  
22 duct of applied epidemiological research on the  
23 prevention of such defects; and

24                           (C) to provide information and education  
25 to the public on the prevention of such defects.

1           “(3) FOLIC ACID.—The Secretary shall carry  
2 out section 317K through the Center.

3           “(4) CERTAIN PROGRAMS.—

4           “(A) TRANSFERS.—All programs and  
5 functions described in subparagraph (B) are  
6 transferred to the Center, effective on the date  
7 of the enactment of the Children’s Health Act  
8 of 2000.

9           “(B) RELEVANT PROGRAMS.—The pro-  
10 grams and functions described in this subpara-  
11 graph are all programs and functions that—

12           “(i) relate to birth defects, folic acid,  
13 cerebral palsy, mental retardation, child  
14 development, newborn screening, autism,  
15 fragile X syndrome, fetal alcohol syndrome,  
16 pediatric genetics, or disability prevention;  
17 and

18           “(ii) were carried out through the Na-  
19 tional Center for Environmental Health as  
20 of the day before the date of the enactment  
21 of the Act referred to in subparagraph (A).

22           “(C) RELATED TRANSFERS.—Personnel  
23 employed in connection with the programs and  
24 functions specified in subparagraph (B), and  
25 amounts available for carrying out the pro-

1           grams and functions, are transferred to the  
2           Center, effective on the date of the enactment  
3           of the Act referred to in subparagraph (A).  
4           Such transfer of amounts does not affect the  
5           period of availability of the amounts, or the  
6           availability of the amounts with respect to the  
7           purposes for which the amounts may be ex-  
8           pended.”; and

9           (3) in subsection (b)(1), in the matter pre-  
10          ceding subparagraph (A), by striking “(a)(1)” and  
11          inserting “(a)(2)(A)”.

12 **TITLE VII—EARLY DETECTION,**  
13 **DIAGNOSIS, AND TREATMENT**  
14 **REGARDING HEARING LOSS**  
15 **IN INFANTS**

16 **SEC. 701. SHORT TITLE.**

17          This title may be cited as the “Newborn and Infant  
18 Hearing Screening and Intervention Act of 2000”.

19 **SEC. 702. PURPOSES.**

20          The purposes of this title are to clarify the authority  
21 within the Public Health Service Act to authorize state-  
22 wide newborn and infant hearing screening, evaluation  
23 and intervention programs and systems, technical assist-  
24 ance, a national applied research program, and inter-  
25 agency and private sector collaboration for policy develop-

1 ment, in order to assist the States in making progress to-  
2 ward the following goals:

3           (1) All babies born in hospitals in the United  
4 States and its territories should have a hearing  
5 screening before leaving the birthing facility. Babies  
6 born in other countries and residing in the United  
7 States via immigration or adoption should have a  
8 hearing screening as early as possible.

9           (2) All babies who are not born in hospitals in  
10 the United States and its territories should have a  
11 hearing screening within the first 3 months of life.

12           (3) Appropriate audiologic and medical evalua-  
13 tions should be conducted by 3 months for all  
14 newborns and infants suspected of having hearing  
15 loss to allow appropriate referral and provisions for  
16 audiologic rehabilitation, medical and early interven-  
17 tion before the age of 6 months.

18           (4) All newborn and infant hearing screening  
19 programs and systems should include a component  
20 for audiologic rehabilitation, medical and early inter-  
21 vention options that ensures linkage to any new and  
22 existing state-wide systems of intervention and reha-  
23 bilitative services for newborns and infants with  
24 hearing loss.

1           (5) Public policy in regard to newborn and in-  
2           fant hearing screening and intervention should be  
3           based on applied research and the recognition that  
4           newborns, infants, toddlers, and children who are  
5           deaf or hard-of-hearing have unique language, learn-  
6           ing, and communication needs, and should be the re-  
7           sult of consultation with pertinent public and private  
8           sectors.

9   **SEC. 703. PROGRAMS OF HEALTH RESOURCES AND SERV-**  
10                   **ICES ADMINISTRATION, CENTERS FOR DIS-**  
11                   **EASE CONTROL AND PREVENTION, AND NA-**  
12                   **TIONAL INSTITUTES OF HEALTH.**

13           Part P of title III of the Public Health Service Act,  
14           as added by section 511 of this Act, is amended by adding  
15           at the end the following section:

16   **“SEC. 399M. EARLY DETECTION, DIAGNOSIS, AND TREAT-**  
17                   **MENT REGARDING HEARING LOSS IN IN-**  
18                   **FANTS.**

19           “(a) STATEWIDE NEWBORN AND INFANT HEARING  
20           SCREENING, EVALUATION AND INTERVENTION PRO-  
21           GRAMS AND SYSTEMS.—The Secretary, acting through the  
22           Administrator of the Health Resources and Services Ad-  
23           ministration, shall make awards of grants or cooperative  
24           agreements to develop statewide newborn and infant hear-



1 ing screening, evaluation and intervention programs and  
2 systems for the following purposes:

3           “(1) To develop and monitor the efficacy of  
4 state-wide newborn and infant hearing screening,  
5 evaluation and intervention programs and systems.  
6 Early intervention includes referral to schools and  
7 agencies, including community, consumer, and par-  
8 ent-based agencies and organizations and other pro-  
9 grams mandated by part C of the Individuals with  
10 Disabilities Education Act, which offer programs  
11 specifically designed to meet the unique language  
12 and communication needs of deaf and hard of hear-  
13 ing newborns, infants, toddlers, and children.

14           “(2) To collect data on statewide newborn and  
15 infant hearing screening, evaluation and intervention  
16 programs and systems that can be used for applied  
17 research, program evaluation and policy develop-  
18 ment.

19           “(b) TECHNICAL ASSISTANCE, DATA MANAGEMENT,  
20 AND APPLIED RESEARCH.—

21           “(1) CENTERS FOR DISEASE CONTROL AND  
22 PREVENTION.—The Secretary, acting through the  
23 Director of the Centers for Disease Control and Pre-  
24 vention, shall make awards of grants or cooperative  
25 agreements to provide technical assistance to State

1 agencies to complement an intramural program and  
2 to conduct applied research related to newborn and  
3 infant hearing screening, evaluation and intervention  
4 programs and systems. The program shall develop  
5 standardized procedures for data management and  
6 program effectiveness and costs, such as—

7 “(A) to ensure quality monitoring of new-  
8 born and infant hearing loss screening, evalua-  
9 tion, and intervention programs and systems;

10 “(B) to provide technical assistance on  
11 data collection and management;

12 “(C) to study the costs and effectiveness of  
13 newborn and infant hearing screening, evalua-  
14 tion and intervention programs and systems  
15 conducted by State-based programs in order to  
16 answer issues of importance to state and na-  
17 tional policymakers;

18 “(D) to identify the causes and risk factors  
19 for congenital hearing loss;

20 “(E) to study the effectiveness of newborn  
21 and infant hearing screening, audiologic and  
22 medical evaluations and intervention programs  
23 and systems by assessing the health, intellectual  
24 and social developmental, cognitive, and lan-

1           guage status of these children at school age;  
2           and

3           “(F) to promote the sharing of data re-  
4           garding early hearing loss with State-based  
5           birth defects and developmental disabilities  
6           monitoring programs for the purpose of identi-  
7           fying previously unknown causes of hearing  
8           loss.

9           “(2) NATIONAL INSTITUTES OF HEALTH.—The  
10          Director of the National Institutes of Health, acting  
11          through the Director of the National Institute on  
12          Deafness and Other Communication Disorders, shall  
13          for purposes of this section, continue a program of  
14          research and development on the efficacy of new  
15          screening techniques and technology, including clin-  
16          ical studies of screening methods, studies on efficacy  
17          of intervention, and related research.

18          “(c) COORDINATION AND COLLABORATION.—

19          “(1) IN GENERAL.—In carrying out programs  
20          under this section, the Administrator of the Health  
21          Resources and Services Administration, the Director  
22          of the Centers for Disease Control and Prevention,  
23          and the Director of the National Institutes of Health  
24          shall collaborate and consult with other Federal  
25          agencies; State and local agencies, including those

1 responsible for early intervention services pursuant  
2 to title XIX of the Social Security Act (Medicaid  
3 Early and Periodic Screening, Diagnosis and Treat-  
4 ment Program); title XXI of the Social Security Act  
5 (State Children’s Health Insurance Program); title  
6 V of the Social Security Act (Maternal and Child  
7 Health Block Grant Program); and part C of the In-  
8 dividuals with Disabilities Education Act; consumer  
9 groups of and that serve individuals who are deaf  
10 and hard-of-hearing and their families; appropriate  
11 national medical and other health and education spe-  
12 cialty organizations; persons who are deaf and hard-  
13 of-hearing and their families; other qualified profes-  
14 sional personnel who are proficient in deaf or hard-  
15 of-hearing children’s language and who possess the  
16 specialized knowledge, skills, and attributes needed  
17 to serve deaf and hard-of-hearing newborns, infants,  
18 toddlers, children, and their families; third-party  
19 payers and managed care organizations; and related  
20 commercial industries.

21 “(2) POLICY DEVELOPMENT.—The Adminis-  
22 trator of the Health Resources and Services Admin-  
23 istration, the Director of the Centers for Disease  
24 Control and Prevention, and the Director of the Na-  
25 tional Institutes of Health shall coordinate and col-

1       laborate on recommendations for policy development  
2       at the Federal and State levels and with the private  
3       sector, including consumer, medical and other health  
4       and education professional-based organizations, with  
5       respect to newborn and infant hearing screening,  
6       evaluation and intervention programs and systems.

7               “(3) STATE EARLY DETECTION, DIAGNOSIS,  
8       AND INTERVENTION PROGRAMS AND SYSTEMS; DATA  
9       COLLECTION.—The Administrator of the Health Re-  
10       sources and Services Administration and the Direc-  
11       tor of the Centers for Disease Control and Preven-  
12       tion shall coordinate and collaborate in assisting  
13       States to establish newborn and infant hearing  
14       screening, evaluation and intervention programs and  
15       systems under subsection (a) and to develop a data  
16       collection system under subsection (b).

17               “(d) RULE OF CONSTRUCTION.—Nothing in this sec-  
18       tion shall be construed to preempt any State law.

19               “(e) DEFINITIONS.—For purposes of this section:

20               “(1) The term ‘audiologic evaluation’ refers to  
21       procedures to assess the status of the auditory sys-  
22       tem; to establish the site of the auditory disorder;  
23       the type and degree of hearing loss, and the poten-  
24       tial effects of hearing loss on communication; and to  
25       identify appropriate treatment and referral options.

1 Referral options should include linkage to State co-  
2 ordinating agencies under part C of the Individuals  
3 with Disabilities Education Act or other appropriate  
4 agencies, medical evaluation, hearing aid/sensory aid  
5 assessment, audiologic rehabilitation treatment, na-  
6 tional and local consumer, self-help, parent, and  
7 education organizations, and other family-centered  
8 services.

9 “(2) The terms ‘audiologic rehabilitation’ and  
10 ‘audiologic intervention’ refer to procedures, tech-  
11 niques, and technologies to facilitate the receptive  
12 and expressive communication abilities of a child  
13 with hearing loss.

14 “(3) The term ‘early intervention’ refers to pro-  
15 viding appropriate services for the child with hearing  
16 loss, including nonmedical services, and ensuring  
17 that families of the child are provided comprehen-  
18 sive, consumer-oriented information about the full  
19 range of family support, training, information serv-  
20 ices, communication options and are given the op-  
21 portunity to consider the full range of educational  
22 and program placements and options for their child.

23 “(4) The term ‘medical evaluation by a physi-  
24 cian’ refers to key components including history, ex-  
25 amination, and medical decision making focused on

1 symptomatic and related body systems for the pur-  
2 pose of diagnosing the etiology of hearing loss and  
3 related physical conditions, and for identifying ap-  
4 appropriate treatment and referral options.

5 “(5) The term ‘medical intervention’ refers to  
6 the process by which a physician provides medical  
7 diagnosis and direction for medical and/or surgical  
8 treatment options of hearing loss and/or related  
9 medical disorder associated with hearing loss.

10 “(6) The term ‘newborn and infant hearing  
11 screening’ refers to objective physiologic procedures  
12 to detect possible hearing loss and to identify  
13 newborns and infants who, after rescreening, require  
14 further audiologic and medical evaluations.

15 “(f) AUTHORIZATION OF APPROPRIATIONS.—

16 “(1) STATEWIDE NEWBORN AND INFANT HEAR-  
17 ING SCREENING, EVALUATION AND INTERVENTION  
18 PROGRAMS AND SYSTEMS.—For the purpose of car-  
19 rying out subsection (a), there are authorized to be  
20 appropriated to the Health Resources and Services  
21 Administration such sums as may be necessary for  
22 each of the fiscal years 2001 through 2005.

23 “(2) TECHNICAL ASSISTANCE, DATA MANAGE-  
24 MENT, AND APPLIED RESEARCH; CENTERS FOR DIS-  
25 EASE CONTROL AND PREVENTION.—For the purpose

1 of carrying out subsection (b)(1), there are author-  
 2 ized to be appropriated to the Centers for Disease  
 3 Control and Prevention such sums as may be nec-  
 4 essary for each of the fiscal years 2001 through  
 5 2005.

6 “(3) TECHNICAL ASSISTANCE, DATA MANAGE-  
 7 MENT, AND APPLIED RESEARCH; NATIONAL INSTI-  
 8 TUTE ON DEAFNESS AND OTHER COMMUNICATION  
 9 DISORDERS.—For the purpose of carrying out sub-  
 10 section (b)(2), there are authorized to be appro-  
 11 priated to the National Institute on Deafness and  
 12 Other Communication Disorders such sums as may  
 13 be necessary for each of the fiscal years 2001  
 14 through 2005.”

## 15 **TITLE VIII—CHILDREN AND** 16 **EPILEPSY**

17 **SEC. 801. NATIONAL PUBLIC HEALTH CAMPAIGN ON EPI-**  
 18 **LEPSY; SEIZURE DISORDER DEMONSTRATION**  
 19 **PROJECTS IN MEDICALLY UNDERSERVED**  
 20 **AREAS.**

21 Subpart I of part D of title III of the Public Health  
 22 Service Act (42 U.S.C. 254b) is amended by adding at  
 23 the end the following section:

24 **“SEC. 330E. EPILEPSY; SEIZURE DISORDER.**

25 **“(a) NATIONAL PUBLIC HEALTH CAMPAIGN.—**



1           “(1) IN GENERAL.—The Secretary shall develop  
2           and implement public health surveillance, education,  
3           research, and intervention strategies to improve the  
4           lives of persons with epilepsy, with a particular em-  
5           phasis on children. Such projects may be carried out  
6           by the Secretary directly and through awards of  
7           grants or contracts to public or nonprofit private en-  
8           tities. The Secretary may directly or through such  
9           awards provide technical assistance with respect to  
10          the planning, development, and operation of such  
11          projects.

12          “(2) CERTAIN ACTIVITIES.—Activities under  
13          paragraph (1) shall include—

14                 “(A) expanding current surveillance activi-  
15                 ties through existing monitoring systems and  
16                 improving registries that maintain data on indi-  
17                 viduals with epilepsy, including children;

18                 “(B) enhancing research activities on pa-  
19                 tient management and control of epilepsy;

20                 “(C) implementing public and professional  
21                 information and education programs regarding  
22                 epilepsy, including initiatives which promote ef-  
23                 fective management and control of the disease  
24                 through children’s programs which are targeted  
25                 to parents, schools, daycare providers, patients;

1           “(D) undertaking educational efforts with  
2           the media, providers of health care, schools and  
3           others regarding stigmas and secondary disabili-  
4           ties related to epilepsy and seizures, and also  
5           its affects on youth;

6           “(E) utilizing and expanding partnerships  
7           with organizations with experience addressing  
8           the health and related needs of people with dis-  
9           abilities; and

10           “(F) other activities the Secretary deems  
11           appropriate.

12           “(3) COORDINATION OF ACTIVITIES.—The Sec-  
13           retary shall ensure that activities under this sub-  
14           section are coordinated as appropriate with other  
15           agencies of the Public Health Service that carry out  
16           activities regarding epilepsy and seizure.

17           “(b) SEIZURE DISORDER; DEMONSTRATION  
18           PROJECTS IN MEDICALLY UNDERSERVED AREAS.—

19           “(1) IN GENERAL.—The Secretary, acting  
20           through the Administrator of the Health Resources  
21           and Services Administration, may make grants to  
22           States and local governments for the purpose of car-  
23           rying out demonstration projects to improve access  
24           to health and other services regarding seizures to en-

1 courage early detection and treatment in children  
2 and others residing in medically underserved areas.

3 “(2) APPLICATION FOR GRANT.—The Secretary  
4 may make a grant under paragraph (1) only if the  
5 application for the grant is submitted to the Sec-  
6 retary and the application is in such form, is made  
7 in such matter, and contains such agreements, as-  
8 surances, and information as the Secretary deter-  
9 mines to be necessary to carry out this subsection.

10 “(c) DEFINITIONS.—For purposes of this section:

11 “(1) The term “epilepsy” refers to a chronic  
12 and serious neurological condition which produces  
13 excessive electrical discharges in the brain causing  
14 recurring seizures affecting all life activities. The  
15 Secretary may revise the definition of such term as  
16 the Secretary.

17 “(2) The term “medically underserved” has the  
18 meaning applicable under section 799B(6).

19 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the  
20 purpose of carrying out this section, there are authorized  
21 to be appropriated such sums as may be necessary for  
22 each of the fiscal years 2001 through 2005.”.

1 **TITLE IX—SAFE MOTHERHOOD;**  
2 **INFANT HEALTH PROMOTION**  
3 **Subtitle A—Safe Motherhood Moni-**  
4 **toring and Prevention Research**

5 **SEC. 901. SHORT TITLE.**

6 This title may be cited as the “Safe Motherhood Mon-  
7 itoring and Prevention Research Act”.

8 **SEC. 902. MONITORING; PREVENTION RESEARCH AND**  
9 **OTHER ACTIVITIES.**

10 Part B of title III of the Public Health Service Act,  
11 as amended by section 602 of this Act, is amended by in-  
12 serting after section 317K the following section:

13 “SAFE MOTHERHOOD

14 “SEC. 317L. (a) MONITORING.—

15 “(1) PURPOSE.—The purpose of this subsection  
16 is to develop monitoring systems at the local, State,  
17 and national level to better understand the burden  
18 of maternal complications and mortality and to de-  
19 crease the disparities among population at risk of  
20 death and complications from pregnancy.

21 “(2) ACTIVITIES.—For the purpose described in  
22 paragraph (1), the Secretary may carry out the fol-  
23 lowing activities:

24 “(A) the Secretary may establish and im-  
25 plement a national monitoring and surveillance

1 program to identify and promote the investiga-  
2 tion of deaths and severe complications that  
3 occur during pregnancy.

4 “(B) The Secretary may expand the Preg-  
5 nancy Risk Assessment Monitoring System to  
6 provide surveillance and collect data in each of  
7 the 50 States.

8 “(C) The Secretary may expand the Ma-  
9 ternal and Child Health Epidemiology Program  
10 to provide technical support, financial assist-  
11 ance, or the time-limited assignment of senior  
12 epidemiologists to maternal and child health  
13 programs in each of the 50 States.

14 “(b) PREVENTION RESEARCH.—

15 “(1) PURPOSE.—The purpose of this subsection  
16 is to provide the Secretary with the authority to fur-  
17 ther expand research concerning risk factors, pre-  
18 vention strategies, and the roles of the family, health  
19 care providers and the community in safe mother-  
20 hood.

21 “(2) RESEARCH.—The Secretary may carry out  
22 activities to expand research relating to—

23 “(A) encouraging preconception coun-  
24 seling, especially for at risk populations such as  
25 diabetics;

1           “(B) the identification of critical compo-  
2           nents of prenatal delivery and postpartum care;

3           “(C) the identification of outreach and  
4           support services, such as folic acid education,  
5           that are available for pregnant women;

6           “(D) the identification of women who are  
7           at high risk for complications;

8           “(E) preventing preterm delivery;

9           “(F) preventing urinary tract infections;

10          “(G) preventing unnecessary caesarean  
11          sections;

12          “(H) an examination of the higher rates of  
13          maternal mortality among African American  
14          women;

15          “(I) an examination of the relationship be-  
16          tween domestic violence and maternal complica-  
17          tions and mortality;

18          “(J) preventing smoking, alcohol and ille-  
19          gal drug usage before, during and after preg-  
20          nancy;

21          “(K) preventing infections that cause ma-  
22          ternal and infant complications; and

23          “(L) other areas determined appropriate  
24          by the Secretary.

25          “(c) PREVENTION PROGRAMS.—

1           “(1) IN GENERAL.—The Secretary may carry  
2 out activities to promote safe motherhood,  
3 including—

4           “(A) public education campaigns on  
5 healthy pregnancies and the building of part-  
6 nerships with outside organizations concerned  
7 about safe motherhood;

8           “(B) education programs for physicians,  
9 nurses and other health care providers; and

10           “(C) activities to promote community sup-  
11 port services for pregnant women.

12           “(d) AUTHORIZATION OF APPROPRIATIONS.—For the  
13 purpose of carrying out this section, there are authorized  
14 to be appropriated such sums as may be necessary for  
15 each of the fiscal years 2001 through 2005.”.

## 16       **Subtitle B—Pregnant Mothers and** 17           **Infants Health Promotion**

### 18       **SEC. 911. SHORT TITLE.**

19           This subtitle may be cited as the “Pregnant Mothers  
20 and Infants Health Protection Act”.

### 21       **SEC. 912. PROGRAMS REGARDING PRENATAL AND POST-** 22           **NATAL HEALTH.**

23           Part B of title III of the Public Health Service Act,  
24 as amended by section 902 of this Act, is amended by in-  
25 serting after section 317L the following section:

1           “PRENATAL AND POSTNATAL HEALTH

2           “SEC. 317M. (a) IN GENERAL.—The Secretary, act-  
3 ing through the Director of the Centers for Disease Con-  
4 trol and Prevention, shall carry out programs—

5           “(1) to collect, analyze, and make available data  
6           on prenatal smoking, alcohol and illegal drug usage,  
7           including data on the implications of such activities  
8           and on the incidence and prevalence of such activi-  
9           ties and their implications;

10           “(2) to conduct applied epidemiological research  
11           on the prevention of prenatal and postnatal smoking,  
12           alcohol and illegal drug usage;

13           “(3) to support, conduct, and evaluate the ef-  
14           fectiveness of educational and cessation programs;  
15           and

16           “(4) to provide information and education to  
17           the public on the prevention and implications of pre-  
18           natal and postnatal smoking, alcohol and illegal drug  
19           usage.

20           “(b) GRANTS.—In carrying out subsection (a), the  
21 Secretary may award grants to and enter into contracts  
22 with States, local governments, scientific and academic in-  
23 stitutions, Federally qualified health centers, and other  
24 public and nonprofit entities, and may provide technical  
25 and consultative assistance to such entities.



1       “(c) AUTHORIZATION OF APPROPRIATIONS.—For the  
2 purpose of carrying out this section, there are authorized  
3 to be appropriated such sums as may be necessary for  
4 each of the fiscal years 2001 through 2005.”.

5                   **TITLE X—REVISION AND**  
6                   **EXTENSION OF PROGRAMS**  
7                   **Subtitle A—Pediatric Research**  
8                   **Initiative**

9   **SEC. 1001. SHORT TITLE.**

10       This subtitle may be cited as the “Pediatric Research  
11 Initiative Act of 2000”.

12   **SEC. 1002. ESTABLISHMENT OF PEDIATRIC RESEARCH**  
13                   **INITIATIVE.**

14       Part B of title IV of the Public Health Service Act,  
15 as amended by section 112 of this Act, is amended by add-  
16 ing at the end the following:

17                   “PEDIATRIC RESEARCH INITIATIVE

18       “SEC. 409D. (a) ESTABLISHMENT.—The Secretary  
19 shall establish within the Office of the Director of NIH  
20 a Pediatric Research Initiative (referred to in this section  
21 as the ‘Initiative’). The Initiative shall be headed by the  
22 Director of NIH.

23       “(b) PURPOSE.—The purpose of the Initiative is to  
24 provide funds to enable the Director of NIH to provide—

25                   “(1) increased support for pediatric biomedical  
26 research within the National Institutes of Health to

1 ensure that the expanding opportunities for advance-  
2 ment in scientific investigations and care for chil-  
3 dren are realized;

4 “(2) enhanced collaborative efforts among the  
5 Institutes to support multidisciplinary research in  
6 the areas that the Director deems most promising;  
7 and

8 “(3) the development of adequate pediatric clin-  
9 ical trials and pediatric use information to promote  
10 the safer and more effective use of prescription  
11 drugs in the pediatric population.

12 “(c) DUTIES.—In carrying out subsection (b), the Di-  
13 rector of NIH shall—

14 “(1) consult with the Director of the National  
15 Institute of Child Health and Human Development  
16 and the Directors of the other national research in-  
17 stitutes, in considering their requests for new or ex-  
18 panded pediatric research efforts, and consult with  
19 the Administrator of the Health Resources and Serv-  
20 ices Administration and other advisors as the Direc-  
21 tor determines to be appropriate;

22 “(2) have broad discretion in the allocation of  
23 any Initiative assistance among the Institutes,  
24 among types of grants, and between basic and clin-  
25 ical research so long as the—

1           “(A) assistance is directly related to the ill-  
2           nesses and conditions of children; and

3           “(B) assistance is extramural in nature;  
4           and

5           “(3) be responsible for the oversight of any  
6           newly appropriated Initiative funds and annually re-  
7           port to Congress and the public on the extent of the  
8           total extramural support for pediatric research  
9           across the NIH, including the specific support and  
10          research awards allocated through the Initiative.

11          “(d) AUTHORIZATION.—For the purpose of carrying  
12          out this section, there are authorized to be appropriated  
13          such sums as may be necessary for each of the fiscal years  
14          2001 through 2005.

15          “(e) TRANSFER OF FUNDS.—The Director of NIH  
16          may transfer amounts appropriated under this section to  
17          any of the Institutes for a fiscal year to carry out the pur-  
18          poses of the Initiative under this section.”

19          **SEC. 1003. INVESTMENT IN TOMORROW’S PEDIATRIC**  
20    **RESEARCHERS.**

21          Subpart 7 of part C of title IV of the Public Health  
22          Service Act, as amended by section 921 of this Act, is  
23          amended by adding at the end the following:

24          “INVESTMENT IN TOMORROW’S PEDIATRIC RESEARCHERS

25                    “SEC. 452G. (a) IN GENERAL.—In order to ensure  
26          the future supply of researchers dedicated to the care and

1 research needs of children, the Director of the Institute,  
2 after consultation with the Administrator of the Health  
3 Resources and Services Administration, shall support ac-  
4 tivities to provide for—

5           “(1) an increase in the number and size of in-  
6           stitutional training grants to pediatric departments  
7           of medical schools and to children’s hospitals; and

8           “(2) an increase in the number of career devel-  
9           opment awards for health professionals who are in  
10          pediatric specialties or subspecialties and intend to  
11          build careers in pediatric basic and clinical research.

12          “(b) AUTHORIZATION.—For the purpose of carrying  
13          out this section, there are authorized to be appropriated  
14          such sums as may be necessary for each of the fiscal years  
15          2001 through 2005.”.

## 16           **Subtitle B—Other Programs**

### 17          **SEC. 1011. CHILDHOOD IMMUNIZATIONS.**

18          Section 317(j)(1) of the Public Health Service Act  
19          (42 U.S.C. 247b(j)(1)) is amended in the first sentence  
20          by striking “1998” and all that follows and inserting  
21          “1998 through 2003.”.

1 **SEC. 1012. SCREENINGS, REFERRALS, AND EDUCATION RE-**  
2 **GARDING LEAD POISONING.**

3 Section 317A(l)(1) of the Public Health Service Act  
4 (42 U.S.C. 247b–1(l)(1)) is amended by striking “1994”  
5 and all that follows and inserting “1994 through 2003.”.

6 **TITLE XI—CHILDHOOD**  
7 **SKELETAL MALIGNANCIES**

8 **SEC. 1101. PROGRAMS OF CENTERS FOR DISEASE CONTROL**  
9 **AND PREVENTION AND NATIONAL INSTI-**  
10 **TUTES OF HEALTH.**

11 Part P of title III of the Public Health Service Act,  
12 as amended by section 703 of this Act, is amended by add-  
13 ing at the end the following section:

14 **“SEC. 399N. CHILDHOOD SKELETAL MALIGNANCIES.**

15 “(a) IN GENERAL.—The Secretary, acting as appro-  
16 priate through the Director of the Centers for Disease  
17 Control and Prevention and the Director of the National  
18 Institutes of Health, shall study environmental and other  
19 risk factors for childhood skeletal cancers, and carry out  
20 projects to improve outcomes among children with child-  
21 hood skeletal cancers and resultant secondary conditions,  
22 including limb loss. Such projects shall be carried out by  
23 the Secretary directly and through awards of grants or  
24 contracts to public or nonprofit entities.

25 “(b) CERTAIN ACTIVITIES.—Activities under sub-  
26 section (a) include—

1           “(1) the expansion of current demographic data  
2 collection and population surveillance efforts to in-  
3 clude childhood skeletal cancers nationally;

4           “(2) the development of a uniform reporting  
5 system under which treating physicians, hospitals,  
6 clinics, and states report the diagnosis of childhood  
7 skeletal cancers, including relevant associated epide-  
8 miological data; and

9           “(3) support for the National Limb Loss Infor-  
10 mation Center to address, in part, the primary and  
11 secondary needs of persons who experience childhood  
12 skeletal cancers in order to prevent or minimize the  
13 disabling nature of these cancers.

14          “(c) COORDINATION OF ACTIVITIES.—The Secretary  
15 shall assure that activities under this section are coordi-  
16 nated as appropriate with other agencies of the Public  
17 Health Service that carry out activities focused on child-  
18 hood cancers and limb loss.

19          “(d) DEFINITION.—For purposes of this section, the  
20 term ‘childhood skeletal cancer’ refers to any malignancy  
21 originating in the connective tissue of a person before skel-  
22 etal maturity including the appendicular and axial skel-  
23 eton. The Secretary may for purposes of this section revise  
24 the definition of such term to the extent determined by  
25 the Secretary to be appropriate.

1       “(e) AUTHORIZATION OF APPROPRIATIONS.—For the  
2 purpose of carrying out this section, there are authorized  
3 to be appropriated such sums as may be necessary for  
4 each of the fiscal years 2001 through 2005.”.

5                   **TITLE XII—ADOPTION**  
6                   **AWARENESS**  
7           **Subtitle A—Infant Adoption**  
8                   **Awareness**

9 **SEC. 1201. SHORT TITLE.**

10       This subtitle may be cited as the “Infant Adoption  
11 Awareness Act of 2000”.

12 **SEC. 1202. GRANTS REGARDING INFANT ADOPTION AWARE-**  
13                   **NESS.**

14       Subpart I of part D of title III of the Public Health  
15 Service Act, as amended by section 801 of this Act, is  
16 amended by adding at the end the following section:

17 **“SEC. 330F. CERTAIN SERVICES FOR PREGNANT WOMEN.**

18       “(a) INFANT ADOPTION AWARENESS.—

19               “(1) IN GENERAL.—The Secretary shall make  
20 grants to national, regional, or local adoption organi-  
21 zations for the purpose of developing and imple-  
22 menting programs to train the designated staff of el-  
23 igible health centers in providing adoption informa-  
24 tion and referrals to pregnant women on an equal

1 basis with all other courses of action included in  
2 nondirective counseling.

3 “(2) BEST-PRACTICES GUIDELINES.—

4 “(A) IN GENERAL.—A condition for the re-  
5 ceipt of a grant under paragraph (1) is that the  
6 adoption organization involved agree that, in  
7 providing training under such paragraph, the  
8 organization will follow the guidelines developed  
9 under subparagraph (B).

10 “(B) PROCESS FOR DEVELOPMENT OF  
11 GUIDELINES.—

12 “(i) IN GENERAL.—The Secretary  
13 shall establish and supervise a process de-  
14 scribed in clause (ii) in which the partici-  
15 pants are—

16 “(I) an appropriate number and  
17 variety of adoption organizations that,  
18 as a group, have expertise in all mod-  
19 els of adoption practice and that rep-  
20 resent all members of the adoption  
21 triad (birth mother, infant, and adop-  
22 tive parent); and

23 “(II) affected public health enti-  
24 ties.



1           “(ii) DESCRIPTION OF PROCESS.—The  
2           process referred to in clause (i) is a proc-  
3           ess in which the participants described in  
4           such clause collaborate to develop best-  
5           practices guidelines on the provision of  
6           adoption information and referrals to preg-  
7           nant women on an equal basis with all  
8           other courses of action included in non-  
9           directive counseling.

10           “(iii) DATE CERTAIN FOR DEVELOP-  
11           MENT.—The Secretary shall ensure that  
12           the guidelines described in clause (ii) are  
13           developed not later than 180 days after the  
14           date of the enactment of the Children’s  
15           Health Act of 2000.

16           “(C) RELATION TO AUTHORITY FOR  
17           GRANTS.—The Secretary may not make any  
18           grant under paragraph (1) before the date on  
19           which the guidelines under subparagraph (B)  
20           are developed.

21           “(3) USE OF GRANT.—

22           “(A) IN GENERAL.—With respect to a  
23           grant under paragraph (1)—

24           “(i) an adoption organization may ex-  
25           pend the grant to carry out the programs

1 directly or through grants to or contracts  
2 with other adoption organizations;

3 “(ii) the purposes for which the adop-  
4 tion organization expends the grant may  
5 include the development of a training cur-  
6 riculum, consistent with the guidelines de-  
7 veloped under paragraph (2)(B); and

8 “(iii) a condition for the receipt of the  
9 grant is that the adoption organization  
10 agree that, in providing training for the  
11 designated staff of eligible health centers,  
12 such organization will make reasonable ef-  
13 forts to ensure that the individuals who  
14 provide the training are individuals who  
15 are knowledgeable on the process for  
16 adopting a child and are experienced in  
17 providing adoption information and refer-  
18 rals in the geographic areas in which the  
19 eligible health centers are located, and that  
20 the designated staff receive the training in  
21 such areas.

22 “(B) RULE OF CONSTRUCTION REGARDING  
23 TRAINING OF TRAINERS.—With respect to indi-  
24 viduals who under a grant under paragraph (1)  
25 provide training for the designated staff of eli-

1           gible health centers (referred to in this subpara-  
2           graph as ‘trainers’), subparagraph (A)(iii) may  
3           not be construed as establishing any limitation  
4           regarding the geographic area in which the  
5           trainers receive instruction in being such train-  
6           ers. A trainer may receive such instruction in a  
7           different geographic area than the area in  
8           which the trainer trains (or will train) the des-  
9           ignated staff of eligible health centers.

10           “(4) ADOPTION ORGANIZATIONS; ELIGIBLE  
11           HEALTH CENTERS; OTHER DEFINITIONS.—For pur-  
12           poses of this section:

13                   “(A) The term ‘adoption organization’  
14                   means a national, regional, or local  
15                   organization—

16                           “(i) among whose primary purposes  
17                           are adoption;

18                           “(ii) that is knowledgeable on the  
19                           process for adopting a child and on pro-  
20                           viding adoption information and referrals  
21                           to pregnant women; and

22                           “(iii) that is a nonprofit private enti-  
23                           ty.

24                   “(B) The term ‘designated staff’, with re-  
25                   spect to an eligible health center, means staff of

1 the center who provide pregnancy or adoption  
2 information and referrals (or will provide such  
3 information and referrals after receiving train-  
4 ing under a grant under paragraph (1)).

5 “(C) The term ‘eligible health centers’  
6 means public and nonprofit private entities that  
7 provide health-related services to pregnant  
8 women.

9 “(5) TRAINING FOR CERTAIN ELIGIBLE  
10 HEALTH CENTERS.—A condition for the receipt of a  
11 grant under paragraph (1) is that the adoption orga-  
12 nization involved agree to make reasonable efforts to  
13 ensure that the eligible health centers with respect  
14 to which training under the grant is provided  
15 include—

16 “(A) eligible health centers that receive  
17 grants under section 1001 (relating to vol-  
18 untary family planning projects);

19 “(B) eligible health centers that receive  
20 grants under section 330 (relating to commu-  
21 nity health centers, migrant health centers, and  
22 centers regarding homeless individuals and resi-  
23 dents of public housing); and

1           “(C) eligible health centers that receive  
2           grants under this Act for the provision of serv-  
3           ices in schools.

4           “(6) PARTICIPATION OF CERTAIN ELIGIBLE  
5           HEALTH CLINICS.—In the case of eligible health cen-  
6           ters that receive grants under section 330 or 1001:

7           “(A) Within a reasonable period after the  
8           Secretary begins making grants under para-  
9           graph (1), the Secretary shall provide eligible  
10          health centers with complete information about  
11          the training available from organizations receiv-  
12          ing grants under such paragraph. The Sec-  
13          retary shall make reasonable efforts to encour-  
14          age eligible health centers to arrange for des-  
15          ignated staff to participate in such training.

16          “(B) All costs of such centers in obtaining  
17          the training shall be reimbursed by the organi-  
18          zation that provides the training, using grants  
19          under paragraph (1).

20          “(C) Not later than one year after the date  
21          of the enactment the Children’s Health Act of  
22          2000, the Secretary shall submit to the appro-  
23          priate committees of the Congress a report eval-  
24          uating the extent to which adoption informa-  
25          tion, and referral upon request, is provided by

1 eligible health centers. Within a reasonable time  
2 after training under this section is initiated, the  
3 Secretary shall submit to the appropriate com-  
4 mittees of the Congress a report evaluating the  
5 extent to which adoption information, and refer-  
6 ral upon request, is provided by eligible health  
7 centers in order to determine the effectiveness  
8 of such training. In preparing the reports re-  
9 quired by this subparagraph, the Secretary  
10 shall in no respect interpret the provisions of  
11 this section to allow any interference in the pro-  
12 vider-patient relationship, any breach of patient  
13 confidentiality, or any monitoring or auditing of  
14 the counseling process or patient records which  
15 breaches patient confidentiality or reveals pa-  
16 tient identity.

17 “(b) APPLICATION FOR GRANT.—The Secretary may  
18 make a grant under subsection (a) only if an application  
19 for the grant is submitted to the Secretary and the appli-  
20 cation is in such form, is made in such manner, and con-  
21 tains such agreements, assurances, and information as the  
22 Secretary determines to be necessary to carry out this sec-  
23 tion.

24 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the  
25 purpose of carrying out this section, there are authorized

1 to be appropriated such sums as may be necessary for  
2 each of the fiscal years 2001 through 2005.”.

3 **Subtitle B—Special Needs Adoption**  
4 **Awareness**

5 **SEC. 1211. SPECIAL NEEDS ADOPTION PROGRAMS; PUBLIC**  
6 **AWARENESS CAMPAIGN AND OTHER ACTIVI-**  
7 **TIES.**

8 Subpart I of part D of title III of the Public Health  
9 Service Act, as amended by section 1202 of this Act, is  
10 amended by adding at the end the following section:

11 **“SEC. 330G. SPECIAL NEEDS ADOPTION PROGRAMS; PUBLIC**  
12 **AWARENESS CAMPAIGN AND OTHER ACTIVI-**  
13 **TIES.**

14 “(a) SPECIAL NEEDS ADOPTION AWARENESS CAM-  
15 PAIGN.—

16 “(1) IN GENERAL.—The Secretary shall,  
17 through making grants to nonprofit private entities,  
18 provide for the planning, development, and carrying  
19 out of a national campaign to provide information to  
20 the public regarding the adoption of children with  
21 special needs.

22 “(2) INPUT ON PLANNING AND DEVELOP-  
23 MENT.—In providing for the planning and develop-  
24 ment of the national campaign under paragraph (1),  
25 the Secretary shall provide for input from a number

1 and variety of adoption organizations throughout the  
2 States in order that the full national diversity of in-  
3 terests among adoption organizations is represented  
4 in the planning and development of the campaign.

5 “(3) CERTAIN FEATURES.—With respect to the  
6 national campaign under paragraph (1):

7 “(A) The campaign shall be directed at  
8 various populations, taking into account as ap-  
9 propriate differences among geographic regions,  
10 and shall be carried out in the language and  
11 cultural context that is most appropriate to the  
12 population involved.

13 “(B) The means through which the cam-  
14 paign may be carried out include—

15 “(i) placing public service announce-  
16 ments on television, radio, and billboards;  
17 and

18 “(ii) providing information through  
19 means that the Secretary determines will  
20 reach individuals who are most likely to  
21 adopt children with special needs.

22 “(C) The campaign shall provide informa-  
23 tion on the subsidies and supports that are  
24 available to individuals regarding the adoption  
25 of children with special needs.



1           “(D) The Secretary may provide that the  
2 placement of public service announcements, and  
3 the dissemination of brochures and other mate-  
4 rials, is subject to review by the Secretary.

5           “(4) MATCHING REQUIREMENT.—

6           “(A) IN GENERAL.—With respect to the  
7 costs of the activities to be carried out by an  
8 entity pursuant to paragraph (1), a condition  
9 for the receipt of a grant under such paragraph  
10 is that the entity agree to make available (di-  
11 rectly or through donations from public or pri-  
12 vate entities) non-Federal contributions toward  
13 such costs in an amount that is not less than  
14 25 percent of such costs.

15           “(B) DETERMINATION OF AMOUNT CON-  
16 TRIBUTED.—Non-Federal contributions under  
17 subparagraph (A) may be in cash or in kind,  
18 fairly evaluated, including plant, equipment, or  
19 services. Amounts provided by the Federal Gov-  
20 ernment, or services assisted or subsidized to  
21 any significant extent by the Federal Govern-  
22 ment, may not be included in determining the  
23 amount of such contributions.

24           “(b) NATIONAL RESOURCES PROGRAM.—The Sec-  
25 retary shall (directly or through grant or contract) carry

1 out a program that, through toll-free telecommunications,  
2 makes available to the public information regarding the  
3 adoption of children with special needs. Such information  
4 shall include the following:

5           “(1) A list of national, State, and regional or-  
6           ganizations that provide services regarding such  
7           adoptions, including exchanges and other informa-  
8           tion on communicating with the organizations. The  
9           list shall represent the full national diversity of  
10          adoption organizations.

11          “(2) Information beneficial to individuals who  
12          adopt such children, including lists of support  
13          groups for adoptive parents and other postadoptive  
14          services.

15          “(c) OTHER PROGRAMS.—With respect to the adop-  
16          tion of children with special needs, the Secretary shall  
17          make grants—

18                 “(1) to provide assistance to support groups for  
19                 adoptive parents, adopted children, and siblings of  
20                 adopted children; and

21                 “(2) to carry out studies to identify the reasons  
22                 for adoption disruptions.

23          “(d) APPLICATION FOR GRANT.—The Secretary may  
24          make an award of a grant or contract under this section  
25          only if an application for the award is submitted to the

1 Secretary and the application is in such form, is made in  
 2 such manner, and contains such agreements, assurances,  
 3 and information as the Secretary determines to be nec-  
 4 essary to carry out this section.

5 “(e) FUNDING.—For the purpose of carrying out this  
 6 section, there are authorized to be appropriated such sums  
 7 as may be necessary for each of the fiscal years 2001  
 8 through 2005.”.

9 **TITLE XIII—TRAUMATIC BRAIN**  
 10 **INJURY**

11 **SEC. 1301. SHORT TITLE.**

12 This title may be cited as the “Traumatic Brain In-  
 13 jury Act Amendments of 2000”.

14 **SEC. 1302. PROGRAMS OF CENTERS FOR DISEASE CONTROL**  
 15 **AND PREVENTION.**

16 (a) IN GENERAL.—Section 393A of the Public  
 17 Health Service Act (42 U.S.C. 280b–1b) is amended—

18 (1) in subsection (b)—

19 (A) in paragraph (1), by striking “and” at  
 20 the end;

21 (B) in paragraph (2), by striking the pe-  
 22 riod and inserting “; and”; and

23 (C) by adding at the end the following:

24 “(3) the implementation of a national education  
 25 and awareness campaign regarding such injury (in

1 conjunction with the program of the Secretary re-  
2 garding health-status goals for 2010, commonly re-  
3 ferred to as Healthy People 2010), including the na-  
4 tional dissemination of information on—

5 “(A) incidence and prevalence;

6 “(B) secondary conditions arising from  
7 traumatic brain injury upon discharge from  
8 hospitals and trauma centers.”;

9 (2) in subsection (d)—

10 (A) in the second sentence, by striking  
11 “anoxia due to near drowning.” and inserting  
12 “anoxia.”; and

13 (B) in the third sentence, by inserting be-  
14 fore the period the following: “, after consulta-  
15 tion with States and other appropriate public or  
16 nonprofit private entities”.

17 (b) NATIONAL REGISTRY.—Part J of title III of the  
18 Public Health Service Act (42 U.S.C. 280b et seq.) is  
19 amended by inserting after section 393A the following sec-  
20 tion:

21 “NATIONAL PROGRAM FOR TRAUMATIC BRAIN INJURY

22 REGISTRIES

23 “SEC. 393B. (a) IN GENERAL.—The Secretary, act-  
24 ing through the Director of the Centers for Disease Con-  
25 trol and Prevention, may make grants to States or their  
26 designees to operate the State’s traumatic brain injury

1 registry, and to academic institutions to conduct applied  
2 research that will support the development of such reg-  
3 istries, to collect data concerning—

4           “(1) demographic information about each trau-  
5 matic brain injury;

6           “(2) information about the circumstances sur-  
7 rounding the injury event associated with each trau-  
8 matic brain injury;

9           “(3) administrative information about the  
10 source of the collected information, dates of hos-  
11 pitalization and treatment, and the date of injury;  
12 and

13           “(4) information characterizing the clinical as-  
14 pects of the traumatic brain injury, including the se-  
15 verity of the injury, the types of treatments received,  
16 and the types of services utilized.”.

17 **SEC. 1303. PROGRAMS OF NATIONAL INSTITUTES OF**  
18 **HEALTH.**

19           (a) INTERAGENCY PROGRAM.—Section 1261(d)(4) of  
20 the Public Health Service Act (42 U.S.C. 300d–61(d)(4))  
21 is amended—

22           (1) in subparagraph (A), by striking “degree of  
23 injury” and inserting “degree of brain injury”;

24           (2) in subparagraph (B), by striking “acute in-  
25 jury” and inserting “acute brain injury”; and

1           (3) in subparagraph (D), by striking “injury  
2           treatment” and inserting “brain injury treatment”.

3           (b) DEFINITION.—Section 1261(h)(4) of the Public  
4 Health Service Act (42 U.S.C. 300d-61(h)(4)) is  
5 amended—

6           (1) in the second sentence, by striking “anoxia  
7           due to near drowning.” and inserting “anoxia.”; and

8           (2) in the third sentence, by inserting before  
9           the period the following: “, after consultation with  
10           States and other appropriate public or nonprofit pri-  
11           vate entities”.

12          (c) AUTHORIZATION OF APPROPRIATIONS.—Section  
13 1261 of the Public Health Service Act (42 U.S.C. 300d-  
14 61) is amended by adding at the end the following:

15           “(i) AUTHORIZATION OF APPROPRIATIONS.—For the  
16           purpose of carrying out this section, there are authorized  
17           to be appropriated such sums as may be necessary for  
18           each of the fiscal years 2000 through 2004.”.

19 **SEC. 1304. PROGRAMS OF HEALTH RESOURCES AND SERV-**  
20 **ICES ADMINISTRATION.**

21           Section 1252 of the Public Health Service Act (42  
22 U.S.C. 300d-51) is amended—

23           (1) in subsection (b)(3)—

24                   (A) in subparagraph (A)(iv), by striking  
25                   “representing traumatic brain injury survivors”

1 and inserting “representing individuals with  
2 traumatic brain injury”; and

3 (B) in subparagraph (B), by striking “who  
4 are survivors of” and inserting “with”;

5 (2) in subsection (c)—

6 (A) in paragraph (1), by striking “, in  
7 cash,”; and

8 (B) in paragraph (2), by amending the  
9 paragraph to read as follows:

10 “(2) DETERMINATION OF AMOUNT CONTRIB-  
11 UTED.—Non-Federal contributions under paragraph  
12 (1) may be in cash or in kind, fairly evaluated, in-  
13 cluding plant, equipment, or services. Amounts pro-  
14 vided by the Federal Government, or services as-  
15 sisted or subsidized to any significant extent by the  
16 Federal Government, may not be included in deter-  
17 mining the amount of such contributions.”;

18 (3) by designating subsections (e) through (h)  
19 as subsections (g) through (j), respectively; and

20 (4) by inserting after subsection (d) the fol-  
21 lowing subsections:

22 “(e) CONTINUATION OF PREVIOUSLY AWARDED  
23 DEMONSTRATION PROJECTS.—A State that received a  
24 grant under this section prior to the date of the enactment  
25 of the Children’s Health Act of 2000 may compete for new

1 project grants under this section after such date of enact-  
2 ment.

3 “(f) USE OF STATE GRANTS.—

4 “(1) COMMUNITY SERVICES AND SUPPORTS.—A  
5 State shall (directly or through awards of contracts  
6 to nonprofit private entities) use amounts received  
7 under a grant under this section for the following:

8 “(A) To develop, change, or enhance com-  
9 munity-based service delivery systems that in-  
10 clude timely access to comprehensive appro-  
11 priate services and supports. Such service and  
12 supports—

13 “(i) shall promote full participation by  
14 individuals with brain injury and their  
15 families in decision making regarding the  
16 services and supports; and

17 “(ii) shall be designed for children  
18 and other individuals with traumatic brain  
19 injury.

20 “(B) To focus on outreach to underserved  
21 and inappropriately served individuals, such as  
22 individuals in institutional settings, individuals  
23 with low socioeconomic resources, individuals in  
24 rural communities, and individuals in culturally  
25 and linguistically diverse communities.



1           “(C) To award contracts to nonprofit enti-  
2 ties for consumer or family service access train-  
3 ing, consumer support, peer mentoring, and  
4 parent to parent programs.

5           “(D) To provide individual and family  
6 service coordination or case management sys-  
7 tems.

8           “(E) To support other needs identified by  
9 the advisory board under subsection (b) for the  
10 State involved.

11       “(2) BEST PRACTICES.—

12           “(A) IN GENERAL.—State services and  
13 supports provided under a grant under this sec-  
14 tion shall reflect the best practices in the field  
15 of traumatic brain injury, shall be in compli-  
16 ance with title II of the Americans with Disabil-  
17 ities Act of 1990, and shall be supported by  
18 quality assurance measures as well as state-of-  
19 the-art health care and integrated community  
20 supports, regardless of the severity of injury.

21           “(B) DEMONSTRATION BY STATE AGEN-  
22 CY.—The State agency responsible for admin-  
23 istering amounts received under a grant under  
24 this section shall demonstrate or express a will-  
25 ingness to obtain expertise and knowledge of

1           traumatic brain injury and the unique needs as-  
2           sociated with traumatic brain injury.

3           “(3) STATE CAPACITY BUILDING.—A State may  
4           use amounts received under a grant under this sec-  
5           tion to—

6                   “(A) educate consumers and families;

7                   “(B) train professionals in public and pri-  
8           vate sector financing (such as third party pay-  
9           ers, State agencies, community-based providers,  
10          schools, and educators);

11                   “(C) develop or improve case management  
12          or service coordination systems;

13                   “(D) develop best practices in areas such  
14          as family or consumer support, return to work,  
15          housing or supportive living personal assistance  
16          services, assistive technology and devices, be-  
17          havioral health services, substance abuse serv-  
18          ices, and traumatic brain injury treatment and  
19          rehabilitation;

20                   “(E) tailor existing State systems to pro-  
21          vide accommodations to the needs of individuals  
22          with brain injury (including systems adminis-  
23          tered by the State departments responsible for  
24          health, mental health, labor, education, mental

1           retardation/developmental disorders, transpor-  
2           tation, and correctional systems);

3           “(F) improve data sets coordinated across  
4           systems and other needs identified by a State  
5           plan supported by its advisory council; and

6           “(G) develop capacity within targeted com-  
7           munities.”;

8           (5) in subsection (g) (as so redesignated), by  
9           striking “agencies of the Public Health Service” and  
10          inserting “Federal agencies”;

11          (6) in subsection (i) (as redesignated by para-  
12          graph (3))—

13                (A) in the second sentence, by striking  
14                “anoxia due to near drowning.” and inserting  
15                “anoxia.”; and

16                (B) in the third sentence, by inserting be-  
17                fore the period the following: “, after consulta-  
18                tion with States and other appropriate public or  
19                nonprofit private entities”; and

20          (7) in subsection (j) (as so redesignated), by  
21          amending the subsection to read as follows:

22          “(j) AUTHORIZATION OF APPROPRIATIONS.—For the  
23          purpose of carrying out this section, there are authorized  
24          to be appropriated such sums as may be necessary for  
25          each of the fiscal years 2001 through 2005.”.

1     **TITLE XIV—PREVENTION AND**  
 2             **CONTROL OF INJURIES**

3     **SEC. 1401. AUTHORIZATION OF APPROPRIATIONS FOR PRO-**  
 4                     **GRAMS OF CENTERS FOR DISEASE CONTROL**  
 5                     **AND PREVENTION.**

6             Section 394A of the Public Health Service Act (42  
 7 U.S.C. 280b-3) is amended by striking “and” after  
 8 “1994” and by inserting before the period the following:  
 9 “, and such sums as may be necessary for each of the  
 10 fiscal years 2001 through 2005.”.

11     **TITLE XV—HEALTHY START**  
 12             **INITIATIVE**

13     **SEC. 1501. SHORT TITLE.**

14             This title may be cited as the “Healthy Start Initia-  
 15 tive Continuation Act”.

16     **SEC. 1502. CONTINUATION OF HEALTHY START PROGRAM.**

17             Subpart I of part D of title III of the Public Health  
 18 Service Act, as amended by section 1203 of this Act, is  
 19 amended by adding at the end the following section:

20     **“SEC. 330H. HEALTHY START FOR INFANTS.**

21             “(a) IN GENERAL.—

22                     “(1) CONTINUATION AND EXPANSION OF PRO-  
 23             GRAM.—The Secretary, acting through the Adminis-  
 24             trator of the Health Resources and Services Admin-  
 25             istration, Maternal and Child Health Bureau, shall

1 under authority of this section continue in effect the  
2 Healthy Start Initiative and may, during fiscal year  
3 2001 and subsequent years, carry out such program  
4 on a national basis.

5 “(2) DEFINITION.—For purposes of paragraph  
6 (1), the term ‘Healthy Start Initiative’ is a reference  
7 to the program that, as an initiative to reduce the  
8 rate of infant mortality and improve perinatal out-  
9 comes, makes grants for project areas with high an-  
10 nual rates of infant mortality and that, prior to the  
11 effective date of this section, was a demonstration  
12 program carried out under section 301.

13 “(3) ADDITIONAL GRANTS.— Effective upon in-  
14 creased funding beyond fiscal year 1999 for such  
15 Initiative, additional grants may be made to States  
16 to assist communities with technical assistance, rep-  
17 lication of successful projects, and State policy for-  
18 mation to reduce infant and maternal mortality and  
19 morbidity.

20 “(b) REQUIREMENTS FOR MAKING GRANTS.—In  
21 making grants under subsection (a), the Secretary shall  
22 require that applicants (in addition to meeting all eligi-  
23 bility criteria established by the Secretary) establish, for  
24 project areas under such subsection, community-based  
25 consortia of individuals and organizations (including agen-

1 cies responsible for administering block grant programs  
2 under title V of the Social Security Act, consumers of  
3 project services, public health departments, hospitals,  
4 health centers under section 330, and other significant  
5 sources of health care services) that are appropriate for  
6 participation in projects under subsection (a).

7 “(c) COORDINATION.—Recipients of grants under  
8 subsection (a) shall coordinate their services and activities  
9 with the State agency or agencies that administer block  
10 grant programs under title V of the Social Security Act  
11 in order to promote cooperation, integrity, and dissemina-  
12 tion of information with Statewide systems and with other  
13 community services funded under the Maternal and Child  
14 Health Block Grant.

15 “(d) RULE OF CONSTRUCTION.—Except to the extent  
16 inconsistent with this section, this section may not be con-  
17 strued as affecting the authority of the Secretary to make  
18 modifications in the program carried out under subsection  
19 (a).

20 “(e) MEDICALLY APPROPRIATE ULTRASOUND SERV-  
21 ICES; MEDICALLY APPROPRIATE SERVICES FOR AT-RISK  
22 MOTHERS AND INFANTS.—

23 “(1) IN GENERAL.—The Secretary may make  
24 grants to health care entities to provide—

1           “(A) for pregnant women, ultrasound serv-  
2           ices provided by qualified health care profes-  
3           sionals upon medical indication and referral  
4           from health care professionals who provide com-  
5           prehensive prenatal services; and

6           “(B) for pregnant women or infants, other  
7           health services (including prenatal care, genetic  
8           counseling, and fetal and other surgery) that—

9                   “(i) are determined by a qualified  
10                  treating health care professional to be  
11                  medically appropriate in order to prevent  
12                  or mitigate congenital defects (including  
13                  but not limited to spina bifida and  
14                  hydrocephaly) or other serious obstetric  
15                  complications (including but not limited to  
16                  placenta previa, premature rupture of  
17                  membranes, or preeclampsia); and

18                   “(ii) are provided during pregnancy or  
19                  during the first year after birth.

20           “(2) ELIGIBLE PROJECT AREA.—The Secretary  
21           may make a grant under paragraph (1) only if the  
22           geographic area in which services under the grant  
23           will be provided is a geographic area in which a  
24           project under subsection (a) is being carried out,  
25           and if the Secretary determines that the grant will

1 add to or expand the level of health services avail-  
2 able in such area to pregnant women and infants.

3 “(3) TRANSPORTATION AND SUBSISTENCE EX-  
4 PENSES FOR CERTAIN PATIENTS.—The purposes for  
5 which a grant under paragraph (1)(B) may be ex-  
6 pended include paying, on behalf of a pregnant  
7 woman who is in need of the health services de-  
8 scribed in such paragraph, transportation and sub-  
9 sistence expenses to assist the pregnant woman in  
10 obtaining such health services from the grantee in-  
11 volved. The Secretary may establish such restrictions  
12 regarding payments under the preceding sentence as  
13 the Secretary determines to be appropriate.

14 “(4) CERTAIN CONDITIONS.—A condition for  
15 the receipt of a grant under paragraph (1) is that  
16 the applicant for the grant agree as follows:

17 “(A) In the case of a grant under para-  
18 graph (1)(A), if ultrasound services indicate  
19 that there is a fetal anomaly or other serious  
20 obstetric complication, the applicant will refer  
21 the pregnant woman involved for appropriate  
22 medical services, including, as appropriate, for  
23 health services described in paragraph (1)(B)  
24 provided by grantees under such paragraph.



1           “(B) If the applicant provides nondirective  
2           pregnancy counseling to patients and is not  
3           subject to the condition under section 330F(b),  
4           such counseling provided by the applicant to pa-  
5           tients will include (but is not limited to) the  
6           provision of adoption information and referrals.

7           “(5) RELATIONSHIP TO PAYMENTS UNDER  
8           OTHER PROGRAMS.—A grant may be made under  
9           paragraph (1) only if the applicant involved agrees  
10          that the grant will not be expended to pay the ex-  
11          penses of providing any service under such para-  
12          graph to a pregnant woman to the extent that pay-  
13          ment has been made, or can reasonably be expected  
14          to be made, with respect to such expenses—

15                 “(A) under any State compensation pro-  
16                 gram, under an insurance policy, or under any  
17                 Federal or State health benefits program; or

18                 “(B) by an entity that provides health  
19                 services on a prepaid basis.

20           “(6) EVALUATION BY GENERAL ACCOUNTING  
21          OFFICE.—

22                 “(A) IN GENERAL.—During fiscal year  
23                 2004, the Comptroller General of the United  
24                 States shall conduct an evaluation of activities  
25                 under grants under paragraph (1) in order to

1 determine whether the activities have been ef-  
2 fective in serving the needs of pregnant women  
3 with respect to ultrasound services and the  
4 other health services described in paragraph  
5 (1)(B). The evaluation shall include an analysis  
6 of whether such activities have been effective in  
7 reducing the disparity in health status between  
8 the general population and individuals who are  
9 members of racial or ethnic minority groups.  
10 Not later than January 10, 2005, the Comp-  
11 troller General shall submit to the Committee  
12 on Commerce in the House of Representatives,  
13 and to the Committee on Health, Education,  
14 Labor, and Pensions in the Senate, a report de-  
15 scribing the findings of the evaluation.

16 “(B) RELATION TO GRANTS REGARDING  
17 MEDICALLY APPROPRIATE SERVICES FOR AT-  
18 RISK MOTHERS AND INFANTS.—Before the date  
19 on which the evaluation under subparagraph  
20 (A) is submitted in accordance with such  
21 subparagraph—

22 “(i) the Secretary shall ensure that  
23 there are not more than three grantees  
24 under paragraph (1)(B); and

1           “(ii) an entity is not eligible to receive  
2           grants under such paragraph unless the  
3           entity has substantial experience in pro-  
4           viding the health services described in such  
5           paragraph.

6           “(e) FUNDING.—

7           “(1) GENERAL PROGRAM.—

8           “(A) AUTHORIZATION OF APPROPRIA-  
9           TIONS.—For the purpose of carrying out this  
10          section (other than subsection (e)), there are  
11          authorized to be appropriated such sums as  
12          may be necessary for each of the fiscal years  
13          2001 through 2005.

14          “(B) ALLOCATIONS.—

15          “(i) PROGRAM ADMINISTRATION.—Of  
16          the amounts appropriated under subpara-  
17          graph (A) for a fiscal year, the Secretary  
18          may reserve up to 5 percent for coordina-  
19          tion, dissemination, technical assistance,  
20          and data activities that are determined by  
21          the Secretary to be appropriate for car-  
22          rying out the program under this section.

23          “(ii) EVALUATION.—Of the amounts  
24          appropriated under subparagraph (A) for a  
25          fiscal year, the Secretary may reserve up

1 to 1 percent for evaluations of projects car-  
2 ried out under subsection (a). Each such  
3 evaluation shall include a determination of  
4 whether such projects have been effective  
5 in reducing the disparity in health status  
6 between the general population and indi-  
7 viduals who are members of racial or eth-  
8 nic minority groups.

9 “(2) MEDICALLY APPROPRIATE ULTRASOUND  
10 SERVICES; MEDICALLY APPROPRIATE SERVICES FOR  
11 AT-RISK MOTHERS AND INFANTS.—

12 “(A) AUTHORIZATION OF APPROPRIA-  
13 TIONS.—For the purpose of carrying out sub-  
14 section (e), there are authorized to be appro-  
15 priated such sums as may be necessary for each  
16 of the fiscal years 2001 through 2005.

17 “(B) ALLOCATION.—Of the amounts ap-  
18 propriated under subparagraph (A) for a fiscal  
19 year, the Secretary shall make available not less  
20 than 10 percent for providing ultrasound serv-  
21 ices under subsection (d)(1)(A) (provided by  
22 qualified health care professionals upon medical  
23 indication and referral from health care profes-  
24 sionals who provide comprehensive prenatal  
25 services) through visits by mobile units to com-

1           munities that are eligible for services under  
2           subsection (a).”.

3 **TITLE XVI—ORAL HEALTH PRO-**  
4 **MOTION AND DISEASE PRE-**  
5 **VENTION**

6 **SEC. 1601. ORAL HEALTH PROMOTION AND DISEASE**  
7 **PREVENTION.**

8           Part B of title III of the Public Health Service Act,  
9 as amended by section 912 of this Act, is amended by in-  
10 serring after section 317M the following section:

11       “ORAL HEALTH PROMOTION AND DISEASE PREVENTION

12           “SEC. 317N. (a) GRANTS TO INCREASE RESOURCES  
13 FOR COMMUNITY WATER FLUORIDATION.—

14           “(1) IN GENERAL.—The Secretary, acting  
15 through the Director of the Centers for Disease  
16 Control and Prevention, may make grants to States  
17 and Indian tribes for the purpose of increasing the  
18 resources available for community water fluorida-  
19 tion.

20           “(2) USE OF FUNDS.—A State shall use  
21 amounts provided under a grant under paragraph  
22 (1)—

23                   “(A) to purchase fluoridation equipment;

24                   “(B) to train fluoridation engineers;

25                   “(C) to develop educational materials on  
26 the benefits of fluoridation; or

1           “(D) to support the infrastructure nec-  
2           essary to monitor and maintain the quality of  
3           water fluoridation.

4           “(b) COMMUNITY WATER FLUORIDATION.—

5           “(1) IN GENERAL.—The Secretary, acting  
6           through the Director of the Centers for Disease  
7           Control and Prevention and in collaboration with the  
8           Director of the Indian Health Service, shall establish  
9           a demonstration project that is designed to assist  
10          rural water systems in successfully implementing the  
11          water fluoridation guidelines of the Centers for Dis-  
12          ease Control and Prevention that are entitled “Engi-  
13          neering and Administrative Recommendations for  
14          Water Fluoridation, 1995” (referred to in this sub-  
15          section as the ‘EARWF’).

16          “(2) REQUIREMENTS.—

17          “(A) COLLABORATION.—In collaborating  
18          under paragraph (1), the Directors referred to  
19          in such paragraph shall ensure that technical  
20          assistance and training are provided to tribal  
21          programs located in each of the 12 areas of the  
22          Indian Health Service. The Director of the In-  
23          dian Health Service shall provide coordination  
24          and administrative support to tribes under this  
25          section.

1           “(B) GENERAL USE OF FUNDS.—Amounts  
2           made available under paragraph (1) shall be  
3           used to assist small water systems in improving  
4           the effectiveness of water fluoridation and to  
5           meet the recommendations of the EARWF.

6           “(C) FLUORIDATION SPECIALISTS.—

7           “(i) IN GENERAL.—In carrying out  
8           this subsection, the Secretary shall provide  
9           for the establishment of fluoridation spe-  
10          cialist engineering positions in each of the  
11          Dental Clinical and Preventive Support  
12          Centers through which technical assistance  
13          and training will be provided to tribal  
14          water operators, tribal utility operators  
15          and other Indian Health Service personnel  
16          working directly with fluoridation projects.

17          “(ii) LIAISON.—A fluoridation spe-  
18          cialist shall serve as the principal technical  
19          liaison between the Indian Health Service  
20          and the Centers for Disease Control and  
21          Prevention with respect to engineering and  
22          fluoridation issues.

23          “(iii) CDC.—The Director of the Cen-  
24          ters for Disease Control and Prevention

1           shall appoint individuals to serve as the  
2           fluoridation specialists.

3           “(D) IMPLEMENTATION.—The project es-  
4           tablished under this subsection shall be  
5           planned, implemented and evaluated over the 5-  
6           year period beginning on the date on which  
7           funds are appropriated under this section and  
8           shall be designed to serve as a model for im-  
9           proving the effectiveness of water fluoridation  
10          systems of small rural communities.

11          “(3) EVALUATION.—In conducting the ongoing  
12          evaluation as provided for in paragraph (2)(D), the  
13          Secretary shall ensure that such evaluation  
14          includes—

15                 “(A) the measurement of changes in water  
16                 fluoridation compliance levels resulting from as-  
17                 sistance provided under this section;

18                 “(B) the identification of the administra-  
19                 tive, technical and operational challenges that  
20                 are unique to the fluoridation of small water  
21                 systems;

22                 “(C) the development of a practical model  
23                 that may be easily utilized by other tribal, state,  
24                 county or local governments in improving the



1 quality of water fluoridation with emphasis on  
2 small water systems; and

3 “(D) the measurement of any increased  
4 percentage of Native Americans or Alaskan Na-  
5 tives who receive the benefits of optimally fluo-  
6 ridated water.

7 “(c) SCHOOL-BASED DENTAL SEALANT PROGRAM.—

8 “(1) IN GENERAL.—The Secretary, acting  
9 through the Director of the Centers for Disease  
10 Control and Prevention and in collaboration with the  
11 Administrator of the Health Resources and Services  
12 Administration, may award grants to States and In-  
13 dian tribes to provide for the development of school-  
14 based dental sealant programs to improve the access  
15 of children to sealants.

16 “(2) USE OF FUNDS.—A State shall use  
17 amounts received under a grant under paragraph (1)  
18 to provide funds to eligible school-based entities or  
19 to public elementary or secondary schools to enable  
20 such entities or schools to provide children in second  
21 and sixth grades with access to dental care and den-  
22 tal sealant services. Such services shall be provided  
23 by licensed dental health professionals in accordance  
24 with State practice licensing laws.

1           “(3) ELIGIBILITY.—To be eligible to receive  
2 funds under paragraph (1), an entity shall—

3           “(A) prepare and submit to the State an  
4 application at such time, in such manner and  
5 containing such information as the state may  
6 require; and

7           “(B) be a public elementary or secondary  
8 school—

9           “(i) that is located in an urban area  
10 in which and more than 50 percent of the  
11 student population is participating in fed-  
12 eral or state free or reduced meal pro-  
13 grams; or

14           “(ii) that is located in a rural area  
15 and, with respect to the school district in  
16 which the school is located, the district in-  
17 volved has a median income that is at or  
18 below 235 percent of the poverty line, as  
19 defined in section 673(2) of the Commu-  
20 nity Services Block Grant Act (42 U.S.C.  
21 9902(2)).

22           “(d) DEFINITIONS.—For purposes of this section, the  
23 term ‘Indian tribe’ means an Indian tribe or tribal organi-  
24 zation as defined in section 4(b) and section 4(c) of the  
25 Indian Self-Determination and Education Assistance Act.

1       “(e) AUTHORIZATION OF APPROPRIATIONS.—For the  
 2 purpose of carrying out this section, there are authorized  
 3 to be appropriated such sums as may be necessary for  
 4 each of the fiscal years 2001 through 2005.”.

5                   **TITLE XVII—VACCINE**  
 6                   **COMPENSATION PROGRAM**

7 **SEC. 1701. SHORT TITLE.**

8       This title may be cited as the “Vaccine Injury Com-  
 9 pensation Program Amendments of 2000.”.

10 **SEC. 1702. CONTENT OF PETITIONS.**

11       (a) IN GENERAL.—Section 2111(c)(1)(D) of the  
 12 Public Health Service Act (42 U.S.C. 300aa–11(c)(1)(D))  
 13 is amended by striking “and” at the end and inserting  
 14 “or (iii) suffered such illness, disability, injury, or condi-  
 15 tion from the vaccine which resulted in inpatient hos-  
 16 pitalization and surgical intervention, and”.

17       (b) EFFECTIVE DATE.—The amendment made by  
 18 subsection (a) takes effect upon the date of the enactment  
 19 of this Act, including with respect to petitions under sec-  
 20 tion 2111 of the Public Health Service Act that are pend-  
 21 ing on such date.

22                   **TITLE XVIII—HEPATITIS C**

23 **SEC. 1801. SHORT TITLE.**

24       This title may be cited as the “Hepatitis C and Chil-  
 25 dren Act of 2000”.

1 **SEC. 1802. SURVEILLANCE AND EDUCATION REGARDING**  
2 **HEPATITIS C.**

3 Part B of title III of the Public Health Service Act,  
4 as amended by section 1601 of this Act, is amended by  
5 inserting after section 317N the following section:

6 “SURVEILLANCE AND EDUCATION REGARDING HEPATITIS  
7 C VIRUS

8 “SEC. 317O. (a) IN GENERAL.—The Secretary, act-  
9 ing through the Director of the Centers for Disease Con-  
10 trol and Prevention, may (directly and through grants to  
11 public and nonprofit private entities) provide for programs  
12 to carry out the following:

13 “(1) To cooperate with the States in imple-  
14 menting a national system to determine the inci-  
15 dence and prevalence of cases of infection with hepa-  
16 titis C virus, including the reporting of chronic hepa-  
17 titis C cases.

18 “(2) To identify and contact individuals who  
19 became infected with such virus as a result of receiv-  
20 ing blood transfusions prior to July 1992 when the  
21 individuals were infants, small children, or adoles-  
22 cents.

23 “(3) To provide appropriate referrals for coun-  
24 seling, testing, and medical treatment of individuals  
25 identified under paragraph (2) and to ensure, to the

1 extent practicable, the provision of appropriate fol-  
2 low-up services.

3 “(4) To develop and disseminate public infor-  
4 mation and education programs for the detection  
5 and control of hepatitis C, with priority given to re-  
6 cipients of blood transfusions; women who gave birth  
7 by caesarean section; children who were high-risk  
8 neonates; veterans of the Armed Forces; and health  
9 professionals.

10 “(5) To improve the education, training, and  
11 skills of health professionals in the detection and  
12 control of cases of infection with hepatitis C, with  
13 priority given to pediatricians and other primary  
14 care physicians.

15 “(b) LABORATORY PROCEDURES.—The Secretary  
16 may (directly and through grants to public and nonprofit  
17 private entities) carry out programs to provide for im-  
18 provements in the quality of clinical-laboratory procedures  
19 regarding hepatitis C, including reducing variability in  
20 laboratory results on hepatitis C antibody and PCR test-  
21 ing.

22 “(c) AUTHORIZATION OF APPROPRIATIONS.—For the  
23 purpose of carrying out this section, there are authorized  
24 to be appropriated such sums as may be necessary for  
25 each of the fiscal years 2001 through 2005.”.

1     **TITLE XIX—NIH INITIATIVE ON**  
2             **AUTOIMMUNE DISEASES**

3     **SEC. 1901. SHORT TITLE.**

4             This title may be cited as the “NIH Autoimmune  
5     Diseases Initiative Act of 2000”.

6     **SEC. 1902. JUVENILE DIABETES, JUVENILE ARTHRITIS,**  
7             **LUPUS, MULTIPLE SCLEROSIS, AND OTHER**  
8             **AUTOIMMUNE-DISEASES;             INITIATIVE**  
9             **THROUGH DIRECTOR OF NATIONAL INSTI-**  
10            **TUTES OF HEALTH.**

11            Part B of title IV of the Public Health Service Act,  
12     as amended by section 1002 of this Act, is amended by  
13     adding at the end the following:

14                     “AUTOIMMUNE DISEASES

15            “SEC. 409E. (a) EXPANSION, INTENSIFICATION, AND  
16     COORDINATION OF ACTIVITIES.—

17                     “(1) IN GENERAL.—The Director of NIH shall  
18            expand, intensify, and coordinate research and other  
19            activities of the National Institutes of Health with  
20            respect to juvenile-onset diabetes, rheumatoid arthri-  
21            tis, systemic lupus erthematosus, multiple sclerosis,  
22            Sjogren’s syndrome, scleroderma, chronic fatigue  
23            syndrome, Crohn’s disease and colitis (in this section  
24            referred to as ‘autoimmune diseases’).

1           “(2) ALLOCATIONS BY DIRECTOR OF NIH.—

2           With respect to amounts appropriated to carry out  
3           this section for a fiscal year, the Director of NIH  
4           shall allocate the amounts among the national re-  
5           search institutes that are carrying out paragraph  
6           (1).

7           “(3) ADDITIONAL DISEASES OR DISORDERS.—

8           In addition to the diseases or disorders specified in  
9           paragraph (1), the term ‘autoimmune disease’ in-  
10          cludes for purposes of this section such other dis-  
11          eases or disorders as the Secretary determines to be  
12          appropriate.

13          “(b) COORDINATING COMMITTEE.—

14                 “(1) IN GENERAL.—The Secretary shall estab-  
15                 lish a committee to be known as Autoimmune Dis-  
16                 eases Coordinating Committee (referred to in this  
17                 subsection as the ‘Coordinating Committee’).

18                 “(2) DUTIES.—The Coordinating Committee  
19                 shall, with respect to autoimmune diseases—

20                         “(A) provide for the coordination of the ac-  
21                         tivities of the national research institutes; and

22                         “(B) coordinate the aspects of all Federal  
23                         health programs and activities relating to such  
24                         diseases in order to assure the adequacy and  
25                         technical soundness of such programs and ac-

1           activities and in order to provide for the full com-  
2           munication and exchange of information nec-  
3           essary to maintain adequate coordination of  
4           such programs and activities.

5           “(3) COMPOSITION.—The Coordinating Com-  
6           mittee shall be composed of the directors of each of  
7           the national research institutes involved in research  
8           with respect to autoimmune diseases and representa-  
9           tives of all other Federal departments and agencies  
10          whose programs involve health functions or respon-  
11          sibilities relevant to such diseases, including the  
12          Centers for Disease Control and Prevention and the  
13          Food and Drug Administration.

14          “(4) CHAIR.—From among the members of the  
15          Coordinating Committee, the Committee shall des-  
16          ignate an individual to serve as the chair of the  
17          Committee. With respect to autoimmune diseases,  
18          the Chair shall serve as the principal advisor to the  
19          Secretary, the Assistant Secretary for Health, and  
20          the Director of NIH, and shall provide advice to the  
21          Director of the Centers for Disease Control and Pre-  
22          vention, the Commissioner of Food and Drugs, and  
23          other relevant agencies.

24          “(5) FULL-TIME STAFF.—The Secretary shall  
25          ensure that the Coordinating Committee is staffed



1 and supported by not fewer than three scientists or  
2 health professionals for whom such service is a full-  
3 time Federal position. The Secretary shall in addi-  
4 tion ensure that the Committee is provided with  
5 such administrative staff and support as may be  
6 necessary to carry out the duties of the Committee.

7 “(c) ADVISORY COUNCIL.—

8 “(1) IN GENERAL.—The Secretary shall estab-  
9 lish an advisory council to be known as the Auto-  
10 immune Diseases Public Advisory Council (referred  
11 to in this subsection as the ‘Advisory Council’).

12 “(2) DUTIES.—The Advisory Council shall pro-  
13 vide to the Director of NIH and the Coordinating  
14 Committee under subsection (b) recommendations on  
15 carrying out this section, including the plan under  
16 subsection (d).

17 “(3) COMPOSITION.—The Advisory Council  
18 shall be composed exclusively of not more than 18  
19 members appointed to the Council by the Secretary  
20 from among individuals who are not officers or em-  
21 ployees of the United States. The Secretary shall en-  
22 sure that the membership of the Advisory Council  
23 includes—

1           “(A) scientists or health professionals who  
2           are knowledgeable with respect to autoimmune  
3           diseases;

4           “(B) representatives of autoimmune dis-  
5           ease patient advocacy organizations, including  
6           organizations advocating on behalf of diseases  
7           affecting small patient populations; and

8           “(C) patients and parents of children with  
9           such diseases, including autoimmune diseases  
10          affecting small patient populations.

11         “(d) PLAN FOR NIH ACTIVITIES.—

12           “(1) IN GENERAL.—The Coordinating Com-  
13          mittee shall develop a plan for conducting and sup-  
14          porting research and education on autoimmune dis-  
15          eases through the national research institutes, shall  
16          review the plan not less frequently than once each  
17          fiscal year, and shall revise the plan as appropriate.

18         The plan shall—

19           “(A) provide for a broad range of research  
20          and education activities relating to biomedical,  
21          psychosocial, and rehabilitative issues, including  
22          studies of the disproportionate impact of such  
23          diseases on women; and

1           “(B) establish priorities among the pro-  
2           grams and activities of the National Institutes  
3           of Health regarding such diseases.

4           “(2) CERTAIN ELEMENTS OF PLAN.—The plan  
5           under paragraph (1) shall, with respect to auto-  
6           immune diseases, provide for the following:

7           “(A) Research to determine the reasons  
8           underlying the incidence and prevalence of the  
9           diseases.

10          “(B) Basic research concerning the eti-  
11          ology and causes of the diseases.

12          “(C) Epidemiological studies to address  
13          the frequency and natural history of the dis-  
14          eases, including any differences among the  
15          sexes and among racial and ethnic groups.

16          “(D) The development of improved screen-  
17          ing techniques.

18          “(E) Clinical research for the development  
19          and evaluation of new treatments, including  
20          new biological agents.

21          “(F) Information and education programs  
22          for health care professionals and the public.

23          “(3) RECOMMENDATIONS OF ADVISORY COUN-  
24          CIL.—In developing the plan under paragraph (1),  
25          and reviewing and revising the plan, the Coordi-

1 nating Committee shall consider the recommenda-  
2 tions of the Advisory Council regarding the plan.

3 “(4) IMPLEMENTATION OF PLAN.—The Direc-  
4 tor of NIH shall ensure that programs and activities  
5 of the National Institutes of Health regarding auto-  
6 immune diseases are implemented in accordance  
7 with the plan under paragraph (1).

8 “(e) REPORTS TO CONGRESS.—The Coordinating  
9 Committee under subsection (b)(1) shall annually submit  
10 to the Committee on Commerce of the House of Rep-  
11 resentatives, and the Committee on Health, Education,  
12 Labor and Pensions of the Senate, a report that describes  
13 the research, education, and other activities on auto-  
14 immune diseases being conducted or supported through  
15 the national research institutes, and that in addition in-  
16 cludes the following:

17 “(1) The plan under subsection (d)(1) (or revi-  
18 sions to the plan, as the case may be).

19 “(2) The recommendations of the advisory  
20 council under subsection (c) regarding the plan (or  
21 revisions, as the case may be).

22 “(3) Provisions specifying the amounts ex-  
23 pended by the National Institutes of Health with re-  
24 spect to each of the autoimmune diseases included in  
25 the plan.

1           “(4) Provisions identifying particular projects  
2           or types of projects that should in the future be con-  
3           ducted or supported by the national research insti-  
4           tutes or other entities in the field of research on  
5           autoimmune diseases.

6           “(f) AUTHORIZATION OF APPROPRIATIONS.—For the  
7           purpose of carrying out this section, there are authorized  
8           to be appropriated such sums as may be necessary for  
9           each of the fiscal years 2001 through 2005. The author-  
10          ization of appropriations established in the preceding sen-  
11          tence is in addition to any other authorization of appro-  
12          priations that is available for conducting or supporting  
13          through the National Institutes of Health research and  
14          other activities with respect to autoimmune diseases.”.

15       **TITLE XX—GRADUATE MEDICAL**  
16       **EDUCATION PROGRAMS IN**  
17       **CHILDREN’S HOSPITALS**

18       **SEC. 2001. EXTENSION OF AUTHORIZATION OF APPROPRIA-**  
19       **TIONS.**

20           Section 340E(f) of the Public Health Service Act (42  
21       U.S.C. 256e(f)) is amended—

22           (1) in paragraph (1)(A)—

23           (A) in clause (i), by striking “and” at the  
24           end;

1 (B) in clause (ii), by striking the period  
2 and inserting “; and”; and

3 (C) by adding at the end the following:

4 “(iii) for each of the fiscal years 2002  
5 through 2005, such sums as may be nec-  
6 essary.”; and

7 (2) in paragraph (2)—

8 (A) in subparagraph (A), by striking  
9 “and” at the end;

10 (B) in subparagraph (B), by striking the  
11 period and inserting “; and”; and

12 (C) by adding at the end the following:

13 “(C) for each of the fiscal years 2002  
14 through 2005, such sums as may be nec-  
15 essary.”.

16 **TITLE XXI—SPECIAL NEEDS OF**  
17 **CHILDREN REGARDING**  
18 **ORGAN TRANSPLANTATION**

19 **SEC. 2101. SHORT TITLE.**

20 This title may be cited as the “Pediatric Organ  
21 Transplantation Improvement Act of 2000”.

1 **SEC. 2102. ORGAN PROCUREMENT AND TRANSPLANTATION**  
2 **NETWORK; AMENDMENTS REGARDING NEEDS**  
3 **OF CHILDREN.**

4 (a) IN GENERAL.—Section 372(b)(2) of the Public  
5 Health Service Act (42 U.S.C. 274(b)(2)) is amended—

6 (1) in subparagraph (J), by striking “and” at  
7 the end;

8 (2) in each of subparagraphs (K) and (L), by  
9 striking the period and inserting a comma; and

10 (3) by adding at the end the following subpara-  
11 graphs:

12 “(M) recognize the differences in health  
13 and in organ transplantation issues between  
14 children and adults throughout the system and  
15 adopt criteria, polices, and procedures that ad-  
16 dress the unique health care needs of children,

17 “(N) carry out studies and demonstration  
18 projects for the purpose of improving proce-  
19 dures for organ donation procurement and allo-  
20 cation, including but not limited to projects to  
21 examine and attempt to increase transplan-  
22 tation among populations with special needs, in-  
23 cluding children and individuals who are mem-  
24 bers of racial or ethnic minority groups, and  
25 among populations with limited access to trans-  
26 portation, and

1           “(O) provide that for purposes of this  
2           paragraph, the term ‘children’ refers to individ-  
3           uals who are under the age of 18.”.

4           (b)   STUDY   REGARDING   IMMUNOSUPPRESSIVE  
5 DRUGS.—

6           (1) IN GENERAL.—The Secretary of Health and  
7           Human Services (referred to in this subsection as  
8           the “Secretary”) shall provide for a study to deter-  
9           mine the costs of immunosuppressive drugs that are  
10          provided to children pursuant to organ transplants  
11          and to determine the extent to which health plans  
12          and health insurance cover such costs. The Sec-  
13          retary may carry out the study directly or through  
14          a grant to the Institute of Medicine (or other public  
15          or nonprofit private entity).

16          (2) RECOMMENDATIONS REGARDING CERTAIN  
17          ISSUES.—The Secretary shall ensure that, in addi-  
18          tion to making determinations under paragraph (1),  
19          the study under such paragraph makes recommenda-  
20          tions regarding the following issues:

21                 (A) The costs of immunosuppressive drugs  
22                 that are provided to children pursuant to organ  
23                 transplants and to determine the extent to  
24                 which health plans, health insurance and gov-  
25                 ernment programs cover such costs.



1 (B) The extent of denial of organs to be  
2 released for transplant by coroners and medical  
3 examiners.

4 (C) The special growth and developmental  
5 issues that children have pre- and post- organ  
6 transplantation.

7 (D) Other issues that are particular to the  
8 special health and transplantation needs of chil-  
9 dren.

10 (3) REPORT.—The Secretary shall ensure that,  
11 not later than December 31, 2000, the study under  
12 paragraph (1) is completed and a report describing  
13 the findings of the study is submitted to the Con-  
14 gress.

## 15 **TITLE XXII—MISCELLANEOUS** 16 **PROVISIONS**

17 **SEC. 2201. REPORT REGARDING RESEARCH ON RARE DIS-**  
18 **EASES IN CHILDREN.**

19 Not later than 180 days after the date of the enact-  
20 ment of this Act, the Director of the National Institutes  
21 of Health shall submit to the Congress a report on—

22 (1) the activities that, during fiscal year 2000,  
23 were conducted and supported by such Institutes  
24 with respect to rare diseases in children, including  
25 Friedreich's ataxia; and

1           (2) the activities that are planned to be con-  
2           ducted and supported by such Institutes with respect  
3           to such diseases during the fiscal years 2001  
4           through 2005.

5           **TITLE XXIII—EFFECTIVE DATE**

6           **SEC. 2301. EFFECTIVE DATE.**

7           This Act and the amendments made by this Act take  
8           effect October 1, 2000, or upon the date of the enactment  
9           of this Act, whichever occurs later.

          Passed the House of Representatives May 9, 2000.

Attest:

                          JEFF TRANDAHL,

*Clerk.*