106TH CONGRESS BSSION H.R. 4365

### AN ACT

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

106TH CONGRESS 2D SESSION

# H.R. 4365

## **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.

- This Act may be cited as the "Children's Health Act
- 3 of 2000".

#### 4 SEC. 2. TABLE OF CONTENTS.

- 5 The table of contents for this Act is as follows:
  - Sec. 1. Short title.
  - Sec. 2. Table of contents.

#### TITLE I—AUTISM

- Subtitle A—Surveillance and Research Regarding Prevalence and Pattern of Autism
- Sec. 101. Short title.
- Sec. 102. Surveillance and research programs; clearinghouse; advisory committee.
- Subtitle B—Expansion, Intensification, and Coordination of Autism Activities of National Institutes of Health
- Sec. 111. Short title.
- Sec. 112. Expansion, intensification, and coordination; information and education; interagency coordinating committee.

## TITLE II—RESEARCH AND DEVELOPMENT REGARDING FRAGILE X

- Sec. 201. Short title.
- Sec. 202. National Institute of Child Health and Human Development; research on fragile X.
- Sec. 203. National Institute of Child Health and Human Development; loan repayment program regarding research on fragile X.

#### TITLE III—JUVENILE ARTHRITIS AND RELATED CONDITIONS

- Sec. 301. National Institute of Arthritis and Musculoskeletal and Skin Diseases; research on juvenile arthritis and related conditions.
- Sec. 302. Information clearinghouse.

## TITLE IV—REDUCING BURDEN OF DIABETES AMONG CHILDREN AND YOUTH

- Sec. 401. Programs of Centers for Disease Control and Prevention.
- Sec. 402. Programs of National Institutes of Health.

#### TITLE V—ASTHMA TREATMENT SERVICES FOR CHILDREN

Sec. 501. Short title.

#### Subtitle A—Treatment Services

- Sec. 511. Grants for children's asthma relief.
- Sec. 512. Technical and conforming amendments.

#### Subtitle B—Prevention Activities

Sec. 521. Preventive health and health services block grant; systems for reducing asthma-related illnesses through urban cockroach management.

Subtitle C—Coordination of Federal Activities

Sec. 531. Coordination through National Institutes of Health.

Subtitle D—Compilation of Data

Sec. 541. Compilation of data by Centers for Disease Control and Prevention.

#### TITLE VI—BIRTH DEFECTS PREVENTION ACTIVITIES

Subtitle A—Folic Acid Promotion

Sec. 601. Short title.

Sec. 602. Program regarding effects of folic acid in prevention of birth defects.

Subtitle B—National Center on Birth Defects and Developmental Disabilities

Sec. 611. National Center on Birth Defects and Developmental Disabilities.

## TITLE VII—EARLY DETECTION, DIAGNOSIS, AND TREATMENT REGARDING HEARING LOSS IN INFANTS

Sec. 701. Short title.

Sec. 702. Purposes.

Sec. 703. Programs of Health Resources and Services Administration, Centers for Disease Control and Prevention, and National Institutes of Health.

#### TITLE VIII—CHILDREN AND EPILEPSY

Sec. 801. National public health campaign on epilepsy; seizure disorder demonstration projects in medically underserved areas.

#### TITLE IX—SAFE MOTHERHOOD; INFANT HEALTH PROMOTION

Subtitle A—Safe Motherhood Monitoring and Prevention Research

Sec. 901. Short title.

Sec. 902. Monitoring; prevention research and other activities.

Subtitle B—Pregnant Mothers and Infants Health Promotion

Sec. 911. Short title.

Sec. 912. Programs regarding prenatal and postnatal health.

#### TITLE X—REVISION AND EXTENSION OF CERTAIN PROGRAMS

Subtitle A—Pediatric Research Initiative

Sec. 1001. Short title.

Sec. 1002. Establishment of pediatric research initiative.

Sec. 1003. Investment in tomorrow's pediatric researchers.

Subtitle B—Other Programs

- Sec. 1011. Childhood immunizations.
- Sec. 1012. Screenings, referrals, and education regarding lead poisoning.

#### TITLE XI—CHILDHOOD SKELETAL MALIGNANCIES

Sec. 1101. Programs of Centers for Disease Control and Prevention and National Institutes of Health.

#### TITLE XII—ADOPTION AWARENESS

#### Subtitle A—Infant Adoption Awareness

- Sec. 1201. Short title.
- Sec. 1202. Grants regarding infant adoption awareness.

#### Subtitle B—Special Needs Adoption Awareness

- Sec. 1211. Short title.
- Sec. 1212. Special needs adoption programs; public awareness campaign and other activities.

#### TITLE XIII—TRAUMATIC BRAIN INJURY

- Sec. 1301. Short title.
- Sec. 1302. Programs of Centers for Disease Control and Prevention.
- Sec. 1303. Programs of National Institutes of Health.
- Sec. 1304. Programs of Health Resources and Services Administration.

#### TITLE XIV—PREVENTION AND CONTROL OF INJURIES

Sec. 1401. Authorization of Appropriations for programs of Centers for Disease Control and Prevention.

#### TITLE XV—HEALTHY START INITIATIVE

- Sec. 1501. Short title.
- Sec. 1502. Continuation of healthy start program.

## TITLE XVI—ORAL HEALTH PROMOTION AND DISEASE PREVENTION

Sec. 1601. Oral health promotion and disease prevention.

#### TITLE XVII—VACCINE COMPENSATION PROGRAM

- Sec. 1701. Short title.
- Sec. 1702. Content of petitions.

#### TITLE XVIII—HEPATITIS C

- Sec. 1801. Short title.
- Sec. 1802. Surveillance and education regarding hepatitis C.

#### TITLE XIX—NIH INITIATIVE ON AUTOIMMUNE DISEASES

- Sec. 1901. Short title.
- Sec. 1902. Juvenile diabetes, juvenile arthritis, lupus, multiple sclerosis, and other autoimmune-diseases; initiative through Direction of National Institutes of Health.

## TITLE XX—GRADUATE MEDICAL EDUCATION PROGRAMS IN CHILDREN'S HOSPITALS

Sec. 2001. Extension of authorization of appropriations.

## TITLE XXI—SPECIAL NEEDS OF CHILDREN REGARDING ORGAN TRANSPLANTATION

Sec. 2101. Short title.

Sec. 2102. Organ Procurement and Transplantation Network; amendments regarding needs of children.

#### TITLE XXII—MISCELLANEOUS PROVISIONS

Sec. 2201. Report regarding research on rare diseases in children.

#### TITLE XXIII—EFFECTIVE DATE

Sec. 2301. Effective date.

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
- "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
- through the Director of the Centers for Disease
- 15 Control and Prevention, shall (subject to the extent
- of amounts made available in appropriations Acts)
- 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-
- tism and related developmental disorders.
- 23 "(2) Recipients of awards for establish-
- MENT OF CENTERS.—Centers under paragraph (1)
- shall be established and operated through the award

of grants or cooperative agreements to public or nonprofit private entities that conduct research, including health departments of States and political subdivisions of States, and including universities and other educational entities.

- "(3) CERTAIN REQUIREMENTS.—An award for a center under paragraph (1) may be made only if the entity involved submits to the Secretary an application containing such agreements and information as the Secretary may require, including an agreement that the center involved will operate in accordance with the following:
  - "(A) The center will collect, analyze, and report autism and pervasive developmental disorders data according to guidelines prescribed by the Director, after consultation with relevant State and local public health officials, private sector developmental disorder researchers, and advocates for those with developmental disorders;
  - "(B) The center will assist with the development and coordination of State autism and pervasive developmental disorders surveillance 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

"(D) The center will identify eligible cases and controls through its surveillance systems and conduct research into factors which may cause autism and related developmental disorders; each program will develop or extend an area of special research expertise (including, but not limited to, genetics, environmental exposure to contaminants, immunology, and other relevant research specialty areas).

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

"(1) The Centers for Disease Control and Prevention shall serve as the coordinating agency for autism and pervasive developmental disorders surveillance activities through the establishment of a clearinghouse for the collection and storage of data generated from the monitoring programs created by this section. The functions of such a clearinghouse 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.

"(e) Report to Congress.—The Secretary shall 8 prepare and submit to the Congress, after consultation with and comment by the advisory committee under sub-10 11 section (d), an annual report regarding the prevalence and 12 incidence of autism and other pervasive developmental disorders, 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 other pervasive developmental disorders, and the need for 16 17 additional research into promising lines of scientific in-18 quiry.

"(f) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for 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

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

### "(b) Interagency Coordinating Committee.—

- "(1) IN GENERAL.—The Secretary shall ensure that there is in operation an interagency committee to be known as the 'Autism Coordinating Committee' (referred to in this subsection as the 'Committee') to coordinate all efforts within the Department of Health and Human Services concerning autism, including activities carried out through the National Institutes of Health under this section and activities carried out through the Centers for Disease Control and Prevention under section 317H.
- "(2) Membership.—The Committee shall be composed of such directors of the national research institutes, such directors of centers within the Centers for Disease Control and Prevention, and such other officials within the Department of Health and Human Services as the Secretary determines to be appropriate. The Committee may include representatives of other Federal agencies that serve children with autism, such as the Department of Education.
- "(3) Meetings.—The Committee shall meet not less than twice per year.
- 25 "(c) Centers of Excellence.—

- "(1) IN GENERAL.—The Director shall under subsection (a)(1) make awards of grants and contracts to public or nonprofit private entities to pay all or part of the cost of planning, establishing, improving, and providing basic operating support for centers of excellence regarding research on autism.
- "(2) Research.—Each center under paragraph (1) shall conduct basic and clinical research into autism. Such research should include investigations into the cause, diagnosis, early detection, prevention, control, and treatment of autism. These centers, as a group, shall conduct research including but not limited to the fields of developmental neurobiology, genetics, and psychopharmacology.
- "(3) Services for patients.—A center under paragraph (1) may expend amounts provided under such paragraph to carry out a program to make individuals aware of opportunities to participate as subjects in research conducted by the centers. The program may, in accordance with such criteria as the Director may establish, provide to such subjects referrals for health and other services, and such patient care costs as are required for research. The extent to which the center can demonstrate availability and access to clinical services shall be considered by

- the Director in decisions about awarding the grants to applicants which meet the scientific criteria for funding.
  - "(4) COORDINATION OF CENTERS; REPORTS.—
    The Director shall, as appropriate, provide for the coordination of information among centers under paragraph (1) and ensure regular communication between such centers, and may require the periodic preparation of reports on the activities of the centers and the submission of the reports to the Director.
  - "(5) Organization of centers.—Each center under paragraph (1) shall use the facilities of a single institution, or be formed from a consortium of cooperating institutions, meeting such requirements as may be prescribed by the Director.
  - "(6) Number of centers; duration of support.—The Director shall provide for the establishment of not less than five centers under paragraph (1), subject to the extent of amounts made available in appropriations Acts. Support of such a center may be for a period not exceeding 5 years. Such period may be extended for one or more additional periods not exceeding 5 years if the operations of such center have been reviewed by an appropriate technical 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
- and implement a program to provide information
- and education on autism to health professionals and
- the general public, including information and edu-
- 16 cation on advances in the diagnosis and treatment of
- autism and training and continuing education
- through programs for scientists, physicians, and
- other health professionals who provide care for pa-
- tients with autism.
- 21 "(2) STIPENDS.—The Director may use
- amounts made available under this section to pro-
- vide stipends for health professionals who are en-
- 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**

### 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)

- shall use the facilities of a single institution, or be formed from a consortium of cooperating institutions, meeting such requirements as may be prescribed by the Director of the Institute.
- "(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.
- "(7) AUTHORIZATION OF APPROPRIATIONS.—

  For the purpose of carrying out this subsection,

  there are authorized to be appropriated such sums

  as may be necessary for each of the fiscal years

  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	section (a) of this section, apply to the program estab- lished in such subsection in the same manner and to the
<ul><li>19</li><li>20</li></ul>	
	lished in such subsection in the same manner and to the
20	lished in such subsection in the same manner and to the same extent as such provisions apply to the National
<ul><li>20</li><li>21</li></ul>	lished in such subsection in the same manner and to the same extent as such provisions apply to the National Health Service Corps Loan Repayment Program estab-

- 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
- "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.
- 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
- "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-
- panding research to better assess the prevalence of
- 11 type 2 diabetes in youth and determine the extent to
- which type 2 diabetes is incorrectly diagnosed as
- type 1 diabetes among children;
- 14 "(2) assisting States in establishing coordinated
- school health programs and physical activity and nu-
- trition demonstration programs to control weight
- and increase physical activity among youth; and
- "(3) developing and improving laboratory meth-
- ods to assist in diagnosis, treatment, and prevention
- of diabetes including, but not limited to, developing
- 21 noninvasive ways to monitor blood glucose to prevent
- 22 hypoglycema and improving existing glucometers
- that measure blood glucose.
- 24 "(c) Authorization of Appropriations.—For the
- 25 purpose of carrying out this section, there are authorized

- to be appropriated such sums as may be necessary for each of the fiscal years 2001 through 2005.". 3 SEC. 402. PROGRAMS OF NATIONAL INSTITUTES  $\mathbf{OF}$ 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 inserting 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
- paragraph (1) with respect to type 1 diabetes are 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

	29
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.
- "(a) AUTHORITY TO MAKE GRANTS.— 23
- 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

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 Sec3 retary for a grant under this section in
  4 such form and manner as the Secretary
  5 may require.
  - "(ii) REQUIRED INFORMATION.—An application submitted under this subparagraph shall include a plan for the use of funds awarded under the grant and such other information as the Secretary may require.
  - "(B) Requirement.—In awarding grants under this section, the Secretary shall give preference to eligible entities that demonstrate that the activities to be carried out under this section shall be in localities within areas of known or suspected high prevalence of childhood asthma or high asthma-related mortality (relative to the average asthma prevalence rates and associated mortality rates in the United States). Acceptable data sets to demonstrate a high prevalence of childhood asthma or high asthma-related mortality may include data from Federal, State, or local vital statistics, claims data under 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;
- "(2) develop, in consultation with appropriate
   Federal agencies and professional and voluntary
   health organizations, a Federal plan for responding
   to asthma; and
- "(3) not later than 12 months after the date of the enactment of the Children's Health Act of 2000, submit recommendations to the appropriate committees of the Congress on ways to strengthen and improve the coordination of asthma-related activities of 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.".

## **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

- or not planning a pregnancy) to consume on a daily basis a dietary supplement that provides an appropriate level of folic acid.
- "(2) To conduct research with respect to such education and training, including identifying effective strategies for increasing the rate of consumption of folic acid by women of reproductive capacity.
  - "(3) To conduct research to increase the understanding of the effects of folic acid in preventing birth defects, including understanding with respect to cleft lip, cleft palate, and heart defects.
  - "(4) To provide for appropriate epidemiological activities regarding folic acid and birth defects, including epidemiological activities regarding neural tube defects.
- "(b) Consultations With States and Private Entities.—In carrying out subsection (a), the Secretary shall consult with the States and with other appropriate public or private entities, including national nonprofit private organizations, health professionals, and providers of health insurance and health plans.
- "(c) TECHNICAL ASSISTANCE.—The Secretary may directly or through grants or contracts) provide technical assistance to public and nonprofit private entities in carrying out the activities described in subsection (a).

9

10

11

12

13

14

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 or
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-
- 12 TITLE VII—EARLY DETECTION,

ceding subparagraph (A), by striking "(a)(1)" and

- 13 **DIAGNOSIS, AND TREATMENT**
- 14 **REGARDING HEARING LOSS**
- 15 **IN INFANTS**

inserting "(a)(2)(A)".

16 SEC. 701. SHORT TITLE.

10

- 17 This title may be cited as the "Newborn and Infant
- 18 Hearing Screening and Intervention Act of 2000".
- 19 **SEC. 702. PURPOSES.**
- 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:

10

11

12

13

14

15

16

17

18

19

20

21

22

23

- 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.
  - (2) All babies who are not born in hospitals in the United States and its territories should have a hearing screening within the first 3 months of life.
  - (3) Appropriate audiologic and medical evaluations should be conducted by 3 months for all newborns and infants suspected of having hearing loss to allow appropriate referral and provisions for audiologic rehabilitation, medical and early intervention before the age of 6 months.
  - (4) All newborn and infant hearing screening programs and systems should include a component for audiologic rehabilitation, medical and early intervention options that ensures linkage to any new and existing state-wide systems of intervention and rehabilitative services for newborns and infants with 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
- Disabilities Education Act, which offer programs
- specifically designed to meet the unique language
- and communication needs of deaf and hard of hear-
- ing newborns, infants, toddlers, and children.
- 14 "(2) To collect data on statewide newborn and
- infant hearing screening, evaluation and intervention
- programs and systems that can be used for applied
- 17 research, program evaluation and policy develop-
- 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
- Director of the Centers for Disease Control and Pre-
- vention, shall make awards of grants or cooperative
- 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-

guage status of these children at school age;
and

"(F) to promote the sharing of data regarding early hearing loss with State-based birth defects and developmental disabilities monitoring programs for the purpose of identifying previously unknown causes of hearing loss.

"(2) NATIONAL INSTITUTES OF HEALTH.—The Director of the National Institutes of Health, acting through the Director of the National Institute on Deafness and Other Communication Disorders, shall for purposes of this section, continue a program of research and development on the efficacy of new screening techniques and technology, including clinical studies of screening methods, studies on efficacy of intervention, and related research.

## "(c) COORDINATION AND COLLABORATION.—

"(1) IN GENERAL.—In carrying out programs under this section, the Administrator of the Health Resources and Services Administration, the Director of the Centers for Disease Control and Prevention, and the Director of the National Institutes of Health shall collaborate and consult with other Federal 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 Treatment Program); title XXI of the Social Security Act (State Children's Health Insurance Program); title 5 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.

"(2) Policy Development.—The Administrator of the Health Resources and Services Administration, the Director of the Centers for Disease Control and Prevention, and the Director of the National Institutes of Health shall coordinate and col-

21

22

23

24

2 at the Federal and State levels and with the private 3 sector, including consumer, medical and other health

laborate on recommendations for policy development

- 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:
- "(1) The term 'audiologic evaluation' refers to procedures to assess the status of the auditory system; to establish the site of the auditory disorder; the type and degree of hearing loss, and the potential effects of hearing loss on communication; and to identify appropriate treatment and referral options.

- Referral options should include linkage to State coordinating agencies under part C of the Individuals with Disabilities Education Act or other appropriate agencies, medical evaluation, hearing aid/sensory aid assessment, audiologic rehabilitation treatment, national and local consumer, self-help, parent, and education organizations, and other family-centered services.
  - "(2) The terms 'audiologic rehabilitation' and 'audiologic intervention' refer to procedures, techniques, and technologies to facilitate the receptive and expressive communication abilities of a child with hearing loss.
  - "(3) The term 'early intervention' refers to providing appropriate services for the child with hearing loss, including nonmedical services, and ensuring that families of the child are provided comprehensive, consumer-oriented information about the full range of family support, training, information services, communication options and are given the opportunity to consider the full range of educational and program placements and options for their child.
  - "(4) The term 'medical evaluation by a physician' refers to key components including history, examination, and medical decision making focused on

- symptomatic and related body systems for the purpose of diagnosing the etiology of hearing loss and related physical conditions, and for identifying appropriate treatment and referral options.
  - "(5) The term 'medical intervention' refers to the process by which a physician provides medical diagnosis and direction for medical and/or surgical treatment options of hearing loss and/or related medical disorder associated with hearing loss.
  - "(6) The term 'newborn and infant hearing screening' refers to objective physiologic procedures to detect possible hearing loss and to identify newborns and infants who, after rescreening, require further audiologic and medical evaluations.

## "(f) AUTHORIZATION OF APPROPRIATIONS.—

- "(1) STATEWIDE NEWBORN AND INFANT HEAR-ING SCREENING, EVALUATION AND INTERVENTION PROGRAMS AND SYSTEMS.—For the purpose of carrying out subsection (a), there are authorized to be appropriated to the Health Resources and Services Administration such sums as may be necessary for each of the fiscal years 2001 through 2005.
- "(2) TECHNICAL ASSISTANCE, DATA MANAGE-MENT, AND APPLIED RESEARCH; CENTERS FOR DIS-EASE CONTROL AND PREVENTION.—For the purpose

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

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	<b>EPILEPSY</b>
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 a
23	the end the following section:
24	"SEC. 330E. EPILEPSY; SEIZURE DISORDER.
25	"(a) National Public Health Campaign —

"(1) IN GENERAL.—The Secretary shall develop 1 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.

- "(2) CERTAIN ACTIVITIES.—Activities under paragraph (1) shall include—
  - "(A) expanding current surveillance activities through existing monitoring systems and improving registries that maintain data on individuals with epilepsy, including children;
  - "(B) enhancing research activities on patient management and control of epilepsy;
  - "(C) implementing public and professional information and education programs regarding epilepsy, including initiatives which promote effective management and control of the disease through children's programs which are targeted to parents, schools, daycare providers, patients;

12

13

14

15

16

17

18

19

20

21

22

23

24

1	"(D) undertaking educational efforts with
2	the media, providers of health care, schools and
3	others regarding stigmas and secondary disabil-
4	ities 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.
- "(2) APPLICATION FOR GRANT.—The Secretary
  may make a grant under paragraph (1) only if the
  application for the grant is submitted to the Secretary and the application is in such form, is made
  in such matter, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out this subsection.
- 10 "(c) Definitions.—For purposes of this section:
- "(1) The term "epilepsy" refers to a chronic and serious neurological condition which produces excessive electrical discharges in the brain causing recurring seizures affecting all life activities. The Secretary may revise the definition of such term as the Secretary.
- "(2) The term "medically underserved" has the
  meaning applicable under section 799B(6).
- "(d) Authorization of Appropriations.—For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for 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 burder
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	<b>Infants Health Promotion</b>
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.

	00
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	<b>EXTENSION OF PROGRAMS</b>
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

- ensure that the expanding opportunities for advancement in scientific investigations and care for children are realized;
- "(2) enhanced collaborative efforts among the Institutes to support multidisciplinary research in the areas that the Director deems most promising; and
- "(3) the development of adequate pediatric clinical trials and pediatric use information to promote
  the safer and more effective use of prescription
  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;
  - "(2) have broad discretion in the allocation of any Initiative assistance among the Institutes, among types of grants, and between basic and clinical research so long as the—

23

24

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
- pediatric specialties or subspecialties and intend to
- 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) the expansion of current demographic data
  collection and population surveillance efforts to include childhood skeletal cancers nationally;
- "(2) the development of a uniform reporting system under which treating physicians, hospitals, clinics, and states report the diagnosis of childhood skeletal cancers, including relevant associated epidemiological 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.
- "(d) DEFINITION.—For purposes of this section, the term 'childhood skeletal cancer' refers to any malignancy originating in the connective tissue of a person before skeletal maturity including the appendicular and axial skeleton. The Secretary may for purposes of this section revise the definition of such term to the extent determined by 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-

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-

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 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.

"(b) APPLICATION FOR GRANT.—The Secretary may
make a grant under subsection (a) only if an application
for the grant is submitted to the Secretary and the application is in such form, is made in such manner, and contains such agreements, assurances, and information as the
Secretary determines to be necessary to carry out this section.

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	<b>Subtitle B—Special Needs Adoption</b>
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.

## "(4) Matching Requirement.—

"(A) IN GENERAL.—With respect to the costs of the activities to be carried out by an entity pursuant to paragraph (1), a condition for the receipt of a grant under such paragraph is that the entity agree to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs.

"(B) Determination of amount contribution.—Non-Federal contributions under subparagraph (A) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the 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
- adoption organizations.
- 11 "(2) Information beneficial to individuals who
- adopt such children, including lists of support
- 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
- adoptive parents, adopted children, and siblings of
- adopted children; and
- 21 "(2) to carry out studies to identify the reasons
- 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

this section shall demonstrate or express a will-

ingness to obtain expertise and knowledge of

24

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

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

13

14

15

16

17

18

- "(2) DEFINITION.—For purposes of paragraph (1), the term 'Healthy Start Initiative' is a reference to the program that, as an initiative to reduce the rate of infant mortality and improve perinatal outcomes, makes grants for project areas with high annual rates of infant mortality and that, prior to the effective date of this section, was a demonstration program carried out under section 301.
  - "(3) Additional grants.— Effective upon increased funding beyond fiscal year 1999 for such Initiative, additional grants may be made to States to assist communities with technical assistance, replication of successful projects, and State policy formation to reduce infant and maternal mortality and morbidity.
- "(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
- 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

add to or expand the level of health services available in such area to pregnant women and infants.

- "(3) Transportation and subsistence expenses for certain partients.—The purposes for which a grant under paragraph (1)(B) may be expended include paying, on behalf of a pregnant woman who is in need of the health services described in such paragraph, transportation and subsistence expenses to assist the pregnant woman in obtaining such health services from the grantee involved. The Secretary may establish such restrictions regarding payments under the preceding sentence as the Secretary determines to be appropriate.
- "(4) CERTAIN CONDITIONS.—A condition for the receipt of a grant under paragraph (1) is that the applicant for the grant agree as follows:
  - "(A) In the case of a grant under paragraph (1)(A), if ultrasound services indicate that there is a fetal anomaly or other serious obstetric complication, the applicant will refer the pregnant woman involved for appropriate medical services, including, as appropriate, for health services described in paragraph (1)(B) 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

determine whether the activities have been effective in serving the needs of pregnant women with respect to ultrasound services and the other health services described in paragraph (1)(B). The evaluation shall include an analysis of whether such activities have been effective in reducing the disparity in health status between the general population and individuals who are members of racial or ethnic minority groups. Not later than January 10, 2005, the Comptroller General shall submit to the Committee on Commerce in the House of Representatives, and to the Committee on Health, Education, Labor, and Pensions in the Senate, a report describing the findings of the evaluation.

"(B) Relation to grants regarding Medically appropriate services for atrisk mothers and infants.—Before the date on which the evaluation under subparagraph (A) is submitted in accordance with such subparagraph—

"(i) the Secretary shall ensure that there are not more than three grantees 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

to 1 percent for evaluations of projects carried out under subsection (a). Each such evaluation shall include a determination of whether such projects have been effective in reducing the disparity in health status between the general population and individuals who are members of racial or ethnic minority groups.

('(2) MEDICALLY APPROPRIATE JULTBASOUND

- "(2) Medically appropriate ultrasound services; medically appropriate services for at-risk mothers and infants.—
  - "(A) AUTHORIZATION OF APPROPRIA-TIONS.—For the purpose of carrying out subsection (e), there are authorized to be appropriated such sums as may be necessary for each of the fiscal years 2001 through 2005.
  - "(B) ALLOCATION.—Of the amounts appropriated under subparagraph (A) for a fiscal year, the Secretary shall make available not less than 10 percent for providing ultrasound services under subsection (d)(1)(A) (provided by qualified health care professionals upon medical indication and referral from health care professionals who provide comprehensive prenatal 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	serting 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.

## "(b) COMMUNITY WATER FLUORIDATION.—

"(1) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention and in collaboration with the Director of the Indian Health Service, shall establish a demonstration project that is designed to assist rural water systems in successfully implementing the water fluoridation guidelines of the Centers for Disease Control and Prevention that are entitled "Engineering and Administrative Recommendations for Water Fluoridation, 1995" (referred to in this subsection as the 'EARWF').

## "(2) Requirements.—

"(A) Collaboration.—In collaborating under paragraph (1), the Directors referred to in such paragraph shall ensure that technical assistance and training are provided to tribal programs located in each of the 12 areas of the Indian Health Service. The Director of the Indian Health Service shall provide coordination and administrative support to tribes under this 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

- "(D) the measurement of any increased percentage of Native Americans or Alaskan Natives who receive the benefits of optimally fluoridated water.
- 7 "(c) School-Based Dental Sealant Program.—
  - "(1) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention and in collaboration with the Administrator of the Health Resources and Services Administration, may award grants to States and Indian tribes to provide for the development of school-based dental sealant programs to improve the access of children to sealants.
    - "(2) USE OF FUNDS.—A State shall use amounts received under a grant under paragraph (1) to provide funds to eligible school-based entities or to public elementary or secondary schools to enable such entities or schools to provide children in second and sixth grades with access to dental care and dental sealant services. Such services shall be provided by licensed dental health professionals in accordance 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. 3170. (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

- extent practicable, the provision of appropriate follow-up services.
- "(4) To develop and disseminate public information and education programs for the detection and control of hepatitis C, with priority given to recipients of blood transfusions; women who gave birth by caesarean section; children who were high-risk neonates; veterans of the Armed Forces; and health professionals.
- "(5) To improve the education, training, and skills of health professionals in the detection and control of cases of infection with hepatitis C, with priority given to pediatricians and other primary 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.
- "(c) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there are authorized to be appropriated such sums as may be necessary for 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-

tivities and in order to provide for the full communication and exchange of information necessary to maintain adequate coordination of such programs and activities.

- "(3) Composition.—The Coordinating Committee shall be composed of the directors of each of the national research institutes involved in research with respect to autoimmune diseases and representatives of all other Federal departments and agencies whose programs involve health functions or responsibilities relevant to such diseases, including the Centers for Disease Control and Prevention and the Food and Drug Administration.
- "(4) CHAIR.—From among the members of the Coordinating Committee, the Committee shall designate an individual to serve as the chair of the Committee. With respect to autoimmune diseases, the Chair shall serve as the principal advisor to the Secretary, the Assistant Secretary for Health, and the Director of NIH, and shall provide advice to the Director of the Centers for Disease Control and Prevention, the Commissioner of Food and Drugs, and other relevant agencies.
- "(5) Full-time staff.—The Secretary shall 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 fulltime Federal position. The Secretary shall in addi-3 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

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

- "(1) In General.—The Secretary shall establish an advisory council to be known as the Autoimmune Diseases Public Advisory Council (referred to in this subsection as the 'Advisory Council').
- "(2) Duties.—The Advisory Council shall provide to the Director of NIH and the Coordinating Committee under subsection (b) recommendations on carrying out this section, including the plan under subsection (d).
- "(3) Composition.—The Advisory Council shall be composed exclusively of not more than 18 members appointed to the Council by the Secretary from among individuals who are not officers or employees of the United States. The Secretary shall ensure that the membership of the Advisory Council 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-

ernment programs cover such costs.

25

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:

Clerk.