

H.R. 274 After it became Title I of:
PUBLIC LAW 106-310—OCT. 17, 2000

**AUTISM STATISTICS, SURVEILLANCE,
RESEARCH AND EPIDEMIOLOGY ACT (ASSURE)
OF 2000 (H.R. 274)**

Prime Sponsor: Mr. Christopher H. Smith (NJ)

H.R. 274 Incorporated as Title I of P.L. 106-310

Signed by the President on October 17, 2000

Public Law 106-310
106th Congress

An Act

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

Oct. 17, 2000
[H.R. 4365]

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

Children's Health Act of 2000.
42 USC 201 note.

SECTION 1. SHORT TITLE.

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

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DIVISION A—CHILDREN'S HEALTH

TITLE I—AUTISM

SEC. 101. EXPANSION, INTENSIFICATION, AND COORDINATION OF ACTIVITIES OF NATIONAL INSTITUTES OF HEALTH WITH RESPECT TO RESEARCH ON AUTISM.

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

“EXPANSION, INTENSIFICATION, AND COORDINATION OF ACTIVITIES OF NATIONAL INSTITUTES OF HEALTH WITH RESPECT TO RESEARCH ON AUTISM

“SEC. 409C. (a) IN GENERAL.—

“(1) EXPANSION OF ACTIVITIES.—The Director of NIH (in this section referred to as the ‘Director’) shall expand, intensify,

42 USC 284g.

and coordinate the activities of the National Institutes of Health with respect to research on autism.

“(2) ADMINISTRATION OF PROGRAM; COLLABORATION AMONG AGENCIES.—The Director shall carry out this section acting through the Director of the National Institute of Mental Health and in collaboration with any other agencies that the Director determines appropriate.

“(b) CENTERS OF EXCELLENCE.—

“(1) IN GENERAL.—The Director shall under subsection (a)(1) make awards of grants and contracts to public or non-profit 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. The centers, as a group, shall conduct research including the fields of developmental neurobiology, genetics, and psychopharmacology.

“(3) SERVICES FOR PATIENTS.—

“(A) IN GENERAL.—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.

“(B) REFERRALS AND COSTS.—A program under subparagraph (A) may, in accordance with such criteria as the Director may establish, provide to the subjects described in such subparagraph, referrals for health and other services, and such patient care costs as are required for research.

“(C) AVAILABILITY AND ACCESS.—The extent to which a center can demonstrate availability and access to clinical services shall be considered by the Director in decisions about awarding grants to applicants which meet the scientific criteria for funding under this section.

“(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.—

“(A) IN GENERAL.—The Director shall provide for the establishment of not less than five centers under paragraph (1).

“(B) DURATION.—Support for a center established under paragraph (1) may be provided under this section for a period of not to exceed 5 years. Such period may be extended for one or more additional periods not exceeding 5 years if the operations of such center have

Grants.
Contracts.

been reviewed by an appropriate technical and scientific peer review group established by the Director and if such group has recommended to the Director that such period should be extended.

“(c) FACILITATION OF RESEARCH.—The Director shall under subsection (a)(1) provide for a program under which samples of tissues and genetic materials that are of use in research on autism are donated, collected, preserved, and made available for such research. The program shall be carried out in accordance with accepted scientific and medical standards for the donation, collection, and preservation of such samples.

“(d) PUBLIC INPUT.—The Director shall under subsection (a)(1) provide for means through which the public can obtain information on the existing and planned programs and activities of the National Institutes of Health with respect to autism and through which the Director can receive comments from the public regarding such programs and activities.

“(e) FUNDING.—There are authorized to be appropriated such sums as may be necessary to carry out this section. Amounts appropriated under this subsection are in addition to any other amounts appropriated for such purpose.”

Appropriation
authorization.

SEC. 102. DEVELOPMENTAL DISABILITIES SURVEILLANCE AND RESEARCH PROGRAMS.

42 USC 247b-4b.

(a) NATIONAL AUTISM AND PERVASIVE DEVELOPMENTAL DISABILITIES SURVEILLANCE PROGRAM.—

(1) **IN GENERAL.**—The Secretary of Health and Human Services (in this section referred to as the “Secretary”), acting through the Director of the Centers for Disease Control and Prevention, may make awards of grants and cooperative agreements for the collection, analysis, and reporting of data on autism and pervasive developmental disabilities. In making such awards, the Secretary may provide direct technical assistance in lieu of cash.

(2) **ELIGIBILITY.**—To be eligible to receive an award under paragraph (1) an entity shall be a public or nonprofit private entity (including health departments of States and political subdivisions of States, and including universities and other educational entities).

(b) CENTERS OF EXCELLENCE IN AUTISM AND PERVASIVE DEVELOPMENTAL DISABILITIES EPIDEMIOLOGY.—

(1) **IN GENERAL.**—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall establish not less than three regional centers of excellence in autism and pervasive developmental disabilities epidemiology for the purpose of collecting and analyzing information on the number, incidence, correlates, and causes of autism and related developmental disabilities.

(2) **RECIPIENTS OF AWARDS FOR ESTABLISHMENT OF CENTERS.**—Centers under paragraph (1) shall be established and operated through the awarding 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 disabilities data according to guidelines prescribed by the Director, after consultation with relevant State and local public health officials, private sector developmental disability researchers, and advocates for those with developmental disabilities.

(B) The center will assist with the development and coordination of State autism and pervasive developmental disabilities surveillance efforts within a region.

(C) The center will identify eligible cases and controls through its surveillance systems and conduct research into factors which may cause autism and related developmental disabilities.

(D) The center will develop or extend an area of special research expertise (including genetics, environmental exposure to contaminants, immunology, and other relevant research specialty areas).

(c) **CLEARINGHOUSE.**—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall carry out the following:

(1) The Secretary shall establish a clearinghouse within the Centers for Disease Control and Prevention for the collection and storage of data generated from the monitoring programs established by this title. Through the clearinghouse, such Centers shall serve as the coordinating agency for autism and pervasive developmental disabilities surveillance activities. The functions of such a clearinghouse shall include facilitating the coordination of research and policy development relating to the epidemiology of autism and other pervasive developmental disabilities.

(2) The Secretary shall coordinate the Federal response to requests for assistance from State health department officials regarding potential or alleged autism or developmental disability clusters.

(d) **DEFINITION.**—In this title, the term “State” means each of the several States, the District of Columbia, the Commonwealth of Puerto Rico, American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, the Virgin Islands, and the Trust Territory of the Pacific Islands.

(e) **AUTHORIZATION OF APPROPRIATIONS.**—There are authorized to be appropriated such sums as may be necessary to carry out this section.

42 USC 247b-4c. **SEC. 103. INFORMATION AND EDUCATION.**

(a) **IN GENERAL.**—The Secretary shall establish and implement a program to provide information and education on autism to health professionals and the general public, including information and education 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 patients with autism.

(b) **STIPENDS.**—The Secretary may use amounts made available under this section to provide stipends for health professionals who are enrolled in training programs under this section.

(c) **AUTHORIZATION OF APPROPRIATIONS.**—There are authorized to be appropriated such sums as may be necessary to carry out this section.

SEC. 104. INTER-AGENCY AUTISM COORDINATING COMMITTEE.

42 USC 247b-4d.

(a) **ESTABLISHMENT.**—The Secretary shall establish a committee to be known as the “Autism Coordinating Committee” (in this section referred to 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 and the Centers for Disease Control and Prevention under this title (and the amendment made by this title).

(b) **MEMBERSHIP.**—

(1) **IN GENERAL.**—The Committee shall be composed of the Directors of such national research institutes, of the Centers for Disease Control and Prevention, and of such other agencies and such other officials as the Secretary determines appropriate.

(2) **ADDITIONAL MEMBERS.**—If determined appropriate by the Secretary, the Secretary may appoint to the Committee—

(A) parents or legal guardians of individuals with autism or other pervasive developmental disorders; and

(B) representatives of other governmental agencies that serve children with autism such as the Department of Education.

(c) **ADMINISTRATIVE SUPPORT; TERMS OF SERVICE; OTHER PROVISIONS.**—The following shall apply with respect to the Committee:

(1) The Committee shall receive necessary and appropriate administrative support from the Department of Health and Human Services.

(2) Members of the Committee appointed under subsection (b)(2)(A) shall serve for a term of 3 years, and may serve for an unlimited number of terms if reappointed.

(3) The Committee shall meet not less than two times each year.

SEC. 105. REPORT TO CONGRESS.

42 USC 247b-4e.

Not later than January 1, 2001, and each January 1 thereafter, the Secretary shall prepare and submit to the appropriate committees of Congress, a report concerning the implementation of this title and the amendments made by this title...

Deadline.