Public Law 105–168
105th Congress

An Act

To provide surveillance, research, and services aimed at prevention of birth defects, and for other purposes.

Apr. 21, 1998
[S. 419]

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

Birth Defects Prevention Act of 1998.

SECTION 1. SHORT TITLE; FINDINGS.

42 USC 201 note.

(a) SHORT TITLE.—This Act may be cited as the "Birth Defects Prevention Act of 1998".

42 USC 247b–4 note.

(b) FINDINGS.—Congress makes the following findings:

(1) Birth defects are the leading cause of infant mortality, directly responsible for one out of every five infant deaths.

(2) Thousands of the 150,000 infants born with a serious birth defect annually face a lifetime of chronic disability and illness.

(3) Birth defects threaten the lives of infants of all racial and ethnic backgrounds. However, some conditions pose excess risks for certain populations. For example, compared to all infants born in the United States, Hispanic-American infants are more likely to be born with anencephaly spina bifida and other neural tube defects and African-American infants are more likely to be born with sickle-cell anemia.

(4) Birth defects can be caused by exposure to environmental hazards, adverse health conditions during pregnancy, or genetic mutations. Prevention efforts are slowed by lack of information about the number and causes of birth defects. Outbreaks of birth defects may go undetected because surveillance and research efforts are underdeveloped and poorly coordinated.

(5) Public awareness strategies, such as programs using folic acid vitamin supplements to prevent spina bifida and alcohol avoidance programs to prevent Fetal Alcohol Syndrome, are essential to prevent the heartache and costs associated with birth defects.

SEC. 2. PROGRAMS REGARDING BIRTH DEFECTS.

Section 317C of the Public Health Service Act (42 U.S.C. 247b–4) is amended to read as follows:

"PROGRAMS REGARDING BIRTH DEFECTS

"SEC. 317C. (a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall carry out programs—

"(1) to collect, analyze, and make available data on birth defects (in a manner that facilitates compliance with subsection

(d)(2)), including data on the causes of such defects and on the incidence and prevalence of such defects;

"(2) to operate regional centers for the conduct of applied epidemiological research on the prevention of such defects; and

Public information.

"(3) to provide information and education to the public on the prevention of such defects.

"(b) ADDITIONAL PROVISIONS REGARDING COLLECTION OF DATA.—

"(1) IN GENERAL.—In carrying out subsection (a)(1), the Secretary—

"(A) shall collect and analyze data by gender and by racial and ethnic group, including Hispanics, non-Hispanic whites, Blacks, Native Americans, Asian Americans, and Pacific Islanders;

"(B) shall collect data under subparagraph (A) from birth certificates, death certificates, hospital records, and such other sources as the Secretary determines to be appropriate; and

"(C) shall encourage States to establish or improve programs for the collection and analysis of epidemiological data on birth defects, and to make the data available.

Establishment.

"(2) NATIONAL CLEARINGHOUSE.—In carrying out subsection (a)(1), the Secretary shall establish and maintain a National Information Clearinghouse on Birth Defects to collect and disseminate to health professionals and the general public information on birth defects, including the prevention of such defects.

"(c) GRANTS AND CONTRACTS.—

"(1) IN GENERAL.—In carrying out subsection (a), the Secretary may make grants to and enter into contracts with public and nonprofit private entities.

"(2) SUPPLIES AND SERVICES IN LIEU OF AWARD FUNDS.—

"(A) Upon the request of a recipient of an award of a grant or contract under paragraph (1), the Secretary may, subject to subparagraph (B), provide supplies, equipment, and services for the purpose of aiding the recipient in carrying out the purposes for which the award is made and, for such purposes, may detail to the recipient any officer or employee of the Department of Health and Human Services.

"(B) With respect to a request described in subparagraph (A), the Secretary shall reduce the amount of payments under the award involved by an amount equal to the costs of detailing personnel and the fair market value of any supplies, equipment, or services provided by the Secretary. The Secretary shall, for the payment of expenses incurred in complying with such request, expend the amounts withheld.

"(3) APPLICATION FOR AWARD.—The Secretary may make an award of a grant or contract under paragraph (1) only if an application for the award 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 the purposes for which the award is to be made.

"(d) BIENNIAL REPORT.—Not later than February 1 of fiscal year 1999 and of every second such year thereafter, the Secretary

shall submit to the Committee on Commerce of the House of Representatives, and the Committee on Labor and Human Resources of the Senate, a report that, with respect to the preceding 2 fiscal years—

"(1) contains information regarding the incidence and prevalence of birth defects and the extent to which birth defects have contributed to the incidence and prevalence of infant mortality;

"(2) contains information under paragraph (1) that is specific to various racial and ethnic groups (including Hispanics, non-Hispanic whites, Blacks, Native Americans, and Asian Americans);

"(3) contains an assessment of the extent to which various approaches of preventing birth defects have been effective;

"(4) describes the activities carried out under this section; and

"(5) contains any recommendations of the Secretary regarding this section.

"(e) APPLICABILITY OF PRIVACY LAWS.—The provisions of this section shall be subject to the requirements of section 552a of title 5, United States Code. All Federal laws relating to the privacy of information shall apply to the data and information that is collected under this section.

"(f) AUTHORIZATION OF APPROPRIATIONS.—For the purpose of carrying out this section, there are authorized to be appropriated $30,000,000 for fiscal year 1999, $40,000,000 for fiscal year 2000, and such sums as may be necessary for each of the fiscal years 2001 and 2002.".

Approved April 21, 1998.

LEGISLATIVE HISTORY—S. 419:

CONGRESSIONAL RECORD:
Vol. 143 (1997): June 12, considered and passed Senate.
Vol. 144 (1998): Mar. 10, considered and passed House.
WEEKLY COMPILATION OF PRESIDENTIAL DOCUMENTS, Vol. 34 (1998):
Apr. 21, Presidential remarks.

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