

**(d) Applicability of privacy laws**

The provisions of this section shall be subject to the requirements of section 552a of title 5. All Federal laws relating to the privacy of information shall apply to the data and information that is collected under this section.

**(e) Advisory committee**

Notwithstanding any other provision of law, the members of the advisory committee appointed by the Director of the National Center for Environmental Health that have expertise in birth defects, developmental disabilities, and disabilities and health shall be transferred to and shall advise the National Center on Birth Defects and Developmental Disabilities effective on December 3, 2003.

**(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 fiscal years 2003 through 2007.

(July 1, 1944, ch. 373, title III, §317C, as added Pub. L. 102-531, title III, §306(a), Oct. 27, 1992, 106 Stat. 3494; amended Pub. L. 103-443, title XX, §2008(i)(1)(B)(iii), June 10, 1993, 107 Stat. 213; Pub. L. 105-168, §2, Apr. 21, 1998, 112 Stat. 43; Pub. L. 106-310, div. A, title VI, §611, Oct. 17, 2000, 114 Stat. 1119; Pub. L. 108-154, §2, Dec. 3, 2003, 117 Stat. 1933; Pub. L. 111-256, §2(f)(1), Oct. 5, 2010, 124 Stat. 2644.)

## AMENDMENTS

2010—Subsec. (a)(4)(B)(i). Pub. L. 111-256 substituted “intellectual disabilities;” for “mental retardation;”.

2003—Subsec. (a)(2)(A). Pub. L. 108-154, §2(1)(A), substituted “, developmental disabilities, and disabilities and health” for “and developmental disabilities” and “subsection (c)(2)” for “subsection (d)(2)”.

Subsec. (a)(2)(D), (E). Pub. L. 108-154, §2(1)(B)-(D), added subpars. (D) and (E).

Subsecs. (b), (c). Pub. L. 108-154, §2(2), (4), redesignated subsecs. (c) and (d) as (b) and (c), respectively, and struck out former subsec. (b) which related to additional provisions regarding collection of data.

Subsec. (d). Pub. L. 108-154, §2(4), redesignated subsec. (e) as (d). Former subsec. (d) redesignated (c).

Subsec. (d)(1). Pub. L. 108-154, §2(3)(A), added par. (1) and struck out former par. (1) which read as follows: “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;”.

Subsec. (d)(3). Pub. L. 108-154, §2(3)(B), inserted “, developmental disabilities, and secondary health conditions among individuals with disabilities” after “defects”.

Subsec. (d)(5) to (7). Pub. L. 108-154, §2(3)(C)-(E), added pars. (5) and (6) and redesignated former par. (5) as (7).

Subsec. (e). Pub. L. 108-154, §2(5), added subsec. (e). Former subsec. (e) redesignated (d).

Subsec. (f). Pub. L. 108-154, §2(6) substituted “such sums as may be necessary for each of fiscal years 2003 through 2007.” for “\$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.”

2000—Pub. L. 106-310, §611(1), substituted “National Center on Birth Defects and Developmental Disabilities” for “Programs regarding birth defects” in section catchline.

Subsec. (a). Pub. L. 106-310, §611(2), added subsec. (a) and struck out heading and text of former subsec. (a) relating to Secretary’s responsibility, acting through

the Centers for Disease Control and Prevention, to carry out programs regarding birth defects.

Subsec. (b)(1). Pub. L. 106-310, §611(3), substituted “subsection (a)(2)(A) of this section” for “subsection (a)(1) of this section” in introductory provisions.

1998—Pub. L. 105-168 amended section generally, substituting present provisions for provisions which directed Secretary to encourage and assist States in collection and analysis of epidemiological data on birth defects and to establish and maintain National Information Clearinghouse on Birth Defects, required report not later than July 1, 1993, and biennially thereafter, and authorized appropriations for fiscal years 1993, 1994, and 1995.

1993—Pub. L. 103-43 made technical amendment to directory language of Pub. L. 102-531, §306(a), which enacted this section.

## CHANGE OF NAME

Committee on Commerce of House of Representatives changed to Committee on Energy and Commerce of House of Representatives, and jurisdiction over matters relating to securities and exchanges and insurance generally transferred to Committee on Financial Services of House of Representatives by House Resolution No. 5, One Hundred Seventh Congress, Jan. 3, 2001.

Committee on Labor and Human Resources of Senate changed to Committee on Health, Education, Labor, and Pensions of Senate by Senate Resolution No. 20, One Hundred Sixth Congress, Jan. 19, 1999.

## CONGRESSIONAL FINDINGS

Pub. L. 105-168, §1(b), Apr. 21, 1998, 112 Stat. 43, provided that: “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.”

## DEFINITIONS

For meaning of references to an intellectual disability and to individuals with intellectual disabilities in provisions amended by section 2 of Pub. L. 111-256, see section 2(k) of Pub. L. 111-256, set out as a note under section 1400 of Title 20, Education.

**§ 247b-4a. Early detection, diagnosis, and interventions for newborns and infants with hearing loss****(a) Definitions**

For the purposes of this section only, the following terms in this section are defined as follows:

**(1) Hearing screening**

Newborn and infant hearing screening consists of objective physiologic procedures to de-

tect possible hearing loss and to identify newborns and infants who, after rescreening, require further audiologic and medical evaluations.

**(2) Audiologic evaluation**

Audiologic evaluation consists of 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 IDEA part C coordinating agencies 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.

**(3) Medical evaluation**

Medical evaluation by a physician consists of 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.

**(4) Medical intervention**

Medical intervention is 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.

**(5) Audiologic rehabilitation**

Audiologic rehabilitation (intervention) consists of procedures, techniques, and technologies to facilitate the receptive and expressive communication abilities of a child with hearing loss.

**(6) Early intervention**

Early intervention (e.g., nonmedical) means providing appropriate services for the child with hearing loss 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.

**(b) Purposes**

The purposes of this section are to clarify the authority within the Public Health Service Act [42 U.S.C. 201 et seq.] to authorize statewide newborn and infant hearing screening, evaluation and intervention programs and systems, technical assistance, a national applied research program, and interagency and private sector collaboration for policy development, in order to assist the States in making progress toward the following goals:

(1) All babies born in hospitals in the United States and its territories should have a hearing screening before leaving the birthing facility. Babies born in other countries and residing in the United States via immigration or

adoption should have a 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 statewide systems of intervention and rehabilitative services for newborns and infants with hearing loss.

(5) Public policy in regard to newborn and infant hearing screening and intervention should be based on applied research and the recognition that newborns, infants, toddlers, and children who are deaf or hard-of-hearing have unique language, learning, and communication needs, and should be the result of consultation with pertinent public and private sectors.

**(c) Statewide newborn and infant hearing screening, evaluation and intervention programs and systems**

Under the existing authority of the Public Health Service Act [42 U.S.C. 201 et seq.], the Secretary of Health and Human Services (in this section referred to as the "Secretary"), acting through the Administrator of the Health Resources and Services Administration, shall make awards of grants or cooperative agreements to develop statewide newborn and infant hearing screening, evaluation and intervention programs and systems for the following purposes:

(1) To develop and monitor the efficacy of statewide newborn and infant hearing screening, evaluation and intervention programs and systems. Early intervention includes referral to schools and agencies, including community, consumer, and parent-based agencies and organizations and other programs mandated by part C of the Individuals with Disabilities Education Act [20 U.S.C. 1431 et seq.], which offer programs specifically designed to meet the unique language and communication needs of deaf and hard-of-hearing newborns, infants, toddlers, and children.

(2) To collect data on statewide newborn and infant hearing screening, evaluation and intervention programs and systems that can be used for applied research, program evaluation and policy development.

**(d) Technical assistance, data management, and applied research**

**(1) Centers for Disease Control and Prevention**

Under the existing authority of the Public Health Service Act [42 U.S.C. 201 et seq.], the Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall make awards of grants or cooperative

agreements to provide technical assistance to State agencies to complement an intramural program and to conduct applied research related to newborn and infant hearing screening, evaluation and intervention programs and systems. The program shall develop standardized procedures for data management and program effectiveness and costs, such as—

(A) to ensure quality monitoring of newborn and infant hearing loss screening, evaluation, and intervention programs and systems;

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

(C) to study the costs and effectiveness of newborn and infant hearing screening, evaluation and intervention programs and systems conducted by State-based programs in order to answer issues of importance to State and national policymakers;

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

(E) to study the effectiveness of newborn and infant hearing screening, audiologic and medical evaluations and intervention programs and systems by assessing the health, intellectual and social developmental, cognitive, and language 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**

Under the existing authority of the Public Health Service Act, 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.

## **(e) Coordination and collaboration**

### **(1) In general**

Under the existing authority of the Public Health Service Act [42 U.S.C. 201 et seq.], 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 responsible for early intervention services pursuant to title XIX of the Social Security Act [42 U.S.C. 1396 et seq.] (Medicaid Early and Periodic Screening, Diagnosis and Treatment Program); title XXI of the Social Security Act [42 U.S.C. 1397aa et seq.], (State Children's Health Insurance Program); title V of the Social Security Act [42 U.S.C. 701 et seq.] (Maternal and Child Health Block Grant Program); and part C of the Individuals with Disabilities Education Act [20

U.S.C. 1431 et seq.]; consumer groups of and that serve individuals who are deaf and hard-of-hearing and their families; appropriate national medical and other health and education specialty organizations; persons who are deaf and hard-of-hearing and their families; other qualified professional personnel who are proficient in deaf or hard-of-hearing children's language and who possess the specialized knowledge, skills, and attributes needed to serve deaf and hard-of-hearing newborns, infants, toddlers, children, and their families; third-party payers and managed care organizations; and related commercial industries.

### **(2) Policy development**

Under the existing authority of the Public Health Service Act, 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 collaborate on recommendations for policy development at the Federal and State levels and with the private sector, including consumer, medical and other health and education professional-based organizations, with respect to newborn and infant hearing screening, evaluation and intervention programs and systems.

### **(3) State early detection, diagnosis, and intervention programs and systems; data collection**

Under the existing authority of the Public Health Service Act, the Administrator of the Health Resources and Services Administration and the Director of the Centers for Disease Control and Prevention shall coordinate and collaborate in assisting States to establish newborn and infant hearing screening, evaluation and intervention programs and systems under subsection (c) and to develop a data collection system under subsection (d).

### **(f) Rule of construction**

Nothing in this section shall be construed to preempt any State law.

### **(g) Authorization of appropriations**

#### **(1) Statewide newborn and infant hearing screening, evaluation and intervention programs and systems**

For the purpose of carrying out subsection (c) under the existing authority of the Public Health Service Act [42 U.S.C. 201 et seq.], there are authorized to the Health Resources and Services Administration appropriations in the amount of \$5,000,000 for fiscal year 2000, \$8,000,000 for fiscal year 2001, and such sums as may be necessary for fiscal year 2002.

#### **(2) Technical assistance, data management, and applied research; Centers for Disease Control and Prevention**

For the purpose of carrying out subsection (d)(1) under the existing authority of the Public Health Service Act, there are authorized to the Centers for Disease Control and Prevention, appropriations in the amount of \$5,000,000 for fiscal year 2000, \$7,000,000 for fiscal year 2001, and such sums as may be necessary for fiscal year 2002.

**(3) Technical assistance, data management, and applied research; National Institute on Deafness and Other Communication Disorders**

For the purpose of carrying out subsection (d)(2) under the existing authority of the Public Health Service Act, there are authorized to the National Institute on Deafness and Other Communication Disorders appropriations for such sums as may be necessary for each of the fiscal years 2000 through 2002.

(Pub. L. 106–113, div. B, §1000(a)(4) [title VI, § 601], Nov. 29, 1999, 113 Stat. 1535, 1501A–276.)

REFERENCES IN TEXT

The Public Health Service Act, referred to in subsecs. (b) to (e) and (g), is act July 1, 1944, ch. 373, 58 Stat. 682, as amended, which is classified generally to this chapter (§201 et seq.). For complete classification of this Act to the Code, see Short Title note set out under section 201 of this title and Tables.

The Individuals with Disabilities Education Act, referred to in subsecs. (c)(1) and (e)(1), is title VI of Pub. L. 91–230, Apr. 13, 1970, 84 Stat. 175, as amended. Part C of the Act is classified generally to subchapter III (§1431 et seq.) of chapter 33 of Title 20, Education. For complete classification of this Act to the Code, see section 1400 of Title 20 and Tables.

The Social Security Act, referred to in subsec. (e)(1), is act Aug. 14, 1935, ch. 531, 49 Stat. 620, as amended. Titles V, XIX, and XXI of the Act are classified generally to subchapters V (§701 et seq.), XIX (§1396 et seq.), and XXI (§1397aa et seq.), respectively, of chapter 7 of this title. For complete classification of this Act to the Code, see section 1305 of this title and Tables.

CODIFICATION

Section was enacted as part of the Departments of Labor, Health, and Human Services, and Education, and Related Agencies Appropriations Act, 2000, and not as part of the Public Health Service Act which comprises this chapter.

**§§ 247b–4b to 247b–4d. Repealed. Pub. L. 109–416, § 3(b)(1)–(3), Dec. 19, 2006, 120 Stat. 2829**

Section 247b–4b, Pub. L. 106–310, div. A, title I, §102, Oct. 17, 2000, 114 Stat. 1107, related to developmental disabilities surveillance and research programs.

Section 247b–4c, Pub. L. 106–310, div. A, title I, §103, Oct. 17, 2000, 114 Stat. 1108, related to information and education.

Section 247b–4d, Pub. L. 106–310, div. A, title I, §104, Oct. 17, 2000, 114 Stat. 1109, related to Inter-agency Autism Coordinating Committee.

**§ 247b–4e. Repealed. Pub. L. 109–416, § 3(b)(4), Dec. 19, 2006, 120 Stat. 2829; Pub. L. 109–482, title I, § 104(b)(3)(D), Jan. 15, 2007, 120 Stat. 3694**

Section, Pub. L. 106–310, div. A, title I, §105, Oct. 17, 2000, 114 Stat. 1109, related to annual report to Congress concerning the implementation of this section and sections 247b–4b to 247b–4d and 284g of this title.

EFFECTIVE DATE OF REPEAL

Repeal by Pub. L. 109–482 applicable only with respect to amounts appropriated for fiscal year 2007 or subsequent fiscal years, see section 109 of Pub. L. 109–482, set out as an Effective Date of 2007 Amendment note under section 281 of this title.

**§ 247b–4f. Research relating to preterm labor and delivery and the care, treatment, and outcomes of preterm and low birthweight infants**

**(a) Omitted**

**(b) Studies and activities on preterm birth**

**(1) In general**

The Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, may, subject to the availability of appropriations—

(A) conduct epidemiological studies on the factors relating to prematurity, such as clinical, biological, social, environmental, genetic, and behavioral factors, and other determinants that contribute to health disparities and are related to prematurity, as appropriate;

(B) conduct activities to improve national data to facilitate tracking the burden of preterm birth; and

(C) continue efforts to prevent preterm birth, including late preterm birth, through the identification of opportunities for prevention and the assessment of the impact of such efforts.

**(2) Report**

Not later than 2 years after November 27, 2013, and every 2 years thereafter, the Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, shall submit to the appropriate committees of Congress reports regarding activities and studies conducted under paragraph (1), including any applicable analyses of preterm birth. Such report shall be posted on the Internet website of the Department of Health and Human Services.<sup>1</sup>

**(c) Pregnancy risk assessment monitoring survey**

The Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, shall—

(1) continue systems for the collection of maternal-infant clinical and biomedical information, including electronic health records, electronic databases, and biobanks, to link with the Pregnancy Risk Assessment Monitoring System (PRAMS) and other epidemiological studies of prematurity in order to track, to the extent practicable, all pregnancy outcomes and prevent preterm birth; and

(2) provide technical assistance, as appropriate, to support States in improving the collection of information pursuant to this subsection.

**(d) Evaluation of existing tools and measures**

The Secretary of Health and Human Services shall review existing tools and measures to ensure that such tools and measures include information related to the known risk factors of low birth weight and preterm birth.

**(e) Authorization of appropriations**

There is authorized to be appropriated to carry out this section, \$2,000,000 for each of fiscal years 2019 through 2023.

<sup>1</sup> So in original.