

(d) Nonduplication

In carrying out programs under this section, the Secretary shall minimize duplication and supplement, not supplant, existing efforts of the type carried out under this section.

(e) Peer review

Nothing in this section shall be construed to interfere with the scientific peer-review process at the National Institutes of Health.

(July 1, 1944, ch. 373, title XI, §1116, as added Pub. L. 110-204, §7, Apr. 24, 2008, 122 Stat. 711; amended Pub. L. 110-237, §1(a)(7), May 27, 2008, 122 Stat. 1557; Pub. L. 113-240, §9, Dec. 18, 2014, 128 Stat. 2855.)

AMENDMENTS

2014—Subsec. (a)(1)(C) to (E). Pub. L. 113-240, §9(1), added subpars. (C) and (D) and redesignated former subpar. (C) as (E).

Subsec. (c). Pub. L. 113-240, §9(2), substituted “section 283 of this title” for “section 403 of the National Institutes of Health Reform Act of 2006”.

2008—Subsec. (a)(1)(B). Pub. L. 110-237 substituted “, or” for “and or”.

§ 300b-16. Authorization of appropriations for newborn screening programs and activities

There are authorized to be appropriated—

(1) to carry out sections 300b-8, 300b-9, 300b-10, and 300b-11 of this title, \$11,900,000 for each of fiscal years 2015 through 2019; and

(2) to carry out section 300b-12 of this title, \$8,000,000 for each of fiscal years 2015 through 2019.

(July 1, 1944, ch. 373, title XI, §1117, as added Pub. L. 113-240, §10, Dec. 18, 2014, 128 Stat. 2856.)

§ 300b-17. Report by Secretary**(1) In general**

The Secretary of Health and Human Services shall—

(A) not later than 1 year after December 18, 2014, submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives a report on activities related to—

(i) newborn screening; and

(ii) screening children who have or are at risk for heritable disorders; and

(B) not less than every 2 years, submit to such committees an updated version of such report.

(2) Contents

The report submitted under this section shall contain a description of—

(A) the ongoing activities under sections 300b-8, 300b-9, and 300b-11 through 300b-14 of this title; and

(B) the amounts expended on such activities.

(Pub. L. 113-240, §11(b), Dec. 18, 2014, 128 Stat. 2856.)

CODIFICATION

Section was enacted as part of the Newborn Screening Saves Lives Reauthorization Act of 2014, and not as part of the Public Health Service Act which comprises this chapter.

PRIOR PROVISIONS

Prior sections 300c to 300c-4 were repealed by Pub. L. 94-278, title IV, §403(a), Apr. 22, 1976, 90 Stat. 407.

Section 300c, act July 1, 1944, ch. 373, title XI, §1111, as added Aug. 29, 1972, Pub. L. 92-414, §3, 86 Stat. 650, authorized Secretary to make grants and enter contracts with public and private entities for establishment of screening, treatment, and counseling programs with respect to Cooley’s Anemia.

Section 300c-1, act July 1, 1944, ch. 373, title XI, §1112, as added Aug. 29, 1972, Pub. L. 92-414, §3, 86 Stat. 651, required that any participation by an individual in any Cooley’s Anemia programs should be on a purely voluntary basis.

Section 300c-2, act July 1, 1944, ch. 373, title XI, §1113, as added Aug. 29, 1972, Pub. L. 92-414, §3, 86 Stat. 651, provided for making of grant upon application to Secretary and listed certain requirements to be met by applicant.

Section 300c-3, act July 1, 1944, ch. 373, title XI, §1114, as added Aug. 29, 1972, Pub. L. 92-414, §3, 86 Stat. 652, authorized Secretary to establish a program with Public Health Service to provide for screening, counseling, and treatment with respect to Cooley’s Anemia.

Section 300c-4, act July 1, 1944, ch. 373, title XI, §1115, as added Aug. 29, 1972, Pub. L. 92-414, §3, 86 Stat. 652, provided for Secretary’s submission of a report to President for transmittal to Congress annually.

PART B—SUDDEN UNEXPECTED INFANT DEATH, SUDDEN INFANT DEATH SYNDROME, AND SUDDEN UNEXPECTED DEATH IN CHILDHOOD

CODIFICATION

Pub. L. 116-273, §2(1), Dec. 31, 2020, 134 Stat. 3352, substituted “Sudden Unexpected Infant Death, Sudden Infant Death Syndrome, and Sudden Unexpected Death in Childhood” for “Sudden Infant Death Syndrome” in part heading.

Pub. L. 94-278, title IV, §403(b)(2), Apr. 22, 1976, 90 Stat. 409, redesignated part C heading as part B heading.

§ 300c-11. Addressing sudden unexpected infant death and sudden unexpected death in childhood**(a) In general**

The Secretary may develop, support, or maintain programs or activities to address sudden unexpected infant death and sudden unexpected death in childhood, including by—

(1) continuing to support the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry of the Centers for Disease Control and Prevention and other fatality case reporting systems that include data pertaining to sudden unexpected infant death and sudden unexpected death in childhood, as appropriate, including such systems supported by the Health Resources and Services Administration, in order to—

(A) increase the number of States and jurisdictions participating in such registries or systems; and

(B) improve the utility of such registries or systems, which may include—

(i) making summary data available to the public in a timely manner on the internet website of the Department of Health and Human Services, in a manner that, at a minimum, protects personal privacy to the extent required by applicable Federal and State law; and

(ii) making the data submitted to such registries or systems available to research-

ers, in a manner that, at a minimum, protects personal privacy to the extent required by applicable Federal and State law; and

(2) awarding grants or cooperative agreements to States, Indian Tribes, and Tribal organizations for purposes of—

(A) supporting fetal and infant mortality and child death review programs for sudden unexpected infant death and sudden unexpected death in childhood, including by establishing such programs at the local level;

(B) improving data collection related to sudden unexpected infant death and sudden unexpected death in childhood, including by—

(i) improving the completion of death scene investigations and comprehensive autopsies that include a review of clinical history and circumstances of death with appropriate ancillary testing; and

(ii) training medical examiners, coroners, death scene investigators, law enforcement personnel, emergency medical technicians, paramedics, emergency department personnel, and others who perform death scene investigations with respect to the deaths of infants and children, as appropriate;

(C) identifying, developing, and implementing best practices to reduce or prevent sudden unexpected infant death and sudden unexpected death in childhood, including practices to reduce sleep-related infant deaths;

(D) increasing the voluntary inclusion, in registries established for the purpose of conducting research on sudden unexpected infant death and sudden unexpected death in childhood, of samples of tissues or genetic materials from autopsies that have been collected pursuant to Federal or State law and for which the parent or guardian has provided informed consent for inclusion in such registries;

(E) disseminating information and materials to health care professionals and the public on risk factors that contribute to sudden unexpected infant death and sudden unexpected death in childhood, which may include information on risk factors that contribute to sleep-related sudden unexpected infant death or sudden unexpected death in childhood; or

(F) providing information, referrals, or peer or follow-up support services to families who have experienced sudden unexpected infant death or sudden unexpected death in childhood.

(b) Application

To be eligible to receive a grant or cooperative agreement under subsection (a)(2), a State, Indian Tribe, or Tribal organization shall submit to the Secretary an application at such time, in such manner, and containing such information as the Secretary may require, including information on how such State will ensure activities conducted under this section are coordinated with other federally-funded programs to reduce infant and child mortality, as appropriate.

(c) Technical assistance

The Secretary shall provide technical assistance to States, Tribes, and Tribal organizations receiving a grant or cooperative agreement under subsection (a)(2) for purposes of carrying out the program in accordance with this section.

(d) Reporting forms

(1) In general

The Secretary shall, as appropriate, encourage the use of sudden unexpected infant death and sudden unexpected death in childhood reporting forms developed in collaboration with the Centers for Disease Control and Prevention to improve the quality of data submitted to the Sudden Unexpected Infant Death and Sudden Death in the Young Case Registry, and other fatality case reporting systems that include data pertaining to sudden unexpected infant death and sudden unexpected death in childhood.

(2) Update of forms

The Secretary shall assess whether updates are needed to the sudden unexpected infant death investigation reporting form used by the Centers for Disease Control and Prevention in order to improve the use of such form with other fatality case reporting systems supported by the Department of Health and Human Services, and shall make such updates as appropriate.

(e) Definitions

In this section:

(1) Sudden infant death syndrome

The term “sudden infant death syndrome” means a sudden unexpected infant death that remains unexplained after a thorough case investigation.

(2) Sudden unexpected infant death

The term “sudden unexpected infant death” means the sudden death of an infant under 1 year of age that when first discovered did not have an obvious cause. Such term includes such deaths that are explained, as well as deaths that remain unexplained (which are known as sudden infant death syndrome).

(3) Sudden unexpected death in childhood

The term “sudden unexpected death in childhood” means the sudden death of a child who is at least 1 year of age but not more than 17 years of age that, when first discovered, did not have an obvious cause. Such term includes such deaths that are explained, as well as deaths that remain unexplained (which are known as sudden unexplained death in childhood).

(4) Sudden unexplained death in childhood

The term “sudden unexplained death in childhood” means a sudden unexpected death in childhood that remains unexplained after a thorough case investigation.

(f) Authorization of appropriations

For the purpose of carrying out this section, there is authorized to be appropriated \$12,000,000 for each of fiscal years 2022 through 2026.

(July 1, 1944, ch. 373, title XI, §1121, as added Pub. L. 116-273, §2(2), Dec. 31, 2020, 134 Stat. 3352.)

PRIOR PROVISIONS

A prior section 300c-11, act July 1, 1944, ch. 373, title XI, § 1121, as added Apr. 22, 1974, Pub. L. 93-270, § 3(a), 88 Stat. 91; amended Apr. 22, 1976, Pub. L. 94-278, title IV, § 403(b)(1), 90 Stat. 409; S. Res. 4, Feb. 4, 1977; Aug. 1, 1977, Pub. L. 95-83, title III, § 306(a), 91 Stat. 389; Dec. 19, 1977, Pub. L. 95-215, § 8(a), 91 Stat. 1507; Nov. 8, 1978, Pub. L. 95-613, § 2, 92 Stat. 3094; Dec. 12, 1979, Pub. L. 96-142, title II, § 202, 93 Stat. 1070; H. Res. 549, Mar. 25, 1980; Aug. 13, 1981, Pub. L. 97-35, title XXI, § 2193(a)(1)(C), 95 Stat. 827, related to sudden infant death syndrome counseling, information, educational, and statistical programs, prior to repeal by Pub. L. 97-35, title XXI, § 2193(b)(1), Aug. 13, 1981, 95 Stat. 827. For effective date, savings, and transitional provisions relating to the amendment and repeal of prior section by Pub. L. 97-35, see section 2194 of Pub. L. 97-35, set out as a note under section 701 of this title.

§ 300c-12. Sudden infant death syndrome research

From the sums appropriated to the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the Secretary shall assure that there are applied to research of the type described in subparagraphs (A) and (B) of subsection (b)(1)¹ of this section such amounts each year as will be adequate, given the leads and findings then available from such research, in order to make maximum feasible progress toward identification of infants at risk of sudden infant death syndrome and prevention of sudden infant death syndrome.

(July 1, 1944, ch. 373, title XI, § 1122, as added Pub. L. 96-142, title II, § 202, Dec. 12, 1979, 93 Stat. 1072; amended Pub. L. 99-158, § 3(a)(6), Nov. 20, 1985, 99 Stat. 879; Pub. L. 103-437, § 15(a)(1), Nov. 2, 1994, 108 Stat. 4591; Pub. L. 109-482, title I, § 104(b)(2)(B), Jan. 15, 2007, 120 Stat. 3693; Pub. L. 110-154, § 1(b)(10), Dec. 21, 2007, 121 Stat. 1827.)

REFERENCES IN TEXT

Subsection (b), referred to in text, was repealed by Pub. L. 109-482, title I, § 104(b)(2)(B)(i), Jan. 15, 2007, 120 Stat. 3693. Prior to repeal, subparagraphs (A) and (B) of subsection (b)(1) read as follows:

“(A) the (i) number of applications approved by the Secretary in the fiscal year reported on for grants and contracts under this chapter for research which relates specifically to sudden infant death syndrome, (ii) total amount requested under such applications, (iii) number of such applications for which funds were provided in such fiscal year, and (iv) total amount of such funds; and

“(B) the (i) number of applications approved by the Secretary in such fiscal year for grants and contracts under this chapter for research which relates generally to sudden infant death syndrome, including high-risk pregnancy and high-risk infancy research which directly relates to sudden infant death syndrome, (ii) relationship of the high-risk pregnancy and high-risk infancy research to sudden infant death syndrome, (iii) total amount requested under such applications, (iv) number of such applications for which funds were provided in such fiscal year, and (v) total amount of such funds.”

AMENDMENTS

2007—Pub. L. 110-154 substituted “Eunice Kennedy Shriver National Institute of Child Health and Human Development” for “National Institute of Child Health and Human Development”.

Pub. L. 109-482 struck out subsec. (a) designation before “From the sums” and subsecs. (b) and (c) which re-

lated to annual report on data relating to applications for grants and contracts for research on sudden infant death syndrome and annual estimate of amounts requested for such research.

1994—Subsecs. (b)(1), (c). Pub. L. 103-437 substituted “Energy and Commerce” for “Interstate and Foreign Commerce”.

1985—Subsec. (a). Pub. L. 99-158 struck out “under section 289d of this title” before “, the Secretary”.

EFFECTIVE DATE OF 2007 AMENDMENT

Amendment 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 a note under section 281 of this title.

§ 300c-13. Continuing activities related to stillbirth, sudden unexpected infant death and sudden unexplained death in childhood

(a) In general

The Secretary of Health and Human Services shall continue activities related to still birth, sudden unexpected infant death, and sudden unexplained death in childhood, including, as appropriate—

(1) collecting information, such as socio-demographic, death scene investigation, clinical history, and autopsy information, on stillbirth, sudden unexpected infant death, and sudden unexplained death in childhood through the utilization of existing surveillance systems and collaborating with States to improve the quality, consistency, and collection of such data;

(2) disseminating information to educate the public, health care providers, and other stakeholders on stillbirth, sudden unexpected infant death and sudden unexplained death in childhood; and

(3) collaborating with the Attorney General, State and local departments of health, and other experts, as appropriate, to provide consistent information for medical examiners and coroners, law enforcement personnel, and health care providers related to death scene investigations and autopsies for sudden unexpected infant death and sudden unexplained death in childhood, in order to improve the quality and consistency of the data collected at such death scenes and to promote consistent reporting on the cause of death after autopsy to inform prevention, intervention, and other activities.

(b) Report to Congress

Not later than 2 years after December 18, 2014, the Secretary of Health and Human Services shall submit to Congress a report that includes a description of any activities that are being carried out by agencies within the Department of Health and Human Services, including the Centers for Disease Control and Prevention and the National Institutes of Health, related to stillbirth, sudden unexpected infant death, and sudden unexplained death in childhood, including those activities identified under subsection (a).

(Pub. L. 113-236, § 2, Dec. 18, 2014, 128 Stat. 2831.)

CODIFICATION

Section was enacted as part of the Sudden Unexpected Death Data Enhancement and Awareness Act,

¹ See References in Text note below.