propriate publicity of the availability and voluntary nature of such services.

(July 1, 1944, ch. 373, title XI, § 1105, as added Pub. L. 94–278, title IV, § 403(a), Apr. 22, 1976, 90 Stat. 409.)

PRIOR PROVISIONS

A prior section 300b–4, act July 1, 1944, ch. 373, title XI, § 1105, as added May 16, 1972, Pub. L. 92–294, § 3(c), 86 Stat. 139, authorized Secretary to establish a program within the Public Health Service with respect to sickle cell anemia with such program to be made available through facilities of Public Health Service, prior to repeal by Pub. L. 94–278, title IV, § 403(a), Apr. 22, 1976, 90 Stat. 407.

§ 300b–5. Sickle cell disease and other heritable blood disorders research, surveillance, prevention, and treatment

(a) Grants

(1) In general

The Secretary may award grants related to heritable blood disorders, including sickle cell disease, for one or more of the following purposes:

(A) To collect and maintain data on such diseases and conditions, including subtypes as applicable, and their associated health outcomes and complications, including for the purpose of—

(i) improving national incidence and prevalence data;

(ii) identifying health disparities, including the geographic distribution, related to such diseases and conditions;

(iii) assessing the utilization of therapies and strategies to prevent complications; and

(iv) evaluating the effects of genetic, environmental, behavioral, and other risk factors that may affect such individuals.

(B) To conduct public health activities with respect to such conditions, which may include—

(i) developing strategies to improve health outcomes and access to quality health care for the screening for, and treatment and management of, such diseases and conditions, including through public-private partnerships;

(ii) providing support to community-based organizations and State and local health departments in conducting education and training activities for patients, communities, and health care providers concerning such diseases and conditions;

(iii) supporting State health departments and regional laboratories, including through training, in testing to identify such diseases and conditions, including specific forms of sickle cell disease, in individuals of all ages; and

(iv) the identification and evaluation of best practices for treatment of such diseases and conditions, and prevention and management of their related complications.

(2) Population included

The Secretary shall, to the extent practicable, award grants under this subsection to eligible entities across the United States to improve data on the incidence and prevalence of heritable blood disorders, including sickle cell disease, and the geographic distribution of such diseases and conditions.

(3) Application

To seek a grant under this subsection, an eligible entity shall submit an application to the Secretary at such time, in such manner, and containing such information as the Secretary may require.

(4) Priority

In awarding grants under this subsection, the Secretary may give priority, as appropriate, to eligible entities that have a relationship with a community-based organization that has experience in, or is capable of, providing services to individuals with heritable blood disorders, including sickle cell disease.

(5) Eligible entity

In this subsection, the term ''eligible entity'' includes the 50 States, the District of Columbia, the Commonwealth of Puerto Rico, the United States Virgin Islands, the Commonwealth of the Northern Mariana Islands, American Samoa, Guam, the Federated States of Micronesia, the Republic of Marshall[1] Islands, the Republic of Palau, Indian tribes, a State or local health department, an institution of higher education, or a nonprofit entity with appropriate experience to conduct the activities under this subsection.

(b) Demonstration program for the development and establishment of systemic mechanisms for the prevention and treatment of sickle cell disease

(1) Authority to conduct demonstration program

(A) In general

The Administrator, through the Bureau of Primary Health Care and the Maternal and Child Health Bureau, shall continue efforts, including by awarding grants, to develop or establish mechanisms to improve the treatment of sickle cell disease, and to improve the prevention and treatment of complications of sickle cell disease, in populations with a high proportion of individuals with sickle cell disease, including through—

(i) the coordination of service delivery for individuals with sickle cell disease;

(ii) genetic counseling and testing;

(iii) bundling of technical services related to the prevention and treatment of sickle cell disease;

(iv) training of health professionals; and

(v) identifying and establishing other efforts related to the expansion and coordination of education, treatment, and continuity of care programs for individuals with sickle cell disease.

(B) Geographic diversity

The Administrator shall, to the extent practicable, award grants under this section[2] to eligible entities located in different regions of the United States.

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[1] So in original. Probably should be preceded by ''the''.

[2] So in original. Probably should be ''this subsection''.

(2) Additional requirements

An eligible entity awarded a grant under this subsection shall use funds made available under the grant to carry out, in addition to the activities described in paragraph (1)(A), the following activities:

(A) To facilitate and coordinate the delivery of education, treatment, and continuity of care for individuals with sickle cell disease under—

(i) the entity's collaborative agreement with a community-based sickle cell disease organization or a nonprofit entity that works with individuals who have sickle cell disease;

(ii) the sickle cell disease newborn screening program for the State in which the entity is located; and

(iii) the maternal and child health program under title V of the Social Security Act (42 U.S.C. 701 et seq.) for the State in which the entity is located.

(B) To train nursing and other health staff who provide care for individuals with sickle cell disease.

(C) To enter into a partnership with adult or pediatric hematologists in the region and other regional experts in sickle cell disease at tertiary and academic health centers and State and county health offices.

(D) To identify and secure resources for ensuring reimbursement under the medicaid program, State children's health insurance program, and other health programs for the prevention and treatment of sickle cell disease.

(E) To provide or coordinate services for adolescents with sickle cell disease making the transition to adult health care.

(3) National coordinating center

(A) Establishment

The Administrator shall enter into a contract with an entity to serve as the National Coordinating Center for the demonstration program conducted under this subsection.

(B) Activities described

The National Coordinating Center shall—

(i) collect, coordinate, monitor, and distribute data, best practices, and findings regarding the activities funded under grants made to eligible entities under the demonstration program;

(ii) develop a model protocol for eligible entities with respect to the prevention and treatment of sickle cell disease;

(iii) develop educational materials regarding the prevention and treatment of sickle cell disease; and

(iv) prepare and submit to Congress a final report that includes recommendations regarding the effectiveness of the demonstration program conducted under this subsection and such direct outcome measures as—

(I) the number and type of health care resources utilized (such as emergency room visits, hospital visits, length of stay, and physician visits for individuals with sickle cell disease); and

(II) the number of individuals that were tested and subsequently received genetic counseling for the sickle cell trait.

(4) Application

An eligible entity desiring a grant under this subsection shall submit an application to the Administrator at such time, in such manner, and containing such information as the Administrator may require.

(5) Definitions

In this subsection:

(A) Administrator

The term ''Administrator'' means the Administrator of the Health Resources and Services Administration.

(B) Eligible entity

The term ''eligible entity'' means a Federally-qualified health center, a nonprofit hospital or clinic, or a university health center that provides primary health care, that—

(i) has a collaborative agreement with a community-based sickle cell disease organization or a nonprofit entity with experience in working with individuals who have sickle cell disease; and

(ii) demonstrates to the Administrator that either the Federally-qualified health center, the nonprofit hospital or clinic, the university health center, the organization or entity described in clause (i), or the experts described in paragraph (2)(C), has at least 5 years of experience in working with individuals who have sickle cell disease.

(C) Federally-qualified health center

The term ''Federally-qualified health center'' has the meaning given that term in section 1905(*l*)(2)(B) of the Social Security Act (42 U.S.C. 1396d(*l*)(2)(B)).

(6) Authorization of appropriations

There is authorized to be appropriated to carry out this subsection, $4,455,000 for each of fiscal years 2019 through 2023.

(July 1, 1944, ch. 373, title XI, § 1106, as added and amended Pub. L. 115–327, §§ 2, 3, Dec. 18, 2018, 132 Stat. 4468, 4469.)

REFERENCES IN TEXT

The Social Security Act, referred to in subsec. (b)(2)(A)(iii), is act Aug. 14, 1935, ch. 531, 49 Stat. 620. Title V of the Act is classified generally to subchapter V (§ 701 et seq.) 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 712(c) of Pub. L. 108–357, formerly set out as a note under section 300b–1 of this title, which was transferred to this section, redesignated as subsec. (b), and amended by Pub. L. 115–327, § 3, was based on Pub. L. 108–357, title VII, § 712(c), Oct. 22, 2004, 118 Stat. 1559.

PRIOR PROVISIONS

A prior section 300b–5, act July 1, 1944, ch. 373, title XI, § 1106, as added Apr. 22, 1976, Pub. L. 94–278, title IV, § 403(a), 90 Stat. 409, related to an annual report to President and Congress on administration of this part, prior to repeal by Pub. L. 97–35, title XXI, § 2193(b)(4), Aug. 13, 1981, 95 Stat. 827.

Another prior section 300b–5, act July 1, 1944, ch. 373, title XI, §1106, as added May 16, 1972, Pub. L. 92–294, §3(c), 86 Stat. 139; amended Aug. 29, 1972, Pub. L. 92–414, §4(3), 86 Stat. 652, related to an annual report to President and Congress on administration of this part, prior to repeal by Pub. L. 94–278, title IV, §403(a), Apr. 22, 1976, 90 Stat. 407.

AMENDMENTS

2018—Subsec. (b). Pub. L. 115–327, §3(b), transferred section 712(c) of Pub. L. 108–357 to this section and redesignated it as subsec. (b). See Codification note above.

Pub. L. 115–327, §3(a)(1), substituted ''sickle cell disease'' for ''Sickle Cell Disease'' wherever appearing.

Subsec. (b)(1)(A). Pub. L. 115–327, §3(a)(2), substituted ''shall continue efforts, including by awarding grants, to develop or establish mechanisms to improve the treatment of sickle cell disease, and to improve the prevention and treatment of complications of sickle cell disease, in populations with a high proportion of individuals with sickle cell disease'' for ''shall conduct a demonstration program by making grants to up to 40 eligible entities for each fiscal year in which the program is conducted under this section for the purpose of developing and establishing systemic mechanisms to improve the prevention and treatment of Sickle Cell Disease''.

Subsec. (b)(1)(B). Pub. L. 115–327, §3(a)(3), substituted ''Geographic diversity'' for ''Grant award requirements'' in heading, struck out cl. (i) designation and heading before ''The Administrator shall'', and struck out cl. (ii) which related to priority in awarding grants.

Subsec. (b)(2)(E). Pub. L. 115–327, §3(a)(4), added subpar. (E).

Subsec. (b)(6). Pub. L. 115–327, §3(a)(5), substituted ''$4,455,000 for each of fiscal years 2019 through 2023'' for ''$10,000,000 for each of fiscal years 2005 through 2009''.

§ 300b–6. Applied technology

The Secretary, acting through an identifiable administrative unit, shall—

(1) conduct epidemiological assessments and surveillance of genetic diseases to define the scope and extent of such diseases and the need for programs for the diagnosis, treatment, and control of such diseases, screening for such diseases, and the counseling of persons with such diseases;

(2) on the basis of the assessments and surveillance described in paragraph (1), develop for use by the States programs which combine in an effective manner diagnosis, treatment, and control of such diseases, screening for such diseases, and counseling of persons with such diseases; and

(3) on the basis of the assessments and surveillance described in paragraph (1), provide technical assistance to States to implement the programs developed under paragraph (2) and train appropriate personnel for such programs.

In carrying out this section, the Secretary may, from funds allotted for use under section 702(a) of this title, make grants to or contracts with public or nonprofit private entities (including grants and contracts for demonstration projects).

(July 1, 1944, ch. 373, title XI, §1107, as added Pub. L. 95–626, title II, §205(d)(1), Nov. 10, 1978, 92 Stat. 3584; amended Pub. L. 97–35, title XXI, §2193(b)(5), Aug. 13, 1981, 95 Stat. 827.)

AMENDMENTS

1981—Pub. L. 97–35 substituted provisions relating to allotments under section 702(a) of this title for provisions relating to appropriations under section 300b(b) of this title.

EFFECTIVE DATE OF 1981 AMENDMENT, SAVINGS, AND TRANSITIONAL PROVISIONS

For effective date, savings, and transitional provisions relating to amendment by Pub. L. 97–35, see section 2194 of Pub. L. 97–35, set out as a note under section 701 of this title.

§ 300b–7. Tourette Syndrome

(a) In general

The Secretary shall develop and implement outreach programs to educate the public, health care providers, educators and community based organizations about the etiology, symptoms, diagnosis and treatment of Tourette Syndrome, with a particular emphasis on children with Tourette Syndrome. Such programs may be carried out by the Secretary directly and through awards of grants or contracts to public or nonprofit private entities.

(b) Certain activities

Activities under subsection (a) shall include—

(1) the production and translation of educational materials, including public service announcements;

(2) the development of training material for health care providers, educators and community based organizations; and

(3) outreach efforts directed at the misdiagnosis and underdiagnosis of Tourette Syndrome in children and in minority groups.

(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.

(July 1, 1944, ch. 373, title XI, §1108, as added Pub. L. 106–310, div. A, title XXIII, §2301, Oct. 17, 2000, 114 Stat. 1157.)

§ 300b–8. Improved newborn and child screening for heritable disorders

(a) Authorization of grant program

From amounts appropriated under section 300b–16 of this title, the Secretary, acting through the Administrator of the Health Resources and Services Administration (referred to in this section as the ''Administrator'') and taking into consideration the expertise of the Advisory Committee on Heritable Disorders in Newborns and Children (referred to in this section as the ''Advisory Committee''), shall award grants to eligible entities to enable such entities—

(1) to enhance, improve or expand the ability of State and local public health agencies to provide screening, counseling, or health care services to newborns and children having or at risk for heritable disorders;

(2) to assist in providing health care professionals and newborn screening laboratory personnel with education in newborn screening, counseling, and training in—

(A) relevant and new technologies in newborn screening and congenital, genetic, and metabolic disorders;

(B) the importance of the timeliness of collection, delivery, receipt, and screening of specimens; and