

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.)

**Editorial Notes**

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.)

**Editorial Notes**

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.

**Statutory Notes and Related Subsidiaries**

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

(C) sharing of medical and diagnostic information with providers and families;

(3) to develop and deliver educational programs (at appropriate literacy levels) about newborn screening counseling, testing, follow-up, treatment, and specialty services to parents, families, and patient advocacy and support groups;

(4) to establish, maintain, and operate a system to assess and coordinate followup and treatment relating to congenital, genetic, and metabolic disorders; and

(5) to improve the timeliness of—

(A) the collection, delivery, receipt, and screening of specimens; and

(B) the diagnosis of heritable disorders in newborns.

**(b) Eligible entity**

In this section, the term “eligible entity” means—

(1) a State or a political subdivision of a State;

(2) a consortium of 2 or more States or political subdivisions of States;

(3) a territory;

(4) a health facility or program operated by or pursuant to a contract with or grant from the Indian Health Service; or

(5) any other entity with appropriate expertise in newborn screening, as determined by the Secretary.

**(c) Approval factors**

An application for a grant under this section shall not be approved by the Secretary unless the application contains assurances that the eligible entity has adopted and implemented, is in the process of adopting and implementing, or will use amounts received under such grant to adopt and implement the guidelines and recommendations of the Advisory Committee that are adopted by the Secretary and in effect at the time the grant is awarded or renewed under this section, which shall include the screening of each newborn for the heritable disorders recommended by the Advisory Committee and adopted by the Secretary.

**(d) Coordination**

The Secretary shall take all necessary steps to coordinate programs funded with grants received under this section and to coordinate with existing newborn screening activities.

**(e) Limitation**

An eligible entity may not use amounts received under this section to—

(1) provide cash payments to or on behalf of affected individuals;

(2) provide inpatient services;

(3) purchase land or make capital improvements to property; or

(4) provide for proprietary research or training.

**(f) Voluntary participation**

The participation by any individual in any program or portion thereof established or operated with funds received under this section shall be wholly voluntary and shall not be a prerequisite to eligibility for or receipt of any other service or assistance from, or to participation in, another Federal or State program.

**(g) Supplement not supplant**

Funds appropriated under this section shall be used to supplement and not supplant other Federal, State, and local public funds provided for activities of the type described in this section.

**(h) Publication**

**(1) In general**

An application for a grant under this section shall be made public by the State in such a manner as to facilitate comment from any person, including through hearings and other methods used to facilitate comments from the public.

**(2) Comments**

Comments received by the State after the publication described in paragraph (1) shall be addressed in the application for a grant under this section.

**(i) Technical assistance**

The Secretary shall provide to entities receiving grants under subsection (a) such technical