sections (a) and (b) [see section 401 of Pub. L. 94–278, set out as a Short Title of 1976 Amendment note under section 201 of this title] shall take effect July 1, 1976.''

SHORT TITLE OF 1976 AMENDMENT

For short title of title IV of Pub. L. 94–278, which enacted this part, omitted former part B of this subchapter, redesignated former parts C and D of this subchapter as parts B and C of this subchapter, respectively, as the ''National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act'', see section 401 of Pub. L. 94–278, set out as a note under section 201 of this title.

DEMONSTRATION PROGRAM FOR THE DEVELOPMENT AND ESTABLISHMENT OF SYSTEMIC MECHANISMS FOR THE PREVENTION AND TREATMENT OF SICKLE CELL DISEASE

Pub. L. 108–357, title VII, §712(c), Oct. 22, 2004, 118 Stat. 1559, as amended by Pub. L. 115–327, §3(a), Dec. 18, 2018, 132 Stat. 4469, which was formerly set out as a note under this section, was transferred to section 300b–5(b) of this title by Pub. L. 115–327, §3(b), Dec. 18, 2018, 132 Stat. 4470.

CONGRESSIONAL DECLARATION OF PURPOSE

Pub. L. 94–278, title IV, §402, Apr. 22, 1976, 90 Stat. 407, as amended by Pub. L. 95–626, title II, §205(a), Nov. 10, 1978, 92 Stat. 3583; Pub. L. 111–256, §2(i), Oct. 5, 2010, 124 Stat. 2644, provided that: ''In order to preserve and protect the health and welfare of all citizens, it is the purpose of this title [see section 401 of Pub. L. 94–278, set out as a Short Title of 1976 Amendment note under section 201 of this title] to establish a national program to provide for basic and applied research, research training, testing, counseling, and information and education programs with respect to genetic diseases, and genetic conditions, such as Sickle Cell anemia, Cooley's Anemia, Tay–Sachs disease, cystic fibrosis, dysautonomia, hemophilia, retinitis pigmentosa, Huntington's chorea, muscular dystrophy, and genetic conditions leading to intellectual disabilities or genetically caused mental disorders.''

[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.]

§ 300b–2. Voluntary participation by individuals

The participation by any individual in any program or portion thereof under this part 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, any other program.

(July 1, 1944, ch. 373, title XI, §1103, as added Pub. L. 94–278, title IV, §403(a), Apr. 22, 1976, 90 Stat. 408.)

Editorial Notes

PRIOR PROVISIONS

A prior section 300b–2, act July 1, 1944, ch. 373, title XI, §1103, as added May 16, 1972, Pub. L. 92–294, §3(c), 86 Stat. 138; amended Aug. 29, 1972, Pub. L. 92–414, §4(3), 86 Stat. 652, was identical to this section, prior to repeal by Pub. L. 94–278, title IV, §403(a), Apr. 22, 1976, 90 Stat. 407.

§ 300b–3. Application; special consideration to prior sickle cell anemia grant recipients

(a) Manner of submission; contents

A grant or contract under this part may be made upon application submitted to the Secretary at such time, in such manner, and containing and accompanied by such information, as the Secretary may require, including assurances for an evaluation whether performed by the applicant or by the Secretary. Such grant or contract may be made available on less than a statewide or regional basis. Each applicant shall—

(1) provide that the programs and activities for which assistance under this part is sought will be administered by or under the supervision of the applicant;

(2) provide for strict confidentiality of all test results, medical records, and other information regarding testing, diagnosis, counseling, or treatment of any person treated, except for (A) such information as the patient (or his guardian) gives informed consent to be released, or (B) statistical data compiled without reference to the identity of any such patient;

(3) provide for community representation where appropriate in the development and operation of voluntary genetic testing or counseling programs funded by a grant or contract under this part; and

(4) establish fiscal control and fund accounting procedures as may be necessary to assure proper disbursement of and accounting of Federal funds paid to the applicant under this part.

(b) Considerations for grants and contracts under section 300b–1 of this title

In making grants and entering into contracts for any fiscal year under section 241 of this title for projects described in section 300b–1 of this title the Secretary shall give special consideration to applications from entities that received grants from, or entered into contracts with, the Secretary for the preceding fiscal year for the conduct of comprehensive sickle cell centers or sickle cell screening and education clinics.

(July 1, 1944, ch. 373, title XI, §1104, as added Pub. L. 94–278, title IV, §403(a), Apr. 22, 1976, 90 Stat. 408; amended Pub. L. 95–626, title II, §205(c), Nov. 10, 1978, 92 Stat. 3584; Pub. L. 97–35, title XXI, §2193(b)(2), (3), Aug. 13, 1981, 95 Stat. 827.)

Editorial Notes

PRIOR PROVISIONS

A prior section 300b–3, act July 1, 1944, ch. 373, title XI, §1104, as added May 16, 1972, Pub. L. 92–294, §3(c), 86 Stat. 138; amended Aug. 29, 1972, Pub. L. 92–414, §4(3), 86 Stat. 652, authorized grants to be made upon application to Secretary and required supervision of programs by applicant, confidentiality of test results, medical records and other information obtained from treated person, community representation in programs, assurances by applicant that priority will be given to persons of child bearing years, and demonstration by applicant of proper fiscal control and accounting procedures, prior to repeal by Pub. L. 94–278, title IV, §403(a), Apr. 22, 1976, 90 Stat. 407.

AMENDMENTS

1981—Subsec. (a)(4), (5). Pub. L. 97–35, §2193(b)(2), redesignated par. (5) as (4). Former par. (4), which related to testing and counseling requirements, was struck out.

Subsec. (b). Pub. L. 97–35, §2193(b)(3), struck out subsec. (b) which related to grants and contracts under

section 300b of this title. Former subsec. (c) was redesignated (b) and, as so redesignated, struck out reference to section 300b of this title.

Subsec. (c). Pub. L. 97–35, § 2193(b)(3), redesignated subsec. (c) as (b).

Subsec. (d). Pub. L. 97–35, § 2193(b)(3), struck out subsec. (d) which related to procedures applicable to grants, etc., under section 300b of this title.

1978—Subsec. (a). Pub. L. 95–626, § 205(c)(1), inserted requirement that application contain assurances for an evaluation whether performed by applicant or by Secretary and that grant or contract be made available on less than a statewide or regional basis.

Subsec. (d). Pub. L. 95–626, § 205(c)(2), added subsec. (d).

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–4. Public Health Service facilities

The Secretary shall establish a program within the Service to provide voluntary testing, diagnosis, counseling, and treatment of individuals respecting genetic diseases. Services under such program shall be made available through facilities of the Service to persons requesting such services, and the program shall provide appropriate 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.)

Editorial Notes

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.

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