

nia, 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.)

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.)

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).

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.)

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. Repealed. Pub. L. 97-35, title XXI, §2193(b)(4), Aug. 13, 1981, 95 Stat. 827

Section, 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.

A 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.

EFFECTIVE DATE OF REPEAL, SAVINGS, AND
TRANSITIONAL PROVISIONS

For effective date, savings, and transitional provisions relating to repeal 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-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

(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;