ment with a comprehensive Sickle Cell Disease treatment center that does not receive funds from the National Institutes of Health.

''(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.

''(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, $10,000,000 for each of fiscal years 2005 through 2009.''

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.)

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