STUDY OF ADOLESCENT PREGNANCY; REPORT NOT LATER THAN NOVEMBER 10, 1979

Pub. L. 95–626, title VIII, § 801, Nov. 10, 1978, 92 Stat. 3602, which provided for a study of the problem of adolescent pregnancies and the effectiveness of existing programs and a report, was repealed by section 955(b) of Pub. L. 97–35.

§ 300a–29. Omitted

CODIFICATION

Section, Pub. L. 95–626, title III, § 301, Nov. 10, 1978, 92 Stat. 3590, provided that grants or contracts made under this subchapter would be considered to have been made under this chapter for the purposes of sections 300*l*–2(e) and 300m–3(c)(6) of this title.

PART B—IMPROVING COORDINATION OF FEDERAL AND STATE PROGRAMS

§ 300a–41. Repealed. Pub. L. 97–35, title IX, § 955(b), title XXI, § 2193(f), Aug. 13, 1981, 95 Stat. 592, 828

Section, Pub. L. 95–626, title VII, § 701, Nov. 10, 1978, 92 Stat. 3601; Pub. L. 96–88, title V, § 509(b), Oct. 17, 1979, 93 Stat. 695, related to improving coordination of Federal and State policies and programs.

EFFECTIVE DATE OF REPEAL

Pub. L. 97–35, title IX, § 955(b), Aug. 13, 1981, 95 Stat. 592, provided that the repeal of this section is effective Oct. 1, 1981.

For effective date, savings, and transitional provisions relating to the repeal of this section by section 2193(f) of Pub. L. 97–35, see section 2194 of Pub. L. 97–35, set out as a note under section 701 of this title.

SUBCHAPTER IX—GENETIC DISEASES, HEMOPHILIA PROGRAMS, AND SUDDEN INFANT DEATH SYNDROME

CODIFICATION

Pub. L. 94–278, title IV, § 403(b)(3), Apr. 22, 1976, 90 Stat. 409, substituted ''GENETIC DISEASES'' for ''GENETIC BLOOD DISORDERS'' and inserted ''HEMOPHILIA PROGRAMS'' in subchapter heading.

Pub. L. 93–270, § 3(b), Apr. 22, 1974, 88 Stat. 92, inserted ''AND SUDDEN INFANT DEATH SYNDROME'' at end of subchapter heading.

Pub. L. 92–414, § 4(1), Aug. 29, 1972, 86 Stat. 652, substituted ''GENETIC BLOOD DISORDERS'' for ''SICKLE CELL ANEMIA PROGRAM'' as subchapter heading and designated such former subchapter heading as part A heading, substituting ''Programs'' for ''Program''.

PART A—GENETIC DISEASES

CODIFICATION

Pub. L. 94–278, title IV, § 403(a), Apr. 22, 1976, 90 Stat. 407, substituted ''Genetic Diseases'' for ''Sickle Cell Anemia Programs'' in part A heading.

Pub. L. 92–414, § 4(1), Aug. 29, 1972, 86 Stat. 652, redesignated subchapter IX heading as part A heading and substituted ''Sickle Cell Anemia Programs'' for ''Sickle Cell Anemia Program''.

§ 300b. Repealed. Pub. L. 97–35, title XXI, § 2193(b)(1), Aug. 13, 1981, 95 Stat. 827

Section, act July 1, 1944, ch. 373, title XI, § 1101, as added Apr. 22, 1976, Pub. L. 94–278, title IV, § 403(a), 90 Stat. 407; amended Nov. 10, 1978, Pub. L. 95–626, title II, § 205(b), (d)(2), (e), 92 Stat. 3583, 3584; Pub. L. 96–88, title V, § 509(b), Oct. 17, 1979, 93 Stat. 695; Aug. 13, 1981, Pub. L. 97–35, title XXI, § 2193(a)(1)(B), 95 Stat. 826; Jan. 4, 1983, Pub. L. 97–414, § 8(*o*), 96 Stat. 2061, related to testing, counseling, information and education programs.

A prior section 300b, act July 1, 1944, ch. 373, title XI, § 1101, as added May 16, 1972, Pub. L. 92–294, § 3(c), 86 Stat. 137; amended Aug. 29, 1972, Pub. L. 92–414, § 4(2), 86 Stat. 652, authorized Secretary to make grants and enter contracts with public and nonprofit private entities with respect to establishment of voluntary sickle cell anemia screening and counseling programs and to develop and disseminate informational and educational materials relating to sickle cell anemia, prior to repeal by Pub. L. 94–278, title IV, § 403(a), Apr. 22, 1976, 90 Stat. 407.

EFFECTIVE DATE OF 1981 AMENDMENT AND REPEAL, SAVINGS, AND TRANSITIONAL PROVISIONS

For effective date, savings, and transitional provisions relating to the amendment and repeal of this section 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–1. Research project grants and contracts

In carrying out section 241 of this title, the Secretary may make grants to public and nonprofit private entities, and may enter into contracts with public and private entities and individuals, for projects for (1) basic or applied research leading to the understanding, diagnosis, treatment, and control of genetic diseases, (2) planning, establishing, demonstrating, and developing special programs for the training of genetic counselors, social and behavioral scientists, and other health professionals, (3) the development of programs to educate practicing physicians, other health professionals, and the public regarding the nature of genetic processes, the inheritance patterns of genetic diseases, and the means, methods, and facilities available to diagnose, control, counsel, and treat genetic diseases, and (4) the development of counseling and testing programs and other programs for the diagnosis, control, and treatment of genetic diseases. In making grants and entering into contracts for projects described in clause (1) of the preceding sentence, the Secretary shall give priority to applications for such grants or contracts which are submitted for research on sickle cell anemia and for research on Cooley's anemia.

(July 1, 1944, ch. 373, title XI, § 1102, as added Pub. L. 94–278, title IV, § 403(a), Apr. 22, 1976, 90 Stat. 408.)

PRIOR PROVISIONS

A prior section 300b–1, act July 1, 1944, ch. 373, title XI, § 1102, as added May 16, 1972, Pub. L. 92–294, § 3(c), 86 Stat. 138, authorized Secretary to make grants and enter contracts with public and private entities and individuals for projects concerned with research, research training in diagnosis, treatment and control of sickle cell anemia, informational and educational programs with respect to sickle cell anemia and development of counseling and testing programs, prior to repeal by Pub. L. 94–278, title IV, § 403(a), Apr. 22, 1976, 90 Stat. 407.

EFFECTIVE DATE

Pub. L. 94–278, title IV, § 403(c), Apr. 22, 1976, 90 Stat. 410, provided that: ''The amendments made by subsections (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 sub-

chapter, 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, provided that:

''(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 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 [probably means this subsection] for the purpose of developing and establishing systemic mechanisms to improve the prevention and treatment of 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) GRANT AWARD REQUIREMENTS.—

''(i) GEOGRAPHIC DIVERSITY.—The Administrator shall, to the extent practicable, award grants under this section [probably means this subsection] to eligible entities located in different regions of the United States.

''(ii) PRIORITY.—In awarding grants under this subsection, the Administrator shall give priority to awarding grants to eligible entities that are—

''(I) Federally-qualified health centers that have a partnership or other arrangement with a comprehensive Sickle Cell Disease treatment center that does not receive funds from the National Institutes of Health; or

''(II) Federally-qualified health centers that intend to develop a partnership or other arrangement 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 Ane-

mia, 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