

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 Sec-

retary 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