

§ 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 non-profit private entities.

(b) Certain activities

Activities under subsection (a) of this section 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 par-

ents, families, and patient advocacy and support groups;

(4) to establish, maintain, and operate a system to assess and coordinate followup and treatment relating to congenital, genetic, and metabolic disorders; and

(5) to improve the timeliness of—

(A) the collection, delivery, receipt, and screening of specimens; and

(B) the diagnosis of heritable disorders in newborns.

(b) Eligible entity

In this section, the term “eligible entity” means—

- (1) a State or a political subdivision of a State;
- (2) a consortium of 2 or more States or political subdivisions of States;
- (3) a territory;
- (4) a health facility or program operated by or pursuant to a contract with or grant from the Indian Health Service; or
- (5) any other entity with appropriate expertise in newborn screening, as determined by the Secretary.

(c) Approval factors

An application for a grant under this section shall not be approved by the Secretary unless the application contains assurances that the eligible entity has adopted and implemented, is in the process of adopting and implementing, or will use amounts received under such grant to adopt and implement the guidelines and recommendations of the Advisory Committee that are adopted by the Secretary and in effect at the time the grant is awarded or renewed under this section, which shall include the screening of each newborn for the heritable disorders recommended by the Advisory Committee and adopted by the Secretary.

(d) Coordination

The Secretary shall take all necessary steps to coordinate programs funded with grants received under this section and to coordinate with existing newborn screening activities.

(e) Limitation

An eligible entity may not use amounts received under this section to—

- (1) provide cash payments to or on behalf of affected individuals;
- (2) provide inpatient services;
- (3) purchase land or make capital improvements to property; or
- (4) provide for proprietary research or training.

(f) Voluntary participation

The participation by any individual in any program or portion thereof established or operated with funds received under this section 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, another Federal or State program.

(g) Supplement not supplant

Funds appropriated under this section shall be used to supplement and not supplant other Federal, State, and local public funds provided for activities of the type described in this section.

(h) Publication**(1) In general**

An application for a grant under this section shall be made public by the State in such a manner as to facilitate comment from any person, including through hearings and other methods used to facilitate comments from the public.

(2) Comments

Comments received by the State after the publication described in paragraph (1) shall be addressed in the application for a grant under this section.

(i) Technical assistance

The Secretary shall provide to entities receiving grants under subsection (a) of this section such technical assistance as may be necessary to ensure the quality of programs conducted under this section.

(July 1, 1944, ch. 373, title XI, §1109, as added Pub. L. 106-310, div. A, title XXVI, §2601, Oct. 17, 2000, 114 Stat. 1164; amended Pub. L. 110-204, §2, Apr. 24, 2008, 122 Stat. 705; Pub. L. 110-237, §1(a)(1), May 27, 2008, 122 Stat. 1556; Pub. L. 113-240, §2, Dec. 18, 2014, 128 Stat. 2851.)

AMENDMENTS

2014—Subsec. (a). Pub. L. 113-240, §2(1)(A), in introductory provisions, substituted “section 300b-16 of this title” for “subsection (j)” and “and taking into consideration the expertise of the Advisory Committee” for “and in consultation with the Advisory Committee”.

Subsec. (a)(2). Pub. L. 113-240, §2(1)(B), amended par. (2) generally. Prior to amendment, par. (2) read as follows: “to assist in providing health care professionals and newborn screening laboratory personnel with education in newborn screening and training in relevant and new technologies in newborn screening and congenital, genetic, and metabolic disorders;”.

Subsec. (a)(4). Pub. L. 113-240, §2(1)(D)(i), substituted “followup and treatment” for “treatment”.

Subsec. (a)(5). Pub. L. 113-240, §2(1)(C), (D)(ii), (E), added par. (5).

Subsec. (c). Pub. L. 113-240, §2(2), substituted “application for a grant under this section” for “application submitted for a grant under subsection (a)(1)”.

Subsec. (h). Pub. L. 113-240, §2(3), substituted “application for a grant under this section” for “application submitted under subsection (c)(2) of this section” in pars. (1) and (2).

Subsec. (j). Pub. L. 113-240, §2(4), struck out subsec. (j) which authorized appropriations for fiscal years 2009 to 2013 to provide grants for carrying out activities under subsec. (a).

2008—Subsecs. (a) to (c). Pub. L. 110-204, §2(1), added subsecs. (a) to (c) and struck out former subsecs. (a) to (c) which provided for grants to promote screening, counseling, or health care services to newborns and children having or at risk for heritable disorders, enumerated permissible uses of grants, and set out grant applicants’ eligibility requirements.

Subsecs. (d) to (i). Pub. L. 110-204, §2(2), (3), added subsec. (d) and redesignated former subsecs. (d) to (h) as (e) to (i), respectively. Former subsec. (i) redesignated (j).

Subsec. (j). Pub. L. 110-237 added subsec. (j) and struck out former subsec. (j). Prior to amendment, text read as follows: “There is authorized to be appropriated—

“(1) to provide grants for the purpose of carrying out activities under section (a)(1), \$15,000,000 for fiscal year 2008; \$15,187,500 for fiscal year 2009, \$15,375,000 for fiscal year 2010, \$15,562,500 for fiscal year 2011, and \$15,750,000 for fiscal year 2012; and

“(2) to provide grant for the purpose of carrying out activities under paragraphs (2), (3), and (4) of subsection (a), \$15,000,000 for fiscal year 2008, \$15,187,500 for fiscal year 2009, \$15,375,000 for fiscal year 2010, \$15,562,500 for fiscal year 2011, and \$15,750,000 for fiscal year 2012.”

Pub. L. 110-204, §2(4), added subsec. (j) and struck out former subsec. (j). Prior to amendment, text read as follows: “There are authorized to be appropriated to carry out this section such sums as may be necessary for each of the fiscal years 2001 through 2005.”

Pub. L. 110-204, §2(2), redesignated subsec. (i) as (j).

§ 300b-9. Evaluating the effectiveness of newborn and child screening and followup programs**(a) In general**

The Secretary shall award grants to eligible entities to provide for the conduct of demonstration programs to evaluate the effectiveness, including with respect to timeliness, of screening, followup, counseling or health care services in reducing the morbidity and mortality caused by heritable disorders in newborns and children.

(b) Demonstration programs

A demonstration program conducted under a grant under this section shall be designed to evaluate and assess, within the jurisdiction of the entity receiving such grant—

(1) the effectiveness of screening, treatment, counseling, testing, followup, or specialty services for newborns and children at risk for heritable disorders in reducing the morbidity and mortality associated with such disorders, including, as appropriate, through the assessment of health and development outcomes for such children through adolescence;

(2) the effectiveness of screening, treatment, counseling, testing, followup, or specialty services in accurately and reliably diagnosing heritable disorders in newborns and children in a timely manner;

(3) the availability of screening, counseling, testing or specialty services for newborns and children at risk for heritable disorders;

(4) methods that may be identified to improve quality in the diagnosis, treatment, and disease management of heritable disorders based on gaps in services or care; or

(5) methods or best practices by which the eligible entities described in section 300b-8 of this title can achieve in a timely manner—

(A) collection, delivery, receipt, and screening of newborn screening specimens; and

(B) diagnosis of heritable disorders in newborns.

(c) Eligible entities

To be eligible to receive a grant under subsection (a) of this section an entity shall be a State or political subdivision of a State, or a consortium of two or more States or political subdivisions of States.

(July 1, 1944, ch. 373, title XI, §1110, as added Pub. L. 106-310, div. A, title XXVI, §2601, Oct. 17, 2000, 114 Stat. 1165; amended Pub. L. 110-204, §3, Apr. 24, 2008, 122 Stat. 706; Pub. L. 110-237, §1(a)(2), May 27, 2008, 122 Stat. 1556; Pub. L. 113-240, §3, Dec. 18, 2014, 128 Stat. 2852.)

AMENDMENTS

2014—Pub. L. 113-240, §3(1), inserted “and followup” after “child screening” in section catchline.