STATE OF NEW YORK

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2023-2024 Regular Sessions

IN SENATE

January 17, 2023

Introduced by Sens. SANDERS, BROUK, CLEARE, COMRIE, GIANARIS, JACKSON, KENNEDY, KRUEGER, MAYER, MYRIE, SEPULVEDA, SKOUFIS -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law, in relation to creating the sickle cell disease detection and education program

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Article 24 of the public health law is amended by adding a new title 1-C to read as follows:

TITLE I-C

SICKLE CELL DISEASE DETECTION AND EDUCATION PROGRAM

Section 2415. Sickle cell disease detection and education program; establishment.
2416. Grants to approved organizations.
2417. Grants to community-based organizations.
2418. Annual report.
2419. Advisory council.

§ 2415. Sickle cell disease detection and education program; establishment. 1. There is hereby created within the department the sickle cell disease detection and education program, hereafter referred to in this title as the "sickle cell disease services program" or "the program", to promote screening and detection of sickle cell disease, especially among unserved or underserved populations; to educate the public regarding sickle cell disease and the benefits of early detection; and to provide counseling and referral services. For purposes of this title, "unserved or underserved populations" means people having inadequate access and financial resources to obtain sickle cell disease screening and detection services, including people who lack health coverage or whose health coverage is inadequate or who cannot meet the

EXPLANATION--Matter in *italics* (underscored) is new; matter in brackets [-] is old law to be omitted.

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financial requirements of their coverage for accessing detection services.

2. The program shall include:

(a) establishment of a statewide public education and outreach campaign to publicize evidence based sickle cell disease screening, detection and education services. The campaign shall include: general community education, outreach to specific underserved populations, evidence based clinical sickle cell disease screening services, and an informational summary that shall include an explanation of the importance of clinical examinations and what to expect during clinical examinations and sickle cell disease screening services;

(b) provision of grants to approved organizations under sections twenty-four hundred sixteen and twenty-four hundred seventeen of this title;

(c) compilation of data concerning the program and dissemination of such data to the public; and

(d) development of health care professional education programs including the benefits of early detection of sickle cell disease and clinical examinations, the recommended frequency of clinical examinations and sickle cell disease screening services, and professionally recognized best practices guidelines.

§ 2416. Grants to approved organizations. 1. The commissioner shall make grants within the amounts appropriated to approved organizations for the provision of services relating to the evidence based screening and detection of sickle cell disease as part of this program. The services shall include but not be limited to:

(a) promotion and provision of early detection of sickle cell disease, including clinical examinations and sickle cell disease screening services;

(b) provision of counseling and information on treatment options and referral for appropriate medical treatment;

(c) dissemination of information to unserved and underserved populations, to the general public and to health care professionals concerning sickle cell disease, the benefits of early detection and treatment, and the availability of sickle cell disease screening services;

(d) identification of local sickle cell disease screening services within the approved organization's region;

(e) provision of information, counseling and referral services to individuals diagnosed with sickle cell disease; and

(f) provision of information regarding the availability of medical assistance, including medical assistance under title eleven of article five of the social services law, to an individual who requires treatment for sickle cell disease.

2. The commissioner shall give notice and provide opportunity to submit applications for grants under the program. In order to be considered for a grant, an applicant must show evidence of the following, relating to the services the applicant proposes to provide:

(a) ability to provide and to ensure consistent and quality services under the program;

(b) expertise in providing the service;

(c) capacity to coordinate services with physicians, hospitals and other appropriate local institutions or agencies;

(d) ability to provide the service to unserved or underserved populations; and

(e) ability to provide the service in accordance with the standards specified in subdivision three of this section.

Applications shall be made on forms provided by the commissioner.

3. The commissioner shall develop standards for the implementation of grants under the program by approved organizations, which shall ensure the following:

(a) integration of the approved organization with existing health care providers;

(b) maximizing third party reimbursement;

(c) provision of services to unserved or underserved populations.

4. Within the amounts of state or federal funds appropriated for the program, approved organizations may be authorized by the department to provide such services for populations served under this title. Services may include evidence based screening, patient education, counseling, follow-up and referral.

§ 2417. Grants to community-based organizations. 1. The commissioner shall make grants within amounts appropriated for community-based organizations to provide post diagnosis counseling, education and outreach programs for persons diagnosed with sickle cell disease based upon criteria to be developed by the commissioner.

2. For the purposes of this section, "community-based organizations" shall mean free-standing organizations in which sickle cell disease survivors hold significant decision-making responsibility, and which offer a broad range of sickle cell disease education and support services free of charge.

3. The commissioner shall provide notice and opportunity for community-based organizations to submit applications to provide post-diagnosis sickle cell disease counseling, education and outreach programs. Such applications shall be on forms established by the commissioner.

4. Every organization receiving grants under this title shall submit to the commissioner, on or before October first of each year, a report of such organization's activities, including an assessment of the organization's programs and such data as the commissioner deems relevant and necessary to accomplish the purposes of the program.

§ 2418. Annual report. The commissioner shall submit on or before December first of each year, an annual report to the governor and the legislature concerning the operation of the program. The reports shall include the experience of the program in providing services under this title. The annual report shall include strategies for implementation of the sickle cell disease awareness program and for promoting the awareness program to the general public, state and local elected officials, and various public and private organizations, associations, businesses, industries, and agencies. Organizations receiving grants under this title shall provide data and assessments as the commissioner may require for the report. The report shall include any recommendations for additional action to respond to the incidence of sickle cell disease in this state.

§ 2419. Advisory council. 1. There is hereby established in the department the sickle cell disease detection and education program advisory council, for the purpose of advising the commissioner with regard to the program.

2. The advisory council shall advise and make recommendations to the commissioner regarding the promotion and implementation of programs under this title.

3. The commissioner shall appoint twenty-one voting members of the advisory council, which shall include representation of health care professionals, consumers, patients, with one voting member who shall be a person who has or has had sickle cell disease. The commissioner shall appoint one member as a chairperson. The members of the council shall

receive no compensation for their services, but shall be allowed their actual and necessary expenses incurred in performance of their duties.

4. A majority of the appointed voting membership of the board shall constitute a quorum.

5. The advisory council shall meet at least twice a year, at the request of the department.

§ 2. Subdivision 1 of section 207 of the public health law is amended by adding a new paragraph (r) to read as follows:

(r) Sickle cell disease including but not limited to screening, prevention, and treatment information. The program shall include an advisory council under this section that shall include patients with sickle cell disease and their families and health care providers specializing in treating sickle cell disease, among others.

§ 3. This act shall take effect immediately.