

CHAPTER 242

AN ACT concerning sickle cell disease and making an appropriation.

BE IT ENACTED *by the Senate and General Assembly of the State of New Jersey:*

1. a. The Department of Health, in consultation with the Department of Human Services, shall establish a three-year sickle cell disease pilot program, under which federally qualified health centers shall be selected by the Department of Health for the purposes of developing and implementing comprehensive sickle cell disease treatment programs and services. The Department of Health shall select federally qualified health centers for participation in the pilot program on a competitive basis based on criteria to be established by the Commissioner of Health. First priority shall be given to federally qualified health centers located in the municipalities of Jersey City, Newark, Paterson, Plainfield, Trenton, Camden, and, subject to the availability of funds provided pursuant to section 2 of this act, to federally qualified health centers in other municipalities which demonstrate a patient population in that geographic area that is in need of sickle cell disease care. The federally qualified health centers selected for participation in the pilot program shall be eligible for financial support from funds appropriated to the department pursuant to section 2 of this act.

b. The purpose of the pilot program shall be to:

(1) link outpatient sickle cell disease care to sickle cell disease care in inpatient health care settings and other health care settings, which may include, to the extent permitted by law, telehealth services;

(2) provide coordinated, comprehensive, team-based medical, behavioral health, mental health, social support, and other services under the supervision of health care professionals who have expertise in treating individuals with sickle cell disease;

(3) foster outreach to individuals and families with sickle cell disease and providers of medical, nursing, and social services who serve and treat persons with sickle cell disease;

(4) promote sickle cell disease education and awareness including, but not limited to, education and public awareness campaigns in partnership with community organizations, sickle cell disease awareness groups, and youth organizations;

(5) develop initiatives to build a State medical workforce of clinicians who are knowledgeable about the diagnosis and treatment of sickle cell disease; and

(6) establish practices for the collection of in-State data on sickle cell disease to monitor incidence, prevalence, demographics, morbidity, health care utilization, and costs.

c. Federally qualified health centers seeking to participate in the pilot program shall develop comprehensive sickle cell disease treatment programs and services that provide coordinated, comprehensive, team-based medical, behavioral health, mental health, social support, and monitoring services under the supervision of health care professionals who have expertise in treating individuals with sickle cell disease.

d. The Department of Health shall coordinate with federally qualified health centers participating in the pilot program and other health care facilities and health care professionals to establish centers of excellence for sickle cell disease research and innovation, as determined by the Commissioner of Health.

2. There is appropriated from the General Fund to the Department of Health the sum of \$10,200,000, which sum shall be used by the department to support the purposes of this act through the provision of grants to federally qualified health centers selected pursuant to

subsection a. of section 1 of this act for the duration of the pilot program. Any unexpended funds shall revert to the General Fund once the pilot program expires.

3. This act shall take effect immediately and shall expire three years thereafter.

Approved January 8, 2024.