

ASSEMBLY HEALTH COMMITTEE

STATEMENT TO

ASSEMBLY, No. 4052

with committee amendments

STATE OF NEW JERSEY

DATED: JUNE 5, 2023

The Assembly Health Committee reports favorably and with committee amendments Assembly Bill No. 4052.

As amended by the committee, this bill establishes a three-year sickle cell disease pilot program and appropriates \$10,200,000.

Under the bill, the Department of Health (department), in consultation with the Department of Human Services, is to establish a three-year sickle cell disease pilot program, under which federally qualified health centers are to be selected by the department to develop and implement comprehensive sickle cell disease treatment programs and services. The department is to 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 (commissioner). First priority is to be given to federally qualified health centers located in Jersey City, Newark, Paterson, Plainfield, Trenton, Camden, and, subject to the availability of funds, 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 are to be eligible for financial support from funds appropriated to the department.

The purpose of the pilot program is 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, if 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;

(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.

Federally qualified health centers seeking to participate in the pilot program are to 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. The department is to 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.

COMMITTEE AMENDMENTS:

The committee amendments:

- 1) make technical changes to the title and synopsis and changes involving numbering, style, and usage;
- 2) revise the effective date to make the bill take effect immediately;
- 3) provide that the pilot program will be located in federally qualified health centers as opposed to comprehensive treatment centers established within federally qualified health centers;
- 4) provide that the purpose of the pilot program is to develop and implement comprehensive sickle cell disease treatment programs and services;
- 5) provide that funds may be available for municipalities that are not given priority under the bill under certain conditions;
- 6) provide that pilot program is to extend beyond inpatient health care to other health care settings and to be conducted under the supervision of health care professionals who have expertise in treating individuals with sickle cell disease; and
- 7) provide that sickle cell disease education and awareness is to include education and public awareness campaigns in partnership with community organizations, sickle cell disease awareness groups, and youth organizations.