STATE OF NEW YORK

8924

IN SENATE

March 28, 2024

Introduced by Sen. PARKER -- 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 requiring the health equity council to issue mandates related to the treatment of sickle cell disease

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

Section 1. Paragraph c of subdivision 6 of section 243 of the public health law, as added by chapter 684 of the laws of 2023, is amended to read as follows:

c. The council shall consider the feasibility of the following**, and notwithstanding the findings, shall issue mandates to the commissioner for**:

(i) the 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;

(ii) the provision of grants to approved organizations;

(iii) the compilation of data concerning sickle cell disease and dissemination of such data to the public; [~~and~~]

(iv) the 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**;**

(v) the establishment of regional sickle cell centers to provide team-based, integrated care including pain management, mental health, trait testing, and genetic counseling;

(vi) the implementation of workforce development in primary and specialty care with a focus on sickle cell disease; and

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

LBD15055-01-4

(vii) the support of long-term surveillance of sickle cell disease complications, mortality, health services utilization, and cost throughout the lifespan of sickle cell disease patients to understand which populations are most vulnerable and identify emerging trends for action.

§ 2. Subdivision 1 of section 206 of the public health law is amended by adding a new paragraph (w) to read as follows:

(w) consider, adhere to, and act upon all advice, recommendations and mandates provided by the health equity council pursuant to subdivision six of section two hundred forty-three of this chapter.

§ 3. This act shall take effect immediately.