AMENDED IN ASSEMBLY APRIL 11, 2019

CALIFORNIA LEGISLATURE—2019–20 REGULAR SESSION

ASSEMBLY BILL No. 1105

Introduced by Assembly Member Gipson

February 21, 2019

An act to add and repeal Section 125040 ~~to~~ *of* the Health and Safety Code, relating to sickle cell disease, making an appropriation therefor, and declaring the urgency thereof, to take effect immediately.

LEGISLATIVE COUNSEL'S DIGEST

AB 1105, as amended, Gipson. Sickle cell disease.

Existing law establishes the State Department of Health Care Services, and requires the department to administer various health programs, including the Genetically Handicapped Persons Program, under which medical care is provided to persons with genetically handicapping conditions, including sickle cell disease. Existing law authorizes the State Department of Public Health to make grants or contracts for demonstration projects to determine the feasibility of alternate methods of testing for sickle cell disease, to provide counseling services, to evaluate the social consequences of the identification of sickle cell trait carriers, to provide training in genetic counseling, and to conduct research on the prevention of sickle cell disease.

This bill would require the State Department of Public Health, in collaboration with the State Department of Health Care Services, to establish a 3-year sickle cell disease center pilot program that would utilize a competitive grant program to establish 5 sickle cell disease centers as special care centers. The bill would require the centers to link outpatient care to inpatient care, and provide coordinated, comprehensive, team-based medical, behavioral health, mental health,

social support, and surveillance services to adults with sickle cell disease. The bill would require the State Department of Public Health, among other things, to enhance statewide surveillance of sickle cell disease. The bill would repeal these provisions on January 1, 2025. The bill would appropriate $15,000,000 from the General Fund to the State Department of Public Health for implementation and administration of the pilot program. By appropriating these moneys from the General Fund, the bill would make an appropriation.

This bill would declare that it is to take effect immediately as an urgency statute.

Vote: ⅔. Appropriation: yes. Fiscal committee: yes. State-mandated local program: no.

The people of the State of California do enact as follows:

SECTION 1. The Legislature hereby finds and declares all of the following:

(a) Sickle cell disease is a painful, rare, complex, progressively debilitating, and potentially fatal inherited blood disorder. Sickle cell disease has suffered from inattention and inadequate resources in California, causing devastating personal and societal costs.

(b) Californians with sickle cell disease suffer poor health, die at younger ages and at higher rates, and have higher rates of emergency room visits and hospitalizations compared to people who suffer from sickle cell disease and live in other states. The lifespan of Californians with sickle cell disease is about 43 years of age, a shorter lifespan than the population in this country and the African American community, as well as shorter than sickle cell disease populations living in other states.

(c) People with sickle cell disease suffer frequent bouts of agonizing pain that may require opioid analgesics. Sickle cell disease pain crises frequently lead to emergency department visits and hospitalizations at an estimated cost of $2.4 billion per year in this country. Yet efforts to address the nation’s opioid epidemic are inadvertently restricting sickle cell disease patient access to needed pain management.

(d) Care fragmentation for Californians with sickle cell disease is high. California’s lack of health care infrastructure for sickle cell disease, specifically preventive, team-based specialist care for adults, drives poor health outcomes.

(e) Resources are also inadequate to track the numbers of Californians with sickle cell disease, their health care quality, utilization, outcomes, costs, and quality of life. This limits a full understanding of sickle cell disease's impact, including evaluating any systemic improvements that are implemented.

(f) From 7,000 to as many as 13,000 Californians have sickle cell disease. About 75 to 100 California babies are born with sickle cell disease each year. These babies inherited the sickle cell gene from both parents. About 85 percent of Californians born with sickle cell disease are African American, 10 percent are Hispanic, and 5 percent are either White, Native American, or Asian.

(g) Approximately 3,500 babies are born each year in California with sickle cell trait, having inherited a sickle cell gene from one parent. About 55 percent of these babies are African American, 40 percent are Hispanic, and 5 percent are either White, Native American, or Asian. Sickle cell trait is not a disease and most affected people do not have sickle cell disease symptoms. However, people with sickle cell trait can pass on the sickle cell gene to their children.

(h) Public and health care provider awareness about sickle cell disease is limited, particularly that sickle cell disease affects Hispanic populations, which is California's largest ethnic group. While national figures indicate that one in 10 persons with sickle cell disease is Hispanic, that rate may be higher in California, given the state's increasingly large numbers of residents claiming more than one race or ethnicity.

(i) There are advances in prolonging life expectancy for individuals with sickle cell disease. Recent national attention concerning sickle cell disease has been reported from the United States Assistant Secretary for Health, the United States Surgeon General, the United States Department of Health and Human Services Office of Minority Health, the federal Centers for Disease Control and Prevention, the National Academy of Sciences, the American Society of Hematology, and the federal Centers for Medicare and Medicaid Services. Despite the coverage, poor access to knowledgeable care and life-altering treatments has limited the impact of these advances for the majority of persons with sickle cell disease in the United States, and particularly those living in California.

(j) Because sickle cell disease is rare, specialty teams are required that can accurately diagnose, prevent, reduce, and treat sickle cell disease's multiorgan complications and acute episodes. The need for these expert sickle cell disease teams is increasing in California, especially since over 95 percent of children with sickle cell disease now live into adulthood.

(k) There is a shortage of sickle cell disease specialists and integrated comprehensive teams in California that provide the coordinated medical, social, educational, and behavioral health services that patients and community clinicians need. The sickle cell disease specialist shortage is most acute for adults with sickle cell disease. There are few hematologists trained and willing to care for California adults with sickle cell disease. As a result, the majority of adults with sickle cell disease are forced to obtain care in hospital emergency departments and other non-sickle cell disease specialty settings. In 2008, fewer than 500 of the estimated 3,000 California adults with sickle cell disease in California were followed in a comprehensive sickle cell disease center. Consequently, adults with sickle cell disease suffer from poor quality of life, and hospitals suffer from avoidably high sickle cell disease emergency room visits, hospitalizations and readmission rates, and costs. California's low outpatient Medi-Cal reimbursement rates, particularly for preventive services, contribute to these shortages.

(*l*) Community health workers and patient navigators strengthen sickle cell disease comprehensive specialty teams. They expand access to care by bridging cultural, linguistic, and geographic barriers, providing care coordination services, thereby helping to improve health outcomes. However, there are insufficient numbers of community health workers and patient navigators that are dedicated to serving Californians with sickle cell disease statewide, due to a lack of resources to support sickle cell disease and of community-based organizations that provide oversight, training, and accountability.

(m) A regional approach is recommended for rare disorder health care delivery and surveillance. Hemophilia, a blood disorder five times more rare than sickle cell disease, has been regionalized for health care delivery and surveillance for over two decades. Improvements in mortality, morbidity, and costs, as well as being

part of national surveillance systems, are benefits to getting care within the regional network.

(n) The lack of a robust and well-resourced sickle cell disease specialty care center network limits California's involvement in scientific advances and patient access to new and potentially better therapies. Clinical trials to test the safety and effectiveness of new sickle cell disease therapies are best conducted in sickle cell disease specialty care centers where patients are closely monitored by sickle cell disease expert clinicians who can rapidly and accurately monitor sickle cell disease complications.

(o) The State of California's current Medi-Cal managed care design is not structured to adequately address the ongoing health of individuals with rare complex disorders, such as sickle cell disease. Moreover, the Medi-Cal managed care system does not provide clinical trial sites for rare disorders. This reduces access to the many new sickle cell disease therapeutics in development for Californians.

(p) Given that the majority of individuals with sickle cell disease are Medi-Cal beneficiaries and that many expensive hospitalizations are avoidable, improving access to comprehensive outpatient sickle cell disease care, particularly for adults, is cost effective for the State of California.

(q) The California Sickle Cell State Action Plan was developed in 2018, combining input from over 50 sickle cell stakeholders representing patients, community-based organizations, clinicians, researchers, and policy and public health professionals. This action plan outlines long-term goals and strategies to improve health care systems and increase education and awareness about sickle cell disease and sickle cell trait in California.

SEC. 2. Section 125040 is added to the Health and Safety Code, immediately following Section 125035, to read:

125040. (a) The State Department of Public Health, in collaboration with the State Department of Health Care Services, shall establish a three-year sickle cell disease center pilot program. The pilot program shall do all of the following:

(1) Establish five sickle cell disease centers as special care centers.

(A) The ~~department~~ *departments* shall ensure that the centers meet standards and criteria similar to the special care centers certified by the California Children's Services Program, pursuant

to Article 5 (commencing with Section 123800) of Chapter 3 of Part 2.

(B) The ~~department~~ *departments* shall provide grants to establish the centers, and shall enter into contracts with nonprofit organizations and community-based organizations on a competitive basis to achieve the objectives of this section.

(C) The established centers shall link outpatient care to inpatient care, and provide coordinated, comprehensive, team-based medical, behavioral health, mental health, social support, and surveillance services to adults with sickle cell disease.

(D) The centers shall be established in the following counties:

(i) Los Angeles.

(ii) Madera.

~~(iii) Oakland.~~

(iii) Alameda

(iv) San Bernardino.

(v) San Diego.

(2) Foster outreach to individuals and families with sickle cell disease, and providers of medical, nursing, and social services that serve persons with sickle cell disease, to promote education and awareness of the disease and make available services to adults with sickle cell disease.

(3) Develop initiatives to build the State of California's medical workforce of clinicians who are knowledgeable about evidence-informed diagnosis and treatment of sickle cell disease.

(4) Enhance statewide surveillance of sickle cell disease to monitor incidence, prevalence, demographics, morbidity, health care utilization, and costs.

(b) This section shall remain in effect only until January 1, 2025, and as of that date is repealed.

SEC. 3. The sum of fifteen million dollars ($15,000,000) is hereby appropriated from the General Fund to the State Department of Public Health for purposes of implementing and administering the sickle cell disease center pilot program established in Section 125040 of the Health and Safety Code. The department may use the moneys to pay for the reasonable costs relating to the establishment and oversight of the pilot program, including administrative costs, outreach, building the sickle cell disease workforce, and enhanced sickle cell disease surveillance, as required by those provisions.

SEC. 4. This act is an urgency statute necessary for the immediate preservation of the public peace, health, or safety within the meaning of Article IV of the California Constitution and shall go into immediate effect. The facts constituting the necessity are:

Sickle cell disease is a painful, rare, complex, progressively debilitating, and potentially fatal inherited blood disorder. Sickle cell disease has suffered from inattention and inadequate resources in California, causing devastating personal and societal costs. Therefore, for purposes of improving the health and well-being of Californians with sickle cell disease, at the earliest possible date, it is necessary to establish a three-year sickle cell disease center pilot program, to establish five sickle cell disease centers as special care centers, and to implement these efforts as soon as practicable.

O