BILL ANALYSIS

H.B. 181
By: Johnson, Jarvis
Public Health
Committee Report (Unamended)

BACKGROUND AND PURPOSE

Texans with sickle cell disease (SCD) are often subjected to inadequate care in health care settings due to a lack of knowledge of their diagnosis. A recommendation by the National Institutes of Health called for a monitoring system to be implemented for sickle cell patients containing demographic, laboratory, clinical, treatment, and outcome information. Despite this recommendation, little progress has been made over the years toward implementing such a system in Texas. Some patients cannot access sickle cell clinics where the clinical data is primarily collected. Furthermore, administrative data is often unreliable as it contains miscoded patient information. This incomplete picture of SCD leaves thousands of Texans with inadequate health outcomes as a result. The exact number of people living with SCD is unknown because no existing data collection system is comparable to other national registries for diseases such as cancer and cystic fibrosis. The Department of State Health Services (DSHS) does not currently have an adequate monitoring system for individuals with SCD as they transition from adolescence into adulthood. The Sickle Cell Task Force recommended in their 2022 report that Texas should implement statewide sickle cell surveillance throughout the lifespan of sickle cell patients and that the registry access existing monitoring frameworks, improve upon them, and include the transition period from pediatric to adult care, as this transition period is where the most morbidity and mortality often occur. Lastly, the task force recommended that Texas enter the national conversation about sickle cell surveillance by sharing data with certain agencies and organizations leading SCD surveillance research. This effort will produce robust data for Texans who suffer from this debilitating disease and pave the way for a national understanding of what it means to live with SCD while improving health outcomes. H.B. 181 seeks to address these issues by requiring DSHS to establish and maintain a sickle cell registry.

CRIMINAL JUSTICE IMPACT

It is the committee's opinion that this bill does not expressly create a criminal offense, increase the punishment for an existing criminal offense or category of offenses, or change the eligibility of a person for community supervision, parole, or mandatory supervision.

RULEMAKING AUTHORITY

It is the committee's opinion that rulemaking authority is expressly granted to the executive commissioner of the Health and Human Services Commission in SECTION 1 of this bill.

ANALYSIS

H.B. 181 amends the Health and Safety Code to require the Department of State Health Services (DSHS) to establish and maintain a sickle cell disease registry for use as a single repository of accurate, complete records of sickle cell disease cases to aid in the cure and treatment of the disease in Texas. The bill requires the registry to include a record of sickle cell disease cases that occur in Texas, and any other information concerning such cases that the executive commissioner of the Health and Human Services Commission considers necessary and appropriate for the cure or treatment of the disease. The bill requires a health care facility,

defined by the bill as a licensed hospital or any other facility that provides diagnostic or treatment services to patients with sickle cell disease, to provide DSHS with data that DSHS considers necessary and appropriate concerning cases of sickle cell disease in a form and manner prescribed by DSHS.

H.B. 181 authorizes DSHS to do the following for purposes of implementing the bill's provisions:

- execute necessary contracts;
- receive data from health care facilities concerning sickle cell disease cases to record and analyze the data directly related to the disease; and
- compile and publish statistical and other studies derived from the data to provide in an accessible form information that is useful to physicians, other medical personnel, and the public.

The bill requires the executive commissioner to adopt rules as necessary to implement the bill's provisions and to develop by rule guidelines to obtain information from health care facilities regarding sickle cell disease cases, protect the confidentiality of individuals diagnosed with the disease, and ensure that the registry is developed in a manner consistent with the federal Health Insurance Portability and Accountability Act of 1996 and related regulations, and other applicable laws and regulations governing disclosure of health information.

H.B. 181 requires DSHS to submit an annual report to the legislature of information obtained under the bill's provisions and authorizes DSHS, in cooperation with other sickle cell disease reporting organizations and research institutions, to publish reports it determines are necessary to carry out the bill's purposes.

EFFECTIVE DATE

September 1, 2023.