BILL ANALYSIS

Senate Research Center
88R1925 SRA-D

H.B. 181
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Health & Human Services
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Engrossed

AUTHOR'S / SPONSOR'S STATEMENT OF INTENT

The exact number of people who live with sickle cell disease (SCD) is unknown because there is no national data collection system comparable to the National Program of Cancer Registries. Very little is known about adults with sickle cell because historically, sickle cell patients did not live well into adulthood as they do now. These issues exacerbate the knowledge gap about this disorder and substantiate the need to establish a registry in Texas. The National Institutes of Health published a statement in 2008 recommending that a surveillance system be implemented for sickle cell patients and that the monitoring system contain demographic, laboratory, clinical, treatment, and outcome information.

H.B. 181 would mandate that the Department of State Health Services forms a sickle cell registry. The Sickle Cell Task Force recommended in their report that Texas should implement statewide sickle cell surveillance throughout the lifespan of sickle cell patients. The Task Force also suggested that the registry access existing monitoring frameworks, improve upon them, and include the transition period from pediatric to adult care. This transition period is where the most morbidity and mortality occurs. Lastly, the Task Force recommended that Texas enter the national conversation about sickle cell surveillance by sharing data with the Centers for Disease Control, Sickle Cell Disease Association of America, Inc., and other agencies and organizations leading SCD surveillance research. This effort would not only produce robust data for Texans who suffer from this debilitating disease but would also add to the national picture of the overall burden of sickle cell disease.

H.B. 181 would help fill the gap of knowledge about how many people deal with SCD and its impact on their daily lives. In Texas, there is an incomplete picture of SCD. Clinical data is unsubstantial because they usually exclude a large number of sickle cell patients. Many patients do not have access to sickle cell clinics, where the clinical data is primarily collected. Administrative data is unreliable because most of this data contains miscoded information about patients.

H.B. 181 amends current law relating to the establishment of the sickle cell disease registry.

RULEMAKING AUTHORITY

Rulemaking authority is expressly granted to the executive commissioner of the Health and Human Services Commission in SECTION 1 (Section 52A.004, Health and Safety Code) of this bill.

SECTION BY SECTION ANALYSIS

SECTION 1. Amends Subtitle B, Title 2, Health and Safety Code, by adding Chapter 52A, as follows:

CHAPTER 52A. SICKLE CELL DISEASE REGISTRY

Sec. 52A.001. DEFINITION. Defines "health care facility."

Sec. 52A.002. REGISTRY; CONTENTS. (a) Requires the Department of State Health Services (DSHS) to establish and maintain a sickle cell disease registry in accordance

with this chapter for use as a single repository of accurate, complete records of cases of sickle cell disease to aid in the cure and treatment of sickle cell disease in this state.

(b) Requires that the sickle cell disease registry include:

(1) a record of cases of sickle cell disease that occur in this state; and

(2) any other information concerning cases of sickle cell disease that the executive commissioner of the Health and Human Services Commission (executive commissioner) considers necessary and appropriate for the cure or treatment of sickle cell disease.

Sec. 52A.003. DATA FROM HEALTH CARE FACILITIES. Requires a health care facility to provide to DSHS, in the form and manner prescribed by DSHS, data DSHS considers necessary and appropriate concerning cases of sickle cell disease.

Sec. 52A.004. DEPARTMENT POWERS; RULES. (a) Authorizes DSHS, to implement this chapter, to:

(1) execute necessary contracts;

(2) receive data from health care facilities concerning cases of sickle cell disease to record and analyze the data directly related to the disease; and

(3) compile and publish statistical and other studies derived from data obtained under this chapter to provide, in an accessible form, information that is useful to physicians, other medical personnel, and the public.

(b) Requires the executive commissioner to adopt rules as necessary to implement this chapter.

(c) Requires the executive commissioner by rule to develop guidelines to:

(1) obtain information from health care facilities regarding cases of sickle cell disease;

(2) protect the confidentiality of individuals diagnosed with sickle cell disease in accordance with Section 159.002 (Confidential Communications), Occupations Code; and

(3) ensure that the registry is developed in a manner consistent with:

(A) the Health Insurance Portability and Accountability Act of 1996 (Pub. L. No. 104-191);

(B) regulations adopted under that Act; and

(C) other applicable laws and regulations governing disclosure of health information.

Sec. 52A.005. REPORTS. (a) Requires DSHS to submit an annual report to the legislature of the information obtained under this chapter.

(b) Authorizes DSHS, in cooperation with other sickle cell disease reporting organizations and research institutions, to publish reports DSHS determines are necessary to carry out the purposes of this chapter.

SECTION 2. Requires the executive commissioner to adopt rules necessary to implement Chapter 52A, Health and Safety Code, as added by this Act, as soon as practicable after the effective date of this Act.

SECTION 3. Effective date: September 1, 2023.