BILL ANALYSIS

Senate Research Center 86R13699 EAS-D

H.B. 3405 By: Johnson, Jarvis et al. (Miles) Health & Human Services 5/2/2019 Engrossed

AUTHOR'S / SPONSOR'S STATEMENT OF INTENT

Sickle cell disease (SCD) results from a gene mutation that causes red blood cells to become fragile, break down rapidly, and change shape from a round disc to a sickle shape. SCD affects just over 100,000 Americans. That's less than 0.03 percent of the U.S. population. Moreover, the vast majority of the 100,000 Americans affected by SCD have been historically marginalized by the medical community and the American social conscious at large. SCD primarily affects people of color and as such, has not merited the same attention as other diseases which primarily affect white Americans.

Following the final report published by the Sickle Cell Advisory Committee and the committee's subsequent dissolution in 2018, H.B. 3405 would create the sickle cell task force. The task force would be charged with raising awareness of SCD, identifying and reporting on the effectiveness, feasibility of creation, continuation, implementation, and impact of SCD awareness campaigns outlined by the advisory committee, and carrying out recommendations made in the sickle cell advisory committee's final report as directed by the executive commissioner of the Health and Human Services Commission.

One overarching recommendation made by the sickle cell task force was based on the importance of awareness. The task force called for statewide awareness campaigns and the creation of Medicaid/Medicare managed care organization partnerships in order to raise awareness of SCD and treatment options available. Thus, the sickle cell task force will be charged with raising awareness of SCD and SCD treatment options.

Moreover, per the advisory committee's recommendation, the task force would be charged with implementing a statewide sickle cell surveillance mechanism implemented by the DSHS. The surveillance tool would be used to track the level of treatment offered to those with SCD from infant care through adulthood. The task force would also be charged with leveraging community health workers in order to better support those with SCD.

H.B. 3405 amends current law relating to the establishment of a sickle cell task force.

RULEMAKING AUTHORITY

This bill does not expressly grant any additional rulemaking authority to a state officer, institution, or agency.

SECTION BY SECTION ANALYSIS

SECTION 1. Amends Subtitle B, Title 2, Health and Safety Code, by adding Chapter 50, as follows:

CHAPTER 50. SICKLE CELL TASK FORCE

Sec. 50.001. ESTABLISHMENT OF TASK FORCE. Requires the executive commissioner of the Health and Human Services Commission (executive commissioner), in collaboration with the members appointed to the Newborn Screening Advisory Committee to represent the sickle cell community, to establish and maintain a task force to raise awareness of sickle cell disease and sickle cell trait.

Sec. 50.002. DUTIES. (a) Requires the task force to study and advise the Department of State Health Services on implementing the recommendations made in the 2018 Sickle Cell Advisory Committee Report published by the Sickle Cell Advisory Committee or any other report the executive commissioner determines is appropriate.

(b) Authorizes the executive commissioner to assign tasks to the task force to accomplish the purposes of this chapter.

Sec. 50.003. COMPOSITION OF TASK FORCE. Provides that the task force is composed of the following members appointed by the executive commissioner:

- (1) two members from community-based organizations with experience addressing the needs of individuals with sickle cell disease;
- (2) two physicians specializing in hematology;
- (3) two members of the public, each of whom either has sickle cell disease or is a parent of a person with sickle cell disease or trait; and
- (4) one representative of a health-related institution.

Sec. 50.004. ADMINISTRATIVE SUPPORT. Requires the executive commissioner to provide administrative support services at the request of the task force.

Sec. 50.005. PRESIDING OFFICER; MEETINGS. (a) Requires the task force to elect a presiding officer from among its membership.

- (b) Requires the task force to meet at the call of the presiding officer.
- (c) Requires the task force to hold its first meeting not later than December 1, 2019. Provides that this subsection expires September 1, 2021.

Sec. 50.006. COMPENSATION; REIMBURSEMENT; GIFTS, GRANTS, AND DONATIONS. Provides that a task force member is not entitled to compensation for service on the task force but is entitled to reimbursement for actual and necessary expenses incurred in performing task force duties. Authorizes the task force to accept gifts, grants, and donations to pay for those expenses.

Sec. 50.007. ANNUAL REPORT. Requires the task force, not later than December 1 of each year, to prepare and submit to the governor and the legislature an annual written report that summarizes the task force's work and includes any recommended actions or policy changes endorsed by the task force.

SECTION 2. Provides that the sickle cell task force is not required to comply with the reporting requirements under Section 50.007, Health and Safety Code, as added by this Act, until December 1, 2020.

SECTION 3. Effective date: September 1, 2019.