

By: Rose

H.B. No. 1481

A BILL TO BE ENTITLED

AN ACT

relating to sickle cell disease health care improvement and the sickle cell task force.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:

SECTION 1. Subchapter A, Chapter 533, Government Code, is amended by adding Section 533.0091 to read as follows:

Sec. 533.0091. SICKLE CELL DISEASE TREATMENT; HEALTH HOMES.

(a) In this section, "health home" means a primary care provider or, if appropriate, a specialty care provider, incorporating into patient care several features, including comprehensive care coordination, family-centered care, and data management, that are focused on improving outcome-based quality of care and increasing patient and provider satisfaction.

(b) The commission shall:

(1) in collaboration with the sickle cell task force established under Chapter 52, Health and Safety Code:

(A) ensure that health care services provided under a managed care plan to recipients diagnosed with sickle cell disease align with national clinical practice guidelines and protocols for sickle cell disease treatment;

(B) consider using sickle cell clinical evaluation and treatment guidelines, including those recommended by the American Society of Hematology or the Children's Hospital of Philadelphia; and

1                   (C) increase sickle cell disease education for  
2 Medicaid providers, including emergency room providers; and

3                   (2) use the commission's Texas Healthcare Learning  
4 Collaborative to identify opportunities for improving health  
5 outcomes of recipients diagnosed with sickle cell disease by:

6                   (A) reducing hospital admissions and  
7 readmissions; and

8                   (B) connecting those recipients to a sickle cell  
9 disease health home or sickle cell disease expert.

10                  (c) The commission shall establish one or more health homes  
11 in this state for recipients diagnosed with sickle cell disease to:

12                   (1) reduce barriers preventing recipients diagnosed  
13 with sickle cell disease from receiving necessary health care;

14                   (2) prevent unnecessary hospitalizations and  
15 vaso-occlusive crises;

16                   (3) avoid duplication of services; and

17                   (4) reduce costs associated with sickle cell disease  
18 treatment.

19                  (d) A health home established under this section must:

20                   (1) provide to a recipient diagnosed with sickle cell  
21 disease:

22                   (A) comprehensive care management;

23                   (B) care coordination;

24                   (C) health promotion;

25                   (D) comprehensive transitional and follow-up  
26 care;

27                   (E) patient and family support; and

1                    (F) referral to community and social support  
2 services; and

3                    (2) use the existing Medicaid managed care delivery  
4 system in a manner that avoids duplication of services and payment.

5            SECTION 2. Sections 52.0003 and 52.0007, Health and Safety  
6 Code, are amended to read as follows:

7            Sec. 52.0003. COMPOSITION OF TASK FORCE. The task force is  
8 composed of the following members appointed by the executive  
9 commissioner:

10                    (1) two members from community-based organizations  
11 with experience addressing the needs of individuals with sickle  
12 cell disease;

13                    (2) two physicians specializing in hematology;

14                    (3) two members of the public, each of whom either has  
15 sickle cell disease or is a parent of a person with sickle cell  
16 disease or trait; ~~and~~

17                    (4) one representative of a health-related  
18 institution;

19                    (5) one representative of the Texas Education Agency;  
20 and

21                    (6) one representative of the commission.

22            Sec. 52.0007. ANNUAL REPORT. (a) Not later than December 1  
23 of each year, the task force shall prepare and submit to the  
24 governor and the legislature an annual written report that  
25 summarizes the task force's work and includes any recommended  
26 actions or policy changes endorsed by the task force.

27                    (b) The task force shall, in collaboration with the

1 commission, include in the task force's annual report  
2 recommendations for improving sickle cell disease education for  
3 health care providers.

4 SECTION 3. Subtitle B, Title 2, Health and Safety Code, is  
5 amended by adding Chapter 52A to read as follows:

6 CHAPTER 52A. SICKLE CELL DISEASE CARE EDUCATION AND TREATMENT

7 Sec. 52A.001. DEFINITION. In this chapter, "sickle cell  
8 task force" means the sickle cell task force established under  
9 Chapter 52.

10 Sec. 52A.002. SICKLE CELL DISEASE SURVEILLANCE SYSTEM. (a)  
11 Using grant money awarded by the Centers for Disease Control and  
12 Prevention's Sickle Cell Data Collection Program, the department  
13 shall establish and maintain a voluntary sickle cell disease  
14 surveillance system to determine:

15 (1) the number of individuals with sickle cell disease  
16 in this state;

17 (2) the manner in which individuals with sickle cell  
18 disease use health care services; and

19 (3) health outcomes of individuals with sickle cell  
20 disease.

21 (b) The sickle cell disease surveillance system must  
22 include:

23 (1) a de-identified record of individuals diagnosed  
24 with sickle cell disease or sickle cell trait in this state; and

25 (2) any other de-identified information concerning  
26 cases of sickle cell disease or sickle cell trait that the  
27 department considers necessary and appropriate.

1        (c) An individual who is diagnosed with sickle cell disease  
2 or sickle cell trait may voluntarily register with the department  
3 for inclusion in the sickle cell disease surveillance system.

4        (d) After an individual registers with the department under  
5 Subsection (c), a health care facility or health care provider who  
6 treats the individual shall provide to the department, in the form  
7 and manner the department prescribes, data the department considers  
8 necessary and appropriate concerning cases of sickle cell disease.

9        (e) The executive commissioner by rule shall develop  
10 guidelines to:

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

13                (2) protect the confidentiality of individuals  
14 diagnosed with sickle cell disease in accordance with Section  
15 [159.002](#), Occupations Code; and

16                (3) ensure the sickle cell disease surveillance system  
17 is developed in a manner consistent with:

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

20                        (B) regulations adopted under that Act; and

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

23        (f) Information obtained under this section is confidential  
24 and privileged and:

25                (1) is not subject to disclosure under Chapter [552](#),  
26 Government Code;

27                (2) is not subject to subpoena or discovery or

otherwise compelled to be produced in any administrative, civil, criminal, or other proceeding; and

(3) may not be introduced into evidence in any administrative, civil, criminal, or other proceeding.

(g) The department may compile and publish statistical and other studies derived from de-identified data obtained under this chapter.

(h) The executive commissioner shall adopt rules necessary to implement this section.

Sec. 52A.003. TEXAS HEALTH SERVICE AUTHORITY EMERGENCY DEPARTMENT ENCOUNTER NOTIFICATIONS SYSTEM. The Texas Health Services Authority established under Chapter 182 shall collect and analyze clinical data and use the emergency department encounter notifications system to ensure an individual diagnosed with sickle cell disease is not incorrectly identified as an individual who misuses opioid drugs.

Sec. 52A.004. EMERGENCY AND PRIMARY CARE MEDICINE GRADUATE MEDICAL EDUCATION PROGRAM CURRICULUM. (a) In this section, "graduate medical education program" and "medical school" have the meanings assigned by Section 58A.001, Education Code.

(b) A medical school in this state that offers an emergency medicine, family medicine, or internal medicine residency program shall include in the curriculum requirements for the program education focused on sickle cell disease and sickle cell trait. The medical school may enter into agreements as necessary for the purposes of this section.

Sec. 52A.005. INFORMATION FOR PUBLIC SCHOOL DISTRICT

1 PERSONNEL. (a) The Texas Education Agency shall partner with  
2 sickle cell disease community-based organizations to provide  
3 information on sickle cell disease and sickle cell trait to public  
4 school districts and district staff, including school nurses,  
5 teachers, and coaches.

6 (b) The commission in collaboration with the sickle cell  
7 task force shall explore methods for improving sickle cell disease  
8 education and awareness within the public school system and provide  
9 recommendations to the Texas Education Agency on the improvement  
10 methods.

11 SECTION 4. (a) Not later than the second anniversary of the  
12 date the Health and Human Services Commission establishes a health  
13 home for Medicaid recipients diagnosed with sickle cell disease in  
14 accordance with Section 533.0091(c), Government Code, as added by  
15 this Act, the commission shall submit to the governor and the  
16 legislature a report on the effects of using a health home for those  
17 recipients, including:

- 18 (1) health outcomes of those recipients; and  
19 (2) cost savings to this state associated with sickle  
20 cell disease treatment.

21 (b) The Health and Human Services Commission may include the  
22 report required under Subsection (a) of this section with the  
23 annual report the sickle cell task force is required to submit under  
24 Section 52.0007, Health and Safety Code, as amended by this Act.

25 SECTION 5. As soon as practicable after the effective date  
26 of this Act, the executive commissioner of the Health and Human  
27 Services Commission shall:

1           (1) in accordance with Section 1945, Social Security  
2 Act (42 U.S.C. Section 1396w-4), seek from the appropriate federal  
3 agency an amendment to the state's Medicaid state plan to implement  
4 Section 533.0091, Government Code, as added by this Act, and the  
5 commission may delay implementing that section until the state plan  
6 amendment is approved;

7           (2) appoint the new members of the sickle cell task  
8 force as required by Section 52.0003, Health and Safety Code, as  
9 amended by this Act; and

10          (3) apply for a grant from the Centers for Disease  
11 Control and Prevention's Sickle Cell Data Collection Program to  
12 establish a voluntary sickle cell disease surveillance system under  
13 Section 52A.002, Health and Safety Code, as added by this Act.

14          SECTION 6. Section 52A.004, Health and Safety Code, as  
15 added by this Act, applies to residents entering an emergency  
16 medicine, family medicine, or internal residency program at a  
17 medical school in this state on or after January 1, 2024.

18          SECTION 7. This Act takes effect September 1, 2023.