

## **BILL ANALYSIS**

H.B. 3554  
By: Simmons  
Public Health  
Committee Report (Unamended)

### **BACKGROUND AND PURPOSE**

According to the National Organization for Rare Disorders, there are over 10,000 rare diseases that together affect more than 30 million Americans. The bill author has informed the committee that, with more than 10,000 known rare diseases, it is difficult for state policymakers and government officials to have an in-depth understanding of the needs of their rare disease community and that this lack of awareness contributes to common and harmful obstacles that rare disease patients face, such as delays in diagnosis, misdiagnosis, lack of treatment options, high out-of-pocket costs, and limited access to medical specialists. H.B. 3554 seeks to give the rare disease community a stronger voice in state government and bring stakeholders together on a regular basis to discuss and develop solutions to issues impacting a state's rare disease community by establishing the Texas Rare Disease Advisory Council.

### **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 this bill does not expressly grant any additional rulemaking authority to a state officer, department, agency, or institution.

### **ANALYSIS**

H.B. 3554 amends the Health and Safety Code to establish the Texas Rare Disease Advisory Council to advise the governor, state agencies, and private entities that provide health care services or other treatment to individuals diagnosed with rare diseases in Texas on strategies for improving health outcomes for those individuals. The bill defines "rare disease" as a disease, disorder, or condition that affects fewer than 200,000 individuals in the United States.

H.B. 3554 requires the Department of State Health Services (DSHS) to provide to the advisory council resources, personnel, and other administrative support as necessary for the council to carry out its duties under the bill's provisions. The bill sets out the composition of the 23-member advisory council as follows:

- the following 11 members appointed by the governor:
  - one representative of DSHS;
  - one representative of the Health and Human Services Commission;
  - one representative of the Texas Department of Insurance;
  - one representative of the Texas Education Agency;
  - one geneticist practicing in Texas;
  - one registered nurse or advanced practice registered nurse licensed and practicing in Texas with experience in treating rare diseases;

- one hospital administrator of a hospital in Texas that provides care to individuals diagnosed with a rare disease;
  - one pharmacist licensed and practicing in Texas with experience dispensing prescription drugs used in treating rare diseases;
  - one representative of the biotechnology industry;
  - one representative of a health insurance company; and
  - one physician licensed and practicing in Texas with experience in treating rare diseases;
- the following six members appointed by the lieutenant governor:
  - one representative of an academic research institution in Texas that receives grant funding for rare disease research;
  - one physician licensed and practicing in Texas with experience in treating rare diseases;
  - one individual who is 18 years of age or older and who is diagnosed with a rare disease;
  - two individuals who are, or previously served as, caregivers for an individual diagnosed with a rare disease; and
  - one representative of an organization that provides care or other support to individuals diagnosed with a rare disease in Texas; and
- the following six members appointed by the speaker of the house of representatives:
  - one representative of an academic research institution in Texas that receives grant funding for rare disease research;
  - one physician licensed and practicing in Texas with experience in treating rare diseases;
  - one individual who is 18 years of age or older and who is diagnosed with a rare disease;
  - two individuals who are, or previously served as, caregivers for an individual diagnosed with a rare disease; and
  - one representative of an organization that provides care or other support to individuals diagnosed with a rare disease in Texas.

The bill establishes that advisory council members serve staggered four-year terms, with the terms of one-half of the members, or as near to one-half as possible, expiring February 1 of each odd-numbered year and requires a vacancy on the advisory council to be filled for the unexpired term in the same manner as the original appointment.

H.B. 3554 requires the governor to annually select from among the advisory council members a presiding officer and an assistant presiding officer and requires the advisory council to meet at the call of the advisory council's presiding officer and on request by a majority of the advisory council members. A majority of the voting members of the advisory council constitutes a quorum. The bill authorizes a meeting conducted under the bill's provisions to be in person or by video conference call, as determined by the advisory council's presiding officer. The bill requires the advisory council to provide notice of upcoming advisory council meetings on the DSHS website.

H.B. 3554 requires the advisory council to do the following:

- consult with experts on rare diseases and solicit public comment to develop policy recommendations for improving the treatment of rare diseases in Texas;
- develop strategy recommendations for academic research institutions of higher education in Texas to facilitate continued research on rare diseases;
- develop strategy recommendations for health care providers to better recognize and diagnose rare diseases to improve patient treatment; and
- make recommendations to DSHS and other state agencies on matters affecting individuals diagnosed with a rare disease, including emergency preparedness and response resources for a pandemic or natural disaster.

The bill requires the advisory council to provide DSHS with those strategy recommendations for publication on the DSHS website.

H.B. 3554 requires the advisory council, not later than September 1 of each year, to prepare and submit to the governor and commissioner of state health services a report that includes a summary of the advisory council's activities for the preceding year and recommendations for legislative or other action on rare disease research and care. The advisory council must publish the report on the DSHS website. The bill makes statutory provisions relating to the duration of state agency advisory committees inapplicable to the advisory council.

H.B. 3554 requires the appropriate appointing authority, not later than December 1, 2025, to appoint the initial members to the advisory council as required by the bill's provisions with the initial members' terms expiring as follows:

- the terms of five members appointed by the governor, three members appointed by the lieutenant governor, and three members appointed by the speaker of the house of representatives expiring February 1, 2029, and
- the terms of six members appointed by the governor, three members appointed by the lieutenant governor, and three members appointed by the speaker of the house of representatives expiring February 1, 2031.

H.B. 3554 requires the advisory council to conduct its first meeting not later than January 1, 2026, and to submit the first report required under the bill's provisions not later than September 1, 2026.

#### **EFFECTIVE DATE**

September 1, 2025.