

**GREEN SHEET REDIGEST**

**HB 460**

**2021 Regular Session**

**Hollis**

**HEALTH/LDH: Establishes the Rare Disease Advisory Council within the Louisiana Department of Health**

-----

DIGEST

Proposed law provides for the creation of the Louisiana Rare Disease Advisory Council within the La. Dept. of Health to serve in a resource capacity to any public and private agency located in this state that provides services for a person who has been diagnosed with a rare disease.

Proposed law provides for the membership of the advisory council and requires, to the extent practicable, every organization or entity that provides a nomination to the advisory council to strive for diversity in the appointment on the basis of race, ethnicity, sex, professional or educational background, and geographic residency.

Proposed law provides that the advisory council shall hold its initial meeting no later than Oct. 1, 2021. Proposed law further provides that the council shall meet at least quarterly in a calendar year and at any other time necessary.

Proposed law provides that the council shall not have authority on any matter relating to the La. Dept. of Health or the Drug Utilization Review Board and provides that the board is not required to follow the recommendations of the advisory council.

Proposed law provides that nothing in proposed law requires the advisory council, the Drug Utilization Review Board, or any state agency to consult with a person on any matter or meet with any specific expert or stakeholder.

Proposed law provides that an advisory council member shall not receive any compensation for serving on the advisory council.

(Adds R.S. 36:259(B)(38) and R.S. 40:1122.1)

Summary of Amendments Adopted by Senate

Committee Amendments Proposed by Senate Committee on Health and Welfare to the reengrossed bill

1. Clarifies the placement of the advisory council within the La. Dept. of Health.
2. Makes technical changes.