

Subject Minnesota Rare Disease Advisory Council

Authors Reyer and others

Analyst Elisabeth Klarqvist

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Overview

In 2019, language was enacted requesting the University of Minnesota to establish an advisory council on rare diseases and providing for membership and duties of the advisory council. This bill amends that section to establish the Minnesota Rare Disease Advisory Council in statute, rather than requesting that it be established; provides that the advisory council is housed in the Council on Disability; reassigns authority to appoint advisory council members from the Board of Regents to the governor; authorizes the advisory council to appoint an executive director and hire staff; and modifies the duties of the advisory council.

Summary

Section	Description
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1	Minnesota Rare Disease Advisory Council.
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Amends § 137.68. Establishes the Minnesota Rare Disease Advisory Council in statute, rather than requesting that it be established by the University of Minnesota, and makes changes to provisions governing the membership, operations, and duties of the advisory council.

Subd. 1. Establishment. Renames the advisory council the Minnesota Rare Disease Advisory Council. Establishes the advisory council in statute, rather than requesting that the University of Minnesota establish the advisory council, and provides that the advisory council is housed in the Council on Disability.

Subd. 2. Membership. Reassigns authority to appoint public members to the advisory council from the Board of Regents or a designee to the governor, and allows the governor to appoint people with other areas of expertise as identified by the advisory council. Requires public members to reflect statewide representation. Allows members to be reappointed to the advisory council for additional terms according to the advisory council's operating procedures, and strikes obsolete language.

Section	Description
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Subd. 3. Meetings. Strikes obsolete language, and requires advisory council meetings and notices of meetings to comply with open meeting laws.

Subd. 3a. Chairperson; executive director; staff; executive committee. A new subd. 3a requires the advisory council to elect a chairperson and other necessary officers. Provides that the advisory council shall be governed by an executive committee, and allows the executive committee to appoint subcommittees and work groups. Requires the advisory council to appoint an executive director, and allows the executive director to employ and direct a staff.

Subd. 4. Duties. Modifies duties listed for the advisory council to include addressing problems faced by patients with rare diseases when changing health plans; identifying and addressing barriers faced by patients with a rare disease to obtaining care due to prior authorization requirements; recommending and implementing best practices to ensure health care providers are informed about recognizing and treating rare diseases; advising and consulting with the Department of Human Services; advising on and advancing policy initiatives at the state and federal levels; and receiving funds and issuing grants.

Subd. 5. Conflict of interest. Provides that advisory council members are subject to the advisory council's conflict of interest policy in its operating procedures, rather than the conflict of interest policy of the Board of Regents.

Subd. 6. Annual report. No changes.

This section is effective July 1, 2022.

2 **Appropriations.**

Provides that the unexpended balance of appropriations from the general fund to the Board of Regents for the advisory council on rare disease shall be under the control of the Minnesota Rare Disease Advisory Council and the Council on Disability.

This section is effective July 1, 2022.

3 **Revisor instruction.**

Directs the revisor of statutes to renumber the section establishing the Minnesota Rare Disease Advisory Council as Minnesota Statutes, section 256.4835, and to make necessary cross-reference changes consistent with the renumbering.

This section is effective July 1, 2022.



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