

ARIZONA STATE SENATE

Fifty-Fifth Legislature, First Regular Session

AMENDED FACT SHEET FOR S.B. 1680

newborn screening program; testing

<u>Purpose</u>

Requires the Newborn Screening Program (Program) to include all congenital disorders included on the Recommended Uniform Screening Panel (RUSP). Modifies Program fees, timeline and recommendation requirements.

Background

The Director of the Department of Health Services (DHS) must establish the Program to ensure the testing for and reporting of congenital disorders in newborns is conducted in an effective and efficient manner. The Director of DHS (Director) must establish a Newborn Screening Advisory Committee (Committee), composed of specified health care practitioners and agency representatives and directors, to provide annual recommendations and advice to DHS regarding tests that should be included in the Program. Any Committee recommendation must include a cost-benefit analysis. Further, the Director may establish, by rule, a fee that may be collected to operate the Program. The fee established by the Director may not exceed \$36 for the first specimen and hearing test (A.R.S. § 36-694).

The RUSP is a list of disorders that the Secretary of the U.S. Department of Health and Human Services (U.S. HHS) recommends for states to screen as part of their state universal newborn screening programs. Disorders on the RUSP are chosen based on evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder and the availability of effective treatments. It is recommended that every newborn be screened for all disorders on the RUSP. Although individual states ultimately determine what disorders to screen for, the RUSP establishes a standardized list of disorders recommended by the Secretary of the U.S. HHS (U.S. Health Resources and Services Administration).

There is no anticipated fiscal impact to the state General Fund associated with this legislation.

Provisions

- 1. Requires the Program to include all congenital disorders included on the RUSP adopted by the Secretary of the U.S. HHS for both core and secondary conditions.
- 2. Requires, beginning January 1, 2022, that disorders added to the core and secondary conditions lists of the RUSP be added to Arizona's Newborn Screening Panel (Panel) within two years.
- 3. Directs the Committee to provide annual recommendations on newborn screening best practices and emerging trends, rather than on tests to be included in the Program.

- 4. Removes prescribed Committee membership and the requirement that Committee recommendations include a cost-benefit analysis.
- 5. Requires the Director to present any change to the fee associated with the Program to the Joint Legislative Budget Committee for review.
- 6. Requires specified health insurers and the Arizona Heath Care Cost Containment System (AHCCCS) to update hospital rates to reflect changes in the Program fee within 60 days after DHS adjusts the fee.
- 7. Includes grants received by DHS in the Newborn Screening Program Fund.
- 8. Requires DHS to add spinal muscular atrophy and x-linked adrenoleukodystrophy to the Panel by January 1, 2022.
- 9. Requires DHS to add all remaining core and secondary conditions included on the RUSP as of January 1, 2022, to the Panel by January 1, 2024.
- 10. Contains a legislative intent clause.
- 11. Makes technical and conforming changes.
- 12. Becomes effective on the general effective date.

Amendments Adopted by Committee

- 1. Reinstates the requirement that the Director establish a Committee and directs the Committee to provide recommendations on newborn screening best practices and emerging trends.
- 2. Specifies that health insurers regulated by insurance statute must update hospital rates to reflect changes in the Program fee.
- 3. Requires AHCCCS to update hospital rates that include newborn screening to reflect Program fee changes for AHCCCS contractors.

Senate Action

HHS 2/18/21 DPA 7-0-1

Prepared by Senate Research February 19, 2021 CRS/JP/kja