RDLA Policy Primer:
Newborn Screening Policy Primer

Background:

Newborn screening is a critical public health program that facilitates the screening of babies for serious conditions for which early interventions or treatments are available. Early detection, diagnosis, and intervention can prevent death or disability. Each year, millions of babies in the U.S are routinely screened, using a few drops of blood from the newborn's heel. Newborn screening tests for certain genetic, endocrine, and metabolic disorders, as well as hearing loss and critical congenital heart defects. This testing takes place prior to discharge from the hospital or birthing center.

The Newborn Screening Saves Lives Act of 2007 became law (P.L. 110-204) on April 24, 2004 and facilitated federal guidelines in newborn screening, established grant programs for newborn screening education and outreach, and implemented coordination of follow up care. At the time of the legislation's passage, only 15 states and DC required newborns to be screened for 29 core conditions as recommended by the Health Resources and Services Administration/American College of Genetics' 2004 Report.

Among the infrastructure authorized by the federal legislation is the U.S Department of Health and Human Services Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) which meets regularly to provide national newborn screening system oversight and makes recommendations to the federal screening panel. The Recommended Uniform Screening Panel (RUSP) as of 2021 had 35 core conditions, with reporting of 26 secondary conditions.

Challenges:

While the ACHDNC makes recommendations of conditions to be added to the federal RUSP, implementation of screening programs vary widely by state, leading to disparate health outcomes. While some states screen for thirty diseases, other states screen for over sixty. Essentially, whether a newborn's potentially life-altering condition may be screened for and caught early enough to benefit from intervention, is dependent on the state in which the baby is born.

Policy recommendations:

The Newborn Screening Saves Lives Act governs newborn screening at the federal level. The federal newborn screening programs:

- Assist states in improving and expanding programs,
- Support parent and provider education,
- Ensure laboratory quality and community surveillance, and
- Facilitate adding conditions to the Recommended Uniform Screening Panel (RUSP).

The Newborn Screening Saves Lives Reauthorization Act of 2021 reauthorizes these critical existing federal programs, and will also:

- Reauthorize federal programs intended to support states' screening program enhancements, parent and healthcare provider educational resource expansion, primary care follow-up services improvements, and advancements in the science of newborn screening. These federal programs include funding to the Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH).
- Reauthorize the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, which provides national newborn screening system oversight and makes recommendations to Secretary of Health and Human Services as to conditions that should be included on the federal screening panel.

Resources:

https://www.cdc.gov/newbornscreening/index.html

https://everylifefoundation.org/wp-content/uploads/2019/07/NBSSLA-One-Sheet.pdf

https://everylifefoundation.org/newborn-screening/policy-background/

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