

BILL ANALYSIS

C.S.H.B. 790
By: Crownover
Public Health
Committee Report (Substituted)

BACKGROUND AND PURPOSE

Currently the Texas Department of State Health Services conducts newborn screening for phenylketonuria (PKU), heritable diseases and hypothyroidism. Texas screens newborns for eight disorders. Blood samples are collected on filter paper after pricking a newborn's heel within 48 hours of birth for seven of the disorders. The eighth disorder is newborn hearing screening which does not require a blood test. Two screenings are conducted – one at birth and another at the baby's two week check-up.

These disorders have no immediate visible effects on a baby, but unless detected and treated early, can cause physical problems, mental retardation and even death. There are currently no federal guidelines for newborn screening and the numbers of disorders for which newborns are screened varies by state.

The American College of Medical Genetics (ACMG) released recommendations ("Newborn Screening: Toward a Uniform Screening Panel and System") to the Health Resources and Services Administration (HRSA) in 2004. Since then, state legislatures have begun re-evaluating the number of disorders for which their state screens and exploring expansions of these screens.

Screening methodologies, including a Tandem Mass Spectrometry, would allow Texas to screen for the 29 disorders in the ACMG core panel. The substitute would expand newborn screening in Texas to protect the health and welfare of the state's newborns.

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

The substitute directs the Department of State Health Services (department) to conduct a study to determine the most cost effective method for conducting newborn screening. Obtain proposals or information on newborn screening and provide a cost comparison for the department to perform the newborn screening services to the costs of outsourcing screening to a private lab. In performing these duties the department may consult with:

- physician that is a clinical geneticist;
- physician that practices family medicine;
- pediatrician;
- a hospital representative;
- representative a nonprofit organization devoted to the prevention of birth defects; and
- a parent of a child that has been diagnosed with a genetic malady.

If the department determines that the department's performance of newborn screening services is more cost-effective, then the department shall obtain the methodologies, equipment, and hire the necessary employees to administer the newborn screening. If the department determines that outsourcing of newborn screening is more cost-effective, the department shall contract for the resources and services necessary to conduct newborn screening using a competitive procurement process.

The department shall review the newborn screening program to determine efficacy, cost effectiveness, and whether adjustments to the program are necessary to protect the welfare of the state's newborns and to maximize the number of screenings that may be conducted with the

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funding available for screening. The department shall file a report on the revised program with the Legislative Budget Board not later than September 1 of each even-numbered year.

The department may adjust the amounts charged for newborn screening fees, fees assessed for follow-up services, tracking confirmatory testing and diagnosis.

To the extent funding is available for newborn screening, the department shall require newborn screening tests to screen for disorders listed in the core uniform panel of the ACMG report or another report as determined by the department to provide more appropriate newborn screening guidelines.

EFFECTIVE DATE

September 1, 2005.

COMPARISON OF ORIGINAL TO SUBSTITUTE

The substitute adds, to the extent funding is available, the department could expand screening to the full number recommended by the ACMG report or another report with appropriate newborn screening guidelines. The substitute states that the department shall conduct a study to determine the most cost-effective method for administering newborn screening . The substitute also states that the department may consider input from stakeholders. The department shall file a report on revised screening program to the Legislative Budget Board each even numbered year. The substitute also allows for the department to adjust the fee for newborn screening to help follow-up aspects of the program. The date for implementing the newborn screening program has been extended. The substitute adds that department shall conduct a study to determine the most cost effective way of conducting new born screening.