# **BILL ANALYSIS**

Senate Research Center 79R17650 YDB-F C.S.H.B. 790 By: Crownover (Nelson) Health & Human Services 5/18/2005 Committee Report (Substituted)

## AUTHOR'S/SPONSOR'S STATEMENT OF INTENT

The Texas Department of State Health Services (DSHS) screens newborns for eight disorders. These disorders have no immediate visible effects on a baby, but unless detected and treated early, they 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.

In 2004, the American College of Medical Genetics (ACMG) released recommendations to the Health Resources and Services Administration concerning a uniform newborn screening panel. Several states have begun re-evaluating the number of disorders for which they screen and are exploring expansions of existing screening programs.

C.S.H.B. 790 requires the state to expand screening to the 29 disorders recommended by the ACMG, as funds become available. Additionally, C.S.H.B. 790 requires DSHS to conduct a study to determine the most cost-effective method for administering newborn screening, and it also allows DSHS to adjust the fee for newborn screening to facilitate follow-up aspects of the program.

## **RULEMAKING AUTHORITY**

Rulemaking authority is expressly granted to the executive commissioner of the Health and Human Services Commission in SECTION 2 (Section 33.004, Health and Safety Code) of this bill.

## SECTION BY SECTION ANALYSIS

[While the statutory reference in this bill is to the Texas Department of Health, the following amendments affect the Department of State Health Services, as the successor agency to the Texas Department of Health.]

SECTION 1. Amends the heading to Chapter 33, Health and Safety Code, to read as follows:

### CHAPTER 33. PHENYLKETONURIA, OTHER HERITABLE DISEASES, HYPOTHYROIDISM, AND CERTAIN OTHER DISORDERS

SECTION 2. Amends Subchapter A, Chapter 33, Health and Safety Code, by adding Section 33.004, as follows:

Sec. 33.004. STUDY ON NEWBORN SCREENING METHODOLOGY AND EQUIPMENT. (a) Requires the Texas Department of Health (department), not later than March 1, 2006, to conduct a certain study, determine certain disorders, and obtain certain proposals.

(a-1) Requires the department, not later than October 1, 2005, to review and study the National Newborn Screening and Genetics Resources Center's assessment of the screening program in this state. Authorizes the executive commissioner of the Health and Human Services Commission, based on the findings and recommendations in the assessment, to adopt rules for the department to implement a newborn screening program. Provides that in adopting rules for the newborn screening program, the department and the executive commissioner are authorized and required to take certain actions.

(a-2) Provides that this subsection and Subsection (a-1) expire January 1, 2007.

(b) Authorizes the department, in accordance with rules adopted by the executive commissioner of the Health and Human Services Commission, to implement a newborn screening program.

(b-1) Requires the department, not later than March 1, 2006, to file with the governor's office a written report of the results and conclusions of the study conducted by the department under Subsection (a). Provides that this subsection expires January 1, 2007.

(c) Requires the department, if the department determines under Subsection (a) that the department's performance of newborn screening services is nore cost-effective than outsourcing newborn screening, to obtain the use of screening methodologies, including tandem mass spectrometers, and hire the employees necessary to administer newborn screening under this chapter.

(d) Requires the department, if the department determines under Subsection (a) that outsourcing of newborn screening is more cost-effective, to contract for the resources and services necessary to conduct newborn screening using a competitive procurement process.

(e) Requires the department to periodically review the newborn screening program as revised under this section to determine the efficacy and cost-effectiveness of the program and determine whether adjustments to the program are necessary to protect the health and welfare of this state's newborns and to maximize the number of newborn screenings that may be conducted with the funding available for the screening.

(f) Authorizes the department to adjust the amounts charged for newborn screening fees, including fees assessed for follow-up services, tracking confirmatory testing, and diagnosis.

SECTION 3. Amends Section 33.011, Health and Safety Code, by amending Subsection (a) and adding Subsection (a-1), as follows:

(a) Requires the physician attending a newborn child or the person attending the delivery of a newborn child that is not attended by a physician to subject the child to screening tests approved by the department for phenylketonuria, other heritable diseases, hypothyroidism, and other disorders for which screening is required by the department.

(a-1) Requires the department, to the extent funding is available for the screening, to require newborn screening tests to screen for disorders listed in the core uniform panel of newborn screening conditions recommended in the 2005 report by the American College of Medical Genetics entitled "Newborn Screening: Toward a Uniform Screening Panel and System" or another report determined by the department to provide more appropriate newborn screening guidelines to protect the health and welfare of this state's newborns.

SECTION 4. Amends Section 33.014(a), Health and Safety Code, as follows:

(a) Provides that if, because of an analysis of a specimen submitted under Section 33.011, the department reasonably suspects that a newborn child may have phenylketonuria, another heritable disease, hypothyroidism, or another disorder for which the screening tests are required, the department is required to notify the person who submits the specimen that the results are abnormal and provide the test results to that person. Authorizes the department to notify certain persons that the results of the analysis are abnormal and recommend further testing when necessary.

SECTION 5. Amends Section 33.031(a), Health and Safety Code, as follows:

(a) Authorizes all newborn children and other individuals under 21 years of age who have been screened, have been found to be presumptively positive through the newborn screening program for phenylketonuria, other heritable diseases, hypothyroidism, or another disorder for which the screening tests are required, and may be financially eligible to be referred to the department's services program for children with special health care needs.

SECTION 6. Amends Section 33.032(a), Health and Safety Code, to authorize the department, within the limits of funds available for this purpose and in cooperation with the individual's physician, to provide services directly or through approved providers to individuals of any age who meet the eligibility criteria specified by board rules on the confirmation of a positive test for phenylketonuria, other heritable diseases, hypothyroidism, or another disorder for which the screening tests are required.

SECTION 7. Requires the department, not later than November 1, 2006, to implement the expanded newborn screening program using the most cost-effective methods as determined by the department under Section 33.004, Health and Safety Code, as added by this Act.

SECTION 8. Effective date: September 1, 2005.