

**LEGISLATIVE SERVICES AGENCY
OFFICE OF FISCAL AND MANAGEMENT ANALYSIS**

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FISCAL IMPACT STATEMENT

LS 6165
BILL NUMBER: SB 139

DATE PREPARED: Jan 8, 2002
BILL AMENDED:

SUBJECT: Birth Defects Registry.

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FUNDS AFFECTED: **GENERAL**
 DEDICATED
 FEDERAL

IMPACT: State

Summary of Legislation: This bill requires the State Department of Health to: (1) inform parents of children with birth problems about physicians and local community resources; (2) implement an education program to assist specified individuals in reporting birth problems; (3) review the birth records of a newborn with birth problems to verify the accuracy of the information; and (4) consult with specified persons to analyze collected birth problems data to implement policies concerning identification and prevention of birth problems. (The introduced version of this bill was prepared by the Health Finance Commission.)

Effective Date: July 1, 2002.

Explanation of State Expenditures: This bill requires the Department of Health (DOH) to inform parents of children with birth problems about physicians and community resources. The First Steps program rules require an extensive public awareness program and emphasize a focus on primary referral sources and physicians and hospitals. DOH believes this requirement can be accomplished with minimal cost.

The bill also requires the DOH to develop and implement an education program to assist hospitals, physicians, local health departments, and other health care providers to comply with the requirements of the Birth Problems Registry. The resources and rules of the First Steps program target these groups for the public awareness and "child find" activities of the program. These resources, located in each county, targeted to a slightly broader group of infants and toddlers, could potentially be utilized at minimal cost through a cooperative agreement with the DOH to improve reporting on the electronic birth certificate and subsequent reporting of developmental birth problems.

The bill requires the DOH to review the birth records of newborns reported to have birth problems to verify the accuracy of the information. Estimates of the size of the group that would require review vary from a low of 7,000 to a high estimate of 11,000. Low-birth weight infants (6,500) comprise the largest group of birth problems that are required to be reported. DOH estimates that approximately 9,000 cases would be reported

each year that would require a physical review. DOH estimates that each record would cost \$30 -\$40 to review. The DOH estimate would require \$270,000 to \$360,000 if DOH were the only agency to review records. Additionally local hospitals with reportable birth problems would be required to make records available for audit at some opportunity cost to the facility. The DOH also estimates that they would need to randomly sample an additional 9,000 records to identify missing cases. This would double the cost of the record review, and if data interfaces are available with other program reporting systems, may be duplicative.

First Steps targets this entire at-risk group and is required to perform “child find”, data collection regarding the number of infants and toddlers with disabilities, and evaluation and assessment, as well as the service coordination and provision of services. First Steps eligibility is based on a statement or report signed by a physician indicating that the child’s condition is likely to lead to a developmental delay. The child is required to have a multidisciplinary evaluation and assessment that includes a review of pertinent records for medical history and current health status. (Presumably, this would include a review of the newborn medical record.) Children can be considered eligible for First Steps from birth through two years of age and for risk factors that include:

- Limited maternal prenatal care
- Maternal prenatal substance abuse
- Severe prenatal complications
- Asphyxia
- Very low birth weight
- Small for Gestational Age
- Severe postnatal complications

Other conditions at birth or through age two that First Steps defines as having a high probability of developmental delay include:

- Chromosomal abnormalities or genetic disorders
- Neurological Disorders
- Congenital malformations
- Sensory impairment including hearing and vision
- Severe toxic exposure
- Severe infectious exposure
- Atypical Developmental Disorder

If the resources and requirements of the First Steps program were coordinated with the reporting and review requirements of the birth problems registry, the DOH may require fewer funds than estimated. First Steps reported cumulative child enrollment for services for the year ended March 31, 2001, as: age 0-1 year, 2,018; age 1-2 years, 3,901; and age 2-3 years, 5,458. A few additional children’s parents did not request services. First Steps reports provision of services to approximately 6% of the state’s age 0-3 population - this includes the assessment and evaluation. Dr. David Weaver, in testimony to the Health Finance Commission, stated that 1 in 20 (5%) of children born would have a birth defect. First Steps may already be reviewing many of these children’s medical records already.

The bill also requires DOH to consult with an epidemiologist with expertise regarding birth problems, academic institutions, advocacy groups, and health care providers to analyze birth problems data to develop intervention and prevention policies. DOH estimates this would require 1,000 hours of consulting time at \$50 per hour for an epidemiologist.

The DOH estimates \$500,000 in computer consulting and software development costs to develop electronic interfaces and edits with other databases in order to identify possible missing cases. Potential system

interfaces might involve the Children with Special Health Care Needs program, Newborn Screening, First Steps, Hoosier Healthwise, Maternal and Child Services, and the Women, Infants, and Children(WIC) program.

Background: The Department reports that the source of the data entered in the Birth Problems Registry is the electronic birth certificate submitted to the Department. The Department reports that the Birth Problems Registry would require an annual operating budget of \$300,000 to operate a “minimally competent birth problems registry”. The Department used \$127,000 of birth registry funds last year for programing expenses for the electronic birth certificate system to improve the reporting to the registry. Registry operating expenses for FY 2001 were approximately \$25,000. PL 93-2001 was enacted by the Legislature with the implementation contingent on the success of DOH in securing funding. The operating components of the bill were estimated to cost \$128,000 in FY 2002 and \$123,000 in FY 2003.

Explanation of State Revenues: *Background:* Currently, the Birth Problems Registry is totally funded by the fee revenue of \$2 collected for each birth certificate search. The Department collected \$66,700 in fees in FY 2001. An increase of \$1 in the fee charged for the Birth Problems Registry would raise an additional \$25,000 annually. This fee would need to be increased substantially in order to cover the entire cost of the expanded registry. Increases in the fees are performed under the Department’s rule-making authority. If the fees are not increased, funding from an alternative source would be needed. The Department is not required to implement the changes in the Birth Problems Registry required under PL. 93-2001 until funding is identified. The Department has applied for grant funding for the Birth Problems Registry expansion from the Centers for Disease Control (CDC). The three-year grant is anticipated not to exceed \$200,000 annually if the state is awarded the grant.

Explanation of Local Expenditures: If the DOH reviews 9,000 hospital charts of children indicated to have a reportable birth problem, county-owned hospitals would be required to make those records available to the Department personnel. The fiscal impact would be dependent upon the numbers of children born with reportable birth problems at individual facilities.

Explanation of Local Revenues:

State Agencies Affected: State Department of Health.

Local Agencies Affected: County-owned hospitals.

Information Sources: Marilyn Cage, Legislative Liaison for the Department of Health, (317) 233-2170; PL93-2001, Fiscal Note; First Steps Rules at 470 IAC 3.1-6-1; Statement of David Weaver, M.D., *Birth Defects Surveillance in Indiana*, Testimony to the Health Finance Commission on September 26, 2001; *2000 Annual Performance Report of Indiana’s Early Intervention System for Infants, Toddlers and Their Families*, Family and Social Services Administration; First Steps Web Page http://www.state.in.us/fssa/first_step/