House
Legislative
Analysis
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NEWBORN SCREENING TESTS: INCREASE FEES

Senate Bill 592 as passed by the Senate
First Analysis (6-17-99)

Sponsor: Sen. John J. H. Schwarz, M.D.
House Committee: Appropriations
Senate Committee: Health Policy (Discharged)

THE APPARENT PROBLEM:

The Public Health Code requires all newborn infants to be tested for seven specific metabolic diseases that cause mental or physical impairment, as well as for other treatable but otherwise disabling conditions as designated by the Department of Community Health. The laboratory work for the tests is performed by the department, and the program had been fully supported by fees in past years. A base price for the battery of tests is set by statute, but is adjusted annually to reflect the yearly change in the Detroit Consumer Price Index. The current base rate of $25 for the tests was set by Public Act 81 of 1992, and, with the yearly price increases due to inflation, the fee has risen to the current rate of $29.38.

According to information supplied by the House Fiscal Agency, the department is expecting a shortfall for fiscal year 1999-2000 due to declining birth rates and the need to upgrade the newborn screening process to implement more reliable and safer testing methodologies. In addition, it has been noted that there is a lack of program services in the state that address adult onset genetic diseases. It has therefore been proposed to increase the statutory base rate for the battery of newborn tests in order to raise the revenue necessary for the continuation of the newborn testing program, the needed program upgrades, and to develop programs and educational materials relating to adult onset genetic diseases.

THE CONTENT OF THE BILL:

The bill would amend the Public Health Code to increase the fee for the required blood tests performed on newborns from a base rate of $25 to a base rate of $39. As under current law, the fee would be adjusted annually to reflect the cumulative annual percentage change in the Detroit Consumer Price Index.

MCL 333.5431

BACKGROUND INFORMATION

Since 1965, the Public Health Code has required that newborn infants be tested for phenylketonuria (PKU), a rare disorder that can cause severe, irreversible brain damage. Tests for hypothyroidism, galactosemia, biotinidase deficiency, and maple syrup urine disease, along with tests for sickle cell anemia and "other treatable but otherwise disabling" conditions as designated by the Department of Community Health, were added in 1986 by Public Act 300. PKU occurs in one in 12,000 newborns, while one in 5,000 has hypothyroidism, one in 60,000 has galactosemia, one in 200,000 has maple syrup urine disease, one in about 70,000 has biotinidase, and one in 400 has sickle cell anemia. All of these diseases can cause mental impairment or death, and all are treatable.

A base fee for the battery of tests was placed in statute in 1987 by Public Act 14, and was subsequently raised to $25 by Public Act 81 of 1992. Public Act 81 also added testing for congenital adrenal hyperplasia (CAH), an inherited defect in which the body cannot properly synthesize a hormone produced by the adrenal glands, to the list of metabolic diseases for which testing is required. CAH occurs in about one of every 15,000 newborns, and can cause death within a matter of weeks after birth if not diagnosed and treated.

FISCAL IMPLICATIONS:

The current fee for the newborn testing program is $29.38 for the battery of seven tests. The fee is based on the statutory fee of $25 plus the annual inflationary adjustments since 1992 (the year that Public Act 81, which set the fee at $25, took effect). According to the House Fiscal Agency, assuming 125,000 births annually, the fee increase proposed by the bill is estimated to increase revenues from newborn screening tests by $1,202,500. (6-9-99)

ARGUMENTS:

For:

The newborn screening program has been in place for decades, and, at one time, was fully supported by the fees charged for the battery of required tests. However, according to information supplied by the Department of Community Health, the program has operated at a loss for several years. One of the main reasons contributing to the revenue deficit has been the state's declining birth rate; though there are fewer newborns to test, there are also fewer fees collected to cover certain fixed costs of the program.

In addition, to be in compliance with new national testing standards, the department must upgrade some laboratory equipment and supplies and change the reagent (materials that react to substances in the blood) used for some of the tests. Also, the department has contracts with medical management centers to provide follow-up services for those infants who test positive to any of the seven diseases (more than 1,400 infants and children so far with the numbers increasing each year); the fees paid to these centers have not been increased since 1987 and so are insufficient to cover the staffing needed to manage these cases.

According to the both the department and the House Fiscal Agency, the increase in the base fee for the tests should be adequate to fully support the program and also allow for the upgrades in laboratory equipment and testing methodologies needed to meet federal standards. The fee should be raised so that the program can be continued. The newborn screening program provides an easy and relatively inexpensive way to test for several serious and debilitating, but highly treatable, metabolic diseases. Though most of these diseases are relatively rare, all of them result in disabling conditions (primarily brain damage) or death if not diagnosed and treated early. Therefore, the cost/benefit ratio of preventive testing of newborn infants makes good public health sense and good fiscal sense.

For:

There appears to be a lack of program services to address adult onset genetic diseases. Recent developments in medical genetics have also shown a need for public education materials on the subject. Some people feel that a program addressing these concerns should be developed. The fee increase proposed by the bill would not only make the newborn screening program fully self-supporting again and provide for necessary upgrades, but it would also provide some revenue that could be used to expand the Hereditary Disorders Program to develop a program pertaining to adult onset genetic diseases consistent with initiatives from the federal Center for Disease Control, Office of Genetics and Disease Prevention. The revenue increase would also allow the development of informational materials that could be used to educate the general public regarding health and social issues related to advances in genetics.

POSITIONS:

The Department of Community Health strongly supports the bill. (6-15-99)

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■This analysis was prepared by nonpartisan House staff for use by House members in their deliberations, and does not constitute an official statement of legislative intent.