

Department of Legislative Services
Maryland General Assembly
2014 Session

FISCAL AND POLICY NOTE
Revised

Senate Bill 654
Finance

(Senator Middleton, *et al.*)

Health and Government Operations

Health - Down Syndrome - Required Information

This bill requires the Department of Health and Mental Hygiene (DHMH) to identify up-to-date, evidence-based, written information about Down syndrome. This information must be provided to health care facilities and providers, who may provide the information to expectant parents who receive a prenatal test result for Down syndrome and parents of a child diagnosed with Down syndrome.

Fiscal Summary

State Effect: DHMH expenditures increase minimally for translation services, as well as printing and mailing costs; however, DHMH advises these costs can be absorbed with existing budgeted resources. Revenues are not affected.

Local Effect: The bill does not affect local governmental finances.

Small Business Effect: None.

Analysis

Bill Summary: DHMH must identify up-to-date, evidence-based, written information about Down syndrome that:

- has been reviewed by medical experts and national and local Down syndrome organizations;
- is designed for use by an expectant parent who receives a prenatal test result for Down syndrome or a parent of a child who receives a diagnosis of Down syndrome;

- is culturally and linguistically appropriate for potential recipients of the information; and
- addresses physical, developmental, educational, and psychosocial outcomes; life expectancy; clinical course; and intellectual and functional development and treatment options for individuals with Down syndrome as well as includes contact information for national and local Down syndrome education and support programs and services, such as information hotlines, resource centers, and clearinghouses.

DHMH must provide this information to health care facilities and health care providers that provide prenatal care, postnatal care, or genetic counseling to expectant parents who receive a prenatal test result for Down syndrome and parents of a child diagnosed with Down syndrome. The information must be available on the DHMH website.

A health care facility or health care provider may provide, as culturally and linguistically appropriate, the information from DHMH to an expectant parent who receives a prenatal test result for Down syndrome or to the parent of a child diagnosed with Down syndrome.

Current Law/Background: No provision of law requires information to be given to expectant parents who receive a prenatal test result for Down syndrome or parents of a child diagnosed with Down syndrome.

The U.S. Centers for Disease Control and Prevention (CDC) define Down syndrome as a condition in which a person has an extra chromosome, which is almost always chromosome 21. The medical term for having an extra chromosome is “trisomy.” CDC reports that Down syndrome is the most common chromosomal condition diagnosed in the United States. Each year, about 6,000 babies are born with Down syndrome in the United States, which is approximately 1 in every 700 babies.

CDC further reports that there is a two-stage testing process to detect Down syndrome during a pregnancy. First, screening tests are done, which involve assessing the risk for Down syndrome based on maternal age, taking a blood test, and performing an ultrasound to look for Down syndrome signs in development. If a screening test detects a risk or an abnormality, diagnostic tests are then used to determine whether a baby may have Down syndrome. Diagnostic tests are more intrusive and are generally only done if the risk of Down syndrome is high and requested by the mother. After a baby is born, a doctor can sometimes tell by examining the baby, or the baby’s blood can be checked to test for the condition.

DHMH reports that, in 2013, 60 babies were born in the State with Down syndrome, and over the last five years, cases of Down syndrome have ranged from 51 to 113 with an average of 71 per year. DHMH further advises that this is likely an underestimate of the

true incidence since it only gets reports from birth hospitals and some children are diagnosed after their birth admission.

Additional Information

Prior Introductions: None.

Cross File: None.

Information Source(s): Department of Health and Mental Hygiene, U.S. Centers for Disease Control and Prevention, Department of Legislative Services

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