

Department of Legislative Services
 Maryland General Assembly
 2019 Session

FISCAL AND POLICY NOTE
 Third Reader - Revised

House Bill 761

(Delegate Patterson, *et al.*)

Health and Government Operations

Education, Health, and Environmental Affairs

Health – Sickle Cell Disease – Steering Committee and Services

This bill alters the membership of the Statewide Steering Committee on Services for Adults with Sickle Cell Disease and expands the intent of the Sickle Cell Anemia Subtitle within the Health-General Article to include providing resources for detecting sickle cell disease (SCD) and supporting individuals with SCD. The bill also authorizes the Maryland Department of Health (MDH), in consultation with the steering committee, to provide specified services related to SCD in the State. **The bill takes effect June 1, 2019.**

Fiscal Summary

State Effect: No effect in FY 2019. General fund expenditures increase by \$90,500 in FY 2020 for MDH to reestablish the steering committee and hire additional staff. Future year expenditures include funds to provide meaningful grant support to community-based organizations to support the additional services specified in the bill and fulfill the expanded intent of the subtitle. Revenues are not affected.

(in dollars)	FY 2020	FY 2021	FY 2022	FY 2023	FY 2024
Revenues	\$0	\$0	\$0	\$0	\$0
GF Expenditure	90,500	585,800	588,600	591,500	594,600
Net Effect	(\$90,500)	(\$585,800)	(\$588,600)	(\$591,500)	(\$594,600)

Note:() = decrease; GF = general funds; FF = federal funds; SF = special funds; - = indeterminate increase; (-) = indeterminate decrease

Local Effect: The bill is not anticipated to materially affect local government finances or operations.

Small Business Effect: None.

Analysis

Bill Summary:

Statewide Steering Committee on Services for Adults with Sickle Cell Disease

The bill repeals the requirement that the steering committee (1) include representatives of the Genetic Alliance and faith-based organizations and (2) seek grant funding to meet specified objectives. However, the steering committee must identify funding sources for implementing or supporting the actions, studies, policies, regulations, or laws recommended by the steering committee, including funding from State, federal, and local government and private sources.

Maryland Department of Health

MDH, in consultation with the steering committee, may provide services relating to SCD, including:

- educational programs on SCD for individuals, families, caregivers, health care providers, and others affected by the disease;
- social services support to individuals with SCD;
- testing;
- genetic counseling;
- assistance with any available reimbursement for medical expenses related to SCD;
- education and counseling services after the receipt of sickle cell trait test results from the State's newborn screening program; and
- any other programs or services that are necessary to decrease the use of acute care services by individuals who have SCD.

MDH must provide these services through community-based organizations to the extent practicable.

Current Law/Background: Generally, the intent of the Sickle Cell Anemia Subtitle within the Health-General Article is to educate parents and physicians regarding homozygous sickle cell anemia and to monitor each affected infant's health in that regard.

Statewide Steering Committee on Services for Adults with Sickle Cell Disease

Chapter 435 of 2007 established the Statewide Steering Committee on Services for Adults with Sickle Cell Disease to establish institutional and community partnerships and a statewide network of stakeholders who care for individuals with SCD. The steering

committee is also charged with educating individuals with SCD, the public, and health care providers about options for care of SCD in Maryland. The steering committee must seek grant funding to (1) develop and establish a case management system for adults with SCD; (2) establish an adult SCD day infusion center; (3) develop, implement, and lead a State comprehensive education and treatment program for adults with SCD; and (4) develop and implement a health care provider awareness and education campaign to increase provider awareness of health care disparities, community dynamics, cultural practice, behavioral and psychosocial issues, and the use of standardized treatment and emergency room protocols. The Prevention and Health Promotion Administration (PHPA) within MDH advises that the steering committee last met in 2008.

MDH advises that it discussed reconvening the steering committee with remaining members who still resided in Maryland in 2015. Those members felt the steering committee was not needed to address issues related to SCD at the time, and the steering committee was, therefore, not reconvened. MDH has subsequently committed to soliciting interested community and clinical members to participate on the steering committee and will request that the reconstituted committee identify areas of interest to examine.

Sickle Cell Anemia

Sickle cell anemia is a severe hereditary form of anemia in which a mutated form of hemoglobin distorts the red blood cells into a crescent shape at low oxygen levels. The sickle cells die early, which causes a constant shortage of red blood cells. When the cells travel through small blood vessels, they get stuck and clog the blood flow. This can cause pain and other serious problems such as infection, acute chest syndrome, and stroke.

[According to the U.S. Centers for Disease Control and Prevention \(CDC\)](#), sickle cell anemia affects approximately 100,000 Americans. Sickle cell anemia is particularly common among those whose ancestors came from sub-Saharan Africa, and the disease occurs among about 1 of every 365 Black or African American births.

In Maryland, all newborn babies are screened for SCD. Maryland has the lowest death rate in the United States among children with SCD.

Symptoms and complications are different for each person and can range from mild to severe. Treatment options are different for each person depending on the symptoms. CDC recommends that people with SCD should drink 8 to 10 glasses of water every day and eat healthy food. They should also not get too hot, too cold, or too tired, especially during physical activity.

Sickle Cell Testing in Maryland

MDH advises that the Laboratories Administration, Newborn & Childhood Screening Division provides congenital and hereditary screening for approximately 55 known serious medical disorders. The screening includes sickle cell trait and disease testing and identifies newborns that are “at risk” for potential disorders. Information is also provided on whether additional diagnostic testing is required.

MDH further advises that the Newborn & Childhood Screening Division historically provided testing services for sickle cell in adults. However, testing for adults ended in December 2018, as the laboratory only received approximately one sample per quarter. Notwithstanding, sickle cell test results are currently maintained by the State Public Health Laboratory. Reports are provided to the submitters of the request and can be provided to third parties such as local health departments upon written request and with the submitter’s express authorization.

State Expenditures: General fund expenditures increase by \$90,475 in fiscal 2020, which accounts for a 30-day start-up delay. This estimate reflects the cost of hiring one nursing program administrator to coordinate, staff, and participate in the steering committee; serve as a liaison between the steering committee and MDH; oversee strategic and operational planning for services to be provided by community-based organizations; and provide technical assistance for services expanded under the bill. It includes a salary, fringe benefits, one-time start-up costs, and ongoing operating expenses.

	<u>FY 2020</u>	<u>FY 2021</u>
New Position	1.0	–
Salary and Fringe Benefits	\$82,460	\$82,402
One-time Start-up Costs	4,890	0
Ongoing Expenses	3,125	3,425
Grants to Community-based Organizations	<u>0</u>	<u>500,000</u>
Total State Expenditures	\$90,475	\$585,827

Beginning in fiscal 2021, following the development of priorities and goals by the steering committee, expenditures increase to include \$500,000 annually to provide meaningful grant support for community-based organizations to provide the SCD services authorized under the bill and to fulfill the expanded intent of the subtitle. Oversight of the grants can be handled by steering committee support staff. This estimate reflects the amount of general fund support necessary to meaningfully implement the bill’s provisions. To the extent that private funding is available, general funds may be offset.

Future year expenditures reflect a full salary with annual increases and employee turnover and ongoing operating expenses, in addition to continued grant funding.

Additional Information

Prior Introductions: None.

Cross File: SB 600 (Senator Nathan-Pulliam) - Education, Health, and Environmental Affairs.

Information Source(s): Maryland Association of County Health Officers; Maryland Department of Health; Department of Legislative Services

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