Department of Legislative Services

Maryland General Assembly
2019 Session

FISCAL AND POLICY NOTE
First Reader

House Bill 761 (Delegate Patterson, *et al.*)
Health and Government Operations

Health - Sickle Cell Disease - Steering Committee, Services, Testing, and Funding (Sickle Cell Treatment Act of 2019)

This bill requires the Maryland Department of Health (MDH), in consultation with the Statewide Steering Committee on Services for Adults with Sickle Cell Disease, to provide specified services related to sickle cell disease (SCD) in the State. The membership and purpose of the steering committee is modified. The bill also requires a local health department (LHD) to provide SCD testing and counseling at no cost to any individual who is referred by specified health care practitioners. **The bill takes effect June 1, 2019.**

Fiscal Summary

State Effect: No effect in FY 2019. General fund expenditures increase by $190,500 in FY 2020 for MDH to reestablish the steering committee, hire additional staff, and conduct a study. Future year expenditures include additional staff and grants to community-based organizations to support additional services. Revenues are not affected.

(in dollars)	FY 2020	FY 2021	FY 2022	FY 2023	FY 2024
Revenues	$0	$0	$0	$0	$0
GF Expenditure	190,500	628,900	627,900	632,100	636,500
Net Effect	($190,500)	($628,900)	($627,900)	($632,100)	($636,500)

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

Local Effect: Potential significant operational and fiscal impact for LHDs, as discussed below. **This bill imposes a mandate on a unit of local government.**

Small Business Effect: None.

Analysis

Bill Summary: Generally, the bill expands the intent of the Sickle Cell Anemia Subtitle of the Health-General Article to include providing resources for detecting SCD and supporting individuals with SCD, in addition to the current intent 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

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. 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, must 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;
- establishing SCD infusion centers in the State;
- 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.

The Maryland Public Health Laboratory must provide an individual's sickle cell screening test results to any LHD or entity contracting with the LHD that is providing sickle cell services to the individual on request, with the individual's authorization. An LHD must notify an individual if any testing conducted by MDH is positive for SCD.

Current Law/Background:

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 LHDs upon written request and with the submitter's express authorization.

Sickle Cell Disease Infusion Centers

SCD infusion centers are designed to provide rapid and specialized care for SCD pain crises and function as alternatives to emergency departments (EDs). SCD-focused care delivered through infusion centers may reduce patient ED utilization and result in lower rates of hospitalization for adults with SCD pain crises.

In 2017, MDH reported the results of a study that reviewed adult SCD infusion center models and sought to provide a comparative analysis between the comprehensive care model and the multidisciplinary specialty clinic model in order to determine the feasibility of establishing additional adult SCD infusion centers in Maryland. Preliminary research and analysis of a select number of sickle cell centers in the United States suggested that a comprehensive infusion center with appropriately trained staff and wraparound services could improve care quality and reduce ED visits by nearly 50%. The report noted that the success of the infusion center model could be attributed to expedited pain management, knowledgeable staff who provide competent services, individualized treatment and patient treatment plans that address social service needs, and underlying behavioral self-care factors. However, the report concluded that an in-depth statistical analysis by a health economist would be necessary to further evaluate cost efficiency and quality concerns,

corroborate trends, and provide final recommendations about the feasibility of a new center.

State Expenditures: General fund expenditures increase by $190,475 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; provide oversight of and technical assistance for services required under the bill; and serve as a resource for LHDs. It includes a salary, fringe benefits, one-time start-up costs, and ongoing operating expenses. It also includes $100,000 in fiscal 2020 only for contractual services to perform an in-depth analysis of factors relevant to sickle cell infusion centers and provide recommendations for establishing infusion centers in the State. Expenses related to providing sickle cell lab test reports can be absorbed by the State Public Health Laboratory with existing resources.

	FY 2020	**FY 2021**
New Positions	1.0	0.5
Salaries and Fringe Benefits	$82,460	$117,536
One-time Start-up Costs	4,890	4,890
Ongoing Expenses	3,125	6,447
Contractual Services	100,000	0
Grants to Community-based Organizations	0	500,000
Total State Expenditures	**$190,475**	**$628,873**

Beginning in fiscal 2021, expenditures increase to include $500,000 annually in grants for community-based organizations to provide SCD services. PHPA estimates that grants will need to be provided to at least four organizations across the State in order to meet the bill's requirements. As a result, fiscal 2021 expenditures also reflect the hiring of one part-time (50%) health programs coordinator for administration of funding to community-based organizations, including grantee monitoring and site visits where applicable.

Future year expenditures reflect full salaries with annual increases and employee turnover and ongoing operating expenses.

This analysis does not include the cost of establishing SCD infusion centers in the State, as any decisions related to establishing additional SCD infusion centers will be based on the results of the study conducted by the health economist. Should the study indicate that the construction of additional centers is required, expenditures increase significantly.

Local Expenditures: The Maryland Association of County Health Officers (MACHO) advises that LHDs must hire additional staff to provide SCD testing and counseling at no

cost to any individual referred to the LHD by health care providers, notify a person whose test is positive, and provide specified services to individuals who have been identified as having SCD. MACHO estimates that the impact in each LHD depends on the size of the LHD and the population served. A small LHD would likely require a part-time (50%) community health nurse (CHN) and associated administrative support, while a medium LHD would need at least one full-time CHN and a part-time (50%) administrative support position. A larger LHD, MACHO estimates, would require one to two CHNs and one full-time administrative support position to operate the programs. All LHDs will also incur costs related to testing, equipment, and travel costs. While a specific estimate of the costs incurred by each size of LHD is not available at this time, total expenditures are likely to be significant.

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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