HB 851

Department of Legislative Services

Maryland General Assembly
2006 Session

FISCAL AND POLICY NOTE
Revised

House Bill 851 (Delegate Nathan-Pulliam, *et al.*)
Health and Government Operations Education, Health, and Environmental Affairs

Department of Health and Mental Hygiene - Adult Sickle Cell Anemia - Study

This bill requires the Department of Health and Mental Hygiene, consulting with the Office of Minority Health and Health Care Disparities and stakeholders, to report on adult sickle cell anemia in Maryland to specified legislative committees by December 1, 2006. The report must include recommendations on • improving the quality of care; • reducing the mortality rate of diagnosed adults; • assisting health care institutions without clinics; • the amount of general funds required to address the previous recommendations; and • any available funding sources.

The bill takes effect June 1, 2006 and terminates May 31, 2007.

Fiscal Summary

State Effect: General fund expenditures could increase by $24,400 in FY 2007 for DHMH to conduct the required research and write the required report due by December 1, 2006. No effect on revenues.

(in dollars)	FY 2007	FY 2008	FY 2009	FY 2010	FY 2011
Revenues	$0	$0	$0	$0	$0
GF Expenditure	24,400	0	0	0	0
Net Effect	($24,400)	$0	$0	$0	$0

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

Local Effect: None.

Small Business Effect: None.

Analysis

Current Law: The Office for Genetics and Children with Special Health Care Needs was created in March 2000 through the merger of the Office for Hereditary Disorders and The Children's Medical Services in the Department of Health and Mental Hygiene.

The office has two missions:

- to reduce death, illness, and disability from genetic disorders, birth defects, and chronic diseases and injuries and to improve the quality of life for these individuals; and
- to protect and promote the health of Maryland's children with special health care needs by assuring a family-centered, community-based, comprehensive, coordinated, and culturally appropriate system of special health care.

Chapter 443 of 2004 created the Office of Minority Health and Health Disparities within DHMH to advocate for the improvement of minority health care and help the Secretary of Health and Mental Hygiene identify, coordinate, and establish priorities for programs, services, and resources that the State should provide for minority health and health disparities issues. The office, among other duties, must obtain funding, and contingent upon the funding, provide grants to community-based organizations and historically black colleges and universities to conduct special research, demonstration, and evaluation projects for targeted at-risk racial and ethnic minority populations and support ongoing community-based programs designed to reduce or eliminate racial and ethnic health disparities and develop the criteria for awarding the grants.

By the fifteenth day of each regular session of the General Assembly, DHMH must submit an annual report on the office to the Governor and the General Assembly on: (1) the projects and services developed and funded by the office and the health care problems the grant funds are intended to ameliorate; and (2) any recommendations for administrative or legislative action it deems appropriate. It is the General Assembly's intent that the office be funded with federal and special funds.

Background: Sickle cell anemia is an inherited condition in which a person's red blood cells are shaped in the form of a sickle or crescent instead of being round. These sickle cells die prematurely and cannot easily flow through a person's body because of their shape. The cells can slow or block blood flow, and the oxygen the blood cells carry, to certain parts of the body.

Symptoms of the disease are: anemia, a shortage of red blood cells; periodic pain; swollen hands and feet, often accompanied by pain and fever; jaundice; frequent

infections; stunted growth; and vision problems. Sickle cell anemia can lead to a number of complications including stroke; acute chest syndrome (chest pain, fever, and difficulty breathing); organ damage, including damage to kidneys, liver, and spleen; blindness; and other complications, such as open sores and gallstones.

In the United States, sickle cell anemia primarily affects African Americans and Hispanics.

Since 1985, newborns in Maryland have been screened to identify babies with sickle cell disease and get them into a comprehensive care program coordinated by the Office for Genetics and Children with Special Health Care Needs before they reach three months old. However, there is not an organized program for adults.

According to the U.S. Census, approximately 4,000 African American adults in Maryland have sickle cell anemia. The Sickle Cell Center for Adults at Johns Hopkins is the only facility in Maryland dedicated to providing comprehensive services for individuals with sickle cell disease. Many adult patients are in poor health, with few adult patients able to hold a job, according to DHMH. Most patients have their care through Medicaid or Medicare. DHMH further advises that there are very few psychosocial support services available for these patients. The two currently operating sickle cell disease support groups are more oriented to children. An adult patient support group, The Sickle Cell Connection, has dwindled. Most adult sickle cell disease patients have a primary care provider but many do not receive regular specialty care. Pain management services are underutilized and some patients struggle with addiction to pain medications.

The office advises that it is interested in improving services for adult patients as the first birth cohort identified through newborn screening approaches 21 years old. The office supports a transition clinic for adolescents and young adults with sickle cell disease at Johns Hopkins. According to the office, this has been successful, but it is only practical for those living in the Baltimore Metro Area.

Massachusetts, New Jersey, and Pennsylvania have programs that provide services to adult sickle cell populations.

State Expenditures: General fund expenditures could increase by an estimated $24,370 in fiscal 2007, which accounts for the six months of expenditures due to the bill's June 1, 2006 effective date and the December 1, 2006 reporting deadline. This estimate reflects the cost of hiring a contractual coordinator of special programs to conduct research on the needs of the adult patient population with sickle cell disease and the providers who care for them, and to evaluate available resources. It includes a salary, fringe benefits, one-time start-up costs, and operating expenses.

Salary and Fringe Benefits	$18,460
Operating Expenses	5,910
Total FY 2007 State Expenditures	**$24,370**

Additional Information

Prior Introductions: None.

Cross File: None.

Information Source(s): Department of Health and Mental Hygiene; "Sickle cell anemia," MayoClinic.com; Department of Legislative Services

Fiscal Note History: First Reader - March 10, 2006
ncs/jr Revised - House Third Reader - March 28, 2006

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