Report of the Maryland Statewide Steering Committee on Services for Adults with Sickle Cell Disease: Executive Summary

Sickle Cell Disease (SCD) is a genetic blood disorder that affects more than 3,300 Marylanders. Over the past two decades, Maryland has made tremendous strides, through the use of comprehensive services, in *reducing mortality rates* and *improving the overall quality of life* for children and adolescents with SCD. Such comprehensive services, however, ***do not*** exist for many of Maryland's adults who are coping with SCD. The lack of comprehensive medical and social services for adults compromises their health and quality of life. Subsequently, it may lead to worse health outcomes and increased health care costs – the majority of which is financed by taxpayers. The Statewide Steering Committee on Services for Adults with Sickle Cell Disease was charged to address specific strategies and practices needed to facilitate the provision of comprehensive health care, help to improve the overall quality of life for adults with SCD, and reduce the public burden associated with health care costs for the uninsured and underinsured. In addressing the Committee's charge, issues surrounding access to care, reducing health care costs, health care services, and quality of life resources emerged.

The report is divided into five sections. The first provides an introduction to Sickle Cell Disease and the problem in providing services to adults with SCD. The second section reports on the committee charge, meetings, subcommittee formation, activities, and events. The third presents the issues surrounding the charge and reports findings of the committee's examination of these issues. The fourth section offers recommendations for continued improvement in services for adults with SCD. The final section concludes the report with recognition of the challenges involved and a request to continue its work as a Committee.

Summary of Committee Recommendations:

- Developing a statewide patient registry and identify a medical home for each patient
- Ensuring access to Medicaid or low cost private insurance
- Developing and promoting standard treatment protocols in emergency departments and other urgent care facilities
- Shifting resources toward comprehensive specialty care and preventive care models such as regional infusion centers
- Providing educational, employment, and psychosocial services to patients with SCD
- Increasing public awareness and education about sickle cell disease and sickle cell trait