



## Virginia Department of Planning and Budget **Economic Impact Analysis**

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**12 VAC 5-191 State Plan for the Children with Special Health Care Needs Program**  
**Virginia Department of Health**  
**Town Hall Action/Stage: 5664 / 9164**  
February 10, 2021

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### **Summary of the Proposed Amendments to Regulation**

As directed by legislation, the State Board of Health (Board) proposes to establish provisions for a new Adult Comprehensive Sickle Cell Clinic Network. The proposed text mostly mirrors the existing text for the current Pediatric Comprehensive Sickle Cell Clinic Network.

### **Background**

Sickle cell disease (SCD) is a group of inherited, lifelong blood disorders that affects the red blood cells. SCD affects every organ in the body. Complications include severe pain, stroke, acute chest syndrome, organ damage, and in some cases premature death.

Over the last several decades, pediatric care and medical advances have increased life expectancy for persons with SCD. However, according to the Virginia Department of Health (VDH), health care delivery systems and public health initiatives supporting the optimal transfer from pediatric to adult care have not kept pace with the growing adult population. Increased sickle cell-related mortality has been shown in 18-30 year olds, with the highest rate of acute care encounters and re-hospitalizations in this age group compared to the older group of patients who would be expected to have increased illness and complications due to advancing age.<sup>1</sup> VDH believes this demonstrates a need to improve the coordination of care and the transition of young adults with sickle cell from pediatric to adult medical care.

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<sup>1</sup> Source: VDH

Chapter 503 of the 2020 Acts of Assembly<sup>2</sup> mandates that the Board “adopt regulations to implement an adult and pediatric comprehensive sickle cell clinic network.” The current regulation already includes provisions for the Board to work with comprehensive pediatric sickle cell centers to assure early entry into care within the first several months of life to prevent life threatening conditions. This is the Pediatric Comprehensive Sickle Cell Clinic Network (pediatric network). The proposed action would add text to the regulation that mostly mirrors the existing text, but would apply to adults with SCD, and would enable the creation of an Adult Comprehensive Sickle Cell Clinic Network (adult network).

The proposed text describes the adult network as “a statewide group of clinics and subspecialty providers that provide comprehensive medical and support services that are collaborative, family centered, culturally competent, community based and outcome oriented for individuals age 18 and older living with sickle cell disease.” Further, the proposed text states that the adult network provides the following direct health care services and enabling services:

1. Multidisciplinary evaluation and treatment from a team of professionals that may include a physician, nurse, social worker, community health worker or patient navigator.
2. Partnering with pediatric sickle cell providers to help facilitate and coordinate the transition of adolescents and young adults with sickle cell disease from pediatric to adult care and services.
3. Assistance in linking patients with primary care practitioners, a medical home, and subspecialists.
4. Educational genetic counseling to explain the inheritance pattern of the variants of sickle cell disease and diagnostic studies to ensure the accurate diagnosis of sickle cell disease.
5. Patient and family education related to all aspects of the diagnosis consistent with cultural and language needs.
6. Collaborative care between primary and subspecialty care providers.
7. Information, referral, and partnership with community-based sickle cell support programs.
8. Promotion of peer or family support that may include postsecondary education and vocational assistance.
9. Training and technical assistance to educate community and health care providers about best practices and evidence-informed standards of care for individuals with sickle cell disease.

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<sup>2</sup> See <https://lis.virginia.gov/cgi-bin/legp604.exe?201+ful+CHAP0503>

10. Collection of surveillance data to monitor incidence, prevalence, demographics, morbidity, mortality, health care utilization, and costs in order to identify disease burden in the Commonwealth.

According to VDH, the short-term goal of the proposed regulatory change is the establishment of an adult network. The long-term goals are a reduction in the rate of emergency department visits for adults with sickle cell in the 18-30 age group, and an increase in the number of adults who continue into specialty care and establish a medical home with a specialty care provider.

### **Estimated Benefits and Costs**

VDH currently contracts with health care systems to run four regional centers for the pediatric network. Chapter 1289 from the 2020 Acts of Assembly includes \$305,000 annually for the adult network.<sup>3</sup> VDH would be responsible for overseeing the allocation of the \$305,000 to support the cost of implementing the proposed adult network through contracts for adult regional centers. The agency plans to issue a Request for Proposal for this purpose.

While VDH would oversee implementation of the proposed adult network through contracts with health care systems to create and run the regional centers, the health care systems would be responsible for operating the regional centers and the full associated costs beyond the allocated funds. The agency estimates that a total of \$2,471,891 annually would be required to fully staff four regional centers.<sup>4</sup> As currently occurs with the existing pediatric network, costs would be supported by health insurance, as well as sliding scale fees and other resources.<sup>5</sup>

VDH believes that the development of the adult network would substantively improve the care of adult sickle cell patients. In particular, it is expected to increase the likelihood of successful transfer of care from pediatric to adult providers. Improved care coordination within the clinic network can potentially decrease emergency room visits, hospitalizations and readmission rates. Thus, in addition to potentially improved health outcomes for adults with SCD, health care system costs may potentially decrease as well.

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<sup>3</sup> It is not included as a separate earmark, but VDH states that it is included as part of Item 301 – State Health Services. See <https://budget.lis.virginia.gov/item/2020/1/HB30/Chapter/1/301/>

<sup>4</sup> VDH's estimate is based on assuming that each regional center would employ one hematologist, one nurse practitioner, one nurse, and one social worker. See page six of the Agency Background Document for more detail. [https://townhall.virginia.gov/L/GetFile.cfm?File=58\5664\9164\AgencyStatement\\_VDH\\_9164\\_v2.pdf](https://townhall.virginia.gov/L/GetFile.cfm?File=58\5664\9164\AgencyStatement_VDH_9164_v2.pdf)

<sup>5</sup> Source: VDH

## **Businesses and Other Entities Affected**

The proposed regulation would affect people who have SCD, as well as health care systems and providers who deliver health care services to individuals living with SCD. There are approximately 4,909 individuals living with SCD in the Commonwealth.<sup>6</sup> VDH has indicated that four regional centers are anticipated for the adult network.

### **Small Businesses Affected:**

The proposed amendments would not likely adversely affect small businesses.

### **Localities<sup>7</sup> Affected<sup>8</sup>**

The proposed regulation would not likely create costs for local governments. Although the proposed adult network would likely have four regional centers intended to cover SCD patients throughout the Commonwealth, it is not yet known in which localities the regional centers would be located.

### **Projected Impact on Employment**

The proposal would likely increase total employment. VDH believes each of four adult regional centers would need to hire a hematologist, a nurse practitioner, a nurse, and a social worker, resulting in 16 additional jobs.

### **Effects on the Use and Value of Private Property**

If private health care systems are among the entities with which VDH contracts for the adult network, their values may increase with the associated increase in business. The proposal would not affect real estate development costs.

### **Legal Mandates**

**General:** The Department of Planning and Budget has analyzed the economic impact of this proposed regulation in accordance with § 2.2-4007.04 of the Code of Virginia (Code) and Executive Order 14 (as amended, July 16, 2018). Code § 2.2-4007.04 requires that such economic impact analyses determine the public benefits and costs of the proposed amendments. Further the report should include but not be limited to: (1) the projected number of businesses or other entities to whom the proposed regulatory action would apply, (2) the identity of any localities and types of businesses or other entities particularly affected, (3) the projected number of persons and employment positions to be affected, (4) the projected costs to affected businesses or entities to implement or comply with the regulation, and (5) the impact on the use and value of private property.

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<sup>6</sup> Ibid

<sup>7</sup> “Locality” can refer to either local governments or the locations in the Commonwealth where the activities relevant to the regulatory change are most likely to occur.

<sup>8</sup> § 2.2-4007.04 defines “particularly affected” as bearing disproportionate material impact.

**Adverse impacts:** Pursuant to Code § 2.2-4007.04(D): In the event this economic impact analysis reveals that the proposed regulation would have an adverse economic impact on businesses or would impose a significant adverse economic impact on a locality, business, or entity particularly affected, the Department of Planning and Budget shall advise the Joint Commission on Administrative Rules, the House Committee on Appropriations, and the Senate Committee on Finance within the 45-day period.

If the proposed regulatory action may have an adverse effect on small businesses, Code § 2.2-4007.04 requires that such economic impact analyses include: (1) an identification and estimate of the number of small businesses subject to the proposed regulation, (2) the projected reporting, recordkeeping, and other administrative costs required for small businesses to comply with the proposed regulation, including the type of professional skills necessary for preparing required reports and other documents, (3) a statement of the probable effect of the proposed regulation on affected small businesses, and (4) a description of any less intrusive or less costly alternative methods of achieving the purpose of the proposed regulation. Additionally, pursuant to Code § 2.2-4007.1, if there is a finding that a proposed regulation may have an adverse impact on small business, the Joint Commission on Administrative Rules shall be notified.