Expanding Access to Sickle Cell Disease Treatment in Virginia

POLICY OPTIONS IN BRIEF

Option: Request that VDH provide an update on the plan for the statewide SCD registry (Option 1, page 8).

Option: Provide funds to VDH to assess treatment, transition, mental health, and psychosocial support needs for patients at treatment centers (Option 2, page 23).

Option: Provide funds to VDH to assess transportation needs for patients at treatment centers (Option 3, page 24).

Option: Direct VDH to develop a plan to provide information on patients' sickle cell status for providers in the ED (Option 4, page 26).

Option: Direct BON and BOM to require unconscious bias and cultural competency training as a condition for licensure renewal (Option 5, page 27).

Option: Direct DMAS to report on the status of participation in Cell and Gene Therapy Access Model (Option 6, page 28).

Option: Direct DMAS develop a comprehensive SCD program (Option 7, page 29).

Option: Direct DMAS to determine feasibility of state participation in optional SCD benefit or Medicaid health homes for SCD. (Option 8, page 30).

FINDINGS IN BRIEF

VDH identifies and monitors cases of SCD in Virginia and is improving surveillance through a statewide registry
VDH programs effectively identify potential cases of SCD at birth, facilitate diagnostic testing and entry into care, and provide education and counseling for individuals with SCD and their families. Recent legislation addresses additional gaps in disease surveillance by requiring VDH to establish a statewide sickle cell disease registry.

SCD treatment centers provide access to specialized SCD care but lack capacity for needed treatment and support services
Most treatment centers receive state funding to cover a portion of the cost of providing support services for patients with SCD. State funds do not cover the full cost of these services nor the costs of treatment. Additional information is needed to understand the resources required to address unmet need at treatment centers.

Providers' lack of knowledge about SCD and bias about individuals with SCD can delay appropriate care
Emergency department providers may be unfamiliar with how to care for SCD patients, feel uncomfortable prescribing opioids, or perceive adults with SCD to have increased risk of substance abuse, despite evidence to the contrary. Delayed treatment may cause worse outcomes than if treatment were initiated in a timely manner.

Addressing cost and insurance barriers could improve treatment access for individuals with SCD
Patients with SCD may delay or avoid care, or discontinue treatment or medications, due to costs. Stakeholders also reported difficulties with insurers' utilization management processes, particularly when seeking approval for opioids and disease-modifying therapies. While Medicaid covers an array of services for eligible individuals with sickle cell disease, opportunities may exist to expand coverage and improve standardization of care across MCOs.

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