



Sickle Cell Disease Comprehensive Care Act (S. 721 / H.R. 5178)

FACT SHEET

REQUEST: Support the Sickle Cell Disease Comprehensive Care Act.

Affecting nearly 100,000 Americans, sickle cell disease (SCD) is an inherited, lifelong disorder, which results in patients' red blood cells becoming rigid and sickle-shaped causing them to block blood and oxygen flow to the body. Individuals with SCD are living longer but unfortunately, many receive uncoordinated, inconsistent care, leading to poor clinical outcomes, avoidable complications, low quality of life, and increased costs to the healthcare system. Improving access to high-quality outpatient care will improve quality of life for individuals with SCD and reduce costs associated with visits to the emergency department (ED) and inpatient hospital stays. At the University of Virginia, a program to coordinate care for those living with SCD reduced inpatient and/or observational admissions by 30 percent, readmissions by 46%, and total costs of care by 20%.¹

A Centers for Medicare & Medicaid Services (CMS) report found that approximately 50% of individuals in the U.S. with SCD are covered by Medicaid. The Sickle Cell Disease Comprehensive Care Act, which was found by the Congressional Budget Office to save \$4 million in the 10-year budget window, directs CMS to establish a SCD Health Home to improve access to comprehensive, high-quality, outpatient care, which will be available to Medicaid beneficiaries with SCD in states that submit a state plan amendment (SPA).

Key Components of the Legislation Include:

- ***Allowing states to submit a SPA to establish a Health Home for patients with SCD as the single qualifying condition.***
 - Health Homes are a proven care delivery model in Medicaid that have been used by states to improve quality, enhance care, and reduce unnecessary costs.
 - Congress has expanded this model several times already, including to cover children with complex medical conditions.
 - Other Health Home models covered Medicaid beneficiaries with two or more chronic conditions, one chronic condition at the risk of another, or a mental health need.
- ***Ensuring SCD patients have access to coordinated clinical, mental health, and ancillary services to address their physical, mental, and social needs.***
 - Services may be provided by a "designated provider," which may be a physician, a team of professionals linked to a designated provider, or a community health team.
 - Designated providers will provide comprehensive care management; care coordination, comprehensive transitional care from inpatient to other settings; patient and family support; and referral to community and social support services.
 - Individualized, comprehensive, patient-centered care plans will be developed for eligible Medicaid beneficiaries.
- ***States that opt to establish a SCD Health Home will receive federal medical assistance percentage (FMAP) equal to 90% for 8 fiscal quarters for providing medically necessary services to treat SCD patients cared for under the program.***

For additional information in the House, please contact:

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For additional information or to cosponsor the legislation in the Senate, please contact:

- Gloria Nunez in Senator Cory Booker's office at Gloria_Nunez@booker.senate.gov
- Meghan McCully in Senator Tim Scott's office at Meghan_McCully@scott.senate.gov

¹ <https://www.healthcareitnews.com/news/how-uva-healths-medicine-home-program-reduces-hospitalizations-and-readmissions>