

Sickle Cell Disease Partnership Releases Findings from Medicaid Survey

Survey of Medicaid Directors Provides Fresh Insights on the Critical Role Medicaid Plays in Helping Americans with Sickle Cell Disease

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(WASHINGTON, D.C.)

Today, the [Sickle Cell Disease Partnership](#) released new findings from its *Medicaid & Sickle Cell Disease Survey* conducted of current and former Medicaid directors, contributing fresh insights about how Medicaid provides access to care and treatment for Americans with Sickle Cell Disease (SCD). About half of the estimated 100,000+ Americans with SCD are enrolled in Medicaid.

SCD is a [rare, genetic blood disorder](#) that primarily affects Black and Latino individuals in the United States. Individuals with SCD start to have signs of the disease during the first year of life. Individuals with SCD can experience different complications, but many of the common ones are very serious, including recurring pain crises, infection, acute chest syndrome, lung problems, severe and chronic pain, and stroke.

The *Medicaid & Sickle Cell Disease Survey* is released to coincide with National Minority Health Month. This month is a time to raise awareness about the importance of improving the health of racial and ethnic minority communities and reducing health disparities. The Partnership's new survey of Medicaid directors provides unique and timely insights on:

- How Congress can incentivize state Medicaid programs to offer comprehensive, coordinated care to individuals with SCD by advancing and enacting *The Sickle Cell Disease Comprehensive Care Act*, H.R. 7432 / S.996.
- Opportunities for federal policymakers in Congress and CMS to tweak Medicaid program standards to strengthen access to care and treatment for Americans with SCD.
- How state Medicaid programs can ensure robust provider participation in Medicaid and how Medicaid P&T Committees can learn from the experience of individuals in their state with SCD.
- State Medicaid programs can leverage strategies to improve health equity, like partnering with state & local organizations that serve individuals with SCD.
- The CMS Innovation Center can keep collaborating with the community and key stakeholders and state Medicaid leaders as they plan to launch the Access Model

“This survey highlights many positive actions that Medicaid leaders at the federal and state levels can take to improve access to care and treatment for Americans with SCD; but unfortunately, it

also shows gaps in state and federal actions,” said Brett Giroir, M.D., Senior Advisor to the Sickle Cell Disease Partnership. “For too long, our nation’s efforts to address this painful, debilitating disease have been woefully inadequate, leaving patients and families behind – without access to high-quality care and without sufficient progress toward new treatments and cures,” Giroir said. He continues, “Sickle cell disease affects African Americans at a disproportionate rate, with one in 13 African Americans carrying the gene that causes sickle cell disease. As a matter of improving health equity and strengthening health outcomes, every policymaker with influence over the Medicaid program should care about the results of this survey.”

The survey comes at a time of heightened interest by policymakers about health equity and the Administration’s [announcement](#) that the CMS Innovation Center is “aiming for rolling launch dates with states joining the [Cell and Gene Therapy Access] model throughout 2025.” The Innovation Center has [published](#) both a Request for Applications for biopharmaceutical manufacturers and guidance for state Medicaid programs regarding a State Letter of Intent. It also comes on the heels of CMS recently publishing a new webpage on Medicaid.gov, “Improving Care for Sickle Cell Disease,” that collects the agency’s analysis and guidance respective to SCD and Medicaid.

The [Sickle Cell Disease Partnership](#) is a federal policy and advocacy alliance of health [care organizations](#) committed to advancing actionable federal health care policies that will improve the lives of patients living with [Sickle Cell Disease](#). The Partnership aspires to work collaboratively across the federal policy community to translate the recommendations of a [National Academies report](#) into legislative and administrative actions in Congress and the Executive Branch.

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