

EXECUTIVE SUMMARY

On April 23, 2024, 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 [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.

The Partnership's *Medicaid & Sickle Cell Disease Survey* includes qualitative perspectives from Medicaid directors on multiple aspects of sickle cell disease (SCD) and Medicaid. Key findings from the survey are below.

- 1. Medicaid Health Homes Are an Important Tool that Congress Should Tailor to Improve SCD Care.** Multiple respondents highlighted how a Medicaid Health Home model could be tailored to help ensure individuals with SCD get the services they need. Medicaid Health Homes providers will integrate and coordinate all primary, acute, behavioral health, and long-term services and supports to treat the whole person. As of [December 2023](#), about 20 states and the District of Columbia had [implemented](#) a total of 35 health home programs. CMS [found](#) that Health Homes reduced costs, improved quality and patient experience, and strengthened outcomes. Unfortunately, under current law, there are some limitations with regard to how individuals with SCD may be helped through a Medicaid Health Home.

Why It Matters: Survey respondents suggested adding SCD as a qualifying condition for Medicaid Health Homes and incentivizing states to create SCD-specific Health Homes. The Partnership strongly supports this approach and has endorsed bipartisan House legislation that would effectuate this approach.

[H.R.7432](#), *The Sickle Cell Disease Comprehensive Care Act*, sponsored by U.S. Reps. Burgess (R-TX, 26), Danny Davis (D-IL, 7), and Darren Soto (D-FL, 9) would incentivize state Medicaid

programs to establish a Health Home to provide comprehensive, coordinated care for individuals with SCD enrolled in Medicaid, regardless of whether or not the state has a Health Home for another condition.

- 2. Getting Medicaid Utilization Management Right Is Critical to Enable Care for Individuals with SCD.** A majority of current and former Medicaid directors responding to the survey said it is “very important” or “important” that state Medicaid programs adopt approaches to utilization management and that their Pharmacy and Therapeutics (P&T) committees consider the specific and unique clinical needs and personal preferences of individuals living with rare diseases such as SCD.

Why It Matters: Individuals living with SCD often say Medicaid utilization management protocols make it harder to access timely, quality care.

- 3. Lived Experiences from Individuals with SCD Is Important for P&T Committees, And Evidence Is Critical.** Most respondents said patient advocate testimony in P&T committee meetings is “strongly considered” or “considered” when making subsequent P&T decisions. Respondents also highlighted a need to combine personal experiences with data and evidence to build the “business case” for Medicaid programs.

Why It Matters: In many states, the Medicaid Pharmacy and Therapeutics Committee is responsible for reviewing information on specific drugs and helping determine the use of medications in Medicaid, including the development and maintenance of a Medicaid drug formulary (including placement of drugs on a Preferred Drug List and utilization controls.) However, P&T committees without an understanding of the medical realities of SCD and lived experience of individuals with SCD are less well-informed to make important decisions that impact access to treatments in Medicaid.

- 4. Robust Provider Participation in Medicaid Is Critical for Timely Access, Especially Access to Specialists.** Most respondents noted that the most prominent challenge to sufficient participation of clinicians to treat individuals with SCD are low Medicaid reimbursement rates for physicians, especially with respect to specialists. To address this, a majority of respondents identified the importance of (1) strategies to engage specific providers and the broader care system to address the challenge of timely access to care; and (2) using specific contractual requirements with managed care organizations (MCOs) as an important way to address concerns about low reimbursement rates and low provider participation.

Why It Matters: Research and the lived experience of individuals with SCD show that timely access to the range of clinicians needed to treat SCD is inconsistent and often not timely or adequate.

- 5. The [Cell and Gene Therapy Access Model on SCD](#) from the CMS Innovation Center Must Address Cost Considerations, Patient Input, and Coverage of Support Services.** The vast majority of respondents said it is “very important/important” that the Model include support

for medical follow-up care and ancillary services related to gene therapy treatment, as well as supportive social services to address needs like transportation, lodging, childcare, etc. A majority of respondents highlighted two dynamics that will be critical for success from a state Medicaid director perspective: (1) fundamental coverage and payment design considerations, and (2) the input of the SCD community of patients, families, community-based organizations, and providers in a state seeking to participate in such Model, including patient testimony on the costs associated with SCD treatment.

Why it Matters: The Access Model is a novel utilization of Innovation Center authorities to help improve access to gene therapies approved to treat SCD. CMS is accepting state Medicaid applications to participate in the model as soon as January 2025.

6. **Medicaid Programs Have Important Tools To Improve Health Equity.** A majority of respondents highlighted the importance of Medicaid managed care organizations in operationalizing opportunities to improve health equity and identified strategies to do so. A majority of respondents stressed the importance of partnerships with state and local organizations to improve health equity and identified related strategies to effectuate this priority.

