SICKLE CELL DISEASE PARTNERSHIP

Understanding the Value of Medicaid Coverage for Sickle Cell Disease

About Sickle Cell Disease (SCD)

SCD is a chronic, debilitating disease that is also the most common inherited blood disorder in the United States -- affecting approximately 100,000 Americans. This devastating condition requires comprehensive, lifelong medical care, with patients facing an average life expectancy more than 20 years shorter than the general population, and half of SCD patients dying before the age of 45.

What Happens in SCD?

The body produces abnormal hemoglobin – the protein in red blood cells that carries oxygen through the body. This causes red blood cells to become rigid and take on a crescent or "sickle" shape, unlike healthy, round red blood cells. These sickled cells:

- Die earlier than normal cells, causing a chronic shortage of red blood cells.
- Become sticky and hard, leading to blockages in blood vessels.
- Prevent proper oxygen delivery to the body's tissues and organs.

Health Complications

- Daily chronic pain
- Recurring and life-altering pain crises that occur when sickle cells block blood flow
- Organ and bone damage affecting the lungs, kidney, spleen, and brain
- Chronic anemia
- Increased risk of serious infections
- Acute chest syndrome, a life-threatening lung complication
- Leg ulcers
- Stroke
- Co-morbidities, including asthma and kidney disease

Medicaid's Role for the SCD Population

The Importance of Continuous Coverage

Continuous Medicaid coverage is crucial for managing SCD effectively:

- More than half of all individuals with SCD are Medicaid or CHIP enrollees, with approximately 52,524 Medicaid enrollees in 2021.
- About 49% of Medicaid enrollees with SCD have severe forms of the disease requiring more frequent medical care.
- Coverage disruptions put patients at significant risk: 30.4% of children experience interruptions or loss of Medicaid coverage in their first three years of life.
- When coverage is maintained, 98.3% receive needed outpatient visits, 59.3% receive necessary inpatient care, and 75.5% can access emergency services when crises occur.

Cost of Care Analysis

- Basic annual costs for Medicaid enrollees with SCD ($22,600) are more than double typical enrollees ($9,175).
- For severe cases, annual costs reach nearly $200,000, driven by emergency visits (averaging 25/year) and hospitalizations (averaging 9/year).
- SCD can be associated with $4-6 million in direct lifetime medical costs, not including patient-incurred costs.
- End-organ damage significantly increases costs -- patients with stroke incur costs 4.68 times higher than those without complications.
- Approximately 65 percent of individuals with SCD report resigning from a job/role due to the impacts of the disease.

Impact on Families and Cost Management

- Out-of-pocket costs are nearly 4x higher for individuals with SCD, averaging $44,000 over their lifetime.
- Annual out-of-pocket expenses can consume 5-10% of household income without adequate coverage.
- Patients with complications spend 56-62 days receiving care annually, severely limiting work opportunities and family income.
- Early intervention through consistent coverage is crucial -- Medicaid insures over 80% of children with SCD in their first three years, enabling vital preventive care

Health Care Utilization and Value

Coverage Impact and Care Management:

- Approximately 90% of Medicaid enrollees with SCD maintain coverage year-over-year, enabling crucial continuity of care and access to treatments and pain management.
  - The 10% of Medicaid enrollees with SCD who do not maintain coverage year-over-year is largely due to fluctuating eligibility determinations.
- Consistent coverage helps prevent costly emergency care -- without coverage, SCD patients often solely rely on emergency services, contributing to $2.4 billion in avoidable annual ED costs.

Emergency Care Patterns:

78% of Medicaid/CHIP enrollees with SCD had an emergency department visit in 2017, with 49% requiring at least one inpatient hospital stay.

30.4% of ED visits result in hospital admission.

SCD patients with organ damage spend 52-62 days receiving healthcare services annually, compared to 21-25 days for those without complications.

Integral SCD Programs in Medicaid

Medicaid provides several critical mechanisms to support individuals with SCD, demonstrating its essential role in ensuring comprehensive care and treatment access.

Cell & Gene Therapy (CGT) Access Model

This multi-year initiative (with program implementation beginning in 2025) allows CMS to directly negotiate with drug manufacturers for increased cost savings primarily through outcomes-based agreements between manufacturers and states who opt-in to the model, increases access to potentially transformative treatments, ties cost to therapy performance, and provides implementation and financial support to state Medicaid programs.

SCD Provider Toolkit

The toolkit focuses on strengthening the infrastructure across care settings to better enable care management and assist providers with supporting the needs of individuals with SCD. The toolkit includes six sections designed to equip providers in delivering quality SCD care across the care team, including information on screening and diagnosis, treatment options, the importance of comprehensive and managed care, the transition from pediatric to adult care, and payment and coverage information.

The SCD Partnership is a multi-sector policy and advocacy collaboration of patient advocates, health care providers, biopharmaceutical manufacturers, and other health care stakeholders committed to advancing policies that will improve the lives of those living with SCD.

To learn more, visit: www.sicklecellpartnership.org