



The Sickle Cell Treatment Act of 2003: The Law's Provisions and Opportunities for Advocacy

Introduction

The Sickle Cell Treatment Act of 2003 (SCTA) provides an important opportunity to work with federal and state policymakers to implement public policies that will ultimately lead to improved care and health outcomes for those living with sickle cell disease (SCD). As groups move forward to take action under this law, it will benefit these stakeholders to know what challenges to enhanced SCD services remain and what tools the SCTA includes to aid advocates working on this important issue. The SCTA includes three major provisions, described in the following sections.

Provision 1: New Optional Medicaid SCD Benefit

The new optional Medicaid benefit created by the SCTA clarifies that states can cover both primary and secondary preventative services related to SCD through Medicaid. Although states generally could have covered these services prior to the SCTA's enactment, the importance of the SCTA in this regard is that it both made it absolutely clear these services can be covered by state Medicaid programs and gives states additional flexibility around the services.

Provision 2: Medicaid Reimbursement for Education and Other Services Related to SCD Prevention and Treatment

The SCTA makes it clear that if public education campaigns are specifically targeted around individuals who have SCD or carry the sickle cell trait, the non-medical expenditures—including administrative expenses—associated with such campaigns can be reimbursed by the federal government under the standard Medicaid administrative matching rate of 50 percent (i.e., for every dollar spent on an SCD public education campaign, the federal government will reimburse a state 50 cents). Activities considered related to public education campaigns include services, such as genetic counseling, to find and educate individuals with SCD who are likely to be Medicaid eligible and education efforts targeted at these individuals related to prevention of SCD complications.

Provision 3: Creation of a National Coordinating Center: The Sickle Cell Disease Treatment Demonstration Program

The SCTA also authorizes the Sickle Cell Disease Treatment Demonstration Program which has as its goals increasing access to treatment for those with SCD, ensuring consumers and providers are better educated about SCD, and improving the coordination of services for those with SCD. To further these goals, the SCTA provides for the United States Department of Health and Human Services Health Resources and Services Administration (HRSA) to make grants to up to

40 eligible entities during each federal fiscal year (FFY) in which the program is conducted to aid in the development and creation of systems to improve SCD prevention and treatment.

In FFY 2010, HRSA also awarded a grant to National Initiative for Children's Healthcare Quality (NICHQ), in conjunction with Boston Medical Center and the Sickle Cell Disease Association of America (SCDAA) to serve as the National Coordinating Center (NCC) for the program. The aim of the NCC is to collect, coordinate, monitor, and distribute data, best practices, and findings from activities by the other program grantees. The NCC is also charged with the development of a model protocol for eligible entities and the development of educational materials on the prevention and treatment of SCD.

How the Bill Benefits the States

The SCTA adds a set of SCD-related services to the existing list of covered services for individuals who are currently eligible for Medicaid. Medicaid already covers most of the services in the bill under the regulations governing payment for physician services, prescribed drugs, and clinical services. However, in proposing the new SCD-specific package of services, the bill allows states to do the following:

1. Combine services to target specific needs of persons with SCD.
2. Offer additional services as part of the SCD package that might not be covered otherwise by Medicaid or, if covered, would be hard for the state to restrict coverage for narrow groups.
3. Use Medicaid money to work with providers to better serve areas with a high prevalence of SCD in fields such as education and counseling, which are currently not reimbursed by Medicaid.
4. Create opportunities for states and providers to partner to determine "best practices" such as the most effective and efficient use of medical resources toward SCD treatment and education.

Opportunities for Advocacy

As noted previously, the SCTA provides an important opportunity to work with federal and state policymakers to implement public policies that will ultimately lead to improved health outcomes for those living with SCD. Specifically, the first two provisions of the SCTA described above—the new optional Medicaid SCD benefit and Medicaid administrative reimbursement for SCD education initiatives—require action by states to ensure their potential to improve health outcomes for people with SCD becomes a reality. To date, neither has largely been implemented by state Medicaid programs. The third provision of the SCTA, establishing the Sickle Cell Disease Treatment Demonstration Program, has been implemented but could still benefit from sustained advocacy aimed at working with federal policymakers to ensure funding for the program is maintained and expanded over the coming years. Guidance on undertaking advocacy on these issues can be found in the policy brief on the SCTA produced by Community Catalyst with the SCDAA.