



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

### **Introduction**

The Sickle Cell Treatment Act (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). In 2003, Senators Jim Talent (R-MO) and Charles Schumer (D-NY) and Representatives Danny Davis (D-IL) and Richard Burr (R-NC) garnered bipartisan support for the SCTA, which was signed into law by President George W. Bush in 2004 as an amendment to the American Jobs Creation Act (Public Law Number 108-35). The SCTA was the first major legislative initiative in more than 30 years focused on SCD.<sup>1</sup> As groups move forward to take action under this law, it will benefit SCD stakeholders to understand the law's key provisions as well as to identify opportunities for advocacy created by the law that can lead to implementing policies that will improve health outcomes for individuals with SCD.

Approximately 90,000 to 100,000 individuals in the United States have SCD. The disease, an inherited blood disorder resulting in the production of abnormally shaped red blood cells, can produce a variety of medical complications including anemia, infection, pain, stroke and vision loss. SCD is much more common among Black or African-Americans and Hispanic-Americans in comparison to other demographic groups, occurring in 1 in 500 Black or African-American births and 1 in 36,000 Hispanic-American births, making treatment and education about SCD an important health equity issue.<sup>2</sup> While there is no cure for SCD, in the past few decades there have been significant improvements to life expectancy for individuals living with the disease as more effective treatments have become available. Individuals can now live into their forties or fifties, if not longer, and have productive lives if they receive proper care.<sup>3</sup>

Adequate research support for SCD and investment in high-quality care delivery systems have both been lacking.<sup>4</sup> Historically, other chronic childhood diseases (such as cystic fibrosis) that affect a smaller number of children than SCD have received greater federal support for research.<sup>5</sup> Health outcomes for individuals living with SCD have improved in recent generations, in part due to better disease modifying therapy and the more effective application of older treatments; more effective monitoring and prophylaxis; and, generally, better supportive care services. However, systemic tracking of care processes and outcomes does not occur, nor are there mechanisms to assure adoption of guidelines for treatment. Care for adults with SCD is

particularly fragmented. Increased access to treatments and high quality, coordinated services improve health outcomes.<sup>6</sup>

### **Provisions of the Sickle Cell Treatment Act of 2003**

The SCTA includes three major provisions. These are:

1. Creating a new, optional Medicaid benefit that explicitly allows states to increase reimbursement for SCD treatments including chronic blood transfusions and stroke prevention, in addition to adding genetic counseling and testing as reimbursable services.<sup>7</sup>
2. Making available Medicaid reimbursement (at the 50 percent federal administrative matching rate) for public education campaign activities specifically related to SCD.<sup>8</sup>
3. Authorizing the Sickle Cell Disease Treatment Demonstration Program to improve access to services for those with SCD in addition to improving and expanding patient and provider education around SCD.<sup>9</sup>

Each of these provisions is discussed in greater detail below.

#### **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 law's enactment, the SCTA both makes it absolutely clear that these services can be covered by state Medicaid programs and gives states additional flexibility around the services. For example, states can now reimburse providers for services aimed at treating SCD (such as transcranial Doppler studies and blood transfusions) at a higher rate than it would for pay for similar services aimed at treating other diseases.<sup>10</sup>

Missouri was one of the first states to implement the optional Medicaid benefit in 2007, effectively increasing access to a broader spectrum of services for individuals with SCD who receive coverage from Medicaid. In particular, Missouri's inclusion of SCD in its chronic care improvement program (CCIP) extended access to a variety of chronic disease management services to patients with SCD. Maryland convened a task force that encouraged legislators to add the optional benefit to their Medicaid programs but have not yet successfully implemented them.<sup>11</sup>

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

In general, Medicaid cannot be used to finance public education campaigns. However, 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 for half the cost). Activities that are considered related to public education campaigns include services, such as genetic screening and counseling, that will identify individuals with

SCD or sickle cell trait who are likely to be Medicaid eligible and provide them with information related to prevention of SCD complications. In creating a new service bundle, this provision allows organizations to conduct outreach with non-medical personnel to educate high-risk communities about SCD and carriers of sickle cell trait, providing new opportunities to include this population in a system of care. It also allows non-medical personnel, such as counselors, to spend time with sickle cell trait carriers and SCD patients and families to discuss disease management. This flexibility to fund SCD public education campaigns remains unique and specific to SCD. For other conditions, the Centers for Medicare & Medicaid Services (CMS) has made it clear that “Expenditures related to any public education campaigns not specific to SCD remain unallowable under Medicaid.”<sup>12</sup>

Under the bill, states could pay for outreach, counseling, and other non-medical services in a variety of ways. In one scenario, payment could resemble fee-for-service reimbursement for medical services. States might also designate certain entities to serve as contractors for the program and provide them a lump sum payment upfront. There are few federal constraints except that the activity must relate to Medicaid. Thus, it would not be permissible to use the Medicaid money to pay for public service announcements (PSAs) aimed at the general population rather than the Medicaid beneficiary population specifically.

### **Provision 3: Creation of a Demonstration Program to Establish Systematic Mechanisms for SCD Prevention and Treatment**

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 that 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 grants to be made by the United States Department of Health and Human Services (HHS) Health Resources and Services Administration (HRSA) during each federal fiscal year (FFY), to up to 40 eligible entities where the program is conducted to aid in the development and creation of systems to improve SCD prevention and treatment.<sup>13</sup> Selected entities may use their grant for purposes including education, treatment (including genetic counseling and testing), and enhancement of continuity of care for individuals with SCD. Grantee organizations may also use funds for training health professionals and identifying and securing additional federal funds to continue SCD treatment.

In FFY 2010, HRSA entered into a contract 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 program grantees. The NCC is also charged with the development of a model protocol for eligible entities with respect to the prevention and treatment of SCD.<sup>14</sup> You can find more information about the NCC by visiting [http://www.nichq.org/our\\_projects/sickle\\_cell\\_landing\\_page.html](http://www.nichq.org/our_projects/sickle_cell_landing_page.html).

### **How the Law 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 law under the regulations governing payment for physician services, prescribed drugs, and

clinical services. However, in proposing the new SCD-specific package of services, the law 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 otherwise covered by Medicaid or would be difficult for the state to restrict to the narrow group of SCD patients.
3. Use Medicaid money to conduct outreach, education and genetic counseling in areas with a high prevalence of SCD and sickle cell trait carriers, 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 a Result of the Sickle Cell Treatment Act of 2003**

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—the new optional Medicaid SCD benefit and Medicaid administrative reimbursement for SCD and sickle cell trait education initiatives—require action by states to ensure individuals with SCD and carriers of the trait are identified and those who qualify for medical assistance are connected to services. 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 to some extent, but could benefit from sustained advocacy aimed at working with federal policymakers to ensure funding for the program is maintained and expanded over the coming years.

Community Catalyst has established that six capacities successfully enable state advocacy organizations to move policy agendas forward. These six capacities are: (1) analyzing complex policy issues; (2) using media and other communications strategies to build timely public and political support; (3) developing and implementing campaigns; (4) building a strong grassroots base of support; (5) building and sustaining strong, broad-based coalitions; and (6) generating resources from diverse sources to support all of these activities.<sup>15</sup> These capacities are relevant to advocacy efforts related to the SCTA.

For instance, both the optional Medicaid benefit and the Medicaid reimbursement for public education to identify individuals with SCD and sickle cell trait require similar advocacy strategies that employ the capacities outlined above. The goal of advocacy around these Medicaid provisions is to have states add the optional Medicaid benefit to their Medicaid state plan through an amendment submitted to CMS for federal approval. This is the formal mechanism by which a state adds a new Medicaid benefit, and it is how states would develop and implement a public education plan around SCD.

**To achieve these goals, the first step should be to convene a coalition of interested and diverse stakeholders in a state.** Ideally, stakeholders with different but complementary strengths—such as grassroots organizing and decision-maker advocacy— should be part of the

coalition to ensure the coalition as a whole is as effective as possible. In the same vein, the coalition will be more persuasive with policymakers if it represents a broad group of stakeholders including, but not limited to, health and disease group advocates, businesses, payers, providers and faith-based organizations. Additionally, if the coalition is being convened in a state where there is also a grantee through Sickle Cell Disease Treatment Demonstration Program, or other groups with expertise in SCD, those organizations should be approached to bring their expertise to the coalition as well.

**This coalition would then need to educate itself about both SCD—its prevalence and complications—and the Medicaid SCD policies discussed above.** Of particular importance will be ensuring all members of the coalition understand the need to address issues around access to SCD treatments as well as how the Medicaid SCD policies will ultimately improve health outcomes for those living with SCD. Consensus around these issues among members of the coalition is essential. Given the high profile of Medicaid as a policy issue following the Supreme Court's ruling on the Affordable Care Act (ACA), coalition members should work to build their knowledge of the policy environment relevant to Medicaid in their state.

**Once the coalition has educated itself on the basic issues, it can develop a campaign aimed at educating state policymakers about these same issues.** The specific campaign plan developed by each state SCD Medicaid coalition should be tailored to the state's unique political environment. Generally, it will include brief policy papers, SCD Medicaid data and cost modeling (as is possible) to educate policymakers about the Medicaid SCD policies, and a communications strategy aimed at ensuring the arguments in the policy papers reach the right audiences as well as other strategies as necessary. Because so many states face challenging fiscal situations, campaigns can emphasize not only the number of individuals affected by SCD but also the current cost of care and the potential savings associated with more effective prevention and treatment.

**To proceed with advocacy on this issue at the federal level, the steps are similar to what has already been outlined above for the advocacy aimed at Medicaid SCD policies at the state level.** One advantage this federal effort has over the state effort at the outset is that participating organizations already likely have a strong base of knowledge about the issues involved. That said, those participating in this campaign should proceed in a very similar manner as the state Medicaid SCD coalitions. They should develop a campaign that includes a plan to create products that educate policy makers about the successes of the program and make the argument about why funding should be continued and even expanded. The plan should also include a communications strategy that identifies key policymakers to engage and develops messages that will be persuasive for that audience.

**It is important for participants in any Medicaid SCD coalition to consider that the most significant challenge they will likely face is concern by policymakers about the cost of implementing these policies.** This a greater concern for the Medicaid optional benefit—particularly if the coalition decides to advocate for the state to not only add the benefit but also to push for a higher Medicaid reimbursement for certain SCD services to increase their availability to individuals on Medicaid with SCD. However, SCD and sickle cell trait carrier outreach campaigns undertaken by state Medicaid programs will likely have at least some additional

expense associated with them. Given that increasing state Medicaid expenditures is always a challenging argument to make with policymakers, the coalition should specifically anticipate this concern and develop arguments to counter it as part of their campaign planning process. As a starting place, the coalition should develop—if possible—its own cost estimate of implementing these policies, which will increase its credibility with policymakers from the outset. Moreover, the coalition could explore the potential for additional funding streams—such as foundation monies or provider organization support—which would decrease the budget impact of a service and reimbursement increase.

**Another likely barrier in getting states to draw down Medicaid funding for SCD public education is the fact that, as explained above, Medicaid generally does not fund public education but is permitted to do so when it is related to SCD.** The coalition should clearly highlight that under SCTA, administrative activities related to outreach and education are reimbursable at the standard matching rate. These activities are directed to identify individuals with sickle cell disease or carriers of the gene who may qualify for medical assistance for treatment and prevention. Matching funds are also available for education of stroke risk factors and prevention of strokes for individuals who may qualify for medical assistance. The coalition should be prepared to explain clearly that the SCTA permits this type of activity. Citing and even providing a copy to policymakers of [State Medicaid Director Letter #05-003<sup>16</sup>](#), which explicitly states the position of CMS on this issue, will resolve any questions about the permissibility of using Medicaid funding for SCD public education.

Additionally, advocacy around the Sickle Cell Disease Treatment Demonstration Program—while distinct from the strategy discussed for the Medicaid provisions of the SCTA—is also important. The goal of this advocacy is to ensure funding for the program is at least sustained—and potentially expanded—through September 2015, when the grants made in 2010 are scheduled to end, and beyond. The SCTA authorizes grants to up to 40 organizations under the program and, given that only nine organizations are currently receiving grants, this means there is an opportunity to educate federal policymakers about the importance of ensuring the program is adequately funded to maximize its effectiveness in achieving its goal of facilitating the development and creation of systems to improve SCD prevention and treatment.

**Also similar to the state Medicaid SCD campaigns, although perhaps even more significant, is the challenge that organizations participating in the campaign will face as result of federal budget outlook.** For the foreseeable future, it is likely that the political environment at the federal level will be dominated by concerns about the federal deficit and debt and so any conversation about spending will need to take this into account to be successful. Given this reality, maintaining existing funding for the SCTA should be the first priority and an expansion of funding should only be addressed if a political window of opportunity opens where this becomes feasible. Advocates may find Congressional champions for sustained funding among Members who are on the Congressional Black Caucus or those still in office who supported the SCTA or the NIH Revitalization Act of 1993 (Public Law Number 103-43), stipulations of which aimed to increase minority representation in health care research.

## Conclusion

SCD is a serious health issue; more widespread public knowledge about the disease, increased

access to effective treatments, and better coordination of services for individuals with the disease will make a positive impact on health outcomes. Fortunately, the SCTA contains policy tools that can help with all of these. However, advocacy to ensure that each of these policies are implemented to the fullest extent possible is needed at the state level to turn the SCTA's potential into a reality for those living with SCD and to ensure the continued funding of these initiatives. This paper provides a starting point for those interested in helping to move this issue forward but it will take a sustained commitment to advocacy from a diverse range of stakeholders to make sure the SCTA fulfills its promise.

### About This Brief

The SCDA is the nation's leading lay advocacy organization for individuals with SCD. SCDA is acutely aware of the disparities in health care services across the lifespan for individuals with SCD, as well as the lack of comprehensive genetic counseling and public awareness. Through yearly advocacy on Capitol Hill, SCDA advocates for policies and programs that impact individuals and families affected by SCD.

The coordinating center for the grant, National Initiative for Children's Healthcare Quality and SCDA, engaged Community Catalyst, an organization with expertise in health care policy analysis and advocacy on the state and federal levels, to develop this brief. This paper aims to support that work through an explanation of the SCTA and a discussion of implementation challenges and opportunities. Moreover, this paper is intended to serve as a launching pad for grantees and SCDA member organizations to advocate for enhanced services and education, as outlined in the SCTA.

This work is funded by the Health Resources and Services Administration.

<sup>1</sup> Lauren A. Smith, Suzette O. Oyeku, Charles Homer, and Barry Zuckerman, "Sickle Cell Disease: A Question of Equity and Quality," *Pediatrics* 117 (2006): 1764. doi:10.1542/peds.2005-161.

<sup>2</sup> "Sickle Cell Disease: Data & Statistics," Centers for Disease Control and Prevention, accessed March 13, 2012, <http://www.cdc.gov/NCBDDD/sicklecell/data.html>.

<sup>3</sup> "What is Sickle Cell Anemia?," National Heart Lung and Blood Institute, accessed March 13, 2012, <http://www.nhlbi.nih.gov/health/health-topics/topics/sca/>.

<sup>4</sup> Lauren A. Smith, Suzette O. Oyeku, Charles Homer, and Barry Zuckerman, "Sickle Cell Disease: A Question of Equity and Quality," *Pediatrics* 117 (2006): 1764. doi:10.1542/peds.2005-161.

<sup>5</sup> Ibid, 1764-1765.

<sup>6</sup> Ibid, 1767.

<sup>7</sup> State Medicaid Director Letter #05-003, 1. <https://www.cms.gov/smdl/downloads/smd092905.pdf>.

<sup>8</sup> Ibid, 2.

<sup>9</sup> "Sickle Cell Disease Programs," Health Resources and Services Administration, accessed March 14, 2012, <http://mchb.hrsa.gov/programs/sicklecell/index.html>.

<sup>10</sup> State Medicaid Director Letter #05-003, 2.

<sup>11</sup> Maryland Statewide Steering Committee on Services for Adults with Sickle Cell Disease, *Expanding Comprehensive Services for Adults with Sickle Cell Disease* (Baltimore, MD: Maryland Department of Health and Mental Hygiene, 2008). 2-10.

<http://www.msa.md.gov/megafile/msa/speccol/sc5300/sc5339/000113/011000/011252/unrestricted/20090141e.rtf>.

<sup>12</sup> State Medicaid Director Letter #05-003, 2.

<sup>13</sup> State Medicaid Director Letter #05-003, 4.

<sup>14</sup> "Working to Improve Sickle Cell Healthcare," National Initiative for Children's Healthcare Quality, accessed March 9, 2012, [http://www.nichq.org/our\\_projects/treatment\\_demonstration.html](http://www.nichq.org/our_projects/treatment_demonstration.html).

<sup>15</sup> Community Catalyst, *Consumer Health Advocacy: A View from 16 States* (Boston MA: Community Catalyst, 2006), 16.

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[http://www.communitycatalyst.org/doc\\_store/publications/consumer\\_health\\_advocacy\\_a\\_view\\_from\\_16\\_states\\_oct\\_06.pdf](http://www.communitycatalyst.org/doc_store/publications/consumer_health_advocacy_a_view_from_16_states_oct_06.pdf).

<sup>16</sup> <https://www.cms.gov/smdl/downloads/smd092905.pdf>