# National Disability Rights Network
# October 2005 Q and A

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Question: I have a client who was recently diagnosed with sickle cell disease. I heard that Medicaid now provides coverage for treatment of sickle cell. Is that true? Can you explain the program to me?

Answer: In 2004, Congress passed and the President signed legislation creating a new optional Medicaid benefit for sickle cell disease. The legislation provides flexibility for states in covering blood transfusions, genetic counseling and testing and other treatments and services to individuals with sickle cell trait and sickle cell disease. Additionally, federal matching funds are available for education and outreach activities for those individuals who carry the sickle cell gene and may qualify for medical assistance.

## Background

Approximately 2.5 million people in the United States carry the sickle cell trait. Of those, about 70,000 have sickle cell disease. Sickle cell disease is most commonly found in African-Americans, though Latinos and individuals of Caribbean, Mediterranean and Middle Eastern descent are also known to have it. Between eight and ten percent of African-Americans carry the sickle cell trait.[1] In the United States, 1800 babies are born every year with sickle cell disease. Globally, 300,000 infants are born annually with the disease.

Sickle cell disease (SCD) is an inherited defect in blood that causes normally round blood cells to take on a sickle shape. Sickle-shaped blood cells clog the blood stream, creating obstructions that result in severe medical complications. Individuals with sickle cell disease are at risk for a number of health problems, including infections, acute lung problems, pulmonary disease and pulmonary hypertension, and kidney failure. Children with SCD can experience frequent pain episodes, during which time spleen enlargement and other life threatening complications can develop. Children with SCD are at increased risk for a stroke, which occur in thirty percent of children with SCD and can strike children as young as 18 months.

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[1] JEAN D. WILSON, HARRISON'S PRINCIPLES OF INTERNAL MEDICINE 1544 (12 ed. 1991). According to Senator Charles Schumer of New York, new immigration trends in New York, including rising immigration of individuals from West Africa, appear to be driving a sharp increase in sickle cell disease in many communities in the New York area. National Health Law Program, *Medicaid Act to Include Sickle Cell Disease*, HEALTH ADVOCATE, Fall 2004.

The disease can be detected in newborns through an inexpensive blood test. Currently, all fifty states and the District of Columbia require universal screening of newborns for sickle cell disease.[2]

Sickle cell disease, because of its complex nature, requires comprehensive as well as continuous care for children and adults. Necessary services include newborn screening, genetic counseling, and education of patients and their family members.[3] A preferred treatment for children with SCD is the use of prophylactic penicillin to prevent the onset of severe bacterial infections, which can result in increased sickling of red blood cells.[4] One of the most effective treatments for children and adults is the provision of monthly blood transfusions by which sickle blood cells are removed and replaced with normal blood cells.

**New Medicaid benefit**

On October 22, 2004, President Bush signed the American Jobs Creation Act of 2004,[5] which created a new optional Medicaid benefit for sickle cell disease. The statute, passed with significant bi-partisan support, amended Title XIX of the Social Security Act to provide the benefit and also make available federal matching funds for education and outreach to individuals with SCD who may be eligible for the Medicaid program. More recently, the Centers for Medicare & Medicaid Services (CMS) issued a Dear State Medicaid Director letter to inform states of the new provisions.[6] The September 29, 2005 letter explains what benefits are included and which administrative services will receive federal matching funds.

The statute defines medical assistance in the Medicaid program as including primary and secondary medical benefits for individuals who have SCD.[7] Those services include chronic blood transfusion (with deferoxamine chelation), genetic counseling and testing of individuals

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[2] National Newborn Screening and Genetics Resource Center, National Newborn Screening Status Report: U.S. National Screening Status Report Updated 10/21/05, *available at* http://genes-r-us.uthscsa.edu/nbsdisorders.pdf.

[3] Guidelines by the U.S. Department of Health and Human Services' Agency for Healthcare Research and Quality (formerly the Agency for Health Care Policy and Research) recommend screening of all newborns for sickle cell disease, administering protective doses of penicillin to ward off infection in infants whose initial test reveals presence of the disease, and improving genetic counseling for couples with the sickle cell trait. AHCPR Pub. No. 93-0562, April 1993.

[4] *See id.*

[5] Pub. L. No. 108-357.

[6] *See* CENTERS FOR MEDICARE AND MEDICAID SERVICES, Dear State Medicaid Director Letter SMDL #05-003, September 29, 2005.

[7] *See* 42 U.S.C. § 1396d(a)(27).

with SCD and sickle cell trait for treatment and prevention of symptoms of SCD, and other treatment and services to prevent individuals with SCD who have suffered from a stroke from having another one.[8]

In addition to health care services, the Act provides federal matching funds at a rate of fifty percent for identification and education of individuals who have SCD or sickle cell trait and are likely to be eligible for Medicaid.[9] This includes education on how to identify such individuals.[10] Funding is also available for educating those individuals about the risk of strokes and other complications and how they can prevent strokes and complications from developing.[11] According to the Dear State Medicaid Director Letter, administrative activities specified in the statute would have been permitted under the previous Medicaid statute.[12]

The Dear State Medicaid Director letter informs states that CMS has developed state plan preprint pages for new SCD optional benefits.[13] After they have completed the CMS clearance process, the regional offices will be able to distribute them to states.[14]

Part of the Act calls for the creation of demonstration projects to develop and establish mechanisms to improve prevention and treatment of Sickle Cell Disease.[15] These will include coordination of service delivery for individuals with SCD, genetic counseling and testing, and training of health professionals.[16] The Administrator of the demonstration project, through the Bureau of Primary Health Care and the Maternal and Child Health Bureau, will make grants to forty treatment centers and will contract with an entity to serve as the National Coordinating Center.[17] The statute includes annual appropriations of $10,000,000 for each fiscal year from

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[8] 42 U.S.C. § 1396d(x).

[9] 42 U.S.C. § 1396b(a)(3)(E).

[10] *Id.*

[11] *Id.*

[12] *See* CENTERS FOR MEDICARE AND MEDICAID SERVICES, Dear State Medicaid Director Letter SMDL #05-003, at 2.

[13] *See* CENTERS FOR MEDICARE AND MEDICAID SERVICES, Dear State Medicaid Director Letter SMDL #05-003, at 2.

[14] *Id.*

[15] 42 U.S.C. § 300b-1.

[16] *Id.*

[17] *Id.*

2005 through 2009 for the treatment centers and National Coordinating Center.[18]

**Analysis**

The new Medicaid benefit is significant because of the federal matching funds it makes available to states for services to identify and treat sickle cell disease. While all states require universal screening of newborns for sickle cell disease, it is not clear what funds they use to cover the testing. The legislation, as described above, indicates that Medicaid benefits may include genetic counseling and testing of those with sickle cell disease or sickle cell trait, but it says nothing about testing of individuals who are not already identified as having the disease or trait.

While the legislation does not describe services for individuals who have not yet been identified as carriers of sickle cell disease or sickle cell trait, Medicaid already covers them for many adults and children. In fact, the Act itself states

> [n]othing in subsections (a)(27) or (x) of section 1905 of the Social Security Act . . . shall be construed as implying that a State Medicaid program under title XIX of such Act could not have treated, prior to the date of enactment of this Act, any of the primary and secondary medical strategies and treatment and services described in such subsections as medical assistance under such program, including as early and periodic screening, diagnostic, and treatment services under section 1905(r) of such Act.[19]

Services to treat sickle cell disease or prevent the onset of symptoms, including provision of blood transfusions, can be currently covered as federally-mandated Medicaid services if offered as a hospital inpatient or outpatient service, a service provided by a federally-qualified health center or a physician service. Additionally, the provision of prescription drugs, like prophylactic doses of penicillin, or case management services can already be offered to Medicaid-enrolled children through the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) Program. While states have the option of covering either service for adults, they are required to cover them for children enrolled in Medicaid.

In terms of administrative activities, the legislation does make federal matching funds available for outreach and education services for sickle cell disease. The Dear State Medicaid Director letter authorizes public education activities "performed specifically with respect to SCD," allowing services to identify and educate individuals who have sickle cell disease or sickle cell trait and are likely to qualify for Medicaid. However, it goes on to say that public education campaigns not specific to SCD are not allowed under Medicaid. This statement appears at odds

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[18] *Id.*

[19] *See* 42 U.S.C. § 1396d(a)(2).

with other guidance provided by CMS in the past.[20] While the letter explains the new opportunities for states to conduct outreach on sickle cell disease, it should not be allowed to close the door on past or present activities to provide health education to Medicaid-enrolled individuals about Medicaid-covered services for other health conditions.

**Advocacy Tips**

There are several activities advocates can undertake to ensure their state's success in implementing the new legislation. Advocates can and should find out whether their states will provide the new optional benefit. If their state plans to make additional benefits available to individuals with sickle cell disease, advocates should offer input on how those services are provided and how outreach and education can be effectively performed. Many states have treatment and educational programs in place to prevent and treat sickle cell disease. Advocates should work with state officials to see if Medicaid funding is available for services provided in those programs.[21] Additionally, advocates can work with community-based organizations to inform local groups and individuals about the new benefit. As advocates already do, they should inform individuals about how they can apply for Medicaid benefits and obtain medically necessary services to treat sickle cell disease and even prevent onset of symptoms.

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[20] *See* HEALTH CARE FINANCING ADMINISTRATION, CHILD CARE AND MEDICAID: PARTNERS FOR HEALTHY CHILDREN– A GUIDE FOR CHILD CARE PROGRAMS (June 1998)(stating that Medicaid will reimburse at the administrative rate health education campaigns and health fairs if they are targeted specifically to Medicaid services for Medicaid-eligible children). *See also* Letter from Arthur J. O'Leary, Associate Regional Administrator, HCFA Region II, to Sue Kelly, Deputy Commissioner, New York Division of Health and Long Term Care (Dec. 1994); Letter from Sally K. Richardson, Director, Health Care Financing Administration, to State Medicaid Directors (Dec. 10, 1994); Letter from S.V. Cain, Chief Medicaid Operations Branch, to Mrs. Mary Dean Harvey, Director, Nebraska Department of Social Services (Aug. 6, 1993)(encouraging state Medicaid use of Health Diary, a self-help book for pregnant and parenting mothers from pregnancy to second year of life).

[21] *See* National Conference of State Legislatures, Minority Health Laws: Sickle Cell Anemia, June 2005, *available at* http://www.ncsl.org/programs/health/sickle.htm.

**Resources on Sickle Cell Disease and Medicaid Coverage**

- Centers for Medicare and Medicaid Services
  Jean Sheil, Director, Family and Children's Health Program Group
  Jean.Sheil@cms.hhs.gov

- The Sickle Cell Information Center
  www.scinfo.org

- Sickle Cell Disease Association of America, Inc.
  www.sicklecelldisease.org

- National Health Law Program
  www.healthlaw.org