DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop S2-01-16
Baltimore, Maryland 21244-1850

CENTERS for MEDICARE & MEDICAID SERVICES

Center for Medicaid and State Operations

SMDL #05-003

September 29, 2005

Dear State Medicaid Director:

A new optional Medicaid benefit for sickle cell disease (SCD) was included in the American Jobs Creation Act of 2004 (AJCA) (Pub. L. No. 108-357), which was signed by the President on October 22, 2004. Section 712 of the AJCA amends title XIX of the Social Security Act (the Act) in order to provide a new optional benefit in the Medicaid program and to make available Federal matching funds for education and outreach to Medicaid eligible adults and children with SCD. This letter is intended to provide you with information regarding the new SCD benefit and to briefly explain its provisions.

First, section 712(a) of the AJCA amends section 1905(a) of the Act, which contains the definition of medical assistance, to include primary and secondary medical benefits for individuals who have SCD. These benefits include:

1. Chronic blood transfusion (with deferoxamine chelation) to prevent strokes for individuals with SCD who are at high risk for strokes;

2. Genetic counseling and testing to treat SCD individuals or individuals with the sickle cell trait and prevent symptoms; and

3. Other treatments and services to prevent SCD individuals who have had a stroke from having another stroke.

Section 712(a)(2) of the AJCA states that the addition of these SCD benefits shall not be construed as implying that a state Medicaid program, prior to the addition of these benefits, could not have treated any of the primary and secondary medical strategies and treatment and services as medical assistance under its Medicaid program, including early and periodic screening, diagnostic, and treatment services. However, the new provision offers additional flexibility to states. For example, under this benefit, states could:

- Cover additional services as part of the SCD benefit that might not otherwise be covered in the state plan;

- Reimburse for SCD services at a different rate than they pay for similar services provided to individuals with other diseases. For example, under this benefit, if a state wanted to increase reimbursement rates for SCD blood transfusions, it could do so through rate setting for the SCD benefit without having to increase reimbursement for all Medicaid blood transfusions. Reimbursement levels, however, must still be set within current Federal guidelines; and

- Establish different coverage limits for SCD services under Federal amount, duration, and scope provisions at 42 CFR section 440.230 from those that apply to services in other benefit categories in section 1905(a) of the Act.

Second, section 712(b) of the AJCA amends section 1903(a)(3) of the Act to add a new subsection (E) that emphasizes the availability of matching funds for the costs of certain administrative activities performed with respect to SCD. The administrative activities specified by this legislation, in general, would have been permitted under the previous Medicaid statute. However, this legislation makes it clear that the costs of activities related to conducting public education campaigns are allowable and may be claimed under Medicaid if they are performed specifically with respect to SCD. Expenditures related to any public education campaigns not specific to SCD remain unallowable under Medicaid.

Also, the amended section 1903(a)(3)(E) of the Act makes clear that the Federal matching rate for these activities is 50 percent. The allowable administrative activities specified in section 1903(a)(3)(E) of the Act, essentially representing outreach, are as follows:

- Services to identify and educate individuals who are likely to be eligible for medical assistance under the title and who have SCD or are carriers of the sickle cell gene, including education on how to identify such individuals; or

- Education regarding the risks of strokes and other complications, as well as the prevention of stroke and other complications, in individuals who are likely to be eligible for medical assistance under this title and who have SCD.

The costs for administrative activities allowed under this subsection should be included and reported with all other administrative costs reported at the 50 percent Federal matching rate.

Section 1903(a)(3)(E) of the Act, as amended by the AJCA, does not alter our view of what constitutes Medicaid outreach. Rather, the new provision specifies SCD as a target for outreach.

The Centers for Medicare & Medicaid Services (CMS) has developed state plan preprint pages for the new SCD optional benefit. They are currently going through the CMS clearance process. We will provide the regional offices with those preprint pages for distribution to states once they have been approved.

The CMS contact for this new legislation is Ms. Jean Sheil, Director, Family and Children's Health Program Group, who may be reached at (410) 786-5647 or Jean.Sheil@cms.hhs.gov.

Enclosed is a copy of the legislation pertaining to the SCD benefit. We hope this information is helpful to you.

Sincerely,

/s/

Dennis G. Smith
Director

Enclosure

cc:

CMS Regional Administrators

CMS Associate Regional Administrators
for Medicaid and State Operations

Martha Roherty
Director, Health Policy Unit
American Public Human Services Association

Joy Wilson
Director, Health Committee
National Conference of State Legislatures

Matt Salo
Director of Health Legislation
National Governors Association

Brent Ewig
Senior Director, Access Policy
Association of State and Territorial Health Officials

Sandy Bourne
Legislative Director
American Legislative Exchange Council

Trudi Matthews
Senior Health Policy Analyst
Council of State Governments

SEC. 712. INCLUSION OF PRIMARY AND SECONDARY MEDICAL STRATEGIES FOR CHILDREN AND ADULTS WITH SICKLE CELL DISEASE AS MEDICAL ASSISTANCE UNDER THE MEDICAID PROGRAM.

(a) OPTIONAL MEDICAL ASSISTANCE-

(1) IN GENERAL- Section 1905 of the Social Security Act (42 U.S.C. 1396d) is amended--

(A) in subsection (a)--

(i) by striking `and' at the end of paragraph (26);

(ii) by redesignating paragraph (27) as paragraph (28); and

(iii) by inserting after paragraph (26), the following:

`(27) subject to subsection (x), primary and secondary medical strategies and treatment and services for individuals who have Sickle Cell Disease; and'; and

(B) by adding at the end the following:

`(x) For purposes of subsection (a)(27), the strategies, treatment, and services described in that subsection include the following:

`(1) Chronic blood transfusion (with deferoxamine chelation) to prevent stroke in individuals with Sickle Cell Disease who have been identified as being at high risk for stroke.

`(2) Genetic counseling and testing for individuals with Sickle Cell Disease or the sickle cell trait to allow health care professionals to treat such individuals and to prevent symptoms of Sickle Cell Disease.

`(3) Other treatment and services to prevent individuals who have Sickle Cell Disease and who have had a stroke from having another stroke.'.

(2) RULE OF CONSTRUCTION- Nothing in subsections (a)(27) or (x) of section 1905 of the Social Security Act (42 U.S.C. 1396d), as added by paragraph (1), 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.

(b) FEDERAL REIMBURSEMENT FOR EDUCATION AND OTHER SERVICES RELATED TO THE PREVENTION AND TREATMENT OF SICKLE CELL DISEASE- Section 1903(a)(3) of the Social Security Act (42 U.S.C. 1396b(a)(3)) is amended--

(1) in subparagraph (D), by striking `plus' at the end and inserting `and'; and

(2) by adding at the end the following:

`(E) 50 percent of the sums expended with respect to costs incurred during such quarter as are attributable to providing--

`(i) services to identify and educate individuals who are likely to be eligible for medical assistance under this title and who have Sickle Cell Disease or who are carriers of the sickle cell gene, including education regarding how to identify such individuals; or

`(ii) education regarding the risks of stroke and other complications, as well as the prevention of stroke and other complications, in individuals who are likely to be eligible for medical assistance under this title and who have Sickle Cell Disease; plus'.

(c) DEMONSTRATION PROGRAM FOR THE DEVELOPMENT AND ESTABLISHMENT OF SYSTEMIC MECHANISMS FOR THE PREVENTION AND TREATMENT OF SICKLE CELL DISEASE-

(1) AUTHORITY TO CONDUCT DEMONSTRATION PROGRAM-

(A) IN GENERAL- The Administrator, through the Bureau of Primary Health Care and the Maternal and Child Health Bureau, shall conduct a demonstration program by making grants to up to 40 eligible entities for each fiscal year in which the program is conducted under this section for the purpose of developing and establishing systemic mechanisms to improve the prevention and treatment of Sickle Cell Disease, including through--

(i) the coordination of service delivery for individuals with Sickle Cell Disease;

(ii) genetic counseling and testing;

(iii) bundling of technical services related to the prevention and treatment of Sickle Cell Disease;

(iv) training of health professionals; and

(v) identifying and establishing other efforts related to the expansion and coordination of education, treatment, and continuity of care programs for individuals with Sickle Cell Disease.

(B) GRANT AWARD REQUIREMENTS-

(i) GEOGRAPHIC DIVERSITY- The Administrator shall, to the extent practicable, award grants under this section to eligible entities located in different regions of the United States.

(ii) PRIORITY- In awarding grants under this subsection, the Administrator shall give priority to awarding grants to eligible entities that are--

(I) Federally-qualified health centers that have a partnership or other arrangement with a comprehensive Sickle Cell Disease treatment center that does not receive funds from the National Institutes of Health; or

(II) Federally-qualified health centers that intend to develop a partnership or other arrangement with a comprehensive Sickle Cell Disease treatment center that does not receive funds from the National Institutes of Health.

(2) ADDITIONAL REQUIREMENTS- An eligible entity awarded a grant under this subsection shall use funds made available under the grant to carry out, in addition to the activities described in paragraph (1)(A), the following activities:

- (A) To facilitate and coordinate the delivery of education, treatment, and continuity of care for individuals with Sickle Cell Disease under--
  - (i) the entity's collaborative agreement with a community-based Sickle Cell Disease organization or a nonprofit entity that works with individuals who have Sickle Cell Disease;
  - (ii) the Sickle Cell Disease newborn screening program for the State in which the entity is located; and
  - (iii) the maternal and child health program under title V of the Social Security Act (42 U.S.C. 701 et seq.) for the State in which the entity is located.
- (B) To train nursing and other health staff who provide care for individuals with Sickle Cell Disease.
- (C) To enter into a partnership with adult or pediatric hematologists in the region and other regional experts in Sickle Cell Disease at tertiary and academic health centers and State and county health offices.
- (D) To identify and secure resources for ensuring reimbursement under the medicaid program, State children's health insurance program, and other health programs for the prevention and treatment of Sickle Cell Disease.

(3) NATIONAL COORDINATING CENTER-

- (A) ESTABLISHMENT- The Administrator shall enter into a contract with an entity to serve as the National Coordinating Center for the demonstration program conducted under this subsection.
- (B) ACTIVITIES DESCRIBED- The National Coordinating Center shall--
  - (i) collect, coordinate, monitor, and distribute data, best practices, and findings regarding the activities funded under grants made to eligible entities under the demonstration program;
  - (ii) develop a model protocol for eligible entities with respect to the prevention and treatment of Sickle Cell Disease;
  - (iii) develop educational materials regarding the prevention and treatment of Sickle Cell Disease; and
  - (iv) prepare and submit to Congress a final report that includes recommendations regarding the effectiveness of

the demonstration program conducted under this subsection and such direct outcome measures as--

(I) the number and type of health care resources utilized (such as emergency room visits, hospital visits, length of stay, and physician visits for individuals with Sickle Cell Disease); and

(II) the number of individuals that were tested and subsequently received genetic counseling for the sickle cell trait.

(4) APPLICATION- An eligible entity desiring a grant under this subsection shall submit an application to the Administrator at such time, in such manner, and containing such information as the Administrator may require.

(5) DEFINITIONS- In this subsection:

(A) ADMINISTRATOR- The term `Administrator' means the Administrator of the Health Resources and Services Administration.

(B) ELIGIBLE ENTITY- The term `eligible entity' means a Federally-qualified health center, a nonprofit hospital or clinic, or a university health center that provides primary health care, that--

(i) has a collaborative agreement with a community-based Sickle Cell Disease organization or a nonprofit entity with experience in working with individuals who have Sickle Cell Disease; and

(ii) demonstrates to the Administrator that either the Federally-qualified health center, the nonprofit hospital or clinic, the university health center, the organization or entity described in clause (i), or the experts described in paragraph (2)(C), has at least 5 years of experience in working with individuals who have Sickle Cell Disease.

(C) FEDERALLY-QUALIFIED HEALTH CENTER- The term `Federally-qualified health center' has the meaning given that term in section 1905(l)(2)(B) of the Social Security Act (42 U.S.C. 1396d(l)(2)(B)).

(6) AUTHORIZATION OF APPROPRIATIONS- There is authorized to be appropriated to carry out this subsection, $10,000,000 for each of fiscal years 2005 through 2009.

(d) EFFECTIVE DATE- The amendments made by subsections (a) and (b) take effect on the date of enactment of this Act and apply to medical assistance and services provided under title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) on or after that date.