HRSA Hemoglobinopathies Programs:
Sickle Cell Disease Newborn Screening Follow-Up Program(SCDNBSP) and Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program (SCDTDP)

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Maternal and Child Health Bureau (MCHB)
Health Resources and Services Administration
Health Resources and Services Administration (HRSA)

- America’s healthcare safety net - HRSA is the primary Federal agency for improving access to health care services for people who are uninsured, isolated or medically vulnerable

- Maternal and Child Health Bureau (MCHB) - Provides leadership to improve the physical and mental health, safety and well-being of the maternal and child health population which includes all of the nation’s women, infants, children, adolescents, and their families, including fathers and *children with special health care needs.*

  https://mchb.hrsa.gov/
Division of Services for Children with Special Health Needs (DSCSHN)

Mission
To provide national leadership to expand and strengthen access to a system of services for children and youth with special health care needs and their families as they grow and transition through adulthood

Vision
Optimal health and quality of life for all children and youth with special health needs and their families

Children and Youth with Special Health Care Needs (CYSHCN)

• Children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services or a type or amount beyond that required for children generally
  • Nearly 20% of U.S. children under age 18 years
  • One in five U.S. families
  • Services needed from multiple systems – health care, public health, education, mental health, and social services

• Medically complex children

The Hemoglobinopathy Program consists of programs designed to ensure individuals with sickle cell disease have access to comprehensive evidence-based care in a Medical Home that promotes prevention and chronic disease management.

The programs will use Community Health workers (CHW) and telementoring/telemedicine strategies to empower patients to be partners in decision-making and increase the number of providers treating sickle cell disease and providing evidence-based care.
What is a Medical Home?

• A cultivated partnership between the patient, family, and primary provider in cooperation with specialists and support from the community

• Principles of a Medical Home:
  o **Personal Provider** – Ongoing relationship with provider to provide comprehensive care
  o **Provider Directed Medical Practice** – provider leads a team who collectively assumes responsibility for care of the patient
  o **Coordinated and/or integrated Care** – Care is coordinated across all elements of the health care system and the patient’s community to ensure the patient get the indicated care when and where they need it
  o **Quality and Safety** – Deliver evidence-based care, are accountable for continuous quality improvements, actively seek patient input in decision making, and other measures are met to assure quality care
  o **Enhanced Access to Care** – Care is available through open scheduling, expanded hours and enhanced communication strategies between patients and providers

Six core systems outcomes for CYSHCN

1. **Community-based Services**
   - Ensure community services are organized for easy use by families.

2. **Access to Medical Home**
   - The number of children with special health care needs who have a medical home that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.

3. **Adequate Insurance**
   - The number of children who are adequately insured.

4. **Early Continuous Screening**
   - Ensure children are screened early and continuously for special health care needs.

5. **Transition to Adulthood**
   - The percent of adolescents with special health care needs who have received the services necessary to transition to all aspects of adult life, including adult health care, work, and independence.

6. **Families as Partners**
   - Ensure families are partners in decision making.
The Chronic Care Model

The Chronic Care Model

Community
Resources and Policies
Self-Management Support

Health Systems
Organization of Health Care
Delivery System Design
Decision Support
Clinical Information Systems

Improved Outcomes
Informed, Activated Patient
Productive Interactions
Prepared, Proactive Practice Team

Developed by The MacColl Institute
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Sickle Cell Disease

Treatment Demonstration

Regional Collaborative Program
SCD Treatment Demonstration Program Successes

• The SCDTDP’s four regions include roughly half of the 100,000 individuals with sickle cell disease in the United States. Of the estimated 56,733 individuals with sickle cell disease in the SCDTCP’s four regions, the SCDTDP has directly touched ~14% (~8000 patients) of these patients through its site-lead providers.

• One region, the Pacific Sickle Regional Collaborative, has shown particular progress
  • Between 2015 and 2016, the number of patients receiving care from the region’s site-lead providers increased 36%.
  • Over the 3 year grant cycle, the number of SCD patients on hydroxyurea increased 26%, from 403 to 537
## SCDTDP Medicaid/MCO Data Collection Success

<table>
<thead>
<tr>
<th>Region</th>
<th>Data Received</th>
<th>Pending Data</th>
<th>Can Not Submit Data</th>
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<tbody>
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<td>California MCO</td>
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New Sickle Cell Regional Structure: Entire USA

Five regional coordinating centers cover the entire United States.


- **Southeast Region**: Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee.

- **Midwest Region**: Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin, North Dakota, and South Dakota.

- **Heartland and Southwest Region**: Iowa, Missouri, Arkansas, Louisiana, Nebraska, Kansas, Oklahoma, and Texas.

SCDTDP Program Objectives

10% increase in the following measures:

• providers participating in telementoring and telemedicine
• providers using recommended treatments and prevention.
• sickle cell patients on hydroxyurea
• sickle cell patients have recommended pneumococcal vaccinations.
• sickle cell patients have Transcranial Doppler Ultrasound (TCDs).
• adolescents with sickle cell have transition plans.

The ability to obtain the number of individuals with sickle cell disease served by the program in the past year.
ECHO Model

Translating sickle cell guidelines into practice for primary care providers with Project ECHO
Lisa Shook, et al

- During the first 6 months of STORM TeleECHO, 6 monthly teleclinics have been conducted
- 38 registered participants from 7 states including all states in the STORM region and 4 observers
- An additional 26 participants who have attended clinics without registering
- Nearly 100% of participants have reported an increase in knowledge about SCD management as a result of STORM TeleECHO

Citation: Med Educ Online 2016, 21: 33616 - http://dx.doi.org/10.3402/meo.v21.33616
Sickle Cell Disease Newborn Screening Follow-up Program
Provide support for a Sickle Cell Newborn Screening Technical Assistance Center (TAC) that will work with community-based organizations (CBOs) to improve the care of individuals identified with sickle cell disease and sickle cell trait through education and coordinating services.
Sickle Cell Disease Newborn Screening Follow-Up Program

• Ensure individuals with sickle cell disease receive appropriate follow-up services by supporting (Community-based Organizations) CBOs focused on SCD and increasing the use of Community Health Workers.

• Program Objectives
  o Train at least 150 CHWs
  o Increase the numbers of partnerships that CBOs have with stakeholder within their state
  o Assist individuals with sickle cell disease served by CBOs and receiving care in a patient-centered medical home
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