

## Division of Services for Children with Special Health Needs (DSCSHN) FACT SHEET

DSCSHN is one of five divisions of the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB). It plays a national leadership role in the development and implementation of comprehensive, community-based, family-centered, culturally competent, coordinated systems of care for children and youth with special health needs (CYSHCN) and their families. DSCSHN also takes the lead in responding to emerging issues for CYSHCN and their families in the U.S. and abroad. It plays an important role in translating genetics research into practice.

Children and youth with special health needs include all children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally. According to the National Survey of Children with Special Health Care Needs 2005-2006 (NS-CSHCN), approximately 14% of children and youth under the age of 18 in the United States are estimated to have special health needs. The Division's Integrated Services Branch (ISB) and the Genetic Services Branch (GSB) work to achieve six critical systems outcomes set out in the Healthy People 2020 National Health Objectives. These include:

- Family /professional partnership at all levels of decision-making;
- Access to coordinated comprehensive care within a medical home;
- Access to adequate private and/or public insurance to pay for needed services;
- Early and continuous screening for special health needs;
- Organization of community services for easy use;
- Youth transition to adult health care, work, and independence.

**Integrated Services Branch** The Integrated Services Branch supports the core "systems" framework for the six systems outcomes listed above, and implements these outcomes through both non-categorical and condition-specific programs.

**Family Professional Partnership/Cultural Competence** This program supports grants to implement *Family to Family Healthcare Information and Education Centers for Families of Children with Special Health Care Needs* in every state and the District of Columbia in keeping with Section 5507(b) of the Affordable Care Act. These centers provide information, training, technical assistance and peer support to families of children with special health care needs so they can make better informed decisions about their children's health and be better able to participate in systems building activities in their communities and states. The program also supports two National Resource Centers, the National Resource Center ~~on~~ for Family Professional Partnership for CYSHCN to promote family-centered care at the national, state, and local levels, and the National Center for Cultural

Competence to increase the capacity of health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems.

**Medical Home** Access to care through a medical home improves continuity and quality of care for all children and assures comprehensive coordinated care for CYSHCN and their families. This program is a collaborative effort among child health professionals, CYSHCN, and their families to assure universal access to medical homes, as well as to support quality improvement toward medical home implementation for child health professionals. Medical homes should be accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective as described by the American Academy of Pediatrics Policy Statement. Partnerships with families have been established for the planning, development, and oversight of the medical home. The program supports a National Resource Center, the National Center for Medical Home Implementation to provide leadership, technical assistance, promising practices, and other resources to assist providers, families, communities and state programs to implement quality medical homes.

**Health Insurance and Financing** Health insurance and financing plays a critical role in assuring appropriate access to care for children with special health care needs. While almost 60% of CYSHCN nationally meet the health insurance core outcome, significant disparities still exist based on poverty race/ethnicity and functional ability. The Health Insurance and Financing Program focuses on three key strategies to improve access to adequate health insurance and financing: 1) expand insurance to include uninsured CYSHCN; 2) close the benefit gaps and assure that CYSHCN have access to needed benefits and services, including those not financed through health insurance; and 3) improve the financing and reimbursement of services. With the passage of the Affordable Care Act, the focus of the program will be on assuring that health care reform meets the needs of CYSHCN and their families. This program supports a National Center dedicated to improving health insurance and financing for CYSHCN.

**Early and Continuous Screening** Multiple studies demonstrate that early detection and intervention have significant academic, social, and economic benefits. The Division promotes early and continuous screening in multiple domains consistent with the periodicity schedule of the American Academy of Pediatrics (AAP) and *Bright Futures for Children*. Approximately 3 of every 1,000 infants born in the U.S. have a significant hearing loss, making this the most common birth defect. The Universal Newborn Hearing Screening and Intervention program supports grants to States for the implementation of universal newborn hearing screening prior to hospital discharge and subsequent reduction of loss to follow-up after failure to pass newborn hearing screening so that infant with confirmed hearing loss can be enrolled into a program of early intervention as early as possible. The goal is to place all infants identified with hearing loss in an early intervention program by 6 months of age. One National Resource Center is also supported. Many state newborn hearing screening programs are extending screening efforts in community health centers, private pediatrician offices and early head start programs.

**Community Integrated Services** One of the most frustrating aspects of the service system for families and of CYSHCN is the complexity and fragmentation of services at the community level. Multiple programs, each with their own eligibility requirements, policies, procedures and funding serve children and youth with special health care needs. While national survey data indicates that families are fairly satisfied with services in their community, disparities exist across age, race/ethnicity and communities. This program funds a National Center designed to support states and communities, and to develop the leadership and capacity to provide organized, easy to use community services for families of children and youth with special health care needs.

**Transition to Adult Health Care** The *Health Care Transition* program supports National Resource Center to provide information, tools, resources and connections to adolescent health and transition expertise nationwide through information dissemination, and technical assistance. The Center helps providers, policy makers, youth and families of youth with special health care needs to understand how they can work together to change systems which better prepare youth to make the transition to adulthood, including moving from the pediatric to the adult health care system; from secondary to post-secondary education; and to employment and self-sufficiency. The center also assists programs in supporting youth participation in systems activities, such as youth councils, and in training youth to be partners in their own care to make more informed decisions and with professionals in building systems more inclusive of and appropriate for transitioning youth and young adults.

In addition to supporting the core systems program, the ISB supports initiatives on Special Populations and issues including:

**Traumatic Brain Injury (TBI)** The purpose of the Traumatic Brain Injury (TBI) program is to improve and advance state-based service systems to better assure that TBI survivors and their families receive the help they need with as few obstacles as possible. The program consists of two separate initiatives. One is a grant program for state government “lead agencies for TBI,” to provide funds that will link together the various services and service systems, recovering individuals with TBI need---education, social services, physical and vocational rehabilitation, and assistive technology. The second initiative is the Protection and Advocacy grant program to advocate for and support families in accessing services and negotiating settlements for denial of services. The program also supports a National Resource Center that develops materials for and about the TBI program.

**Project Access: Improving Care to Children with Epilepsy:** This program provides grants to improve access to care for children and youth with epilepsy, especially those living in medically underserved and rural areas and racial and ethnic minority populations. The program also supports a national continuous quality improvement strategy using a learning collaborative model, and works with the National Epilepsy Foundation to develop public education and awareness campaigns. The program has demonstrated positive outcomes in key areas such as enhanced dialogue and collaboration between families and their healthcare providers; improved access and reduced wait time associated with

referrals to specialists; increased knowledge of and integration with community support services; improved access to a medical home; and improved coordination of care.

**Vision Screening:** This program funds a National Center for Children's' Vision Screening to support the public health role in assuring a continuum of eye care for young children within the healthcare delivery system. This program addresses the screening and follow-up component of that continuum by providing national leadership in the development of the statewide vision screening and intervention component of programs for all children four years of age, prior to school entry. It assists states to coordinate existing vision screening activities within their state, working closely with 3-5 states to develop and implement a uniform statewide strategy for universal vision screening by age 4, determining a mechanism for uniform data collection and reporting and establishing a state Title V performance measure for vision screening.

**State Implementation for Improving Services for Children and Youth with Autism Spectrum Disorder (ASD) and other Developmental Disabilities:** The purpose of this program is to improve access to comprehensive, coordinated health care and related services for children and youth with ASD and other developmental disabilities. The program supports grantees implementing existing plans and those just in the planning stages to improve the system of services for children and youth with special health care needs who have ASD and other developmental disabilities through partnerships between professionals and families of children and youth with ASD, access to a culturally competent family-centered medical home which coordinates care with pediatric subspecialties and community-based services, access to adequate health insurance and financing of services, early and continuous screening for ASD and other developmental disabilities, community services organized for easy use by families, and transition to adult health care. It also supports a national Evaluation contract that evaluates progress across all ASD programs

### **Genetics Services Branch**

The legislation for MCHB also establishes a genetic services program for genetic disease testing, counseling, and information development and dissemination programs and for grants relating to hemophilia, sickle cell disease and other genetic disorders. To implement this legislation, the **Genetic Services Branch** plans, develops, monitors, implements, and evaluates programs for genetic services, including services for hemophilia, thalassemia and sickle cell disease. The programs assist Regions, States and communities to develop and strengthen health care and public health infrastructure for genetic services through promoting a close partnership among consumers of those services and public health programs, organizations, health care professionals, the scientific genetics community and the general public.

**Genetic and Newborn Screening Services and Public Health Infrastructure** The purpose of this program is to enhance and expand State genetic and newborn screening programs, to promote the quality of those services, to facilitate the development and coordinated use of health information systems to improve links between screening programs, State systems of care for CYSHCN, and the medical home.

**Translational Genetic Services** This program is designed to help State officials, health care providers, public health professionals, families, and individuals respond to new scientific findings and technologies in the fields of genetics and newborn screening, with special consideration of the financial, ethical, legal, and social implications that surround the understanding and the uses of genetic medicine and technology. Projects focus on the integration and translation of genetic research and medicine across States and communities using an underlying approach to regional equity and access issues as a way to address and resolve the needs and misdistribution of genetic resources.

As part of its translational genetics activities the Branch funds seven **Regional Genetics and Newborn Screening Services Collaborative**, inclusive of all States in each region, and one National Coordinating Center, to enhance and support the genetics and newborn screening capacity of States across the nation by undertaking a regional approach to determine and resolve the needs and misdistribution of genetic resources and expertise across the region. The projects are to establish infrastructure to ensure that individuals with heritable disorders and their families have access to quality care and appropriate genetic expertise and information in the context of a medical home that provides accessible, family-centered. In addition activities within the regions are structured to strengthen communication and collaboration among public health, individuals, families, primary care providers, and genetic medicine and other subspecialty providers.

**Delivering Genetic Services** Community genetic service programs are designed to integrate federal, state or locally funded genetics services within communities or geographic areas into existing systems of care to reduce the duplication and fragmentation of services, while enhancing outreach, and improving availability, efficiency, cost-effectiveness as well as quality of care. Through this program, the Branch funds projects for a Thalassaemia Program to support 3 Thalassaemia comprehensive care centers; a National Sickle Cell Disease and Newborn Screening Program with 17 community-based sickle cell disease projects and a national sickle cell disease coordinating center; a Sickle Cell Disease Treatment Demonstration Program with 4 regional networks and a coordinating center; and a National Hemophilia Program with 12 regional centers and 130 hemophilia treatment centers.

The Genetic Services Branch also staffs the **Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children**. The Committee's purpose is to provide advice and recommendations to the Secretary concerning grants and projects and technical information to develop policies and priorities that will enhance the ability of the State and local health agencies to provide for newborn and child screening, counseling and health care services for newborns and children having or at risk for heritable disorders. In addition, the Committee gives advice and guidance to the Secretary regarding the most appropriate application of universal newborn screening tests, technologies, policies, guidelines and programs for effectively reducing morbidity and mortality in newborns and children having or at risk for heritable disorders.

## **Program Contact**

Bonnie Strickland, PhD  
Director, Division of Services for Children with Special Health Needs  
Phone: 301-443-2350

**Media**

HRSA Office of Communications (301) 443-3376; [press@hrsa.gov](mailto:press@hrsa.gov)