



**DIVISION OF SERVICES FOR CHILDREN WITH SPECIAL HEALTH NEEDS (DSCSHN)**

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The DSCSHN is one of five divisions of the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB).

**Integrated Services Branch** - promotes leadership and support for the development and implementation of innovative, replicable models of community based care for children with special health needs in six program areas: Family Professional Partnership/Cultural Competence, Screening, Medical Home Financing/Managed Care, Community Integrated Services and Healthy & Ready to Work.

**Addressing Federal Goals:** Healthy People 2010 Objective 16.23, to implement service systems for children and youth with special health care needs (CYSHCN)

President's New Freedom Initiative to reduce barriers to community services and independent living

**WHAT'S HEALTH GOT TO DO WITH TRANSITION? EVERYTHING!**

*Health Impacts All Aspects of Life*

Success in the classroom, within the community, and on the job requires that young people with special health care needs stay healthy. To stay healthy, young people need an understanding of their health and to participate in their health care decisions.

**The MCHB Vision:** MCHB believes in a future America in which the right to grow to one's full potential is universally assured through attention to the comprehensive physical, psychological, and social needs of the MCH population. We strive for a society where children are wanted and born with optimal health, receive quality care, and are nurtured lovingly and sensitively as they mature into healthy, productive adults. The Bureau seeks a Nation where there is equal access for all to quality health care in a supportive, culturally competent, family and community setting.

**Who are CYSHCN?** Children and youth with special health care needs include those 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. It is estimated that 18 million children in the United States have these special health needs.

**State Title V CSHCN Programs** -Every state and the District of Columbia has a Title V Program for Children with Special Health Care Needs (CSHCN) that is funded, in part, through the Federal Title V Maternal and Child Health Block Grant. These programs began in 1935, when Congress passed the Social Security Act, a law designed to bring some financial and health security into the lives of America's most vulnerable citizens.

The **President's New Freedom Initiative** (NFI, Executive Order 13217) is a significant effort to build on past success and increase opportunities, including integrating people with disabilities into the workforce, increasing access to technology, and expanding educational opportunities for all people with disabilities to ensure full integration in American society. Page III-39 of the HHS section of the *Delivering On The Promise* "HRSA's Maternal and Child Health Bureau will take the lead in developing and implementing a plan to achieve appropriate community-based services systems for children and youth with special health care needs and their families. Specific barriers include access to:

- 1) comprehensive, family-centered care
- 2) affordable insurance
- 3) early and continuous screening for special health care needs and
- 4) **transition services to adulthood.**

With respect to families of such children, issues relate to family satisfaction and the complexity and organization of services resulting from fragmentation and multiple funding streams. Developing a plan to address these barriers is a "necessary first step to improving access to community-based services for children with special health care needs."

## HEALTHY & READY TO WORK (HRTW)

NATIONAL CENTER  
[www.hrtw.org](http://www.hrtw.org)

HRTW provides information and connections to health and transition expertise nationwide – from those in the know, doing the work and living it!

This site focuses on **understanding systems, access to quality health care, and increasing the involvement of youth.**

It also includes **provider preparation plus tools and resources** needed to make more informed choices!

In 1996, MCHB's Division of Services for Children with Special Health Needs (DSCSHN) began a new initiative that targeted youth with special health care needs. For many years MCHB was well known and respected for its comprehensive coordinated programs for children. However, lacking was a dedicated effort for those children who grew up, many of whom who had outlived their diagnoses, and needed supports to be adults who could live the lives they choose.

Early work in transition stemmed from Surgeon General Koop's final conference in 1989 that focused on Transition of Youth with Special Health Care Needs. Shortly afterwards the DSCSHN funded demonstration grants in this area. Some of these met with only modest success, as the climate to prepare children, youth, their families and the systems that served them was not receptive yet. Since the eighties other federal agencies also funded transition demonstration grants (OSERS, RSA), but none had integrated a health component.

During the 1990's, legislative mandates affecting children with special health care needs (CSHCN) underwent sweeping reform. Much attention focused on providing system support for young children's educational and health needs under a federal initiative called "Healthy and Ready to Learn." But what happened when these same children became youth with special health care needs (YSHCN)? Were programs and services supporting the other end of the spectrum "Healthy and Ready To Work?"

In response to this dilemma, MCHB/DSCSHN announced the new grant initiative "Healthy and Ready to Work" in December 1996. Nine states (CA, IA, KY, LA, MA, ME, MN, OH and OR) and one national center (FL) were awarded grants in Phase One (1996-2001), Phase Two (2001-2005) included six grants located in or have a strong working relationship with their state Title V Programs (AZ, IA, KY, ME, MS, and WI). Today there are 10 states who are funded to implement integrated systems of services for CSYCHN.

### **Making A Difference: HRTW Projects Learned.....**

- Many youth with special health care needs (YSHCN) have no experience managing their own health care, making medical appointments or even discussing the specifics of their medical conditions;
- Many YSHCN want education and employment opportunities, but feel the adults around them either have extremely low expectations of their abilities and future prospects, or present barriers to attaining a degree of independence that would be considered normal for a young adult without special health care needs;
- In some cases families are unaware of the existence of programs and resources that could help;
- Pediatric and adult health care professionals often do not communicate, much less collaborate, to achieve a successful transition of care from one to the other as the children mature;
- Typically, the health care system does not interact with the education, rehabilitation or insurance systems in planning or facilitating transition.