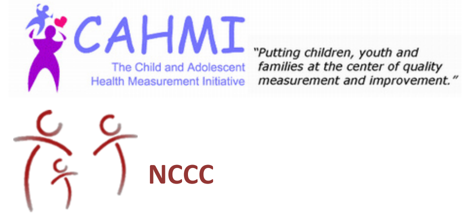

MCHB National Centers

Family Voices National Center for Family Professional Partnerships (NCFPP)

The NCFPP provides leadership on implementing the core component of a system of care for children and youth with special health care needs (CYSHCN) working to increase the capacity of families to partner in decision making at all levels. The NCFPP works nationally with F2FHICs, the FV network, other family leaders and their professional partners in implementing this core component. http://www.familyvoices.org

National Center for Cultural Competence (NCCC)

The NCCC provides national leadership and contributes to the body of knowledge on cultural and linguistic competency within systems and organizations. Major emphasis is placed on translating evidence into policy and practice for programs and personnel concerned with health and mental health care delivery, administration, education and advocacy. http://nccc.georgetown.edu/

Healthy & Ready to Work National Resource Center (HRTW)

The Center works with State Title V CSHN programs and their partners to improve and enhance health care transition for CYSHCN. The Center provides resources, information and technical assistance addressing the transition to adult systems and services including strategies to maintain health insurance and increasing the involvement of youth in health care decisions and policy making. The website includes tools and resources for providers, families and youth. www.hrtw.org

The National Center for Medical Home Initiatives for Children with Special Needs

The National Center of Medical Home Initiatives for Children with Special Needs provides support to physicians, families, and other medical and non-medical providers who care for children with special needs so that they have access to a medical home. http://www.medicalhomeinfo.org/index.html

The Catalyst Center

A national center dedicated to improving health care insurance and financing for children and youth with special health care needs (CYSHCN). www.catalystctr.org

Champions for Inclusive Communities (ChampionsInC)

A leadership and resource center designed to support states and communities in organizing services so families of children and youth with special health care needs (CYSHCN) can use them easily and families are satisfied. http://www.championsinc.org

National Center for Hearing Assessment and Management (NCHAM)

This National Resource Center (NRC) assists state agencies and other federal and non-federal partners in the development and operation of sustainable statewide Early Hearing Detection and Intervention (EHDI) systems. http://www.infanthearing.org

CAHMI Data Resource Center

Part of the Child & Adolescent Health Measurement Initiative. Provides leadership and resources for measuring and communicating information about the quality of healthcare for young children (0-3), teens (12-21), and children with chronic conditions. http://cahmi.org/pages/Sections.aspx?section=14

Achieving Community-Based Service Systems for Children and Youth with Special Health Care Needs

The six core National Performance Measures (NPM) for Children and Youth with Special Health Care Needs cannot be achieved in isolation. Below are a few examples of integrating the outcomes at the community level.

OUTCOME 1: Families as Partners

Family	Families are recognized as the experts in the care of their child in a manner that respects their culture and family priorities and are involved at the program and policy level.
Screening	Families are advised why screening should periodically occur, what is being evaluated.
Medical Home	Families are informed partners in health care decision making.
Health Insurance	Families know how to get health care insurance and what the plan reimburses.
Community	Family leaders are present in all communities, providing families with resources and supports.
Transition	Families prepare medical documentation to expedite eligibility for adult services/supports. Families teach essential skills to prepare youth for transition to adult services and support.

OUTCOME 2: Screening

Family	Screening services and information are family friendly and promote health literacy.
Screening	Screening occurs at developmental milestones to prevent secondary disabilities.
Medical Home	Screening is routinely provided by the community based primary care provider.
Health Insurance	Screening is reimbursed by EPSDT and private insurance.
Community	Local interagency clinics coordinate screening referrals to help families connect to need services.
Transition	Screening occurs periodically to maximize quality of life to and prepare youth for adulthood.

OUTCOME 3: Medical Home

Family	Medical Home staff partner with families to develop care plans, coordinate services.
Screening	Medical Home routinely conducts screening (developmental, secondary disabilities & services)
Medical Home	Medical Home is provided in the family's community.
Health Insurance	Medical Home services are properly coded and reimbursed (public, private or combination).
Community	Medical Home staff are members of community coalitions to integrate services.
Transition	Medical Home staff teaches youth for eventual transfer to adult health services.

OUTCOME 4: Adequate Health Insurance and Financing

Family	Families receive assistance in understanding their health insurance coverage and getting payment for services.
Screening	Insurance benefit packages adequately reimburse for screening services.
Medical Home	Insurance coding, eligibility requirements and medical necessity documentation is understood.
Health Insurance	Affordable insurance coverage is available for all families of CYSHCN.
Community	Community outreach workers help families access health insurance and other financing.
Transition	Insurance plans seamlessly cover dependents to age 30.

OUTCOME 5: Easy-to-use Community Based Services

Family	Families provide feedback and are compensated partners on community coalitions, driving strategic planning.
Screening	Community screening public awareness campaigns are culturally effective.
Medical Home	Medical Homes are community-based, conveniently located and accessible.
Health Insurance	Community has benefit navigators, skill care coordinators and cultural liaisons to assist families.
Community	Community providers blend funds, develop common applications, and coordinate services plans.
Transition	Community provides inclusive opportunities for youth to become mentally healthy & productive.

OUTCOME 6: Transition to Adulthood

Family	Family members mentor/coach youth in advocating for themselves to the best of their ability.
Screening	Youth are screened routinely for health issues, particularly mental health.
Medical Home	Youth receive support to develop and apply skills in partnering with their medical home.
Health Insurance	Youth are advised how to sustain health care insurance coverage before they reach age 18.
Community	Youth access community resources and supports to fully participate in their community.
Transition	Youth are healthy to live the life they want, work, have fun and be safe in the community.

Tool developed in February 2009 by MCHB/HRSA/DSCSHN, Lynda Honberg, and National Center representatives Diane Behl (Champions Inc) and Patti Hackett (Healthy & Ready to Work), with support from Meg Comeau (Cataylst Center), and Tawara Goode (National Center for Cultural Competence).