

AMCHP Fact Sheet

Children and Youth with Special Health Care Needs

BACKGROUND

In the United States, approximately 11.2 million children and youth, or 15.1 percent, have special health care needs.ⁱ These children have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and require extensive health services. They may be enrolled in many programs for their specific needs, including Medicaid/State Children's Health Insurance Program (SCHIP), Social Security Income and Early Intervention. Title V plays a critical role helping children and families navigate those systems and access appropriate services. State maternal and child health programs serve more than 43.3 million women, infants, children and adolescents.ⁱⁱ These programs also provide, fund and coordinate services for 3.2 millionⁱⁱⁱ of the 11.2 million children and youth with special health care needs (CYSHCN). These programs are funded by the Title V Maternal and Children Health Services Block Grant. Authorized by the Social Security Act, Title V is the only federal program devoted to improving the health of all women, children and families.

AMCHP ACTIVITIES

Ease of Use for Community-Based Services: In both 2013 and 2014, AMCHP, in partnership with the National Center for the Ease of Use of Community-based Services, conducted an Action Learning Collaborative (ALC) that focuses on improving ease of use of services for Latino families with CYSHCN. The ALC features ongoing distance-learning opportunities and site visits. Teams from NC, OR, IN, NH, RI and NM attended. In May 2014, ALC participants will travel to Albuquerque, NM to discuss strategies relevant to improving access for Hispanic families with CYSHCN through the utilization of community health workers.

National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs: In March 2014, AMCHP, with support from the Lucile Packard Foundation for Children's Health, released a groundbreaking set of standards and companion background white paper designed to help communities, states, and the nation build and improve systems of care for CYSHCN. The standards address the core components of the structure and process of an effective system of care for CYSHCN. They were derived from a comprehensive review of the literature, early project guidance from more than 30 key informants, case studies of standards currently in use within selected sites, and input and guidance from a national work group comprised of national and state leaders representing state Title V CYSHCN programs, state Medicaid agencies, pediatric providers, health plans, children's hospitals, families/consumers, health services researchers, and others. They are intended for use or adaptation by a wide range of stakeholders at the national, state and local level. AMCHP is currently working on Phase II of the project, which will focus on utilization of the developed system standards by states and the development of an accompanying online toolkit.

State Public Health Autism Resource Center (SPHARC): AMCHP continues to direct SPHARC, a comprehensive resource center for state Title V programs and others interested in improving systems for children, youth and families with autism spectrum disorder and other developmental disabilities. AMCHP maintains the SPHARC listserv and hosts a variety of technical assistance activities, including bimonthly SPHARC technical assistance calls, peer-to-peer exchange programs to bring together State Autism Planning and Implementation Grantee teams, resources and profiles from state grantees, and targeted technical assistance and mentorship. The SPHARC website can be accessed at amchp.org/SPHARC.

About AMCHP

The Association of Maternal & Child Health Programs (AMCHP) is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs.

AMCHP supports state maternal and child health programs and provides national leadership on issues affecting women and children.

AMCHP works with national and state partners to link CYSHCN to appropriate services and promote quality systems of care. With support from the Maternal and Child Health Bureau, the Centers for Disease Control and Prevention (CDC), and private foundations, AMCHP assists families and state CYSHCN programs with policy and legislative analysis, targeted research, and coordination of national meetings and publications. AMCHP also provides training and leadership development opportunities to Title V CYSHCN

Learn The Signs. Act Early.: AMCHP administers the Act Early State Systems Grants program, funded through the CDC National Center on Birth Defects and Developmental Disabilities. The seven active Act Early systems grants are designed to develop and promote systems that increase awareness of developmental milestones, warning signs of concern, and the importance of monitoring and tracking children's development.

Leadership Institute for State Title V CYSHCN Directors: The goal of this leadership program is to improve the effectiveness of state Title V CYSHCN directors to lead and transform their programs in a time of change by providing targeted, intensive, and ongoing training. More than 40 CYSHCN directors across the nation currently participate in the program, consulting each other on issues relevant to leading state CYSHCN programs.

Action Learning Collaborative-Taking a Leadership Role in Transitioning to Medicaid Managed Care: AMCHP provides targeted technical assistance for a subset of seven state teams comprised of state Title V CYSHCN directors and their key partners (e.g., Medicaid and CHIP programs, provider groups, health plans, Insurance Exchange representatives, families/consumers) as they participate in an ALC focused on states transitioning CYSHCN into Medicaid managed care arrangements.

PUBLICATIONS

- National Standards for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs [March 2014 – [White Paper](#) and [Set of Standards](#)]
- The Affordable Care Act and Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities [[May 2012](#)]
- Environmental Scan: How State Title V Programs Are Responding to Autism Spectrum Disorder and Other Developmental Disabilities [[November 2011](#)]
- Roles for State Title V Programs: Building Systems of Care for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities [[October 2011](#)]
- Executive Summary – Roles for State Title V Programs: Building Systems of Care for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities [[October 2011](#)]
- Environmental Scan: State Title V Program Response to Autism Spectrum [[December 2009](#)]
- Models of Care for CYSHCN [[November 2009](#)]

STAFF CONTACTS

Program

Treeby Brown, Associate Director, Child and Adolescent Health; tbrown@amchp.org

Kate Taft, Senior Program Manager, Children and Youth with Special Health Care Needs; ктаft@amchp.org

Veronica Helms, Program Manager, Children and Youth with Special Health Care Needs; vhelms@amchp.org

Alma Reyes, Program Associate, Child and Adolescent Health; areyes@amchp.org

Policy

Karen Van Landeghem, Senior Advisor, National Center for Health Reform Implementation; kvan@amchp.org

Carolyn McCoy, Senior Policy Manager, National Center for Health Reform Implementation; cmccoy@amchp.org

For more information:

Learn more about all of these activities and download publications online at amchp.org.

ⁱ National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved [04/21/14] from www.childhealthdata.org.

ⁱⁱ Health Resources and Services Administration, Maternal and Child Health Bureau. Title V Information System. The Number of Individuals Served by Title V, by Class of Individual. Annual Report Year 2012. Retrieved [04/21/2014] from mchdata.hrsa.gov/TVISReports/special/special_prgsch04_result.aspx.

ⁱⁱⁱ Health Resources and Services Administration, Maternal and Child Health Bureau. Title V Information System. The Number of Individuals Served by Title V, by Class of Individual. Annual Report Year 2012. Retrieved [04/21/2014] from mchdata.hrsa.gov/TVISReports/special/special_prgsch04_result.aspx.

