



AMCHP Releases National Standards for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs

MAR. 13, 2014, WASHINGTON, DC - The Association of Maternal & Child Health Programs (AMCHP), with support from the Lucile Packard Foundation for Children's Health, announces the release of 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 children and youth with special health care needs (CYSHCN).

"This set of standards, built around a framework and the guidance of a diverse set of stakeholders, represents one of the first efforts of its kind to comprehensively and systematically collect and categorize system standards that affect CYSHCN and their families," said AMCHP President Millie Jones.

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 levels.

Overall, CYSHCN are defined as children birth to age 21 who have or are *at increased risk* for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. In a recent national survey, children with a chronic condition birth to age 18 represented approximately 15 percent of the entire child population in the United States.

"Creating a comprehensive, quality system of care for CYSHCN has been one of the most challenging areas for state health leaders," said Debra Waldron, MD, MPH, director and chief medical officer, Iowa Child Health Specialty Clinics. "The Affordable Care Act is extending coverage to millions of uninsured children and adults, designing essential health benefits, and implementing new provisions to achieve the 'Triple Aim' of improving the patient experience of care, improving the health of populations, and reducing health care costs. These changes are heightening the need for system standards."

In 1982, Surgeon General C. Everett Koop held a *National Workshop on Children with Handicaps and Their Families*. The goals of that national meeting were to "develop strategies for comprehensive services needed by children with special health care needs, address the challenges and burdens of the families of these children, and stimulate community resources." Since that first meeting and a subsequent national report in 1987, local, state and national level efforts to advance comprehensive systems of care for CYSHCN have improved the state of the art and practice in serving this population of children.

"We anticipate that these standards will help guide wise decisions by policymakers and payers to improve systems of care for children with special needs and their families," said Dr. Edward Schor, senior vice president at the Lucile Packard Foundation for Children's Health. "As states continue to transform how they pay for care for this population, evidence-based guidelines for optimal care and support for CYSHCN will be essential to ensure that their care isn't compromised."

About AMCHP: 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 members come from the highest levels of state government and include directors of maternal and child health programs, directors of programs for children with special health care needs, and other public health leaders who work with and support state maternal and child health programs. AMCHP members directly serve all women and children nationwide, and strive to improve the health of all women, infants, children and adolescents, including those with special health care needs, by administering critical public health education and screening services, and coordinating preventive, primary and specialty care. Our membership also includes academic, advocacy and community-based family health professionals, as well as families themselves.

About the Foundation: The Lucile Packard Foundation for Children's Health works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the Foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life for families. The Foundation is a public charity, founded in 1997.

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