

National Standards for Systems of Care for Children and Youth with Special Health Care Needs

Fact Sheet

The **National Standards for Systems of Care for Children and Youth with Special Health Care Needs** (CYSHCN) are designed to help state health policymakers, families, providers, health plans and others transform and improve the capacity, performance, and delivery of a system of care for CYSHCN and their families. The National Standards provide an essential framework that states can use to help ensure that this group of children receive comprehensive, coordinated, family-centered, quality care.

For decades, numerous national reports, initiatives, and research described and called for frameworks, standards, and measures to advance a comprehensive system of care for CYSHCN and their families. The publication and dissemination of the National Standards resulted in a nationally endorsed set of structural and process standards that can be used and applied within health care and public health systems and other child-serving systems to improve health care quality and health outcomes for this population of children.

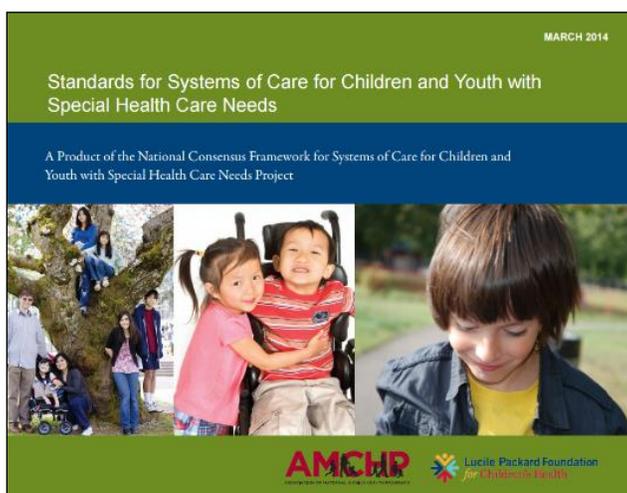
The National Standards provide a critically important framework that highlights specific system requirements for health providers and plans serving CYSHCN. Additionally, the National Standards offer operational and measurable guidelines for state systems of care serving CYSHCN.

DEVELOPMENT OF THE NATIONAL SYSTEMS STANDARDS OF CARE FOR CYSHCN

The National Standards were developed using a multipronged approach involving an extensive literature review, key information interviews, case studies of sites using systems standards, and guidance and input from a national work group comprised of diverse stakeholders. For more information about the development of the Standards, please see the [Standards White Paper](#).

The National Standards work group was initially convened in July and November of 2013 to discuss key considerations in the development of a set of standards, identify areas of further content development, and examine policy implications influencing systems that serve CYSHCN. The original National Standards were vetted and fully endorsed by the national work group. The work group continues to meet periodically to review updates to the Standards, as policies and systems influencing care for CYSHCN change.

The National Standards were built using the existing six core outcomes for CYSHCN, developed by the Maternal and Child Health Bureau, and widely used by state Title V programs, provider groups, health services researchers and other stakeholders. The six core outcomes frame the domains, process and structural standards that together represent a comprehensive system of care for CYSHCN.



A CRITICAL TOOL FOR IMPROVING SYSTEMS OF CARE FOR CYSHCN

According to the *National Survey of Children's Health*, children with special health care needs represent nearly 20% of the entire child population in the US. This population of children typically receive services and supports from multiple systems. Within any one system, CYSHCN may be served by multiple clinical and community-based providers. Creating a comprehensive, high-quality system of care for this group is challenging, particularly during a time of rapid change in states' health care delivery and financing systems.





States are seizing the opportunity to use the National Standards to make improvements in their health care service delivery systems serving CYSHCN. States are using the National Standards to:

- ❖ BUILD PARTNERSHIPS WITH INTERDISCIPLINARY STAKEHOLDERS
- ❖ DEVELOP STATE TITLE V CYSHCN STRATEGIC AND FIVE-YEAR STATE ACTION PLANS
- ❖ IMPROVE THE QUALITY OF CARE ACROSS SYSTEMS SERVING CYSHCN
- ❖ PROMOTE PROGRAM AND POLICY CHANGE

KEY PRODUCTS AND INITIATIVES

Several products and tools were and continue to be developed following dissemination of the National Standards:

- ❖ White Paper from the National Consensus Framework for Systems of Care for CYSHCN
- ❖ Organizational Standards Assessment Tools
- ❖ Medicaid managed care contracting tool
- ❖ Three Learning Collaboratives of interdisciplinary state teams

OPPORTUNITIES TO IMPROVE SYSTEMS OF CARE FOR CYSHCN

The landscape in which CYSHCN are served has shifted. Health care delivery systems and new payment models have changed the environment, creating new opportunities for child-serving systems to collaborate and partner to improve the quality of care for CYSHCN.

“The standards add a great deal of depth to our discussions of systems of care and allow us to conduct a systematic evaluation across different domains that are relevant to different stakeholders... Educating people about the standards has also forged relationships that were not there or not yet fully developed.”

-Carl Tapia, M.D., Associate Medical Director, Texas Children’s Health Plan

“Having these new standards...has raised the visibility of the need for doing things differently now for CYSHCN than for other populations so that we can really deliver valuable services.”

–Jennifer Kyle, RN, MA Director, Population Strategy, UnitedHealthcare Community & State

THE FUTURE OF THE STANDARDS: STANDARDS 2.0 IS HERE

Re-released in July 2017, Standards 2.0 was updated to increase the readability and ease of use while also maintaining its integrity and essential content.



Version 2.0 of the National Standards for CYSHCN uses and builds upon the critical domains, elements, and standards from the original National Standards work (Version 1.0), while streamlining content for easier use by states and stakeholders. The Standards were also reviewed and updated with changes federal guidance or regulations in mind. Check out our National Standards interactive web page by [visiting: www.amchp.org/programsandtopics/CYSHCN/projects/NationalStandards!](http://www.amchp.org/programsandtopics/CYSHCN/projects/NationalStandards/)

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