

A Critical Tool to Improve Systems of Care for Children and Youth with Special Health Care Needs

Tips for Medicaid on Implementing the National Standards

What are the National Standards?

The **National Standards for Systems of Care for Children and Youth with Special Health Care Needs (CYSHCN)** are designed for state health policymakers, Medicaid programs, health plans, and providers to work together to improve systems of care for CYSHCN and their families. The National Standards provide an essential framework that these groups can use to ensure that these children receive comprehensive, coordinated, family-centered, quality care.

The National Standards outline core components for health providers and health insurers, as well as guidelines for state systems of care serving CYSHCN. They are built on the expectation that children, youth, and families of CYSHCN are active, core partners in decision-making at all levels of health care and health services, and that care is based on the best information and evidence available.

Why do the National Standards matter?

According to the 2016 National Survey of Children's Health, **one in five children in the U.S. has special health care needs**. Also, among families of CYSHCN, four out of five report that their children do not receive care in a well-functioning system. Creating a comprehensive, high-quality system of health care for CYSHCN can be challenging due to the need for services and support from multiple systems such as health, education, and social services.

The National Standards are a set of guidelines, widely endorsed around the entire country, that can be used within health care, public health systems, and other child-serving systems to improve health care quality and health outcomes for CYSHCN. Additionally, the National Standards offer operational and measurable guidelines for improving systems of care serving CYSHCN.

How can Medicaid programs use the National Standards?

- Reference as a framework for understanding the key elements of a comprehensive system of care for CYSHCN.
- Coordinate and collaborate with all entities that are providing care for CYSHCN.
- Develop Medicaid managed care programs and services.
- Draft or amend Medicaid managed care contracts.
- Serve as a guide for managed care and medical homes for CYSHCN.
- Promote coverage and payment strategies so that comprehensive care is accessible, affordable, and continuous.
- Identify areas for quality improvement and quality measurement.
- Consistently evaluate processes and feedback to determine where improvements can be made.
- Provide information in clear, health-literate ways for families of CYSHCN.



Acknowledgement: This publication was created by the Association of Maternal & Child Health Programs, in partnership with the National Academy for State Health Policy and supported with funding from the Lucile Packard Foundation for Children's Health.

How are Medicaid programs implementing the National Standards?

There are several ways states have successfully used the National Standards.

- **Delaware:** Used the National Standards as a resource to perform a comprehensive analysis of Delaware's system of care for children with medical complexity and publish a legislatively mandated [Plan for Managing the Health Care Needs of Children with Medical Complexity](#).
- **Massachusetts:** Used the National Standards to develop quality measures and strengthen the Medicaid Managed Care system within the state.
- **Rhode Island:** Used the National Standards as a resource to inform and update the Rhode Island Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Schedule.
- **Virginia:** Used the National Standards to help develop new managed care programs to serve CYSHCN: CCC Plus and Medallion 4.0.

What resources are available to Medicaid programs to implement the National Standards?

The Association of Maternal & Child Health Programs and the National Academy for State Health Policy have developed several tools and resources to assist with the implementation of the National Standards. These tools can be used by various stakeholders, including Medicaid, to determine which of the standards are currently areas of strength and which are areas for improvement. See below for a selection of some of the tools.

- **National Standards:** Complete set of comprehensive standards, recently streamlined to increase readability and ease of use. Includes a [White Paper](#) on the development of and evidence-base for the National Standards.
- **Communications tools:** Includes a [Standards Fact Sheet](#) and [Standards Presentation Tool](#).
- **National Committee for Quality Assurance (NCQA) Crosswalk:** Demonstrates how the National Standards correlate to the NCQA accreditation standards to allow health plans to better incorporate the accreditation standards to meet the needs of CYSHCN.
- **Medicaid Managed Care Contracting Tool:** Provides guidelines for developing language for contracts with Medicaid Managed Care Organizations that are specific for use with CYSHCN.
- **Data and Quality Measurement Resources:** A series of interactive learning modules on how state programs – including Title V and Medicaid – can use data and quality measures to improve systems of care for CYSHCN, as well as a [compendium of quality measures](#).
- **Organizational Assessment Tools:** Helps single or multiple organizations examine how well the organization(s) is structured to provide and improve quality care to CYSHCN and their families.
- **Systems Improvement Alignment Tool:** Helps organizations determine how their programs align with the National Standards and can be shared with partners to identify and assess projects for potential collaboration.
- **Partnership Profile:** Identifies strengths and areas of needed growth across partners serving CYSHCN.
- **Examples of the Standards in Action:** Case studies, webinars, and other examples of how state systems and program have used and implemented the National Standards in their work.

Access all these resources, and more:

- **The National Standards Online Toolkit:** <https://nashp.org/toolkit-national-standards-for-children-and-youth-with-special-health-care-needs/>
- **Mobile-friendly site:** <http://cyshcnstandards.amchp.org>

National Standards
for CYSHCN