

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

Tips for Title V Programs 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, Title V programs, providers, and health plans 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 plans, 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 Title V Programs use the National Standards?

- Educate staff and partners on the key elements of comprehensive systems of care for CYSHCN.
- Use as a framework to develop Title V five-year action plans and strategic plans for care of CYSHCN.
- Inform CYSHCN data and feedback collected for the Title V five-year needs assessments.
- Coordinate and collaborate with all entities that are providing care for CYSHCN, particularly to inform agreements between Title V and Medicaid.
- Develop processes that allow for ease of enrollment and transition for CYSHCN.
- Provide information in clear, health-literate ways for families of CYSHCN.
- Develop measures to assess the impact on CYSHCN related National Performance Measures.
- Promote coverage and financing strategies so that comprehensive care is accessible, affordable, and continuous.
- Consistently evaluate processes and feedback to determine where improvements can be made.

“The Standards can provide a means to convene and educate stakeholders who are interested in state-level action to improve the overall system of care for CYSHCN. They provide a common language, are evidence-based practice and can be used as the “north star” to guide us to move systems forward.”

– Susan Chacon, MSW, LISW, New Mexico Title V Director for Children's Medical Services, Children and Youth with Special Health Care Needs Program; AMCHP Board President (2017-2018)



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How are Title V Programs implementing the National Standards?

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

- **[New Mexico](#)**: Developed cross-agency partnerships and a joint set of objectives for incorporating the National Standards, including identifying a standard definition for CYSHCN for Medicaid contracts; establishing manuals and recommendations for youth transition; and expanding family leadership and engagement as partners.
- **[New York](#)**: Conducted a systems mapping project to evaluate state services for CYSHCN and referenced the National Standards as a guide to develop solutions and address gaps.
- **[Washington](#)**: Used the National Standards to guide efforts to improve policies and practices that impact insurance adequacy for Washington CYSHCN.
- **[Kansas](#)**: Conducted regional tours, family surveys, and planning meetings to assess performance and improve health care delivery, particularly around family partnerships.

“Kansas has utilized the National Standards in strategic planning on a number of occasions — resulting in the program making systemic improvements, the launch of a new care coordination and service delivery model, training and education opportunities for partners, and creating structure and alignment among partners and subcontractors.”

- Heather Smith, MPH, Director, Special Health Services, Kansas Department of Health and Environment

What resources are available to Title V 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 and organizations, including Title V programs, 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](#).
- **[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 individual 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.
- **[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](#).
- **[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