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

Tips for Health Care Providers 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 health care providers, health plans, and state health programs and policymakers 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 Providers 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.
- Serve as a guide for medical homes and managed care for CYSHCN.
- Develop processes that allow for ease of enrollment and transition for CYSHCN.
- Identify areas for quality improvement and quality measurement.
- Consistently evaluate processes and feedback to determine where improvements can be made.
- Promote coverage and payment strategies so that comprehensive care is accessible, affordable, and continuous.
- Provide information in clear, health-literate ways for families of CYSHCN.

"The National Standards provide constructs for improving and advancing the system of care for CYSHCN. Implementing the standards at the national, state, and local levels will allow for a consistent approach to improving the health of all CYSHCN."

– Debra Waldron, MD, MPH, FAAP, Senior Vice President, American Academy of Pediatrics

How have the National Standards been successfully implemented?

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.
- **Georgia:** Used the National Standards to assess needs, train providers on providing useful services, develop consistency in service delivery across agencies, and improve quality of service.
- **Kansas:** Conducted regional tours, family surveys, and planning meetings to assess performance and improve health care delivery, particularly around family partnerships.

What resources are available to implement the National Standards through a medical home model of care?

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 health care providers, 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.
- **Assessment Tools:** Helps providers examine how well they provide and improve quality care to CYSHCN and their families.
- **Systems Improvement Alignment Tool:** Helps providers determine how they 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.
- **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**