

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

## Tips for Families on Working with 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 families, state health policymakers, health care providers, and health insurers 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 CYSHCN receive comprehensive, coordinated, family-centered, quality care.

The National Standards provide the key ingredients for a health system that supports CYSHCN and their families - from doctors, nurses, and hospitals, to health insurers and the state public health department. 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. have 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 practical and measurable guidelines for how CYSHCN can get the best care possible.

### How can Families use the National Standards?

- Counter local policies that overlook the needs of CYSHCN with official guidelines that recognize the key elements of comprehensive systems of services for CYSHCN.
- Understand how systems *should be* working to ensure all children and families receive services that respect a family's cultural and language.
- Promote how families and CYSHCN can be active partners in all levels of health-related services.
- In partnership with other stakeholders, work in health systems to constantly evaluate activities and offer feedback to find chances to improve.
- Share with other families to help them understand how they can advocate for their child(ren).

*“The National Standards are a huge step forward in building systems that partner with families. Every child is different, and every family is different. The National Standards recognize that honoring our diversity and respecting the family as the constant in a child's life are necessary to improving our children's health.”*

– Nora Wells, Executive Director, [Family Voices](#)



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## How have the National Standards been successfully implemented?

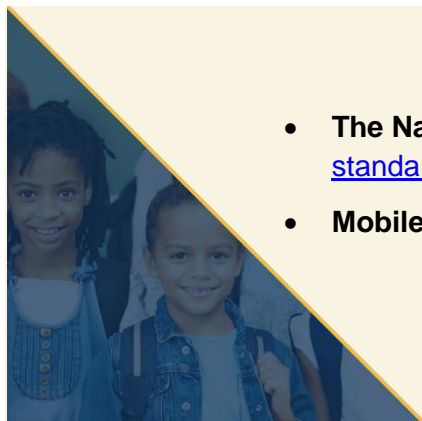
There are several ways states have successfully used the National Standards.

- **Iowa:** The Family Navigator Network used the Standards as an education and empowerment tool in training for the network and for the Iowa Family Leadership Training Institute, helping families advocate for system changes at the health care provider, program, and policy levels.
- **Georgia:** Families Advocating for Voices of Resilience, Inc. used the National Standards to assess needs, train health care providers on providing useful services, develop consistency in service delivery across agencies, and improve quality of services.
- **Kansas:** The Special Health Services Program conducted regional tours, family surveys, and planning meetings to assess performance and improve health care delivery, particularly around family partnerships.
- **Minnesota:** The Department of Health assessed the performance of the care coordination system to identify potential responsibilities throughout the system with the goal of fostering connections and networks between parents and coordinators.

## What resources are available to Families to work with the National Standards?

The Association of Maternal & Child Health Programs and the National Academy for State Health Policy developed several tools and resources to assist with the implementation of the National Standards. These tools can be used by various stakeholders, including families of CYSHCN, family-led organizations, and organizations focused on family partnership and engagement, to determine which of the standards are currently areas of strength and which are areas for improvement. These tools include:

- **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.
- **Examples of the National Standards in Action:** Case studies, webinars, and other examples of how organizations, systems, and programs have used 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**