

Case Study: Implementing the National Standards for Systems of Care for Children and Youth with Special Health Care Needs

Iowa's Title V CYSHCN Program: Using the National Standards to Build Family Leadership and Partnership

Iowa's Title V Children and Youth with Special Health Care Needs (CYSHCN) program has a long history of building the infrastructure for family-centered care and partnerships. Employing family professionals has been an essential strategy for Iowa's ability to deliver Title V services to all families, and increasingly the focus is on serving families from a diverse range of backgrounds. The Title V CYSHCN program's history of building meaningful family engagement began with the civil rights movement for individuals with disabilities. Julie Beckett,¹ long-time child health and disability rights advocate and Iowa's first family navigator, paved the way for Iowa Title V to employ other family-to-family support professionals. Across the states, individuals serving in these roles are known as parent consultants, parent partners, and/or family navigators. The intent to include families in the maternal and child health (MCH) workforce is embedded in a strengths-based approach to family-professional partnerships, which is grounded in the [National Standards for Systems of Care for CYSHCN \(National Standards\)](#). All of Iowa's Title V CYSHCN programs are driven by the foundational National Standard, which states that families of CYSHCN are active, core partners in decision-making in all levels of care. The Iowa Title V CYSHCN program uses the National Standards throughout its programs to build family leadership capacity across the state.

National Standards: Building Family Leadership Capacity and Advocacy in Working within Health Care Systems

Since 2016, the Iowa Family Leadership Training Institute (IFLTI) has trained more than 50 parents and caregivers of CYSHCN to develop advocacy skills and promote family-professional partnerships. As is done with all of Iowa's Title V CYSHCN programs, the IFLTI aligns with the Family as Core Partners foundational National Standard. The IFLTI trains parents and caregivers on advocacy at individual, community, policy, provider, and systems levels. The National Standards are used in these trainings to teach families how to strengthen systems by promoting shared decision-making with health care and other service providers about the best approaches to care for their own child(ren) and for children statewide.

IFLTI expands the advocacy skills that emerging family leaders attain through a 1:1 mentorship from an established peer leader. The IFLTI curriculum aligns with the National Standards to train family leaders to actualize the core tenets of family-centered care. With guidance from the IFLTI, training participants use the National Standards as the reference tool to evaluate the extent to which systems of care in their communities engage in family-centered care. Another goal of the training is to impart skills and knowledge for participants to work effectively with partners across the system of care for CYSHCN.



The alignment of the IFLTI curriculum with the National Standards helps families understand the following components of family-centered care:

How systems should be working to ensure all children and families receive needed services and supports

Who to partner with to ensure CYSHCN and their families receive comprehensive, coordinated, family-centered quality care.

¹ [Julie Beckett](#) is the mother of Katie Beckett who was the first child to receive a waiver to obtain Medicaid Home and Community-Based Services. The [Katie Beckett waiver](#) was granted in 1981 and has become a vehicle for many persons with disabilities to receive care at home or in their communities.

Using the National Standards as an Empowerment Tool to Advocate for Family-Centered Care in Iowa

Similar to how the National Standards are predicated on the expectation that children, youth, and families served by CYSHCN programs are active, core partners in decision-making at all levels of health care and health services, the Iowa Title V CYSHCN program provides a platform for families to provide meaningful input into planning, developing, and evaluating programs and policies. Using language from the National Standards, the Iowa Title V CYSHCN program adopted the following system standard as part of their overall strategic plan:

“Health systems that serve CYSHCN [must] have a family advisory board or committee, inclusive of families of CYSHCN that guides their policies, programs, and quality improvement activities and offers family members training, mentoring, and reimbursement for their participation as active members of these boards and committees.”

To achieve this standard of the strategic plan, Iowa Title V created the Iowa Family Advisory Council (FAC) in 2014. The council is comprised of members living in rural and urban areas across the state. The majority of the representation is mothers, but the FAC also includes one father and one youth member. Each FAC member receives a copy of the National Standards in their orientation packet, which are a key reference to Iowa’s family-centered approach to comprehensive primary care. Iowa’s family-centered approach to primary care also is holistic (values looking at the whole person), embraces communication with patients and families, and emphasizes coordination of care. Each February, the FAC participates in a “Day on the Hill” with the Iowa Legislature. FAC members have taken the National Standards to these visits. In one case, a FAC member referenced the National Standards along when speaking with a legislator about the need for patient/family-centered care coordination in Iowa.

Lessons Learned and Next Steps

- For Iowa Title V CYSHCN, embedding the National Standards throughout its practices as an evidence-based, nationally vetted framework promotes the value of gaining the family perspective in all aspects of systems of care for CYSHCN.
- The National Standards provide context for training family leaders to provide peer support to families navigating the systems of care for their CYSHCN.
- Iowa’s Title V program will continue to train family leaders to build awareness of the need for actualizing family-centered care in Iowa’s systems of care for CYSHCN. Specifically, Iowa Title V CYSHCN uses both the Version 1.0 and Version 2.0 versions of the National Standards simultaneously when they build programs to help families advocate with providers or health systems. Version 1.0 includes a domain for all standards related to family-professional partnerships. This version is useful to focus on, embed, and promote family-centered care and family partnership. Version 2.0 is a streamlined version of Version 1. It retains the standards of the first version, either in the foundational standards or in one of the eight relevant domains. Version 2.0 is useful for highlighting how family-professional partnerships standards are integrated across domains of interest to various partners in systems of care for CYSHCN.²
- Iowa continues to use the National Standards as a foundational guide for planning and assessing the performance of the Title V CYSHCN program. Future plans are in the works to explore opportunities



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, Palo Alto, California. The views presented here are those of its authors and not necessarily those of the Foundation or its directors, officers or staff.

² [Version 1.0](#) of the National Standards was released in 2014. The [streamlined version 2.0](#) was released in 2017.

that will ensure all families living in Iowa have access to culturally and linguistically appropriate care coordination and resources, which follow the guidance of the National Standards.

References:

- Maternal and Child Health Title V Block Grant FY 2020 Application/FY18 Annual Report for Iowa. Available from: https://mchb.tvisdata.hrsa.gov/uploadedfiles/StateSubmittedFiles/2020/IA/IA_TitleV_PrintVersion_FY20.pdf

Access the National Standards, resources, and more information at:

- **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**