

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

Rhode Island's Title V Program: Using National Standards to Guide Improvements in Statewide Care Coordination

A priority of the Rhode Island Department of Health's (RIDOH's) Title V Maternal and Child Health (MCH) and Children and Youth with Special Health Care Needs (CYSHCN) program is to improve the systems of care for CYSHCN, especially as it pertains to enhancing care coordination. Rhode Island's Title V Program coordinates closely with key partners—such as Medicaid, health plans, and public health policy groups—that seek to optimize and incentivize health care financial and service delivery models to improve care coordination, health care quality, and health outcomes among MCH and CYSHCN populations. The Rhode Island Title V program used the [National Standards for Systems of Care for CYSHCN](#) (National Standards) as a resource to provide statewide partners with shared principles and direction to ensure family-centered, comprehensive care coordination.

Improving Care Coordination in Primary Care Medical Homes

In 2008, Rhode Island's Office of the Health Insurance Commissioner launched the [Care Transformation Collaborative of Rhode Island](#) (CTC) to bring together key health care stakeholders to promote care for adult patients with chronic illnesses through the patient-centered medical home (PCMH) model. CTC is a multi-practice, multi-payer initiative through which health care practices share a common contract with all the payers. The contract supports transformation through technical support, collaborative learning, and per-member per-month payments to practices. In 2013, the adult PCMH initiatives' demonstrated success spurred the development of a PCMH-Kids initiative to extend the transformation to practices that serve children.

Rhode Island's Title V Program served a key role in helping plan, develop, and implement PCMH-Kids. RIDOH contributed to the initial steering committee convened by Rhode Island Medicaid and the Rhode Island Office of the Health Insurance Commissioner. Stakeholders also included pediatricians; family doctors; payers; child-serving community organizations; the Rhode Island Department of Children, Youth and Families; parent and patient voices; and child health advocates.

Early stakeholder conversations observed that adult models of case management and insurance infrastructures were not as relevant or meaningful for children and families (see *text box*). Rhode Island's Title V staff used the National Standards to guide partners in visioning what an ideal, well-functioning system of care should look like for CYSHCN and their families. Title V staff also discussed the key components for family-centered, coordinated, ongoing comprehensive care within a medical home. Title V staff provided PCMH-Kids practitioners a copy of the Standards, and several providers participated in a facilitated walkthrough of the Standards. The ability to reference standards vetted by state and national leaders provided critical backing for what a family-centered approach to care coordination should look like and provided a clear picture that care coordination integrates physical health, oral health, mental health, and community-based services.

The PCMH-Kids Steering Committee identified differences in the needs for children and families and the adult CTC models:

For Adults:

- Case management models focused on specific disease entities.
- Health insurance models used risk determination algorithms based on health care utilization and costs.

For CYSHCN:

- Care coordination needed to be comprehensive and family-centered.
- The adult risk determination models did not provide adequate measures to identify children at-risk and their families who could benefit from care coordination.
- Often practitioners could identify at-risk children and families based on the specific chronic condition, whether or not they visited multiple providers, the results of basic needs screens, and children and their families' presenting concerns in clinical sessions.

When PCMH-Kids launched in 2015, Rhode Island’s Title V program provided training on care coordination. The National Standards were referenced in these trainings as a framework for effective care coordination for CYSHCN, and as an explanation for why the trainings used a [family-centered, comprehensive approach](#)¹. PCMH-Kids aimed to address a critical unmet need for care coordination that not many primary care practices were providing at the time. The National Standards helped practitioners understand their role in the system of care and how care coordination must become a key component of their work. Furthermore, nurse case managers who had been hired as care coordinators under the PCMH-Kids initiative were able to understand the ways that care coordination for children needed to differ from the care coordination practices for adult medicine.

Improving Care Coordination in Specialty Care

As primary care sites developed a better understanding of their role in care coordination as part of the PCMH-Kids initiative, the Rhode Island team became more aware of their need to engage more health plans and specialty practices in improving care coordination for CYSHCN. A multidisciplinary workgroup² from Rhode Island participated in the National Academy for State Health Policy’s learning collaborative entitled “[To Strengthen Medicaid Managed Care for CYSHCN with Chronic and Complex Health Needs](#).” In this platform too, the National Standards provided a framework for the Rhode Island team to better understand effective care coordination for CYSHCN. As part of this learning collaborative, the Rhode Island team used the care coordination standards within the National Standards as a framework to analyze care coordination services that a specific group of CYSHCN received while enrolled in Medicaid managed care within a community specialty care center.

The analysis identified numerous barriers to providing care coordination:

- Limited communication between care coordinators
- Lack of official designation for some care coordinators by Medicaid, which prevents providers from getting reimbursed
- Inability of care coordinators to authorize services, which causes delays in providing care

The Rhode Island team is exploring policy changes to address these barriers, such as identifying a lead care coordinator. The team found the National Standards served as an organizing framework that provides detailed steps on how to actualize the concepts of family-centered, comprehensive care coordination. As an example, one way that Rhode Island ensures family-centered care coordination is that families have been trained as and are accepted (often preferred) as care coordinators.

Lessons Learned and Next Steps

Rhode Island’s Title V team found that the National Standards served as an evidence-based, nationally vetted framework to understand how to provide effective care coordination and systems of care for CYSHCN and their families. Key partners use the National Standards to achieve a shared understanding of how to implement effective care coordination. The National Standards provide a context to identify steps the state must do differently to improve care coordination. Rhode Island continues to use the National Standards as a tool to



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¹ A second edition of the Pediatric Care Coordination Curriculum was released in 2019 and is available at:

<https://medicalhomeinfo.aap.org/tools-resources/Documents/PCCC%202nd%20Edition/Full%20Pediatric%20Care%20Coordination%20Curriculum.pdf>.

² Rhode Island’s Learning Collaborative team members included representatives from the RIDOH Title V program, Medicaid, [CEDAR providers](#) (state-designated health homes that provide care coordination for CYSHCN), children’s hospital, and a health plan that covers CYSHCN in Rhode Island.

improve systems of care in various ways from identifying those CYSHCN who can benefit from care coordination; engaging families and youth in meaningful ways; and improving access to community-based services.

References:

- Maternal and Child Health Title V Block Grant FY 2020 Application/FY18 Annual Report for Rhode Island. Available from: https://mchb.tvisdata.hrsa.gov/uploadedfiles/StateSubmittedFiles/2020/RI/RI_TitleV_PrintVersion_FY20.pdf.
- Flanagan P; Lange E. A Statewide Pediatric Care Transformation Journey. RIMJ. Dec 2018:20-23. Available at: <http://www.rimed.org/rimedicaljournal/2018/12/2018-12-20-pcmh-kids-flanagan.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**