

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

## ▶ New York's Title V CYSHCN Program: Using the National Standards as a Framework for Action Planning and Data Analysis

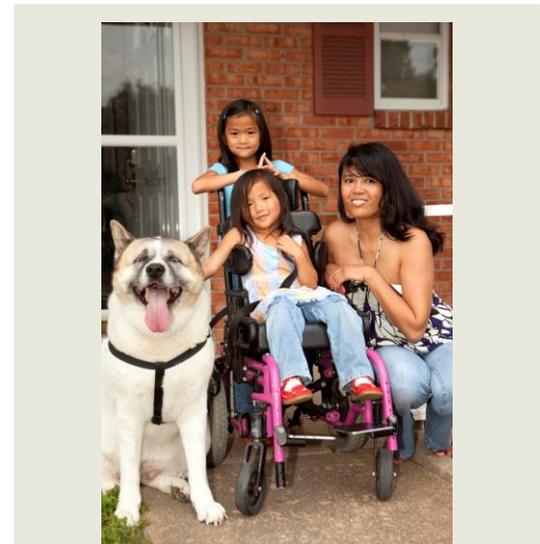
The Division of Family Health, housed within the New York State Department of Health, administers the state's Title V program and oversees the protection and improvement of maternal and child health. New York's Title V program aims to incorporate national guidelines into state-level work wherever possible. New York's Title V staff use the National Standards for Systems of Care for CYSHCN (the National Standards) as a framework upon which individuals from different backgrounds can form a common understanding of the needs that an ideal system of care could address.

New York recently utilized the National Standards as a reference tool for planning initiatives to increase supports to address the special health care needs of children and youth.<sup>1</sup> New York analyzed existing CYSHCN data through a systems mapping project to evaluate the states' services for CYSHCN to inform future state public health priorities, strategies, and program activities.<sup>1</sup>

### Systems Mapping Project to Identify Barriers to Care Among Families of CYSHCN

New York began its systems mapping project to identify the connections and relationships that exist among programs and services and to identify specific issues, gaps and barriers in the system of public health programs and services for CYSHCN and their families. Title V staff facilitated discussions with families of CYSHCN to identify barriers and areas for improvement within the current system of care. These discussions allowed for systematic data collection while also enriching data with anecdotal input. New York conducted interviews with more than 130 families of CYSHCN of differing regions, races, conditions, ages, and needs.

The analysis of family feedback identified a common call for 1) further information provided at the time of diagnosis and at multiple points at which families connect with the service system; 2) expansion of social opportunities for CYSHCN and their parents; and 3) better assistance with the financial strain associated with caring for CYSHCN. Title V staff plan to further analyze the feedback and use it to inform and enhance its CYSHCN program. New York intends to incorporate evidence-based practices that align with the National Standards, as well as with guidelines released by other public health and professional organizations, such as the American Academy of Pediatrics' Bright Futures.



*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.*

In utilizing family input to direct its improvement efforts, New York is responding to the call for engagement of CYSHCN and their families as active, core partners involved in decision making in all levels of care, a foundational principle noted in the National Standards.

## Lessons Learned and Next Steps

New York found that tying its work, such as the systems mapping project, to the National Standards promotes stakeholder support and valuation of its projects through using data to pinpoint barriers to care.. New York plans to continue to use the National Standards to inform processes, support decision-making, and guide the development of solutions to further engage families in creating a system of care that best serves CYSHCN. New York will continue to use the National Standards as a framework as it moves towards strengthening the health care system that ensures consistency, equal access, and widespread support for children and families of CYSHCN.



**Access the National Standards, resources, and more, 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**

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<sup>i</sup> Maternal and Child Health Services Title V Block Grant: New York FY 2018 Application/FY 2016 Annual Report. Created September 29, 2017. Available from: [https://mchb.tvisdata.hrsa.gov/uploadedfiles/StateSubmittedFiles/2018/NY/NY\\_TitleV\\_PrintVersion.pdf](https://mchb.tvisdata.hrsa.gov/uploadedfiles/StateSubmittedFiles/2018/NY/NY_TitleV_PrintVersion.pdf)