



## NATIONAL CENTER FOR MEDICAL HOME IMPLEMENTATION

A cooperative agreement between the Maternal and Child  
Health Bureau/HRSA and the American Academy of Pediatrics

# National Center for Medical Home Implementation (NCMHI) State Title V / Children and Youth with Special Health Care Needs (CYSHCN) Technical Assistance and Resources Needs Assessment Project

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## OVERVIEW

This document presents key findings from the NCMHI Maternal Child Health (MCH) Title V / CYSHCN Programs Technical Assistance and Resources Needs Assessment Project conducted in 2017-2018. The purpose of this project was to gain insights from MCH Title V / CYSHCN programs on how the NCMHI can better provide technical assistance and resources to states focused on National Performance Measure 11 (medical home) and/or patient-/family-centered care.

Using a mixed-methods approach, an electronic survey targeting state MCH Title V / CYSHCN directors was conducted during fall 2017. Of the 113 individuals who received the survey, a total of 50 (44.2%) completed the survey. In addition to the survey, key informant telephone interviews were conducted with ten teams comprised of state MCH Title V / CYSHCN directors and other program staff. The ten participating state teams were located in the four major regions of the United States as follows: Northeast (n=2), South (n=3), Midwest (n=2), and West (n=3).

## KEY FINDINGS

- The **top five NCMHI resources** ranked as most useful by survey respondents included the following:
  - [Promising Practices](#)
  - [State Profiles](#)
  - [State Pages](#)
  - [State At-a-Glance Table](#)
  - [Toolkit/Online Resource Guide](#)
- The **top five types of NCMHI technical assistance** rated by survey respondents as most important in advancing the medical home model included the following:
  - Access to [care coordination resources](#) and information related to measurement, implementation, and training/education
  - Assistance in designing [culturally competent](#) community-based medical home projects or initiatives
  - Customized and targeted one-on-one [technical assistance](#) from NCMHI staff and experts with Title V / CYSHCN programs (via email, telephone or otherwise)
- Resource guides to help with implementation of [key medical home functions](#) in practices and states
- “How to” tutorials on topics related to [family engagement](#) and [team-based care](#)
- Based on interviews with state teams, the **most important emerging trends** that will affect services for CYSHCN and their families in their states, centered around the following themes:
  - Uncertainty regarding changes to Medicaid/Medicaid managed care/Medicaid waiver 1115
  - Mental and behavioral health / delivery systems for patients with mental health issues
  - Telehealth
  - Access to health care for immigrant families
  - Lack of available transportation options for getting to and from medical appointments
  - Lack of specialty and subspecialty care/provider shortages

- State teams' most commonly requested suggestions for **technical assistance and resources** included the following:
  - Identify funding, financing, and affordability strategies relevant to medical home and CYSHCN
  - Provide profession-specific medical home orientation training resources for new staff and stakeholders
  - Facilitate medical home stakeholder partnerships, collaboration, and systems integration
  - Provide education and information, and raise awareness to all medical home stakeholders
  - Identify relevant measurement, evaluation, and evidence-based strategies
  - Ensure CYSHCN and their families are involved in planning and implementing medical home initiatives and policies, especially at the national level
- Nearly all state teams expressed concern that **many families of CYSHCN lack access to pediatric subspecialists/specialists and/or lack transportation options for getting to and from medical appointments.**
  - Most teams expressed the opinion that telehealth has great potential to help CYSHCN and families who lack transportation options for getting to and from medical appointments
  - Some mentioned that one of the challenges with implementing telehealth is the time it takes to establish the programs
- The **most commonly reported challenges** to advancing family-centered care (FCC) centered around the following themes:
  - Providing sufficient training for families and clinician in FCC
  - Language barriers / lack of sufficient resources to meet the needs of culturally and linguistically diverse families
  - Differences in how families and providers understand and experience FCC
  - Lack of specialty and subspecialty care/provider shortages
  - Lack of resources / reimbursement for care coordination
- While most state teams mentioned that their states were focused on transition, many discussed their **transition initiatives** separately from their medical home efforts, suggesting an opportunity for the NCMHI to clarify the role of the medical home in supporting transition.
- Most state teams interviewed expressed the need for **improved partnerships with state Medicaid agencies**, especially with regard to shared definitions, measures, communication, and involvement / collaboration related to CYSHCN and medical home initiatives. Some teams mentioned that it would be helpful to clarify and develop a shared understanding of the unique care coordination needs of CYSHCN.

## DISCUSSION AND NEXT STEPS

According to these results, state MCH Title V/CYSHCN directors have found NCMHI technical assistance and resources to be useful and important in advancing the medical home model, and patient/family-centered care, in their states. However, reported health care trends affecting CYSHCN—especially regarding changes to Medicaid, integration of mental health services, telehealth, lack of access to transportation and specialists/subspecialists—suggest that states may need additional support in their efforts to provide CYSHCN and families with patient/family-centered care within the medical home.

To address the state teams' requests for technical assistance in the areas of financing strategies; medical home orientation training; building stakeholder partnerships especially with Medicaid agencies; and ensuring that CYSHCN and their families

are included in planning and implementing medical home initiatives and policies, NCMHI will implement the following strategies:

- Solicit and promote state MCH Title V/CYSHCN programs through its Promising Practices initiative
- Collaborate with and promote technical assistance centers and resources focused on healthcare financing and medical home specifically related to CYSHCN
- Involve parent partners / leaders more concertedly in the development of all NCMHI projects and resources
- Develop a series of communications promoting relevant medical home tools and resources for state MCH Title V/ CYSHCN directors

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