



THE NATIONAL ALLIANCE
TO ADVANCE ADOLESCENT HEALTH



National Center for a
System of Services for
Children and Youth
with special health care needs

FROM THE AMERICAN ACADEMY OF PEDIATRICS

A Review of Medicaid Managed Care Contracts to Inform the CYSHCN Blueprint Roadmap

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for the

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Executive Summary

Medicaid is the single most important source of coverage for children and youth with special health care needs (CYSHCN), and the vast majority of Medicaid-insured CYSHCN are served in managed care arrangements. Recognizing this, Medicaid managed care contracts (MCCs) represent an important source of information for the National Center for Systems of Services for CYSHCN in its efforts to develop a Roadmap for state Title V CYSHCN agencies to advance health equity, quality of life and well-being, financing, and access for CYSHCN and their families. We examined Medicaid managed care contracts (MCCs) 17 states, which were selected based on their use of the National Systems of Care Standards for CYSHCN, to answer four research questions about health equity, family engagement, cross-system partnerships, and accountability for CYSHCN.

The most common MCC provisions found related to health equity were development of health equity/cultural competency plans, quality assessment and improvement related to reduction in health disparities and social determinants of health, and equity-focused screening, data collection, and reporting. The most common provisions related to family engagement were having a general definition of family-centered care, representation on advisory councils/quality improvement (QI) committees, and care management and treatment planning. The most common provisions related to cross-system partnerships were referrals to community organizations, collaborative initiatives to address social determinants of health, and coordination with community organizations around services for children. Lastly, the most common provisions related to system of services accountability were performance measurement and QI for CYSHCN and/or special-needs populations and reference to specific standards, policies, and procedures (see Table 1).

Introduction

Medicaid covers almost half of children and youth with special health care needs (CYSHCN) in the US. According to the 2022 National Survey of Children’s Health, 45% of CYSHCN under age 18 rely on Medicaid alone or in combination with private insurance, making it the single most important source of coverage for those with chronic and disabling conditions.¹ The vast majority of Medicaid-insured CYSHCN are served in Medicaid managed care arrangements.

The purpose of this report is to help inform state Title V programs in considering potential areas of collaboration with Medicaid related to the Blueprint for Change for CYSHCN.² This report, which is part of a larger environmental scan completed for the National Center for Systems of Services for Children and Youth with Special Health Care Needs (National Center), examines selected Medicaid managed care contracts (MCCs) and Requests for Proposals (RFPs). State Title V CYSHCN Programs and Medicaid agencies have a long history of working together and are required by law to collaborate to ensure that women and children, including those with special health care needs, are provided needed preventive care, treatment, and follow-up.

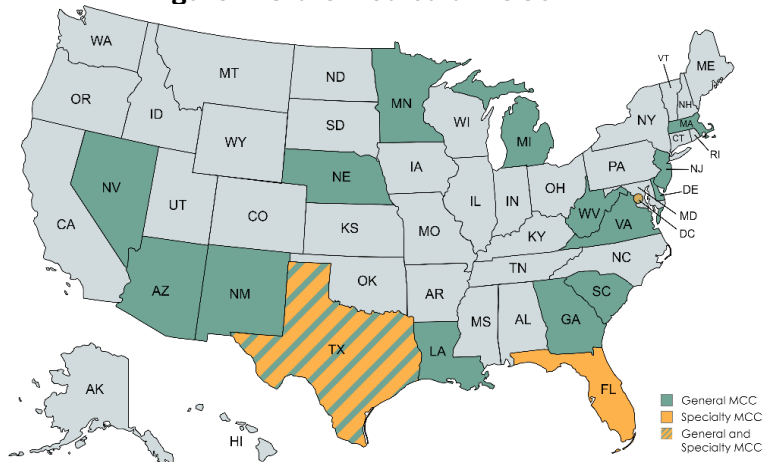
Methods

We analyzed 16 general Medicaid MCCs and 3 specialty MCCs in 17 states (Figure 1) for policy and program provisions related to the questions below. These general and specialty (S) MCCs were selected based on a survey the National Academy for State Health Policy conducted in 2019 to identify states using the National Standards for CYSHCN in their Medicaid program.³ The MCCs reviewed were in effect as of July 2023. The four questions that guided the analysis were:

1. Are systemic causes of health inequities addressed in Medicaid MCCs?
2. Is family engagement in the design, provision, and oversight of care to CYSHCN specified in MCCs?
3. Do MCCs include cross-system partnerships that align health and community supports for CYSHCN and their families?
4. Is accountability for a system of services for CYSHCN and their families part of MCCs?

A small workgroup made up of state Title V leaders, family advocates, and National Center representatives met twice to discuss and finalize the four questions above. For each of the above questions, we present MCC provisions organized by selected framework topics. We also include examples of distinctive provisions selected either because of reference to CYSHCN or the MCC specification detail. Please click [here](#) to view a supplemental table with the actual Medicaid MCC provisions.

Figure 1. State Medicaid MCCs



Findings

Table 1 provides a summary of the most common Blueprint-related categories found in MCCs. More detail about the provisions can be found in the following sections.

Table 1. Most Common MCC Provisions Relevant to the Blueprint for Change

Health Equity
a. Development of health equity/cultural competency plans
b. Quality assessment and improvement related to reduction in health disparities and social determinants of health
c. Equity-focused screening, data collection, and reporting
Family Engagement
a. General definition of family-centered care
b. Representation on advisory councils/quality improvement (QI) committees
c. Care management and treatment planning
Cross-System Partnerships
a. Referrals to community organizations
b. Collaborative initiatives to address social determinants of health
c. Coordination with community organizations around services for children
System of Services Accountability
a. Performance measurement and QI for CYSHCN and/or special-needs populations
b. Reference to specific standards, policies, and procedures

1. Health Equity

Are systemic causes of health inequities addressed in Medicaid MCCs?

Of the 16 general Medicaid MCCs and three specialty (S) MCCs examined in 17 states, all but three states (GA, SC, VA) included at least one provision related to health equity. The most common provisions were focused on the development of health equity/cultural competency plans (16 provisions), quality assessment or improvement (13 provisions), and screening or evaluation of social determinations of health (SDOH), health-related social needs (HRSN), or health disparities (12 provisions). With few exceptions, states' equity initiatives were not specific to CYSHCN.

MCC provisions on health equity were categorized by type of approach, adapted from CMS and Institute for Healthcare Improvement (IHI) equity frameworks.⁴ Both frameworks address equity-focused data collection and analysis, strategies to address multiple SDOH, equity in policy/procedures, community partnerships, culturally tailored services, and equitable payment models.

Medicaid MCC equity provisions are presented below from most to least common and are followed by examples of distinctive provisions. In some categories, the number of provisions may not equal the number of states as some states included more than one related provision. Click [here](#) for a supplemental spreadsheet with full Medicaid MCC provision language.

Table 2. Medicaid MCC Provisions on Health Equity

1. Use of health equity/cultural competency plans, quality measurement and improvement, and financial incentives 35 provisions in 11 states		
Strategy	# of provisions	# of state(s)
a. Development of health equity and/or cultural competence plan	16	8 (DC-S, DE, LA, MI, NJ, NM, TX, TX-S, WV)
b. Quality assessment or performance improvement related to SDOH or reduction in health disparities	13	5 (DC, DC-S, LA, MN, NE, NJ)
c. Payment innovations/provider incentives aimed at health equity	5	4 (LA, MA, NE, WV)
d. Measures of cultural and linguistic competence	1	1 (NM)
2. Equity-focused screening, data collection, and reporting 19 provisions in 8 states		
Strategy	# of provisions	# of state(s)
a. Screening or evaluation for SDOH, health-related social needs (HRSN), or health disparities	12	6 (AZ, DC, DC-S, DE, MA, NE, WV)
b. Data collection and/or analysis that identifies race, ethnicity, language, disparities, and/or culture	5	2 (LA, NV)
c. EHR system and staff training on reporting of HRSN	2	1 (MA)
3. Education, training, policies, and governance procedures 12 provisions in 6 states		
Strategy	# of provisions	# of state(s)
a. Cultural competency/health equity/HRSN training for providers/staff	5	4 (DC-S, DE, LA, MA)
b. Information/education on community resources, education, and programs for disease management	3	3 (DE, FL-S, MA)
c. Use of National Committee on Quality Assurance (NCQA) equity accreditation or distinction standards	2	2 (DE, NE)
d. Policies and procedures to develop a workforce to increase support for behavioral health and developmental disabilities	1	1 (LA)
e. Designated pediatric expert to support CYSHCN	1	1 (MA)
4. Partnerships with community organizations to improve referral processes and health equity 10 provisions in 8 states		
Strategy	# of provisions	# of state(s)
a. Collaboration with community-based organizations (CBOs) or community members to address health equity	7	6 (AZ, LA, MI, MN, VA, WV)
b. Advisory group to promote equity that includes community members	3	3 (DE, NE, WV)

Box 1. Examples of Distinctive MCC Provisions on Health Equity

- A. **Louisiana** allows MCOs to earn their health equity withhold back based on performance. The MCO is required to develop a multi-year health equity plan that includes results on quality measures to identify/address disparities, staff/provider training requirements related to equity, social needs/equity questions in the Health Needs Assessment and mechanisms to close the referral loop to act on identified social risk factors, and engage a variety of enrollees/populations in the health equity approach. A Health Equity Administrator is the single point of contact for all matters related to health equity.
- B. **Michigan** requires MCOs to maintain a multi-year plan to incorporate social determinants of health into their process for analyzing data to support population health management, including which determinants will be added, method for collecting and analyzing the data, manner in which social determinant risk determinants are validated, timeline, and plan for training staff and care managers to use the data. Data such as medical and dental claims data, pharmacy data, and laboratory results, supplemented by Utilization Management data, Health Risk Assessment results and eligibility status (e.g., members enrolled in Children’s Special Health Care Services) must be used to address health disparities, improve community collaboration, and enhance care coordination, care management, targeted interventions, and complex care management services.
- C. **Nevada** requires MCOs to use predictive modeling tools to stratify members by risk and identify those who are appropriate for care coordination and case management supports. The stratification model must consider physical, behavioral, and social determinant of health needs identified through data sources such as claims, pharmacy, utilization data, laboratory results, health needs assessments and other screenings/assessments, referral information, and census or other geographic data. The model should include methods to identify racial and ethnic health disparities.
- D. **New Mexico** requires MCOs to develop and implement a cultural competence/sensitivity plan to ensure it provides culturally competent services to its members. The MCO shall also conduct initial and annual organizational self-assessments of culturally and linguistically competent-related activities and integrate related measures into its internal audits, performance improvement programs, member satisfaction surveys, and outcomes-based evaluations.

2. Family Engagement

Is family engagement in the design, provision, and oversight of care to CYSHCN specified in MCCs?

Of the 16 general Medicaid MCC and 3 specialty MCC contracts examined, all but five MCCs (NJ, NM, SC, TX-S, VA) in our review included at least one provision related to family-centered care/family engagement. The most common provision was including a general definition of family-centered care as part of the sections on definitions, medical home, or care coordination (8 provisions). The next most common provisions were around methods for engaging enrollees with SHCN in care management and treatment planning (4 provisions), representation through a patient/family advisory council (4 provisions), and participation on Quality Improvement (QI) committees or focus groups (4 provisions).

To categorize the MCC provisions, we used the Family Voices’ Framework for Assessing Family Engagement in Systems Change.⁵ The domains in this framework are *commitment* (family engagement is normalized and included throughout the activities that impact the organization at the systems level), *transparency* (access to the knowledge that allows all partners to fully participate in the process, and maximize their own effectiveness), *representation* (the process by which family leaders stand in for the rest of their community

in systems-level activities such as needs assessment and strategic planning), and *impact* (what the organization is doing differently because it has engaged families in creating systems-level change).

Family engagement provisions are presented below in Table 3 from most common to least common, followed by examples of distinctive provisions (Box 2). In some categories, the number of provisions may not equal the number of states as some states included more than one related provision. Click [here](#) for a supplemental spreadsheet with full Medicaid MCC provision language.

Table 3. Medicaid MCC Provisions on Family Engagement

1. Representation 14 provisions in 6 states		
Strategy	# of provisions	# of state(s)
a. Use of patient/family advisory council	4	4 (LA, MA, MI, NE)
b. Participation on QI committees or focus groups	4	3 (FL-S, MA, NE)
c. Participation on Local Interagency Planning Teams and Regional Action teams for children with serious emotional disturbances/substance use disorder	2	1 (GA)
d. Experience/approach for engaging diverse families when designing services and addressing adverse childhood experiences (ACEs) and trauma and disparate outcomes	2	1 (LA)
e. Engagement of trusted messengers and community-based organizations (CBOs)	1	1 (LA)
f. Policies and procedures providing enrollees and families opportunity to provide input related to access and member services	1	1 (MI)
2. Commitment 11 provisions in 8 states		
Strategy	# of provisions	# of state(s)
a. General definition of family-centered care as part of the definitions, medical home, or care coordination sections	8	6 (AZ, DC, DC-S, GA, MA, NE, WV)
b. Designation of MCO advocate staff to address member/family concerns	2	2 (AZ, DE)
c. Title-V attested PCP assignment for CYSHCN providing family-centered care	1	1 (MI)
3. Transparency 8 provisions in 6 states		
Strategy	# of provisions	# of state(s)
a. Methods for engaging enrollees with SHCN in care management and treatment planning	4	4 (GA, LA, MN, TX)
b. New enrollee orientation on family-centered care and family involvement with care and treatment planning	2	1 (DC, DC-S)
c. Development of family-centered care plan for CYSHCN with family and care team	2	1 (MI)
4. Impact 1 provision in 1 state		
Strategy	# of provisions	# of state(s)
a. Use of feedback from enrollees/family members to improve programs, including health equity initiatives	1	1 (LA)

Box 2. Examples of Distinctive Approaches on Family Engagement

- A. Delaware** requires MCOs to employ Member Advocates to communicate and collaborate with members and their families, advocacy groups, providers, community-based organizations, subcontractors, downstream entities, MCO staff, and state staff to identify and address concerns related to member access to care, quality of care, health equity, member experience of care, and health related social needs.
- B. Louisiana** requires MCOs to use feedback from enrollees/family members to identify and execute program improvements (e.g., community engagement; home visiting programs; collaboration with community-based organizations, douglas, and/or community health workers; and provider training).
- C. Massachusetts** requires MCOs to have a Patient/Family Advisory Committee. The Advisory Committee provides regular feedback on issues of enrollees care and services; identifies and advocates for preventive care practices to be utilized by the MCO; is involved with development and updating of cultural and linguistic policies and procedures; advises on the cultural appropriateness and member-centeredness of services, programs, and trainings; and provides input on member experience survey results and other data.
- D. Michigan** requires MCOs to assign CYSHCN Title V members to PCPs that provide family-centered care. The PCP must provide written attestation that they meet certain qualifications, including that they are willing to accept enrollees with potentially complex health conditions, regularly serve and have a mechanisms to identify children or youth with complex chronic health conditions, provide longer appointments when children have complex needs and require more time, has experience coordinating care for children who see multiple professionals, has a designated professional responsible for care coordination, and provides services appropriate for health care transition (e.g., transition assessment tool and adoption of a transition policy that is publicly posted and specifies the transition time frame, transition approach, and legal changes that take place in privacy and consent at age 18).

3. Cross-System Partnerships in MCCs

Do MCCs include cross-system partnerships that align health and community supports for CYSHCN and their families?

Of the 16 general Medicaid MCC and 3 specialty MCC contracts examined, all but one MCC (NE) included at least one provision related to cross-sector partnerships. The most common provisions were referrals to community organizations (8 provisions), followed by working with community organizations to link and coordinate services for children (6 provisions) and identifying and addressing HRSN (6 provisions). To categorize the MCC examples, we drew on UCLA's framework for cross-sector partnerships to address childhood adversity and improve life course health⁶ and RAND/RWJF culture of health action framework.⁷

Medicaid MCC cross-system partnership provisions are presented below from most common to least common, followed by examples of distinctive provisions. In some categories, the number of provisions may not equal the number of states as some states included more than one related provision. Click [here](#) for a supplemental spreadsheet with full Medicaid MCC provision language.

Table 4. Medicaid MCC Provisions on Cross-Sector Partnerships

1. Cross-sector collaboration for individual care planning and care coordination 19 provisions in 12 states		
Strategy	# of provisions	# of state(s)
a. Working with community organizations to link and coordinate services for children (e.g., school-based services, child protection, behavioral health, and developmental disabilities service organizations, etc.)	6	5 (DE, GA, MA*, NJ, TX*, TX-S*)
b. Title V and Medicaid MCO coordination	3	2 (TX*, TX-S*, WV)
c. Collaboration of health plans, outside partners, providers, and members to promote continuity of care and care management	3	3 (MI, NV, NM)
d. Interagency collaboration	3	1 (VA)*
e. Use of Community Resource Coordination Groups	2	1 (TX, TX-S)
f. Medical information shared between MCO and schools	1	1 (AZ)
g. Coordination of medical needs with social service needs	1	1 (MN)
2. Information and referral to community resources and social supports 14 provisions in 7 states		
Strategy	# of provisions	# of state(s)
a. Referrals to community organizations	8	5 (DC-S, FL-S, MA*, TX, TX-S*, VA)
b. Use of community resource registry	5	2 (DE, TX, TX-S*)
c. Identification of community advocates to provide culturally competent services, including methods of outreach and referral	1	1 (NM)
3. Initiatives to align health and social supports 13 provisions in 7 states		
Strategy	# of provisions	# of state(s)
a. Identification of and efforts to address health-related social needs	6	3 (DE, MA*, VA)
b. Community collaboration to address health disparities	3	2 (MI*, WV)
c. Community-based coalitions between the MCO, rehabilitative services, and disability services	2	1 (TX*, TX-S*)
d. Creation of public health goals in partnership with public health agency that align with community health assessments	1	1 (MN*)
e. Development and implementation of a County Engagement strategy	1	1 (MN)
4. Mechanisms that ensure cross-sector collaboration (this section could include data sharing, financing, quality measurement) 10 provisions in 9 states		
Strategy	# of provisions	# of states
a. MCO designated staff as member advocates to help coordinate and communicate with schools and community organizations/state agencies	2	2 (DE, SC)
b. Evaluation of community engagement and health-related social needs initiatives	2	2 (DE, LA)
c. Use of joint collaborative protocol with system stakeholders	1	1 (AZ)
d. Provision of MCO data on Integrated Health Partnerships Demonstration	1	1 (MN)
e. Collaboration with primary care practices to implement and measure effectiveness of evidence-based interventions to reduce health disparities	1	1 (MI)
f. Participation in local interagency planning teams to coordinate services for children	1	1 (GA*)
g. Reporting of efforts to engage key partners and establish community-based partnerships	1	1 (VA*)
h. Provision of SDOH data to inform partnerships with community resources	1	1 (WV)

5. Collaborative planning to assess community needs 7 provisions in 5 states		
Strategy	# of provisions	# of state(s)
a. Participation in collaborative community health assessments	5	4 (MI*, MN*, TX*, TX-S*, WV)
b. Participation in population health initiatives in partnership with community-based organizations and MCOs	2	1 (LA)
6. Leadership commitment and stakeholder buy-in 5 provisions in 4 states		
Strategy	# of provisions	# of states
a. Participation in stakeholder/interagency advisory group	3	2 (DE, GA*)
b. Participation in state/local crisis systems of services collaboratives/workgroup	1	1 (LA)
c. Senior leadership involvement in collaborative, cross-system health management strategies	1	1 (NV)

*This provision is included in more than one category.

Box 3. Examples of Distinctive Provisions on Cross-System Partnerships

- A. **Massachusetts** requires screening of each member for HRSN upon enrollment and use of the results when creating a care plan and coordinating care. It is also required that community and social supports be identified to address their HRSN and information be shared about how to contact supports and the accessibility of the supports. The MCO is also required to assist the members in attending referral appointments, including coordinating transportation assistance and following up after missed appointments.
- B. **Minnesota** requires the MCO to collaborate with the local public health agency and community organizations providing health services in the area on local public health community health assessments and the implementation of community health improvement plans, in order to align their public health priority areas with those of local public health agencies.
- C. **South Carolina** requires the MCO to include an interagency liaison who is responsible for coordinating the provision of services with HCBS waivers, community resources, Medicaid and other state agencies, and any other community entity that traditionally provides services for members.
- D. **West Virginia** requires the MCO to collaborate with the Office of Maternal Child & Family Health care coordinators to share plans of care for CYSHCN and collaborate as appropriate on QI activities, education, and other initiatives targeted at improving the care and health outcomes for CYSHCN.

4. System of Services Accountability

Is accountability for a system of services for CYSHCN and their families part of MCCs?

Of the 16 general Medicaid MCO and 3 specialty MCO contracts examined, all but two states (SC, TX) included at least one provision related to ensuring accountability for CYSHCN specifically or special health care needs populations generally (note: special health care needs is commonly referred to as “special needs” in the MCCs). The most common provisions were related to analysis of CSHCN performance measure data (9 provisions), quality assessment performance improvement (QAPI) or performance improvement programs (PIP) efforts inclusive of CYSHCN (9 provisions), and using Consumer Assessment of Healthcare Providers & Systems (CAHPS) children with chronic condition survey (5 provisions). The frameworks that informed the categorization of MCC provisions were IHI’s framework for effective care⁸ and NASHP’s system of care standards.⁹

Medicaid MCC accountability provisions are presented below from most common to least common, followed by examples of unique provisions. In some categories, the number of provisions may not equal the number of states as some states included more than one related provision. Click [here](#) for a supplemental spreadsheet with full Medicaid MCC provision language.

Table 5. Medicaid MCC Provisions on System of Services Accountability

1. Performance measurement and quality improvement 23 provisions in 14 states		
Strategy	# of provisions	# of state(s)
a. Analysis of performance measure data for special needs, including CSHCN	9	6 (AZ, MA, MN, NV, TX-S, VA)
b. QAPI or PIP efforts inclusive of CYSHCN	9	7 (GA, LA, MA, MI, NJ, TX-S, WV)
c. Using CAHPS Children with Chronic Condition Survey	5	5 (DC-S, LA, NE, NM, NV)
2. Reference to standards, policies, and procedures 11 provisions in 6 states		
Strategy	# of provisions	# of state(s)
a. Accountability policies and procedures	5	5 (AZ, DC-S, FL-S*, NE, VA*)
b. NCQA Complex Case Management Standards and Guidelines for Health Plan	1	1 (DC)
c. NCQA Standards and Guidelines for the Accreditation of Health Plans	1	1 (VA)
d. NCQA Utilization Management	1	1 (NM)
e. National Standards for Systems of Care for CYSHCN 2.0	1	1 (FL-S)*
f. Standards to ensure access to care, screening, diagnosis, referral, and identification of CYSHCN	1	1 (DC-S)
g. Financial incentives to reinforce VBP and quality measures	1	1 (VA)

*This provision is included in more than one category.

Box 4. Examples of Distinctive Provisions on Accountability

- A. **Florida specialty** requires use of the National Standards for Systems of Care for Children and Youth with Special Health Care Needs 2.0, development and administration of a training curriculum for care coordinators tailored to the needs of members and their families, targeted transition planning for members transitioning into adulthood, a designated Transitions Specialist to support complex transitions to adulthood, and establish enrollee focus groups in order to better understand the challenges members and their caregivers are facing to address and remove any barriers to care.
- B. **Minnesota** requires the MCO to have mechanisms to assess the quality and appropriateness of care furnished to enrollees with SHCN and to identify persons with SHCN through claim data. They must also report a SHCN summary describing efforts to identify enrollees that may need additional services.
- C. **New Mexico** requires the MCO to use the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Adult and Child [Survey Instruments](#), including the Children with Chronic Conditions to assess Member satisfaction as part of the HEDIS requirements and report the results of the CAHPS survey to the Human Services Department.
- D. **Virginia** requires the MCO to develop a comprehensive system of care* for services to children ages 13-18 years. The contract calls for: 1) an increase in EPSDT rates; 2) efforts to prevent and/or reduce obesity, asthma, or other chronic conditions; 3) focus on teens and adolescent health, including trauma-informed care, ACEs and resilience; and 4) focus on CYSHCN, providing transition planning to help teens and young adults prepare for changes following their 18th birthday.

*This provision uses the terminology “system of care” as opposed to “system of services” which is the terminology used within the Blueprint for Change.

Conclusion

This environmental scan of Medicaid MCCs offers numerous Blueprint-related provisions and distinctive examples that could lead to collaborative efforts between Medicaid and Title V, building on the long history of interagency partnerships. Table 1 lists the most common provisions. Many of the examples in this report do not specifically reference CYSHCN members and their families. This could represent an opportunity for state Title V agencies to elevate CYSHCN needs and partner on strategies for advancing the system of services.

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