

## Assessing the System of Care for CYSHCN:

### National Standards for Systems of Care Statewide Systems of Care Assessment Tool: **Single-Organization**

#### Background

A robust system of care for CYSHCN strengthens the overall pediatric health care infrastructure, benefiting all children and supporting the potential for a healthy, productive adulthood. The National Standards for Systems of Care for CYSHCN is a set of structure and process standards that together represent the necessary components of a comprehensive, quality system of care for CYSHCN. These standards are grounded in the six core outcomes for systems of care for CYSHCN that were developed by the federal Maternal and Child Health Bureau, Health Resources and Services Administration and based on a comprehensive review of the literature, key informant interviews, case studies of standards for CYSHCN currently in use in Title V, Medicaid and health plans within selected State/Jurisdictions and consensus from the national work group. A detailed description of how the National Standards were developed is available by clicking [here](#).

#### What is the Purpose of the Single-Organization Statewide Systems of Care Assessment Tool?

This State/Jurisdiction systems assessment tool is designed to be a self-assessment tool for entities serving CYSHCN and their families including, but not limited to Title V programs, state Medicaid and CHIP, health plans, provider groups, families and family partner organizations. The tool was developed to be used in conjunction with the National Standards and serves two purposes. This tool allows organizations to assess how well their organization and system is structured to assure access to and quality of care for CYSCHN and their families. Additionally, the tool includes key questions for stakeholders to assess their capacity to implement or improve policies and processes that are outlined in the National Standards.

#### Who should complete the tool?

This self-assessment is designed to be completed by members of a **single organization**, e.g., state Medicaid, a single health plan or the Title V program. The goal is for all stakeholder groups engaged in serving CYSHCN will share their self-assessment results to assess the broader system of care for CYSHCN using the *Multiple-Organization Statewide Systems of Care Analysis Tool* and determine priority actions steps.

#### How do I complete the tool?

Fill out each section of the tool as completely as possible from the perspective of your organization or affiliation. In each section, there are 4-7 statements describing policies and/or procedures. After each of these statements, there are two sets of questions:

- 1) Respond (yes/no) if your organization has the policies and procedures described in the statement. If you do not have enough information to answer, select “not applicable to my organization” and indicate which entity in your State/Jurisdiction would have this information. Following an answer of “yes”, please rate the effectiveness of those policies and procedures. Some follow-up questions ask for descriptive information, such as the definition of CYSHCN.

- 2) There is a close-ended question asking you to rate your ability and or authority to implement or improve the policies and procedures described. Indicate your organization’s authority as strong, moderate, or weak. Please provide a brief explanation for your rating.

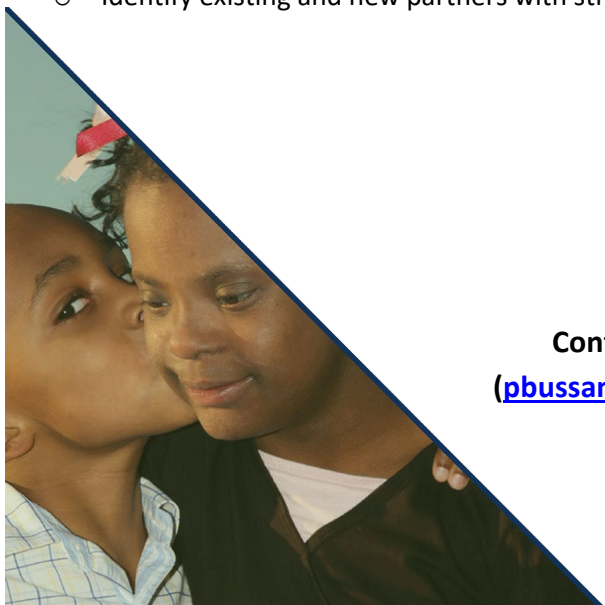
Following the questions for each domain, there is a summary question as to whether or not you feel this domain is a priority in your State/Jurisdiction. *Respondents are encouraged to use the Notes space to expound on your answer choices, describe State/Jurisdiction-specific nuances or context, note follow-up questions or issues to discuss with partners, and/or list action steps.*

### **What other ways can I use the tool?**

Your answers provide a snapshot of how well your organization is structured to serve CYSHCN and their families. Additionally, the summary statement identifies priority areas for your organization to work individually and in partnership with others.

The tool can be used to achieve the following to improve the system of care for CYSHCN:

- Identify strengths and weaknesses or areas for improvement within your organization;
- Prioritize action steps your organization;
- Identify areas to collaborate with partners;
- Identify existing and new partners with strengths that your organization can leverage.



**Contact Paige Bussanich at the Association of Maternal & Child Health Programs ([pbussanich@amchp.org](mailto:pbussanich@amchp.org)) with any questions or technical assistance needs related to this assessment tool.**

**Assessing the System of Care for CYSHCN Using System Standards**  
**ABRIDGED SINGLE-ORGANIZATION STATEWIDE SYSTEM OF CARE FOR CYSHCN ASSESSMENT TOOL**

State/Jurisdiction: \_\_\_\_\_

Date: \_\_\_\_\_

**Type of Agency Completing this Tool:**

- Title V   
  State Medicaid   
  CHIP   
  Health Plan/Insurer   
  Provider (please specify \_\_\_\_\_)   
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

*When providing answers in this tool, please do so from the perspective of the organization or system in which you work or are affiliated.*

**Foundational Standards**

The [National Standards \(Version 2.0\)](#) are guided by four essential principles that should be in place to ensure a comprehensive, quality system of care for CYSHCN. Indicate if the following principles are embedded in your own organization’s vision, mission, and/or work:<sup>1</sup>

- **Children and families of CYSHCN are active, core partners in decision making in all levels of care.**  
 Yes     No     Somewhat
- **All services and supports for CYSHCN are implemented and delivered in a culturally competent, linguistically appropriate, and accessible manner to best serve CYSHCN and their families. All written materials provided to CYSHCN and their families are culturally appropriate, provided in the primary language of the CYSHCN and their family, and in a manner and format appropriate for children and their parents or caregivers who have limited English proficiency, lower levels of literacy, or sensory impairments.**  
 Yes     No     Somewhat
- **Insurance coverage for CYSHCN is accessible, affordable, comprehensive, and continuous.**  
 Yes     No     Somewhat
- **All care provided to CYSHCN and their families is evidence-based where possible, and evidence-informed and/or based on promising practices where evidence-based approaches do not exist.**  
 Yes     No     Somewhat

OPTIONAL - Comments: \_\_\_\_\_

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<sup>1</sup> In-depth assessment tools are available for Foundational Standards #1 and #3 based on the Family-Professional Partnerships and Insurancing and Financing domains in Version 1.0 of the National Standards. Please email Paige Bussanich at the Association of Maternal and Child Health Programs (AMCHP) at [pbussanich@amchp.org](mailto:pbussanich@amchp.org) for more information.

## 1. Identification, Screening, Assessment and Referral

### 1.1. My organization defines CYSHCN based upon the following criteria (Check all that apply) :

- Diagnosis
- The child’s eligibility for Supplemental Security Income (SSI)
- The child’s eligibility for another program (Please specify) \_\_\_\_\_
- The definition used by the federal Maternal and Child Health Bureau and the American Academy of Pediatrics)<sup>2</sup>
- Other (Please specify) \_\_\_\_\_

### 1.2. My organization has a mechanism in place for identifying CYSHCN upon enrollment and transfer between insurance coverage (e.g., public and private).

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which have the authority to implement and/or ensure this standard:

- Title V  State Medicaid  CHIP  Health Plan/Insurer  Provider (please specify \_\_\_\_\_)  Family/Consumer
- Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures.  Strong  Moderate  Weak

OPTIONAL - Comments:

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### 1.3. There are policies and procedures in my organization to assure that all children, including CYSHCN, receive periodic, developmentally appropriate, and recommended comprehensive screenings, in accordance with Bright Futures or other approved pediatric guidelines (both as part of preventive visits and in response to triggering events such as hospitalization, trauma, or sudden onset of new symptoms).

Yes

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(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization's authority to implement or improve these kinds of policies and procedures.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**1.4. Within my organization, there are policies and procedures to document newborn screening efforts, results, and referrals for further assessment, and communicate these to other screening entities, including the newborn's medical home.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization's authority to implement or improve these kinds of policies and procedures.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**1.5. State/Jurisdiction newborn screening information is delivered to providers and parents in a timely fashion, and arrangements for necessary follow-up services are documented. If indicated, repeat screening results and follow-up are communicated by the hospital or State/Jurisdiction program to the newborn's health plan, medical home, and specialty providers.<sup>16</sup>**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

Title V  State Medicaid  CHIP  Health Plan/Insurer  Provider (please specify \_\_\_\_\_)  Family/Consumer

Other (please specify \_\_\_\_\_)

Please rate our organization's ability to implement or improve these kinds of policies and procedure.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**1.6. My organization has policies and procedures to demonstrate follow-up with a hospital or State/Jurisdiction health department when newborn screening results are not received.<sup>17</sup>**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

Title V  State Medicaid  CHIP  Health Plan/Insurer  Provider (please specify \_\_\_\_\_)  Family/Consumer

Other (please specify \_\_\_\_\_)

Please rate our organization's ability to implement or improve these kinds of policies and procedure.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**1.7. My organization has policies and procedures to document initial health assessment within 90 days<sup>18</sup> of enrollment in a health plan.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V   
 State Medicaid   
 CHIP   
 Health Plan/Insurer   
 Provider (please specify \_\_\_\_\_)   
 Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate our organization’s ability to implement or improve these kinds of policies and procedure.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**1.8. My organization has policies and procedures to ensure further screening assessments, results and referrals are documented and coordinated with the child’s medical home and health plan.<sup>19</sup>**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V   
 State Medicaid   
 CHIP   
 Health Plan/Insurer   
 Provider (please specify \_\_\_\_\_)   
 Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate our organization’s ability to implement or improve these kinds of policies and procedure.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**1.9. My organization has policies and procedures to ensure the needed services are referred to the CYSHCN following a screening and assessment to include pediatric specialist, therapies, and other service systems.<sup>20</sup>**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V   
  State Medicaid   
  CHIP   
  Health Plan/Insurer   
  Provider (please specify \_\_\_\_\_)   
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate our organization’s ability to implement or improve these kinds of policies and procedure.    Strong    Moderate    Weak

OPTIONAL - Comments:

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**1.10. My organization has policies and procedures for protocols and documentation methods are in place for the child’s medical home to follow-up and ensure referred services were accessed and to provide any assistance needed in accessing care regardless of the original entity conducting a screening and referral.**

- Yes  
 (IF YES) How effective are those policies and procedures?    Very effective    Somewhat effective    Not effective  
 No  
 Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:  
 Title V   
  State Medicaid   
  CHIP   
  Health Plan/Insurer   
  Provider (please specify \_\_\_\_\_)   
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate our organization’s ability to implement or improve these kinds of policies and procedure.    Strong    Moderate    Weak

OPTIONAL - Comments:

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**DOMAIN SUMMARY**



Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your State/Jurisdiction, do you think this Domain is currently a critical area to address within your State/Jurisdiction?  Yes  No IF YES, please note that an in-depth assessment tool for this Domain is available.<sup>3</sup>

Notes: (OPTIONAL use this space to elaborate on your answer choices, describe State/Jurisdiction-specific nuances or context, note follow-up questions or issues to discuss with partners, and/or list action steps that could be taken.)

## 2. Eligibility and Enrollment

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<sup>1</sup> Those children and youth who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally; McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137–140, 1998

**2.1. My organization is actively involved in outreach to promote access to health insurance for children in my State/Jurisdiction?**

Yes

(IF YES) How effective is that outreach?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization's authority to implement or improve this kind of outreach.  Strong  Moderate  Weak;

OPTIONAL - Comments:

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**2.2. In my organization, there are policies and procedures to assure that families of CYSHCN are provided culturally and linguistically appropriate explanations of (1) the covered health benefits available to them and (2) the procedures for accessing providers and needed care.**

Yes (IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization's authority to implement or improve these kinds of policies and procedures.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**2.3. My organization has policies and procedures to assist children transitioning from one form of insurance to another (e.g., from Medicaid to commercial insurance) and from one health plan to another.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

Title V  State Medicaid  CHIP  Health Plan/Insurer  Provider (please specify \_\_\_\_\_)  Family/Consumer

Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**2.4. In my organization, there are policies and procedures to assure that all information provided to families of CYSHCN for determining insurance eligibility and enrolling a child into public or private coverage is culturally appropriate and provided in a manner and format appropriate for a child or their caregiver, including for families who have limited English proficiency or sensory impairments.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

Title V  State Medicaid  CHIP  Health Plan/Insurer  Provider (please specify \_\_\_\_\_)  Family/Consumer

Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**2.5. In my organization, there are policies and procedures in place for transitioning CYSCHN between non-network and network providers, including communication with the medical home and family.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization's authority to implement or improve these kinds of policies and procedures.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**2.6. Health plans in my State/Jurisdiction/territory have policies and procedures in place to allowing CYSHCN who are newly enrolled or have recently changed plans to continue seeing out-of-network providers for up to six months after enrollment.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction/territory which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization's authority to implement or improve these kinds of policies and procedures.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**DOMAIN SUMMARY**

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your State/Jurisdiction, do you think this Domain is currently a critical area to address within your State/Jurisdiction?  Yes  No IF YES, *please note that an in-depth assessment tool for this Domain is available.*<sup>4</sup>

Notes: (OPTIONAL use this space to elaborate on your answer choices, describe State/Jurisdiction-specific nuances or context, note follow-up questions or issues to discuss with partners, and/or list action steps that could be taken.)

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<sup>2</sup> To request this and other National Standards assessment tools, please email Paige Bussanich at The Association of Maternal and Child Health Programs (AMCHP) at [pbussanich@amchp.org](mailto:pbussanich@amchp.org)

### 3. Access to Care

#### 3.1. My organization has an ongoing system in place to identify health care providers who will serve CYSHCN in my State/Jurisdiction.

Type of Provider	Response (Check One)		
	Yes	No	Not Applicable
<b>Primary Care Providers</b>	<input type="checkbox"/> Yes (IF YES) How effective is that system? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which are the authority to implement and/or ensure this standard: <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<b>Pediatric Specialists</b>	<input type="checkbox"/> Yes (IF YES) How effective is that system? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which are the authority to implement and/or ensure this standard: <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<b>Oral Health Providers</b>	<input type="checkbox"/> Yes (IF YES) How effective is that system? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which are the authority to implement and/or ensure this standard: <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<b>Mental Health Providers</b>	<input type="checkbox"/> Yes (IF YES) How effective is that system? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which are the authority to implement and/or ensure this standard: <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)

Please rate your organization's authority to implement or improve this kind of system.    Strong    Moderate    Weak.

OPTIONAL - Comments:

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**3.2. The health plans serving CYSHCN in my State/Jurisdiction have reasonable access requirements and wait times in place all levels of oral, mental and habilitative services. Same-day appointments are made available for urgent care services.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Please rate your organization's authority to implement or improve these kinds of policies and procedures within health plans.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**3.3. My organization has policies and procedures to ensure transportation assistance for families with difficulties accessing needed medical services for their children.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer
- Other (please specify \_\_\_\_\_)

Please rate your organization's authority to implement or improve these kinds of policies and procedures.  Strong  Moderate  Weak.

OPTIONAL - Comments:

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**3.4. My organization has policies and procedures in place supporting the use of satellite programs, electronic communications, and telemedicine to enhance access to specialty care and regional pediatric centers of excellence, where available, and other multidisciplinary teams of pediatric specialty providers.**

Yes (IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Please rate your organization’s authority to implement or improve these kinds of policies and procedures within health plans.  Strong  Moderate  Weak  
 OPTIONAL - Comments:

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**3.5. The health plan networks serving CYSHCN in my State/Jurisdiction have policies and procedures in place explaining how CYSHCN choose and/or are assigned to a primary care provider (PCP) and how they may change their PCP.**

Yes (IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective  
 No

Please rate your organization’s authority to implement or improve these kinds of policies and procedures within health plans.  Strong  Moderate  Weak  
 OPTIONAL - Comments:

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**3.6. Pediatric specialists serving CYSHCN in my State/Jurisdiction who have demonstrated clinical relationship as the coordinator of all care including health supervision and anticipatory guidance may serve as the primary care provider (PCP).<sup>36</sup>**

Yes  
 (IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective  
 No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer
- Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures.  Strong  Moderate  Weak  
 OPTIONAL - Comments:

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**3.7. My organization has policies and procedures in place documenting a child’s plan of care and specifying how they access pediatric specialists (in-person or via telemedicine).**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

Title V  State Medicaid  CHIP  Health Plan/Insurer  Provider (please specify \_\_\_\_\_)  Family/Consumer

Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**3.8. The health insurance programs serving CYSHCN in my State/Jurisdiction cover medically necessary services to include medical conditions and/or disorders that result in health impairments and disability, ensuring age-appropriate growth and development and functional capacity. These services include long term service and support to have access to community living, achieve person centered goals and live and work in the setting of their choice. <sup>37, 38</sup>**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Please rate your organization’s authority to implement or improve these kinds of policies and procedures within health plans.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**3.9. The health plans serving CYSHCN in my State/Jurisdiction cover comprehensive habilitative services in addition to rehabilitative services, and are of like type and substantially equivalent in scope, amount, and duration to rehabilitative services.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective  
 No

Please rate your organization’s authority to implement or improve these kinds of policies and procedures within health plans.  Strong  Moderate  Weak  
 OPTIONAL - Comments:

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**3.10. Authorization processes takes into account the unique needs of CYSHCN and are simplified to promote access to services. <sup>43</sup>**

Yes  
 (IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective  
 No

Please rate your organization’s authority to implement or improve these kinds of policies and procedures within health plans.  Strong  Moderate  Weak  
 OPTIONAL - Comments:

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**3.11. The health plans serving CYSHCN in my State/Jurisdiction allow families of CYSHCN to access to second opinions from qualified health care providers with restrictions to such opinions. <sup>44</sup>**

Yes  
 (IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective  
 No

Please rate your organization’s authority to implement or improve these kinds of policies and procedures within health plans.  Strong  Moderate  Weak  
 OPTIONAL - Comments:

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**DOMAIN SUMMARY**

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your State/Jurisdiction, do you think this Domain is currently a critical area to address within your State/Jurisdiction?  Yes  No IF YES, please note that an in-depth assessment tool for this Domain is available.<sup>5</sup>

Notes (OPTIONAL use this space to elaborate on your answer choices, describe State/Jurisdiction-specific nuances or context, note follow-up questions or issues to discuss with partners, and/or list action steps that could be taken.)

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<sup>3</sup> To request this and other National Standards assessment tools, please email Paige Bussanich at The Association of Maternal and Child Health Programs (AMCHP) at [pbussanich@amchp.org](mailto:pbussanich@amchp.org)

## 4. Medical Home

**4.1. My organization provides CYSHCN with a medical home capable of coordinating services to meet the child’s medical, dental, and social-emotional needs.**

- Yes
- No
- Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction the authority to implement and/or ensure this standard:
  - Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer
  - Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to incorporate or improve language defining medical homes for CYSHCN in its policies and procedures or in that of other organizations.     Strong     Moderate     Weak

OPTIONAL - Comments:

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**4.2. The medical home provides team-based care that is led by a primary care clinician and/or pediatric subspecialist and in which the family is a core member.<sup>46</sup>**

- Yes
- No
- Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction the authority to implement and/or ensure this standard:
  - Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer
  - Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to incorporate or improve language defining medical homes for CYSHCN in its policies and procedures or in that of other organizations.     Strong     Moderate     Weak

OPTIONAL - Comments:

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Pediatric Preventive and Primary Care

**4.3. My organization defines pediatric preventative and primary care as care that focuses on overall health, wellness, and prevention of secondary conditions.**

Yes

(IF YES) What is your system’s definition of preventive and primary care for CYSHCN? \_\_\_\_\_

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which are the authority to implement and/or ensure this standard:

- Title V   
  State Medicaid   
  CHIP   
  Health Plan/Insurer   
  Provider (please specify \_\_\_\_\_)   
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures.   
 Strong   
 Moderate   
 Weak.

OPTIONAL - Comments:

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**4.4. CYSHCN receive recommended immunizations according to the Advisory Committee on Immunization Practices (ACIP).<sup>46</sup>**

Yes

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V   
  State Medicaid   
  CHIP   
  Health Plan/Insurer   
  Provider (please specify \_\_\_\_\_)   
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate these recommendations.

Strong   
 Moderate   
 Weak

OPTIONAL - Comments:

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Medical Home Management

**4.5. My organization has policies and procedures to ensure all medical homes provide access to health care services 24 hours a day, seven days per week.**

- Yes (IF YES) How effective are those policies and procedures?  
 Very effective  
 Somewhat effective  
 Not effective  
 No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V  
 State Medicaid  
 CHIP  
 Health Plan/Insurer  
 Provider (please specify \_\_\_\_\_)  
 Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

- Strong  
 Moderate  
 Weak

OPTIONAL - Comments:

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**4.6. My organization has policies and procedures for medical homes to utilize scheduling systems to recognize additional time involved with caring for CYSHCN.<sup>54</sup>**

- Yes (IF YES) How effective are those policies and procedures?  
 Very effective  
 Somewhat effective  
 Not effective  
 No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V  
 State Medicaid  
 CHIP  
 Health Plan/Insurer  
 Provider (please specify \_\_\_\_\_)  
 Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

- Strong  
 Moderate  
 Weak

OPTIONAL - Comments:

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**4.7. My organization has policies and procedures to mandate medical home providers perform comprehensive health assessments.<sup>55</sup>**

- Yes (IF YES) How effective are those policies and procedures?  
  Very effective  
  Somewhat effective  
  Not effective  
 No  
 Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:  
 Title V  
  State Medicaid  
  CHIP  
  Health Plan/Insurer  
  Provider (please specify \_\_\_\_\_)  
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

- Strong  
  Moderate  
  Weak

OPTIONAL - Comments:

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**4.8. My organization has policies and procedures to ensure pre-visit assessments are conducted by the medical home and family to evaluate if the team has comprehensive data to provide care in an appropriate manner.<sup>56</sup>**

- Yes (IF YES) How effective are those policies and procedures?  
  Very effective  
  Somewhat effective  
  Not effective  
 No  
 Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:  
 Title V  
  State Medicaid  
  CHIP  
  Health Plan/Insurer  
  Provider (please specify \_\_\_\_\_)  
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

- Strong  
  Moderate  
  Weak

OPTIONAL - Comments:

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**4.9. My organization ensures accommodations for special needs are made available by the medical home to include home visits instead of office visits.**

- Yes (IF YES) How effective are those policies and procedures?  
 Very effective  
 Somewhat effective  
 Not effective  
 No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V  
 State Medicaid  
 CHIP  
 Health Plan/Insurer  
 Provider (please specify \_\_\_\_\_)  
 Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

- Strong  
 Moderate  
 Weak

OPTIONAL - Comments:

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**4.10. My organization has policies and procedures to ensure medical home conducts activities to support CYSHCN and their families regarding self-management of child’s health care.**

- Yes (IF YES) How effective are those policies and procedures?  
 Very effective  
 Somewhat effective  
 Not effective  
 No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V  
 State Medicaid  
 CHIP  
 Health Plan/Insurer  
 Provider (please specify \_\_\_\_\_)  
 Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

- Strong  
 Moderate  
 Weak

OPTIONAL - Comments:

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**4.11. My organization has policies and procedures to ensure medical home implements a plan of care that includes patient/family identified goals.<sup>57</sup>**

- Yes (IF YES) How effective are those policies and procedures?  
  Very effective  
  Somewhat effective  
  Not effective  
 No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V  
  State Medicaid  
  CHIP  
  Health Plan/Insurer  
  Provider (please specify \_\_\_\_\_)  
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

- Strong  
  Moderate  
  Weak

OPTIONAL - Comments:

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**4.12. My organization has policies and procedures for medical home serving CYSHCN has to follow for updating records and medication management.<sup>58</sup>**

- Yes (IF YES) How effective are those policies and procedures?  
  Very effective  
  Somewhat effective  
  Not effective  
 No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V  
  State Medicaid  
  CHIP  
  Health Plan/Insurer  
  Provider (please specify \_\_\_\_\_)  
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

- Strong  
  Moderate  
  Weak

OPTIONAL - Comments:

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**4.13. My organization has policies and procedures for medical home to integrate care with other providers and ensure information is shared effectively with family and other care providers.**

- Yes (IF YES) How effective are those policies and procedures?  
  Very effective  
  Somewhat effective  
  Not effective  
 No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V  
  State Medicaid  
  CHIP  
  Health Plan/Insurer  
  Provider (please specify \_\_\_\_\_)  
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

- Strong  
  Moderate  
  Weak

OPTIONAL - Comments:

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**4.14. My organization has policies and procedures for medical home to effective conduct transition of care to ensure preference for health services and sharing of information across systems.<sup>59</sup>**

- Yes (IF YES) How effective are those policies and procedures?  
  Very effective  
  Somewhat effective  
  Not effective  
 No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V  
  State Medicaid  
  CHIP  
  Health Plan/Insurer  
  Provider (please specify \_\_\_\_\_)  
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

- Strong  
  Moderate  
  Weak

OPTIONAL - Comments:

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**4.15. My organization has policies and procedures to ensure medical home performs tracking of care by sending proactive reminders to families and clinician of services needed via a registry or other mechanism.<sup>60</sup>**

- Yes (IF YES) How effective are those policies and procedures?  
  Very effective  
  Somewhat effective  
  Not effective  
 No  
 Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:  
 Title V  
  State Medicaid  
  CHIP  
  Health Plan/Insurer  
  Provider (please specify \_\_\_\_\_)  
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

- Strong  
  Moderate  
  Weak

OPTIONAL - Comments:

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Care Coordination and Care Planning

**4.16. My organization has policies and procedures promoting access to patient and family-centered care coordination that integrates physical, oral, mental health, and community-based services.**

- Yes  
 (IF YES) How effective are those policies and procedures?  
  Very effective  
  Somewhat effective  
  Not effective  
 No  
 Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which have the authority to implement and/or ensure this standard:  
 Title V  
  State Medicaid  
  CHIP  
  Health Plan/Insurer  
  Provider (please specify \_\_\_\_\_)  
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to implement or improve these kinds of policies and procedures internally or in other organizations.

- Strong  
  Moderate  
  Weak

OPTIONAL - Comments:

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**4.17. My organization’s requirements for care coordinators for CYSHCN include the following: (Check only those that apply)**

- serve as a member of the medical home team, <sup>62, 63</sup>
- have ongoing relationships with families, medical care providers, and other partners in care, <sup>64</sup>
- use biopsychosocial assessments to help families articulate goals and priorities for care which takes into account social determination that impact the health of their child, <sup>65</sup>
- assist in managing care transitions of CYSHCN across settings and developmental stages, and <sup>66</sup>
- provide appropriate resources to match the health literacy level, primary language, and culture of CYSHCN and their family <sup>67</sup>

Please rate your organization’s ability to implement or improve the components of care plans for CYSHCN.    Strong    Moderate    Weak

OPTIONAL - Comments:

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**4.18. My organization has policies and procedures to ensure a plan of care is jointly developed, shared and implemented with the CYSHCN, their family and primary care provider, and specialist serving as principal coordinating physician and health care team. <sup>68</sup>**

Yes

(IF YES) How effective are those policies and procedures?    Very effective    Somewhat effective    Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which have the authority to implement and/or ensure this standard:

- Title V    State Medicaid    CHIP    Health Plan/Insurer    Provider (please specify \_\_\_\_\_)    Family/Consumer
- Other (please specify \_\_\_\_\_)

Please rate your organization’s ability to implement or improve these kinds of policies and procedures internally or in other organizations.

Strong    Moderate    Weak

OPTIONAL - Comments:

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**4.19. My organization has policies and procedures to ensure the family strengths are respected in the delivery of care, extended family members are included in decision based upon the family’s wishes and the plan of care includes family-driven goals. <sup>69</sup>**

Yes

(IF YES) How effective are those policies and procedures?    Very effective    Somewhat effective    Not effective

No

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Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which have the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization's ability to implement or improve these kinds of policies and procedures internally or in other organizations.

- Strong    Moderate    Weak

OPTIONAL - Comments:

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*Pediatric Specialty Care*

**4.20. My organization has policies and procedures to provide comprehensive specialty services, including behavioral health services, acute services in a 24-hour clinical setting, intermediate services, and outpatient services and community support services by specialty providers as needed by CYSHCN.**

Yes

(IF YES) How effective are those policies and procedures?    Very effective    Somewhat effective    Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which have the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization's ability to implement or improve these kinds of policies and procedures internally or in other organizations.

- Strong    Moderate    Weak

OPTIONAL - Comments:

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**4.21. My organization's policies and procedures allow pediatric primary care and specialty care providers to share management for the care of CYSHCN.**

Yes

(IF YES) How effective are those policies and procedures?    Very effective    Somewhat effective    Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V   
  State Medicaid   
  CHIP   
  Health Plan/Insurer   
  Provider (please specify \_\_\_\_\_)   
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures in your organization or in other organizations.

- Strong   
  Moderate   
  Weak

OPTIONAL - Comments:

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**DOMAIN SUMMARY**

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your State/Jurisdiction, do you think this Domain is currently a critical area to address within your State/Jurisdiction?  Yes     No    IF YES, *please note that an in-depth assessment tool for this Domain is available.*<sup>6</sup>

Notes (OPTIONAL use this space to elaborate on your answer choices, describe State/Jurisdiction-specific nuances or context, note follow-up questions or issues to discuss with partners, and/or list action steps that could be taken.)

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<sup>4</sup> To request this and other National Standards assessment tools, please email Paige Bussanich at The Association of Maternal and Child Health Programs (AMCHP) at [pbussanich@amchp.org](mailto:pbussanich@amchp.org)

### 5. Community-based Services and Supports

**5.1 My organization has interagency or cross-system agreements with the following organizations to provide access to comprehensive home and community-based supports for CYSHCN and their families:**

Type of Organization	Response (Check One)			
	Yes	If yes, are these agreements structured to:	No	Not Applicable- please indicate the agencies/entities in your State/Jurisdiction which are the authority to implement and/or ensure this standard
<b>Family Organizations</b>	<input type="checkbox"/> Yes (IF YES) How effective is that system? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> Promote family support through linking families to family organizations and other services and supports, <input type="checkbox"/> Promote shared financing, where appropriate, <input type="checkbox"/> Establish systems for timely communications and appropriate data sharing, <input type="checkbox"/> Ensure access and coordination of services <input type="checkbox"/> Promote collaboration between community-based organizations and agencies, providers, health care systems, and families, and <input type="checkbox"/> Specify responsibilities across the various providers, and community-based agencies <sup>78</sup>	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<b>Public Health Departments/ Agencies</b>	<input type="checkbox"/> Yes (IF YES) How effective is that system? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> Promote family support through linking families to family organizations and other services and supports, <input type="checkbox"/> Promote shared financing, where appropriate, <input type="checkbox"/> Establish systems for timely communications and appropriate data sharing, <input type="checkbox"/> Ensure access and coordination of services <input type="checkbox"/> Promote collaboration between community-based organizations and agencies, providers, health care systems, and families, and <input type="checkbox"/> Specify responsibilities across the various providers, and community-based agencies <sup>78</sup>	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<b>Education</b>	<input type="checkbox"/> Yes (IF YES) How effective is that system?	<input type="checkbox"/> Promote family support through linking families to family organizations and other services and supports,	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer

	<input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> Promote shared financing, where appropriate, <input type="checkbox"/> Establish systems for timely communications and appropriate data sharing, <input type="checkbox"/> Ensure access and coordination of services <input type="checkbox"/> Promote collaboration between community-based organizations and agencies, providers, health care systems, and families, and <input type="checkbox"/> Specify responsibilities across the various providers, and community-based agencies <sup>78</sup>		<input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<b>Early Intervention (Part C)</b>	<input type="checkbox"/> Yes (IF YES) How effective is that system? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> Promote family support through linking families to family organizations and other services and supports, <input type="checkbox"/> Promote shared financing, where appropriate, <input type="checkbox"/> Establish systems for timely communications and appropriate data sharing, <input type="checkbox"/> Ensure access and coordination of services <input type="checkbox"/> Promote collaboration between community-based organizations and agencies, providers, health care systems, and families, and <input type="checkbox"/> Specify responsibilities across the various providers, and community-based agencies <sup>78</sup>	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<b>Special Education</b>	<input type="checkbox"/> Yes (IF YES) How effective is that system? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> Promote family support through linking families to family organizations and other services and supports, <input type="checkbox"/> Promote shared financing, where appropriate, <input type="checkbox"/> Establish systems for timely communications and appropriate data sharing, <input type="checkbox"/> Ensure access and coordination of services <input type="checkbox"/> Promote collaboration between community-based organizations and agencies, providers, health care systems, and families, and <input type="checkbox"/> Specify responsibilities across the various providers, and community-based agencies <sup>78</sup>	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)



<p><b>Child Welfare Agencies</b></p>	<p><input type="checkbox"/> Yes (IF YES) How effective is that system? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective</p>	<p><input type="checkbox"/> Promote family support through linking families to family organizations and other services and supports, <input type="checkbox"/> Promote shared financing, where appropriate, <input type="checkbox"/> Establish systems for timely communications and appropriate data sharing, <input type="checkbox"/> Ensure access and coordination of services <input type="checkbox"/> Promote collaboration between community-based organizations and agencies, providers, health care systems, and families, and <input type="checkbox"/> Specify responsibilities across the various providers, and community-based agencies<sup>78</sup></p>	<p><input type="checkbox"/> No</p>	<p><input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V    <input type="checkbox"/> State Medicaid    <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)</p>
<p><b>Mental Health Providers</b></p>	<p><input type="checkbox"/> Yes (IF YES) How effective is that system? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective</p>	<p><input type="checkbox"/> Promote family support through linking families to family organizations and other services and supports, <input type="checkbox"/> Promote shared financing, where appropriate, <input type="checkbox"/> Establish systems for timely communications and appropriate data sharing, <input type="checkbox"/> Ensure access and coordination of services <input type="checkbox"/> Promote collaboration between community-based organizations and agencies, providers, health care systems, and families, and <input type="checkbox"/> Specify responsibilities across the various providers, and community-based agencies<sup>78</sup></p>	<p><input type="checkbox"/> No</p>	<p><input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V    <input type="checkbox"/> State Medicaid    <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)</p>
<p><b>Home Health Care Providers</b></p>	<p><input type="checkbox"/> Yes (IF YES) How effective is that system? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective</p>	<p><input type="checkbox"/> Promote family support through linking families to family organizations and other services and supports, <input type="checkbox"/> Promote shared financing, where appropriate, <input type="checkbox"/> Establish systems for timely communications and appropriate data sharing, <input type="checkbox"/> Ensure access and coordination of services <input type="checkbox"/> Promote collaboration between community-based organizations and agencies, providers, health care systems, and families, and</p>	<p><input type="checkbox"/> No</p>	<p><input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V    <input type="checkbox"/> State Medicaid    <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)</p>

		<input type="checkbox"/> Specify responsibilities across the various providers, and community-based agencies <sup>78</sup>	
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Please rate your organization’s authority to implement or improve these kinds of cross-system agreements.  Strong  Moderate  Weak.

OPTIONAL - Comments:

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Respite Care

**5.2 My organization has respite services, both planned and emergency, available to all families and caregivers of CYSHCN.**

Yes

(IF YES) How effective are those services?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer
- Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures internally and/or in other organizations.

Strong  Moderate  Weak

OPTIONAL - Comments:

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**5.3 My organization has policies and procedures in place to screen families/caregivers for respite care needs, communicate when respite services are available in their communities, and to ensure timely referrals for families of CYSHCN with emergency respite needs.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer

Other (please specify \_\_\_\_\_)

Please rate your organization's authority to implement or improve these kinds of policies and procedures internally and/or in other organizations.

Strong  Moderate  Weak

OPTIONAL - Comments:

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**5.4 My organization has mechanisms to inform and assist families/caregives access available respite services which may be provided in a variety of settings, on a temporary basis, including the family home, respite centers, or residential care facilities.**

Yes

(IF YES) How effective are those procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V   
  State Medicaid   
  CHIP   
  Health Plan/Insurer   
  Provider (please specify \_\_\_\_\_)   
  Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization's authority to implement or improve these kinds of policies and procedures internally and/or in other organizations.

Strong  Moderate  Weak

OPTIONAL - Comments:

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**5.5 My organization provides transportation or assist with coordination of transportation when out-of-home respite services are needed.**

Yes

(IF YES) How effective are those services?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V   
  State Medicaid   
  CHIP   
  Health Plan/Insurer   
  Provider (please specify \_\_\_\_\_)   
  Family/Consumer

Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures internally and/or in other organizations.

Strong  Moderate  Weak

OPTIONAL - Comments:

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*Palliative and Hospice Care*

**5.6 My organization has policies for pediatric palliative and curative care (concurrent care).**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer
- Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies internally and/or in other organizations.

Strong  Moderate  Weak

OPTIONAL - Comments:

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**5.7 My organization has policies for palliative care ensuring the use of family-centered models of care that respect the CYSHCN and their family’s preferences, values, and cultural beliefs, and provide family access to psychosocial screening and referrals to needed supports and services.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies internally and/or in other organizations.

- Strong     Moderate     Weak

OPTIONAL - Comments:

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Home-Based Services

**5.8 My organization’s covered benefits include home health care for CYSHCN and supportive care for the family provided by licensed professionals with pediatric experience.**

Yes

(IF YES) How adequate is that coverage?     Very adequate     Somewhat adequate     Very inadequate

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consume  
 Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve those benefits for CYSHCN.     Strong     Moderate     Weak

OPTIONAL - Comments:

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**DOMAIN SUMMARY**

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your State/Jurisdiction, do you think this Domain is currently a critical area to address within your State/Jurisdiction?  Yes  No IF YES, please note that an in-depth assessment tool for this Domain is available.<sup>7</sup>

Notes (OPTIONAL use this space to elaborate on your answer choices, describe State/Jurisdiction-specific nuances or context, note follow-up questions or issues to discuss with partners, and/or list action steps that could be taken.)

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<sup>5</sup> To request this and other National Standards assessment tools, please email Paige Bussanich at The Association of Maternal and Child Health Programs (AMCHP) at [pbussanich@amchp.org](mailto:pbussanich@amchp.org)

## 6. Transition to Adulthood

(FOR INDIVIDUAL DIRECT SERVICE ORGANIZATIONS--INCLUDING HEALTH PLANS AND INSURERS AND TITLE V AGENCIES THAT PROVIDE OR FUND DIRECT SERVICES)

### Pediatric Health Care Setting

**6.1. Within my organization, there are policies and procedures that describe our approach to transition from pediatric to adult health care for YSHCN and their families, including identification and recruitment of adult health care providers.**

Yes

If yes, are these policies shared with YSHCN and families?

Yes, consistently       Sometimes       No

No

**6.2. My organization's requirements for plans of care address transition from pediatric to adult health care.**

Yes

If yes, the care plan includes (check all that apply):

**Transition Policy** - developed with consumer input and shared and discussed with youth and families beginning at ages 12-14 and regularly reviewed as part of ongoing care.<sup>85</sup>

**Transition Readiness:** A standardized, scorable tool to determine youth's understanding of self-care and use of health care, initially done with youth and caregiver at age 14 and periodically reassessed by the pediatric provider.

(Other (please specify \_\_\_\_\_))

No

**6.3. My organization has a transfer of care checklist for YSHCN when care responsibility changes from pediatric to adult health providers.**

Yes

If yes, the transfer checklist includes (check all that apply):

Cover Letter

Final transition readiness/self-care assessment

Updated plan of care

Updated medical summary and emergency care plan

Legal documents, condition fact sheet, additional records as needed

Transfer Completion – confirmation with adult providers of residual responsibility for patient care; ensure there is communication with adult provider confirming transfer and offering pediatric consultation assistance, as needed.

No

Adult Health Care Setting

**6.4. Within my organization, there are policies and procedures that State/Jurisdictions the approach to accepting and partnering with new young adults regarding their first visit and ongoing care with health care provider.**

Yes

If yes, are these policies shared with YSHCN and families?

Yes, consistently       Sometimes       No

No

**6.5. Within my organization, there are policies and procedures on how to welcome and orientate a YSHCN into the adult providers' practice and to identify any special needs and/or preferences.**

Yes

If yes, are these policies shared with YSHCN and families?

Yes, consistently       Sometimes       No

No

**6.6. My organization's requirements for plan of care for initial visit:**

Yes

If yes, the care plan includes (check all that apply):

- Address concerns about transfer
- Clarify adult approach to care
- Conducting self-care assessments
- Review health priorities of current plan of care
- Update and share medical summary and emergency care plan
- (Other (please specify \_\_\_\_\_))

No

**6.7. My organization has policies and procedures to ensure the YSHCN receives assistance and is assisted with connections to adult specialist and other support services for ongoing care.**

Yes

If yes, are these policies shared with YSHCN and families?

Yes, consistently       Sometimes       No

No



## DOMAIN SUMMARY

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Notes (OPTIONAL use this space to elaborate on your answer choices, describe State/Jurisdiction-specific nuances or context, note follow-up questions or issues to discuss with partners, and/or list action steps that could be taken.)

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## 7. Health Information Technology

### 7.1. My organization uses electronic health record systems for providers serving CYSHCN that meet HIPAA and meaningful use requirements.

Yes

(IF YES) How adequately does the system meet those requirements?  Very adequate  Somewhat adequate  Very inadequate

No

Unsure

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

Title V  State Medicaid  CHIP  Health Plan/Insurer  Provider (please specify \_\_\_\_\_)  Family/Consumer

Other (please specify \_\_\_\_\_)

Please rate your organization's ability to implement or improve the electronic health systems for providers serving CYSHCN.  Strong  Moderate  Weak

OPTIONAL - Comments:

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### 7.2. My organization ensures medical homes have the capacity to exchange and maintenance clinical information electronically.

Yes

(IF YES) How adequately does the system meet those requirements?  Very adequate  Somewhat adequate  Very inadequate

No

Unsure

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

Title V  State Medicaid  CHIP  Health Plan/Insurer  Provider (please specify \_\_\_\_\_)  Family/Consumer

Other (please specify \_\_\_\_\_)

Please rate your organization's ability to implement or improve the electronic health systems for providers serving CYSHCN.  Strong  Moderate  Weak

OPTIONAL - Comments:

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**7.3. My organization has policies and procedures that assure families of CYSHCN have easy access to their child’s electronic health record?**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer
- Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures internally and/or in other organizations and systems.

Strong  Moderate  Weak

OPTIONAL - Comments:

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**7.4. My organization has policies and procedures that specify how electronic health information can be exchanged across a child’s care settings, including detailed procedures for cross-systems agreements about exchanging information.**

Yes

(IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which are the authority to implement and/or ensure this standard:

- Title V     State Medicaid     CHIP     Health Plan/Insurer     Provider (please specify \_\_\_\_\_)     Family/Consumer
- Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures internally and/or in other organizations and systems.

Strong  Moderate  Weak

OPTIONAL - Comments:

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## DOMAIN SUMMARY

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your State/Jurisdiction, do you think this Domain is currently a critical area to address within your State/Jurisdiction?  Yes  No IF YES, *please note that an in-depth assessment tool for this Domain is available.*<sup>9</sup>

Notes (OPTIONAL use this space to elaborate on your answer choices, describe State/Jurisdiction-specific nuances or context, note follow-up questions or issues to discuss with partners, and/or list action steps that could be taken.)

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## 8. Quality Assurance and Improvement

### 8.1 My organization enacts a specific and ongoing assurance and quality improvement process that is specific to providers and systems serving CYSHCN and their families.

Process	Response (Check One)		
	Yes	No	Not Applicable; please indicate the agencies/entities in your State/Jurisdiction which are the authority to implement and/or ensure this standard
<input type="checkbox"/> Families of CYSHCN are represented on the primary care provider QI teams and health plan QI teams			
<input type="checkbox"/> Periodic monitoring of network provider capacity to ensure the full continuum of children’s physical, oral, and mental health needs are met on a timely basis			
<input type="checkbox"/> Promotion of geographic accessibility to needed services <sup>91</sup>			
<input type="checkbox"/> Periodic monitoring of utilization of care, appropriateness of care, and compliance with all system standards for CYSHCN <sup>92</sup>			
<input type="checkbox"/> Conducting experience of care surveys with families of CYSHCN and youth (including targeted feedback from relevant racial/ethnic and language groups) to obtain feedback and assess their experiences with care <sup>93</sup>			

<input type="checkbox"/> Assessment of out of pocket expenses, lost work burden, and other sources of stress on families, and  <input type="checkbox"/> Assessment of child outcomes, including measures of health and functional status.			
<input type="checkbox"/> Title V	<input type="checkbox"/> Yes (IF YES) How effective is that process? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<input type="checkbox"/> State Medicaid	<input type="checkbox"/> Yes (IF YES) How effective is that process? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization; <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<input type="checkbox"/> CHIP	<input type="checkbox"/> Yes (IF YES) How effective is that process? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<input type="checkbox"/> Health Plan/Insurer	<input type="checkbox"/> Yes (IF YES) How effective is that process? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<input type="checkbox"/> Provider (please specify _____)	<input type="checkbox"/> Yes (IF YES) How effective is that process? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)

<input type="checkbox"/> Family/Consumer	<input type="checkbox"/> Yes (IF YES) How effective is that process? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)
<input type="checkbox"/> Other (please specify _____)	<input type="checkbox"/> Yes (IF YES) How effective is that process? <input type="checkbox"/> Very effective <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Not effective	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable to my organization <input type="checkbox"/> Title V <input type="checkbox"/> State Medicaid <input type="checkbox"/> CHIP <input type="checkbox"/> Health Plan/Insurer <input type="checkbox"/> Provider (please specify _____) <input type="checkbox"/> Family/Consumer <input type="checkbox"/> Other (please specify _____)

OPTIONAL - Comments:

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**8.2 My organization has policies requiring a team review of health outcomes for CYSHCN, including measures of health and functional status.**

Yes

(IF YES) How effective are those policies and procedures?    Very effective    Somewhat effective    Not effective

Which of the following groups are involved in the team review?    Medicaid    Selected health providers    Families    Title V CYSHCN program

Public health    Health plans    Other (Please specify) \_\_\_\_\_

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

Title V    State Medicaid    CHIP    Health Plan/Insurer    Provider (please specify \_\_\_\_\_)    Family/Consumer

Other (please specify \_\_\_\_\_)

Please rate your organization's authority to implement or improve these kinds of policies and procedures internally and/or in other organizations and systems.

Strong    Moderate    Weak

OPTIONAL - Comments:

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**8.3 . My organization has policies and processes that include members of the integrated care team for CYSHCN in the utilization review and appeals processes.**

Yes

(IF YES) How effective are those policies and procedures? Very effective Somewhat effective Not effective

No

Not applicable to my organization; please indicate the agencies/entities in your State/Jurisdiction which the authority to implement and/or ensure this standard:

Title V  State Medicaid  CHIP  Health Plan/Insurer  Provider (please specify \_\_\_\_\_)  Family/Consumer

Other (please specify \_\_\_\_\_)

Please rate your organization’s authority to implement or improve these kinds of policies and procedures internally and/or in other organizations and systems.

Strong  Moderate  Weak

OPTIONAL - Comments:

**DOMAIN SUMMARY**

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