OVERVIEW

Background
The Affordable Care Act (ACA) and other health reforms within states bring significant change to the health system landscape. Although the primary goal of federal and state health reform is to extend health insurance coverage to millions of uninsured children and adults, it also presents an opportunity to improve the quality of care and improve health outcomes for one of our nation’s most vulnerable groups: children and youth with special health care needs (CYSHCN). Key stakeholders, such as Title V CYSHCN programs, families and consumers, health plans, private insurers, state Medicaid and CHIP agencies, pediatricians and family physicians, can seize this opportunity and work together to create a comprehensive, quality system of care for CYSHCN and all children. 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.

To foster action within states to improve the quality of systems of care for CYSHCN, in 2013 the Lucille Packard Foundation supported the Association of Maternal and Child Health Programs to convene a workgroup of national and state leaders—representing state Title V CYSHCN programs, health plans, Medicaid and CHIP agencies, pediatric providers, children’s hospitals, insurers, health services researchers, families/consumers, and others— to develop a set of structure and process standards that together represent the necessary components of a comprehensive, quality system of care for CYSHCN. Based on existing standards work and discussions in several national expert meetings, the workgroup agreed upon a set of standards called The National Standards for Systems 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 states and consensus from the national work group. A detailed description of how the national standards were developed is available by clicking here or visiting http://cshcn.wpengine.netdna-cdn.com/wp-content/uploads/2014/03/Developing-Structure-and-Process-Standards-White-Paper.pdf. The workgroup’s national consensus standards are organized into the 10 domains listed below. (Copies of the detailed standards under each domain area can be found by clicking here or visiting http://cshcn.wpengine.netdna-cdn.com/wp-content/uploads/2014/05/Developing-Structure-and-Process-Standards-Charts.pdf.)
1. Screening, Assessment and Referral
2. Eligibility and Enrollment
3. Access to Care
4. Medical Home, including Pediatric Preventive and Primary Care; Care Coordination; and Pediatric Specialty Care
5. Community-based Services and Supports, including Respite Care; Palliative and Hospice Care; and Home-based Services
6. Family Professional Partnerships
7. Transition to Adulthood
8. Health Information Technology
9. Quality Assurance and Improvement
10. Insurance and Financing

This state assessment tool is a condensed version of the Standards for Systems of Care for CYSHCN, organized in sections according to the Standard’s ten domains. An in-depth assessment tool for each Domain, which assesses each standard within a particular Domain, is available.¹

Purpose of the Abridged Single-Organization Statewide Systems of Care Assessment Tool
This state systems assessment tool is designed to be a practical self-assessment tool for Title V CYSHCN 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 has two primary purposes. First, it allows organizations to assess how well their organization and system is structured to assure access and quality of care for CYSHCN and their families according to the national standards. And second, but no less important, it includes key questions for stakeholders to assess their capacity to implement or improve policies and processes that are outlined in the national standards. This particular tool was designed to be completed by members of a single organization (e.g. state Medicaid, a single health plan or the Title V CYSHCN program) with the hope that all stakeholder groups engaged in the system of care for CYSHCN would then come together to share their self-assessment results and assess the broader system of care for CYSHCN using the Multiple-Organization Statewide Systems of Care Analysis Tool² and determine priority actions steps.

¹ To request this and other National Standards assessment tools, please email Meredith Pyle at The Association of Maternal and Child Health Programs (AMCHP) at mpyle@amchp.org
² Ibid.
How to Complete the Tool

Fill out each section of the tool as completely as you can from the perspective of the organization in which you work or are affiliated. In each section, there are 4-7 statements describing policies and/or procedures. After each of these statements, there are two sets of responses needed:

1) First, respond (yes/no) whether your organization has the policies and procedures described in the statement. If you do not have enough information to answer definitively, select “not applicable to my organization” and indicate which entity in your state would have this information. For those who answer “yes”, there is usually a follow-up question asking the respondent to rate how effective they think those policies and procedures are. Sometimes the follow-up question asks for more descriptive information, such as the definition of CYSHCN or of medical homes for CYSHCN used by the organization or system.

2) Next, there is a close-ended question asking respondents to rate their ability and or authority to implement or improve the policies and procedures described. Indicate your organization’s authority as “strong”, “moderate”, or “weak” and then a space provided for an optional, brief explanation for your rating.

Following the questions for each domain, there is a simple summary question as to whether or not you feel this Domain is currently a critical area to address within your state. There is a space for “Notes.” Respondents are encouraged to use this space to elaborate on your answer choices, describe state-specific nuances or context, note follow-up questions or issues to discuss with partners, and/or list action steps that could be taken.

Ways to Use the Tool

Your organization’s answers to the tool provide a snapshot of how well your organization is structured to serve CYSHCN and their families and priority areas for your organization to work alone and in partnership with others. In either case, the tool can be used to achieve multiple results, including to:

- Identify relative strengths and weaknesses or areas for improvement within your organization
- Prioritize action steps your organization can take -- either alone or in partnership with other key state stakeholders -- to improve the system of care for CYSHCN
- Identify areas where you can work with partners to improve the system of care for CYSHCN
- Recognize existing and new partners with strengths that your organization can leverage to improve the system of care for CYSHCN
Assessing the System of Care for CYSHCN Using System Standards

ABRIDGED SINGLE-ORGANIZATION STATEWIDE SYSTEM OF CARE FOR CYSHCN ASSESSMENT TOOL

State: ___________________________ 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 assessment tool, please do so from the perspective of the organization or system in which you work or are affiliated.

1. 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)  
□ Other  (Please specify) ________________

---

3 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
1.2 Within my organization, there are policies and procedures in place for the identification of CYSHCN (including new and ongoing enrollees).

☐ 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 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:  
______________________________________________________________________________________________  
______________________________________________________________________________________________  

1.3 Within my organization, there are policies and procedures in place to communicate new enrollment of CYSHCN to other systems/sectors.

☐ 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 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:  
______________________________________________________________________________________________  
______________________________________________________________________________________________  

______________________________________________________________________________________________  

______________________________________________________________________________________________
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 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:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

1.5 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
(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 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:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________
1.5.a. My organization has policies and procedures to document and relay the results of such screening to the child’s medical home, family, and, as feasible, all other entities serving the child (e.g. specialists, child care and schools).

☐ 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 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:

_______________________________________________________________________________________________________________________________

_______________________________________________________________________________________________________________________________

DOMA IN SUMMARY

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your state, do you think this Domain is currently a critical area to address within your state?

☐ Yes  ☐ No  IF YES, please note that an in-depth assessment tool for this Domain is available. 4

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

4 To request this and other National Standards assessment tools, please email Meredith Pyle at The Association of Maternal and Child Health Programs (AMCHP) at mpyle@amchp.org
2. Eligibility and Enrollment

2.1 My organization is actively involved in outreach to promote access to health insurance for children in the State?

☐ 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 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:
____________________________________________________________________________________________________________________________
____________________________________________________________________________________________________________________________

2.2. My organization has policies and procedures to assist children transition 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 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:
____________________________________________________________________________________________________________________________
____________________________________________________________________________________________________________________________
2.3 My organization has policies and procedures to ensure that all newly enrolled children who are identified as CYSHCN receive a documented initial assessment of their needs, and this assessment is conducted in collaboration with the child’s family or caregiver.

☐ 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 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:
__________________________________________________________________________________________________________________________________________

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 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:
__________________________________________________________________________________________________________________________________________
2.5 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 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:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

DOMAIN SUMMARY

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

Notes (OPTIONAL use this space to elaborate on your answer choices, describe state-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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5 To request this and other National Standards assessment tools, please email Meredith Pyle at The Association of Maternal and Child Health Programs (AMCHP) at mpyle@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, including primary care providers, specialty providers including pediatric specialists, oral health providers, and mental health providers.

<table>
<thead>
<tr>
<th>Type of Provider</th>
<th>Response (Check One)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary Care Providers</strong></td>
<td>□ Yes (IF YES) How effective is that system? □ Very effective □ Somewhat effective □ Not effective</td>
</tr>
<tr>
<td></td>
<td>□ No □ Not applicable to my organization; please indicate the agencies/entities in your state 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 ____________)</td>
</tr>
<tr>
<td><strong>Pediatric Specialists</strong></td>
<td>□ Yes (IF YES) How effective is that system? □ Very effective □ Somewhat effective □ Not effective</td>
</tr>
<tr>
<td></td>
<td>□ No □ Not applicable to my organization; please indicate the agencies/entities in your state 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 ____________)</td>
</tr>
<tr>
<td><strong>Oral Health Providers</strong></td>
<td>□ Yes (IF YES) How effective is that system? □ Very effective □ Somewhat effective □ Not effective</td>
</tr>
<tr>
<td></td>
<td>□ No □ Not applicable to my organization; please indicate the agencies/entities in your state 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 ____________)</td>
</tr>
<tr>
<td><strong>Mental Health Providers</strong></td>
<td>□ Yes (IF YES) How effective is that system? □ Very effective □ Somewhat effective □ Not effective</td>
</tr>
<tr>
<td></td>
<td>□ No □ Not applicable to my organization; please indicate the agencies/entities in your state 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 ____________)</td>
</tr>
</tbody>
</table>

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

OPTIONAL - Comments:
3.2 The health plan networks serving CYSHCN in my state include essential community providers (e.g., Federally Qualified Health Centers, Title V providers, family resource/support organizations, local health departments, and/or other community-based care clinics).

☐ Yes
(IF YES) To what extent are essential community providers incorporated into the health plan networks serving CYSHCN in your state?
☐ Many are included  ☐ Some are included  ☐ Very few are included
☐ No

(For health plans serving CYSHCN): Please rate your organization’s ability to integrate essential community providers into your network.
☐ Strong  ☐ Moderate  ☐ Weak.
OPTIONAL - Comments:
_____________________________________________________________________________________________________________________________
________________________________________________________________________________________________________

(For other organizations): Please rate your organization’s ability to work with health plans serving CYSHCN to integrate essential community providers into their networks.  ☐ Strong  ☐ Moderate  ☐ Weak.
OPTIONAL - Comments:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

3.3 The health plan networks serving CYSHCN in my state include children’s hospitals, academic medical centers, regional perinatal intensive care centers and other tertiary centers that provide care to CYSHCN.

☐ Yes
(IF YES) To what extent are these kinds of organizations incorporated into the health plan networks serving CYSHCN in your state?
☐ Many are included  ☐ Some are included  ☐ Very few are included
☐ No
(For health plans serving CYSHCN): Please rate your organization’s ability to integrate these organizations into your network.

Strong  Moderate  Weak.

OPTIONAL - Comments:

_____________________________________________________________________________________________________________________________

_____________________________________________________________________________________________________________________________

(For other organizations): Please rate your organization’s authority and/or authority to work with health plans to integrate these kinds of organizations into their networks.  Strong  Moderate  Weak.

OPTIONAL - Comments:

_____________________________________________________________________________________________________________________________

_____________________________________________________________________________________________________________________________

3.4 The health plans serving CYSHCN in my state have policies and procedures that allow a child changing plans or insurers to continue using an out-of-network provider for a substantial time period (e.g. up to six months after enrollment).

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:

_____________________________________________________________________________________________________________________________

_____________________________________________________________________________________________________________________________

3.5 The health plan networks serving CYSHCN in my state allow access to pediatric specialists specified in a child’s care plan without prior authorization, whether or not such specialists participate in the network.

Yes  (IF YES) How effective are those policies and procedures?  Very effective  Somewhat effective  Not effective  No
3.6 My organization has policies and procedures to support the use of telemedicine or other electronic means to promote access to specialty providers for 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 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:
_____________________________________________________________________________________________________________________________  
_____________________________________________________________________________________________________________________________

3.7 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 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:
_____________________________________________________________________________________________________________________________  
_____________________________________________________________________________________________________________________________
DOMAIN SUMMARY

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

Notes (OPTIONAL use this space to elaborate on your answer choices, describe state-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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6 To request this and other National Standards assessment tools, please email Meredith Pyle at The Association of Maternal and Child Health Programs (AMCHP) at mpyl@amchp.org
4. Medical Home

4.1 My organization’s policies and procedures include language that defines medical homes serving CYSHCN.

☐ Yes (IF YES) This definition of medical homes includes criteria in the following areas: (Check all that apply): ☐ Primary care provider availability
☐ Family partnerships with the provider ☐ Care coordination ☐ Quality improvement
☐ No
☐ Not applicable to my organization; please indicate the agencies/entities in your state 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 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:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

Pediatric Preventive and Primary Care

4.2 My organization has policies and procedures that allow all newly enrolled families of CYSHCN to choose their own primary care provider.

☐ 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 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:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________
4.3 My organization has a definition of preventive and primary care for CYSHCN as care that focuses on overall health, wellness, prevention of secondary conditions, and promotion of behaviors across all life stages.

☐ 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 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 incorporate such a definition of preventive and primary care for CYSHCN its own or other organizations/systems.

☐ Strong  ☐ Moderate  ☐ Weak.

OPTIONAL - Comments:
____________________________________________________________________________________________________________________________

_________________________________________________________________________________________________________________
4.5 My organization’s requirements for care plans for CYSHCN include the following: (Check only those that apply)

☐ The care plan must be jointly developed and updated by the primary care provider, the child’s family, members of the health care team serving the child, and individuals outside of the health care system

☐ The care plan must integrate physical, developmental, mental, oral, and vision health?

☐ The care plan must identify and address children’s needs that fall outside of the health care system

☐ My organization does not develop care plans for CYSHCN

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

OPTIONAL - Comments:
______________________________________________________________________________________________________________________________
______________________________________________________________________________________________________________________________

Pediatric Specialty Care

4.6 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 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:
______________________________________________________________________________________________________________________________
______________________________________________________________________________________________________________________________
DOMAIN SUMMARY

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your state, do you think this Domain is currently a critical area to address within your state? □ Yes □ No  

Notes (OPTIONAL use this space to elaborate on your answer choices, describe state-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 To request this and other National Standards assessment tools, please email Meredith Pyle at The Association of Maternal and Child Health Programs (AMCHP) at mpyle@amchp.org
5. Community-based Services and Supports

5.1 My organization has interagency or cross-system agreements that assure CYSHCN and their families receive screening, referrals, and access to comprehensive home and community-based supports, including respite care.

☐ Yes
(IF YES) How effective are those agreements? ☐ Very effective ☐ Somewhat effective ☐ Not effective
☐ No
☐ Not applicable to my organization; please indicate the agencies/entities in your state 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 cross-system agreements. ☐ Strong ☐ Moderate ☐ Weak.

OPTIONAL - Comments:
____________________________________________________________________________________________________________________
____________________________________________________________________________________________________________________

5.2 My organization has policies and procedures that include family organizations as key partners in making recommendations and referrals to home 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 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:
____________________________________________________________________________________________________________________
____________________________________________________________________________________________________________________
5.3 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 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:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

5.4 My organization has policies for pediatric hospice care that incorporate family-centered care 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 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:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________
5.5 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 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:

_______________________________________________________________________________________________________________________________

_______________________________________________________________________________________________________________________________

DOMAIN SUMMARY

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your state, do you think this Domain is currently a critical area to address within your state? ☐ Yes ☐ No

IF YES, please note that an in-depth assessment tool for this Domain is available.  

Notes (OPTIONAL use this space to elaborate on your answer choices, describe state-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 To request this and other National Standards assessment tools, please email Meredith Pyle at The Association of Maternal and Child Health Programs (AMCHP) at mpyle@amchp.org
6. Family Professional Partnerships

6.1 My organization requires that families of CYSHCN be fully engaged as partners in development of policies and procedures affecting the health of CYSHCN.

☐ Yes
(If YES) Please briefly describe these requirements in your system and provide examples of family engagement in this area.

How effective are those requirements?  ☐ Very effective  ☐ Somewhat effective  ☐ Not effective
☐ No
Please rate your organization’s ability to more fully engage families as partners in development of policies and procedures.  ☐ Strong  ☐ Moderate  ☐ Weak.

OPTIONAL - Comments:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

6.2 My organization requires that family representatives be included in quality improvement activities affecting CYSHCN.

☐ Yes
(If YES) How effective are those requirements?  ☐ Very effective  ☐ Somewhat effective  ☐ Not effective
☐ No
Please rate your organization’s ability to more fully engage families in quality improvement activities affecting CYSHCN.  ☐ Strong  ☐ Moderate  ☐ Weak.

OPTIONAL - Comments:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

6.3 My organization requires the engagement of families in review of outreach and educational materials to assure they reflect family-centered care and cultural and linguistic competency.

☐ Yes
(If YES) How effective are those requirements?  ☐ Very effective  ☐ Somewhat effective  ☐ Not effective
☐ No
Please rate your organization’s ability to more fully engage families in review of outreach and educational materials. □ Strong □ Moderate □ Weak.

OPTIONAL - Comments:

_____________________________________________________________________________________________________________________________

DOMAIN SUMMARY

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

Notes (OPTIONAL use this space to elaborate on your answer choices, describe state-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. Transition to Adulthood

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

7.1. 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

7.2. 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 readiness/self-care assessment
☐ Goals and prioritized actions
☐ Medical summary and emergency care plan
☐ (Other (please specify ________________________________________________________)  ☐ No

7.3. 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):

☐ Final transition readiness/self-care assessment
☐ Final plan of care
☐ Current medical summary and emergency care plan
☐ Date transfer package sent to adult provider
DOMAIN SUMMARY

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your state, do you think this Domain is currently a critical area to address within your state? □ Yes □ No. IF YES, please note that an in-depth assessment tool for this Domain is available.¹⁰

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

¹⁰ To request this and other National Standards assessment tools, please email Meredith Pyle at The Association of Maternal and Child Health Programs (AMCHP) at mpyle@amchp.org
8. Health Information Technology

8.1 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 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:
____________________________________________________________________________________
____________________________________________________________________________________

8.2 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 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:
____________________________________________________________________________________
____________________________________________________________________________________
8.3 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 which are the authority to implement and/or ensure this standard:
☐ Title V  ☐ State Medicaid  ☐ CHIP  ☐ Health Plan/Insurer  ☐ Provider (please specify _______________)
☐ 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

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your state, do you think this Domain is currently a critical area to address within your state? ☐ Yes  ☐ No  IF YES, please note that an in-depth assessment tool for this Domain is available.11

Notes (OPTIONAL use this space to elaborate on your answer choices, describe state-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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11 To request this and other National Standards assessment tools, please email Meredith Pyle at The Association of Maternal and Child Health Programs (AMCHP) at mpyle@amchp.org
9. Quality Assurance and Improvement

9.1 My organization has quality assurance and improvement policies and procedures that are specific to providers and systems serving CYSHCN and their families.

☐ 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 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:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

9.2 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
☐ Medicaid  ☐ Selected health providers  ☐ Families  ☐ Title V CYSHCN program
☐ Public health  ☐ Health plan  ☐ Other (Please specify) _____________
☐ No
☐ Not applicable to my organization; please indicate the agencies/entities in your state 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:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________
9.3 My organization has policies and procedures for periodic review of utilization of services among 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 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:
____________________________________________________________________________________________________________________________
______________________________________________________________________________
____________________________________________________________________________________________________________________________

9.4. 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 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:
____________________________________________________________________________________________________________________________
____________________________________________________________________________________________________________________________
9.5 My organization routinely collects and assesses experience of care information from families of CYSHCN and youth with special health care needs.

☐ Yes
(If YES) How effective is that system? ☐ Very effective ☐ Somewhat effective ☐ Not effective
☐ No

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

OPTIONAL - Comments:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

9.6. In my state, there is a systematic, ongoing process to determine whether there is adequate pediatric provider capacity, including shortages, for primary care, specialty care, mental health and dental/oral health care.

☐ Yes
(IF YES) How effective is that process? ☐ Very effective ☐ Somewhat effective ☐ Not effective
☐ No

Please rate your organization’s authority to implement or improve this kind of process in your state. ☐ Strong ☐ Moderate ☐ Weak.

OPTIONAL - Comments:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________
The text reads:

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your state, do you think this Domain is currently a critical area to address within your state? □Yes □No If YES, please note that an in-depth assessment tool for this Domain is available.

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

10.1 In my state, there are policies requiring all public and private insurers to provide reasonable premiums and cost sharing for CYSHCN?

- Yes
- No

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

Please rate your organization’s authority to implement or improve these kinds of policies in your state.

- Strong
- Moderate
- Weak

OPTIONAL - Comments:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

10.2 In my state, there are policies requiring public and private insurers to offer coverage for habilitative services for children that is no more restrictive than their coverage for rehabilitative services. (e.g. with regard to kind, duration, scope, amount of services covered)

- Yes
- No

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

Please rate your organization’s authority to implement or improve these kinds of policies in your state.

- Strong
- Moderate
- Weak

OPTIONAL - Comments:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________
10.3 Insurers and health plans serving CYSHCN in my state use an authorization process that is simple and that recognizes the unique needs of CYSHCN without unduly delaying access to care?
   - Yes
   - No

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

Please rate your organization’s authority to implement or improve these kinds of processes internally and/or in other organizations and systems.
   - Strong
   - Moderate
   - Weak.

OPTIONAL - Comments:
_____________________________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

10.4 Insurers and health plans serving CYSHCN in my state have policies and procedures for coverage of second opinions without restrictions to those opinions.
   - Yes
   - No

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

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:
__________________________________________________________________________________________________________
_____________________________________________________________________________________________________________________________

10.5 My organization has been involved in making policy recommendations about covered services for CYSHCN in my state.
   - Yes
   - No

(IF YES) For which of the following types of insurance has your organization been involved in making policy decisions about coverage for CYSHCN?
   - Medicaid
   - CHIP
   - Commercial Insurance
   - ACA Health Exchange Plans
   - Other (Please specify) ________________________________
DOMAIN SUMMARY

Based on your responses to questions in this section and your knowledge of current and emerging issues for CYSHCN in your state, do you think this Domain is currently a critical area to address within your state? □Yes □No IF YES, please note that an in-depth assessment tool for this Domain is available.¹³

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

¹³ To request this and other National Standards assessment tools, please email Meredith Pyle at The Association of Maternal and Child Health Programs (AMCHP) at mpyle@amchp.org