

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 states 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 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 CYSHCN 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 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.

Respondents are encouraged to use the Notes space to expound 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.

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.

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)¹
- Other (Please specify) _____

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:

¹ 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*

- 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 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:

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.²

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.)

² To request this and other National Standards assessment tools, please email Sarah Beth McLellan at The Association of Maternal and Child Health Programs (AMCHP) at smclellan@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 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.*³

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.)

³ To request this and other National Standards assessment tools, please email Sarah Beth McLellan at The Association of Maternal and Child Health Programs (AMCHP) at smclellan@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.

Type of Provider	Response (Check One)		
	Yes	No	Not Applicable
Primary Care Providers	<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 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 _____)
Pediatric Specialists	<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 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 _____)
Oral Health Providers	<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 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 _____)
Mental Health Providers	<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 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:

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

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

OPTIONAL - Comments:

3.6 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.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 Sarah Beth McLellan at The Association of Maternal and Child Health Programs (AMCHP) at smclellan@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 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 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:

Care Coordination and Care Planning

4.4 My organization has policies and procedures promoting access to care coordinators for all medical homes serving 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 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:

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 CYSCHCN.

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 IF YES, please note that an in-depth assessment tool for this Domain is available.⁵

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.)

⁵ To request this and other National Standards assessment tools, please email Sarah Beth McLellan at The Association of Maternal and Child Health Programs (AMCHP) at smclellan@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/Consumer
 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.*⁶

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.)

⁶ To request this and other National Standards assessment tools, please email Sarah Beth McLellan at The Association of Maternal and Child Health Programs (AMCHP) at smclellan@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.*⁷

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.⁸

⁸ To request this and other National Standards assessment tools, please email Sarah Beth McLellan at The Association of Maternal and Child Health Programs (AMCHP) at smclellan@amchp.org

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.)

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 _____) 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

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.⁹

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.)

⁹ To request this and other National Standards assessment tools, please email Sarah Beth McLellan at The Association of Maternal and Child Health Programs (AMCHP) at smclellan@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

Public health Health plans 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:

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 Sarah Beth McLellan at The Association of Maternal and Child Health Programs (AMCHP) at smclellan@amchp.org

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

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

No

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

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

No

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

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

No

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

(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 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

(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) _____

No

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.)

¹¹ To request this and other National Standards assessment tools, please email Sarah Beth McLellan at The Association of Maternal and Child Health Programs (AMCHP) at smclellan@amchp.org