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, since all children have the potential for having a special health care need at some point in their lives.

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 full standards document, including existing national principles and frameworks, federal requirements or relevant federal law, and the overall availability of relevant quality measures for each standards 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
DIRECTIONS for IN-DEPTH State Systems Assessment Tool: Standards for Systems of Care for CYSHCN

Purpose of the In-Depth State Systems Assessment Tool
This In-Depth State Systems Assessment tool is designed to be used by states to take a deeper look into the System Standards, once your organization has used the “Abridged Single-Organization Statewide Systems of Care Assessment Tool”1.

This state assessment tool is designed to be a practical, quantifiable self-assessment tool for Title V CYSHCN programs, state Medicaid and CHIP, health plans, provider groups, families and family partner organizations. It allows single organizations which are part of the system(s) of care for CYSHCN 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. It includes key questions for stakeholders to assess their capacity to implement or improve each of the policies and processes that are outlined in the national standards. The tool was designed to be completed by members of a single stakeholder groups (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 determine priority actions steps. A multi-organization assessment summary tool is under development.

How to Complete the Tool (A sample of a completed Domain (Screening, Assessment, and Referral) assessment is shown after the Directions.)
The tool is organized into tables, with one table for each Standard Domain. Organizations can choose to assess one, several, or all Domains according to the organization’s preference, need, and priorities. Each Domain table is organized by standard – each standard is a row, and each column contains a specific question for that standard.

- **Column A** contains the specific standard to be assessed.
- **Column B** assesses the existence and effectiveness of policies and procedures within their organization for the standard. Respondents are asked if policies and procedures are in place, and if so, to rate the effectiveness of existing policies and procedures relevant to the particular standard as “not effective”; “somewhat effective”; or “very effective.” There is a point value associated with each rating – 1 point for not effective; 2 points for “somewhat effective” and 3 points for “very effective.” Respondents select a rating and then enter the point value in the “enter score” box in that cell. If policies and procedures for this standard are not in place, the point value is “0”. If this standard is not applicable to the organization using the tool, than no score is entered for that standard.
- **Column C** identifies which agencies, entities and/or organizations within the respondent’s state would be responsible for or have the authority for implementing the particular standard. Respondents check all relevant responses.
- **Column D** assesses the respondent organization’s authority to implement or improve policies and procedures that support the particular standard. Respondents are asked to rate their organization’s ability as “none”, “weak”; “moderate”; or “strong”. There is a point value associated with each rating – 0 points for none; 1 point for weak; 2 points for “moderate” and 3 points for “strong.” Respondents select a rating and then enter the point value in the “enter score” box in that cell.
- **Column E** provides space for responding organizations to indicate any local, state or national measures that relate to each particular standard.

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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
The last row of the each Domain table allows respondents to calculate two summary measures for the Domain. The scores from each cell in Column B are totaled and divided by the highest possible total score; and the scores from each cell in Column D are totaled and divided by the highest possible total score. This results in two indicator scores; one for effectiveness (Column B) and one for organizational influence (Column D). Indicator scores range from “0” to “1”, with a score of “0” representing no effectiveness or organizational influence on the Domain, and a score of “1” representing the highest possible degree of effectiveness and organizational influence on the Domain.

Interpreting Domain Scores

- **Organizational Effectiveness Indicator:**

  0.00 to 0.33 – If your organization’s effectiveness indicator score falls within this range, your organization’s ability or effectiveness around this Domain is very low. If your organization’s score is closer to zero, you may have little or no authority or ability to impact this Domain unless you identify and partner with the entity or entities within your state that do have the authority or ability to influence this domain. If your organization’s score is closer to 0.33, check your Influence Indicator – if it is high for this Domain, consider what your organization can do internally to improve policies and procedures for the standards in this Domain.

  0.34 to 0.65 – If your organization’s effectiveness indicator score falls within this range, your organization’s ability or effectiveness around this Domain is moderate. Consider ways in which you may be able to strengthen the effectiveness of policies and procedures for each standard in this Domain.

  0.66 to 1.00 – If your organization’s effectiveness indicator score falls within this range, your organizational effectiveness for this Domain is high. You should reflect on what factors have led to your organization’s success in this area and consider a submission to [AMCP’s Innovation Station](http://www.amchp.org/programsandtopics/BestPractices/InnovationStation/Pages/default.aspx) to share your knowledge and experience around this Domain with other states.

- **Organizational Influence Indicator:**

  0.00 to 0.33 – If your organization’s influence indicator score falls within this range, your organization has no or weak influence or authority to ensure implementation of the standards within this Domain without building or strengthening partnerships with the entities in your state that do have the authority to address the standards under this Domain. Refer to Column C and reflect on the existing or possible partnerships your organization has with the agencies you indicated in Column C.

  0.34 to 0.65 – If your organization’s influence indicator score falls within this range, your influence or authority to ensure implementation of the standards within this Domain is moderate. Consider ways in which you may be able to use your organization’s authority to strengthen the effectiveness of policies and procedures for each standard in this Domain.

  0.66 to 1.00 – If your organization’s influence indicator score falls within this range, your influence or authority to ensure implementation of the standards within this Domain is strong. Look back at your effectiveness indicator and if it is less than 0.66, consider ways in which you may be able to use your organization’s authority to strengthen the effectiveness of policies and procedures for each standard in this Domain.
DIRECTIONS for IN-DEPTH State Systems Assessment Tool: Standards for Systems of Care for CYSHCN

System Principles, Standards and Key Questions for Assessment of State Systems of Care for CYSHCN

DOMAIN: SCREENING, ASSESSMENT, AND REFERRAL

SAMPLE: Screening, Assessment and Referral (sample responses are highlighted)

State: ______ Name of State _______ Date: __________ Enter Date You Are Completing the Assessment

Type of Agency Completing this Tool:  
- X 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.

<table>
<thead>
<tr>
<th>Column A</th>
<th>Column B</th>
<th>Column C</th>
<th>Column D</th>
</tr>
</thead>
<tbody>
<tr>
<td>System Standards (Structure and Process)</td>
<td>Within my organization, there are policies and procedures in place for this standard:</td>
<td>What agencies/entities in your state have the authority to implement and/or ensure this standard? (Check all that apply.)</td>
<td>Please rate your organization’s authority to implement or improve policies and procedures that support this standard.</td>
</tr>
</tbody>
</table>

1. Promptly after enrollment in a health plan, all CYSHCN are provided a documented initial assessment that is conducted in collaboration with the child’s family or caregiver.¹

- □ Yes  
  - (IF YES) How effective are those policies and procedures?  
    - □ 1 Not effective  
    - □ 2 Somewhat effective  
    - □ 3 Very effective

- □ No (Enter “0” for score, below.)
- □ X Not applicable to my organization

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

- 0 None
- □ 1 X Weak
- □ 2 Moderate
- □ 3 Strong

OPTIONAL: Why?

Enter Score: 1

State Legislature

Enter Score: 1
2. The child’s health plan and medical home have a documented plan and process to demonstrate how they follow-up with a hospital or state health department when newborn screening results are not received.2

<table>
<thead>
<tr>
<th>Yes (IF YES) How effective are those policies and procedures?</th>
<th>Title V</th>
<th>Enter Score:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ 1 Not effective</td>
<td>□ State Medicaid</td>
<td></td>
</tr>
<tr>
<td>□ 2 Somewhat effective</td>
<td>□ CHIP</td>
<td></td>
</tr>
<tr>
<td>□ 3 Very effective</td>
<td>□ Health Plan/Insurer</td>
<td></td>
</tr>
<tr>
<td>□ No (Enter “0” for score, below.)</td>
<td>Provider (please specify)</td>
<td></td>
</tr>
<tr>
<td>□ X Not applicable to my organization</td>
<td>□ Family/Consumer</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>

3. All children, including CYSHCN, receive periodic, developmentally appropriate, and recommended comprehensive screenings (to include screening for physical health, oral health, mental health, developmental, and psychosocial needs, and cultural and linguistic needs, preferences or limitations) as part of a well-child visit or other preventive visit and in response to triggering events such as hospitalization, trauma, or sudden onset of new symptoms, in accordance with Bright Futures Guidelines.

<table>
<thead>
<tr>
<th>Yes (IF YES) How effective are those policies and procedures?</th>
<th>Title V</th>
<th>Enter Score:</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ 1 Not effective</td>
<td>□ State Medicaid</td>
<td></td>
</tr>
<tr>
<td>□ X 2 Somewhat effective</td>
<td>□ CHIP</td>
<td></td>
</tr>
<tr>
<td>□ 3 Very effective</td>
<td>□ Health Plan/Insurer</td>
<td></td>
</tr>
<tr>
<td>□ Not applicable to my organization</td>
<td>Provider (please specify)</td>
<td></td>
</tr>
<tr>
<td>□ X Family/Consumer</td>
<td>Birth Hospitals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>□ Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>

As the Title V agency, we can use our Cooperative Agreement with Medicaid to reach out to Medicaid and its Managed Care Organizations to encourage adoption of this standard.

<table>
<thead>
<tr>
<th>Enter Score:</th>
<th>2</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>X Title V</td>
<td>3</td>
<td>Strong</td>
</tr>
<tr>
<td>State Medicaid</td>
<td>2</td>
<td>Moderate</td>
</tr>
<tr>
<td>CHIP</td>
<td>1</td>
<td>Weak</td>
</tr>
<tr>
<td>Health Plan/Insurer</td>
<td>0</td>
<td>None</td>
</tr>
<tr>
<td>Provider (please specify)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family/Consumer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Enter Score:</th>
<th>3</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title V</td>
<td>3</td>
<td>Strong</td>
</tr>
<tr>
<td>State Medicaid</td>
<td>2</td>
<td>Moderate</td>
</tr>
<tr>
<td>CHIP</td>
<td>1</td>
<td>Weak</td>
</tr>
<tr>
<td>Health Plan/Insurer</td>
<td>0</td>
<td>None</td>
</tr>
<tr>
<td>Provider (please specify)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family/Consumer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### DIRECTIONS for IN-DEPTH State Systems Assessment Tool: Standards for Systems of Care for CYSHCN

**4. Screening efforts, results and referrals for further assessment are documented, relayed to the child’s medical home and family, and, to the extent feasible, coordinated among all screening entities, including but not limited to clinical care settings, medical homes, child care settings, and schools.**

<table>
<thead>
<tr>
<th>Yes</th>
<th>(IF YES) How effective are those policies and procedures?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 Not effective</td>
</tr>
<tr>
<td></td>
<td>2 Somewhat effective</td>
</tr>
<tr>
<td></td>
<td>3 Very effective</td>
</tr>
</tbody>
</table>

| No (Enter “0” for score, below.) | X Not applicable to my organization |

Enter Score:

**5. Following a screening and assessment, the CYSHCN and their family are referred to needed services including pediatric specialists, therapies, other service systems such as Early Intervention, Special Education, family organizations and community-based agencies, and follow-up is provided to ensure such referrals are completed. In turn, those services and systems should ensure follow-up to the child’s medical home and other members of the child’s care team after referral visits.**

<table>
<thead>
<tr>
<th>Yes</th>
<th>(IF YES) How effective are those policies and procedures?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 Not effective</td>
</tr>
<tr>
<td></td>
<td>X 2 Somewhat effective</td>
</tr>
<tr>
<td></td>
<td>3 Very effective</td>
</tr>
</tbody>
</table>

| No (Enter “0” for score, below.) | Not applicable to my organization |

Enter Score:

---

**We could use our existing partnerships w/Medicaid and state chapter of AAP to encourage pediatricians to implement this standard. State law XX-XX mandates birth hospital reporting of screening and follow-up, but this does not extend to primary care.**

---

**We currently use our existing partnerships w/Medicaid and state chapter of AAP to encourage health plans and pediatricians to implement this standard; our program worked closely with partners to recommend certain screening tools and promote Bright Futures.**

---
6. Regardless of the entity conducting a screening and referral, protocols and documentation methods are in place for the primary care provider, medical home or other such entity to follow-up with the child and family in areas including: assessment of follow-up received, barriers to care, and, where feasible, assistance in addressing barriers to obtaining needed follow-up.\(^4\)

- Yes
  - (IF YES) How effective are those policies and procedures?
    - 1 Not effective
    - 2 Somewhat effective
    - 3 Very effective
- \(\times\) No (Enter “0” for score, below.)
- Not applicable to my organization

Enter Score: \(0\)

Referral/Follow-up:

1. Following a screening and assessment, the CYSHCN and their family are referred to needed services including pediatric specialists, therapies, other service systems such as Early Intervention, Special Education, family organizations and community-based agencies, and follow-up is provided to ensure such referrals are completed. In turn, those services and systems should ensure follow-up to the child’s medical home and other members of the child’s care team after referral visits.\(^2\)

- Yes
  - (IF YES) How effective are those policies and procedures?
    - 1 Not effective
    - 2 Somewhat effective
    - 3 Very effective
- \(\times\) No (Select “0” for score, above )
- Not applicable to my organization

Enter Score: \(2\)
2. Regardless of the entity conducting a screening and referral, protocols and documentation methods are in place for the primary care provider, medical home or other such entity to follow-up with the child and family in areas including: assessment of follow-up received, barriers to care, and, where feasible, assistance in addressing barriers to obtaining needed follow-up.\(^6\)

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

- No (Select “0” for score, above)
- Not applicable to my organization

<table>
<thead>
<tr>
<th>Enter Score:</th>
<th>1</th>
</tr>
</thead>
</table>

As a convener of entities serving CYSHCN in our state, we could use our multi-stakeholder, statewide CYSHCN collaborative to focus on this issue to improve the consistency of implementation of this standard across providers and organizations serving CYSHCN.

SUMMARY: SCREENING, ASSESSMENT and REFERRAL

Effectiveness Indicator:

Total of Scores from Column B (Policies and Procedures) column: 7 / 24 = 0.29

Organizational Influence Indicator:

Total of Scores from Column D (Ability to Implement and Improve) column: 15 / 24 = 0.63

Additional Notes: None.

ENDNOTES:

4 Ibid.
5 Ibid.
6 Ibid.