TX Action Learning Collaborative: National Standards for Systems of Care for CYSHCN

January 21, 2015

Children’s Policy Council

http://www.amchp.org/AboutAMCHP/Newsletters/member-briefs/Documents/Standards%20Charts%20FINAL.pdf
National Standards for Systems of Care for Children and Youth with Special Health Care Needs

**What:** the consensus of national experts across multiple systems

**Why:** designed to help communities and states build and improve systems of care for CYSHCN

- **Screening, Assessment and Referral**
- **Eligibility and Enrollment**
- **Access to Care**
  - Medical Home: Pediatric Preventive and Primary Care; Care Coordination; Pediatric Subspecialty Care
- **Community-based Services and Supports:** Respite Care; Palliative and Hospice Care; Home-based Services
- **Family Professional Partnerships**
- **Transition to Adulthood**
- **Health Information Technology**
- **Quality Assurance and Improvement**
- **Insurance and Financing**

**Disclaimer:** The National Standards are meant to supplement, not substitute, federal statute and regulatory requirements under Medicaid, the ACA and other relevant laws and are intended for use or adaptation by a wide range of stakeholders at the national, state and local levels.
29 Standards focus on:
- Medical team; care coordination
- 24-7 access; additional time for visits
- Prevention and Treatment
- Routine, emergent and urgent needs are met

Relevant System Partners:
- Health Plans/Insurers
- Primary Care
- State
- Families
<table>
<thead>
<tr>
<th>Medical Home: Overall (10 Standards)</th>
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<tbody>
<tr>
<td><strong>Primary Care</strong></td>
</tr>
<tr>
<td>1. Provide access to health care services 24 hours, seven days a week</td>
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<tr>
<td>2. Provide health care services that encourage the family to share in decision making, and provide feedback</td>
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<td>3. Perform comprehensive health assessments</td>
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<tr>
<td>4. Promote an integrated, team-based model of care coordination</td>
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<td>5. Develop, maintain, and update a comprehensive, integrated plan of care that has been developed with the family and is shared with families and providers</td>
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<td>6. Support self-management of CYSHCN’s health and health care</td>
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<td>7. Promote quality of life, health development and behaviors across all life stages</td>
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<td>8. Integrate care with other providers; effective info sharing with families and providers</td>
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<td>9. Active care tracking that includes proactive reminders to families and clinicians of services needed via a registry or other mechanism</td>
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<td>10. Provide effective, evidence-based care</td>
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### Medical Home: Pediatric Preventive and Primary Care (9 Standards)

#### Health Plans/Insurers
- 3. All children, including CYSHCN, have access to medically necessary and preventive services to promote optimal health
- 5. Reasonable access to routine, episodic, urgent and emergent health care are provided

#### Health Care Providers
- 1. (PCP) Bright Futures Guidelines for screening and well care including oral and mental health are followed
- 2. (PCP) Care focuses on overall health, wellness and prevention of secondary conditions
- 3. All children, including CYSHCN, have access to medically necessary and preventive services to promote optimal health
- 4. (PCP) All children, including CYSHCN, receive recommended immunizations
- 5. Reasonable access to routine, episodic, urgent and emergent health care are provided
- 6. Reasonable wait times and same day appointments are available for physical, oral and mental health care
- 7. Accommodations for special needs (i.e. home vs. office visits) are available
- 8. Scheduling systems that recognize additional time in caring for CYSHCN
- 9. Pre-visit assessments are completed with family to ensure provision of family-centered care and needed referrals

#### State
- 3. All children, including CYSHCN, have access to medically necessary and preventive services to promote optimal health
- 5. Reasonable access to routine, episodic, urgent and emergent health care are provided
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<thead>
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<th>Health Plans/Insurers</th>
<th>Health Care Providers</th>
<th>State</th>
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<td>1. All CYSHCN have access to patient and family-centered care coordination.</td>
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<td>3. A plan of care* is jointly developed, shared and implemented among PCP, specialists, family and CYSHCN, and others as needed.</td>
<td>2. Care Coordinators serve as member of medical home team; assist in managing CYSHCN transitions; and provide appropriate resources to CYSHCN and families.</td>
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<td>*addresses health problems; identifies strengths and needs of child and family; routinely evaluated and updated; delineates roles of all participating entities</td>
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Medical Home: Pediatric Specialty Care (7 Standards)

Health Plans/Insurers

1. Shared management of CYSHCN between pediatric primary care and specialty providers is permitted.
4. Pediatric centers of care are available to CYSHCN and their families when needed.
6. Durable medical equipment and home health services are customized for CYSHCN.
7. A full continuum of children’s behavioral health services are provided.

Health Care Providers

2. Systems such as satellite programs, electronic communications, and telemedicine are used to enhance access to specialty care and multidisciplinary teams of pediatric specialty providers.
3. Physical, oral and mental health are coordinated and integrated.
4. Pediatric centers of care are available to CYSHCN and their families when needed.
7. A full continuum of children’s behavioral health services are provided.

State

2. Systems such as satellite programs, electronic communications, and telemedicine are used to enhance access to specialty care and multidisciplinary teams of pediatric specialty providers.
5. The system serving CYSHCN includes Title V CYSHCN programs, LENDs and UCEDDs, where available.
7. A full continuum of children’s behavioral health services are provided.
9 Standards focus on:
- Families are active members of the team
- Connection with family organizations, peer support
- Strength-based; Informed
- Culturally and linguistically appropriate

Relevant System Partners:
- Health Plans/Insurers
- Primary Care
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• 3. Families are connected to family and peer support organizations.  
• 5. Care is delivered in culturally appropriate ways.  
• 6. Families get information in family-chosen methods.  
• 7. All written materials provided to CYSHCN and their families are culturally, linguistically and literacy-level appropriate.  
• 8. Health systems that serve CYSHCN solicit feedback from the family and children.  
• 9. Health systems that serve CYSHCN have a family advisory board of committee, inclusive of families of CYSHCN. | • 1. Families are active, core members of the medical home team.  
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Next steps

Use data

Courageous conversations

Relationships and learning

Define the goal

MCH Performance
Medical home
National Standard
Healthy People 2020
### Texas

#### Medical Home Profile at a Glance

<table>
<thead>
<tr>
<th>Texas</th>
<th>National Rate</th>
<th>Range across States</th>
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<tbody>
<tr>
<td>40.1%</td>
<td>43.0%</td>
<td>34.2% - 50.7%</td>
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#### Care coordination

- Texas is below average in receiving effective care coordination
- Just over half of families get care coordination when needed
- Only 22% got any help arranging or coordinating care

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**Medical Home Performance Profile for Children with Special Health Care Needs (CSHCN)**

**Data Source:** 2008/10 National Survey of Children with Special Health Care Needs (NS-CSHCN)

**Prevalence of Medical Home in Texas**

<table>
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<th>CSHCN (Age 0-17 Years)</th>
<th>State</th>
<th>Nation</th>
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<td>Met all medical home criteria</td>
<td>40.1%</td>
<td>43.0%</td>
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**Components of Medical Home**

**Accessibility**

- Has a personal doctor or nurse: 94.4% (State) vs. 90.1% (Nation)

**Family-Centered Care (% who report "Usually" or "Always")**

- Doctor spends enough time: 73.5% (State) vs. 77.5% (Nation)
- Doctor listens carefully: 86.8% (State) vs. 87.7% (Nation)
- Doctor provides needed information: 83.4% (State) vs. 82.4% (Nation)
- Doctor helps parent feel like partner in care: 85.0% (State) vs. 87.0% (Nation)

**Comprehensive**

- Had no problems getting referrals when needed: 68.7% (State) vs. 76.6% (Nation)
- Has a usual source for both sick and well care: 86.1% (State) vs. 99.3% (Nation)

**Coordinated (% among CSHCN Receiving 2 or More Types of Services)**

- Received effective care coordination, when needed: 53.3% (State) vs. 56.0% (Nation)
- Received any help with arranging or coordinating care: 22.2% (State) vs. 21.4% (Nation)
- Very satisfied with communication between doctors, when needed: 59.4% (State) vs. 62.7% (Nation)
- Very satisfied with communication between doctors and school, when needed: 54.9% (State) vs. 53.1% (Nation)

**Culturally Effective (% who report "Usually" or "Always")**

- Doctor is sensitive to family customs and values: 87.5% (State) vs. 85.9% (Nation)

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Prepared by the Child and Adolescent Health Measurement Initiative (CAHMI) in collaboration with the American Academy of Pediatrics (AAP), with funding from the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services.

70 DSRIP projects increase medical homes

24 DSRIP projects provide care coordination

21 DSRIP projects include children

Medical homes
- In 2011, Texas received a federal 1115 waiver to provide funding for uncompensated care and improved health care quality
- Only 5% of projects in TX focus on medical home improvement
- Only 1% of projects increasing access to medical home or care coordination had plans to include children and/or youth

[Link: http://www.hhsc.state.tx.us/1115-RHP-Plans.shtml]
• Title V 5 Year Needs Assessment
• Landscape Survey of MHWG Members
• Implementation of MHWG post-call survey
Texas

Family Professional partnerships
• Texas meets the national average from the NS-CSHCN 09/10
• Are we on track to meet our 2018 state goal?

MATERNAL & CHILD HEALTH (MCH) MEASURES

<table>
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<tr>
<th>Title V - Maternal Child Health National Performance Measures</th>
<th>State 2013 Results</th>
<th>State 2018 Goal</th>
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<td>The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive. (CSHCN survey)</td>
<td>70.3%</td>
<td>75%</td>
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**Vision:** To enhance the development and promote the principles of the Patient-Centered Medical Home model within the state of Texas for CYSHCN through the promotion of the National Standards For Systems of Care for CYSHCN

**Goal:** To improve systems of care related to medical home/care coordination and family professional partnerships through the formation of an Action Learning Collaborative via the Medical Home Workgroup
By November 2015, the Medical Home Workgroup strategic plan will incorporate medical home/care coordination and family professional partnership domains from the National Standards for Systems of Care for CYSHCN.

By September 2015, the Medical Home Workgroup will include engaged key stakeholders representing geographic, managed care, policy, and family groups participating in the majority of calls.
By September 2015, the ALC steering committee will educate 75% of key stakeholder about the national standards

By November 2015, the Medical Home Workgroup strategic planning committee will have an implementation plan for the strategic plan

By September 2015, the number of physicians on the medical home workgroup call endorsing participation in medical home transformation activities will increase by 25% AND 4B. By September 2015, the number of families participating on the medical home workgroup call endorsing participation in planning activities will increase by 25%