The National Standards for Systems of Care for Children and Youth with Special Health Care Needs: New Frontiers in Implementation for Title V and Partners

AMCHP 2017 Annual Conference
Saturday, March 4, 2017
1:30-4:30PM
Learning Objectives

• Increase knowledge of how states are using the National Standards to improve systems of care for CYSHCN

• Increase understanding how Standards can be applied by Title V MCH/CYSHCN Programs

• Apply new tools to identify opportunities to use the Standards to further state goals/work
Agenda

• Welcome/Introduction Activity
• National CYSHCN Systems Standards: Background and New Resources
• State Examples: New Frontiers in Implementing the National Standards
• Systems Alignment & Partnership Activity
• Action Steps & Evaluation
• Adjourn
Icebreaker Activity

- What is your current use of the Standards?

  - Not familiar with them
  - Heard of them but haven’t use yet
  - Referenced Standards in my work
  - Incorporated into work or action plans
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<tr>
<th>Not Familiar with them</th>
<th>Heard of the but haven’t used yet</th>
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<tr>
<td>What is one activity you have done to improve systems of care for CYSHCN in your state?</td>
<td>If there a piece of the Standards that you think could be used in your state? If so, what?</td>
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<tr>
<th>Referenced Standards in my work</th>
<th>Incorporated into work for action plans</th>
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<tr>
<td>Describe one way you have referenced the Standards in your work?</td>
<td>How have you used the Standards in your work or state action plan? Do you have any helpful tips of others?</td>
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National Standards to Improve Systems of Care for CYSHCN: Background and New Resources
What are the National Standards for Systems of Care for CYSHCN?
Why National Standards?

- Need for focus on unique needs of CYSHCN and their families
- Rapidly changing health care environment
  - e.g., service delivery system, new payment models
- Shifts of CYSHCN population to managed care arrangements
- Changing role of Title V MCH/CYSHCN programs
- Policy and regulatory opportunities
- Long-standing recommendations on need for standards
How were the Standards Developed?

- Over 30 interview with key informants
- National Work Group Guidance and Input
- Managed Care Contracting Standards
- National standards (e.g. NCQA medical home)
- Literature Research
- Background White Paper
- Standards for Systems of Care for Children and Youth with Special Health Care Needs
  A Product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project
- State Standards Currently in use
- Existing National Principles and Frameworks
Who Guided this Process?

- Federal Partners
- Families and Consumers
- Health Plans
- Policy and Health Scientists
- State Title V Programs
- Medicaid and CHIP Programs
- Researchers
Overall System Outcomes for CYSHCN:

1. **Family Professional Partnerships**: Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive.

2. **Medical Home**: CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home.

3. **Insurance and Financing**: Families of CYSHCN have adequate private and/or public insurance and financing to pay for the services they need.

4. **Early and Continuous Screening and Referral**: Children are screened early and continuously for special health care needs.

5. **Easy to Use Services and Supports**: Services for CYSHCN and their families will be organized in ways that families can use them easily and include access to patient and family-centered care coordination.

6. **Transition to Adulthood**: Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

7. **Cultural Competence**: All CYSHCN and their families will receive care that is culturally and linguistically appropriate (attends to racial, ethnic, religious, and language domains).

Core Domains for System Standards:

1. **Screening, Assessment and Referral**

2. **Eligibility and Enrollment**

3. **Access to Care**

4. **Medical Home, including**:
   - Pediatric Preventive and Primary Care
   - Care Coordination
   - Pediatric Specialty Care

5. **Community-based Services and Supports, including**:
   - Respite Care
   - Palliative and Hospice Care
   - Home-based Services

6. **Family Professional Partnerships**

7. **Transition to Adulthood**

8. **Health Information Technology**

9. **Quality Assurance and Improvement**

10. **Insurance and Financing**
### System Principles, Standards and Availability of Quality Measures for Systems of Care for CYSHCN

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<th>SYSTEM DOMAINS</th>
<th>System Standards (Structure and Process)</th>
<th>Existing National Principles and Frameworks</th>
<th>Federal Requirements or Relevant Federal Law</th>
<th>Overall Availability of Relevant Quality Measures</th>
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| SCREENING, ASSESSMENT, AND REFERRAL | Screening and Assessment: | Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, American Academy of Pediatrics
Draft Structure and Process Measures for Integrated Care for People with Dual Eligibility for Medicare and Medicaid, National Committee for Quality Assurance | Early and Periodic Screening, Diagnosis and Treatment (EPSDT) screening requirements for children enrolled in Medicaid:
- comprehensive health and developmental history
- comprehensive unclothed physical exam
- vision and hearing screening and referral to a dental provider
- appropriate immunizations
- lab tests
- anticipatory guidance
Federal Medicaid managed care regulations for screening of CYSHCN
The Patient Protection and Affordable Care Act (ACA) requires that Bright Futures Guidelines be followed as the standard that provides the basis for eligible preventive services | Healthy People 2020 Measures
National Quality Forum Measures
Children’s Health Insurance Program Reauthorization Act (CHIPRA) Core Measures
National Survey of Children’s Health |

*Children are screened early and continuously for special health care needs.*
Title V Use and Implementation of the Standards

- Written into Title V Block Grant
- Shared with partners
- Framework to convene stakeholders
- Incorporated into contracts
What are states saying about the National Standards?

The National Standards:

- Recognize the systemic needs of all CYSHCN
- Address systems of care comprehensively
- Based on evidence-based or evidence-informed practices

“Having these new standards...has raised the visibility of the need for doing things differently now for CYSHCN than for other populations so that we can really deliver valuable services.”

-Jennifer Kyle, RN, MA
Director, Population Strategy, UnitedHealthcare
Community & State
Partnership Building

“The standards add a great deal of depth to our discussions of systems of care and allow us to conduct a systematic evaluation across different domains that are relevant to different stakeholders... Educating people about the standards has also forged relationships that were not there or not yet fully developed”

-Carl Tapia, M.D., Associate Medical Director, Texas Children’s Health Plan

- State Title V Programs collaborated with Medicaid managed care organizations
- Revised Medicaid managed care contracts to promote collaboration and partnerships
Improving Care Across Systems through Policy and Program Change

• **Tool for families and stakeholders** to identify core elements of a comprehensive system

• **Identified action steps** for policy and practice level change

• Incorporated Standards into county and community-level public health systems
Key Products Available:

Products
- White Paper
- Standards Booklet
- Single & Multi-Organizational Standards Assessment Tools
- Standards Overview: PowerPoint Template
State Systems Assessment Tool

- Practical self-assessment tool for Title V CYSHCN programs, state Medicaid and CHIP, health plans, provider groups, families and family partner organizations
- Allows stakeholders to assess how well their organization and system is structured to address Standards
- Includes key questions to assess capacity to implement or improve policies and processes outlined in the National Standards
- Springboard to action planning
COMING SOON!

• Updated Organizational Assessments
• Systems Alignment Tool
• Partnership Profile
• Medicaid Managed Care Contracting tool
• NCQA Standards Crosswalk
• Standards 2.0
• Action Learning Collaborative
Standards 2.0: Streamlined for Implementation & Spread

- Streamlined domains & creation of Essential Principles
- Focus on systems level standards
- Updates based on new guidance / federal regulations
- Removal of roles, where possible
- Elimination of repeated concepts
- Simplification → appendix
State Examples: New Frontiers in Implementing the National Standards
Minnesota Example: Incorporating the National Standards for Systems of Care for CSHCN into a Systems Assessment

Sarah Cox, MSW
Background Information... Care Coordination in MN

• 56% of MN CYSHN needing care coordination actually received it\(^1\)

• Families receiving fragmented or duplicative services
• Unnecessary stress and frustration for parents and coordinators!
• Parents are “coordinating the coordinators”
• Lots of uncertainty on what is occurring across Minnesota regarding care coordination (i.e., who is doing what?)

\(^1\) 2011/2012 National Survey of Children’s Health
MN Care Coordination Systems Assessment & Action Planning Project

Main purposes:

- To **assess** what is occurring across the state around the provision and receipt of care coordination services
- To bring together coordinators and parents as a means of fostering connections and networks
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| Life Course Theory        | • Considers how choices and access early in life impacts future outcomes  
                          | • Considers life span of the child – transitions, etc.                                                                                      |
| Social Determinants of    | • Considers the multiple components of the system that impact the family and how they work together  
                      | Health / Systems Theory                                                                                                                  |
|                           | • Considers different barriers and experiences of families outside of the “health care” arena                                             |
| Social Ecological Model   | • Understands that barriers and supports occur at all levels                                                                               |
| Systems Support Mapping   | • Utilizes eco-mapping and care mapping approaches to map out pathways of experiencing the system                                           |
| Standards for Systems of  | • Defines “how” we achieve coordinated system of care                                                                                      |
| Care for CSHCN            |                                                                                                                                              |
Standards Related to Assessment

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

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| CARE COORDINATION (as part of the medical home and integrated with community-based services) | 1. All CYSHCN have access to patient and family-centered care coordination.  
2. To provide optimal coordination and integration of services needed by the child and family, care coordinators:  
   o serve as a member of the medical home team  
   o assist in managing care transitions of CYSHCN across settings and developmental stages  
   o provide appropriate resources to match the health literacy level, primary language, and culture of CYSHCN and their family  
3. A plan of care is jointly developed and shared among the primary care provider and/or the specialist serving the child. | • Definition of Care Coordination (See Appendix A)  
• National Quality Forum Framework for Care Coordination (See Appendix A)  
• Key Elements of High-Performing Pediatric Care Coordination Framework (See Appendix A)  
• The Functions of Care Coordination (See Appendix A)  
• 2013 Special Needs Plans Structure and Process Measures (See SNP Element 1), National Committee for Quality Assurance (NCQA)  
• A Standardized Approach to a Shared Plan of Care | | • NSCYSHCN  
• CAHPS |
### CARE COORDINATION

Pediatric care coordination is a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs in order to achieve optimal health and wellness outcomes.

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<th>National Quality Forum Framework for Care Coordination:</th>
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<td>1. A proactive plan of care that includes follow-up monitoring of progress toward patient-specific goals</td>
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<td>2. Communication between and among all members of the health care team and the patient, emphasizing shared decision-making with families</td>
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<td>3. Use of standardized, electronic information systems</td>
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<td>4. Coordinated efforts to optimize safety and accuracy during handoffs, or transfers between health care settings</td>
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### Key Elements of High-Performing Pediatric Care Coordination Framework:

1. Needs assessment for care coordination and continuing care coordination engagement
2. Care planning and communication
3. Facilitating care transitions (inpatient, ambulatory)
4. Connecting with community resources and schools
5. Transition to adult care
6. Transition to adult care

### The Functions of Care Coordination:

1. Establish relationships with children, youth, and families through introductory visits dedicated to setting expectations for care coordination
2. Promote communication with families and among professional partners, and define minimal intervals between communications
3. Complete a child/youth and family assessment
4. Working with the family, develop a written care plan, including a medical summary, action plan, and, if needed, an emergency plan, that reflects mutual goals
5. Arrange for, set up, and coordinate referrals, and track referrals and test results
6. Provide condition-specific and related medical, financial, educational, and social supportive resource information, while coaching for the transfer of skills supportive of partnerships with families to care for their children and youth
7. Ensure the health care team integrates multiple sources of health care information; communicate this summary, thereby building caregiver skills and fostering relationships between the health care team and families
8. Support and facilitate all care transitions from practice to practice and from the pediatric to adult systems of care
9. Coordinate family-centered team meetings (across organizations as needed)
### Assessment Handout:

Used to figure out potential responsibilities in individual systems support maps and statewide framework categories

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**DEFINITIONS**

Children and Youth with Special Health Needs (CYSHN): CYSHN are those 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.

Care Coordination: Care coordination for CYSHN is a family-centered, relationship-based, assessment-driven, team-based, and interdisciplinary activity designed to meet the needs of CYSHN, while enhancing the caregiving capabilities of families. Care coordination takes into consideration a continuum of child/family needs—including: health, medical, education, social, early intervention, nutrition, mental/behavioral/emotional health, community partnerships, and financial—to achieve optimal health and wellness.

**EXAMPLE CARE COORDINATION RESPONSIBILITIES**

1. Demonstrate and apply knowledge of the philosophy/principles of comprehensive, community-based, family-centered, developmentally appropriate, culturally sensitive care coordination services
2. Facilitate family access to medical home providers, staff, and resources
3. Assist with or promote the identification of patients in the practice with special health care needs (such as CYSHN), add to registry and use to plan and monitor care
4. Assess child/patient and family needs and unmet needs, strengths, and assets
5. Initiate family contacts; create ongoing processes for families to determine and request the level of care coordination support they desire for their child/youth or family member at any given point in time
6. Build care relationships among family and team; support the primary care-giving role of the family
7. Develop care plan with family/youth/team (emergency plan, medical summary, and action plan as appropriate)
8. Carry out care plans, evaluate effectiveness, monitor in a timely way and effect changes as needed; use appropriate transition timetables for interventions within care plans
9. Serve as the contact point, advocate, and informational resource for family and community partners/payers
10. Research, find, and link resources, services, and supports with/for family
11. Educate, counsel, and support; provide developmentally appropriate anticipatory guidance; in a crisis, intervene or facilitate referrals appropriately
12. Cultivate and support primary care & subspecialty co-management with timely communication, inquiry, follow up and integration of information into the care plan
13. Coordinate inter-organizationally among family, medical home, and involved agencies; facilitate “wrap-around” meetings or team conferences and attend community/school meetings with family as needed and prudent; offer outreach to the community related to the population of CYSHN
14. Serve as a medical home quality improvement team member, help to measure quality, and to identify, test, refine, and implement practice improvements
15. Coordinate efforts to gain family/youth feedback regarding their experience of health care (focus groups, surveys, other means); participate in interventions which address family/youth articulated needs

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Contact Information:

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National Standards for Systems of Care for CYSHCN
The Kansas Experience

Saturday, March 4, 2017
AMCHP Conference
Kansas City, MO
The Kansas Special Health Services Programs includes: newborn screening services; early intervention services for those at risk for developmental delay, ages birth to three; specialty health care services for those with eligible conditions, ages 0 – 22; and genetic medical treatment services for those identified through the newborn metabolic screening.
Special Health Care Needs (SHCN)

Program Purpose

To promote the functional skills of persons, who have or are at risk for, a disability or chronic disease.
Using the Standards

- Strategic Planning
  - SHCN Action Plan
  - Title V Needs Assessment
- Grant Planning
  - Systems Integration
- Workforce Development
  - Staff Performance
Using the Standards

**Regional Tours**
- 2 Domains per Phase
- 30 Regional Meetings
- 2 Year Timeframe

**Surveys**
- Provider Survey
- Consumer Survey
- Data Analysis

**Planning Meetings**
- Define Success
- Measure Success?
- Community Engagement
Next Steps

• Continue Regional Tour, Survey and Planning Meetings
  – Phase 3 – Spring 2017
    • Screening, Assessment & Referral
    • Transition to Adulthood
  – Phase 4 – Fall 2017
    • Insurance and Financing
    • Family Professional Partnerships
  – Phase 5 – Spring 2018
    • Quality Assurance and Quality Improvement
    • Health Information Technology

• State Plan Revisions (SHCN and Title V)
Questions

Heather Smith, MPH
Special Health Services Director
Title V CYSHCN Director
Kansas Department of Health and Environment, Bureau of Family Health
heather.smith@ks.gov
785-296-4747
Using the Standards Partnership & Alignment Tools
<table>
<thead>
<tr>
<th>Corresponding National Standard Domain</th>
<th>Lead Agency</th>
<th>Program/Project/Policy</th>
<th>Description of Program/Project/Policy including Goals and Objectives</th>
<th>Partners and Collaborators</th>
<th>Prioritization of Project within Agency</th>
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<td>Partner, e.g., Medicaid, Family Organizations</td>
<td>Shared Ventures: Previous and Current Collaborations</td>
<td>Rank Partnership Use Collaboration Scale Below</td>
<td>Describe Unique Strengths of Partnership</td>
<td>Describe Specific Barriers to Partnership</td>
<td>Addressing Challenges and Overcoming Barriers to Partnership: Action Steps</td>
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Group Activity:

- Break into groups by Standards domain
- Use **Systems Alignment tool** to identify existing CYSHCN systems improvement efforts related to that domain (share as a group)
- Use **Partnership Tool** to identify collaborations related to those efforts, as well as opportunities strengthen partnerships
- Share: 1) as a group and 2) themes or take-aways during report-out
Wrapping-Up: Key take-aways and Action Steps
Thank you for your participation!

*Enjoy the rest of the conference*

For more information, visit:

http://www.amchp.org/programsandtopics/CYSHCN/Pages/default.aspx