Improving Systems of Care for Children and Youth with Special Health Care Needs

Learning Collaborative on Improving Quality and Access to Care in Maternal Child Health
Breakout Session
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AIM

To improve the health, development, and well-being of children and youth with special health care needs in partnership with families, service providers, communities, states, and policy makers.
Title V programs
Six Quality Indicators of a System of Services

- Individuals & Families
- Families as Partners
- Transition to Adulthood
- Access to Medical Home
- Early, Continuous Screening
- Adequate Insurance

State & organization systems
Objectives

• Discussion of Systems Standards
• State Integration Models
• Lessons Learned in Iowa
National Standards for Systems of Care for Children and Youth with Special Health Care Needs

These standards represent the consensus of national experts across multiple systems and are designed to help communities, states, and the nation build and improve systems of care for CYSHCN. They are meant to supplement, not substitute, federal statute and regulatory requirements under Medicaid, and other relevant laws and are intended for use or adaptation by a wide range of stakeholders at the national, state and local levels.
National Standards for Systems of Care for Children and Youth with Special Health Care Needs

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| S & A | R | • Early identification including newborn screening  
| Needs identified by insurance plans  
| EPSDT and Bright Futures  
| Documented, transportable plans of care | • Families are active members of the team  
| Connection with family organizations, peer support  
| Strength-based; Informed  
| Culturally and linguistically appropriate |
| E & E | • Outreach & coordination with community organizations  
| Policies for transitions between plans and for gaps in coverage  
| Comprehensive member services with specialty staff | • Youth engagement  
| Transition and transfer of care policies and processes  
| Transition assessment and plan in place and current  
| Coordination between pediatric and adult providers |
| At C | • Statewide access  
| Physical, mental health, dental and specialty care - with provider choice  
| Transportation and interpreter supports | • Use of electronic health record systems; meaningful use  
| Families are partners in electronic health information (EHI)  
| HIT incorporates CMS health policy priorities  
| EHI is accessible and shared across care settings |
| MH | • Medical team; care coordination  
| 24-7 access; additional time for visits  
| Prevention and Treatment  
| Routine, emergent and urgent needs are met | • Quality assurance and improvement processes for CYSHCN  
| Child medical record reviews include sample of CYSHCN  
| Utilization review/appeals for CYSHCN include integrated care team |
| C - BS & S | • Patient and family centered  
| Respite services; home-based services  
| Palliative and hospice care  
| Transportation and interpreter supports | • Plans are affordable and no risk for loss of benefits  
| Coverage/payment facilitates access to needed providers  
| Comprehensive habilitative services coverage  
| Promote care coordination and medical homes |
5 Standards focus on:
• Statewide access
• Physical, mental health, dental and specialty care - with provider choice
• Transportation and interpreter supports

Relevant System Partners:
• Health Plans/Insurers
• Primary Care
• State *(specify Medicaid, Title V, Legislature)*
• Families
Access to Care (5 Standards)

Health Plans/Insurers

- 2. Pediatric specialists who are the demonstrated clinical coordinator of care, are able to serve as a PCP for CYSHCN.
- 3. Freedom of choice to select PCP and written policies and procedures re: choice/assignment of PCP in place.
- 4. Access to pediatric subspecialists specified in a child’s plan of care is provided without prior authorization from child’s PCP or health plan whether or not such specialists participate in a health plan’s provider network.
- 5. Transportation assistance is provided to families with difficulties accessing needed medical services.

Primary Care

- 4. Access to pediatric subspecialists specified in a child’s plan of care is provided without prior authorization from child’s PCP or health plan whether or not such specialists participate in a health plan’s provider network.
- 5. Transportation assistance is provided to families with difficulties accessing needed medical services.

State (specify)

- 1. The system has the capacity to ensure CYSHCN geographical and timely access to appropriate primary and specialty services, including in- and out-of-network providers and referrals.
- 5. Transportation assistance is provided to families with difficulties accessing needed medical services.
Implications for Use in States

- Partnering with Medicaid/CHIP agencies on content of contracts with managed care organizations for systems of care for CYSHCN.
- Monitoring the impact of shifts of CYSHCN to managed care arrangements.
- Development of structure and process measures for systems of care for CYSHCN
- Assessing the system of care for CYSHCN in a state.
- Part of strategic planning for the state Title V CYSHCN program (e.g., focus of investments, program retooling)
- Quality improvement efforts
State Models
State Integration Grants

Twelve states completing three year project (2014-2107); four states joined for year 2 and 3

Convene and work with key partners including Title V, Medicaid, families, health officials, providers, evaluators and others

Emphasis on quality improvement and collaborative innovation within a cross-state learning community
Goals

Select the AIM statement and measures to be used by each of the Strategy Teams

- Cross-systems Care Coordination
- Shared Resource
- Integration

Select common Key Drivers for each of the Strategy Teams

Share experiences and resources related to activities being used by states to impact improvements in specific areas
Goals

**Cross-Systems Care Coordination:** By October 2017, increase by 20% over baseline - or, for states starting with a baseline of 0, achieve 20% - the % of targeted CYSHCN who have a Shared Plan of Care.

**Integration:** By October 2017, an agency-level written agreement will be developed between two or more state, or regional-level entities to improve the timely receipt of information following the initial referral of a CYSHCN by a medical home.

**Shared Resource:** By October 2017, 50% of families and medical home providers of CYSHCN contacting the shared resource (SR) for a needed specialist, support or service will obtain a needed specialist, support, or service
Iowa Journey
Clinical Services
Any child or youth with a chronic physical, developmental, behavioral, or emotional concern is eligible to receive services through one of CHSC’s community-based regional centers.

Care Coordination
CHSC works with families, local providers, and stakeholders to access services and arrange care for children and youth with special health care needs.

Family to Family Support
CHSC provides families with individualized problem solving and emotional support as they care for their child or youth with special health care needs.

Systems Building
As a public health entity, CHSC works to build partnerships and expand available services and supports for children and youth in communities across Iowa.

Iowa’s System of Care for CYSHCN (2009 model)
Iowa’s Children with Special Health Care Needs (2010-2012)

Specialized Health Homes Provide the Coordination and Support Needed to Assist the Child in Meeting their Optimal Potential.

**Specialized Health Homes include:**
- A multi-disciplinary team of providers including medical staff who coordinate care and link families to locally based services and supports.
- Family-to-Family Support services to provide peer support and service navigation.
- A strengths based perspective that is individualized and builds on each child and family’s informal and natural supports.

**Medical Diagnosis or Condition:**
- Severe enough to impair a major body system and/or health status.
- Frequently becomes unstable or has an unpredictable course.
- Requires medical management from one or more specialists to maintain health.
- Frequent hospitalizations or visits to ER.
- Frequent consultations with or treatments from one or more specialists.

**Medical Diagnosis Has Complex or Long-Term Effects:**
- Condition usually stable, however illness or crisis exacerbates conditions.
- Regular physician visits.
- Requires medical management from one or more specialists to maintain health.
- Periodic consultation with or treatment from one or more specialists.

**Medical Diagnosis With Limited Effects:**
- Condition is stable and the course of treatment is predictable.
- Routine preventive care with primary care physician.
- May see specialist annually for consultation.

**No Special Health Care Needs:**

A Specialized Health Home is not a building or place of residence; it’s an approach to care that provides families with a team of professionals that work together to meet the needs of children and youth with complex needs.
Iowa System of Care Model (2012)

Community Level: System of Care
- Collaboration; Preparedness; Linkages to services; School based preventive services; Focus on prevention; Early identification; Quality Improvement; Accessible treatment; Population health

State Level:
- Workforce development; Payment reform; Health information technology innovations; Data analysis; Resources; State level collaboration, coordination, and monitoring

Practice Level: Pediatric Integrated Health Home
- Care coordination; Case management; Individual/family support; Electronic health records; Integration of mental and physical health

Policy Development
- Collaborative Agency Partnerships
- Accessible Providers
- Hospitals
- Natural Supports
- EBP Training and Services
- Healthcare Subspecialists
- Recreational Supports
- Faith Based Supports
- Peer to Peer and Family to Family Support Services

Continuous Quality Improvement
- Education Support Services
- Standard Screening Processes
- Tele-health
- Housing
- Electronic Health Record
- Safe Neighborhoods
- Care Coordination
- Systems Building

Clinical Care
- Family Support

Systems Development
- Education and Advocacy
- Statewide Systems

HRSA Maternal & Child Health
State Implementation Grants to Enhance Systems Integration for CYSHCN
Systems Integration Academy - IOWA

Principal Investigator: Brad Richardson
Project Director: Vickie Miene
Program Coordinator: Drew Martinez
Evaluation Contact: Kellee Thorburn McCrory (NRC)

Aim: By October 2017, 20% of CYSHCN enrolled in the CHSC PIH program, stratified as severe, will have a shared plan of care (SPoC) in place.

Care Coordination

- Explore value-based payment opportunities
- Use blended funding streams to integrate care coordination activities
- Dedicate resources to support Family Advisory Council
- Engage family organizations across Iowa to support the implementation of a SPoC
- Develop talking points to educate stakeholders about SPoC including the benefits of using a SPoC and family involvement
- Include attributes and benefits of SPoC in existing technical assistance efforts
- Focus on pilot provider area to deliver trainings on SPoC
- Create Family Advisory Council
- Educate families about principles of shared decision making
- Develop SPoC using existing standards and system models
- Solicit input from Implementation Resource Team to develop SPoC template
- Engage families in developing, reviewing, and implementing a SPoC
- Develop protocols for SPoC including drafting, testing, and disseminating SPoC Council
- Engage system partners in the development of the SPoC
- Understand the role of shared decision making in various cultures
- Engage family and provider organizations that represent culturally diverse populations
- Create awareness of family role in shared decision making process
- Create awareness of the SPoC and individualized care coordination activities
- Promote adoption of SPoC across systems
- Build provider competency to effectively develop and utilize a SPoC
- Align existing technical assistance activities to support SPoC outreach, education, and training
- Develop SPoC data sharing protocol with input from families about privacy concerns
- Develop family leaders by enhancing advocacy skills
- Identify champions in schools and medical homes
- Encourage the use of electronic health records to document and track SPoC and associated activities

Drivers

Families
Providers
Policy
System

Activities

Use of Resources (Funding)
Community Support
Training & Education
Engagement (Family Engagement and Cross-Systems Agreement)
Cultural Competence
Outreach & Marketing
Infrastructure (Capacity & Infrastructure)
Data Sharing
Engaged Leadership
Health Information Technology

Drivers

Aim: By October 2017, an agency-level written agreement will be developed between the Iowa Department of Education, Iowa Medicaid Enterprise, and Title V to improve the timely exchange of information for CYSHCN.

Integration

- Utilize the Advisory Council to explore value-based payment opportunities
- Explore funding streams to implement system integration activities including consultative models to build capacity
- Incentivize implementation of the Triple Aim through studying value-based payment models
- Identify new and support existing natural and informal supports for families
- Engage health systems and state agencies to support community-based integration efforts
- Develop and implement community engagement activities to promote population health
- Promote equal access to services and supports for families in rural areas
- Educate families about shared decision making and family involvement
- Develop talking points to illustrate how integration can lead to the achievement of the Triple Aim
- Teach providers to follow evidence-based practices including age-appropriate surveillance and screening
- Incentivize providers and families to participate in continuing education activities based on best practices and the Packard standards
- Create Family Advisory Council and Systems Integration Advisory Council that include family representation
- Engage families in the development, review, and implementation of integration strategies
- Engage provider and family organizations representative of diverse populations
- Address cultural barriers to integration
- Develop Implementation Resource Team to develop draft language for agency-level agreements
- Advocate for agreements to share information regarding family stories and assure privacy of families during exchange of information
- Review information from other states that have successfully navigated privacy concerns associated with integration strategies
- Identify possible resources or existing capacity to facilitate data sharing between collaborating agencies
- Assure privacy for families during exchange of information
- Engage key decision-makers at the system level including family leaders
- Develop Shared Resource to promote system integration
- Promote the use of electronic health records
- Support increased use of e-health including telehealth in rural areas

Drivers

Use of Resources
Community Support
Training & Education
Engagement (Family Engagement)
Cultural Competence
Outreach & Marketing
Infrastructure (Capacity & Infrastructure)
Data Sharing
Engaged Leadership
Health Information Technology

Activities

Use of Resources (Funding)

Drivers

Aim: By October 2017, 50% of families and medical home providers of CYSHCN contacting the Shared Resource for a needed specialist, support, or service, will obtain a needed specialist, support, or service.

Shared Resource

- Explore awareness of available funding and support
- Commit ongoing funding through the Title V Block Grant
- Identify additional funding to continually update
- Create, grow, and sustain the Shared Resource Committee through family and provider representation
- Engage Advisory Council in launch and ongoing promotion of Shared Resource
- Connect with providers to assure accuracy of Shared Resource content
- Develop feedback loop for users of the Shared Resource
- Utilize existing family support organizations to promote and host educational opportunities
- Utilize existing technical assistance activities to educate providers about the Shared Resource
- Create Family Advisory Council
- Develop content for Shared Resource in consultation with Family Advisory Council
- Beta test Shared Resource with families and children and youth with special health care needs and their providers
- Provide culturally-specific training for families to use the Shared Resource
- Engage and sustain involvement of culturally diverse representatives
- Engage organizations that represent culturally diverse populations
- Develop Shared Resource dissemination plan for families
- Develop Shared Resource dissemination plan for providers
- Link Shared Resource to partner websites
- Track analytics for website utilization
- Solicit feedback from Family Advisory Council, System Integration Advisory Council, and Shared Resource Committee to assure accuracy of content
- Include educational information about HIPAA and FERPA to promote responsible data sharing between families and providers
- Utilize System Integration Advisory Council as champions of Shared Resource
- Develop Shared Resource to promote use of evidence based practices to improve population health
- Create awareness of e-health technology
- Introduce new technology as made available
Title V Challenges in Iowa

State Level

- Policy and advocacy
- Systems building tools
- Coordinate network of services
- Address workforce shortage and disparity of distribution of qualified providers

Community Level

- Institutional implementation
  - Dissemination of information
  - Engaging stakeholders
- Implementation of new models
- Leverage funding streams
- Address access (rural-technology-innovation)
Recommendations for Enhancing System of Care for CYSHCN (public health perspective)

**Assessment:** monitoring and surveillance of the needs of CYSHCN; gap analysis and resource allocation

**Policy development:** family/consumer partnership; state plan refinement (systems standards and value based payment methodology); dissemination/communication

**Assurance:** implementation resource team; workforce development; shared resource; evaluation and quality improvement
Added Value through Action Steps

Multi-layered and family centered care coordination
• Collaborate with service providers to ensure that families have access
• Community child health teams coordinate services with agencies
• Whole person perspective

• M Health

• Family engagement leader.
  • Family Navigators
  • Developed a standardized training program 2014

• Partnerships with agencies
  • Schools, community agencies, non-profit organizations
Measure of Success

All children with special health care needs achieve their optimal potential; all youth with special health care needs attain a successful transition to adult living; all families of children with special health care needs are meaningful partners.
Contact Information

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