Improving Systems of Care for Children and Youth with Special Health Care Needs
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Treeby Brown
Chief, Integrated Services Branch
Division of Services for Children with Special Health Needs (DSCSHN)
Maternal and Child Health Bureau (MCHB)
Health Resources and Services Administration (HRSA)

Health Resources and Services Administration (HRSA)

HRSA’s Mission:
To improve health and achieve health equity through access to quality services, a skilled health workforce and innovative programs.
Maternal and Child Health Bureau (MCHB)

MCHB’s Mission:
To provide leadership, in partnership with key stakeholders, to improve the physical and mental health, safety and well-being of the maternal and child health (MCH) population which includes all of the nation’s women, infants, children, adolescents, and their families, including fathers and children with special health care needs.

MCHB and Children and Youth with Special Health Care Needs (CYSHCN)

The Maternal and Child Health Bureau’s (MCHB) vision is for optimal health and quality of life for all children and youth with special health needs and their families. Creating an effective system of care for children and youth with special health care needs to achieve optimal outcomes is one of the most challenging and pressing roles for public health leaders at the national, state and local level.
MCHB and Children and Youth with Special Health Care Needs (CYSHCN)

Systems of care for CYSHCN depend on ensuring families are partners in care; there is early and continuous screening; children and youth have access to a medical home to provide coordinated care that is community-based; there is adequate insurance and funding to cover services that are easy to access; and families and providers plan for transition to adult care and services.

Overview of Presentation

- Who is in the System of Care?
- Frameworks for Understanding the System of Care
- Systems of Care Across States: Practice and Program Level
- What We Know and What We Need to Know Better
- Approaches to Improving Systems of Care
- MCHB Approaches to Improving Systems of Care
Defining the System

- **Children with Special Health Care Needs:** Those who have or 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.

- **The System:** children, families, providers (health, education, social services), community-based services, policy makers, insurers, payers, program staff and more.

Understanding the System

Program Goals

- Early and continuous screening for special health needs.

National Centers

- Early, Continuous Screening
- Access to Medical Home
- Families as Partners
- Transition to Adult
- Adequate Insurance
- Community-Based Services
- Grant Programs

**FAMILY CENTERED CARE CULTURAL & LINGUISTIC COMPETENCE/RECIROCITY**
Understanding the System

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 financial aid 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 are easy to use, accessible, and can be used across the lifespan
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 (affords 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

Families as Partners in Care

Levels of engagement

- Direct care
- Organizational design and governance
- Policy making

Consultation
- Patients receive information about a diagnosis
- Organization surveys patients about their care experiences
- Public agency conducts focus groups with patients to ask opinions about a health care issue

Involvement
- Patients are asked about their preferences in treatment plan
- Hospital involves patients as advisors or advisory council members
- Patients’ recommendations about research priorities are used by public agency to make funding decisions

Partnership and shared leadership
- Treatment decisions are made based on patients’ preferences, medical evidence, and clinical judgment
- Patients co-lead hospital safety and quality improvement committees
- Patients have equal representation on agency committees that make decisions about how to allocate resources to health programs

Factors influencing engagement:
- Patient (beliefs about patient role, health literacy, education)
- Organization (policies and practices, culture)
- Society (social norms, regulations, policy)
Defining the System Across States

What do we know about systems at the practice level?

Image source: http://www.lpfch.org/cshcn/blog/2016/01/06/key-reports-2015
Image source: https://www.dshs.texas.gov/cshcn/
What do we know about the system at the program level?

What do we need to know better?

- Which supports are most effective in moving communities and states to a functioning system of care for CYSHCN?
- Which strategies and evidence-based practices are most effective in helping states make progress on performance measures?
- To what extent do contract provisions in Medicaid Managed Care address the needs of CYSHCN and their families?
- How to evaluate and demonstrate the impact of engaging families in program and policy development?
Improving Systems of Care: The Practice Level

• Identification of CYSHCN and the complex care subset
• Recognition of the intersection between medical home and transition
• Improving the transition from child to adult system of services
• Best practices for family engagement

Improving Systems of Care: The Program Level

• Evidence-based practices from states/implementation of systems standards
• Resources to support states in developing innovative approaches to ensure CYSHCN receive cost-effective quality care
• Better understanding of state programs (CYSHCN profiles) and common competencies for leadership
• Articulation of needs of CYSHCN in larger health care systems
Approaches to Systems Change at MCHB

• Common frameworks
• Common measurement
• Strong state–federal partnership to coordinate and align programs
• Common elements across programs
  • Family Engagement
  • Innovation, including telehealth
  • Intersection of Medical Home and Youth Transition
  • Coordinated Care
  • Recognition of children with medical complexity

Contact Information

Treeby Williamson Brown
Chief, Integrated Services Branch
Email: tbrown2@hrsa.gov
Phone: 301-945-9661

Division of Services for Children with Special Health Needs (DSCSHN)
Maternal and Child Health Bureau (MCHB)
Health Resources and Services Administration (HRSA)
Web: mchb.hrsa.gov
Twitter: twitter.com/HRSAgov
Facebook: facebook.com/HHS.HRSA
Mississippi - Children and Youth with Special Health Care Needs Program

- Mississippi Children and Youth with Special Health Care Needs Program (CYSHCN), formerly known as the Children’s Medical Program (CMP), provides care coordination service for children. With the changes in the healthcare delivery system, Mississippi began transitioning its role from providing direct services to enabling services (respite, case management and outreach/education) population based services and capacity building services (systems of care, needs assessment, policy development) to support children and their families.

- The Title V program provides registered nurses and social workers in the public health districts and central office to provide care coordination to the CYSHCN population. Typically, care coordination is provided for children who need specialty medical care or have chronic or disabling conditions.

- The program has a total of 1839 active cases; 1476 are Medicaid eligible & 363 have private insurance.
Transformation – Successes

- In 2014, CYSHCN Program began transformation efforts to increase capacity for population health initiatives and identify gap filling services to support children and their families reach optimal health. The program implemented quality improvement strategies, training, monitoring and increased collaboration with other agencies to improve systems of care and increase parental involvement.

- The Systems Integration funding provided one additional staff member to lead and focus on care coordination and build capacity to increase the percentage of CYSHCN with a Shared Plan of Care (SPoC).

- This transformation work included but not limited to: developing relationships with providers, families, schools, care coordination for families, promote family engagement activities and increase the number of CYSHCN with a medical home, dental home, healthcare coverage, and access to community resources.

- The goals of system integration has been implemented into Title V MCH Block Grant by assuring that public health staff coordinate and navigate the system: to and use data, to develop policies and implement interventions to improve the health of the populations.

Challenges

- Continuous stakeholder and partner leadership/engagement

- Collaboration with insurance payers for care coordination reimbursements

- Memorandum of Understanding (MOU) and Memorandum of Agreement (MOA) in timely manner to establish core responsibilities of stakeholders
Innovations to Improve Systems of Care in Mississippi

- Partnership with UMMC, State Tertiary Center to pilot a Shared Plan of Care (SPoC) at MS Complex Care Clinic and Adolescent Health Clinic
- Close the referral loop for CYSHCN to community based services
- Implementation of (SPoC) among providers, families, schools and care coordinators.
- Partnering with MS Families For Kids and other stakeholders to implement the Help Me Grow Mississippi, implement resource call center for families
- Participate in several CoIIN (Collaborative Innovative Improvement Network) partnerships to improve and promote system change for CYSHCN
- Partnership with 13 States to exchange information as it relates to improving systems (program success) for CYSHCN by identifying gaps in services, healthcare delivery system changes, care coordination, educational and resource materials and other barriers.
Partnerships assist with building Systems of Care

- The family-centered approach includes multiple stakeholders that the family envision being a part of their system
- MS Dept. of Health Care Coordinators are the “boots on the ground” to assist CYSHCN and families to become more successful with their medical social and educational needs through home visits, care planning and coordinating with families based on needs and community resources
- Partners capture data to determine needed and replicate practices, exemplify good stewardship & accountability for the resources, offer prompt response time for services, and provide patients/families with wraparound services such as educational counseling, preventative health care to help reduce ER visits and to improve quality of life for children

Sustaining Efforts to Improve Care for CYSHCN

- The key to improving the System that serves children involves the evaluation of progress towards the national standards:
  - Family Partnerships
  - Medical Home
  - Early/continuous screening
  - Insurance & Financing
  - Availability of Services & Support
  - Transition to Adulthood
- Continue building relationships, partnerships and collaborations with multiple stakeholders through Memorandum of Agreements to establish a collective impact framework and move the need to improve the overall health of children
- Improving systems that serve young children is essential to improve population health
Systems of Care for CYSHCN in Texas

Rachel Jew
Title V CSHCN Director

CYSHCN in Texas

Data from 2009/10 NS-CSHCN and 2014 Texas CYSHCN Outreach Survey

- An estimated 919,876 children in Texas have special health care needs (13.4% of all children)
- 40.1% of CYSHCN in Texas receive coordinated, ongoing, comprehensive care within a medical home
  - 71.6% of respondents to the 2014 CYSHCN Outreach Survey coordinate their child’s care themselves
  - 54% of families reported they did not have a medical provider where they live
- 35.4% of youth with special health care needs (12-17 years old) receive the services necessary to transition to adult health care, work, and independence
  - 20 percent of respondents to the 2014 CYSHCN Outreach Survey felt prepared for their child to transition to adulthood
  - Over 40 percent of respondents indicated that they had not prepared for transition
Public Health Activities

- Oversee Title V CSHCN Community-Based Contracts
- Facilitate state workgroups
- Serve on councils, committees, forums
- Implement special projects
- Serve on conference planning committees
- Develop and disseminate resources

Collaborative Partnerships

- Families and Texas Parent to Parent
- Texas Health Steps Online Provider Education
- CSHCN Health Care Benefits Program
  - Regional case management
- Navigate Life Texas
- Texas Education Agency
- STAR Kids Medicaid Managed Care
STAR Kids

Tamela Griffin, Director for Office of Policy
Texas Health and Human Services Commission
Medicaid and CHIP Services Department

STAR Kids Background

• Senate Bill 7, 83rd Legislature, Regular Session, 2013, directed HHSC to establish a mandatory, capitated STAR Kids managed care program to provide Medicaid benefits to children and young adults with disabilities. The bill also:
  • Requires incorporating one of the state’s 1915(c) waiver programs, the Medically Dependent Children Program (MDCP)
  • Requires consultation with the STAR Kids Medicaid Managed Care Advisory Committee and Children’s Policy Council on the establishment and implementation of the program
STAR Kids Implementation

- STAR Kids operates statewide across 13 services areas.
  - Managed Care Organizations (MCOs) must maintain an adequate network in their service areas, but may also contract with providers throughout the state.
- Serves about 163,000 members.
- Texas is contracted with 10 MCOs.
  - 5 community-based plans and 5 national plans
- Families have a choice between at least two health plans in their service area and may request to change at any time.
- Services started November 1, 2016.

STAR Kids Populations

- Category 1: All Medicaid services will be delivered through a STAR Kids MCO.
  - Children and young adults age 20 and younger who:
    - Receive Supplemental Security Income (SSI) and SSI-related Medicaid
    - Receive SSI and Medicare (dual eligible)
    - Receive Medicaid through the Medicaid Buy-In (MBI) or Medicaid Buy-In for Children (MBIC) program
    - Receive services through the Medically Dependent Children Program (MDCP) waiver
    - Get Medicaid through the Health Insurance Premium Payment Program (HIPP) and meet STAR Kids eligibility requirements
STAR Kids Populations

- Category 2: Medicaid acute care services and some long-term services and supports (LTSS) will be delivered through a STAR Kids MCO, but waiver LTSS will be delivered by the state.
  - Children and young adults age 20 and younger who receive intellectual and developmental disabilities (IDD) waiver services including:
    - Community Living Assistance and Support Services (CLASS)
    - Deaf-blind with Multiple Disabilities (DBMD)
    - Home and Community-based Services (HCS)
    - Texas Home Living (TxHmL)

STAR Kids Populations

- Category 3: Medicaid acute care services and some LTSS will be delivered through a STAR Kids MCO, but waiver LTSS will be delivered through state-contracted providers.
  - Children and young adults age 19 and younger who receive Youth Empowerment Services (YES) waiver services
STAR Kids Populations

- Category 4: Medicaid acute care services will be delivered through a STAR Kids MCO, but waiver LTSS will be delivered through the facility.
- Children and young adults age 20 and younger who reside in a community-based intermediate care facility for individuals with intellectual disabilities or in a nursing facility.

STAR Kids Excluded Populations

- Individuals excluded from participating in STAR Kids include:
  - Adults age 21 years or older
  - Children and young adults age 20 and younger enrolled in STAR Health (Medicaid program for children in state conservatorship)
  - Children and young adults age 20 and younger who reside in a pediatric nursing facility, a state veteran’s home, or in a state supported living center
Provider Contracting

- Providers must enroll with Texas Medicaid and must contract with and be credentialed by an MCO to provide Medicaid managed care services.
- Rates are negotiated between the provider and the MCO.
- Processes such as authorization requirements and claims processing may be different between MCOs.
- Even though MCOs may have different prior authorization and claims processing procedures, all plans are still held to the same contractual requirements regarding providing timely care and timely paying claims.

STAR Kids Services

- STAR Kids integrates the delivery of acute care services, pharmacy services, behavioral health services, and LTSS benefits.
- MCOs must provide covered services in the same amount, duration, and scope as outlined in the Medicaid state plan.
STAR Kids LTSS

1. Medicaid state plan LTSS available to all STAR Kids members for whom they are medically or functionally necessary:
   - Private duty nursing (PDN)
   - Prescribed Pediatric Extended Care Centers (PPECCs)
   - Personal care services (PCS)
   - Community First Choice (CFC)
   - Day Activity and Health Services (DAHS)

2. Medically Dependent Children Program (MDCP) waiver services, available to members who meet income, resource, and medical necessity requirements for nursing facility level of care

STAR Kids LTSS: MDCP

Services available to MDCP waiver participants will not change in STAR Kids. These include:

- Adaptive aids
- Minor home modifications
- Transition assistance services
- Employment Assistance*
- Flexible family support services*
- Financial Management Services*
- Respite services*
- Supported employment*

*These services are available through the Consumer Directed Services (CDS) option
STAR Kids Key Features

Three main features of STAR Kids:

- Comprehensive, strengths-based needs assessment
  - Every member is assessed using a tool called the STAR Kids Screening and Assessment Instrument (SK-SAI), specially designed to help STAR Kids MCOs and providers understand members’ strengths, preferences, and needs.

- Person-centered planning and service design
  - Every member has an individual service plan (ISP) that documents their specific strengths, service needs, and goals.
  - The ISP is shared with the family, other case managers, and providers.

Ongoing service coordination

- Every member has access to service coordination, both telephonically and in person.
- Members and their families can always ask for more or less service coordination.
STAR Kids Service Coordination

- MCOs must provide each member a sufficient level of service coordination to meet the unique needs of members as specified in their contracts.
  - Members are assigned to one of three levels depending on need

  **Level 1**
  - Most medically complex members, including MDCP waiver recipients
  - Assigned a named service coordinator
  - Minimum of four in person visits and monthly phone contacts annually

  **Level 2**
  - Less medically complex members, but who need LTSS or behavioral health services
  - Assigned a named service coordinator
  - Minimum of two in person visits and bi-monthly phone contacts annually
STAR Kids Service Coordination (con’t)

• Level 3
  • All members not meeting Level 1 or 2 criteria
  • Not assigned a named service coordinator unless requested
  • Minimum one in person visits and three phone contacts annually

STAR Kids Service Coordination

• MCO nurses, social workers, and other professionals with necessary skills to coordinate care provide service coordination including:
  • Identification of needs (e.g., physical health, mental health, LTSS)
  • Development of a service plan to address identified needs
  • Assistance to ensure timeliness and coordinated access to services and providers
  • Attention to addressing the unique needs of members
  • Coordinating with other (non-capitated) services as necessary and appropriate
Transition Planning

• Transition planning, a special feature of STAR Kids, helps teens and young adults prepare for changes following their 21st birthday.

• MCOs must begin STAR Kids transition planning when their members turn 15.
  • MCO transition planning is delivered using a team approach.
  • The named service coordinator and transition specialist work closely together.

STAR Kids: Member Protections
Independent Consumer Support System

• HHSC maintains a managed care consumer support system independent of MCOs to assist members and families in understanding the coverage model and in the resolution of problems regarding services, coverage, access and rights.
• This system consists of HHSC’s Medicaid and CHIP Services Department, Office of the Ombudsman, the state’s managed care enrollment broker, and community support from the Aging and Disability Resource Centers (ADRCs).

Member Protections

• All STAR Kids members may continue seeing existing providers for six months after implementation, even if the provider is out of network.
• STAR Kids MCOs have voluntarily extended this allowance to twelve months for primary care providers (PCPs) and specialists.
• Continuity of care
  • For acute care services (like therapies): six months, or until the authorization expires, or until the MCO does a new assessment.
  • For LTSS: six months or until the MCO does a new assessment.
Member Protections

• Extended authorizations for Personal care services/Community First Choice, Private duty nursing, and therapy services expiring in October and November by 90 days to prevent provider confusion and gaps in care.

• Assessment prioritization
  • MCOs will triage members and assess those with unmet needs first.
  • Those served by waiver programs, including Medically Dependent Children Program (MDCP), will be assessed last.

Member Protections

• HHSC worked with the Texas Department of Insurance to allow STAR Kids health plans to contract with out-of-area providers.
  • Out-of-area providers contracted with an MCO will be considered in network, may be reimbursed at an in network rate, and may be listed in the provider directory.
Member Protections

- Families with private insurance
  - Can continue to see their existing commercial Primary Care Provider (PCP).
  - Commercial PCPs who do not bill Medicaid must enroll in Medicaid through an abbreviated process as ordering, referring, or prescribing (OPR) providers.
  - HHSC has delayed enforcement of OPR enrollment until October 2017.

Member Protections

- Referrals
  - Most STAR Kids health plans do not require referrals to continue to see existing specialists.
  - Health plans have clarified and documented their referral policies in their member manuals.
Significant Traditional Providers

- A Significant Traditional Provider (STP) is a provider who has traditionally served Medicaid clients.
- All Medicaid providers that delivered services to the SK population prior to implementation are STPs for STAR Kids, so it is inclusive of all provider types.
- MCOs must offer STPs the opportunity to be a part of the contracted MCO network.
- MCOs will reach out to STPs.
  - STPs may initiate the contact.
  - STPs must accept MCO conditions for contracting and credentialing.

Questions?
Thank you

STAR Kids Webpage:
https://hhs.texas.gov/services/health/medicaid-and-chip/programs/star-kids

General questions:
Managed_Care_Initiatives@hhsc.state.tx.us