

Appendix F: Stakeholder Strategic Planning Meeting Reports

Phase 1 Systems Planning Meeting Summary, May 2016

Medical Home & Community-Based Services and Supports

Phase 2 Systems Planning Meeting Summary, November 2016

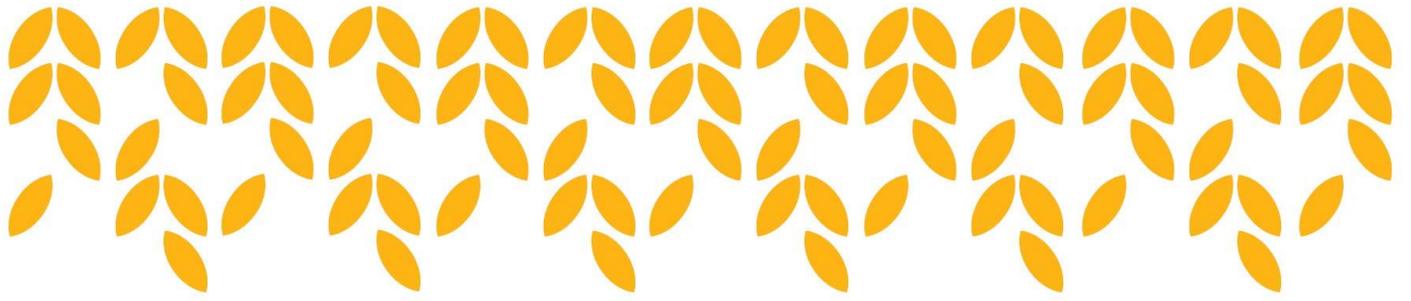
Access to Care & Eligibility and Enrollment

Phase 3 Systems Planning Meeting Summary, May 2017

Screening, Assessment and Referral & Transition to Adulthood

Phase 4 Systems Planning Meeting Summary, September 2017

Family-Professional Partnerships and Insurance & Financing



KDHE Special Health Care Needs Program Systems Planning

Meeting Summary May 2016

Prepared by:



**WICHITA STATE
UNIVERSITY**

**COMMUNITY ENGAGEMENT
INSTITUTE**

*Center for Organizational
Development and Collaboration*



KDHE Special Health Care Needs Program

Systems Planning

Meeting Summary

May 2016

Introduction

In May of 2016, the Kansas Department of Health and Environment Special Health Care Needs Program hosted a group of key stakeholders from across the state to discuss issues related to systems integration for two domains within the National Standards of Care for Children and Youth with Special Health Care Needs. These stakeholders engaged in a reflective and participatory process that focused on the *Medical Home* and *Community-Based Systems and Supports* domains of the National Standards. They were asked to review community input that was previously collected both in-person and by electronic survey; articulate a vision for success for each domain; identify potential opportunities and barriers to cross-system coordination; and discuss strategies for engaging potential partners in the integration process.

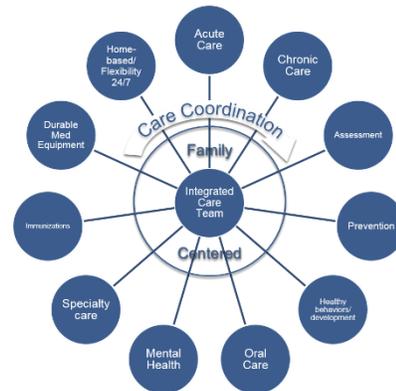
This report is a reflection of the conversations that occurred within the meeting and is divided by domain. Detailed notes from the meeting discussions and a list of meeting participants are available upon request from the KDHE Special Health Care Needs Program.

Medical Home

CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home model.

- National Standards of Care for Children and Youth with Special Health Care Needs

The National Standards for CYSHCN medical home model encompasses a number of services and systems including those pictured at right. Meeting participants were presented with community input regarding Kansas' ability to meet the current standards (detailed in separate reports) and discuss in small groups what they considered to be the most important changes that would be needed if Kansas is going to make progress on meeting these standards and where they thought new connections need to be made, based on the community's responses (See Appendix A).



Defining Success

Considering the community input and the resulting conversations, participants were asked to define success from a variety of different perspectives.

For ***Children and Youth with Special Health Care Needs and their Families***, participants stated that success would be defined as safe, effective, affordable care that would be integrated, person-centered, and easy to access. The system would be one that provides culturally responsive care that works for families – providing “carrots”, not “sticks” – and allows for whole family health to be achieved. This would mean that families would be educated about the resources and the choices they offer to responsibly self-manage their care; understand their rights within the system; and trust the system to help them become functioning members of their community.

For ***Providers***, the system would allow for truly patient-centered care that resulted in improved health outcomes and providers could go home knowing that they’ve done their jobs well. All of the “spokes” of the wheel would actually exist – achieved through community partnerships and effective inter-disciplinary teams. Providers would be part of collaborative network, one that includes health plans who trust that care providers know the patient’s needs best and allows for good follow-up by providers. There would be clear expectations, reasonable caseloads, and aligned priorities among the collaborating partners. There would be a universal system of care for patients, allowing patients to access services through “no wrong door”. Universal enrollment for providers in health plans that allows for adequate reimbursement rates, reducing clinical “work-arounds” and allowing professionals to work at their best 100% of the time.

For ***Referral Networks***, the group determined that success would include an easy, transparent, process that would equip and empower families to the level that they can be most successful. Resources would be available to families close to home and referral providers could count on a fiscally sound network to be available when they send families for assistance. There would be effective, bi-directional, communication and coordination amongst providers, including those who are located out of the state. For patients that require hospitalization, the process would begin with quality discharge planning and all providers would have access to an accurate and up-to-date list to make this possible. Families who enter the system are engaged and educated and providers teach them the skills they need to advocate for themselves.

Measuring success

Participants indicated that there are a number of existing metrics that could help progress on these efforts. These include:

- Consumer satisfaction scores
- Number of certified medical homes based on predicted population to be served
- Number of services accessed
- Number of preventative health, oral health (etc.) visits
- National survey for Children’s Health metrics
- Quantitative measures of health out comes
- Number of Shared Plans of Care
- National Health Care Quality metrics

This data is currently being collected by a variety of sources, including:

- Federally Qualified Health Centers
- Schools
- KDHE Bureau of Community Health Systems
- Hospitals/practices/service providers

- CAP/HEDIS for Managed Care Organizations
- Local Health Departments
- Community Mental Health Centers
- Large employers
- Health disparities researchers
- Kansas Health Institute
- Disease foundations (American Diabetes, American Heart, etc.)
- Families
- Professional societies (American Academy of Pediatrics, etc.)

After reviewing information gathered from the community input sessions regarding potential partners (reported separately), participants were asked to consider on whose actions success most depends. They indicated this would include families, insurers, clinicians, educators of students and health professionals, KDHE, and policy makers (including elected officials, professional associations, and foundations).

Cross-System Coordination

Partners who were present at the meeting were asked to divide into groups based on the domain they felt most informed and passionate about to discuss three questions related to cross-system coordination. Three small groups within each domain considered each question and were asked to indicate responses they agreed with by placing an asterisk next to the comment (*) and then prioritize the top three ideas to call out to the larger group for consideration. These priorities are listed in red.

What new opportunities exist for cross-system coordination?

- Patient/family navigators *
- Extend services geographically – telemedicine *
- Reliable/dependable transportation and interpretation resources
- Learn what resources are – robust promotion of Kansas Resource Guide *
- Incentives for cross-system sharing (from payer sources) *
- Leverage partnerships to increase recruitment and retention of pediatric specialty providers *
- MCOs provide forums for providers to meet and leave resources (webinars)
- Clarification of what MH is and definition of Mental Health
- Improved communication between community stakeholders
- Leverage partnerships to increase use of technology – enhance communication between partners
- Increase portability of information/records and ability to share these
- Innovate new models of care that meet our unique needs and resources
- Integrated care model (simplified)
- Cooperatives between states

What barriers are there to cross-system coordination?

- Lack of reimbursement/ coverage (medical and mental health) *
- Lack of resources, including time *
- Access to care *
- Lack of communication *
- Knowledge deficit *
- Lack of direction (hub/point person) *
- Lack of collaboration *
- Cost of services *
- Clinical judgement vs. standardization *
- Appropriate utilization
- Lack of trust across the board *
- Lack of family knowledge of resources
- Lack of discharge planning
- Kansas resource guide not updated
- Lack of unified medical records/interfaces/HIPPA
- Lack of vision (providers and legislators)
- Lack of shared vision
- Geography – travel long distances and funds to make that travel
- Provider motivation – that that provider's passion
- Lack of some sub-specialty providers such as metabolic genetics

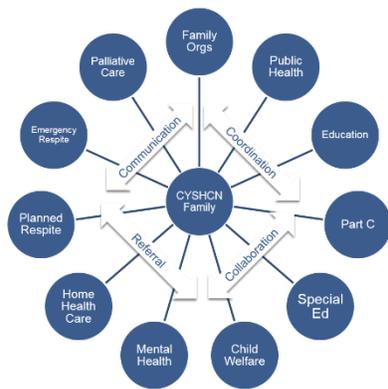
What is the best way to engage partners?

- Have a clear vision from highest level to lowest level **
- Incentives aligned – what is important to each partner
- Get stakeholders a seat at the table – bring together small groups **
- Reimbursement/ Pay for performance (incentives)
- Shared risk/shared responsibility/increase vesting (incentives) *
- Develop the infrastructure to integrate and engage partners *
- Realistic expectations *
- Flexibility *
- Share and measure outcomes/success
- Benchmark outside of the system – look at other best practices
- Simplified/ease of access
- Pilot/training/learning before implementation
- Success stories
- Increased communication
- Newsletters from organizations from a trusted source
- Building relationships/networking

Community-Based Services and Supports Domain

Services for CYSHCN and their families will be organized in ways that families can use them easily.

- *National Standards of Care for Children and Youth with Special Health Care Needs*



The National Standards for CYSHCN model for Community-Based Services and Supports encompasses a number of services and systems including those pictured at left. Meeting participants were presented with community input regarding Kansas' ability to meet the current standards (detailed in separate reports) and discuss in small groups what they considered to be the most important changes that would be needed if Kansas is going to make progress on meeting these standards and where they thought new connections need to be made, based on the community's responses (See Appendix A).

Defining Success

Considering the community input and the resulting conversations, participants were again asked to define success from a variety of different perspectives.

For ***Children and Youth with Special Health Care Needs and their Families***, participants stated that success would include opportunities for whole family health – families/caregivers and siblings whose physical, emotional, and social support needs are met. Families would be empowered to be responsible and successful in managing their care with increased expectations for their quality of life. There would be effective coordination and collaborations across the lifespan that includes access to qualified providers, partnerships with schools for in- and out-of-school resources and smooth transitions as needs change. When parents ask questions, they will receive clear answers and experience open sharing of information from providers that results from a person/family-centered approach to care.

For ***Providers***, success would encompass the ability to share relevant information across provider networks and work within interdisciplinary teams. There would be adequate reimbursements – perhaps in the form of “bundled” billing – and billing for coordination would be an allowed expense.

For ***Referral Networks***, success would include more engagement of “unusual” voices. There would be adequate resources to refer families to and these could be located through a searchable database that includes many systems of care, including access to satellite hospital/clinic services. The website might also include a centralized “help” button that contacts a trained professional that can offer personalized support and would track referrals. Ultimately, improved patient outcomes would allow programs to become more sustainable.

Measuring success

Participants indicated that there are a number of existing metrics that could help progress on these efforts. As mentioned under the Medical Home domain, this data is being collected by variety of existing resources.

These metrics include:

- “Ease of Use” framework
- Patient access to every component
- Consumer satisfaction
- Utilization of shared resource guide
- Number of enrolled, individual claims (catastrophic vs. natural progression of the disease)
- Quality of life for families
- Provider engagement reports
- Decreased healthcare costs
- ACEP.org

After reviewing information gathered from the community input sessions regarding potential partners (reported separately), participants were asked to consider on whose actions success most depends. They indicated this would include families; Community Developmental Disability Organizations; Aging and Disability Resource Centers; Community Mental Health Centers; insurers; providers (including home health and intensive supports); policy makers; communities; and the lead agencies within the state, including KDHE and the Kansas Department of Aging and Disability Services. Participants in today’s meeting noted that one key partner that might have been overlooked are local technology providers who would be instrumental in the success of efforts around telehealth.

Cross-Systems Coordination

Partners who were present at the meeting were asked to divide into groups based on the domain they felt most informed and passionate about to discuss three questions related to cross-system coordination. Three small groups within each domain considered each question and were asked to indicate responses they agreed with by placing an asterisk next to the comment (*) and then prioritize the top three ideas to call out to the larger group for consideration. These priorities are listed in red.

What new opportunities exist for cross-system coordination?

- Federal grant for statewide system-building *
- Federal incentives for outcomes *
- Technology */telehealth
- Getting the right groups together to fund and act on creative new approaches
- Shared resources
- Leverage social media
- Compatible EMRs/HIE
- Bureau of Family Health/Special Health Services leadership is responsive and seek input from stakeholders and needs to be expanded and sustained
- Leveraging non-traditional supports and services
- New data collection
- Sharing data
- Integrate cross system coordination into state curricula (Med Schools, Nursing, therapies, etc.)
- More education across the cross-coordination system already in place

Note: group move all ideas into three priorities.

What barriers are there to cross-system coordination?

- Funding for services, technology, education, training, reimbursement **
- Lack of knowledge of needs and resources **
- Language/communication barrier between patients, professionals, insurers, clinicians **
- Time – not enough for families or providers *
- Apathy/hopelessness of providers – burnout *
- Lack of technology
- No incentives
- Not part of job description
- Is the family included?
- No HIPPA waiver
- Lack of resources/staff providers
- Systems are silos
- Lack of leadership/willingness to engage
- Attrition of seasoned maternal/child health professionals
- Not person centered
- Turnover in all aspects of the cross-coordination system.
- Discord between what the “state” things is important vs. providers vs. insurers vs. families vs. members

What is the best way to engage partners?

- Identify individual partner needs and clearly articulate how collaboration meets that need *
- Sustainable/accurate network (Database/resource network across disciplines) *
- Publicize outcomes that are encouraging
- Advocacy *
- Community outreach/education
- Identifying credible and influential champion for the process
- Financial incentives
- Simplifying the system
- Ease of contracting *
- Start with the families
- Going where they are *
- Reaching out and having a conversation *
- Providing tools and resources and CMEs as incentives to providers and incentives to families
- Top referring provider to community-based and health care providers

Next Steps

Staff from the KDHE Special Health Care Needs Program will use the work of the stakeholders who participated in this meeting, along with the information gathered over the past few months, to identify opportunities to move the process of systems integration forward. The SHCN Program plans to hold similar processes over the next 18 months related to the remaining domains within the National Standards to then assemble a more holistic plan for systems integration. Partners will be asked to engage in a variety of ways to assure the overall success of the system and to improve outcomes for children and youth with special health care needs and their families.

Prepared by:



WICHITA STATE
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Table Discussion

Please choose someone from your table to record your responses to the following questions and then submit to the WSU team to be included in the meeting report.

Medical Home Domain

What are the most important changes needed if Kansas is going to make progress on meeting these standards?

Table 1

- KDHE interacts, influences the State Legislature and develop a vision for kids health care in Kansas
- Support and funding to make sure all kids have insurance
- We need care coordination for all children with special health care needs. Needs to be a requirement from MCOs.
- Service for all kids geographically. Sedgwick County should be the hub for care. Create hubs.
- Innovative in how we provide transportation and reimbursement.
- Reliance of fee for services vs. providing coordinated comprehensive care (value-based model for care)

Table 2

- Availability of services
- More in-network providers/provider availability
- Transportation
- Dental care

Table 3

- Transportation (antiquated technology) – promoting tele-health with providers/families
- Lack of providers
- Differentiate between behavioral health and mental health services

Table 4

- Limited tele-health – cost of start-up
 - Providers are interested but connectivity is an issue
- Outreach to providers to get buy-in to have clinics in the area
- Documented SS# for members or family for gas/transportation

Table 5

- Transportation (appropriate with child's needs)
- Access to specialty
 - Medical home providers
 - Tele-medicine
- Access care coordination
 - MCOs role?

Table 6

- Private and public insurance reimbursements changes are not motivating to providers – one key example is regarding home care talent
- Completing Medicaid applications and maintaining eligibility for families are cumbersome processes and disrupt continuity of care and preventive care.
- Vulnerable (e.g. impoverished, foster care, etc.) are more likely to utilize emergency room care and not preventive care
- Establishing and restoring trust with providers the families need to rely on for comprehensive/preventive care. You can't expect folks who have transient and disproportionately powerful relationships with providers without nurturing that relationship.
- Providers are financially incentivized for preventive care but families are not and need to be.

Where do new connections need to be made?

Table 1

- Commitment by multiple factions to work together and collaboration. Legislation -> providers, KDHE
- Create a cohesive model
- Children's Hospital with support from community – endorsements for support
- Legislature has to support medical home model and provide funding.

Table 2

- Communication of resources
- Simplify process to access resources/care
- Provide major centers of care with information on resources available in Kansas

Table 3

- Behavioral health – oasis promotion/cognitive therapy
- Mental health
- Financial services
- Community supports/peer groups/social groups
- Social emotional education/parenting education
- Oral health
- Community-based organization with capability to be a tele-health site

Table 4

- Connections between local providers and specialists to increase tele-med access
- Resources for transportation with partnerships to include community resources, churches, NEMT
- Language barriers

Table 5

- Care coordination – How do families navigate the systems?
- How to make connections?
- Funding for care coordinators
- Community level – resources decrease

- Less connection to outside of state insurance – needs to coordinate – not looking at the big picture

Table 6

- Head Start utilizes family advocates (assigned to a family from the child's age of 3 through program) who introduce and accompany families to community-based health clinic appointments. Family navigation by an established and trusted member of the family's team helps introduce and normalize relationship-building with care providers.
- Trauma-informed care PLUS ACES must be integrated into care for all CYSCHN – see Head Start for an example.

Table Discussion

Please choose someone from your table to record your responses to the following questions and then submit to the WSU team to be included in the meeting report.

Community-Based Services and Supports Domain

What are the most important changes needed if Kansas is going to make progress on meeting these standards?

Table 1

- Education about what services are and how to access them.
- Geographic issues -> innovative to create hubs in Kansas to provide
- Increase capacity of qualified services
- Increase communication and coordination between CBS and Medical Homes (school)
- Create navigators to help families get resources
- Reimbursement for respite care
- Understanding “value-based” care

Table 2

- Low reimbursement rate – need increase (i.e. nurses, PT, OT, ST)
- School funding
- Awareness/communication
- Education

Table 3

- Utilizing care coordination
- Regional family navigators who are aware of community resources/bilingual
- More funding
- Skills database to assist with connecting skilled workers with CYSHCN and their families
- Community education, training, and networking

Table 4

- 504/IEP
- Respite services
- Consistency with providers
- Family Support organizations – support groups
- Reimbursement rates
- Outreach volunteer clinics

Table 5

- Funding
- Building capacity
- Respite care – great need
- Better services through schools to refer families – get information into schools

- Emergency services not existing
- Foster care system – difficult to get workers
- Service delivery system – can't be sustained due to great need – use taps it out
- School ill equipped to meet needs – medical needs, school nurse cuts

Table 6

- Critical LACK of licensed qualified professional and paraprofessional medical/mental health disability providers who can provide community-based services
- Systems are not current regarding compensation appropriately (e.g. 2008 reimbursement rates from the state of Kansas)
- Educating health professionals!!!!!!! PROMISE grant in Wichita (technical college grant – emerging, pays for tuition and books for nurses)
- CRITICAL LACK of various non-professional care providers– private health plan vs Medicaid – kids kicked off SED waiver which provided attendant care, respite care, and case management wrap around – missed 3 months of services of a non-professional care provider services are discontinued by Medicaid and lose access/waiver eligibility – no fault of family, lack of capacity within the system
- Staff turnover and capacity – last thing kids with trauma and adjustment issues need to have is caregiver turnover – especially for mental health services.
- Poor customer support, poor quality of care available to clients who are Medicaid recipients – so referrals to private providers are nurtured so Head Start family advocates have more options of providers to send publicly insured families to.

Where do new connections need to be made?

Table 1

- Increased communication between providers so we are not duplicating services or omitting services
- Someone to help motivate families
- Shared vision from providers and family about long term care
- Have someone neutral to help navigate systems – not DCF or threats for care.

Table 2

- Updated information on resources
- Guidelines for referral - err on side of coverage as opposed to qualification
- Overall communication

Table 3

- DD Providers/CCHD contract for development of program to train and promote respite providers and advocate for coverage of service.
- MCO negotiations for affordable services for private pay
- Development of vocational training program for respite providers – similar to CMA training
- Development of continuing education for respite providers
- Educating DD providers on various services available
- HCBS and Foster Care

Table 4

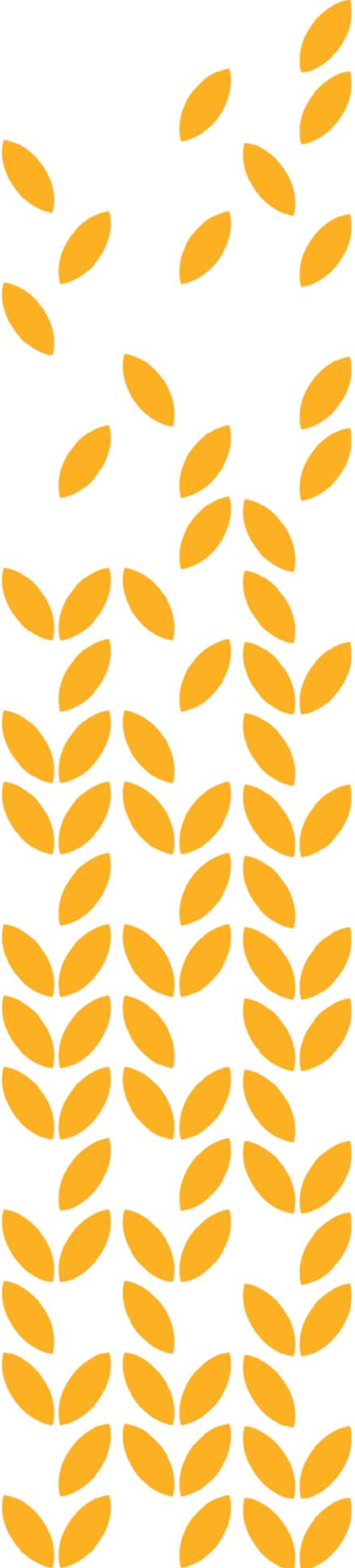
- Border states
- Respite services
- Education to communities
- Working poor – who advocates for them

Table 5

- Applying for waivers and needs – disconnect between agencies
- Parents as teachers – school districts
- 0-3 years – recruiters, limited slots
- Parents educated to teach parents
- Food stamps, other services – applications hard to navigate

Table 6

- EDUCATORS need to be hooked up with private companies and state systems to subsidize education to produce more health professionals. If there is such a great debt load following school, nurses gravitate to acute care facilities rather than providing community-based services.
- Schools of nursing and nursing educators need to partner with state health systems – provide onsite clinic services without passing through insurance
- Federal-state partnerships need to be open to fund more experimental technologies – mobile clinics, telemedicine at appropriate rates
- Part C is effective, but part B is less likely to cover home care causing kids to be pulled from class time at school to receive OT etc.



CYSHCN Systems Planning Meeting Summary

*Prepared for KDHE
Special Health Care Needs Program*

November 11, 2016



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KDHE Special Health Care Needs Program

Systems Planning

Stakeholder Meeting Summary
November 2016

Introduction

In November 2016, the Kansas Department of Health and Environment Special Health Care Needs Program hosted a group of key stakeholders from across the state to discuss issues related to systems integration for two domains within the National Standards of Care for Children and Youth with Special Health Care Needs. These stakeholders engaged in a reflective and participatory process that focused on the *Access to Care* and *Eligibility and Enrollment* domains of the National Standards. They were asked to review community input that was previously collected both in-person and by electronic survey; articulate a vision for success for each domain; identify potential opportunities and barriers to cross-system coordination; and discuss strategies for engaging potential partners in the integration process.

This report is a reflection of the conversations that occurred within the meeting and is divided by domain. Data reports used and a list of meeting participants are available upon request from the KDHE Special Health Care Needs Program.

Access to Care

There are five standards within the Access to Care domain. These include:

1. The system has the capacity to ensure CYSHCN geographical and timely access to appropriate primary and specialty services, including in-network providers and timely referrals to out-of-network physical, mental and dental care providers, pediatric primary care and pediatric subspecialists, children's hospitals, pediatric regional centers where available, and ancillary providers.
2. Pediatric specialists who have a demonstrated clinical relationship as the clinical coordinator of care for a CYSHCN, among other responsibilities, are able to serve as a primary care provider (PCP) for CYSHCN.
3. Freedom of choice in selecting a primary care provider and written policies and procedures describing how enrollees choose and are assigned to a PCP, and how they may change their PCP is in place.
4. Access to pediatric specialists (face-to-face or via telemedicine) specified in a child's plan of care is provided without prior authorization from a child's primary care provider or Contractor (e.g., health plan) whether or not such specialists participate in a Contractor's provider network.
5. Transportation assistance is provided to families with difficulties accessing needed medical services.

Meeting participants were presented with community input regarding Kansas' ability to meet the current standards (detailed in separate reports). They were then asked to have small-group discussions regarding the information identifying stand-out items and identifying the most important changes that would be needed if Kansas is going to make progress on meeting these standards (See Appendix A).

Defining Success

Considering the community's input and the resulting conversations, participants were asked to define success from a variety of different perspectives.



For *Children and Youth with Special Health Care Needs and their Families*, participants stated that success would be defined as being well informed consumers of services who have access to system navigators that can help them locate a culturally competent network of providers. They would have access to appropriate legal representation, when needed, for a variety of issues unique to children with special health care and developmental needs. Families would be able to work with a network of providers that is adequate enough to allow them to choose services that best meet their family's needs and is sustainable enough to remain that way.

Success for *providers* would mean also mean a stable, sustainable network made so by adequate incentives and reimbursement rates, a knowledgeable and competent workforce with clearly defined roles, and access to the technology and resources they need to provide quality services. Providers would experience fewer bureaucratic “hoops” to jump through, enhanced collaboration across systems, and have confidence that these other systems are there to support families and the network itself.



Measuring Success

Participants indicated that there are a number of organizations that could help measure progress on these efforts including KidsCount, the National Committee for Quality Assurance (NCQA), the Kansas Department of Health and Environment (KDHE), the Centers for Medicare and Medicaid Services (CMS), as well as most insurance and ancillary service providers. These metrics include:

- Increased health outcomes
- Decreased missed appointments
- Decreased inpatient admissions/emergency department visits
- Improved caregiver health – access to health care for themselves
- Increased number of pediatric providers against national benchmarks
- Decreased provider turnover
- Increased telehealth access
- Decreased travel time and wait times for appointments
- Decreased lapsed authorizations
- Decreased lapses in coverage
- Increase in the number of shared plans of care
- Increased number of case managers
- Number of changes to different insurance providers
- Decreased out of pocket expenses
- Increased number of bilingual providers

Cross-System Coordination

Partners who were present at the meeting were asked to divide into groups to discuss three questions related to cross-system coordination. Each group had the opportunity to add responses and then one group was asked to prioritize the top three ideas for consideration. These priorities are listed in red.

What new opportunities exist for cross-system coordination?

- Enhanced telemedicine utilization – hospitals
- Outreach clinics with specialists traveling to outlying counties
- Geographic flexibility for out of state services/networks
- Partnerships with universities to recruit and retain students to become providers and retention of service providers
- Multiple disciplines all in same building
- Single site access team clinics
- As a site in communication with specialists
- Logistical coordination of transportation services
- Resource collaboration in the community meeting frequently (medical and nonmedical) – Shared resources
- Retention of qualified providers (all)
- Pilot programs and sharing successful models
- Develop shared measures, systems
- Multiple disciplines have education about other disciplines/understand each other
- Culturally appropriate standards
- Regionalization to develop and provide services
- Pharmacy – if uninsured – all screen patient for prescription assistance through drug company
- Mobile outreach sedation dentistry
- Incentivize training of new specialists

What barriers are there to cross-system coordination?

- Disparate funding (own sets of regulations)
- Lack of focus on patient – more focus on health system/corporate success (don't share because seen as a competitor)
- Different tech systems and no interface
- Different levels of technology and connectivity available
- Too much reactive communication vs. proactive communication
- Non-complementary and poorly understood roles
- Insufficient time in helping to coordinate care
- Step Therapy with medications
- Lack of cultural sensitivity and competence, language barriers
- Network adequacy – across disciplines
- High turnover rates and brain drain (frustration)
- Too many forms for families
- Paperwork/staff for providers - \$ administrative overhead
- Lack of providers for ALL disciplines
- Lack of insurance or funds/compensation rate results in decreased providers
- Lack of proactive communication between resources (schools, Part C, WIC, Health Departments)
- Transportation – reliable transportation, reimbursement model is too cumbersome and not applicable to majority of families
- Lack of education/knowledge
- Competition among providers/MCOs/insurance providers
- Caregiver burnout
- Information sharing concerns
- Blurred roles
- Lack of dental health providers and coverage

What is the best way to engage partners?

- Round robin/networking meetings
- Interagency coordinating councils (including families)
- Incentives – participate (e.g. state and federal tax deductions, student federal loan forgiveness, % of student loans/tuition @ university reimbursed)
- Vision – intrastate<influence/\$
- Webinars and conferences with evidence-based practices
- Tele-med benefits
- Ask how we can help
- Support groups/social media
- Collaborate/define – Health Information Exchanges/Records – agree on right set of records
- Bridges services between new doctor and previous doctor (i.e. “just in time” consultation, cultural diversities)
- Definition/alignment between referring providers around indication for reason for referral and goals
- Family support
- Utilizing community resources (e.g. schools, health departments) to share information
- Transparency – participating, making a difference
- Grants
- Share successes

Eligibility and Enrollment

There are six standards of care within the Eligibility and Enrollment domain. These include:

1. Outreach activities to enroll children into public and private insurance coverage include strategies designed and proven to be effective in reaching CYSHCN and their families, and are coordinated with relevant family organizations at the state and community level.
2. Continuity of care is ensured during periods of enrollment and transition such as changes in or temporary loss of insurance coverage (public and private).
3. Written policies and procedures are in place for transitioning CYSHCN between non-network and network providers and communication with the medical home and family to ensure continuity of care.
4. Written policies and procedures are in place allowing CYSHCN who are newly enrolled or have recently changed health plans to continue seeing out-of-network providers, for up to six months after enrollment.
5. A comprehensive member services program with specialized staff and linkages to relevant family organizations at the state and local level is available to provide information and assistance to CYSHCN and their families in areas including: family resource needs, insurance coverage options, eligibility and enrollment questions, covered and non-covered services, navigating the medical and community system of care available for CYSHCN,14 enrollee status, complaints and grievances, and selection of a primary care provider or other such medical home with experience in serving CYSHCN.

6. Written and oral information that is provided for purposes of determining insurance eligibility and enrolling a child into public or private insurance coverage is culturally appropriate and provided in a manner and format appropriate for a child or their caregiver, including for those families who have limited English proficiency or sensory impairments.

As with the previous domain, meeting participants were presented with community input regarding Kansas' ability to meet the current standards (detailed in separate reports). They were then asked to have discussions in small groups identifying stand-out items and identifying the most important changes that would be needed if Kansas is going to make progress on meeting these standards (See Appendix A).

Defining Success

Considering the community's input and the resulting conversations, participants were again asked to define success from a variety of different perspectives.

For ***Children and Youth with Special Health Care Needs and their Families***, there would be access to coverage for all children including non-citizens who are legally residing in the country. Families would be informed of the services for which they are eligible and receive the information at the right times – when they need to know it. Coverage and care would be affordable. Eligibility would be based on diagnosis and/or level of need rather than income level and would allow for lifetime coverage when needed. Families would have a single point of entry into coverage and services, out-of-pocket expenses would be considered when applying and deductibles would roll over to a new provider when a change in coverage is necessary or desired. Ultimately, payment issues would be resolved between payers and providers, shielding families from these challenges and allowing them to concentrate on everyday living experiences.



For ***providers***, success would include adequate reimbursement for services, including assisting families with enrollment in insurance coverage, and maintenance of highly qualified staff to help navigate the appropriate systems. A successful system would include single-point-of-entry electronic applications that automatically trigger eligibility and enrollment for a variety of programs. Providers would be able to spend less time on payment issues and more time in direct patient care, leading to improved health outcomes for their patients.

For ***referral networks***, the number of children screened would increase, those with special health care needs would be identified sooner, and there would be an increase in the number of families who are successfully referred to the services they need. Providers of these services would be adequately compensated for their efforts in order to provide a sustainable, stable network of care.

Measuring Success

Participants indicated that there are a number of existing metrics that could help measure progress on system integration improvements. These metrics include:

- Decreased number of denials and appeals – benefits
- Decreased number of denials for coverage – more appropriate referrals
- Decrease in number of self-pay
- Increase in number with coverage
- Improved health outcomes
- Decreased number of days with lapsed care
- Decreased clearinghouse and coding calls to answer questions
- Decreased uncompensated care
- Decrease in catastrophic care
- Equitable access to insurance and utilization
- Decreased staff turnover
- Increased health equity – social determinants of health

Cross-System Coordination

As mentioned earlier in this report, partners who were present at the meeting were asked to divide into groups discuss three questions related to cross-system coordination. The following is a description of the opportunities, barriers and engagement strategies discussed for this domain. Group priorities are listed in red.

What new opportunities exist for cross-system coordination?

- Eligibility is diagnosis driven
- Shared data system – systems talk to each other
- Navigation/education at local facilities
- Single point of entry for eligibility determinations
- One application for multiple programs/referrals
- Universal healthcare
- Local assistance available – reimbursable service
- Part C model available without Part C – health/education are not mutually exclusive
- Health literacy levels
- Quicker turnaround for eligibility
- Enrollment convenient to client location
- Lean, simplify, eliminate waste repetition
- Lifetime eligibility for chronic medical conditions
- Modify income guidelines to include more families
- Education of all possible referral sources

What barriers are there to cross-system coordination?

- Lack of knowledge
- Current process not user friendly (long applications)
- Poor hand-offs between providers during process of establishing eligibility creates disruptions and inefficiencies
- Lack of communication/language barrier
- Differing requirements/guidelines
- Lack of consistency of information provided and benefits
- Health literacy
- Not buy in about importance of going through process – competing priorities
- Income guidelines too stringent – “a cliff versus a slope” – consider expenses
- People not aware of all covered services
- HIPPA concerns
- Data system security
- Territorial issues “my” families, system, data, impact on jobs
- Different answers, different days
- Confusion between eligibility issues and benefit issues
- Constant change – systems and providers
- Length of time between application and approval (KanCare)
- Unclear whose responsibility this is (following up and following through)
- Limited cognitive ability of applicants requires increased agency support
- Lack of cultural competence and language

What is the best way to engage partners?

- General education of services to all partners, families, and MCOs
- More availability of care/service coordinators (case managers)
- Care coordination plan created and shared with all agencies involved
- Early childhood (0-5) providers (e.g. Part C, Early Childhood centers, home-based programs, etc.)
- Health departments
- Financial incentive for providers
- Communication between partners
- Make it simple
- Common goal – everyone on the same page
- Common language
- Providing avenue for everyone to come together
- Get families connected with navigators/advocates
- Transparency/recommendations/results
- Consistency among MCOs – all healthcare work together
- Development of one stop shop (includes info and links)
- Kansas Services Website to link to federal/local services (do have links to DCF, child support, TANF, medical/XIX/KanCare applications)

Identifying Needs and Contributions

Because there is currently not a single coalition structure that is responsible for the oversight of efforts toward successfully meeting the National Standards of Care for Children and Youth with Special Health Care Needs, the stakeholders who were present were asked to consider what is needed to maintain relationships to make progress and what their individual sectors could contribute to the process.

Participants noted that it would be helpful to identify the approximate number of consumers that are impacted and unify those families to work toward change. It was also suggested that continued communication, trust among partners, and trustworthy processes are important to maintaining cross-system relationships. Continued communication could take the form of bulletins from providers, including KDHE, to keep partners informed regarding changes within the system or a forum that would allow partners to discuss electronic options that might be available to improve access to care. Ultimately, the group stated that there needs to be strong leadership with a vision – or mandate - for how care will be provided to this population in Kansas. This leadership would be similar to an “Executive Sponsor” used in healthcare quality improvement projects who drive the efforts and hold interested parties accountable to the work.

The following are the contributions that were offered:

- As chair of Pediatric department – find ways to collaborate
- Academic System – how do we incentivize specialists?
- FQHCs – be a one stop for clients. Gives opportunity to collaborate, educate, and fill gaps
- Nursing schools – develop and offer a micro-credential for complex care
- Family Advisory Council – meet with insurance commissioner and share concerns
- “Empower” over “enable” families by giving them knowledge
- Local health departments/Public Health – meet clients where they are and raise them up. Give them a “soft place to land”
- Should always be assistance to help move through the system
- Kansas Council on Disabilities – state-to-state work on transition tools for families
- Parent to parent support
- KDHE – supporting telehealth, outreach specialty clinics, healthcare enrollment for all
- MCOs – provide “delegated vendor” oversight to improve transportation services

Next Steps

KDHE will use the information gathered at this meeting to inform efforts to improve the system of care for Children and Youth with Special Health Care Needs in Kansas. They plan to continue seeking information from families, communities, and system partners for the remaining domains in the National Standards in 2017.

Prepared by:



WICHITA STATE
UNIVERSITY
COMMUNITY ENGAGEMENT
INSTITUTE
*Center for Organizational
Development and Collaboration*

Table Discussion

Please choose someone from your table to record your responses to the following questions and then submit to the WSU team to be included in the meeting report.

Access to Care Domain

Given what you've just learned from stakeholders about meeting and not meeting these standards, what stands out for you?

Table 1

- Inadequate network of physicians
- Many physicians won't take Medicaid or private pay
- Providers don't receive pay for time spent for provider care coordination
- Doctors without borders – why can't they go periodically to rural areas to serve them
- Despite US CPT codes (CCPT 99490, 99487, 99489) aren't reimbursable
- Consistent, reliable transportation not a given

Table 2

- Need to integrate specialty care in rural areas
- Number of providers an issue
- Served by specialists? Sustainable? Competition with providers?
- Holistic care more important than where it comes from for future care. Pool resources instead.
- Billable services – some areas of specialty (__ Peds) has poor reimbursement
- Outreach services – CMH, Wesley, VC – to collaborate – these health care providers compete
- XIX reimbursement – impact on providers being able to serve
- Uninsured – not a good match between access and reimbursement
- Language – surveys in Spanish. Gap in services

Table 3

- Demographic information shared/integrated with results
- Human resource issues – nursing shortage, specialist shortages in rural areas
- Transportation issues
- Timelines for services, as well as equipment. Training/in-service on special equipment
- Behavioral health access is not timely, especially in urgent situations

Table 4

- Transportation – families don't know it is available
- Doctor not accepting more than 2 well visits per day so if you have three kids, then you have to schedule two days



**KDHE SHCN Systems Integration Meeting
November 3, 2016**



Table 5

- Need more clarity on what we are expecting from each other – clarifying roles and expanding linkages
- Capacity issue in Kansas on all levels of medical care. What are the alternatives? In SE Kansas – a town has made it so that a PCP is local in their small community (at the school) – been successful. Whereas, when one PCP trying to cover too many – can't do job adequately. Or a PCP that will go to the home – is one in Wichita. Or provide telemed for this.
- In the state of Kansas, still a lack of education on what services are offered and what an individual is eligible for. Need more media to educate and vice versa – state needs to get out there and see what individuals, families, and guardians deal with on a daily basis. Use webinars, telemed, etc., MORE!

Table 6

- Transportation
- Dental
- PCP vs. specialist issues
- More negatives pointed out than negatives
- DME providers
- Mobile telehealth

What are the most important changes needed if Kansas is going to make progress on meeting these standards?

Table 1

- Medicaid expansion
- Expand availability of telehealth services
- Ongoing effort to improve transportation access and routine re-education to recipients of eligibility guidelines.
- Need someone in local/rural area who is knowledgeable about scope of available resources.

Table 2

- Extending specialty services across geographic areas. Needs collaboration, efficiency, and sustainability
- Resources available for our providers
- Chronic complex care should be a subspecialty
- Insurance providers compensate nursing care by family caregivers. Parents providing skilled nursing care need to be paid as providers. Caregivers caring for adults with disabilities can receive payment to care for the adult but parents/siblings of kids are not.

Table 3

- Improve reimbursement for services
- Expand what is covered
- Help educational system to train providers and keep them in the state. MOU to stay here
- Universal screening tools and training to use them and increase referral system for follow up, if needed

Table 4

- Transportation that is reliable, that families know about
- Insurance companies – both state and private – talking to each other

Table 5

- CAPACITY!!
- Education on both sides
- Piloting some creative ways to reach those that have the needs! Webinars...
- Credentialing alternatives to help build care and capacity – break down more silos

Table 6

- Language barriers
- Understand supply and demand to close gaps
- Drill down on specific issues to identify solutions
- Technology assistance and utilizing more
- Sedation and dentistry providers
- Increase education
- Improved process to close gaps

Table Discussion

Please choose someone from your table to record your responses to the following questions and then submit to the WSU team to be included in the meeting report.

Eligibility and Enrollment Domain

Given what you've just learned from stakeholders about meeting and not meeting these standards, what stands out for you?

Table 1

- People who need insurance often don't consider coverage differences – only the premium when looking through healthcare.gov
- It is unclear what insurance companies have in place to quickly recognize a lapse in coverage and proactively approach the former member to evaluate why. Do they even see it as their responsibility to help them re-establish insurance?

Table 2

- Retention of highly qualified staff – know what's available
- We want families enrolled in insurance
- Transition coverage – programs
- 18 year old emancipated – parent has to have permission/consent
- Roll-over deductibles – requires policy change to not start over
- Qualify and not access – not all enrolled
- Loss of resources if we refer
- Financial insecurity of provider service
- Diagnosis driven vs. federal poverty level/guidelines
- Annual and lifetime
- At time of diagnosis – check on these programs you might have benefit

Table 3

- Lack of understanding of eligibility criteria
- Some parents/families feel standards are not being met
- Offering definitions of medical necessity
- Navigator availability varies from location to location

Table 4

- KanCare is long and complicated and families give up unless someone guides them
- Families won't question "experts". "Experts" being scheduling person saying you have to schedule with ARNP or how to fill out insurance paperwork
- Collaboration between systems – medical insurance and the provider



Table 5

- Getting the word out of importance of taking advantage of the information and education that is available
- Time is an issue and prioritizing for families as this enrollment/eligibility may not be the immediate fire that needs put out
- Persons not having the support systems available to assist
- Education, advocacy – need to get the participants “hooked”
- Making the information easier to understand

Table 6

- Inconsistent policies and procedures across providers
- Gap when change of insurance
- Lack of knowledge regarding claims process (people don’t know what is needed for approval – supporting documentation) – need for education
- Sustainable system requires realistic expectations

What are the most important changes needed if Kansas is going to make progress on meeting these standards?

Table 1

- Legislation change – expand Medicaid

Table 2

- Education regarding services available
- Sustainable services available
- Cultural competence
- Are services not just what seems to need but actually are helpful
- Need to understand what a service is and how it can help that person
- Income too high to qualify for services – fall through the cracks
- Flex spending account different for CYSHCN
- Tax laws about health care reimbursement for gas to appointment

Table 3

- Common/uniform definitions
- Increased outreach, navigators – consistent statewide
- Expanded population of who is eligible for coverage
- Make more people aware of how to enroll, location of navigators
- Expand Medicaid

Table 4

- Consistency within insurance covered services (within the same policy)
- Clear definition of how to qualify. Both state and private insurance

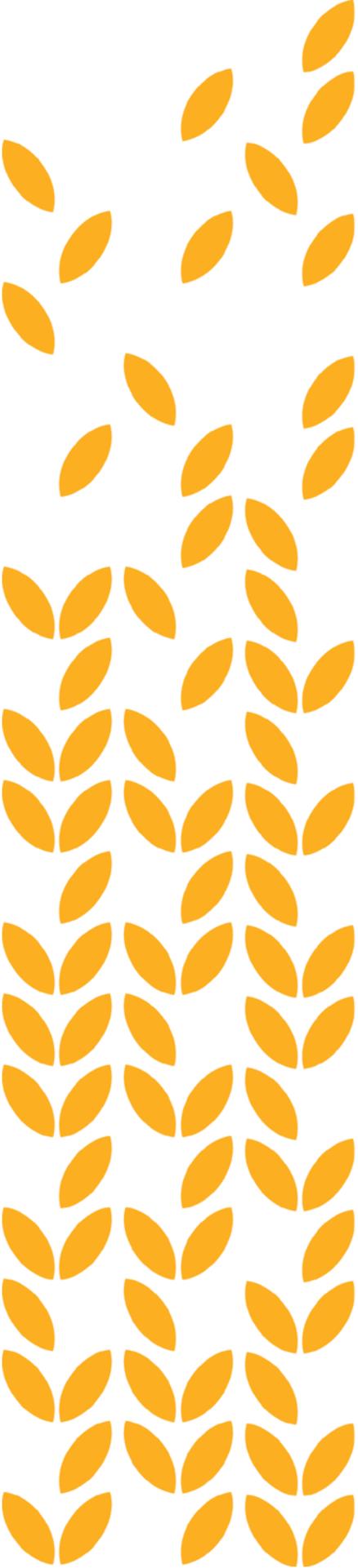
Table 5

- More local assistance for education, advocacy and advertisement
- Consistent minimum standards and reviewing to assure increased education, access to car services

- Challenge standards that aren't appropriate including at a federal level
- Pilot projects across all demographics – technology access in pilot towns/families for eligibility and enrollment

Table 6

- Lack of consistency between national definition and state definition
- People who are eligible are not aware
- Include CYSHCN on Medicaid enrollment form – shouldn't be dual process, educate them about benefits
- Different payment structure for CYSHCN – like their own waiver – would ensure continuity of care
- Lots of duplicity in a lot of the processes
- Physicians should create continuum of care (avoid transitions to multiple physicians)
- Migrant eligibility?



CYSHCN Systems Planning Meeting Summary

*Prepared for KDHE
Special Health Care Needs Program*

May 10, 2017



**WICHITA STATE
UNIVERSITY**

**COMMUNITY ENGAGEMENT
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KDHE Special Health Care Needs Program

Systems Planning

Stakeholder Meeting Summary
May 2017

Introduction

In May 2017, the Kansas Department of Health and Environment Special Health Care Needs Program hosted a group of key stakeholders from across the state to discuss issues related to systems integration for two domains within the National Standards of Care for Children and Youth with Special Health Care Needs. These stakeholders engaged in a reflective and participatory process that focused on the *Transition to Adulthood* and *Screening, Assessment and Referral* domains of the National Standards. They were asked to review community input that was previously collected both in-person and by electronic survey; articulate the most important changes in order to fully meet those standard domains; identify potential change agents and their actions to make positive changes; discuss potential partners and their strategies for making the improvement process easier; and identify opportunities and barriers for making those changes.

This report is a reflection of the conversations that occurred within the meeting and is divided by domain. Data reports used and a list of meeting participants are available upon request from the KDHE Special Health Care Needs Program.

Transition to Adulthood

The seven standards for Pediatric Settings include:

1. A policy and process for transition preparation and planning for youth with special health care needs (YSHCN) and their families as they prepare to move between pediatric and adult care systems is in place within the health plan and medical home. YSHCN are encouraged to learn about and engage in their health care as part of this process.
2. An individual flow sheet or registry for identifying transitioning YSHCN is maintained by the health plan and medical home to track completion of the transition process.
3. A transition readiness assessment and plan of care, including a medical summary and emergency care plan, are first developed when a YSHCN reaches age 14, and then regularly updated in partnership with the youth and her/his family or caregiver. A family's cultural beliefs are respected in the development of the transition plan.
4. A transfer package including a final transition readiness assessment, plan of care with transition goals, and medical summary and emergency plan is prepared and communicated with the new adult medical home, prior to the transfer of a YSHCN from a pediatric to an adult medical home.
5. The pediatric medical home is available for consultation assistance with the adult medical home, as needed.
6. A process is in place in the pediatric medical home to ensure that follow-up of a YSHCN is provided 3 – 6 months after transfer to an adult medical home to confirm transfer and elicit feedback on their transition experience.
7. Transition quality improvement includes collaboration and, for some YSHCN, co-management between pediatric and adult health care providers.

The five standards for Transition to Adulthood related to Adult Settings include:

1. A policy describing the adult medical home approach to accepting and partnering with new YSHCN, including legal changes at age 18, is in place.
2. An individual flow sheet or registry for identifying transitioning YSHCN through 26 years of age is maintained by the health plan and medical home to track completion of the transition process.
3. A process for identifying providers who are interested in caring for YSHCN exists at the adult medical home and health plan levels.
4. A process for welcoming and orienting young adults exists within the adult medical home.
5. A process for confirming the transfer between the pediatric and adult medical home is in place to assist the YSHCN with ongoing care management and referral to adult specialists and other community supports and elicit feedback about their experience of care.

Most Important Changes

Regional meeting results were presented sharing suggested strategies for meeting standards within the domain (detailed in separate reports). Participants were asked to have small-group discussions identifying stand-out strategies and selecting the top three the most important changes that would be needed if Kansas is going to make progress on meeting these standards.

Participants stated that the most important changes needed would be special needs **education** for adult care providers so they would be willing to accept YSHCN who are transitioning to adult care. The next most important change identified was the creation of **reimbursement** models to incentivize providers to serve the population. In addition, participants discussed that the reimbursement models would need to include behavioral health providers and others involved in transition-related work. The third prioritized change was the creation of an effective **referral system** by developing comprehensive electronic referral networks and a statewide resource list of adult providers willing to take YSHCN. An effective referral system would need to include a designated staff person at primary care provider offices to assist in the transition referral process.

For a complete list of recommended changes, see **Appendix A**.

Potential Change Agents, Actions, & Evidence

Related to those three most important changes needed for meeting the Transition to Adulthood standards, participants were asked to identify potential change agents, suggested actions, and evidence of change. The following table summarizes participants’ responses.

Issues	Who Group/Sector/Org.	Do what?	Evidence – How will we know/measure?
Education	Adult Providers	<ul style="list-style-type: none"> • Increased knowledge, skills, and collaboration 	<ul style="list-style-type: none"> • Provide services they didn’t previously provide
Reimbursement	Insurers (Public)	<ul style="list-style-type: none"> • Reimbursement for transition-related work 	<ul style="list-style-type: none"> • # of times code is billed • Youth would perceive a successful transition

Referral	<ul style="list-style-type: none"> • KDHE • Local Providers 	<ul style="list-style-type: none"> • Build a comprehensive referral system (KDHE) • Local providers engage in the referral system sharing their willingness to take YSHCN 	<ul style="list-style-type: none"> • YSHCN can find an adult provider • Complete resource about availability of providers
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Potential Facilitators and Strategies

Partners at the stakeholder meeting were asked to discuss what partners are in a position to facilitate those changes noted above. The following are their suggestions:

Education

- Facilitators: Medical schools
 - Strategy 1: Add to medical school curriculum & residency
 - Strategy 2: Implement standardized patient program
 - Strategy 3: Develop certifications for nurses & mid-level providers
- Facilitators: Project ECHO/Tele Health
 - Strategy: Publicize opportunities for case consultation
- Facilitators: Associations (e.g. American Academy of Pediatrics [AAP])
 - Strategy: Promote as part of conferences

Reimbursement

- Facilitators: Families
 - Strategy: Influence KanCare 2.0 and insurers
- Facilitators: AAP and APA (American Psychological Association)
 - Strategy: Create policy statements
- Facilitators: Providers
 - Strategy: Accept pay for performance
- Facilitators: KanCare
 - Do a pilot trial for mandate

Referral

Several facilitators were identified for the strategy of influencing providers to network and provide information.

- LHD (Local Health Department), CMHC (Community Mental Health Centers)
- AAP, APA, and other profession organizations
- Part C
- Board of Education (schools) & Teachers' Association, school social workers
- Special Education Cooperatives
- Insurers
- Kansas Hospital Association

Potential Opportunities and Barriers

Each table discussed potential opportunities and barriers for cross-system coordination in the Transition to Adulthood domain.

Potential opportunities

- Improved continuity of care
- Better services through cross system coordination & partnerships
- Education
- Provide survey to adult providers to assess education needs to care for CYSHCN
- Increased awareness
- Partnering – doctors working together to provide appropriate transitioning care of SHCN child to adult care
- Strengths brought to table by multiple partners (diverse strengths)
- Competing values
- Avoid duplication of services
- Timing of KanCare 2.0
- Lots of partners
- Continuity of care
- Bright Futures guidelines
- Open communication between pediatric and adult providers
- Child can learn to advocate for themselves if able (using assessment tool will aid in determination)
- Helping identify 0-3 needs through collaborations
- Gathering targeted case managers, care coordinators, care managers, & foster care case managers to discuss effects related to adult transitions across the life span
- You know ahead of time when person will transition – can start early with conversation
- Health home framework → allow for systems to work together → allows for wrap-around services
- Telehealth
- Standardize system of reporting & planning/life coordination
- Increase in participation
- Decrease in frustration
- Better quality of care
- Better focus on transitions over life span
- Schools start transition at 14 – opportunity for others to follow with Vocational Rehabilitation focus also to integrate (e.g. meeting behavioral & medical to allow for appropriate employment opportunities)
- More integrated supports (Family, community, church, etc.)

Potential barriers

- Communication and time commitment
- Competing values
- Competition
- Different communication means
- No funding reimbursement through Title XIX or lack of funding
- Conflicting priorities
- Who has the authority?
- Knowing “who’s who” to connect “who’s doing what”

- Acronyms/lack of a common language
- Lack of clarity about the system (i.e. reimbursement)
- Lots of partners
- Parents letting go
- Lack of self-advocacy education towards independence (heavy parent involvement)
- Lack of communication
- Not a defined age for transitioning with SHCN population (“18 or 21” or later)
- Increase office visit time without reimbursement
- Finding service providers
- Children who move into KS
- Funding can’t keep up with need
- Time for meeting
- Care coordinating agencies haven’t prioritized this area
- HIPAA can be a barrier to share info
- Time for providers to allow for a good transition (e.g. 15 min appointment times)
- Not all providers enrolled with all MCOs
- Providers willing to take CYSHCNs may not be local
- Telehealth reimbursement
- Don’t always have resources (human & financial) for guardianship
- Often falls on social workers, “whole team” doesn’t always take responsibility
- Current lack of training
- Potential lack of participation
- Language barriers with systems

Screening, Assessment, and Referral

The six standards for Screening and Assessment include:

1. Upon enrollment and transfer between insurance coverage (e.g., public and private), a consistent and culturally and linguistically appropriate mechanism for identifying CYSHCN, including children with significant health conditions, is in place to ensure that these children are referred to appropriate types and sources of enhanced care.
2. 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.
3. State newborn screening information is delivered to providers and parents in a timely fashion and arrangements made for necessary follow-up services are documented. If indicated, the need for repeat screening and follow-up is communicated to the health plan and providers by the hospital or state program.
4. 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.
5. 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.
6. 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.

The two standards for Referral/Follow-up include:

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. 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.

Most Important Changes

As with the previous domain, regional meeting results were presented with community input regarding Kansas' ability to meet the standards as well as suggested strategies for meeting standards (detailed in separate reports). Participants were then asked to have discussions in small groups identifying stand-out items and selecting the top three the most important changes that would be needed if Kansas is going to make progress on meeting these standards.

Prioritized changes included enhanced **provider education** addressing a lack of or inadequate practice; educating providers regarding appropriate needed services (e.g. specialists, therapists, early intervention, etc.); and increasing statewide education for providers. The next most important change identified was creating a **child data tracking** system through a state electronic health system including electronic forms with required fields and standardized data collection. One suggested implementation involved developing and expanding the Kansas Health Information Network (KHIN) to improve capabilities and increase access to more providers. Participants also identified **billing/reimbursement** as important area for change in order to meet the screening, assessment & referral standards. Reimbursement models need to allow for a broad scope of providers for screening and assessment such as LPNs, RNs, and Social Workers. Billing and reimbursement models should incentivise completion of the Kan Be Healthy and facilitate use of appropriate billing codes so that consumers do not miss out on any screenings that were billed but not completed.

For a complete list of recommended changes, see **Appendix B**.

Potential Change Agents, Actions, & Evidence

Participants were asked to identify potential change agents, suggested actions, and evidence of change as they related to the three most important changes for meeting Screening, Assessment and Referral standards. The following table summarizes participants' responses.

Issues	Who Group/Sector/Org.	Do what?	Evidence – How will we know/measure?
Provider Education	Providers	<ul style="list-style-type: none">• Gain new knowledge, skills, attitudes to increase screening/assessment	<ul style="list-style-type: none">• Increased use of assessment (more complete assessment)

Child Data Tracking	Cooperative State-level Child-serving Agencies	<ul style="list-style-type: none"> • Support child data tracking system that triggers care coordination 	<ul style="list-style-type: none"> • Increase in care coordination • Existence of tracking system and triggers • Parent satisfaction surveys • Reduction in incomplete referrals
Billing/ Reimbursement	Providers/Designee (coder), Insurers	<ul style="list-style-type: none"> • Provider uses correct code for appropriate screening • Insurers change code claims configuration to better reflect if qualified professional did screening 	<ul style="list-style-type: none"> • Complete all appropriate & needed screenings

Potential Facilitators and Strategies

Partners at the stakeholder meeting were asked to discuss what partners are in a position to facilitate those changes noted above. Their responses are below:

Provider Education

- Facilitators: Providers
 - Strategy: Create competition
- Facilitators: Medical schools
 - Strategy: Incorporate families with SHCN into education and standardized patient program
- Facilitators: AAP Kansas Chapter, Insurers, Licensing Boards
 - Incentivize use of referral sources

Child Data Tracking System

- Facilitators: Providers, Insurers, Screeners, & Families
 - Strategy: Need to be open to the new system and educated about using the system
- Facilitators: Insurers
 - Strategy: Need to include code to support child data tracking system

Billing/Reimbursement

- Facilitators: Insurance companies
 - Strategy: Incentivize accurate coding (don't pay for wrong/inappropriate codes)
 - Strategy: Differential rate for pay-for-performance
- Facilitators: Providers
 - Strategy: Be clear about designation of codes to particular types of providers
- Facilitators: AAP
 - Strategy: Recommend/define appropriate screenings through Bright Futures

Potential Opportunities and Barriers

Each table discussed potential opportunities and barriers for cross-system coordination in the Screening/Assessment/Referral domain.

Potential Opportunities

- Partnerships to increase communication between PCP, parent, school, daycare, and other
- Cross agency collaboration & coordination
- Increase compliance of preventative health, early intervention – increase participation
- Care coordination to help families find & utilize needed resources
- Increased referrals to community resources
- EMR documentation system that provides screening prompts & follow up referrals
- Ongoing safety net screenings
- Parents advocating for child to navigate through school system & be successful
- Multiple places & entities that can do screenings besides physicians
- Advancing technology devices (vision pre-screening tool)
- Reach-out to non-traditional screeners (Lions Club)
- Braided funding for services & devices
- KIDOS (ECCS Impact) 4+ years – developmental health focus in EC, community level at statewide implications
- Help Me Grow – statewide initiative
- Awareness/marketing & recognition
- To follow up on data/results from screenings
- Proper assessment by correct provider → proper referral
- Existing local agencies across state (LHDs, schools) as new partners
- Better set guidelines for SHCN screenings when condition requires accommodations
- Differentiate between physician basic level vision/oral screening with follow-up referral (and reimburse this) and screenings by specialist after physician referral (reimburse this too)

Potential barriers

- Lack of standardized process for follow-up
- Poor parent follow-up
- Greater chance for lack of follow-up if not already a system in place (if using new partners)
- Lack of providers able to make accommodations to special populations/lack of specialists
- Who's doing the work?

- Who's educating the providers?
- Advocacy for families & provider education
- Lack of resources & knowledge of resources
- Parental denial of failed screening
- No system to link the various providers to share data
- No willingness (time) to share data
- Not being aware of new technology
- Families whose language is not English will encounter difficulties in getting resources and services
- EMR system & multitude of other data systems do not align (no common interface)
- HIPPA or other confidentiality concerns (restraints or restrictions)
- Who monitors correct completion of assessment?
- Lack of clear understanding between providers and families of what is available
- Barrier to proper coding perception underfunded for screening pieces

Next Steps

KDHE will use the information gathered at this meeting to inform efforts to improve the system of care for Children and Youth with Special Health Care Needs in Kansas. They plan to continue seeking information from families, communities, and system partners for the remaining domains in the National Standards in fall 2017 and spring 2018.

Prepared by:



Appendix A

Transition to Adulthood Domain

What are the most important changes needed if Kansas is going to make progress on fully meeting these standards?

Education

- Enhance special needs education to adult care providers, so they are more willing to accept children with complex medical conditions
- Importance of transition planning (when + How to begin adult providers + What to do +When referral received)
- Prepare families to educate on process (e.g. resource mapping with timeline)
- Provide specialized training for medical providers during school or post-education
- Universities/educational institutions offer specific training for providers in regards to CYSHCN (continuing EDU, establish courses in various, etc.)

Reimbursement

- Creative reimbursement models to incentivize providers to serve the population
- Include behavioral health providers as primary and others as needed for transition planning
- Allow funding for overlap
- Higher reimbursement rates for YSHCN to increase the number of providers
- Reimbursement for transition-related work

Referral Systems

- Increase functionality of KHIN as well as utilization by medical providers
- Develop comprehensive electronic referral network
- Having a designated staff person at PCP office to assist with referral transition process
- Develop a statewide complex resource list of adult providers willing to take children with special health care needs that are transitioning to adult care
- Case managers restored to all populations

Communication

- Increase provider network and communication

Standardized Plan & Tools

- Lack of standardized plan
- Families and providers use a standardized tool for transition readiness assessment

Extend Services Beyond Current System

- Practice standards for transition planning for all children that address medical, educational, and community settings
- KSDE include health transition in individualized learning plans for all students
- Board of Education and insurers offer care coordination for all children and YSHCN and support effort of coordination

Appendix B

Screening, Assessment & Referral Domain

What are the most important changes needed if Kansas is going to make progress on fully meeting these standards?

Provider Education/Family Education

- Address lack of or inadequate practice by providers
- Educating providers regarding appropriate needed services (e.g. specialists, therapists, early intervention, etc.)
- Reducing the wait time on referrals by trained professionals and providers
- Increase statewide education for providers and families
- Better communication about babies who don't pass screens with parents
- Parent engagement, empowerment, and education
- Increase parental or caregiver education regarding normal child development – teach how to screen at home and have resources available for them to go get appropriate help

Child Data Tracking

- State electronic health system including electronic forms with required fields/standardized data collection
- Develop and expand KHIN to improve capabilities and increase access to more providers

Billing/Reimbursement

- Reimbursement models allow for broad scope of providers for screening/assessment (LPN, RN, and Social Workers)
- Billing/reimbursement ensure all screenings are completed as part of the KBH
- Providers to bill correct billing codes appropriate to actual screening – this way consumer does not miss out on any screenings that were billed but not completed

Screening Outside of Systems

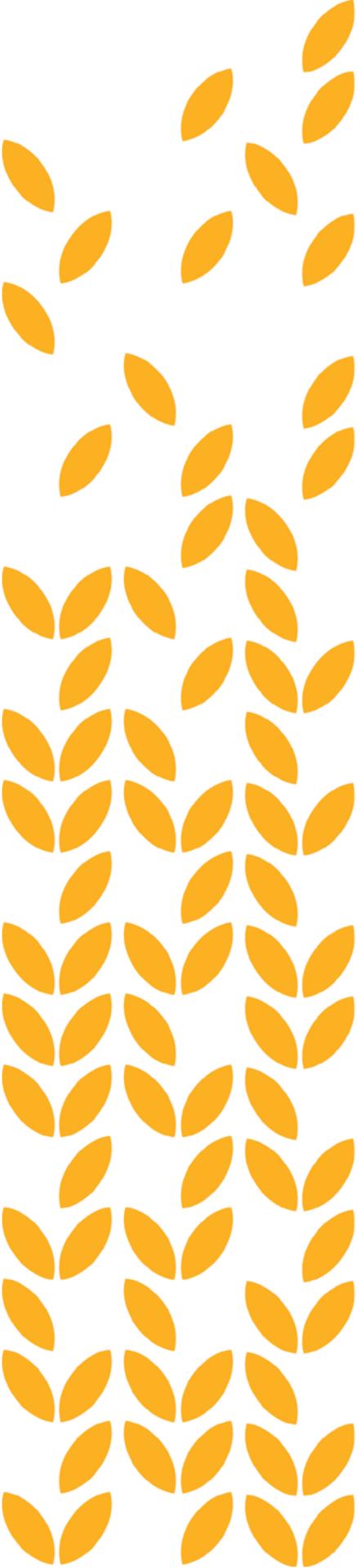
- Developers of clinical pathways assure include appropriate screenings, referrals, and follow-up (e.g. TBI)
- Universal screening despite insurance coverage

Resource Directory

- A network to monitor referrals/assessments/follow-up
- Additional education regarding what's available
- Assess resources to address the identified health issues
- Post-hospitalization follow-ups/referrals
- Address increase resources to meet needs identified in screening process

Care Coordination

- Coordination among local providers across multiple sectors
- KDHE & insurers – all youth with SHCN will have care coordination and screenings done annually



CYSHCN Systems Planning Meeting Summary

*Prepared for KDHE
Special Health Care Needs Program*

October 16, 2017



WICHITA STATE
UNIVERSITY

COMMUNITY ENGAGEMENT
INSTITUTE

Center for Organizational
Development and Collaboration

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KDHE Special Health Care Needs Program

Systems Planning

Stakeholder Meeting Summary
October 2017

Introduction

In September 2017, the Kansas Department of Health and Environment Special Health Care Needs Program hosted a group of key stakeholders from across the state to discuss opportunities and challenges related to systems integration primarily related to the *Family Professional Partnerships* domain of the National Standards of Care for Children and Youth with Special Health Care Needs (CYSHCN). The National Standards outline opportunities for organizations and systems to partner with families to make decisions at all levels including care delivery, program planning and systems planning.

Stakeholders were asked to review and reflect on community input that was previously collected both in-person and by electronic survey; identify and prioritize areas within the system that can be improved or enhanced in order to fully meet the national standards; identify potential change agents and their actions to make positive changes; and identify opportunities and barriers for cross-system collaboration.

This report is a reflection of the discussions that occurred within this meeting. Data reports used and a list of meeting participants are available upon request from the KDHE Special Health Care Needs Program.

Care Delivery

The following includes national standards related to partnering with families to make decisions about care delivery:

Family Professional Partnerships (pp. 20-21)

- Families are active, core members of the medical home team.
- Family priorities and concerns are central to care planning and management.
- Families are connected to family organizations, peer support and family support programs.
- Family strengths, including cultural and ethnic identities, are respected in the delivery of care.
- Care is delivered in culturally appropriate ways, respecting family desires for inclusion of extended family members in decision making.
- Families receive information about the services and supports that they will receive in a method chosen by the family (e.g., written, verbal, language of choice).
- All written materials provided to CYSHCN and their families are culturally appropriate, provided in the primary language of the CYSHCN and their family, and provided in a manner and format appropriate for children and their parents or caregivers who have limited English proficiency or sensory impairments.

Health Information Technology (p. 23)

- Families have easy access to their electronic health information and the opportunity to contribute to the record.

Improving Family Professional Partnerships in Care Delivery

Regional meeting information presented included suggested strategies for meeting standards within this area (detailed in separate reports). Stakeholders participated in small-group discussions to identify or propose strategies. We then focused on three priority strategies that would allow systems that serve CYSHCN in Kansas to make progress on meeting standards. (For a complete list of suggested opportunities, see **Appendix A.**) Within each priority, participants were asked to identify the change or improvement they would like to see, how it would be measured, and what system partners could do to support those efforts.

Priority 1: Health care coverage providers (insurers) offer mentoring programs to families that educate and empower families to advocate on behalf of themselves and their children.

Measures: Reduction in emergent care visits, increase family satisfaction, improved family health

Proposed Partner Strategies:

- **Legislators** pass legislation to mandate these programs.
- **Families** demand support from their coverage provider.
- **KDHE** add rule to KanCare regulations for Medicaid Providers.
- **Community service providers** advocate to persuade coverage providers to provide this type of education and support.
- **Rare disease organizations** exert political influence with health coverage providers.

Priority 2: Community providers work to simplify access to services.

Measures: Reduction in inpatient hospitalization, increased family satisfaction, children are absent from school less frequently due to medical challenges, increased service utilization

Proposed Partner Strategies:

- **Health coverage providers** simplify their authorization processes.
- **Legislators** support adequate funding for programs that serve families of children with special health care needs.
- **KDHE** incentivizes the use of tele-health systems.
- **KDHE Division of Health Care Finance** provide education related to the billing codes needed to access reimbursement.

Priority 3: Families drive the services being offered.

Measures: Increase in new services being offered, reduction in hospitalizations, increase in family satisfaction, children are absent from school less frequently due to medical challenges, increased service utilization, reduction in family unemployment

Proposed Partner Strategies:

- **Providers** will collaborate with care coordinators.
- **Schools** will improve individualization of Individual Education/Family Service Plans and 504 accommodations.
- **School inter-cooperatives** will partner with other health organizations.
- **??** will create navigation and coordination programs.
- **Nurses** will provide information to families.
- **Families Together** will continue to provide education and services to empower families.
- **Infant-Toddler (Part C) Program** will continue in their current role as partners with families.

Program and Health Systems Planning

The following includes national standards related to partnering with families to make decisions about program and health systems planning:

Program Planning:

Family Professional Partnerships (p. 21 – modified)

- [Organizations] that serve CYSHCN have a family advisory board or committee, inclusive of families of CYSHCN that guides their policies, programs and quality improvement activities.

Quality Assurance and Improvement (p. 24)

- [The state,] Health plans, [providers] and insurers have a specific and ongoing quality assurance (QA) and quality improvement (QI) process in place for CYSHCN and their families. This includes:
 - families of CYSHCN as members of the primary care provider and health plan QI teams
 - experience of care surveys of families of CYSHCN and youth (including targeted feedback from relevant racial/ethnic and language groups) to obtain their feedback and assess their experiences with care
 - The utilization review and appeals processes for CYSHCN include members of a child's integrated care team.

Health Systems Planning:

Family Professional Partnerships (p.21)

- Health systems that serve CYSHCN solicit feedback from the family and children on the experience of care that they receive.
- Health systems that serve CYSHCN have a family advisory board or committee, inclusive of families of CYSHCN that guides their policies, programs and quality improvement activities and offers family members training, mentoring, and reimbursement for their participation as active members of these boards and committees.

Improving Family-Professional Partnerships in Planning Efforts

As in the previous discussion, regional meeting information was presented that included suggested strategies for meeting standards within this area (detailed in separate reports). Stakeholders participated in small-group discussions to identify or propose strategies. We then focused on three priority strategies that would allow systems that serve CYSHCN in Kansas to make progress on meeting standards. (For a complete list of suggested opportunities, see **Appendix A.**) Within each priority, participants were asked to identify the change or improvement they would like to see, how it would be measured, and what system partners could do to support those efforts.

Priority 1: Program and system leadership promote advisory boards that prioritize family participation, improved accessibility for families, and conversation about potential changes. They then assure communication with families about changes made that are a result of family participation.

Measures: Increase in family attendance in advisory board activities and actual changes in the program or system as a result.

Proposed Partner Strategies:

- **KDHE** will provide leadership and support to local programs who create family advisory boards.
- **Large rare disease organizations** will provide education and support.
- **Technology organizations** will find new, creative ways to obtain family feedback.
- **Families** will use their voice and tell their stories.
- **Kansas Youth Empowerment Association** will provide youth mentorship and empowerment skills.
- **Families Together** will train families on advocacy and leadership skills.
- **Mentor families** will empower other families through shared personal experience.

Priority 2: Local community networks will coordinate feedback opportunities and family advisory groups and include decision makers in those groups. They will also provide feedback to families on any changes that were made or other impacts of the feedback they provide.

Measures: Increase in legislator participation in local networks, increase in family advisory groups, there will be fewer meetings and increased coordination, decrease in barriers leading to an increase in participation.

Proposed Partner Strategies:

- **Families** will speak out and use their advocacy skills to persuade others.
- **Successful Advisory Boards** (like the Interagency Coordinating Councils) can share their success stories and demonstrate changes to the community.
- **KDHE** will provide technical assistance to local family advisory boards.
- **State agencies** will communicate with one another and share successes.
- **Funders** will mandate community partnerships as a condition of receiving funds.

Priority 3: Navigators and mentors will help families find strength in their voice and teach advocacy skills.

Measures: Increase in families advocating for themselves and others, decrease in need for care coordination, families have improved access to services, funding is better spent on what is needed, fewer mandates, increase in families who report feeling empowered.

Proposed Partner Strategies:

- **Families** will celebrate their successes and teach the same for others.
- **Communities** will replicate successful models.
- **Funders** will incentivize families to be mentors/navigators by providing help with child care or other financial support.
- **Health coverage providers** will incentivize mentorships.
- **Parent Leadership Conference** will continue to recognize and award family successes.
- **Businesses and local news media** will recognize and award family successes.
- **State agencies** will provide training and create resources.

Potential Opportunities and Barriers

As a final discussion, stakeholders were asked to participate in small group discussions to identify potential opportunities and barriers to cross-system collaboration for the overall improvement of Family Professional Partnerships.

Potential Opportunities

- Extending funds to use for educating families on services
- Broad view of services
- Serving more people
- Growth involving collaborative services -- uniting and valuing importance
- One stop shop (Navigator)
- Collaborative meetings that involve statewide involvement
- Multi-agency collaborations (local and state)
- Help communities to understand what the issues are, along with what resources are available
- Communities to learn about success and foster continuous success stories
- Creation of formal structures
- Engage families more
- Family peer support
- Emergency Management System (EMS) education and training
- Share information/collaboration

Potential barriers

- Territorial – geographic and professional
- No money/funding
- Time – time away from family, job
- Job security
- Narrow minded about services
- Not taking a holistic approach to these issues
- No opportunities for educating others on existing programs
- Need for empowerment, enabled society is not willing to stand on their own when they can
- Buy-in from communities and investors
- Time and who leads the charge?
- Time to educate/turnover
- Rules and regulations, i.e. HIPPA

Next Steps

KDHE will use the information gathered at this meeting to inform efforts to improve the system of care for Children and Youth with Special Health Care Needs in Kansas. They plan to continue seeking information from families, communities, and system partners for the remaining domains in the National Standards in the Spring 2018.

Prepared by:



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Care Delivery

What are the most important strategies for improvement needed if Kansas is going to make progress on fully meeting these standards?

Health Coverage Providers (Insurers)

- Need to provide mentoring
- Empower families and decision makers
- Pharmaceutical companies work better with insurers and families
- State provides program planning/guidance as needed.
- Focus on Early Education/Prevention

Community Providers

- Simplify access to services
- Parent driven service offerings
- Adaptable services
- Navigators available as needed
- Provide evening and weekend hours.
- Share positive stories
- Be able to provide or connect families if language is a barrier

Families

- Family driven services
- Families having a voice and provided resources
- Family education on emergency planning

Program and Health Systems Planning

What are the most important changes needed if Kansas is going to make progress on fully meeting these standards?

Program and System Leadership

- Prioritize families
- Leaders attend system change meetings
- Make advisory board meetings more accessible/ local/ convenient time
- Provide feedback on what is going on currently

Community Networks

- Coordinate/collaborate existing groups to lessen the amount of meetings
- Coordinate feedback opportunities for families, rather than more surveys
- Develop more diverse family advisory councils, including legislators, insurers and funders

Navigators/Mentors

- Help families find their voice
- Help families advocate for their care.