Appendix D: State Plan Regional Meeting Summaries

Phase 1 Regional Meeting Summary Report, April 2016
Medical Home & Community-Based Services and Supports

Phase 2 Regional Meeting Summary Report, October 2016
Access to Care & Eligibility and Enrollment

Phase 3 Regional Meeting Summary Report, May 2017
Screening, Assessment and Referral & Transition to Adulthood

Phase 4 Regional Meeting Summary Report, September 2017
Family-Professional Partnerships and Insurance & Financing
Regional Meeting Report

for

KDHE Special Health Care Needs Program

April 2016
Introduction

The Kansas Department of Health and Environment Special Health Care Needs Program asked the Wichita State University Community Engagement Institute to assist them in hosting six (6) regional input meetings across the state of Kansas as part of their state planning process related to Systems Integration. These meetings were held between February 24 and April 19, 2016 in Topeka, Wichita, Pittsburg, Salina, Hoxie and Garden City.

Process Description

At each meeting, participants were given the opportunity to hear an overview of the Special Health Care Needs program and a brief overview of the National Standards for Systems of Care for Children and Youth with Special Health Care Needs as presented by Heather Smith, Director of Special Health Services at the Kansas Department of Health and Environment Bureau of Family Health. Following a question and answer period, participants were then asked to discuss four standards chosen from the Medical Home and Community Based Services and Supports domains. Discussion took place in small groups and was focused on three questions:

- What is working well?
- What is missing?
- Who else needs to be involved in helping Kansas meet this standard?

The results of these discussions are included below.

Executive Summary

Respite Care

Representatives from across the state reported that respite care, especially on an emergency basis, is a very limited resource that is primarily available to those children and youth receiving Behavioral Health services and/or Home-Community Based Services (HCBS) through the Medicaid Waivers. In areas where the services are available, there are few qualified providers. In the Western part of the state, participants reported that many families and communities have developed a natural support system of relatives and community activities such as Mom’s Day Out to provide temporary care for their children.

Home-Based Services

Participants across the state reported that there is an effective system of care for children under the age of three years and for older children who qualify for and receive HCBS Waiver services. This system includes infant-toddler services through the education system, home health care agencies (including Local Health Departments), early childhood home visiting programs, and providers within the disability services system.

There is a reported lack of funding streams to provide similar services to older children who are privately insured or ineligible for the Medicaid waivers. Several areas of the state report there is also a lack of qualified providers and it can be difficult for families to locate staff that they trust to care for their children at home. Participants in Northwest Kansas also reported that the relatively low and fluctuating number of children in the area who require these types of services make it difficult for programs to sustain themselves.

Pediatric Preventative and Primary Care

Providers and families from across the state reported that there is an effective network of providers from a variety of sectors that create a system of preventative care for children and their families. This system includes Local Health Departments, school and parish nursing, along with traditional health care providers. Many participants reported that screening is an available and helpful resource. Participants also cited state tracking systems such as WebIZ and EpiTrax as helping providers better identify and track local health issues and trends.
Transportation was reported as a significant barrier to accessing preventative care in every part of the state, even when the child has medical coverage. Additionally, participants reported that dental services are very limited for those children who are eligible for Medicaid or uninsured. In the more rural parts of the state, a lack of providers — especially those with pediatric training — was reported as an ongoing issue for families.

**Pediatric Specialty Care**

Specialty Clinics who provide mobile services or have satellite clinics across the state were reported to provide quality care to families who need them. However, scheduling is often a challenge and the opportunity is not available in all areas of the state.

Each region, including the more urban parts of the state, reported a limited number of specialty providers available in local areas and that families often have to travel to neighboring states to receive required care and access is limited by insurance restrictions and lack of transportation. Options for telemedicine are currently limited but seen as opportunities to improve access to care.

**Discussion Results**

| Health providers and plans have a system in place for ensuring timely referrals for families of Children and Youth with Special Health Care Needs with emergency respite needs. |

### Respite Care

**What’s working?**

**Topeka**
- We know that the service exists and is available but don’t know enough to know what is working.

**Wichita**
- Nothing
- Kids on waivers – however, not everything works
- Not a whole lot
- Was built in for SED children
- Concept of respite care
- Motivation and desire to provide the service
- On waiver – hire
- Some family members can be hired to do respite

**Salina**
- Ability to provide last minute breaks
- Respite houses for mental health

**Hoxie**
- Limited respite available for youth with behavioral health needs who are receiving community-based services from the CMHC but not in their home communities.

**Garden City**
- Starting of a referral process
- Primary providers
- Church groups – mom-to-mom
- For referral
  - RCDC
  - PAT
  - Head Start
  - KCSL
- Natural supports in place so respite is not used
- May utilize other programs such as camps, dances, etc.

**Pittsburg**
- The foundation has been laid for this
- Needs are defined
- Training and guidelines
- It’s an identified service
- Coordinated Resource Support Services (CRSS) in Parsons but difficult to access
What’s missing?

**Topeka**
- How to find the services
- Licensed? Regulated?
- Not caregiver/family friendly
- Timely access
- Is it accessible to all CYSHCN
- Education about respite care for caregiver/family
- How to contact
- Who is eligible?
- Where are they located?
- Capacity/providers available
- Help with children that don’t have special needs (i.e. siblings)
- Training for those who care for the children (all different types of disabilities)
- What’s defined as “emergency”?  
- Too many siloes
- Difficult to obtain
- Not timely
- More local awareness needed
- Need more communication between state and local
- More local providers need to be made aware
- Emergency care

**Pittsburg**
- Trust by family with quality of care
- Lack of provider availability
- Inconsistency
- Emergency respite
- Not accessible to those that do qualify
- Limits from resource families
- The service itself
- State general funds for respite
- Lack of programs or lack of awareness of available programs
- Not much consistency of available services across counties

**Salina**
- No available, trained respite caregivers (Pay rate, hours, burnout, private help)
- Not raising compassionate people who are engaging and understanding
- Meeting people where they are – don’t judge!
- Holistic care – diet, exercise
- Would like to see respite facilities spread across Kansas that can be used in extreme emergencies that would allow the child to stay there safely and well-cared for.
- Lack of providers
- Travel far to get service – don’t have transport vehicle or money
- Only identified individuals with special needs, i.e. Mental Health, can have the service
- Cut backs in finances have hurt ability to pay higher salary
- Limited certification criteria to prevent others from providing service
- Have to have specialty location

**Wichita**
- Everything – Funding and Training
- Training for medical needs – not everyone is equipped to deal with special needs
- Don’t know how to reach out to other entities
- Availability
- People – appropriate staff - to provide the service
- Coordination of care
- Global understanding
- Who can provide respite? Specialized skills
- How paid? Qualified to care – has the skills
- Number of providers is too small – poor pay

**Hoxie**
- Respite opportunities for kids with other special health care needs
- Not enough providers and not enough support for the ones that do exist. Supports that are needed include training, education, and funding to pay providers
- No short term respite (Mom’s Day Out, etc.)
Hoxie (cont.)
- Lack of knowledge on the part of providers. Few families want to take on the responsibility and the liability of caring for these kids.
- Transportation – access to and funding if they do have a car

Garden City
- Knowledge of this service:
  - What is it?
  - Who provides it?
  - Who qualifies?
  - Who to contact?
  - How does it work?
  - Who decides who is eligible?
  - How is it different from other possible supports and services?

Who needs to be involved to help Kansas meet this standard?

Topeka
- Providers
- Caregivers/families
- MCOs
- Medical professionals
- KDHE
- KDADS
- Insurance companies
- Mental Health providers

Pittsburg
- Recruitment and retention of providers
- Family
- State representatives for change
- MCOs
- Doctors
- All healthcare professionals
- HCBS providers
- Community health providers
- DCF
- Legislators

Wichita
- MCOs
- KDHE
- DCF
- Volunteers
- Medical students
- Social work students
- Nonprofits
- All payers
- The state
- Medical homes
- Entire team that includes multiple sectors/systems
- Collaboration involving the funding stream
- Parents advocate with legislators
- Providers interested in doing care

Salina
- Schools
- Educators
- Insurance Companies
- Employers (industry standard)
- Social Services (DCF)
- Faith based
- Elected officials
- Those involved in licensing standards and setting rates
- Providers
- Families/caregivers

- Partners to collaborate with
- Qualified respite providers
- Education of staff and families
- Families having problems finding the time to take a break
- Waiting list for SDSI services
- Unknown what services are available
- Funding
- Parents do not trust providers’ qualifications or the quality of service
Salina (cont.)
- Legislative support

Hoxie
- CMHCs
- Elected officials
- MCOs

Garden City
- KanCare Providers
- Waiver providers
- Schools/Special Ed/Nurses
- tiny-K programs
- Parents
- Nursing agencies
- Physicians
- DCF
- Foster care
- Case managers
- Mental health
- Qualified staff to assist MCOs
- Medical providers
- School nurses
- Churches
- Volunteers

**Home-Based Services**

| Home health care is a covered benefit for CYSHCN that includes health care for the child and supportive care for the family, and is provided in the family’s home by licensed professionals who have experience in pediatric care. |

**What’s working?**

**Topeka**
- Services from the Technology Assisted waiver

**Wichita**
- Some therapies for children under age 3 (but even that is limited)
- There is a program, a plan.
- Technology Assisted Waiver program
- Care coordination
- Discharge planning
- Durable Medical Equipment

**Pittsburg**
- Community services – mental health
- Home health
- Craig home health care
- Current providers are visible
- Providers doing outreach
- MCO case managers
- HCBS Providers

**Salina**
- If available, the services that are there are working (i.e. HCBS, TA Waiver)
- Are ok with waivers
- Mental health community based services – case management, ACP, Parent Support, therapy
- TARC – community based for IDD children/youth
- Infant/Toddler network is good

**Hoxie**
- Early Head Start home visiting
- Part C services for those who qualify
- Private home health care

**Garden City**
- RCDC/tiny-K therapies
- RCDC TCM
- Short-term home checks through hospitals following dismissal
- RCDC newborn follow-up
- Craig Home Care/Home health agencies
Garden City (cont.)
- Referrals to home health from MCOs
- Volunteers (Qualified)
- RCDC/Parents as Teachers
- Compass Mental Health
- Head Start
- SDSI
- Health Department home visits

What's missing?

Topeka
- Awareness
- No one is coordinating these services
- Does private insurance pay?
- Document medical necessity
- Uninsured – accessibility?
- Education on services
- Transportation/language barriers
- Not a provided service under most insurance companies
- Lack of providers
- People needing home based assistance that are not “technology” based or are not within the age criteria

Wichita
- Advocacy skills for parents
- Consistency in applying standards for eligibility
- Depth of services for people with multiple types of needs
- Adequate reimbursement
- SED – no training for parents
- Only certain things are covered or reimbursed
- Loss in funding to cover needs
- Only coverage for U.S. citizens
- Lack of qualified professionals to meet the need (ex: LPNs, health aides)
- Kids fall between the cracks – don’t meet eligibility. Waiver integration won’t expand eligibility just give a different model for service delivery.

Salina
- Patient centered collaboration
- Availability in rural areas
- MCOs – Kid Screen Coordinator program discontinued
- Overall integrative case management
- Better access for >21 years of age

Pittsburg
- Multi-training
- Continuity
- Consistency
- Hard to build trust and relationships
- Coordination of services
- Lack of provider to provider communication
- Pediatric experience
- Information about what is available
- Providers
- Lack of funding for non-waiver people/wait list
- Backup nurse shortage

SHCN Regional Meetings
February – April 2016
Salina (cont.)

- Stigma of getting help
- Cuts in services and providers limit quick access
- Turnover in case management and other providers
- Lack of information and knowledge
- Need case manager in various provider offices to connect to resources

Hoxie

- Providers/qualified staff. No one specializes in pediatrics.
- Population of children is declining and makes it difficult to sustain programs because there aren’t enough kids to serve.
- Families don’t want to apply for services due to feeling judged by service providers or treated poorly.

Who needs to be involved to help Kansas meet this standard?

Topeka

- Providers
- MCOs
- Private insurance
- Family/patient/caregivers
- KDADS
- KDHE
- Medical
- Medical Association
- Legislative support

Pittsburg

- Providers
- Family advocates
- Community partners
- State representatives
- Family involvement
- Physicians
- MCOs
- HCBS providers and CDDOs
- Legislators

Wichita

- Payers
- Nonprofits
- Medical community need be involved and educated
- MCOs
- KDHE
- DCF
- The State
- Students
- Providers
- Nurses
- Home health care companies

Garden City

- Home-based school (SpEd) services are very limited, if at all
- DME for home use
- Follow-up/monitoring
- Providers’ knowledge in pediatric care
- Qualified (or any) home caregivers
- Parents don’t know what is available
- Referral from local facilities and surrounding states
- Referrals from specific MCOs
- Staffing to provide services
- Specialized medicine – ENT, audiology, speech, PT, OT
- More information for services available
- Many local services disappear when child turn 3 years old – have to travel after that

Salina

- Local/regional/State elected officials
- Insurance companies
- Life planners
- Providers
- Health department
- Local physicians
Salina (cont.)
- Families/caregivers
- Legislative support

Hoxie
- Private home health
- Economic development folks to attract families and providers to the area
- Community support for health related issues

Garden City
- Part C & B providers (IDEA)
- Health Departments
- T/A Waiver providers
- KanCare
- Home health agencies
- Case managers
- Private health insurance companies
- Families
- Physicians
- Social Services/DCF
- Schools
- Community partners
- Volunteers

Pediatric Preventative and Primary Care

| All children, including CYSHCN, have access to medically necessary services to promote optimal growth and development, maintain and avert deterioration in functioning, and to prevent, detect, diagnose, treat, ameliorate, or palliate the effects of physical, genetic, congenital, developmental, behavioral, or mental conditions, injuries, or disabilities.

What’s working?

Topeka
- Private insurance paying 100% for preventative care
- Medicaid pay 100%
- It’s available if you have transportation and can pay for it

Wichita
- Most children have some form of health insurance
- MCOs have outcome data
- Increase in Medicaid eligibility
- Least restrictive environment – individualized homes and care
- Collaborative counsel
- Developmental screening – available programs
- Pediatric residency clinics a great help
- Safety net clinics

Pittsburg
- Immunizations require connect to care provider
- Screening process by medical providers and Head Start, WIC, Child Care
- For ALL children
- Standard of Care
- Community Health Center of Southeast Kansas
- Small amount of independent providers
- MCOs attempting to bridge the gap
- Some schools picking up slack
- Cherokee county Public Mental Health
- Spring River Mental Health
- Local and county health departments
- School screenings
- Early intervention services and preschool
- Local clinics
- Grant funding for projects
- CYSHCN program
- Dietitian
- Teachers
Salina
- Pediatricians
- Immunizations
- Screenings
- School nurses
- Parish nurses
- Rural health incentives
- Existing agencies do a good job
- Those covered by insurance of some sort
- Dental, spine, vision, hearing screens at schools
- All early childhood services (i.e. Parents as Teachers)
- KAN Be Healthy screenings

Hoxie
- Mandatory KBH (EPSDT) screens for clients with Medicaid
- Head Start helps make sure these screens are done.
- EpiTrax is notifying communities regarding lead warnings and allows providers access to supports to deal with the issue in their community
- Immunization programs

What’s missing?

Topeka
- Uninsured – no coverage
- Home based
- Coverage gap – dental
- Adequate time to treat SHCN patient
- Inconsistency in preventative care/secondary preventative access
- Not all medically necessary preventive care/service is covered
- Local pediatricians
- Communication between local and state
- Adequate diagnosis of issues, esp. epilepsy
- Adequate providers (especially specialists in mental health, genetics, epilepsy, and autism across the spectrum)

Garden City
- Kids who have pediatricians or Family practitioners usually get in and get care
- RCDC Health Steps/ECBG screening and referrals
- Health Departments refer, immunize, WIC (where available)
- School nurses
- KCSL screening and referral
- Medicaid payouts
- Newborn screening and hearing test
- Immunizations
- School collaborations
- Primary care physicians with pediatric specialty
- WebIZ
- Genesis program provides dental varnishes and exams
- Garden City County Health address cultural needs
- Schools promote health and oral care

Wichita
- Behavioral health – knowing when to access especially with dual diagnosis. When to access medical vs. mental health.
- Insurance covering preventative care
- Insurance paying for diagnostic care
- Medication coverage – limitations on medications
- Adequate Medicaid reimbursements to make physicians able to accept those patients (that leads to poor access to care)
- Parental understanding of the importance of preventative care.
- Lack of knowledge for parents as kids transition to adulthood
- Number of kids vs. Number of providers
- Insurance – either on Medicaid or can’t afford it
Wichita (cont.)

- Insurance company determines medical necessity – physicians order and insurance denies
- Special needs care at school
- Don’t have providers
- Know where we need to go, but not getting there
- Higher level of integration and consistency
- Trained professionals (pediatricians)
- Mental health
- Outside of Wichita and KC there are fewer options
- ER access when primary care not available
- Availability in rural areas

Pittsburg

- Mental health screenings not being used
- Provider availability
- Access to pediatricians
- Provider enrollment in MCOs
- MCO education for families
- Specialty Care availability
- Dental
- Mental health
- Telemedicine being able to bill
- Primary care providers in rural areas
- Funding
- County youth coalition involvement

Salina

- Copays
- Dental care
- Gaps
- Not enough providers
- Too quick to give meds, etc.
- Not enough mental health
- Funding
- Need more education
- Nutrition
- Activity
- Technology

Hoxie

- Resource for providers and knowledge of the resources that do exist
- Providers
- Someone to enforce standards. Head Start is often the one that is informing providers of the standards and it would help to have someone with more authority monitoring this.
- There is a disconnect between health care providers and social service providers

Garden City

- Dental – don’t see kids; don’t take Medicaid; not enough providers
- Education – parents knowing what’s available/where to go
- Transportation
- Not all counties provide WIC
- Shortage of access to appropriate mental and physical health
- Interpreters
- Private pay
- Deductibles for primary care is too high
- Failure to do required screens
- No continuity in medical paperwork/documents
- EPSDT forms are hard to use
- Caps on new Medicaid patients
- Primary Care Providers
- Timely appointments
- Dental – don’t take Medicaid and must travel if you need sedation
- Language barriers
Who needs to be involved to help Kansas meet this standard?

**Topeka**
- Providers
- Payers – private insurance/Medicaid
- Children
- Family/caregiver
- Could we do tele-medicine in rural areas to help kids get diagnosed?
- Mental health
- Specialty providers
- KDADS
- KDHE
- MCOs
- Legislative

**Salina**
- Insurance companies
- Elected officials
- Schools
- Educations
- Providers
- Colleges/Universities
- Towns/counties
- Case managers/care coordinators
- Doctors
- Families/caregivers
- Funders
- Legislative support

**Wichita**
- Payers
- Education system
- Providers
- Parents
- DCF
- Foster care
- MCOs
- State
- Students
- Team players with multiple disciplines with agreed upon goals and mission
- County Health Departments across the State
- Outreach from hospitals (Peds) to help rural areas – Residency Care programs, Family Practice, Peds

**Hoxie**
- Economic Development
- County Commissioners

**Garden City**
- Families
- Health departments
- Physicians/clinics
- Mental health
- RCDC (all programs)
- Schools
- Care coordinators at MCOs
- DCF
- Legislators
- Hospital recruiters
- Medicaid providers
- Oral health

**Pittsburg**
- Providers – all types
- MCOs
- Health Departments
- National organizations (American Pediatrics Association)
- Good nurses
- Families
- Legislators
- County youth coalitions
- Delta dental (grants and education)
**Pediatric Specialty Care**

Pediatric centers of care (e.g., cardiac, regional genetics, end stage renal disease, perinatal care, transplants, hematology/oncology, pulmonary, craniofacial, and neuromuscular) are available to CYSHCN and their families when needed.

**What’s working?**

**Topeka**
- Specialty clinic available that travel across the state
- It’s available if you have transportation and can pay for it
- KU specialty clinic – travel/mobile
- Telemedicine (but is it sufficient?) St. Jude’s
- Shriners
- Durable Medical Equipment (DME) financial assistance
- Specialty providers/hospitals in urban areas

**Salina**
- Some systems are available to some populations
- Good care when you get there
- Checks and balances for fraud
- The specialists who are out there do a great job
- Specialty clinics have a holistic/team approach to work with families
- Televideo when available works well, more funding is becoming available

**Wichita**
- It’s available, but has a long wait list and is often far from home. What we do have does work.
- Wesley is building a Children’s Hospital
- Recruiting more specialists
- More emphasis on pediatrics
- Awareness of integration
- Holistic view
- Specialty clinics and wheelchair clinic – SHCN program
- Children’s Mercy Hospital outreach in Wichita – increased access to specialists
- Family advocacy – Families Together
- KU Pediatric Subspecialty Clinics

**Pittsburg**
- Outreach specialty clinics
- KU Med
- Children’s Mercy
- Assistive technology in Parsons

**Hoxie**
- Telemedicine – at the Educational Service Center and High Plains Mental Health Center

**Garden City**
- RCDC helps with transportation, interpreters, and case management to coordinate appointments to get 0-5 families to Wichita, KC, etc.
- Ric Pierson/orthoptist monthly clinics at RCDC
- Pediatric cardiologist visits Garden City monthly
- Level 3 NICU in Garden City
- Doctors quickly make referrals
- Labs are done locally so family doesn’t have to travel as often
- Docs telecommute
- MCO pays travel
- Dominican Sisters of Presence provide interpreters
- Natural supports
What's missing?

Topeka
- Available geneticists
- Could we do tele-med in rural areas to help kid get diagnosed?
- Complicated process to be approved for DME
- Transportation/expense
- Lack of specialty doctors in Kansas
- Approval of specialty services across state lines
- Education to navigate the medical system
- Capacity – available, but not accessible. Can’t get in to see them, too busy or don’t see children. Garden City people go to Denver.
- Dual diagnosis – some go to Chicago
- Lack of providers – congenital orthopedic issues
- Training for key people – nurses, care coordinators, etc.

Wichita
- Reimbursements and lack of providers, especially rural.
- Good communication between specialists and between specialists and primary care doctors.
- Innovation – how to do more with what we already have.
- Timely access – long waits for appointment times.
- Recruiting to Kansas
- Not enough pediatric nurses or providers
- No program at WSU for Pediatric Nurse Practitioners
- 18 month waiting list
- No specialty care here – sent elsewhere
- Family penalized for care (where they live, etc.) Divorce rates high
- Chain reaction – families sent elsewhere, nurses have no work. Kids come back – have no support
- Lots to be done!
- Consistency throughout the State
- Logistics – locations, transportation
- Access for rural areas – outlying areas are without specialists
- Currently missing in Wichita but changing with Wesley Children’s Hospital
- CMH has more specialists

Pittsburg
- PCP involvement
- More providers
- Family support
- Medication costs
- Treatment costs
- Accessibility
- Communication between specialty providers
- Family choice for care/satisfaction
- MCO contracts
- Coinsurance costs
- Outreach programs
- More telemedicine
- Better communication network
- Travel assistance (non-emergency medical transport)
- Availability of specialists in rural areas
- KU Cerebral Palsy Clinic closed – lack of specialized clinics
- Funding
- Have to stay in state
- Training and education for school systems
- Sedation dentistry
- Insurance coverage

Salina
- Private insurance doesn’t help
- Consistency with standards
- Education
- Checks and balances for fraud
Salina (cont.)
- Not enough centers to provide care
- More incentives
- Board certified pediatric psychiatrists are few as well as other specialty docs
- Information about specialty
- Transportation to specialty service – cab can be far and costly
- Small clinics open doors to bring in specialist once a month
- Support to rural hospitals
- Funding to rural areas to bring specialist and technology

Hoxie
- Providers – though the need is very low in this region
- Better coordination when returning from NICUs out of state
- Advocacy for partnerships with other states

Who needs to be involved to help Kansas meet this standard?

Topeka
- Hospitals
- Medical schools
- School nurses
- Parents
- MCOs – Care Coordinator (training)
- Insurance companies
- KDADS
- KDHE

Wichita
- Telehealth
- Medical community needs training
- Universities
- Legislature for credentialing
- Local hospitals
- Payers
- Specialists
- Schools
- Home health companies
- MCOs
- Doctors

Garden City
- Wheelchair, CP, etc. clinics in SW KS
- All specialties are far away
- ER docs with peds knowledge
- MCO coverage for out of state care, emergency trips
- Facilities are 4-5 hours drive from western KS
- Staff in local facilities need specialty training
- No residing specialists
- Appropriate medical equipment in facilities to meet needs
- Limited knowledge of where to refer
- Financial assistance
- Behavioral health
- 24 hour or mobile clinics
- MCO paperwork is overwhelming for travel assistance

Pittsburg
- MCOs
- Providers
- Hospitals
- Family advocates
- Families
- Medical schools
- Schools

Salina
- More specialists
- Who trains? Should Military train specialized providers
- Major health care facilities
- Foundations (Cancer, Diabetes, Cardiac, Genetics)
- Insurance
Salina (cont.)
- Families/caregivers
- Providers
- Legislators

Hoxie
- NICU partners in border states and Texas (including Denver, CO and Carney, NE)

Garden City
- Practitioners from within the state and outside the state (KC, Denver)
- Families
- Legislators – scholarships and trusts to educate Nurse Practitioners
- Home health agencies
- Hospitals
- Doctors
- Insurance Companies
- Schools
- Health Departments
- MCOs
- Information Technology - Telemedicine

Prepared by:
KDHE Special Health Care Needs Program
Regional Community Input Sessions

Report
October 2016
Introduction
The Kansas Department of Health and Environment Special Health Care Needs (SHCN) Program hosted six (6) regional input meetings across the State of Kansas as part of their state planning process related to Systems Integration for Children and Youth with Special Health Care Needs. These meetings were held between August 25 and September 29, 2016 in Lawrence, Chanute, Hutchinson, Concordia, Garden City and Colby and engaged a total of 43 participants, including service providers and parents/families of children with special health care needs.

At each meeting, participants were given the opportunity to hear an overview of the Special Health Care Needs program and a brief overview of the National Standards for Systems of Care for Children and Youth with Special Health Care Needs as presented by Kayzy Bigler, Special Health Care Needs Program Manager at the Kansas Department of Health and Environment Bureau of Family Health. Following a question and answer period, participants were asked to discuss standards from within the Access to Care and Eligibility and Enrollment domains of the National Standards. Responses from these discussions are highlighted in this Executive Summary followed by detailed results of the discussions.

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.

Stakeholders from across the state reported that access to all types of care is better in urban centers than in rural parts of the state. Even in urban centers, there may be existing providers, but growing wait lists make timely access an issue. Access to care is limited for those children who are uninsured or covered by Medicaid due to an increasing lack of providers who will serve these populations or are not qualified to do so. Concern about Medicaid reimbursement rates was a common theme with regard to access to care for the Medicaid population. Many also reported that access to care is inhibited by the lack of knowledge – on the part of parents and providers – regarding the resources that do exist in their particular area of the state and beyond. Across the state, particularly in rural areas, providers across systems are continually working to find new ways to partner to increase opportunities for children and families to receive the care they need closer to home. Participants report that new state regulations
have helped increase access by allowing Advanced Practice Registered Nurses to provide care, where other changes have reduced access to ancillary services such as Physical Therapy. For all areas of the state, transportation continues to be one of the larger barriers to families accessing care. Transportation systems that are in place for Medicaid patients are reported to work well when they work but there are frequent failures within the system that result in patients missing appointments and even being “fired” by providers due to lack of attendance.

Overwhelmingly, across the state, participants reported that parents who are persistent and supported in their efforts to obtain quality care for their children are the most successful, despite the many barriers placed in front of them. Ultimately, positive relationships between providers and families – as well as those among the providers themselves – are a key component of successful care.

**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, enrollment 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.

Across the state, parents and providers reported that accessing insurance coverage is easier when there is a local person who can assist in processing applications and navigating the challenges of paperwork and bureaucratic processes. While wait lists for processing KanCare applications are increasing, some point to this as a sign that awareness of the program is increasing and more families are seeking coverage. Federally Qualified Health Centers, Safety Net Clinics, and healthcare-related ministries are working diligently to reach out to families who need coverage regardless of their ability to pay, despite limited human and financial resources. Participants reported the most significant barrier they experience is inconsistent rules among all types of insurance providers and inconsistent interpretation and implementation of policies within individual insurers. This is a particular challenge when families need to change insurer for any variety of reasons.

As with the Access to Care Domain, participants felt that patience and persistence were key to being successful in getting adequate coverage for care. One widely-held perception among those who attended the regional meetings was that insurers will automatically deny claims (as a matter of policy) only to reverse the decision later, when pressed. It was also again noted that building positive relationships among families and the providers they encounter strongly influences patient care.
Next Steps

Information from these regional meetings will be combined with results from a statewide survey of service providers and families that measured their perceptions of Kansas’ current ability to meet the Standards for Systems of Care. (The content, methods, and results of this survey are published separately.) This data will be used as a part of a facilitated planning process to advance the process statewide for developing a comprehensive system of care in Kansas.
**Access to Care**

**Introduction**

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.

**Large Group Discussion**

Following a brief overview of the standards, participants were asked the following questions:

**What evidence do we have that the State of Kansas is meeting these standards?**

**Lawrence**

- Families able to pick provider
- Transportation covered by KanCare
- Some systems/communities operate well (others do not)
- Urban centers in general mean more access, choice, transportation
- Providers have incentive to meet prior authorization

**Chanute**

- Good communication between the YMCA and schools in the area to work out accommodations for CYSHCN
- Received funding to support CYSHCN to attend camps

**Hutchinson**

- More urban areas have increased access
- Access with traditional insurance (timely authorization)
- Medicaid appears to meet needs on paper
- New Children’s Hospital has attracted new providers/specialists
- Open mindedness to creatively meet needs
- Families excited about new providers closer to home
Concordia
• Detailed IFSP/IEPs
• MCOs measure timely access
• Developmental Disability Reform Act protects rights, single point of entry, referral, geographic access

Garden City
• Lakin Hospital providing care to new patients
• APRNs providing care
• Some new PT rehab
• Good access to services for children under 5 years old
• Lakin providing pediatric PT
• Schools contract with hospital to meet mandates for therapies
• Home health nursing

What evidence do we have that the State of Kansas is not meeting these standards?

Lawrence
• Only x number of Medicaid doctors. Not an adequate network. Big list of providers but each one limits number served
• Amerigroup requires contract for one child in some cases – no longer partners with Children’s Mercy
• Lack of consumers knowing transportation is available
• Stories repeated of transportation not reliable, especially out west
• Traveling families from rural Kansas compete for Medicaid slots with providers in urban Kansas
• Waiting lists
• Need to look practice-to-practice (or to hospitals) for data about waiting lists if we want evidence that we’re meeting the standard
• Support for research is going away – tends to focus on individual providers, not a global look
• Specialty clinics not working for families of children with complex medical needs

Chanute
• Often experience conflicts between the needs of the child and child care licensing standards
• Staff in after school programs are not well trained in working with CYSHCN
• Documented immigration status is a barrier
• Parents often don’t know where to start to get help

Colby
• Programs exist- ITS, pediatric clinic
• Few dental providers
• Have level 2 NICU
• Pediatric wing at the hospital
• Wheelchair clinic in Hays
• Small county hospitals trying to meet needs

Hutchinson
• West and Southeast KS have much travel
• Challenges with CMS regulations and telemedicine - Prevents provider payment
• Prior authorization process is slow after service starts – risky. All 3rd party insurance
• Forced to work with providers they aren’t familiar with
• Timeliness is an issue as kids develop and needs change
• Competing needs for families
• Barriers create more challenges later
• Medicaid reimbursement reduction limits providers and that limits choice
• Fewer providers can mean no service
• Families give up without support especially when transient, etc.

Concordia
• Rural access
• Access to dental care & sedation dentistry
• Children’s hospitals
• Some providers weary of scheduling appointments due to slow reimbursement
• Lack of qualified Physical/Occupational/Speech Language Therapy professionals
• Schools
• Workforce
• Credentialing
• Telemedicine doesn’t meet access need
• Especially mental health
• Foster care lacks coordination
### Garden City
- Geographic access not met for all of the state
- Rumor is that hospital not recruiting new MDs
- Some clinics not accepting Medicaid or self-paid
- Lack of pediatric training
- Mental health services - long wait, infrequent appointments
- Schools not offering PT
- Most dentists don’t accept Medicaid
- Genesis dental screening/varnish in schools
  - Fluoride in water
- Genesis taking Medicaid and other services too
- Pediatric cardiologist once a month
- Pediatric neurologist in KC
- Wichita has 2 doctors who specialize in developmental disabilities

### Colby
- Low access to a few providers, reimbursement rates
- tiny-K struggles with staffing
- Limited MH - low communication between partners
- Foster care communication
- Need better notice
- Lack of transportation
- Employer resistance
- Change in Prescription stepdown legislation
- PT now requires PhD to practice

### Individual Reflections
Participants were asked to personally reflect on what they do as an individual or organization to help meet these standards and what is holding them back from being successful.

<table>
<thead>
<tr>
<th>Lawrence</th>
<th>Colby</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What do you do to help meet these standards?</strong></td>
<td><strong>What’s holding you back from meeting these standards?</strong></td>
</tr>
<tr>
<td>Provide families information about SHCN</td>
<td>Lack of knowledge of resources outside of area</td>
</tr>
<tr>
<td>Assist families with arranging transportation</td>
<td></td>
</tr>
<tr>
<td>Identifying MH providers in proximity of patient homes and eligibility requirements</td>
<td></td>
</tr>
<tr>
<td>Staying informed</td>
<td></td>
</tr>
<tr>
<td>Complying with our sons medical team’s recommendations, treatment and Plan of Care (POC)</td>
<td></td>
</tr>
<tr>
<td>Driving multiple times per year for lab draws &amp; appointments that are not available in Topeka</td>
<td></td>
</tr>
<tr>
<td>Driving long distances</td>
<td>Long waiting lists</td>
</tr>
<tr>
<td>Working with people I don’t like</td>
<td>Insurance referrals</td>
</tr>
<tr>
<td>Seek support to educate myself through school, CDDO, MCO etc. about systems of care</td>
<td>Time, single parent, financial struggle, care of other family members</td>
</tr>
<tr>
<td>Support parents to find resources</td>
<td>Cuts in funding, limitations to meet billable criteria</td>
</tr>
<tr>
<td>Educate myself</td>
<td></td>
</tr>
<tr>
<td>Be informed</td>
<td>Burn out</td>
</tr>
<tr>
<td>Advocate</td>
<td></td>
</tr>
<tr>
<td>People call me when they have trouble knowing other options</td>
<td></td>
</tr>
<tr>
<td>I can call contacts/leaders within by organization to ask for help resolving issues</td>
<td></td>
</tr>
<tr>
<td>Create resource lists</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SHCN Regional Meetings  
February - April 2016
<table>
<thead>
<tr>
<th><strong>Chanute</strong></th>
<th><strong>Hutchinson</strong></th>
</tr>
</thead>
</table>
| - Advocate for families  
- Research what community resources are available  
- Provide timely response to identified and suspected disabilities and disorders and access to team of providers  
- Inform consumers of dental providers who accept Medicaid/KanCare  
- Inform/convince dental providers of the NEED to accept Medicaid/KanCare consumers in their practice  
- Educate members on resources available & how to navigate the system  
- Being able to support families as they troubleshoot complex systems and navigate confusing waters is helpful  
- Case manage those on SHCN – work to get services necessary for members  
- Educate members on resources available and how to navigate the system  
- Assure choice of providers, services, etc. is known  
- Access Interpreter services, provide regular education to staff regarding how to access etc.  
- Be available & assist when authorization issues present  
- Helping share information that makes access possible for others  
- Listening to what others are doing or experiencing  | - State policies and managed care organizations that are not child of family centered but focused on dollar amount  
- Parents & physician ID later rather than earlier  
- Follow through  
- Belief there is a problem  
- Motivation to respond  
- Inconsistency across the state in services offered/provided  
- Member willingness to follow through on necessary care  
- Population & geographic challenges (Western KS, SE KS)  
- Borderline cities & higher reimbursement rates in MO, NE, & CO approved by state legislature  
- Not understanding how the system works  |
| **Chanute** | **Hutchinson** |
| *Only one participant – not discussed* | - Programs don’t know what questions to ask. Could benefit from SHCN training.  
- Not sure how to get telemedicine started in my area  
- No one in my community communicates about physician recruitment  
- Access to families as well as resources available  
- Scheduling limitations for timeliness  
- Reimbursement rates have not increased since 2008 for home nursing services. This prevents staffing and creative service provision in all areas  
- Having up to date information statewide for families  |  

**Chanute**

**Hutchinson**

- Advocate for families  
- Ability to help recruit physicians/dentists  
- Ability to offer Telemedicine services with proper TA support  
- Serve as a safety net for immunizations/minimal health care  
- Remote services for families to access care  
- Provide location, services, advocacy, staff, and support to metro and rural area families to promote access to care  
- We share information with parents & child care providers when available about health care options, resources etc.  
- Referrals to doctors who are flexible  
- Looking for resources from families who have seen a need and created something  
- Resources  
- Partners  
- Not enough choices on specialty doctors  
- Location?  
- Specialty hospitals
<table>
<thead>
<tr>
<th><strong>Authorization</strong></th>
<th><strong>Easy communication</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Provide care in rural areas of the state</td>
<td>• Due mostly to low Medicaid reimbursement, we have a difficult time finding caregivers. We have many children who need care but no one available for them</td>
</tr>
<tr>
<td>• Awareness for staff who work directly with families</td>
<td>• Regulations</td>
</tr>
<tr>
<td>• Keeping apprised of the changing state and federal regulations</td>
<td>• Lack of payment for provided services</td>
</tr>
<tr>
<td>• Seek funding</td>
<td>• The service delivery system is ever-changing so what did work might not work this time</td>
</tr>
</tbody>
</table>

**Concordia**

<table>
<thead>
<tr>
<th><strong>Education providers</strong></th>
<th><strong>Insurance providers</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Insurance providers</td>
<td>• Insurance #1 - not all self-funded insurance required to have special needs riders. Autism in particular. Most states require it.</td>
</tr>
<tr>
<td>• Funding in rural areas</td>
<td>• Rural access</td>
</tr>
<tr>
<td>• Searching for state funding</td>
<td>• Finding people to listen</td>
</tr>
<tr>
<td>• Talked to many people- no help</td>
<td>• Lack of options</td>
</tr>
<tr>
<td>• Help meet it by providing choice and options counseling; information and referral</td>
<td>• Poor/inadequate array of services for children w/ autism.</td>
</tr>
<tr>
<td>• Provide referrals for individual services for those that need it.</td>
<td>• Fragmented systems of care- hard to keep up with all the available resources &amp; where</td>
</tr>
<tr>
<td>• Seek out referral services</td>
<td>• Waiting lists</td>
</tr>
<tr>
<td>• Come to meetings like this to learn and ensure parents voices are heard</td>
<td>• No coordination of service providers. Expends a lot of time/effort to locate resources for individuals</td>
</tr>
<tr>
<td>• Educating myself- networking with other parents- where do they get care- on line what providers are out there</td>
<td>• Our area lacks children’s services for all needs</td>
</tr>
<tr>
<td>• Information about providers</td>
<td>• Specialty services in our areas</td>
</tr>
<tr>
<td>• PPO limitations</td>
<td>• Training provider for special needs</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Work for an organization</strong></th>
<th><strong>Knowledgeable about care needed</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Give info &amp; referral to organizations / individuals</td>
<td>• Grant money- not enough</td>
</tr>
<tr>
<td>• Advocate for people’s rights- disability</td>
<td>• Fact that Kansas hasn’t taken Medicaid funding from federal government</td>
</tr>
<tr>
<td>• Vote</td>
<td>• Not training enough people- lack of coordination between schools (universities) and agencies</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Helping families with known resources</strong></th>
<th><strong>Not knowing all resources available</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Working to get telehealth available- it would be helpful</td>
<td>• Residential/housing placement</td>
</tr>
<tr>
<td>• Attend community meetings to learn more about agencies- networking.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Promote programs and hire qualified service providers to meet the needs of students</strong></th>
<th><strong>Lack of qualified professionals in Kansas</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Work with parents as a team to access and implement services</td>
<td>• Finances (lack of)</td>
</tr>
</tbody>
</table>
**Garden City**

- Offer 100-mile coverage area
- Parents have the say in the days & times that they need. We accommodate as we have the staffing
- We refer parents to providers so we gather information about the providers in our region. This may be physicians, behavioral health specialists, TeleMed access, people who transport, etc.
- Coordinate appointments/transportation within local to out of county care
- Be the middle person care management for those non-English speaking families
- Assist families in making appointments
- Schedule transportation through KanCare
- Help facilitate PA process with doctor
- Find a doctor to help client (*Not very knowledgeable of this at this time- but am working on it)
- Family services coordinator
- Help families fill out paperwork
- Call to locate providers:
  - Dental
  - Doctor
  - Mental health services, etc.
- We refer parents to providers so we gather information about the providers in our region. This may be physicians, behavioral health specialist, TeleMed access, people who transport, etc.
- Our lists become outdated. Providers quit, move, are no longer covered, change jobs, etc. We don’t know everybody & everything
- At times ability to assist family due to case load/last minute appointments
- Transportation for those families who don’t have KanCare
- Transportation is not always reliable
- Finances- families cancel due to $
- Knowledge and understanding of where to go for answers. This will come with time & experience
- Slow process for KanCare applications
- Lack of providers
- Lack of providers willing to take KanCare
- Transportation- KanCare
  - Patient fired from dental services because KanCare ride didn’t pick them up
- MCO does not agree/authorize
- Distance between families and providers in areas, especially counties west of Hays
- Lack of increase in funding, especially within state for programs- not increased since 2008
- Difficult to locate qualified staff for local area
- So many services denied that after a while it is difficult to know where to go next
- Western Kansas travel and lack of professional resources (specialists)
- Funding
- Find providers/staff
- Overload- so much work to do and not enough players & time to address
- Feel like we are swimming upstream
- Lack of providers and choices of providers

**Colby**

- Work with the MCOs to get authorization for out-of-area services
- Explore options with other organizations for assistance- home modifications, transportation services, etc.
- We provide diagnosis
- Know where resources are in the region & state
- We provide evaluation and therapeutic services for children birth to age 3 - no cost to families- provide professionals in pediatric- ECSE, PT, OT, SLP, RN
- We provide early prenatal information and care to families with newborns
- Advise families & individuals other avenues they can access for help or giving the info for them to know who to contact if I can’t/don’t know the answer
- Access local resources for families
- Assist with IEPs, meetings, etc.
- We provide diagnosis
- Know where resources are in the region & state
- We provide evaluation and therapeutic services for children birth to age 3 - no cost to families- provide professionals in pediatric- ECSE, PT, OT, SLP, RN
- We provide early prenatal information and care to families with newborns
- Advise families & individuals other avenues they can access for help or giving the info for them to know who to contact if I can’t/don’t know the answer
- Access local resources for families
- Assist with IEPs, meetings, etc.
Small Group Discussion

After a short discussion in small groups about their above reflections, participants were then asked to consider to additional questions:

Do you know anyone who is frequently able to successfully overcome barriers related to these standards and if so, what are they doing?

Lawrence
- Strong parents – don’t take no for an answer
- Parents who serve on advisory boards
- Parents who use list-serves to stay knowledgeable
- Amerigroup staff – organization, team work, follow through
- Parents – who are persistent and ask questions
- Providers – working with challenging people

Chanute
- Parents – persistence

Hutchinson
- Child Care Aware reaches a large number of parents
- Parents that can be persistent, aggressive advocate for their child – maybe doesn’t always “win,” but makes presence known
- Specific diagnoses get better opportunities
- Work outside system rather than struggle to access the system (going to a church group)
- Learn to “work the system” keep working and working
- Relationships – keep working, build network of relationships (before you need them)

Concordia
- Persistence
  - Seeking resources
  - On the phone
- Find an advocate
- Collaborating with others
- Identify & develop new resources
  - Grant and private sources, policy resources
- Think outside the box
- Advocate for change

Garden City
- Advocates who develop relationships with physicians
- Families who have pediatricians: tend to have better success
- Relationships between primary care and specialists – quicker to refer
- RCDC: provide training outside the city - it builds new relationships and familiarity
- Families with private insurance sometimes have better access (because of authorization)
- Ministry does good outreach and bilingual. Presence in the community. Gap filling
- Persistent, faith-based organizations. Goal to help people, listening to clients and where the needs are. Meeting people where they are

Colby
- Families Together helps overcome barriers within the school system by being an advocate for families and are still located in the region.
- Partnering with other organizations to maximize funding that is available.
- Families that do well are the ones that have the ability to pay for transportation to get where they need and have the ability to be away from work.
- Some health care providers in the area that know what kids need and get them referred fairly quickly. They are willing to help facilitate the referrals which may be faster than a parent calling in.
- Hays Children’s Center has been able to partner with local elected officials to advocate for funding support.
- Families that have education and resources that come together to form parent support groups and using their voice. Often these families have strong support networks that allow them to do the work. (But get tired bearing the responsibility)
What additional ideas do you have for possible strategies for meeting the standards?

**Lawrence**
- Find a support person
- Call MCO or Insurance
- Educate PCPs on more holistic models
- Checklists of needs
- Early identification
- Parent awareness
- Provider buy-in
- Knowledge of risk factors
- Reimbursement rates
- Telemedicine
- Web-based workshops for providers

**Chanute**
- Persistence is key – can’t give up when trying to get access. Many parents get defeated and stop trying.
- Programs should accept information from families as they are the experts on their child.

**Hutchinson**
- One stop care (CP Clinic) all-inclusive, holistic approach
- Take services to the family, not the family to them (Part C)
- Hybrid healthcare
- Telemedicine
- Specialty Med – hybrid home specialist
- Educate the payer sources to make more informed decisions
- Consistency with MCOs is important
- Common language – understandable guidelines
- Educating family, providers, MCOs, state agencies, CDDOs
- Tele-health reimbursable
- Increase rates
- Pay for services

**Concordia**
- Funds to fill gaps
  - Medicaid expansion
  - Avoid 4% rate cut to KanCare providers
  - School funding
- Public awareness
  - Resources available- information and referral
  - Tell the story- the benefit to kids/families
- Gather data: regarding need for access
- Be specific in advocacy
  - What you need/want
  - Why you want it
  - How much it will cost

**Garden City**
- They will see anyone regardless of type of insurance or ability to pay. Sliding scale
- FCHD maternal and child health, make resources available like WIC. Changed to more accessible hours.
- Home based services is a strategy to increase access
- All HDs provide gap filling services (screening, KBH, immunizations etc.)

**Colby**
- Advocacy at the state and federal levels for adequate funding and support.
- Engaging families in advocacy efforts
- State needs to be adequately taxed so that funds are available and are used for their original intent.
- Need to open ability to practice for PT, OT, SLP Assistants – or resources to contract with Registered PTs who can supervise the aides
- Transportation funding for providers – travel time is not reimbursable.
- Create opportunities to fill staffing vacancies.
- Increase reimbursement rates so that we can keep providers that we have.

---

### Eligibility and Enrollment

**Introduction**

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, eligibility and enrollment 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.

**Large Group Discussion**

Following a brief overview of the standards, participants were asked the following questions:

**What evidence do we have that the State of Kansas is meeting these standards?**

**Lawrence**
- Transition: discussions beginning 6-12 months before aging out of eligibility – comes from payer/MCO side
- Navigation: Providers (e.g. Children’s Mercy) make good referrals
- Tiny-K assists in “all of the above” related to eligibility and enrollment
- Peer support/holistic approaches
- Access to medical Home model – want this
- Several places in which young children identified

**Chanute**
*Participant reported no experience in this area*

**Hutchinson**
- Providers help families walk through the process (helps us get paid) Best interest for all
- Lot of talk at local and state level = increased awareness (but not progress)
- Caseloads and wait lists are increasing
- Increased education from employers re options. HR offices an ally
- Occasionally have MCO staff who are effective and explain things well

**Concordia**
- Transfer of services between CDDOs
- Military- access to TriCare Echo for those moving into the state
- Waiting list for services shows that outreach is happening
- All pregnant women w/o insurance qualify for KanCare
- Babies are automatically covered for 60 days after birth
- Good communication- families are accessing KanCare
- Transition planning for students with IEPs includes applying for services/KanCare
- Excellent navigators to help apply for KanCare

**Garden City**
- New applications can be processed locally
- KDHE KanCare staff out stationed in other cities
- KanCare navigators placed ACA Marketplace
- Cover Kansas hosting local activities
- Every delivery gets a visit from a navigator
- Navigators doing both ACA & KanCare
- Dominican hospital used to pay premium if there’s going to be a gap/lapse
Garden City (cont.)
- HCBS Waiver case managers help navigate continuity of care
- Amerigroup helps with events
- Sunflower social worker has started
- Amerigroup focuses on transition with teens
- Johnny Appleseed reaching out for advocacy stories

What evidence do we have that the State of Kansas is not meeting these standards?

Lawrence
- If someone loses coverage, few are there to “pick up the ball” – “not my job”
- School districts not using IEP process to create transition plans – missed opportunity
- We experience “disdain”
- I am doing administrative work – don’t get help with navigation
- For families, this is overwhelming, especially in culture that resist asking for help
- Payers have a “policy” to deny three times
- Advocates/families get exhausted
- Do not have access any more to medical home
- Must visits healthcare.gov, see a certified certifier before going to a safety net clinic
- Safety net clinics do not always give you access to preferred doctor
- Though some insurance companies provide extra navigators for families of CYSHCN, not all are and not all families know to ask
- Lack of communication about exceptions that limit services (e.g. Transportation limitations not communicated)
- Outreach reduces after age 5

Chanute
Participant reported no experience in this area

Hutchinson
- Frequently caught in a loop for info – passing the buck
- Process is so lengthy and complicated that folks give up of drop out
- Inconsistent interpretation and implementation internal and external

Colby
- ITS talks about this with families, also hospitals are doing this
- Many families have insurance
- Good partnership w/ UTDS- Healthy Start
- Sound Beginnings helps identify families
- FQHC available to serve all despite $$
- Providers we have are good, want to help, passion

Concordia
- Lack of communication- families don’t apply for continued coverage (KanCare)
- Insurance companies don’t always educate families about resources and coverage they’re eligible for
- Lack of understanding – how to deal with non-citizens
- KanCare
  o Backlog of applications/renewal applications
  o Easy to inadvertently lose coverage
  o Applications denied the first time
- Applications denied due to small errors

Garden City
- MCOs not as visible as they used to be
- Communication breakdown when family chooses a different provider
- Inconsistent info from insurers

Colby
- Many families in coverage gap- less exp. To pay penalty
- Families don’t understand mail they get
- MCO policy change that families can’t automatically switch MCOS if doctor drops contract
- Clearinghouse delay
- KMAP system not upgraded to access
# Individual Reflections

Participants were asked to personally reflect on how they do as an individual or organization to help meet these standards and what is holding them back from being successful.

<table>
<thead>
<tr>
<th>What do you do to help meet these standards?</th>
<th>What’s holding you back from meeting these standards?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lawrence</strong></td>
<td></td>
</tr>
<tr>
<td>• Ask about insurance status of families</td>
<td>• I feel within my scope of expertise, I’m doing what I can</td>
</tr>
<tr>
<td>• Carry KanCare apps to outstation locations</td>
<td></td>
</tr>
<tr>
<td>• Carry SHCN apps to outstation locations</td>
<td></td>
</tr>
<tr>
<td>• Maintain current list of safety net clinics</td>
<td></td>
</tr>
<tr>
<td>• I have insurance however there is a gap – our insurance does not cover PKU nutrition which is a medical necessity and we do not qualify for significant assistance with KDHE-C SHN. This needs to be addressed for future PKU families.</td>
<td>• PKU families having to pay out of pocket for medical coverage</td>
</tr>
<tr>
<td>• My own care coordination</td>
<td>• It’s time for the system to look at how other states cover PKU individuals from birth to death regardless of income! States that have a great policy (NE, AK, WI)</td>
</tr>
<tr>
<td>• I have insurance</td>
<td></td>
</tr>
<tr>
<td>• Educate self</td>
<td>• Spending so much time calling and navigating said insurance</td>
</tr>
<tr>
<td>• Find peers to learn from</td>
<td>• Paying for that insurance 😔</td>
</tr>
<tr>
<td>• Request help from current providers</td>
<td></td>
</tr>
<tr>
<td>• Organize/file</td>
<td></td>
</tr>
<tr>
<td>• Make contact lists</td>
<td></td>
</tr>
<tr>
<td>• Understand requirements clearly to ensure passing accurate info that doesn’t mislead families</td>
<td></td>
</tr>
<tr>
<td>• Advocate as needed</td>
<td></td>
</tr>
<tr>
<td>• Learn all I can about family</td>
<td></td>
</tr>
<tr>
<td>• Assess and list specific needs of family &amp; prioritize them with family</td>
<td></td>
</tr>
<tr>
<td>• Be informed</td>
<td>• Limited outreach</td>
</tr>
<tr>
<td>• Provided education to staff to understand screening/enrolling in HealthCare.gov</td>
<td>• Wear lots of hats – don’t always focus on eligibility/enrollment</td>
</tr>
<tr>
<td>• Proactively reach out to SHCN agencies to request communication when changes in services occur</td>
<td></td>
</tr>
<tr>
<td>• Challenge state to improve</td>
<td></td>
</tr>
<tr>
<td>• Explaining Services</td>
<td></td>
</tr>
<tr>
<td>• Education</td>
<td>• Accurate info</td>
</tr>
<tr>
<td>• Ask Questions</td>
<td>• Current info</td>
</tr>
<tr>
<td>• Forwarding eligibility issues up when there seems to be an error in coding to KDHE</td>
<td>• Knowing how whole system works</td>
</tr>
<tr>
<td>• Working with providers and educating on waiver access</td>
<td>• Continuity</td>
</tr>
<tr>
<td>• Educating team regarding avenues for families to correct eligibility</td>
<td></td>
</tr>
<tr>
<td>Chanute</td>
<td>Hutchinson</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Participating in trainings re: eligibility</strong></td>
<td><strong>Knowing current resources</strong></td>
</tr>
<tr>
<td><strong>We have eligibility standards for our program that we conform to</strong></td>
<td><strong>Transitions plans to Part B services</strong></td>
</tr>
<tr>
<td><strong>Knowledge of current resources</strong></td>
<td><strong>Outreach efforts to early ID kids</strong></td>
</tr>
<tr>
<td><strong>Transition plans to part B services</strong></td>
<td><strong>Changing tools/measurement</strong></td>
</tr>
<tr>
<td><strong>Outreach efforts to early ID kids</strong></td>
<td><strong>$ and more providers</strong></td>
</tr>
<tr>
<td><strong>We strive to educate consumers on the availability of dental coverage in Medicaid/KanCare for children</strong></td>
<td><strong>Change in eligibility to Part B (hearing loss not automatic qualifier -- IS in Part C for example)</strong></td>
</tr>
<tr>
<td><strong>Arrange my time to be able to make the calls needed to insurance co, etc.</strong></td>
<td><strong>Lack of resources - funding</strong></td>
</tr>
<tr>
<td><strong>Remind families to prepare for transitions as early as they can to avoid excess pressure of time crunch</strong></td>
<td><strong>It’s an exhausting process that is time-consuming and frustrating because I can’t connect with insurance during work hours</strong></td>
</tr>
<tr>
<td><strong>Tracking the information I do have access to and sharing it</strong></td>
<td><strong>Not knowing options for certain ages, needs, or locations</strong></td>
</tr>
<tr>
<td><strong>MCOs outreach to members attempt to facilitate services</strong></td>
<td><strong>Lack of communication</strong></td>
</tr>
<tr>
<td><strong>Member willingness to participate</strong></td>
<td><strong>Member engagement</strong></td>
</tr>
</tbody>
</table>

**Chanute**  
*Participant reported no experience in this area*

**Hutchinson**

- Offering assistance with paperwork to try and get enrolled in MCO
- Offering to call insurance company to check eligibility for coverage on certain services
- Employers provide access information
- Let families and child care providers know about insurance option through net resource center and with net wellness program
- Educate myself and others
- Reach out to resources when I don’t know
- Our team will assist our families to ensure they are able to apply – usually Medicaid
- Inform staff and families of resources and rights
- Contract with public and private insurance for payment of services
- Sending families to local providers of navigation, CDDOs etc. for info on enrollment
- Clients not enrolling in insurance programs
- System is confusing for families to navigate
- Make sure more child care provider know and share the information with their parents
- Mean people
- Even when we try to help the families, we often can’t figure out how to navigate it either
- Regulations
- Complex system
- Inconsistent messages from providers of navigation
- Waiting lists frustrate families and providers

**Concordia**

- Contacted local representatives
- Contacted the state
- Talked to the school district
- CDDO services as a navigator to help peoples access and maintain public insurance coverage
- I work to inform people of the benefits of insurance/Medicaid briefs to help people navigate the systems
- No- feedback or minimal feedback
- Insurance or no way to add rider for special needs
- Procedural changes made at state level which are not well communicated to the local level
- Each insurance is vastly different for each individual
- Not having enough resources
- I look for resources that inform people to better understand their current insurance

- Pay for services myself
- Use a cost sharing program

- Asking speakers to peer support/ learning how to navigate the system
- Advocating
- Recommending disability rights
- Talks/speaking on ACH act and public/private insurance options

- If online application automatically denied, why have online application?
- Unaware of what is available & how to access it
- Need catastrophic healthcare safety net

- Time & money
- Consolidating/ what services do what services coordinate service providers
- Learn what is available without competition with other agencies
  - For example- the organization I work for doesn’t want us to recommend a “competing for grant money” other organization.

- Not very familiar w/ all insurance guidelines, programs, protocols, polices/procedures

<table>
<thead>
<tr>
<th>Garden City</th>
</tr>
</thead>
<tbody>
<tr>
<td>- We do not really provide services but we let families know about providers and events through our Monday Memo, flyers, &amp; emails. We partner w/ Cover KS to get this info to provide</td>
</tr>
<tr>
<td>- Provide families with information regarding the options</td>
</tr>
<tr>
<td>- Direct families to appropriate agencies</td>
</tr>
<tr>
<td>- Direct families to KDHE- Outreach to fill out KanCare application</td>
</tr>
<tr>
<td>- Assist families in applying for SSI (will help get insurance coverage)</td>
</tr>
<tr>
<td>- Assist clients with KanCare application and navigation (Marketplace) application</td>
</tr>
<tr>
<td>- Make phone calls to KanCare regarding letters-questions clients may have</td>
</tr>
<tr>
<td>- Parents report lack of follow through from the agency</td>
</tr>
<tr>
<td>- Received same paperwork to complete for eligibility 2 or 3 times per person</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Colby</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Provide resources and information to families-help them walk through the process- or help them find the individual who can help</td>
</tr>
<tr>
<td>- Helping to locate and diagnose conditions</td>
</tr>
<tr>
<td>- Help families access &amp; check with the</td>
</tr>
<tr>
<td>- Lack of communication or availability of communication with other agencies</td>
</tr>
<tr>
<td>- Lack of funding for programs</td>
</tr>
</tbody>
</table>

| Middle class families don’t meet financial |
clearinghouse about getting KanCare requirements and can’t afford private insurance

- Direct them to places for info/applications & most help them complete because they don’t understand
- Teach them how to follow up & most often help them with it
- Be there when they get frustrated because it takes so long to be approved
- Time for approvals or denials for families that fall in the cracks
- Helping families understand letters-applications- but not billable

- Educate- research options for them
- Talk to others- KDADS, DCF, KDHE get more information out radio, TV, ads, doctor office on what people need to do
- TCM age 3+ not paid to do that
- Medicaid renewable apps fall through- lose services & meds as a result
- The state lack of consistency, information, staff, & availability

- To assure families/children have insurance and, if not, to help them obtain insurance
- Length of time between application & receiving notification of eligibility

**Small Group Discussion**

After a short discussion in small groups about their above reflections, participants were then asked to consider to additional questions:

**Do you know anyone who is frequently able to successfully overcome barriers related to these standards and if so, what are they doing?**

**Lawrence**
- Persistent caregivers
- Support People -- Build Trust
- ACA navigators – persistence & knowledge

**Chanute**
- Participant reported no experience in this area

**Hutchinson**
- Head Start – trust
- Providers refer to sources
- Hospital social workers
- Connie Z !! <3
- Find out who the decision maker is – be persistent
- Families Together
- Local CDDOs

**Concordia**
- Well connected- up to date
  - Borrow expertise from others
  - Networking
  - Provider & parent
- Read KanCare materials
- Early screening & diagnosis
- Follow up on concerns
- Coordination; teams work together

**Garden City**
- Navigators catch the families while they are still in the birthing hospital
- Staff process applications locally
- Parents who are resourceful and navigate their own insurance – who have made contacts and use resources.
- Parents who follow through
- Parents who are persistent
- Staff and parents who know the right questions and ask the right questions of insurers (sometimes the insurer won’t volunteer information) (sometimes there is inconsistency within and between agencies)
- Parents who document answers and organize information
- Families Together use the CareING Notebook as a strategy to teach parents the skill to document and organize
- iHealth for teens for their transition to adult healthcare (and other skills).
  - Amerigroup promoting this too
- MCO case manager who touches base frequently and keeps parent on toes
- Nurses who advocate

**Colby**
- Families have patience with process, persistence, are willing to make frequent follow up phone calls.
What additional ideas do you have for possible strategies for meeting the standards?

Lawrence
- School based outreach
- Develop programs/systems to support educating families and providers
- Keep current resources
- Know stipulations
- Be proactive

Chanute
*Participant reported no experience in this area*

Hutchinson
- Get info out there to families and clinics
- Allocated positions to navigate families with options/differences

Concordia
- Open up communication w/ primary care providers about resources available
- Get to know insurance company and benefits

Garden City
- Someone (a case manager) willing to advocate to get things done (as well as being persistent)

Colby
- Improve the KanCare eligibility and enrollment process. Especially for crisis funding approval.
- Assure that KanCare eligibility is retroactive to date of application. (This is unclear)
- KDADS approval for waiver services
- Assuring families have access to applications in multiple formats – not just electronic.
- Assure that providers who are first part of contact have tools to facilitate enrollment – applications on hand.
- Use media more effectively to communicate opportunities and changes.
- Don’t always rely on mail system to communicate due to postal processes being slow in rural areas. If you do – expand due dates. Notice for public meetings need to be enough in advance to allow families time to make arrangements to attend.
- Assure there is communication in rural parts of the state.
Introduction

The Kansas Department of Health and Environment Special Health Care Needs (SHCN) Program hosted six (6) regional input meetings across the State of Kansas as part of their state planning process related to Systems Integration for Children and Youth with Special Health Care Needs. These meetings were held between March 16 and April 18, 2017 in Leavenworth (NE Kansas), Manhattan (North Central Kansas), Coffeyville (SE Kansas), Wichita (South Central Kansas), Dodge City (SW Kansas) and Hays (NW Kansas) and engaged a total of 73 participants, including service providers and parents/families of children with special health care needs.

At each meeting, participants were given the opportunity to hear an overview of the Special Health Care Needs program and a brief overview of the National Standards for Systems of Care for Children and Youth with Special Health Care Needs as presented by staff from the Special Health Care Needs Program at the Kansas Department of Health and Environment Bureau of Family Health. Following a question and answer period, participants were asked to discuss standards from within the Screening, Assessment, and Referral and Transition to Adulthood domains of the National Standards. Responses from these discussions are highlighted in this Executive Summary followed by detailed results of the discussions.

Screening, Assessment and Referral

This section of system standards is divided between Screening and Assessment and Referrals. For the regional meetings, discussion focused on Screening and Assessment Standard #5 and Referral/Follow-up Standard #1 (both highlighted in blue below).

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.

Participants across the state agreed that there are good systems for screening in place for newborns, children under the age of five years, and children who are enrolled in Medicaid – though these systems primarily focus on physical health and less on behavioral health screening. In Western Kansas, it was noted that they are seeing increased screenings by pediatricians and young physicians who seem to be more aware of the developmental screening guidelines. Local Health Departments were noted as significant partners for completing screenings, as were early childhood programs such as the Tiny-K providers and Head Start and local school districts.

However, many areas reported that, though the Kan-Be-Healthy system is in place, some providers are not following the guidelines to fully complete them and do not understand that, nationally, the Bright Beginnings guidelines are recommended for all children, not just those enrolled in Medicaid. Participants also expressed concern that there are still many children who do not get identified for services until there is a problem in school or a crisis of some kind, indicating that early screenings may not have occurred. Significant gaps in oral health care and behavioral health care for younger children were also noted.

**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.

Across the State, participants indicated that the newborn screening process is a good example of a screening and referral process that is done well as it includes an embedded follow-up process to assure families get connected to services. It was also noted that Tiny-K networks are generally effective at referral and follow-up. Local Health Departments and early childhood programs were reported to have State systems for tracking data which allow service providers to give and receive information across systems.

While many supports and systems are in place for young children, especially those who are Medicaid eligible, families who have private insurance or are uninsured are less formally tracked and coordination of care is less available. Many reported that there is less coordination and communication among service providers and referral sources when children become school age, and this is especially true for older youth.

Participants from across the State suggested a variety of strategies to assist in making progress toward meeting the national standards that were discussed. These included creation of universal electronic screening forms with mandated fields to assure they are complete; ongoing education of parents and providers about best practices for screening, assessment, and referral; and expanding access to information exchanges to allow for better tracking across systems.

**Transition to Adulthood**

The system standards for Transition to Adulthood are divided for Pediatric and Adult Settings. For the regional meetings, discussion focused on Pediatric Setting Standard #3 and Adult Setting Standard #3 (both highlighted in blue below).
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.

Participants from across the state report that select youth, such as those in foster care, those who receive Home and Community-Based Waiver services or those with an Individualized Education plan in their local schools, are most often receiving transition planning services, though these processes do not consistently involve youth and/or their families. Children’s Mercy hospital was noted to have a number of tools that are youth/family-centered to assist with creating medical transition plans. Families Together was also noted to support families through the transition process. In Western Kansas, it was reported that some youth are put in the difficult position of choosing whether to graduate with their high school class versus receiving services until age 21 to receive ongoing transition support.

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.

Participants from across the state reported many challenges related to services to support transitioning youth. Many stated that there are a number of pediatric providers who do follow youth into adulthood so that they do not have to establish new relationships along the way. However, providers who do best at this often get overwhelmed with referrals and some discontinue providing services as a result. There was a consistent concern that transition planning is not occurring with youth early enough, if at all and that a lack of overall communication among service providers contributes to youth not receiving adequate support.
Suggested strategies for making progress included establishing local interagency coordinating councils similar to those that are mandated for early childhood networks across the state; working with Electronic Health Record providers to create system flags for transition planning; and the creation of standardized forms to assist in the process.

**Next Steps**

Information from these regional meetings will be combined with results from a statewide survey of service providers and families that measured their perceptions of Kansas’ current ability to meet all of the Standards for Systems of Care in each of the above stated domains. (The content, methods, and results of this survey are published separately.) This data will be used as a part of a facilitated planning process to develop a comprehensive system of care in Kansas.
KDHE Special Health Care Needs Program
Regional Community Input Sessions

September 2017
Introduction
The Kansas Department of Health and Environment Special Health Care Needs (SHCN) Program hosted six (6) regional input meetings across the State of Kansas as part of their state planning process related to Systems Integration for Children and Youth with Special Health Care Needs. These meetings were held between August 1 and September 7, 2017 in Overland Park (NE Region), Salina (North Central Region), Independence (SE Region), Wichita (South Central Region), Garden City (SW Region) and Hays (NW Region) and engaged a total of 48 participants, including service providers and parents/families of children with special health care needs.

At each meeting, participants were given the opportunity to hear an overview of the Special Health Care Needs program and a brief overview of the National Standards for Systems of Care for Children and Youth with Special Health Care Needs as presented by staff from the Special Health Care Needs Program at the Kansas Department of Health and Environment Bureau of Family Health. Following a question and answer period, participants were asked to discuss standards from within the Family-Professional Partnership domain of the National Standards. This document also includes standards related to Family-Professional Partnerships in two other domains that were also discussed. Responses from these conversations are highlighted in this Executive Summary followed by detailed results of the discussions.

Levels of Family-Professional Partnerships
The National Standards outline opportunities for organizations and systems to partner with families to make decisions at all levels of the CYSHCN system: Care Delivery; Program Planning and Systems Planning.

Standards related to Care Delivery include:

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.
Participants across the state agreed that the State’s system for Infant/Toddler Services does a good job of including parents in the care delivery process, primarily because policy mandates parent involvement in the development of Individualized Family Service Plans for children under the age of 3 years and programs targeting young children integrate the philosophy of parents as a child’s first and best teacher. Other systems that were noted as doing this well were the Home-Community Based Services (HCBS) Waiver programs, including those for children with Intellectual/Developmental Disabilities (I/DD) and Severe Emotional Disturbance (SED), as well as Federally Qualified Health Centers (FQHCs). Again, these systems all have policy that requires family input into service planning and care delivery. Some areas of the state noted that parent support resources such as Families Together and parent support groups are strong and becoming more parent-led.

Statewide, participants noted challenges with meeting standards related to culturally appropriate materials and care. In many areas there is a wide variety of languages spoken but resources only for families who speak English or Spanish. In the North Central part of the state there was a noted concern that school districts are less flexible in incorporating family input – families report arriving to Individualized Education Plan (IEP) meeting with the plan already developed and ready to sign without having had discussion with the family. Other parts of the state reported that in some instances, parent input is requested but not received because families don’t feel safe providing feedback or feel that their opinions are overshadowed by those of the professionals involved.

Parents and professionals who participated from across the state suggested that the system continue to make every effort to gather input from families and communicate in culturally appropriate ways. They suggest that service delivery programs provide training to families on how to advocate on behalf of their children and find tangible ways to communicate to parents that their feedback is valued as part of the care delivery process.

**Standards related to Program Planning include:**

**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.

Across the State, participants indicated nearly all programs collect some sort of client/patient feedback, usually in the form of satisfaction surveys or consumer focus groups. It was reported that it is a mandated requirement for Infant/Toddler programs to incorporate this feedback into their program planning and health departments actively review data to make appropriate changes. While a number of programs across the state report having Family Advisory Councils, the KDHE Special Health Services Family Advisory Council (FAC) was held an exemplary model of this practice. The FAC is actively involved in program planning for Special Health Services as well as providing input on the CYSHCN system as a whole.

While it was noted that most programs use some sort of client satisfaction survey, participants also noted that the sheer number of surveys that families receive from a variety of sources may also be a barrier to collection of valid data. The need for a closed loop for feedback was noted as a way to encourage families to participate – if families don’t feel their feedback is incorporated into program policy and practice, they are less likely to respond. It was also
seen as important to help families understand when feedback cannot result in change – such as conflict with federal regulations, etc.

For organizations who would like parents to be more involved in an advisory capacity, it was suggested that organizers find creative ways to engage families that are more reflective of when and how families might be available such as meeting scheduling and access to social media opportunities. It was also suggested that programs be more proactive in collecting and including feedback from children and youth with special health care needs who are receiving services, not just their parents and/or caretakers.

**Standards related to Health Systems Planning include:**

**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.

Similarly to the Program Planning area, the KDHE SHCN Family Advisory Council was held as an example of positive involvement of families in the systems planning process as were local and state Interagency Coordinating Councils (ICCs) for the Infant/Toddler service systems. The *Becoming a Mom* program was also mentioned as having included parents in the development process.

Participants noted that systems decisions are often made without families being present or providing other means of input, particularly in relation to health care providers and the KanCare system. It was also noted that Emergency Management Systems across the state tend to be less consumer focused and have much work to do to become more connected to the families they serve in their local communities. More than one area of the state reported that the Foster Care system in Kansas is ill-equipped to care for children with special health care needs, resulting in children perhaps being returned to their home of origin before the family is ready to provide a safe environment and care.

Suggestions for improvement were also similar to those made in the area of Program Planning. Examples included creative opportunities for families to participate, including incentives and family advisory boards where currently none exist.

**Next Steps**

Information from these regional meetings will be combined with results from a statewide survey of service providers and families that measured their perceptions of Kansas’ current ability to meet all of the Standards for Systems of Care in each of the above stated domains. (The content, methods, and results of this survey are published separately.) This data will be used as a part of a facilitated planning process to develop a comprehensive system of care in Kansas.
Introduction
For each level of Family-Professional Partnerships, staff from the Wichita State University Community Engagement Institute reviewed the relevant standards and led participants through large and small group discussions to determine what is going well, what needs improvement, and strategies for forward movement. (See Executive Summary for a full listing of standards for each section.)

Family-Professional Partnerships: Care Delivery

Large Group Discussion

What is going well in this area and how do we know?

Overland Park
- Infant/Toddler Programs – I felt empowered as a parent; there are no waiting lists
- Special Health Care Needs – teaching parent advocacy and what to expect from care coordination; hear good things about supportive referrals
- Schools – have not received complaints
- Some providers do a good job of referring (Children’s Mercy) – have talked to satisfied patients
- Children’s Mercy connects with schools

Garden City
- Early intervention – write goals around parent priorities, interpreters are provided, some documents are available in Spanish
- Health Department – making referrals to appropriate services
- Case Managers – link to peer support
- Electronic Medical Record (EMR) – make lab results available, Contact physicians

Hays
- Agencies strive to work together – ICC parents involved
- Parents have the opportunities to be engaged
- Culturally sensitive materials available in early intervention – given care delivery options to choose (or not), documentation about what early intervention does
- Surveys that ask parents what care delivery they want
- Individualized Family Service Plan (IFSP) asks families to be involved in decisions

- Treatment planning interviews every 90 days for children in mental health
- Severe Emotional Disturbance (SED) Waiver has specific requirements for family feedback – parents can change or disagree with suggestions
- Home-Community Based Service (HCBS) Waiver for Individuals with Intellectual/Developmental Disabilities (I/DD) – family driven service may or may not have goals, no decisions without the parent
- Support Groups (Downs’ Syndrome and Autism) – Parents have taken over
- Families Together – we share their information
- Women, Infants, & Children (WIC) – parents involved

Independence
- Recognizing there are medical homes
- Safety Net Clinic is currently meeting most of these standards
- Part C of IDEA has dedicated family service coordination – ensure family involvement
- Schools report they have family involvement as a requirement of Part B of IDEA
- Organizations use the Ages & Stages Questionnaire (ASQ) to identify children with needs and make referrals – this assessment requires parent input
- Autism Rocks program from KU
- Increase in education programs
- Child Find programs
• Getting to the point where paper is not the only way to communicate with families. Using iPads and texting more often
• Community Baby Showers have been a shining star in this area
• Family Engagement Nights were successful but funding for these has ended. Provided food and activities to engage families

Salina
• Electronic Medical Record (EMR) helps engage families and tracking needs and requirements – can screen for vaccinations, vision screens
• Part C of IDEA Infant/Toddler (I/T) programs do a good job of learning families’ needs – they train staff on how to visit with families
• When programs help families locate local services – Parents as Teachers (PAT) have helped with Cedar House
• Central Kansas Mental Health Center (CKCMHC) takes services into schools to reduce stigma
• Schools identify kids and refer to CKCMHC – they help families follow through with services
• CKCMHC allows any family member that is identified to participate – family comes to school to work with MH provider

What is not going well and how do we know?

Overland Park
• Many programs (Parents as Teachers, HCBS Waivers, IDD services) have waiting lists
• Lacking respite care – nowhere to send families
• Don’t have written materials in all the languages that are served – things get lost in interpretation; conversations aren’t logged
• Programs using family members as interpreters
• Some providers show bias – families aren’t heard; input from professionals “trumps” parent input
• Providers can’t be open all hours and some parents don’t have leave – some families can’t get their child to service
• Refugee system process – simple compliance issues

Garden City
• Written materials for Early Intervention – languages limited to English and Spanish

Wichita
• Cerebral Palsy Research Foundation (CPRF) requires that families be included in the evaluation process
• Handouts are provided in Spanish and interpreters are provided for face-to-face interactions
• Home Health Care services allow families to participate in the nurse selection process (even if they are mandated to use a certain agency)
• Organizations make choice available whenever possible
• Multiple ways to provide feedback to the program
• Self-advocacy programs are available for peer support
• Phone apps are available to help keep medical records and take them with you
• Specialty clinics have added Families Together as an onsite partner
• Kansas is ahead of some states on family advocacy
• CPRF asks specifically about parent concerns

Hays
• Interpreter Services – limited (event for Spanish)
• Translation Services – Arabic dialects, Chinese
• Fort Hays State University (FHSU) has a sister school in China that sends students – no materials, no funds for translation
• Hearing impairment – limited services
• Limited parenting – mental health issues, drug-involved, parents choose not to participate
• Culture clash – where what we think children need is different from parents

Independence
• Leadership that doesn’t “buy in” to family involvement
• Roadblocks to transitions/communication
  o Parents don’t know they can transition or that providers may change
  o Services don’t always transition from one waiver to another
• Information not always given at a time when families can “hear” it
• KanCare system challenges
• Lack of quality family support systems
• Lack of professional development resources for culturally appropriate interactions and communication (Traditions, etc.)
• Just not there yet on these standards
• Families don’t have means to access Electronic Health Information. (No internet, prepaid phones, etc.)

Salina
• We alienate families – they shut down, don’t show, don’t follow through
• Family support groups are lacking – no Downs’ Syndrome Support group
• Making sure families get something out of supports is lacking – offering supports not at the right time or location
• Not asking parents what they want – school support, early education, no one asked me or my son
• We create guidelines without parent input
• Parents of low vision children don’t know what resources are available – it takes time and time matters

Wichita
• Getting information to families early on
• Number of doctors’ office with a holistic approach to care
• Families don’t have easy access to electronic medical records
• Families don’t have consistent ways to contribute to the medical record
• Professionals aren’t always in the home to address social determinants of health and it takes too long to get them connected
• Kansas Health Information Network is under-leveraged. Parents need to have access

Table Discussion
Participants in each region were asked to consider information shared during the large group conversation and identify ideas for current practices that should be stopped, others that should continue, and strategies that could be started to help move the system forward as they relate to each area of Family-Professional Partnerships.

In the area of Care Delivery:

<table>
<thead>
<tr>
<th>Stop Doing</th>
<th>Keep Doing</th>
<th>Start Doing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overland Park</strong></td>
<td><strong>Keep Doing</strong></td>
<td><strong>Start Doing</strong></td>
</tr>
<tr>
<td>• Stop de-valuing parents thoughts and feelings</td>
<td>• Empowering – Advocacy for parents</td>
<td>• Educating/informing families early. Prenatal services, rights, how to advocate. Impact later could be huge!</td>
</tr>
<tr>
<td>• Do not underestimate parents’ knowledge regarding their child</td>
<td>• Teaching families to advocate</td>
<td>• Partner with families instead of just instructing them</td>
</tr>
<tr>
<td>• Using family/friends to interpret</td>
<td>• Provide referral and follow-up</td>
<td>• Using simplified language</td>
</tr>
<tr>
<td>• Traditional 8-5 hours</td>
<td>• Coordination of services/agencies</td>
<td>• Written materials in their language</td>
</tr>
<tr>
<td>Location</td>
<td>Actions</td>
<td>Changes</td>
</tr>
<tr>
<td>--------------</td>
<td>-------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Garden City</td>
<td>• Stop having one or two places of referral</td>
<td>• Working to provide better or more choices of care</td>
</tr>
<tr>
<td></td>
<td>• Stop having limited choices for medical referral</td>
<td>• Materials in numerous languages and culturally appropriate</td>
</tr>
<tr>
<td></td>
<td>• Stop not giving parents an option of specialists of referrals</td>
<td>• Providing written materials in all languages</td>
</tr>
<tr>
<td></td>
<td>• Stop mailing information parents will never read, save money</td>
<td>• Providing written information in many languages</td>
</tr>
<tr>
<td></td>
<td>• Families being active core member of medical home team</td>
<td>• Allow parents more choices with medical specialists for referrals</td>
</tr>
<tr>
<td></td>
<td>• Continue culturally appropriate considerations</td>
<td>• Really allow parents to choose method of communication</td>
</tr>
<tr>
<td></td>
<td>• Making progress for making health records easily accessible online</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Involving families</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• EMR access for families</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Providing support</td>
<td></td>
</tr>
<tr>
<td>Hays</td>
<td>• Placing our values upon others whether age, culture,</td>
<td>• More interpretive services, locate funds to get staff to do this</td>
</tr>
<tr>
<td></td>
<td>• Enabling families because they will not do it / know we will – giving</td>
<td>• Start training to help family do for themselves to stop enabling</td>
</tr>
<tr>
<td></td>
<td>them less responsibility</td>
<td>• Teach cultural diversity</td>
</tr>
<tr>
<td></td>
<td>• Recognize cultural differences with regard to health care choices</td>
<td>• Empowering families to be better advocates for themselves</td>
</tr>
<tr>
<td></td>
<td>“Don’t expect everyone to fit our expectations”</td>
<td>• Help parents know more about electronic health records and that they can make any necessary</td>
</tr>
<tr>
<td></td>
<td>• Keep providing interpretive services and expand</td>
<td>changes</td>
</tr>
<tr>
<td></td>
<td>• Keep involving families at every step</td>
<td>• Expand/promote support groups for parents</td>
</tr>
<tr>
<td></td>
<td>• Keep surveying for satisfaction</td>
<td>• Find more resources for interpretation/translation for multiple languages</td>
</tr>
<tr>
<td></td>
<td>• Collaboration among agencies and share resources</td>
<td>• Promote cultural competence among providers</td>
</tr>
<tr>
<td>Independence</td>
<td>• Starving funding streams</td>
<td>• Increasing awareness of available resources</td>
</tr>
<tr>
<td></td>
<td>• Mass mailings</td>
<td>• Increasing resources and supports to address need</td>
</tr>
<tr>
<td></td>
<td>• Repeated information</td>
<td>• A clear navigational path</td>
</tr>
<tr>
<td></td>
<td>• Bolster capacity of professionals working with non-English speaking</td>
<td>• Individualized in-home education</td>
</tr>
<tr>
<td></td>
<td>families</td>
<td>• Recruit more parents</td>
</tr>
<tr>
<td></td>
<td>• Collaboration and communication</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Telling stories with data</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Baby showers/meals/gas cards</td>
<td></td>
</tr>
<tr>
<td>Location</td>
<td>Issues and Solutions</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>----------------------</td>
<td></td>
</tr>
</tbody>
</table>
| Salina   | - Information dumping  
- Authoritative approach  
- Stop “pigeon-holing”  
- Telling families what they want  
- Using different communication strategies to reach the parents  
- Aware of resources in the area  
- Listening to families about what works at home  |
|          | - Give parents back some power and trust in knowing their child  
- Support parents and help attain without diagnosis  
- Help ensure language and information are understood  
- Navigators at school  
- Partnering with Special Education  
- Start having “navigator” as liaison between parents and school  
- Simplify processes to access services  |
| Wichita  | - Treating nursing professionals as babysitters  
- Compensate accordingly for the nursing profession  
- Basing your care around diagnosis instead of their abilities  
- Stop working in siloes (no communication)  
- Stop and listen to family  |
|          | - Educating parents about their rights and responsibilities  
- Family focus and empowerment  
- Peer support groups and parent groups  |
|          | - Teaching parents to think as partners  
- Integrated care, easier access to EMR  
- Start educating parents on options  |

**Program Planning**

**Large Group Discussion**

What is going well in this area and how do we know?

**Overland Park**
- Collect client satisfaction data – clinic collects every visit
- Federal reporting for Infant/Toddler requires parent involvement – all families see it (is the process burdensome?)
- Infant/Toddler programs use the data – this is required. Helps us see where we are not doing well.
- Health Department uses the data – is integrated into staff education
- Parents at Greenbush will share informally – mention this when they call again and send it along to others

- Individuals with Disabilities Education Act (IDEA) requires a procedure for complaints – leads to technical assistance
- Healthy Families involves families in planning – have a notebook to collect ideas
- Interagency Coordinating Councils (ICC) require a parent member – they shape how the meetings are run
- Individual Family Service Plan process is family driven
- Healthy Families programs have the families create their own goals
- Health Departments’ Family Planning program has a family advisory board
**Garden City**
- Family Advisory Board – involved in program planning
- Early Intervention – family satisfaction survey, Part B/C transition
- Doctors’ offices – satisfaction surveys
- ICC – parents included, parents from distant counties
- Russell Child Development Center – parents on board of directors
- Tiny-K families – called at random, included in the improvement plan

**Hays**
- Local ICC – invited to partners in decisions
- Family Advisory Council
- Mental Health board of directors includes a parent with SED
- Early Intervention – have surveys, board includes family members
- Human Rights Committee – approve behavior support plans
- Mental health – random phone call asking for patient satisfaction

**Independence**
- KDHE Family Advisory Council
- Satisfaction surveys but tough to get them back

**Salina**
- Heartland has parent policy council – parents serve as officers and voting members (Head Start)
- SHCN program has Family Advisory Council (FAC) – influences other programs

**Wichita**
- CPRF follow-up service surveys
- Family focus groups at CPRF
- Centers for Medicaid and Medicare Services (CMS) certification requires evidence of family partnerships; Quarterly advisory committee of parents
- SHCN program requires family involvement
- Emergency Management Services have outcomes that require documentation of work with families and use of family input. State EMS created a communication tool for EMS and Emergency Departments
- SHCN Family Advisory Council

**What is not going well and how do we know?**

**Overland Park**
- Health Department does not have an advisory board
- Even when it’s required, we don’t make it easy to participate – transportation; parents aren’t ready; overuse willing families
- Some parent engagement is not family friendly – not sure what their role is; using jargon
- Fail to make program changes based on parent struggle
- Gap between people making decisions and families – unintended consequences

**Garden City**
- We give surveys but not sure how results are incorporated
- ICC – hard to include the parent in ICC work, hard for parents to talk about policies, could try meeting to include more distant counties…right now meetings in Garden City for 13 county area
- Federally Qualified Health Centers are mandated to have a 51% consumer board
- Better at giving outlets to get feedback (Social media, etc.)
- Completion survey for *Becoming a Mom* program
- MCH/WIC program survey
- Incentives for completing surveys

**Hays**
- Local SHCN – no survey, no parent advisory board
- Tiny-K families get two surveys – it’s confusing, low response rate
- Maternal Child Health (MCH) Home Visiting – low response rate
- Too many surveys – KanCare, physicians, schools, SHCN

**Independence**
- There is a disconnect. Programs can’t always use input. Sometimes things that are shared can’t be changed.
- Hard to get a representative sample of families
- Way a survey is given matters
• Survey overkill. Too many surveys may lead families to question whether feedback is really wanted.

Salina
• Families not well represented – school boards, activity boards
• Not in a position to act on opinions – or have a policy-making role
• Special Education transition and work study – would look different if families involved. It would teach life skills

Wichita
• Gap: Pediatric hospice services. Parents will be key to advocating for these services
• Hard to engage families who are already overwhelmed
• Families lack time and meetings don’t always match their schedules
• Families don’t want to burn bridges and so they aren’t honest when providing feedback
• Need to have ways to provide input that are nontraditional
• Lack of legislative partners who champion SHCN

Table Discussion
Participants in each region were asked to consider information shared during the large group conversation and identify ideas for current practices that should be stopped, others that should continue, and strategies that could be started to help move the system forward as they relate to each area of Family-Professional Partnerships.

In the area of Program Planning:

<table>
<thead>
<tr>
<th>Stop Doing</th>
<th>Keep Doing</th>
<th>Start Doing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overland Park</strong></td>
<td>• Program changes without family/client involvement</td>
<td>• Find creative ways to engage families in Councils (child care, time, and days to accommodate families)</td>
</tr>
<tr>
<td></td>
<td>• Scheduling day time meetings/no daycare</td>
<td>• More family involvement</td>
</tr>
<tr>
<td></td>
<td>• Placing blame</td>
<td>• Make service/meetings more meaningful to families</td>
</tr>
<tr>
<td></td>
<td>• Possibly stop mailing surveys for feedback and create a different method to collect</td>
<td>• Actually implement the changes when possible</td>
</tr>
<tr>
<td></td>
<td>• Stop making the appeals process so difficult</td>
<td>• Go to parents instead of inviting them to meetings (Parks, schools, in home)</td>
</tr>
<tr>
<td></td>
<td>• Appeal process is too difficult for family members of child’s team are not included (Medicaid)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Parental/family involvement in program advisory board(s)</td>
<td>• More agency collaboration</td>
</tr>
<tr>
<td></td>
<td>• Family advisory board very important to get family input</td>
<td>• Better ways to communicate and recruit family member for advisory boards</td>
</tr>
<tr>
<td></td>
<td>• Encouraging families to be involved in boards and leadership roles</td>
<td>• Create a local family advisory board</td>
</tr>
<tr>
<td></td>
<td>• More options for surveys (phone, email, mail)</td>
<td>• Finding out more about how survey results and phone calls are incorporated into our program</td>
</tr>
<tr>
<td><strong>Garden City</strong></td>
<td>• Continue collection of data on service delivery and utilize data to make program changes and improvements</td>
<td>• Encouraging parents to attend advisory</td>
</tr>
<tr>
<td></td>
<td>• Family Advisory Council for SHCN</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Taking parents’ feedback regarding the program and what they want from it.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Engage families in program activities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Doing surveys (updating and revising as needed)</td>
<td></td>
</tr>
<tr>
<td>Region</td>
<td>Problems</td>
<td>Solutions</td>
</tr>
<tr>
<td>--------</td>
<td>----------</td>
<td>-----------</td>
</tr>
</tbody>
</table>
| Hays   | • Overwhelming families with surveys come from each program and state level. If families are involved with multiple agencies | • Family as part of boards and local ICC  
• Surveys—feedback is needed  
• Providing opportunities for families and agencies to come together for partnership opportunities | • Coordinating surveys between local and state so families aren’t so confused  
• Contact a random sampling of family members by phone to get feedback on care/treatment and improvements that can be made |
| Independence | • Asking for feedback  
• Surveys – can utilize information to make improvements | • Meeting families where they are at  
• Collect meaningful data  
• Sharing feedback with families and communities  
• Make sure they are aware of current policies and procedures |
| Salina | • Stop the one size fits all  
• Stop the authoritative approach (come down to family level)  
• Siloed services  
• Thinking we know what parents want/need | • Do survey and then follow up  
• Be aware of the needs once survey is completed (who follows through?)  
• Surveys and information gathering processes | • Health and full picture of individual “user perspective”  
• Total needs of child/adult families  
• Partnering for the approach  
• Give families input into designing – like a “users perspective”  
• Feedback loop – let people know how they have made a difference |
| Wichita | • Making things so complex  
• Changing names/programs/organizational structures so much. Very confusing and hard to keep up with  
• Being reactive instead of proactive  
• Excluding families in planning | • Asking parents for their input and opinion.  
• Information clear and easy to find  
• SHCN FAC  
• Current involvement of board members  
• Keep growing and expanding parent/child involvement | • Telling success stories so people will know how it happened  
• State programs need to ask families what has worked and share it.  
• Social media to allow for input  
• Leveraging technology  
• Add legislator to Advisory Board  
• More ethical inclusion of all groups – “representation is given”  
• Create a youth council with outlined, fun meetings and an annual summit. Kids were |
Large Group Discussion

What is going well in this area and how do we know?

**Overland Park**
- State Interagency Coordinating Council has parent representation – this is mandated
- Special Health Services has a Family Advisory Council (FAC) – parents set the agenda and develop programming
- FAC is building a peer-to-peer system – parent-led
- Family Data Institute – invites parent feedback

**Garden City**
- Family Advisory Board – quality improvement planning
- Special Health services – parents reimbursed
- Hospital – satisfaction survey
- *Becoming a Mom* program – parents were involved in development, has surveys
- Elementary school – has advisory council
- Local ICC – parents involved
- Some Managed Care Organizations (MCOs) – have family engagement

**Hays**
- Family Advisory Council – institutionalized parent feedback

**What is not going well and how do we know?**

**Overland Park**
- Decisions are made for families with no parents present – occurs

**Garden City**
- Hospital/Pediatric Office – don’t have survey or advisory board
- KanCare – doesn’t have family engagement

**Hays**
- KanCare has not parent advisory – offer no training or reimbursement
- Low population/high geographic area – hard to engage parents

**Independence**
- First responder systems are less consumer focused, not patient centered
- Families are “trapped” by system challenges and can’t offer feedback

*National Association for the Mentally Ill (NAMI) support groups and support for parent involvement*  
*MCOs (some) have advisory board*  
*KDHE Family Advisory Council*  
*Public surveys/regional*  
*Open meetings*  
*Public forums*  
*Community Health Assessment/Community Health Improvement Plan process*  
*Voting – Advocacy Efforts*  
*Starting conversations with Emergency Services*  
*Interagency Coordinating Councils (ICC) – parents are included*  
*SHCN FAC serves dual role at program and systems levels*
• Foster children with SHCN not adequately served due to lack of trained foster parents. May get sent to home of origin too soon because there are no alternatives to care for them.

**Salina**
• Medical intervention and education don’t coordinate well – needs a bridge
• Can’t attend meetings because of time/location – no respite during the day, always at the same time

**Wichita**
• Providers are not aware of systems providing opportunities for families to provide input

---

**Table Discussion**
Participants in each region were asked to consider information shared during the large group conversation and identify ideas for current practices that should be stopped, others that should continue, and strategies that could be started to help move the system forward as they relate to each area of Family-Professional Partnerships.

In the area of Health System Planning:

<table>
<thead>
<tr>
<th>Stop Doing</th>
<th>Keep Doing</th>
<th>Start Doing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overland Park</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Not making decisions about families without family input</td>
<td>• Mandates for parental involvement</td>
<td>• Initiate more councils with families</td>
</tr>
<tr>
<td></td>
<td>• Keep fighting for health care/education rights</td>
<td>• Consider families’ input before making decisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Address multiple languages and making sure the family understands</td>
</tr>
<tr>
<td><strong>Garden City</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Don’t forget about the rural areas of the state</td>
<td>• Family advisory boards or committees</td>
<td>• Hospital/local healthcare advisory board of committee creation</td>
</tr>
<tr>
<td>• Stop assuming these things are happening</td>
<td>• Family satisfaction survey</td>
<td>• More effective methods to collect feedback data</td>
</tr>
<tr>
<td>• Stop forgetting about rural areas</td>
<td>• Keep the surveys</td>
<td>• Provide more virtual options for participants</td>
</tr>
<tr>
<td>• Assuming all these things are happening (advisory boards and parent involvement)</td>
<td>• Vocalize ICC’s parent reps</td>
<td>• An advisory board at hospital</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Start family advisory board for hospital, health department, KanCare, clinics, etc</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Other options for parents to be able to attend, virtually, evenings, location</td>
</tr>
<tr>
<td><strong>Hays</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Family advisory counsel</td>
<td>• Reimbursements from MCOs for family participation and involvement</td>
</tr>
<tr>
<td></td>
<td>• Support groups that encourage family involvement</td>
<td>• Involving families in meeting through</td>
</tr>
<tr>
<td>Independence</td>
<td>• Making foster care placement decisions based on SHCN</td>
<td>• Self-advocacy groups</td>
</tr>
<tr>
<td>--------------</td>
<td>------------------------------------------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Salina</td>
<td>• Making the service area so large</td>
<td>• Trying to attend meetings that are scheduled</td>
</tr>
<tr>
<td></td>
<td>• Making it unknown to families</td>
<td>• Attending meetings</td>
</tr>
<tr>
<td></td>
<td>• Blaming parents when they don’t attend</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Criticizing when people are unable to attend</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Making service delivery areas too broad</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wichita</td>
<td>• Living in our bubbles (siloes)</td>
<td>• Asking parents</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Let them know that their feedback matters</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Let parents know results of feedback</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>