

November 2018

The Kansas State Plan for

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



Completed by the Kansas Special Health Care Needs Program  
*in consultation with EnVisage Consulting, Inc.  
the Kansas University Center for Public Partnerships and Research,  
and the Wichita State University Community Engagement Institute*

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## Overview

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Children and youth with special health care needs (CYSHCN) are a diverse group of children defined, by the Department of Health and Human Services Maternal and Child Health Bureau, as “children birth to age 21 who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” This can range chronic conditions such as asthma or diabetes, to developmental disabilities such as Down syndrome or autism, to medically complex health issues such as spina bifida or other congenital disorders, to children with behavioral or emotional conditions. An estimated 120,822 CYSHCN represent 17.3% of the overall KS child population. The Kansas State Plan for Systems of Care for CYSHCN is intended for agencies and organizations serving CYSHCN and stakeholders, including parents, caregivers, and individuals, in supporting Kansas to achieve the *Standards for Systems of Care for CYSHCN* (referred to as “Standards” throughout this document) to strengthen collaboration, support systems integration and improve service delivery for CYSHCN.

The Kansas Department of Health and Environment, Special Health Care Needs (KS-SHCN) Program, as part of the Title V Maternal and Child Health Block Grant, is dedicated to building capacity, infrastructure, and support systems of care for CYSHCN to assure children and their families receive services that are accessible, continuous, comprehensive, coordinated, compassionate, culturally competent and family-centered. As a state program, KS-SHCN promotes the functional skills of persons, who have or are at risk for a disability or chronic disease, providing specialized medical services to infants, children and youth up to age 21 who have eligible medical conditions. Additionally, the program provides services to persons of all ages with metabolic or genetic conditions screened through the Newborn Screening. Services may include diagnostic evaluations, treatment services or care coordination.

In order to fully achieve a comprehensive system of care and improve health outcomes, it is critical to recognize that all children have the potential for having a special health care need at some point in their life. Therefore, the framework provided by the *Standards* includes components that are not only relevant to CYSHCN, but to the general pediatric population. Over time, it has been noted that creating a comprehensive, quality system of care for CYSHCN has been a challenging endeavor, especially stakeholders such as state Title V CYSHCN programs, health plans, private insurers, state Medicaid and CHIP agencies, primary care providers, health care teams, and families. For decades, state and national champions have advocated for the development of a framework or set of standards or measures to support a comprehensive system of care for CYSHCN and their families. The *National Consensus Framework for Improving Quality Systems of Care for Children and Youth with Special Health Care Needs* project was created to develop such a set of standards. The development of the *Standards* was strategic, evidence-based/evidence-informed, and engaged a diverse group of national stakeholders. These standards are based on a comprehensive review of the literature, key informant interviews, case studies of standards for CYSHCN currently in use in Title V, Medicaid and health plans within selected states and consensus from the national work group. A detailed description of how the standards were developed available at <http://www.amchp.org/AboutAMCHP/Newsletters/member-briefs/Documents/Standards%20Charts%20FINAL.pdf>.

The *Standards* are intended for use by a range of national, state and local stakeholder groups including state Title V CYSHCN programs, health plans, state Medicaid and CHIP agencies, pediatric provider organizations, children’s hospitals, insurers, health services researchers, families/consumers and others. The *Standards* are designed to supplement, not substitute, federal statute and regulatory requirements under Medicaid, the ACA and other relevant laws.

## ■ The Role of Title V

The Kansas Department of Health and Environment (KDHE) is responsible for the administration of programs carried out with allotments under Title V. The Title V Maternal and Child Health (MCH) Services Block Grant program is administered by the Bureau of Family Health (BFH) in the Division of Public Health. The mission of the Bureau is to “provide leadership to enhance the health of Kansas women and children through partnerships with families and communities.” KDHE convenes the Kansas Maternal and Child Health Council and contracts with local public health departments (independent entities) across the state to ensure coordination of MCH services within a coordinated, family-centered system.

The Title V mission is to improve the health and well-being of the nation’s mothers, infants, children and youth, including children and youth with special health care needs, and their families. Title V legislation and the MCH Service Block Grant Program enables states to: a) provide and assure mothers and children access to quality MCH services; b) reduce infant mortality and the incidence of preventable diseases; c) provide rehabilitation services for blind and disabled individuals; and d) provide and promote family-centered, community-based, coordinated care, and facilitate the development of community-based systems of services.

Title V is responsible for promoting the health of all mothers and children, which includes an emphasis on CYSHCN and their families and the development of life course theory has indicated that there are critical stages, beginning before a child is born and continuing throughout life, which can influence lifelong health and wellbeing. To assist with planning how to achieve these objectives, the Kansas Title V conducted a Five-Year Needs Assessment (2016-2020) process utilizing a mixed methods approach relying on continuous input from a diverse team of key informants, partners, and community members as well as broad public input. This comprehensive process and broad approach assisted with identifying key priorities to ensure an intended plan of action to effectively improve and address maternal and child health. The Kansas Title V needs assessment resulted in eight state priorities, selected with the Title V mission, purpose, legislation, and measurement framework in mind. (Note: New Block Grant Guidance provided an opportunity to consolidate and one priority was dropped in 2018).

1. Women have access to and receive coordinated, comprehensive services before, during and after pregnancy.
2. Developmentally appropriate care and services are provided across the lifespan.
3. Families are empowered to make educated choices about infant health and well-being.
4. Communities and providers support physical, social, and emotional health.
5. Professionals have the knowledge and skills to address the needs of maternal and child health populations.
6. Services are comprehensive and coordinated across systems and providers.
7. Information is available to support informed health decisions and choices.

Of these state priorities, Priority 6 is assigned to the CYSHCN domain, however it addresses all children in the way that KDHE strives to provide services: comprehensively and inclusively. As a Title V program, one of the main goals of KS-SHCN is care coordination, so that children and their families can navigate systems to gain optimal health in a consistent and comprehensive way. Throughout the Needs Assessment process, it became apparent that family support was emerging as a high need and that those supports include access to care (transportation, especially in rural communities, and providers who will treat CYSHCN especially oral health). As the assessment progressed family support also expanded into the need for social-emotional support and respite for parents/caregivers. Providers were also a high need given that many

are not specialists, and many do not practice near rural communities. Family-centered medical homes need support and partnerships can be explored based on the needs presented. This can include existing structures that KDHE can support as well as engaging MCO's and primary care providers, implementing telehealth, and professional development training. This priority exemplifies the collaboration and partnership building principles that KDHE promotes and is willing to sustain so that all with children with special health care needs are considered children first.

## ■ Special Mentions

***Thank you to each and every partner who provided input, feedback, and support during the development of this plan!***

A special thanks to Envisage Consulting, Inc. and the Kansas University Center for Public Partnership and Research for their support throughout the KS-SHCN Strategic Planning process. This process was the catalyst to developing this type of a statewide plan.

A special thanks to Wichita State University for their facilitation, leadership, analysis, and support throughout the state plan development activities. Without this support, this plan would not be possible.

A special thanks to the Leadership Team who developed the process utilized during the state plan development.

To all stakeholders who participated in the regional meetings, online surveys, and key stakeholder planning meetings, our deepest gratitude and appreciation for input, expertise and lived experienced that contributed to the development of this plan. Contributing partners consisted of family members, local health departments, managed care organizations (insurers), hospital partners, medical and mental health providers, early-intervention providers, universities, home health care providers, developmental disability organizations, federally qualified health centers, early childhood educators, and other community organizations.

## Summary of Strategic and State Plan Meetings

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This plan is the culmination of a variety of key activities that provided the necessary data, public input, and strategic direction necessary for the development of a family-centered plan. There are three distinct initiatives that contributed to this plan.

1. **KS-SHCN Strategic Planning:** This effort began in 2013 with a focus on a specific state program population to assure greatest positive impact on families served through that program.
2. **National Standards for Systems of Care for Children and Youth with Special Health Care Needs:** The release of these Standards in 2014 provided direction in which Kansas programs could strive to meet the needs of Kansas families.
3. **State Implementation Grants for Enhancing the System of Services for CYSHCN through Systems Integration:** This federal grant award in 2015 provided the necessary administrative and financial support to engage communities and stakeholders through a series of meetings and other key activities.

Detailed information around these initiatives follows.

## ■ KS-SHCN Strategic Planning

In July 2013, KS-SHCN began an extensive strategic planning process including a series of meetings with key stakeholders, surveys, community meetings, and input from the Special Health Services Family Advisory Council (SHS-FAC). The strategic planning began as an opportunity to assess the state program on the following metrics:

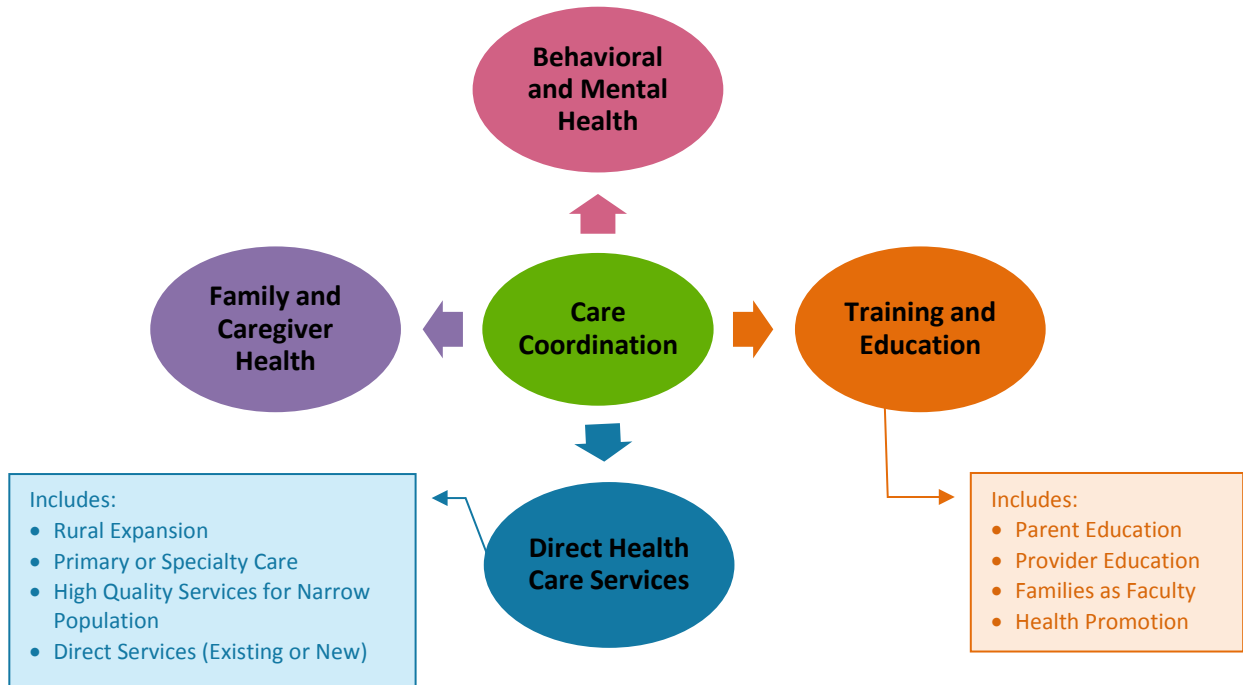
1. Increasing the value of the program for those served  
*Identified through qualitative data collected through stakeholder input sessions.*
2. Evaluating relevancy of program services offered for families  
*Identified through analysis of existing direct service and clinic service provision data.*
3. Evaluating cost-effectiveness of direct and clinical services  
*Identified through a cost-analysis of all funding sources, including contracts and clinical services.*
4. Identifying opportunities for improvement and alignment with state and federal programs  
*Identified through utilizing quality improvement methodology, statute and regulation review, and the Transformation of the Maternal and Child Health Block Grant, aka "MCH 3.0."*

Early in the process, it was clear that a shift was needed in the services provided, policies and procedures, and accountability of subcontracted partners. This shift in the "way of doing business" required extensive review and evaluation prior to making changes within the program. This document will provide an overview of the strategic planning process, outcomes and expected changes, and next steps for the KS-SHCN Program.

The initial phase of Special Health Care Needs (SHCN) Strategic Planning involved a group of staff and clinic partners and a group of family leaders who met in July and August of 2013. Each group identified five policy priorities for consideration.

Professional Priorities	Family Leader Priorities
1. Care Coordination	1. Care Coordination
2. Parenting Education (focus on financial counseling, effective advocacy, partnering with providers)	2. Families as Faculty Program (focus on provider knowledge of SHCN needs and family impact)
3. Behavioral and Mental Health	3. Family and Caregiver Health
4. Focus on High Quality Services for a Narrowed Population	4. Expansion of All Service Systems to Rural Communities
5. Primary Medical Care Coverage	5. Behavioral and Mental Health

Two priorities, Care Coordination and Behavioral/Mental Health, overlapped the two groups. Other priorities were similar, resulting in five priority issues. These priorities were then presented for in-depth consideration at the second phase of the strategic planning.



The second phase of the strategic planning engaged stakeholders, including community organizations and agencies, and family leaders in conducting an analysis of the current systems’ strengths, weaknesses, opportunities, and threats (a.k.a. a SWOT analysis) and identifying gaps within the system. The SWOT and Gap analyses provided necessary information throughout the planning process about resources and the current capacity of those resources to serve families. Additionally, key concepts and themes emerged, to assist in the development of overall objectives and strategies in the third phase of the strategic planning process. Key concepts are outlined in Appendix A.

Upon completion of this analysis, the SHS-FAC reviewed each priority and the related key concepts and drafted the following definitions around each priority.

**Cross-System Care Coordination**

•“Patient and family-centered approach that utilizes team-based and assessment activities designed to meet the needs of children and youth while enhancing the capabilities of families. It addresses interrelated medical, behavioral, educational, social, developmental, and financial needs to achieve optimal health.”

**Family Caregiver Health**

•“Supporting the physical, emotional, social, and financial well-being of families with CYSHCN, particularly that of the family caregivers. A family caregiver is any individual, including siblings, who supports and cares for another person and may or may not be a biological relative.”

**Behavioral Health Integration**

•“Collaborative services for the prevention and treatment of mental health conditions that support the functioning of children, youth, and families in all settings, including home, community, school, and work. Efforts should be focused on keeping children in their home and/or community.”



### Training & Education

- “Supporting diversity in the provision of services for the special health care needs (SHCN) population through training and education of families, community members, medical and community providers, local and state service programs, and legislators. This includes family and youth leadership development in building a stronger advocacy network in Kansas.”

### Direct Health Services and Supports

- “Services delivered one-on-one between a health professional and patient, which may include primary, specialty, or ancillary health services, such as: inpatient and outpatient medical services, allied health services, medications, and pharmaceutical products, laboratory testing, xray services, and dental care. Access to highly trained specialists or services not generally available in most communities may also be included in this definition.”

The third phase of the strategic planning process was designed around the development of objectives to address the five new priorities of the KS-SHCN program. Stakeholders were convened for a final planning meeting to review the analysis from phase 2 and the definitions providing guidance by the SHS-FAC. The group worked together to draft objectives for each priority. Upon completion of the objectives, internal discussions ensued to create strategies and measures to guide the work. The strategies were approved by the SHS-FAC and integrated into the overall Title V 2020 State Action Plan. Overall, KS-SHCN developed a robust action plan, with 5 priorities and a total of 14 objectives and 31 total strategies. The complete KS-SHCN 2020 Strategic Plan can be found in Appendix A.

## ■ Standards for Systems of Care for CYSHCN

One purpose of the KS-SHCN strategic planning was to align program services and contractual supports with the “Standards for System of Care for Children and Youth with Special Health Care Needs.” This began with the strategic planning efforts, however has been enhanced with the KS-SHCN 5-Year Plan and KS-SHCN continues to build infrastructure and capacity for increased services for all CYSHCN in Kansas.

In September 2015, KS-SHCN was awarded the “State Implementation Grants for Enhancing the System of Services for CYSHCN through Systems Integration” grant to support access for CYSHCN to receive services through an accessible, continuous, comprehensive, coordinated, compassionate, culturally competent, and family-centered medical home. One goal of that grant was to develop a multi-system state plan that supports system standards and enhanced services for children and youth with special health care needs.

All activities under this grant were aligned with the *Standards* and integrated into KS-SHCN and Title V activities and provide framework as to the purpose and intent of this state plan. However, this plan encompasses much more than the KS-SHCN or Title V systems, and it is desired the plan will include each of the ten domains and system partners serving CYSHCN within these domains.





Throughout the development of these standards, national stakeholders and key informants provided information about the existing system of care and identified key themes. More detail about these can be found in Appendix C. The following is an excerpt from this document to highlight some of the key themes and provide context as to how the above domains were created.

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- *A need for and potential role of standards to strengthen systems of care for CYSHCN was acknowledged.*
  - *CYSHCN need to be considered in current health service delivery reforms in states.*
  - *System standards should promote and foster systems integration within health care delivery systems and other child-serving systems.*
  - *Standards should build on existing national frameworks for CYSHCN.*
  - *Standards for CYSHCN should be aligned with existing adult health care standards.*
    - *Focus standards on the system components rather than condition specific issues, such as: care coordination and medical home; access to care; cultural competence; family-centered care; transition; and information technology and safeguards, including Electronic Health Records.*
  - *Standards should address identification and screening of CYSHCN and issues of difficult transitions between coverage types.*
  - *Efforts to promote quality measurement and improvement to address health outcomes should be considered in the development of standards.*
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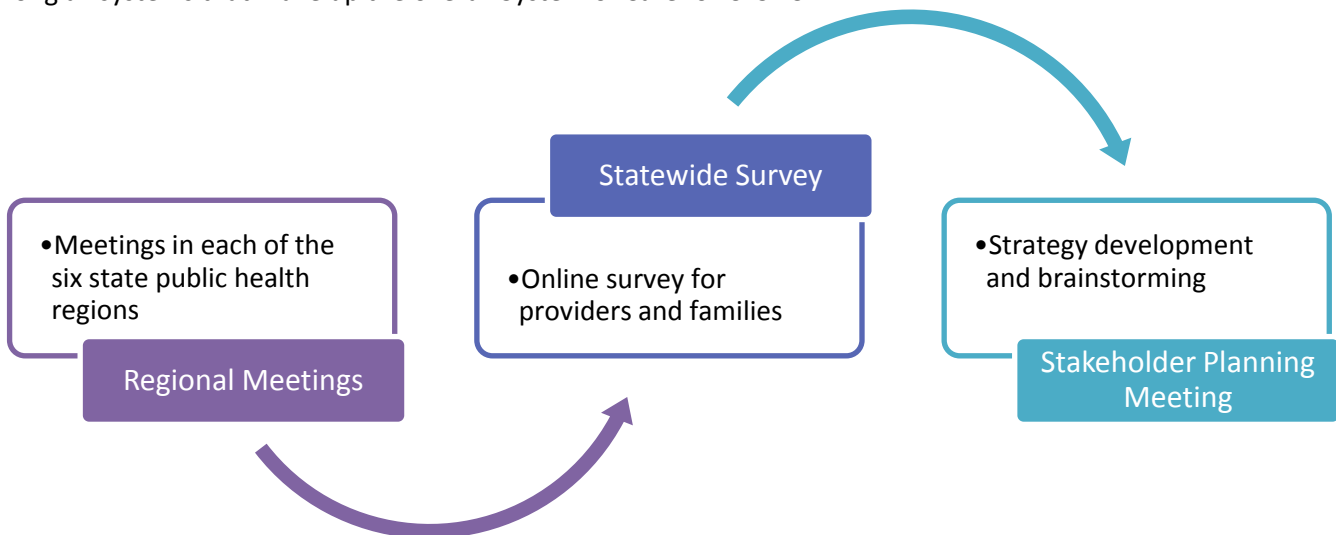
In 2017, the *Standards for System of Care for Children and Youth with Special Health Care Needs, Version 2.0*, was released, reiterating the intense need of these standards and taking into account the utilization across the country by national, state, and local stakeholder groups – even outside of the Title V arena. This broad utilization provided additional need for updates to the *Standards* to increase readability and ease of use. The most significant changes included the adoption of the “Foundational Standards” - designed to be inclusive of any system that serves the CYSHCN population – Family-Professional Partnerships and Insurance & Financing. The individual standards that were found within these two domains in Version 1.0 were integrated and aligned across relevant domains in Version 2.0.

It should be noted that the work to develop the state plan was nearly final when the *Standards: Version 2.0* were released and therefore the community work was finalized utilizing the framework under Version 1.0. For ease of alignment and collaborative work around the newest version of the *Standards*, this State Plan report has been aligned with the *Standards: Version 2.0*.

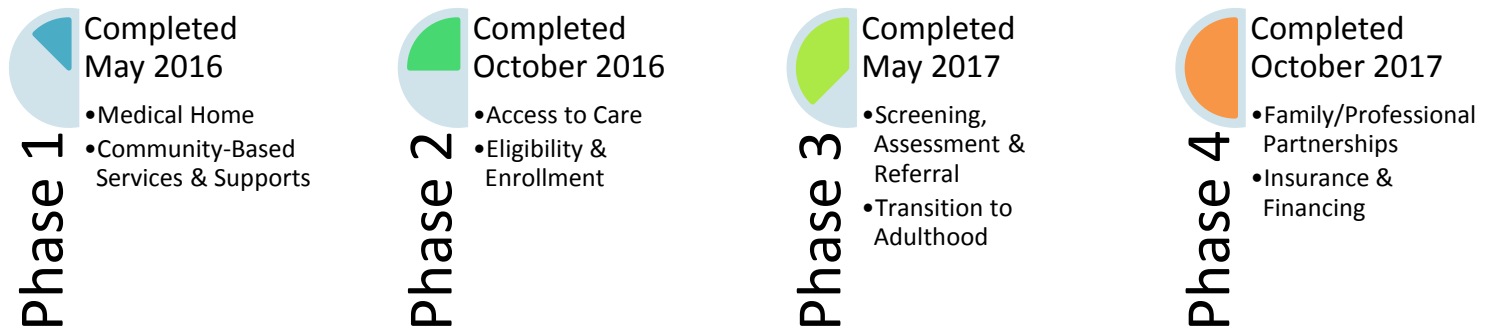
As stated previously, one of the goals of this grant is to “develop a multi-system state plan that supports system standards and enhanced services for children and youth with special health care needs.” With this in mind, KS-SHCN set out to develop a state plan that would meet the needs of the overall system of care, rather than simply developing a plan to meet the grant objectives.

## State Plan Development Activities and Findings

Due to the extensive nature of this plan, the plan was conducted in stages and is believed to be an ongoing document with continual focus on each domain and the related standards in the future. Each phase conducted utilized a community engagement process and engaged the most appropriate partners for each domain. Each stage utilized the same process, see diagram below, with the ultimate outcome of a plan that includes a shared vision and ownership among all systems that make up the overall System of Care for CYSHCN.



Through the qualitative data received through the regional meetings, the quantitative data received through the survey, and the strategies presented at the planning meeting, each stage will ultimately create a shared vision for the domains discussed.



### ■ Regional Meetings

For each phase, KS-SHCN partnered with the Wichita State University Community Engagement Institute to host six (6) regional input meetings across the state of Kansas. These were located in each of the public health regions and were strategically located in different cities/towns in each phase. At each meeting, participants were given the opportunity to hear an overview of the KS-SHCN program and a brief overview of the *Standards for Systems of Care for CYSHCN*. Following a question and answer period, participants were then asked to discuss four standards chosen from domains being examined.

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?*

### ■ Statewide Surveys

In partnership with the Wichita State University's Center for Applied Research and Evaluation (CARE), KS-SHCN conducted an online survey to gain input from provider and families about how well the current system is meeting the *Standards*. The survey concentrated on participants' perceptions of the core domains of specific focus during that phase. The purpose of the survey was to gather input from service providers and consumers about how well the current system is meeting those specific *Standards*.

The survey was anonymous, only asking the region they live in and where they receive/provide services. Additionally, we asked if the respondent was a service provider or a consumer/family member/caregiver for the purpose of identifying any differences in opinion. Ultimately, the respondents were asked to rate how well they thought the current system met the *Standards*. Survey questions were reworded for consumers to support the varying literacy needs of those participating in the survey and used a Likert scale (1= "not well at all" to 4= "very well") to gauge how things were going.

### ■ Stakeholder Planning Meetings

To complete each phase, KS-SHCN hosted a group of key stakeholders from across the state to discuss issues related to systems integration for domains within the *Standards*. These stakeholders engaged in a reflective and participatory process and were asked to:

- Review the community input that was previously collected (regional meetings and statewide survey)
- Articulate a vision for success for each domain
- Identify potential opportunities and barriers to cross-system coordination
- Discuss strategies for engaging potential partners in the integration process

With regard to each domain, meeting participants were presented with community input regarding Kansas’ ability to meet the current standards and discuss in small groups what they considered to be the most important changes that would be needed if Kansas is going to make progress on meeting these standards and where they thought new connections need to be made, based on the community’s responses. Additionally, the participants were split into groups, based on the domain they felt most informed and passionate about, to discuss three questions related to cross-system coordination.

- What new opportunities exist for cross-system coordination?
- What barriers are there to cross-system coordination?
- What is the best way to engage partners?

## Key Recommendations

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Considering the community input and the resulting conversations, key stakeholders were asked to define success from a variety of different perspectives (family, provider, and referral networks), develop metrics of this success, and discuss collaboration opportunities. This section will outline for each of the *Standards* domains, the definitions of “success” and opportunities for cross-system coordination or collaboration.

### ■ Foundational Standards for Systems of Care for CYSHCN

There are four essential principles that make up the foundation of a system of care for children and youth with special health care needs. These principles support active partnership with families, services that meet families where they are and address the specific needs of individuals and families, adequate insurance coverage, and evidence-based and evidence informed practice.

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Children and families of CYSHCN are active, core partners in decision making in all levels of care.

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All services and supports for CYSHCN are implemented and delivered in a culturally competent, linguistically appropriate, and accessible manner to best serve CYSHCN and their families.

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Insurance coverage for CYSHCN is accessible, affordable, comprehensive, and continuous.

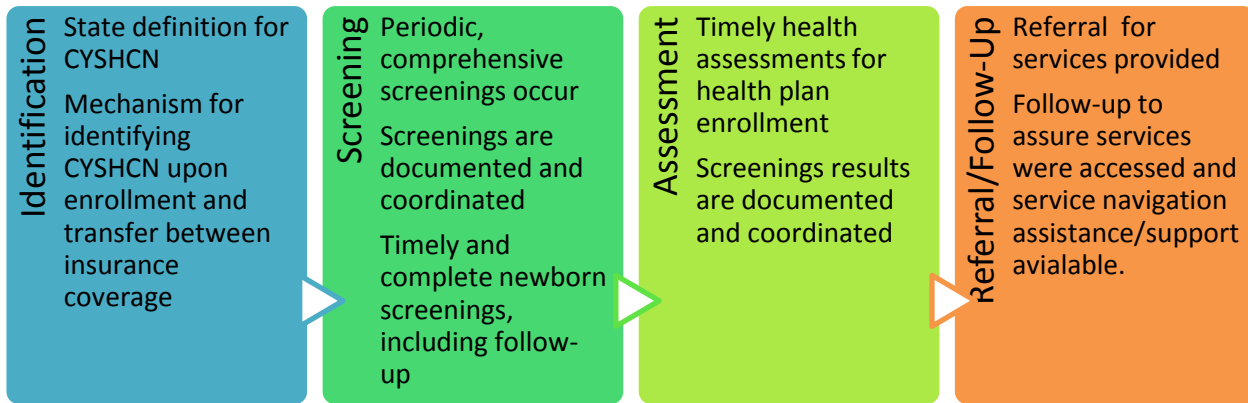
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All care provided to CYSHCN and their families is evidence-based where possible, and evidence-informed and/or based on promising practices where evidence-based approaches do not exist.

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### ■ Domain 1: Identification, Screening, Assessment and Referral

This domain focuses on addressing the overall system outcome that all children are screened early and continuously for special health care needs. This domain includes 10 standards broken down into four areas: Identification, Screening, Assessment and Referral.



Defining Success

For **CYSHCN and their Families**, participants stated that success would be defined as:

- Screening programs focused on physical, developmental, oral, and behavioral health for children of all ages.
- Assure effective follow-up occurs following screenings to assure referral mechanisms are in place to address the medical, social, and community service needs of CYSHCN and their families.
- Coordination among service providers and referral sources at all ages.

For **Providers**, the system would:

- Provide educational programs that support enhanced knowledge and awareness of developmental screening guidelines among pediatricians and physicians.
- Focused initiatives around the Bright Futures Guidelines for all populations.
- Increased communication among providers to monitor service delivery and coordinated care.
- Ongoing education of parents and providers about best practices for screening, assessment, and referral.

For **Referral Networks**, the group determined that success would include:

- Establish partnerships with early childhood programs, local health departments, providers and others in the referral network to assure early screening programs are in place.
- Support coordinated and integrated referral processes and protocols to address needs before, during, and after concern is noted or crisis is experienced.
- Integrated processes that support effective coordination and communication across service systems.
- Universal electronic screening forms with required fields to assure complete referral information is available to support coordinated supports.
- Cross-system collaboration and access to information exchanges to support referral monitoring and tracking.

### Measuring Success

After reviewing information gathered from the community input sessions regarding potential partners, participants were asked to consider on whose actions success most depends and what we should look at/consider in measuring our success. They indicated this would include providers, state agencies, early childhood programs, insurers, medical schools, licensing boards, and any individual or organization engaged in Kansas screening, assessment, and referral systems.

The following are some specific metrics that could be captured and analyzed to show progress on these *Standards*.

- Increased utilization of universal screening assessment
- Number of completed developmental screenings
- Quantitative measures of access to care coordination services
- Consumer satisfaction among screening, assessment, and referral services
- Number of completed referrals

There were several notable initiatives or activities described throughout this process that would provide opportunity for data collection, measurement, and evaluation of the overall system of care for CYSHCN, most specifically the creation of a child data tracking system through a state electronic health system including electronic forms with required fields and standardized data collection. One suggested implementation involved developing and expanding the Kansas Health Information Network (KHIN) to improve capabilities and increase access to more providers.

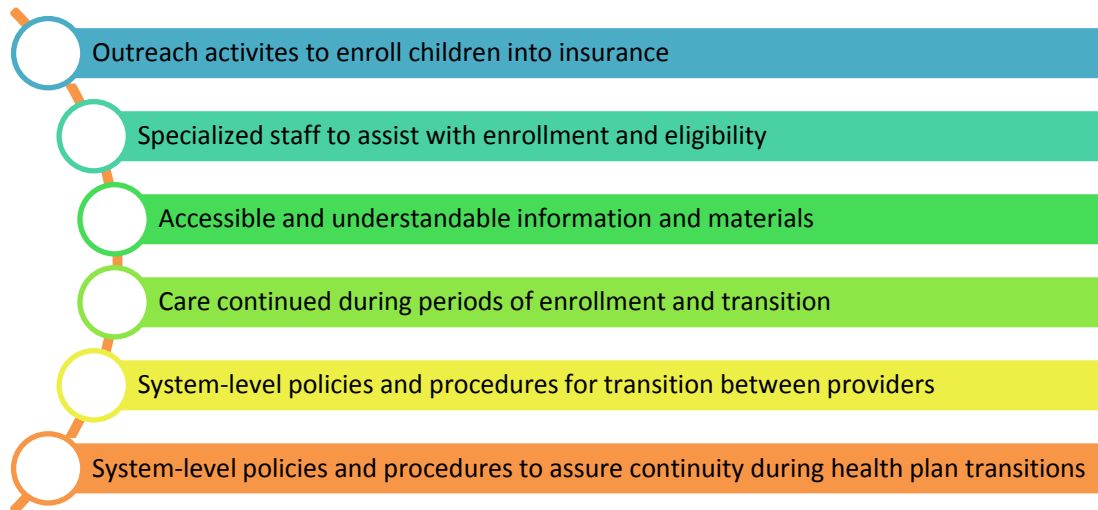
### Cross-System Coordination

Throughout the meeting, participants were asked to describe opportunities and barriers around effective cross-system coordination to make progress towards the vision and definition of success outlined through the process. Ultimately, the group identified that there were several existing and ongoing initiatives that could be leveraged and assist in forward movement, while recognizing barriers around development of new data systems and insurance billing and reimbursement. The most prominent themes from the group discussion under each area is listed below. The full list can be viewed in Appendix F.

Opportunities to support...	Barriers to address...	For strong engagement, we need...
...providers around the use of the Bright Futures guidelines.	...lack of standardized screening tools and follow-up processes.	...improved parent and family engagement/follow-through.
...focus on screening and assessment activities for the non-Medicaid and middle/late childhood populations.	...data and information sharing challenges across systems, including addressing data transfers/common data interface.	...all system partners (e.g. state agencies, local community-based programs, insurers, etc.) working collaboratively for a common goal.
...increased collaboration through cross-system care coordination.	...time and resources needed to conduct screenings and provide appropriate follow-up (especially for medical providers).	...clarity around who is screening and providing follow-up.

## ■ Domain 2: Eligibility and Enrollment in Health Coverage

This domain focuses on assuring appropriate programs and supports are in place to assure children and families are enrolled in health coverage that meets their needs. This domain should not be confused with assuring accessible, affordable, comprehensive, or continuous insurance coverage. This domain includes 6 Standards that focus on:



### Defining Success

For **CYSHCN and their Families**, participants stated that success would be defined as:

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

For **Providers**, the system would include:

- Adequate reimbursement for services, including assisting families with enrollment in insurance coverage, and maintenance of highly qualified staff to help navigate the appropriate systems.
- Single-point-of-entry to electronic applications that automatically trigger eligibility and enrollment for a variety of programs.
- Providers would spend less time on payment issues and more time in direct patient care, leading to improved health outcomes for their patients.



For **Referral Networks**, the group determined that success would result in:

- An increase in the number of children screened, identifying children with special health care needs sooner.
- An increased number of families who are successfully referred to the services they need.
- Adequate compensation to providers for their efforts in providing a sustainable and stable network of care.

Measuring Success

Participants indicated that there are several existing metrics that could help measure progress on system integration improvements. They indicated this would include providers, local health departments, state agencies, families, insurers, nursing and medical schools, federally qualified health centers, among others. These metrics include:

- Number of benefit denials and appeals
- Number of coverage denials
- Amount uncompensated care & self-pay
- Number of days with lapsed care
- Decreased clearinghouse and coding calls to answer questions
- Decrease in catastrophic care

In addition to the variety of insurance claim data that could indicate that the system is adequately matching insurance coverage needs to the most appropriate coverage options, there were other measures that would indicate success in this area such as improved health outcomes, a focus on health equity and addressing social determinants of health, and equitable access to and utilization of insurance coverage options.

Cross-System Coordination

In addition to what is outlined below, this process uncovered a very long list of opportunities, barriers, and partner engagement strategies. The top three from the group under each area is listed below. The full list can be viewed in Appendix F.

Opportunities to support...	Barriers to address...	For strong engagement, we need...
...diagnosis-driven eligibility to insurance coverage options.	...lack of knowledge of coverage options and eligibility requirements.	...general education of coverage options for providers, families, and managed care partners.
...shared electronic transfer of insurance data to support insurance eligibility determinations and timely enrollment.	...poor coordination during points of transition among providers and/or health plans to prevent disruption of care.	...care coordination plan shared among families, providers, and insurance companies to assure the plan is adequately covered.
...education programs for families and providers at the local level.	...difficult to navigate systems and application processes that are not user-friendly.	...increased availability to care/service coordinators.

### ■ Domain 3: Access to Care

This domain focuses on assuring appropriate access to primary and specialty services. This domain includes 11 Standards that focus not only on the access to services, providers, subspecialists, children’s hospitals, pediatric regional centers, and ancillary providers, but on access.

#### Defining Success

For **CYSHCN and their Families**, participants stated that success would be defined as:

- Well informed consumers of services who have access to system navigators that can help them locate a culturally competent network of providers.
- Access to appropriate legal representation, when needed, for a variety of issues unique to children with special health care and developmental needs.
- Families would be able to work with a network of providers adequate enough to allow them to choose services that best meet their family’s needs and is sustainable enough to remain that way.

For **Providers**, the system would include:

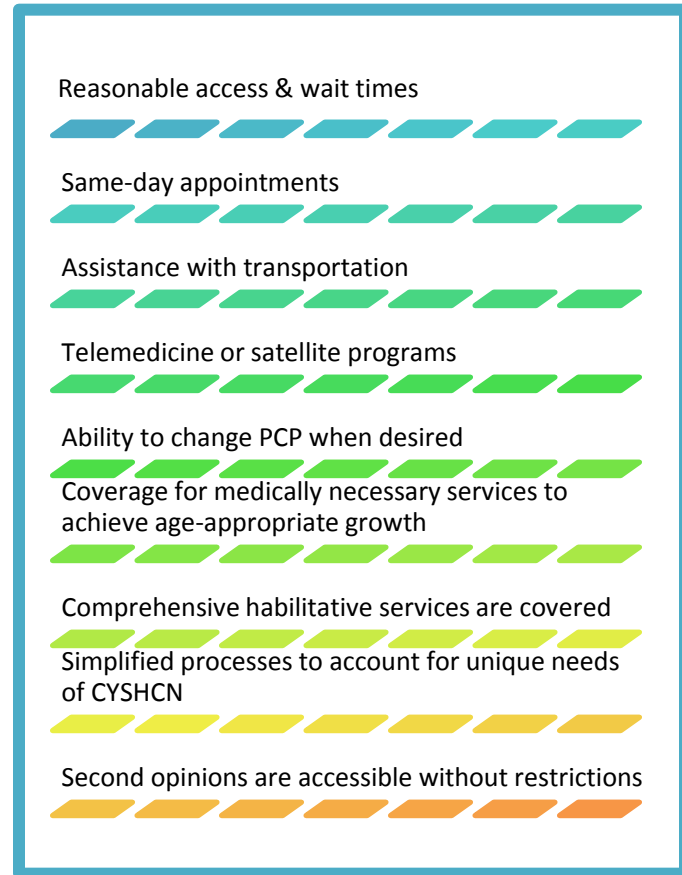
- A stable, sustainable network.
- Adequate incentives and reimbursement rates.
- A knowledgeable and competent workforce with clearly defined roles.
- Access to the technology and resources they need to provide quality services.
- Providers would experience fewer bureaucratic “hoops” to jump through, enhanced collaboration across systems, and have confidence that these other systems are there to support families and the network itself.

The group did not note any specific success statements for referral networks for this domain, however it is expected that the above would directly and indirectly support the overall network of referral providers.

#### Measuring Success

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

- Number of missed appointments, inpatient admissions, and emergency department visits
- Decreased travel time and wait times for appointments
- Decreased lapsed authorizations and coverage
- Increase in the number of shared plans of care
- Decreased out of pocket expenses



Many of the metrics above would be available through access to insurance utilization data, however the group also noted the importance of looking at improved health outcomes for the patient, but also for the entire family. Discussion showed that access to care for the CYSHCN specifically is great, but a truly effective and successful system of care would also measure the access to care for the family caregiver to assure their needs are met as well. Additional measures include increased access to telemedicine services, care coordinators and case managers, and bilingual providers. Another measure of an adequate system was related to satisfaction among providers (decreased provider turnover and burn out) and families (number of request to change PCP or insurance providers).

**Cross-System Coordination**

As with many other domains, the group brainstormed long lists of opportunities to support the system, barriers, and strategies to engage partners. The top priorities from the group under each area is listed below. The full list can be viewed in Appendix F.

Opportunities to support...	Barriers to address...	For strong engagement, we need...
...enhanced telemedicine and outreach clinics utilization through clinics and hospital partnerships.	...differing level of technology and connectivity available to support expansion to telemedicine.	...opportunities for networking, learning, and coordinating at state and local level – with families.
...service delivery across networks and state lines.	...shifted focus from patient-care to business model for providers.	...shared vision with shared influence and aligned funding expectations/requirements.
...partnerships with nursing and medical university to recruit and retain providers.	...insurance challenges (poor provider reimbursement rates, cumbersome processes for providers and families, etc.).	...incentives to participate (e.g. state and federal tax deductions, loan forgiveness programs, etc.)

**Domain 4: Medical Home**

This domain focuses on addressing the overall system outcome that all CYSHCN will receive family-centered, coordinated, ongoing comprehensive care within a medical home. This includes access to a medical home capable of providing or coordinating services as a team, with the family as a core member.

The Medical Home domain encompasses a number of services and systems – including those pictured to the right – and is broken down by 4 categories: Pediatric Preventive and Primary Care, Medical Home Management, Care Coordination, and Pediatric Specialty Care.

**Pediatric Preventive and Primary Care** as part of the medical home, which assures care is focused on overall health, wellness and prevention. **Medical Home Management** ultimately assures that the medical home practice is accessible and coordinated to support the individual needs of the CYSHCN. **Care**



**Coordination** as part of the medical home, and integrated with community-based services, assures that all CYSHCN have access to patient- and family-centered care coordination and that family strengths and needs are centered in the shared plan of care. **Pediatric Specialty Care** focuses on comprehensive and coordinated services that include specialty, behavioral, acute care, intermediate, and outpatient services and community support services. In total, there are 21 Standards in this domain. *It is acknowledged that the information below may not address all Standards within in this domain.*

### Defining Success

For **CYSHCN and their Families**, participants stated that success would be defined as:

- Safe, effective, affordable care that would be integrated, person-centered, and easy to access.
- The system would provide culturally responsive care that works for families – providing “carrots”, not “sticks” – and allows for whole family health to be achieved.
- Consumers and families would be educated about the resources and the choices they offer.
- Consumer and families would be empowered and equipped to responsibly self-manage their care, understand their rights within the system, and trust the system to help them become functioning members of their community.

For **Providers**, the system would:

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

For **Referral Networks**, the group determined that success would include:

- Easy, transparent processes that would equip and empower families to the level that they can be most successful.
- Resources would be available to families close to home and referral providers could count on a fiscally sound network to be available when they send families for assistance.
- There would be effective, bi-directional, communication and coordination amongst providers, including those who are located out of the state.
- For patients that require hospitalization, the process would begin with quality discharge planning and all providers would have access to an accurate and up-to-date list to make this possible.

- Families who enter the system are engaged and educated and providers teach them the skills they need to advocate for themselves.

**Measuring Success**

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

The following are some specific metrics that could be captured and analyzed to show progress on these *Standards*.

- Consumer satisfaction scores of their medical home provider(s)
- Number of certified medical homes based on predicted population to be served
- Number of services accessed
- Number of preventative health and oral health visits
- Quantitative measures of health outcomes
- Number of shared plans of care

Throughout the discussion there were two data sources specifically named during the discussion, the National Survey for Children’s Health and the Centers for Medicaid and Medicare Healthcare Quality Measures.

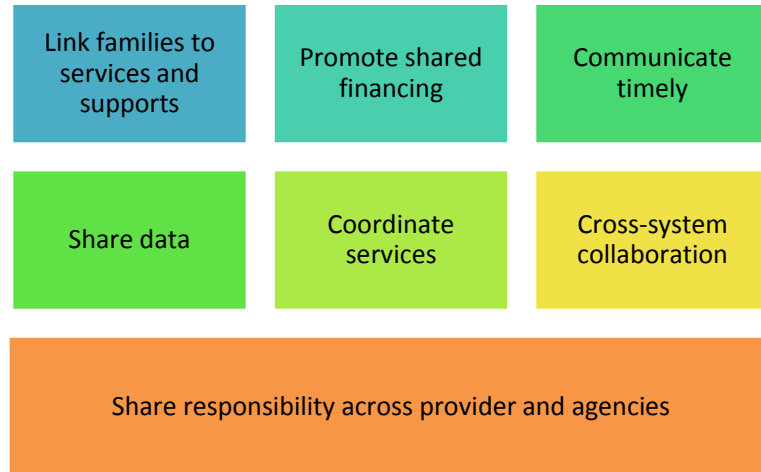
**Cross-System Coordination**

The group identified that the number one way to support cross-system coordination around the Medical Home domain was a clear vision, from the highest level to the lowest level. This would assist the necessary partners in sharing the risk and responsibility and, in turn, the necessary time and resources investment needed to address each of the top themes outlined below. The full list can be viewed in Appendix F.

Opportunities to support...	Barriers to address...	For strong engagement, we need...
...patient/family navigators within the community and medical home practices.	...reimbursement or coverage for medical, dental, and mental health services.	...opportunities to engage with other stakeholders around these topics.
...geographic extension of services, specifically utilizing telemedicine.	...lacking resources available for the provision of medical home services, specifically the time necessary to add more to an already taxed and resource-limited system.	...aligned incentives based on partner needs, expectations, requirements, and desires.
...families’ ability to acquire reliable and dependable transportation and interpretation resources.	...access to primary and specialty care in rural areas of the state.	...reimbursement/ Pay for performance (incentives).

## ■ Domain 5: Community-Based Services and Supports

This domain focuses on addressing the overall system outcome that all CYSHCN and their families are provided access to comprehensive home and community-based supports. This includes assurance of agreements and partnership between health systems and community agencies to promote the items listed to the right.



Similar to the Medical Home domain, the Community-Based Services and Supports domain is extremely cross-cutting, with shared sub-categories with individual Standards, and encompassing of a number of services and supports. There is a total of seven Standards, crossing three sub-categories: Respite Care, Palliative and Hospice Care, and Home-Based Services.

**Respite Care** focuses on both planned and emergency respite services and that families are screened for respite care needs regularly. These Standards also provide for education and information dissemination around available respite services and assistance with accessing such resources when needed. **Palliative and Hospice Care** assures that curative and palliative care are both available and offered to CYSHCN. It is also noted that this portion of the domain focuses heavily on the family-centered model of care that respect the family’s preferences, values, and cultural beliefs. **Home-Based Services** focuses on assurance that home health care is a covered benefit for CYSYCN and that the care is provided by those with experience working with the pediatric population and includes both health care for the child and supportive care for the family. *It is acknowledged that the information below may not address all Standards within in this domain.*

### Defining Success

For **CYSHCN and their Families**, participants stated that success would be defined as:

- Includes opportunities for whole family health – families/caregivers and siblings whose physical, emotional, and social support needs are met.
- Families would be equipped an empowered to be responsible and successful in managing their care with increased expectations for their quality of life.
- Effective coordination and collaboration across the lifespan that includes access to qualified providers, partnerships with schools for in- and out-of-school resources and smooth transitions as needs change.
- When parents/caregivers ask questions, they receive clear answers and experience open sharing of information from providers that results from a person/family-centered approach to care.

For **Providers**, the system would:

- Encompass the ability to share relevant information across provider networks and work within interdisciplinary teams.

- Provide adequate reimbursements – perhaps in the form of “bundled” billing – and billing for coordination would be an allowed expense.

For **Referral Networks**, the group determined that success would include:

- More engagement of “unusual” voices or non-traditional partnerships.
- There would be adequate resources to refer families to and these could be located through a searchable database that includes many systems of care, including access to satellite hospital/clinic services. With a centralized “help” button that contacts a trained professional that can offer personalized support and would track referrals.

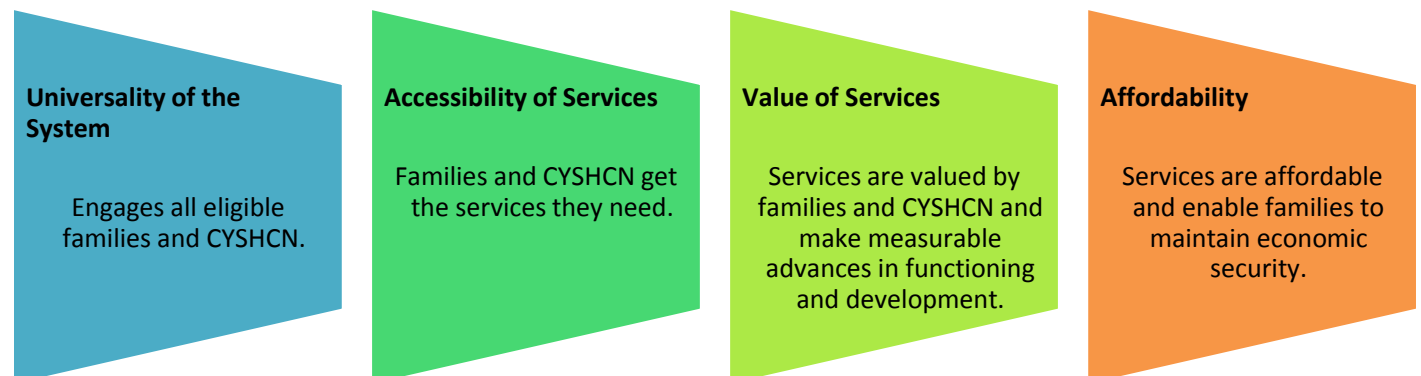
**Measuring Success**

The Community-Based Services and Supports domain encompasses several services and systems – including those pictured to the right. Specific partners directly noted in the meeting include the Community Developmental Disability Organizations; Aging and Disability Resource Centers; Community Mental Health Centers; insurers; home health providers; policy makers; communities; and the lead state agencies (KDHE and KDADS). Participants indicated the following metrics could help progress on these efforts.

- Consumer satisfaction
- Utilization of shared resource guide
- Number of enrolled, individual claims (catastrophic vs. natural progression of the disease)
- Quality of life metrics for families
- Provider engagement reports
- Decreased healthcare costs



Specifically, the National Center for Ease of Use of Community-Based Services was noted as a “framework” that could be considered for future planning in this arena. This framework focuses on:





Ultimately, it was noted that this framework and measuring the accessibility to community-based services and supports around each of the sub-categories within this domain will improve patient outcomes and allow programs to become more sustainable.

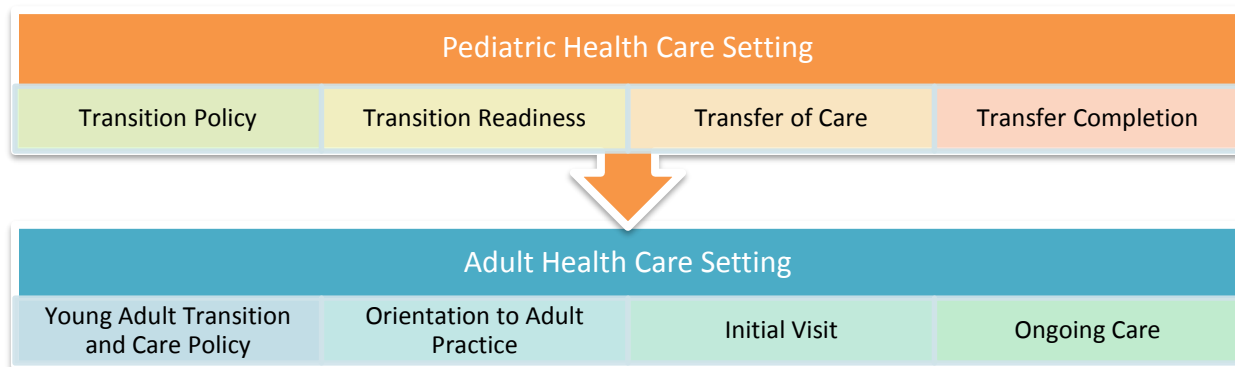
**Cross-System Coordination**

As with many other domains, the group brainstormed long lists of opportunities to support the system, barriers, and strategies to engage partners. The top priorities from the group under each area is listed below. The full list can be viewed in Appendix F.

Opportunities to support...	Barriers to address...	For strong engagement, we need...
...use of blended funding (state/federal) to support system-building initiatives.	...lack of resources (funding and technology).	...shared vision with clearly articulated collaboration needs identified.
...collaboration with non-traditional partners to assure and provide supports and services.	...lack of awareness and understanding of the needs.	...sustainable and accurate resource network (such as database that can work across disciplines).
...technology initiatives to make services more accessible, such as telehealth.	...language and communication barriers between patients, providers, and insurers.	...to see successful collaboration in this area (promote encouraging initiatives or outcomes).

**■ Domain 6: Transition to Adulthood**

This domain focuses on assuring youth with special health care needs receive the services necessary to make transition to adult care. This domain is separated out by pediatric and adult health care settings and includes a total of 8 Standards.



**Defining Success**

For **CYSHCN and their Families**, participants stated that success would be defined as:

- Education would be available on the importance of transition planning and guide families on when to begin the process and what the transition process entails, including resource mapping.
- Designated staff at primary care provider offices to assist in the transition referral process.

For **Providers**, the system would:

- Adult care providers would be educated to understand and equipped to address the unique needs of YSHCN who are transitioning to adult care.
- Reimbursement models, inclusive of behavioral health and transition-related services, would incentivize providers to serve the CYSHCN population into adulthood.

For **Referral Networks**, the group determined that success would include:

- An effective referral system would be established through a comprehensive electronic referral network and a statewide resource list of adult providers willing to accept YSHCN as patients.

Measuring Success

After reviewing information gathered from the community input sessions regarding potential partners, participants were asked to consider on whose actions success most depends and what we should look at/consider in measuring our success. They indicated this would include pediatric and adult health care providers, insurers, families, medical schools, provider practice organizations, local providers, community mental health centers, among others. Participants indicated the following metrics could help progress on these efforts.

- Demonstrated increase of knowledge, skills, and collaborative efforts among providers
- Number of times transition code is utilized
- Youth perception and satisfaction of transition activities
- Number of YSHCN with an adult primary care provider
- Number of referrals completed to adult health care providers

Cross-System Coordination

As with many other domains, the group brainstormed long lists of opportunities to support the system, barriers, and strategies to engage partners. The top priorities from the group under each area is listed below. The full list can be viewed in Appendix F.

Opportunities to support...	Barriers to address...	For strong engagement, we need...
...standardized transition education among providers and families to support effective transitions.	...lack of clarity around how the system works for transition (e.g. reimbursement, services, resources, etc.).	...collaborative partnerships that focus on the distinct strengths of each agency to support the coordination of transition activities.
...coordinated transition efforts to reduce duplication of services and lapse in continuity of care.	...limited time and financial resources and competition with other priorities.	...stronger communication between pediatric and adult health providers.
...partnerships through care coordination with other transition-related programs and partners.	...parents lack of encouragement and support for their YSHCN to become independent.	...alignment of transition-related priorities and strategic conversations to address the need.

## ■ Domain 7: Health Information Technology

This domain focuses on the accessibility and availability of electronic health information, resources and capacity for providers around health information exchange, family access to their health information, and cross-system processes that support information exchange.

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Electronic health information should be accessible, retrievable, and available across systems and meet meaningful use requirements.

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Medical homes have the capacity for electronic health information and exchange, including maintenance of clinical information.

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Families have easy access to their electronic health information.

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Documented processes exist for exchanging health information across care settings, including an agreement about exchanging information, the types of information to be exchanged, time frames for exchanging information, and to what extent referrals are made electronically.

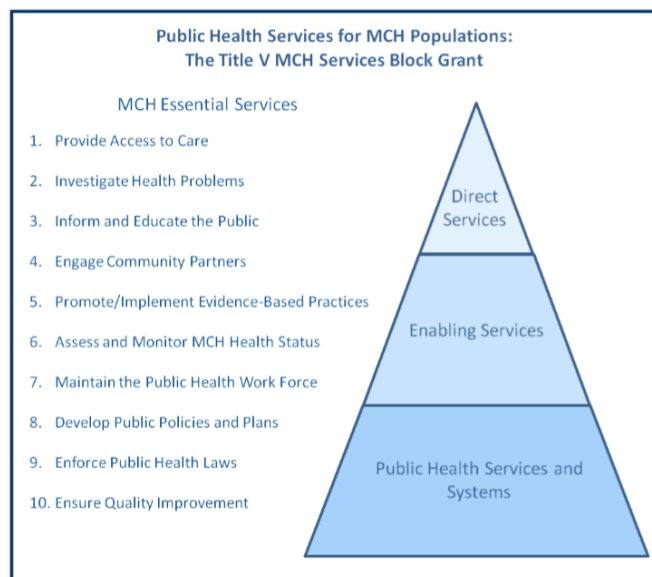
Additional work is needed to determine what success looks like in Kansas related to these domain Standards. This domain was unable to be included in the final phase of the state plan development process, however Kansas Title V is working to align resources to support this final phase of the state plan development by 2020, in conjunction with the next Five-Year Needs Assessment.

## ■ Domain 8: Quality Assurance and Improvement

This domain focuses assuring systems of care for CYSHCN engage in ongoing quality assurance (QA) and quality improvement (QI) to ultimately ensure CYSHCN needs are met on a timely basis. These Standards include:

- Family representation in system QI activities
- Monitoring of system capacity
- Promotion of geographic accessibility to services
- Monitoring of utilization of care, appropriateness of care, and compliance with system standards
- Surveys to assess experience of care for families of CYSHCN, including targeted efforts from high-risk and racial populations
- Assessment of out of pocket expenses, lost work burden, and other sources of family stress
- Assessment of child outcomes

One of the 10 MCH Essential Services is to “Ensure Quality Improvement” and aligns with the foundation of the Maternal and Child Health Services Block Grant services – Public Health Services and Systems. This domain includes three standards that are dedicated to this work.



In addition to the above components of QA and QI, additional Standards outline that anytime a child medical record review is conducted in a practice setting it should include a representative sample of CYSHCN and the utilization review and appeals process for CYSHCN includes members of the child's integrated care team.

Additional work is needed to determine what success looks like in Kansas related to these domain Standards. This domain was unable to be included in the final phase of the state plan development process, however Kansas Title V is working to align resources to support this final phase of the state plan development by 2020, in conjunction with the next Five-Year Needs Assessment.

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## Next Steps

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The compilation of this report is a good start to addressing these standards, however further action is required. There is much work to be done to fully identify the current and future capacities to address these Standards within the various systems of care for CYSHCN.

### Planning Activities for Quality Assurance & Improvement and Health Information Technology

As noted previously, additional work around the final two domains, Quality Assurance and Improvement and Health Information Technology, is needed.

**Title V Planned Activities:** This is being considered a part of the upcoming Title V Needs Assessment, to be completed by October 2020.

### Expanded Planning Activities Related to the Functional Standards

During the state planning process, Family-Professional Partnerships and Insurance and Financing were briefly addressed. More intensive work is needed to fully engage and embrace the intent behind these foundational standards.

**Title V Planned Activities:** This will be integrated into the upcoming Title V Needs Assessment, to be completed by October 2020.

### Partnership Building and Integration

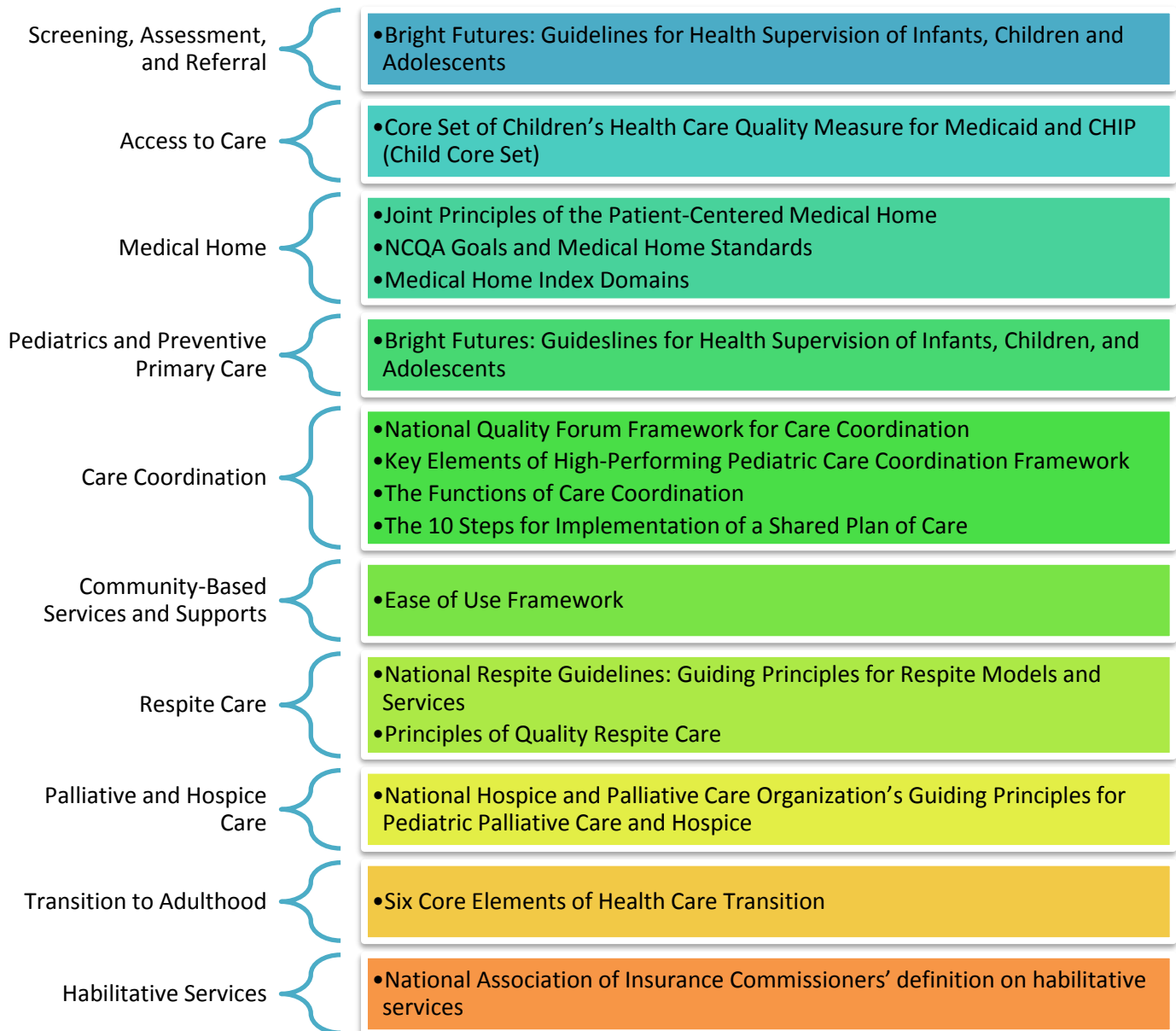
It is evident that the Standards cannot be met by one program, state agency, non-profit organization, or national entity alone. Just like the adage says, "It takes a village to raise a child." Similarly, it will take all of us, working together, in tandem and in collaboration, to assure a quality system of care for children and youth with special health care needs.

These Standards are only a guide for states, designed to supplement, not substitute, federal statute and regulatory requirements under Medicaid and other relevant federal laws, to help guide our actions and priorities. It is not the responsibility of any one agency or organization in Kansas to work towards building and cultivating partnerships across systems. It is the responsibility of each of us that play a vital role in helping CYSHCN and their families thrive and succeed in our communities. Continued conversation is needed, and will likely emerge from organic interactions, planned activities, or funded initiatives, but from what we learned through this process, it will happen because of a shared goal and vision for systems of care for CYSHCN.

**Title V Planned Activities:** Alignment and integration within the Title V Needs Assessment and other such assessments across the system of care for CYSHCN. Dissemination of State Plan

**National Principles and Framework Review and Research**

Throughout both iterations of the Standards work at the national level, a variety of national principles and/or frameworks are referenced. Frameworks, guidelines, or principles noted include:



**Planned Activities:** Some of these will likely be integrated into the upcoming Title V Needs Assessment, to be completed by October 2020.

## Appendices

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- **Appendix A. KS-SHCN 2020 Strategic Plan**
- **Appendix B. Kansas Title V 2020 5-Year Plan**
- **Appendix C. Standards for Systems of Care for CYSHCN: Version 2.0**
- **Appendix D. Regional Meeting Reports**
- **Appendix E. Consumer and Provider Standards Survey Reports**
- **Appendix F. Systems Planning Meeting Summary Reports**