

Appendix A: SHCN Strategic Plan

■ CARE COORDINATION

All children and youth with special health care needs (CYSHCN) receive family-centered, coordinated care.

Definition

“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.”

Objectives & Strategies

Assist, empower and equip individuals and families to navigate systems for optimal health outcomes throughout the life course.

1. Develop, monitor and evaluate a patient-centered care coordination action plan for all SHCN clients.
2. Complete the online navigational tool kit to provide resources and services

Improve communication and outreach among service providers, individuals, and families to help with coordination of care.

1. Implement communication and referral protocols for SHCN Care Coordinators and providers.
2. Expand KS-SHCN to have care coordinators located in all regions.

Increase collaboration between the KS-SHCN and other systems of care to support change.

1. Engage MCO's and primary care providers in collaborative coordination for SHCN clients.
2. Provide support to agencies working with foster homes and the foster care system in serving CYSHCN in foster care.

Key Themes

- **Treat the whole family**, not just the child, but all of those components – child care for other children, transportation to and from appointments, coordination of services, parent/caregiver support, teaching /training, parent physical & mental health, recovery issues, coordinating all the coordinators
 - Health care system trains you to focus on specific medical problem, but families have to focus on life
 - Develop relationships with the families
 - Understand that the child's challenges affects the family as well: need to educate, simplify the system, focus on relationships
- **Increase awareness** of available resources; still a lack of awareness about what's available
- **Improve care** statewide, particularly at the **local level and in rural areas**. Suggested two-pronged approach:
 - **Provide care regionally** (Garden City, Hays, Salina), not just in Kansas City and Wichita.
 - **Connect regional and local providers with national experts** on certain medical conditions to help access most current, evidence-based practices and services.
 - **Simplify the system**. Maximize the benefits of care coordination without letting these activities become burdensome or duplicative. **Clearly define roles and scopes of providers and health care teams, organizations and programs** to fill gaps and maximize coordination while minimizing overlaps and avoiding unnecessary bureaucracy.

■ FAMILY AND CAREGIVER HEALTH

Support optimal health and well-being for family caregivers of CYSHCN.

Definition

“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 support and cares for another person and may or may not be a biological relative.”

Objectives & Strategies

Support activities and initiatives to educate family caregivers on the importance of taking care of their own health needs and the impact of their health on those they care for.

1. Utilize KS-SHCN “Family Caregiver Assessment” to identify needs and resources for family members of KS-SHCN clients.
2. Provide education about how the role as a caregiver can impact their health and the ability to care for their loved one.

Engage and support collaboration among systems for the provision of respite services for SHCN family caregivers in order to proactively address their health care needs, including physical, emotional, and dental health.

1. Conduct a respite care needs assessment, including fiscal note, payment opportunities, and family impact.
2. Develop and implement a caregiver relief model to support families in meeting the parents physical and mental health needs.
3. Provide support for local partners to host sibling workshops or activities.

Provide training and education opportunities to support informed, engaged, empowered and equipped family caregivers and providers.

1. Develop a progressive family leadership program to empower and equip families as strong MCH advocates.
2. Provide family and sibling peer supports for those interested in being connected to other families with similar experiences.

Key Themes

- Biggest gap is **lack of awareness** of what is currently available. Both providers and families lack awareness of available resources.
- **Improve support for families. Family is an integral part of the plan.** How can the family be healthy to sustain the child’s health? Infant-Toddler Services does a nice job with this until the child reaches their third birthday, however this approach doesn’t really continue as the child grows.
 - If child is diagnosed after the age of 3 years, the family doesn’t get those services.
 - **Is there a way to pay families who provide care to children that is over and above what they would normally be expected to do** – would save funds overall *and* impact poverty. Poverty is a big predictor of family health issues. Also, is family reimbursement available for caregiving if child is over 18 years?
- Find assistance and resources for children who do not qualify for services but still have needs.

■ BEHAVIORAL AND MENTAL HEALTH

Behavioral health needs and supports will be integrated into the Kansas Special Health Care Needs system of care.

Definition

“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.”

Objectives & Strategies

Collaborate with other agencies serving individuals with behavioral health needs to support an integrated continuum of care.

1. Engage behavioral health partners (KDADS, KAIMH, NAMI, CMHCs) to assess possible opportunities for KS-SHCN to support the behavioral health field.
2. Build partnerships with providers and case managers to identify appropriate referrals for families and inform partners of, and offer support through, the SHCN Care Coordination efforts.
3. Partner with Medicaid to provide support for behavioral health telehealth clinics.

Educate families about behavioral health issues and provide referrals and resources of available services and peer supports.

1. Reduce stigma through community awareness and education, including parent and client education materials about behavioral health.
2. Partner with NAMI to offer youth and adult education programs to KS-SHCN clients.

All KS-SHCN families will be encouraged to have a behavioral health assessment and if needed, be supported in obtaining necessary services.

1. Integrate behavioral health supports into the KS-SHCN action plan, if applicable.
2. Develop follow-up protocols for families referred for behavioral health services and offer additional support as needed to assure services are received.

Key Themes

- **Need pre- and post- transitional services** for multiple transition points
- **Psychiatric Residential Treatment Facilities (PRTFs)** have limited capacity and other gaps
- **No routine early intervention or screening process** for behavioral or mental health; wait too long to identify problems
- **Need ability to bill without a specific diagnosis**
 - Allow parents/caregivers to reach out, access services, get questions answered without having to fear a label
- **Lack of community services**, need consistency
- **Respite care**

■ Training and Education

Support a society that is culturally sensitive, well-informed, and respectful of all people with disabilities through training and education.

Definition

“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.”

Objectives & Strategies

Equip and empower children, youth, and families to advocate for needed services, supports, and family/professional partnerships.

1. Provide youth-focused and youth-driven initiatives, such as Faces of Change, to support successful transition, self-determination and advocacy.
2. Conduct “Care Coordination: Empowering Families” trainings for parents of CYSHCN.

Provide training and education for providers to promote diversity, inclusion, and integrated supports in the provision of services for the SHCN population.

1. Host webinars and online trainings for health providers on caring for CYSHCN, adapting from the Caring for People with Disabilities course. Promote through conferences, grand rounds, webinars, etc.
2. Offer information and training to child care and education providers to support inclusion within those settings and assure higher quality care for CYSHCN.

Key Themes

- Increase awareness of available resources; **educate providers and communities about Families Together**
- Consider policy direction regarding training and education standards; need **requirement for the care of CSHCN among licensed providers** (hospitals, nurses, physician assistants, dental hygienists, etc.)
- Educate people in all the places where children are; **train community members and organizations how to respond to and ensure safety** (at a minimum) of children with special health needs; this includes teachers, child care providers, emergency responders, etc.

■ Direct Health Care Services

Provide gap-filling health services for CYSHCN and their families through partnerships, collaboration, and direct care supports.

Definition

“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.”

Objectives & Strategies

Collaborate with agencies and providers in the oral health system to support increased access to, and payment of, oral health services for CYSHCN.

1. Conduct a statewide needs assessment on oral health services for CYSHCN.
2. Provide dental hygienist services within KS-SHCN specialty clinics.

Partner with public and private insurance companies to enhance coverage of services for individuals with special health care needs for primary and specialty care.

1. Identify needed insurance policy advocacy needs and partner with organizations to inform insurers on the needs for CYSHCN.
2. Provide support/data for families to continue advocacy for state support of hemophilia and life-long coverage for PKU formula.

Increase support for outreach clinics & utilization of telehealth for the CYSHCN population.

1. Develop pilot project for developmental assessment telehealth clinics.
2. Support increased outreach of wheelchair seating clinics.
3. Build capacity and support initiatives to expand telehealth for KS-SHCN clinics.

Key Themes

- **Lack of pediatricians and specialists** in the state of Kansas
- Need to market for and **increase awareness of the services that the SHCN program** provides
- **Need effective regionalization**, resulting in more services and increased capacity regionally (beyond Kansas City and Wichita)