SHCN Action Plan 2016-2020
Last Revised 6/30/17

Priority	Objective	Strategy	Outcomes
1. All children and youth with special health care needs (CYSHCN) receive family-centered, coordinated care.	1.1. Assist, empower and equip individuals and families to navigate systems for optimal health outcomes throughout the life course.	1.1.1. Develop, monitor and evaluate a patient-centered care coordination action plan for all SHCN clients. 1.1.2. Complete the online navigational tool kit to provide resources and services	• SHCN families will be supported and feel comfortable coordinating care and navigating systems. o MEASUREMENT: NSCH Indicator 4.9d (Medical Home Component: Effective care coordination, CYSHCN) – Baseline: 27.8% of KS CYSHCN families reported they did not receive one or more elements of coordination / Goal: 20% by 2020. • Families will experience a decreased need of care coordination supports. o MEASUREMENT: % of "Level 3 Clients" who move to "Level 2" or "Level 1" (SHCN Data Tracking) – Baseline: TBD / Goal: 5% improvement each year.
	1.2. Improve communication and outreach among service providers, individuals, and families to help with coordination of care.	1.2.1. Implement communication and referral protocols for SHCN Care Coordinators and providers. 1.2.2. Expand KS-SHCN to have care coordinators located in all regions.	• SHCN staff can assure effective communication to support care coordination and document patient outcomes. o MEASUREMENT: NSCH (Section 5: Satisfaction with communication among providers) – Baseline: 68% of KS CYSHCN families reported they are "very satisfied" with the communication among their child's doctors and other health providers / Goal: 75% by 2020 • SHCN providers will have access to care coordinators for support and assistance in their community. *NOTE: This could be in-person or remote access.* o MEASUREMENT: % of "Level 2 & 3 Clients" in which care coordination assistance/support has been offered to their primary and specialty care providers (SHCN Data Tracking) – Baseline: TBD / Goal: 5% improvement each year.
	1.3. Increase collaboration between the KS-SHCN and other systems of care to support change.	1.3.1. Engage MCO's and primary care providers in collaborative coordination for SHCN clients. 1.3.2. Provide support to agencies working with foster homes and the foster care system in serving CYSHCN in foster care.	• SHCN care coordinators will be connected with foster care and MCO case managers to provide technical assistance and support for SHCN clients. o MEASUREMENT: % of "Level 2 & 3 Clients" in which care coordination assistance/support has been offered to foster care and MCO case managers (SHCN Data Tracking) – Baseline: TBD / Goal: 10% improvement each year.

2. Support optimal health and well-being for family caregivers of CYSHCN.	2.1. 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.	2.1.1. Utilize KS-SHCN "Family Caregiver Assessment" to identify needs and resources for family members of KS-SHCN clients. 2.1.2. Provide education about how the role as a caregiver can impact their health and the ability to care for their loved one.	• Family caregivers of children on the SHCN program will complete a family caregiver assessment to assist the SHCN Care Coordinator in identifying needs and resources. o MEASUREMENT: % of SHCN clients in which the primary family caregiver completes the assessment. (SHCN Data Tracking) – Baseline: TBD after first 6 months of implementation / Goal: 15% improvement each year. o MEASUREMENT: % of SHCN clients in which the assessment identifies needs with completed referrals for services. (SHCN Data Tracking) – Baseline: TBD after first 6 months of implementation / Goal: 15% improvement each year. • Family caregivers experience improved physical and mental health. o MEASUREMENT: NSCH Indicator 6.3 and 6.3a (% of CYSHCN mothers/fathers whose physical and mental health are BOTH excellent or very good) – Mothers: Baseline: 51.5% / Goal: 60% by 2020 Fathers: Baseline: 58.9% / Goal: 65% by 2020
	2.2. 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.	2.2.1. Conduct a respite care needs assessment, including fiscal note, payment opportunities, and family impact. 2.2.2. Seek partnerships and funding opportunities for a sustainable respite pilot project. 2.2.3. Provide support for local partners to host sibling workshops or activities.	• Family caregivers feel supported and experience reduced stress from parenting a CYSHCN. o MEASUREMENT: NSCH Indicator 6.12 (% of CYSHCN parents who usually/always feels stress from parenting) – Baseline: 16.5% / Goal: 10% by 2020 • Siblings will feel more connected with peers and local resources through sibling workshops. o MEASUREMENT: % of siblings who felt the sibling workshop helped them feel more connected and supported as a sibling of a CYSHCN (Post-Workshop Evaluation) Baseline: TBD after first year's workshops / Goal: 10% improvement each year
	2.3. Provide training and education opportunities to support informed, engaged, empowered and equipped family caregivers and providers.	2.3.1. Develop a progressive family leadership program to empower and equip families as strong MCH advocates. 2.3.2. Provide family and sibling peer supports for those interested in being connected to other families with similar experiences.	• Family members of CYSHCN will be prepared to advocate for quality of care for their child. o MEASUREMENT: NSCH Quality of Care Summary Measure (% of CYSHCN who meet the three system performance measures) – Baseline: 37.9% / Goal: 45% by 2020 o MEASUREMENT: % of parents who felt their supported leadership experience improved their ability to advocate for their child's needs (KS Parent Leadership Survey) / Baseline: TBD after first year of formal program / Goal: 10% improvement each year

3. Behavioral health needs and supports will be integrated into the Kansas Special Health Care Needs system of care.	3.1. Collaborate with other agencies serving individuals with behavioral health needs to support an integrated continuum of care.	3.1.1. Engage behavioral health partners (KDADS, KAIMH, NAMI, CMHCs) to assess possible opportunities for KS-SHCN to support the behavioral health field. 3.1.2. Build partnerships with behavioral health providers and case managers to identify appropriate referrals for families and inform partners of, and offer support through, the SHCN Care Coordination efforts. 3.1.3. Partner with Medicaid to provide support for behavioral health telehealth clinics.	• The KS-SHCN program will experience stronger connections and make more referrals to the behavioral health community. o MEASUREMENT: # of behavioral health referrals made for clients and family caregivers (SHCN Data Tracking) - Baseline: TBD / Goal: 5% improvement each year *The other outcomes will be developed as infrastructure and system capacity building activities and the partnership/collaboration with partners is expanded, for example the number of patients served and improved outcomes through behavioral telehealth clinics. **As this is a new focus area for KS-SHCN, we have not fully integrated this objective into the Title V State Action Plan. Inclusion may be possible at a later time, based on our involvement in this system.
	3.2. Educate families about behavioral health issues and provide referrals and resources of available services and peer supports.	3.2.1. Reduce stigma through community awareness and education, including parent and client education materials about behavioral health. 3.2.2. Partner with NAMI to offer youth and adult education programs to KS-SHCN clients.	**UNDER DEVELOPMENT** – looking at valuable behavioral health data sources and working with partners to identify existing data rather than creating new data sources or data points.
	3.3. All KS-SHCN families will have a behavioral health assessment and be supported in obtaining necessary services.	3.3.1. Integrate behavioral health assessment results in the KS-SHCN action plan resources/referrals. 3.3.2. Develop follow-up protocols for families referred for behavioral health services and offer additional support as needed to assure services are received.	• SHCN clients receive a behavioral health screening or assessment, which is shared among all service providers working with the family. o MEASUREMENT: % of “Level 2 & 3” SHCN clients with a behavioral screenings on file with the program (SHCN Data Tracking) - Baseline: TBD in first year after implementation / Goal: 10% improvement each year o MEASUREMENT: % of “Level 2 & 3” SHCN clients who sign records sharing agreements with KS-SHCN to assure their medical, community, and other service providers have copies of screening/assessment results. – Baseline: TBD in first year after implementation / Goal: 5% improvement each year

4. Support a society that is culturally sensitive, well-informed, and respectful of all people with disabilities through training and education.	4.1. Equip and empower children, youth, and families to advocate for needed services, supports, and family/professional partnerships.	4.1.1. Provide youth-focused and youth-driven initiatives, such as Faces of Change and Plan It Live It, to support successful transition, self-determination and advocacy. 4.1.2. Conduct "Care Coordination: Empowering Families" trainings for parents of CYSHCN.	• Youth participating in the Faces of Change will self-report improvements in self-efficacy in five core areas of development (learning, connecting, thriving, working, and leading). o MEASUREMENT: % of youth participants who show improvement in one or more areas (Faces of Change pre/post self-efficacy assessment) – Baseline: TBD in first year after implementation / Goal: 10% improvement each year • Parents are empowered to engage a variety of valued members of their child's care team. o MEASUREMENT: % of parents who respond they are more likely to include new individuals on their child's care team (Training Pre/Post) – Baseline: TBD after first training / Goal: 10% improvement each training
	4.2. Provide training and education for providers to promote diversity, inclusion, and integrated supports in the provision of services for the SHCN population.	4.2.1. 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. 4.2.2. Offer information and training to child care and education providers to support inclusion within those settings and assure higher quality care for CYSHCN.	**UNDER DEVELOPMENT –** Will adapt from course syllabus from previous Caring for People with Disabilities class, including a pre/post test to determine level of understanding and capacity for change. • Parents will experience fewer issues finding qualified child care providers to care for children who are not of school age. o MEASUREMENT: NSCH Indicator 6.14 (% of families in which anyone in the family had to quit a job, not take a job, or greatly change a job because of problems with child care) – Baseline: 11.2% / Goal: 8% by 2020 **This is not yet specific to CYSHCN, sample sizes in the 2011/12 survey were too low for a reliable measurement. o MEASUREMENT: SHCN "Level 2 & 3" clients in which anyone in the family had to quit a job, not take a job, or greatly change a job because of problems with child care – Baseline: TBD after first 6 months of implementation / Goal 5% improvement each year.

5. Provide gap-filling health services for CYSHCN and their families through partnerships, collaboration, and direct care supports.	5.1. Collaborate with agencies and providers in the oral health system to support increased access to, and payment of, oral health services for CYSHCN.	5.1.1. Conduct a statewide needs assessment on oral health services for CYSHCN. 5.1.2. Provide dental hygienist services within KS-SHCN specialty clinics.	**UNDER DEVELOPMENT** – Additional outcomes will be developed through the CYSHCN oral health needs assessment. Possibilities: improved identification of oral diseases, injuries, and craniofacial disorders leading to timely referral for care and coordination of services • KS-SHCN clients will experience fewer oral health problems. o MEASUREMENT: NSCH Indicator 1.2a (% of CYSHCN, ages 1 to 17) who had oral health problems in the past 12 months) – Baseline: 26.5% / Goal: 15% by 2020 o MEASUREMENT: KS-SHCN clients with a self-reported preventive dental visit in the past 12 months (SHCN Data Tracking) – Baseline: TBD / Goal: 10% improvement each year
	5.2. Partner with public and private insurance companies to enhance coverage of services for individuals with special health care needs for primary and specialty care.	5.2.1. Identify needed insurance policy advocacy needs and partner with organizations to inform insurers on the needs for CYSHCN. 5.2.2. Continue advocacy for state support of hemophilia and life-long coverage for PKU formula.	• KS-SHCN clients will experience fewer issues with insurance coverage for medically necessary needs. o MEASUREMENT: NSCH Indicator 3.4 (% of CYSHCN whose insurance coverage is usually/always adequate to meet their needs) – Baseline: 75.2% / Goal: 85% by 2020
	5.3. Increase support for outreach clinics & utilization of telehealth for the CYSHCN population.	5.3.1. Develop pilot project for developmental assessment telehealth clinics. 5.3.2. Support increased outreach of wheelchair seating clinics. 5.3.3. Build capacity and support initiatives to expand telehealth for KS-SHCN clinics.	• SHCN clients receive a developmental screening or assessment, which is shared among all service providers working with the family. o MEASUREMENT: % of “Level 2 & 3” SHCN clients with a developmental screenings on file with the program (SHCN Data Tracking) - Baseline: TBD in first year after implementation / Goal: 10% improvement each year o MEASUREMENT: % of “Level 2 & 3” SHCN clients who sign records sharing agreements with KS-SHCN to assure their medical, community, and other service providers have copies of screening results. – Baseline: TBD in first year after implementation / Goal: 5% improvement each year **UNDER DEVELOPMENT** – outcomes for the wheelchair seating clinics will be pulled from the family impact information from the previously completed ROI analysis // Telehealth outcomes are being developed through the AMCHP Workforce Development Center Cohort 2 Project.