CSHCN
Work Group Packet

Priority Overview Page: This includes the priority, a list of the objectives, and the selected performance measures (NPM = National Performance Measure / SPM = State Performance Measure).

Priority State Action Plan (SAP) Table: This outlines the key strategies within each objective. This also outlines another level of measurement (ESM = Evidence-based/-informed Strategy Measure).

Priority Resources: This outlines key initiatives, partners, websites, and other resources that you might want to look at or dig into related to your priority. These include a reference of where it might align in the SAP…but may or may not be directly called out in the table.

Priority Key Acronyms and Data: A compilation of acronyms that you might come across in conversations with your priority work. The key data outlines National Outcome Measures (NOMs) that are related to your priority population. This is in addition to the NPMs, SPMs, and ESMs noted elsewhere. Another resource is the NPM-NOM_Measures Table – this is where you can find the data trends for all of the measures associated with our work.

Priority Data Summaries**:** These are the data summaries that will be included in the 2023 MCH Services Block Grant Application that will be submitted with our plan in August 2022.

PRIORITY 5

Communities, families, and providers have the knowledge, skills, and comfort to support transitions and empowerment opportunities.

CHILDREN WITH SPECIAL HEALTH CARE NEEDS

OBJECTIVE 5.1
Increase the proportion of adolescents and young adults who actively participate with their medical home provider to assess needs and develop a plan to transition into the adult health care system by 5% by 2025.

OBJECTIVE 5.2
Increase the proportion of families of children with special health care needs who report their child received care in a well-functioning system by 5% by 2025.

OBJECTIVE 5.3
Increase the proportion of families who receive care coordination supports through cross-system collaboration by 25% by 2025.

NPM 12: *Transition: Percent of adolescents with and without special health care needs, ages 12-17, who received services necessary to make transition to adult health care*

PRIORITY 5: Communities, families, and providers have the knowledge, skills, and comfort to support transitions and empowerment opportunities.

Domain: Children with Special Health Care Needs

NPM 12: Transition (Percent of adolescents with and without special health care needs, ages 12-17, who received services necessary to make transition to adult health care)

ESM: Percent of youth with special health care needs, ages 12 to 21, who have one or more transition goals achieved on their action plan by the target completion date

OBJECTIVE 5.1: Increase the proportion of adolescents and young adults who actively participate with their medical home provider to assess needs and develop a plan to transition into the adult health care system by 5% by 2025.

Strategy	Description
5.1.1	Provide technical assistance and support to local health agencies and medical home providers of families served through the Kansas Special Health Care Needs Program (KS-SHCN) to incorporate transition readiness education and resources for youth ages 12 and older.
5.1.2	Promote the implementation of evidence-based practices and policies with providers serving adolescents and young adults to support transition from pediatric to adult health systems.
5.1.3	Partner with health care professional organizations to engage with insurers to support adequate reimbursement for transition care services.

OBJECTIVE 5.2: Increase the proportion of families of children with special health care needs who report their child received care in a well-functioning system by 5% by 2025.

Strategy	Description
5.2.1	Implement national standards through a collaborative network of programs, providers, partners, and families dedicated to advancing the Kansas State Plan for Systems of Care for Children with Special Health Care Needs (CSHCN).
5.2.2	Expand the partnership between Title V and Medicaid to strengthen coordinated services and supports for CSHCN in managed care and home and community-based services programs.
5.2.3	Assess gaps in insurance coverage, adequacy, and affordability for families of CSHCN and engage with key partners to support modification of policies and practices to advance and increase access and coverage of necessary medical and social services.
5.2.4	Partner with Medicaid and the behavioral health agency to implement policy change to allow family caregivers the opportunity to serve as nursing caregivers through waivers when appropriate.
5.2.5	Assess statewide barriers to accessing primary and specialty care services for families of CSHCN, including palliative care, multi-disciplinary specialty care teams, telehealth, and primary care medical homes.

OBJECTIVE 5.3 Increase the proportion of families who receive care coordination supports through cross-system collaboration by 25% by 2025.

Strategy	Description
5.3.1	Provide technical assistance and support to child welfare agencies working with family foster homes to improve coordination across systems and align services for CSHCN in foster care.
5.3.2	Expand KS-SHCN Care Coordination eligibility to support families transitioning out of early intervention services, assuring they are connected to appropriate community-based services and resources.
5.3.3	Provide quarterly Systems Navigation Trainings for parents of CSHCN.

CSHCN Resources

See also the Child, Adolescent, and CSHCN Supporting Document from the recent MCH Block Grant Application.

https://www.kdhe.ks.gov/DocumentCenter/View/5321/Program-Activities-Children-Adolescent-and-CSHCN-PDF

Obj	Description	Website
5.1.1	**The Future is Now, THINK BIG!:** A series of transition planning booklets to help teens prepare for transition to adult living. The booklet consists of an easy-to-use checklist on: Self-advocacy; Health & Wellness; Healthcare System; Social & Recreation, Independent Living Skills; and School & Work. *This was designed for youth with disabilities/SHCN. Title V has goals to review and assure it meets the needs for all youth.*	https://kansasmch.org/fac-materials.asp#future-now
5.1.2	**GotTransition:** National resource center to assist youth and young adults transition from pediatric to adult health care (i.e., health care transition/HCT).	https://www.gottransition.org/
5.1.2	**Charting the LifeCourse:** A framework driven by the core belief that "all people have the right to live, love, work, play and pursue their life aspirations." Includes tools to organize ideas, visions, and goals, and problem-solve, navigate, and advocate for supports across all life stages (infancy to late adulthood) and recognizes the person in the context of their families and community with a focus on achieving life outcomes (health, education, employment, community inclusion, etc.)	https://www.lifecoursetools.com/
5.1.2	**Federal Youth Transition Plan**: National strategies to support Title efforts across systems (e.g., education, labor, social security).	https://www.dol.gov/odep/pdf/20150302-FPT.pdf
5.2.1	**State Plan for Systems of Care for CSHCN:** Systems of care assessment and strategic plan developed for the Title V CSHCN program. *It is desired to update this plan in the coming years, including expansion regarding the financing systems of care for CSHCN.*	https://www.kansasmch.org/documents/domains/CYSHCNStatePlan_FINAL_11.2018.pdf
5.2.1	**National Standards for CSHCN:** Comprehensive set of system standards for CSHCN across eight domains. *These standards were the framework for alignment in the development of the KS State Plan for SOC.*	http://cyshcnstandards.amchp.org/app-national-standards/#/
5.2.1	**National Care Coordination Standards:** A set of standards that support high-quality care coordination practice. Include six domains important for all care coordination. *These standards are the framework for the development of the KS Holistic Care Coordination initiative.*	https://www.nashp.org/national-care-coordination-standards-for-children-and-youth-with-special-health-care-needs/
5.2.2	**Home and Community Based Service (HCBS):** System of community based supports and services for persons in Kansas with disabilities. There are seven HCBS waiver programs in KS. This is a Medicaid program, however oversight and administration is through the Kansas Department for Aging and Disability Services (KDADS).	https://kdads.ks.gov/kdads-commissions/long-term-services-supports/home-community-based-services-(hcbs)-programs
5.2.2	**OneCare Kansas:** Special Medicaid program to provide coordination of physical and behavioral health care with long term services and supports for people with chronic conditions (e.g., asthma, bipolar, schizophrenia, major depression). *This model is really aligned wiht the KS-SHCN Care Coordination and Title V HCC models - in terms of services/care coordination.*	https://kancare.ks.gov/consumers/onecare-ks-members
5.2.3	**Leadership Education in Neurodevelopmental and Related Disabilities (LEND):** Training program at KU that provides graduate and post-graduate level professionals from a variety of disciplines the necessary preparation for becoming future leaders in the field of developmental disabilities for the improvement of the health of infants, children, and adolescents with disabilities.	https://www.kumc.edu/school-of-medicine/academics/departments/pediatrics/academics/leadership-education-in-neurodevelopment-and-related-disabilities-(lend).html
5.2.3	**Catalyst Center:** National resource center to support Title V CSHCN programs in maximizing and leveraging resouces and partnerships to assure adequate health insurance coverage and financing options for systems of care for CSHCN.	https://ciswh.org/project/the-catalyst-center/
5.2.5	**KS-SHCN Program:** State program that provides holistic care coordination services, financial assistance to a variety of services, multi-disciplinary specialty care clinics, and many other services. *Medical and financial eligibility requirements apply.*	https://www.kdhe.ks.gov/747/Special-Health-Care-Needs

5.3.2	**Holistic Care Coordination:** Title V initaitive to expand holistic care coordination from population-specific programming through the KS-SHCN program to broad public health implementation and pediatric primary care. These efforts align and connect with state-wide efforts to expand access to community health workers (CHWs) and establish sustainable funding for the services provided by CHWs and HCC providers.	https://www.kdhe.ks.gov/825/Holistic-Care-Coordination
5.3.3	**Systems Navigation Training for Families:** A free training for parents with special needs children where parents will learn how to identify a medical home, plan for transitions, cope with stress, locate support systems, learn advocacy skills, organize and find resources, navigate health care and insurance systems, and increase communication and coordination between multiple providers.	https://www.kdhe.ks.gov/799/Systems-Navigation-Training-for-Families

CSHCN Key Acronyms

BCC	Bridges Care Coordinator
CSHCN	Chidlren with Special Health Care Needs (Title V Domain Population)
DAP	Direct Assistance Program (KS-SHCN Service)
DHCF	Division of Health Care Finance (agency Division which includes Medicaid)
HCT	Health Care Transition
IDEA	Individuals with Disabilities Education Act (Special Education)
IEP	Individualized Education Plan
IHP	Individualized Health Plan
ITS	Infant Toddler Services (Part-C of IDEA, tiny-k, early intervention)
KS-SHCN	Kansas Special Health Care Needs Program
LEND	Leadership Education in Neurodevelopmental and Related Disabilities
MCO	Managed Care Organization
SO	Satellite Office (KS-SHCN Local Point of Entry)
SOC	System of Care
YSHCN	Youth with Special Health Care Needs

CSHCN Key Data (Related to NPMs 11, 12, and 15)

Alignment based upon Table 3 in the Block Grant Guidance Appendices

NOM 17.1	Percent of children with special health care needs (CSHCN), ages 0 through 17
NOM 17.2	Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system
NOM 17.3	Percent of children, ages 3 through 17, diagnosed with an autism spectrum disorder
NOM 17.4	Percent of children, ages 3 through 17, diagnosed with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (ADD/ADHD)
NOM 18	Percent of children, ages 3 through 17, with a mental/behavioral condition who receive treatment or counseling
NOM 19	Percent of children, ages 0 through 17, in excellent or very good health
NOM 25	Percent of children, ages 0 through 17, who were unable to obtain needed health care in the past year

Table 3. Evidence-based/informed National Performance and Outcome Measure Linkages*

National Outcome Measure		National Performance Measure														
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
#	Short Title	Well-woman visit	Low-risk cesarean delivery	Risk-appropriate perinatal care	Breastfeeding	Safe sleep	Developmental screening	Injury hospitalization	Physical activity	Bullying	Adolescent well-visit	Medical home	Transition	Preventive dental visit	Smoking	Adequate insurance
1	Early prenatal care															
2	Severe maternal morbidity	X	X												X	
3	Maternal mortality	X	X												X	
4	Low birth weight	X													X	
5	Preterm birth	X													X	
6	Early term birth	X													X	
7	Early elective delivery															
8	Perinatal mortality	X		X											X	
9.1	Infant mortality	X		X	X	X									X	
9.2	Neonatal mortality	X		X											X	
9.3	Postneonatal mortality	X			X	X									X	
9.4	Preterm-related mortality	X		X											X	
9.5	SUID mortality				X	X									X	
10	Drinking during pregnancy	X														
11	Neonatal abstinence syndrome	X														
12	Newborn screening timely follow-up															
13	School readiness						X									
14	Tooth decay/cavities													X		
15	Child mortality							X								
16.1	Adolescent mortality							X		X	X					
16.2	Adolescent motor vehicle death							X			X					
16.3	Adolescent suicide							X		X	X					
17.1	CSHCN															
17.2	CSHCN systems of care										X	X	X	X		X
17.3	Autism															
17.4	ADD/ADHD															
18	Mental health treatment										X	X				X
19	Overall health status						X		X		X	X		X	X	X
20	Obesity								X		X					
21	Uninsured															
22.1	Child vaccination															X
22.2	Flu vaccination										X					X
22.3	HPV vaccination										X					X
22.4	Tdap vaccination										X					X
22.5	Meningitis vaccination										X					X
23	Teen births	X									X					
24	Postpartum depression	X														
25	Forgone health care											X				X

* Includes linkages based on expert opinion or theory in the absence of empirical scientific evidence. Associations with available empirical scientific evidence that is mixed or inconclusive are not included. This table is subject to revision as new scientific evidence becomes available. By definition, NPMs must be linked to at least one NOM; however, not all NOMs must have linked NPMs, as they may be important to monitor as sentinel health indicators regardless.

CSHCN
Plan Narrative

FY 2023 Data
Summary

NPM 12: Transition (Percent of adolescents with and without special health care needs, ages 12-17, who received services necessary to make transition to adult health care)

Many barriers can keep adolescents and their families from navigating the transition to adult health care. These include fear of having a new provider or health care system, not being prepared or supported by health care providers during the transition process, lack of communication between new and previous providers, limited training among adult health care providers, and socioeconomic factors.[1] Monitoring the extent to which Kansas adolescents with and without special health care needs (SHCN) receive services to aid in this transition can inform efforts to better support adolescents and their families in future.

Data on receiving services necessary to transition into adult health care are collected by the National Survey of Children's Health (NSCH). Receipt of necessary transition services is based on three components: (a) whether the adolescent had a chance to speak with a doctor or other health care provider privately at their last medical care visit; (b) whether the provider worked with the adolescent to gain skills to manage health/health care and understand health care changes at age 18; and (c) whether the provider discussed the shift to adult health care providers (if needed). Only adolescents ages 12-17 are included in this indicator.

Transition Services Among Kansas Adolescents with SHCN

According to the 2019-2020 NSCH (two years of data combined), only 33.5% of Kansas adolescents with SHCN, ages 12-17, received services necessary to make transitions to adult health care (95% confidence interval [CI]: 24.6%-43.8%). This was significantly higher than the nationwide estimate for adolescents with SHCN, which was only 22.5% (95% CI: 20.6%-24.6%).

Around half (53.4%) of Kansas adolescents with SHCN had a chance to speak with a doctor or other health care provider privately at their last medical care visit (95% CI: 44.1%-62.5%). For 76.5% of adolescents with SHCN, the provider had worked with the adolescent to gain skills to manage health/health care and understand health care changes at age 18 (95% CI: 67.8%-83.5%). For only 28.1% of adolescents with SHCN,* the provider discussed the shift to adult health care providers (if needed) (95% CI: 18.8%-39.6%).

Due to small sample size, comparisons could not be made between different subpopulations of adolescents with SHCN.

* Indicator has a confidence interval width >20% points, >1.2 times the estimate, or that is inestimable and should be interpreted with caution.

Transition Services Among Kansas Adolescents without SHCN

Compared to Kansas adolescents with SHCN, a significantly lower percentage of those without SHCN, ages 12-17, received services necessary for transition into adult health care, at only 20.6% (95% CI: 15.9%-26.4%). The estimate for Kansas adolescents without SHCN was not significantly different from the nationwide estimate for adolescents without SHCN, which was 17.6% (95% CI: 16.5%-18.8%).

Compared to Kansas adolescents with SHCN, a significantly lower percentage of those without SHCN had had a chance to speak with a doctor or other health care provider privately at their last medical care visit (40.5%; 95% CI: 33.7%-47.7%). In addition, a significantly lower percentage of those without SHCN had had the provider work with them to gain skills to manage health/health care and understand health care changes at age 18 (58.6%; 95% CI: 50.2%-66.5%). Meanwhile, the percentage of Kansas adolescents without SHCN whose providers discussed the shift to adult health care providers (if needed) (29.3%; 95% CI: 20.4%-40.1%) was not significantly different than among those with SHCN.

Among adolescents without SHCN, there was not enough evidence to show that the percentage receiving necessary transition services differed significantly based on whether they had a medical home. Among those whose care met medical home criteria, 24.1% received services necessary for transition into health care (95% CI: 17.5%-32.2%), compared to 17.4% among those whose care did not meet the criteria for being a medical home (95% CI: 11.2%-26.0%). However, a significantly higher percentage of those whose care met medical home criteria had had the provider work with them to gain skills to manage health/health care and understand health care changes at age 18 (72.5%; 95% CI: 62.1%-80.9%), compared to those whose care did not meet the criteria for being a medical home* (45.6%; 95% CI: 33.5%-58.2%).

The percentage of adolescents without SHCN receiving necessary transition services also did not differ significantly based on either the household's poverty level, or whether the child currently had adequate health insurance and were continuously insured in the past year. For instance, the estimate among those with current, adequate, and continuous insurance in the past year was 18.7% (95% CI: 13.4%-25.6%), compared to 24.6% among those who either currently had inadequate or no insurance and/or had a gap in insurance coverage in the past year (95% CI: 16.1%-35.5%).

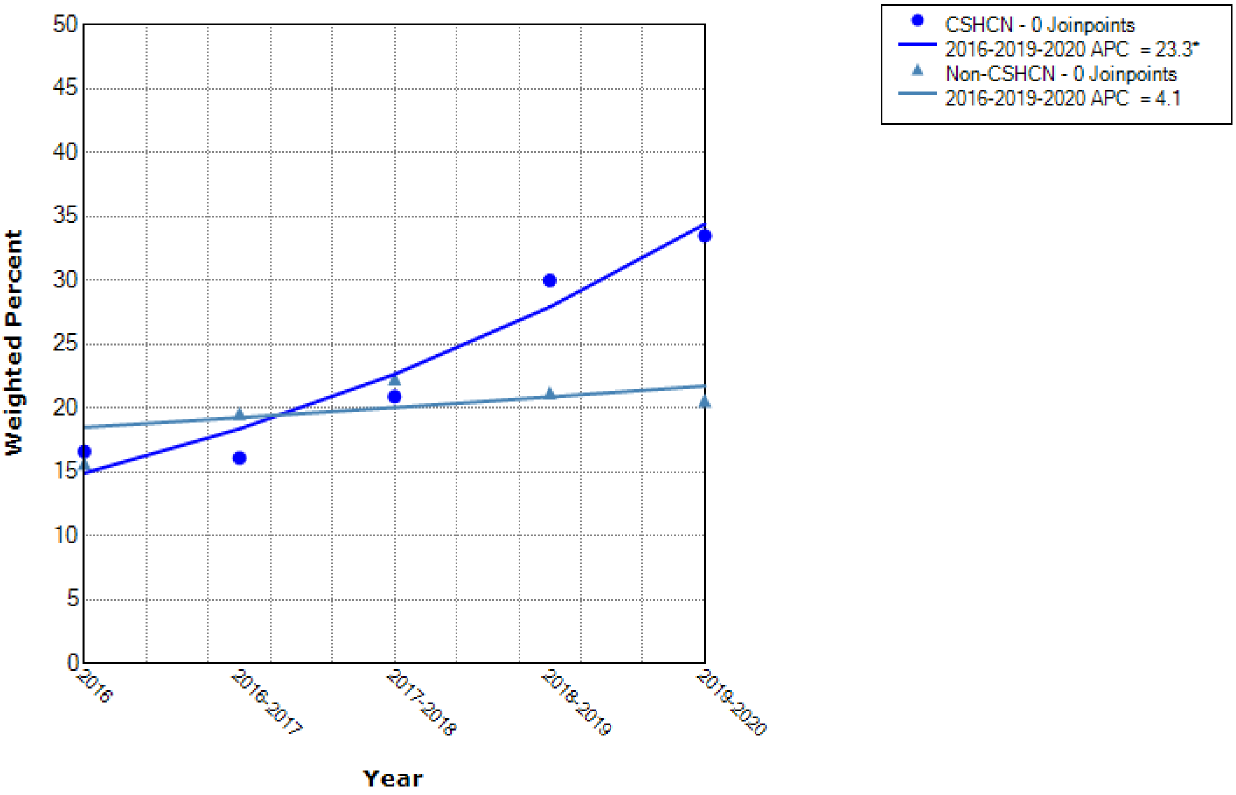
The percentage of adolescents without SHCN receiving necessary transition services also did not vary significantly based on metropolitan status. Among those living inside a principal city within a metropolitan statistical area, 17.7% received necessary transition services (95% CI: 10.9%-27.3%), compared to 25.4% of those who lived within a metropolitan statistical area but not in a principal city (95% CI: 17.2%-35.9%), and 19.6% among those who did not live in a metropolitan statistical area (95% CI: 11.9%-30.6%).

* Indicator has a confidence interval width >20% points, >1.2 times the estimate, or that is inestimable and should be interpreted with caution.

Trends in Receipt of Transition Services

From 2016 (single-year estimate) to 2019-2020 (two-year estimate), Kansas adolescents with SHCN experienced significant improvement in receiving services necessary to make transition to adult health care, with an annual percent change of 23.3% (95% CI: 10.3%-37.7%). Although those without SHCN also experienced an increase, it was not statistically significant.

Weighted Percent of Adolescents with and without Special Health Care Needs (SHCN), Ages 12-17, Who Received Services Necessary to Make Transition to Adult Health Care, Kansas, 2016-2020†



* Indicates that the Annual Percent Change (APC) is significantly different from zero at the alpha = 0.05 level.
† Note: After 2016, state-level estimates were produced using two-year combined data.
Source: U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), National Survey of Children’s Health (NSCH)

1. White PH, Cooley WC; TRANSITIONS CLINICAL REPORT AUTHORING GROUP; AMERICAN ACADEMY OF PEDIATRICS; AMERICAN ACADEMY OF FAMILY PHYSICIANS; AMERICAN COLLEGE OF PHYSICIANS. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home [published correction appears in Pediatrics. 2019 Feb;143(2):]. Pediatrics. 2018;142(5):e20182587. doi:10.1542/peds.2018-2587