Transition Initiatives

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 adult health care systems by 5% by 2025.

HCT Systems of Care

Focused implementation activities related to health care transition (HCT) were limited during the 2025 reporting period. While transition remains a priority for the Title V program and the Kansas Special Health Care Needs (KS-SHCN) program, staff time and programmatic efforts were directed toward other priority areas during this time. Initial discussions with internal staff and key partners highlighted opportunities to strengthen transition-related supports and resources moving forward. These conversations identified a need for additional staff development and consistent tools to support care coordinators and providers in implementing transition planning practices with adolescents and young adults.

KS-SHCN continues to recognize that effective transition planning requires a holistic approach that addresses the broader needs of youth and families, including health care, education, employment, housing, and social supports. While specific initiatives were not implemented in 2025, these discussions have helped inform planning efforts and priorities for the coming year.

Health Care Transition (HCT) Planning

The KS-SHCN program recognizes the importance of early and thoughtful transition planning for youth with special health care needs (YSHCN) as they prepare to move from pediatric to adult health care systems. Transition discussions can be complex for youth, families, and providers and may involve addressing concerns about increased independence, changes in care teams, and navigating adult service systems.
During the 2025 reporting period, focused activities related to provider education on health care transition were limited as the program navigated internal transitions and shifting priorities. As a result, there were fewer opportunities for structured outreach or education for providers on transition planning. Care coordinators also reported limited opportunities to engage providers in transition-related conversations during this time. Through internal discussions, the KS-SHCN team identified the need to strengthen internal knowledge and consistency among care coordinators regarding transition guidance and best practices. These conversations highlighted the importance of ensuring that care coordinators have access to consistent information and resources to support families when transition-related needs arise.

Transition planning for youth aging out of the SHCN program remains an important consideration for the program, as it supports youth with special health care needs as they move into adulthood.

Systems Initiatives

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.

CSHCN Systems Alignment and Integration

Many factors contribute to the CSHCN population being an at-risk and vulnerable population, such as inequities, disparities, community health factors, adverse childhood experiences, food insufficiency, unsafe housing, access to services, including behavioral health and foster care. All these needs are considered when evaluating the holistic approach to care coordination services; however, these services are only provided to individuals who meet the KS-SHCN program criteria. For this reason, the CSHCN Director and the Screening & Surveillance Section Director have worked to build partnerships with internal and external stakeholders to address the needs of the CSHCN population in Kansas.

According to the 2023-2024 (two-year combined) National Survey of Children's Health (NSCH), 23.1% of children in Kansas have special healthcare needs, as measured by the CSHCN screener. While 21.5% have one current or lifelong health condition, 21.9% have two or more. Additional data showed that 27.9% of Kansas children ages 3-17 years had one or more reported mental, emotional, developmental, or behavioral problems. Data indicate that CSHCN who experience two or more ACEs have increased in previous measures, currently at 34.3% (up from 34.2% in 2022-2023), as well as more non-CSHCN reporting not having any adverse childhood experiences (from 65.4% in 2022-2023 to 67.5% in 2023-2024); however, it is not a significant increase.

Title V in Kansas recognizes that it takes a village and that not one person or group can do the work alone. Making collaboration across systems vital to strengthening systems and supports for Kansans. Title V staff place great emphasis on collaborating with local and state agencies in various ways to support the Title V population, especially children and youth with special healthcare needs. While new partnerships are forged each year, ongoing partnerships are also nurtured. Some examples of special health care needs partnership work can be found below:

- Over the course of FFY25, partnerships and collaboration with external partners were strengthened through continued engagement with the Kansas Council on Developmental Disabilities (KCDD). Participation on the council increased awareness of programmatic work and initiatives supporting children and youth with special health care needs, and created opportunities for bidirectional resource sharing. This collaboration also supported the promotion of KCDD initiatives across platforms within the section where the Special Health Care Needs (SHCN) program is housed. One example of this partnership was the dissemination and use of a behavioral health toolkit developed by KCDD, designed specifically for children with intellectual and developmental disabilities and their families, which was shared broadly and incorporated into SHCN care coordination meetings with families to support access to developmentally appropriate behavioral health resources.
- Over the past year, the referral initiative between the Kansas Newborn Screening Programs and the Special Health Care Needs (SHCN) program was temporarily paused due to leadership transitions in both programs. While referrals from the screening programs continued during this period, capacity for consistent follow-

up was limited due to leadership transitions. In 2026, recurring meetings with new program leadership have been established to strengthen coordination and increase the number of children diagnosed through newborn screening who are connected to and served by the SHCN program.

- New in FFY25, Title V expanded its partnerships to support families and individuals with an autism diagnosis in a variety of ways. One was the SHCN program, which evaluated its capacity to serve as a gap-filling service for families with a diagnosis that creates significant barriers to living a healthy and high-quality life. As a result, we have adapted our criteria to provide systems navigation support for families when needed or when it is lacking. Another way was to partner with the Kansas Department for Aging and Disability Services (KDADS) to develop and convene a Statewide Autism Coalition. More on this coalition can be read about below.

Insurance and Financing Systems of Care for CSHCN

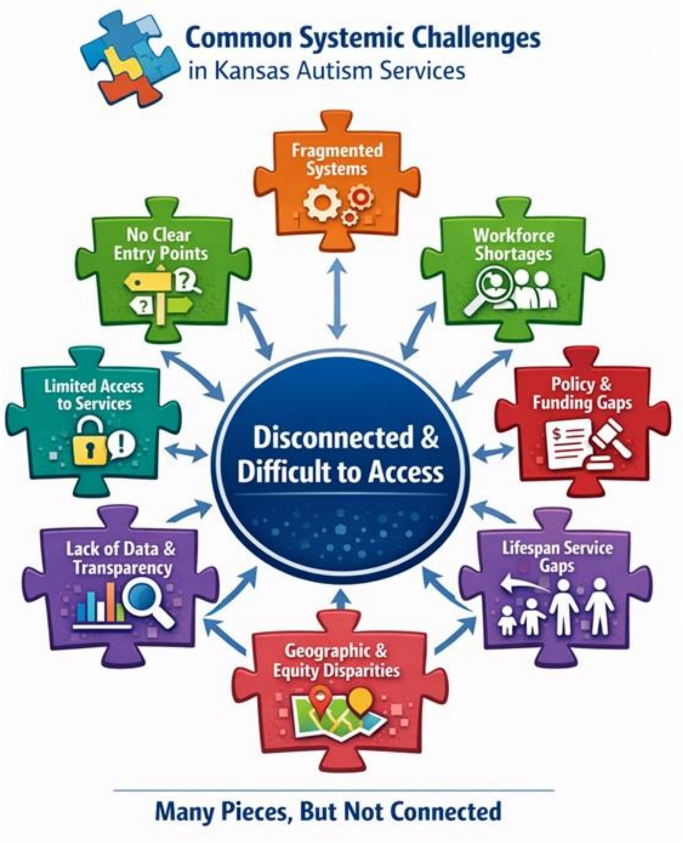
During the 2025 reporting period, limited progress was made on activities to identify and address gaps in the financing of systems of care for children with special health care needs (CSHCN). Staff turnover and changes in key partner roles impacted the continuity of this work, including established connections with Medicaid and other system partners.

As a result, planned efforts to build upon the previously completed environmental scan and further assess financing barriers were not advanced during this period. While the environmental scan findings remain available and relevant, no additional activities were conducted to expand upon this work in FY25.

These challenges highlighted the importance of stable cross-system partnerships and consistent communication channels to support ongoing systems-level work related to financing and access to care.

Statewide Autism Coalition

The official launch of a Statewide Autism Coalition began during FFY25, starting with the first meeting in March. While conversations had begun more than a year before, progress toward forming a coalition had stalled. At the same time, a partner state agency, the Kansas Department for Aging and Disability Services (KDADS), waited on a grant related to autism work in Kansas. In January 2025, we met with KDADS leadership and agreed to partner and co-lead a statewide autism coalition.



Starting in March, the new coalition met monthly for one-hour meetings, which were an open invitation for anyone who had an interest in improving the current systems that support individuals with autism and their families, including state agencies, partners, providers, families, and individuals with personal experience, ending the year with up to 66 interested individuals in the coalition. However, about 30 people would regularly join the meetings; those who could not were kept up to date via emails between meetings.

Key activities in FFY25:

- The coalition officially began in March 2025
- Began with a focus on making the 2021 Autism Task Team's recommendations report actionable.
- Developed an agreed-upon mission and vision for the coalition.
    - Mission: The Kansas Statewide Autism Coalition works to strengthen service coordination, expand access to resources, and shape informed policy through collaborative partnerships with individuals with autism, their families, service providers, and agencies across the state.
    - Vision: A Kansas where individuals with autism and their families are empowered, embraced by all communities, and have equitable access to high-quality supports and services.
- Created 3 core work groups to focus on different areas: access, Workforce, and Policy.

The coalition has been building momentum through discussions, shared knowledge, and experiences, ending FFY25, poised to begin developing action plans for each work group to move work forward toward desired outcomes in improving our state systems.

Other Systems Work

KSKidsMAP

Partnership with the Kansas PMHCA Program: Children with special health care needs, including those with autism spectrum disorder, often present with complex developmental, behavioral, and co-occurring mental health needs that can be challenging to manage in primary care settings. Through consultation, training, and resource support, primary care physicians and clinicians are better equipped to identify concerns early, coordinate care across systems, and support children and families with timely, developmentally appropriate interventions. As such, KSKidsMAP expanded its Pediatric Mental Health Team to include an interdisciplinary neurodevelopment specialty. The 'KANDID Team' (KSKidsMAP for Autism, Neurodevelopmental Disorders, and Intellectual Disabilities) offers case consultations, specific TeleECHO Clinic sessions, webinars, and an annual in-person conference. The expanded pediatric mental health expert team includes physicians board-certified in child and adolescent psychiatry, neuropsychiatry, and pediatrics, as well as developmental-behavioral pediatrics, a child and adolescent clinical psychologist, and a licensed social worker, all with expertise in KANDID populations. Throughout this Report Period, the KANDID Team delivered targeted training and workforce development activities to strengthen primary care capacity to support children and youth with autism spectrum disorder. In April, aligning with Autism Acceptance Month, KSKidsMAP hosted a four-session Autism Webinar Series focused on autism identification, diagnosis, and management in primary care settings. Sessions addressed autism screening tools, guidance for supporting families while awaiting diagnosis, management of common medical concerns, and recognition and treatment of psychiatric comorbidities across childhood and adolescence. Continuing education credits were provided, and live attendance across sessions ranged from 60 to 86 participants, reflecting strong practitioner engagement and demand for practical, autism-specific guidance.

KSKidsMAP
Pediatric Mental Health

Autism
WEBINAR SERIES

Join KSKidsMAP every Thursday in April for a FREE webinar series on Autism diagnosis and management in primary care, led by KSKidsMAP's expert pediatric mental health team. Gain valuable insights and practical strategies to support patients with autism in your clinical setting. CEs provided.

Thursdays
April 2025

Time
Noon - 1 p.m.

Location
Virtual via Zoom

REGISTER

1-800-332-6262
wichita.kumc.edu/KSKidsMAP

SESSIONS

April 3, 2025
Screening Tools for Autism in the Primary Care Setting
Bridget Clark, D.O., child & adolescent psychiatrist; pediatrician

April 10, 2025
Next Steps: What to Do While Waiting for Diagnosis & What Diagnosis Means
Zachary Blackhurst, Ph.D., clinical child psychologist

April 17, 2025
Common Medical Issues & How to Manage in Primary Care
Valarie Kerschen, M.D., developmental & behavioral pediatrician

April 24, 2025
Psychiatric Comorbidities Through Childhood & Adolescence
Cassie Karlsson, M.D., child & adolescent psychiatrist

The KANDID Team also convened a one-day, autism-focused workshop on transitioning to adulthood, supporting providers in addressing the unique clinical, behavioral, and systems-level needs of adolescents and young adults with autism. Together, these activities enhanced physician knowledge, promoted developmentally informed care, and strengthened primary care readiness to support children and youth with autism and their families across the lifespan. Fifty physicians and clinicians attended the in-person workshop.

KSKidsMAP
Pediatric Mental Health

Autism, Neurodevelopmental Disorders and Intellectual Disabilities Annual Conference

Transitioning to Adulthood

A free conference for physicians and clinicians focused on supporting neurodiverse youth during the transition to adulthood

About

KSKidsMAP is excited to announce this year's conference topic: **Transitioning to Adulthood** for patients with autism, neurodevelopmental disorders and intellectual disabilities. Learn from child and adolescent psychiatrists, psychologists, developmental pediatricians, and other experts on challenges patients and families face as youth become adults. Open to all primary care physicians and clinicians, and behavioral health clinicians.

Topics

- Recognizing and treating existing and emerging psychiatric disorders
- Understanding common behavioral challenges
- Guardianship
- Transition of care to adult providers
- Resources for families and more!

Partners

Heartspring
KANSAS CHAPTER
American Academy of Pediatrics

Date
Friday, May 2, 2025

Time
8 a.m. Registration/check-in
3:30 p.m. Closing remarks

Location
Heartspring Conference Center
8700 E. 29th St. N
Wichita, Kansas 67226

Cost
Free for all attendees

Included
Continuing Education Credits
Breakfast, Lunch, and Snacks

Registration

Click HERE to register or use the QR code

More information:
kskidsmap@kumc.edu

Care Coordination Initiatives

Objective 5.3: Increase the proportion of families of children with special health care needs who receive care coordination supports through cross-system collaboration by 25% by 2025

Holistic Care Coordination: SHCN Program

Holistic Care Coordination is a foundational component of the SHCN Program's structure. During recent staffing and program alignment shifts within the bureau, the need for a more consistent foundation for care coordinators was identified, including the development of a structured learning pathway and dedicated training opportunities. During FFY25, the Title V CSHCN Director, the Screening & Surveillance Section Director, and the SHCN Program Manager discussed potential training needs. The Title V CSHCN Director spent some time exploring options available in other states for training and shared resources that may be useful for the program. However, a single training source was not identified during this period.

One internal tool identified for the program's use is the Holistic Care Coordination Toolkit, developed by the Kansas Title V team, largely by the Systems of Care Consultant around 2022/2023, a position that is no longer present in the bureau. This toolkit was created in alignment with the National Care Coordination Standards for CYSHCN and continues to offer practical tools to support family-centered, cross-sector care coordination. While dedicated work has not occurred over the last couple of years, the toolkit remains a valuable resource for care coordinators, program staff, and community partners.

The reason this tool was not identified sooner for use was directly related to staff losses over the past couple of years. Reintroduction of this toolkit will be a strong starting point for the SHCN Program, with the potential to lay the foundation for future training and implementation efforts for internal use.

Systems Navigation Training for Families

The Systems Navigation Training for Families (SNTF) program has been under a multi-year review during the 2024 and 2025 FFYs, and no training was offered to families in 2025. This review process has included efforts to understand better the structure, content, and delivery of the training, which is designed to be led by families with lived experience for other families seeking to navigate complex systems of care.

Progress in this area has been gradual, in part due to program transitions that led to a loss of internal knowledge from the prior training implementation. As a result, efforts have focused on rebuilding understanding of the model and assessing how it can best meet the needs of families of children with special health care needs in Kansas.

Title V continues to recognize the value of SNTF as a family-centered approach to strengthening systems navigation knowledge and support.

Care Coordinator Training and Workforce Development

Training and workforce development for staff supporting children and youth with special health care needs (CYSHCN) remained an identified priority during the 2025 reporting period; however, limited progress was made toward implementing new training initiatives. Changes in program staffing and structure impacted the continuity of this work and the ability to advance previously identified efforts.

Discussions among program leadership continued to highlight the need for a more consistent foundation for care coordinators, including structured training opportunities and a defined learning pathway. Similar to broader care coordination efforts, variability in training and resource utilization across staff underscored the importance of strengthening internal consistency in practice.

Exploration of training resources and models, including those utilized by other states, occurred during this period, and relevant materials were shared for consideration. In addition, existing internal resources, such as the Holistic Care Coordination Toolkit, were identified as potential tools to support workforce development. While these resources were not formally implemented during the reporting period, they remain available to support future training efforts.

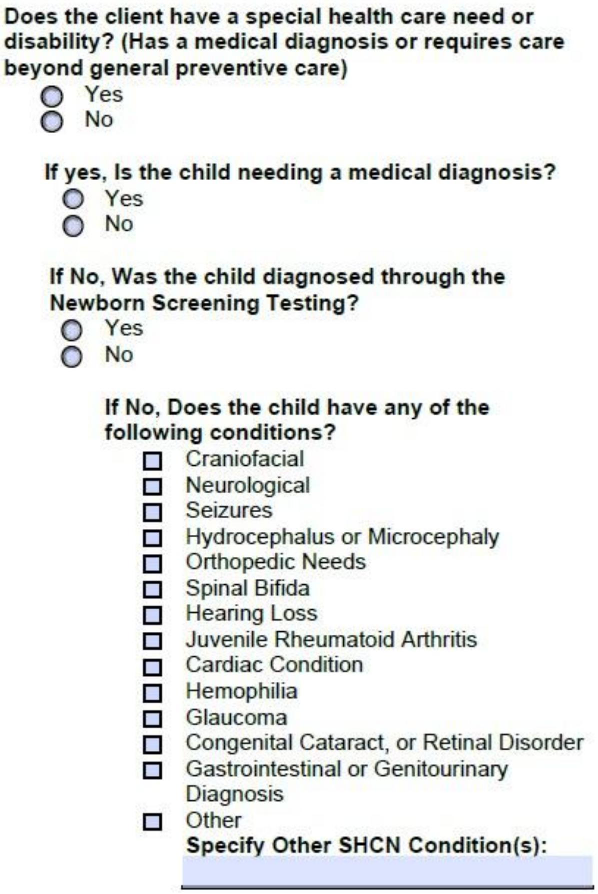
Overall, activities during FFY25 primarily focused on identifying needs and available resources rather than implementing new workforce development strategies.

Other CYSHCN Work

SHCN Screener:

The SHCN Screener was being entered into the DAISEY reporting system that our aid-to-local (ATL) partners use for their visit form. The updated SHCN Screener questions were designed to align with those of the National Survey of Children's Health (NSCH), with the aim of providing the Title V team and partners with a clearer picture of the CYSHCN population in Kansas.

The SHCN Program manager and the Screening & Surveillance Section Director worked with the Community Partnership Unit Director and their team to update the questions. As both parties considered the questions, desires, needs, and outcomes, it was decided to narrow the focus of the questions. Around the same time, the NSCH identified the need to update its survey, and this was also taken into consideration. The questions were then developed to identify individuals who would qualify for the KS-SHCN Program.



Does the client have a special health care need or disability? (Has a medical diagnosis or requires care beyond general preventive care)

- ○ Yes
- ○ No

If yes, Is the child needing a medical diagnosis?

- ○ Yes
- ○ No

If No, Was the child diagnosed through the Newborn Screening Testing?

- ○ Yes
- ○ No

If No, Does the child have any of the following conditions?

- ☐ Craniofacial
- ☐ Neurological
- ☐ Seizures
- ☐ Hydrocephalus or Microcephaly
- ☐ Orthopedic Needs
- ☐ Spinal Bifida
- ☐ Hearing Loss
- ☐ Juvenile Rheumatoid Arthritis
- ☐ Cardiac Condition
- ☐ Hemophilia
- ☐ Glaucoma
- ☐ Congenital Cataract, or Retinal Disorder
- ☐ Gastrointestinal or Genitourinary Diagnosis
- ☐ Other

Specify Other SHCN Condition(s):

The questions were added to the infant/child/adolescent MCH form on DAISEY. Evaluation of the updated questions will happen annually to ensure families are connected to supportive resources.

Program Policy & Service Delivery Changes

In 2025, the Special Health Care Needs (SHCN) Program undertook a comprehensive program evaluation to strengthen policy alignment, clarify program roles, and improve the quality, consistency, and equity of service delivery for children and youth with special health care needs. Building on the structural transitions identified in the prior year, the SHCN Program Manager and Screening & Surveillance Section Director led an extensive review of program policies, practices, staffing roles and responsibilities, and operational workflows.

This evaluation included a detailed assessment of program materials and family-facing resources; the application, assessment, and renewal processes; and the development of standardized training to support consistent action planning. The program restructured its renewal process to improve service clarity and continuity. It revised its care coordination model to emphasize comprehensive care coordination as the primary function, with financial supports serving as a secondary, supportive component. Additional activities included revising the program’s decision schema to reduce confusion for referring providers, updating income guidelines, and conducting a systematic review of client cases to ensure compliance with payer-of-last-resort requirements. The program also re-established relationships with Medicaid providers to improve coordination across systems of care and reviewed satellite office support structures to ensure consistent care coordination statewide.

Collectively, these efforts represent a significant step toward strengthening program infrastructure, improving service consistency, and positioning the SHCN Program to deliver high-quality, family-centered care coordination aligned with Title V priorities and the needs of Kansas families.

The Child Safety Learning Collaborative (CSLC), Suicide and Self-Harm Prevention

Kansas Title V has been participating in the Child Safety Learning Collaborative (CSLC) Suicide and Self-Harm Prevention (SSHP) work group since December 2023, with the Title V MCH Director and the Director of the Injury & Violence Prevention Programs leading the collaborative effort.

The team decided they would like to participate in a second cohort opportunity and wrote a new application to continue in Cohort 2 towards the end of FFY25, using the Title V Needs Assessment that was being developed to select the work group they would take part in. The team decided to once again participate in the Suicide and Self-Harm Prevention (SSHP) work group. The Title V leadership and our partners with Injury and Prevention view participation in Cohort 2 of the CSLC as a critical opportunity to build on the foundational work initiated during the previous cycle.

The CSLC model offers a robust framework for cross-jurisdictional learning and shared innovation. Through exposure to expert guidance, national best practices, and peer collaboration, Kansas aims to shape strategies that are both evidence-informed and sustainable within the state's unique context. Kansas continues to face alarming youth suicide rates that exceed national averages and are particularly high among adolescents with special health care needs (CYSHCN). The recent Title V Needs Assessment findings underscore the urgency of addressing suicide and self-harm prevention as a priority area. By participating in Cohort 2, the Kansas team will focus on strengthening its coordinated suicide prevention approach through systems alignment, data-informed action, and family-centered practices.

The Kansas Title V CSHCN Director is a co-lead of this effort in partnership with the Director of the Injury & Violence Prevention Programs and an advanced epidemiologist working with the Zero Suicide Program from the Bureau of Health Promotion. The Title V MCH Director has continued to be a support as needed throughout Cohort 2.

After the application to join Cohort 2 was accepted, the team reviewed the plans and the work completed in Cohort 1. It concluded that they would like to change the focus for Cohort 2 to take advantage of the renewed opportunity. Before the end of FFY25, the team planned to review a heat map of incidents across Kansas, in conjunction with the locations of our Aid-to-Local (ATL) grantees that selected the adolescent population as one of their served populations. Additional conversations on how to support the SHCN Program Care Coordinator team and SHCN Program Satellite Offices in a way similar to how the team is looking to support the ATL grantees have been ongoing. By the end of FFY25, momentum for this project was slowly but consistently building.

Medical Home

Medical Home was a key topic of discussion during the FFY25 Needs Assessment process and the development of the new 5-year State Action Plan. Conversations frequently centered on how to strengthen and re-establish Medical Home as a core focus for children and youth with special health care needs (CYSHCN). While the concept of Medical Home has remained present in program language over time, a consistent, shared understanding of its components and implementation has diminished due to program and system changes in recent years.

During FFY25, Title V leadership prioritized developing a clearer, shared understanding of the Medical Home model and its core components to align programs better. These efforts were intended to ensure that staff are equipped to integrate Medical Home principles into their work as the program moves into the next State Action Plan cycle.

For the CYSHCN population, discussions emphasized care coordination as a central component of the Medical Home model. Efforts to strengthen care coordination practices, including identifying training needs and existing resources, were recognized as key strategies for supporting CYSHCN and their families within a well-functioning system of care. While no new Medical Home-specific initiatives were implemented during this time, these discussions informed priorities and areas of focus for the future.