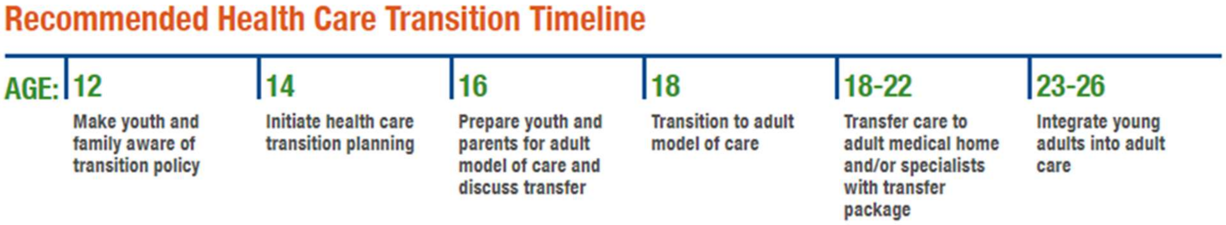
Transition Initiatives

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.

Health Care Transition (HCT) Planning: The approach to HCT for was intended to support the development and promotion of a comprehensive transition plan for providers when engaging youth and their caregivers in the planning process. Transition discussions can be a sensitive subject, especially for youth with special health needs (YSHCN) entering unknown territory, and many challenges may present themselves. Some of the identified challenges include:

- YSHCN may be concerned about what more will be expected of them.
- Parents/caregivers can have trouble "letting go," as so much of their life has been focused on caring for the adolescent.
- Adult health care providers can be hard to find (particularly in rural areas) or lack experience in providing care to YSCHN or their specific medical needs.
- YSCHN may struggle to find flexibility in employment schedules and/or concerns about missing school.
- YSHCN transition planning takes additional time and resources for busy provider practices, where reimbursement for transition is not widely available.
- Pediatric and adult providers may need several consultation visits to support the YSHCN and their family.

The KS-SHCN Program has continued recommending evidence-based models, such as the Six Core Elements of Health Care Transition 2.0 through GotTransition (depicted below). These elements provide practical guidelines and recommendations to providers when developing their own transition planning protocols or curriculum. The KS-SHCN team has continued to discuss transition with families and caregivers and help them identify transition goals.



Recommended Health Care Transition Timeline

AGE:	12	14	16	18	18-22	23-26
	Make youth and family aware of transition policy	Initiate health care transition planning	Prepare youth and parents for adult model of care and discuss transfer	Transition to adult model of care	Transfer care to adult medical home and/or specialists with transfer package	Integrate young adults into adult care

Due to leadership changes and onboarding new staff, the KS-SHCN Program was not able to focus on on-going transition training for themselves to share with clients. With a new program director and section director overseeing the program, the decision was made to do a complete review of the program during FFY24. Education and technical support for providers on transition planning has not been as consistent as desired. This discovery led to the identification of a need to ensure ongoing professional development for KS-SHCN staff to create a level of comfort in applying their knowledge and best practices when working with providers. KS-SHCN leadership recognizes that a well-trained workforce improves engagement and support to both providers and families and will continue to be a focus in the coming year.

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 looking at the holistic approach to care coordination services, however these services are only provided to those who meet KS-SHCN program criteria. For this reason, the CSHCN Director and the Screening & Surveillance Section Director continued to build partnerships with internal and external partners to help address the needs of the special needs' population in Kansas. According to the National Survey for Children's Health (NSCH) in 2023, data shows 22.2% of children have special health care needs based on the CSHCN screener in Kansas. While 21.6% have one current or lifelong health condition, 21.2% have two or more current or lifelong health conditions. Additional data showed that 26.8% of Kansas children ages 3-17 year had one or more reported mental, emotional, developmental or behavioral problems. Data indicate that CSHCN experience two or more ACEs has decreased in previous measures currently at 18.7% (down from 35.3%), as well as more non-CSHCN reporting not having any adverse childhood experiences (from 16.9% to 59.7%) potentially suggesting a positive direction in both measures. While the data subset for Kansas specific indicators is small at this time for special health care needs, starting in FY22 the Title V Directors focused on expanding the data sets for this population in subsequent years. Allowing a better view of Kansas' strengths and weakness for the special health care needs population. That coupled with the expanded definition for CYSHCN in the NSCH will show a better picture of the needs children and families have across Kansas.

Title V in Kansas recognizes that it takes a village and that not one person or group can do the work alone. For this reason, collaboration across systems is vital to strengthening systems and supports for Kansans. Title V staff put great emphasis on working with local and state agencies to partner in a variety of ways to support the Title V population especially for children and youth who have special health care needs. While new partnerships are forged each year ongoing partnership continue to be nurtured as well. Some examples of special health care needs partnership work can be found below:

- KDHE and the Bureau of Family Health continued their work with the Kansas Council on Developmental Disability (KCDD). The Screening & Surveillance Section Director began filling this role during FFY24 being the voice for Title V's work with the SHCN population.
- One project that was entered into with the council was a partnership in developing and holding a Supported Decision-Making (SDM) Summit for families who had transition age youth. Often, families do not know that there are alternatives to guardianship, so this summit was designed to assist families in understanding their options and what fits best for their adolescent and family. This summit was held in-person and streamed live with positive reviews from those who participated. Topics covered were: What supported decision-making is and the alternatives to guardianship that families can consider, Life Course model and how it can be used for SDM, a panel consisting of a young adult who used SDM, his aid, and a leading expert on SDM. Speakers for the summit consisted of individuals with special needs who had/or were currently using SDM for their transition into adulthood and other experts in the field of SDM. Plans have begun with partnership from KCDD, Kansas Department of Education (KSDE) and Title V for the next SDM summit that will focus on educators who support adolescents as they begin their transition journey.
- One that is especially important is working with Medicaid to get CHW service coverage through a possible State Plan Amendment. This is a collaborative effort between United Health Ministries, Medicaid, BHP and Title V. Research has been conducted; draft proposal developed using specific terminology; CHW supervision requirements; code

mapping and training have all been part of the work. While there is still lots of work to go it is the hope of the Title V team that this will be amendment will be approved so some components of the CHW work can reimbursed.

- Through partnership with the Screening and Surveillance programs within the Bureau of Family Health (BFH) the KS-SKCN program has refined its referral process to include not only the Newborn Screening Programs but the Birth Defect program as well. Families are referred from these programs to the KS-SHCN program who then follow up with families using a secure postcard invite to apply for the program. This is then followed up with a phone call to answer question families might have about the program. The move was made to a postcard process due to families not answering calls from numbers they were not familiar with. The first postcard lets them know that their child medically qualifies for the program and that a care coordinator will be calling in a few days to explain how the KS-SHCN program works. If no phone contact is made additional postcards and an application, follow. This data is tracked and monitored with a goal of a 5% increase annually based on completed applications submitted to the KS-SHCN program.

Insurance and Financing Systems of Care for CSHCN: The Title V MCH Director, CSHCN Director and the HCC Consultant worked to implement a three-phase approach to identifying gaps and barriers in the financing of systems of care for the SHCN population in Kansas. This process was to include an environmental scan & service assessment; review of what insurance financing looks like in other states; and face-to-face meetings to gain more concrete information. All phases were designed to build from one another to lead to the development of a state plan to address identified needs. However, due to vacancies in these positions at differing times, only the environmental scan FY23. The remainder of this work will be evaluated upon hiring for the CSHCN Director to determine next steps.

Holistic Care Coordination in Kansas

Environmental Scan and Literature Review

Kansas Department of Health and Environment

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During FY24, the Title V MCH Director along with KDHE Communications and the Kansas Health Institute (KHI) worked to publicize the results of the HCC environmental scan. The results of the environmental scan were shared via social media posts and short videos. The report was published on the KHI website and is available at https://www.khi.org/articles/holistic-care-coordination-in-kansas-environmental-scan-and-literature-review/.

Autism Coalition: Convening in May 2024, Title V began leading coalition activities focused on making the 2021 Autism Task Team's recommendations report actionable. The Coalition is still in the early stages of development but has been making progress on creating a common agenda and measurables that will bring together partners working with individuals with ASD to The coalition brings together several state agencies as well as community partners.

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

Bridges Care Coordination: The Bridges program faced challenges following the retirement of the former Title V CSHCN Director who developed it. In response, leadership decided to transition the program to the Children and Families Section, where the Kansas Early Childhood Developmental Services (KECDS, formerly Kansas Infant Toddler Services) Program resides. This shift allows KECDS to take the lead on the Bridges program, as it is designed to be a bridge to local services for children aging out of Part C when they don't qualify for Part B.

At the end of FFY24 the KECDS Program Manager was working on a contract with Families Together, the Kansas Family-to-Family organization, to assist with the program.

Systems Navigation Training for Families: There was a significant amount of change at the start of FFY24, with the SHCN programming moving into a new section. Additionally, the trainers for the Systems Navigation Training for Families (SNTF) ended their agreement with the Kansas Title V Team. Through the review of the SNTF work, it was found that much of the resources and foundational information was lost during that transition.

The Title V CSHCN Director was able to determine that the original SNTF was developed by the Region 4 Midwest Genetics Collaborative, which had unfortunately lost funding in the months prior to this work transitioning internally.

The internal leadership team consisting of CSHCN Director, Screening & Surveillance Section Director, and the SHCN Program Manager were able to meet with two of the authors of the original training to understand the historical background of the program. The team was able to obtain permission to review and revise materials from this group and it will continue to be a point of discussion and work over the upcoming year.

Systems Navigation Training for Youth: Due to a change in leadership and staffing, it was determined that the SNTY project should be placed on hold for the time being. The Title V CSHCN Director and the Adolescent Health Consultant recognize the importance of this work and agreed to revisit this project at the appropriate time.

Universal NPM: Medical Home—Care Coordination

Percent of children with and without special health care needs, ages 0 through 17, who receive needed care coordination.

According to the National Survey of Children's Health, in 2021-2022, 50.2% of children with special health care needs, ages 0 through 17, were reported to have a medical home (95% confidence interval [CI]: 44.3%-56.1%). From 2017-2018 to 2021-2022, this estimate experienced a decreasing trend via Joinpoint regression software, though not statistically significant.

Care Coordinator Training and Workforce Development: The Title V CSHCN Director, Screening and Surveillance Director, and KS-SHCN Program Manager used the last year to complete a comprehensive review of the KS-SHCN program and the services it provides.

Through this review, the need for foundational and consistent care coordination training was needed for the KS-SHCN needs care coordination. The Title V CSHCN Director has started reaching out to other Title V programs in surrounding states to identify potential trainings and reviewing potential options.

Other KS-SHCN Initiatives

Peer Supports for CSHCN: While the KS-SHCN Program recognizes the importance of peer-to-peer supports, the Supporting You network that was established in recent years was not effectively addressing the need. The program failed to gain momentum and was not effective in recruitment of mentors and mentees. As a result, the contract with the vendor for the Supporting You Network was not renewed at the end of SFY24. Ensuring that peer-to-peer supports are available to YSHCN, and their families remained a focus and the Title V CSHCN Director connected with Families Together, Inc. The goal of this collaboration was to work with Families Together Inc, which hosts the Kansas Family-to-Family Health Information Center and build their peer support program which is aimed at families with CYSCHN. At the end of FFY24, a contract was in development with Families Together Inc.

SHCN Screener: The SHCN Screener was intended to be added to the DAISEY Data System, which would be part of the infant/child/adolescence visit form for providers who use DAISEY. The key materials that need to be developed or created to support this update, which included:

- Training guidance to show how to use and score the screener.
- A decision schema to assist those using the tool to be able to refer to the correct agency/provider, as needed.
- A training webinar to support local partners in the successful use of this new tool prior to implementation.

The goal for this addition was to ensure all referrals would be tracked and monitored to make sure children are getting connected with the appropriate resource.

The SHCN Screener in the DAISEY data system had a portion updated to identify more children to be referred to the KS-SHCN Program in FY24. This portion that was developed helped identify individuals who could be referred to the SHCN Program.

After the agreement of the partial screener expansion, the National Survey of Children’s Health announced a redesign of their survey, which the expansion had been based on to align with how SHCN was counted at the national level. Due to that redesign, KDHE decided to hold on further expansion.