# **Children with Special Health Care Needs (CSHCN):** 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.*

## *Activities During Federal Fiscal Year 2023*

KS-SCHN Transition Action Plans: Throughout the Title V Needs Assessment and implementation of the HCC model, transition planning for youth and adolescents ages 12 and older has been an identified service gap. Youth with special health care needs (YSCHN) and their families generally do not receive guidance on transition planning from their health care providers or other support systems. Additionally, health professionals continue to note the importance of health care transition (HCT), but many have struggled to incorporate transition planning into their practices. Providers state that they lack the capacity and resources to effectively plan for transition with their adolescent patients, despite an interest in doing so.

The KS-SHCN program policy continues to require the development of at least one transition goal with an action plan for any CSHCN client (ages 12-21 years). The program's goal is to assist clients in accomplishing a successful transition that takes into consideration not only the clients age but also their developmental abilities when offering appropriate transition materials and tools. All transition age clients and their families, regardless of their participation in care coordination services or client's level of care, were offered these tools and resources (e.g. Think Big Transition planning booklets, transition websites, information on how to talk to your doctor, filling a prescription, understanding your medical condition). The program continues to adopt the GotTransition recommended HCT timeline.


Care Coordinators continue to work with CSHCN and their families to develop goals that meet their needs and help them grow and become proficient in all aspects for growth and development throughout the life span. Transition is not only focused on transitioning from pediatric to adult health care systems but transitioning in all aspects of life (e.g. self-advocacy, health and wellness, health care systems, social and recreation, independent living skills, education). To support adolescents, in their transition needs a multi-faceted approach is required which is used as part of the HCC approach but can also be used as stand-alone components for all youth. HCT is also covered as part of the Systems Navigation Training for Families curriculum.

Preparing for Transition Booklets: The KS-SHCN team continued to disseminate the Future Is Now, Think Big transition resources developed by the Family Advisory Council. This series of resource booklets are shared with all children/youth and their families on the KS-SHCN program and partners across the state. There are 3 booklets in the series, targeted for different age groups and shifts from supporting parents of young children to help them be independent, to building the partnership between the parent and child/pre-teen, and then finally to the youth to fully prepare them for transition. The content of these booklets was developed by the FAC several years ago but are still applicable to today's population. These booklets are also promoted with local MCH grantees as an opportunity to support/promote transition preparation within the communities.

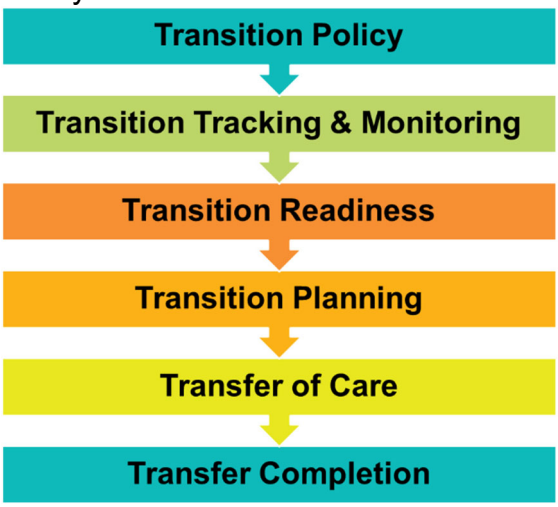
The program team has discussed with the Child and Adolescent Consultant about modifying these to be more inclusive for all children/youth not just those with special health needs. The Child and Adolescent Consultant has started an initial review of the materials to determine what changes/alterations need to be made to make the resources more inclusive. The SHCN program also hosted an intern to help identify what transition topics were needed to make these resources more inclusive and the Child and Adolescent Consultant is currently going through those. Once a draft has been developed the plan is to ask the Family Advisory Council SHCN work group to review and provide ideas and suggestions for changes that can make these more user-friendly for children and youth, both with and without special health needs

Transition Direct Assistance Program: The KS-SHCN team had intended to develop a Transition Direct Assistance Program (TR-DAP) to meet the needs of adolescent who qualify for the KS-SHCN program. The KS-SHCN team had begun a review of the existing transition tools and resources currently shared with adolescents and their families, an external review of other transition tools and resources, and sought input from youth on what they think would be helpful. Care coordinators planned to engage adolescents and their families on the program in discussions around their thoughts and ideas regarding transition and document their feedback. However, due to changes in the KS-SHCN team this project was put on hold. Based on the results of the next five-year needs assessment, this work may be revisited.

Health Care Transition Planning: To develop a comprehensive transition plan, providers must engage 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.




KS-SHCN has been recommending evidence-based models, such as the Six Core Elements of Health Care Transition 2.0 through GotTransition.org (depicted below). These elements provide practical guidelines and recommendations to providers when developing their own transition planning protocols or curriculum. In addition, the American Academy of Pediatrics (AAP)/Bright Futures has provided information on other evidence-based resources to help healthcare providers implement transition practices and policies which have been incorporated into patient and provider resources.

KS-SHCN Care Coordinators and staff have been available to offer technical support to providers of mutual clients, assisting them to problem solve challenges and barriers to creating transition plans for their CSHCN patients.

HCT Systems of Care: Title V continues to monitor insurance and financing needs related to HCT and work with both public and private insurers to support adequate reimbursement rates for transition. HCT practices require additional time during medical appointments and wrap around supports to help guide youth and families through this process. Providers have shared that without adequate reimbursement it is challenging to take the time to work on effective HCT planning. Recognizing effective transition planning must look holistically at the youth's needs (e.g., family needs, education, social, housing, employment), KS-SHCN works with YSHCN and their families to discuss the importance of transition and to set holistic goals to help them reach their full potential and ensure a smooth transition into adult living.

This holistic approach aligns with many other systems and agencies. Utilizing The 2020 Federal Youth Transition Plan: A Federal Interagency Strategy as a guide, Title V

engages in efforts across systems to support the vision outlined in this plan. It should be noted that this plan is presented by the Federal Partners in Transition (FPT) Workgroup and is reflective of a cross-systems approach to provide supports and services to youth with disabilities. Several federal departments and agencies were involved, including the Departments of Education, Health and Human Services, Labor, and the Social Security Administration. While Title V is not named specifically in this plan, there is clear alignment to the Kansas Title V vision for supporting transition through the population health/system of care lens.

Transfer of Care: Once an adult provider is identified, the pediatric provider should begin the transfer of client information, including up-to-date medical records, to ensure a smooth transition of care. For clients with special health care needs, there may be multiple specialists on the care team, making consistent and frequent communication between all providers a critical part of the care team's service delivery. The HCC provided through KS-SHCN can supports these communication efforts by utilizing strategies and tools identified through GotTransition.org. KS-SHCN continued to review evidence-based transition tools and resources to be share with providers, health agencies, families and especially adolescents.

The more a youth can assess where they are in the transition journey and have resources to help guide them as they move through this process, the higher their success rate. Program staff feel the addition of a transition portfolio is a valuable tool to help guide youth and their families to transition readiness and success. The portfolio includes a transition checklist, a list of members on the care team with contact information, medications, the patient's challenges and strengths, a current copy of their Action Plan or SPoC and their dreams and hopes for their future. The portfolio also has a resource section that lists SSI or disability contact information, legal resources, career options and training, support groups, housing, and other items of need for the youth. A question/concern form is included that can be completed prior to medical appointments to share with providers and facilitate open dialog during visits. The Transition Portfolio has been embedded as part of the Systems Navigation Training for Families.

Local MCH Agencies: The following are examples of how some of the local MCH grantee agencies have made progress toward objective 5.1 during the reporting period.

- Crawford County Health Department set goals with Special Health Care Needs (SHCN) families specific to transition as part of their action plan. They provided Think Big (Preparing for Transition Planning) guides specific to the child's age range. As part of yearly renewals, at age 17 and 18 specific letters were mailed to families that address guardianship transition plans.
- Linn County Health Department conducted hearing screenings with several children and adolescents found to have hearing difficulties. They provided services to 28 CSHCN.
- Miami County Health Department served 31 clients with SHCN. The Special Health Care Needs Care Coordinator worked closely with KDHE staff, and shadowed Crawford County's Special Health Care Needs Program, to receive

further training and ensure that clients 'needs are met. They implemented the Bridges Program and completed the Families Together Parental Rights Training and Individualized Education Program (IEP) Development Training.

- Saline County Health Department enhanced their referral process for those with special health care needs by connecting with Independent Connection through their Integrated Referral and Intake System (IRIS) network. They also collaborated with Independent Connection to form the Saline County Maternal Child Peer support group. They wanted to ensure that those with children who had disabilities or mothers with their own disabilities felt they had a safe space to share where they felt welcomed. Additionally, they provided local and state resources available to all peer support attendees to include SHCN populations. There were 34 mothers and support people who attended session 5 where the SHCN program was highlighted in addition to case support management for anyone who has any questions about the SHCN program. They continued to refer to Central Kansas Cooperative in Education (CKCIE), OCCK, Choices, Disability and Planning Organization of Kansas (DPOK), and Independent Connection as needed.

## *Plans for Federal Fiscal Year 2025*

Health Care Transitions (HCT) Systems of Care: The Kansas Title V team recognizes the importance for youth and young adults to have adequate health insurance. Insurance, while not thought of by most adolescent as they are transitioning into adulthood, is critical for them to have access too. The Title V team continues to monitor insurance and financial needs related to HCT by working with both public and private insurers to support adequate reimbursement rates for transition.

The Holistic Care Coordination (HCC) model uses a lens that focuses on all aspects of moving from adolescence to adulthood. This includes all aspects of life including self-advocacy, health and wellness, health care systems, social and recreation, independent living skill, and education. Effective HCT takes additional time and effort by providers during medical appointments to make sure the adolescent has all the services in place they need for a successful transition, however without adequate reimbursement, this becomes challenging and if the adolescent has special health care needs it becomes even more time intensive and difficult. Title V will continue to work with providers to understand that HCT is not just medical but helps them understand all the needs of an adolescent (e.g., family needs, education, social, housing, employment). The KS-SHCN Care Coordinators will continue to work with the adolescent, their family, and providers to understand the importance of transition and to develop holistic transition goals to help them reach their full potential and have a smooth and successful transition into adulthood.

Health Care Transition (HCT) Planning: Within the SHCN program, every client aged 12 and up will continue to have a transition goal included in their action plan which will continually be monitored and supported by the SHCN Care Coordinators. Care coordinators provide youth and their families a variety of tools and resources depending on the youth's transition needs. They also share the Think Big Transition booklets with

all youth and families on the program. These booklets provide general examples of what transition skill milestones the youth should be achieving based on their age or developmental age (birth -6 years, 7-13 years, and 13 year and up). These free booklets will continue to be made available to schools, partners, and families upon request.

SHCN Care Coordinators will also continue to refer families to the Got Transition website for additional resources. The Got Transition Readiness Assessment tool will continue to be recommended by care coordinators for youth on the program to complete. The Got Transition website will continue to be promoted by the CSHCN Director with partners across the state and as a resource for System Navigation Trainings for Families (SNTF) and System Navigation Training for Youth (SNTY).

During FY25, the Special Health Care Needs (SHCN) program will focus on developing and training the Care Coordinators to be able to give supports to families as their children enter the transition age ranges. There will be a special focus on clients ages 18-21 who are aging out of the SHCN program. The CSHCN Director will work with the SHCN Program to develop a transition toolkit for those aging out that can be provided to parents, caregivers, and care professionals.