Children with Special Health Care Needs (CSHCN) Objective 5.1 Transition Initiatives

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REPORT – October 2021 through September 2022

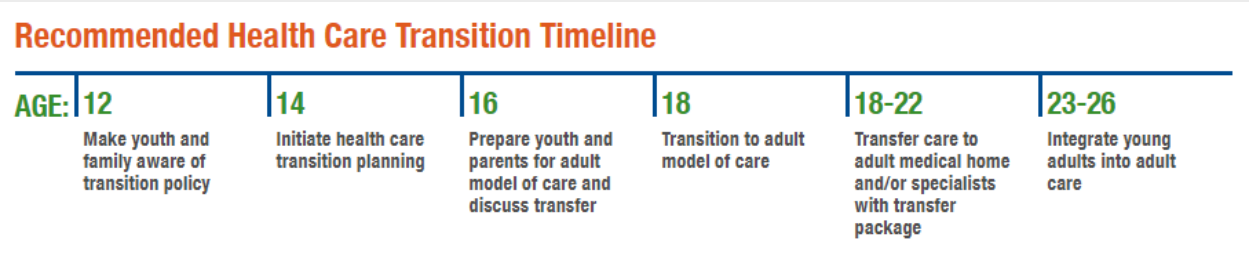
Health Care Transitions (HCT) Systems of Care: Educating youth on transition needs and where to access resources was identified as an area that could be moved forward with the support from an intern with guidance from both the MCH and CYSHCN Directors. The Systems Navigation Training for Families (SNTF) was used as a model to guide the intern in the development of a Systems Navigation Training for Youth (SNTY). The project began with the intern researching transition materials, videos, websites, special needs populations and more to become familiar with what youth would need to help them become empowered as they move into adulthood and independence. Once the research was complete, the intern developed fliers for the promotion of focus groups to help inform the project curriculum and structure. Three focus groups were conducted virtually, and one was held in person. A total of 82 youth engaged in the focus groups leading to a wealth of information about what youth need and want to learn. Since the intern was only a few years older than the youth in the focus groups, they were able to relate to the intern, leading to more open information and idea sharing. Through the information gathered, research conducted, and guidance from the Title V Directors, the intern was able to put together a comprehensive training plan that included: training PowerPoints; a youth transition engagement snapshot; a focus groups evaluation summary; a Youth Transition Training Quick View; a trainer instruction manual; recommendations on SNTY dates/times; a final written report; and recruitment materials for young adults to recruit as participants in train the trainer sessions that will enable them to lead the trainings as contracted staff in the future. This program was developed so that youth can learn from someone they can identify with, so there is a concerted effort to develop trainers that are young adults. The SNTY is designed for all youth, with and without special health care needs, so finalization of the training, recruitment and training of trainers and other program logistics will be a share responsibility of the CYSHCN Director and Child/Adolescent Health Consultant.

While several ideas were developed to strengthen transition supports over the last year many were delayed due to staffing shortage and turn over in staff. With a decrease in staff capacity, the KS-SHCN program at fifty percent and a vacant Child/Adolescent Health Consultant, moving new projects forward was a challenge. During this time frame staff took on additional tasks to keep the work moving for the clients on the KS-SHCN program and other broad Title V special health care needs and child and adolescent work.

Health Care Transition (HCT) Planning: Assisting youth and their families through the critical phase of transition was identified as a top need during the most recent needs assessment, by not only the Title V team, medical and community partners, but also families. For this reason, it was selected as one of Kansas's National Priority Measures (NPM 12). While NPM 12 is for youth with and without special health care needs, the Kansas Special Health Care Needs (KS-SHCN) program developed and implements a high-quality Holistic Care Coordination (HCC) program that has led to a great starting point for delivery of expanded health care transition services, with the intent to spread and scale tools, resources, and information to all youth. As new tools and resources are developed, they are added to the Whole Healthy You webpage for all adolescents to use.

As part of the KS-SHCN training curriculum the importance of HCT is discussed. Strategies and tools are provided to assist the care coordinators when working with youth and their families in the development of transition action plan goals. The program implemented a policy that all action plans must contain a least one

transition goal for all clients ages 12 –21. Staff are familiar with the Got Transition website and the tools and resources it offers. They use it as needed to support a youth in their transition planning. Transition plans follow the Got Transition recommended Heath Care Transition Timeline shown below.



Youth are encouraged to talk to their medical home providers about their transition needs during their annual well-child checkups. Action plans that have been developed by the youth and their care coordinator are able to be shared with the youth's medical home providers. Action plans are updated and modified based on input from the family, youth, and providers as needed.

Transfer of Care: As adolescents with special health care needs move into the transfer of care stage one of the first steps is to identify an adult provider. This means not only identifying an adult provider but one who is covered by the youth's insurance and is comfortable with the youth's special health care need. This can be a barrier for many with special health care needs. Not only does Kansas have a lack of providers, especially in rural areas, but also finding providers with the expertise and comfort level to provide medical services to those with certain medical conditions can be a challenge. Once a provider is selected, then the process of communication between the pediatric provider and the adult provider begins. This includes a transfer of client's information, up to date medical records, most resent shared plan of care, a copy of a transition readiness assessment, emergency care plan, legal documents, condition fact sheet, and any other client information that would lead to a successful transition. Ideally, communication between providers should occur to discuss the clients unique medical need and establish a process where the pediatric provider can provide consultation to the adult provider, if needed.

The KS-SHCN Care Coordinators assist adolescent clients and their families in the transfer of care process. SHCN currently has 18 children on the program that are within their transition window and are being supported in the finalization of their transition plan. In the last year, we have aided an addition 4 individuals in their transition journey who were aging out of the SHCN program. A variety of resources and guidance in selecting an adult provider that is covered by the adolescent's insurance is provided as needed. Many tools and resources are used to help with the transition experience such as:

1. GotTransition.org that provide a variety of transition resources with one of the most important being the Transition Readiness Assessment tool.
2. Creating a Good Life- Life Course Framework Creating A Good Life: A LifeCourse Framework - KCDD - Kansas Council on Developmental Disabilities are tools that can be used for transition and long-term planning.
3. Transitions Workbooks designed by the Kansas Family Advisory Council. These are available in English and Spanish and offered for three different age or developmental age ranges.

Other transition resources and approaches that are reviewed, aligned with, and utilized as appropriate to continue to strengthen transition work in Kansas include:

1. https://www.dol.gov/sites/dolgov/files/odep/pdf/20150302-fpt.pdf
2. Supported Decision Making
3. National Care Coordination Standards for Children with Special Health Care Needs

Originally, plans were in place to develop a transition portfolio however, due to staffing shortages and feedback from an intern who worked on the Systems Navigation Training for Youth (SNTY) project a Youth Transition Training Quick View was developed instead. The quick view has been developed; however its

implementation has been delayed due to staffing shortages but is available to youth on the KS-SHCN program. If identified as a need later, a transition portfolio might still be developed in the future.

Local MCH Agencies:

- Barton County Health Department educated their community about the services available through their CSHCN program. They attended two large events, Convoy of Hope and the community baby shower, and presented on a local radio show.
- Community Health Center of Southeast Kansas assisted 100% of child clients with special health care needs with transitioning from a pediatric care provider to an adult provider at age 17.
- Crawford County Health Department focused on promotion of CSHCN services, such as transition assistance, provided in their region. They shared CSHCN brochures, decision schema posters, and Family Advisory Council postcards with neighboring health departments in Bourbon, Cherokee and Labette counties, as well as KanCare case managers, to acquaint new staff with the program and reacquaint those who had been solely focused on the pandemic response for the past two years. They also completed Transition to Adulthood training and formed a new partnership with a coordinator from the Kansas Department for Children and Families (DCF) who will help promote and provide CSHCN transition services.

PLAN – October 2023 through September 2024

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 is not something most adolescents think about as they are transitioning into adulthood but 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 (e.g., 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 works with providers to understand that HCT is not just medical but helps them understand the holistic approach that includes all aspects of an adolescent's needs (e.g., family needs, education, social, housing, employment). The KS-SHCN Care Coordinators 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 FY24, The CSHCN Director will be researching reimbursement supports for transition services with Medicaid and other insurance providers in the state to determine what is currently available to youth and their families. The director will engage with members of the Family Advisory Council, conduct focus groups, and implement a family survey to identify what transition supports are reimbursable currently and where there are gaps. Based on information learned, a work plan will be created with prioritized items such as transition activities that need to be funded by Medicaid and other insurers to improve transition services for youth with special health care needs.

For many families, costs associated as children with special health care needs begin to age out of the program are one of the barriers preventing children from taking the next step in independent or self-sufficient living settings. SHCN looks to add a direct assistance program (DAP) specifically focused on reimbursement or upfront coverage for costs associated with transition.

Local MCH Agencies:

- Barton County Health Department will increase the number of times transition education is provided to MCH clients by 10% (122 times).
- Community Health Center of Southeast Kansas will assist 100% of special needs children in the MCH program in transitioning care from infancy into adulthood and beyond. The most common transition is from a pediatric to an adult provider. Providers and MCH Case Managers will provide direct support in transition services.
- Crawford County Health Department will continue to serve as a SHCN satellite office, providing transition and care coordination services as well as participating in the BRIDGES pilot program.
- Miami County Health Department will start using a transition readiness assessment with their clients aged 12-21. Since this is the first year they hope to have assessments completed by 25% of their clients.
- Nemaha County Community Health Services will begin completing transition readiness assessments for all adolescents who have a well visit. This will expand on the transition readiness assessments they complete with CSHCN. Transition readiness assessments for CSHCN will be documented in Welligent and assessments completed as part of the adolescent well visit, for those not eligible for the CSHCN program, will be documented in DAISEY

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