

## Children with Special Health Care Needs (CSHCN) Objective 5.3 Care Coordination Initiatives

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### REPORT – October 2021 through September 2022

**Holistic Care Coordination (HCC):** Kansas Title V utilizes the [National Care Coordination Standards for Children and Youth with Special Health Care Needs](#), developed by the National Academy for State Health Policy, as the guiding framework for the holistic care coordination services provided to clients on the KS-SHCN program, the Bridges pilot, and all HCC expansion work noted in the cross-cutting section. Information about the standards is shared with partners across the state and assistance is provided to any partner or agency wanting to implement these standards within their practice. The Kansas Title V team has and will continue to participate in the National Care Coordination Standards work group as requested.

Work continued on the development and implementation of the Holistic Care Coordination Technical Assistance (HCC-TA) project with support from the KS-SHCN Care Coordinators. This project is designed to offer holistic care coordination (HCC) supports to providers across the state to help them establish, train and support HCC work in their practices. Read more about this in the cross-cutting report and plan.

The HCC work continues to be foundational within the Title V work. While originally developed for use by the KS-SHCN program, the long-term vision was to spread and scale to other providers across the state and within other Bureau of Family Health programs. The KS-SHCN program continues to use the HCC approach with all clients on the program who meet medical or SSI qualification standards. As part of the HCC work, a new referral process has been under development that will expand HCC work to a wider population of children with special needs. This new process includes a SHCN screener to help identify more children who might qualify for HCC services and will be used with a variety of partners to determine who should be referred for HCC services.

**Bridges Care Coordination Pilot:** The Bridges Pilot program was designed to support children and families as they are transitioning out of the Kansas Early Childhood Developmental Services (KECDS, formally called Infant Toddler Services) upon the child's third birthday and into the Early Childhood Special Education (ECSE) services or community services. This is a time that many families have expressed a feeling of being overwhelmed in knowing how to navigate the systems of care for their child. Bridges was designed to help fill that challenge by providing holistic care coordination services to provide a smooth and stress-free experience for the child and their family. This process begins prior to the child's third birthday. The local KECDS staff share information about the Bridges program with families and assist them in completing a simple application. The KECDS staff then send that application to their local Bridges Care Coordinator and invite them to the next appointment/meeting with the child and family for a warm handoff.

Upon receipt of the application the Bridges Care Coordinator (BCC) then enters the child's information into the data system and sends the family a welcome letter. Once the warm hand off meeting occurs the BCC begins working with that family directly, following Kansas Title V Holistic Care Coordination (HCC) model. This model is designed to be strength based, family and child centered, meet the family where they are and uses a holistic approach (medical - physical and mental, education, social, financial and legal) that looks at all aspects of the child and family's life. Working together, the BCC and family determine the strengths and needs of the child and family to develop an Action Plan to use as a guide while navigating the systems. BCCs

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provide ongoing support, referrals, and assistance as needed while helping the families learn how to independently navigate the complex systems of care successfully.

Once training was completed by all BCCs and KECDS partnerships were established, the referral process began in April of 2021. The target pilot population goal consisted of 60 plus children/families within various locations in Kansas (frontier, rural and urban) and in both English and Spanish. Monthly surveys were distributed to both BCCs and KECDS via SurveyMonkey to gather data and feedback on what was working and what changes needed to be made. Feedback included: minor changes to the application (adding KECDS staff's phone/email information), possible refinement of referral process (currently under consideration), development of check in postcards, and modification to support better data reporting within the current EHR system.

Monthly touch point meetings were held with each BCC to provide ongoing support and assistance. Trainings were limited to one-on-one trainings and coaching between the BCC's and the CYSHCN Director during the monthly touch points due to the pandemic. Quality improvement and quality assurance measures are used to monitor fidelity and program outcomes. This information is shared with the BCC team to help strengthen program services and fidelity.

During FY 2022, the Bridges program was challenged in expansion due to the COVID 19 pandemic and staff shortages within KECDS and Special Health Care Needs internal and satellite offices. While the pilot originally had five pilot sites, one site discontinued services, leaving only four sites. However, two new sites were recruited to become Bridges providers for 2023. The pilot currently has 30 plus children/families with one family whose primary language is Spanish. Additional funding sources and staffing options are being investigated to be able to move Bridges out of a pilot project into a fully sustainable program. With the long-term goal of offering this to all families across that state who have children exiting the KECDS program.

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**Systems Navigation Training for Families (SNTF):** Due to the COVID 19 pandemic, the Systems Navigation Trainings for Families were put on hold since these are an in-person event. There was consideration around developing a virtual version however, because many of the activities require interaction between participants to make a strong impression, especially when sharing their personal stories and connecting with others, It was decided to focus on the train the trainer model and development of a Spanish version.

During FY 2022 the KS-SHCN team had a 50% turn over in staff, making it a challenge to move this work forward. Work resumed at the end of the fiscal year with two new trainings being scheduled for winter of 2023. The train the trainer model was refined along with a review and update of the training materials and tools. A trainer recruitment application and evaluation review process are under development and will be used to increase the number of trainers across the state. Development of a Spanish Training has continued

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## PLAN – October 2023 through September 2024

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**Holistic Care Coordination:** Kansas Title V continues to use the [National Care Coordination Standards for Children and Youth with Special Health Care Needs](#) developed by the National Academy for State Health Policy as the guiding framework for the holistic care coordination services provided to clients on the KS-SHCN program. The Special Health Care Needs (SHCN) program continues to grow a network of referral sources for issues including, but not limited to, medical complications, behavioral health conditions, assistive technologies, surgery providers, physical therapists, and education assistance. Care Coordinators continue to attend trainings and webinars in order to maintain knowledge of community partners and referral sources to best provide services for families within SHCN.

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**Bridges Care Coordination (BCC) Pilot:** The Bridges Pilot program was designed to support children and families as they are transitioning out of Part C upon the child's third birthday and into the Part B or other community services. This is a time, that may families have expressed a feeling of being overwhelmed in knowing how to navigate the systems for care for their child. Additionally, the Bridges Pilot would provide support to those who would not qualify for Part B services upon graduation of Part C services, yet still required support in navigating the system. Bridges was designed to help fill that challenge by providing holistic care coordination services that have been used by the KS-SHCN team successfully for many years, to provide a smooth and stress-free experience for the child and their family.

Monthly touch point meetings will continue to be held with each BCC to provide ongoing support and assistance. Trainings will be developed based on feedback from the BCC's and identified needs from the CYSHCN Director. This includes a one day in-person trainings that will include the following training curriculum: BCC basics review that will include mock case plan review and team brainstorming and ASQ screening training. Yearly meeting will be held with the KECDS sites where additional feedback and partnership ideas can be discussed to better inform the program. Quality Improvement and quality assurance measures will continue to be used by the CSHCN Director to monitor fidelity and program outcomes. This includes a review of Action Plans to identify the greatest need for parents and support the BCC with additional training in those areas. The information gathered will also be used to provide virtual training webinar for families and make sure these topics are covered in the Systems Navigation Trainings for Families that Bridges families are invited to participant in when held in their locations. A Bridges Family Survey that was developed in the Spring of 2023 will continue to be sent to families every six months to gain their feedback.

Currently, Bridges is looking to expand referral locations across the state through care coordinators via satellite offices and the possible use of Community Health Workers as BCCs. Additionally, funding sources are being evaluated to further expand the Bridges program to provide increased capacity for referrals and care coordination.

**Systems Navigation Training for Families (SNTF):** SNTF will continue with a training session offered within each region of the state. These trainings are for families who have children with special needs who want to learn more about services and supports in Kansas and how to effectively navigate them. These trainings not only provide education and resources to families but an opportunity for peer-to-peer support between participants.

During FY24, an application will be developed for individuals with lived experiences supporting individuals with special needs to apply to become trainers. Each applicant will go through an interview process and once accepted will be offered a contract to provide this training curriculum to others. The CSHCN Director will provide the initial training, monitoring, evaluation, and on-going support for all trainers. The curriculum will be updated and include a new formatted look. The most exciting addition to the curriculum will be a personal family story video told by a former Family Advisory Council member through her lens not only as a parent, but the care coordination role she plays for her child. All participants will complete a pre- and post-assessment and changes can be made to the trainings based on feedback. Trainers will also complete a self-assessment that can be reviewed with the CSHCN Director to gain additional training and support where needed.

Translating the SNTF curriculum to Spanish will be pursued in FY24 along with recruiting and training Spanish speakers to serve as trainers. The goal for FY24 is to hold a minimum of four trainings in different location across Kansas.

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**Systems Navigation Training for Youth (SNTY):** SNTY was designed to help youth with and without special needs understand transition and how to navigate the process and systems. During FY24, the SNTY curriculum will be finalized and applications for youth trainers will be developed and disseminated to colleges for recruitment. The SNTY trainers will go through an interview process and be offered a contract to conduct these trainings in different regions of the state. Pre- and post-surveys will be completed by all participants to evaluate the effectiveness of the curriculum and trainers and to make modification where needed. Self-assessments will be completed by the trainers and shared with the CSHCN Director who will provide the initial training, monitoring, evaluation, and on-going support for each trainer. Since this is a new curriculum, a Plan Do Study Act will be done regularly to evaluate the training structure, activities, curriculum, and trainers. The goal is to hold the first one in the Spring of 2024 and then begin to hold a minimum of 2 each year after that.

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**Local MCH Agencies:**

- Barton County Health Department will improve care coordination supports by reaching out to at least ten agencies in their region, that offer services to support children with special health care needs and their families, to complete a resource map and establish stronger referral process between the health department and external partner.
  - Community Health Center of Southeast Kansas will ensure 100% of CSHCN and their families served by MCH staff will have access to and receive care coordination services provided by MCH Case Managers.
  - 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 develop a protocol for Children with Special Health Care Needs referral processes: currently, there is not a protocol in place.
  - Nemaha County Community Health Services will maintain their care coordination services to those in the CSHCN Program. Care coordination services are documented in Welligent. Internal chart audits will be conducted to measure number of participating clients and the care coordination received. They have a trained CSHCN care coordinator who manages care coordination for CSHCN in nine counties.
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