

## Children with Special Health Care Needs (CSHCN) Objective 5.2 Systems Initiatives

Contact: Kayzy Bigler, [Kayzy.Bigler@ks.gov](mailto:Kayzy.Bigler@ks.gov)

### REPORT – October 2021 through September 2022

**KS-SHCN and Medicaid Partnership:** The KS-SHCN team and CYSHCN Director value the importance of a collaborative partnership with Medicaid Managed Care Organizations (MCOs) to provide the best services and supports possible to the clients on the SHCN program. This partnership begins with a monthly shared report to identify mutual clients. The report includes the MCO care coordinator's name and contact information, and the services that the client receives from both the SHCN program and the MCOs. Communication happens between the MCO care coordinator, client/family and the SHCN care coordinator to make sure things are flowing smoothly and the client/family's needs are being met. Any identified gaps in services or supports are addressed by the SHCN care coordinator in partnership with the family. The KS-SHCN care coordinators work collaboratively with the MCO care coordinators, navigators or case managers to ensure that there is no duplication of services and to help advocate for coverage through the MCO for the family as needed. Anytime that an individual on our program is also on Medicaid, our care coordinators reach out to the MCOs to get in contact with the case manager to best determine how to further assist the child. Most recently, we have had a family that was completely unaware that their child was approved for a waiver. Through this strategic partnership, our care coordinator was able to notify the family and work collaboratively with an MCO to provide a bathroom remodel which allowed for increased accessibility for the child in their own home. This partnership started several years ago and continues to be strengthened each year.

The CSHCN Director worked closely with Medicaid staff to develop and refine the process for agencies who specialize in wheelchair settings to become approved services providers. This collaborative effort has increased availability of seating services in Kansas while still holding providers to high professional criteria as experts in their field. Joint reviews of new provider applications occur with input from Title V before a final determination is made by Medicaid. Once a new seating center provider is approved, they are then trained on Medicaid billing and allowed to start billing Medicaid for services while the KS-SHCN program fills any non-covered specialized items/parts for children on the KS-SHCN program.

The partnership between the Title V programs and Medicaid continues to be a strong focus within the Title V work. With review, modifications, and updates to the Memorandum of Understanding every few years this allow for the growth and expansion of the partnership in a productive way.

**Insurance and Financing Systems of Care for CSHCN:** Upon release of the [National Standards for Systems of Care for Children and Youth with Special Health Care Needs, Version 2.0 | Lucile Packard Foundation for Children's Health](#), the Title V team began using this guiding framework for the KS-SHCN program. This has been shared frequently with partners across the state in hopes that they adopt these standards as best practice within their facility and implement policies and procedures that align with the standards. Due to the change of the CSHCN Director position becoming full time, there is more opportunity for ongoing monitoring, implementation and alignment of the standards within the Title V and KS-SHCN program's goals, objective, policies and activities, further strengthening services and supports for this vulnerable population.

Due to a shortage in staff for the KS-SHCN program during this time period, the CSHCN Director lead the SHCN team and assumed multiple components of the day-to-day operations of the KS-SHCN program until a

---

new SHCN Program Manager was hired in July 2022. This created a barrier of being able to move some of the systems work forward, as originally anticipated. While work continued with Medicaid on several areas, the original plan to identify gaps in insurance coverage, inadequacies across coverage options and review the affordability of coverage for CSHCN population was not completed. This will continue to be worked on moving forward now that the KS-SHCN team is fully staffed and will be aligned with the National Standards and the Kansas Systems of Care State Plan, so strategies, partnerships, and policies can be developed to overcome these challenges.

The KS-SHCN program has continued to provide quality services and supports for families on the program even during a staff shortage. Services include: HCC services for those who qualify with an eligible medical condition or receive SSI; for those who also meet financial eligibility they can choose Direct Assistance Programs (DAP's) to assist with financial expenses; Special Bequest Funding for those who meet requirements; KS-SHCN strategic Plan activities; staff workforce training (that included some staff reaching their CHW certification); transition tools and supports; peer supports; and family and consumer engagement efforts.

***CSHCN Systems Alignment and Integration:*** Many factors contribute to the CSHCN population being an at-risk and vulnerable population such as inequities, disparities, social determinants of health, adverse childhood experiences (ACEs), and access to services including behavioral health and foster care. These factors 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 or the Bridges pilot criteria. For this reason, the CSHCN Director continues 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) 2020-2021, data shows 20.7% of children have special health care needs based on the CSHCN screener. While 21.6% have one current or lifelong health condition, 20.1% have two or more current or lifelong health conditions. Additional data showed that 24.3% of Kansas children ages 3-17 year had one or more reported mental, emotional, developmental, or behavioral problem(s). Data indicate that CSHCN experience two or more ACEs at a much greater rate (35.3%), as compared to non-CSHCN (16.9%).

While the data subset for Kansas specific indicators is small at this time for special health care needs, the Title V Directors focused in, FY 2022, to expand 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.

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. Member of the FAC with children that have been involved with the behavior health and/or foster/adopt system have also promoted partnerships through connecting with the Kansas Department for Aging and Disability Services (KDADS) and the Kansas Division of Children and Families (DCF) state agencies to ensure the family voice is heard and that referral services can be better aligned to complement each other and provide supports to families while utilizing a family centered approach. While new partnerships are forged each year, ongoing partnership continue to be nurtured as well. Some examples of special health care needs partnerships:

***Kansas Division of Children and Families (DCF):*** Title V Directors, members of the Family Advisory Council (FAC), Kansas Department for Aging and Disability Services (KDADS) and Kansas Division of Children and Families (DCF) partnered to strengthen the family centered approach by ensuring family voices are being heard and referrals to services are appropriate, timely and supportive of individual family needs. Meetings were held for FAC members to share their personal story with DCF on their experience with the system and gave concrete ideas and possible solutions to improve the system. Members of the DCF team were very

---

---

responsive and appreciated the families sharing their lived experiences. While this was emotionally difficult for many of the families, they also expressed that it was very healing and rewarding to know that they were able to share and possibly improve services for others. One outcome of this interaction was that FAC members were called on to provide more information one-on-one with DCF staff and many were asked to participate on DCF councils or workgroups as they developed their next statewide plan. The Title V Directors were also asked to be part of the committee and workgroups to develop DCF's Statewide Assessment. A collaboration meeting was held with DCF leadership and the CSHCN Director to talk about referrals to the SHCN program and other ways Title V could assist children in the system and the staff and foster families who support them. The CSHCN Director held a virtual statewide presentation on the SHCN program and Title V CYSHCN work for all DCF contract workers and identified staff.

*Kansas Department for Aging and Disability Services (KDADS):* The Title V Directors routinely work with KDADS staff on a variety of projects. One effort was to survey waiver recipients on changes made to waivers due to the pandemic, also in collaboration with the University of Kansas (KU). A survey was developed by Title V based on waiver changes that occurred due to the COVID 19 pandemic and administered to families of waiver receipts. Survey results were then analyzed by the team at KU with feedback shared with KDADS and Medicaid. This led to a continuation or modification of services that had been implemented during the pandemic to assist families. Key finding from the analysis were the importance of coverage for telehealth services, paid family caregivers, and paid family specialty caregivers.

*Kansas Council on Developmental Disabilities (KCDD):* The CSHCN Director has been a consistent member and partner of the KCDD for many years. This has included being part of various sub workgroups. During fiscal year 2022, there was a change in the CSHCN Director position. The new CSHCN Director had substituted at the KCDD meetings and has worked with the KCDD staff in the past, so moving into this role on the council was seamless.

One project started 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 67 participants in attendance. Post survey responses showed positive reviews with 85% of those who completed the survey stating that they would be able to apply what they learned during the summit and would recommend SDM summits/trainings to others in the future. The summit offered:

- An explanation of SDM and alternatives to guardianship that families can consider,
- The 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.

---



*Bureau of Health Promotion (BHP):* Through collaboration with BHP, the direct linkage between the HCC work and Community Health Workers (CHW) activities was identified. CHW's use a holistic approach very similar to the HCC work, so it was natural that a partnership between the two be forged. A component of this partnership allowed one SHCN Care Coordinator to participate in the new CHW certification training that has been developed free of charge. This has allowed SHCN staff to achieve certification status and identify possible gaps where further training may need to be developed. The Title V team is at the discussion table for various CHW activities and initiatives. A collaborative effort between BHP, United Health Ministries, Medicaid, and Title V has begun to get CHW service coverage through a possible State Plan Amendment. To work towards a State Plan Amendment, research has been conducted, a draft proposal has been written and includes CHW supervision requirements, code mapping, and training expectations. While there is still lots of work to go, it is the hope of the Title V team that this amendment will be approved so some components of the CHW work can be reimbursed.

Another collaboration with BHP is Title V's involvement in a possible expansion of the CHW workforce to assist those on the Home and Community Based (HCBS) Intellectual Disabilities (IDD) Waiver wait list. The HCBS wait list for those with IDD is approximately 10 years in length. This leads to many barriers for children and their families in getting the services and supports they so desperately need. The possibility of using CHWs to assist families currently on the waitlist through getting approved for Medicaid, community resource linkages, system navigation assistance, and more, is being considered.

*Screening and Surveillance Programs:* Through partnership with the Screening and Surveillance programs within the Bureau of Family Health (BFH) the KS-SHCN 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 with a multifaceted approach to reach families, inform them of the program, and provide information on how to apply. An initial phone call is provided by a SHCN care coordinator to let a family know that there will be some information mailed to them about our program and that if they have any questions about the program or are interested in learning more, they are available to assist. Once a postcard has been sent for families to apply for the program, another follow-up with a phone call is provided if referral has not been made or if no contact with the family has been documented through first attempts. The move to incorporate postcards in the process was 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. Throughout this fiscal year, we have recorded a total of 4 referrals from

---

newborn screening, 6 through hearing aid screening, and 1 referral from birth defects, which are all programs housed under screening and surveillance.

---

## **PLAN – October 2023 through September 2024**

---

***CSHCN Systems Alignment and Integration:*** For children with special health care needs to receive care in a well-functioning system it calls for strong partnerships and collaboration among a variety of state and local partners. Kansas Title V believes that partnership is key and will continue to strengthen collaborative efforts with current and newly identified partners in FY24. Below is a list of key activities that will be worked on over the next year with specific partners, however as new partnerships are formed systems alignment and integration will continue to grow.

***Department of Children and Families (DCF):*** The CSHCN Director will continue to work with staff from DCF to help them link children with special needs in the foster system to the SHCN program.

***Kansas Department of Aging and Disability Services (KDADS):*** The CSHCN Director will continue to partner with KDADS regarding Home and Community Based Services.

***Bureau of Health Promotion:*** The CSHCN Director will continue to be on the board of Safe Kids Kansas and work collaborative to improve safety messages for children with special health care needs. The KS-SHCN program continues to partner in the smoke and carbonmonoxide detector initiative established between the programs several years ago. The director also participates on Palliative Care Council meeting bring the child perspective to the council. While the council understand the needs for adults the needs for children with chronic special needs is not always addressed. The director will be researching palliative care services currently provided in other states, how they are funded, and the information shared with families who need it.

***Kansas Commission on Disability Concerns:*** The CSHCN Director will continue as the Secretary's designee for KDHE. This allows for a variety of partnership connection with a wide variety of agencies in the state who provide services and supports for those with disabilities.

***Kansas Council on Developmental Disabilities (KCDD):*** The SHCN Director will continue to be an active member of this council and also serve as part of the governance sub-committee. The director will partner with the KCDD staff to hold a Supported Decision Making Summit focused on educators who work with transitioning youth.

***Bureau of Family Health Programs:*** Referrals are passed from a variety of programs within the Bureau from newborn screenings to home visiting programs.

***Medicaid:*** The partnership between Title V and Medicaid in approving new Seating Centers in the state will continue to occur. A survey will be developed to gather information from current seating centers to determine if additional centers and providers need to be recruited. A specific protocol will be developed to outline the step by step approval process and information resource will be developed for seating center applicants. The CSHCN Director will also be working with Medicaid on financing for orthodontic services, palliative care and others identified through the insurance research work. One additional Medicaid project will be to work with Medicaid and the MCO's on a referral process to identify children with special health care needs that might qualify for the KS-SHC program.

---

***Insurance and Financing Systems of Care for CSHCN:*** With the change in the Title V staffing structure, the CSHCN Director has more flexibility to engage with various existing and potential partners in higher systems

---

---

level discussions and activities to advance the systems of care work in Kansas. A core component of the CSHCN Directors work plan is to continue to strengthen ongoing partnership, while reaching out to forge new ones. With the knowledge that the more connections and partnerships formed lead to improvements in the systems of care to ensure each child with a special health care need receives care in a well-functioning system. This also allows for more opportunity for ongoing monitoring, implementation and alignment of the standards within the Title V and KS-SHCN program's goals, objective, policies and activities, further strengthening services and supports for this vulnerable population.

The original plan to identify gaps in insurance coverage, inadequacies across coverage options, including transition services, and review the affordability of coverage for CSHCN population was not completed in 2023 due to staffing shortages and the CSHCN Directors increased workload. This will continue to be worked on moving forward now that the KS-SHCN team is fully staffed and will be aligned with the National Standards and the Kansas Systems of Care State Plan, so strategies, partnerships, and policies can be developed to overcome these challenges.

---

**Local MCH Agencies:**

- Barton County Health Department will improve documentation of services provided to children with special health care needs. In the most recent full program year, they served six children with special health care needs other than those who qualify for the Kansas Special Health Care Needs Program. They believe their client base likely includes more children with special health care needs than what their reports show (1%) and they want to better identify, document and connect these families to services. They will do this by training all MCH staff on the definition of CSHCN and how to document it on the DAISEY forms.
- CHC of Southeast Kansas will provide and advocate for care that creates a positive experience for children and their families (e.g. sensory rooms, sedation dentistry, etc.); continue to work with specialty centers (e.g. KU) in the provision of services via televideo or on-site that reduces the logistics burden on families; connect families to all available services; facilitate enrollments/participation in state-funded initiatives, develop a local resource guide for families with updated contact information and participation requirements; create a peer support group for family members of children with special health care needs; offer educational sessions of interest; and complete a comprehensive needs assessment for CSHCN in Southeast Kansas.
- Miami County Health Department will partner with a local health coalition and CHW to develop and update a resource list to include a variety of health care providers as well as at least two community agencies and organizations addressing five separate social determinants of health.

# Your input matters!

Give feedback on this domain and others by completing our feedback survey.

[Give Feedback!](#) >



KANSAS  
MATERNAL &  
CHILD HEALTH