

Children with Special Health Care Needs (CSHCN) Other Initiatives

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REPORT – October 2021 through September 2022

Peer Supports for CSHCN: The KS-SHCN program continues to be part of the Supporting You (SY) Network with a focus on families who have loved ones with special needs. SY provides one-on-one peer support from a parent/caregiver with similar life experiences as the person requesting the support. The program originally only focused on families who met the medical criteria for the KS-SHCN program but changed that in FY 22 to include all special health care needs conditions and disabilities. Recruitment for Connected and Supporting Peers is ongoing with the Peer Support Administrator providing guidance and support to them as they enroll in the SY Network. The Peer Support Administrator and CSHCN Director work collaboratively to increase awareness of the SY Network to both families and providers. More information on SY can be found in the Cross-Cutting Domain.

Care Coordinator Training and Workforce Development: The KS-SHCN program offered a series of webinar trainings to Satellite Office staff in the Winter of 2022 to help them reestablish the protocols and procedures required by the KS-SHCN program to be a Satellite Office. Many Satellite Office were struggling to keep up with clients during the COVID-19 pandemic causing some to discontinue services and others that requested more assistance to meet their client's needs. This led to many clients being assisted by the main office staff in Topeka instead of in their local communities. Once things slowed down with the pandemic Satellite Office team members were excited to get back to their SHCN work. A one-day training was held in Topeka in July 2022 to provide additional trainings and support to Satellite Offices based on request from the Satellite Office staff and identified needs shared by the Topeka team including the Lead Care Coordinator. The main topics included information on outreach and promotion on programming, the Direct Assistance Program, the data collection tool, and program updates.

The CSHCN Director oversees a contract with the Leadership Education in Neurodevelopmental Disabilities (LEND) program to provide trainings and support to childcare providers around a variety of disabilities. Often childcare providers do not have the knowledge and skills to feel confident in providing services to children with special health care needs or disabilities making it more difficult for families to find quality childcare. Through this contract, now in its second year, the LEND staff have provided over 25 webinars and trained over 3,000 childcare providers ranging from potty training, social skills, specific conditions like ASD, to behavior management techniques and skills. Through this contract a Developmental Disability Certification Program for childcare providers began during the reporting period and will be completed in FY 2023. This certification increases childcare provider knowledge and skill while increasing the number of providers comfortable and willing to accept children with special needs into the childcare setting.

Program Policy & Service Delivery Changes: Program policy and services are reviewed annually by the KS-SHCN team and CSHCN Director to identify any changes to the health care industry, program, and community needs. Changes are then made and monitored using quality improvement or quality assurance tools to make sure they are having the effect as intended. No major changes to the KS-SHCN program were noted during this reporting period.

There were no changes to Satellite Office during this reporting year. One Satellite Office is being closely monitored to ensure policies and procedures as agreed upon in their SHCN agreement are followed. If this Satellite Office is unable to improve their services as specified in their contract, they will no longer be a Satellite Office. Additional Satellite Office are being recruited in needed areas of the state where there is not local coverage. There is an increased need in many regions of the state for Spanish speaking Satellite Office staff. These areas of the state are currently being serviced by the Topeka SHCN team. All clients are getting quality services and supports but being able to receive them in their location would be beneficial since local providers know the resources in their area best.

Updates to the KS-SHCN data system are needed, but due to KS-SHCN staffing capacity and the merging of the current data provider with another company, this has been a challenge to accomplish. There is a need to develop reliable reports within the data system that can easily be pulled and monitored.

Policies and services have had to be modified regularly due to the formula shortage that has been affecting the clients with PKU and others who need specialized formula. This has been an ongoing issue for most of the last 2 years. One month of emergency supplies were issued to every client when the pandemic first occurred, but as supplies continue to be difficult to get, the process has become time intensive and stressful for both families and staff. Changes to client's regular formula orders have had to be adjusted by the nutritionist based on what formula is available at that time. Even then supply amounts are limited so ordering has to occur more frequently leading to more staff time required. Many times, the formulas that are available are higher cost requires careful monitoring of the KS-SHCN budget. The program staff will continue working closely with the formula companies, families, and nutritionists to make sure the client's needs are being met.

With the unwinding of Medicaid due to the Public Health Emergency (PHE) lifting, the KS-SHCN team has been communicating with families regularly to prepare them for this occurrence. They are making sure that families have updated information listed with the KS-SHCN program and with Medicaid. They are encouraging families to have their Medicaid applications completed and ready to be submitted when the PHE is lifted.

PLAN – October 2023 through September 2024

Peer Supports for CSHCN: Families who have children with special health care needs often experience things that others do not, so to have support from another who has a shared lived experience can be very helpful. Because of this, the KS-SHCN program is part of the Supporting You Network. Parents are able to share what they have learned with one another and provide/receive emotional support. During FY24 the KS-SHCN team will continue to promote the Supporting You network with families on the program and through outreach opportunities. See Cross-Cutting Domain for more information.

Care Coordinator Training and Workforce Development: SHCN continues to provide yearly trainings to the satellite offices to ensure alignment on care coordination practices and a unified approach to patient care plans. Additionally, SHCN care coordinators are evaluating the potential benefits of completing Community Health Worker trainings.

Special Health Care Needs Screener: The CSHCN Director will be working with the MCH program and the DAISEY data system team on the implementation of a Special Health Care Needs tool. Training guidance will be developed to show how to use and score the screener. A decision schema will be developed to assist those using the tool to be able to refer to the correct agency/provider, as needed. A training webinar will be developed to support local partners in the successful use of this new tool prior to implementation.

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