

Children with Special Health Care Needs (CSHCN): Systems Initiatives

Objective 5.2: Increase the proportion of families of children with special health care needs who report their child received care in a well-functioning system by 5% by 2025.

Activities During Federal Fiscal Year 2023

KS-SHCN and Medicaid Partnership: A focus for FY23 to build stronger partnerships with the Division of Healthcare Finance (DHF), which is the organization that oversees Medicaid in Kansas. During FY23, the Title V CYSHCN Director continued to support DHF in their work with seating centers. The Title V CYSHCN Director helped to provide outreach around seating centers and the way organizations can become seating centers in the state. Additionally, the Title V CYSHCN Director helped with onboarding a new seating center to help increase access to this service for a greater portion of the SHCN population.

The Title V program also began to pursue reimbursement for HCC services provided by KS-SHCN. Research on care coordination financing models has begun and will be used to drive discussions with Medicaid and private insurers. It is believed that adequate reimbursement will help providers bring in the revenue to support having a Care Coordinator on staff to work with families and assist in their goals of establishing a comprehensive medical home.

Insurance and Financing Systems of Care for CSHCN: The Title V MCH Director, CSHCN Director and the HCC Consultant worked to implement a three-phase approach to identifying gaps and barriers in the financing of systems of care for the SHCN population in Kansas. This process was to include an environmental scan & service assessment; review of what insurance financing looks like in other states; and face-to-face meetings to gain more concrete information. All phases were designed to build from one another to lead to the development of a state plan to address identified needs. However, due to vacancies in these positions at differing times, only the environmental scan was completed in this reporting period. The remainder of this work will be evaluated upon hiring for the new CSHCN Director to determine next steps.

Local MCH Agencies:

The following are examples of how some of the local MCH grantee agencies have made progress toward objective 5.2 during the reporting period.

- Barton County Health Department trained their staff and Juvenile Services staff on the use of IRIS which will aid the service delivery system in providing seamless care for CSHCN. They continued efforts to increase awareness of their SHCN program and participation in the IRIS network through outreach to six medical providers.
- Crawford County Health Department (CCHD) provided holistic care coordination services and connected clients to health care professionals for diagnostic services. They offered direct assistance programs and helped clients by

submitting medical needs to the SHCN Special Bequest Committee. They had a family share that they were better able to navigate community services after receiving care coordination from CCHD.

- Kearny County Hospital maintained strong partnerships with Russell Child Development Center and Craig Home Care Services which are their referral partners for CSHCN. Referral options include a fax to RCDC or calling RCDC while client is in office to schedule the appointment for them. Craig Home Care Services provides in home medical and nursing care for CSHCN.
- Nemaha County Community Health Services (NCCHS) is a CSHCN Satellite Office. They helped a family get needed supplies as reported under objective 5.3 but they also helped the family learn how to navigate the health care system. The family shared that before help from NCCHS, it would take weeks to get an answer or call-back from the family's specialty provider, but now they generally get an answer or call-back within a few days.

Plans for Federal Fiscal Year 2025

CYSHCN Systems Alignment and Integration: Title V and public health recognize the importance of an integrated approach for optimal health outcomes, therefore learning about services offered across the state and building partnerships and referral sources is critical to meeting the needs of the CYSHCN population. In FY25, the Title V CYSHCN Director will continue to learn about the current systems in place and SCHN services provided by other state agencies and state-level collaboratives. Once a thorough understanding of how the current systems work and inter-relate, the CYSHCN Director will work to develop recommendations for how to improve system alignment and efficiency. Being new to the role, the CYSHCN Director will spend FY25 learning the systems and key players, building relationships with programs that help support and/or identify children and youth with special healthcare needs.

Insurance and Financing Systems of Care for CYSHCN: With the change in the Title V staffing structure, the CYSHCN 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 CYSHCN Directors work plan is to continue to strengthen ongoing partnerships, while reaching out to forge new ones. With the knowledge that the more connections and partnerships formed leads 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. During FY25, the CYSHCN Director will be working to develop partnerships with the Managed Care Organizations (MCOs).

System Services and Supports for Individuals with Autism Spectrum Disorder (ASD): Individuals with ASD, intellectual disability (ID) and other neurodevelopmental disorders (ND) meet criteria for additional psychiatric disorders at rates that are significantly higher than in the general population. A recent meta-analysis examining prevalence of

psychiatric disorders in adolescents and adults with ID showed an estimated pooled prevalence of 33.6%, with mood disorders being the most common, followed by anxiety disorders. Even higher rates of co-occurring disorders have been found in youth with ASD, some of whom will, of course, also have ID, with rates ranging from 27%-95%. The most frequent diagnoses in youth with ASD are anxiety disorders (upwards of 40%), ADHD and depressive disorders. Rates of conduct and oppositional defiant disorders are also high.

While stress, financial and time burdens are significant for families of youth with ASD/ID, the presence of co-occurring psychiatric disorders further exacerbates their problems. Children with ASD/ID and comorbid conditions are likely to need additional treatment, including psychopharmacology and therapies, as well as experience crisis situations linked to ongoing behavioral and emotional difficulties. Access to services may also be limited, either because of lack of expertise or structural issues related to the financing of publicly funded health services. In many states, funding streams providing resources for youth with psychiatric disorders are separate from those providing resources for youth with ASD/ID/ND.

In mental health professional shortage areas, primary care has become the default mental health service. This is as much the case for youth with ASD/ID/DD and co-occurring psychiatric disorders, as it is for those who do not have underlying neurodevelopmental disorders. Approaches that are designed to enhance the knowledge, confidence and skills of PCPs have been employed for both mental health disorders and for ASD.

As such, KSKidsMAP has expended their approach to provide case consultation, wellness resources, referrals and other support to PCPs who are providing care in their own practices to children and adolescents with neurodevelopmental disorders. The KSKidsMAP Autism, Neurodevelopmental and Intellectual Disabilities (KANDID) extension offers expert consultations to physicians and clinicians enrolled who seek guidance on screening, assessment and management of these complex disorders. KSKidsMAP anticipates PCP needs around screening in early childhood, ongoing monitoring, evaluation, management and treatment of common medical comorbidities (e.g., gastrointestinal problems, seizure disorders, sleep), and co-occurring psychiatric disorders (e.g., ADHD, anxiety and mood disorders).

The goals of KSKidsMAP KANDID are to: 1) provide ongoing case consultations to PCPs to support them in providing care for this patient population; 2) make resources, such as toolkits and practice guidelines, accessible to PCPs; and 3) provide wellness resources for professionals to support them in expanding their services to a challenging patient population.

In order to address these needs, KSKidsMAP has expanded their Pediatric Mental Health Team (PMHT) to include a child and adolescent psychiatrist with special expertise in diagnosis and management of neurodevelopmental disorders, a child and adolescent psychologist with ASD experience, and a developmental behavioral

pediatrician. All practitioners are available to provide psychiatric case consultations and facilitate at least four KSKidsMAP TeleECHO Clinic sessions annually focused on KANDID topics. Further, KSKidsMAP is partnering with the Kansas Academy of Family Physicians (KAFP) to offer a one-day KANDID training workshop as part of the KAFP Annual Conference in November 2024. KSKidsMAP is exploring partnership opportunities for additional ASD training for pediatricians with the Kansas Chapter American Academy of Pediatrics (KAAP). More information about KSKidsMAP is included in the Cross Cutting Section.

Autism Coalition: Convening in May 2024, Title V is leading coalition activities focused on making the 2021 Autism Task Team's [recommendations report](#) actionable. The Coalition is in early stages of developing a strategic plan with common agenda and measurables then will bring together partners working with individuals with ASD to identify what work is happening and where as well as gaps in services. The coalition brings together several state agencies as well as partners working with ASD. A key activity of this coalition over the next year will be identifying the work that is occurring and gaps in the system which can be addressed through the recommendations report or through other recommendations of coalitions members.