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INTRODUCTION

The Kansas Department of Health & Environment is responsible for administering the Title V Maternal and Child Health (MCH) Services Block Grant for the State of Kansas [funded through the U.S. Department of Health & Human Services (HHS), Human Resources & Services Administration (HRSA), Maternal and Child Health Bureau (MCHB)]. The MCH Block Grant and affiliated programs are organized within the Division of Public Health, Bureau of Family Health.

The Title V MCH Block Grant plays a key role in the provision of maternal and child health services in Kansas, including the Kansas Special Health Care Needs (KS-SHCN) program. Service or programs funded with Title V funding through the KS-SHCN program must support program priorities, outcomes, and measures while furthering identified mutual objectives and supporting respective responsibilities.

KS-SHCN Program

For the purposes of the KS-SHCN Aid to Local (ATL) grant applications*, refer to the following definition:

“Children and youth with special health care needs (CYSHCN) are those who have, or are at risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

Target Population for Services

Activities must address needs of the children and youth with special health care needs (CYSHCN) population and is defined as children and youth, age birth through 21 years, “who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.” It is not expected to limit services or supports under this grant proposal to those actively receiving services through the KS-SHCN program.

Services may be extended to adults over age 21 with genetic conditions screened for and diagnosed through the Kansas Newborn Screening program. A complete list of these conditions can be found on the KS Newborn Screening website at www.kdheks.gov/newborn_screening/index.html.
KS-SHCN ATL Requirements

Applications for funding must clearly outline the type of service to be addressed by the activities within the proposal (definitions can be found in the Title V 2016-2020 MCH Services Pyramid). The request for funds must clearly describe the activities and/or services to be provided and alignment with one or more of the outlined priorities, performance measures, populations, and types of service.

KS-SHCN began an extensive strategic planning process in July 2013 consisting of stakeholder meetings and engagement of families, medical providers, community partners, and program staff. The strategic planning process focused around four key principles:

1. Increasing the value of the program for those served.
2. Evaluating relevancy of program services offered for families.
3. Evaluating cost effectiveness of direct and clinical services.
4. Identifying opportunities for improvement by utilizing quality improvement methodology.

Through this process, five new SHCN priorities emerged.
KS-SHCN Priorities

Cross System Care Coordination
“Patient and family-centered approach that utilizes team-based and assessment activities designed to meet the needs of children and youth while enhancing the capabilities of families. It addresses interrelated medical, behavioral, educational, social, developmental, and financial needs to achieve optimal health.”

Family Caregiver Health
“Supporting the physical, emotional, social, and financial well-being of families with CYSHCN, particularly that of the family caregivers. A family caregiver is any individual, including siblings, who supports and cares for another person and may or may not be a biological relative.”

Direct Health Services & Supports
“Services delivered one-on-one between a health professional and patient, which may include primary, specialty, or ancillary health services, such as: inpatient and outpatient medical services, allied health services, drugs and pharmaceutical products, laboratory testing, x-ray services, and dental care. Access to highly trained specialists or services not generally available in most communities may also be included in this definition.”

Behavioral Health Integration
“Collaborative services for the prevention and treatment of emotional disorders that support the functioning of children, youth, and families in all settings, including home, community, school, and work. Efforts should be focused on keeping children in their home and/or community.”

Training & Education
“Supporting diversity in the provision of services for the special health care needs (SHCN) population through training and education of families, community members, medical and community providers, local and state service programs, and legislators. This includes family and youth leadership development in building a stronger advocacy network in Kansas.”
# FINANCIAL SUMMARY

During the SFY18, nine (9) organizations were awarded:

<table>
<thead>
<tr>
<th>Contract</th>
<th>Total Award</th>
<th>Total Spent</th>
<th>Unspent</th>
<th>% Spent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carriage Parkway</td>
<td>$37,710</td>
<td>$37,710</td>
<td>-</td>
<td>100%</td>
</tr>
<tr>
<td>CPRF</td>
<td>$155,705</td>
<td>$155,705</td>
<td>-</td>
<td>100%</td>
</tr>
<tr>
<td>Craig Home Care</td>
<td>$48,005</td>
<td>$27,552</td>
<td>$20,453</td>
<td>57%</td>
</tr>
<tr>
<td>KUMCRI KC</td>
<td>$101,453</td>
<td>$62,517</td>
<td>$38,936</td>
<td>62%</td>
</tr>
<tr>
<td>KUMCRI Clinical Services</td>
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<td>$101,253</td>
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</tr>
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<td>KUMCRI Genetics</td>
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<td>KYEA</td>
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<tr>
<td>Oral Health Kansas</td>
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<tr>
<td>Southeast Kansas</td>
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<td><strong>TOTAL</strong></td>
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<td><strong>$551,000</strong></td>
<td><strong>$64,017</strong></td>
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</tr>
</tbody>
</table>

![Bar chart showing total award and spent amounts for each contract]
CEREBRAL PALSY RESEARCH FOUNDATION (CPRF)

Proposal:

In accordance with Title V Mother and Child Health Services guidelines and Kansas Special Health Care Needs program priorities, CPRF provides much needed wheelchair/posture-seating services in Wichita and through several outreach clinics. Person-centered wheelchair modifications improve health and functional capacities of the clients and provide an indispensable foundation for successful growth and development in the home, school, and community for individuals with cerebral palsy, spina bifida, and similar physical disabilities.

To assure the quality standards of its program, CPRF focuses on three means of feedback:
1. A post-services family satisfaction survey and a more longitudinal, anonymous survey of family satisfaction with the intervention product and the clinic services;
2. Process measures of the efficacy of its clinic services; and
3. Long-standing collegial partnerships with other community medical professionals, nonprofit disability services providers and durable medical equipment providers, public school districts, and the Wichita State University College of Engineering.

Most of services provided are considered direct through clinic operations, however enabling services are obtained through our outreach clinics and public health services and systems are addressed through multiple in-service trainings and tours that are provided throughout the year to legislators, local government officials, university students and therapy associations.
<table>
<thead>
<tr>
<th>Goal</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Patients wheelchairs and seating systems will provide alignment for health</td>
<td>For those patients who have alignment issues after services at CPRF, patient's will show improvement in their alignment for breathing, circulation, and activities of daily living as measured by changes from baseline scores during evaluation compared to final scores given after delivery of services.</td>
</tr>
<tr>
<td>2. Patients wheelchairs and seating systems will provide skin protection</td>
<td>For those patients who require advanced seating, after services at CPRF, patients seating system will maximize pressure distribution to key weight bearing sites. This will be measured by changes from baseline scores during evaluation compared to final scores given after delivery of services.</td>
</tr>
<tr>
<td>3. Patient’s wheelchairs will have optimal configuration for best self-mobility</td>
<td>For those patients who are self-mobile, after services at CPR, their wheelchairs will be optimally configured for best self-mobility. This will be measured by changes from baseline scores during evaluation compared to final scores given after delivery of services.</td>
</tr>
<tr>
<td>4. Patient’s wheelchair will provide maximum comfort</td>
<td>For those patients who report pain while in their wheelchair, after services at CPRF, patients will show improvement in their levels of comfort. This will be measured by changes in baseline scores during evaluation compared to final scores given after delivery of services.</td>
</tr>
</tbody>
</table>
Below are the report findings of “pre” and “post” tests completed by the Occupational Therapists (OTs) and Physical Therapists (PTs) for clients receiving services from CPRF under this grant.

<table>
<thead>
<tr>
<th>Goal</th>
<th>Pre</th>
<th>Post</th>
<th>Pre</th>
<th>Post</th>
<th>Pre</th>
<th>Post</th>
<th>Pre</th>
<th>Post</th>
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<td>Goal 1</td>
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<td>2.51</td>
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<tr>
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<td>2.51</td>
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<td>2.46</td>
<td>4.64</td>
<td>2.37</td>
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<tr>
<td>Goal 3</td>
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<td>2.98</td>
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<td>3.00</td>
<td>4.66</td>
<td>3.05</td>
<td>4.63</td>
</tr>
<tr>
<td>Goal 4</td>
<td>2.46</td>
<td>4.75</td>
<td>2.61</td>
<td>4.75</td>
<td>2.46</td>
<td>4.75</td>
<td>2.47</td>
<td>4.62</td>
</tr>
</tbody>
</table>

CPRF provided outreach clinics in Hays (2), Garden City (3), Liberal (2), Salina (1) and Dodge City (1).

### CPRF Seating Clinics

<table>
<thead>
<tr>
<th>Quarter</th>
<th># Patients Served</th>
<th>SHCN # Served</th>
</tr>
</thead>
<tbody>
<tr>
<td>First</td>
<td>208</td>
<td>19</td>
</tr>
<tr>
<td>Second</td>
<td>221</td>
<td>29</td>
</tr>
<tr>
<td>Third</td>
<td>194</td>
<td>33</td>
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<td>Fourth</td>
<td>182</td>
<td>32</td>
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<td>TOTAL</td>
<td>805</td>
<td>113</td>
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### Outreach Seating Clinics

<table>
<thead>
<tr>
<th>Quarter</th>
<th># of Clinics</th>
<th># Patients Served</th>
<th>SHCN # Served</th>
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</thead>
<tbody>
<tr>
<td>First</td>
<td>2</td>
<td>13</td>
<td>1</td>
</tr>
<tr>
<td>Second</td>
<td>2</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>Third</td>
<td>3</td>
<td>14</td>
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<tr>
<td>Fourth</td>
<td>2</td>
<td>12</td>
<td>1</td>
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<tr>
<td>TOTAL</td>
<td><strong>9</strong></td>
<td><strong>53</strong></td>
<td><strong>6</strong></td>
</tr>
</tbody>
</table>
COMMUNITY HEALTH CENTER SOUTHEAST KANSAS (CHC/SEK)

Proposal:
The Community Health Center Southeast Kansas (CHC/SEK), is the largest provider of pediatric services in rural southeast Kansas serving more than 16,000 children annually. It has a dedicated full-time Special Needs Care Coordinator who primarily serves low-income children throughout the region. This individual, along with 80+ health professionals, identify and connect children to resources including the SCHN program to ensure these children have an established culturally competent primary medical, dental and, if needed, behavioral health home and assist families in making application for and accessing all the services and resources for which they are eligible. With most of this region critically underserved, limited public transportation, an aging medical and dental community and a declining number of providers accepting Medicaid, gaps in services are growing wider. Per the CYSHCN (Children and Youth with Special Health Care Needs) 2011 Family Survey, access to dental, health screening and vision/hearing services were the most common unmet medical needs of those responding -- a gap CHC/SEK can fill directly or through its relationships with local providers throughout southeast Kansas. At the same time, with this region the poorest in the state, many of the families of these children struggle to meet basic needs, let alone adequately provide all the resources that would benefit and improve the quality of life of their child and their family. Through care coordination and assisting families in navigating the ever-increasing complexities of the healthcare system, disparities in the care to low-income children with special needs will be reduced and, in many cases eliminated.
Outcomes:

- The CHC/SEK-CYSHCN Care Coordinator received a total of 117 referrals and worked with 136 patients throughout the contract year; the average time spent with clients was two hours with an average of four contacts.
- CHC/SEK partnered with KS-SHCN to host the Family Care Coordination Training on September 23, 2017. The training was informational and well received by the group of attendees.
- Provided education to all health professional throughout CHC/SEK focusing on the care of children with special health care needs - 48 classes throughout the contract year.
- The CHC/SEK CYSHCN Care Coordinator continued to reduce barriers to care by arranging transportation to and from medical appointments, interpreter services, and insurance plan enrollment.
- All families served by the CYSHCN Care Coordinator continue to receive peer support in person, via telephone, via virtual support or are referred to local support groups when appropriate. The monthly support group in Pittsburg continues as the CYSHCN Care Coordinator assesses other sites for an additional support group.
- The CYSHCN Care Coordinator continues to assess all family members for a medical home, dental and behavioral health services along with self-care of each family member.
- CHC/SEK collaborated with the University of Kansas Telehealth ROCKS program. The program includes Project ECHO, linking expert specialty physicians with primary care providers, school health employees and behavioral health providers in rural communities, and Project OASIS—which provides telehealth services in specialty practices to children in rural areas. The specialty telehealth sessions (OASIS) occurred once a week in the sensory friendly telehealth room at the CHC/SEK Pittsburg location as well as in area schools. Specialty services provided included Parent Child Interactive Therapy, Pediatric Psychiatry, Psychological Strategies for Behavioral Concerns and Toileting. The CYSHCN Care Coordinator facilitates these appointments. 13 Educational series were held total during the Contract period.

Greatest Achievements:

- Connecting a family to multiple healthcare providers and assisting as a liaison between different healthcare providers: Dalton’s story – Thirteen years old whose IQ scores dropped from 113 to 67, in addition to showing disruptive behaviors.
- Connecting a family to multiple resources over stressful holiday season: Jackson’s Story – A five years old boy diagnosed with autism.
- Assisting an older child receive a diagnosis of autism so he could get the resources he needs for college and adulthood: Jake’s Story - A seventeen years old young man who was accepted into a national University that offers a program for those on the spectrum.
- Addressing an addiction issue in a SHCN family: Dan’s Story – a thirteen years old boy diagnosed with intellectual delay and autism dealing with his father’s alcohol addiction (Full story – attachment #1)

Partnerships:
Area Health Education Center, Southeast Kansas Regional Education Center, KU Medical Center and Children’s Mercy, Families Together, Inc., KCSSL Healthy Families of Crawford and Cherokee Counties, Communities in Schools, Pittsburg Police Department, Department for Children and Families, Big Brothers Big Sisters of Crawford County, SEK Interlocal 637, TASN (Kansas Technical Assistance System Network), Healthy Families of Crawford and Cherokee Counties, My Family, The Family Resource Center, The Jerry Hamm Early Learning Center, Behavior Checker, Child Find, Live Well Crawford County, Healthy Hawks, LYFTE (Lifting Young Families Towards Excellence).

As follows, the annual data tracking report from CHC/SEK with the data of all patients served during SFY18.

### SHARED PLAN OF CARE

#### Annual Data Tracking Report

<table>
<thead>
<tr>
<th>Category</th>
<th>ADHD</th>
<th>Obesity</th>
<th>Asthma</th>
<th>Autism</th>
<th>Mental Health Disorder</th>
<th>Seizure Disorder</th>
<th>Diabetes</th>
<th>Traumatic/Brain Injury</th>
<th>Speech Delay</th>
<th>Sensory Processing Disorder</th>
<th>Developmental Delay</th>
<th>Intellectual Disability</th>
<th>Speech/Language Delay</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of SHCN with POC</td>
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<td>3</td>
<td>4</td>
<td>31</td>
<td>15</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>23</td>
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<td>1</td>
</tr>
<tr>
<td>Number of SHCN with POC</td>
<td>12</td>
<td>3</td>
<td>4</td>
<td>31</td>
<td>15</td>
<td>4</td>
<td>4</td>
<td>3</td>
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<td>4</td>
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<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Number of SHCN with POC</td>
<td>12</td>
<td>3</td>
<td>4</td>
<td>31</td>
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<td>4</td>
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<tr>
<td>Number of SHCN with POC</td>
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<td>31</td>
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<td>Number of SHCN with POC</td>
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<td>2</td>
<td>22</td>
<td>1</td>
<td>1</td>
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</tr>
</tbody>
</table>
CRAIG HOME CARE

Proposal:

The Hospital to Home Transition program is intended to fill a gap that exists today for this critical process. Craig Home Care will coordinate the transition and education process to ensure the best possible success in the transition to home for pediatric patients participating on the KS HCBS Technology Assisted (TA) Waiver program under KanCare requiring high-tech home nursing services, along with children that do not rise to this level of medical need to qualify for the TA Waiver but still need transitional services. They will accomplish this by providing an increased level of education and coordination (both initially and on-going) to caregivers and families, increased surveillance and support in the home, and increased coordination and partnership with the discharging institution and insurers.

Craig Home Care has specialized in providing high-tech pediatric nursing services since 1994. Improving the quality of life and outcomes for medically fragile children and their families has been their mission and focus. Their vision is to be the go-to premier agency in the mid-west (possibly nation) that leads the industry in programs and nursing services for home care for medically fragile children.

Craig Home Care

<table>
<thead>
<tr>
<th>Total Award</th>
<th>Total Spent</th>
<th>Unspent</th>
</tr>
</thead>
<tbody>
<tr>
<td>$48,005</td>
<td>$27,552</td>
<td>$20,453</td>
</tr>
</tbody>
</table>
Outcomes:

- 7 patients were discharged from hospital and into the “Hospital to Home” (H2H) team’s care during the contract year. Any of these patients experienced an Emergency visit.
- Families reported an increased awareness of state and community resources.
- Most caregivers reported that the Hospital to Home program was instrumental in connecting them with different services in their area, often going beyond what the hospital can provide, especially given the distance between some caregiver’s homes and the hospital. Regarding to acting as a liaison with emergency services and utilities in the area, caregivers were impressed by the effort put forward by the team to assure that proper authorities were notified.
- Caregivers reported most of what they learned came from their nursing staff and their time in the hospital. This is understandable as all participants spent many months in the hospital, compared to just a few weeks that they spent with the Hospital to Home program. The greater time they spent with their hospital providers often led to more comfort with the processes they learned.
- When families received information from the hospital, the Hospital to Home program helped to provide reassurance when they would have otherwise become overwhelmed with the information they were receiving from the hospital. The information coming from the hospital often addressed contingencies already in place with the Hospital to Home program.
- Every mother interviewed was impressed with the services received during the hospital to home transition. Every mother would recommend the Hospital to Home Program, specifically for having a point person they could identify. One caregiver reported that the program staff was able to anticipate her needs.
KUMCRI - KANSAS CITY SPECIALTY TEAM CLINIC SUPPORT

Proposal:
The Specialty Team Clinic Support, a project from the Kansas University Medical Center Research Institute (UKMCIRI) Inc. provides direct service and non-clinical support to individuals with *Cystic Fibrosis (CF)*, *Cleft Lip and Cleft Palate (CL/CP)* or *Phenylketonuria (PKU)*. The services include addressing the needs of patients served through assessment, monitoring and education to promote optimal health outcomes. As well as, provide appropriate referrals based upon assessment results.

The multi-disciplinary specialty clinics for each condition also serves as a training clinic for health care students from various disciplines, medical providers and trainees in the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program.

The project will impact overall health outcomes for children and youth with special health care needs by providing regular multidisciplinary assessment, treatment and/or monitoring. Care coordination will be provided to assist with addressing medical, behavioral, educational, social, developmental and financial barriers that may impact health. The Social Worker will provide direct services and care coordination for patients seen in the CF and CL/CP clinics, held weekly and monthly, respectively. In addition, Social Work support will be provided in the PKU clinic.

The Social Worker will remain actively engaged in various quality improvement projects aimed at improving patient outcomes, patient satisfaction and clinical operations in the CF and CL/CP clinics. Some of the projects include: the development and implementation of a Family Advisory Board and implementation of a formal transition program in the CF clinic.

![KUMCRI - SPECIALTY CLINIC](chart.png)
Outcomes:

- 1st Cystic Fibrosis (CF) Education Day held in August 2017.
- Screenings:
  - 69 caregivers were screened for depression and anxiety.
  - 35 patients, age 12 and older were screened for depression and anxiety.
- Three Cystic Fibrosis outreach clinics were conducted in Pittsburg, KS.
- Social Worker served as a Quality Improvement Coach for the Cystic Fibrosis Foundation.
- Social Worker attended Sexuality and Disabilities training and will use the information in the specialty clinics, as well as explore offering the training in partnership with LifeShare.
- During the 4\textsuperscript{th} quarter, weekly meetings were held with LEND nutrition students to educate in female and child health as it impacts neurodevelopmental health.
- Educated on treatment of PKU and children with eating issues.
- Social Worker and PKU Dietician/Coordinator continued to provide an overview of SHCN program and services to families attending the specialty clinics, as well as with community organizations and agencies. 12 families were referred to the program during the contract year.
- Social Worker was able to develop workarounds regarding the implementation challenges for the satisfaction survey and explored if an electronic survey can be developed and implemented.
  - Satisfaction data in the CF clinic continues to be obtained from Patient and Family Experience of Care survey implemented by the CF Foundation.
  - Paper surveys were still distributed in CL/CP clinic; however, the return rate continued to be low and consistent administering of the paper surveys was a challenge. The Social Worker will continue to work with the CL/CP nurse coordinator to improve the distribution and collection of the surveys.
- Families/patients continue to complete an annual biopsychosocial to identify needs and family stressors. The information is used to assist families with linkage to resources in order to overcome the challenges.
- The CF Rise Transition program was implemented in the CF Clinic. The clinic Dietician served as the lead on the program. The program targeted teens and younger patients. The formal program was developed by the CF Foundation.
- The Social Worker and PKU Dietician/Coordinator continued to provide education to patients and families on a variety of topics, such as nutrition, academic success, self-esteem, social engagement, employment, stress management, mental and physical health, adherence, etc.
- LEND Trainees and medical students continued to provide services and supports in the specialty clinics. The clinics allowed the trainees and medical students with the opportunity to increase their awareness about the special health care needs population.
- The CF Family Advisory Board was developed, and it meets quarterly. The board has assisted the CF team with planning and hosting the first CF Education Day.

- The board encountered several challenges:
- Finding a common time and date that works for families to meeting
- Not allowing CF children to be present has been hard for some families to secure babysitters.
- Establishing standard expectation for members’ roles and duties.

**Partnership:**
Wyandotte County Community Developmental Disabilities Organization

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**Summary of Specialty Clinics held during the contract period:**

<table>
<thead>
<tr>
<th>Type of Clinic</th>
<th># of Clinics</th>
<th># of Patients Served</th>
<th># of SHCN Served</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cleft Lip/Palate</td>
<td>9</td>
<td>47</td>
<td>2</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>61</td>
<td>190</td>
<td>7</td>
</tr>
<tr>
<td>PKU</td>
<td>10</td>
<td>26</td>
<td>15</td>
</tr>
<tr>
<td>TOTAL</td>
<td>80</td>
<td>263</td>
<td>24</td>
</tr>
</tbody>
</table>
Proposal:
This endeavor targets underserved children, ages 1-17, with neurodevelopmental needs. Activities provide immediate care to children and their families, build the local infrastructure and train current and future providers in neurodevelopmental disabilities. This project is accomplished through collaboration with a network of local providers.

Long standing initiatives:
The KU developmental outreach team includes a clinic coordinator/registered dietitian, social worker, MD, PhD psychologist, and a licensed speech therapist who assess/screen the child and provide recommendations that address the physical, emotional, educational and social needs of the child. The family’s biopsychosocial needs are also addressed. The child's evaluation report is given to providers and the family. Training and education are provided to local providers and Leadership in Education and Neurodevelopmental and Related Disorders program trainees through participation in the evaluation process.

Activities piloted during SFY17:
- A social worker and dietitian completed biopsychosocial and nutrition screenings and provided recommendations/referrals as needed.
- Piloted telehealth site in Greenbush.

New activities for the SFY18 year:
- Local providers will attend the evaluations for the purpose of participation/observation. After clinic, local providers and the team will focus on building the local infrastructure through presentations and case discussion. Gaps in local services and local providers’ skill and knowledge will be identified which will direct the development of projects that will lead to greater self-sufficiency in the community. At the end of clinic, providers will complete a satisfaction survey.
- Market KU's telehealth clinics pertinent to CYSHCN to providers.
- Refine the evaluation process to more comprehensively assess all children with neurodevelopmental needs.
- Include Kickapoo children in the Prairie Pottawatomi Band Nation outreach. Remove barriers to travel to the clinic. Assess the area's potential for telehealth-related services.
- Track percent of Level 2 and 3 SHCN clients with a developmental screening on file with the program, and those who agree to share it with other healthcare providers.
Outcomes:
- Average 52% of children diagnosed with an autism spectrum disorder
- 7% of children with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (ADD/ADHD)
- 10/26/2018 - Newborn Screening Advisory Council Meeting. Attended with LEND student.
- 10/30/2018 Presented Metabolic Disorders, Newborn Screening and Children with Eating Issues at the LEND course.
- Casey Redding, Audiologist and his student, conducted a hearing clinic in conjunction with the Dodge Outreach clinic in April 2018 - 13 children received a hearing screening.
- During the 4th quarter, in-service training was conducted at the Dodge and Hays outreach clinics - 67 individuals attended. 24 students observed the evaluation clinic held in Hays and participated in a post clinic debrief with two providers.

Summary of Developmental Clinics held during the contract period:

<table>
<thead>
<tr>
<th>Quarter</th>
<th>Location</th>
<th># of Clinics</th>
<th># of Patients Served</th>
<th># of SHCN Served</th>
</tr>
</thead>
<tbody>
<tr>
<td>First</td>
<td>n/a</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Second</td>
<td>Junction City &amp; Mayetta</td>
<td>2</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>Third</td>
<td>Girard</td>
<td>1</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Fourth</td>
<td>Dodge City and Hays</td>
<td>2</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td><strong>5</strong></td>
<td><strong>19</strong></td>
<td><strong>0</strong></td>
</tr>
</tbody>
</table>
**Proposal:**

Individuals with intellectual and developmental disabilities are at high risk for low academic achievement and impaired health. American Indian and Alaska Native children are at an even higher risk due to sociocultural factors that can influence how often AI/AN families access preventative health services and disability services. This disability services improvement plan is intended to share the results of a regional needs assessment through community education events and structured technical assistance. The dissemination of this information will be targeted at Kansas tribal leadership, lead education agencies, Indian Health Services, county and state health offices, the University of Kansas Medical Center and affiliates, and the Kansas Department of Health and Environment.

This needs assessment will also be presented in scholarly journals and Kansas state conferences to share as a model for other communities and state agencies who seek to assess the disability service needs of diverse communities. A key component of this information dissemination process includes the presentation of needs assessment findings to the KDHE Special Health Care Needs Program and affiliated agencies to work on gaps in service delivery and discuss opportunities for state and tribal partnerships.

The overarching project for this funding year will be to development a strategic plan, based on results of the 2017 Kansas Tribal DD Needs Assessment, to build partnerships, train community providers on best practices for screening, assessing and treating young AI/AN children with disabilities or special health care needs, and fostering community capacity to address health disparities and improve early childhood programs.

<table>
<thead>
<tr>
<th>KUMCRI - TRIBAL SERVICES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Award</strong></td>
</tr>
<tr>
<td>$2,000</td>
</tr>
<tr>
<td>$4,000</td>
</tr>
<tr>
<td>$6,000</td>
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<td>$8,000</td>
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</tr>
<tr>
<td>$12,000</td>
</tr>
<tr>
<td>$14,000</td>
</tr>
</tbody>
</table>

| **Total Spent**           |
| $8,485                    |

| **Unspent**               |
| $3,858                    |

| **Unspent**               |
| $1,518                    |

1
Outcomes:

- Project lead and student attended 2017 Kansas Tribal Health Summit in August 2017. They conducted presentation on best practices in working with Kansas Tribal Communities.
- Participated in Kickapoo Head Start Welcome Back Health Fair. Conducted developmental and hearing screenings on incoming preschool students.
- Attended Native Children’s Research Exchange in September 2017 to share goal of improvement plan in Kansas tribes.
- Needs assessment methods and strategic plan goals were presented at the American Speech-Language-Hearing Association in November 2017.
- Project lead is now officially on the Kansas Tribal Health Summit Planning Committee at the Kansas University Center for Developmental Disabilities. With this new position, project lead will work with key community members and health professionals to develop a strategic plan.
- Developmental screenings were provided as requested by tribal communities. Records and numbers of screenings were being closely tracked. Project lead work with Tribal Health Summit board to establish plans for an intertribal disability coalition.
- Project lead presented with psychologist Leni Swails, PhD at Prairie Band Potawatomi Boys and Girls Club in December 2017.
- Project lead and students presented poster at EHDI Conference in March 2018 in Denver. Presentation included referral rates for community screening events and a culturally tailored audiogram for Native American families in Kansas. Poster received an award.
- A Child development summit was held on 4/17/18 in Mayetta, KS.
- A summary of the needs assessment findings and plans for partnership were presented to the Prairie Band Potawatomi Council on June 21.

Partnerships:

- Partnering with Kansas Parent Advocacy network to bring resources to Kansas tribal communities.
- Kansas University Center on Community Health and Development.
- Haskell Indian Nations University/KU Bridge Program.
- Technical assistance provided to University of South Dakota on engaging with tribal communities and assessing needs of tribal communities.
- The partnership with the PBPN Head Start and Tribal Council is a major milestone for a KS-SHCN funded project. The KS-SHCN program is encouraged to continue fostering this relationship along with the interaction with the KS Tribal Health Summit Committee.
KUMCRI - WICHITA CERBRAL PALSY & MEDICALLY COMPLEX

Proposal:
The Department of Pediatrics will develop a multi-specialty clinic to serve children with Cerebral Palsy and/or those who are Medically Complex (CP/MC Clinic). The clinic will be held 3 to 4 Wednesdays a month (40 times per year) with 10 to 12 patients scheduled per clinic. The purpose of the clinic is to provide high quality, integrated comprehensive care to children and youth with special health care needs (CYSHCN). As such, a panel of subspecialists and experts will be engaged during the clinics to provide health care to these children. The CP/MC Clinic will be supervised and coordinated by a general pediatrician, Dr. Sivamurthy.

The CP/MC Clinic activities will be supported by a coordinating person, or navigator, who can connect families to services across healthcare systems. Families engaging with the CP/MC Clinic will receive the following:

a) multidisciplinary care;
b) education, including disease specific information and health maintenance information;
c) ongoing care management and coordination;
d) an "About Me" binder that is updated at each appointment with the patient's medical records, physician names and contact info, allergies and all medications;
e) a Shared Plan of Care and emergency care plan;
f) referrals to appropriate subspecialists, ancillary providers and therapists; and
g) communication back to their primary care provider.

<table>
<thead>
<tr>
<th>Total Award</th>
<th>Total Spent</th>
<th>Unspent</th>
</tr>
</thead>
<tbody>
<tr>
<td>$101,695</td>
<td>$101,253</td>
<td>$442</td>
</tr>
</tbody>
</table>

KUMCRI - CP/MC

$120,000
$100,000
$80,000
$60,000
$40,000
$20,000
$-

1

Total Award | Total Spent | Unspent
Outcomes:

- CP/MC Clinic began August 23th, 2017.
- 100% of our patients seen in CP/MC clinic progress notes are faxed to the PCP after every clinic and those that did not have a PCP available the CP/MC clinic facilitated getting a PCP.
- 98.5% - 100% of patients served in the CP/MC clinic received an “About Me” notebook if they met Families Together criteria. The “About Me” notebook contains patient's medical records, physicians’ names and contact information, allergies and all medications. This notebook was updated at each appointment.

- The Nurse Manager and Care Coordinator:
  - provided every patient with a SHCN brochure and discussed areas that it may benefit the family.
  - Coordinate care for multiple appointments with specialists.
  - Contacted transport for patient that needed authorization from Insurance.
  - Coordinate with school nurse, home health nurse, and family to change feeding schedule for patient.
  - Provided assistance with coordinating delivery of new hospital bed and removal of old hospital bed.
  - Provided education to parents on equipment usage and when to call for assistance.

- PCP surveys was sent to all providers of current patients on 2/27/2018. As of 3/31/18, 22% of PCP surveys have been returned with 40% agreeing the CP/MC communicates adequately and is a benefit to their patients.
Summary of CP/MC Clinics held during the contract period:

<table>
<thead>
<tr>
<th>Quarter</th>
<th># of CP/MC Clinics</th>
<th># of Patients Served</th>
<th># of SHCN Served</th>
</tr>
</thead>
<tbody>
<tr>
<td>First</td>
<td>5</td>
<td>38</td>
<td>5</td>
</tr>
<tr>
<td>Second</td>
<td>10</td>
<td>80</td>
<td>13</td>
</tr>
<tr>
<td>Third</td>
<td>9</td>
<td>69</td>
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</tr>
<tr>
<td>Fourth</td>
<td>9</td>
<td>63</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>33</td>
<td>250</td>
<td>56</td>
</tr>
</tbody>
</table>

**Partnerships:**

- Dr. Shah, Neurology and Families Together.
- Elizabeth Biggs, Speech Therapist from HeartSpring, shadowed in CPMC clinic April 25, 2018, as a potential partner.
- Lisa Hacker, Speech Pathologist from Wesley Medical Center, came to clinic on June 20, 2018 to begin partnering with the CPMC clinic. She agreed to provide services once per month.
- Cassie Bumstead, dietician, agreed to come to CPMC clinic one Wednesday per month, effective date July 18, 2018.
- The clinic added Dr. Weihe, pediatric orthopedic physician, to their team. He came to clinic the 2nd Wednesday of every month.
- During the 4th quarter, met with Speech Coordinator at Via Christi St. Francis for referral process for Speech Swallow Study.
KUMCRI - WICHITA GENETICS

Proposal:
The purpose of this collaboration is to provide family-centered, community-based, coordinated care for children diagnosed to have conditions detected by newborn screening or special health care needs that have a genetic etiology. Best practice guidelines recommend infants with metabolic conditions or birth defects, and children with intellectual disability, seizures or autism have a genetic evaluation. The role of a geneticist, genetic counselor and metabolic dietician is to evaluate these infants and children to determine if there is a diagnosis and provide condition specific education and management recommendations.

Families evaluated will receive the following:

a) comprehensive genetic evaluation;
b) education, including disease-specific information, an emergency care plan if necessary and health maintenance information;
c) referral to care coordination services;
d) referrals to appropriate subspecialists, ancillary providers and therapists; and
e) communication back to their primary care provider.

The primary anticipated health outcomes include decreasing morbidity and mortality of conditions detected by newborn screening. In addition, the results of the genetic evaluation will inform health supervision for children with birth defects, developmental delay and autism. Finally, understanding the reason for a child's special health care needs and accurate education about a genetic condition promotes parental coping and psychosocial adaptation to the diagnosis which is a critical component of comprehensive family-centered care.
Outcomes:
PKU Clinic:
Dr. Beltran has been providing oversight, supervision and management of PKU patients in the Metabolic Clinic since October 2016. The primary provider in the Metabolic Clinic is Dr. Sivamurthy, pediatrician. He bills for patient evaluation. The metabolic dietitian, Charlotte evaluates patients with Dr. Sivamurthy. Dr. Beltran reviews the management of each case, reviews the plan of care, and reviews lab results – all of which are non-billable. In summary, Dr. Sivamurthy evaluated patients in the Metabolic Clinic and Dr. Beltran provided consultation and expert supervision on complex case management. All providers in the clinic spent substantial time during non-clinic hours reviewing and following up on metabolic labs, reviewing food records, completing forms for school, letters of medical necessity, educated patients about formula and low protein food coverage options and followed up with necessary paperwork.

b. The team distributed 21 “howmuchphe.org” subscriptions to patients with PKU. Howmuchphe is an online tool for patients to enter and track their daily protein and Phe intake, as well as, track them over time. The tool also provides information on Phe content in > 7000 food items and recipes. The tool permits the patient to export their data to the metabolic dietician for review. This tool permits the metabolic dietician to calculate Phe intake and modify the diet accordingly.

c. All patients who attend the PKU clinic are provided information about the special health care needs program and offered an application.

d. All patients attending the PKU clinic participate in a survey regarding clinic services and patient satisfaction. A detailed report summarizing responses is attached (Attachment #2).

e. All patients are referred to the clinic’s social work services as indicated by assessment of their needs (such as those who need assistance regarding insurance coverage and travel assistance).

f. For patient with PKU who are dually enrolled as SHCN clients, their services are all handled by the SHCN Care Coordinator in the Topeka office.

g. Based on feedback from SHCN, the team has revised the outcomes specific to PKU clinic to be stated in the SMART context. This will be reflected in the FY19 reports.
Summary of PKU Clinics held during the contract period:

<table>
<thead>
<tr>
<th>Quarter</th>
<th># of PKU Clinics</th>
<th># of Patients Served</th>
<th># of SHCN Served</th>
</tr>
</thead>
<tbody>
<tr>
<td>First</td>
<td>2</td>
<td>17</td>
<td>0</td>
</tr>
<tr>
<td>Second</td>
<td>3</td>
<td>28</td>
<td>14</td>
</tr>
<tr>
<td>Third</td>
<td>3</td>
<td>22</td>
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</tr>
<tr>
<td>Fourth</td>
<td>3</td>
<td>23</td>
<td>20</td>
</tr>
<tr>
<td>Total</td>
<td>11</td>
<td>90</td>
<td>44</td>
</tr>
</tbody>
</table>

**Partnerships:**

- Developed partnership with Wesley Children’s Hospital infusion center, pharmacy and Biomarin (company supplying Vimizin, an enzyme replacement therapy for Morquio syndrome).

- Other lab partnership initiated: Biomarin, Recordati Rare Diseases, Alexion
KANSAS YOUTH EMPOWERMENT ACADEMY (KYEA)

Proposal:
Faces of Change is a cross-disability, statewide program focused on youth leadership development through civic engagement. Team members are in the age range of 17 to 25 and have a disability/special healthcare need. Members must have existing leadership skills and now be looking to enhance those skills to become effective leaders on a local, state, and national level.
Faces will occur in Topeka, one weekend a month, from April through November. Sessions will focus on an area contributing to effective leadership, such as authentic leadership, leader expectations, and effective communication, just to name a few. An emphasis on health, such as self-care and managing emotions, will be made. With strategic topics, members will be thinking about their own personal and professional health practices. Speakers, discussions, and team builders are utilized to address topics. Opportunities to network with one another occur at the end of the day.
Each weekend will have a leadership challenge, which is an independent assignment allowing members to prepare for the next session. The biggest portion of the assignments will be the implementation of a Community Change Project. The Community Change Project is a local activity that each member will create, implement, and lead in their own community. Evaluation through individual self-efficacy assessments, leadership assessments, monthly session evaluations, and annual follow up with graduates for three years post participation will occur.
Research demonstrates, and we firmly believe that, by enhancing leadership skills, young adults will demonstrate increased self-efficacy, self-determination, and feel connected on a social and civic level to their community, which leads to better quality of health. This will result in seeing more diversity among the faces holding leadership roles and positions in Kansas.
Outcomes:
• During November 2017, six (6) students completed the program and graduated:
  ➢ Allie H. - hard of hearing
  ➢ Danielle D. - learning/anxiety
  ➢ Fabien S. - blind/anxiety
  ➢ Taylor N. - learning/anxiety
  ➢ Patrick D. - mental health/Cerebral Palsy
  ➢ Whitney D. - mental Health/Autism
• Sent out 500 letters and applications to recruit the class of 2018.
• KYEA conducted 11 interviews and 10 participants were accepted.
• Patrick, alumni from the 2017 class showed interest in becoming our intern for 2018. He was trained and assisted with some interviews and completed a couple on his own.
• March 2018, first session with the 2018 class started. Although 10 participants were accepted, only 9 were in attendance.
• KYEA submitted a grant to the Westar Foundation and received $2,500.

Partnerships:
• Nathan Troyer – Leavenworth Paraprofessional
• Beth Burnett – Resource Center for Independent Living
• NAMI Kansas – assist with recruitment
• Celeste Houston (2016 Faces of Change Alumni
• Rocky Nicolas – Disability Rights Center
• Senator Vicki Schmit – Kansas Legislature
• Melissa Jarboe – returning speaker
• Miriam Hysten – retired nurse and foster care youth service worker
• Thad Allen – Edward Jones Financials Advisory
• Chad Wilkens – Kansas Medically Underserved Organization
• Martie Rison – Mize Houser and Associates
• Kay Farley – retired from the University Bookstore
## Community Change Projects for the 2018 Class

<table>
<thead>
<tr>
<th>Participant's Name</th>
<th>Location</th>
<th>Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ashlee</td>
<td>Kansas City / Wichita</td>
<td>Implemented a group for incoming freshman at Wichita State University to provide support through their transition from high school to college.</td>
</tr>
<tr>
<td>Makayla</td>
<td>Beloit</td>
<td>Provided appreciation gifts/gestures to her local firefighters, EMT’s, and law enforcement.</td>
</tr>
<tr>
<td>Madison</td>
<td>Florida</td>
<td>Developed a monthly movie night in which there was an opportunity for her community to meet new people and build support networks.</td>
</tr>
<tr>
<td>Noah</td>
<td>Newton</td>
<td>Implemented a clothing drive for the local foster care agency in his area. His original idea was to do a monthly jam session or poetry night similar to Madison’s idea.</td>
</tr>
<tr>
<td>Sean</td>
<td>Topeka</td>
<td>Developed a youth advocacy group where youth with disabilities learn how to advocate and actually participate in advocacy opportunities.</td>
</tr>
<tr>
<td>Gabe</td>
<td>Lawrence</td>
<td>Implemented a voter registration drive. His original idea was to make an accountability system for his KU scholar hall when it came to chores and responsibilities mandated to living there.</td>
</tr>
<tr>
<td>Rachel</td>
<td>Rozalia</td>
<td>Coordinated and implemented a diaper drive for a specific non-profit agency in her area. Her original idea was to do presentations about options other than abortion for this organization, but the organization was not ready for her to do this.</td>
</tr>
<tr>
<td>Nicole</td>
<td>Junction City</td>
<td>Painted and wrote inspiration quotes on rocks and give them out to people in her town. Her original idea was to do a monthly movie night similar to Madison’s idea.</td>
</tr>
</tbody>
</table>
ORAL HEALTH KANSAS (OHK)

Proposal:

Oral Health Kansas' proposal was to continue dental hygiene services provided in cleft lip/cleft palate clinics in Kansas City throughout the year. This project will ensure children with cleft lip/cleft palate in the Kansas City areas have access to dental hygiene services throughout the year. Dental hygienists from Oral Health Kansas will be assigned to serve children and their families at specialty clinics. Each hygienist will conduct the following services at each clinic every time the child visits: complete an oral assessment; document findings for families and clinic records; explain findings to families by showing signs of health and oral disease; demonstrate appropriate daily oral home care to child and families, followed with written descriptions and samples of toothbrushes appropriate for the child's condition; apply fluoride varnish when appropriate; and respond to families' requests for names of dental clinics in their community that can serve their child. These services will provide families with the opportunity to improve and maintain their children's oral health by adopting effective daily oral hygiene and eating habits that eliminate or reduce tooth decay and periodontal disease, which are the most common chronic disease among children. Oral health services at specialty clinics will be measured first by numbers of children seen for an initial visit.

ORAL HEALTH KANSAS

Total Award $3,516
Total Spent $1,424
Unspent $2,091
Outcomes:

- Dental hygiene services were provided at Cleft Lip Clef Palate Clinics in Kansas City:

<table>
<thead>
<tr>
<th>Clinic Location</th>
<th># of CL/CP Clinics</th>
<th># of Families seen</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kansas City</td>
<td>4</td>
<td>24</td>
</tr>
</tbody>
</table>

Some of the services provided include:

- Visual screenings
- Fluoride varnishes
- Toothbrush prophy
- Tooth brushing demonstrations
- Flossing demonstrations
- Mouth cleaning demonstrations
- Counseling on nutrition and eating habits
- Oral Health Facts on the following subjects:
  - Toothpaste Tips
  - Healthy Snacks Limit Acid Attacks
  - Brushing Up for Healthy Teeth
  - Choose the Right Container
  - Lift the Lip
  - They’re Not Just Baby Teeth
- Some materials provided during clinics:
  - Power toothbrush
  - Traditional toothbrushes
  - Flossing picks
- Hygienist interviewed each child and family to help identify ways she could address their individual oral health needs.
- Hygienist routinely referred families to dentists when they needed a referral and emphasized the importance of establishing dental homes.
- Oral Health Kansas is also participating in a new initiative in the state, the KanCare Meaningful Measures Collaborative. This newly-formed group will collect and analyze data that measures KanCare. We were encouraged that dental was included in this group and hope this can be an avenue to access new data, such as Medicaid dental providers.
Dan’s Story

Dan is a thirteen-year-old boy who has been having difficulty in school. His father brought him in for an autism evaluation. The CYSHCN Care Coordinator met with them and determined there were some behavioral problems, but very few signs of autism. The family was referred to KU Telehealth ROCKS for Parent Child Interactive Therapy. This would be scheduled at CHC/SEK and facilitated by the CYSHCN Care Coordinator.

During the therapy sessions, it was observed that Dan and his father seemed very angry with each other. It was also noted that Dan was not capable of answering questions like a typically developing 13-year-old. The psychologist and the CYSHCN Care Coordinator reviewed Dan’s Individualized Education Plan together and immediately noticed Dan’s IQ score was 60. Upon talking with Dan’s father, they realized that no one had ever diagnosed Dan with an Intellectual Delay.

This diagnosis and the significance it would have on Dan’s life were explained to his father. Interventions were put in place at home to help Dan with daily tasks. However, Dan’s father refused to follow through. He repeatedly called his son “stupid”, claimed his son was “playing dumb” and threatened to turn him over to the state. One day during Dan’s individual session with the psychologist Dan said he was “angry at his dad for being drunk all the time.”

The CYSHCN Care Coordinator and the psychologist talked to Dan’s father in Dan’s absence to inquire about Dan’s internal anger. Dan’s father admitted he had been abusing alcohol for the past six months and that he needed help. The CYSHCN Care coordinator immediately made an appointment for him with the Addiction Treatment Center located at CHC/SEK. Dan’s father has been sobered for 63 days. He and Dan are getting along wonderfully and enjoy spending time together. Dan’s father is in the process of applying for disability for Dan in order to further help his individual needs and to help set him up for adulthood.
Attachment #2: KUMCRI – Wichita – Genetics

Genetics Satisfaction Survey - Annual Results FY2017-2018

On average, 17 patients complete the survey each quarter.

New or Returning Patient

<table>
<thead>
<tr>
<th>Quarter</th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Respondents</td>
<td>25</td>
<td>20</td>
<td>15</td>
<td>10</td>
</tr>
<tr>
<td>Percent of Respondents</td>
<td>100.0%</td>
<td>80.0%</td>
<td>60.0%</td>
<td>50.0%</td>
</tr>
</tbody>
</table>

New or Returning Patient - Year Total

- New (%) 6%
- Returning (%) 94%
Genetics Satisfaction Survey - Annual Results FY2017-2018

Patient age group is equally divided between adults 18+ years and children younger than 18 years.
The annual average for the three measures demonstrating customer service remains high (Concerns met=90%, Satisfaction=99%, Quality=99%). However, quarterly trends show room for improvement in the area of addressing and meeting the concerns of patients. There were no specific suggestions for improvement indicated in the comments.

![Customer Service Graph]

The annual average for communicating with patients regarding their plan of care (POC) remains high (receiving POC=93%, understanding POC=90%). Although, satisfaction survey demonstrates room for improvement in Q4, there were no specific suggestions indicated in the comments.

![Plan of Care Graph]
Genetics Satisfaction Survey - Annual Results FY2017-2018

The most frequently reported (mode) travel distance to the clinic is less than 25 miles, but a large proportion of respondents travel more than 100 miles.