Kansas Department of Health and Environment

SPECIAL HEALTH CARE NEEDS PROGRAM

Annual Report SFY 2020

Kansas Department of Health and Environment

Special Health Care Needs

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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

The program promotes the functional skills of persons, who have or are at risk for a disability or chronic disease. The program is responsible for the planning, development, and promotion of the parameters and quality of specialty health care in Kansas in accordance with state and federal funding and direction. 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."

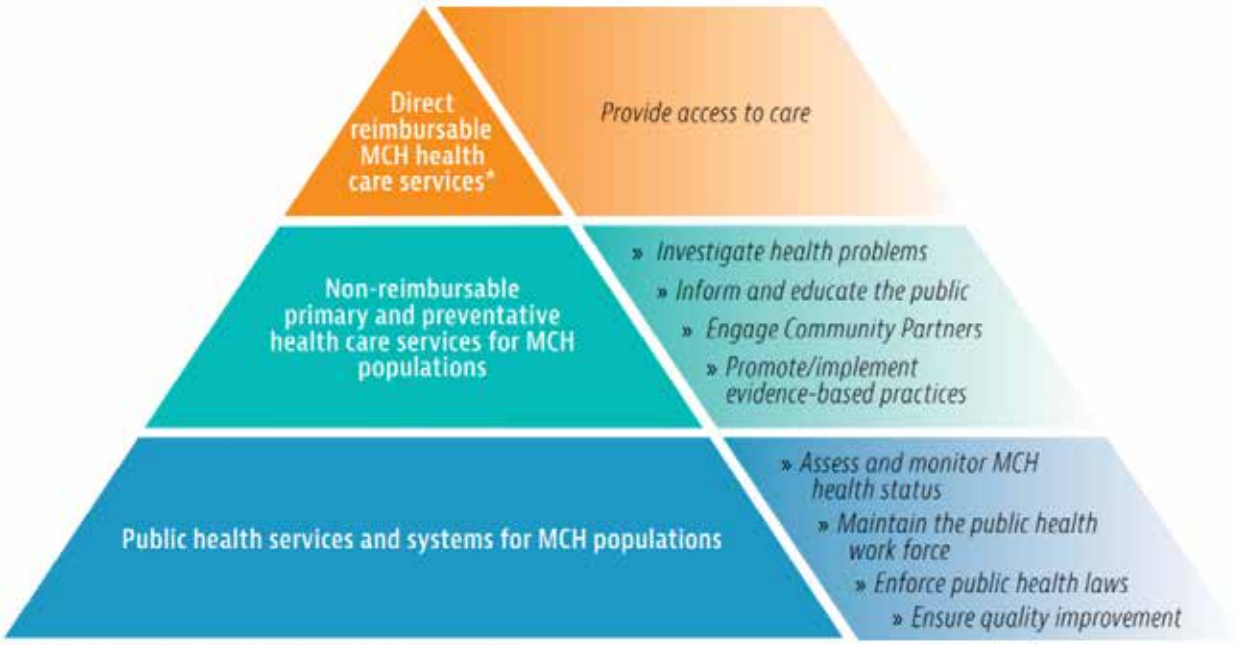
Target Population for Services

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 metabolic conditions screened for and diagnosed through the Kansas Newborn Screening program, such as Phenylketonuria (PKU) and Maple Syrup Urine Disease (MSUD, that require specialized metabolic formulas.

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 align 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 SFY20, six (6) organizations were awarded:

2020

GRANTEE	TOTAL AWARD	TOTAL SPEND	BALANCE
CPRF	$353,705.00	$353,705.00	$0.00
KUMCRI - SPECIALTY	$22,120.00	$20,078.14	$2,041.86
KUMCRI -CP/MC	$150,000.00	$150,000.00	$0.00
KYEA	$30,394.00	$13,077.95	$17,316.05
Southeast Kansas	$39,060.00	$39,060.00	$0.00
Wichita Cleft Lip	$17,400.00	$17,400.00	$0.00
TOTAL	$612,679.00	$593,321.09	$19,357.91

SFY 2020 CONTRACTS

CEREBRAL PALSY RESEARCH FOUNDATION (CPRF)

Financials:

CONTRACT AWARD:	$ 353,705
YEARLY EXPENSES:	$ 353,705
ENDING BALANCE:	$ 0

Proposal: To provide gap-filling direct health services through this grant that will focus on:

- Partnering with public and private insurance companies to enhance coverage of services for individuals with special health care needs for primary and specialty care, and
- Increasing support for outreach clinics & utilization of telehealth for the CYSHCN population.

Specifically, this application requested assistance with gap-filling services related to wheelchair and posture seating needs of children ages 0-25 years who have any disability requiring a wheelchair and seating system and who reside primarily in Central, Southeast, and Western Kansas. Activities implemented can be described utilizing the collective impact framework as follows***:***

1) ***Frame a Common Agenda:*** Program participants share an understanding of the problem. Clients and families have a need for posture seating services, but there is a lack of skilled therapists and technicians in their communities. Medical professionals understand that without appropriate and timely posture seating services, secondary complications can develop. Those outside of the end-user or medical professional have a greater understanding of the problem and consequences as a result of targeted outreach and education.

2) ***Agree on Shared Measurement*****:** All CPRF funders, including KS-SHCN, have measurable outcome expectations, from basic demographics, to ease of financial burden on families, and most importantly, the benefits for clients served. All data is measured and reported, some quarterly, some biannual, and some on an annual basis. The most important metric reported to all funders is the value of service to the client through data collection at pre- and post-seating system completion measuring.

3) ***Take Mutually Reinforcing Action:*** The combination of funders as stated previously shows the multiple agencies and foundations working together towards a shared goal to address the need for posture seating services throughout Kansas that are currently underfunded and inaccessible.

4) ***Communicate (LEARN) Continuously:*** In addition to the demographic and performance outcomes measured by therapists, staff and funders share client satisfaction survey results to better understand the real-life impacts of wheelchair seating services for clients. Quality Assurance of operational performance of clinicians and staff is also conducted. Clinic operations are modified as needed to accommodate clients more readily. Therapists also attend trainings to keep abreast of the latest technologies that will assist in providing the most efficient service delivery to clients.

5) ***Build Infrastructure:*** CPRF management is continuously evaluating key resource requirements such as therapists, technicians, support staff, and facilities to be prepared to fill this critical service delivery both short and long term. Based on client feedback through focus groups, CPRF recently renovated its clinic space, allowing for an enlarged and designated waiting area, expanded evaluation rooms, and inclusion of video games for clients to use while waiting.

Goals & Objectives:

#1: Patient wheelchair seating systems will provide alignment for good health.	#2: Patient wheelchair seating systems will provide skin protection.	#3: Patient wheelchairs will have optimal configuration for best self-mobility.	#4: Patient wheelchairs will provide maximum comfort.
For patients who have alignment issues, they will show improvement in their alignment for breathing, circulation, and activities of daily living, as measured by changes from baseline scores during evaluation and final scores given after delivery of CPRF seating clinic services.	For patients who require advanced seating, the patient's seating system will maximize pressure distribution to key weight bearing sites as measured by changes from baseline scores during evaluation and final scores given after delivery of CPRF seating clinic services.	For patients who are self-mobile, their wheelchairs will be optimally configured for best self-mobility as measured by changes in baseline scores during evaluation and final scores given after the delivery of CPRF seating clinic services.	For patients (can be from caregiver report) who report pain while seated in their wheelchair, they will show improvement in their levels of comfort as measured by changes in baseline scores during evaluation and final scores given after delivery of CPRF seating clinic services.

What was accomplished …

CPRF provided ten (10) outreach clinics in:

- Hays – 2
- Garden City – 4
- Liberal – 2
- Salina – 2

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.

Data	1st. Quarter		2nd. Quarter		3rd. Quarter		4th. Quarter	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Goal #1	2.30	4.26	2.39	4.36	2.47	4.18	2.68	4.22
Goal #2	2.46	4.43	2.55	4.64	2.45	4.46	2.68	4.59
Goal #3	2.95	4.74	2.93	4.71	3.04	4.76	3.80	4.92
Goal #4	2.42	4.59	2.55	4.75	2.42	4.67	2.70	4.73

CPRF Seating Clinics

Quarter	**# Patients Served**	**# Unduplicated**	**# SHCN Served**
First	212	157	22
Second	229	171	38
Third	186	152	22
Fourth	95	81	12
TOTAL	**722**	**561**	**94**

CPRF Outreach Seating Clinics

Quarter	**# of Clinics**	**# Patients Served**	**# Unduplicated**	**# SHCN Served**
First	2	14	14	0
Second	3	16	16	0
Third	2	7	7	0
Fourth	4	4	4	1
TOTAL	**11**	**41**	**41**	**1**

COMMUNITY HEALTH CENTER SOUTHEAST KANSAS (CHC/SEK)

Financials:

CONTRACT AWARD:	$ 39,060
YEARLY EXPENSES:	$ 39,060
ENDING BALANCE:	$ 0

Proposal: CHC/SEK, as the largest provider of pediatric services in all-rural southeast Kansas and serving more than 16,000 children annually, is seeking continued support for its dedicated full-time Special Needs Care Coordinator to serve low-income children throughout the region. This individual, along with our 80+ health professionals, identifies and connects children to resources including the SCHN program, ensures these children have an established culturally-competent provider of medical, dental and behavioral health services and assist families in making application for--and accessing all--services and resources for which they are eligible. 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 hopefully eliminated.

The community health center continues to work with the University of Kansas School of Medicine in their development of educational resources for families of special needs children through Tele-Health Rocks, as well as Children's Mercy through their Beacon program. As the health home for most of their families, services are readily available to all members and provided on a sliding fee schedule making them affordable ($15 per medical visit which includes lab and x-rays).

CHC/SEK currently provides an integrated model of care with a behavioral health specialist embedded in the clinics providing real-time interventions. Additionally, behavioral health staff are also available in three school districts with plans to double this in 2019/2020. These staff members have been especially valuable as advocates for our special needs children who can be misunderstood and disruptive in a traditional environment. Traditional counseling (including marriage counseling) and treatment is also provided directly regardless of ability to pay and has proven beneficial to many of our families. CHC/SEK also provides addiction treatment which is often a need for adults and older adolescents in the families we serve.

This provider is the oral health safety net for the target population throughout the nine counties of southeast Kansas with six dental clinics in five southeast Kansas counties. To address a major gap in oral health care, CHC/SEK has supported a dentist through her pediatric dentistry residency. She will be the ONLY full-time pediatric dentist in rural Kansas and will be providing both in-clinic and in-hospital sedation dentistry, which is essential for special needs children. Additionally, the agency would equip the clinic to accommodate patients in wheelchairs to eliminate all barriers to care. They will also continue to provide outreach services to centers/children with special needs. In specialty care, they will continue to provide clinic space for Children's Mercy/KU at no cost for their specialty clinics (such as Cystic Fibrosis), as well as their special programs (Telehealth Rocks). CHC/SEK also has specialty services available through Vigilias/Free State which makes pediatric specialists available to patients at multiple sites (Baxter Springs, Pittsburg, Parsons, Coffeyville and Iola).

What was accomplished …

		ADHD	Obesity	Developmental Delay	GI Disorder	Tic Disorder	Hearing Loss	Intellectual Delay	CMV	Asthma	Autism	Mental Health	Cancer	
Standard Sub-Measures	Number of CYSHCN with a POC **developed** by the PCP with input from specialist	4	0	31	2	2	2	4	1	0	15	6	3	70
	Number of CYSHCN with a POC **developed** by the PCP with input from family	4	0	31	2	2	2	4	1	0	15	6	3	70
Additional Sub-Measures (adding on new measures as appropriate and based upon capacity of clinic)	Number of CYSHCN with a POC that includes family preferences and strengths	4	0	31	2	2	2	4	1	0	15	6	3	70
	of CYSHCN with a POC that includes chronic condition protocols	4	0	0	2	2	0	0	1	0	4	1	3	17
	Number of CYSHCN with a POC that includes an emergency plan	4	0	0	0	1	0	4	1	0	4	6	3	23
	Number of CYSHCN with a POC that includes legal documents (advance directives, DNR, guardianship, medical authority/power of	0	0	0	0	0	0	4	0	0	0	0	0	4
	Number of CYSHCN with a POC that includes clinical goals	4	0	31	2	2	2	4	1	0	15	6	3	70
	Number of CYSHCN with a POC that includes family personal goals	4	0	31	2	2	2	4	1	0	15	6	3	70

	OUTCOMES			
	Prevented		**Occurred**	
	#	Description	#	Description
1st Quarter	4	ER Visit	6	Referral to subspecialist
	1	Hospitalization	10	Advised family/patient on home management
	11	Subspecialist Visit	1	Referred to specialized therapies
	2	Specialized therapies (PT, OT, etc)	0	Referral to community agency
Patients Seen	18		17	
2nd Quarter	2	ER Visit	2	Referral to subspecialist
	0	Hospitalization	6	Advised family/patient on home management
	15	Subspecialist Visit	6	Referred to specialized therapies
	0	Specialized therapies (PT, OT, etc)	9	Referral to community agency
Patients Seen	17		23	
3rd Quarter	0	ER Visit	0	Referral to subspecialist
	0	Hospitalization	6	Advised family/patient on home management
	13	Subspecialist Visit	0	Referred to specialized therapies
	0	Specialized therapies (PT, OT, etc)	7	Referral to community agency
Patients Seen	13		13	
4th Quarter	0	ER Visit	0	Referral to subspecialist
	0	Hospitalization	6	Advised family/patient on home management
	17	Subspecialist Visit	0	Referred to specialized therapies
	0	Specialized therapies (PT, OT, etc)	11	Referral to community agency
Patients Seen	17		17	

- CHC/SEK Worked with 144 families during this contract year.
- Educational sessions for “Kansas Connecting Communities” were provided by Project ECHO:
- A monthly support group for CYSHCN was available at CHS/SEK in Pittsburg.
- One hundred percent of the participants completed a Shared Plan of Care.
- One hundred percent of clients participating in the program were screened by the CYSHCN

- Care Coordinator for Medicaid eligibility or other insurance available to them. The CYSHCN Care Coordinator is certified in Insurance Marketplace enrollment and has the ability to enroll clients when needed.
- CHC/SEK staff worked directly with school boards, school staff and administrators to determine gaps in behavioral health care for students. As a result, CHC/SEK have 11 dedicated social workers in school districts throughout SE Kansas. Students work directly with licensed social workers in their schools to receive behavioral health services. CHC/SEK worked with the Medicaid Managed Care Organizations, which resulted in additional reimbursement on a per member/per month basis for targeted populations, and it is anticipated this will expand. The CYSHCN Care Coordinator ensured that transportation services, provided by staff and available through a contract with General Public Transportation, are available in order for clients to attend and receive necessary services. Three specialty telehealth sessions were attended by participants to receive behavioral health services they may not have otherwise received in rural Kansas. Specialty services included Pediatric Psychiatry and Parent Child Interaction therapy provided by highly recognized physicians from the University of Kansas Medical Center.
- Seventy-nine **(79)** caregivers received education from the CYSHCN Care Coordinator about their children's medical care.
- CHC/SEK immediately responded to the COVID pandemic by creating a Walk In Respiratory Clinic, separating well and sick visits in the clinic setting, working with county officials to coordinate drive through testing sites and utilizing virtual visits when possible. To continue well child visits, the mobile medical van was utilized to separate children from the waiting area.
- CHC/SEK provided:
  - **150** office visits
  - **204** telephone encounters
  - **14** school visits
  - **9** specialty telehealth visits in order to receive behavioral health services. These services were available through KU Medical Center and Children's Mercy Hospital in Kansas City.
- CHC/SEK utilized a Patient Satisfaction Survey process meeting Patient Centered Medical Home requirement. Individual clients/consumers were also interviewed periodically specific to individual programs or projects. CHC/SEK also conducted independent patient surveys specific to sites which was expected to be helpful in the design of additional programs.

KUMCRI - KANSAS CITY SPECIALTY TEAM CLINIC SUPPORT

Financials:

CONTRACT AWARD:	$ 22,120
YEARLY EXPENSES:	$ 20,078.14
ENDING BALANCE:	$ 2,041.86

Proposal: The Specialty Clinic Support project will continue to provide direct service and non- clinical support to individuals with Cystic Fibrosis (CF) and Cleft Lip and Cleft Palate (CL/CP) seen in the respective clinics at The University of Kansas Health System.

The Social Worker will continue to educate patients and caregivers on the importance of self-care, behavioral and mental health at clinic visits. In addition to providing educational materials, patients, age 12 and older, will receive early identification and intervention services to address mental health concerns. As a part of their clinic visit, patients will be asked to complete the PHQ-9 Depression screening tool and GAD-7 Generalized Anxiety Disorder screening tool. The activities seek to increase patient and caregiver knowledge of behavioral health issues and strategies for maintaining emotional and behavioral wellness. As well as, reduce the stigma of mental and behavioral health by utilizing the proposed strategies.

The Specialty clinics will continue to serve as a learning platform for field education and training opportunities. Students, trainees in the Leadership in Education and Other Neurodevelopmental Disorders (LEND) program and health professionals will continue to provide services and supports in the specialty clinics. The LEND programs provides long-term, graduate level interdisciplinary training as well as interdisciplinary services and care. The purpose of the LEND training program is to improve the health of infants, children, and adolescents with disabilities. Their participation in the clinics will increase their knowledge and ability to provide services and supports to the special health care needs population.

The promotion of oral health services and supports will continue in the CL/CP clinic. Unfortunately, the dental hygienist services were no longer provided due to loss of funding to support the provider. However, the Social Worker continued to work with the CL/CP Orthodontist to provide services and support to patients facing barriers in addressing their oral healthcare needs.

What was accomplished …

- The Social Worker continued to provide services and supports to children and families attending the Cystic Fibrosis (CF) and Cleft Lip and Cleft Palate clinics. The CF clinics were held weekly, and the CL/CP clinics were held monthly. The social worker assisted patients/families with coordinating services and supports related to school, orthodontic care, insurance, patient assistance programs, medical transportation and caregiver wellness. LEND Trainees, medical students and health professionals continued to provide services and supports in the specialty clinics. The learning experiences are aimed at building the capacity of future and current medical professions, under the supervision of clinic providers.
- The social worker continued to provide caregiver health education at clinic visits. Families and patients continued completing psychosocial assessments and clinic questionnaires. The information gathered was used to guide clinic visits, treatment plans and/or social services. Continued formal and informal assessment of behavioral and mental health needs of patients and clients. Mental health educational resources are distributed during clinic visits, and referrals to Psychologists are made as needed. CF patients/families participated in the Experience of Care Survey sponsored by the CF Foundation to gather information on family/consumer satisfaction.

Summary of Specialty Clinics held during the contract period:

Type of Clinic	# of Clinics	# of Patients Served	Unduplicated	# of SHCN Served
Cystic Fibrosis	52	173	153	5
Cleft Lip/Palate	9	57	53	1
TOTAL	**61**	**230**	**206**	**6**

KU – WICHITA PEDIATRICS CP/MC CLINIC

(Kansas University – Wichita Pediatrics Medically Complex Children Clinic)

Financials:

CONTRACT AWARD:	$ 150,000
YEARLY EXPENSES:	$ 150,000
ENDING BALANCE:	$ 0

Proposal: The goal of the KU Wichita Pediatrics is to continue its multi-specialty clinic to serve children with Cerebral Palsy and/or those who are medically complex. This year the clinic will transition their name from Cerebral Palsy/ Medically Complex to the Medically Complex Clinic (MCC), as this gives more credence to the types of patients seen. The clinic will be held, at minimum, 33 times per year, with a goal of 3 to 4 Wednesdays a month; 8 to 10 patients will be scheduled per clinic. Under the direction of Dr. Sivamurthy, the purpose of the clinic is to provide high quality, integrated comprehensive care to children and youth with special health care needs (CYSHCN).

Utilizing the collective impact framework (Kania and Kramer 2011), the KUSM-W Department of Pediatrics, and specifically the CP/MC Clinic, will act as the backbone organization, providing staff and clinic oversight to support the initiative. As such, they will be responsible for setting a common agenda with patients, primary care providers and subspecialists, measuring results (including patient satisfaction), coordinating a plan of action that is mutually reinforcing, and continuous communication.

To accomplish these goals, families engaging with the CP/MC Clinic will receive the following:

- Multidisciplinary Care.
- Education, including disease-specific information and health maintenance information.
- Ongoing care management and coordination.
- An “About Me” binder including the patient's medical records, physician names and contact info, allergies and all medications.
- A Shared Plan of Care.
- Referrals to appropriate subspecialists, ancillary providers and therapists.
- Communication back to their primary care provider.
- Access to a social worker who will assist with Durable Medical Equipment and socio-economic needs.

The project will leverage the central role and successful partnerships of KU Wichita Pediatrics to bridge traditional subspecialty silos and limit barriers to care. We have a strong track record of successful partnerships with diverse local and regional healthcare systems, state entities, and private medical practices throughout the region.

What was accomplished …

- While the intent was to hold a minimum of 33 clinics this year, due to the COVID pandemic this goal was not reached, but 31 clinics did occur.
- New patients accounted for 20% of all patients seen at the CP/MC clinic.
- Patient/family satisfaction surveys were given to every patient that attended clinic. Each survey was reviewed by the CP/MC Clinic team and changes were made accordingly where possible.
- Discussion began on ways to help family's transition as their child turns 21 which included development of a transition packet and transition clinics in the future. The first transition clinic is scheduled to occur in the 3rd quarter of this fiscal year.
- The nurse manager and social worker attended the Kansas School Nurse Conference and provided brochures and business cards.
- One hundred percent (100%) of patients seen in CP/MC clinic had progress notes faxed to their primary care physician within one week following clinic.
- Qualified patients received their CareING notebooks provided by Families Together.
- The nurse manager and social worker continue to assist Dr. Uhlig in educating medical students on social issues surrounding families with children who require special health care. Each month, one of the CP/MC families attend the Community Week rotation for medical students to discuss their challenges. A group of students attend a CP/MC clinic each month and give presentations to their classmates on the services provided. Possible SHCN clients were identified through assessment at the beginning of each clinic. These discussions helped families talk about their needs including diagnostic, treatment, and possible case management services. Dr. Melissa Hopper, PsyD meets with every family to ensure parents are supported as they care for children with special needs, referring to counseling services if indicated. Almost 100% of parents and caregivers report they have no time for themselves and are often overwhelmed by caring for a child with special needs. CP/MC partnerships included: Neurology, Orthopedics, Psychology, Occupational, Physical, and Speech Therapy, USD 259 Wichita Public Schools, CPRF, Grace Med Dental Clinic, Families Together, Orthotist, and Dietician.

Summary of CP/MC Clinics held during the contract period:

Quarter	# of Clinics	# of Patients Served	# of SHCN Served	# Unduplicated
First	10	79	7	61
Second	9	63	14	62
Third	9	68	5	67
Fourth	3	20	3	20
TOTAL	**31**	**230**	**29**	**210**

KANSAS YOUTH EMPOWERMENT ACADEMY (KYEA)

Financials:

CONTRACT AWARD:	$ 30,394
YEARLY EXPENSES:	$ 13,078
ENDING BALANCE:	$ 17,316

Proposal: The Kansas Youth Empowerment Academy has a mission to educate, mentor, and support youth with disabilities to be contributing members of their community. KYEA has the experience to deliver activities that enhance youth leadership and set the stage for young people with disabilities to become contributing, productive citizens and advocates. The target population is youth between the ages 5 through 25 years with any disability.

KYEA reaches youth across the state, and participation in activities is not limited to one geographic area. Services delivered to youth are based on a "progressive leadership program model" with one-to-one and group activities providing the foundation for successful implementation. Providing supports that build self-esteem, self-advocacy skills and knowledge of resources for these at-risk youths lessens the potential of them facing a lifelong pattern of unemployment.

This year, KYEA is doing something they had never done before, which is to integrate the Faces of Change program, that was once only for youth with disabilities, to an all-inclusive program affording youth without disabilities the same opportunity. Though this is a major shift from the mission, KYEA firmly believes in the importance of inclusion. Not only will youth with disabilities be in a safe environment, learning side by side about leadership with their peers, but those youth without disabilities will gain a greater understanding and appreciation for people with disabilities, as well as the opportunity to value the philosophies of inclusion and independent living. Programs and Services include:

- *Job Description of a Leader* – Identifying what true leadership means to each participant and the characteristics of true leaders.
- *P.A.V.E The Way* – Understanding the definition and purpose, passion and finding yourself.
- *Language of Leadership* – Exploring and understanding the various types of non-verbal communication and how to use them effectively, along with the various forms of written communication.
- *Leading From The Front* – Understanding the importance of modeling leadership behavior and learning the skills necessary to build trusting relationships and effective teams.
- *Leading From The Side* – Understanding the importance of caring and learning about others in relation to your leadership journey, learning the skills necessary to appreciate and add value to the lives of others.
- *Leading From The Back* – Learning how to see the potential in others by trusting your intuition, encouraging others and mentoring new leaders.
- *Look At This Face* – Learn to recognize when it's time to end a project and move to another and techniques in performing an evaluation of your projects.

What was accomplished …

1. All team members were given brochures about SHCN services.
2. All team members have entered their primary care doctor in their phone contacts.
3. All team members have learned about self-care and managing emotions.
4. All team members have practiced the W-I-N assertiveness technique, which can be used with parents, friends, teachers and doctors.
5. All team members have expressed individual accommodations and have used them throughout the program.

Class Graduated in 2019:

Participant	Location	Project
Kirstianna	Topeka	The Beautiful Project, Facebook page promoting self-love and inner beauty.
Shane	Tonganoxie	Installation of ADA door on 1 of 2 banks in his town.
Cameron	Topeka	Created and implemented Procrastinators Anonymous (Group and Facebook page).
Curtis	Leavenworth	Survival Kits for Homeless (assembled and distributed 10 kits).
Lindsey	Lawrence	YouTube series including various interviews with those who have diverse backgrounds and challenges.
Elizabeth	Goddard	Baby Bags for NICU Families.
Rick	Nickerson	High School Morning Motivation (Morning announcements over loud speaker with motivation quotes).

WICHITA CLEFT LIP/PALATE & CRANIOFACIAL CLINIC

Financials:

CONTRACT AWARD:	$ 17,400
YEARLY EXPENSES:	$ 17,400
ENDING BALANCE:	$ 0

Proposal: The project is a clinic composed of multi-disciplinary healthcare professionals who care for children born with cleft and craniofacial anomalies. Our clinic team is certified by the American Cleft Palate and Craniofacial Association (APCA), the governing body overseeing cleft and craniofacial care in the United States. The group consists of a fellowship-trained pediatric plastic surgeon who leads the team. Other disciplines offered by the clinic include ENT, oral surgery, orthodontics, dentistry, speech pathology, audiology, and nursing.

This project directly impacts children and youth with special healthcare needs born with the conditions listed below, along with their approximate incidence in the general population:

- Cleft lip/palate – 1/500 live births
- Craniosynostosis – 1/1000 live births
- Other craniofacial conditions, like Treacher Collins, Pierre Robin, DiGeorge syndrome, etc.

The reason for this clinic's existence is that these children have many medical, surgical, and psychosocial needs, requiring treatment from multiple specialists, throughout their lives.

Annual attendance at a multidisciplinary clinic is critical to:

1. make sure needs are being addressed
2. optimize health outcomes

To ensure optimal outcomes for each child, the nurse coordinator would follow up with children and their families after their clinic appointment to help them access the medical treatments recommended during the clinic visit. Our nurse also screens for and addresses any financial, social and/or psychological issues that may be deterrents to positive outcomes. Given that financial constraints are often a hindrance to care for many children, she also would act as a liaison between the family and external support resources, educating and referring patients to programs such as KS-SHCN.

Additionally, we educate both patients and healthcare providers. Having a child with a craniofacial anomaly can be intimidating; therefore, we have developed a comprehensive guide for families with children who have cleft lip/palate and craniosynostosis. We would like to make available other similar resources. Our pediatric plastic surgeon, who was recruited by Wesley Children's Hospital, has done several outreach trips to educate providers around the state and make them aware of our services and engages in educational webinars with healthcare providers throughout Kansas.

What was accomplished …

- All families were seen by a multidisciplinary team of providers, including a social worker, who screened for psychosocial and economic obstacles for access to care. The social worker was a new addition to the team during the first quarter and has been essential to care coordination and access.
- A summary letter of recommendations from the team is sent to the family within 10 days. A week after letters were sent, the nurse called to review recommendations with the family and to answer questions.
- Each family at clinic was made aware of the SHCN program and the assistance it can provide to care for children with Cleft Lip & Palate. Brochures were made available to 100% of families.
- 100% of patient referred for special procedures, specialist evaluation, speech services, initial orthodontic evaluation, surgical procedures or dental care were accomplished.
- 100% of the referrals to other health care providers were sent within a week of clinic.

Summary of Cleft Lip/Palate Clinics held during the contract period:

Quarter	*# of Clinics*	*# of Patients Served*	*# of SHCN Served*	*# Unduplicated*
First	1	19	1	19
Second	2	23	0	23
Third	1	13	3	13
Fourth	2	21	1	21
TOTAL	**6**	**76**	**5**	**76**

Satisfaction survey results (averages):

Description	Very Satisfied %	Somewhat Satisfied %	Somewhat Dissatisfied %
SCHEDULING (accessibility, helpfulness & explanation)	94	3	3
WAITING (time spent, accommodations)	77	15	8
INDIVIDUAL PROVIDERS DURING CLINIC (time spent, questions answered, information given, additional concerns, skill and knowledge)	95	5	0
FOLLOWUP (contacting team coordinator, scheduling with individual providers, recommendations)	92	6	2
OVERALL ASSESSMENTS (Overall and clinical care, surgical care, surgical outcome, inclusion in team, response to concerns, recommendations clear)	93	5	2

With the input of our families who were concerned about the wait times and congestion in clinic, we have adopted staggered appointment times and two clinic room with speech pathologists. This has improved the flow of clinic tremendously and decreased wait times. Families and patients have enjoyed this change according to the survey.

Some of the comments received in these surveys:

- Positive: “awesome team, helpful in learning about what is next in my child’s treatment, answers all questions, efficient, one of best clinics my child is involved in, easy to reach, gave ideas and comments to watch for, have been coming to Cleft Clinic for 12 years, a great asset for the Wichita area, thanks for running this program, the quality of the clinic has improved greatly over the past few years”, etc.
- Negative: “last minute notification of appointment, more communication needed.” Given this last comment regarding appointment notification, we have started to send a letter notifying of appointment 6 weeks prior to appointment and requesting to call and schedule appointment.