



RankenJordan®

PEDIATRIC BRIDGE HOSPITAL

Transitioning kids from hospital to home

Community Health Needs Assessment
June 2016

Executive Summary

When defined by others, a medically complex child is a diagnosis. A high intensity user of a complicated health care delivery system with needs centered on medications, technology dependence, caregiver ability, and specialists. A small subset of the general population. When asked to define themselves, a medically complex child is simply a child.

In 2010, the U.S. Congress passed the Patient Protection and Affordable Care Act. This piece of legislation includes numerous changes to healthcare in the United States, in particular, handing down new requirements for non-profit hospitals. One such requirement states a non-profit hospital must conduct a Community Health Needs Assessment (CHNA) every three years. Through such assessments, these hospital are to define the community they serve, identify health needs of that community, and create an implementation plan to address those needs.

The 2013 Community Health Needs Assessment (CHNA) conducted by Ranken Jordan sought to identify health needs of medically complex children through input from various stakeholders. By design Ranken Jordan's care delivery model relies on continual needs assessment in order to effectively care for its community. The CHNA process sought to broaden established means of needs assessment to ensure and reaffirm Ranken Jordan's understanding of what medically complex children need.

The predominant finding of the CHNA is that medically complex children need quality of life.

Due to the significant weight of this finding and its alignment with Ranken Jordan's very purpose the same initiative of quality of life remained our focus throughout our 2016 CHNA process. We continued to solicit information from those who represent the interest of the community and further refined our initiative to provide medically complex children and their families quality of life through community programming and navigation of health resources.

In summary, their report contains background information on Ranken Jordan, an overview of our community, our process used to solicit community input and need prioritization, and implementation plan.

Background

Ranken Jordan Pediatric Bridge Hospital

Ranken Jordan is a 34-bed pediatric specialty hospital in St. Louis, Missouri designed specifically to care for medically complex children (MCC) from infancy to early adulthood. Ranken Jordan offers an inpatient program and several outpatient programs, including outpatient therapy, intensive day treatment, a physiatry clinic and a comprehensive orthopedic rehabilitation clinic. Our mission is to provide a continuum of care for these children and their families regardless of their ability to pay.

The Ranken-Jordan Home for Convalescent Crippled Children opened its doors April 9, 1941, under the supervision of Mary Ranken Jordan and her husband Clay Jordan. Operating from their Ladue, Missouri home, they – along with a small staff – took in children from the St. Louis area suffering from polio, osteomyelitis and bone tuberculosis.

In the 1960's, the Ranken-Jordan Home expanded to allow more children and a larger staff. However, by the early 2000s, Ranken Jordan was outgrowing the 15,000 square-foot, 26-bed home and was taking care of children with more complex conditions.

The children cared for within Ranken Jordan required not only state-of-the-art equipment but also highly specialized clinical professionals. Therefore, in 2002, Ranken Jordan began its transition of licensure from "home" to "children's hospital." Despite the change in status, the original mission of Mary Ranken Jordan and Clay Jordan remained the same. Thus, The Ranken Jordan-Home for Convalescent Crippled Children was known as Ranken Jordan Pediatric Bridge Hospital.

In 2004, just 2 years after the transition, Ranken Jordan moved out of the Ladue home and relocated to Maryland Heights, Missouri, into a newly-built 62,000 square-foot, 34-bed facility. The current hospital building houses ultramodern equipment and is specifically designed to entice patients to get out of their rooms and engage in daily life-centered activities.

Inpatient Care

Ranken Jordan's Inpatient Program provides care through a multidisciplinary team approach that works to seamlessly coordinate care provided by doctors and therapists, and exposes each child to the expertise of multiple caregivers. We also include all caregivers directly involved in caring for the child as part of the child care team – from referring doctors, specialists, therapists and social workers – to ensure every child receives highly personalized treatment and allows us to address every issue facing the

child and family in a comprehensive and holistic manner. Our patients improve because we treat the child not the illness.

Outpatient Care

Ranken Jordan's comprehensive Outpatient Program offers a variety of services to children primarily to age 21 who are recovering from injuries, dealing with developmental delays or living with chronic conditions.

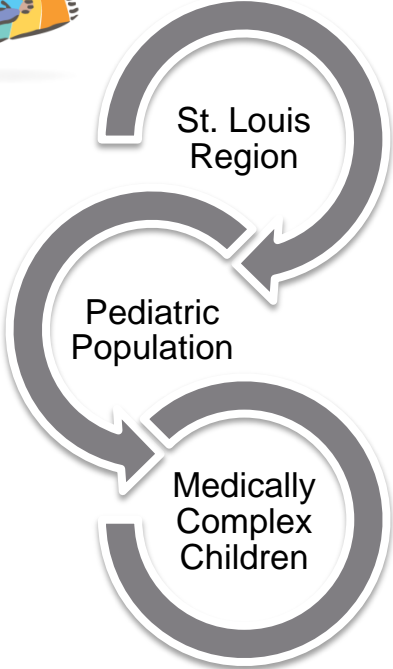
We collaborate with the child's referring physicians, treating therapists and insurance company to coordinate care and ease the process for the family. All our services are available on-site and are customized for each child.

For more information please go to rankenjordan.org

Community Served

Community Definition

Ranken Jordan is one of only a handful of hospitals in the country that provides rehabilitation and sub-acute medical treatment for medically complex children. For purposes of this CHNA, Ranken Jordan defines “community” as medically complex children and families in the St. Louis Region. This definition takes into account the geographic location of the hospital facility just outside St. Louis, Missouri, the target population of pediatrics, and the hospital’s principal function of serving only medically complex children.



Geographic Location

Located in Maryland Heights, Missouri, Ranken Jordan is centrally situated in the Midwest. Although it treats patients from both across and outside of the United States, the majority of patients come from Missouri and Illinois.

While serving patients and families from many communities across the bi-state region, from Fiscal Year 2013 to Fiscal Year 2015 an average of 67% of all inpatient discharges were from the St. Louis Region. In light of such high utilization rates from this region, Ranken Jordan identifies this as its primary geographic service area.



The St. Louis Region is comprised seven counties Franklin (MO), Jefferson (MO), Madison (IL), St. Charles (MO), St. Clair (IL), St. Louis City (MO), and St. Louis (MO).

The St. Louis Region is the 20th largest areas in the United States spanning both sides of the Missouri and Mississippi rivers.¹ The St. Louis Region boasts cultural and recreational opportunities, a remarkable low cost of living, and an “exceptional quality of life”.²

- The St. Louis region ranked No. 3 in the country for library services on the 2015 "America's Most Literate Cities" study published by Central Connecticut State University. In addition, St. Louis was named the 10th most literate city overall for 2015, based on six key indicators of literacy, which included newspaper circulation, number of bookstores, library resources, periodical publishing resources, educational attainment, and Internet resources.³
- St. Louis ranked as having the 12th highest volunteer rate in the nation among large U.S. cities for 2013, according to a study published by the Corporation for National & Community Service. The study found that St. Louis had a volunteer rate of 30.6% in 2013, with over 614,100 adult volunteers contributing an average of about 30.5 hours of service per resident.⁴

¹ St. Louis Regional Chamber. 1 January 2016. <<http://www.stlregionalchamber.com/>>

² St. Louis Regional Chamber. 1 January 2016. <<http://www.stlregionalchamber.com/>>

³ Id.

⁴ Id.

St. Louis Region Demographic Snap Shot^{5,6,7,8,9,10}

Population, 2015 Estimate	St. Louis Region	Missouri¹¹	Illinois¹²
Total Population	2,556,097	6,083,672	12,859,995
Persons below 18	14.9%	22.9%	23.0%
White	74.7%	83.3%	77.3%
Non-White	34.2%	16.7%	22.7%
Total Households	1,010,645	2,361,232	4,778,633
Median Household Income	\$53,612	\$47,764	\$57,166
Home Ownership Rate	93.2%	67.9%	66.9%
Median Home Value	\$146,257	\$136,700	\$175,700
High School Graduate or higher			
– persons over 25	79%	88.0%	87.6%
Bachelor degree or higher			
– persons over 25	36.1%	26.7%	31.9%
Persons below Poverty Level	13.0%	15.5%	14.4%

Target Population

Ranken Jordan treats only pediatric patients. The American Academy of Pediatric defines “pediatrics” as the “specialty of medical science concerned with the physical, mental, and social health of children from birth to young adulthood. Pediatric care encompasses a broad spectrum of health services ranging from preventive health care to the diagnosis and treatment of acute and chronic diseases”.¹³

“Pediatrics is a discipline that deals with biological, social, and environmental influences on the developing child and with the impact of disease and dysfunction on development.

⁵ U.S. Census Bureau. (2010). State and County Quickfacts. “Franklin County, Missouri” 1 June 2016 <<http://quickfacts.census.gov/qfd/states/29/29071.html>>.

⁶ U.S. Census Bureau. (2010). State and County Quickfacts. “Jefferson County, Missouri” 1 June 2016 <<http://quickfacts.census.gov/qfd/states/29/29099.html>>.

⁷ U.S. Census Bureau. (2010). State and County Quickfacts. “St. Charles County, Missouri” 1 June 2016 <<http://quickfacts.census.gov/qfd/states/29/29183.html>>.

⁸ U.S. Census Bureau. (2010). State and County Quickfacts. “St. Louis County, Missouri” 1 June 2016 <<http://quickfacts.census.gov/qfd/states/29/29189.html>>.

⁹ U.S. Census Bureau. (2010). State and County Quickfacts. “Madison, Illinois” 1 June 2016 <<http://quickfacts.census.gov/qfd/states/17/17119.html>>.

¹⁰ U.S. Census Bureau. (2010). State and County Quickfacts. “St. Clair, Illinois” 1 June 2016 <<http://quickfacts.census.gov/qfd/states/17/17163.html>>.

¹¹ U.S. Census Bureau. (2010). State and County Quickfacts. “Missouri” 1 June 2016 <<http://quickfacts.census.gov/qfd/states/29000.html>>.

¹² U.S. Census Bureau. (2010). State and County Quickfacts. “Illinois” 1 June 2016 <<http://quickfacts.census.gov/qfd/states/17000.html>>.

¹³ American Academy of Pediatrics. “Definition of Pediatrician”. *Policy Statement*. Volume 135 Issue 4 (April 2015) Web. 4 April 2016. <<http://pediatrics.aappublications.org/content/135/4/780>>.

Children differ from adults anatomically, physiologically, immunologically, psychologically, developmentally, and metabolically”.¹⁴

Ranken Jordan’s staff includes well-trained pediatric specialists, Pediatric Advanced Life Support (PALS) certified nurses and allied health professionals experienced in managing the needs of patients with complex medical conditions. Ranken Jordan’s team of physician specialists, include experts in pediatrics, internal medicine, physical medicine and rehabilitation (physiatry), orthopedics and child and adolescent psychiatry.

Principal Function

Medically Complex Children (MCC) are children fighting to live with the rarest and most severe, functionally limiting, complicated, and life-threatening health problems of the pediatric population.¹⁵ These “medically extreme catastrophic patients” are who Ranken Jordan cares for. As a specialty pediatric hospital Ranken Jordan has been granted substantive waivers by the Missouri Department of Health and Senior Services from compliance with material hospital licensure requirements governing the establishment and operation of an emergency department, and b) the provision of pathology, radiology, laboratory, and central services. Such designation sets Ranken Jordan apart from other inpatient pediatric acute care facilities and allows them to focus solely on treating the most medically complex children. With an estimated prevalence of 0.4% of children with special health care needs (CSHCN)¹⁶ this small sub-set of children is one of the fastest growing populations. Increasing prevalence of MCCs is likely attributed to increased survival rates of infants born prematurely, those born with congenital anomalies, those with chronic conditions, and improved treatments for acute illnesses in fields such as intensive care and oncology.¹⁷ Growth in survivorship, while medical successes, has resulted in rising rates of complications and childhood disability.

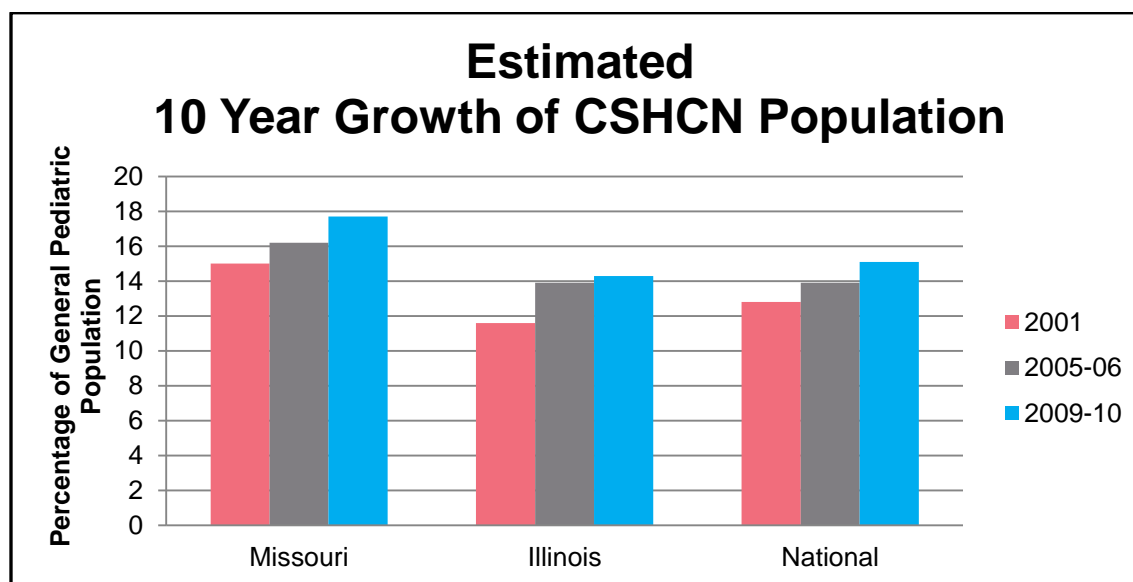
¹⁴ *Id.*

¹⁵ Berry, Jay G. “What Children with Medical Complexity, Their Families, and Healthcare Providers Deserve from an Ideal Healthcare System”. *Lucile Packard Foundation for Children’s Health*. Briefing Paper. 2015. Web. 29 June 2015. < <http://www.lpfch.org/publication/what-children-medical-complexity-their-families-and-healthcare-providers-deserve-ideal>>.

¹⁶ Bruce-Barrett, C., Cohen, E., Friedman, J., Nicholas, D., and Adams, S. (2007). *Saunders Care: The Complex Care Navigation Program*. Toronto, Ontario: Hospital for Sick Children.

¹⁷ *Id.*

10 Year Growth of Children with Special Health Care Needs



Source: National Survey of Children with Special Health Care Needs
<<http://www.childhealthdata.org/learn/NS-CSHCN>>.

It is suspected the MCCs account for as much as one-third of pediatric health care spending, consuming 56 times as many health resources as healthy children.¹⁸ MCCs have high rates of emergency department utilization, the proclivity for frequent readmission, long lengths of stay, and poor care coordination.¹⁹ In children's hospitals, MCCs account for approximately 55% of hospital cost for all admission and 85% of cost for 30-day unplanned hospital readmissions.²⁰

While awareness of and focus on MCCs is gaining traction, there are considerable inconsistencies in the way these children are defined, with no single widely recognized or adopted definition of 'medically complex child' in research literature.²¹ The umbrella of 'medically complex child' used to identify children who²²:

- Have chronic disorders associated with high care needs and a high potential for significant comorbidities.
- Usually have multisystem disorders.
- Have disorders that are frequently individually rare.
- Typically require special medication and/or technologies.
- Have needs that can be unpredictable due to the instability of their condition.

¹⁸ Id.

¹⁹ Id.

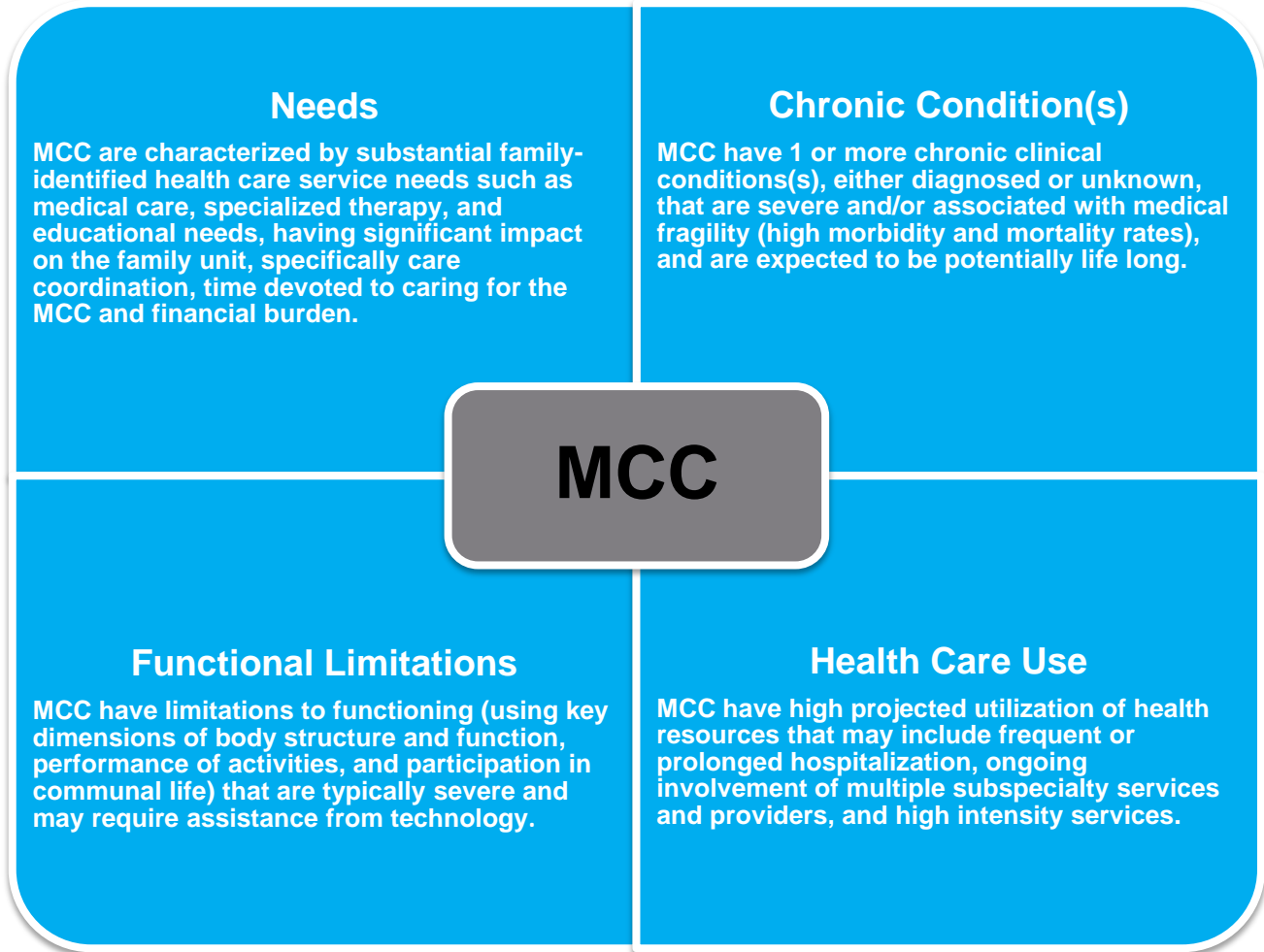
²⁰ Supra, note 17.

²¹ Supra, note 16.

²² Rosenbaum, MD, P. "Report of the Paediatric Complex Care Coordination Expert Panel." 5 Jan 2013
<<http://www.pcmch.on.ca/LinkClick.aspx?fileticket=e3SaxcMZ8w0%3D&tabid=93>>.

- Require care from highly knowledgeable providers.

Ranken Jordan has adopted definitional framework by Cohen et al²³ to identify medically complex children. This framework is based on four domains²⁴:



Representative diagnoses of children with medically complex conditions include: chronic lung disease, genetic disorders, complications of prematurity, congenital heart disorders, cerebral palsy, neurologic, orthopedic and respiratory conditions, post-acute burn treatment, HIV/AIDS, feeding or metabolic disorders, spina bifida, traumatic brain injury, coma recovery, sickle cell disease, short bowel syndrome and congenital anatomical malformations. These diagnoses are often accompanied by one or several comorbidities, and many also present with some form of developmental delays and intellectual disabilities.

²³ Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. "A National Profile of Caregiver Challenges Among More Medically Complex Children With Special Health Care Needs". *Arch Pediatr Adolesc Med.* 2011;165(11):1020-1026. doi:10.1001/archpediatrics.2011.172. 4 June 13 <<http://archpedi.jamanetwork.com/article.aspx?articleid=1107633>>.

²⁴ *Id.*

Common diagnoses of Ranken Jordan patients include:

Infants & Toddlers	Preschool, School-Age Children	Teens & Young Adults
<ul style="list-style-type: none">• Complications from prematurity• Short bowel syndrome• Developmental delay• Congenital abnormalities of the brain, airway, heart, GI or GU tract• Failure to thrive and feeding disorders• Neonatal abstinence• Complications of abuse or neglect	<ul style="list-style-type: none">• Complications from severe illness or prolonged hospitalization• Osteomyelitis• Neuromuscular disorders, muscular dystrophy• Orthopedic or CNS injuries• Metabolic disorders• Burns and other wounds	<ul style="list-style-type: none">• Traumatic brain injury• Myelomeningocele, spina bifida• Cerebral palsy• Spinal cord injury

Source: Ranken Jordan – A Pediatric Specialty Hospital <rankenjordan.org>.

“Caregiving for a medically complex child can be a very reqrding, yet herculean, strenuous, stressful, and time-consuming task”.²⁵ Caregivers of medically complex children report both a higher number of hours spent per week coordinating care for their MCC and hours spent providing direct home care per week. Families of MCCs also report higher rates of health care related financial problems and interference with their ability to maintain employment, higher number of physician visits, school days missed, and variable health care needs of their child as well as difficulties in navigating and obtaining medical and nonmedical services.²⁶

²⁵ Supra, note 16.

²⁶ *Id.*

Missouri, Illinois, and National Demographics and Socioeconomic Profile of Children with Special Health Care Needs

	Missouri	Illinois	United States
Percent of CSHCN:	17.7%	14.3%	15.1%
Estimated Number of CSHCN	252,734	452,574	11,203,616
Percent of CSHCN who are medically complex²⁷:	0.4%	0.4%	0.4%
Ranken Jordan's Estimate - Number of Medically Complex Children	1,011	1,810	44,814
Prevalence of CSHCN by Category:	State %	State %	National %
Age			
0-5 years	11.4	9.2	9.3
6-11 years	21.9	16.3	17.7
12-17 years	20.0	17.4	18.4
Sex			
Male	19.9	16.2	17.4
Female	15.5	12.3	12.7
Race			
White, non-Hispanic	73.8	57.7	59.3
African-American	16.1	18.7	16.1
Hispanic/Latino	3.9	18.0	16.8
Other	6.2	5.6	7.8
Poverty Level based on Household Income			
0-99% of Federal Poverty Level	18.4	13.1	16.0
100-199% of Federal Poverty Level	21.0	16.5	51.4
200-399% of Federal Poverty Level	15.4	14.1	14.5
Education Level of Parents			
Less than High School	7.8	9.0	9.6
High School Graduate	21.8	18.6	20.5
More than High School	70.4	72.3	69.9
Family Structure			
Two parent family – biological or adoptive	54.1	55.7	56.9
Two parent family – at least one step parent	9.4	7.3	9.6
Mother only	29.5	30.4	25.7
All other family structures	7.1	6.6	7.8
Health Insurance			
Insured at time of survey	97.7	98.8	96.5
Not insured at time of survey	3.5	1.2	3.5

Source: National Survey of Children with Special Health Care Needs <<http://www.childhealthdata.org/learn/NS-CSHCN>>.

Note: Percentages are weighted to population characteristics.

²⁷ See supra note 4.

Purpose

Ranken Jordan is committed to being a leader in providing intensive transitional care and living support for children with complex medical conditions and their families and works to distinguish itself by its expertise, service, high quality and safe patient care, communication, coordination, innovation and relationship building. Through this commitment, Ranken Jordan actively assesses the health needs of the community it serves through its inclusive multi-disciplinary team care delivery model, and attunes its offered programs and services to those needs.

Recently enacted healthcare reform legislation, The Patient Protection and Affordable Care Act (PPACA), requires non-profit hospital organization to conduct a CHNA once every three taxable years, and to adopt an implementation strategy to address the community's health needs identified through the assessment process. These non-profit hospitals are required to document their CHNA in a written report that includes:

- A description of the community served by the hospital facility and how that community was determined;
- A description of the process and methods used to conduct the assessment;
- A description of how the hospital took into account input from persons who represent the broad interests of the community served;
- A prioritized description of all of the community health needs identified through the CHNA, as well as a description of the process and criteria used in prioritizing such health needs;
- A description of the existing health care facilities and other resources within the community available to meet the community health needs identified through the CHNA.

The CHNA has been completed to continue Ranken Jordan's commitment to being a leader in providing care for medically complicated children and their families, to meet the requirements as set forth by healthcare reform legislation, and to formalize the health needs assessment process engrained in its care delivery model. This CHNA will serve as a guide for planning and development of an implementation plan.

Process and Methods

The very nature of Ranken Jordan’s care delivery model is centered on continual needs assessment of our patients and their families. In order to enhance our already extensive understanding of the needs of the patients and to meet regulatory requirements Ranken Jordan initiated a process to conduct a CHNA beginning in 2012 which identified quality of life as the most prevalent need of our community. Quality of life for medically complex children and their families goes beyond the specialists, medications and technologies to things such as socialization, community engagement, and family.

While conducting our current needs assessment we found that quality of life continues to be the predominant for our community. Ranken Jordan has elected to remain focused on ways to improve quality of life through enhancement of established programs and services and the creation of new opportunities.

QUALITY OF LIFE

- Community Programming
- Navigation of Health Resources
- Caregiver Support Services

This 2016 CHNA is comprised of both quantitative and qualitative data components to refine how Ranken Jordan address this need.

- **Internal Focus Group** – comprised healthcare providers with expertise in the care for medically complex children.
- **Patient and Family Advisor Council** – comprised on 8 community members and 3 facilitators to make recommendations to Ranken Jordan regarding patient care.
- **One on One Interview** – numerous internal and external resources.
- **Community Programming Surveys** – of community participants in Ranken Jordan’s programming.

- **Community Member Surveys** – of community members regarding current services and potential opportunities.

In addition, input representing the broad interest of the community was gathered from Ranken Jordan’s community partners:

- Challenger Baseball
- Recreation Council of Greater St. Louis
- Pattonville School District
- Special School District
- St. Louis Society For the Physically Disabled
- St. Louis ARC
- Missouri Conservation Department
- Down Syndrome Association of Greater St. Louis
- Hidden Valley Ski Resort
- DASA (Disabled Association Special Athletes)
- Maryland Heights Parks & Recreation
- Special Olympics
- Variety
- SPENSA
- St. Louis County Library
- St. Louis Art Museum
- Parents as Teacher

As was present throughout the data collection process for the 2013 CHNA, there are still limitations in completing a needs assessment for the community. While medically complex children are gaining traction and attention as a population, true research into this population is still in its infancy stages. In general available literature seeks to introduce what a medically complex child is and stress their exorbitant consumption of healthcare dollars. Resources that are available remain inconsistent as to how to specifically classify these children, and the heavily relied upon National Study of Children with Special Health Care Needs was not originally designed to focus on high medical complexity and is quickly aging.²⁸

²⁸ See supra note 9.

Health Care Resources: The St. Louis Region offers various health services: throughout the geographic area. The following is a sampling of those resources that may be available for medically complex children.

- Alton Memorial Hospital
- Arnold Urgent Care
- Barnes West Primary Care
- Barnes-Jewish Hospital
- Belleville Pediatrics
- Blue Fish Pediatrics
- Brentwood Pediatrics
- Center Pointe Urgent
- Centre Point Hospital
- Children's Clinic
- Christian Hospital
- Concentra Urgent Cares
- Downtown Urgent Care
- Family Care at Christian Hospital
- Fast Track Urgent Care
- Fenton Pediatrics
- Forest Park Pediatrics
- Hampton Village Pediatrics
- Horizon Pediatrics
- Kids Docs
- Lemay Urgent Care Center
- Memorial Hospital
- Mercy Clinics Pediatrics
- Mercy Hospital St. Louis
- Mid Rivers Family Physicians
- Missouri Baptist Medical Center
- O'Fallon Convenient Care
- O'Fallon Family Medicine
- Orthopedic Urgent Care
- Our Urgent Care
- Overland Urgent Care
- People's Health Center
- Preferred Pediatrics
- Saint Louis University Hospital
- Shriners Hospitals for Children
- Smiley Urgent Care Center
- South County Urgent Care
- South County Pediatrics
- SSM Cardinal Glennon Children's Medical Center
- St. Anthony's Fenton Urgent Care
- St. Anthony's Medical Center
- St. Clair Pediatrics
- St. Elizabeth's Hospital
- St. Louis Children's Hospital
- St. Louis Primary Care Associates
- St. Luke's Pediatric Care Center
- St. Luke's Urgent Care
- Total Access Urgent Care

Primary Data

Patient Family Advisory Council

Background: In January 2013, Ranken Jordan founded its Patient and Family Advisory Council (PFAC). Consisting of staff, present and former patients and family members, PFAC's original vision was to be a transformational force in the evolution and advancement of patient and family-centered care in pediatrics, maximizing outcomes for patients and families through collaboration and teamwork. In 2015, PFAC undertook a process to revitalize the council and ensure it was attaining what the original founders envisioned.

New energy and focus was brought to the council who set about redefining the mission and vision of the group. PFAC also works to create a patient and family-centered environment which promotes the best possible medical and emotional outcomes for Ranken Jordan patients and family members. Goals of PFAC include:

- Enhance communication between patients, family members, and the Ranken Jordan team.
- Empower patients, family members and staff through continuous education
- Identify and address patient and family needs in all aspects (body, mind, and spirit) throughout their Ranken Jordan journey and during the transition home.
- Promote the best possible medical and emotional outcomes for patients and family members.

Initially meeting bi-monthly, PFAC is scheduled to meet once a month for approximately 2 hours. Participation is voluntary.

PFAC: Meeting on a monthly basis, PFAC connects current and former patients from Ranken Jordan. At meetings, participants are given a platform to express struggles, concerns, highs and lows of being a medically complex patient or family member. Because of this organic opportunity for conversation, PFAC

Mission:

- To be organized for the sole purpose of making recommendations to Ranken Jordan Pediatric Bridge Hospital's health care team to enhance their ability to deliver the highest standard of safe, comprehensive, and compassionate care.

Vision:

- To ensure that every patient and family Ranken Jordan Pediatric Bridge Hospital services has a positive experience which will help them bridge to the next stage of healing.

meetings are an excellent source of information for the needs assessment. Two staff liaisons, a registered nurse and a social worker, are present at meetings. These staff liaisons work to identify themes of needs identified by council members, guide meetings if and when they become emotionally charged, and provide feedback to Ranken Jordan's leadership.

Several needs were discussed including the best time to approach patients and caregivers with a satisfaction survey and helping to hone in on the best time in which to have initial care conferences for patients and caregivers. The major focus of the council has centered on caregiver support with members expressing the difficulty finding and connecting to others with similar diagnosis and began crafting an idea for a mentorship program. The premise of the mentor program would go beyond simply a surface connection of one MCC caregiver to another but aligning mentors with others in similar situations or diagnoses.

Identified Need:

- Caregiver Support

Internal Focus Group

Background: In April 2013, PFAC was resourced to facilitate a focus group for the 2013 CHNA. In total, 8 community persons participated. Discussion was held in an organic conversational setting. A staff facilitator prompted the focus group with the broad question of "what do members of this community need" and allowed the group to discuss thoughts and opinions on the matter. Ultimately the focus group identified several needs that fall into the overarching category of 'quality of life'.

Because of the quality of information gleaned from the 2013 focus group the decision was made to again resource this particular research tool.

Focus Group:

In April 2016, Ranken Jordan conducted an internal focus group to solicit feedback on the needs of medically complex children. Participants were specifically recruited because of their similarity of interactions with medically complex children and their caregivers. The group was capped at no more than 10 participants and held in a comfortable setting to encourage open and frank discussion. Ultimately, nine individuals participated in the focus group which was moderated by graduate student from St. Louis University's College of Public Health and Social Justice.

Participants were asked to discuss two predetermined questions, one question to address needs of the community in a broad sense and a follow up questions centered on caregiver support issues.

1. What are the top challenges that medically complex children face?
2. We have identified health literacy and smoking as two challenges parents in our community face. In what ways can Ranken Jordan address these issues?

Drawing on their combined experience of over thirty years working with medically complex children, participants discussed several challenges faced by the community. Those challenges included:

- Accessibility
- Medical coverage for equipment
- Integration into the outside community
- Supportive service beyond therapy
- Sibling involvement

Once discussion on the umbrella topic concluded participants we asked to consider and discuss two specific caregiver issues. In response to health literacy, thoughts concentrated on how to better facilitate communication between physicians and the community, utilizing therapy as a conduit. For medically complex children and their caregivers at Ranken Jordan their capacity to obtain, process and understand health information and services needed to make appropriate decisions is a multi-faceted issue. A significant number of Ranken Jordan's patients and caregivers are low income and a low level of education. These difficulties coupled with the enormous amount of information they must master with regard to their or their child's diagnosis is massive undertaking. Highlights of participant discussion include:

- Follow up with patients and caregivers post specialist appointments to address concerns
- More frequent communication with physicians to improve parent understandings of medical records, forms, etc.

With much emphasis on the dangers of smoking, Ranken Jordan is sensitive to this issue. Smoking is used as a coping mechanism for the MCC population. However, the respiratory status of a patient may necessitate changes in smoking habits of the patient, their caregiver or both. In response to issue, participants talked through the prevalence of smoking in Ranken Jordan's community and ways in which to provide support for those striving and/or needing to make a change such as offering smoking cessation

Participants:

- Inpatient Physical Therapists
- Outpatient Physical Therapists
- Infection Preventionist
- Physical therapy assistant
- Physical Therapy Clinical Coordinator

classes, providing education from physicians to review the risks of smoking and connecting them with outside resources.

Identified Need:

- Community Programming
- Caregiver Support

One on One Discussions

Background: Ranken Jordan’s care delivery model is built on a multidisciplinary care team working with and continually assessing the needs of medically complex children. This needs assessment process occurs at the bedside, in the swimming pool, in the family lounge, on the playground, at a high school football game, in a care conference and countless other places and opportunities. While the assessment might not always take a formalized approach, identified needs are taken very seriously. Without constant communication, brain storming, discussion, and exploration into what a medically complex child needs Ranken Jordan would cease to be Ranken Jordan.

Needs assessment doesn’t just happen between direct care providers and members of the community but also at the leadership levels through networking, creating, and advocating for, on behalf of and with medically complex children and their families.

Discussions: Leadership from Ranken Jordan solicited input through meetings, telephone conversations, tours of our facility. These discussions link Ranken Jordan with representatives from other children’s hospitals, but representatives in the political landscape as well. Significant portions of time were dedicated to networking with resources addressing various facets of the MCC world to gain knowledge in what approaches are working and what needs are have been identified.

Discussions completed by care providers are Ranken Jordan are extremely important and they are the best opportunity for medically complex children to speak for themselves. Because of their extensive knowledge

Multidisciplinary Team:

- Pediatric nurse practitioners
- Recreational therapists
- Child life specialists
- Speech-language therapists
- Social workers
- Nurses and CNAs
- Physical therapists
- Pediatric pharmacists
- Occupational therapists
- Respiratory therapists
- Dietitians
- A music therapist
- Care coordinators
- Chaplain
- School liaison
- Patient transportation

and familiarity with this population, care providers are able to give medically complex children the opportunity to communicate their needs through non-traditional channels. As was seen in the 2013 CHNA process and daily care at Ranken Jordan medically complex children just want to be a child.

Identified Need:

- Community Programming
- Navigation of Health Resources
- Caregiver Support

Community Program Participant Survey

Background: Historically, Ranken Jordan provided respite care to families with medically complex children. Through this program, Ranken Jordan offered families time to have their children cared for by trained professionals to provide caregivers much needed time away from overwhelming care demand and concerns. As the program grew, Ranken Jordan recognized the opportunity to transition its respite program, which allowed families one 24 hour period of respite per year, to a community program, giving families several shorter periods of respite spread through the year. Not only does the community programming work towards the goal of mental health and wellbeing for caregivers, it is also focused on creating a social networking for MCCs. Community programs are open to Ranken Jordan patients, MCCs in the St. Louis Region, and children of all abilities.

During the 2013 CHNA process, surveys were distributed for participants at the end of each community program event. These surveys are used to gather data regarding if the event met expectations, suggestions for future events, and overall satisfaction with the event itself. In total, 115 surveys were collected during the 2013 CHNA process

Participant Surveys: For the 2016 CHNA process, Ranken Jordan continued to disseminate surveys to

From July 2013 through June 2016:

- 126 community programs
- Over 150 participant surveys returned

Activities include:

- Music Mania
- Family Night
- Self-Development Classes
- Challenger Baseball
- Cooking Classes
- Movie Nights
- Fitness Classes

participants of community programs. These surveys are the same format as the 2013 CHNA survey, and are used to make immediate changes to our community programming as well as establish future programs.

Area of Opportunity:

- Community Programming
- Resource Navigation

Community Member Survey

Background: For over ten years Ranken Jordan has utilized surveys as a means of data collection from patients and their caregivers. These patient satisfaction surveys have been used to gage the care given at Ranken Jordan, allowing for identification of what we do really well and opportunities for improvement. Throughout their use various formats have been trialed, whether such surveys were conducted in-house or after discharge, if they were conducted by staff members or a third-party, and whether phone calls or mailed surveys with a pre-stamped and addressed envelope garnered the best response. No matter the format, there are barriers to response. In the last three years, we have begun using a printed survey and either handing them out for completion before the patient and/or caregiver leave the building or mailing them to the patient’s address has the highest return rate.

Surveys: In April 2016, we used our experience with surveying the medically complex community to conduct a survey for this CHNA. A random distribution group of fifty patients was selected and an eight-teen question survey was prepared. The survey contained both questions the focus on the patient experience as well and the caregiver. Twenty-two percent of surveys mailed were returned, keeping in line was the rate of return for our patient satisfaction surveys.

For medically complex children themselves, the results of the survey overwhelmingly indicate a perceived need of friendships and cultivating meaningful skills for the future. For caregivers, results of the survey indicate that health literacy is not a prevalent perceived need. These results contradict needs expressed through one on one interviews with caregivers. The dichotomy between the two responses may be the difficulty in translating health literacy to an easy to complete and comprehend survey. When asked

Please select the top two challenges that you believe your child faces:

- Developing friendships with same cognitive/physical abilities
- Reconnecting with old friends
- Cultivating meaningful skills for the future
- Accepting physical limitations
- Adjusting to a life depending on medical technology.
- Having an adequate support system.

“how often are medication labels easy to understand”, 55% of responses indicated always, while 45% of responses indicated often. However, during one on one interviews confusion surrounding medication administration is common as medically complex children and their caregivers are attempting to manage multiple prescriptions, dosing schedules, interactions and side effects.

Identified Need:

- Community Programming
- Caregiver Support

Identified Need & Prioritization

Members of Ranken Jordan leadership reviewed data collected throughout the 2016 CHNA process. Upon review, the overarching health need of the community is quality of life. Once identified and formally adopted, Ranken Jordan prioritized four initiatives in order to address that need. Two of the initiatives have been brought forward from the 2013 CHNA and one initiative has been added through the current process.

Identified Need

Medically complex children and their families face extraordinarily complex, difficult, and overwhelming health problems on a daily basis. With as many as 15 specialist, countless medications, numerous appointments and the threat of readmission seemingly always lurking, medically complex children and their families want to simply live life.

While topics such as obesity education, diabetes awareness, and asthma training, are valuable and make sense as an offering by health care providers to the general pediatric community, these topics may be a little difficult an on offering to address needs of medically complex children. These children and their families have already been diagnosed with obesity, asthma, diabetes, and a host of other clinical issues.

Initiatives: Ranken Jordan formalized three initiatives in order to address 'quality of life' for its community. These initiatives were weighted with the following factors:

- Impact of the initiative
- Consequences of not addressing the initiative.
- Existing resources.
- Specific requests made by the community.

Based on the conclusions of the CHNA conducted, Ranken Jordan identified 'quality of life' as the overarching unmet need for its pediatric medically complex community.

To provide quality life for its community, Ranken Jordan has committed to the following initiatives:

1. Community Programming
2. Health Resources Navigation
3. Caregiver Support

INITIATIVE: Community Programs

Objective 1: Increase availability of community programming events

- Expand Ranken Jordan's existing community programming.
- Collaborate with community partners to develop and promote events.
- Offer quarterly socialization opportunities at Ranken Jordan and various locations.

Objective 2: Increase vocational skills for older medically complex children

- Expand Ranken Jordan's therapy group program aimed at developing job skills and résumé building.
- Create and offer volunteer positions within Ranken Jordan based on vocational skills.
- Promote awareness and education to the local business community, with the aim of building workplace opportunities for medically complex children.

Objective 3: Increase communication throughout the community

- Create and disseminate a newsletter throughout the community to be a voice for the medically complex community.
- Create a web presence specifically dedicated to community programming.
- Collaborate with community partners to advertise, promote, and encourage participation in offered events.

INITIATIVE: Navigation of Health Resources

Objective 1: Provide care coordination assistance

- Provide support and assistance with access to existing community resources.
- Promote awareness and caregiver education of existing community resources.
- Provide care coordination to medically complex children living in the home and in need of services.
- Increase autonomy for caregivers of medically complex children.

INITIATIVE: Caregiver Support

Objective 1: Smoking Cessation

- Provide educational resources regarding smoking cessation
- Promote awareness of the risks of smoking
- Provide connection with community resources for smoking cessation

Objective 2: Respite Space

- Provide support for caregivers through a dedicated space allowing for decompression and stress relief for mental health reasons
- Promote utilization of the room by caregivers