

Ranken Jordan – A Pediatric Specialty Hospital

Community Health Needs Assessment
& Implementation Plan

June 2013



Ranken Jordan
A Pediatric Specialty Hospital.

Introduction

Ranken Jordan – A Pediatric Specialty 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—A Pediatric Specialty 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



Executive Summary

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

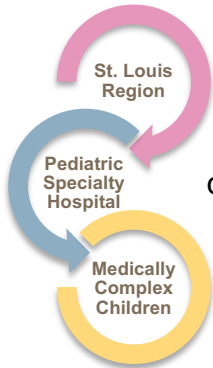
When defined by children in this population, a medically complex child is simply a child. A child with needs centered on socialization, development, and play.

Community Health Needs Assessment: In 2012, Ranken Jordan initiated its formal community health needs assessment (CHNA) with a purpose of identifying the health needs of its target population. As a specialty pediatric hospital, treating only the most medically complex children, Ranken Jordan relies on continual assessment in order to deliver effective care. This CHNA process sought to expand pre-established means of data collection from members of the community.

Based on CHNA findings, medically complex children and their families need 'quality of life'. The children and families who comprise the community as defined by Ranken Jordan identify needs that allow them to feel like children, to move beyond the qualifier of medically complex, and enjoy life.

Implementation Plan: In order to address 'quality of life' for medically complex children and their families, Ranken Jordan will expand its existing community programming and engage the community. Strategies to accomplish this goal include providing support, information, creating opportunities for socialization, promoting integration, and solidifying a community network.

Community Overview



For purposes of this CHNA, Ranken Jordan defines “community” as medically complex children and families in the St. Louis Region. This definition is based upon the geographic region in which Ranken Jordan is located, and the patient population treated by the hospital as Ranken Jordan exclusively treats children with complex medical needs.

Geographic Region: 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. Located in Maryland Heights, Missouri, Ranken Jordan treats patients from across Missouri and Illinois. Within this two state region, the primary service area is St. Louis County and the neighboring counties of St. Louis City, St. Charles, Franklin, Jefferson, Madison, and St. Clair (Collectively referred to in this report as ‘St. Louis Region’). This primary service area for Ranken Jordan includes the following zip Codes:

Table 1. Primary Service Area Zip Codes Served

MISSOURI			
County	Zip Code	County	Zip Code
Franklin	63014	St. Louis	63074
Franklin	63015	St. Louis	63088
Franklin	63039	St. Louis	63114
Franklin	63056	St. Louis	63117
Franklin	63060	St. Louis	63119
Franklin	63068	St. Louis	63121
Franklin	63069	St. Louis	63122
Franklin	63077	St. Louis	63123
Franklin	63080	St. Louis	63124
Franklin	63084	St. Louis	63125
Franklin	63089	St. Louis	63126
Franklin	63090	St. Louis	63127
Jefferson	63010	St. Louis	63128
Jefferson	63016	St. Louis	63129
Jefferson	63020	St. Louis	63130
Jefferson	63028	St. Louis	63131
Jefferson	63041	St. Louis	63132

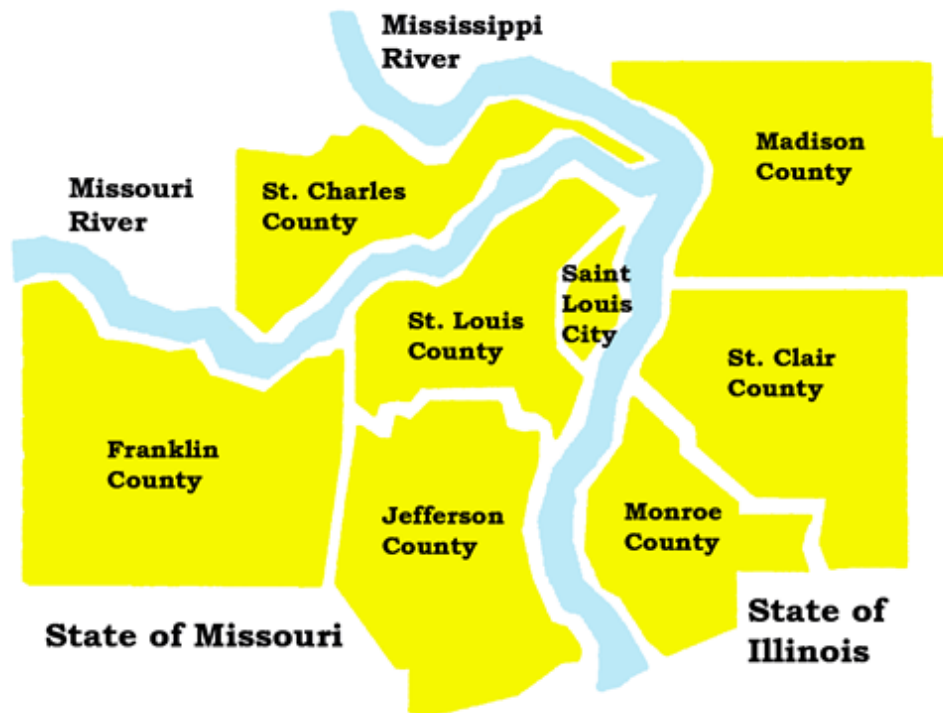
Jefferson	63048	St. Louis	63133
Jefferson	63049	St. Louis	63134
Jefferson	63050	St. Louis	63135
Jefferson	63051	St. Louis	63136
Jefferson	63052	St. Louis	63137
Jefferson	63065	St. Louis	63138
Jefferson	63070	St. Louis	63140
St. Charles	63301	St. Louis	63141
St. Charles	63303	St. Louis	63143
St. Charles	63304	St. Louis	63144
St. Charles	63341	St. Louis	63146
St. Charles	63348	St. Louis City	63101
St. Charles	63366	St. Louis City	63102
St. Charles	63367	St. Louis City	63103
St. Charles	63368	St. Louis City	63104
St. Charles	63376	St. Louis City	63106
St. Charles	63385	St. Louis City	63107
St. Louis	63005	St. Louis City	63108
St. Louis	63011	St. Louis City	63109
St. Louis	63017	St. Louis City	63110
St. Louis	63021	St. Louis City	63111
St. Louis	63025	St. Louis City	63112
St. Louis	63026	St. Louis City	63113
St. Louis	63031	St. Louis City	63115
St. Louis	63033	St. Louis City	63116
St. Louis	63034	St. Louis City	63118
St. Louis	63038	St. Louis City	63120
St. Louis	63042	St. Louis City	63139
St. Louis	63043	St. Louis City	63147
St. Louis	63044	St. Louis City	63177

ILLINOIS

County	Zip Code	County	Zip Code
Madison	62002	St. Clair	62201
Madison	62010	St. Clair	62203
Madison	62018	St. Clair	62204
Madison	62021	St. Clair	62205
Madison	62024	St. Clair	62206
Madison	62025	St. Clair	62207
Madison	62034	St. Clair	62208
Madison	62035	St. Clair	62220
Madison	62040	St. Clair	62221
Madison	62046	St. Clair	62223

Madison	62048	St. Clair	62225
Madison	62061	St. Clair	62226
Madison	62062	St. Clair	62239
Madison	62084	St. Clair	62240
Madison	62095	St. Clair	62243
Madison	62234	St. Clair	62258
Madison	62294	St. Clair	62260
St. Clair	62059	St. Clair	62269

Below is a map¹ of the St. Louis Region.



Source: St. Louis City Recorder <<http://www.stlouiscityrecorder.org/areacounties.html>>.

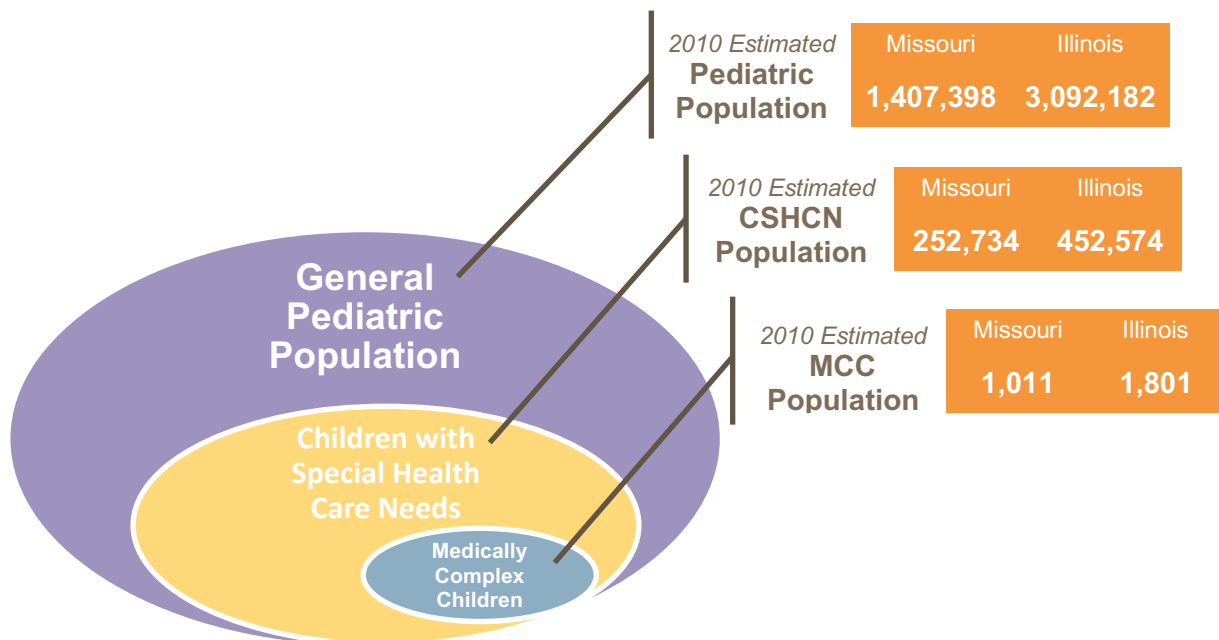
Principal Function and Target Population: For purposes of this CHNA, Ranken Jordan further refined its definition of community served by taking into account its principal function as a specialty hospital its target population of medically complex children.

Ranken Jordan is recognized as a specialty hospital, meaning it has been granted substantive waivers by the Missouri Department of Health and Senior Services from

¹ "Websites for St. Louis Area Counties, State of Missouri, and State of Illinois." Websites for St. Louis Area Counties, State of Missouri, and State of Illinois. 4 April 2013 <<http://www.stlouiscityrecorder.org/areacounties.html>>.

establishing and operating an emergency department, waivers as they relate to the provision of pathology, radiology, laboratory, and central services, and is not licensed to operate more than sixty (60) beds. This designation as a specialty hospital allows Ranken Jordan to deliver non-duplicative and cost saving care.

The children who come to Ranken Jordan are among the most seriously ill and injured. Neff et al² published a study identifying medically complex children, those children who comprise Ranken Jordan’s patient population, as “medically extreme catastrophic patients”³ and estimates that this very small subset of the general pediatric population represents 0.4% of children with special health care needs (CSHCN).⁴ This medically complex sub-set of children consume 56 times as many health resources as healthy children, have a high risk of repeated hospitalizations and experience poor care coordination.⁵



Source: U.S. Census 2010 < <http://www.census.gov/>>.^{6,7}
 Source: National Survey of Children with Special Health Care Needs <<http://www.childhealthdata.org/learn/NS-CSHCN>>.^{8,9}

² Neff JM, Sharp VL, Muldoon J, Graham J, Myers K. *Profile of Medical Charges for Children by Health Status Group and Severity Level in a Washington State Health Plan*. Health Serv Res. 2004;39(1):73– 89

³ *Id.*

⁴ *Id.*

⁵ 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.

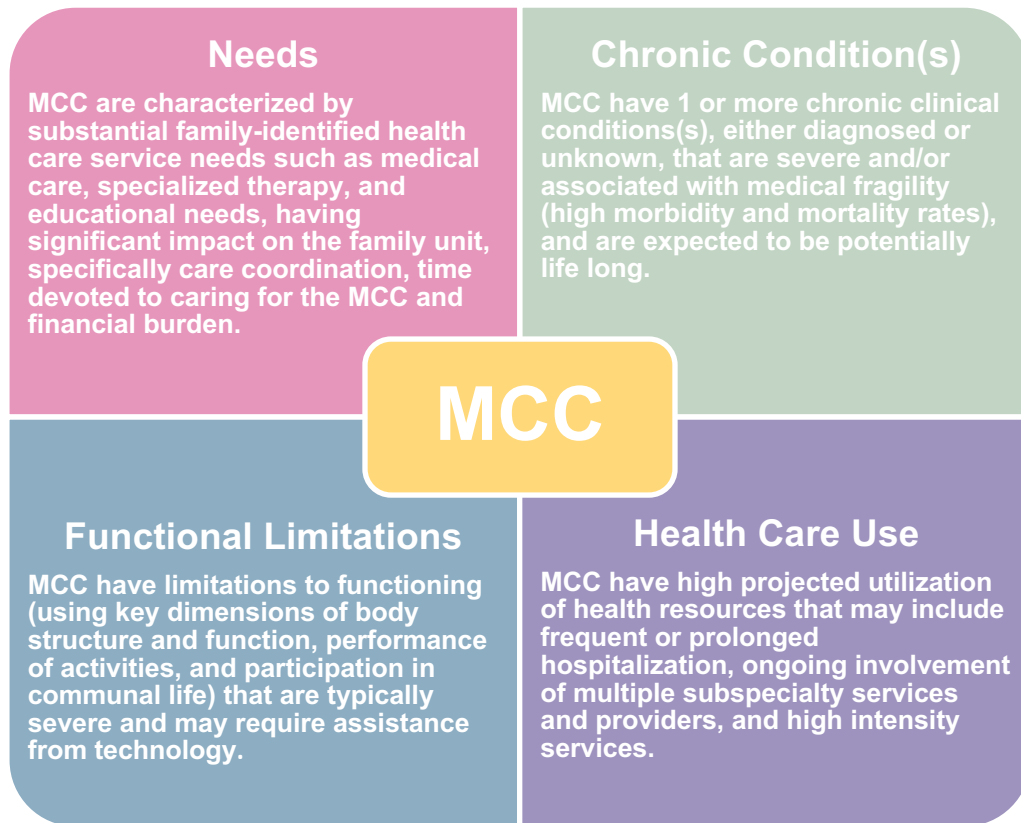
⁶ U.S. Census Bureau. (2010). *State and County Quickfacts*. “Missouri” 4 April 2013 <<http://quickfacts.census.gov/qfd/states/29000.html>>.

⁷ U.S. Census Bureau. (2010). *State and County Quickfacts*. “Illinois” 4 April 2013 <<http://quickfacts.census.gov/qfd/states/17000.html>>.

⁸ U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2009–2010*. 12 Jan 2013 <<http://www.childhealthdata.org/browse/snapshots/cshcn-profiles?rpt=9&geo=1>>.

Note: The estimate of the MCC population for both Missouri and Illinois is Ranken Jordan’s application of the 0.4% to the CSHCN population estimate by the National Survey of Children with Special Health Care Needs.

Despite increased awareness and focus on medically complex children, there are considerable inconsistencies in the way these children are defined, with no single widely recognized or adopted definition of ‘medically complex child’. Ranken Jordan looks to the definitional framework by Cohen et al¹⁰ which identifies medically complex children based on 4 broad domains¹¹:



Source: “Children with Medical Complexity: An Emerging Population for Clinical and Research Initiatives” <<http://pediatrics.aappublications.org/content/127/3/529.full.pdf>>.

Common identifiers of this community are children having chronic and often multisystem disorders, disorders that are frequently individually rare, typically require numerous medications and/or are technology dependent, regularly have complex emotional and

⁹ U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (2008). *The National Survey of Children with Special Health Care Needs Chartbook 2009–2010*. 12 Jan 2013 <<http://www.childhealthdata.org/browse/snapshots/cshcn-profiles?rpt=9&geo=15>>.

¹⁰ 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>>.

¹¹ *Id.*

social issues, are medically fragile, have needs that can be unpredictable due to the instability of their condition(s)¹².

Common conditions 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>.

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:

¹² 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>>.

- 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

The very nature of the Ranken Jordan’s care delivery model has embedded within it a continual process of health needs assessment for the community it serves. Ranken Jordan initiated a process to conduct its first formalized CHNA beginning in 2012 and continuing into 2013. The CHNA is designed to identify needs for and barriers to health and health services, through a process of research, analysis and prioritization. The needs identified through this CHNA process align with the needs Ranken Jordan works to address for patients and families every day.

**QUALITY
OF LIFE**

- *Community Programming*
- *Navigation of Health Resources*

This CHNA is comprised of both quantitative and qualitative data components.

- **Secondary Statistical Data Profile** – depicting demographic and socioeconomic measures, health indicators, and other statistics for the defined community. This data was retrieved from several publicly available resources.
- **Focus Group** – facilitated through Ranken Jordan’s Patient and Family Advisory Council, a focus group was held in April 2013. Comprised of 8 community members, the focus group discussed and identified needs of medically complex children and their families.
- **Needs Assessment Action Group** – of persons familiar with providing care the defined community to discuss and identify needs of medically complex children and their families.
- **Surveys** – of community participants in Ranken Jordan’s programming.

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

Throughout the data collection process, several limitations were identified. In general, medically complex children are a subset of the pediatric population that has yet to be studied and classified extensively. Resources that are available are inconsistent regarding definition of classification of these children, while other data elements are simply unavailable. Significant barriers are present regarding geographic based data, and where available its limited to state level estimates. Due to increased awareness of this high-cost, high-need population, improved data resources are expected for future CHNA processes.¹³

¹³ See *supra* note 9.

The National Study of Children with Special Health Care Needs was not originally designed to focus on high medical complexity and lacks related clinical information and health care use information that may help capture more medically complex children.¹⁴ Additionally, nonmedical service need is characterized as a single question, preventing identification of specific community-based services that may be particularly lacking and there is no external validation of study responses.¹⁵

Demographic & Socioeconomic Profile

Bi-State Area

Ranken Jordan treats patients from across Missouri and Illinois. Demographic and socioeconomic statistics of both states are consistent with those found across the United States. The data provided in the chart below, including age, racial composition, median income, households below poverty level, and educational level, was obtained from the US Census Bureau, based on census data from 2010.

Table 2: State and National Demographic and Socioeconomic Data

	Missouri ¹⁶	Illinois ¹⁷	United States ¹⁸
Population, 2012 Estimate	6,021,988	12,875,255	313,914,040
	<i>State %</i>	<i>State %</i>	<i>National %</i>
Age – 2011 Estimate			
Persons under 5 years	6.4	6.4	6.5
Persons under 18 years	23.5	24.1	23.7
Persons over 65 years	14.2	12.7	13.3
Sex – 2011 Estimate			
Male	49.0	49.1	49.2
Female	51.0	50.9	50.8
Race – 2011 Estimate			
White	84.0	78.0	78.1
Black	11.7	14.8	13.1
Hispanic/Latino	3.7	4.8	16.7
Asian	1.7	4.8	5.0
Two or more races	1.9	1.7	2.3
Financial (2007-2011)			
Median Income	\$47,202	\$56,576	\$52,762

¹⁴ See *supra* note 9.

¹⁵ See *supra* note 9.

¹⁶ U.S. Census Bureau. (2010). *State and County Quickfacts*. “Missouri” 4 April 2013 <<http://quickfacts.census.gov/qfd/states/29000.html>>.

¹⁷ U.S. Census Bureau. (2010). *State and County Quickfacts*. “Illinois” 4 April 2013 <<http://quickfacts.census.gov/qfd/states/17000.html>>.

¹⁸ U.S. Census Bureau. (2010). *State and County Quickfacts*. “USA” 4 April 2013 <<http://quickfacts.census.gov/qfd/states/00000.html>>.

Persons below Federal Poverty Level	14.3	13.1	14.3
Education Level (2007-2011)			
High school graduate or higher – persons over 25	86.8	86.6	85.4
Bachelor degree or higher – persons over 25	25.4	30.7	28.2
Language (2007-2011)			
Language other than English spoken at home	6.1	22.0	20.3
Geography - 2010			
Land in square miles	68,741.52	55,518.93	531,905.43
Population Density – 2010 Estimate			
Persons per square mile	87.1	231.1	87.4

Source: U.S. Census 2010 < <http://www.census.gov/>>.

Primary Service Area

Ranken Jordan's primary service area consists of 8 counties collectively referred to in this report as the St. Louis Region. The St. Louis Region has an estimated population of 2,042,088 and encompassing 4,374 square miles.

Missouri counties: Franklin, Jefferson, St. Charles, St. Louis and St. Louis City.

Table 3: Missouri Counties Demographic and Socioeconomic Data

Missouri					
	Franklin Co.¹⁹	Jefferson Co.²⁰	St. Charles Co.²¹	St. Louis Co.²²	St. Louis City²³
Population, 2012 Estimate	101,412	220,209	368,666	1,000,438	318,172
	County %	County %	County %	County %	County %
Age – 2011 Estimate					
Persons under 5 years	6.3	6.7	6.5	5.8	6.8
Persons under 18 years	24.3	24.8	25.2	23.0	21.2
Persons over 65 years	14.2	11.5	11.7	15.2	10.9
Sex – 2011 Estimate					
Male	49.6	49.7	49.1	47.3	48.4
Female	50.4	50.3	50.9	52.7	551.6
Race – 2011 Estimate					

¹⁹ U.S. Census Bureau. (2010). State and County Quickfacts. "Franklin County, Missouri" 4 April 2013 <<http://quickfacts.census.gov/qfd/states/29/29071.html>>.

²⁰ U.S. Census Bureau. (2010). State and County Quickfacts. "Jefferson County, Missouri" 4 April 2013 <<http://quickfacts.census.gov/qfd/states/29/29099.html>>.

²¹ U.S. Census Bureau. (2010). State and County Quickfacts. "St. Charles County, Missouri" 4 April 2013 <<http://quickfacts.census.gov/qfd/states/29/29183.html>>.

²² U.S. Census Bureau. (2010). State and County Quickfacts. "St. Louis County, Missouri" 4 April 2013 <<http://quickfacts.census.gov/qfd/states/29/29189.html>>.

²³ U.S. Census Bureau. (2010). State and County Quickfacts. "St. Louis City, Missouri" 4 April 2013 <<http://quickfacts.census.gov/qfd/states/29/29510.html>>.

White	97.0	96.7	91.3	71.0	46.2
Black	1.0	1.0	4.4	23.4	48.3
Hispanic/Latino	1.5	1.7	2.9	2.6	3.6
Asian	0.4	0.7	2.3	3.6	2.9
Two or more races	1.1	1.3	1.6	1.8	2.2
Financial (2007-2011)					
Median Income	\$50,098	\$56,400	\$71,458	\$58,630	\$34,402
Persons below Federal Poverty Level	11.10	10.3	4.9	9.7	26.0
Education Level (2007-2011)					
High school graduate or higher – persons over 25	84.9	86.7	92.8	91.5	81.9
Bachelor degree or higher – persons over 25	16.7	16.7	34.5	39.3	27.7
Language (2007-2011)					
Language other than English spoken at home	2.2	3.4	6.1	8.6	9.3
Geography - 2010					
Land in square miles	922.68	656.63	560.44	507.80	61.91
Population Density – 2010 Estimate					
Persons per square mile	110	333.1	643.2	1,967.2	5,157.5

Source: U.S. Census 2010 < <http://www.census.gov/>>.

Illinois Counties: Madison and St. Clair

Table 4: Illinois Counties Demographic and Socioeconomic Data

Illinois		
	Madison Co. ²⁴	St. Clair Co. ²⁵
Population, 2012 Estimate	15,654	9,474
	County %	County %
Age – 2011 Estimate		
Persons under 5 years	6.9	5.2
Persons under 18 years	26.9	19.5
Persons over 65 years	14.8	23.8
Sex – 2011 Estimate		
Male	49.7	50.3
Female	50.3	49.7
Race – 2011 Estimate		
White	98.1	96.5
Black	0.5	0.8
Hispanic/Latino	1.4	1.9
Asian	0.4	0.2
Two or more races	0.8	1.8
Financial (2007-2011)		
Median Income	\$56,333	\$32,553

²⁴U.S. Census Bureau. (2010). State and County Quickfacts. "Madison, Illinois" 4 April 2013 <<http://quickfacts.census.gov/qfd/states/17/17119.html>>.

²⁵ U.S. Census Bureau. (2010). State and County Quickfacts. "St. Clair, Illinois" 4 April 2013 <<http://quickfacts.census.gov/qfd/states/17/17163.html>>.

Persons below Federal Poverty Level	8.9	18.7
Education Level (2007-2011)		
High school graduate or higher – persons over 25	93.9	83.6
Bachelor degree or higher – persons over 25	20.2	12.0
Language (2007-2011)		
Language other than English spoken at home	1.4	2.0
Geography - 2010		
Land in square miles	561.01	669.98
Population Density – 2010 Estimate		
Persons per square mile	27.9	14.6

Source: U.S. Census 2010 < <http://www.census.gov/>>.

Population Trend: Overall, the entire population of the St. Louis Region has seen a growth rate of approximately .41%.

Table 5: St. Louis Region General Population

St. Louis Region Six Year Population Trend²⁶							
		2006	2007	2008	2009	2010	2011
Missouri	Franklin County	99,341	100,265	101,149	101,422	101,543	101,938
	Jefferson County	213,105	214,948	216,409	217,764	219,056	219,480
	St. Charles County	337,992	345,395	351,179	356,902	361,725	365,151
	St. Louis County	1,002,050	999,389	998,331	998,618	998,772	998,692
	St. Louis City	320,131	317,959	317,955	318,842	319,008	318,069
Illinois	Madison County	266,164	267,382	268,232	268,978	269,314	268,459
	Monroe County	31,644	32,139	32,533	32,848	33,009	33,306
	St. Clair County	263,445	264,764	266,518	268,489	270,399	270,259

Source: St. Louis Regional Chambers <<http://www.stlrcga.org/x64.xml>>.

²⁶ St. Louis Regional Chambers. "St. Louis Area Population Demographics". 6 June 13 <<http://www.stlrcga.org/x1832.xml>>.

Educational Resources: The St. Louis Region is home to several colleges and universities, both private and public, with an enrollment of over 119,000 students in area four-year institutions, producing more than 25,000 new graduates with bachelor’s, master’s, doctorate, or professional degrees each year.²⁷

Table 6: St. Louis Region Four Year Colleges and Universities

Four Year Colleges and Universities in the St. Louis Region²⁸					
College/University	Total Enrollment	Bachelor’s Degrees	Master’s Degrees	Doctoral-Professional Degrees	State
Blackburn College	598	122	0	0	IL
Aquinas Institute of Theology	192	0	68	4	MO
Barnes-Jewish College Goldfarb School of Nursing	653	326	34	0	MO
Brown Mackie College	255	0	0	0	MO
Chamberlain College of Nursing	7,002	1,438	0	0	MO
Columbia College-St. Louis	950	84	11	0	MO
Concordia Seminary	401	0	114	12	MO
Covenant Theological Seminary	767	0	138	7	MO
Eden Theological Seminary	199	0	33	5	MO
Fontbonne University	2,532	468	388	0	MO
Greenville College	1,605	381	87	0	IL
Harris-Stowe State University	1,716	142	0	0	MO
Hickey College	461	32	0	0	MO
ITT Technical Institute-Arnold	848	75	0	0	MO
ITT Technical Institute-Earth City	1,082	57	0	0	MO
Kenrick Glennon Seminary	120	14	15	0	MO
Lindenwood University	11,345	1,270	1,347	81	MO
Logan College of Chiropractic	1,104	209	51	264	MO
Maryville University	3,676	552	243	24	MO
McKendree University	3,299	551	341	0	IL
Missouri Baptist University	5,062	345	432	0	MO
Missouri College	1,051	42	0	0	MO
Missouri Tech	143	13	0	0	MO
Principia College	532	102	0	0	IL
Ranken Technical College	2,103	20	0	0	MO
Saint Louis University	17,709	1,627	727	743	MO
Sanford-Brown College-Fenton	1,176	36	0	0	MO
Sanford-Brown College-St. Peters	748	18	0	0	MO

²⁷ St. Louis Regional Chambers. “College and Universities”. 6 June 13 <<http://www.stlrcga.org/x513.xml>>.

²⁸ *Id.*

Southern Illinois University at Edwardsville	14,133	2,158	721	117	IL
St. Louis Christian College	337	46	0	0	MO
St. Louis College of Pharmacy	1,215	0	0	179	MO
Stevens College of Business & Arts	200	39	0	0	MO
University of Missouri-St. Louis	16,791	2,011	771	104	MO
University of Phoenix-St. Louis	6778	100	21	0	MO
Vatterott College-North Park	1,848	6	0	0	MO
Vatterott College-Sunset Hills	805	19	0	0	MO
Washington University	13,820	1,666	1,455	737	MO
Webster University	9,260	967	1,711	5	MO

Source: St. Louis Regional Chambers <<http://www.stlrcga.org/x64.xml>>.

Work Force: The St. Louis Region’s work force is representative of the American population, with several large companies including Boeing and Anheuser Busch located within the region.

Table 7: St. Louis Region Work Force

St. Louis Region Work Force ²⁹	
Total Labor Force	1,449,770
Total Employment	1,320,729
Total Unemployment	129,041
Unemployment Rate	8.90%

Source: St. Louis Regional Chambers <<http://www.stlrcga.org/x64.xml>>.

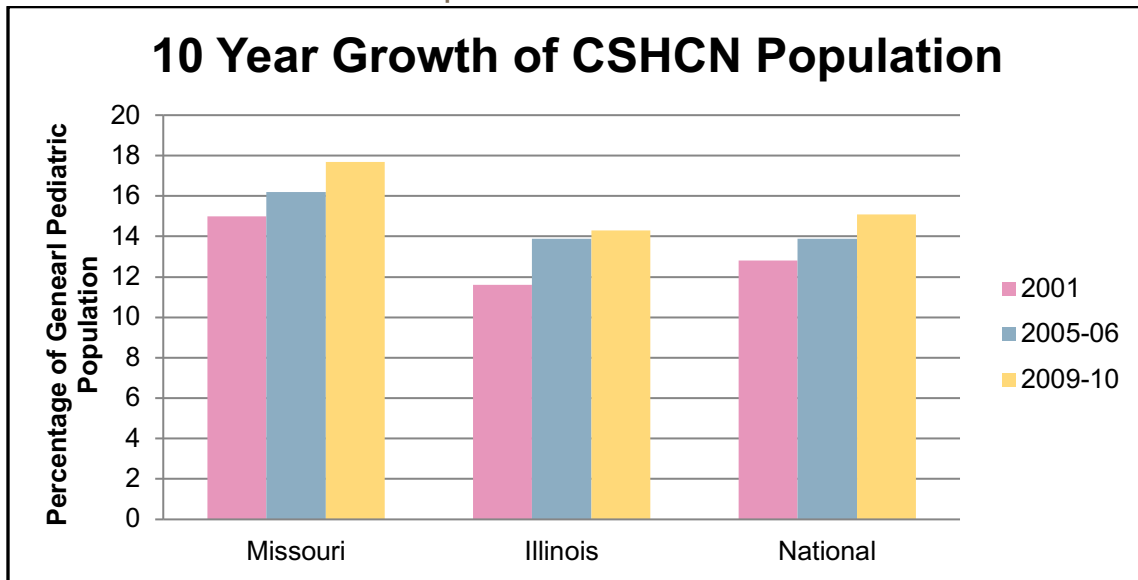
²⁹ St. Louis Regional Chambers. “College and Universities”. 6 June 13 < <http://www.stlrcga.org/x342.xml>>.

Health Care Resources: The St. Louis Region offers various health services: throughout the geographic area. The following is a sampling of those resources

- 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

Medically Complex Children: While advances in medicine and technology have led to continued drops in mortality rates of children and adolescent with previously fatal diagnoses and/or injuries, these same advances have created a dramatic upswing in the prevalence of children with complex and chronic health needs.³⁰ Medically complex children comprise approximately 0.4% of the below represented CSHCN population.^{31,32, 33}

Table 8. 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>.

³⁰ Haddad, M. J. (2009). *Value and Affordability in Paediatrics Ensuring Equitable Care in Paediatrics in the Toronto Central Local Health Integration network*. 1 Jan 2012 <<http://www.sickkids.ca/Hospital-Utilities/22854-Value-Affordability-Paediatrics-Report.pdf>>.

³¹ See *supra* note 7.

³² See *supra* note 8.

³³ U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2009–2010*. 12 Jan 2013 <<http://www.childhealthdata.org/browse/snapshots/cshcn-profiles?rpt=9&geo=1>>.

Below is the Missouri, Illinois, and National demographics and socioeconomic profile of children with special health care needs.

Table 9. Missouri, Illinois, and National Demographics and Socioeconomic Profile of Children with Special Health Care Needs

	Missouri ³⁴	Illinois ³⁵	United States ³⁶
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 complex³⁷:	0.4%	0.4%	0.4%
Ranken Jordan's Estimate - Number of Medically Complex Children	1,011	1,810	44,814
<i>Prevalence of CSHCN by Category:</i>	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.

³⁴ See *supra* note 7.

³⁵ See *supra* note 8.

³⁶ See *supra* note 30.

³⁷ See *supra* note 4.

Below are demographics of the CSHCN population by complexity.³⁸

Table 10. Children with Special Health Care Needs Demographics by Complexity

CSHCN Demographics by Complexity			
	Less Complex %	More Complex %	
	(n=9,897,116)	(n=324,323)	P Value
Age			
0-5 years	20.6	30.5	
6-11 years	37.1	39.4	< .001
12-17 years	42.2	30.1	
Sex			
Male	59.4	58.8	.81
Female	40.6	41.2	
Race /Ethnicity			
White	65.3	66.2	
Black	16.3	12.4	.14
Hispanic/Latino	11.7	14.2	
Multiple or Other	6.6	7.2	
Poverty Level			
≤ 100 %	18.8	24.7	
> 100-200%	21.8	27.0	
> 200-300%	16.0	14.7	< .001
> 300-400%	14.2	13.9	
> 400%	29.2	19.9	
Household Education Level			
Less than High School	6.8	6.4	
High school Graduate	23.1	23.5	.94
Beyond High School	70.1	70.1	
Primary Language			
English	95.4	93.5	.13
Other	4.6	6.5	
Insurance Type			
Private	68.8	57.6	
Public	27.6	41.0	< .001
Uninsured	3.6	1.4	

Source: A National Profile of Caregiver Challenges among More Medically Complex Children with Special Health Care Needs < <http://archpedi.jamanetwork.com/article.aspx?articleid=1107633>>.

Health Status

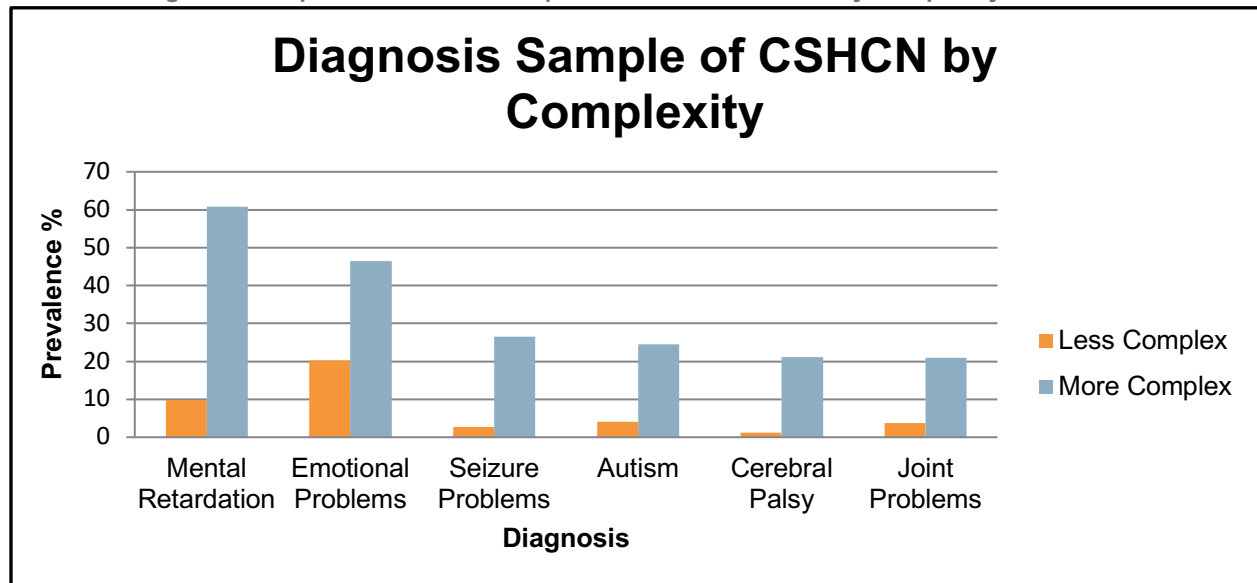
For medically complex children, the impact of their health status is far reaching, with often times overwhelming effects on the educational, social, and emotional domains of

³⁸ See *supra* note 9.

the child’s life. These effects, however, are not siloed within the experiences of the MCC, but can have dramatic consequences on familial structure and functionality.

Diagnosis Characteristics: In comparison to children with less complex health care needs, medically complex children have a higher number of diagnoses, a higher prevalence of mental retardation and emotional problems, seizure disorders, autism, cerebral palsy, and joint problems.³⁹

Table 11. Diagnosis Sample of Children with Special Health Care Needs by Complexity



Source: A National Profile of Caregiver Challenges among More Medically Complex Children with Special Health Care Needs < <http://archpedi.jamanetwork.com/article.aspx?articleid=1107633>>.

Family Burden: Children with complex medical needs can have significant effects on the family’s finances, employment status, mental and physical health. These demands may require families to invest large amounts of time in providing care to the child, learning and understanding the diagnoses and conditions of the child, cut down on parental work hours, face higher than average out-of-pocket health care costs, and significant time coordinating their child’s health care.⁴⁰

³⁹ *Id.*

⁴⁰ *Id.*

Care Burden: Caregivers of medically complex children report both a higher number of hours spent per week coordinating care for their MCC and hours spend providing direct home care per week. Families of MCC also report higher rates of health care related financial problems and interference with their ability to maintain employment.⁴¹

Table 12. Family Care Burden for Children with Special Health Care Needs by Complexity

Family Care Burden for CSCHN by Complexity⁴²		
	Less Complex	More Complex
	(n=9,897,116)	(n=324,323)
	<i>Average Number</i>	<i>Average Number</i>
Hours spent per week providing:		
Care Coordination	0	2
Home Care	1	11-20
	<i>Reported %</i>	<i>Reported %</i>
In the last 12 months:		
Family paid > \$1,000 out of pocket for health care	19.1	46.3
Child's health care caused financial problems	16.8	56.8
Family member stopped working because of child's health care needs	12.0	54.1
Family member cut down on work hours because of child's health care needs	15.4	45.6

Source: A National Profile of Caregiver Challenges among More Medically Complex Children with Special Health Care Needs < <http://archpedi.jamanetwork.com/article.aspx?articleid=1107633>>.

Medical Care Use and Unmet Needs: Families of MCC report a 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.⁴³

Table 13. Medical Care Use for the Children with Special Health Care Needs by Complexity

Medical Care Use for CSCHN by Complexity⁴⁴		
	Less Complex	More Complex
	(n=9,897,116)	(n=324,323)
	<i>Average Number</i>	<i>Average Number</i>
Child's health care needs:		
Usually Stable	5.4	35.0
Changes sometimes	27.9	33.0
Changes all the time	66.9	32.0
Receipt of:		
Early intervention served at 3 years or younger	19.0	82.2
Special education services for age range of 3-17 years	27.0	76.9

⁴¹ *Id.*

⁴² *Id.*

⁴³ *Id.*

⁴⁴ *Id.*

	<i>Reported %</i>	<i>Reported %</i>
Number in the last 12 months:		
School days missed	19.1	46.3
Physician visits	16.8	56.8
Emergency department visits	12.0	54.1
Family member cut down on work hours because of child's health care needs	15.4	45.6

Source: A National Profile of Caregiver Challenges among More Medically Complex Children with Special Health Care Needs < <http://archpedi.jamanetwork.com/article.aspx?articleid=1107633>>.

Primary Data

Focus Group

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 vision is 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. While establishing a venue to gather needs assessment information, 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.

Focus Group: In April 2013, PFAC was resourced to facilitate a focus group. 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 and vet thoughts

and opinions. Ultimately the focus group identified several needs that fall into the overarching category of 'quality of life'.

The community served by Ranken Jordan, and represented by the focus group, face extraordinarily complex, difficult, and overwhelming health concerns on a daily basis. During conversation, focus group participants expressed that while thoughts and worries concerning medical equipment, diet, medication, appointments and specialists happen on a constant basis, because they are frequent and high intensity users of health care services, their needs are psychosocial in nature and center around experiencing life in a way that resembles their counterparts in the general population as closely as possible. As expected, opportunity for socialization was a common theme of the focus group discussion, as many MCC are socially disenfranchised. This holds especially true for those members of the community who have a before and after diagnoses/injury view of life.

Areas of Opportunity:

- Community Programming
- Community Socialization and Communication

Needs Assessment Action Group

Background: Two major barriers exist in collecting meaningful data regarding the needs of medically complex children:

- Health needs of medically complex children are generally reported by caregivers - secondary observers.
- Medically complex children face physical and cognitive limitations that render them unable to meaningfully participate in or respond to traditional means of data collection.

In response to these barriers, Ranken Jordan has developed a needs assessment process that gathers the health needs information through collaboration, observation and evaluation.

Action Group: In February 2013, Ranken Jordan formed a needs assessment action group comprised of physical therapists, occupational therapists, speech therapists, child life specialists, and a recreational therapist from among its staff. The purpose of this action group is to create therapeutic group programs for medically complex children in the St. Louis Region. These therapeutic group programs are centered on general areas of interest for children and adolescents, i.e. sports, job skills, social skills, and blend therapeutic and developmental benefit with socialization in a group setting.

Action group members use their experience with, and knowledge of, medically complex children's abilities, needs, limitations and barriers regarding the general pediatric community, layered with confusion of available resources, frustrations with finding

services and desires voiced by patient families to a choose theme in which to build a therapy group programs around. Once a theme is selected, action group members carve out a structure for each specific therapeutic group program, formalizing goals, session length, program duration, action group facilitators and participation size. The therapeutic group program is then introduced through a staged process. For initial offerings, participants are hand selected for each individual therapeutic group program from Ranken Jordan existing patient population. Second offerings are available for participation by children in the Ranken Jordan existing patient population as well as those children participating in Ranken Jordan's community programming.

Information is gathered throughout each offering, evaluating if participants are meeting formalized goals, if program addressed recognized health needs of the community, and any necessary changes. Therapeutic group programs included: yoga, social skills, job skills, sports skills, managing your words.

Areas of Opportunity:

- Community Programming
- Navigation of Health Resources

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.

Participant Surveys: In 2012, several community programming events were held by Ranken Jordan. At the completion of each event, surveys are distributed to participants. These surveys are used to gather data regarding if the event met expectations, suggestions for future events, and overall satisfaction with the event itself. 115 surveys were collected during the CHNA process.

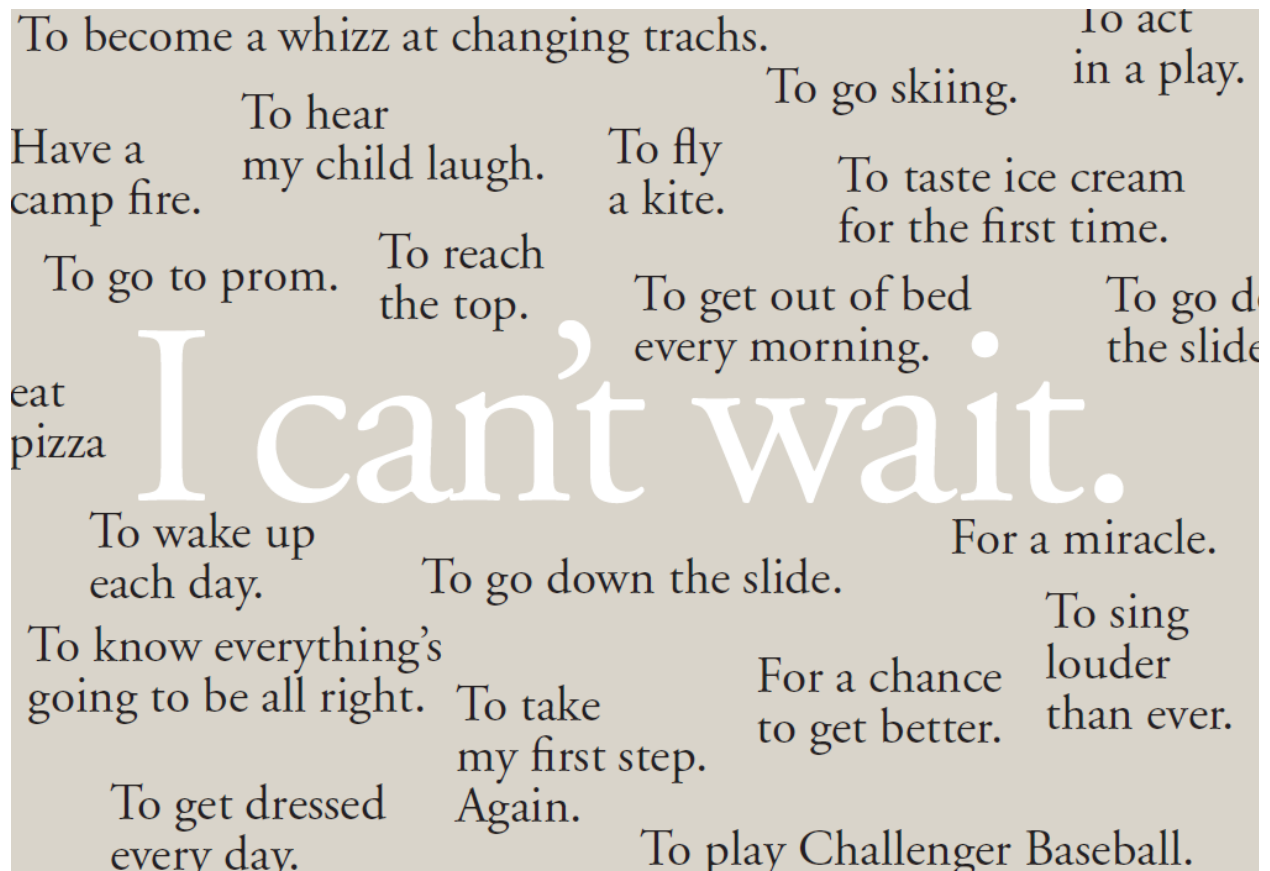
Area of Opportunity:

- Community Programming
- Resource Navigation

Identified Need & Prioritization

Process: Members of Ranken Jordan leadership reviewed data collected throughout the CHNA process. Using this data, one overarching health need was identified: 'quality of life'. Once identified, Ranken Jordan formalized and prioritized two initiatives in order to address that need: community programming and navigation of health resources.

Identified Need: Medically complex children and their families face extraordinarily complex, difficult, and overwhelming health problems on a daily basis. Pervasive thoughts of equipment, diet, medication, appointments and specialists serve as a constant reminder that the child is medically complex. Viewing life through the lens of medical complexity, Ranken Jordan's community desires opportunities to allow them to participate in activities in a way that are not constrained by words like ability, limitation, diagnoses, congenital defect or injury. This community desires dance class, summer camp, karate, baseball, time with friends, laughter and memories.



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

Implementation Plan

Overall Goal: Through this implementation plan, Ranken Jordan’s goal is to address the unmet need for ‘quality of life’ for the medically complex child and their family through commitment to its vision of being a “leader in providing intensive transitional care and living support” and distinction for its “expertise, service, high quality and safe patient care, communication, coordination, innovation and relationship building”. Ranken Jordan recognizes that this implementation plan is a living document that will be assessed and revised as it is put in place.

Community Partners: Ranken Jordan recognizes the value of collaboration with other organizations and agencies to accomplish its goal and increase the impact for this subset of the pediatric population.

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.
- Expand advertising of Ranken Jordan's events to increase awareness and participation.
- 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.

Appendix A

Focus Group

Staff Facilitator:

Shari Riley, RN, MSN
Administrator of Quality & Safety

Participants Representing the Community:

Names have been redacted to respect the privacy of the participants.

Community Representative

- Parent of a Medically Complex Child
- Parent of a Medically Complex Child
- Parent of a Medically Complex Child
- Parent of a Medically Complex Child
- Parent of a Medically Complex Child & Ranken Jordan Board of Directors Member

Medically Complex Children

- Former Inpatient, Current Volunteer of Ranken Jordan
- Former Inpatient and Outpatient of Ranken Jordan
- Former Inpatient, Current Outpatient of Ranken Jordan

Appendix B

Needs Assessment Action Group Members:

Catharine Costello, OTR/L

Susan Gammon, MSOT, OTR/L

Christine Gartner, PT

Carrie Hefley, CCLS

Allyson Kranz, MHS, CCC-SLP

Janine Roe, CTRS

Lisa Roeslein, DPT

Jaana Schweitzer, CCLS

Amanda Sondgrass, CCLS

Resources

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