2012

Children's Behavioral Health Needs Assessment

for Greater Kansas City

Developed and Coordinated by the Children's System Change Committee

REACH healthcare foundation

Health Care Foundation OF GREATER KANSAS CITY

MARC Mid-America Regional Council

ACKNOWLEDGEMENTS

The Children's System Change Committee would like to recognize the Reach Healthcare Foundation and the Health Care Foundation of Greater Kansas City for the financial support that made this report possible; the members of the Children's System Change Committee and the Metropolitan Mental Health Stakeholders Committee for their involvement and leadership in the study's preparation; and the providers and consumers who contributed important input through surveys conducted by Collaborative Research, LLC.

This report is dedicated in memory of William H. Kyles, former chair of the Metropolitan Mental Health Stakeholders.

CONTRIBUTING PROVIDERS

Community Mental Health Centers	Comprehensive Mental Health Services, Inc. Johnson County Mental Health Southeast Kansas Mental Health Services Tri-County Mental Health Service Truman Medical Center Wyandot Center/ PACES
Foster Care System	The Andrew Drumm Institute
Juvenile Justice System	Jackson County Family Court
Psychiatric Residential Treatment Facilities	Crittenton Children's Center Spofford Home
School Districts	Kansas City, MO School District Center #58 School District School District 257 (Allen County, KS-Iola) Platte County, MO R-III School District Sherwood R-VIII (Cass County, MO) School District Lafayette County, MO School District Gardner-Edgerton US 231 School District
Pediatricians/Pediatric Facilities	Children's Mercy Pediatrics Northland Pediatrics Pediatric Associate Pediatric Care North Pediatric Group, Inc.
Mental Health Practitioners	Comprehensive Psychiatric Associates

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EXECUTIVE SUMMARY

An estimated one in 10 children in the United States today has a diagnosable mental disorder, and proportions are even higher among children and youth in the child welfare and juvenile justice systems.

Early intervention and coordinated systems of care are critical, proven ways to improve outcomes for children, but not all children and families are able to access quality behavioral health care.

Before we can successfully introduce system change, we need to fully understand the scope of the problem in Greater Kansas City.

In July 2011, the Children's System Change Committee, working through the Mid-America Regional Council's Regional Health Care Initiative, commissioned a Children's Behavioral Health Needs Assessment for Greater Kansas City to evaluate gaps and barriers to care and develop recommendations to improve access to an integrated and well-coordinated system of quality behavioral health care for children in the metropolitan area. The assessment was funded by the Health Care Foundation of Greater Kansas City and the REACH Healthcare Foundation.

The committee commissioned this study in order to identify the action steps necessary to realize a vision that all children of the Kansas City metropolitan area, — especially those from families that are uninsured, underinsured or rely on Medicaid, should have improved access to quality behavioral health care.

Primary research included a consumer survey of 602 children and caregivers; a survey of 30 behavioral health care providers, and nine intensive interviews. A limitation of the consumer survey is that it focused on children receiving behavioral health care, rather than a random sample of the population.

Secondary research included county demographic profiles, a literature review, policy scans in both Kansas and Missouri, and a resource inventory.

The needs assessment led to key recommendations from committee, which were further refined at a community forum held on January 19, 2012, and attended by more than 130 mental health stakeholders. These recommendations include:

1. Informing resources to expedite entry to care.
2. Publicizing awareness of behavioral health services.
3. Working to make child behavioral health affordable and accessible.
4. Reducing or eliminating gaps between suspected, diagnosed and treated behavioral health issues, and eliminating or reducing barriers and gaps to care access.
5. Incorporating assessment of history of abuse/trauma, family history of behavioral health/substance abuse, and high-risk pregnancy into health screenings by all providers.

Action steps to advance the recommendations were outlined at the community forum, and these action steps are now being used by the committee and the regional behavioral health community to create systemic change in the Kansas City metropolitan area.

INTRODUCTION

In July 2011, the Children's System Change Committee, working through the Mid-America Regional Council's Regional Health Care Initiative, commissioned a Children's Behavioral Health Needs Assessment to evaluate gaps and barriers to care and develop recommendations to improve access to an integrated and well-coordinated system of quality behavioral health care for children in the Kansas City metropolitan area. The assessment was funded by the Health Care Foundation of Greater Kansas City and the REACH Healthcare Foundation.

The Mid-America Regional Council, commonly known as MARC, is a nonprofit association of city and county governments and the metropolitan planning organization for the bistate Kansas City region. In 2006, responding to community interest, MARC launched the Regional Health Care Initiative (RHCI) to help promote innovative, collaborative approaches to providing health care to the uninsured and medically underserved.

The RHCI's behavioral health component works with the Metropolitan Mental Health Stakeholders (MMHS) to identify opportunities to strengthen, improve access to and more closely integrate mental health, substance abuse, correctional, developmental disability and physical health care services.

The MMHS oversees the Children's System Change Committee, a formal planning and advisory body charged with the development of recommendations and ongoing assessment of transformational initiatives to enhance behavioral health care for children in the region.

The committee commissioned this study in order to identify the action steps necessary to realize a vision that all children of the Kansas City metropolitan area, — especially those from families that are uninsured, underinsured or rely on Medicaid, should have improved access to quality behavioral health care. Specifically, the charge for this needs assessment was to provide expertise and guidance in researching local and national children's behavioral health models, collecting and analyzing responses to a needs assessment of families and providers, and outlining specific action steps.

The assessment is intended to guide the development of a framework for a coordinated community system that improves access to quality, integrated and accessible behavioral health care for vulnerable and underserved children of Greater Kansas City.

The term "behavioral health" refers to a state of mental or emotional health and/or choices and actions that affect wellness. Behavioral health problems may include substance abuse or misuse, alcohol and drug addiction, serious psychological distress, suicide, and mental and substance use disorders. The term is also used to describe the service systems encompassing the promotion of emotional health, the prevention of mental and substance use disorders and related problems, treatments and services for mental and substance use disorders, and recovery support.

— Substance Abuse and Mental Health Services Administration (SAMHSA)

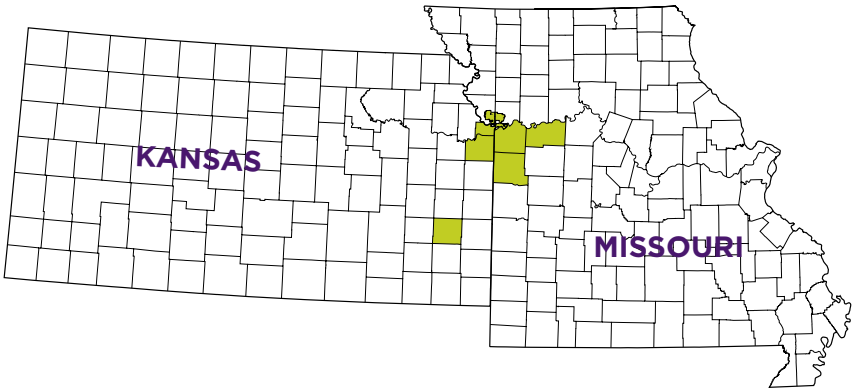
METHODOLOGY

The Children's System Change Committee led the children's behavioral health needs assessment, with input from more than 130 stakeholders.

Primary research included a series of surveys and interviews:

- **Consumer survey:** 602 respondents were surveyed. For younger children, the survey was completed by parents and other caregivers, while transitional youth spoke for themselves. The survey focused on determining behavioral health needs of children aged birth to 25 — both met and unmet — and barriers to care. Three special populations were analyzed in detail: foster care children, children in the juvenile justice system and transitional youth. The survey was administered to consumers already receiving behavioral health care, rather than a random sample of the population.
- **Provider survey:** 30 behavioral health providers, including community mental health centers and foster care providers, responded to an online survey.
- **Interviews:** Nine intensive interviews were conducted with representatives from community mental health centers, Early Head Start programs, children's hospitals, and psychiatric residential treatment facilities to further inform study findings.

Primary research was conducted in Allen, Johnson and Wyandotte counties in Kansas; and in Cass, Jackson and Lafayette counties in Missouri, along with the portions of Clay and Platte counties that are part of the city of Kansas City, Mo. The areas surveyed are contiguous parts of the Kansas City metropolitan area with the exception of Allen County, Kan., a rural county about 100 miles to the southwest.



Secondary research added context to the findings of the primary research. This hybrid approach provides a basis to compare the results to the general pediatric population, corroborating findings or highlighting areas where the Kansas City metropolitan area differs. Secondary research, detailed in the appendices of this report, included:

- **County profiles:** Details were researched for each of the counties in the service area to provide epidemiologic data, demographics and behavioral risk information.
- **Literature review:** A detailed literature review of child behavioral health was conducted.
- **Policy scan:** Financing policies for child behavioral health services in Missouri and Kansas were reviewed and compared to national policies for child and adult behavioral health services.
- **Continuum of care and resource inventory:** All contacts were catalogued during the needs assessment, compiling a listing of 150 resources for children's behavioral health.

KEY FINDINGS FROM PRIMARY RESEARCH

Consumer Survey

A survey focused on determining behavioral health needs of children aged birth to 25 was conducted, and 602 responses were received. For younger children, the survey was completed by parents and other caregivers, while transitional youth spoke for themselves. The survey was administered to consumers already receiving behavioral health care, rather than a random sample of the population. Survey results were analyzed in detail for three special populations: children in foster care (13 percent of the total); children in the juvenile justice system (12 percent of the total); and transitioning youth ages 16–25 (25 percent of the total; some may also be in the foster care or juvenile justice systems).Highlights of the survey results are summarized here. For detailed results, see Appendix B-1.

Access to Care

No access issues were reported as insurmountable, but respondents raised concerns about affordability.

- 10.4 percent, all of whom were privately insured, stated that the cost of their behavioral services was 'never' affordable.
- 20.5 percent of respondents have issues with affordability of co-payments
- 7.2 percent of respondents stated that their health insurance rarely or never allowed their child to see the doctor or behavioral health clinicians that they needed.

Types of Behavioral Health Care Needed

Survey respondents provided details that gave the System Change Committee a better understanding of the types of care that are needed and currently being provided in the Kansas City region. This data will help stakeholders evaluate behavioral health services to ensure that the needs of children and transitioning youth are being addressed.

Levels of Care Needed

- 19.8 percent of all respondents reported children with 'severe' levels of care needed, as stated by the clinician. (For foster care, 88 percent were reported as severe; for juvenile justice, 71 percent.)
- 43.7 percent of all respondents reported children needed 'moderate' levels of care, as stated by the clinician. (For foster care, 12 percent were reported as moderate; for juvenile justice, 20 percent.)
- 36.5 percent of all respondents reported a 'mild' level of care needed, as stated by the clinician. (For juvenile justice, 9 percent were reported as mild.)

History of Abuse or Family History of Behavioral Health Issue

- 29.3 percent of all respondents reported their child had a history of abuse.
- 57.5 percent of all respondents reported that their child had a family history of issues with mental health and/or substance abuse.

Fragmentation of Care

Survey responses cited the fragmentation of care, particularly related to children with co-occurring disorders and multiple case managers (school, community-based mental health, physical health) as problematic, and respondents often assumed case-coordination duties.

Use-Need-Barrier-Gap Analysis

Consumers were asked about services used, including the ease of care entry upon diagnosis and/or referral, service needs and their correlation to barriers ("need service and had trouble getting") and gaps ("need service and couldn't obtain"). A comparison of service use, needs, barriers and gaps was conducted for all respondents, with further segmentation by the three special populations (Appendix B–1). The consumer responses quantify self-reported service use, need, barriers to access and gaps. The following tables display all respondents' ranking of services that represent the continuum of care for behavioral health.

USE	
Services most frequently used	
1	Assessment of behavioral health issue
2	Education to deal with behavioral health issue
3	Specialist to treat child
4	Coordination with other systems of care (e.g., school)
5	Inpatient services
6	Emergency placement
7	Transportation to/from services
8	Intensive outpatient services
9	Respite care
10	Partial outpatient (day services)
11	Crisis services when acute
12	Outpatient substance abuse
13	Detoxification
14	Inpatient substance abuse

NEED	
Services most needed, whether used or not	
1	Education to deal with behavioral health issue
2	Assessment of behavioral health issue
3	Coordination with other systems of care (e.g., school)
4	Specialist to treat child
5	Respite care
6	Transportation to/from services
7	Crisis services when acute
8	Emergency placement
9	Inpatient services
*10	Partial outpatient (day services)
*10	Intensive outpatient services
11	Outpatient substance abuse
12	Detoxification
13	Inpatient substance abuse

BARRIERS	
Need services, but have trouble getting	
1	Coordination with other systems of care (e.g., school)
2	Transportation to/from services
3	Respite care
*4	Education to deal with behavioral health issue
*4	Specialist to treat child
5	Crisis services when acute
6	Emergency placement
7	Assessment of behavioral health issue
*8	Inpatient services
*8	Partial outpatient (day services)
*8	Intensive outpatient services
9	Outpatient substance abuse

GAPS	
Need services but can't get	
1	Coordination with other systems of care (e.g., school)
2	Transportation to/from services
3	Respite care
4	Specialist to treat child
5	Crisis services when acute
6	Emergency placement
7	Education to deal with behavioral health issue
*8	Inpatient services
*8	Partial outpatient (day services)
*8	Intensive outpatient services

Not all services were ranked by respondents in each category.
* Indicates tied ranking

Provider Survey

To ensure provider input for a comprehensive needs assessment, 30 child behavioral health providers from across the bistate region, including community mental health centers and foster care providers, responded to an online survey.

Issues raised by providers closely matched those reported by consumer survey respondents, including:

- The fragmented nature of the current behavioral health system.
- The explosive growth of reported behavioral health issues in the school system as the field has migrated to a community and outpatient focus for provision of care.
- The need to further recognize the role of psychological trauma in behavioral health care.
- The need for broader, community-based screenings based on protocols developed by behavioral health professionals (school systems, pediatric and family practice offices, etc.)
- The need for expedited referral mechanisms upon initial assessment.
- The high levels of unmet need experienced by transitioning youth when migrating from a child behavioral health system to an adult one.
- The urgency to fully integrate behavioral health provisions with physical health care.
- An increasing demand for child behavioral health services despite declining reimbursement, particularly related to uninsured and underinsured clients.
- Increased outcome expectations by funders, despite eroding reimbursement, with significant concerns about Medicaid with economic climate.

Detailed responses from the provider survey are outlined in Appendix B-2.

Providers' Rank of Barriers to Service Access for Children and Families			
	Percent that said it is a critical issue	Percent that said it is sometimes an issue	Percent that said it is not an issue
Perceived Cost	20%	60%	20%
Lack of knowledge about services	40%	60%	
Transportation to services	60%	40%	
Health insurance coverage for services	20%	60%	20%
Co-payments for services	20%	60%	20%
Stigma, concerns about confidentiality	20%	80%	

Interviews

Nine intensive interviews were conducted with representatives from community mental health centers, Early Head Start programs, children's hospitals, and psychiatric residential treatment facilities to further inform study findings. Key issues are summarized below, and details are provided in Appendix B-3.

Community Mental Health Centers

- The system is fragmented, requiring more intensive care coordination among multiple sectors, with an emphasis on school systems. Fragmentation is also exacerbated by the bistate (Kansas/Missouri) service area.
- More resources for children are needed at an earlier age to prevent or reduce mental health issues in toxic environments related to poverty and psychological trauma.
- Concerns were expressed about a significant rise in incidence of behavioral health issues coupled with reduced reimbursement.

Psychiatric Residential Treatment Facilities

- Interviewees articulated the case for additional facilities to meet the need in high-severity populations.
- Interviewees discussed evidence-based protocols that validate care and progress, as well as quantitative measures to display outcomes.
- Facilities are significantly impacted by recent decisions in Kansas to eliminate or reduce admissions and/or reauthorizations.

Children's Hospitals

- Interviewees discussed co-occuring disorders in child behavioral health, along with the need for emphasis/assessment of high risk pregnancy, maternal alcohol use, the role of maternal environment in prenatal periods, and the growing incidence of autism spectrum disorder.
- Interviewees lauded the Missouri Department of Insurance's decision to mandate insurer coverage for autism.

School Systems

- Interviewees expressed concerns that school-based emotional issues are on the rise, with increased severity and explosive violence. Factors in this rise may include the lack of inpatient resources and numerous environmental stressors, including a worsening economy, absence of one or both parents (some due to military obligations) and drug use by parents.
- School nurses and other personnel expressed frustration with the inability to effectively deal with individualized, high-intensity child and family issues, due to time constraints, legal concerns and the professional scope of practice.
- Schools need more resources to effectively handle behavioral health in the school arena through expedited referral and linkage to behavioral health care services.

RECOMMENDATIONS

The System Change Committee identified key recommendations from the needs assessment. These recommendations were further refined at a community forum held on January 19, 2012, and attended by more than 130 mental health stakeholders. Through the workgroup dialogue at the forum, action steps to advance the recommendations were outlined, and these action steps are now being used by the committee and the regional behavioral health community to create systemic change in the Kansas City metropolitan area. In particular, the System Change Committee has begun to focus its work on the first, third and fifth action items outlined below.

1. Inform resources to expedite entry to care.

1.1 Improve ways to effectively use school health personnel to refer at-risk students to care, pulling resources into schools for certain levels of intervention.

1.2 Work with pediatricians as the single most important referral source to behavioral health.

1.3 Promote awareness of behavioral health issues to helpful resources, including EAP, family guidance centers, community groups and churches

1.4 Connect behavioral health services with resources/organizations that are not medical or behavioral health-oriented and have fewer legal restrictions.

1.5 Provide shorter, more frequent out-of-home placements.

1.6 Use personal care attendants (in-home staff) to provide respite care, educate family and offer a structured environment for the child.

1.7 Ensure assessment of trauma to inform care.

1.8 Smooth transition of the child back into home and school with supports to maintain the child in the home.

2. Publicize awareness of behavioral health services.

2.1 Develop a campaign to produce literature on available services with a focus on underserved families, particularly those requiring translation and/or transport.

2.2 Review respite care services and publicize need for this service to eligible populations.

2.3 Develop a media campaign to make the community aware of behavioral health and self-help and care services.

2.4 Provide linkages to Community Mental Health Centers.

2.5 Provide referrals to, and ensure capacity for, home visits.

3. Work to make child behavioral health affordable and accessible.

3.1 Meet with State Departments of Insurance in Kansas and Missouri and private health insurers on the recurrent perception of unaffordable copayments for parents/guardians/transitioning youth.

3.2 Work to ensure access to behavioral health specialists.

3.3 Employ a wrap-around approach to standardize care, provide integrated points of contact, minimize cost duplication and provide constancy for children.

3.4 Blend funding through the use of federal and state monies, ensuring sufficient funds for juvenile justice and foster care youth.

3.5 Conduct an economic analysis of the return-on-investment for preventive behavioral health at young age.

3.6 Narrow or close the reimbursement divide between time-based physical health and encounter-based behavioral health.

3.7 Enact system change at the bistate level: ensure ability to consent for treatment; coordinate service requirements between states; and coordinate service requirements between under and over 18 years of age.

3.8 Work with the Office of Medicaid to contract with Medicaid plans that are responsive to the needs of consumers and providers.

4. Reduce or eliminate gaps between suspected, diagnosed and treated behavioral health issues. Eliminate or reduce barriers and gaps to care access.

4.1 Narrow the gap between behavioral health issues that are suspected vs. diagnosed vs. treated.

4.2 Focus on the school system due to issues with the legal definition of intellectual disability (IDEA) and current score-based education systems (e.g., MAP testing, Iowa Test of Basic Skills Scores).

4.3 Address capacity issues for school-based referrals to CMHCs (the barrier of a child needing to 'fail' before being able to access services).

4.4 Review different thresholds for accessing services (type and intensity) between Kansas (functional need, eligibility) and Missouri (initial diagnosis, functional need).

4.5 Assess the impact of full implementation of the Affordable Care Act on CMHC capacity. Realize actual mental health parity.

4.6 Resolve gaps (need service and can't get) in coordination with other systems of care and lack of ability to access respite care for those that are eligible.

4.7 Address why transitioning youth do not receive behavioral health services.

4.8 Coordinate the use of technology to improve services, including telepsychiatry; new staff scheduling models; and electronic central databases of child/family history, including both medical and behavioral health history.

4.9 Publicize youth-oriented resources for peer networks such as Facebook/I-Home.

4.10 Identify funding resources for realistic support infrastructure (transportation, employment, housing, parent education/outreach).

5. Incorporate assessment of history of abuse/trauma, family history of behavioral health/substance abuse, and high-risk pregnancy into health screenings by all providers

5.1 Formally incorporate the history of abuse/trauma, family behavioral health history and high-risk pregnancy into all health assessments, with specific inclusion of trauma-informed tools.

5.2 Adopt trauma-informed care as a community preventive health focus.

5.3 Develop and use a standardized assessment tool among all agencies so all providers are aware of issues, including family background of mental health or substance use and genetic concerns.

5.4 Integrate physical and behavioral health assessment at all levels with:
- Screening protocols used in all child health settings
- Mental health awareness training provided to ALL school personnel
- Detailed behavioral health training on child-specific screening and referral protocols for local emergency departments, pediatricians and family practice doctors
- Behavioral health rounds incorporated into all physical health staff training

5.5 Offer PBIS (Positive Behavioral Interventions and Support), a school-wide intervention.

5.6 Identify early risk factors (e.g., homelessness, toxic environment, transitioning youth, history of psychological trauma).

5.7 Create a network of local psychological trauma specialists.

5.8 Formally identify advocates in assessment (e.g., school, family, host family, and social capital including peers or e-peer networks).

Appendices

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Appendix A: Definitions

The following definitions of behavioral health terms come from the Substance Abuse and Mental Health Services Administration (SAMHSA).

BEHAVIORAL HEALTH: The term "behavioral health" refers to a state of mental/emotional health and/or choices and actions that affect wellness. Behavioral health problems include substance abuse or misuse, alcohol and drug addiction, serious psychological distress, suicide, and mental and substance use disorders. The term is also used to describe the service systems encompassing the promotion of emotional health, the prevention of mental and substance use disorders and related problems, treatments and services for mental and substance use disorders, and recovery support.

CHILDREN'S BEHAVIORAL HEALTH: Behavioral health consists of services for children (ages 0-25) with intellectual and developmental disabilities, mental illness and/or drug and alcohol addictions.

CHILDREN WITH SERIOUS EMOTIONAL DISORDER: Children from birth to age 18 (Note: age groups vary significantly at federal and state levels) who currently have, or at any time during the last year had, a diagnosable mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria specified within the Diagnostic and Statistical Manual.

CHRONIC SUBSTANCE USE DISORDER: Defined using diagnostic codes from the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM). An individual would be diagnosed as having alcohol, tobacco and/or drug abuse or dependence based on the presence of one or more of the following five ICD-9 diagnostic codes:

291, Alcohol Psychoses
292, Drug Psychoses
303, Alcohol Dependence Syndrome
304, Drug Dependence
305, Nondependent Drug Abuse

Ten ICD-9 diagnostic codes are for medical illnesses specifically caused by alcohol and other drug use:

425.5, Alcoholic Cardiomyopathy
535.3, Alcoholic Gastritis
571, Chronic Liver Disease and Cirrhosis
571.0, Alcoholic Fatty Liver
571.1, Acute Alcoholic Hepatitis
571.2, Alcoholic Cirrhosis of Liver
571.3, Alcoholic Liver Damage, Unspecified
357.6, Polyneuropathy Due to Drugs
648.3, Pregnancy Complicated By Drug Dependence

BI-DIRECTIONAL INTEGRATION: SAMHSA defines bi-directional integration of behavioral health and primary care services as integrating mental health and substance abuse treatment services in primary care settings and primary care in mental health and substance abuse treatment settings.

CO-OCCURRING DISORDERS: Individuals who have at least one mental disorder as well as an alcohol or drug use disorder. While these disorders may interact differently in any one person, at least one disorder of each type can be diagnosed independently of the other.

PREVENTION: Prevention refers not only to interventions that occur before the initial onset of a disorder, but also to interventions that prevent co-morbidity, relapse, disability, and the consequences of severe mental illness for families.

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Appendix B: Primary Research

The three categories of primary research conducted in this needs assessment were a **consumer survey** (families/guardians of children with behavioral health issues and, in limited circumstances, emancipated or transitioning youth; a **provider survey** aimed at child behavioral health care providers; and **key informant interviews** of providers and funders of regional child behavioral health care. This triad of input allows for comparison of responses from behavioral health providers to the consumers or families of consumers that they serve.

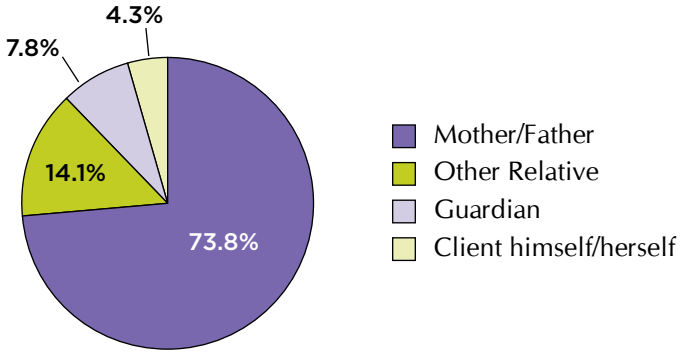
1. Consumer Survey

The consumer survey was facilitated by Collaborative Research, with agency staff helping some clients and families complete the instrument. The sample frame of 600 respondents was derived using the general child population (ages 0-25) in the survey area shown on page 3. The actual response rate was 602, or 101 percent of the target sample frame, at a 99 percent confidence level and 5.0 confidence interval.

A. Demographics

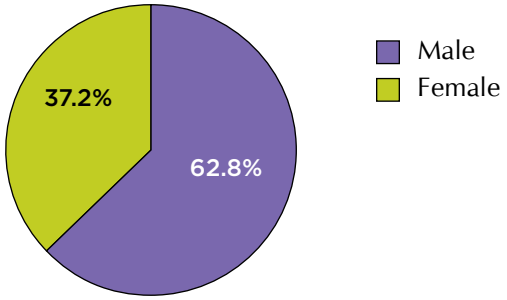
Respondent Role/Relationship

Survey participants were asked to identify their roles with respect to the child receiving behavioral health services. The mother or other relative (typically female) was the prime respondent.



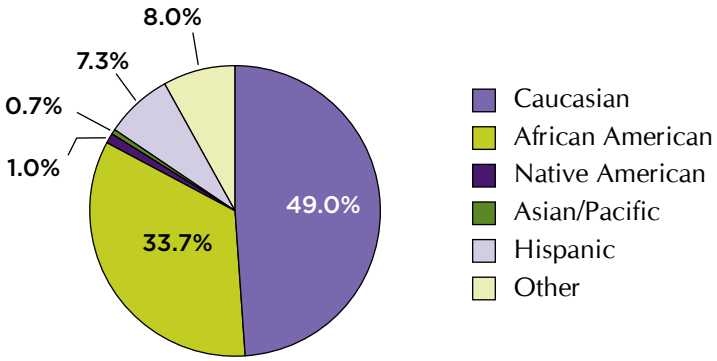
Child's Gender

Respondents reported that 63 percent of children receiving behavioral health services were male and 37 percent female. This is consistent with results of the provider survey (66 percent male and 34 percent female) but varies significantly from the general pediatric population (49 percent male and 51 percent female). This difference is consistent with findings from the literature review.



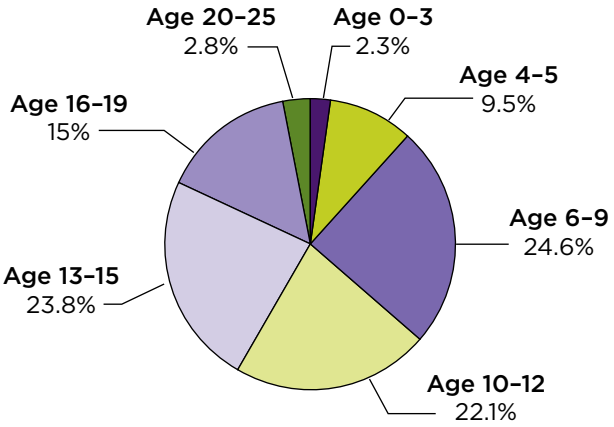
Child's Racial or Ethnic Background

Nearly half of consumer survey respondents were white (49 percent), and approximately one-third were African American. These results were similar to the provider survey (53 percent white and 31 percent African American). Hispanics represented 7 percent of the total in the consumer survey, but only 3 percent in the provider survey.



Child's Age Group

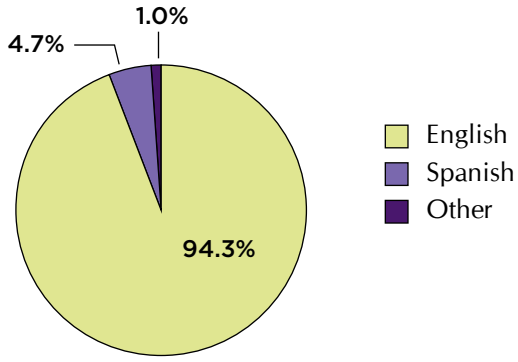
Respondents to the consumer survey were split fairly evenly among 6–9 year olds (25 percent), 10–12 year olds (22 percent) and 13–15 year olds (24 percent, with smaller percentages in the younger and older age groups These results mirrored the provider survey in most categories.



Nationality and Language Spoken at Home

Only 12 of the 602 respondents reported being born in a country other than the United States — less than 2 percent. Of these 12, five were from Central America, two each from the middle east and Vietnam, and one each from Somalia, Bosnia and South America.

Only 5.7 percent speak a language other than English in their homes. This is consistent with data reported by the U.S. Census Bureau for Missouri (5.9 percent) but lower than Kansas (10.5 percent) and the nation as a whole (20.1 percent).



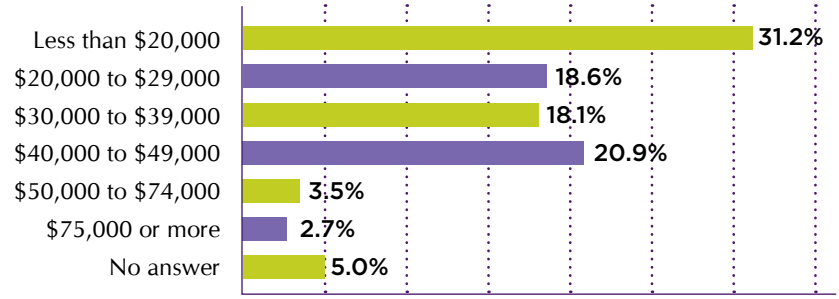
Type of School Attended

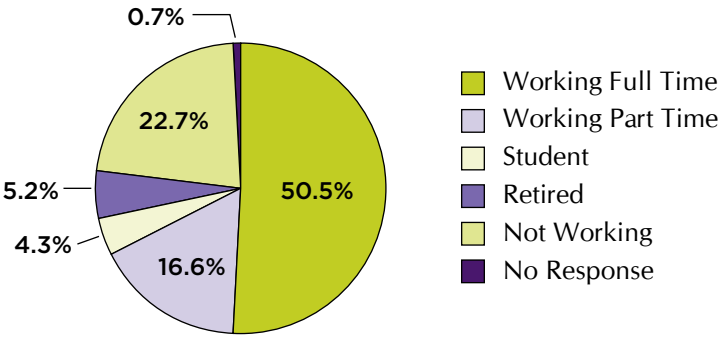
The high incidence of unmet need and concerns about behavioral health in school systems merits further research into any correlations between the type of school, level of education and location of school systems for children seeking behavioral health services.

Type of School	Number
Elementary (Public)	222
Elementary (Religious)	10
Charter School	17
Middle School	119
High School	128
Vocational School	1
Home School	6
Not Yet of School Age	29
Graduated, Working or Not in School	38
College	22
Not Answered	99

Family Income and Work Status

The majority of respondents have family incomes of less than $20,000 per year, and 90 percent earn less than $49,000 per year. This finding mirrors the federal poverty rankings reviewed in the county profiles (Appendix C-1) and reflects the uninsured/underinsured client base of local behavioral health providers.





B. Psychiatric Epidemiology

Behavioral Health Issues

Responses to the consumer survey indicate that mood disorders, including anxiety, are the most common behavioral health issues suspected, diagnosed or treated. The "Delta" column indicates the variance between the behavioral health issue first suspected and the issue ultimately treated. For mood disorders, the variance between "suspected of" and "treated for" is significant. Depression and ADHD/ADD also have high Delta values, while personality disorders, development delay and eating disorders are low. *Non-behavioral health clinicians and parents/guardians should be educated on the importance of addressing suspected issues in a proactive manner.*

Behavioral Health Issue	Suspected	Diagnosed	Treated	Delta
Mood Disorders (Including Anxiety)	310	272	151	121
Personality Disorders	98	91	88	3
Depression	115	103	40	63
ADHD/ADD	174	105	65	40
Substance Abuse	87	63	46	17
Autism Spectrum Disorders (Including Aspergers)	90	76	64	12
Developmental Delay	109	93	91	2
Eating Disorder	26	18	15	3

A detailed breakdown of mood disorders indicates high incidence of anxiety disorders, phobias and trauma-related PTSD. This detail further magnifies the importance of trauma-informed care.

Mood Disorders	Suspected	Diagnosed	Treated
Panic Disorder	13	12	7
Obsessive/Compulsive Disorder	5	4	3
Post-Traumatic Stress Disorder	19	19	19
Anxiety Disorder	144	130	82
Phobias	86	78	36
Social Phobia	*30*	*23*	*3*
Agoraphobia	*13*	*6*	*1*
Total	**310**	**272**	**151**

Age Onset

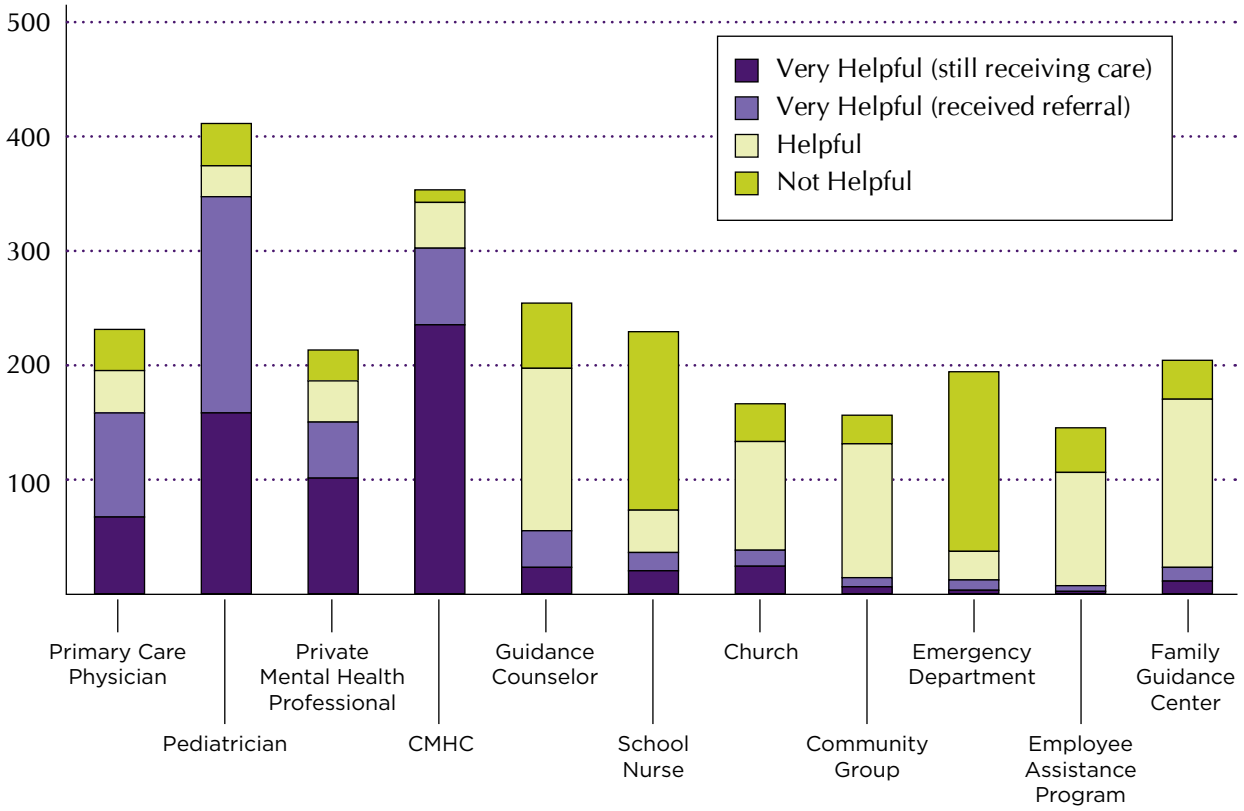
In the consumer survey, the age of the child at the onset of the behavioral health issue was slightly lower than that found in the national literature for review for anxiety and behavior disorders, and the same for mood disorders.

Mental Disorder	Age Onset (Literature Review)	Age Onset (Consumer Survey)
Anxiety Disorder	6	5
Behavior Disorder	11	9
Mood Disorder	13	13

C. Resources for Entry into Behavioral Health Services

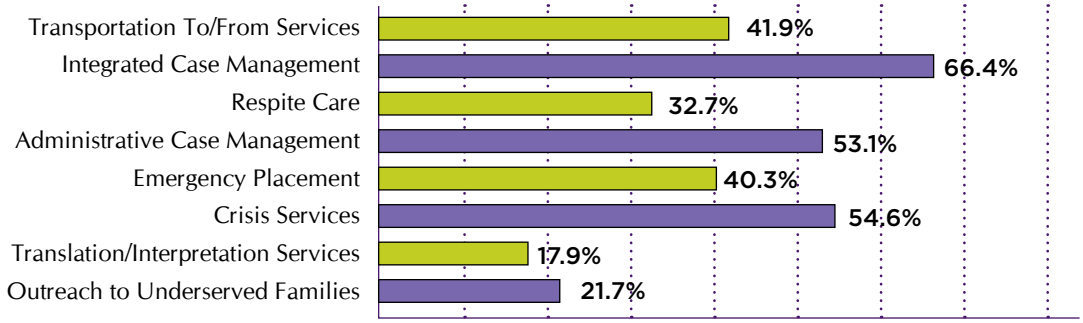
Helpfulness of Initial Source of Entry

When asked where they first turned for help and how effective that resource was, consumers gave the highest ratings (most helpful) to pediatricians, Community Mental Health Centers and private mental health practitioners. School nurses and emergency departments were among the least helpful.



D. Awareness of Available Resources

Consumers were asked whether they were aware of the available services listed below. Low use of these services by needy clients may indicate a low understanding of both availability and eligibility.



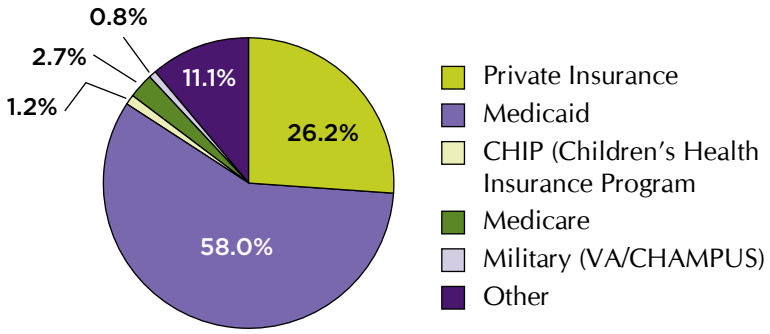
E. Access to Behavioral Health Services

Type of Insurance and Affordability

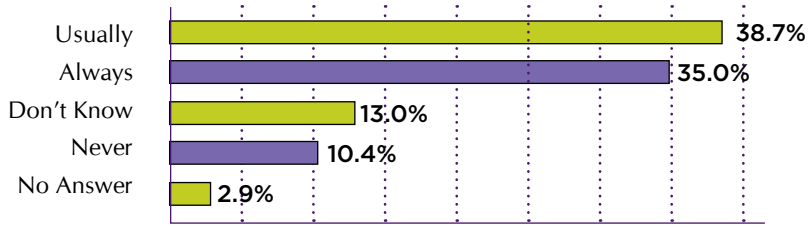
Most respondents were insured by Medicaid, followed by private insurance or other (described as limited employer-sponsored plans with poor behavioral health benefits).

Respondents were asked if the costs for behavioral health care services NOT covered by insurance were affordable. Of the 10.4 percent who said these costs were never affordable, all were privately insured.

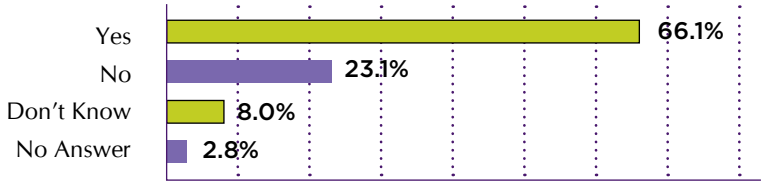
The number of respondents indicating difficulty meeting co-pays corresponds to those with private health insurance that offers limited or no behavioral health benefits.



Are costs not covered by health insurance affordable?

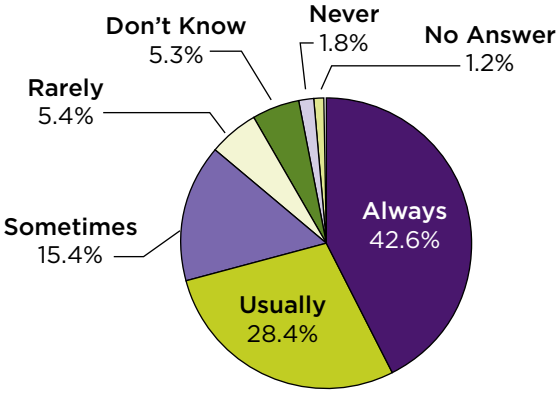


Are copays affordable?



Access to Specialists

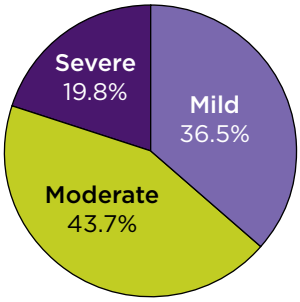
The majority of respondents with health insurance — 70 percent — said their plans always or usually allow their children to see other doctors that they need.



F. Acuity and History

Acuity

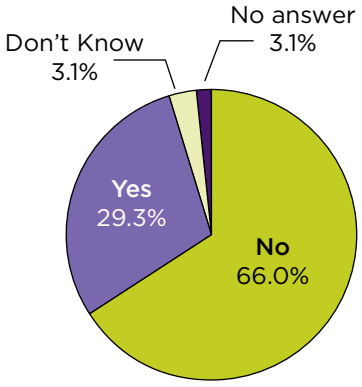
Respondents were asked to describe, or tell how their behavioral health care professional has described, the child's behavioral health issue as mild, moderate or severe. While self-reported, it was clear that most respondents provided classifications that had been made by behavioral health professionals. Only 7 percent of respondents did not answer this question.



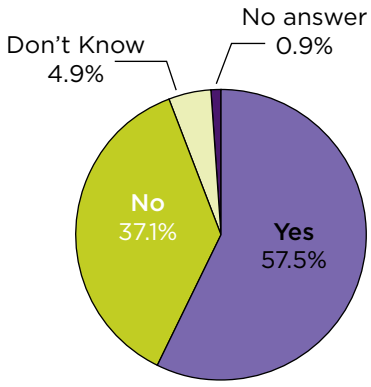
History

Almost 30 percent of respondents noted a prior history of abuse (emotional, sexual or physical) related to the child in the current or prior household.

The majority of respondents — 57.5 percent — reported a family history of mental health or substance abuse issues.



History of Abuse Related to Child



Family History of Mental Health/Substance Abuse

G. Presenting Issues

Mental Health and Substance Abuse Issues

More than 85 percent of respondents said the child had been diagnosed with a mental health issue. For the 2.9 percent who answered "not sure," there was confusion about whether overlapping issues of intellectual or developmental delays constituted mental health issues.

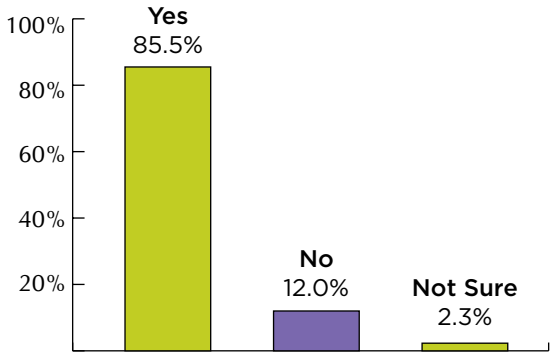
When asked if they had ever been referred to substance abuse counseling or treatment, an overwhelming 90.2 percent of respondents answered yes. Another 9.6 percent said no, and 0.2 percent chose not to answer.

Co-occuring Disorders

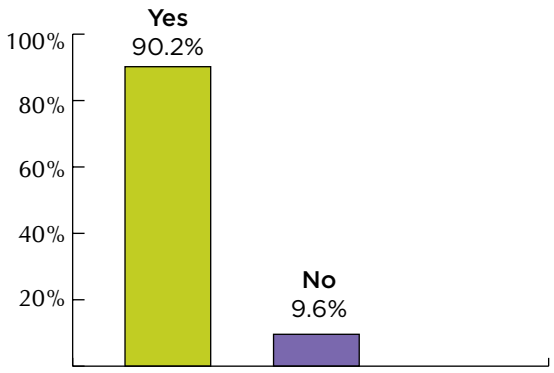
More than 90 percent of respondents indicated the child had been diagnosed as having both mental health and substance abuse issues.

Common psychiatric disorders seen in patients with co-occuring addiction issues include schizophrenia, bipolar disorder, borderline personality disorder, major depression, anxiety and mood disorders, post-traumatic stress disorder, pathological gambling, sexual and eating disorders, conduct disorders and attention-deficit disorder.

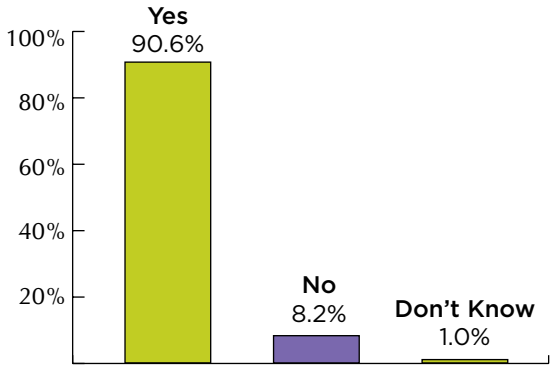
Patients being greated for mental health disorders also often abuse substances such as alcohol, nicotine, opiates, sedatives, stimulants, marijuana, hallucinogens and prescription drugs.



Diagnosis of Mental Health Issue



Referred for Substance Abuse Counseling or Treatment



Diagnosis of Both Mental Health and Substance Abuse Issues

H. Use-Need-Barrier-Gap Analysis Segmentation

Consumers were asked about services used, including the ease of care entry upon diagnosis and/or referral, service needs and their correlation to barriers ("need service and had trouble getting") and gaps ("need service and couldn't obtain"). A comparison of service use, needs, barriers and gaps for all respondents is provided on page 5. The charts below compare the rankings of all respondents to those of the three special populations — foster care, juvenile justice and transitional youth.

Use

The top three services *used* by all respondents — assessment, education and specialist treatment — were the same for the three special populations. Juvenile justice alone ranked crisis services in the top three.

USE COMPARISON			
Rank	**All Respondents**	**Rank**	**Foster Care**
1	Assessment of behavioral health issue	1	Assessment of behavioral health issue
2	Education to deal with behavioral health issue	2	Education to deal with behavioral health issue
3	Specialist to treat child	3	Specialist to treat child
4	Coordination with other systems of care	4	Crisis services when acute
5	Inpatient services	5	Coordination with other systems of care
6	Emergency placement	6	Transportation to/from services
7	Transportation to/from services	*7	Emergency placement
8	Intensive outpatient services	*7	Inpatient services
9	Respite care	8	Partial outpatient (day services)
10	Partial outpatient (day services)	9	Intensive outpatient services
11	Crisis services when acute	10	Respite care
12	Outpatient substance abuse	11	Outpatient substance abuse
13	Detoxification	12	Detoxification
14	Inpatient substance abuse	13	Inpatient substance abuse
Rank	**Juvenile Justice**	**Rank**	**Transitional Youth**
*1	Assessment of behavioral health issue	1	Assessment of behavioral health issue
*1	Education to deal with behavioral health issue	2	Education to deal with behavioral health issue
2	Specialist to treat child	3	Specialist to treat child
3	Crisis services when acute	4	Crisis services when acute
*4	Emergency placement	5	Coordination with other systems of care
*4	Inpatient services	6	Intensive outpatient services
5	Coordination with other systems of care	7	Emergency placement
6	Intensive outpatient services	8	Inpatient services
7	Transportation to/from services	9	Partial outpatient (day services)
8	Partial outpatient (day services)	10	Transportation to/from services
9	Respite care	11	Respite care
10	Detoxification		
*11	Outpatient substance abuse		
*11	Inpatient substance abuse		

Not all services were ranked by respondents in each category. * Indicates tied ranking.

Need

The top three services *needed* by all respondents were education, assessment and care coordination. These ranked 1–4 for the three special populations, with foster care children ranking care coordination higher.

NEED COMPARISON			
Rank	**All Respondents**	**Rank**	**Foster Care**
1	Education to deal with behavioral health issue	1	Assessment of behavioral health issue
2	Assessment of behavioral health issue	2	Coordination with other systems of care
3	Coordination with other systems of care	3	Education to deal with behavioral health issue
4	Specialist to treat child	4	Specialist to treat child
5	Respite care	5	Respite care
6	Transportation to/from services	6	Transportation to/from services
7	Crisis services when acute	7	Crisis services when acute
8	Emergency placement	8	Emergency placement
9	Inpatient services	9	Inpatient services
*10	Partial outpatient (day services)	*10	Partial outpatient (day services)
*10	Intensive outpatient services	*10	Intensive outpatient services
11	Outpatient substance abuse	*10	Outpatient substance abuse
12	Detoxification	11	Inpatient substance abuse
13	Inpatient substance abuse		
Rank	**Juvenile Justice**	**Rank**	**Transitional Youth**
1	Education to deal with behavioral health issue	1	Assessment of behavioral health issue
2	Assessment of behavioral health issue	2	Education to deal with behavioral health issue
3	Specialist to treat child	3	Coordination with other systems of care
4	Coordination with other systems of care	4	Specialist to treat child
5	Transportation to/from services	*5	Respite care
6	Respite care	*5	Transportation to/from services
7	Crisis services when acute	6	Partial outpatient (day services)
8	Partial outpatient (day services)	7	Intensive outpatient services
9	Emergency placement	*8	Crisis services when acute
*10	Inpatient services	*8	Emergency placement
*10	Intensive outpatient services	*8	Inpatient services
11	Detoxification		
12	Outpatient substance abuse		
13	Inpatient substance abuse		

Not all services were ranked by respondents in each category. * Indicates tied ranking.

Barriers

The top services that represented a *barrier* were similar for the three special populations and all respondents. Juvenile justice ranked education as a higher barrier to care resolution, and only transitional youth ranked crisis services in the top three.

BARRIER COMPARISON			
Rank	**All Respondents**	**Rank**	**Foster Care**
1	Coordination with other systems of care	1	Coordination with other systems of care
2	Transportation to/from services	2	Transportation to/from services
3	Respite care	3	Specialist to treat child
*4	Education to deal with behavioral health issue	4	Education to deal with behavioral health issue
*4	Specialist to treat child	5	Crisis services when acute
5	Crisis services when acute	*6	Emergency placement
6	Emergency placement	*6	Inpatient services
7	Assessment of behavioral health issue	7	Partial outpatient (day services)
*8	Inpatient services	*8	Intensive outpatient services
*8	Partial outpatient (day services)	*8	Assessment of behavioral health issue
*8	Intensive outpatient services		
9	Outpatient substance abuse		
Rank	**Juvenile Justice**	**Rank**	**Transitional Youth**
1	Coordination with other systems of care	1	Coordination with other systems of care
2	Specialist to treat child	2	Transportation to/from services
*3	Education to deal with behavioral health issue	*3	Crisis services when acute
*3	Coordination with other systems of care	*3	Respite care
*4	Crisis services when acute	*4	Assessment of behavioral health issue
*4	Respite care	*4	Education to deal with behavioral health issue
*5	Assessment of behavioral health issue	*4	Emergency placement
*5	Inpatient services	*4	Partial outpatient (day services)
6	Emergency placement		
*7	Partial outpatient (day services)		
*7	Intensive outpatient services		

Not all services were ranked by respondents in each category. * Indicates tied ranking.

Gaps

The top service identified as a *gap* was the same for all respondents and two of the three special populations — coordination with other systems of care.

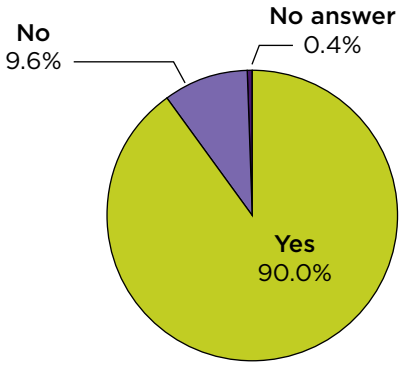
GAP COMPARISON			
Rank	**All Respondents**	**Rank**	**Foster Care**
1	Coordination with other systems of care	1	Coordination with other systems of care
2	Transportation to/from services	2	Respite care
3	Specialist to treat child	3	Transportation to/from services
4	Crisis services when acute	4	Crisis services when acute
5	Respite care	*5	Specialist to treat child
6	Emergency placement	*5	Emergency placement
7	Education to deal with behavioral health issue	6	Inpatient services
*8	Inpatient services	*7	Assessment of behavioral health issue
*8	Partial outpatient (day services)	*7	Education to deal with behavioral health issue
*8	Intensive outpatient services	*7	Intensive outpatient services
Rank	**Juvenile Justice**	**Rank**	**Transitional Youth**
1	Coordination with other systems of care	1	Inpatient substance abuse
2	Emergency placement	2	Transportation to/from services
3	Transportation to/from services	3	Crisis services when acute
*4	Crisis services when acute	*4	Education to deal with behavioral health issue
*4	Partial outpatient (day services)	*4	Inpatient services
*4	Respite care	*5	Assessment of behavioral health issue
*5	Education to deal with behavioral health issue	*5	Specialist to treat child
*5	Specialist to treat child	*5	Coordination with other systems of care
*5	Intensive outpatient services		
*6	Assessment of behavioral health issue		
*6	Inpatient services		
*6	Detoxification		
*6	Outpatient substance abuse		
*6	Inpatient substance abuse		

Not all services were ranked by respondents in each category. * Indicates tied ranking.

I. Unmet Needs

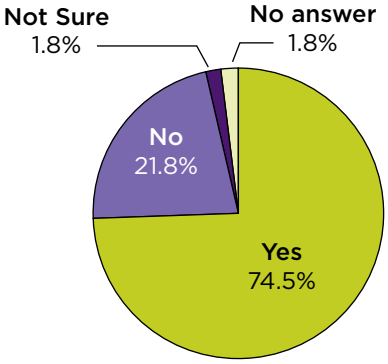
Mental Health

Of those respondents who indicated that the child had been diagnosed with a mental health issue, nearly 10 percent had not received mental health counseling.



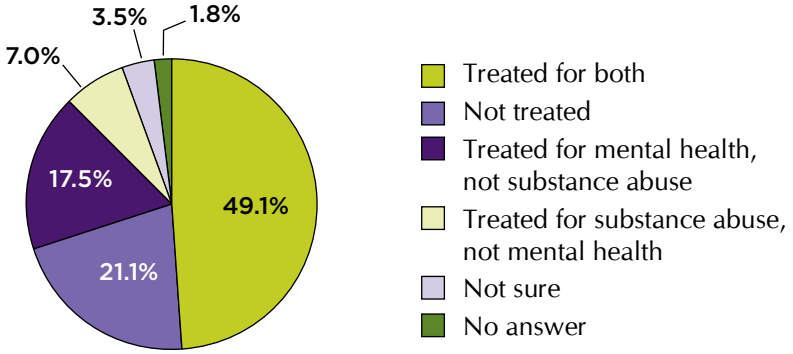
Substance Abuse

Of those respondents who indicated that the child had been diagnosed with a substance abuse issue, more than 20 percent said they had not received threatment.



Co-Occuring Disorders

Of those respondents who indicated that the child had been diagnosed with both a mental health and a substance abuse issue, 15 percent said they had received no treatment, while 36 percent had received treatment for one issue but not both.



Reasons for not seeking treatment	Resolved issue	Didn't like services	Didn't like providers	Didn't have transportation	Time/Day of services didn't work	Couldn't afford services	Could afford service, not copay	Scared	Afraid others would find out	Don't know
Didn't receive mental health treatment	2	1	3	3	0	1	1	2	1	1
Didn't receive substance abuse treatment	3	0	0	1	0	0	1	2	0	1
Didn't receive mental health or substance abuse treatment	6	0	0	2	0	0	0	1	0	0
Received mental health but not substance abuse treatment	10	0	0	2	0	0	0	1	1	0
Received substance abuse but not mental health treatment	5	0	0	1	0	0	0	1	0	0

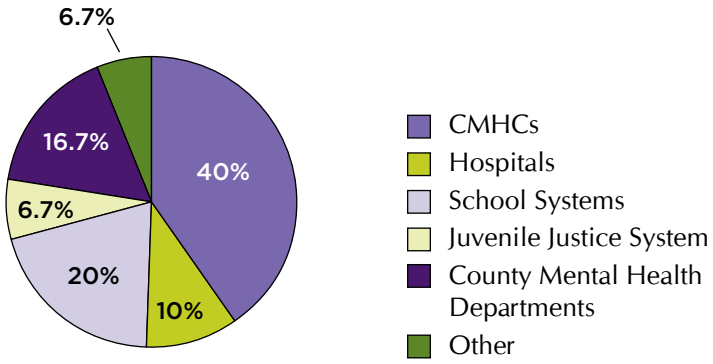
2. Provider Survey

In addition to consumers, 30 behavioral health care providers were surveyed to inform the analysis of children's behavioral health needs in Greater Kansas City. The providers surveyed included community mental health centers, school systems, psychiatric residential treatment facilities, psychiatric divisions or departments at two children's hospitals, mental health/substance abuse boards, the Missouri Department of Mental Health, the Kansas Department of Social and Rehabilitation Services, and private behavioral health care practices.

A. Organization Characteristics

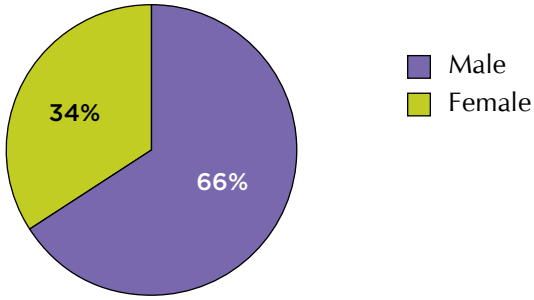
Type of Provider

The majority (40 percent) of providers responding to the survey were Community Mental Health Centers (CMHCs), while 20 percent were from school systems. These percentages are closely correlated to the consumer survey respondents, 40 percent of whom were clients of CMHCs and 18 percent from school systems.



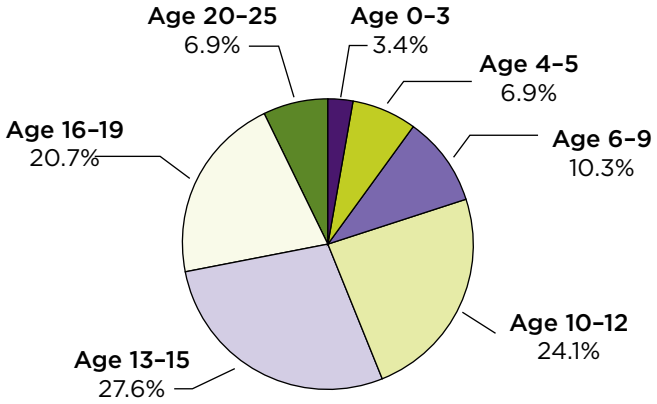
Client Gender

The gender split (two-thirds male and one-third female) noted by providers is consistent with results of the consumer survey and comparable to national statistics for children's behavioral health. This split is the reverse of the gender breakdown normally seen in adult behavioral health.



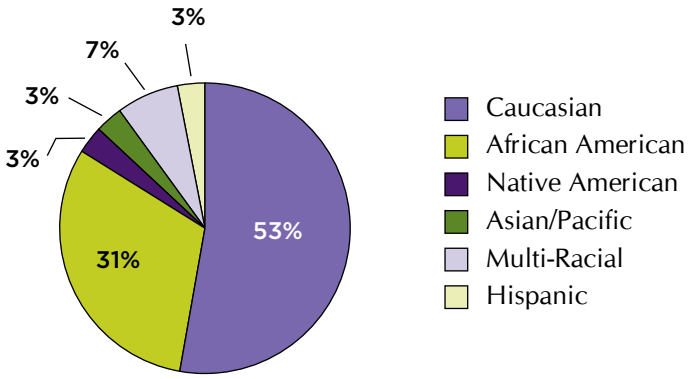
Client Age Range

The age ranges given by providers for their pediatric behavioral health clients varied somewhat from those given by respondents to the consumer survey (page 16). In the consumer survey, 36 percent of children fell in the lowest three age categories (under age 9), while in the provider survey only 20 percent were in those age groups. Concerns have been raised about late entry into behavioral health care, despite numerous studies indicating the early onset of mental health issues.



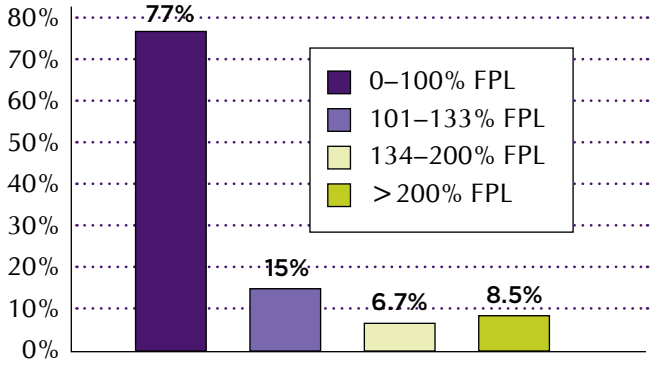
Clients' Racial or Ethnic Background

The majority of behavioral health clients were white or African American. Very few were identified as Hispanic or multi-racial, despite local studies that indicate Hispanic clients now represent about 9 percent of children or youth suffering from mental illness. However, in a separate survey question, providers identified 10 percent of their clients as having an Hispanic or Latino ethnic background, indicating there may have been some confusion among providers on ethnicity vs. race.



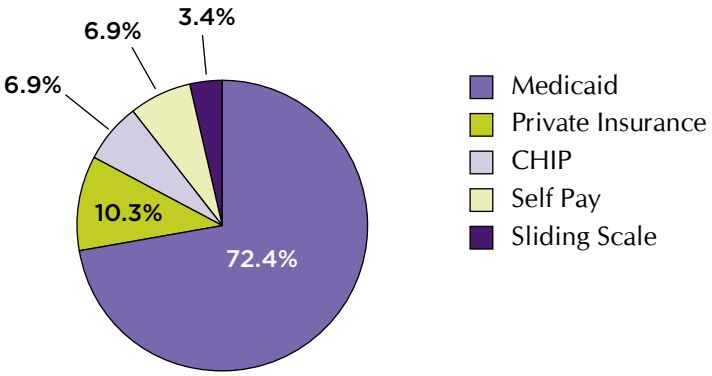
Poverty Level

Providers reported that 98 percent of their clients have incomes below 200 percent of Federal Poverty Level, consistent with the 94 percent reported in the consumer survey.



Payment Types

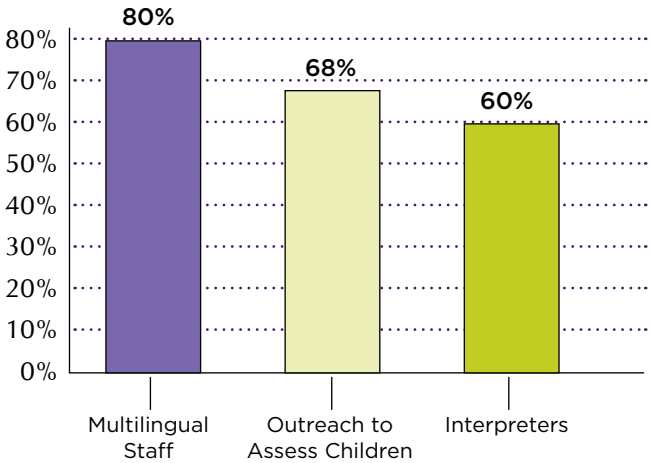
Providers reported that Medicaid was the most common method of payment (72 percent) for their behavioral health clients, followed by private insurance, Children's Health Insurance Program (CHIP) and self pay.



B. Programs/Services Offered

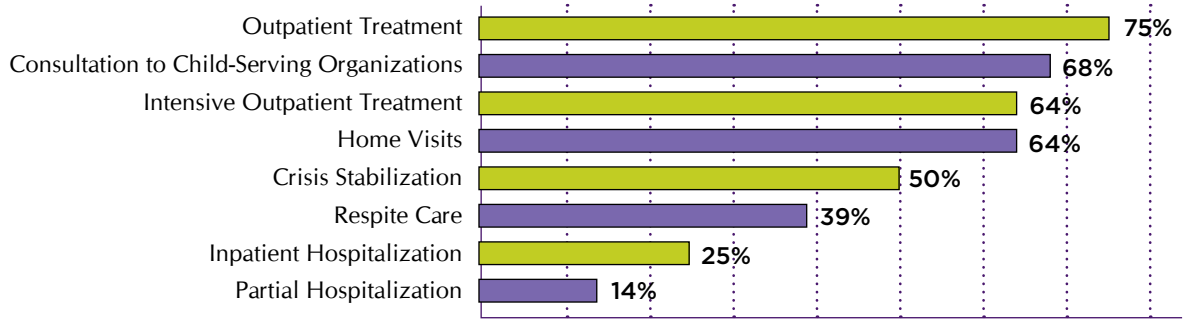
Targeted Services

The majority of providers surveyed offer both multicultural and multilingual services.



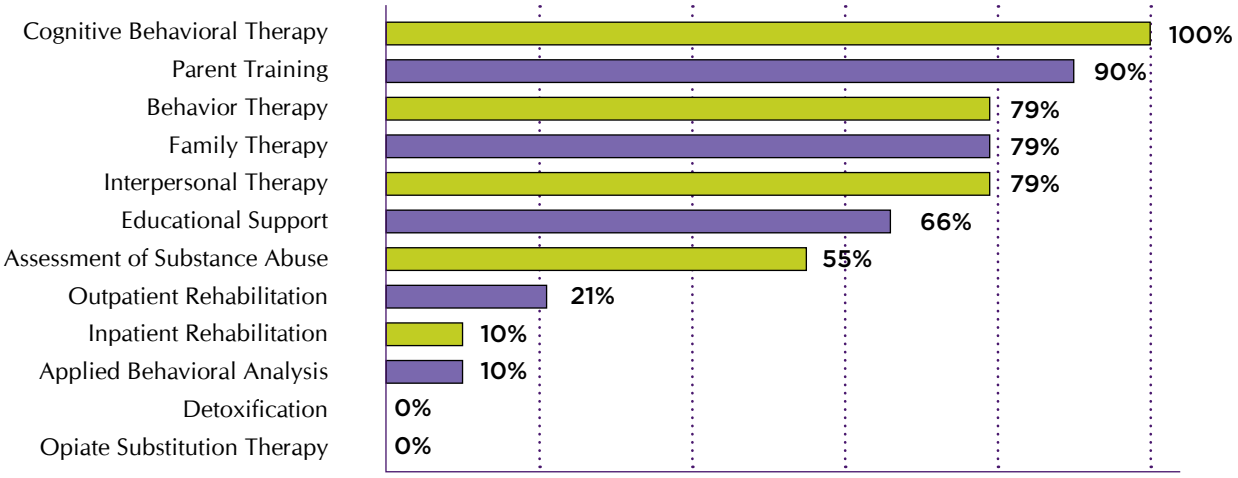
Programs for Children and Families

Providers were asked to identify the types of programs they offer children and families. Outpatient treatment for ambulatory behavioral health clients was the most prevalent type of service offered, followed by consultation, intensive outpatient treatment, home visits and crisis stabilization.



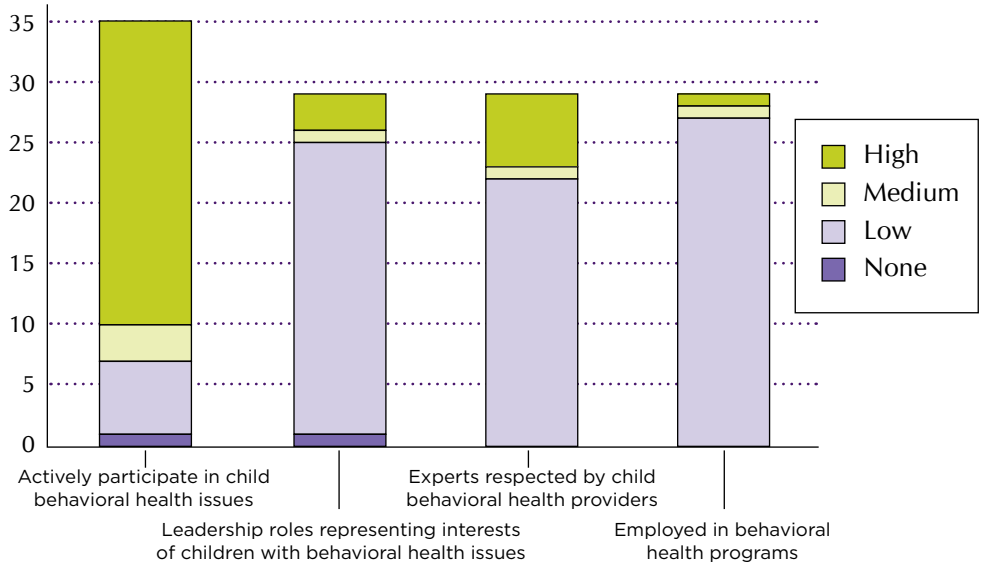
Evidence-Based Child and Adolescent Intervention

Providers were also surveyed about the types of evidence-based interventions — such as assessment, training and education, therapy, and rehabilitation — offered to children and families.



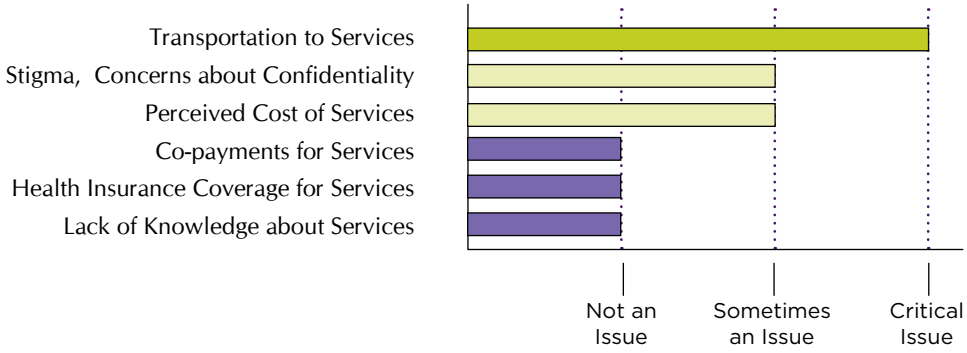
C. Consumer-Driven Care

Providers were asked to rate the amount of consumer involvement in child behavioral health services in their communities as high, medium, low or none.



D. Barriers and Gaps

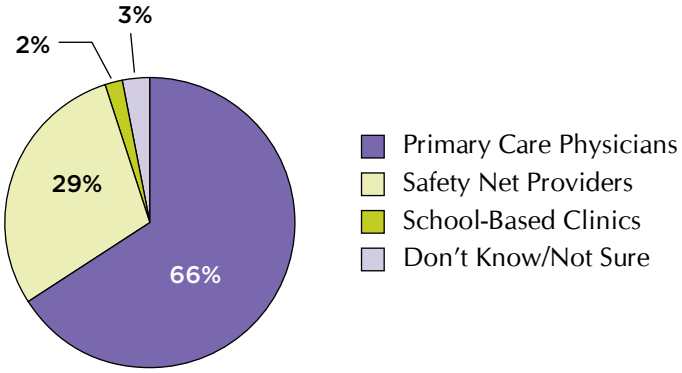
The provider perspective on barriers to behavioral health service access differed from the consumer perspective, with transportation ranking as the highest perceived barrier. Providers also rated concerns about stigma/confidentiality and perceived costs as significant barriers.



D. Integration of Physical and Behavioral Health

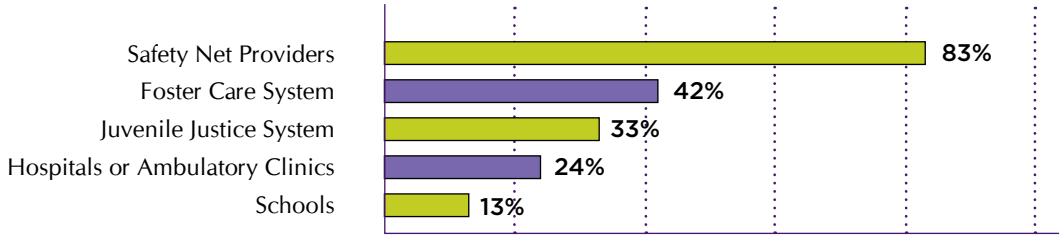
Physical Health Care Services

Most providers surveyed indicated that their clients receive physical health care services from primary care physicians. A combined 32 percent — almost one-third — use safety net providers and school-based clinics.



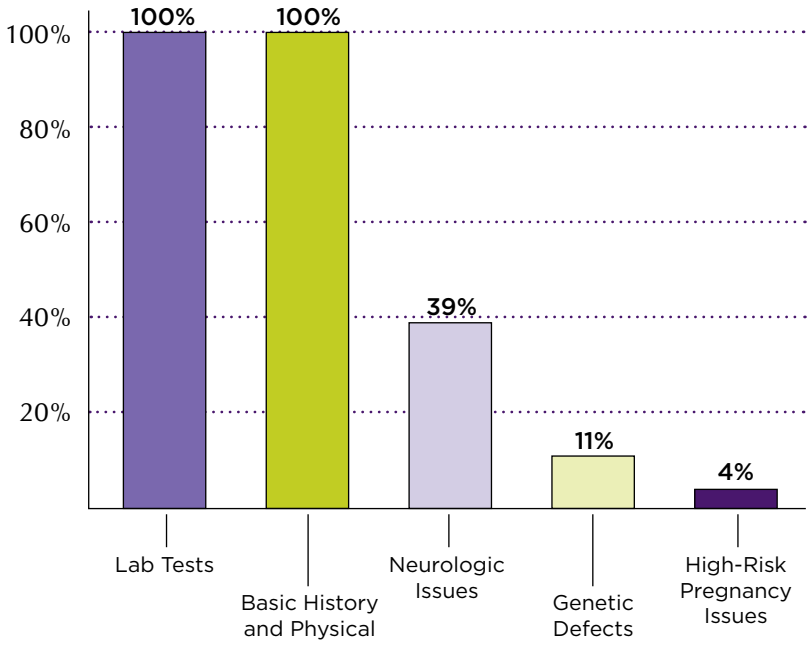
Referrals from Physical Health Care Providers

When asked what physical health care providers refer clients to them for behavioral health care, more than 80 percent of providers said they receive referrals from safety net clinics. Foster care and juvenile justice systems also referred significant numbers of clients.



Physical Health Screening by Behavioral Health Providers

Behavioral health care providers surveyed commonly monitor basic physical health, conducting patient histories and physicals and ordering lab tests, but most do not screen for behaviorally related issues such as neurologic deficits, genetic defects or a maternal history of high-risk pregnancies.



Ideal Integration Concepts

When asked about ideal concepts for integrating behavioral and physical health care, all providers surveyed said that physical health care providers should be available at behavioral health locations and vice versa. All also recommended dynamic referral and expedited treatment protocols. Three-quarters of the providers named co-located services and screening, brief intervention, referral and treatment protocols as ideal concepts.

Barriers to Integration

The issues providers identified as barriers to the integration of behavioral and physical health stem primarily from different reimbursement systems (time-based vs. encounter-based), followed by physician vs. therapist driven systems of care, time limitations for adequate screening in physical health settings, and lack of screening protocols.

3. Intensive Interviews

In addition to the consumer and provider surveys, a series of intensive interviews were held with key informants as part of the primary research for this analysis of children's behavioral health needs in Greater Kansas City. The interviews were conducted in 2011, and included four sectors: community mental health centers, psychiatric residential treatment facilities, psychiatric divisions or departments at regional children's hospitals, and selected school systems and preschools.

A. Community Mental Health Centers

Tri-County Mental Health Services

Tri-County Mental Health Services (TCMHS) works to bring a full range of confidential, affordable and effective behavioral health services to the residents of Clay, Platte and Ray counties in Missouri. TCMHS exists to provide prevention and recovery-oriented mental health and substance abuse services which are quality assured and responsive to consumer needs.

Key discussion points:

- In 2008, the children's inpatient unit at the Western Missouri Mental Health Center was closed, and children of last resort were farmed out to safety net providers. These children were difficult to serve, with uncertainty about what type of system was needed to minimize inpatient cases. The Children's Enhancement Project was created to provide resources to treated difficult kids. The CEP, largely comprised of professional parent homes and intensive in-home services, as seen its budget fall from $1.5 million to $750,000.
- The children's behavioral health system serves worried-well and mild cases well; is adequate for moderate severity; and does not handle severe cases as well as it should.
- School-based emotional issues are on the rise, with increased severity and explosive violence related to the lack of an inpatient resource and numerous environmental stressors, including a worsening economy, absence of one or both parents (some due to military obligations), and drug use by parents.
- The Northland instituted a tax levy which provides $4 million, helping to fund more services than Jackson County can provide with its $1.5 million levy.
- Further comparison of the adult behavioral health system to the child behavioral health system is warranted, as is comparison of the child behavioral health systems in the two states, Missouri and Kansas. The states treat the triad of developmentally/intellectually disabled, mental health and substance abuse differently, with issues of supply and demand along the care continuum.

Comprehensive Mental Health Services

Established in 1969, Comprehensive Mental Health Services, Inc. (CMHS) is a community mental health and substance abuse treatment center that describes its mission as providing the highest quality of behavioral services, in partnership with individuals, families and the community. CMHS is a community-based organization that primarily serves the needs of eastern Jackson County, Mo. It has eight locations, five of which are oriented towards mental health and three towards substance abuse. CMHS also provides mental health first aid to community health care providers, including first responders. It offers four programs that serve families and children:

- Youth Targeted Case Management/Community Psychiatric Rehabilitation — Case managers provide services on a weekly basis to help children and youth with behavioral health issues

remain in their homes. Case managers can help coordinate care among a variety of community social service and treatment providers, referring families to needed services, acting as an advocate and monitoring treatment plans.

- CSTAR Adolescent Drug and Alcohol Rehabilitation — CSTAR provides intensive, community-based outpatient treatment services for youth ages 12–18 who have a substance use, abuse or dependency problem. Three levels of care can be provided, from one to five days per week depending on need. The program has a limited capacity to provide for specialized foster care for youth who need to be away from their own homes for a period of time in order to begin work on their substance abuse issues. Services provided include substance abuse education, individual and group substance abuse counseling, family therapy and case management. CSTAR staff coordinates with schools and other community social service and treatment providers to provide a continuity of care for the youth in the program.

- School Services — In the school program, services include ndividual and family treatment, group counseling and education, parent and child education on mental health issues, sexual abuse prevention, teacher education, teacher and school staff consultation, and drug education and prevention. Services are provided on-site at numerous schools in Eastern Jackson County.

- Treatment Family Home and Respite Care — Treatment Family Home providers are foster families specially trained to provide care for children and youth with severe emotional and behavior disorders and/or with substance abuse problems. Children and youth admitted for services need an out-of-home placement, but not the intensive care provided by a psychiatric residential treatment center. The length of stay in the Treatment Family Home program ranges from several weeks to several months, based on clinical need. Treatment Family Home providers are also available for respite care services. Respite care provides short-term care (one to two weekends per month). Respite care can be used when a child or youth is in crisis but does not need an inpatient psychiatric facility. Respite care is used to maintain at-risk children in their homes and communities.

Truman Medical Center

Truman Medical Center (TMC) has four primary care clinics that serve more than 15,000 uninsured and underinsured individuals with behavioral health care needs each year. For more than four decades, TMC Behavioral Health has been a leader in providing mental health and substance abuse services to the people of Kansas City. Driven by a mission to provide services that support wellness, TMC Behavioral Health recognizes that emotional well-being and physical health are closely connected. Services address many and varied issues through the continuum of life — from birth to bereavement — that impact the health and happiness of individuals and families.

The interview focused on TMC's Futures Program, which focuses on children and families. Futures serves children, adolescents and transition-aged youth with a serious emotional disturbance (SEC) or serious and persistent mental illness (SPMI) up to age 25. Services include community psychiatric rehabilitation; individual, family, and group therapy; psychiatry; psychology; psychosocial rehabilitation; peer support; and family support.

Key discussion points:

- Consumers should be involved in the development and delivery of services at all levels of the organization. Assessment and documentation should be in a language the consumer understands. In addition to consumer advisory councils, organizations could invite and support consumers to serve on committees, departmental meetings and agency boards.

- There is a lack of developmentally appropriate supported living environments for young adults. To address this issue, TMC is partnering with a local developer to create a developmentally appropriate and trauma-informed apartment complex. Other developmentally appropriate options should be explored for young adults who would require a higher level of assistance to live in the community.
- Providers often use terms like "person-centered," "strengths-based," etc., but actual services do not always reflect these principles. For an organization to become person-centered, strengths-based, trauma-informed, etc., requires a culture shift, not just a new vocabulary.
- Residential placement is often seen as the first intervention of choice, before less restrictive interventions have been tried. The Children's Enhancement Project has demonstrated that when given the freedom to use funds in a flexible and creative manner, interventions can be created and tailored to the unique need of the individual, preventing the need for residential placement for many consumers.
- Funding often dictates how services are provided. Separate funding for MR/DD, CPS, ADA, Children's Division and Family Courts can create artificial barriers to collaboration. While inter-agency agreements to share in funding are possible, differing divisions have various restrictions about how their dollars can be used.
- Eligibility criteria for adult mental health services are very different from children's mental health services. This can be a significant barrier in the young person's transition from adolescence to adulthood.
- More mental health services are needed in schools. For a CMHC/school partnership to be successful, it is necessary to have clear leadership and buy-in from all stakeholders. Ideally, service providers should be able to bill Medicaid for therapy services provided in a school.

Wyandot Center PACES

For a young person struggling with mental, emotional or behavioral challenges, life becomes a series of bewildering twists and turns. In spite of their best efforts, families can be overwhelmed by the obstacles. Wyandot Center's PACES program helps children and families find their way out of this maze. PACES services are offered to residents of Wyandotte County, Kan., using a sliding fee scale based on family size and household income.

PACES services include case management; youth support and enrichment opportunities; parent support; groups to learn and model behavioral skills; psychiatric services and medicine clinic; adolescent outpatient substance abuse treatment; Wyandot Academy, offering specialized day treatment in a school setting; crisis respite care for families; Project Redirect for youth and families involved with the court system, or who have had involvement with the Juvenile Intake and Assessment Center; and school-based programs training youth in peer counseling and HIV prevention.

Key discussion points:

- Psychiatric residential treatment facilities are often over-used. Flaws in the system allow them to be deployed as an initial strategy, rather than after outpatient or community-based care fails.
- Kids may end up recycling through the residential system, becoming 'hardened' and losing contact with family. lThis can lead to worse outcomes, including secondary traumatization due to separation from family.
- In the 1990s, mental health reform moved reimbursement from state hospitals to community mental health system. The focus changed from school and home-based to institutional care.

In 2007, the behavioral health care system 'drifted' with the loss of effort by the child welfare system to retain kids in the community, especially in homes. In recent years, there has been a lack of rehabilitative services for kids. It is a myth that rehabilitation can occur effectively in outpatient settings. Over the last seven years, the system has seen the removal of complementary or support/wrap-around services.

B. Psychiatric Residential Treatment Facilities

Crittenton Children's Center

Crittenton's clients include foster care children and juvenile justice youth. Crittenton offers a pre-adolescent unit, an adolescent unit, and in-home services. Transitioning youth comprise a significant population.

Crittenton is the first provider south of the Iowa border to provide children's psychiatric hospital services, and it is the only such provider in four states (Kansas, Missouri, Iowa and Nebraska). It includes a 54-bed hospital and a 64-bed residential unit for youth ages 13 to 18. The hospital accommodates children ages five to 18, and can also serve children as young as age three. It is the only hospital in the Kansas City area with a pre-adolescent unit.

Specialized residential beds are available for intensive residential, children who are privately insured and TriCare recipients (Wisconsin, South Dakota, Nebraska, Kansas and Missouri). A juvenile aggressions unit covers Iowa and Illinois in addition to Kansas and Missouri. Children as young as five with significant history of psychological trauma can be admitted to this unit. Foster care referrals come primarily from Jackson County, with some from Cass County.

Crittenton uses four evidence-based practices: Dialectical Behavior Therapy (DBT), used for spectrum mood disorders, bipolar disorders, sex abuse and chemical dependency; Eye Movement Desensitization and Reprocessing (EMDR), used for post-traumatic stress disorder; Trauma-Focused Cognitive Behavioral Therapy (TFCBT), used for child & parent issues and PTSD; and Chemical Dependency Intensive Outpatient Program (CDIOP), used for substance use for transitioning youth.

Crittenton Community Support offers a transition program for families that have children ages three to 18 in the hospital, with limited meetings for residential youth and their families. This family therapy is designed to prevent re-hospitalizations and to connect the family to the community.

Spofford Home

Since 1916, Spofford has been a leading provider of prevention and therapeutic treatment services for children ages four to 12 suffering from the effects of physical and sexual abuse, neglect, and mental health disorders. Services include residential treatment, school-based case management, SCAMPS summer day camp and additional specialized services. At the time of the interview, Spofford was serving 50 residential patients; 10 transitioning youth through its Family Focus outpatient program; and 40 indivduals through its school-based program.

Key Discussion Points

- State policies and budget cuts are a concern. Recent policy changes in Kansas have been interpreted to reduce the number of children placed or re-enrolled in residential settings. Initial placement approves a 90-day stay, with rescreening or "re-up" documentation required every 30–60 days.
- Facilities can have difficulty with cash flow as a result of differing state policies. Missouri reimburses Psychiatric Residential Treatment Facilities (PRTFs) for the bed day, and therapies must be separately billed once per week. Kansas historically reimburses with a bundled rate

or per diem that includes therapeutic interventions. The Kansas Department of Children and Families conducts ongoing audits of a PRTF stay vs. the Missouri Department of Mental Health's unaudited authorizations.

- Spofford continues to track children after discharge to ensure that they are recovering, with referral linkage tracking into community-based mental health centers and some children with co-occurring behavioral and physical health issues into acute care hospitals.
- There is a common sense in the behavioral health community that 'residential' is a bad word. There are perceptions that residential treatment 'doesn't work,' that children placed in residential settings stay too long, and that these children, once placed, cycle back in. The truth is that PRTFs have a strong, traditional co-occurring emphasis on substance abuse and mental health, strong medical case management, and skills-based orientation for child and family in school and family settings.
- Missouri's MAP testing (Missouri Assessment Project or Measures of Academic Progress) and "No Child Left Behind" have resulted in a scores- or achievement-based system for teachers and administrative personnel with no or little time left for individualized attention in schools. There is a tendency to place children with behavioral health issues into special education.
- Schools often 'mainstream' all children with little or no flexibility or freedom. Children with behavioral health issues need customization through individualized instruction, smaller classroom settings, sn emphasis on appropriate behavior in the classroom, and intense modeling/ coaching by and with the teacher.
- At Spofford, special education materials and functional assessments are specifically tailored to each child, with an emphasis on safety of the child and the adults with whom he or she will interact (teachers, parents and others) and on helping the child attain emotional management. The key objective is for the parent to know what to do when the child acts out. Coping and de-escalation skills are components of this family training.
- Disease attitudes are a concern. There is a perception that many children 'grow out of' behavioral health issues, especially for very young children. Pediatricians, psychologists and therapists may erratically refer young children into and out of behavioral health services until they reach eight to 10 years of age, when more intensive treatment of persistent symptoms is the norm.
- Families need help navigating a fragmented and confusing system. Extreme assistance is required for families of children with behavioral health issues due to multiple, fragmented and over-lapping funding systems. This is especially true for families of children with co-occurring disorders (behavioral and physical health).
- Integration among PRFTs, CMHCs and other systems of care is essential. Many families are so stressed to pay for intense care that they must relinquish custody of their child to get help. Authorizations by regional CMHCs for after-care range widely, from 30 days post-PRTF to six months.
- Private insurance does not understand residential care and treats it like an acute care hospitalization. Many insurers require weekly authorizations to approve four-hour treatment schedules, compared to Medicaid or CHIP authorizations that allow weekly or monthly unlimited intensive therapy sessions. Using a physician vs. counselor focus, they often presume a quick 'fix.' Respite care is often denied, despite state approval of this service as a medical necessity for children placed in residential settings.

- There is often a perception that children in PRTFs need to go off medication. The reality is that many of these children, prior to a residential admission, have typically been on psychotropic medications. A baseline is conducted upon admission specific to their diagnosis or diagnoses.

C. Children's Hospitals

Children's Mercy Hospital

Children's Mercy Hospitals and Clinics is a comprehensive pediatric medical center, with the only free-standing children's hospital between St. Louis and Denver. Children's Mercy provides state-of-the-art care for children from birth to age 18 from throughout Missouri and Kansas and beyond.

Key Discussion Points

- The Department of Mental Health typically divides children's behavioral health issues into three major sections -— mental retardation/developmental disabilities, psychiatric services, and substance abuse — and there is an assumption that all patients neatly fit into one of these three sections. Children 'ping-pong' among the three, often fitting uneasily into one section though their clinical conditions could qualify for all three. Dually or triply diagnosed ('co-occurring') conditions in children include:
    - Autism spectrum disorder and mental health/severely emotionally disturbed
    - Mentally retarded/developmentally disabled with behavioral (often mental) health condition
    - Mental health and substance abuse (classic 'co-occurring')
    - Mental health and physical health condition (prime for bi-directionally integrated)
- Budgets for the Missouri Department of Mental Health and the Kansas Department of Chidren and Families have been steadily decreasing since the 1980s. Their share of the total state budget has retracted from 10 percent to a current 6 percent despite greater need, flat or increased use of services, and increased severity. Inpatient or residential units have been closed, with conversion to a community or outpatient based system of care.
- Deficits in the service continuum include a lack of critical-access, wrap-around services; lack of an inpatient component despite increased severity and need; a focus on group homes, moving to residential vs. inpatient settings; the increase and rise of Autism Spectrum Disorder, including milder forms such as Asperger's syndrome.
- The need for further integration of physical and behavioral health is pronounced, with the ability for children to remain home-based if they can be followed regularly through a true partnership between behavioral health and physical health providers.
- Another issue is coordination of care for transitioning youth who reach adulthood and aren't sure where or how to receive services but can't live independently.
- On a positive note, the Missouri Department of Insurance invested in care for Autism Spectrum Disorder, mandating that private insurers cover this care up to a $40,000 cap per year. Three centers for ASD have been formed in Missouri — Children's Mercy in Kansas City, one in Columbia and one in St. Louis.

University of Kansas Hospital — Department of Adolescent Psychiatry

Child psychiatrists at the University of Kansas Hospital are medical doctors with at least three years of residency training in general psychiatry and an additional two years in child psychiatry. These doctors specialize in the diagnosis and treatment of mental, behavioral and developmental disorders in children and adolescents, using a team approach to diagnosis and treatment. They are also faculty members at the University of Kansas School of Medicine and participate in national research projects.

The University's TeleKidcare® program uses Internet videoconferencing to provide face-to-face care for students who can't travel to the clinic. TeleKidcare reaches children and adolescents at schools, child care centers, mental health centers and rural clinics.

Key discussion points:

- The primary support system for children with behavioral health issues is often the primary care physician and not a mental health provider.
- The school system is a major focus for care currently not provided or assessed.
- The role of faith-based organizations in behavioral health should be explored.
- There is a need to clarify the role of psychologists or psychiatrists in referrals from primary care, school or social service organizations.

D. School Systems

Operation Safe Base — Iola, Kan., USD #257

Operation Safe Base is a fee-free program for low-income families in the small, rural community of Iola, Kan. For the past four years, Operation Safe Base has used grant funding to support a program that helps children receive free immunizations, physicals, vision care, head lice checks and treatment, dental care and school supplies. Operation Safe Base received a grant from the REACH Foundation to fund a comprehensive physical fitness and behavioral health intervention. This program involved three elementary schools and two counselors with activities that included dental health, mental health and physical activities. It focused on children of drug-addicted parents, many of whom had developmental disabilities.

Key discussion points:

- Children in this largely rural community need better structure in a comprehensive physical and behavioral health delivery system to ensure care while reducing the stigma of receiving behavioral health services; a 'Place Matters' emphasis, with a focus on children with one or both parents in significant substance abuse situations (largely crystal meth) that has resulted in the child often being placed in foster care; better data or some type of registry to determine what interventions work best; and a prevention focus to understand how to head off the issues of not having a good starting place or trust of parents or adult guardians.
- Barriers include parental push-back, with a lack of understanding or willingness to have their children receive behavioral health services; the need for individual counseling versus the tendency to place children in groups, since stigma is a major issue in small rural areas; and the need to teach children life skills given the unstable situation of many parents and families.

Early Head Start Programs (El Centro and Mattie Rhodes)

Early Head Start works to foster the healthy development of children from prenatal care through age three across all areas of development (physical, cognitive, social-emotional and language). Early Head Start also engages parents in their role as the primary caregiver and teacher of their children.

Key discussion points:

- Early Head Start children are often underserved in all aspects of their life. Seeds must be sown early to impact any type of outcome other than a life of poverty. Service provision should be designed to intervene prior to crisis points.
- Provide support to immigrant children to give them skills to have good physical and mental health. Focus on literacy, especially for Spanish-speaking individuals many of whom are illiterate in their own language. Language barriers often make parent-teacher conferences difficult or impossible.
- There is a cultural divide on standardized, quantitative focus of the current educational system.
- Many children with behavioral health issues are expelled from school systems, with a high percentage of teens not in school.
- Build on successes such as Project Eagle, an effort by Early Head Start to assess every child in Wyandotte County and identify toxic living conditions leading to behavioral health issues at an early age.
- In Mexican culture, many parents believe that children should be sent to school later and not to early pre-school. Many have with issues of citizenship; cultural discomfort with mental and physical health treatment, believing this betrays personal weakness or defect; issues with support services, such as a lack of transportation or housing; and different ways of interacting (strong familial social networks, often distrustful of neighbors).
- Fear of any authority figure is an issue for many undocumented immigrants.
- The system is not prepared to handle the cultural diverse nature of the emerging demographic mix, including the influx of immigrants from Somalia, Vietnam and other areas.

Appendix C: Secondary Research

The secondary research conducted for this needs assessment includes profiles of each of the counties included in the study; a review of relevant literature; a scan of current policies in both Kansas and Missouri and at the national level; and an overview of the continuum of care in Greater Kansas City and currently available resources.

1. County Profiles

County profiles were developed using census data to provide a baseline of the pediatric population (ages 0–25) in the counties studied. The bistate study area includes Cass, Jackson and Lafayette counties in Missouri, along with the portions of Clay and Platte counties that comprise Kansas City North; and Allen, Johnson and Wyandotte counties in Kansas. In addition to census data, socioeconomic information (e.g., federal poverty level) and behavioral risk data were provided. The general population data was compared with the demographic data of Consumer Survey respondents to determine any disparities or variance between the general pediatric population in the study area and that of survey respondents.

A. Demographics

The tables below compare the pediatric population (ages 0–25), gender, age at diagnosis and race/ethnicity for the general population (entire study area) and Consumer Survey respondents. In the entire study area, there are 423,881 residents under the age of 18, and 556,052 under the age of 25. There were 602 respondents to the Consumer Survey.

Total Pediatric Population, Age 0–25				
	Study Area		Consumer Survey	Variance
	Number	% of Total	% of Total	
Allen County, Kan.	3,009	0.7%	3%	2%
Johnson County, Kan.	135,132	32%	12%	(20%)
Wyandotte County, Kan.	43,181	10%	17%	7%
Cass County, Mo.	26,237	6%	3%	(3%)
Jackson County, Mo.	172,393	41%	45%	4%
Lafayette County, Mo.	8,017	2%	2%	—
Clay County, Mo.*	35,912	8%	10%	10%
Platte County, Mo.*			8%	

**Clay and Platte numbers include only those portions in Kansas City, North.*

Race/Ethnicity of Pediatric Population, Age 0–18				
	Study Area		Consumer Survey	Variance
	Number	% of Total	% of Total	
White, not Hispanic	313,672	74%	46%	(28%)
African-American, not Hispanic	55,105	13%	35%	22%
Hispanic	33,910	8%	8%	—
Multi-Race	12,716	3%	9%	6%
Other	8,478	2%	2%	—

Gender of Pediatric Population, Age 0–18				
	Study Area		Consumer Survey	Variance
	Number	% of Total	% of Total	
Male	207,522	49%	63%	14%
Female	216,359	51%	37%	(14%)

Age at Diagnosis				
	Study Area		Consumer Survey	Variance
	Total Pop.	% of Total	% of Total	
0–3	123,864	29%	2%	(27%)
5–9	115,176	27%	32%	5%
10–15	114,638	27%	34%	7%
16–18	70,203	17%	15%	(2%)
18–19	38,732	28%	11%	(11%)
20	18,980		6%	
21	19,936			
22–24	64,523			

B. Children in Poverty

The table below compares the poverty level of residents in the general study area to the Consumer Survey respondents. More than three times the number of survey respondents are living at or below 200 percent of the Federal Povery Level than in the general population. Further comparison is provided by county in the following tables.

Federal Poverty Level		
	Study Area	Consumer Survey
EXTREME		
< 99% FPL	4.9%	31.2%
LOW		
100–124% FPL	6.2%	18.6%
125–149% FPL		18.1%
150–184% FPL	15.5%	20.9%
185–199% FPL		
SUBTOTAL: At or below 200% FPL	**26.6%**	**88.8%**
MEDIUM	73.3%	
200–399% FPL		3.5%
HIGH		
400–500% FPL		2.7%

ALLEN COUNTY, KAN.		
	Pediatric Population	**Consumer Survey**
Extreme (< 50% FPL)	7.1%	41.9%
Below FPL	6.0%	58.1%
100–124% FPL	6.1%	—
125–149% FPL	3.8%	—
150–184% FPL	10.4%	—
185–199% FPL	2.5%	—
>200% FPL	64.1%	—

CASS COUNTY, MO.		
	Pediatric Population	**Consumer Survey**
Extreme (< 50% FPL)	3.0%	23.0%
Below FPL	5.1%	25.7%
100–124% FPL	2.2%	22.4%
125–149% FPL	3.5%	13.5%
150–184% FPL	5.0%	10.2%
185–199% FPL	3.0%	5.2%
>200% FPL	78.3%	—

JOHNSON COUNTY, KAN.		
	Pediatric Population	**Consumer Survey**
Extreme (< 50% FPL)	2.1%	12.3%
Below FPL	3.1%	21.8%
100–124% FPL	2.1%	23.7%
125–149% FPL	2.2%	32.5%
150–184% FPL	3.7%	3.9%
185–199% FPL	1.7%	1.7%
>200% FPL	85.1%	4.1%

JACKSON COUNTY, MO.		
	Pediatric Population	**Consumer Survey**
Extreme (< 50% FPL)	6.9%	36.9%
Below FPL	8.0%	12.8%
100–124% FPL	4.6%	23.2%
125–149% FPL	5.1%	11.1%
150–184% FPL	6.2%	12.0%
185–199% FPL	2.5%	1.8%
>200% FPL	66.7%	2.2%

WYANDOTTE COUNTY, KAN.		
	Pediatric Population	**Consumer Survey**
Extreme (< 50% FPL)	8.5%	38.5%
Below FPL	11.7%	22.9%
100–124% FPL	6.6%	26.6%
125–149% FPL	5.8%	12.0%
150–184% FPL	8.4%	—
185–199% FPL	3.5%	—
>200% FPL	55.5%	—

LAFAYETTE COUNTY, MO.		
	Pediatric Population	**Consumer Survey**
Extreme (< 50% FPL)	4.1%	28.2%
Below FPL	6.9%	16.9%
100–124% FPL	3.7%	33.7%
125–149% FPL	5.9%	15.9%
150–184% FPL	6.9%	5.3%
185–199% FPL	4.1%	—
>200% FPL	69.4%	—

CLAY AND PLATTE COUNTIES, MO.*		
	Pediatric Population	**Consumer Survey**
Extreme (< 50% FPL)	3.4%	23.4%
Below FPL	4.0%	24.0%
100–124% FPL	2.7%	32.7%
125–149% FPL	2.8%	12.8%
150–184% FPL	5.6%	5.6%
185–199% FPL	2.2%	1.5%
>200% FPL	79.4%	—

**Clay and Platte numbers include only those portions in Kansas City, North.*

In every county in the study area, the number of children living in poverty included in the Consumer Survey is far greater than that of the general pediatric population.

Children in Extreme Poverty		
	Pediatric Population	**Consumer Survey**
Missouri		
Cass	3.0%	23.0%
Clay/Platte	3.4%	23.4%
Jackson	6.9%	36.9%
Lafayette	4.1%	28.2%
Kansas		
Allen	7.1%	41.9%
Johnson	2.1%	12.3%
Wyandotte	8.5%	38.5%

The consumer survey respondents reflect the lowest socioeconomic strata of the general population. This targeted group reflects the clients of the providers who helped recruit survey respondents, who focus on serving the uninsured and underinsured.

The response also validated findings from the literature review that residents living above 200 percent of the Federal Poverty Level (FPL) are experiencing barriers in accessing behavioral health services due to issues with co-payments, restrictive managed care plans and employer-sponsored health insurance that does not provide mental health benefits. These respondents correlated to employers with fewer than 50 employees.

In Kansas, Wyandotte County and Allen County had the highest percentages of extreme poverty among the general population, with 8.5 percent and 7.1 percent, respectively. The Consumer Survey mirrored this low socio-economic status with 39 percent and 42 percent reporting incomes in that lowest strata. The remainder of Allen County reported at the next lowest level, from 100-124 percent of FPL. Wyandotte County had a wider spread, possibly due to its urban nature, but had no consumers report more than 150 percent of the FPL.

In Missouri, Jackson County reported the next highest poverty level at the extreme tier, or below 50 percent of FPL. This was also reflected in the Consumer Survey, with Jackson County having the third highest overall response rate from that strata in the study area, at 37 percent.

The remainder of the five counties reflected their overall general population profile, with Johnson County being the wealthiest. The stack ranking of the extreme poverty strata shows a comparison between the general population profile and the Consumer Survey response.

C. Local Behavioral Health Data

Publicly Financed Services for Serious Emotional Disorders

The 2008 Kids Count report developed by the Annie E. Casey Foundation indicates that the Clay/ Platte County portion of the study area had the highest percentage of children receiving public services for Serious Emotional Disorders (SED), followed by Jackson County. Jackson County had the second highest overall number of children receiving public SED mental health services in the state of Missouri in 2008, after St. Louis County.

Children Receiving Publicly Financed Services for SED			
	Pediatric Population	**# Receiving Services**	**% Receiving Services**
Cass County	26,237	190	0.7%
Clay/Platte Counties*	35,912	521	1.9%
Jackson County	172,393	2,245	1.3%
Lafayette County	8,017	72	0.9%
Allen County	3,009	23	0.8%
Johnson County	135,132	290	0.2%
Wyandotte County	43,181	148	0.1%
Total	1,655,670	3,657	0.2%

Source: Citizens for Missouri's Children (2008) and Kansas Action for Children (2009)

Children Hospitalized for Mental Health Issues

Allen and Wyandotte counties have higher rates of children hospitalized for mental health issues than the 2010 state average of 3.4 per 1,000, with rates of 7.5 and 3.8 respectively. Johnson County fell below the state rate, with 1.7.

In Missouri, Jackson County, with a rate of 13.2, was the only county in the study area to exceed the state rate of 12.7.

Children Hospitalized for Mental Health Issues	
	Rate per 1,000 Population
MISSOURI	**12.7**
Cass County	7.4
Clay County	9.3
Jackson County	13.2
Lafayette County	9.4
Platte County	8.0
KANSAS	**3.4**
Allen County	7.5
Johnson County	1.7
Wyandotte County	3.8
Total	4.8

Referrals for Juvenile Law Violations

Lafayette County is the only county in the study area with a higher rate (84.7 per 1,000) of juvenile law violation referrals than the Missouri average (55.6 per 1,000). The data is defined as referral to one of the 45 juvenile courts for acts that would be violations of criminal law if conducted by an adult.

Referrals for Juvenile Law Violations, Age 10–17	
	Rate per 1,000 Population
MISSOURI	**55.6**
Cass County	40.1
Clay County	44.2
Jackson County	28.7
Lafayette County	84.7
Platte County	34.8

Source: Citizens for Missouri's Children (2007)

Out-of-Home Placement

Jackson County is the only county in the study area with an Out-of-Home placement rate (juvenile justice and foster care) higher than that of the state in 2008. Missouri's overall rate was 3.8 per 1,000, while Jackson County's was 5.0 per 1,000.

Out-of-Home Placement (Juvenile/Foster)	
MISSOURI	**5,418**
Cass County	45
Clay County	42
Jackson County	845
Lafayette County	10
Platte County	13

Source: Citizens for Missouri's Children (2008)

Child Abuse and Neglect

The 2008 Kids Count report indicates that Johnson and Wyandotte counties had the second and third highest rates of reported child abuse and neglect in Kansas. Missouri Kids Count indicates that Jackson and Lafayette counties had rates higher than the state average. Only Cass County fell below the state average among Missouri counties in the study area.

Child Abuse and Neglect	
MISSOURI	**45,628**
Cass County	484
Clay County	1,084
Jackson County	5,926
Lafayette County	291
Platte County	421
STUDY AREA	**8,206**

Source: Citizens for Missouri's Children (2008)

2. Literature Review

A literature review of national child behavioral health research was conducted to establish a baseline and compare and contrast findings from the primary research completed for this analysis.

A. Facts About Children's Behavioral Health

National research supports the following statements.

- **Children's mental health problems are widespread.**
  Mental health problems are common and begin at a young age, with 20 percent of America's 80 million children (or 16 million youth) diagnosed with a mental health disorder.[1] Estimates vary widely, from a low of 5 percent[2] to a high of 17.6–22 percent.[3]

- **One in 10 children has a diagnosable mental disorder.**
  One in 10 youth has serious mental health problems severe enough to impair his/her function at home, school or in the community, with the onset of major mental illness thought to occur as early as seven to 11 years old. Factors that predict mental health problems can be identified at an earlier age, as early as in the three-to-five age group.[4]

- **Children and youth from low-income households are at increased risk for mental health problems.**
  Among low-income children and youth ages 6–17, one in five, or 21 percent, have mental health problems.[5] Of this 21 percent, more than half (57 percent) come from households with incomes below the federal poverty level. Mental health problems are two to four times as prevalent for children living in poverty than for those living above the federal poverty level.

- **A greater proportion of children and youth in the child welfare and juvenile justice systems have mental health problems than children and youth in the general population.**
  Half the children and youth in the child welfare system have mental health problems, and 67 to 70 percent of youth in the juvenile justice system have a diagnosable mental health disorder.[6]

- **Unmet need is a significant factor in children's behavioral health.**
  Unmet need is defined as having a diagnosed need for mental health with referral for services, but either not receiving these services in a one-year period following that referral or failing to be properly evaluated. Studies indicate that only 21 percent of children who needed mental health evaluations received them,[7] with rates of mental health service utilization lowest among preschool children. Only 50 percent of children with mental and emotional problems at any age receive adequate treatment[8]

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1 President's New Freedom Commission on Mental Health (2003).
2 Simpson, G.A., Bloom, B., Cohen, R.A., Blumberg, S. and Bourdon, K.H., "U.S. Children with emotional and behavioral difficulties: Data from the 2001, 2002, and 2003 National Health Interview Surveys." *Advance Data from Vital Health and Statistics*, 360. Hyattsville, MD: National Center for Health Statistics (2005).
3 Stiffman, A.R., Hadley-Ives, E., Doré, P., Polgar, M., Horvath, V.E., Striley, C. and Elze, D., "Youths' Access to Mental Health Services: The Role of Providers' Training, Resource Connectivity, and Assessment of Need." *Mental Health Services Research*, 2:3 (2000).
4 Roberts, R. E., Roberts, C. R. and Xing, U., "Rates of DSM-IV psychiatric disorders among adolescents in a large metropolitan area." *Journal of Psychiatric Research*, 41, 959-967 (2007).
5 National Mental Health Association.
6 Skowyra, K. R. and Cocozza, J. J., "Blueprint for change: A comprehensive model for the identification and treatment of youth with mental health needs in contact with the juvenile justice system." Delmar, NY: The National Center for Mental Health and Juvenile Justice and Policy Research Associates, Inc. (2006).
7 Kataoka, S.H., Zhang, L. and Wells, K.B., "Unmet Need for Mental Health Care among U.S. Children: Variation by Ethnicity and Insurance Status," *American Journal of Psychiatry,* 159:9, 1548–1555 (2002).
8 National Mental Health Association.

with an estimated two-thirds of all children with mental health problems not receiving any services.[9] Parents of children failing to return for treatment following initial assessment or treatment frequently cited failure of providers to offer practical information.

- **Latino children and youth are less likely to receive services for their mental health problems than children and youth of other ethnic groups with marked disparities in receiving care.**

  Almost one third (31 percent) of white children and youth receive mental health services.[10] Only 13 percent of children from diverse racial and ethnic backgrounds receive mental health services.[11] An alarming 88 percent of Latino children have unmet mental health needs.[12]

- **Inappropriate diagnoses of children's mental health problems — over- or under-diagnosis — are prevalent, with lack of information or availability about evidence-based treatment.**

  Lack of a unified infrastructure in provision of behavioral health services results in multiple missed opportunities for prevention, early identification, expedited treatment, fragmented treatment services and low priority for resources.[13]

- **Mental health services and supports vary depending on the state in which a child or youth with mental health needs lives.**

  There is a 30 percent difference between the states with the highest and lowest unmet need for mental health services (51 percent to 81 percent).[14]

- **Even some children and youth with the most intense needs and some who are insured do not receive services.**

  An alarming 85 percent of children and youth in need of mental health services in the child welfare system do not receive them.[15] Seventy-nine percent of children with private health insurance and 73 percent with public health insurance have unmet mental health needs.[16] The percentage of boys with difficulties was almost twice as high as the percentage of girls with difficulties (6.3 percent vs. 3.3 percent). Children living in single-mother families (7.0 percent) were more likely to have had difficulties than children living in two-parent families (4.0 percent). Poverty was significantly related to whether or not children had difficulties. In 2003, children in poor families (7.8 percent) were more likely to have had difficulties than children in families that were not poor (4.6 percent). In 2003, children with Medicaid or other public health insurance coverage (8.7 percent) were approximately twice as likely to have had difficulties as were children with private health insurance (3.5 percent) or children with no health insurance coverage (5.2 percent).

- **Use of services varies among children with behavioral health problems.**

  Among children who had difficulties in 2003, 39.2 percent had a contact with or visit to a general doctor for an emotional or behavioral problem, compared with 2.6 percent of children without difficulties indicated. Almost half (44.5 percent), had contact with a mental health professional compared with 4.7 percent of children without difficulties indicated. More than one-fifth (22.7 percent) received special education services, compared with 1.1 percent of children without difficulties indicated.

9 U.S. Department of Health and Human Services (2009).
10 Ringel, J. S. and Sturm, R., "National estimates of mental health utilization for children in 1998." *Journal of Behavioral Health Services & Research*, 28:3, 319-333 (2001).
11 Ibid.
12 Kataoka, et al. (2002)
13 Ibid.
14 U.S. Substance Abuse and Mental Health Administration (SAMHSA), Office of Applied Studies. *National Survey on Drug Use and Health* (2011).
15 Simpson, et al. (2005)
16 Kataoka, et al. (2002)

- **Parent-described behavioral health difficulties impacted child functions.**
  In 2003, 55 percent of the children described by their parents as having difficulties that lasted one month or longer were distressed by their difficulty. Most children with parent-reported difficulties that lasted one month or longer had difficulty with home life (84.6 percent). A majority of children with difficulties that lasted one month or longer had difficulty with friendships (71.6 percent), and learning (71.2 percent).

- **A gap exists between need and treatment for youth with substance use disorders that sometimes occur with mental health problems.**
  Fewer than 10 percent of the more than 1.4 million youth between 12–17 years of age who needed substance abuse treatment in 2004 received specialty facility-based substance abuse treatment.[17] Children and youth with mental health problems have lower educational achievement, greater involvement with the criminal justice system, and fewer stable and longer-term placements in the child welfare system than children with other disabilities. When treated, children and youth with mental health problems fare better at home, in schools and in their communities.

- **Preschool children face expulsion rates three times higher than children in kindergarten through 12th grade — a factor partly attributed to lack of attention to social-emotional needs.**
  African-American preschoolers are three to five times more likely to be expelled than their Caucasian, Latino, or Asian-American peers.[18]

- **Elementary school children and youth who have mental health problems are more likely to be unhappy at school, be absent, or be suspended or expelled.**
  In the course of the school year, these children may miss as many as 18 to 22 days.[19] Their rates of suspension and expulsion are three times higher than their peers. Among all students, African-American students are more likely to be suspended or expelled than their Caucasian peers (40 percent vs. 15 percent).[20]

- **Youth in high school with mental health problems are more likely to fail or drop out of school.**
  Up to 14 percent of these youth receive mostly D and F grades (compared to 7 percent for all children with disabilities).[21] Up to 44 percent of them drop out of school.[22]

- **Youth in the child welfare and juvenile justice systems who have mental health issues do less well than others.**
  Children with mental health issues in the child welfare system are less likely to be placed in permanent homes.[23] They are also more likely to be placed out of home in order to access services.[24]

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17 U.S. Substance Abuse and Mental Health Administration (SAMHSA), Office of Applied Studies. *National Survey on Drug Use and Health* (2005)

18 Gilliam, W. S., "Prekindergartens left behind: Expulsion rates in state prekindergarten programs" *FCD Policy Brief*, 3. New York, NY: Foundation for Child Development (2005).

19 Blackorby, J. and Cameto, R., "Changes in school engagement and academic performance of students with disabilities." In *Special Education Elementary Longitudinal Study (SEELS) Wave 1 Wave 2 Overview*, 8.1-8.23. Menlo Park, CA: SRI International (2004).

20 Ibid.

21 Blackorby, J., Cohorst, M., Garza, N. and Guzman, A., "The academic performance of secondary school students with disabilities." In *The Achievements of Youth with Disabilities During Secondary School*. Menlo Park, CA: SRI International (2003).

22 Wagner, M., "Youth with disabilities leaving secondary school." In *Changes Over Time in the Early Post School Outcomes of Youth with Disabilities: A Report of Findings from the National Longitudinal Transition Study (NTLS) and the National Longitudinal Transition Study-2 (NTLS2),* 2.1-2.6. Menlo Park, CA: SRI International (2005).

23 Smithgall, C., Gladden, R. M., Yang, D. H. and Goerge, R., "Behavioral problems and educational disruptions among children in out-of-home care in Chicago." *Chapin Hall Working Paper*. Chicago, IL: Chapin Hall Center for Children at the University of Chicago (2005).

24 Hurlburt, M. S., Leslie, L. K., Landsverk, J., Barth, R., Burns, B., Gibbons, R. D., Slymen, D. J. and Zhang, J., "Contextual predictors of mental health service use among children open to child welfare." *Archives of General Psychiatry*, 61:12, 1217-

These children are more likely to over-rely on restrictive and/or costly services such as juvenile detention, residential treatment and emergency rooms.[25] Young adults in the child welfare system experience mental health problems and drug and alcohol dependence at a significantly higher rate than the general population.[26]

- **Inadequate physical health systems fail to address the alarming high mortality related to those with serious behavioral health issues.**
  Among children in 2003 who had difficulties, 39.2 percent had a contact or visit to a general doctor for an emotional or behavioral problem, compared with 2.6 percent of children without difficulties indicated.

B. Effective Public Policy Strategies

National research indicates that the following public policies are effective for children, youth and families facing mental health issues.

- **Improve access to mental health consultation with a specific focus on young children.**
  Preschools with access to mental health consultation have lower expulsion rates.[27]

- **Coordinate services and hold child- and youth-serving systems accountable.**
  Robust service coordination in the child welfare system reduces gaps in access to services between African-American and white children and youth.[28]

- **Provide mental health services and supports that meet the developmental needs of children.**
  Treatment and supports designed using developmental frameworks are more likely to respond to the changing needs of children and youth.[29]

- **Apply consistent use of effective treatments and supports.**
  A range of effective treatments exists to help children and youth with mental health problems to function well in home, school and community settings.[30]

- **Engage families and youth in their own treatment planning and decisions.**
  Family support and family-based treatment are critical to children and youth resilience. Youth and family engagement fosters treatment effectiveness.[31]

1224 (2004).

25 U.S. House of Representatives, Committee on Government Reform, Minority Staff Special Investigations Division (2004); Pottick, K., Warner, L. A. and Yoder, K. A, "Incarceration of youth who are waiting for community mental health services in the United States" (2005); "Youths living away from families in the US mental health system: Opportunities for targeted intervention." *Journal of Behavioral Health Services & Research*, 32:2, 264-281; and Almgren, G. and Marcenko, M. O., "Emergency room use among foster care sample: The influence of placement history, chronic illness, psychiatric diagnosis, and care factors." *Brief Treatment and Crisis Intervention*, 1:1, 55-64 (2001).

26 Pecora, P. J., Williams, J., Kessler, R., Downs, C., O'Brien, K., Hiripi, E. and Morello, S., "Assessing the effects of foster care: Early results from the Casey National Alumni Study." Seattle, WA: Casey Family Programs (2003).

27 Gilliam (2005).

28 Hurlburt et al. (2004).

29 Knitzer, J. and Cohen, E., "Promoting resilience in young children at the highest risk: The challenge for early childhood mental health." In *Promoting Resilience in Young Children and Families*. Baltimore, MD: Brooks Publishing (Forthcoming); and Horner, R. H., Sugai, G., Todd, A. W. and Lewis-Palmer, T., "Schoolwide positive behavior support: An alternative approach to discipline in schools." In *Individualized Supports for Students with Problem Behaviors : Designing Positive Behavior Plans*. New York, NY: Guilford Press (2004).

30 Yannacci, J. and Rivard, J. C., "Matrix of children's evidence-based interventions." Alexandria, VA: Centers for Mental Health Quality and Accountability, NASMHPD Research Institute (2006).

31 McKay, M. M., Hibbert, R., Hoagwood, K., Rodriguez, J., Murray, L., Legerski, J., et al. "Integrating evidence-based engagement interventions into 'real world' child mental health settings." *Brief Treatment and Crisis Intervention*, 4:2, 177-186 (2004); and Christenson, S. L. and Havsy, L. H., "Family-school-peer relationships: Significance for social, emotional, and academic learning." In *Building Academic Success on Social and Emotional Learning: What Does the Research Say?*, 59-75.

- **Provide culturally and linguistically competent services.**
  Attention to providers' cultural and ethnic competence leads to improved mental health outcomes and greater adoption of evidence-based practices.[32]

- **Implement concrete strategies to prevent and identify mental health problems and intervene early.**
  Empirically supported prevention and early intervention strategies support children and youth resilience and ability to succeed.[33]

- **Actively provide consultation and capacity building activities.**
  Provide consultation and activities with personnel, youth, family members and other stakeholders in communities, agencies and states as they plan and implement transition supports and services across the transition domains of education, employment, living situation, personal adjustment and community-life functioning.

- **Design and conduct evaluations.**
  Design and conduct evaluations to improve the effectiveness of transition programs and outcomes for young people with emotional or behavioral disorders and their families in collaboration with communities, agencies and states.

- **Formulate and disseminate effective practices, programs and policies.**
  Develop practices, programs and policies to inform stakeholders of factors associated with the development and sustainability of effective transition systems for these youth and their families.

C. Condition-Specific Facts

The review of national literature and research also identified certain data and findings related to specific behavioral health conditions.

- **Anorexia Nervosa**
  Anorexia affects one in every 100 to 200 adolescent girls and a much smaller number of boys.[34] Approximately 1 percent of adolescent girls develop anorexia nervosa. One in 10 cases lead to death from starvation, cardiac arrest or suicide.[35]

- **Anxiety Disorders**
  One in 10 young people have an anxiety disorder.[36] Studies suggest that children or adolescents are more likely to have an anxiety disorder if their parents have anxiety disorders.[37]

- **Attention Deficit/Hyperactivity Disorder (ADHD)**
  30 to 40 percent of children diagnosed with ADHD have relatives with the same type of problem.

New York, NY: Teachers College Press (2004).

32 Halliday-Boykins, C., Schoenwald, S. and Letourneau, E. J., "Caregiver therapist ethnic similarity predicts youth outcomes from empirically based treatment." *Journal of Clinical Child and Adolescent Psychology*, 73:5, 808-818 (2005); and Schoenwald, S., Letourneau, E. J. and Halliday-Boykins, C., "Predicting therapist adherence to transported family-based treatment for youth." *Journal of Clinical Child and Adolescent Psychology*, 658-670 (2005).

33 Masten, A. S. and Powell, J. L., "A resilience framework for research, policy, and practice." In *Resilience and Vulnerability: Adaptation in the Context of Childhood Adversities.* New York, NY: Cambridge University Press (2003); Fergus, S. and Zimmerman, M. A., "Adolescent resilience: A framework for understanding healthy development in the face of risk." *Annual Review of Public Health*, 26, 399-419 (2004); and Greenberg, M. T., Domitrovich, C. and Bumbarger, B., "The prevention of mental disorders in school-aged children: Current state of the field." *Prevention & Treatment*, 4:1, (2000).

34 U.S. Department of Health and Human Services (2011).

35 National Institute of Mental Health (2011).

36 MacLean, M.G., Embry, L.E. and Cauce, A.M., "Homeless adolescents' paths to separation from family: Comparison of family characteristics, psychological adjustment, and victimization." *Journal of Community Psychology*, 27:2, 179-187 (1999).

37 Ibid.

ADHD is the most common psychiatric condition affecting children, estimates in prevalence in childhood range from 5–10 percent with 50 percent never diagnosed.[38]

- **Bipolar Disorder (Manic-Depression)**

  Almost one-third of six- to 12-year-old children diagnosed with major depression will develop bipolar disorders within a few years.[39]

- **Bulimia Nervosa**

  Reported rates of bulimia nervosa vary from one to three out of every 100 young people.[40]

- **Conduct Disorder**

  As many as one in 10 children and adolescents may have conduct disorder.[41]

- **Co-Occurring Disorders**

  There is a tendency to group co-occurring disorders despite their distinct etiology. The Substance Abuse and Mental Health Services Administration estimates that 7 to 10 million individuals in the United States have at least one mental disorder as well as an alcohol or drug use disorder.[42]

  A number of terms have been used to describe people in this category, including dually diagnosed, MICA (mentally ill chemical abusers), MISA (mentally ill substance abusers), CAMI (chemical abuse and mental illness) and SAMI (substance abuse and mental illness).[43]

  Some of the most common psychiatric disorders seen in patients with co-occurring addiction issues include schizophrenia, bipolar disorder, borderline personality disorder, major depression, anxiety and mood disorders, post-traumatic stress disorder, sexual and eating disorders, conduct disorders and attention deficit disorder.

  Patients being treated for mental health disorders also often abuse substances such as alcohol, nicotine, sedatives, stimulants, marijuana, hallucinogens and prescription drugs.

- **Depression**

  Recent studies show that, at any given time, as many as one in every 33 children may have clinical depression. The rate of depression among adolescents may be as high as one in eight.[44] Studies have also shown that more than 20 percent of adolescents in the general population have emotional problems and one-third of adolescents attending psychiatry clinics suffer from depression.[45]

- **Juvenile Justice**

  It is estimated that between 118,700 and 186,600 youths who are involved in the juvenile justice system have at least one mental disorder.[46] According to an Office of Juvenile Justice and Delinquency Prevention study of juveniles' response to health screenings conducted at the admission of juvenile facilities, 73 percent of juveniles reported having mental health problems and 57 percent reported

38 Harvard Mental Health Letter (2011).
39 Johnson, S., "Therapist's Guide to Clinical Intervention." *Journal of the American Academy of Child and Adolescent Psychiatry* (2004).
40 MacLean, et al. (1999).
41 Ibid.
42 COCE Overview Paper #2: Screening, Assessment, and Treatment Planning for Persons With Co-Occurring Disorders. Co-Occurring Center Of Excellence, SAMHSA (2006).
43 Public Policy Statement on Co-Occurring Addictive and Psychiatric Disorders, American Society of Addiction Medicine (2011).
44 MacLean, et al. (1999).
45 Canadian Journal of Continuing Medical Education (2009).
46 The National Coalition for the Mentally Ill in the Criminal Justice System (2011).

having prior mental health treatment or hospitalization.[47] Of the 100,000 teenagers in juvenile detention, estimates indicate that 60 percent have behavioral, mental or emotional problems.[48]

- **Learning Disorders**
  It is thought that anywhere from 15–2- percent of children with ADHD have a condition known as a "specific learning disability" and perhaps 50 percent of children with learning disability have ADHD.[49]

- **Schizophrenia**
  Schizophrenia is rare in children under 12, but occurs in about three out of every 1,000 adolescents.[50]

- **Suicide**
  Suicide is the third leading cause of death for 15–24 year olds and the sixth leading cause of death for 5–15 year olds.[51] More teenagers and young adults died as a result of suicide in 1999 than cancer, heart disease, HIV/AIDS, birth defects, stroke and chronic lung disease combined.[52] For every older teen and young adult who takes his or her own life, 100–200 of their peers attempt suicide. Between 500,000 and 1 million young people attempt suicide each year.[53]

D. Children's Behavioral Health Care Services

Children's behavioral health care services reviewed in national literature include:

- **Prevention, Early Intervention and Community-Based Services**
  There is positive evidence for home- and community-based treatments compared to historic institutional care, and for school-wide systems of positive behavioral support.

- **Evidence-Based Treatment**
  Evidence-based treatments include multi-systemic therapy, intensive case management and treatment in foster care; cognitive behavioral treatments for depression and anxiety; behavioral-based interventions, including parent training and behavioral modification for ADHD; behavioral parent training and video modeling for conuct problems; and, for anger control, problem-solving skill training, multi-systemic therapy (MST), delinquency prevention and parent-child interaction treatment.

- **Inpatient Child Psychiatric Services**
  Inpatient psychiatric admissions for children between the ages of five and 13 years increased by 82 percent between 1996 and 2007 — from 155.45 discharges per 100,000 in 1996 to 283.04 in 2007. During that same time period, the number of inpatient days per admission more than doubled, from 1,845 days per 100,000 in 1996 to 4,370 days in 2007. The proportion of inpatient days paid by private sources decreased from 36 percent to 21 percent over the same decade. Adolescent psychiatric admissions (ages 14-19) also increased, but at a slower rate (14 percent), from 63.60 per 100,000 discharges in 1996 to 969.03 discharges in 2007. Inpatient days per admission increased by 40 percent, with a reduction in days paid by private sources of 30 percent.[54]

47 The Office of Juvenile Justice and Delinquency Prevention (1994).
48 Ibid.
49 Mayo Clinic Letter, Hyperactivity and Attention Deficit Disorder in Children (2011).
50 MacLean, et al. (1999).
51 Johnson, S. (2004)
52 U.S. Centers for Disease Control and Prevention (2011).
53 American Association of Suicidology (2010).
54 Blader, J., "Acute Inpatient Care for Psychiatric Disorders in the United States,1996 Through 2007." Department of Psychiatry and Behavioral Science, Stony Brook University (2011).

Psychiatric Utilization Study				
		1996	2007	Change
Children Ages 5–13	Psychiatric discharges per 100,000	155.45	283.04	+82%
	Inpatient days per admission per 100,000	1,845	4,370	+137%
	Percent of inpatient days paid by private sources	36%	21%	-15%
Adolescents Ages 14–19	Psychiatric discharges per 100,000	683.60	969.03	+14%
	Inpatient days per admission per 100,000	5,882	8,247	+40%
	Percent of inpatient days paid by private sources	52%	22%	-30%

Studies demonstrate issues with underutilization and early termination of service.[55] One study found that 92 percent of children with serious emotional disturbances received mental health services from two or more systems, and 19 percent, from four or more systems.[56]

National studies also note issues such as concerns about costs and access to care, including long waiting lists, as well as social stigma related to mental health treatment.

E. Stigma and Care Entry

Stigmatization of those who are perceived as different from the norm in some important way includes an array of personal, interpersonal and structural components that can create substantial social inequalities in life circumstances. Evidence exists that internalized stigma impacts the lives of people with severe mental illness, but there is little data on the prevalence of clinically significant internalized stigma.

One study investigated the prevalence and demographic correlation of significantly elevated levels of internalized stigma in two samples of people with severe mental illness living in the community.[57] At intake, stigma scores were higher for "third person views" (views reflecting assessment of attitudes and behaviors of other people) versus their own perception. This belief in 'third person' views correlated to higher levels of stigma. The findings suggest that individuals typically consider themselves less stigmatizing than others. First person views were more sensitive to change following an anti-stigma intervention.[58]

F. Financing

Two distinct funding flows support children's behavioral health — insurance-based funding, attached to individual children; and public program funds that finance community mental health centers, school-based clinics, welfare and the juvenile justice system.

- Children represent 28 percent of the population nationally but account for only 14 percent of total health expenditures — of which 7 percent goes to behavioral health.
- Behavioral health expenses averaged $984 per child (inpatient services, 39 percent; physician services, 24 percent; drugs, 22 percent; non-physician, 10 percent; emergency department, 3 percent; and hospital outpatient, 2 percent).[59]
- Behavioral health carve-outs cover 80 percent of insured children with psychiatric disorders.

55 Stiffman, et al. (2000).

56 Hoven, C.W., et al., "Mental Health Service Use by Disturbed Youth: Five Service Systems vs. the Community." Paper presented at the 126th Annual Meeting of the American Public Health Association, Washington, D.C.; and Blader, J. (2011).

57 Yanos, P. T., Roe, D., Markus, K. and Lysaker, P. H., "Pathways between internalized stigma and outcomes related to recovery in schizophrenia spectrum disorders." *Psychiatric Services*, 59:12, 1437–1442 (2008).

58 Quinn, N., Smith, M., Fleming, S., Shulman, A. and Knifton, L., "Self and others: the differential impact of an anti-stigma program, stigma." *Research and Action Newsletter*, 1:1 (2011).

59 Frank, R. and Glied, S., "Better but not well: Mental health policy in the United States since 1950." Baltimore, MD: Johns Hopkins University Press (2006).

- Care coordination between mental and physical systems of care can result in an estimated savings of 30-40 percent, but there are issues with appropriate referral, utilization and coordination.
- Out-of-pocket costs are a concern, with higher co-payments and deductibles associated with mental health.

F. Best Practices

The following best practices for addressing mental health and substance abuse needs of children and families are compiled from a report published by the Child Welfare League of America in January 2008.

- **Prevention**
  - Promotion of positive mental health and substance use
  - Effective assessment for early identification of factors that contribute to behavioral health problems
  - Services designed to prevent escalation of behavioral health issues
  - Easy access to screening, assessment, services and intervention at early levels beginning at birth
  - Family support services
- **Protection**
  - Timely and accurate screening, assessment, treatment plans, therapeutic interventions and placement
  - Focus on reducing out-of-home placement
  - Least restrictive, most normative environment customized to child's needs with focus on attachment, development and safety
  - Family input and involvement unless prohibited by court mandate
- **Family**
  - Focus on strengthening and stabilizing family relationships
  - Prevent unnecessary separation of child from families
  - Families, including foster families, fully involved in all aspects of planning and service delivery
  - Children and families as primary drivers of service planning
  - Support services offered, including parenting education, family therapy, foster parent involvement with family of origin where possible, education about behavioral health and child development.
- **Permanency**
  - Focus on child forming bond with at least one unconditional, committed adult
  - Attachment issues are key to producing functional adults and transiting to adult system of care
- **Access**
  - Consideration of geographic distance and time constraints in service receipt
  - Consideration of time first assessed to intake to initiation of services
  - Availability of culturally competent services with staff reflective of community served
  - System allowing for intermittent, non-linear use of services
  - Ongoing check-ups/check-ins to monitor status of child
  - Use of assistive technology, including teleconference and/or video-conference
  - Transportation accommodation
  - Use of non-traditional, faith-based, community, social, school and home-based services
  - Use of informal and formal support services

- **Appropriateness**

  Protocols and communication regarding:
  - How case management and service coordination occurs
  - Process for utilization management and clinical protocols through an episode of care
  - Level of care and related involvement of child and family in treatment planning, selection of services, supports and planning for design and delivery of services
  - Specific focus on transition of child to adult behavioral health system as they 'age out'

- **Client Rights, Involvement, Satisfaction**
  - Children and families as active participants in all phases of treatment planning, identification of services and supports, and service delivery based on their customized strength and need assessment
  - Satisfaction routinely assessed using sound research methods
  - Data used to continuously improve services.

- **Screening and Assessment**
  - Comprehensive behavioral health assessment at the initiation of services and at regular intervals using a standardized protocol
  - Initial assessment conducted within 24 hours of first visits
  - Identify level of care to stratify treatment by most urgent including youth at danger to themselves or others
  - Assess internalized and externalized levels of distress
  - Conducted by professional combining developmental with behavioral health expertise
  - For out-of-home placements, incorporate comprehensive behavioral health assessment within 60 days of placement or sooner, dependent on severity of needs determined in initial screening process with involvement of child or adolescent psychiatrist

- **Treatment**
  - Use clinical protocols to guide treatment planning
  - Incorporate customized assessment of child/family strengths and weaknesses
  - Use evidence-based protocols to guide interventions

- **Supportive Services**
  - Identify stressors — such as poverty, lack of housing, lack of transportation, lack of linkage to adult behavioral health system, problems in school — using informal and formal support

- **Quality**
  - Ensure accreditation of agencies and licensure and certification of staff through credentials review
  - Document appropriate supervision, training and professional development
  - Provide culturally competent, appropriate and sensitive care reflective of the community served
  - Use evidence-based protocols proven to provide the desired outcome based on that intervention
  - Document outcomes, indicators, and methods used to monitor, track and report performance

- **Effectiveness**
  - Document therapeutic value of services provided
  - Document cost and effectiveness of services including prevention
  - Regularly evaluate programs

3. Policy Scan

Federal and state policies play a critical role in children's behavioral health care. A brief scan of these policies helps provide a framework for understanding how children and families are impacted and what challenges exist.

A. Federal Financing and Policies

SAMHSA Block Grants

The Substance Abuse and Mental Health Services Administration (SAMHSA) is a federal agency established by Congress in 1992. Each year, SAMHSA awards block grants to states to allow states to address their unique behavioral health issues. There are two block grants, the Substance Abuse Prevention and Treatment Block Grant (SABG) and the Community Mental Health Services Block Grant (MHBG).

SAMHSA defines bi-directional integration of behavioral health and primary care services as integrating mental health and substance abuse treatment services in primary care settings and primary care in mental health and substance abuse treatment settings. SAMHSA directs states to use block grants to supplement services covered by Medicaid, Medicare and private insurance, funding programs in four specific areas:

- Priority treatment and support services for individuals without insurance.
- Priority treatment and support services for low-income individuals with needs not covered by Medicaid, Medicare or private insurance.
- Prevention activities and services.
- Collection of performance and outcome data to measure ongoing effectiveness of behavioral health promotion, treatment and recovery support services.

SAMHSA seeks consistency in the states' efforts to assess their behavioral health needs and plan for those needs. SAMHSA also believes that increased accountability through the establishment of performance indicators is critically important for both block grants.

SAMHSA Block Grants, FY 2011–2012		
	Missouri	**Kansas**
Substance Abuse Prevention and Treatment Block Grants	$26,016,004	$12,224,677
Community Mental Health Services Block Grants	$7,018,889	$3,091,154

Source: www.samhsa.gov

Social Security Disability Insurance and Supplemental Security Income

A total of 13.6 million people receive federal disability benefits: 7.6 million receive Social Security Disability Insurance (SSDI) and 4.4 million receive Supplemental Security Income (SSI); 1.6 million receive both. To receive SSDI, a person must have paid social security taxes, and the monthly benefit is based on the worker's earnings. SSI pays benefits to people with low income and limited resources who are 65 or older, or blind or disabled, regardless of earnings. In 2010, the average monthly SSI payment was $500. Maximum payments equal $674 for individuals and $1,011 for couples. Many states also provide additional benefits, such as Medicaid, to those who qualify for SSI.

SSI and Medicaid currently provide support for severely disabled children suffering from ADHD, speech delays, autism spectrum disorder and bipolar disorders. When the program began in 1974, SSI provided funding for children with Down syndrome, cerebral palsy, blindness and mental retardation. In 1990, a class action lawsuit reached the Supreme Court and fundamentally changed the way that the Social Security Administration determined eligibility for children with an expansion of children eligible for the program. Further legislative changes to welfare in 1996 caused some low-income families to apply for SSI because of its higher benefit levels and no work requirements or time limits.

Costs have escalated by 40 percent since 2002 — partly, according to advocates for these benefits, because many children previously categorized as mentally retarded are now diagnosed with autism spectrum disorder. Currently, these programs provide about $10 billion per year for behavioral health care services for 1.2 million low-income children with severe disabilities, but some in Congress have proposed limiting these benefits.

- **Medicaid**

Under Title XIX of the Social Security Act, Medicaid is a joint federal-state funded program that provides health care coverage to low-income individuals and families. Medicaid eligibility is based on family size and household income. Medicaid is the largest program providing medical and health-related services to America's poorest people. Within broad national guidelines provided by the federal government, each state:

- Establishes its own eligibility standards (In Missouri, 300 percent of federal poverty level; in Kansas, 200 percent)
- Determines the type, amount, duration and scope of services
- Sets the rate of payment for services
- Administers its program

Services typically included under Medicaid are:

- Inpatient hospital care, residential treatment centers, group homes
- Clinic services provided by a physician or under physician supervision
- Prescription drugs
- Rehabilitation services and/or outpatient hospital services
- Targeted case management
- Home and community based services in lieu of institutionalized care in states that have obtained a waiver (Kansas – 6, Missouri – 7)

Even though enrollments are increasing, 33 states have plans to cut Medicaid provider rates in 2012 based on a decline in general revenues.

- **Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)**

EPSDT is the child-health component of the Medicaid program. Under EPSDT, Medicaid entitles all eligible children to receive:

- Periodic screening services, including comprehensive physical examination and vision, dental and hearing screens
- Medically necessary services within the scope of the federal program to correct or improve defects and treat physical and mental illnesses and conditions, even if the state in which the child resides has not specifically directed to cover that condition.

State Children's Health Insurance Program (SCHIP)

Under Title XXI of the Social Security Act, SCHIP is designed to provide health care for children from working families with incomes too high to qualify for Medicaid but too low to afford private health insurance. Under SCHIP, the state can choose to provide child healthcare assistance to low-income, uninsured children through a separate program, a Medicaid expansion or a combination of the two.

SCHIP targets low-income children and in most states defines them as children under the age of 19 not living in families with incomes at or below the federal poverty level. Children eligible for Medicaid must be enrolled in Medicaid and are not eligible for SCHIP. To be eligible for SCHIP, children cannot be covered by any other group health insurance. If a state chooses to expand Medicaid eligibility for SCHIP, the children who qualify under SCHIP are entitled to EPSDT. If a state chooses to develop a separate program, it must include the same benefits as one of several benchmark plans (such as state employee benefit plan, standard Blue Cross/Blue Shield preferred provider option under the federal employee health benefit plan, or coverage offered by an HMO with the largest commercial non-Medicaid enrollment in the state) or have an equivalent actuarial value to any of these plans. Plans based on the equivalent actuarial value must include at least 75 percent of the actuarial value in the benchmark plan for mental health and substance abuse treatment.

Individuals with Disabilities Education Act (IDEA), Part B

Through IDEA, the Office of Special Education Programs for the U.S. Department of Education helps states provide all children (defined as ages 3-21 years) with disabilities receive an appropriate public education. IDEA emphasizes special education and related services designed to meet unique needs of disabled children and prepare them for employment and independent living. Children with emotional disturbance (ED) may be eligible for special education and related services under IDEA. Some children with Attention Deficit Hyperactivity Disorder (ADHD) may also receive services.

Eligibility is determined by a multi-disciplinary team of qualified school professionals and parents, based on a full and individual evaluation of the child. In addition to special education delivered in the least restrictive environment, eligible children may also receive related services to assist them, including:

- Speech-language pathology and audiology services
- Psychological services
- Physical and occupational therapy
- Recreating, including therapeutic recreation
- Counseling services, including rehabilitation counseling
- Social work services in schools
- Parent counseling and training

Each public school child who receives special education and related services under IDEA must have an individualized education program (IEP) that details the child's goals, needed special education and services and where they will be provided. For a child whose behavior impedes his/her own learning or that of others, the IEP team should consider positive behavioral interventions, strategies and supports to address the behavior. The IDEA also provides the functional behavior assessments and developmental of behavior intervention plans for students who present challenging and disruptive behavior.

Head Start

Head Start is a federal pre-school program designed to provide educational, health, nutritional and social services. Services are primarily provided in a classroom setting to help low-income children begin school ready to learn. Head Start legislation requires that at least 90 percent of these children

come from families with incomes at or below the federal poverty level; at least 10 percent of the enrollment in each local program must be available to children with disabilities.

B. State Financing and Policies

Missouri Voluntary Placement Agreements

Missouri Senate Bill 923 and House Bill 1453 were established to correct a significant problem in the provision of mental health services for children in Missouri. These bills established a statewide protocol that allows parents to gain mental health services for their children in residential settings through a voluntary placement agreement (VPA) without relinquishing custody of the child. The Missouri Department of Mental Health and the Department of Social Services' Children's Division (work together to support parents and families during this process.

Reimbursement for Psychiatric Residential Treatment Facilities

Kansas pays a per diem that includes therapy for children in Psychiatric Residential Treatment Facilities (PRTFs), while Missouri pays for bed days only, with separate billing for therapies. This reimbursement differential has become a major issue since May 2011, with the Kansas Department of Children and Families denying Missouri placements, resulting in the closure of at least two agencies — New Hope Heartland and Norwich.

Other Kansas Services

- Kansas has a 1915(c) waiver for school-based services.
- Independent Living programs support youth in transitioning to adult services and self-sufficiency, including support for completion of secondary and post-secondary education, training programs, room and board assistance, life skills, leadership opportunities and free medical services through the Medical Card Extension Services.
- Kansas has advanced status for both information technology and outcome-focused decision making in mental health.
- Kansas has home- and community-based waivers for children with serious emotional disturbances.

Other Missouri Services

- Foster Care: Missouri supports families and youth through state legislation and active involvement in mental health authority decision making.
- In Missouri, custody diversion and transfer of custody protocols decrease the number of children going into state custody solely to access mental health services through a partnership with child welfare and publicly funded mental health centers. Families can access Medicaid and IV-E funding when diverted from state custody if out-of-home placement is required.

C. Special Populations

A review of state policy systems for transitioning youth found the following:

- Almost half of the states reported having at least one program that specifically focused on young adults and two states were systematically focusing on developing services for young adults statewide.
- Half of the states did not offer a single program specifically tailored to young adults. Those that did offer young adult programs most commonly did so in only one part of the state.
- Most types of transition supports were offered more often for children, rather than in adult mental health systems.
- All states had differences in eligibility criteria or priority population definition for child and adult mental health services, with the adult definitions more commonly being narrower.

- A small number of states "grandfathered" the eligibility of some or all adolescents as they reached the upper age limit for children's services.
- Many states were not using the federal definition of serious mental illness to determine service eligibility or priority population. Most of these states were using a more narrow definition.
- Adult mental health administrators cited leadership, prioritization, and lack of funding as the key characteristics impacting the development of transition for young adults.
- In response to extremely limited funding and severe budget cuts, many states have had to restrict eligibility to the most disabled populations and/or limit services to only the most basic ones. This was cited as the rationale for not providing specialized services to young adults.

4. Continuum of Care and Resource Inventory

The table below provides an overview of the continuum of services currently available in Kansas City in the areas of mental health and substance abuse for children and adolescents. The continuum is broadly defined and encompasses those supports necessary for a healthy life for members of the community. Findings from this needs assessment are plotted out within the continuum where applicable, ranking each as adequate, inadequate, fragmented, or with a deficit/gap in services.

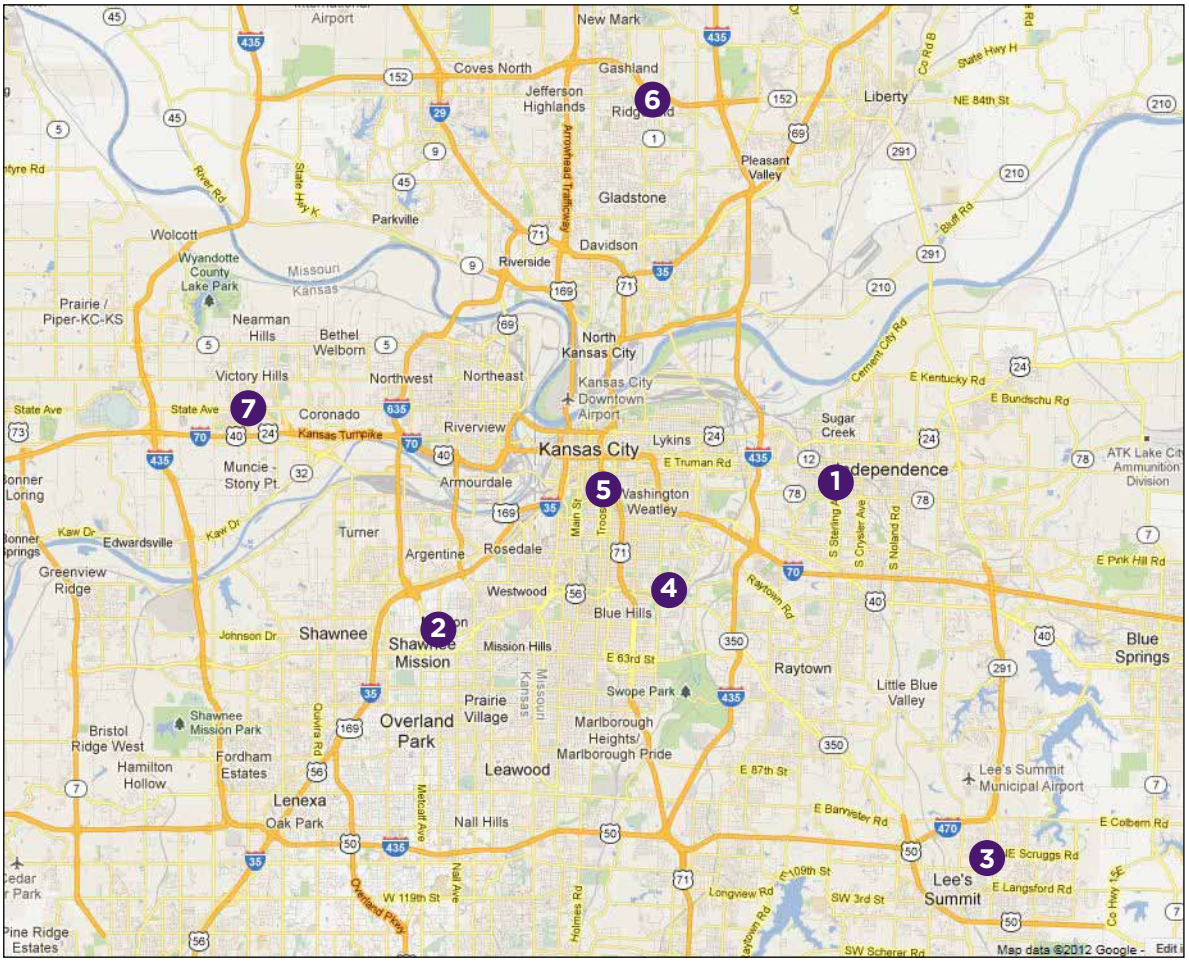
KEY
- ▲ Adequate
- ● Fragmented
- ■ Deficit/Gap
- ▼ Inadequate

	Prevention/Early Intervention	Outpatient	Community-Based	Day Programs	Respite Services	Treatment Homes	Residential	Sub-Acute	Acute
Reimbursement	▼	▼	▼				▼		
Capacity		▼	▼		▲	▲	▲		
Barriers to Access	▼								
Gaps in Access	▼				▲	▲	▲		
Cultural/Linguistic									
School-Based	▼	●	●						
Co-Occuring Disorders	▼	●	●					■	■
Wait Time for Appointment		▼					■		
Special Populations									
Foster Care		▼	▼				■		
Juvenile Justice		▼	▼				■		
Transitioning Youth		▼	▼				■		
Rural Children		▼	▼				■		

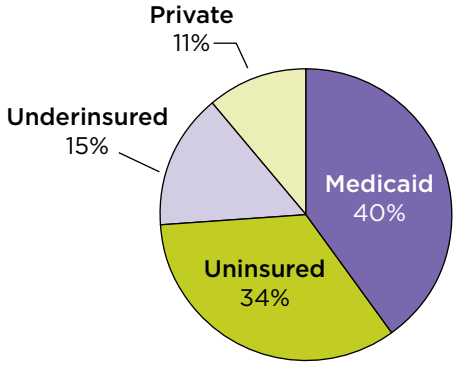
A. Community Mental Health Centers

In 2010, Kansas City area Community Mental Health Centers (CMHCs) served more than 62,000 people, of whom 31 percent were children — 12 percent ages 0–12 and 19 percent ages 13–18. Seven CMHCs provide child behavioral health services in the Kansas City metropolitan area. Each CMHC addresses teh needs of residents in specific geographic areas. Funding, licensure and accreditation are from the Missouri Department of Mental Health (DMH) and the Kansas Department of Children and Families (DCF), as well as the national Commission on Accreditation of Rehabilitation Facilities (CARF).

Community Mental Health Centers in the Kansas City Metropolitan Area



1. **Comprehensive Mental Health**
   10901 E. Winner Rd.
   Independence, MO 64052
2. **Johnson County Mental Health**
   6000 Lamar Ave.
   Mission, KS 66202
3. **ReDiscover**
   901 NE Independence Ave.
   Lee's Summit, MO 64086
4. **Swope Health Services**
   3801 Blue Pkwy.
   Kansas City, MO 64130
5. **Truman Medical Center Behavioral Health**
   2211 Charlotte St.
   Kansas City, MO 64108
6. **Tri-County Mental Health**
   3100 NE 83rd St.
   Kansas City, MO 64119
7. **Wyandot Center**
   7840 Washington Ave.
   Kansas City, KS 66112



CMHC Payer Mix

Community Mental Health Centers Range of Services

	Comprehensive Mental Health	Johndon County Mental Health	ReDiscover	Swope Health Services	TMC Behavioral Health	Tri-County Mental Health	Wyandot Center
Psychiatry	●	●	●	●	●	●	●
Medications	●	●	●	●	●	●	●
Indiv/Group/Family Therapy	●	●	●	●	●	●	●
Case Management	●	●	●	●	●	●	●
Occupational Therapy	●	●			●	●	
Employment Services	●	●	●	●	●	●	●
Agency-Owned Housing	●	●	●	●		●	
Attendant Care	●	●					●
Day Treatment	●	●	●	●	●	●	●
Partial Hospital			●				
Intensive Outpatient Program	●		●	●	●	●	
Crisis Services	●	●	●	●	●	●	●
Respite Services	●	●			●	●	●
Pharmacy	●		●		●		●
Psychosocial Testing	●	●	●	●	●	●	●
Dual Diagnosis (MH & SA)	●	●	●	●	●	●	●
Dual Diagnosis (MH & Chronic PE Illness)			●	●	●	●	
MH/Deaf	●	●		●			
Serious & Persistent Mental Illness	●	●	●	●	●	●	●
Substance Abuse	●	●	●	●	●	●	
SED Children	●	●	●	●	●	●	●
Homeless	●	●		●	●		●
Families	●	●	●	●	●	●	●
School-Based	●	●	●	●		●	●
Bullying	●		●				

B. Residential Facilities

Two residential psychiatric treatment facilities in the Kansas City metropolitan area currently serve children with behavioral health needs.

- **Spofford Home**

  The Spofford Home, located in South Kansas City, Mo., is a leading provider of prevention and therapeutic treatment services for children ages 4–12 suffering the effects of physical and sexual abuse, neglect, and mental health disorders. Services include:

  - **Residential Treatment** — Intensive residential treatment is available for young children with severe emotional and behavioral problems stemming from physical and sexual abuse, neglect, and mental health disorders.
  - **School Based Case Management** — Family resource specialists at Spofford work with school personnel to identify and address social factors that contribute to school failure.
  - **SCAMPS Summer Day Camp** — Spofford Change Action and Mastery Programs (SCAMPS) is a summer day camp for children ages 6–12 that specializes in providing social skills development, particularly peer interaction, conflict resolution and self-confidence.

- **Crittenton Children's Center**

  Crittenton, located in South Kansas City, Mo., offers a wide range of services including a psychiatric hospital, residential treatment, specialized residential units and community-based services.

  - **Psychiatric Hospital** — Inpatient care for children ages 4—18.
  - **Residential Treatment** — Residential treatment for adolescents exhibiting high-risk, out-of-control behavior with the objective to gain control, achieve academic success and function safely within their family structure. Treatment includes individual, group and family therapy in addition to chemical dependency prevention and recovery programs, career counseling, expressive therapy and residential education.
  - **Specialized Residential Units** — Three specialized programs include the Juvenile Aggression Group (JAG), which serves adolescents, primarily males, who have serious chronic psychiatric conditions and numerous failed placements due to aggressive behaviors; the Intensive Residential Unit, designed to serve dependents of the military through a regional contract focusing on short-term intensive treatment in a residential setting; and Family Focus, which serves youth as they move from a residential to a home setting.
  - **Community-Based Services** — These include foster care adoption and case management; chemical dependency; in-home care and treatment; Head Start Trauma Smart (weekly, on-site mental health therapy with a licensed clinical social worker that focuses on cognitive behavioral therapy for Head Start children); and parent and professional training seminars.

C. Acute Care

Two hospitals in the Kansas City area provide child behavioral health care services for acute care.

- **Children's Mercy Hospital**

  Children's Mercy Hospital, located in midtown Kansas City, Mo., operates a developmental and behavioral sciences section. This section has 24 doctorate-level psychologists, seven developmental pediatricians, four child and adolescent psychiatrists and five licensed clinical social workers who specialize in family therapy. The section uses an active consultation-liaison service involving 12 psychologists dedicated to the care of specific pediatric subspecialty sections and patient populations. Treatment of autism spectrum disorders and co-occurring disorders defined as mental health and physical health issues are specialties of Children's Mercy.

- **University of Kansas Medical Center**

  The University of Kansas Medical Center, located near midtown Kansas City, Kan., includes a Division of Child and Adolescent Psychiatry. The mission of this division is to conduct research on psychiatric disorders affecting youth and their families; to provide excellent multidisciplinary training to the next generation of mental health providers and investigators; to deliver a broad range of innovative clinical services to young people and their families; to provide subspecialty consultation to clinicians throughout the state of Kansas; and to represent the mental health needs of children and adolescents at all levels of policy planning.

D. Children's Enhancement Project

The closing of the children's inpatient unit at Western Missouri Mental Health Center in November 2008 presented a challenge for children's service agencies in the Kansas City area. The Children's Enhancement Project was created to fill the gap left by the closing of these beds that served children with serious emotional disorders. The CEP's target population includes children and adolescents with co-occurring conditions. Its goal is to serve these children with intensive "wraparound" services to decrease or eliminate the need for inpatient or residential services while improving their quality of life and functioning level.

Mid-America Regional Council

600 Broadway, Suite 200
Kansas City, MO 64105
Phone 816-474-4240 Fax 816-421-7758
www.marc.org