

**Final Project Report**  
**Hospitalization of Adolescents**  
**in the Kansas Mental Health System**

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## EXECUTIVE SUMMARY

The purpose of the current study was to explore the reasons for utilization of state hospital services for adolescents. Data were gathered from three sources: (1) state and private inpatient facilities (2) qualitative case studies with caregivers and providers of 14 youth and (3) stakeholder feedback regarding the feasibility of a regional model of state administered inpatient services for children and adolescents.

Two state hospitals in Kansas currently serve adolescents from ages 13 to 18: (1) Rainbow State Hospital (RSH) in the Kansas City area, covering 46 counties on the eastern side of the State, and (2) Larned State Hospital (LSH) which is slightly southwest of central Kansas and covers 59 counties on the western side of the state.

In FY 2005, *Larned State Hospital (LSH)* admitted 36% (96) of adolescents ages 13 to 18 and *Rainbow State Hospital (RSH)* admitted 64% (172). The gender of youth admitted was almost evenly distributed with slightly more males than females, 53% and 47% respectively. The majority of youth were Caucasian (75%), and between the ages of 15 and 17 (70%). Most lived either with parents, family members or foster parents in a private residence (85%). The mean length of stay was 20 days at LSH and 22 days at RSH.

Analysis of state and private inpatient data on lengths of stay from local and state hospitals in FY 2005 indicates that the state hospitals fulfill a distinct role within the current system of care for adolescents: **State Hospitals provide the intermediate length of inpatient treatment** between acute psychiatric hospitalizations and longer stays in Level VI residential facilities. Acute hospitals, designed to provide 3 to 7 day treatment, kept adolescents on average 5.04 days. If longer term stabilization is needed, a level VI screen is pursued. A total of **11 of 14 (79%) adolescents in this study were being discharged to a residential facility** or teams were discussing the need for a level VI placement.

Qualitative analysis of 56 interviews with families and service providers of these 14 adolescents indicates that **acute behaviors warranting a psychiatric crisis occurred in the context of already existing emotional and behavioral difficulties**. However, triggers were comparable to normal developmental stressors all youth experience in adolescence such as the demands of school work, rebellion against authority, and effects of peer influences. The specific triggers for youth in state custody are less clear. Provider interviews and content analysis of hospital records depict a general pattern of self-harm as youth experience more controlled environments and less freedom, which is a form of rebellion against imposed limits.

**A consistent protective factor identified was that all the youth had supportive, involved parents or guardians.** Most adolescents and their

families were involved in some sort of formal intervention prior to their admission to the state hospital. Nine families were involved in Community Mental Health services and were receiving intensive community based services (CBS) just prior to state hospital admission. **No families were receiving the full array of CBS for various reasons such as family choice or agencies did not have the service available to offer.** In addition, 9 youth had been involved with Juvenile Intake and Assessment (JIA); only one youth was in JJA custody (and had never been involved in mental health services of any kind). Nine youth were receiving individual special education services (2 for gifted; 7 for Behavior Disorders or Learning Disorders). Two youth were not in school prior to admission due to behavioral difficulties, and families were pursuing alternative schooling.

**Although youth were ultimately hospitalized, most participants felt high quality services were provided to youth and families in order to circumvent hospitalization.** In 5 case studies, providers were focused on family and youth strengths & resiliencies. In 6 case studies, families said providers conveyed commitment to the work. Two case studies indicated families felt supported in the escalating crisis that resulted in admission to the state hospital.

The constant stress caregivers and community based providers experience working with acute crisis situations can create tension within the teams and feelings of wanting to place blame. Some teams were able to work effectively through these tensions by acknowledging differences and getting outside help to bridge the gap between differing perceptions.

**Consistent with the findings from a study of young children admitted to state hospitals, medication side-effects and access to continuous medication services was also a serious concern for families and providers of youth age 13 and over.** All 14 youth in this sample received prescribed psychotropic medications as a part of their treatment before admission to the state hospital. Youth were on an average of 3.64 medications, with a range of 1 to 9. The most frequently prescribed medications were anti-psychotics (10 youth) and anti-depressants (4). Lack of access to outpatient medication stabilization contributed to the overall stress caregivers felt overseeing their youth's care.

**Furthermore, in all 14 cases, there was a critical point at which access or continuation of intensive stabilizing services may have prevented more restrictive levels of care.** As one provider pointed out, it was at these times, when everyone was feeling hopeless or wanting to walk away, that families needed the support the most.

**The majority of the families in this sample received little help managing psychiatric crises.** Crisis stabilization service quality varied according to agency policy. In general, the hotlines were not helpful to families. Times when hotline responders were helpful, parents received practical coaching to manage

youth behavior. Police were the most frequent mobile crisis responders causing one participant to say, "*We might as well train them then!*"

**Multiple systems issues affected the quality of care for youth in state custody. Foster homes with resources to manage youth who experience frequent psychiatric crisis (such as those in this study) were difficult to find.** In addition, these youth were not in placements long enough to get CBS started. Youth often ended up in a Level VI until they reached the 180 day maximum length of stay and then bounced between emergency shelters and private hospitals. As a result, school records and medication history on these youth were difficult to trace.

School/mental health collaboration during transition times such as discharge or in escalating crisis situations prior to admission were paramount to prevent further crises. Some school staff reported frequent contact with mental health; some did not and would like more.

Supports for youth with co-occurring disorders (PDD spectrum or Mild MR and Mental Health) were not available to the youth in this study.

**Perception of appropriateness of state hospital admissions varied somewhat between families and providers.** Five families did not feel the State Hospital was an appropriate placement but was the only option identified at the time of the psychiatric crisis. The remaining nine families were either unsure, did not have an opinion and/or trusted professional recommendations. All 37 providers interviewed reported the State Hospital was an appropriate placement for these 14 adolescents, given the resources available to the communities at that particular point in time. Experienced CBS providers and inpatient hospital staff indicate that some youth (due to their personality traits, limited coping and minimal response to CBS) will need to be hospitalized no matter what.

**Factors that limit choices for admission** to facilities other than the State Hospital include limited crisis stabilization services in rural/frontier areas and lack of transportation options. In addition, youth who are transferred from private facilities have no other option if their private insurance has run out or if they are in state custody.

In a majority of the case studies (10 of 14), if longer term treatment was needed an admission to a Level V or VI facility was explored. It is plausible that Level V and VI facilities serve the same population of youth who access the state hospitals and thus could serve as the existing regional services to develop. Family and provider experiences of the quality of Level V and VI services were mixed. If these facilities are to be considered in the development of more regional models of care, the present study supports further exploration into the administration of Level V and VI facilities.

## **Areas of possible improvement**

### **1. Continue to Develop a Family Driven System of Care.**

Incorporate the growing knowledge-base of effective roles for families within all levels of the system of care. This family driven model requires regular communication regarding interventions and active assessment of their effectiveness to meet the high expectation. Parent support providers within each individual CMHC can be utilized to assist in shaping local family driven systems of care.

### **2. Identify Youth who are at Increased Risk for Hospitalization.**

Develop plans to examine the demographics youth who are at increased risk for hospitalization by closely examining the demographics of youth who are re-admitted within short periods of time. Develop a plan for assessing the quality of care for these youth. Ongoing analysis of demographics of youth entering the state hospitals should be examined as well as information regarding the need for hospitalization from all stakeholders' perspectives.

### **3. Enhance Family Centered Crisis Response Services and Teams.**

Develop meaningful crisis plans for youth who are involved in CBS. Two families involved in CBS could discuss clear steps to follow in an escalating crisis and felt supported during the crisis by CBS providers. More work could be done on individual crisis plans to understand the specific triggers and specific actions to take in the situation. Find out what families say they need in a crisis situation and what a crisis is to that family. Notify on call staff regarding what the family may be expecting when calls come in after hours.

Implement strategies to rejuvenate staff and families dealing with the affects of acute and chronic crises. Services are often provided in highly intense, emotionally charged circumstances which can create tensions in the working relationships that must be resolved. One strategy identified in this study employed by a group of CBS providers was to conduct stress debriefing sessions for the wraparound team after the occurrence of a critical incident. The debriefing brought all the important "players" together to "restock and recharge" resources within the team. Demonstrating self-care strategies in the teaming process improves the overall mental health of teams. This enables them to work effectively through and process tensions that will inevitably arise in parent-provider and provider-to-provider relationships (Osher & Osher 2002). In addition, families are able to express their needs when in crisis and the team can discuss future crisis de-escalation strategies.

Develop collaborations with law enforcement. Law enforcement officers were involved in the majority of the crises warranting state hospitalization. One provider in the study noted, "*we might as well train them to work with our kids!*" One agency provided onsite trainings for law enforcement regarding crisis planning. In addition they provided coaching to parents about what to tell law enforcement when they arrived. Another agency provided "*police cheat sheets*" or "*tips*" to keep in patrol cars for psychiatric crisis de-escalation as well as crisis line numbers for police to contact for consultation.

#### **4. Increase Awareness and Provide More Education in Schools Regarding Psychiatric Risk Factors for Adolescents.**

*Increase awareness and provide more education in schools about how to refer youth like [name]. We need more education for parents. I think they had a clue about what was going on, but I don't think they had any awareness as to the extent of the issues with [name] until it was almost too late. [Private Hospital Staff]*

#### **Increase Access to Services at Critical Points.**

Refine access standards regarding emergent referrals (requiring a response within 24 hours). Emergent criteria could be revised to include youth who are screened at crisis centers, have police interventions, are admitted to private psychiatric hospital or are suspended from school. In addition these agencies should be informed of emergent criteria to know when to contact the CMHC to set up an appointment. One agency in the present study employs a crisis case manager who provides initial case management services for youth and families who have been screened into or diverted from the State Hospital. Families and community based providers as well as hospital staff in the current study indicated this position was helpful to gain needed information and get the necessary services set up promptly.

#### **5. Continue to Develop the Full Array of CBS.**

Some community mental health centers are not able to offer the full array of services defined in the current Medicaid State Plan.

Respite Care services as one provider noted, continue to be an “*underdeveloped, highly desired*” that could divert many acute hospitalizations. Results from a randomized trial indicate that families receiving at least 24 hours of respite per month were less likely to use an out of home placement. If families did use an out of home placement, fewer days were needed. Two CMHCs were developing respite services at the time of the present study.

Attendant Care services, which can also be a form of respite, continue to be difficult to staff and maintain in some areas of the state. A previous study of experienced programs relay that full time AC staff, rather than part-time crisis oriented AC staff, tend to stay in their positions longer, contributing to a more stable pool of available workers (Davis, Logan, Petr & Walter, 2004). One youth in the present study was most stable in the community when attendant care services were provided on a regularly scheduled basis. Another youth would become agitated when regularly scheduled appointments were missed. The family reported that missed appointments were a possible trigger for crisis.

Multiple providers in the present study identified the need for more qualified foster homes for youth with complex mental health needs. To be effective, these homes can not be overloaded with too many youth. To start, foster parents in the existing pool can be identified. Incentives can be provided to workers to identify families who may have the aptitude to become Therapeutic Foster Homes (TFH). The homes should be well supported and incorporated within an array of community based services.

**6. Explore the Population and Services Provided in Level V and VI Facilities. Establish Family Driven Outcomes.**

Compile data on the demographic characteristics of children and adolescents admitted to substantiate the theory that these facilities serve a similar population of children and adolescents served in the state hospitals. Identify the general staffing patterns, credentials, administrative structures and interventions provided. Identify what facilities, if any, specialize in serving specific sub-populations of youth such as youth who experience developmental disabilities. Develop indicators of quality services. Incorporate a family driven paradigm of systems evaluation of services within Level V and VI facilities (see number 1 above).

## Table of Contents

<b>Introduction</b>	<b>1</b>
<b>Background</b>	<b>2</b>
<b>Psychiatric Hospital Utilization: National data</b>	<b>4</b>
<b>Kansas State Hospitals Services Compared with National Averages</b>	<b>5</b>
<b>Adolescents in Kansas State Hospitals Fiscal Year 2005</b>	<b>6</b>
<b>Kansas Private Hospitals</b>	<b>10</b>
<b>Adolescents in State Hospitals -- A Qualitative Multiple Case Study</b>	<b>12</b>
Study Questions	13
Methods	13
Participants	15
Transcription	15
Analysis -- Coding and Reliability	15
Trustworthiness of Findings -- Participant Feedback	16
<b><u>Findings</u></b>	
<b>Study Question 1. Characteristics of Adolescents</b>	<b>17</b>
1.1 Strengths, Resiliencies, and Protective Factors	17
1.2 Sample Demographics	18
<b>Study Question 2. Circumstances Surrounding Admission</b>	<b>19</b>
2.1 Acute Behaviors in Context	19
2.2 Psychiatric Crisis Warranting Hospitalization	19
<b>Summary Study Question 2</b>	<b>22</b>
<b>Study Question 3. Array of Services Youth Received Prior to Admit</b>	<b>22</b>
3.1 Mental Health Services	22
3.2 Child Welfare Services	23
3.3 School	24
3.4 Juvenile Justice or Law Enforcement Involvement	24
<b>Summary Study Question 3</b>	<b>24</b>
<b>Study Question 4. Quality of Services &amp; Factors Affecting Quality</b>	<b>25</b>
4.1 In General Participants Felt High Quality Services Were Provided	25
4.2 Complicating Factors Affecting Quality	26
4.3 Medication Related Factors	28
4.4 Access to Services at Critical Points	29
4.5 Services Coordination & Continuity	30
<b>Summary Study Question 4</b>	<b>34</b>

## Table of Contents

<b>Study Question 5. Appropriate Admissions to the State Hospital</b>	<b>35</b>
5.1 Family Perspectives	35
5.2 Provider Perspectives	35
5.3 Complicating Factors	36
<b>Summary Study Question 5</b>	<b>38</b>
<b>Study Question 6. Feasibility of Regional Models</b>	<b>38</b>
6.1 Current Levels of Care	38
6.2 Level V and VI Facilities General Practices	39
6.3 Family Experiences with Level V & VI	40
6.4 Family Involvement in Treatment is Ideal	41
6.5 What Will be the Safety Net	41
<b>Summary Study Question 6</b>	<b>42</b>
<b>Summary of Qualitative Findings</b>	<b>43</b>
<b><u>Areas of Possible Improvement</u></b>	<b>44</b>
1. Continue to Embrace a Family Driven System of Care	44
2. Develop Plans to Examine Youth At Increased Risk for Hospitalization	44
3. Enhance Family Centered Crisis Response Services and Teams	45
4. Early Identification and Access to Community Based Services (CBS)	45
5. Continue to Develop the Full Array of CBS	46
6. Explore Level V and VI Population, Structures, Services & Establish Outcomes	47
<b>References</b>	<b>48</b>
<b>Appendices</b>	
Appendix A: Kansas Department of Health and Environment Population Density Stratification by State Hospital Catchment Area and CMHC	
Appendix B: Interview Guide for Study Participants	
Appendix C: Screener Interview Guide	
Appendix D: Code List	
Appendix E: Participant Feedback	

## INTRODUCTION

*She drove herself to a friend's house and was sobbing uncontrollably when she got there saying "I love you, I'm sorry. I don't know what's going on." The friend called me right away to get her. She had a long sleeved shirt on and jeans so I didn't really know she had cut herself up. I came home, and I called my family doctor, who directed us to the hospital emergency room. When we got there apparently she had a razor blade and she had her hand in her shirt. She was sobbing and heaving and apparently cutting on the way to the hospital, blood was everywhere. They actually said if she needed stitches there was nothing to stitch it to. [Parent]*

Age = 17

First serious suicide attempt of two in a 3 month interval warranting state hospitalization

Multiple acute private hospitalizations

*Everything I thought was fine. He had talked to a friend and evidently he said something that upset him and I went in there. I was in there just talking to him just prior to the incident and I thought everything was fine. I walked in there and found him unconscious. That's when I freaked out and couldn't get him to respond to me. I called 911 and they came and got him and took him to the hospital and then they flew him by helicopter to another hospital. He almost died. He took over 90 pills. The doctor told me if I'd have been even a half hour later he may not have made it. [Parent]*

Age =15

Third suicide attempt in the last year warranting state hospitalization

Multiple acute private hospitalizations.

Names of youth in the quotes were replaced with she and he pronouns to protect confidentiality of youth and their families.

These two adolescents were experiencing a psychiatric crisis and fortunately, these suicide attempts described above were not successful. A psychiatric crisis is occurring when an individual faces a barrier to "important life goals" that seems "insurmountable when applying their usual means of problem solving" (Lange, 2006, p. 6). Some crises may be gradual or some may be unexpected and acute. These latter emergency crises situations need prompt attention (Walter, Parks & Petr, 2004).

Where adolescents and their families go for help is often dependent upon circumstances such as when risk is noticed and by whom, when and where a crisis happens, whether preventive services are in place, and accessibility of crisis intervention services. Crisis for adolescence are also affected by caregivers' abilities and more broadly the communities' capacity to manage the crisis (Pumariega & Winters, 2003). In extreme situations such as the two described above, families must seek care in general hospital emergency

departments. Of all youth under the age of 18, youth between the ages of 13 to 18 had the highest annual rate (139.5 per 10,000 population) of visits to emergency departments for mental health emergencies between 1993 and 1999 (Sills & Bland, 2002). Families may also seek help from community mental health centers, private mental health providers, school counseling services, and other informal organizations such as church counseling centers.

According to the educational and mental health systems, roughly 20% of youth are at risk or have a diagnosable disorder that meets the Diagnostic Statistical Manual (DSM) criteria. Furthermore, 5% of youth experience a Serious Emotional Disturbance (SED) or intense behavioral problems. Roughly 15 % of youth are at risk for problem behaviors (Friedman, Kutash & Duchnoswski as cited by Kutash, Duchnowski & Lynn, 2006).

Adolescence in general can be a difficult life phase. Adolescence is defined by Meriam-Webster's online dictionary as "the state or process of growing up" and "a stage of development prior to maturity" (retrieved May 15, 2006, <http://www.m-w.com/dictionary/adolescence>). In this maturing process, the individual's biological, cognitive and psychological understanding about themselves and the world around them is changing. In addition, during adolescence there are typically at least two changes in school setting. These adjustments require individuals to endure a certain amount of stress and understandably cause a range of emotions and reactivity. Some stressors are inherent in adolescence, therefore it is important to distinguish what is normal.

Some resulting "normal" developmental behaviors include; feeling awkward or strange about one's body, having high expectations with periods of low self-esteem; acting moody, realizing and verbalizing parent faults and imperfections, acting illogically when overwhelmed or stressed, being shy, worrying about being normal, being self consciousness, changing relationships rapidly, experimenting with drugs or alcohol, and testing of rules and limits set by authority (American Academy of Child and Adolescent Psychiatry, Normal Adolescent Development Fact Sheet, Retrieved May 15, 2006 from <http://www.aacap.org/publications/factsfam/develop.htm>).

## **BACKGROUND**

Kansas' community based psychiatric crisis response services for all individuals, including adolescents, have been developing since the passage of the Mental Health Reform Act of 1990. This act designated the primary responsibility for the provision of mental health services to the 27 local community mental health centers (CMHC) across the state of Kansas. The act was the culmination of a movement that began in the mid 1980s to establish a public mental health system that provided community based care rather than institution based care in response to community crisis. One component of the act was to make CMHCs "gatekeepers" to the state hospitals in order to divert unnecessary psychiatric hospitalizations.

This meant that when an adolescent presented in the local hospital emergency room for an attempted suicide or serious self harm, the hospital contacted their local CMHC and a qualified mental health professional (QMHP) conducted an assessment to determine the level of care needed to meet the adolescent's mental health and safety needs. This procedure became known as the Mental Health Reform Screen (Mental Health Screening

Policy and Procedures Handbook, April 2002). The screening tool was created to assess mental health history, support systems, risk factors, and clinical impressions. If the QMHP determined hospitalization was unnecessary, an alternative community services and safety plan was to be developed. The screening procedure was intended to be a component of a crisis response system attached to an array of services administered by CMHCs.

From 1990 to 1996, other elements of mental health reform were implemented in phases beginning with the eastern part of the state and moving to the western part of the state. State hospital bed capacity was significantly reduced with the closing of Topeka State Hospital in 1997. In addition reform efforts continued to de-emphasize inpatient care while promoting community based alternatives. For example, there was a 42% decrease in bed capacity from 1990 to 2002 in the Larned State Hospital catchment area for youth ages 5 to 17 (Flamik, Sohm & Brooks, 2006). At the same time state funding was re-allocated to CMHCs in the form of block grant funding and new Medicaid billable services (such as case management and attendant care).

Kansas was not alone in efforts to reform the public mental health system. Vermont, Massachusetts, New Hampshire, Ohio, and Pennsylvania significantly downsized and some eliminated their state hospital services for children and adolescents. Still some stakeholders questioned the utilization of inpatient services: if they were not needed why did some youth continue to need to be re-hospitalized? During the same time frame, Pottick, Warner, Isaacs, Maderscheid, Milazzo-Sayre and Henderson (2002) compared inpatient and outpatient service utilization nationwide and found that inpatient rates increased by 143% while outpatient utilization increased only 65% from 1986 to 1997.

Some of the increase in inpatient utilization in this time frame may also have been a result of the emergence of more acute inpatient settings to serve children and adolescents. These units focused on short term crisis stabilization and significantly shorter lengths of stay (usually 3 to 5 days). Furthermore, in Kansas, admission to these private facilities was not contingent upon a CMHC screen and was more accessible to families with private insurance. Children and adolescents may have been hospitalized multiple times in a private setting before state hospitalization was utilized or the CMHCs were accessed to provide assistance.

Subsequently, a growing body of evidence from the community based systems of care literature began to document a subpopulation of youth who entered the systems of care with extreme functional impairment and risk factors, thus requiring longer lengths of stay to stabilize (Laygo, Brooke & Stephens, 2005). It stands to reason that in Kansas this subpopulation is comprised of those that need the longer inpatient care option (20 to 30 days) and are currently almost exclusively served by Larned State Hospital and Rainbow Mental Health Facility.

Rapid resource reallocation and dramatic decreases in bed capacity have resulted in contrasting stakeholder views about the need for inpatient services within the service array in Kansas. One view purports inappropriate admissions are occurring due to system related phenomena such as underdeveloped crisis intervention services, fragmented service delivery, and effects of staggered implementation of mental health reform funding. Conversely, other stakeholders have confirmed that there is a need for longer term inpatient

resources to provide medication stabilization, regardless of the availability of community based services (Walter, Davis & Petr, 2005). Lastly, stakeholders have pondered the feasibility of more regional models of state administered inpatient care to facilitate more family and community involvement in the treatment process.

A study conducted in FY 2005 on young children admitted to state hospitals found that state hospitals provided a unique role and function within the system of care as an intermediate length treatment option. Overall, the children's admissions to the state hospital were appropriate given the resources available to families and providers at the time. All 12 children in the study received some type of mental health service prior to admission, though none received the full array available in the Medicaid State Plan. Some areas for improvements in community based mental services were suggested, though it is unclear if these improvements would have prevented the hospitalization of any of the children in the sample. The conclusion was that the state can not confidently consider closing state hospitals for young children, unless resources in the communities are consistently available.

The purpose of the following endeavor was to increase understanding of utilization of state administered inpatient services for adolescents. Qualitative interviews were conducted with key informants to illuminate the psychiatric crisis warranting inpatient hospitalization for 14 adolescents. The qualitative findings are primarily constructed from caregivers' perspectives, triangulated with local providers' expert knowledge of practices within their respective communities. Stakeholder feedback regarding the feasibility of a regional model was also gathered to continue work on this issue initiated in the "*Admission of Young Children to State Hospitals*" report (Walter, Davis & Petr, 2005) as well as to summarize possible next steps.

## **PSYCHIATRIC HOSPITAL UTILIZATION: NATIONAL DATA**

### ***Characteristics of adolescents in inpatient treatment facilities***

The most recent available national data about the characteristics of youth utilizing inpatient mental health services draw upon the 1997 Client/Patient Survey Sample (CPSS) (Pottick et al., 2002). The CPSS consists of a sample of over 4,000 children and adolescents, and provides information on their socio-economic background, prior services, and family situation.

### ***Sociodemographic data***

CPSS data indicate that of youth admitted to all types of inpatient services<sup>1</sup> in 1997, the majority (67.6%) were adolescents ages 13 to 18. Gender was distributed almost evenly with 50.8% male and 49.2% female patients. A majority of youth in inpatient facilities were Caucasian (67.4%), 16.1% were African American, and 14% Hispanic (2.6% other). In contrast to youth admitted to residential care<sup>2</sup>, far more young people admitted to inpatient facilities lived with a parent (72.5% as opposed to only 53% of residential youth), and only

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<sup>1</sup> Includes State/County mental hospitals, private psychiatric hospitals and non-federal general hospitals that keep youth over 24 hours.

<sup>2</sup> Includes residential treatment centers for emotionally disturbed youth and freestanding hospitals that provide multiple services while youth reside on campus.

18.4% of inpatient youth had ever lived away from relatives prior to admission (compared to more than 40% of residential youth). The two main sources of payment for hospitalization were private insurance (48.3%) and Medicaid (37.6%) (Pottick et al., 2002).

### ***Functioning and diagnoses***

Youth admitted to inpatient facilities showed significant impairments of functioning (54.7% had GAF scores of 50 or below and 79.4% had GAF scores of 60 or below). The largest number of diagnoses fell into the mood disorder category (44.3%) followed by disruptive disorders (17.4%). Other disorders included psychotic (7.2%), personality (5.6%), anxiety (4.9%), alcohol or drug use (4.9%), or developmental disorders (4.3%). Forty three percent had two psychiatric diagnoses.

### ***Presenting problems***

Inpatient youth most often presented with anxious or depressed mood (64.5%), suicidality (55.4%), aggression (48.7%), family problems (47.3%), and difficulties coping at school (44.4%). A substantial number also presented with drug and alcohol use (25.7%), delinquent behaviors (24.5%), and a history of being abused or neglected (20.3%) (Pottick et al., 2002).

### ***Prior mental health services***

Eighty four percent of youth in inpatient facilities had received mental health services prior to hospitalization: 55.4% had received services from a private practice mental health professional; 42.4% had been admitted to inpatient treatment before; 33.3% had received outpatient mental health services; and 13.2% had been in residential treatment (4.2% other/unknown services) (Pottick et al., 2002).

## **KANSAS STATE HOSPITALS SERVICES FOR ADOLESCENTS COMPARED WITH NATIONAL AVERAGES**

### ***Penetration rates, lengths of stay (LOS) and readmissions***

Table 1 below summarizes statistics from the federal government's Center for Mental Health Services (CMHS), a division of Substance Abuse and Mental Health Services Administration (SAMHSA). This data is summarized from the CMHS Uniform Reporting System (<http://www.mentalhealth.samhsa.gov/cmhs/MentalHealthStatistics/URS2004.asp>). According to this data base, in fiscal year (FY) 2004, Kansas served 294 children and youth aged 0 to 17 in state psychiatric hospitals, a penetration rate of 0.42 per 1,000. The average LOS for those discharged during FY 2004 was 31 days. Nationally, the average penetration rate was 0.23, and the average length of stay was 82 days. Of the 222 discharges for youth aged 13 to 17 in Kansas, 18 (8.1%) were readmitted within 30 days of discharge; 37 (16.7%) were readmitted within 180 days of discharge. The national average of all states reporting readmissions (ages 13 to 17) within 30 days and 180 days of discharge were 6.4% and 14.6% respectively. Thus, compared to national averages, state hospital readmissions for adolescents in Kansas were slightly higher; however, Kansas state hospitals served a larger percentage of youth, with substantially shorter lengths of stay (average of 51 fewer days than the national average).

**Table 1 CMHS Uniform Reporting System Data FY 2004**

	<b>Kansas State Hospitals</b>	<b>All State Hospitals in the Nation</b>
<b>Ages 0-17</b>	<b><u>Penetration Rates per 1000 youth</u></b>	
	<b>.42/1000</b>	<b>.23/1000</b>
<b>Ages 13-17</b>	<b><u>Readmission within 30 days</u></b>	
	<b>8.1%</b>	<b>6.4%</b>
	<b><u>Readmission within 180 days</u></b>	
	<b>16.7%</b>	<b>14.6%</b>
	<b><u>Average Length of Stay</u></b>	
	<b>31 days</b>	<b>82 days</b>

**CHARACTERISTICS OF ADOLESCENTS IN KANSAS STATE HOSPITALS FY 05**

In FY 2005, *Larned State Hospital (LSH)* admitted 36% (96) of the total State Hospital admissions for adolescents. The gender of youth admitted was almost evenly distributed with slightly more females than males, 53% and 47% respectively. The majority of youth were Caucasian (70%), and between the ages of 15 and 17 (74%). Most lived either with parents, family members or foster parents in a private residence (86%), and 57.3% of them carried multiple psychiatric diagnoses. The mean length of stay was 20 days (see Table 2).

In the same time frame, *Rainbow State Hospital (RSH)* admitted 64% (172) of the total State Hospital admissions for adolescents ages 13 to 17. The majority of youth were males (56%) Caucasian (78%), and between the ages of 15 and 17 (63.6%). Most lived either with parents, family members or foster parents in a private residence (84.3%), and 69.8% of them carried multiple psychiatric diagnoses. The mean length of stay was 22 days (see Table 3).

**Tables 2 & 3. Demographics of Adolescents Admitted in FY 2005 to State Hospitals**

<b>Table 2. Larned State Hospital FY 2005 (June 2004 to July 2005)</b>			<b>Table 3. Rainbow State Hospital FY 2005 (June 2004 to July 2005)</b>		
<u>Admissions</u>	96 (36% of total admissions)		<u>Admissions</u>	172 (64% of total admissions)	
<u>Gender</u>	47%	45 male	<u>Gender</u>	56%	98 male
	53%	51 female		43%	74 female
<u>Ethnicity</u>	70%	67 Caucasian	<u>Ethnicity</u>	78%	134 Caucasian
	6%	6 African American		13%	23 African American
	13%	12 Hispanic		6.9%	12 Hispanic
	3%	3 Native American		.5%	1 Native American
	8%	8 Other		1.2%	2 Other
<u>Living upon Admission</u>			<u>Living upon Admission</u>		
Private Residence	86%	83	Private Residence	84%	145
Jail/Detention	6.3%	6	Jail/Detention	8.7%	15
Group Home	4.2%	4	Group Home	6.4%	11
Hospital/Other Institution	3.1%	3	Hospital/Other Institution	0.6%	1
At least 2 Diagnosis	54.5%	yes	At least 2 Diagnosis	60%	yes
Mean LOS	20 days		Mean LOS	22 days	
Median LOS	17		Median LOS	16	

***The most frequently recorded primary diagnoses***

The most frequently recorded primary diagnoses for adolescents admitted to Rainbow State Hospital in FY 2005 were Bipolar Disorder (26%), Attention Deficit Hyperactivity Disorder (14.4%), Reactive Attachment Disorder (10.3%), and Oppositional Defiant Disorder (7.2%). Rainbow State Hospital reported all diagnosis given to every youth admitted in FY 2005 (a total of 291 diagnosis were reported for the 172 admissions).

Larned State Hospital reported all diagnoses on record admitted in FY 2005 as well. The 96 adolescents had a total of 176 diagnoses between them. The most frequently recorded primary diagnoses were Attention Deficit Hyperactivity Disorder (10.2%), Major Depressive Disorder (9.7%), and Depressive Disorder (8%).

*Most frequently recorded Diagnosis Related Groups (DRG)* were mood disorders for both Rainbow and Larned State Hospitals (37% and 29%) respectively; followed by disorders usually first diagnosed in infancy, childhood, and adolescence (34.6% and 25%); and lastly, substance related disorders (15.3%) for Larned admissions and anxiety related disorders (8.9%) for Rainbow. Table 4 on the next page provides an overview of diagnoses as well as DRGs.

**Table 4. Most Frequently Recorded Primary Diagnosis and Diagnosis Related Groups for Adolescents upon Discharge from the State Hospitals in FY 2005**

<u>Other</u>	1 (.3%)	2 (1.1%)
<b>TOTAL DIAGNOSIS REPORTED</b>	<b>291 Reported on 172 Adolescents</b>	<b>176 Reported on 96 Adolescents</b>
<u>Mood</u>	107 (37%)	51 (29%)
Depressive Disorder	14 (4.8%)	14 (8%)
Major Depressive Disorder	17 (5.8%)	17 (10%)
Bipolar Disorder	76 (26%)	11 (6.3%)
Mood Disorder NOS	0	5 (2.8%)
Dysthymia	0	4 (2.3%)
<u>Disorders of Infancy, Childhood//Adolescence</u>	101 (34.6%)	44 (25%)
Attention Deficit Hyper-activity Disorder	42 (14.4%)	18 (10%)
Conduct Disorder	0	12 (6.8%)
Oppositional Defiant Disorder	21 (7.2%)	10 (5.7%)
Disruptive Behavior Disorder	3 (1%)	2 (1.1%)
Pica	0	1 (.6%)
Asperger's Disorder	0	1 (.6%)
Reactive Attachment Disorder	30 (10.3%)	0
Retts Disorder	4 (1.4%)	0
Developmental Coordination Disorder	1 (.3%)	0
<u>Anxiety</u>	26 (8.9%)	4 (2.3%) all PTSD
Post Traumatic Stress Disorder	20 (6.8%)	4 (2.3%)
Anxiety Disorder	2 (.7%)	0
Generalized Anxiety Disorder	2 (.7%)	0
Obsessive Compulsive Disorder	2 (.7%)	0
<u>Substance Related Disorder</u>	22 (7.5%)	27 (15.3%)
<u>Psychotic Disorder</u>	16 (5.5%)	9 (5.1%)
<u>Adjustment Disorder with...</u>	11 (3.8%)	22 (12.5%)
Mixed Disturbance Emotions and Conduct	3 (1%)	11 (6.25%)
Depressed Mood	8 (2.7%)	7 (4%)
Anxiety	0	1 (.6%)
Unspecified	0	3 (1.7%)
<u>Impulse-Control Disorder NOS</u>	4 (1.4%)	8 (4.5%)
<u>Eating Disorder</u>	3 (1%)	2 (1.1%)

*Regional referral patterns* for FY 2005 can be gleaned from the Tables 5 and 6 for Rainbow and Larned respectively, as well as from Appendix A. The highest number of referrals for Rainbow came from the six urban counties and one semi-urban county in the eastern part of Kansas, which together accounting for 119 of 172 admissions. These counties are listed in rank order in Table 5 below.

**Table 5. Counties with Highest Number of Referrals to RSH in FY 2005**

Counties and representative CMHC	City in County with a CMHC office	# of Referrals (%)
1. Shawnee Family Service & Guidance Center	Topeka	49 (28%)
2. Wyandot Wyandot Center for Behavioral Helath	Kansas City	24 (14%)
3. Sedgwick Comcare/MHA/Family Conslt.	Wichita	18 (10%)
4. Johnson Johnson County Mental Health	Mission	13 (8%)
5. Douglas Bert Nash Mental Health Center	Lawrence	8 (5%)
6. Geary Pawnee Mental Health Center	Junction City	7 (4%)
		<b>Total = 119 of 172</b>

The highest number of referrals (accounting for 54 of the 96 admissions) for *Larned State Hospital* came from 8 counties that are represented in rank order in Table 6 below. All of the counties, except Rooks, had at least one CMHC satellite office within the county. (See Appendix A for further explanation of these geographic variables by CMHC.)

**Table 6. Counties with Highest number of referrals to LSH in FY 2005**

Counties and representative CMHC	Town in County with a CMHC office	# of Referrals (%)
1. Ford Area Mental Health Center	Dodge City	9 (9%)
2. Saline Central Kansas Mental Health Center	Salina	9 (9%)
3. Seward Southwest Guidance Center	Liberal	8 (8%)
4. Ellis High Plains Mental Health Center	Hayes	7 (7%)
5. Barton The Center for Counseling Conslt	Great Bend	6 (6%)
6. Finny Area Mental Health Center	Garden City	5 (5%)
7. Pawnee The Center for Counseling and Conslt	Larned	5 (5%)
8. Rooks High Plains Mental Health Center	None	5 (5%)
		<b>Total = 54 of 96</b>

## **KANSAS PRIVATE HOSPITALS**

### ***Characteristics***

Table 7 on the next page summarizes data relating to youth admissions to private hospitals in FY 2005. Fourteen to sixteen year-olds account for 69.4% of all adolescents admitted. The majority of youth were female (56.5%) and Caucasian (73.3%). Black or African American comprised 9.8% followed by, Hispanic (1.1%), and American Indian/Alaskan and Native Hawaiian, .95% and .51% respectively. The rest of were youth (14.3%) were either “unknown” or in the “other” category.

### ***Most utilized private hospitals***

The three highest utilized private inpatient facilities were Prairie View in Newton (597 admissions), Via Christi Good Shepard in Wichita (280) and Kaw Valley Center in Kansas City (215). The average overall length of stay was 5.18 days. Lengths of stay at Kaw Valley Center were on average 1.24 days longer.

**Table 7. Demographics of Adolescents Admitted to Private Hospitals FY 2005**

HOSPITAL	# ADMITTED (%)	AGE						SEX		LOS (days)	
		13 (%)	14 (%)	15 (%)	16 (%)	17 (%)	18 (%)	Male(%)	Female(%)	Mean	Range
Bob Wilson Memorial Grant County Hospital - Ulysses	1 (.1) <sup>1</sup>		1 (.3)						1 (.1)	1	1-1
Coffeyville Regional Medical Center	61 (3.9)	8 (3.1)	13 (4.3)	20 (5.1)	20 (5.1)			30 (4.3)	31 (3.5)	6.52	1-12
Hospital District #1 of Crawford County - Girard	1 (.1)	1 (.4)							1 (.1)	1	1-1
Hutchinson Hospital	22 (3.9)		6 (2)	8 (2)	8 (2)			3 (.4)	19 (2.1)	4.95	1-11
Mercy Regional Health Center Inc. - Manhattan	1 (.1)		1 (.3)					1 (.1)		1	1-1
Mitchell County Hospital Health Systems - Beloit	1 (.1)				1 (.3)				1 (.1)	2	2-2
Morton County Health System - Elkhart	3 (.2)			1 (.3)	2 (.5)			2 (.3)	1 (.1)	2.33	2-3
Mt. Carmel Regional Medical Center - Pittsburg	5 (.3)				5 (1.3)				5 (.6)	5.2	3-8
Salina Regional Health Center	2 (.1)	2 (.8)							2 (.2)	8.5	6-11
St. Catherine Hospital - Garden City	72 (4.6)	13 (5.2)	17 (5.6)	18 (4.6)	24 (6.1)			31 (4.5)	41 (4.6)	4.97	1-15
Stormont-Vail HealthCare - Topeka	202 (12.8)	32 (13.9)	44 (14.5)	62 (15.8)	64 (16.2)			83 (12)	119 (13.4)	5.34	0-14
University of Kansas Hospital - Kansas City	107 (6.8)	22 (8.7)	22 (7.3)	33 (8.4)	30 (7.6)			54 (7.9)	53 (6)	4.31	0-10
Via Christi Regional Medical Center - Wichita	280 (17.8)	55 (21.8)	52 (17.1)	90 (30)	83 (21)			120 (18)	160 (18)	4.3	1-15
Wesley Medical Center - Wichita	4 (.3)		3 (1)		1 (.3)				4 (.4)	2.25	1-3
Kaw Valley Center	215 (13.6)	39 (15.5)	40 (13)	54 (13.8)	43 (10.9)	38 (31)	1 (1)	89 (13)	126 (14)	6.44	1-19
Prairie View	599 (38)	80 (32)	104 (34)	106 (27)	114 (29)	86 (69)	107 (99)	272 (40)	325 (37)	5.04	1-18
<b>TOTALS</b>	<b>1574</b>	<b>252(16)<sup>2</sup></b>	<b>303(19)</b>	<b>392(25)</b>	<b>395(25)</b>	<b>124(8)</b>	<b>108(7)</b>	<b>685(44)</b>	<b>889(56)</b>	<b>5.18</b>	<b>0-19</b>

<sup>1</sup> Bob Wilson Memorial Grant County Hospital – Ulysses accounted for .1% of all adolescents ages 13 to 18 admitted to private hospitals in FY 2005

<sup>2</sup> 13 year olds accounted for 16% of adolescents

### ***Most frequently recorded primary diagnosis***

Prairie View reported the top two frequently recorded diagnosis as Mood Disorder Not otherwise Specified and Major Depressive Disorder Recurrent. The rest of the inpatient data were combined into one database; with the top two most frequently recorded diagnoses were Bipolar I Disorder and Depression with Psychotic Features.

**Table 8. Most Frequently Recorded Primary Diagnosis for Adolescents in Private Hospitals FY 2005**

	Hospitals Prairie View	Via Christi	Kaw Valley Center	Stormont Vail	KU Med
# of Total Admissions	599	280	215	202	107
<b>Diagnosis Related Groups</b>					
Mood Disorders		170 (61%)	188 (87%)	179 (89%)	73 (68%)
Disorders Diagnosed in Childhood/Adolescence	Unable to identify % per diagnosis as data request was sent in aggregate form.	69 (25%)	11 (5%)	7 (3.5%)	15 (14%)
Adjustment Disorders		19 (7%)	7 (3%)	None	4 (3.7%)
Impulse Control Disorders		8 (3%)	None	None	1 (.9%)
Anxiety Disorders		5 (2%)	1 (.5%)	7 (3.5%)	2 (1.9%)
Psychotic Disorders		4 (1%)	8 (3.7%)	9 (4.5%)	7 (6.5%)
Somataform Disorders		2 (.7%)	None	None	1 (.9%)
Other Disorders		2 (.7%)	None	None	1 (.9%)
Mild Mental Retardation		1 (.4%)	None	None	None
<b>Top 2 Primary Diagnosis Overall</b>					
	Mood Disorder Not Otherwise Specified (NOS)	Depressive Disorder with Psychotic Features 101 (36%)	Bi-polar I Disorder 143 (67%)	Episodic Mood Disorder 72 (36%)	Episodic Mood Disorder 40 (37%)
	Major Depressive Disorder Recurrent, severe without psychotic features	Oppositional Defiant Disorder 40 (14%)	Major Depressive Disorder 41 (19%)	Depressive Disorder NOS 50 (25%)	Depressive Disorder with Psychotic Features 17 (16%)

### **ADOLESCENTS ADMITTED TO STATE HOSPITALS -- A QUALITATIVE MULTIPLE CASE STUDY**

To illuminate the circumstances surrounding the admission of adolescents to state mental health facilities, this multiple case study took an in-depth look at a convenience sample of fourteen adolescents, ages 13 to 18, who were admitted to or residing at one of the two state mental hospitals in the months of October 2005 through January 2006.

## STUDY QUESTIONS

Six study questions were developed based on findings from a review of the literature, stakeholder feedback and a previous report, *Admission of Young Children to State Hospitals* (Walter, Davis & Petr, 2005).

1. What are the characteristics (strengths, ages, gender, ethnicity, living situation, diagnostic information, etc) of adolescents admitted to the State Hospitals?
2. What were the circumstances (acute behaviors, events at home, school, and secure facilities) that led to this most recent admission?
3. What was the array of services youth received prior to admissions and how long did they receive services?
4. What was the quality of services provided to adolescents and families prior to hospitalization and what factors affected quality?
5. Considering the answers questions 1-4, were admissions to the State Hospital deemed appropriate from all stakeholders' perspectives?
6. What other factors should be considered to explore the feasibility of regional models of state administered inpatient care for children and adolescents?

## METHODS

### Access

Access to potential study participants was gained through Rainbow (RSH) and Larned State (LSH) Psychiatric Hospitals. Beginning in October 2005, the state hospitals informed the families of the study in two different ways based their preferences: 1.) Rainbow placed a letter in admission packets to parents or guardians which outlined the basic purpose and procedures of the study and became a part of the admission procedures; 2.) Larned hospital social workers informed families of the study upon their initial contact and gave them the same letter 3 to 10 days after admission. The letter requested families' permission for University of Kansas researchers to contact them to explain the study in more detail. When families consented to be contacted, designated staff at the state hospitals forwarded families' basic contact information to the project manager, who then called potential family participants to explain the project in detail, and request their consent to participate in the study.

### **Sample recruitment & data collection**

When families agreed to participate, formal consent forms were signed by families and two researchers met with family participants at a time and location of the families' choosing (all were in family residences) to conduct a 90-120 minute face-to-face interview. During this initial interview, families consented to give researchers access to information on file at the hospitals. Family participants also identified community mental health service providers, school personnel, child welfare workers, or other sources able to offer additional insights

into the situation prior to and leading up to hospital admission. Families gave written consent for these sources to release information to researchers.

The total sample for this study consisted of 14 case studies. In the time period from October 1, 2005, through January 30, 2006 *Rainbow* referred 14 cases to researchers. These cases were either at RSH on October 1<sup>st</sup> or were admitted thereafter. Seven of the 14 families could either not be contacted or declined participation. A total of 7 RSH families participated in the study. *Larned* referred 9 cases who were admitted between October 1, 2005, through January 30, 2006. Of these 9 cases, one family canceled the interview (due to a family situation) and another family could not be reached. Seven LSH families agreed to participate in the study.

### ***Interviewing***

Family interviews were conducted by the project manager with another researcher present to record field notes. Upon completion of the family interviews, the project manager approached community providers identified by families, obtained providers' consent to participate, and conducted either face-to-face or phone interviews. Most community provider interviews were conducted over the phone due to the time-sensitive nature of data collection. If adolescents were transferred from a private hospital setting or other secure setting to the state hospital (9 cases), the project manager also contacted these facilities to obtain information about reasons for the transfer. In some instances, agencies required agency specific consents to participate in the study as well. Each agencies' individual protocol was followed.

Interview questions were developed to guide the qualitative inquiry (see Appendices B & C). Questions posed to families elicited their recollection of the circumstances that led to the need for hospitalization (events leading to admission, crisis response, etc.); the sequence of events (such as who did they contact first, how did they transport the child, etc.); experiences with the screening and admission process; changes and transitions in the child's or family's life within the past year; and the range and quality of services received from mental health providers (including previous hospitalizations), schools, and other service systems (such as child welfare providers). If youth were transferred to the state hospital, the interviewer inquired about reasons for the transfer.

Akin to the family interviews, questions posed to service providers focused on their involvement with the family, the type and quality of services delivered prior to and during the crisis, communication and collaboration with other providers, and precipitating factors. If youth were transferred to the state hospital, reasons for the transfer were explored.

Questions posed to state hospital screeners focused on the initial impression of the child, diversion attempts, screeners' professional background, training, and more general questions about the perceived effectiveness of screenings. If youth were transferred to the state hospital, the interviewer inquired about reasons for the transfer. Staff at local hospitals were asked to identify reasons for transfers and related barriers and challenges. All participants were asked to make recommendations for the improvement of services. In addition, participants were asked to give their impressions of the feasibility of developing more regional services for children and adolescents. Lastly, hospital case records for the

14 youth, including demographic information, a psycho-social history and assessment, and screening forms were main sources of information for this study.

## PARTICIPANTS

For the 14 case studies, a total of 56 interviews (63 participants) were conducted (see Table 8. Case Matrix): sixteen interviews with family members (includes 3 youth), 38 interviews with professionals directly or indirectly involved in providing services to the youth and their families. Some service providers did not return multiple phone calls. At least 3 sources were contacted for all of the 14 case studies.

**Table 9. Case Matrix**

Case #	Family	Screeener	MH Case Manager	Other MH provider <sup>1</sup>	School personnel <sup>2</sup>	State Agency <sup>3</sup>	Regional Hospital or Other Secure Facility <sup>4</sup>
*1	XY	X	n/a	XX	X	XX	
*2	X	X	n/a	n/a	n/a	X	X
*3	X	X	n/a	n/a		n/a	X
4	XY	X	n/a	n/a		X	n/a
*5	X		X	X		n/a	X
6	XX			X	X	n/a	n/a
7	X	X	X	X	XX	n/a	n/a
8	X		X	X	X	n/a	n/a
*9	XX	X	n/a	n/a	n/a	X	X
*10	X			XX	X	n/a	X
*11	XX		X			n/a	X
12	XX			X	X	n/a	n/a
*13	XX		X		X	n/a	X
*14	X		n/a	n/a	n/a	X	X
<b>Participants</b>	<b>21</b>	<b>6</b>	<b>5</b>	<b>9</b>	<b>8</b>	<b>6</b>	<b>8</b>

<sup>1</sup> Includes 5 therapists, 3 parent support specialists, 1 discharge specialist.

<sup>2</sup> includes 5 special education teachers, 1 social worker, 1 principal, 1 school counselor.

<sup>3</sup>Includes the child welfare workers and juvenile justice workers

<sup>4</sup> Includes private psychiatric hospitals, level six, detention centers and correctional facilities

\* = Transferred from local hospital to state hospitals or other secure facility just before this SH admission.

X = number of Xs indicates number of participants; Y indicates youth interview.

## TRANSCRIPTION

All family interviews were audio-taped and transcribed for analysis. Interviews with service providers were audio-taped. To expedite the analysis for the provider interviews, a domain focused method of interviewing and transcription was utilized (Freundlich & Padgett, 2004) in which the interviewer takes detailed notes regarding domains of interest and transcribes notes while listening to the tape for illustrative quotes.

## ANALYSIS - CODING AND RELIABILITY

All transcripts were entered into an Atlas.ti qualitative data base (Muhr, 1997) for coding and data management. In order to maximize consistency, the project manager took primary responsibility for coding all interviews.

Data were analyzed using **constant comparisons** in three main ways:

1. Within case studies: Which main themes emerge within each case study? Which key information is shared by all sources for the case study and which information diverges?
2. Across case studies: Which themes emerge across case studies? How are they similar or different? Which themes are unique to particular case studies?
3. Within source: Grouping interviews by their source (such as all family interviews, all case manager interviews, etc.) which common themes emerge? Which information is unique to a particular source?

Another researcher with specialized knowledge in qualitative naturalistic inquiry served as a “peer debriefer” (Lincoln & Guba, 1985, p. 308). The peer debriefer’s (PD) role was to provide the primary inquirer with a fresh perspective regarding all aspects and processes (method, analysis, results, etc.) of the naturalistic inquiry. The PD provided consultation regarding reliability of categories by blindly coding one interview. The PD created her own codes and compared these categories against the project manager’s categories. Six discrepancies were found and categories were revised to incorporate feedback. A total of 45 categories were utilized (see Appendix D). The PD then reviewed the consistency of the code categories with the research questions and found high internal consistency as well as traceable and logical category development. Overall, the PD found the coding process highly dependable.

#### **TRUSTWORTHINESS OF FINDINGS-PARTICIPANT FEEDBACK**

In order to establish if the sample was similar to typical hospital populations beyond the FY 2005 comparison group, and to assure credibility and confirmability of data (Lincoln & Guba, 1985), preliminary findings were sent to all research participants as well as the state hospital clinical staff in July 2006 (56 draft reports were mailed out). The packets that were mailed out included a self-addressed stamped envelope to return their written feedback. In addition, the project staff contacted this group of participants by phone at least once to illicit a response. Feedback was provided by 15 (28%) of the study participants (5 families, 2 therapists, 5 case managers, and 3 administrators). A summary of stakeholder feedback can be found in Appendix E.

## FINDINGS

### Study Question 1. What are the Characteristics (Strengths, Resiliencies and Protective Factors, Ages, Gender, Ethnicity, Living Situation, Diagnostic Information, etc) of Adolescents Admitted to the State Hospitals?

#### 1.1 Strengths, Resiliencies, and Protective Factors

All of the 14 youth experienced serious traumatic life events at one point in time in their young lives. *A consistent protective factor identified was that all the youth had supportive, involved parents or guardians.* The project manager was struck by families' ability to provide a balanced perspective of setbacks and celebrations regarding caregivers' experiences rearing these 14 youth.

Common strengths noted more than once by families included: empathy (7), high intelligence (6), determined and passionate (5), creative and artistic (4 youth), self advocacy (4), pride in appearance (3), spirituality (3), loyalty (2), and humor (2).

*He is really smart, and a good-looking youth...he cares way too much. He would see people holding up a sign, homeless people, and he'd be like I have to give all my money. I think that's why he's got that anger towards God, because he's like how are all these people suffering. All of this bad stuff that's on the news, and I think he feels so deeply.*

#### 1.2 Sample Demographics

Table 10, below, represents the sample demographics from both hospitals. There were slightly more females (57.1%) than males (42.9%) in both hospital samples.

All but one youth in the *LSH* sample were Caucasian (85.7%). The majority of youth at *LSH* were ages 15-17 (71.5%). Most youth lived with parents or family members (85.7%). Mood Disorders accounted for 86% (6) of the primary diagnosis most of the youth (85.7%) carried multiple psychiatric diagnoses.

Ethnicity distributions in the *RSH* sample were more diverse. The majority of youth were Hispanic and Caucasian (71.5% combined). The majority in the *RSH* sample were ages 15-17 (57.2%). Most youth lived with parents or grandparents; two youth were in state custody at the time of the study. Mood Disorders accounted for 71% (5) of the primary diagnosis in the *RSH* sample.

In terms of the geographic population density characteristics of home counties (see last row on Table 9), this convenience sample is slightly more representative of frontier, rural, and densely settled rural counties (accounting for 57% admitting counties) than it is semi-urban and urban counties (43%). Overall in 2005, urban and semi-urban counties accounted for 58% of the admissions to State Hospital, while densely settled rural, rural and frontier counties accounted for 42% of the admissions.

**Table 10. Sample Demographics by Hospital**

	<b>Larned Sample</b>	<b>Rainbow Sample</b>
Total=14	7	7
Gender	42.9% male 57.1% female	42.9% male 57.1% female
Ethnicity	85.7% Caucasian 14.3% African American	28.6% Caucasian 14.3% African American 14.3% Hispanic 14.3% Native American 28.6% Caucasian Hispanic
Age	28%: 13 42.9%: 15 14.3%: 16 14.3%: 17	28.6%: 13 14.3%: 14 14.3%: 15 28.6%:16 14.3%: 17
Living Upon Admission	71.4%: With parents 14.3%: Kinship 14.3%: Adoption	57.1%: With parents 14.3%: Kinship 14.3%: Foster Care 14.3%: Correctional Facility
Multiple Diagnoses	85.7% yes	85.7% yes
Primary Diagnosis on Screen	<u>86% Mood Disorders-6 youth</u> Major Depressive 3 Bipolar 2 Dysthymia 1 PTSD 1	<u>71% Mood Disorders-5 youth</u> Bipolar 4 Major Depressive 1 Conduct Disorder 1 ADHD 1
Population Density of Home County	71.4% Rural 14.3% Frontier 14.3% Semi-urban	57.1% Urban 14.3% Semi-urban 14.3% Densely-settled rural 14.3% Frontier

## **Study Question 2. What Were the Circumstances (Acute Behaviors, Events at Home, School, and Secure Facilities) that Led to this Most Recent Admission?**

### **2.1 Acute Behaviors in Context**

Acute behaviors occurred in the context of already existing emotional and behavioral difficulties resulting in **frequent, sometimes chronic, crisis situations**.

- In all 14 case studies, participants reported a history of psychiatric difficulties with the adolescent.
- In 7 case studies there was a family history of serious mental health difficulties such as suicide (2), and an Axis I mental health diagnosis (5) in a biological relative.
- In 6 case studies, data indicate a history of child abuse or neglect or a strong suspicion thereof.
- In 3 case studies, there is a history of biological parent drug abuse, 2 of which are currently in recovery.

### **2.2 Psychiatric Crisis Warranting Hospitalization**

#### **2.2.1 Triggers for the Acute Crisis and Setting**

##### **Stress response to academic expectations**

- Seven youth experienced stress and acted out when prompted to complete school work.

##### **Peer related**

- Conflicts with peers and peer perceptions triggered psychiatric crisis for 6 youth in the sample. Conflicts included: recent “*break ups*” with love interests (3 youth); conflicts with peers at school (3).

##### **Restrictions of freedom of youth in secure facilities<sup>1</sup>**

- Case study history analysis indicates 2 youth have an overall pattern of self-harm in response to restrictions of freedoms.
- Case study 1-By parent and youth report, one crisis was a result of being in isolation in a juvenile detention facility that “*just stresses me out.*” By provider report the youth refused to participate in the required activities. Subsequently, the youth was placed in isolation. The hospital admission evaluation indicates that increased anger over restrictions of freedom and feelings of missing family lead to feelings of hopelessness and resulting suicidal gestures.
- Case study 2-The other youth was in a level VI facility. There are conflicting reports as to the events that triggered the crisis. One report is that the youth perceived that he had to make a decision about living with his parent again after many years of out-of-home placements. He was “*stressed out*” and made suicidal statements as a result. The parent reported that youth makes suicidal gestures when he is told he will get to come home and “*he does not get to come home.*” The youth’s perspective was unavailable.

##### **Reaction to imposed limits set by authority**

- 5 crisis events started at home when parents were “*setting a limit.*”

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<sup>1</sup> Includes private psychiatric hospitals, level VI residential treatment centers, detention centers and correctional facilities.

### **2.2.2 Specific Behaviors Warranting Hospitalization**

- Voiced wanting to hurt self or showed intent (5)
- Ran away from home or school (5)
- Voiced wanting to hurt (“kill”) others (3)
- Physical aggression (3)
- Ingested harmful substances or overdosed (2)
- Destroyed property (2)
- Cut self (2)
- Experienced hallucinations (2)
- Attempted to hang self (1)
- Threat of physical aggression toward parent (1)

### **2.2.3 Initial Contacts in Response to Behaviors**

- Parents called police or 911 (5)
- Parents took youth to emergency room (ER) (3)
- Secure facility, where youth resided contacted state custody providers (2)
- Therapist contacted police (1)
- School contacted mother, case manager, then police (1)
- Parents took youth to a shelter (1)
- Youth called CMHC (1)

### **2.2.4 Screening Process**

- In general, screens are conducted in secure settings rather than family homes due to safety concerns. These 14 screens were conducted at the CMHCs (6); private hospitals (4); ERs (2); a group home (1) and a school (1)
- Parents or family were involved (by phone or in person) in the screening process for 11 of the screens. In 3 cases, parents were contacted and notified after the screen had been completed.
- Other mental health providers were involved in 4 cases (2 case managers and 2 therapists).
- Parents said they were consulted about choices for an alternative to state hospitalization in 6 cases.

### 2.2.5 Admission Process

- Families (11) indicated that the admission was a tiresome process.<sup>1</sup> This finding is congruent with families' perceptions of the admission process for young children.

*The screen was done at noon that day. We were told they would leave with secure transport at 7 PM. We ended up leaving at 8:30 PM and arriving at the hospital at 1 AM. Upon arrival at the hospital it was shift change, so we waited 45 minutes. We could hear them arguing "I ain't doing it. He's yours. No, he's not! Who brought them back here? They don't need to be back here. That's your patient!" So we sat there for about 45 minutes waiting for them to decide who was going to take us. Then we drove back home got to bed at 3 AM, woke up for work at 5 AM. [Parents]*

- One mental health provider (beyond the screener) was involved in admission process.
- Families were present in 5 admissions; proximity and time of day limited some families from being involved in the process.
- Transportation to the state hospital was provided by Secure Transport services or police in 13 instances, parents transported in one instance.

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<sup>1</sup> The admission process includes the initial contact upon screening to signing all the paperwork at the hospital and caregivers traveling back home.

**Summary for Study Question 2: What Were the Circumstances (Acute Behaviors, Events at Home, School, and Secure Facilities) that Led to this Most Recent Admission?**

Acute behaviors occurred in the context of already existing emotional and behavioral difficulties that youth and their families had been experiencing for a long time. All youth experienced significant risk factors for psychiatric crises. In twelve cases, stressful events that all youth experience in adolescence such as the demands of school work, rebellion against authority, and effects of peer influences quickly escalated into a psychiatric crisis.

The specific triggers from parents' perspectives leading to admission for the two youth in secure facilities were less clear. Record reviews showed a general pattern that these two youth resorted to self-harm as they experienced more controlled environments and less freedom.

Initial responses to these acute crises most frequently involved calling the police or 911. All screens were completed in a secure setting such as an ER or CMHC. As a general rule, screens are not conducted in family homes due to safety concerns. Most often, secure transport or the police provided transportation to the State Hospital. Parents are involved when they can be as proximity and time of day limits family involvement in the admission process. Of the 11 families who were able to be involved, all reported that the admission process was arduous.

**Study Question 3. What Was the Array and Length of Services Youth Received Prior to Admit?**

**3.1 Mental Health Services**

**3.1.1 Community Mental Health Services**

Nine youth were involved in intensive community based services with a CMHC. The length of involvement ranged from a few months to many years.

- Eight of the nine youth were receiving **medication services**. The frequency of contact was at least once a month.
  - Advance Registered Nurse Practitioners provided services to 3 youth.
  - Psychiatrists provided services to 5 youth.
- All Nine youth received **case management (CM)** services (two were school based only).
  - 2 families had been in services for years and received CM as needed.
  - 2 families had been in services for 6-7 months.
  - 3 families had been receiving services for 4 months.
  - 2 families had been in services for less than 2 months.
- Eight received **therapy services** (6 out-patient, 1 home-based, and 1 school-based).
  - In 4 instances, therapists were new to the case.

- In 2 instances, appointments have not been regular enough to track.
- In 2 instances, therapists have been working with the families for 6-8 months.
- Four families received **parent support services** (one additional family who chose not to participate).
- Services are offered on an as needed basis when the family or agency requests assistance. Length of involvement ranged from 1 to 3 years.
- Two youth received **attendant care (AC)** (one additional family chose not to participate).
- Two AC providers were working with youth less than 3 months.
- One youth participated in **psycho-social group** (one youth was waiting to get into group; one declined due to the discomfort with the topic of group).
- No families had received **respite** before this most recent hospitalization (offered to one family who chose not to participate).

### **3.1.2 Private Outpatient Mental Health Services**

- One family utilized a private therapist and family practitioner for medications. The therapist had worked with the family for many years.
- One family saw a private psychiatrist for medication management for less than one year.

### **3.1.3 Crisis Stabilization Services**

#### **Acute inpatient stabilization**

- Ten youth had received private inpatient services at some point prior to their admission to the state hospital. Lengths of stay were 3 to 7 days.
- Six youth were transferred directly from acute inpatient units to the State Hospital.

#### **Mobile crisis response**

- CM responded at school for one youth
- Parents brought youth to a secure setting such as hospital or CMHC in 6 cases, where they met the screener.
- Police were called and responded in 4 of these acute crisis situations (3 at home and 1 at school).
- Remaining 3 youth were already in a secure setting when the crisis occurred.

### **3.1.4 Level IV, V, & VI Residential Treatment Facilities**

- Four youth had utilized residential facilities prior to admission to the SH.
- Two were transferred directly to the SH from a Level VI facility

## **3.2 Child Welfare Services**

Four youth were in child welfare custody.

- Each youth had at least 2 workers; one through SRS and the other was a child welfare provider assigned to their specific region.
- Length of involvement ranged from 3 months to several years.

### **3.3 School**

Nine youth had Individual Education Programs (IEPs).

- Seven IEPs addressed behavior and learning disorders and had been in place at least 3 years.
- Two youth were on gifted IEPs.
  - Two parents were unclear about youth academic aptitude due to frequent placement changes.
  - Two youth were not in school due to behavior problems.
  - One youth was on an IEP in the past but had “*graduated*”.

### **3.4 Juvenile Justice or Law Enforcement Involvement**

Nine youth had been taken to Juvenile Intake and Assessment (JIA) at least once; 3 just before this most recent admission.

- 3 during a crisis at home or school
- 6 when the youth ran away from home
  - One youth was in JJA custody and receiving case management services at the time of the study.
  - Police provided secure transport in 5 of these state hospital admissions.

#### **Study Question 3 Summary: What Was the Array of Services Youth Received Prior to Admit and How Long Did They Receive Services?**

Most youth (10) had received acute inpatient services at some point prior to their admission to the State Hospitals. Nine were involved in Community Mental Health services and received intensive community based services (CBS) just prior to state hospital admission. No family received the full array available for various reasons such as family choice or lack of availability of services at the CMHC (respite, attendant care, and psychosocial). In addition 9 youth had been involved with JIA previously. However, only one youth was in JJA custody; this youth was never involved in prior CBS or private mental health services. Nine youth were on IEPs (2 for gifted; 7 for BD or LD). Two youth were not in school prior to admission due to behavior difficulties. The families of these youth were pursuing alternative schooling.

## **Study Question 4. What Was the Quality of Services Provided to Adolescents and Families Prior to Hospitalization and What Factors Affected Quality?**

### **4.1 In general families, providers and staff identified indicators of quality services in order to circumvent hospitalization in 11 of the 14 case studies.**

Even though youth were ultimately hospitalized, the majority of responses indicate that high quality services were provided.

#### **4.1.1 Providers were Focused on Family and Youth Strengths & Resiliencies (Found in 5 Case Studies)**

*[Parent was speaking about the CM]*

*She's my right arm. I wanted her because she had 5 kids of her own and you would be able to deal with me because you were a mom. It's a different knowledge base that she brings to the situation. My [name of youth] is like 5 kids and you never know which kid you're going to get. And it can be really fun.*

*[CM]*

*Yeah, he's a fun kid.*

*[Parent]*

*He is, and nobody else understands that. And he is so funny and he doesn't mean to be.*

*[CM]*

*Kind of like my 2 year old, maybe?*

*[Parent Speaking] But then he's so advanced that other kids just, he's into political satire now. And other kids are just like what is this? They don't get the jokes.*

*[CM] He's funny.*

*This family has effected change in the organization. Policies or procedures have changed as a result of this family's willingness to express valid concerns. At one point in time, the community based staff would do a lot of shopping with the kids and buy the kids a lot of stuff that the parents might not have been able to afford. It may have been a want not a need. In turn the parents are feeling bad because they can not afford that for the kid. The wrong messages were being sent. The attitude of well, I have the money what I say will be bought versus what the parent is saying what they want their child to wear or to have. [Community Based Provider]*

*In the last 2 months she has made a tremendous turnaround. She is being released in a few days. We are all hoping and praying that the turnaround we have seen stays when she goes into a foster-home. After that we will continue the re-integration process. When she decides to do something it is just full throttle. Her coping skills seem to be really good right now! [Child Welfare Provider]*

#### **4.1.2 Families Said Providers Conveyed Commitment to the Work (Found in 6 Case Studies)**

*This lady stuck with my daughter. She put forth a very valiant effort and she did not give up. I remember she sat here crying and she told my daughter I don't care what you do to me, I'm not leaving you. I almost wanted to cry because she was a great lady. She stuck it out, and her and my daughter ended up becoming really good friends. She did a lot for my daughter. [Parent talking about a Community Provider]*

*I spent 4 hours with her yesterday. She listens. When I got involved with [Worker Name] and we started making that bond, then I started going to her and saying hey, you need to put some lead in somebody's butt here, because I've been yelling for the last 4 years stating that something else is wrong with [Name of youth] and they need to do something, and nobody would do it. So [Worker name] would go to bat for me. [Parent talking about a community provider]*

#### **4.1.3 Providers were Accessible and Families Felt Supported in Escalating Crisis Situations (Found in 2 Case Studies).**

Case Study 1-When a parent was not accessible the CM responded to an escalating crisis at school. The CM sat with family through the entire screening and admission process to the State hospital.

Case Study 2-The family had a solid crisis plan and knew what specific steps to follow in the event the youth ran away. The therapist had given the on-call screener a "heads up" regarding the families' wishes and her recommendations.

### **4.2 Some Themes Emerged as Complicating Factors Affecting the Quality of Services Provided.**

#### **4.2.1 Parent Provider Relationships Factors**

- Some (6) families discussed their perceptions of past or present relationship tensions with providers that affected quality of services.

*We clashed big time. The case manager came here and demanded, one day, to take [name] out to eat. Okay, I know that's not part of case management unless that's part of a goal they are working on. I said no, you are not taking him . I literally had the case manager crying...I've learned how to do it now. When it comes to my kid I really have a bad temper, because I'm very protective, especially of this one. If we had felt listened to, if services were provided in a way that were consistently helpful we wouldn't be here where we are today. There's no way we would be here today where I'm at right now with him being in a group home. [Parent]*

*He was angry at the case manager and didn't want to go. A couple of times he skipped out before they came. I said you need to go to these in order to keep your medical card, and two, you need these classes. Whatever problems you have you need to work them out. That's easier said than done with [name]....Right before all this happened this last time...we ran into the case manager. We both said hi and the case manager ignored us, just walked by us. And [name] said see dad? I told you. I said well, I have to agree with you because I thought that was very rude. That was the last time we had contact with the case manager before the suicide attempt. [Parent]*

*The case manager instigated both hospitalizations, like they don't know how to do anything else but state hospital...the case manager said if he were his kid he wouldn't be putting up with it, he would put him in lockdown. Hello, you're not this child's father. I really have a problem with that issue. My child responds stubbornly, bull-headedly and illogically. But it is very predictable when a threat like that is made. [Parent]*

- Agencies were responsive to parent concerns that were voiced openly; however, some families were hesitant in other situations to voice concerns for fear needed supports would be jeopardized.

*There had been problems with the family understanding the policies and procedures of what to expect from the mental health center from the mental health center's perspective. Talking to the parent, I found they had come to expect certain things from service providers based on previous experiences. I took a strengths perspective with the parent and asked what worked for you back then. I took the information and shared it with providers within our agency trying to get them to understand that if you are seeing the family once a week it needs to be consistent. This was paramount because the parent had two children involved in services plus their own life to manage. When you're managing all that, it is a scheduling nightmare. We needed to try to get scheduling to be consistent for this family. Part of it was educating our staff on the importance of this. [Mental Health Provider]*

*Our experience working with our current case manager has been awesome. We had one just prior to this current one...our values didn't mesh. They weren't the same because he came from a religious background and...it reached a point when we were having issues that we needed to discuss and all he would say was well, we all need to pray about it. And even though I'm from a religious background basically, that doesn't always work. We need to intercede and look at meds and do some intervention. And that's when we were trying to get attendant care in the school for last year. And he just blew me off. And finally I was upset and I was screaming at him on the phone and he hung up on me because I was*

### **4.3 Medication Related Factors**

All 14 youth in this sample received prescribed psychotropic medications before they were admitted to the state hospital.

Youth were on an average of 3.64 medications; the range was 1 to 9. The most frequently prescribed were anti-psychotics (10 cases) and the anti-depressants (4).

#### **4.3.1 Side-effects**

In 9 instances parents reported that medication side-effects created some additional challenges to manage.

- Rapid weight gain (7) was the most commonly reported side-effect
  - Rapid weight gain resulted in high blood pressure for three adolescents and additional medications were prescribed to address the high blood pressure.
  - Three parents discussed fasting as a result of rapid weight gain
- "Zombie" effects such as be failure to show affect and feeling numb were discussed in 4 instances.
- Nausea was mentioned in 3 instances.
- Liver failure had occurred in 1 instance.

*He gained weight and the other kids were teasing him about his weight. Yeah. They decided omega 3 fish oil would be good for him, so started putting him on that and we started trying to adjust the diet. The cholesterol is almost normal now. Triglycerides are still up and then they told us that his thyroid wasn't functioning right. They said that the lithium was damaging it and that it might damage the kidney. Then I'm taking him back to our family doctor going I'm giving this kid stuff that's exploding inside his body. I can't keep doing this. The family doctor said the psychiatrist wants us to take this. We'll just have to deal with it. What choices do you really have? [Parent]*

### 4.3.2 Monitoring & Compliance

- Some medications require diligent monitoring. Monitoring was difficult for some families due to the lack of access to prescribing providers and interruptions from multiple hospitalizations.
- Medication compliance issues linked to unpleasant side-effects was mentioned as a factor in 7 of the 14 cases.

In summary, participants from 6 case studies reported that hospitalization resulted from a need for medication “*changes, evaluations, or stabilizations.*”

*The doctor, you can't really get a hold of him. It has to be an emergency to be able to get real fast contact with him. And I have called him and if he gets a message and if he thinks it's important... I've actually gotten called back from him a couple of times. But usually it's just memos that get sent to him. [Parent]*

*The last med check, the nurse clinician decided to take him off the Prozac and put him on Lumnito because she thought he might be Bipolar. And that's where all the problems started when he came off the Prozac... I'm real confident that it's going to go a lot better because I'm not going to let them take him off Prozac again. And we're going to do a Depakote level at least every month. And I'm going to know what the numbers are, not just that they are ok. I am sure the medication change contributed to the most recent admission [Parent]*

## 4.4 Access to Services at Critical Points

### 4.4.1 In all 14 cases studied, at least one and most often two respondents identified a point in time where services were not accessible at a critical point.

- Two youth were not receiving any mental health services prior to admission to the state hospital and their families had no knowledge of CBS
- One youth had multiple encounters with crisis services at the local CMHC, a private therapist, and law enforcement but was never informed of or referred to CBS.
- One youth had recently been raped and had been having difficulties at school and was abusing alcohol. The situation escalated to the point that the youth was aggressive with her family and was taken into JJ custody. Screener was “*shocked*” considering the mental health history identified in the screening process that this youth had not received any counseling prior to psychiatric hospitalization.
- One youth entered state custody as a Child in Need of Care after a critical incident at home. The youth was in CBS, there was some indication services were not as intensive as they could have been.

*Over all, there is a general feeling that if mental health providers don't feel like they are making any progress, or they don't feel like they can help, they will throw their hands up and walk away and sometimes that is at a crucial point when we need their help the most. I think that was one of the facilitating factors in this case, in terms of this youth coming into custody. This parent was doing things, getting her into acute care settings. At the same time the acute care hospitalization was only for a couple of days. That doesn't solve the problem. A parent, especially a single parent can get overwhelmed very quickly. [Child Welfare Provider]*

#### **4.4.2 Crisis Stabilization Services**

- One family received on site support from their CM and felt supported during the acute crisis.
- Most families managed the crisis on their own and had been instructed by providers to contact the crisis line or the police in response to the acute crisis situation.
- Six families in more urban locations were told to take youth to a crisis center.
- One family felt the response by the mental health center created more of a crisis.

*Parent had concerns about the steps on the crisis plan and frustration with what to do. Specifically, with the lack of available therapists or representatives from the agency during a crisis they were having. When calling the 1-800 number they did not really receive appropriate information from the person on the other end. Families in this area would like to see that there would be something more available, rather than having to go through the police department. [Mental Health Provider]*

### **4.5 Services Coordination and Continuity**

#### **4.5.1 Quality of Care for Youth in State Custody**

- Workers contacted parents when changing placements or when youth were having behavior issues or in case plan reviews.
- One youth was told he would be going home on the weekend. The request was not processed before the weekend and as a result his behaviors escalated into a crisis warranting psychiatric hospitalization.
- Concerning reintegration, a great deal of pressure rests on the youth who must “*work the programs*” to get a chance to go back home. Youth are “*impulsive*” end up “*blowing*” the placement due to behaviors related to their serious emotional disturbance. This results in a need for a more restrictive level of care.
- Providers have high caseloads and multiple demands. When youth are in a safe placement providers “*breathe a sigh of relief and do not have as much contact as they probably should.*”

In general providers relayed at the time of this study that there was a shortage of foster homes with the resources to manage youth with serious emotional disturbance and

current policies on restriction for Level VI length of stay (LOS) contributed to the living situation instability for youth in custody.

- Youth were just starting to “*settle in and work the program*” when reauthorization was needed for continued stay in a Level VI.
- Few foster homes were available after the 180 maximum stay in Level VI, consequently these youth were often placed in emergency shelters.

*Level VI facilities need to stop being a dumping ground for youth they can't find foster homes for. We need more money to train foster homes. We need good foster homes and need not to overload the foster homes. [Hospital Staff]*

*We now have the 72 hour rule. If a youth is disrupted out of a placement, is termed homeless because no one can find a placement for them, then the Consortium or the MHC where the youth is currently located is responsible for getting a CBST meeting together and getting a mental health screen done after 72 hours so that that youth can get placed in a level VI placement so that youth is no longer homeless. They are putting tighter restrictions on it so that the youths who need to be there can't be...Once they have met the 180 day restriction, whether they have met their treatment goals or not, there is no re-integration into a foster home. It's like here youth sink or swim. We see those youths back. We have one right now. These youths then end up in shelters or they get into a fight or try to commit suicide then they end up back here [Private Hospital Staff]*

#### **4.5.2 Living Situation Instability Effects Service Coordination and Continuity of Community and School Services**

- Youth are not in a homelike placement long enough to wrap services around them.

*In every foster home she has been at, she has gotten services. And it takes two weeks to get all those services set up and then 2 weeks to get the treatment plan in place, and then within a month [name] is out of there. Sometimes when she is moving we don't have but 24 hours notice. It is very difficult to make sure that those services are in there and that they stay, and at the same time we can't guarantee that a foster home close to this youth's home will be available. It is usually in a whole new town and services have to start all over again. [Child Welfare Provider]*

- Medical providers had difficulty conducting medical evaluations and they did not know what medications had been tried and the subsequent effects.

- In 3 cases report coordination of youth care was difficult because stays were short in acute settings and multiple stays created more school absences.

*He would also go into another facility on a Thursday or Friday and get out on a Tuesday the following week, so by the time you find out where he is to send the schoolwork, he is already out. [School Administrator]*

#### **4.5.3 School Mental Health Collaboration**

- For youth in stable placements, school personnel (4) in the sample felt they could use more school-based mental health consultation in to reinforce other mental health treatment.

*Would be helpful to know what strategies were successful with this youth while in the hospital or to know what the CMHC is doing with him so that we could make things consistent for this youth at school. [School Staff]*

*When we are transitioning placements [from the hospital back into the community] like that, it is nice to have as much contact with mental health providers as possible. We [school staff] are caught up in the humdrum of everyday life and we are the people that have to smooth that transition. Sometimes it is hard to know some of the subtleties of behaviors related to the mental health needs. [School Staff]*

- Personnel at two schools reported receiving school-based crisis intervention from mental health center staff. These interventions were helpful to stabilize youth at school.
- In 2 cases, school work was not given to the SH upon admission or during the stay for two youth. As a result, these youth experienced increased stressed in the transition back to school.

#### **4.5.4 Law Enforcement Mental Health Collaboration**

- In the absence of crisis hotlines or mobile crisis response efforts in some areas, families and schools frequently contacted Law Enforcement (LE).
- In one area, the CMHC had regular contact with local LE and provided training regarding the needs of youth in psychiatric crisis. Families reported this connection helped when LE were called upon to respond to the crisis situation.
- According to a few providers, some LE escalated the crisis situation. LE were unavailable for interviewing.

#### 4.5.5 Coordination with Developmental Services Systems

- Three families in the sample tried to access these services without success.

*We need something as a state agency that deals with youth that are not only mentally ill but that are on that borderline mentally retarded line as well, which is a huge factor with things that are going on with this youth because s/he doesn't always understand. This youth is 2 points above being able to be referred to the developmental services, so that holds a huge bearing on getting him/her to understand certain aspects in relationship to her mental illness. We don't have anything that helps out with those grey areas. [Child Welfare Provider]*

- All formal service providers interviewed regarding these 3 case studies as well as the families (8 participants) indicated that services to this particular group of youth with co-occurring mental health and developmental needs are severely lacking.

*Both of these families have youth with developmental delays. The MH center says they don't want to get into the DD business. However we either need to get into it to a degree so that families can get those needs met or contract with outside providers so that families can get those needs met. The Autism Resource Center at KU Med center they don't take a med card yet. They do some great social skills groups that would be great for youth with developmental delay, but they are so expensive families can't afford it. If we are not going to get into the business, then we need to open doors to refer the families to the appropriate services that the waivers will pay for to get these youths the services they need. Otherwise we are not treating the whole person. [CBS Provider]*

**Study Question 4 Summary: What Was the Quality of Services Provided to Adolescents and Families Prior to Hospitalization and What Factors Affected Quality?**

**Although youth were ultimately hospitalized, most participants felt high quality services were provided to youth and families in order to circumvent hospitalization.** In 5 case studies, providers were focused on family and youth strengths & resiliencies. In 6 case studies, families said providers conveyed a commitment to the work. Two case studies indicated families felt supported in the escalating crisis warranting admission to the state hospital.

The constant stress caregivers and community based providers experience working with acute crisis situations can create tension within the teams and feelings of wanting to place blame. Some teams were able to effectively work through these tensions by acknowledging differences and getting outside help to bridge the gap between differing perceptions.

Consistent with the findings in the FY 2005 study, *medication side-effects and access to continuous medication services* were also a serious concern for families and providers of adolescents. All 14 youth in this sample received prescribed psychotropic medications as a part of their treatment before admission to the state hospital. Youth were on an average of 3.64 medications, with a range of 1 to 9. The most frequently prescribed medications were anti-psychotics (10 youth) and anti-depressants (4). Lack of access to outpatient medication stabilization contributed to the overall stress caregivers felt overseeing their youth's care.

Furthermore, in all 14 cases, there was a critical point at which access or continuation of intensive stabilizing services may have prevented more restrictive levels of care. As one provider pointed out, it was at these times, when everyone was feeling hopeless or wanting to walk away, that families needed the support the most.

Families in this sample received little help managing psychiatric crises. Crisis stabilization service quality varies according to agency policy. In general, the hotlines were not helpful to families. Times when hotline responders were helpful, parents received practical coaching to manage youth behavior. Police were the most frequent mobile crisis responders causing one participant to say, "*We might as well train them then!*"

Multiple systems issues affected the quality of care for youth in state custody. Foster homes with resources to manage youth who experience frequent psychiatric crisis (such as those in this study) were difficult to find. In addition, these youth were not in placements long enough to get CBS started. Youth often ended up in a Level VI until they reached the 180 day maximum length of stay and then bounced between emergency shelters and private hospitals. As a result, school records and medication history on these youth were difficult to trace.

School/mental health collaboration during transition times such as discharge or in escalating crisis situations prior to admission were paramount to prevent further crises. Some areas reported frequent contact with mental health; some did not and would like more.

Supports for youth with co-occurring disorders (PDD spectrum or Mild MR and Mental Health) were not available to the youth in this study.

## **Study Question 5. Considering the Answers to Questions 1-4, Were These Appropriate Admissions to the State Hospital from Stakeholders' Perspectives?**

### **5.1 Appropriate Admission-Family Perspectives**

Five families did not feel the state hospital was an appropriate placement for their adolescent.

- Three youth had recently been to the state hospital. Families did not feel the prior services were helpful to them and did not feel there was any other option for inpatient treatment at the time.
- Two parents of youth, who had never been to the state hospital, had expectations of a shorter length of stay. No other treatment choices were offered during the screen.

*I really anticipated she was going to be there 72 hours and she was going to come home. I felt like she needed a little emotional break. And I wanted her to get back into routine as quickly as possible. But I think there was other things that maybe we could have done differently. I truly believe that youths can become institutionalized if you're not real careful about how you work with them. It's easy to be into an institution and then say okay, today's gym and swim and tomorrow is arts and crafts. They don't learn how to deal with people in chaos and family. [Parent]*

The other nine families were either unsure, did not have an opinion, and/or trusted professional recommendations regarding the appropriateness of a state hospital admission.

### **5.2 Appropriate Admissions-Provider Perspectives**

All providers (37) interviewed regarding the 14 youth reported that admission to state hospital was the appropriate placement for youth given the circumstances at the time.

- All CBS providers from CMHCs (representing 8 youth) indicated that all community resources had been exhausted and a state hospital stay was the last resort.

*It is not like mom was not supportive. It is not like she was not there for her.... I have to believe that everyone on the team did what we thought was the most appropriate to do with her. I don't know that the hospital did anything for her that was not done in the community. This kid has been to the SH before, knows the program. I work with a lot of kids like this. They know what they have to do to get out and go do what they want to do again. If they are presenting the right way to the hospitals, there is nothing the hospitals can do to keep them there. [CBS Provider]*

*This was an appropriate admission given the resources available to the family and the community at the time, considering the amount of effort that has been put into the case over a long period of time. I have done 4 out of 5 discharge plans with [name], trying different things. More or less services. We have tried different types of psycho-social group and Attendant Care. School has really bent over backwards too. [CBS provider]*

- Furthermore, these 8 youth and families had been in CBS for at least 2 years, worked with multiple providers, and had multiple prior hospitalizations. There was a general sense from providers that hospitalization will be needed as a part of the array of services for a small sub-group of adolescents, regardless of the level of community supports.

*Even with case management, attendant care and therapy, you might have a kid who is impulsive like this who ends up in the hospital. I see this kid as one who is going along and a stressor happens and her coping skills are concrete. She also has borderline traits, a lot have to do with her personality. People with those traits tend to decompensate quickly when they are in crisis. [Psychiatrist]*

### **5.3 Complicating Factors**

#### **5.3.1 Rural/Frontier Reality<sup>1</sup> for Crisis Stabilization**

- Most of the samples' mental health providers in rural and frontier counties indicated that options for crisis stabilization outside of the state hospital were "very limited" in their respective areas (5 providers).
- Families who do not have a means for transportation to an alternative placement usually end up at state hospital.
- Staff in CMHCs' satellite offices do not have the "luxury" of "back-up" or emergency departments to assist with crisis de-escalation in the communities.

#### **5.3.2 Transfers**

Nine of the 14 youth were transferred from secure facilities to the state hospital.

- Six youth were transferred from acute inpatient units.
- Two came from level VI residential treatment centers.
- One came from a juvenile correctional facility.
- Reasons for transfers cited in screening forms were:
  - The need for a longer length of stay to stabilize on medications or diminish suicidal/homicidal ideation (6).

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<sup>1</sup> Note these findings were derived from a small sample and not intended to represent perspectives of all providers working in rural and frontier regions of the state.

- Youth in secure facilities were unable to safely participate in current setting due to their mental health needs (3).
- Reasons for transfers from practitioner experiences included:
  - The need for a longer length of stay beyond what an acute inpatient setting provides (2 providers).
  - Private insurance runs out for care in the acute setting (3 providers).
- Though many of the youth in this study presented with a high risk to run, no respondents endorsed the need for the state hospital admission because it was a secure facility that would keep youth from running.

### **5.3.3 Financing Plays a Role in Decisions to Admit**

- Thirteen youth were receiving Medicaid assistance prior to admission.
  - 5 youth were enrolled in the Home and Community Based Services SED Waiver.
  - 8 retained Medical benefits from Child Welfare involvement or met poverty guidelines to qualify.
  - Two families were told during the screening process that their only option was the state hospital since they were receiving Medicaid.

### **5.3.4 State Custody Requirements for Admissions to Secure Facilities**

- All screeners (6) reported that coordinating admissions for youth in state custody was time consuming and caused delays. These findings support the findings from the FY 2005 report regarding admissions for young children. Screeners must obtain permission from the legal guardians to gain admission to any secure facility. In some instances, the youth are admitted to the state hospital on an involuntary admission, until the worker can be reached to sign the necessary paperwork during normal business hours.

**Study Question 5 Summary: Considering the Answers to Questions 1-4, Were These Appropriate Admissions to the State Hospital from Stakeholders' Perspectives?**

Perception of appropriateness of admission depended on participant group. Five families did not feel the SH was an appropriate placement, while the remaining nine families were either unsure, did not have an opinion, and/or trusted professional recommendations. All 37 providers interviewed reported SH was an appropriate placement for these 14 youth. Experienced CBS providers and inpatient hospital staff indicate that some youth (due to their personality traits and limited coping) are going to need hospitalization regardless of community supports that are provided.

Complicating factors limiting alternatives to SH, included limited crisis stabilization services in rural/frontier areas and lack of transportation options.

Financing may have played a role in the decision to admit to SH. The majority of the youth (13) in the sample were receiving Medicaid funding prior to admission and two families were told state hospital was where they were going to go *because* they were receiving Medicaid funding.

**Study Question 6. What Other Factors Should be Considered to Explore the Feasibility of Regional Models of State Administered Inpatient Care for Children and Adolescents?**

Questions regarding a regional model were open ended and intended to elicit an open dialogue regarding stakeholders ideas and impressions regarding the development of a regional model of care. The purpose for this method of questioning was stated to stakeholders; to facilitate more family involvement and keeping youth closer to their homes. No specific details regarding ideas for a structure of a regional model were given to inductively develop a theory for the development of regional models of care. The themes that emerged from the interviews are listed below.

**6.1 Consider the Current Levels of Care for this Population of Adolescents**

Table 9 below depicts youth served in three LOS levels of out of home care for psychiatric and behavioral stabilization. Community hospitals typically serve youth for 3-10 days. State hospitals continued to fulfill the need for an intermediate range length of stay (means range from 22 to 20 for Rainbow and Larned respectively, see Table 9). Lastly, Level V<sup>1</sup> and VI<sup>1</sup> facilities provide a 30 to 180 length of stay.

<sup>1</sup> At the time of the present study Psychiatric Residential Treatment Facilities (PRTFs) were referred to as Level V and VI facilities.

**Table 9: Current Levels of Care FY 2005 Admissions and Lengths of Stay for Adolescents**

Type of Facility	# Served	LOS
1. Community Hospitals	1574	5.18
2. Larned State Hospital	96	20
Rainbow State Hospital	172	22
3. Level V & VI	?	30-180 days

Furthermore, some youth (6 of 14 in the current study) who needed a continued stay in a secure environment were transferred from the state hospitals to a level V or VI residential treatment facility. In addition, a level VI placement was being discussed as a future option in 4 additional cases. **In summary, 71.4% (10 of 14 youth) in the sample had been or would soon be placed in a level V or VI facility for more lengthy treatment. It is plausible that Level V and VI facilities are the existing regional facilities that serve the same population of youth who are utilizing the state hospitals.**

### **6.2 Level V and VI Facilities General Practices**

Admission to a Level VI is initiated by a local qualified mental health provider for consideration of a 30 day stay. A re-screen must occur to establish the need for a continued stay. According to one level VI Administrator in the present study, most youth do not stay more than 90 days. The maximum amount of time youth may stay in these facilities is 180 days.

Participants in could give little detail regarding the structure and interventions provided within Level V and VI facilities, and there were differing opinions regarding the effectiveness of services in these facilities. However, providers in the current study consistently endorsed the need for more of these “*highly structured*” facilities. Some stakeholders posited that current policies limiting total length of stay to 180 days negatively affected youth in foster care who are not able to be placed in a foster home.

*They are putting tighter restrictions on it so that the kids who need to be there can't be. Once they have met the 180 day restriction whether they have met their treatment goals or not there is no re-integration into a foster home, it's like here kid sink or swim. We see those kids back. we have one right now. These kids then end up in shelters or they get into a fight or try to commit suicide then they end up back with me. [Private Hospital Staff]*

**In summary, providers interviewed could give little details regarding the structure and interventions provided in these facilities, however, they consistently endorsed the need for more of these “*highly structured*” facilities, especially for youth who are difficult to place in foster homes.**

### 6.3 Family Experiences with Level V and VI

Families were told by hospital staff, and community based providers that Level V and VI facilities would keep youth “safer” than they would be at home. The longer length of stay would provide more time to “*understand what is behavioral and what is mental.*”

The state hospital recommended treatment in a level VI facility for one youth upon discharge. Upon trying to gain access this family was told they would need to relinquish custody to gain admission to a Level VI facility by a local child welfare administrator. Subsequently, the youth ended up in a juvenile detention facility because his parents could not manage his aggressive behavior at home.

One family of a youth who was sent to a Level VI facility was not in agreement with providers’ (including CMHC and hospital providers) recommendation for admission to a level VI. The parents were told this was the “safest” place due to the mental health intervention that was needed. Upon admission, the parents reported that the youth had run at least three times. This youth was still gone at the time of the interview.

*She was gone all night with one other kid. I got very upset. I said you guys weren’t going to let me bring her home because you didn’t think it was safe, and yet you let her run? You let them walk out? They don’t have any locked doors at this place. Why is it safe? All they can do is report it to the police and give them a description. But the police told us that they have so many runaways from this place they don’t take it seriously. They’re tired of them. That’s all they do. Police have to go there and stop the fights. They had one youth try to set one of the houses on fire, and they’re runaways. They said they don’t even hardly look for them. They don’t bother about it.*  
[Parent]

Two child welfare providers endorsed the parent’s perception that some youth in Level V and VI facilities frequently run.

*Youth are not counted as a runaway unless they are gone 24 hours, that is our protocol. This youth runs away frequently. Took off in the rain one time, was gone 30 minutes and came back, refused to come inside and carried that on for a couple of hours. That is pretty repetitive.* [Child Welfare Provider]

There was some indication that the services provided are helpful to families and one youth in the present study reported that he preferred to go to a group home over the state hospital due to the families’ previous experience with an older sibling.

*Yeah, ever since his sister had been in a group home he wanted to go there because he said he has to work through his problems and he can’t do it here....they were very, very parent-therapist, let’s work together. We’re going to work together. We had visits where we all sat together and discussed her therapy, discussed what was going on with her, what changes had happened, everything.* [Parent]

**In summary, one family had difficulty gaining access to a Level VI facility. Families' experiences of success with the services in level V and VI facilities were mixed. One parent reported concerns for safety as youth were known to run from these facilities. This concern was validated by providers. Another family had a positive experience with treatment provided.**

#### **6.4 Family Involvement in Treatment is Ideal**

Families unanimously endorsed the idea of having their youth closer to home, especially families who had to travel great distances ( more than 3 hours) to visit their youth in the state hospital. Ten providers in the current study endorsed the idea of regional models of care for the convenience to families who would be able to participate in the treatment process. Other providers either did not have an opinion or felt the current system of care was sufficient to meet the needs of children and adolescents. Concerns were voiced by providers, however, regarding the allocation these resources for children and adolescents in rural and frontier regions of the state. Finding staff, especially psychiatrists, would be challenging in more rural and frontier regional facilities.

#### **6.5 What Will Be the Safety Net?**

Providers voiced a need for a treatment of last resort when all other options in the community have failed or are not available.

*I believe that the state hospital is necessary for children and adolescents because at this point we don't have any other resources for youth who are in crisis and parents or foster parents who are saying I can't do this right now. We don't have any other resources. The state hospital is a vital resource to us because there is no other option. If we had some short-term crisis stabilization services available, it may not be as vital. They have been talking about the shutting down the state hospital children's unit for years. The thought of that scares me because we don't have the resources in place to be able to do that and to be able to handle the consequences. The resources that are available are Good Shepard and Prairie View. This youth did go to Good Shepard for a brief period of time. Again the transportation is an issue to get youth down there. A lot of families don't have the resources and viable transportation. The other issue is getting the parents involved in treatment. The parents can't participate in counseling or family counseling. Those are issues that I think hinder western Kansas in being able to adequately serve the population here. There is a need for more of the crisis stabilization and I know the state hospital is moving more into, but sometimes there is a need for 4-6 weeks length of stay. [Therapist]*

*It is important to keep the state hospitals because they seem to have a better understanding of what we are dealing with in regards to mental illness. The private hospital psychiatric teams don't understand in that short amount of time what families are dealing with. I have had families who have had multiple hospitalizations and it all looks very behavioral so the assumption is that the youth's behavior is because the parent is doing something they are not supposed to do. The state hospitals have a better handle on the youth because they keep them long enough to see the behaviors parents see, then staff are not quite so judgmental after they see that. I am tired of hearing they may shut State Hospitals down. It is a good place, they do a good job. [Parent Support Worker]*

**Study Question 6 Summary: What other factors should be considered to explore the feasibility of regional models of state administered inpatient care for children and adolescents?**

A factor to be considered when exploring regional models of care should be the levels of care that a majority of these adolescents in the current study had accessed or would soon access. Seventy one percent (10 of 14) youth in the sample had been or would be placed in a level V or VI facility for more lengthy treatment. It is plausible then that level V and VI facilities are the existing regional services that serve the same population of youth who are utilizing the state hospitals. Further study is needed to substantiate this theory.

If Level V and VI facilities are to be considered as existing regional services, general practices or interventions provided in level V and VI facilities should be examined. Providers interviewed could give little details regarding the structure and interventions provided in level V and VI facilities. However, providers consistently endorsed the need for more of these “*highly structured*” facilities, especially for youth who are difficult to place in foster homes.

Families' experiences with level V and VI services were mixed. One family had difficulty gaining access. One family indicated their youth had run and it was common knowledge that youth were known to run from these facilities. This concern was validated by providers. Another family had a positive experience with treatment provided in a Level VI facility. Further study is needed to identify what interventions are provided in these facilities, who gains access and for what purpose.

There is a need for a safety net, such as the state hospitals, while a regional service model is explored and potentially developed. In addition, providers and families conveyed that state hospitals provide expertise and interventions that currently can not be duplicated within the current system of care.

## **SUMMARY OF QUALITATIVE FINDINGS**

All youth in the present study experienced significant risk factors for a psychiatric crisis prior to their admission to the state hospital. Triggers for the crises were easily identified by stakeholders and somewhat predictable.

Most of the youth (13 of 14) in the study were involved with some type of mental health services prior to their admission to the state hospital. The exception was one youth who entered the juvenile justice system and received inpatient hospitalization after coming into custody. Services varied with regard to intensity based on family choice and the availability of services in that particular area of the state. Furthermore, two families were unaware of intensive community based services until after the youth's admission to the state hospital.

Although youth were ultimately hospitalized, the majority of families receiving CBS felt quality services were provided in order to circumvent hospitalization. Specific indicators of quality services included the providers' focus on family and youth strengths as well as their high commitment to their work. In two case studies, clear meaningful crisis plans had been developed and utilized prior to this most recent admission to the state hospital.

Factors found to affect the quality of services provided prior to hospitalization included: unresolved parent provider relationship tensions, medication issues, access to services at critical points, and lack of family centered crisis response services. Though families were thankful to be able to call upon law enforcement for assistance, the punitive approach may have escalated some of the crises. Frequent changes in placement and/or multiple inpatient admissions made it difficult to coordinate school and community based services for some youth. Lastly, services were difficult to access for youth who experienced developmental delays. There is a gap in the service system for youth with co-occurring mental health and developmental needs.

Perception of appropriateness of admission differed by participant groups responding to the question. Five families did not feel the state hospital was an appropriate placement, while the remaining nine families were either unsure, did not have an opinion, and/or trusted professional recommendations. All 37 providers interviewed reported that the admission to the state hospital was appropriate for these 14 youth at that particular point in time. Experienced CBS providers and inpatient hospital staff indicate that some youth (due to their personality traits and limited coping) are going to need hospitalization regardless of the community supports that are provided.

In terms of length of treatment the state hospitals provided an intermediate length (20-22 days) of treatment that was not available in any other setting. In a majority of the case studies (10 of 14), if longer term treatment was needed an admission to a Level V or VI facility was explored.

It is plausible that Level V and VI facilities serve the same population of youth who access the state hospitals and thus could serve as a starting point for the development of the regional services. Family and provider experiences of the quality of Level V and VI services were mixed. If these facilities are to be considered in the development of more regional models of care, the present study supports further exploration into the structure and services provided in level V and VI facilities.

## **AREAS OF POSSIBLE IMPROVEMENT**

### **1. CONTINUE TO EMBRACE A FAMILY DRIVEN SYSTEM OF CARE**

#### ***1.1 Capitalize on the Role of the Families as the Driving Force for Systems Change.***

There is a growing knowledge-base of effective roles for families within all levels of the system of care. Parents are the first crisis responders, teachers, and mental health providers that youth experience. Families hold the expertise and knowledge about what works best for their children. Unlike policy makers who may leave their positions for other professional opportunities, parents' responsibilities as default policy analysts and advocates will never change. Embracing this "family driven" paradigm involves shifting from a symptom reduction model of evaluating effectiveness of services to an "expectation of success" model where providers plan interventions that place the families' strengths and abilities at the forefront of treatment planning (Osher & Osher, 2002). This model requires much more communication regarding interventions and active assessment of their effectiveness to meet the high expectation. Parent support providers within each individual CMHC can be utilized to assist in shaping local family driven systems of care.

### **2. DEVELOP PLANS TO EXAMINE YOUTH WHO ARE AT INCREASED RISK FOR HOSPITALIZATION**

#### ***2.1 Closely Examine the Demographics of Youth who are Re-admitted Within a Short Periods of Time.***

For instance, the present study identified two youth who had been in state custody for at least 3 years and been in mostly secure facilities such as Juvenile Detention and level V and VI facilities there. These youth had multiple inpatient admits to the state and private hospitals that were fairly predictable according to all participants interviewed and records reviewed. Increased restrictions of freedoms with a combination of missing families resulted in suicidal gestures for these two youth. Families indicated that communication with providers were not as frequent and as timely as they would have liked. Furthermore, providers in both of these case studies were concerned regarding services once these youth aged out of the system.

A plan for assessing the quality of care for these youth should be developed by the juvenile justice, child welfare and children's mental health systems. The plan should include an in-depth investigation of family, youth and providers' perspectives. If current practices are insufficient, deficits in quality of care should be addressed immediately. Standards of practice (such as minimum contacts in a time period or model of intervention) for the providers to youth in state should be examined closely for youth who experience serious emotional disturbance.

Ongoing analysis of demographics of youth entering the state hospitals should be examined as well as information regarding the need for hospitalization from all stakeholders' perspectives.

### **3. ENHANCE FAMILY CENTERED CRISIS RESPONSE SERVICES AND TEAMS**

#### ***3.1 Develop Meaningful Crisis Plans For Youth Who Are Involved in CBS.***

Two families involved in CBS could discuss clear steps to follow in an escalating crisis and felt supported during the crisis by CBS providers. More work could be done on individual crisis plans to understand the specific triggers and specific actions to take in the situation. Find out what families say they need in a crisis situation and what is a crisis to that family. Notify on call staff what family may be expecting when calls come in after hours.

#### ***3.2 Implement Strategies to Rejuvenate Staff and Families Dealing with the Affects of Acute and Chronic Crises.***

Services are often provided in highly intense, emotionally charged circumstances which can create tensions in the working relationships that must be resolved. One strategy identified in this study employed by a group of CBS providers was to conduct stress debriefing sessions for the wraparound team after the occurrence of a critical incident. The debriefing brought all the important “*players*” together to “*restock and recharge*” resources within the team. Demonstrating self-care strategies in the teaming process improves the overall mental health of teams. This enables them to work effectively through and process tensions that will inevitably arise in parent-provider and provider-to-provider relationships (Osher & Osher 2002). In addition, families are able to express their needs when in crisis and the team can discuss future crisis de-escalation strategies.

#### ***3.3 Develop Collaborations with Law Enforcement***

Law enforcement officers were involved in the majority of the crises warranting state hospitalization. One provider in the study noted, “*we might as well train them to work with our kids!*” One agency provided onsite trainings for law enforcement regarding crisis planning. In addition they provided coaching to parents about what to tell law enforcement when they arrived. Another agency provided “*police cheat sheets*” or “*tips*” to keep in patrol cars for psychiatric crisis de-escalation as well as crisis line numbers for police to contact for consultation.

### **4. EARLY IDENTIFICATION AND ACCESS TO COMMUNITY BASED SERVICES**

#### ***4.1 Increase Public Awareness Regarding the Identification of Psychiatric Risk Factors.***

All families in this study were able to identify when they first started noticing problems at home or at school after the onset of certain stressors such as a death in the family. The course of treatment may be different if youth are referred or enter therapy at the onset of stressors instead of at crisis point.

*Increase awareness and provide more education in schools about how to refer youth like [name]. We need more education for parents. I think they had a clue about what was going on, but I don't think they had any awareness as to the extent of the issues with [name] until it was almost too late. [Private Hospital Staff]*

The state can consider expanding the school based primary prevention efforts funded through the Children's Cabinet to support early identification and prevention of mental health crises for children and adolescents.

#### ***4.2 Increase Timely Access to Community Based Services at Critical Points.***

Refine access standards regarding emergent referrals (requiring a response within 24 hours). Emergent criteria could be revised to include youth who are screened at crisis centers, have police interventions, are admitted to private psychiatric hospital or are suspended from school. In addition these agencies should be informed of emergent criteria to know when to contact the CMHC to set up an appointment. One agency in the present study employs a crisis case manager who provides initial case management services for youth and families who have been screened into or diverted from the state hospital. Families and community based providers as well as hospital staff in the current study indicated this position was helpful to gain needed information and get the necessary services set up promptly.

### **5. CONTINUE TO DEVELOP THE FULL ARRAY OF COMMUNITY BASED SERVICES TO CIRCUMVENT STATE HOSPITALIZATION**

Some community mental health centers are not able to offer the full array of services defined in the current Medicaid State Plan.

#### ***5.1 Respite Care Services***

Respite Care services as on provider noted, continue to be an "*underdeveloped, highly desired*" that could divert many acute hospitalizations. Results from a randomized trial indicate that families receiving at least 24 hours of respite per month were less likely to use an out of home placement. If families did use an out of home placement, fewer days were needed. Two CMHCs were developing respite services at the time of the present study.

#### ***5.2 Attendant Care Services***

Attendant Care services, which can also be a form of respite, continue to be difficult to staff and maintain in some areas of the state. A previous study of experienced programs relay that full time AC staff, rather than part-time crisis oriented AC staff, tend to stay in their positions longer, contributing to a more stable pool of available workers (Davis, Logan, Petr & Walter, 2004). One youth in the present study was most stable in the community when attendant care services were provided on a regularly scheduled basis. Another youth would become agitated when regularly scheduled appointments were missed. The family reported that missed appointments were a possible trigger for crisis.

#### ***5.3 Foster Homes for Youth with Complex Mental Health Needs***

Multiple providers in the present study identified the need for more qualified foster homes for youth with complex mental health needs. To be effective, these homes can not be

overloaded with too many youth. In addition foster parents need a high level of skill and training and support for the increased responsibility they will be taking on. Swaim, Walter, and Petr (2003) provide a summary of promising practices for recruitment, training, and support of Therapeutic Foster Parents following a review of the national literature regarding best practices in therapeutic foster care (report may be accessed at <http://www.socwel.ku.edu/occ/cmh/report8.pdf>). To start, foster parents in the existing pool can be identified, incentives can be provided to workers to identify families who may have the aptitude to become Therapeutic Foster Homes (TFH). The homes should be well supported and incorporated within an array of community based services.

## **6. EXPLORE LEVEL V AND VI POPULATION, STRUCTURES, SERVICES PROVIDED AND ESTABLISH OUTCOMES**

### ***6.1 Population Served***

Compile data on the demographic characteristics of children and adolescents admitted to substantiate the theory that these facilities serve a similar population of children and adolescents served in the state hospitals.

### ***6.2 Services Provided***

Identify the general staffing patterns, credentials, administrative structures and interventions provided. Identify what facilities, if any, specialize in serving specific sub-populations of youth such as youth who experience developmental disabilities.

### ***6.3 Establish Outcomes***

Develop indicators of quality services. Incorporate a family driven paradigm of systems evaluation of services within Level V and VI facilities (see number 1 above).

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The federal government's Center for Mental Health Services (CMHS), a division of Substance Abuse and Mental Health Services Administration (SAMHSA), collects data from states via the CMHS Uniform Reporting System (<http://www.mentalhealth.samhsa.gov/cmhs/MentalHealthStatistics/URS2004.asp>).

# **APPENDICES**

## Appendix A: Kansas Department of Health and Environment Population Density Stratification by State Hospital Catchment Area and CMHC

KDHE Population Density Stratification	Rainbow Counties	Larned Counties	Statewide Counties
Urban: 150 + persons per square mile	6	0	6
Semi-urban: 40 - 149.9 persons per square mile	8	3	11
Densely-Settled Rural: 20 - 39.9 persons per square mile	12	8	20
Rural: 6 to 19.9 persons per square mile	17	18	35
Frontier: Less than 6 persons per square mile	3	30	33
<b>Totals:</b>	<b>46 18 CMHCs</b>	<b>59 9 CMHCs</b>	<b>105 27 CMHCs</b>

Larned Catchment Area CMHCs	County	Strat. Name 2004 est.	Admissions FY 05
Area Mental Health 13 Counties 17 Admissions (17.7% of the total)	Ford	D-S Rural	9
	Finney	D-S Rural	5
	Morton	Frontier	1
	Grant	Rural	1
	Gray	Rural	1
	Greeley	Frontier	0
	Hamilton	Frontier	0
	Hodgeman	Frontier	0
	Kearney	Frontier	0
	Lane	Frontier	0
	Stanton	Frontier	0
	Wichita	Frontier	0
	Scott	Rural	0
Central Kansas 5 Counties 10 Admissions (10.4%)	Saline	Semi-Urban	9
	Dickinson	D-S Rural	1
	Lincoln	Frontier	0
	Ellsworth	Rural	0
	Ottawa	Rural	0
High Plains 20 Counties 26 Admissions (27.1%)	Ellis	D-S Rural	7
	Rooks	Rural	5
	Graham	Frontier	3
	Phillips	Rural	3
	Osborne	Frontier	2
	Rush	Frontier	1
	Sherman	Frontier	1
	Smith	Frontier	1
	Norton	Rural	1
	Russell	Rural	1
	Thomas	Rural	1
	Cheyenne	Frontier	0
	Decatur	Frontier	0
	Gove	Frontier	0
	Logan	Frontier	0
	Ness	Frontier	0
	Rawlins	Frontier	0
	Sheridan	Frontier	0
	Trego	Frontier	0

**Appendix A: Kansas Department of Health and Environment Population Density Stratification by State Hospital Catchment Area and CMHC (continued)**

<b>Larned Catchment Area CMHCs</b>	<b>County</b>	<b>Strat. Name 2004 est.</b>	<b>Admissions FY 05</b>
High Plains (Continued)	Wallace	Frontier	0
Horizons	Reno	Semi-Urban	4
5 Counties	Harper	Rural	2
8 Admissions (8.3%)	Kingman	Rural	1
	Pratt	Rural	1
	Barber	Frontier	0
Iroquois Center	Clark	Frontier	0
4 Counties	Comanche	Frontier	0
0 Admissions	Edwards	Frontier	0
	Kiowa	Frontier	0
Prairie View	Harvey	Semi-Urban	2
3 Counties	McPherson	D-S Rural	1
3 Admissions (3.1%)	Marion	Rural	0
Southwest Guidance Center	Seward	D-S Rural	8
4 Counties	Haskell	Rural	2
11 Admissions (11.5%)	Meade	Frontier	1
	Stevens	Rural	0
Sumner County	Sumner	D-S Rural	2
1 County			
2 Admissions (2.1%)			
The Center for Counseling and Consultation	Barton	D-S Rural	6
4 Counties	Pawnee	Rural	5
13 Admissions (13.5%)	Stafford	Frontier	2
	Rice	Rural	0
Out of Catchment	Osage		2
5 Admissions (5.2%)	Bourbon		2
	Sedgwick		1
Out of State 1 Admission (1%)			1
<b>96 Total Admissions LSH</b>			

**Appendix A: Kansas Department of Health and Environment Population Density Stratification by State Hospital Catchment Area and CMHC (continued)**

<b>Rainbow Catchment Area CMHCs</b>	<b>County</b>	<b>Strat. Name 2004 est.</b>	<b>Admissions FY 05</b>
BertNash-1 County 8 Admissions (4.7%)	Douglas	Urban	8
Cowley County 1 Admission (.58%)	Cowley	D-S Rural	1
Crawford	Crawford	Semi-Urban	0
Family Life Center 2 Admissions (1.7%)	Cherokee	D-S Rural	2
Family Service and Guidance Center 1 County 49 Admissions (28.5%)	Shawnee	Urban	49
Four County 4 Counties 5 Admissions (2.9%)	Wilson Elk Chautauqua	Rural Frontier Rural	2 0 0
	Montgomery	Semi-Urban	3
Franklin County 2 Admissions (1.2%)	Franklin	Semi-Urban	2
Johnson County 13 Admissions (7.6%)	Johnson	Urban	13
Kanza Guidance Center 4 Counties 4 Admissions (2.3%)	Brown Jackson Nemaha Doniphan	Rural D-S Rural Rural D-S Rural	2 1 1 0
Labette Center	Labette	D-S Rural	0
Mental Health Assoc/Comcare/Family Consultation 18 Admissions (10.5%)	Sedgwick	Urban	18
Mental Health Center of East Central Kansas 7 Counties 6 Admissions (3.5%)	Lyon Greenwood Morris Osage Chase Coffey Wabaunsee	Semi-Urban Rural Rural D-S Rural Frontier Rural Rural	4 1 1 0 0 0 0
Miami County	Miami	Semi-Urban	0
Pawnee 10 Counties 21 Admissions (12.2%)	Geary Marshall Washington Mitchell Riley Pottawatomie Cloud Jewell Clay Republic	Semi-Urban Rural Rural Rural Semi-Urban D-S Rural Rural Frontier Rural Rural	7 4 4 2 2 1 1 0 0 0
South Central Counseling Center 4 Admissions (2.3%)	Butler	Semi-Urban	4

**Appendix A: Kansas Department of Health and Environment Population Density Stratification by State Hospital Catchment Area and CMHC (continued)**

<b>Rainbow Catchment Area CMHCs</b>	<b>County</b>	<b>Strat. Name 2004 est.</b>	<b>Admissions FY 05</b>
Southeast Kansas	Allen	D-S Rural	3
6 Counties	Woodson	Rural	2
9 Admissions (5.2%)	Bourbon	D-S Rural	1
	Neosho	D-S Rural	1
	Anderson	Rural	1
	Linn	Rural	1
The Guidance Center	Leavenworth	Urban	3
3 Counties	Atchison	D-S Rural	2
5 Admissions (2.9%)	Jefferson	D-S Rural	0
Wyandot Center for Behavioral Healthcare	Wyandotte	Urban	24
24 Admissions (14%)			
Out of Catchment (.58%)			1
			<b>172 total Admissions RSH</b>

Date \_\_\_\_\_

<i>Indicate respondent</i>				
FAMILY	CMHC case mgr.	SCHOOL	HOSPITAL	OTHER: _____

**I. Youth and Family Demographics (From Screen)**

- A. Age
- B. Race
- C. Gender
- D. Socioeconomic status *What are the financial resources from the screening form?*  
 \_\_\_Employed \_\_\_Unemployed \_\_\_Other \_\_\_\_\_  
 \_\_\_Medicaid\_\_\_Private Insurance

**Family Respondents only -What is your household’s yearly income?**

- E. *Is youth currently on the HCBS SED Waiver? How long have you been on the Waiver?*
- F. *Diagnosis*
- G. *Family /Child History-Make up of current household*

**Note: For provider interviews identify length of relationships**

**II. Circumstances Leading to Admission-(From Initial contact to Screen to Hospital)** *Use visual timeline on next page as a visual when interviewing family*

**What were the sequence of events that led to hospitalization?**

A. *Initial Contact*

**Where did you first meet with someone regarding or talk to someone regarding [the youth’s] admission to the state hospital?**

**With whom did you meet?**

B. *Transportation to screen*

**How did \_\_\_\_\_get transported to the screen and by whom?**

**Who was with you?**

C. *Delays/Duration of Screening & Admission*

**How long did you wait and where?**

**What was this experience like for you?**

*D. Transportation to Hospital*

**Did you then go to the hospital?**

**How did you get to the hospital?**

**Who transported and how was this decided?** (*secure transport, police*)

**Was the CMHC involved? Who was it?** \_\_\_\_\_

**Was anyone else involved from [the child's] school, other agencies or family members?**

*C. Delays/Duration of Screening & Admission (continued from above)*

**From beginning to end (screening to admission) how long did this process take?**

**What are your thoughts about how to make this process easier?**

*E. Impression of hospital intake procedures/staff*

**Who at the hospital did you speak with when [the child] was admitted to the hospital?**\_\_\_\_\_

**What did they tell you about what you can expect?**

**What paperwork did you fill out?**

**How long did this take?**

**What did you appreciate about this experience, what could be improved?**

*F. Perceptions*

**What are your perceptions, thoughts and feelings about the pre-admission screening process?**

**What works well?**

**What does not work well?**

**Do you think there was any information that was not gathered that would have been more helpful for the hospital to know about [the child] or [the family] prior to admission?**

How could this process be improved?

Did you agree with the conclusions of the screening? Why or Why not?

**III. Reasons for most recent Hospitalization**

**A. What was the *primary reason* \_\_\_\_\_ was admitted to the hospital?**

*B. Life Changes and Transitions*  
**Any major changes [the youth] in the last year?**

*living situation (moves, entering foster care, group home, juvenile detention),  
school environment (changed schools),  
home situation/family dynamics(loss/death/birth/divorce/adoption/re-marriage)*

**Did any of these changes directly contribute to this most recent admission?**

C. Need for a Secure Facility

**Was \_\_\_\_\_ admitted to the hospital because he/she needed to be in a more secure facility?**

*What were the reasons? Run risk, more intensive medical care, look for adolescent specific reasons.*

Added 10-4-05 **Was \_\_\_\_\_ admitted for a competency to stand trial evaluation? If so get the name of the Judge. \_\_\_\_\_ and county responsible \_\_\_\_\_.**

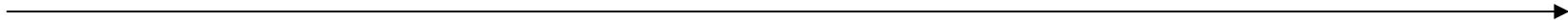
**What were the pending charges?**

**How long had \_\_\_\_\_ been experiencing difficulties that led to the need for legal intervention?**

**Visual Timeline**

*Include time frames on this timeline from initial contact to hospital admission*

*List people involved who they met with, who transported and get approximate times*



#### IV. Services Received Prior to Hospitalization

##### A. What services did [the child] receive before going to the hospital?

(check all that apply & describe)

- CMHC services – List and get duration of service provision for each

- Medication services \_\_\_\_\_ (Started on \_\_\_\_\_)

**Where do you receive psychiatry services? What has your experiences with this service been?**

**Who provided prescribed and monitored these medications?**

**How many medications is your child on and how long?**

**What medications has your child been on in the past?**

- School services (on IEP since \_\_\_\_\_, or being evaluated since \_\_\_\_\_)

**What interventions does your child receive at school?**

**Is \_\_\_\_\_ on an IEP?**

- Child Welfare (Started on \_\_\_\_\_)

**Has SRS ever been involved with \_\_\_\_\_**

- MR/DD (Started on \_\_\_\_\_)

**Has \_\_\_\_\_ received any services for developmental delays?**

- JJA \_\_\_\_\_ (Started on \_\_\_\_\_), if not in JJA did the youth have any Law Enforcement contact get name of officer \_\_\_\_\_

**Has \_\_\_\_\_ ever been in contact with the police? What were the circumstances?**

- Private mental health services \_\_\_\_\_ (Started on \_\_\_\_\_)

**Has \_\_\_\_\_ ever received any other mental health services from a private provider?**

- Other \_\_\_\_\_ (Started on \_\_\_\_\_)

**B. Intensity**

1. How many times a week did [the child/ family] receive services?
2. Was this enough?
3. Did you want to receive/provide more services?
4. Did you have a crisis plan? What were the details of this plan? What would it look like if you did have one?
5. What was helpful?
6. What was not helpful? What would have been more helpful?
7. What additional Services or Supports were needed, if any?

**V. Family Involvement in prior services**

## A. Family Involvement

1. How involved is the family? Please explain

## B. Contact?

1. How often did you speak with service providers/ family regarding treatment per week?
2. Was that over the phone or in person?

## C. Approach

1. Were you involved in assisting to write your child's treatment plan?
2. What did you talk about and how were you approached by the service provider?
3. How would you describe your relationship with the family?
4. If other providers are involved with the family, how often do you speak with all the providers? Please explain.

## D. Empowering interactions and increasing coping skills of the family

1. What skills have you or the family learned to better meet the needs of \_\_\_\_\_?
2. For Families...Did you feel as though the workers (any particular worker) helped [the family] gain confidence and skills in parenting \_\_\_\_\_?

**For Providers...What skills has the family gained that have helped them parent this particular youth since you have been working with them?**

**Can you give an example of this?**

3. Was anything missing services? If yes, what else was needed?

**VI. What Changes to practice and policy would help better serve like  
in the community?**

**From your perspective what is the role of the state hospital within the service array?**

Probes if needed

**Thinking about your responses to this interview ...Do you think [the child's] admission to the state hospital could have been prevented in anyway? If so, how?**

**If appropriate admission, what was the primary reason? (*note see above reason and validate response*)**

**Is there anything else that you haven't previously mentioned, that you feel is important for state level policy makers to know about what is needed for youth youth like \_\_\_\_\_?**

**Is there anything else that you haven't previously mentioned, that you feel is important for practitioners to know?**

**Screeners Background**

How long have you been a screener?

What is your professional degree?

What is your primary role within the agency?

Do you do screening for adults and youth?

**Circumstances Leading to Admission and Screening Process**

Where was this child's screen conducted?

Who provided the transportation?

What were your initial impressions?

How involved was the family?

On a scale from 1-10 (1 being the lowest and 10 being the highest) how involved was the family in the screening process?

Please explain

How long did the screen take? *Get what was actually recorded on the screen and compare with what screener says.*

Did someone from the CMHC go with the parent/guardian or SRS worker to the hospital if the youth was admitted?

**Services Received**

Were \_\_\_\_\_ and his/her family involved in CBS or outpatient services?

*If yes, what were those services?*

Did the child and family have a crisis plan and did you as the screener have access to or knowledge of the plan?

*If yes, what was the crisis plan for this youth?*

Did you work with casemanagers or therapists during the screen?

*If in services with the CMHC, Did you get a “heads up” from this youths’ providers regarding the need for a screen? What was this information?*

**Conclusions from the Screening**

In this case, what factors made you decide this youth (did not need or needed to be) hospitalized?

Did anyone else involved think differently?

If you could create something that would keep this youth close to home but still safe what would you create for them?

**Safety and the Need for a Secure Facility**

Was [the child] placed in or transferred to the hospital because you felt that he/she needed to be in a secure facility to maintain safety?

If no, what were the reasons?

If yes, what do you think it would have taken to keep \_\_\_\_\_(your child) out of the hospital but still safe?

**Changes to Practice and Policy to Assure Prevention of State Hospitalization for Adolescents**

What training do you think screeners need to have?

What are your thoughts about the screening process?

What is useful?

What is not useful?

What would be more useful?

Does the pre-admission screening process prevent unnecessary hospitalization for Adolescents?

Added 11/4/05

What variables affect the length of the screening process? Compliance, # of individuals involved, youth involved with multiple systems)

Does time of day and screener experience affect the decision to admit a youth?

Please explain answer

Are there any changes to practice and policy you think need to be made to assure prevention of state hospitalization for Adolescents?

Thoughts on a Standardized Training

What are your thoughts on establishing a basic standard training for screeners?

What should be included that specifically includes assessing children?

What about skills in interviewing families?

What do screeners need to know about CBS?

## Appendix D: Code List

### I. Youth and Family Demographics

- A. Diagnosis
- B. Child Characteristics
- C. Family Member History
- D. Current Living Arrangement

### II. Circumstances Leading to Admission

- A. Circumstances/Behaviors Leading to Need for State Hospitalization
- B. Sequence of Events
  - 1. Initial Contact
  - 2. Screening Process
  - 3. Transportation
  - 4. Admission Process
- C. Screener Variables Added 4-7-06
  - 1. Screener Background Added 4-7-06
  - 2. Screener Training, Skills & Knowledge Added 4-7-06
- D. Appropriateness of Placement Added 4-21-06 Based on Peer Debriefing

### III. Reasons for Most Recent Hospitalization

- A. Living Situation Instability
- B. Transfer
- C. Medication Management

### IV. Services Received

- A. School Services
- B. Crisis Planning/Intervention
- C. Medication Management
- D. Child Welfare
- E. CMHC Services
  - 1. Case Management
  - 2. Attendant Care
  - 3. Psycho social Group
  - 4. Parent Support Groups & Services
  - 5. Therapy Services
  - 6. Respite Care
- F. Quality of Services
  - 1. Youth Satisfaction Services
  - 2. Coordination Across Systems
  - 3. Access
  - 4. Continuity
  - 5. Family Centered
  - 6. Parent Involvement
  - 7. Financing Added 4-21-06
  - 8. Parent Provider Relationships Parent Perspective Added 4-21-06
  - 9. Parent Provider Relationships Provider Perspective Added 4-21-06
- G. Law Enforcement Contact
- H. Hospital Services
- I. Developmental Services
- J. Length of Service Relationships Changed 4-6-06
- K. Private Hospital Services Added 4-21-06

### V. Residential Facilities

### VI. Parent & Youth Resilience

### VII. Post Hospital Developments VII Added 4-7-06

### VIII. Next Steps

## Appendix E-Adolescent Hospital Study Participant Feedback Summary 1

Study participants (56) were mailed or emailed a feedback summary as well as a draft of the full report. Participants could write a response to the summary in the spaces provided or schedule a phone interview to give feedback. In addition, project staff contacted all the participants by phone to schedule a phone interview. Feedback was provided by 15 (28%) of the study participants (5 families, 2 therapists, 5 case managers, and 3 administrators).

Summary of Participant Feedback to Findings on Study Question 1: Sample Demographics. All of the 14 youth experienced serious traumatic life events at one point in time in their young lives. A consistent protective factor identified was that all the youth had supportive, involved parents or guardians. Please list any other strengths, resiliencies and protective factors you have noticed.

***This statement is very important!!***

**Other protective factors participants mentioned were community supports, and church (2).**

***I have found church, church family, and pastors to be a strong presence for many of our young people. I am assuming that these youngsters have a spiritual life that may also maintain strength and foster resilience***

Summary of Participant Feedback on Findings for Study Question 2: What Were the Circumstances (Acute Behaviors, Events at Home, School, and Secure Facilities) that Led to this Most Recent Admission?

***This is consistent but I would add that substance misuse issues have contributed to a portion of our crisis work... We tend to see crisis and self-harm issues together presenting frequently at private hospital inpatient for this age.***

***I am curious as to gender differences in this area of triggers and self-harm. Are there are a different set of issues or triggers by gender. [Inpatient Hospital Staff]***

**Law enforcement involvement has pros and cons.**

***We have real good luck with our law enforcement and our court system out here in most of our counties. If we send somebody involuntary they're real good about doing the transport. And in a few cases they'll even do a transport of someone who's voluntary if certain things are right. That's getting more and more rare because of their own liability issues. It used to they'd, here in this county, at least, they would do it just about any time we asked them to. But anymore, because of their own liability, if they were to, say, be transporting somebody and be in an accident on the highway on the way there, they would have to justify why they had someone in the car being***

***transported to the state hospital who was not under arrest or anything like that. [Mental Health Provider in a Rural Area]***

***We've decided that we're not sure we're going to call the police unless it really gets out of hand, because they're not all that helpful. We had an incident with our other child, and we called and the policeman was talking to somebody on the phone. He said well, basically, what I think happened is grandma told him no and he just lost his cool. And I thought now I called you guys for help. [Guardian]***

Transportation during the initial response was an issue, especially if youth were at school and parents could not be reached to transport. Occasionally, secure transport was an option, if the police could not transport. In addition some parents may not have had adequate transportation, needed money for gas, or additional support to be involved due to their own mental health condition.

When families could be involved and transport during the admission process they re-confirmed that the hospital admission process resulted in a very long day.

***My child was at home - I had to take her to police station for initial screening. It took forever. Admission was done late at night - it took 3-4 hours. I had a problem dealing with this [Parent]***

Summary of Participant Feedback on Findings for Study Question 3: What Was the Array of Services Youth Received Prior to Admit and How Long Did They Receive Services?

One participant confirmed that the youth who typically go to the state hospital have been in services for a long time. Another participant was curious about the number of youth who were receiving psychiatric services or medication management, prior to hospitalization.

***I would estimate nearly 90% of adolescents are on medications at time of admit with children at a lower use percentage. [Inpatient Hospital Provider]***

Summary of Participant Feedback on Study Question 4: What Was the Quality of Services Provided to Adolescents and Families Prior to Hospitalization and What Factors Affected Quality?

Access to CBS affects the quality of services. Participants validated Respite, and Parent Support Services are not available to all families who could benefit from them.

***In some counties in Kansas, the process to gain access to services is way too long and parents/families become frustrated and give up on services***

***before they can actually start. There needs to be a consistent way throughout KS that children and families can get services quicker. [Unknown]***

***In home family services are hard to find. [Unknown]***

Two participants discussed the need for better services to families after youth go into the hospital.

***I think we need to advocate for good inpatient coordination and discharge planning with CBS to maintain the inpatient gains. This is a service that is no longer being funded. Also coordination with medical providers to assure safety of medications that can affect the metabolism for these children. I see a new CBS service for med assistance for first 30 days post psychotropic usage.***

In addition to general access problems, the quality of CBS services prior to hospitalization were affected by lack of established relationships with CBS providers, minimal choice of providers in remote areas and access to continuous medication services.

Medication services are disrupted by insurance coverage changes and if families did not have insurance coverage, medications were too expensive to purchase.

With regard to tension in the treatment teams, one provider said that their role is to be a buffer for the parent to manage their frustration.

***Not that I want to trivialize the work that we do as a community mental health agency, but sometimes just having someone to blow off steam to and fuss and cuss at, rather than at a kid or at a judge or somebody like that, that is a positive therapeutic process for that family. And if through that we can teach them how to appropriately vent those feelings and where to appropriately address those, then I've accomplished something significant. I get cut off at the knees every now and then. Well, you know, I'm a big guy. I can take it. I really do think that's part of the process is kind of getting fussed and cussed at every now and then. There's always a teachable moment there. And after everything blows over then we say all right, now let's talk about what just happened. What could we have done different? What could I have done different to help you through that? What could you have done different to have communicated more appropriately? There are teachable moments all the way around. Without the processing it's not quite so therapeutic. [Provider]***

Feedback participants agreed that there was a critical moment at which access or continuation of services may have prevented more restrictive levels of care.

***I do agree with this totally. It is extremely hard dealing with all the problems. A lot harder than anyone else can understand. [Parent]***

Participants said some Crisis intervention hotlines were helpful and others were not.

Concerning youth in state custody, access to the state hospital for youth is not so difficult but access to other stabilizing CBS or private inpatient services is difficult. One youth was in 9 placement in 3 months without accessing any CBS prior to these restrictive placements. Youth was not involved in the present study.

***I guess to me it would be interesting to see how many times they ended up going back there and so what was not being done that they ended up going back. That would be my interest, because I had a client that was in a level 6, went to the state hospital, went back to a level 6, went to another level 6, went back to The state hospital, and then we placed her home and she's done fine. So it's like what could we have done to prevent her from going. I think she went to 9 placements in 3 months because it was like different levels. So what could we have done the first time that that could have been dealt with. [Child Welfare Provider]***

Two parents in the study were encouraged to place their youth in foster care to obtain needed services.

***I chose not to put my child in foster care. She was not in state custody. Surprising how many people thought putting her in foster care was a good idea, even pushed it. No Way. [Parent]***

Coordination with multiple service providers such as schools and the developmental disability organizations can be difficult as it is hard sometimes to establish the lead agency, but as another provider indicated it was possible.

***Recently, my agency (CMHC) held a discharge planning meeting in which the special education of the receiving school. This was the MOST wonderful meeting I have attended. The school was fully prepared for the students' return. The school continued the same, or at least very similar, behavior plan, curriculum, hours of service, staff/student ratio. It WORKED! [Provider]***

## Appendix E-Adolescent Hospital Study Participant Feedback Summary 5

Summary of Participant Feedback on Study Question 5: Considering the Answers to Questions 1-4, Were These Appropriate Admissions to the State Hospital from All Stakeholders' Perspectives?

**Two participants re-affirmed that these admissions were appropriate.**

**One family member indicated the admission was inappropriate and that no choice was offered. The parent only had a medical card through the Home and Community Based Services Serious Emotional Disturbance Waiver.**

*I was told I had to put my child in the State Hospital. No choice - I had no health insurance, no help (financial) from her other parent and I had a lot of trouble getting a medical card for her. I really did not want her in a state hospital due to stigma and I felt they did not help her the first 2 times, but I was given no choice. It is all about the money. If you're rich and have insurance you're fine - if poor no problem. Middle class but you make too much money but you can't afford insurance forget it they do not care.*

**[Parent]**

**Another family member indicated they agreed with hospitalization because they did not want to send their child into juvenile justice custody.**

*Yeah, but the choices weren't all that great. He could go to the state hospital or he could go to juvie. We didn't want him to go to juvie, because then that gives him a record. So we elected to take him to the state hospital. So we did. We left here about 10:30, 11:00 at night and went to The state hospital and got home about 4:00 in the morning.*

**[Parent]**

Summary of Participant Feedback on Study Question 6: What other factors should be considered to explore the feasibility of regional models of state administered inpatient care for children and adolescents?

**At the time of the present study participants felt that level 5 and 6 were not equipped to handle youth with this level of need. The treatment provided in most of the facilities is not best practice for youth with SED, more often they were used for placement and not treatment (7 feedbacks participants).**

*The treatment at most of the facilities is based on some sort of discipline system with levels and privileges. If the kid does what they are told to do, they move up the levels and get more privileges. If they don't, they lose privileges, maybe secluded or restrained. From what I have seen, most have a room that is stripped with a window in the door where they stick kids for seclusion. Reminded me of old institutions. My understanding is the research into these sorts of approaches doesn't really show they are effective. And in the rare case that it does work, it is frequently not the sort of thing that families can replicate in the real world so you end up right back*

***where you started from. We see little in the way of meaningful therapy. The kids have to get a certain number of hours a week of therapy but it is primarily provided in a group format. We find this to be of minimal value and are constantly pushing for family therapy and individual therapy. It rarely happens. Currently, the treatment they get is primarily whatever is happening in the facility milieu which is provided by staff who would be similar to AC workers (young, little training or experience).***

***[Administrator]***

***I think the problem with the level 6 is they're just understaffed and they can't handle that many youth. But I also know people that work in level 6 personally, so it's like they may have just too many intakes in one day and then if one escalates then it may cause the whole place to escalate and there's just not enough workers in that, because they never know how many they're going to have in there. They may have only one R.N. on at a time and that's too much for one R.N. to handle. I think that needs to be a standard for child staff ratios because you have one R.N. on the floor with 14 kids, I think that could be dangerous.***

***[Child Welfare Provider]***

***Funding for more appropriately ran level V & VI's would be great. However, at this time Level V's cannot (rarely if able) be sought by private individuals. Level VI's often do not provide adequate therapeutic treatment. Many do not focus on treating the parents and/or families. Many level VI's are used to "store" the children in foster care with high needs/risks, which is appropriate but they still need appropriate therapeutic treatment. Also the foster care agencies/case managers need to be involved with the treatment process so they can continue to assist the child when they have the level VI environment.***

***[Unknown]***

***My child ran from facility— was not safe—fights, attacks, running everyday. Facility in another location was much more secure – some running but not like the other facility. I feel locations a big factor. One is in the middle of town. The other is on outskirts of town. More police cooperation in the later. State hospitals lock down at least I knew he was safe there.***

***[Parent]***

***Yeah, it's been my experience that we look it and we talk about it and we want it, but it's awfully hard to get. For a quality super 5 or 6, we're looking at having to go east of I-135, which is a 4 hour shot for us and while it's not a whole lot to get in the car and drive 4 hours, you run into diminished networking ability and lack of first-hand knowledge of administrator, admissions people. I know a few folks at super 5s and 6s just because I used to work in that neck of the woods over there, but by and large, once I get***

***outside of the network of folks I've worked with previously, I don't know squat about this facility or that facility, and no one else out here really does.  
[Case manager]***

***The providers need to stay involved with families while youth are in facilities. While child in placement, sending CMCH should be able to bill for Parent Support Services to help family prepare for child's return. Just because the child is "gone" does not mean that the parents do not need support. Fortunately, my center allows me to do limited work with these families.  
[Provider]***

***My real fear is that the facilities will use this report as evidence to support their facilities and push to do the state hospital part. We cannot get kids discharged from these facilities now, even when the entire treatment team agrees that the kid is done with the level 6 program. I think our state hospital bed days would go through the roof. Frequently it is our experience that the issue is placement, not treatment.  
[Administrator]***

**CBS providers and one family said they have difficulty getting youth out of the facilities.**

***"The residential facility was probably the best thing for her, but I called her everyday and went to see her every weekend. This I think helped her so much to see I did not give up on her and that I loved her and wanted her home. I had to fight to get her home –her counselor there would have kept her forever if she had her way. Her and I did not get along. I am trying to be a better parent there are still days I feel like a terrible one. I never thought my child would have done all those things – drugs, sex, running away. I have a time with totally trusting her, and I worry that she will again have those problems. And I don't know if I can handle it if she does."  
[Parent]***

**1. CONTINUE TO EMBRACE A FAMILY DRIVEN SYSTEM OF CARE**

**1.1 Capitalize on the Role of the Families as the Driving Force for Systems Change.**

***Parents need a voice on the board of directors for CMHC's as well as other local agencies. Meaningful evaluations and assessments by consumers that are received by non-defensive providers would serve the system better.  
[Provider]***

***Overall, much more training needed on what family centered means. Talk is cheap-I'm ready to see action!  
[Provider]***

2. DEVELOP PLANS TO EXAMINE YOUTH WHO ARE AT INCREASED RISK FOR HOSPITALIZATION

2.1 *Closely Examine the Demographics of Youth who are Re-admitted Within a Short Periods of Time.*

**Enhance Discharge Planning**

***Discharge planning for youth must include the family/education and any other agencies involved with the youth. Also allow time for receiving community to have staff in place. When youth screened for hospital, allow local CMHC to provide needed services to family to prepare for discharge-over.***

***[Provider]***

**Provide Intensive Parent Support Services to Parents While Youth are Out of the Home**

***Currently the waiver stops if child is hospitalized in residential placement or juvenile detention center. This time could be used to work with the family to learn needed skills to develop self care skills, to address their own grief and loss issues. Also time could be used to bring on board school staff, extended family members, and neighbors. Would be helpful to use time child is out of home to deliver extensive Parent Support Services.***

***[Provider]***

**Variables Impacting Increased Risk**

***The care was not right first time - meds not right, counseling fell short. It is not a quick fix.***

***[Parent]***

3. ENHANCE FAMILY CENTERED CRISIS RESPONSE SERVICES AND TEAMS

***All these areas are important and need improved on.***

***[Parent]***

3.1 *Develop Meaningful Crisis Plans For Youth Who Are Involved in CBS.*

***Right On! Youth and other family members.***

***[Unknown]***

3.2 *Implement Strategies to Rejuvenate Staff and Families Dealing with the Affects of Acute and Chronic Crises.*

***Would be helpful.***

***[Unknown]***

### 3.3 Develop Collaborations with Law Enforcement

**Provide training when officers take initial law enforcement training.**

**[Provider]**

#### 4. EARLY IDENTIFICATION AND ACCESS TO COMMUNITY BASED SERVICES

4.1 Increase Public Awareness Regarding the Identification of Psychiatric Risk Factors.

**Very important.**

**[Unknown]**

4.2 Increase Timely Access to Community Based Services at Critical Points.

**Need and Stigma. My agency staff that feels before A/C services start the CM should know the client very well. This has led to a long wait before needed services are started.**

**[Provider]**

#### 5. CONTINUE TO DEVELOP THE FULL ARRAY OF COMMUNITY BASED SERVICES TO CIRCUMVENT STATE HOSPITALIZATION

**I had none of these. I do not know if they would have helped or not.**

**[Parent]**

##### 5.1 Respite Care Services

**Respite Care services should be provided by a stable provider that child/parent get to know and trust for overnight care. How many SED children can 1 provider care for during the same time period?**

**[Provider]**

##### 5.2 Attendant Care Services

**Attendant Care staff needs to work hours that "fit" a family's schedule. Such as being available evenings and weekends. Staff needs to gain more understanding of the family's perspective and strengths.**

**[Unknown]**

##### 5.3 Foster Homes for Youth with Complex Mental Health Needs

**The service system needs to stay connected to birth family. The birth family needs to be seen as a resource, not a stumbling block.**

**[Unknown]**

#### 6. EXPLORE LEVEL V AND VI POPULATION, STRUCTURES, SERVICES PROVIDED AND ESTABLISH OUTCOMES

**One participant suggested including a measure of the level of family involvement in future outcomes tracking for these facilities.**