April 2005

HOME AND COMMUNITY-BASED SERVICES: MENTAL HEALTH WAIVER FOR CHILDREN AND YOUTH WITH SEVERE EMOTIONAL DISTURBANCE

INDEPENDENT EVALUATION

The University of Kansas School of Social Welfare

Office of Child Welfare and Children's Mental Health

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Sharon T. Barfield, Cheryl Holmes, Alexander Barket, Ronna Chamberlain, and Susan K. Corrigan

INDEPENDENT EVALUATION OF HOME AND COMMUNITY-BASED SERVICES: MENTAL HEALTH WAIVER FOR CHILDREN AND YOUTH WITH SEVERE EMOTIONAL DISTURBANCE

EXECUTIVE SUMMARY

The Kansas Department of Social and Rehabilitation Services (SRS), Division of Health Care Policy (HCP) received a state Waiver through the federal Centers for Medicare and Medicaid Services (CMS) for children and youth, under the age of 22, living with severe emotional disturbance (SED) who are at risk for hospitalization. Eligibility for the Medicaid Home and Community-Based (HCBS)/SED Waiver is determined on two levels: mental health needs (clinical eligibility) and financial status. However, the Waiver permits the fiscal test to be based on the child's income, significantly expanding the potential to serve this target population, described above. For the children and youth covered by the Waiver, Community Mental Health Centers (CMHCs) can bill Medicaid for intensive community-based services (CBS) in an effort to maintain the children and youth in the home and community.

The study of the first phase of the Kansas HCBS/SED Waiver was completed by the University of Kansas School of Social Welfare, Office of Social Policy Analysis and Community Development in June 2000. A follow-up study of children and youth served under the Waiver has been completed covering the period from October 2000 to September 2004. The purpose of the current study is to examine access to, quality of, and cost neutrality of the services provided under the SED Waiver. Additionally, the views of various stakeholders about systemic dynamics related to the Waiver were considered important.

This evaluation used a multi-pronged approach that included the following:

- ✓ Record reviews conducted during site visits to CMHCs,
- ✓ focus groups with CMHC direct service staff and parents of children covered by the Waiver during CMHC site visits,
- ✓ analyses using secondary databases,
- ✓ the use of additional data sources,
- ✓ executive and state level focus groups, and
- ✓ a survey of CBS Directors, CMHC Executive Directors, and SRS/HCP Field Staff.

Key findings for children and youth served by the Kansas SED Waiver include the following:

With regard to Access to Care, findings of this evaluation indicate that the target population in the State of Kansas is being served under the Waiver, per its intent as a hospital diversion program. These children and youth had high acuity levels, evidenced

by clinically significant Child Behavior Checklist (CBCL) scores and higher CBCL scores than all children receiving CBS as well as the finding that almost a third of the children had previous hospitalizations. The children's access to CBS that maintain them in the home and community is supported by their outcomes described in the Quality of Care section of this report and the fact that few children with previous hospitalizations had been recently re-hospitalized.

During focus groups, parents unanimously expressed a desire to maintain their children in the home and community rather than have them hospitalized and they credited CMHCs for helping achieve this desire. One parent indicated that during a difficult period, ***"They [CMHC) staff] jumped in and we had the crisis that wasn't."*** Rather, the situation was described as a ***"short term thing"*** **where** ***everybody really came together and we've never had to have her in the hospital again."***

> ***"They [CMHC] staff] jumped in and we had the crisis that wasn't."***
>
> **Parent of child on the SED Waiver**

Another parent described being at his breaking point and ***"pulling out my hair"*** when his child was hospitalized before he was aware of CBS. He said that within days of contacting the CMHC, the family had a case manager, a home therapist, and a room packed full of people ready to help. With humor, he added, ***"I'm talking standing room only, take out the table."*** He concluded saying, ***"We could never have afforded it without the SED Waiver. It has given us so much hope. We've come such a long way."***

> ***"I'm talking standing room only, take out the table."***
>
> **Parent of child on the SED Waiver**

With regard to Quality of Care, findings of this study indicate that children served by the Waiver in the State of Kansas are receiving high quality care. Services were found to be strengths-based, family-centered, and delivered through a wraparound model. A few stakeholders said wraparound meetings are not always held per the intent of the model.

Clearly, service providers and parents are aware of the power of the wraparound process.

One case manager indicated:

> ***Sometimes you see a lot of tears from parents [at meetings] because all of a sudden everybody is talking about the child's strengths. And, that's the first time some parents hear anything good about their child.***

Of wraparound meetings, one parent said:

> ***We found out what strengths our kids have, and that was the biggest thing. When you've been in the muck, you think there's nothing good. It makes you stop and see what their strengths are. You re-examine and, not everything they do is bad. You see the good in them and work through things.***

With regard to the Client Status Report (CSR) outcome variables, the children did extremely well. During the last quarter of observation, almost all children were living in family homes; and a large majority of the children were without law enforcement contact, earned average or above average grades, and attended school regularly. When viewed over time, children whose services are covered by the Waiver did slightly better than all children on these variables, except for law enforcement contact. Overall, the children showed statistically significant improvement in their clinical conditions as indicated by the change in CBCL scores. These findings are noteworthy, particularly given that children on the Waiver are at greater risk of hospitalization and required to meet a higher clinical threshold for eligibility into the program than all children receiving CBS. The effectiveness of CBS in maintaining children in the home and community is also highlighted by the finding that few children with previous hospitalizations had been recently re-hospitalized. On the Kansas Consumer Satisfaction Survey, both parents of youth on the Waiver, and youth on the Waiver expressed high degrees of both overall satisfaction and satisfaction with services received at CMHCs.

In focus groups, parents spoke poignantly about the helpfulness and quality of services covered by the Waiver that were received at CMHCs. They had very positive things to say about CMHC services and service providers. One parent said, ***"This place [CMHC] has been wonderful, absolutely wonderful. I cannot say enough good things about the mental health center or the people working here."*** Case managers were described as "angels" and "Rocks of Gibraltar." Parents value the parenting classes provided by Parent Support Specialists. One introspective parent ***"embraced"*** the changes the CMHC was able to help the family make ***"in the home as well"*** and praised the parenting skills learned from the center's Parent Support Specialist because **children are *"not born with instructions on their backside."***

> **Children are *"not born with instructions on their backside."***
>
> **Parent of child on SED Waiver about helpfulness of parenting classes**

A condition of the Waiver is that services provided under the community-based plan must cost less or no more than the cost of hospitalization. With regard to Cost Neutrality, the average annual per capita cost of both physical and mental health care provided the children was roughly half the average annual per capita cost of hospitalization. Clearly, the cost of maintaining children in their homes and communities through the provision of CBS is cost effective and significantly less expensive than the cost of hospitalization. The value of the program is not only in the cost savings of CBS compared to hospitalization, but also in the quality of life and the experience of being in a supportive home and community environment.

With regard to Systemic Dynamics Related to the Waiver, the reports of stakeholders described in this report are summarized as follows: The SED Waiver has had a positive impact on the mental health system of care in the State of Kansas. Not surprisingly, some barriers and challenges related to providing high quality services for children covered by the Waiver were identified, and described in this evaluation. CMHC administrative staff have expanded their service capacity and made accommodations where called for, candidly indicating limitations on their ability to do so in some circumstances.

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INDEPENDENT EVALUATION

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ACKNOWLEDGMENTS

The inquirers and authors of this evaluation would like to thank all direct service staff and administrative staff of the community mental health centers visited for their hospitality and time as well as for the important services they provide children and families. We were greatly impressed with the exemplars of excellence in community-based practice that we encountered in the process of conducting this evaluation. We would also like to extend our appreciation to the SRS/HCP community-based services program team and Field Staff. We especially extend our sincere thanks to the families who participated in this study and allowed us privileged insight into their worlds. These families truly are the experts on their lives and those of their children.

HOME AND COMMUNITY-BASED SERVICES
MENTAL HEALTH WAIVER FOR CHILDREN AND YOUTH WITH SEVERE EMOTIONAL DISTURBANCE

INDEPENDENT EVALUATION – APRIL 2005

Introduction

In 1997, the Kansas Department of Social and Rehabilitation Services (SRS), Division of Health Care Policy (HCP) received a state Waiver for children and youth living with severe emotional disturbance (SED) through the federal Centers for Medicare and Medicaid Services (CMS), formerly known as the federal Health Care Financing Administration (HCFA). This Waiver, designed as a hospitalization diversion program, permits the State of Kansas to make specific changes in Medicaid rules for children living with SED who are at risk of being hospitalized. For the children and youth covered by the Waiver, Community Mental Health Centers (CMHCs) can bill Medicaid for intensive community-based services (CBS) in an effort to maintain the children and youth in the home and community.

SED Waiver Background

On June 16, 1997, the Kansas SRS/HCP received approval from CMS to implement the state Waiver for children and youth, under the age of 22, diagnosed with SED who are at risk of being hospitalized. The Medicaid Home and Community-Based Services (HCBS)/SED Waiver essentially permits specific changes in Medicaid rules and funding to offer mental health services to children and families within the target population. In its application, the Waiver is designed to divert children and youth from hospitalization through the provision of CBS available from local CMHCs. During the first year, approximately 600 children were served under the Waiver through a formula based on historical service levels, with an ultimate capacity planned at 1,300 when full funding was realized.

Eligibility for the Waiver is determined on two levels: mental health needs (clinical eligibility) and financial status. However, the Waiver permits the latter test to be based on the child's income and not the family's income, significantly expanding the potential to serve this population. Clinical eligibility is determined by the CMHCs while the Local SRS Office of Economic Employment Support determines financial eligibility. The family has four choices regarding services for their child or children. They can pursue the HCBS SED Waiver, access admission to a State Mental Health Hospital, meet with a Parent Support Specialist to obtain additional information, or decline all services.

The elements of family choice and participation in the treatment planning process are critical features of the Waiver program regulations. Families have the option to invite other family members or caregivers, service providers, significant others, and members of the community to participate in the planning process as equal team members directing the provision of services in a wraparound process. Recognizing the importance of school performance as part of children's overall success, school representatives are considered primary members of the treatment team. All members are encouraged to attend wraparound meetings. The wraparound approach to treatment planning is individualized, strengths-oriented, family-centered, and community-based. This process seeks to coordinate mental health services with other community services and resources to develop the most comprehensive and realistic plan possible.

Once clinical and financial eligibility have been established, an initial meeting of the wraparound team is held to identify strengths and needs to develop the Plan of Care. The wraparound team can be reconvened whenever needed or desired but is required to meet once a year during the Annual Review Process. Medicaid requires a review and update of the plan of care every three months. Some centers conduct wraparound meetings at this time as well.

Children and youth participating in the Waiver are Medicaid eligible, granting them both physical and mental health services through the Kansas Medicaid State Plan. Coverage also includes dental, vision, and prescription expenses. Additionally, the Waiver provides funds for four additional mental health services, not ordinarily covered under Medicaid: 1) wraparound facilitation; 2) parent support and training; 3) respite care; and 4) independent living services. A condition of the Waiver is that both physical and mental health services provided under the community-based plan must cost less or no more than the costs of hospitalization.

Purpose

A study of the first phase of the Kansas SED Waiver was completed by The University of Kansas School of Social Welfare, Office of Social Policy Analysis and Community Development in June 2000. A follow-up study of children and youth served under the Waiver has been completed covering the period from October 2000 to September 2004. The purpose of the current study is to examine access to, quality of, and cost neutrality of services provided under the Kansas SED Waiver.

Methodology

The present study was designed to describe the population and evaluate the service delivery strategies, service provision, costs billed to Medicaid, and consumer outcomes for the renewal phase of the Waiver, which was implemented from the period between

October 1, 2000 and September 30, 2005. It should be noted that this study was not intended to evaluate the participating centers individually, but to look at the SED Waiver from a systems perspective. This emphasis was clearly communicated to all participants in the course of this study.

Databases

Several databases were used for this evaluation, both primarily and secondarily. These databases are described below and referenced in pertinent sections where findings are presented. These databases, which will be elaborated with descriptors, include:

- ✓ The primary database consisting of record reviews completed during site visits
- ✓ The AIMS 1555 database, a larger secondary database, which covers the time period from January 2004 through September 2004
- ✓ Medicaid Management Information System (MMIS), a secondary database that contains Medicaid billing information by transaction and procedure code
- ✓ The AIMS 2000 database generated using AIMS data for the period from January 2000 through September 2004

Specifically, this evaluation was completed using a multi-pronged approach that included the following:

Primary Database*:* The primary database contains the data used for this report, except where otherwise noted. This database was created from record reviews completed during site visits to CMHCs using a standard data collection instrument. The Automated Information Management System (AIMS) database, described below, was used for sampling CMHCs for site visits and records for review.

> The Automated Information Management System (AIMS) is a comprehensive data set that includes data on demographic, client status, and encounter data for individuals served through the Kansas Community Mental Health Centers. Data are used for a variety of purposes including federal and state quality improvement programs and to monitor CMHC contacts under Mental Health Reform (Kansas Department of Social and Rehabilitation Services, p. 2).

For sampling purposes, twelve CMHCs were selected for on-site visits during which time records of children on the Waiver were reviewed. The records reviewed from these twelve centers will be referenced as phase two of the primary database. Additionally, record reviews conducted for a different study completed for SRS/HCP during the Waiver renewal period on this same population of children were utilized so that records over a longer time period could be included and a broader sample could be provided. These additional record reviews will be referenced as phase one of the primary database.

In order to select a sample representative of the entire population served by the SED Waiver in the State of Kansas, the phase one data were considered based on criteria that included CMHC service outcomes, population, and geographic location, encompassing centers located in urban, average density, and rural areas. Then, 12 CMHCs were carefully selected using proportionate stratified sampling based of these criteria to complete the sample and ensure a representative state-wide sample. A sampling frame consisting of all cases in the AIMS database for the CMHCs selected was generated. Finally, using systematic sampling, cases were randomly selected by Client AIMS ID numbers from the sampling frame.

The sample for both phase one and phase two combined is comprised of 211 records. These records constitute 13.6% of the average of 1,555 children served under the SED Waiver in the State of Kansas in 2004. All records reviewed during both phases of data collection were randomly selected using systematic sampling.

As part of the SRS/HCP process of monitoring standards and quality assurance, all CMHCs in the State of Kansas submit Client Status Reports (CSRs) on a quarterly basis. The CSRs contain extensive fields for tracking that include data such as demographics, services provided, custody status, reimbursement sources, and educational placement. The CSRs also contain outcome variables such as Residential Placement, Law Enforcement Contact, Academic Performance, School Attendance, and CBCL Scores. Quarterly reports are issued based on the CSR submissions that are used for a variety of purposes, including quality improvement. These CSRs are housed in the AIMS database.

Data were extracted from the AIMS database and matched with records reviewed. A total of 211 records were matched with CSR outcome variables. For phase one, 62 records were matched with CSR data. For phase two, 149 cases were matched with CSR data. Outcomes for all variables were not available for all children. Eight cases were missing Academic Performance outcomes; nine cases were missing School Attendance outcomes; and one case was missing Child Behavior Checklist (CBCL) scores.

With regard to record reviews, case records of the various children in this evaluation were matched with the randomly selected AIMS numbers at the CMHC sites visited. Records were carefully reviewed according to a process of Clinical Data Mining conceptualized by Auslander, Dobrof, and Epstein (2001) as “The location, retrieval, codification, computerization, analysis, and interpretation of available clinical information for studying client characteristics, social worker interventions and client outcomes” (p. 131). All documents in the records such as the intake form, progress notes, and Waiver paperwork were carefully scrutinized, and the data were entered into the standardized record review form.

AIMS 1555: In addition to the primary database, a larger secondary database was created from AIMS. The most recent three quarters of the children’s AIMS data (SFY05Q1, SFY04Q4, and SFY04Q3, which cover the time period of January 2004

through September 2004) were compiled into one data set for analysis. Evaluators had initially planned to include SFY04Q2 so that data would be available for a full year. However, several of the CMHCs did not have data for that quarter due to undergoing computer systems conversions. Inclusion of this quarter of data without these centers, two of which were large urban areas, would have skewed the analyses. One of those two urban CMHCs is still undergoing conversion and, therefore, does not have data for any of the three quarters selected for inclusion in the analyses. One other medium sized CMHC did not have data for the first of the three quarters (SFY04Q3).

Each CMHC submits data to the AIMS system for each person receiving mental health services through its center once a quarter. For the purpose of this study, evaluators assembled three quarters of data. Therefore, individual children could have up to three entries of data. The total number of duplicated cases for the three quarters was 16,793. In order to arrive at an unduplicated number of children on the Waiver, evaluators selected the unique identifiers for children who were on the Waiver for at least one of the three quarters under study. For those children who were on the Waiver more than one of the three quarters, only the most recent quarter's data were included. The unduplicated count for this analysis of children on the Waiver for at least one of the three quarters under study was 1,555.

Medicaid Management Information System (MMIS): MMIS is comprised of provider and recipient eligibility records, Medicaid claims from providers, services to recipients and program expenditures (Centers for Medicare and Medicaid Services). Because MMIS contains Medicaid billing information by transaction and procedure code, evaluators requested and received MMIS data for children receiving services paid by the SED Waiver. All procedure codes were requested for two time periods – October 2000 through September 2001 (federal fiscal year 2001) and October 2002 through September 2003 (federal fiscal year 2003). Evaluators then met with SRS/HCP staff to select procedure codes that would reflect mental health services that children would receive in the community (e.g., not including services delivered when hospitalized). A list of these services is shown on page 67 of this report.

Once the data were received, they were reduced to only those procedure codes selected above that were delivered by CMHCs. Then the units of service for each procedure code were calculated by dividing the Total Reimbursed Amount by the reimbursement rate available at that time, which was provided by SRS – Medicaid staff. Services were billed as either Service Units or Time Units. Service Units were billed as units of service regardless of the amount of service-provision time (i.e., Pharmacological Management and Case Consultation). Time Units were time-dependent and billed according to the amount of service-provision time (i.e., Case Management and Individual Community Support).

AIMS 2000: Data from the CSR Quarterly Reports that are generated using AIMS data for the period from January 2000 through September 2004 were used to observe

outcomes over time of both children on the Waiver and all children receiving CBS. The conversion for housing of CSRs from a previous system to AIMS took place during July 2001 (Fiscal Year 2002, Quarter 1). Therefore, no data are shown for that quarter. Some difficulties were incurred after this transition period, which account for irregularities in CBCL scores for two subsequent quarters and school attendance and academic performance data for one subsequent quarter.

Additional Data Sources

Additional data sources include the following:

- ✓ Site visit focus groups with CMHC direct service staff and parents
- ✓ Executive and state level focus groups
- ✓ Kansas Consumer Satisfaction Survey for Children's Mental Health Report
- ✓ Kansas Medicaid Program HCFA 372 Annual Reports

The views, suggestions, and feedback of CMHC staff, parents, and other stakeholders about the initiative were considered important. These participants and data-gathering modalities are described below:

- ***Site Visit Focus Groups*** – Focus groups were held separately with CMHC direct service staff and parents whose children received services paid for by the SED Waiver using a standard question format.

- ***Executive and State Level Focus Groups*** – Evaluators met with the following four groups in the summer and fall of 2004 to collect data:

  - ❖ CBS/Children's Directors at one of their regularly scheduled bimonthly meetings. These individuals work at CMHCs and typically oversee CBS, of which Waiver services are a part. Total participants = 20

  - ❖ CMHC Executive Directors at their Association's Public Policy committee meeting. They are typically the head administrator at the local CMHCs. Total participants = 9

  - ❖ SRS Field Staff at their monthly meeting. Among other duties, Field Staff investigate complaints received about CMHCs/service delivery and work toward a resolution of the problem. Total participants = 12

  - ❖ SRS/HCP staff at a meeting specifically scheduled for the purpose of data collection for this study. HCP is a state level division that oversees the Waiver program. Total participants = 5

The first three groups (CBS Directors, Executive Directors, and Field Staff) were asked to complete a survey and participate in answering open-ended questions. SRS/HCP members were asked to participate in open-ended questions only because the survey questions tended to be more program-specific and not applicable to a state-level perspective.

Some of the survey questions were asked of all three groups; other questions were asked only of one or two groups, as appropriate.* Details are provided in each section of this report that indicate which group was responding to the question.

Kansas Consumer Satisfaction Survey for Children's Mental Health Report: Keys for Networking, a consumer advocacy group in the State of Kansas, conducts ongoing consumer satisfaction surveys of families and youth who receive CBS. The University of Kansas analyzes the surveys and reports findings. The percentages of parents and youth reporting high degrees of satisfaction are given, and mean scores are given on a scale from 0 – 4, with 0 indicative of Very Dissatisfied and 4 indicative of Very Satisfied. These consumer satisfaction ratings are given in Appendix A.

Kansas Medicaid Program HCFA 372 Annual Reports: As part of receiving the Waiver, the State of Kansas is required to submit annual HCFA 372 Reports that document the cost of services provided to children under the Waiver compared to costs of hospitalization. The reports from 10/01/00 through 10/30/03 were reviewed, and numbers were extracted to document the cost neutrality of the program. The fourth year of the renewal period report, 10/01/03 – 09/30/04, will not be available in time for inclusion in this evaluation.

SRS Field Staff Contact Data: Within SRS/HCP exists a unit of Field Staff who, among other duties, receive and investigate complaints or "contacts" regarding services delivered by CMHCs. These data were analyzed for Fiscal Years 2003 and 2004.

In order to evaluate accessibility of services, quality of services, cost neutrality, and systemic dynamics related to the Waiver, specific questions were formulated for each section of this evaluation. These questions are given below and again, in the coinciding sections within the body of this report.

**One Field Staff member may be responsible for up to four CMHCs. For some of the survey questions, Field Staff members provided an answer for each CMHC in their catchment area. However, two CMHCs were not reported on by Field Staff due to recent changes in which Field Staff covered these areas. The Field Staff who had recently acquired these centers were not familiar enough with them to provide any rating on service capabilities. Details are provided with the findings as to whether the Field Staff were answering broadly or CMHC-specifically.*

Access to Care

A) Are services accessible to children and families who qualify for the SED Waiver?

1. What are the demographic characteristics of children served under the SED Waiver?
2. What are the CBCL scores of children served under the SED Waiver?
3. What are the numbers and percentages of children who have been previously hospitalized and what were their types of out-of-home placement?
4. How many children on the Waiver have been recently hospitalized and what were their lengths of stay?
5. What are the diagnoses of the children who have been recently hospitalized?
6. Are families given a choice between hospitalization and maintaining their children in the home and community by utilizing CBS?
7. What are the numbers of children served through the SED Waiver?
8. What numbers and percentages of children on the Waiver are covered by other payee sources?
9. How has the demand for services covered by the Waiver impacted provider capacity and related issues such as staffing?
10. What types of outreach and education are done by CMHCs?
11. What are the degrees of satisfaction with access to services among parents whose children are on the Waiver and those with other payee sources?

Quality of Care

The State of Kansas expects CMHCs within the system of care to provide CBS for children and youth according to "best practices" and has adopted a model of strengths-based, family-centered services to be delivered through a wraparound process. In order to determine the quality of care provided children covered by the SED Waiver, researchers designed a series of questions to be answered with data from the children's records, CSR outcomes, secondary databases, qualitative data, and other data sources. These questions are:

B) What is the quality of care provided children and families served under the SED Waiver?

1. What are the types and frequencies of service utilization?

2. Has a wraparound model been implemented for consumers of services covered by the SED Waiver?

3. What is the composition of wraparound teams?

4. What is the relationship between team membership and established goals?

5. Are the services provided strengths-based?

6. Are the services provided family-centered?

7. What are the CSR outcomes on the variables of Residential Status, Law Enforcement Contact, Academic Performance, and School Attendance?

8. What are the degrees of change the children demonstrated as measured by the difference in CBCL scores from baseline, near time of intake, to the last quarter of observation?

9. What are the reasons given for ending Waiver participation?

10. What mechanisms are in place for monitoring safeguards and standards to assure that quality services are being provided children and families on the Waiver?

11. What are the numbers and content of complaints regarding children on the Waiver filed with SRS/HCP Field Staff?

12. What are the degrees of parental and youth satisfaction with the quality of care provided youth covered by the Waiver and those with other payees?

Cost Neutrality

C) Are services provided to children and families served by the Waiver cost neutral or more cost effective than hospitalization?

1. What is the average annual cost for the delivery of CBS per child for children covered by the Waiver, and how does this cost compare with the yearly cost of hospitalization?

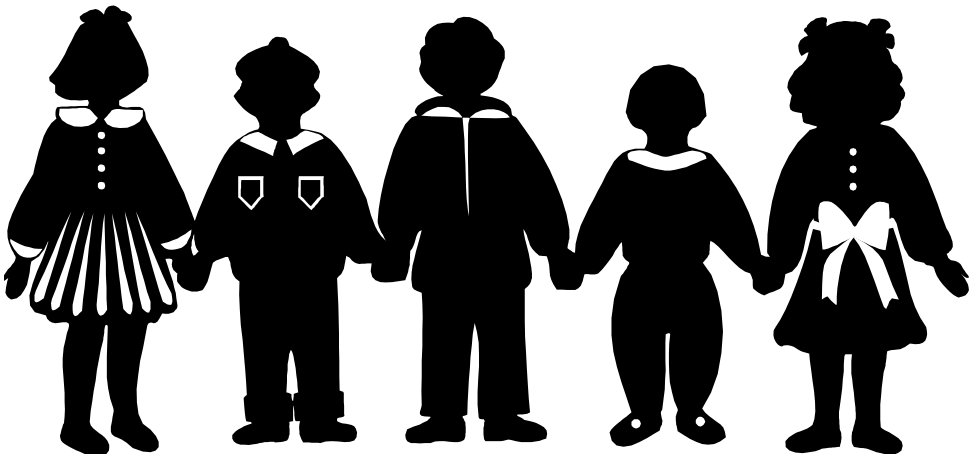
Systemic Dynamics Related to the Waiver

D) What systemic dynamics have been noted related to the SED Waiver?

1. What improvements in the mental health system of care have occurred as a result of the Waiver?

2. What are the barriers and challenges related to service provision under the Waiver?

FINDINGS



ACCESS TO CARE

Findings

All findings in this evaluation pertain to children and youth in the State of Kansas. The terms children and youth will be used interchangeably in this report. As highlighted in the methodology section, findings are based on results from the primary database except where otherwise indicated. It is important to note that any differences in findings between phase one and phase two of the primary database could be a feature of the CMHCs visited, other variables, or actual changes within the system of care.

Access to Care

Population and Demographics

Question A1: What are the demographic characteristics of children served under the SED Waiver?

The demographic characteristics of the youth considered in this evaluation are summarized in Table 1. Overall, the 211 youth included in this evaluation ranged in age from two to 19, with a mean age of 11.94. Of these youth, 66 (31.3%) are female and 145 (68.7%) are male. The racial composition of the group includes 186 (88.2%) Caucasians, nine (4.3%) Black/African Americans, eight (3.8%) Latina/Latinos, and eight (3.8%) of multiple race. At the time of data collection, 188 youth (89.1%) lived with family members such as biological parents, step-parents or a combination of biological and step-parents, 24.2% of whom resided with single mothers. Five youth (2.4%) lived with grandparents. Fourteen youth (6.6%) resided with adoptive parents, and four (1.9%) resided with foster parents.

The 62 youth included in phase one ranged in age from two to 19, with a mean age of 12.72. Of these youth, 22 (35.5%) are female and 40 (64.5%) are male. The racial composition of the group includes 55 (88.7%) Caucasians, three (4.8%) Black/African Americans, two (3.2%) Latina/Latinos, and two (3.2%) of multiple race. At the time of data collection, 60 youth (96.8%) lived with family members such as biological parents, step-parents or a combination of biological and step-parents, 27.4% of whom were living with a single mother. One youth (1.6%) resided with adoptive parents, and one (1.6%) resided with foster parents.

The 149 youth included in phase two ranged in age from four to 19, with a mean age of 11.62. Of these youth, 44 (29.5%) are female and 105 (70.5 %) are male. The racial composition of the group includes 131 (87.9%) Caucasians, six (4.0%) Black/African Americans, six (4.0%) Latina/Latinos, and six (4.0%) of multiple race. At the time of data collection, 128 youth (85.9%) lived with family members such as biological parents, step-parents or a combination of biological and step-parents, 22.8% of whom resided with single mothers. Five youth (3.4%) lived with grandparents. Thirteen youth (8.7%) resided with adoptive parents, and three (2%) resided with foster parents.

Table 1. Demographic Characteristics of Children, n/%

Variable	Attribute	Phase One n	Phase One %	Phase Two n	Phase Two %	Total n	Total %
Cases (211)		62	29.4	149	70.6	211	100.0
Age	6 and under	3	4.8	15	10.1	18	8.6
	7-9	7	11.3	22	14.8	29	13.7
	10-12	22	35.5	46	30.9	68	32.2
	13-15	13	21.0	49	32.9	62	29.4
	16 and older	17	27.4	17	11.4	34	16.1
	Total	62	100.0	149	100.0	211	100.0
	Mean (SD)	12.72(3.60)		11.62(3.51)			11.94(3.56)
Gender	Female	22	35.5	44	29.5	66	31.3
	Male	40	64.5	105	70.5	145	68.7
	Total	62	100.0	149	100.0	211	100.0
Race	Caucasian	55	88.7	131	87.9	186	88.2
	Black/African American	3	4.8	6	4.0	9	4.3
	Latina/Latino	2	3.2	6	4.0	8	3.8
	Multiple Race	2	3.2	6	4.0	8	3.8
	Total	62	100.0	149	100.0	211	100.0
Living Arrangements	Birth parents	25	40.3	53	35.6	78	37.0
	Birth mother	17	27.4	34	22.8	51	24.2
	Birth father	4	6.5	5	3.4	9	4.3
	Parents & step-Parents	14	22.6	36	24.2	50	23.7
	Grand parents	0	0	5	3.4	5	2.4
	Adoptive parents	1	1.6	13	8.7	14	6.6
	Foster parents	1	1.6	3	2.0	4	1.9
	Total	62	100.0	149	100.0	211	100.0

As described on page five, a larger secondary database, referenced as AIMS 1555, was created using AIMS data. An analysis of this data shows the following demographic findings:

- Of the approximately 1,555 children on the Waiver, 569 (36.6%) were in three urban areas.*
- Of the approximately 1,555 children on the Waiver, 1,063 (68.4%) are male and 490 (31.5%) are female.

** Some data for FY04Q2 were missing due to computer system conversions at CMHCs, two of which were large urban areas. One of two urban CMHCs was still undergoing conversion at the time of this report and did not have data for any of the three quarters selected for inclusion in analyses.*

- Of those with race reported, 1,252 children (84.0%) are Caucasian, 82 (5.5%) are Black/African American, 63 (4.2%) are Latino/Latina, 44 (3.0%) are of multiple race, and 45 (3.3%) were reported as other.

- Findings from this larger, secondary database, containing data for all children covered by the Waiver are similar to those from the primary database of record reviews, which supports the representativeness of the sample selected for on-site record reviews.

Identified Strengths of Youth

The identified strengths of youth are quantified in Table 2. **Overall, of 211 records reviewed, 207 (98.6%) clearly indicated multiple strengths of the youth**. Of 62 case records reviewed during phase one, 58 (95.1%) clearly indicated multiple strengths of the youth. A strengths assessment was in the process of being completed for one child (1.6%). During phase one, the inquiry team was unable to locate strengths assessments in 4.9% of the records. Of 149 records reviewed during phase two, 100% clearly indicated multiple strengths of youth.

These strengths were collapsed into attribute domains. Those domains and the most commonly noted strengths are as follow:

- **Education**: attends school regularly, has completed certain grade in school or task, completes homework, enjoys social functions at school, gets along with teachers, earns good grades, is on the honor roll, intelligent, good memory, likes to learn, good at or enjoys certain subjects, and completes homework
- **Creative/Artistic**: artistic, creative, curious, inquisitive, draws well, and insightful
- **Good Health**: active, energetic, in good health, good motor skills, and well-groomed
- **Independent**: determined, independent, is individual, and works or plays independently
- **Outgoing:** articulate, sense of humor, outgoing, talkative, and verbal
- **Responsible/Motivated**: responsible, motivated, achieves goals, does chores, helps around house, and responds to interventions
- **Well-Behaved**: well-behaved, complies with rules, follows directions, and no contact with law
- **Family**: Good bond with mother or father or grandparents, and has fun with family
- **Peer Relations/Community Integration:**
  Engaged -- Enjoys animals, enjoys outdoor activities, plays musical instrument, reads, has hobbies; *Involved* -- Active in outside activities and groups; active in Boy Scouts, Girl Scouts, and church or sports

- **Interpersonal Skills/Other Personal Qualities:**
  Caring -- affectionate, caring, compassionate, generous, kind, and loving; *Social* -- charming, cooperative, friendly, gets along well with others, helpful, displays leadership skills, likable, makes friends, social, and polite.

Table 2. Identified Strengths of Youth (n/%)

Phase	Yes	No
One (n = 61)*	58 (95.1%)	3 (4.9%)*
Two (n = 149)	149 (100%)	0 (0%)
Total (n = 210)*	207 (98.6%)	3 (1.4%)

** One assessment in process of completion*

The assessment of strengths varies within the system of care. Some centers conduct extensive assessments of strengths upon which to build whereas others address strengths in a more cursory manner. More consistency in the identification of strengths was noted at sites visited during phase two of data collection than during phase one.

It is important to note that the intent was to collect strengths of both youth and their families. However, the reviewers were only able to find strengths of families in 16% of the records reviewed during phase one and 60% of the records reviewed during phase two. When these strengths were found, they were important and often poignant. For example, some of these attributes include: motivated and works hard to care for family, family pulls together, mom works two jobs to care for family, mom stays home to care for children, involved, concerned, caring, positive influence, interested in helping in any way, parents divorced but work together for child, parents love child very much, and mother caring for child despite surgery and chemo therapy for cancer.

Identified Diagnoses of Youth

The children, included in the primary database, have a variety of diagnoses, as indicated on record reviews (see Table 3). In instances where multiple diagnoses were present, all diagnoses are given, without regard to their designation as primary or secondary diagnoses because these designations were not always clear in the records reviewed. The diagnoses were collapsed into diagnostic categories that are described after Table 3.

Overall, the most frequently occurring diagnostic categories were Attention Deficit Disorder (ADD/ADHD), Mood Disorders, and Behavior Disorders. ADD/ADHD was identified in 118 instances (55.9%), Mood Disorders in 91(43.1%), and Behavior Disorders in 88 (41.7%).

The most frequently occurring categories of diagnoses for phase one were ADD/ADHD and Mood Disorders. For phase one, 33 children (53.2%) were diagnosed with ADD/ADHD and 31 children (50%) with Mood Disorders.

For phase two, the most frequently occurring diagnostic categories were ADD/ADHD and Behavior Disorders. For this phase, 85 children (57%) had ADD/ADHD and 64 children (43%) had Behavior Disorders.

The incidence of Pervasive Developmental Disorders Co-occurring with other mental health disorders increased from 1.6% during phase one to 4.7% during phase two. The incidence of Asperger's Disorder increased from 1.6% during phase one to 3.4% during phase two. The incidence of Anxiety Disorders increased from 9.7% during phase one to 28.2% during phase two.

A dual diagnosis of ADD/ADHD and Behavior Disorder existed in 48 children (19%) during phase one. This comorbidity rate remained near constant at 18.6% during phase two. During phase one, a dual diagnosis of Mood Disorder and ADD/ADHD was noted in 23 children (9.1%). This comorbidity rate remained constant at 9.1% during phase two.

Table 3. Diagnoses of Children, by Diagnostic Category (n/%)

Diagnosis	Phase One n	Phase One %	Phase Two n	Phase Two %	Total n	Total %
Attention Deficit Disorders (ADD/ADHD)	33	53.2	85	57.0	118	55.9
Mood Disorders	31	50.0	60	40.3	91	43.1
Behavior Disorders	24	38.7	64	43.0	88	41.7
Anxiety Disorders	6	9.7	42	28.2	48	22.7
Adjustment Disorders	8	12.9	14	9.4	22	10.4
Learning Disorders Co-occurring with Other Mental Health Diagnoses (Co-morbid)	5	8.1	8	5.4	13	6.2
Psychosis	3	4.8	6	4.0	9	4.3
Family Relational Disorders (Co-morbid)	4	6.5	4	2.7	8	3.7
Drug and Alcohol Disorders (Co-morbid)	2	3.2	1	.7	3	1.4
Eating and Elimination Disorders	2	3.2	6	4.0	8	3.8
Pervasive Developmental Disorders (Co-morbid)	1	1.6	7	4.7	8	3.8
Asperger's Disorder	1	1.6	5	3.4	6	2.8
Problem Related to Abuse or Neglect (Co-morbid)	0	0	3	2.0	3	1.4
Others	3	4.8	8	5.4	12	5.7
Total	123	198.4*	313	210.2**	436	206.5***

Percent based on 62 cases* * Percent based on 149 cases* ****Percent based on 211 cases*

The diagnoses in Table 3 were collapsed into categories as follow:

- **Adjustment Disorders:** Various Adjustment Disorders including With Mixed Disturbance of Emotions and Conduct, with Disturbance of Conduct, With Mixed Anxiety and Depressed Mood, and Unspecified
- **Anxiety Disorders:** Generalized Anxiety Disorder, Obsessive Compulsive Disorder, Post Traumatic Stress Disorder, Social Phobia, and Reactive Attachment Disorder of Early Childhood
- **Asperger's Disorder:** Asperger's Disorder
- **Attention Deficit Disorders (ADD/ADHD):** Attention-Deficit/Hyperactivity Disorder, Combined Type, Predominantly Inattentive Type, and Predominantly Hyperactive-Impulsive Type Not Otherwise Specified (NOS)
- **Behavior Disorders:** Intermittent Explosive Disorder, Conduct Disorder, Oppositional Defiant Disorder, and Disruptive Behavior Disorder NOS
- **Drug and Alcohol Disorders Co-Occurring with Other Mental Health Diagnoses:** Alcohol Dependence and Polysubstance Dependence
- **Eating and Elimination Disorders:** Eating Disorder NOS, Encopresis, Enuresis, and Pica
- **Family Relational Disorders Co-Occurring with Other Mental Health Diagnoses:** Parent Child Relational Problems
- **Learning Disorders Co-Occurring with Other Mental Health Diagnoses:** Reading Disorder and Learning Disorder NOS
- **Mood Disorders:** Major Depressive Disorder, Bipolar Disorder, and Dysthymic Disorder
- **Pervasive Developmental Disorders Co-Occurring with Other Mental Health Disorders:** Autistic Disorder, Pervasive Developmental Disorder NOS, Childhood Disintegrative Disorder, and Rett's Disorder
- **Problems Related to Abuse or Neglect Co-Occurring with Other Mental Health Diagnoses :** Physical Abuse of Child (Victim), Neglect of Child (Victim), and Sexual Abuse of Child (Victim)
- **Psychosis:** Schizophrenia and Brief Psychotic Disorder
- **Others:** Chronic Tic Disorder, Gender Identity Disorder, Disorder of Adolescent Child NOS, Personality Change Due to Head Injury Aggressive Type, Personality Change Due to Seizure Disorder, Phonological Disorder, Tourettes Disorder, Disorder of Adolescent Child NOS

The AIMS 1555 database was used to provide the primary diagnoses of the entire population of children served by the Waiver. Only primary diagnoses, provided in

AIMS, were included in this database. The numbers and percentages of those diagnoses, shown in Table 4, are not collapsed into the above diagnostic categories.

The most frequently occurring diagnosis was Attention Deficit Disorder. Of the 1,555 children, 395 (25.4%) had this diagnosis.

The next most frequently occurring diagnoses were Oppositional Defiant Disorder and Bipolar Disorders. Of the 1,555 children, 192 (12.3%) had a diagnosis of Oppositional Defiant Disorder and 183 (11.8%) had a diagnosis of Bipolar Disorder.

The least occurring diagnoses were Panic Disorder and Borderline Personality Disorder. Of the 1,555 children, one child each (0.1%) had these diagnoses.

Table 4. Primary Diagnoses of Children (N/%)

Diagnosis	N	%
Attention Deficit Disorder	395	25.4
Oppositional Defiant Disorder	192	12.3
Bipolar Disorders	183	11.8
Major Depression	127	8.2
Disruptive Behavior Disorders	89	5.7
Depressive Disorders	52	3.3
Adjustment Disorders	52	3.3
Mood Disorders	46	3.0
Asperger's Disorder	43	2.8
Anxiety Disorders	41	2.6
Post Traumatic Stress Disorder	36	2.3
Conduct Disorder	25	1.6
Impulse Control Disorders	25	1.6
Dysthymic Disorder	24	1.5
Obsessive Compulsive Disorder	17	1.1
Tic Disorders	11	0.7
Psychotic Disorders	10	0.6
Reactive Attachment Disorder of Infancy of Early Childhood	9	0.6
Schizophrenia	10	0.6
Separation Anxiety Disorder	6	0.4
Pervasive Developmental Disorder (Co-morbid)	6	0.4
Panic Disorder	1	0.1
Borderline Personality	1	0.1
No Diagnostic Code Listed	111	7.1
Other	43	2.8
Total	1,555	99.9

In order to compare the diagnoses from the primary database with those of the entire population of children served by the Waiver, the diagnoses in Table 4 above were collapsed into the same diagnostic categories used in the primary database, given on page 17 of this report. Table 5 contains these primary diagnoses by diagnostic categories.

The most frequently occurring diagnostic categories were Mood Disorders, ADD/ADHD and Behavior Disorders. Of the children, 432 (27.8%) had Mood Disorders, 420 (27.0%) had ADD/ADHD, and 306 (19.9%) had Behavior Disorders.

Findings from the primary database of record reviews were very similar to those of the entire population of children served by the Waiver. Whereas the AIMS 1555 analysis considered primary diagnoses only, the primary database considered all diagnoses on the records reviewed. The top three diagnostic categories for both the entire population in AIMS 1555 and the primary database were Mood Disorders, ADD/ADHD, and Behavior Disorders, supporting the representativeness of and generalizability of findings from the primary database.

Table 5. Primary Diagnoses by Diagnostic Categories (N/%)

Diagnostic Category	N	%
Mood Disorders	432	27.8
Attention Deficit Disorders (ADD/ADHD)	420	27.0
Behavior Disorders	306	19.7
Anxiety Disorders	110	7.0
Adjustment Disorders	52	3.3
Asperger's Disorder	43	2.8
Psychosis	20	1.2
Pervasive Developmental Disorders (Co-morbid)	6	.06
Other	55	3.5
No Diagnostic Code Listed	111	7.1
Totals	1,555	100.0

Acuity

Question A2: What are the CBCL scores of children served under the SED Waiver?

As previously indicated, the CSRs that CMHCs submit on a quarterly basis are maintained in the AIMS database. Among the outcome variables on the CSRs are CBCL scores. CSR outcome variables from the AIMS database were merged with the primary database to answer Question A2 and other subsequent questions.

- Per Table 6, at baseline, near time of intake, the overall mean of Internalizing CBCL scores of the 210 youth considered in this study was 71.1. The overall mean of Externalizing CBCL scores of these youth was 72.9.
- Overall, the mean of Internalizing and Externalizing CBCL scores of these 210 youth fell in the clinically significant range.
- At baseline, the mean of Internalizing CBCL scores of the 62 children included in phase one was 69.4. The mean of Externalizing scores for these children was 71.6.
- At baseline, the mean of the Internalizing CBCL scores of the 148 children included in phase two was 71.8 and the mean of the Externalizing CBCL scores was 73.4.

Table 6. Acuity: CBCL Scores

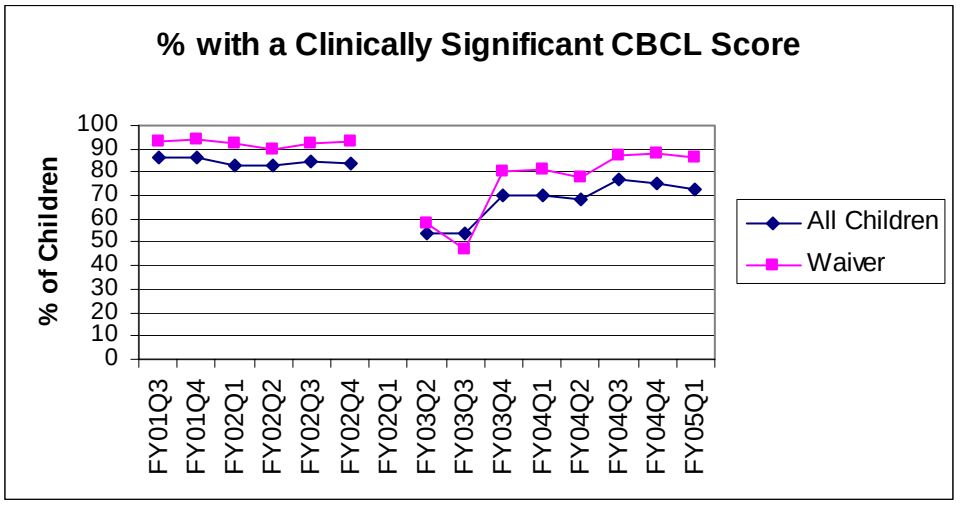
Variable	Attribute	Phase One n	Phase One Score	Phase Two n*	Phase Two Score	Total n	Total Score
Mean CBCL Baseline Scores	Internalizing	62	69.4	148	71.8	210	71.1
Mean CBCL Baseline Scores	Externalizing	62	71.6	148	73.4	210	72.9

** CBCL scores for one child were not in CSRs*

In addition to the above findings from the primary database, findings from AIMS 2000 will be shown here and on pages 51 through 54. Analyses were performed for 15 reporting quarters on the outcome variable of CBCL scores. Findings from these analyses are given in Chart 1, which illustrates the percentages of clinically significant CBCL scores of all children and Waiver children.

- For FY01Q3, 93% of Waiver children had clinically significant scores, compared to 86% of all children.
- For FY05Q1, 86% of Waiver children had clinically significant scores while 73% of all children had clinically significant scores.
- **The Waiver is intended to serve children with clinically significant problems and intense needs who are at risk for hospitalization. The above findings over time indicate that this target population is being served under the Waiver, as intended.**

Chart 1 . Acuity: CBCL Scores, All Children and Waiver (%)*



***As indicated in the methodology section of this report, the conversion for housing of CSRs from a previous system to AIMS took place during July 2001 (Fiscal Year 2002, Quarter 1). Therefore, no data are shown for that quarter. Although some difficulties were incurred with CBCL scores after this transition period, which account for the irregularities in CBCL scores for two subsequent quarters, data stability was restored thereafter.*

Question A3: What are the numbers and percentages of children who have been previously hospitalized and what were their types of out-of-home placement?

Previous hospitalizations shown in AIMS are based on historical information. Therefore, previous hospitalizations could have occurred during a time period prior to a child entering CBS or subsequent to a child entering CBS.

- Per Table 7, of the 211 children in the primary database, 60 (28.4%) had been previously hospitalized.
- Of the 62 records reviewed during phase one, 20 children (32.3%) had been previously hospitalized.
- Of the 149 records reviewed during phase two, 40 children (26.8%) had been previously hospitalized.

Table 7. Acuity: Previous Hospitalizations (n/%)

Variable	Attribute	Phase One n	Phase One %	Phase Two n	Phase Two %	Overall n	Overall %
Previous Hospitalizations	Yes	20	32.3	40	26.8	60	28.4
Previous Hospitalizations	No	42	67.7	109	73.2	151	71.6
	Total	62	100.0	149	100.0	211	100.0

The AIMS 1555 database described on page five of this report was utilized for findings presented in Tables 8, 9, and 10.

- Per Table 8, of 1,555 Waiver children, 335 (21.5%) had been previously hospitalized.
- **Of those 335 children, only 25 (7.5%) had been re-hospitalized during the most recent quarter and 310 (92.5%) had not been hospitalized during the most recent quarter.**
- Of the 1,220 children who had not been previously hospitalized, only 2.2% had been hospitalized during the most recent quarter.

Table 8. Acuity: Previous Hospitalizations (N/%)

Previous Hospitalization	N	%	Hospitalized During Most Recent Quarter N	Hospitalized During Most Recent Quarter %
Yes	335	21.5	25	7.5
No	1,220	78.5	27	2.2
Totals	1,555	100	52	9.7

Table 9 displays the types of placement facilities for the 335 children on the Waiver who had previous hospitalizations.

- The most utilized facility was private psychiatric hospitals where 176 children (52.5%) were placed, followed by general hospital psychiatric wards where 98 children (29.3%) were placed.
- The least utilized facilities were inpatient substance abuse and residential care within a state correctional facility, with three children (.9%) placed at each.

Table 9. Types of Out-of-Home-Placement Facilities (N/%)

Type of Facility	N	%
Private psychiatric hospital	176	52.5
General hospital psychiatric ward	98	29.3
State mental health hospital	36	10.7
Out-of-home crisis stabilization	19	5.7
Inpatient substance abuse (excl. detox)	3	0.9
Residential mental health within a state correctional facility	3	0.9
Totals	335	100.0

Question A4: How many children on the Waiver have been recently hospitalized and what were their lengths of stay?

Of the 1,555 children, 52 were in a hospital or hospital-like setting during the most recent quarter.

- 25 (48%) were hospitalized between 1 and 7 days,
- 17 (33%) were hospitalized between 8 and 20 days,
- 4 (8%) were hospitalized between 21 and 30 days, and
- 6 (12%) were hospitalized 31 days or more.

Following the 15th day a child has been hospitalized, Waiver coverage is terminated. There are alternative funding mechanisms that may be put into place at that time. When the child returns to their community following hospitalization, they may move back onto the Waiver.

Question A5: What are the diagnoses of the children who have been recently hospitalized?

A more in-depth analysis was conducted on the 52 children who had days in a hospital-type setting (state hospital, private psychiatric hospital, or crisis resolution) during the most recent quarter.

Findings are given in Table 10 as follows:

- Of the 52 children with hospitalizations in the most recent quarter of the AIMS 1555 database, the most frequently occurring diagnosis was Bipolar Disorder, followed by ADD/ADHD.
- Of these 52 children, 13 (25.0%) had a diagnosis of Bipolar Disorder and eight (15.4%) had a diagnosis of ADD/ADHD.
- No diagnostic code was listed for eight (25.0%) of the children.
- Of the 52 children, 22 (42.3%) had some type of mood disorder (Bipolar, Major Depression, Mood Disorder, or Depressive Disorder).

Table 10. Children Hospitalized in Most Recent Quarter by Diagnoses (N/%)

	Children with Days in Hospital for Most Recent Quarter N	All Children in Data Set Regardless of Hospitalization N	Children Hospitalized Most Recent Quarter %*	Children Hospitalized Most Recent Quarter %**
Diagnosis	**N**	**N**	**%***	**%****
Bipolar Disorder	13	183	7.1	25.0
Attention Deficit Disorder	8	395	2.0	15.4
No Diagnostic Code Listed	8	111	7.2	15.4
Oppositional Defiant Disorder	5	192	2.6	9.6
Major Depression	4	127	3.1	7.7
Asperger's Disorder	3	43	7.0	5.8
Mood Disorder	3	46	6.5	5.8
Depressive Disorder	2	52	3.8	3.8
Post Traumatic Stress Disorder	2	36	5.6	3.8
Conduct Disorder	1	25	4.0	1.9
Impulse Control Disorder	1	25	4.0	1.9
Tic Disorder	1	11	9.1	1.9
Adjustment Disorders	0	52	0	0
Anxiety Disorder	0	41	0	0
Autistic Disorder	0	6	0	0
Borderline Personality Disorder	0	1	0	0
Disruptive Behavior Disorder	0	89	0	0
Dysthymic Disorder	0	24	0	0
Obsessive Compulsive Disorder	0	17	0	0
Panic Disorder	0	1	0	0
Psychosis	0	10	0	0
Reactive Attachment Disorder	0	9	0	0
Schizophrenia	0	10	0	0
Separation Anxiety Disorder	0	6	0	0
Other	1	43	2.3	1.9
Totals	52	1,555	N/A	99.9

**Percentages based on N of all children in data set compared by specific diagnoses*

***Percentages based on total N of children hospitalized during most recent quarter (52)*

Table 11 delineates hospital lengths of stay by diagnoses.

Of the six children with 31+ days in a hospital setting:

- Four (66.7%) had a primary diagnosis of Bipolar Disorder, one (16.7%) had a diagnosis of Major Depression, and one (16.7%) did not have a diagnostic code listed.
- Only one child had a previous hospitalization shown prior to that quarter.
- Three children had no other payment source listed other than the Waiver. The other three had no insurance/private pay, meaning that without the Waiver, the families would be responsible for all service provision costs.

Table 11. Hospital Days by Diagnoses (N/%)

	Days in a Hospital Setting During Last Quarter				
Diagnosis	**1-7 days**	**8-20 days**	**21-30 days**	**31+ days**	**Total N/%**
Bipolar Disorder	6	3	0	4 (66.7)	13(25.0)
Attention Deficit Disorders	4	3	1	0	8 (15.4)
No Diagnostic Code Listed	1	5	1	1 (16.7)	8(15.4)
Oppositional Defiant Disorder	4	1	0	0	5(9.6)
Major Depression	2	0	1	1 (16.7)	4(7.7)
Mood Disorder	3	0	0	0	3(5.8)
Pervasive Development Disorders (Co-morbid)	2	1	0	0	3(5.8)
Depressive Disorder	1	0	1	0	2(3.8)
Post Traumatic Stress Disorder	1	1	0	0	2(3.8)
Conduct Disorder	0	1	0	0	1(1.9)
Tic Disorder	0	1	0	0	1(1.9)
Impulse Control Disorder	1	0	0	0	1(1.9)
Other	0	1	0	0	1(1.9)
Totals	25	17	4	6 (100.1)	52 (99.9)

Question A6: Are families given a choice between hospitalization and maintaining their children in the home and community by utilizing CBS?

Records reviewed during site visits contained **Family Assurance forms that were dated and signed** by parents. In focus groups held during site visits, when asked, some parents did not recall signing these forms but added that, due to the large amounts of paperwork

they had signed, it would be easy to forget specific documents. **Parent focus-group participants unanimously expressed a desire to maintain their children in the home and community rather than have them hospitalized and they credited CMHCs for helping achieve this desire**.

When asked about a choice between CBS and hospitalization, one parent explained that at the time her daughter had been hospitalized, prior to being placed on the Waiver, she needed the stabilization provided by the hospital. This parent was uncertain whether this same stabilization could have been provided by the use of CBS at that time. However, she indicated her daughter had subsequently been maintained by CBS, which the family preferred to hospitalization.

Parents of children who had been previously hospitalized emphasized that they had not been re-hospitalized subsequent to receiving CBS. After one hospitalization, a parent said without CBS covered by the Waiver that his daughter would be *"back there by now."* Many spoke of ways in which hospitalization had been averted by the use of CBS. One parent, whose child had been hospitalized twice prior to being on the Waiver, said that without the Waiver, *"we would be back where we started."* Instead, during one period of escalation, CBS, including respite care, restored the child's balance. The mother said that respite *"gives us [parents] a break, too."*

One parent indicated that during a difficult period, ***"They [CMHC staff] jumped in and we had the crisis that wasn't."*** Rather, the situation was described as a *"short term thing"* where *"everybody really came together and we've never had to have her in a hospital again."* In this situation, attendant care and home-based family therapy were credited with averting hospitalization.

One family said that without Waiver services there would have been several times in their son's life when they would have had to explore residential care and *"that breaks your heart to have to give up your child, wanting the best for them."* The Waiver was described as providing *"an option to keep him in the home and the community where he belongs."* The family considered the consequences their child would face when returning to the community, asking if a child has been in a "*structured environment and then they're going to go out in the real world, if they haven't been trained in the real world, what have you gained?"*

Parents **described the stressor of hospital expenses** accrued prior to receiving CBS. Parents with private insurance described leaving hospitals with their children, encumbered with thousands of dollars of debt. One parent, whose child had used the lifetime insurance maximum, described the Waiver as a *"sanity keeper."* This parent added, *"It was heart-wrenching to know that in order to help your child that you have to decide between food and mental health care."*

One mother and father described the extreme difficulty of maintaining jobs and caring for other children while staying with their hospitalized child. The father, an over-the-road truck driver, said he was at his breaking point and *"pulling out my hair."* He said that within days of contacting the CMHC, they had a case manager, a home therapist, and a room packed full of involved people ready to help. With humor, he added, ***"I'm talking standing room only, take the table out."*** He concluded, saying, ***"We could never have afforded it without the SED Waiver. It has given us so much hope. We've come such a long way."***

Question A7: What are the numbers of children served through the SED Waiver?

Data for Table 12 were derived from the Kansas Medicaid Program HCFA 372 annual reports for the first three periods, spanning 10/2/2000 through 9/30/2003. Because the HCFA 372 annual report covering 10/2/2003 through 9/30/2004 is not yet available, data for the time period January 2004 through September 2004 were derived from the AIMS 1555 database.

Table 12 gives the numbers of children who have been served under the Waiver.

Table 12. Children Served Under Waiver (N)

Reporting Period	N
10/02/00 through 09/30/01	1,151
10/01/01 through 09/30/02	1,269
10/01/02 through 09/30/03	1,563
01/01/04 through 09/30/04	1,555

Question A8: What numbers and percentages of children on the Waiver are covered by other payee sources?

Data contained in Table 13, which gives a summary of the payee sources for children on the Waiver, were derived from the AIMS 1555 database.

- The most common payee source was private insurance, which covered 788 children (50.7%) followed by 352 children (22.6%) who had no insurance, private pay.
- Of 1,555 children, 429 (27.6%) were covered by the Waiver only.
- The least common payee sources were Foster Care that covered 11 children (0.7%) and Juvenile Justice, which covered one child (0.1%).

Table 13. Payee Sources (N/%)

Payee	N	%*
Waiver	1555	100
Private Insurance	788	50.7
Waiver Only	429	27.6
No Insurance – Private Pay	352	22.6
Medicaid	301	19.4
Healthwave	58	3.7
Foster Care	11	0.7
Juvenile Justice	1	0.1
Other	21	1.4

** Children on the Waiver can have multiple forms of insurance. Therefore the percentages shown exceed 100%.*

Question A9: How has the demand for services covered by the Waiver impacted provider capacity and related issues such as staffing?

Themes that emerged from the qualitative data of the executive and state level focus groups and related indicators are given below:

Staffing

When CBS Directors were asked to select all of the ways their organization provides wraparound services, almost two-fifths (40%) reported that their organization has a wraparound facilitator. For one-fourth (25%), the case manager who is working with the child coordinates wraparound services. One of these respondents noted that the parent support specialist is trained to provide this service as well. Roughly one-third (30%) have both case managers and wraparound facilitators, with one respondent indicating that the parent gets to choose which person coordinates this service. One respondent (5%) checked "other" without elaboration.

Table 14. Wraparound Facilitation by Service Provider (n/%)

Service Provider	N	%
Wraparound Coordinator	8	40
Case Manager	5	25
Both	6	30
Other	1	5
Total	20	100

Both CBS Directors and Executive Directors were asked in which ways their agencies have made staffing changes in the last two years in order to serve children on the Waiver. Of the combined 29 participants reporting, three-fourths reported hiring additional case management staff. Two-fifths hired respite staff. The same number reported hiring other new staff, which included attendant care/case management assistants, psychosocial leaders/aides, psychiatrists, qualified mental health professionals (QMHPs)/clinicians, Advanced Registered Nurse Practitioners, and support staff to handle plans of care authorizations.

Table 15. Staffing Changes to Accommodate Service Needs (n/%)

Staff Hired	n	%
Case Management	22	76
Parent Support Specialists	12	41
Other New Staff	12	41
Respite	8	28
Independent Living Staff	3	10
Neither Hired Nor Reduced Staff	2	7
Reduced Staff	0	0

Executive Directors were asked if their organizations had hired contract staff to assist with staffing. Three of the nine reported having hired contract staff, including wraparound and parent support specialists, clinicians, and child psychiatry staff.

Service Delivery

Field Staff, CBS and Administrative Directors were asked to check which description best captured their agency's ability to provide the four Waiver services. For this question, Field Staff answered for each CMHC individually. Therefore, although there were 41 respondents, the total n for this question is 54 (25 Field Staff, 9 Executive Directors, and 20 CBS Directors).

Table 17. CMHC Ability to Provide Four Waiver Services (n/%)

Service	We can easily meet demand n (%)	We can meet demand but cannot meet any additional demand n (%)	We cannot currently meet demand n (%)	We do not offer this service n (%)	Missing n (%)
Parent Support	29 (54)	13 (24)	11 (20)	0 (0)	1 (2)
Respite	6 (11)	18 (33)	23 (43)	5 (9)	2 (4)
Wraparound	35 (65)	14 (26)	5 (9)	0 (0)	0 (0)
Independent Living	17 (31)	9 (17)	2 (4)	18 (33)	8 (15)

Of the 41 respondents, 14 provided written comments related to providing the four Waiver services.

- Seven of the 14 dealt with Respite Services.
    - Three noted that the CMHC contracts to provide respite and the availability of the service depends on the contractor as well as limits set by the Kansas Department of Health and Environment (KDHE) through licensing (e.g., limits on the number of children in the home at one time).
    - Two dealt with staffing issues (one is currently hiring; another spoke of turnover and difficulty anticipating family need for this service).
    - One spoke of the importance of respite and how lifting the limit on hours would be helpful.
    - One stated that respite is not provided at that particular center.*
- Six of the 14 dealt with Independent Living. With the exception of one comment that noted that the center does not provide Independent Living services, the other five explained that goals related to independent living are often addressed through psychosocial or case management services.
- The last comment noted that one particular center was in the process of hiring parent support staff which had been referenced above as a service where the demand could not be met.

**Since these data were collected, one center in the system added respite through a contract, which may be this center. As previously indicated, centers were told they would not be identified by name.*

Parent Fee Program

In the fall of 2002, SRS/HCP implemented the Parent Fee Program at the direction of the Kansas Legislature. This program requires parents to share in the cost for services delivered under the three Waiver programs in the State of Kansas (MR/DD, TA – Technology Assistance, and SED). Fees are based on the parents' adjusted gross income and the number of exemptions claimed on the most recent federal tax return starting with no fee, for those families under 200% of the Federal Poverty Level (FPL) and increasing to $174 a month, for those families over 600% of the FPL, with no fee capitation (Information obtained from the SRS Parent Fee Program Panel Brochure, September 2003).

Data provided by SRS/HCP showed that in FY 2003, of 1,563 families, 239 (15.3%) receiving services through the SED Waiver paid $59,339 in Parent Fees, or approximately $248 per family, on average. This amount projected for FY 2004 was

$76,495. The Parent Fee was expected to generate a considerable amount of revenue. In light of the small amount of funds rendered and related administrative costs, some question whether the Parent Fee Program is producing funds sizeable enough to pay for itself.

Since this policy change occurred midway through the SED renewal period, evaluators asked Field Staff, CBS Directors, and Executive Directors to what extent, if any, the Parent Fees had affected families. Of the 40 (out of 41 respondents) who answered this question, one-third felt it had not had any negative impact, and about one-half felt the fee had a negative impact, but only for a few families.

Table 16. Impact of Parent Fee Program (n/%)

The Parent Fee has:	n	%
Not had any negative impact	13	32.5
Had a negative impact but only for a few families	19	47.5
Has had a negative impact on many families	0	0.0
Not sure/had not heard any concerns	8	20.0
Total	40	100.0

Question A10: What types of outreach and education are done by CMHCs?

CBS and Executive Directors were asked what kinds of outreach their agencies had done to educate families about Waiver services. Their answers are summarized as follows. Some respondents provided more than one answer.

17 COMMUNITY: Through presentations in the community, attending community meetings, contacting community partners
10 CENTER MEETINGS: Through meetings provided at the center (i.e., family meetings, parent support meetings/groups)
8 INTAKE/PRE-INTAKE: When families enter service/at intake
8 MANUAL: A manual/brochures describing Waiver services
3 WORD OF MOUTH: Word of mouth/one-on-one contact
3 PROVISION OF SERVICES: Waiver information is shared when providing other services (e.g., case management)

Concerns Shared by Field Staff

The 12 Field Staff were asked a limited number of questions based on their experiences working with families who had expressed concerns related to Waiver services. Field Staff answered for each CMCH individually, so the total number of respondents (n) was 25.

- When asked how often they have contacts from families requesting to be placed on the Waiver but who were not found eligible, Field Staff reported that this has occasionally been a concern at only two CMHCs. Information was missing for an additional two CMHCs.

- When asked how often they have contacts from families requesting to continue on the Waiver but who were told their eligibility will end, Field Staff reported that this has been an occasional concern at only three CMHCs. Information was missing for two additional CMHCs.

Field Staff were then asked about the common reasons why families reported being concerned about losing Waiver eligibility. Ten of the 12 Field Staff responded to this question. Eight of the 10 referred to the need to have assistance paying for services. Four spoke of the ability to receive mental health services that were not billable except on the Waiver (e.g., respite) or the ability to receive a comprehensive array of mental health services that the families would not otherwise be able to afford. Two spoke of the fear of change – needing intensive services in the future and not being able to receive them.

What Else?

All participants were asked what else they would like to tell evaluators about Waiver services in Kansas. Ten people had the following comments. Some commented on more than one issue.

- Three spoke of the success seen because Waiver services are available in Kansas.
- Three dealt with data – it would be helpful to compare the number of hours provided to children on the Waiver with children receiving CBS who are not on the Waiver; studying how children are found eligible; and a note that respite hours will not always be seen in billable time when it is provided through contract.
- Two dealt with Independent Living – limits to using this service due to low reimbursement rate; and that it is often provided through other services, making it hard to assess how often it is used.
- One spoke of the perception at times that some in the community have that anyone is or should be Waiver-eligible.
- One mentioned that there are no flex funds directly available through the Waiver.

- One expressed a problem with Waiver eligibility being lost due to SRS not processing the paperwork to maintain eligibility.

The impressions of CMHC administrative staff about what children are gaining access to the Waiver were considered important. Therefore, in focus groups, CMHC administrative staff were asked to describe who was being served through the Waiver. Their responses are given below:

- ✓ Those with private insurance and no insurance; some are new to service, others have been in service a while. Some families come into service asking to be on the Waiver.
- ✓ People in crisis
- ✓ Some who have been in outpatient services for a while but instead of improving are continuing to deteriorate
- ✓ Some children coming out of the hospital whom the Waiver helps keep from being readmitted
- ✓ Some children already on Medicaid but in need of the additional four Waiver services
- ✓ Some children dually diagnosed with mental health disorders and mental retardation/developmental disabilities (MR/DD) who are not eligible for the MR/DD Waiver but are needing services

***Question A11: What are the degrees of satisfaction with access to services among parents whose* children are on the Waiver and those with other payee sources?**

Kansas Consumer Satisfaction Survey (Family and Youth)

Keys for Networking, a consumer advocacy group in the State of Kansas, conducts ongoing consumer satisfaction surveys of families and youth who receive CBS covered by Medicaid. The University of Kansas analyzes the surveys and reports findings of the Kansas Consumer Satisfaction Survey (KCSS). The percentages of parents and youth reporting high degrees of satisfaction on a number of indicators are reported. Mean scores are given on a scale from 0 to 4, with 0 indicative of Very Dissatisfied and 4 indicative of Very Satisfied. These consumer satisfaction ratings are provided in Appendix A.

Findings from the KCSS (Petr & Martin, 2004) for September 2003 to July 2004 were considered for both parents and youth. With regard to access to services, both parents

whose children are on the Waiver and parents whose children are not on the Waiver reported high levels of satisfaction. One statistically significant difference was found between the two groups. Parents of children on the Waiver were significantly more satisfied than parents of children not covered by the Waiver with the time between their first call to the CMHC and intake.

There were no significant differences in youth satisfaction between those with Waiver coverage and others. Among the youth, 83.30% of youth covered by the Waiver said they knew how to reach someone at the CMHC compared to 78.80% of youth not on the Waiver. Of the youth who tried to reach someone at the CMHC, more youth not on the Waiver (89.70%, mean of 3.19) were satisfied with how quickly they received help than youth on the Waiver (82.00%, mean of 3.22).

Findings of this evaluation support the fact that children targeted to be served by the Waiver are gaining access to it. Children covered by the Waiver in the State of Kansas have significant mental health needs and are at risk of hospitalization, per the Waiver's intent as a hospital diversion program.

QUALITY OF CARE

Quality of Care

Question B1: What are the types and frequencies of service utilization?

Table 18 and Chart 2 display the total types and frequencies of service utilization from the primary database.

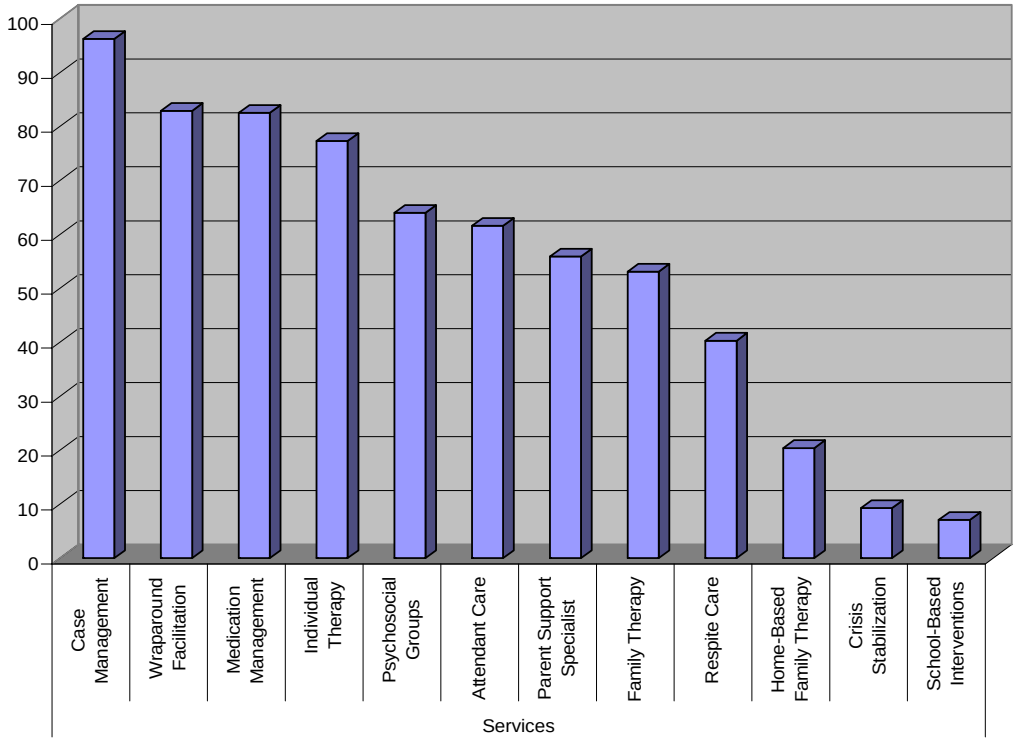
- Case management was the most frequently used service (96.2%), followed by wraparound facilitation (82.9%), medication management (82.5%), individual therapy (77.3%), and psychosocial groups (64.0%).

- Home-based therapy, crisis stabilization, and school-based interventions were the least rendered services.

Table 18. Types and Frequencies of Service Utilization (n/%)

Service	**n**	%
Case Management	203	96.2
Wraparound Facilitation	175	82.9
Medication Management	174	82.5
Individual Therapy	163	77.3
Psychosocial Group	135	64.0
Attendant Care	130	61.6
Parent Support Specialist	118	55.9
Family Therapy	112	53.1
Respite Care	85	40.3
Home-Based Therapy	43	20.4
Crisis Stabilization	11	9.3
School-Based Interventions	15	7.1
Other	82	38.9

Chart 2. Types and Frequencies of Service Utilization



Wraparound

Clearly, service providers and parents are aware of the power of the wraparound process. When talking about how teams are formed for all children receiving CBS, one case manager said:

> *We ask the families. We encourage them to invite people involved in the child's life, like their pastor, a neighbor, or a friend. I have had big meetings where the neighbors and all kinds of people came. People would say, "Hey, after school you can bring him by my house. I'll give you a break." And then families realize there are always people that can help and that's what we should be doing, trying to get all the people in their life involved, not just the clinical team, not just the school.*

Another case manager indicated:

> ***Sometimes you see a lot of tears from parents [at meetings] because all of a sudden everybody is talking about the child's strengths. And, that's the first time some parents hear anything good about their child.***

Yet another case manager articulated:

> *The kid's self-esteem really rises [at meetings] when he hears all the good things about him instead of all the bad things.*

A parent said:

> *She [case manager] had all the people we needed at the meeting. We have three goals we work towards using different action steps and it involves the school and the school teams, and an aunt. It helps the teachers understand.* ***We found out what strengths our kids have, and that was the biggest thing. When you've been in the muck, you think there's nothing good. It makes you stop and see what their strengths are. You re-examine and, not everything they do is bad. You see the good in them and work through things. That may take a long time because you've been mad at your kids because they get in so much trouble. We looked at the strengths and then looked at what they needed to improve and how we could do that. That's the biggest thing I got from wraparound. Now, when I get angry with my kids, it helps to come up with something good.***

Another parent indicated she had felt intimidated by school personnel who seemed "professional" at previous school meetings, but felt supported and empowered by the presence of CMHC staff at school meetings. This mother's perception was that she was heard and more respected at school after the first wraparound meeting.

Wraparound Model Implementation

Question B2: Has a wraparound model been implemented for consumers of services covered by the SED Waiver?

Overall, of the 211 cases reviewed, reviewers were able to locate documentation of wraparound teams for 207 (98.1%). Reviewers were unable to locate documentation of wraparound teams for four cases (1.9%). **Of the 62 cases reviewed during phase one, reviewers were able to locate documentation of wraparound teams for 58 (93.5%). This documentation was found in 100% of the 149 cases reviewed during phase two. Wraparound meetings were facilitated by wraparound facilitators 63.1% of the time, by case managers 34.2% of the time, and by parent support specialists 2.7% of the time.**

Although there is variability between centers within the system of care, progress notes document wraparound meetings. Most centers had separate sections for the documentation of these meetings. Some records contained documentation of meetings but did not indicate which team members were present. One center's records contained the minutes of the meetings, signatures of members present, and the date of the next scheduled meeting.

Staff described the orchestration of meetings as challenging, considering the frequent schedule conflicts of team members. **In centers that employed a full-time wraparound facilitator, whose sole responsibility was to manage the scheduling and meeting of teams, the wraparound process was most faithful to the intent and purpose of the model**. **Staff members indicated that meetings are best attended when held in conjunction with other activities, such as meetings at schools or when members have other appointments at the mental health centers.**

Wraparound Team Membership

The participation of families and community members in the treatment planning process is a critical feature of the Waiver program. The opinions of individuals involved in a child's life are represented by their membership on that child's wraparound team. This membership affords participants the opportunity to voice their preferences that guide the direction of service provision, such as developing goals and the types of services rendered.

Question B3: What is the composition of wraparound teams?

Table 19 contains the total composition of team membership as follows:

- During phase one, the child's primary caretaker, including father **or** mother, was a team member 98.3% of the time. A foster mother was not listed as a team member in one case (1.7%).

- During phase two, the primary caretaker was a team member 100% of the time. Parents were members of 144 teams (96.6%). During phase two, grandparents, as primary caregivers, were members of five teams (3.4%).

- For phase two, youth as team members increased to 137 (91.9%) from 45 (77.6%) for phase one. It should be noted that these numbers could be an under-representation of actual membership as reflected in case records.

- Case manager or wraparound facilitator membership was similar during both phases of data collection at 96.6% during phase one and 98.7% during phase two.

- More attendant care workers (14.1%) and parent support specialists (32.9%) were team members during phase two compared to 1.7% and 15.5% respectively during phase one.

Table 19. Composition of Team Membership (n/%)

Team Members		Phase One n (%)*	Phase Two n (%)**
Child/Youth		45 (77.6)	137 (91.9)
Family members	Mother only ***	51 (87.9)	138 (92.6)
	Mother and father	25 (43.1)	70 (47.0)
	Father only	6 (10.3)	6 (4.0)
	Grandparent (as Primary Caretaker)	0 (0)	5 (3.4)
	Grandfather	4 (6.9)	2 (1.3)
	Grandmother	5 (8.6)	7 (4.7)
	Other relatives	15 (25.9)	29 (19.5)
School personnel		36 (62.1)	71 (47.7)
Other service systems (SRS, Foster care, Juvenile Justice		7 (12.1)	11 (7.4)
Family friends		7 (12.1)	22 (14.8)
Community members		2 (3.4)	19 (12.8)
Other caregivers		2 (3.4)	17 (11.4)
Case manager/wrap facilitator		56 (96.6)	147 (98.7)
Counselor/therapist		35 (60.3)	114 (76.5)
Attendant care		1 (1.7)	21 (14.1)
Group leader		2 (3.4)	15 (10.1)
Parent Support Specialist		9 (15.5)	49 (32.9)
Psychiatrist		18 (31.0)	64 (43.0)****

** Percentages based on 58 teams*
*** Percentages based on 149 teams*
******Includes foster mothers***
*****Includes Nurse Practitioners*

- Per Table 20, **overall, school personnel were represented as members of 107 teams (51.7%)**

- **For phase one, school personnel were members of 36 teams (62.1%). For phase two, school personnel were members of 71 teams (47.7%).**

- **Overall, natural supports,** including grandparents, other relatives, family friends, community members, and other caregivers **were members of 131 teams (63.3%).**

- **Natural supports were members of 35 teams (60.3%) at the sites visited during phase one and 96 teams (64.4%) at sites visited during phase two.**

- Overall, primary caregivers, including fathers, mothers, and grandparents (if primary caregivers) were well represented as members of 303 teams, at 146.4%, or almost one and one-half caregivers per team on average.

- During phase one, 84 primary caregivers were team members (144.8%). During phase two, 219 primary caregivers were team members (147%).

Table 20. Team Membership (n/%)

	Parents	Primary Caregivers	Natural Supports	School	Child	Mental Health Center
Phase One (n=58)	57 (98.3)	84 (144.8)	35 (60.3)	36 (62.1)	40 (69.0)	120 (206.9)
Phase Two (n=149)	144 (96.6)	219 (147.0)	96 (64.4)	71 (47.7)	137 (91.9)	410 (275.2)
Total (n=207)	201 (97.1)	303 (146.4)	131 (63.3)	107 (51.7)	177 (85.5)	522 (252.2)

1. Parents: includes father or mother
2. Primary Caregivers: includes fathers, mothers and grandparents (if primary caregivers), who together comprise more than 100%, as team members
3. Natural supports: includes grandparents, relatives, friends, other caregivers, and community members
4. Mental Health Center: includes attendant care workers, case managers, counselors, parent support specialists, psychiatrists, and group leaders who, together, comprise more than100% membership on teams

Established Goals

Goals collected from the records reviewed were collapsed into categories as follow:

- **Goals Related to Education:** improve school attendance, improve educational performance, improve attention, keep up with school work, and improve behaviors and social skills at school

- **Goals Related to Self-Improvement:** improve personal appearance, increase self-esteem, increase social skills, increase coping skills, increase communication skills, learn patience, utilize positive thinking, and express feelings appropriately
- **Goals Related to Symptoms:** deal with ADHD symptoms; decrease anxiety; reduce impulsivity; stabilize mood, suicidal ideation or suicide attempts; reduce incidents of self-harm; diminish sexual acting out; stabilize after release from hospital; and deal with trauma of abuse
- **Goals Related to Child Responsibility:** remain drug free, participate in therapy, take responsibility for own actions, comply with court diversion, take medications, increase compliance with authority, decrease stealing, and have no new law enforcement problems
- **Goals of Family:** obtain resources, participate in therapy, improve family relationships and communication, live in safe environment, create a safety plans for parents, acknowledge special needs of the child, improve parenting skills, and use positive parental attitude with kids
- **Goals Related to Child's Relationship in Family:** improve relationship with parents, improve relationship with siblings, follow rules of the family, and follow instructions at home
- **Goals Related to Peer Relationships/Community Integration:** increase and/or improve friendships, maintain healthy relationships with peers, community participation, respect others and property, and enjoy and increase leisure activities
- **Goals Related to Anger:** control or express anger appropriately, manage physical aggression, anger management, and control abuse of other children

Question B4: What is the relationship between team membership and established goals?

Several factors appear to influence team membership such as the child's needs, the reasons parents are seeking services, and goals established**.**

- Per Table 21, during phase one, the most frequently defined goals related to anger, education, the child's self-improvement, and child responsibility.

- During phase one, natural supports were team members 87% of the time when goals related to the family, 70.6% of the time when goals related to the child's responsibility, 60.5% of the time when goals related to the child's self-improvement, and 59.5% of the time when goals related to education.

- School personnel were team members 62.8% of the time when goals related to anger, 62.5% of the time when goals related to peer relationships/community integration, 60% of the time when goals related to symptoms, and 58.6% of the time when goals related to the child's relationship in the family.

Table 21. Plan Members in Established Goal Categories, Phase One (n/%)

Goal Category	Client	Case manage	Coun-Selor	Psychia-trist **	Natural Support	School Personnel
Education (n=42)	30(71.1)	40(95.2)	22(52.4)	10(23.8)	25(59.5)	22 (52.4)
Employment (n=4)	3(75)	4(100)	3(75)	0(0)	2(50)	2 (50)
Self-improvement (n=38)	23(60.5)	35(92.1)	22(57.9)	10(26.3)	23(60.5)	22 (57.9)
Symptoms (n=25)	17(68)	24(96)	19(76)	9(36)	13(52)	15 (60)
Child Responsibility (n=34)	23(67.6)	30(88.2)	17(50)	10(29.4)	24(70.6)	19 (55.9)
Family (n=23)	13(56.5)	20(87)	12(52.2)	7(30.4)	20(87)	8 (34.8)
Child Relationship in Family (n=29)	22(75.9)	27(93.1)	17(58.6)	7(24.1)	16(55.2)	17 (58.6)
Peer Relationships/Community Integration (n=32)	22(68.8)	28(87.5)	18(56.3)	10(31.3)	16(50)	20 (62.5)
Anger (n=43)	32(74.4)	39(90.7)	23(53.5)	9(20.9)	23(53.5)	27 (62.8)

**Percentages based on number of goals established in specific category by case*
***Includes Nurse Practitioners*

- Per Table 22, during phase two, the most frequently defined goals related to education and the child's relationship in the family, followed by anger and symptoms.

- During phase two, natural supports were team members 68% of the time when goals related to the child's relationship in the family, 65% of the time when goals related to education, 64.2% of the time when goals related to the child's symptoms, and 62.9% of the time when goals related to anger.

- School personnel were team members 100% of the time when goals related to employment, 50% of the time when goals related to education, 49.3% of the time when goals related to peer relationships/community integration, and 48.5% of the time when goals related to anger.

Table 22. Plan Members in Established Goal Categories, Phase Two (n/%)

Goal Category	Client	Case manage	Coun-Selor	Psychi-atrist **	Natural Support	School Personnel
Education (n=100)	91(91)	99(99)	78(78)	45(45)	65(65)	50(50)
Employment (n=2)	2(100)	2(100)	2(100)	0(0)	0(0)	2 (100)
Self-improvement (n=78)	71(91)	76(97.4)	56(71.8)	31(39.7)	41(52.6)	25(32.1)
Symptoms (n=81)	73(90.1)	80(98.8)	63(77.7)	33(40.7)	52(64.2)	29(35.8)
Child Responsibility (n=64)	58(90.6)	63(98.4)	47(73.5)	27(42.2)	39(60.9)	22(34.4)
Family (n=22)	19(86.4)	22(100)	16(72.7)	8(36.4)	6(27.3)	7(31.8)
Child Relationship in Family (n=100)	90(90)	99(99)	78(78)	44(44)	68(68)	45(45)
Peer Relationships/ Community Integration (n=69)	65(94.2)	68(98.6)	52(75.4)	28(40.6)	5(7.2)	34(49.3)
Anger (n=97)	88(90.7)	96(99)	71(73.2)	40(41.2)	61(62.9)	47(48.5)

**Includes Nurse Practitioners*

Question B5: Are the services provided strengths-based?

The strengths of youth derived from the record reviews are identified in Table 2 on page 15 of this report. Through the course of this review, evaluators found exemplary indicators of CBS program practices based on a strengths-based model. Progress notes reflected a focus on strengths and often goals were set to encourage clients to focus more on their personal strengths. Some programs were stronger in this area than others.

When discussing services provided for both children on the Waiver and children not on the Waiver, direct service providers described services based on a strengths perspective. They used terminology such as being strengths-based or strengths-oriented, and focusing on strengths. Some representative quotes include:

> *I work from client strengths to meet their needs, one-on-one, because everyone is different. You never know what you're going to get into and you always have to treat families with respect.*

> *I call the way I work stepping into their [the clients'] world. As the kids improve, the kids are empowered, the parents are empowered, and the teachers are empowered.*

We have children in foster care who have been moved so many places that they forget they have strengths. They don't feel like they belong or have a place. So, we keep working on identifying strengths.

If I get stuck with families, it's going back to the basics, back to strengths and needs, back to what can be different.

Additionally, a discussion of strengths-based services related to the wraparound process is located on pages 36 and 37 of this report.

Question B6: Are the services provided family-centered?

Family-centeredness was considered as indicated by the degree to which goals were developed collaboratively, or the extent to which parental concerns were addressed by the establishment of goals related to those concerns. Data were analyzed to determine the consistency between the goals established and the reasons parents were seeking services for their child or children**.**

- Per Table 23, during phase one, parents most commonly sought help due to concern about their child's anger and symptoms, followed by problems at school, and the child's relationship with other family members.

- During phase one, when parents were concerned about particular issues, **CMHCs established goals related to those issues 100% of the time, with the exception of symptoms, where goals were established 73.5% of the time**.

It should be noted that goals were codified into specified goal categories, which limited the evaluators' discretion for the identification of goals in some cases. Although in some instances when goals that precisely identified symptoms were not listed in the records, often other goals were established that indirectly addressed the symptoms. For example, if a child had a symptom of withdrawing, a goal related to peer relationships/community integration, such as increasing community participation, indirectly addressed the parental concern about the child's symptom.

Table 23. Reasons Parents Were Seeking Services and Goals Established, Phase One (n/%)

Goal Category	Number and Percentage of Reasons Parents Seeking Services	Number and Percentage of Cases in Which Goals Were Established	Consistency Between Reasons Parents Seeking Services and Goals Established
Education	26 (17.3)	42 (15.6)	100%
Employment	0 (0)	4 (1.5)	NA
Child's Self-Improvement	5 (3.3)	38 (14.1)	100%
Symptoms	34 (22.7)	25 (9.3)	73.5%
Child Responsibility	14 (9.3)	34 (12.6)	100%
Family	7 (4.7)	23 (8.5)	100%
Child Relationship in Family	21 (14)	29 (10.7)	100%
Peer Relationships /Community Integration	9 (6)	32 (11.9)	100%
Anger	34 (22.7)	43 (15.9)	100%
Totals	150 (100)	270 (100)	100%

- Per Table 24, during phase two, parents most commonly sought services because of concern about the child's relationship in the family, followed by symptoms, anger, and school problems.

- For phase two, when parents were concerned about specific issues, **goals to address those issues were established 100% of the time,** with the exception of anger and symptoms, where goals were established **98% and 69.2% of the time respectively.**

As previously indicated, it should be noted that goals were codified into specified goal categories, which limited the evaluators' discretion for the identification of goals in some cases. Although in some instances when goals that precisely identified symptoms were not listed in the records, other goals were established that indirectly addressed the symptoms. For example, if a child had ADHD symptoms, a goal related to school, such as "improve attention," indirectly addressed the parental concern about the child's symptom.

Table 24. Reasons Parents Were Seeking Services and Goals Established, Phase Two (n/%)

Goal Category	Number and Percentage of Reasons Parents Seeking Services	Number and Percentage of Cases in Which Goals Were Established	Consistency Between Reasons Parents Seeking Services and Goals Established
Education	91 (19.7)	100 (15.6)	100%
Employment	0 (0)	2 (1.5)	NA
Child's Self-Improvement	13 (2.8)	78 (14.1)	100%
Symptoms	117 (25.3)	81 (9.3)	69.2%
Child Responsibility	31 (6.7)	64 (12.6)	100%
Family	1 (.2)	22 (8.5)	100%
Child Relationship in Family	80 (30.2)	100 (10.7)	100%
Peer Relationships /Community Integration	31 (6.7)	69 (11.9)	100%
Anger	99 (21.4)	97 (15.9)	98%
Totals	463 (100)	613 (100)	100%

Criteria were established to determine degrees of family-centeredness and a classification of family-centered services. The reasons parents were seeking services were compared with goals established. If there was a corresponding goal for every reason parents were seeking services, the case was considered perfectly consistent. This category is rigorous, somewhat analogous to making 100% on every test taken in school. If the reasons parents were seeking services were partially reflected in the goals, the case was considered partially consistent. The two degrees of family-centeredness, perfect and partial, combined comprise the classification of family-centered services. If reasons parents were seeking services were not consistent with any goals established, the case was considered to be not family-centered.

- As indicated in Table 25**,** overall, of 211 cases, 121 (57.3%) were partially consistent and 82 (38.9%) were perfectly consistent, **for a total of 203 cases (96.2%) that were family-centered. Eight cases (3.8%) were not family-centered.**

- **For phase one,** of 62 cases, 29 (46.8%) were partially consistent and 25 (40.3%) were perfectly consistent, with **54 cases (87.1%) classified as family- centered and eight (12.9%) classified as not family-centered.**

- **For phase two,** of 149 cases, 92 (61.7%) were partially consistent and 57 (38.3%) were perfectly consistent, with **149 (100%) of cases meeting the criteria for family-centeredness.**

Table 25. Family-Centeredness (n/%)

	Partially Consistent	Perfectly Consistent	Family-Centered	Not Family-Centered
Phase One (n= 62)	29 (46.8)	25 (40.3)	54 (87.1)	8 (12.9)
Phase Two (n=149)	92 (61.7)	57 (38.3)	149 (100)	0 (0)
Totals (n=211)	121 (57.3)	82 (38.9)	203 (96.2)	8 (3.8)

Additionally, parents of children on the Waiver and parents of children not on the Waiver report high levels of satisfaction with the family-centered items on the KCSS (Appendix A). For example, on the indicator of satisfaction with opportunities to participate in treatment planning, 92.1% of parents with children on the Waiver were satisfied, with a mean of 3.42 while 92.6% of parents with children not on Waiver were satisfied, with a mean of 3.39. Both groups of parents indicated high levels of satisfaction with location of appointments and appointment times.

Client Status Report Outcomes

Question B7: What are the CSR outcomes on the variables of Residential Placement, Law Enforcement Contact, Academic Performance, and School Attendance?

Cases Matched With Client Status Reports

In order to answer question B7, CSR data were extracted from the AIMS database and matched with records reviewed. A total of 211 records were matched with CSR outcome variables for the last quarter of observation in this evaluation. For phase one, 62 records were matched with CSR data. For phase two, 149 cases were matched with CSR data. Outcomes for all variables were not available for all children. Eight cases were missing Academic Performance outcomes; nine cases were missing School Attendance outcomes; and one case was missing CBCL scores.

Residential Placement:

- Per Table 26, overall, among 211 children, 209 (99.05%) lived in family homes, with one in a group home and one in residential care.

- For phase one, among 62 children, 61 (98.39%) lived in family homes. One child (1.61%) was in residential care.

- For phase two, among 149 children, 148 (99.33%) lived in family homes. One child was living in a group home (.67%).

Table 26. Residential Placement (n/%)

Placement	Phase One n/%	Phase Two n/%	Total n/%
Family Home	61 (98.39)	148 (99.33)	209 (99.05)
Group Home	0 (0)	1 (.67)	1 (.47)
Residential Care	1 (1.61)	0 (0)	1 (.47)
Totals	62 (100)	149 (100)	211 (100)

Law Enforcement Contact:

- Per Table 27, overall, of 211 youth, 198 (93.8%) had no law enforcement contact, 10 (4.7%) had one contact, and three (1.4%) had two contacts.

- For phase one, of 62 cases, 50 (80.6%) had no law enforcement contact, nine (14.5%) had one contact, and three (4.8%) had two contacts.

- For phase two, of 149 cases, 148 (99.3%) were without law enforcement contact and one (.7%) had one contact.

Table 27. Law Enforcement Contact (n/%)

Number of Contacts	Phase One n/%	Phase Two n/%	Total n/%
None	50 (80.6)	148 (99.3)	198 (93.8)
One	9 (14.5)	1 (.7)	10 (4.7)
Two	3 (4.8)	0 (0)	3 (1.4)
Totals	62 (100)	149 (100)	211 (100)

Academic Performance:

- Per Table 28, overall, of 203 children, 178 (87.7%) earned average or above average grades and 25 (12.3%) had failing or below average grades.

- Of the 55 cases matched for academic performance for phase one, 48 (87.3%) had average or above average grades and seven (12.7%) had failing or below average grades.

- Of the 148 cases matched on this variable for phase two, 130 (87.8%) had average or above average grades and 18 (12.2%) had failing or below average grades.

- On a scale from 1 to 4, with 1 indicative of failing grades and 4 indicative of above average grades (A or B), the total mean score was 3.26, with a mean of 3.20 and 3.28 for phases one and two respectively.

- Overall, the children included in this study demonstrated very good academic performance.

Table 28. Academic Performance (n/%)

Grades	Phase One n/%	Phase Two n/%	Total n/%
Average or Above Average	48 (87.3)	130 (87.8)	178 (87.7)
Failing or Below Average	7 (12.7)	18 (12.2)	25 (12.3)
Total	55 (100)	148 (100)	203 (100)
Mean Scores	3.20	3.28	3.26

Based on scale from 1 to 4, with 1 indicative of failing grades and 4 indicative of above average grades (A or B)

School Attendance:

- Per Table 29, overall, among 202 children, 172 (85.1%) attended school regularly and 21 (10.4%) attended more often than not, with nine (4.5%) attending infrequently or not attending. The mean score was 3.79 on a scale from 1 to 4.

- For phase one, of 54 children, 41 (75.9%) attended school regularly and eight (14.8%) attended more than not, with five (9.3%) attending infrequently or not attending, demonstrating a mean score of 3.61.

- For phase two, of 148 children, 131 (88.5%) attended school regularly and 13 (8.8%) attended more than not, with 4 (2.7%) attending infrequently, for a mean of 3.86.

Table 29. School Attendance (n/%)

Category	Phase One n/%	Phase Two n/%	Total n/%
4. Attends Regularly	41 (75.9)	131 (88.5)	172 (85.1)
3. Attends More Than Not	8 (14.8)	13 (8.8)	21 (10.4)
2. Attends Infrequently	2 (3.7)	4 (2.7)	6 (3.0)
1. Not Attending	3 (5.6)	0 (0)	3 (1.5)
Totals	54 (100)	148 (100)	202 (100)
Mean Scores	3.61	3.86	3.79

Question B8: What are the degrees of change the children demonstrated as measured by the difference in CBCL scores from baseline, near time of intake, to the last quarter of observation?

Child Behavior Checklist (CBCL) Scores:

Analyses were performed to determine differences on Internalizing and Externalizing CBCL scores from baseline to post-test. The mean baseline, the mean last quarter, and the mean amount of change are given in Table 30.

- **Overall, the Internalizing scores of youth improved 5.3 points on average. This change was statistically significant at $p = < .05$.**

- **Overall, the Externalizing scores of youth improved 4.3 points on average, a statistically significant difference at $p = < .05$**

- **Overall, youth showed significant improvements in terms of both Internalizing and Externalizing scores.**

- **The Internalizing scores of youth included in phase one improved 2.1 points on average, a change that did not reach a statistical significance level.**

- **The Externalizing scores of youth included in phase one improved 1.8 points on average, a change that was not statistically significant.**

- **The Internalizing scores of youth included in phase two improved 6.7 points on average, a statistically significant improvement at *p* = <.05.**

- **The Externalizing scores of youth included in phase two improved 5.3 points on average, statistically significant at *p* = < .05.**

Table 30. Change in Internalizing and Externalizing CBCL Scores

Although higher CBCL scores indicate children are functioning more poorly, ***when the mean of the last quarter is subtracted from the baseline mean, a minus change indicates scores got worse and positive change indicates improvement.***

	Phase One n	**Baseline**	**Last quarter**	**Change**
Mean of Internalizing Score	62	69.4	67.3	**2.1**
Mean of Externalizing Score	62	71.6	69.8	**1.8**
	Phase Two n	**Baseline**	**Last Quarter**	**Change**
Mean of Internalizing Score	148	71.8	65.1	**6.7***
Mean of Externalizing Score	148	73.4	68.1	**5.3***
	Total n	**Baseline**	**Last Quarter**	**Change**
Mean of Internalizing Score	210	71.1	65.8	**5.3***
Mean of Externalizing Score	210	72.9	68.6	**4.3***

**** p = < .05***

CSR Outcomes Over Time

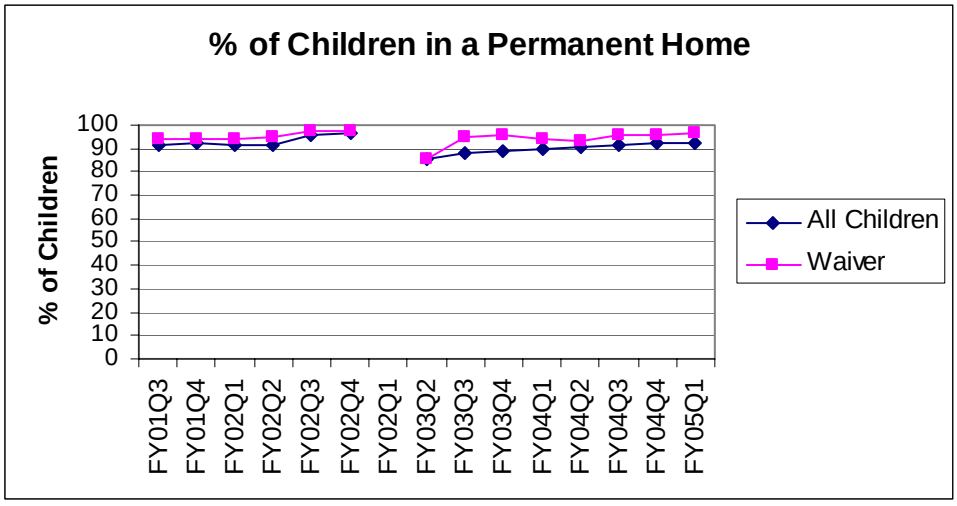
In addition to the above findings, analyses using the AIMS 2000 database, described on page six of this report, were performed for 15 reporting quarters on the outcome variables of Residential Placement, School Attendance, Academic Performance, and Law

Enforcement Contact for all children receiving CBS and children on the Waiver to look at data over time. As previously indicated, the conversion for housing of the CSRs from a previous system to AIMS took place during July 2001 (Fiscal Year 2002, Quarter 1). Therefore, no data are shown for that quarter in findings given in Charts 3, 4, 5, and 6 below. Some difficulties were incurred after this transition period, which account for missing school attendance and academic performance data for one subsequent quarter in Charts 4 and 5. Otherwise, system stability had been restored.

- Per Chart 3, there was little difference between all children receiving CBS and children covered by the Waiver on the outcome variable of Residential Placement. Children covered by the Waiver enjoyed a slightly higher level of permanent home placements.

- For example, for FY05Q1, 96.3% of children on the Waiver lived in permanent homes compared to 92.0% of all children.

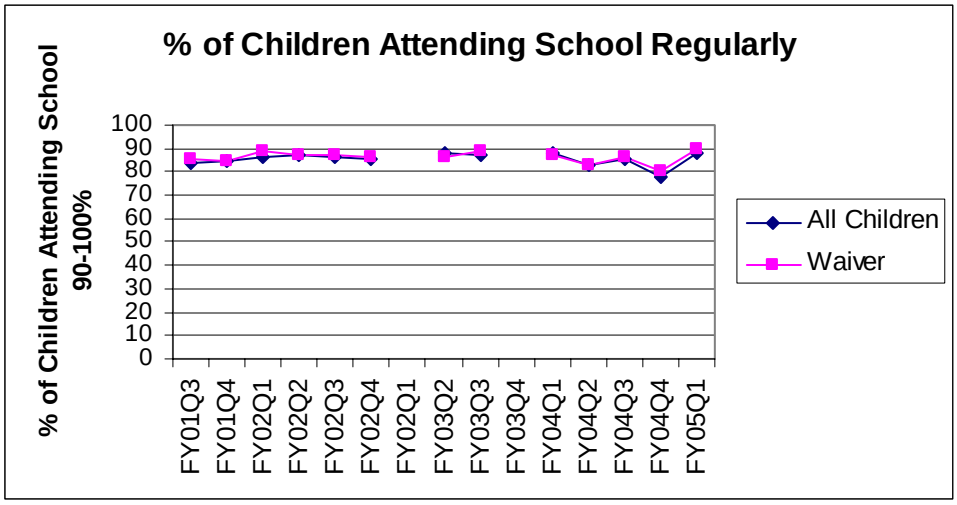
Chart 3. Children in a Permanent Home (%)



- As depicted on Chart 4, only slight differences were noted between children covered by the Waiver and all children on the outcome variable of School Attendance. Children on the Waiver had slightly higher school attendance.

- For example, for FY05Q1, 89.5% of children on the Waiver attended school regularly while 87.8% of all children attended regularly.

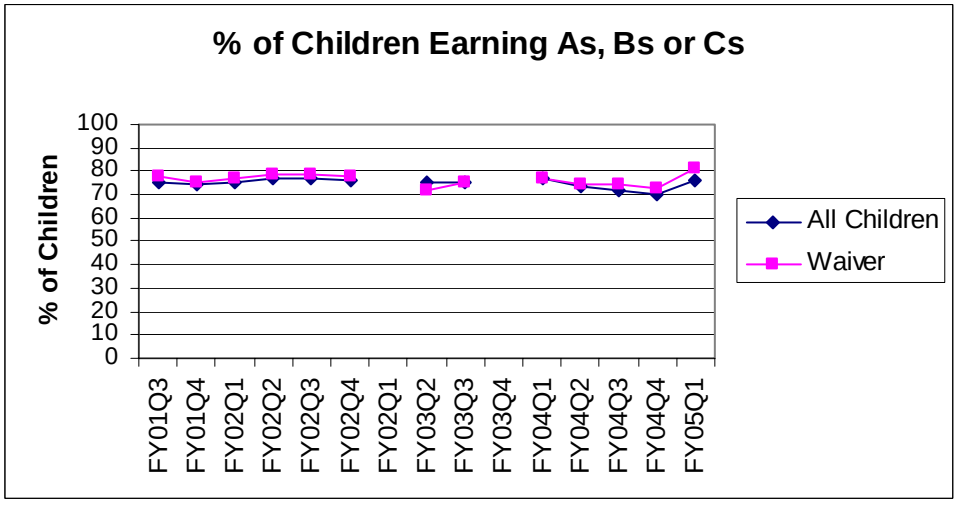
Chart 4. School Attendance (%)



- Per Chart 5, the outcomes on Academic Performance were similar between all children and children on the Waiver, with children on the Waiver demonstrating slightly higher achievement.

- For example, for FY05Q1, 80.8% of children on the Waiver had average or above average grades while 76.4% of all children had average or above average grades.

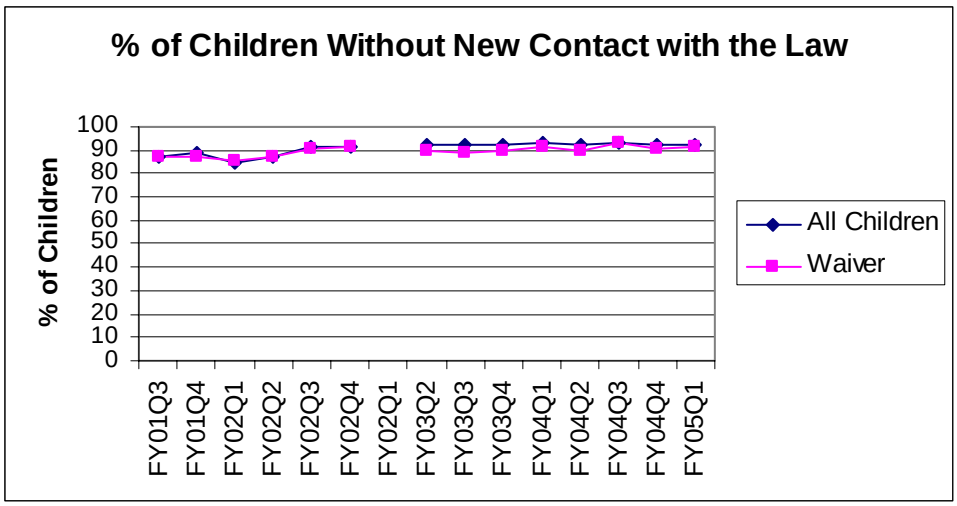
Chart 5. Academic Performance (%)



- Per Chart 6, the two groups of children demonstrated similar outcomes with regard to Law Enforcement Contact, with slightly more children not on the Waiver being without contact.

- For example, for FY05Q1, 91.2% of children on the Waiver were without Law Enforcement Contact while 92.6% of all children were without Law Enforcement Contact.

Chart 6. Law Enforcement Contact (%)



Findings of this study indicate that children served by the SED Waiver in the State of Kansas receive high quality services. **With regard to the CSR outcome variables of Residential Placement, Law Enforcement Contact, Academic Performance, and School Attendance, the children did extremely well. During the last quarter of observation, almost all children in the primary database were living in family homes; and a large majority of the children were without law enforcement contact, earned average or above average grades, and attended school regularly. When viewed over time, children whose services were covered by the Waiver did slightly better than all children on these four outcome variables, except law enforcement contact. Overall, the children demonstrated statistically significant improvement in symptoms as evidenced by the change in Internalizing and Externalizing CBCL scores from baseline to the last quarter of this study. These findings are noteworthy, particularly given that children on the Waiver are at greater risk of hospitalization than all children receiving CBS and required to meet a higher clinical threshold for eligibility into the program.**

Question B9: What are the reasons given for ending Waiver participation?

The AIMS 1555 database was used for findings presented in Table 31.

- The most common reason given for case closures was that service plan goals were met, with 29 cases (25.0%) falling in this category; followed by family/youth choice, with 24 cases (20.7%) falling in this category.
- The least common reasons were state hospital placement and loss of clinical or financial eligibility, both with eight cases (6.9%).
- In the records reviewed, details about the reasons for closure were often not provided.

Table 31. Reasons for Case Closure (N/%)

Reason for Case Closure	N	%
Service Plan Goals Met	29	25.0
Family/Youth Choice	24	20.7
Moved out of CMHC Catchment Area	20	17.2
Residential Placement	17	14.7
Lack of Cooperation	10	8.6
State Hospital Placement	8	6.9
Loss of Clinical/Financial Eligibility	8	6.9
Total	116	100.0

Question B10: What mechanisms are in place for monitoring safeguards and standards to assure that quality services are being provided children and families on the Waiver?

As indicated previously, each CMHC submits CSRs for each client served on a quarterly basis. The CSRs contain extensive fields for tracking that include data such as demographics, services provided, custody status, reimbursement sources, and educational placement. The CSRs also contain outcome variables such as Residential Placement, Law Enforcement Status, Academic Performance, School Attendance, and CBCL Scores. Quarterly reports, based on the CSR submissions, provide data that can be used for a variety of purposes, including quality assurance. Among the CSR report tables are those that specifically track the outcomes for children on the Waiver by CMHC.

The delivery of services for individuals on the HCBS SED Waiver are coordinated by the CMHCs. Each CMHC is licensed by the State of Kansas to ensure compliance with state

regulations. Social and Rehabilitation Services, Division of Health Care Policy (SRS/HCP) is responsible for licensing the CMHCs and the licensing is a function of the SRS/HCP Field Staff. Field Staff also provide quality assurance monitoring of CMHC operations, which includes the SED Waiver. Training and qualification requirements for service providers are established by policy through SRS/HCP and the State Medicaid Agency. SRS/HCP monitors service delivery through the prior authorization of the four Waiver services on all electronic Waiver Plans of Care. All individual service providers must meet state requirements specific to their profession, and completion of training requirements is documented at the CMHC. Each individual on the SED Waiver must meet clinical eligibility as determined by a Qualified Mental Health Professional (QMHP) employed by the CMHC. The QMHP also has responsibility for the oversite of plans of care. Technical assistance is provided to the CMHCs by SRS/HCP staff. Field Staff are assigned to specific CMHCs and provide a variety of services in addition to the licensing of the CMHCs, such as monitoring CMHC activity for quality assurance, and investigating complaints made about services rendered.

During executive and state level focus groups, the SRS/HCP community-based services program team and SRS/HCP Field Staff described quality assurances and monitoring system in place in Kansas for the Waiver. The quality assurance themes that emerged from the qualitative data and related items are bulleted below:

- **Overall**
  - There are several types of outcomes that are tracked, including CSR outcomes and aspects of consumer satisfaction. Both sources of data allow for separate analyses of outcome variables for children on the Waiver. The children are assessed to be doing well if the outcomes look good.
  - Access targets track the amount of time to get to the initial appointment and ongoing appointments.
  - Field Staff also review the CSR outcome data and if outcomes are low for a particular center, Field Staff will work with the center to create a performance improvement plan. Field Staff also work with centers on the results of the satisfaction survey.
  - CMHCs have contractual obligations to meet specific outcome standards – performance improvement plans can be created around these standards.
  - Penetration rates are monitored for each CMHC. The goal is for CMHCs will be within a certain range of the statewide penetration rate. SRS/HCP staff work with CMHCs that are very high or very low compared to the statewide average.

- Reports are generated on Waiver plans for each CMHC. The reports include the number of Waiver plans submitted, the number submitted inaccurately, and, when applicable, reasons for termination.

❖ **Field Staff Specific**

- Field Staff see their role as being one to help the CMHCs improve performance so that the system continues to show improvement.
- Field Staff handle local concerns through a grievance process. The issues expressed through this process are tracked separately for children on the Waiver.
- If several contacts are received about the same issue at the same CMCH, the Field Staff will work with the center on correcting the problem.
- Field Staff conduct licensing visits that include Waiver reviews at the CMHCs every two years.
- Field Staff assist centers with decisions about balancing medical necessity and the rights of the family.

❖ **Policy**

- There are exceptions in place for children who do not meet the set clinical eligibility standards but still appear to need the Waiver.
- The four Waiver services require pre-authorization, which is tracked on a center-by-center basis.

❖ **Education**

- SRS/HCP provides state-wide training to SRS local office staff and child welfare contractors on community-based services and how to access them. Field Staff believe these trainings have helped prevent out-of-home placements by increasing knowledge about which services are available to keep children in the home. They also attend parent advocacy and parent support meetings to hear concerns and help solve problems. Field Staff also attend meetings with families if there is a specific concern which needs follow-up with the center.
- When Field Staff see exemplary practices related to the Waiver, they share this information with other CMHCs. They also share information on evidenced-based practices.

❖ **Audits**

- Electronic Data Systems (EDS) (the fiscal agent) conducts regular service audits and has a team specifically for the Waiver. They audit documentation and billing information and review progress notes and medical necessity. They have also offered to do pre-audits in an effort to help CMHCs improve. These pre-audits would occur without a recoupment associated with them.

Question B11: What are the numbers and content of complaints filed with SRS/HCP Field Staff regarding children on the SED Waiver?

Evaluators requested and received the previous two years of data on complaints or "contacts" submitted to Field Staff regarding children on the Waiver for the state fiscal years 2003 and 2004. The findings presented in Table 32 are as follows:

A total of 29 contacts were recorded – 11 in FY03 and 18 in FY04. Although the numbers of contacts have increased, the number of children being served through the Waiver has increased as well.

In FY03, the 11 contacts were associated with six CMHCs. In FY04, the 18 contacts were associated with nine CMHCs.

The contacts can be filed with the Field Staff from anyone. It may be a parent or family member, another state agency representative, a community agency representative or a combination of those groups working together. As seen in the table below, the majority of contacts (51.7%) were made by consumers/parents/family members.

Table 32. Complaints Filed by Contact Source (n/%)

Source of Contact	Fiscal Year 2003 n	Fiscal Year 2004 n	Fiscal Years 2003 and 2004 n/%
Consumer, Parent, or Family Member	7	8	15 (51.7)
Agency Representative	3	3	6 (20.7)
State Agency Representative	0	2	2 (6.9)
Family Member/Parent and Other Agency Together	1	3	4 (13.8)
Blank	0	2	2 (6.9)
Totals	11	18	29 (100)

When a contact is filed, the concern is documented, and the performance issues are tracked. One contact can be about several issues. These data for children on the Waiver are summarized below in Table 33.

- For State Fiscal Years 2003 and 2004, a total of 29 complaints were filed.

- Of these 29 complaints, the highest number and percentage were categorized as pertaining to issues of Access/Availability with 19 complaints (65.5%), followed by Timeliness with 12 complaints (41.4%), and Continuity with eight complaints (27.6%).

- Of these 29 complaints, the lowest numbers and percentages were categorized as pertaining to issues of Prevention/Early Detection and Safety, with one complaint (3.4%) each.

- **It is noteworthy that no complaints were filed with regard to either Self-Determination/Client Choice or Competency.**

Table 33. Complaints by Performance Issue Category and State Fiscal Year (n/%)

Performance Issue Category	Complaints in Category FY 2003 n/%*	Complaints in Category FY 2004 n/%**	Complaints in Category FYs 2003 and 2004 n/%***
Access/Availability	8 (72.7)	11(61.1)	19(65.5)
Timeliness	3(27.3)	9(50.0)	12(41.4)
Continuity	4(36.4)	4(22.2)	8(27.6)
Appropriateness	3(27.3)	3(16.7)	6(20.7)
Effectiveness	1(9.1)	3(16.7)	4(13.8)
Respect & Caring	2(18.2)	2(11.1)	4(13.8)
Clients' Rights	0	2(11.1)	2(6.9)
Efficiency	0	2(11.1)	2(6.9)
Prevention/Early Detection	1(9.1)	0	1(3.4)
Safety	0	1(5.6)	1(3.4)
Self Determination/Client Choice	0	0	0(0)
Competency	0	0	0(0)

Complaints can fall into several categories; therefore, percentages total exceeds 100%
** Percentages based on number of complaints filed in fiscal year 2003 (11)*
*** Percentages based on number of complaints filed in fiscal year 2004 (18)*
**** Percentages based on number of complaints filed in fiscal years 2003 and 2004 combined (29)*

Definitions for above categories are given in the boxed area below:

Dimensions of Performance

Access/Availability: The degree to which appropriate services and supports are available to meet the consumer's needs.

Timeliness: The degree to which the services and supports are provided to the consumer at the most beneficial or necessary time.
Appropriateness: The degree to which the services and supports provided are relevant to the consumer's clinical needs.
Effectiveness: The degree to which the services and supports are provided in the correct manner to achieve the desired projected outcome for the consumer.
Continuity: The degree to which the consumer's services and supports are coordinated among disciplines, among organizations, and over time.
Safety: The degree to which the risk of an intervention and risk in the service environment are reduced for the consumer and others, including the provider.
Efficiency: The relationship between the outcomes and the resources used to provide client services and supports.
Respect and Caring: The degree to which those providing services and supports do so with sensitivity and respect for the consumer's needs, expectations, and individual differences.
Client Rights: The degree to which those providing services and supports articulate consumer's rights, promote the exercise of those rights, assure all staff are knowledgeable of those rights and treat consumers accordingly.
Self Determination/Client Choice: The degree to which the consumer participates in his or her own treatment and is offered choices in receiving services and supports.
Competency: The degree to which the service provider adheres to professional and/or organizational standards of care and practice, and is able to promote wellness and recovery as well as satisfaction of the consumer.
Prevention/Early Detection: The degree to which interventions, including the identification of risk factors, promote wellness and recovery and prevent disease.

In addition to the above grievance system, many CMHCs have their own quality assurance personnel to monitor quality and process consumers concerns. It should be noted that some families who have had involvement with social service agencies are reportedly reluctant to contact bodies such as SRS to file complaints. Therefore, the numbers provided in Table 33 above may be an under-representation of actual consumer complaints, or may reflect the CMHCs' ability to problem-solve before a formal grievance process is needed.

Question B11: What are the degrees of parental and youth satisfaction with the quality of care provided youth covered by the Waiver and those with other payees?

Kansas Consumer Satisfaction Survey (Family and Youth)

As depicted in Appendix A, both parents and youth reported high levels of satisfaction with CBS on the KCSS. There was little difference between the satisfaction of parents with youth whose services are covered by the Waiver and parents with youth whose

services are not covered by the Waiver. The percentages of parents and youth reporting high degrees of satisfaction are given. Mean scores are given on a scale from 0 to 4, with 0 indicative of Very Dissatisfied and 4 indicative of Very Satisfied.

When asked if they would recommend the CMHC to friends and family, 93.30% of parents with youth on the Waiver indicated they would while 90.70% of parents with youth not on the Waiver so indicated. Among parents of youth on the Waiver, 92.30% reported overall satisfaction with services while 89.40% of parents of youth not on the Waiver reported overall satisfaction with services. The overall satisfaction mean was 3.44 for both families on the Waiver and families not on the Waiver. Satisfaction with service providers was high and similar among both groups, with the most conspicuous difference in satisfaction being that parents on the Waiver were more satisfied (mean of 4.00) with respite care than parents not on the Waiver (mean of 1.58). On family-centered items, both groups of parents reported high satisfaction, with little difference between parents of youth on the Waiver and parents of youth not on the Waiver.

Although the overall quality of care outcome ratings for both groups of parents were high, statistically significant differences between the two groups served were found on three indicators. Parents on the Waiver reported significantly better outcomes than parents not on the Waiver on the following items:

1) As a result of services received, my child is better at handling daily life.
2) As a result of services received, my child gets along better with family members.
3) As a result of services received, my child is better able to cope when things go wrong.

With regard to youth satisfaction, both youth whose services are covered by the Waiver and youth not covered by the Waiver reported high levels of satisfaction with services. When asked if they would recommend the CMHC to friends and family, 87.30% of youth on the Waiver responded affirmatively, and 85.50% of youth not on the Waiver responded affirmatively. Among youth on the Waiver, 93.60% reported overall satisfaction with services while 90.90% of youth not on the Waiver reported overall satisfaction with services. The overall mean satisfaction of youth on the Waiver was 3.36; the overall mean of youth not on the Waiver was 3.27. Satisfaction with service providers was high among both groups, with one statistically significant difference. On the item "Worker does not talk too much about past and what happened a long time ago," 90.60% of youth not on the Waiver were satisfied (mean 3.61) and 81.10% of youth on the Waiver were satisfied (mean 3.32).

With regard to medications, youth covered by the Waiver were significantly more satisfied than youth not covered by the Waiver on two items: 1) how their medications were working and 2) "Does [your] doctor/nurse ask about how medications make you feel." Of the youth on the Waiver, 77.90% reported taking medications for mental health

reasons compared to 72.30% among youth not on the Waiver, which could be a feature of the higher levels of acuity among youth on the Waiver than those who are not.

What Did the Parents Say?

From site-visit focus groups **with parents who were volunteer participants, themes that emerged and intertwined** included **worry and distress, satisfaction with CMHC services, and the relief families experience** as a result of the Waiver.

Parents spoke poignantly about the helpfulness and quality of services covered by the Waiver that were received at CMHCs. One parent said the whole family was *"worn out and torn apart"* and CBS *"brought peace to the family where we can live a normal life."* Another representative quote is:

> *This place [CMHC] has been wonderful, absolutely wonderful. I cannot say enough good things about the mental health center or the people working here. They have been a Godsend.*

Parents **shared success stories about their children** as a result of receiving Waiver services. One parent described her daughter as a *"very difficult child and wonderful daughter"* who had many problems in school. Teachers had given up on her, doubting she would be able to *"dig herself out of her hole."* To the teachers' amazement, the youth started doing very well, graduated from high school, and was pursuing additional education.

Along with parental satisfaction with the quality of services received, in various ways, parents expressed their **concerns about what might happen to their children without Waiver services**. Some thought their children would have become "throwaway kids" in a society that does not know how to deal with them. They feared their children would end up in the court system, the hospital, or residential care. One mother described a daughter *"headed toward trouble"* who had learned social skills and was now *"able to make friends and keep them"* because of Waiver services. The mother concluded by saying *"No matter what you believe in, hope that we can stay on the Waiver for my daughter's sake, so she will be able to continue turning into the great person she is inside."*

Parents had very positive things to say about CMHC services and service providers. Parents value case management, parent support, attendant care, family therapy, and respite care. No parent focus-group participants had negative comments about CMHC services or service providers. Case managers were described as "angels" and "Rocks of Gibraltar." Of a case manager, one parent said, *"She goes way beyond to help in any way she can."* Another parent who felt school personnel considered her a bad parent who couldn't control her child, said their case manager *"helped the teacher*

understand." Respite care was cited as "a lifesaver." One parent described parenting her child alone while helping her husband who was in a nursing home and added, *"You wear yourself down and need a little break once in a while."*

Parents value the parenting classes provided by **Parent Support Specialists.** One parent said he thought that if his daughter went to the hospital for a week or ten days, they would *"fix her"* only to discover that soon the family would be back at *"square one"* without the benefit of stabilizing CBS. This introspective parent *"embraced"* the changes the CMHC was able to help the family make *"in the home as well"* and praised the parenting skills learned from the center's Parent Support Specialist because **children are *"not born with instructions on their backside."*** Another parent described their learned parenting philosophy, saying:

> *When your kids have trouble you want to be protective because you think they're not going to be able to deal with all that's coming at them. Then you realize you can't be so protective, that you have to let them learn that decisions have natural consequences. Kids are very resilient. You try to put them under your wing and make sure the world doesn't get to them, but the best thing you can do is let the world get to them.*

Medication services and payment for medications were seen as important and one key to keeping children in the community. Parents expressed concern about losing this medication coverage. Some parents reported living in fear of their children being hospitalized or going to jail because when they miss medications, *"you have kids who are sick, doing things they wouldn't ordinarily do, getting into all kinds of trouble."* With the Waiver, how to pay for medications is one less thing to worry about. One parent was relieved and able to say, *"Whew, I don't have to worry about that."*

Parents discussed working hard to pay bills and buy groceries. Many parents reported that without the Waiver, they would be deeply in debt, especially for prescriptions. Prior to being placed on the Waiver, a single parent faced a $400.00 bill when they went to pick up their son's monthly medications. So, the parent picked up a few tablets, went home, and anguished about how to get the rest of the prescriptions.

One mother said as a result of the Waiver ***"a lot of the stress is gone."*** She described always being anxious and worried about how to pay for medications. Even with insurance, the family couldn't afford the large monthly co-pay for their child's prescriptions. If a prescription had to be changed, an additional co-pay expense was incurred.

The dynamics of one family were explained by the mother. This mother of a child who had recently been placed on the Waiver said, ***"It has been a lifesaver.*** *My husband got laid off, so we would have really been in trouble. Before we had insurance but it only paid so much. One trip to the hospital for our son exhausted all our mental health for a*

year. And he has to have his medications. I would go without my medicine so he could have his." The child had just gotten his sixth medications refill and the family was starting to feel *"more secure."* The mother stated, *"We will be paying off the hospital bill forever, but even though my husband got laid off, we're seeing a little bit of daylight."* Of the necessary medications the parents need, the mother said, *"If we didn't have enough to pay the co-pay, we [parents] would go without."* She reported that the father was taking blood pressure medication. She said that he could become explosive when his blood pressure was high, which affected the whole family system, including the child.

A Parent Support Specialist explained these systemic interactions:

> *A lot of times when parents are in very stressful situations, they know that mental health will never turn their backs on them, but, as parents, they usually feel responsible. I find that when this burden is taken off their shoulders, they start taking better care of themselves, they start smiling more, and the children start getting better, too, because that stress affects the kids.*

What Did CMHC Direct Service Providers Say?

In focus groups during site visits, all CMHC direct service providers described the Waiver as **extremely valuable** for a variety of reasons. Themes about the Waiver's value that emerged from the qualitative data and intertwined include its:

- **financial component**, **paying for medications** and **services**,
- the **relief parents experience due to medication and service coverage**
- the **helpfulness of services provided,**
- the **acuity of children served,**
- the **helpfulness of wraparound meetings**, and
- the **desirability of maintaining children in the home and community with CBS**.

Underlying these themes was a **family-centered, strengths-based philosophy.**
The Waiver was described as **extremely valuable** by all staff members due to **fiscal considerations. These considerations were particularly applicable with regard to the cost of medications** and the **relief parents experience** from concern about how or if they can pay for their children's medications. One service provider said parents are, *"able to get that [concern about paying for medications] out of the way so they can actually deal with what's going on in the family or with their child."* Staff members described the Waiver as both a blessing and a curse, explaining that parents become anxious and are reluctant to get off of the Waiver because they cannot, otherwise, pay for their children's medications.

Most service providers described the **services** provided under the Waiver as a source of **relief for parents.** One staff member said, *"This mother was finally able to take a deep sigh of relief, knowing that finally she has some support. She doesn't feel so alone and…has some space for herself and to regroup."* Attendant care, respite care, and parent support were cited as particularly helpful. CMHC staff described parents as extremely grateful for services covered by the Waiver and supported these services as being provided to **children with severe conditions most at risk for hospitalization**. A representative quote is:

> *Parents who get extra services [respite, attendant care, parent support] are so grateful.* ***They're the families that need that extra support, with the most difficult children.***

All service providers discussed the **desirability of community-based services** under the Waiver. One service provider pointed out that CMHCs want to keep children *"as close to home as possible;"* adding *"That's part of our mission, to deliver services to all children and their families, as close to their home as possible."* Another staff said, *"I think it [the Waiver] is* ***extremely valuable*** *because a lot of the kids that are on the Waiver would not be able to afford the* ***intensive treatment they need to be maintained in the home."***

Most staff cited **wraparound meetings** as an important part of the service provision process. Meetings were described as a venue for getting everybody on the *"same wave length."* Families were described as looking forward to meetings, which give them an opportunity to focus on their children and have their voices heard. A service provider said:

> *With the team aspect there are lots of people, there's lots of input. The family is involved and it just seems to run smoother when we know we have meetings and the family knows they have them and the child knows they have them. It provides the formality that a lot of people need, the structure that's necessary to keep people going and on task.*

One service provider who cited the **strengths-based** aspect of wraparound meetings as helpful described the process of conducting a **strengths assessment** that gives him *"an overall picture of what a child needs in the* ***community…*** ***with the family,"*** concluding that this **process helps give direction to service planning.** Others liked the fact that services are individualized in this planning process.

One staff member found wraparound meetings particularly helpful in **building relationships and promoting understanding with other services systems and community members**, indicating *"It is neat to get to see a lot of community people working with a family. On one team we have a pastor and a police officer on another. It's neat to get to see their roles and they see mental health roles.*

COST NEUTRALITY

Cost Neutrality

Question C1: What is the average annual cost for the delivery of CBS per child for children covered by the Waiver, and how does this cost compare with the yearly cost of hospitalization ?

Using data reported on the **HCFA 372 annual report for the Kansas SED HCBS Waiver**, cost neutrality has been documented in Table 34 as follows:

- For the time period between 10/01/02 and 09/30/03, the average annual cost of services covered by the Waiver per child was $13,587.35. For the same time period, the annual cost of mental health hospitalization per child was $26,236.00.
- For the time period between 10/01/01 and 09/30/02, the average annual cost of services covered by the Waiver per child was $13,331.04, compared to hospitalization cost of $25,596.00 during the same time period.
- For the time period between 10/01/00 and 09/30/01, the average annual cost of services covered by the Waiver per child was $4,613.00, compared to hospitalization cost of $24,972.00 during the same time period.

- The cost of Waiver services given includes both physical and mental health care provided the children.

Table 34 . Cost of Services Covered by Waiver and Cost of Mental Health Hospitalization

Time Period	Report Type	Unduplicated Waiver Recipients Served N	Cost of Waiver Services (Factor D and Factor D' Combined*)**	Cost of Hospitalization (Factor G and Factor G' Combined*)
10/01/02 – 09/30/03	Initial	1,563	$13,587.35	$26,236.00
10/01/01 – 09/30/02	Lag	1,269	$13,331.04	$25,596.00
10/01/00 – 09/30/01	Lag	1,151	$4,613.00	$24,972.00

*** Waiver costs include medical health care expenses as well as mental health care cost.*

The fourth year of the renewal period (10/01/03 – 09/30/04) was not be available in time for inclusion in this report.

Text in boxes below taken from HCFA 372 annual report

*The requirement for the waiver is that the costs for **Factor D plus Factor D' must be less than or equal to the costs for Factor G plus Factor G'**. These items are described below. These

definitions are from the Medicaid Home and Community-Based Services Waiver Streamlined Renewal Format. The page numbers are listed after the definition.

Factor D is the estimated annual average per capita Medicaid cost for home and community-based services for individuals on the waiver program. (p. 12)

Factor D' is the cost of all State plan services (including home health, personal care and adult day health care) furnished in addition to waiver services WHILE THE INDIVIDUAL WAS ON THE WAIVER. [Also], the cost of short-term institutionalization (hospital, NF, or ICF/MR) which began AFTER the person's first day of waiver services and ended BEFORE the end of the waiver year IF the person returned to the waiver. (p. 15)

Factor G is the estimated annual average per capita Medicaid cost for hospital, NF, or ICF/MR care that would be incurred for individuals served on the waiver, were the waiver not granted (p.17).

Factor G' is the cost of all State plan services furnished WHILE THE INDIVIDUAL WAS INSTITUTIONALIZED. [Also], the cost of short-term hospitalization (furnished with the expectation that the person would return to the institution) which began AFTER the person's first day of institutional services (p. 18).

Service Package

The MMIS database was used to procure data held in Table 35. The MMIS Data were analyzed to see in what dollar amount, time amount, and for what number of children a mental health "community" service package was delivered for two different time frames during the Waiver renewal period. As indicated in the methodology section, services were billed as either Service Units or Time Units. Service Units were billed as units of service regardless of the amount of service-provision time (i.e., Pharmacological Management and Case Consultation). Time Units were time-dependent and billed according to the amount of service-provision time (i.e., Case Management and Individual Community Support). The purpose of the analysis was to obtain a statewide perspective, not to evaluate individual CMHCs.

Table 35 . Service Procedure Codes

Procedure Code	Procedure Label	Type of Service
90782	Medication Administration	Billed as Service Unit
90847	Family Therapy	Billed as Service Unit
90853	Group Therapy	Billed as Service Unit
90862	Pharmacological management	Billed as Service Unit
99244	Case Consultation	Billed as Service Unit
99245	Case Consultation	Billed as Service Unit
Y9114	Med Review by RN	Billed as Service Unit
Y9514	Psychiatric Preadmission Assessment (max 3 hours)	Billed as Service Unit
Y9569	Behavioral Management Readmission Assessment (Screen for L6) max 3 hrs	Billed as Service Unit

Procedure Code	Procedure Label	Type of Service
90805	Individual Therapy (20-30 minutes)	Billed as Time Unit
90806	Individual Therapy (45-50 minutes)	Billed as Time Unit
90807	Individual Therapy (45-50 minutes)	Billed as Time Unit
90808	Individual Therapy (75-80 minutes)	Billed as Time Unit
90810	Individual Therapy (20-30 minutes)	Billed as Time Unit
90812	Individual Therapy (45-50 minutes)	Billed as Time Unit
90826	Individual Therapy (45-50 minutes)	Billed as Time Unit
W1304	Adolescent Partial hospitalization	Billed as Time Unit
Y9111	In-home Family Therapy	Billed as Time Unit
Y9116	Partial hospitalization activity	Billed as Time Unit
Y9117	Targeted Case Management	Billed as Time Unit
Y9118	Community Supportive Psychiatric Treatment	Billed as Time Unit
Y9119	Individual Community Support (ICS of AC)	Billed as Time Unit
Y9544	Mental Health Attendant Care	Billed as Time Unit
Y9565	Child & Adolescent Psychosocial	Billed as Time Unit
Y9570	Behavioral Management Readmission Assessment	Billed as Time Unit
Y9700	Wraparound	Billed as Time Unit
Y9701	Independent Living	Billed as Time Unit
Y9702	Parent Support	Billed as Time Unit
Y9703	Respite Care	Billed as Time Unit

As indicated in Table 36, the delivery of Waiver services grew between the two years under study.

- The total number of children served increased by 75%.
- The total dollar amount for services delivered increased by 95%.
- The total number of hours increased at the same rate as the increase in children served (76%).
- The average cost per child for this group of procedure codes was $8,340 in FFY01 and $9,261 in FFY03, an 11% increase.
- The average hours spent per child for services paid as Time Units (dependent on a specific service-provision time interval) went from 202 in FFY01 to 211 in FFY03, relatively unchanged.

The fact that the average cost per child increased between the two time periods without seeing a similar increase in the average number of hours is most likely a reflection of the increased reimbursement rate for several of the more critical procedure codes, such as case management, attendant care, and the four Waiver services.

Table 36. Service Delivery

	Federal Fiscal Year	
Category	**2001**	**2003**
Unduplicated Count of Children Receiving These Services*	1,237	2,167
Total Reimbursed Amount Spent for this Service Package	$10,316,314.72	$20,067,554.20
Mean Reimbursed Amount of Service Package per Child	$8,340.00	$9,261.00
Total Units of Services Delivered (billed as both service unit and time unit)	250,317.15	457,285.69
Total Service Units Delivered (billed as service unit, regardless of time spent)	41.79	164.55
Total Time Units Delivered (based on service-provision time intervals)	250,275.35	457,121.14
Mean Number of Hours of Time Units (based on service-provision time intervals) Delivered per Child	202	211
Total Hours Spent for Services Billed as Service Units and Time Units Combined	204,100.15	358,737.10

**This number was totaled from each CMHC and therefore, could contain a double count for children who have moved between CMHCs.*

The costs for this package of "community" procedure codes analyzed for this study were compared to all Waiver costs (including physical health cost) and to hospital costs, as documented by the FFY03 HCFA report.

- The average annual per capita cost of both physical and mental health care was roughly half the average annual per capita cost of hospitalization.

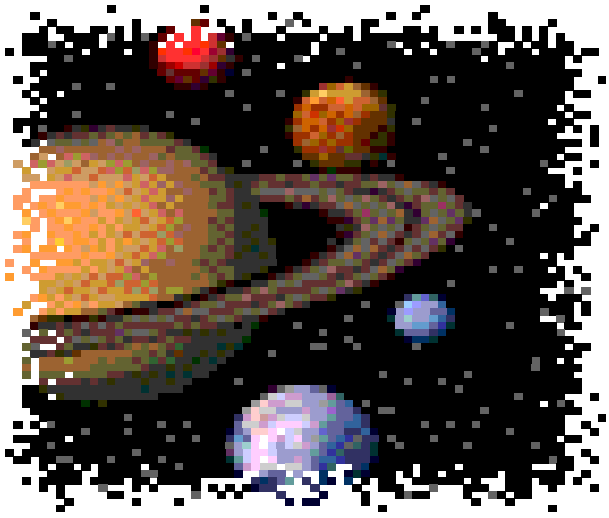
- The average annual per capita mental health costs for this group of children with intensive needs comprised roughly 68% of their total Medicaid costs and were slightly over one-third the average annual per capita cost of hospitalization.

Table 37. Community Mental Health Service Costs Compared to Total Waiver Costs

	Average per capita cost for *"community" mental health* procedure codes for children on the Waiver	**Average per capita cost for all Medicaid expenditures for children on the Waiver**	**Average per capita cost of hospitalization**
FFY 2003	$9,261	$13,587	$26,236

Based on the above amounts of service units and expenditures, as well as the number and percentage of children without hospitalizations and/or re-hospitalizations, previously discussed, children on the Waiver are receiving the necessary levels of service needed to maintain them in their homes and communities, per the intent of the Waiver. Clearly, the cost for maintaining children in their homes and communities through the provision of CBS is cost effective, and significantly less expensive than the cost of hospitalization.

SYSTEMIC DYNAMICS RELATED TO THE WAIVER



Systemic Dynamics Related to the Waiver

Question D1: What improvements in the mental health system of care have occurred as a result of the Waiver?

Questions D1was addressed with the qualitative data from the executive and state-level focus groups, unless otherwise specified. Stakeholders include CMHC administrative staff, encompassing Executive Directors and Children's Directors, the SRS/HCP community-based services program team, and SRS/HCP Field Staff. Findings from the data are presented in an aggregated form, from which several themes emerged. These themes and bulleted points are given below:

- **Increased Community Resources and Services**
  - Array of Services: CMHCs have a broader array of services from which to choose and a way to bill for these services. Ten years ago the choices were therapy, medication, and hospitalization.
  - Infrastructure for System of Care: The infrastructure for the system of care has expanded. The funding coming into the CMHCs through the Waiver has allowed the centers to build services. This capacity and array of services ultimately benefit all children who need mental health care. However, it is important to understand that the Waiver is successful as a part of the system of care in Kansas and includes not only the four Waiver services but the entire array within the state plan.
  - Parent Support and Wraparound: Parent support and wraparound services are provided to children not on the Waiver at most CMHCs.
  - Services Make a Difference: The evidence that these services are making a difference can be seen in the fact that the costs for the Waiver have doubled but the overall costs for Medicaid have stayed stable, despite rate increases in 2001. It also indicates that natural supports are being used.
  - Increased Access: Many families have increased access to mental health services. More children are being served due to this increase. In Addition, when the financial barriers are lessened, the parents are more likely to engage in treatment and may even seek out services they need for themselves.
  - Increased Awareness: Individuals have an increased awareness of mental health services. Even when families come off the Waiver, they are empowered and know how to advocate for their needs.

- **Improvements in Outcomes**
  - Hospital Stays: The lengths of hospital stays have decreased. Although overall admissions have gone up in line with the expansion of CBS, the average stay is shorter. Hospitalization is now about stabilization; kids aren't growing up in state hospitals anymore.
  - Keeping Children in the Community: Without the Waiver, there would be more children in juvenile justice, foster care and in the hospital for longer periods of time. There would be more suspensions, more referrals to alternative educations and higher High School drop out rates. Parents have specifically reported that without the Waiver, their child would be hospitalized or placed in state custody. The content of the improvement cited here is congruent with what parents said in focus groups, delineated on page 62 of this report.

- **Changes in Specific Services**
  - Wraparound: Wraparound has become a philosophy for the Kansas system, rather than just a service. Most CMHCs are providing this service to all children, not just those on the Waiver.
  - Parent Support Specialists: Parent Support Specialists are able to support families at team meetings and at meetings in the community (e.g., Individual Education Plans). They successfully re-emphasize the parent perspective. Parent Support Specialists can support case management services, allowing case managers to spend more time with the children. They have also taken on crisis resolution with parents and they are often the first point of contact in crisis situations. For some parents, they function as a "warm line."
  - Respite: The development of respite for all children has grown.

- **Changes in Culture**
  - Service Provision: The Waiver has helped shift the culture from outpatient clinical work done at the office to CBS. There is more of a focus on case management and the functional needs of children and families.
  - Collaboration: The Waiver encourages stakeholders to talk to each other and promotes collaboration.
  - Staff and Schools: Staff works more as a team and involves the schools more often.
  - Family-Driven Services: A parent support network has been created. There is an increased focus on services being family-driven. For example,

families are now participating in the Association of Community Mental Health Center's committees.

- Earlier Intervention: As a result of receiving intervention earlier, the youth's conditions are improving. However, some young adults are falling through the cracks because they do not meet the adult SPMI criteria. Although the youth function well with supportive services, many with threshold conditions need continued support as adults, which is not readily available if they do not meet the adult SPMI criteria.
- Continuity of Care: There is more continuity and treatment following the children.

❖ **Fiscal Implications**

- Enhanced Options: The Waiver has enhanced options for children with private insurance, for whom services other than therapy, medication management and hospitalization were not reimbursable. This has allowed a population to receive services who otherwise wouldn't.
- Prescription Drug Coverage: Coverage for prescription drugs has been an important part of preventing hospitalization, although medication is needed long term to keep the children stabilized.
- Family Finances: The Waiver has allowed some children to get services without their causing significant financial hardships for their families (e.g., bankruptcy).
- Family Relief from Stressors: Families on the Waiver are dealing with children with challenging behaviors. The Waiver assures a payment source for the services their child needs and allows the family to deal with the other stressors in their lives that come with having a child with SED who is at risk for hospitalization. Families are more likely to seek services their children need if the financial barrier has been removed.

Question D2: What are the barriers and challenges related to service provision under the Waiver?

Question D2 was addressed with qualitative data from the executive and state-level focus groups, unless otherwise specified.

❖ **Policy**

- Parent Fee: The Parent Fee is a barrier for some families. There are some families who choose not to utilize the Waiver because of the fees although data are not readily available to track this.

- Eligibility: If a family has two children and one is on Healthwave (Kansas State Children's Health Insurance Program) and then the other child becomes eligible for the Waiver, the child on the Waiver is considered to be institutionalized. This consideration can be significant because the "institutionalized" child is no longer calculated in the family ratio and therefore, the "smaller" family size may no longer qualify for Healthwave. When this situation occurs, the family ultimately has to decide which child gets coverage.
- Flex Funding: There is a lack of non-categorical/flex funding. This funding would be helpful for items such as home modifications and technology assistance.
- Respite Hours: The cap on respite hours is a barrier.

❖ **Paperwork**

- Family Stress: The paperwork associated with the Waiver can be a stressor to families struggling to keep their children at home. Some centers support families through this process but this is an area where continued growth would be beneficial.
- CMHC Paperwork: Paperwork can be a barrier for center staff. Centers have to estimate how many hours of each service will be needed on the plan of care. If they overestimate to allow for the flexibility that is needed to serve this population, they are held accountable for providing what is on the plan of care. However, if they estimate low and more is needed, then the plan of care must be amended.
- Completion of Paperwork by SRS:
    - In some areas, there have been problems with the required Waiver paperwork being completed by SRS in a timely manner or that having been lost.
    - At meetings, CMHC staff cited delays in prior authorization of Waiver services as problematic and indicated that the Waiver position needs to be filled.*

**In another study being conducted for SRS/HCP on children receiving CBS, staff members at several CMHCs cited delays in getting Waiver paperwork completed by SRS as problematic.*

❖ **Community**

- SRS and Local CMHCs: Coordination and communication between SRS and local CMHCs could reportedly use improvement in some areas. For example, timing of the financial and clinical eligibility components for being placed on the Waiver is sometimes not coordinated. Local SRS offices sometimes complete the financial eligibility determination without advising the local CMHCs that the fiscal determination has been made.

- Professionals in the Community: Some professionals in the community who are working with families do not refer the children to the Waiver. It may be because they aren't aware of CBS or the Waiver because the these services are not "on their radar screen."

- School Systems: Some school systems do not cooperate well with CMHCs. For example, they reportedly do not want mental health professionals to come into the classroom.

- Foster Care: There is difficulty tracking children in foster care due to the frequency of placement moves.

❖ **Education**

- Misconceptions about the Waiver: Some community agencies have misconceptions about the Waiver. Some confuse the process with the Kansas MR/DD Waiver while others mistakenly think that the Waiver is required to access CBS. Some think that eligibility for SED and Waiver are the same. Continued education is needed.

- Medical Necessity: Parents do not understand the specifics of the Waiver and CBS. For example, there are misunderstandings about medical necessity with the Waiver. It is important to outline from the very beginning that Waiver services and eligibility will not be provided on an ongoing maintenance level. The families have to be in "dire straits" to become eligible, then they find some stability and do not want to risk going back to the point they were before. Some families see the Waiver as an entitlement. There is a need to clarify medical necessity.

❖ **Dual Diagnosis (MR/DD and MH)**

- MR/DD and SED Waivers: The interface between the MR/DD and SED Waivers needs clarification, particularly for children with the Autism spectrum disorder.

- Children with Dual Diagnoses: Some children who are dually diagnosed (MR/DD and MH) are falling between the cracks of the two Waivers. Other children who would be better served on the MR/DD Waiver but due to waiting lists, choose the SED Waiver. HCP is considering a way to expand service coverage to catch the children with higher cognitive abilities that do not meet the criteria for the MR/DD Waiver. However, there are services that the children with MR/DD need that are not available on the SED Waiver.

❖ **Services**

- Service Definitions: The service definitions are broadly defined in an effort to allow local areas to tailor services into their specific needs. However, this dynamic can have a reverse effect, when some CMHCs implement the services more narrowly out of a concern of being audited.

- Staffing: Staff shortages due to difficulties in recruitment, training, and retention are evident and most problematic with attendant care and respite. One barrier to hiring these staff members is reported to be the low reimbursement rate, which makes the salary lower than what individuals can make working at a fast food restaurant. There is also a need for more formal training for respite care workers.

- Respite Care Licensing: The lack of licensed homes for respite care is a barrier as is the difficulty in developing a respite program due to licensing issues and other "red tape."*

- Respite Care Settings: The place of service for respite is a barrier. Families have to leave their homes to get respite since it can only be provided in the home or in a licensed facility.

- Service Availability: The unavailable of certain services when they are needed and provided in the manner that would be most helpful (i.e., respite and attendant care) is problematic. Having the specific kind of attendant care person desired (i.e., male or African American) is also difficult at times.

- Independent Living Billing: Independent living services are not billed under that code. Rather it is usually provided through other codes such as case management and psychosocial, making it hard to track the use of independent living services.

**In another study being completed for SRS/HCP, parents sited barriers to receiving respite care related to KDHE licensing that they considered unreasonable. For example, respite could not be provided in a home because the ceilings were slightly less than eight feet high.*

- Wraparound Billing: Since wraparound is delivered to many children not covered by the Waiver, a question was raised about the possibility of including this service in the regular Medicaid code.

- Parent Support Specialist Requirements: Parent support specialists' requirements are a barrier in low population areas making it hard to find individuals with the required credentials.

- Geographic Distances: There are difficulties overcoming large geographic distances to provide home-based services.

- Delayed Service Provision: Some services, such as respite, are included in treatment plans but are not provided.

- Wraparound Implementation: Wraparound meetings have not always been provided in the ideal – either they did not occur, occurred but the family did not feel listened to, had not occurred for a long time, occurred only in response to a problem instead of being proactive or only involved a small number of people (e.g., parent and case manager only).

- One participant reported that the Waiver has removed barriers – it "keeps children from crashing and burning."

❖ **Insurance Companies**

- Private Insurance Coverage: The Waiver has to use public dollars to pay for CBS to prevent hospitalization that private insurance companies choose not to provide. Some private insurance companies drop coverage when they realize a child is on the Waiver. Some will not authorize therapy hours because they know the Waiver will provide it.

- Medical Necessity: There are some reports of private insurance companies encouraging families to go onto the Waiver so they don't have to pay for costs. However, this has had a negative unintended consequence for the child. When Medicaid officials see that the insurance company has refused authorization, they often interpret it as though the service is not medically necessary.

- Education: More education of private insurance companies is needed.

❖ **Financial**

- Services for Parents: Some parents need services but can't afford them and the Waiver only covers the child or children.

- Fear of Losing Waiver Coverage: Some parents are dissatisfied when they are told their child has met the goals of the plan and will be taken off the Waiver. The parents are concerned about losing the services and medical benefits that allowed their child to stabilize.

- Medication Coverage: When a child comes off the Waiver and does not qualify for regular Medicaid, the family's ability to pay for the medications that helped the child to stabilize is severely compromised. Some families with private insurance (with prescription coverage), cannot afford the co-pay. A "meds only" medical card has been suggested.

SUMMARY
CONCLUSIONS

Summary/Conclusions

Access to Care

The Waiver is intended to serve children with clinically significant problems and intense needs who are at risk for hospitalizations. Findings of this evaluation indicate that this target population in the State of Kansas is being served under the Waiver, per its intent as a hospital diversion program. The children had a variety of identified strengths and diagnoses. The children whose services are covered by the Waiver had high acuity levels, as evidenced by clinically significant Child Behavior Checklist (CBCL) scores and higher CBCL scores than all children receiving community-based services (CBS) over the Waiver renewal period. Almost a third of the children in this study had previous hospitalizations. Children covered by the Waiver in the State of Kansas have severe mental health conditions and are at risk of hospitalization, per the Waiver's intent as a hospital diversion program. The children's access to CBS that maintain them in the home and community is demonstrated by their outcomes described in the Quality of Care section of this report and the fact that few children with previous hospitalizations had been recently re-hospitalized. It is unclear whether some children are unable to access services due to the Parent Fee.

Quality of Care

Findings of this evaluation indicate that children served by the SED Waiver in the State of Kansas are receiving high quality care, evidenced, in part, by services found to be strengths-based, family-centered, and delivered through a wraparound model. Some variability with regard to the documentation of fidelity to the wraparound model was noted in progress notes of the records reviewed. Whereas some centers excelled in the documentation of meetings in their paperwork, others were weaker in this area. This dynamic could be a feature of less emphasis being placed on paper work at some centers or a lack of fidelity to the model in the implementation process at some CMHCs. A few stakeholders said wraparound meetings are not always held per the intent of the model.

School representatives and natural supports as team members are considered integral to service delivery. School personnel were members of over half of the wraparound teams. Natural supports were members of almost two-thirds of the wraparound teams.

With regard to the CSR outcome variables of Residential Placement, Law Enforcement Contact, Academic Performance, and School Attendance, the children did extremely well. **During the last quarter of observation, almost all children were living in family homes; and a large majority of the children were without law enforcement contact, earned average or above average grades, and attended school regularly. When viewed over time, children whose services are covered by the Waiver did better than all children on these four outcome variables, with the exception of law enforcement contact. Overall, the children showed statistically significant improvement in their**

clinical conditions as indicated by the change in Internalizing and Externalizing CBCL scores from baseline, near the time of intake, to the last quarter of this evaluation. **These findings are noteworthy, particularly given that children on the Waiver are at greater risk of hospitalization and required to meet a higher clinical threshold for eligibility into the program than all children receiving CBS.** The effectiveness of CBS in maintaining children in the home and community is also highlighted by the fact that few children with previous hospitalizations had been recently re-hospitalized.

Cost Neutrality

A condition of the Waiver is that services provided under the community-based plan must cost less or no more than the cost of hospitalization. **The average annual cost of CBS for children covered by the Waiver was roughly one-third the average annual cost of hospitalization. The average annual per capita cost of both physical and mental health care provided these children was roughly half the average annual per capita cost of hospitalization. Clearly, the cost for maintaining children in their homes and communities through the provision of CBS is cost effective and significantly less expensive than the cost of hospitalization.**

Based on the amounts of service expenditures, number and percentage of children without hospitalizations and/or re-hospitalizations, and CSR outcomes, children on the Waiver are receiving the levels of services needed to maintain them in their homes and communities, per the intent of the Waiver. Both parents and direct service providers emphasize the desirability and importance of maintaining children in a home and community setting to promote their current well-being as well as their developmental readiness for successful adult living. **The value of this program is not only in the cost savings of CBS compared to hospitalization, but also in the quality of life and the experience of being in a supportive home and community environment.**

Systemic Dynamics Related to the Waiver

The reports of stakeholders described in this report are summarized as follows:

The SED Waiver has had a positive impact on the mental health system of care in the State of Kansas. Not surprisingly, some barriers and challenges related to providing high quality services for children covered by the Waiver were identified, and described in this evaluation. CMHC administrative staff have expanded their service capacity and made accommodations where called for, candidly indicating limitations on their ability to do so in some circumstances**.**

RECOMMENDATIONS

Recommendations

- First, CMHCs in the State of Kansas should be recognized and commended for the exemplary work they do and the difference they make in the lives of children and families.

- During the intake process into the Waiver program, it is recommended that CMHCs utilize a consistent practice to explain and emphasize to parents that they have a choice between hospitalization and CBS. A state-wide brochure could be developed to provide an overview of the program; what to reasonably expect; details about what services are available and how they are to be delivered, including information such as the frequency of wraparound teams; and who to contact with questions or concerns.

- Trainings for CBS Directors and Coordinators are needed every one to two years, as a refresher and to provide details for new staff. For example, content could include explanations about how often wraparound meetings are to be held, who should be in attendance, and how meetings are to be documented.

- Explore options for providing post-Waiver medication support, such as a type of Medication-Only Waiver coverage, as a part of maintaining the stability of children who have been stabilized as well as making room for serving other children in need.

- Conduct a study to examine the impact of the Family Fee. This study could identify the number of families for whom the fee is a financial hardship; whether data already exist that identify how many families are not pursuing the Waiver due to the fee; and to what extent some families are not pursuing the Waiver because of the cost and are, therefore, not appearing in the data analyses.

- According to Davis, Logan, Petr, and Walter (2004) CMHCs that successfully recruit and retain Attendant Care Workers (ACWs) employ a variety of tactics. For example, CMHCs utilize Parent Support Specialists to engage parents, implement “shadowing” into the training program, and increase knowledge within the center about what ACWs can do. Centers conduct analyses of characteristics of workers who stay over time and target identified demographics accordingly when hiring. Flexibility, especially to staff who are mothers, was found to be a reason workers tended to stay in the position over time. This flexibility is used to market the position to new hires. Seasoned ACWs are encouraged to refer potential employees, and one agency pays a bonus of fifty dollars to the referring worker if the new hire stays for three months. This attendant care report, available at the URL in the reference section of this report, could be more widely disseminated to CMHCs.

- Conduct a study to examine the barriers and possible solutions to recruiting and retaining Respite Care Workers. The study could identify children for whom this service is most critical to their success and locate areas where creative solutions to meeting the demand for respite care have been implemented. The study could examine the licensing regulations and "red tape" reported as barriers to respite service provision.

- Conduct a study to examine the requirements for hiring Parent Support Specialists, seen as a barrier to service provision. Review or research potential solutions to filling and retaining Parent Support Specialists, as well as reviewing the requirements associated with this position.

- Clarify how and when the Independent Living codes for services are to be used to meet goals related to independent living as opposed to addressing identified goals through case management or psychosocial groups.

- Conduct a study to examine the reasons for ending Waiver participation in more depth, particularly for reasons such as "family decision" or "lack of participation."

- A low number of complaints were filed with SRS. It is unclear whether this low number is an accurate reflection of the complaints individuals have or if other dynamics may explain the limited number of contacts. An exploratory examination of this process for filing complaints and possible options for improvement, if needed, is warranted to provide a better understanding of the issue. For example, findings would show whether parents are reluctant to contact SRS, as some suggest, and/or if grievances are being effectively addressed at the CMHC level. Centers that effectively solution-build when differences arise between parents and centers could be identified. A body that would offer parents an alternative contact venue might be considered.

- Some CMHCs are reported to provide strong support for families when they are completing the Waiver paperwork. Identify what those centers are doing that could be shared with CMHCs statewide.

- Clarify the method CMHCs should employ to estimate service amounts on the plan of care. This clarification could guide centers as to whether service amounts should be listed based on what is expected to be provided or on what might be needed in an effort to avoid later amendments.

- Authorize filling the state-level position assigned to prior approval of Waiver services as soon as possible so this process can be completed in a timely manner.

- Develop a brochure for families in a user-friendly format and make it widely and readily available. This brochure could include summary information about CBS and Waiver services as well as how they are different, who is eligible, and how to access the respective services.

- Identify the gaps in service provision in instances where children have a dual diagnosis of MR/DD and SED. Clarify and disseminate guidelines as to which children are better served on the SED Waiver and which children are better served on the MR/DD Waiver. For children who qualify for both Waivers and opt for the SED Waiver due to the MR/DD Waiver waiting list, look into which system offers the most suitable array of services to better meet the children's needs. The capacity of the mental health system could be expanded to serve these children, if their parents elect the mental health system for service provision.

- Although insurance parity has been discussed for many years, examine how to develop a modified version of insurance parity whereby private insurance companies would bear more of the cost for mental health services than they currently do. With input from all stakeholders involved, perhaps some level of parity could be developed that is reasonable and fair to involved parties.

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Appendix A

Kansas Consumer Satisfaction Survey (Parents and Youth)

Table A1. Kansas Family Satisfaction Survey, Completed by Parents or Caregivers

Category and Survey Item	**Waiver n = 895**		**Non-Waiver n = 1243**	
Access to Services	**Waiver %**	**Waiver Mean ***	**Non-Waiver %**	**Non-Waiver Mean ***
Time between first call and intake ($p < .05$)	92.90%	3.34	85.80%	3.17
Time between intake and next appointment	90.80%	3.27	86.50%	3.17
Someone explained policies and procedures	82.40%		77.70%	
Given written information about policies and procedures	85.80%		78.20%	
Given written information about client rights and responsibilities	88.70%		81.80%	
Quality of Care/Services	**Waiver %**	**Waiver Mean***	**Non-Waiver %**	**Non-Waiver Mean***
Case Management		3.34		3.41
Individual Therapy		3.30		3.36
Group Therapy		3.22		3.19
Family Therapy		3.24		3.33
In-Home Family Therapy		3.17		3.25
Medication Management		3.36		3.28
Attendant Care		3.26		3.24
Quality of Care/ Services	**Waiver %**	**Waiver Mean***	**Non-Waiver %**	**Non-Waiver Mean***
After-school Programs/Psychosocial Group		3.23		3.28
Wraparound Facilitation		3.19		3.23
Independent Living		2.57		2.57
Respite Care		2.46		2.83
Parent Support Specialist		3.19		3.31
Quality of Care: Family-Centered Items	**Waiver %**	**Waiver Mean***	**Non-Waiver %**	**Non-Waiver Mean***
Explanation about services provided by CMHC staff	92.80%	3.37	91.30%	3.35
Opportunities to participate in treatment planning	92.10%	3.42	92.60%	3.39
Appointment times	87.80%	3.29	89.80%	3.28
Location of appointments	95.0%	3.39	94.30%	3.35
Told who to contact if you had complaint	67.30%		63.40%	

Category and Survey Item	Waiver n = 895		Non-Waiver n = 1243	
Ever dissatisfied enough to complain to someone at CMHC	26.70%		23.60%	
Satisfaction with response to complaint	58.10%	2.64	50.90%	2.55
Quality of Care/ Service Providers	**Waiver %**	**Waiver Mean***	**Non-Waiver %**	**Non-Waiver Mean***
Service provider chosen to consider (top five)				
Case Manager				
Individual Therapist				
Psychiatrist or Nurse Practitioner				
Family Therapist				
Attendant Care Worker				
Chose provider they were rather dissatisfied with	21.90%		20.90%	
Treats us with respect		3.54		3.59
Helps us get help we want from family, friends, and community		3.22		3.23
Points out what my child and family do well		3.26		3.29
Makes it clear that we, and not the worker, are responsible for deciding…		3.33		3.34
Helps my family meet our needs as we see them		3.13		3.17
Suggests things that we can do for our child that fit into…		3.18		3.22
Understands that I know my child better than anyone else does		3.36		3.35
Makes sure we understand our family's rights		3.38		3.36
Wants to hear what we think about the services we're receiving		3.15		3.21
Encourages me to speak up during meetings with professionals		3.25		3.27
Quality of Care/Service Providers	**Waiver**	**Waiver Mean***	**Non-Waiver**	**Non-Waiver Mean***
Case Manager		3.47		3.50
Individual Therapist		3.20		3.17
Family Therapist		3.11		3.38
Group Therapist		2.86		3.50
Attendant Care Worker		3.03		3.10
Parent Support Specialist		3.41		3.61
Psychiatrist or Nurse Practitioner		3.67		2.72

Category and Survey Item	Waiver n = 895		Non-Waiver n = 1243	
Respite Care Worker		4.00		1.58
Overall Quality of Care Outcomes	**Waiver %**	**Waiver Mean***	**Non-Waiver %**	**Non-Waiver Mean***
As result of services received, my child is better at handling daily life. (p <.05)	84.60%	3.13	81.40%	3.05
My child gets along better with family members. (p <.05)	79.40%	3.03	77.40%	2.95
My child gets along better with friends and other people.	82.10%	3.02	81.40%	3.00
My child is doing better at school and/or work.	80.20%	3.07	78.90%	3.05
My child is better able to cope when things go wrong. (p < .05)	76.1%	2.93	72.90%	2.86
Overall Satisfaction	**Waiver %**	**Waiver Mean**	**Non-Waiver %**	**Non-Waiver Mean**
Would you refer friends and family to the CMHC	93.30%	3.56*	90.70%	3.54*
How satisfied are you the services your child has received	92.30%	3.44**	89.40%	3.44**

** Scores based on scale from 0 to 4, with 0 indicative of Very Dissatisfied and 4 indicative of Very Satisfied*

*** Scores based on scale from 0 to 4, from Never to Always*

Table A2 .Kansas Youth Satisfaction Survey, Completed by 708 Youth

Category and Survey Item	Waiver n = 318		Non-Waiver n = 390	
Access to Services	**Waiver %**	**Waiver Mean***	**Non-Waiver %**	**Non-Waiver Mean***
Do you know how to get hold of someone at CMHC?	83.30%		78.80%	
Have you ever tried to get hold of someone?	24.50%		24.70%	
How satisfied were you with how quickly you received the help?	82.00%	3.22	89.70%	3.19
How satisfied were you with the help you received?	89.00%	3.23	89.70%	3.28
Quality of Care/Services	**Waiver %**	**Waiver Mean***	**Non-Waiver %**	**Non-Waiver Mean***
Case Management		3.44		3.42
Individual Therapy		3.21		3.20
Group Therapy		2.95		2.87
Family Therapy		2.99		3.03
In-Home Family Therapy		3.00		2.96

Category and Survey Item	Waiver n = 318		Non-Waiver n = 390	
Quality of Care/Services	**Waiver %**	**Waiver Mean***	**Non-Waiver %**	**Non-Waiver Mean***
Medication Management		3.44		3.20
Attendant Care		3.33		3.33
After-school Programs/Psychosocial Group		3.05		3.12
Wraparound Facilitation		3.12		2.97
Independent Living		3.16		3.10
Respite Care		3.10		2.73
Quality of Care/Service Providers				
Service provider chosen to consider (top five)				
Case Manager				
Individual Therapist				
Psychiatrist or Nurse Practitioner				
Family Therapist				
Attendant Care Worker				
Quality of Care/Service Providers	**Waiver %**	**Waiver Mean***	**Non-Waiver %**	**Non-Waiver Mean***
Trust the worker	84.80%	3.45	89.00%	3.67
Not blamed for things that happen by the worker	93.70%	3.70	96.20%	3.79
Worker helps you see the good things about yourself.	88.30%	3.59	89.60%	3.68
Worker does not tell things to your parents that were going to be private.	86.60%	3.52	88.50%	3.56
Worker understands what you are trying to tell them.	80.20%	3.17	85.20%	3.55
Worker knows how to help you with issues	80.00%	3.25	83.30	3.50
Does not expect you to meet goals that are too hard for you.	74.80%	3.05	87.40%	3.54
Helps parents see good things about you.	74.80%	3.32	83.70%	3.54
Helps you plan for the future.	67.60%	3.01	74.30%	3.31
Helps to keep problems from getting too big	78.40%	3.27	80.50%	3.45
Asks you to help decide which issues to focus on	75.50%	3.19	78.30%	3.38
Usually listens to what you want, not just what your parents want	74.90%	3.10	76.60%	3.33
Worker does not talk too much about past and what happened a long time ago. p =	81.10%	3.32	90.60%	3.61

Category and Survey Item	Waiver n = 318		Non-Waiver n = 390	
<.05)				
Meets with you as often as you need them to	68.50%	3.05	82.90%	3.49
Worker dependable; do what they say they will do	85.30%	3.43	86.70%	3.62
If dissatisfied or have complaint, can talk to worker	78.40%	3.27	87.00%	3.60
Treats you with respect and dignity	90.10%	3.63	93.10%	3.76
Quality of Care/Medications	**Waiver %**	**Waiver Mean***	**Non-Waiver %**	**Non-Waiver Mean***
Take medication for mental health reasons	77.90%		72.30%	
Doctor/nurse explain reason for taking medications	88.50%	3.60	80.10%	3.43
Doctor/nurse explain side effects of medications might be	79.10%	3.41	73.40%	3.25
Doctor/nurse ask how medications make you feel? (p <.05)	94.60%	3.85	87.40%	3.62
How satisfied with how medications working. (p <.05)	91.70%	3.29	80.70%	3.06
Overall Quality of Care Outcomes	**Waiver %**	**Waiver Mean***	**Non-Waiver %**	**Non-Waiver Mean***
As a result of the services I received, I am better at handling daily life.	80.20%	3.25	76.30%	3.18
As a result of the services I received, I get along better with family members.	72.00%	3.1	69.40%	3.08
As a result of the services I received, I get along better with friends and other people.	77.60%	3.28	81.90%	3.37
As a result of the services I received, I am doing better at school and/or work.	77.10%	3.27	72.80%	3.18
As a result of the services I received, I am better able to cope when things go wrong.	73.40%	3.19	68.50%	3.09
Overall Satisfaction	**Waiver %**	**Waiver Mean**	**Non-Waiver %**	**Non-Waiver Mean**
Would you refer friends and family to the CMHC?	87.30%	3.27*	85.50%	3.26*
How satisfied are you with the services you have received?	93.60%	3.36**	90.90%	3.27**

** Scores based on scale from 0 to 4, with 0 indicative of Very Dissatisfied and 4 indicative of Very Satisfied*

*** Scores based on scale from 0 to 4, from Never to Always*