**University of Kansas**
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# ASSESSING THE NEED FOR CHANGE IN THE KANSAS PUBLIC MENTAL HEALTH SYSTEM:

## INTEGRATING THE FAMILY VOICE AND SYSTEMS INFORMATION

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## INTRODUCTION

The Kansas Social and Rehabilitation Services – Division of Health Care Policy (SRS-HCP) contracted with the University of Kansas School of Social Welfare (KU) to examine issues surrounding opening the Medicaid mental health provider network to licensed masters' level providers, with emphasis given to the impact on the children's mental health system. This request arose out of previous inquiry into this topic. In February of 2004, SRS-HCP solicited written feedback on the issue from community stakeholders, including representation from family members, child welfare contractors, private providers, school systems, hospitals, community mental health centers, universities, and various advocacy, professional and consumer associations. Respondents were asked to attend a roundtable discussion in April 2004 to discuss the results and advise SRS on next steps. These next steps included an objective analysis of the present capacity of the public mental health system (e.g., access, choice) and possible outcomes of the proposed changes. The stakeholder group also recommended inclusion of greater family and consumer input on this issue.

In order to address these recommended next steps, KU gathered data from both national and state sources. National data included a survey of states that have either opened their Medicaid provider network or have a mental health system similar to Kansas. State data included all relevant information such as family and youth satisfaction, timeliness of services, system complaints, and provider statistics. In order to increase the parent/family voice, focus groups were held across the state with family members/foster parents of children and youth receiving mental health services in both public and private venues. Although this study's emphasis is on child/youth and family issues, portions of the data relate to issues that affect both the adult and children's mental health systems.

As we examine the system, it is useful to consider the current structure and goals of the Kansas public mental health system as well as its development. The public system in Kansas is comprised of mental health supports that vary from highly restrictive (state hospitals) to non-restrictive (Community Mental Health Centers or CMHCs, private providers, self-help groups), with options in between (residential care facilities). One of the guiding principles of the system of care in Kansas is that services and supports are best provided in the community when at all possible. This principle was formalized with the passage of the Mental Health Reform Act of 1990. To help ensure that services would be community-based, CMHCs were given a gatekeeping responsibility that included screening for all state hospital admissions and providing supportive community services to individuals discharged or diverted from the hospital. This role has evolved and the CMHCs are now identified as the local coordinating agencies for mental health services in Kansas. In this role, CMHCs are obliged to serve all people seeking mental health services who are found in need of such services. The Kansas system of care is organized to maximize the integration of services, which is considered critical for successful treatment of individuals in the target population (i.e., adults with Serious and Persistent Mental Illness or SPMI and children with Serious Emotional Disturbance or SED; Morrissey, Johnsen, & Calloway, 1997).

**Research Questions**: What is the present state of the Kansas public mental health system with regard to service issues such as access and choice? How would the proposed change to expand the Medicaid network to masters' level providers affect the system?

# METHODOLOGY

## National Data

1. Literature Review
   A review of the literature was completed on service delivery in the public mental health system and effects of privatization on the system. This review captures information relevant to both adult and children's mental health systems.

2. State Surveys
   Five states were contacted that have either a mental health system similar to Kansas or that have recently changed their provider network. The state Children's Mental Health Director and/or the state Medicaid office provided information about the system and the effects of any changes that have been made to the system.

## Kansas Specific Data

1. Parent/Foster Parent Survey and Focus Groups
   Between December 2004 and March 2005, KU staff conducted 12 focus groups with parents and foster parents from across the state. Participants were asked to complete a two page survey followed by a 1 to 1 ½ hour focus group. A total of 79 parents and foster parents participated in the focus groups and 68 surveys were completed. Some parents came as a couple and completed only one survey and other participants chose not to complete a survey. The surveys were completed before the start of the focus group. The survey and focus group questions delved into parents' overall experience of obtaining service in public and private venues (with particular emphasis on Medicaid-reimbursed services), including satisfaction with services and importance placed on different aspects of service. Families were selected in the following four ways:
   - Six CMHCs were selected to represent urban, mid-size and rural communities, as well as western, central, and eastern Kansas. KU staff met with families at these centers who attended a regularly scheduled family night meeting sponsored by the CMHC.
   - State foster care contractors were asked to convene four groups of foster parents who had foster children in mental health services at a CMHC. The location of the groups was varied to include representation of urban, mid-size and rural communities, as well as western, central, and eastern Kansas.
   - Keys for Networking, a state parent advocacy organization, was asked to convene a group of parents whose children had received Medicaid-reimbursed mental health services, regardless of whether the services were delivered by a CMHC or a private provider.
   - National Alliance for the Mentally Ill (NAMI), a state affiliate of a national mental health advocacy organization, was asked to convene a group of parents whose children had received Medicaid-reimbursed mental health services, regardless of whether the services were delivered by a CMHC or a private provider.

2. Parent Support Specialists Survey and Focus Group
   All Parent Support Specialists (PSS) were mailed a survey and 23 of the 51 surveys were completed. A follow-up focus group, attended by 22 PSS, was held at a regularly scheduled state meeting to discuss the findings and obtain additional information. Parent Support Specialists were chosen because they work with a considerable number of families in the mental health system and have access to a broad range of parent views.

3. Kansas Parent and Youth Satisfaction Survey
   Parents and youth age 12 and older who receive Medicaid-reimbursed case management services are asked to complete satisfaction surveys annually (*Kansas Family Satisfaction Survey* and *Kansas Youth Satisfaction Survey*). Data from the Family Survey for September 2003 – July 2004 was examined for all parents. In addition, the satisfaction of foster parents was compared to that of all other parents.

4. Service Statistics
   The number of individuals served at CMHCs for state fiscal years 2003 and 2004 was examined. This data was obtained from the *Performance Partnership Block Grant Implementation Report.*

5. Field Staff Contacts
   Contact Data on complaints filed through the SRS Field Staff for state fiscal years 2003 and 2004 was examined.

6. Data on Access Standards
   Data on state access standards (i.e., the acceptable amount of time between the consumer/family's first contact with the CMHC to the time of the first scheduled appointment) for state fiscal year 2005, quarter 1 (July through September 2004) was examined. This data was obtained from the *Kansas Public Mental Health Services Quarterly Quality Improvement Report* produced by the Mental Health Consortium, which utilizes AIMS (Automated Information Management System) data to track whether access standards are met for all enrolled consumers at CMHCs who are entering service. In an effort to further increase the accuracy of this information, both the date and time, rather than just the date, for the initial contact and scheduled appointment will be required beginning in January 2005.

7. Other State Reports
   Two recent reports that included information on mental health services in the State of Kansas were used to supplement parental input:
   - The Children's Alliance of Kansas convened two groups of foster parents in June 2004 to solicit suggestions for improvements to the foster care system. The summary of these meetings was presented in *Foster Parent Discussion Groups: Gathering Feedback for System Improvement.*
   - Every five years, the Kansas Department of Health and Environment conducts a needs assessment as part of its Title V funding. This assessment was recently conducted in preparation for federal fiscal years 2006 through 2010. A panel of 77 stakeholders representing state agencies, universities, local health providers/departments, advocacy groups and non-profit organizations located throughout the state served as experts. The results, which are currently posted for public comment, are contained in the report, *Kansas Maternal and Child Health 5-Year Needs Assessment (2005).*

8. Mental Health Provider Statistics
   Kansas Behavioral Science Regulatory Board (BSRB) data from 2004 on the number of providers who could qualify as Qualified Mental Health Providers (i.e., those qualified to screen for admittance to the state hospital) was examined.

# NATIONAL PICTURE

## Literature Review

A search of the national literature for information related to service delivery in public and private mental health systems was undertaken. Although this issue has broad social and financial ramifications, relatively little has been written on the effect of privatizing a public system of mental health service delivery and less was found on examining the direct effects on an existing state system. The literature is characterized by strong views for and against privatization; however, proponents on both sides of the issue encourage a tempered approach to change (Schnapp, Bayles, Raffoul, & Schnee, 1999; Hogan, 1996; Paulson, 1988). For example, Hogan (1996) examined many positives aspects of privatization, but warned that "the divergent and complex structure of the public system and its emphasis on services that extend beyond those in private health care plans means that the fit must be examined closely..." (p. 22).

The public mental health system is defined and organized differently in each state. In Kansas, the system is comprised of entities that are state run (e.g., State Mental Hospitals), individual private providers (i.e., psychiatrists and Ph.D. psychologists), and non-profit agencies that receive significant government funding (e.g., CMHCs). The CMHCs in Kansas are private entities that receive funding from state and local government. Thus, the Kansas system is a private-public partnership in which the CMHCs hold the majority of risk for those seeking services (i.e., required to serve all consumers in need regardless of ability to pay). The CMHCs are the main provider of outpatient clinical services in the public system (along with psychiatrists and Ph.D. psychologists) and the only provider of community-based services (e.g., crisis services, case management, attendant care). The literature in this area examines the issue of privatization of the system in general, but does not specifically address the Kansas question of opening the Medicaid mental health provider network. Many pertinent issues were raised that related to the research questions of this report and these will be examined. The issues consistently raised in the literature concerning privatization of the public mental health system include effects on: access to service, quality of service, integration of service, consumer choice, and financial solvency.

### Access to Service

It is generally expected that access to service would increase if a greater number of mental health providers were added to the system (Oliver, 2002; Surles & Shore, 1996; Paulson, 1988). This increase would most likely take place for consumers in urban areas where the vast majority of providers are located. It is unclear whether any significant change would be experienced in frontier and rural areas, as general workforce issues result in an ongoing shortage of mental health providers in both public and private entities (Gale & Deprez, 2003). In addition, increased access would likely be applicable to individuals with less significant mental health needs and not for consumers in the target population (Paulson, 1988). Some authors noted that often a "creaming" process can occur by private providers in which services are concentrated on those consumers with less significant needs who demand less time and coordination (Stoner, 1983). When this process occurs, the consumers in the target population receiving high intensity, high cost services are left to the public system (Paulson, 1988). The literature review indicates that privatization may result in increased access for urban consumers with less significant needs; however, the possible effect this may have on the system as a whole merits serious consideration.

Quality of Service

The issue of quality of service is often examined in the context of the purpose of the public system, which was built as a safety net for those with the most significant mental health needs (Schnapp, Bayles, Raffoul, & Schnee, 1999). Given the purpose of the system, the public sector has significantly greater experience and history of innovation in providing services for individuals in the target population (Hogan, 1996; Judge & Smith, 1983). Privatization and the introduction of competition are generally noted to increase quality by raising the emphasis on outcomes, effectiveness of services, and use of best practices (Schnapp, Bayles, Raffoul, & Schnee, 1999). However, these positive aspects of privatization are already established in the public sector in many states. In addition, those outside of the public system often lack expertise in how to serve consumers with the greatest needs. Oliver (2002) noted that there are "legitimate differences between the mental health needs of those traditionally served in the private sector versus those served in the public sector" (p. 328-329). A consistently voiced concern about private sector providers, particularly those in private practice, is that they would experience greater difficulty with and decreased motivation to track outcomes (Paulson, 1988; Schnapp, Bayles, Raffoul, & Schnee, 1999). With fewer checks and balances and less ability to measure outcomes for all consumers, it would be difficult to track and thus assure the quality of services received from private providers (Schnapp, Bayles, Raffoul, & Schnee, 1999). The literature review generally supports the public system's expertise in serving the target population and tracking service quality outcomes.

Integration of Service

Integration of service is considered to be a critical factor in successfully meeting the needs of individuals with significant mental health concerns (Morrissey, Johnsen, & Calloway, 1997). Public systems generally provide the wide array of services needed by these consumers and mandate coordination between providers (Drew, 1994; Paulson, 1988). When services are provided by private entities, there is rarely a mechanism to mandate coordination and increased management oversight would be needed to enforce such a mandate. In addition, because these services are not reimbursable, there is little financial motivation for private providers to work with other providers (Paulson, 1988; Stoner, 1983). If integration of service decreases, it is likely that quality of service will follow. The literature review generally supports the public system as more adept at providing integrated care.

Consumer/Family Choice

The public system of service delivery maximizes some positive aspects of service (e.g., integration) in part by limiting other aspects, specifically consumer choice. Certain public systems, like the one in Kansas, provide the majority of outpatient services through one entity (e.g., CMHCs). Consumers receiving Medicaid-reimbursable services can choose the local CMHC or work with a private psychiatrist or Ph.D. psychologist. By adding more providers and building in competition, a greater level of choice can be achieved. However, this choice is only meaningful when consumers can adequately evaluate differences in the quality of service (Oliver, 2002). As opposed to making choices about physical health services, decisions about mental health needs are complicated by the fact that mental health treatment approaches are less well standardized and mental health utilization patterns are complex (McFarland, 1994). Decisions about the quality and appropriateness of mental health services are thus more difficult and consumers are left with little information on which to make these serious decisions (Stoner 1983; Ghere, 1981). Again, for the reasons listed in previous sections, the benefits of a wider provider network would be available to those with less significant mental health needs and the positive features of the public system, such as integration of service, may decrease with the addition of private providers. However choice and control are important components of successful treatment (Osher & Osher, 2002). In February of 2003, the President's New Freedom Commission

subcommittee on Medicaid released a policy statement on the utilization of Medicaid in the mental health system. Principles and policy goals were developed that address many of the issues examined in this review (e.g., integration of community services, use of best practices, access to needed services) including consumer choice and control. Integrating choice into the public system, rather than changing the system, is one option to address this issue. The literature review emphasizes the importance of consumer choice and control as well as the difficulties associated with implementing choice.

Financial Considerations

When introducing greater privatization to a public system, the financial impact on the system is considered along side the impact to the consumer and family. Often private competition is introduced into public systems to decrease costs (Oliver, 2002; Savas, 1987), and a few state systems have noted cost savings when tracked over three years (Huskamp, 1998). It is unclear how these cost saving impact the consumer or the system over a longer period of time. The cost savings were often a result of decreased utilization of services. When tracked over time, this reduction may lead to more significant problems if the reduction was due to a lack of appropriate treatment. When profit is a motivator in the private sector, cost containment can take the form of limiting needed services. When consumers in need of mental health services do not receive them, more costly and much less desirable alternatives may result such as state hospitals admissions or contact with the criminal justice system (Schnapp, Bayles, Raffoul, & Schnee, 1999). When privatization is introduced, financial resources are often diverted to management tools for monitoring private providers to avoid under and overutilization. Schnapp et al. (1999) suggest that profit motivation and increased administrative costs will tax an already underfunded system. The literature reviewed is mixed on the financial impact of privatization, with suggestions of cost savings tempered by the potential risk of lowered outcomes and increased cost over time.

In summary, the review of the literature illuminated strengths and challenges of both public and private systems. Many authors note the importance of maintaining the safety net that the public system currently provides for those with the most significant mental health needs and the fewest resources. Changes to the system should be carefully considered so as to preserve the strengths of the public system while minimizing the challenges.

## State Consultation

Five states were contacted in December 2004/January 2005 that either have a mental health system similar to Kansas or have recently changed their provider network. The state Children's Mental Health Director and/or the state Medicaid office provided information. Detailed state-specific information can be found in the attachment to this report. Issues that were raised about Medicaid provider networks included:

- A need for a clear understanding of the core mission of the Kansas public mental health system and the impact of any proposed change was emphasized. The Kansas system was often referenced as a model program with a strong national reputation.
- Access generally increased with broadening the Medicaid provider network; however the increase was seen in urban areas as the change did not address limited workforce issues common to providing mental health services in rural areas.

- Cost of service provision generally increased with broadening the Medicaid provider system and strong cost control efforts have been necessary in many states (e.g., Arkansas's cost for community-based services doubled and the mental health costs are reported to be 'out of control').
- Children and youth in the target population (i.e., those experiencing Serious Emotional Disturbance or SED) were generally and preferably served in the public mental health system due to:
    - the greater array of services typically available and required in the public system
    - the ability to provide and responsibility for a higher coordination of care in the public system
    - the more limited resources of mental health providers outside of the public system to meet the high needs of the consumers in the target populations
- In some states, broadening the Medicaid provider network resulted in a lessening of accountability in the delivery of mental health services and concerns about the effect on quality of care.
    - Standards of care often differed between public and private systems. The public system is typically held to access standards that often could not be implemented with private providers. The public system also is typically held to a "no refusal" policy that often could not be implemented with private providers. Thus, opening the network can produce a greater choice of providers, but often resulted in what some states referred to as "cherry picking" with private providers choosing to serve consumers with lower need that required less time.
    - Some states reported a concern about the effect of opening the provider network on the quality of services, but had no way to evaluate this concern. In states without quality assurance and outcomes processes, little is known about the impact of broadening the Medicaid provider network on quality or outcomes. In addition, one question raised in other states was whether a private provider could be required to submit to rigorous quality assurance and outcomes processes.
    - Some management tools were difficult to maintain in states with a broadened provider network. These tools included: single point of entry to inpatient or other high end care; responsibility for limiting length of stay when inpatient options are utilized; responsibility for coordinating care between the inpatient setting, the family, and other community service providers; and responsibility to provide certain core required services.

# KANSAS FINDINGS

The information in this section is organized according to common themes that developed out of data collected from parent surveys and focus groups. Evaluators held twelve groups throughout the state during which parents[1] were asked to complete a survey and participate in a focus group. The parents involved in the groups were identified by CMHCs, Keys for Networking, NAMI, or private foster care contractors. Some families received mental health services for their children through a CMHC only; others received services from both a CMHC and private provider(s).

Regardless of the service delivery source, parents were asked to answer questions regarding their perception of how the provision of mental health services was working for their family. An overview of the major themes communicated by parents through this data collection process is provided below. The themes reflect issues that were raised by multiple parents across different groups. In addition, individual quotes used in the text are representative of the views of many parents. Other data sources have been integrated under the appropriate themes.

## Services

- On the survey, parents were asked to rank order six important features of service, with a ranking of "one" denoting the highest valued feature. The highest ranked feature was **"the care my child receives is high quality,"** with 59% selecting this as their number one or number two choice. The two characteristics rated the lowest of the six were: "services are coordinated between providers or programs" and "my child/family can select among providers (both in and outside of the center)".[2]

- Parents reported the **range of services found at the CMHCs is particularly useful**, including the opportunity to receive a wide array at one location. Case management and parent support services were highly valued by parents whose children received these services. In referring to the value of the array of services for children with SED, one parent stated, "At this point I couldn't even fathom working with a private provider, just because they don't and can't provide that wraparound kind of service that we've gotten from [the CMHC]. It's just not available."

  Some families reported that the CMHCs were very helpful in **explaining the array of available services** and assisted the families in obtaining services at the CMHC and in the community. Other families reported frustration with the limited information provided about available services at the CMHCs. Some parents reported that they had to advocate strongly for their children to get the services they believed were necessary. One parent, for example, stated, "I feel like I have to make myself into this super-assertive person, and putting myself out there, because it is important for the kids."

- Some families **received needed services, but not at the level recommended** for their child. Others reported that services like case management were delivered sporadically. **Other participants received the services they needed in a timely manner** and were quite complimentary of both the services and the staff at the CMHCs.

- Families in several of the focus groups reported that they had experienced **difficulties with services being offered but not delivered**. Services that were most commonly reported in focus

[1]The word "parents" will be used to refer to both biological and foster parents, unless the issue is specific to foster parents. In this latter case, "foster parents" will be used.

[2] The other three characteristics were: "as parent(s), I/we are full members of the treatment team"; "trained staff are available to my child/family in a crisis"; and "anyone who needs it should have access to mental health care."

groups and on the survey to be difficult to obtain included attendant care, respite care, therapy and case management. During focus group discussions, parents also reported a desire for more parent support services. When asked to respond to an open-ended survey question about the greatest challenge in receiving services at a CMHC, the most common responses related to scheduling difficulties or the need for a specific service or increased intensity of a service.

Data from the *Kansas Family Satisfaction Survey (FY2004)* showed that of the 2,241 parents who responded, 90.3% were satisfied with services overall. However, when parents involved in the focus groups were surveyed about more specific issues related to the initiation of services:

- One-third of the families were satisfied with how quickly services started.
- Another one-third reported that some services were initiated quickly, but they had to wait for other important services.
- Thirteen percent of families reported waiting too long for the intake appointment.
- The same percent (13%) reported that the intake was completed quickly but they had to wait too long for services to begin. Many families reported that by the time they sought the help of the CMHC, services were needed quickly.

## Staffing

- Multiple focus group participants reported a belief that there were **staffing shortages at the CMHCs.** These shortages were reported at the Parent Support Specialist focus group as well and were attributed to the increasing number of families and children requesting service. Data from the *Kansas Block Grant Implementation Report (2003 and 2004, Table 2A)* showed that from state fiscal year 2003 to state fiscal year 2004, there was a 12% growth in the number of people served at Kansas CMHCs. The largest increase was in the 17 year old and under category, which increased 16% in this one year period of time.

  The Kansas Department of Health and Environment report *Kansas Maternal and Child Health 5-Year Needs Assessment (2005)* [3] listed improvements in behavioral/mental health as one of the top three priority areas for children and adolescents. Specifically, the report noted that behavioral health has been a priority for the previous five years and more progress was needed (KDHE, 2005, p. 23). Two of the weaknesses in this area identified through the SWOT Analysis (strengths, weaknesses, opportunities, and threats) were the shortage of mental health professionals and waiting periods for mental health services.

- The **need for more providers** was reported to affect the amount of time it took to get an intake appointment, the frequency with which children could be seen, and/or the range of hours in which appointments could be offered. Parents wanted increased availability of **after-school therapy appointments**, particularly for children struggling in school.

  When children had an appointment and the therapist had to cancel (e.g., due to personal illness, weather, etc.) some focus group participants reported long delays in rescheduling the service. As one parent stated, "That process has a serious weak point. If anywhere in the process there's a stumble [such as a therapy cancellation], it sets you back, not just by a day. It sets you back by weeks. [The therapist] . . . was pretty sick several days in a row . . ., but there was no back up plan."

[3] This report is currently available for public comment with the goal of submitting it as part of the MCH Title V Block Grant in July 2005.

Two other data sources containing information about the need for more providers were reviewed with the following findings:

Data from the 2,422 parents involved in the *Kansas Family Satisfaction Survey (FY2004)* was reviewed: 89.9% were satisfied with the time between the first call and intake, and 88.4% were satisfied with the time between intake and the next appointment.

The *Kansas Public Mental Health Services Quarterly Quality Improvement Report (FY04 Q4)* was also examined. This report, produced by the Mental Health Consortium, monitors the amount of time that elapses from the consumer's first contact with the CMHC to the time of the first scheduled appointment. Data reviewed for the most recent quarter showed the following information for individuals entering service:

FY05Q1 (July through September 2004) Statewide Totals for Urgent, Routine (10 working days), and Routine (14 working days) Access Standards*

| | **Urgent (served within 72 hours)** | **Routine 10 days** | **Routine 14 days** |
|---|---|---|---|
| **July-Sept 2004** (calculations based on hours and major holidays excluded) | Number of cases: 588<br>Number of cases served within 72 hours: 488<br>**Percent of cases scheduled service within 72 hours: 87.46** | Number of cases: 8505<br>Number of cases served within 10 days: 7449<br>**Percent of cases scheduled service within 10 days: 87.58** | Number of cases: 8505<br>Number of cases served within 14 days: 7766<br>**Percent of cases scheduled service within 14 days: 91.31** |

*See page 3 Item 6 of this report for changes in how the data is calculated.

- Families experienced a variety of responses when they wanted to **change to a different provider within the CMHC**. Some experienced ease with making a switch while others experienced difficulties, either due to staffing shortages or, less frequently, to an informal policy at the center. Parents thought it should be possible to change providers if it would allow for a more productive professional relationship and better outcomes. One parent stated, "The only problem that I'm having right now is that there's only two child therapists. One is totally booked up and the other one we tried and we just don't see eye to eye. It's something that I'm not comfortable with. So right now my child does not have a child therapist."
- Some families reported that **provider turnover** was an issue with both clinical and community-based services. Turnover was difficult for the child and parent, often resulting in a slowing of progress. In addition, some parents expressed concern about the amount of time it took to assign new staff.

## Crisis and Concerns

- **Families valued the crisis services offered through CMHCs.** When ranking the six important features of service on the survey completed for this report, 41% of those responding listed "trained staff are available to my child/family in a crisis" as their number one or number two choice. Focus group participants reported that **increased after-hours crisis services** were needed in some areas. Specifically, some families reported a need for greater options when a crisis screen did not result in hospitalization. Participants reported that when in crisis, consultation with a local mental health professional was greatly preferred to contacting the police.

- Most parents were able to work with a variety of CMHC staff to **address concerns about the services** their family and child(ren) received through the CMHC. Common personnel they approached were case managers, parent support specialists, and therapists. Few parents reported

that they had contacted **SRS Field Staff**; however, when they were contacted, parents generally reported satisfaction with the process and outcome. The main reason given for not approaching Field Staff was the association with SRS. Many parents reported a belief that the custody of their child would be at risk if SRS staff were involved. In addition, some parents reported apprehension about raising concerns to any staff member due to the belief that there may be repercussions from the CMHC. Although small in number, these families were uneasy about possible difficulties if the CMHC was their only option for services.

- There were 156 unduplicated contacts to SRS Field Staff in state fiscal year 2003 and 93 unduplicated contacts in state fiscal year 2004. This includes children and adults, target and non-target population, and Medicaid and non-Medicaid clients. These numbers represent less than 1% of the population served at CMHCs for both years. Around 60% of the contacts over this two year period dealt with the degree to which appropriate services and supports were available to meet the consumer's needs.

## Systems Issues

- Concerns were raised by parents of **children dually diagnosed with mental illness and developmental disabilities** (e.g., Autism). Some described receiving critical services for their child through a CMHC. Others reported that once they informed CMHC staff that their child had a developmental disability such as Autism, they were told that appropriate services were not available for their child at the CMHC. Although parents were aware that children with a dual diagnosis of developmental disability and mental illness currently do not fit well into either system, they requested further study and a speedy resolution of this issue as neither system had adequately embraced the needs of these families.

- **Communication is reportedly lacking in some areas.** This issue takes a variety of forms. For some, it involves notification of appointment cancellations, notification of changes or termination of services, and knowledge of therapy goals. For others, it involves a commitment from those involved in the child's life to communicate with each other. As one parent described: "[Psychiatrists] don't have time. They have too many patients, the private sector, and I think it's better at [the CMHC] end. The case managers are more willing to seek that information from the outside agency or therapist than the other way around. Because I know I've signed waivers for my private therapist and psychiatrist to contact [the CMHC] any time, case managers, anybody. I don't think it's ever been done."

- **Parents often described difficulties working within the schools system,** and spoke highly of CMHCs that were able to help support children and parents with educational issues as well as support children while at school. Specific issues with the school systems were many and included lack of mental health training for teachers and other personnel, difficulty gaining cooperation from the schools such as obtaining copies of Individualized Education Program (IEPs), and the isolation of children with mental illness due to "behavioral" issues.

## Family Supports

- Many parents were **grateful for the support they received** at CMHCs. They preferred it when the whole family was seen as part of the process. When asked on the survey about the greatest benefit families had received from a CMHC as opposed to another provider, a common open-ended response dealt with the support the parent, child or entire family received. Parent Support Specialists were highly valued, and hiring more staff in these positions was a common suggestion from families.

- Parents want to be **involved, listened to and a part of the team**. One parent summarized this desire when saying:

> "I like how [the therapist] talks to me first, then he talks to [the children]. That helps. He can take a chance to talk and see how I'm feeling, not just about [my child]. Because it's like a cancer. It affects the whole family. It doesn't just affect just one person. That helps. To me I feel like I connect with [the therapist], and that helps me to want to come out here. Before I came out, I thought why am I coming out here and wasting my time and filling out papers. It took me a while to get to this point where I want to do this."

- The **alternatives that CMHCs could offer for covering the cost of mental health services** were highly valued. These choices included the SED Waiver and sliding scale payment system. One parent expressed the importance of the waiver:

> "We didn't even know that the waiver existed until we got [to the CMHC]. And [we] honestly were about to go bankrupt just trying to pay for his prescriptions. They were running us three to four hundred dollars a month, plus paying the out of pocket expense for the other providers that we were seeing too. We literally were about to file bankruptcy, because we just couldn't keep going. But we had no choice, because [our child] had to have the services. So we got here and they told us about the waiver. I can remember sitting down there in the office and they're telling us about the waiver and I just burst into tears, because I was just so relieved to know that there was some help."

- **Frustration was expressed when decision makers did not appear to appreciate or understand the realities of living with and supporting a child with SED**. In several groups, parents felt that living with a child with SED would offer decision makers, including legislators, a better understanding of how their decisions affected families. Although most parents did not speak to specific systems issues, one parent did express the following concern when discussing how fortunate parents felt to have access to the mental health services available in Kansas. The concern related to expanding the recent HealthWave changes to all Medicaid services.

> "I guess that is my concern for what the state's looking to do. I feel like if, in fact, the state, the legislature, whoever, goes in the direction they're going, they're going to really, really undo what to me is a very progressive model for working with kids in mental health services. I hope they look long and hard and do some real serious talking with people who are in the system before they start making decisions that are going to make that very difficult."

## Issues Specific to Foster Parents

During the focus groups with foster parents, the following issues were identified that appeared to be specific to caring for foster children.

- Foster parents expressed a strong desire to be an **active, valued member of their foster child's treatment team**. More than other caregivers, they reported that their role on the team was often unclear. At times, this lack of clarity was reported to be a result of poor preparation of foster parents in managing mental health issues. At other times, it was reported to be due to the general lack of clarity of the role of the foster parent in the foster child's life. Foster parents expressed a desire for more information about their foster child's mental health concerns, including the opportunity to talk with clinical staff. Some foster parents indicated that they wanted to know the therapy goals so that they could work on them at home. One foster parent stated: "I really think

the foster parents need to be better utilized by the mental health system because there's so much information that we have that I think could really help them."

A report produced by the Children's Alliance, based on meetings with foster parents, found that one of the top three concerns of foster parents related to communication and support, with priority given to the issue of improvement of communication to and support of foster parents. "Both discussion groups ranked this as having primary importance in avoiding conflict and promoting progress. A key dimension of this discussion was a strong feeling on the part of the participants that agencies should include foster parents as full members of the child team. Many of the foster parents participating had experienced from agencies or the courts that their input and role was secondary or not quite as important as the other members of the team" (June 2004, p. 3).

- Results of the survey and focus groups indicate that foster parents were significantly less satisfied with services than other participants. This is consistent with the *FY2004 Kansas Family Satisfaction Survey (KFSS)* data. The KFSS data was examined and satisfaction of foster parent respondents was compared to all other respondents. Of the 193 foster parents reporting, 82.5% said that overall, they were satisfied with the services their foster child had received. This compared to 90.9% of the other 2,159 respondents, a significant difference at the 0.001 level.

  A report produced by the Children's Alliance, based on meetings with foster parents, found that mental health service was one of the top three issues identified with a priority given to the issue of timely access to therapy. "This issue was ranked as number 3 in the more western regions of the state and number 4 in eastern regions. The foster families raised this issue consistently in addition to the importance of choice of therapists both to maintain the therapeutic relationship established with foster child and having a therapist who could work effectively with the foster family" (June 2004, p. 3).

- Like other parents involved in this study, **foster parents were very complimentary of mental health case management** services. Those foster families not receiving case management often reported more difficulty managing their foster child's mental health services and working within the system.

- Foster parents reported **a need for specific information** about what to expect from the mental health system and how to effectively advocate for children in their care. Some foster parents reported feeling ill prepared to work with a child with mental health issues and were unsure of their role in the treatment process.

- Foster parents often spoke of delays in receiving **medication evaluations**. These delays were particularly problematic when a child was newly placed in their home and arrived with a small amount of medication and without a prescription.

## SUMMARY

In response to a request from SRS-HCP, an examination of the issues surrounding opening the Medicaid mental health provider network to licensed masters' level clinicians was initiated. The study was focused on the impact of this change on the children's mental health system. National and state data were collected to answer the following questions: 1) What is the present state of the Kansas public mental health system in regard to service issues such as access and choice?; 2) How would the proposed change to expand the Medicaid network affect the system?

In regard to service issues, the results of the current study indicate that a significant majority of participating parents believe the present system is meeting their child and family's needs. They reported that the wide range of services and supports provided by the public mental health system was critical to treatment success. Although satisfied, some parents did identify areas in need of additional attention. Concerns about access to some CMHC services (e.g., respite care, attendant care) were expressed. Some parents also reported difficulty in accessing therapy at desired times or at recommended frequencies. When the issue of choice was raised, it was usually in regard to a desire for greater choice within the CMHC in order to maintain the integration of care.

In contrast to this larger group, a smaller percentage of families voiced major concerns. While additional study would be needed to more clearly define the reasons for these concerns, two main issues emerged. From both the focus group results and state-wide indicators, foster parents report lower levels of satisfaction with managing mental health services for foster children as well as with their preparation to manage their role in the system. In addition, concerns were raised by parents of children dually diagnosed with mental illness and developmental disabilities (e.g., Autism). These concerns were focused on limited availability of services in either system to meet the unique needs of these children and families.

In general, satisfaction was higher when parents believed that their needs were addressed in an open and flexible manner, even when a "perfect" or desired solution was not obtained. Most parent concerns were successfully resolved through informal contact with various staff at the CMHC. When necessary, formal checks and balances were available (e.g., SRS Field Staff) and appeared to work well when utilized. However, there appear to be gaps in the present system leading to a lack of opportunity for satisfactory resolution for some parents.

Although challenges within the Kansas public mental health system were identified in this study, a significant majority of parents reported satisfaction with the services provided to their child or children and family. Given the results of this study, targeted changes to the system appear indicated as opposed to sweeping reforms. Suggestions for targeted changes are detailed below.

## CONSIDERATIONS FOR NEXT STEPS

Based on the summary of the data, several possible areas for future effort emerged:

1. The Kansas public mental health system has a formal oversight process. One aspect of this process is directed by SRS Field Staff. Field Staff investigate complaints received about CMHCs, as well as conduct bi-yearly licensing visits. Field Staff thus provide an important check on the system. However, opportunities exist to further support and complement this oversight process.

    a. The creation of a **statewide Quality Assurance Committee** would offer a forum for stakeholders to review systems data (e.g., performance information and complaint data) and collaborate on recommendations for system advancement. This committee, comprised of selected representatives from advocacy groups, parents of children with SED, CMHCs, Parent Support Specialists, and state-level representatives from SRS, would be a structured group with formal membership and clear lines of authority and responsibility.

    b. A new position of **state-level ombudsperson** would complement the work of Field Staff by providing a confidential option independent of SRS and the CMHCs. While most families involved in this study were satisfied with the services they received at the CMHCs, some families reported a need for an alternative option for resolving concerns as they did not feel comfortable with the current grievance process or were dissatisfied with the outcome. An ombudsperson would have authority to work within the system to mediate specific situations. For example, in a situation when provider choice was felt to be limited (e.g., due to staffing issues), the ombudsperson could help both the family and the CMHC explore realistic solutions. The ombudsperson would work closely with Field Staff, as well as contribute to systems improvement through membership on the statewide Quality Assurance Committee (see above). If created, contact information for this new position should be posted at each CMHC and provided to all families receiving CMHC services.

    c. The creation of a **Statewide Parent Advisory Council** and a **Statewide Youth Advisory Council** would allow the parent and youth voice to play a stronger role in the Kansas System. These councils would facilitate greater parent and youth input on state-level decisions; systems oversight such as identifying trends or gaps in the system; and family/youth education on issues related to mental health and related services.

2. Parent Support Specialist services were highly valued by families, who often asked for more access to this service. Exploration of **expansion of Parent Support Specialist** services to a greater number of parents, as well as to those who presently have access, would be beneficial.

3. The public mental health system has experienced rapid growth, with a significant increase in the number of individuals seeking service. However, the supply of some staff at CMHCs has reportedly been unable to meet the demand for a variety of reasons. The challenge is to maintain the many positive aspects that the system currently provides while meeting family needs.

    a. **Explore the options for increasing staff at CMHCs**. Examples might include use of Block Grant funding to offer RFPs to encourage creative solutions.

    b. **Staffing issues in rural and frontier areas warrant special attention**, particularly given the geographic realities and workforce challenges of these areas. Solutions identified for urban areas are often not applicable to rural and frontier regions.

c. **Provision of specialty care** to youth with low incidence presenting problems (e.g., sexual acting out behaviors and eating disorders) is difficult to manage. Studies suggested in #4 below may help define the specific need for specialty care and possible solutions.

d. Explore the possibilities of and barriers to **contracting with private providers** who could help address staffing shortages. Issues to explore include the responsibility and liability the CMHCs accept for the services provided by contractors, as well as the need to track outcomes and ensure coordinated services.

4. The significant majority of parents who participated in this study reported satisfaction with the services provided to their child and family. However, there appears to be a subset of parents/families who report lower overall levels of satisfaction or dissatisfaction with services. More specific information is needed on the factors that lead to lower levels of satisfaction or dissatisfaction and the reported barriers to obtaining the services their children and families need to maintain stability. The results of this study suggest at least two areas that warrant further examination:

    a. A broad look at **what factors lead to high and low levels of satisfaction** with mental health services across both the target and non-target population. The goal of this study would be to determine if there is a subset of families with specific needs that the system is not currently designed to serve.

    b. A specific examination of the **services and supports rendered to foster families** by both the mental health and the foster care systems to identify what is working well and where modifications or changes may be necessary.

    It is recommended that both studies involve family and CMHC input, chart reviews and secondary data analyses from across the state to identify the optimal services, supports, and/or approaches for these children and families.

5. A growing area of concern relates to services for **children who are dually diagnosed with mental illness and developmental disabilities**. Further examination is needed to identify how to adequately meet the needs of these children and their families across the two service systems.

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# ATTACHMENT
## State-Specific Information on Medicaid Provider Networks

### 1. Arkansas

Public Mental Health System

- Managed care (Primary Care Physician Case Management)
- Prior authorization needed for most mental health services
- Community Mental Health Centers and private, for-profit centers provide most service.

Status of Independent Masters' Level Providers

- State contracts with "any willing provider" which includes master's level providers.
- State has restricted the array of services that can be provided by master's level providers and reimbursement is low.
- Impact on the system is unknown due to low number of providers at this level (about 100 across the state).

Current Status of System

- System reported to be financially "out of control"
- Opening of an array of community-based services (Psychiatric Rehabilitation Option) in 2000 to private, for-profit centers has led to a doubling of costs and much higher utilization of service per recipient.
- Opening of the Psychiatric Rehabilitation Option was hoped to decrease inpatient hospital utilization, but this has not occurred. From 2000-2003, inpatient psychiatric Medicaid costs more than doubled.
- Greater fragmentation has occurred due to opening of Psychiatric Rehabilitation Option.
- Problems occur with over-identification of SED as services for children with this diagnosis receive higher reimbursement.
- Although access has increased overall, problems still exist in rural parts of the state.
- Impact on quality is unknown as the state does not track treatment outcomes.
- It was recommended that the role of the public mental health system be defined and priorities established prior to making changes to the system. It was noted that once changes are made, it is difficult to return to a prior system.

### 2. Minnesota

Public Mental Health System

- Managed care (80% of children served) and fee-for-service
- County board is the local mental health authority.
- County agencies and licensed/certified non-profit agencies provide services.

Status of Independent Masters' Level Providers

- Includes Licensed Clinical Social Workers, recently added Licensed Marital and Family Therapists (LMFT), does not include Licensed Professional Counselor.
- Services provided only within licensed/certified agencies at this time; no prohibition on solo practicioners but discouraged.
- State covers the Medicaid match for all agencies.

Current Status of System

- State does not have access to information about changes after adding LMFTs to the provider network, although some data indicates an increase in psychiatric hospitalization rates.
- Coordination of services is reported to be low.
- Quality of service is a concern and the state is considering limiting the scope of service provided by LMFTs to non-diagnostic services.

### 3. Missouri

Public Mental Health System

- Managed care and fee-for-service
- Psychologists received parity with psychiatrists in August 2003 to serve the adult population. Prior to this time, licensed psychologists could serve only children 0-20.
- In areas where managed care is not available, private master's level providers can bill fee-for-service for children only. Fee-for-service providers are not restricted to community mental health centers.
- The Department of Mental Health (DMH) is involved only with Targeted Case Management and Community Psychiatric Rehabilitation. These services are provided by DMH licensed providers (Administrative Agents/community mental health centers). For the other services, the providers/agencies work with the Division of Medical Services (the state agency responsible for the administration of the Missouri Medicaid Program) or the managed care providers.

Status of Independent Masters' Level Providers

- Licensed and Provisional Clinical Social Workers, and Licensed and Provisional Professional Counselors can deliver mental health services to children ages 0-20 and can work independently.
- Services such as case management are provided through the community mental health centers.

Current Status of System

- The state is currently phasing in Prior Authorization requirements for all fee-for-service providers, estimating a full implementation by July 2005. This is in an effort to curb costs.

### 4. North Carolina

Public Mental Health System

- Fee-for service with the exception of a 5-county managed care project
- Prior authorization for outpatient services after trigger point (26 visits for children) through one state-wide vendor
- Community Mental Health Centers typically provide service to the target population.

Status of Independent Masters' Level Providers

- Licensed Clinical Social Workers and Psychiatric Certified Nurse Specialists/Practicioners were allowed to provide outpatient services to children in 2001.
- January 1, 2005, the system was opened to "any willing provider" including Licensed Psychological Associates, Licensed Professional Counselors, and Licensed Marital and Family Therapists.

- Reimbursement for provider is tied to provider-type with most master's level providers receiving 75% of the full rate

Current Status of System

- Currently in process of 7-year mental health reform roll out
- Changes to the system were implemented due to long waits for services under the prior system. With few access standards for initiation of services, waiting lists were commonplace and the wait for an initial evaluation was often more than 6 weeks.
- As significant changes are currently in process, little is known about the effect on coordination of services, cost or psychiatric hospitalization rates.

**5. Ohio**

Public Mental Health System

- Fee-for-service
- The Ohio Dept. of Job and Family Services (ODJFS) is the single state Medicaid agency. The Ohio Dept. of Mental Health has an interagency agreement with ODJFS to provide the community mental health portion of Medicaid.
- There are 50 regional boards covering the state. These boards do not provide direct service. The boards contract for services with agencies only, not with solo practitioners. The Ohio Dept. of Mental Health (ODMH) certifies and reviews the contracted agencies. A Medicaid contract is issued to any requesting agency that is certified by ODMH. Contracts are for one year; certifications are for three years.

Status of Independent Masters' Level Providers

- Masters' level practitioners provide community mental health services as employees of contracted agencies. Provider qualifications vary by service.
- ODJFS also has a mental health component benefit. Some mental health providers, including social workers, can contract directly with ODJFS to provide that benefit.

Current Status of System

- This system has been in place since the early 1980's and is reported to be working well.
- The state has proposed the addition of Assertive Community Treatment (ACT) for adults and Intensive Home Based services for children through the current framework. They have several other initiatives in progress to improve the system such as uniform cost reporting and clinical systems improvement.