



Developing a Study on Effective Parent to Parent Support Services in the Kansas Children's Behavioral Health System

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INTRODUCTION

Kansas provides fertile ground to assess the effectiveness of parent to parent support. The professional parent role has been established in the children's behavioral health system of care since the early 1990s (Davis-Groves, Barfield, McCave, & Corrigan, 2007). The Parent Support Specialist (PSS) service is a Medicaid reimbursable via the Home and Community Based Services/Serious Emotional Disturbance (HCBS-SED) Waiver. Services provided by Parent Support Specialists (PSS) via the Waiver are termed "Parent Support and Training." Services provided by PSS funded through the Family Centered System of Care (FCSC) grant are often referred to as "Parent Support." In the following report, the term PSS refers to all services that Parent Support Specialists may provide.

Previous work in this area of study included preparing and disseminating an initial study that described the effective components of PSS services. Throughout the dissemination process, researchers sought opportunities to develop a collaborative evaluation of PSS services with community partners.

PURPOSE

This report details steps taken in fiscal year (FY) 2008 toward designing and developing continued study with community partners. Specifically, continued study will explore the impact of PSS services on the outcomes of families whose children receive community-based Community Mental Health Center (CMHC) services. This continued study is a crucial component of a broader research endeavor to establish parent to parent support as an evidenced based practice (EBP) in a children's behavioral health system of care. Specifically, this report describes 1) the development of an EBP in a children's behavioral health system of care, 2) the collaborative design and development of the current study, and 3) the implementation of the study at three sites.

1. DEVELOPING AN EVIDENCED-BASED PRACTICE IN A CHILDREN'S BEHAVIORAL HEALTH SYSTEM OF CARE

1.1 Steps for Developing PSS as an EBP

The literature acknowledges multiple obstacles in integrating evidence-based practices (EBPs) in community practice settings for children and families (Luongo, 2007). Research and training efforts to transfer EBPs to the “real world” have failed to take into account variables such as individual business operations, organizational structure, and fit with program values (Hoagwood, Burns, & Weisz, 2002; Luongo, 2007). There have been few efforts made to move EBP development and validation out of laboratory settings and into typical community practice. Even with considerable evidence that traditional approaches to EBP training have little impact on practice (Carrol & Rounsaville, 2003), state and federal governments continue to expend significant financial resources on EBP training for front line providers. Burns (2003) suggests a Community Intervention model (see Appendix A) to guide development of an EBP in a community setting. The model, however, does not incorporate the Participatory Action Research (PAR) approach that is informing EBP development in the Kansas behavioral health system. PAR is a method for engaging communities in research activities in which community stakeholders are involved in designing, implementing, and interpreting research results (Washington, 2004). All stakeholders are considered equal partners and share responsibility in achieving authentic, contextually relevant results. The PAR approach necessitates more fluidity between EBP development steps, as the research process is a collaborative effort of community partners and researchers. A model for developing an EBP in a behavioral health system of care utilizing a PAR approach does not exist. Kansas is in a unique position to contribute to the knowledge base.

1.2 Progress Toward PSS EBP Development

Current literature (Burns, 2003; McNeece & Thyer, 2004) indicates that the PSS Study Team and collaborative community partners have made considerable progress on EBP development. Our work has produced a summary of the best available evidence on parent-to-parent support interventions in children's behavioral health systems of care. This laid the foundation for the current study that will 1) manualize the phases of PSS intervention within the context of the practice setting and 2) document the PSS program's theory of change. Researchers hypothesize that the peer aspect of parent-to-parent PSS services accelerates the relationship building process in a unique way, leading to more efficient use of services and better outcomes (e.g., increasing family empowerment, reducing caregiver strain, and improving children's outcomes).

The literature review along with stakeholder input was utilized to develop an inquiry into effective PSS practices. Results indicate that the majority of PSS providers are family members of a person living with mental illness or serious emotional disturbance. These

shared life experiences allow PSS providers to develop credible relationships with parents, fostering hope for the future. Effective PSS providers view parents as the primary resource for improving family well-being. Parents learn constructive ways to be involved in their children's lives and communities. Stakeholders describe effective PSS providers as approachable, honest, diplomatic, and passionate. Parent Support Specialist providers are most effective in agencies that embrace the family perspective brought to the treatment process by PSS providers. A code of ethics, supervision, training, and access to PSS peers facilitate professional development (Davis-Groves et al., 2007).

In FY 2008 the effectiveness findings and PSS practice wisdom were utilized to design, develop, and implement the current study. Specifically, community partners (i.e., PSS providers and CBS directors) and researchers refined study components through a detailed feedback process. Then community partners were asked for guidance to select sites for the current study. Three sites were chosen to implement the current study. The remainder of this report describes the steps taken to develop a contextually relevant EBP for Kansas parent to parent services.

2. COLLABORATIVE DESIGN AND DEVELOPMENT OF CONTINUED STUDY

This study consists of two components which are highlighted below. Both were collaboratively designed and developed with experienced PSS service providers utilizing a PAR approach. Maximizing PSS expertise allows for developing a model that is adaptable in multiple CMHC contexts.

2.1.0 Longitudinal Study of PSS Services

The first component examines longitudinally (i.e., over time) how PSS services impact outcomes for families whose children receive services through a CMHC. Specifically the study will

- 1) assess families' baseline functioning when they are referred to PSS services,
- 2) identify the specific family needs that the PSS intervention addresses,
- 3) track Medicaid mental health services utilization before and after referral to PSS services,
- 4) monitor child and family outcomes (caregiver strain, family empowerment, and child strengths/behaviors) after PSS services begin, and
- 5) assess relationship development between the PSS service provider and the parent.

2.2.0 PSS Model Development & Implementation Evaluation

The second component documents and refines the Kansas model of effective parent-to-parent-support. Specifically, this component of study will document the essential aspects of the PSS intervention. Model development will be informed by multiple stakeholders including parents, PSS providers, administrators, and other team members. This part of the study begins the construction of PSS EBP protocol within practice settings. The protocol will provide a foundation for the development of a fidelity tool.

2.3.0 Research Approach

The approach used in this study is termed Participatory Action Research (PAR). PAR is a method for engaging communities in research activities. Utilizing PAR, researchers seek "maximum participation of all individuals whose lives are affected by the issue under study" (Nelson, Orchocka, Griffin, & Lord, 1998, p. 885). Researchers collaborate with community stakeholders in designing and implementing research as well as interpreting results (Washington, 2004). All stakeholders are considered equal partners and share responsibility in achieving authentic, contextually relevant results. Scrimshaw, White, and Koplan (2001, p. 7) emphasize that "the research is conducted *with* communities, not *on* communities."

Researchers and communities alike benefit from this approach. Researchers increase their knowledge of community stakeholder needs and perspectives, resulting in

improved research design, enhanced implementation, and more accurate interpretation of findings. Stakeholders benefit through expansion of their research knowledge and skills that can be used to improve outcomes for their communities and to influence potential funders (Washington, 2004).

To accurately implement a PAR approach, community partners and researchers must both understand the approach and develop mutually agreed upon procedures. This procedure development process can be time intensive on the front end but pays off in the immediate uptake of research findings into policy and practice, even prior to the completion of the study. This is a marked departure from conventional scientific inquiry whose results are not accessible to interested parties until data collection is fully concluded and analysis is complete. Only then are findings published for general public consumption.

Participatory Action Research is particularly well suited to evaluation of parent to parent support services provided within the context of the Kansas children's behavioral health system. PAR partnerships between researchers and peer support providers have been implemented successfully when evaluating interventions involving adult consumers of mental health services (Nelson et al., 1998) and parents of children with a broad range of disabilities (Santelli et al., 1998). For the purposes of this study, the collaborative nature of PAR strengthens the entire context in which the PSS EBP treatment model is being developed and consequently reduces threats to external validity of the research. Further, benefits to PSS stakeholders are being evidenced already (see detailed description in Section 2.5.0 of this report).

2.3.1 Incorporating PSS Practice Wisdom in the Research Design

The PSS services statewide network is an essential partner in the research process. The network consists of parent professionals from across the state of Kansas who are experienced with family preferences and unique community characteristics. The network's presence in the system of care represents a model for successfully integrating and sustaining family voice in a behavioral health system of care. In addition, the network's members have extensive practice expertise. For instance, the initial study findings indicated that over half of participants have served as PSS for 1 to 2 years, one quarter between 5 and 7 years, averaging a longevity of over 3 years.

Given the great amount of feedback and insight provided by PSS providers in the initial study and their interest in the dissemination of those results, the entire PSS group was consulted during the current study development process.

2.3.2 Building Partnerships

The network statewide meetings provided a key avenue to facilitate partnership. During the meetings, we are able to present recent study findings and the current study proposal to as many PSS providers as possible. We pursued this opportunity to build a

relationship with the group and gain feedback during the development and implementation phases.

Upon the suggestion of the Children and Family Consumer Affairs Representative, researchers engaged PSS providers in regional groups. Some regional PSS groups had already formed and were holding regular meetings, while others had not. At a statewide PSS network meeting, the research team organized PSS providers into regional groups and facilitated focus groups. The goals of the focus groups were to 1) introduce the study proposal, 2) discuss the teams' desire to gain more feedback, and 3) set dates for regional meetings.

The research team attended 12 focus groups around the state from June 2007 to September 2007. The goals for the focus groups were to 1) present the proposal for continued study, 2) present key findings from the FY 2007 study illustrating what makes PSS programs successful, and 3) request PSS guidance in nominating sites for implementation of the future study. The focus groups were audio-taped, and the tapes were then transcribed and analyzed. From there, the resulting themes from the focus groups were incorporated back into the research design development as described below.

2.4.0 Contextualizing the Model - PSS Recommendations

Several recommendations for the study proposal were made by PSS providers. Some of these recommendations reinforced the existing proposal and strengthened the usefulness and potential benefit of the study. In the following section, a summary of PSS recommendations are described, then the revised study processes, protocols, and next steps are presented.

2.4.1 Systems Changes Impacting Model Implementation

The Kansas behavioral health system, of which PSS services is a part, underwent a significant change on July 1, 2007. At that time, the system was converted from a fee-for-service model to a managed care entity. The Kansas Department of Social and Rehabilitation Services, Disability and Behavioral Health Services (SRS/DBHS) contracted management of the new Prepaid Ambulatory Health Plan (PAHP) with Kansas Health Solutions, a corporation sponsored by the CMHCs. As a part of this change, Medicaid reimbursement for delivery of a portion of services was opened to a greater number of mental health practitioners outside the CMHCs in an effort to enhance consumer choice and service access. In addition, Medicaid billing regulations changed for certain community based services, resulting in the elimination of some services from the community-based services array.

Considering the changes, PSS providers indicated that initiating the study in the summer of 2007 had advantages and disadvantages that needed to be considered. First, an

advantage of starting in the midst of multiple system changes is that the study may show the stabilizing force of PSS services because PSS providers remain accessible to families throughout treatment. Since the systems change, some PSS providers reported that families needed their assistance sorting out new provider roles and tasks. For example, some families who previously had one case manager now had two: one provider for Community Psychiatric Supportive Treatment (CPST) and one for Targeted Case Management (TCM).

However, the ongoing adjustment to system change was also seen as having potential disadvantages. For example, some agencies allow providers other than PSS providers to bill their activities as parent support services. According to PSS providers, this procedure creates confusion among providers on treatment teams in agencies that had historically only had the PSS provider billing the PSS Medicaid waiver service. The network emphasized a strong desire for continued research to preserve the integrity of the parent-to-parent component of the PSS service in the system.

The next steps in the research process were carefully planned. Researchers sought to find sites for continued study that would honor the PSS network input. The research team invested considerable energy finding sites for continued study that possessed the following successful PSS program components identified in the FY 2007 study.

- 1) PSS providers are family members of a child with SED.
- 2) PSS providers are knowledgeable and understand their role in the agency.
- 3) Programs refer families to PSS services at the onset of all services. This program component was difficult to find in actual program practice. Most agencies would like to refer to PSS services at the onset of all services but do not do so in routine practice because they do not have enough PSS service providers on staff to offer the service to all families. Thus, researchers sought sites for continued study that were open to referring families to PSS services at the onset of all services and included families who had been receiving other services prior. Other services may include outpatient therapy and other community based services written in the treatment plan. These services could include case management, individual community support, home-based family therapy, etc.
- 4) Program staff utilize a team approach.
- 5) PSS providers receive regular, sensitive supervision. Sensitive supervision means that supervisors take active steps to support PSS as they transition from a consumer to a provider role within the agency, including
 - listening to PSS concerns or challenges they face in the role,
 - coaching on establishing their role with families,

- listening to feedback PSS provide about program practices that do not support family-driven values,
- encouraging PSS to access their peers for mentoring and support,
- mentoring PSS and treatment team members to successfully integrate the PSS role within the team,
- coaching PSS on how to promote themselves within the agency, and
- educating team members about how they may utilize the PSS service.

6) Staff values the PSS perspective on the treatment team.

This step required more time than originally planned but was necessary to find sites that would support study implementation and further parent-to-parent support model development.

2.4.2 Stakeholder Engagement

Early on it became apparent that PSS providers wanted a voice in the development of the study proposal and in the selection of sites. PSS providers indicated that it was imperative to provide information to CBS directors in order to get their support and feedback on the study as well as to disseminate the findings from the first study. Also, PSS providers told us that it was important to engage administrators, direct staff, and PSS providers at other sites throughout the study process.

To operate within the PAR model, the research team sought opportunities to integrate the PSS/family perspective into the research process. In November 2007, the research project incorporated a Family Evaluator with several years of experience in providing parent support services within the Kansas behavioral health system of care and who promoted family empowerment through the utilization of research. The primary role of the Family Evaluator on the PSS study is to help the research team understand issues from a PSS perspective and in their context by 1) consulting on research activities, 2) supporting effective partnering with stakeholder groups, and 3) participating in building a research team that embraces the family-driven approach.

With the assistance of the Family Evaluator, the research team began acting on PSS recommendations for stakeholder engagement. First, in July 2007, a letter was sent out statewide to CBS directors, executive directors, and PSS providers for the purpose of obtaining directors' support and involvement in continued study of PSS services. The letter introduced the researchers' desire to partner with directors in the design and implementation of continued study. Finally, the letter notified stakeholders that researchers would be attending the statewide Children's Directors meeting in August 2007.

A presentation was prepared and presented to CBS directors (the presentation is available on the University of Kansas (KU) School of Social Welfare's website at <http://www.socwel.ku.edu/occ/projects/articles/PSS%20Support%202007.pdf>).

The purpose was to share the initial study findings, describe development of continued study, and seek CBS directors' support and involvement in the continued study. The presentation allowed researchers to introduce the PAR approach. Additionally, CBS directors were invited to participate in the scheduled regional meetings to hear the most current study proposal and focused discussions on study logistics. The regional meeting schedule was provided and a sign-up sheet was passed around for researchers to contact CBS directors to explore future involvement. Fourteen CBS directors signed up for more involvement.

Subsequently, in November 2007, another letter was distributed to all directors and PSS providers. The letter updated the feedback received at the regional focus groups where PSS providers and participating supervisors were asked to apply their practice expertise to the design and site selection process.

The feedback analysis highlights the benefits of grounding the research process in community practice. For example, the focus groups facilitated discussions with practitioners about the most effective PSS practices and asked them to apply the key findings to their practice. The feedback from PSS providers illustrated that the research process was having an impact on their practice. A survey was developed to document the impact of research engagement and is described in section 2.5.0 on page 14.

2.4.3 Study Participants

PSS providers recommended the inclusion of multiple participant groups. These participant groups, their individual attributes, and rationales for inclusion are discussed below.

- Family member participants should include parents, grandparents, or others with significant caregiving responsibilities. Family members who have received PSS services can give a "real" account of what makes PSS services effective. PSS providers also suggested including both waiver and non-waiver families as participants because of varying family needs and appropriate interventions, as well as families with children and youth of varying ages and their community based programs. Some PSS providers reported that they served families with children as young as age 3. These children and their families may be involved in preschool-age programs. PSS providers practice experience helped to make the study truly representative of all family member that may be affected by PSS services.
- Supervisors who have demonstrated high quality, supportive supervision to PSS providers are important to include as study participants, particularly those

supervisors who take steps toward integrating the PSS role on treatment teams. For example, some PSS providers said their supervisors encourage staff to utilize the PSS services by recommending PSS consultation to guide sensitive conversations.

- The entire wraparound team could provide useful information because of the varying perspectives. Inclusion of the following variety of providers is necessary because of team members' unique contributions.
 - PSS providers who have or have had family members with SED. PSS providers thought family providers' perspective was important to document in the course of further study. Providers with varying years of experience, representing multiple community contexts, should be included.
 - Therapists who frequently refer families to PSS services. Therapists could provide a unique perspective on when PSS services are needed and insight into how these services impact the treatment process.
 - Case managers who have an ongoing positive relationship with the youth. Case managers focus on youth and could provide insight into how PSS services positively impact youth. PSS providers recommended that with the split of Case Management into TCM and CPST, there would be value in including both groups as participants. PSS providers recognized that if resources are limited, TCM is the logical choice because of their role as coordinator of services.
 - Attendant care workers who spend a large amount of time with youth. They may possess detailed insight about youth behavior changes.
 - Community Members. In keeping within the true spirit of wraparound, PSS providers also suggested including outside community members as potential participants (e.g., teachers, neighbors, and club leaders), since they have direct interaction with the youth.

With these recommendations in mind, procedures for involving and recruiting study participants were developed and are described below.

2.4.4 Study Participant Recruitment Protocol

- Family member participant protocol will follow PSS recommendations. For the longitudinal study, referrals will be taken for family members who are newly

referred to PSS services. The families* will be approached by a designated PSS CMHC employee to briefly explain the study and obtain parent/guardian permission to give researchers their names. Researchers will then coordinate with CMHC staff to schedule the first research engagement with families. CMHC staff will ask families how they prefer to meet researchers, at the CMHC with the PSS present or over the phone. CMHC staff will then notify the researchers regarding the the family's preference and researchers will set up the first research engagement with the family. At the first research engagement with the family, researchers will pursue full consent. Researchers will also seek child and youth participation via an assent procedure in the first engagement with the family. Upon gaining parent and child/youth consent/assent to full participation, researchers will seek permission to contact the family's PSS and one other CMHC service provider with whom the family is working. The family will be asked to give the name of the provider on the team who they perceive has the most knowledge of their child's functioning. Family member participants will be recruited until 20 family members are involved in the study.

- Service provider participants from the wraparound team will be contacted by researchers after family members have consented. The study will be explained to them in detail. If they consent to participate, provider participants will be offered the opportunity to complete the BERS-II online or over the phone with researchers.
- Other team members' perspectives (community members, agency supervisors, and experienced PSS providers) will be gathered in the course of the model development and implementation evaluation. The data to be collected and procedure is described in section 2.4.6 of this report.

2.4.5 Site Selection

PSS recommendations, research methodology, and project resources were all taken into consideration for site selection.

- Parent support specialists recommended considering only sites with PSS providers who receive regular, sensitive supervision (see discussion on page 7—successful program component number 5). They indicated that supportive supervisors would enhance the feasibility of completing data collection. PSS providers supported including sites that employ PSS providers who are family members. Lastly, PSS providers indicated that it was important to consider the culture of the community and the culture of the CMHCs, as certain areas such as frontier counties are very different from urban counties. This also means understanding

* Family participant refers to primary caretakers, legal guardians, resource parents, and grandparents.

the practice context when there is only one PSS provider serving a CMHC as opposed to two or more PSS providers.

- Appropriate research methods available to achieve the four broad aims were considered. Specifically, to assess the unique contribution of the parent to parent support services, researchers thought it would be best if PSS did not operate in other roles such as wraparound facilitator and case manager. In addition, sites whose programs refer to PSS services at the point of entry into all CMHC services will provide a better baseline than those who refer later. Lastly, in keeping with PAR methods, researchers sought to identify CMHC partners with expert practice knowledge of PSS interventions at all levels of CMHC operations (practice, supervision, and administration). These aspects were assessed through site visits with potential partner CMHCs.
- The project resources would only allow for the study to be conducted at three sites. Though multiple PSS providers expressed interest in participating in the study, sites had to be carefully chosen to represent all the unique attributes of PSS providers described above, as well as represent different geographic regions of the state.
- After disseminating the parameters to PSS providers at statewide and regional meetings (including a CBS Director's meeting), several CMHCs nominated themselves or another CMHC. The final selection for study sites was made by CMHC CBS Directors and the KU Research Team, with assistance from the SRS Consumer/Family Liaison. Two CBS directors volunteered to be study sites. The final site was considered for its expertise and the service delivery approach of the CBS team. This particular site has a PSS provider (Virginia Standley), several case managers, and an Executive Director who were involved in the development and implementation of the original KanFocus grant that allowed for the initial hiring of a PSS provider as an employee of a CMHC. Virginia was one of the first eight PSS providers employed in a CMHC in 1999 and possesses expert knowledge of parent support services. The three pilot sites chosen to participate were Labette Center for Mental Health, Mental Health Association of South Central Kansas, and Area Mental Health Center.

2.4.6 Data Collection

The original proposal procedures presented to PSS providers are described below, followed by the PSS recommendations. The last part of this section describes the measures and data collection intervals.

- In the original proposal, data collection was to start within 1 week of referral and continue weekly for the next 6 weeks. These measurement intervals were developed based on the FY 2007 study finding that PSS providers have the potential to impact outcomes quickly via rapid relationship development. In

addition, the literature on therapeutic change suggests that change occurs early in relationship development, often within the third to fifth meetings (Hubbel, Duncan, & Miller, 1999). Feedback from PSS providers indicated that this time frame was not workable given a number of factors. They noted that PSS providers generally need more time to develop rapport with families. In addition, the PSS provider may not be able to fill out assessment measures accurately and completely after knowing the family for only a short time. PSS providers indicated that some families are referred during crisis and may not have the time or energy to participate in the study when they are first referred. PSS providers also questioned whether 2 months would be long enough to gather meaningful data. They suggested that data collection begin within 1 month of referral with follow-up every 3 months for 1 year.

- PSS providers validated that it was important to include a focus on the unique relationship between PSS providers and families and to include a measure designed to capture relationship strengths. They also indicated that it would be helpful to show them the measures to be utilized in the study. PSS providers felt this would be helpful to assure the selected measures would yield outcomes relevant to their work with families. In addition, PSS providers suggested the development of a concrete, detailed research protocol that would provide information about the implementation of the study including how staff would fill out the study measures, how much time it would take, and who would be responsible for gathering data.

With these recommendations in mind, data collection procedures were developed and are described below.

- Data collection will begin within 1 month of referral to PSS services, then again at 3 months, 6 months, 9 months, and 12 months. All participants will be asked to fill out standardized measures developed for families and youth who experience SED.
- Parents/caregivers will complete the following:
 - Working Alliance Inventory (WAI) (Horvath & Greenberg, 1986; Tracey & Kokotovic, 1989)
 - Family Empowerment Scale (FES) (Koren, DeChillo, & Friesen, 1992)
 - Behavioral and Emotional Rating Scale, 2nd Edition (BERS-II) (Epstein, 2004)
 - Caregiver Strain Questionnaire (CGSQ) (Brannan, Heflinger, & Bickman, 1997)
- Youth age 12 and over will be asked to complete the youth report form of the BERS-II, with youth age 11 and under completing it with the assistance of researchers and caregivers.

- Parent support specialist providers will be asked to complete the WAI and FES.
- The other provider participant with the best knowledge and relationship with the youth will be asked to complete an observer form of the BERS-II. This provider will be determined by the families when the study is explained to them in detail.
- All provider participants, family participants, and PSS providers will have the opportunity to participate in the model development interviews and focus groups. Interviews and/or focus groups will be set up with longitudinal study sites when 6 and 12 months of data (outcome and service utilization) have been collected. In addition, the PSS study team will conduct focus groups at the PSS statewide network meetings on each stage of the model development. All participants will be provided with an information statement that explains the purpose of the research activity. The purpose will be to ask stakeholders to 1) respond to aggregate outcome and service utilization data, 2) provide feedback on the model development findings, and 3) complete a survey on the impact of their participation in the research process. The interviews and focus groups will be taped, transcribed, and analyzed.

2.5.0 Research Engagement Impacts PSS Providers

Through continued engagement with PSS providers, researchers learned that study activities affected PSS providers and communities. For example, one PSS provider indicated that filling out a survey during the FY 2007 study assisted with understanding her primary functions within the children’s mental health service array. Researchers sought to understand how engagement in the study impacted PSS, particularly since researchers regularly attended PSS Statewide Network meetings and provided information beneficial to PSS practice.

To further understand the impact of engagement, a survey was developed in FY 2008 to assist researchers in understanding how a participatory approach to the study impacts PSS providers’ practice. Following participation in PSS study activities with researchers, PSS providers who consented to participate completed a survey that allowed for an anonymous feedback loop.

Completion of the survey by PSS providers occurred three times in FY 2008 at two Statewide Network meetings (November 2007 and January 2008) and the PSS Annual Conference held in April 2008. Results suggest that PSS providers experience practice benefits from this involvement. Some of the written comments from PSS providers are as follows:

I was validated and felt like it was one of the few times that I saw a list of exactly what I do and see each day in my work.

Gives me information and feedback about how I can be a better PSS.

*Give time to process what I do on a daily basis for families...pause to think.
Increased discussion with other PSS.*

It helped me stop and think what impact I can have in families.

The more info we have the better we can serve our families.

*This is so important for us as a way to strengthen our role within our particular
CMHCs and to build our self-esteem as we continue to struggle to help our
families within our State and local constraints.*

Findings from the last two surveys, with at least 45 PSS providers completing the survey once, showed that PSS involvement in each research activity was viewed as positive and meaningful. Further, the majority of participating PSS providers expressed a desire to continue involvement in future research activities and identified the types of activities that they preferred, as noted below.

- The majority of PSS providers reported some level of impact by the research activities in which they participated (81.3% in January; 96.2% in April).
- The majority of PSS providers also reported being satisfied or very satisfied with the activities (90.6% in January; 89.3% in April).
- The majority of PSS providers expressed a desire to continue some level of involvement in future research activities (75.0% in January; 88.9% in April). In January, 37.5% of the group stated a strong desire for continued involvement; in April, 40.7% said the same.
- 45 PSS providers identified the following ways they would like to continue involvement in research activities. At least half the group selected more than one activity.
 - Involvement at PSS Statewide meetings (50.0% in January; 78.6% in April)
 - Communication with researchers by email (43.8% in January; 64.3% in April)
 - Communication with CMHC administrators and direct staff about activities (28.1% in January; 34% in April)
 - Participation in a smaller research advisory group (31.3% in January; 28.6% in April)

3. IMPLEMENTATION

Once implementation sites were selected, researchers began expanding partnerships. Meetings with administrators and agency staff were set at the three sites. These meetings provided an orientation to 1) the PAR approach, 2) the FY 2007 study, and 3) the study proposal. In addition, researchers gathered feedback on study procedures and engaged administrators in discussions regarding the feasibility of conducting the study at their agencies. In this process, researchers learned about multiple variables that agencies must consider prior to involvement. Specifically, administrators needed to understand the necessary time commitment and how participation in the study would affect billable time. Since agency staff expressed concerns about being “maxed out” with normal expectations, administrators sought information on all the study specifics to inform staff and obtain their support. In addition, contractual relationships were negotiated to meet the agencies’ financial needs and expectations, ensuring participation over the year-long process. Administrators were engaged in discussions about a fair compensation rate for staff participation in the study.

In order to fully understand the PSS intervention model (i.e., which PSS activities are related to outcomes), the KU research team developed a means to operationalize and break down the core components of the PSS model in the PSS practice setting. The model development is broken into phases. The first phase, initial engagement, includes the referral process and the first PSS contacts and activities with families. The KU team developed a questionnaire with the help of the Family Evaluator and one of the long-standing PSS providers/supervisors in the state. Findings from the FY 2007 study and the PSS Training Manual (KidsTraining Team, 2006) also provided important information to include in the questionnaire. The questionnaire was developed to obtain detailed information about the early phase of intervention. Examples of questions included the following: *How does the referral process work at your CMHC? What is your main goal when first meeting with families? How do you accomplish your goal?* The KU research team interviewed each of the PSS providers at the three study sites by phone. The conversations were audio-taped so that content can be analyzed for core components of the PSS service early intervention phase. Eventually all other phases of intervention (e.g., work/treatment, termination) will be operationalized. Documentation of the phases of PSS intervention will significantly contribute to EBP development of PSS services, which may strengthen fidelity across the state of Kansas.

Additionally, the PSS Study Team is evaluating the PSS program’s theory of change, namely how interventions impact outcomes. Researchers hypothesize that the peer aspect of parent to parent PSS services accelerates the relationship building process in a unique way, leading to more efficient use of services and better outcomes (e.g., increasing family empowerment, reducing caregiver strain, and improving children’s outcomes). Parents trust that a peer (e.g., parent to parent PSS provider) will view their circumstances nonjudgmentally from the same perspective as themselves because they have “walked in their shoes.” Further, a veteran parent symbolizes “living proof”

evidence that better outcomes are possible. Thus, the peer component of parent to parent PSS services brings a new one-of-a-kind credibility to the treatment process. This is important to understand in order to generalize the PSS intervention across sites. This data will be gathered with quantitative methods to confirm the initial impressions from qualitative exploration in the FY 2007 study.

4. IMPLICATIONS

The study approach has implications for the Kansas behavioral health services system. First, stakeholders were involved from the outset of the research process. This helps to ensure the external validity of the results. In addition, service providers (PSS and their program administrators) have immediate access to best practice knowledge and receive technical assistance applying research findings to practices. Second, the study process organizes groups of PSS providers who are able to share information supporting effective service delivery to families on the HCBS-SED Waiver. Third, the model development attends to context variables such as effective supervision practices, organizational culture, and daily business operations. Attending to these context variables also helps ensure valid results that are meaningful to communities and their research partners. By investing in the development of a context appropriate PSS EBP, the State capitalizes on established expertise within the PSS statewide network and supports further training and integration of family voice within the children's behavioral health system. In summary, the commitment to the PAR approach pays off in the uptake of research findings into practice.

5. SUMMARY AND NEXT STEPS

5.1 Continue Implementation of the Current Research Project

Researchers will keep in regular contact with all research participants (family members, PSS providers, and service providers) throughout the study. As mentioned above in the study participant recruitment protocol, at 6 and 12 months, researchers will conduct semi-structured interviews, administer a brief survey on the impact of the research process, and present themes in the aggregate concerning outcome and service utilization data.

During the semi-structured interviews, families will be asked for feedback about what made or would have made the PSS intervention helpful to them at initiation of PSS services. In addition, researchers will gather this feedback from agency staff and administrators regarding the early engagement phase. The survey will assess the families' satisfaction and feedback concerning their interactions with the researchers and their engagement in the research process. The same survey will be utilized with staff. Themes present in the aggregate outcome and service utilization data will be presented to families and agency staff.

Family member participants will be reimbursed for each data collection interval. Agencies will receive reimbursement for the time agency staff spend coordinating and participating in the study.

A summary of the following components will be included in the FY 2009 end-of-the-year report: 1) families' baseline functioning upon referral to PSS services, 2) specific family needs that the PSS intervention addresses according to the Medicaid definition, 3) family utilization of behavioral health services before and after referral to PSS services, 4) child and family outcomes (family empowerment, caregiver strain, child strengths, and child behaviors) before and after PSS intervention, and 5) assessment of relationship development between the PSS provider and the parent.

5.2 Begin Developing a Fidelity Tool for the PSS Model

As described above, there is no EBP for parent to parent support services in a system of care; this project signifies the first step. However, the KU Research Team and PSS partners have made a considerable contribution to the evidence base. The developing PSS model will be studied as it is implemented at two of the study sites (Mental Health Association and Labette Center for Mental Health). The other study site (Area Mental Health) will be utilized as a test site for a PSS model implementation evaluation. This site does not have experienced PSS providers and thus provides a practice setting to assess the "goodness of fit" in another practice setting. In addition, new PSS providers will be trained at this site to implement the PSS model. The training procedure will be developed in collaboration with the KU School of Social Welfare, Wichita State

University's Training Technology Team, and the Kansas Department of Social and Rehabilitation Services Division of Disability and Behavioral Health Services (SRS-DBHS). Implementation protocols will be monitored closely. Variables that contribute to sustainability of the model (organizational structure, leadership style, and family driven practice principles) will be assessed. This implementation evaluation will later be utilized to develop a fidelity tool, in the event that PSS services are established as an EBP.

As discussed above, the PSS statewide network represents a wealth of diverse practice wisdom and the family perspective. This wisdom is critical to include in the documentation of the PSS model. The bimonthly statewide network meetings are an opportunity for PSS providers to share effective intervention strategies and gain support to enhance their work. A component of effective PSS practice identified in the previous study was access to PSS peers. The PSS statewide network meetings facilitate connection and sharing of ideas as well as trouble shooting about how to encourage family driven mental health services. These networking opportunities are likely to become a viable component of the PSS EBP fidelity tool as the network supports individualized implementation of PSS practice principles. In fact, a critique of traditional human service EBP training models (e.g., single continuing education event or classes) is that they do not foster the ongoing development of practitioners in their practice environments (Luango, 2007). Thus, regular and consistent researcher and PSS stakeholder contact is essential to 1) maximize PSS practice wisdom in model development and 2) assess the influence of the PSS network on implementing parent-to-parent support services as an EBP. The PSS Study Team would like to develop a plan with the PSS statewide network officers and the Consumer/Family Liaison to develop a plan for contact with the PSS network.

5.3 Identify Next Steps on Types of Involvement in Research

The majority of PSS providers participating in research activities expressed a desire to continue some level of involvement in future research activities (93.5% in January; 88.9% in April). In January, 35.5% of the group stated a high desire to continue being involved; in April, 40.7% said the same. The research team would like to explore next steps with the PSS statewide network and the Children and Family Consumer Affairs Representative and develop goals to achieve their desired level of involvement.

5.4 Continue Collaboration with State-Level Policy Makers

The Children and Family Consumer Affairs Representative plays a critical role in the implementation and evaluation process. The Children and Family Consumer Affairs Representative works closely with the PSS statewide network and supports activities that enhance their training and education opportunities. The research process supports the Children and Family Consumer Affairs Representative by providing immediate access to best practice knowledge and providing technical assistance by applying research

findings to practice. In addition, regular contact with the Children and Family Consumer Affairs Representative is crucial to ensure that research activities fully integrate the PSS role within the Kansas behavioral health system.

5.5 Develop Fidelity Monitoring Plan

Kansas is in a unique position to further establish PSS services as an effective service within a behavioral health system of care. Kansas has an established statewide training network via Wichita State University's Training Technology Team and SRS-DBHS. The original training for PSS providers was developed in partnership with PSS providers working in the CMHC service system and is delivered by PSS providers. The training model parallels the service delivery approach of PSS providers. The training represents a model of partnership recognizing parent providers' expertise and importance in both development and delivery. As the PSS model is being developed and evaluated, the University of Kansas School of Social Welfare researchers will begin discussions with the Wichita State University's Training Technology Team and SRS-DBHS to plan for soliciting, training, implementing, and monitoring fidelity of the developing PSS model in FY 2010. Plan development will follow the participatory action research approach which incorporates a consensus building procedure. All stakeholders, including families, will have a voice and input into a contextually relevant procedure. The plan will be included in the FY 2009 end-of-the-year report. SRS-DBHS will provide final review and approval of the fidelity monitoring plan.

APPENDIX A

Clinic/Community Intervention Development Model

(from Hoagwood, Burns, & Weisz, 2002, pp. 335-337)

Step 1: Theoretically and Clinically Informed Construction, Refinement, and Manualizing of the Protocol within the Context of the Practice Setting Where It Is to Be Delivered

As with any new therapy or service, the first step is to develop, pilot test, and refine a manual for the protocol. The scientific and theoretical literature is useful in identifying the constructs and the rationale for the intervention and the hypothesized explanation for intended outcomes, but the experiences of clinicians, practitioners, or other mental health providers within the setting in which the treatment or service is to be developed are essential for ensuring that the protocol reflects the needs and capacities of those who will ultimately deliver it.

Step 2: Initial Efficacy Trial Under Controlled Conditions to Establish Potential for Benefit

An initial test of the protocol occurs in this step under controlled conditions and with children who have significant problems but not severe pathology. Typically these children will be recruited for the study and will not have been referred for treatment in service settings. This step is intended to assess whether the service compared to a control condition results in positive outcomes among children, who are usually volunteers. The purpose of this step is to ensure that the protocol does no harm and has the potential to be beneficial. The controlled conditions also enable the investigator to test whether the hypothesized relationship between the intervention and the consequences is supported.

Step 3: Single-Case Applications in Practice Setting, with Progressive Adaptations to the Protocol

This step involves a series of pilot tests for cases referred from the practice setting to research-trained practitioners or clinicians who are familiar with the protocol. Across the series of individual cases, adaptations will be made to the protocol to reflect what is learned about individual variations. The object is to keep the development and refinement of the protocol closely connected to practice, with increasing involvement of real-world cases in real-world practice settings. At the same time, an equally important goal is to maintain sufficient scientific control over the testing of the new protocol such that the intervention is developed in an ethical and scientific manner, and no harm is done to the participants. This third step therefore should involve supervision from both the

research team that has developed the manualized protocol and from the practitioner or clinical staff, to ensure confidence that the protocol is appropriate for the needs of the clients, clinical staff, and practice setting.

Step 4: Initial Effectiveness Test, Modest in Scope and Cost

This step involves a trial of the newly adapted protocol within the practice setting itself. Clients who are typically seen in the practice are randomly assigned to either receive the new protocol or to receive services as usual. The protocol is delivered by research-trained staff, generally not yet by actual practice staff, in order to assess the impact of the new protocol under slightly more controlled conditions than are normal in practice settings.

Step 5: Full Test of the Effectiveness Under Everyday Practice Conditions, Including Cost-Effectiveness

This step entails a randomized field trial in which the protocol is tested within the practice setting itself. Clients are randomly assigned to receive either the protocol or services as usual; the actual clinic or practice-setting staff members are randomly assigned to either deliver the new protocol or to deliver services as usual. Outcomes are tracked for their long-term (i.e., at least 12-month) impact, and a range of outcomes is assessed, including cost-effectiveness. Embedded within this trial can be tests of those moderators or mediators hypothesized to be related to outcome variations.

Step 6: Effectiveness of Treatment Variations, Effective Ingredients, Core Potencies, Moderators, Mediators, and Costs

A variety of studies can be launched in this step to address factors that impinge upon outcomes—for example, tests of outcome moderators and tests of variations in the treatment or service, such as differential impact of treatment for children alone versus children plus parents. Also included here would be tests of the mediators of child improvement (i.e., the change processes that potentiate outcomes). Tests of treatment variations and mediators are especially important in our efforts to keep treatments streamlined and efficient. Findings will be very relevant circumstances where pared-down versions of the treatment and service may be requested. Outcomes attained or not attainable through such minimized versions need to be understood. Tests of augmented models of the protocol can fit within this step as well.

Step 7: Assessment of Goodness of Fit Within the Host Organization, Practice Setting, or Community

This step involves a series of studies to assess organizational characteristics that may influence the willingness of practitioners to adopt or to use the protocol or the ability of the institution, agency, or practice setting to sustain the service with fidelity to improved outcomes. Studies in this step would include examination of features of the organizational culture or context that impeded or facilitate the uptake or adoption of the new protocol. Variables such as workplace flexibility, practitioner autonomy, leadership style, productivity requirements, incentive structure, workplace staff turnover, practitioner motivation, or attitudes towards change may influence both the ability of clinicians or providers to use the new service and the ability of the organization or practice environment to sustain it.

Step 8: Dissemination, Quality, and Long-Term Sustainability Within New Organizations, Practice Settings, or Communities

The difference between this final step and the previous one is that this involves a series of studies about the feasibility of dissemination of the effective treatment or service to multiple agencies, organizations, clinics, or communities. The purpose of this step is to examine the range of variations in organizational culture or context across multiple practice settings that facilitate the uptake of the effective service, generate long-term outcomes, and sustain the service within the sociology of improved practice. Improvements in practice depend upon knowledge of those structural elements of agencies, clinics, schools, or other practice environments that interfere with or support the quality of care and the delivery of quality services (e.g., fiscal structure; extent to which families are engaged in treatment development, selection, or delivery; clinician autonomy or motivation; workplace flexibility). Studies of variations in practice environments that enable providers to deliver the service with fidelity to the protocol will lead to improvements in the quality of care across a range of delivery agencies.

REFERENCES

- Brannan, A. M., Heflinger, C. A., & Bickman, L. (1997). The Caregiver Strain Questionnaire: Measuring the impact on the family of living with a child with serious emotional problems. *Journal of Emotional and Behavioral Disorders, 5*(4), 212–222.
- Burns, B. J. (2003). Children and evidence-based practice. *Psychiatric Clinics of North America, 26*, 955-970.
- Carroll, K. M., & Rounsaville, B. J. (2003). Bridging the gap between research and practice in substance abuse treatment: A hybrid model linking efficacy and effectiveness research. *Psychiatric Services, 54*, 333-339.
- Davis-Groves, S. A., Barfield, S. T., McCave, E., & Corrigan, S.K. (2007). *Parent support: Building structures that support and assist children*. Lawrence, University of Kansas School of Social Welfare, Office of Child Welfare and Children's Mental Health.
- Epstein, M. H. (2004). *Behavioral and Emotional Rating Scale—Second edition*. Austin, TX: PRO-ED.
- Hoagwood, K., Burns, J. J., & Weisz, J. R. (2002). A profitable conjunction: From science to service in children's mental health. In B.J. Burns & K. Hoagwood (Eds.), *Community treatment for youth: Evidence based interventions for severe emotional and behavioral disorders* (pp. 327-338). New York: Oxford University Press.
- Horvath, A., & Greenberg, L. (1986). The development of the Working Alliance Inventory. In L. Greenberg & W. Pinsoff (Eds.), *The psychotherapeutic process: A research handbook* (pp. 529–556). New York: Guilford Press.
- Hubbel, M. A., Duncan, B. L., & Miller, S. D. (1999). *The Heart and Soul of Change*. Washington, D.C.: American Psychological Association.
- KidsTraining Team. (2006). *Parent Support Specialist Training*. Wichita, Kansas: Author.
- Koren, P. E., Dechillo, N., & Friesen, B. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology, 37*(4), 305-321.
- Luongo, G. (2007). Re-thinking child welfare models to achieve evidence-based practices. *Administration in Social Work, 31*(2), 87-96.

- McNeece, C. A., & Thyer, B. A. (2004). Evidenced Based Practice and Social Work. *Journal of Evidenced Based Social Work, 1*(1), 7-25.
- Nelson, G., Ochocka, J., Griffin, K., & Lord, J. (1998). "Nothing about me, without me": Participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors. *American Journal of Community Psychology, 26*(6), 881-912.
- Santelli, B., Singer, G. H. S., DiVenere, N. Ginsberg, C., & Powers, L. E. (1998). Participatory action research: Reflections on critical incidents in a PAR project. *Journal of the Association for Persons with Severe Handicaps, 23*(3), 211-222.
- Scrimshaw, S. C., White, L., & Koplan, J. P. (2001). The meaning and value of prevention research. *Public Health Reports, 116*(Suppl 1), 4-9.
- Tracey, T. J., & Kokotovic, A. M. (1989). Factor structure of the Working Alliance Inventory. *Psychological Assessment, 1*(3), 207-210.
- Washington, W. N. (2004). Collaborative/participatory research. *Journal of Health Care for the Poor and Underserved, 15*(1), 18-29.