

LESSONS FROM THE TRENCHES—MAKING FAMILY-DRIVEN, COMMUNITY-BASED RESEARCH WORK

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Introduction

Research on a statewide model of professional parent-to-parent support services in Kansas began in 2005. Since the beginning, relationship building has been a mutual priority between university researchers and parents of youth living with serious emotional disturbance (SED) who are parent-to-parent support providers. Parent involvement has grown steadily since, resulting in parent-professional collaboration at every level and stage of the research process. In this presentation, a panel of parents and researchers described ways to maximize meaningful involvement in a family-driven, community-based research project

from four vantage points—academic researcher, parent researcher, parent-to-parent support provider, and parent receiving parent-to-parent support services. Benefits and realities of this collaborative approach were discussed. In addition, researchers presented preliminary findings from an impact survey designed to promote candid parent-partner feedback about this collaborative process.

Background and Context

Kansas provides fertile ground for study of the parent-to-parent support role in a children's mental health system of care as it has been established and sustained since the mid-1990s. The catalyst for the professional parent role began in 1994 when the Substance Abuse and Mental Health Service Administration (SAMHSA) awarded funding to a system of care development project in the Southeast area of the state. Professional parent-to-parent support services, provided by Parent Support and Training (PST) providers, were developed as a component of the project's community-based mental health services array. PST providers were hired as employees of the participating community mental health centers. This successful family-directed system of care model was later expanded as a statewide initiative.

For the past decade, legislators and the state mental health authority have remained committed to the success of the statewide system of care, guaranteeing sustainability of both the community-based model and the PST role within the mental health system. This level of support makes this particular model of PST services ideal for evaluation. In 2005, the Kansas Social and Rehabilitation Services—Division of Disability and Behavioral Health Services contracted with the University of Kansas School of Social Welfare (KU) to examine issues surrounding PST services. Thus far, effective PST practices have been identified along with next steps to sustain the infrastructure of the service (Davis-Groves, Barfield, McCave, & Corrigan, 2007). A longitudinal study is currently underway to assess impact of PST services over time on youth and family outcomes. Researchers are also documenting a model of effective PST practice and developing a fidelity monitoring procedure for the model.

Participatory action research (PAR), a method for engaging communities in research activities, is the approach used in this study. The researchers concluded that it was essential for parent voice to be at the forefront of the research process; PST practice expertise and knowledge gained through life experience as a parent of a youth living with SED were considered key ingredients to project success. Partnership with PST providers was the logical choice to fill this gap on the research team. As the collaborative process commenced, it became evident to researchers that the research method needed to mirror the family-driven process used to develop the PST service model. Application of a family-driven paradigm meant engaging families in meaningful roles at every step of the process, from developing research questions and study design to interpreting data and presenting findings and conclusions (Osher &

Osher, 2002). Thus, researchers abandoned a traditional research model in which parent involvement would have been marginalized to the role of research subject or source of data (McCormack & Slaton, 1998) in favor of a PAR approach.

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 community partners alike benefit from a PAR approach. Researchers increase their knowledge of 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).

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, Singer, DiVenere, Ginsberg, & Powers, 1998). The approach bridges the gap between the world of research and evaluation and the “real” issues of families of youth living with SED (Huff, 1998). For the purposes of this study, the collaborative nature of PAR strengthens the entire context for which the PST model is being developed and, consequently, reduces threats to external validity of the research. Benefits to PST stakeholders are being evidenced already through use of an impact survey that provides a method to analyze and improve the participatory research process.

Research Question and Methods

In order to assure the research process was meaningful, relevant, and beneficial to community participants, researchers developed a brief survey that asks the following questions: 1) how much of an impact have the research activities had? and 2) how satisfied are participants with the research process? Participants are asked to rate their level of impact and satisfaction on a scale from 1 (no impact/satisfaction) to 4 (high impact/satisfaction). Space is provided for descriptions under each rating. Lastly, participants are asked to “describe what is going well and what could be improved.” The participants are asked to give themselves a unique identifier (last four digits of their home phone number) so that change may be tracked over time. Researchers hypothesized that when

participants are provided the opportunity to relay impact, satisfaction, and constructive feedback in the course of a research endeavor, they feel more impact from and more satisfaction with the research process over time.

In the course of the first two years of practicing PAR, researchers also noticed the need to have regular process evaluations with community participants to determine that the right procedures/research protocols were in place. When these process evaluations occurred, researchers made the commitment to administer an impact survey to provide one more means of gathering constructive anonymous feedback.

There are three potential participant groups that have received or will receive an opportunity to complete an impact survey—parents, PST providers, and other direct service staff involved in the longitudinal study still in progress.

- Parents are approached to fill out the impact survey after six and twelve months of involvement in the research.
- PST providers are recruited to complete the survey at their statewide network meetings when researchers complete a research activity. In addition, the PST providers who are involved in the longitudinal study are asked to complete an impact survey after process evaluation discussions with researchers.
- Direct service staff are also asked to complete impact surveys after twelve months of involvement in the longitudinal study.

Research Findings

Key preliminary findings are based on two participant groups (parents and PST providers). Surveys have been administered to the PST providers at their statewide network meetings on three occasions between January 2008 and January 2009 and at one process evaluation research activity (n=67). Thus far, five parents have completed the survey a total of seven times (i.e., two parents at six and twelve months).

- **Key Finding 1: The majority of PST and parents are reporting some level of impact from the research activities.**

When asked, “How much of an impact have the research activities had on you and/or your work?” the majority (87.0%) of PST providers reported some level of impact by the research activities in which they participated. PST involvement in the research process was viewed as positive and meaningful by the PST Statewide Network and during a process evaluation research activity (n=67).

All parents (100%) reported that they experienced some level of impact from the research activities in which they were involved, with 29% experiencing a high impact. Qualitative comments shared by parents

indicate that being involved in study activities gives them a chance to talk with other parents and gain confidence which motivates them to help their children. The following description provided by a parent poignantly illustrates the potential PAR offers for meaningful involvement of families, “*Very encouraged to come to [research meetings] because I was part of something big.*”

- **Key Finding 2: The majority of PST and parents are satisfied or very satisfied with the research activities.**

When asked, “How satisfied are you with the research implementation process?” the majority of both PST providers (92.0%) and parents (85.7%) reported being satisfied or very satisfied with the research activities. Qualitative comments made by both PST providers and parents describe a sense of empowerment gained through the process. One PST provider wrote, “*I was validated and felt like it was one of the few times I saw a list of exactly what I do and see each day in my work.*”

- **Key Finding 3: Constructive feedback indicates all participants are providing helpful feedback to improve the research implementation process. Techniques are implemented immediately.**

Providers indicated that researchers were communicating well and that researchers’ efforts to accommodate and be flexible supported provider participation. They also identified the need to examine strategies to improve parent participation.

Parents also provided constructive feedback about ways to improve the research process, such as providing private space for parents to complete study measures at the meetings and reducing the paperwork and number of questions that comprise the set of parent measures.

Conclusions and Next Steps

Lessons From the Trenches (Realities of Collaborative Research): Benefits to the research process have been experienced by all—researchers, PST providers, and parents. For example, research meetings have turned out to be another avenue for parent support. Some parents report feeling empowered and motivated to get help for their children. PST providers feel they are making an important contribution to sustainability of their role. Challenges have occurred as well. Support needed from PST providers to promote parent participation has been difficult to provide since it is an additional responsibility. Financial reimbursement to an agency for longitudinal study involvement does not entirely compensate the effort. Parents may have difficulty completing several standardized measures. Researchers must sustain individual attention with

every participant—from agency administrators to PST providers to parents—over time to ensure that all have the support they need to remain involved.

Keys to Success:

- PST providers need ongoing support from their agency and good rapport with their co-workers and the families they serve in order to participate in a research project. A trusting relationship, flexibility, and good communication with researchers are also essential for successful PST provider involvement.
- Parents need a trusting relationship with researchers and a safe environment to be candid with their input for successful participation. They also need flexibility in involvement since family and life demands may compete with their efforts to participate.
- Agency administrators need financial support; their agencies have costs when involved in research projects. They may also need approval from the agency's governing body to participate.
- Parents hired as members of research teams need skill in balancing the dual role of parent advocate and researcher. It is essential for parent researchers who are not community members to be respectful of their visitor roles and to facilitate the sharing of various and diverse perspectives that participating PST providers and family members bring to the process.
- Academic researchers need to build and maintain relationships with partners that invite meaningful involvement while, at the same time, respecting the constraints partners face. Providing funding for all partners shows tangible respect for the contributions each stakeholder makes to the process.

Next Steps: Further lessons will emerge as community participants continue to provide feedback that informs the participatory process. Researchers will continue to utilize impact survey findings as a means to strengthen collaborative research practice.

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