# Elevating stakeholder voice: Considering parent priorities in model development for community mental health center services

Kaela Byers *, Toni Johnson, Sharah Davis-Groves, Kathy Byrnes, Tom McDonald

*University of Kansas, School of Social Welfare, 1545 Lilac Lane, Twente Hall, Lawrence, KS 66045 USA*

## ABSTRACT

Peer-support services, including Parent Support and Training, have traditionally subscribed to a strict definition of what it means to qualify as a peer, and therefore as a provider of these services. This article examines views of peer and non-peer stakeholders in Kansas CMHCs on additional characteristics of "peer-ness." The findings of this analysis result in a call for a broadening of the definition of "peer" in order to creatively meet the needs of families in the current service climate while still providing support for upholding the family-driven paradigm that brought about inclusion of parent voice in the treatment process—a hallmark of the PST service.

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## 1. Introduction

Parent Support and Training (PST) is a peer-to-peer service provided in the Kansas Community Mental Health Centers (CMHC) child services system of care for parents of children experiencing serious emotional disturbance (SED). The purpose of PST is to provide support, education, and assistance navigating the mental health system from a peer who has previously experienced similar challenges. Central to the philosophy behind the intervention is the idea that parents should have a voice at the table as an equal part of the treatment team in the provision of mental health services to their children.

In the spirit of this family-driven value, parents of children with a serious emotional disorder (SED) who were either providing or receiving PST services were included as a stakeholder group in a recent study using Concept Mapping methodology to establish stakeholder consensus on the core components of the model of PST service as provided in CMHCs in Kansas (Johnson, Byers, Byrnes, Davis-Groves, & McDonald, 2013). Including this group of stakeholders ensured the inclusion of parent voice not only in the provision of services but also in the development of a service model. This process was successful in establishing stakeholder consensus on the core components of the Kansas PST model. However, some differences arose consistent with differences in the literature regarding what provider qualifications identify one as a "peer." These differences led to additional research

questions in an effort to explore this issue and implications for practice. The following research questions are examined in this article: 1) Are there significant mean differences in importance ratings of PST provider qualifications for different stakeholder groups, specifically parents of children with SED who are receiving or providing PST services versus all other stakeholders? 2) Are there significant differences in importance ratings of PST provider qualifications within the caregiver stakeholder group? This article empirically examines these differences in an effort to elevate parent voices for consideration in ongoing model development and implementation, thus upholding the family-driven principles underlying Parent Support and Training Services.

## 2. Background

### 2.1. History of family-driven support services

Family involvement within mental health treatment for children with emotional or behavioral disturbances has advanced substantially in the past 20 years. Historically, children with serious emotional disturbance (SED) were thought to come from dysfunctional families with parents contributing to the problem (Friesen & Koroloff, 1990; Knitzer, 1993; Osher, Van Kammen, & Zaro, 2001). The children's mental health systems of care and family movements of the late 1980s dispelled that myth, heralding a paradigm shift in which family members began to be recognized as experts who possess knowledge for solutions to challenges (Osher & Osher, 2002). Both movements asserted that parents have a right to be involved in the design and delivery of services and supports necessary for their youth to live in communities rather than institutions. Both also advocated that parents cope more effectively when adequate, individualized supports

* Corresponding author. Tel.: +1 785 864 3824; fax: +1 785 864 5277.
*E-mail addresses:* kaela@ku.edu (K. Byers), tkjohns@ku.edu (T. Johnson), shdavis@ku.edu (S. Davis-Groves), kbyrnes@ku.edu (K. Byrnes), t-mcdonald@ku.edu (T. McDonald).

are available (Friesen, Griesbach, Jacobs, Katz-Leavy, & Olson, 1988; Friesen & Koroloff, 1990; Stroul & Friedman, 1988).

Then in 1989, the first national organization was formed to represent family voices in provision of mental health services—The National Federation of Families for Children's Mental Health (NFFCMH) (Spencer, Blau, & Mallery, 2010). This was followed by the establishment of funding by family advocates to develop a national network of state-level, family-run organizations to provide information and support to families and youth with mental health needs (Spencer et al., 2010). Momentum continued to build for honoring family voice in mental health systems of care when in 2002 a family leader – Jane Adams, from the Kansas Chapter of NFFCMH and Board President – participated in the New Freedom Commission on Mental Health. The work of the Freedom Commission produced goals to transform mental health care in America, including a specific goal stating that "mental health care must be consumer and family driven" (Spencer et al., 2010 p 177; NFC, 2003). Subsequently, in 2004, The Substance Abuse Mental Health Services Administration (SAMHSA) asked the NFFCMH to define Family Driven care (Spencer et al., 2010). In response to this request, the following definition of the term "Family Driven" was developed:

> Family driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory, and nation. This includes: choosing culturally and linguistically competent supports, services, and providers; setting goals; designing, implementing and evaluating programs; monitoring outcomes; and partnering in funding decisions (Spencer et al., 2010 p. 177).

### 2.2. Parent support services defined

Parent support and training services and programs operationalize the family-driven paradigm as they are designed to attend to the needs of parents of children with emotional and behavioral disturbances through a variety of formats—individual vs. group, clinician- vs. peer-led, paid provider vs. volunteer (Gyamfi et al., 2010; Hoagwood et al., 2010). Numerous parent-to-parent peer support services of this type have been developed through a variety of partnerships between children's mental health systems of care initiatives, family-run children's mental health advocacy organizations affiliated with the NFFCMH, and/or state mental health authorities (Gyamfi et al., 2010; NFFCMH, 2008). The predominant model has been a parent-to-parent support service provided to parents in need by veteran parents who have navigated the mental health system with their child and who are employed by family run organizations.

The peer aspect of this service is generally regarded as the key to the PST service. This concept is supported by the synthesis of the literature on peer-to-peer parent support (in mental health, disability or chronic illness, or general parenting) and peer support in adult mental health published by the Research and Training Center for Children's Mental Health (Robbins et al., 2008) suggesting that the parent-to-parent or "consumer" aspect allows unique relationships to develop between newly referred parents and veteran parents resulting in higher recipient "self-reported satisfaction, quality of life, and social functioning outcomes" (Solomon & Drain, 2001 p. 25) as compared to those receiving other non-peer services.

In a subsequent review, Hoagwood et al. (2010) narrowed the focus to those parent support programs for parents/caregivers of youth with mental health needs, while expanding their search to include programs delivered not just by peer family members, but also by clinicians or parent–clinician teams. Review of these studies showed little consistency in outcomes selected to evaluate the effectiveness of the programs making comparison difficult. This review also highlighted the need for future research on parent support services to include: 1) a

comprehensive service model with a clear conceptual framework; 2) a theory of change describing what changes to expect and how they are expected to occur through implementation of the program; and 3) outcome measures that are best suited to assess expected changes (Hoagwood et al., 2010). In addition, while this review conducted by Hoagwood et al. (2010) included programs with a variety of peer involvement models, it did not compare outcomes of various program based on how peer providers were incorporated into the program model, likely due to the inconsistency of outcomes measured by various studies in the review which made comparison among programs difficult.

Therefore there is some empirical support in the literature for varied applications of peer-to-peer support models as reported in the review conducted by Robbins et al. (2008) demonstrating increases in the outcomes previously discussed when using peer-provider models. However, these outcomes were not compared in their review across other programs using various definitions of "peer-ness" to determine if any particular peer definition or model exceeded others in terms of improved outcomes. Additionally, though Hoagwood et al. (2010) did broaden the scope of their inquiry to include different types of peer programs they were not able to compare outcomes across programs and therefore similar results have not yet been confirmed in the children's mental health services literature. So while use of a peer support model is conceptually important as it conforms to the family-driven paradigm, there is not yet a preponderance of empirical evidence supporting use of these programs in children's mental health in general or for any particular model of peer support specifically.

### 2.3. Parent support qualifications—or "peer-ness"

In addition to the absence of empirical support for the use of a particular definition of "peer" in parent support services in children's mental health, there is also no current consensus on what constitutes a "peer" and qualifies one to provide a peer-provided service. In an effort to articulate a clear conceptual framework for Parent Support Services, The Federation of Families for Children's Mental Health recently developed materials that identify the core competencies of Parent Support Providers. The core competencies are built upon the knowledge that caregivers have gained from "raising a child with emotional, developmental, behavioral, substance use or mental health challenges" (Purdy, 2010). Thus the Federation promotes that Parent Support Providers must first have this shared experience and be able to articulate their lessons learned to parents in need of support.

In contrast, in some states – such as Kansas – Medicaid reimbursable services have been developed to sustain and expand Parent Support programs within public behavioral health systems. With this statewide expansion, the Parent Support service has evolved to include a broader definition of peer providers as well as ways in which the service may be delivered. This administration of Parent Support Services was a natural progression statewide, as agencies recruited and hired dedicated Parent Support and Training Providers. For example, some mental health agencies in Kansas started to employ foster parents of youth with emotional or behavioral disorders/special needs, and other family members of youth with special needs—such as siblings, aunts, uncles, or grandparents. These and other deviations from the Federation's definition of "peer" in hiring practices in Kansas are a result of many factors, including the rural and frontier make-up of a large portion of the state which presents significant challenges to service implementation. Some challenges faced by mental health center administrators for filling these roles with traditionally qualified peer support providers have included limited applicant pools and the need to hire one provider to fulfill multiple service roles due to the low population density. In these cases service providers delivering PST services in Kansas may be more loosely identified as a peer through other types of qualifications.

While these practices are in contrast to the definition of "peer-ness" set forth by the Federation of Families for Children's Mental Health, it is