

BARRIERS AND CHALLENGES IN A PEER SUPPORT PROGRAM FOR FAMILY CAREGIVERS  
OF CHILDREN WITH EMOTIONAL AND BEHAVIORAL DISORDERS

By

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## INTRODUCTION

The field of children's mental health has been recently moving away from an individual and pathological focus towards an understanding of familial context and the identification of strengths. With this movement has come an increase in systems of care, in which formal and informal supports and institutions come together. Care and support are child-centered, family-focused, community-based, strengths-based, and culturally competent (Stroul & Friedman, 1986). These systems of care (SOC) attempt to provide comprehensive care by incorporating these values into the many venues and service providers involved, including children's services, juvenile justice, and traditional mental health care.

One of the key aspects in SOC is that services and care should be family driven and utilize the families' natural supports (Stroul & Friedman, 1986). Family education and support services have been introduced as a means of combating some of the challenges, such as stigmatization, prevalent in traditional care models (Gyamfi et al., 2010). It is evident then, that peer support would likely be a natural component of SOC for children and adolescent mental health as well. Family peer support programs often hold the same values, and provide support that is consumer-driven and often family-focused. These programs may be particularly important for parents whose children have emotional or behavioral disorders; a survey of many such families found that 72% indicated emotional support was the most helpful aspect of care (Gyamfi et al., 2010). In several states, Medicaid has begun to acknowledge this by including peer support as reimbursable.

The following study is a qualitative examination of two peer support programs for families with children who have emotional or behavioral issues. Specifically, it uses an ecological model to examine barriers and challenges to program implementation and success from the viewpoint of both family caregivers and supporters. This expands on a previous study (Pullmann, VanHooser, Hoffman, & Heflinger, 2010) that looked at one of these programs by looking specifically at barriers and challenges and compares the findings to those from an additional program.

## **PEER SUPPORT PROGRAMS**

The published research literature on peer support interventions has largely focused on adults. Peer support interventions for adults with physical and mental health issues have been implemented widely with evaluated success. In these programs, adults with similar problems have been trained to provide emotional and social support, often while assisting the individual to adapt, garner resources, and find support in other areas. These interventions have been demonstrated to decrease social isolation (Dunn et al., 1999), decrease negative symptoms (Castelein et al., 2008) and depression (Preyde, 2007), increase optimism (Dunn et al., 1999) and self-efficacy (Weber et al., 2007), improve quality of life (Felton et al., 1995; Klein et al., 1998), increase treatment adherence and satisfaction (Simpson & House, 2002), and reduce hospitalization rates (Simpson & House, 2002). In addition to positive outcomes for those receiving the support, positive outcomes have been shown for those individuals providing the peer support. For example, being a peer supporter was found to improve confidence, self-esteem, and role functioning and to decrease depression in a study by Schwartz and Sendor (1999), which indicates bi-directional relations.

### **Programs for Family Caregivers**

Peer support programs for family caregivers of children with special needs have been implemented and evaluated as well. Many of the studies available focus on family caregivers of children with physical health problems. Preyde (2007) found that when mothers of preterm infants had contact via telephone by a parent who had been in a similar situation, the mothers reported an increased sense of confidence in their parenting, felt more knowledgeable about their children's health conditions, and reported less stress, anxiety, and depression. Parent evaluations of an educational and peer support hospital-based group for parents of children with cancer revealed satisfaction with found it to be helpful (Foreman, Willis, & Goodenough, 2005). Similar programs have been conducted with parents of children with developmental delays (Iscoe & Bordelon, 1985), chronic lung disease (Nicholas & Keiltry, 2007), juvenile rheumatoid arthritis (Ireys, H., Sills, E., Kolodner, K., & Walsh, B., 1996), chronic illnesses (Ireys, Chernoff, Devet, & Kim, 2001), and infants in the neonatal intensive care unit (Roman et al., 1995). Programs aim not only to provide social support and lessen emotional difficulties for the family caregivers,

but also hope that such changes will promote improved parenting skills and service acquisition to benefit the children.

Some elements of peer support programs have also been implemented for families of children with emotional and behavioral disorders as part of the system of care movement and in other parent programs. These programs provide a vital role in promoting positive outcomes through family education and support. For example, the Peer Support Program provided peer group support for parents of sexually abused children (Alaggia, Michalski, & Vine, 1999). The Finger Lakes Family Support Project included peer group support and parent consultants to help serve families of children with emotional and behavioral problems (Friesen & Wahlers, 1993). Friesen and Wahlers found that the majority of children in the program to have stayed in their parents' custody, and that families experienced a reduction in stress. Professional family associates have also been found to help families negotiate the mental health service system for their child and reduce barriers (Koroloff, Elliot, Koren, & Friesen, 1994). Sakwa and Ireys (2006) wrote about Program Connections, which provided peer social support and educational workshops and theorized that the affirmational support provided would provide more positive parenting and partnering with other service providers. A randomized control trial showed parents in the experimental group to have a significantly higher mean increase in perceived social support, and that a larger percentage of that group went from high anxiety to low anxiety (though statistical significance was not mentioned here). A study that aimed to determine feasibility and efficacy of a phone-based peer support program for parents of a student with an emotional disturbance had the most comprehensive outcome measures, looking not only at program satisfaction, which was high, but also at parent and youth functioning, which both improved (Kutash, Duchnowski, Green, & Ferron, 2011).

Although evaluations of many peer support programs have revealed positive outcomes, not all research supports their effectiveness. For instance, the addition of a peer supporter did not decrease depressive symptoms more than phone calls from primary care nurses in an intervention with patients starting antidepressant drug therapy (Hunkeler et al., 2000). Pillemer & Sutor (2002) also found no effect of peer supporters when studying peer support for family caregivers of relatives with Alzheimer's. Additionally, family caregiver support program evaluations have theorized but only infrequently tested



improved child outcomes. This leads to a need for further research into peer support programs to better understand why significantly positive outcomes are not always the result.

### **Barriers and Challenges**

Given the mixed outcomes of peer support research despite a strong theoretical base, there seems to be a set of barriers and challenges inhibiting program success. No matter which type of respondent indicated the concerns, these barriers and challenges affect supporters and participants alike by making program participation and success more difficult.

#### **Peer supporters.**

The relationship between peer supporter and participant was noted to be a challenge for supporters. In a study of an HIV medication adherence peer support program, supporters were challenged by the resistance of participants who did not wish to change themselves at all (Marino, Simoni, & Silverstein, 2007). Similarly, Marino et al. (2007) found supporters to be frustrated with the sense that certain people just could not be helped. In a study of a multi-site program for parents of children with developmental delays, nine out of thirteen programs reported parents simply not being interested in participating, and supporters in that program claimed the most difficult part of the job was not being able to help a family enough (Iscoe & Bordelon, 1985).

Funding was cited as an additional barrier to success in such programs. Sakwa and Ireys (2006) noted that even with positive evaluation results, securing funding after the study was completed was difficult. Manalo (2008) conducted focus groups with family support staff in a community-based family support program. This study uncovered three major barriers to program implementation. First, inadequate funding was found to lead to unused resources and a smaller breadth of services offered. Confusing, tedious, and difficult funding rules and regulations resulted in extra work for the support workers, which they viewed as inefficient. The funding system often caused a delay in reimbursement that hindered the already stretched budget. These funding issues additionally lead to concerns regarding the program's stability, with workers fearing program termination.

Systemic issues were also stated to be challenges in peer support programs. Manalo (2008) found the rigid boundaries regarding service eligibility to hinder program success. Families considered part of the community that could have benefitted from the program were turned down based on their zip code. Finally, this study found workers to feel isolated from the lead agency, citing inadequate communication within the collaborative. Moran, Jacobs, Bunn, and Bifulco (2007) also discovered conflict between family support workers and other professionals in the system; issues related to communication and system protocols caused challenges for the workers and possible barriers to success. It was noted by one program that “gaining credibility in the community” was of great importance, particularly in order to gain referrals (Sakwa & Ireys, 2006, p. 106). This is key because it shows a challenge related to the system as a whole as opposed to a specific program.

The literature shows a number of distinct challenges that confront family support staff in regards to their professional identity. Through interviews with peer support workers in a psychiatric facility, Meehan, Bergren, Coveney, and Thorney (2002) found the peer supporters faced workplace constraints regarding their job descriptions. Without a proper description for the peer supporters, there was confusion among peer supporters and other staff on the jobs of the supporters. Similarly, in a study of social workers working in a similar job function as many peer supporters, and also within a multi-agency collaboration, family support workers were found to struggle with developing a professional identity within a system of several hierarchies and competing images (Moran et al., 2007). In a hospital-based support group for parents, Foreman, Willis, & Goodenough (2005) found unit staff to view the program “as a social work rather than the a multidisciplinary initiative (p. 15). Additionally, nurses in the unit were concerned the support group would lead to “tattling” on the nurses. Lack of buy in from other hospital workers was challenging to the supporters not only personally in regards to respect, but also in its impact on patient participation. Lastly, Iscoe and Bordelon (1985) found peer supporting parents had difficulties in gaining the respect from other professionals necessary for program referrals.

### **Participants.**

Even fewer studies appear to have examined challenges and barriers participants face in peer support programs for families. In one of the few, Boudin (1998) conducted a qualitative study about a

group support program for incarcerated mothers. Although the majority of the findings revolved around program implementation description and anecdotal positive outcomes, participants reported the abrupt ending of emotional support at the end of this program to be a pitfall of the program. Although parents found the program helpful, they mentioned needing more time with the program and with their supporter. New parents of children with developmental delays in a support program noted wanting more information about their child's disability and more contact with other parents (Iscoe & Bordelon, 1985).

The supporter/participant relationship was seen as a challenge for participants as well. In a study of a peer support program for parents of a child with chronic lung disease, major challenges in the connection between participant and supporter were found (Nicholas & Keiltry, 2007). Qualitative interviews revealed that scheduling, personality incompatibilities, and trouble establishing a relationship with the supporter each surfaced as potential obstacles to successful participation in the program. This difficulty was also found in a peer support health education program for participants with diabetes (Richert, Webb, Morse, O'Toole, & Brownson, 2007).

Although the above challenges may be linked to decreased program engagement, two studies found barriers specific to initial program participation. Richert, Webb, Morse, O'Toole, and Brownson (2007) found participants were concerned with the labeling of "diabetic" that came with program participation. This sense of stigma also was found in a peer support program for police officers with emotional concerns (Goldstein, 2005).

### **Gaps in the Literature**

Though there have been many studies examining peer support programs, only a very small number have examined programs specifically targeting parents or other family caregivers. This is an important distinction due to the focus being shifted from the individual with the problem or diagnoses to their family caregiver and/or family. There have also been few studies evaluating the effectiveness of these programs, and of these studies, most focus on families with children with physical rather than mental or behavioral concerns. Further more, many studies have focused on group support programs as opposed to one-on-one peer support. Undoubtedly, there are differences in the experiences of both peer-supporters and participants in these types of programs. Additionally, though there are studies on peer support programs, and studies on

various supporting professionals in multi-agency family support teams, there appears to be a dearth of studies specifically examining peer support programs working within a system of care with multiple agencies.

Of the few examples of family support and education groups for parents of children with special needs that are available, even fewer have focused specifically on the role of peer support (as opposed to other program components). In order to completely understand the effect of peer support, these processes must become a target of study. Often family support services are mentioned as an outcome of some other type of system intervention (e.g., Holden et al., 2007) and not the subject of distinct evaluation. Hoagwood (2005) reviewed the literature on family-based services and found effective multi-family support programs, but none specified the role of peer support, potentially due to all programs being group models. Robbins et al. (2008) reviewed studies of parent-to-parent programs and found that there are no consistent determinations of what family support entails, and none that examined barriers and challenges within the program.

Additionally, there appears to be an overall lack of studies that examine barriers or challenges within these programs, and even fewer that make this the central focus of their research. The majority of research into peer support programs has focused only on the benefits to supporters and participants (Salzer & Shear, 2002; Marino, Simoni, & Silverstein, 2007; Schwartz & Sandor, 1999; Edwards, Nash, Yates, Walsh, Fentiman, McDowell, Skerman, & Najman, 2000; Castelein, Bruggeman, van Busschbach, van der Gaag, Stand, Knegtering, & Wiersma, 2008; Preyde, 2007). Understandably the positive outcomes of these studies are useful in promoting peer support programs in policy; however, this leaves a gap in the research and does not give direction for program development, increased participation, and improved participant outcomes. Munson, Hussey, Stormann, and King (2009) used focus groups to examine the experience of family advocates in a system of care (similar in role to peer supporters), but indicated that future research needed to be done to identify what they saw as barriers or challenges in order to improve the program. One study that did look specifically at some program challenges lacks formulation on sampling, recruitment, and other procedures that would lend confidence to the findings (Moran et al., 2007).

## **THEORETICAL MODEL**

The ecological model, originally theorized by Bronfenbrenner (1986), is a useful way to examine elements from various systems and levels that contribute to an outcome. Going beyond characteristics at the individual level allows for a more complete understanding of a situation. Although originally applied to children's development, this model is valuable for the development and success of social organizations as well. Previous research has examined the methods of identifying ecological elements to assess social environments and behavior settings (Barker, 1968; Moos and Lemke, 1983), some specifically with consumer-run organizations (Brown, Shepherd, Wituk, & Meissen, 2007). Although "consumer-run" should not be confused with "peer support", the involvement of previous consumers as the new providers indicates this may be a particularly useful approach for examining peer support programs for families. The present study uses a similar approach, focusing on the behavioral and structural issues within the complete system in which these programs operate. In addition to the individual level, the family, community, program, and system levels were included in analysis.

## **RESEARCH QUESTIONS**

This study aims to answer the following questions:

- a) What are the barriers and challenges to program success and implementation from the family caregivers' and supporters' perspectives?
- b) How do perceived barriers and challenges vary between family caregivers and supporters in the two programs?
- c) Is the ecological model an appropriate framework for understanding these barriers and challenges? What level(s) are barriers and challenges most frequently found?

## METHODS

### **Context: Community of Care and Statewide Advocacy**

Participants for this study have successfully engaged and participated in one of two programs for families with a child with an emotional or behavioral disorder (EBD) in a southeastern state, from here on out referred to as “Community of Care” and “Supporting Families”. Supporting Families is run out of “Statewide Advocacy”, a non-profit organization that works to promote children’s health and education programs. Community of Care is run jointly by Statewide Advocacy and a mental health agency. Both programs aim to serve families of children with emotional and behavioral disorders with providing assistance in navigating the various service systems and giving referrals to specialized resources (counseling, health care, lawyers, etc.). Each family works individually with a Family Support Provider (FSP) and a Behavior Specialist (with Supporting Families) or a Clinical Caseworker (with Community of Care). The role of FSPs and the programs as a whole are the focus of this research.

FSPs are trained peer support professionals who have had the personal experience of caring for a family member with a psychiatric disorder. Statewide Advocacy has recently begun certifying FSPs, enabling their services to be billed to Medicaid. The role of FSPs is to support these families as they attempt to navigate the service system in a way that best meets their needs by giving emotional and practical support. The FSP also helps to create a Child and Family Team with formal and informal supports chosen by the family. These teams aim to develop individualized plans of action to maximize child and family outcomes and to maintain the child’s current placement in their community. These plans include a wide array of services including individual and group therapy, family therapy, parenting skills training, 24-hour behavioral crisis assistance, intensive, in-home therapeutic skill-building with the family, in school support, respite care, and formal and informal services. The goal is for the FSP to support the family caregivers in leading the Child and Family Team meetings and taking action toward success. Care strives to be child-centered, family-focused, community-based, strengths-based and culturally competent. FSPs aim to foster a sense of hope and resilience and assist family caregivers in being advocates for their families.

Although Community of Care and Supporting Families both share the same goals and FSP role descriptions, there are some differences that must be acknowledged. First of all, in Community of Care, the

Clinical Caseworker takes the lead as the wraparound facilitator whereas this role falls to the FSP in Statewide Advocacy. Additionally, Statewide Advocacy hires and supervises both FSPs and behavioral specialists in Supporting Families. Statewide Advocacy hires and supervises the FSPs for Community of Care, but the mental health agency hires and supervises the Clinical Caseworkers, as well as physically houses Community of Care. Finally, the referral system differs between the two due to funding. Community of Care requires the index clients to have an official emotional or behavioral disorder diagnosis, whereas Supporting Families only requires evidence of emotional or behavioral disorder symptoms. Community of Care thus can receive referrals from anywhere while Supporting Families receives referrals mainly through the Department of Children Services (DCS) and occasionally through the juvenile justice system. Finally, Community of Care serves families that live primarily in a rural area, whereas Supporting Families serves urban, suburban, and rural families. This study involves the qualitative analysis of existing interviews with Community of Care caregivers and FSPs and the conducting and analyzing of qualitative interviews with Supporting Families caregivers and FSPs.

### **Recruitment of Study Participants**

With Community of Care, staff members provided researchers with a list of referred from families from which a purposive sample was selected. FSPs or community liaisons closest to the selected family caregivers then informed them of the study and asked for permission to give their contact information to researchers. Researchers then contacted family caregivers to explain the project and schedule interviews. With Supporting Families, staff contacted engaged family caregivers to ask for permission to share their contact information with researchers who set up interviews. Staff with Statewide Advocacy provided researchers with names and addresses of family caregivers who did not engage with the program and two letters were sent to each of them. None of the un-engaged family caregivers returned contact.

All FSPs in both programs were asked to participate in the study. Community of Care FSPs were asked to participate in person and by phone. Supporting Families FSPs were asked to sign up via paper at a staff meeting if they were interested. Staff participation from both programs was kept confidential from staff supervisors.

## **Data Collection Procedures**

Informed consent was completed in person with all participants before the interviews began. FSP interviews took place at the program offices, and family caregiver interviews occurred at their choice between the program office or their homes. Interviews ranged in length but averaged about 60 minutes long and were conducted by graduate students and a professor. Family caregivers from Supporting Families were given \$50 gift cards to a discount department store for their time, and in the previously completed study, family caregivers from Community of Care were given \$20 for their time with an additional \$5 for transportation costs if they came to the program office for the interview. Both studies were reviewed and approved by the institutional review board at the researcher's university.

## **Sample**

The verbatim transcriptions of three interviews with FSPs and four interviews with family caregivers previously conducted with Community of Care in 2007 were re-analyzed for this project. All of these family caregivers were currently engaged with the program at the time of the interview. Five interviews with FSPs and seven interviews with family caregivers from Supporting Families were conducted in 2009 specifically for this project. All five of these FSPs were either currently engaged with the program or had completed their time with it. These interviews were also transcribed verbatim before analysis.

The final sample for this study consists of eight interviews with individual FSPs, all of whom are female, and who spoke on their experiences with various families. The eleven interviews with family caregivers included thirteen total family caregivers of nine distinct target children. These participants included mothers (n=7), fathers (n=2), grandmothers (n=3), and one grandfather. Target children ranged in age from seven to seventeen and were predominantly male (n=8 of 11).

## **Instrument**

Community of Care staff co-created an interview guide with researchers. This guide was used for interviews within both programs with the two different groups: engaged family caregivers and FSPs (see Appendix A). Questions were created to get a better understanding of the program as a whole, and to learn about barriers and challenges to program success and implementation. Each guide begins with the question,



"Tell me about your experience with the Supporting Families program" in order to allow for the participant to give a narrative about their experience. Specific probing questions were also included in the interview guide to gain further information for each of the groups. The primary questions asked of family caregivers were in regards to specific services they had received, how the program benefitted the family, what was most helpful, what could be improved, what the challenges for family participation were, and their perceived challenges and barriers. Probing questions for the FSPs included benefits to the approach, why they chose to become involved, challenges within the program and system, challenges with clients, and advice to future family support endeavors.

### **Data Analyses**

Transcripts were imported into NVivo, a qualitative analysis software. A grounded theory approach like that described by Auerbach and Silverstein (2003) was used. In the first level of analysis, text from each interview was searched for relevant content related to barriers and challenges to program participation and success. A number of questions yielded applicable responses, such as "How could this program have better served your family?", "What may hinder other families from participating in the program?", "What made you decide for your family to participate in this program?" and "What challenges do you see within the process of this program?". At this level, it was important to distinguish between problems in someone's life, and problems related to program success and participation.

In the second level of analysis, relevant text was coded into repeating ideas. Because a grounded theory approach was used, codes were not pre-determined but instead were informed by an initial read of the text locating recurring themes (such as difficulties with other agencies). Some references were given more than one theme code. In the third and final level of analysis, recurring themes were coded by the ecological level(s) to which they apply. In this exploratory study, the framework was developed for enhancing basic understanding rather than for testing a theory. Due to the exploratory and descriptive nature of this study, inter-rater reliability was not determined.

## FINDINGS

The original intent was to discuss the findings from these interviews by ecological level. Upon analysis, it became clear that each barrier and challenge in these programs affect and is caused by more than one level, with much overlap between levels. However, some clear themes came through that illustrate the barriers and challenges evident in these peer support programs for families with a child with an emotional or behavioral disorder.

Table 1 illustrates the themes as they appeared between programs and between supporters versus family caregivers.

Table 1  
*Comparison of Themes between Programs and Participant Type*

	<b>Supporting Families</b>	<b>Community of Care</b>
<b>Family caregivers</b>	<ul style="list-style-type: none"> <li>• Concern for being judged</li> <li>• Programmatic concerns</li> <li>• Disagreement/Conflict between supporter and family caregiver</li> <li>• Difficulties with other agencies</li> <li>• Lack of family member participation</li> <li>• More time needed in program</li> <li>• More needed for target client</li> </ul>	<ul style="list-style-type: none"> <li>• Concern for being judged</li> <li>• Programmatic concerns</li> <li>• Disagreement/Conflict between supporter and family caregiver</li> <li>• Difficulties with other agencies</li> <li>• Lack of family member participation</li> <li>• More time needed in program</li> <li>• More needed for target client</li> <li>• New program difficulties</li> <li>• Poverty/Rurality</li> <li>• Unclear understanding of the program</li> </ul>
<b>FSPs</b>	<ul style="list-style-type: none"> <li>• Concern for being judged</li> <li>• Family caregiver mindset/Lack of family caregiver buy-in</li> <li>• Difficulties with other agencies</li> <li>• Lack of FSP professional identity</li> <li>• Funding and referral difficulties</li> <li>• More needed for target client</li> <li>• Programmatic concerns</li> <li>• Lack of family member participation</li> <li>• More time needed for target client</li> </ul>	<ul style="list-style-type: none"> <li>• Concern for being judged</li> <li>• Family caregiver mindset/Lack of family caregiver buy-in</li> <li>• Difficulties with other agencies</li> <li>• Lack of FSP professional identity</li> <li>• Funding and referral difficulties</li> <li>• Poverty/Rurality</li> <li>• New program difficulties</li> <li>• Unclear understanding of the program</li> </ul>

## **New Program Difficulties**

One of the most common response themes for the Community of Care program was in relation to new program difficulties. At the time of the staff interviews, Community of Care was in its 18th month of operation, and at the time of the family caregiver interviews, in its 21<sup>st</sup> month. Some statements were made regarding conflict between the partnering agencies and learning which set of rules to follow. A number of barriers and challenges were related to a management staff member not fulfilling his or her duties as perceived by FSPs. The program had also recently changed its policy regarding who has first contact with families. When the community liaisons were in this role as opposed to the FSPs, participation was a concern.

FSP: "...the way they do it there is, I'll get a referral and I'll read it and I'll think 'yeah well this family really needs our program, they need our help' but there the community liaison makes the initial contact, and they may not do that the first week or the second week or the third week... for the FSP to have to wait on the professional to find time to get in touch with that family, to me, if it's a need, it's a need, it's an immediate need, it's not something that should wait 2 or 3 or 4 weeks down the road to get addressed...because then I'm worryin, you know, 'what is this family doin?' It's either done hit the fan, or fell all to pieces, or solved itself by the time we get involved."

## **Unclear Understanding of the Program**

Some of the new program difficulties, such as the director not fulfilling his or duties, contributed to what caregivers and FSPs in Community of Care felt was an unclear understanding of the program within the community.

FSP: "I think people are starting to get the wrong perception of us, they think we're a money agency. We've had them come in, well, I need help with this, I need help with that, and they're not even a client here. The word's getting out that we actually help people. But you've got to be here. You've got to be a client, you've got to have child and family team meetings and stuff like that. I think after we establish ourselves and stuff like that, it's gonna get better."

## **Difficulties with other Agencies**

There were also many responses related to difficulties with other agencies. These responses were related to the local department of children's services not fulfilling their obligations, poor experiences with other agencies leading to family caregivers' hesitance to participate, and barriers to receiving program recommended services from other agencies.

FSP: "Probably the biggest challenge is when the Department of Children Services is involved, asking the Department of Children Services' case manager to follow through depending on the need. Sometimes, you know, things can wait a week or two. Most of the time they can't, so that can sometimes be a barrier or a hindrance."

### **Concern for Being Judged**

Both FSPs and family caregivers noted a concern that family caregivers (and in one instance, teachers) have about being judged by others for being involved in the program. This was related to being worried about DCS involvement, being told what to do by FSPs, and having others in the community think less of their family.

FSP: “The hindrance I think a lot of times is because it is a small community and that stigma of mental illness sometimes prevents families from calling us, because even though it’s confidential, they still have in their mind, somebody may see me coming out of the building and wonder what I’m doing. So that’s the hindrance is that stigma from being in a small community, you know that they may be found out I guess or something.”

### **Poverty/Rurality**

This stigma was also part of another recurring theme: poverty/rurality. In a small, rural community, there is a greater stigma towards mental health as well as a greater risk of one’s program involvement becoming public knowledge. Individuals in the area also felt the impact of poverty in that they could not afford private transportation to program meetings, etc. but living in a rural area, public transportation options were not available. The rural region also made it difficult for individuals to come to child and family team meetings and for families to access resources only available in a more urban area.

Family caregiver: “And I said, “I really want to learn how to drive. I really do.” But with the office of Vocational Rehab, and you know the program tried to talk with them, to say hey is there any way we can speed this along, to get her to where she can get her drivers, but you know, they were like, “no”. And I want to learn how to drive, but I don’t want to teach myself, I would prefer to have a teacher. And I gave them contact at the United Cerebral Palsy Foundation, and they were like, ‘If you lived closer to the office, we could help you. But you’re too far away, I don’t really know what to do to help you.’”

### **Family Caregiver Mindset/Lack of Family Caregiver Buy-In**

Many FSPs noted that family caregivers’ mindsets were often challenges to program success and that lack of family caregiver buy-in was often a barrier to their participation in the program. It’s likely this was tied to stigma regarding mental illness, past experiences with other agencies, and a concern for being judged.

FSP: “I have another family that I worked with and most of the time parents have hooks, you can hook in on an emotional level, and I have a parent...who I just could not hook in on. And then finally realizing that this parent doesn’t have the hook, she either doesn’t have the ability, or she’s unwilling, it’s one of the two. I just think that she’s unwilling to try to make things better. She wants everyone

else to do it so, those are probably the challenges... Or having a parent who, who thinks that the child is the problem, it's the child's behaviors and thinking that, you know, that there's nothing wrong with their parenting style."

### **Disagreement/Conflict Between Supporter and Family Caregiver**

Potentially due to some of the family caregiver mindset concerns above, some family caregivers noted their having some conflict or disagreement with their FSP. This included personality clashes, different beliefs of what was best for the target client, and concerns over what the supporter should do in certain situations.

Family caregiver: We were kind of a little bit taken aback. [FSP] is very abrupt and can be very condescending... And it's not appreciated and as parents, we're goin through enough you know. We're dealin, our lives are just so stressful and we're tryin to do the right thing. The last thing we need is someone to jump down our throat and to treat us like that.

### **Lack of FSP Professional Identity**

FSPs, especially in the longer running Statewide Advocacy program, saw their lack of professional identity as a challenge in their work. Though generally considered to be professionals within the program, they were not in the larger system, and this was found to be disheartening.

FSP: "We have constantly had to beat down the perceptions for me to define what professional is. And I think more or less, and when I say for me, I know that this program with all my bein, this program would not be what it is without, without the FSPs. It just wouldn't. But they view the views of what people, people's definition of professional, which in our work dynamic, bein a counselor, it's the degrees, it's havin the masters, the PhD. And if you don't have those credentials behind your name that you're not knowledgeable, and you don't know what you're doin."

### **Funding and Referral Difficulties**

FSPs in both programs found problems in being eligible for funding (sometimes related to their lack of professional identity), actually getting reimbursed, getting enough funding, and receiving appropriate referrals.

FSP: "...just the way the referrals, the limited way the referrals are comin in and the way the funding is, I need to set it up billable, make sure all the billable is in order, is gonna work, before two years down the road and they're not gonna pay because you didn't cross that 't', you know, that type thing."

### **More Time Needed for Families in Program**

In part due to the funding difficulties mentioned above, FSPs and family caregivers alike mentioned a need for families to have more time in the program. Because of the intricate nature of the funding, one

family caregiver also mentioned wishing she had more certainty about how much longer they had.

Family caregiver: “See, that’s what I’m saying – I don’t know if Community of Care just has so many kids...I just feel like everything’s so short. And I think that’s because of money, too.”

Family caregiver: “You can say ‘I’m gonna do this for 3 months and you should be fixed’. Well that sounds wonderful but sometimes it’s not logical.”

### **More Needed for Target Client**

Along with more time, family caregivers responded that they felt as if the program was not doing enough for their child and that the child’s behaviors were not changing as they’d like. Some family caregivers mentioned specific things they needed (such as a male role model for their child) while others just noted the program hadn’t helped the child.

Family caregiver: “I talked with [FSP] the other day, I said, “You know [FSP], I really think that ya’ll need to focus more on the child than the parent. This child needs to be in a support group with other children that have the same problem he has. So he can hear some of the solutions they have, some way other than the anger and the, the stuff. I said, ‘I really feel like he needs to be in a support group more than we do. We’re doing all we can do.’”

### **Programmatic Concerns**

In addition to family caregivers noting the programs’ focus on the parents instead of the child as a problem, family caregivers and FSPs had concerns with other ways in which the program was run. Family caregivers noted FSPs and behavior specialists not having enough experience and not being available enough. FSPs were challenged by not being considered professionals within their programs and with the driving required of them.

FSP: “One other thing, I think is somethin and that is just to me more financially feasible is that, dependin on the size of the area that the agency is goin to provide family support services, that in order to be more cost effective, I would think that, to have a supporter serve children in a certain area ... if I serviced the children in this area, she services the children in this area, that’s gonna save the agency money in mileage reimbursement when they have to pay us, its gonna most importantly save our time... they need to look at the, the placement geo-geographically where the clients are...”

### **Lack of Family Member Participation**

Both Statewide Advocacy and Community of Care lead with the premise that the whole family is integral in bringing about positive change. FSPs and family caregivers mentioned instances of secondary family caregivers not participating in the program, family caregivers arguing, and index clients choosing not to participate themselves.

Researcher: “Has Community of Care helped at all with any of the interactions with [child’s father]?”

Family caregiver: “Well, upon my request, they didn’t offer anything, but upon my request because of just who he is and everything, I said, “Don’t even bother.” Because, for one thing, [supporter] is African-American and he’s very, my ex-husband is very prejudiced, it just wouldn’t have worked, right off the bat. He’s very judgmental based on people’s physical appearances, I mean he would have had a problem with [community liaison, who is very short ]. In the long run it just probably would have caused more drama. I mean they offered. You know, everybody suggested, you know, “Shouldn’t we....” I’m like, “Yeah, that would be great if we lived in a perfect world!” but you know, unfortunately he’s just not open to it.”

### Ecological Level Findings

Table 2 illustrates that the majority of recurring themes in barriers and challenges could be understood by more than one ecological level, with many being part of three or more levels. For example, the issue “concern for being judged” applies to the individual level, since it affects individuals and is sometimes done just by individuals. It applies to the program level, because family caregivers are concerned that the program as a whole will judge them. In the community, specifically the rural area Community of Care operates in, there is a mental health stigma that family caregivers try to avoid. This issue is present in a systemic way due to an overall fear of the child services field judging the family caregivers. Barriers and challenges were found most frequently within the individual, system, and program. This is similar to the barriers and challenges found in the literature, which fell mostly in these levels as well.

Table 2  
*Recurring Themes and the Ecological Levels to Which They Apply*

	Individual	Family	Program	Community	System
Concern for being judged	X		X	X	
Poverty/Rurality				X	X
Family caregiver mindset/Lack of family caregiver buy-in	X	X			
Programmatic concerns	X		X		
New program difficulties	X		X	X	X
Disagreement/Conflict between supporter and family caregiver	X				
Difficulties with other agencies	X		X		X
Lack of family member participation	X	X			
Lack of FSP professional identity	X		X		X
Funding and referral difficulties			X		X
More time needed in program					X
More needed for target client	X		X	X	X
Other/Isolated	X		X		

## **Initial Responses**

Despite the number of responses related to the barriers and challenges FSPs and family caregivers experienced, it is important to note that the interviews also showed a high level of satisfaction with the programs both as staff members and participants.

Researcher: “Have there been any sort of hassles or challenges or barriers to working with the program?”

Family caregiver(mother): “No, no, I was like amazed how Statewide Advocacy, how they bend over backwards to help us.”

Family caregiver (father): “Yes, I’m amazed at the coming to the house, I mean...I think that is almost unbelievable.”

Family caregiver: “I can’t, you know, I’m kinda the type that I usually can find something, well this needs to be changed, or this can be done to make it a little bit better but, I cant really give you suggestion for if a change needs to be made. I mean maybe there does, but I sure cant think of it. It worked, it’s worked for us.

## **DISCUSSION**

This study sought to uncover the barriers and challenges perceived by family supporter programs and family caregivers in the participation and success of peer support programs for family caregivers of children with emotional and/or behavioral disorders in order to inform future service delivery. Despite positive outcomes in the evaluations of similar programs, and praise for the programs studied at hand, it is clear that such barriers and challenges exist. What is potentially most striking is the number of barriers and challenges related to the system as a whole, given that one of the objectives of these programs is to help navigate the intricacies within the system. In a similar vein, it is interesting to note that fewer barriers and challenges fell into the family level than any other level, further indicating that service delivery change needs to be focused outside of the family.

Many of the barriers and challenges found in this study were the same or similar to barriers and challenges noted in previous studies of similar programs. The need for more time (Boudin, 1998), more needed in general (Iscoe & Brdelon, 1985), stigma concerns (Richert et al., 2007; Goldstein, 2005), and conflict between supporters and participants (Nicholas & Keiltry, 2007; Richert et al., 2007) were all noted by caregivers in Community of Care and Supporting Families as well as other programs.

Barriers and challenges noted by peer supporters in this study were also matched to previous findings: lack of professional identity (Meehan et al., 2002; Moran et al., 2007; Foreman et al., 2005; Iscoe



& Bordelon, 1985), difficulties with other agencies (Moran et al., 2007; Sakwa & Ireys, 2006; Manalo, 2008), funding issues (Sakwa & Ireys, 2006; Manalo, 2008), feeling more is needed (Iscoe & Bordelon, 1985), and frustration with participant mindset (Marino et al. 2007; Iscoe & Bordelon, 1985). Hoagwood et al. (2010) found that a crucial component of family-lead family support programs that differed from clinician-lead programs was the focus on advocacy (both advocating for the families and teaching advocacy skills). In a system where peer supporters must struggle to advocate for themselves, it may be even more difficult for them to advocate and teach advocacy for and the families.

There were some findings from the present study that are new to the literature: new program difficulties, unclear understanding of program, poverty/rurality, programmatic concerns, and lack of family member participation. The first three of these are likely specific to the programs researched here, and lack of family member participation is specific to family-based peer support programs. It is also possible that since this study asked questions specifically probing for difficulties, more secondary or underlying concerns came out.

### **Limitations**

The most serious limitation to this study is the relatively small number of participants, and that all family caregiver participants had engaged with the programs – no unengaged family caregivers agreed to participate. Though some inferences can be drawn about barriers to participation based upon FSPs' and engaged family caregivers' experiences, much more could be learned from the experiences of individuals who chose not to participate in the program. The referral and engagement process are, in and of themselves, crucial to understand in order to understand how to better enhance program participation and success. Additionally, this study focused only on the family caregivers and FSPs. As evidenced by findings, other individuals, such as behavior specialists, community liaisons, and other agency professionals, are important to program success and participation as well. Finally, the findings from this study are mostly exploratory and thus cannot be generalized to other peer support programs of this nature. That said, much can be learned about the barriers and challenges explored here and how they may apply to other programs and agencies.

### **Implications for Research**

It is imperative for future research to access the viewpoints and experiences of families that did not engage, through choice or through circumstance, with the programs. In this process, programs may better understand how to recruit and retain families. Longitudinal research that involves interviewing families at each step throughout the referral, engagement, participation, and termination process would be useful as well. The findings of this study show that such programs are not perfect and have room for improvement; research could also be useful in determining what barriers and challenges are the most problematic.

### **Implications for Practice**

A clear implication for practice from these findings is the need for peer support programs to forge positive relationships with other agencies. This may lead to a better recognition of supporters as professionals, timely and appropriate referrals, consistent funding, and ensuring wraparound and system of care principles are in place. In practice, there's a clear need for supporters to advocate for themselves in the profession. There also appears to be a clear need for new programs to concern themselves with the negative effects of program startup issues, particularly the reputation of the program within the community and system.

Due to past negative experiences and the intersection of fear over being judged by others and needing to come to terms with the situation, there is a breakdown at the place where family caregivers become engaged. It is imperative that there be a way of ensuring family caregivers better understand the program and feel more comfortable with the prospects of having more people from the system in their lives.

## Appendix A

### Guiding Framework for Interviews

#### *Participating Family Caregivers:*

- 1) Tell me about your experience with the Supporting Families program.
- 2) Probes:
  - How did you first hear about the services offered by Supporting Families?
  - Why did you choose to get involved with Supporting Families?
  - What have you received from your involvement with Supporting Families?
  - In what ways has involvement with Supporting Families impacted your child's well-being?
  - In what ways has involvement with Supporting Families impacted your personal well-being?
  - What has been the most helpful thing about being involved with Supporting Families?
  - What, if anything, makes Supporting Families different from other agencies or places where you have attempted to get help for your child(ren)?
  - What could Supporting Families do to improve your experience or better assist you and your family?
  - What challenges do you face in participating with Supporting Families? [transportation, scheduling, friend/neighbor opinions, etc.]
  - What are the challenges for families with the process employed by Supporting Families as you see them?

#### *Family Support Providers:*

- 1) Tell me about your experience with the Supporting Families program.
- 2) Probes:
  - How did you first hear about the services offered by Supporting Families?
  - Why did you choose to get involved with Supporting Families?
  - In what ways have you benefited from your involvement with Supporting Families?
  - What are the challenges with the process employed by Supporting Families as you see them?
  - What do you feel makes Supporting Families unique as a mental health agency?
  - What do you feel makes Supporting Families unique as a place of employment in the human services field?
  - What are the benefits you see of the unique structure of Supporting Families as a co-located mental health professional office and family advocacy group?
  - What are the challenges you face specific to the unique structure of Supporting Families?
  - What are the challenges you face specific to the clients you serve?
  - If another agency were attempting to start a similar endeavor, what is the first piece of advice you would give them?

## Appendix B

### Script for Initial Phone Contact

“Hi, my name is \_\_\_\_\_, and I’m a doctoral student at the university. We are doing a research study about the Supporting Families program. [Staff who gained consent] at Statewide Advocacy let us know that you might be interested in participating in the study. Can I tell you a little bit about the study now, or is there a better time to talk?”

#### *Family caregiver participants*

“We are trying to learn more about mental health services for children in [southeastern state]. We would like to talk to families whose children have received services from Supporting Families to find out your thoughts and opinions on the services, the referral process, and what you think are the benefits and challenges of the way Supporting Families operates. We would also like to talk about the benefits and challenges of having a service like this in your community. We will be able to pay for your time in participating. Whether you participate or not is totally up to you and will not affect your services in any way. Anything you tell us will be confidential.”

#### *Family Support Providers:*

“We are trying to learn more about mental health services for children in [southeastern state]. We would like to talk to staff from Supporting Families to find out your thoughts and opinions on the services, the referral process, and what you think are the benefits and challenges of the way Supporting Families operates. We would also like to talk about the benefits and challenges of having a service like this in your community. Statewide Advocacy has agreed that you can use work time for this interview, but it will be private and they will not know whether or not you actually participated. Whether you participate or not is totally up to you and will not affect your job in any way. Anything you tell us will be confidential.”

#### *Continue with this for all interviews:*

The interview would take about an hour. If you are unable to travel to Statewide Advocacy, an interviewer will gladly come to your home or a place that is convenient for you. The interviewer will be a graduate student from the university. The questions asked will be about your experience with Supporting Families. If you are willing, the researcher will audiotape the interview. The tape will be transcribed and then destroyed.

You do not have to participate in the interview. If you choose to, then want to stop at any time during the interview, that is fine. If you decide not to participate, any relationship you have with the interviewer or the university or Statewide Advocacy will not be harmed in any way. Everything you tell the interviewer will be confidential, meaning that names will not be connected with the information you give in any way. As with any study, there is a small possibility that confidentiality will be broken, but we will do everything possible to see that does not happen.

By participating in this research study, you will be helping to develop a better understanding of children’s mental health services, perceptions about the services of Supporting Families and reasons why people stay involved in or leave agencies such as Supporting Families. You would be able to have a copy of any reports that are written as a result of this study. Do you have any questions?” “Does this study sound like something you might be interested in participating in?”

*If the person says no, thank them for their time and end the call.*

*If the person says yes, say:*

“Can we schedule a time to meet? We will be doing interviews on [DATES]. Would you be able to come to the Statewide Advocacy offices on any of those days? We can also send a researcher to your home if you prefer.”

## Appendix C

### Script for Initial Phone Contact of Family Caregivers by Supporting Families

“Good morning (afternoon/evening), my name is \_\_\_\_\_ and I am the director of the Supporting Families program at Statewide Advocacy. I am calling you about an opportunity to be interviewed by staff at the university. They are doing a study about the Supporting Families program and want to talk privately with parents who have had any contact with us. Can I tell you a little bit about the study now, or is there a better time to talk?”

“Statewide Advocacy is trying to improve our Supporting Families program and has asked the university to conduct an independent and private study so that family members can feel free to say whatever they want. They would like to talk to families whose children have had any contact with Supporting Families to find out your thoughts and opinions on the services, the referral process, and what you think are the benefits and challenges of the way Supporting Families operates. They will be able to pay you for your time in participating. Whether you participate or not is totally up to you and will not affect your services in any way. Anything you tell them will be confidential. They are only providing us with a group-level report with no names.”

“Does this study sound like something you might be interested in participating in?”

*If the person says no, thank them for their time and end the call.*

*If the person says yes, say:*

“Do I have your permission to give the following information to Vanderbilt: Your name and phone number, the best time of day to reach you, your child’s age and gender.”

*If the person says no, thank them for their time and end the call.*

*If the person says yes, get the information and then say:*

“Thank you for your interest and help in this.”

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