

What Family Support Specialists Do: Examining Service Delivery

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Abstract This study describes services provided by family support specialists (FSS), peer advocates in programs for children with serious psychiatric conditions, to delineate differences between recommended components of FSS services and services actually provided. An analysis of qualitative interview and observational data and quantitative survey data from 63 staff at 21 mental health programs in New York identified that FSS and other staff have generally similar ideas about FSS services, and that these perceptions of activities are generally congruent with what FSS actually did. Implications of findings are discussed in the context of developing competencies and quality indicators for FSS.

Keywords Family support services peer advocate · Child mental health · Mental health program

Introduction

Peer advocates are paraprofessionals whose work enhances engagement and improves the quality of care for individuals with chronic health issues including diabetes (Lorig et al. 2003), cancer (Emmons et al. 2003), HIV (Broadhead et al. 2002; Lyons et al. 1996), and serious mental health conditions such as schizophrenia and bipolar disorder (Chinman et al. 2000; Kane and Blank 2004). Peer advocates, who usually have personal experience with health and mental health conditions, provide outreach (Latkin et al. 2003), deliver information about health and mental health conditions and resources (National Alliance on Mental Illness 2007; Resnick et al. 2004), provide case management services (Chinman et al. 2000), and conduct educational and support groups (Sands et al. 2001; Sands and Solomon 2004). The evidence base suggests that peer-delivered interventions are associated with positive outcomes including medication adherence (Hoagwood 2005), increased attendance at health appointments (Druss et al. 2010), improvements in symptoms and functioning (Greenfield et al. 2008), and reduced crisis events and hospitalizations (Klein et al. 1998).

Children's public mental health services differ substantially from adult services (Hoagwood et al. 2001). Children experience more rapid developmental changes (e.g., cognitive, physical) than adults, so service systems must be prepared to address a broader range of developmental conditions than adult services (Hoagwood et al. 2001). Mental health treatment for children must always consider the family context including how parents or others perceive the child's illness, and how involved they may be in treatment. Finally, child mental health services, unlike most adult mental health services, frequently involve integration of multiple service settings and providers, including primary care settings, welfare systems, juvenile

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justice, and especially schools, which provide up to 80 % of mental health services to children (Burns et al. 1995).

Over the past two decades, a peer model of service delivery has emerged in the children's public mental health system for families of children with serious mental health conditions. The nomenclature varies from state to state: these individuals may be called peer advisors, parent partners, family peer advocates, family support specialists, among other names. We will refer to them as family support specialists. Family support specialists (FSS), who are former or current caregivers of children with identified mental health needs, provide family support services including information or education about services and parental rights, tangible assistance (e.g. respite, transportation), skills, (e.g., parenting techniques), direct advocacy, and emotional support (Hoagwood et al. 2010). FSS are perceived as trustworthy and credible role models by virtue of their shared experiences, and growing evidence suggests peer-delivered family support is associated with important family outcomes, including decreased levels of parental anxiety (Ireys and Sakwa 2006), improvements in caregiver self-care, empowerment, and communication styles (Brister et al. 2012), and engagement in their child's services (Elliot et al. 1998; Gyamfi et al. 2010; Hoagwood 2005). FSS can either operate embedded in professional service programs such as a child mental health clinic (e.g., employed as part of the treatment team or part of a larger service model), or in stand-alone peer programs (in which FSS that operate independently, outside of a team, and typically as part of a family run organization such as the National Alliance on Mental Illness, and who advocate independently of the program where the family is seeking services).

There has been increased attention to peer-delivered family support, due in part to a growing evidence base documenting the effectiveness of peer-delivered family support (Hoagwood 2005), worsening workforce shortages in the mental health field (Hoge et al. 2007), and substantial growth in national family-based organizations such as the National Alliance on Mental Illness (2007) and the Federation for Families. Kentucky, Florida, and New York, among other states, are either in the process of or have created a credential for peer advocates, with specific eligibility requirements. Once credentialing is achieved, states will provide FSSs with ongoing training and supervision and seek reimbursement for their services (e.g., Florida Peer Network, Inc., n.d.; Families Together in New York State, n.d). For example, in New York, a home and community-based services (HCBS) Waiver program for children at risk for institutionalization includes as a core element family support services provided by FSS. These FSS work alongside a team of professionals including individualized care coordinators, respite workers and skill builders, to provide support services to families.

Despite these advancements, there is little work detailing what FSSs do in encounters with families, especially in programs for children who have serious mental health needs. Hoagwood et al. (2010) conducted a comprehensive review of family support services in children's mental health to identify typologies of family support services. In their review of more than 200 programs, they identified five salient components of family support. These components are (1) informational/educational support, defined as education about child behavior and development, the course of mental illness and its impact, treatment options, child and family service systems, and other resources; (2) instructional/skills development support, defined as skill building directed at either coaching the caregiver on ways to address their child's illness or associated behaviors or directed at addressing the caregiver's well-being, (3) emotional and affirmational support, defined as shared communication among families and between providers and families to promote the caregiver's feelings of being affirmed, understood and appreciated; (4) instrumental, support, defined as concrete services such as respite care, transportation, and flexible funds for emergencies; and (5) advocacy support, which is provision of specific information about parental rights and resources, coaching on how to effectively negotiate for services, or provision of direct advocacy to obtain services for a caregiver or child. Advocacy support also included leadership skill building to develop the caregiver as an advocate at policy and service system levels. Hoagwood et al. (2010) concluded that although family-delivered support may be an important adjunct to existing services for parents, research is needed to more rigorously evaluate family support services.

In addition to Hoagwood et al.'s (2010) review, we found three studies that describe FSS activities. In Rodriguez et al. (2011), FSSs described their job functions, demonstrating that FSS provided a variety of services, including information/education, one-on-one advocacy, tangible assistance (e.g., childcare, transportation vouchers) parenting skills, and emotional support. Davis et al. (2011) conducted qualitative interviews with parent advocates to understand specific activities when working with families in publicly funded mental health programs. They described their day-to-day activities as including service system advocacy and support, parent education and empowerment, emotional and social support, resource information and linkage, and material services and supports (e.g., transportation). Given that each study describes FSS self report and family perspectives of their activities but does not observe FSS to understand what they actually do, Wisdom et al. (2011) conducted a pilot study of a walk-through methodology to examine the feasibility and acceptability of using observational methods to observe FSS actual activities in four programs in New York.

A Walkthrough is an in vivo method of participant observation for studying service delivery and quality of care in response to a standardized patient scenario. Wisdom et al. (2011) found that the walkthrough process was both feasible and acceptable to FSS as a way of evaluating services. Consistent with previous studies (Davis et al. 2011; Rodriguez et al. 2011), there was substantial variability in services provided by FSSs.

These studies are informative initial steps in understanding FSS service delivery because they describe FSS and parent perspectives of the multiple job responsibilities of FSSs. These studies also suggest a research agenda: (1) Many of the terms used (e.g., empowerment) would benefit from specific operationalization to aid in both educational and evaluative activities. (2) Studies indicate significant variability in the services provided by FSS, even (as in Wisdom et al. 2011) in response to the same family scenario, which suggests utility in determining the proportion of time spent on various services rather than simply whether they occur. (3) Aside from descriptions from studies of published interventions that include FSS delivered services, studies that have more directly examined what FSS do rely exclusively on *perceptions* of FSS activities either self-reported by FSS or reported by other individuals (e.g., parents). Systematic observation of FSS' activities are a crucial next step to determine what FSS actually do when they provide services to families, particularly because self report of providers' behavior with respect to evidence-based treatments correlates poorly with what they actually do (Hurlburt et al. 2010).

It is crucial to understand services FSS provide because of the need to have a foundation for assessing the effectiveness of FSS in increasing engagement, providing information, promoting skills, and reducing parental stress (Costello et al. 1996; Farmer et al. 1999), with the goal of improving service quality to children and families. This study describes services provided by FSSs in a specific type of service program for children with serious psychiatric conditions (HCBS Waiver programs) to delineate differences between recommended components of FSS and services actually provided. This is the first study using mixed methods (e.g., interview and observation) to integrate (1) interview data on FSS and other staff perceptions of FSS activities with (2) quantified observational data delineating FSS service delivery components to document variation in service content given a standardized patient presentation to obtain a more comprehensive and complete understanding of FSS activities. We use mixed methods to build upon prior descriptions of activities conducted by FSSs (Davis et al. 2011; Rodriguez et al. 2011; Wisdom et al. 2011) to enrich findings obtained by each method (Creswell and Plano Clark 2007). Integrating multiple sources of data—in this case, multiple informants and

observations—allows both a more comprehensive picture of actual services provided and an opportunity to examine where differences exist between informants' perceptions or between perceptions and observations. Examining consistency and inconsistency across multiple methods is a key component in a mixed methods study (O'Cathain 2010; Wisdom et al. 2012).

Research questions are structured to understand individuals' perceptions, observed activities, and areas of consistency and inconsistency between them: (1) How do FSS and non-FSS staff (Program Director, Individualized Care Coordinator) compare in their perceptions of what FSS do in HCBS Waiver programs? (2) How do FSS describe the services they provide to families? (3) What does the walkthrough indicate FSS actually do in standardized family scenarios in HCBS Waiver programs? And (4) How do Program Director, Individualized Care Coordinator, and FSS perceptions of what FSS do in HCBS Waiver programs compare to what FSS do in standardized family scenarios?

Methods

Overview of Study Methods

This study collected data from staff at 21 HCBS Waiver programs in New York State that have embedded FSS. See Table 1 for study design overview. Researchers collected qualitative data via (1) structured and semi-structured interviews with clinic administrators, individualized care coordinators, and FSS ($N = 63$ interviews) and (b) quantified qualitative data from walkthroughs conducted with $N = 21$ FSS. Each data source was analyzed independently and integrated into a cohesive set of results, including identification of congruent and incongruent findings between methods. Although statistical tests were underpowered, analyses were conducted to help guide future research.

Participants and Recruitment

In New York State, Home and Community Based Services (HCBS) Waiver Programs are an intensive, community-based program serving children between five and 17 years of age (prior to their 18th birthday) with serious emotional disturbances, at-risk for out of home placement. There are 33 HCBS Waiver programs within located within NYS.

HCBS Waiver Programs are federally approved programs authorized under Title XIX of the Social Security Act; these programs provide states flexibility to design and offer a mix of service options in order to meet the needs of specific groups of individuals who would otherwise require institutional care. HCBS Waiver program staff generally include at least: (a) *Agency Administrator*, usually the CEO of a large

Table 1 Research questions and data sources to describe what FSS do

| Research questions | Qualitative data sources | | Quantitative data sources | |
|--|--|---|---|---|
| | Qualitative interviews with FSS and other non-FSS staff ($N = 63$) | Walkthroughs conducted with FSS ($N = 21$) | Structured interviews with FSS and other non-FSS staff ($N = 63$) | Quantified data from walkthroughs with FSS ($N = 21$) |
| (1) Comparison of FSS and non-FSS staff (Program Director, Individualized Care Coordinator) perceptions of what FSS do | | | Comparison of FSS vs non-FSS endorsement of FSS activities | |
| (2) How do FSS describe what they do? | FSS description of activities from interview | FSS actual description to parent in walkthrough | | |
| (3) What does the walkthrough indicate FSS actually do? | | | | Quantification of observations of FSS activities in walkthrough |
| (4) How do FSS and non-FSS staff perceptions of what FSS do compare to what FSS actually do in walkthroughs? | | | FSS vs non-FSS endorsement of FSS activities | Quantification of observations of FSS activities |

mental health agency that oversees several programs including the HCBS Waiver program; (b) *Program Director*, usually a master's level clinician who is responsible for the overall management of the program; (c) *Individualized Care Coordinator*, who conducts intake and screening, assessment of needs, service plan development, monitoring of goals, and consultation; (d) *FSS*, who are peer providers of services with experience as a parent of a child with mental health needs and who provide advocacy and support for parents of children with mental health issues; (e) *Skillbuilders*, who assist the child in acquiring, developing, and addressing functional skills and support, both social and environmental (f) *Respite Workers*, who provide a break for the family and the child to ease stress at home and improve family harmony, (g) *Crisis Response Workers*, who implement activities to stabilize occurrences of child/family crisis, and who provide intensive interventions in the home when a crisis response service is not enough. Staff selected for this study included the Program Directors, Individualized Care Coordinators, and FSS.

Of the 33 eligible HCBS programs, nine programs chose not to participate in the current study and three programs were not eligible to participate as they either did not have at least a half-time FSS or an FSS on staff for at least 6 months. Twenty-one programs (70 %) agreed to host study staff at site visits. The 21 participating programs did not differ from the rest of the non-participating HCBS programs across the state in terms of program capacity (number of families that can be served ranged from 12 to 144; mean = 48.9, SD = 37.5) and region of the state, with at least half the programs in each of the five regions participating in the study; participation rates were highest in the Western (and most rural) regions of the state. The sample of FSSs who took

part in the study also did not differ from the population of FSSs employed in this type of program across the state. They had at least a high school degree (71.5 %), and 19.1 % had a bachelor's degree or some graduate education; one had a Master's degree in social work. At the site visit, study staff conducted interviews with the Program Director, Individualized Care Coordinator, and FSS, and administered the Walkthrough to the FSS.

Table 2 describes characteristics of all interviewed participants, including Program Directors, Individualized Care Coordinators, and FSS. All Individualized Care Coordinators and FSS were women; most Program Directors were as well. Program directors tended to have masters degrees and social work license. Individualized Care Coordinators had bachelors or masters' degrees, and FSS tended to have high school, some college, or bachelors degrees. Tenure at agency varied by job title.

Procedures

Staff Interviews

Interviews with Program Directors, Individualized Care Coordinators, and FSS gathered both quantitative and qualitative data about staff roles and activities in the HCBS Waiver program. Quantitative portions of interviews consisted of structured questions that included demographic data and questions asking staff to endorse which services FSS provided in their program. Qualitative portions of interviews were semi-structured and asked respondents to describe staff interactions, what FSS in their program did, and (FSS only) how FSS described their role to parents.

Table 2 Description of program director (PD), individualized care coordinators (ICC), and family support services (FSS) study participants

| | PD (N = 21) N (%) | ICC (N = 21) N (%) | FSS (N = 21) N (%) |
|--|----------------------|-----------------------|-----------------------|
| Female | 15 (71.4 %) | 21 (100.0 %) | 21 (100.0 %) |
| Mean age (SD) | n/a | 38.0 (6.9) | 48.6 (11.1) |
| Educational background | | | |
| High school, some college, or associates | 0 (0) | 0 (0) | 15 (71.5) |
| Bachelor's degree or some graduate school | 3 (14.3) | 7 (33.3) | 4 (19.1) |
| MSW or Master's in family therapy/counseling | 15 (71.5) | 8 (38.1) | 1 (4.8) |
| PhD in psychology or MD | 1 (4.8) | 0 (0) | 0 (0) |
| Other | 2 (9.5) | 6 (28.6) | 1 (4.8) |
| Licensure/credentials | | | |
| Family development credentials | 0 (0) | 1 (4.8) | 5 (23.8) |
| PEP certification ^a | 0 (0) | 0 (0) | 10 (47.6) |
| Social work license | 13 (61.9) | 4 (19.1) | 0 (0) |
| Psychology license | 1 (4.8) | 0 (0) | 0 (0) |
| Other | 2 (9.5) | 4 (19.1) | 2 (9.5) |
| Length of tenure at agency | | | |
| 1–11 months | 1 (4.8) | 0 (0) | 3 (14.3) |
| 1–5 years | 10 (47.6) | 20 (95.2) | 15 (71.5) |
| 6–10 years | 8 (38.1) | 1 (4.8) | 3 (14.3) |
| 11+ years | 2 (9.5) | 0 (0) | 0 (0) |

n/a Data not available

^a PEP parent empowerment program (Olin et al. 2010)

Walkthroughs

Adapted from computerized clinical guideline development (Horsky et al. 2003), business and management (Gustafson 2004), and medical training (Carney et al. 1999), walkthroughs have been used in behavioral health to identify areas for improvement in admission procedures (Ford et al. 2007) and to pilot screening processes for a clinical study (Fussell et al. 2008). In addition, walk-throughs can uncover assumptions, inconsistencies, and limitations of routine practice, and are useful in generating ideas for improving organizational processes (Ford et al. 2007), a critical issue as New York State moves to integrate FSS services into public children's mental health services.

Briefly, the walkthrough was conducted by having a trained FSS who was part of the research staff approach the program FSS as a parent enrolling in HCBS services and seeking family support services. Program FSS were fully briefed prior to the walkthrough and provided consent to take part in the role play and be audio-taped. The research FSS presented a standardized family scenario tested in focus groups and a pilot study with five primary presenting problems [her child's school situation, child's upcoming court date, family safety issues, daughters' well-being, and parent's job; see Wisdom et al. (2011) for details] and audiotaped the program FSS responses to the information.

The Walkthrough for each FSS was role-played as two meetings; an initial meeting between the FSS and "parent" was followed (after a break) by a simulated second, follow-up

meeting. No deception was used: the program FSS knew at every stage of the process about the walkthrough. An interviewer conducted a debriefing at the end of the walkthrough to elicit FSS' responses to the walkthrough procedure, including how realistic the family scenario was and how true-to-life the FSS' responses were. Each FSS completed both parts of the walkthrough and data for both walkthroughs were combined and analyzed together within each FSS.

Data Analysis

Staff Interview Data

Quantitative data from staff interviews was coded and aggregated for presentation. All transcripts of qualitative portions of interviews were thematically coded using Atlas.ti, qualitative analysis software that aids the coding, organization, and retrieval of text. Thematic analysis seeks to extract themes from qualitative data by identifying common ideas across interviews and aggregating sections of data from interviewees into conceptual themes to describe multiple aspects of a larger concept. Trained coders, including doctoral and masters' level researchers and the research FSS, began analyses by delineating a preliminary coding scheme and applying it to sample text; an iterative process refined the coding scheme to ensure all relevant themes were captured (Miles and Huberman 1994). Once the coding scheme was finalized, coders applied the final code list to all transcripts,

including 10 % blinded double-coding to assess inter-rater consistency, to identify passages of text associated with each coded theme. Passages of text were assigned multiple codes when appropriate. Inter-rater consistency was 86 %; identified discrepancies were resolved.

Walkthrough Qualitative Content Analysis

Content analysis is a method of qualitative analysis that categorizes and quantifies frequency of specific aspects discussed in qualitative data; it counts instances of data and essentially quantifies the qualitative data. To conduct the content analysis, both parts of each FSS's walkthrough were combined into a single walkthrough transcript. Next, all text in each walkthrough transcripts was divided into unique "units" of FSS activity, each of which represented an effort by the FSS to "do" something with the standardized parent. Each unit was coded for content with categories from Hoagwood and colleagues' (2010) systematic review of FSS services which refer to broad categories of FSS tasks; an additional category of "gathers information" was added because it emerged as a substantial activity of FSS. Eight coders (masters and doctoral-level) received 2 days of training in qualitative content analysis and completed test-transcripts until they achieved reliability of at least 80 %. Coders worked in pairs and completed weekly test transcripts to verify reliability during coding. Coders reviewed all interview transcripts in teams of two and highlighted each discrete functionally meaningful concept or statement. Coders then assigned to each discrete unit a content code. Units were coded as meeting criteria for the code if they provided the information, support, etc. to the standardized parent during the walkthrough scenario; advocacy, instructional, and instrumental services were indicated as present if the FSS indicated he or she would provide that service (e.g., if a FSS said she would advocate on behalf of the parent at the school, this was counted as advocacy). These codes were then analyzed in several ways: (1) they were summed across FSS to indicate the total types of activities occurring across all FSS, and (2) we calculated within-FSS proportions of activities.

Results

Research Question 1: How do FSS and Non-FSS Staff (Program Director, Individualized Care Coordinator) Compare in Their Perceptions of What FSS do in HCBS Waiver Programs?

The frequency of activities endorsed in interviews by Program Directors, Individualized Care Coordinators, and FSS are presented in Table 3 (left side) categorized by themes of FSS activities outlined by Hoagwood et al.

(2010). Although all or nearly all respondents agreed that FSS provide emotional support, advocacy, and skill building (all above 90 %), there was greater discrepancy in the proportion of different staff categories as to whether FSS conduct additional activities with parents, including support groups, recreation activities, and crisis management and respite, the latter two functions potentially assumed by the crisis and respite workers on the waiver team. The differences between Program Director, Individualized Care Coordinators, and FSS frequency of reporting the provision of instrumental concrete services [$\chi^2(2, N = 63) = 4.69, p = 0.089$] and recreational activities [$\chi^2(2, N = 63) = 4.96, p = 0.084$] demonstrated a trend toward significance. No other differences approached statistical significance, although given the small sample size, there was insufficient power to detect significant differences.

Research Question 2: How do FSS Describe the Services They Provide to Families?

To answer this question, we reviewed two sources of data: (a) FSS responses to open-ended interview question, "How do you describe yourself as a FSS to families?" and (b) review of walkthrough data to determine how they actually described themselves in the walkthrough scenario and talked with standardized parents about their services. More universal themes are presented first, with less endorsed themes presented after.

FSS collectively described themselves via interview data and walkthrough data as a parent of a child with special needs who works with families to provide empathy, understanding, to make the parent feel more comfortable, to describe their personal experience when relevant and appropriate, and to provide knowledge to assist the family in caring for themselves and their child. One FSS described herself in the walkthrough (to the standardized patient) as:

I'm a parent that has been through some difficult times with my own children who are grown now, but part of the reason I was hired for this position is I can really empathize and understand with what it might feel like as a parent who really has some challenges.

FSS also described themselves in terms of the services they offer to families. FSS described offering (a) emotional support (perspective, objectivity, just to talk), (b) educational support (parent training, budgeting/money skills, communication skills) (c) links to resources (community resources, housing, other parents, cash assistance, transportation), and (d) advocacy/self-care and empowerment for families to eventually navigate and advocate for themselves. Many FSS described themselves to families as

Table 3 Comparison of FSS, PD, and ICC perceptions of FSS activities and actual frequency of FSS activities from Walkthrough

| Content | Data source | | | | |
|--|--|-----------|-----------|---|---|
| | Frequency endorsed in Interviews as offered by the FSS | | | Actual frequency in Walkthrough Scenarios | |
| | FSS (%) | PD (%) | ICC (%) | FSS (%) | Proportion of responses by individual FSS (% range) |
| Informational/educational support | | | | 21 (100) | 21.5–67.8 |
| Active referral | 20 (95.2) | 20 (95.2) | 18 (85.7) | | |
| Passive referral | 21 (100) | 18 (85.7) | 18 (85.7) | | |
| Emotional/affirmational support | | | | 21 (100) | 7.8–38.4 |
| Emotional support | 21 (100) | 21 (100) | 21 (100) | | |
| Instructional skills development support | | | | 21 (100) | 1.5–17.8 |
| Support groups for parent | 19 (90.5) | 16 (76.2) | 18 (85.7) | | |
| Support groups for family | 12 (57.1) | 9 (42.9) | 15 (71.4) | | |
| Support groups for child | 1 (4.8) | 3 (14.3) | 2 (9.5) | | |
| Parent skill building | 20 (95.2) | 19 (90.5) | 19 (90.5) | | |
| Instrumental support | | | | 21 (100) | 0–3.9 ^a |
| Instrumental/concrete services* | 19 (90.5) | 13 (61.9) | 15 (71.4) | | |
| Recreation* | 14 (66.7) | 7 (33.3) | 12 (57.1) | | |
| Crisis management | 5 (23.8) | 6 (28.6) | 8 (38.1) | | |
| Respite | 5 (23.8) | 3 (14.3) | 3 (14.3) | | |
| Advocacy support | | | | 7 (33) | 0.0–3.2 |
| Advocacy | 21 (100) | 20 (95.2) | 20 (95.2) | | |
| Other | | | | | |
| Gathers information | | | | 21 (100) | 9.3–37.9 |

* Trending toward statistical significance, $p < 0.10$

^a Note all FSS provided this service at least once; one FSS provided this service as 0 % of services due to rounding

willing to offer whatever the parent needs. For example, one FSS described her services to a standardized parent in the walkthrough as:

My primary role is to be here and assist you in whatever needs you see that your family has that fall within our program. I don't have trips to Disney World in my pocket, but I'm here for you. Sometimes just for an ear, sometimes a sounding board, sometimes I have worked with parents that might need some help with putting a budget together that works, or better nutritious meals.

What FSS self-report and as well as what other staff members think FSS provide for families is somewhat consistent. Program Directors and Individualized Care Coordinators think that FSS provide (a) emotional support, (b) advocacy, (c) active referral and (d) parent skill building. The walkthrough coding of the initial and follow up visit with our standardized parent yielded these observations of what FSS actually did in these two sessions. We observed FSS doing the following; asking questions, planning and strategizing, contextualizing services and

giving opinions. For example, this FSS outlined during the interview how the HCBS team, including the FSS and respite worker) decides on recreational activities:

Yeah, the team kind of develops [community based services depending on the child's] interest. Knowing that he liked video games and he likes basketball, that respite worker can maybe lead him to more community outings so that he can develop friendships, whatever might be available to him, whether it's structured basketball game or a playground situation. They could also go to movies, or mini golf, or whatever is available, if he's happy doing it. I'm encouraging you to take that time if you possibly can for yourself, or even for your girls, you and your girls reconnect. It's a much needed break.

Other FSS worked with parents to develop specific skills. One of the unique ways in which FSS achieved this was through role play. In the exemplar below from a walkthrough, the FSS role-plays with the parent to prepare her to answer questions she may be asked by her lawyer about her son's legal issue:

Table 4 Frequencies of content from $N = 21$ walkthroughs with FSS

| Content | Frequency | % |
|--|-----------|------|
| Informational/educational support | 2,298 | 45.6 |
| Gathers information/history | 1,161 | 23.0 |
| Emotional/affirmational support | 1,160 | 23.0 |
| Instructional skills development support | 335 | 6.6 |
| Instrumental support | 59 | 1.2 |
| Advocacy support | 21 | 0.4 |
| Total | 5,034 | |

FSS: If the attorney were to say something like, “What is your son doing? What do you think he’s being charged with? Do you understand what he’s being charged with?” how might you answer [those questions]? Do you understand what he’s being charged with, why we’re in court?”

Standardized Parent: For shoplifting, I understand he’s being charged for shoplifting.

FSS: Okay, and [the attorney might ask you], “What does that look like? Where was he? What did he take?”

Standardized Parent: He supposedly took a cap.

This example shows how FSS can work with parents to provide a peer’s perspective of “someone who’s been there” and can facilitate engagement with clinicians or, in this case, with an attorney about her child’s situation.

Question 3: What Does the Walkthrough Indicate FSS Do in Standardized Family Scenarios in HCBS Waiver Programs?

In the content analysis of 21 walkthroughs, we identified 5,034 unique “units” of FSS activities (See Table 4). The most frequent FSS activity was “*informational and educational support*”, which represented almost half of all activities (45.6 %). “*Gathering information and history*” and “*emotional and affirmational support*” each were 23.0 % of all activities. All other activities, including “*instructional/skills development support*” (6.6 %), “*instrumental support*” and “*advocacy support*,” account for a negligible amount of FSS responses.

Research Question 4: How do Program Director, Individualized Care Coordinator, and FSS Perceptions of what FSS do in HCBS Waiver Programs Compare to what FSS do in Standardized Family Scenarios?

The right two columns of Table 3 indicate a summary of FSS activities as actually conducted in the walkthrough. The FSS

column indicates the proportion of FSS who provided that service during the walkthrough scenario; data indicate all FSS provided each service at least once during the walkthrough except for advocacy services. The right column indicates the within-FSS calculation of how much each FSS provided each services. For example, FSS, Program Directors and Individualized Care Coordinators agreed that FSS provide *informational and educational support* (more than 85 % in all categories). In the walkthrough scenarios, although all FSS provided informational and educational support at least once, FSS ranged from a low of providing informational and educational support in 21.0 % of the sessions to a high of providing it in 67.8 % of their total services.

All three staff groups were unanimous that FSS provide *emotional and affirmational support*; in the walkthrough scenarios, FSS provided this support as 7.8–38.4 % of the services.

For *instructional skills development*, all staff groups generally agreed that FSS provide parent skill building and were more variable on whether the FSS provided support groups for parents, children, and families. In the walkthroughs, all FSS provided instructional/skills development at least once, but overall, it constituted a small portion of their services provided (1.5–17.8 %).

Gathering information, a category not included in Hoagwood et al.’s (2010) review, constituted a substantial portion of FSS services during the walkthroughs (9.3–37.9 %) and was the next most frequently used category of services. This is likely due to the fact that the walkthrough scenario focused on initial intake and follow-up, where information gathering is usually the salient service.

In the *instrumental support* category, FSS reported in interviews that they provided instrumental services and recreation services more frequently than the program directors and individualized care coordinators did, and there were generally low frequencies of endorsement of crisis management and respite services by all staff groups in interviews. In the walkthroughs, although all FSS provided instrumental support at least once, it was a very low frequency service provided (0–3.9 %).

Advocacy support, despite its identification as an important activity by FSS in the interviews, was used rarely in the walkthroughs; only a third of FSS demonstrating advocacy in the walkthrough, and those FSS who did provide advocacy services, it was only 0.0–3.2 % of all services delivered, potentially more likely to occur in later follow-up sessions when the needs of the parent and child would be more clearly understood.

Discussion

This study provides critical information about FSS activities, including a unique comparison of what staff and FSS

report what FSS do with families in contrast to what FSS actually do in realistic, standardized scenarios with families. This information is an important step toward understanding both how teams that provide services to children conceptualize FSS' roles and going beyond current literature to describe what FSS actually do in a walkthrough exercise with families.

HCBS Waiver program staff appear generally to be in agreement about what activities the embedded FSS provide. Almost all staff agree that FSS provide emotional support and advocacy, and there are few differences between what FSS report they provide and how their colleagues see their contributions, with differences between only two categories of services (instrumental/concrete services and recreational activities) approaching statistical significance. The current literature indicates a range of what advocates may do (e.g., Hoagwood et al. 2010), and on an operational level, within HCBS Waiver programs and likely within teams, these activities are in general consistently described by staff. Hoagwood et al. (2010) identified role clarity and uneven expectations and responsibilities across program settings as a challenging issue for FSS and a barrier to effective integration of FSS into mental health teams for children. To address this challenge, it would be useful to intervene on both policy and practice levels. Policies should identify specific roles and responsibilities for FSS to move away from the “whatever a parent needs,” to clearly delineating parameters of responsibilities, the unique functions to be provided by FSS, and clarifying FSS role on teams. In practice, agencies that employ FSS should provide education and training to all staff who come into contact with FSS so that the entire organization is aligned with their perception of FSS and their understanding of what services are offered. There is a clear need to establish clear practice parameters at the program and individual FSS provider level on standards of care (See Olin et al. 2013 this issue).

Given that the standardized parent walkthrough simulated only the first two sessions with parents, it is likely these data underestimate the instrumental support that FSS provide to parents, as the first sessions are typically focused on understanding the family's situation and building rapport. Should initial sessions be organized differently? Depending on what information is received about the parent in advance, it may be useful for FSS to follow practice from other helping professions (e.g., psychologists, social workers) that delineate a shorter amount of time for an initial assessment (limited to one session) to gather information and identify goals and interventions for future sessions.

The walkthrough also demonstrated acceptability among FSS as a realistic and feasible method to obtain a general understanding of FSS services. Although somewhat limited in its current form in that it only assesses the first two

sessions, it may be a useful tool for programs to assess how service delivery is provided by FSS and by other staff. It is an important alternative to the laborious observational methods often used to assess behavior—methods often unrealistic in real-world research—but it yields commensurate data. Walkthroughs have demonstrated utility in assessing service delivery patterns and gaps and improving problematic processes that impede service delivery (Ford et al. 2007; Fussell et al. 2008).

This study has several limitations. The walkthrough only addressed the first two sessions and provides a limited view of FSS activities. All study activities took place in a subset of HCBS Waiver programs in New York State and included only a subset of program staff, so these findings may not generalize to the remaining HCBS Waiver programs in New York State, to other programs with FSS (such as school-based programs), to standalone peer support programs, and states where FSS goals and activities might be different. Despite these limitations, this study demonstrates both novel methods for assessing, in an in vivo and standardized way, how FSS are working with families and adds to the growing literature on FSS activities to help improve quality. Walkthroughs can be used as training tools to ensure appropriate procedures are followed (Fussell et al. 2008), as a qualitative component to a randomized assignment study (e.g., Kutash et al. 2011), or as a supplement to supervision.

Ultimately, this study suggests many questions that future researchers should address: What are the most potent functions provided by FSS? How can quality of FSS services be enhanced? What are the best ways to ensure all staff have a shared understanding of FSS services? What are the best organizational strategies to integrate FSS into the service delivery context? What are the most effective models for training (and providing ongoing supervision to) FSS? What are cost-effective ways to evaluate service delivery of FSS both independently and as part of a team of care providers?

The Parent Empowerment Program training (Jensen and Hoagwood 2008) and the national credentialing process currently in operation (Purdy 2012) has developed specific competencies for FSS, including engagement and listening skills; knowledge of the mental health service system; and linkage to health and other services. These approaches bode well for promoting standards and ensuring excellence in service. In addition, quality indicators for service provision (see Olin et al. 2013 this issue) based on actual FSS services will be particularly useful in refining thinking about ways to improve the quality of peer-delivered services.

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