

Parent Engagement and Family Peer Support Services in Wraparound

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Introduction

- Family peer support (FPS) is provided by a family member with lived experience caring for a child with mental health needs who is trained and supervised to provide support to other families.¹
- FPS services are provided by a family peer support partner (FPSP) who²:
 - Provide emotional support
 - Identify people that a family wants on their Child and Family Team
 - Help families decide what they want and need
 - Support families in their efforts to get their needs met
 - Work with families to prepare for meetings
 - Attend meetings with families
 - Link families to support groups, educational programs, and other family activities.
- Family peer support is provided as part of intensive community based care management and treatment services for children with serious emotional and behavioral difficulties, called Wraparound.
- There is limited information regarding how caregivers are informed about FPS and their resulting expectations, reasons why caregivers might accept or refuse FPS services, specific FPS services received, as well as the perceived impact of FPS on the individual and family-level functioning.
- Such information will identify quality improvement needs within this service delivery model, as well as provide more generalizable knowledge regarding caregiver engagement in FPS services that could inform various program models serving families and children with serious emotional and behavioral difficulties.
- The current study explores caregiver perceptions of family peer support (FPS) offered as part of Wraparound services:
 - How caregivers were informed about FPS
 - Their expectations about FPS
 - Reasons for accepting or refusing FPS
 - FPS services received
 - Perceived impact of FPS on individual and family-level functioning.

Methodology

- From June 2014 through August 2014, participants from the Maryland Crisis and At Risk for Escalation diversion services for children (MD CARES) longitudinal study were recruited.
- Caregivers were eligible if they were 18 years or older, English speaking, and had signed consents to participate in the MD CARES longitudinal study from January 1st, 2012 through December 13th, 2013 (n=62).
- Potential participants were contacted by phone, and if unreachable, recruitment letters were sent. Of n=62 potential participants, 18 could not be reached by phone or mail, 8 refused, 5 were contacted but never scheduled, and 35 agreed to meet with research staff.
- Research staff scheduled private interviews with caregivers and obtained written consent; allowing research staff access to their data from the MD CARES longitudinal study. A total of 35 caregivers (56% of eligible caregivers) consented to participate in the study.
- Interviews consisted of (A) demographic questions; (B) open-ended, semi-structured questions; and (C) close-ended, structured questions. Sections were read aloud to participants, responses to sections A and C were documented in a computerized data collection form (Qualtrics). Section B's responses were audio-recorded to assist in data collection and analysis.
- Interviews lasted 30-60 minutes and participants received \$20 for their participation.
- Written transcripts of audio-recorded interviews were reviewed for accuracy. Quantitative data was analyzed via descriptive and bivariate statistical methods. Open-ended survey responses were analyzed by comparing and contrasting participants' responses in order to summarize emerging themes.

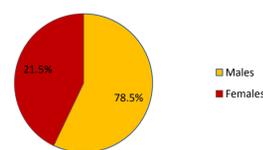
Demographics

Table 1 and Figure 1 present demographic information on study participants, as well as the youth enrolled in Wraparound.

Participant Gender	%	N
Male	11%	4
Female	89%	31
Participant Age		
Average Age of Participant	50 years	
Relationship Status		
Single	40%	14
Married	20%	7
Divorced	14.3%	5
Separated	11.4%	4
Widowed	8.6%	3
Refused	5.7%	2
Annual Household Income		
Less than \$5,000	17%	6
\$5,000-\$14,999	11%	4
\$15,000-\$24,999	23%	8
\$25,000-\$34,999	37%	13
\$35,000-\$99,999	6%	2
Refused/Don't Know	6%	2
Employment Status		
Full Time	28.6%	10
Part Time	17.1%	6
Retired	17.1%	6
Unemployed	17.1%	6
Disabled	11.5%	4
Other (self-employed/stay at home)	8.6%	3

Days Youth Lived in Participant Household in past 6 Months	%	N
180 Days	54%	19
Less than 180 Days	46%	16
Average Number of Days		117
Youth's Living Situation		
Living with Participant	60%	21
Not Living with Participant	40%	14

Figure 1: Youth Gender (n=35)



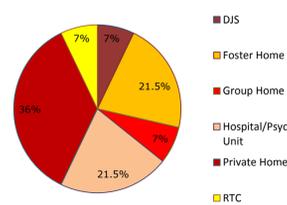
Findings

Demographics, continued.

Table 2 presents the number of children under the age of 18 and the number of adults living in the study participant's home. Figure 2 presents youth's living situation at the time of the interview when not living with the respondent.

Children	%	N	Adults (age 18+)	%	N
0	17%	6	1	34%	12
1	29%	10	2	43%	15
2	31%	11	3	14%	5
3	20%	7	4	9%	3
4	3%	1			

Figure 2: Youth's Living Situation (n=14)



Wraparound Services

At the time of the interview, the majority of participants (80%; 28) no longer received Wraparound services, 9% (3) were still enrolled in Wraparound and 11% (4) were unaware if their youth was receiving or not receiving services.

Informed

Table 3 illustrates who introduced study participants to FPS services.

	%	N
Care coordinator	60%	21
DSS worker	14%	5
Youth's therapist	3%	1
FPSP services followed youth	3%	1
Do not remember hearing about FPSP/Did not hear about FPSP	20%	7

Expectations

Caregivers based their expectations of family peer support services on their family needs and what they were explained regarding the role of the FPSPs. Table 4 shows the expectations of the caregivers interviewed.

Category	Count	Category	Count
Resources (basic needs, finance, housing, transportation, employment, bills, education on mental health)	17	Resources (socialization)	11
Support (someone to talk to during crisis)	15	Mentorship	7
Mentorship	7	Activities (camp, recreation center, out of the home activities)	6
Respite	5	Motivation/Coaching	5
Referrals (services in the community)	5	Counseling	4
Improved Parenting Skills	5	School Work/Tutor	2
In-Home Services	2		
Support Groups (parent groups)	2		
Crisis Intervention (PRN, medication administration)	1		
Meeting Attendance (court, school, Wraparound)	1		
Extreme Change	1		

Accepted/Refused Services

- The majority of participants (96%; 27) chose to work with a FPSP when offered; one caregiver refused services; 17% (7) were never informed or offered family peer support.
- From the 27 that chose to work with a FPSP, over half (59%; 16) chose to receive services at the initial offering of FPSP services. Of those who chose not to accept FPSP services in the beginning (11), 64% (7) did receive services at a later point in the Wraparound process.
- A few families (4) never received services. Reasons expressed:
 - Scheduling issues (n=1)
 - Never mentioned again, youth involved in activities (n=1)
 - Youth was admitted to inpatient services (n=1)
 - Caregiver informed about FPS months after being enrolled in Wraparound (n=1)

Termination of Services

- Many families (78%; 18) never decided to terminate services, although FPSP services terminated nevertheless. Some reasons identified:
 - The FPSP stopped contact with family after 4 months ("maybe FPSP left the organization").
 - FPSP services started 2 months before the youth was discharged from Wraparound services.
 - Youth was admitted to a Residential Treatment Center (RTC).
 - FPSP services just seemed to phase out.
- Of families that decided to stop services (22%; 5), reasons given by caregivers were:
 - Youth was improving so services were no longer needed (n=2)
 - FPSP was not helping the family (n=1)
 - Inconsistency and scheduling issues (n=1)
 - Perception of FPS as a temporary service (n=1)

Findings

Needs Met

Most families (70%; 16) reported FPSPs meeting the needs of their families; the rest expressed an unsatisfactory performance of FPSP workers. Some reasons given:

- FPSP was unresponsive and did not return phone calls (n=1)
- Family needed more help than FPSP could provide (n=1)
- FPSP only met with family once (n=2)
- Didn't have time and youth not interested (n=1)
- Didn't help with housing/resources (n=2)

Impact

The impact of working with FPSPs varied by families but was overall positive. FPSPs helped not just caregivers, but the youth and the entire family. Table 5 displays the different ways FPSPs had an impact on the caregiver, youth and family.

Category	Count	Category	Count
Support System	8	Support System	10
Friendship	8	Mentor	6
Comforted	8	Behavior/Attitude Improvement	6
Greater Knowledge about Resources	8	Improved Coping Skills	5
Advice (confidence/motivation)	8	Increased Confidence	5
Stress Relief	5	Social Involvement	3
Respite	4	Improved Social Network	3
Relate/Understand Youth Better	4	Encouragement	3
Dealing with Youth	3	Improved Academics	3
Job	3	Positive Male Role Model	2
Coping Skills	2	Positive FPSP/Youth Relationship	1
Improved Perspective	2	Access to Basic Needs (community resources)	1
Found Therapist	1	Improved Finances	1

Most Helpful

Participants described many positive aspects of receiving family peer support services. The most helpful aspects of FPS identified for the caregiver, youth, and family are shown in table 6.

Category	Count	Category	Count
Someone to Talk to	16	Support	7
Knowledge to Help Youth	5	Mentor	6
Respite	2	Out of Home Activities	4
		Becoming Closer with Family	3
		Resources	5

Services

Caregivers were asked to identify the services they needed, to rate the priority of each service as high priority (1), medium priority (2), or low priority (3), and to indicate whether these were provided by their FPSP. This information is presented in tables 7 and 8.

Services Needed	Mean Score	Priority Level	Rank	Frequency	Percent
Making specific, clear, realistic recommendations	1.10	1	21	60%	
Provide information about resources and services	1.11	2	19	54%	
FPSP using experiences for caregivers to feel hopeful	1.13	3	16	46%	
Provide information about Wraparound process	1.13	4	15	43%	
Listening to concerns	1.15	5	20	57%	
Help making decisions about child	1.15	6	13	37%	
Provide information about child's diagnosis	1.17	7	12	34%	
Provide concrete services (i.e. transportation, help obtaining community resources)	1.17	8	12	34%	
Assistance with navigating court or legal processes	1.17	9	6	17%	
Provide information on how to access mental health services	1.18	10	17	49%	
Provide information about child's development	1.21	11	14	40%	
Help developing & practicing an appropriate crisis plan	1.21	12	14	40%	
Assistance with navigating mental health service system	1.25	13	12	34%	
Making list of concerns for CFT team members & meetings	1.26	14	19	54%	
Following up on progress toward family vision, goals and needs	1.27	15	16	46%	
Building a partnership	1.28	16	18	51%	
Stating the purpose of meetings	1.28	17	18	51%	
FPSP using experiences for caregivers to feel there are others with same challenges	1.29	18	14	40%	
Providing information about rights in multiple service systems	1.31	19	16	46%	
Assistance with navigating school system	1.40	20	10	29%	
Assistance with navigating medical health system	1.43	21	7	20%	
Helping to identify ways to take care of self	1.55	22	11	31%	
Helping organize documents to advocate for youth	1.63	23	8	23%	

Findings

Services, continued.

Table 8 depicts information on services provided by FPSPs to families.

Services Provided	Frequency	Percent
Listening to concerns	18	51%
Provide information about resources and services	17	49%
Provide information on how to access mental health services	15	43%
Making specific, clear, realistic recommendations	14	40%
Making list of concerns for CFT team members & meetings	14	40%
Stating the purpose of meetings	14	40%
Provide information about Wraparound process	13	37%
FPSP using experiences for caregivers to feel hopeful	12	34%
Help developing & practicing an appropriate crisis plan	12	34%
Building a partnership	12	34%
Following up on progress toward family vision, goals and needs	11	31%
FPSP using experiences for caregivers to feel there are others with same challenges	11	31%
Providing information about rights in multiple service systems	11	31%
Help making decisions about child	10	29%
Provide information about child's diagnosis	10	29%
Provide information about child's development	10	29%
Assistance with navigating mental health service system	9	26%
Assistance with navigating school system	8	23%
Helping to identify ways to take care of self	8	23%
Provide concrete services (i.e. transportation, help obtaining community resources)	7	20%
Assistance with navigating medical health system	6	17%
Helping organize documents to advocate for youth	5	14%
Assistance with navigating court or legal processes	4	11%

Discussion

Most participants who were offered FPS by their care coordinator accepted FPS services. Of those who received services, many highlighted a number of ways such services positively impacted themselves, their children, and their families. Among the most helpful aspects of working with a FPSP include having someone to talk to, support for youth, and being overall helpful. Emotional support and having someone to talk to were among the most commonly received FPSP services. These services aligned with what participants identified as some of the most common needs.

Reasons for refusing FPSP services included the perception of too many workers coming into the home, youth was in current crisis, or that FPSP services were not offered by the Wraparound care coordinator. Although 54% of participants heard about FPSP services through their Wraparound care coordinator (as was expected), over 1/3rd were not informed by the care coordinator, and 20% were never informed at all. Need to train Wraparound care coordinators and other brokers/gatekeepers to FPSP services around exactly what FPSPs do and why they should be offered to parents. It is also important to inquire as to how these brokers/gatekeepers perceive FPSP services, as any negative perception or lack of knowledge has implications for how FPSP services are presented to caregivers.

Many participants had expectations that FPSP would work directly with youth and indicated that FPSP had a direct impact on youth functioning as well. Given that FPSP services are typically billed as services to parents (and in fact many FPSPs shy away from efforts to link their activities directly to youth outcomes), one has to question if the "billing" is correct? Are FPSPs who work directly with youth working outside their scope of practice? The information gathered by this study suggests that FPSP do have a direct impact on youth outcomes as they appear to directly work with youth in some families.

Thirty percent of caregivers indicated that FPSPs were not able to meet their needs. The most concerning of reasons is that FPSPs were not responsive or only met with family once. For all activities "needed" by caregivers, there were invariably a few participants who never received the activity by the FPSP. The biggest discrepancy between need and service provision involved the activity of "Making specific, clear, realistic recommendations", which was also rated as being the highest priority among caregivers. This discrepancy requires further exploration: what type of recommendations were needed by caregivers? How was this need not met? What would these recommendations look like? Or do caregiver expectations need to be adjusted?

Although there are a number of areas worthy of increased quality control and further questions remaining, data suggest that FPSP services are generally positively regarded by caregivers receiving Wraparound services in Maryland.

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