

ISSUE BRIEF FAMILY-TO-FAMILY PEER SUPPORT: MODELS AND EVALUATION



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Families, Policymakers, and Service Providers

who care for children and youth with mental health challenges are seeking strategies for successful outcomes. Finding the unique combination of treatment, services, and supports can be a struggle. One strategy is to provide family-to-family peer support, where families receive education, information, and the support of others who have similar experiences.

This issue brief describes the goals of family-to-family peer support and specifically addresses three areas:

- Organizational models for the provision of family-to-family peer support
- Provision of family-to-family support services, including training and certification of peer support providers
- Measurement of outcomes

INTRODUCTION

When a child needs mental health services, there can be many approaches to treatment, including counseling, special education, therapeutic day treatment, respite care, play therapy, intensive in-home counseling, and other types of services and supports. These types of services and supports are needed in order to keep children and youth with mental health challenges at home, in school, and in their community. Family-to-family¹ (F2F) peer-delivered support for families of children and youth with mental health challenges is a rapidly growing component of the service array (Hoagwood et al., 2010). The growing awareness of the benefits of F2F peer-delivered support has evolved from a confluence of several factors: advocacy by families drawing on their own experience in accessing and managing the care of their children; studies documenting high levels of burden and strain in families and the key role of this strain in driving service use (Angold et al., 1998; Farmer, Burns, Angold, & Costello, 1997); the increasing commitment

to the family-driven care movement in which families take on a primary decision-making role in the care of their child (e.g., goal setting, service design, outcome monitoring); and evidence indicating the importance of family involvement in treatment outcomes.

F2F support has existed as a resource for families for more than 25 years, but has evolved rapidly in recent years. Changes include greater specification of program models (including staff qualification requirements for providers and intervention strategies), development of training resources (including core competencies and certification guidelines), and efforts toward establishing F2F support as a billable service.

This issue brief describes the goals of F2F services, provides examples of three organizational structures for delivering F2F services, outlines some key components of successful F2F service programs, and describes some studies and promising measurement tools that describe and track the impact of F2F services. We hope this issue brief will generate ideas for community leaders and others who are working to develop or enhance family-to-family peer support services and for evaluators who are working to demonstrate their impact.

GOALS OF F2F SUPPORT

The core goals of F2F support, as derived from a variety of sources (Gyamfi et al., 2010; Hoagwood, 2005; Hoagwood et al., 2008; Koroloff, Elliott, Koren, & Friesen, 1994, 1996; Osher, Penn, & Spencer, 2008; Robbins et al., 2008), have been categorized as follows:

- **Decrease isolation.** Parent support providers (PSPs) help family members identify and access their own formal and informal support network and community resources (i.e., churches, provider organizations, and support networks, including those available online).



- **Decrease internalized blame.** PSPs can assist in decreasing the feelings of stigma and blame that families may experience regarding the mental health problems of their children.
- **Increase realization of importance of self-care for parents.** PSPs can help families increase their awareness of the need for self care.
- **Take action.** PSPs can help increase a family's ability to learn how to take action through gaining knowledge and actively engaging in their child's services.
- **Increase feelings of self-efficacy.** PSPs can help caregivers and other family members feel stronger and more positive about their skills and abilities in caring for their children.
- **Increase acceptance and appreciation of child's challenges and increase ability to work with both formal and informal supports.** PSPs can help families understand and care for their children and increase their ability to work in partnership with treatment providers.

ORGANIZATIONAL MODELS OF F2F PEER SUPPORT

The growth in F2F peer support has included the development of diverse organizational models. These models vary in the scope of services offered, PSP training and other workforce issues, and reimbursement mechanisms. The heterogeneity of models makes the development and implementation of outcome measures challenging. Three successful F2F programs that illustrate a range of organizational and structural models are described below.

External Model. In an external model, F2F services are provided via an independent, family-run, nonprofit organization. The Families' Child Advocacy Network (FCAN) provides F2F support services through PSP staff as a paid contractor for Erie County, New York. All PSPs are trained in the Parent Empowerment Program (PEP), a statewide training and consultation program developed with family advocates and parent advisors for parents of children and youth

with mental health challenges to provide peer support. FCAN is reimbursed on a fee-for-service basis. As a paid contractor for the county, FCAN uses billable codes for family support, group recreation, skill building, mentoring, and language interpretation services.

Internal Model. In an internal model, PSPs are employed by a children's mental health provider agency. Hathaway-Sycamores Child and Family Services is one of the largest nonprofit children's mental health providers in Los Angeles County, California. Initially, PSPs were hired as part of the agency's wraparound program, which featured child and family teams comprising a facilitator (case manager), a child and family specialist (direct behavioral support), a clinician, and a parent support provider. There was a deliberate commitment to redirect funds from savings and risk pools to increase the role of the PSP within the agency. This resulted in the development of the agency's F2F program and the ability for parents to work in all agency programs as PSPs. The PSPs are able to bill Medicaid for 15–20% of the services they provide. In addition to providing direct services, this organization's management structure offers PSPs the opportunity to participate in its operations and management by interviewing potential staff members, serving on agency workgroups, and co-training in all curricula offered by the agency. The agency's personnel structure allows access to a defined career ladder for PSPs from management to the executive level.

Blended Model. In a blended model, F2F support occurs both within an established mental health treatment provider setting and through an independent family-driven organization. One example of this model is the Family Involvement Center (FIC) in Maricopa County, Arizona. FIC screens, trains, and supports PSPs who are employed by non-family-run children's behavioral health providers, and also employs PSPs to provide F2F services directly. FIC operates as a fully licensed Medicaid provider organization specializing in parent and youth support services, and also functions as a community resource center for informal family support.



KEY ELEMENTS TO SUCCESS OF PSPS PROVIDING F2F SERVICES

Whether an internal, external, or blended model is used for PSPs to provide F2F services, certain elements are required for a successful program. Some of those elements and lessons learned from the three organizations highlighted earlier are described below.

Financing F2F Peer Support Services. Family organizations, states, and counties use a variety of strategies to finance F2F peer support activities. Family organizations are funded with combinations of state general revenue funds, Medicaid service delivery and administrative case management dollars, and Federal discretionary grants. F2F peer support activities often can be funded through Medicaid if they are medically necessary, are consistent with the child and family plan, and are provided by a PSP who is approved by the state Medicaid authority or supervised by a licensed or certified individual. Another funding source is fee-for-service activities that are reimbursed by various entities, including child welfare, education, and juvenile justice funding sources. Organizations that routinely monitor fiscal realities and advocate for themselves are more likely to be successful and sustainable over time. Fiscal accountability is a driving force behind the decisions of funding sources. Reimbursement for services is more likely to be available to those organizations that can demonstrate that their services or programs benefit families.

The basic premise of being supported by someone who has lived through a similar experience (and survived) is at the heart of this movement. Parents report over and over again, “I thought I was the only one going through this” and “I could not have done this without the support of my parent partner.”

Required Staff Qualifications. A major qualification for a PSP to provide F2F services is knowledge and experience gained by raising a child with mental health challenges and successfully navigating child-serving systems. This experience and knowledge is considered crucial to being able to successfully develop productive relationships with

families receiving services. When families are able to talk with others who have had similar experiences, feelings of isolation and stigma can be reduced and positive coping strategies can be increased. Increased positive coping methods can reduce stress, help build capacity to feel more in control, and assist in identifying and implementing strategies to reduce barriers and encourage appropriate action. Other required staff qualifications include strong time management skills, cultural and linguistic competence, organizational and documentation skills, basic computer literacy, the ability to document program outcomes in writing, and the ability to communicate effectively with families.

Recruitment and Retention. Recruitment efforts for PSPs should focus on parents whose children have mental health challenges and who have developed strong advocacy skills and the capacity to navigate the child-serving system. To retain highly qualified PSPs, organizations should offer and support career paths for PSPs within the organization. PSPs may be in a second career or may have filled a variety of other roles before entering this profession. If not provided a clear career path or opportunities for advancement, PSPs may leave the position or drift to a role within the agency that does not use or value their experience. Supervision and support of PSPs is critical for job satisfaction and retention. Such support can be provided through weekly meetings with an experienced PSP, clinical supervision as needed, and coaching.

When F2F peer support is provided within a non-family-run service agency, there may be a need to increase attention to the organizational culture to create a family-friendly work environment. For example, it is important for organizational leadership to be committed to the value of strong family partnerships and to create strategic alliances within family/professional teams at all administrative levels (e.g., pairing clinical residential director and PSP supervisor).

Staff Training and Support for Skill Development in Core Competencies. Although experience in parenting a child with mental health challenges is a fundamental requirement for a PSP who provides F2F services, success in the role depends on a

number of key skills or competencies. For example, there are identified skills and competencies that are especially effective in providing family support services in a wraparound approach (Miles, 2008; Osher et al., 2008; Penn & Osher, 2008) and for parent advocates who work in PEP programs (Jensen & Hoagwood, 2008).

An initiative sponsored by the National Federation of Families for Children’s Mental Health (FFCMH) will provide an avenue for national certification of PSPs to ensure that those in the field meet consistent and high standards of performance (Purdy, 2010). A national certification process will insure that uniform national standards will be met through training and testing on a set of core competencies and knowledge for PSPs who provide F2F services. The identified core competencies and knowledge base focus on ethics, confidentiality, effecting change, behavioral health treatment and prevention, educational systems and processes, local resources, communication, parenting for resiliency, advocacy across systems, empowerment, wellness, and natural supports (National Federation of Families for Children’s Mental Health, <http://ffcmh.org>).

Lessons Learned

- Agencies and organizations need to be flexible in their financing methods. The use of diverse funding streams broadens the possibilities for creating and sustaining F2F programs.
- Clearly specified staff qualifications and job requirements, staff training, support, and supervision are needed.
- The role of PSPs needs to be clearly communicated with other service providers and agency staff to avoid misunderstandings or unrealistic expectations.
- Blending personal experience with a professional role requires unique and dedicated organizational supports and training on maintaining professional boundaries.
- Organizations should develop focused recruitment and retention strategies to identify and support qualified staff, including addressing organizational culture and developing career paths.

EVALUATION OF FAMILY-TO-FAMILY SUPPORT

The growth of F2F support services provided by PSPs has not been consistently accompanied by efforts to develop rigorous and comprehensive evaluation strategies (Hoagwood et. al., 2009; Robbins et al., 2008). Collecting and reporting outcome data for new and innovative services such as F2F are critical for several reasons. The first is accountability. It is important to provide government, private funders (corporate and individual), and other supporters with evidence that the resources they expend produce positive benefits. Such evidence will gain favorable recognition for F2F by funders and decision makers, which will lead to stability in financial support. Second, outcome measurement will provide a feedback loop for quality improvement to determine effective practices, recruit and retain qualified staff, motivate volunteers, and encourage families to participate in family-to-family efforts. Finally, outcome measurement will facilitate the development of formal research efforts of F2F and its integration with other types of services.

A description of some of the measurement approaches being used currently is given below.

Measuring Service Use. A first step in evaluating F2F services has been to document the types, number, and intensity of services performed by PSPs. Many programs have developed uniform reporting forms to tally the number of families served and the type, frequency, and duration of contacts, including telephone contacts. As F2F support programs have grown, assessment of the types and quality of services has become more common. For example, the FIC contracts with the Arizona State Department of Behavioral Health to provide System of Care Practice Reviews (Hernandez, Worthington, & Davis, 2005) that evaluate child and family team quality and practices according to system of care principles. FCAN uses

“We knew Parent Advocates were doing good things but nobody really knew except for the families.”



Journey Mapping (Kibel, 1999) to record qualitative data that describe F2F support services provided at each encounter with the family. The PEP training model uses a 27-item checklist that tracks F2F support services that focus on the provision of emotional support, action planning, information, advocacy, and skill development (Hoagwood et al., 2009; Olin et al., 2010a, 2010b; Rodriguez et al., 2010). Kansas Keys for Networking uses a Targeted Parent Assistance Database to track the number of families served per hour, per day, and per month; the nature of the service (e.g., support, training, education); and the clinical or functional progress made by each family (Adams Westmoreland, Edwards, & Adams, 2006).

Measuring Satisfaction With Services. Formal studies that measured satisfaction with F2F services provided by PSPs found that parent caregivers consider F2F programs as helpful and valuable (Davidson & Fristad, 2004; Hoagwood et al., 2010; Kutash, Duchnowski, Green, & Ferron, 2010). For example Kutash et al. (2010) found that 98% of parents provided the highest rating for PSPs in the Parent Connections program, a 15-month family support and education program of workshops co-led by a PSP and a clinician, and weekly telephone follow-up by the PSP that focused on increasing parent engagement in the education and treatment of their child (Ireys, Chernoff, Stein, DeVet, & Silver, 2001; Ireys & Sakwa, 2006).

Measuring Outcomes for Families. A small number of studies have measured caregiver outcomes to determine effectiveness of individual F2F programs; only three included a control group in the design (Ireys et al., 2001; Kutash et al., 2010; Rodriguez et al., 2010). Examples of caregiver outcome constructs and related measures used in F2F evaluation are listed below.

Access and Participation in Services

- Contact with Mental Health Service Professionals Index (Bickman, Heflinger, Northrup, Sonnichsen, & Schilling, 1998)
- Services Assessment for Children and Adolescents (Horowitz et al., 2001)

Caregiver Empowerment

- Family Assessment of Needs and Strengths (Craig, 2010)
- Family Empowerment Scale (Koren, DeChillo, & Friesen, 1992)
- Family Participation Measure (Friesen, 2001)
- Vanderbilt Mental Health Self Efficacy Questionnaire (Bickman, Earls, & Klindworth, 1991)
- Working Alliance Inventory (Horvath & Greenberg, 1989)

Caregiver Well-Being

- Caregiver Strain Questionnaire (Brannan, Heflinger & Bickman, 1997)
- Center for Epidemiological Studies Depression Scale (Radloff, 1977)
- Child & Adolescent Needs and Strengths (Lyons, 1999)
- Multidimensional Social Support Inventory: Revised (Bauman & Weiss, 1995)
- Ohio Scales: Hopefulness Subscale (Ogles, Melendez, Davis, & Lunnen, 2001)

Measuring Access to and Participation in Services.

Studies show inconsistent results in the effect F2F support services have in increasing family access to and participation in services. In a quasi-experimental study Koroloff et al. (1996) reported positive effects of F2F outreach to low-income families of 4- to 18-year-olds identified as needing mental health services. Kutash and Duchnowski (2009) found that children of families participating in the Parent Connections program used more school-based mental health services than those whose families did not receive this F2F service. Hoagwood and colleagues (2009) and Rodriguez and colleagues (2010), however, did not find an impact on caregiver access to or participation in services in an experimental pilot study that tested the effectiveness of F2F support services using the PEP training model. Also, a study of a workshop program that addressed caregiver empowerment did not demonstrate changes in service use, although it did show an increase in caregivers' sense of services efficacy and knowledge (Bickman et al., 1998).

Measuring Empowerment. Caregiver empowerment is an important goal of F2F and has been measured as a key outcome by several programs. Staff from family support organizations in western New York selected items from different versions of the Child & Adolescent Needs and Strengths (Lyons, 1999) that referenced the caregiver. Several of these related to empowerment: advocacy (knowledge of needs, rights, and services, and satisfaction with child's progress), education, and skill development (ability to listen, communicate, and organize). The resulting instrument is the Family Assessment of Needs and Strengths (FANS), a 15-question tool reflecting the caregiver's needs and strengths. An initial analysis of the FANS data at baseline and follow-up from 93 caregivers showed improvement in advocacy, education, and skills (Craig, 2010).

Using the Family Empowerment Scale, Koroloff et al. (1996) found that parents involved in F2F support services were more involved with other parents, community volunteer activities, and advocacy; modest but significant differences between the intervention and comparison groups in both family and service system empowerment were reported. Kutash et al. (2010) reported a greater increase in mental health services efficacy and empowerment from baseline to follow-up for parents in the Parent Connections program than for parents in the comparison group. In several studies that evaluated the impact of PEP training, PSPs were randomly assigned to the PEP training group or a comparison group. Families who received support from a PEP-trained PSP showed greater gains in feelings of self-efficacy than families in the comparison group (Rodriguez et al., 2010).

Measuring Caregiver Well-Being. Caregiver health and perceived support are key outcomes for some F2F programs. Again looking at the initial analysis of FANS data on parent support in western New York, items fell into two clusters relevant to this area: support groups and respite (caregiver's talents, hobbies, recreation, and social resources) and optimism and involvement in their child's care. A comparison of the difference between the baseline and follow-up scores was used to indicate whether a parent or caregiver was doing better, stayed the same, or got worse on each item. Of 193 caregivers

followed from baseline to follow-up, one fourth reported doing better on items related to support groups and respite, 20% reported doing better for caregiver optimism, and 12% reported doing better for caregiver involvement (Craig, 2010). Caregiver well-being was a focus of the Parent Connections program. Perceived social support as measured by items from the Multidimensional Social Support Inventory (Bauman & Weiss, 1994) showed significant increase over the course of the intervention, and a higher percentage of mothers in the experimental group reported decreased anxiety.

Measuring Child Outcomes. F2F programs are focused on support and empowerment of caregivers; therefore, child outcomes would be secondary to increased self-efficacy, empowerment, and caregiver wellbeing. Few studies have tracked child outcomes. There has been one report of positive effects on children and youth (Kutash et al., 2010). That study found that the Parent Connections program, which focused on improved parent involvement in school, resulted in higher rates of children and youth attendance and more positive change in reading scores over time compared to those in the control group. For those children and youth whose parents showed high levels of caregiver strain, the effects were more pronounced; the level of impairment, behavioral and emotional functioning, and reading scores improved.

LESSONS LEARNED

One of the barriers to determining the effectiveness of F2F has been the lack of consistency in the structure and goals of the programs. Until 2006, none of the published research studies used a standardized model or included fidelity or implementation measures. It is crucial to tie outcomes for families to the goals of F2F. As an example, the National Federation of Families chapter in Montgomery County, Maryland, in collaboration with the Georgetown University Center for Child and Human Development, recently developed a measure, the Family Journey Assessment (Serkin, Anthony, & Holland, 2010), which is designed to be completed by PSPs in collaboration with caregivers. The 36 items on the core scale were developed using the experience of PSPs and are based on their relevance to the important movement,



process, and experience of family journey. The items link closely to the goals of F2F as defined by the FFCMH initiative and reflect the goals of activation (pursuing options), effective collaboration/decision making, advocacy, self-efficacy, and reduced caregiver strain.

SUMMARY AND RECOMMENDATIONS

This issue brief presents a consensus statement about the goals of Family-to-Family peer support activities. The brief describes three organizational models for offering F2F supports and the common issues shared by these organizations as they recruit, hire, train, and supervise Parent Support Providers. Finally, the issue brief summarizes what we know about the evaluation of F2F peer support activities.

Organizations that offer F2F peer supports agree that there are a number of human resource issues related to the successful employment of PSPs. First, clear written job descriptions are needed that specify the educational and experiential prerequisites of the position as well as the roles, tasks, and responsibilities of PSPs. There seems to be fairly strong consensus that one job requirement is previous experience caring for a child or youth with mental health challenges. There is also agreement that recruitment activities should focus on identifying parents who have experience in navigating child-serving systems and who either have experience with, or demonstrate a readiness to move into support and advocacy roles.

Another area of agreement is that there is a set of core competencies and skills for PSPs and that training and supervision activities should address these core competency areas. These skill areas include oral and written communication, mentoring, advocacy, knowledge of the local children's system of care, team facilitation, confidentiality, and ethics. There is recognition that the role of PSPs is important in the manner in which it blends personal experience with professional responsibilities. This requires skillful supervision, coaching, and supports. Finally, there is recognition of the need for career paths for PSPs so that there are clear opportunities for advancement into managerial and leadership roles.

One of the opportunities on the horizon for F2F peer support is the FFCMH's new initiative to develop

national certification standards and competencies for PSPs. Certification requirements will increase the credibility and accountability of PSPs, and provide clarity and uniform expectations regarding role expectations.

This issue brief offers a summary of evaluation activities, measures, and results, highlighting the need for consistent goals for F2F programs, use of fidelity or implementation measures, and agreement among evaluators regarding standard outcome measures to assess key domains such as caregiver empowerment and well being, access to and use of services, and child outcomes.

FUTURE DIRECTIONS

F2F peer support is an emerging field that is increasingly invested in demonstrating improved outcomes for families of children and youth in need of mental health services. The increased focus on measuring outcomes is in line with the increased recognition of the importance of accountability and outcomes for all consumer peer support efforts.

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ENDNOTES

¹ The term family-to-family (F2F) is used to describe the type of support offered. The term parent support provider (PSP) is used to describe the person serving as a peer mentor. We use the National Federation of Families for Children’s Mental Health’s definition of PSP: “A person who has experience parenting a child with emotional, behavioral (including substance abuse) or mental health challenges and who has specialized training in helping other parents understand children’s mental health.” PSP is a broad term that can be used to include parents, grandparents, or other family members who serve in the role of parenting a child or youth who has received mental health services.

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