

BUILDING FAMILY-TO-FAMILY SUPPORT PROGRAMS: RATIONALE, GOALS, AND CHALLENGES



Many states and communities are working to strengthen their child mental health systems by supporting intensive home and community-based services for children with serious emotional or behavioral disabilities and their families. Family-to-family support programs, often operated by family-led organizations, are an essential component of these efforts. The President's New Freedom Commission on Mental Health supports this concept by recommending that child-serving systems increase the opportunities and capacities of consumers to share their inspiration, knowledge, and skills.

Family-to-family support has intuitive appeal. In theory, families who are facing similar challenges of raising children with serious emotional or behavioral disabilities can find common ground and prevent feelings of isolation or hopelessness

by sharing practical information, providing encouragement to each other, and swapping stories of survival. But the actual task of developing, implementing, and sustaining meaningful family-to-family support programs presents major conceptual, logistical, and financial challenges. Few scientific studies on effective family support practices are available and specific techniques for building family-to-family support programs remain ill-defined.

Parent Connections was a joint project of Families Involved Together (FIT), a parent-to-parent support organization, and faculty from the Johns Hopkins School of Public Health. This team of parents and researchers worked longer than five years developing, implementing, and evaluating the program. The development and evaluation of the project was supported in part by a major

grant from the National Institute of Mental Health.

This article is intended to highlight program theory and format, challenges encountered, and key scientific theories and findings. This material may provide insight and direction for family support organizations, mental health programs, and others wishing to craft a useful approach to providing peer support for families in their own communities.

Types of Support

We define support as "information leading people to believe they are esteemed and valued and that they belong to a network of mutual obligations" (Cobb, 1976). We view Parent Connections as a method for generating family-to-family support by offering intensive personal attention and information-sharing oppor-

tunities, thereby building a network of mutual obligations among participating parents. As a practical matter, this was achieved by linking “veteran” parents with parents of school-aged children with serious emotional or behavioral disabilities. Knowing that the veteran parents had “walked in their shoes” helped participating parents feel a sense of trust and safety, which in turn allowed them to expand their ability to learn, make changes, and manage the needs of their children more successfully.

The staff of Parent Connections dubbed the veteran parents Parent Support Partners (PSPs). Our PSPs had children over 18 years old who had been identified as having emotional or behavioral disabilities when still in school. The PSPs worked with seven or eight families and were paid for up to 10 hours of work per week. They made weekly telephone calls to each assigned mother, and worked to build a supportive relationship with each family. The intervention also included a series of 15 educational workshops facilitated collaboratively by parent advocates and mental health professionals. The workshops provided opportunities for PSPs and families to meet each other, strengthen support networks, and share expertise. The goal of these activities was to provide informational, affirmational, and emotional support to participating parents.

Informational Support is shared information about childhood behaviors, developmental transitions, parenting skills, coping techniques, and community resources. This type of support can be offered over the phone or by mail. However, a large part of this support occurred during our educational workshops. These sessions provided a safe environment for parents to admit what they didn't know, the first step toward building a stronger foundation of knowledge. In addition, the PSPs helped their assigned mothers identify difficulties, issues, or unmet needs, and then modeled various ways to find alternative strategies for resolving these issues or meeting these

needs. PSPs also encouraged mothers to discuss their children's care with mental health and education professionals and to increase their access to relevant and up-to-date information, knowledgeable advice-givers, and needed services.

Affirmational support is focused on enhancing a mother's confidence in her own parenting. PSPs sought to reassure mothers that their concerns were appropriate and shared by others in similar situations. To do this, PSPs continuously sought out opportunities to identify parenting competencies. This feedback encouraged mothers'

challenges of raising a child with a serious emotional or behavioral disorder. Basic information about where to get help, how to overcome administrative obstacles, and how to perform effectively in crisis situations was provided through PSP contacts and the educational workshops. Increasing a parent's knowledge level in this way can contribute to more effective parenting, thereby improving a child's functioning and preventing further deterioration of his or her mental health.

Support can help parents deal more effectively with their own wor-

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positive self-evaluations and elevated them to the roles of “expert” and potential “advisor.”

The PSPs provided emotional support by establishing a relationship of trust. They aimed to listen closely to a mother's concerns, demonstrate a continued interest in her viewpoints and experiences, and communicate an understanding of her feelings. PSPs also encouraged the growth of mothers' natural support networks by discussing means for finding and strengthening emotionally supportive relationships with relatives, friends, church members, and other key people.

Program Theory

Parent Connections is a family-to-family support program that encompasses five primary principles or assumptions that are drawn from specific theories of social support and related concepts. (For further details see Ireys, DeVet, & Sakwa, 2002.)

A strong support network linking relevant information and resources can improve parents' responses to the

ries and doubts. Virtually all parents of children with serious emotional or behavioral disabilities have serious doubts about whether they have the knowledge and emotional resources required to help their children grow into capable, independent adults. Encouragement by a trusted supporter can help parents overcome their fears and manage their potentially crippling anxiety.

Support can diminish feelings of stigma. Parents of children with serious emotional or behavioral disorders often cannot find naturally occurring sources of support in their communities because stigma prevents parents from freely discussing their child's emotional or behavioral disorders with relatives, neighbors, or church congregants. Without personal knowledge of the causes, signs, and treatment of children's emotional disorders, family members, neighbors, and others are not likely to understand the special challenges parents face. Too often, this lack of empathy leads to blaming and judgmental thinking. As a result, the parent and child become isolated from those who should serve as their

system of natural supports. The process of family-to-family support essentially “grafts” experienced parents into the social network of families struggling with their child’s behaviors and needs.

Family-to-family support may allow professional treatment to work more effectively. Parents who have sufficient support may be more likely to stay in treatment, develop collaborative relationships with the child’s therapist, make use of resources in the educational system, and implement effective behavior management techniques at home. Confident, knowledgeable parents are more capable of partnering with providers from various child-serving systems. Overall, family support and education programs can increase the value of mental health and educational services.

Building parents’ knowledge and skills can produce a heightened sense of efficacy, both at home and within the mental health and education systems. Parent Connections designed workshops to increase parents’ capacity to identify and advocate for more appropriate services to meet their child’s needs, use behavior modification techniques effectively with their child, and be aware of their own strengths and limitations. Better skills in these areas can lead directly to behavior changes at home and better access to appropriate treatments.

Implementation Challenges

In the process of developing, implementing, and evaluating Parent Connections, we encountered several obstacles. First, we had to find the right PSPs. Although many parents of children with serious emotional and behavioral disabilities want to “give back” and help other parents, an effective PSP requires additional attributes. These include being able to listen carefully, to distinguish between “help” and “support,” and to manage their own emotional reactions to the struggles of other families. Therefore, we required PSPs to be parents of young adults who had received mental health services as a child or adolescent. This allowed them to communi-

UNMASKING LENA

For so many years, I wore an invisible mask. Before I came to Families Involved Together, the acronym F.I.T. meant Faking It ‘Till (I make it). As a wounded child, one of my disguises was laughter. Unfortunately, I made poor choices in men that led me to becoming a single mother. Though I love my son very much, his special needs presented great challenges. The responsibility of motherhood brought on additional stress that caused me to indulge in unhealthy behavior. Years later, I finally sought help from



a wonderful community program and I began to put my life’s puzzle back together. While this process set my life on a better path, I had not totally let go of my mask.

One day, I ran into a friend who was working as a Parent Support Partner at Families Involved Together. She said FIT was looking for new support partners and that I should call for an interview. I was accepted and invited to participate in FIT’s Parent Connections project. I attended many hours of training that prepared me to offer constructive encouragement toward growth and insight by parents just like myself. The sessions were quite intense at times. We were learning information and skills that I wished I had known while raising my son. Despite that regret, I noticed that something new was happening to me.

Eventually, I was matched with several parents who were going through what I had struggled with years before. Many began the Parent Connections workshops looking very down-

trodden. They felt as if they had come to the end of the line. They expressed great fear for their children’s future—and their own.

My assigned parents and I spoke by phone during the week and met in-person at the scheduled workshops.

These educational sessions presented ideas and skill-building that these parents had never experienced. In time, the parents seemed to develop a sense of trust and affection when we spoke or met. When they graduated,

the mothers were no longer sad and apprehensive. They were bright and hopeful. They shared with me how much the program—and I—had meant to them. I listened to them tell me how much I had done for them and the changes they were able to make because of my friendship and support.

I was, of course, very proud and happy for their success knowing I had contributed to it. But more than that, I also began to realize that, somehow, my own life had also totally changed—a metamorphosis of sorts. I had dropped my wooly outer layer, which was my defense mechanism. I had emerged as something quite beautiful. Now clothed with knowledge and truth, I was able to fly above past circumstances and soar into my own fantasy. I had arrived! I finally had discovered my true “FIT” and become the person I was meant to be—one without a mask, one without pretense.

Lena Gladden

cate their personal experiences while maintaining some emotional distance from the day-to-day issues of raising a young child. We also established a three-stage process for recruiting PSPs. In the first stage, we developed an interview that assessed a mother's ability to maintain boundaries and objectivity, avoid being judgmental, and encourage trust and self-confidence in others. In the second stage, all parents who were accepted on the basis of the interview participated in a short-term, skill-building training. This served as a way for us to get to know them and for them to get to know the program. In most cases, those who were not suited for the position dropped out. Those who stuck with the program participated in the third stage of the training: an intensive program designed to further strengthen their listening and communication skills.

Second, we had to find a way to invite families to participate in Parent Connections. We pursued several routes, including a general invitation to families associated with Families Involved Together. In addition, we worked with all of the major child mental health clinics and schools in the area to help identify parents who might be interested in participating.

Third, we needed to provide continuing support to PSPs during the months in which they were working with families. To accomplish this, PSPs met weekly with the program directors to share their own concerns, find their own affirmational support, and develop effective ways of responding to difficult situations that arose with their assigned families. The solidarity that developed within the team of PSPs was critical in sustaining their commitment to the project.

Fourth, it was important for administrative purposes to ask PSPs to document their work. The PSPs were effective listeners, coaches, and advocates but, for some, recording their good works proved quite formidable. The process for tracking their activities had to be modified more than once to accommodate the needs of both the PSPs and supporting agencies. Even-

tually reporting forms were developed that combined the right levels of simplicity and comprehensiveness.

Our final hurdle was obtaining additional funding to continue the program after the research project was complete. Despite positive results from the evaluation, it was difficult to

comes at the very end of a project can lead to detecting temporary negative effects brought about by a sense of loss as the program is terminating. This common response by participants can obscure an otherwise more enduring positive effect. In addition, we viewed one year as a more natural



identify a continued funding source because this type of program is not typically reimbursable under public or private health insurance plans. We were, however, able to combine the dollars of two private foundations to continue Parent Connections for one year beyond the study.

Evaluation Results

We evaluated Parent Connections using a randomized controlled clinical trial design with two groups: a low-dose control group and an experimental group. The control group received a packet of information on services and resources for families of children with serious emotional disorders. The experimental group received the identical information packet. Additionally, they were offered the opportunity to participate in the full Parent Connections program.

Although the evaluated program lasted 15 months, data were collected at enrollment and 12 months post-enrollment. We used this approach because our experience with similar studies suggested that measuring out-

intervention assessment period than 15 months.

The project utilized data collected from 257 families enrolled at baseline. We examined effects on child functioning and the impact on maternal mental health and perceived support. Perceived social support was measured using items from the Multidimensional Social Support Inventory (MSSI; Bauman & Weiss, 1994). These items were used to assess perceived availability of support across five areas, including having someone to confide in or having someone to talk to about the child's needs. For example, one item asks: "Does anyone show that they are interested in and want to understand your concerns about raising a child with a serious emotional or behavioral disorder?" Items from this scale have been used in prior evaluations of similar parent support programs (Ireys, et al., 1996; Ireys, et al., 2001). To assess perceived adequacy of support, interviewers asked parents whether they got the support they needed all, most, some, or none of the time.

On the measure of perceived

breadth of support, the mean increase for the experimental group was significantly greater than for the control group. At the second data collection point, all participants were asked “whether there was ever a time in the last year when you wished you could have talked to someone about your child’s condition,” and, if they did wish this, whether they actually talked to anyone. About three-quarters

in light of the many factors that influence the functioning of low-income, urban families. Nevertheless, what we have learned represents an important step toward a better understanding of how to support parents of children with serious emotional or behavioral disabilities. Our findings should encourage further study of Parent Connections or other well-defined models of family-to-family support.

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Building parents’ knowledge and skills can produce a heightened sense of efficacy, both at home and within the mental health and education systems.

of mothers in the experimental group indicated that they wished they could have talked to someone and of these about three-quarters actually did so. In contrast, about two-thirds of mothers in the control group indicated that they wished they could have talked to someone and of these only about half actually did so.

To assess changes in maternal mental health status, we examined whether the two groups differed with respect to change in levels of anxiety. Nine percent of the mothers in the control group moved from high anxiety at baseline to lower anxiety 12 months later. In contrast, 22 percent of the mothers in the experimental group moved from high to lower anxiety.

Conclusion

This study is an example of a methodologically strong evaluation of a theory-driven, family-to-family support program for low-income families with high-risk children and multiple other stressors. Overall, the study provides evidence that Parent Connections produced modest positive effects. It is not surprising that the program demonstrated only a modest impact

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Diane Dvoskin Sakwa has addressed the need for change in child and adolescent systems of care as both parent and advocate by sharing her encouragement, knowledge, and voice with thousands of families and professionals for close to 20 years.

Henry T. Ireys is currently a Senior Researcher at Mathematica Policy Research, Inc., in Washington DC and for many years has been examining the effectiveness of support programs for families of children with special needs.

