Involving Families in the Care of Persons with Schizophrenia and Other Serious Mental Illnesses: History, Evidence, and Recommendations

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Abstract

Families of individuals with schizophrenia and other serious mental illnesses often provide considerable support to their ill relatives, yet many remain unaware of or unable to access resources and information to help them effectively manage their caregiver role. Consequently, family members may experience burden and subsequent distress. There is substantial evidence to suggest that participation in family services and family involvement in a consumer's clinical care can minimize family burden, leading to better outcomes for the consumer and the family. Unfortunately, few families have contact with their relatives' treatment teams, and even less participate in formal support or educational programs. There are a number of consumer-, family-, provider-, and service-related barriers, which may inhibit family involvement. However, many of these barriers can be overcome when a more individualized, tailored approach to working with families is used. The current paper provides an overview of the impact of mental illness on the family and the role of the family in recovery, a summary of available services, and recommendations for ways to work with consumers and families to overcome barriers to family involvement and increase the likelihood of family participation in care.

Key Words: Family Involvement, Family Services, Schizophrenia, Serious Mental Illness

Introduction

There is extensive evidence supporting the benefits of family involvement in the mental healthcare of consumers with schizophrenia and other serious mental illnesses. Participation in intensive family services, such as family psychoeducation (FPE), has been associated with significant reductions in relapse/rehospitalization rates (as much as 50% for programs lasting nine months or more) (1, 2); better employment rates (3, 4) and social functioning (5); greater hope and empowerment among consumers (6); less family distress and burden (7); and, better family functioning overall (8). Although limited in their impact on relapse rates, less intensive family services, such as brief education, family consultation, peer-led programs, and family involvement in ongoing clinical care, have also been associated with positive outcomes, including greater self-efficacy in coping with a relative's mental illness (9), less distress and worry (10), and greater knowledge of mental illness among family members (11). Despite the apparent benefits, few families...
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participate in formal family services or are actively involved in their relatives’ mental healthcare, suggesting the need to change the way we think about providing services to families.

The Impact of Mental Illness on the Family

Consumers with schizophrenia and other serious mental illnesses often rely on family members for support. Family members are typically the first to notice signs of the onset or reemergence of symptoms and, as a result, often initiate and facilitate treatment. Consumers often spend a considerable amount of time with family members, who provide ongoing emotional support and assistance in coping with symptoms. Many families also provide practical assistance, such as transportation to appointments, housing, and financial assistance or management. Ongoing contact with family has been shown to benefit consumers in a number of ways. Family contact has been associated with better work performance, role performance (12), and social role functioning (13) among individuals with schizophrenia. Greater family contact has also been shown to be associated with reductions in substance use among individuals with serious mental illness and co-occurring substance use disorders (14), residential independence in individuals with schizophrenia (15), and greater housing stability (16). Thus, families often support consumers in their treatment and recovery goals and help advocate for better care, which can result in more appropriate treatment and better outcomes.

While many family members find their caregiving role rewarding (10), the effort required to support individuals with schizophrenia and other serious mental illnesses can overwhelm families, resulting in objective and subjective burden. Objective burden refers to disruptions to the family unit associated with having a relative with an illness, such as changes in family member roles and relationships (i.e., increased responsibilities) and financial hardship (i.e., loss of income) (17). Objective burden is often associated with a loss of social support and reduced participation in social activities, due not only to the time demands of caregiving responsibilities, but also the discomfort in discussing the illness and its effects. Alternatively, subjective burden involves the psychological impact of the illness on family members (18). Having a family member with a mental illness can lead to increased distress among family members, particularly those who serve as primary caregivers. Family members often worry about the safety and health of the consumer, fear potential relapse, and experience anxiety over who will care for the consumer in their absence. Primary caregivers may also experience depression, grief, and anger in reaction to the additional responsibilities, challenges, and personal loss associated with their caregiver status, and may struggle to cope with their relatives’ own grief and loss over prior functioning, abilities, and future goals (18).

Objective and subjective family burden may create a stressful family environment, which, in turn, may negatively impact the health and well-being of the consumer. Many studies have demonstrated that high levels of so-called “expressed emotion (EE),” measured by the presence of critical or hostile comments or emotional over involvement in consumer-family interactions, are associated with greater risk of relapse among persons with schizophrenia (19). High EE may be a marker of stress. Utilization of interventions that provide information, support, and problem-solving strategies can minimize family burden (7, 10, 20, 21), which, in turn, can lead to more positive consumer-family interactions and more rewarding family relationships. Ultimately, reductions in family burden can play a key role in improving family relationships, increasing the potential for enhanced functioning and long-term success for consumers and their families.

The Needs of Families of Consumers with Schizophrenia

Past studies have documented the need for information and support among families of individuals with schizophrenia and other serious mental illnesses. Previous studies of family needs have found that families require ongoing support, information on the nature of mental illness and available treatments, and assistance in developing coping strategies and problem-solving skills (18, 22-26). Others studies have highlighted the need for information on the structure and function of the mental health system, ways to successfully navigate the system to ensure the receipt of optimal care, community resources (i.e., housing, employment), and planning for the future (27). Moreover, the need for information, guidance, and support does not appear to dissipate over time, but rather changes in the content, focus, and intensity of the services needed to adequately address those needs.

Family Services and Programs

A number of programs have been created in an attempt to address family needs, from high-intensity interventions such as Family Psychoeducation (FPE) and peer-based education to lower-intensity services such as brief education and family consultation. Moreover, informal contact between families and mental health providers and family involvement in a consumer’s ongoing clinical care have also proven useful in providing education and support to families and additional support to consumers.
**Family Psychoeducation Programs**

Family Psychoeducation (FPE) programs were designed to improve family communication and problem-solving skills and offer family support with the goal of reducing expressed emotion among family members. Family Psychoeducation is a structured program, administered by a trained mental health professional. It can be provided in multiple-family or single-family formats, and can include both the family and consumer or the family only. Two of the most widely used and evaluated FPE programs are Multifamily Group Treatment (MFG) (28) and Behavioral Family Treatment (BFT) (29). Multifamily Group Treatment is led by a mental health professional and involves several families meeting as a group in order to receive information on mental illness, support, and group-based practice in problem solving around issues or problems associated with an illness (28). An MFG program typically lasts from nine months to two to three years, starting with an initial series of joining and alliance-building sessions with consumers and families followed by a half- or day-long educational workshop. Upon completion of the educational workshop, the multifamily groups commence, typically on a biweekly basis, with sessions focusing on helping consumers and families learn and practice problem-solving techniques. In contrast, BFT is usually conducted with an individual family, with sessions held on a weekly or biweekly basis from nine months to up to two years depending on consumer and family need. Behavioral Family Treatment starts with an assessment of individual strengths, weaknesses, needs, and treatment goals, and then, based on those assessments, moves to education on relevant topics (i.e., psychosis, its nature and course, relapse prevention and treatment), communication skills training, problem-solving training, and, finally, assistance in managing unique problems or goals identified by the consumer and/or family (29).

Numerous studies have found that participation in an FPE program that lasts at least nine months and includes illness education, problem solving, crisis intervention, and emotional support can reduce consumer relapse and rehospitalization rates by as much as 50% (1, 2). Other studies have found that FPE leads to better employment rates (3, 4), reductions in negative symptoms (30), improvements in social functioning (5), greater life satisfaction, and increased knowledge, hope, and empowerment (6) among consumers. Participation in FPE has also been associated with reductions in subjective family burden and distress (7, 8, 31, 32), improvements in well-being (7), and overall family functioning (8). The extensive evidence for the efficacy and benefit of FPE for individuals with schizophrenia and other serious mental illnesses and their families has led to the designation of FPE as an evidence-based practice (33) and to recommendation of its use by the Schizophrenia Patient Outcomes Research Team (PORT) (34) and the American Psychiatric Association (35). Moreover, as a result of its established efficacy, Substance Abuse and Mental Health Services Administration (SAMHSA) chose FPE as one of the evidence-based practices for which a toolkit was developed in an effort to promote widespread dissemination and implementation of FPE.

**Ultimately, reductions in family burden can play a key role in improving family relationships, increasing the potential for enhanced functioning and long-term success for consumers and their families.**

**Brief Family Interventions**

Briefer interventions, such as brief family psychoeducation or family consultation, have been proposed as alternative strategies for decreasing burden, increasing knowledge of mental illness and treatment, and improving coping skills among family members (36). Although the benefits of these programs do not appear to be as extensive as FPE, with shorter family programs (i.e., less than six months) demonstrating little impact on relapse or rehospitalization rates, these interventions may be particularly useful in cases where more intensive services are not needed, are not readily available, or are not of interest to families. Family consultation typically involves anywhere from one to five sessions with a mental health professional. Initial meetings are focused on assessing consumer and family needs with later meetings aimed at identifying strategies for resolving specific issues or addressing specific goals, such as the provision of education or information, coping skills development, or referrals to community resources and programs. Brief family education has also been proposed as a less intensive alternative to FPE. The content and structure of brief family education varies, but is typically conducted in a group format, led by a mental health professional or peer consultant, and often held on a weekly basis for a designated period of time (i.e., anywhere from six to ten weeks). However, other family educational programs, such as the Veterans Affairs-based Support and Family Education program (SAFE), are held on a monthly basis, are ongoing, and allow family members to join at any time (37). Despite the potential benefits of these programs, research on family consultation and brief family education has been limited. Although Solomon and colleagues (9) found that families who received family consultation and family psy-
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choeducation reported greater self-efficacy in coping with a relative’s mental illness, program participation did not increase family contact with community services or with the relative’s mental health providers (38). Sherman and colleagues found that participation in the SAFE program was associated with greater knowledge of mental illness and Veterans Affairs (VA) resources, better self-care, and reduced distress among caregivers (37). Thus, briefer interventions such as family consultation may not impact concrete consumer outcomes like relapse rates, but rather influence knowledge, attitudes, and quality of family relationships.

Moreover, the need for information, guidance, and support does not appear to dissipate over time, but rather changes in the content, focus, and intensity of the services needed to adequately address those needs.

Peer-Led Educational Programs

Peer-based educational programs, such as the Family-to-Family Education Program (FFEP) and Journey of Hope, are community-based programs offered through the National Alliance on Mental Illness (NAMI) and designed to provide family members with education on mental illness and information on available treatments and resources, enhance family problem solving and communication skills, and provide support. The Family-to-Family Education Program is a free, twelve-week program for caregivers of consumers with serious mental illness, delivered by trained family members who are also previous graduates of the class. Participation in FFEP has evidenced a number of benefits to the family, including greater perceived empowerment in the family, in the community, and in the service system; less displeasure with and worry about an ill relative (10); reduced subjective burden, increased knowledge of mental illness and the mental health service system; and, better self-care (39). Journey of Hope is a similar, albeit slightly less time-intensive course, held weekly for one-and-a-half to two hours for eight weeks. Similar to FFEP, this program provides family members with information on mental illness and its treatment, crisis management, problem solving, and communication, as well as support. Journey of Hope is a free program administered by trained family members and available to all interested caregivers. Numerous benefits of participation in the Journey of Hope program have been reported, including greater knowledge of mental illness and decreased need for information on mental illness and its treatment, community resources, coping with a relative’s symptoms, and problem solving (11). In addition, family members who participated in the program evidenced greater caregiver satisfaction (40), better emotional role functioning, more positive views of their relationship with the consumer, and fewer symptoms of depression than those who did not participate in the program (41).

Informal Family-Provider Contact and Family Involvement in Ongoing Clinical Care

Lastly, consumers, families, and providers often benefit from even minimal family-provider contact and the inclusion of family in ongoing clinical care. For example, a single family visit during inpatient hospitalization has been shown to be associated with reduced risk for future hospitalization (42). Provider outreach to families, even if minimal, has been viewed positively by both families and mental health providers (43). Informal family-provider contact provides opportunities for educating families on mental illness, allowing the family to better understand a consumer’s behaviors, and offer more appropriate support. Informal family-provider contact may also serve as a bridge to more formal family programs and support services.

Involving family in a consumer’s clinical care is also of benefit to providers. Family members spend considerably more time with the consumer, and as such, are often privy to information not readily accessible to treatment providers. Family members often have important information concerning a consumer’s current health and well-being, past experiences with an illness, stressors or triggers that lead to symptom exacerbation, and knowledge of the consumer’s personal strengths, resiliencies, and coping skills, all of which could prove invaluable in determining appropriate treatment goals and designing effective treatment plans. Moreover, family members can help problem solve around particular issues or concerns, and identify ways to support the consumer in the community, thus increasing the likelihood of progress toward, and achievement of, recovery goals.

Use of Family Services and Family Involvement in Mental Healthcare

Despite the benefits of family involvement, few families are actively involved in their relatives’ mental healthcare, and even fewer participate in formal family programs. Often times, contact with treatment providers occurs in the context of a crisis or during inpatient hospitalization, not as part of regular outpatient care (43). As few as 31 to 40% of consumers report that their families have had contact with their treatment providers in the past year (44, 45), and in some cases as many as 40% of consumers have reported that their families have never had contact with the treatment team.
(45). Participation in formal family services occurs even less frequently (6, 46, 47). Few families have participated in FPE programs, family consultation, or family education.

A number of consumer-, family-, provider- and system-level barriers may impact family involvement in both formal and informal family services (31, 48). Consumer barriers such as limited knowledge of family programs and the benefits of family involvement in care, privacy concerns, current health status, and fear of additional family burden, can lead consumers to choose not to include family in their care. Family-related barriers often include lack of knowledge of mental illness; mental health treatments and how to access available services; privacy concerns; time constraints; transportation difficulties; increased burden; and, prior negative experiences with the mental health system (31, 48). Finally, provider and system-level barriers, such as reimbursement concerns; workload and time constraints; insufficient training or access to training in family services; agency policies that limit the ability to provide family services; confidentiality guidelines; and, skepticism over the utility of family interventions may influence provider willingness to make attempts to engage families in care (31, 48). Although efforts have been made to increase participation in family services by addressing knowledge- and training-related barriers, most of these efforts have met with limited success. For example, an eight state project to test the effectiveness of the use of toolkits for disseminating FPE and other evidence-based practices resulted in few families receiving family psychoeducation (49). Efforts to disseminate FPE to thirty-five sites in New York was replaced with a less intensive, family consultation model due to dissemination difficulties and the perception that FPE did not meet the needs and preferences of families (50). The limited success of these efforts suggests that greater emphasis on assessing the needs of consumers, families, and preferences concerning how to address these needs is warranted and can help to determine the most effective means by which to provide family services.

Changing How We Involve Families in Care

The paradox between the strong evidence base supporting the use of family services and the limited use of such services highlights the need for greater consumer and family input regarding family services and how to involve families as partners in their relatives’ mental healthcare. The President’s New Freedom Commission on Mental Health (51) and the Institute of Medicine (52) both advocate for greater use of consumer- and family-centered, recovery-oriented approaches to mental healthcare. At the heart of consumer- and family-centered care are efforts to provide education on mental illness and effective treatments, to acknowledge and address consumer and family needs and preferences, and to provide choices regarding treatment strategies. As such, consumers, families, and providers work together to decide which services best reflect their needs and preferences. Such initiatives underscore the benefits of family involvement and the importance of partnering with consumers and families regarding treatment decisions. The more families and consumers are involved and invested in consumer mental healthcare, the more likely desired outcomes and goals (i.e., employment, improved health, medication adherence) can be identified and achieved, shifting the focus of treatment from managing crises to improving functioning and achieving personal goals. With the needs of consumers and families in mind, providers can better match services to the needs and preferences of consumers and families and maximize the benefits of family involvement.

Recommendations

Make Active Attempts to Discuss Family Involvement with Consumers

Most consumers with schizophrenia and other serious mental illnesses have regular contact with a family member or support person and are interested in having these individuals involved in their mental healthcare (53). For example, Young and colleagues (54) found that 68% of consumers with schizophrenia receiving outpatient care reported having a close family member, while Murray-Swank and colleagues (53) found that 97% of veterans surveyed reported having a family or family-like relationship. Moreover, regular contact with family is common, with daily or weekly contact with family occurring in two-thirds or more of families (27, 53).

Despite interest in additional family support, many consumers have limited knowledge of available family services and the potential benefits of involving family in their care. By engaging the consumer in a discussion regarding family involvement in treatment, providers can gain a better understanding of the consumer’s support network, assess the consumer’s level of interest in family involvement, and determine how family involvement should be structured to best meet the consumer’s needs. Initiating a discussion of family involvement creates an opportunity to educate consumers on the benefits of family involvement and options with regard to family services. As such, providers can assist consumers in identifying ways in which family could support the consumer in his recovery and how the consumer, family, and provider can work together to help him better manage his illness. This discussion should include an inquiry about who the consumer considers to be family, the extent of the consumer’s contact with family members and his perception of the relationship, and ways in which family members have
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supported the consumer in the past. Moreover, providers should inquire about aspects of the consumer's life that he would like to change or improve, or any personal recovery goals that he would like to achieve, and the potential benefits of family involvement in assisting him to achieve those goals (see Murray-Swank et al. [55] and NAMI New York's White Paper [56] for a more detailed discussion of strategies for discussing family involvement with consumers and families). It is important to note that inclusion of supportive individuals should not be limited to family members. Support networks often include persons outside the family, such as friends or peers, religious figures, or Alcoholics Anonymous or Narcotics Anonymous sponsors (55), many of whom have supported the consumer in managing his illness in the past and could serve as a partner in supporting him in the future.

Although many consumers are interested in family involvement, others may be uncertain about involving family members or other support persons in their care. Limited knowledge of family programs and their benefits, and concerns about privacy, stigma, and additional family burden may lead to ambivalence about family involvement. Engaging consumers in a discussion of family involvement creates the opportunity to educate them on available family services and the potential benefits of family involvement. Specifically, it can help consumers identify benefits specific to their own personal goals. In some cases, consumers may be concerned that health information may be disclosed without their knowledge or consent. Working with consumers to determine the extent to which they would like family involved in their care could help to alleviate some of these concerns by clearly outlining which family members will be involved in which service, what topics can be discussed, and any limitations on information that can be shared with family members (48). Perceived stigma may also affect a consumer's willingness to allow family involvement. Consumers may be concerned that family members will view them or treat them differently if they know more about their illness or symptoms. Finally, many consumers fear that greater family involvement will create additional burden for family members, many of whom already provide consumers with substantial support (55). Thus, it is critical that clinicians explore and address the concerns of consumers and make attempts to alter negative attitudes and overcome consumer ambivalence toward family involvement.

Make Active Attempts to Engage Families in Care

Considering the obstacles that may preclude family involvement, active outreach on the part of providers may be needed in order to engage families in care. As previously noted, family members experience a number of barriers to involvement. Many family members have limited knowledge of mental illness, the mental health service system, and available family services, which may prevent them from seeking assistance. Provider outreach to families could help consumers and families obtain greater knowledge of their relatives' mental illness, and learn how to access treatments and resources, which would help families to better advocate for themselves and their relatives (57). Limited knowledge of the mental health service system, including how treatment is provided and the various roles or duties of treatment team members, can also deter family involvement. Active efforts on the part of providers to connect with family members and provide them with education on treatment models and the role of different service providers could help in forging a partnership.

Family members may also express reluctance to be involved due to concerns about the consumer's privacy. Family members may feel more comfortable being involved if a consumer has discussed interest in family involvement with his provider prior to family contact. Once a consumer has agreed to allow a provider to have contact with the family, a release of information that outlines stipulations regarding family contact can be obtained. While providers may not be able to provide specific information about a consumer's mental health status or treatment without a release of information, general information on mental illness and its treatment, family support services, and community resources to families can be given to interested family at any time (48).

Stigma associated with mental illness and prior negative experiences with the mental health system can also hinder family involvement. Fear of stigma can lead family members to conceal their relative's illness or avoid discussing their relative and the impact of the illness on the family with others (58). In addition, reluctance may stem from concerns that others may blame the family for the consumer's health problems or view the family as contributing to problems and setbacks (48). By reaching out to families and making efforts to develop positive relationships based on mutual respect and empathy, providers can correct misperceptions that contribute to perceived stigma, minimize the impact of prior negative experiences, and overcome ambivalence regarding involvement (48, 58). Practical difficulties, such as a lack of time, transportation, or energy can also impede family involvement in care and may require greater flexibility on the part of providers in the scheduling and implementation of family services (36). Providers can use telephone contact to complement in-person contact, offer evening and weekend hours to better accommodate family members' schedules, and arrange brief interventions focused on problem solving and education when formal services are not desired or feasible.
Assess Family Needs and Preferences Regarding Family Services

Knowledge of mental illness, its etiology, and its treatment; strategies for assisting a relative to cope with an illness and obtain needed services; and, the need for support often vary from family to family. Similarly, consumer and family preferences concerning how best to meet educational, informational, and support needs also differ. Needs and preferences may depend on a number of factors, including the family situation and environment, the family member’s relationship to the consumer, and the consumer’s stage of illness and recovery. As such, the needs and preferences of families may vary among families and within families over time, underscoring the need for ongoing discussion and evaluation.

For example, families typically serve as the primary social contact and ongoing social support network (59, 60) for individuals experiencing their first psychotic episode. Having never experienced or witnessed psychosis, families may not fully understand the changes they observe in their relatives or have knowledge of how to access appropriate services to assist them. Thus, individuals with emerging psychosis and their families may need education on psychosis: its etiology, treatment, course and outcomes, and relapse prevention, as well as information on accessing mental health services. Similarly, families of consumers dealing with a re-emergence of symptoms and potential relapse may also need more intensive education, information, and support and may benefit from more structured programs, such as FPE or Family-to-Family Education (45). In contrast, families of consumers who have made significant progress in their recovery have likely developed skills and knowledge to assist the consumer and to better cope with the consumer’s illness. These families may require more targeted information, such as information on employment services and opportunities, housing, increasing and improving social relationships, relapse prevention, or problem solving. In these cases, briefer, time-limited interventions that focus on a circumscribed problem or goal may be more appropriate.

The relationship of the primary caregiver to the consumer may also impact the type of need. Parents or older caregivers often need assistance in, and information on, fostering consumer independence and planning for future care. Spouses or partners may need information, guidance, and support to cope with emotional, social, and financial losses they may experience as a result of their new caregiver role, as well as intimacy concerns and child-rearing issues (45). While adult children or siblings may experience many of the same needs as other caregivers, issues unique to these individuals may need to be addressed. Siblings may experience guilt due to the fact that they did not develop an illness, concern that they may develop an illness (45), or harbor negative feelings as a result of past experiences associated with a relative’s illness. Similarly, children may have concerns about developing the illness (45), and need assistance in understanding past experiences with their parents and how parent illness may have impacted those experiences.

Consumer and family preferences concerning the mode and method in which family services are provided can vary as well. Drapalski and colleagues (27) assessed the information and support needs of families of adults with mental illness and their preferences concerning family services. Most families preferred that information and support be provided by a mental health professional (63%) and on an as-needed basis (58%); however, greater variability in the preferred mode and method was evident. While many families preferred that information be delivered in person (29%) or in writing (21%), others preferred telephone contact. Similarly, some families preferred meeting in a mental health clinic (29%), others in their own homes (23%), and still others near their homes (17%). In an assessment of consumer interest in, and views on, family participation in care, two-thirds of the consumers interested in family involvement indicated a preference for communication training, and over 50% preferred counseling with a mental health provider (53).

Numerous studies have found that participation in an FPE program that lasts at least nine months and includes illness education, problem solving, crisis intervention, and emotional support can reduce consumer relapse and rehospitalization rates by as much as 50% (1, 2).

Finally, special attention must be paid to cultural differences, which may impact family involvement and influence work with families. Conceptualizations of mental illness, perceived goals and expected outcomes of treatment, views on acceptable treatment strategies, and the perceived role of family and the provider in supporting the consumer in his recovery may differ based on cultural norms and values. As such, family interventions may not work as well for some groups (61), and highlight the importance of acculturation (62) and intervention format (61) in the provision of family services.

As previously stated, the variability in the needs of families and the potential for these needs to change over time highlights the importance of ongoing assessment. Ongoing assessment of family needs can provide important information concerning specific areas in which families require ad-
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ditional information and support, which can then be used to tailor treatments and services to better meet the needs of consumers and their families. Moreover, by gaining a greater understanding of the family and its role in the consumer’s recovery, providers can identify ways to build upon family strengths and bolster supports to promote recovery.

Putting it All Together: Working with Consumers and Families to Help Them Make Decisions about Family Involvement and Family Services

Once needs and preferences have been determined, providers can work with families to decide which family services would be appropriate and feasible and outline steps for involving the family in the consumer’s ongoing clinical care. Helping families to make decisions concerning participation in family services often involves determining which service best addresses needs and most closely matches preferences. Preferences are often a reflection of barriers and obstacles, and, as such, can be used to determine ways to involve families that are both helpful to the family and increase the likelihood that participation will occur. For example, some families may benefit from more intensive services such as FPE; however, family and work responsibilities, transportation, financial limitations, or time constraints may make participation in an intensive intervention impractical or unappealing. In these cases, family education, family consultation, or ongoing contact with providers may be more feasible. For families who need additional support, but are unable or unwilling to participate in programs held at a mental health facility, or for those whose relatives are reluctant to participate in more intensive services with the family, peer-led educational groups held in community settings, and in many cases without the consumer present, can serve as an alternative means for obtaining education and support. Helping families to consider their options regarding family services and involvement ensures that they have the knowledge of available family services, what participation in each service entails, and the potential benefits of each. With this knowledge, families are able to make a more informed decision concerning which services would be most feasible and of the most benefit.

Assisting families in making decisions about their involvement also requires that providers be knowledgeable of available services and ways to access those services. Providers need to know which local treatment centers offer family psychoeducation, brief family education, family consultation, or other supports for families with serious mental illness. Additionally, knowledge of specific providers trained in supplying family services is essential, particularly when family services are not available within a consumer’s current mental health treatment facility. Information on locally held peer-led education programs such as Family-to-Family Education and Journey of Hope can be easily accessed through the National Alliance on Mental Illness web site (www.nami.org).

Identify Ways and Take Steps to Become More “Family Friendly”

Lastly, the differing needs of consumers and families and potential barriers to participation in traditional services suggest the need for providers and agencies to think critically about the family services they offer, and if those services adequately address the needs and preferences of the consumers and families they serve. Similar to individual needs assessments conducted with consumers and families, evaluating the services available to families, and the strategies used to involve families in ongoing clinical care, can help mental health agencies and individual providers identify ways to improve the quantity and quality of the family interventions they provide.

Increasing the “family friendliness” of an agency can occur in a variety of ways. First, becoming more family friendly may require thinking more flexibly about the provision of care and exploring alternative strategies for how services are provided. Evening and weekend hours or provision of home-based services may be required in order to accommodate family member schedules and, when possible, e-mail and phone contact could be used to supplement in-person meetings (36). Agencies may also want to develop routine strategies for including family in ongoing clinical care. This may involve developing protocols for providers that outline steps for approaching consumers regarding family involvement from the outset of care and encouraging family involvement in treatment planning and other clinical services. In addition, information on the benefits of family involvement and brochures outlining family services available to families at a given agency and in the community (i.e., NAMI programs) should be made available in waiting rooms (36). Moreover, agencies may wish to develop a resource library that includes educational materials (i.e., handouts, brochures, books, videos) and information on community resources that can be used by consumers, families, and providers alike. Lastly, agencies can improve provider knowledge, expertise, and comfort in working with families of consumers with mental illness by creating opportunities for staff training and education. Training opportunities may include developing local trainings aimed at increasing provider knowledge about the benefits of family involvement and the types of family services, strategies for approaching consumers about family involvement, and ways to include family in consumer treatment. In addition, support of staff members seeking train-
### Table 1: Descriptions of Various Family Interventions and Services and Resources for Learning More about Each Service

<table>
<thead>
<tr>
<th>Family Intervention</th>
<th>Focus</th>
<th>Structure</th>
<th>Books/Manuals</th>
<th>Resources</th>
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| Family Psychoeducation      | • Illness education  
• Development of problem-solving and communication skills  
• Support                                                               | • Varies depending on the FPE program (i.e., single- vs. multiple-family format, location of program, presence of the consumers, etc.)  
• Typically lasts from 9 months to several years  
• Delivered by a trained mental health professional                       | • Multifamily Groups in the Treatment of Severe Psychiatric Disorders (28)  
• Behavioral Family Therapy for Psychiatric Disorders (29)  
• Bipolar Disorder: A Family-Focused Treatment Approach (63)  
• Schizophrenia and the Family: A Practitioner’s Guide to Psychoeducation and Management (64)  
• Families as Partners in Mental Health Care: A Guide to Implementing Family Work (65) | • SAMHSA FPE Toolkit  
• See mentalhealth.samhsa.gov/cmhs/CommunitySupport/toolkits |
| Brief Family Education      | • Content varies but typically includes education on mental illness, its treatment, coping strategies, community resources, and other relevant topics | • Varies depending on the program  
• Typically held on a weekly basis for 6–10 weeks although it can be ongoing with rolling admission  
• Led by a trained mental health professional                                      | • Support and Family Education Program (SAFE) (37); w3.ouhsc.edu/Safeprogram/  
• Families as Partners in Mental Health Care: A Guide to Implementing Family Work (65) | |
| Brief Family Consultation   | • Resolving specific issues or addressing specific goals identified by the consumer and/or family  
• Referrals to community resources and programs                             | • Typically 1–5 sessions, with booster sessions and follow-up consultations available  
• Delivered by trained mental health professionals                           | • Mental Health Association of Southeastern Pennsylvania Training and Education Center; www.mhasp.org/services/  
• The New York Family Institute for Education, Practice, and Research; www.nysfamilyinstitute.org/ | |
| Peer-Led Family Interventions | • Education on mental illness, its treatment, community resources, problem-solving, and communication skills  
• Support                                                                    | • Typically 8–12 week program, 1 to 1½ hour sessions  
• Programs held in the community  
• For caregivers of consumers with SMI  
• Delivered by trained family member                                           | • National Alliance on Mental Illness; www.nami.org | |
| Family Friendly Agency      | • Greater involvement of family members in consumers’ ongoing care       | • Consumer and family involvement in treatment planning and participation in decision about ongoing care  
• Provision of information on and access to family services through on-site availability of educational materials and referrals to family services  
• Program structures that accommodate families (i.e., use of phone and possibly e-mail contact; evening and weekend program hours) | • The Complete Family Guide to Schizophrenia: Helping Your Loved One Get the Most Out of Life (66)  
• Coping with Schizophrenia: A Guide for Patients, Families and Carers (67)  
• Integrated Treatment for Dual Disorders: A Guide to Effective Practice (68) | • “The Family Forum: Directions for the Implementation of Family Psychoeducation for Severe Mental Illness” (36)  
• “Practical Interviewing Strategies for Building an Alliance with the Families of Patients who Have Severe Mental Illness” (55)  
• “Helping Families to Help Their Loved Ones with Serious Mental Illness: A White Paper of the National Alliance on Mental Illness of New York State” (56) |

FPE=family psychoeducation; SAMHSA=Substance Abuse and Mental Health Services Administration; SMI=severe mental illnesses
Family Involvement

ing in specific family service models, such as FPE, family consultation, or family education, is warranted, particularly in cases when these services are needed but not currently available within an agency. Some materials and resources for learning more about involving families and family programs are provided in Table 1.

Conclusions

Consumers, families, and providers can benefit substantially from greater family involvement in consumer clinical care, as well as from participation in family service programs. However, the needs of families and their preferences concerning involvement often vary from family to family and over time. In order to ensure that families are offered and, ultimately, provided services that best address their needs and reflect their preferences, consumer and family input is crucial. By initiating a dialogue with consumers and families regarding family involvement and the role of family and supportive others in recovery, providers can help consumers and families to make more informed decisions concerning family involvement and the services that best meet their needs. Moreover, these discussions can help to uncover potential barriers to family involvement and provide a forum for working with consumers and families to address and potentially overcome them, thus increasing the likelihood of family involvement and, subsequently, better outcomes for consumers.

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References


