Family Intervention in Early Psychosis
Treatment Workgroup
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I. Summary of Presentations:

STEP: Nick Breitborde, Ph.D.

The Specialized Treatment Early in Psychosis (STEP) program was developed as a collaboration between the Yale University School of Medicine and the Connecticut Department of Mental Health and Addiction Services (DMHAS), and was funded by the DMHAS, the National Institute for Mental Health, and the Donaghue Foundation. The STEP care team was comprised of a psychiatrist (who provided overall leadership for the STEP Program), psychologist (who served as the clinical team leader and director of family services), and two to three social workers or nurses (who provided individual case management and community-based recovery support services). With the exception of the psychologist, members of STEP team dedicated less than 0.50 FTE to providing STEP services with the rest of their effort dedicated to providing care to other individuals served by the larger ambulatory service for SMI in which STEP is located.

Although, family work is a key component of coordinated multi-element care for individuals with first-episode psychosis, families may vary with regard to the intensity of family services needed to effectively support them and their relative with first-episode psychosis. Drawing on the ‘principle of sufficiency,’ the STEP family work program (Breitborde and Srihari, 2012) provides each family with the least intensive intervention that will alleviate their current distress and reduce the likelihood of future negative outcomes (e.g., continued distress for the caregiver or worsening of symptoms for the individual with psychosis). More specifically, families participating in the program progress through a series of increasingly intensive interventions (i.e., orientation to the clinic → joining sessions → multifamily group psychoeducation). Families decide whether to progress to more intensive stages of this family work program based on personal preference in combination with suggestions from family clinicians. STEP family services are provided by the psychologist who also served as the STEP clinical team leader.

During “orientation to the clinic,” family members are invited to participate in their relative’s first clinical meeting at STEP. At this visit, the Director of Family Services: (i) encourages and establishes open and ongoing communication between the family and the STEP care team; (ii) introduces family members to the other members of the STEP care team; and (iii) provides family members with written psychoeducation materials on caring for a relative with psychosis.

Families who opt to participate in joining sessions, complete a series of individual appointments with the Director of Family Services that review and/or identify: (i) the biological contributors to psychosis; (ii) the stress-diathesis model of symptomatic relapse; (iii) their relative’s unique early warning signs of an impending worsening of psychotic symptoms; (iv) family member’s explanatory model of their relative’s symptoms/distress; (v) the ‘critical period’ hypothesis for
psychotic disorders; and (vi) family members’ uncertainty with regard to their relative’s illness. In total, these activities are designed to provide informational support, to facilitate increased hope among family members (e.g., highlighting the improved outcomes that may result when care is provided early in the course of a psychotic illness), and to assist in the management of the normative distress and worry that may accompany caring for a relative with a potentially chronic illness (e.g., reducing distressing uncertainty among family members with regard to their relative’s illness). Developing a greater understanding of the family’s explanatory model of their relative’s symptoms/distress can allow the STEP care team to better tailor the overall treatment plan so that it is more consistent with the needs, beliefs, and values of the individual with psychosis and her/his family.

Multifamily groups sessions are provided using a modified version of the protocol outlined by McFarlane (2002). While the majority of sessions involve the completion of structured-problem solving activities geared toward addressing challenges experienced by members of the group, occasional sessions are reserved for educational activities. More specifically, outside speakers are brought in to present to the group on topics of interest identified by the family members. These educational sessions provide an opportunity for families to receive informational support on topics may fall outside of the range of expertise of the group leader (e.g., mental health estate planning). Individuals with first-episode are not required to attend multifamily group meetings with their family members so as to avoid having family members’ access to this service be dependent on the level of motivation and/or engagement of the individual with psychosis. Although there are some challenges associated with providing family psychoeducation within a group setting, preliminary evidence suggests that, when presented with the option to participate in single and/or multifamily psychoeducation, families of individuals with first-episode psychosis are more likely to participate in multifamily psychoeducation (Breitborde et al., in press). Providing psychoeducation in a group format may also reduce the staffing requirements needed in the provision of family psychoeducation.

**NAVIGATE: Kim Mueser, Ph.D.**

**Family Intervention in the NAVIGATE Program**

In the **NAVIGATE program** for first episode psychosis, (Mueser et al., 2015) which was developed and evaluated as part of the NIMH *Recovery After Initial Schizophrenia Episode* (RAISE) initiative (Kane et al., 2015), the family intervention component is call the Family Education Program (Glynn et al., 2014). The NAVIGATE team is comprised of five individuals, who provide four core services: the director of the NAVIGATE team (who leads the team, and usually also serves as the family clinician), the prescriber (who provides individualized pharmacological management), the supported employment and education specialist (who helps the person pursue work or school goals), and two clinicians who provide Individual Resiliency Training (IRT: an individualized illness self-management program aimed on helping people achieve personal recovery goals through enhanced resiliency skills, knowledge about psychosis and its treatment, relapse prevention, processing the experience of psychosis, and learning more effective skills for coping with symptoms and pursuing social and other goals, and improved health behaviors).
As the NAVIGATE team was designed to be implemented in routine mental health treatment settings, and supported by existing health insurance plans, including settings in which a relatively low rate of new cases of first episode psychosis accrue, the positions of staff members on the NAVIGATE team are usually part-time, not full time. Experience with the NAVIGATE program is based on working with several sites during the piloting of the intervention, and subsequently working with 17 centers that participated in a cluster randomized controlled trial of the program. Sites were free to make modifications in the recommended configuration of the team, although the basic composition of the NAVIGATE team was maintained at most of the sites.

The director of the program was selected as the preferred person to also be the family clinician because this person is most often the first point of contact for individuals and families seeking services from NAVIGATE (i.e., engagement at earliest possible point). Because of the relatively slow rate of referrals at treatment settings where the NAVIGATE program was designed to be implemented, the Family Education Program was designed to be implemented using a single family rather than multiple family format, in order to avoid families having to wait before a family group was formed. Family sessions can be provided at either the clinic or home, or a combination of both. Persons with first-episode psychosis are included in all the different parts of the program (see below), although they can also choose to opt out of participation of some parts. For example, the information covered in the family education sessions overlaps with information provided in the IRT sessions, so some individuals with first-episode psychosis choose not to participate in those family sessions.

The Family Education Program includes the following components, which were offered to all families: an individual meeting with each family member to understand their perspective, family education (10-12 sessions of information about psychosis and treatment, stress reduction techniques, developing relapse prevention plan, building up resiliency and strengths), monthly check-ins (to review progress, identify concerns), family consultation (1-2 sessions per problem as needed, with clinician led problem solving to address issues raised by the family), and modified intensive skills training (8-12 sessions of communication skills and problem solving training to address high levels of family stress and tension).

The flexibility and individualization of the Family Education Program are illustrated by the variety of different services available within the program, covering the broad range of functions of family intervention programs described above. The hope-inspiring and resiliency focus of the program are addressed by presenting information about psychosis and its treatment in a matter-of-fact but upbeat manner, while underscoring evidence of each family’s resiliency in the face of the challenge. Family members are given opportunities to talk about and process their experience with the relative developing the psychotic episode. In the IRT sessions, individuals with first-episode psychosis develop a personal narrative aimed at processing their experience with their psychotic episode and treatment, which may be shared with family members during family sessions. The person’s personal recovery goals are articulated in the IRT sessions, and shared and updated regularly with the family in order to ensure their support.
II. Synthesis of Presentation and Points of Discussion/Clarification

The two presentations suggested common and overlapping principles in their overall approach to working with families. These include a recovery focus, flexibility, and an orientation to collaborating with families. Both models also define family broadly, offer an array of services, and include the family in the assessment and treatment planning process.

The programs also differ in several respects that impact delivery of the service. NAVIGATE offers a global menu of options for the person with first-episode psychosis and family members. A shared decision making approach is then used to determine what approach(es) the person with first-episode psychosis and family will use with the treatment team. The STEP approach clearly includes some choice, but the foundation of delivery of the service components builds on a stepped approach with increasingly more intensive services delivered according to need. In addition, STEP provides multiple family groups in which participation of the individual with psychosis is not required, while NAVIGATE generally includes the individual with first-episode psychosis and relatives together in a single family modality, although family sessions without the individual with first-episode psychosis may be held with that individual’s permission.

III: Implementation Challenges Raised in Discussion

a. How to ensure adequate utilization of family services? Discussion focused on strategies to engage families, give choice, and build on family-peer relationships. There was also mention of the difficulty of creating the choice process because families may have no experience with the possibilities (e.g., especially for multi-family groups).

b. How to manage and incorporate alternative (i.e., non-clinical) illness models of family members/caregivers? This requires being sensitive to individuals’ and families’ explanatory models of illness.

c. How to ensure that the family service is developmentally appropriate for teens and young adults and takes into account the importance of the developing independence of this age group while acknowledging that family can and really needs to help during this time?

d. How best to facilitate and harness the potential benefit having family members provide peer support to other family members, either by having a family member as part of the team, working with NAMI or other options? In that context, it was also noted that family member supporters or advocates need to be trained and/or have an understanding that the family members around the hopefulness and recovery orientation of these new models.

e. A major challenge or question touched upon was what to do when families are experiencing other difficulties not directly related to the member’s psychiatric disorder (e.g., poverty, homelessness, legal
problems, unemployment, etc.)? Greater psychosocial disadvantages can significantly inhibit important family work to be done. Programs have difficulty knowing what to do, where and how they can help, and where to draw the line.

f. For both children who are under 18 as well as for those who the system considers to be adults, how best to engage first with the youth with psychosis around family involvement and support?

g. Families may play in the overall leadership and oversight of model implementation as a part of community engagement and relevance.
IV. Appendix (Background Information)

The majority of individuals who experience a first episode of psychosis live with or have ongoing contact with family members. However, family members typically know little about the nature of psychosis or its treatment. Furthermore, the pathways taken by individuals and families to accessing effective treatment are often long and circuitous, resulting in a significant build-up of stress and strain on the entire family. Therefore, family intervention aimed at providing support, education, and referral to needed resources should be a core service of all first episode psychosis treatment programs.

This document provides a brief overview of family intervention services for first episode psychosis. First, different formats for providing family services are described, followed by the broad functions family programs may serve. Then, basic principles governing family programs are summarized.

Format of Family Intervention Program

Family intervention programs vary in format across three dimensions: single vs. multiple family groups, home vs. clinic based (or some combination thereof), and degree of inclusion of the individual with first-episode psychosis in family sessions. There are advantages (and disadvantages) to each type of format.

The primary advantage of individual-based family intervention is it does not require multiple participating families to implement. A related advantage is that it may be easier to engage some families of persons with a first episode psychosis in the individual family sessions than in multiple family groups (Montero et al., 2005), as the latter requires some degree of public acceptance of the mental illness diagnosis. The main advantage of multiple family groups is that they provide potent opportunities for support and validation of family members’ (including relative’ with psychosis) experiences. The cost effectiveness of multiple family groups for individuals with first-episode psychosis has also been clearly demonstrated (Breitborde et al. 2009). Most programs that rely on multiple family groups provide some individual single family work as well.

Home-based family intervention, in which family sessions are conducted at the home of a relative, the person with first-episode psychosis, or some other convenient space in the community, has the probable advantage of facilitating the engagement of more families, and more family members, by increasing ease of access compared to clinic-based family services. Although this has not been formally evaluated, the results of one study suggest this may be the case. In this study of multi-episode persons with schizophrenia, two family intervention programs were compared: “supportive” family treatment (educational workshop for relatives only and monthly clinic-based support groups for the whole family) and “applied” family treatment (supportive treatment plus home-based behavioral family therapy, beginning with weekly sessions). Attendance rates at any of the monthly support group meetings ranged across the five sites between 50% and 70% (for families assigned to either the supported or applied condition), while over 90% of the families in the applied condition received some home-based family sessions (Mueser...
et al., 2001). Home visits can also provide the clinician with information about the environment in which the person with first-episode psychosis (and/or relatives) lives, which can yield valuable insights that can inform the family work. One practical solution often recommended in family psychoeducation programs is to offer a combination of home-based family services, early on for the purposes of engaging family members, and to then shift the locus of treatment to the clinic, or to employ a combination of clinic-based and home-based services (Mueser and Glynn, 1999).

Family intervention programs, both for first episode psychosis and multi-episode individuals, generally include the person with psychosis in family sessions. Some programs that use a “survival skills workshop” similar to that originally developed by Anderson, Reiss, and Hogarty (1986) do not include the person with psychosis in the workshop. However, in these programs the individual with psychosis is included in subsequent support group or group-based problem solving sessions, along his or her family and/or other families.

Family members are often the first point of contact with treatment services for first episode psychosis. In addition, there are other situations in which it can be useful for a clinician to meet with family members without the individual with psychosis being present (e.g., when assessing the needs of the family, when discussing something that the person with psychosis prefers not to talk about, when the person with psychosis has difficulty sitting through a family session or has covered the material elsewhere and okay with not participating in one or more sessions). Therefore, family programs for first episode psychosis are usually designed to be flexible in ability to provide services to relatives when the individual with psychosis is not present, although the reimbursement for such services can be problematic.

**Broad Functions of Family Intervention for First Episode Psychosis**

Family intervention programs serve a broad range of functions for families, including case management, collaboration with the treatment team, support, solving problems, and other stress reduction techniques. These functions are briefly described below.

**Case management.** Families of individuals with psychosis who have experienced a recent onset of psychosis are often in midst of experiencing multiple stressors or crises, only some of which may involve the person with psychosis. Socioeconomic strains, health, legal, or marital problems can all interfere with the ability of relatives to play a role in helping the individual with psychosis participate actively in treatment. Helping families access critical resources for resolving or containing these crises can be critical to engaging them in the person’s treatment early on in the program, and over the long-term as well.

**Education.** Family programs for both persons who have experienced a first episode of psychosis or multiple episodes routinely seek to educate family members about the nature of psychosis (and specific disorders, when appropriate) and its
treatment. Teaching is typically done using a variety of different resources (e.g., handouts), based on principles of psychoeducation, such as didactic presentation of information, interactive teaching, eliciting the expertise (i.e., experience) of the individual with psychosis and family members, helping individuals relate information to their own experiences, flexible use of language to facilitate comprehension, and sensitivity to different cultural perspectives on mental illness.

**Collaboration.** Family intervention is provided with the aim of developing a working relationship between the treatment team and the family for the purposes of optimizing treatment and recovery. This collaboration can be reflected in many different ways, depending on the program and the nature of the family, such as: involving family members in treatment planning and reviews, providing family members with access to the treatment team to convey concerns or provide information (e.g., via phone calls, scheduled visits), showing family members that the treatment team appreciates their input and perspectives, and understanding and respecting values that are central to the family.

**Support.** Having a loved one develop a mental illness can be a devastating experience for everyone in the family, especially early on in the course of the disorder, when family members often understand so little about what has happened. Showing understanding, empathy, and support for these difficult experiences is an important part of family intervention, and may facilitate developing a therapeutic relationship. When family services are provided in the context of multiple family groups, opportunities for peer support and validation (between persons with psychosis and relatives and of different families) may also be present.

**Solving problems.** Families coping with a loved one who has recently developed a mental illness experience a multitude of challenges or problems, and are often in dire need of help solving problems, or referrals to critical resources that can address the stressor. Family intervention programs provide practical assistance to family members to help them solve problems when they arise, and referrals to other sources that can provide needed assistance.

**Other stress reduction strategies.** All of the aforementioned functions of family intervention can reduce stress in the family, including: providing critical resources, helping family members understand the nature of mental illness, seeking active and genuine collaboration, showing support and understanding, and providing practical assistance when needed. Additional strategies may also be employed as needed to further reduce stress in families, such as teaching communication and problem solving skills using skills training methods (e.g., modeling, role playing).

**Principles of Family Intervention**

Family intervention programs for people experiencing a first episode of psychosis share a core set of operating principles, many but not all of which stem
from family psychoeducation work for persons with multiple psychiatric episodes. These principles are briefly described below.

**Broad definition of family.** The term “family” is used broadly to refer to people who, according to the person with psychosis, have a close, caring, non-professional relationship with him or her. This includes the usual family members (e.g., parents, siblings, children, spouses, aunts or uncles), as well as partners and friends. This definition can also extend to including other caring individuals, such as a member of the clergy.

**Permission of the individual with psychosis.** Although family members are sometimes involved in helping a relative get into treatment for a first episode of psychosis, their continued involvement in treatment occurs with the permission of the individual with first-episode psychosis. Many persons with first-episode psychosis want their family members involved in their treatment from the outset. However, the advantages of family involvement are not always obvious to everyone. Therefore, it is important for a member of the treatment team (e.g., family clinician) to explain about the nature of family intervention, and to explore with the individual with first-episode psychosis the pros and cons of involving the family in treatment (e.g., How can family support help the person achieve his or her goals?). Such exploration is often effective at harnessing individuals’ motivation to include their family in treatment.

**Engagement at the earliest possible point.** Motivation to participate in family intervention is typically highest during or immediately following a crisis, or another upsetting experience. Reaching out to and connecting with family members as soon as possible after a person has begun to be engaged in treatment for first episode psychosis maximizes the chances of successfully engagement. When family members are instrumental in helping the individual with first-episode access services, this can be accomplished very early by meeting with family members, and maintaining that connection as the individual with first-episode psychosis him/herself becomes engaged as well.

**Flexible, individualized services.** Each family’s needs are unique, and family intervention programs are provided in a flexible manner (e.g., scheduling of appointment times that are convenient for family members, providing specific services tailored to the family), individualized to each family’s needs and preferences.

**Hope-inspiring and resiliency focused.** Families are often bewildered by what has happened to their member, and are frightened of what it means for the person to have developed a psychosis. It is important to provide information about the nature of psychosis and its treatment in a recovery-oriented manner that is both factually accurate and that provides realistic hope for functional and symptomatic improvement, and the ability of the person to live a good quality and contributing life in the community even in face of persisting symptoms or challenges. Observing,
drawing attention to, and further building up resiliency in the family for bouncing back after an episode of psychosis is an important facet of family work.

**Collaborative.** While collaboration in the treatment of first episode psychosis is one function of family intervention, family services are more broadly guided by a collaborative approach in which the treatment team views the family as an important ally and resource with valuable expertise about the person with first-episode psychosis to share with the treatment team. This recognition has the effect of validating and bolstering family members’ own unique experiences and knowledge, and making them feel like valued members of the treatment team. This collaborative approach also breaks down some of the professional hierarchy that can separate the treatment team from the family, and interfere with effective and open communication.

**Informed by the trauma of psychosis.** The experience of psychotic symptoms can be frightening to people who have them, and to the people they are close to in their lives. Treatment can also be anxiety-provoking and upsetting, especially when it involves coercive methods such as involuntary hospitalization, forced medication, seclusion, and restraints. There are other traumatic elements related to the development of a psychotic episode. Observing a close family member decline in functioning, and stop being him/herself can be upsetting, and provoke anxiety as to when (or whether) the person will ever return to his or her former self. Furthermore, learning that one (or one’s relative) has a mental illness can have a devastating effect on one’s identity and self-esteem. Family intervention programs for first episode psychosis are sensitive to these traumatizing effects, and seek to create opportunities to help family members’ process their experiences, and come to a constructive understanding and perspective on what has happened to their loved one and the overall the family.
References


