The OnTrackNY Program
Resources for Working with Families

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I. Family Intervention Program

A. Overview of the Family Intervention Program

Families often play a significant role in the lives of the individuals with first episode psychosis (FEP). Families typically serve as the primary social contact and ongoing social network for persons with FEP, and a majority of persons with FEP are living with family members at the point when psychotic symptoms begin to emerge. As such, family members often have the role of the primary caregiver and advocate for their ill relative, providing ongoing emotional support, help in coping with symptoms, and practical assistance such as housing, transportation, and financial support. In addition, family members are often the ones to initiate and coordinate treatment as symptoms emerge or worsen.

Families may not fully understand the personality and behavior changes they observe in their relative or know how to access services available to help them. Moreover, observing these personality and behavior changes in a family member and experiencing their effects can be traumatic. Anxiety associated with concerns regarding the safety, health, and well-being of their relative is common. Feelings of grief, loss, and, at times, anger and frustration associated with the additional responsibilities placed on them and the challenges they face in attempting to support their relative are common as well. Family members struggle with the possibility that they may need to change their expectations concerning a relative’s functioning, capacities, and future goals, while trying to find ways to help their relative cope with his/her own feelings of grief and loss associated with the effects of an illness (Drapalski, Leith, & Dixon, 2009). Another challenge is coping with the fluctuating insight that persons with FEP have regarding their illness which can lead to limited adherence to treatment. As a result, families of persons with FEP often experience substantial distress.

The involvement of family members in the lives of persons with FEP, as well as the needs of these family members, underscores the importance of including families in the treatment of participants. Family members often spend considerably more time with the person with FEP than the provider does. Consequently, they often have information about their family member’s current and past health, well-being, and functioning outside the treatment setting; potential stressors or triggers that may have been associated with the emergence of symptoms; and personal strengths which can prove invaluable to the provider in treatment planning. Moreover, families can support persons with FEP with their treatment and recovery goals in the community. However, a host of barriers to family involvement have been identified; recent work suggests the need for flexible family services that are specific to families’ particular problems or questions at the time (Drapalski et al., 2008). Recognizing the importance of involving families in treatment, most multi-element treatment programs designed for persons with FEP have attempted to engage family members and have offered families services.

The OnTrackNY program recognizes the importance of family involvement and thus is designed to pay special attention to families and to engage family members in the treatment process as soon as treatment begins. In the OnTrackNY Team Manual, the importance of families is stressed, and
strategies to be used by the team to reach out to and engage families at the start of treatment are highlighted. This manual provides further and more in-depth instruction regarding specific interventions to be used with participants and families around family-related goals.

B. How It’s Done: Our Model of Family Services

The OnTrackNY program provides a family program which offers family services designed to meet the individualized needs and preferences of the participants and families. Efforts will be made to include families (both traditional and non-traditional families and significant others) in all aspects of treatment. This will include initial outreach and engagement efforts and a detailed assessment of participant and family needs. The team will encourage family involvement in treatment planning, treatment decisions, and ongoing care, and will assist family members in forging a collaborative relationship with the treatment team. The primary clinician and other team members will also work to establish an ongoing dialogue with the family and provide them with access to team members in order to answer questions and share pertinent information. In addition, families will be offered more intensive family services including monthly family psychoeducational groups, individual family consultation, and information on community resources when needed. Components of formal nine-month family psychoeducation programs guide our offerings.

Although involving family and supportive others will be an important goal of the primary clinician, we expect that there will be a certain amount of variability in how that involvement is initiated and maintained. In many cases, participants will be interested in family involvement and family members may be involved from the outset of treatment. However, involving family may be more challenging in cases where the participant and/or the family is disinterested or ambivalent about family involvement or when the participant and family members have differing views regarding how involvement should occur. In all cases, involving families will include the following components: 1) participant and family engagement; 2) an assessment of participant and family needs and preferences; 3) treatment planning around family services; and 4) an ongoing evaluation of family needs. However, given that interest in and preferences concerning family involvement may vary considerably, the team should think flexibly concerning when and how these components should be used and should tailor strategies to meet the needs and preferences of each participant and family member. Consequently, although these components are necessary and should be used with each participant/family, implementation of these steps may be fluid or somewhat overlapping (e.g., in cases where family involvement occurs from the outset) or more discrete and structured (e.g., when the participant and/or family is ambivalent about involvement).

Early sessions with participants will include a focus on family and family involvement in care. Either as part of or upon completion of the initial assessment, the primary clinician will engage the participant in a discussion of family involvement. If necessary, the primary clinician will use motivational interviewing techniques and exercises to help individuals identify potential benefits of family involvement and ways that family can support the participant in their recovery. The primary clinician will use shared decision making (SDM) strategies to assist individuals in making decisions regarding family participation (see Team Manual for a description of SDM). For participants who
express interest in family involvement or in cases where family is already involved in a participant’s care, the primary clinician will actively attempt to involve family members in the participant’s treatment planning, treatment decisions, and other aspects of their ongoing clinical care. In a parallel fashion, the primary clinician will meet with family members to develop rapport, to obtain information concerning treatment and recovery goals, and to assess and identify family needs. Based on the participant and family assessments, the primary clinician will provide family members with information on the family services provided by the team and those offered in the community. The primary clinician will then use motivational enhancement and shared decision making techniques to assist family members in making decisions concerning which family services, if any, they would like to receive.

For participants who are under 18 years old, a family member or legal guardian will need to be included in all treatment decisions and treatment planning, regardless of the participant’s preference. Although minors may have less say in whether families are involved or not, to the extent possible, the primary clinician will work with the participant to identify benefits of family involvement and ways in which the family can assist the participant in achieving individual recovery goals. The primary clinician will also assist participants and families in developing and utilizing a shared decision making approach to treatment decisions in an effort to encourage both participant and family input and, ultimately, agreement with regard to treatment goals and decisions.

C. Essential Components of Involving Families

1. Family-friendly Team

OnTrackNY programs must be family-friendly. Providers will have an understanding of the unique needs and challenges of the families of persons with first episode psychosis and skills in working with families. Members of the team will work to minimize potential barriers to family involvement by establishing an open dialogue with families and providing family members with telephone access to the team outside of regularly scheduled appointments in order to share information and answer questions.

Team members will also have knowledge of community agencies, organizations, and services that may be of benefit to families of participants and will provide information on and referrals to these services as needed.

2. Participant Engagement

One of the primary goals of the primary clinician will be to work to engage the participant in care. This process will include a series of discussions to assess the participant’s needs, goals and preferences regarding services to be utilized to help them achieve their goals. For many participants, the discussion of family involvement, potential benefits of family involvement, and preferences regarding family involvement will be part of the ongoing connecting/engagement process. As the primary clinician works with the participant to identify treatment and recovery goals, he or she
should also initiate a discussion of the potential benefits of family involvement and begin to identify specific ways that family members might support the participant in achieving those goals.

**a. Engaging in a discussion of family involvement with participants**

Many participants have limited knowledge concerning how families can be involved in their care and the potential benefits of involving their family in their care. Thus, as part of the engagement process, the primary clinician should attempt to gain a better understanding of the participant’s support network, the participant’s relationship and interactions with family, and the participant’s level of interest in family involvement. The primary clinician educates the participant regarding the potential benefits of involving family (e.g., better course of illness, fewer hospitalizations, better social and work functioning) and the variety of ways that family can be involved in care (e.g., transportation to appointments, assistance with treatment planning, providing support in getting a job or attending school). The primary clinician helps the participant to begin to think about how family involvement could assist him or her in the recovery process and how the participant, family, and team can work together to help the participant better manage his or her illness.

Using a casual, conversational style, the primary clinician uses active listening and careful questioning to initiate a discussion of family involvement with the participant. Questions that can be used to initiate or continue this discussion include:

- So previously we identified a number of goals you have for your recovery. You mentioned X, Y, and Z. How do you think your family might help you in achieving those goals?
  - What might be some other benefits to having your family more involved in your care?
- How might more information/education on the difficulties you are dealing with help your family? How would your family knowing more help you?
- How could your family help you work toward the goals you have for your recovery?
- What do you think your family might need in order to assist you in achieving your goals?
- How has your family supported you in the past? What has been helpful? Not so helpful?
- Have you wanted your family to have a chance to talk with your treatment team? How would contact with the treatment team be helpful for your family? For you?

(Family Institute for Education, Practice & Research, & New York State Office of Mental Health, 2007; Glynn et al., 2010.)

The primary clinician will use motivational interviewing techniques and exercises to help participants identify potential benefits of family involvement and ways that family members can support the participant in his or her recovery (see Appendix). With the information gained from these discussions and exercises, the primary clinician will use SDM techniques to assist participants in making decisions regarding family involvement (see OnTrackNY Team Manual).
b. Addressing participants who do not want or who are ambivalent about family involvement

Some participants may not want their family members involved in their treatment or may be ambivalent about involving family in their care. There may be several reasons for this:

- **Delusions may involve family members.** While there may be some situations in which delusions about family members preclude family involvement until treatment resolves or reduces these symptoms, clinicians should attempt to find common ground with the participant and determine if there are specific ways or certain situations in which the participant feels comfortable having the family involved or which allow for family support despite the delusion. A person-centered approach in which the participant is encouraged to define the terms of family involvement often opens the door for including the family in treatment.

- **Shame.** Mental illness can bring shame on the family and/or the participant. Sometimes the participant wants to protect family from shame or stigma associated with having a family member with a mental illness by limiting the family’s knowledge of and involvement in their treatment. In other cases, participants may be concerned that family members will view them or treat them differently if they knew the full extent of their illness or symptoms. Addressing shame and perceived stigma requires educating the participant. Here it is especially important to be sensitive to cultural beliefs.

- **Trauma.** In some instances, another reason for not wanting family involvement may relate to trauma history within the family. These issues need to be addressed on a case by case basis in a manner that is consistent with legal requirements.

For those participants who are reluctant or ambivalent about involving family in their care, the primary clinician will continue to work with him or her to explore potential benefits of family involvement and ways in which the participant may want his or her family to be involved. The primary clinician will continue to reassess the need for and interest in family involvement throughout the course of the intervention and will work with participants to determine when and how family involvement may be helpful. In addition, participants will have the option of selecting other important people to include in their treatment, including “non-traditional” family members.

The primary clinician can use several strategies when talking with participants who do not want family members involved in their care:

- Identifying one family member to have involved in care, rather than insisting on the entire family. This person would then be the family contact and serve as the point person for the whole family.

- Explaining to the participant how family members can be helpful and relating this to the participant’s personal goals; exploring how the family has been supportive or helpful in other areas of the participant’s life and how this could be applied to involvement in his or her treatment.

- Determining whether a family member can be helpful for particular activities/tasks. The primary clinician can use motivational enhancement exercises, such as decisional balance and values clarification, as a way to structure this discussion (see Appendix). These exercises can help the primary clinician and participant to identify ways in which family members can be helpful and
supportive. The goal is to explore specific ways in which a family member might be useful (e.g., transportation, securing services, etc.). For example: “I realize that you are uncertain about how having a family member involved can be helpful. Let’s talk for a minute about your goals and how a family member could assist you in meeting those goals.” For many participants, goals for family assistance/involvement are not always directly related to treatment (e.g., help remembering to take medication or keep appointments). Rather, some participants will want family members’ assistance with recovery goals such as returning to school/work, developing relationships, and being more independent.

- Revisiting the topic with the participant. Let the participant know that because having family or other supportive individuals can be important to a good recovery in FEP and because the participant may feel differently about family involvement later on, the topic of family involvement is one that will be revisited.
- Considering with the participant whether there is some significant other, such as a friend, extended family member, or other supportive individual, who could be involved in treatment in lieu of family members. This would likely be less workable with younger participants, who will generally need parental consent to have others involved in their treatment. However, for participants aged 18 or over, it may be possible to select a friend or some other individual who is important to the participant and might be helpful. If a participant has such a significant other to involve in care, it is important to discuss the role of this individual, as well as whether, later on, a role for family members can be found in addition to that of the non-family significant other.

3. Family Engagement

It is rare that family members don’t want to be involved in treatment in some way. Psychosis is disruptive to the family, and family members are generally in need of guidance and may have lots of questions. They are often in shock and overwhelmed. Family members may need education and information about psychosis and treatment, as well as practical advice, including guidance in how to talk to the participant and information on the mental health treatment system, the role of treatment providers, and how to access available services and resources.

If the participant is interested in family involvement, the primary clinician should continue active engagement of the family in the participant’s care and should involve the family in initial treatment planning and coordination. In many cases, the primary clinician will have begun to establish a relationship with the family during initial meetings with the participant and as part of the needs assessment. In an effort to continue to build rapport and engage the family, the primary clinician should engage in active outreach to families after the initial contact has been made. As part of the engagement process, the primary clinician should provide information concerning his/her background, discipline, role on the treatment team, and planned interactions with the participant and family. This includes discussing the primary clinician’s primary role in the participant’s treatment and education about how the team is committed to working with the participant and family members to address their needs. The primary clinician should clarify that he/she will serve as the primary contact for the participant and family and will provide ongoing support, education, and assistance as needed. In addition, the primary clinician should indicate that often, families of individuals with psychosis may have additional needs and preferences concerning involvement and that the primary clinician will also
be working with the family to identify their own educational and support needs and preferences regarding how they would like to be involved in the participant’s care.

At the start, families often have misinformation about psychosis and why their family member is experiencing it. The primary clinician may need to address the following:

- Family members often experience guilt. The primary clinician may need to help family members understand that they did not cause the illness and the illness is not their fault.
- A diagnosis of schizophrenia can be viewed as a "life sentence." Family members of participants with FEP often have no information about psychosis. The primary clinician can educate them that different people have different courses of illness, and that there is good reason to be hopeful that early treatment will lead to better outcomes. It is also critical to convey at the first family encounter the concept of recovery and how it is possible to have a full and meaningful life outside of the mental health system – work, marriage, community involvement, parenting, etc. — even with ongoing symptoms.
- Expect and allow for a wide range of emotional responses (e.g., grief, anger, denial, etc.) and changes in these responses over time. All of these responses are normal reactions.
- Family members should be encouraged to articulate any fears they may have.

4. Balancing Goals of Participants and Families

At the start of treatment, the primary clinician will have to balance the needs of both participants and family members. In some cases, the goals of participants and family may diverge. In addition, illness acuity can impact the participant’s judgment, especially at the beginning of treatment. A strategy for initiating and continuing a forum for discussion is needed. This forum can be implemented as part of the Family Engagement and Needs Assessment (see Appendix). This assessment can be done with the participant and family members present, or it can be done separately if the participant wants to talk without family members present or vice versa. The primary clinician can then highlight the areas in which participants, families, and the treatment team agree. Some programs, such as the early intervention program at UCLA, have found that participants and families tend to agree in two important areas:

- Resuming “normal life”
- Improving the participant’s school, work, and social functioning

Anything involving symptoms is often much more contentious. Once the needs assessment is done and some preliminary goals are agreed upon, it is important to review and revise the needs assessment at regular intervals. This is because goals and feelings shift over time: what took precedence at the beginning of treatment may have resolved or improved, and participants’/family members’ different areas of need may have emerged.
D. Assessing Family Needs and Preferences

1. Participant Assessment

Part of the primary clinician’s ongoing efforts to assess participant needs should include an examination of the participant’s relationships and interactions with family and other supportive individuals and the potential benefits of involving family in the treatment process. The primary clinician should help participants to identify key people who are currently involved in their care, describe their relationship and the nature of their interactions with their family (both positive and negative), and discuss their perception of their families’ thoughts or understanding of their difficulties and of mental health treatment.

Questions that can be used to assess the participant-family relationship include:

- Tell me about your family. Are there any other individuals you consider to be “like” family to you?
- Are you currently living with your family? How is that going? What are some good points about living with them? Any problems with living with them? If not living with them, why not?
- What are your family’s thoughts about/understanding of your difficulties? What led up to you needing to get treatment?
- How does your family feel about you getting mental health treatment?
- What is your family’s understanding of the goals you have for your recovery?

(Glynn et al., 2010).

Once the primary clinician has a general understanding of the participant-family relationship, he or she engages the participant in a discussion of how family involvement might serve to assist the participant in achieving their recovery goals, as noted above in the section on participant engagement.

2. Family Needs Assessment

The focus of the family needs assessment is to identify the needs of the family and how these needs can best be met. Although in many cases the assessment will be conducted with the participant present, the assessment may be conducted with the family only. In these cases, it may be helpful to meet briefly with the participant and family members together to discuss the outcome of the family needs assessment.

If the primary clinician has had limited or no previous contact with the family, initial conversations should include introductions and the collection of contact information. The primary clinician should provide education on ways in which families can be involved in ongoing care and can support their relative in recovery. This should include ways that the family can work collaboratively with the treatment team by being involved in treatment planning, helping the participant make decisions...
about medication, etc., as well as ways that family members can obtain education and support for themselves.

The primary clinician should highlight the fact that the goals of the family needs assessment are to talk about ways to involve the family in the participant’s care, to discuss the family’s needs, and to identify ways to meet those needs. As in the participant assessment, the primary clinician should use active listening and careful questioning to initiate a discussion of family involvement with the participant present. The primary clinician should prompt the participant to discuss his or her goals and how the participant feels that family members could assist him or her in achieving those goals:

“I spoke with X earlier to discuss how her family could be more involved in her treatment and assist her in her recovery. X, when we met you identified some initial goals and we discussed ways in which your family might be able to help you achieve those goals. Tell us a little bit about what those goals were …”

The primary clinician should elicit and discuss family members’ reactions to the participant’s goals and encourage the family to discuss their own needs and how they would like to be involved in the participant’s care. Additional questions that can be used to assess family needs include:

- What are your thoughts about X’s current goals? How might you be able to help with those goals?
- Are there any problems or concerns you have about X and her treatment?
- What do you think you might need in order to help X with these problems/goals?
- Any other needs/concerns that you have?
- Are there other things you would like to be different/better for X?

(Family Institute for Education, Practice & Research, & New York State Office of Mental Health; 2007; Glynn et al., 2010).

If a participant or family member is having difficulty discussing his/her needs or concerns, or does not mention important information that was previously discussed, the primary clinician should attempt to facilitate a discussion using information from previous sessions and contacts to highlight ways that the family has supported the participant in the past and how that might translate into ways that the family can support the participant with current goals. The primary clinician also points out similarities between participant and family needs and how the family could help support the participant with those needs.

E. Treatment Planning around Family Services

Once the needs and preferences of the family have been determined, the primary clinician can work with the participant and family to decide which family services would best address the family needs and outline steps for involving the family in the participant’s ongoing care.
1. Discussion of Ways That Needs Can Be Addressed

The primary clinician should offer suggestions of ways family needs can be addressed based on his/her knowledge of the family needs and of services available to the participant and family. This discussion should include a brief description of each potential option that could be used to address the family need/goal and how that service may help to address the need/goal. These options may include:

- Ongoing, regular meetings with the primary clinician: Ongoing, regular weekly or biweekly sessions with the primary clinician may be offered. The specific focus of these sessions may vary depending on the individual family needs; however, generally speaking, these sessions will serve to provide ongoing engagement, communication, education, and support.

- Psychoeducation: All participants and family members should be offered education on psychosis, its treatment, etc. Provision of quality information that families/participants can use on a need-to-know basis is very important at the first encounter and throughout the course of treatment. Family members should be provided with handouts (see Appendix) that explain in simple terms what psychosis is, what treatments are available, and what family members can do to assist their loved ones with psychosis. The primary clinician can also recommend online resources, basic pamphlets and DVDs if available. In addition, all participants/family members should be invited to attend the monthly family educational groups. Individual educational sessions may be offered as needed or in cases where the participant and/or family are not interested in or able to attend the monthly family educational groups.

- Monthly family psychoeducational groups: Group educational sessions for participants and family members are held once a month, led by the primary clinician. Sessions include the presentation of information/education on topics relevant to participants and family members, and group problem-solving around specific problems identified by group members.

- Peer-led educational/support programs: Information on and referrals to other community-based, peer-led family programs (e.g., NAMI’s Family to Family or other education/support services) may be provided.

- Brief family consultation: Brief family consultation may be offered in order to address a specific problem or a particular need, when the problem cannot be addressed in the context of the meetings with the primary clinician. The consultation will be conducted by the primary clinician and may include focused skills training on conflict resolution, compromise and negotiation, problem-solving, and/or communication skills.

- Limited family contact: Limited family contact involves less intensive contact/involvement than that offered in the ongoing meetings. In these circumstances, the nature and extent of contact with the family will vary substantially from family to family, largely dependent on their needs and preferences. This may involve weekly, biweekly, or monthly telephone calls, or intermittent sessions with the primary clinician to check in regarding family needs/concerns and to provide support on an as-needed basis.
2. Identification of Next Steps and Development of a Plan for Implementation

Once potential options have been discussed, the primary clinician works with the participant and family members to decide on what the next steps for involving family should be. In some cases, these may involve a few of the options available to families (e.g., regular meetings with the primary clinician, monthly family psychoeducational groups, etc.). If the participant and family disagree on what the next step should be, or if the participant and family are unsure about what step to take, the primary clinician should help the participant and family members discuss the pros and cons of each option and help them come to a consensus on their next step. Together, the primary clinician, participant, and family members should work to develop a plan for completing the next step (e.g., scheduling an appointment for the participant and family to meet with the primary clinician, scheduling an appointment for family consultation, agreeing on a family member contacting NAMI, etc.).

F. Re-evaluation of Family Needs

Family needs often change over time, depending on a variety of factors such as the current family situation, stage of illness and recovery, and the family member’s relationship with the ill relative. Even after the initial family needs assessment has been completed and the family has been connected with the appropriate services, family needs should continue to be assessed on a more informal, ongoing basis. If, while working with participant and family, the primary clinician determines that the needs of family members have changed and require additional services, the primary clinician will work with the participant and family to connect them with services to address those needs. In addition, a more formal re-evaluation of family needs, similar to that which was conducted at the beginning of treatment, will be conducted as part of the participant’s ongoing treatment planning. Information concerning family involvement and family services obtained from this assessment will then be incorporated into the participant’s treatment plan and, if necessary, the primary clinician will help connect the family with additional services.

G. More Intensive Interventions and Ongoing Support for Families

The primary clinician will provide ongoing communication, support, and education to all families; however, in some cases, families may require more intensive services in order to meet their specific needs. There are several additional options for more intensive family intervention, including monthly family psychoeducational groups, family consultation, and referral to community-based family services/resources.

1. Monthly Family Psychoeducational Groups

All participants and families will be encouraged to participate in monthly family psychoeducational groups that are organized and facilitated by the primary clinician. The team leader will attend and co-facilitate the first few monthly groups, and other members of the treatment team may attend and
present information depending on the topic. Further information on these groups is provided in the Recovery Coaching Manual.

The Monthly Family Educational Groups accommodate approximately 3-8 families, are offered monthly, and are coordinated by the primary clinician. Each group lasts approximately 1 ½ hours and includes presentations on informational and educational topics particularly relevant to families of clients with first episode psychosis, as well a group discussion of any problems or issues that group members may be facing. Each group begins with an educational component that lasts for the first half of the group. The first four group topics are ones that have been identified as important for most clients and families: (1) understanding psychosis, (2) the etiology and causes of psychosis, (3) recovery from psychosis, and (4) treatment for psychosis. Subsequent group topics will be chosen by group members at the end of the monthly group session based on the group members’ current needs and preferences. Topics may include crisis prevention and planning, communication skills, setting limits and boundaries, co-morbid substance abuse, transition and discharge planning, etc. The second half of the group includes a group discussion of problems or issues that family members may be facing. The primary clinician will facilitate this discussion and help group members resolve any issues or concerns. When appropriate, problem-solving and communication skills can be modeled within the group to help members resolve immediate issues, address communication concerns, and provide additional opportunities for skill-building.

Admission to these groups is ongoing, and families can join whenever they want and attend as many as they want. Outlines and materials for several Monthly Family Educational Groups are provided in the Appendix.

2. Brief Family Consultation

It is to be expected that family-specific issues may arise that need to be addressed outside of the more standard family interventions that are provided. Examples include economic pressures, medical issues, divorce, legal issues, and interpersonal conflicts that are not specifically connected to the participant. Each of these issues can have a profound impact on the family and deleterious consequences for the participant. The primary clinician can work one-on-one with a family to address a specific problem or a particular need utilizing recover coaching strategies. These sessions could include focused skills training on conflict resolution, compromise and negotiation, problem-solving, and/or communication skills. The goal of these consultations is for the primary clinician to teach targeted skills to help reduce stress and conflict, such as:

- Communication skills, including active listening, expressing positive and negative feelings, and compromise and negotiation
- Problem-solving skills, including identifying a problem, generating possible solutions, evaluating the pros and cons of each solution, and making a decision concerning which solution to implement
• These skills can then be applied to current problems experienced by the family within the sessions. Examples of appropriate situations for brief family consultation include:
  • A participant is having trouble using skills he/she is learning to express feelings to a parent (e.g., the participant wants to tell his parent to stop “reminding” him about taking his medication)
  • A participant’s parents are having trouble communicating with each other about their child’s situation and condition without yelling
  • A participant and his/her family member have a problem they don’t know how to solve (e.g., the participant wants to try a new activity and a parent objects to this)

This consultation should be focused, specific to a particular problem or skill, and brief, lasting 1-3 sessions. Multiple rounds of consultation may be warranted in some circumstances. For example, if a client is working with the primary clinician on social skills, it might be useful to have a parent attend periodically for a consultation in which the client uses the skills he/she is learning and the parent learns what social skills training is about and the client’s goals for learning and implementing new skills. It is important to note that these consultation are not family therapy per se, they are not the appropriate place to work out issues related to complex family dynamics or difficult problems. The goal of these consultation sessions is to teach and practice skills that can be used to improve clients’ functioning or family members’ interactions with or about the client.

Prior to the first consult session, the primary clinician, in collaboration with the team, should map out a plan for the 1-3 consult sessions and be ready to start training in the first session. In the first consult session, the primary clinician can discuss the role of the consult and present the plan developed with the team, asking the client/family for their thoughts and ideas in order to incorporate these into the plan. Once the primary clinician and the client/family members agree on the plan, training can begin. Content for these consults can be taken from the SST or Coping Skills outlines presented above.

3. Linking Families to Community-based Services and Resources

In addition to the family resources offered by the team, the primary clinician should provide information on other agency-based or community-based family services available to the participant and family. These include family services, educational workshops/seminars, or support groups offered at the participant’s clinic or other local mental health agencies or programs, and education and support services offered through NAMI. The primary clinician should discuss these options with the participant and family members and work with them to determine if any of these services would meet their needs. If family members are interested in community-based services, the primary clinician will assist the family with connecting to these services.

H. Special Situations Involving Families: Violence

Aggression and violence can be common in FEP. Aggression can include verbal aggression, physical aggression, and/or violence. Violence in FEP has been found to be associated with male gender, alcohol and drug misuse, involuntary hospital admission, poor insight into illness, and past violence.
Several studies have found that violence and aggression remain fairly common over the first two years following diagnosis and can be an important factor in re-hospitalization.

Violence must be assessed by the primary clinician as part of the needs assessment that includes family members. If needed, the primary clinician can discuss violence and aggression separately with family members and help them develop a plan for how to respond and react in volatile situations. This plan can include specification of warning signs of violence, use of within-family coping strategies, and contacting professionals and agencies when within-family strategies do not work. It is important that the primary clinician and the family work out the timing for the sequence of problem-solving so that families understand not to wait too long before calling professionals/agencies for assistance. The primary clinician and the family members should include the participant in this process if possible. Importantly, violence – including verbal aggression and physical aggression – can also be directed at the person with FEP. It is not uncommon for people with FEP to experience violence in inpatient units (take downs, restraint) and by police. There may also be instances in which a person with FEP may be criminally victimized or may be the target of verbal and/or physical aggression from immediate family or extended family members. Violence directed toward the individual in FEP must be assessed, as it may have an impact on how the family works together and the extent of contact that the participant wants to have or not have with family members.
I. Family Intervention Program Materials
The Family Voice: What Do Families Experience?
Joyce Burland and Laurie Flynn

“It’s hard to overstate the devastating impact of psychosis on the family. Each person in the family will have their own reaction but nobody will be unaffected. Whether psychotic symptoms manifest insidiously over many months or suddenly in only a few weeks, they create an environment of crisis, confusion, grief and fear. Imagine seeing your son or daughter, sibling or spouse become quite literally a stranger. The formerly cheerful person may become moody, withdrawn and nearly silent. The warm and helpful daily contributor to family harmony is now an angry, suspicious and accusatory person. There may be discussion of improbably weird ideas and conversations with taunting voices only he or she can hear. The regular world, and the rhythm and routine that lends structure to our day, seem very far away. Trying to understand and manage increasingly erratic and frightening behavior totally dominates family life. For some caregivers the home becomes a prison they can’t leave unless another family member is “on duty” with the unstable and sometimes hostile consumer. Other family members are neglected and overwhelmed in the chaos. Everyone feels helpless, exhausted and somewhat desperate. Families are emotionally isolated and may disagree about what to do, bringing another layer of tension to the household. Life with a psychotic family member feels a lot like riding on a rollercoaster at breakneck speed – while blindfolded. Days of near normal calm are suddenly punctuated by terrifying threats of harm to self or others, or angry episodes triggered by imaginary enemies. Absolutely nothing seems to make sense and nothing can be predicted. It takes a tremendous amount of energy and advance planning to manage mundane thing like business travel, shopping for groceries, routine house and yard work, and running errands. No longer can you anticipate and enjoy family birthdays and other social events. As the weeks and months drag on amid deepening distress, families feel growing sadness, grief and guilt. How could this happen to our loved one?? What does it mean?? Will he or she ever get better?? Will our old life ever be regained? Over time and after many emotionally draining crises, family members may begin to lose all hope.”
“In the wake of intense trauma and life dislocation brought on by a psychotic break, families need humane and gentle guidance to see them through the shock and fear they experience. Three things will matter the most to them: understanding, compassion and respect. Understanding must center in a provider’s clarity regarding the clinical normalcy of families’ trauma responses, so they are not miscast as problem families on the basis of their behaviors. Shock may look like maladaptive detachment, but it is not; forgetfulness must not be confused with disinterest; anger protects against the grief of shattered dreams; obsessive worry may seem intrusive, but it is unavoidable in traumatic circumstances. Misinterpretation of these normative family reactions is common in the field, leading to negative judgments which are fundamentally iatrogenic in trauma care. Compassion provides the most nourishing and beneficial approach, letting families know that you empathize with their sense of desperation, their need to ward off painful recognition, and their seemingly irrational belief that everything will go back to the way it was. Family strength may not be readily apparent in this early stage of adaptation to trauma, but it is there. The key to liberating it is respect, defined as a continuing and growing appreciation of the family’s expertise in knowing the circumstances and resources of the person they love who is struggling forward, their commitment to care in the face of heart-rending reversals, and their willingness to forfeit anything that stands in the way of their loved one’s well-being. Families will unite with the treatment team when given understanding, compassion and respect. When people are traumatized, let them be and just give them what they need.”
Family Engagement and Needs Assessment

Participant Name: __________________________ Medical Record Number: ___________

QUESTIONS FOR PARTICIPANT:

Who is in your family?

What is your family like? What are your family relationships like?

Who are you closest to? Are there people not related to you, who are like family to you?

How have things been for you and your family lately?

What is your family’s understanding of what you’ve been going through lately? How do they feel about you getting mental health treatment?

Do you have any worries about your family?

What do you think your family might need at this time? How might having them involved in your treatment with us be helpful for them, and for you?

Here are some of the ways our team can help your family; which options would be best for you and your family?

☐ Your family member(s) can come to your appointments with you, and we can all meet together sometimes.

☐ We can meet with your family member(s) separately, without your being there, if you prefer.

☐ We can call your family members if we have important information to share with them, and they can call us if they have information to share with us.

☐ We can meet with your family member(s) at their home if it’s too difficult for them to come to our office.

☐ We can invite your family to our monthly family groups, where they can meet other families, learn more about our program, and get information, help and support.

☐ We can let your family know about resources in the community that might be helpful to them.

☐ We can work with your family to help them learn specific skills, such as good communication, problem-solving, conflict resolution, and crisis prevention.
## Questions for Family Members

- How do you understand what your family member has been going through lately?
- What are your thoughts about your family member’s current goals?
- How might you be able to help with those goals?
- Are there any problems or concerns you have about your family member and his/her treatment?
- What do you think you might need in order to help your family member with these problems/goals?
- Are there any other needs/concerns that you have?
- Are there other things you would like to be different/better for your family member?
- How can we be helpful to you and your family member?

### Notes:

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**Clinician Signature:** ____________________________ **Date:** __________
FAMILY MEETING: ________________________________ DATE: ____________

Who is attending the initial family meeting?

How has the family been coping with the participant’s experiences?

What is the family’s understanding of the participant’s difficulties?

What led to the participant getting mental health treatment?

How does the family feel about the participant getting mental health treatment?

What are the family’s questions, concerns, and needs at this time?

What does the family think about the participant’s goals and prospects for recovery?

- What services are the family interested in receiving?
  - Attending appointments with the participant.
  - Meeting with team members without the participant present, if the participant agrees.
  - Staying in touch with the team through telephone contact.
  - Home visits from the team to discuss the participant’s treatment and progress.
  - Attending monthly family groups to meet other families, learn more about our program, and get information, help and support.
  - Learning about resources in the community that might be helpful to them:
    - NAMI
    - Other Self-Help/Support Groups: ___________________________
    - Other: ____________________________________________________
  - Family Consultation with the team’s Recovery Coach to work on specific skills, such as good communication, problem-solving, conflict resolution, and crisis prevention.
  - Other: ____________________________________________________

Notes:

______________________________________________________________

______________________________________________________________

Clinician Signature: ________________________________ Date: __________
**Family Involvement Decisional Balance – Instructions**

This task involves identifying reasons that the participant might want his/her family to be more involved in his/her treatment, identifying specific ways in which he/she would like family to be involved, and helping strengthen his/her commitment to involving family. The participant is asked to complete the modified decisional balance form. With coaching from the team leader, the participant lists both the potential benefits and the downsides of family involvement using this sheet. The team leader should prompt the participant to complete the form. However, the team leader can use information gained from previous discussion/assessments to help inform the exercise.

**Instructions:**

“I want you to have the chance to think systematically about the pros and cons of involving your family in your care. Let’s look at this form where we can list your reasons. What would be all the good points of having your family involved in your care?”

Have the participant fill out the form. As the participant identifies potential benefits to having family involved, the team leader may want to query the participant as to how a particular outcome may also benefit them in terms of treatment and recovery if this is not clear.

Once the participant has listed the positives to family involvement, the team leader should prompt him/her to list the negatives

“What would be the negatives of having your family involved in your care?”

Have the participant fill out the section regarding the negatives.

“Ok, now I would like you to go back and circle the most important reasons to have your family involved and the most important reasons not to have your family involved. Which reasons really count?”
Family Involvement Decisional Balance Form

Good Outcomes from Having Family More Involved in Care:
1. 
2. 
3. 
4. 
5. 
6. 
7. 
8. 
(Examples: relatives might feel calmer if they know the doctor, might be able to manage medication better, relatives might be able to help me more if I have a symptom flare-up, relatives might be able to help me reach some of my goals)

Challenges from Having Family More Involved in Care
1. 
2. 
3. 
4. 
5. 
6. 
7. 
8. 
(Examples: might risk privacy, might feel too controlled, might lead to more fights)

This exercise is from the Family Member Provider Outreach Manual:
Values Clarification Exercise

The goal of this exercise is to help participants clarify their personal values and how they relate to family involvement in care, through the use of the values clarification exercise. The team leader first provides three pieces of paper labeled “Very Important,” “Moderately Important,” and “Little or No Importance” at the top. Participants are given the list of values cards and asked to sort them into three piles (very important, moderately important, little or no importance). These values cards include concrete issues of interest to most persons (e.g., “getting along with my family”) and those of special relevance to persons with serious psychiatric illnesses (e.g. “staying out of the hospital,” “keeping symptoms to a low level,” “not embarrassing myself in public”). If a participant says “I don’t know,” the team leader prompts with, “Make your best guess.” If this does not help the participant make a choice, the team leader can make a “Do Not Know” category.

“I want to understand what is really important to you in life. Here is a set of life values cards. They describe experiences and values that are important to some people but not to others. Would you please read each one and then put in the pile which reflects how important that value is personally, to you?”

After all the cards are sorted, the team leader then takes the pile of most importance and discusses how family might be related to each value by asking the participant:

“How do you think your family being involved in your care and getting more support might be related to (this value)?”

Life Values for the Cards

- Living independently in my own apartment or house
- Paying my bills
- Getting along with my family
- Having a fun social life
- Having friends
- Being self-sufficient
- Meeting new people
- Having a partner
- Dating
- Staying out of the hospital
- Feeling proud of myself
- Having nice clothes
- Having a nice car
- Not embarrassing myself in public
- Having something productive to do with my time
- Having extra money
- Keeping my symptoms to a low level
- Having a hobby
• Helping others
• Making others who care about me proud
• Recovering from my mental/emotional problems
• Reducing stress
• Having a strong religious/spiritual life
• Being in good physical health
• Creativity
• Going to school
• Working

Important values and their relation to family involvement are noted on a separate sheet of paper by the team leader. Values that are inconsistent with family involvement are discussed with the client. For example, the client may value “being self-sufficient” and believe that family involvement in care may conflict with this goal. The team leader helps the client resolve the discrepancy between the value and family involvement. For example, in the situation just mentioned, the provider would ask the participant if he/she has known of self-sufficient individuals (perhaps friends or relatives) who still consult with others about health decisions.

This exercise is from the Family Member Provider Outreach Manual:

Motivational Enhancement to Increase Commitment to Family Collaboration and Resolve any Potential Ambivalence about Family Involvement

Motivational Interviewing
Motivational interviewing is a client-centered, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence. Motivational interviewing is designed to help clients identify specific ways in which family involvement could be helpful, explore ways they would like family to be involved or not be involved, and to resolve any ambivalence they may have regarding having their relatives working with the treatment team. The session should be conducted in a casual, conversational style. Rather than utilizing confrontation, the provider uses active listening and careful questioning to assist clients in moving toward a greater commitment to having their relatives collaborate in their care. Interactional style is a critical component of motivational interviewing. The overarching principles of interpersonal interaction in this session are as follows:

Principle 1: Express Empathy.
- Acceptance facilitates change.
- Skillful reflective listening is fundamental.
- Ambivalence about change is normal.

Principle 2: Develop Discrepancy.
Change is motivated by a perceived discrepancy between present behavior and important personal goals or values. Whenever possible, the client rather than the provider should present the arguments for change.

Principle 3: Avoid Arguments and Direct Confrontation.
- Avoid arguing for change.
- Resistance is not directly opposed.

Principle 4: Roll with Resistance.
- New perspectives are invited but not imposed.
- The client is a primary resource in finding answers and solutions.
- Resistance is a signal for the provider to respond differently.

- The client’s belief in the possibility of change is an important motivator.
- The provider’s own belief in the person’s ability to change becomes a self-fulfilling prophecy.
- While the format is semi-structured, all interactions should follow a conversational style utilizing the OARS interaction format:
  - Ask Open-Ended Questions
  - Affirm Positive Statements
- Listen Reflectively – continuing the client’s statements, guessing feelings, moving to a deeper level of feelings (amplified reflective listening)
- Summarize what the client has said

The goal is to establish a collaborative relationship with the client wherein he/she works with the provider to help identify the benefits to having family involved and how they would like their family involved, develop a stronger commitment to working with the treatment team, and, if necessary, resolve any ambivalence about the team being involved with the relative. The general format for interaction is as follows: the provider asks open-ended questions, the client responds, and the provider summarizes the response, utilizing an empathic stance. Summarizing, restatements, and affirmations are crucial. The provider should monitor the number of direct questions asked and avoid asking more than two questions in a row.

In all conversations, the provider strives to support “change talk,” which works against maintaining the status quo (disengagement). The key elements of change talk include helping clients:

- Recognize disadvantages of the status quo
- Recognize advantages of change
- Express optimism about change
- Express intention to change

Many questions can be used to elicit change talk when working with a client. Some examples are listed below.

**Examples of Open-Ended Questions to Evoke Change Talk:**

**1. Disadvantages of the status quo**
- What worries you about your current situation?
- What kinds of difficulties have your problems brought to your family?
- Have you noticed your family struggling with concerns about you?
- Have you noticed your situation stressing out your family?
- What difficulties or hassles have you had in relation to your current situation?
- How is your situation stopping you from doing what you want to do in life?
- What do you think will happen if you don’t change anything? Would involving your family offer another opportunity for change?

**2. Advantages of change**
- How would you like for things to be different?
- What would be the good things about your family helping you get a better handle on your situation?
- What might be good about your family understanding your situation a little better/getting more information on how they might support you? If you could make this change and you could get better immediately, by magic, how might things be better for you?
- Do you think your family might benefit from more support/information?
• What would be the advantages of having your family work more closely with your doctor and your treatment team?

3. **Optimism about change**
   • What encourages you to think that family collaboration might help?
   • What do you think would work for you, if you decided to try to be more open to your family participating in your care?
   • How confident are you that you can make this change? What would make you feel more confident?

4. **Intention to change**
   • What are you thinking about encouraging your family to be more involved in your care at this point?
   • I can see that you’re feeling stuck at the moment. What’s going to have to change for you to stay involved? What do you think you might do?
   • How important is improving your situation? How much do you want to do this?

As clients respond to these questions, the provider’s goal is to reiterate statements they make supporting positive change, while acknowledging impediments and discouragement. The provider should utilize frequent summaries and restatements of clients’ input. This technique both assures clients that they have been heard and helps clarify the specifics of the client’s comprehension of the situation.

This handout is from the Family Member Provider Outreach Manual:
Special Issues in Substance Abuse Treatment in First Episode Psychosis Family involvement. Family members will likely have information regarding a client’s drug or alcohol use and want to be involved in decisions around substance use and treatment, especially for young clients. The ways in which family members will work together with clients and treatment providers will need to be discussed and negotiated at the start of substance abuse treatment. The primary clinician may need to coordinate and streamline efforts with families around substance use and incorporate these into other family work that is taking place. A specific area that the primary clinician can work to address is to educate families about the stages of change model, and how family members are often at a different stage regarding substance use than the client. This may help family members to be more understanding about the process of change and why behavior change happens slowly.
Preparing for Treatment After the Team
Helping the family prepare for transition to care in the community

The primary clinician can assist the family during the transition to community care in different ways. First, the primary clinician can deliver a monthly family education group on transition (see Monthly Family Group Materials in the Appendix). The primary clinician can either hold the group in the regular family group time or convene a special family group to discuss transition issues. If family members are interested in several transition-themed groups, the primary clinician can arrange to have several groups on this topic. Second, if a particular family needs extra assistance with planning for the transition, the primary clinician can do the above activities with family members and clients together. For example, if the family and the client need to visit a new agency in the community, the primary clinician can accompany them on this visit.

Another example would be working with the family to review “tools” for communicating so that when they are no longer meeting with the team, the family can talk to each other about treatment- or illness- or recovery-related issues. This could involve writing up a coping skills plan for the family in the same way the primary clinician does with the individual client – a generic coping plan that the family can use for most situations plus a specific plan for any particular situation that the family is predicting might be difficult to deal with or talk about together.
Family Involvement in Safety Planning

Completing Safety Planning
Developing a safety plan with participants and families is a key activity at the beginning of treatment. All participants will have a safety assessment during their initial contact with the primary clinician and will complete a safety plan with the primary clinician. Those participants who are at high risk of suicide or self-harm (defined as those with a history of suicide attempts or self-harm or those who report frequent suicidal ideation) will complete a safety plan in the same session as the safety assessment; those participants assessed at lower risk should have a safety plan completed within their first month of participation in the OnTrackNY program. Two strategies make up the safety planning intervention: safety planning, and attention to treating psychotic symptoms. Safety planning is the first, short-term stage of intervention (to be conducted by the primary clinician), and antipsychotic medication change is the second, more long-term component (to be addressed by the psychiatrist). For more details, see the Safety Planning section in the Team Manual.

Tailoring Safety Planning for FEP
There are several ways in which development of the safety plan must be tailored for FEP:

Involve family members. Family members should be involved in the development of the safety plan. Family involvement is important for several reasons. Family members can help with concrete ideas to use in the safety plan, especially when the participant is symptomatic and may be unable to suggest practical coping strategies that can be used to maintain safety. Family members can also serve as contacts who can watch for concerning signs such as increased isolation, depression and substance use and alert the treatment team of changes in mood that might precede attempts at self-harm. Family members should be allies in identifying external messages of hopelessness and chronicity, whether via a drug company advertisement, a Hollywood movie, a TV ad or newspaper article. They should discuss exposure to these messages, particularly when the person with FEP was present, and openly identify to the participant the message as lacking support from scientific studies on recovery. In addition, because research shows an increased risk for suicide in individuals with high expectations for achievement, these expectations must be addressed, and the clinician should work to enlist family members to express to the participant their understanding of the illness and their acceptance that expectations may need to change, either temporarily or permanently. The family member can communicate to the participant that his/her family understands why the participant is having difficulty and that the family does not hold the participant responsible.

Additional Information About Safety Planning (Family Related)
Contacting family members or friends who may offer help to resolve a crisis.
This step involves planning for action to be implemented when internal coping strategies or socializing with others does not alleviate the crisis. Participants may choose to inform family members or friends that they are experiencing a suicidal crisis. However, given the complexity of deciding if participants
should or should not disclose to others that they are thinking about suicide, the clinician and participant should work collaboratively to formulate an optimal plan. This will include weighing the pros and cons of disclosing their suicidal state to a person who may offer support. Thus, participants may choose to enlist individuals who may help to distract themselves (as indicated in Safety Planning Step 3), as well as individuals who will assist in managing a suicidal crisis as indicated in Safety Planning Step 4. For both of these steps, participants should be asked about the likelihood that they would contact these individuals and to identify potential obstacles and ways to overcome them. In developing safety plans with participants with FEP, many of whom will be late adolescents, it may be important to identify key adults to participate in the plan. Adolescents will determine which family members or other responsible adults are more likely to have a calming and effective coping influence. Some family members, particularly those with whom the adolescent has frequent conflicts, may not be good candidates to enlist to participate in the safety plan. Family members can also be coached to help the participant use the safety plan. In addition, special care must be taken when helping the participant identify individuals other than family members who may offer support and distraction from the suicidal crisis.
References and Recommended Readings

For a complete list of Recommended and Suggested Resources for OnTrackNY, please consult the Center for Practice Innovation’s Learning Management System:
http://practiceinnovations.org/

Suggested reading and resources

**Topic: Family Involvement/Support/Education/Interventions**

**Articles:**


**Manual:**
APPENDICES

1. Monthly Family Group Materials ........................................................................................................... 35
2. Family Involvement Decisional Balance – Instructions ........................................................................... 110
3. Values Clarification Exercise ................................................................................................................... 112
4. How Can Family Members Help Handout .............................................................................................. 114
5. Family Consultation Handout .................................................................................................................. 115
**Monthly Family Group Materials**

**Introduction to First Monthly Family Education Group**

I. **Introductions and Welcome**
   A. Describe role of the primary clinician on team.
   B. Introduce any other team members who are present.
   C. Have participants introduce themselves. Suggest they say their names, where they are from, and how long they have been working with the team.

II. **Describe the Monthly Family Meetings**
   A. **Purpose.** The purpose of these meetings is to provide information to family members about topics related to psychosis and its treatment. We have found that often family members are eager to learn about these topics so they can better understand and help their loved ones who are experiencing psychosis. It can also help to answer some questions they have about psychosis and its treatment. We have a number of meetings planned based on some topics that family members usually find helpful. These include: what is psychosis, what causes psychosis, and recovery from psychosis, but if you have a topic that you are interested in learning about, you can let me know and we will plan to address it in one of these meetings. We want these meetings to focus on topics that you feel will be most helpful to you. Also, these meetings provide a way for family members to meet each other, share their experiences, and receive support.

   B. **Structure.** Each meeting has two parts. First, we will start with an informational session on a specific topic. That part of the meeting will take approximately 45 minutes. This will be followed by some time to discuss and potentially problem-solve around any problems/issues that may have come up in the past month in your efforts to support your family member, your efforts to cope, or any additional questions or concerns you might have, which will take the remainder of our time together.

   Also, we hope that these meetings are helpful and people are able to attend. However, there will of course be times when you can't make it. That's OK. Feel free to come whenever you can make it. If you miss some weeks, that's OK. You are always welcome. If you miss a meeting and you are interested in the topic, let us know and we can repeat the topic or make sure you get the information.

   C. **Topics.** Today we are going to talk about psychosis: what it is, what are some commons symptoms of psychosis, and the different phases of psychosis.

III. **Ask for questions**
Monthly Family Meeting 1 - What is Psychosis?

Part I: Presentation on Specified Educational Topic

Materials Needed:

Handout: Common Symptoms of Psychosis
Handout: Phases of Psychosis

TOPIC 1: What is Psychosis?

- Psychosis involves a loss of contact with reality and difficulty telling the difference between what is real and what is not.
- Psychosis can affect the way a person thinks, feels, and acts.
- 3 out of every 100 people experience psychosis at some point in their lives.
- The first episode of psychosis typically occurs in a person’s late teens or early twenties.
- Symptoms may emerge suddenly or develop gradually over time.
- Psychosis occurs in both men and women of every ethnicity, culture, and socioeconomic group.
- Symptoms of psychosis vary from person to person and over time.
- Psychosis is treatable and most people recover.

Common Symptoms of Psychosis

- Hallucinations
  - Hallucinations cause people to hear, see, taste, or feel things that are not there.
  - Hallucinations can seem very real. For that reason, people who experience hallucinations often have difficulty believing that they are not real and that their senses may be tricking them.
  - Examples of hallucinations include:
    a. hearing noises or voices that others don’t hear
    b. seeing things that other don’t see
    c. having unusual sensations in one’s body

Discussion: Ask group members if they can share examples of any hallucinations they may have experienced or that they have observed in a family member.

Delusions

Delusions are beliefs that a person holds despite evidence that those beliefs are not true or accurate.

Examples include:
- Believing that one is being watched or followed
- Believing that someone else is controlling one’s thoughts
• Believing that others want to harm you
• Believing that things in the environment have a special meaning just for you

Discussion: Ask group members if they can describe any beliefs or thoughts they may have had or they may have observed in their loved one that may not be entirely accurate or where they may question the accuracy. Ask them how these delusions have affected the individual and the family.

(Group leaders: clients may attend the group along with their family members; some may continue to have delusions that are strongly held; based on your knowledge of the group members and their symptoms you may decide to skip this discussion or temper it a bit.)

Confused thinking
One’s thoughts, and the expression of those thoughts, don’t connect together in a way that makes sense.

Examples include:
• Thoughts don’t make sense.
• Thoughts are jumbled together.
• Thoughts are racing too fast or are coming too slow

Discussion: Ask group members if they have had any difficulty communicating with others or have observed a family member appearing to have difficulty communicating their thoughts? What have they noticed? How has that affected the family’s ability to effectively communicate or interact with one another?

Changes in Behavior
• Spend more time alone
• Have less interest in socializing with friends and family, going to work or school, or otherwise engaging in activities one used to enjoy.
• Not taking care of oneself as well as one used to (e.g., not bathing or dressing, may appear disheveled).
• Behaviors that don’t seem to fit with the situation such as laughing when talking about something sad or upsetting or for no apparent reason.

Discussion: Ask group members if they have had noticed any changes in their behavior or have observed changed in a family member? What have they noticed?

Other symptoms that often go along with psychosis
• Depression: Low mood, sadness, less interest in activities
• Anxiety: Excessive fear or worry, feeling uncomfortable or anxious
• Mania: Elevated or irritable mood, heightened arousal or energy level
Discussion: Group leaders should highlight the fact that individual may experience other symptoms that may be either associated with the symptoms (e.g. mania for someone with schizoaffective disorder) or a result of the symptoms (e.g. anxiety due to concerns that being followed; depression associated with life changes due to illness).

TOPIC 2: Phases of Psychosis

Group leaders: Should distribute handout on phases of psychosis. Introduce the topic by highlighting the fact that although each person’s experience of psychosis is unique, typically an episode or period of psychosis involved 3 phases.

Prodromal phase

Early warning phase of psychosis
- Individual starts to experience mild symptoms or vague signs that something is not quite right.
- Family members begin to notice unusual behavior or signs that some is not quite right.

Early warning signs include:
- Changes in sleep or appetite
- Changes in emotions (anxiety, depression, suspiciousness, irritability, depression)
- Problems in thinking (difficulty with concentration, memory, organizing thoughts)
- Changes in behavior (social withdrawal, decreased energy or motivation, difficulty functioning at work, home, school)

Discussion: Ask group members if they can recall any early warning signs they may have experienced or observed? What was their understanding of it? What did they do?

Group leaders: Highlight the fact that family are often one of the first to notice these warning signs and that by knowing these signs or symptoms, the client and family member can develop a plan for what to do in that situation so they can get additional support and prevent the symptoms from worsening.

Active phase
- Individual is clearly experiencing symptoms of psychosis.
- Typically these include hallucinations and/or delusions but can also include disorganized thinking or behavior

Group leaders: Acknowledge that family members may not know what to do or who to contact to help their loved one get the extra support they may need if their symptoms worsen. It can be helpful for the client, family and team to develop a plan for what to do in that situation.
Recovery phase
- Individual starts to feel like themselves again.
- Often associated with a decrease in symptoms and an increase goal-directed activities
- Each person experiences the recovery phase differently. The path taken to get to this phase can vary considerably from one person to another.

TOPIC 3: Categories of Psychosis

*Group leaders: Write each one on the board and briefly describe each. Briefly describe how diagnoses are made and highlight the fact that sometimes it can take some time before the diagnosis is clear.*

Psychosis can be a symptom of several types of disorders.

**Schizophrenia or Schizoaffective disorder**
When psychotic symptoms last for a substantial period of time (6 months or more); schizoaffective- when both psychotic symptoms and mood symptoms last for a substantial period of time

**Bipolar disorder**
Psychotic symptoms appear within the context of fluctuating moods which includes both extreme highs (elevated mood) and extreme lows (depression)

**Major Depression**
Major depression with psychosis-when psychotic symptoms occur only when a person is depressed

**Substance abuse**
Use of or withdrawal from alcohol or other drugs such as marijuana, cocaine, heroin can be associated with symptoms. Oftentimes the symptoms resolve soon after the effects of the substances subside but can last a little longer. Other medical causes such as brain injury or delirium: psychosis can be associated with head injury or certain physical illnesses that disrupt brain functioning. In these cases people usually also have memory and attention problems and at times confusion.

**Final Discussion Regarding Educational Information:**

*Group leaders should encourage a discussion of any of the information presented during the session and address any questions from the group.*
Part II: Discussion Concerning Issues/Problems Faced Over the Past Month

NOTE TO PCs: Consider use of Recovery Videos if applicable to illustrate the concepts covered in this session.

After questions concerning the educational information have been addressed, group leaders should inquire if group members have faced any particular problems/had any issues arise in their efforts to cope or in trying to support their family member in their efforts to cope with client’s illness over the past month. The group leaders should work with the group to help resolve any issues or concerns. When appropriate, group leaders may engage in a problem-solving or communication skills exercise with group members to help resolve an immediate issues, address communication concerns, and support skill-building.
Common Symptoms of Psychosis
(Handout for Group 1)

**Hallucinations**
Hallucinations cause people to hear, see, taste, or feel things that are not there

Examples:
- Hearing noises or voices that other don’t hear
- Seeing things that other don’t see
- Having unusual sensations in one’s body

**Delusions/False Beliefs**
Beliefs that a person holds despite evidence that those belief are not true or entirely accurate

Examples:
- Believing that one is being watched or followed
- Believing that someone else is controlling one’s thoughts
- Believing that others want to harm you
- Believing that things in the environment have a special meaning just for you

**Confused thinking**
One’s thoughts, and the expression of those thoughts, don’t connect together in a way that makes sense.

Examples:
- Thoughts don’t make sense.
- Thoughts are jumbled together.
- Thoughts are racing too fast or are coming too slow

**Changes in Behavior**
Examples:
- Spend more time alone
- Have less interest in socializing with friends and family, going to work or school, or otherwise engaging in activities one used to enjoy.
- Not taking care of oneself as well as one used to (e.g., not bathing or dressing, may appear disheveled)
- Behaviors that don’t seem to fit with the situation such as laughing when talking about something sad or upsetting or for no apparent reason.
Phases of Psychosis
(Handout for Group 1)

**Prodromal phase**
Early warning phase of psychosis

- Individual starts to experience mild symptoms or vague signs that something is not quite right.
- Family members begin to notice unusual behaviors or signs that something is not quite right.
- Early warning signs may include changes in sleep/appetite; changes in emotions, problems in thinking; and/or changes in behavior.

**Active phase**
An individual is clearly experiencing symptoms of psychosis.

- Typically these include hallucinations and/or delusions but can also include disorganized thinking or behavior.

**Recovery phase**
- Individual starts to feel like themselves again.
- Often associated with a decrease in symptoms and an increase in goal-directed activities.
- Each person experiences the recovery phase differently. The path taken to get to this phase can vary considerably from one person to another.
What Causes Psychosis?

**Discussion:** Ask group members what they think causes psychosis/mental illness? Anything that others have said or that they have heard others say?

*Group leaders can highlight commonly held myths about the causes of psychosis and other mental illnesses such as: that mental illness don’t exist, are caused by poor parenting, are caused by being lazy or weak, are caused by the devil, etc.; and help to correct them by identifying them as myths. Emphasize the point that many of these myths developed as a way to explain behaviors that people didn’t understand.*

**What We Know: Overview of Causes**

**Overview**
- We are still working to fully understand why and how psychosis occurs.
- The development of psychosis appears to be influenced by a combination of biological/genetic, psychological, and environmental factors.
- Biological factors (genes) may make an individual more vulnerable to or have a greater risk for developing psychosis.
- Environmental factors (stressors) increase the likelihood that symptoms are expressed.

**Biological factors (genes)**
- Refers to the structure of the brain, chemicals in the brain, and genes that may make an individual more vulnerable to or increase the risk for developing psychosis.

**Biology**
- Psychosis is believed to be associated with an imbalance in chemicals in the brain called neurotransmitters.
- Neurotransmitters are chemicals that transmit impulses or signals throughout the brain and central nervous system.
- The neurotransmitter dopamine is associated with symptoms of psychosis.
- Many medications work to correct this imbalance.
- Genes: Research suggests that some people may have a genetic predisposition to developing psychosis.
- People who experience psychosis are more likely to have a close relative who has experienced psychosis.
- Maybe add in here heritability of schizophrenia/bipolar, etc. to highlight that this is relevant to other mental illnesses.
(Group Leaders: Family members may be concerned that because development of the illness may be due in part to biological or genetic factors, they or other family members (e.g., children) may develop the illness. Group leaders should stress the fact that although having a relative may increase the likelihood, that another family member may develop psychosis, it doesn’t mean that a person will definitely develop an illness.)

**Psychological**
- Personality, personal beliefs, thoughts, experiences, etc.
- Environmental factors (stressors) can increase the likelihood that symptoms are expressed.
- Stressful events in the environment
- Stressful events can increase an individual’s vulnerability to psychosis.
- High levels of stress can trigger the onset of symptoms or an increase in symptoms over time
- Stressful events can include a traumatic life event, a significant loss, increased responsibilities associated with school/work, or a physical illness.

**Substance use**
- Substance use can trigger the onset of symptoms or an increase in symptoms over time.
- Drugs such as marijuana, speed or LSD are particularly likely to trigger symptoms.
- However, substance use is generally not the underlying cause of psychosis.

(Group Leaders: Some people with psychosis and/or their family members may think that substance use is the cause. Group leaders should emphasize that while substance use may trigger symptoms, if the symptoms were just a result of substance use then they would go away once a person stopped using. Remember that families are looking for a sensible reason for the change in their loved one and substance use is frequently cited as a cause by both the individuals and family.)

**Common Family Reactions**
Group leaders: Group leaders should introduce the idea that psychosis significantly affects not only the person with psychosis but also each family member. Each family member will have their own reaction and each family member will be affected.

**Discussion:**
Ask group members how they or their family member with psychosis responded when they first started experiencing or noticing symptoms. How did they feel? What did they think? What did they do?

Group leaders should list and discuss reactions provided by group members on the board. Several common reactions are listed below:
- **Confusion and shock:** not sure what is going on, hard to make sense of experiences and understand what is happening to them
- **Fear and anxiety**
- **Anger and frustration**
- **Grief, sense of loss, or sadness**
- **Helplessness**
- **Feeling overwhelmed**
- **Shame and guilt**
- **Distancing or isolation**
Common Effects on the Family:

Discussion:

Ask family members how they reacted when their loved one first started experiencing symptoms. How did they feel? What did they think? What did they do? What reactions did the family member notice in their relative or in their relationship with their relative?

- Group leaders should list and discuss reactions provided by group members on the board.
  Several common reactions are listed below:
  - Confusion and shock: Family members may not understand changes they see in a loved one; person who is normally cheerful may become moody and withdrawn, angry or fearful
  - Fear and anxiety: May talk about things and have ideas that are seem impossible, irrational, don’t make any sense; May say they see things and hear things that you can’t see or hear
  - Anger and frustration
  - Grief, sense of loss, or sadness
  - Helplessness: Not sure what to do to help or where to get help
  - Feeling overwhelmed: Not sure what to do; feel that they need to make things better
  - Shame and guilt: Feel like somehow they are to blame; it is their fault; they could have done something to prevent it
  - Distancing or isolation: spend less time with others because

*Group leaders: Many common reactions to psychosis experienced by individuals with psychosis will be similar to those experienced by their family members. Group leaders should highlight this fact.*

Final Discussion Regarding Educational Information:

Group leaders should encourage a discussion of any of the information presented during the session and address any questions from the group.

Part II: Discussion Concerning Issues/Problems Faced Over the Past Month

*NOTE TO PCs: Consider use of Recovery Videos if applicable to illustrate the concepts covered in this session.*

After questions concerning the educational information have been addressed, group leaders should inquire if group members has faced any particular problems/had any issues arise in their efforts to cope or in trying to support their family member in their efforts to cope with client’s illness over the past month. The group leaders should work with the group to help resolve any issues or concerns. When appropriate, group leaders may engage in a problem-solving or communication skills exercise with group members to help resolve an immediate issues, address communication concerns, and support skill-building.
What is psychosis?
(Handout Group 2)

Psychosis occurs when a person loses contact with reality. The word “psychosis” scares some people, but it actually describes an experience that many people have. Three out of every 100 people experience psychosis at some time in their lives, and most of them recover.

What causes psychosis?
Psychosis could have a number of different causes, and many researchers are working to understand why psychosis occurs. Some popular ideas are:

- **Biological:** Some people are more likely to develop psychosis because of their biology or their heredity. Many cases of psychosis have been linked to problems with neurotransmitters, or the chemical messengers that transmit impulses throughout a person’s brain and central nervous system. In addition, the relatives of people who experience psychosis are more likely to experience psychosis themselves.
- **Other factors:** A person’s first episode of psychosis can be triggered by stressful events or by drug use (especially use of marijuana, speed, or LSD).
Monthly Family Meeting 3 – Recovery from Psychosis

Part I: Presentation of Specified Educational Topic

Materials Needed:
Handout: What is Recovery?
Handout: What Can Families Do to Help a Relative in their Recovery?

What is Recovery?

Discussion: Ask group what their understanding of recovery is? Have they heard this term before? What does this mean to them?

Defining Recovery

1) Description of recovery

Recovery has been described as:

- “...a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles”
- “It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness.”
- “...involves the development of new meaning and purpose in one’s life as one grows beyond the effects of mental illness” (Anthony, 1993).

2) Recovery is different for each person

Often involves:

- A reduction in symptoms: less or no hallucinations
- Improved relationships: feel more comfortable around others, more interested and comfort interacting with others, spending time with friends and family
- Connections with the outside world: engaged in work, school, volunteer activities, hobbies/other leisure or recreational activities
- Focus on important personal life goals: more likely to make plans for the future, set goals and take steps towards reaching them
What Helps People in their Recovery from Psychosis?

Group leaders should point out the fact that recovery is not the same thing as responding to treatment. While a majority of people have a substantial reduction in symptoms or remission of symptoms that is not always the case. Although individuals can’t always control how they respond to treatment (e.g. medications), they do have control over other aspects of their recovery. There are many things that people can do in addition to typical treatment to help them learn ways of relating to and successfully managing one’s illness so that they are able to move forward in life.

Participation in treatment

- Talking with providers about treatment options and working with providers to decide which treatments/services would best serve the individual
- Attending appointments regularly
- Asking questions if there are things you don’t understand, feel haven’t been explained, or information you would like to know
- Being honest with providers about whether treatment is working or not working. There are a number of treatment options to choose from if one does not seem to be working.
- Identifying and focusing on personal goals
- Identifying what you would like to change or see different
- Is there something you would like to be doing that you are not doing now?
- Working with providers to identify personal goals and what steps are necessary to reach those goals
- Making use of supports

Support network in the community

- Family, friends, and other supportive people in their life
- Professionals
- Treatment providers, school counselors, or other professionals
- Peers
- Support groups for people with psychosis or for family members of people experiencing psychosis

Discussion:

Engage group members in a discussion regarding things that may help their family members in their recovery. If group members (clients and/or family members) who have been in the program for a while are in attendance, ask them if they would be willing to share some things that they feel were helpful to them in the recovery process.

Group Leader should reiterate the fact that recovery is different for each person. As such, what helps a person to feel well/move forward may vary from person to person. Identifying what is helpful for your family member is what is most important.

What Can Family Members Do to Help?

- Learn about psychosis and its treatment: This will help you understand what is happening and get help for your family members if they need it.
• Knowledge is key, the more you know the better able you will be able to help support your relative
• There is a lot of information out there and the team can help you access it
• Work together with the treatment team to develop goals and help support your relative in taking steps towards meeting them.
• Be an advocate for your family member in order to make sure that they are getting the supports and services they need.
• Share your observations (e.g. problems, changes in behavior, triggers, improvements, effective coping skills) and your knowledge (e.g. when you notice changes in your relative’s behavior and what you notice)

Family members often have information that can help the team work more effectively with a client; this may include information on symptoms, warning signs or triggers, things that have worked/not worked in terms of treatment; coping skills and strengths.

*Group leaders: Acknowledge the fact that many family members may feel uncomfortable about getting too involved out of concerns about privacy, being blamed for their family member illness or current problems, prior negative experiences with mental health services/providers. Stress that getting involved with treatment providers and sharing and obtaining information is all done in an effort to help the family better support the family member.*

• When possible, provide practical supports such as transportation, financial assistance, etc. as needed. Maintain a positive, supportive atmosphere at home. Try to reduce the amount of stress in the home
• environment.
• Learning effective communication skills can help reduce stress and help to maintain a supportive environment.

*Example:* Tell families that if their relative suddenly lost their hearing, it might be normal and seem useful to begin yelling at the person to get them to hear better, but that may not be effective. Families may need to learn additional ways to communicate effectively, such as learning sign language or speaking directly to the person so they can read the speaker’s lips.

With psychosis, families may also need to learn more effective ways to communicate. The ways they used to communicate may no longer work when their relative’s brain is working differently.

*Group leaders: Make sure to point out to family members that it may not be that families and/or clients are doing it wrong; it is just that other ways may be more effective.*

**Make efforts to include your family member in family and social activities.**
Remind families that their family member may not feel comfortable participating in social activities at first, and that they know best what they are able to handle.
Example: Families may ask an ill relative to join them at the holiday dinner table, but if a family member is feeling paranoid, he or she may not want to be at the holiday table with unfamiliar faces. If families are aware of this ahead of time and can prepare, they will be less likely to pressure their ill relative to be a part of those activities. He or she may be perfectly able to handle having dessert in the kitchen with only some of the cousins, rather than the whole crowd.

What Can Families Do to Help Themselves?

Impact of mental illness on the family

Psychotic symptoms are stressful and at times can be traumatic for those involved, including family members. Family members may also experience a number of emotions—shock, fear, sadness, anger, frustration, etc.

Supporting a family member can also lead to stress, anxiety, feeling overwhelmed, helpless, etc.

Sometimes families can become so focused on the ill family member and how they are doing that they forget to take care of themselves, stop doing things they enjoy, etc.

Take care of yourself

Learn ways to take care of yourself and learn ways to manage stress.

Discussion: Have group members identify things that they use or do to reduce stress or anxiety. These may include things like walking/exercising, reading for pleasure, calling/visiting with friends, etc.

Make time to do things that you enjoy.

Discussion: Have group members identify things that they enjoy. Are there things they stopped doing when their relative became ill that they would like to start doing again?

• Get your questions answered.
• There are a number of ways this can be done: Written information, articles, books, videos, internet, etc.
• Talk to treatment providers, other families, or your family member.

Group leaders: Make sure to stress the importance of family members talking with each other—the fact that the best way to understand what is going on with their family member and how their family member would like them to help is to hear it from them; note that sometimes communicating with each other isn’t always easy and the team can help with that as well.

Make use of your current social supports and develop new supports

• Talk to friends and family
• Don’t isolate yourself from others
• Develop relationships with your family member’s treatment providers/team
• Connect with other families that have similar experiences (e.g., this group; NAMI family to family and support groups, online supports, etc.)

Group leaders: You may want to point out that oftentimes family members will shy away from contacts with friends/family due to uncertainty as to how to discuss or reluctance/discomfort about discussing the relative’s illness. Fear that others may view or treat them or their family member differently and/or negatively, or that others may avoid/distance themselves if they knew (i.e. stigma) may also lead family members to distance themselves from current supports. However, having someone that can provide support when you need it, can be very important.

Final Discussion Regarding Educational Information:
Group leaders should encourage a discussion of any of the information presented during the session and address any questions from the group.

Part II: Discussion Concerning Issues/Problems Faced Over the Past Month

NOTE TO PCs: Consider use of Recovery Videos if applicable to illustrate the concepts covered in this session.

After questions concerning the educational information have been addressed, group leaders should inquire if group members have faced any particular problems/had any issues arise in their efforts to cope or in trying to support their family member in their efforts to cope with the client’s illness over the past month. The group leaders should work with the group to help resolve any issues or concerns. When appropriate, group leaders may engage in a problem-solving or communication skills exercise with group members to help resolve any immediate issues, address communication concerns, and support skill-building.
**What is Recovery?**

*(Handout for Group 3)*

**Recovery** has been described as:

"...a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness.

...involves the development of new meaning and purpose in one’s life as one grows beyond the effects of mental illness” (Anthony, 1993).

Recovery is different for each person but often involves thing like:

- A reduction in symptoms (e.g. fewer or less disruptive hallucinations; ...)
- Improved relationships (e.g., feeling more comfortable around others, more interest in interacting with others, spending more time with friends and family)
- Connections with the outside world (e.g. engaged in work, school, volunteer activities, hobbies/other leisure or recreational activities)
- A focus on important personal life goals (e.g., more likely to make plans for the future, set goals, and take steps towards reaching them)
What Helps People in their Recovery from Psychosis?

(Handout for Group 3)

Just as recovery is different for each person, what helps a person to feel well/move forward can vary from person to person. That is why it is important for you and your family member to identify what is most helpful or most important in their recovery.

Participation in treatment

Talking with providers about treatment options and working with providers to decide which treatments/services would best serve the individual.

- Attending appointments regularly.
- Ask questions if there are things you don’t understand, feel haven’t been explained, or information you would like to know.
- Being honest with providers about whether treatment is working or not working.

Identifying and focusing on personal goals

- Identifying what you would like to change or see different.
- Is there something you would like to be doing that you are not doing now?
- Working with providers to identify personal goals and what steps are necessary to reach those goals.

Making use of supports

- Support network in the community
  - Family, friends, and other supportive people in their life
- Professionals
  - Treatment providers, school counselors, or other professionals
- Peers
- Support groups for people with psychosis or for family members of people experiencing psychosis
What Can Family Members Do to Help/Support their Family Member?

(Handout for Group 3)

• Learn about psychosis and its treatment

• Work together with the treatment team to develop goals and help support your relative in taking steps towards meeting them.

• Be an advocate for your family member in order to make sure that they are getting the supports and services they need.

• Share your observations (e.g. problems, changes in behavior, triggers, improvements, effective coping skills) and your knowledge (e.g. when you notice changes in your relative’s behavior and what you notice).

• When possible, provide practical supports such as transportation, financial assistance, etc., as needed.

• Maintain a positive, supportive atmosphere at home. Try to reduce the amount of stress in the home environment.

• Make efforts to include your family member in family and social activities.
What Can Families Do to Help/Support Themselves?

(Handout for Group 3)

- Learn ways to take care of yourself and learn ways to manage stress.
- Make time to do things that you enjoy.
- Get your questions answered. This can be accomplished through written information, articles, books, videos, internet, or talking to treatment providers, other families, or your family member.
- Make use of your current social supports and develop new supports.
Monthly Family Meeting 4 – Treatment for Psychosis

Part I: Presentation of Specified Educational Topic

Materials Needed:
Handout: Antipsychotic Medications Recommended by the OnTrackNY Team
Handout: OnTrackNY Team First-line Antipsychotic Medications: Common Side Effects and
Handout: OnTrackNY Team Second-line Antipsychotic Medications: Common Side Effects

Treatments for Psychosis

Discussion:
Ask group about their understanding of treatment for psychosis? What treatments have they heard of? How/where do they get information about treatment? What works and what does not work?

Treatment for Psychosis: Overview
The plan for today is to discuss different types of services/treatments for psychosis. This will include:

1. Overview of the treatment team
2. Pharmacological treatments
3. Psychosocial treatments
4. Other support services

The Treatment Team

- The treatment team includes several mental health professionals who provide different treatments/services aimed at helping individuals who have experienced psychosis achieve their treatment/recovery goals.
- The team offers a collaborative approach that relies on everyone’s strengths and energy. This means that each member of the team has certain strengths, knowledge, and expertise that they bring to the table.
- Members of the team:

Primary clinician
- Works with an individual and their family to help identify treatment goals and develop a plan for getting them met.
- Helps to coordinate care.
- Connects people with resources- both those provided by the team as well as those offered in the community.
- Assists individuals in building and/or strengthening their communication and coping skills.
- Helps the individual practice and refine these skills so he/she is ready to use them in real-life situations.
• Works with interested individuals to reduce behaviors such as drinking, drug use, and smoking that may block one from achieving recovery goals and increase behaviors that can assist them in reaching their goals.

**Psychiatrist**
• Works together with an individual and their family to help them make decisions about medication use and to identify medications that may be helpful in reducing symptoms.
• Works with the team to monitor the effectiveness of medication and resolve any medication side effects.

**Supported Education and Employment Specialist**
• Helps individuals to identify employment and school related goals.
• Assists individuals in finding work/getting enrolled in school, and provides supports to increase the likelihood of success.

**Client**
• Works with the team to identify personal goals and steps needed to reach those goals.
• Discusses personal treatment options with the team and works with them to decide what services/treatments would be most helpful.

**Family Member**
• Works with the team to identify ways to support the client.
• Discusses which family services, if any, might be helpful in aiding the family to support their relative and themselves.

**Treatment for Psychosis**

*Group Leader: Discuss the fact that there are a number of treatments for psychosis. Each has been shown to be helpful to individuals experiencing psychosis. Part of the client and family’s job in collaborating with the rest of the team is to decide which treatments will best help the client to reach their treatment goals. Each person’s goals may be different and these goals may change over time, so this will be an ongoing discussion.*

1) Pharmacological Treatment (e.g. medications)

**Pharmacological Treatment Overview**
• For many individuals, medications can be helpful in reducing symptoms as well in preventing symptoms than are diminished (or are no longer present) from reemerging.
- The decision to begin medication treatment and the choice of using specific medications, is one that should be shared among the client, family members and treatment team.
  - Medications commonly used for the treatment of psychosis include:
    - Antipsychotic medications that target psychotic symptoms
    - Medications that target other psychiatric symptoms
    - Medications that assist individuals in coping with medication side effects

**Antipsychotic Medications: Overview**

Distribute handout: Antipsychotic Medications Recommended by the OnTrackNY Team

*Group Leader (ideally the psychiatrist)*: Group leader should review the handout on antipsychotic medications recommended by the team. As part of this review they should highlight that:

1. Antipsychotic medications can help decrease symptoms of psychosis and prevent symptoms that are diminished (or are no longer present) from reemerging.
2. All of these medications are effective in treating psychosis; however, they differ from one another in terms of which neurotransmitters they target, possible side effects associated with their use, and their effectiveness in targeting specific symptoms.
3. Define first-generation and second-generation antipsychotics.
4. Note that they can be taken orally or as an injection, and that while the effect of some may be noticeable after a few days, for others it can take two to four weeks.

*Group Leader*: After reviewing the handout, the group leader should point out that medication may work differently across individuals. A certain medication may work particularly well for one person but not as well for another person. Similarly, a medication might work well for a person but have a number of side effects that are difficult to tolerate. As a result, clients may need to try a few medications before they figure out which works best for them. This is why it is very important for clients to be open and honest with the psychiatrist and the rest of the team about whether the medication is working or not, any side effects they are experiencing, and any concerns other they have about the medication.

**Antipsychotic Medication and Side Effects**

*Group Leaders*: Note that like most medications, each medication has possible side effects. Side effects are typically unexpected and sometimes unwanted and undesirable effects of medication.

**Discussion:**
Have you or your relative ever experienced side effects as a result of a certain medication? What did you or your relative experience? What did you do about it?
Common Side Effects of Antipsychotic Medications

Distribute Handouts: OnTrackNY Team First-line Antipsychotic Medications: Common Side Effects and OnTrackNY Team Second-line Antipsychotic Medications: Common Side Effects

*Group leader:* Review handouts on common side effects of antipsychotic medications. In reviewing these handouts provide a definition/description and examples of each side effect discussed.

*Group leader:* Stress to group members that although some individuals that take these medications may experience the side effects discussed, not everyone that takes these medications will experience them.

Just because you take a medication doesn’t mean you will definitely experience the side effects. However, some of these side effects are common and may be annoying, inconvenient, or uncomfortable if they do occur. Therefore, it is important to know the common side effects of the medications that your family member is taking so that if they do experience these, you and your family member can work with the team to decide the best way to address them.

Coping with Side Effects of Medications

- As mentioned previously, it is important to inform the psychiatrist or other member of the team about any medication side effects as soon as they occur so you, the client and the team can decide how best to address them.
- Some side effects will subside over time so they may decide to wait a week or two to see if they diminish.
- If they do not subside, there are a number of ways that side effects can be minimized:
  - The dose of the medication may be lowered.
  - The medication may be changed to a different drug that causes fewer side effects.
  - Other medications may be prescribed to help with side effects.

Other Medications

- Antipsychotic medications may not be effective for all symptoms.
- In those cases, other medications may be prescribed, including:
  - Antidepressant medications (e.g. Lexapro, Paxil, Prozac, Zoloft)
  - Mood stabilizers (e.g. lithium, Depakote, Tegretol)
  - Anti-anxiety medications or sedatives (e.g. Ativan, Klonopin, Xanax)
- These medications may also have side effects. If you are taking any of these, talk with the psychiatrist/the team about possible side effects.

2) Psychosocial Treatments

*Group Leader:* Highlight the fact that there are also a number of psychosocial treatments that have been shown to be very helpful for individuals experiencing psychosis, particularly when they are used in conjunction with medication. These include:
**Individual Counseling and Support**
- Provided by Primary clinician
- Meet one-on-one to discuss issues or problems a person may be facing

**Supported Education and Employment**
- The Supported Education and Employment Specialist works with the individual to:
  - Identify and clarify educational and work-related goals.
  - Help individuals find a job/school that matches their interests.
  - Identify supports needed to be successful and helps to make sure those supports are in place.
- The plan for the individual and any supports are highly individualized and based on each person’s needs/preferences (e.g. transportation, advocacy, working with teacher/employer and providing them with information, assistance about work/school relationships).

**Coaching/Skills Training/Psychoeducation**
Provided by the Primary Clinician and involves teaching and learning a new skill or doing a structured exercise or activity directly related to an individual’s goals.

1. **Social Skills Training**
   a. Involves helping individuals learn and practice communication and skills.
   b. These skills are important in developing and maintaining relationships with other people and being successful in school, work, or other social settings (e.g., dating, developing and sustaining friendships, job interview skills, medication management skills).

2. **Coping Skills Training**
   a. Involves helping individuals learn strategies for coping with difficult feelings or situations in order to decrease stress in their lives (e.g., anxiety or depression).

3. **Behavioral Activation**
   a. Involves helping people identify and carry out pleasant activities in the community as a way to decrease isolation and depression.

4. **Substance Use Treatments**
   a. Involves increasing motivation to change unhealthy substance use behaviors and identify behavior change goals.
   b. Involves teaching skills to effectively deal with social pressures and stressful situations that lead to unhealthy behaviors and strategies to cope with urges, cravings, high-risk situations, and relapses.

5. **Psychoeducation**
   a. Involves providing individuals with information or helping them explore a particular topic about which they want to learn more about.
Resources for Families
Family education programs focused on providing information, education and support.

1) Monthly family meetings
   • Monthly groups focused on providing information/education, skill building, and mutual support; topics are chosen by attendees and are flexible and largely dependent on the needs of the group.

2) NAMI’s Family to Family Program
   • Group offered in the community focused on providing education, communication and problem-solving, skills building, and support.

3) Family Consultation
   • Conducted with individual families, time-limited, focused on a particular issue or concern.
   • Individual work around a particular issue that has come up; could be related to communication, skill building, problem-solving, conflict resolution, etc.

4) Family Support Groups
   • Opportunities for mutual support

Other services
• Case management, assistance with housing, income assistance
• Linking with community resources (e.g., NAMI, Self-help groups for substance use (AA, NA), Specialized trauma services)

Discussion:
• Engage group members in a discussion about services provided? Any other ones they have heard of/are interested in learning more about?

Final Discussion Regarding Educational Information:
• Group leaders should encourage a discussion of any of the information presented during the session and address any questions from the group.

Part II: Discussion Concerning Issues/Problems Faced Over the Past Month

NOTE TO PCs: Consider use of Recovery Videos if applicable to illustrate the concepts covered in this session.

After questions concerning the educational information have been addressed, group leaders should inquire if group members have faced any particular problems/had any issues arise in their efforts to cope with or in trying to support their family member in their efforts to cope with client’s illness over the past month. The group leaders should work with the group to help resolve any issues or concerns. When appropriate, group leaders may engage in a problem-solving or communication skills exercise with group members to help resolve any immediate issues, address communication concerns, and support skill-building.
Antipsychotic Medications Recommended by the OnTrackNY Team*
(Handout for Group 4)

For most people with first-episode psychosis, antipsychotic medications can be very helpful. Research has shown that for most (about 50-90%) people with first-episode psychosis, the symptoms of psychosis lessen or go away within the first year of antipsychotic treatment. This can lead to better safety and quality of life.

For many people with schizophrenia and other mental illnesses, antipsychotic medications can reduce troublesome symptoms, as shown by dozens of studies dating back over 40 years. However, about 20 percent of people receive no benefit at all from taking antipsychotic medications and 25 to 30 percent only get some benefit. That is why medication alone is often not enough; for most people, psychosocial interventions together with the appropriate medication work best.

<table>
<thead>
<tr>
<th>First-Generation Antipsychotics</th>
<th>Second-Generation Antipsychotics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medications that have been available for many years (also called typical or conventional)</strong></td>
<td><strong>Newer antipsychotic medications (also called atypical)</strong></td>
</tr>
<tr>
<td>Loxapine (Loxitane)</td>
<td>Aripiprazole (Abilify)</td>
</tr>
<tr>
<td>Perphenazine (Trilafon)</td>
<td>Risperidone (Risperdal)</td>
</tr>
<tr>
<td></td>
<td>Ziprasidone (Geodon)</td>
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<table>
<thead>
<tr>
<th>First-line treatments (oral)</th>
<th>First-line treatments (injectable)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loxapine (Loxitane)</td>
<td>Fluphenazine decanoate (Prolixin)</td>
</tr>
<tr>
<td>Perphenazine (Trilafon)</td>
<td>Haloperidol decanoate (Haldol)</td>
</tr>
<tr>
<td>Aripiprazole (Abilify)</td>
<td>Aripiprazole extended release (Abilify Maintena)</td>
</tr>
<tr>
<td>Risperidone (Risperdal)</td>
<td>Olanzapine pamoate (Zyprexa Relprevv)</td>
</tr>
<tr>
<td>Ziprasidone (Geodon)</td>
<td>Paliperidone palmitate (Invega Sustenna)</td>
</tr>
<tr>
<td></td>
<td>Risperidone microspheres (Risperdal Consta)</td>
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</table>

<table>
<thead>
<tr>
<th>Second- line treatment (oral)</th>
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</thead>
<tbody>
<tr>
<td>Clozapine</td>
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</tbody>
</table>

*Other antipsychotic medications are available and may be prescribed.
What are the advantages of taking antipsychotic medication?
Antipsychotic medications are some of the most powerful tools available for reducing psychotic and other psychiatric symptoms and decreasing the risk of relapses. When prescribed in the right way, antipsychotic medications can help a person feel calmer, less upset or anxious, sleep better, think more clearly, feel more comfortable around other people, and get along better in daily life.

Do antipsychotic medications cause side effects?
People have very different reactions to medications. Some people who take antipsychotic medications experience only a few side effects or none at all, while other people will experience several side effects. Often a medication will produce side effects at the beginning of treatment, and those side effects decrease as the person’s body gets used to it.

Many people with first-episode psychosis are particularly sensitive to the side effects of antipsychotic medications. Therefore, it is very important for individuals to talk with their doctors about the specific side effects that are associated with any antipsychotic medication they are considering for treatment, and to promptly report to the health care team any distressing side effects he or she experiences.

Fortunately, there are a number of different antipsychotic medications available, and individuals may need to work with their doctors to try a few different drugs in order to find the one that is just right the one that works the best and causes the fewest side effects.

When first- and second-generation antipsychotic medications have been compared for the treatment of a first-episode of psychosis, researchers have typically not found differences in clinical effects. These two groups of medications are, however, very different in terms of the side effects they cause. Even within each group, different medications have different side effects.

The main advantage of the newer antipsychotic medications is that they are less likely to cause the muscle movement side effects, such as muscle stiffness, mild tremors, restlessness, and muscle spasms that are caused by the older generation of medications. The newer drugs also cause significantly fewer problems related to sexual difficulties. However, both the older and newer antipsychotic medications can cause weight gain, and some of the newer ones are even more likely to do so. This may increase a person’s risk of getting diabetes, high cholesterol, and other medical illnesses, and so close monitoring of weight gain while taking antipsychotic medications is required.

Your doctor and health care team will talk to you about how they will periodically monitor you for weight gain and other potentially bothersome side effects of antipsychotic medications. If you recognize that you are having side effects, it is important to contact your doctor as soon as possible. Your doctor will help you evaluate how serious the side effects are and what can be done about them. It is up to you to decide what side effects you can tolerate and what risks you are willing to accept.
Strategies for Preventing or Minimizing Side Effects of Antipsychotic Medications

People have very different reactions to medications. Some people who take antipsychotic medications experience only a few side effects, while others may experience several. Sometimes side effects become so troubling that people decide to stop taking their antipsychotic medications, which can lead to a return of psychotic symptoms and can interfere with recovery.

The good news is that there are many ways to help prevent or minimize the risks of side effects from antipsychotic medications. Some of these include:

- Having your doctor lower the dose of antipsychotic medication to lessen certain side effects.
- Having your doctor add another medication to prevent or treat certain side effects.
- Having your doctor switch you to another antipsychotic medication that causes fewer side effects.

It is very important for you and your doctor to be aware if side effects of antipsychotic medications develop. Always tell your doctor right away if you notice any changes or problems from taking medications. The sooner you and your health care team become aware of a side effect, the easier it will be to manage it and help prevent it from occurring again and becoming very bothersome.

Below are listed some side effects of antipsychotic medications that can happen fairly soon (within hours or days) after taking the medication. These can be minor or severe, depending on the specific medication and individual reaction.

<table>
<thead>
<tr>
<th>What you may feel or notice</th>
<th>What you can do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tired or sleepy, sleeping too much</td>
<td>Schedule a brief nap during the day. Get some exercise, such as walking. Ask your doctor about taking your medication in the evening before you go to bed.</td>
</tr>
<tr>
<td>Trouble falling or staying asleep</td>
<td>Learn about sleep hygiene and relaxation techniques. Ask your doctor about taking your medication in the morning or sometime during the day.</td>
</tr>
<tr>
<td>Extreme restlessness</td>
<td>Find a vigorous activity that you enjoy, such as jogging, skating, aerobics, sports, outdoor gardening, swimming, or bicycling. Talk to your doctor.</td>
</tr>
<tr>
<td>Low blood pressure</td>
<td>You may feel dizzy or lightheaded when standing up or moving quickly. Avoid getting up quickly from a sitting or lying down position. Hold on to something to avoid falls.</td>
</tr>
<tr>
<td>Muscles feel stiff, tense, crampy, or painful</td>
<td>Try doing muscle stretching exercises, yoga, or getting regular exercise. Take a short walk. Talk to your doctor.</td>
</tr>
<tr>
<td>Shakiness or tremors</td>
<td>Talk to your doctor.</td>
</tr>
<tr>
<td>What you may feel or notice</td>
<td>What you can do</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>Constipation (problems with bowel movements)</td>
<td>Eat foods high in fiber such as bran cereals, whole grain breads, fruits, and vegetables. You should also drink plenty of water. Engaging in regular exercise may be helpful. If necessary, your doctor may prescribe a laxative.</td>
</tr>
<tr>
<td>Dry mouth</td>
<td>Take frequent sips of water. Chew sugarless gum or suck on sugarless hard candy.</td>
</tr>
<tr>
<td>Blurry vision</td>
<td>For mild blurry vision, talk to your doctor about getting reading glasses. These can often be bought without a prescription.</td>
</tr>
<tr>
<td>Increased appetite and weight gain</td>
<td>Emphasize healthy foods in your diet, such as fruits, vegetables, and grains. Cut down on sodas, desserts, and fast foods. Engage in regular exercise. Go on a diet with a friend or join a weight reduction program.</td>
</tr>
</tbody>
</table>

There are other side effects that may take longer to show up (weeks, months, or even years) after taking antipsychotic medication. These side effects can range from mild to severe, depending on the individual and the specific medication. Regular monitoring for these side effects by your doctor is needed.

<table>
<thead>
<tr>
<th>What you may feel or notice</th>
<th>What you can do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Muscle movements that you cannot control or stop (called tardive dyskinesia or TD)</td>
<td>Talk with your doctor.</td>
</tr>
<tr>
<td>Sexual problems such as low sex drive, trouble with erections, ejaculation or reaching orgasm</td>
<td>Talk with your doctor.</td>
</tr>
<tr>
<td>For women who should be having regular periods, periods do not come every month or stop</td>
<td>Talk with your doctor.</td>
</tr>
<tr>
<td>Milk leakage from the breasts</td>
<td>Talk with your doctor.</td>
</tr>
<tr>
<td>Increases in blood sugar or diabetes</td>
<td>Your doctor will test your blood sugar regularly. Other medications may need to be prescribed to lower blood sugar.</td>
</tr>
<tr>
<td>Increases in cholesterol</td>
<td>Your doctor will test your cholesterol regularly. Other medications may need to be prescribed to lower cholesterol.</td>
</tr>
</tbody>
</table>
There are some side effects of antipsychotic medications that are serious or may be life-threatening and require medical attention right away. The antipsychotic medication may need to be stopped. As with all side effects, some are more likely with certain antipsychotics than others.

<table>
<thead>
<tr>
<th>Side effects that may require immediate medical attention</th>
<th>What to look for</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute dystonia</td>
<td>Sudden muscle spasm or cramping, making neck twist, eyes roll back, or jaws lock up. Difficulty talking, swallowing, or breathing.</td>
</tr>
<tr>
<td>Seizures</td>
<td>Sudden disturbance in muscle movement and changes in mental state.</td>
</tr>
<tr>
<td>Stroke</td>
<td>Sudden loss of blood supply to the brain, causing difficulty in talking, numbness or tingling, or weakness in the arms or legs.</td>
</tr>
<tr>
<td>Allergic reaction</td>
<td>Skin rash, trouble breathing.</td>
</tr>
<tr>
<td>Neuroleptic malignant syndrome</td>
<td>High fever, stiff muscles, sweating, fast or irregular heartbeat, high blood pressure, confusion.</td>
</tr>
</tbody>
</table>
Clozapine

**Why is clozapine prescribed?**
Clozapine is an antipsychotic medication used to treat schizophrenia and other similar conditions. Antipsychotic medications are effective in reducing symptoms of psychosis. They also shorten the time to recovery and help prevent symptom relapses. Clozapine is used when other antipsychotic medications have not been effective. Clozapine is the only antipsychotic medication effective in treatment-resistant schizophrenia.

**Why are regular blood tests needed?**
Before you start clozapine, you will have a blood test to make sure you can start this medication. This is because, rarely, clozapine can lower the number of white blood cells in your blood. White cells fight infection. If you have too few white blood cells, it will be harder for your body to fight off infections.

You will have regular blood tests for as long you continue to take clozapine. Your doctor will tell you when and where to have these tests. You will have your blood tested every week for the first 6 months and then you may be able to have your blood tested every 2 weeks. After you have been on clozapine for 1 year without having any problems, it may be possible for you to have your blood tested only once a month.

It is very important that you do not miss these blood tests, otherwise for your safety, you will not be able to receive any more clozapine. Therefore, your cooperation with the blood testing is vital.

**What will happen when clozapine is first taken?**
Clozapine, like many other medications, may not produce any effects right away. It may take several days or even weeks for some symptoms to improve. In the beginning, some people find that clozapine makes them feel more relaxed and calm. Later, other symptoms should begin to improve.

**Is clozapine addictive?**
No, clozapine is not addictive. However, if you stop taking clozapine suddenly, you may experience uncomfortable medication withdrawal effects.

**Can I drink alcohol while I am taking clozapine?**
It is recommended that people taking clozapine should not drink alcohol. This is because both antipsychotic medications and alcohol can cause drowsiness (sleepiness). If the two are taken together, severe drowsiness can result. This can lead to falls and accidents. Also, drinking alcohol may make symptoms of psychosis worse.

**Is it OK to stop taking clozapine when symptoms go away?**
No. If you stop taking clozapine, your original symptoms are very likely to return. Most people need to be on clozapine for quite a long time, sometimes years. You should discuss any plans you have to reduce or stop taking clozapine with your doctor.

**Can cigarette smoking have any effects on clozapine?**
Yes. People who smoke cigarettes may increase the breakdown of clozapine in the body. This may
be important if you are a heavy smoker and then suddenly reduce or even stop smoking completely. Before reducing or stopping smoking, be sure to speak to your doctor first.

What kinds of side effects can clozapine cause?
People have very different reactions to medications. Some people who take clozapine experience only a few side effects while others may experience several. Many side effects will lessen and should go away after a few weeks. The table below lists some of the more common side effects associated with clozapine, but this is only a partial listing of possible side effects. Talk with your doctor for more information about the full range of side effects for clozapine or if you are concerned that clozapine may be causing a side effect.

<table>
<thead>
<tr>
<th>Side effects</th>
<th>What should I do if this happens to me?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tired or sleepy, sleeping too much</td>
<td>Schedule a brief nap during the day. Get some exercise, such as walking. Ask your doctor about taking your medication in the evening before you go to bed.</td>
</tr>
<tr>
<td>Constipation (problems with bowel movements)</td>
<td>Eat foods high in fiber such as bran cereals, whole grain breads, fruits, and vegetables. You should also drink plenty of water. Engaging in regular exercise may be helpful. If necessary, your doctor may prescribe a laxative.</td>
</tr>
<tr>
<td>Excessive salivation (drooling)</td>
<td>This tends to wear off over time. Your doctor may prescribe another medicine to treat this side effect.</td>
</tr>
<tr>
<td>Tachycardia (palpitations or fast heart beat)</td>
<td>This is most common in the first few weeks of treatment. Speak to your doctor if this side effect does not wear off or becomes bothersome.</td>
</tr>
<tr>
<td>Increases in cholesterol</td>
<td>Your doctor will test your cholesterol regularly. Other medications may need to be prescribed to lower cholesterol.</td>
</tr>
<tr>
<td>Weight gain</td>
<td>Try to eat healthy foods, such as fruits, vegetables, and grains. Cut down on sodas, desserts, and fast foods. Engage in regular exercise. Go on a diet with a friend or join a weight reduction program.</td>
</tr>
<tr>
<td>Increases in blood sugar or diabetes</td>
<td>Your doctor will test your blood sugar regularly. Other medications may need to be prescribed to lower blood sugar.</td>
</tr>
<tr>
<td>Low blood pressure</td>
<td>You may feel dizzy or lightheaded when standing up or moving quickly. Avoid getting up quickly from a sitting or lying down position. Hold on to something to avoid falls.</td>
</tr>
<tr>
<td>Reduced white blood cells</td>
<td>Your blood will be tested as described above.</td>
</tr>
<tr>
<td>Seizures</td>
<td>Seizures sometimes occur in people who receive high doses of clozapine. Sometimes, anticonvulsants are prescribed.</td>
</tr>
</tbody>
</table>
Monthly Family Meeting 5 – Crisis Prevention and Planning
Part I: Presentation of Specified Educational Topic

Materials Needed:
Handout: Components of a Crisis Plan

Introduction to Crisis Prevention and Planning
- Although we hope that most of the time individuals will be doing well, it is possible that at some point you/your family member may experience a mental health crisis. Mental health crises can occur even if an individual has been following their treatment plan and is using coping skills and supports that may have been effective in the past.
- When a crisis occurs, it can be scary and overwhelming for everyone involved. Individuals who are feeling distressed or experiencing a crisis may not know what to do to help him/herself feel better as well as whom or where to turn to get additional support. Similarly, family members may not know what to do to help their family member and may not have information about whom to contact to get additional assistance or support.
- Although crises sometimes appear to come on rather quickly and without much warning, more often than not, there are warning signs that a person may be experiencing greater distress and may possibly be in crisis. Knowing these warning signs can help you recognize times when you/your family member may need additional support to manage and minimize the crisis.
- For this reason, it can be extremely helpful to discuss and develop a plan for what to do should you or your family become distressed; or if a crisis occurs so that everyone is on the same page with regards to how the situation should be handled and everyone feels more prepared to take action when necessary.
- This meeting will focus on how to recognize signs of a potential crisis and how to use this knowledge to prevent a crisis from occurring. In addition, we will talk about how you might develop a plan for what you/your family member can do should a crisis occur.

What Do We Mean by Mental Health Crisis

*Group leader: In order to plan what to do in the event of a mental health crisis, we must first understand what constitutes a mental health crisis.*

**Discussion:**
Ask group members how they define a mental health crisis? What would be some examples of a mental health crisis? Have they or their family member experienced this before? What did they learn from that experience? Is there anything about the situation that they would have liked to have gone differently/been handled differently?
Defining a Mental Health Crisis

A mental health crisis is a situation in which a person is unable to use their typical coping skills or resources effectively and as a result experiences symptoms or engages in behaviors that may put him/her at risk.

• This may include:
  o Having difficulty thinking clearly; behaving in a disorganized way
  o Thinking about, threatening, or acting in aggressive and/or potential harmful ways either towards him/herself or someone else (e.g. suicidal thoughts or action, thoughts or actions aimed at harming someone else)
  o Intense mood swings or mood states (e.g. being so high, hyper, excited that the person is not their normal self or gets into trouble; feeling so depressed that a person can’t take care of themselves)
  o Having hallucinations or delusions that become too difficult to manage, extremely distressing or overwhelming, or cause a person to behave in a way that may be dangerous.

• While symptoms may diminish or lessen over time, some people may continue to experience symptoms. Experiencing symptoms or even an increase in symptoms does not necessarily constitute a crisis; however, this may be a warning sign you/your family member could benefit from additional support or assistance.

Developing a Crisis Plan

Group leaders: Group leaders should reiterate the goals of the crisis plan and why it can be useful for all involved. Leaders can describe “crisis or safety planning” as being analogous to planning for other potential emergencies such as fire/disaster drills to stress the idea that although we hope that we won’t have to use them, we plan ahead so that we will feel more prepared to act should an emergency occur.

Discussion:

• Has anyone ever discussed developing a crisis plan with you/do you have a crisis plan? What might be the benefits of having a plan? How do you think it might help you/your family member if a crisis should emerge? What might be the downsides to not having a plan? Have you ever had to use one? If so, how did it go?
• What do you think you would want to include in a crisis plan? Who do you think should be involved in helping develop one and why?

Group leaders: Family members can be an important part of developing and implementing a crisis plan. Family members can help suggest coping strategies that can be used. Sometimes family members recognize warning signs that you may not be aware of or notice. As a result, they may be able to watch for these signs and prevent the crisis by helping you put your plan into place before it hits a crisis level.
Components of a Crisis Plan

There are several basic components to crisis or safety planning:

- Identifying warning signs or red flags that suggest that a person may need some additional support
- Identifying coping strategies or tools that a person can attempt before contacting other supports
- Identifying people who you can ask for help if personal coping strategies are not working as well as you like
- Professionals or agencies you can contact if other coping strategies don’t work

1) Warning signs or red flags

- The first step in developing a crisis or safety plan is to identify any warning signs or red flags that may suggest that a person is not doing so well.
- Warning signs can vary from individual to individual which is why it is important to take notice of and try to identify an individual’s personal warning signs. Family members can be particularly helpful in doing this with their loved one who has psychosis and may even be able to identify warning signs that are not readily apparent to the young person.
- Some examples of common warning signs individuals experience/family members observe are:
  - Changes in sleep (e.g. sleeping more, sleeping less, waking up throughout the night)
  - Increases in hallucinations or delusions
  - Changes in thinking (e.g. racing thoughts, trouble thinking clearly or formulating thoughts, greater suspiciousness/paranoia)
  - Increased irritability, agitation, angry outbursts, increases in arguments/conflicts
  - Changes in mood (e.g. feeling down or depressed, feeling more anxious or increased worry, feeling hopeless, extremely elevated mood, mood swings)
  - Isolation/withdrawal (e.g. less interest/involvement in social activities, hobbies or other activities typically enjoyed)
  - Reduced involvement in treatment (e.g. not taking medications, less involvement in mental health services)
  - Thoughts of harming themselves or someone else (this can include command hallucinations)

Discussion:
Ask group members if they have ever thought about warning signs that they experience or have noticed their family member experience, that let them know they might need some additional support? Do these warning signs sound familiar? Any others that weren’t listed?

2) Using Personal Coping Strategies

- When a person recognizes that they are becoming more distressed they can begin to use coping strategies to minimize and/or manage the distress.
- An effective coping strategy for one person may not be an effective strategy for another.
• Moreover, an effective strategy for one situation or stressor may not be effective for another.
• That’s why it can be helpful for individuals to come up with a number of coping strategies that they know are helpful for them.
• Family members can play an important role in helping the young person to: 1) recognize when they seem to be more distressed, 2) helping the young person identify coping strategies they can use to minimize their distress, and 3) possibly being part of the strategy for managing distress.

Discussion:
What are some effective coping strategies for you/your family member? Do you find that certain ones work better in certain situations than others?

3) Connecting with family members/friends/others to get support
Connecting with others when you are distressed or feeling overwhelmed can help in a couple different ways:

• Socializing with or simply being around other people can sometimes help to distract a person from thoughts or experiences which may be posing some difficulty. Socializing with others may also help minimize distress by helping a person feel more connected with others.
• Connecting with family members/friends/others can also be very helpful.
• Family members/friends/supportive others can help the young person figure out ways to minimize distress he/she may be feeling or help to resolve the crisis altogether. This may include helping to identify other coping strategies or resources that might be available to—maybe some the young person is not able to identify on their own. As a result, as part of developing a plan it can be helpful for the young person to identify several people that he/she feels comfortable reaching out to when in distress or in crisis.
• For some, simply being in a social setting when feeling distressed can help him/her feel more comfortable or safe, more connected with others, or more relaxed and less distressed.
• Therefore, it also be helpful to identify social settings that a person can seek out if they are unable to reach one of their social supports.
• These can include things like local coffee shops, book stores or library, churches, AA/NA meetings, support groups, etc.

Discussion:
Are there specific people that you find yourself reaching out to when you need additional support? How does this help you? Are there certain social settings in which you feel more safe or comfortable? Places that when you are in you feel more connected to others?

4) Contacting Professional and Agencies
• There may be times where these coping strategies that you or your family member used may not work as well as you/your family would like and despite best efforts additional assistance may be needed to help in managing a crisis.
• Mental health professionals or mental health agencies can be important resources in helping a person when they are distressed or in crisis and in helping family members to ensure that their family member is getting the support that they need.

• Therefore, it is important to know who to contact when additional assistance is needed and to have the contact information for those individuals readily available so that everyone is on the same page in terms of the steps that should be taken.

• This may include:

  • Who you/your family member would like you call during typical clinic hours (e.g. who is the person or place they should call first, if they can't reach that person/place who should they call next)?

  • What to do if this doesn't occur during normal clinic hours (e.g. call the pager, call 911, go to the emergency room)?

  • Are there any other people that should be called (e.g., family members, friends, providers)? Are there any specific things the young person would like others to do (e.g., ask someone to do something that would help support him/her; ask someone to take care of something for him/her while getting help)?

  • Any other action steps the young person would like others to follow?

  • List of things that have worked well when in crisis before or made getting help go more smoothly; things that did not work well and that the young person would like to avoid.

**Final Discussion Regarding Educational Information:**

*Group leaders should encourage a discussion of any of the information presented during the session and address any questions from the group.*

**Part II: Discussion Concerning Issues/Problems Faced Over the Past Month**

**NOTE TO RCs: Consider use of Recovery Videos if applicable to illustrate the concepts covered in this session.**

*After questions concerning the educational information have been addressed, group leaders should inquire if group members has faced any particular problems/had any issues arise in their efforts to cope or in trying to support their family member in their efforts to cope with client’s illness over the past month. The group leaders should work with the group to help resolve any issues or concerns. When appropriate, group leaders may engage in a problem-solving or communication skills exercise with group members to help resolve any immediate issues, address communication concerns, and support skill-building.*
Components of a Crisis Plan

(Handout for Group 5)

Identifying Warning Signs
- signs or signals that might suggest that additional support may be needed
- this can include changes in thinking, mood, or behavior

Identifying Coping Skills or Strategies
- coping strategies or skills that can be used to manage or minimize distress

Identifying Family/Friends/Others You Can Turn to for Support or Assistance
- who a person feels comfortable reaching out to when in distress or in crisis

Mental Health Professional or Agencies You or Your Family Member Can Contact to Get Additional Support
- who to call during typical clinic hours (e.g. who should be called first, if they can’t be reached who should be called next)
- what to do if someone needs to be contacted outside of normal clinic hours
- specific things others need to do
- other action steps that should be followed
Monthly Family Meeting 6 – Communication Tips and Tools

Part I: Presentation of Specified Educational Topic

Introduction to Communication Skills

- Communication can be stressful for families; however, being able to effectively communicate with each other is extremely important for families. Effective communication can be particularly important when a person in a family is experiencing symptoms of psychosis or other mental health symptoms.
- Sometimes individuals experiencing symptoms of psychosis may also have difficulties with memory, concentration, or the ability to process information effectively and efficiently. In addition, sensory experiences such as hallucinations, misperceptions or errors in thinking can be distracting and can cause individuals to lose focus when interacting with others. At times, this can make communication between family members difficult and lead to frustration and additional stress for the entire family.
- This additional stress, in turn, can lead to greater symptoms in the family member experiencing psychosis in addition to increasing distress among other family members. Therefore, by finding ways to communicate more effectively with each other you can reduce the amount of stress you and/or your family member may be experiencing.

The Impact of Psychosis on Communication

Discussion:
Ask group members how they think psychosis or symptoms of psychosis could impact communication? In what ways could it make it more difficult? Have any of the group members noticed/experienced communication difficulties in the family? What do they think has caused the difficulties?

There are a number of reasons why difficulties in communication may occur.

Feeling overwhelmed or overstimulated

Most of us have been in situations where we felt a bit overwhelmed, like things were too loud, there were too many people, too much commotion, etc. Some individuals experiencing psychosis may be particularly sensitive to this and when they feel overwhelmed or overstimulated may decide that it is better to remove themselves from the situation.

Helpful ways to respond:
- If this happens, try not to take it personally. Sometimes a family member may need to take a little break or time out from a situation.
Social situations may be stressful for individuals experiencing psychosis.

For some, interacting with others, even family members, can be anxiety provoking. As a result, individuals with psychosis may avoid initiating social interactions and seek to escape them when initiated by others.

Individuals experiencing psychosis may also be more sensitive to conflict and criticism. As a result, they may withdraw from or attempt to avoid interactions with others due to fear of criticism or rejection.

Helpful ways to respond:
- Try to be patient and understanding. Do what you can to minimize the anxiety or discomfort your family member may be experiencing.
- If a family member is more comfortable one on one or in smaller groups, you may want to limit the length or frequency of situations where there have to be in larger groups.
- Help your loved one gain confidence in his/her social skills and ability to reduce anxiety and/or discomfort in social situations by practicing with your family member. Make efforts to interact with your family member and as they start to feel comfortable, provide them with opportunities to interact socially with others.

Symptoms of psychosis

Some individuals with psychosis may hear noises or voices that other people can’t hear or see things that others don’t seem to see. Not surprisingly, for some, these voices or visions can be intrusive, distracting, and make it difficult to focus during a conversation.

- Ask the group: Have you ever been in a situation where two people have tried to talk with you at the same time? Were you able to focus on what each person was saying or were you only able to truly hear bits and pieces from each?
- Sometimes, it may appear that a family member is not listening to what others are saying or he/she responds in a way that doesn’t seem to make sense to you given the topic of the conversation. They may have difficulty sticking to one topic and seem to jump from one topic to another without an apparent reason. Hallucinations can be so distracting that it can make it difficult to pay attention to and fully process information during a conversation. As a result, he/she may miss important pieces or parts of the conversation.

Helpful ways to respond:
- It can be helpful to make sure that your communication is brief, focused, and to the point. You may want to repeat important points to make sure that your family member has understood if they seem distracted or if they didn’t appear to understand.
- Try to avoid arguing with your family member about the accuracy of false beliefs or hallucinations. This is likely to be ineffective and can lead to increased family stress and possibly an argument.
How to Improve Your Family Communication

Group leaders: Many families are good communicators, but we can all benefit from reviewing and practicing some of the basics of good communication from time to time.

Discussion:
What do you feel are effective tools/strategies to communicating effectively with others? Anything you tried that worked particularly well? Anything that did not work so well?

Suggested strategies or tools for effective communication: Be simple, brief, and to the point
- Stick to 1-2 sentences or statements; only ask one question at a time and give your family member time to answer
- This will minimize confusion and make it more likely that the other person will hear and understand what you are saying

Keep your communication focused
- Keep conversations focused on one subject at a time
- If you jump from topic to topic it will make it more difficult for others to concentrate on what you are saying and to understand the point you are trying to make.
- You may want to give an example of this: Example: “I am upset that you have not been taking you medication. I am concerned that because it seems like your voices are getting worse and you have been spending a lot of time by yourself. Plus, you haven’t really been talking with us and spending time with the family. We really need to figure out a time to schedule a dinner with the rest of the family. You’ll need to check to see what your schedule is at work so we can do that.”

Focus on behavior and be specific
- It is much easier for someone to change a behavior than it is to change their feelings or personality
- Focusing on the behavior that is making you feel the way you do and be specific about what that behavior is making you feel, that way you will help others better understand what you are trying to say.

Examples:
OK: I am proud of you.
BETTER: I am really proud of how hard you have been working at school.

OK: I am really concerned about you.
BETTER: I am concerned about you because you seem to be spending a lot of time alone in your room.
Listen to what others have to say
- You will better understand what your family member is trying to say if you listen; listening is a skill and you may need to make a conscious effort to listen to your family member when you are having a conversation, especially if you are angry, upset, or frustrated.
- Everyone is entitled to express how they feel or their thoughts on a subject and to be heard by the person that they are speaking with.

You can let your family member know that you are listening in a number of ways
- You can make comments like “uh-huh” or “okay”
- You can repeat back what the other person says to show them that you are listening and that you understand the point they are trying to make.
- You can use nonverbal cues, like eye contact and nodding, to show that you are listening.
- Use “feeling” and “I” statements to let family members know how you are feeling in a supportive and noncritical way.

Feeling statements
Use a feeling word to help family members better understand what you are feeling (e.g. angry, upset, happy, pleased, concerned, sad, proud)

I statements
Using I statement makes it clear that you are the one experiencing the feeling or thought.
Ex: I am proud of the work you have done
Ex: I am concerned that you seem to be feeling more depressed lately

Stay calm and be patient
Do your best to remain calm and patient; the more calm and patient you are the greater the likelihood that you will get a better response.

Tone of voice
People tend to respond better and are more likely to listen to what you are saying if you express your thoughts or feelings with a calm tone of voice.

Group leader: may want to use discriminant modeling here to demonstrate the difference; for example, model an example of saying “It would really be helpful if you could clean up your room” in a calm tone of voice and then in an angry/frustrated tone of voice. Have group members discuss the difference between the two and how they are likely to respond to both.

Listen to what your family member is saying
- When a person is angry/frustrated they are more likely to interrupt the other person they are talking to.
- Try to listen to what they have to say before expressing you own thoughts.

Be respectful of each other
- Make sure each person has a chance to talk and do not interrupt each other. Everyone has the right to be heard.
• Do not talk down to your family member (e.g. “You are acting like a child,” “You don’t know what you are talking about”) or call each other other names.

**Limit other distractions that might make communication more difficult**

• The more distractions a person is facing the harder it is to communicate effectively. While you may not be able to minimize some distractions (e.g. psychotic symptoms) you can limit environmental ones.
• Turn off the TV or the radio
• If need be, go to a quiet room or somewhere away from others not involved in the conversation

*Group leader: Some individuals with psychosis may benefit from additional communication or social skills training to help him/her feel more confident and comfortable interacting with others or in specific situations (e.g. work, dating, job interviews, etc). Similarly, some families may benefit from strengthening their communication within the family. Group leaders should let group members know that in this group they touched on some of the basics of effective communication but that the OnTrackNY team provides a number of services that can help individuals and families strengthen their communication skills and help them communicate more effectively and successfully, including social skills groups, working individually on communication skills, or working with the family to strengthen communication within the family.*

**Final Discussion Regarding Educational Information:**

*Group leaders should encourage a discussion of any of the information presented during the session and address any questions from the group.*

**Part II: Discussion Concerning Issues/Problems Faced Over the Past Month**

**NOTE TO RCs: Consider use of Recovery Videos if applicable to illustrate the concepts covered in this session.**

*After questions concerning the educational information have been addressed, group leaders should inquire if group members have faced any particular problems/had any issues arise in their efforts to cope or in trying to support their family member in their efforts to cope with the client’s illness over the past month. The group leaders should work with the group to help resolve any issues or concerns. When appropriate, group leaders may engage in a problem-solving or communication skills exercise with group members to help resolve an immediate issues, address communication concerns, and support skill-building.*

*Given the topic of this session, if appropriate and if the group members are willing, the group leaders can engage in a communication skills exercise with the group members. The group leaders can either choose a particular communication issue/situation mentioned during the group or one of the key communication skills (e.g., expressing positive feelings, expressing negative feelings, making a request, compromise and negotiation, etc.). Group leaders then can model how the skill is done and if group members are willing, have one or two families practice.*
Monthly Family Meeting 7: Stigma

Part I: Presentation of Specified Educational Topic

Materials Needed:
Handout: What is Stigma?
Handout: Facts and Myths about Mental Illness

Introduction Experiential Exercise:

Group Leader ask group members to raise their hand if:
- You went to a doctor’s appointment in the past year.
- You were admitted to a hospital for any reason over the past year.
- You took any medication over the past year.

How would your feelings about raising your hand in a group setting change if you were asked to raise your hand:
- If you saw a mental health professional over the past year.
- If you took psychiatric medications over the past year.

Discussion:
- How would you feel about answering the second set of questions in a public setting? How are these questions different from the previous ones? What makes them different?
- How does this activity relate to your loved one’s experience of having a mental illness?

What is Stigma? (Give “What is Stigma” handout and “Myth/Facts” handout).
- Mental Illness Stigma is the negative attitudes and discrimination that people with mental health problems face as a result of stereotypes and biases about mental illnesses that are believed by individuals, groups, and/or social institutions.
- Stigma comes from STEREOTYPES that some members of society hold about people with mental illnesses.

Discussion:
What are some common stereotypes about people with mental illness/people receiving mental health treatment?
Where do you think stigma/stereotypes come from? What are some sources of stigma?
Possible answers:
- Portrayals of individuals with mental illnesses as violent/unable to contribute to society (e.g. the media/movies/books)
- Lack of knowledge/ignorance
- Fear of what is different
- Avoidance/lack of exposure to people with a mental illness
- Acquaintances/sometimes even family/friends
One thing that is important to be aware of is that these stereotypes are false.

Discussion:

What do you see as evidence for why these stereotypes are false?

See the handout “Facts and Myths about Mental Illness” for a list of these myths. These stereotypes are FALSE, but they can still affect a person’s life. So when a person is faced with them or finds him/herself thinking about them it is important to try to remember that they are not true.

How do you think stigma impacts a person with a mental illness? Possible answers:
- Feel angry, disrespected, dismissed, sad, frustrated, worthless
- Social discomfort
- Feeling Different/alienated from others
- Isolation; may avoid people/places (can lead to reduced social support)
- Decreased self-esteem
- Problems in loved one’s getting/maintaining employment
- Challenges in getting housing
- Insurance Issues
- Seeking treatment (According the NIMH, one in four or five adults has a diagnosable mental disorder in a given year. However, only about half seek treatment. This can be attributed to many causes, including lack of access to treatment/lack of insurance. However, stigma is also a likely culprit).

What is internalized stigma, and what are its impacts?
Sometimes stigma can even come from within ourselves. Internalized Stigma (also called Self Stigma) is when people stigmatize themselves by believing that negative stereotypes about people with mental health problems are true of themselves. One false stereotype is that people with mental health problems are erratic, unpredictable, and undependable. A person who internalizes this might come to believe that because they are receiving mental health treatment/have a diagnosis, they then must also be erratic, unpredictable and undependable. Therefore, because they don’t feel that they are dependable, they may decide that they cannot hold down a job. Other consequences include:

- Feeling embarrassed of having a mental illness, although it is not his/her fault
- Low self-esteem / beating themselves up
- Anger at themselves
- Depression, isolation, fear or disinterest in trying new things
- Having lowered expectations for the future
How does stigma impact families?
Sometimes families experience stigma because they have a family member who has a mental health diagnosis or is receiving mental health treatment. “Associative Stigma” is a term for the stigma and discrimination of others due to their association with a relative with a mental illness.

Unfortunately, the history of mental health treatment in America contributed to the stigmatization of families. For example, in the 1960’s mental health professionals were taught that schizophrenia was caused by being raised by a cold/unavailable mother (which has since been discredited). This unfortunately contributed to a culture of “family blaming.” Although this has been shown to be untrue, some individuals may still believe this and some family members still experiences this judgment from others sometimes.

Discussion:
What are some other stereotypes/myths about family members of individuals with mental illness? Have you or your family members ever experienced these?

Possible answers:
- The family (oftentimes the mother) is to blame for their child’s illness
- Mental illness is a result of bad parenting
- Family is to blame when a person is not doing well/if a relative relapses
- Parents of children with mental illness are not as responsible or caring as other parents
- Family is responsible for taking care of the individuals/responsible for their actions/behavior

How do you think stigma might affect a family member?
- Lead to anger, depression, guilt/blame, frustration
- Could isolate, separate themselves from their social support
- Often, an understandable result of social stigma is that family members attempt to conceal their families member’s illness/treatment from others. Studies have shown 1/5 to 1/3 of families report a strained relationship with other family members or friends as a result of their family member’s illness.
- Similar to an individual experiencing psychosis, family members may stigmatize themselves

What can you do to combat stigma?
One thing that is important to be aware of is that these stereotypes are false. So when you are faced with them or find yourself thinking about them try to remind yourself that they are not true.

On a small scale:
- Be aware the stereotypes are false; so when you are faced with them or find yourself thinking about them try to remind yourself they are not true so you don't internalize them.
- Point out and help to correct any misconceptions about mental illness by sharing knowledge.
• Share your story with others.
• Educate yourself about mental illness and recovery: workshops, presentations, articles/books, OnTrackNY Team Family Nights, NAMI Family to Family.
• Praise your loved one and yourself for seeking help and support.
• Surround yourself with people who are supportive.

**On a larger scale:**

Get involved in larger advocacy efforts and groups like NAMI stigma busters, On our Own, legislative efforts, responding to stigmatizing materials in the media, etc.

Remember that you are not alone! Research has shown that one in four Americans will experience a serious mental illness at some point during the course of his or her life. That means that mental illness has touched most families as well. Many celebrities have disclosed their mental health struggles: Mariah Carey, Rosie O’Donnell, Oprah Winfrey, Elton John, Robin Williams, and Ben Affleck.

**Discussion question:**
If there was one message you would want to give the public about mental illness, what would it be?

**NOTE TO RCs: Consider use of Recovery Videos if applicable to illustrate the concepts covered in this session.**

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What is Stigma?
(Handout for group 7)

Negative attitudes and assumptions directed towards people with mental illnesses. It is disrespectful and harmful to everyone.

Myths about mental illness are false, but common. Believing them can lead people to avoid, disrespect or discriminate against people who have mental illnesses.

Fear of being treated badly (fear of stigma) can discourage people with mental illnesses and their families from getting assistance and striving to reach their goals.

An estimated 44 million Americans experience a mental disorder in any given year.

Yet, many people would rather tell employers they committed a petty crime and served time in jail than admit to being in a psychiatric hospital.

What is stigma?
Stigma leads to fear, avoidance, mistrust, and even violence against people living with mental illness and their families. And it can cause families and friends to turn their backs on people with mental illness.

Stigma can also lead individuals who have mental illness to feel badly about themselves.

To avoid stigma...

DO use respectful person-first language, such as “a person with schizophrenia” or “someone using mental health services”

DO focus on a person’s abilities and strengths, not his or her limitations.

DO tell someone, respectfully, if they express a stigmatizing attitude.

DO learn more about mental illness, helpful treatments, and the strengths of people who live with it.

DON’T use terms like crazy, lunatic, maniac

DON’T use someone’s diagnosis instead of their name, such as “a schizophrenic” or “the mental patient”

DON’T use generic labels such as retarded, or “the mentally ill”

DON’T portray successful persons with disabilities as exceptions to the usual

DON’T avoid or discriminate against people who receive mental health services

Adapted from “Anti-Stigma: Do You Know the Facts” (SAMHSA’s Center for Mental Health Services, and the National Mental Health Association)
# Facts and Myths about Mental Illness?

(Handout for group 7)

<table>
<thead>
<tr>
<th>FALSE MYTH</th>
<th>TRUE FACTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with mental illness are dangerous</td>
<td>People with mental illness are much more likely to be victims of violence rather than perpetrators. As in the general population, only a very small percentage of people with mental illness ever commit violent acts.</td>
</tr>
<tr>
<td>People with mental illness do not make significant contributions to society.</td>
<td>Abraham Lincoln, Catherine Zeta-Jones, Jim Carrey, Beethoven, Ernest Hemingway, Shawn Colvin, Brooke Shields, John Nash, Herschel Walker, are just some of the many accomplished people who have or had a mental illness. Non-famous people with mental illness make important contributions to society and their families and communities every day.</td>
</tr>
<tr>
<td>People who have a mental illness cannot get better.</td>
<td>People can and do recover from and manage mental illness, when they have the proper tools and support. Many people with mental illnesses are in recovery and leading active lives. Sometimes, people with mental illness completely recover.</td>
</tr>
<tr>
<td>People with mental illness need constant assistance.</td>
<td>Many people with mental illnesses live independently in their own houses or apartments, manage their own money, arrange their own social activities and hold jobs. Everyone, mental illness or not, needs assistance sometimes.</td>
</tr>
<tr>
<td>Mental illness is a sign of personal weakness - people with mental illness could get better if they really wanted to.</td>
<td>Mental illness is an illness, just like heart disease and diabetes. It is not a character flaw, a weakness or laziness. Recovery from any illness is more successful when the person has the proper support.</td>
</tr>
<tr>
<td>People with mental illness are unpredictable and unreliable.</td>
<td>Like everybody, people with mental illness can sometimes behave in unpredictable ways. However, most of the time, people with mental illness present few surprises to those who know them. Once they know themselves, people with mental illness can be aware of what they can commit to and carry through. Most are very dedicated to their values and responsibilities.</td>
</tr>
<tr>
<td>People with mental illness are stupid.</td>
<td>Many studies show that most mentally ill people have average or above average intelligence. Mental illness, like physical illness, can affect anyone regardless of intelligence, social class, or income level.</td>
</tr>
</tbody>
</table>
Monthly Family Meeting 8: Substance Abuse FEP

Part I: Presentation of Specified Educational Topic

Materials Needed:
Handout: Psychoactive Substances and Their Effects
Handout: Consequences of Drug Use in Patients with Mental Illness
Handout: Reasons Why People with Mental Illness Use Drugs
Handout: Triggers to Alcohol and Drug Use

I. Psychoeducation on alcohol and drugs generally and in FEP

A. Define psychoactive substances and describe their effects

Drugs are also called psychoactive substances and they affect the way people feel, how they think, or how they perceive the world around them. Examples include alcohol, marijuana, and cocaine. This handout (Psychoactive Substances and Their Effects) helps to explain the effects of each of them.

Review handout. Ask family members what they know, their experience.

B. Explain how substances affect people with a mental illness

Substances such as alcohol, marijuana, and cocaine can produce even more serious effects in people with a mental illness. Psychoactive substances can have a negative effect on mental illness in two ways. First, the substances can directly affect the brain chemicals responsible for the illness, which make the illness worse. Second, substances can interfere with medications used to treat mental illness, making them less effective. People with a mental illness are often highly sensitive to the effects of psychoactive substances like alcohol and cocaine. This means that people with a mental illness are often affected by even small quantities of drugs.

C. Consequences of drug use in people with a mental illness

Substance use can cause a variety of different negative effects in persons with a mental illness. The specific consequences depend on the individual and the type of substance used. Some of the most common consequences experienced by persons with a mental illness are listed on this handout (Consequences of Drug Use in Patients with Mental Illness).

Family members can also experience many negative consequences of their loved one’s substance use. Family members often have to give their loved ones money or have things taken from them by the family member with mental illness to procure substances. Family members often experience a lot of anger, worry, fear, and unhappiness because of their loved one’s substance use. Family members are often asked to run their loved one’s lives, take care of them both when they have increased symptoms of mental illness and when they are high, hung-over, or in withdrawal.
Have some discussion here – ask family members about their experiences.

II. Reasons for substance use

A. Your loved ones are not trying to hurt you with their drug use

People with a mental illness use drugs for lots of reasons. Here is a handout that summarizes them (Reasons Why People with Mental Illness Use Drugs). It’s important to understand why people use drugs because it helps us to understand that they are not using simply to get into trouble or because they are weak or bad. Really, your loved ones use drugs to feel better and to fit in, and after a while they just use drugs without even thinking about it. It becomes a habit. We need to remember this because helping your loved ones can get frustrating and can take a long time. No one knows this better than you – you have been trying to help them for a long time now. But if we can remember that they are not trying to hurt us with their drug use, I think we will be able to keep being positive and supportive. Also, learning why people use drugs shows us several places where we might be able to help.

Have some discussion here – ask family members about their experiences.

B. Explain habits, cravings, and triggers

1. Habits

People who continue to use drugs/drink even though bad things can happen to them have developed a HABIT of using which means they have gotten used to using drugs/alcohol when they feel a certain way or in different situations. A habit is a routine – something that you do without thinking about it-like sitting in the same seat every day in class or at the dinner table. Habits are things we do automatically, without thinking. Some habits are useful, like saying ‘Thank you’ when someone holds an elevator door open for us. Other habits are not useful, like biting your fingernails or scratching a sore. Using drugs/drinking can be a habit that is not very useful: you can use without thinking about whether you really want to or not because you are used to doing it at a certain time or in a certain place, or when someone asks you to.

2. Cravings

Another reason people use drugs is because they have cravings. Cravings are very strong physical urges or needs to use/drink. Sometimes a craving can be so strong it hurts, and the person can’t think of anything else until they take the drug/drink to reduce the bad feelings. Cravings are the body’s way of telling us that it really needs something, like hunger pangs. In the case of hunger, the body has a natural need for food, and when it needs more, it sends out signals that are hard to ignore, kind of like an alarm going off that says, “Feed me.” Cravings occur because drugs gradually make changes to the brain. When a person first start using drugs, the brain doesn’t expect it, it just reacts to the sudden change caused by the chemicals. Gradually, the brain starts to adapt, and after a while it needs the drug to function properly. Unlike your stomach, brain cells don’t mess around by sending out gentle reminders
to eat: they hit you with a sledge hammer: “I want drugs NOW and I’m going to make you feel miserable until I get some.”

The important thing to remember is that a craving doesn’t last forever. When a craving begins, it will increase for several minutes, hit its peak (the point where it feels the worse), and then begin to fade away. Depending on what drug and how much a person uses, this process may take as little as about 7 to 10 minutes. One reason that people become dependent on drugs is that the drug immediately removes the craving and any uncomfortable feelings that come with it. But, remember, the craving will go away on its own if the person waits it out. We will talk about ways to cope with those times when cravings seem overwhelming. The longer that someone goes without using drugs/alcohol, the fewer cravings he/she has. Also, the longer a person goes without using, the amount of time between cravings increases. We will also talk about how to avoid situations that produce cravings and make it easier to wait it out until the craving goes away.

In order to understand your loved one’s substance use, we need to think about the different situations or things that lead him/her to use. Lots of times people experience physical cravings in certain situations that they connect to their drug use. Sometimes, there are people, places, or things that the young person connects to using that can cause cravings. We call them “triggers,” because they can trigger, or cause, a craving. Triggers can be people, places, things, times of day, emotions, or physical feelings that a person learns to associate with drug use. The two become connected, so that these things or situations become powerful reminders of drug use. This handout summarizes some common triggers (Triggers to Alcohol and Drug Use).

3. Triggers and high-risk situations (HRSs)

Cravings can be triggered by people, places or things that a person connects to using/drinking. This happens because things the person associates with using or drinking – such as people, places, feelings, situations, objects, times of day, smells/sounds/sensations – can remind him/her of the pleasurable feelings they get from actually using drugs/drinking.

Put flow chart on board:

Triggers ===> People ===> Remember ===> Cravings
or Causes    Places,       pleasurable       Urge to Use etc.
            Things          feelings

Different types of triggers:

- **People** - sometimes being with a person that you have used with in the past or that you use with now, is all it takes for you feel like you want a hit or a drink.

- **Places** - just being somewhere that you used, or even being in the area where you use or used can cause you to crave.

- **Things/Times of Day** - sometimes different things or certain times of the day can be a trigger for some people to want to use drugs or alcohol. For example, seeing the drug, or maybe seeing a pipe may trigger you to want to use. Also, you may want to use more when you have just gotten paid, just eaten a meal, or when you get up in the morning, or before
you go to bed at night.

- **Smells/sounds/sensations** - for some people, the smell of the drug/alcohol, or even the smell of cigarettes can be triggers to use. Also, the sound of traffic or certain kinds of music can be a trigger. Some other triggers may include seeing someone having a drink or taking a hit.

- **Feelings** - Sometimes people use when they feel a certain way. Some people use when they are feeling good, and other people tend to use more often when they are feeling bad.

Sometimes, several triggers will often occur together, which can make it really difficult to not use/drink. High-risk situations occur when there is more than one trigger. When the young person is in a situation where his triggers are present, he is in what we call a high-risk situation. These situations are called High-risk situations because there is a high risk that the individual will use when he is in them. High-risk situations occur where there is more than one trigger or when there is one really strong trigger.

**Part IV: Discussion Concerning Issues/Problems Faced Over the Past Month**

**NOTE TO RCs: Consider use of Recovery Videos if applicable to illustrate the concepts covered in this session.**

After questions concerning the educational information have been addressed, group leaders should inquire if group members have faced any particular problems/had any issues arise in their efforts to cope or in trying to support their family member in their efforts to cope with client’s illness over the past month. The group leaders should work with the group to help resolve any issues or concerns. When appropriate, group leaders may engage in a problem-solving or communication skills exercise with group members to help resolve an immediate issues, address communication concerns, and support skill-building.
### Psychoactive Substances and Their Effects

(Handout for group 8)

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Slang Names</th>
<th>How is it Taken?</th>
<th>What are the Effects?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol</td>
<td>Booze Brew</td>
<td>Drinking</td>
<td>Relaxation, Sedation, Slowed Reaction Time, Impaired Judgment, Loss of Inhibition</td>
</tr>
<tr>
<td>Marijuana</td>
<td>Pot Reefer Weed Joint Dope Grass</td>
<td>Smoking Eating</td>
<td>Relaxation, Mild Euphoria, Altered Sensory Experiences, Fatigue, Anxiety, Panic, Increased Appetite, Paranoia</td>
</tr>
<tr>
<td>Cocaine</td>
<td>Coke Crack Rock Ready</td>
<td>Snorting Smoking Injection</td>
<td>Increased Alertness/Energy, Decreased Appetite, Positive Feelings, Anxiety, Tension, Feeling Jittery, Racing Heart, Paranoia</td>
</tr>
<tr>
<td>Heroin</td>
<td>Smack Horse H</td>
<td>Injection Snorting</td>
<td>Euphoria, Pain Relief, Sedation, Slowed Reaction Time, Impaired Judgment</td>
</tr>
</tbody>
</table>
Consequences of Drug Use in INDIVIDUALS with A Mental Illness
(Handout for group 8)

Health Consequences:
- Symptom relapses or hospitalizations
- Depression and increased risk of suicide
- Risky sexual behavior and infectious disease
- Health problems

Social Consequences:
- Legal problems
- Housing instability or homelessness
- Financial problems
- Family conflict
- Poor social relationships
- Anger and violence problems
- Poor work or role functioning
- Giving up important activities

Victimization Consequences:
- Becoming a target for predators
- Exposure to dangerous situations

Substance-Related Consequences:
- Increased tolerance
- Using more substances than planned
- Cravings
- Withdrawal (such as headaches, nausea, tremors)
- Spending large amounts of time involved in getting or using drugs
REASONS WHY PEOPLE WITH A MENTAL ILLNESS USE DRUGS
(Handout for group 8)

1. **To Be Social**: People with a mental illness may feel that using drugs or alcohol helps them better relate to others and makes them less anxious around other people. Sometimes, they feel pressured to use by other people and don’t know how to say “No.”

2. **To Feel Normal**: Some people with mental illness use substances because it helps them feel "normal" and accepted by others. Sometimes people feel as though they don’t have a mental illness or are different from others when they are using drugs or alcohol.

3. **To Self-Medicate**: Other people use substances in an attempt to reduce unpleasant symptoms. People sometimes use substances to reduce anxiety, depression, sleep problems, tension, hallucinations (like hearing voices), and medication side effects.

4. **To Feel Pleasure**: Some individuals use substances because it is one of the few sources of pleasure they experience. Sometimes they believe it enhances other enjoyable activities.

5. **Out of Habit**: Some people who have used drugs or alcohol for a long period of time continue to use simply because it has become part of their daily routine -- a habit. They use substances automatically, without much thought, almost like brushing your teeth or taking a shower.

6. **Due to Cravings or Withdrawal**: Individuals who use larger quantities of substances may develop cravings for these substances, or they may experience withdrawal symptoms if they stop using them suddenly. These symptoms are often physical symptoms like nausea, headaches, or tremors. Substance use for these individuals may be primarily motivated by the desire to avoid the cravings or withdrawal symptoms.
A trigger is something that an individual connects to drug use that can cause him or her to have a craving.

Triggers can be:

1. **People:** Sometimes being with a person that they have used within the past can make people want to use drugs.

2. **Places:** Just being somewhere that they used, or even being in a similar area where they have used, can cause people to have cravings.

3. **Things:** Sometimes different things that are associated with drug use can be a trigger. For example, seeing a beer commercial, pipe, a needle, or the actual drug.

4. **Certain Times:** Certain times of the day can be a trigger for some people to want to use drugs. For example, some people use more in the morning or evening. Also, triggers can be certain times of the year, like around the holidays, or certain times of the week, like over the weekend or when payday comes.

5. **Smells, Sounds, and Sensations:** For some people, the smell of the drug, or even the smell of cigarettes can be triggers to use. Also, the sound of traffic or certain kinds of music can be a trigger.

6. **Feelings:** Sometimes people use when they feel a certain way. Some people use when they are feeling good, and other people tend to use more often when they are feeling bad.

7. **Combinations:** Sometimes, many triggers occur together, and this can make it really difficult for someone to not use drugs. For example, if someone is with a good friend who uses drugs, walking through a neighborhood where drugs are sold, and they have money in their pocket because they just got paid, it might make the person want to use. These sorts of situations can be really hard for people to deal with. We call these High Risk Situations.
Monthly Family Meeting 9: Substance Abuse in FEP

Part I: Presentation of Specified Educational Topic

Materials Needed:
Handout: Community Resources: Information on Self-Help Groups for Family Members and Friends of Substance Users

I. Different stages of change
It’s important for you to know that lots of people who use drugs have the same sort of pattern: there are times when they are not using and things are going well mixed in with times when they are using and things are not going well. For people who don’t use drugs, it is often confusing to try to understand why people use and why they can’t see how bad it is for them and how many problems it causes. It is also confusing to try to make sense of why people start using again after a long time of being clean.

What we know from working with lots of people who use drugs is that drug use is kind of like a cycle, and people may go through many times of using and non-using before they stop for good.

There are different points in this cycle that people can go through: 1) times when they are using and don’t want to stop no matter how bad things seem; 2) times when they are using and would like to stop but aren’t sure how; and 3) times when they want to stop and ask for help and ideas and ways to stop that might work. Others might be at the stage where they have stopped for a little while and are trying to keep it up, and many will relapse and go back in the cycle and have to work their way through again.

The important thing to remember is that just because your loved one is using now doesn’t mean that you and I together can’t help him get to another stage in the cycle. We just have to figure out how to move him from just thinking about stopping to trying it out for a while. Some people think that yelling at their loved will get him to stop.

II. Harm reduction
Another thing that we think is important is that anyone who needs or wants treatment for drug use should be able to get it. At many treatment programs, clients are not able to attend if they are using drugs. This is often tough for a family member who has finally convinced their loved one to go to treatment, only to have the treatment program tell the client to leave because he is not able to stop using right away.

We think that anyone who needs or wants treatment should be able to attend our groups, even if they are using. So, as part of the young person’s participation in the treatment group, he/she does not have to be abstinent from using drugs. We use what’s called a harm reduction approach and view any reductions in use as a positive step that will decrease the client’s overall level of harm. This means that the young person can come to groups even if he/she is still using. We feel that that is the time when he/she really needs treatment the most. There are several reasons why we think this
is a good approach. **First**, people with psychosis sometimes have a lot of trouble thinking and understanding things, and this makes it really hard for them to stop using. Stopping can take a long time and lots of hard work, and much of the work at the beginning of treatment is focused on helping them to be comfortable in treatment and help them get to their treatment appointments on time. Many clients need a lot of time to feel comfortable attending sessions and sitting with a group of people. Any reductions in use made at any point in this process are significant in and of themselves, and may bring a client closer to eventually attempting abstinence. **Second**, clients often abuse lots of substances, making it very unlikely that they could totally stop using drugs at the start of treatment. We want clients to stop using, but cutting down on their use is also praised and encouraged when someone is unwilling or unable to abstain. **Third**, requiring clients to totally stop using right away could very well turn some clients off to treatment, especially people who are not sure about stopping. We try to get people who are using to think about stopping or cutting down, and to teach them skills that they can use when they decide to stop. This is a new idea for a lot of people: that you can go to treatment while still using drugs.

**IV. Barriers to change**

*Change is very hard. It’s hard for all of us and it’s hard for your loved ones. There are lots of things that keep people from making changes that would be good for them.*

*Generate discussion about what makes it hard to change substance use. Keep a list on the board. There are positive things about drug use. Discuss how this means that clients will have to learn other ways to feel better without using drugs/drinking and that this can be a difficult process for many people.*

People often feel bad when they don’t make a change that they know they should make.

*Generate discussion around what keeps their loved ones from changing and how they think their loved ones feel about this.*

Getting support, learning what’s helped others – can be good ways to get ideas or help cope with feelings.

**V. Discussion Concerning Issues/Problems Faced Over the Past Month**

**NOTE TO RCs:** Consider use of Recovery Videos if applicable to illustrate the concepts covered in this session.

*After questions concerning the educational information have been addressed, group leaders should inquire if group members has faced any particular problems/had any issues arise in their efforts to cope or in trying to support their family member in their efforts to cope with client’s illness over the past month. The group leaders should work with the group to help resolve any issues or concerns. When appropriate, group leaders may engage in a problem-solving or communication skills exercise with group members to help resolve an immediate issue, address communication concerns, and support skill-building.*
These community organizations provide information and support to people receiving mental health services and their families. They all will welcome your calls, letters, or email. If one does not meet your needs, try another. “Family” refers to anyone with a close family-like relationship, regardless of biological or legal status.

1. **The National Alliance for the Mentally Ill (NAMI),** http://www.nami.org. NAMI is a national support and advocacy organization of and for families and friends of people with serious mental illness. Local family support groups, phone assistance, practical support, and other resources are available for free.

   *Maryland: NAMI MD* is located at 10630 Little Patuxent Parkway, Columbia, MD 21044-3264 410-884-8695 info@namimd.org and the web site is www.namimd.org

   *DC: NAMI National* is located at 3803 Fairfax Dr, Ste 100, Arlington, VA 22203. 703-524-7600 or the helpline at 800-950-6264

2. **On Our Own of Maryland, Inc.** is a statewide mental health client education and advocacy network, sponsoring workshops and conferences throughout the year. Also many of its affiliates/chapters across the state have (free) drop-in centers, support groups, and other activities – call for a list.

   1521 South Edgewood Street, Suite C, Baltimore, MD 21227 Phone: 410/646-0262 or 800/704-0262 http://www.onourownmd.org/ E-Mail: onourown@frontiernet.net

3. **Depression and Related Affective Disorders Association (DRADA).** A client and professionally run organization working to alleviate the suffering of depression and bipolar disorder through free support groups and one-to-one peer support – both for people receiving services and for their family members – as well as education and information. Works with the Psychiatry Department of Johns Hopkins University.

   Meyer 3-181, 600 North Wolfe Street, Baltimore, MD 21287-7381 Phone: 410/955-4647 or from Washington, D.C. 202/955-5800 http://www.med.jhu.edu/drada; E-mail: drada@jhmi.edu

4. **West Virginia Mental Health Clients Association.** Available to answer questions about client activities in West Virginia. 1036 Quarrier 208A, Charleston, WV 25301; Phone: 800/598-7303 or 304/345-7312 http://www.contac.org/WVMHCA
5. **Black Mental Health Alliance, Inc.** Provides training, education, consultation, support groups, and resource referral regarding mental health and related issues, with guiding principles of concern for others, integrity, respect for diversity & empowerment.

2901 Druid Park Drive, Suite A110, Baltimore, Maryland 21215; Phone: 410/225-7600

6. **Office of Client Affairs/Maryland Mental Hygiene Administration.** State office with a wealth of information about statewide client organizations. Also active in addressing and advocating for mental health system issues. 201 W. Preston Street, 4th floor, Baltimore, MD 21201; Phone: 410/225-1381

7. **National Mental Health Association.** Dedicated to promoting mental health, preventing mental disorders and achieving victory over mental illnesses through advocacy, education, research and service. A wealth of information and advocacy, and OnTrackNYs to local & state Mental Health Associations.

1021 Prince Street, Alexandria, VA 22314-2971; Phone: 703/684-7722 or 800/969-NMHA
http://www.nmha.org

8. **The National Empowerment Center, Inc.** Run by mental health clients/survivors, the NEC provides a wide variety of hopeful, useful information about mental illnesses, recovery, advocacy, referrals, and client organizations, as well as policy work.599 Canal Street, Lawrence, MA 01840; Phone: 800/769-3728 http://www.power2u.org
Monthly Family Meeting 10: Substance Abuse in FEP

Part I: Presentation of Specified Educational Topic

Materials Needed:
Handout: Ways to Reward Abstinence
Handout: Positive Reinforcement for not Using Drugs
Handout: Rules for Calm and Effective Communication
Handout: Coping with Frustration

I. Encouragement and support for getting help

Friends and family members can be help clients stay in treatment. Significant others can help remind clients why treatment is important, express support as they enter and continue treatment, and give help as they pursue treatment.

II. Assist the team

Treatment professionals can learn about the client from the family. Although we have knowledge about substance abuse treatment in patients with psychosis, you have far more knowledge about your loved one in particular. This information can be very useful during treatment. The family knows the client better than we do. Many times we are meeting the client for the first time and because we don’t have an established relationship with him/her, it can be difficult to get them to come to see us or to attend a treatment group. Your role is important because you have been around the your loved one for a long time, and know things about what has been helpful in the past. You have a good chance of being able to convince the young person to go to the doctor’s appointments, take medication, and attend treatment groups. He/she sees you as someone who loves and cares about him/her. Our thinking is that if you can work together with us, maybe we can figure out how to best get your loved one to attend treatment and get him more of what he needs once treatment starts.

III. Positive Reinforcement for Non-Drug Using Behaviors

The goal of this section is to identify ways that a family member can reward the client for not using, and teach him/her how to properly use positive reinforcement.

A. Identify ways that the family can reward abstinence

Let’s try to come up with ways that you can reward your loved one when he is not using. Here is a handout (Ways to Reward Abstinence) with some ideas that have been helpful in the past. Let’s come up with some ideas about which of these things you would feel comfortable doing to reward your relative when he is not using. Sometimes, the short-term consequences of not using can be a positive influence in someone’s decision to stay clean. For example, if your relative is specifically rewarded or complimented for staying clean, this can help him stay clean in the future. We call these rewards positive reinforcement, because it is reinforcing non-drug using behavior. However, there are certain rules about how and when you should use positive reinforcement. This handout summarizes some of the rules (Positive Reinforcement for Not Using Drugs).
B. Teach family how to apply positive reinforcement
1. First, it is important that you can tell when your relative is under the influence or hung-over. Rewards should only be given when he is clean, sober, and not hung-over.
2. It is important to communicate to your relative that the reward is being given because he is not using (Refer to examples in Ways to Reward Abstinence Handout).
3. It is also important to realize that using positive reinforcement is different from what we call “rescuing” or “enabling.” Rescuing is when people do things for the client that they are unable to do because of substance use or hangovers. For example, doing laundry or mailing out bills for clients who are too high to do it themselves. Enabling means that people do things that make it easier for clients to use drugs. For example, calling the client’s workplace to tell the boss that he is sick and won’t be in. Positive reinforcement, on the other hand, means you are rewarding non-drug using behavior.

C. Rules of calm and effective communication
Review handout. Calm and effective communication is always important when talking to your loved one about drug use or anything else.

IV. Coping with Frustration
This section teaches the family ways to cope with frustration. When discussing this material, be sure to tailor the discussion to that particular client/family, and to review the following key points (sample questions in italics):

Explain why frustration might occur. A tough situation might test your ability to remain calm while going through these skills. This is particularly relevant to situations in which the young person is using or has recently used, or in other situations in which you don’t feel perfectly safe with him. You might do your best to use these communication skills, but there might come a time when you get frustrated. We need to have some sort of plan for what you can do if you start getting frustrated, either while you are using these skills, or because whatever issues you are talking about don’t seem to be getting solved.

Devise a plan for coping with frustration. There are several different things you can do to cope with this frustration. Let’s come up with a plan for what might be helpful for you if this occurs. This handout (Coping with Frustration) lists several different ideas.

VI. Discussion Concerning Issues/Problems Faced Over the Past Month

NOTE TO RCs: Consider use of Recovery Videos if applicable to illustrate the concepts covered in this session.

After questions concerning the educational information have been addressed, group leaders should inquire if group members have faced any particular problems/had any issues arise in their efforts to cope or in trying to support their family member in their efforts to cope with client’s illness over the past month. The group leaders should work with the group to help resolve any issues or concerns. When appropriate, group leaders may engage in a problem-solving or communication skills exercise with group members to help resolve any immediate issues, address communication concerns, and support skill building.
WAYS TO REWARD ABSTINENCE
(Handout for group 10)

1. **Praise**: Praise your loved one for entering treatment and trying to stay clean (i.e., give positive verbal feedback).

   "John, I am so happy that you decided to start treatment, and you are clean, sober, and attending your groups. You are doing a great job, and I’m proud of you!"

2. **Support**: Offer your loved one support during the difficult transition into treatment (i.e., give positive verbal feedback, offer to help them with a problem).

   "John, I am so happy that you are clean and sober right now. I know it can be difficult trying to stay clean, is there anything you need my help with?"

3. **Offer Help**: Offer to help your loved one by doing a favor (i.e., take them shopping, give them a ride).

   "Since you’re clean and sober and you’ve been working so hard in treatment, how about I take you to the store today and help you with your grocery shopping?"

4. **Spend Time Together**: Spend time with your loved one doing a fun activity that does not involve drugs (i.e., go to a movie, church, or out to dinner, go to visit family or friends who do not use).

   "I love spending time with you when you’re not using. How about going to a movie on Saturday night?"

5. **Give Other Rewards**: There are plenty of other things that can be rewarding (i.e., cooking a favorite meal or dessert, giving a card or small gift, giving bus fare).

   "You’ve been doing such a great job attending your groups that I’m going to cook your favorite meal tonight."
Positive reinforcement for not using drugs
(Handout for group 10)

Positive reinforcement means rewarding your family member when he is clean and sober!

TIPS TO REMEMBER:

1. Be sure that your loved one is NOT under the influence of drugs.

2. Rewards are given only when your loved one is clean, sober, and not hung-over.

3. Link the reward with being clean and sober right now.

4. If your loved one starts using, give a “time-out” from positive reinforcement and do not give any rewards.

5. Don’t confuse positive reinforcement with “rescuing” or “enabling.” Remember that rewards are only given when your loved one is clean, sober, and not hung-over.

6. Let your loved one experience the natural consequences for using drugs.
Rules of calm and effective communication
(Handout for group 10)

Be Brief.
When people talk a lot, we often tune them out after the first few sentences. It can be hard for clients to follow after a while.

Be Positive.
Using negative statements and blaming can make the other person more upset and less willing to talk.

Be Specific and Clear.
Lots of times when people argue, they bring up things that happened hours, days, or even years ago. It is important to be specific and clear about what is going on in the present to understand current problems.

Label your Feelings.
Sometimes we think that others know what we are thinking and feeling when they really don’t. Other people might not be able to tell if we are angry or upset, so we need to tell them if we want them to know. We can’t expect them to read our minds.

Offer an Understanding Statement.
Try to put yourself in the other person’s shoes and then let them know that you understand how they feel. You can say something like, “It’s probably really hard for you to go to all of these treatment groups along with your doctor’s appointments.”

Accept Partial Responsibility (When Appropriate).
If you honestly feel as though you are partly at fault for the argument, let the other person know that you take some of the responsibility.

Offer to Help.
Offering to help lets the other person know that they are not alone and that you are there to support them and help them in any way you can.
Coping with frustration
(Handout for group 10)

Talking with a friend or family member about their substance use can be difficult, and sometimes very frustrating. There might be times that the person doesn’t want to talk about their problem, and they might get angry, or even violent, and this can be very frustrating. This handout gives some suggestions on how to cope with frustration.

Ask for Help.
Contact a relative, friend, NA sponsor, or treatment provider who can lend a helping hand. Sometimes, just talking to another person who understands can help you feel less frustrated.

Take A Break.
It is OK to take a break from the situation. People who use drugs can be difficult to talk to when they are high or hung-over. In this case, you can wait until the person is clean and sober to talk to them. Remember that if the person is high and you feel as though you are in danger, then leave the situation right away and go to a safe place.

Find a Pleasant Activity.
Find a pleasant activity to do like going for a walk, watching TV, or going to a movie. Such activities can help to decrease frustration and improve your mood. This will put you in a better frame of mind to deal with the issue.

Do Something Relaxing.
Sometimes doing deep breathing or relaxation exercises can be very helpful in relieving frustration. This will help you relax so that you can deal with the situation when you are feeling better.

Call the Police.
If all else fails, and the interaction gets dangerous, you should call the police.
Monthly Family Meeting 11: Disclosure

Part I: Presentation of Specified Educational Topic

Materials Needed:
Handout: Disclosing to Others

Brief Review of Previous Session on Effects of Stigma and Self-Stigma

In the past, we spoke about stigma and self-stigma and how that can impact individuals that experience psychosis and their family members.

Group leader: Can anyone tell the group what stigma is? What is self-stigma? How can stigma and self-stigma affect individuals that experience psychosis? How does it affect family members?

- Stigma is the negative attitude and discrimination that people with mental health problems face as a result of stereotypes and biases about mental illness that are believed by individuals, groups, and/or social institutions.
- Internalized Stigma (also called Self Stigma) is when people stigmatize themselves by believing negative stereotypes about people with mental health problems are true of themselves.
- Effects: Social discomfort; feeling different/alienated/isolated, decreased self-esteem; problems getting/maintaining employment, housing, having lowered expectations for one’s future; feeling angry, disrespected, dismissed, sad, frustrated, worthless

Introduction to Disclosure

- One of the things we talked about before was the fact that stigma or self-stigma can sometimes lead people to attempt to conceal their illness/treatment or their family member’s illness/treatment from others.
- There is often a fear that if you were to tell someone, even another family member or a close friend, that you or your family member had an illness, that this person may not be supportive, may reject or distance themselves from you, blame you or hold you responsible, or stigmatize you in some other way.
- As a result family members and individuals with psychosis may be reluctant to be as open with others about what they are going through/have gone through, which can lead to fewer opportunities for getting support.

Discussion
Have you discussed having psychosis/your family member having psychosis with others? How did you make the decision to tell that person? Was it easy/difficult? Why? Have you struggled/are you struggling with the decision to disclose to anyone? What makes you uncertain about whether or not you want to disclose?
Deciding to Disclose

- The decision to disclose is not simple. There is no hard and fast rule for who needs to know that you are receiving treatment and how much information they need to know. Disclosure is not an all or nothing, black or white, right or wrong issue. No one can tell you whether you should or should not disclose to others and who you should disclose to.
- Choosing to disclose is a personal, individualized decision although it can often help to do this with the support of other family, friends, treatment providers, etc.
- Weighing the pros and cons of the decision, deciding what is in your own best interest and what feels most comfortable to you can be helpful when trying to decide whether to disclose


The group leader should have family members create a list of pros and cons of disclosing the mental illness; facilitate discussion surrounding the costs and benefits of disclosure. You may want to write ideas generated up on a board if one is available.

Group leader: Like we discussed, choosing to tell someone and talk about your illness or your family member’s illness is not always an easy decision. Just like any decision, it can often involve weighing the pros and cons of being more open with that person. So what might be some possible benefits of telling someone about your illness/that you are receiving treatment? What might be some cons?

Possible pros:
1. You don’t have to worry so much about hiding the illness for others and/or explaining confusing behaviors to others.
2. You don’t have to spend as much energy keeping it a secret. You don’t have to spend so much energy trying to avoid discussing you or your family member’s experience or feel guilty not being as open or truthful with others.
3. You could relieve some shame that you may experience associated with the illness in the family.
4. Others may be able to provide additional support or future assistance in supporting you and/or your family member.
5. Others may have similar experiences/be coping with similar situations that you may not be aware of and you and they could both feel less alone.
6. May provide the opportunity to correct misconceptions that others may have about psychosis, mental health treatment, families of individuals experiencing psychosis, etc. Thus, you may increase the likelihood that this person may respond to you/your family member in a more supportive, positive way.

Potential cons:
1. You risk being vulnerable.
2. It is possible that others might not respond as positively as you would have hoped.
3. You or your loved one/family might be excluded or experience stigma/ discrimination.
Once You Decide to Disclose

There are several things you will want to consider once you have made a decision to disclose.

Deciding who to disclose to

- There may be different reasons why you might choose to disclose to someone.
- You might disclose to another family member or friends because you feel like they will be supportive and you want them to know what is going on with you.
- You might tell an employer or a teacher because you have had to miss several days because of appointments.

Deciding what to tell

- It’s your decision how much information you share. How much information does that person need to know? How much information do you feel comfortable having them know?
- This will likely vary depending on the person. You may share more information with a family member or close friend than a neighbor or employer or co-worker.

Deciding who should disclose/tell

- Supporting family members in their decision to tell others and helping them figure out the most comfortable way to do that can be very important.
- In some cases, a family member may want to disclose the information themselves, other times a family member may want you to disclose the information (e.g., when someone is a minor and disclosing to a teacher/school; to another family member).
- It can be important to talk about and make decisions together about how, who, when, and what to disclose.

Important Factors That Can Make One Feel More Comfortable Disclosing to Others

(adapted from Hyman, I. Self-Disclosure and Its Impact on Individuals Who Receive Mental Health Services. HHS Pub. No. (SMA)-08-4337 Rockville, MD. Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, 2008)

Group leaders: As we mentioned telling others about an illness is not always easy but there are several things that those who have successfully shared their illness/treatment with others suggest that can help to make this easier.

For each below, the group leader may want to discuss and ask the group members how they think that could help someone feel more comfortable sharing information about their relatives/their own illness.

- Being educated about you or your family member’s own experience/illness so that you will feel more comfortable providing information to others when needed.
- Disclosing to someone you trust first.
• Knowing that how much you decide to share is up to you. You are in control of how much to share with others and should not feel pressured or obligated to sharing more than you feel comfortable sharing.
• Feeling safe when you self-disclose (e.g. this could be related to who you disclose to, the situation or place you disclose in, how it’s done)
• You should disclose in the way that you feel most comfortable. Some people like to be spontaneous and share information with others in the moment if it feels right. Others feel more comfortable and less anxious if they are able to plan out how to tell someone and consider how they might respond to questions or response they might encounter.

Discussion
What would make you feel more comfortable when talking about your illness or your family member’s illness? What would cause you discomfort/make you more reluctant to disclose?

Final Discussion Regarding Educational Information:
*Group leaders should encourage a discussion of any of the information presented during the session and address any questions from the group.*
Part II: Practice Disclosing to Others or Discussion Concerning Issues/Problems Faced Over the Past Month

If group members want to practice disclosing

*Given the topic of this session, if appropriate and if the group members are willing, the group leaders can engage in a skills exercise with the group members focused on illness/treatment. Group leaders should first model how the skill is done. Example of situations that can be modeled are telling another family member about a loved one's illness/treatment, explaining to a friend that you haven’t been calling/been able to spend as much time with them lately because of a family members illness, talking to a teacher/administrator to get support for a family member at school. If group members are willing, have one or two families practice.*

If group members DO NOT want to practice disclosing

Part III: Discussion Concerning Issues/Problems Faced Over the Past Month

NOTE TO RCs: Consider use of Recovery Videos if applicable to illustrate the concepts covered in this session.

*After questions concerning the educational information has been addressed, group leaders should inquire if group members has faced any particular problems/had any issues arise in their efforts to cope or in trying to support their family member in their efforts to cope with client’s illness over the past month. The group leaders should work with the group to help resolve any issues or concerns. When appropriate, group leaders may engage in a problem-solving or communication skills exercise with group members to help resolve any immediate issues and address communication concerns.*
Disclosing To Others
(Handout for group 11)

Things to Consider Once You Decide to Disclose

Who should you disclose to?

How should you disclose?

Who should do the disclosing?

Factors that May Increase Your Comfort in Telling Someone Else about a Family Member’s Illness

Being knowledgeable about you or your family members own experience/illness

Disclosing to someone you trust first.

Knowing that how much you share is up to you.

Feeling safe when you self-disclose (e.g. this could be related to who you disclose to, the situation or place you disclose in, how it’s done)

You should disclose in the way that you feel most comfortable (e.g., spontaneously or in the moment versus planned).
Family Involvement Decisional Balance – Instructions

This task involves identifying reasons that the participant might want his/her family to be more involved in his/her treatment, identifying specific ways in which he/she would like family to be involved, and helping strengthen his/her commitment to involving family. The participant is asked to complete the modified decisional balance form. With coaching from the team leader, the participant lists both the potential benefits and the downsides of family involvement using this sheet. The team leader should prompt the participant to complete the form. However, the team leader can use information gained from previous discussion/assessments to help inform the exercise.

Instructions:

“I want you to have the chance to think systematically about the pros and cons of involving your family in your care. Let’s look at this form where we can list your reasons. What would be all the good points of having your family involved in your care?”

Have the participant fill out the form. As the participant identifies potential benefits to having family involved, the team leader may want to query the participant as to how a particular outcome may also benefit them in terms of treatment and recovery if this is not clear.

Once the participant has listed the positives to family involvement, the team leader should prompt him/her to list the negatives

“What would be the negatives of having your family involved in your care?”

Have the participant fill out the section regarding the negatives.

“Ok, now I would like you to go back and circle the most important reasons to have your family involved and the most important reasons not to have your family involved. Which reasons really count?”
Family Involvement Decisional Balance Form

Good Outcomes from Having Family More Involved in Care:
1. 
2. 
3. 
4. 
5. 
6. 
7. 
8. 
(Examples: relatives might feel calmer if they know the doctor, might be able to manage medication better, relatives might be able to help me more if I have a symptom flare-up, relatives might be able to help me reach some of my goals)

Challenges from Having Family More Involved in Care
1. 
2. 
3. 
4. 
5. 
6. 
7. 
8. 
(Examples: might risk privacy, might feel too controlled, might lead to more fights)

This exercise is from the Family Member Provider Outreach Manual:
Values Clarification Exercise
The goal of this exercise is to help participants clarify their personal values and how they relate to family involvement in care, through the use of the values clarification exercise. The team leader first provides three pieces of paper labeled “Very Important,” “Moderately Important,” and “Little or No Importance” at the top. Participants are given the list of values cards and asked to sort them into three piles (very important, moderately important, little or no importance). These values cards include concrete issues of interest to most persons (e.g., “getting along with my family”) and those of special relevance to persons with serious psychiatric illnesses (e.g. “staying out of the hospital,” “keeping symptoms to a low level,” “not embarrassing myself in public”). If a participant says “I don’t know,” the team leader prompts with, “Make your best guess.” If this does not help the participant make a choice, the team leader can make a “Do Not Know” category.

“I want to understand what is really important to you in life. Here is a set of life values cards. They describe experiences and values that are important to some people but not to others. Would you please read each one and then put in the pile which reflects how important that value is personally, to you?”

After all the cards are sorted, the team leader then takes the pile of most importance and discusses how family might be related to each value by asking the participant:

“How do you think your family being involved in your care and getting more support might be related to (this value).calendar

Life Values for the Cards
- Living independently in my own apartment or house
- Paying my bills
- Getting along with my family
- Having a fun social life
- Having friends
- Being self-sufficient
- Meeting new people
- Having a partner
- Dating
- Staying out of the hospital
- Feeling proud of myself
- Having nice clothes
- Having a nice car
- Not embarrassing myself in public
- Having something productive to do with my time
- Having extra money
- Keeping my symptoms to a low level
- Having a hobby
• Helping others
• Making others who care about me proud
• Recovering from my mental/emotional problems
• Reducing stress
• Having a strong religious/spiritual life
• Being in good physical health
• Creativity
• Going to school
• Working

Important values and their relation to family involvement are noted on a separate sheet of paper by the team leader. Values that are inconsistent with family involvement are discussed with the client. For example, the client may value “being self-sufficient” and believe that family involvement in care may conflict with this goal. The team leader helps the client resolve the discrepancy between the value and family involvement. For example, in the situation just mentioned, the provider would ask the participant if he/she has known of self-sufficient individuals (perhaps friends or relatives) who still consult with others about health decisions.
How Family Members Can Be Helpful

What is the role of the family in recovery from psychosis?

Family members can be extremely important in the recovery process. The person may have difficulty in the early period with many things which used to be easy for them. When a person is recovering from their psychotic episode you can provide love, stability, understanding and reassurance, as well as help with practical issues. There are many ways that family members can help a person in recovery from psychosis. Family members can:

- Help the person with psychosis get to treatment appointments and work with their treatment team.
- Stay in regular contact with the treatment team.
- Advocate for the person with psychosis to get the support he/she needs.
- Learn about psychosis so you know what is happening.
- Assist with remembering and initiating appointments and activities.
- Observe and report symptoms the person with psychosis may not be aware of.
- Include the person with psychosis in family and social activities.
- Maintain a safe, positive, supportive atmosphere at home.
- Help with finances.
- Take care of yourself and get your questions answered.
- Understand the goals that your loved one has for recovery.
- Be patient.
- Attend family support groups in your area so learn how other families cope and support the recovery of loved ones.
Family Consultation

A. Continued Connecting

The goal of connecting is for the consumer, family, and clinician to continue to get to know one another and for the provider to gain a better understanding of the family and their current needs.

1. Continue to establish rapport. Initially, the clinician should engage in casual conversation with the family and consumer to establish rapport.

2. Provide an overview of ongoing family consultation. Introduce the overall goal of ongoing consultation. Explain the purpose and process of the consultation as it related to the consumer’s recovery: “The goal of family consultation is to figure out ways to address a specific, focused problem.

In order to achieve this goal, I meet with the consumer and family to assess what is needed, and then, in collaboration with the consumer and family, we come to an agreement on steps to be taken to address the identified issues or a specific situation. Family consultation typically involves 1 to 4 sessions that are 45 to 60 minutes in length and can be conducted with or without the consumer.”

3. Outline agenda for the session. Get to know more about the consumer and family. Discuss how the consultation process can help them address the identified need/problem. Develop a plan to address the identified want/need/goal and identify to first step to reaching that goal.

B. Planning and Providing Next Steps

Figure out the best way to address the family’s wants/needs. Depending on the identified goals and plans, the consultation could proceed in a number of ways.

1. Outline next steps. Next steps should be clearly outlined by the end of the session. Options may include:
   - Further consultation session to address problem (when problem cannot be addressed or plan cannot be implemented in this session).
   - Provide community resources to address problem.
   - Provide education.
   - Problem solving with consumer and family regarding identified problems.
   - Referral to other family services (e.g., NAMI referral, Family to Family, or other education/support services).

Consultant should provide a brief description of each potential option that could be used to address the goal and how it may help to address the goal.
2. Develop a plan for implementation. In collaboration with consumer and family, identify next step and develop a plan for implementing the first step. Work together with consumer and family member to help them decide on an appropriate next/first step. If the appropriate next step is unclear, if there is disagreement on what the next step should be, or if the consumer/family is uncertain about which step to take the consultant should engage consumer and family member in an evaluation of the pros and cons of each option in order to help them come to an agreement on the next step. Develop a detailed plan for how to complete the next step (e.g., schedule next appointment for education/consultation/problem-solving; plan for contacting NAMI for services including who will do it, when).

3. Closing and next steps. Ask if the consumer or family has anything else to add. Summarize the main points of the session, especially as they pertain to the family involvement in the consumer’s care. Remind the consumer and family of the next step (could be additional session to clarify problem/goal, to provider education or engage in problem solving; or taking next step to contact community referrals). Inquiring what session was like for the consumer and family. If additional consultation sessions are required, schedule next appointment. If no additional sessions are required inform consumer and family that you will contact them in 1-2 weeks to follow-up and assess if any additional services are needed. Thank the family and consumer for attending.

C. Follow-up in Ongoing Family Consultation

Follow-up can be conducted by telephone or in person with both consumer and family to obtain feedback and complete the consultation.

1. Reconnecting
   ■ Casual conversation.
   ■ Get reacquainted, Check in with consumer and family concerning how things are going in general.
   ■ Restate the purpose of the consultation based on the outcome of the prior consultation (e.g., the identified problem, identified plan, and next step).
   ■ Discuss experience with implementing first step: Was the first step implemented? How did it go? Any problems with implementing the first step? Have their wants/needs/goals been addressed? Is there anything else that the clinician can assist them with?
   ■ Acknowledge the positive steps that the consumer and family have taken.
   ■ Acknowledge the steps they have taken to address the identified problem.
   ■ Emphasize family member participation as a commitment to the consumer’s recovery and strength.
   ■ Acknowledge consumer’s willingness to have their family involved as taking positive steps toward identifying and initiating strategies to assist in treatment/recovery.
   ■ Thank the consumer and family for their participation or schedule an additional meeting if necessary.
D. Do’s and Don’ts for the Family Consultation

1. What to Do

■ Collect information before you meet with the consumer and family member from the consumer, other providers, medical record, and family.

■ Start each meeting with a casual conversation and review the goals of the session.

■ Explain to the consumer and family member what you are doing, and why you think it is important for them to seriously consider your recommendations.

■ Be prepared with written materials, audiovisual materials, and experiences as a clinician to give family members the information they need.

■ Be aware of any cultural considerations you may need to take into account when working with a consumer and their family.

■ End each meeting with a casual conversation and summarizing.

2. What Not to Do

■ Family consultation is not family therapy; do not turn the meeting into a family therapy session.

■ Do not feel the need to stick too rigidly to your initial plan. The consumer and/or family member’s needs may change or important issues may need to be addressed before you can focus on the identified problem.

■ Don’t forget to bring necessary materials (i.e., handouts, required information) to the session.

Family consultation sessions were adapted from the Consumer Centered Family Consultation Manual developed by the Family Institute for Education, Practice, & Research: Family Institute for Education, Practice & Research, & New York State Office of Mental Health. (2007). Competency training in Consumer Centered Family Consultation. Unpublished manuscript, Department of Psychiatry, University of Rochester, Rochester, NY.