

Family Treatment and Resources Manual



University of Maryland School of Medicine Contributors:

Melanie Bennett, Ph.D., Amy Drapalski, Ph.D.:

RAISE Connection and OnTrackNY Contributors:

Lisa Dixon, M.D., M.P.H., Tom Jewell, Ph.D., Anne Smith, LMSW, Sarah Piscitelli, M.A. Iruma Bello, Ph.D., Helle Thorning, Ph.D., Ellen Lukens, Ph.D., and Liza Watkins, LMSW



Center for Practice InnovationsSM
at Columbia Psychiatry
New York State Psychiatric Institute
Building best practices with you.

Table of Contents

I. Vision for Evidence-Based Family Services	5
A. Rationale for Evidence-Based Family Treatment	5
1. Role of families in first episode psychosis treatment.....	6
B. Framework for OnTrackNY's Family Treatment.....	7
1. Family Treatment Activities	8
2. Components of OnTrackNY Family Treatment.....	8
3. Focus the OnTrackNY Family Treatment on Assisting the Young Person	8
4. Importance of Matching Services Delivered to Individual Preferences.....	9
II. How It's Done: Our Model of Family Treatment Services	9
A. Initial Engagement and Needs Assessment	10
1. Essential Components for Promoting Participant and Family Engagement.....	11
B. Treatment Planning and Identification of Interventions.....	17
1. Discussion of ways that needs can be addressed	17
2. Re-evaluation of family needs	18
3. More intensive interventions and ongoing support for families	19
4. Special Issues in Substance Abuse Treatment in First Episode Psychosis Family involvement	19
III. "How To" Guidance for OnTrackNY Family Interventions	19
A. Family Psychoeducation via Five Core Family Units	19
B. Family Consultation	20
C. Multiple Family Psychoeducation Groups.....	23
1. The purpose of family psychoeducation groups	23
2. Logistics and Format of Family Psychoeducation Groups	24
3. Family Psychoeducation Group Tips:.....	25
D. Structured Problem-Solving Intervention.....	25
1. The six steps for problem-solving:	26
2. Tips for common situations encountered during the problem-solving exercise:.....	27
3. Example of a problem-solving session.....	28
E. Crisis Prevention Planning.....	29
1. Family Involvement in safety and crisis planning	29
2. Mental Health Crisis Description	30
3. Developing a Crisis Plan.....	30
F. Linking Families to Community-based Services and Resources.....	36
G. Special Situations Involving Families: Violence	36
H. Discharge Planning – Including Family Members.....	37
1. Include family members in the discharge planning process.....	37
2. Explore several aspects of discharge planning with families.	38
IV. Appendix.....	42
A. The Family Voice: What Do Families Experience?	42
B. The Family Voice: What Is Needed To Work Effectively with Families?	43
C. Family Engagement and Needs Assessment	44
D. Family Involvement Decisional Balance – Instructions.....	47
E. Family Involvement Decisional Balance Form	48

F. Values Clarification Exercise	49
G. Motivational Enhancement to Increase Commitment to Family Collaboration and Resolve any Potential Ambivalence about Family Involvement	51
1. Motivational Interviewing	51
2. Examples of Open-Ended Questions to Evoke Change Talk.....	52
H. Introducing the Core Units to Family Members	54
I. Core Unit 1: Treatment for Psychosis	56
J. Core Unit 2: Psychotic Experiences: Symptoms, Causes, and Recovery	65
K. Core Unit 3: Shared Decision Making with Families and Clients	72
L. Core Unit 4: Common Family Experiences in First Episode Psychosis	77
M. Core Unit 5: Crisis Prevention and Planning	84
N. Monthly Family Group Materials	94
1. Introduction to First Monthly Family Education Group	94
O. Monthly Family Meeting 1 - What is Psychosis?	95
1. Part I: Presentation on Specified Educational Topic.....	95
2. Part II: Discussion Concerning Issues/Problems Faced Over the Past Month	98
3. Common Symptoms of Psychosis (Handout Group 1)	99
4. Phases of Psychosis (Handout Group 1)	100
P. Monthly Family Meeting 2 - What Causes Psychosis?	101
1. Part I: Presentation on Specified Educational Topic.....	101
2. Part II: Discussion Concerning Issues/Problems Faced Over the Past Month	104
3. What is psychosis? (Handout group 2)	105
Q. Monthly Family Meeting 3 – Recovery from Psychosis	106
1. Part I: Presentation of Specified Educational Topic	106
2. Part II: Discussion Concerning Issues/Problems Faced Over the Past Month	110
3. What is Recovery? (Handout Group 3)	111
4. What Helps People in their Recovery from Psychosis? (Handout Group 3).....	112
5. What Can Family Members Do to Help/Support their Family Member? (Handout Group 3) ..	113
6. What Can Families Do to Help/Support Themselves? (Handout Group 3)	114
R. Monthly Family Meeting 4 – Treatment for Psychosis	115
1. Part I: Presentation of Specified Educational Topic	115
2. Part II: Discussion Concerning Issues/Problems Faced Over the Past Month	120
3. Antipsychotic Medications Recommended by the OnTrackNY Team* (Handout Group 4)	121
4. OnTrackNY Team First-line Antipsychotic Medications: Common Side Effects (Handout Group 4)	122
5. OnTrackNY Team Second-line Antipsychotic Medications: Common Side Effects (Handout Group 4)	126
S. Monthly Family Meeting 5 – Crisis Prevention and Planning	128
1. Part I: Presentation of Specified Educational Topic	128
2. Part II: Discussion Concerning Issues/Problems Faced Over the Past Month	132
3. Components of a Crisis Plan (Handout Group 5)	133
T. Monthly Family Meeting 6 – Communication Tips and Tools	134
1. Part I: Presentation of Specified Educational Topic	134
2. Part II: Discussion Concerning Issues/Problems Faced Over the Past Month	138

U.	Monthly Family Meeting 7: Stigma.....	139
1.	Part I: Presentation of Specified Educational Topic	139
2.	What is Stigma? (Group 7 Handout)	143
3.	Facts and Myths about Mental Illness? (Group 7 Handout)	144
V.	Monthly Family Meeting 8: Substance Abuse in FEP	145
1.	Part I: Presentation of Specified Educational Topic	145
2.	Part II: Discussion Concerning Issues/Problems Faced Over the Past Month	148
3.	Psychoactive Substances and Their Effects (Group 8 Handout)	149
4.	Consequences of Drug Use in Individuals with A Mental Illness (Group 8 Handout)	150
5.	Reasons why people with a mental illness use drugs (Group 8 Handout)	151
6.	Triggers to alcohol and drug use (Group 8 Handout).....	152
W.	Monthly Family Meeting 9: Substance Abuse in FEP	153
1.	Part I: Presentation of Specified Educational Topic	153
2.	Discussion Concerning Issues/Problems Faced Over the Past Month	154
3.	Community Resources: Information on Self-Help Groups for Family Members and Friends of Substance Users (Group 9 Handout)	155
X.	Monthly Family Meeting 10: Substance Abuse in FEP	157
1.	Part I: Presentation of Specified Educational Topic	157
2.	Discussion Concerning Issues/Problems Faced Over the Past Month	159
3.	Ways to reward abstinence (Group 10 Handout).....	160
4.	Positive reinforcement for not using drugs (Group 10 Handout).....	161
5.	Rules of calm and effective communication (Group 10 Handout).....	162
6.	Coping with frustration (Group 10 Handout).....	163
Y.	Monthly Family Meeting 11: Disclosure	164
1.	Part I: Presentation of Specified Educational Topic	164
2.	Part II: Practice Disclosing to Others	167
3.	Part III: Discussion Concerning Issues/Problems Faced Over the Past Month.....	168
4.	Disclosing To Others (Group 11 Handout)	169
V.	References and Recommended Readings.....	170

I. Vision for Evidence-Based Family Services

Imagine how you would feel if, after developing psychosis as a young person, you were linked to a specialized treatment team that could work with both you and your family members in ways the evidence has proved to be most effective? Imagine your family was taught practical skills to best help you through this difficult period; provided with emotional support by a team who also instilled hope for your future; equipped you with problem solving skills related to psychosis; taught communication skills; provided you with regular contact with other families who were “in the same boat” and involved you as a partner in relapse prevention and crisis planning to help you in case your symptoms re-emerge or get worse? What would you think if at the end of your time with your treatment team, regardless of how things in the family were when you started, your family was equipped with accurate information, knowledge, hope and practical skills to continue supporting you (as needed) in your recovery?

This is the vision for OnTrackNY family therapeutic interventions to help the young person and his/her supports obtain the resources they need during this important and challenging time in their lives. This manual outlines how the OnTrackNY model translates this vision into practical activities and interventions for young people and their families.

A. Rationale for Evidence-Based Family Treatment

Fortunately, there is a large and robust evidence base that informs and guides efforts to involve families of people with psychosis in their treatment (Dixon et al., 2001; Dixon et al., 2010). The evidence points to a specific set of family therapy approaches for psychosis – called family psychoeducation - that go beyond providing information and concrete support to family members (McFarlane et al., 2003). Evidence-based family psychoeducation programs embody the following fifteen principles and activities:

1. Coordinate all elements of treatment and rehabilitation to ensure that everyone is working toward the same goals in a collaborative, supportive relationship.
2. Pay attention to both the social and the clinical needs of the consumer.
3. Provide optimum medication management.
4. Listen to families’ concerns and involve them as equal partners in the planning and delivery of treatment.
5. Explore family members’ expectations of the treatment program and expectations for the consumer.
6. Assess the strengths and limitations of the family’s ability to support the consumer.
7. Help resolve family conflict by responding sensitively to emotional distress.
8. Address feelings of loss.
9. Provide relevant information for the consumer and his or her family at appropriate times.
10. Provide an explicit crisis plan and professional response.
11. Help improve communication among family members.
12. Provide training for the family in structured problem-solving techniques.
13. Encourage family members to expand their social support networks—for example, to participate in family support organizations such as NAMI.
14. Be flexible in meeting the needs of the family.
15. Provide the family with easy access to another professional in the event that the current work with the family ceases (Dixon et al., 2001)

There is also emerging support for the cost-effectiveness of family psychoeducational interventions for early psychosis (Addington, McCleery, & Addington, 2005; Breitborde, Woods, & Srihari, 2009).

1. Role of families in first episode psychosis treatment

Families play a pivotal role in the recovery process of young people who have experienced a first episode of psychosis (FEP) (Glynn, 2012; Szmukler et al., 2003). Many young people (50-70%) are living with family when psychotic symptoms emerge (Addington, Addington, Jones, & Ko, 2001) and family members often serve as their primary social network. Unsurprisingly, families are usually the first to observe the signs and symptoms of psychosis (Norman, Malla & Manchada, 2007), connect young people to treatment (O'Callaghan et al., 2010; Shin et al., 2010; Chung et al., 2010; Fridgen et al., 2012) and are frequently present at first contact with the mental health system (O'Callaghan et al., 2010). In addition, families offer ongoing support and guidance in accessing and maintaining treatment involvement (Cocchi, Meneghelli, Erlicher, Pisano, Cascio, & Preti, 2013; Fridgen et al., 2012; Rabinovitch, Be'chard-Evans, Schmitz, Joober, & Malla, 2009). Clinicians can provide assistance and services during the early stages of a young person's illness to enhance families' care of the young person (Addington, Coldham, Jones, Ko, & Addington, 2003).

1. **Moving beyond the traditional family therapy focus on family dysfunction and “fixing” a broken family.**

Historically, family therapy, for persons with psychosis, has tended to emphasize family dysfunction and/or family etiology as precipitating the onset and/or maintenance of psychosis. Although there is an emerging literature suggesting that some forms of psychosis may be partially related to traumatic events (Freedman, 2017; McGrath et al., 2017), it is also clear that many different factors play a role in the onset of psychosis. In the majority of cases, there is no evidence to suggest that family dynamics are to blame. Further, there is little evidence to suggest that traditional forms of family therapy are effective in working with the majority of people with psychosis.

2. **Family Psychoeducation: a trauma-informed, strengths-based family therapy**

The OnTrackNY model includes interventions centered on family involvement, particularly family psychoeducation. Of the family therapy approaches for psychosis, family psychoeducation has the most substantial evidence base and its key components are crucial to the OnTrackNY model (Lucksted, McFarlane, Downing, Dixon and Adams, 2012; McFarlane et al., 2003; McFarlane, 2002).

Family psychoeducation benefits both the family members and the individuals with psychosis. For families, participation in family interventions have been linked to an increase in family well-being and the reduction of family stress (Jeppeson et al., 2005; Petersen et al., 2005; Berglund, Vahlne & Edman 2003). The positive impact of psychosocial family interventions for individuals with psychosis includes decreased relapse rates and hospital admissions, improvements in general social impairment, and enhanced medication adherence in individuals with chronic psychosis (Magliano et al., 2005; Pharoah, Mari, Rathbone, & Wong, 2010). The provision of support to families throughout care is shown to be a significant factor in treatment engagement for persons with FEP (Stowkowy 2012; Conus, 2010; Doyle, 2014), and greater family involvement in care has been associated with improved treatment adherence,

care continuity after hospitalization, higher employment rates and increased hope for individuals, empowerment, and knowledge of illness.

B. Framework for OnTrackNY's Family Treatment

As noted above, 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 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. Many family members experience 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. Family members struggle with the possibility that they may need to change their expectations concerning a relative's functioning, capacities, and immediate 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 ambivalence about participating in 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.

A host of barriers to family involvement in treatment 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. OnTrackNY family interventions for psychosis align with recommendations made by expert consensus (e.g., The Schizophrenia PORT team/authors; Dixon et al., 2010). Given the evidence base, the family treatment offered through OnTrackNY based on the core principles and activities of family psychoeducation. The overarching goals of the OnTrackNY family treatment approach include:

- Improve knowledge, coping skills, treatment/recovery and lives of the young people enrolled
- Improve knowledge, support and coping skills for family members
- Foster a collaborative environment where family members and young people can work together with OnTrackNY practitioners to address psychosis

The specific combination of family treatment approaches is described below.

1. Family Treatment Activities

- Five Family Core Units: These are five content areas that should be delivered to all families across individual meetings or multi-family groups which include psychoeducation about psychosis, FEP treatment, shared decision making, relapse prevention, and understanding family experiences.
- Brief family consultations: Semi-structured family consultation which consists of a series of family meetings that are time-limited and focused on a specific topic. Brief family consultation can be done more than once, regarding several topics, while the young person is receiving services
- Structured problem-solving: An approach for helping families manage difficulties that arise which can be delivered via individual family meetings as well as during family groups
- Multiple family groups: Monthly, 90-minute multi-family psychoeducation groups

2. Components of OnTrackNY Family Treatment

- Coordinating all aspects of care and providing the family with access to all team members
- Partnering with families and understanding their needs and concerns
- Providing families with education about the treatment program and exploring their expectations
- Providing families concrete and emotional support to leverage their strengths and promote resiliency in a flexible and accessible manner
- Providing families psychoeducation about psychosis and schizophrenia
- Teaching families coping, communication and structured problem-solving skills for dealing with emotional distress, resolving family conflicts and improving communication across family members
- Teaching and involving families in the development of wellness, relapse prevention and crisis management plans for the participant
- Encouraging and linking families to other sources of support as needed (e.g., individual therapy, *NAMI*, other support organizations, etc.)

3. Focus the OnTrackNY Family Treatment on Assisting the Young Person

The OnTrackNY family treatment activities are designed to help the young person achieve his/her recovery goals. In other words, the family interventions are primarily for serving the young person and his/her recovery; they are not solely to support the family. The idea is that by providing interventions that support the family in developing their understanding of what the young person is going through and

effective skills for navigating this shift in within the family structure as a result of a first episode of psychosis, the family can, in turn, support the young person. However, it is also clear that providing family psychoeducation benefits the family members themselves.

Big picture: When family members are informed about psychosis and taught psychosis-related coping and problem-solving skills, then the family is best positioned to support the young person and manage the stress and anxiety related to providing that support.

4. Importance of Matching Services Delivered to Individual Preferences

Team members aim to match specific components of the OnTrackNY family treatment with what young people and families really want and need. It is critical that teams understand family members' highly individual experiences and respond to them in tailored ways (Lucksted, et al., 2016). There is flexibility, within the array of evidence-informed family treatment activities in OnTrackNY to offer a variety of choices. How does a practitioner make this match? The simple answer is that the match should be made using a shared decision making process with both the young person and their family members. Practitioners can use the *Family Engagement and Needs Assessment*, (described below and found in this manual) to begin getting to know the family and understand their priorities and needs. In some cases, practitioners can use the *Family Engagement and Needs Assessment* combined with an "initial consultation" approach – which would include recommendations (by OnTrackNY practitioners) for families and young people to consider.

II. How It's Done: Our Model of Family Treatment Services

The OnTrackNY program provides a family treatment approach, which offers a combination of 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 delivery of the *Five Family Core Units*, monthly family psychoeducational groups, individual family consultation sessions, problem-solving and skills training, and information on community resources when needed.

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 situations 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 scenarios, involving families will include the following components: 1) participant and family

engagement; 2) initial (and ongoing) assessment of participant and family needs and preferences; 3) treatment planning around family interventions; 4) delivery of specific activities and interventions individualized based on the treatment plan; and 5) transition planning and support. However, given that interest in and preferences for family involvement may vary considerably, the team should think flexibly about 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).

A. Initial Engagement and Needs Assessment

Early sessions with participants will include a focus on family and family involvement in care. Either as part of or following 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 informed and preference-based decisions regarding family participation (see *Team Manual* for a description of SDM). For participants who express interest in family involvement or in situations where the 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 ongoing clinical care. In a parallel fashion, the Primary Clinician will meet with family members to develop rapport, understand their perspectives, obtain information regarding 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 about the family services provided by the team and those offered in the community. The Primary Clinician will then use motivational enhancement techniques and a SDM framework to assist family members in making decisions concerning which parts of the family treatment, if any, they would like to receive. Ideally, all involved families should receive at least the five core units across individual sessions.

On the other hand, for those participants who refuse family involvement, the Primary Clinician will follow the participant's lead. At the same time, the Primary Clinician will continue to work with the participant on identifying ways in which the family might be helpful with goal achievement throughout treatment. Primary Clinicians should be able to highlight for participants specific ways of involving family members that do not necessitate full disclosure or involvement of the family in all aspects of treatment. For example, a young person can decide to have the family member only attend the family group but not have individual sessions with the Primary Clinician or other team members. Similarly, the young person can decide to allow the family to be involved in certain types of discussion such as work and school goals while limiting the divulgence of other information shared with the team. It is important that OnTrackNY providers think about and present family involvement in a nuanced way so that participants understand the utility and range of ways that they can decide to have their families participate in the treatment.

Participants who are under 18 years old must have their guardians (typically family members) involved in certain aspects of treatment because the young person is at a developmental stage where parental involvement and consent is needed and also sharing of information is state and federally mandated.

Transparency about requirements and rights can help build and maintain relationships with the young person and their family. A family member or legal guardian will need to be included in all treatment planning and decisions, 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.

Tips for working with families and minors:

- **Educate minors and their guardians about the guardian's right to know.** A clear understanding of the parameters of what information must be shared e.g., safety concerns, can help participants feel more comfortable sharing their feelings and experiences without fear that every statement will be relayed to the guardians. It can also help guardians become partners in ensuring safety while supporting the young person's privacy preferences and emerging autonomy.
- **Be clear that the guardian has final say in treatment decisions,** for example, certain medical decisions. Ensure that the participant's preferences are prioritized and honored as much as possible. Consider offering regular family meetings so that family members have protected time for questions, concerns, and problem solving. This can help reduce as-needed or crisis-related communications and decisions.
- **Explore strategies for information sharing and decision making.** For example, aim to discuss concerns and decisions with the participant first. Help empower the young person with communication and self-advocacy skills. Strategize when and how information might be disclosed including: who will be present, who will disclose (participant/team member), when (immediately, by a deadline), where (phone, in person) and the participant's preferences for next steps. When making decisions, use the shared decision making framework as much as possible.
- **Within the legal/agency requirements, find common ground.** Refer back to young person's and parent's beliefs, values and goals. Identify areas that everyone can agree on (e.g., staying out of the hospital, graduating from school).
- **Plan for transition into adulthood with the individual and their guardian.** Discuss how the parent might honor the young person's preferences and emerging autonomy while continuing to provide safety and support. Consider sharing information about the "neglect/overprotect" paradigm.

1. Essential Components for Promoting Participant and Family Engagement

a. 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.

1. 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 recovery, 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. The Primary Clinician should help participants to identify key people who are currently, or might potentially be, 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 initiate or continue this discussion 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?
- 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?
- 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).

2. 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 their 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.

3. Strategies for talking with participants who do not want family members involved in their care

- Identify one family member to involve 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.
- Explain to the participant how family members can be helpful and relate this to the participant's personal goals; explore 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.

- Determine 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.
- Revisit 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.
- Consider 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 minors, 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.

b. Family Engagement

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 FEP 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 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. Strategies for promoting 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 on 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 the information in the *Family Core Units*, including information concerning his/her background, discipline, role on the treatment team, and planned interactions with the participant and family. The Primary Clinician will explain his/her role in the participant's treatment, and provide education on 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. And, there are things they can do to help support recovery.
- 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 from 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.

c. **Balancing Goals of Participants and Families: Using the Family Engagement and Needs Assessment**

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 focus of the *Family Engagement and Needs Assessment* is to identify the needs of the family and how these needs can best be met.

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 Engagement and 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. If the participant is present, the Primary Clinician should prompt the participant to discuss his or her goals and how they think family members could assist him or her in achieving those goals. An example of how a discussion could take place is as follows:

Share the client's goals: "I spoke with [young person] earlier to discuss how family could be more involved in her treatment and assist in her recovery. She had some ideas of how the family could help her achieve her goals. Let's start by having [young person] tell us a little bit about her goals and how she would like you to support her in reaching them."

Explore the family's wants, needs and goals for treatment involvement: "Now I would like to share a document called the *Family Engagement and Needs Assessment*. This will help us have a conversation so that I can hear from you, as family members, about things like:

- What are your wants and needs?
- Whether you have any preferences for YOUR involvement in [relative's name]'s treatment?
- How the OnTrackNY team can support you - as you're supporting [relative's name]."

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

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 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 might also point out similarities between participant and family needs and how the family could help support the participant with those needs. (Family Institute for Education, Practice & Research, & New York State Office of Mental Health; 2007; Glynn et al., 2010).

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.

B. Treatment Planning and Identification of Interventions

Once the needs and preferences have been determined, work together to decide which family services would best address the family needs and outline next steps for involving the family in the young person’s ongoing care. In some cases, these next steps 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 young person and family disagree, or are unsure of the next steps, the Primary Clinician should use SDM to discuss the pros and cons of each option and come to a consensus on next steps. Together, the Primary Clinician, young person, and family members should work to develop a plan for completing the next step (e.g., scheduling an appointment for the young person and family to meet with the Primary Clinician, scheduling an appointment for family consultation, agreeing on a family member contacting NAMI, etc.). An example of how a conversation could take place is as follows:

“Thank you for being so open and forthcoming with your responses. What I would like to do now is work together to try and come up with a plan on what to do next. I have a few thoughts on ways we might proceed however, before I make any suggestions, let’s review the needs assessment together and prioritize from the most urgent needs to the least urgent (but still important) needs.

Once we have completed that, let’s review the different types of family involving services that we have here at OnTrackNY. Then, we can discuss which options might address your needs and come up with a plan for family involvement and what to do next. Does that sound okay with everyone?”

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 available services. Describe each service option and discuss how it might be used to address the family need/goal. These options may include:

- **Psychoeducation (Delivering the 5 Core Family Units):** All participants and family members should be offered the 5 core family units as a foundational set of concepts and educational information that will provide the families with an understanding of FEP and its treatment. Discussion of these core units and other psychoeducational materials will likely occur across several meetings with the family. 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 as additional resources. 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 education groups.

- **Additional supportive family meetings:** Even after delivering the five core units, families might benefit from meeting regularly with the Primary Clinician for the purposes of communication, collaboration and support. These meetings should be regularly scheduled and for some families might occur over the phone.
- **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 is time-limited (e.g., 1-3 meetings) 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.
- **Crisis support:** Family members should be informed of the available crisis support services (including the team's 24/7 crisis line and medical back-up services), what situations to use them in, and the relevant contact information.
- **Low-level family contact:** Low-level 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.
- **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.

2. Re-evaluation of family needs

Family needs often evolve over time, depending on factors like socioeconomic status, stage recovery, and the nature of the family member's relationship with their relative. Even after the initial Family Engagement and 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 the Primary Clinician determines that the family's needs have shifted 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.

3. 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.

4. 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.

III. "How To" Guidance for OnTrackNY Family Interventions

A. Family Psychoeducation via Five Core Family Units

The Primary Clinician will offer five core units (content available in the appendix) to all families that take place across several meetings, in order to ensure that all families are provided psychoeducation about psychosis and its treatment, information and training on shared decision making, normalization and information about experiences commonly identified by families with a loved one diagnosed with FEP, and information and strategies related to crisis prevention and planning. The content for these Five Core Units are structured within the manual as follows:

Core Unit 1: Treatment for Psychosis

Core Unit 2: Psychotic Experiences: Symptoms, Causes, and Recovery

Core Unit 3: Shared Decision Making with Families and Clients

Core Unit 4: Common Family Experiences in First Episode Psychosis

Core Unit 5: Crisis Prevention and Planning

Clinicians should first focus on building rapport and understanding the family's needs before beginning the core units. The *Family Engagement and Needs Assessment* should be completed prior to

the delivery of these core units so that the information delivered via the core units can be tailored to the young person's and family's needs and goals. For example, if the family has the goal of understanding the young person's symptoms, particular attention can be paid to delivering the information in core unit 2 during the initial meetings.

Clinicians are encouraged to check in with the family and re-evaluate needs regularly, since core unit information might influence the family's preferences and goals throughout their time working with the team. Any new information or revised goals should inform future discussion during the delivery of the core units.

The structure of the core units can be flexible. However, we suggest that you follow steps 1-4 below. Different families may want or need to go through the information at different paces. It is important that you go through the following steps at a pace that allows time for understanding, discussion and reflection:

1. Delivery of information around a specific unit
2. Discussion of the relevance of this unit to the family's experience including answering questions (e.g., discussion of examples of what they have noticed with their relative, how they understand the experience, and how they have dealt with it)
3. Engaging the family in formal problem-solving strategies around related issues they might be struggling with (if applicable) to develop an action plan that they can try out at home
4. Discussion of any other questions or concerns the family member might have around the unit.

Core units should be delivered with the goals of addressing: a) family needs, and b) ways the family may become meaningfully involved in working with the OnTrackNY team and supporting the young person's recovery goals. Core units can be delivered:

- To the family with the young person, or just the family.
- To all family members involved, ideally as a group or to just individual family members who want to participate.
- During regularly scheduled meetings or when convenient, based on availability and level of involvement.
- Wherever it best suits the family (e.g., in the office or at the family's home).
- In the suggested order so that information builds as people participate in more core units or as-needed to address issues that the family is facing at this time (e.g., crisis prevention and planning before psychoeducation about symptoms).

B. Family Consultation

It is expected that young person-specific and family-specific issues that need to be addressed in a more focused and individualized way may arise. Examples include economic pressures, medical issues, divorce, legal issues, and interpersonal conflicts that may or may not be connected to the participant. Each of these issues can still have a profound impact on the family and negative consequences for the young person.

Consultation can be provided to the entire family around how to handle stressful or difficult situations in reference to their potential impact on the young person. For example, it would not be recommended to

provide consultation to parents who are on the verge of divorce and want advice about divorcing or fixing their marriage. However, we would recommend family consultation to help the same parents understand the impact of stress or conflict related to the divorce on the young person, and strategies to reduce the likelihood the young person will be negatively impacted (e.g., the parents could argue loudly in private, not in front of the young person). A recommendation could also be made that the parents attend outside family counseling for their marital problems.

The Primary Clinician can work one-on-one with a family to address a problem or particular need utilizing recovery coaching strategies. The goal of the consultation sessions are for the primary clinician to teach, demonstrate (when appropriate) and give people the opportunity to practice skills that can be used to improve young people's functioning or family members' interactions with or about the young person and to reduce stress and conflict. Skills include:

- Communication skills such as 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, together, making a decision concerning which solution to implement.

Skills can then be applied to current concerns experienced by the entire family. Examples of appropriate situations for family consultation include:

- There is a lot of family disagreement about whether the young person should stay in school or get a job.
- The young person and his/her family member have a problem they don't know how to solve (e.g., young person wants to try a new activity and parent objects to this).
- The young person is having trouble using skills he/she is learning to express feelings to a parent (e.g., young person wants to tell parent to stop "reminding" him/her about taking his/her medication).
- There is an impending divorce, and the young person's parents are having trouble communicating with each other about their child's situation and condition.
- Family member does not understand symptoms, and just keeps trying to "talk young person out of" the symptoms (e.g., "the voices aren't real so just ignore them").
- The young person's parents are having trouble communicating with each other about their child's situation and condition without yelling.

It is important to note that these consultations are not the same as traditional family therapy, per se. They are not the appropriate place to work out issues related to complex family dynamics. Prior to the first consult session, the Primary Clinician, in collaboration with the team, should map out a plan for the one to three-1 hour consultation sessions and be ready to start any skills training in the first session. In the first consultation session, the primary clinician can discuss the role of the consultation and present the plan developed with the team, asking the young person/family for their thoughts and ideas in order to incorporate these into the plan. Once the primary clinician and the young person/family members agree on the plan, skills training can begin.

There should be a clear beginning, middle and end to the consultation services. The beginning phase may be called **Continued Connecting**. The goal of connecting is for the young person, family, and primary practitioner to continue to get to know one another and for the provider to gain a better understanding of the family and their current needs. The primary clinician should do the following:

- Continue to establish rapport by engaging in casual conversation
- Provide an overview of family consultation by explaining the purpose and process of the consultation as it relates to the young person's recovery
- Outline the agenda for the session by discussing how the consultation process can help them address the identified need/goal, by developing a plan to address the identified need/goal and identify concrete steps toward reaching that goal.

The middle phase may be called **Discussion and Planning Next Steps**. The goal of discussion and planning next steps is to figure out the best way to address the family's wants/needs. Depending on the identified goals, the primary clinician could proceed in a number of ways:

- Discuss and explore the young person and family's concerns and perspectives about the goal/topic.
- Lay the groundwork that you want to hear from everyone in the room
- Listen to everyone in the room; make statements that let people know they are being heard
- Summarize the various perspectives as the meeting unfolds
- Brainstorm aloud with everyone about what might best help address the concerns/goals
- Consider making recommendations
- Identify next step with the young person and family member, clearly outline them and help them develop a plan for implementing them.
- Some options of next steps may include:
 - Skills training (teach information, demonstration, practice)
 - Problem solving with young person and family regarding identified problem
 - Provide education
 - Further consultation session(s) to address problem
 - Linkage with community resources to address problem
 - Referral to other professional family services

The end phase may be called **Follow-up and Future Consultation**. Follow-up can be conducted by telephone or in person with both the young person and family to obtain feedback and complete the consultation by doing the following:

- Reconnecting through brief casual conversation
- Check in with young person and family concerning how things are going in general
- Restate the purpose of the consultation based on the outcome of the prior consultation
- Discuss experience with consultation thus far
- If there was a problem-solving session, ask about how things are going with next steps? How did it go? Any concerns? Have their concerns/goals been addressed?
- Acknowledge the positive steps that the young person and family have taken
- Emphasize family member participation as a commitment to the person's recovery
- Encourage the family to remain involved in supporting the young person, and express your desire to remain connected with family

- Leave the door “open” for future consultation

Consultation Tips:

- Explain to the young person and family member what you are doing, and why you think it is important for them to seriously consider your recommendations – use shared decision making
- Be prepared with written materials, audiovisual materials, and experiences as a practitioner 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 young person and their family
- End each meeting by summarizing
- Do not feel the need to stick too rigidly to your initial plan. The young person and/or family member’s needs may change or important issues may need to be addressed before you can focus on the identified concern.

C. Multiple Family Psychoeducation Groups

(*Of note, for those families who do not attend groups, this information and process can be delivered individually across multiple meetings).

Family Psychoeducation is a method for working with, not on, families. It is designed to improve the families’ knowledge by combining clear, accurate information about mental illness with training in problem solving, communication skills, coping skills and the development of social supports (McFarlane, 2002). The goals are to markedly improve the young person’s quality of life and reduce family stress.

1. The purpose of family psychoeducation groups

- To provide information about topics related to psychosis and its treatment.
- To help family members learn about topics related to psychosis and its treatment so that they can better understand and help the young person who is experiencing psychosis.
- To answer questions that the OnTrackNY participant and his/her family members may have about psychosis and treatment.
- To add additional topics about which the OnTrackNY participant and his/her family members may be interested in learning.
- To provide a way for family members to meet each other, share their experiences and give/receive support.

All OnTrackNY participants and family members will be encouraged to participate in monthly family psychoeducational groups. Admission to these groups is ongoing. Family members can join whenever they want and attend as many as desired, with or without the young person. The groups are organized and facilitated by the primary clinician, and the team leader should also attend and co-present information depending on the topic.

Prior to the young person and family members entering the groups it is important that the practitioner engage (a process commonly referred to as “joining”) the young person and their family members. It is recommended that the practitioner discuss the multiple family groups during sessions with the young person, as well as meet 2-3 times with the family individually. Joining sessions is a social intervention

designed to create a bond between the participants, family members and the practitioner. Here are a few of the benefits to engaging in joining sessions:

a. For the young person:

- To inform and prepare them to enter psychoeducational group (if the OnTrackNY team plans to have the group with families and young people)
- To hear about his/her concerns and feelings around how the family is dealing with mental illness without the family being present
- To allow them to discuss their thoughts and concerns about attending the group
- To allow them to discuss their thoughts and concerns about their family attending the group
- To communicate hope for recovery

b. For the family members:

- To continue connecting and building a rapport with the family
- To establish a mutual collaborative relationship with the family members
- To build the foundation for an ongoing relationship
- To hear about family concerns and feelings around mental illness without the young person being present
- To inform and prepare them to enter psychoeducational group
- Family members are sometimes in shock and are overwhelmed and may not be ready to enter a group setting without a connection to the practitioner
- The family members may have a lot of questions around psychosis that they aren't able to ask in a group setting
- To listen for family's strengths and challenges
- To communicate hope for recovery

2. Logistics and Format of Family Psychoeducation Groups

The family psychoeducation groups accommodate approximately 3-8 families, are offered monthly, and last approximately 90 minutes. During this time, there are presentations on informational and educational topics particularly relevant to families of the young person that has first episode psychosis. In addition, there is group discussion of any problems or issues that group members may be facing.

In order for the groups to be beneficial and the group members to understand what is being offered, it is suggested that the practitioner do the following prior to presenting on the educational materials:

- Familiarize him/herself with the materials that they will be teaching
- Have practice sessions regarding any unfamiliar material with a colleague beforehand
- Modify the language to fit the audience
- Prepare stories and/or examples to make the materials meaningful and relatable to attendees' situations

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 the young person and for his/her family members:

- (1) understanding psychosis
- (2) the etiology and causes of psychosis
- (3) recovery from psychosis
- (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.

3. Family Psychoeducation Group Tips:

- Make sure to stay within the allotted time of the meeting. This helps keep things predictable for all involved.
- Manage group interactions by developing rules as a group and discuss how they will be addressed if not followed.
- Build in time to have productive discussions and Q&A times, but don't let it stop the teaching process.
- Address issues that may keep the families from attending the meetings (e.g., childcare issues, involving younger siblings etc.).
- If new families join the group after it has been up and running, make sure to complete introductions and review the group rules.

Further information on the content for these groups is provided in the *Monthly Family Educational Group Outlines and Materials* are provided in the Appendix.

D. Structured Problem-Solving Intervention

Solving problems in a systematic way can lead to better outcomes, and allows the young person, family and others to discuss and explore the decision-making process. The 6-step process to problem-solving (McFarlane et al., 2002), helps to organize potentially emotionally laden material into a step-by-step, sequential process used to systematically arrive at a solution. In addition, this process assists all the parties involved with devising a plan of action to address a problem or challenging situation.

When introducing the problem-solving process, the clinician will first orient everyone to the process and provide a rationale for engaging in a structured problem-solving approach. This rationale might include the evidence base for this approach, letting everyone know that while problem solving does not always result in a guaranteed solution, it can help deal with stress and reduce tension, and is designed to increase predictability and calm the environment. Clinicians might reinforce the idea that "we are all putting our heads together to come up with solutions." Furthermore, they might reinforce the notion that

some of the most challenging problems can be broken down into more manageable pieces; suggest that the problem-solving process is helpful for everyone in the family and inquire if people want to set aside a meeting for problem solving.

1. The six steps for problem-solving:

1. Discuss the problem or goal - All family members talk about the problem or goal and pay attention to what each person says. It is especially important for the people most involved to talk about how the problem affects them. When everyone has expressed opinions, family members try to arrive at a common definition of the problem or goal. This may require family members to compromise with each other. Wording the problem or goal positively in terms of how to change something can facilitate accomplishing this step. Clinicians should write down the specific definition of the problem/goal agreed upon by the family members. During the discussion, it may become clear that the problem actually involves a decision to be made.
2. Brainstorm at least three possible solutions - At the beginning of this step, family members review previous attempts to resolve the problem. This review helps avoid repeating the same mistakes. Then, everyone identifies as many potential solutions to the problem as possible. Clinicians can also offer possible solutions based on the evidence and/or what they know has worked for others in the past. Do not evaluate the solutions at this time. Even “fantasy solutions”, outlandish ideas, and humorous responses can be included. Everyone should contribute at least one idea, and refraining from criticism is important.
3. Briefly evaluate each solution - List the advantages and disadvantages of each idea for solving the problem or achieving the goal.
4. Choose the best solution - Try to pick the easiest solution that is likely to work. Family members should agree on the solutions(s) selected. Sometimes, one or two solutions are clearly favored by everyone. Other times, family members may differ as to which solutions they prefer. It is possible that solutions may need to be modified or compromises made in order for the family members to reach agreement.
5. Plan the implementation - When family members agree on how they want to solve the problem or achieve the goal, they need to formulate a plan to put their ideas into action. This plan addresses four key elements:
 - Time-frame - When will different parts of the plan be accomplished?
 - Resources - Are any special resources needed to carry out the plan (e.g., money, skills, information)?
 - Roles - Who is responsible for doing what? Remember, the clinician can be part of the plan.
 - Possible obstacles - What could interfere with putting the plan into actions? How might these obstacles be avoided and dealt with if they arise?
6. Review Implementation at the next meeting; modify as needed - After the family has agreed upon a plan, a date is set to meet again and evaluate whether the plan was successful. At the meeting, the family members are asked to discuss what transpired. The clinician should praise efforts that have been made to implement the plan and evaluate whether further efforts are necessary to solve the problem or achieve the goal. The follow-up meeting can occur a few days or a week later. During the follow-up meeting, the practitioner will focus on how things went. Was anything achieved? What were the downsides? How did the plan work? Celebrate any small steps or gains. After discussing,

review the plan and revise as needed. One option might be to try another solution from the first meeting.

2. Tips for common situations encountered during the problem-solving exercise:

- **One person does not want to be involved in solving the problem:** In general, there are several possible strategies for dealing with the difficulty of one person not wanting to be involved in solving the problem. First, an attempt can be made to redefine the problem so the person becomes more interested in participating in the discussion. Second, the person can be encouraged to participate with prompts such as, "Are you willing to at least give it a try for the next half hour or so with everyone else?" Third, the clinician can acknowledge the person does not want to participate, but asks if it's okay if the rest of the people to work on it, and the person can jump in at any time if s/he changes his/her mind (i.e., the person can choose to listen but not offer input). A final strategy to use when one person will not participate in structured problem-solving, is to meet without that person (although this should only be considered after all other attempts to involve that person are exhausted).
- **Choosing among multiple problems:** Families may be besieged by many problems. Decisions must be made regarding which problems should be addressed first, second, and so on. The most important consideration when prioritizing problems is the urgency of the problem. Crisis oriented problems, such as suicidal thoughts, self-destructive behavior, violence or threats of violence toward others, or marked worsening in symptoms, must be addressed immediately. The next type of problems to be addressed are those related to a possible symptom relapse. If there are no clear priorities, it can be helpful to start with a challenge that is likely to result in success so that the family can experience positive changes and build confidence in the process.
- **The problem or goal is too broad and it is unclear where to start:** Some problems or goals may be so large they seem to be insurmountable. Breaking down a large problem into small, manageable chunks can aid the process of problem solving. To break the problem down into smaller elements, identify what needs to be changed first, second, etc. Try to make each element small enough so that it can be solved, and work on only one step at a time.
- **Participants do not follow through on plans:** There is usually one of three basic reasons why family members do not follow through on a plan that has been agreed upon during a consultation meeting in the treatment team: 1) they forget; 2) they do not know exactly what they are supposed to do; 3) they do not believe the plan selected will lead to the best solution. Strategies for overcoming these obstacles are as follows:
 - Provide reminders
 - Clarify exactly what each person's role is and what he or she is expected to do.
 - Sometimes people do not participate in a plan because they do not really believe that the plan will work, or they disagree with the definitions of the problem itself. If someone repeatedly does not follow through on the plan, despite reminders, this possibility should be explored. The solution to the problem may need to be adjusted in order to involve everyone who is pertinent.
- **No matter how hard the family tries, the problem cannot be solved:** Sometimes it is difficult to solve a problem or achieve a goal despite many attempts. When all reasonable efforts have been made, redefining the problem or goal can be a useful strategy.

Remember:

- Go slow and don't hesitate to revise your own work/writing
- Maintain a hopeful attitude
- Keep the mood as light as possible
- Be sure any critiques or criticism of ideas during brainstorming are addressed (e.g., "there are no wrong answers here")
- Don't allow the conversation to jump from one topic/problem to another
- The practitioner can be a part of the action plan
- Select a solution and follow through with a slow, practical discussion of the plan for next steps
- Make sure that everyone agrees to "try" the plan that is set up
- Remind everyone that no one is to blame for an unsuccessful outcome, if that happens, once the strategy is attempted and reviewed at a next meeting

3. Example of a problem-solving session

A seventeen-year-old boy that was recently diagnosed with first episode psychosis lives with his mother, father and younger sister. One day, the son and younger sister got into an argument and the son punched a hole in the wall and told his sister the next time it would be her face. The parents felt that the son was experiencing an increase in his symptoms. A consultation meeting with all family members was scheduled for the next day with the clinical team. During the consultation meeting, after several minutes of discussion about the problem, everyone agreed to define the problem as "What can the family do to help address ___'s [client] overwhelming feeling like he might punch his sister and beat her up?" The young person and family identified five different possible solutions (without judging any of the ideas that were generated):

- Re-evaluate the son's medication regimen with the prescriber.
- The practitioner will arrange for an evaluation from the OnTrackNY treatment team.
- The son will go to the hospital where he was previously admitted and receive an evaluation and possible admission.
- The son will stay with his grandmother, which constitutes a much calmer household situation, for a few days or weeks until he feels more stable.
- The daughter will stay with the grandmother until the son feels more stable.
- Hope that things will be okay since he has never punched a family member before.
- Start a rigorous daily exercise routine so that he can get some of his anger/aggression out.

After considering the advantages and disadvantages of each possible solution, the family members agreed that the best solution in the short term was number four, because the son felt the situation was urgent, and he was most comfortable going to stay with his grandmother. It was also agreed that the son would continue to work with the OnTrackNY treatment team and have his medications re-evaluated. A plan to implement the solution included the following steps:

1. The mother would call the grandmother to make the arrangements.
2. The father would take the son home to pack and then over to his grandmother's house.
3. The mother and her daughter would go to the mall to give the father and son time to pack.
4. The father would drive his son to the grandmother's house.

5. The primary clinician would talk with the other treatment team members to arrange the medication evaluation process.

E. Crisis Prevention Planning

Families can play a key role in crisis planning and prevention for young people experiencing first episode psychosis. Even if the young person has been following the recovery-oriented treatment plan and is using coping skills and supports that may have been effective in the past, they may experience a mental health crisis that can be scary and overwhelming for everyone involved. Family members may not know what to do to help their family member or who they can contact to get additional assistance or support. Crisis prevention planning can help family members identify warning signs and respond to varying levels of emergency by using personal coping strategies, connecting with others for support, and/or contacting professionals.

In many cases, family crisis prevention planning parallels the planning process used with clients. Typically, the OnTrackNY team will first work with the young person on a plan to recognize signs of a crisis and steps they can take to alleviate it. A supplemental family crisis plan, created by the client, PC and family, can build on the client's plan to identify ways that family members can help recognize warning signs and take action steps. This can include:

- Safety planning*: Upon the start of treatment, the providers and client will have completed the assessment for suicidality and, when needed, created a suicide safety plan in which careful assessment, triage, and implementation of the safety planning intervention are employed (see Team Manual).
- Crisis planning: If a client does not meet threshold for suicidality, but does experience symptoms that put him/her at risk and/or are concerning to the client, their family members, and/or the provider, the team can guide the development of a crisis plan that identifies potential mental health emergencies and steps for minimizing or managing consequences.

**See the Team Manual for guidance on safety planning with participants.*

1. Family Involvement in safety and crisis planning

Safety and crisis planning can help everyone feel more prepared to take action when necessary. Family members should be involved in the development of the safety and/or crisis plan and/or crisis plan. Family involvement is important for several reasons. Family members can help with concrete ideas to use in the safety and/or crisis plan, especially when the participant is having difficulty suggesting 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 shift, at least temporarily. 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.

2. Mental Health Crisis Description

Family members might feel uncertain about how to identify a mental health crisis or gauge its severity. Some family members might have seemingly high thresholds for crisis e.g., those with family history of domestic violence, serious mental health problems, or complex psychosocial factors. Other family members might identify most behaviors, even non-crisis ones, as concerning. Most people fall somewhere in between, so it is important to learn how each person views crises and to use that understanding when creating a plan.

Describe to the family what a mental health crisis could look like: "A mental health crisis is a situation in which a person is unable to use their usual coping skills or resources effectively and as a result experiences symptoms or engages in behavior that may put them at risk. This may include:

- Having difficulty thinking clearly; behaving in a disorganized way
- 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)
- Intense mood swings or mood states (e.g. being so high, hyper, excited that that person is not their normal state or they get into trouble; feeling so depressed that a person can't take care of themselves)
- 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 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 that the young person and their family members could benefit from additional support or assistance.

3. Developing a Crisis Plan

In the OnTrackNY Team Manual there is a Wellness Management Plan that providers can complete with participants to help manage crises. If the Primary Clinician has developed the Wellness Management plan with the young person already, the provider can (with the young person's permission) discuss the plan with the family. In some cases, the plan may already involve the family. For example, the young person indicated if they were starting to experience a crisis s/he would tell a specific family member and ask for help. The practitioner can work with the family to continue developing the young person's wellness plan, and discuss ways the family might add support.

In other cases, there may not yet be a wellness plan in place. The practitioner can consider involving the young person and the family together to develop the wellness plan. Below are the questions that can be asked of the young person.

- 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?

Make the family members aware that they too play an important role in developing and implementing a the plan. There are many ways that the family members can assist when and if a crisis arises. Below is a list of some ways that the family members can help:

Strategies for staying well: The family can help the young person identify people, places or things that help the individual feel healthy, calm, and in control of their recovery.

Things to avoid: The family can help the young person identify those things that get in the way of staying well. These might include triggers to symptoms or behaviors that impede recovery.

Relapse prevention: The family can help identify warning signs that the young person may not be aware of or notice.

Strategies for managing early warning signs: The family can learn more about the client's internal coping strategies and help support use, as well as help brainstorm additional coping strategies and tools. They might also be able to help identify distractions that have worked in the past or might help in the future and participate in creating distractions for the young person.

Families can be well positioned to notice warning signs given that young people often live with or have frequent contact with family members. Young people might feel more comfortable disclosing warning sign thoughts and behaviors to family members than others, particularly in early treatment. Additionally, family members who knew the client before, during and after onset might have richer context for differentiating baseline behaviors from unusual or warning sign behavior. Warning signs can vary from individual to individual and family members are sometimes able to identify warning signs that are not readily apparent to the young person.

"Family members can be an important part of developing and implementing a crisis plan. Sometimes family members recognize warning signs that you [the young person] may not be aware of or notice. Family members can help brainstorm coping and help-seeking strategies. As a result, they may be able watch for these signs and help you put your plan into place before it hits a crisis level."

Examples of common warning signs that people experience and/or family members observe:

- 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 argument/conflicts
- Changes in mood (e.g. feeling down or depressed, feeling more anxious or worry a lot, 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)
- Being more sensitive to light or sounds
- Experiencing an increase or return of psychotic symptoms
- Missing work or school

Work with clients and family members to identify warning signs. It can be helpful to identify stressful situations that have contributed to a crisis occurring in the past and to identify possible warning signs that may have been present during that time. Discuss overlaps and differences between each person's perspective on what constitutes a warning sign, and how young people, families, and team members might communicate when these red flags arise.

Action steps: The family can support the young person in implementing some concrete steps to help prevent a relapse. These might include skills the young person might want to use or who they need to call to get additional support.

Make the family aware that when a young person recognizes that they are becoming distressed they can use coping strategies to reduce and/or manage their thoughts and emotions. Inform the families that internal coping activities serve as a way for people to distract themselves from crisis and may prevent distressing thoughts or feelings from escalating. Distraction is a first-line strategy that can strengthen a sense of self-efficacy and mastery over distressing, or suicidal feelings thus promoting empowerment.

Family members can better support coping if they are aware of the purpose and process of identifying and utilizing coping strategies. Family members who are unfamiliar with coping strategies might be confused or concerned if they see their family member participating in a coping strategy without explanation. For example, a parent might be worried or feel dismissed if, during the middle of a disagreement, the young person begins doing deep breathing without explanation.

With the client's permission, review the client's coping strategies with the client and family members. Describe the activities and discuss the order of priority- the strategies that are most likely to be effective or the easiest to do may be listed at the top. Talk about some possible times and situations when they might be used (e.g., at work or in the middle of the night), and how they might be used (e.g., when alone or with other people). Provide the family members with the skills to reinforce the coping strategies that the young person uses across different environments. This might mean teaching them the steps so they can walk the young person through using these during a time of crisis or even reminding young people and encouraging them to use the coping strategies when they notice any early warning signs that the young person is distressed. Talk about how participating in such activities may also help young people experience some enjoyment, build mastery, or foster a sense of meaning in their lives. Highlight that the primary aim of identifying and doing such activities is to facilitate a distraction from the crisis.

Examples of coping strategies:

Listening to inspirational music, going for a walk, playing with pets, taking a bath or shower, going online, exercising, engaging in a hobby, doing chores, using relaxation techniques or reading.

After reviewing the strategies, the client, Primary Clinician and family members can use a problem solving approach to anticipate potential barriers to using strategies and discuss ways that family members might help. There are many different things the family can do to reduce a mental health crisis such as:

- Recognize events or situations that contributed to a mental health crisis in the past.
- Review the safety plan and/or crisis prevention plan and follow it.
- Be conscious of when the young person is under stress.
- Communicate observations of possible early warning signs.
- Support the young person's use of strategies emotionally e.g., encouragement to follow crisis plans and/or logistically e.g., connecting the young person with others for help.
- Participate in strategies for coping with stress e.g., use relaxation techniques, walking together.
- Assist the young person in staying in treatments that help him/her recover.
- Help them use medication effectively (as-needed and/or over time).
- Connect the young person with others when they are distressed or feeling overwhelmed.

Discuss with the client and family: "What are some effective coping strategies for you/your family member? Some young people ask their family member to remind them of coping skills, provide space to try skills by themselves, and/or use coping skills together. How can your family member be supportive of using coping skills? What might stand in the way? "

Family members can play an important role in helping the young person to recognize increasing distress and to help the young person identify coping strategies they can use to minimize their distress. Providers should inform families that the next-level strategy is to use socialization. If internal coping strategies are ineffective, the young person can use two types of socializing strategies: socializing with people in their natural social environment or visiting healthy social settings.

Family members are often part of the natural social environment and can act as a built-in social support, especially when young people are disconnected from, or have always had a limited social group. When socializing with family or others, the young person may or may not inform them that they are experiencing a crisis and are in need of help. Socializing without explicitly notifying others of the distressing or suicidal state may assist in distracting participants from their thoughts, or help them to feel connected with others and thus, alleviate the crisis. Highlight to families that this strategy is not intended as a means of seeking specific help with crisis, suicidal or otherwise. A crisis may also be alleviated if individuals feel more connected with other people or feel a sense of belongingness.

Participants might also plan to connect with family members or others if engaging in the natural social environment does not ameliorate the crisis. Family members might be one of several people listed as a good "distractor," or they might be on the top of the list. Family members who are aware of their place and status on the list might be able to improve their accessibility to the participant (e.g., responding promptly to text messages) or they might identify times that they will be unavailable (e.g., traveling without phone service) in advance. The list of individuals who may be contacted is prioritized, and phone numbers are included. Family members can encourage social interaction with other members on the list

who might be good “distractors” and might even provide means of contact). In the event no contacts are available, the family member might help the participant identify safe social settings such as a local coffee shop, house of worship, library or AA meeting, especially if the participant has a limited social circle

Share with family members/participants ways that connecting with others can help:

Socializing with or simply being around other people can distract the young person from challenging thoughts or experiences. Socializing with other may also help minimize distress by helping the young person feel more connected with others.

Family members/friends/supportive others can help the young person figure out ways to minimize the 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. As a result, part of developing a plan might include developing a list of people with whom the young person feels comfortable and supported who they can reach out to when experiencing distress.

For some, simply being in a social setting when feeling distressed can help him/her feel safer, more connected with others, or more relaxed and less distressed.

Identify social settings that the person can go to 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.

Managing a relapse: The family can help the young person articulate and determine who are those people that the young person wants involved if they are experiencing a relapse (or help the young person to contact) which, may include the team, or other professionals/agencies. They can also become informed about the young person’s preferences about what needs to be taken care of and who should be responsible for taking care of which things.

This step involves planning for actions that can be taken when internal coping strategies or socializing with others does not help with the crisis. Participants may choose to inform family members or friends that they are experiencing a suicidal or other type of high-risk crisis. However, given the complexity of deciding if participants should or should not disclose to others that they are thinking about suicide, the clinician, participant, and family should work collaboratively to formulate an optimal plan. This will include weighing the pros and cons of disclosing their suicidal or other high-risk thoughts to a person who may offer support, like family. Participants should be asked about the likelihood that they would contact the individuals identified in previous steps to discuss their thoughts and feelings and ways to cope with them.

Of note, although we are discussing crisis planning with family members in this section, which entails respecting participants preferences, it is important to keep in mind that when working with minors, there might be guardians (family or otherwise) whom the team is required to contact in certain situations. This possibility should be discussed with the participant and the guardians at the beginning of treatment. In addition to guardians, 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. In addition, special care must be taken when helping the participant identify individuals other than family members who may offer support.

It is important to acknowledge with family members and participants that fear of being involuntarily hospitalized for reporting suicidal impulses or other high-risk thoughts can be a major disincentive to reporting such impulses. Participants may learn to disguise intent and underreport to family and providers in order to avoid involuntary commitment. It is important to explicitly discuss the grounds for invoking involuntary measures with the client and family and to emphasize that involuntary hospitalization is only used as a way to protect the participant until the acute suicidal or other high-risk has passed. The participant and family must know that discussing suicidal ideation is not, in and of itself, grounds for involuntary hospitalization. Involuntary measures, especially when invoked “by surprise,” can undermine the alliance with the participant and relationships within the family. The stance related to acting to protect a participant when he or she is a danger to himself or herself comes from the goal of helping the participant with FEP pass through periods of high risk rather than supporting self-destructive behavior. Express to families that periods of high risk do pass and getting through them is the priority. Emphasize that, when in doubt, the family can contact the team for support and guidance.

If the family members are listed as contacts, they can be coached to help the participant use the safety plan by discussing the coping strategies that the young person has identified so that they can effectively provide support in the moment rather than resorting to calling the team or emergency services. Talk with the family member and participant about steps the family member might take:

- Discuss strategies the family member can use to assess risk. If there is a non-negotiable zone with regards to intent to harm the self or others, it needs to be discussed well in advance so it does not come as a surprise.
- Identify approaches to alleviate distress and reduce risk.
- Discuss individuals the young person would like to receive help from during a crisis and how and when to contact them; including other family members

Contacting Professional and Agencies

This step involves planning for actions to be taken when internal coping strategies, socializing with others, or asking for help does not alleviate the 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 support is obtained. Therefore, it is important for both clients and family members to know who to contact when additional assistance is needed and to have contact information for those individuals readily available. Equally important is ensuring that everyone “is on the same page” in terms of the steps that should be taken. This may include:

- Who the young person or family member would like to call during typical clinic hour (e.g. who is the person/place that they should call first, and 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 them while they are getting help)?
- Any other action steps the young person would like others to follow?
- Any ideas from the family on who they can contact or the role family might play in initiating/following-up on contacts?
- List of things that have worked well during prior crises or made getting help go more smoothly.
- List of things that did not work well and that should be avoided.

With the participant and family, create a list of professionals who should be contacted, including their phone numbers and hours of availability, and list the contacts in order of priority.

Suggestions for Creating a Wellness Management Plan

It can be very helpful to have family members, practitioners and other supporters involved in making the *Crisis Prevention Plan* and helping to carry it out. Before developing a crisis plan the young person should be encouraged to talk with supportive people in his/her life and ask them to help come up with a list of early warning signs. They should also come up with a list of suggestions in making a plan for responding to an early warning sign and asked them whether they would be willing to play a specific part in carrying out the plan. After writing up a crisis prevention plan, everyone should receive a copy and keep available. The plan should contain:

- Reminders of past triggers
- Reminders of past early warning signs
- What helps the young person when they are having an early warning sign
- Who they would like to assist them
- Who they would like contacted in an emergency

The following recommended Crisis Planning document can be found in the Resources and Recommended Readings section: *Developing a Crisis Prevention Plan – Questions*

F. Linking Families to Community-based Services and Resources

In addition to the 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.

G. 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.

H. Discharge Planning – Including Family Members

1. Include family members in the discharge planning process.

In many cases, the OnTrackNY team has engaged and worked with the families of participants on an ongoing basis. Although the degree to which involvement varies from family to family, one area in which OnTrackNY teams are strongly encouraged to engage with families is around discharge planning. The transition of the young person from OnTrackNY services to other services (as needed) is a particularly important time for family members to be equipped with information and strategies to best assist their relative once the team is no longer providing services.

As mentioned in the *OnTrackNY Primary Clinician Manual*, it is important to raise the issue of discharge with both the young person and the family approximately 3-6 months prior to a discharge. Share with all persons involved that the more people who collaborate and put their heads together to plan and prepare for discharge from OnTrackNY, the better and more smoothly the planning process and post-discharge experiences may go. This 3-6 month period allows for the family and the team to try to reduce intensity of services and start trying out other types of supports as a way of evaluating what may work for the young person when discharge occurs. It allows an opportunity to determine if the individual is actually ready to be discharged from the team or whether s/he needs to stay with the team for a longer period. Clearly communicating to the family that this is a time for exploration and trying out different options, might help reduce some of their fears and anxieties related to discharge.

2. Explore several aspects of discharge planning with families.

There are several different aspects of the discharge planning process that can be discussed and explored with families. See below for the types of areas for which OnTrackNY teams are encouraged to discuss and collaborate with family members.

a. Family thoughts, reactions and concerns about discharge.

Young people as well as their families will have a range of thoughts/reactions about moving on from the OnTrackNY team. In some cases, families may feel relieved that their loved one is doing well and ready for less intense services. In other cases, families will be worried about what will happen next and whether things might take a turn for the worse once the OnTrackNY team is no longer providing services. It is important to explore the family's reactions by asking questions to understand their perspectives and concerns. Examples of questions are:

- I'm hoping we can take some time to talk about your thoughts and reactions to the upcoming transition. What are your thoughts about [relative's name] being discharged from OnTrackNY services?
- What are your biggest concerns about [relative's name] ending services here?
- What kinds of challenges do you anticipate?
- What things do you think will go well?
- Are there things you want/need from us as we prepare for discharge?

b. Reflections about people's experiences with OnTrackNY

Some families may wish to spend some time reflecting upon their experiences with the OnTrack team and how the team's involvement has impacted their relative's life as well as their own lives. Team members might ask:

- How has [relative's name]'s involvement with OnTrackNY impacted his/her life?
- How has your family's involvement with OnTrackNY impacted your life?
- Do you have any feedback for our team?

c. Hopes, concerns and expectations about community services

Discuss with families their hopes, concerns and expectations about their relative transitioning (if needed) to other community-based services. This should be done using the *Transition Planning Tool*, which is used by the Primary Clinician with clients. Consider ways to be encouraging to family members and instill hope, as well as discuss the realities of treatment as usual in typical mental health settings. It may be important to convey that community services can range in how "user-friendly" and flexible they are, and might differ from OnTrackNY, especially regarding family inclusion.

Discussing family members' hopes, concerns and expectations may naturally lead to an important conversation about specific community services. Further, it may provide an opportunity to provide psychoeducation and brainstorm with families about ways they can advocate for their relative and themselves in terms of obtaining the types of services they want and need.

d. Learn about specific services available in the community

Encourage family members to learn about community services that may be available in their specific community. Ideally, the family and OnTrackNY practitioners can investigate community services together and/or the team may have information, brochures, websites, etc., already prepared and available for families. The types of community services that the OnTrackNY team can discuss with families include but are not limited to the following:

- Community mental health centers; licensed mental health clinics
- Personalized Recovery Oriented Services (PROS) programs [in New York State]
- Different levels of acute services depending on their relative's situation (e.g., local mobile crisis teams and psychiatric emergency departments)
- Private service providers, especially if there are any providers local to the family that may specialize in psychosis and endorse recovery-oriented practices
- Peer-based programs, such as a local Mental Health Association (MHA), for people in recovery from psychiatric issues
- The local chapter of the National Alliance on Mental Illness, which typically has many support and education-based opportunities for both family members and the person with a psychiatric condition
- Supports for work and school through the individual's current employer or school program.
- Expanding the social networks by determining who in the young person's social network can be instrumental for supporting different life areas/pursuits (e.g., socializing, engaging in hobbies, joining sports activities, etc.).

e. Continue connections with supportive people

It may be helpful to review with family members whether they have developed or deepened any friendships or family relationships that have been supportive to them and the young person while enrolled in OnTrackNY. The OnTrackNY team may encourage family members to remain connected with any supports they've found helpful during their tenure with OnTrackNY. Often these types of relationships can continue to be supportive when there are intentional efforts by the family to continue and deepen these relationships.

f. Connecting with local Chapter of the *National Alliance on Mental Illness (NAMI)*

Encourage the family to consider contacting the local NAMI chapter to find out about the support and educational services offered. Even if they did not connect with NAMI during the time their relative was involved in OnTrackNY, some families may find it helpful to develop new connections and relationships with other family members who may have similar experiences. Networking with NAMI members can also be a great way to learn the "ins and outs" of community services.

g. Families as primary supports

Once again using the *Transition Planning Tool* and being guided by the client's preferences, involve the family early on in a discussion of what things family members may need or wish to support during the transition from OnTrackNY services and after discharge occurs. The young person should be included in this conversation and have a voice and provide input regarding the types of things that may be helpful

for family members to do to support the discharge process. Examples of the types of things families may need to take on are:

- Extra time and energy to understand health insurance and any changes related to switching to a different provider (e.g., coverage, co-pays).
- Identifying other supports or people to help the family with coping and problem solving (if needed) in the future – this can include professional and non-professional supports.
- Establishing new working relationships with new providers
- Coping with concerns or stress – both for the family members and for the program participant - related to not having the flexibility and reliability of OnTrackNY team available in the future.
- Taking on any additional activities as per the wishes of the young person, such as any additional desires of the young person for companionship, emotional support, problem solving, assistance with coping strategies, etc.
- Practicing new routines and skills to ensure a seamless transition prior to discharge and altering plans as needed.

h. Ways families may advocate for services for the young person

How might families advocate for the young person and still be involved in services despite the change in providers? How might they respond if providers attempt to eliminate them from the discussions once their relative starts services elsewhere? Explore strategies that families might employ - with discussion, input and buy-in from their relatives - to help shape the services and supports with which their loved one can become involved. Some examples of ways that families may consider advocating for the best possible services are below.

- Ask a lot of questions about the program prior to a relative enrolling in services [see next section below].
- Ensure the program adopts a person-centered, recovery-oriented approach to treatment by asking about their philosophy and guiding vision for their program and services.
- Ask for a tour of the behavioral health facility/program prior to making a decision to enroll in services.

Talk with families about the types of questions they should ask any potential new providers. Ask for their input about developing additional questions based on their family situation. Sample questions include:

- What is the range of services available to [relative's name] if s/he were to receive services here?
- How much choice to people have about the frequency, duration and nature of the services offered?
- What is your/program's approach to working with people in recovery after a first episode of psychosis? What kind(s) of theoretical orientation do you/program most commonly adopt when working with younger populations (e.g., cognitive behavioral, psychoeducational, psychodynamic)?
- To what extent are clients' families involved with the services you provide? In what ways do you typically support (with relative's consent) family member involvement?
- How often does a client typically meet with the prescriber? Are there certain days/times each week that the prescriber works at the program?
- How do you handle after-hours crises or emergency situations?

i. Following up with OnTrackNY after discharge

Invite clients and families, at least in the short term, to occasionally (e.g., monthly) follow-up with your team via phone about how things are going and whether the community service connections that were planned are developing into adequate support for the young person. Your team should be clear with the family that although OnTrackNY can no longer provide services to the young person after discharge, the team can brainstorm with families and in some cases help troubleshoot and/or link families with services post-discharge (for a period of time that is determined by your OnTrackNY team, such as 3- or 6-months).

j. What to do if things are not going well after discharge?

Families often want to know what to do if their relative experiences recurring symptoms and/or begins to experience a crisis situation, especially if they are not connected to community services. Ideally, your OnTrackNY team has worked with the young person and family to develop a relapse prevention or crisis plan. Please refer to the crisis prevention planning section in the OnTrackNY Family Intervention Manual for additional details about developing a plan prior to discharge.

k. Check-in about any other thoughts

As the discharge from OnTrackNY services gets closer, consider asking the family, "Do you have any questions or thoughts about [relative's name]'s discharge that we have not yet discussed?" This gives the family another opportunity to share their perspectives and raise any additional issues that may not have been discussed already.

IV. Appendix

A. 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 things 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."

B. The Family Voice: What Is Needed To Work Effectively with Families?

Joyce Burland and Laurie Flynn

"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."

C. 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:

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?

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

- ☐ 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: _____

Notes:

Clinician Signature: _____ Date: _____

D. 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 Primary Clinician, the participant lists both the potential benefits and the downsides of family involvement using this sheet. The Primary Clinician should prompt the participant to complete the form. However, the Primary Clinician 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?"

E. 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:

Glynn, S.M., Cohen, A.N., Murray-Swank, A., Drapalski, A., Dixon, L. (2010). Family Member Provider Outreach

(FMPO) Manual. Unpublished manual, VA Maryland Health Care System, Baltimore, MD.

F. 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:

Glynn, S.M., Cohen, A.N., Murray-Swank, A., Drapalski, A., Dixon, L. (2010). Family Member Provider Outreach (FMPO) Manual. Unpublished manual, VA Maryland Health Care System, Baltimore, MD.

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

1. 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:

1. Principle 1: Express Empathy.
 - Acceptance facilitates change.
 - Skillful reflective listening is fundamental.
 - Ambivalence about change is normal.
2. 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.
3. Principle 3: Avoid Arguments and Direct Confrontation.
 - Avoid arguing for change.
 - Resistance is not directly opposed.
4. 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.
5. Principle 5: Support Self-Efficacy.
 - 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.

2. Examples of Open-Ended Questions to Evoke Change Talk

- **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?

- **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?

- **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?
- 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:

Glynn, S.M., Cohen, A.N., Murray-Swank, A., Drapalski, A., Dixon, L. (2010). Family Member Provider Outreach (FMPO) Manual. Unpublished manual, VA Maryland Health Care System, Baltimore, MD.

H. Introducing the Core Units to Family Members

Purpose. The Primary Clinician will offer up to five core units to interested families to ensure that all families receive information and training on the treatment for first episode psychosis (FEP), relevant psychoeducation about psychosis, information and training on engaging in shared decision making, knowledge about typical family experiences, and strategies for crisis prevention and planning. The delivery of these core units may also help to enhance engagement with the family members and provide the team with understanding the family's cultural framework while emphasizing resiliency, identifying family's needs and preferences, and discussing the time-limited nature of the FEP intervention.

OnTrackNY Family Program Core Units

- Treatment for Psychosis
- Psychotic Experiences: Symptoms, Causes, and Recovery
- Shared Decision Making with Families and Clients
- Common Family Experiences in First Episode Psychosis
- Crisis Prevention and Planning

Delivery of Core Units. Core units should be delivered in a flexible manner and with the goals of addressing: a) family needs, and b) ways the family may become meaningfully involved in working with the OnTrackNY team and supporting the young person's recovery goals.

Core units can be delivered:

- To the family with the young person, or just the family.
- To all family members involved, ideally as a group or to individual family members.
- During regularly scheduled meetings or when convenient, based on availability and level of involvement.
- In one meeting or over course of multiple meetings
- Wherever it best suits the family (e.g., in the office or at the family's home, or over the phone).
- In the suggested order so that information builds as people participate in more core units or as-needed to address issues that the family is facing at the moment (e.g., crisis prevention and planning before psychoeducation about symptoms).

Introducing the core units to a family typically should not occur until the Primary Clinician has started to get to know the family members and their needs. Ideally, the *Family Engagement and Needs Assessment* (located within this manual) should be completed prior to the delivery of these core units so that the content of the core units can be tailored to the client and family's preferences. For example, if the family has the goal of understanding the client's symptoms, particular attention can be paid to delivering this information first. Clinicians are encouraged to re-evaluate the family's needs regularly, since core unit information might influence the family's preferences and goals over time. Whenever possible, delivery of the Family Core Units should correspond with the delivery of the client's core units (see the CAR manual) such that the young person and family have the same information and opportunities to ask questions and provide insight as they engage in the treatment planning process with the team.

Sample Introduction to the Family Core Units

"Over time we have found that there are a few particular topics that families appreciate talking to us about early on in their loved one's treatment. It's critical that families have the opportunity to learn about the team and how we can work with you and your loved one around the challenges your family may be facing. We also know that you may have many questions regarding _____'s [insert young person's name here] mental illness and how to best cope as a family. As such, we have created five Family Core Units that contain information we think every family of a young person with FEP may want to discuss with their treatment team. It's recommended that families participate in these units when their loved one is first getting involved with the team because discussion of the material may inform the type of help that we provide moving forward. Family members know their loved ones the best and are a very important part of the treatment team.

"As with everything that happens with the team, we want these Core Units to be useful for all of you, so if topics come up that you aren't interested in right now or if you'd like to spend more time on specific topics that are more relevant to your current situation please, let us know. We can be flexible so that the information you get is the information you want. "

****If the family members have not yet met the team, refer to the Collaborative Approach to Recovery (CAR) Manual**

Core Unit Format. Though structure of the core units can be flexible we have organized the units into four steps that build on one another for optimal facilitation of a discussion. Once again, remember that these core units will happen across several meetings so it is very likely that you will not get to all the steps below during one meeting with a family. It is important that you go through the following steps at a pace that allows time for understanding and reflection and offer time for problem solving and questions at the end of each session even if all of the information from the core unit could not be covered that session:

Delivery of information provided in a specific unit.

- Discussion of the relevance of this unit to the family's experience including answering questions the family may have (e.g., discussion of examples of what they have noticed with their loved one, how they understand the experience, and how they have dealt with it).
- Structured problem solving around related issues they might be struggling with (if applicable) and the development of an action plan that they can try out at home.
- Discussion of any other questions or concerns the family member might have around the unit.

I. Core Unit 1: Treatment for Psychosis

Vignette: Kim is a 22-year-old woman who is new to the OnTrackNY team. Kim lives at home with her parents and brother and reports being very close with them. Over the past few months, Kim's parents noticed that she was spending most of her time alone in her room and seemed more tired and anxious than usual. At first her parents thought she was "just going through a phase," but when Kim told her mom that she had been hearing distressing voices, her parents took her to the ER.

During initial engagement and assessment meetings, Kim stated that it is important to her that her whole family be involved in her treatment and able to help her make decisions. When conducting the Family Engagement and Needs Assessment, Kim's father noted that he overcame depression as a teenager, despite doctors pushing harmful medications on him. He chose not to take medication and instead found the "personal medicine" of prayer to be healing. He wonders where prayer might fit in with treatment, and whether it can replace the medication his daughter was prescribed in the hospital. He notes that even though Kim's medications seem to be helping her a great deal, there are worrisome side effects. Kim's father would like to learn more about the OnTrackNY treatment model, the different members of the team, their roles and how OnTrack might be different from other treatments they could choose for their daughter.

During Core Unit 1, Kim's family would like to learn more about the team and the services they offer so that they can work together with the team and Kim. The PC offers to invite the psychiatrist to join today's meeting and discuss the family's concerns around medication and since this is ok with the family, the PC and psychiatrist review the information already gathered in the Family Engagement and Needs Assessment to prepare for the discussion. Kim, who is already familiar with the team structure, decides to meet with the SEES during this time to talk about college applications.

Introduction to Unit and Rationale

The purpose of this unit is to orient families to the different types of services and treatments for psychosis available through OnTrackNY. Though there is a lot for family members to learn about first episode psychosis, research has shown that family members are eager to learn about available treatment options so they can best assist in the young person's recovery. If the client is present during the unit, check in with him/her regularly to make sure they are comfortable with the material and to gather his/her thoughts.

Script for Introducing Core Unit 1:

The OnTrackNY program is made up of a team of specialists who work with a young person (and family) to create a personal treatment plan. In Core Unit 1, we will review: the team members, their roles, and the OnTrackNY services available to young people and their families. These services include: medication management, individual counseling, substance abuse treatment, relapse and wellness management, employment/education support, assistance with coping and communication skills, case management and care coordination, peer support, and resources for families.

Before we get started I want to encourage you to stop me at any time to ask questions and/or share. I would like this to be an open discussion that can continue over multiple sessions as needed as part of our ongoing work together.

Treatment Team:

In this section you will introduce family members to the treatment team's structure, services, and aims. Be careful not to assume that family members know about the mental health system and how a mental health team works together. Some families may already understand some aspects of the mental health system from prior experiences. However, for some families may have never interacted with the mental health system or the information you provide might differ from what they have been told in the past. It is important to periodically check in with family members to see if they have any questions and to clarify misconceptions or concerns.

Team Members and Roles: The OnTrackNY team includes several mental health professionals who provide a range of treatments/services designed to help individuals who have experienced psychosis achieve their treatment/recovery goals. Each team member brings specialized knowledge and expertise to the collaborative work. The team approach relies on everyone's strengths and energy. The members of the treatment team include the:

Primary Clinician:

- Works with an individual and their family to help identify treatment goals and develop a plan for getting them met
- Facilitates monthly groups for individuals and for families
- Provides supportive and CBT-Based psychotherapy
- Coordinates care and connects people with resources - both those provided by the team as well as those offered in the community
- Assists with building and/or strengthening communication and coping skills
- Helps practice and refine these skills for real-life situations
- Engages client in wellness and crisis planning, as well as suicide prevention
- Works with interested individuals to reduce behaviors such as drinking, drug use, and smoking that may block one from achieving recovery goals and to increase behaviors that can assist them in reaching their goals

Psychiatrist/Prescriber & Nurse:

- Works together with an individual and their family to determine whether the individual would like to consider medications and, if so, 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
- Discusses medication management topics like: filling and picking up prescriptions, medication payment, tracking how medication is taken (forgotten doses, etc.), observing benefits and monitoring side effects

- Collaborates to identify health and wellness goals (such as weight loss) and plans (like exercise and nutrition) to build healthy behaviors
- Runs wellness groups on topics of interest to young people and for family members

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
- Provides ongoing supports, as needed and/or requested by the young person and family, to help individuals remain in school or competitive employment

Peer Specialist

- Brings first-hand experience with emotional and/or mental distress (often called “mental illness”) and a history of active engagement in a process of self-discovery and/or recovery related to those struggles.
- Unlike other members of OnTrackNY staff, provides young person with mutual peer support and a commitment to “learning together rather than helping.”
- Forms hope-based relationships with clients and families that support learning and growing through challenge and crisis.
- Facilitates engagement with OnTrackNY team by forging strong connections with participants and families, encouraging help-seeking, and at times serving as a bridge between team members and participants when they experience ambivalence about treatment.
- Understands, shares and discusses multiple frameworks for understanding life experiences such as psychosis with participants, families and the rest of the OnTrackNY team.
- Collaborates with participants to clarify their personal visions and develop their wellness toolkit.
- Influences team culture by advocating for clients, promoting a youth friendly approach and encouraging the use of recovery oriented language.

Client:

- Works with the team to identify personal goals and steps needed to reach those goals
- Participates in discussion of treatment options with the team and works with them to decide what services/treatments would be most helpful
- Informs team about personal medicine strategies and works with team to integrate strategies into treatment plan
- Provides information on health history of client and family
- Participates in crisis mitigation, response and management
- Works with team to identify family members who can be included in treatment and discusses how they might be involved (please refer to the Family Engagement and Needs Assessment in the Team Manual)

Family Member:

- May or may not be a blood relative but is someone that 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
- Often key collaborators in seeking services, engaging in treatment, and supporting in the recovery process and can offer practical (e.g., transportation), financial (e.g., living expenses), and emotional (e.g., encouragement) supports, particularly if the young person lives at home
- Provides information on health history of client and family (especially if client is a minor)
- Participates in crisis mitigation, response and management

Script: As you can see there are many people on the treatment team. It includes your relative and you, as family members. We believe that all of us can play a very important role in the recovery journey. This is a good time for us to discuss any questions, issues or concerns that you may have around the treatment team and how we can work together.

OnTrackNY Treatment Components

A) Pharmacological Treatment (i.e., medications):

For many individuals, medications can be helpful in reducing symptoms as well as preventing symptoms that are diminished (or are no longer present) from reemerging. The decision to begin medication treatment, the choice of specific medications, and the plan for obtaining and taking medications should be shared among the client, family members and the rest of the 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

Sample Dialogue: There are a number of treatments that have been shown to be effective for psychosis. Collaborating with family members when making decisions about treatment and can assist young people in reaching their treatment goals. Ultimately it is up to [name of young person] to make decisions around medication, but we realize that you may have some helpful thoughts and suggestions and we want to hear them. Each person's goals may be different and these goals may change over time, so this will be an ongoing discussion. Let's just have a brief discussion on the following:

- What is your understanding of treatment for psychosis?
- Are there any treatments that you have heard of and would like to discuss?
- How and where do you get information about treatment?
- What are your hopes/expectations for treatment?
- What works and what does not work?

A1) Antipsychotic Medications

The OnTrackNY prescriber should ultimately introduce the topic of medication to the client and family and discuss any specific medication needs. However, it is also very important for the PC to provide psychoeducation and discuss side effects and generally be a resource for concerns around medication.

In this section, it is recommended that you use the handout: *Antipsychotic Medication*, which is recommended by the OnTrackNY Team. Please highlight the following information:

- Antipsychotic medications can help decrease symptoms of psychosis and prevent symptoms that are diminished (or are no longer present) from reemerging.
- 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.
- Define first-generation and second-generation antipsychotics
- Antipsychotics can be taken orally or as an injection
- The effect of some antipsychotic medications may be noticeable after a few days, for others it can take two to four weeks to see a result.

Sample Dialogue: 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, people may need to try a few medications before they figure out which works best for them. Therefore, it is very important for you and other family members to be aware of any side effects that [name of loved one] may be having and, with their permission, to share them and your concerns with one another and with the OnTrackNY team as soon as you are aware of them. The team is eager to work with you and your loved one over time to find the medication that works best for them.

A2) Other Medications:

- Antipsychotic medications may not be effective for all symptoms the individual may be experiencing. In some situations, 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)

Sample Dialogue: These medications may also have side effects. It is best to talk with the prescriber/team over time about possible side effects and to monitor them closely.

A3) Medication Side Effects:

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

It is important to have a discussion with the prescriber and even review the OnTrackNY Medical Manual prior to discussing common side effects of antipsychotic medications with participants and families, since this is the prescriber's area of expertise. In reviewing the Medical Manual, you will have an opportunity to become familiar with a definition/description and examples of each side effect discussed. Stress to participants and families that although some individuals that take these medications may experience the side effects discussed, not everyone that takes these medications will experience them.

Sample Dialogue: Each medication has possible side effects. However, it is important to keep in mind that not everyone taking medications experiences side effects. My goal is to give you information about side effects so that you can feel more comfortable speaking about them and getting detailed information from the prescriber. Typical medication side effects may include: 1) weight gain; 2) other metabolic side effects such as high blood sugar or increased fats in the blood, like cholesterol; 3) hormone changes and associated effects, including: stopping of menstrual cycles or periods (for women); milk leaking from breasts (can happen for men and women); and less interest in or ability to have sex; 4) motor side effects which means abnormal movements and 5) feeling tired or slowed down.

Prescribers try to prevent or decrease these side effects by using the lowest effective dose of each medication and having individuals take medications at optimal times during the day. For example, if our prescriber knows that a medication often makes people sleepy, he/she will recommend that your loved one take it take the medication at night to avoid annoying daytime drowsiness. When needed, other medications to manage side effects may be prescribed.

Let's talk more about your experience with side effects:

- Have you or your relative ever experienced side effects because of a certain medication?
- What did you or your relative experience?
- What did you do about it?

A4) Coping with Side Effects

The team can work together to observe and monitor side effects. Sometimes family members or the rest of the team will notice side effects that the client doesn't, or the client will experience side effects that the family member and team can't see.

Sample Dialogue: It is important to inform the prescriber or other member of the team about any medication side effects as soon as they occur so that we can all discuss together and come up with a plan on how best to address them. Some side effects will subside over time so you may decide to wait a week or two to see if they diminish. If they do not subside, there are several 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

B) Psychosocial Treatments:

There are several psychosocial treatments that have been shown to be very helpful for individuals experiencing psychosis, particularly when they are used in conjunction with medication. What we mean when we say "psychosocial treatments" is treatments that take into consideration the individual's psychological health (i.e., internal to each of us) and the social factors that may influence him/her. Family members who are familiar with these treatment services are better equipped to support their use. Psychosocial treatments are an effective way to improve the quality of life for individuals with mental illness and their families. They can lead to fewer hospitalizations and less difficulties at home, at school and at work.

Sample Dialogue: The team can utilize a variety of psychosocial services, depending on client preferences and needs. Services include: learning and practicing skills for building and enhancing relationships; coping with difficult feelings and situations; managing stress; doing enjoyable activities and connecting with the community, building motivation and identifying goals for changing substance use habits, and learning information on health, wellness and other topics important to the client.

Based on the client's preferences, families can be key supports in identifying opportunities to use skills and practicing them in daily life. The following are the list of treatments that the OnTrackNY team offers:

B1) Individual Counseling and Support:

The Primary clinician works with the individual to:

- Meet one-on-one to discuss issues or problems a person may be facing
- Provide individual family consultations

B2) Supported Education and Employment:

The Supported Education and Employment Specialist (SEES) 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.
- Help young people and families understand the connection between engagement in age-appropriate work and school activities and overall wellness and recovery.

The education and employment plan will be 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).

B3) Coping/Social Skills Training/Psychoeducation:

Young people with FEP often experience challenges around socializing, engaging in enjoyable activities and utilizing healthy coping strategies in the way they would have prior to developing psychosis. These following services, provided by the Primary Clinician, involve teaching and learning a new skill or doing a structured exercise or activity directly related to an individual's goals. Family can help support social skills training—clients and family members can use and practice skills together to enhance communication and relationships both within the family and with other people.

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

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

Involves helping people identify and carry out pleasant activities in the community to decrease isolation and depression. These activities can be done independently or with identified family members.

4. Substance Use Treatments

- a. Involves increasing motivation to change unhealthy substance use behaviors.
- 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

Involves providing individuals with information or helping them explore a particular mental health topic in a way that is useful for their recovery

B4) Resources for Families:

OnTrackNY family education programs focused on providing information, education and support.

1) Monthly family group meetings

Monthly groups focused on providing information/education, skill building, problem-solving and mutual support; topics are chosen by attendees and are flexible and largely dependent on the needs of the group.

2) 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.

Family education programs in the community:

NAMI's Family to Family Program

Group offered in the community focused on providing education, communication and problem-solving, skills building, and support

Sample Dialogue: It is highly recommended that family members take advantage of all of the resources available to you. It will assist you in understanding what is happening with your loved one biologically, mentally, physically and emotionally. In addition to these benefits, it is important that you have a method to be able to discuss mental health issues and wellness, skill building, and receive mutual support from others that are living with similar experiences.

In addition to the four psychosocial treatments there are also the following services:

C) Other services:

Other services, typically provided by the Primary clinician, are:

- Coordination of community services to meet individual and family needs, for example health, housing, transportation and income needs
- Linking with community resources (e.g., NAMI, Self-help groups for substance use (AA, NA), specialized trauma services)

Sample Dialogue: We have covered a great deal of information during the meeting(s). Are there any questions that you may have regarding any of the topics that we reviewed? There also may be some different therapies and/or support groups that you are considering for yourself [the family member]. If this is the case and you would like information about them, please do not hesitate to contact any one of the team members to discuss. I will be in contact with you soon to let you know what family program we have taking place at the present time and in the future.

Summary of today's meeting:

After delivering the information on treatment for psychosis remember to pass out any handouts you might want to share. Encourage the family to contact you with other questions they may have in general or on the specific topic you just discussed. Also, remember to contact the family to make them aware of how they can attend your multi-family group.

Problem-Solving

If you have already begun engaging the family in problem-solving, discuss related successes and challenges and, if needed, revisit the steps for problem solving.

After delivering the above information, the family might benefit from engaging in some formal problem-solving around a related issue that they might be facing with their loved one. Developing an action plan will start the process of helping families gain skills to better manage the difficulties they are facing.

Remember that the steps for problem solving include:

1. Define the problem
2. List all possible solutions
3. Discuss advantages and disadvantages
4. Choose the solution that best fits
5. Plan how to carry out the solution
6. Review implementation during the next meeting

Refer to the problem-solving section of this manual for detailed information on how to conduct formal problem-solving with clients and families.

J. Core Unit 2: Psychotic Experiences: Symptoms, Causes, and Recovery

Vignette: Since discussing Core Unit 1 topics, Kim's family members have expressed feeling less alone and better equipped to work with the team and support Kim. Kim's parents frequently attend OnTrackNY meetings with Kim and are relieved that she decided to join the program to get help. and that the team is a resource for their family. However, last week Kim's brother looked up psychosis on the internet and was alarmed to read that psychosis leads to "permanent disability."

Kim's family members don't feel clear on what psychosis really is and how to think about it as Kim begins the recovery process. The family set up a few meetings with Kim and the Primary Clinician so they could learn as much as possible about Kim's recent psychotic experiences, expectations for the future, and how they can help.

During Core Unit 2, Kim's parents and brother would like to learn about what is happening to Kim. They are confused about the meaning of psychosis and its causes. Kim's brother suspects that stress was the cause but her parents wonder if it's because they didn't pray enough for her. The family fears that Kim will never be "herself" again and want to know if this "OnTrackNY treatment" will fix her. They would like to be supportive but feel overwhelmed by the recent changes in Kim's behavior, are feeling guilty that they are unsure whether they can handle caring for Kim. The family also wants to learn ways to communicate with Kim when she is "in an emotional state" or seems "shut down." Like many families of young people with FEP, Kim's family hasn't told anyone outside of the family what is going on and worry that other people might shun them all if they found out. At this point, they feel as though they are alone in their struggle and no one can understand what they are going through.

Introduction to Unit 2 and Rationale

The purpose of this unit is to allow families to share their experiences FEP thus far and provide them with clarifying information on symptoms, early intervention and recovery. We have found that family members are eager to learn the information so they can better understand what the young person might be experiencing. If the client is present, check in frequently with him/her while discussing this information to make sure they are comfortable with the material and to allow him/her to weigh in on how the information fits or doesn't fit his/her experiences.

Describe Core Unit 2

First, we'll talk about what we have learned about how your family member has been experiencing symptoms and what's brought your family to the team. Then, we'll provide information on the symptoms, phases and common causes of these experiences. We will also talk about what recovery is, how your family envisions recovery and the role that the OnTrackNY team can play in the recovery process.

Family Experiences

In this section, clinicians will encourage all family members to share their individual experiences related to the young person's development of psychosis. They will strive to meet the family where they are at and use reflective listening to convey understanding. They will also summarize to information shared to ensure they have accurately understood the family's point of view and provide the family the opportunity

to clarify anything that may have been misunderstood. The information gathered during this process should inform the order in which the content in Unit 2 is delivered so that it is tailored to meet the family's specific needs and preferences.

People typically understand their experiences in relation to their cultural, spiritual, or religious beliefs. The terms some people find helpful may not be a good description of other peoples' feelings and experiences. Refer to the *Cultural Formulation Interview* for a guide on facilitating a culturally competent discussion.

Sample Questions:

- People often understand health issues in their own way, which may be similar or different from how doctors describe the issue. How would YOU describe [name's] mental health issues (use the word that the young person uses to describe their experiences)?
- Sometimes people have different ways of describing the problem to family, friends or others in their community. How would YOU describe [name's] problem to them?
- What troubles you most about [name's] problem?

Introduction to Psychosis

The purpose of this section is to describe psychosis and discuss how the family understands psychosis in relation to their family member. Remember to gauge "where the family is at" before beginning psychoeducation and avoid using clinical jargon. For families that might not be open to thinking that their loved one has a mental health problem, you might initially focus on engagement and understanding their point of view and possibly deliver the psychoeducation at a later time or in another meeting.

Sample Introduction: Psychosis can affect the way a person thinks, feels, and acts. Many people in our program have difficulty telling the difference between what is real and what is not. Psychosis is experienced by approximately 3 out of every 100 people at some point in their lives, and so is not as rare as some people might think.

A) Integrating the Family's Understanding of Psychosis

Describe psychosis using the family's words. As individuals begin having these experiences,

- They may have ideas that [insert family's words, e.g. they hear voices, see or sense things that other people don't, feel that someone is out to get them or talking about them, and feel anxious or depressed].
- They might act like they [use client's and/or family's words about behaviors, e.g. want to sleep all the time, are not feeling talkative, do not have energy].
- They might feel [use client's words, e.g. scared, confused, distressed and low in self-worth].

Sample cont'd: The first episode of psychosis typically occurs in a person's late teens or early twenties. Symptoms may start suddenly or develop gradually over time. Family members might notice changes early on or later as they develop. Both men and women of every race, ethnicity, culture, and socioeconomic group have these experiences. Other family members might have had similar experiences. However, the experience of psychosis differs from person to person and may even change over time.

One thing we know from research is that these sorts of experiences are not as uncommon as once believed and that, with the right treatment and support, many people can and do recover.

B) Common Symptoms of Psychosis

Here are some common experiences of psychosis to be shared with the family. The handouts to assist with presenting this material can be found in the *OnTrackNY Family Treatment Manual*.

Hallucinations. Hallucinations cause people to hear, see, taste, or feel things that are not there. Hallucinations seem very real to the people experiencing them. For that reason, people who experience hallucinations often have difficulty believing that they are not real. Examples of hallucinations include:

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

Sample follow up question: In your experience, what are some examples of hallucinations?

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

Sample follow up question: Can you describe any beliefs or thoughts that may not be entirely accurate or where you may question the accuracy?

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

- Thoughts can seem unclear
- Thoughts are jumbled together
- Thoughts are racing too fast or are coming too slow

Sample follow up questions: Have you noticed any difficulty with expressing thoughts? What have you noticed?

Changes in behavior. These can include:

- Spending more time alone
- Sleeping more or less than usual
- Not taking care of oneself as well as one used to (e.g., not bathing or dressing, appearing disheveled)
- Having less interest in socializing, going to work or school, or otherwise engaging in activities one used to enjoy

- Not taking part in usual family activities (e.g., dinner, family parties) or tasks (e.g., household chores, cooking, shopping)
- Behaving in a way that doesn't seem to fit with the situation, such as laughing when talking about something sad or upsetting, or for no apparent reason

Sample follow up questions: Have you noticed any changes in behavior? What have you 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: Unusually good or irritable mood, need for less sleep or more energy than usual

Highlight the fact that the individual may experience other symptoms that are either part of the psychosis (e.g. mania for someone with schizoaffective disorder) or a result of the symptoms (e.g. anxiety due to concerns about being followed; depression associated with life changes due to illness).

Phases and Causes of Psychosis [OPTIONAL]

If the family is interested in the phases and causes of psychosis, refer to the Collaborative Approach to Recovery Manual, Core Unit 1, for a detailed description. The content in this unit can be adapted to families.

Sample phases of psychosis summary: An individual's and their families' understanding of their experiences might change throughout the phases of psychosis. Early experiences might not be as noticeable or concerning as later experiences. They might also be confused with other common developments, like age-related behavioral changes (e.g. becoming more independent), other mental health problems, or substance use. Families are often unfamiliar with treatment and support options and might try to manage these experiences on their own. Often, they reach a tipping point in which symptoms and behaviors become difficult to manage and clients and their family members seek help. Are you interested in learning more about the phases and/or causes of psychosis?

What is Recovery?

It is important for clinicians to emphasize that there is hope for recovery— many people can and do recover. At the start, family members might feel a sense of loss and grief after their loved one becomes ill. They might wonder if their family member will ever “go back” to how they were before the illness, or even feel like they have lost their loved one forever. Understanding how recovery might look, how long it might take, and what role families can play can help to encourage positive, and realistic, expectations of recovery. Connection to other family members or friends who have had a loved one who has recovered and/or stories of recovery can be very helpful.

It is important for clinicians to support family members as they begin to make meaning of the illness and participate in treatment. We know that individuals whose families are involved in help seeking and treatment are more likely to recover. Moreover, when families are involved in treatment, they have a better chance of decreasing the young person's distress and improving their quality of life.

A) 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.”
- “A way of living a satisfying, hopeful, and contributing life even with limitations caused by illness.”
- “...involving the development of new meaning and purpose in one’s life as one grows beyond the effects of mental illness.” (Anthony, 1993).
- “Continuing with your life even though [you] might still have symptoms.”

We believe that there are many ways to work towards recovery goals even when the young person may not be feeling well. Lots of people experience ups and downs with their symptoms and, if they are trying to achieve goals that are meaningful to them, figure out ways to manage symptoms so that they can move on with their lives.

B) Recovery is different for each person

Recovery often involves:

- A reduction in symptoms: fewer, less intense, or no hallucinations
- Improved relationships, including feeling more comfortable around others, more interested in interacting with others, and spending time with friends and family
- Connections with the outside world such as engagement in work, school, volunteer activities, hobbies/other leisure or recreational activities
- Focus on important personal life goals like making plans for the future, setting goals and taking steps towards reaching them

One strength of family involvement is that each family member can help support recovery in his or her own way. The young person’s recovery goals are of high priority, so it is essential that the family understand how the young person views their own recovery. Each family member might have a different idea or hope for recovery, so it can help to find common ground on recovery plans and goals by learning about each person’s hopes and how treatment can help.

C) What Helps People in their Recovery from Psychosis?

Clinicians 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 young people can’t always control how they respond to treatment (e.g. medications), they do have control over other aspects of recovery. There are many things that people can do in addition to typical treatment to help them learn ways to manage symptoms so that they are able to move forward in life. Family members are important supports in this process and should be encouraged to:

- Participate in treatment
- Talk with providers about:

- Treatment options, how to work with providers, and which treatments/services the young person has identified as priority.
- How to support treatment the young person's participation in treatment (e.g., helping to pick up medication and attend appointments regularly).
- How to support treatment goals (e.g., getting a job or staying in school).
- How family members can improve communication with the young person.
- Things they don't understand, feel haven't been explained, or if there is information they would like to know.

Whether their loved one's treatment seems to be working or not working. There might be areas that family members feel their loved one could use additional support around treatment. There are a number of treatment options to choose from if one does not seem to be working.

Identify and focus on personal goals

- Learn about the young person's treatment goals and how the family can support them.
- Identify what the family members would like to change or see different for their loved one.
- Work with providers to identify family goals and what steps are necessary to reach those goals.

Make use of supports

- Build and use a support network in the community including:
- Extended family, friends, and other supportive people
- Professionals e.g., treatment providers, school counselors, or other professionals
- Support groups for family members of people experiencing psychosis

When delivering this unit, consider showing the family the *Voices of Recovery Videos* (found in the Center for Practice Innovation's OnTrackNY website). These videos show actual young people and their family members speaking about their psychosis and recovery journeys.

Summary of today's meeting

The Primary Clinician should ask the family to identify some important points from each meeting and add his/her perspective to this summary.

Problem Solving

After delivering the above information the family might benefit from engaging in some formal problem-solving around a related issue that they might be facing with their loved one. Developing an action plan will start the process of helping families gain skills to better manage the difficulties they are facing.

Remember that the steps for problem solving include:

1. Define the problem
2. List all possible solutions
3. Discuss advantages and disadvantages
4. Choose the solution that best fits
5. Plan how to carry out the solution

6. Review implementation during the next meeting

Refer to the problem-solving section in this manual for detailed information on how to conduct formal problem solving with clients and families.

K. Core Unit 3: Shared Decision Making with Families and Clients

Vignette: Kim, her family, and the PC have been meeting regularly to discuss Core Unit 2 topics. Kim's family members feel less anxious now that they know more about psychosis and are able to be more selective when reading online. Kim and her family feel hopeful about recovery and have started identifying goals.

Kim has a goal of graduating college and has been working with the SEES to re-enroll in classes (she withdrew after her first episode). But Kim's brother is concerned as he believes that school-related stress led to the psychosis and thinks Kim should prioritize working on symptom management with the Primary Clinician and Psychiatrist. Kim worries she will be expelled if she does not graduate soon. She views her brother as overly involved now that she has a "mental illness" and wants to be more independent. Kim's parents are torn; they want Kim to graduate but also want her to stay healthy.

Kim would like to attend the *Core Unit 3* meeting with her parents and brother. She has been telling her family about shared decision-making and thinks it would be helpful for them to learn more so they can use it together. During this meeting, Kim and her family would like to hear how shared decision making can help with identifying goals (like graduating college), weighing out the options, and negotiating steps toward goals, especially when not everyone involved may be in agreement at first. They would like to practice using shared decision making in their family with the support of the primary clinician.

I. Introduction to Unit and Rationale

The purpose of this unit is to introduce the shared decision making approach (SDM) to families. We have found that family members' interest in participating in treatment planning and decisions can vary, although overall, many families are eager to participate in treatment and recovery. Likewise, young people's interest in including family involvement can vary widely from person to person and for the same individual over time. SDM should be used to discuss treatment choices, like family involvement, and to set goals that are meaningful to the young person and their family members.

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 the in whether families are involved, 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.

Description of Core Unit 3: First, we'll talk about shared decision-making, an approach to setting goals and making informed choices. This approach helps us identify goals, outline options, consider pros and cons, think about preferences, make decisions and negotiate areas of disagreement. The process of shared decision making aims to ensure that each person's voice is heard and all points of view are considered during decision making.

Providers and clients may have already started using SDM to discuss treatment choices using SDM tools, which can be found in the OnTrackNY Team Manual like the:

- *Family Engagement and Needs Assessment*
- *Psychiatric Medication and Me- Assessment Tool*
- *Designated Observer Tool*
- *Values Clarification for Family Involvement Tool*
- *Family Involvement Decisional Balance Tool*

Providers and families can also use SDM tools like the SDM Introduction Video by Dr. Pat Deegan to orient individuals and their families to the concepts covered in this unit

Throughout treatment, SDM should be described and modeled by providers so that the young person and their family members can practice and utilize SDM when discussing important topics, whether or not the provider is present.

Sample description of SDM: Setting goals and making decisions can be challenging for us all, especially when there are several options to consider. It can be hard to know 'which choice or direction is right for me at this time. This can be easier or more challenging when several people who care about one another are involved. Furthermore, decision-making can become confusing and difficult if people disagree about what to do next. Because of these challenges, we at OnTrackNY recommend using the Shared Decision Making approach, or SDM, to set goals and make informed choices together.

II. What is SDM and Why is it Important?

SDM is a decision-making strategy that can be used by all individuals involved in treatment to identify goals, problem-solve, make treatment decisions, and revise treatment objectives over time. The SDM process ensures that each person's voice is heard and each point of view is understood as decisions are made together. When describing the SDM process, providers are encouraged to emphasize that:

- We work on identifying things that are important to you and your family members, including how family members can be involved in treatment and supporting goals.
- SDM is an approach to setting goals that will help us make sure we talk about the things that are important to each member of the family, including you [the young person], and that decisions made are within your values and preferences.
- It is important that you [the young person], and each family member, are heard when discussing treatment and the things that are important to you. We will start this process now.
- The SDM approach might be familiar to you, or it may seem a bit unnatural. That's okay. We find that regardless of where a person starts with this process, it's something that people tend to find helpful and more comfortable over time.

- The SDM approach can be used during meetings with providers and also when family members, including [young person], have discussions outside of treatment.

Give family members the *SDM Pocket Card/Handout: Tips for Talking about Important Decisions*, found in the OnTrackNY Collaborative Approach to Recovery (CAR) Manual. Ask family members what s/he thinks about this approach and in which ways this approach might be helpful.

III. SDM – How do we use it?

SDM involves several basic steps that are sometimes woven into conversation and sometimes used explicitly with SDM tools and decision aids. At this point in the unit, providers can describe the several basic steps of SDM and discuss how they might be used in treatment. Be sure to go at a pace that matches the young person's and family's understanding of each step. It may be helpful to periodically check in with people about their understanding and to see if they have questions. The steps involved in the SDM process as applied to families are described below.

Step 1: Choice Talk

The family member identifies issue/goal that is personally important. This can include a range of topics, but it is important that one specific goal or issue be selected to work on at a time. Some examples of typical issues or goals include:

- Establishing how the family might be involved with the treatment team,
- Identifying the preferred way for family members to provide input to the young person as s/he is contemplating treatment options (may vary amongst family members)
- Deciding whether or not to attend the monthly family groups
- Figuring out the level of involvement in the young person's transportation to/from treatment
- Choosing how to best support the health and wellness of the young person
- Discussing how to best support the family in maintaining a healthy family life in the midst of coping with first episode psychosis (e.g., supporting healthy behaviors, maintaining important family routines)
- Exploring whether the family might be involved in a meaningful way in supporting the young person taking appropriate medications.

Start with the first issues/goals and then repeat with the second.

Step 2: Option Talk

For the specific issue selected then all of the relevant options are listed. Below are some examples. Establishing goals might begin with a list of common goals and then for each common goal, the related options.

Example 1: Options for transportation to treatment

- Encourage the young person to arrange their own transportation
- Offer transportation some of the time (when family schedules permit)
- Schedule appointments only when the family member can provide transportation.

Example 2: Options for support regarding taking medications

- The young person takes medication without family member reminders
- The family member offer verbal reminders as agreed upon between the young person and family
- The family member distributes the medication as prescribed

The pros and cons of each option are considered with information and educational materials provided as needed. For example, people might consider the advantages and disadvantages of prioritizing employment, sharing an important meeting with other family members, or increasing a medication dose. In this process, the young person and family members emphasizes her/his goals, values, or preferences; the clinician adds scientific information regarding likely outcomes, side effects, and/or unwanted medication effects (e.g., going with a neuroleptic that has a lesser chance of metabolic syndrome but a higher chance of TD).

Step 3: Decision Talk

Considering preferences and deciding what's best. For example, the individual ranks her/his top three preferences in order, the family member ranks theirs, and the professional does so also. Or following some of the examples above, each person gives an opinion regarding the transportation to treatment or the medication support options. The process can be conducted on paper or verbally.

Once areas of agreement and disagreement are clear, everyone involved negotiates areas of disagreement. For example, they might identify different goals but agree to include each person's top three goals on the treatment plan. If they disagree on the participant arranging their own transportation, they might agree to schedule some appointments for when the family member can attend. Or if there is disagreement about the family member distributing medication (e.g., the young person does not want this), they all might agree to the family member offering a verbal reminder at the end of each day. People are encouraged to work together to figure out a plan to move forward even in areas where there is initial disagreement.

IV. Keeping SDM on track

In using the SDM approach, we might ask ourselves a series of questions that help to figure out if we're really using SDM during meetings. Some of the questions are as follows:

- Are we clear and in agreement about the current issue, problem, or decision?
- Do the young adult, family members and I have all the information we need about this topic?
- Have we identified the relevant options?
- Are we clear how the individual's important values influence this decision?
- Is everyone who needs to be involved here? Are we clear about how the family's important values do or do not weigh into the decision?
- Have we clarified our preferences and any disagreements?
- If we disagree, have we negotiated a compromise?
- Have we put the plan in writing?

Example of how to keep SDM on track:

As an example, consider asking these questions as part of a decision regarding disclosure in supported education.

Does the young adult want to disclose information regarding her/his illness, disability, or needs for accommodations to a teacher? What are the options? For example, who would speak with the teacher? What exactly would be disclosed? What is the goal? What is most important to the young person in this situation – to avoid disclosure or to receive an accommodation? What are the advantages and disadvantages of disclosure and of requesting an accommodation? Does the individual need to speak with a girl/boyfriend, a parent, or a past teacher about this decision? What are the individual's and the clinician's preferences? Have the young adult and clinician negotiated a plan that both believe is ethical, realistic, and likely to meet their goals? Have they written down the specific plan for addressing this situation?

NOTE TO PCs: A list of websites with printable or interactive decision aids can be found in the Center for Practice Innovation's Learning Management System: <http://practiceinnovations.org/>

V. Summary of today's meeting

PC asks the family member to identify some important points from today's meeting. PC adds his/her perspective to this summary.

VI. Problem-Solving

Review implementation of last unit's problem solving. Discuss successes and challenges and, if needed, revisit the steps for problem solving.

After delivering the above information the family might benefit from engaging in some formal problem-solving, using SDM, around a related issue that they might be facing with their loved one. Developing an action plan will start the process of helping families gain skills to better manage the difficulties they are facing.

Remember that the steps for problem solving include:

1. Define the problem
2. List all possible solutions
3. Discuss advantages and disadvantages
4. Choose the solution that best fits
5. Plan how to carry out the solution
6. Review implementation during the next meeting

Refer to the section on problem-solving in this manual for detailed information on how to conduct formal problem-solving with clients and families.

L. Core Unit 4: Common Family Experiences in First Episode Psychosis

Vignette: Kim's family said that shared decision making is helping them to learn about each other's perspectives and how to make decisions together and that they even found common ground on Kim's graduation goal— Kim will return to school part-time. During conversations about school, each family member brought their own feelings and reactions to the changes that have been happening with Kim and their family. Kim's brother, who recently had a baby with his wife, is remains very concerned about how to balance supporting Kim with providing support for his parents and his own growing family.

During *Core Unit 4*, the family would like to continue to share feelings and concerns related to the recent changes in Kim and the family's life and how to improve communication and problem-solving around recovery goals. They would also like to learn about family resources and how to connect with families who have had similar experiences via the OnTrackNY multifamily groups or possibly a community organization not associated with OnTrackNY.

I. Introduction to Unit and Rationale

The purpose of this unit is to share experiences and provide information on common family member reactions to FEP (emotional and practical), and to identify family strengths and strategies for supporting the recovery process. We have found that these discussions can help family members to feel less isolated, improve understanding of individual perspectives and coping, enhance communication, and build skills. If the client is present, check in frequently with him/her while discussing this information to make sure he/she is comfortable with the material, and to hear his/her views about how psychosis has impacted him/her as well as the entire family.

Description of Core Unit 4: *In this unit, we'll first talk about common reactions of people who have a relative experiencing a first episode of psychosis, including emotional reactions and practical changes. Then, we'll talk about ways that family members can support the young person and each other through the recovery process. This includes the ways that your family already provides support, additional (or alternative) ways of creating support, and the role that the OnTrackNY team can play during the recovery process.*

II. Family Experiences

The clinician should encourage all family members to share their respective experiences. S/he should use reflective listening to convey understanding and to validate and normalize feelings surrounding these experiences and reflect back any descriptions of family member relationships and how these dynamics have evolved over time. To ensure their understanding is accurate, the clinician should offer summaries and give the family the chance to provide clarifications and corrections.

It is important to acknowledge the individual relationships within the family and the influence of family roles on perspectives about psychosis and recovery. For example, a parent might feel apprehension about financial stressors related to illness and treatment, whereas a young sibling might be more fearful about the likelihood of developing of mental illness. The clinician should acknowledge that family members sometimes experience tension between each other (marital, sibling, parent-child) as each person develops an understanding of the experiences and envisions recovery goals.

Cultural factors can influence people's understanding and management of mental health problems. The terms some people find helpful may not be a good description of other peoples' feelings and experiences. Refer to the *Cultural Formulation Interview* for guidance on culturally competent discussions (a part of the *DSM-V*, this tool can be found in the back of the *DSM-V* or as a free PDF online).

Sample Introduction: "When people learn that an immediate family member has been (or is) experiencing psychosis, they often have a wide range of emotion and many feelings at once. These feelings can be related to the events surrounding the start of the illness, the experiences/behaviors of the young person, and the changes in day-to-day tasks and family life. Not everyone feels each emotion, nor do these feelings follow any certain order."

Sample Questions:

- When things first started changing with _____, what were your reactions?
- What expectations did you have at the start of this program? What expectations do you have now?
- Since things first began changing, what have you found to be the most helpful? What has not been helpful?
- What hopes do you have? What fears or uncertainties?
- When thinking about the future, what do you imagine? What are your hopes? What are your concerns?
- How do you discuss recent events in your family with other family members or people outside the family? What have been their reactions? How have those reactions affected you?
- How have your family members or loved ones (e.g., friends, relatives, etc.) been involved? In which ways, have they been supportive or unsupportive?
- If you're not discussing recent events with anyone outside of the immediate family, what's keeping you from doing so? What do you think it might be like to share your experiences with other people to whom you're close?

Providing warmth, empathy, and respect for the participants can be invaluable. The aim is to help normalize emotional responses by ensuring that each person has a chance to share their perspective and that all attitudes and feelings are acknowledged in a non-judgmental way.

When delivering this session, clinicians might consider showing the family the Recovery Videos and using the Recovery Videos Manual (found in the Center for Practice Innovations, OnTrackNY page). These videos show actual family members speaking about their experiences related to psychosis and recovery.

A) Emotional Reactions

It is vital to encourage respect of each person's feelings when discussing this topic so that everyone feels comfortable and safe to express him/herself. Share with the families some common emotions and reactions that occur when a loved one develops a psychotic illness. Discuss the ways that these common reactions are relatable or dissimilar to their experiences.

Sample Dialogue: Families from a variety of backgrounds have described similar experiences related to having a family member who has experienced psychosis. Here are some common emotions that can come up. Some of them might be relatable and others might be different from your experience.

- **Sadness** – Some family members and/or the young person may feel sadness that life is different from how it used to be, that the young person no longer feels or seems “like them self” and for the pain that each family member might be going through.
- **Apprehension/worry** – Family members and the young person might feel concerned that the hopes, dreams, and expectations for the young person seem less attainable since the start of illness. Families and/or the young person might wonder whether or how much life may need to adjust due to the onset of psychosis, how long it may last and what to expect.
- **Guilt** – Family members and/or the young person may feel that they played a role in, or are responsible for, the young person developing psychosis. Some might believe that the young person’s ability to get better solely lands on their shoulders (the young person might also believe this).
- **Confusion** – For many family members, the onset of psychosis comes “completely out of the blue.” Some family members and/or the young person may feel confused about the diagnosis of psychosis, the causes of it, associated behaviors, and how to respond. There is often confusion about how long psychosis may last, and whether people need to adjust their hopes and aspirations for the future.
- **Misattribution** – Some may feel that psychosis isn’t a “real” problem, that the young person has full control over symptoms but isn’t using it, or that there is a simple solution, “fix” or “cure” for symptoms.
- **Resentment or embarrassment** - Some family members and the young person may feel resentful or be embarrassed because their lives are so different from that of other families and young people.
- **Anger** – Some feel that it is not fair that they, or their loved one, has psychosis and may feel angry about how the symptoms impact their own lives.
- **Uncertainty about treatment** – Many family members understandably have questions about the different aspects of treatment including, what will be helpful, what will be challenging (such as medication side effects), and how long treatment components may last (such as medication or therapy). For instance, people wonder, “Will I/will my son need this level of treatment forever?”
- **Fear** – Some family members and young people are fearful of what might happen when their loved one is experiencing psychosis. Some people are concerned that the young person may attempt to hurt or kill themselves, or even harm another member of the family or community. Family members and young people can also worry about the heredity of mental illness, and whether other family members will struggle with symptoms of psychosis or other mental health problems.
- **Hope** – Some family members might feel hopeful that the young person will get better, either on their own or with the support of others (family, community, treatment) and go on to pursue their dreams.
- **Motivation** – Some family members might feel motivated to support their family member throughout illness and recovery by learning about psychosis, treatment options, and becoming involved in providing emotional and practical supports (like financial assistance). Some family members might get involved in advocacy or other initiatives to help their loved one or others who have similar experiences.

Share with the family that, while feelings and experiences can be overwhelming and difficult, many family members do adjust and become better able to cope and develop practical skills to manage over time. In other words, they typically won’t have the same intensity of these feelings or reactions forever.

It is important to note that Core Unit 4 discussions are not the appropriate place to work out issues related to complex family dynamics or difficult problems, such as trauma. Providers should connect family members who have higher needs to outside services or specialized care.

B) Practical Changes

Sample Dialogue: Families can be very “resilient,” meaning they can recover, repair, and grow in the face of serious life challenges. Many families emerge from the experience of a loved one developing psychosis strengthened and more resourceful than before. In addition to emotional responses, families often navigate practical changes to adapt to their loved one and family’s needs. Here are some common practical changes- some of these changes might sound more familiar than others.

- **Navigating systems** – Many family members and young people assume roles for which they have minimal preparation or training, such as navigating the mental health system, working out disability and medical benefits and perhaps even negotiating with the legal and criminal justice system.
- **Daily responsibilities** – Family members and young people often redistribute household chores, make changes in employment (include taking time off work, switching or leaving their jobs), and devote time to supporting safety and other needs.
- **Health** – Associated stress and lifestyle changes can impact both physical and mental health. This can include changes in sleeping, eating, and exercise habits, as well as fluctuating levels of distress.
- **Financial** – There are often significant co-pays, travel expenses, and other costs related to dealing with the onset of psychosis in a family member. Young people who had financial independence or contributed to the family might experience disrupted employment due to illness. Likewise, family members who miss or stop work often experience financial strain and worry about how to pay for treatment (even with insurance), housing, education and necessities.
- **Stigma** – Both young people and family members commonly face the complex challenge of stigma. People in the larger society and media often misunderstand mental illness and talk about it in a way that makes people with those experiences feel like they don’t belong and can’t be trusted or are dangerous. Many family members believe they cannot or should not discuss what’s happening with family or friends, either due to stigma concerns or out of respect for their relative’s wishes.
- **Withdrawal from social activities** – Family members and young people will sometimes pause or stop participating in social activities due to time and financial constraints, concerns about how they and the family is perceived by others, difficulty relating to others who haven’t had similar experiences, and/or concern about protecting their loved ones from being exposed to negative attitudes and comments.

Sample introduction: “All families go through life stressors and some stressors may bring a larger shift in the family system than others. Many families, like yours, have strengths that help them change in constructive ways, learn to adapt, recover and grow in the face of serious life challenges.”

What are some of your families’ strengths? Since things first started changing, how has your family grown stronger? What constructive changes have happened?

"Your participation today shows your dedication to learning about psychosis and how it affects you, your loved one and your family. [If the family has difficulty thinking of positive impacts, you can say "It's OK if you can't think of any right now. Sometimes it's hard to think of the positives when everything is so new. Please just remember that families can and do recover and grow."

The young person, if present, should be encouraged to share their points of view. It is important to match conversation tones and topics to their perspectives and goals. The shared experience between the young person with FEP and family members involved can strengthen the family relationship, build resiliency and self-efficacy and be meaningful for all members, particularly as the family learns effective communication and coping strategies.

III. Building and Strengthening Family Supports

A) Identifying Family Strengths

After sharing and discussing common emotions, the provider can articulate strengths that they have observed in the family, reiterate statements that individuals have made supporting positive change, while acknowledging frustrations, discouragement and impediments. Describe strengths using the family's words:

They may have ideas that: [insert the family's words, e.g., the young person can get better, it is possible for the young person to reach goals, the family believes they can be supportive, the family has found support in each other or the community, each family member has at least one strength in their relationship with the young person, the entire family can act like a team]

They might feel: [insert the family's words, e.g., hopeful, optimistic, motivated, dedicated, committed, encouraged, accepting, compassionate]

They might act like they: [insert the family's words, e.g., are educating and empowering themselves, are supporting recovery goals (e.g., providing transportation), are prioritizing safety by following safety and crisis plans, are fostering self-efficacy, optimizing resources and community supports]

B) Strengths and Skill Building

The provider, young person, and family can utilize their strengths when working toward recovery goals. Skills training through family consultation can augment strengths and help enhance the recovery process. Providers can work with the family to identify the strengths they feel confident about and the ones they would like to continue building. Clinicians should aim to identify a specific problem or particular need they would like to address and offer a family consultation training on targeted skills like:

- **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, together, making a decision concerning which solution to implement.

- **Conflict resolution/compromise and negotiation**, including disagreeing with someone without arguing, leaving stressful situations, anger management, responding to complaints, and general problem solving.

Sample Dialogue: *Your family's strengths can be used to work toward and achieve your recovery goals. To enhance strengths, many families benefit from communication and problem-solving training. Training can help families to be more comfortable and confident when talking about goals and plans, particularly when discussing a specific problem or need that is important to one or all family members.*

Family consultations should be focused, targeting a particular problem or skill, and be brief (lasting 1-3 sessions). Information on structuring and planning consultations can be taken from the Social Skills Training or Coping Skills outlines presented in the *Family Involvement Resources Manual*. In addition, the *Monthly Family Meeting 6: Communication Tips and Tools* can guide consultations on communication.

If the family has not yet joined the multi-family groups, describe the group content, format, and logistics and invite them to participate. If multi-family groups are not an option for the family, discuss connecting them with outside community services such as NAMI.

VIII. Summary of today's meeting

The Primary Clinician should ask the family to identify some important points from each meeting and add his/her perspective to this summary.

After delivering the above information the family and client may wish to further engage in the process of sharing their experiences and talking about how they are coping. We recommend offering to spend time in the future hearing about family members' experiences and concerns, while simultaneously focusing on the future and how the entire family can best cope, adapt to what's happening, remain hopeful and recovery oriented, and support the young person.

IX. Problem-Solving

After delivering the above information the family might benefit from engaging in some formal problem-solving, using SDM, around a related issue that they might be facing with their loved one. Developing an action plan will start the process of helping families gain skills to better manage the difficulties they are facing.

Remember that the steps for problem solving include:

1. Define the problem
2. List all possible solutions
3. Discuss advantages and disadvantages
4. Choose the solution that best fits
5. Plan how to carry out the solution
6. Review implementation during the next meeting

Refer to the problem-solving section of this manual for detailed information on how to conduct formal problem-solving with clients and families.

M. Core Unit 5: Crisis Prevention and Planning

Vignette:

Kim's family is relieved that OnTrackNY offers a variety of services and each family member has ideas for how the team can help. Kim's family was especially interested to hear that the team has safety and crisis assistance around the clock. Kim's mother, who often holds herself responsible for not noticing the signs of Kim's first episode sooner, would like to talk more about crisis planning. She is especially concerned about how to manage crises when Kim returns to school since she won't be with her during class.

During Core Unit 5, Kim's mother said that she is glad that they are discussing crisis prevention and planning. Although Kim is doing well, problems might come up and she would like to have a plan in place to prevent or manage difficult situations. She also said that Kim has been telling the family about her conversations with the team on identifying warning signs and coping strategies to lessen or manage an increase in symptoms. Kim's family would like to learn about these warning signs and coping strategies.

1. Introduction to Core Unit 5 and Rationale

The purpose of this unit is to share experiences and to provide families with information about emergency situations, including how to plan ahead for emergencies, manage when they come up and minimize consequences. Even with everyone's best efforts, crises or a relapse after first episode psychosis can happen. We have found that family members are eager to address this topic so they can discuss their experiences, and better understand how to recognize signs that a crisis might occur and what to do about it.

Depending on client needs and preferences, providers can use this unit to discuss the following with families:

Safety planning: Upon the start of treatment, the providers and client will have completed the assessment for suicidality and, when needed, created a suicide safety plan in which careful assessment, triage, and implementation of the safety planning intervention are employed (see Team Manual).

Crisis planning: If a client does not meet threshold for suicidality, but does experience symptoms that put him/her at risk and are concerning to the client, their family members, and/or the provider, the team can guide the development of a crisis plan that identifies potential mental health emergencies and steps for minimizing or managing consequences (described below).

All planning should be done with the client, and if possible with the support of family members. It is important to use client and family's language when discussing safety or crisis planning. If the client is present during this core unit, check in frequently with him/her while discussing this information to make sure he/she is comfortable with the material and to allow him/her to weigh in on how the information fits or doesn't fit his/her experiences.

Describe Core Unit 5: First, we'll talk about what we have learned about how your family member has experienced mental health emergencies in the past, and what your family's experience has been when facing difficult situations. Then, we'll provide information on how we think about or define a crisis situation, and the importance of everyone working together to develop a plan to prepare for the future. We will talk about different parts of a crisis plan, such as recognizing early warning signs, planning ahead for how to best cope with the situation, and how to reach out to others (including professionals) for assistance.

It's important to know that the best case scenario is that we all work together as a team to figure out what to do to best help your relative to prevent and/or deal with emergencies. We think of crisis and safety planning as being similar to planning for other potential emergencies such as fire/disaster drills. 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.

2. Family Experiences

The clinician should encourage all family members to share their individual experiences related to crisis situations, including any present concerns. S/he should meet the family where they are at in terms of describing these experiences and concerns and use reflective listening to convey an understanding of the experience and feelings surrounding it. The clinician should summarize to make sure their understanding is accurate and give the family the chance to correct anything s/he may have misunderstood.

During this conversation, it is important to make explicit statements to convey the idea that the team is not "passing judgment" or criticizing anything the family may believe about a prior crisis. Similarly, it is important to make statements to show the family that the clinician understands that families often try many things – some helpful and some not helpful – to avoid a crisis or deal with a crisis situation. They should convey the idea that families are not to blame for a crisis happening; but families can be an important part of de-escalating crisis in the present and mitigating future crises.

Consider starting by asking the family what they think a crisis is to help establish a tolerance threshold based on what they may have already experienced or what they think is manageable or appropriate within their worldview.

Sample Dialogue: People often understand problems or mental health crisis situations in their own way, which may be similar or different from how professionals describe the problem. We'd like to start by talking about how each of you think of a mental health crisis, including what type of events can happen, who they might involve, and ways of responding to or managing the crisis. This understanding might be based on your experiences or experiences of others you know.

Encourage the family and young person to discuss their personal experiences with mental health emergencies or problems by asking the following questions:

Sample Dialogue:

- Have you or your family member experienced a mental health emergency before? [OR I know we've talked about [name] experiencing a crisis in the past. Let's talk about that more now since that's our topic for today.]

- People often understand problems or mental health crisis situations in their own way, which may be similar or different from how professionals describe the problem. How would YOU describe what happened around the time of [name's] crisis?
- Sometimes people have different ways of describing a crisis to family, friends or others in their community. How would YOU describe what happened before, during and/or after [name's] crisis to them?
- What was the hardest part of dealing with the crisis? Is there anything about the situation that you would have liked to have gone differently/been handled differently?
- What, if anything, did you learn from the experience?
- What worries you the most about [name] having another crisis in the future?*

*The above questions are from the *Cultural Formulation Interview*, a tool that helps facilitate culturally competent discussions. This tool is included in the DSM-V; a free PDF version is available online.

It is critical to understand that young people and their families may initially view the FEP experience and the need for safety planning as frightening. Most family members, however, will find safety planning comforting, as it will help them to manage difficult experiences and outline a plan of action.

3. Introduction to Crisis Prevention and Planning

The purpose of this section is to provide additional background and rationale for discussing crisis prevention and planning. As with other topics, avoid using clinical jargon. A key idea to convey to families is that teamwork and figuring out a crisis prevention plan together has been helpful for many families and people experiencing first episode psychosis.

If the topic did not come up above when talking about family experiences, ask the family if anyone ever discussed developing a crisis plan/do they have a crisis plan?

Sample Dialogue: Although we anticipate that most of the time young people in our program will be doing well, it is possible that at some point you/your family member may experience a mental health problem or emergency. Mental health emergencies can sometimes come up unexpectedly, 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.

For a good part of this discussion, I'd like us to focus on how to recognize signs of a potential emergency 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. This can help everyone be on the same page about how the situation can be handled, and help everyone feel more prepared to take action when necessary.

[If the family has not already talked about this, ask the following question:] Has anyone talked with you about developing a crisis plan? Do you currently have a crisis plan?]

For families in which things are going well and they do not anticipate future crises, it can be helpful to share the idea that "when things are going well" it is actually a good time to think through and plan for a possible crisis in the event that one occurs. That way, everyone is prepared even if the plan is never needed.

4. What Do We Mean by Crisis?: Defining a Mental Health Crisis

Take some time to describe what is meant by a mental health crisis. When possible, use the family's words about how they described crisis situations, and relate their words and experiences to the information below.

Sample Dialogue: First, let's talk about what we mean by a mental health crisis. A mental health crisis is a situation in which a person experiences symptoms or behaves in ways that may put him/her at risk for harm to self or others. Crises are more likely to occur when a person is unable to use their typical coping skills or resources effectively.

There are several common experiences that people may have during a mental health crisis. For example, you mentioned earlier that [name] experienced [insert family's words about their experiences and/or their relative's experiences, e.g., they had a lot of trouble thinking straight or making sense of things; they got really excited and hyper and couldn't sleep in the days leading up to going to the emergency room].

Although each person's experience of a crisis and the things leading up to a crisis are unique, there are some common experiences that people with psychosis describe. These include things like: [review the list below with family].

Common mental health crisis experiences:

- Having difficulty thinking clearly; behaving in a disorganized way
- 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)
- 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)
- 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

It may be important to explain to families that experiencing symptoms or even an increase in symptoms does not necessarily constitute a crisis; however, this may be a warning sign that the person could benefit from additional support or assistance.

5. Developing a Crisis Plan

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 practitioners or the young person may not be aware of or notice. As a result, they may be able to watch for these signs and collaborate with providers put a plan into place before it hits a crisis level (see Designated Observer tool in the OnTrackNY Team Manual).

The purpose of this section is to talk with families about the components of a crisis plan, and get into detail about the types of things that a plan can address. Keep in mind that when a crisis occurs, it can be scary and overwhelming for everyone involved. Practitioners can convey their understanding of the fact that individuals who are feeling distressed or experiencing a crisis may not know what to do to help themselves 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.

When possible, use the family's words about how what they experienced and/or did during a crisis situation, and relate their words and experiences to the information below.

Sample Dialogue: Let's talk about the importance of developing a plan should a crisis occur. 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 or even prevent the crisis.

There are several basic components to crisis or safety planning that I'd like to share with you:

- 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.

Once the practitioner has read the list above, talk with the family about any thoughts or reactions they would like to share. The practitioner may consider asking them the following types of questions:

- What do you think about the things that I just mentioned?
- 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 do you think you would want to include in a crisis plan? Is there anything I missed?

a. Warning signs or red flags

Share with the family that the first step in developing a crisis plan is to identify any warning signs or red flags that may suggest that a person is not doing so well. Review a list of common warning signs, and be sure to add any unique warning signs that the family or client may have already identified based on their own experiences.

Sample Dialogue: 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.

There are several common warning signs that people may experience prior to an emergency situation. For example, you mentioned earlier that [name] experienced [insert family's words about their experiences and/or their relative's experiences, e.g., they started to withdraw and spend a lot more time alone in their room; they started to get really suspicious of some of their friends and stopped seeing or talking with them].

Some common warning signs that people experience and/or family members observe include things like: [review the list below with family].

Common warning signs that individual's 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)

Sample Dialogue: Do these warning signs sound familiar? Are there any others that weren't listed that you experience or have noticed your family member experience, that let you know you/they might need some additional support?

b. Using Personal Coping Strategies

Talk with the family and client about coping strategies. When possible, use the family's/client's words about how they have coped in the past during a crisis situation, and relate their words and experiences to the information below.

Sample Dialogue: 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. 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) identify coping strategies they can use to minimize their distress, and 3) possibly be part of the strategy for managing distress.

Check in with family members and client about what kinds of coping strategies they use. Consider offering examples of common coping strategies. Explore whether they believe their coping strategies are effective.

Sample Dialogue: I'd like to check in with you about your personal coping strategies. What are some effective coping strategies for you/your family member?

- Do you find that certain ones work better in certain situations than others?
- Are there any coping strategies that used to work in the past, but that you've found don't really help lately?

Some common coping strategies that people use include things like: [review the list below].

- Breathing or relaxation exercises
- Do a hobby or activity that can temporarily distract you from unpleasant thoughts or feelings
- Engage in exercise or physical activity regularly
- Reduce or avoid caffeine, sugar, alcohol and nicotine
- Get more sleep – go to bed earlier
- Talk with someone you trust about how you feel
- Time management – prioritize your "to do" list and break it down into smaller parts
- Keep doing household routines (try not to put them on hold)
- Make time to do something you enjoy every day (even if it's only for a few minutes)

c. Connecting with family members/friends/others to get support

Talk with the family and client about how connecting with others when you are distressed or feeling overwhelmed can be helpful. Similar to the other sections above, when possible use the family's/client's words about how they have connected with others for support in the past during a crisis situation, and relate their words and experiences to the information below.

Sample Dialogue: For many people, connecting with others when you are distressed or feeling overwhelmed can help in a couple different ways. For example, you mentioned earlier that [name] experienced [insert family's words about their experiences and/or their relative's experiences, e.g., s/he likes spending time with his/her sister going for a walk or playing cards, and this seems to help him/her feel less distressed; or you are able to relax and distract yourself from worrying when you go to the movies with your husband].

It may be helpful to identify other people or places 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.

Here are some other ways that connecting with others may be helpful [review list below]:

- Socializing with or simply being around other people can sometimes help to distract a person from thoughts or experiences that may be posing some difficulty.
- 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.

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.

Check in with family members and client about the extent to which they connect with others for support. Explore whether there are people, places and/or situations that are more likely to help them cope during times of crisis.

Sample Dialogue: 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 where you feel more connected to others?

d. Contacting Professionals and Agencies

For this section, talk with the family and client about how mental health professionals or mental health agencies can be important resources in helping a person when they are distressed or in crisis. Reassure them that contacting professionals will not automatically lead to a hospitalization or crisis services involvement. Let them know that you would be happy to help provide input about who to contact and when it's necessary to reach out to professionals.

Sample Dialogue: 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.

Sometimes people worry that if they reach out for additional help, they will automatically be hospitalized or that crisis services will automatically become involved. You should know that professionals want you and your relative to stay out of the hospital, and will do everything they can to support all of you so that you can manage your crisis at home. Putting someone in the hospital only happens when there are real safety concerns.

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.

There are some key questions that I'd suggest you ask yourself in figuring out when, how and who to contact for extra support. These key questions include: [review list below]:

- 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)?

6. What Can be Helpful After a Crisis has Occurred?

In spite of everyone's best efforts, mental health crises after a first episode psychosis sometimes happen. While crises are certainly unfortunate, by examining the circumstances in which they occurred, they provide the client and family the opportunity to learn more about what is needed to secure ongoing stability.

If the crisis involved a hospitalization or contact with emergency services, as soon as possible after the discharge the practitioner and family (including the client) should meet to process the situation. The practitioner should inquire into how everyone is coping and be sympathetic and supportive; each participant should be given the opportunity to air his/her concerns. Any prior crisis prevention plans should be reviewed and updated with any newly acquired information, and the practitioner should also ask the participants if there is anything the treatment team could have done differently to help manage the crisis.

Sample Dialogue: Sometimes despite all of our planning and teamwork, a significant crisis or relapse happens. Although this can be discouraging for everyone, if this happens, I think it's important to take some time afterward to talk about it. We definitely wouldn't want to blame anyone. Instead, we can explore the circumstances leading up to the crisis, and re-visit what worked and what did not work about our plan.

In other words, if a crisis were to happen it would be helpful (after the crisis situation has ended) for us to think about what we learned, and how we may consider changing the plan to make it even better for the future. We might ask ourselves questions such as:

- What aspects of the crisis prevention plan worked well?
- What aspects of the plan did not work well? Are there parts of the plan the client and/or family would like to avoid?
- What can we learn from the most recent crisis and events leading up to it?
- How might we take what we learned to help us make changes to the crisis prevention plan going forward?

7. Summary of today's meeting

The practitioner should ask the family to identify some important points from each meeting and add his/her perspective to this summary.

After delivering the above information the family and client may wish to further engage in the process of developing a crisis prevention plan. We recommend offering to spend more time in another session to further develop and write the details of the plan and make sure that the client, family and team have a copy of the plan in a format that can readily access and update.

8. Problem-Solving

Review implementation of last unit's problem-solving. Discuss successes and challenges and, if needed, revisit the steps for problem solving.

After delivering the above information the family might benefit from engaging in some formal problem-solving, using SDM, around a related issue that they might be facing with their loved one. Developing an action plan will start the process of helping families gain skills to better manage the difficulties they are facing.

Remember that the steps for problem solving include:

1. Define the problem
2. List all possible solutions
3. Discuss advantages and disadvantages
4. Choose the solution that best fits
5. Plan how to carry out the solution
6. Review implementation during the next meeting

Refer to the problem solving section of this manual for detailed information on how to conduct formal problem-solving with clients and families.

N. Monthly Family Group Materials

1. Introduction to First Monthly Family Education Group

a. Introductions and Welcome

- Describe role of the Primary Clinician on team.
- Introduce any other team members who are present.
- Have participants introduce themselves. Suggest they say their names, where they are from, and how long they have been working with the team.

b. Describe the Monthly Family Meetings

1. 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.

2. 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.

3. Topics.

Today we are going to talk about psychosis: what it is, what are some common symptoms of psychosis, and the different phases of psychosis

c. Ask for questions

O. Monthly Family Meeting 1 - What is Psychosis?

1. Part I: Presentation on Specified Educational Topic

Materials Needed:

- Handout: *Common Symptoms of Psychosis*
- Handout: *Phases of Psychosis*

a. 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.

b. 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:

- Hearing noises or voices that others don't hear
- Seeing things that other don't see
- 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

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).

c. 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.

1. Prodromal phase

a. 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 something 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.

b. 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.

c. 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.

d. 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.

1. 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

2. Bipolar disorder

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

3. Major Depression

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

4. 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.

e. 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.

2. 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.

3. Common Symptoms of Psychosis (Handout 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.

4. Phases of Psychosis (Handout Group 1)

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.

2. 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.

3. 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.

P. Monthly Family Meeting 2 - What Causes Psychosis?

1. Part I: Presentation on Specified Educational Topic

Materials Needed:

- Handout: *What is Psychosis? (Handout Group 2)*

a. 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.

b. 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

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.

c. 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.

2. 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.

3. 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).

Q. Monthly Family Meeting 3 – Recovery from Psychosis

1. 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?

a. What is Recovery?

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

b. Defining 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).

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

c. 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.

d. 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 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.

e. 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.

f. 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.

2. 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.

3. What is Recovery? (Handout 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 things 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)

4. What Helps People in their Recovery from Psychosis? (Handout 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

5. What Can Family Members Do to Help/Support their Family Member? (Handout 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.

6. What Can Families Do to Help/Support Themselves? (Handout 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.

R. Monthly Family Meeting 4 – Treatment for Psychosis

1. 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*
- Handout: *OnTrackNY Team Second-line Antipsychotic Medications: Common Side Effects*

a. 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?

b. Treatment for Psychosis: Overview

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

- a. Overview of the treatment team**
- b. Pharmacological treatments**
- c. Psychosocial treatments**
- d. Other support services**

c. 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.

d. 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.

e. 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:

- a. Antipsychotic medications can help decrease symptoms of psychosis and prevent symptoms that are diminished (or are no longer present) from reemerging.**
- b. 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.**
- c. Define first-generation and second-generation antipsychotics.**
- d. 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.

f. 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.

Social Skills Training

- Involves helping individuals learn and practice communication and skills.
- 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).

Coping Skills Training

- 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).

Behavioral Activation

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

Substance Use Treatments

- Involves increasing motivation to change unhealthy substance use behaviors and identify behavior change goals.
- 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.

Psychoeducation

- 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.

a. 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.

b. NAMI's Family to Family Program

- Group offered in the community focused on providing education, communication and problem-solving, skills building, and support.

c. 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.

d. 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?

g. 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.

2. 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.

3. Antipsychotic Medications Recommended by the OnTrackNY Team* (Handout 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.

First-Generation Antipsychotics	Second-Generation Antipsychotics
Medications that have been available for many years (also called typical or conventional)	Newer antipsychotic medications (also called atypical)
<i>First-line treatments (oral)</i>	<i>First-line treatments (oral)</i>
Loxapine (Loxitane) Perphenazine (Trilafon)	Aripiprazole (Abilify) Risperidone (Risperdal) Ziprasidone (Geodon)
<i>First-line treatments (injectable)</i>	<i>First-line treatments (injectable)</i>
Fluphenazine decanoate (Prolixin) Haloperidol decanoate (Haldol)	Aripiprazole extended release (Abilify Maintena) Olanzapine pamoate (Zyprexa Relprevv) Paliperidone palmitate (Invega Sustenna) Risperidone microspheres (Risperdal Consta)
<i>Second- line treatment (oral)</i>	
Clozapine	
*Other antipsychotic medications are available and may be prescribed.	

4. OnTrackNY Team First-line Antipsychotic Medications: Common Side Effects (Handout Group 4)

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.

What you may feel or notice	What you can do
<i>Tired or sleepy, sleeping too much</i>	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.
<i>Trouble falling or staying asleep</i>	Learn about sleep hygiene and relaxation techniques. Ask your doctor about taking your medication in the morning or sometime during the day.
<i>Extreme restlessness</i>	Find a vigorous activity that you enjoy, such as jogging, skating, aerobics, sports, outdoor gardening, swimming, or bicycling. Talk to your doctor.
<i>Low blood pressure</i>	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.
<i>Muscles feel stiff, tense, crampy, or painful</i>	Try doing muscle stretching exercises, yoga, or getting regular exercise. Take a short walk. Talk to your doctor.
<i>Shakiness or tremors</i>	Talk to your doctor.

<i>Constipation (problems with bowel movements)</i>	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.
<i>Dry mouth</i>	Take frequent sips of water. Chew sugarless gum or suck on sugarless hard candy.
<i>Blurry vision</i>	For mild blurry vision, talk to your doctor about getting reading glasses. These can often be bought without a prescription.
<i>Increased appetite and weight gain</i>	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.

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.

What you may feel or notice	What you can do
<i>Muscle movements that you cannot control or stop (called tardive dyskinesia or TD)</i>	Talk with your doctor.
<i>Sexual problems such as low sex drive, trouble with erections, ejaculation or reaching orgasm</i>	Talk with your doctor.
<i>For women who should be having regular periods, periods do not come every month or stop</i>	Talk with your doctor.
<i>Milk leakage from the breasts</i>	Talk with your doctor.
<i>Increases in blood sugar or diabetes</i>	Your doctor will test your blood sugar regularly. Other medications may need to be prescribed to lower blood sugar.
<i>Increases in cholesterol</i>	Your doctor will test your cholesterol regularly. Other medications may need to be prescribed to lower cholesterol.

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.

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

5. OnTrackNY Team Second-line Antipsychotic Medications: Common Side Effects (Handout Group 4)

a. 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.

Summary of side effects for clozapine

Side effects	What should I do if this happens to me?
<i>Tired or sleepy, sleeping too much</i>	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.
<i>Constipation (problems with bowel movements)</i>	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.
<i>Excessive salivation (drooling)</i>	This tends to wear off over time. Your doctor may prescribe another medicine to treat this side effect.
<i>Tachycardia (palpitations or fast heart beat)</i>	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.
<i>Increases in cholesterol</i>	Your doctor will test your cholesterol regularly. Other medications may need to be prescribed to lower cholesterol.
<i>Weight gain</i>	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.
<i>Increases in blood sugar or diabetes</i>	Your doctor will test your blood sugar regularly. Other medications may need to be prescribed to lower blood sugar.
<i>Low blood pressure</i>	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.
<i>Reduced white blood cells</i>	Your blood will be tested as described above.
<i>Seizures</i>	Seizures sometimes occur in people who receive high doses of clozapine. Sometimes, anticonvulsants are prescribed.

S. Monthly Family Meeting 5 – Crisis Prevention and Planning

1. Part I: Presentation of Specified Educational Topic

Materials Needed:

Handout: *Components of a Crisis Plan*

a. 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.

b. 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?

c. 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:
 - Having difficulty thinking clearly; behaving in a disorganized way
 - 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)
 - 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)
 - 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.

d. 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.

e. 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

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?

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?

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 other 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 can 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?

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.

f. **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.

2. **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.

3. Components of a Crisis Plan (Handout 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

T. Monthly Family Meeting 6 – Communication Tips and Tools

1. Part I: Presentation of Specified Educational Topic

a. 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.

b. 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.

c. 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.

d. 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.

e. 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?

f. 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 your 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."

g. 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.

h. 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

i. **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)

j. **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

k. **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

l. **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.

m. **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 your own thoughts.

n. **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 names.

o. **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.

p. 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.

2. 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.

U. Monthly Family Meeting 7: Stigma

1. Part I: Presentation of Specified Educational Topic

Materials Needed:

- Handout: *What is Stigma?*
- Handout: *Facts and Myths about Mental Illness*

a. 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).

b. 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

c. 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

d. 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.

e. Discussion question:

If there were 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.

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.

2. What is Stigma? (Group 7 Handout)

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)

3. Facts and Myths about Mental Illness? (Group 7 Handout)

False Myth	True Facts
People with mental illness are dangerous	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.
People with mental illness do not make significant contributions to society.	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.
People who have a mental illness cannot get better.	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.
People with mental illness need constant assistance.	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.
Mental illness is a sign of personal weakness - people with mental illness could get better if they really wanted to.	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.
People with mental illness are unpredictable and unreliable.	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.
People with mental illness are stupid.	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.

V. Monthly Family Meeting 8: Substance Abuse in FEP

1. 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*

a. Psychoeducation on alcohol and drugs generally and in FEP

1. 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.

2. 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.

3. 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.

b. Reasons for substance use

1. 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.

c. 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:



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.

2. 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 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.

3. Psychoactive Substances and Their Effects (Group 8 Handout)

Drug Name	Slang Names	How is it Taken?	What are the Effects?
Alcohol	Booze Brew	Drinking	Relaxation, Sedation, Slowed Reaction Time, Impaired Judgment, Loss of Inhibition
Marijuana	Pot Reefer Weed Joint Dope Grass	Smoking Eating	Relaxation, Mild Euphoria, Altered Sensory Experiences, Fatigue, Anxiety, Panic, Increased Appetite, Paranoia
Cocaine	Coke Crack Rock Ready	Snorting Smoking Injection	Increased Alertness/Energy, Decreased Appetite, Positive Feelings, Anxiety, Tension, Feeling Jittery, Racing Heart, Paranoia
Heroin	Smack Horse H	Injection Snorting	Euphoria, Pain Relief, Sedation, Slowed Reaction Time, Impaired Judgment

4. Consequences of Drug Use in Individuals with A Mental Illness (Group 8 Handout)

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

5. Reasons why people with a mental illness use drugs (Group 8 Handout)

- **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."
- **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.
- **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.
- **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.
- **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.
- **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.

6. Triggers to alcohol and drug use (Group 8 Handout)

A trigger is something that an individual connects to drug use that can cause him or her to have a craving.

Triggers can be:

- **People:** Sometimes being with a person that they have used within the past can make people want to use drugs.
- **Places:** Just being somewhere that they used, or even being in a similar area where they have used, can cause people to have cravings.
- **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.
- **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.
- **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.
- **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.
- **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.

W. Monthly Family Meeting 9: Substance Abuse in FEP

1. 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

a. 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.

b. 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 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.

c. 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.

2. 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 issues, address communication concerns, and support skill-building.

3. Community Resources: Information on Self-Help Groups for Family Members and Friends of Substance Users (Group 9 Handout)

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.

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

- e. 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

- f. 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>**
- g. 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

- h. 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**
- i. 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>

- j. 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>**

X. Monthly Family Meeting 10: Substance Abuse in FEP

1. 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*

a. Encouragement and support for getting help

Friends and family members can 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.

b. 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.

c. 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.

1. 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).

2. Teach family how to apply positive reinforcement

- 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.
- 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).
- 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.

3. 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.

d. 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.

2. 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.

3. Ways to reward abstinence (Group 10 Handout)

- **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!"
- **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?"
- **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?"
- **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?"
- **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."

4. Positive reinforcement for not using drugs (Group 10 Handout)

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

Tips to remember:

- Be sure that your loved one is NOT under the influence of drugs.
- Rewards are given only when your loved one is clean, sober, and not hung-over.
- Link the reward with being clean and sober right now.
- If your loved one starts using, give a “time-out” from positive reinforcement and do not give any rewards.
- 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.
- Let your loved one experience the natural consequences for using drugs.

5. Rules of calm and effective communication (Group 10 Handout)

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.

6. Coping with frustration (Group 10 Handout)

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.

Y. Monthly Family Meeting 11: Disclosure

1. Part I: Presentation of Specified Educational Topic

Materials Needed:

Handout: *Disclosing to Others*

a. 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

b. 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?

c. 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

Group Activity/Discussion

(adapted from Sherman, M.D. (2008). Support And Family Education (SAFE) Program: Mental Health Facts for Families. Oklahoma City VA Medical Center. 3rd edition):

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:

- You don't have to worry so much about hiding the illness for others and/or explaining confusing behaviors to others.
- 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.
- You could relieve some shame that you may experience associated with the illness in the family.
- Others may be able to provide additional support or future assistance in supporting you and/or your family member.
- 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.
- 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:

- You risk being vulnerable.
- It is possible that others might not respond as positively as you would have hoped.
- You or your loved one/family might be excluded or experience stigma/ discrimination.

d. 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 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?

e. 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.

2. Part II: Practice Disclosing to Others

a. 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.

b. If group members DO NOT want to practice disclosing

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 an immediate issues and address communication concerns.

3. 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.

4. Disclosing To Others (Group 11 Handout)

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).

V. References and Recommended Readings

- Addington, J., Addington, D., Jones, B., & Ko, T. (2001). Family intervention in an early psychosis program. *Psychiatric Rehabilitation Skills*, 5(2), 272-286.
- Addington, J., Coldham, E. L., Jones, B., Ko, T., & Addington, D. (2003). The first episode of psychosis: the experience of relatives. *Acta Psychiatrica Scandinavica*, 108(4), 285-289.
- Addington, J., McCleery, A., & Addington, D. (2005). Three-year outcome of family work in an early psychosis program. *Schizophrenia Research*, 79(1), 107-116.
- Berglund, N., Vahlne, J. O., & Edman, Å. (2003). Family intervention in schizophrenia. *Social psychiatry and psychiatric epidemiology*, 38(3), 116-121.
- Breitborde, N., Woods, S., & Srihari, V. (2009). Multifamily psychoeducation for first-episode psychosis: A cost effectiveness analysis. *Psychiatric Services*, 60(11), 1477-1483.
- Cocchi, A., Meneghelli, A., Erlicher, A., Pisano, A., Cascio, M. T., & Preti, A. (2013). Patterns of referral in first-episode schizophrenia and ultra high-risk individuals: results from an early intervention program in Italy. *Social psychiatry and psychiatric epidemiology*, 48(12), 1905-1916.
- Conus, P., Lambert, M., Cotton, S., Bonsack, C., McGorry, P. D., & Schimmelmann, B. G. (2010). Rate and predictors of service disengagement in an epidemiological first-episode psychosis cohort. *Schizophrenia research*, 118(1), 256-263.
- Dixon, L., McFarlane, W. R., Lefley, H., Lucksted, A., Cohen, M., Falloon, I., et al. (2001). Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatric Services*, 52, 903-910.
- Dixon, L. B., Dickerson, F., Bellack, A. S., Bennett, M., Dickinson, D., Goldberg, R. W., et al. (2010). The 2009 Schizophrenia PORT Psychosocial Treatment Recommendations and Summary Statements. *Schizophrenia Bulletin*, 36(1), 48-70.
- Drapalski, A.L., et al. (2008). *The Unmet Needs of Families of Adults With Serious Mental Illness and Preferences Regarding Family Services*. *Psychiatric Services*, 59, 665-662.
- Drapalski, A.L., Leith, J., & Dixon, L. (2009). *Involving Families in the Care of Persons with Schizophrenia and Other Serious Mental Illnesses: History, Evidence, and Recommendations*. *Clinical Schizophrenia & Related Psychoses*, 3, 39-49.
- Fjell, A., et al. (2007). *Multifamily Group Treatment in a Program for Patients with First-Episode Psychosis: Experiences from the TIPS Project*. *Psychiatric Services*, 58, 171-173.
- Freedman, R. (2017). Investigating trauma as a risk factor for psychosis. *Schizophrenia Bulletin*, 43(1), 1-2.

Fridgen, G. J., Aston, J., Gschwandtner, U., Pflueger, M., Zimmermann, R., Studerus, E., ... & Riecher-Rössler, A. (2013). Help-seeking and pathways to care in the early stages of psychosis. *Social psychiatry and psychiatric epidemiology*, 48(7), 1033-1043

Glynn, S. M. (2012). Family interventions in schizophrenia: promise and pitfalls over 30 years. *Current psychiatry reports*, 14(3), 237-243.

Glynn, S.M., Cohen, A.N., Murray-Swank, A., Drapalski, A., & Dixon, L. (2010). *Family Member Provider Outreach (FMPO) Manual*. Unpublished manual, VA Maryland Health Care System, Baltimore, MD.

Jeppesen, P. I. A., Petersen, L., Thorup, A., Abel, M. B., ØEHLENSCHLÆGER, J., CHRISTENSEN, T. Ø., ... & Nordentoft, M. (2005). Integrated treatment of first-episode psychosis: effect of treatment on family burden OPUS trial. *The British journal of psychiatry*, 187(48), s85-s90.

Lucksted, A., McFarlane, W., Downing, D., Dixon, L. & Adams, C. (2012). Recent developments in family psychoeducation as an evidence-based practice. *Journal of Marital and Family Therapy*, 38(1), 101-121.

Lucksted, A., Stevenson, J., Nossel, I., Drapalski, A., Piscitelli, S., Dixon, L., (2016). Family member engagement with early psychosis specialty care. *Early intervention in psychiatry* 1-6.

Magliano, L., Fiorillo, A., Fadden, G., Gair, F., Economou, M., Kallert, T., ... & Palma-Crespo, A. (2005). Effectiveness of a psychoeducational intervention for families of patients with schizophrenia: preliminary results of a study funded by the European Commission. *World Psychiatry*, 4(1), 45-49.

Martens, L., & Addington, J. (2001). *Psychological Well-Being of Family Members of Individuals with Schizophrenia*. *Social Psychiatry and Psychiatric Epidemiology*, 36, 128-133.

McFarlane, W. R. (2002). *Multifamily groups in the treatment of severe psychiatric disorders*. New York: The Guilford Press.

McFarlane, W.R., Dixon, L., Lukens, E.P., & Lucksted, A. (2003). Family psychoeducation and schizophrenia: A review of the literature. *Journal of Marital and Family Therapy*, 29, 223-245.

McGrath, J., et al. (2017). The association between childhood adversities and subsequent first onset of psychotic experiences: a cross-national analysis of 23 998 respondents from 17 countries. *Psychological Medicine*. doi:10.1017/S0033291716003263

Nordentoft, M. (2005). Integrated treatment of first-episode psychosis: effect of treatment on family burden OPUS trial. *The British journal of psychiatry*, 187(48), s85-s90.

Norman, R. M., Malla, A. K., & Manchanda, R. (2007). Delay in treatment for psychosis. *Social psychiatry and psychiatric epidemiology*, 42(6), 507-512.

O'Callaghan, E., Turner, N., Renwick, L., Jackson, D., Sutton, M., Foley, S. D., ... & Kinsella, A. (2010). First episode psychosis and the trail to secondary care: help-seeking and health-system delays. *Social psychiatry and psychiatric epidemiology*, 45(3), 381-391

Rabinovitch, M., Bechard-Evans, L., Schmitz, N., Joober, R., & Malla, A. (2009). Early predictors of nonadherence to antipsychotic therapy in first-episode psychosis. *Canadian journal of psychiatry. Revue canadienne de psychiatrie*, 54(1), 28-35.

Shin, Y. M., Jung, H. Y., Kim, S. W., Lee, S. H., Shin, S. E., Park, J. I., ... & Chung, Y. C. (2010). A descriptive study of pathways to care of high risk for psychosis adolescents in Korea. *Early intervention in psychiatry*, 4(2), 119-123.

Stowkowy, J., Addington, D., Liu, L., Hollowell, B., & Addington, J. (2012). Predictors of disengagement from treatment in an early psychosis program. *Schizophrenia research*, 136(1), 7-12.

Szmukler, G., Kuipers, E., Joyce, J., Harris, T., Leese, M., Maphosa, W., & Staples, E. (2003). An exploratory randomised controlled trial of a support programme for carers of patients with a psychosis. *Social psychiatry and psychiatric epidemiology*, 38(8), 411-418.