- 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