

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.