



CLINICIAN'S TIP SHEET

# Family Involvement in Programming for Early Serious Mental Illness

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You are in the vanguard of an important change in care for people with early symptoms of serious mental illness. As a clinician in a program aimed at young adults with first episode psychosis, you make a life-changing difference. To help the program participant succeed, you'll provide an array of recovery focused services and supports. And you'll forge a strong partnership with both the participant and his or her caring family. This collaboration is unique to each case. But it's your creative flexibility and positive approach that will make it all work, even when there are problems and setbacks. Our Tip Sheet aims to help you get through the challenges.

### WHY IS THE FAMILY IMPORTANT?

**Family is an enduring source of strength and support.** Most of us know when things get tough and we need help, we can call on our family. The love and trust between family members means we rely on them to be there 24/7, especially in a crisis. Our families know us better than anyone, and they are the first to recognize when something is amiss. Family members, especially parents, are invested in the happiness and well-being of their loved ones.

With ESMI, as with any serious illness, **family support is critical to recovery.** Family involvement is a vital component of a successful first episode psychosis (FEP) treatment plan. Families can provide important information and key ongoing observations as treatment and services are provided. As partners in care, family members will be your allies going forward. It is important to understand the emotional impact on the family so a caring connection can be made.



### FAMILIES ARE COMPLEX AND HIGHLY VARIED IN THEIR CIRCUMSTANCES AND REACTIONS TO A FAMILY MEMBER'S EARLY SERIOUS MENTAL ILLNESS.

It is important to remember the **range and complexity of families and their unique circumstances.** Families struggling to deal with Early Serious Mental Illnesses (ESMI) vary widely. Families find themselves in a variety of circumstances when struggling to deal with early serious mental illnesses. Some may be relieved to finally find a resource that can help their family member after multiple failed attempts to get help. Others may be exhausted and demoralized. Family members may disagree about what is happening as they attempt to sort out normal developmental issues from early symptoms of serious mental illness.

Many may face ongoing stress due to their **financial situation.** The family member with a mental illness may not be the only, or even the most critical, problem other family members are facing.

**For some families, this will not be their first experience with mental illness** because others in their family have had similar experiences. These families may be particularly demoralized and distrustful of the effectiveness of your clinical and support interventions. They may be frustrated or angry and reticent to confront these problems again. They may be pessimistic, fearful, and exhausted.

*Families often are exhausted and badly in need of understanding—someone to listen to them. Compassion and concern build trust and partnership.*

**Families with private insurance who have not used public services** in the past may be disturbed by the public mental health clinic setting and confused by the policies and procedures in the public sector.

**Cultural issues will loom large for some families.** Reactions to early psychosis vary greatly across cultures. It is vital that clinicians understand the significance of culture and tradition in order to gain the family's trust. Some families may be ashamed of their relative and feel deeply guilty about not managing their family's problems. Religious issues, which may be important to the family, may conflict with some of your clinical advice. Some families also may worry about how their community will respond to their loved one's mental health diagnosis. Cultural sensitivity will help guide the clinician in offering coping skills and problem-solving techniques that the family can accept and use.

When family relationships are strained or non-existent, **non-related friends may function as a family of choice.** A family of choice is a group of individuals who deliberately choose one another to play significant roles in each other's lives, which could include biological family and others (not necessarily legally related) who are important and meaningful in one's life.

Your challenge is to **understand and accommodate all of this complexity and variability** and find the best path to reaching the participant and his/her family. Family involvement can make a big difference in the participant's engagement, support, and ultimate recovery. Below we have summarized some tips that may be helpful in working with families.

## BEGIN BY LISTENING

To build a bond of trust, **begin by listening.**

- It's hard to overstate the **impact that ESMI can have on the family.** ESMI can bring confusion and upheaval to all family members. Parents are worried and may feel helpless and hopeless. Each person in the family will have their own reaction, but nobody will be unaffected. Families often are emotionally isolated and may disagree about what to do, bringing yet another layer of tension to the household. Life with a family member with a potentially disabling illness often feels a lot like riding on a roller coaster at breakneck speed—while blindfolded.
- Your **help and support as a clinician will go a long way toward reducing distress.** Be sure to take time to hear what the family wants to share and acknowledge how challenging their experiences have been. Share information about your FEP program and the family's role in the program. Demonstrate your confidence that the situation will improve.
- **Families need realistic hope for the future,** and they are eager to support recovery. To see one's son, daughter, or romantic partner gripped by mental illness is to experience a profound feeling of loss of hope and dreams for their future. Listening with true empathy is critical. Encouragement about positive long-term outcomes is important. Hope and a "can do" attitude are essential.
- **Give space for feelings, do not minimize pain and fear,** and keep offering sympathy and support. It takes time to accept the diagnosis and work through grief. Your care and compassion will build trust. **ESMI is not a life sentence.** Today, recovery is the expectation. We have lots of tools to help, and we are addressing this problem early.

- Listen intently to the **family's stories to understand the family context and the culture** that may be affecting the family member's understanding of the situation or limiting the family's engagement with the team.
- Be aware of the lingering **effects of stigma** and the **consequences of discrimination**. While much progress has been made in destigmatizing mental illnesses, much work remains. Embarrassment can cause families to withdraw from some of the natural supports in their community and make problems worse. Inform families of their rights, including rights with their insurance carrier. They may need help obtaining services and benefits covered under their health insurance plan.

### WORKING WITH THE PARTICIPANT TO FACILITATE FAMILY INVOLVEMENT


- A primary goal in ESMI programming is **strong engagement with the program participant**. As part of the initial assessment and needs assessment, you should explore the participant's role and relationship with his or her family. In many cases, the family will already be an important part of the picture. In any case, it is important to understand how the family may be involved in treatment. Remember that initially the participant might feel angry at their family for assertively trying to get them to accept treatment. This is why it is important to ask more than once about involving family.
  - **Explore the participant's goals and wishes.** See how the family may be an important part of achieving those goals. What roles could they play? What should they avoid? Are there ways in which you can work with the family to help align their goals and wishes with those of the participant?
  - **What does the family think** about the current difficulties that the participant is experiencing? What are some of the positive and negative features of the relationships within the family? What could be done to strengthen the positive and help reduce the effects of the negative aspects of the relationships?
- If the participant is **reluctant or ambivalent** about having the family involved, you should continue to explore ways in which the family could help the participant reach his or her goals and be involved in treatment. As you develop your relationship with the participant, return to issues of how things are going with the family. Have new possibilities emerged during the last few months that could be used to strengthen the family's role?
- Use shared decision-making to ensure the **participant weighs the benefits and risks of family involvement** in care thoroughly. Some participants will give an immediate negative response to a request for family involvement in care because they wish to assert their independence and do not fully consider the benefits of having the treatment team help them enlist their family members in their recovery and desire for autonomy. Exploring these potential benefits of family involvement in care with a trusted clinician can be useful



- Acquaint the participant with the **benefits to their family of family involvement**. Some participants are concerned about burdening their relatives, so they are hesitant to ask them to come to sessions. However, if the clinician describes the benefits for relatives—access to the treatment team, having their questions or concerns addressed, being able to relax a bit and be less worried about the participant's situation, learning how to support the participant's recovery—this sometimes helps the participant acquire some perspective on the relatives' situation and engenders interest in family involvement.

### ENGAGING THE FAMILY

- **Respect and praise ongoing caregiving.** Remember that family is “on duty” 24/7! Offering a clear and respectful invitation to participate is key. Be persistent and keep inviting family participation. It may take some time for family to engage as they adjust to new realities and difficult challenges. Listen intently to the family's stories to understand the family context and the cultural overlay that may be affecting the family's understanding of the situation and limiting engagement with the team. Ask about any barriers the family is facing that may prevent their engagement. By the time the participant is engaged, the family may have exhausted sick leave time and may be drained financially and emotionally.
  - Offer a formal **family psychoeducation program** to the family, even if only a minority of the family members will be able to participate. If family attendance is inconsistent, be welcoming and keep the door open. For those who choose not to participate in formal programming, continue to educate them regarding characteristics of the illness, coping and problem-solving strategies, and other aspects of the formal program. Let them know about other family psychoeducation programs and family peer-led support groups that may be available in your community.
  - **Share information and highlight all progress.** Giving “bite-sized” information may be a useful strategy if the family seems overwhelmed. Explain shared decision-making and the family role in recovery. Emphasize that the family is not being blamed and is a vital partner in helping move their family member toward recovery. Offer encouragement and hope. At each meeting, ask, “How are *you* doing? How can we help *you*?” Call, text, and keep in touch.
- Patiently learn about any difficulties and issues that are **barriers to participation**. The program can offer important help. It may link families to the resources and services they and their family member need. Case management is one of the core FEP services. It can make a big difference in maintaining strong family engagement by helping to meet immediate, practical, and often pressing needs. Nothing contributes to success like building a strong team-family relationship.
- **Note who in the family is not showing up** and make an extra effort to involve them. Mothers take on the key family involvement role most often, but fathers, siblings, grandparents, and other extended family members may be important participants.



*Some families may show up only when practical help is needed. The staff can use these meetings as opportunities for education. Crises can be teachable moments, with “bite-sized” bits of information offered.*

- **Keep track of the family's goals** for your participant. Remember that this is their measure of progress. Ask them for specifics:
  - What are your greatest worries today?
  - What problems are most important to fix?
  - What will make it easier for you to help?
- **Addressing practical problems** that the family identifies can strengthen their trust and foster strong engagement. Family caregivers often have practical concerns. Ask about the rest of their family life:
  - How are other kids and family members?
  - Are things going okay at work?
  - Are there other practical issues we can help with?
- Do not use **HIPAA as a shield** to avoid sharing information that the family needs to help, but do explain that the law requires the participant's verbal or written agreement to share different types of medical information if he or she is over age 18. Although the law specifies the age of 18, an 18-year-old may still seem like a dependent child to a family member. The participant can verbally agree to share information with family when they are in the room.
- Consider a **limited consent for release of medical information**. Participants often are willing to share some information with their relatives (e.g., their treatment plan) but less willing to have information shared about other topics (e.g., their sexual relationships or drug use). As an opening strategy to involve families in care, the FEP team can agree to these restrictions, then work with the participant to modify the rules over time if they seem too constricting.
- Withholding basic information about the participant may be felt as blaming and breed resentment. You can work with the participant to develop information-sharing strategies that protect his or her privacy but also include caregiving family members effectively. Remember that HIPAA does not preclude you from getting information from family members, just sharing information about the participant without his or her consent. The clinician's approach can encourage consent to share information with family members. Sometimes it is necessary to meet with the family members to provide guidance and support before the participant is willing to meet with the team.
- Be sure to let families know **they can contact you any time** with questions or to share information. There are not any restrictions on their ability to share their observations, concerns, and insights with the clinician. Encourage families to keep a journal or daily diary to track how things are going and what helps.
- **Home visits can be valuable**. While not all families will welcome this, it often helps engagement to go to their home rather than requiring office visits. Coffee shops or other casual locations may feel much more comfortable than the mental health clinic.



*Invoking HIPAA can mask persistent ideas of family blame with some clinicians. Families sense this bias and report getting little empathy or support from clinicians. This creates a serious barrier to ongoing participation in recovery planning.*

- **Food and flexibility are key** to deepening trust and engagement. One FEP program hosts monthly family dinners as an informal way to help build relationships. The whole family is invited to socialize and enjoy a nice meal with program staff and other family members. This also can serve as an informal support group for both participants and caregivers.

## CHALLENGING SITUATIONS

- **A family member's substance use or mental illness** may make connection difficult, but it is not impossible. Offer support and connections to medical and social services that may be needed. Make a call and set up a therapy appointment or connection to needed support. Remember that parents who are struggling with substance use disorders or mental illness likely care deeply about their kids and want to help. As a clinician, you can help the family member see the strengths they bring to the table and how they can best support their child or loved one. This partnership may encourage a young person to continue with treatment.
- **Providing personal support and help to a struggling family member builds trust.** Your assistance can be an incentive for working cooperatively with the FEP team. Motivational interviewing techniques may be helpful for encouraging and engaging families. Building trust will require lots of patience, but persevere and go the extra mile.
- In situations where there has been any **serious abuse, neglect, or other family trauma**, it often is best to meet with family members separately. Each person may have different experiences, needs, and reactions, so listen carefully. Managing complex family situations to ensure the participant's feeling of safety and to engage family support appropriately can be a challenge with important rewards.
- **Avoid assigning all communication difficulty to "family dysfunction."** This may be an easy excuse to give up on a potentially valuable resource. Suggest conflict resolution and coping strategies that can help improve family life. However, if issues are severe and intractable, refer the family to another resource and focus on the person with ESMI.
- Families are important allies in **crisis and safety planning**. Families often have the most contact with participants and the best sense about how they are doing. It is important to work with them to develop a good sense of when a crisis may be developing and potential coping strategies. Families will have the best understanding of what might work to avoid a crisis and need to be supported when they are managing one. The best strategy for managing a crisis is avoiding it and engaging **families as allies in observing early warning signs** and providing support and feedback to their family member about their observations. Developing and testing coping strategies can help provide concrete plans for avoiding or successfully handling a crisis.
- Encourage the development of a **Psychiatric Advance Directive** when things are going well, so that if a crisis occurs you will be able to work effectively with the family members through the difficult times while respecting the wishes of the participant.

- Be aware of the lingering **effects of stigma** and the **consequences of discrimination**. While much progress has been made in destigmatizing mental illnesses, much work remains. Embarrassment can cause families to withdraw from some of the natural supports in their community and make problems worse. Inform families of their rights, including rights with their insurance carrier. They may need help obtaining the services and benefits of their health plan.
- ESMI programs are exciting, but **some days can be tough for the staff**. Do not be too hard on yourself. When things are difficult, try to take care of yourself. Your positive, consistent support is vital to your patient's recovery.

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## ADDITIONAL RESOURCES

### OnTrackNY

[Family Treatment and Resources Manual](#)

[Delivering Culturally Competent Care in FEP](#)

### National Association of State Mental Health Program Directors (NASMHPD)

Web-Based Course: [Demystifying Psychosis: For Family Members](#)

### Early Assessment and Support Alliance (EASA)

[For Families, Allies, and Young Adults](#)

### NAVIGATE Consultants

[Family Education Manual](#)

### National Alliance on Mental Illness (NAMI)

[Navigating a Mental Health Crisis](#)

[Infographic: Navigating a Mental Health Crisis](#)



## RECOMMENDED CITATION

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