

# **NAVIGATE Family Education Program**

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This manual is the 2020 revision of the Director manual originally developed for the RAISE-ETP study, funded by NIMH. Shirley Glynn is the lead author of the original Family Manual, with collaborators Cori Cather, Susan Gingerich, Jennifer D. Gottlieb, Piper S. Meyer, Kim T. Mueser, and David L. Penn. Shirley M. Glynn, Ph.D. and Susan Gingerich, MSW are the authors of this 2020 revision. The revision updates the original material to reflect 1) new scientific discoveries since the original manual was written, 2) experience providing NAVIGATE treatment in the RAISE-ETP study, and 3) experience of clinics providing NAVIGATE treatment in a wide range of real-world settings. In the Appendix to the introduction to this manual, you will find a list of the major revisions made in the 2020 Family Manual revision.

# Introduction

NAVIGATE is a comprehensive treatment program for people who have experienced a first episode of non-affective psychosis. Treatment is provided by a coordinated specialty care (CSC) team, which helps people work toward personal goals and recovery. More broadly, the NAVIGATE program helps clients navigate the road to recovery from an episode of psychosis, including supporting efforts to function well at home, on the job, at school, and in social situations.

The NAVIGATE team includes the following members: director, family clinician, prescriber, Supported Employment and Education (SEE) specialist, Individual Resiliency Training (IRT) clinician, and whenever possible a peer support specialist and a case manager. The positive results of participation in a research study of the RAISE-ETP program (now called NAVIGATE) are described in Kane et al (2016).

The manual you are now reading describes the Family Education Program and how to implement it. The manual is a 2020 revision of the Family Education manual originally developed for the RAISE-ETP study. The lead author of the original manual was Shirley Glynn, who co-authored this revision with Susan Gingerich. The revision updates the original material to reflect 1) new scientific discoveries since the original manual was written and 2) experience with clinics doing NAVIGATE treatment after the completion of the RAISE-ETP study. In the appendix to the introduction, you will find a list of the major revisions made in the Family Education manual.

Relatives typically respond with a variety of emotions when their loved one develops a psychotic illness—they want to help improve the situation, but they are usually bewildered, confused, and frightened. Many may feel angry or disbelieving about the situation. A small, but not insubstantial number, may have had prior experience of psychotic illness with other family members or themselves, and may feel hopeless or discouraged about the illness in another loved one. Regardless of the relative's response, the NAVIGATE family clinician always has two objectives in every interaction with relatives—1) to reduce the relatives' burden and 2) to help the relatives build on their strengths to create and maintain an environment to support the client's recovery. To meet these objectives, the family clinician must help the relatives cultivate the necessary knowledge, attitudes, and skills to cope effectively with the situation and support the client's progress; this is the work of the family education component of the NAVIGATE program.

## **Philosophical Foundation of Family Work in NAVIGATE**

### **Why Involve Families in Care?**

A first psychotic episode can have a devastating impact on families, but clients who maintain relationships with their relatives and have them involved in their care tend to have better outcomes (Brekke and Mathiesen 1995; Clark 2001; Evert, Harvey et al. 2003). Strong social support can be critical to recovery as can interaction between the treatment team and relatives. For example, Stowkowy et al (2012) found, in a first episode sample, that lack of family involvement in the comprehensive care program predicted client disengagement, while a recent paper on more long-term illness demonstrates that family members interacting with the inpatient staff during a psychiatric admission of their loved one was associated with better discharge planning and increased likelihood that the loved one would attend subsequent outpatient appointments (Haselden et al, 2019).

Conversely, tense, conflictual family relationships are often associated with worse outcomes (Leff and Vaughn, 1985; Butzlaff and Hooley, 1998). Thus, shoring up the relatives' ability to support the recovery of the client is most often the primary treatment goal of providing family education. There are occasional times when a treatment team may have reservations about involving a family member in care because of concerns that the family member has a negative impact on the client. Nevertheless, it is important to recognize that, in many of such cases, the relative still has an impact on the client whether or not the family clinician develops a relationship with him or her. Thus, developing an alliance between the treatment team and the relative is often in the client's best interest as it can be used to improve their relationship, and the ability of the relative to support the client's participation in treatment.

### **Managing Relapses**

In spite of everyone's best efforts, relapse after a first episode of psychosis often occurs. The family clinician must take a thoughtful stance in discussing relapses before one has occurred. While avoiding relapses can be a potent motivator for program participation, emphasizing this benefit may lead to the unfortunate consequence of relapses/hospitalizations being considered "failures." The family clinician should work proactively to counter this thinking. While relapses are certainly unfortunate, by examining the circumstances in which they occurred, they provide the client and his or her relatives with an opportunity to learn more about what is needed to secure subsequent improvement.

Clients and their relatives are encouraged to remain in the NAVIGATE program even after a relapse. As soon as possible after a discharge from a relapse/hospitalization, the clinician and family (including the client, if willing) should meet to process the relapse. The clinician should inquire into how everyone is coping and be sympathetic and supportive; each participant should be given the opportunity to air his or her concerns. The *Plan to Stay Well*, which is part of the "Just the Facts" educational handouts and is also used in IRT, should be completed or reviewed and updated with any newly acquired information, and the clinician should also ask the participants if there is anything the treatment team could have done differently to help manage the crisis. The clinician must be prepared for family members to be discouraged about the relapse, particularly if it appeared that all participants were adhering to the treatment plan prior to its occurrence. Here, the

clinician can highlight (if appropriate) that the length and severity of the relapse may have been minimized, if not prevented, by the hard work everyone embarked upon prior to its occurrence.

### The Importance of Ongoing Engagement and Support

As clients and relatives move through NAVIGATE, there may be periods where things seem to be going very well and other times when things are difficult. There may be times when the family is pleased with the NAVIGATE team and times when it is disappointed. Regardless of how the family feels, it is critical that the NAVIGATE team continue to extend a hand to the family. Ongoing accessibility is the key. Learning to respond to psychosis effectively is a process that takes time, and how individuals feel one day may not reflect how they feel a month later. Family members greatly value a mental health professional “hanging in there” with them for the long haul.

### Imbuing Interactions with Hope

Given how persons with psychosis are portrayed in the media, it is perhaps not surprising that many people are distraught or disbelieving when they learn them or a loved one has a psychotic illness. Similarly, mental health professionals who have been working with more long-term clients may not see many reasons to be hopeful about the outcome of a recently developed psychotic disorder. Nevertheless, it is very important to recognize that we do not yet know the likely outcomes of persons who are just developing psychotic disorders, and there are more reasons to be hopeful than ever before. These reasons include

- With newer treatment advances and more emphasis on community care, there are fewer persons with first episode non-affective psychosis who will experience the severe effects of institutionalization that others before them did. We do not know for certain what benefits programs like supported education, specialized psychotherapy, and better tolerated medications will have in 20 years, but there is reason to believe these innovations will lead to better outcomes.
- Long-term research studies show that even those who have multiple episodes of psychosis tend to improve over time.
- Many clinicians in the public sector have little experience with persons with psychosis who are currently living full non-disabled lives in spite of their illnesses. These people often hold professional jobs, can go into the private sector for care, keep their medical histories private, and are frequently not obviously impaired. Any one of us could be working alongside such a person and not know it. Even though persons working in publicly funded or non-profit clinics may never see them, it is important to remember these individuals are walking testaments to the possibility of recovery.

### Strengths Perspective

It is natural for any clinician interacting with a client to scan for abnormalities—symptoms, odd behavior, withdrawal from life, poor hygiene, speech that may be difficult to understand, etc.—and make this the focus of attention and intervention. In some cases, this is unavoidable, especially then there is a risk of harm or injury. However, it is becoming increasingly apparent that one can “flip the focus” and concentrate on identifying and developing strengths and positives to good

effect. Psychology has shown that it is much easier to build on strengths (things we are already good at) than to try to remediate weaknesses (things we tend to be bad at).

Applying this perspective to the NAVIGATE family work, it is critical that the clinicians work to identify strengths in both relatives and clients and work to shore them up. For example, one first episode psychosis client with whom we worked had never been very social and the development of a psychotic episode in her junior year of high school did not help the situation. Her parents were acutely aware of her isolation and worried about it a great deal. However, the client had many strengths - she had a very pleasant demeanor, she was committed to returning to school even though her concentration was still shaky, she was very respectful to her parents, and liked and still engaged in some sports. This focus on strengths in NAVIGATE helped the parents relax and the client feel proud.

While the clinician was also concerned about the client's social development, she decided to minimize negative comments about the lack of it, praise any suggestion of interaction with peers, and to focus the work on activities where the client could succeed—snowboarding, working out, playing games on the computer—because these were interests and strengths in which the client had skills. The clinician encouraged the relatives to do the same and explained the rationale. Over time, the client began to spend more time in these activities and to develop some acquaintances through doing them. She did not make a dramatic change in her socialization levels, but she experienced the benefits of not being totally alone and could be proud of her accomplishments.

### The Imperative of “Seeing the World through the Participant’s Eyes”

As with all clinical work, the strongest relationships are created when participants feel understood and accepted. The development of a psychosis is overlaid on a whole history of family experiences and situations. Having a child who develops a psychosis may mean very different things in a family where everything seems to have been going fine compared to one where there are other major issues and this is just “one more thing.” It is imperative to avoid assumptions about what the experience means to participants. Rather, it is essential to be a good listener, to pay attention to what is said, to conduct a careful assessment, and to put one's own perspective aside when getting to know the family. For example, some relatives will think medication is a godsend; others will believe in natural healing. Some will think their ill family member should stop doing drugs, and others will be doing drugs with their ill family member. Don't make assumptions about anything. Ask a lot of questions. Try to see the world through each participant's eyes and tailor advice or counsel to that world view—it will make it much more likely that the counsel will bear fruit.

### Shared Decision-Making as a Foundation for the Work

Shared decision-making is a process by which clients and clinicians collaborate to help the client make an optimal health care decision. The client and health provider consider both the likelihood of various outcomes accruing from unique courses of action *and* client preferences. Mutual agreement between the provider and client about a planned course of action is a desired, though not always attainable, outcome. The process of shared decision-making acknowledges that, while providers have a wide array of knowledge about the odds that an intervention is likely to improve a particular situation, the client also has a wide array of knowledge regarding his or her

preferences, attitudes, beliefs, and history. Both the clinician and the client are “experts” on what they know, and both sets of knowledge are important to consider when addressing health problems.

Mental health providers have traditionally been very directive —“You should take this medication” or “You should attend this group”-- and then used any persuasive means possible to try to get the client to follow the recommendation. Shared-decision making offers an alternative framework for clinicians and clients working together. Here, the clinician can recommend treatments based on available scientific evidence, but the client also provides information on what he or she understands, wants, and is willing to do. For example, participation in structured family work of at least nine months has been found to reduce subsequent relapse rates 20-50% (Pitschel-Waltz, Leucht, et al, 2001) over and above medication alone in persons who have had a recent relapse in schizophrenia. However, family work can be demanding and many clients may not want to expend the effort initially to do the treatment.

In the traditional model of mental health treatment, the clinician, if aware of the research, would make the recommendation for family work without offering much rationale and then try to persuade the client and his or her relative to do it. In the shared-decision making model, the clinician would raise the issue of family work with the client along with the information on why the recommendation is being made. The clinician might even mention a few possible types of family work with different advantages and disadvantages, so the client would then have some options. The client would indicate his or her preference and concerns, the two could continue the discussion to make sure that they each understood each other, and some type of family work would be initiated or not, depending on their mutual agreement. The clinician and client would typically agree to revisit the topic in the future to see if the client’s preferences still hold or if new information has changed his/her level of interest in this treatment option.

Shared decision-making is a core foundation of the NAVIGATE program. While the program has many components, it will be up to the individuals in NAVIGATE to make decisions about which components to try, and when, with members of the NAVIGATE team. If the client does agree to family work as described in this manual, the family clinician is likely to play an invaluable role in 1) explaining the shared decision-making concept to relatives, as well as 2) helping relatives be involved in the decision-making process when appropriate as their preferences, knowledge, and history can also be critical in some treatment decisions.

## The Importance of Active Engagement

As will become clear in the Engagement, Orientation, and Assessment Phase below, initiation of family work in NAVIGATE begins with engagement and orientation sessions. However, both the client and the relatives may not be aware initially of the potential benefits of working together with the treatment team, or may be hesitant to become involved with the NAVIGATE program, perhaps due to other role demands, their mental health issues, a lack of understanding of the potential benefits of family work, family conflict, or practical constraints with time or transportation. It is imperative that the NAVIGATE family clinician be prepared for initial reluctance on either the client’s or relatives’ part when the family component of the NAVIGATE program is first presented. This reluctance may make it difficult even to establish an initial engagement meeting with the relatives. In such a case, the family clinician has options:

- If the client is involved in other team members of NAVIGATE, such as the prescriber, the SEE, the case manager or the peer specialist the family clinician can join one of their sessions to provide an opportunity to get to know the family clinician and ask him or her questions.
- If the client attends IRT sessions, it can be helpful to join some of the sessions when family-relevant topics are being discussed (e.g. developing a plan to stay well) and encourage the client to reconsider involving his or her family in care.
- The family clinician can look for opportunities for casual contact with relatives—saying hello in the waiting room or making them aware of community or facility services that might be useful to them—to shore up the relationship and keep lines of communication open.
- With the client’s consent, the family clinician can have an initial home visit with the client and relatives to help discuss the utility of family work in recovery from psychosis.
- Some facilities find it useful to set up occasional social activities--such as picnics, holiday parties, and open houses—for clients and relatives, and these can provide an opportunity to become acquainted with the staff and perhaps more open to ongoing involvement.

Overall, the family clinician should maintain an open attitude and remind him/herself that engagement is often a *process*. As the situation evolves (e.g., the client has an exacerbation, family status changes, or the client develops a stronger relationship with the NAVIGATE team), either the client or the relatives may be willing to become involved and be available for engagement sessions. The overriding principle in the family program is that the family clinician needs to be open, flexible, and make repeated attempts to establish relationships with the client and relatives.

## **Logistics for NAVIGATE Family Work**

In many ways, the guidelines of family work mirror those of traditional individual work—respecting the client, supporting empowerment, thoughtful treatment planning and implementation, shared decision-making, attention to issues regarding mandated reporting, etc. However, family work often raises unique challenges for the family clinician and the agency. The overarching principle in family work is the need for *logistical flexibility*. Family sessions often require more time than individual sessions, they sometimes need to be held at off hours to meet the needs of working individuals, there may be some flux in who actually participates as family constellations change (e.g., sibling going to or coming back from college), and even the venue may be variable—typically sessions are held in the clinic, but home visits may help with engagement, transportation problems, and the like. The setting should be a comfortable room which can easily accommodate all the participants without feeling cramped. As the family confronts new challenges, they may have need for increased contact, though much of this may be by phone.

Issues regarding consent for sharing of information are important and need to be addressed in advance. In NAVIGATE, every client is invited to meet with the family clinician at the beginning of participation in the program and to learn about the potential for family work. Typically, *prior* to beginning family work, an agency will have an interested client sign a consent form for sharing of information for the relatives who participate in the program for its duration. Family clinicians should work closely with the other members of the NAVIGATE team and/or their colleagues at the agency to resolve any logistical issues, since they can “make or break” a successful intervention program.

## Flexibility in Defining the Members of the Support Network

It is important to remember that families come in all kinds of constellations and it is up to the client to define who the important “family” is for them. For most FEP clients, this involves someone from their family of origin (typically a parent or step-parent), but for others it may be a sibling, partner, or friend. The client should be queried at the beginning about who should attend family sessions as his/her supporters; *if the client is living with any kin and/or having frequent contact, it is optimal for those individuals to be involved as they will likely have a significant role in the person’s recovery.* Most often, one of the relatives identified to participate in the program will also serve as an important support person in the other parts of the NAVIGATE program, including but not limited to participating in treatment planning meetings, supporting the client’s decision to take medication, assisting the client in pursuing his or her personal goals, encouraging the use of coping strategies, and being aware of early warning signs of relapse.

## What to Do When the Client or Relative Refuses Family Involvement

One of the benefits of working with first episode clients is that when illnesses are often just developing and situations are in flux, so clients and their relatives may be especially open to suggestions for change or treatment. Thus, during a hospitalization or entry into the NAVIGATE program is an optimal time to introduce family involvement in care. The use of motivational enhancement techniques when interacting with clients and relatives can maximize the likelihood that they will agree to work together during these times of instability and change. Nevertheless, it sometimes happens that clients refuse to have their relatives involved in their care, or relatives refuse to be involved. These obstacles to engagement can reflect long-standing conflicts that have little to do with the illness, or may be more illness related (e.g., the client is paranoid about a relative or angry because he/she initiated hospitalization). In the latter situation, whomever on the NAVIGATE team is working with the client can again raise the topic of family involvement in care as the treatment progresses and the client improves, in the hopes that at some point the client will change his/her mind. *In our initial trial of NAVIGATE, about a third of the participants who initially refused relative participation in mental health care eventually changed their minds.*

Encouragement to involve relatives in care will also be found in the IRT work, which includes asking the client to practice strategies and skills with supporters in the community, and in SEE, where relatives can play a critical role in supporting clients in looking for and keeping jobs. If the relative refuses to become involved in NAVIGATE, the family clinician can ask the client if another family member or friend might be available for involvement and pursue that option. The family clinician can also accept pertinent information from the relatives—through letters, messages, or conversations—though of course he or she cannot disclose any specific information about the client without consent.

## Clients May Choose Not Attend Family Sessions

Ideally, relatives and clients will attend the family educational meetings together. However, sometimes the client will agree to his or her relatives obtaining support, but will not want to attend sessions. It is usually preferable to have the client and his or her relatives receive educational information at the same time. However, since much of the educational material is also covered in IRT, and the client may have other responsibilities, such as school or work, it is understandable that the client may be reluctant to be involved in family sessions where similar information is



covered. If the client consents to family involvement in care but does not want to attend the family education session, relatives should be assured that the family work can continue and that the client will review much of the same material in IRT.

When clients do not want to attend all the family sessions, it is optimal to negotiate with the client that he or she attends occasional family meetings where his or her input would be vital—such as when developing a *Plan to Stay Well*. Most clients will agree to this intermittent participation. They are relieved that someone is helping their relatives more regularly but they can avoid most session conflict and friction. Even if the client attends the family education sessions regularly, the client will likely benefit from reviewing and processing the information independently in IRT sessions after attending joint sessions. In some instances, the client may miss some family education sessions, and the IRT clinician can help him or her to catch up.

Scheduling clients for their NAVIGATE appointments is often challenging. However, it is important to avoid scheduling all family sessions and IRT sessions at the exact same time. This makes it extremely difficult for the client and family to meet together for sessions.

### The Need for Other Family Work

For the majority of clients and families, the work described in the manual will be sufficient to stabilize the client and support recovery while reducing family burden. There are, however, occasional situations where it becomes clear during the family work that there are long-standing problems in the family, typically preceding the development of the psychotic illness, which are interfering with implementing the family program and/or affecting the client's progress. This might include, for example, psychiatric illness in another family member, long-standing conflict between the parents of a client, or parenting difficulties with other children. In such situations, participation in the family program may help but not resolve these issues and other intervention may be needed. Here, the family clinician can be a vital resource in helping identify the problem and helping the relevant family members connect with other, more targeted, treatment. It is essential that the family clinician become an expert on family services in his/her own agency, as well as the local community, so he/she can make referrals as warranted.

### Keeping Family Sessions Low Stress

During a period of first episode psychosis, both the client and relatives may be highly distressed. Because psychosis renders people very susceptible to stress, it is imperative to keep conflict during family sessions to a minimum. The family clinician models a temperate, measured tone at all times. If family members become agitated, the family clinician takes an active role in “cooling things down” by encouraging participants to stay calm, reminding participants of the role of stress in making symptoms worse, suggesting participants take a break and get a drink of water or take a few deep breaths before continuing, and briefly separating participants if necessary. It is preferable not to terminate a session due to conflict as this can convey to the family that the clinician cannot handle the challenges they present; rather, a brief break is usually sufficient to allow family members to recompose themselves and begin participating again.

## Referrals to Relative Support Programs Such as NAMI

Participation in family programs such as the National Alliance on Mental Illness (NAMI) can lead to significant increases in knowledge and reductions in burden (Dixon et al, 2011); however, referrals to such programs can be more complicated in first episode psychosis. Many NAMI programs draw relatives of more long-term clients, and their concerns are often different from those of first episode psychosis relatives. The family clinician should become familiar with the local NAMI groups to know if there is a core of first episode psychosis relatives who attend and with whom new referrals can become acquainted. Often, first episode psychosis relatives can still benefit from participation in the 12 session NAMI Family-to-Family program, which usually has more of a mix of participants, even if the local meetings are skewed more to relatives of long-term clients. It is also important to note that some local NAMI chapters have organized subgroups with expertise in first episode psychosis, and linkage to these groups can be invaluable for NAVIGATE family members new to the experience.

## Working as Part of the NAVIGATE Team

The NAVIGATE program incorporates a team structure and it is critical that the family clinician work closely with the rest of the team to share perspectives and develop and implement the treatment plan. By virtue of his/her work with the relatives, the family clinician is likely to have information about the client's social network that other team members do not. Also, the family clinician can encourage family members to be involved in other aspects of the client's NAVIGATE care, such as the SEE program.

Whenever possible, we recommend the bulk of the educational work be conducted conjointly with clients and families in weekly family sessions. In the overall structure of NAVIGATE, this typically means that, after the engagement into the whole program and an initial family education orientation and assessment meetings, the client will have met a couple of times with the IRT clinician to begin to establish goals, and then the family education will begin. For the successive 12-14 educational sessions, the family clinician will meet with the client and relatives together. As time and circumstances dictate, the client will also be working with the IRT clinician, but this work may be slowed a bit if the client finds it difficult to come to the clinic multiple times a week or participate in more than one meeting a day. In some such cases, some of the IRT work will be deferred until the completion of the initial family sessions and/or the client feels ready to meet with the team multiple times a week.

## Pace and Content of Sessions

There is a great deal of material to cover in the NAVIGATE family program and it is important to use the client's and relatives' time well. To this end, clinicians are encouraged to be directive, structured, and to follow handouts closely. Certainly, some small talk is needed at the beginning and end of each session to facilitate relationships, and there may be occasional sessions in which urgent issues must be handled, but the educational handouts should set the structure for most sessions. While all topics in each session should be covered thoroughly, it is not necessary to go over every word or ask every prompt question.

The content of IRT and Family education sessions do not need to be completely in sync. The family education sessions may proceed more quickly than the IRT sessions or vice versa. For

example, in IRT the client may be doing the Strengths Test and Setting goals, while family sessions may be working on understanding the symptoms of psychosis. This is fine.

## Language

Until the family clinician is clear on how the client and family conceptualize the illness, he/she should avoid using terms such as “illness,” “disorder,” and “sickness.” Mirroring the language of the family can be very helpful in strengthening the alliance. For example, relatives may refer to symptoms as “the recent problems.” The family clinician can therefore refer to “the recent problems” in discussing symptoms. Sessions should be conducted in a conversational style.

## Making Sessions Comfortable

The family clinician expressing warmth, empathy, and respect for the client and relatives can be invaluable. The objective is to make the participants feel valued, by assuring that they have a chance to share their experiences, attitudes, opinions, and preferences. Methods of making the participants feel welcome include:

- Offering decaffeinated coffee or tea, or water if it is available
- Praising positive efforts and participation in sessions
- Being cautious about giving constructive feedback until the family clinician has a clear grasp on the situation being discussed
- Using participants’ names as they are being addressed
- Informing participants that the family clinician has been thinking about them between sessions, if that is true
- Showing interest in client and relatives’ life situations (e.g. a recent job change or health issue).

## Monitoring and Managing Urgent Issues during Family Sessions

In the beginning of every family meeting, it is important to identify and resolve any urgent issues that might compromise the client’s community tenure in the coming weeks. For example, the client’s symptoms may be worsening or there may have been violent incident or the client has run out of medication. During family education, non-urgent issues may also come up. These non-urgent issues are sometimes deferred until the last part of the session or until after the session. Non-urgent issues can also be referred to the treatment team. When problems are identified, the family clinician can give suggestions, use the skills taught in IRT, refer to the case manager or community agencies, and/or make a plan to address the issue through work with the treatment team as appropriate.

## Suicide Risk and Prevention in Early Psychosis

Approximately 5-10% of people with schizophrenia will die by suicide. Further, there is a particularly high risk of suicidality among individuals recovering from their first episode of psychosis (Simon et al, 2018). Indeed, while the acute phase of the illness represents a risky period regarding suicidality, it is during the early recovery phase following remission of psychotic symptoms when most suicides actually occur. Individuals during this phase are beginning to experience the psychological and social impact of the illness, and many are likely to experience “post-psychotic depression” (Birchwood et al., 2000). Depression and suicidal ideation are especially common among individuals who feel engulfed and trapped by their illnesses, and who become hopeless about the future, expecting a loss of social status and limited potential for improvement (Birchwood, 2003). Specifically, suicide risk in early psychosis is highest during the following periods:

- During emerging psychosis (i.e., prodromal phase)
- Immediately prior to hospitalization and immediately following discharge
- Several months following symptom remission (early recovery period)
- After first relapse (i.e., when realization occurs that illness is recurrent)

Given the heightened risk of suicide following a first episode of psychosis, you are strongly encouraged to consider all NAVIGATE clients as being “high risk” and to regularly monitor clients for suicide risk. Risk factors for suicide in early psychosis include:

- Male gender
- Single
- Unemployed
- Suicidal ideation and/or previous suicide attempt(s)
- Good premorbid functioning with high personal expectations
- High premorbid IQ
- Good insight
- Depression and/or hopelessness
- Substance abuse
- Large degree of illness-related deterioration
- Command hallucinations
- Grandiose or persecutory delusions (may result in self-destructive behavior)

- Family history of suicide

Additional factors that may increase the risk of suicidality include:

- Recent loss of social support (e.g. romantic break-up, falling out with friends)
- Isolation/reduced supervision
- Treatment non-adherence
- Environmental stress/conflict (e.g., family conflict or criticism)

The NAVIGATE team should be mindful of the above risk factors, and identify clients who may be at increased risk of suicide. On the NAVIGATE team, the Prescriber routinely assesses for suicidal ideation. Family members may also bring information about their relative's suicidal thinking to their family clinician and thus the family clinician may know that this is a significant clinical issue and need to bring this to the team. If the family clinician becomes aware of suicidal thoughts or statements, in order to evaluate it further, he or she should obtain the following information:

- Frequency of thoughts
- Presence of active intent and plan
- Lethality and availability/feasibility of the plan
- Potential obstacles to implementation of the plan

If clients express active suicidal ideation, hospitalization may be required. If clients express suicidal thoughts without active intent (e.g., "I'd be better off dead"), further evaluation and planning for safety is needed. **In any case, the presence of any suicidal ideation or talk in clients must be communicated immediately to the rest of the NAVIGATE team.** If a client is actively suicidal and other healthcare providers are unavailable, a member of the NAVIGATE team should follow the emergency procedures of his/her agency. Following local agency standards, the following should be documented in the client's chart:

- All risk assessment and safety plans
- All supervision and consultative contacts
- All contacts with outside providers
- Current disposition of client
- Any other action taken on behalf of the client.

## Involving Supporters in Other NAVIGATE Care

As was just mentioned, relatives are encouraged to be active in other parts of the NAVIGATE program, such as SEE and prescriber interventions, and the family clinician can be instrumental in linking the relatives to the other interventions and motivating them to be involved.

## When Participants Do Not See Eye to Eye with the Clinician or with Each Other

If multiple family members attend the sessions, they may have different opinions about many of the topics discussed in NAVIGATE—including, for example the cause of the disorder, the value of medication, and whether substance use makes symptoms worse. Even after the clinician presents the educational material, the participants may still hold to their beliefs. This can be a complicated situation to manage and still keep stress levels in sessions low, which is a core feature of family work in psychosis. The clinician certainly can explore whether there can be a meeting of the minds through gentle probing and use of compromise.

One example of working with family members who have different beliefs is when we worked with one relative who had a strong religious background and believed that faith would cure her daughter of psychosis. The daughter did not share the belief and repeatedly pointed out how much better she felt on medication. The mother was not to be dissuaded of her belief, however, in spite of the daughter's opinion. As we recommend in NAVIGATE family work, the clinician asked if there was a possible compromise available and used the "Compromise and Negotiation" skill in the *"Just the Facts: Effective Communication Handout"*. This involved inviting each person to state their opinion, restate the other person's opinion, and suggest a compromise. In this case, the compromise was that the daughter would keep taking the medication, but not try to change the mother's beliefs, and the mother would keep praying with her church group for a miracle cure. Compromise and negotiation are often a good way to handle differences in NAVIGATE sessions. Another helpful principle is to "agree to disagree respectfully" if all else fails.

## **Techniques in NAVIGATE**

### Positive Reinforcement

In the beginning of treatment, the primary motivator that the family clinician has to offer families is that it is a positive experience to be in the room with him/her. Even when families are working diligently following the guidance offered by the treatment team, change may be slow and sometimes residual symptoms and impaired behaviors remain, making the situation of the client difficult for all. While families are going through these periods, one of the few positives they may experience is the support and encouragement of the NAVIGATE treatment team. To solidify this relationship, team members should be generous with their praise for any positive changes participants are making—no matter how small. The positive reinforcement should highlight specific changes—"I really liked the way you decided to just take a break and go into the other room when you were getting frustrated with (client)". Encouraging family members to note improvements and provide positive reinforcement to each other is a key part of this work. More about this topic will be discussed in the communication section below.

## Motivational Enhancement

A core competency for NAVIGATE family clinicians is motivational enhancement, which includes techniques to increase the client's commitment, both to his/her recovery and treatment.

### I. Motivational Interviewing

Motivational interviewing (Miller & Rollnick, 2012) is a client-centered, directive method for enhancing intrinsic motivation to change by exploring and resolving ambivalence. It can be used for many clinical problems throughout NAVIGATE; the session intervention described here is designed to help clients resolve any ambivalence they may have about mental health treatment. The work is conducted in a casual, conversational style. Rather than utilizing confrontation, the family clinician uses active listening and careful questioning to assist clients to move to 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 during motivational interviewing are as follows:

#### Principle 1: Express Empathy

- Acceptance facilitates change.
- Skillful reflective listening is fundamental.
- Ambivalence about change is normal.

#### Principle 2: Develop Discrepancy

- Change is motivated by a perceived discrepancy between present behavior and important personal goals or values.
- Whenever possible, the client rather than the family clinician should present the arguments for change.

#### Principle 3: Avoid Arguments and Direct Confrontation

- Avoid arguing for change.
- Resistance is not directly opposed.

#### Principle 4: Roll with Resistance

- New perspectives are invited but not imposed.
- The client is the primary resource in finding answers and solutions.
- Resistance is a signal for the family clinician to respond differently.

#### Principle 5: Support Self-Efficacy

- The client's belief in the possibility of change is an important motivator.

- The client's and family's 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 or relative has said

The goal of the family clinician is to establish a collaborative relationship with the client, to resolve any ambivalence about being involved in treatment and to encourage him/her to develop a stronger commitment to working with the treatment team. The general format for interaction is as follows: family clinician asks open-ended questions, the client responds, and the family clinician summarizes the response, utilizing an empathic stance. Summarizing, restatements, and affirmations are crucial. The family clinician should monitor the number of direct questions asked and avoid asking more than two questions in a row.

In all conversations, the family clinician 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 probes can be used throughout the session. Typical ones are listed below. Selected questions can be asked from each section. The following section contains a motivational enhancement discussion that focuses on the client deciding if he/she is willing to join NAVIGATE. The family clinician might start with a statement such as:

- *"So, I know you have been thinking about joining the NAVIGATE program. Let's talk about that."*



## Examples of Open-ended Questions to Evoke Change Talk

Please note that for the clusters of open-ended questions below, it is not necessary to ask of the questions in that cluster.

### 1. Disadvantages of the Status Quo

- *“What worries you about your current situation?”*
- *“What kinds of difficulties have your problems brought to you and your family?”*
- *“What difficulties or hassles have you had in relation to your current situation?”*
- *“How has your situation stopped you from doing what you want to do in life?”*
- *“What do you think will happen if you don’t change anything? Would trying a recovery program offer another opportunity for change?”*

### 2. Advantages of Change

- *“How would you like for things to be different?”*
- *“What would be good about you getting a better handle on your situation?”*
- *“If you could make a change by magic, if you could get better immediately, by magic, how might things be better for you?”*
- *“Do you think you might benefit from more support?”*
- *“The fact that you’re here indicates that at least part of you thinks it’s time to do something to change things. What is prompting you to consider this?”*
- *“What would be the advantages of working with a team of professionals to help you get back on track?”*

### 3. Optimism about Change

- *“What makes you think that if you did decide to put out some effort into improving things, you could?”*
- *“What encourages you to think that some treatment might help?”*
- *“What do you think would work for you, if you decided to try to be more open to participating in a recovery or resiliency program?”*
- *“How confident are you that you can make this change? What would make you feel more confident?”*

#### 4. Intention to Change

- *“What are you thinking about joining the NAVIGATE program 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 family clinician’s goal is to reiterate statements they make supporting positive change, while acknowledging impediments and discouragement. The family clinician should utilize frequent summaries and restatements of client’s input. This technique both assures clients that they have been heard, and helps clarify the specifics of the client’s comprehension of the situation.

## II. Decisional Balance

This task involves identifying reasons for the client or relative to commit to treatment. The participant is asked to complete the modified decisional balance form (see Appendix). With coaching from the family clinician, the potential participant lists positive and negative consequences of committing to mental health treatment on the “Considering Joining” NAVIGATE Decisional Balance sheet. The participant is prompted to take the lead in completing the form, though the family clinician is allowed to make comments, based on information elicited earlier.

- *“I want you to have the chance to think systematically about the pros and cons of joining the NAVIGATE program. Let’s look at this form where we can list your reasons. What would be all the good points of joining NAVIGATE?” (fills out form)*
- *“What would be the negatives of joining NAVIGATE?” (fills out form)*
- *“Ok, now I would like you to go back and circle the most important reasons to joining NAVIGATE and the most important reasons not to join NAVIGATE. Which reasons really count?”*

### **Decisional Balance**

| <b>Joining NAVIGATE</b> | <b>Potential Good Outcomes from Joining NAVIGATE</b> | <b>Potential Bad Outcomes from Joining NAVIGATE</b> |
|-------------------------|--|---|
|                         |  |   |

|                             |  |   |
|-----------------------------|--|---|
|                             |  |   |
|                             |  |   |
| <b>NOT Joining NAVIGATE</b> | <b>Potential Good Outcomes from NOT Joining NAVIGATE</b> | <b>Potential Bad Outcomes from NOT Joining NAVIGATE</b> |
|                             |  |   |
|                             |  |   |
|                             |  |   |
|                             |  |   |

Taken together, what is the best option?

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When the decisional balance is completed, the family clinician asks the client to identify the most important positive consequence of joining and negative consequence of joining NAVIGATE and these are circled on the sheet. The family clinician summarizes the work.

- *“So, you are saying the main good point of joining NAVIGATE would be XXX, but your concerns are YYY. So where do you stand with that? How could we make it easier to give it a try? Would you like to?”*

While the example here is about joining NAVIGATE, the strategy can be used for many clinical issues—not coming to treatment, not taking medication, using drugs—and is likely to be a core aspect of many NAVIGATE interactions.

## Overview of the NAVIGATE Family Program

In the NAVIGATE program, family work is conceptualized as having four phases (adapted from Addington, Collins et al. 2005).

1. Engagement, orientation, and assessment
2. Stabilization and facilitating recovery
3. Consolidating gains
4. Prolonged recovery

The *engagement, orientation, and assessment phase* involves meeting with clients and their relatives to explain about the family work in NAVIGATE in more detail and conducting assessments with family members to identify their strengths, concerns, and illness knowledge level. Based on these interactions, the clinician may help the client and family address immediate pressing concerns prior to beginning the education work; this work is discussed more fully on page 26.

The *stabilization and facilitating recovery phase* involves 12-14 sessions of illness education and beginning work on the development of family and client coping skills.

*Consolidating gains* involves ongoing contact with the treatment team through monthly check-ins and targeted work on specific problems utilizing a family consultation model on an “as needed” basis. If families are having particular difficulties with communicating and solving problems, they can also be offered Modified Intensive Skills Training (MIST), which is a version of a communication and problem-solving skills program called Behavioral Family Therapy (Mueser & Glynn, 1999).

*Prolonged recovery* prepares the family either for the transition of treatment services back to either a primary care practitioner or other mental health team when recovery has been substantive and does not require the client’s continued involvement in the NAVIGATE program. In preparation for transitioning to non-NAVIGATE services, an evaluation of the gains made by the client and family is conducted, and a mutual understanding of the client’s needs, and how they will be addressed, is made.

### Engagement, Orientation, and Assessment Phase

#### Motivating the Client and Relatives to Join Family Education Sessions

The overarching goal of the orientation and assessment phase is to engage family members (including the client) in NAVIGATE and to have an individual meeting with each participant to obtain his/her point of view of his/her family circumstances and understanding of psychosis. Using motivational enhancement techniques, clients are empowered to commit to their care and facilitate family and treatment team collaboration. We recommend that the engagement, orientation and assessment phase begin with an initial 20 minute introductory meeting with the client, two conjoint introductory meetings with all interested family members (including the client), and at least one individual interview with each participant scheduled over a few weeks; the fewer weeks the better, but with some very ambivalent or symptomatic clients, a longer period of engagement or extra

sessions may be required. Core competencies of shared decision-making and motivational enhancement are critical aspects of the engagement phase.

### Inviting the Client to Include Supportive Others in Care

The first meeting with the client to invite him/her to involve relatives in care may occur as part of the orientation to NAVIGATE or with one of the early meetings with the Director. We recommend that the director routinely sets up a 20-minute introductory meeting with the new client and whomever on the team is acting as the family clinician; it is important for this discussion to occur privately with just the clinician and the client. The goal here is to describe the family program to the client, to listen attentively to any concerns the client has, and to determine his/her interest in having his/her relatives attend family education sessions. Many clients will agree right away to their families being involved in family education sessions, even if the client him/herself does not want to attend the sessions. Some will initially be reluctant. Here using a shared-decision making approach, including completing a decisional balance (e.g., completing a pro/con sheet about the advantages and the disadvantages of involving their relatives in their treatment) and using motivational interviewing strategies may be useful.

There are many reasons why clients may refuse relative involvement in their care, and optimally the provider response will be tailored specifically to each one. Some of these are developmental—first episode psychosis often occurs just as clients are of the age where individuating is the norm. Acknowledging the importance of “becoming an adult” while also relating to loved ones may be a useful strategy for providers. Some clients may be angry with their loved ones for seeking treatment for them or other more ephemeral concerns—here the caring and concern of the provider and use of a decisional balance may be useful. The clinician can point out that he/she can help the clients express their views to the relatives, and help them work through any conflicts successfully. Finally, reluctance to involve relatives in care may reflect long-standing conflicts within families, that may or may not be amenable to intervention in NAVIGATE.

It is also important to realize that clients may change their mind about family engagement in care as they progress through the NAVIGATE program. For example, in the original RAISE trial, 36% of the clients who initially refused consent for their families to be involved in family education sessions changed their minds during the program. *Thus, when a client initially refusing family involvement in care, it is important to continue to raise the issue with the client, perhaps during treatment planning meetings or after a significant change in treatment (e.g. hospitalization, step-down in care, etc.).*

### Conjoint Meetings after the Client Consents to Family Involvement in Care

The first joint meeting involves an introduction to the whole NAVIGATE program and a determination if participants wish to continue, using the *Family Introduction to the NAVIGATE Program* handout. This meeting may occur as part of the orientation to NAVIGATE with the Program Director, or may occur a few weeks later, if the client alone joins NAVIGATE first.

If the participants decide to join the NAVIGATE program, the second joint meeting is devoted more specifically to the family component and involves:

- An orientation to the NAVIGATE family education program, using the *Family Education Orientation Sheet*
- Addressing housekeeping issues (e.g. consents for treatment, mandated reporting, etc.)
- Reviewing “Tip Sheet for Helping People in NAVIGATE”
- Distribution of a recovery story ( “Sam’s Story” or “Taavi’s Story”)
- Inquiring about and following up on urgent issues
- Scheduling family assessments (or conducting a family assessment if the timing allows)

It is important to recognize that relatives of persons with serious psychiatric illnesses may exhibit many different types of responses to their ill family member and his/her mental health treatment; the family clinician will benefit from being prepared for this range of responses. Some relatives will have had positive relationships with the mental health treatment team as they seek treatment for the client; others may be very disappointed with the level of services available to their ill relative and be either angry or disengaged; still others will be struggling with so many other pressing issues in their lives (e.g., financial hardship, physical or psychiatric illness in him/herself or other family members, etc.) that it may be difficult for them to prioritize assisting the client. The family clinician must be able to adapt to all of these circumstances, with the goal of trying to solidify the collaboration among the client, the family, and the treatment team to lay the ground work for the subsequent recovery work.

The family clinician should utilize frequent summaries and restatements of each family member’s input. This technique both assures participants that they have been heard, and helps clarify the specifics of the participant’s comprehension of the situation. The family clinician should be especially alert to statements that are either consistent or inconsistent with the current biopsychosocial model of psychiatric illness. Some participants will be very sophisticated in their understanding of the illness, some will have a general lack of knowledge about the illness, and some will have ideas that are in direct contrast with current medical thinking about serious psychiatric illnesses (e.g., “some drug use is good because it helps relax the client,” or “the only thing that will help is prayer”). These are all important to note as this information will serve as the foundation for much of the later educational work.

### Addressing Immediate Pressing Concerns when Clients Enter the Program

Clients and relatives sometimes join the NAVIGATE program with urgent issues that must be addressed prior to starting the main components of the psychosocial interventions. Often these will be raised in early meetings with the project director/family clinician, perhaps before the family assessment even begins. Some of these needs may be one-time requests that are not very difficult to accomplish—a NAVIGATE client may, for example, need a letter from the team to obtain a medical withdrawal from the college semester or to request time off from work. Other issues may also be urgent, but likely require more intensive, ongoing intervention. For example, the NAVIGATE client may be threatening others living in the home or refusing to eat. When a more serious safety or risk issue is brought to the attention of the clinician, it is critical to first consider whether the problem is likely to be successfully managed at home, or whether a more supervised

setting (such as a hospital) is called for, at least in the short-term. If the team and NAVIGATE participants consider care at home the best option, then the problem can be prioritized for attention, even before the family education has begun.

During the engagement and assessment phase, the family clinician should confer with the other members of the team to determine if there are any concerns about urgent issues that must be addressed prior to beginning the formal family education. For example, the relatives may have let another team member know that the client is not sleeping or threatening family members. The family clinician must consolidate this information with the information gleaned in the assessments, and decide, with the team, if the problem is so urgent that immediate action is required and problem-solving cannot be deferred to work after the family education. Urgent problems might include any threat or use of violence, treatment non-adherence, or concerns about any behaviors that risk the client's or relatives' safety. If a problem is urgent, then the family clinician should schedule a meeting with the relatives (and client, if he/she is willing) to discuss the problem and begin to generate solutions with the participants. Note that it will likely take more than one session to address a serious problem, but that once an initial discussion is held, further attention to the issue can be given at the conclusion of each of the upcoming family education sessions.

### Treatment Planning for the Stabilization and Facilitating Recovery Phase

1. Treatment planning to address urgent problems the family has identified;
2. Considering ways the family's belief system about psychiatric illness may beneficially influence how the educational materials are delivered;
3. Recognizing family strengths that can be incorporated into the client's recovery plan; and
4. Beginning to identify families who may need a higher level of ongoing support and skills training subsequent to the educational sessions. Signs that a more intensive course of family work aimed at improving communication and problem-solving skills may be necessary include:
  5. The client not making progress towards goals;
  6. High levels of conflict in family; or
  7. The relative frequently initiating contact with the clinic with many concerns about treatment and/or the client.

Consistent problems in these areas would merit a referral to the more intensive MIST (Modified Intensive Skills Training) program.

### Stabilization and Facilitating Recovery Phase--Family Education about Psychosis

Until recently, many professionals provided minimal information to first episode psychosis clients about the nature of their psychiatric disorder, assuming they were either incapable or not interested in making informed decisions about the treatment of their own condition. Instead, most clients with psychosis were viewed as possessing limited insight and were relegated to the role of passive recipients of treatment. These assumptions have been challenged, and it is now widely recognized that clients are capable of learning more about their mental illnesses and assuming an active role in directing their recoveries. Furthermore, educating clients about their disorder respects the importance of allowing them to participate actively in shared decision-making about their own treatment, and this may avert non-adherence problems that arise out of resentment of an authoritarian medical approach.

## Principles of First Episode Psychosis Family Education

There are several fundamental principles of family education that serve to guide the family clinician. As long as the family clinician keeps these core principles in mind throughout the course of the educational intervention, he or she should be able to make progress toward the goals of education.

### 1. The Importance of Helping Participants Recognize the Psychiatric Disorder

The symptoms of most nonpsychiatric disorders (such as coughing, fever, or chest pains) are easily recognized as being due to physiological problems that are beyond the client's control. In contrast, psychiatric symptoms (e.g., depression, anxiety, social withdrawal) are less readily viewed as reflecting a "disorder" and are more likely assumed to be under the client's voluntary control.

One reason why relatives often believe clients have control over their psychiatric symptoms is that many symptoms are defined by the *absence* of particular behaviors or emotions (e.g., negative symptoms in schizophrenia, avoidance in anxiety disorders), rather than the conspicuous *presence* of other behaviors (e.g., bizarre behavior, responding to internal stimuli). It may be easier to believe that auditory hallucinations are due to a biological or cognitive problem than it is to believe that severe social withdrawal or apathy are part of a disorder.

A second reason why some psychiatric symptoms may be thought to be under voluntary control is that almost everyone has experienced at least mild levels of depression or anxiety with which they have successfully coped and not allowed to interfere much with day-to-day functioning. These experiences can lead to a false impression that psychiatric clients could recover from their problems if only they tried hard enough.

The goal of helping the family recognize the client's psychiatric disorder is achieved chiefly through providing information about the specific symptoms, the likely causes of the illness and the factors that improve or hinder recovery. At the same time, the client is encouraged to pursue his/her dreams, take responsibility in areas where this seems possible, and avoid assuming the "sick role" and diminishing expectations for a full life. Thus, improving coping, avoiding substance use, and using skills are all important concepts.

### 2. The Family Clinician Must be Knowledgeable about the Psychiatric Disorder

Clearly, if family clinicians are to succeed in educating individuals about psychosis, they must be sufficiently knowledgeable about it. Basic knowledge about psychosis includes an understanding of the diagnostic criteria and symptoms of the disorder, its prevalence and longitudinal course, effective psychiatric and psychological treatments, and theories regarding its etiology. Family clinicians must also be conversant with the details of likely long-term diagnoses of non-affective psychosis (i.e. schizophrenia, schizoaffective disorders, delusional disorder). While family clinicians are not expected to be accomplished researchers, the more they know about these disorders, the more comfortable they will be in the educational discussions. At a minimum, they should know more about the disorder than the participants and be at ease fielding questions about it.



Family clinicians cannot be expected to have expertise in every possible area. Rather, they must continually educate themselves as new science becomes available; similarly, family clinicians need not be able to answer every conceivable question raised by the participants but they should know how to find the answers to these questions through resources such as other professionals, books, or journals. In sum, the family clinician must possess an adequate body of knowledge about the disorder and understand how to utilize other resources when necessary in order to educate participants.

### 3. The Family Clinician Must Be Prepared to Address Questions About Changes in Diagnoses

Long term follow-up studies of individuals with a first episode of schizophrenia have shown that almost all individuals who meet criteria for a first episode of schizophrenia (as did approximately half of participants in the original RAISE-ETP study) also meet diagnostic criteria for schizophrenia years later. Individuals whose first psychotic episode had a diagnosis of a mood disorder psychosis or substance induced psychosis sometimes have the same disorder on long-term follow-up but are more likely than individuals with first episode schizophrenia to change diagnostic groups over time. These data are based upon careful assessment of diagnoses performed in research studies.

What causes diagnoses to change over time? There are 3 major causes that family clinicians should be aware of. First, unfortunately, is that the diagnosis done at baseline was not correct. Individuals with first episode psychosis usually do not have prior treatment records to provide information about the history of symptoms. To get the information to make an accurate diagnosis usually requires interviewing the individual but also other sources of information such as family members. The family clinician can help with this information gathering.

If the initial diagnosis was correct, there are two major causes for diagnostic change over time. Modern diagnostic systems determine diagnosis based upon the symptoms that are present and also on the time course of the symptoms. The time course includes how long a particular symptom lasts and also how symptoms overlap (e.g. if an individual has both depressed mood and hallucinations whether these two symptoms always occur at the same time or if one has occurred in the absence of the other). One cause of change in diagnosis is simply that symptoms last for a longer time. *Schizophreniform disorder* and *schizophrenia* have the same types of symptoms but individuals with schizophreniform disorder have had symptoms for less than 6 months and individuals with schizophrenia symptoms for longer than that. The second cause is that the symptoms present change over time or the temporal relationships of symptoms change over time. For example, an individual may have a history of manic symptoms and also hallucinations. During the first episode of illness these all occur at the same time and the initial diagnosis is bipolar disorder. Later, the individual may still has manic symptoms and hallucinations but they have hallucinations at times when they do not have manic symptoms and the diagnosis changes to schizoaffective disorder.

Diagnosis can be a complex topic, especially with individuals with first episode psychosis. Each NAVIGATE team has a team member (or members) with training in diagnosis who can assist in clarifying the diagnosis for an individual.

#### 4. Information is Presented in an Honest, Direct Manner

Family clinicians sometimes feel uncomfortable when talking with a client and his/her relatives about the client's disorder, especially if it is a serious mental illness like schizophrenia or schizoaffective disorder. All too often, professionals have worked with individuals with multi-episode psychosis and are keenly aware of their own limits in treating serious mental illness, and they recognize the difficult and long struggle many clients and relatives will face. Nobody likes to be the bearer of bad news. An understandable response of some professionals is to "protect" these participants from what they perceive to be potentially upsetting information about the client's condition. This occurs particularly in first episode psychosis, when there may still be some doubt about the accuracy of the client's diagnosis and the client and relatives may seem overwhelmed and/or fragile.

The common, but often erroneous, assumption is that clients and relatives will always be shocked and dismayed to learn the client has a specific psychiatric disorder like schizophrenia or schizoaffective disorder. The opposite is often true. Participants frequently express gratitude to professionals who are direct in educating them about their disorder, even when it is a serious one. A vital principle of education is that the family clinician always strives to provide participants directly and honestly with the most accurate facts available about the disorder, while never deliberately withholding information. Through direct communication about the client's disorder, the family clinician creates a supportive and collaborative working relationship with the whole family that will endure throughout the course of therapy.

#### 5. Avoid Making Assumptions about Participants' Beliefs

Clients and relatives come to the experience of a psychosis with a whole life history learning about psychiatric illness through the media, their social networks, and (possibly) personal experiences. The family clinician can have no way in advance of knowing what beliefs participants are bringing to the work. Religious beliefs may color how individuals conceptualize the illness, and even medical and mental health professionals may have ideas that are inconsistent with optimal recovery strategies as supported by scientific research. Thus, the family clinician should not make any assumptions about a shared knowledge and attitude base among participants. Rather, he/she should always ask questions to discern how the participants understand topics prior to presenting the materials in the educational handouts outlined below, and may have to tailor discussions to accommodate unusual beliefs. This is why conducting an initial assessment with each family member is so vital.

#### 6. Education is Interactive

The family clinician cannot rely solely on didactic teaching methods, but must make the educational sessions as interactive as possible. Successful educational sessions require that the family clinician continually elicit the client's experiences with the disorder as well as the family's experience of the disorder through observation and interaction with the client. The family clinician must probe the participants regarding their knowledge about educational topics to be covered, including what they've "heard" about the disorder (e.g. myths, readings they've done, things they have seen on the internet or in movies).

The clinician should "check-in" with participants throughout the sessions regarding the

information presented and the pace of the presentation. Clinician stories and experiences can be invaluable in making critical educational points. The family clinician should ask questions to elicit the participants' understanding of the material that has been presented. In fact, discussion questions are included throughout all the educational handouts. By adopting an interactive approach to education, the family clinician is able to evaluate the participants' acquisition of basic information about the disorder, identify any misinformation they hold about the disorder, and to pace the presentation of new material accordingly. Furthermore, by continually seeking feedback and input, the family clinician avoids the pitfalls of overloading participants with information, resulting in boredom and disengagement.

## 7. The Causes of Psychosis and Disorders on the Schizophrenia Spectrum are Complex

When people think about causes of illnesses, they often think about a single cause, which often may be genetic. For example, people who have a certain abnormality in their genes will all get Huntington's disease and all they need to have to get the illness is to have that genetic abnormality. However, most illnesses do not follow that pattern --instead they have complex causes. One common description of causes is called the *gene-environmental interaction* which means that one's genetic background interacts with things that happen in the environment to either cause or protect one from a disease or modify the course of the disease. For example, some people have a genetic predisposition to heart disease but whether they get heart disease is the result of their genetic factors (biology they were born with) interacting with environmental factors across their lifetime such as diet, exercise and whether they smoke tobacco. For both schizophrenia and bipolar disorder, our current understanding is that the genetic disposition for each consists of many different genes that increase the risk of getting the disorder but each gene by itself contributing only a very little additional risk.

In addition to this genetic contribution there are other factors. For example, we know that *certain characteristics of society*—poverty, membership in some (but not all) immigrant groups and ethnicities, urbanization—all appear to increase the risk of schizophrenia (Morgan & 2010; Pérez-Álvarez et al, 2016). These are sometimes called “social determinants” of health. Similarly, we know that *certain personal experiences*, including negative childhood events and lifetime trauma exposure, as well as substance use, also are associated with increased risk of psychosis and schizophrenia (Bentall et al, 2012; Hunt et al, 2018). It is important to emphasize that we are describing risk factors and there are many individuals who experience these circumstances and *do not* develop a psychiatric disorder.

Scientists have devoted their lifetimes to understanding the etiology of schizophrenia, and though we know more than we did, as clinicians we are still limited when someone asks “Why did this happen to me?” or “Why did this happen to my loved one?” Careful research has provided us with many documented risk factors for psychosis, which we can share with NAVIGATE participants, but how these factors interact within a particular individual to create psychosis, and more long-term schizophrenia, cannot be determined at the present time.

## **Format of Educational Sessions in NAVIGATE**

### **Scheduling**

Sessions should be scheduled weekly or every other week, depending on the availability of the family. A routine schedule is optimal. We anticipate sessions will be 50-60 minutes in length. As noted earlier, it is up to the client, but it is very advantageous for the client to attend some or all of the sessions. For this reason, be cautious about scheduling IRT and Family sessions at the exact same time, which would almost guarantee that the client does not attend family sessions. To optimize the chance that clients will attend at least some family sessions, teams can schedule the IRT sessions and family sessions right after each other or they can schedule the IRT sessions and family sessions on alternate weeks.

### **Topics Covered**

All participants should cover 10 topics—typically session per topic, with extra sessions scheduled for ones that need more emphasis. The ten basic topics are:

- Psychosis
- Medication
- Coping with Stress
- Basic Facts about Alcohol and Drugs
- Healthy Lifestyles
- Facts about Developing Resilience
- Effective Communication
- Developing a Plan for Staying
- Developing a Collaboration with Mental Health Professionals
- A Relative's Guide to Supporting Recovery from Psychosis

### **Session Format**

Sessions can be held in the clinic or at the family's home, depending on clinic resources and family preferences. Even one home visit can aid in engagement and be very informative for the clinician. All the educational sessions follow an agenda based on curriculum that has been prepared in advance, with the pace of teaching tailored to the individual needs of the client and relatives. The agenda involves:

- Greeting participants
- Setting the session agenda
- Asking about urgent issues
- Inquiring about client status (medications, attendance at IRT and SEE, symptoms)
- Following up on out-of-session assignments
- Introducing and teaching new topics
- Developing an out-of-session assignment (if appropriate)
- Problem-solving about other issues if needed

Sessions are usually 50 minutes give or take, depending on content and family involvement. The information can be summarized using visual aids, such as blackboards, whiteboards, as well as the handouts. The teaching format resembles a cross between a classroom, with the family clinician assuming the role of the teacher, and a discussion, with the family clinician acting as a facilitator. The conversation is guided by the family clinician so as to cover the curriculum as planned, while soliciting the experiences and understanding of participants, their comments and questions, throughout the session.

In the educational sessions, the family clinician first provides a brief overview of the material to be covered that day. An interactive discussion centered on that topic follows, with an emphasis on helping the participants comprehend how the information applies to them. Handouts on the topic being covered are provided for all participants during the session, and they are encouraged to review them again prior to the next session. Non-urgent problems can be deferred to the end of the session, as can following up on problems identified in earlier sessions.

### Review Questions

One strategy for helping participants actively process educational information they have learned is for the family clinician to ask open-ended review questions after each topic area has been covered. These questions also provide valuable information to the family clinician about what the participant has learned and in which areas the client needs further education. A convenient time to ask these questions is at the conclusion of a topic or at the beginning of a session in which a new educational topic will be taught. The *Clinical Guidelines* for each topic area include review questions that can be used.

### Use of Educational Handouts

There are two basic approaches to the use of educational handouts in sessions devoted to teaching clients and families about a psychiatric disorder. One strategy is for the family clinician to give an educational handout to participants at the beginning of the session and have them read it (taking turns is fine) as the family clinician reviews and elaborates on the material. This method is best when the family clinician does not use other visual aids to summarize the material during the

session (e.g., blackboard), and when the participants have good reading skills. A second method is for the family clinician to give the participants the handout at the end of the session and request that they review it as a homework assignment. This approach is preferable when the family clinician uses a blackboard during the session, as the handouts can be distracting, or when only some family members read well. The family clinician can use either format, as tailored to the needs of the individual participants.

Each topic has a handout for participants and a clinical guideline handout that directs the family clinician to key points in the relevant handout. *Whenever you give resources to families, whether they are core NAVIGATE materials or supplements you find on the internet, always check in after they have looked at them to be sure they have understood them in the way you intended.*

### Session Materials

Prior to the session, the therapist should assure that all materials for the sessions are available—session materials (manual and *Clinical Guidelines* for the family clinician and a copy of the appropriate handouts for each participant), paper and pens/pencils, markers if a white board is being used. In addition, prior to the first session, a folder or binder should be prepared for the family in which they can keep the educational handouts. The family is encouraged to bring the folder or binder to each session. *The clinician should make a copy of all completed forms and worksheets for his/her records and later review.*

### Complete Content Mastery is not required before Moving to the Next Topic

The content of each session is not necessarily fully assimilated by participants prior to moving on to the next topic. Therefore, it is often necessary to continue to look for opportunities to review previously-covered material when new topics are being discussed. For example, clients with substance use difficulties may improve by using the NAVIGATE substance use material in the IRT and family manual, but nevertheless still be at high risk for relapsing back into using substances following completion of the educational work. In subsequent meetings during the consultation and monthly-check-ins, it is important routinely to check in briefly about the client's substance use, his or her plan for staying well, and any other related issues that may need attention, such as symptoms or circumstances that precipitate use. Similarly, if during a consultation session a relative starts complaining about how "lazy" or "unmotivated" a person in NAVIGATE is, it may be a good time to review the initial "Just the Facts-Psychosis" hand-out to highlight the impact of negative symptoms.

### Education with Symptomatic Clients

Three kinds of client circumstances can make education especially challenging—when clients are too symptomatic to participate effectively in sessions, when clients are very withdrawn and uncommunicative, and/or when they are reluctant to report they have any problems. These situations are quite common in the early phases of first episode psychosis.

In terms of addressing the needs of participants who have a hard time participating because they are still agitated or confused, a number of strategies can be employed. Session length can be abbreviated, frequent (but simple) questions can be directed to the client to keep him/her on course, the family clinician can sit next to the client to orient him or her to what is on the board or

written materials, and clients can be given permission to leave the session early or take a brief break if they wish. In the most severe cases, the initiation of the course of educational sessions can be deferred for a few weeks to see if the client becomes more able to concentrate.

It can also be challenging to work with clients who are very withdrawn and appear to have little to say. Often, this lack of speech may reflect preoccupation with internal stimuli—listening to voices, for example—or the slowed thinking and speech more typical of cognitive difficulties or negative symptoms. When conducting educational sessions with a person with this pattern of speech, it may be very hard to draw the client out and obtain his/her thoughts on the topic being discussed. Here, it is imperative that the family clinician slow the conversation down. Sitting close but across from the client so eye contact can be good may also help facilitate conversation.

When clients are withdrawn or seem to have little to say, the family clinician should direct occasional questions or comments to the client, and then be prepared for a period of silence while the client organizes his/her thoughts to respond. It is sometimes tempting for the clinician or another family member to “fill in the gap” rather than wait for the person in NAVIGATE to speak, but it is very important to provide enough space and time that for the client to provide his/her input on the topic at hand. Sometimes clients are confused or frustrated by their own lack of thoughts and get in the habit of responding quickly and almost automatically with “I don’t know” after almost any question is asked of them. The family clinician should try to get past the “I don’t know” by encouraging a guess, or telling the client to take his/her time, or asking how others might answer the question. The goal here is to give the client the chance to begin to speak his/her own mind, even if it is hard, and to model ways the relatives can do this at home.

Some clients, especially when they are symptomatic, state they do not have a mental health diagnosis. In light of the variable interpretations of unusual beliefs and percepts, cognitive limitations imposed by psychosis and the stigma associated with having a psychiatric illness, this is not surprising. There is little value in trying to persuade these clients of their specific diagnosis as this often only agitates them and erodes the therapeutic alliance. Instead, the family clinician should be curious about how the client understands his/her experience, and spend some time inquiring about this. Often, the client will provide valuable information which can be used to tailor the NAVIGATE interventions to his/her specific views and beliefs. Depending on the circumstances, the clinician has three main options:

1. Many clients will acknowledge they are having “problems,” “difficulties,” or “emotional problems” or “some strange experiences” even if they deny they have psychosis. In such cases, the family clinician can mirror this language when talking about the specific client’s experience and talk more generally about “people who have had psychosis,” not emphasizing that the client has psychosis himself or herself, when conducting the education sessions or using the handouts. If the client reiterates that he/she has problems, but does not have psychosis, the family clinician can say, “We are talking about people who have problems like those you have experienced.” Although this may seem awkward, this strategy actually works in many cases.
2. If the client is insistent that he/she does not have any problems, the family clinician can still offer an abbreviated education component, emphasizing the factors that we understand promote recovery, while continuing to shore up the alliance with the client and his/her loved ones. Topics covered might include:

- Positive recovery stories
- The importance of continuing to stay productive but not to be overwhelmed
- The value of positive family support, and the problems associated with too much nagging and prompting
- The benefits of staying in treatment
- The value of socialization
- The risks of substance use
- The importance of caring for physical health

Here, use of the “Facts about Psychosis” and medication information handouts would be deferred if the client is attending the family sessions. These can be revisited if/when the client seems more open to them.

3. The client may agree to his or her family participating in family education, but may decline to attend himself or herself. Here, the family clinician proceeds with the material as planned and has an “open door” policy for the client. It is helpful to revisit the subject of the client participating, because he or she often changes her mind further in treatment.

### Treatment Planning and the Consolidating Gains Phase

When the initial core of educational handouts has been covered, the family clinician will have a great deal of information about the client and his/her relatives, including the client’s progress on goals and level of program participation, client and family strengths, levels of family conflict, and issues that may interfere with ongoing recovery. Prior to beginning the “Consolidating Gains” phase 3, the family clinician integrates the information learned so far with two objectives 1) treatment planning to address problems the family has identified for which they need help—services may be provided by the family clinician or other members of the team as appropriate and 2) developing a recommended treatment plan for subsequent family work.

Many families will only require a modest level of services from this point, which would typically include monthly contact (“monthly check-ins”) with the treatment team (in person or by phone), invitations to every 6-month treatment team meetings, and “as needed” consultation meetings as problems arise. However, a subset of families will likely benefit from more intensive work, such as modified behavioral family therapy (including Modified Intensive Skills Training, or MIST, which is described later in this manual) or a referral for some other kind of services for a serious family problem (e.g. depression in a relative, domestic violence not related to symptoms, long-standing family tensions or conflict). Indicators of a need for a more intensive level of services include:

- Client not making progress on goals
- High levels of conflict in family



- Relative initiating frequent contact with clinic with many concerns about treatment and/or the client
- Continuing high levels of client symptoms or social dysfunction

In considering whether to recommend a more intensive family program for these families, the family clinician should also take into account 1) family attendance and motivation during the educational sessions and 2) whether the indicators for a need for intensive services reflects an illness management problem or another problem which might be handled through another resource. If the problem seems illness related and the family has been attending sessions, then a recommendation for a course of MIST is made. If the problem seems more related to a non-illness issue, the family can be referred to other resources for appropriate assistance.

### Consolidating Gains Phase

By this point in the NAVIGATE program, the client will have been working with the treatment team for four-six months, and the family clinician will have had time to learn which of the relapse risk factors are impinging on the client, and which protective factors are in place. The client is typically now participating actively in the IRT program and the situation is beginning to improve. At this point, the primary family work goals are to:

- Incorporate knowledge into every day practice
- Support the client's participation in the IRT program
- Monitor relapse risk
- Develop realistic expectations for the client's short-term functioning

The family clinician will be learning of the client's progress through the IRT program staff, as well as having informal contact with the client, and will be making ongoing assessments on how well these objectives are being met.

If the situation is stable, the client is progressing and engaged in treatment, family conflict is moderate to low, and the relatives do not seem highly stressed, the family is offered a moderately intensive family intervention with all of the following components, which are discussed more fully below:

1. Formal monthly contact (monthly check-ins) with the family clinician, either through clinic meetings or planned phone calls; typically, these sessions are conducted face-to-face during the first year of participation in NAVIGATE, and then they can be moved to phone contact for the length of the client's participation in the NAVIGATE program.
2. Invitations to the treatment team review meetings every 6 months for the client throughout the client's participation in the NAVIGATE program.

3. Encouragement to act as natural support persons for clients as they move through IRT and SEE.
4. Brief focused family consultation on an as needed basis throughout length of the client's participation in the NAVIGATE program.

If the situation is unstable, the client is not progressing and/or not engaged in treatment, and/or family conflict is high, the family clinician can recommend a course of modified behavioral family therapy, as taught in Mueser and Glynn (Mueser and Glynn 1999).<sup>1</sup> The treatment includes five phases—(engagement, assessment, education, communication skills training, and problem-solving instruction). In NAVIGATE, the treatment is referred to as Modified Intensive Skills Training (MIST) and requires an additional six months or so past the core NAVIGATE education. Note that families who have already completed the NAVIGATE family education sessions have already received engagement and education and do not need to repeat this; rather, families are offered supplemental communication and problem-solving skills training. Families offered the behavioral family therapy will also be invited to the treatment team meetings held every six months, concurrent with the behavioral family therapy, and will be offered family consultation meetings and discharge planning as discussed in the prolonged recovery phase after termination of the behavioral family therapy.

### Monthly Check-Ins with the Family

It is critical for the client, relatives, and the treatment team to continue to be able to share information. Planned monthly contacts with the family are a forum for this information sharing, as well as providing an opportunity to see how the family is faring. It is preferable for the meetings to be held face-to-face during the first year, with both the relatives and the client participating; however, it is preferable to have the meeting on the phone rather than missing it for a month. After the first year, if the client is doing well, phone check-ins may suffice. Participants should be contacted two days in advance to remind them of the face-to-face meetings. Typical monthly contact meetings would last for 30-45 minutes. As the participants raise issues, the family clinician reviews educational material, gives advice and guidance, or problem-solves to resolve concerns. The family clinician also reminds families, as appropriate, that as clients progress through NAVIGATE, discharge to other treatment is a typical outcome and keeps the long-term focus on moving towards the client and family being as fully integrated into the community as much as possible.

### Invitations to Join Every 6 Month Treatment Team Meetings

Every NAVIGATE client has a full treatment team progress review at least every 6 months. Both the client and relatives are invited to be part of the meeting, provided the client has consented to family involvement in care. The family clinician invites the family to attend during the family meeting prior to the team meeting, and endeavors to schedule the meetings at a time convenient for the family. He/she follows up with a reminder phone call two days before the meeting.

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<sup>1</sup> As behavioral family therapy is fully manualized in the Mueser and Glynn book, it will not be included in this manual, but instead the Mueser and Glynn text will be used as a supplement when needed.

## Encouragement to Act as Supporter for the Client's Participation in IRT and SEE

Generalization of skills is a critical element of the IRT program and one method to promote generalization is to have persons in the client's natural social network be available to practice skills and support their use in the client's everyday life. Relatives can be excellent support persons for the IRT program and the family clinician looks for opportunities to encourage their involvement whenever possible. Similarly, relatives can play a critical role in the client's interest and success at work or school. For example, relatives who are interested in helping support the client's goals by discussing barriers to work or school (e.g. transportation problems, fatigue, etc.) and problem solving them can "make or break" work experiences.

### Brief Focused Family Consultation

During the consolidating gains phase of the NAVIGATE family program, most of the contact between the relatives and the family clinician will occur during the monthly check-in meetings. While many problems and issues can be resolved during these sessions, some problems may require more extended effort to address successfully. Examples of these kinds of issues might include managing an incident of aggression in the home; the client's ongoing problems with substance use; or helping the client prepare to go back to a school in a different state.

When the family clinician becomes aware of important issues, he/she can offer the family a series of meetings wherein he/she can consult with the client and relatives about how to address the issue. These should not be conceptualized as traditional "family therapy" sessions because the family clinician is serving primarily as a consultant and resource to the family. Typically, one to three 45-minute sessions are scheduled over a month's time, with both the family clinician and family members assigned specified homework between sessions to progress on the problem. Families can access multiple courses of family consultation during their participation in the NAVIGATE family program on an as needed basis. They can either request the consultation or a member of the treatment team can suggest it might be useful.

Many families find that working to solve problems *in a systematic way* can lead to better outcomes. Families can learn to use a specific set of strategies to resolve problems and meet goals effectively. In the NAVIGATE family program, we often use this strategy as the foundation of family consultations. Two strategies are available to the clinician—problem-solving or decisional balances. Some situations are *problems to be solved* while some situations involve *making a decision* rather than solving a problem. These are presented in the Appendix.

Families often find that following a specific structure for solving a problem can help to organize the members and keep them focused on the problem at hand. The family clinician helps organize the family and structure the discussion to follow the steps of problem-solving using the consultation handout that is part of the NAVIGATE family materials. Using these steps had been shown to increase the likelihood that successful solutions will be found. The structured approach to solving problems in NAVIGATE follows six steps. The clinician works with family members and focuses on one step at a time.

The six steps are as follows:

- Discuss the problem or goal.
- Brainstorm at least three possible solutions.
- Briefly evaluate each solution.
- Choose the best solution.
- Plan the implementation.
- Review the implementation at the next consultation meeting; modify as needed.

Sometimes people are faced with complex situations that do not immediately lend themselves to the steps of problem solving. They require that a preliminary decision or choice be made before the initiation of problem solving. Typically, such decisions involve major lifestyle changes, such as whether the person in NAVIGATE should continue to live at home, enroll in school, begin using alcohol again, or tell friends about his/her recent problems with psychosis. To help make these difficult decisions, the clinician can introduce the task of conducting a *decisional balance*.

A decisional balance involves learning steps similar to problem solving, including: (1) define the decision to be made; (2) generate a list of the advantages and disadvantages of one decision, and the advantages and disadvantages of another decision; (3) discuss the relative advantages and disadvantages; (4) select the best choice; (5) plan on how to implement the decision; and (6) follow up the plan at a later time. Everyone in the consultation should help give ideas for the decisional balance. Once a course of action has been chosen, a variety of problems or goals can often be identified, to be worked on one at a time, using the problem-solving strategy discussed above.

### Treatment Planning for the Prolonged Recovery Phase of Family Work in NAVIGATE

Clients often stay in the consolidating gains phase until a plan is made for their discharge from NAVIGATE, based on their overall level of improvement. This referral will typically be either to regular clinic care, to other community resources, or to the client's choice of prescriber. It should be noted that some participants will have improved so much that they no longer need specialty mental health care. A discharge plan is developed with the treatment team, client and family and then details reviewed in at least two consecutive meetings in the prolonged recovery phase.

### Prolonged Recovery

Clients may be offered NAVIGATE for a number of years, depending on their sites, and the family will continue with monthly check-ins, invitations to treatment team meetings, and the availability of consultation during this period; typically, after the first year, most family contacts will be by phone, but the option for face-to-face meetings remains. A critical aspect of NAVIGATE is information sharing (with appropriate consents) among the client, relatives, and treatment team, all with an eye to supporting the client's recovery and reducing the family's burden. Many clients will

make sufficient improvements in NAVIGATE and will transition out of the program at some point. The timing and transition will be a result of shared decision-making among all the relevant participants. At the point of transition, the family clinician plans at least two conjoint discharge sessions with the client and relatives. The goals of these sessions are to review progress made in the program, review and refine the discharge plan, and to make referrals to any additional resources needed by the family. These sessions can replace the monthly meetings.

### Treatment Planning Between the Two Discharge Planning Sessions

The family clinician reports to the team about any issues that arose as part of the first meeting and investigates referrals for any resources requested by the family.

### Family Education Contact Sheets and Fidelity

Many NAVIGATE sites like to monitor Family Education activities to assure the manual is being followed. Each session can be documented using the “Family Education Contact Sheet” (see Appendix). The purpose of the contact sheet is to help family clinicians and supervisors keep track of the participant’s progress in treatment, the educational materials covered, the kinds of interventions that are provided (motivational, educational, or cognitive-behavioral), and whether or not the participants are completing home practice assignments. A review of the relevant sheet can also help clinicians remember the key components of each session. On site-supervisors may also find it useful to sit in on an occasional session or to listen to recordings of the family sessions and provide feedback to clinicians on their adherence to the treatment model. This topic is discussed in greater detail in the *Assessing Provider Competence and Fidelity to the Model* chapter in this manual.

## **A Word about Cognitive Adaptation Training**

Cognitive Adaptation Training (CAT) is an intervention that is offered to NAVIGATE Teams which are members of the ESPRITO (Early-Phase Schizophrenia Practice-Based Research to Improve Treatment Outcomes) network. If your NAVIGATE team is part of the ESPRITO Network, please read the following information about CAT.

Cognitive Adaptation Training (CAT) was developed by Dr. Dawn Velligan and her colleagues (Velligan et al., 2008). CAT is a structured approach to compensate for cognitive deficits a client may have by implementing environmental cues and use of reminder tools that can prompt desired behaviors. CAT is typically delivered at a client’s home or in the workplace by a specialist trained in the model. Typically, the clients referred to CAT are struggling to meet their recovery goals. For example, one client had so much trouble deciding what to wear in the morning and took so much time getting ready that she was always late leaving the house. She frequently missed the first part of her college classes, and her grades were dropping. The CAT specialist helped the client organize her closet and make-up so that everything that matched was close to each other, making it easier for the client to get ready in the morning. Another client who worked as a dishwasher at a nursing home had difficulty remembering the specific steps of his job. Because this was a medical facility, there was a precise way he was supposed to sanitize the pots and pans and dishes, and he had a hard time getting the procedures done in order. His job was in jeopardy. The CAT specialist, working with the SEE provider, got permission to go into the workplace and watch how

the job was supposed to be done. She then developed a poster with the steps in order, had it laminated, and placed it right over the sink where the client in NAVIGATE could refer to it. Slowly, with prompting by the SEE specialist, the client learned the steps of the job and started getting better feedback from his manager.

Since much of CAT is done in the home, it will be very important for relatives who live with their loved one in NAVIGATE to be comfortable with the CAT specialist making visits to the residence. The CAT specialist on the team will usually not be the family clinician, but the family clinicians can be encouraging and help inform the relatives about CAT if it is offered to their loved ones, answer questions from relatives about CAT as they are able, and help connect the CAT Specialist with the relatives if they need more information.

## **Organization of the NAVIGATE Family Manual**

After this introduction, this manual is organized by section, with most sections beginning with *Clinical Guidelines* for the clinician followed by participant educational handouts suitable for the section. The *Clinical Guidelines* outline the goals of the sessions, the content, and strategies for troubleshooting implementation challenges, while the handouts are used to convey the critical information in educational and consultation sessions. There are no specific participant handouts for the monthly follow-up meetings, the work in MIST, or the discharge meetings, but there is text in the manual to guide these sessions. There is an appendix with helpful forms and information on promoting provider adherence and fidelity to the module.