

# **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.

## **Authorship of all Manuals for the NAVIGATE Program for First Episode Psychosis**

### **Psychopharmacological Treatment Manual (now entitled “The Quick Guide to NAVIGATE Psychopharmacological Treatment”)**

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### **Director Manual**

The original manual was written by Jean Addington. The author of the revision of 2020 is Susan Gingerich.

### **Individual Resiliency Training (IRT) Manual**

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### **Family Education (FE) Manual**

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### **NAVIGATE Team Members’ Guide**

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# Family Education Program

## Family Manual

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# 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.



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# **Clinical Guidelines for the Engagement, Orientation, and Assessment Phase of Family Education**

# Clinical Guidelines for the Engagement Phase

## Goals

1. Help participants feel comfortable with the NAVIGATE Team approach and staff.
2. Explain the components of NAVIGATE.
3. Answer any participant questions.
4. Schedule the first NAVIGATE family education orientation session, which might include subsequent assessment if there is time.

## Materials Needed

Family Introduction to the NAVIGATE Program

## SESSION STRUCTURE:

- Informal socializing and introductions
- Introduce NAVIGATE program—explain philosophy and components
- Answer any questions
- Problem solve participation obstacles
- Introduce participants to any NAVIGATE staff they have not met
- Set time and date for next meeting--may include scheduling for family assessments

## GENERAL INTERVENTION STRATEGIES:

- The primary goal of this phase is to make participants feel comfortable with the team and to establish an optimistic mindset, emphasizing coping skill development, resiliency and recovery.
- Set a positive tone, give lots of praise and use humor when possible.
- Ask more questions than you make statements; when focusing on educating, introduce topics by asking participants what they know about the topic and use frequent summaries of what participants have said.

- When discussing a given topic (e.g., auditory hallucinations; depression), ask the participants to give concrete examples, which will help them to better remember the concept.
- When there are multiple participants, make sure all get a chance to talk.
- Be prepared for a range of emotions as the information is explored. Concerns and anxiety about the causes of the illness as well as the future are to be expected. Relatives (especially parents) may also express guilt over some perceived responsibility for the development of the illness.
- Keep conflict during the meetings to a minimum. Do not hesitate to be very active in reducing conflict—strategies to reduce conflict include:
  - Highlighting members’ strengths and similarities in participants’ positions.
  - Encouraging family members to treat each other with respect.
  - Having participants talk directly to the therapist and not to each other during conflict.
  - Reminding family members that conflict tends to make symptoms worse.
  - Helping people “agree to disagree” on less critical points.
  - Take a short break (5 mins) in sessions so participants can compose themselves (get a drink of water; get a breath of fresh air, etc.).
  - Schedule shorter sessions if conflict is ongoing and consider moving training on communication skills earlier.
  - Confer with the IRT clinician frequently so that everyone is on the same page about how information is being conveyed; attending team meetings is essential.

## **GENERAL INSTRUCTIONS FOR THE HANDOUT:**

- Review the *Family Introduction to the NAVIGATE Program* handout; summarize each point on each sheet and ask if participants have questions.

# Clinical Guidelines for the Family Orientation and Assessment Phase

## Goals

1. Explain the format of the family education component of NAVIGATE
2. Collect any consents needed for treatment and including relatives in sessions.
3. Review issues about mandated reporting.
4. Review the Tip Sheet for Helping Persons in NAVIGATE
5. Give participants the “Sam’s Story” or “Taavi’s Story” handout
6. Elicit information on the participants’ understanding of symptoms, causes, course, medications, and the impact of stress on the client’s life.
7. Schedule the first NAVIGATE family educational meeting.

## Materials Needed

1. Family Education Orientation Sheet
2. Tip Sheet for Helping Persons in NAVIGATE who are Experiencing High Levels of Distress
3. Any necessary consent forms from your agency
4. *Sam’s Story* or *Taavi’s Story* handout
5. Staff contact info and emergency phone numbers (this handout should be written by the NAVIGATE team and copied for participants)
6. NAVIGATE *Family Member Interview* (copy one per person and plan to schedule individual interview times)

## SESSION STRUCTURE:

- Informal socializing and introductions
- Introduce the Family Education portion of the NAVIGATE program
- Problem solve participation obstacles
- Review guidelines on confidentiality and mandated reporting
- Review Tip sheet
- Conduct assessment or schedule for it—more than one session may be necessary if there are multiple relative participants (some clients and their relatives can do interviews the

same day as the orientation; most will need additional times set up for this purpose)

- Give participants a copy of “Sam’s Story” or "Taavi's Story" to read either for homework or while waiting for assessments. Only one needs to be assigned; choose the unique story that will best match the concerns of the specific participants.
- Set time and date for next meeting

## **GENERAL INTERVENTION STRATEGIES:**

- The primary goal of this phase is to help participants understand the NAVIGATE Family education program and for you to get to know them better.
- Set a positive tone, give lots of praise and use humor when possible.
- Ask more questions than you make statements; use frequent summaries of what participants have said.
- When discussing a given topic (e.g., auditory hallucinations; depression), ask the participants to give concrete examples, which will help them to better remember the concept.
- When there are multiple participants, make sure all get a chance to talk.
- Be prepared for a range of emotions when information is explored. Concerns and anxiety about the causes of the illness as well as the future are to be expected. Relatives (especially parents) may also express guilt over some perceived responsibility for the development of the illness.
- Keep conflict during the meetings to a minimum. Do not hesitate to be very active in reducing conflict—strategies to reduce conflict include:
  - Highlighting members’ strengths and similarities in participants’ positions.
  - Encouraging family members to treat each other with respect.
  - Reminding family members that conflict tends to make symptoms worse.
  - Encourage family members to talk to therapist rather than each other during times of stress in the session.
  - Helping people “agree to disagree” on less critical points.
  - Take a short break (5 mins) in sessions so participants can compose themselves (get a drink of water, get a breath of fresh air, etc.).

- Schedule shorter sessions if conflict is ongoing and consider moving training on communication skills earlier.
- Confer with the IRT clinician frequently so that everyone is on the same page about how information is being conveyed; attending team meetings is essential.

## **GENERAL INSTRUCTIONS FOR THE HANDOUTS:**

- Review the orientation and Tip sheet; summarize each point on each sheet and ask if participants have questions.
- Give each person a copy to take home.
- Conduct an individual interview with each family member, including the client, using the Family Member Interview form; be flexible in scheduling.
- Give participants a copy of “Sam’s Story” or “Taavi’s Story” to read either for homework or while waiting for assessments. Only one needs to be assigned; choose the story that will best match the concerns of the participants.
- Provide participants with staff contact information and emergency phone number (note that this should be prepared in advance by the NAVIGATE team).



# Clinical Guidelines for the Orientation to Family Education

Providing information to families and other supporters so they can assist in recovery from psychosis is a critical aspect of NAVIGATE. Family participation in NAVIGATE should be discussed with all participants in NAVIGATE. Approximately half of the participants in NAVIGATE are likely to participate in joint educational sessions with their relatives and supporters. Some of the other half of the NAVIGATE participants will agree to their relatives' participating in educational sessions, but will not attend the sessions. These clients will receive the basic educational materials in IRT sessions. Typically, the first formal family educational session will begin with a review of the "Introduction to the Just the Facts" handout and then move to the first specific topic "Just the Facts-Psychosis"

## Goals

1. Elicit information on the participants' understanding of symptoms, causes, course, medications, and the impact of stress on the client's life.
2. Provide education that addresses gaps in the participants' knowledge about psychosis, treatment, substance use, strategies to cope with stress, and the role of the family in recovery.
3. Imbue hope.
4. Help participants recognize signs of the psychiatric disorder.
5. Reduce negative emotions in family members.
6. Enlist family members' cooperation with the treatment plan.
7. Facilitate participants' ability to monitor the disorder.

## \*Handouts- Just the Facts

Introductory Handout: "Introduction to Just the Facts Sessions"

1. Psychosis
2. Medications for Psychosis
3. Coping with Stress
4. Basic Facts about Alcohol and Drugs
5. Healthy Lifestyles
6. Strategies to Build Resilience
7. Effective Communication
8. Developing a Plan to Stay Well
9. Developing Collaboration with Mental Health Professionals
10. A Relative's Guide to Supporting Recovery from Psychosis

\* Each Handout takes at least one session to complete; some require two. There is a separate clinical guideline for each handout.

### Bring to every NAVIGATE session

- A copy of all the educational hand-outs so you can review if a topic comes up unexpectedly
- A copy of the completed *Plan to Stay Well* sheet (once it is completed)
- Blank copies of the problem-solving and decisional balance sheets to address unexpected issues
- Copies of all the problem-solving sheets the family has completed (make sure you copy before they leave each session)
- A flip chart and writing utensils

### SESSION STRUCTURE:

- Informal socializing and identification of any major problems.
- Set the agenda.
- Review the previous session. Use the questions at the end of each clinical guideline at the beginning of the next session to be sure the material was clear.
- Discuss/review the home practice assignment. Typically, this would include reviewing the educational hand-out from the prior week. Praise all efforts and problem-solve obstacles to completing home practice.
- Teach new material (or review materials from a previous session if necessary). Take advantage of opportunities to role play and practice skills.
- Summarize progress made in the current session.
- Agree on home practice to be completed before the next session (Consider writing it down to help participants remember). Problem solve any perceived obstacles—“What could get in the way? How will you deal with that?”

### GENERAL TEACHING STRATEGIES:

- The educational process should be collaborative. Do not treat participants as students, but as individuals with whom you are trying to share information reciprocally and come to a common understanding.
- Set a positive tone, give lots of praise and use humor when possible.
- Optimal education involves seeing **the world through the participants' eyes** and then making information relevant.

- Ask more questions than you make statements; when providing education, introduce each topic by asking participants what they know about the topic first and use frequent summaries of what participants have said.
- Use the handouts to “fill in the gaps.”
- When discussing a given topic (e.g., auditory hallucinations; depression), ask the participants to give concrete examples, which will help them to better remember the concept.
- Go at a reasonable pace, but do not force the material on the participants.
- When there are multiple participants, make sure all get a chance to talk.
- Be prepared for a range of emotions as the information is explored. Concerns and anxiety about the causes of the illness as well as the future are to be expected. Relatives (especially parents) may also express guilt over some perceived responsibility for the development of the illness.
- Keep conflict during the meetings to a minimum. Do not hesitate to be very active in reducing conflict. Strategies to reduce conflict include:
  - Highlighting members’ strengths and similarities in participants’ positions.
  - Encouraging family members to treat each other with respect.
  - Reminding family members that conflict tends to make symptoms worse.
  - Encourage family members to talk to therapist rather than each other during times of stress in the session.
  - Helping people “agree to disagree” on less critical points.
  - Take a short break (5 mins) in sessions so participants can compose themselves (get a drink of water, get a breath of fresh air, etc.).
  - Schedule shorter sessions if conflict is ongoing and consider moving training on communication skills earlier.
  - Confer with the IRT clinician frequently so that everyone is on the same page about how information is being conveyed; attending team meetings is essential.

## **GENERAL INSTRUCTIONS FOR THE HANDOUTS:**

- Begin with the “Introduction to Just the Facts Sessions” handout at the beginning of the first educational session to orient participants to the work over the next few months. Briefly review the contents.

- When using the review questions, introduce them as a way to tell if you have been clear but NOT a way to tell if the participants learned anything. The provider should take responsibility about any information that was not understood and be open and willing to clarify any critical information from the prior session.
- Home practice should be reviewed before starting a new handout. The Educational Module provides one of the first opportunities to set up a routine for home practice assignments. By reviewing home practice at the beginning of each session, the participant understands the importance of practicing the skills learned in treatment in his/her own environment.
- Each handout includes: sections of text, main points that are highlighted in boxes, questions, tables, and suggested home practice assignments.
- You can either have participants take turns reading the text out loud or summarize the text for the participants, using Socratic questioning whenever possible to draw out members' understanding and thinking about the material. **When providing education, introduce topics by asking participants what they know about the topic first and then fashioning, as much as possible, the new information around what participants currently believe**
- The highlighted boxes are useful talking points and take-home message for the participant. They can also be used to help the participant to connect facts with his/her own life situation and goals whenever possible.
- Ask the participant highlighted questions to assess the participants' knowledge, and understand his/ her perspective.
- The tables can be completed together or used as a discussion tool to individualize the topic to the participant's situation.
- You can use one of the home practice suggestions or individualize the home practice for the participant.
- Typically, one-two sessions will be spent on each handout; however, with more complicated topics such as psychosis or developing a plan for staying well, more time may be required to cover the material adequately.

# **Clinical Guidelines for “Just the Facts” Participant Educational Handouts**

# Clinical Guidelines for “Just the Facts- What is Psychosis?”

## OVERVIEW:

This topic area covers the basic facts about psychosis and schizophrenia spectrum disorders. You should begin by inquiring about the participants’ understanding of psychosis and answer common questions that people often have about it. About halfway through the material, the link between psychosis and schizophrenia spectrum disorders in the NAVIGATE program is made more explicit. The causes of schizophrenia are presented, and the stress-vulnerability model of the course of schizophrenia spectrum disorders is then detailed, with an eye to supporting positive recovery actions. First episode psychosis is also discussed.

### Goals

1. Elicit information on all of the participants’ understanding of the client’s symptoms, causes, and course of illness.
2. Provide education that addresses gaps in the participants’ knowledge about first-episode psychosis and schizophrenia spectrum disorders.
3. Introduce the stress-vulnerability model to explain the course of schizophrenia spectrum disorders.
4. Provide a message of hope and optimism by outlining the possibilities for treatment and recovery in the future.

### Materials Needed

Educational handouts

1. Introduction to Just the Facts Sessions
2. Just the Facts- Psychosis

## TEACHING STRATEGIES:

- Be prepared to destigmatize symptoms, both by normalizing them or dispelling myths associated with mental illness.
- Keep in mind how knowledge about symptoms can help relatives support recovery.
- Recognize the participants’ current knowledge and experience about psychosis and schizophrenia spectrum disorders.

- Discuss how relatives can elicit information from the person in NAVIGATE if he/she is not attending the session. Help them practice how to approach this person and discuss his/her symptoms or treatment.
- If the client attends, officially designate him/her as someone who has special knowledge in this area—the expert-- and encourage him/her to talk about what experiencing symptoms is like; this strategy can help relatives gain greater empathy.
- Be upfront about the information on what is known and unknown about the causes of schizophrenia. Be sure to emphasize both the biological and social determinant contributions to the development of the disorder.
- We are using the stress-vulnerability model more to explain the course or outcome of the disorder, rather than as a depiction of causes, as so much more needs to be learned about the causes of the illness.

## **TIPS FOR COMMON PROBLEMS:**

- Be prepared for the person in NAVIGATE’S reluctance to acknowledge ever having had symptoms. Accept the reluctance and discuss the symptoms in the spirit of informing the client about possibly relevant information, but not accusing him/her of having them.
  - Focus on experiences, rather than diagnoses, due to the diagnostic uncertainty that occurs following an initial psychotic episode.
  - At times it may be more effective to link learning the contents of the module to a goal that the person has previously identified. For example, you could say, “I think working together on this handout will help you with your goal of going back to school.”
  - Alert relatives that persons who have had an episode of psychosis do not have to acknowledge “illness”; they only have to want to work to improve their situation.
  - Note that many persons who have had a psychotic episode do not believe they are “ill” but will often acknowledge they have “emotional problems” or “emotional challenges.” They will frequently assent that they are having trouble with “focus,” “memory,” “concentration” or “attention” and agree to receiving help in improving these challenges.

## **THE MOST IMPORTANT GOAL OF THE SESSION:**

Help the participants understand the stress-vulnerability model as the foundation for the interventions in NAVIGATE.

## **EVALUATING GAINS:**

- After completing this module it may be helpful to assess how much knowledge the participant has retained about the symptoms and course of psychosis and schizophrenia spectrum disorders. You can assess participants' knowledge using the following questions:
  1. What are some of the symptoms of psychosis?
  2. Does everyone who has psychosis have the same symptoms?
  3. What do you think causes symptoms of schizophrenia and schizoaffective disorder?
  4. How are diagnoses of schizophrenia spectrum disorders made?
  5. Can you tell me a bit about the stress-vulnerability model explaining the course of the problems (disorder)?



# Clinical Guidelines for “Just the Facts- Medication for Psychosis”

## OVERVIEW:

This module provides the basic facts about medication for psychosis, especially schizophrenia spectrum disorders. You will inquire about the participants’ understanding and attitudes toward medication and answer common questions that people often have about medications. As a result, participants will become informed about treatment options for psychosis and help their loved one develop an effective plan to manage medications.

### Goals

1. Provide basic information on which medications are used to treat psychosis, their clinical benefits and side-effects.
2. Help the family support the client in becoming an informed client about his/her medications.
3. Help the participants identify strategies to help him/her take the medications as prescribed.

### Materials Needed

Just the Facts- Medications for Psychosis

## TEACHING STRATEGIES:

- Before teaching the participants about the specific topic, assess their knowledge by asking them what he/she already knows about medications, benefits and side-effects, etc.
- Do not assume that all participants believe medication is a desirable treatment.
- Normalize ambivalence about taking medications. It is important to note that many individuals don’t want to be on medications (for any disease or disorder) and that it is easy to forget to take them.
- Ask the relative if he/she ever has any reluctance or difficulty in following any medication prescriptions he/she may have had (e.g., antibiotics, hypertension medications)—typically they have had this experience, and this may create empathy with the member who has psychosis if he/she is having difficulty taking medication as prescribed.

- When weighing the pros and cons of taking medications, ask the participants to generate as many as they can (i.e., use “brainstorming”). Also, look for either pros or cons that are particularly strong or compelling. For example, the absolute number of pros of taking medications may outweigh the cons, but certain cons may be very important to the participants (e.g., taking medications means that the client is ill or causes weight gain). Help the participants consider how the pros and cons relate to the client’s goals. For example, if a client identifies having better concentration as one of the pros of taking medication, this could be connected to his or her goal of wanting to maintain employment.
- Use behavioral rehearsal, if necessary, to help the relatives prepare for discussion of medications with the client (if not present) and/or the doctor.
- Ask the participants what strategies they use to remember to take medications. Use the table at the end of this handout to identify new strategies.
- Openly acknowledge medications have side effects, but that most can be managed.

## **TIPS FOR COMMON PROBLEMS:**

- Participant says that medications have no benefits, and may insist that they only have disadvantages. Do not challenge the participant on this point. Rather, concede that there are disadvantages, query about any potential advantages missed by the participant, and help the participant identify non-medication strategies that will support recovery if he/she continues to refuse medication.
- Participant reports little interest in learning about medications. Do not force the issue. You can either review the material (but not in great depth) or wait until later in treatment when there is more motivation to learn about them.
- Person NAVIGATE in has poor medication adherence but appears motivated to take medication.
  - Find out if non-adherence is due to motivation or memory difficulties, if you can, and address with targeted interventions.
  - If the former, focus on the pros and cons of taking medications, as well as how medication use relates to his/her broader goals.
  - If the latter, review strategies for remembering to take medications as prescribed such as taking morning medication right after brushing teeth.

## **THE MOST IMPORTANT GOAL OF THE SESSION:**

Help the participants determine how to support the client’s regular medication taking during early recovery

## **EVALUATING GAINS:**

- After completing the handout for this topic, it may be helpful to assess how much knowledge the participants have retained about medications. You can assess a participant's knowledge using the following questions:
  1. What medication is your relative in NAVIGATE on?
  2. What are some common benefits of these medications? How about side-effects?
  3. What are some strategies to try if weight gain is an issue?
  4. If you met someone who just had an initial psychotic episode, what would you advise them to discuss about medication with their prescriber? What sort of questions would you suggest that they ask?
  5. What sorts of strategies are used to help people remember to take medications?

# Clinical Guidelines for “Just the Facts- Coping with Stress”

## OVERVIEW:

The handout for this topic provides an overview on stress: what is stress, what are the signs of stress, and what types of situations cause stress (both in general and for the client in particular). It also provides information on how to prevent and cope with stress. Stress is conceptualized as a potential problem in both the client and relatives' lives.

### Goals

1. Provide information on stress, its signs, causes and consequences.
2. Help the participant identify factors that contribute to their own stress and ways to prevent and manage them.
3. Teach specific relaxation techniques for managing stress.

### Materials Needed

Just the Facts- Medications for Psychosis

## TEACHING STRATEGIES:

- Ask the participant about what stresses him/her out and what strategies he/she uses to manage it.
- Normalize stress as something that everyone experiences.
- Assess the participants' knowledge about his/her own daily hassles and life events as well as his/her perception of the client; fill in the gaps of the knowledge with the handout (life events and daily hassles checklists).
- Informally ask the participants about their own stress reactions and how they manage them. Use exercises such as “signs of stress checklist,” “strategies to prevent stress,” and “how can you cope more effectively with stress,” to complement their knowledge.
- Incorporate the participant's own coping strategies (if he/she has any) into the “individual plan for coping with stress.”
- Find out if the participant is using relaxation techniques. If so, ask which ones and assess their effectiveness. If not, find out which techniques the participant wants to learn. Practice the techniques in the session.

- Ask the participant to practice a relaxation technique during the week.

## **TIPS FOR COMMON PROBLEMS:**

- Participants may use maladaptive coping strategies to manage stress (e.g., substance use). If the participant is willing to discuss them, examine the pros and cons of using such strategies.
- Relatives may not see how becoming good in their own stress management will be relevant to the outcomes of their relatives with psychosis. However, we know persons with psychosis living with relatives who use less nagging, prompting, or criticism do better.
- Time may be short to cover everything in the session. If so, only one relaxation exercise needs to be practiced, but at least one should be practiced.

## **THE MOST IMPORTANT GOAL OF THE SESSION:**

Help participants learn to manage their own stress a bit better, which should reduce tension in the family and have a positive outcome on the person in NAVIGATE.

## **EVALUATING GAINS:**

- After completing the handout for this topic, it may be helpful to assess how much knowledge the participant has retained about stress. You can assess a participant's knowledge using the following questions:
  1. What is stress?
  2. What are some of the stressors your loved one in NAVIGATE experienced before he/she developed psychosis?
  3. What are some ways people experience stress?
  4. What strategies to manage stress do you use? Are there any new ones you will try?

# Clinical Guidelines for “Just the Facts- Basic Facts about Alcohol and Drugs”

## OVERVIEW:

This module is designed to help participants understand reasons for substance use and how it can be particularly problematic in psychosis. Relatives are also offered some tips on supporting abstinence/recovery from substance use.

### Goals

1. Review information on commonly used substances.
2. Review reasons for use, especially as they pertain to person with psychosis.
3. Place substance use in the context of the stress-vulnerability model of ongoing psychosis/schizophrenia.
4. Remind relatives how they can support low levels of use or abstinence.

### Materials Needed

Just the Facts- Basic Facts about Alcohol and Drugs

## TEACHING STRATEGIES:

- Begin by asking participants about what they know about substance use and what role it may play in psychosis.
- Normalize substance use (not abuse) in the culture; the point here is that people with psychosis are uniquely sensitive to substance use effects, even if they do not use more than others.
- Review types of drugs briefly; if the client is present and willing to talk about the impact of various drugs on his/her life, especially regarding symptoms and losses, this is to be encouraged.
- Encourage all participants to recognize perceived benefits (even if they are short-lived) for the substance use for the client—this is a way to create empathy with his/her struggles.
- Review the list of negative outcomes from substance use—make sure the ones the client has experienced are identified.

- Encourage relatives to commit to as many tips for helping with substance use listed in the handout as possible.
- Encourage relatives to praise the participant for even small changes in behavior.
- Given the changing norms about marijuana, anticipate some lively discussion-- about whether it causes psychosis or relieves psychosis

## **TIPS FOR COMMON PROBLEMS:**

- A minority of clients will not be using substances. The clinician can use this module to help the family strengthen the client's resolve not to use.
- Be prepared for varying degrees of openness on this topic among family members; support candor wherever you can but do not allow the client to be badgered or pushed to divulge anything he/she does not wish to.
- If the topic arises, remind participants we do not think substances cause psychoses that last more than a month, but may combine with underlying *vulnerabilities* to develop schizophrenia spectrum disorders that are longer lasting.
- Be prepared to act quickly if tensions arise, using the strategies mentioned at the beginning of the overview to the clinical guidelines. Remind family members that nagging tends to make problematic behaviors worse.
- Some relatives may be unprepared to support abstinence in the client (e.g. be unwilling to reduce their own substance use). Do not fight over this—just point out that the situation may be different for the client because of his/her underlying vulnerability, and any help is positive. Praise any willingness to be supportive.
- It may become clear that family members use substances together. This means the topic may need to be revisited frequently and motivational interviewing used along the way. See the point immediately above.

## **THE MOST IMPORTANT GOAL OF THE SESSION**

Help participants to understand that, while there may be perceived short term benefits, substance use tends to make recovery from psychosis more difficult because people with psychosis are uniquely sensitive to substance use effects.

## **EVALUATING GAINS:**

- After completing the handout for this topic area it may be helpful to assess how much knowledge the participants have retained about medications. You can assess a participant's knowledge using the following questions:
  1. Why do people with psychosis often use alcohol and drugs?
  2. What are two ways relatives can help support reduction or elimination of alcohol or drug use?
  3. Why is substance use a particular problem in a person who has had a psychotic episode?



# Clinical Guidelines for “Just the Facts-Healthy Lifestyles”

## OVERVIEW:

The handout for this topic provides an introduction to health behaviors that can avoid illness down the road and improve mental health. We are encouraging the person in NAVIGATE and family members to be proactive about health while *discouraging* nagging or excessive prompting, which may backfire and make the troublesome behaviors worse.

### Goals

1. Provide a rationale for why developing positive health habits is so important in first episode psychosis.
2. Review good health habits regarding physical activity, eating, smoking, vaping, and sleep.
3. Encourage all participants to commit to 1-2 health improvements
4. Focus the family on modeling and encouraging positive changes rather than criticizing problematic health behaviors in the person in NAVIGATE.

### Materials Needed

Just the Facts- Healthy Lifestyles

## TEACHING STRATEGIES:

- It is likely that across the various families in the NAVIGATE program, there will be tremendous variability in prioritizing health. Always, we need to meet people where they are, and be prepared for differences among members of the same family.
- Introduce each of the 4 health areas by asking family members why it is important and if they are actively working on this health area. Motivational interviewing can be helpful here.
- Be encouraging about any positive statements or progress participants make, and encourage family members to do the same with each other.
- Encourage all participants to apply these health suggestions to their own lives.

## **TIPS FOR COMMON PROBLEMS:**

- Behavior change is hard. Be sympathetic and upbeat about any positive changes. Remember the stages of change model--you may be helping participants move from precontemplation to contemplation stages. This is an accomplishment, even if it seems like actual behavioral change is not happening.
- Health behavior is often an area of conflict among families with a member with first episode psychosis. Prior to developing symptoms, the person in NAVIGATE may have been attentive to at least some aspects of health--perhaps working out, eating healthy--and now they may be doing little or none of these behaviors. In fact, they may be doing the exact opposite--sleeping most of the day, eating junk food--which can exasperate their relatives, and become a source of nagging and conflict. This nagging rarely does any good--there are research data to suggestion nagging often INCREASES the use of a negative health behavior and/or result in social withdrawal. Here are some strategies to counter nagging by family members:
  - Reminding them about negative symptoms and how they may be at play here
  - Educating family members that nagging may inadvertently cause people to do more of the problematic behavior
  - Focusing on small goals for change, especially for the person in NAVIGATE
  - Using modeling and encouragement rather than negative prompting
  - Relatives should continue to work on their own health so they can be strong during this time of challenge

## **THE MOST IMPORTANT GOAL OF THE SESSION:**

Encourage participants to be proactive about improving health, especially as it pertains to the person in NAVIGATE

## **EVALUATING GAINS:**

- After completing the handout for this topic, it may be helpful to periodically assess how much knowledge the participant has retained about resilience. You can assess a participant's knowledge using the following questions:
  1. Why do you think we have a healthy lifestyles section in the NAVIGATE program?
  2. What are some of the health areas we are hoping your family will keep an eye on?
  3. What are some of the best ways you can help your family member in NAVIGATE improve his/her health.

# Clinical Guidelines for “Just the Facts- Strategies to Build Resilience”

## OVERVIEW:

The handout for this topic provides an introduction to the topic of resilience. While much discussion in NAVIGATE is about the resilience of the client, this is also an opportunity to talk about the resilience of the relative and to bolster him/her for any anticipated challenges.

### Goals

1. Define resilience.
2. Review the benefits of resilience.
3. Identify personal characteristics and strengths.
4. Introduce the concept of “resilience stories” and help the participant develop one for his/her own life.

### Materials Needed

Just the Facts- Strategies to Build Resilience.

## TEACHING STRATEGIES:

- In this handout, you will be doing less formal teaching and using more open questions to elicit from the participant his or her understanding of resilience, strengths, and experiences where he or she felt resilient.
- Review the participants’ definition of resilience.
- Review the participants’ strengths.
- Engage the participant in discussion on how resilience is related to well-being and recovery.
- Highlight resilience as something that is relevant to everyone.
- Ask the participant if they know what a “resilience story” is. Engage participants in a discussion of their own resilience experiences; have them tell their own resilience story, and how that situation has impacted their life. This story does not have to be associated with their experience with psychosis. For example, they could discuss how they overcame a difficult situation at a previous job or the loss of a loved one.

- Ask about the qualities they observed in themselves as a function of the resilience story/situation.

## **TIPS FOR COMMON PROBLEMS:**

- Participants might have difficulty identifying a situation where he/she was resilient in the past. In that case, use probes to help the participant remember situations that required resilience (e.g., “what did you do to pick yourself up after a romantic break-up, someone close to you dying, failing an exam, etc.?”).
- Participants may have difficulty coming up with their own strengths. Ask the participant what others have said about him or her in that regard. Also, ask for examples of situations when people seek the participant’s help, advice, etc. Other family members can also remind the participant about resilience they have observed.

## **THE MOST IMPORTANT GOAL OF THE SESSION:**

Connect participants with their own strengths.

## **EVALUATING GAINS:**

- After completing the handout for this topic, it may be helpful to periodically assess how much knowledge the participant has retained about resilience. You can assess a participant’s knowledge using the following questions:
  1. Is there anything in your life that can help you build resilience?
  2. What is an example of a resilience story—a time you overcame the odds and showed what you were made of-- in your own life?

# Clinical Guidelines for “Just the Facts- Effective Communication”

## OVERVIEW:

The handout for this topic is designed to provide a rationale for why improving communication can be important for families with a member dealing with psychosis, as well as strategies to do so. Role-play and home practice are especially important here.

### Goals

1. Remind participants of the cognitive challenges that usually are found in psychosis, so that they are motivated to work on improving their communication, even if it appears strong.
2. Remind participants that conflict and tension typically are reduced when communication is good.
3. Offer clear strategies to improve communication, using the guidelines in the text.
4. Have each family member practice at least one communication skill in the session.

### Materials Needed

1. Just the Facts- Effective Communication
2. Pointers for Good Communication (make a poster of pointers from handout or a large copy of pointers which can be seen by all)

## TEACHING STRATEGIES:

- Remind families that compensating for cognitive deficits from psychosis is the primary reason for working on improving family communication even in families where the baseline conversation skills are strong.
- Discuss the pointers for good communication broadly and then give specifics.
- Reinforce any positive communication you see in the session.
- Set up behavioral rehearsals so each participant practices at least one communication skill—two is even better. Make sure each person:
  - Does at least two rounds of practice on **each** skill he/she chooses.

- Gets positive feedback first from other family members then from you after the first practice.
- Receives one suggestion for change (“One thing you might try to make the role play even better is . . . .) before the second practice
- Practices the role play again.
- Receives more positive feedback.
- Elicit a strong rationale from participants about why home practice is critical to learning new skills.

## **TIPS FOR COMMON PROBLEMS:**

- The participant says, “We talk just fine.” Acknowledge the strength of the participant’s communication skills, but again offer the rationale that extra skill is required because of the situation.
- Participants can be reluctant to do role-plays— you should do the first demonstration, move fast, and give lots of praise for ANY efforts.
- If families are engaged but need more help with their communication, consider offering them a second session of communication skills.
- Be alert to cultural differences; modify guidance as needed by openly discussing cultural issues with family. Sometimes it can be useful to distinguish cultural norms at home or in the neighborhood (e.g. not giving straight eye contact) vs ones that work at the DMV--here we are working on ones that work at the DMV

## **THE MOST IMPORTANT GOAL OF THE SESSION:**

Encourage participants to be “brief, clear, and specific” in their speech.

## **EVALUATING GAINS:**

- After completing the handout for this topic area, it may be helpful to assess how much knowledge the participants have retained about communication. You can assess a participant’s knowledge using the following questions:
  1. What are three of the key points to good communication?
  2. Why is sharpening up good communication vital in families dealing with psychosis?

# Clinical Guidelines for “Developing a Plan to Stay Well”

## OVERVIEW:

This handout provides information and a strategy for early warning sign/relapse prevention planning. Both the concept of a relapse and an early warning sign are introduced, followed by a presentation of a plan to stay well. We hope that most clients in NAVIGATE who are attending family sessions will develop their plans to stay well in these sessions, but some may prefer to develop them in IRT and then present them to their families if they are attending family sessions. If the latter, the content in this family session will need to be revised to consist primarily of the client presenting the completed *Plan to Stay Well*, and the addition of family input if the client consents. Clients can be invited to a conjoint session to present the plan they developed in IRT even if they do not regularly attend family education sessions.

### Goals

1. Educate participants about the fact that symptoms wax and wane but flare-ups can be managed.
2. Acquaint participants with common causes of relapses.
3. Help participants identify early warning signs of relapse.
4. Help participants contribute to developing a *Plan to Stay Well* if the individual in NAVIGATE is willing.

### Materials Needed

Just the Facts- Developing a Plan to Stay Well.

## TEACHING STRATEGIES:

- Be matter of fact about the content; normalize variations in symptoms over time.
- Invite participation from all attendees, but work to assure the client's opinions and preferences are respected.
- If the client attends family sessions, the family can actually identify early warning signs and develop the *Plan to Stay Well* with the client.
- Discuss how relatives can elicit information from the person in NAVIGATE if he/she is not present in the session. Help participants practice how to approach their loved one in

NAVIGATE and discuss his/her symptoms or early warning signs if he/she is not attending family sessions.

- This is a good time to work closely with the IRT clinician to see, even if the client is not attending family meetings regularly, if a family meeting might be useful to develop or review the *Plan to Stay Well*.

## **TIPS FOR COMMON PROBLEMS:**

- Be prepared for participants to be nervous talking about relapses—the experience needs to be normalized and families helped to see these are not-uncommon but can be managed. Also, be prepared that first episode clients may not have experienced a relapse and either the client or relative being reluctant to discuss the possibility a relapse may occur. Participants may also firmly believe that the client will never have a relapse, though the odds are he/she will.
- If the client does not attend any family sessions, it may be impossible for family members to review the *Plan to Stay Well*. However, if the client completes the plan in IRT:
  - The client can be asked to join the family session to discuss his/her *Plan to Stay Well*
  - The relatives can be coached to ask the client to talk about the plan at home, using good communication skills, if the client refuses to attend the family session.

## **THE MOST IMPORTANT GOAL OF THE SESSION:**

Help participants understand that symptoms go up and down, but taking early steps to act on them can often minimize big problems so developing a *Plan to Stay Well* can be very useful.

## **EVALUATING GAINS:**

- After completing this module, it may be helpful to periodically assess how much knowledge the participant has retained about the symptoms and course of psychosis. You can assess a participant's knowledge using the following questions:
  1. What are some of the common reasons for relapse?
  2. What are some of the early warning signs of a relapse?
  3. Has your family member in NAVIGATE had a relapse?
  4. What are some steps to take if the loved one in NAVIGATE starts experiencing early warning signs?



# Clinical Guidelines for “Just the Facts- Developing a Collaboration with Mental Health Professionals”

## OVERVIEW:

This handout for this topic is designed to provide participants with key information about how the professional mental health system works, including types of mental health services, types of staff, facilitating communication, issues of confidentiality, and language. Many participants will be new to the mental health system, and while they have an orientation to the NAVIGATE program, they may have had little other opportunity to acquaint themselves with “how the system works”. This handout serves two purposes--1) socializing family members into NAVIGATE and 2) help families learn about mental health systems so they are prepared when their loved one transitions out of NAVIGATE.

### Goals

1. Inform participants about the types of mental health services typically available, including staff titles, responsibilities, and organization.
2. Help participants learn why communication is important among everyone on the team, and how sharing of information works.
3. Help participants learn about confidentiality laws.
4. Encourage participants to ask for clarification when they do not understand what is being said to them by professionals.

### Materials Needed

Just the Facts- Developing a Collaboration with Mental Health Professionals

## TEACHING STRATEGIES:

- Before teaching the participant about a specific topic, assess his/her knowledge by asking him/her what he/she knows about the local mental health system.
- Ask who the members of the team are that are serving the client; see what participants know; clarify any inaccuracies.
- The confidentiality laws and issues about sharing information can be daunting- go slow, be prepared to discuss the rationale for laws that may seem harsh or obstructive.

- Encourage relatives to be creative in how they think about sharing information with staff.
- Role-play asking a staff member for clarification if they are stumped by something the staff member said.
- Consider revisiting issues with the client around sharing information if this has been a problem in this family--some work in IRT may also help.

## **TIPS FOR COMMON PROBLEMS:**

- Many participants, especially relatives, will have had some very difficult situations arise pertaining to confidentiality. They many want to “tell their story”; this is fine—just be empathic.
- Likely the experience in NAVIGATE is very different from other mental health experiences the families have had, in terms of attentiveness to relatives’ needs. Acknowledge this, if it is brought up.
- You need to educate the participants both about the NAVIGATE program and the rest of the typical mental health system, since people may graduate or transition out of NAVIGATE at some point. Sometimes participants do not have a good context for this material since they are part of a more richly staffed “first episode clinic” but members often transition out this clinic so the general information in this handout can be reviewed again or delayed for first time review until the transition if that seems more appropriate.

## **THE MOST IMPORTANT GOAL OF THE SESSION:**

Encourage relatives to work closely with the professional mental health team, even when it is challenging.

## **EVALUATING GAINS:**

- You can assess a participant’s knowledge using the following questions:
  1. What are the titles and duties of two people typically on a mental health treatment team? Are there people with these responsibilities on the NAVIGATE team?
  2. If your relative does not consent to an open sharing of information between staff and relatives, how can you get information to the team anyway?

# Clinical Guidelines for “Just the Facts- A Relative’s Guide to Supporting Recovery from Psychosis”

## OVERVIEW:

This module is designed to provide relatives with key points on how they can support recovery from psychosis—by supporting engagement in treatment, by keeping conflict and tension in the family to a minimum, and by pursuing personally meaningful goals.

### Goals

1. Review the key points of supporting recovery from earlier handouts:
  - Staying in treatment
  - Avoid drug and alcohol use.
  - Participate in a rehabilitation program and/or find something productive to do.
  - Limit the amount of stress experienced within the family.
2. Inform participants about the link between low rates of family conflict and criticism and better outcomes.
3. Inform participants that data show that the client who has relatives who are pursuing personal goals and continuing to develop themselves does better.

### Materials Needed

Just the Facts- A Relative’s Guide to Supporting Recovery from Psychosis

## TEACHING STRATEGIES:

- Begin by asking participants about recovery supports they are offering; praise all efforts.
- Normalize high levels of tension in families dealing with psychosis, but point out the value of change.
- Pitch the discussion about reducing family conflict and stress in a positive light—you do not want to be perceived as criticizing the family but rather helping members think about things in a new way.
- Encourage all members to take good care of themselves and pursue important goals—health, social, career—as this is a way to model successful living for the client.

## **TIPS FOR COMMON PROBLEMS:**

- Even if the client does not want to take medication, emphasize the importance of staying in treatment so he/she has access to services and support. By this time in the program, the client's preferences regarding medication will be clear and this is not the time to get into a struggle about it. However, it is always good to look for openings to revisit the topic if the client indicates some doubt about not taking medication or he/she is having difficulty achieving goals and might be willing to consider doing a new decisional balance.
- The participants perceive the topics as critical of them. Remind them that this information is offered to all families in NAVIGATE routinely--not personalized for them. Note that occasional criticism among family members is completely normal—the problem is that persons with psychosis may be uniquely sensitive to it.
- Counter any negative feedback by lots of praise to participants for what they are doing well. Many participants may be reluctant to pursue personal goals—here, highlighting their place as vital role models for the recovering client may help. Bad situations can improve with effort.

## **THE MOST IMPORTANT GOAL OF THE SESSION:**

Encourage participants to support engagement in treatment, give praise for positive behavior rather than criticism for negative behavior, and take care of themselves.

## **EVALUATING GAINS:**

- After completing the handout for this topic area, it may be helpful to assess how much knowledge the participants have retained. You can assess a participant's knowledge using the following questions:
  1. What are four ways relatives can help support recovery?
  2. Describe the impact of intensive criticism on a person with psychosis.

# **Handouts for Family Engagement and Orientation Sessions and Family Member Interview Forms for Assessment Sessions**

# Family Introduction to the NAVIGATE Program

- The NAVIGATE program is designed to help a person who has experienced a psychotic episode, and his or her relatives and supporters, learn the skills and information needed to help the person get back on their feet, and work towards having a rich and full life.
- The NAVIGATE program involves a number of different interventions, including medication, individual resiliency training (IRT), help getting back to work or school (Supported Employment and Education or SEE), and a family support and education program to increase the chances of recovery from psychosis.
- These interventions have been shown to be effective in helping people get on with their lives after they have experienced a psychotic episode. *The most important thing we want you to know is that people who have experienced the symptoms of psychosis can still have rich full lives.*
- The person in NAVIGATE will be working with a team to help him/her with his/her goals including a medication prescriber, program director, a clinician for counseling and resiliency training, an expert on work and school issues, and your family clinician. Case managers and peer support specialists may also be part of the team.
- The person in NAVIGATE will learn coping strategies that will help them better manage their situations and reach their goals.

## NAVIGATE Treatment Components

Treatment	Provider	Aims
Medication Management	Psychiatrist, Nurse Clinician, Prescriber	Monitor use of medication to reduce symptoms
Family Education Program (FEP)	NAVIGATE Program Director or another clinician	Provide information and skills to help relatives support their family member's involvement in treatment and to move forward in recovery
Individual Resiliency Training (IRT)	IRT Clinician	Work collaboratively to make progress towards goals and improve functioning
Supported Employment/Education (SEE)	Employment and Education Specialist	Provide support and tips to help the relative in NAVIGATE get back to work/school or stay in work/school

- Your NAVIGATE team may also include two other staff members--a case manager and a peer specialist. The case manager often assists with practical problems, like finding transportation and housing resources and may also coordinate the treatment provided to the client. Peer specialists, who provide support based on their experience of having mental health symptoms at some point in their own lives and still being able to work and have a full life, model growth and provide encouragement to NAVIGATE clients.

# Family Education Program Orientation

Welcome! This program has been developed for families who have a relative recovering from an initial episode of psychosis. We understand that an episode of psychosis can be upsetting and difficult to deal with. We also believe that support from loved ones can be a critical building block in recovery from psychosis.

- In the Family Education Program, you will meet regularly with a family clinician who is a member of the NAVIGATE team. It is ideal to meet with the whole family together, including, of course, the family member who is recovering from an initial episode of psychosis.
- Even if the relative in NAVIGATE does not come to these sessions, other family members should still come to the sessions. The relative in NAVIGATE will be learning much of the same information in other parts of NAVIGATE, so you can still work together.
- Family members will also be invited from time to time to be part of the NAVIGATE Individual Resiliency Training (IRT) and Supported Employment and Education (SEE) programs, as long as the relative in NAVIGATE consents. We value your input.

Stages of NAVIGATE Family Program	Summary
Orientation and Assessment	<ul style="list-style-type: none"> <li>• Overview of the Family Program</li> <li>• Learning more about everyone in the family and how they are coping</li> <li>• This will take 3-4 sessions</li> </ul>
Education	<ul style="list-style-type: none"> <li>• Learning facts about psychosis, medications, coping with stress, optimizing physical health, drug and alcohol use, developing resilience and good communication skills, creating a client <i>Plan to Stay Well</i>, collaborating well with mental health professionals and a relative's guide to supporting recovery.</li> <li>• This usually takes at least 12-14 weekly sessions, and sometimes one or two more</li> </ul>
Ongoing Consultation	<ul style="list-style-type: none"> <li>• Help for the family when it encounters difficulty along the recovery path, offered on an "as needed" basis after completing education.</li> <li>• A consultation usually takes 2-3 sessions</li> </ul>
Ongoing Support from the NAVIGATE Team	<ul style="list-style-type: none"> <li>• Providing support and getting the family's' views on how the person in NAVIGATE is doing and to identify any areas of improvement or concern</li> <li>• This support takes the form of monthly check-in's, either in person or on the phone.</li> <li>• Families are also invited to take part in treatment planning meetings and treatment update meetings.</li> </ul>



Modified Intensive Skills Training (MIST)	<ul style="list-style-type: none"><li>• This is an optional program when family members decide they would benefit from more extended work on improving communication and problem-solving skills.</li><li>• MIST usually takes about 6 months to complete</li></ul>
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- The goals of the NAVIGATE Family Education Program are to:
  - Learn what you already know about the symptoms, causes, course, medications, and the impact of stress on the person in NAVIGATE’s life.
  - Provide information that addresses any gaps in your knowledge about psychosis, treatment, substance use, adopting a healthy lifestyle, strategies to cope with stress, and the role of the family in recovery.
  - Provide realistic hope for recovery.
  - Support relatives.
  - Enlist relatives’ input to, and cooperation with, the treatment plan.
  - Help relatives assist the person in NAVIGATE to monitor his or her symptoms and prevent relapses.
- The Family Education Program is organized into a series of stages, each containing a number of specific topics.
  - Psychosis
  - Medication
  - Coping with Stress
  - Basic Facts about Alcohol and Drugs
  - Healthy Lifestyles
  - Strategies to Build Resilience
  - Effective Communication
  - Developing a Plan to Stay Well
  - Developing Collaboration with Mental Health Professionals.
  - A Relative’s Guide to Supporting Recovery from Psychosis

### Getting Started

- First, we are going to review with you a tip sheet on how you might manage difficult situations you may be encountering in your first few months in NAVIGATE.
- We also have the story of one of our clients with psychosis, who is working on his recovery with his family, which we want to share.

- We will also be asking you questions in an interview to get a better picture of how to best help you.
- Information about your situation helps us figure out what types of treatment your family needs to support recovery from psychosis.
- We also want to end talking a bit about safety and care while we are all getting to know each other.

### **A few words on keeping everyone safe**

The NAVIGATE teams works together closely to support the recovery of participants in the program, and information shared with any member of the team will be shared with other members of the team if it might be useful in developing the strongest recovery plan possible. The NAVIGATE Team is also committed to protecting the safety of all family members. *If you have any concerns that you or your relative in NAVIGATE may not be safe, please let us know.*

As you may know, there are laws that require mental health professionals to get help if there are concerns about the safety of individuals with whom they work. *If anyone on our team has concerns about child abuse, elder abuse, disabled person abuse, or use of child pornography, we will tell the authorities and get help. We will also get help from others if we have concerns that any participant is at risk of doing something to hurt himself or herself or anyone else.*

We are eager to begin this program. We look forward to working with you.

## Tip Sheet for Helping People in NAVIGATE

Psychosis often causes people to experience high levels of distress—such as anxiety, suspiciousness, confused thinking, or unusual thoughts or perceptions. Medications and additional treatments in NAVIGATE usually help with this, but they sometimes take a few weeks or months to achieve their full benefits. In the meantime, many relatives have found the following guidelines useful when interacting with a family member in acute distress.

### Keep expectations minimal at first, but don't let them all go

In addition to having unusual thoughts and perceptions, persons with psychosis may be dealing with unpleasant medication side-effects and confused thinking. They may be so uncomfortable that they stop doing routine activities, such as taking showers, coming to meals, or seeing friends. While relatives should be understanding about how difficult it may be to continue to do day-to-day activities, taking care of oneself often lifts our mood and helps us feel more a part of the world. Relatives should continue to have small but manageable expectations for their family members to maintain their routines, such as washing each day, attending family meals, getting out of the house for some fresh air most days, etc.

### Encourage but do not nag. Choose your battles

People with psychosis are uniquely sensitive to criticism, and this can lead to an increase in symptoms or social withdrawal. When individuals first begin treatment, they may have a hard time functioning. Praise your relative for taking *any* small steps to getting better, and limit nagging and prompting to the essentials. Focus on the priority issues, such as taking medication, attending appointments, getting up for a part of each day. There will be time to deal with bigger issues later.

### Help your relative keep to as close to a normal routine as possible

It is very easy for persons experiencing psychosis to get off their schedules—such as sleeping most of the day and staying up much of the night. This kind of schedule develops for some people because medication side effects make them feel sleepy during the day or because they feel a little “safer” being awake at night when fewer people are around and social demands are less. Unfortunately, sleeping all day may lead to missing appointments and interfere with recovery efforts. While it is important to recognize that persons recovering from psychosis usually need more rest, helping them keep a regular schedule as much as possible can help them get back on track sooner.

### Don't argue with a relative over worrisome thoughts

If the relative in NAVIGATE expresses an unusual thought or experience as a “fact,” don't argue the truth of it. If the relative with psychosis reports an odd belief, such as “The TV is watching me” or “We are not safe here,” arguing with him/her may only prompt him/her to state his/her point more firmly. Few of us like to be contradicted. If the relative offers an odd belief such as “The TV

is watching me” or “We are not safe here,” you don’t have to agree with him or her, but you don’t have to argue either. When people with a psychosis state these types of beliefs, they usually believe them firmly, and hold onto them tenaciously. *Instead of arguing, family members can empathize with the underlying feeling the relative might be having—such as fear, confusion, frustration, or uncertainty.*

Here is an example:

- Person with psychosis— *“We need to leave the restaurant. Everyone is looking at me.”*
- Family Member— *“It sounds like you feel very uncomfortable. I know this is hard. Let me just finish my sandwich and we can go.”* Note that the family member *did not say “No, that is not true. No one is looking at you.”* This statement might only make the person with psychosis argue more strongly that people *are* looking at them

### **Continue to do any enjoyable activities together**

If you and your relative with psychosis used to like watching sports together, see if you can watch a little of a ball game together. If the two of you used to like going for a ride to get a cup of coffee, try to go even if you only spend a short time at the coffee shop. Continue to look for positive, low stress activities to help you feel connected.

### **Take care of yourself**

In times of stress, relatives sometimes neglect their own health and wellbeing. It is important to attend to your own needs, too. Try to eat regular meals, get enough sleep, get out of the house, and do things that help you cope with the stress you are naturally experiencing. Be gentle with yourself.

### **Managing crises**

Many urgent situations can be anticipated—relatives may have a suspicion that the person is NAVIGATE is not taking his/her meds, or is feeling hopeless, or seems to be getting more agitated. You may be able to use the tools you develop in the NAVIGATE family education program to resolve difficulties. Sometimes clients just need a day or two of reduced stress to feel back to their old selves.

However, in more urgent situations, such as when the person is expressing thought of harming themselves or someone else, getting help earlier (rather than later) can help alleviate a lot of stress and reduce the likelihood of hospitalization. Here are some quick guidelines if more help is needed:

1. Have the contact information for the client’s prescriber (psychiatrist or nurse), IRT clinician, and family clinician readily available so you can call right away if you think the person in NAVIGATE needs additional, more urgent, help.

2. Call the clinic for help as early in the day as possible. If you call the clinic at 9:00 in the morning, your relative may be able to see the clinician or prescriber that day. If you call at 4:00 pm, this will be much harder to accomplish and you may end up in the emergency room.
3. Know the emergency procedures for the clinic in advance—your family clinician can help with this. Find out if there is a crisis team that can come out to your house if there is a need for an emergency evaluation and you cannot get to the clinic (like at night or on the weekend)?
4. Err on the side of caution. If there is any issue of safety—you think someone may get hurt or hurt themselves—address the issue immediately!

## Sam's Story

Sam was 23--the assistant art editor of a local magazine, had graduated from a great college a year ago, and was living a wonderful life in San Francisco. He thought things were going very well—so well that he started taking on a lot of extra responsibilities at work and was working very long hours—often leaving the apartment at 7:00 am and not getting home till 8:00 pm at night. His boss was pleased with him. Between work and going out to clubs with friends three or four nights a week, he had a lot going on. In retrospect, he thinks he was partying more than he should have been.

Sam began to have some difficulty settling down at night when he tried to go to sleep—he felt keyed up, with a lot of thoughts on his mind—some about projects at work, some about people he was meeting. He found himself staying up later and later, often only getting a few hours' sleep. He felt more tired in the morning—everything seemed a bit more of an effort—dressing sharply for work, taking a shower. Nevertheless, he thought he was being very creative at work, so much so that he became increasingly convinced others were stealing his ideas and his thoughts. He thought he was thinking so clearly, he was pretty sure they could tell what he was thinking. He started calling his parents at least every other day complaining about his co-workers taking his ideas.

At first his mom and dad just tried to reassure him, but when he started calling them at all hours of the night to complain, they got increasingly nervous. They kept telling him to not worry about what others were doing and just concentrate on himself, but obviously the reassurance was not working. After a couple of weeks, they decided to drive to his apartment one weekend. When they got there, they were shocked—there was artwork and pictures everywhere, the place was a mess and Sam seemed distracted, often mumbling to himself, looking off, very disheveled.

When they saw Sam's apartment and Sam's appearance, his parents were at a loss at what to do. They finally persuaded him to come home with them for a couple of days rest; he was awake most of the nights pacing. On Monday, Sam's mom called her physician and she suggested they take Sam to the emergency room. At first Sam's dad was reluctant—he just wanted his son to “settle down and stop it.” Sam's mother argued that that strategy was not working and since they did not know any psychiatrists or other mental health professionals, they should go to the emergency room. They could not figure out whether to tell Sam where they were going; they finally drove to the hospital and just told Sam they needed to get some help to relax him.

Sam initially did not want to go to the hospital, but admitted he needed some help for sleep and finally agreed to go in. Sam was evaluated at the hospital and admitted. He did not want to be admitted but when the staff told him if he did not sign in voluntarily, they would put him on a hold, he signed in himself. The doctors said he was having a “psychotic” reaction.

Then began the “year of hell” as Sam's father used to say. Sam got out of the hospital and was on medication, but he was slowed and distracted. He was not in any shape to work and his parents had to call and get him a medical leave. Sam's parents were too afraid to have Sam live alone so he stayed with them and they found a local psychiatrist. They tried to be sure one of them was always at home. Sam was clearly depressed and talking about suicide. He was hearing voices that said he should hurt himself and he was doing little with his days; he was not working, he did not see his friends, he was too distracted to watch TV or read.

Another medication was tried, but Sam still thought others could read his thoughts and was very suspicious. He was in and out of the hospital. His parents monitored his medication closely, but little seemed to help. The whole family was stressed. Sam's father's blood pressure was high and his mother's ulcers started acting up. After about 6 months Sam's doctor finally added a new medication—Sam's third—and this one seemed to help a bit. Sam could sleep through the night and quit talking to himself. He still complained he "could not think straight" and he was very withdrawn, but he no longer talked about hurting himself. He did not want to see friends or extended family and spent most of his time in his room. He was "tired" all the time.

Sam's mom and dad (and sometimes his brother when he was home from college) began to see a family mental health clinician who helped explain serious psychiatric illnesses to them. Sam had been in treatment for about 8 months by then, and now had a diagnosis of "schizoaffective" disorder. The family went to sessions for about 6 months every week. They learned about symptoms and stress and medication and about not expecting too much from Sam early on. They started reading up on schizophrenia and schizoaffective disorder. Sam's parents encouraged him to go to the family sessions with them.

For a few months Sam resisted going to family sessions, but he finally agreed to meet with the clinician one time. He liked her—she was not too pushy and she acted like he could go back to work or move out from his parents. He began to feel that something good might happen eventually in his life, that he would not be stuck forever.

Sam did not want to go to all the family sessions but agreed to see a clinician on his own. They started working on managing his symptoms and learning coping skills, using a format like IRT. The clinician kept asking him if he had goals or plans. Sam said he did not see how he could go to work, but he had always thought he would need to get more training in graphic design if he was going to be a successful art editor of a magazine, so he said he might want to try that. The clinician helped him figure out where he could take some classes and they developed strategies so he could keep up with assignments even if he felt tired or confused and to manage it if he felt anxious or suspicious in class.

Sam's father kept asking when Sam was going to get back to work—"be a man"-- but his wife reminded him that Sam seemed to be having some negative symptoms, which she had learned about in the family sessions, and they needed to go slow. She also reminded him that the family clinician had told them nagging would likely make Sam's symptoms worse.

Sam took the classes and did well. Even though he missed some classes because it was hard to get out of bed, the classes he did attend made him remember that he liked art a lot. He even made a couple of acquaintances in the class and agreed to go out with them to celebrate the end of the semester. He decided to continue the classes and get a Master of Arts in graphic design. It took another 18 months, but he felt relieved not to be working and he had some savings he could use to tide himself over. He even got a few freelance jobs.

While he was working on his masters in graphic design, he grew tired of living with his parents and found a studio apartment he could rent (with his parent's help). His parents were very anxious-- they only consented to let him move out if he agreed to meet them twice a week for dinner and to tell them about his medication taking. Sam thought that was a bit much, but he appreciated their

support so he agreed. He did not like being on medication but he was pretty certain it was keeping him out of the hospital and that was enough for him.

It is now seven years later. Progress has been up and down, but Sam is living on his own and works part-time. He has a girlfriend and is in touch with many of his friends from high school and college. He has psychotic symptoms occasionally but nothing he cannot manage. Sam continues to see his psychiatrist and psychologist but less frequently, and most people meeting him would not think there is anything unusual about him. He has not been in the hospital since he got his medication stabilized. He worries a little that he will get sick again, but most days he does just fine.

His family has been able to resume their normal activities; his brother decided to become a neuroscientist to try to understand mental illness better. Sam found out he has a number of strengths that help him be resilient. He is smart, creative, sociable, persistent, appreciative, and courageous. His parents found out they also had a number of traits that help them be resilient—they are caring, loyal, assertive when they need to be, and diligent. Sam and his parents still try to make a point of having dinner once a week—Sam figures it is the least he can do to help them feel ok, and he enjoys their company.



## Taavi's Story

Vanessa, a 37-year-old single African-American mother, was referred to the NAVIGATE program by the social worker when her 16-year-old son, Taavi, was hospitalized for a psychotic episode. Once a B/C student and very active on the football team, over the last few months Taavi had stopped doing schoolwork, was often up all night pacing and working on the a computer project he refused to discuss with anyone, slept through much of the day, and he missed so much school and football practice the coach rarely let him play. One night he started talking about the “engine running inside (him) that would not quit” and the voices he heard in his head which mostly complained about him. He thought he might need to kill himself if they did not stop yelling at him. Vanessa’s uncle had struggled with mental illness, and Vanessa recognized that something was very wrong with Taavi. She thought maybe he had gotten some bad marijuana or pills and that if he could just rest, he would feel better, but the next day he was even more agitated. Finally, she called 911 and he was admitted to the local community hospital.

### **Active Engagement**

Taavi was hospitalized for 7 days. Right before Taavi’s discharge, the hospital social worker told Vanessa about a new program at the local mental health clinic for young people who had developed a psychosis. Vanessa was not quite sure what that was but the social worker was insistent Taavi would need more help, so Vanessa called the clinic and made an appointment to see the NAVIGATE Program Manager/Family Therapist, Kevin. On the phone, Kevin was warm and attentive as she explained her situation and concerns about Taavi. Kevin set up an initial appointment for a morning in the following week, a few days after Taavi’s planned discharge. On the day of the appointment, Taavi refused to get out of bed. Vanessa tried to force him, but he was adamant and she was afraid to upset him. Finally, she asked her older daughter, Qiana, who also lived at home, to watch Taavi while she went to the clinic for the appointment with Kevin.

Vanessa was not sure what to expect and felt badly that Taavi had not come to the clinic with her, but she was very worried and went to the appointment anyway. Kevin agreed to see her and told her “this happens a lot—family members often come alone at first”. He told her about the program—the comprehensive services, the strategy of “meeting people where they are”, and the importance of helping clients set and meet personal recovery goals—and Vanessa liked what she heard. She was especially interested in helping Taavi graduate from high school—he only had to make it two more months and then he would be a senior. Maybe he could get a football scholarship to college if he could get back on track. Kevin also told her they had a family program to help her help Taavi. She was glad of that because she knew she was stressed about Taavi and she thought Qiana was too—she had been frustrated and saying Taavi was “lazy” and just trying to get attention. Kevin told Vanessa that Qiana would be welcome to be part of the family sessions, as would Taavi. Kevin spent some time trying to help Vanessa figure out with next step with Taavi—he offered to come to her house or to set up another appointment at the clinic later in the day when Taavi might be more awake. Vanessa liked the idea of including Qiana in sessions but she thought the house was too messy to have Kevin make a home visit, so she decided to set up a late afternoon appointment the clinic two days later and just bring Taavi initially.

When Vanessa got home, she told Taavi she had met Kevin, that he seemed nice, that they had a good program to help him finish high school, and would schedule appointments in the afternoon when he felt more awake. Taavi was nervous about going back to school—he did not see how he could sit through a days’ worth of classes and he felt too sluggish on the medication to play

football. He was not sure what was wrong with him—that engine inside of him was slower but still there and he still heard the critical voices. He thought he needed some help to figure out what to do so he agreed to go to the appointment with his mother. Taavi liked Kevin when they met—he thought he paid attention, was encouraging, and told Taavi still had a chance at going to college if he wanted. He also listened carefully as Taavi talked about the engine and voices, but did not try to discourage what he was saying or tell him he was “sick”. Taavi still felt shaky about everything and was not certain the medication was helping at all but he appreciated Kevin was hopeful and calm.

Taavi and his mother were introduced to the other NAVIGATE team members—the prescriber, supported employment and education (SEE) specialist, the individual resiliency therapist (IRT), and a peer counsellor. Taavi was not sure they could help him, or if he even needed help, but he knew it was important to his mother so he agreed to be evaluated for the program. He had to go to a couple of meetings with the program psychiatrist and Kevin, but then he was accepted. Vanessa was glad. Although Taavi was a legal minor, Kevin made a point of informing him that he needed to consent to have mother and sister coming to family sessions, but that he did not have to attend them unless he wanted. Kevin asked him about what might be benefits for himself and his family if they learned more about how to help him get back on track, and what might be the problems. Taavi did not like the idea of his family meeting with the staff without him, but he knew his mother really wanted to be part of the family program, so he decided to agree to attend the family meetings with Vanessa and Qiana.

### **Relative’s Individual Assessment**

Vanessa then began the family part of the program. She completed an interview with Kevin—they talked about Taavi, but Kevin was also interested in her life and what bothered her. She talked about how hard it was to be a single working mom, that she always felt badly about the fact that Taavi and Qiana’s father has left when Taavi was a baby, and that she was worried about both of the kids—Taavi because of his illness, and Qiana because she seemed so angry about it. She had seen her uncle struggle in and out of hospitals and homelessness, and she got tearful when she thought about that happening to Taavi. Kevin also spent time helping her identify her strengths and support system; afterwards, she thought it had been a very long interview but she felt more hopeful about Taavi. She also encouraged Qiana to meet with Kevin. Qiana did not want to go to the individual assessment but agreed to go to family education session Vanessa had scheduled the next week.

### **Brief Illness Education**

Taavi, Vanessa, and Qiana attended eleven family education sessions; they were supposed to be weekly, but with Vanessa’s work schedule as a court recorder, sessions were scheduled closer to every two weeks. The family covered several important topics--facts about psychosis (e.g. symptoms prevalence, causes, prognosis, treatment), medication, ways to cope with stress, preventing a relapse, working with the treatment team, and communicating better. Kevin made it very conversational, non-stressful, and gave them useful information sheets to take home.

Taavi also participated in the IRT and set some simple goals—getting some exercise so maybe he could still play football and cutting down on smoking pot because it made him very suspicious. He also began meeting with the FEP SEE specialist and worked on getting back to school and prescriber to figure out the best medication for him.

Vanessa liked three things the most about the family sessions—1) Kevin encouraged Taavi to tell everyone what the engine he experienced and voices he heard were like and how he coped with them. Vanessa had been afraid to ask Taavi about that, but she was curious and glad he was talking about that. 2) Qiana attended the sessions and seemed to get calmer and more supportive of Taavi as she understood more about the illness and how Taavi was struggling. She also shared how frightening it was when Taavi got ill and talked about suicide. 3) Vanessa was afraid that Taavi was going to have to go to the hospital again at some point, but she was reluctant to bring the topic up because she thought Taavi would think she did not have confidence in him. She was very relieved Kevin had them do planning about relapse prevention.

### **Brief Consultation**

By the time the family finished the education sessions, Taavi had been in the NAVIGATE program for six months. He had done many of the IRT basic modules and was getting good coping skills, though he occasionally still heard muffled voices. He had worked closely with the SEE specialist and she had been able to help Taavi finish his junior year in high school by getting some tutoring and credit for some NAVIGATE activities. For example, going to an art museum counted toward his art classes and walking on the school track during the SEE meetings counted towards his physical education credit. The SEE specialist told Vanessa she should ask for an individual education plan (IEP) for Taavi before the end of the school year so he could get some accommodations so he could graduate next year with his class.

Things were going well until Vanessa noticed Taavi seemed more agitated and irritable. Taavi denied he was hearing more voices or feeling stressed, but during the summer, he started getting up later and later, sometimes not until 4 or 5 in the afternoon and then staying up until 4 or 5 in the morning. His behavior was making Vanessa and Qiana tense; Vanessa knew sleeping problems were one of the warning signs they had identified in the family program. She sought a consultation with the Kevin to address two issues—1) Was Taavi having a relapse? and 2) What was Taavi going to be doing during the summer now that school was out? Taavi did not want to attend the consultation session, but Vanessa was able to convince him to come to one session with her; Qiana had to be at work. During the session, Taavi appeared to have a hard time following the discussion although he denied experiencing an increase in symptoms. Kevin reviewed the stress management techniques Taavi had covered in IRT and the family session and also checked in with Taavi about whether he had missed any medication. Taavi said he hated the medication and had stopped right when school ended so he could get in shape over the summer. Vanessa had not realized this and was very upset. Kevin reminded Vanessa that many young people stop taking their medication when they feel a bit better and asked Taavi to come to his next appointment with the prescriber so he could tell him more about his problems with the medication. All the participants also decided to encourage Taavi to meet with the SEE specialist to make a plan to keep busy over the summer. Kevin had a copy of Taavi's *Plan to Stay Well*, and they quickly reviewed it. Vanessa saw that many of Taavi's warning signs were occurring and she was glad she had asked for the meeting.

Kevin spoke with the NAVIGATE team at the next day's meeting, so the prescriber was prepared when Taavi showed up. Taavi was disheveled and had a hard time answering questions. She asked him about the medication and he said he had stopped because he needed to be in better shape for the start of football next month and the medication made him slowed down and hungry all the time. She listened carefully and told him she could change the medication to one that would not have quite so many side effects, if he thought that might be useful. Taavi admitted he

had felt more stressed since he had stopped the medication, and was arguing more with his mother and sister. He said if she had another one he could take and he could take a small dose, he would give it a try.

### **Follow-up**

Taavi spent another 18 months in the NAVIGATE program, before he moved on to a regular treatment team at his clinic. He had ups and downs, but did not have to be hospitalized again. With the help of the IRT and SEE worker, he learned coping and cognitive strategies so he was able to graduate from high school. He ended up not making the football team senior year—he was too slow. That was a blow for him and Vanessa but he was able to pass his classes and start at the junior college, where he through studying real estate might be interesting. He had had trouble remembering to take his medication, and the problem got worse when he finally got a girlfriend and spent many nights at her house. The prescriber suggested he could go on monthly injectable medication, and though he was initially reluctant, Taavi finally agreed. Vanessa was relieved. He continued living with Vanessa while he was in college, and the SEE specialist helped him get a part time job as a courtesy clerk at the grocery store before he left the NAVIGATE program.

Vanessa had ample opportunity to interact with the NAVIGATE team, most often with Kevin, the FEP Project Director/Family Clinician. She also sat in on several meetings with the SEE specialist and Taavi to discuss how to handle negotiations with the school about Taavi's progress. She had also met Taavi's individual IRT therapist and prescriber during the initial orientation sessions. Vanessa was invited to Taavi's treatment team meetings quarterly with all the members of the team. During Taavi's second year in the NAVIGATE program, the primary contact Vanessa had with the treatment team was in these meetings and during occasional consultation meetings with Kevin.

## **NAVIGATE Family Member Interview:**

**(This is a relative version; there is a client version next; an item can be skipped if clinician has already obtained the information)**

### **Background Information**

Name of Family Member: \_\_\_\_\_

Relationship to Client: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

### ***Joining the NAVIGATE Program***

Tell me a little bit about why you decided to join the NAVIGATE program.

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### **Knowledge of relative in NAVIGATE's Disorder**

So tell me a little about \_\_\_\_\_ and how the two of you get along together.

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What do you understand about \_\_\_\_\_'s psychiatric problems?

What are they called? Have you been given a diagnosis? \_\_\_\_\_

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Tell me about the circumstances that led up to \_\_\_\_\_ getting treatment here?  
Why did he/she need help?

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**Causes**

What do you think caused \_\_\_\_\_ mental health problems?

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**Beneficial Factors**

Have you noticed anything that seems to make his or her disorder better?

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**Detrimental Factors**

Have you noticed anything that seems to make his or her disorder worse?

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Has substance use or alcohol been an issue with \_\_\_\_\_?

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Has there been any problem with violence and aggression?

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Any involvement with the criminal justice system?

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**Prognosis**

What do you think will happen with his or her disorder in the future? Are you hopeful he/she can recover and get on with life?

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**Medications**

How do you feel \_\_\_\_\_'s psychiatric treatment is going?

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What do you know about the medication he or she is currently receiving?

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**Type of medicine (or name of medicine) & Dosage**

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What do you see as the benefits of this medication?

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What are the unpleasant effects of this medication?

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What does he or she do to cope with these unpleasant side effects?

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***Taking Medication***

Has he or she been taking medications as the prescriber instructed?

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What types of problems has he or she experienced regarding taking the medication (e.g., forgetting, troubling side effects)?

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***Difficulties Experienced and Coping Strategies Used***

What are the main difficulties you have experienced with \_\_\_\_\_? What worries you the most?

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How do you cope with these difficulties?

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**Strengths**

What are some of \_\_\_\_\_'s good points? Some of his/her strengths?

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What do you like about him/her?

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**Daily Routine**

How do you spend a typical day (get details)? What activities do you spend time doing (e.g., work, chores, hobbies, doing nothing)? (Describe a typical day briefly).

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**Leisure Activities**

What are the things you like to do on a day off from work or a free day? (List several).

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Do you have enough opportunity to do these things?

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What prevents you from doing the things you like?

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**Relationships**

**Current Relationships**

Who are the other members of your family?

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Does your family see eye-to-eye about what is happening with \_\_\_\_\_?

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**Problem Questions**

Any other problems you are currently facing in your life (elicit specific examples)?

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With what problems are other people in your family struggling?

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With what issues, situations, or problems do you feel you need the most help. (*To the therapist: Include any problems of which you have become aware but may not have been identified by the family member as current limitations of functioning (e.g., marital conflict, medical or psychiatric symptoms, lack of friendship, social-skills deficits, substance abuse, financial stress, housing problems, work-related problems, cultural conflicts)?*).

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**Do you have any physical or mental health issues that might impact on your situation with \_\_\_\_\_?**

Any serious medical problems \_\_\_\_\_

Current: \_\_\_\_\_

Past: \_\_\_\_\_

Any mental health treatment: \_\_\_\_\_

Current: \_\_\_\_\_

Past: \_\_\_\_\_

***Closing Questions***

Anything else that you think would be important for me to know?

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Any questions for me before we end?

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## NAVIGATE Client Interview

(This is the version for the person in NAVIGATE; an item can be skipped if clinician has already obtained the information from the relative)

### ***Entry into NAVIGATE***

How did you come to join the NAVIGATE program?

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**Knowledge of Disorder** (Note, if the client does not believe he/she has a psychiatric disorder, mirror the words he/she uses to describe his/her situation in the rest of the interview)

Have you been given a diagnosis for any mental health challenges you have been having?

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What do you believe about that diagnosis? Does it seem to fit?

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What do you think caused these problems?

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### ***Beneficial Factors***

Have you noticed anything that seems to make your problems better?

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***Detrimental Factors***

Have you noticed anything that seems to make your problems worse?

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Has substance use or alcohol been an issue for you?

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Have you had any problems with angry touching or aggression—either you used it or someone else used with you?

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Have you had any involvement with the police or the criminal justice system?

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***Prognosis***

What do you think will happen with your problems in the future?

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***Medications***

How do you feel your psychiatric treatment is going?

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What do you know about the medication you are receiving?

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***Type of medicine (or name of medicine) & Dosage***

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What do you see as the benefits of this medication?

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What are the unpleasant effects of this medication?

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How do you cope with these unpleasant side effects?

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***Taking Medication***

Have you been taking medications as the prescriber instructed?

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What types of problems has you experienced taking the medication (e.g., forgetting, troubling side effects)?

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**Difficulties Experienced and Coping Strategies Used**

What are the main difficulties you have at this time? What worries you the most?

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How do you cope with these difficulties?

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**Strengths**

What are some of your good points and strengths?

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**Daily Routine**

How do you spend a typical day (get details)? What activities do you spend time doing (e.g., work, chores, hobbies, doing nothing)? (Describe a typical day briefly).

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**Leisure Activities**

What are the things you like to do on a day off from work or a free day? (List several).

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Do you have enough opportunity to do these things?

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What prevents you from doing the things you like?

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**Relationships**

***Current Relationships***

Who are the other members of your family?

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How do you get along with your family?

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What kinds of things do you like to do with your family?

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What does your family nag or prompt you about? \

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Currently or in the past have there been any problems with abuse or neglect in your family that you want the NAVIGATE Team to know about?

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Does anyone in your family concern or irritate you? How much time do you spend with them? How would you like it to be different (specify)?

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Does your family see eye-to-eye about what is happening with you?

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**Problem Questions**

Any other problems you are currently facing in your life (elicit specific examples)?

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With what problems are other people in your family struggling?

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With what issues, situations, or problems do you feel you need the most help?

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***Closing Questions***

Anything else that you think would be important for me to know?

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Any questions for me before we end?

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# INTRODUCTION TO “JUST THE FACTS” SESSIONS

We believe that recovery chances are increased if everyone in the family—the person in NAVIGATE and his or her key supporters - learns about the disorder and what can be done to improve the situation. The “Just the Facts” educational handouts review ten basic topic areas critical to first episode psychosis:

- Psychosis
- Medication
- Coping with Stress
- Basic Facts Alcohol and Drugs
- Healthy Lifestyles
- Strategies to Build Resilience
- Effective Communication
- Developing a Plan to Stay Well
- Developing a Collaboration with Mental Health Professionals
- A Relative’s Guide to Supporting Recovery from Psychosis

Each topic area will typically be discussed with the family clinician in one or two sessions. When you review the handouts with your family clinician, you will discuss each topic area and have an opportunity to ask questions and voice your concerns.

**The NAVIGATE team looks forward to collaborating with you.**

# **“JUST THE FACTS” Participant Educational Handouts**

# JUST THE FACTS- PSYCHOSIS

Question to discuss before beginning this handout:

What do you already know about psychosis?

## What is psychosis?

The word psychosis is used to describe conditions which affect the mind and where there appears to have some loss of contact with what others consider real. When someone has these experiences, it is called a “psychotic episode.” Psychosis is most likely to occur in young adults and is quite common. Around *3 out of every 100 people* will experience a psychotic episode in their lifetimes. Psychosis can happen to anyone. Like many other health difficulties, it can usually be successfully treated.

**3 out of every 100 people will experience at least one psychotic episode.**

## Question:

- What did you and your family member in NAVIGATE know about psychosis before your recent experiences?

## What are the symptoms psychosis?

Psychosis can lead to changes in perception and thinking and unusual ideas.

Let's learn more about psychotic symptoms:

We have 5 senses (hearing, vision, touch, taste and smell) that allow us to perceive/experience our environment. **Hallucinations** is the medical term for having a sensory perception when there actually is nothing in the environment to trigger that perception.

- Examples include hearing voices, seeing shapes, feeling things on your skin, having bad tastes or smelling bad odors, all when nothing in the environment is actually there.
- Hallucinations are experienced as being as real as perceptions that are based upon something in the environment.

**Delusions** are incorrect beliefs that people continue to believe firmly even after being presented evidence that the beliefs are incorrect.

- Everyone has had the experience of believing something was true and later finding out that it was not true. So what is the difference between that and a delusion? If something is just a false believe, people will change their belief once there is evidence against the belief. With a delusion, people will not change their belief no matter the evidence.
- Some delusions involve beliefs that are totally impossible such as people far away being able to know exactly in detail the thoughts people have through telepathy or family members not being real people but instead being robots.
- Some delusions involve situations that could happen but are not in fact happening to the person. An example is the belief that a neighbor may want to harm someone. That could happen in real life. What would make the belief a delusion is that the person continues to believe it despite contrary evidence—for example that the neighbor was away on vacation when the person believed they was doing something from their home to hurt the person.

Another group of psychotic symptoms is ***disorganized thinking/speech or disorganized behavior***.

- With disorganized thinking, people's thoughts do not follow logically from one thought to another. Thoughts can be put together that do not belong together or combined in odd ways.
- Similarly, with disorganized speech, people's speech becomes disorganized so that others cannot follow what they are saying –sentences may not make sense or, in severe instances, words within sentences do not flow as they should or made-up words can be used.
- Everyone sometimes says things that others do not understand. So how does disorganized thinking/speech differ? When asked to clarify a statement, people without disorganized thinking/speech will be able to communicate successfully their thoughts to others. Often when people with disorganized thinking/speech are asked to clarify their thinking, the explanations remain difficult or impossible to follow.
- In disorganized behavior, behavior can be odd, lack a relationship to any goal or be inappropriate to the situation. For example, someone walking in a snowstorm wearing clothes for the summertime.

Psychotic symptoms can occur for lots of different reasons, for example as part of some medical and neurological illnesses or from drugs of abuse. People are screened for the different causes of psychosis as part of the NAVIGATE treatment program. NAVIGATE is for people with psychiatric illnesses whose prominent feature is psychotic symptoms. Often, this psychiatric illness is a schizophrenia or a similar disorder, known as schizoaffective disorder. Psychotic symptoms are usually not the only symptoms/experiences people with psychosis have. These other symptoms can include difficulties relating to other people, problems at school or work, and a lack of motivation

or energy to do things. These experiences may linger after the symptoms of psychosis mentioned above have improved.

### Questions:

- Has your family member in NAVIGATE experienced any of these symptoms in the table above? If so, which ones?
- What do you and your family member in NAVIGATE think causes psychosis?
- Have you been told a diagnosis for your family member in NAVIGATE?

### How a Diagnosis is Made

Psychosis is a broad term that can be caused by many things, including medical and psychiatric illnesses. People in a NAVIGATE program have been screened for the causes of psychosis and the assessment has been made that the cause is one of the psychiatric illnesses whose predominate symptoms are psychotic symptoms.

How is a diagnosis made? The first step is to obtain comprehensive information about what symptoms have been present, the time course of the symptoms and how the symptoms have affected the person's life and functioning. Important information can come from the person with psychosis but also from family members. Information gathering will include a clinical interview with the person with psychosis (and sometimes family members) conducted by a specially trained professional, usually a medical doctor, but sometimes a nurse, psychologist, social worker or other mental health practitioner. If they have not already been done, laboratory tests, brain scans or other tests may be ordered to assess medical factors that can contribute to psychotic symptoms (there are currently no laboratory tests that directly can say if someone has one of the psychiatric illnesses that have psychosis as their primary symptoms).

The final step is to take all the information and use it to make the diagnosis. In the US, clinical diagnoses are based upon the DSM-V definitions developed by the American Psychiatric Association. There are many technical rules for making DSM-V diagnoses but the overall method involves finding the presence of specific groups of symptoms, the time course of the symptoms and how the symptoms' effect on functioning. If more than one group of symptoms are present the relationship of the groups to each other is considered in making the diagnosis.

Let's review the major characteristics of the diagnoses that most people in a NAVIGATE program have.

We previously reviewed the psychotic symptoms of hallucinations, delusions, disorganized speech and disorganized behavior. Before we go further, we need to review two other concepts, prodromal and residual symptoms and another group of symptoms named negative symptoms. Prodromal symptoms are a group of less severe symptoms that occur before the appearance of the full psychotic symptoms. Residual symptoms are a group of less severe symptoms that occur after the full psychotic symptoms have improved.

## Overview of the Diagnoses That People in NAVIGATE Treatment Frequently Have

Diagnosis	Symptoms that are considered in making the diagnosis (not all are required)	Timing of Symptoms
Schizophreniform Disorder	delusions, hallucinations, disorganized speech, disorganized behavior, negative symptoms	Symptoms last at least 1 month and cause significant impairment. Symptoms then completely subside before 6 months
Schizophrenia	delusions, hallucinations, disorganized speech, disorganized behavior, negative symptoms	Symptoms last at least 1 month (usually longer than this). The length of the full symptoms and the prodromal and residual symptoms is at least 6 months. Impairment during the disorder is also required
Schizoaffective Disorder	delusions, hallucinations, disorganized speech, disorganized behavior, negative symptoms <u>And</u> mood episodes-significant symptoms of depression or mania	Mood episodes and the symptoms of schizophrenia have been present at the same time for part of the illness. During the illness, a mood episode has been present for the majority of the time. However, hallucinations or delusions at some point in the illness have been present in the absence of a mood episode for 2 weeks or longer.
Other Specified Schizophrenia Spectrum and Other Psychotic Disorder	Symptoms are present that are similar to those of schizophrenia but criteria for a more specific diagnosis are not fulfilled	

- It may be difficult to distinguish schizophrenia from schizoaffective disorder, but fortunately the disorders usually respond to the same treatments and have a somewhat similar course. Here are some of the common symptoms of schizophrenia and schizoaffective disorder.



## Symptoms Associated with Schizophrenia and Schizoaffective Disorder

Symptom	Description	Example
Decline in Social Functioning	Less time socializing, problems at school or work.	Difficulty making friends or spending time with friends or family; spending a lot of time alone in one's room.
Disorganized Behavior	Unpredictable movements or remaining motionless for extended periods.	Standing looking at the sun for hours; staying in a stuck position.
Negative Symptoms	Lack of energy, motivation, pleasure, or emotional expressiveness.	Things that you used to enjoy don't bring the same pleasure; difficulty "getting going" or following through with things; people say that they can't read your facial expression.
Depression	Feeling extremely sad or blue; can affect appetite, sleep, or energy level.	Loss of interest in activities you used to enjoy or feeling sad; sleeping too much; feeling tired and having low energy; not eating enough or eating too much.
Suicidal thoughts	Thoughts that the person may want to harm themselves.	The person feeling that he/she wants to hurt themselves because they feel hopeless or are very angry or see no way out of the situation; sometimes voices tell people they should hurt themselves.
Anxiety	Being nervous; feeling scared, worried or afraid.	Avoiding a situation or experience because of fear; constant worry or concern; difficulty concentrating; physical symptoms such as heart palpitations, perspiration, trembling, or shortness of breath.

There are 2 types of negative symptoms.

- One is diminished emotional expression. People with diminished emotional expression do not communicate emotion to the same degree as others. Their facial expression may be decreased or show no emotion (a so called blank or masked face) or their voice may be monotonous and does not change.

- The other negative symptom is avolition. People with avolition lose the drive to accomplish things, either for accomplishing school or work goals or for personal goals.

## Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own lives. Here are some home practice options for this handout that you can review now or at the end of the session.

1. Discuss the material you have covered thus far in the Just the Facts- Psychosis handout with a family member or another supportive person in your life. What did you learn that you didn't know? How could this information be helpful to you and your family in your current situation? What do you want the members of your family to understand about psychosis?
2. Review the symptoms in the **Symptoms Associated with Schizophrenia and Schizoaffective Disorder**. Identify and write down symptoms your family member in NAVIGATE has experienced.

## What causes Schizophrenia?

Psychotic experiences can be caused by many things, including a number of psychiatric disorders, intoxication with substances of abuse, and some medical illnesses. In this section, we will discuss the known causes of schizophrenia-spectrum disorders. These psychiatric illnesses have psychosis as their predominant symptom and are typically diagnosed in individuals entering the NAVIGATE program.

### First a look Contributing Factors *Inside* the Individual that are Related to Developing a Schizophrenia-spectrum Disorder

Some illnesses have a simple and direct cause. For example, Huntington's disease, a severe neurological disorder, is caused by having extra copies of a specific gene. People born with extra copies of the gene will eventually develop the disease. However, most illnesses (including schizophrenia-spectrum disorders) have complex causes. Genetic and biological factors make the person vulnerable to having the disorder but factors in the environment may affect the onset of the illness, the severity of the illness, or its course. For example, genetic factors may make people liable to heart disease but environmental factors such as diet, exercise and avoiding smoking can influence the development or course of heart disease.

Let's review what is known about schizophrenia-spectrum disorders, starting with biology.

As with other disorders, such as diabetes, hypertension, and heart disease, genetic factors appear to play a role in the vulnerability to psychosis. The chances of a person developing psychosis are higher if a close relative also has a psychiatric disorder. Even so, most family members of a person who has had a psychosis or schizophrenia spectrum disorder *do not* develop psychosis

themselves. For a while, researchers tried to find a schizophrenia-spectrum gene. We now know instead that, if you compare the genetic background of a group of people with schizophrenia-spectrum disorders to the general population, you will find many genes that are different. Each gene seems to have a very small effect at increasing the risk of developing a schizophrenia-spectrum disorder. The mix of risk genes that one person with a schizophrenia-spectrum disorder has may differ from the mix that another person with a schizophrenia-spectrum disorder has. Scientists also think that interactions between genes and aspects of the individual's environment are necessary for schizophrenia to develop.

Researchers have also done a lot of work on brain imaging to try to determine if the brain structure or functions of people with schizophrenia-spectrum disorders are different than those not diagnosed with these disorders. Globally, these studies have found differences between groups of people with schizophrenia-spectrum disorders compared to the general population in brain structure, the connections between different brain regions, and brain chemistry. Scientists think that an imbalance in the complex, interrelated chemical reactions of the brain involving the neurotransmitters (substances that brain cells use to communicate with each other) dopamine and glutamate, and possibly others, plays a role. There is some evidence that problems during brain development before birth may lead to faulty connections. The brain also undergoes major changes during puberty, and these changes possibly could trigger psychotic symptoms in people who are vulnerable due to genetics or brain differences. However, our knowledge in this area is still limited, and is not developed enough for us to have a definitive understanding of how the brains of the people diagnosed with schizophrenia-spectrum disorder differ. People with schizophrenia-spectrum disorders and their families often ask for a test such as a brain scan to determine the diagnosis. However, none of the imaging study findings are specific enough to provide a clear diagnosis at this point.

In summary, there are a number of within the person factors (which are also considered "vulnerabilities") that predispose people to develop a schizophrenia-spectrum disorder. These vulnerabilities typically develop long before the psychotic symptoms.

What about other factors that can modify the start or the course of schizophrenia-spectrum disorders?

### What Environmental Factors and Stressors *outside of the individual* are related to psychosis and schizophrenia spectrum disorders?

We know that *certain characteristics of society*—poverty, membership in some (but not all) immigrant groups and ethnicities, living in the city rather than the country—all appear to increase the risk of psychosis and schizophrenia spectrum disorders. The basis for this is unclear. We also 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 spectrum disorders.

Even as scientists identify these risk factors, we also know there are many individuals who experience these circumstances who *do not* develop a schizophrenia-spectrum disorder. This makes researchers think schizophrenia-spectrum disorders are caused or their course influenced by a *combination* of personal factors in the individual (vulnerabilities) and stress factors in the environment which interact together.

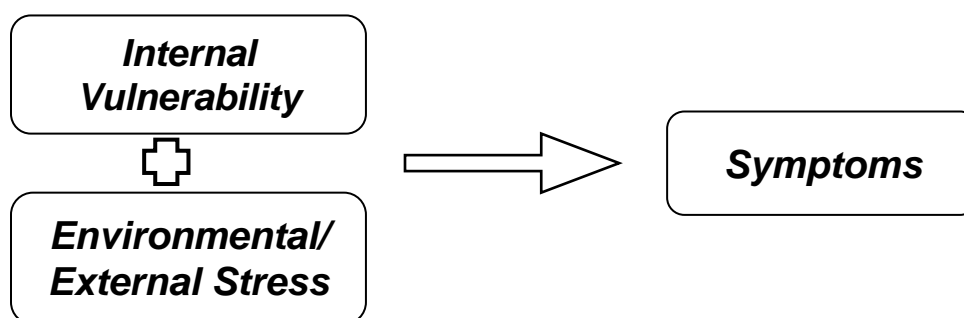
**Psychosis is likely caused by many factors—not just one.**

### How can we improve the Outcome of Schizophrenia-Spectrum Disorders?

While the specific *causes* of schizophrenia-spectrum disorders are not certain, we can use the stress-vulnerability model to explain the course of the illness once symptoms develop. According to this stress-vulnerability model, many of the *vulnerability factors* resulting in psychiatric symptoms common in schizophrenia-spectrum disorders reside in the individual. These include the biological factors we just reviewed but also include 1) differences in how people pay attention, 2) how their nervous systems respond to threats, and 3) how skillful individuals are in social interactions.

These vulnerabilities can be worsened by *environmental stress*—events happening outside the person—and include things like negative life events, abuse and neglect, daily hassles, trauma, and stressful family situations. The stress-vulnerability model can help us understand what influences symptoms of the disorder and how the effects of the disorder can be minimized. Since both stress and vulnerability contribute to symptoms, reducing either one or both can contribute to better outcomes.

### Stress-Vulnerability Model of the Course of Schizophrenia-Spectrum Disorders



#### **More about Vulnerability and Stress**

Stress can trigger the onset of symptoms or make them worse. Going to college, losing a job, breaking up with a boyfriend or girlfriend, not having enough money to live--all are stressful. Family relationships can sometimes be stressful, as can negative life events. People who experience a great deal of trauma in their lives are at greater risk for the development of psychosis.

The way people experience stress is very individual. In fact, what is stressful to one person may not be stressful at all to someone else. For example, some people love roller coasters and others

avoid them at any cost. There is no such thing as a stress-free life, so you can't avoid all stress. But it is helpful to be aware of times when a person is under stress and to learn strategies for coping with it effectively. We will present ways to prevent stress and cope more effectively with stress in the Just the Facts-Coping with Stress Handout.

### **Questions:**

- Are you aware of any vulnerability in your family for any medical problems? What about for psychiatric problems?
- Have there been times anyone noticed the relative in NAVIGATE being under stress? Did that seem related to symptoms?
- What would you say are the stressful situations in your family?

### **A Few Words about Substance Use**

Drugs and alcohol can worsen biological vulnerabilities to develop schizophrenia spectrum disorders. However, we would not say the drugs "caused" these disorders. Many people use drugs and alcohol and never develop any psychiatric problems. However, if a person has a vulnerability to develop psychosis (which is usually initially unknown to him or her), drugs and alcohol can bring it out or make symptoms worse.

- Has anyone in your family struggled with drugs or alcohol? Has the relative in NAVIGATE had any experience with drugs or alcohol related to his/her symptoms?

### **Ways to Reduce Vulnerabilities and Stress in Schizophrenia**

Because both vulnerability and stress contribute to psychotic symptoms, treatment for psychiatric symptoms needs to address both of these factors.

#### **Things people can do to influence the vulnerability factor of psychosis:**

- Stay in treatment
- Avoid street drugs and alcohol
- Take care of physical health
- Develop skills in to manage social interactions successfully.

### **Questions:**

- Have medications helped the relative in NAVIGATE to reduce symptoms?

- Has avoiding (or decreasing) drug and alcohol use helped the relative in NAVIGATE to reduce symptoms?
- What strengths does the relative in NAVIGATE have socially?

**Things people can do to influence the stress factor of psychosis:**

- Engage in meaningful activities
- Develop relationships with supportive people
- Learn strategies for managing stress
- Learn relaxation skills
- Keep family conflict low
- Develop coping strategies for persistent symptoms

Note that the relative in NAVIGATE will learn many strategies and skills in Individual Resiliency Training (IRT) for reducing the stress factor of psychosis

**Questions:**

- What does the relative in NAVIGATE do to reduce stress?
- How do other family members do to reduce stress?

## Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.

1. Explain to a supportive person what the stress-vulnerability model of the course of schizophrenia is. You may do this with the family member in NAVIGATE or someone else close to you.
2. Consider the vulnerability of the relative in NAVIGATE. What is he/she already doing to minimize his/her vulnerability (e.g., taking medication regularly; taking care of their physical health, avoiding alcohol and drugs)? Is there anything more that could be done to minimize the impact of these factors? If so, anything you might recommend?
3. Consider the stress factors of the relative in NAVIGATE. What is the relative in NAVIGATE already doing to minimize stress (e.g., getting some regular exercise, engaging in meaningful activities, talking with friends)? Is there anything more the family member can do to minimize the impact of stress? Is there something that anyone else can do to help reduce stress on the relative in NAVIGATE? If so, select something that could be tried over the next week.

## What is First Episode Psychosis?

First-episode psychosis refers to the first time someone experiences psychotic symptoms. People experiencing a first episode of psychosis may not understand what is happening. The symptoms can be disturbing and completely unfamiliar, leaving the person confused and distressed. It is usually unclear during a first episode what will happen with symptoms over the long run and if the early problem will develop into something more long-term.

## Treatment Recommendations

- What people and their families do make a difference in the person in NAVIGATE's recovery.
- When people experience psychotic symptoms, there are many things they can do to get their life back on track. Joining the NAVIGATE program is the first step.
- Here are some additional recommendations:
  - Stay in treatment
  - Take antipsychotic medication as prescribed
  - Work toward getting life back on track such as returning to work or school
  - Continue to see friends
  - Avoid alcohol, drugs, and nicotine
  - Learn to manage stress
  - Learn strategies to manage symptoms
  - Exercise and eat healthy foods
  - Get on a regular sleep schedule
  - Stay involved in a treatment program
  - Keep communication in the family strong

**Treatment is important in first episode psychosis and the earlier a person receives it the better he or she will feel and do.**



### Questions:

- What treatment recommendations is the person in NAVIGATE already following? How have family members changed their behavior to support him/her?
- What steps could family members take to help your relative get his or her life back on track?

### Will all the symptoms go away?

Most people with psychosis find taking medication reduces symptoms and decreases the possibility of a relapse. The person with first episode psychosis in your family may now be experiencing few or no symptoms if they have been taking medication for a while. However, sometimes the medication does not eliminate all the symptoms of first episode psychosis and people have to learn to cope with them while they pursue their goals and dreams. The situation is not unlike someone who has a “bad back.” Surgery and physical therapy may help, but the pain occasionally flares up and folks have to “nurse” it along while they go to work or school. Medication may help the back pain, but people can still feel the pain sometimes, especially when stress is severe.

It is important to note that it is normal for symptoms of psychosis to flare up during times of stress. People can still have very full lives even if they have some ongoing symptoms of psychosis or occasional flare-ups. Strategies for coping with psychosis symptoms are discussed more in the IRT program, and making a plan to stay well to address symptom flare-ups is discussed in a handout later in the family education program.

### The person in NAVIGATE is already on the road to recovery!

- Individual and family counseling, in addition to antipsychotic medication, have been shown to be effective at improving symptoms and quality of life in people with psychosis
- The NAVIGATE team can assist your family to better manage symptoms, develop a plan for staying healthy and avoiding relapse, and work toward goals

### Question:

- What mental health services could help other family members support your relative in NAVIGATE? Are there any other mental health services other family members might need?

**For additional information about psychosis, please refer to the following web sites:**

- General information, fact sheets, videos, links, and more
  - NIMH Recovery After Initial Schizophrenia Episode Program  
<https://www.nimh.nih.gov/health/topics/schizophrenia/raise/index.shtml>
  - NIMH Fact Sheet-First Episode Psychosis  
<https://www.nimh.nih.gov/health/topics/schizophrenia/raise/fact-sheet-first-episode-psychosis.shtml>
  - National Alliance on Mental Illness (NAMI)  
<https://www.nami.org/earlypsychosis>
  - Strong 365  
<https://strong365.org>
  - *Early Psychosis Intervention Program in Canada:*  
<http://www.psychosissucks.ca/>
  
- Resources for family and friends
  - <https://www.nimh.nih.gov/health/topics/schizophrenia/raise/raise-resources-for-patients-and-families.shtml>
  - <https://www.nami.org/Extranet/FEP-Learning-Community/Programs-and-Sites>
  - <https://www.psychosissucks.ca/how-to-help-a-loved-one-look-past-psychosis>

**Home Practice Options**

- Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.
  1. Check out one of the websites that has information about psychosis.

## Summary Points for Just the Facts- What is Psychosis?

- *Psychosis is a condition which affects the mind and where people have unusual experiences, thoughts, and problems with thinking clearly.*
- *Psychosis is very common, with 3 out of every 100 young people reporting a psychotic experience.*
- *The major symptoms of psychosis include hallucinations, delusions or false beliefs, and confused thinking or other cognitive difficulties.*
- *Everyone experiences psychosis differently.*
- *Psychosis usually has many contributing causes, which are both internal and external to the individual.*
- *The psychosis of most individuals in the NAVIGATE program is caused by schizophrenia or schizoaffective disorder.*
- *External stress and internal biology and thinking processes all contribute to the course of psychotic symptoms in schizophrenia and schizoaffective disorders.*
- *The goals of psychosis treatment are to reduce vulnerability, minimize stress, and improve the ability to cope with stress.*
- *Treatment for psychosis is important and usually the earlier a person receives it the better he/she will feel and do.*

# JUST THE FACTS- MEDICATIONS FOR PSYCHOSIS

Question to discuss prior to beginning this handout:

What do you already know about medications for psychosis?

## Why is medication recommended as part of the treatment for psychosis?

Taking medication regularly can reduce the severity of psychotic symptoms and prevent or minimize relapses. When people take medications regularly as part of their treatment, they are less affected by symptoms and they are less likely to have relapses. In the Just the Facts- Psychosis handout, you learned about the “stress-vulnerability model” of the course of schizophrenia-spectrum disorders; this model guides our treatments for psychosis and schizophrenia-spectrum disorders.

Scientists believe that mental disorders like schizophrenia are caused, in part, by problems in both the structure of the brain and how the brain neurons function. Medications reduce biological vulnerability to psychosis, though it is not certain exactly how they accomplish this. Between 70-90% of people with schizophrenia or schizoaffective who take medication and receive psychosocial treatment experience a significant reduction in symptoms and improved quality of life.

### Question:

- What are your personal beliefs about medication? Do you see benefits of taking medications or do you have concerns about taking medications? Does anyone in the family have concerns about the medication the person in NAVIGATE is on?

## What types of medications are used to treat psychosis?

- The major type of medication that is used to treat psychosis is called antipsychotics. There are many different types and the dosages depend on the individual needs.

### Antipsychotic Medications

- For most people, taking these medications can help reduce current symptoms of psychosis, and crucially, if taken on a regular basis, can substantially reduce the chance that the symptoms come back.

- The first of these medications were developed in the 1950's and many have been developed since then. They all work at decreasing symptoms or decreasing the risk of symptoms returning. They differ in their dosage requirements and side effects.

In NAVIGATE treatment we usually try one of these first.

<b>Generic Name</b>	<b>Brand Name</b>
Aripiprazole	Abilify
Risperidone	Risperdal
Paliperidone	Invega
Quetiapine	Seroquel
Ziprasidone	Geodon

However, there are a number of other antipsychotic medications and you may be taking one of them. Some other commonly used antipsychotics are

<b>Chemical Name</b>	<b>Brand Name</b>
Asenapine	Saphris
Brexiprazole	Rexulti
Cariprazine	Vrylar
Haloperidol	Haldol
lloperidone	Fanapt
Lurasidone	Latuda
Olanzapine	Zyprexa

Clozapine (brand name Clozaril) is also an antipsychotic medication. It differs from other antipsychotics in that it can improve symptoms for people who have tried other antipsychotics and not experienced enough symptom improvement with the other antipsychotics. Unfortunately, clozapine also has more side effects than other antipsychotics so it is not the first antipsychotic used if someone develops a psychosis, but it can be helpful if they do not respond to other medications.

## Ways of taking Medications

Medications in general vary in how often they need to be taken. Some medications can be taken only as needed but others need to be taken daily. However, many studies have shown that antipsychotics work best when taken daily. That can be hard to do as many studies have also found that around half of people have difficulty taking medications on a daily basis.

Some methods people can use to help take medications consistently include:

- Pill boxes
- Setting reminders on your phone or computer or on notes in your home
- Having a family member or friend remind you to take medication

There is another option that some people prefer. Some antipsychotic medications can be taken as injections that last a long time. Most last about a month but some can last up to three months. Many people like taking their medications this way because it means that you don't have to remember to take pills every day. They also don't have to take pills in front of others or have pill bottles to keep track of.

Using injections can have a powerful effect on symptoms. A recent 2 year-long study compared people taking injections and people taking pills. The people taking pills were two times more likely to have to go to the hospital as people getting injections.

### *Common Injectable Antipsychotics*

Generic Name	Brand Name	Time Between Injections
Aripiprazole monohydrate	Abilify Maintena	1 month
Aripiprazole lauroxil	Aristada	1-2 months
Olanzapine pamoate	Zyprexa Relprevv	1 month
Haloperidol decanoate	Haldol decanoate	1 month
Paliperidone	Invega Sustenna	1 month
Paliperidone	Invega Trinza	3 months
Risperidone	Risperdal Consta	2 weeks

### Questions:

- If your relative in NAVIGATE has taken an antipsychotic medication, what have you noticed that it helps with?
- What methods has your relative in NAVIGATE tried to help take medications daily?

- Does your relative in NAVIGATE take medication by injection? What do you like about that method?
- If they don't take medication by injection, have you or they considered talking to the prescriber about this option?

Additional types of medications are sometimes used to help people feel better. These include medications for anxiety, medications for depression and medications to prevent mood swings.

### Additional Medication Possibilities

<b>Medication Category</b>	<b>Possible Benefits</b>	<b>Examples</b>
Mood Stabilizer	Treat problems with extremes of moods, including mania and depression.	Depakote, Lithium, Tegretol, Lamictal, Cymbalta,
Anti-anxiety	Reduce anxiety and feeling overly stimulated.	Xanax, Ativan, Klonopin, Atarax, Catapres, Vistaril
Antidepressant	Treat the symptoms of depression, including low mood, low energy, appetite problems, sleep problems, and poor concentration.	Zoloft, Lexapro, Prozac, Paxil, Celexa, Effexor, Wellbutrin, Remeron
Anticholinergic	Treat the side effects of some medications such as restlessness and muscle stiffness.	Cogentin, Benadryl, Artane

- Important tips to remember about taking medication.
  - Everybody responds differently, so some people may need a higher dose or a different medication for best results.
  - It is recommended that a person with a first episode psychosis continue taking antipsychotic medication even after symptoms are gone to reduce the risk of symptoms returning.

#### **Questions:**

What changes in symptoms have you noticed since the loved one in NAVIGATE beginning medication?

- Which medication(s) have they taken?
- Which symptoms were helped by the medication(s)? Please record your answers below.

Category of medication	Medication used	Benefits experienced
Antipsychotic		
Mood Stabilizer		
Anti-anxiety		
Antidepressant		
Anticholinergic		
Other:		

If you have any questions about medications your loved one was prescribed, talk with him/her and see about making an appointment to discuss your concerns with the prescriber.

### **Cannabinoids for the treatment of psychosis**

At this point, the verdict is still out on whether cannabinoids help in psychosis. Approximately a third of first episode patients have a marijuana use disorder at some point in their lives, and marijuana use has long been known as a risk factor for relapse among first episode patients. The increased relapse risk may be due to the direct effects of some cannabinoids and/or by marijuana abuse being associated with not taking medication as prescribed. The cannabinoid system is complex and there are cannabinoid strategies that may (or may not) have therapeutic effects. Scientists are not certain if cannabinoids help or hurt people who have experienced a psychosis. Further studies are clearly needed to make any recommendations for use. Also, it is important to note that scientific studies of cannabinoids usually employ that meet medications that have been carefully prepared; “street” compounds or unregulated products at stores do not have similar standards. *At this point, the safest thing to do if you have experienced a first episode psychosis is to avoid cannabinoids.*



## Home Practice Options

- Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.
1. Share the table about the benefits of medication created just above with a family member or supportive person (perhaps the relative in NAVIGATE if they are not attending these sessions). Ask the person if he or she has noticed any other benefits with the medication.
  2. If you have any questions about the medications that your family member has been prescribed, make an appointment to discuss your concerns with the prescriber or other members of the NAVIGATE team.

## What are the potential side effects of medications for psychosis?

It is important to be informed about both the potential benefits and the potential side effects of the specific medication that has been prescribed. Psychiatric medications, like other medications, can cause undesired side effects.

- Different medications have different side effects, and not everybody experiences the same side effects.
- Common side effects of antipsychotic medications:
  - Weight Gain
  - Drowsiness
  - Dizziness
  - Restlessness
  - Dry mouth
  - Constipation
  - Blurred vision
  - Increased blood sugar
  - Increased risk of heart disease
  - Sexual side effects

- Many side effects may go away over time. However, people should always tell their prescriber if they are having any side effects.

**If any side effects are experienced, it is important to tell the prescriber right away.**

**Question:**

- What side effects has the relative in NAVIGATE experienced from medication? Please record your answers below.

**Side Effects from Medications**

Category of medication	Specific medication used from this category	Side effects while taking this medication
Antipsychotics		
Mood stabilizers		
Antidepressants		
Antianxiety and sedatives		
Other:		

**What about Weight Gain?**

Some of the most troubling side-effects of the newer antipsychotic medications involve weight gain. There may be many reasons for the weight gain—some of the medications may slow metabolism, people in recovery from psychosis are often less active, and some may eat more to deal with anxiety or boredom. Unfortunately, even if they are not eating more, some clients still gain weight.

Weight gain can be very disturbing to the client and relatives. The medical professionals in NAVIGATE work hard to keep an eye on the problem through frequent weigh-ins and discussions with their clients. Sometimes a change from a medication that is more likely to cause weight gain to one less likely to cause weight gain can help.

The NAVIGATE program addresses weight and other health issues in the IRT program and in the Family program. For example, there is a handout later in the family education to help family members support their relative in maintaining a “Healthy Lifestyle“. Here are some examples of the strategies people can try if weight gain becomes a problem:

- Clients can start watching their food intake. Relatives can help by serving nutritious but not high calorie meals, and by having nutritious snacks available.
- Clients can become more active. Here, relatives can be helpful by asking the client if he/she wants to go for a walk or do some other activity together, like going to the gym together.
- Clients can ask for a referral to a nutritionist to help design a more balanced food plan.

It is important to note that nagging and criticism rarely help the problem. In fact, some studies show that frequent nagging and prompting about weight can increase tension and make the problem worse.

### Questions:

- What did the relative in NAVIGATE do when he/she experienced side effects? If you have any questions about side effects, make an appointment with the prescriber or other members of the NAVIGATE team to discuss.
- Has the relative in NAVIGATE experienced weight gain? If so, has he or she used some strategies already for losing weight or maintaining a healthy weight?

### Check it Out

- ✓ Many people find it helpful to plan out in advance how they might talk to their prescriber if they experience side effects. They then feel more comfortable talking to their prescriber when they are sitting with him or her in the office. Practicing in advance makes people even more comfortable.
- ✓ How do you think the family could help the relative in NAVIGATE talk with the prescriber about concerns about medication and side-effects? It may be helpful for family members to use information from the side-effects mentioned above to make a plan to go over side effects during the next prescriber’s appointment. You can encourage your relative to include the following steps when discussing side effects:

- Introduce the topic of side effects during the prescriber’s visit.
  - *“Recently I have noticed some side effects with my medication. Could we take a moment to discuss this?”*
- Include information about side effect(s) and what help is needed from your prescriber. Be specific.
  - *“After I take my medication, I become very tired and it is difficult to keep awake at work. Do you have any suggestions on how I could be less tired during the day?”*
- Make a plan with the prescriber to resolve the problem.
  - *“What do you suggest doing so I am not hungry or eating all the time?”*
  - *“How can I sit in class if I am feeling like I have to move around and can’t concentrate?”*
- Ask questions if you do not understand
  - *“What if the medication doesn’t work for me?”*
  - *“I feel better. Why can’t I just stop taking the medication?”*
  - *“So are you saying that it is okay to just take all of my medication in the evening before bed or do I need to still take a pill in morning?”*

## How to make an informed decision about taking medications

The first step in getting the best results from medication is to make an informed decision with the prescriber by talking about the potential benefits and risks. In making an informed decision about medications, it is important to learn as much as possible to weigh the potential benefits and possible drawbacks of taking medication. Both the prescriber and the person in NAVIGATE are vital to the decision-making process. The prescriber is an expert about medication and has experience helping others find effective medications, while the client is an expert on his/her experiences and preferences.

It is essential for the person considering taking the medication to be very active in making decisions about medication. After all, he/she is the expert about his/her own experience of psychosis and what makes him/her feel better or worse. It can take time for a person and his/her prescriber to find the medication that is most effective. Talking to the prescriber on a regular basis about how one is feeling, so that the two can work together to find the best medicine, is critical.

- Here are some questions that a person considering medication or a loved one may want to ask his/her prescriber:
  - What are the benefits of taking the medication?

- How long does it take to work?
- Will it interfere with things I want to do such as work or school?
- What are the side effects or other drawbacks of taking the medication?
- At the same time, the person in NAVIGATE should continue to use as many recovery strategies as possible, such as participating in IRT, exercising, maintaining a healthy diet, avoiding alcohol and drugs, and minimizing stress. Recovery takes more than medication.

**It is essential for the person in NAVIGATE to be an active partner with the prescriber when making decisions about medication.**

#### **Question:**

- What are your thoughts about medication as a treatment option for psychosis? How might medication be helpful for symptoms?

#### **Home Practice Options**

- Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.
1. Help make a list of questions that the person in NAVIGATE will ask the prescriber and help him or her practice asking the questions.
  2. Make a list of reasons why it could be important for the relative in NAVIGATE to be involved in decisions about his/her medication.

#### **The Pros and Cons of Taking Medication for Psychosis or Schizophrenia**

To make an informed decision about medications, it is important to weigh the potential benefits (the pros) and the potential drawbacks (the cons) of taking them. The following chart may be useful in summarizing the information:

Pros of taking medications (the benefits)	Cons of taking medications (the drawbacks)
<i>For example-reducing symptoms, preventing symptoms from coming back, keeping symptoms from interfering with the person's life, helping to achieve goals, making progress in other areas of life such as relationships, work or school</i>	<i>For example-difficulty remembering to take the medication, possible side effects, "feeling different," putting on weight</i>

**Question:**

- Do the benefits of taking medication outweigh the drawbacks or vice versa? Why? Has anyone in your family discussed these concerns about medication with the prescriber?

**Check it Out**

- ✓ How can the relative in NAVIGATE talk to his/her prescriber about medications? How can other family members help? Use the information from the table above to help the relative in NAVIGATE make a plan to talk to his/her prescriber about taking medication. Here are some strategies the relative in NAVIGATE can use:
  - Ask the prescriber a question and be specific.
    - Make a list of medication concerns/questions and bring the list to your appointment.
    - No question is too small. Don't be afraid or nervous to ask.

- If it is hard to understand the answer, ask more questions.
  - If you get confused ask for clarification- *“Could you please repeat that? I am not sure that I understand your answer.”*
  - Repeat the answer back to the prescriber to make sure that you understood his or her answer- *“So, let me make sure I understand, you’re saying . . .”*
- Thank your prescriber for his or her help
  - *“Thank you for answering my questions.”*

Family members can help the relative in NAVIGATE practice talking to his/her prescriber to increase his/her confidence.

### Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.

1. Review the list of pros and cons about taking medication. Update as needed.

### Strategies for Taking Medication Regularly

Some medications only need to be taken when there is a specific problem—like aspirin for a headache or ibuprofen for a pulled muscle. Other medications need to be taken regularly every day to continue to have benefits. For example, medications for high blood pressure or high cholesterol need to be taken every day to achieve good effects. Antipsychotics, mood-stabilizers, and antidepressants need to be taken every day to have their benefits.

There is a tendency for people to want to stop taking their antipsychotic medication when their symptoms are less severe or go away. It is very important to keep taking the medication, even when the person does not appear to be having symptoms. By continuing to take the medication, things can continue to go well, and symptoms are not nearly as likely to return unexpectedly in the future.

Here are some tips for taking medication regularly:

- Take medications at the same time every day.
- Make taking medication part of the daily routine (like brushing your teeth).
- Use cues and reminders (e.g., cell phone reminders, calendars, post it notes, pill organizers).

- Remind oneself of the benefits of the medications.
- If your medication schedule is hard to follow, talk to the prescriber about simplifying it.

**Question:**

- Does the relative in NAVIGATE have difficulty *remembering* to take his/her medication? If so, you might use the following chart below to make a plan to help remember to take medication regularly. Here are strategies try:

**Strategies for Getting the Best Results from Medication**

Strategy	Willing to try?	Plan to use this strategy
Talk to the prescriber about simplifying the medication schedule		
Take medications at the same time every day		
Build taking medication into the daily routine		
Use cues and reminders (cell phone alarms and reminders, calendars, post-it-notes, pill organizers)		
Remind oneself of the benefits of taking medications		
Other:		

**Developing strategies to take medication regularly is crucial to recovery.**



## Are Medications forever?

Most people do not like to take medication. Sometimes medications have side-effects and sometimes they are a reminder of problems. However, for most people who have developed psychosis, taking medication can “make or break” whether they can get back on track.

It's natural that the person in NAVIGATE and his/her family often want to know how long the person needs to be on medication. A challenge for people with first episode psychosis is that it is natural to want to be in the minority of people who can be off antipsychotic medications for long periods of time and do okay. *However, most people are not in that group and being off antipsychotic medications has risks of increased rates of relapse and the need to be back in the hospital.* Balancing the benefits and downsides of taking antipsychotic medication long term is a complex decision. Don't make it without careful thought and discussion with the NAVIGATE team.

### Medications usually work well when psychotic symptoms first develop

For some people, their psychotic symptoms stop fairly quickly with the first antipsychotic medication they try. In a recent study, 67% had no psychotic symptoms by 4 weeks of treatment. Some people take longer to improve with their first antipsychotic and people who do not improve sufficiently by 4 weeks can improve substantially if they stay on the same medication for 12 or up to 16 weeks. People who do not benefit enough with the first antipsychotic they try can benefit by trying another antipsychotic.

### Do medications still have benefits after the initial symptoms are reduced or gone?

Once the initial psychotic symptoms are gone, the goal of using antipsychotic medications is to decrease the risk that the symptoms will return. There have been a number of studies comparing continuing antipsychotic medications versus placebo treatment after people improve from their first psychotic episode. These studies followed people for up to 2 years. All found substantially higher relapse rates with placebo treatment. Another group of studies have compared staying on antipsychotics versus being taken off medication completely, with no placebo tablets given. These studies also found substantially higher relapse rates for people not taking antipsychotic medications.

What about after 2 years? Controlled treatment studies that last a long time are very difficult to do so we lack large controlled studies that go beyond 2 years. People move, change doctors, change insurance, or may stop taking medication on their own. Based primarily on long term follow-up studies, what seems to be the case is that most people find they need to continue on medication to live the fullest life possible. A small minority of persons with first episode psychosis (around 10-20%) live successfully for long periods off antipsychotic medication. However, there is no way to tell if you are one of those persons who do NOT need medication in advance, so stopping medication can be very risky.

- For additional information about medications and other forms of treatment for psychosis, please refer to the following web sites:
  - <http://www.nimh.nih.gov/health/publications/mental-health-medications/complete-index.shtml>
  - <https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/antipsychotic-medication>

## Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.

1. The relative in NAVIGATE can make a plan to try one of the strategies for taking medication regularly. The family can help.
2. The relative in NAVIGATE can track when he/she misses any of his/her doses of medication. The family can help set up an easy monitoring system, using a phone or some other recording method as was discussed in the Strategies for Getting the Best Results from Medication table above.

## Summary Points for Just the Facts- Medications for Psychosis

- *Medications reduce the vulnerability to psychosis.*
- *Between 70-90% of people with psychosis who take medication and receive psychosocial treatment experience a significant reduction in symptoms. Many also have an improved quality of life.*
- *The major category of medication that is used to treat psychosis is called antipsychotics.*
- *Additional medications may be used to treat other symptoms.*
- *Taking psychiatric medications can help to reduce symptoms during an acute episode. When taken on a regular basis, medication can reduce the risk of having relapses.*
- *If a person experiences any side effects with medications, it is important to tell the prescriber right away.*
- *Weight gain is a common side effect. Make plans to address this before it becomes a significant problem by talking to the doctor and by learning strategies for maintaining a healthy diet and exercising regularly—we have NAVIGATE modules in IRT and Family for this.*

- *It is important to be an active partner with the prescriber when making decisions about medication.*
- *To make an informed decision about medications, it is critical to weigh the potential benefits (the pros) and the potential drawbacks (the cons) of taking them.*
- *If a person decides to take medications, he/she will get the best results by taking them at the same time every day.*
- *It is helpful to develop strategies for fitting medications into a daily routine.*

# JUST THE FACTS- COPING WITH STRESS

Question to discuss before beginning this handout:

What do you already know about stress?

## What is Stress?

“Stress” is a term people often use to describe a feeling of pressure, strain, or tension. People often say that they are “under stress” or feel “stressed out” when they are dealing with challenging situations or events. In this handout, we will talk about how relatives and the person in NAVIGATE can all cope more effectively with stress.

People who have developed psychosis are often stressed. Furthermore, relatives with a loved one with a psychotic illness often experience high levels of stress, and this stress can impact negatively on themselves and on the ill relative. Persons who develop psychosis seem to have better outcomes if they and their families find positive ways to deal with stress—so good stress management becomes important from everybody in the family.

Here are a few important points about stress:

- Everyone encounters stressful situations.
- Sometimes the stress comes from something positive (like a new job, new apartment, or new relationship) and sometimes from something negative (like being bored, having an argument with someone, or being the victim of crime).
- According to the stress-vulnerability model, stress may lead to an increase in symptoms and is associated with relapse.
- You can develop strategies to help you cope better in stressful situations.
- Family members may be able to help the relative in NAVIGATE deal with stress effectively.

**One in five people report some problem with stress.**

## Question:

- Describe the last time you felt stressed. What was that like? How did you feel? When was the last time you saw your relative in the NAVIGATE program under stress? How could you tell? How did the stress affect his/her symptoms?

## What makes Family Members Feel Stressed? What makes the Relative in NAVIGATE Feel Stressed?

It is important to remember that different people find different things stressful. For example, some people enjoy going to a party and meeting new people while others find it makes them nervous. Some people love their jobs while others are incredibly stressed by them. Knowing what a person finds personally stressful will help him/her cope better.

There are two main types of stress: significant life events and daily hassles.

Significant life events refer to big experiences, and they can be good or bad-- moving, getting married, the death of a loved one, or having a baby. Some life events are more stressful than others; for example, getting a divorce is usually more stressful than changing jobs. Importantly, even positive life events (like having a baby or getting a new job) can be stressful. Below you will find a **Life Events Checklist** to help you identify stressful life events that you have experienced in the past year.

## Life Events Checklist

Put a check mark next to each event that you have experienced in the past year. If the relative in NAVIGATE is not attending the session, circle the stressors he/she experienced in the past year.

- Moving
- Getting married
- New baby
- Divorce or separation
- Injury
- Illness
- New job
- Loss of a job
- Inheriting or winning money
- Financial problems
- Injury or illness of a loved one
- Death of a loved one
- Victim of a crime
- Legal problems
- New boyfriend or girlfriend
- Broke up with a boyfriend or girlfriend
- Went on a diet
- New responsibilities at work
- No place to live
- Hospitalization
- Stopped smoking
- New responsibilities at home
- Drinking or using street drugs caused problems
- Other: \_\_\_\_\_

Total number of life events checked off for you

Total number of life events checked off or circled for the relative in NAVIGATE

**Moderate stress**= 1 event

**High stress**= 2-3 events;

**Very high stress**= more than 3 events

“Daily hassles” are the small daily stresses of everyday life that can add up if they occur over time. They can also contribute to the stress people experience.

### Daily Hassles Checklist

Place a check mark next to each event that experienced in the past week: Circle the hassles your relative in NAVIGATE experienced in the past week if he/she is not attending the session.

- Not enough money for necessities
- Not enough money to spend on leisure
- Crowded living situation
- Crowded public transportation
- Long drives or traffic back ups
- Feeling rushed at home
- Feeling rushed at work
- Arguments at home
- Arguments at work
- Doing business with unpleasant people (sales clerks, waiters/ waitresses, transit clerks, toll booth collectors)
- Noisy situation at home
- Noisy situation at work
- Not enough privacy at home
- Minor medical problems
- Lack of order or cleanliness at home
- Lack of order or cleanliness at work
- Unpleasant chores at home
- Unpleasant chores at work
- Living in a dangerous neighborhood
- Other: \_\_\_\_\_

Total number of life events checked off for you

Total number of life events checked off or circles for the relative in NAVIGATE

**Moderate stress**= 1 or 2 daily hassles

**High stress**= 3-6 daily hassles

**Very high stress**= more than 6

## Questions:

- What is the most stressful life event you have experienced in the past year? How about your relative in NAVIGATE, if he/she is not attending the session?
- What are the most stressful daily hassles you have experienced in the past week? How about your relative in NAVIGATE?

## Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.

1. The relative in NAVIGATE can make a plan to try one of the strategies for taking medication regularly. The family can help.
2. The relative in NAVIGATE can track when he/she misses any of his/her doses of medication. The family can help set up an easy monitoring system, using a phone or some other recording method as was discussed in the Strategies for Getting the Best Results from Medication table above.

## Check it Out

- ✓ How could the family talk together about the stressors the family member in NAVIGATE is under if he/she is not attending the sessions?

## How to Recognize Stress

You could consider making a list of questions you can ask that person and practice asking the questions of your relative. Plan ahead so you can address concerns or questions about the level of stress your family member in NAVIGATE is under, and do it at a quiet, comfortable time with few distractions.

Stress can affect your physical health and emotions as well as your thoughts, behavior, and mood. Recognizing your personal signs of stress can help you do something about it.

Use the following checklist to identify your own personal signs of being under stress.



## Signs of Stress Checklist

Place a check mark next to each sign that experienced in the past week: Circle the experiences your relative in NAVIGATE has complained about in the past week if he/she is not attending the session.

- Headaches
- Sweating
- Increased heart rate
- Back pain
- Change in appetite
- Difficulty falling asleep
- Increased need for sleep
- Trembling or shaking
- Digestion problems
- Stomach aches
- Dry mouth
- Problems concentrating
- Anger over relatively minor things
- Irritable
- Anxious
- Feeling restless or “keyed up”
- Tearful
- Forgetful
- Prone to accidents
- Using alcohol or drugs (or wanting to)
- Other: \_\_\_\_\_
- Other: \_\_\_\_\_

Being aware of signs of stress can help you take steps to prevent it from getting worse.

### **Question:**

- Have you noticed any signs of stress over the last week? What do you do when notice you are under stress? How do you or other family members recognize that the relative in NAVIGATE is under stress?

## Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.

1. Use the signs of stress checklist to track your daily stress over the next week. How many times a week are you feeling stressed? What do you do when you feel stressed?
2. Review the signs of stress checklist with your family member in NAVIGATE.

## Family Members and Stress

Stress can often make people feel irritable and lead to conflict or arguments, especially in families. Unfortunately, family conflict can make psychotic symptoms worse. When relatives learn to deal with stress well, this is one way to reduce tension in families and improve the quality of life for the person in NAVIGATE and their loved ones.

**Improving stress management is critical for ALL family members.**

## Strategies to Prevent or Cope with Stress

- Recognizing stressful situations is the first step to preventing and coping with stress.
- By avoiding some stressful situations, you can focus more of your time on enjoying yourself and achieving your goal(s).
- If you can't avoid stressful situations, you can get better at dealing with the stress they cause.
- Most people find it helpful to be familiar with a variety of stress management strategies.
- Too much stress can contribute to family conflict.

Use the following table to review strategies for dealing with stress and mark whether you already use the strategies or would like to try them.

Strategy	Example	I already use	I would like to try
Recognize situations that caused stress in the past	Think of ways to handle stressful situations. If large holidays with your family make you feel tense, try taking short breaks away from the larger group.		
Schedule meaningful activities	Identify activities that reduce stress. For some people, work is meaningful and enjoyable while other people look to volunteering, hobbies, music, or sports.		
Schedule time for relaxation	Take time to relax each day, to refresh your mind and body from the tensions of the day.		
Have a balance in my daily life	Evaluate your activities and determine if too much activity is causing stress. Be sure to leave time for sleep and for restful, relaxing activities.		
Develop my support system	Seek out people who are encouraging and supportive, rather than critical and pressuring.		
Take care of my health	Be sure you are eating well, getting enough sleep, exercising regularly, and avoiding alcohol or drug abuse to help prevent stress.		
Talk about my feelings	Share positive or stressful feelings with a friend or family member.		
Write down my feelings in a journal	Keep a journal of the positive and negative feelings to avoid bottling up your feelings.		
Avoid being hard on myself. Identify positive features about myself	Create reasonable expectations for yourself, and give yourself credit for your talents and strengths. Identify positive features about yourself and remind yourself of these things when you are feeling stressed.		
Use relaxation or mindfulness techniques	Make a plan to use a relaxation technique such as relaxed breathing, progressive muscle relaxation or imagining a peaceful scene. (see section on 3 relaxation techniques later in the handout); make a plan to use a mindfulness technique such as		
Use positive self-talk	Develop a short phrase to say to yourself when you feel stressed such as "This is hard, but I can do it," or "If I take this one step at a time, I'll be able to handle it."		
Maintain one's sense of humor	It is hard to feel stressed when you are laughing. Make a list of things that make you laugh and try one the next time you feel stressed.		
Participate in religion or other form of spirituality	Make a plan to participate regularly in a religious or spiritual activity.		
Exercise	Work off your stress by making a plan to exercise regularly.		

Listen to music	Put together a playlist of your favorite songs to listen to when you are feeling stressed.		
Do artwork or go to see artwork	Make a plan to fit art into your weekly routine. Read an art book or draw pictures.		
Participate in a hobby	Find a hobby you enjoy. Make a plan to try it out with a friend.		
Other:			

**Reducing stress in the family can help the relative in NAVIGATE avoid worsening symptoms or a relapse, and help you live a more satisfying life.**

**Question:**

- Which strategies for reducing stress are you most interested in trying?

**Home Practice Options**

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.

1. Identify a stressful situation that may occur over the next week. Select a strategy for preventing stress to try out and make a plan to use it in the coming week. Get supplies if you need them (e.g. a journal, a schedule of church activities). Track how well the strategy works to reduce stress.
2. If the person in NAVIGATE is not in the session, other relatives can ask the relative in the NAVIGATE program which stress management strategy he/she might want to try over the next week. Help him/her make a plan to practice the strategy.

**Relaxation Techniques**

Using relaxation techniques can be very helpful in coping with stress. Three types of relaxation techniques are described below:

- Relaxed breathing
- Muscle relaxation
- Imagining a peaceful scene

Relaxation techniques are most effective when they are practiced on a regular basis. When you are first learning a technique, you usually concentrate on doing the steps according to the instructions. As you become familiar with the instructions, you will be able to concentrate more on the relaxation you are experiencing. Choose one of the following techniques and try practicing it daily. After a week, evaluate whether you think the technique is effective for you.

### Relaxed Breathing

The goal of this exercise is to slow down your breathing, especially your exhaling.

#### Steps:

Choose a word that you associate with relaxation, such as CALM or RELAX or PEACEFUL.

- Inhale through your nose and exhale slowly through your mouth. Take normal breaths, not deep ones.
- While you exhale, say the relaxing word you have chosen. Say it very slowly, like this, “c-a-a-a-a-l-m” or “r-e-e-e-l-a-a-x.”
- Pause after exhaling before taking your next breath. If it’s not too distracting, count to four before inhaling each new breath.
- Repeat the entire sequence 10 to 15 times

### Muscle Relaxation

The goal of this technique is to gently stretch your muscles to reduce stiffness and tension. The exercises start at your head and work down to your feet. You can do these exercises while sitting in a chair.

#### Steps:

- *Shoulder shrugs.* Lift both shoulders in a shrugging motion. Try to touch your ears with your shoulders. Let your shoulders drop down after each shrug. Repeat 3-5 times.
- *Overhead arm stretches\*.* Raise both arms straight above your head. Interlace your fingers, like you’re making a basket, with your palms facing down (towards the floor). Stretch your arms towards the ceiling. Then, keeping your fingers interlaced, rotate your palms to face upwards (towards the ceiling). Stretch towards the ceiling. Repeat 3-5 times.
- *Stomach tension.* Pull your stomach muscles toward your back as tight as you can tolerate. Feel the tension and hold on to it for ten seconds. Then let go of the muscles and let your stomach relax, further and further. Then focus on the release from the tension. Notice the heavy yet comfortable sensation in your stomach.

- *Knee raises.* Reach down and grab your right knee with one or both hands. Pull your knee up towards your chest (as close to your chest as is comfortable). Hold your knee there for a few seconds, before returning your foot to the floor. Reach down and grab your left knee with one or both hands and bring it up towards your chest. Hold it there for a few seconds. Repeat the sequence 3-5 times.
- *Foot and ankle rolls.* Lift your feet and stretch your legs out. Rotate your ankles and feet, 3-5 times in one direction, then 3-5 times in the other direction.

\*If it is not comfortable to do step #2 with your arms overhead, try it with your arms reaching out in front of you.

### Imagining a Peaceful Scene

The goal of this technique is to “take yourself away” from stress and picture yourself in a more relaxed, calm situation.

#### Steps:

1. Choose a scene that you find peaceful, calm and restful. If you have trouble thinking of a scene, consider the following:
  - at the beach
  - on a walk in the woods
  - on a park bench
  - on a mountain path
  - in a canoe or sailboat
  - in a meadow
  - traveling on a train
  - in a cabin
  - beside a river
  - next to a waterfall
  - in a tall apartment building, overlooking a large city
  - riding a bicycle
  - on a farm
2. After choosing a peaceful scene, imagine as many details as possible, using all your senses.
3. What does the scene look like? What are the colors? Is it light or dark? What shapes are in the scene? If it's a nature scene, what kinds of trees or flowers do you see? What animals? If it's a city scene, what kind of buildings? What kind of vehicles?
4. What sounds are in your peaceful scene? Can you hear water or the sounds of waves? Are there sounds from animals or birds? From the breeze? From people?
5. What could you feel with your sense of touch? Are there textures? Is it cool or warm? Can you feel a breeze?

6. What smells are there in your peaceful scene? Could you smell flowers? The smell of the ocean? The smell of food cooking?
7. Disregard any stressful thoughts and keep your attention on the peaceful scene.
8. Allow at least five minutes for this relaxation technique.

### **Home Practice Options**

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here is a home practice option for this handout that you can review now or at the end of the session:

Choose at least one of the relaxation techniques and try it out at least 1 time each day for 5-10 minutes for 1 week. Try building up to 20 minutes per day.

## How can I Develop a Plan to cope with my Stress?

In this handout you have identified stressful situations, signs of stress, strategies for preventing stress, and strategies for coping with stress. The following form can help you put this information together as an individual plan for coping with stress.

### Individual Plan for Coping with Stress

Stressful situations to be aware of:

- 1.
- 2.
- 3.

Signs that I am under stress:

- 1.
- 2.
- 3.

My strategies for preventing stress:

- 1.
- 2.
- 3.

My strategies for coping with stress:

- 1.
- 2.
- 3.



## Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.

1. Share your plan for coping with stress with a family member or support person. Ask that person to help you practice one of your strategies for preventing or coping with stress over the next week. If the person is part of your plan, practice the coping strategy with him or her.
2. If your relative in NAVIGATE did not attend the session, offer to help the family member in NAVIGATE practice one of his/her strategies for preventing or coping with stress over the next week. If he/she is willing, help him/her complete an "Individual Plan for Coping with Stress" form.

## Summary Points for Just the Facts- Coping with Stress

- *"Stress" is a term people often use to describe a feeling of pressure, strain, or tension.*
- *Persons with psychosis seem to do better if their relatives exhibit fewer signs of distress*
- *One in five people report some problem with stress.*
- *Life events and daily hassles are both sources of stress.*
- *Being aware of signs of stress can help someone take steps to prevent it from getting worse.*
- *Preventing stress can help someone with psychosis avoid worsening symptoms or having a relapse.*
- *Coping more effectively with stress allows one to focus on goals and important areas in one's life.*
- *Regularly practicing relaxation techniques when you are calm helps you be able to use them when things are stressful*

# JUST THE FACTS- BASIC FACTS ABOUT ALCOHOL AND DRUGS

A question to discuss before beginning this handout:

What do you know already about alcohol and drugs and how they affect psychosis?

Alcohol and drug use are common behaviors that many people engage in. However, it is important to know that people who have had a recent psychosis are very sensitive to the effects of substances: even small amounts of alcohol or drug use can trigger symptoms or interfere with functioning. This handout focuses on talking about substance use and psychosis. If substance use has been an issue for the relative in NAVIGATE, we want you to know that many people with psychosis and substance use problems have been able to reduce and stop using substances, taking control over their lives and their recovery. Even if alcohol or substance use has not been a problem for your loved one in NAVIGATE, we think the problem can be so prevalent in psychosis that learning a little bit more about can be helpful.

## Question:

- Has alcohol or drug use been an issue for the loved one in NAVIGATE in the past couple of months? What makes you think so? How about before his/her psychotic episode?

## Information about Commonly Used Substances

Using alcohol and drugs is a common human behavior that dates back for thousands of years. For example, drinking a beer, a glass of wine, or a mixed drink is common in modern society. Similarly, using drugs such as marijuana, cocaine or speed, or ecstasy to get high, and feel energetic or relaxed is also common. These types of substances can make people feel good, but they can also cause problems for people who have experienced psychosis. This handout covers commonly used substances and their effects. It also explores reasons for using substances and provides some tips to help someone who is using substances.

## Commonly Used Substances and Their Effects

It is helpful to understand what people commonly experience when they use alcohol and drugs. The following table lists examples of both the positive and negative effects of alcohol and drugs.

## Commonly Used Substances and Their Effects

<b>Substance Type</b>	<b>Examples</b>	<b>Positive Effects</b>	<b>Negative Effects</b>
Alcohol	Beer, wine, gin, whiskey, vodka, tequila	-Relaxation -Lighter mood	-Slower reaction time, feeling tired -Socially embarrassing behavior
Cannabis	Marijuana, hash, THC- There are also synthetic versions	-Relaxation -"High" feeling	-Reduced reaction time and coordination -Feeling unmotivated -Feeling tired -Paranoia -Increased anxiety or feeling panicky -Synthetic versions may bring on symptoms that mirror psychosis
Stimulants	Cocaine (powder/or crack), amphetamines (crystal meth., Dexedrine, Ritalin, Adderall, ephedrine	- Feeling alert, energetic -Euphoria	-Increased anxiety -Paranoia and psychosis -Sleeplessness -Feeling jittery
Hallucinogens	Ecstasy, LSD, peyote, mescaline	-Increased sensory experiences -Feeling of well-being	-Bad "trips" -Psychotic symptoms
Opiates	Heroin, morphine, vicodin, Demerol, opium, Oxycontin, Fentanyl	-Positive feeling of well-being -Relaxation -Reduced pain sensitivity	-Drowsiness -Highly addictive -Risk of overdose

## Other Commonly Used Substances and Their Effects

Substance Type	Examples	Positive Effects	Negative Effects
Inhalants	Glue, aerosols, paint	-“High” feeling	-Severe disorientation -Toxic/brain damage
Over-the-counter medications	Cough syrup, antihistamines and related compounds (such as Benadryl and other cold tablets)	-“High” feeling, -Sedation	-Drowsiness
Caffeine	Coffee, energy drinks, some teas, some sodas	-Feeling alert	-Feeling jittery -Interference with sleep
Nicotine	Smoking, chewing tobacco	-Feeling alert -Feels good	-Health problems, such as emphysema, lung/throat/ mouth cancer
Benzodiazepines (Anti-anxiety medication)	Valium, Xanax, Klonopin, Ativan	-Reduced anxiety -Relaxation	-“Rebound anxiety” when medication wears off -Loss of inhibition and coordination -Dulled senses

### Questions:

- Which of these substances have you heard of? Which concern you?
- If the client in NAVIGATE is willing to discuss, he/she can share which substances he /she has tried? Anything he/she has tried (such as over the counter medicines or herbal preparations) that is not on the list?
- What effects (either positive or negative) have family members noticed in their relative in NAVIGATE experiencing from any of the substances they have noticed?

## Why do People Use Alcohol and Drugs?

There are many reasons people use substances. Some of the most common reasons are described below.

### To socialize

Using substances with other people can make you feel like you're "one of the crowd." It can make it easier to meet people, to feel comfortable around people, or just give you something to do with friends to have fun or hang out. Using with friends can also be a way of re-connecting with people you haven't been in touch with for a while. People often use substances together at parties, celebrations, or holidays.

### To have fun

Alcohol or drugs can make people feel good, and fight boredom in their lives. Some substances may make people feel high, relaxed and mellow. Others can cause people to feel alert, energetic, and full of life.

### To improve mood

People may use substances to counteract the effects of feeling bad. Alcohol and drugs can provide temporary relief from feeling depressed, anxious, or angry, although it can also contribute to negative feelings. For example, it is common for people to feel bad about themselves for being unproductive if they are spending a lot of time hung over.

### To cope with symptoms

Some people use alcohol and drugs to cope with symptoms. Alcohol and drugs may provide temporary relief from hearing voices or having other hallucinations. Using substances can sometimes help people relax and be less troubled by paranoid thinking, or being less concerned that other people are looking at them or talking about them or knowing what they are thinking. Some substances can increase concentration, which can help when one's attention easily wanders. Using substances to cope with symptoms can provide some temporary relief, but it can also worsen the problem in the long-run.

### To help with sleep

Alcohol and drugs can make it easier to get to sleep. However, the sleep is often less restful and you may feel groggy in the morning.

### To avoid thinking about problems

People may also use substances as a way of distracting themselves from their problems. For example, people may use alcohol or drugs to distract themselves from problems with work or

school, when they are having conflicts with others, because they are lonely, or because they are unhappy with themselves.

For these individuals, substance use may provide a temporary escape from a variety of life problems.

### **It becomes part of a daily routine**

Some people use substances because it becomes part of their daily routine, and gives them something to look forward to. Everybody needs to have things they care about and look forward to doing, and for some people this includes using alcohol or drugs. For these individuals, using alcohol or drugs is more than just a habit; it is part of their lifestyle and an important part of how they live each day.

### **Chasing the “good old days”**

People who have had a psychotic episode sometimes resume using alcohol or drugs, often with their friends, after their symptoms are under control because they want to experience the same pleasure and enjoyment they previously had from using substances. This may work some of the time, but people often find that they are more sensitive to the effects of substances after their episode, and that the effects aren't as enjoyable as before.

### **Question:**

- Has anyone thought the relative in NAVIGATE may have used substances for any of the reasons described above?

### **Home Practice Options**

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here is a home practice option for this handout that you can review now or at the end of the session:

1. Family members can consider having a conversation with the relative in NAVIGATE about what he/she sees as the pros and cons of substance use at this point in his/her life. Keep calm during the conversation. Try to see the world through your relative's eyes—you do not need to change his/her mind at this time.

## Substance Use and Psychosis

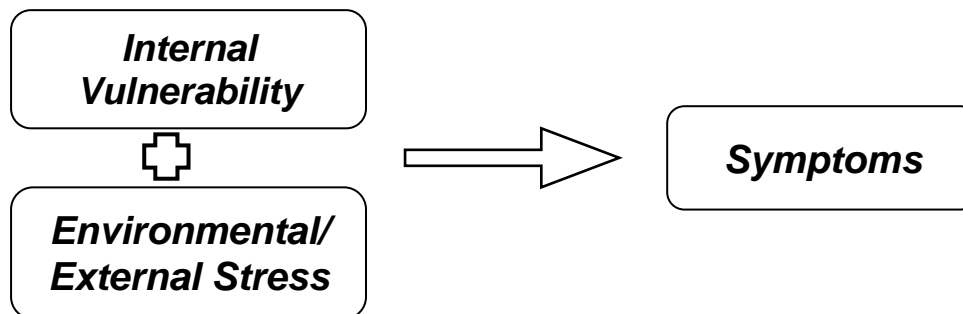
Using alcohol and drugs is common. However, substance use can also cause problems. People who have recently experienced a psychosis are especially sensitive to the effects of substances.

## Revisiting the Stress-Vulnerability Model

Alcohol and drugs can trigger symptoms and relapses of psychosis. The stress-vulnerability model of psychosis helps explain why using even small amounts of substances can make symptoms worse, and lead to relapses and hospitalizations.

The figure below summarizes the stress-vulnerability model of outcomes in schizophrenia, which is also explained here.

### Stress-Vulnerability Model



The symptoms of psychosis are related to internal factors (or vulnerabilities).

- These internal factors and symptoms can be made worse by external stressors:
  - Alcohol and drugs
  - Stress
- These internal factors and symptoms can be improved by:
  - Taking medications
  - Learning effective strategies for coping with stress and symptoms
  - Good social support
  - Engaging in meaningful activities, such as work or school
  - Avoiding alcohol and drug use
  - Developing social competence

- Alcohol and drugs can directly affect the biological factors in the brain that cause psychosis, worsening symptoms.
- Substance use can interfere with the protective effects of medication on reducing symptoms and reducing relapses, leading to worse symptoms and more relapses.

Psychosis makes people very sensitive to alcohol and drug effects. It is not necessarily that a person is drinking or using more than others—they may not be—but even a little bit may make him/her anxious or suspicious or make voices get worse. Even one beer can cause some people with first episode psychosis to have a problem, even if it never did in the past.

### **Question:**

- Has the relative in NAVIGATE appeared to have any change in sensitivity to alcohol or drugs since he/she experienced a psychotic episode? Like getting more suspicious after just one beer?

### **Other Problems Related to Alcohol and Drug Use**

In addition to increasing symptoms and causing relapses, drug and alcohol use can lead to other problems.

#### **Interference with work or school**

Using substances can get in the way of work or going to school. People may have difficulty focusing at work or school, and doing the best they are capable of. Or they may be late or miss work or school, because they were up late the night before or they just don't care as much.

#### **Social Problems**

Substance use often causes conflicts with other people, either family members or friends. Relatives may be concerned about a loved one's use of alcohol or drugs, and this can lead to arguments and tension in the family. Substances can make people less predictable and harder to get along with. For example:

- Acting more irritable or moody than usual.
- Not coming home when expected.
- Not following through on responsibilities to others, such as chores, cooking, or cleaning.
- Not being as involved in friends' lives, such as not returning calls, not keeping up with communication, or canceling plans.



## Questions:

- Have family members told the relative in NAVIGATE they were concerned about his/her substance use?
- Has substance use ever led to arguments or conflicts in with your family?

Substances can also cause problems related to the people with whom one uses. For example: Being impulsive when using, and doing things that are embarrassing or get one in trouble, such as causing a disturbance, getting into fights, or having sex with someone the person doesn't know well.

- Being taken advantage of by other people, either sexually or financially. People may act like they are friends, but only because someone has something they want, such as substances, money, or the use of an apartment.

## Daily living problems

People may not take care of themselves when they are using substances. They may not shower, brush their teeth, or keep up their appearance like they ordinarily would. Or they may not eat well, or take care of their room, apartment, or house.

## Legal problems

Using substances can cause legal problems. For example, driving under the influence of alcohol or drugs is against the law and can result in severe penalties. People may be arrested for acting in an aggressive or disorderly way, or for possessing illegal drugs.

## Safety problems

People may use substances in unsafe situations, such as driving under the influence, going to dangerous neighborhoods in order to buy drugs, or hanging out with people who may take advantage of them or harm them. Using substances can also make it easier to get into accidents, such as car accidents or tripping and falling down.

## Problems achieving goals

Using alcohol or drugs can get in the way of people achieving their personal goals. It may be difficult to sort out whether psychosis or substance use has interfered with a person achieving his or her goals, because the two problems can interact with each other.

## Health problems

Substances can cause a variety of health problems, both short- and long-term. Short-term health problems include weight gain or loss, digestive problems, appetite disturbance, and sleep problems.

Long-term alcohol use can produce many problems, including liver problems such as cirrhosis. Substances such as cocaine, heroin, and amphetamines can cause blood borne infectious diseases such as hepatitis C and the HIV virus if snorting straws or needles are shared between different people. These are blood-borne diseases that can be spread through exposure to an infected person's blood, such as by sharing needles (injecting) or straws (snorting) for using these drugs.

People may also neglect to take care of chronic health conditions such as diabetes or to keep up with health protective behaviors like exercise because they are doing drugs.

## Psychological dependence

Frequent use alcohol or drugs can lead to psychological dependence, such as:

- Spending a lot of time using substances
- Giving up important activities in order to use
- Using more than intended
- Trying unsuccessfully to stop

## Physical dependence

Frequent use of substances can also lead to developing tolerance, so that the person needs to take larger amounts to get the same effect they used to get. Another sign of physical dependence is experiencing withdrawal symptoms if they stop using, such as feeling shaky or nauseous.

## Question:

- Has the relative in NAVIGATE developed any of these problems mentioned above because of substance use?

## Tips to Help with a Relative's Substance Use

Substance use is common in persons with a psychotic episode and it may take some time for the person using the substances to recognize there is a problem. There are things family members can do to help the situation. Here are some tips:

- Continue to use good communication skills about being concerned or worried; prompting and nagging about substance use tends to make it worse.

For example, you can say *“I worry you will relapse when you drink more than a beer. Is there anything I can do to help?”* instead of *“You have to quit drinking. Don’t you remember what the doctor said?”*

- Provide praise for positive changes (e.g. avoiding friends who use substances, going a few days without drinking or using) no matter how small.
- Do not contribute any money that your relative in NAVIGATE may be using for substances.
- Set a good example yourself—do not use substances to excess.
- Give a clear firm consistent message about why you are concerned about what your relative in NAVIGATE is doing that might interfere with his/her recovery.
- Be careful about nagging—you can express your concerns about abstinence, but nagging often makes a problem worse.

### Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here is a home practice option for this handout that you can review now or at the end of the session:

- If your relative appears to have an alcohol or drug problem, decide which of the tips that family members are going to use over the next month and make a plan to try them.

### Summary Points for Just the Facts- Basic Facts about Alcohol and Drugs

- *Many people with a first episode of psychosis use substances.*
- *Common reasons for using substances in psychosis include to socialize, have fun, cope with symptoms, and manage boredom.*
- *People with psychosis are especially sensitive to substance use effects, so just a little bit can make the situation worse.*
- *Relatives can help their loved one with a first episode of psychosis begin to reduce or eliminate use.*
- *Reducing or eliminating substance use can take a long time in first episode psychosis, but it is possible.*

# JUST THE FACTS- HEALTHY LIFESTYLES

Question to discuss before beginning this handout:

What are you doing to keep yourself healthy?

Does your loved one in NAVIGATE have any health habits you would like to encourage?

## The Importance of a Healthy Lifestyle

Why does the NAVIGATE program include information on healthy lifestyles? There are two major reasons.

The first reason is that although people with psychosis vary widely, many find themselves experiencing physical challenges related to overeating, inactivity, smoking, and poor sleep. Each of these physical challenges can eventually lead to developing significant physical illnesses, such as heart disease, diabetes, and some kinds of cancer. If severe, these illnesses have been shown to lead to shorter lifespans for people with psychosis.

NAVIGATE wants to help change this picture! We offer information on improving health in the individual reliance therapy for the person in NAVIGATE, and we provide this module on healthy lifestyle to family members because they can do a great deal to help promote good physical health for themselves and everyone else in the family. Now is a perfect time to begin. It is much more effective to be proactive, rather than wait for problems to develop and try to fix them. This handout will address:

1. Becoming or staying physically active
2. Eating healthy
3. Avoiding starting smoking or quitting smoking or vaping nicotine
4. Getting a good night's sleep

The second reason that NAVIGATE includes information on healthy lifestyles is that good physical health often helps people improve their mental health. For example, living a healthy lifestyle often results in increased energy, better stamina, improved mood, and stronger self-confidence. These kinds of improvements often help people get or stay on track with their lives and achieve their goals, so they are especially important for individuals in the NAVIGATE program.

We know that many of you may also know a lot about how to improve health, but we offer this as a quick review of tips to improve physical well-being with a special eye on how to support your loved one in NAVIGATE's physical health as part of their overall effort to get back on track.

## The Value of Being Positive and Not Nagging

In general, it can be challenging for people to make changes in their health habits. It takes time and patience. And the research shows us that when people feel nagged or “over-prompted,” it makes it harder for them to change. For that reason, we think it is very important for individuals and families to see making changes towards more healthy habits as an opportunity to work together on a mutual goal. *Working together means avoiding nagging and over-prompting, and instead, providing encouragement, support, and collaborative problem-solving and activity.*

Even if the person in NAVIGATE does not choose to develop healthy habits at this time, there are still things family members can do until the person is ready to make any needed changes down the road. Family members can model healthy behavior themselves and they can provide concrete help such as stocking healthy food in the house or offering to go for a walk or to the gym. They can also notice and encourage the person in NAVIGATE when they make even small steps towards healthy habits. They can also be alert for opportunities to do more when the person in NAVIGATE is ready.

### Questions:

- What are some current healthy eating habits that you each have? Are there any habits that you would like to develop?
- What does each of you like to do to stay active? Is there anything you used to like to do that you might like to start again?
- Do you smoke cigarettes or vape nicotine? If so, have you ever tried to quit? What went well, what did not go so well? What do you see as the benefits of stopping?
- In an average week, how many nights do you get a good night's sleep? How many night's do you get poor sleep? Have you noticed any patterns about when you sleep well compared to when you don't sleep well?

The rest of this module will provide some information and tips for each of the health areas noted earlier in this handout: physical activity, healthy eating, smoking, and sleep.

You may want to spend longer on the areas that interest you or concern you the most.

### Physical Activity

Being physically active has many benefits. For example, being active helps people maintain a healthy weight, improve their strength, avoid certain health conditions, have more energy, and improve their mood. It can also provide opportunities for people to do activities with others and give them something to talk about.

The National Institute of Health (NIH) recommends getting 30-60 minutes of exercise or physical activity every day. If everyone in the family is already at that level of activity, that's great. Keep it up. Many people in NAVIGATE tell us, however, that this is challenging. They say that they and their other family members are not getting much exercise. They may be spending a lot of time sitting or lying down.

### Questions:

- What has each of you done in the past 2 or 3 days to stay active? How many minutes per day did you spend each day being active?
- Was there a time in your life when you were more active? What did you do then?

It's important to remember that there are a variety of ways to be active, some of which involve everyday activities like walking to the store or doing chores, while others which involve more organized or structured exercise like going to the gym or doing a sport. Both types of activity count.

For people who want to increase their exercise and activity levels, here are some suggestions that may be helpful:

1. If you are currently not very active, plan to gradually build up to 30-60 minutes of daily activity. For example, you can start with increasing your activity level 10 minutes per day for two weeks, then 15 minutes per day for two weeks, then 20 minutes per day for two weeks, etc.
2. Be more active in your every-day life, like walking to the store or taking the stairs instead of the elevator. Look for "excuses" to get up rather than stay sitting down.
3. Identify how to get involved in an activity, exercise or sport that you enjoy or have enjoyed in the past.
4. Do activities that involve exercise with other people, like friends or family. For example, it's usually more fun to go for a walk or ride a bike or shoot hoops with someone else.
5. Try doing more activities outside if it is safe where you live. Many people find that it is refreshing to be outside and to have a change of environment. In addition, there is more and more research showing being in the fresh air and nature can have a powerful impact on mood.

### Questions:

- Which of the above suggestions do you think would be most helpful?
- If you are interested in making a change in your activity level, what would you like to do first?

If you are the person in NAVIGATE,

- How interested are you in increasing your activity level?

- What might be the benefits of being more physically active?
- How important is it to you to become more active?
- What would you find especially helpful from your family?

If the person in NAVIGATE is interested in increasing their activity level, here are some tips for family members:

- Provide a positive example by engaging yourself in activities that involve exercise.
- Avoid excessive prompting, which can be perceived as nagging.
- Be supportive of the person's efforts. Comment on the good things the person is doing around increasing their activity level.
- Offer to do activities together, such as going for a walk, going to the gym, riding bikes, or following an exercise routine on the internet.
- Ask the person what they would find helpful and supportive from you.

## Healthy Eating

Healthy eating habits can help people in many ways, such as

1. Increasing energy
2. Maintaining a healthy weight
3. Increasing alertness
4. Managing or preventing medical problems such as diabetes, high blood pressure, high cholesterol, or stomach problems

For the person in NAVIGATE, this is an especially good time to be aware of eating healthy. Up until now, they may not have needed to worry about weight. However, with medication, people's metabolism may be slowed down and their appetite may be increased. Psychiatric symptoms often also cause people to withdraw and be less active, so their metabolism slows down. Both of these things increase the risk of gaining weight.

The most effective way to counteract the risk of weight gain is to be proactive. In NAVIGATE, we encourage people to get on top of weight early by attending more to what they eat and how active they are as soon as they can. There is information on this topic in for the person in NAVIGATE in individual resilience therapy (IRT). *If your loved one in NAVIGATE is ready to start improving their eating habits, look for opportunities to help—have healthy food at home, think carefully about which restaurants offer the healthiest menus when you go out. If the person in NAVIGATE does not appear ready to change, remember—you can model good behavior, but nagging and prompting often backfires and makes the person just do more of what the loved ones wish they would do less of!!!!* It may take time.

There are some practical and easy steps that people can take to eat well. The National Institute of Health (NIH) developed the following website to provide some practical strategies for young adults who want to improve their eating habits:

<https://www.niddk.nih.gov/health-information/diet-nutrition/healthy-meals-snacks-teens>

### **1. Take it easy on pizza, soda, and sweets**

Keep in mind that these foods have lots of sugar, salt, and fat.

- Limit cakes, cookies, and other foods made with shortening, butter, and margarine.
- Choose water or fat-free or low-fat milk instead of sugary soda or juice drinks.
- Eat more foods like bananas, beans, and yogurt for potassium to help build strong bones.

### **2. Give your body the right fuel**

- At meals, make half of your plate fruits and vegetables.
- Power up with lean meats, chicken, seafood, eggs, beans, nuts, tofu, and other protein-rich foods.
- Build strong bones with fat-free or low-fat milk products for calcium and vitamin D.
- Choose whole grains, like whole-wheat bread, brown rice, and oatmeal, for half of your grain servings.

### **3. Snack smart**

- Fresh apples, berries, or grapes
- A handful of walnuts or almonds
- A small bag of mini-carrots with a low fat dip
- Low-fat or fat-free yogurt
- String cheese
- Peanut butter on whole-wheat crackers

### **4. Watch portion size and number of portions**

A portion is how much food or beverage you consume at one time. When you eat meals out or already prepared or “processed” foods, they often provide larger and unhealthy portions. You can use these tips to help you eat healthy portions when you eat out or eat at home.



- Avoid "value-sized" or "super-sized meals." You may not realize that one "super-sized meal" may have more calories that you need in a whole day.
- Share your meal or take half home when eating out.
- Choose whole-wheat bread, lean meats, and fresh fruit whenever it's offered
- Take one serving out according to the food label and eat it on a plate rather than straight from the bag.
- Avoid eating in front of the TV, driving, or while you are busy with another activity.

### Questions:

For each family member,

- What are you already doing to eat healthy?
- Are there some eating habits you could improve?
- If you are interested in improving your eating habits, which of the suggestions above do you think would be most helpful?

If the person in NAVIGATE is interested in losing weight or eating more healthily, here are some tips for family members:

- Provide a positive example by eating healthy yourself
- If you are buying groceries have your eye out for more nutritious, less high calorie foods.
- If you do the cooking, prepare more vegetables, salads and whole grains, provide fruit instead of a sugary dessert, bake chicken instead of fry it
- Avoid urging second helpings
- Keep healthy snacks on hand like fruit and cut up vegetables
- Do not stock the refrigerator and cupboard with tempting high calorie foods with low nutritional value (like soda, chips, cookies and ice cream)
- Avoid excessive prompting, and criticism.
- Be supportive of the person's efforts; comment on the good things the person is doing around their eating habits

## Questions:

If you are the person in NAVIGATE,

- What would be the benefits of you eating healthy?
- How important is it for you to eat healthy?
- What would you find especially helpful from your family?

## Smoking and Vaping Nicotine

Here we talk about smoking and vaping nicotine. There is a clear research showing that smoking and vaping nicotine has a very negative effect on people's lungs and their heart. Illnesses related to these behaviors, such as lung cancer and heart disease, can significantly shorten people's life span. There is also clear research that people with psychosis are more likely to smoke than people without psychosis.

In NAVIGATE we stress being proactive about smoking and vaping. If the person in NAVIGATE is not smoking or vaping nicotine, great. If the person is smoking or vaping nicotine, this would be a good time to stop. There is a lot of help available for people who want to stop smoking or vaping, such as the following:

- Smoking cessation programs
- Nicotine patches, gum, lozenges, or nasal spray
- Medications such as Zyban (bupropion) and Chantix (varenicline)

## Questions:

- Who in the family smokes or vapes nicotine?
- Has anyone in the family successfully stopped smoking or vaping?
- If you are interested in stopping smoking or vaping, what do you think would be most helpful to you?

If the person in NAVIGATE is interested in stopping smoking or vaping, here are some tips for family members:

- Provide a positive example by not smoking or vaping yourself
- Encourage the person to use supports, such as smoking cessation programs and medications

- Support the person’s efforts and notice when they make improvements in their smoking or vaping behavior
- Avoid over-prompting or nagging.

### **Questions:**

If you are the person in NAVIGATE and you currently smoke or vape nicotine,

- What would be the benefits of quitting?
- How important is it to you to quit?
- What would you find especially helpful from your family?

### **Sleep**

Sleep is as important as healthy eating and being active. During sleep, our bodies repair and our brains can recover and process information. It is recommended that people get approximately 7 to 8 hours of sleep a night.

Many people have problems with sleep, such as difficulty falling asleep or difficulty staying asleep. Two other common problem when individuals are experiencing (or have experienced) psychosis and are on medication is that they 1) are drowsy all the time and may want to sleep 10 or 15 hours a day and/or 2) they shift their awake time, so they are up most of the night and sleep much of the day. Unfortunately, sleep problems can have a negative effect on people’s physical and mental health.

### **Questions:**

- Who in the family has problems sleeping?
- What is the nature of their sleeping problem?

One of the best ways for people to get a good night’s sleep is improve their “sleep hygiene.” “Sleep hygiene” refers to the habits that people have around their sleeping. Good sleep hygiene includes routines that help a person get a full night’s sleep on a regular basis.

Here are some suggestions for good sleep hygiene:

- Go to bed and get up at the same time every day, regardless of how much sleep you got the night before.
- Exercise during the day so that you feel tired at night
- Avoid napping during the day, even if you didn’t sleep well the previous night.

- Avoid drinking anything with caffeine after 3PM.
- If you smoke or vape nicotine, avoid this for several hours before going to bed.
- Do something relaxing at least 30 minutes before bed, such as reading a book, putting together a puzzle, taking a bath or warm shower, or listening to music
- Before bed, avoid watching things on TV or the internet that may be upsetting.
- Do not keep your cell phone at your bedside unless you turn it off or put it on a nighttime setting.

### Questions:

- Which of the suggestions above do you already follow?
- If you have sleep problems, which of the suggestions would you like to try in order to get a better night's sleep?

If the person in NAVIGATE is interested in improving their sleep, here are some tips for family members:

- Provide a positive example by following the recommendations for good sleep hygiene yourself
- Encourage the person in NAVIGATE to use good sleep hygiene, and offer to assist in such things as exercising during the day (such as taking a walk together) or doing something relaxing before bedtime (such as putting together a puzzle together).
- Avoid over-prompting or nagging.

### Questions:

If you are the person in NAVIGATE

- Do you have sleep problems you would like to address?
- What would be the benefits of addressing any sleep problems you have?
- How important is it to you to improve your sleep schedule or habits?
- What would you find especially helpful from your family?

## Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.

1. Considering the four health areas we have discussed, is there one you would like to change? Is there one thing you can commit to working on over the next two weeks? What do you propose to do?
2. If your relative in NAVIGATE did not attend the session, ask the family member in NAVIGATE if they are working to improve any health behaviors and how other family members could be helpful in supporting this change.

## Summary Points for Just the Facts- Healthy Lifestyles

*When individuals develop mental health problems and go on medications, they are often at risk for also developing physical health problems.*

*It is a great thing for individuals in NAVIGATE to be as proactive as possible in addressing physical health issues.*

*There are many emotional and physical benefits to addressing health issues.*

*When someone is trying to make health changes, family members can be most helpful by*

- *Not nagging or judging*
- *Noticing and encouraging positive changes in other family members*
- *Making it easy for the person who wants to try positive changes—*
  - *by having healthy food in the house*
  - *by preparing healthy meals*
  - *offering to joint positive activities—like walking or going to the gym*
  - *by not smoking or vaping around them*

# JUST THE FACTS- STRATEGIES TO BUILD RESILIENCE

Question to discuss before beginning this handout:

What do you already know about resilience?

## Building Resilience

Resilience is the process of adapting in the face of adversity by building strengths and developing coping skills. It can be understood as “coming back from a hard knock”. For many families, having a loved one develop a psychotic illness is a very distressing occurrence, and requires developing resilience. Resilience is a very individual characteristic, but a characteristic that each person can strengthen. What helps one person, such as creative expression, may not be helpful for another person who finds strength in his or her spirituality.

- Building resilience can help you deal with life’s unexpected challenges.
- Developing resilience serves as a protective factor against stress factors, as discussed in the stress-vulnerability model.
- You can learn to be resilient by becoming aware of your strengths and developing strategies to cope with your life stresses.

Common components of resilience include:

- problem-solving skills
- flexibility
- sense of purpose
- sense of humor
- remaining calm under pressure
- optimizing strengths in difficult situations
- being hopeful
- using healthy coping skills
- increasing positive emotions

- increasing positive experiences
- putting things in perspective
- taking opportunities to grow and change

### Questions:

- What qualities of resilience do you have?
- What strengths have you shown in dealing with life challenges?
- How do you define resilience?

### How can resilience help the family support recovery from psychosis?

- Resilience will help you:
  - Build your strengths.
  - Feel more hopeful about the future.
  - Feel more confident using stress-management techniques.
  - Have “back-up” strength when things look bleak
  - Look toward to a time when no one in the family is consumed with dealing with a psychiatric illness.
- In the NAVIGATE program, family members can build their resilience by
  - Learning more effective coping strategies for stressful situations.
  - Practicing using your stress management techniques to feel more comfortable using them when you are under stress.
  - Building your resources to help you achieve your goals
  - Developing your support system.
- Family members and supporters have an important role in building resilience in persons who have experienced a psychotic episode. They can
  - Reinforce resilient qualities in the person who has experienced the psychosis.
  - Practice effective coping strategies with the person who has experienced the psychosis.

- Support the person with psychosis as he/she take steps towards his/her goals.
- Learn strategies to help the person with psychosis to cope more effectively in times of stress.
- Provide encouragement when it is difficult for the person with psychosis to see him/herself as resilient.

### Questions:

- What would help you strengthen your resilience?
- Who could support you? How?
- What can you and other family members do to support the relative in NAVIGATE's resilience?

One way of shoring up resilience is by emphasizing personal strengths. Personal strengths include traits such as:

Curiosity	Love of learning
Judgment	Ingenuity
Emotional intelligence	Perspective
Valor	Perseverance
Integrity	Kindness
Loving	Citizenship
Fairness	Leadership
Self-control	Prudence
Humility	Appreciation
Gratitude	Hope
Spirituality	Forgiveness
Humor	Passion
Honesty	Zest

### Questions:

- Which of these personal strengths do you have?
- Which personal strengths do you see in other members in your family?



## What is a Resilience Story?

People often find it helpful to think about when they have been resilient in the past as a first step to building more resilience when confronted with new challenges. Think back in your life about stressful situations or events that you successfully overcame. Resilience plays an important role in those stories. It is not always easy to think back about the qualities that make us resilient, but oftentimes people can remember a difficult time in their past and how they got through it. By exploring the process of overcoming adversity in your own life, you can begin to discover the resilient qualities and strengths that could be helpful strategies for you in the future.

- Resilience Stories:
  - Reflect a difficult experience in your life that you were able to overcome.
  - Help you discover resilient qualities within yourself.
  - Provide hope for you to find ways to use resilience in your current situation.
- To help you develop a resilience story, begin by thinking about a situation or event in your life that challenged you.

### Questions:

- How did you face that challenge?
- What do you admire about yourself for facing that challenge?
- It may also be helpful to think about some specific details about your experience.
  - What happened?
  - Why was this difficult for you?
  - Because of this experience, what did you learn about yourself?

### Questions:

- What impact did this event have on your life?
- What were some of the first signs that you would overcome this event?
- How did you prepare yourself to face this challenging event?
- What did you discover about yourself after you faced this event?
- How have you used this new information about yourself?

## Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.

1. Think about a family member or supporter that you see as resilient. Approach that person and ask them to share a resilience story from his/her life. Ask the person what qualities helped him or her get through the experience.
2. Share your resilience story with a family member or supporter. Ask that person what resilient qualities that he or she sees in you. How does that compare to the qualities that you have listed?
3. Share your resilience story with a family member or supporter. Ask that person what resilient qualities that he or she sees in you. How does that compare to the qualities that you have listed?

## Summary Points for Just the Facts- Strategies to Build Resilience

- *You can learn to be resilient by recognizing your strengths and using them and by developing additional strategies to cope with your stress and symptoms.*
- *Building resilience can help you feel more hopeful and confident about the future.*
- *You can build resilience by learning more effective coping strategies and developing support and resources to help you achieve your goals.*
- *A resilience story is a challenging experience that you have had to overcome in your life. Remembering and sharing this story can help you rediscover your strengths.*

# JUST THE FACTS- EFFECTIVE COMMUNICATION

Question to discuss before beginning this handout:

How effective is the communication in your family?

All families need to communicate. Family members have shared interests and concerns, such as running a household, engaging in recreational activities, and solving problems together. Family members also need to be able to express feelings to each other, such as happiness, excitement, anger, sadness, and concern or worry. Effective communication can let people know that they care about and appreciate each other and their efforts. Effective communication can also make it easier for people to express and make requests of others when needed and to resolve conflict when it arises.

## Communication and First Episode of Psychosis

Effective communication can be particularly important when a family member has had an episode of psychosis. Psychosis can disrupt communication in many ways. Some common examples include:

- Not talking and withdrawing from other people when feeling depressed.
- Irritability, anger outbursts, or unpredictable behavior due to mood changes.
- Misunderstanding others, which can lead to anxiety or suspiciousness.
- Unreasonable demands or lack of concern about others because of preoccupation with fears or anxiety.
- Difficulty accurately processing social information, such as facial expressions or hints, which can lead to misunderstandings.

These problems with communication can lead to high levels of stress in families. Conflict among family members can interfere with close relationships and detract from overall family life. In addition, family stress and tension can worsen the course of the psychosis, resulting in more relapses.

## Questions:

- What is good about the communication in your family?
- Are there any problems with communication in your family?

## **Pointers for Good Communication**

Several different strategies can be helpful for improving communication, resolving conflict, and developing a supportive family environment. These tips are especially important when a family includes someone experiencing a first episode of psychosis, because they can help compensate for the cognitive difficulties the individual with psychosis is experiencing.

### **Get to the Point**

Long-winded, roundabout statements can be hard for anyone to follow, but especially by someone who has difficulty concentrating. Problems paying attention and concentrating are common symptoms of psychosis. Being brief and getting to the point quickly makes it easier to get across to the other person, and to be sure one is understood.

### **Express feelings clearly with “I” statements**

Using words such as “angry,” “happy,” “upset,” or “worried” to describe one’s feelings avoids misunderstandings that can occur when people have to guess each other’s feelings. Using “I” statements such as “I feel...” are direct and to the point. When upset feelings are involved, using “I” statements can avoid putting the other person on the defensive, as compared to “blaming you” statements. For example, instead of saying “You pissed me off when you were late for dinner last night,” try saying “I was angry and worried when you came home late for dinner last night. I would appreciate it if you’d be on time next time or call if you’re going to be late.”

### **Speak for yourself and not others**

People often speak for others because they think they know what others are feeling. Families also may use “backchannel communication” to indirectly communicate with each other (for example “Your mother is angry with you”). Speaking for other people and using backchannel communication (either communicating indirectly to others or listening to such messages) naturally leads to misunderstandings since each person is truly an expert on only his or her feelings.

The problems of people speaking for each other can be avoided if everyone is responsible only for expressing his/her own feelings. This change may seem hard for family members who are not used to direct communication, but in the long run it can be helpful to everyone.

### **Listen to the other person**

Family members often know each other so well that they think they know what someone is going to say even before they say it. This can lead to cutting off the other person when he/she is the middle of talking, or not really listening to what he/she has to say. The problem with assuming one knows what the other person has to say is that it is often wrong, and it can interfere with change that both people desperately want. Not listening invalidates the other person’s perspective and implies that change is not possible.

Listening to each other, and letting the other person know that one understands by repeating what he/she is saying and asking questions, can let the person know you are interested and care about what he or she has to say. For example:

John: *"I feel so down and lonely that I drink to feel better."*

Mary: *"It sounds like your mood really affects your drinking. Would planning some regular activities with me be helpful?"*

### **Focus on behaviors rather than personality**

It is easier for people to change behavior than to change personality, attitudes, or feelings. Focusing communications on behavior rather than traits is especially important when you are upset, because you can make it clear to the person what you are upset about. For example:

INSTEAD of saying, *"You are an alcoholic."*

SAY, *"I am concerned because you are drinking so much and I worry about your health."*

INSTEAD of saying, *"You're thoughtless--you only think of yourself."*

SAY, *"I sometimes think you don't care about me because you rarely ask about my feelings. I wish you would show more concern by asking how I'm feeling more often."*

## **Pointers for Good Communication**

- Get to the Point
- Use "I" statements
- Use feeling words
- Speak for yourself and not others
- Listen at least as much as you talk
- Focus on behavior instead of personality

### **Communication Skills**

In addition to using the pointers described above, communication can be improved by following some basic techniques described below. These skills can be used when expressing different feelings to each other, and when there are disagreements or conflicts among family members. The rationale and steps of these communication skills are summarized below.

#### **Expressing positive feelings**

Everyone feels good when his/her efforts are acknowledged. Expressing positive feelings about what someone has done, however small, lets him/her know that they are appreciated. Positive feedback can also let the other person know what one cares about, which can foster change. Expressing positive feelings is especially important when a person has had a psychotic episode

and may feel confused or depressed about it. Positive feelings can be expressed by using the following steps:

- Look at the person.
- Tell the person what he or she did that pleased you.
- Tell the person how it made you feel.

For example:

- *“I’m proud of you that you went to your appointment even though you weren’t feeling like it.”*
- *“Thanks for helping me with the dishes tonight. It really made me feel less stressed.”*
- *“I am so pleased you went to the gym today. How did it go?”*

### **Making positive requests**

All close relationships involve some degree of doing things for each other. How people communicate their wants and needs can have an important impact on how the other person responds. Making a request of another person is most effective when it is clear, specific, and stated in a positive way. The following steps can be helpful when making requests:

- Look at the person.
- Make a specific request.
- Tell the person how you would feel if the request were granted.

For example:

- *“I would appreciate it if you could go shopping for groceries today.”*
- *“I’d like you to come with me to my prescriber’s appointment this Wednesday. I would like your help in explaining my medication side effect to her. I would be relieved to know you can be there with me.”*

### **Expressing Negative Feelings**

Everyone has negative or unpleasant feelings at some point. Some examples of negative feelings are anger, fear, sadness, disappointment, and worry. Being able to express unpleasant feelings constructively is crucial to resolving conflicts and getting along with other people. The following steps can be helpful in expressing and resolving negative feelings:

- Look at the person and talk with a serious voice tone.
- Tell the person what he or she did that displeased you.

- Tell the person how it made you feel—be specific.
- Make a request for change, if possible.

For example:

- *“I was worried when you didn’t come home from work at your usual time. In the future, if you think you’re going to be late, I would be so relieved if you would call or text me.”*
- *“I’m angry that you stopped taking your medication. Can we talk about what your concerns are about the medication and work out a way to get them addressed?”*

### Compromise and negotiation

People don’t always agree on what they want to do together, how to achieve goals, or how to solve problems. Close relationships are based on a degree of “give and take” in which each person gives as well as takes. Being willing to compromise is an effective way of reaching resolution when there is disagreement between people, as outlined in the steps below:

- Explain your viewpoint.
- Listen to the other person’s viewpoint.
- Repeat back what you heard (to show you understand).
- Suggest a compromise.
- Be open to talking over other possible compromises.

For example:

- Jane and Sam argued a lot about whether their 16-year-old daughter Emma should have a curfew.

Jane: *“I am worried Emma will get into trouble if she comes home late. I worry about problems with drinking or boys, and I can’t sleep until she is home. I don’t want her out past 11:00.”*

Sam: *“I know you worry about Emma but she has been trustworthy and often if she goes to the late movie, she won’t even be out by 11:00. It is pretty early for a weekend.”*

Jane: *“So you think Emma is trustworthy and 11:00 is too early to come home if she were going to a movie. But you know I still worry. How about we let her stay out till midnight only one night on the weekend, and the other night on the weekend she needs to be in by 11:00?”*

## Requesting a time-out

Sometimes when a person's feelings become very intense and emotions get heated, it is difficult to communicate effectively or to resolve problems. Taking a break from intense feelings can provide time for people to calm down, collect their thoughts, and be able to deal with the situation as constructively as possible. The following steps can be used to request a time-out:

1. Indicate that the situation is stressful.
2. Tell the person that it is interfering with good communication.
3. Explain that you would like to take a temporary break.
4. Say when you will be ready to talk and problem solve about the situation.
5. During the break, avoid doing things that will make the situation worse, like angry texting or using alcohol or drugs.

For example:

- *"I'm feeling stressed right now by this conversation. I'd like to take a break and discuss this with you later when I'm feeling calmer. I will be back in an hour"*

## Questions:

- Which of these communication skills are members of your family already good at?
- Which of these communication skills do you need to improve on?

## The Importance of practice

Communicating effectively is like any other skill—it takes practice to get good at it. Change is hard for everyone, and people may feel awkward or uncomfortable at first when trying to use the communication recommendations provided in this handout. With practice, the skills of good communication will feel natural over time, and the long-term rewards in terms of the quality of family relationships are well worth the effort.

Sometimes these communication changes seem hard to make and some people think "most people don't speak like this." The point here is to strengthen communication skills over and above "the average" to compensate for concentration and attentional problems that often are part of experiencing psychosis. Here, the goal is to be a better communicator than most people, to support the person in NAVIGATE's recovery.

Each of you will have the opportunity to practice at least one of the communication skills presented in the handout in the session. Which skills would you like to practice? Other family members should watch and make sure all the steps are covered.



## Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here is a home practice option for this handout that you can review now or at the end of the session:

Try one of these new skills each day, recording how it went on the worksheet on the next page.

## Worksheet for Practicing Communication Skills

Instructions: Choose a communication skill you would like to practice over the next week, and try to practice it every day. Write down the skill you would like to practice:

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Use this worksheet to record the day, the person to whom you talked, and what you said.

Day	Person you talked to	Situation	What you said

## Summary Points for Just the Facts- Effective Communication

- *Good communication can compensate for the attention and memory problems that occur with psychosis.*
- *Statements should be brief, specific, and use "I" statements.*
- *Some helpful communication skills include expressing positive feelings, making positive requests, expressing negative feelings, compromise and negotiation, and requesting a break.*
- *Using new ways of talking can be awkward at first, but can be helpful over time.*
- *Practice is important to strengthening to skills.*

## Pointers for Good Communication

- Get to the Point
- Use "I" statements
- Use feeling words
- Speak for yourself and not others
- Listen at least as much as you talk
- Focus on behavior instead of personality

# JUST THE FACTS- DEVELOPING A PLAN TO STAY WELL

The Developing a Wellness Plan module is designed to teach individuals and their relatives and other supporters basic information about how to prevent symptoms from returning. It is often helpful if the individual and relatives and other supporters can meet together with the Family clinician and the IRT clinician to discuss the material in this module.

Question to discuss before beginning this handout:

What do you already know about what can help reduce the chances of symptoms coming back?

## Why Does NAVIGATE Recommend a Wellness Plan?

Symptoms of psychosis tend to vary in intensity over time. Sometimes the symptoms may be absent; sometimes they may be mild or moderate; sometimes they may be strong. When symptoms come back or get worse, the technical term is a “relapse” or an “acute episode.” Although the person in NAVIGATE may only have an episode once or a few times in their lives, there is a chance that they may experience relapses.

However, there are lots of things the person and their family and friends can do to be proactive and significantly increase the chances of staying well and reducing the chances of symptoms coming back. These things are part of a Wellness Plan.

## Questions:

- Has there ever been a time when the symptoms of the person in NAVIGATE improved, but then came back?
- If so, please describe what happened.

## The Importance of proactive

If individuals have recovered successfully from a psychotic episode, they and their supporters can sometimes be reluctant to talk about the potential for symptoms coming back because they prefer to think that it will not happen. They may also be a little afraid that talking about symptoms might make it more likely that they will happen again—kind of like tempting fate. Instead, they want to put the incident “in the past” and not talk about it.

While this attitude is very understandable and common, in life it is usually very helpful to plan in advance for a problem, even if everyone hopes the plan never needs to be used. In some ways it’s like planning for what to do in case of a fire. For example, everyone hopes that a fire will never happen, but it is common to install smoke alarms and practice fire drills just in case. Making a plan

for keeping symptoms from coming back is similar. In NAVIGATE we call such a plan a Plan to Stay Well, although it can have other names.

It is usually best if the person in NAVIGATE and the family work together to develop the Plan to Stay Well. Then they can work as a team to support the plan. The person in NAVIGATE may also be working with their IRT clinician on the same topic.

### **Question:**

- What is one step your family has taken to help prevent or reduce the chance of symptoms coming back for the relative in NAVIGATE?

### **What is Included in a Plan to Stay Well?**

The NAVIGATE Program recommends three parts in a Plan to Stay Well:

Part 1: Preventing Common Causes of Symptoms Coming Back

Part 2: Being Aware of Early Warning Signs

Part 3: Action Steps for Responding to Early Warning Signs

As we go through this handout, we will work together to develop a Plan to Stay Well help the person in NAVIGATE stay well and on track with their goals. There is a blank Wellness Plan on the last page of this module. We will be filling out one part of the plan at a time.

Although we will refer to the plan as the Plan to Stay Well, people can call the plan whatever they want. For example, some people call their plan a “Just in Case Plan,” or a “Staying on Track Plan” or a “Relapse Prevention Plan.”

Before working on the plan, it may be helpful to see an example of a completed plan, such as Karina’s, which she chose to call her “Staying on Track Plan.” Karina’s example is below:

## Karina's Staying on Track Plan

### Part 1. Preventing the Common Causes of Symptoms Coming Back

Common Cause	What I can do to prevent this common cause
Not taking medication regularly	Keep a post-it on my bathroom mirror reminding me to take Rx Put my pill bottle next to my toothbrush in the bathroom
Difficulty coping with high levels of stress:	Talk to my friend Maria when I am upset Walk around the neighborhood once a day Practice relaxed breathing before bed
Using alcohol or drugs	Spend less time with people who drink or take drugs Suggest an alternative activity like playing a video game if someone asks me to use drugs Make at least one friend who doesn't drink or use drugs

### Part 2. Being Aware of Early Warning Signs

#### *My most important Early Warning Signs are:*

- A. Spending most days in my room sleeping
- B. Arguing with people and feeling irritable

### Part 3. Action Steps for Responding to Early Warning Signs

Action Step	Details for taking the Action Step
1. Contact the doctor or other treatment team member	<u>Dr. Miller's phone #: 333-444-5555</u> <u>Crisis phone #: 666-777-8888</u>
2. Get more social support	<u>Ask my sister to watch a movie with me or go for a run</u>
3. Stop or reduce the use of alcohol or drugs	<u>Find an activity other than hanging out at the houses of friends who drink or use drugs</u>
4. Use coping strategies	<u>Get some exercise-like running or biking</u> <u>Use relaxed breathing</u>

#### Questions:

- What might be some advantages of having a plan in case symptoms start to return?
- What do you think of Karina's example plan? How effective do you think it will be?

At the end of this handout, there is a blank plan. As you go through this handout, you will turn to the blank plan to fill in the sections.

## **Part 1 of the Plan to Stay Well: Preventing the Common Causes of Symptoms Coming Back**

There are three common causes of symptoms coming back.

- Stopping medication or not taking it consistently
- Difficulty managing high levels of stress
- Using substances like alcohol and drugs

People can often stay well by developing strategies to prevent these three common causes of symptoms coming back. We will talk about each of the common causes below and how to prevent them.

### **Stopping Medication or Not Taking it Consistently**

In earlier handouts in the Family Education Program, we talked about the role of medication in staying well. When people take their medications consistently, it helps symptoms in two ways: 1) it helps symptoms go away and 2) it helps symptoms not come back. We believe very strongly that medication is one of the most powerful tools for preventing symptoms from coming back, for staying out of the hospital, and for staying on track with goals.

It is especially important to remember that people should not stop taking their medications once they start feeling better. If they do, there is a very high risk that the symptoms will come back.

Here are some strategies for taking medication consistently:

- Developing a schedule for taking medications at the same time every day as part of their daily routine
- Using cues and reminders like cell phone alarms, pill organizers and calendars
- Keeping their medication next to an item they use daily, like their toothbrush or their cell phone charger
- Talking to their doctor or nurse about the possibility of switching to a long-acting injectable medication, which only has to be given once a month or even less often
- Asking someone to remind them of their medication in a friendly way.

There are many ways that the family can support these strategies. For example, the person in NAVIGATE may appreciate the help of their family in setting up a schedule or brainstorming about where to keep their medication. Or the person may appreciate the family going with them to their doctor's appointment to talk about long-acting injectables. Or the person may want a pleasant reminder if they forget to take their medications.

**Question:**

- What are one or two strategies that might be helpful on the Plan to Stay Well help with taking medications consistently?
- *Take a moment to turn to the blank plan at the end of this handout. Complete the first line in Part 1 of the plan by listing strategies you identified for taking medications consistently.*

**Difficulty Managing High Levels of Stress**

High levels of stress can contribute to symptoms returning. Being able to use coping strategies for stress can lessen the effects of stress and reduce the chance of symptoms returning.

There are many strategies for coping with stress, such as the following:

- Exercising
- Practicing mindfulness
- Listening to music
- Talking to a supportive person
- Using relaxation techniques such as relaxed breathing, imagining a peaceful scene and muscle relaxation
- Using positive self-talk, such as talking to oneself in an encouraging, reassuring way

There are many ways that the family can support the person in NAVIGATE in using these strategies. For example, the person might enjoy doing some type of exercise with a family member, such as taking a walk together or going to the gym together. Or the person might find it helpful to talk to a family member about what is causing their stress and they can brainstorm together how to address the situation. The family can also be helpful by keeping conflict in the family at low levels.

**Question:**

- What are a few strategies that you think might be helpful to include on the Plan to Stay Well for coping with stress?
- *Take a moment to turn to the blank plan at the end of this handout. Complete the second line in Part 1 of your plan by listing strategies you identified for coping with stress.*



## Avoiding Substances like Alcohol or Drugs

Even using small amounts of alcohol or drugs can cause symptoms to return for some people. NAVIGATE recommends that participants stop drinking and using drugs or at least cut down significantly on their use of substances.

Several strategies are helpful for quitting or cutting down on alcohol or drugs, such as the following:

- Spending time with people who don't use alcohol or drugs, like sober friends and family members
- Getting involved in fun activities that do not include using drugs and alcohol
- Avoiding situations where it is highly tempting to drink or use drugs
- Removing alcohol, drugs, and over-the-counter medications from the environment
- Getting additional support from a counselor, a family member, a friend, or a group like Alcoholics Anonymous (AA) or Narcotics Anonymous (NA)

There are many ways that the family can help support the person in using these strategies. For example, the person might appreciate the family brainstorming a list of sober friends and family members. The person might appreciate doing some activities together that don't involve alcohol or drugs. And the person may appreciate your lending an ear to talk about some of the challenges of quitting or cutting down on substances.

### Question:

- What are a few strategies you think would be helpful for avoiding substance use?
- *Take a moment to turn to the blank plan at the end of this handout. Complete the third line in Part 1 of the plan by listing strategies for avoiding substance use.*

## Part 2 of the Plan to Stay Well: Being Aware of Early Warning Signs

### What are Early Warning Signs?

Even when people do their best to avoid it, their symptoms may start to come back. This may occur over short periods of time, such as a few days, with very little or no warning. However, often symptoms develop gradually over longer periods of time, such as over several weeks.

There are often changes in the person's inner experience and changes in their behavior when symptoms are just starting to come back. For some people, the changes may be so subtle at first that they may not seem worth noticing. For others, the changes are more pronounced and distressing. When people look back, they often realize that these early changes, even the subtle

ones, were signs that their symptoms were starting to come back. These changes are called “early warning signs.” The quicker that early warning signs are identified and addressed, the more likely that a return of symptoms can be averted.

The family can play a critical role in helping identify and monitor early warning signs.

The following table contains some examples of common early warning signs. You can review this table with the family clinician and discuss whether the person in NAVIGATE ever experienced one or more of these signs before they had symptoms in the past. Put a check mark next to the ones the individual experienced or the family noticed.

### **Examples of common early warning signs**

#### Changes in Behavior

- Withdrawing from others
- Acting impulsively (e.g., spending lots of money)
- Eating less or eating more
- Sleeping too much or too little
- Stopping medication or stopping going to appointments
- Neglecting your appearance

#### Changes in Thinking or Senses

- Problems concentrating
- Hearing voices or sounds that other people don't hear
- Feeling Paranoid
- Problems following a conversation or focusing on a topic

#### Changes in Feelings or Mood

- Feeling irritable or extra-sensitive
- Feeling tense or nervous
- Feeling sad or depressed
- Feeling unsafe or worrying that people are against you
- Feeling angry a lot of the time

### **Unique early warning signs**

Some people have early warning signs that are unique to them. For example, one person's early warning sign was wearing all black clothing when they usually wore bright colors. Another person's unique early warning sign was not returning texts from friends or family members.

#### **Questions:**

- Which early warning signs did you mark in the table?
- Did the person experience any unique warning signs before experiencing symptoms? If so, what were they?

- *Take a moment to turn to the blank plan at the end of this handout. Complete Part 2 of your plan by writing down the early warning signs that you identified.*

### **Part 3 of the Plan to Stay Well: Action Steps for Responding to Early Warning Signs**

It is important to note that the person experiencing early warning signs is not always aware of them. The signs often come on gradually and the person may get used to them and not see them as unusual. Or the person may be reluctant to acknowledge the presence of early signs because they are concerned that talking about them will lead to them having some of the unpleasant experiences they may have had before, such as going to an emergency room or being admitted to the hospital.

Family members are often more aware of the presence of early warning signs and willing to acknowledge them and can therefore help the person in NAVIGATE be proactive in preventing a full return of symptoms. Family members and other supportive people can be the person's extra eyes and ears for detecting early warning signs. For these reasons, family members are especially helpful in Part 3 of the Plan to Stay Well, Action Steps for Responding to Early Warning Signs.

When early warning signs are noted, here are some things that family members can check out:

- Has the person stopped taking medication or is taking it less consistently?
- Is the person drinking or using drugs?
- Have stress levels increased? Has there been a recent change in the person's life? Any new responsibilities?
- Is the person using stress management techniques?
- Is the person still involved in treatment and attending appointments?

In addition, there are four helpful action steps that the person can take and that the family or other supporters can help them with.

1. Contact the doctor, the nurse, or other member of the NAVIGATE team.
2. Get more social support
3. If using drugs or alcohol, stop or reduce substance use
4. Use coping strategies

There are many ways that family members can support the Action Plan. For example, they can:

- Help the person contact the treatment team or call the treatment team on their behalf.
- Provide social support, including doing activities together.
- Give a ride to a self-help group like AA

- Suggest a coping strategy and/or do one together
- Avoid drinking or using drugs themselves
- Stay calm and keep the stress level low in the household

### Questions:

- What do you think is especially important about the action plan?
- *Take a few minutes to turn to the blank plan at the end of this handout. Complete Part 3 of the plan by writing down a few details about each action step.*

### **Putting the Wellness Plan into Practice**

Now it is time to think about preparing to put your plan into action. The plan won't do you any good if it is tucked away and forgotten.

Here are a few tips for putting the *Plan to Stay Well* into practice:

1. Make copies of the plan. Keep copies where you can easily find them, like in your wallet or in your desk drawer. Some people like to scan a copy and keep it on their phone.
2. Share the plan with other people. Family members, friends, and treatment team members benefit from having a copy of the plan. They can help spot early warning signs and take action steps.
3. Practice parts of the plan in advance. For example, the person can start using the coping strategies they identified, like getting regular exercise.
4. Modify the plan when needed. It should be considered a "living document" that is revised and changed over time as needed.

### **Home Practice Options**

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.

1. If the person in NAVIGATE was part of the family Wellness Plan sessions, review the completed family together at home. Check to see if anyone wants to add something to the plan.
2. If the person in NAVIGATE did not attend the family sessions about developing a wellness plan, ask them to review the Plan to Stay Well the family worked on, and to give input on each of the three parts of the plan. For example, do they have additional ideas for preventing the three common causes of symptoms returning? Do they remember early warning signs that are not listed on the plan? What other action steps do they think would be helpful?

## Summary Points for Developing a Plan to Stay Well

- *The three most common causes of symptoms are returning is when people are under more stress, stop taking their medications, or use alcohol or drugs. These common causes can be prevented.*
- *Early warning signs are the subtle changes in a person's inner experience and behavior that signal that symptoms may be starting to come back.*
- *Learning about early warning signs can help someone predict and avoid symptoms returning.*
- *Developing an action plan can help identify steps to get help when anyone in the family notices early warning signs.*
- *A Plan to Stay Well consists of developing plans to prevent common causes of symptoms returning, notice early warning signs, and take action steps if early signs appear.*
- *Friends, family members, practitioners and other supportive people can be helpful in developing a Plan to Stay Well and carrying it out.*

My Plan for \_\_\_\_\_

**Part 1. Preventing the Common Causes of Symptoms Coming Back**

<b>Common Cause</b>	<b>What I can do to prevent this common cause</b>
Not taking medication regularly	
Difficulty coping with high levels of stress:	
Using alcohol or drugs	

**Part 2. Being Aware of Early Warning Signs**

***My most important Early Warning Signs are:***


**Part 3. Action Steps for Responding to Early Warning Signs**

<b>Action Step</b>	<b>Details for taking the Action Step</b>
1. Contact the doctor or other treatment team member	
2. Get more social support	
3. Stop or reduce the use of alcohol or drugs	
4. Use coping strategies	

# JUST THE FACTS- DEVELOPING A COLLABORATION WITH MENTAL HEALTH PROFESSIONALS

Question to discuss before beginning this handout:

What do you already know about collaborating with mental health professionals?

A key objective of the NAVIGATE program is to help relatives and friends work more effectively with the mental health professionals caring for their family members in NAVIGATE. In most cases, outcomes are best when the person who has had a first episode of psychosis, the treatment team, and relatives all work together.

What is involved in effective collaboration? The partnership may include sharing information, for example. Providing input into planning for services may be another component. The earlier this collaboration begins the better. If individuals who have had a first episode of psychosis want relatives or friends involved in treatment, there are many opportunities to work together. If individuals oppose this involvement, collaboration will probably take more time to develop in a trusting way. Even if individuals who have had a first episode of psychosis are totally opposed to their relatives interacting with treatment staff, relatives can still work to educate themselves and improve their own coping and stress management skills. These efforts should still lead to better outcomes.

**A strong collaboration among the person with a first episode of psychosis, relatives, and the treatment team increases the likelihood of a good recovery.**

In this handout, a number of critical issues related to strengthening this partnership will be discussed.

## **Learning about Types of Mental Health Services**

Most communities are divided into what are called catchment areas. A specific mental health agency, funded at least in part by the government, offers services in each area. As a taxpayer, any adult has the right to contact these agencies. He or she can inquire about what services they offer and how to become eligible. Typically, the agency is listed in the telephone book in the government pages or can be found online.

## **The Value of Case Management**

A key question is whether the agency supports a case management system. In the case management system, an individual or team of individuals assumes responsibility for organizing the care of the person with psychosis. This care is not limited to managing the symptoms of the person with psychosis. It also includes providing support in how to meet basic living needs, such as housing or money. A knowledgeable case manager can be an outstanding resource for information on services, how they are paid for, etc.

Agencies differ widely in how they define case management. For some, case management is defined as intermittent meetings with the person with psychosis and the case manager in the office. For others, case management requires more "assertive" effort on the part of a comprehensive case management team. Examples of more assertive case management could include:

- Going out to find the person with psychosis if he or she misses a medication appointment.
- Accompanying the person with psychosis to important appointments at other agencies, such as the Social Security Office.
- Visiting the person with psychosis at home to check in on him or her and offering assistance as needed.

Many studies have shown the value of assertive case management services. They can be vitally important in reducing relapse rates and improving living standards and quality of life of persons with serious psychiatric illnesses.

## **The Value of Peer Support**

Over the past ten year, it has become clear that having individuals who have lived experience of a serious psychiatric disorder like psychosis or schizophrenia can be an invaluable part of the mental health treatment team. These individuals can provide hope and encouragement, while also modeling that recovery is possible. Agencies differ widely in whether they employ peer specialists and what their tasks are, but most good mental health agencies now do include peer specialists, and these peer specialists often undergo specialty training and certification.

## **Improving Relationships with Mental Health Professionals**

### **Organizing Meetings**

If the person with the psychotic episode is willing, it is often helpful for relatives to meet with the loved one and the professional who has primary responsibility for coordinating the patient's care. In a public agency, this is likely to be a social worker or case manager. In a private setting, this is



likely to be a psychiatrist. The person with the psychotic episode and his or her relatives can offer a lot of important information at this meeting, such as:

- Answering questions professionals have about prior episodes of the illness and response to medications and other treatments.
- Providing Input about responses to medications (the person might have only limited memory of these responses) and side effects.
- Developing a treatment plan.

In addition, everyone can also ask questions about strengthening rehabilitation for the person with the episode of psychosis. For example, the person and his or her relatives can ask about new treatment developments and the availability of crisis services. As in all dealings with health care professionals, the best strategy is to be respectful, but persistent, in obtaining answers to its questions. Remember, however, that no one has all the answers to mental illness. Mental health professionals likely share frustrations about slow progress and limited success as well.

**In the NAVIGATE program, we encourage frequent meetings among the individual with the psychosis, relatives, and the treatment team.**

### **Providing Key Information**

Sometimes the individual with the psychosis does not want his or her relatives involved in treatment. However, relatives may believe that they have information critical to the individual's care. What should a concerned relative do? One possibility is to telephone professionals to convey information. In most states, there is no statute or law prohibiting professionals from listening to the information the relative wants to provide. Similarly, the professional can usually answer general questions about the illness and its treatment.

Some professionals will refuse to take such a phone call. In a situation like this, relatives may have to reconsider whether partnership is even possible. They might want to explore other options for providing information. For example, they could write a letter to the professional outlining the important information. They could also try to talk with another healthcare professional who is working with the person with psychosis. Confidentiality issues are discussed in more detail below.

### **Question:**

- What do you want to talk about with the NAVIGATE team? How can you arrange to do it?

## Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here is a possible home practice option for this handout that you can review now or at the end of the session.

Make a list of any concerns you want to discuss with the NAVIGATE team. Bring the concerns to the next meeting with the NAVIGATE team.

## Collaboration in a Crisis

Collaboration in a crisis, when anxiety and uncertainty are high, can be difficult. One helpful technique is preparing a one to two-page description of the individual's history and prior medication response before an emergency situation occurs. This summary can be updated as needed. It can easily be given to crisis workers or emergency room nurses if the need for a quick intervention arises.

Another critical step in managing urgent issues is to develop a structured Plan to Stay Well. Ideally, this plan is developed in advance, and all family members have agreed to it. This topic is discussed more fully in the NAVIGATE Developing a Plan to Stay Well module.

**Preparing in advance can help collaboration in a crisis go much more smoothly.**

## Home Practice Options

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here are some home practice options for this handout that you can review now or at the end of the session.

1. Put together a two-page description of the relative in NAVIGATE's psychiatric history and response to medication.

## **Confidentiality and Disclosure of Information**

### **Confidentiality Laws**

In this country, laws on confidentiality protect interactions with mental health professionals. These laws assure that people seeking therapy are free to disclose their innermost thoughts and feelings. They do not have to fear that their thoughts and feelings will be revealed to others. The only exceptions are a threat of danger to the person or others, evidence of child, elder, or disabled person abuse, use of child pornography, or involvement in some lawsuits.

Confidentiality laws help develop trust between the clinician and the person seeking treatment. These laws are grounded in the belief that the person in treatment can generally act in his or her best interest and can make good decisions about what is best for him/her. Unfortunately, psychosis can sometimes confuse a person's thinking. It can limit the ability to act in one's best self-interest. For example, a person with a psychotic disorder can decide he/she no longer needs treatment before he/she has recovered. He/she may also become suspicious about relatives or go live on the streets. In light of these problems, an optimal treatment plan for the individual is frequently based on open sharing of relevant information early in treatment.

This sharing can take place among the individual with psychosis's concerned relatives and friends, and the treatment team. "Relevant information" does not mean that every single thought the individual with psychosis or relative has is shared with other family members. It refers to circumstances related to managing the situation successfully. Relevant information sharing might include topics like strategies to encourage taking medication regularly, possible symptom flare-ups, what to do in an emergency, and knowledge of and adherence to treatment recommendations. Many readers will be familiar with the HIPAA regulations that are designed to protect privacy. Many mental health professionals are trained to emphasize protection of confidentiality in treatment. They can be reluctant to communicate with relatives and friends of the individual. This reluctance is consistent with the laws protecting patient information disclosure. However, these concerns about confidentiality can sometimes impede effective treatment. This is especially the case when a person with psychosis is not able to act in his or her own best self-interest. In such a situation, communication between the treatment team and relatives can be vital.

### **Communication Options for Relatives**

Relatives do have options in communicating with the treatment team. Under most circumstances, the person in treatment can consent to the treatment team sharing critical treatment planning information with the relative or concerned loved one. Many persons who have experienced an episode of psychosis see the value of having family or other supported involved in their recovery and readily sign a consent form for this purpose.

Sometimes the person in treatment is initially reluctant to have a dialogue between relatives and the treatment team. However, relatives are often a major source of support for the person in treatment. Sharing information is a topic that can be revisited at a later time to create a more

satisfactory arrangement. In these types of situations, establishing a dialogue is really an ongoing process instead of a one-time activity.

What if the person in treatment hesitates to have a dialogue between the treatment team and relatives, but the relatives have important information for the team? In this case, the relatives can ask to provide information to one of the mental health professionals on the team. This information could be provided either on the phone or by letter. Note that the professional would not be able to reveal privileged clinical information in return. In initiating the contact, relatives could acknowledge the dilemma for the professional. The key is to assure the professional that the relative is only providing information. He or she is not trying to obtain information protected by confidentiality laws.

**In the NAVIGATE program, the goal is open sharing of information among the individual, relatives and the treatment team, in order to most effectively support recovery.**

### **Kinds of Professional Roles**

Most people experiencing psychosis are seen by several professionals. These professionals work together in either a formal or informal team. Team members have different roles.

Persons in treatment for psychosis will usually have a psychiatrist or other medication prescriber they see on a regular basis. Typically, these meetings primarily involve clarifying the diagnosis, evaluating current symptoms, and prescribing or adjusting medications. Other healthcare professionals provide most of the additional ongoing counseling and case management. Examples of other healthcare professionals include psychologists, nurses, social workers, case managers, peer specialists and nurses. In NAVIGATE, the treatment team is comprised of a program director, a family clinician (who may also be the program director), individual resiliency training (IRT) clinicians, a supported education and employment worker, and a psychiatrist or nurse practitioner. Many NAVIGATE teams also include case managers and peer specialists.

Often, psychiatrists are scheduled to see individuals for very brief appointments. They may have little time for returning phone calls or meeting with relatives. Relatives can deal with this limited access in several ways:

- Cultivating a relationship with one of the other healthcare professionals working on the NAVIGATE team. This person can sometimes "troubleshoot" for families if there are specific concerns they want to bring to the attention of the treatment team.
- Requesting a meeting with the person in treatment and the psychiatrist, accommodating whatever scheduling the psychiatrist can offer.

### **Advocating for the Person in NAVIGATE**

Recovery from psychosis takes a coordinated effort among the individual, his or her relatives, and the mental health professionals involved. In this handout, and in other parts of our program, family

members may become aware that their relative might benefit from services which he or she is not currently receiving. Unfortunately, many persons with psychosis may be unaware or unable to request the services they need. Here, other family members can play a critical role. Encourage the family member in NAVIGATE to ask for what he or she may need. Family members can also advocate for this need. Consult with the treatment team, because understanding its thinking about what might benefit the relative in NAVIGATE can be essential to developing a strong recovery program. Remember, it is the squeaky wheel that gets the grease!

### **Language that Mental Health Workers Use**

Becoming familiar with the language used by mental health professionals helps communication. Non-professionals often use common terms like "hearing voices" instead of "auditory hallucinations" or "emotions" instead of "affect" or "worrisome thought" instead of "delusion." Mental health professionals will of course understand these terms. However, relatives occasionally come across terms used by mental health professionals that puzzle or confuse them. If a term seems puzzling or confusing, ask! No one should be shy about inquiring about what terms mean when they are used in conversation with professionals.

#### **Question:**

- Are you uncertain of any of the terms members of the NAVIGATE program has used in conversations with you?

### **Home Practice Options**

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here is a home practice option for this handout that you can review now or at the end of the session:

Keep a list of terms you would like defined and bring it to the next NAVIGATE meeting.

**In the NAVIGATE program, the goal is open sharing of information among the individual who has experienced an episode of psychosis, relatives, and the treatment team, in order to most effectively support recovery.**

## Summary Points for Just the Facts- Developing Collaboration with Mental Health Professionals

- *A strong collaboration among the person with a first episode of psychosis, relatives, and the treatment team increases the likelihood of a good recovery.*
- *Frequent meetings among the individual with the psychosis, relatives, and the treatment team can strengthen recovery.*
- *Preparing in advance can help collaboration in a crisis go much more smoothly.*

# JUST THE FACTS- A RELATIVE'S GUIDE TO SUPPORTING RECOVERY FROM PSYCHOSIS

Question to discuss before beginning this handout:

What do you already know about supporting recovery from psychosis?

Loving a family member with a serious psychiatric illness can be challenging. The potential for a relapse and worries about the future often can weigh heavily on a relative's mind. Fortunately, recovery is more likely to occur if a relative encourages a person who has had a psychotic episode to:

- Take medication as prescribed.
- Avoid drug and alcohol use.
- Participate in a rehabilitation program and/or find something productive to do.
- Limit the amount of stress experienced within the family.

## High Levels of Tension Are Common in Many Families Dealing with a Psychotic Episode

Relatives can assume a positive role in managing stress in the family. Research conducted with families has found that a positive family environment among relatives and a person with psychosis plays a very important role in minimizing the progression of symptoms.

When interacting with a person with a serious psychiatric illness, relatives often benefit from attempting to understand what their relative in NAVIGATE is experiencing, i.e. "trying to put themselves in the person's shoes." A person with a psychosis must cope with disturbing symptoms, side effects of prescribed medication, and the fact that he/she has an emotional or mental health problem. These factors can seem like overwhelming challenges for both the person with psychosis and for those who care about him or her. Levels of tension, anxiety, and confusion may be high for both the person who has experienced a first episode of psychosis and his or her relatives.

## Critical Communication Patterns Are a Problem

An experience of psychosis can be devastating. It is not surprising that loved ones of the person with psychosis may frequently feel irritable or "on edge." Sometimes this stress causes the relative to prompt or nag the person who has experienced the first episode of psychosis to try to get things

under control. Criticism in families is normal. However, these types of communication patterns have been related to higher rates of relapse.

Criticism and extreme self-sacrificing behavior, even if done for the own good of the person who is experiencing psychosis, often have a bad effect. Repeated prompting, correcting, and fault-finding may lead to an increase in symptoms. Relatives can become more aware of the behaviors they direct toward the individuals with a first episode of psychosis, and try to reduce ineffective prompting or criticism.

Relatives can become aware of the levels of criticism, nagging, and prompting within the family and attempt to limit the amount they occur. If family members focus on reducing these behaviors, the stress level should lessen. One way to work to reduce criticism is to focus instead on praising desired positive changes, no matter how small they might seem.

**Focus on the positive rather than the negative whenever possible.**

**Question:**

- What are two things family members can praise the relative in NAVIGATE for?

**Home Practice Options**

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here is a home practice option for this handout that you can review now or at the end of the session:

1. Make sure family members praise the relative in NAVIGATE at least once daily over the next week about something positive he/she is doing.

**Extremely Self-Sacrificing Behavior May Create Difficulties**

Many relatives are inclined to be extra watchful in caring for a family member with psychosis. Relatives may be reluctant to leave the person with psychosis unsupervised and may reduce work or social activities in order to increase the time they are available to assist the person. However, persons who have had an episode of psychosis are acutely sensitive to external pressure. They may find this additional supervision to be stressful, and withdraw even more. It may even create guilt in the person with psychosis, who sees his or her family member refuse positive social, job, or leisure opportunities on his or her behalf. Research shows that this self-sacrificing behavior may have the unintended impact of contributing to a worsening of symptoms. In short, relatives need to be sure they "get a life," even though the person in NAVIGATE is still recovering.



**Relatives need to be sure they continue to develop their own lives.**

**Question:**

- What is one activity, perhaps a hobby, family members have let go of but would like to spend more time on?

It is clear that the person who has experienced a psychotic episode can reduce the frequency of relapses by taking his/her medication as prescribed and avoiding the use of drugs and alcohol. The manner in which relatives interact with the person with psychosis may also affect relapses. If relatives minimize the criticism, nagging, and extreme self-sacrificing behavior, they can aid in the reduction of stress within the family. Reducing stress usually reduces the frequency of relapse, and therefore the outcome of the person in NAVIGATE will be improved. As the relative in NAVIGATE improves, this will also have a positive impact on the rest of the family as well!

**Two Good Mottos: Don't sweat the small stuff!  
Choose your battles wisely!**

**Home Practice Options**

Between sessions, most people in our program find it helpful to try putting some knowledge or skill into practice at home, so they can see how it works in their own situation. Here is a home practice option for this handout that you can review now or at the end of the session:

Try to do one fun activity just for yourself this week.

**Summary Points for Just the Facts- A Relative's Guide to Supporting Recovery from Psychosis**

- *Relatives can be important influences in recovery from psychosis.*
- *Conflict in families can increase stress, which can make symptoms worse.*
- *Paying attention to the positive helps reduce stress.*
- *Relatives need to be sure they take care of themselves and have some fun too.*

# **Format for Monthly Check- Ins with the Family**

# 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 provide a forum for this information sharing, as well as providing an opportunity to assess how the family is faring. Meetings should be held in person 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 with relatives may suffice. Participants should be called two days in advance to remind them of the face-to-face meetings. Typical monthly contact meetings would last for 45 minutes.

As the participants raise issues in monthly check-in meetings, the family clinician reviews appropriate educational material, gives advice and guidance, or helps problem-solve to resolve concerns. If formal decision-making or problem-solving might benefit the family, the family clinician can also use the Decisional Balance and Problem-Solving or Goal Setting Sheet from the *Family Consultation to Solve Problems and Make Decisions* section of the manual. 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 “non-mental-health” community as possible.

## Structure of Monthly Check-in Meetings

1. Welcome to the session, and setting the agenda
2. Review of client's current status.
3. Discussion of client's goals and relevant progress and ways family can help with goals.
4. Review of client's participation in treatment program.
5. Monitoring early warning signs.
6. Progress/concerns noted by family

### Welcome to the Session and Agenda Setting (5 Minutes)

Regardless of the main focus of this session, it begins with utilizing the alliance building techniques presented previously and setting the session agenda. In the alliance building stage, the family clinician greets participants warmly and asks how each person's week went, particularly emphasizing “any urgent issues that might get in the way of the work today.” The goal is to be engaging, but not to be deterred by other issues, unless they are critical. The family clinician can say something like the following:

*“It's good to see you all again. The session will run about 45 minutes, and I want to get a clear sense of how XXX is doing in his recovery and answer any questions you have and address any concerns. Any crises or urgent issues we need to address before we begin?”*

## Review of Client Status (10 Mins)

Here, the clinician prompts the client and family to discuss the client's current status. It is important to engage both the client and the relatives in the discussion and identify opportunities to review any of the educational material, as relevant. This is especially important if the relatives are critical of the client.

*(To Client) "XXX, so how have things been going for you over the past month? What has been going well? Any problems? Any symptoms or issues troubling you? How has it been going with the medication? I know it can be hard to keep it all straight—how many times have you missed it in the last couple of weeks?"*

*"How have things been going for you with your family? How have you all been getting along? Have you been seeing any friends? What about drugs or alcohol?"*

*(To Relatives) "How do you think XXX has been doing? What has been going well? What kinds of improvement have you noted? Any problems? Anything you are worried about? Any concerns on your end?"*

## Discussion of Client Goals and Progress, Including Possibilities for Family Assistance (10 Mins)

Here, the clinician prompts the client to discuss his/her treatment goals as well as progress on the goals. It is important to engage both the client and the relatives in the discussion, and to look for opportunities where clinical knowledge and skills can be integrated into family life.

*(To Client) "XXX, remind us all again what goals you have been working on in the IRT program? How about in SEE? How have you been progressing on them? Anything you are proud of? Any problems working on the goals? Have you needed support people for these goals? Has your family been helping? Do you need help from your family?"*

*(To Relatives) "What have you noticed about XXX's work on these goals? Anything come to mind? Any way you have been able to help?"*

## Review of Client Participation in the Treatment Program, Including Discussion of Next Steps and Length of Time in Program (5 Mins)

The objective of this part of the session is to encourage the client to continue to participate in treatment and to evaluate the family's attitudes towards treatment participation. Any obstacles to participation are addressed.

*So, "XXX, how has it been going for you here at the program? Have you been making your appointments? Who are you working with now? Any difficulties with transportation to the clinic or getting there on time? What are you doing in the IRT program? Are you working with the SEE specialist? Anything happening with work or school?"*

*(To Relatives) “What has been going well about XXX coming to the treatment program? How are you feeling about that? Any concerns?”*

*(To All) “You all have been with the program for XX months now—how do you think it is going overall? Any thoughts about how long you might want to continue? Have any of you talked at all about how long you might want to be continuing with us in NAVIGATE?”*

### Monitoring Early Warning Signs (5 Mins)

The goal here is to check for the presence of early warning signs and model this checking for client and relatives. The client’s completed Plan to Stay Well sheet should be available for review.

*“I have a copy of your Plan to Stay Well form here—let’s quickly look it over. Has it changed at all? Are any of your warning signs flaring up? And what about stressors? Are any of the circumstances you mentioned in plan happening now? How have you been handling this?”*

### Opportunities for Family Input (10 Mins)

The goals here are to prompt the family to note any progress in the client, to be sure any family concerns are addressed, and to assess how the family is coping.

*(To relatives) “We talked a bit about the improvements XXX is making—anything you are particularly pleased with? Anything else going well from your perspective? Anything we did not mention that concerns you? Worried about anything else we did not mention yet? How have you all been doing? How are you bearing up?”*

### Closing the Session (5 Minutes)

The session should close with the clinician:

- Asking if participants have anything else to add
- Summarizing the main points covered in the session
- Making a plan for follow-up of any problem-solving done in the session
- Clarifying how the information obtained here will be utilized by the treatment team
- Scheduling the next meeting date
- Thanking the participants for attending

### After the Meeting

Confer with other NAVIGATE team members about any issues raised in the monthly check-in.

# Clinical Guidelines for Family Consultation to Solve Problems and Make Decisions

Consultation is offered to families on an “as needed” basis as problems arise after the education sessions. The family clinician may become aware of the problems from the team, during the monthly check-ins, or because someone in the family alerts him/her to a problem. Usually a course of family consultation will take from 1-5 sessions, with 3 being typical.

## Goals

1. Identify the problem to be solved or decision to be made.
2. Conduct a problem-solving session or decisional balance as appropriate.
3. Schedule a follow-up session as needed.
4. Schedule subsequent meetings as needed to continue problem solving or working on implementing a solution.

## Materials Needed

Educational forms – Family Consultation to Solve Problems and Make Decisions

## TEACHING STRATEGIES:

- Begin by engaging participants in some small talk.
- Elicit the purpose of the meeting from whomever brought up the issue.
- Be prepared to conduct either problem-solving or complete a decisional balance.
- Have family members take on as much responsibility for the meeting as possible.
- Involve all participants.
- Continue in additional sessions until a resolution is found.

## **TIPS FOR COMMON PROBLEMS:**

### **One Person Does Not Want to Solve the Problem**

- In general, there are two strategies for dealing with the difficulty of one person not wanting to be involved in solving the problem. First, an attempt can be made to redefine the problem so the person becomes more interested in participating in the discussion. For example, parents who were upset about their son's refusal to bathe regularly were able to engage him in a discussion by changing their definition of the problem from "*Joseph rarely bathes and smells unpleasant*" to "*Joseph doesn't like it when his parents nag him about bathing.*" The second strategy to use when one person will not participate in solving the problem is to meet without that person. For example, two parents had a daughter who smoked in all rooms of the house, despite clear household rules. Since they were unable to get her to cooperate to solve this problem, the parents chose to meet the family clinician without their daughter to establish consequences for their daughter's breaking the household rules, and then shared them with her. This meeting was held with the daughter's consent.

### **Choosing among Multiple Problems**

- Families may be besieged by many problems. Decisions must be made regarding which problems should be addressed first, second, and so on. The most important consideration when prioritizing problems is the urgency of the problem. Crisis oriented problems, such as suicidal thoughts, self-destructive behavior, violence or threats of violence toward others, or marked worsening in symptoms, must be addressed immediately. The next type of problems to be addressed is those related to a possible relapse of symptoms. For example, the abuse of drugs or alcohol, which can precipitate a relapse, is a high-priority problem. Similarly, if the person with psychosis stops taking medication or has begun to have early warning signs of a relapse, it is important to have a consultation to get help.

### **The Problem or Goal Is Too Broad and It Is Unclear Where to Start**

- Some problems or goals may be so large that they seem to be as insurmountable. Breaking down a large problem into small, manageable chunks can aid the process of problem solving, just as a tall mountain can be climbed by taking many small steps. To break the problem down into smaller elements, identify what needs to be changed first, then second, etc. Try to make each element small enough so that it can be solved, and work on only one step at a time. For example, the client in one family was interested in improving his personal hygiene without prompting from family members. The task of improving hygiene, including bathing regularly, washing hair, brushing teeth, combing hair, and deodorant use, was too great to solve in a single family meeting. However, family members were able to make headway on the problem when they worked on improving only one hygiene area (e.g., brushing teeth) at a time. It is important to praise small steps toward the big goal.

## **The Consultations Result in Arguments**

- Meeting when tension is low and avoiding blaming statements can reduce arguments. Defining the problem very specifically, rather than generally, can also help prevent arguments. Focusing on how to improve things for the future, instead of dredging up the past, helps. When there is a conflict among family members, it is usually because each person has a different viewpoint about a problem that is difficult to change. Taking a brief time-out is also an option.

## **Participants Don't Follow Through on Plans**

- There are three basic reasons why most family members do not follow through on a plan that has been agreed upon during a consultation meeting 1) they forget what they agreed to do; 2) they do not know exactly what they are supposed to do; 3) they do not believe that the plan selected will lead to the best solution. Strategies for overcoming these obstacles are as follows:
  1. Reminding people to follow through on their part of the plan can prevent forgetfulness. Reminders can be verbal or written. Some families post a list of each family member's role in solving a problem. It is helpful to post the list in a prominent spot such as on a bulletin board or the refrigerator.
  2. When a plan is being discussed in the consultation meeting, efforts should be made to clarify exactly what each person's role is and what he or she is expected to do. At the end of the consultation meeting, the clinician should ask every family member to summarize what they promised to do, in order to ensure that everyone knows his/her role.
  3. Sometimes people do not do their part of a plan because they do not really believe that the plan will work, or they disagree with the definition of the problem itself. If someone repeatedly does not follow through on the plan, despite reminders, this possibility should be explored. The solution may need to be adjusted.

## **No Matter How Hard the Family Tries, the Problem Cannot Be Solved**

- Sometimes it is difficult to solve a problem or achieve a goal despite many attempts. When all reasonable efforts have been made, redefining the problem or goal can be a useful strategy. For example, one participant in the NAVIGATE program, Sally, kept saying she wanted to quit smoking. Her parents thought that was a great idea, since her father had developed lung cancer from smoking. Unfortunately, trying to quit smoking was very stressful and Sally got very irritable with her parents and her brother, had a hard time sleeping, and kept worrying about putting on weight because she tended to eat more when she smoked less. While Sally acknowledged that smoking was a problem and not good for her health, the family members decided that they would redefine the goal as "keeping Sally's smoking to less than half a pack a day" over the next three months until she was more stable on her medication and the holidays were over. Sally agreed with the plan and quit smoking about 6 months later.



## **THE MOST IMPORTANT GOAL OF THE CONSULTATION SESSION:**

Resolve the issue the family wants to address.

## **EVALUATING GAINS:**

You should monitor progress by collecting information from all possible sources—the team, client report, family report, monthly check-ins—to see if the issue is improving.

# **Family Consultation to Solve Problems and Make Decisions Participant Handouts**

# Family Consultation to Solve Problems and Make Decisions

Once family members have learned how to support recovery from psychosis in the educational phase of NAVIGATE, they are still likely to confront many challenging situations. In addition to the monthly follow-up meetings, the NAVIGATE team is available on an “as needed” basis to work with families to address issues and problems associated with recovery in psychosis.

Problems may be related to issues confronting the person in NAVIGATE as he/she pursues goals—perhaps problems taking medication regularly, finding friends, learning to budget, or managing urges to use alcohol or drugs. Typically, a consultation will involve 2-3 meetings with the participants and the family clinician, each scheduled one or two weeks apart. For most problems, the more family members who can attend the sessions, the more likely it is that the problem solving will be successful.

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 program, we often use systematic problem-solving and goal-setting as the foundation of family consultations. In this handout, we first discuss how to work on solving problems and present the steps of successful problem solving.

Some situations involve *making a decision* rather than solving a problem. For example, the person in NAVIGATE may need to decide whether to go back to school or to move from where he/she lives. In such a situation, making a decision then leads to problems that need to be solved. To increase the likelihood of making the best choice possible, using a structured approach to making a choice may be helpful. This structured approach is often called a “Decisional Balance.” The “nuts and bolts” of a decisional balance are presented in the second part of this handout.

At the end of the handout you can find a blank Problem-Solving Sheet and a blank Decisional Balance Sheet; your family can use these formats over and over by making copies of these sheets.

**Using a systematic approach can help families solve problems and make decisions better.**

## **Organizing Family Problem-Solving**

Families often find that following a specific structure for solving a problem can help to organize the members and keep them focused on the issue at hand. The family clinician helps organize the family and structure the discussion to follow the steps of problem-solving. Using these steps had been shown to increase the likelihood that successful solutions will be found.

## Steps of Problem Solving and Goal Attainment

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. We encourage everyone to participate actively in the family discussion and all feedback is welcome.

The six steps are as follows:

1. **Discuss the problem or goal.** All family members talk about the problem or goal and pay attention to what each person says. It is especially important for the people most involved to talk about how the problem affects them. When everyone has expressed opinions, family members try to arrive at a common definition of the problem or goal. This may require family members to compromise with each other. Wording the problem or goal positively in terms of how to change something can facilitate accomplishing this step. When family members agree on a specific definition, it is written down. During the discussion it may become clear that the problem actually involves a decision to be made. Strategies for good decision making are discussed below.
2. **Brainstorm at least three possible solutions.** At the beginning of this step, family members review previous attempts to resolve the problem. This review helps avoid repeating the same mistakes. Then, everyone identifies as many potential solutions to the problem as possible. Do not evaluate the solutions at this time. Even “fantasy solutions”, outlandish ideas, and humorous responses can be included. Everyone should contribute at least one idea, and no one is criticized.
3. **Briefly evaluate each solution.** List the advantages and disadvantages of each idea for solving the problem or achieving the goal.
4. **Choose the best solution.** Try to pick the easiest solution that is likely to work. The chosen solution(s) should be agreed upon by the family members. Sometimes, one or two solutions are clearly favored by everyone. Other times, family members may differ as to which solutions they prefer. Solutions may need to be modified or compromises made in order for the family members to reach agreement.
5. **Plan the implementation.** When family members agree on how they want to solve the problem or achieve the goal, they need to formulate a plan to put their ideas into action. This plan addresses four key elements:
  - A. **Time-frame.** When will different parts of the plan be accomplished?
  - B. **Resources.** Are any special resources needed to carry out the plan (e.g., money, skills, information)?
  - C. **Roles.** Who is responsible for doing what?
  - D. **Possible obstacles.** What could interfere with putting the plan in action? How could these obstacles be avoided and dealt with if they occur?

6. **Review implementation at the next consultation; modify as needed.** After the family has agreed upon a plan, a date is set to meet again and evaluate whether the plan was successful. At this meeting, family members will discuss and praise efforts that have been made to implement the plan and evaluate whether further effort is necessary to solve the problem or achieve the goal. The follow-up meeting can be just a few days away or a week away.

#### **Summary of Steps to Solve Problems and Achieve Goals:**

1. Define the problem.
2. Generate possible solutions.
3. Evaluate each possible solution.
4. Choose the best solution or combination of solutions.
5. Plan how to carry out the solution(s).
6. Review implementation of the plan and praise all efforts.

#### **Here is an example**

Four members of a family, including the mother, two sons, and a daughter with first episode psychosis all lived together in a small apartment. One day, the daughter got into an argument with her boyfriend and threatened to throw a lamp at him. The boyfriend left but it appeared to the mother that her daughter was experiencing an increase in her symptoms. A consultation meeting with all family members was scheduled for the next morning with the clinical team. During the consultation meeting, after several minutes of discussion about the problem, everyone agreed to define the problem as “XXXX feels like she might hurt someone.” The family identified six different possible solutions:

1. Take extra medication.
2. Go to the nearest hospital for an evaluation (and perhaps admission).
3. Daughter leaves the apartment.
4. Other family members leave the apartment.
5. Go to the hospital where the daughter was previously admitted.
6. Call the treatment team for an evaluation.

After considering the advantages and disadvantages of each possible solution, the family members agreed that the best solution was number 5, because the daughter felt the situation was urgent, and she was most comfortable going to a hospital where she was familiar with the treatment staff. A plan to implement the solution included the following steps:

1. Clinician calls hospital to see if there are available beds for admission. (If no beds are available, the closest hospital is called).
2. Mother calls Uber for transportation to hospital.

3. Daughter packs clothes and toiletries.
4. One of the brothers accompanies his sister to hospital.

The plan was followed successfully, and the daughter was admitted to the hospital and got the treatment to help.

### Question:

- How does your family usually solve problems?
- What problem do you need to work on today?
- Who can follow-up to see if the solution is implemented?

**Many difficulties in solving problems can be overcome**

### Making Good Decisions

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 best, the clinician can introduce the task of completing 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
6. Follow up the plan at a later time.

Everyone in the consultation meeting should help give ideas for the decisional balance. An example of a decision balance completed by a family to weigh the advantages and disadvantages of their family member with psychosis quitting cocaine is provided in the table below.

## Decisional Balance for Using or Not Using Cocaine

Option A	Potential Good Outcomes from Option A	Potential Bad Outcomes from Option A
Using cocaine	Might have fun	May get depressed
	Feel more normal	May end up in hospital
	Will see friends	Will have to be a newcomer at Cocaine Anonymous again
		Make family upset
Option B	Potential Good Outcomes from Option B	Potential Bad Outcomes from Option B
Not using cocaine	Can buy clothes with cash	Will be bored

Taken together, what is the best option?

Option B: Not using cocaine \_\_\_\_\_

### **After the Decisional Balance is Completed:**

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. For example, with the person who completed the decision balance on cocaine use, his decision to avoid cocaine use resulted in a series of new problems, including:

1. Dealing with cocaine urges;
2. Finding sober friends; and
3. Finding transportation to a Cocaine Anonymous meeting.

## Summary-Problem-Solving and Making Decisions

The client and relatives were then able to define each of these as a specific problem or goal and used the steps of problem-solving that they had previously learned.

1. Solving problems using a structured approach often leads to better outcomes.
2. Everyone's input is important
3. The steps to solve problems and achieve goals are:
  - a. Discuss the problem.
  - b. Brainstorm three possible solutions.
  - c. Briefly evaluate each solution.
  - d. Choose the best solution(s).
  - e. Plan the implementation.
  - f. Review implementation at next family meeting.
4. Families may encounter difficulties in solving problems together, but there are strategies for overcoming obstacles.
5. When there are important decisions to make, listing pros and cons in a decisional balance can be very useful.
6. Both problem solving and decisional balances are important parts of NAVIGATE family consultations.



## **Problem-Solving or Goal-Setting Sheet**

1. *Discuss the problem or goal.* Get everyone's opinion. Try to reach agreement on exactly what the problem/goal is. Write down *specifically* what it is

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2. *Brainstorm at least three possible solutions.* Do not evaluate at this time-- wait till step 3.

3. *Briefly evaluate each solution.* List major advantages and disadvantages.

	<b>Advantages</b>	<b>Disadvantages</b>
(1) _____	_____ _____ _____	_____ _____ _____
(2) _____	_____ _____ _____	_____ _____ _____
(3) _____	_____ _____ _____	_____ _____ _____
(4) _____	_____ _____ _____	_____ _____ _____
(5) _____	_____ _____ _____	_____ _____ _____

4. *Choose the best solution(s).* Consider how easy it would be to implement the solution and how likely it is to be effective.

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5. *Plan the implementation.* When will it be implemented?

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What resources are needed and how will they be obtained?

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Who will do what to implement the solution?

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List what might go wrong in the implementation and how to overcome it.

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Practice any difficult parts of the plan.

Who will check that all the steps of the plan have been implemented?

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6. *Review implementation at next family meeting.* (Date: \_\_\_\_\_) Revise as needed.

## Decisional Balance

<b>Option A</b>	<b>Potential Good Outcomes from Option A</b>	<b>Potential Bad Outcomes from Option A</b>
<b>Option B</b>	<b>Potential Good Outcomes from Option B</b>	<b>Potential Bad Outcomes from Option B</b>

Taken together, what is the best option?

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# **Modified Intensive Skills Training (MIST)**

# Modified Intensive Skills Training (MIST)

## A Variation of Behavioral Family Therapy (BFT) for NAVIGATE

### Overview

Behavioral Family Therapy (BFT) uses educational and social learning techniques to teach family members information about psychiatric disorders and their treatment, and communication and problem-solving skills aimed at lowering stress and promoting family cooperation (Mueser & Glynn, 1999. Gingerich & Mueser, 2006). In addition, BFT facilitates the ability of the family to collaborate with the treatment team to support the client to pursue personal goals. Thus, the overarching goals of BFT are improved illness management, through collaboration between the family and the treatment team, and reduction of family stress.

Sessions include the client and relatives with whom they have regular contact. The program is designed to meet the needs of family members in at least weekly contact, though this level of contact is not essential if a relative or significant other expresses a desire to be involved and a commitment to support the client in coping with his or her illness. Family members benefit from participating in all BFT sessions, although some, such as siblings who do not live nearby, may only attend selected sessions. It is recommended that family sessions include members who are sixteen or older. The clinician may want to meet separately with children in the family to respond to their specific concerns. BFT sessions last about an hour and are conducted on a declining contact basis.

Because BFT is being embedded in NAVIGATE family work after assessment and education, it will be modified slightly here with a greater emphasis on skills training—hence the title Modified Intensive Skills Training (MIST). MIST is a structured program aimed at teaching a specific curriculum, which is tailored to address the unique needs of the family, including the duration of sessions, the number of sessions spent on specific topic areas, and total length of the program. Most families will take about 6 months to complete MIST (e.g., weekly for three months, biweekly for two months and then a monthly follow-up). The structure and principles of BFT outlined above apply to MIST. MIST is divided into five stages, which build knowledge and skills in a step-by-step fashion. Table 1 lists the stages and the general guidelines for the number of sessions. Table 2 lists the typical flow of a session.

MIST can be offered to families who have completed the basic NAVIGATE Family Education, but are still in need of more skills. Families who have stressful communication patterns and have significant difficulties solving problems are likely to benefit the most from MIST. MIST may also be helpful to families when the client is relapsing frequently or not making progress on goals.

In order to fully implement MIST, the family clinician should obtain a copy of Behavioral Family Therapy for Psychiatric Disorders (Mueser and Glynn, 1999), which contains a thorough description of the techniques used in BFT and in MIST, as well as a variety of handouts that can be helpful to provide during MIST. This book is currently out of print, but used copies are available online.

## Assessment

The individual assessment sessions with family members help the clinician revisit the material collected in the initial NAVIGATE family assessments and to identify personal goals for each participant. Some family members may find it difficult to identify personal goals on which to work, because they see their participation strictly as a way to help their relative with mental illness. The clinician can point out that the personal wellbeing of every family member is important and has an effect on overall stress in the family, which in turn affects the course of their relative's mental illness.

Family members who find it difficult to identify personal goals to work on in MIST may benefit from hearing examples of personal goals that others have identified, such as improving physical fitness, developing a hobby or interest (e.g., music, art, sports, crafts), socializing more often, learning ways to reduce stress, eating more nutritional meals, and going out more often as a couple. If goals are very ambitious, the clinician can help break them down into small steps that can be accomplished one at a time in the 6 months of MIST. Note that the client may prefer to work on his/her IRT goal.

## Family Review of Education

For this stage of MIST, the clinician meets with the whole family in 1-2 sessions to review the key points of the NAVIGATE family education program covered at the beginning of the program. The summary points from each of the handouts can be used, with the ultimate objective being to assure that all participants can explain the vulnerability-stress model in their own words, as this serve is the foundation for the subsequent skills training. The clinician pauses frequently to ask questions to make sure family members understand, and to help them apply the information to their own experiences. The person in NAVIAGATE is identified as the "expert" in the psychiatric illness and is asked to share what he or she has experienced. In educational sessions, it is important for the clinician to create an atmosphere where family members feel free to ask questions, express their opinions, and even to disagree with each other.

## Structure of MIST Sessions

In MIST sessions, the clinician follows a structured agenda, which is outlined in Table 2. The structure includes reviewing family members' goals (identified and broken down into steps during the assessment stage), teaching new material, and developing home assignments to follow up what they are learning in the sessions. A fundamental component of all home assignments is asking the family to conduct a weekly family meeting where they review information or practice skills taught in sessions. These family meetings may be very short at first (15 minutes) as the members become comfortable talking with each other about psychiatric illness. Later in MIST, weekly family meetings are typically longer as they include practicing specific communication skills or solving problems together.

Near the beginning of each session, the clinician inquires whether the family meeting was held and how it went. If the family has met, the clinician provides positive feedback, and if they did not meet, the clinician problem solves with them about any obstacles they encountered. If the clinician follows up routinely in this fashion, most family members will get into the habit of meeting together on their own in between sessions and doing home assignments.

## Communication Skills Training

Some families have excellent communication skills and need only a brief review, as provided in the NAVIGATE educational stage in the handout “Effective Communication.” Other families need specific training in communication skills to reduce stress in the household and to prepare them to discuss and solve problems in the next phase of MIST. In contrast to the communication skills review in the NAVIGATE educational program, the skills training in MIST is more detailed and directive. The clinician notes that good communication skills are helpful to any family, and are especially important when a family encounters stress or problems, such as those caused by psychosis. Communication skills are taught using the steps of social skills training (Bellack, Mueser, Gingerich, & Agresta, 2004; Gingerich, 2002; Liberman, Derisi, Mueser, 2001), as described below. The clinician:

1. Establishes a rationale for learning the skill. Asks family members why they think it could be helpful to learn (or strengthen) the skill.
2. Breaks down the skill into 3-4 steps.
3. Demonstrates the skill in a role play. Ask the family for feedback regarding the specific steps of the skill.
4. Asks a family member to practice the skill in a role play, while others observe.
5. Elicits positive feedback about what was done well in the role play. Provides extra positive feedback as necessary.
6. If needed, provides a suggestion about how the person could perform the skill even better.
7. Asks the family member to repeat the role play, requesting that he or she implement the suggestion for improvement.
8. Asks family members to provide positive feedback and suggestions for additional improvement in the skill.
9. Engages each family member in one or more role plays, providing positive feedback and suggestions for improvement after each role play.
10. Develops a home assignment with family members to practice the skill in their everyday life.

Communication skills training in MIST focuses on six skills:

- Expressing Positive Feelings
- Making a Positive Request
- Expressing Unpleasant Feelings (such as annoyance or sadness)
- Active Listening
- Compromise and Negotiation
- Requesting a Time-Out

Some families may need training in only one skill, whereas others may benefit from learning more skills. One or two training sessions (and occasionally more) are usually necessary for family members to learn one skill. Reproducible handouts of communication skills and home assignments (such as “Catch a Person Pleasing You” for practicing the skill of Expressing Positive Feelings) are available in Mueser & Glynn (1999) and Mueser et al. (2003). An example of a skill sheet is depicted in Table 3.

## Problem Solving

In the NAVIGATE Family program, the consultation meetings and MIST meetings both involve problem-solving. In the consultation sessions, the goal is to help family members solve problems. However, one of the main goals of MIST is to *teach* families a systematic method of solving their own problems, rather than just helping solve them. The clinician emphasizes the importance of family members learning collaborative problem-solving skills in order to solve problems on their own, rather than relying on professionals. Learning how to solve problems empowers the family to be more self-sufficient and able to deal with a variety of situations that may arise. The six steps of problem solving are summarized in Table 4.

In family problem solving, a “chairperson” is elected who guides the family through the steps and makes sure that everyone has input throughout the process. In addition, someone is usually asked to act as a “secretary,” to write down the results of the problem solving on a summary sheet (see the Problem-Solving Record in Mueser & Glynn, 1999) so that family members can refer back to it. The role of the chairperson and secretary can be combined.

At the beginning of teaching problem solving, the clinician first explains the steps and demonstrates them by working on a specific problem with the family. The clinician should first help the family choose a problem or goal which is not extremely difficult to solve, such as identifying an activity that the family could do together or selecting a consistent time for weekly family meetings. Initially, the clinician takes the role of “chairperson,” helping members go through all 6 steps. As the family members gain experience, family members rotate taking on the role of the “chairperson,” and they gradually begin to do more and more problem solving on their own, with less and less assistance from the clinician.

As the family gets better at problem solving, they can tackle more challenging problems related to the client, such as finding a part-time job, reducing substance use, making friends, or developing coping strategies for persistent symptoms, as well as working on the goals of other family members. Generally, we recommend family members complete problem-solving and successfully implement the solutions for at least two problems before moving to every other week sessions, and at least four problems before moving to monthly check-ins.

## Termination

When family members have gained an understanding of psychosis and have made significant progress in their communication and problem-solving skills, the clinician works with them to plan for ending the intervention and then move to monthly check-ins and ongoing consultation in NAVIGATE. Some families take longer than others to complete MIST, depending on the knowledge and skills with which they started and the complexity of problems they experience. Likewise, families vary in the supports they require to maintain the progress they have made.



## References

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**Table 1: Stages of MIST**

BFT Stage	Approximate # of sessions
1. Assessment	1 session per family member; 1 optional family session
2. Education Review	1 family session
4. Communication skills training	4-6 family sessions
5. Problem-solving training	5-8 family sessions
6. Termination	1 family session

**Table 2 Structure of MIST Sessions**

<b>Activity</b>	<b>Time Period</b>
Welcome family members to the session, socialize informally, review the family's week	2-3 minutes
Review individual family members' goals	5 minutes
Review home assignment and family meeting	5-15 minutes
Present psychoeducational topic or teach skill	20-30 minutes
Develop home assignment (including meeting together as a family) to follow up what was taught in session	5 minutes
Summarize session and thank members for their participation	2-3 minutes
Optional: If necessary, reserve time to problem-solve urgent problems raised in the session (e.g. Crises)	5-15 minutes at the end of the session

### **Table 3: Steps of Expressing Unpleasant Feelings**

- Look at the person.
- Tell the person what he or she did to displease you. Be specific.
- Tell the person the feeling it gave you. Be specific.
- Make a positive request for change, if possible, so that the situation can be prevented in the future.

## Table 4: Step-By-Step Problem Solving

### Problem-Solving or Goal-Setting Sheet

1. *Discuss the problem or goal.* Get everyone's opinion. Try to reach agreement on exactly what the problem/ goal is. Write down *specifically* what the problem/ goal is.

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2. *Brainstorm at least three possible solutions.* Do not evaluate at this time-- wait till step 3.

3. *Briefly evaluate each solution.* List major advantages and disadvantages.

	<b>Advantages</b>	<b>Disadvantages</b>
(1) _____	_____ _____ _____	_____ _____ _____
(2) _____	_____ _____ _____	_____ _____ _____
(3) _____	_____ _____ _____	_____ _____ _____
(4) _____	_____ _____ _____	_____ _____ _____
(5) _____	_____ _____ _____	_____ _____ _____

4. *Choose the best solution(s).* Consider how easy it would be to implement the solution and how likely it is to be effective.

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5. *Plan the implementation.* When will it be implemented?

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What resources are needed and how will they be obtained?

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Who will do what to implement the solution?

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List what might go wrong in the implementation and how to overcome it.

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Practice any difficult parts of the plan.

Who will check that all the steps of the plan have been implemented?

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6. *Review implementation at next family meeting.* (Date: \_\_\_\_\_) Revise as needed.

# Discharge Planning

# Discharge Planning

As the client and family are leaving the NAVIGATE program, the family clinician plans at least two conjoint sessions with the client and relatives. The goals of these sessions are to review progress made in the program, refine the discharge plan, and to make referrals to any additional resources needed by the family. These sessions can replace the monthly meetings. The format for these 45 minutes sessions is as follows:

## First Family Discharge Planning Session

### Introduction, Alliance Building, and Agenda Setting (5 Minutes)

Regardless of the main focus of this session, it begins with utilizing the alliance building techniques presented previously and setting the session agenda. In the alliance building stage, the clinician greets the participants warmly and asks how each person's week went, particularly emphasizing "any urgent issues that might get in the way of the work today." The goal is to be engaging, but not to be deterred by other issues, unless they are critical. The agenda for the session includes:

1. Review of client's current status
2. Begin/continue discussion of discharge planning
3. Review of client's participation in treatment program
4. Monitoring early warning signs
5. Referrals to community resources for family

*"It's good to see you all again. The session will run about 45 minutes, and the primary issue we will be discussing is XXX's transition out of the NAVIGATE program. Are there any crises or urgent issues we need to address before we begin?"*

### Review of Client Status (5 Mins)

Here, the clinician prompts the client and family to discuss the client's current status. It is important to engage both the client and the relatives in the discussion, and to look for opportunities to review any relevant educational material.

*(To Client) "XXX, so how have things been going for you over the past month? What has been going well? Any problems? Any symptoms or issues troubling you? How has it been going with the medication? I know it can be hard to keep it all straight—how many times have you missed it in the last couple of weeks?"*

*"How have things been going for you with your family? How have you all been getting along? Have you been seeing any friends? What about drugs or alcohol?"*

*(To Relatives) "How has XXX been doing? What has been going well? What kinds of improvement have you noted? Any problems? Anything you are worried about? Any concerns on your end?"*



## Discussion of Discharge Planning (10 Mins)

Here, the clinician begins or continues the discussion of the recommended treatment plan, and inquires about what the client and relatives perceive their needs to be. The clinician should be prepared to “fill in the gaps” if the client is uncertain about any aspect of the discharge planning.

(To Client) *“You have been talking with the team here about graduating from NAVIGATE. Why don’t you tell your family a bit about that? How are you feeling about that? What do you think about this change? What might be good about it? What might be hard? I know you have been talking with the team—will you be getting any further treatment? Where? What will you do to make that happen? Have you made any contact yet? Do you anticipate any obstacles? How can I help?”*

(To Relatives) *“What do you think about this change? What might be good about it? What might be hard? What are your concerns?”*

## Review of Client Participation in the Treatment Program (10 Mins)

The objectives of this part of the session are to review the client’s progress, identify future plans, and have the family acknowledge the client’s progress.

(To Client) *“Tell us a bit about your progress on your goals. How are you feeling about what you have accomplished? What are you most pleased about? What remains for you to work on?”*

(To Relatives) *“What has been going well for XXX since his/her coming to the treatment program? How are you feeling about his/her progress?”*

## Monitoring Early Warning Signs (5 Mins)

The goal here is to check for the presence of early warning signs and model this checking for client and relatives. You should bring to the meeting a copy of the client’s completed early warning sign sheet.

*“Sometimes a change of care can be stressful, so we want to keep an eye on this. I have a copy of your Plan to Stay Well here—let’s quickly look it over. Any of your warning signs flaring up? And what about stressors? Any of these circumstances you mentioned happening now? How have you been handling this? How will you remember to keep monitoring your warning signs even when you leave our program? How can you all work together to do that?”*

## Issues Raised for the Family by Discharge (10 Mins)

The goals here are to prompt the family to identify any needs that should be included as part of the discharge plan and/or to follow-up on prior referrals as appropriate.

(To relatives) *“When you think of XXX leaving NAVIGATE, what issues come up for you? If you need support, any ideas how you might get it? What resources do you have? Do you need any referrals from us?”* (Provides information as needed)

## Closing the Session (5 Minutes)

The session should close with:

- Asking if participants have anything else to add.
- Summarizing the main points covered in the session.
- Reminding client and relatives of tasks to be accomplished before the final session (e.g., appointments with new care providers, following up on referrals for support).
- Asking client and relatives to be prepared to give him/her feedback on NAVIGATE at the next session.
- Scheduling the final meeting date.
- Thanking the participants for attending.

## Treatment Planning Between the Two Discharge Planning Sessions

The clinician should report to the team about any issues that arose as part of the first discharge meeting and investigate referrals for any resources requested by the family.

## **Final Discharge Planning Session**

The goal of this session is to reiterate any recommendations made to the family about the discharge and to say goodbye to the family.

## Introduction, Alliance Building, and Agenda Setting (5 Minutes)

This session begins with utilizing the alliance building techniques presented previously and setting the session agenda. In the alliance building stage, the clinician should greet the participants warmly and ask how each person's week went, particularly emphasizing "any urgent issues that might get in the way of the work today." The goal is to be engaging, but not to be deterred by other issues, unless they are critical. The agenda for the session includes:

1. Review of client's current status.
2. Finalizing the discussion of discharge planning.
3. Review of client's participation in treatment program.
4. Monitoring early warning signs.
5. Follow-up on referrals to community resources for family.
6. Getting feedback on program.
7. Review of family strengths.

*“It’s good to see you all again. The session will run about 45 minutes, and the primary issue is that we will be saying good bye to you all today. Any crises or urgent issues we need to address before we begin?”*

### Review of Client Status (5 Mins)

Here, the clinician prompts the client and family to discuss the client’s current status. It is important to engage both the client and the relatives in the discussion, and to identify opportunities to review relevant educational material.

*(To Client) “XXX, so how have things been going for you over the past month? What has been going well? Any problems? Any symptoms or issues troubling you? How is leaving NAVIGATE going? Do you notice yourself under any particular stress?”*

*(To Relatives) “How has XXX been doing? What has been going well? Any problems? Anything you are worried about? Any concerns on your end?”*

### Discussion of Discharge Planning (10 Mins)

Here, the clinician continues the discussion of the recommended treatment plan, and inquires about what the client and relatives perceive their needs to be. You should be prepared to “fill in the gaps” if the client is uncertain about any aspect of the discharge planning.

*“So, I have here a summary of the discharge recommendations from our end—we have talked about all of these—here, let me give you a copy—any questions?”*

### Review of Client Participation in the Treatment Program (10 Mins)

The objectives of this part of the session are to review the client’s progress, identify future plans, and have the family acknowledge the client’s progress.

*(To Client) “So, when you look over your work in NAVIGATE, which accomplishments are you most pleased with? What are you most surprised by? How are you feeling as you leave?”*

*(To Relatives) “What has been going well about XXX since his/her coming to the treatment program? How are you feeling about his/her progress?”*

### Monitoring Early Warning Signs (5 Mins)

The goal here is to check for the presence of early warning signs and model this checking for client and relatives. The clinician should bring a copy of the client’s completed Plan to Stay Well sheet to the meeting.

*“We talked about how a change of care can be stressful so we want to keep an eye on this. Let’s review your Plan to Stay Well—here is a copy. Any of your warning signs flaring up? And what about stressors? Any of these circumstances you mentioned happening now? How have you*

*been handling this? How will you remember to keep monitoring your warning signs even when you leave our program? How can you all work together to do that?"*

### Follow- Up on Referrals as Needed (5 Mins)

The goal here is follow-up on any referrals for additional services given to client and relatives.

*"So, what were you going to follow-up on since our last meeting? How did that go? Any obstacles with which you want my help?"*

### Obtaining Feedback on Navigate Program (10 Mins)

The goal is to provide every participant with an opportunity to discuss strengths and weaknesses of the NAVIGATE program, including but not limited to the family component.

*"I asked each of you last time to be thinking about what you had liked about the NAVIGATE program, and what we might improve. We are always trying to make things even better for clients and their families."*

*"I am going to ask about the overall NAVIGATE program and then about the family part. So, what did you like about the overall NAVIGATE program (solicits feedback from each participant; uses active listening skills but does not evaluate responses). So what could be improved in the program—anything you disliked? (solicits feedback from each participant; uses active listening skills but does not evaluate responses).*

*"What about the family portion? What did you like? What was helpful? (solicits feedback from each participant; uses active listening skills but does not evaluate responses). So what could be improved in the family program—anything you disliked?" (solicits feedback from each participant; uses active listening skills but does not evaluate responses)*

*"Thanks for your feedback. I really appreciate it. I will make sure the team gets your input".*

### Acknowledgement of Family Strengths (5 Mins)

The goal here is to acknowledge the family's progress and strengths. The clinician should be prepared to mention an asset of each attendee.

*"I have been thinking about when I first met you and how things have changed. I think of the progress you have made (describes) and the strengths I have admired (mentions). I have admired (describes at least one asset for each participant). I am glad XXX is doing well enough to leave, but I am sad to see you all go."*

*"Anyone else have any final words? Ok, I wish you all the best."*

## Closing the Session (5 Minutes)

The session should close with:

- Asking if participants have anything else to add.
- Summarizing the main points covered in the session.
- Thanking the participants for attending.

# **Clinical Guideline for Discharge Planning**

# Clinical Guideline for Discharge Planning

Discharge from Navigate may be prompted by several circumstances—client progress, relocation, changes to another treatment team. During family meetings, the family clinician will put the expected timeline of progress in NAVIGATE in context, so discharge will not come as an unexpected event. At least two sessions should be devoted to specific discussion of family need and treatment transitions, as outlined in the section on discharge above. Most clients in NAVIGATE will be receiving referrals to other treatment programs by this point, typically involving stepped down care.

## Goals

1. Assure family understands next treatment options
2. Respond to any questions family has about discharge
3. Reinforce strengths family has exhibited.
4. Obtain feedback on NAVIGATE program.

## Materials Needed

List of referrals to subsequent treatment, copies of plan to Stay Well, copies of discharge recommendations

## TEACHING STRATEGIES:

- Begin by engaging participants in some small talk.
- Remind family about impending discharge.
- Be prepared to conduct either problem-solving or complete a decisional balance if there are specific concerns about discharge/termination that require attention.
- Involve all participants.
- Take time to highlight any strengths or progress participants have evidenced

## THE MOST IMPORTANT GOAL OF THE SESSION:

Shore up family strengths and make sure members understand recommended next steps.

# APPENDIX



# Major Revisions to the 2020 Version of the NAVIGATE Family Manual

1. Included a “Healthy Lifestyles” module to mirror IRT and help families support proactive health behavior in clients in NAVIGATE.
2. Added the “Basic Facts about Alcohol and Drugs” module as a standard module for all families, instead of being optional. This was done to reflect the high rates of substance use in the original NAVIGATE sample.
3. Updated the information on causes and factors that influence the course of psychosis and schizophrenia-spectrum disorders to include social determinants and personal factors such as a history of trauma.
4. Clarified use of the stress-vulnerability model of schizophrenia more to explain the *course* or *outcome* of the disorder, rather than as a depiction of its causes, as so much more needs to be discovered about the etiology of the illness.
5. Added more information about engaging clients around family involvement in care.
6. Added a baseline client interview to obtain his/her view on issues in the family.
7. Updated the medication information to be current.
8. Included more strategies to monitor family clinician fidelity to the intervention.
9. Provided two family stories of participation in NAVIGATE—Sam’s Story (good pre-morbid functioning; economic resources) and Taavi’s Story (single parent family; client under 18). The clinician can select the story which appears to best match the needs of the family and NAVIGATE participants.

## Decisional Balance

Option A	Potential Good Outcomes from Option A	Potential Bad Outcomes from Option A
Option B	Potential Good Outcomes from Option B	Potential Bad Outcomes from Option B

Taken together, what is the best option?

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## Problem-Solving or Goal-Setting Sheet

1. *Discuss the problem or goal.* Get everyone's opinion. Try to reach agreement on exactly what the problem/ goal is. Write down *specifically* what the problem/ goal is.

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2. *Brainstorm at least three possible solutions.* Do not evaluate at this time-- wait till step 3.

3. *Briefly evaluate each solution.* List major advantages and disadvantages.

	<b>Advantages</b>	<b>Disadvantages</b>
(1) _____	_____ _____ _____	_____ _____ _____
(2) _____	_____ _____ _____	_____ _____ _____
(3) _____	_____ _____ _____	_____ _____ _____
(4) _____	_____ _____ _____	_____ _____ _____
(5) _____	_____ _____ _____	_____ _____ _____

4. *Choose the best solution(s).* Consider how easy it would be to implement the solution and how likely it is to be effective.

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5. *Plan the implementation.* When will it be implemented?

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What resources are needed and how will they be obtained?

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Who will do what to implement the solution?

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List what might go wrong in the implementation and how to overcome it.

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Practice any difficult parts of the plan.

Who will check that all the steps of the plan have been implemented?

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6. *Review implementation at next family meeting.* (Date: \_\_\_\_\_) Revise as needed.

# Assessing Provider Competence and Fidelity to the Model

It can also be challenging to keep skills up after one has learned an evidence-based practice. Even if one demonstrates excellent skills during training, over time providers often want to “add their own spin” to their work, and they often have years of experience to inform any changes they might make in the model. Here, we discuss some tips to address these concerns.

## Monitoring NAVIGATE Family Education Quality

It is a delicate balance for a provider to keep faithful to the key components of any evidence-based mental health practice and still feel they are able to use their own personality and gifts to conduct the intervention. Over time, it is easy for providers to “drift” away from the core tenets of the intervention, but this is not desirable. There are a couple of strategies to address drift: Provider self review and manager review.

The “Family Education Fidelity Scale” is available as a tool to monitor fidelity to the intervention; both self review and manager review can be useful. The fidelity ratings cover the key ingredients of family work utilizing a 5 point scale from 1 = unsatisfactory to 5 = excellent. The purpose of monitoring fidelity is to measure the extent to which family clinicians are implementing the treatment as intended by the model and to provide family clinicians with ongoing feedback about the implementation of the family work with clients.

## Provider Self-Review

One way is for providers to keep aligned with the NAVIGATE family education intervention is to use the *Family Education Fidelity Scale* to direct their work. The scale includes the key components of the intervention, and reviewing the scale and the appropriate clinical guidelines *before* a session (even if they have done the session tens of times) often helps them keep “on track”. Particularly after a challenging session, it can be useful to review the fidelity scale and the guidelines again to determine if all the material was covered, or if and when things diverted from the planned content. The provider can then do some self-reflection to determine if the diversion was needed (such as may be required by a symptom or medication crisis) or if greater effort to keep on the planned agenda could have been helpful

## Manager Review

Another strategy to address drift is for a manager or supervisor to occasionally listen in on a family education session and use the *Family Education Fidelity Scale* to provide feedback to the provider. Some managers find it easiest to just rotate in and join a session for each provider on a quarterly or biannual basis, while others ask the provider to record a session and the manager and provider can listen to the session together and both discuss and rate the session on the fidelity scale. Areas of concern can then be addresses. Of course, in the latter case, the participants would need to consent to the recording in advance. Feedback from listening to the family sessions and measuring fidelity can be used during supervision to help clinicians stay faithful to the model. The feedback also can help family clinicians identify clinician strengths as well as weaknesses, which can be addressed during supervision, leading to better client outcomes.

## Family Education (FE) Fidelity Scale

Fidelity ratings are based on observation of a family session or listening to an audiotape of a family session.

Clinician: \_\_\_\_\_

Site: \_\_\_\_\_

Date of Session: \_\_\_\_\_

Module & Topic: \_\_\_\_\_

Date of Rating: \_\_\_\_\_

Name of Rater: \_\_\_\_\_

Overall Session # \_\_\_\_\_

### **TYPE OF FAMILY SESSION**

- Educational Session
- Monthly Check-in
- Family Consultation
- Modified Intensive Skills Training (MIST)
  - Communication Skills Training
  - Problem-Solving Session
- Other (specify) \_\_\_\_\_

### **PERSONS WHO ATTENDED SESSION**

- Client
- Mother
- Father
- Spouse/Partner
- Siblings (specify number) \_\_\_\_\_
- Children (specify number) \_\_\_\_\_
- Other relatives (specify number) \_\_\_\_\_
- Non-family members (specify number)
- RAISE Team Members (specify number) \_\_\_\_\_
- Professionals OTHER THAN RAISE Team Members (specify number) \_\_\_\_\_

## General Guidelines for FE FIDELITY Scale

<b>1</b> Unsatisfactory or not Observed	<b>2</b> Needs Improvement	<b>3</b> Satisfactory	<b>4</b> Very Good	<b>5</b> Excellent	<b>NA</b> Not Applicable
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**NOTE: SOME ITEMS ARE MARKED AS NOT APPLICABLE TO CERTAIN TYPES OF FAMILY SESSIONS. FOR EXAMPLE, IN MONTHLY CHECK-IN'S, CLINICIANS ARE NOT EXPECTED TO USE SKILLS TRAINING STRATEGIES.**

\_\_\_\_ 1. Agenda Setting

- Set specific agenda at the beginning of session
- Elicit other issues from client for agenda
- Implement specific agenda

Comments:

\_\_\_\_ 2. Review of Home Assignment (not applicable to monthly check-ins)

- Review prior home assignment
- Reinforce any efforts to complete home assignment
- Identify and problem solve obstacles to completing home assignment
- If client or family struggles to complete home assignment from previous session, help to complete in session

Comments:

\_\_\_ 3. Use of family education handouts and worksheets

- Utilize handouts and worksheets to guide the session
- Answer and elicits questions
- Stay focused on topic

Comments:

\_\_\_ 4. Motivational Enhancement Strategies

- Connect material and session content to client's goals
- Promote hope and positive expectations
- Explore pros and cons of change
- Reinforce "change" talk
- Reframe experiences in a positive light

Comments:

\_\_\_ 5. Educational Strategies

- Provide information
- Connote client as expert in his or her experience of illness
- Connote all family members as expert in their own experience
- Elicit family members' experience related to presented material
- Adapt language to family's preferences
- Break down information into manageable chunks
- Provide interim summaries
- Ask questions to check for understanding

Comments:



\_\_\_ 6. Positive Reinforcement and Shaping

- Praise successive approximations (small steps) towards completion of home assignments, progress towards goals, using of strategies and learning of skills
- Give positive, specific feedback about learning and using information, strategies and skills
- Celebrate completion of modules
- Reinforce on-topic comments and ignore off-topic comments

Comments:

\_\_\_ 7. Skills Training Strategies (not applicable to monthly check-in sessions)

- Use following skills training strategies for teaching families to use skills themselves (such as relaxation, communication, & problem-solving)
- Establish/elicit rationale for skill
- Discuss steps of skill
- Model (demonstrate) the skill
- Help family members practice the skill in one or more role plays (or other exercise, such as deep breathing)
- Provide feedback, starting with positive
- Help family members develop plan to practice skill outside the session

Comments:

\_\_\_ 8. Guiding family through steps of problem-solving

- Follow up on any previous problem-solving as needed
- Identify and define problem or issue for current consultation, getting everyone's point of view
- Generate possible solutions, getting everyone's point of view
- Weigh pros and con's of possible solutions, getting everyone's point of view
- Select solution to try, getting everyone's input
- Make a plan to implement the solution

Comments:

\_\_\_ 9. Developing Home Assignment (not applicable to monthly check-in sessions)

- Help family members develop specific home assignment to practice or review material covered in session or take steps towards solving a problem or achieving a goal
- Help family members identify specific days, times, and places for completing the assignment
- Identify and problem solve potential obstacles
- Practice assignment in session if indicated
- Enlist help of others or access additional resources if indicated

Comments:

\_\_\_ 10. Structuring the Session and Using Time Efficiently (structure for each type of family session is provided below)

- Cover the content of the session at a pace that's comfortable for the client
- Tactfully limit peripheral or unrelated discussion
- Direct session appropriately, following structure of type of family as follows:
  - Education session: announce agenda, review home assignment, review previous family meeting, review written materials/worksheets, use role plays as appropriate, develop home practice option
  - Monthly check-in: announce agenda, review client's current status, discuss client's goals and relevant progress and ways family can help with goals, review client's participation in treatment program, monitor early warning signs, identify progress and concerns noted by family, make a plan for further contact or action if needed
  - Family consultation: announce agenda, identify problem or issue for current consultation, generate possible solutions, weight pros and cons of possible solutions, select solution to try, make a plan to implement solution
  - MIST: announce agenda, review home assignment, review previous meeting, review educational material, teach communication skill, teach problem-solving skill, develop home assignment

Comments:

\_\_\_\_ 11. Therapeutic Relationship

- Convey warmth and empathy
- Express understanding and compassion about unpleasant experiences
- Show flexibility in responding to each family member's concerns

Comments:

\_\_\_\_ 12. Recovery/Resiliency Focus

- Express hope and optimism for the future
- Support or enhance each family member's self-efficacy
- Use of recovery and resiliency language when appropriate
- Help each family member take an active role in shared decision-making
- Expression of confidence all family members can make progress towards their goals
- Help all family members identify and build their own resiliency skills

Comments:

\_\_\_\_\_ 13. Overall quality of session—Note this is *NOT* intended to be an average of the above scores, but rather a composite rating of how well the session was aligned with the manual and NAVIGATE philosophy while still meeting the participants' needs. For example, adept handling of a crisis session might rate a 4, even if only a few specific session items were covered because of the emergency.

- Materials taught effectively using combination of motivational, educational and cognitive behavioral strategies
- Flexible and responsive to emergent needs, issues or unexpected challenges
- Reduces family distress as needed

Comments: