**JUST THE FACTS - DEVELOPING A COLLABORATION 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.

What is 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 person with psychosis's care. 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.

**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 the psychiatrist. 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.
  + Input about responses to medications (the person might have only limited memory of these responses) and side effects.
  + Developing a treatment plan.

In addition, relatives can also ask questions about strengthening rehabilitation for their relative with the episode of psychosis. For example, relatives can ask about new treatment developments and the availability of crisis services. As in all dealings with health care professionals, the family's 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.

Questions:

* + 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 are some home practice options for this handout that you can review now or at the end of the session.

**1.** 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 relapse prevention plan. Ideally, this plan is developed in advance, and all family members have agreed to it. This topic is discussed more fully in the NAVIGATE Relapse Prevention handout.

**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 2 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, 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 need treatment before he/she has recovered.

He/she may also become suspicious about relatives. 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, their relatives are 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 dialogue is really an ongoing process instead of a one-time activity.

What if the person in treatment hesitates to have 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 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, social workers, case managers, and nurses. In NAVIGATE, the treatment team is comprised of a program director, a family clinician (may also be the program director), individual clinicians, a supported education/employment worker, and a psychiatrist or nurse practitioner.

Often, psychiatrists are scheduled to see individuals for very brief periods. 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.

Questions:

* + 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 are some home practice options for this handout that you can review now or at the end of the session.

**1.** 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-- Just the Facts - Developing Collaboration with Mental Health Pr ofessionals**

* + *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.*