Clinical Guidelines for "Just the Facts" Participant Educational Handouts

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Clinical Guidelines for "Just the Facts-What is Psychosis?"

OVERVIEW:

This topic area covers the basic facts about psychosis. You can inquire about the participants' understanding of illness and answer common questions that people often have about mental illness. As a result, participants will become informed about the illness and be able to more actively be involved in the recovery of their loved ones.

Goals

- 1. Elicit information on all of the participants' understanding of the client's symptoms, causes, and course of illness.
- **2.** Provide psychoeducation that addresses gaps in the participants' knowledge about firstepisode psychosis.
- **3.** Introduce the stress-vulnerability model.
- **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, either 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.

- 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 recognize 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 empathy.

- Be prepared for the person in NAVIGATE'S denial of having ever had symptoms. Accept the denial and discuss the symptoms in the spirit of informing the client, but not accusing him/her of having them.
 - Focus on symptoms, 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 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 it is the basis for all 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. 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 experience with symptoms?

 - 3. What do you think causes symptoms?4. How are diagnoses of psychosis made?
 - 5. What do you know about treatments for psychosis, like therapy?
 - 6. Can you tell me a bit about the stress-vulnerability model?

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Clinical Guidelines for "Just the Facts-Medication for Psychosis"

OVERVIEW:

This module provides the basic facts about medication for psychosis. 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 her take the medications as prescribed.

Handout Needed

Educational handout - 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). 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.

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 and help the participant identify additional strategies that will support recovery.
- 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.
- Client has poor medication adherence.
 - 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 figure out how to support the client's regular medication taking during early recovery

- 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. What medications are used to treat psychosis?
 - 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, how would you advise them to talk to their doctor? What sort of questions would you suggest that they ask their doctor?
 - 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.

Handout Needed

1. Just the Facts-Coping with Stress

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 some) 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.

- 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 can 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.

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.

- 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 is the difference between daily hassles and life events?
 - 3. What are some ways that people experience stress?
 - 4. How would you teach someone an individual plan for coping with stress?

Clinical Guidelines for "Just the Facts-Strategies to Build Resiliency"

OVERVIEW:

The handout for this topic provides an introduction to the topic of resilience. While much discussion in NAVIGATE is about the resiliency 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 "resiliency stories" and help the participant develop one for his/her own life.

Handout Needed

1. 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 participant's strengths.
- Engage the participant in discussion on how resilience is related to well-being and recovery.

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

- Participant 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 after a break-up, someone dying, failing an exam, etc.?").
- Participant 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.

THE MOST IMPORTANT GOAL OF THE SESSION:

Connect participants with their own strengths.

- 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 "Relapse Prevention Planning"

OVERVIEW:

This handout for this topic provides information and a strategy for relapse prevention planning. Both the concept of a relapse and an early warning sign are introduced, followed by a discussion of triggers that can bring about relapse. Finally, a plan for responding to early warning signs is discussed.

Goals

- 1. Educate participants to the idea that symptoms wax and wane but flare-ups can be managed.
- 2. Help participants identify OBSERVABLE early warning signs.
- 3. Help participants identify potential triggers for symptom flare-ups
- **4.** Help participants consider developing a relapse prevention plan and develop one if wiling.

Materials Needed

1. Educational forms - Relapse Prevention Planning

TEACHING STRATEGIES:

- Be matter of fact about the content; normalize variations in symptoms over time.
- Discuss how relatives can elicit information from the person in NAVIGATE if he/she is not present in the session. Help them practice how to approach this person and discuss his/her symptoms or early warning signs if he/she is not attending family sessions.
- If the client attends, the family can actually discuss early warning signs, triggers, and develop a relapse prevention plan. This is more difficult, though possible, if the client does not attend.

The relapse prevention section of the IRT is very extensive—this is a good time to work with the IRT clinician to see, even if the client is not attending family meetings, regularly, if a family meeting might be useful.

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 normal but can be managed. Also, be prepared that first episode clients may not have experienced a relapse. They may also firmly believe that they will never have one.
- If the client does not attend, it may be impossible to complete a relapse prevention plan. However, the client will complete a relapse prevention plan in IRT and the relatives could be coached to ask the client to talk about the plan, using good communication skills.

THE MOST IMPORTANT GOAL OF THE SESSION:

Help participants understand that symptoms go up and down, but early steps to act on them can often minimize big problems.

- 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 signs of a relapse?
 - 2. What are some of the common triggers for a relapse?3. Has your family member in NAVIGATE had a relapse?

 - 4. What is your family's relapse prevention plan?

Clinical Guidelines for "Just the Facts - Developing 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 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".

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

Educational handout: Just the Facts - Developing 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.
- 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.

- 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 client both about the NAVIGATE program and the rest of the 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 off 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.

- 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 – 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.
- **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. Educational Handout: Just the Facts–Effective Communications
- 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 improving family communication.
- 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 <u>each</u> 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.

- 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 one, 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 issues with family.

THE MOST IMPORTANT GOAL OF THE SESSION:

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

- 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 "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:
 - 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.
- 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

1. Educational handout: 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.

- The participants perceive the topics as critical of them. Remind them that this
 information is offered to all families in NAVIGATE routinely. Note that occasional
 criticism in families 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.

- 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.

Clinical Guidelines for "Just the Facts – Basic Facts about Alcohol and Drugs"

OVERVIEW:

This is an optional module 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.
- 4. Remind relatives how they can support low levels of use.

Materials Needed

1. Educational handout: 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 participants 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.

- Be prepared for varying degrees of openness on this topic between families; support candor wherever you can.
- 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 psychosis and thus the ultimate development of symptoms.
- Be prepared to act quickly if tensions arise, using the strategies mentioned at the beginning of the overview to the clinical guidelines.
- 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 together. This means the topic may need to be revisited frequently. 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.

- 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?