K. Core Unit 3: Shared Decision Making with Families and Clients

Vignette: Kim, her family, and the PC have been meeting regularly to discuss Core Unit 2 topics. Kim's family members feel less anxious now that they know more about psychosis and are able to be more selective when reading online. Kim and her family feel hopeful about recovery and have started identifying goals.

Kim has a goal of graduating college and has been working with the SEES to re-enroll in classes (she withdrew after her first episode). But Kim's brother is concerned as he believes that school-related stress led to the psychosis and thinks Kim should prioritize working on symptom management with the Primary Clinician and Psychiatrist. Kim worries she will be expelled if she does not graduate soon. She views her brother as overly involved now that she has a "mental illness" and wants to be more independent. Kim's parents are torn; they want Kim to graduate but also want her to stay healthy.

Kim would like to attend the *Core Unit 3* meeting with her parents and brother. She has been telling her family about shared decision-making and thinks it would be helpful for them to learn more so they can use it together. During this meeting, Kim and her family would like to hear how shared decision making can help with identifying goals (like graduating college), weighing out the options, and negotiating steps toward goals, especially when not everyone involved may be in agreement at first. They would like to practice using shared decision making in their family with the support of the primary clinician.

I. Introduction to Unit and Rationale

The purpose of this unit is to introduce the shared decision making approach (SDM) to families. We have found that family members' interest in participating in treatment planning and decisions can vary, although overall, many families are eager to participate in treatment and recovery. Likewise, young people's interest in including family involvement can vary widely from person to person and for the same individual over time. SDM should be used to discuss treatment choices, like family involvement, and to set goals that are meaningful to the young person and their family members.

For participants who are under 18 years old, a family member or legal guardian will need to be included in all treatment decisions and treatment planning, regardless of the participant's preference. Although minors may have less say in the in whether families are involved, to the extent possible, the Primary Clinician will work with the participant to identify benefits of family involvement and ways in which the family can assist the participant in achieving individual recovery goals. The Primary Clinician will also assist participants and families in developing and utilizing a shared decision making approach to treatment decisions in an effort to encourage both participant and family input and, ultimately, agreement with regard to treatment goals and decisions.

Description of Core Unit 3: First, we'll talk about shared decision-making, an approach to setting goals and making informed choices. This approach helps us identify goals, outline options, consider pros and cons, think about preferences, make decisions and negotiate areas of disagreement. The process of shared decision making aims to ensure that each person's voice is heard and all points of view are considered during decision making.

Providers and clients may have already started using SDM to discuss treatment choices using SDM tools, which can be found in the OnTrackNY Team Manual like the:

- *Family Engagement and Needs Assessment*
- *Psychiatric Medication and Me- Assessment Tool*
- *Designated Observer Tool*
- *Values Clarification for Family Involvement Tool*
- *Family Involvement Decisional Balance Tool*

Providers and families can also use SDM tools like the SDM Introduction Video by Dr. Pat Deegan to orient individuals and their families to the concepts covered in this unit

Throughout treatment, SDM should be described and modeled by providers so that the young person and their family members can practice and utilize SDM when discussing important topics, whether or not the provider is present.

Sample description of SDM: Setting goals and making decisions can be challenging for us all, especially when there are several options to consider. It can be hard to know 'which choice or direction is right for me at this time. This can be easier or more challenging when several people who care about one another are involved. Furthermore, decision-making can become confusing and difficult if people disagree about what to do next. Because of these challenges, we at OnTrackNY recommend using the Shared Decision Making approach, or SDM, to set goals and make informed choices together.

II. What is SDM and Why is it Important?

SDM is a decision-making strategy that can be used by all individuals involved in treatment to identify goals, problem-solve, make treatment decisions, and revise treatment objectives over time. The SDM process ensures that each person's voice is heard and each point of view is understood as decisions are made together. When describing the SDM process, providers are encouraged to emphasize that:

- We work on identifying things that are important to you and your family members, including how family members can be involved in treatment and supporting goals.
- SDM is an approach to setting goals that will help us make sure we talk about the things that are important to each member of the family, including you [the young person], and that decisions made are within your values and preferences.
- It is important that you [the young person], and each family member, are heard when discussing treatment and the things that are important to you. We will start this process now.
- The SDM approach might be familiar to you, or it may seem a bit unnatural. That's okay. We find that regardless of where a person starts with this process, it's something that people tend to find helpful and more comfortable over time.

- The SDM approach can be used during meetings with providers and also when family members, including [young person], have discussions outside of treatment.

Give family members the *SDM Pocket Card/Handout*: Tips for Talking about Important Decisions, found in the OnTrackNY Collaborative Approach to Recovery (CAR) Manual. Ask family members what s/he thinks about this approach and in which ways this approach might be helpful.

III. SDM – How do we use it?

SDM involves several basic steps that are sometimes woven into conversation and sometimes used explicitly with SDM tools and decision aids. At this point in the unit, providers can describe the several basic steps of SDM and discuss how they might be used in treatment. Be sure to go at a pace that matches the young person's and family's understanding of each step. It may be helpful to periodically check in with people about their understanding and to see if they have questions. The steps involved in the SDM process as applied to families are described below.

Step 1: Choice Talk

The family member identifies issue/goal that is personally important. This can include a range of topics, but it is important that one specific goal or issue be selected to work on at a time. Some examples of typical issues or goals include:

- Establishing how the family might be involved with the treatment team,
- Identifying the preferred way for family members to provide input to the young person as s/he is contemplating treatment options (may vary amongst family members)
- Deciding whether or not to attend the monthly family groups
- Figuring out the level of involvement in the young person's transportation to/from treatment
- Choosing how to best support the health and wellness of the young person
- Discussing how to best support the family in maintaining a healthy family life in the midst of coping with first episode psychosis (e.g., supporting healthy behaviors, maintaining important family routines)
- Exploring whether the family might be involved in a meaningful way in supporting the young person taking appropriate medications.

Start with the first issues/goals and then repeat with the second.

Step 2: Option Talk

For the specific issue selected then all of the relevant options are listed. Below are some examples. Establishing goals might begin with a list of common goals and then for each common goal, the related options.

Example 1: Options for transportation to treatment

- Encourage the young person to arrange their own transportation
- Offer transportation some of the time (when family schedules permit)
- Schedule appointments only when the family member can provide transportation.

Example 2: Options for support regarding taking medications

- The young person takes medication without family member reminders
- The family member offer verbal reminders as agreed upon between the young person and family
- The family member distributes the medication as prescribed

The pros and cons of each option are considered with information and educational materials provided as needed. For example, people might consider the advantages and disadvantages of prioritizing employment, sharing an important meeting with other family members, or increasing a medication dose. In this process, the young person and family members emphasizes her/his goals, values, or preferences; the clinician adds scientific information regarding likely outcomes, side effects, and/or unwanted medication effects (e.g., going with a neuroleptic that has a lesser chance of metabolic syndrome but a higher chance of TD).

Step 3: Decision Talk

Considering preferences and deciding what's best. For example, the individual ranks her/his top three preferences in order, the family member ranks theirs, and the professional does so also. Or following some of the examples above, each person gives an opinion regarding the transportation to treatment or the medication support options. The process can be conducted on paper or verbally.

Once areas of agreement and disagreement are clear, everyone involved negotiates areas of disagreement. For example, they might identify different goals but agree to include each person's top three goals on the treatment plan. If they disagree on the participant arranging their own transportation, they might agree to schedule some appointments for when the family member can attend. Or if there is disagreement about the family member distributing medication (e.g., the young person does not want this), they all might agree to the family member offering a verbal reminder at the end of each day. People are encouraged to work together to figure out a plan to move forward even in areas where there is initial disagreement.

IV. Keeping SDM on track

In using the SDM approach, we might ask ourselves a series of questions that help to figure out if we're really using SDM during meetings. Some of the questions are as follows:

- Are we clear and in agreement about the current issue, problem, or decision?
- Do the young adult, family members and I have all the information we need about this topic?
- Have we identified the relevant options?
- Are we clear how the individual's important values influence this decision?
- Is everyone who needs to be involved here? Are we clear about how the family's important values do or do not weigh into the decision?
- Have we clarified our preferences and any disagreements?
- If we disagree, have we negotiated a compromise?
- Have we put the plan in writing?

Example of how to keep SDM on track:

As an example, consider asking these questions as part of a a decision regarding disclosure in supported education.

Does the young adult want to disclose information regarding her/his illness, disability, or needs for accommodations to a teacher? What are the options? For example, who would speak with the teacher? What exactly would be disclosed? What is the goal? What is most important to the young person in this situation – to avoid disclosure or to receive an accommodation? What are the advantages and disadvantages of disclosure and of requesting an accommodation? Does the individual need to speak with a girl/boyfriend, a parent, or a past teacher about this decision? What are the individual's and the clinician's preferences? Have the young adult and clinician negotiated a plan that both believe is ethical, realistic, and likely to meet their goals? Have they written down the specific plan for addressing this situation?

NOTE TO PCs: A list of websites with printable or interactive decision aids can be found in the Center for Practice Innovation's Learning Management System: http://practiceinnovations.org/

V. Summary of today's meeting

PC asks the family member to identify some important points from today's meeting. PC adds his/her perspective to this summary.

VI. Problem-Solving

Review implementation of last unit's problem solving. Discuss successes and challenges and, if needed, revisit the steps for problem solving.

After delivering the above information the family might benefit from engaging in some formal problem-solving, using SDM, around a related issue that they might be facing with their loved one. Developing an action plan will start the process of helping families gain skills to better manage the difficulties they are facing.

Remember that the steps for problem solving include:

1. Define the problem
2. List all possible solutions
3. Discuss advantages and disadvantages
4. Choose the solution that best fits
5. Plan how to carry out the solution
6. Review implementation during the next meeting

Refer to the section on problem-solving in this manual for detailed information on how to conduct formal problem-solving with clients and families.