## Engaging families as helpful members of the treatment team for youth experiencing early psychosis

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DIVERSE CULTURES,
GENDERS,
PERSPECTIVES,
AND EXPERIENCES

NON-JUDGMENTAL AND AVOIDING ASSUMPTIONS

RESPECTFUL, CLEAR AND UNDERSTANDABLE

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# Engaging families as helpful members of the treatment team for youth experiencing early psychosis

- Audience participation:
  - www.menti.com
  - Code: 4928 8547

#### Agenda

- 1. Benefits and challenges related to involving family members/loved ones in treatment
- 2. Case examples & discussion
- 3. Resources & tips

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# What are the benefits of involving families in treatment for youth experiencing early psychosis?

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#### Menti slide

#### Better recovery outcomes

## Benefits of family engagement

Increased engagement in treatment and recovery goals

Support both the young adult and family members

Family engagement is a component of Coordinated Specialty Care (CSC) programs for early psychosis

# What are the challenges that come up when trying to engage families in early psychosis treatment?

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#### Menti slide

#### Case examples & discussion

#### Case #1

Yusuf is an 18-year-old cis-male. He lives with his parents and two younger brothers in Boston. His parents are immigrants from Sudan but he and his brothers were born in the US. He was referred to the clinic by his school counselor after he was observed to be talking to himself and acting strangely (collecting pieces of trash in his locker and wearing a hood and two hats). Yusuf disclosed to the school counselor that he hears the Devil talking to him and sometimes worries that kids in the neighborhood are trying to steal his thoughts. He wears the hood and hats to protect himself. He has also started to carry a pocketknife "for protection." Yusuf and his parents initially indicated interest in treatment. However, Yusuf attended only 1 out of every three scheduled sessions and parents did not attend any scheduled sessions after the intake. The family therapist would periodically reach Yusuf's dad on the phone and schedule an appointment, but they would not be reachable (either by phone or zoom) at the time of the appointment. During one of the sessions, Yusuf told his counselor that his parents told him that the medications he is prescribed might be addictive and he should stop taking them.

#### Case #2

Sammie is a 24-year-old Caucasian woman who recently moved back home to live with her parents after being let go from her job. She parents have become increasingly concerned that Sammie hardly leaves the house, seems distracted, and has difficulty multitasking. Their concern increased after Sammie got upset when her mom asked her to take out the trash saying, "I just can't right now with everything. I'm just so confused all the time. It's impossible to focus and to know what is really going on." At the clinic intake, Sammie was reluctant to talk about her experiences and the team worked closely with her parents to get collateral information. After a few weeks, Sammie opened up to her clinical team and shared more details about hearing different voices, seeing shadowy figures, and an increasing concern that she is in danger. She then immediately withdrew her consent to allow her team to talk with her parents stating, "I don't want to scare or worry them." She shared feeling like a "failure" and doesn't want them to be monitoring and judging her on what she can and can't do.

#### Case #3

Seb is a 14-year-old trans male living with a single mom. They have always been very close and Seb considers his mom to be his closest friend. Seb told his mom last year that he was hearing voices that distracted him while he was at school. He began refusing to attend school when he also started to experience "shameful thoughts and images." He would not tell his mom what these were specifically, but he noted that the shameful thoughts were triggered when he saw younger children playing. He began avoiding the school playground. After a few weeks, he began feeling triggered by seeing any children younger than 10. And eventually he required that mom help him to avoid even seeing pictures of children in magazines, computer or TV. Mom noted feeling overwhelmed by the need to try to keep Seb safe from all these triggers. She took family leave from work in order to be more available to help Seb avoid triggers. She called the clinic often, making suggestions to the clinical team about how to better serve Seb. For example, she asked them to remove any magazines with pictures of children from the waiting area. She also asked if Seb could start working with a different therapist because Seb appeared more upset after a recent session.

#### Resources & Tips

## Ingredients of Effective Family Programs

- Empathic/ accepting/ non-blaming/ nonpathologizing
   (families are stressed and doing the best they can)
- 2. Hopeful/enhancing development and coping of all family members.
- 3. Foster communication with treatment team.
- 4. Increase social support.
- 5. Basic components:
  - 1. Psychoeducation
  - 2. Communication enhancement training
  - 3. Structured problem solving

#### Navigate Family Education Program

Orientation/ Assessment (2 family sessions, 1 individual session each family member)	Overview of the Family Program Learning more about everyone in the family and how they are coping
Education (10-12 sessions)	Learning facts about psychosis, medications, coping with stress, how relatives can be helpful, and good communication
Ongoing Consultation	2-3 sessions "as needed" after completing education
Ongoing Support from Team	Monthly check-ins with therapist, MD and other providers
Behavioral Family Therapy/Modified Intensive Skills Training (MIST)	Optional program when family members decide they would benefit from more extended work on improving communication and problem solving skills

http://navigateconsultants.org/manuals/

Stigma and shame

Confidentiality concerns

Avoidance/ denial

Treaters find family off-putting

Obstacles
To Family
Treatment

Family not interested

Therapist lack of comfort/ experience

Language barriers

Family too busy/ overburdened

# What families need at beginning of treatment

Hope – hopeful attitude about capacity for treatment to be helpful and for family participation in treatment to increase effectiveness of treatment

Education - information about psychosis and treatment and role of the family (via family sessions, online videos, book recommendations)

Advocacy – help relative learn effectively communicate with treatment team and advocate for needed resources

Resources – e.g., information, family support group, NAMI, internet resources, Mass Rehab, DMH

## Some common family treatment dilemmas and what can help

#### Dilemmas with Carer:

Dilemma	What can help
Carer wants to use family meeting to tell you every last detail about what is wrong with the client	Talk separately with family member, listen to concerns and talk with carer about prioritizing
Carer expects you to provide a report on what the client talks about in therapy	Without condescending, talk with carer about importance of private communication to build trust and for treatment to be effective.
Carer wants to direct the treatment (fantasy– if you tell him to do it he will)	Talk with carer individually – validate his/her concerns and wishes for you to do the same thing with a different result, may share your strategy to some extent
Carer worries the treatment will be harmful to the client	Encourage carer to discuss concerns with you, provide validation and support as well as information.

#### **Dilemmas with Carer Cont:**

Dilemma	What can help
Carers are parents who hate each other	Begin meeting with each parent separately, highlight shared concerns about client and importance of working together to co-parent effectively.
Carer is extremely anxious/ burnt out/ needs a break	Support carer in getting help via individual treatment, asking for help from extended family, friends, church, etc., and taking time for self.
Carer sees symptomatic behaviors as volitional personality flaws (laziness, stubbornness, etc)	Psychoeducation, talking with other families through NAMI or multifamily group
Carer has limited resources (financial constraints, demanding work, caring for other relatives, carer has mental illness, etc)	Help family obtain needed supports (SSI, IHT, PT1, etc). Consider home visit and evening availability

#### Dilemmas with Clients:

Dilemma	What can help
I don't want you talking with my parents about what I say	Clarify that confidentiality (aside from limits re safety) will be maintained. Focus is on helping family provide better support to them. Highlight ways in which it may be in their best interest to have family participate.
Concerns that family treatment creates burden on family	Share research on effectiveness of family treatment in reducing rehospitalization and family distress
Client does not want to participate	Ok to meet just with parents at first. Family provider may continue finding ways to get to know the client. Some clients decide to participate eventually when invited again at a later time.

\*Note: family treatment is easiest to set up at the beginning of treatment when it is presented as a regular part of treatment.

#### Additional resources

- NAVIGATE (RAISE) Family Manual
  - http://navigateconsultants.org/2020manuals/family\_2020.pdf
- NAMI Family to Family Program
  - http://namimass.org/programs/nami-family-to-family
- CEDAR Family Information Webpage:
  - https://cedarclinic.org/for-families-2/
- Collaborative and Proactive Solutions
  - https://livesinthebalance.org/walking-tour/
  - (\*"kids do well if they can")
- Supportive Parenting for Anxious Childhood Emotions
  - https://www.youtube.com/watch?v=VUayeUlc\_Gs
  - Lebowitz Breaking Free of Child Anxiety and OCD

#### Contact Us

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