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Delivering Culturally Competent Care in FEP

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I. Development and Objectives of this Guide

This Guide focuses on how culture affects the care of individuals experiencing a first episode of psychosis (FEP). It describes key concepts and principles, best practices, and case examples to help individuals with FEP, their supports, and providers work together to implement culturally competent early intervention services, prevent cultural misunderstandings, and enhance recovery outcomes.

The Guide was developed through a participatory process involving a series of workgroup meetings with OnTrackNY providers and focus groups with OnTrackNY participants and their families. Many of the case examples included in the Guide derive from assessments conducted with the DSM-5 Cultural Formulation Interview (CFI), a standardized set of open-ended questions used to identify the role of culture in a person's and family's experience of illness and care. The CFI has been incorporated into the OnTrackNY routine evaluation procedures.

Specific objectives:

1. Define culture and present key principles of culturally competent care.
2. Provide a framework for understanding the bidirectional relationship between symptoms of psychosis and culture to help providers conceptualize these issues within the framework of the OnTrackNY model and its various treatment components.
3. Illustrate, via case examples, how culture shapes participants' understandings of their experience with FEP and their treatment expectations, affecting the overall care of participants in Coordinated Specialty Care programs and their families.
4. Outline key principles and best practices for delivering culturally competent care to participants and their supports within the OnTrackNY treatment model.

II. Culture and First Episode Psychosis

In this Guide, we define culture as the way in which individuals make sense of the world based on their background and experiences. Culture is an evolving process of meaning-making, rather than a static set of characteristics. Multiple aspects of individuals' social backgrounds can provide a basis for their cultural orientation, including their age, class, race/ethnicity, gender, sexual orientation, faith, occupation, language, and, for some, immigration and acculturation. That means that our interpretations of the events of our lives are not only personal but also cultural, in the sense that these understandings develop out of our belonging to and/or participation in diverse social groups that transmit traditions of meaning about the world. For example, devout Christians may interpret their experience of illness in light of their Christian tenets and values. Thus, everyone is influenced by his or her culture(s), not just racial/ethnic minority groups. In fact, each person is a mix of various cultural backgrounds, which interact with one another and evolve over time.

How does this relate to FEP? Culture matters in the treatment of FEP because it affects how individuals and families interpret their experience with the illness. This includes how they understand what is happening and whether the experience is perceived as something pathological and/or severe. Likewise, cultural interpretations also influence when and from whom help is sought (e.g., from a friend, a faith

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leader, a primary care clinician, a mental health professional), what the expected treatment is, how long it should last, and what role the individual and the family should take in providing care. For instance, the person and family's cultural framework might affect how long it takes them to initially connect with treatment (duration of untreated psychosis), what kind of providers to engage within the OnTrackNY treatment model, decisions about medications, and level of participation in psychotherapy or other interventions offered.

It is important to remember that, in addition to the participant's culture, the cultures of the providers delivering the treatment can influence the way it is delivered and how it is received. These cultures include each team member's socio-cultural background, the cultures of their respective professional disciplines, the organizational culture of the OnTrackNY team, and that of the larger agency providing care. Additionally, culture shapes the way providers interpret the views of participants and families, their ability to accept explanations that are radically different from clinical ones, and their ability to effectively communicate with participants and families. One way this might be manifested in Coordinate Specialty Care teams like OnTrackNY is through the focus on providing youth-oriented services. Teams make a concerted effort to present themselves, their workspace, and their treatment strategies in a way that is youth-friendly and flexible.

The cultural framework through which a person, the family, and the OnTrackNY team "make sense" of the illness and treatment is always affected by "structural" factors – such as the person's access to concrete goods and services – as well as a set of power dynamics – such as their ranking in the social hierarchy relative to the treatment team and agency. These structure and power-related factors can strongly influence individuals' and clinicians' interpretation of the illness, the therapeutic relationship between participant and provider, the resources available for treatment, and the delivery of services. For example, a person's assessment of the severity of their illness, and the decision to seek professional services, are often affected by their ability to afford treatment and by past experiences of care, including experiences with stigma or discrimination. It is important to assess the impact of these structure and power-related factors on how the person and family make sense of the FEP experience and how they think about treatment.

Therefore, we urge everyone involved, including individuals with FEP, their families/supports, and providers, to always take into consideration the influence of culture on all aspects of illness and treatment. This Guide provides suggestions for how to do this.

III. Key Principles for Culturally Competent Care

At the outset, it is important to note several key principles of culturally competent FEP care:

1. **Develop Cultural Competence:** We use the term "cultural competence" because it connotes a professional practice that providers are responsible for developing, grounded in culturally relevant knowledge, skills, and attitudes. However, it is important to maintain an attitude of "cultural humility" that communicates a genuine appreciation for the role of the person and the family as experts on their own experience and its interpretation, as well as on the perspectives of their community. Providers should cultivate the view that the medical approach is only one of many alternative ways of understanding FEP. The process for finding individual meaning undertaken by individuals and their

families is a key component of recovery. It is essential to always treat the individual's and family's views with respect, while simultaneously presenting the empirical evidence for clinical care.

2. **Understand Personal Biases:** OnTrackNY team members should engage in an ongoing process of self-reflection, which will help make explicit their perspectives and conceptualization about the psychotic experiences of OnTrackNY participants. The team members should consider and engage in discussion to explore how their own cultures (personal, organizational, professional) may shape these views. We all use cognitive shortcuts ("stereotypes") to help manage new information; sometimes these shortcuts lead to biases, many of which we do not realize we have. A practice of self-reflection helps identify and challenge these stereotypes and biases that may be affecting service delivery. Individual team members could engage in this process by asking themselves questions very similar to those in the Cultural Formulation Interview. OnTrackNY teams may also use these questions when discussing the treatment of individual participants to help identify potential sources of therapeutic misattunement or to enhance treatment strategies. Examples of these questions are:

   - *What do I think is happening to the person?*
   - *What do I think is most troubling to him/her?*
   - *Why do I think this is happening? What are its causes?*
   - *What do I think is the help (s)he needs?*
   - *How are my own professional, organizational, and personal experiences or identities shaping my views on these topics?*

3. **Use Person-Centered Language:** It matters what terms we use to refer to the service users and to describe their experiences of suffering. Most individuals prefer not to be narrowly defined by diagnostic labels (e.g., "FEP patient," "schizophrenic," etc.), OnTrackNY has a commitment to the use of inclusive language that actively opposes stigma and empowers participants toward recovery. Providers should avoid disempowering terms, which do not allow for the diversity of the person's background to emerge beyond the narrow frame of the illness. It is precisely this background information that we need to help us understand the person's interpretations of illness and desired services. Terms that may be used instead include "individuals," "young adults," or "participants."

From a culturally informed perspective, we should consider that for some people "psychosis" or "first-episode psychosis" are not words that reflect their experience. These terms come from the clinical arena. Some people talk about hearing voices, seeing things, having spiritual experiences, having a tantrum, or other non-medical terms while others may think nothing is wrong at all. Research has shown that an individual's satisfaction with treatment is higher if the treatment team uses the person's vocabulary in the process of care. The team should attempt to match the language used by participants and families unless the terms are pejorative.

Psychoeducation can be used to clarify language used by participants and their supports that is clinically inaccurate (e.g., if the family refers to psychosis as "seizures") since sometimes this might be due to a misunderstanding or different interpretation of clinical jargon. An example of a term in need of unpacking may be "depression," which can convey multiple meanings, ranging from temporary unhappiness to a recurrent and severe clinical condition. During this process, it is important to remember that cultural explanations of illness can be strongly rooted and tied to larger aspects of meaning, including concepts of morality and blame.

Psychoeducation may need to proceed slowly, acknowledging several possibly competing factors: 1. The ultimate authority for meaning-making lies with the person and the family; 2. Clinical knowledge is limited and evolving; and 3. Empirical evidence has predictive and therapeutic value and underlies the effectiveness of the services provided by the treatment team. This guide includes illustrations of a culturally competent approach to psychoeducation.

Providers should elicit the individual's and the family's preferences for which terms the team should use to describe the various aspects of their identity. These include pronouns (e.g., he, she, they, the person's name), the names of religious communities (e.g., Protestant, Christian, Evangelical, Pentecostal), and racial/ethnic terms (e.g., black, African American, West Indian, a specific national group, such as Haitian). In this guide we use "white" to refer to US-born individuals of non-specified European background, "African American" to refer to US-born individuals of African descent not connected to the Caribbean, "West Indian" to refer to persons of African descent whose background hails from the English-speaking Caribbean, "American" to refer to US-born individuals (e.g., Afghani American), and "immigrant" to refer to persons born outside the US (e.g., West African immigrant). We try to avoid the dichotomous construction "him/her" by referring to "the person" and use the hybrid "(s)he" or the terms "they/their/them" when needed.

IV. Main Themes and Best Practices

This section elaborates on key cultural themes identified in FEP and illustrates them using case examples of individuals participating in OnTrackNY. These examples depict how culture shapes the way individuals and families make sense of their experiences with psychosis, past help-seeking, and expectations of ongoing care. In presenting each cultural theme, we discuss potential challenges, ethical dilemmas, and opportunities for engagement that may arise. Then, we provide examples of best practices focused on how to best address these challenges, dilemmas, and opportunities that are based on the experience of the OnTrackNY treatment teams, participants, and family members.

A. Theme: Religion and Spirituality

Theme: Role of religion and spirituality in making sense of and coping with the FEP experience

Religion and spirituality can provide crucial support to the person with FEP and their family. However, religion and spirituality can also increase barriers to engaging in care and pursuing recovery. Individuals may develop unduly strong or even delusional feelings of guilt or self-rejection resulting from a harsh negative evaluation of prior transgressions or by thinking they are being punished for these. Interpreting psychosis as spiritual experiences may prevent some from seeking or staying in treatment. FEP providers should engage participants and their families in a discussion of how religion and spirituality are viewed as beneficial in order to help develop a broader, more balanced understanding of the experience. For instance, individuals and families might benefit from discussing ways of finding positive meaning in FEP-related experiences or identifying how religious worship can serve as an effective coping strategy for distress, which can be reinforced in treatment. Ongoing engagement with the religious and spiritual communities of participants and their families as a way of increasing knowledge and finding common ground can be very useful to this process.

1. Sub-themes, Scenarios and Best Practices

1. The individual's and family's religious views are in conflict with those of the treatment team.
2. The religious views of the treatment providers interfere with treatment delivery.
3. Religion or spirituality serves as a major source of support and provides the individual/family with a framework for understanding FEP.
4. Religious beliefs contribute to increased psychotic experiences or other symptoms.

Next, we describe clinical scenarios related to each sub-theme, delineate best practices, and illustrate how providers might implement these best practices drawing from case material.

a. Clinical Scenarios: Sub-theme 1

The person's and/or the family's religious views are in conflict with treatment

Jean-Claude is a 22-year-old male Haitian immigrant who is devoutly Christian and believes that what he is experiencing is possession by a demon rather than symptoms of psychosis. He originally agreed to take medications, which helped reduce his symptoms. Upon discharge from the hospital, he was advised by his family to stop taking medications and pray instead. The team has tried various strategies for providing psychoeducation, but the family is adamant that the only thing they believe will help is continued prayer in hopes that the symptoms improve. The family refuses to speak with the team about treatment or their objections to medications; however, they mentioned that they don't believe the participant is old enough to take medications. Jean-Claude participates in talk therapy and takes liquid vitamins but no psychiatric medications. He feels that the meds "slow [him] down" and this causes the demon to slow down too, so he worries that the demon will not be able to escape his body when religious helpers are praying over him.

Jeremy is a 26-year-old white man who is devoutly Catholic and from an upper-middle-class background. He believes that God is telling him that he needs to go out and preach the gospel, like a prophet calling the people to repent. This interpretation leads him to think that part of God's plan is that he should become homeless and follows an itinerant life preaching in the streets. Since following this path, Jeremy is "joyous" and "peaceful" because he feels he is doing God's will. The team is very concerned for his safety because he goes missing for days, engages with people he does not know well, and sleeps on the streets. At those times, Jeremy's parents do not know where he is and are very worried about him. His delusions and his itinerant lifestyle also interfere with his participation in treatment.

Taína is an18-year-old Dominican American woman whose family is coping with her FEP symptoms by taking her to an exorcist and making her drink holy water and wear various charms. The family's intense concern about the situation and their view that it may have a demonic origin has greatly increased the participant's fear of her symptoms. In therapy, Taína and the clinician agreed that the psychosis was precipitated by childhood sexual abuse and subsequent neglect by the parents.

b. Best Practices: Sub-theme 1

1. **Establish trust:** Communicate that the treatment team is open to a range of interpretations and providers are really interested in helping, rather than pushing a non-religious perspective. The

process of trust-building should be seen as a "long game," which can follow an up-and-down course, in which episodes of apparent mistrust alternate with periods of a trusting therapeutic relationship. Sometimes fellow members of the person's spiritual or religious community or spiritual leaders may act as brokers to help overcome communication barriers between families and clinicians, especially in situations in which the relationship has broken down. It may be useful to maintain ongoing contact with the religious advisors (e.g., priest, minister) as the situation progresses (if the person and family agree).

- *Using the above examples of Jean-Claude, Jeremy, and Taína, here are several ways in which an OnTrackNY team might work with these participants and their families: During the initial assessment and engagement phase, the Primary Clinicians would utilize the Cultural Formulation Interview to gain a better understanding of everyone's perspective. During this process it is essential to invite the family to explain their religious perspective and validate how important this conceptualization is to them. In Jeremy's case this process could help elaborate the similarities and differences between how Jeremy and his family understand the tenets of his religion. These details would provide everyone with a starting point for respecting Jeremy's beliefs and behaviors while finding a way to explore if there might be some way to develop flexibility in his thinking and/or prepare a safety plan with which everyone can agree moving forward.*

- *It would also be important to ask the family if they have any members of their religious community who share and support their ideas about what is happening. Invite the family to incorporate these religious advisors into the treatment by attending a meeting with the clinician or even offering to go and meet at the place of worship.*

- *Provide information about the team's interventions and clearly delineate how these are not contradictory to the recommendations of the religious perspective and rather encourage the family to integrate both. For instance, this might mean working with Jean-Claude using a shared decision making framework to discuss decisions about medications and liquid vitamins.*

- *Take the time to understand the family's perspective across time and their interactions with the team and be open and willing to withhold judgment about the avenues they pursue with regards to their religious beliefs. For example, when working with Taína and her family, the team might perform home visits to build trust. Through continued discussion and psychoeducation, everyone might develop a shared understanding whereby traumatic exposure is incorporated into the family's view of the illness' origin. While not dismissing the family's claim that she was possessed, the team might be able to introduce another explanation that both the participant and the family can agree with, thus reducing her fears of the illness.*

2. **Understand Normality and Normativity:** With the help of the family and potentially the spiritual advisor, clarify both the normality and the normativity of the individual's experience. That is, do the participant's relatives and religious/spiritual fellows consider the person's experience as pathological (abnormal) but typical and understandable (normative): a condition they know? Or is the experience bizarre and unfamiliar (non-normative)? The latter often inspires more fear and appears more severe (abnormal) than a familiar condition.

- *For example, for both Jean-Claude and Taína who hold onto a strong religious interpretation of their experiences (e.g., possession and demons), relatives and members of their religious*

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community may find the experience abnormal but normative. By contrast, in the case of an individual who feels God is talking to him through a TV set, those who share his religious views may see this as abnormal and non-normative.

3. **Discuss Traditional and Spiritual Healing Practices:** Engage the individual and family in discussing the pros and cons of interpreting psychotic experiences as spiritual and of using traditional healing systems. The goal here should be to provide psychoeducation about the condition without risking disengagement by offending strongly held religious beliefs. Multiple perspectives should be negotiated to arrive at a healing narrative, without abandoning clinical judgment. This "common ground" is not a matter of minimizing or ignoring differences but instead of building on a common desire to help the person and the family. In this process, it is important to preserve a stance of "cultural humility" in which the individual's and family's views are treated with respect and curiosity, while simultaneously presenting the empirical evidence for clinical care. It may be possible to combine traditional healing systems with psychiatric treatment approaches. For example, medication may be presented as just one of a series of options that are part of the OnTrackNY program.

   ▪ *One way to find common ground is to ask questions that help you as a clinician understand what aspects of the spiritual interpretation are important to the young person and the family. For Taína it might mean understanding what is important about seeing something as a demonic possession. Does it give the family a sense of control and familiarity with tools about how to fix it (e.g., prayer)? Does it also give them a sense that the problem is time-limited (e.g., an exorcism will cure it), and does it give them access to a community of natural supports whom they trust (e.g., the religious group)? Gaining a better understanding of these specific pieces of the puzzle will allow the team to find ways in which they can provide concrete tools for making things better and offer additional supports as Taína and her family try different approaches and figure out what works best for them. This is one moment in which having a relationship with the religious leader might help clarify the details and identify common ground between treatment and religious beliefs and practices. Furthermore, if the family members connect around their religious practices and the young person identifies with these, then the team should make sure to highlight the importance of these beliefs and ways in which they are a strength and source of support for the individual and the family.*

4. **Be Mindful of Language:** Be aware of the language used to describe religious views. Medical providers often speak of their evidence as "knowledge" (e.g., "we know this medicine will help") and the views of the participants as "beliefs" (e.g., "you believe in spirits"). The former connotes much more "truth sense" than the latter. Participants and their families, by contrast, may be more certain of the "truth" of their spiritual experience than of the efficacy claims of medicine. It is important that our language does not reveal doubt about the legitimacy of individuals' experience.

5. **Balance Self-Determination and Duty to Care:** Be prepared to find a balance between the provider's duty to care and the individual's and family's right to determine what level of potential risk they are willing to assume, their "dignity of risk." The video entitled, *Spirit of OnTrack Duty to Care vs. Dignity of Risk* might be a useful tool to help the team have these discussions. Furthermore, the *Values Clarification Exercise* might help illustrate what the participant finds important. The clinician and/or family should be prepared to "yield the ground" on a situation that is important to the participant (e.g., a strongly held belief that God instructs him/her not to take medications) in order

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to help establish trust in the clinicians' and family's fundamental commitment to the person's welfare. This is particularly important during the early stages of treatment, which are focused on engagement and assessment. However, the clinician and family also need to maintain a clear focus on the person's safety. Ensuring safety while maintaining engagement often requires an explicit conversation between team members, families, and individuals about the actions or behaviors that the individual would like to pursue and the supports that can be provided to maximize safety and wellbeing. One approach is to utilize the process of shared decision making to arrive at a compromise about important decisions, since it allows for an understanding of each person's values and preferences. The Safety Planning tool can also be very helpful when developing a plan with participants and family members when there are significant safety concerns. Additionally, it might be helpful to prepare a Wellness Recovery Action Plan (WRAP) and Psychiatric Advance Directives based on these discussions and negotiations. For instance, the safety of an individual who sees himself as a prophet may not be jeopardized by spending many hours evangelizing others in the street (and seen as part of his "dignity of risk"). However, becoming homeless in a dangerous urban center may be agreed upon as a threat to his safety that may require hospitalization or another agreed-upon intervention.

- *We can see an example of this delicate and complex balance between dignity of risk and duty to care in Jeremy's story. Jeremy's team stayed in close touch with him and his family after he decided to live in a tent city with a religious group. Although concerned for his welfare, Jeremy's family felt that it was important to him to be able to travel every day to Times Square to pray and carry signs related to his religious beliefs. However, at one point he decided to leave the tent city to pursue his prophetic activities day and night and became homeless in New York City. As per their prior agreement, this led to Jeremy's hospitalization. This instance illustrates the importance of adhering to a treatment agreement to preserve safety while at the same time trying to remain flexible in the face of very strongly held – even when delusional – religious views. This example also illustrates the importance of empowering the family by giving them tools and strategies to navigate these complexities effectively and in a way in which they feel comfortable.*

c. Clinical Scenarios: Sub-theme 2

The religious views of the treatment providers interfere with treatment delivery

Scott is a 21-year-old lower-middle-class white man from a family with a strong commitment to atheism whose parents do not want him to participate in the nearest OnTrackNY program because it is housed within a faith-based host agency. They are concerned about what they perceive as the built-in spiritual messages of this agency and how the clinicians might impart this to their son during treatment. Instead, the family spends scarce funds to transport him regularly to a non-denominational program upstate; however, the distance and financial burden will interfere with his ongoing participation.

Rubén is a 19-year-old mainland-born Puerto Rican man, active member of a Pentecostal church along with his family, who is distraught about his daily marijuana use because "it is evil." He feels a strong drive to smoke, but once the intoxication wears off he feels "cut off from the Holy Spirit" and is afraid he is incurring eternal damnation in the afterlife. The family is unaware of the extent of his smoking, and he is afraid of their moral judgment if they find out. His previous mental health clinicians did not discuss the

moral and religious implications of the substance abuse, focusing instead only on its illegality. According to him, the clinicians "were afraid to talk about evil; they said everybody had a different opinion about it and they did not want to impose their view." Rubén discontinued treatment in part because of what he perceived as a lack of engagement with his main concerns.

d. Best Practices: Sub-theme 2

1. **Foster a sense of openness:** Foster a general attitude of openness and curiosity regarding the religious or anti-religious views of individuals and families. The treatment team should create a safe space for OnTrackNY participants to express their views about religion and spirituality. This may feel uncomfortable, since Western and secular societies tend to consider religion and spirituality as belonging to the private realm. In contrast, some team members may feel that they should be free to explicitly express their religious views as part of the care they provide. As with any other personal disclosure, this should be done judiciously and for therapeutic benefit. Some questions clinicians can use to get this conversation going include:

    - *Can you explain your religion or spiritual system and its practices?*
    - *What role does religion or spirituality play in your life?*
    - *What are some of the things you like in this area? What about those you don't?*

2. **Develop a balanced worldview that incorporates different beliefs:** The treatment team should establish ongoing procedures to help team members, as well as individuals and families, maintain a balanced and critical stance about the role their own views of socio-cultural phenomena play in clinical care. These topics could be discussed regularly during clinical supervision and/or in team meetings. In addition, case conferences may be devoted to illustrative cases, such as situations in which clinicians and participants successfully negotiated initially conflictive positions.

    - *For example, some clinicians may find a family's views about religion and spirituality – whether for or against – bizarre or fundamentally detrimental to the person's mental health and opposed to good clinical practice. Sometimes this perspective can result from lack of information or even outright animosity to certain religious or anti-religious positions. The treatment team should strive to maintain an ongoing process of self-awareness about their own views about religion or spirituality and become more informed about a range of views and practices involving religion and spirituality, including establishing connections with community-based groups focused on these issues. Sometimes experiencing a very averse reaction or dismissing specific beliefs brought in by participants and families can serve as a signal that the team member might want to gather more information (e.g., online, speaking to community leaders or others with expertise) about those specific beliefs and develop self-awareness about their own personal biases. Furthermore, in the case of Scott, clinicians might spend time informing incoming participants and their families that, although the team is housed within a faith-based agency, they practice cultural competency when delivering the treatment and therefore abstain from promoting any religious beliefs or doctrines.*

e. Clinical Scenarios: Sub-theme 3

Religion or spirituality serves as a major source of support and provides the individual/family with a framework for understanding FEP

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Ronke is an 18-year-old female African immigrant who feels her delusions and hallucinations are "a gift from God." When she escaped an abusive home environment and was living on the street, members of her church took her into their home and gave her the necessary support to continue treatment. Ronke feels a heightened sense of reality or connection with the divine at times during her psychosis, but at other times she is terribly upset about possibly sinning in some way or being tempted by demonic forces. She is worried that medication will blunt her ability to have the positive spiritual experiences but is also distressed by their negative aspects. Ronke is uncertain about what treatment course to pursue.

Kanen is an 18-year-old Native American man who received combined psychiatric treatment and traditional healing while he was hospitalized for FEP. After he recovered from his single episode to date, the family attributed his improvement primarily to the traditional interventions rather than the psychiatric medications.

Yamila is a 16-year-old African American woman who is coping with substantial parental discord, which tends to exacerbate her psychotic symptoms. Although the mother and father seem to be arguing about her difficulties with school, there are long-standing conflicts in their relationship. At the same time, the parents' strong Christian background provides a common ground for them to reflect on their shared values as a couple, agreeing on the role of the father as the spiritual "lead" for the family. They also agree on the importance of forgiveness as a necessary step to move forward.

f. Best Practices: Sub-theme 3

1. **Understand the role of religion in the person's life:** Explore the role that religious and spiritual communities play in the person's life. What spiritual or religious practices do the individual and family find most helpful in coping with FEP and its consequences? How can the most helpful aspects be strengthened? How can similar supports be encouraged in other areas of a person's life so that (s)he has multiple sources of support? What spiritual or religious practices do the individual and the family find least helpful in coping with FEP? How can their impact be lessened? Faith, spirituality, and religion can foster resilience, emotional wellbeing, and social support, and may facilitate recovery among individuals with FEP and their families. Spiritual and/or religious practices that individuals and families may find helpful include prayer, reading of sacred texts, listening to talks or sermons, practicing rituals, joining group activities at their place of worship, participating in spiritually based fellowships (e.g., Twelve-Step groups), seeking religious counseling, and participating in public worship.

    - *With both Ronke and Kanen, it is important that the team understands the participants' and families' views about religion. For Ronke, understanding her religious community might be crucial to fostering ways in which church members help and support each other with both emotional and concrete needs, as these connections will continue beyond the participant's tenure in OnTrackNY. In Kanen's case, one way to build an alliance with the family is to understand their perspective on how the traditional interventions function and how different people in the community utilize these. This might also help illustrate whether these healing practices can serve as a continued coping mechanism for the participant and the family moving forward*

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2. **Establish common ground with spiritual advisors:** With the individual's and/or family's permission, establish common ground with the spiritual advisor(s) to provide continuity of care and to strengthen the person's supports. Engaging these advisors can help bridge potential gaps between clinical and spiritual goals by discovering areas of commonality.

  - *For example, in the case of Yamila's family, contact with the minister led to a focus in therapy on the importance of forgiveness, considered a key Christian teaching. Using the culturally congruent language of the parents' faith community facilitated their reconciliation and helped reconnect them to the Church as a source of support. Lessening the family conflict substantially reduced the participant's psychotic symptoms and increased her base of support.*

g. Clinical Scenarios: Subtheme 4

Religious beliefs contribute to increased psychotic or other symptoms

Benjamin is a 27-year-old white man who converted to Catholicism from Judaism and is very concerned about his own past "sins" and the sins of humanity. He adheres very strongly to the notion that suffering can be redemptive, in imitation of the redemptive example of Christ and the "suffering servant" described by Isaiah. Therefore, Benjamin participates in situations where it is possible for him to suffer or feel guilty, as a way of redressing the pain and misbehavior of other people. For example, he remains friends with people who are clearly exploiting him for money or support, or he enters into a homosexual relationship with an older man that causes him substantial guilt, as he holds firm to the belief that homosexuality is a sin. Benjamin remains very concerned about being condemned to eternal hell, but hopes that his voluntary suffering will prevent this from happening.

Melissa is a 22-year-old Dominican American woman who is bisexual and initially felt that she could not tell her mother because of the mother's religious objections against homosexuality. The parents first responded to the disclosure of the daughter's bisexuality by sprinkling her with holy water and by being harshly critical to get her to change her behavior. However, Melissa's mother also revealed privately to the clinician that she had had sexual experiences with both men and women in her youth. This revelation, plus exploration of the couple's religious views, helped them to find a way of focusing on the loving and forgiving elements of Christianity in their relationship with the participant.

Amadi is a 26-year-old male West African immigrant who attributes his psychosis to his and his family's conversion to Christianity and abandonment of their traditional animistic beliefs. He realizes members of his community may see some of his psychotic symptoms as positive, indicating a special relationship with God. Amadi, however, understands them as evidence of African gods' and spirits' displeasure, as well as specific individuals' retribution for something that he did to them in the past. He has not gone back to his church since his discharge from the hospital, afraid of worsening his symptoms.

h. Best Practices: Sub-theme 4

1. **Determine if there is a religious interpretation:** Obtain as much information as possible about the range of views that the religious or spiritual group holds regarding the individuals' behaviors or thoughts that are considered abnormal. The Cultural Formulation Interview questions may be useful

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in this regard. The "official position" of a doctrine that contributes to harsh condemnation or self-judgment by the person or the family may not be the only one within the religious/spiritual tradition. For example, some Roman Catholic perspectives about homosexuality differ from those held by Church leaders. In some cases, views or explanations that uphold a religious tradition but are not as harsh or punitive may be available. Supporting an individual or family to consider alternative views may help lessen their emotional pain and give way to acceptance and reconciliation.

2. **Family engagement:** Engage the family as much as possible in a process of open reflection regarding the person's vulnerability to internalizing an unduly harsh and potentially delusional judgment of guilt or low self-esteem that could lead to grave suffering, including an increase in psychotic symptoms or engaging in self-harm. Relatives and religious leaders may not realize that, if they take a position that is usually regarded in their community as a firm rejection of sinful behavior, it may be understood by someone with FEP as a much more severe condemnation and trigger extreme self-rejection as a result of delusional thinking. The clinical team may want to encourage a reconciliation process between the person, the family, and the religious community in a way that acknowledges the person's struggles with his/her views and/or identity in the context of the tradition.

3. **Relationships with religious leaders and experts:** Establish ongoing relationships with members of various religious and spiritual communities, including traditional leaders, who have experience coping in an open, thoughtful way with differences between the group's official position(s) and alternative views. These individuals can act as brokers to help the person and family as they struggle with religious and spiritual conflicts.

   - *In all three scenarios above, the team might have conversations that help them understand if the participant and family's interpretation of the religion is accurate and the only valid interpretation. This might mean engaging in conversations about heaven and hell, ways to find redemption from a religious perspective, or the role of retribution within specific religions to help participants and families develop a more flexible understanding and practice if possible. Sometimes this might require inviting experts, other family members, or trusted religious leaders into the discussion to share broader and diverse perspectives.*

B. Theme: Family Culture

Theme: Cultural aspects of family relations that affect how the individual and the family respond to the challenge of FEP symptoms

Families are the main engines through which culture is re-created and transmitted to each generation, since the family is the most important of all "social groupings" in our society, especially for youth and adolescents. Families can develop unique "micro-cultures" of their own, which distill and combine, sometimes in radical ways, the influences of larger social forces. For example, one family's dynamics may act out authoritarian cultural values in much harsher ways than other families. When treating individuals with FEP, aspects of culture that are particularly salient include: 1) the impact of intergenerational acculturation differences; 2) the effect of conflictive or authoritarian family dynamics on the course of illness and care, including communication of family members with the participant and with the treatment team; and 3) the impact of culture on the family's perception of the individual's functioning.

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1. Sub-themes, Scenarios and Best Practices:

1. Intergenerational acculturation differences that affect views about FEP and/or treatment
2. Impact of culture-related family dynamics on illness course and/or treatment
3. Effects of culture on views about the participant's functioning

Next, we describe clinical scenarios related to each sub-theme, delineate best practices, and illustrate how providers might implement these best practices drawing from case material.

a. Clinical Scenarios: Sub-theme 1

Intergenerational acculturation differences that affect the individual's and family's views about FEP and/or treatment

Amita is a 20-year-old Hindu woman, who immigrated from India before age 5, and lives with her very traditional parents. Her parents are concerned about the participant's "Americanization," afraid that she will not follow through with a marriage that was arranged in her infancy to a young man she has met very briefly and who lives in India. The parents are also concerned about her coming home after dark, what she wears, and that she goes to parties and other school activities where there may be drinking or drug use. Amita has a male friend she sees frequently, but denies to her family that there is any romantic interest. The severity of FEP symptoms appears to fluctuate depending on the level of family pressure she perceives.

George is a 19-year-old US-born Indonesian American man whose immigrant parents want to be involved in every aspect of his care. He feels uncomfortable including them to this extent, stating that "some things are my business," especially the substance abuse-related aspects of care that address the marijuana use associated with his initial psychotic episode. George feels his parents "would never understand" his substance use or his desire to not pursue the family retail business. His parents, by contrast, argue that it is typical for parents to have a strong voice in making treatment decisions in the case of adolescents such as George.

Iris is a 24-year-old Chinese-born female college graduate with two hospitalizations due to acute psychosis. She was initially engaged and participating in OnTrackNY treatment but quickly discontinued medication after starting to work at a financial institution. Further exploration revealed that Iris' parents are non-English speaking and live between China and North America. Iris' family appears to be pressuring her not to pursue FEP treatment, to return to her previous high-functioning level quickly, and not to tell anybody about the hospitalizations. Iris' mother has yelled at the participant for coming to get help from OnTrackNY, afraid that knowledge about her diagnosis in their community will ruin the family. Instead, the family wants Iris to see an herbalist.

b. Best Practices: Sub-theme 1

1. **Create a safe space to discuss differing perspectives:** Create a safe space to explore the perspectives of the person and key family members regarding the illness and the treatment, focusing especially on any difference of views across generations and immigrant vs. native-born individuals.

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- *For example, in the case of Iris, a family meeting could explore the views of each family member, normalizing any differences as logical variations in perspectives, given their life circumstances (e.g., age, gender, place of birth). Particularly during the early phases of the work, it is important to maintain a neutral attitude of expectant inquiry, whereby all views are elicited without judgment, in an attempt to understand the range of family perspectives.*

2. **Include interpreters:** When communicating with less-acculturated family members, include interpreters if any linguistic barriers exist. Remember that individuals who have sufficient language fluency to engage in simple exchanges, such as arranging a family meeting, may lack the fluency to comfortably express complex emotions and situations in therapy.

3. **Focus on points of convergence:** Once the range of views is clarified, focus first on points of convergence to start a dialogue that can eventually help to negotiate differences on key issues, such as the nature of the illness, the treatment approach, or shared concerns or goals (e.g., the person's wellbeing or career objectives). The goal is to arrive at either a confluence of views or a creative détente, which acknowledges unresolved differences but allows therapeutic work to continue.

   - *For example, the team, the individual, and the family may agree to prioritize psychotherapy over medication, or to dial back those treatments after initial recovery to emphasize more functional activities, such as those directed towards work or school integration, while keeping a watchful eye for the return of symptoms. This strategy might be helpful in a case like Amita's where the family defines functioning based on marriage and Amita perceives this as adding a lot of pressure.*

4. **Understand the influence of all family members:** Ascertain whether there are family members who are central to the family dynamics and decision making but whose influence is not immediately obvious and requires exploration.

   - *For example, a grandparent, great uncle/aunt, or godparent (sometimes in another country) may be a key thought leader or decision maker, yet never interact with the clinical team. If the participant and family agree, direct contact with this person (e.g., via telephone) may be attempted. Alternatively, the family interacting with the team may choose to mediate for the distant relative.*

5. **Understand cultural values are not universal:** Keep in mind that the modern, Western values of individual autonomy and individuation, which are expected to be applied even in the case of young adolescents, are a cultural priority not necessarily shared by all cultures. These are key values for health disciplines, which aim to empower each person to decide about their own health choices. Many families (including among white Americans) may instead feel that the older generation (or certain members of it, such as men) should make the decisions for the rest of the family, especially in the case of adolescents. It is important to clarify what the views of the participant and family are regarding autonomy and individuation. It is also useful to have periodic discussions about these topics with the treatment team, in order to arrive at a consistent perspective that can be reinforced by all team members.

   - *For example, in George's situation, there is a disconnect between George's perspective regarding level of family involvement and the parents' perspective. The team might help*

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George and his parents find some common ground so that they can more effectively communicate about their expectations and his personal goals. Additionally, although initially the team might relate to George because his cultural frame is more familiar, it is important to understand whether there are any aspects of the parents' cultural identity that George values and circumstances where he might defer to them to make life decisions. Having these conversations during family meetings or even during team meetings might help clarify some of the important treatment goals to pursue, including possibly strengthening the relationship between George and his parents since they remain his primary source of support.

6. **Address differences directly:** If marked differences are found regarding these values among the treatment team, the individual with FEP, and the family, address these differences directly, if possible. Just clarifying what the various positions are may achieve enough mutual understanding and respect to enable some key decisions to be made. It may not be necessary to agree on the larger societal values in order to collaborate on specific aspects of treatment.

c. Clinical Scenarios: Sub-theme 2

The impact of culture-related family dynamics on the course of illness and/or treatment, including affecting communication within the family and with the treatment team

Victor is a 17-year-old Filipino American young man whose family culture is dominated by his father, who was physically abusive to him earlier in his childhood. Both parents consider the repeated beatings the youth suffered an acceptable form of corporal punishment, as they were subjected to similar treatment during their childhood in the Philippines. However, the mother is frequently silent on this and other topics, so the team does not fully understand her views. The participant reports symptoms of PTSD resulting from the beatings. Focusing on the history of abuse makes the parents very uncomfortable, and there is a concern that the family may disengage from care if the topic is pursued in greater depth with the parents. The father already seems uncomfortable interacting with a female, non-MD therapist.

Jack is a 16-year-old white man from a mixed class background: the mother's origin is upper-middle-class while the father's is working class. Family dynamics are defined around the opinions of the mother; while the participant's and the father's views are suppressed. For example, in one family session, the young man said he would like to invite friends over. The father's comment, "I think that is a good idea," was immediately followed by the mother kicking the father under the table; she proceeded to explain why being social is not helpful at the participant's age. The youth or the father did not dispute her opinion. The mother also objects to the term "schizophrenia" – she calls it "the S-word" – and has imposed a kind of "gag order" against its use by the team; she only permits that certain symptoms be mentioned. The mother's dominance affects every aspect of communication within the family, since disagreements are not openly discussed.

Tony is a 19-year-old white man whose relationship with his upper-middle-class, highly educated parents became very strained after his first hospitalization for paranoia and a disorganized thought and speech process. His mother frequently emails or leaves voice mails for the primary clinician with questions about the participant's diagnosis and treatment. It appears that he is not included in these discussions, even when the mother wanted to transfer his care to another program. Tony, on the other hand, verbalizes

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not wanting to talk with his parents about his experiences and feels that he is dismissed as "the sick child." At the same time, he follows his mother's suggestions without question, such as meeting with a second therapist in another program, going to expressive language therapy, and getting genetic testing for medications. Tony's mother seems to expect to direct the treatment without engaging the participant in the discussion.

d. Best Practices: Sub-theme 2

1. **Help everyone develop awareness of the family dynamics:** Help the individual and family members become aware of their family dynamics through the use of family intervention strategies. Awareness about family conflicts is essential since these often contribute to worsening the person's condition. If FEP symptoms have strained family relationships, the treatment team may help improve communication by eliciting a description of how the illness has affected previous communication patterns within the family. This may help promote greater awareness of ineffective or conflictive communication patterns and support greater mutuality in communication. For example, families may react to the difficult feelings created by the presence of FEP symptoms by attempting to "take over" the care of their relative in an effort to "defeat" the illness. Families and individuals used to being very successful at managing challenges may find the possibility of powerlessness over the pace or degree of recovery very difficult to handle. More egalitarian communication patterns may suffer as a result of these dynamics, or more hierarchical patterns may be reinforced. During treatment, it may be useful to acknowledge the family's strong investment in wanting their relative to succeed. At the same time, the team can help the family carry out a pros-and-cons analysis of alternative strategies; for example, "taking over" the decision-making power from the person with FEP risks more difficulties later on in terms of them achieving independence.

   - *Example: A person's family constitutes a "micro-culture," in which broader cultural influences such as gender roles, parenting behaviors, and class-based perspectives are distilled into a family-specific worldview and/or series of practices. These views and practices may be idiosyncratic, yet dominate the family dynamics thoroughly, such as in the case of Jack. At other times, they may contradict the views of the clinical team and of society, such as the use of corporal punishment in the case of Victor. This form of disciplining can be quite severe and yet normative in some societies, as opposed to the legal and cultural position against these practices taken in the US.*

2. **Team should engage in self-assessment:** Engage in a process of self-assessment to discover if members of the clinical team are finding certain family micro-cultures difficult to manage, such as situations where one parent is dominating the rest of the family or effectively excluding the participant from making decisions about care. In these situations, clinical teams should aim to strike a balance between three desired outcomes: (1) attempting to "correct" the family dynamics, (2) preserving the role of the family as a main support system for the person, and (3) not alienating the family from treatment. This balance can be hard to maintain and in certain situations of outright abuse it may be legally, therapeutically, and ethically necessary to intervene directly to change the family status quo. In other cases (e.g., of mild-moderate corporal punishment that is usually sanctioned by the parents' culture[s] of origin), it may be useful to remember that around the world there is a diversity of views on this subject. Finding common ground with the family is a key goal of

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this process. For example, it may be possible to explore alternate forms of discipline that are culturally congruent but do not run the risk of escalating into physical abuse.

e. Clinical Scenarios: Sub-theme 3

Situations in which culture affects the individual's and the family's views regarding the person's functioning

Malik is a 25-year-old Afghani American man who is living at home with his parents and three younger siblings. Despite his cerebral palsy, he was able to function largely independently prior to the onset of his FEP symptoms. Since his first psychiatric hospitalization, however, Malik has been ambivalent about setting goals for himself. He has become more dependent on his mother and other relatives, refusing to go out alone or to plan for future employment. For example, he insists that his mother remain by his side when they go to the mall, not even tolerating a brief separation. Malik often says "I know my family will take care of me for the rest of my life" and therefore is not very concerned about working towards greater independence.

Aziz is a 22-year-old Muslim Indian man from an affluent background who lives in the suburbs. The parents are frustrated with him because he has been given substantial status in the family as the only male and now is "not living up" to their expectations due to a mix of FEP symptoms, drug use, and reckless behavior. Aziz's parents feel he could do more to overcome the symptoms and to attain the expected social status. They want more face time with the psychiatrist (male) than the primary clinician (female).

Matt is a 25-year-old white man from an affluent Manhattan neighborhood who is experiencing pressure from his mother and brother to apply for SSI. Prior to back-to-back psychiatric hospitalizations for his initial psychotic symptoms, Matt was employed by a technology company and was financially independent from his family. Matt has had a slow recovery from FEP symptoms, resulting in the loss of his job. He thinks he will recover sufficiently to find new work, but his family worries that this is his new baseline and that he should lock in government benefits as soon as possible. He is unsure, concerned that receiving Social Security benefits will be stigmatizing and will become an obstacle, both psychologically and practically, to seeking employment.

Christopher is an 18-year-old male West Indian immigrant who lives with his single mother after completing half a semester of college. She feels strongly that "a man his age" should be independent and has enrolled him in community college. Christopher wants to be independent but worries about failing his classes and/or a return of symptoms of psychosis and mania. Due to his concern, Christopher has limited social interactions and spends much of his time alone playing video games. He feels unsupported by and detached from his mother.

f. Best Practices: Sub-theme 3

1. **Provide information and hope:** The clinical team can play an instrumental role in providing information and hope to the individual and the family about the range of positive outcomes that may result from FEP treatment. It is equally important to provide a clear-eyed appraisal of risks, potential disabilities, and ongoing challenges, tailored to the clinical presentation of the individual. Participants

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and families may have misinformed expectations of potential outcomes, either overly negative or overly positive. It is essential for teams to provide psychoeducation about possible outcomes, while considering the impact that this information can have, given individuals' and families' cultural expectations and concerns (e.g., career hopes, fear of stigmatization). Ongoing evaluation of the possibilities and limitations facing the person is crucial to the ongoing treatment and to the management of the team's relationship with the individual and the family. Peer specialists can be particularly helpful by grounding these discussions with examples from their own lived experience.

- *For example, in the case of severely ill individuals or those with a comorbid medical condition, like Malik, the family may need ongoing support transitioning from their aspirations for the young person to a different set of expectations – or to a slower timing for them – that more realistically correspond to the current clinical picture. This might include helping the family identify strategies that they can practice to ease Malik's comfort level in public and slowly work towards reinforcing independence by building confidence and decreasing anxiety so that he can better tolerate separation from family members. At the same time, it is important that the team not prematurely close the door on possible improvements (especially given the fluidity of some FEP presentations). The team may need to help the family "mourn" their previous expectations and adjust to the participant's present circumstances, all while paying attention to the cultural meaning of these expectations.*

  The team should also help the individual attain many of the goals that (s)he aspired to prior to the illness (e.g., schooling, career, leisure activities, marriage, children). Some of these goals may need to be postponed until the person has improved, rather than being abandoned altogether. It may be useful to focus on how the individual is growing in the context of adversity and developing coping skills that can be applied over the process of recovery. Discussions in treatment about how it is natural for goals to change and for the person's path to be nonlinear or different from what was expected may also be very useful. Concrete activities that can help the person and family cope include talking with graduates of OnTrackNY who were able to achieve or successfully reframe their goals and watching recovery-oriented videos about FEP. This is depicted in Matt's scenario. In his case, the team might offer to work with him and his family to delineate the options between the two extreme poles of either being employed at a job that provides a high income or applying for SSI, while taking into account Matt's values and preferences.

2. **Effectively balance safety and risk:** There is an ongoing tension between safety and risk that the youth and family need to manage, with team support. This tension may take the form of questions like: is it worth trying to go back to college or will I/my relative get sick again? For example, how much school debt will I/my relative incur? Will working delay my recovery or in fact support it? The answers vary according to the individual, and take place within cultural contexts. For example, cultures vary as to who is supposed to make this decision: the individual or the family. The priority placed on attaining goals in order to have self-worth, the level of risk considered worthwhile in seeking these goals, and the specifics of the goals desired vary culturally. Elements of the person's and family members' backgrounds that can affect these values and goals include gender, age, national origin, class, and level of education. Open-ended questions such as the following may be useful:

- What is important for you in your life? Do you have some specific goals in terms of things you want to do? What are they?
- Is your FEP condition affecting your plans for achieving these goals? How?
- If so, what are you doing to cope with these changes? What do you find most helpful in this process? Least helpful? Are there people whose suggestions you find most useful?
- What do your family, friends or others in your community think about your goals and plans?
- Are there ways of looking at things with which you particularly agree? Or disagree? If so, what do you do to reconcile their ideas and yours?

3. **Explore and help families manage their emotions:** Parents and other relatives may experience a wide range of feelings about the emergence of the illness or their inability to prevent it (e.g., guilty, fearful, overwhelmed, isolated, angry). Assistance should be provided to manage these feelings, in a way that aligns with the family's cultural expectations. Providing psychoeducation based on empirical evidence may be useful (e.g., that FEP is not caused by an unrelated activity during the mother's pregnancy, such as smoking). However, strongly held views may be harder to influence, such as religious beliefs regarding punishment for past actions. In some societies, this is taken as a spiritual fact, and the team's opposition may be understood as ignorance or, worse, religious prejudice or competition. It may be more useful to explore the religious interpretation, possibly with the help of a trusted relative, friend or spiritual advisor, in order to explore complementary or alternative explanations or ways of coping with the associated guilt.

C. Theme: Language Barriers

Theme: Challenges due to language barriers between providers, participants, and families in FEP care

Individuals with limited English proficiency (LEP) constitute a growing proportion of the US population. It is crucial – legally, clinically, and ethically – that their care be of the same quality and availability as those of English-language services. Under federal law and regulations, federally funded health services must provide free-of-cost, competent interpretation to individuals with LEP and cannot deny services based on LEP. Furthermore, research has shown that providing LEP individuals care in their language can improve engagement, treatment efficacy, and satisfaction with services.

General Principles for Working with Interpreters:

1. When working with an individual or family member who has limited English proficiency, the use of a qualified interpreter is the best practice if a bilingual provider is not available. A qualified interpreter is someone proficient in English and the language(s) (s)he will interpret, with knowledge of relevant medical terminology, and with experience interpreting in mental health settings. Thus, a "bilingual" program staff member may not have the needed training and experience to provide competent interpretation. Relying on a family member or friend as interpreter is not good practice. Telephonic or face-to-face interpretation may be used; however, telephonic interpretation may be much less effective or even clinically inappropriate when working with highly symptomatic individuals (e.g., when an individual is experiencing auditory hallucinations or has paranoid delusions involving telecommunication devices).

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2. Sometimes it may not be obvious whether a qualified interpreter is needed to best serve a person. This determination can be done by exploring proficiency and preference using the following question:

- How well do you speak English (not at all, a little, well, very well)? Individuals who indicate that they speak English less than "well" must be offered an interpreter. At times, individuals who indicate that they speak English "well" would benefit from having an interpreter. The following follow-up questions can help make this determination:

  o In what language do you prefer to receive medical care? If an individual indicates that (s)he speaks English "well" but prefers another language for receiving medical care, then (s)he should be offered an interpreter. Allow for changes as treatment proceeds: individuals who initially do not request an interpreter may ask for one later, and vice-versa.
  o In what language do you feel most comfortable expressing your emotions and most intimate experiences? Similarly, individuals who indicate they speak English "well" but feel most comfortable expressing emotions or intimate experiences in a different language should be offered an interpreter.

3. Individuals and families may need to be empowered to make informed decisions regarding interpreters. This can be done by providing information about the benefits of a qualified interpreter and the risks of working with an untrained bilingual individual, and by addressing concerns regarding the trust and confidentiality of interpreters (i.e., that, like clinicians, they are professionally bound not to disclose information). Concerns about confidentiality may be more acute in smaller language communities, where the individual and/or the family are more likely to encounter the interpreter in non-clinical settings. In those instances, individuals or families may prefer a telephonic interpreter to increase anonymity. In addition to providing information about interpreters to individuals and families, providers ought to create an open environment for them to express any preferences they may have (e.g., interpreter's gender or age group, telephonic vs. in-person interpretation). An individual or family member may choose not to involve a qualified interpreter despite the provider's recommendation and after receiving information about the benefits of working with one. In that case, and if the provider feels that the individual's safety and quality of care will be compromised, the provider may consider letting the individual or family member know that the provider needs an interpreter.

Integrating and working with qualified interpreters effectively in FEP care requires a series of best practices. These include, for example, the following activities carried out by the provider:

Before the session:

- o Arrange for an interpreter: consider using the same interpreter, if possible, for all sessions with the participant or relative.
- o Brief the interpreter: give them an overview of the purpose of the session, cultural issues that may bear on the situation, key clinical issues, and terms that (s)he should be prepared to interpret.
- o Discuss with the interpreter the best method of interpretation to be used (e.g., consecutive or simultaneous)

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- Decide on the optimal sitting arrangements, including where to place the phone in the case of telephonic interpretation.

During the session:

- Orient all parties: ask the interpreter to introduce him/herself to the individual or family member, and explain the role of the interpreter, emphasizing that the interpreter is there to interpret and not to provide clinical recommendations.
- Ensure quality of care by:
  - Keeping in mind any preferences expressed by the individual and the family.
  - Speaking directly to the patient, not to the interpreter.
  - Being mindful of your pace and the words or phrases that you use.
  - Avoiding psychiatric or medical jargon. If mentioning a term is important or necessary, then make sure to explain it and that the explanation is interpreted.
  - Being aware of cultural differences between you, the interpreter, and the participant and relatives, and of potential misunderstandings among all involved. In some instances, the provider may have to request clarification from the individual or the family.

After the session:

- Debrief with the interpreter about the session, addressing any concerns about the interaction or the interpretation; obtain input from the interpreter about any issues that may have been miscommunicated or may require follow up. However, keep in mind that the interpreter is usually not a clinician.
- Debrief with the participant and/or family member about the session, exploring how they felt about interaction, what worked for them and what did not, and if the individual and/or the family would want something to be changed for future sessions.

1. Sub-themes, Scenarios and Best Practices

1. Situation in which individual treatment is provided with the help of interpreters but other services are hard to access due to language barriers
2. Situation in which care is delivered with the help of interpreters but the quality of interpretation is suboptimal

Next, we describe clinical scenarios related to each sub-theme, delineate best practices, and illustrate how providers might implement these best practices drawing from case material.

a. Clinical Scenario: Sub-theme 1

Situation in which individual treatment is provided with the help of interpreters but other services are hard to access due to language barriers

José is a 17-year-old male immigrant from Central America with a recent initial hospitalization who presents to outpatient care with psychotic and somatic symptoms. His English is very limited, he has an 8th grade education from his country of origin, and his family is not involved in his care. While the primary clinician speaks some Spanish, individual treatment relies on telephone interpreter services.

However, access to other services, such as supported employment and education or group therapy, is limited due to systemic lack of Spanish-language capacity. The young man wants to work and send money back home.

b. Best practices: Sub-theme 1

1. **Become familiar with federal guidelines:** Federal and state mandates require publicly funded services to provide language supports to individuals who need them. These mandates include Title VI of the Civil Rights Act, President Clinton's Executive Order on Limited English Proficiency (LEP), and, in New York State, Governor Cuomo's Executive Order 26. The federal standards on Culturally and Linguistically Appropriate Services (CLAS) are best practices increasingly applied by accreditation bodies to evaluate the quality of services delivered, including the use of interpreters when needed (available at: https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=53).

2. **Seek equitable care:** Providers should seek accommodations to provide equitable services to individuals with LEP. If bilingual providers are not available, equitable care may consist of providing access to interpreters for services needed by the participant and family. For example, José may be able to access supported employment services with the help of telephonic interpreters.

   - *Example: Providing access to group therapy is more difficult, given the delays to the group process from the sequential interpretation of the group verbal content. To overcome this barrier, some OnTrackNY teams have developed language-specific group therapy sessions for the most common languages in that team's participant roster (e.g., Spanish). However, this is not possible for less common languages. As OnTrackNY teams proliferate, it may be possible to bring together participants and families from several OnTrackNY teams who speak the same language in order to provide language-specific group therapy.*

c. Clinical Scenario: Subtheme 2

Situation in which care is delivered with the help of interpreters but the quality of interpretation is suboptimal

Jenny is a 17-year-old female immigrant from Colombia who was treated during her first hospitalization with the help of a US-born Latino clerical worker at the same hospital who acted as an ad-hoc interpreter. The clerical worker worked in administration but was part of a pool of bilingual employees organized by the hospital to provide linguistic interpretation, despite having minimal training. After discharge, the young woman took her medication inconsistently. Once she started treatment with the help of a professional interpreter at OnTrackNY, she was surprised at the different terminology used in her care. It became evident that the untrained interpreter had used popular terms to refer to her condition (which translated into "symptoms of being crazy" in English) and her medication (roughly, "downers") rather than less stigmatizing or professional terms. The worker was also counseling the young woman, without the clinicians' knowledge, not to take the full dose of the prescribed medication "because it was too strong for somebody your age and the doctors don't always know that." In OnTrackNY, the young woman chose to take her medication as prescribed.

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Best Practices: Sub-theme 2

1.   **Become familiar with the level of knowledge and recovery orientation of providers:**
     Interpreters, like any provider, vary in the extent to which they incorporate a recovery orientation in their work. Teams should clarify this aspect of an interpreter's training, since it is possible that the interpreter translates recovery-oriented language used by the clinician into potentially more stigmatizing language. This may happen in an attempt to carry out what interpreters call "lowering the register": turning terms that require more formal education to comprehend, such as "psychosis," into words that are more commonly accessible to all segments of the population.

2.   **Provide training and information to interpreters:** FEP teams may choose to conduct an orientation session with all new interpreters working with them. This session may include a description of key principles for culturally competent FEP care, such as shared decision-making, recovery orientation, etc. This is an opportunity to stress that interpreters must follow the professional standard requiring all verbal content to be interpreted. There should be no side-bar conversations between the individual and the interpreter that the provider is not privy to, or vice-versa, no side comments between interpreters and clinicians. It may be logistically difficult to conduct a full orientation session with telephonic interpreters, who rotate constantly and may vary from encounter to encounter. However, even a very brief orientation prior to the interpreted session would be helpful. Basic interpreting principles include:

     o   Use of de-stigmatizing language and therapeutic orientation
     o   Commitment to shared decision-making and a recovery approach
     o   All verbal content must be interpreted
     o   No paraphrasing: even if verbal content is delusional or tangential, it should be interpreted as fully as possible

D. Theme: Gender and Sexuality

Cultural constructs of gender and sexuality within FEP treatment

Cultural processes involving gender and sexuality may emerge during FEP treatment. Culture affects how individuals experience their own gender identity and sexual orientation, often by highlighting certain options and minimizing others. For example, over the last decade people in many countries – youth in particular – are more likely than previously to experience gender and sexuality in ways that transcend the traditional gender binary of male and female or the dichotomous categories of gay and straight. This change is due largely to the influence of socio-cultural movements promoting greater acceptance of diversity in these areas. Culture also determines how aspects of gender and sexuality are expressed. Cultural norms govern, for example, what counts as masculine or feminine behavior or which sexual acts many consider appropriate. Cultural processes thus influence how much support individuals receive to explore alternate identities or expressions. Stigma and discrimination are ever-present realities in the lives of many people and should be actively assessed and countered. The following examples illustrate situations in which culture exerts a palpable influence in how individuals with FEP and their families engage with gender and sexuality.

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1. Sub-themes, Scenarios and Best Practices

1. Situations in which cultural constructions of gender expression and gender identity emerge in care
2. Situations in which cultural constructions of sexual expression and sexual orientation emerge in care

Next, we describe clinical scenarios related to each sub-theme, delineate best practices, and illustrate how providers might implement these best practices drawing from case material.

a. Clinical Scenario: Sub-theme 1

Situations in which cultural constructions of gender expression and gender identity emerge in treatment

Rafi is a 23-year-old Bangladeshi American man who is being pressured by his parents to marry and have children because "it is [his] duty to [his] family." The family identified several potential brides for him during his hospitalization, but he does not want to meet them. At this point, Rafi is focused on improving from his FEP symptoms first before embarking on what he feels will be a life-changing step.

Jeff is a 19-year-old white man from upstate NY who lives with his divorced mother. He is very stressed because he feels he is not living up to his expectation to "be the man of the house." This involves, for example, influencing his mother's decisions regarding relationships because he thinks she has been making "wrong" choices about men. Jeff also wants to "be a professional and make money" but is discouraged because he feels incapable of achieving his educational and employment goals.

Miles is a 17-year-old white trans man from rural upstate NY who lives with both his parents. He is very anxious about how he is perceived by peers at school and by his parents who refuse to call him by his preferred name and pronouns and still call him by his birth name. While his mother is willing to bring him in for counseling at an LGBTQAI counseling center she is doing so because Miles recently was hospitalized twice for suicidal ideation. Their family is close by and they are part of a rural church and community.

b. Best Practices: Sub-theme 1

1. **Understand the normative gender and sexual expressions in the cultural context:** Issues related to gender and sexuality can emerge in FEP care not only among gender or sexual minorities but also among individuals who follow traditional roles. Two of the examples above describe situations in which a young man had mixed feelings about not fulfilling the typical "male role" according to his understanding of what constitutes appropriate gender expression in his family and community.

   ▪ *In Rafi's scenario, the team might spend some time learning about typical Bangladeshi traditions around marriage and expectations that the family might have. They then can help Rafi and his family come to a reasonable compromise given Rafi's preferences within the context of his symptoms. These types of discussions might inform the team about broader community pressures that the family might be feeling and how to manage these feelings. Additionally, they might help Rafi and his family have more detailed conversations about each individual's expectations and how to adjust to the current circumstances given what*

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the family is currently facing related to Rafi's symptoms of psychosis. The same type of process would be useful to clarify the views on expected age and gender-based norms for behavior held by Jeff, his mother, and their community. It might be harder for staff to visualize these norms as "cultural" if they are considered very familiar, but it can be useful to identify them as such in order to imagine alternative views and behaviors to consider.

2. **Understand the cross-section between psychosis and cultural gender/sexual norms:** FEP symptoms can interfere, sometimes markedly, with the person's ability to fulfill a desired gender role. This discrepancy may be intensely distressing, in part because it touches on a fundamental aspect of one's sense of self: the symptoms are not something the person has, but instead are affecting who the person is. The team may respond by helping the person distinguish between the interpersonal and intra-familiar aspects of the conflict, in an effort to help create a non-stigmatizing space where the person can reflect on their own individual experience and discover a set of authentic preferences. Within the interpersonal sphere, this is also an opportunity to separate the impact of the FEP symptoms from more basic aspects of gender expression and gender identity.

    - *For example, when addressing intra-familiar conflicts regarding gender expression and identity, it is important to clarify the views of the various family members. This may be difficult, as these views are often experienced as taken-for-granted, commonsense assumptions rather than conscious choices. Reaching the stage of naming everyone's perspective is already an achievement. This process may reveal greater heterogeneity of views than initially assumed by the participants – for example, one parent may be more accepting of alternative gender identities or expressions than the other. Discovering a range of views within the family may help overcome rigid black-and-white thinking and allow more room for different views to coexist. This type of discussion might benefit Jeff and his family, by clarifying the ways in which his and his mother's expectations converge and ways in which they differ, as this might help relieve some of the pressure Jeff perceives regarding his responsibility to take care of the household.*

3. **Preserve and strengthen family and community support:** Given the individual's vulnerability as a result of their developmental stage and presence of psychotic symptoms, an important goal of treatment is to preserve the support of the family and community. However, this goal must be balanced against the potential harm that may derive from harsh familial intransigence with respect to the person's desired gender expression and identity. The team should strive to avoid a situation where the person has to choose between the family and an authentic gender experience.

    - *This is an important point in the case of Miles and his family. Across several sessions, discussions might focus on understanding Miles' point of view and that of his parents. It might be feasible to gradually find some common ground that they can all rally around so that the family can continue to support Miles even when they hold a different perspective about his gender and sexuality. For instance, having the parents make any movement towards acceptance of Miles' gender identity might be an important step toward recovery. Even speaking about transitioning, what it entails, and when would be an appropriate time for this step, based on Miles' preferences, might be novel and empowering for everyone. At the same time, another important strategy for strengthening family support could include validating and normalizing the parents' point of view and how difficult it must be for them to change their views regarding the tenets of gender and sexuality given their cultural*

framework and community of outside support. Understanding the parents' fears and reservations, and providing psychoeducation about transgender issues, might be helpful.

c. Clinical scenario: Sub-theme 2

Situations in which cultural constructions of sexual expression and sexual orientation emerge in treatment

Mira is a 23-year-old orthodox Jewish American woman who became much more sexually expressive during her first episode of psychotic mania than had been typical for her. Usually a reserved, private person, she became verbally flirtatious in a highly sexualized way, bought more revealing clothes, and visited a bar, seeking to "meet married men." After treatment reduced the manic symptoms, she became upset by her behavior, which she remembered vividly but incompletely. Mira was tormented by the possibility that she had actually participated in sexual activities at the bar that she did not remember, though this seemed unlikely to the clinical team. She was also upset by what the appearance of these symptoms "said about me in terms of how I really feel," adding, "what kind of a person am I?"

Pedro is 20-year-old male immigrant from Ecuador, whose awareness of his sexual orientation has evolved over time, starting before the onset of his FEP symptoms. After an initial episode of heterosexual activity at age 16, he became aware of having fantasies about sex with men. He began a romantic and sexual relationship with an older Latino man, but periodically also has had affairs with women he meets at work or in social clubs. Pedro feels his sexual orientation is "up to me" and does not appreciate other people's attempts to classify him. He lives with his traditional Latino family, who are concerned that he might be gay and that this is a result of his FEP condition. Family members have approached the team to pursue possible therapy to "correct" his sexual orientation.

Fred is a 22-year-old white man involved in a romantic relationship with a woman who is concerned about a worsening in his incipient sexual side effects if his antipsychotic medication dose were to increase. He has already noted some difficulty sustaining an erection on his current dose. He is concerned that his girlfriend would leave him if he became sexually impotent.

d. Best Practices: Subtheme 2

1. **Help team members maintain a balanced stance regarding their own views on sexuality:** Adolescence and early adulthood is often a time when individuals explore their sexual identity. Cultural norms about what constitute appropriate sexual expressions and orientations have varied over time as well as across social groups in a given time period and society. In the US and many other countries, cultural norms pertaining to sexuality have evolved considerably in recent decades. It is common to find generational tensions within families as to what are considered appropriate expressions of sexuality. It is also possible to find differences of opinion among providers on these issues. Teams may consider instituting procedures similar to those discussed above (e.g., supervision, team discussions, case conferences) to help providers maintain a balanced and critical stance about the role their own views of sexuality play in clinical care.

   - *For example, in the case of Pedro, it is unclear whether FEP symptoms are having an effect on his sexual expression and orientation. Sexual orientations that are evolving, fluid, and*

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non-dichotomous are becoming more openly accepted. In addition, multiple sex partners are the norm in many communities, now and in the past, especially for certain ages and genders. The biggest source of potential distress for this young man regarding his sexuality may actually stem from the conflict it is producing in the family. A non-judgmental, supportive approach is needed that first elicits the perspectives of the person and the family members and then attempts to bridge them. Take the cue from the person regarding how much disclosure (s)he desires and to what degree (s)he believes it is possible to arrive at a common understanding.

2. **Understand the family's view on appropriate sexual behavior:** Some families may hold strict or even punitive ideas as to what constitutes decent and proper sexual behavior. In these cases, it may be difficult to negotiate a common understanding. Cultural brokers – such as FEP program staff who come from similar socio-cultural backgrounds – may suggest resources that may help bridge these disparate views, such as respected community members or advocates. As in the case of family conflicts related to gender identity, avoid if at all possible a situation where the person feels that (s)he has to choose between the family and an authentic sense of self.

3. **Understand and clarify volitional behaviors compared to symptom-driven behaviors:** FEP conditions can influence the way in which sexuality is experienced. For example, some manic episodes can be associated with hypersexual behavior that is not in keeping with the person's usual sexual activity. This can be very disconcerting for the person and the family. The team can be instrumental in preventing demoralization and a damaging sense of shame and guilt by normalizing hypersexuality as a characteristic symptom of mania, regardless of personality, inherent "decency," or cultural background.

   ▪ *For example, in Mira's situation where the manic episode has subsided, it would be helpful to support the individual as (s)he distinguishes between ego-dystonic symptoms associated with a manic episode and intrinsic moral character flaws. When religious or moral traditions have been transgressed, even without intent, it may be helpful to explore with the person and family whether their cultural community provides atoning activities that lead to a sense of closure or self-forgiveness. Consultation with a spiritual leader may sometimes be indicated.*

4. **Understand and discuss sexual side effects related to medications:** Remember also the potential impact of the sexual side effects of psychotropic medication. Managing these is essential to ensuring sustained participation in care, medication taking, and trust in the clinician. For many people, and men in particular, sexual expression or performance are intermingled with their gender identity.

   ▪ *For example, in Fred's case, the presence of sexual side effects may lead him to feel that he is "less of a man" and that this will have dire consequences, such as being unable to sustain a meaningful romantic relationship. Therefore, it may be critical to engage the individual in a dialogue to understand the source of any self-rejecting feelings and the extent of their sexual and gender-based expectations. This may help the individual develop a new understanding of sexuality and gender-related concerns, and ultimately prevent disengagement from treatment.*

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E. Theme: Youth Culture

Most OnTrackNY participants with FEP are adolescents and young adults. Generation-specific cultural issues may become prominent in their care, such as those related to video games and internet use, particularly through social media. Concerns about the isolating aspect of video games may be balanced with alternative opportunities for engagement via online connections. Furthermore, the use of technology (e.g., texting and email) as a primary source of communication might be something that the treatment team leverages in order to promote engagement. Some agencies have policies and procedures for utilizing technology while simultaneously taking into account safety and privacy concerns. At the same time, it is important for providers to realize that this is an area where the available technology is ahead of the rules and regulations that are readily available and therefore some innovation and development of policies might be necessary.

1. Sub-themes, Scenarios and Best Practices

1. Cultural issues specific to adolescents and young adults

a. Clinical Scenarios: Sub-theme 1

Jim is a 17-year-old Korean American man with prominent negative symptoms (e.g., lack of motivation, apathy). His parents are very worried about him because he spends most of the day and late into the night playing video games. He seems to have very little social contact, being unable to return to high school so far due to his FEP symptoms. His parents have tried to interest him in their Korean American church, but he usually refuses to go to services with them.

Tanika is a 19-year-old African American woman who has been feeling withdrawn and disconnected from others. Prior to the onset of FEP symptoms, she was known among her peers as a highly creative person who enjoyed many forms of artistic expression, including in the arts program of her high school and by posting her own photographs and those of others on Instagram. Over the course of OnTrackNY treatment, she was able to channel her creativity by taping music videos on her smartphone, which she shared with her friends through social media.

b. Best Practices: Sub-theme 1

1. **Develop an awareness of the internet/gaming culture:** Become conversant in the gaming and Internet culture of the OnTrackNY participants. Not only will this provide topics for engaging the youth in conversation and therapy but also it may become evident that they are less socially isolated than they appear. Many video games have a multiplayer mode enabling gamers to be part of an online community.

    - *For example, Jim was actually playing the video game Destiny with the same 3-4 friends every day. This is a multiplayer "shooter" game in which players adopt the persona of a powerful warrior and work together or in opposition to achieve a mission. During the game, there is frequent brief verbal communication between players but no visual contact, other than through the image of their game avatar. Many individuals with strong negative symptoms enjoy this form of interaction, as they are able to engage other people and feel*

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motivated to perform the game tasks for long periods of time. However, during these interactions they are able to share only a very limited aspect of themselves and their experience. The strong fantasy element of the game can also fuel some types of delusions. It is important to examine the pros and cons of video game involvement for each person, including as these change over time, in order to leverage the positive aspects of the hobby for their recovery.

The OnTrackNY team discovered that several participants were playing the same video game without realizing it, though with different friends. A therapy group was brought together so that they could discuss how the game helped reduce their negative symptoms. The discussion gravitated to the more general topic of how difficult they found engaging the outside world to be and the pros and cons of staying home and channeling their interactions through the format of the game.

2. **Understand social media and if possible use smartphone for communicating:** Smart phones and social media have become the standard ways for adolescents and young adults to communicate. Teams can choose to leverage the advantages of these communication platforms to encourage participants' social interactions as well as creativity.

   - *For example, Tanika was able to re-invent her creative self by developing simple, web-based music videos. Via social media, individuals can present idealized versions of themselves, emphasizing the positive or fantasized aspects of their experience. This process can boost their self-esteem, but it can also become discouraging if they come to believe their lives pale in comparison to others' or if they become exposed to online bullying. Thoughtful discussion of the role of web-based interactions can be an important aspect of FEP therapy.*

V. Organizational Culture of OnTrackNY

In presenting this Guide on the role of culture in FEP care, it is important to turn our gaze back on the OnTrackNY team, a process of reflexivity that is fundamental to contemporary anthropological theories. Each OnTrackNY team is a social entity, and as such has evolved a group view, shared values, and set of practices; in effect, an organizational culture. Key elements of this culture that deserve some attention include the centrality of shared decision making, a team-based approach to care, the inclusion of the family in clinical care, and a recovery orientation.

In this section, we explore important best practices about these central clinical concepts and practices that are a fundamental part of the OnTrackNY model, drawing from several scenarios.

a. Clinical Scenarios

Terry is 17-year-old white man who was re-hospitalized a few weeks after enrolling in OnTrackNY. The inpatient unit social worker asked the OnTrackNY therapist why the team asked participants whether they wanted to take medications. They should take medications, she thought, if they want to get well.

Farah is a 26-year-old Pakistani American woman with 1 year of reduced FEP symptoms who feels ready to look for a job with the assistance of the supported education and employment specialist in OnTrackNY. Her family, however, thinks that she "cannot work." They are concerned that she is not ready for the added stress of the job search and of regular employment, which they fear will cause her to have a recurrence of symptoms.

Pete is a 16-year-old white man whose family insists that they should be informed of everything he says in therapy. They agree in principle that confidentiality is a desirable value, but feel that he is too young to know what he is doing and that the OnTrackNY team should not be in a position to decide what the family should and should not know.

b. Best Practices

1. **Commitment to shared decision making:** A commitment to shared decision-making is a strongly held OnTrackNY value. Clinical care must be based on the preferences of the individual and the family, in negotiation with the clinical team. The team has an active role, contributing its clinical expertise while also taking responsibility for assessing and intervening when there are safety concerns, for example, by reducing the risk of suicide and violent behavior. This emphasis on basing treatment goals on participant and family preferences is gaining ground in mental health services, but is not ubiquitous. At times, this OnTrackNY value may be challenged by other components of the health system. The team remains steadfastly committed to the dissemination of the shared decision making approach. However, applying shared decision making principles can be more complex when the preferences of the family and the participant do not coincide. In the examples above of Farah and Pete, for instance, these participants disagreed with their families about a key aspect of care. OnTrackNY shares the modern, Western values of individualism and autonomy, but also attempts as much as possible to arrive at a consensus between the views of the individual and those of the family. A shared decision-making process has been developed at OnTrackNY for dealing with disagreements such as these.

   - *Farah, the 26-year-old, for example, is legally and clinically able to make independent decisions, even if this involves assuming the risk of potential recurrence. Moreover, she is endorsing an approach that OnTrackNY and other programs have found efficacious: a recovery orientation, here expressed as the search for employment. Recovery involves the person's commitment to meaningfully engage with his or her own care, including a process of returning, as much as possible, to the life trajectory that existed prior to its onset. The role of the team in this case was to clarify and address the family's concerns in order to help the participant make the best possible decision and to maximize the family's support. It was useful to assess whether intergenerational differences in acculturation were contributing to the situation. Traditional parents may see their role in decision making as extending longer than in other US families, especially for female offspring.*

   - *In the case of Pete, the 16-year-old whose family wants to be informed about everything discussed in therapy, the situation is a more complicated one. Being an unemancipated minor, under the cultural values codified in our clinical and legal*

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systems, he does not have full autonomy to keep his care confidential from his parents. OnTrackNY addresses these situations on a case-by-case basis, using a shared decision making approach to resolve the disagreements. The team developed the rules of this particular episode of care with all parties, negotiating an understanding in which some of what was discussed in therapy could remain private as long as it did not involve unsafe behavior. What behavior met this threshold for lack of privacy was spelled out in advance, and included, for instance, any disclosure of illegal drug use, since both the participant and the parents felt that this would be dangerous for him given his FEP symptoms.

VI. Conclusions

It is important to develop a cultural competent framework from which to deliver services within coordinated specialty care. This will promote engagement and collaboration, allow for more person-centered interventions to be delivered, and help increase the effectiveness of services provided. The focus groups used to develop this guide highlighted the most common themes that practitioners identified when working with young people with FEP. The overarching categories to be mindful of in this work include: a) Religion and Spirituality, b) Family Culture, c) Language Barriers, d) Gender and Sexuality, e) Youth Culture, and f) Organizational Culture of OnTrackNY. We now summarize several crosscutting best practices for each of these categories.

a. Religion and Spirituality

- Establish trust with participants and families by being open to different perspectives, fostering inclusiveness and curiosity about the individual's beliefs and spiritual experiences, and exploring the various beliefs and practices that are part of team members' lives.
- Develop familiarity with the individual's religious/spiritual perspective by understanding the specific components of religious/spiritual teachings and the role they play in the individual's life, discussing traditional healing practices, and determining normality and normativity in the participant's culture(s) around beliefs and behaviors.
- Enhance the therapeutic relationship by developing a shared language about religion/spirituality, incorporate different beliefs and perspectives to understand the presenting issues, and find common ground among the views of family members, spiritual advisors, and the treatment provided by the team. Spend time developing ongoing collaborative relationships with family members and spiritual advisors to inform treatment.
- Balance individuals' dignity to take risks as they figure out their goals with the team's duty to care.

b. Family Culture

- Spend time exploring and understanding the unique family dynamics, the specific roles that each family member plays and how much influence they each have, and understand and be open to the idea that cultural values around these issues are not universal.

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- Create a safe space for participants, family members, and team members to discuss differing perspectives. In doing so, also try to identify the various ways in which family members communicate and manage their emotions. If needed, interpreters should be included.
- Focus on points of convergence across diverse perspectives to establish common ground and lay the foundation for collaboration while at the same time directly addressing differences in opinions that are important to care and the individual's and family's well-being.
- Engage as a team in a process of self-assessment that allows each member to uncover and share biases they may have in their worldview as well as express difficulties they may experience when working with certain families.
- Balance safety and risk-taking as a team through the use of shared decision making with individuals and their families.
- Convey hope about recovery, provide concrete information, and employ problem-solving strategies to support healthy and supportive family dynamics.

c. Language Barriers

- Become familiar with federal and state mandates that require publicly funded services to provide language supports to individuals who need them.
- Work with qualified interpreters rather than bilingual staff members, family members or friends who do not have interpreter training. When possible, obtain face-to-face interpretation instead of telephonic. Provide family with information about the utility of interpreter services and follow best practices before, during, and after a session with an interpreter.
- Seek accomodations to provide equitable services across all activities provided by the program rather than just when working with the primary therapist.
- Become familiar with the interpreter's level of knowledge about mental health and recovery orientation. Provide training and information about first episode psychosis and the OnTrackNY treatment model to interpreters prior to the beginning of the session to ensure consistent application of the OnTrackNY model and more accurate information exchange.

d. Gender and Sexuality

- Develop an understanding of typical gender and sexual expressions for all individuals with whom the team is working, particularly since aspects of gender and sexuality can emerge for individuals who identify as sexual minorities as well as for those who identify with more traditional roles. This includes understanding how symptoms of psychosis can affect the person's ability to fulfill a desired gender or sexual role.
- Aspire to a balanced stance regarding team members' personal views about sexuality and the appropriate developmental exploration that occurs in adolescence along with the variability that has existed across time regarding what constitutes appropriate or acceptable cultural expressions of sexuality and gender.
- Strive to understand the family's views on what constitutes appropriate sexual behaviors and to serve as cultural brokers to help bridge disparate views between the participants and their support networks. This might require enlisting into the conversation the help of respected community members or advocates.

- Preserve and strengthen identified family and community supports, particularly given the vulnerability experienced by young individuals with psychosis.
- Clarify symptom-driven versus volitional expressions of gender/sexuality in order to target demoralization, shame, and guilt associated with symptom-driven behaviors.
- Understand and discuss sexual side effects associated with antipsychotic medications.

e. Youth Culture

- Develop an awareness of young people's interests and the ways they communicate.
- Develop an awareness of internet/gaming culture, for example by incorporating these activities into therapeutic activities or team discussions and by asking the young person to provide some education to the team.
- Understand social media and if possible use smartphones to engage participants, since young people tend to feel more comfortable with text messaging and other forms of web-based relating.

f. Organizational Culture of OnTrackNY

- Spend time as a team discussing and developing a common understanding of the team-based approach, shared values, and set of flexible, client-driven practices specific to OnTrackNY.
- Emphasize a commitment to shared decision making, person-centered care, the inclusion of the family in the treatment approach, and a focus on promoting recovery-based individual strengths and goals.

VII. Resources

The following resources related to the role of culture in FEP care may be useful for providers, participants with FEP symptoms, and family members:

Articles/Writings
- Article on racial disparities in diagnosing psychosis:
  https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4274585/\
  > Schwartz, R. & Blankenship, D. (2014). Racial disparities in psychotic disorder diagnosis: A review of empirical literature. World Journal of Psychiatry, 4(4), 133-140. http://dx.doi.org/10.5498/wjp.v4.i4.133

- Article on cultural aspects involved in the misdiagnosis of psychosis:
  http://www.afrocentric.info/Baobab/EIAAM/Readings/Whaley_Mistrust%20copy.pdf
  > Whaley, A. L. (2001). Cultural mistrust: An important psychological construct for diagnosis and treatment of African Americans. *Professional Psychology: Research and Practice, 32*(6), 555-562. http://dx.doi.org/10.1037/0735-7028.32.6.555

- Article on possible causes of racial misdiagnosis of first-episode psychosis:
  http://www.psychiatrist.com/JCP/article/Pages/1997/v58n10/v58n1010.aspx
  > Strakowski, S., Hawkins, J., Keck, P., McElroy, S., West, S., Bourne, M., Sax, K., & Tugrul, K. (1997). The Effects of Race and Information Variance on Disagreement Between Psychiatric Emergency Service and Research Diagnoses in First-Episode Psychosis. The Journal of Clinical Psychiatry, 58(10), 457-463.

- Piece on cultural humility:
  http://www.apa.org/pi/families/resources/newsletter/2013/08/cultural-humility.aspx
  > Waters, A. & Asbill, L. (2013, August). Reflections on cultural humility: Given the complexity of multiculturalism, it is beneficial to understand cultural competency as a process rather than an end product. American Psychological Association Children Youth and Family (CYF) News. Retrieved from http://www.apa.org/pi/families/resources/newsletter/2013/08/cultural-humility.aspx

- Article on cultural humility: Medical Education Online article on cultural humility:
  https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4742464/
  > Prasad, S., Nair, P., Gadhvi, K., Barai, I., Saleem Danish, H. & Philip, A. (2016). Cultural humility: treating the patient, not the illness. Medical Education Online, 21, Published online: http://dx.doi.org/10.3402/meo.v21.30908

- Article on teaching residents cultural humility:
  http://www.montefiore.org/documents/Bridging-the-Gap-A-Curriculum-to-Teach-Residents-Cultural-Humility.pdf
  > Anderson Juarez, J., Marvel, K., Brezinski, K., Glazner, C., Towbin, M., Lawton, S. (2006). Bridging the Gap: A Curriculum to Teach Residents Cultural Humility. Family Medicine, 38(2), 97-102. http://www.stfm.org/fmhub/fm2006/February/Jennifer97.pdf

- Document from Australia on cultural assessment:
  http://www.mhima.org.au/pdfs/Cultural_aware_tool.pdf
  > Seah E., Tilbury F., Wright B., Rooney R., Jayasuriya, P., (2002). Cultural Awareness Tool: Understanding Cultural Diversity in Mental Health. Retrieved from Multicultural Mental Health Australia website: http://www.mhima.org.au/pdfs/Cultural_aware_tool.pdf

Videos
- Video on cultural humility:
  https://thesocialworkpractitioner.com/2013/08/19/cultural-humility-part-i-what-is-cultural-humility/
  > Moncho, C. August 19, 2013. Cultural Humility, Part I — What Is 'Cultural Humility'?. Retrieved from https://thesocialworkpractitioner.com/2013/08/19/cultural-humility-part-i-what-is-cultural-humility/

Websites
- SAMHSA pages on behavioral health equity:
  https://www.samhsa.gov/behavioral-health-equity

- SAMHSA page on working with specific populations related to mental health:
  https://www.samhsa.gov/specific-populations

- National Network to Eliminate Disparities in Behavioral Health (NNED):
  http://nned.net/

- Culturally and Linguistically Appropriate Services (CLAS) standards:
  https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=53

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