

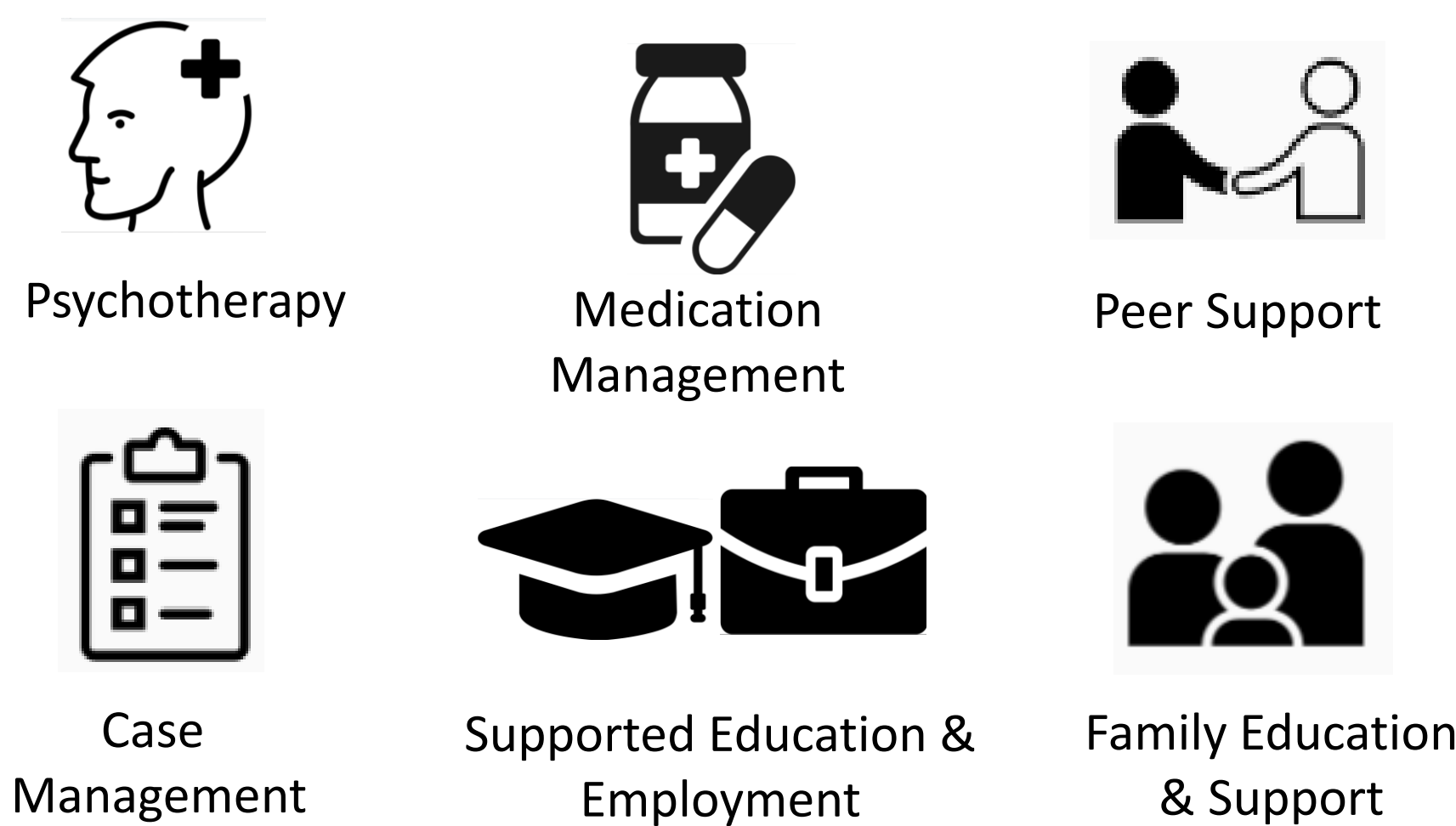
# New Insights into Sustaining Early Intervention Engagement Among Black Clients of U.S. CSC

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## Introduction

- Coordinated Specialty Care (CSC) is evidence-based, multidisciplinary care recommended for young adults experiencing psychosis.
- In the U.S., African American clients, on average, enter CSC later (i.e., at an older age and with a longer duration of untreated psychosis), present with more severe symptoms, receive fewer services, and are more likely to disengage from CSC than White or other client groups.
- This supplement study within the Connection Learning Healthcare System EPINET hub sought to hear directly from African American CSC clients about the process and dynamics of CSC engagement towards addressing these services and outcomes disparities.

## CSC Components



Interviewees described **ENGAGEMENT** as the degree to which they were candid, disclosing, genuine, and invested while interacting with CSC staff, in contrast to guarded, distant, present but not *present*, or absent.

## Methods

- Semi-structured interviews with African-American clients receiving CSC in Maryland & Pennsylvania focused on accounts of contact & engagement with mental health care, CSC specifically, and factors affecting initial and ongoing CSC engagement.
- After informed consent, audio-recorded, remote interviews were conducted by an African-American man older than interviewees or an Arab-American woman around their age. Participants were paid \$40. Transcripts were checked against the recordings for accuracy.
- We employed thematic analysis using primarily inductive coding focused on "Engagement is affected by..." with many iterative cycles of code development, team discussion, refinements, and clarification of emerging themes / concepts.

## Results

### RELATIONSHIP IS CENTRAL

Interviewee's engagement was shaped by how much they felt seen, heard, treated as a "worthwhile whole person" by CSC staff, especially by therapists and prescribers. This was enhanced the more CSC staff were:

- Responsive, consistent, pro-active & listening
- Kind, warm, non-judgmental, calm, patient, including during crises
- Interested & engaged with interviewee's priorities and needs
- Informative so interviewees knew what to expect
- Capable of serious conversations without 'knee-jerk' reactions
- Willing to have clients control treatment & other decisions
- Invested in developing a trusting relationship over time

*"They actually listen to what I have to say. We have conversations, too, where sometimes we would talk about sports or we would talk about we would talk about what's going on with my day-to-day life and everything. So it's more than just talking about my mental health is why I appreciate it."*

*"Everyone was really warm and welcoming. The whole time I was there, it was very warm and welcoming, open. They explained everything, like what was going to happen, all about the program, what things are going to look like, before I even got there. So I wasn't really anxious at all."*

### MEDICATION DISCUSSIONS

foster engagement when interviewees felt genuine "shared decision making," personal agency, and being "treated as an adult." They felt distrustful, unsafe, & less engaged when feeling pressured or judged, insufficiently informed, or worried what would happen if they were candid about symptoms.

*" [Previous psychiatrist] like really made me feel like he was listening to me. If I asked for a certain medication, and he didn't want to give it to me, at least he was like, 'Well, let's try this alternative to that,' and at least would tell me why he didn't want to give me the medication I wanted. ... So all my meds are take as needed and to me, that's really, really listening to me."*

*"One of the things I'm really upset about, I feel like [CSC] made me gain 40 pounds. That I'm still trying to get off. Okay? Because [psychiatrist] never told me that one of the side effects with the antipsychotic drugs [was weight gain]"*

*"[Psychiatrist] didn't really tell me anything. I felt like I had to keep digging for answers [about medications], you know, honestly. Like she would-- she would answer it but she wasn't, like, I didn't really feel heard by her."*

### RACE

was important to feelings of relationship, safety, & engagement:

- Meeting a racially diverse team,
- Experiencing equitable treatment,
- Noting staff familiarity with African-American cultural touchstones,
- Staff occasionally asking about their experiences re race, comfort, respect within CSC
- Not simplifying complex racial identities and evolving feelings
- Wariness with a new non-Black clinician, trust taking a bit longer.
- Staff respecting interviewees who don't see racial identity as central

*"There's definitely [staff] diversity. They're not some strangers or some randos or people who are out of touch with today's day and age.... So I think that definitely appeals very well to me."*

*"They just got to give me treatment and be my therapist. They don't need to do all that with me and my culture and shit. They don't need to... I just get my treatment and get outta there."*

### SOCIO-CULTURAL MESSAGING

Interviewees referenced family, community, & history (often medical & societal racism) as sources of messages about mental health, which in turn impact their thinking and CSC engagement, including:

- Silence: mental health / illness / care is a taboo topic
- A person is weak, broken, or bad if they need mental health care
- A person has failed and is to blame if they have a mental health crisis
- Mental health is important, worth taking care of
- Mental illness is a medical condition that needs to be treated
- Mental health problems are something many people go through and deserve compassion & respect

*"[My culture] taught me that, first of all, you don't need it [MH care] ... if you need it, then there's probably something wrong with you, but it also just really taught me to avoid it until recently."*

*"[I was taught] that you have to take care of it. It's important. Mental, spiritual and physical health ...the three pillars "*

Men stressed the interplay of "male" & "mental health"

*"Whenever you're a male and you're going through [mental health] things, the world isn't very friendly, to males who aren't standing on their own. "*

*"To me and I'm sure my peers, it's [men in mental health care] probably like almost unheard of. So, whenever I do tell somebody that I'm in therapy, I'm commended for it. It's kind of like a brave step, in that way. So, I have respect because of it."*

### SAMPLE

N	18 interviewees
Age	19-39 (Mean: 25)
Gender	11 identified as men, 5 as women, 1 as non-binary, and 1 as a trans man.
Interview durations	27 to 79 minutes (mean: 51 minutes)

### SOCIAL SUPPORT VARIES

Interviewees described a range of emotional & practical responses from friends and family, each with parallel effects on CSC engagement:

- "Being happy for me" that CSC is helpful.
- Abstractly encouraging CSC attendance and engagement
- Providing rides, financial support, company to appointments
- Not wanting to hear about CSC or mental health, others asking
- Some attending family meetings or therapy; others decline
- Friends were usually seen as supportive; family was more mixed

*"My parents are very supportive. I talk to my sisters [and] they [also] agree with what I'm going through..."*

*"Even though I'm all go-go for therapy, my parents don't really believe that therapy is medicine .... So family therapy, the family support group that [CSC] has, they refuse to do it."*

*"[My friends] were supportive in my diagnosis ... being understanding that I do experience hearing voices and that it does get to me sometimes. And so they'll try to keep me from going to places that might flare up my or exacerbate my symptoms."*

## Conclusions

African American CSC clients see their relationships with CSC staff as the dominant proximal shaper of engagement, with medication discussions as an important nexus, social support and sociocultural messaging as contributors, and race shaping all of these in important ways.