

Family Member/Support Person Engagement During Care For First Episode Psychosis

Challenges & Strategies to Move Us Forward

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Financial Disclosures

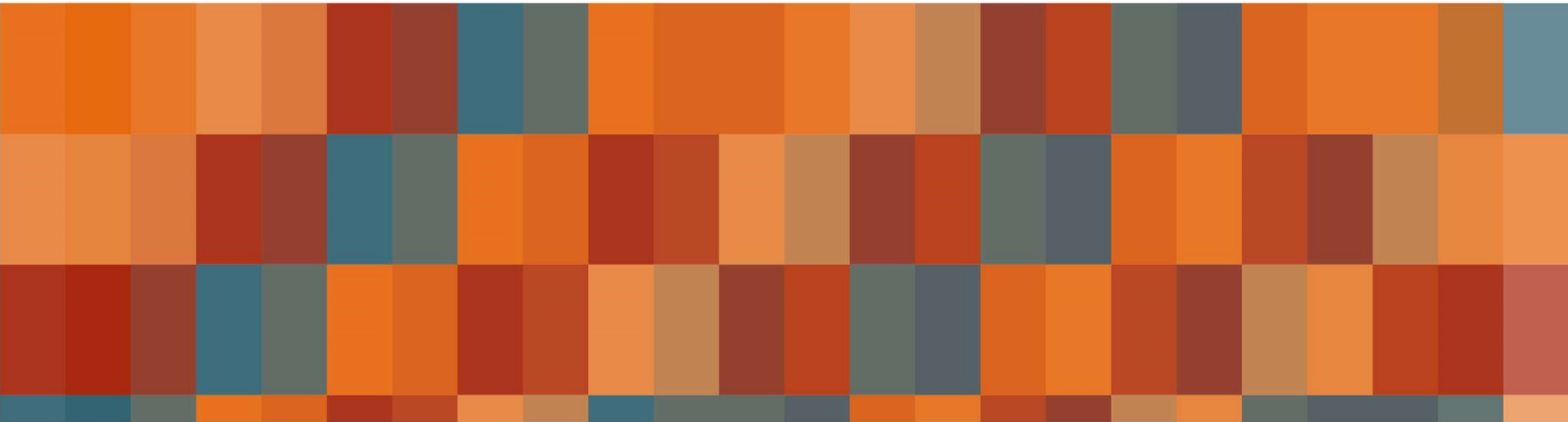
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Objectives

- Explore family member experiences prior to and during care that impact engagement.
- Describe the importance of family/support person involvement and how experiences prior to coordinated specialty care can impact individual outcomes
- Describe racial inequities in family engagement
- Describe how community outreach and campaigns can be used to improve initial engagement among families

LET'S START WITH
PATHWAYS TO CARE...



What is Pathways to Care?

"The sequence of contacts with individuals and organizations prompted by the distressed person's efforts, and those of his or her significant others, to seek help as well as the help that is supplied in response of these efforts."

EXPERIENCES
THAT
PREDATE
PRODROME
PERIOD

PRODROMAL
PERIOD

ONSET OF PSYCHOSIS

PATHWAYS TO CARE

Pathways to Mental Health Services

Misattribution of symptoms

Stigma

Uncertainty

Multiple diagnoses

Hospitalizations

Multiple sources of support

Multiple contacts with MH services


**POSITIVE AND NEGATIVE
EXPERIENCES**



RACIALLY & ETHNICALLY DIVERSE
FAMILIES' PATHWAYS TO CARE
ARE INEQUITABLE

Family Member Experience

"[Inpatient facility] wanted to detain [my son] for the 90 days and they wanted to put him indefinitely in the State Hospital, [that's] when you have criminal activity you did crime, and I kept trying to explain to the county designated responder this is a young man who has never been in trouble with the police! He went to a parochial school, he is an upstanding citizen, he's a college student! But she wouldn't listen to me, her staff wouldn't listen to me, it was basically, I feel that because my son was African American he was targeted and we have to do what they say because once you get involuntarily committed you have no say in it."



**FAMILY MEMBERS HAVE A KEY
ROLE IN FACILITATING THE
PATHWAY TO MENTAL HEALTH
SERVICES & OTHER
RESOURCES & SUPPORT**

Why Focus on Family Members?

- Large majority (88%) of individuals reside with a family member
- Responsible to keeping and attending appointments
- Financial support
- Emotional support

Why We Involve Family Members?

- Primarily responsible for the initiation of treatment or first hospitalization
- Limited family involvement is linked to a longer duration of untreated psychosis
- Interactions with family members and inpatient staff is associated with the initiation of outpatient services

Compton et al., 2008. Mode of onset of psychosis and family involvement in help-seeking as determinants of duration of untreated psychosis
Haselden et al., 2019. Family involvement in psychiatric hospitalizations: Associations with discharge planning and prompt follow-up care
Oluwoye et al., 2020. Family experiences prior to the initiation of care for first-episode psychosis: A meta-synthesis of qualitative studies.

Importance of Family Members

- Family contact is associated with better work performance.
- Living without a family member at discharge and lack of family involvement is a predictor for disengagement.
- Family engagement increases service user engagement.

Brekke & Mathiesen, 1995, The effects of parental involvement on the functioning of noninstitutionalized adults with schizophrenia

Conus et al., 2010. Rate and predictors of service disengagement in an epidemiological first-episode psychosis cohort

Stowkowy et al., 2012, Predictors of disengagement from treatment in an early psychosis program

Oluwoye et al., 2022. Taking a look at how family member engagement influences service user engagement in New Journeys: A coordinated specialty care program

Family Engagement & Outcomes



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The impact of early family contact on quality of life among non-Hispanic Blacks and Whites in the RAISE-ETP trial



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To the Editors,

Family members play a key role in providing support and initiating care for loved ones experiencing their first episodes of psychosis (FEP) (Addington et al., 2005; Marino et al., 2015; Conus et al., 2010). Previous literature demonstrates the importance of connecting and involving family members in treatment and its impact on client outcomes (Compton, 2005; Lucksted et al., 2015; Jones et al., 2019). Studies have suggested that supportive family relationships serve as a protective factor against negative experiences and expectations among Black families,

among Black ($n = 139$) and white ($n = 173$) participants during treatment.

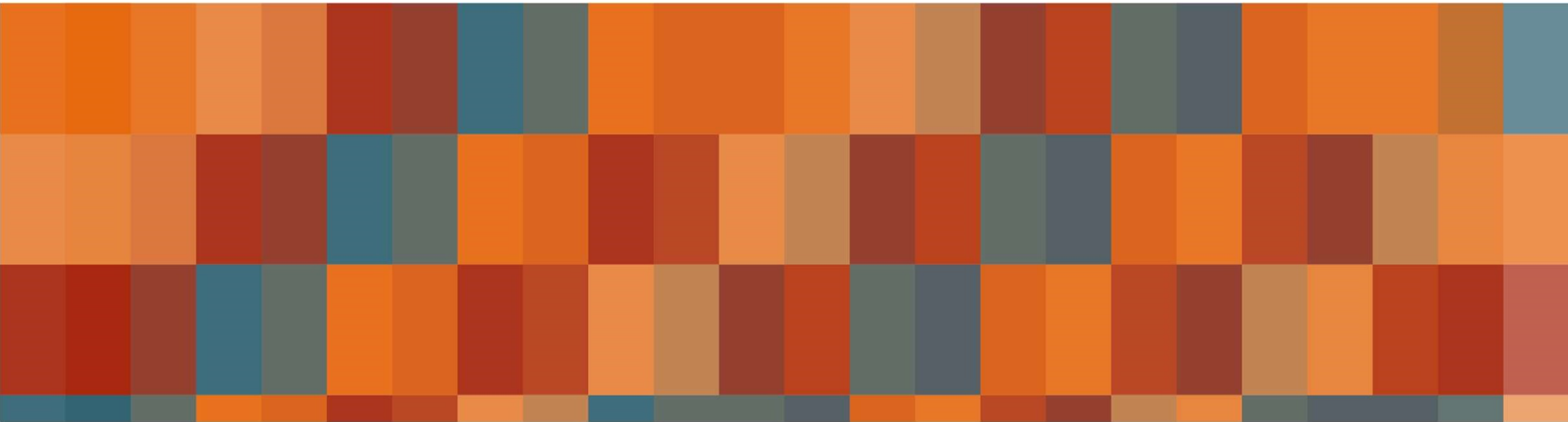
The 21-item Heinrichs-Carpenter Quality of Life Scale (QLS) was administered at baseline, 6, 12, 18, and 24-months with higher scores are indicative of better functioning (Heinrichs et al., 1984). Early family contact was assessed by 'Has your family met with a mental health provider to help them understand and address your situation?' was obtained with the Service Use and Resource Form that was administered at baseline (Rosenheck et al., 2003). The DUP was defined as the time period between the onset of symptoms and initial treatment and was assessed in weeks. Treatment group was also used as a covariate. To account for the nested structure of the data, we fitted each mixed effect model with individuals and sites as random intercepts, controlling for treatment group and DUP, using Stata 15.0. As in prior studies, each model also controlled for linearized time (square root transformation) (Kane et al., 2015). To examine the 2-way interaction between race and early family contact, post hoc pairwise comparisons were performed using Bonferroni correction for multiple comparisons. For continuous outcomes, unstandardized regression coefficients are presented with 95% confidence intervals (CI) and p -value ($\alpha = 0.05$).

Black/African American families with no prior contact with a mental health provider had lower QoL.

Oluwoye et al., 2020. The impact of early family contact on quality of life among non-Hispanic Blacks and Whites in the RAISE-ETP trial



REACHING EARLY INTERVENTION SERVICES



Stages of Engagement

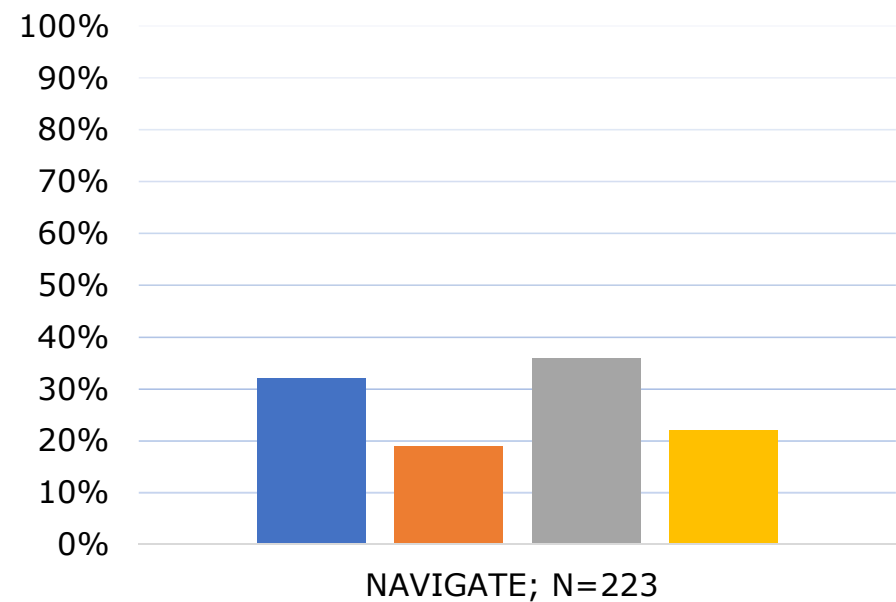
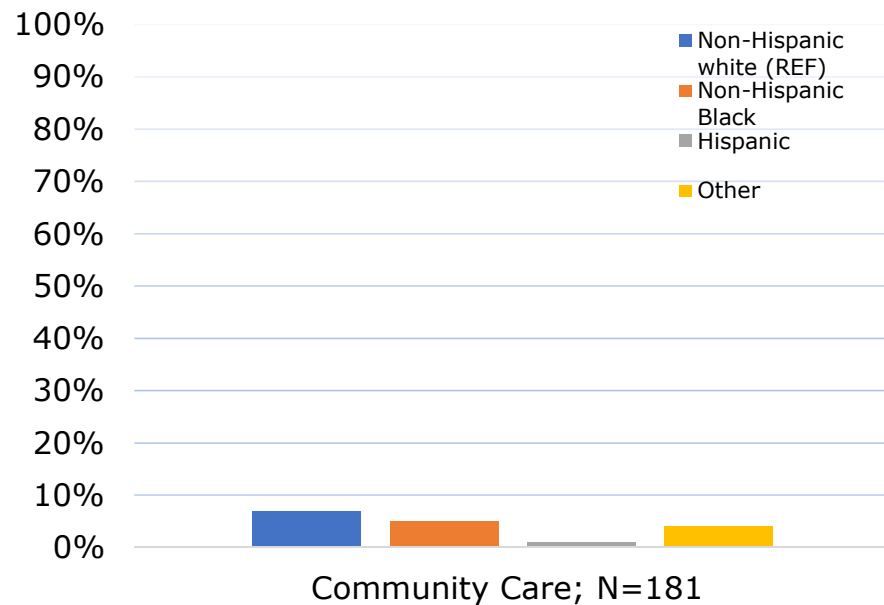
FAMILY
ENGAGEMENT

Continuous Engagement
During Care



**10-50% OF FAMILY
MEMBERS ARE ENGAGED
IN CSC**

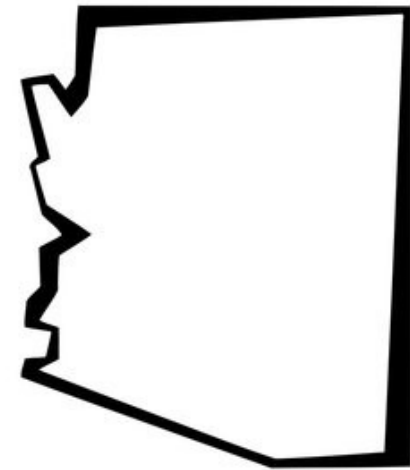
Family Engagement in RAISE-ETP



Rates of family engagement

Early Psychosis Intervention Center (EPICENTER)

- 22% participated in individual family psychoeducation
- 44% participated in group psychoeducation.



A R I Z O N A

Rates of family engagement

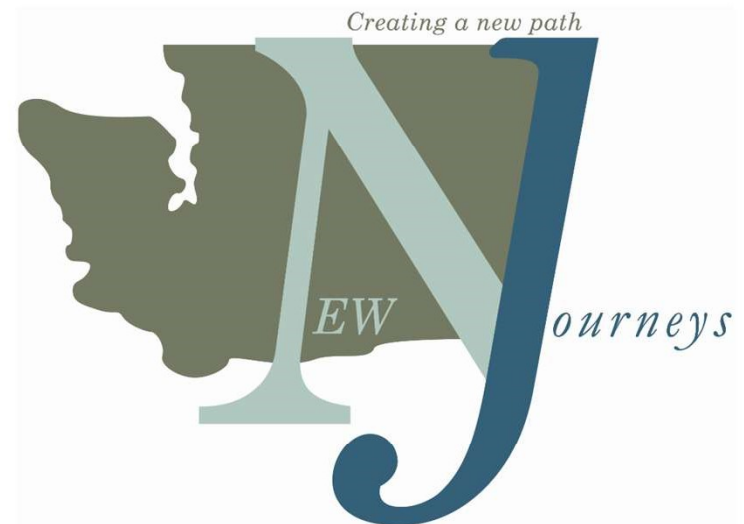
OnTrackNY

- 84% had contact with CSC providers at 3 months
- 41% of service users requested conditional or no family involvement



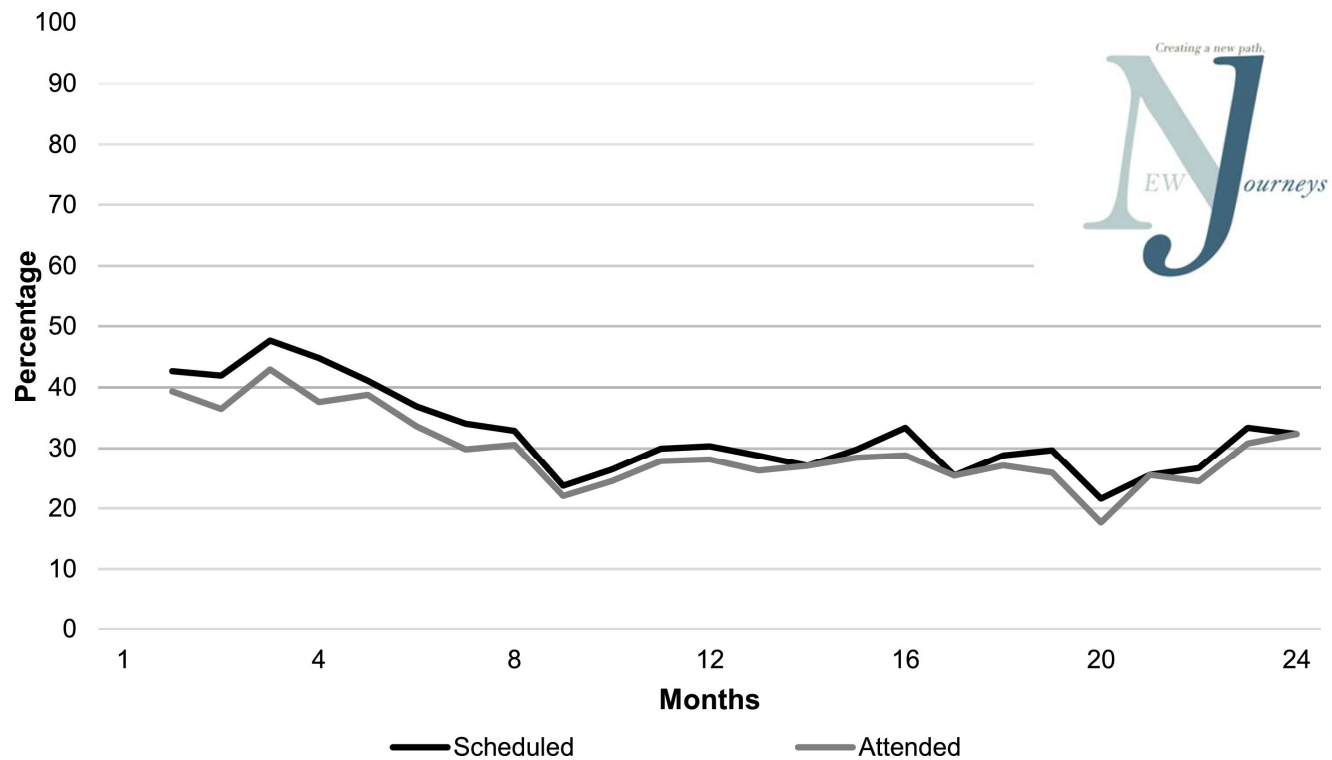
Rates of family engagement

- 70% participated in at least one individual family psychoeducation
- 39% attended psychoeducation in the first month



Oluwoye et al., 2020. Understanding differences in family engagement and provider outreach in New Journeys: A coordinated specialty care program for first episode psychosis

Rates of engagement in New Journeys



Oluwoye et al., 2020. Understanding differences in family engagement and provider outreach in New Journeys: A coordinated specialty care program for first episode psychosis

Stages of Engagement

**FAMILY
ENGAGEMENT**

Initial Engagement
Pathways to Care



Continuous Engagement
During Care



EARLY CONTACT LINKED TO BETTER
OUTCOMES



NEGATIVE EXPERIENCES LEADS TO
LACK OF ENGAGEMENT



ENGAGEMENT INCREASES
ENGAGEMENT



BARRIERS TO FAMILY ENGAGEMENT



Barriers to engagement

I. Stressors and Obstacles that Compete with Treatment

II. Treatment Demands and Issues

III. Perceived Relevance of Treatment

IV. Relationship with the Therapist

V. Critical Events

I. Stressors & Obstacles

During the course of loved ones' treatment I experienced a lot of stress in my life

I. Stressors & Obstacles that Compete

II. Treatment Demands & Issues

III. Perceived Relevance of Treatment

IV. Relationship with the Therapist

V. Critical Events

II. Treatment Demands & Issues

Scheduling of appointment times made it hard to attend

I. Stressors & Obstacles that Compete

II. Treatment Demands & Issues

III. Perceived Relevance of Treatment

IV. Relationship with the Therapist

V. Critical Events

III. Perceived Relevance of Treatment

My loved one has a new or different set of problems

I. Stressors & Obstacles that Compete

II. Treatment Demands & Issues

III. Perceived Relevance of Treatment

IV. Relationship with the Therapist

V. Critical Events

IV. Relationship with the Therapist

The therapist did not seem confident that treatment would work for my loved one

I. Stressors & Obstacles that Compete

II. Treatment Demands & Issues

III. Perceived Relevance of Treatment

IV. Relationship with the Therapist

V. Critical Events

V. Critical Life Events

Interruptions in Treatment
(e.g., placed in inpatient)

Family Dynamics & Other Family Issues
(e.g., family substance use)

Household Changes
(e.g., changes in medical insurance)

I. Stressors & Obstacles that Compete

II. Treatment Demands & Issues

III. Perceived Relevance of Treatment

IV. Relationship with the Therapist

V. Critical Events

Summary of Family Member Needs

- Treatment relevance - family member needs and expectations
- Relationship building - consistency
- Stress management, flexibility
- Treatment demands – clarity and involvement

ENGAGEMENT



**FAMILY MEMBER
PERSPECTIVES ON HOW
CAN WE IMPROVE
ENGAGEMENT**

Theme I: Support

SUPPORTIVE INTERACTIONS

POSITIVITY

WORKING WITH COLLEGES/UNIVERSITIES &
EMPLOYERS

Theme II: Knowledge

EDUCATING COMMUNITY ORGANIZATIONS

UNDERSTANDING SIGNS & SYMPTOMS

AVAILABLE RESOURCES & SERVICES IN THE
COMMUNITY

Theme III: Communication

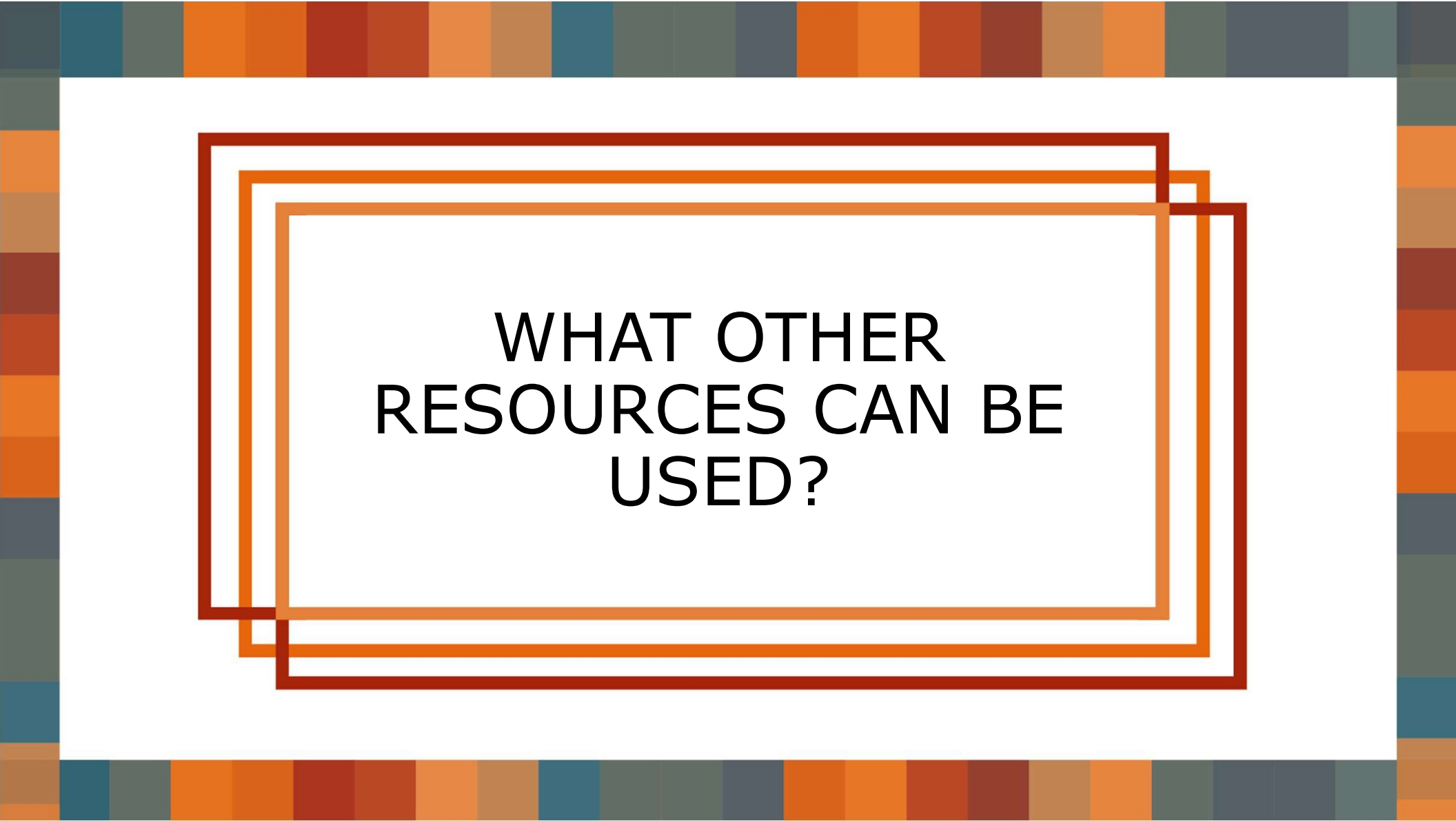
VALUED AND LISTENED TO BY CLINICIANS

BILINGUAL STAFF

Theme IV: Access

AVAILABILITY OF SERVICES

TIMELY REFERRALS



WHAT OTHER
RESOURCES CAN BE
USED?

Current Efforts

- Family Peers to address continuous engagement in CSC
- Family Motivational Engagement Strategies (FAMES) to improve continuous engagement in CSC
- Family Peer Navigators to improve initial engagement and access to care for Black/African American families



TRANSFORMATION

TRANSFORMATION I want to see...

- Services that address the needs of family members
- Improved navigation between systems of care
- Community-informed resources and support
- More diversity in the workforce