Diversity, equity & inclusion in early psychosis with a focus on pathways to and through care

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New England MHTTC & MMHC Grand Rounds

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SAMHSA
Substance Abuse and Mental Health Services Administration

MHTTC
Mental Health Technology Transfer Center Network
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Acknowledgment

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At the time of this publication, Miriam E. Delphin-Rittmon, Ph.D, served as Assistant Secretary for Mental Health and Substance Use in the U.S. Department of Health and Human Services and the Administrator of the Substance Abuse and Mental Health Services Administration.

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Presented 2022

The MHTTC Network uses affirming, respectful and recovery-oriented language in all activities. That language is:

- Strengths-based and hopeful
- Inclusive and accepting of diverse cultures, genders, perspectives, and experiences
- Healing-centered and trauma-responsive
- Inviting to individuals participating in their own journeys
- Person-first and free of labels
- Non-judgmental and avoiding assumptions
- Respectful, clear and understandable
- Consistent with our actions, policies, and products

Adapted from: https://mhcc.org.au/wp-content/uploads/2019/08/Recovery-Oriented-Language-Guide_2019ed_v1_20190809-Web.pdf

Diversity, equity & inclusion in pathways to & through Coordinated Specialty Care

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Conceptualizing pathways to & through care

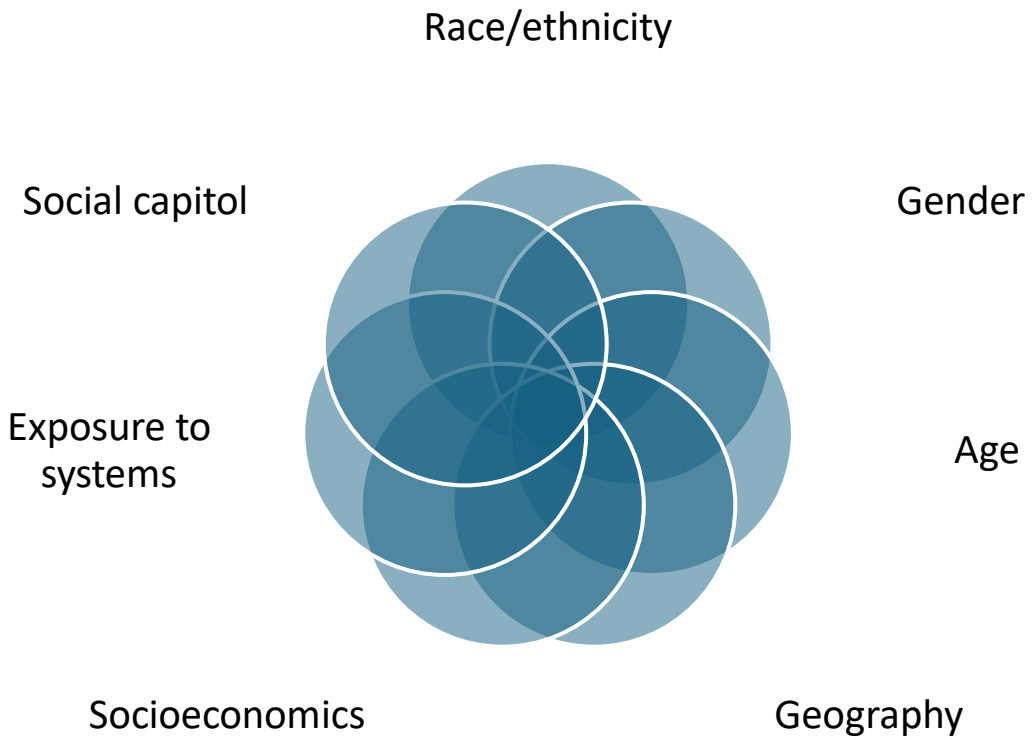
- where are the strongest referral pathways?
- who is & isn't eligible?
- do pathways scaffold or undermine trust?
- how much privilege or tenacity is needed to advocate for access?

- who is and isn't eligible?
- who initiates services?
- what are the earliest motivations for enrollment?
- How are families involved and supported?

- rapport with providers
- alignment with how the program understands problems & solutions
- perceptions of benefit

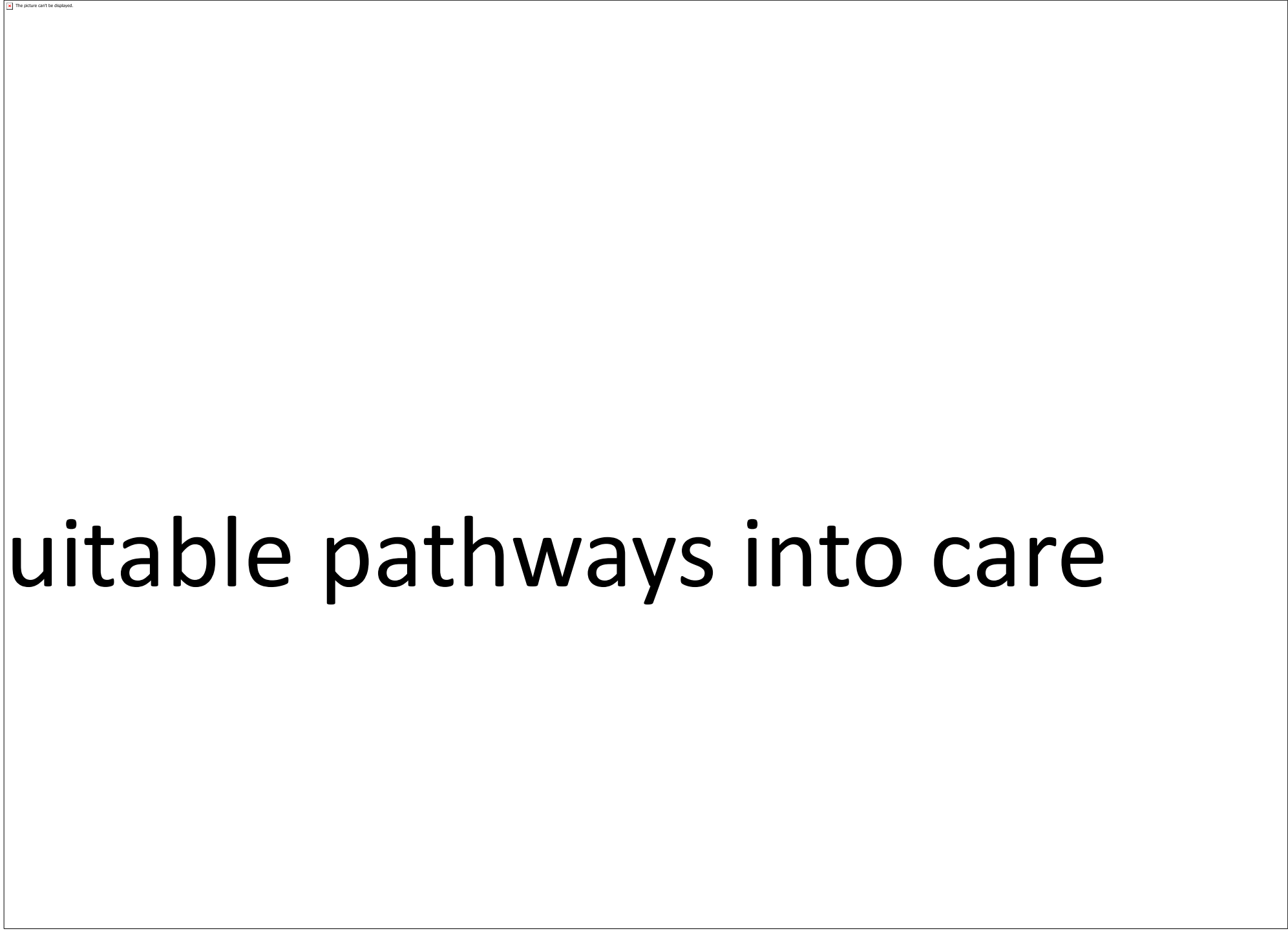
- insurance stratification
- psychosis expertise
- psychiatric rehabilitation, employment & education supports
- homelessness
- incarceration

Conceptualizing DEI



what positionalities were centered when we...

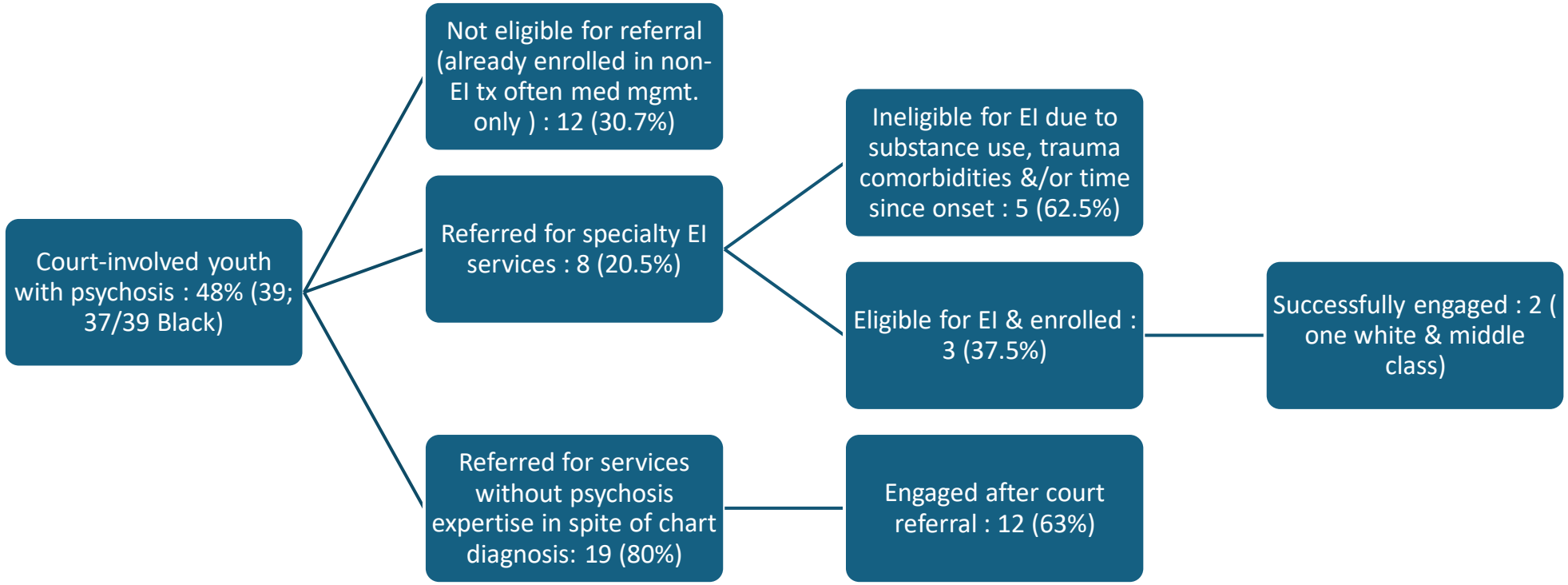
- decided where to focus outreach?
- decided what the eligibility criteria would be?
- decorated the clinic?
- designed the intake process?
- created the discharge protocols?
- trained the team?



(in)equitable pathways into care

Pathways into care: case study from Tampa, FL

- Project initiated by Public Defender's office – so many juveniles appear to have psychosis – why aren't they making it into CSC?

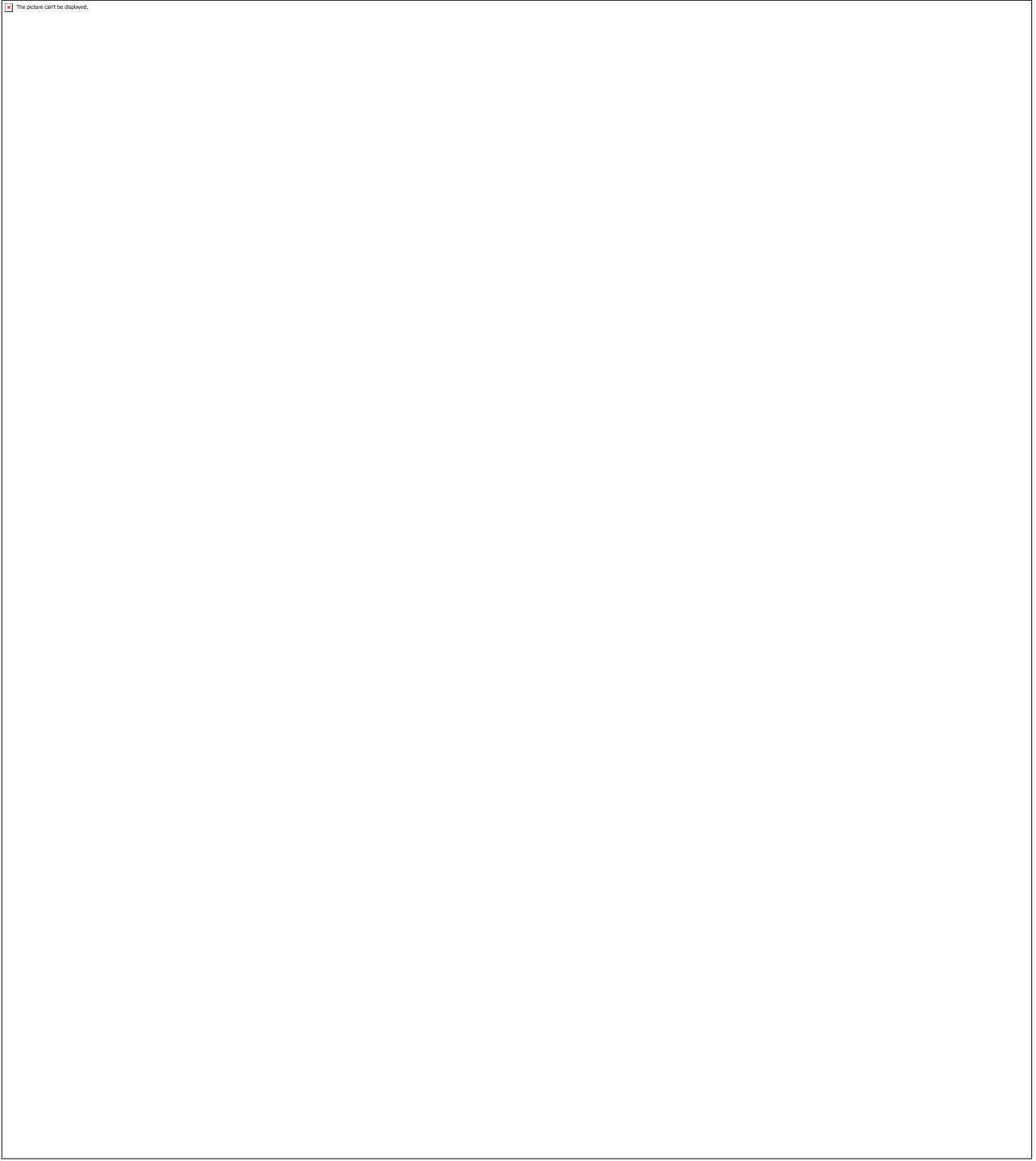


Interviews with family or guardians (n = 12)

- Generally overwhelmed by poverty / struggling to make ends meet
  - Limited transportation (often no cars), multiple jobs and caregiving responsibilities for both children & elders
  - Transportation to multiple appts each week seeming entirely out of reach
- Often both family & impacted child do not see “psychosis” as the problem
  - Either skeptical of psych meds or uncertain as to why meds alone aren’t enough
- Inability to make it to appointments/assessments, inability to receive or return phone calls (no minutes left, couldn’t pay phone bills etc)
- Youth without family (out of home residential care, court-appointed guardian, etc.)
  - “no one cares about this kid, no one is advocating them, they’re [experiencing severe psychosis] and falling through the cracks. You’ll read about them having shot someone or themselves in the paper one day”

Discussion of ineligibility with CSC team

- Often lengthy histories of trauma, substance use, hospitalizations, psychotropic meds, & ‘extreme states’ or voices + 6 or more diagnoses on average and often “low IQ” or IDD
  - Exceeding maximum duration of untreated psychosis (DUP) criteria (per model followed : “evidence suggests these interventions are not effective if DUP is too long”_
  - Uncertain primary diagnosis / messy diagnostic picture
- Even when eligible, many families unable or unwilling to enroll



Thought Experiment:

What would CSC look like if it were designed for minoritized, multi-systems involved, highly disadvantaged youth and their families?

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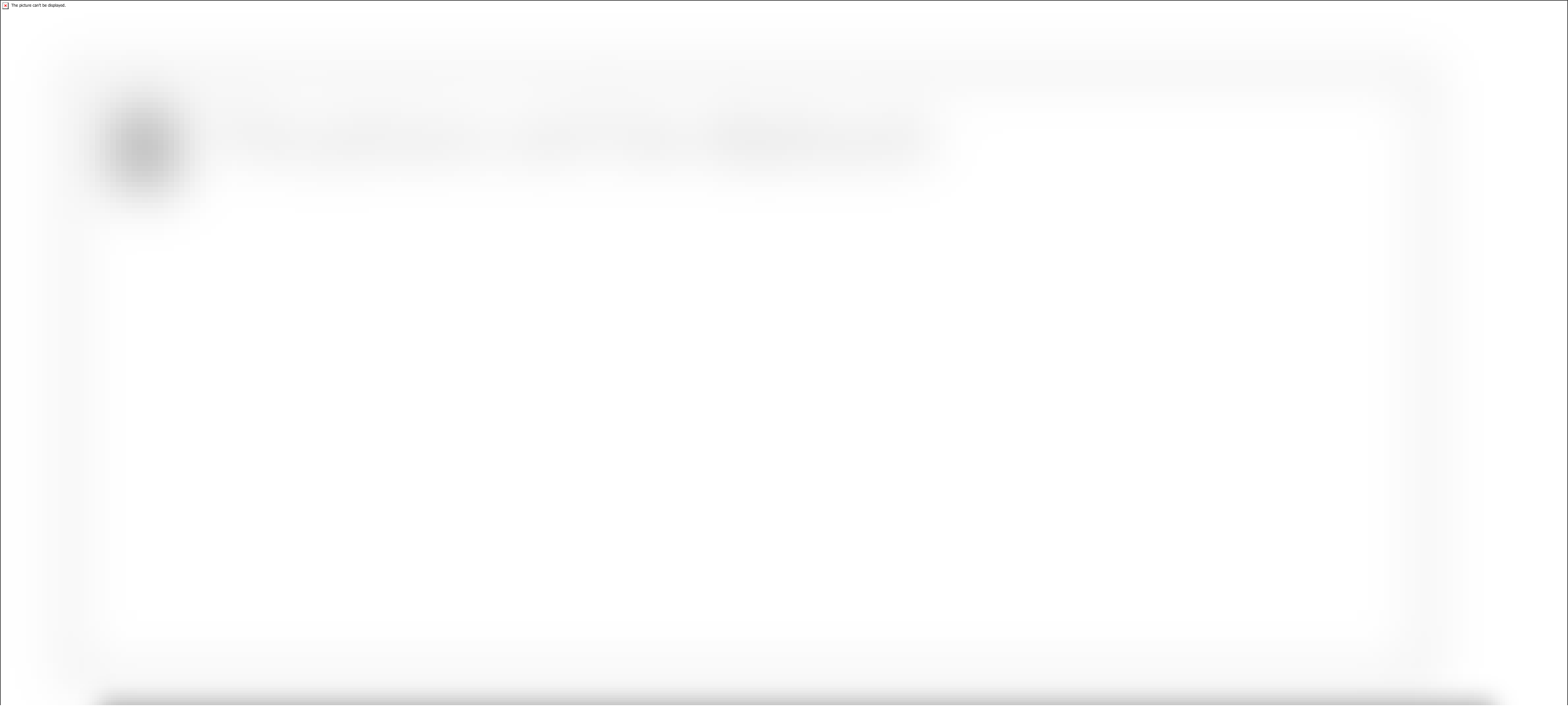
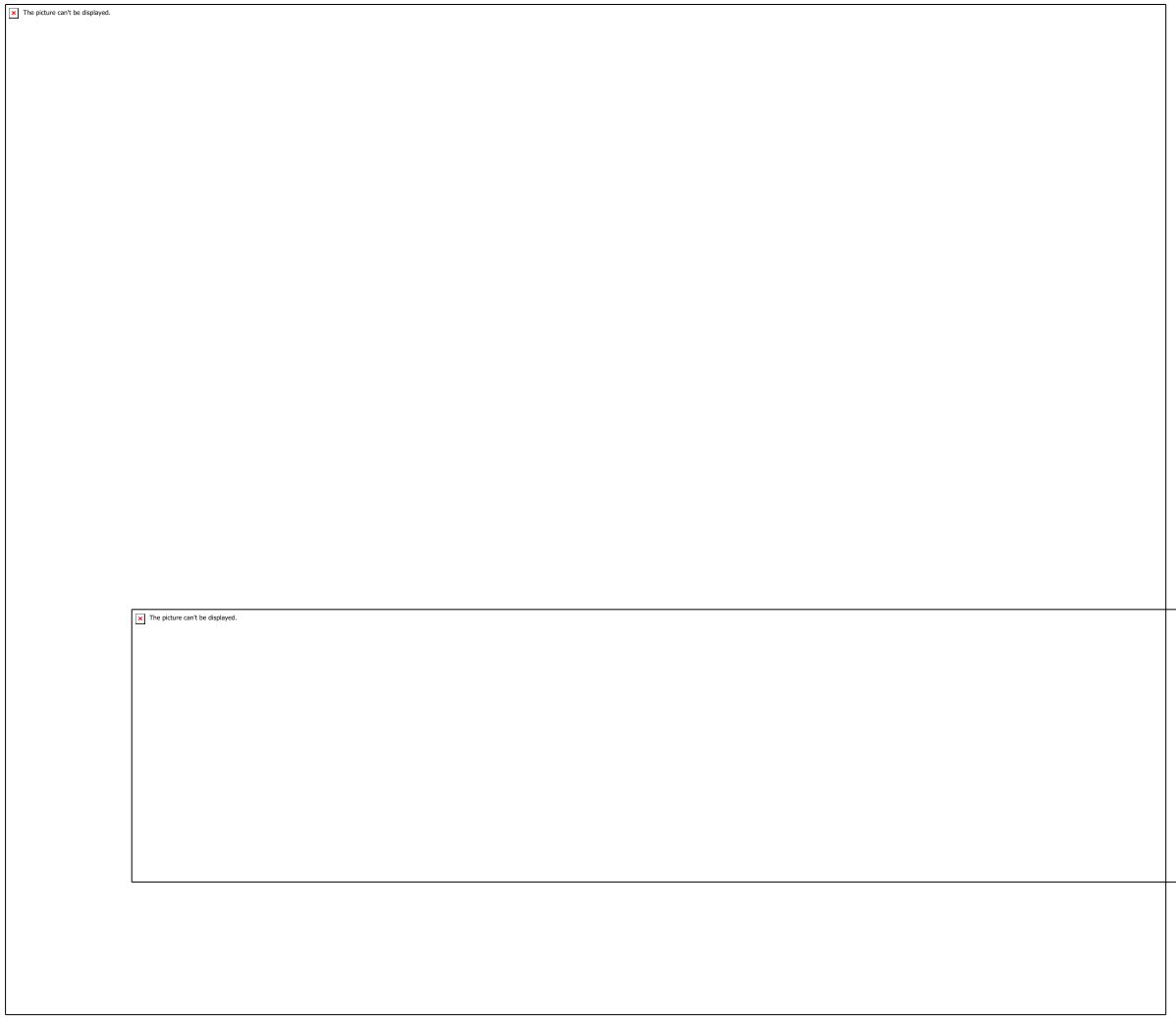
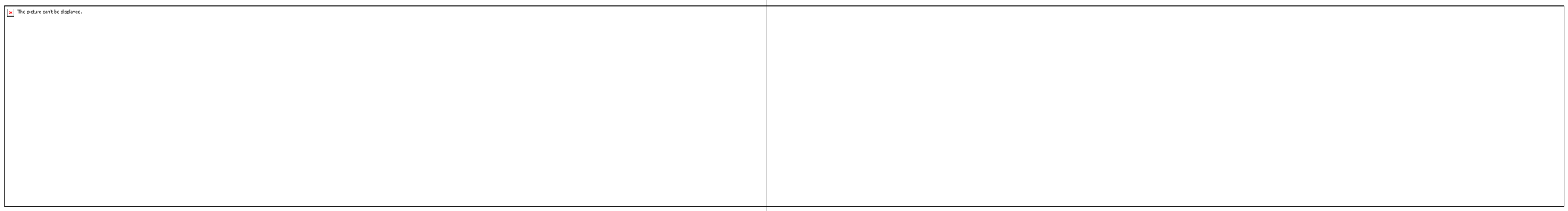


(in)equitable pathways through care

A reminder: who benefitted / didn’t benefit from RAISE?





Quantitative data on all clients discharged from NY State CSC

- Total N = 1458
- data is not censored (percents are uncorrected for clients who remain enrolled)
  - Less than 40% completed the program
  - Almost 50% unilaterally withdrew or stopped attending appts/communicating, on average before reaching one year
- Not all discharge is bad, but there are large numbers of clients who disengage or are administratively discharged, simultaneously with very concerning outcomes – e.g. not in work or school

	All Clients	Dicharge context clusters				
	Overall, N = 1,458	**1, N = 474**	**2, N = 556**	**3, N = 258**	**4, N = 170**	**overall p-value**
Reason for Discharge						
complete	575 (39.4%)	426 (89.9%)	37 (6.7%)	23 (8.9%)	89 (52.4%)	<0.001
client termination	497 (34.1%)	33 (7.0%)	291 (52.3%)	116 (45.0%)	57 (33.5%)	<0.001
unable to contact	208 (14.3%)	1 (0.2%)	140 (25.2%)	64 (24.8%)	3 (1.8%)	<0.001
moved	103 (7.1%)	0 (0.0%)	66 (11.9%)	21 (8.1%)	16 (9.4%)	<0.001
other	75 (5.1%)	14 (3.0%)	22 (4.0%)	34 (13.2%)	5 (2.9%)	<0.001
Early Discharge						
Discharge(365+ days)	783 (53.7%)	473 (99.8%)	139 (25.0%)	68 (26.4%)	103 (60.6%)	<0.001
Early Discharge (<365 days)	675 (46.3%)	1 (0.2%)	417 (75.0%)	190 (73.6%)	67 (39.4%)	<0.001
Length of Treatment	512 (376.8)	879 (268.1)	286 (229.8)	289 (214.0)	569 (391.6)	<0.001
Age Categories						
<18	193 (13.2%)	74 (15.6%)	1 (0.2%)	117 (45.3%)	1 (0.6%)	<0.001
18-20	493 (33.8%)	188 (39.7%)	227 (40.8%)	78 (30.2%)	0 (0.0%)	<0.001
21-25	614 (42.1%)	182 (38.4%)	273 (49.1%)	57 (22.1%)	102 (60.0%)	<0.001
26-30	153 (10.5%)	29 (6.1%)	55 (9.9%)	6 (2.3%)	63 (37.1%)	<0.001
>30	5 (0.3%)	1 (0.2%)	0 (0.0%)	0 (0.0%)	4 (2.4%)	<0.001
Gender						
Female	379 (26.0%)	119 (25.1%)	142 (25.5%)	54 (20.9%)	64 (37.6%)	0.001
Male	1,069 (73.3%)	354 (74.7%)	409 (73.6%)	204 (79.1%)	102 (60.0%)	<0.001

	All Clients	Discharge context clusters				
	Overall, N = 1,458	**1, N = 474**	**2, N = 556**	**3, N = 258**	**4, N = 170**	**overall p-value**
Reason for Discharge						
complete	575 (39.4%)	426 (89.9%)	37 (6.7%)	23 (8.9%)	89 (52.4%)	<0.001
client terminate	497 (34.1%)	33 (7.0%)	291 (52.3%)	116 (45.0%)	57 (33.5%)	<0.001
unable contact	208 (14.3%)	1 (0.2%)	140 (25.2%)	64 (24.8%)	3 (1.8%)	<0.001
moved	103 (7.1%)	0 (0.0%)	66 (11.9%)	21 (8.1%)	16 (9.4%)	<0.001
Race/Ethnicity						
White (Non-Hispanic)	342 (23.5%)	101 (21.3%)	135 (24.3%)	35 (13.6%)	71 (41.8%)	<0.001
Black (Non-Hispanic)	532 (36.5%)	166 (35.0%)	227 (40.8%)	103 (39.9%)	36 (21.2%)	<0.001
Asian (Non-Hispanic)	122 (8.4%)	34 (7.2%)	41 (7.4%)	14 (5.4%)	33 (19.4%)	<0.001
Hispanic	373 (25.6%)	147 (31.0%)	112 (20.1%)	91 (35.3%)	23 (13.5%)	<0.001
Multiracial	32 (2.2%)	16 (3.4%)	5 (0.9%)	6 (2.3%)	5 (2.9%)	0.029
Highest Education Level						
<HS	306 (21.0%)	65 (13.7%)	0 (0.0%)	241 (93.4%)	0 (0.0%)	<0.001
HS or GED	322 (22.1%)	109 (23.0%)	196 (35.4%)	17 (6.6%)	0 (0.0%)	<0.001
Some College	629 (43.2%)	289 (61.0%)	340 (61.5%)	0 (0.0%)	0 (0.0%)	<0.001
College Graduate	167 (11.5%)	11 (2.3%)	17 (3.1%)	0 (0.0%)	139 (81.8%)	<0.001
Post-graduate study	31 (2.1%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	31 (18.2%)	<0.001
Currently Employed/In School						
No	591 (40.6%)	162 (34.2%)	275 (49.6%)	110 (42.6%)	44 (25.9%)	<0.001
Yes	865 (59.4%)	312 (65.8%)	279 (50.4%)	148 (57.4%)	126 (74.1%)	<0.001

Qualitative data on sociostructural stratification during & following CSC

- Who benefits when it comes to CSC supports for career development / reintegration?
- Qualitative interviews with discharged CSC clients and their families (total N = 30)

Qualitative sub-groups

Substantial structural disadvantage, applied for/receiving SSI	•Disproportionately Black •Multigenerational poverty & disability •Two sub-groups: high impairment, mixed or low impairment
Socioeconomic privilege but pronounced disability, applied for/receiving SSI	•Disproportionately White •Substantial resources
Lower SES background, working in low wage non-career-track job, considering SSI	•Mixed ethnoracial backgrounds •Total wages at or below the level of average monthly SSI payment
Lower SES background, working in low wage job but with clear goals for mobility	•First & second generation immigrants over-represented
Mixed SES, college-educated extended family, in college, graduate school or career-track	• Disproportionately White and Asian, aspired to or planning on college prior to onset •Lower levels of disability and/or greater response to medications or therapy

How are mental health services potentially exacerbating inequalities?

- **For high disadvantage clients, SSI often perceived as necessary by providers to meet basic needs (vs work/school)**
  - Medicaid – coverage of group homes, residential settings, intensive SMI services
  - Subsidized housing/ Sec 8 Vouchers
  - Additional benefits linked to disability
  - Following SSI application: providers discourage work – fear active work will lead to denial

- **Employment during CSC & in post-CSC voc rehab**
  - Vocational support services oriented toward rapid placement in low wage part-time jobs
  - Rationale conclusion for many is that SSI is better
    - "I mean, what really are the options anyway? I would be better off on SSI"
- **Higher education**
  - Far fewer barriers & greater supports for clients from college educated families
    - "Flight path" from the prototypical low-wage-work-emphasis of supported emp staff
  - Services themselves most often described as providing assistance with applications, not substantive coaching, study skill building, campus navigation

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Thought Experiment Redux:

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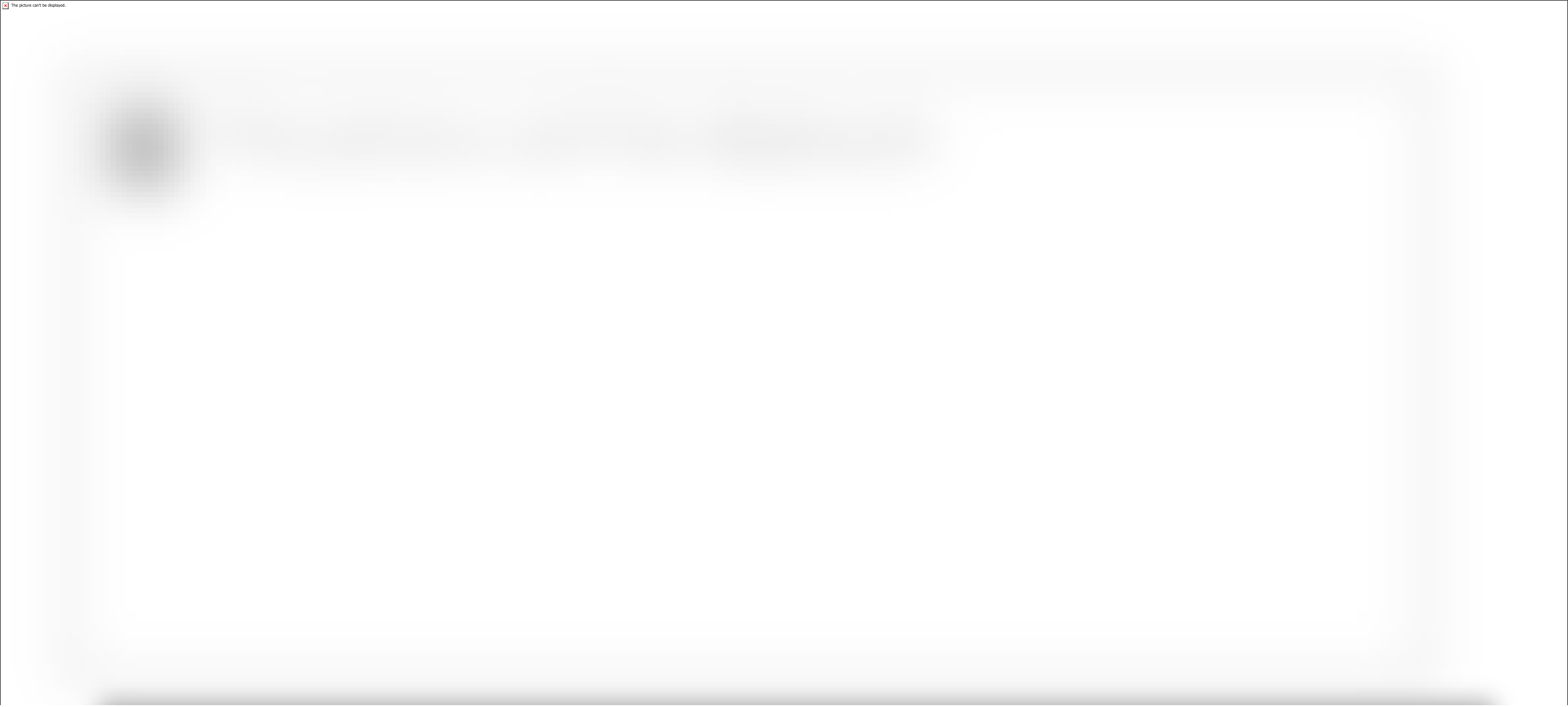

transforming services for equity

systemic change

re-grounding service design in the needs of those 'most impacted' (by psychosis & intersecting systems of oppressi

- consultation, qualitative
  integration of those wit
  knowledge of
  - poverty, food insecuri
    precarity
  - multi-systems involve
    separation, family loss

local analysis

- who is/isn't getting into CSC (and why)
- who is/isn't staying in CSC (and why)
- whose outcomes portend long-term poverty (and why)

policy change

- SSI, housing, access to education, disability justice

  Refusing that CSC be used as an alibi to avoid deeper injustices

Martin Luther King Jr, Where do we go from here?

I want to say to you as I move to my conclusion, as we talk about “Where do we go from here?” that we must honestly face the fact that the movement must address itself to the question of restructuring the whole of American society. There are forty million poor people here, and one day we must ask the question, “Why are there forty million poor people in America?” And when you begin to ask that question, you are raising a question about the economic system, about a broader distribution of wealth. When you ask that question, you begin to question the capitalistic economy. And I’m simply saying that more and more, we’ve got to begin to ask questions about the whole…. We are called upon to help the discouraged beggars in life’s marketplace. But one day we must come to see that an edifice which produces beggars needs restructuring.

What I’m saying today is that we must go from this convention and say, “America, you must be born again!”

And so, I conclude by saying today that we have a task. Let us go out with a divine *dis*satisfaction.

MHTTC
Mental Health Technology Transfer Center Network
Funded by Substance Abuse and Mental Health Services Administration

The purpose of the MHTTC Network is technology transfer - disseminating and implementing evidence-based practices for mental disorders into the field.

Funded by the Substance Abuse and Mental Health Services Administration (SAMHSA), the MHTTC Network includes 10 Regional Centers, a National American Indian and Alaska Native Center, a National Hispanic and Latino Center, and a Network Coordinating Office.

Our collaborative network supports resource development and dissemination, training and technical assistance, and workforce development for the mental health field. We work with systems, organizations, and treatment practitioners involved in the delivery of mental health services to strengthen their capacity to deliver effective evidence-based practices to individuals.
Our services cover the full continuum spanning mental illness prevention, treatment, and recovery support.

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