

UNIVERSITY OF MISSOURI-ST LOUIS
3RD EARLY PSYCHOSIS
CONFERENCE

From Breaking Points to
Turning Points:
Supporting Moral Agency
& Recovery for Youth
Experiencing Early
Psychosis

Presenter: Neely Lorenzo Myers,
PHD

Neely Lorenzo Myers

**BREAKING
POINTS**

*Youth Mental Health Crises
and How We All Can Help*

Main Points

1. Moral Agency is important for mental health.

2. The ways a young person experiences early psychosis and the efforts to respond have consequences for moral agency.

3. Experiencing psychosis can be a “Turning Point” if we attend to youths’ material, moral & medical needs at this critical time.



Introduction

“It’s like everyone tells a story about themselves inside of their own head. Always. All of the time. That story makes you what you are. We build ourselves out of THAT story.”

Patrick Rothfuss, *The Name of the Wind*





My Research: Recovery Innovations



I am an Anthropologist.

- Study of human adaptation
- Long-term relationships
- Cross-cultural comparisons
- Team-based Ethnography

I conduct Mental Health Innovations Research.

- How to design care to help people recover (or prevent the need for it)



How social context shapes mental illness & health:



Experience

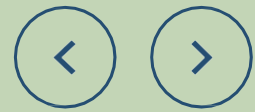
Understanding

Social

Response

Treatment

Outcomes

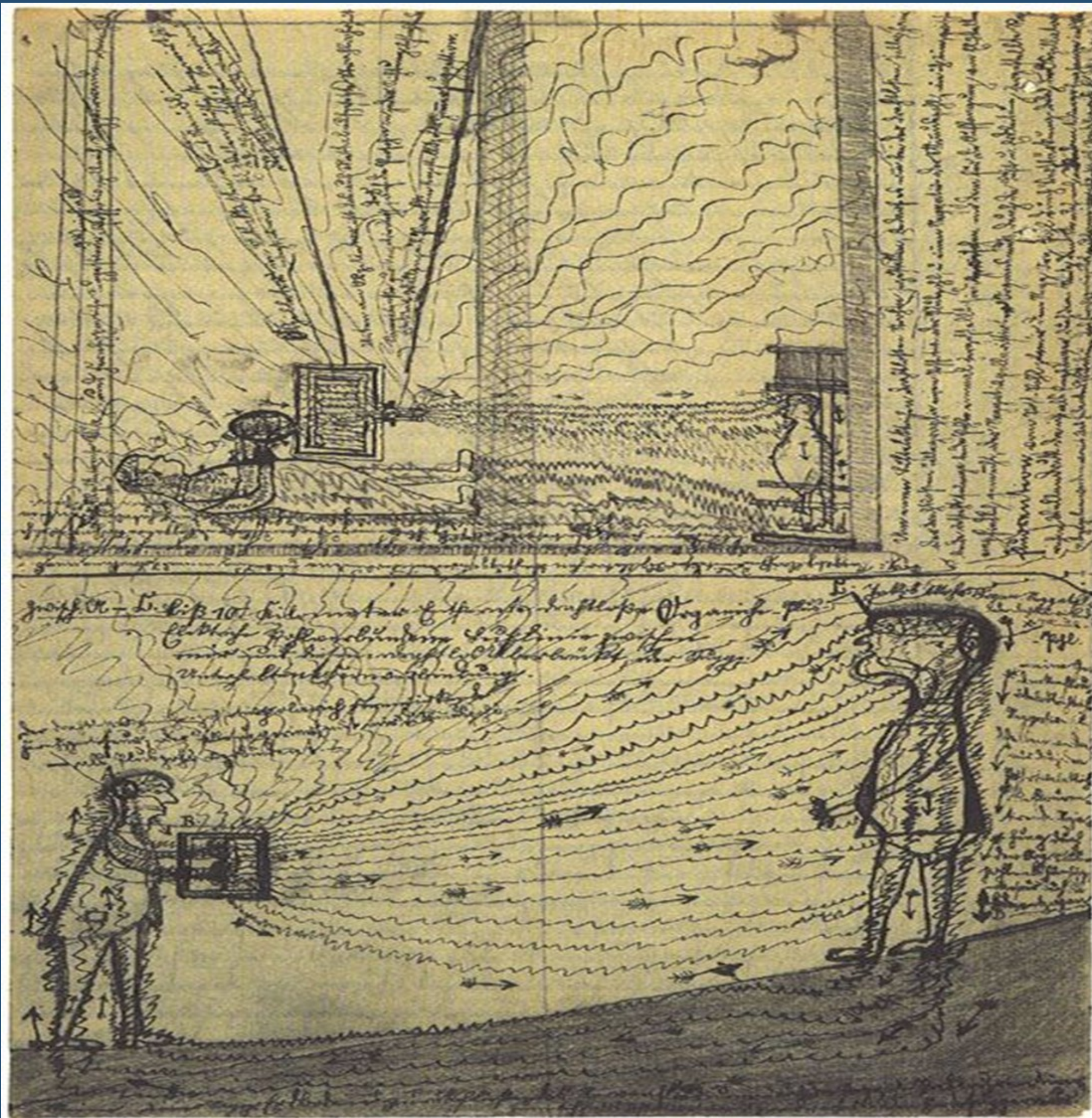


Contested Terms

CONSUMERS
SERVICE USERS
USERS/REFUSERS
MAD PERSONS
SURVIVORS
EX-PATIENTS
C/S/XERS
MEMBERS
CLIENTS
PARTICIPANTS
PEERS
PSYCHIATRIC PATIENTS
PERSONS WITH SERIOUS MENTAL
ILLNESS PERSONS WITH PSYCHIATRIC
DISABILITIES
PERSONS DIAGNOSED WITH ...

PERSONS LABELLED AS...

PERSONS WITH LIVED
EXPERIENCE



Artist Credit: Jakob
Mohr, Beweise (Proofs,
1912), Prinzhorn
Collection, University of
Heidelberg



“Identity”
by SMU
student Lauren
Villarreal



Artist John
Hood



What can
we all do?

Medica

Material

Mora



1. Moral Agency is important for mental health.

AGENCY:



Ability to act like a locally “good enough” person in ways that make possible intimate connections to others when they recognize you as a good person

Building on anthropology, philosophy, & ethics experts:

(Erika Blacksher, Sue Estroff, Angela Garcia, Linda Garro, Kim Hopper, Arthur Kleinman, Tanya Luhmann, Cheryl Mattingly, Martha Nussbaum, Jason Throop, Margaret Urban Walker, Norma Ware)

MORAL:

based on local moral worlds and what it means to be a “good enough” person in a particular social context



RECOVERY'S EDGE

AN ETHNOGRAPHY OF
MENTAL HEALTH CARE
AND MORAL AGENCY

Neely Laurenzo Myers



Mad Activists
User-Survivor Researchers
People with Lived
Experience Peer Specialists



06
Jm



MORAL:

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3 Key Aspects of Moral Agency



Autobiographical Power
-- playwright (or editor)



Social Bases of Self-Respect
-- audience



Peopled Opportunities
-- practice your role

(Arthur Frank, E. Saks, B. Lewis, Jenkins, Kirmayer & Gold;
Davidson, Ware, Anthony, Schiller & Bennett, Nussbaum, Nudel;
Rowle)

Diminished Moral Agency



Replenished Moral Agency



Moral Agency

- Key driver of recovery
- Being able to act in a way that others recognize as “good” and so makes possible intimate relationships with others
- Beginning of “journey,” not end





Group Discussion

Do you have any questions so far?

What are some of the sources of moral agency in your life?

Do you have any young people in your life and what kinds of moral agency seem relevant for them?

What are some ways that moral agency is diminished in your own life or for young people around you?



2. The ways a young person experiences early psychosis and efforts to respond have consequences for moral agency.



Decision-Making and Treatment Dropout for Young Persons Experiencing Early Psychosis

National Institute of Mental Health R03 (Primary Investigator: Myers)



Early Intervention Services

Prevent long term negative outcomes:

- Interpersonal
- violence Suicide
- Rehospitalizations



ESMI TTA CENTER
SAMHSA's National Training and Technical Assistance Center for Early Serious Mental Illness

Support for individuals and families, providers, and community partners.

samhsa.gov/esmi-ta-center **SAMHSA**

Good for Governments

Cost-Saving

(Heinssen et al., 2014)



~50% do not show up for follow-up appointments

~30% do not attend followup appointments even with specialty services

Recruitment & Procedures

- Early psychosis “critical period” ~4-6 months
- Initial interview in hospital
- Up to 6 months: Up to 4 follow up home visits, open-ended, person-centered interviews with young person & key supporters

What matters to them?



Sample



- **47 Young People**
 - 50% Male identifying/50% Female
 - identifying Mean Age = 23 Years
 - 50% Middle to Upper Socioeconomic
 - Status 73% from ethnoracially minoritized groups
 - 40% Latino/a
 - 30% Black
 - 16% White
 - 50% Immigrants
 - 23% First Generation
 - 27% Second Generation
- **19 Key Supporters**

2/3 identified as female & parents
- **12 Mental Health Providers**
- **16 Black Pastors engaging Black youth & families**

Social Determinants



- **Immigrants (50%) are more “at risk” for developing psychosis**
- **Being a person from an ethnoracially minoritized group (73%) shapes pathways to and through care**
 - Longer Duration of Untreated Psychosis
 - More negative and complex pathways to care
 - Engagement is a challenge
 - US-based research is limited

Intersectionality: e.g., Crenshaw, 1989
Immigration: e.g., Selten, et al., 2020;
Minoritization: e.g., Anglin, 2021;



Developmental Context

- Young people transitioning to adulthood (ages 18-30)
- More likely to take risks
- A time when one is trying to prove yourself as an adult with a valued identity
- Trying to accumulate moral agency



Methods

- Team
Ethnography
- 141, 1-2 hour interviews over time at up to 4 different time points at least 3 weeks apart
- 75+ Home/Community Visits
- ~5000 pages interview transcripts &
- fieldnotes Team data analysis and coding
(Dedoose)

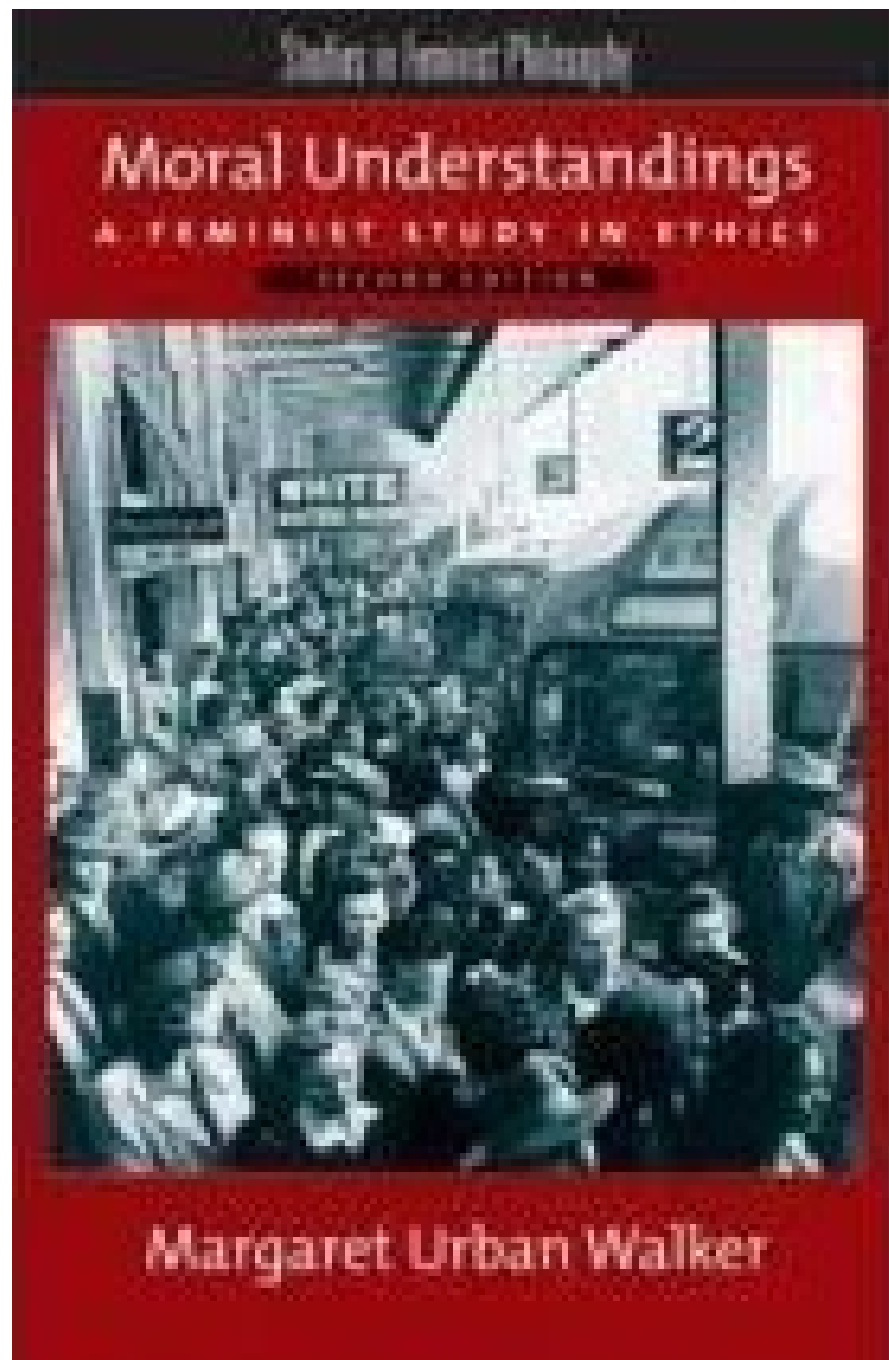


Results



TABLE 3. Ranking of factors identified by young adults and key supporters as affecting treatment decision making after the young adult's initial hospitalization for psychosis

| Factor | All participants (N=37) | | | Young adults (N=18) | | | Key supporters (N=19) | | |
|------------------------------|-------------------------|----|----|---------------------|----|-----|-----------------------|----|----|
| | Rank | N | % | Rank | N | % | Rank | N | % |
| Desire to get back to normal | 1 | 36 | 97 | 1 | 18 | 100 | 1 | 18 | 95 |
| Care on offer is not enough | 2 | 29 | 78 | 4 | 13 | 72 | 2 | 16 | 84 |
| Police involvement | 3 | 26 | 70 | 3 | 14 | 78 | 4 | 12 | 63 |
| Feeling worse | 4 | 25 | 68 | 3 | 14 | 78 | 5 | 11 | 58 |
| Relationship repair | 4 | 25 | 68 | 4 | 13 | 72 | 4 | 12 | 63 |
| Paying for care | 5 | 23 | 62 | 2 | 15 | 83 | 7 | 8 | 42 |
| Living independently | 5 | 23 | 62 | 3 | 14 | 78 | 6 | 9 | 47 |
| Distrusting diagnoses | 5 | 23 | 62 | 5 | 12 | 67 | 5 | 11 | 58 |
| Social substance use | 5 | 23 | 62 | 5 | 12 | 67 | 5 | 11 | 58 |
| Feeling disempowered | 6 | 21 | 57 | 3 | 14 | 78 | 8 | 7 | 37 |
| Transportation issues | 7 | 20 | 54 | 5 | 12 | 67 | 7 | 8 | 42 |



“We need to keep on keeping straight who we are, and who we have given others to understand we are, in moral terms. We also need to sustain or refurbish our understanding of moral terms themselves, of what it means to talk about kindness, respect, friendship or obligation.”

--Margaret Urban Walker, feminist philosopher, Moral Understandings



“I didn’t mean to be harmful to her or anything. It just happened that way.”

Amy, 26
years



3 Key Aspects of Moral

Agency

- 1) Autobiographical Power
 - playwright (or editor)
- 2) Social Bases of Self-Respect
 - audience
- 3) Peopled Opportunities
 - practice your role



Mental/ Moral Breakdown



- **Shared sense that one is a “good enough” person breaks down.**
- **Mutual incomprehensibility between a person and their loved ones**
- **When taken-for-granted ideas about what is good, beautiful or true are no longer shared**



Photo Credit: Phillip Deus, Unsplash

Emerging Symptoms shaped Moral Agency



“So that’s the worst part: that voice sounds believable, so we start believing in it and since you’re in that psychosis—you’re already psychotic—you just believe it without a doubt because it’s your mind, so you’re like—you just believe your own mind, you know?”

James, 20 years, @ state hospital < >



**Photo Credit:
Jeremy
Bishop,
Unsplash**

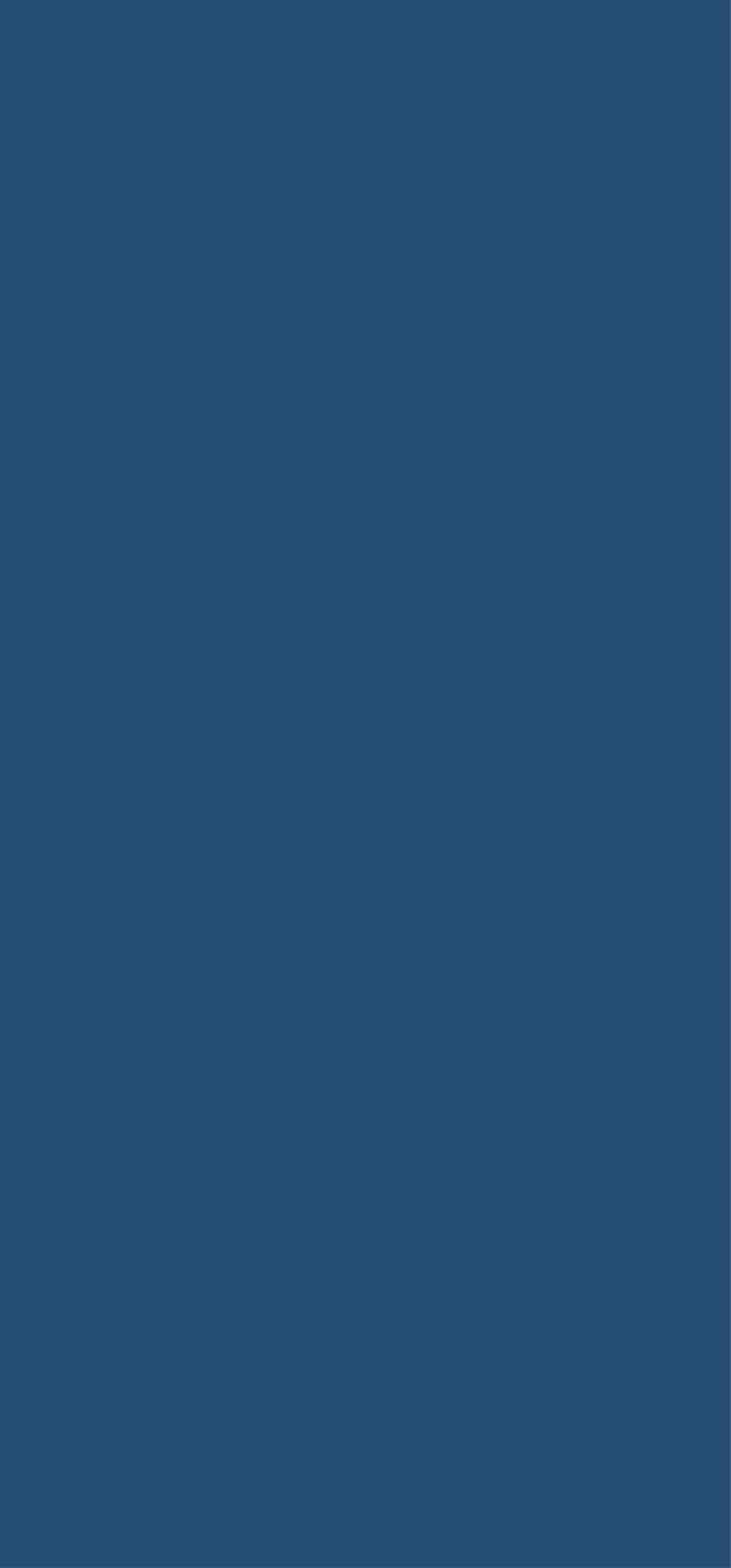


Photo Credit Mattheus Ferrero, Unsplash

“So that’s the worst part: that voice sounds believable, so we start believing in it and since you’re in that ~~psychosis~~ ^{psychosis}, it felt like an amoeba... And you don’t know how long it’s going to last. You can’t necessarily control your body. You just can’t function. Like you can’t do anything really. All you can do is sit there and try not to freak out.”



Corrina, 24
years





Marcus: I want to be the best that I can be. I: That's great.

Marcus: I want to prove that I'm the best one to do it... Keep working with people I need to work with so that I can have my business at all times. Stay focused.

[Long pause. Too long.]

I: Are you distracted by someone [outside the glassed in cube]? Marcus: Mmmhmmm

I: Who is it?

Marcus: Someone who guides me. I: Guides you? Yeah?

Marcus: Yeah.

Marcus, 19 years, @ hospital





“It just popped in my head. I should jump off [the bridge] to see if it's real, to prove that it's not real. I didn't do it, but I could've. I'm sure lots of people do. I'm sure there's lots of worse stories.”

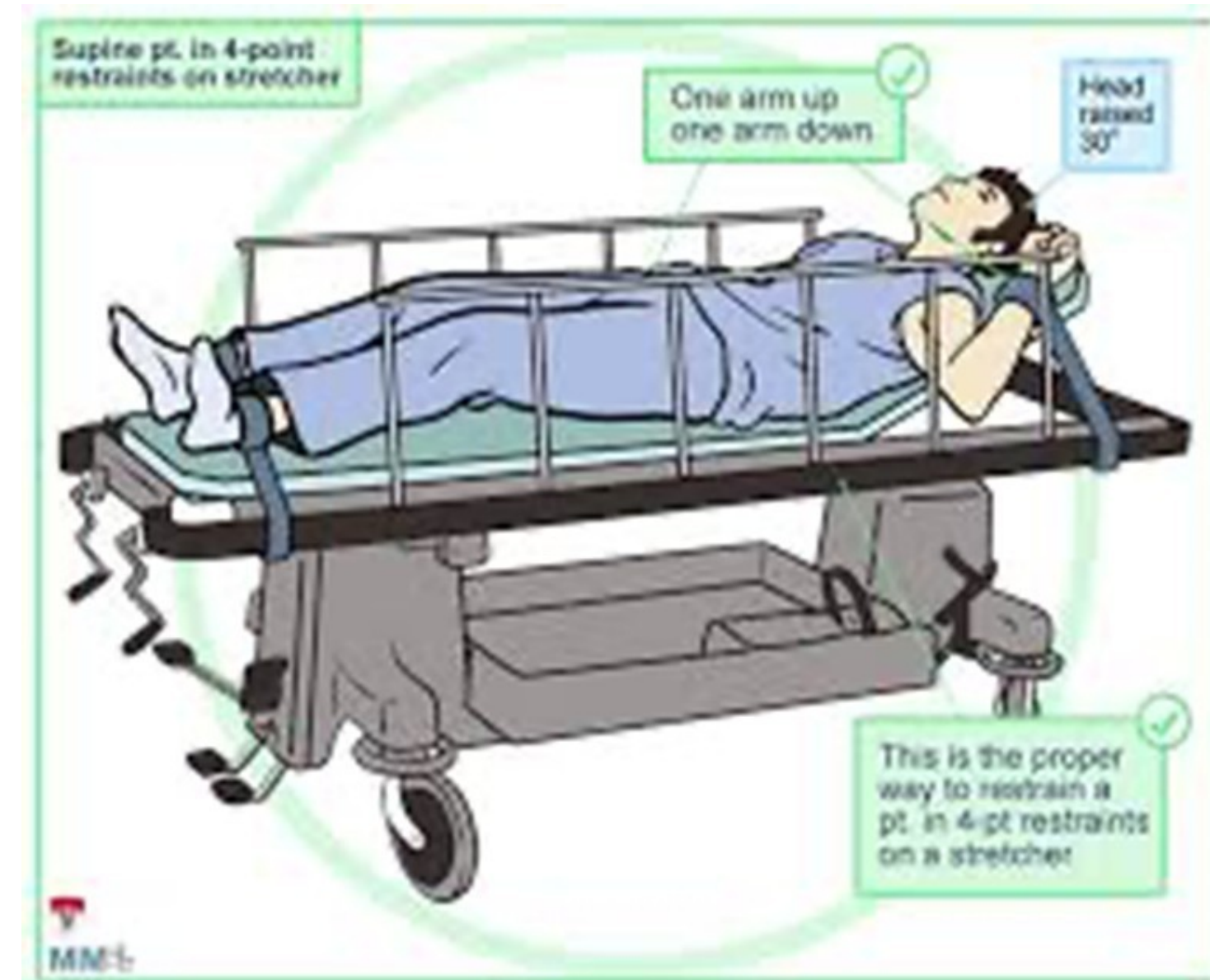
Amy, 26
years



Emergent Care Shapes Moral Agency



Artist Credit: Emily Flake



Amy: And so, they took me to [the hospital] and

...

Me: Okay, the police took you in there.

Amy: Yeah. And, uh, and of, of course, they admitted me. I was going crazy ... And the first night they admitted me they had a camera where they had to take a picture. And I guess it set me off and I tried to smash it, and they had to put me in four-point restraints.

Me: Oh.

Amy: Yeah...

Me: So, how do you feel now about what, what they've done?

Amy: Um, it's pretty humiliating.





Photo Credit Unsplash: Omar Lopez

Autobiographical

Power

‘I wanted to go to therapy. But the fact that I was brought there by cops— since I don’t like authority figures – and I think a lot of people don’t like authority figures, period – I think that added to my hostility...I was at the breaking point where I needed help...I would have gone to therapy. But, you know, I don’t know if I would have gone to a hospital.’



Miranda, 25 years @home

Social Bases of Self-Respect

Gideon: 5 years from now, what I hope is to have completed my college degree either chemistry or ... I'm a little interested in psychology too, as well.

I: Do you think your experience increased your interest in psychology?

Gideon: Yeah. I want to help people in a different way. Expressionally. Like take them out more because they've been institutionalized. Institutionalizing is good to prevent people from harming other people, but at the same time you need to take them out. It's like you're torn apart from the world. It makes things worse. You can't even go to the bathroom without someone swiping a card. It is too much. It just destroys you. I think it just makes you mentally disturbed.



Gideon, 19 years @hospital



Photo Credit Unsplash: Graham Hunt

Peopled Opportunities



Interviewer: So you would want...

Miranda's mom: Resources in the community.

Someone that we can reach out to that is knowledgeable in what's going on with her, to help the family get through it because we didn't know how to communicate with her when she was psychotic. I was scared I'd say the wrong thing. And again, it was like we were walking on eggshells.

There's just not resources out there for families

do ~~it~~ think
- Miranda's Mom @ home

Medical *and* Moral Dimensions of Experience



- Symptoms are overwhelming; harm relationships
- Family and friends can no longer help
- Catalytic event + Police
- Involuntary or voluntary hospitalizations
- Disruption from work, school and social life
- Return home with few family, vocational or educational supports
- Side effects are a struggle

Refusers Stories...

Refusers are **ACTIVELY SEEKING** to preserve or restore **MORAL AGENCY** by refusing



Autobiographical

Power

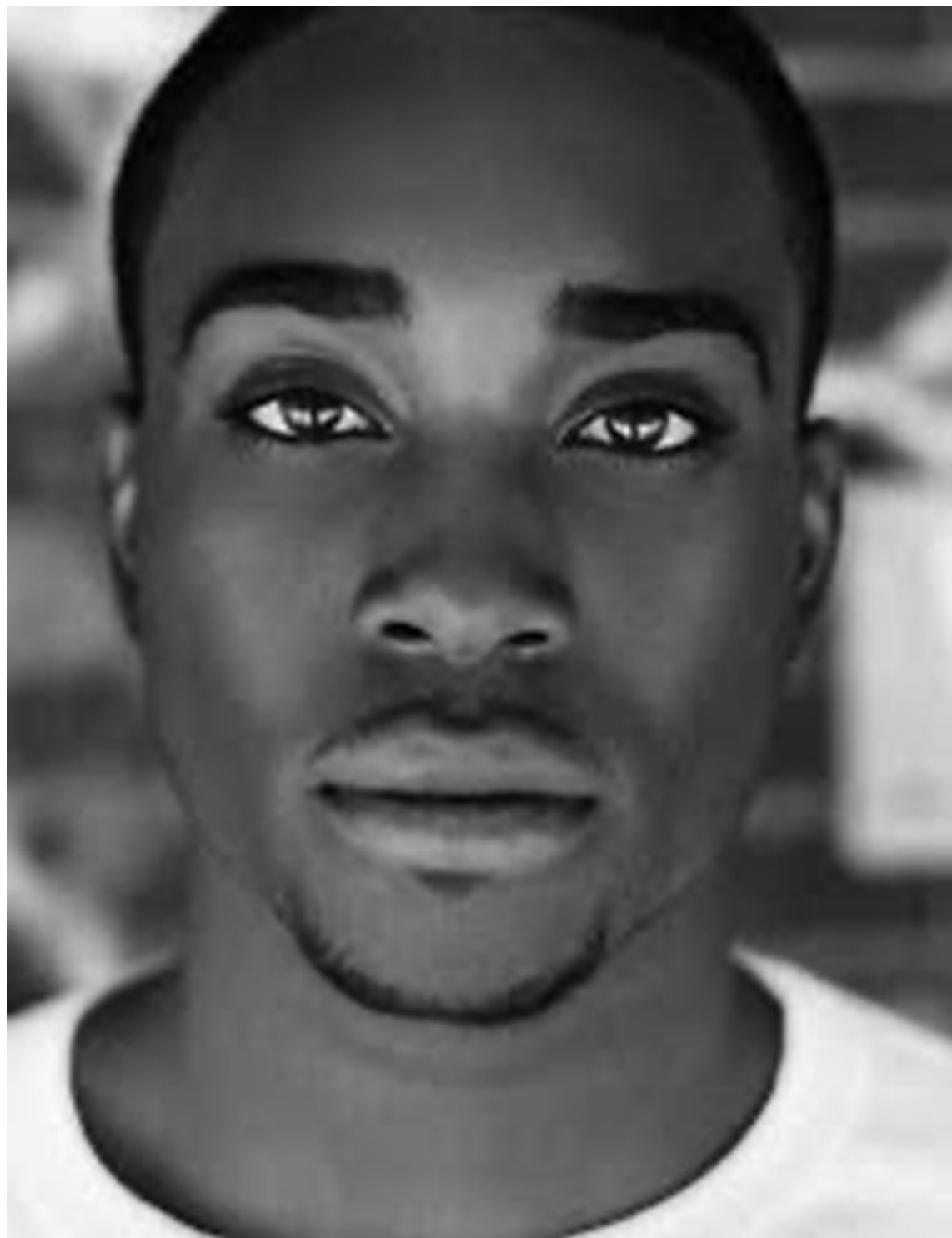
Daphne: Yeah, I don't like the follow-up. I don't like my medication that I'm taking. Today I went a day without taking my medication and I feel wonderful. It's a sunny day at sunset, you know? So, I like that. And when I'm taking that— it's not right. I'm not going to have any refills for next month.

I: So, what do you dislike about the medication?

Daphne: Now? I mean, me as a person, I don't like being on drugs. I don't like taking pills, medicine. Growing up, in my childhood, I never had to go into the hospital. Never. So now, being – showing up and going to these appointments and stuff, I do not like it.

That's just from a person that don't hardly go around clinics and > stuff.

Daphne_10 @home



Social Bases of Self-Respect

“I don't know, sometimes I feel like I would be better off just with the schizophrenia. If the government just like had like an island just...took people with mental illness ...just put them on an island to just live out the rest of our lives like that. If they'd have done that, I wouldn't even know the difference. I think once your mind goes off reality, I don't think it goes back. I don't think the medicine that we have fixes everything and takes you back to how you were before.

I think it just like stops the symptoms, but like the other stuff you lose, I don't

think you gain it back. It's almost better to have the schizophrenia and still have your body parts working like they should. Like pros and cons, like would you still want to have schizophrenia but still have your male organs working like they were...like being a man.”





Peopled Opportunities

Elijah's mom: Yes, yes, yes, because he has prayed and asked God for something and he sees it. You know, within a short space of time, he sees the result of praying. He will tell you also. Yes.

I: So he's definitely, completely with you, with the praying and helping him in this way?

EM: Right. But you see, being an American born, sometimes, "I don't want to pray, you pray alone today and that stuff." Sometimes I will insist; sometimes, I will leave him alone. I tell you, there is nothing prayer cannot do, nothing, if you believe in God and believe in God solely, and walk in the right path, enemies will come like a flood, but God will lift His hand and move all of them, and eventually He will succeed.



-Elijah's Mom, @home

Replenishing Moral Agency: Refuser Ariana's

Story



Autobiographical Power & the Social Bases of Self-Respect

Ariana: Are you the Chaplain?

Me: No. I am a volunteer here. Would you like to talk?

A: I gave blood three times!

M: Oh, that's nice.

A: In high school, like a charity thing. And I did pretty well in high school.

A: Stop nodding! Why are you nodding?

M: I am sorry.

A: [Breathing heavily.] See? It's bad, right? It's bad breath. It's Ebullah. We are all going to die of Ebullah, which is in our lungs and it's spread through our bad breath.

--Ariana, 24 @hospital



A: People think I'm crazy.

I: What do you think?

A: I think I'm a good girl trying to save the world... It's not very easy to do.

-Ariana @hospital



Peopled Opportunties

A: My brother is like, 'So Ariana, you went to the crazy house and now you're taking care of my child. How does it feel?' I'm like, 'You know what? It feels like I'm not crazy.'

I: Right.

A: But we were just joking about it. It was joke after joke.

-Ariana, 24, @ home



- Refusing medical care did not work well for everyone
- Many could have used medicine as a tool
- But for refusers, refusing treatment was a strategy to help protect and replenish moral agency lost during the crisis and emergency response

Users

Stories

Why use services?

- Family history of serious mental health concerns
- Disability income can be a respectable source of income for impoverished families (e.g., Hansen, Bourgois & Drucker, 2014)
- For material support, especially housing

Autobiographical Power & Social Bases of Self- Respect

Interviewer: Do you think you need mental healthcare?

Callista, 22: Yeah because I need [services].

I: You need [services]? Why do you need [services]?

C: **To get a paycheck** and pills prescribed to my name and given out to my name.

I: What kind of pills are these?

C: For bipolar and schizophrenia.

I: Okay what about a paycheck where would that come from?

C: That's coming from the government.

I: Okay.

C: And **that paycheck** is going to be for my daughter.

I: Really? Do you know anyone else that has gotten **a paycheck**?

C: Yeah, my friend and she's my aunt.

I: Is she like you, as you say, is she bipolar too?

Peopled Opportunities

Corinna, 23: I wouldn't have kept going unless they were like, "You don't have anywhere to stay unless you go to this doctor."



Group Discussion

- What kinds of moral needs and concerns do you see in your own role with young persons having similar experiences?
- How does moral agency work in your “local” world of the clinic/agency?
- Consider:
 - Autobiographical Power (Editor)
 - Social Bases of Self-Respect (Audience)
 - Peopled Opportunities (Practice)



3. Psychosis can be a turning point if we attend to material, moral and medical needs during this critical time.

Improving Engagement



Help young persons “get back to normal” or to something even better than they were before.

- What is their story? Include mutual support, faith-based interventions (guides), arts-based interventions (expression)
- Reverse pathologizing rituals that harm a person’s sense of moral agency (e.g., police intervention, restraints, unnecessary hospitalizations, extreme diagnoses, overmedication)
- Help them repair relationships, reconnect and stay connected to people who matter most.
- It may be that people want to engage in moral support more than medical support — that needs to be okay; we can start there.



Warning Signs

Recognize warning signs, especially:

- Isolation
- Substance misuse/self-medicating
- Core relationship problems
- Lack of sleep
- Sudden drop in performance

Diagnostic Neutrality



- Psychotic? They don't want THAT story.
- What is most helpful for them to know about psychosis?
- It can be substance induced
- It might happen once & never again
- It is often a reaction related to traumatic experiences, including in childhood
- Psychosis is part of: PTSD, Bipolar Disorder, Depression
- They don't need to be afraid all the time it will happen again, but they need to take care

Partner with & educate frontline prescribers



Let people say no to treatment but still come in for support



Consider a person's local moral world, especially their parents' thoughts on treatment & religion



Encourage shared decision-making

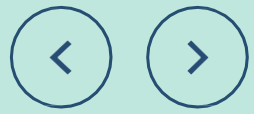


Look out for ADHD & antidepressant medications

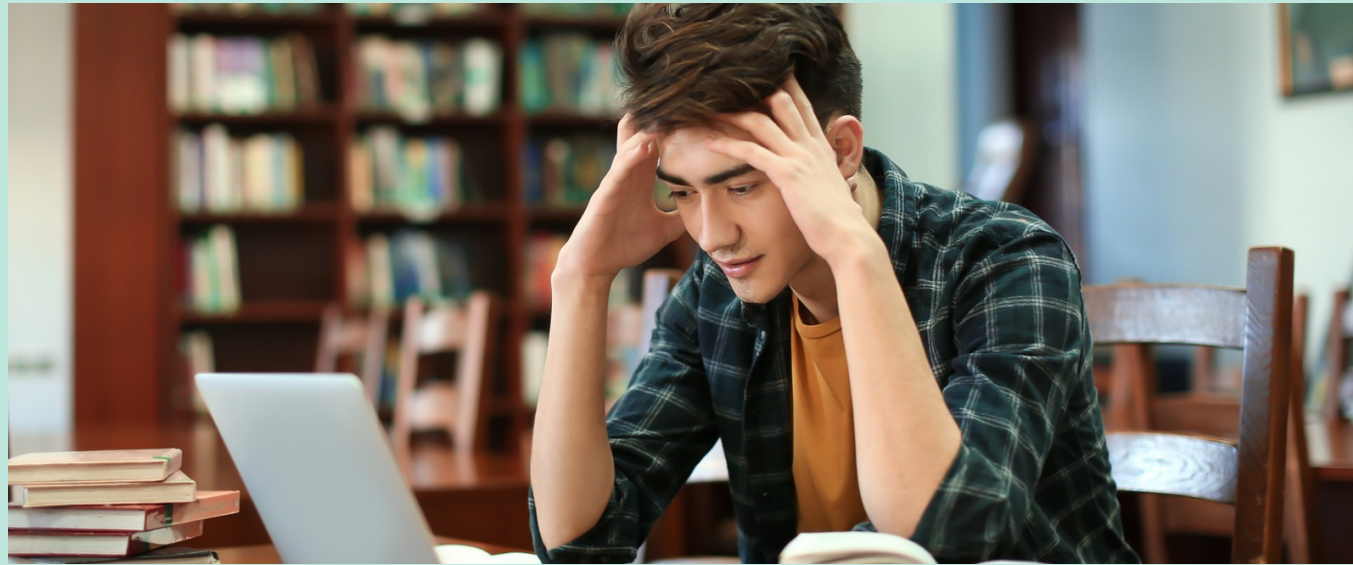
Mutual Support

- Hearing Voices Groups
- Inner Compass
- Initiative
Fireweed Collective
- (formerly Icarus Project)
Students with Psychosis
- (student- run)
Work with chaplain, faith-based
- groups
Sober student groups,
sports teams (Phoenix app)





Educational Advocacy



- 4/5 of persons with EP have educational disruptions
- Typical disruption is 1.5
- years

Financial debt for lost semesters is common



- Help students receive accommodations: flexible testing, attendance, and resources

Seek to understand & address substance misuse



- **50% of youth with EP have comorbid substance use disorder.**
- **70% report cannabis misuse.**

Take Action

- Foster sober students' groups
- Foster sober student events
- Education about risks of cannabis and psychedelic use

What impact has this
lecture had on you?

What might you
try/do differently?

Main Points

1. Moral Agency is important for mental health.

2. The ways a young person experiences early psychosis and the efforts to respond have consequences for moral agency.

3. Psychosis can be a “Turning Point” if we attend to material, moral & medical needs at this critical time.

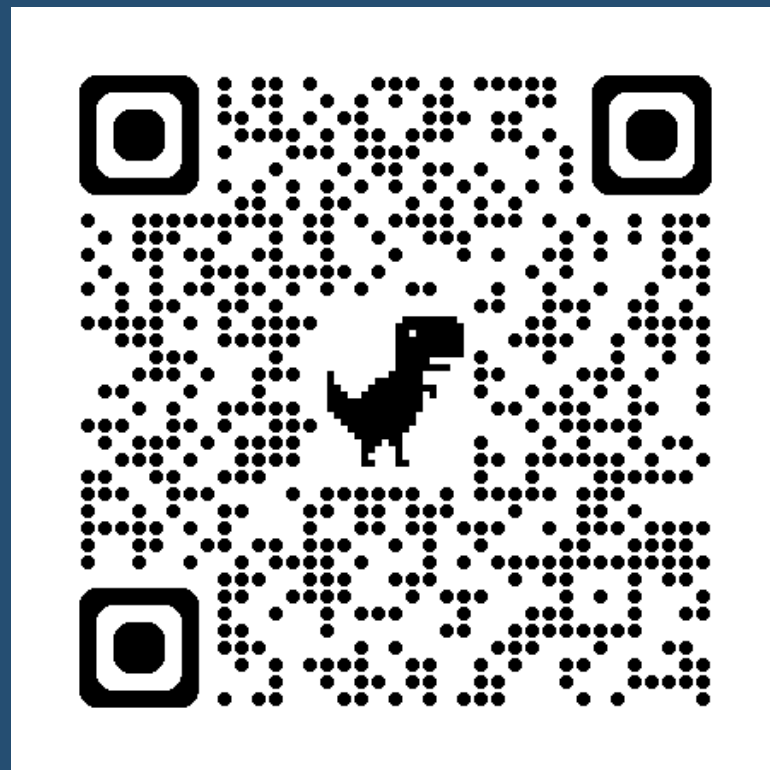




Thank you!

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There is so much work to do to offer support, but the good news is there is so much we can do.



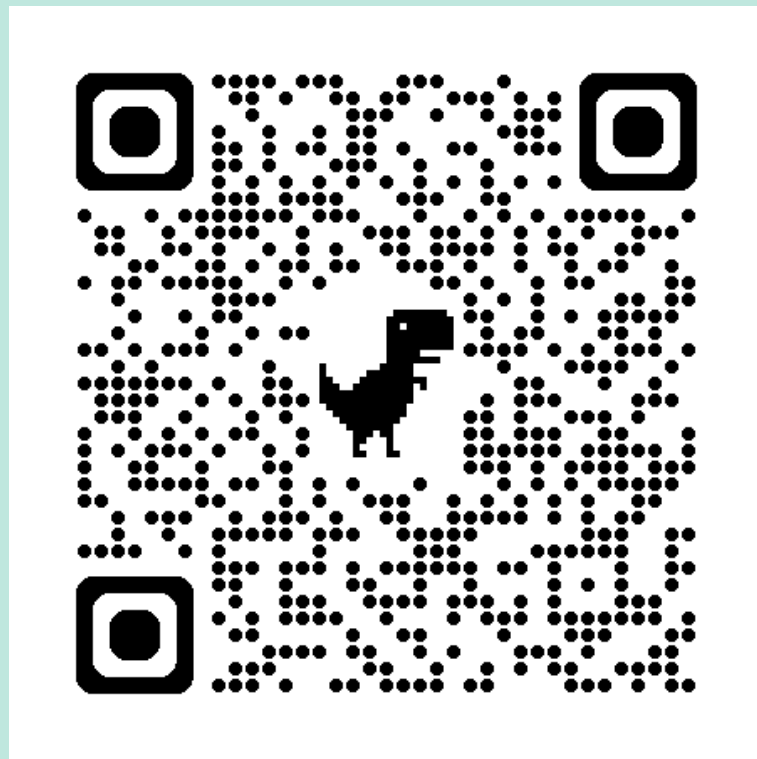
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BREAKING POINTS

*Youth Mental Health Crises
and How We All Can Help*

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