

**”How do you care for
yourself and others?”**

**Co-Designing systems of care with
People Who Use Drugs**

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PRESENTER DISCLOSURE



Presenter: **Ginetta Salvalaggio**

Relationships with financial sponsors:

Any direct financial relationships, including receipt of honoraria:

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Membership on advisory boards or speakers' bureaus:

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Alberta Government, Alberta Innovates

Membership on advisory boards or speakers' bureaus:

Patents for drugs or devices :

Other :

Illuminate Partners Corp

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Potential for conflict(s) of interest:
N/A

Introduction

- Polycrisis of health, sociopolitical, and environmental threats
- Need for community-centered innovation to adapt complex systems of health and social care
- Displacement as opportunity...
 - Collaborative research with People Who Use/Have Used Drugs (PWUD) to co-create services in *okimaw peyesew kamik*, an inner city social service hub in Edmonton, Alberta.

OBJECTIVE

- Document PWUD priorities for health interventions within a polycrisis state



Study design

- Narrative and arts-based research with PWUD who access inner city services.
- Community-based participatory research (CBPR) informed by complexity theory
- Iterative four-phase approach:
 - i. Pre-data collection,
 - ii. Formal data collection,
 - iii. Readjusting, and
 - iv. Accountability

Community Advisory Group review and guidance
University of Alberta HREB approval



Setting and Participants



Hybrid front-line team

- Academic
- Trainee
- Lived experience

5 months in mid-2024

- Nonprofit services
- Mobile pop-ups
- Pivot to common gathering spaces for under-represented subpopulations

Final N = 215 participants

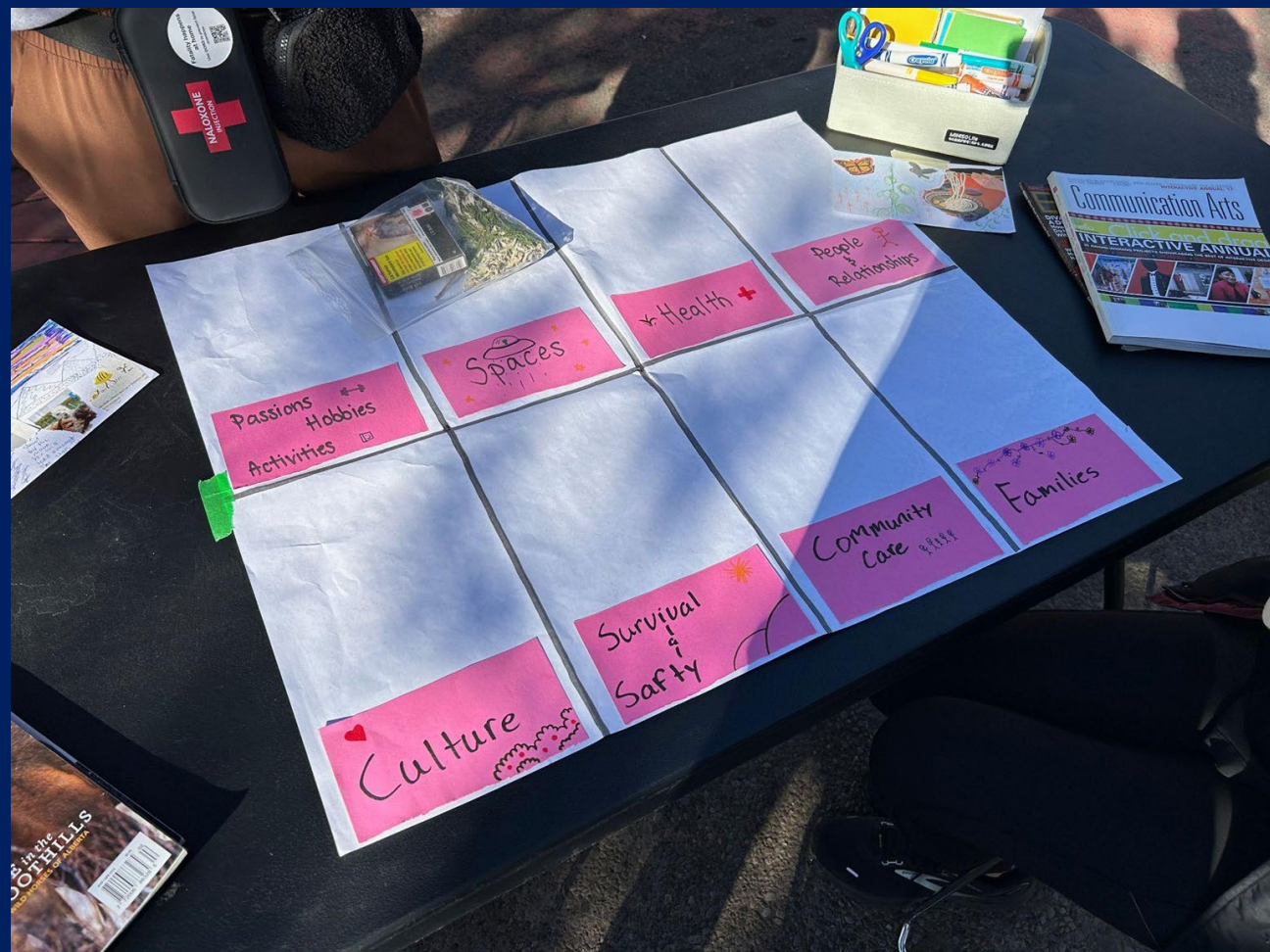
Primary Data Source: SenseMaker Micro-Narratives

- RAs worked with participants to record their story on SenseMaker
 - *Tell us about a specific moment that really stands out for you over the past year, when you were caring for yourself or for others*
- Participant adds context and self-interprets their story on triads, dyads and MCQs:
 - *What title would you give your story?*
 - *What is your story about?*
 - *Reflecting on your experience, in an imagined better future, what would have been different?*
- Core team sensemaking sessions



Secondary Data Source: Arts-Based Asset-Mapping

Complementary, optional arts-based exercise: “How do you care for yourself and others in the community?” or “What do you carry in your bundle to help care for yourself and others in the community?”



- Involved mini-collages, with responses recorded on a participatory bar chart

Findings: Key themes

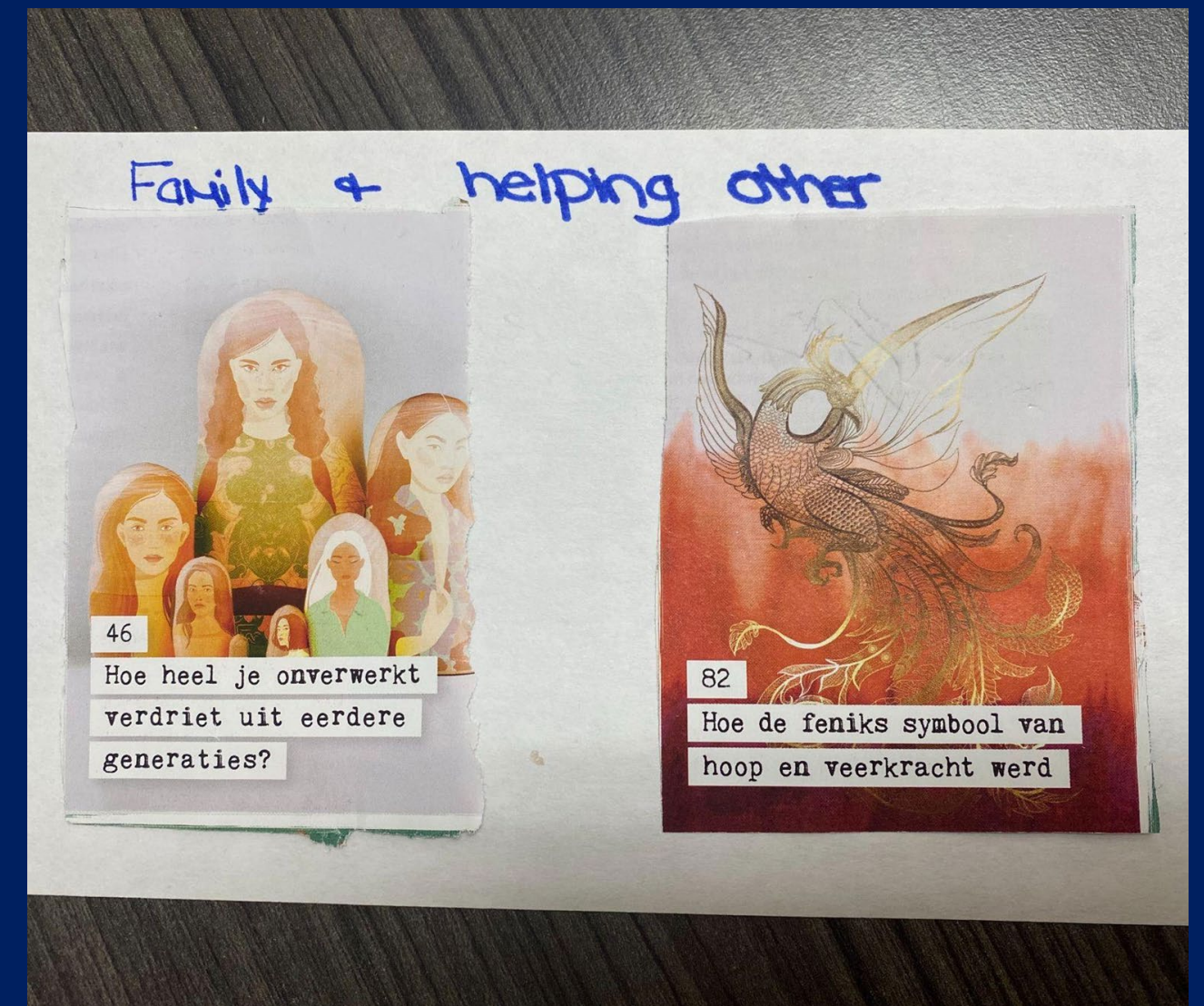
1. Care for each other
2. Professional supports
3. Transition supports
4. Criminalization
5. Space to be



Caring for self and caring for community as fundamentally intertwined

Community members are actively engaged in mutual aid and support. With very few other options available, the well being of the helpers themselves is a concern. There are key opportunities to support natural helpers with resources and education.

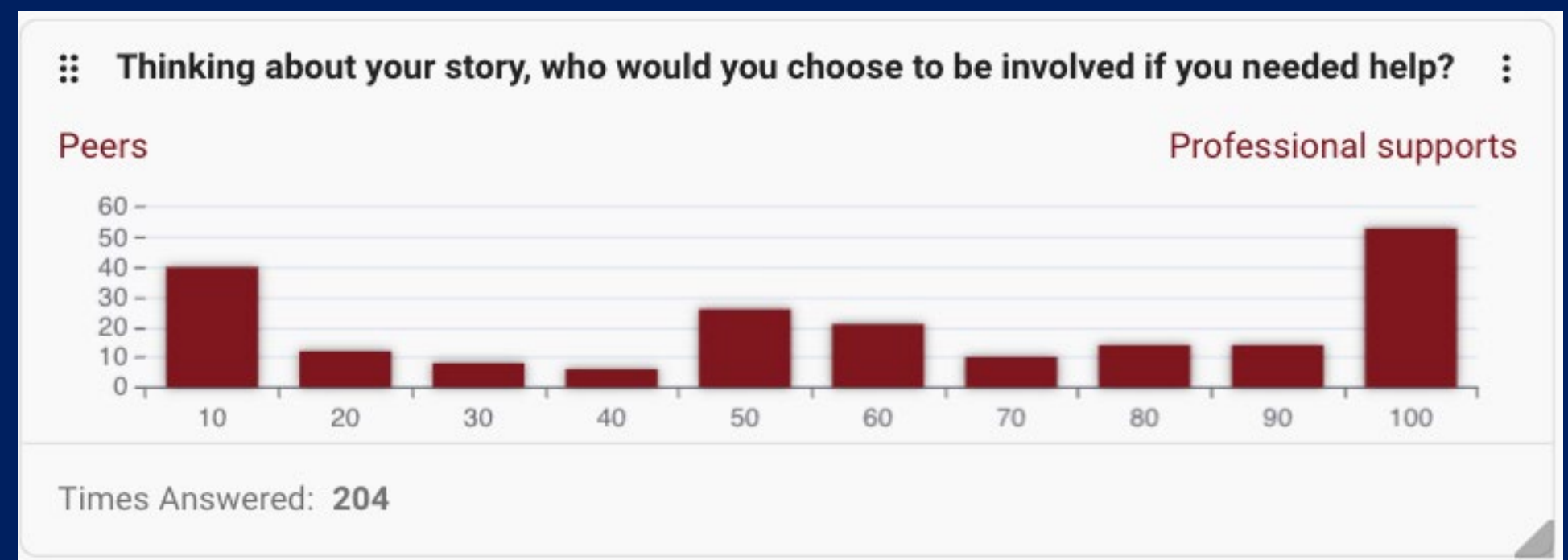
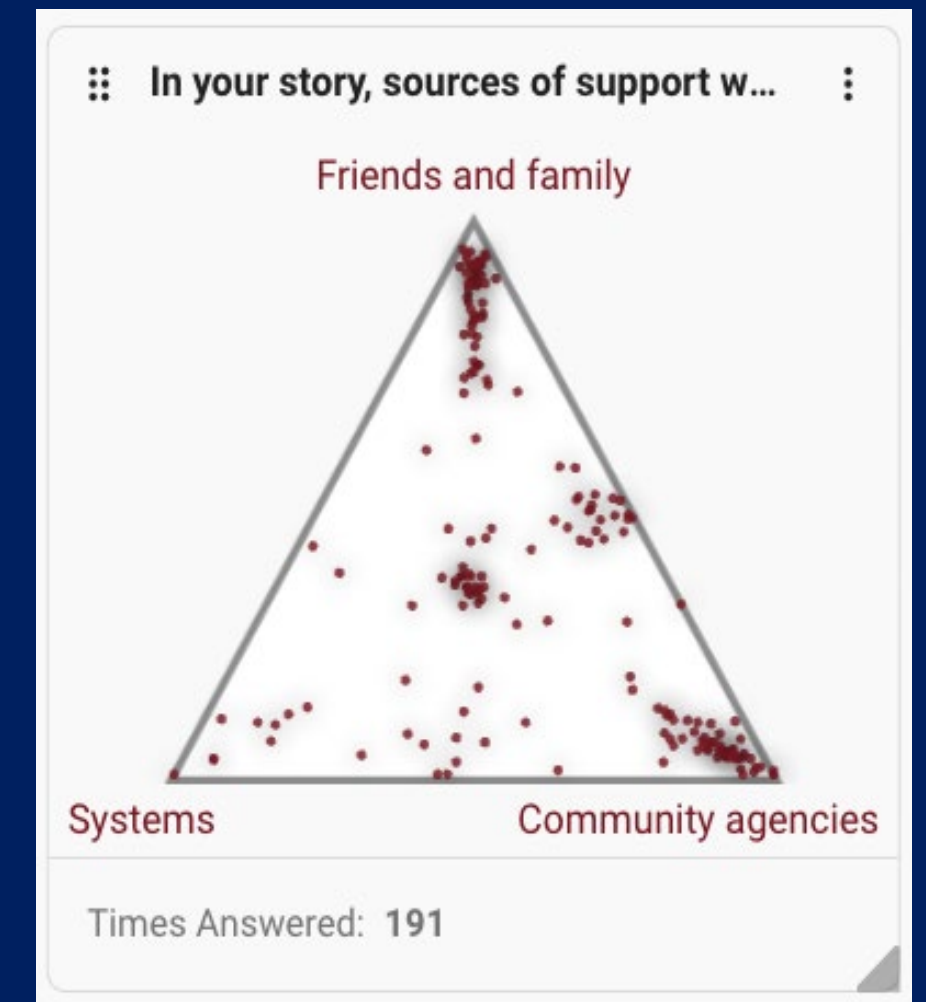
*“I walk a lot, minimum 15-20km. In the winter time, I carry a big backpack with blanket, candles, food, fluids. When I was walking around the river valley, I saw a person laying there and checked on him. It was -20 below. He was shaking quite a bit, and wasn't himself. I wanted to help so I got him to calm down. I called emergency services... Over the year, I've checked-in with a lot of people to make sure they were okay. I cover a lot of ground with walking, it's therapeutic and I like to get outside of the downtown core.”
(Walking in the valley)*



Needing formal services to support health and wellness

Care among family and friends is fundamental to the community, but community members are also looking for professional supports and formal services for health and wellness.

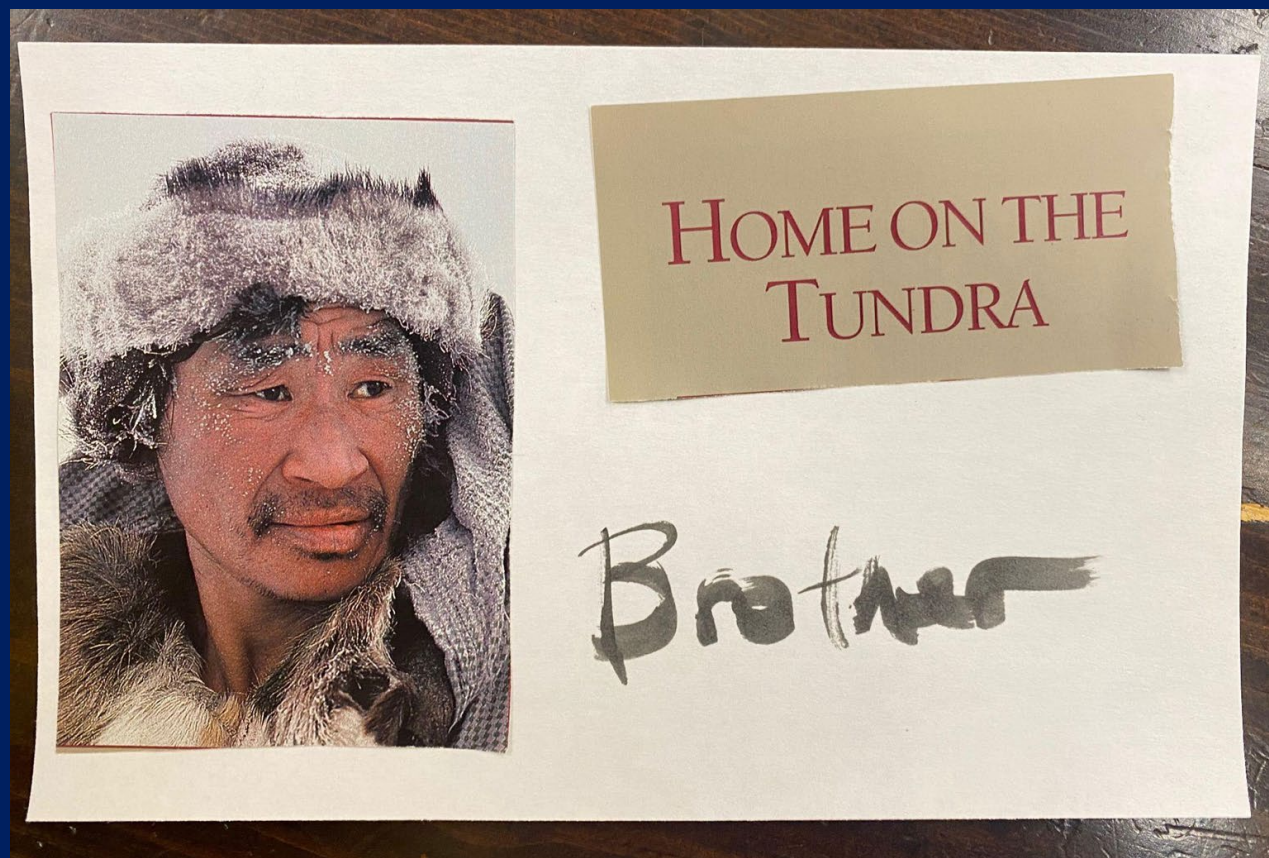
"...CHEW is like a family to me. If I didn't have here to come to, I would have gone insane just being at home. It means a lot to me to have community - with all kinds of people. I like how this place, they try to have to have something everyday. Like it's art, cooking, something to do to keep us busy and learn. ...some people have negative ideas of drop ins and shelters, they don't know, they could learn more about how these services are good." (How CHEW makes me feel!!)



Centering both “housing” and “home”

Housing transitions are a critical time period that needs relational support, opportunities for connection and meaning, and mental health care.

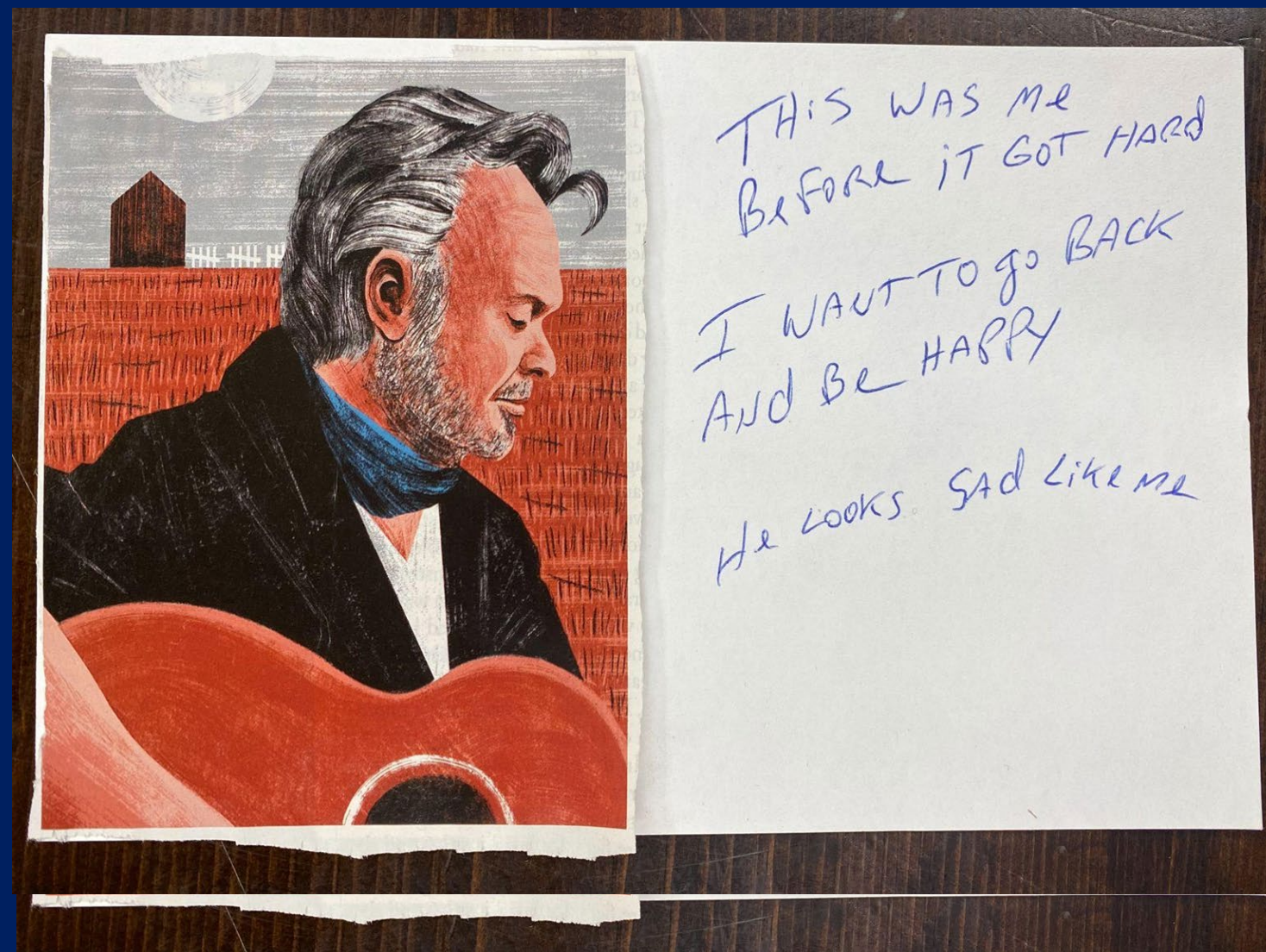
“The old staff from across the street is gone, how am I supposed to get clean, whose supposed to point me in the right direction. Having a staff member that's going to be there for you that cares, help us through these addictions, rough patches, get housing. You can't just pick a person off the street and put them in a home, it creates more harm than good. I have no place to go, I walk all night, I'm so exhausted. We need a transitional program, from homelessness's to non-homeless. It creates anxiety and depression. A lot of people don't want to lose their housing so they build these walls up and never let people in. I think this is our biggest struggle, getting people off the streets and into apartments.” (Just one day in my life)



Moving from the lens of criminalization to service utilization

Criminalization is undermining community members' ability to care for themselves.

Experiences of stigma and discrimination often relate to a mentality of punishment and surveillance not limited to criminal justice system (e.g. public spaces, hospital etc)

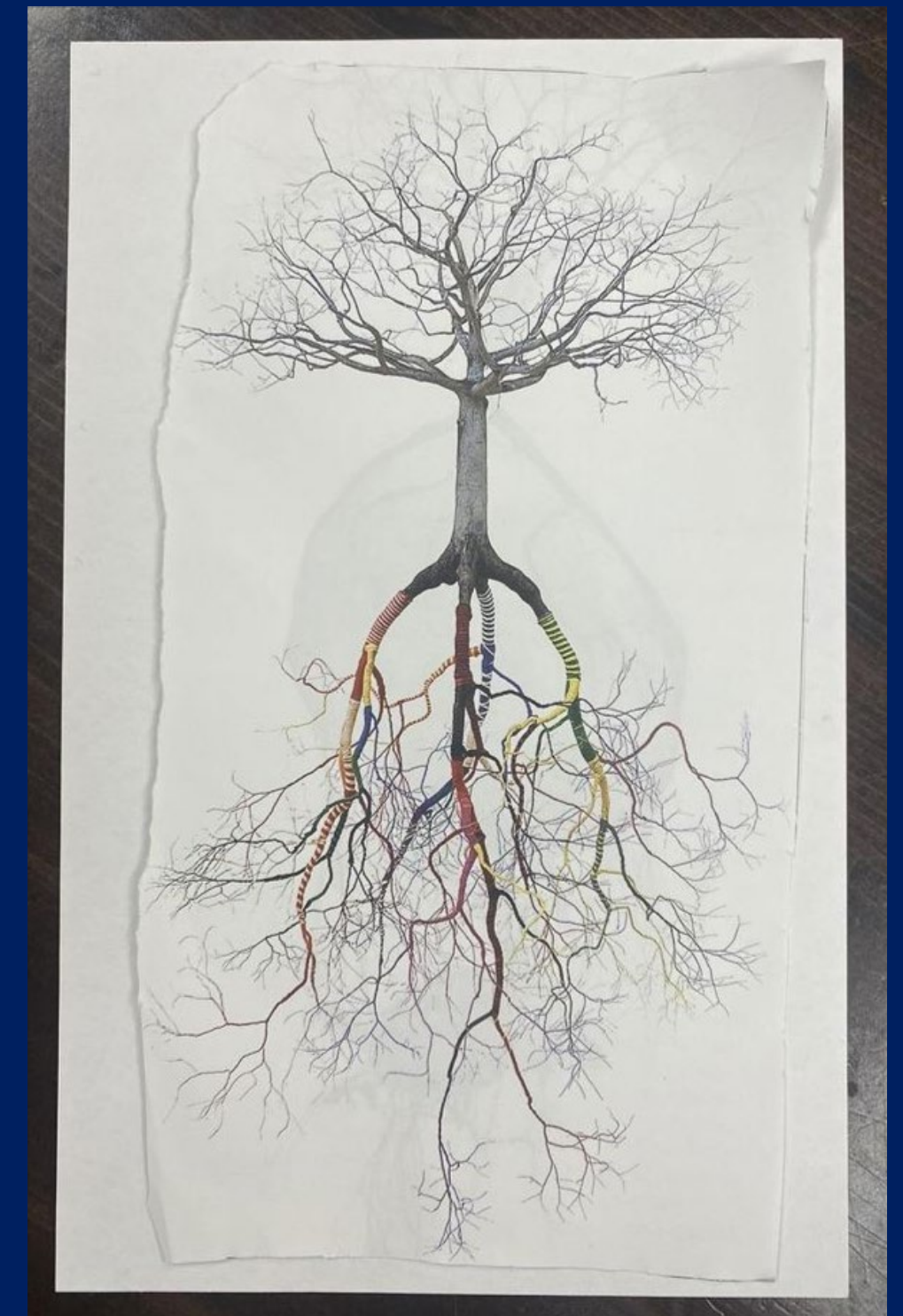


*“Our home may not have walls but it's still our home, where we can have a sense of belonging. How can you take all of our stuff and expect us to get housed... Why can't we have a place to be, a place with showers, toilets, power... The camp sweeps - they take our identity. ...”
(Why us?)*

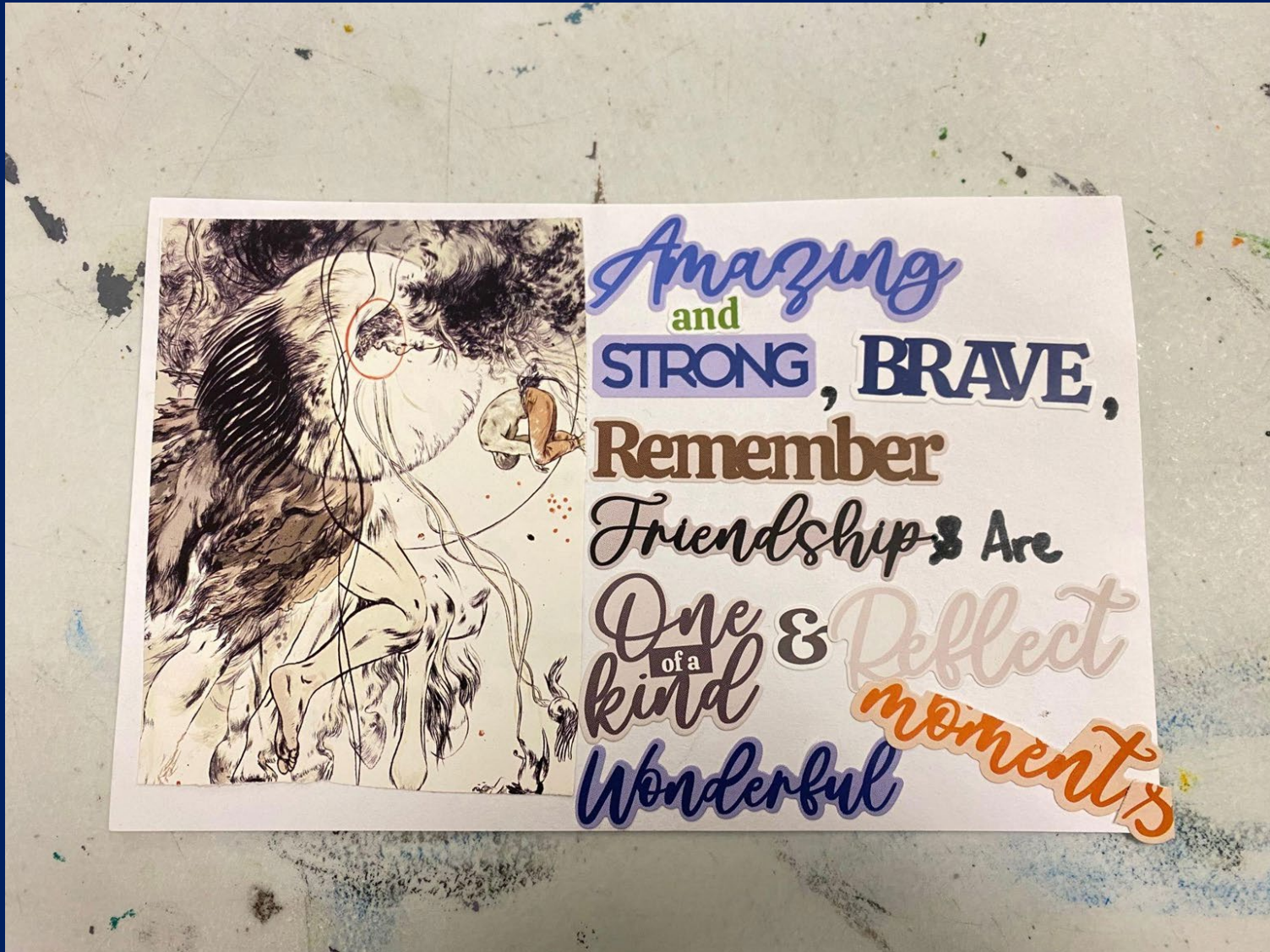
Visiting and connection as a way to build and repair relationships, and to heal

Community members desire opportunities for reflection, recreation and income generation. Visiting (“Keeoukaywin”) and connecting are key to sense of self and belonging, relationships, and healing.

Workshops at the Boyle Street would help people find a hobby and create something beautiful. Talking to people and getting to know them, giving them advice, it helps everyone. Sharing my story about my journey of sobriety is something I'm passionate about, to help others around me. I saw a lot of people die or OD in front of me. It was really scary. My family, they know what I've gone through, they helped find me downtown on the streets. I'm honest with them so I can help them. I teach them to be safe. I used to be in the lifestyle ... (Kookum's story)



Conclusion



As a matter of equity and social justice, there is an urgent need for contextually relevant and locally adaptive, partnered responses to health threats facing PWUD. PWUD imagine a future that centers relationship and collective care paired with meaningful support from, and safety within, formal systems.

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- Elaine Hyshka



THANK YOU!



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