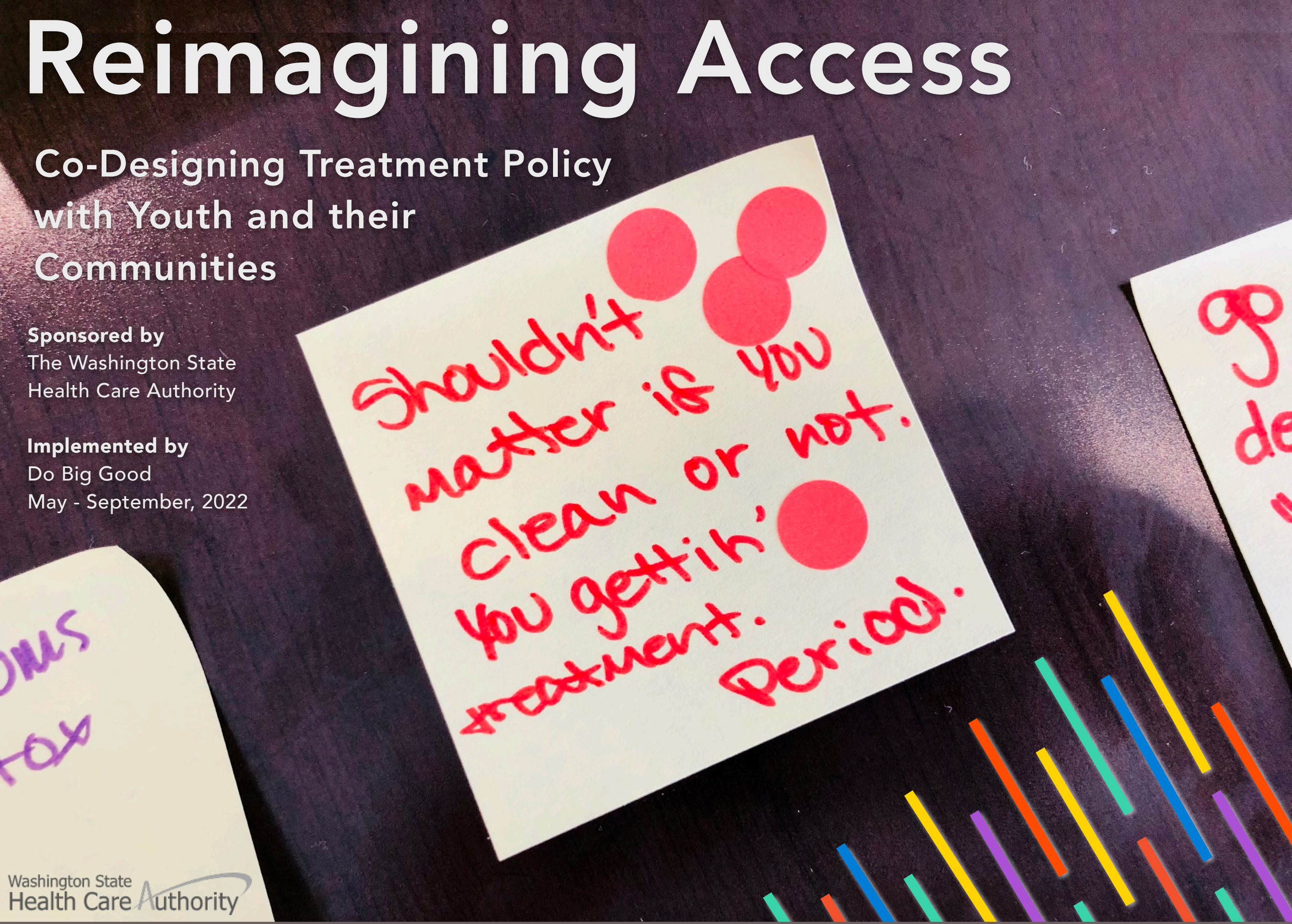
Reimagining Access

Co-Designing Treatment Policy with Youth and their Communities

Sponsored by
The Washington State Health Care Authority

Implemented by
Do Big Good
May - September, 2022

Washington State Health Care Authority



Youth-generated post-it from co-design session at Sea Mar Visions Youth Treatment Center in Bellingham (August 15, 2022)

Do Big Good

Executive Summary

Reimagining Access was a five-month collaboration between the Washington State Health Care Authority (HCA) and Seattle-based co-design firm Do Big Good. Its purpose was to reimagine access to treatment for substance use disorders (SUD) and co-occurring disorders (COD) with young people and their communities. The recommendations emerging from that process are as follows:

Co-Design Steps

How to Create With, Not For

3 Youth votes (●) for youth and community-generated policy proposals (New Horizons Ministries, Seattle, August 23, 2022)

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What is Co-Design?

Co-design is a set of methods used to solve problems *with* partners by sharing knowledge and power.

1. Define the Problem

Design processes begin by identifying the problem that needs a creative solution. What makes co-design different is that partners participate in problem definition.

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Problem Definition with Partners

Design processes begin by identifying the problem to be solved. What makes co-design different is that partners participate in problem definition. For Reimagining Access, we began with the problem statement from the request for proposal (RFP):

> ***Problem Statement**: Over the last several years there's been a decline in the number of young people being identified, referred, and admitted to receive treatment for substance use and co-occurring disorders, although research and data shows an increase in need for this treatment, including psychological distress, suicidal ideation, and suspected overdoses.*

Once we engaged partners, the scope of the problem expanded. Partners saw access not only in identification, referral, and admittance, but also in the ability to access safe treatment once admitted and to access continuing care during recovery.

We've focused the recommendations in this report on entry into treatment in order to align with the RFP problem statement. In recognition of youth and community partners' broader feedback, solutions, and requests, we've also created a section titled "Other Partner Concerns" at the end of this report (p. 41), which reflects the broader definition of access.

DESIGN GLOSSARY

- **Co-Design** Set of creative methods used to solve problems with partners by sharing knowledge and power.
- **Design** An intentional creative process or plan emerging from that process.
- **Equity Design** Process to dismantle systems of oppression and (re)design towards liberation and healing by centering the power of communities historically impacted by the oppressive systems being (re)designed.*
- **Human-Centered Design** Set of methods used to solve problems with partners by sharing knowledge, but not necessarily power. The end-user's perspective and needs are included, though the designer can retain creative control.
- **Partner** Person directly impacted (affected) by the problem, also referred to as a stakeholder.
- **Participatory Design** Set of methods used to solve problems by inviting partners into the creative process. Partner participation is seen as beneficial, but not required.
- **Power** Control over outcomes.**

2. Engage Partners

Partners are the individuals directly affected by the problem. In co-design, partners are active collaborators in defining the problem and creating the solution.

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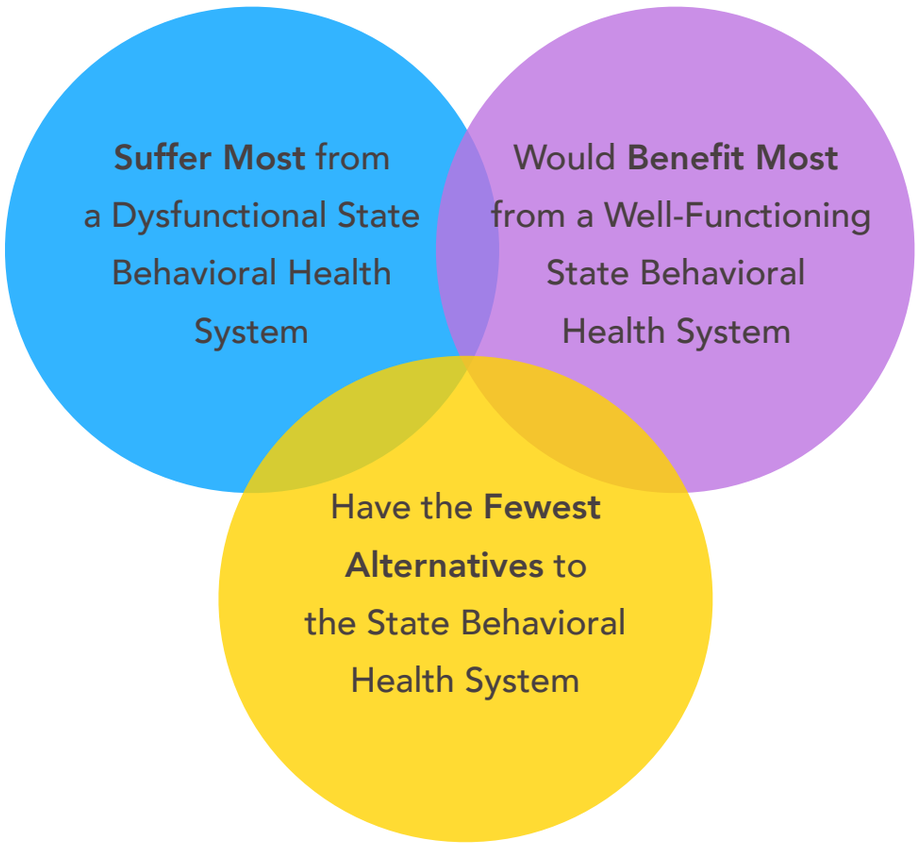
Youth Engagement Objectives

Reimagining Access included two partner groups: youth and young adults (YYA)* aged 13 to 24 with lived experience accessing or seeking to access SUD treatment in Washington state and the community of adults who support them in gaining access.

Most-Impacted Partner Model

By Do Big Good LLC



Youth and Young Adults: Engagement Objectives

Of these two groups, young people are most directly impacted by the problem of obstacles to access as they are the ones receiving (or failing to receive) treatment. In addition, equity design (definition on p. 6) teaches us that a just and equitable co-design process must center the power of communities historically impacted by the oppressive systems being reimagined.

With this analysis in mind, we developed the model at left to illustrate which young people would be most impacted by barriers to access: those who suffer most in the current system, who would benefit most from a better functioning system, and who have the fewest alternatives. Based on that model, we identified high-acuity youth with low access to financial and social resources as those most directly impacted by access barriers.

This focus caused us to seek out co-design participants for our youth cohort who are currently or previously in inpatient settings or who were clients of other crisis services, such as drop-in centers for homeless youth. We also took into account structural inequality, making a particular effort to engage Black, Indigenous, and other youth of color, differently abled and LGBTQ+ youth, and youth who are undocumented, rural, and low income.

 *In this report we use the term "youth" as a shorthand for the longer phrase "youth and young adults."

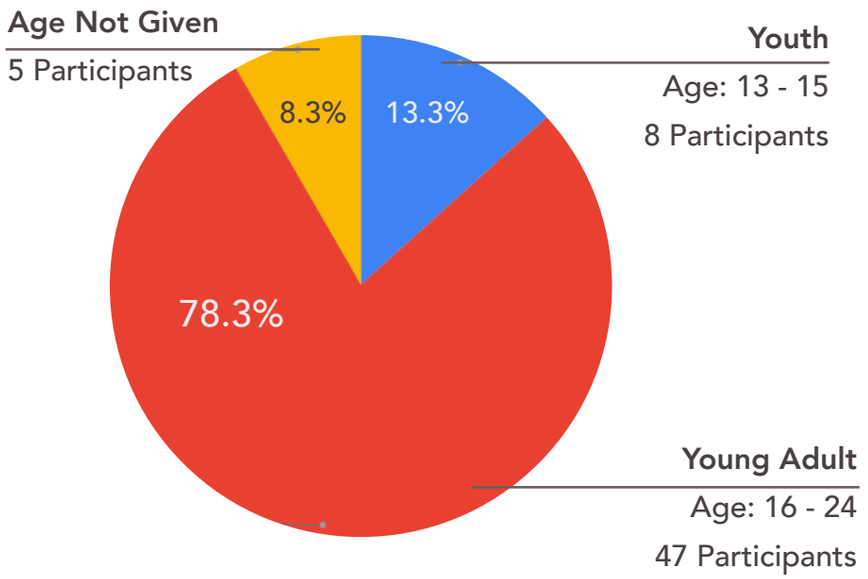
Youth Engagement Results

Youth and Young Adults: Engagement Results

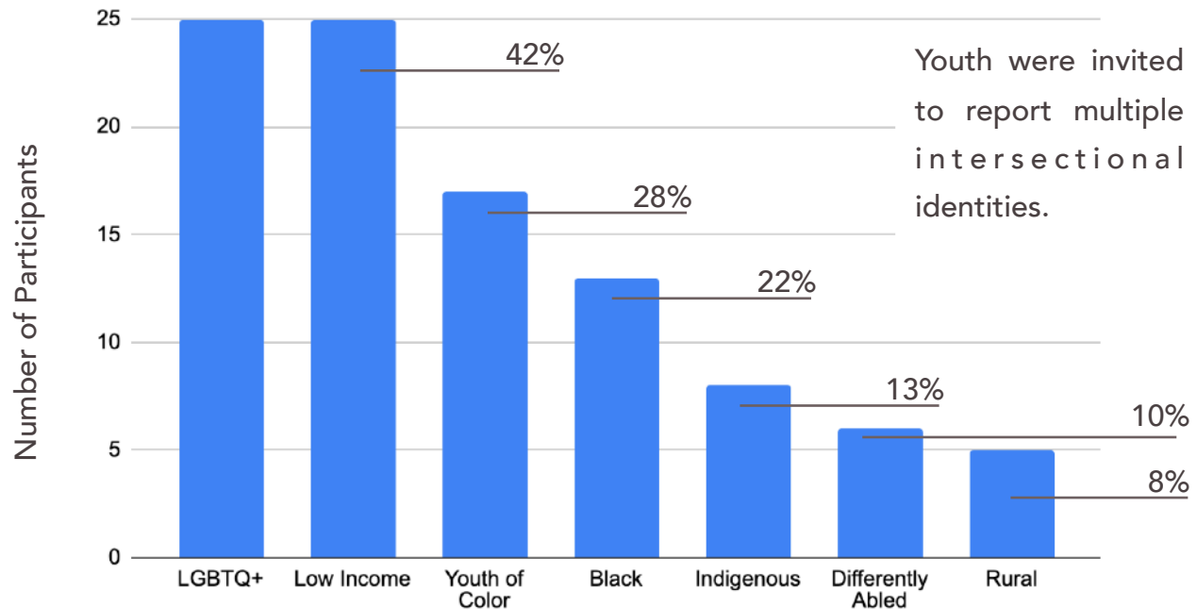
We co-designed with sixty (60) youths and young adults during Reimagining Access, 51 with lived experience accessing or receiving substance use disorder (SUD) co-occurring disorder (COD) treatment in Washington and 9 with peer relationships to other young people with that experience.

We engaged fifty (83%) through in-person co-design sessions, three (5%) through virtual sessions, seven (12%) through one-on-one interviews, and eleven (18%) across multiple formats. The age and identity breakdowns are as follows.

Participant Ages

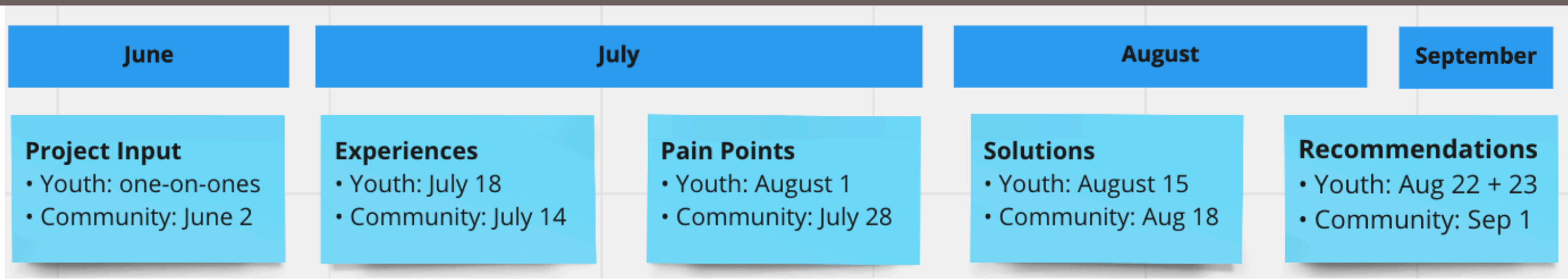


Participant Identities



We had high success engaging Black (22%), Indigenous (13%), and LGBTQ+ and low income youth (42% each). In the future, we hope to improve our age representation, as only 13% of participants were in the 13 - 15 year age range, due to challenges in outreach. We also hope to engage more rural youth in future projects (see p. 49). They represented 8% of our sample, despite making up 19.3%* of the state's population.

Youth Engagement Challenges and Solutions



Youth Engagement Challenges

Reimagining Access kicked off in early May of 2022 with the goal of beginning virtual co-design sessions for both youth and community members in June. We immediately experienced obstacles in this plan. Youth outreach took triple the allotted time. While we expected to complete outreach by late May, but it was not until mid-June that the first youth co-design session confirmed their participation. This represented a dramatic change in our project plan. In order not to delay the project timeline (above), we held our first youth co-design session as a series of one-on-one phone interviews, instead of the planned virtual session. In the future, we propose two (2) months for youth outreach, a number proposed to us by Lily Cory, Adolescent Programs Co-Design Manager at the Department of Children, Youth, and Families (DCYF), which matched our experience.

Engaging Youth In-Person

We also realized quickly that while we could engage adult community members though virtual Zoom sessions, youth would not engage in this way. Instead, we found that we needed to host in-person sessions at locations where youth were already meeting, such as drop-in centers and residential treatment facilities. Throughout the entire process, we were only able to engage three young people (5% of our total) through online meetings. We suggest that in-person sessions at existing meeting locations become the default means of youth engagement and that future budgets account to the additional travel and costs of this in-person work.

Community Objectives and Results

For community members supporting youth in accessing treatment, we did not use the most-impacted partner model (p. 8) or demographic focus we took with the youth. Instead, we built on the role-based list in the RFP (below). Most of the community members we spoke to were youth-serving behavioral health providers.

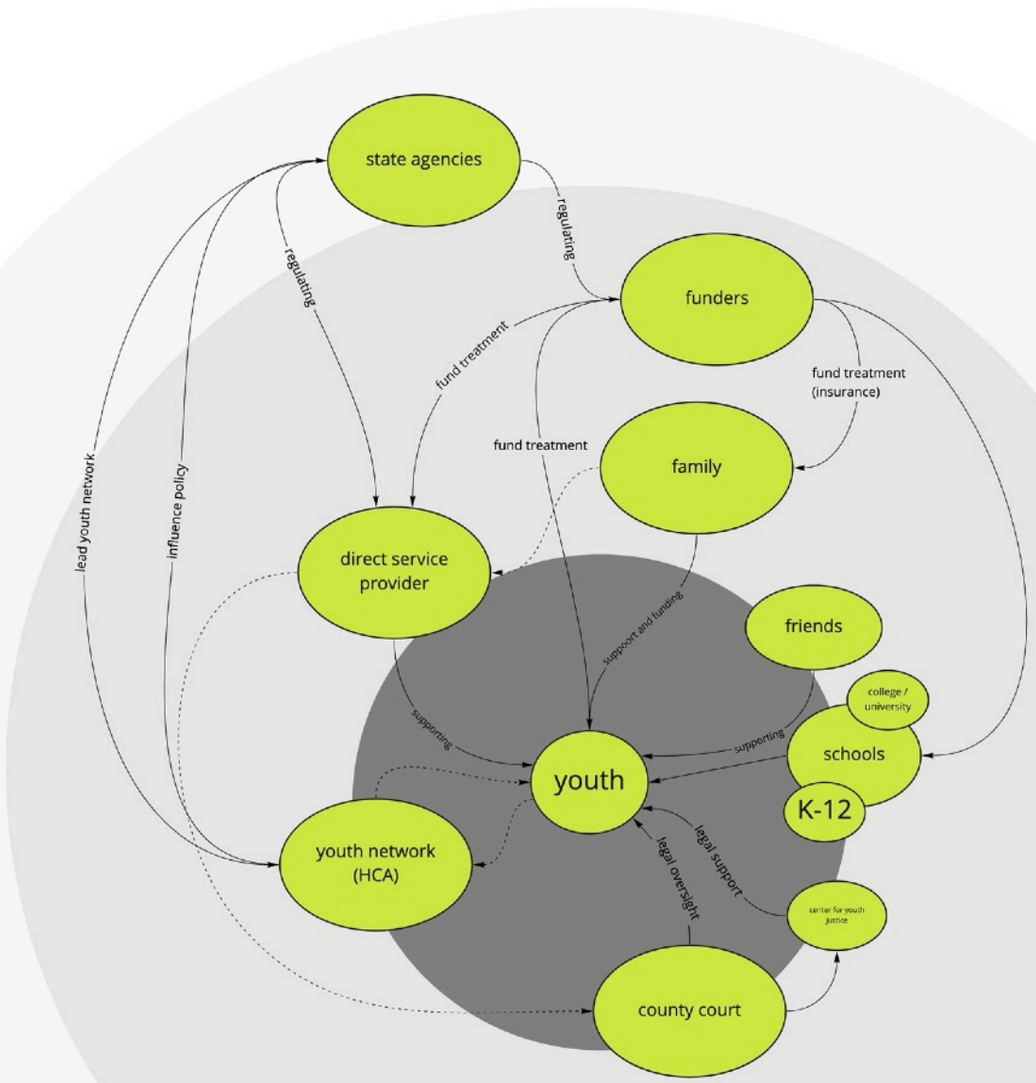
- Behavioral health providers: 24 participants*
- Young adult serving organizations, non-profits: 23 participants
- Families of youth and YYA with lived experience accessing and receiving SUD/COD treatment services: 5 participants
- Housing and recovery support programs: 3 participants
- Juvenile Justice system: 1 participant
- Insurance companies in private sector: 1 state, 0 private

We began community outreach by working with HCA to map the youth SUD treatment landscape, which we visualized in two ecosystem maps. The first conceptual model shows the support structure around youth as a set of concentric circles (right). The second (next page) divides community into four categories and was more helpful to our outreach.

Reimagining Access engaged twenty-eight (28) community members from across the state, eighteen (64%) through virtual sessions alone and ten (36%) through one-on-one interviews, with 61% of session participants attending more than one. We hope to engage more community in the future, which we think will be easier after the summer.

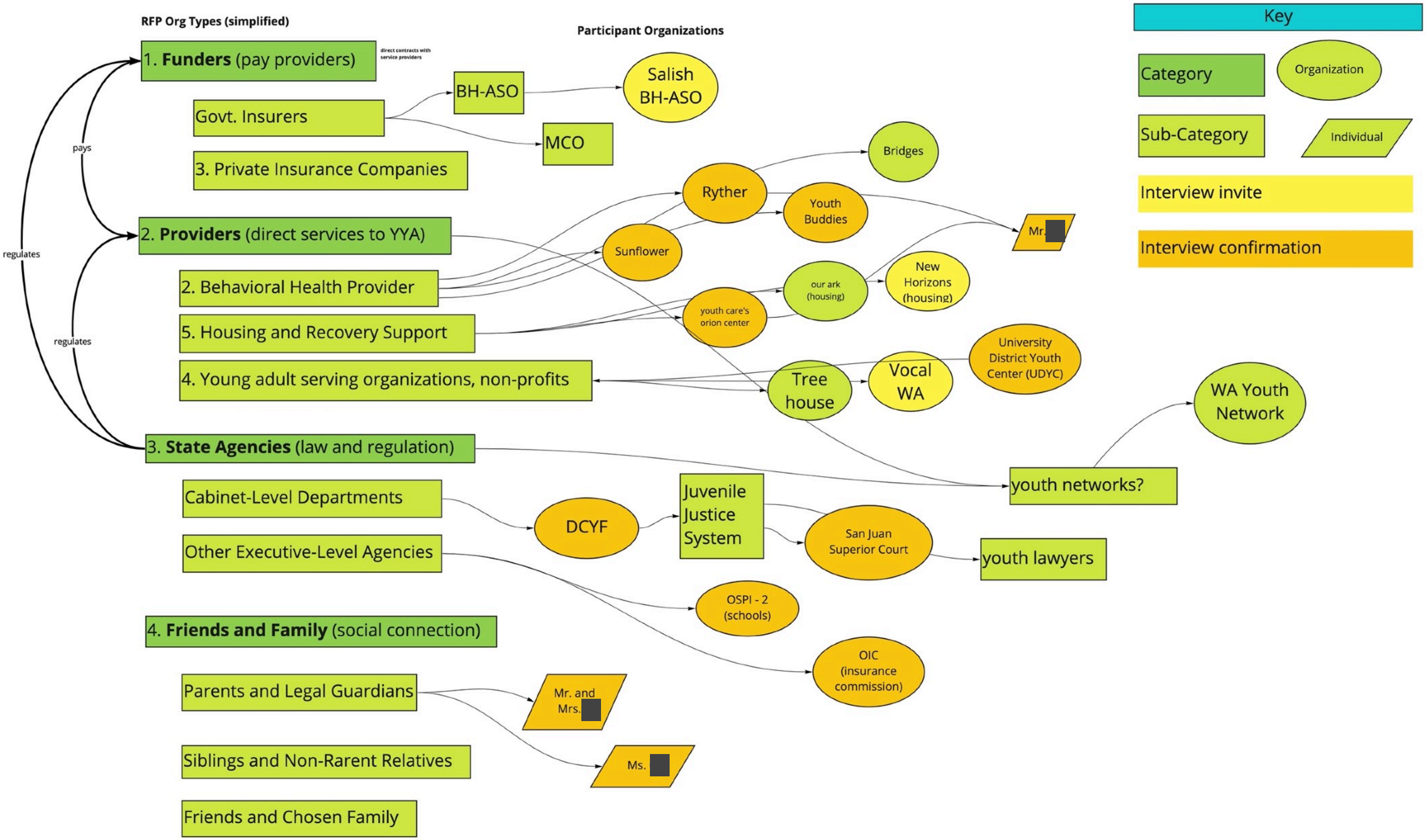
Community Ecosystem Map

Youth-Centric Diagram



 *As with youth, community members were able to hold multiple roles, such as a youth-serving + behavioral health provider.

Community Ecosystem Map



3. Co-Create Solutions

Once engaged, we guided youth and community through a five-phase workshop series, beginning with project feedback and ending with access solutions created and prioritized by partners.

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The Co-Design Sessions

Session 1	Session 2	Session 3	Session 4	Session 5
Project Input	**Experiences**	**Pain Points**	**Solutions**	**Recommendations**

Co-Designing the Process

Our five-phase co-design arc began in June with an opportunity for both youth and community partners to give input on the project, co-designing the process with us.

Grounding in Lived Experience

Co-design grounds all decisions in the lived experiences of those directly affected by the problem. With that in mind, we used a design tool called a "journey map" to diagram access experiences on a visual timeline.

Identifying Recurring Problems

In co-design, pain points emerge from experiences. These recurring problems indicate the source of the challenge identified in the problem statement. Resolving those pain points is the means of generating solutions.

Youth-Led Ideas for Change

In co-design, solutions emerge out of pain points through open-ended brainstorming. To be youth-centered, we brainstormed with youth first, then had community respond to their suggestions.

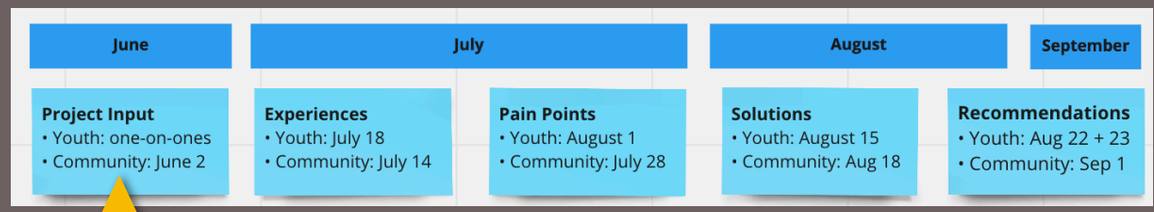
Youth Voting and a Pivot

The final phase of co-design is partner selection of solutions. We conducted youth voting on the solutions emerging from the co-design process, then refocused final recommendations based on a request from the YYACC.*

Session 1: Project Input

Youth Session: Phone Interviews

Community Session: Virtual



Co-Designing the Process

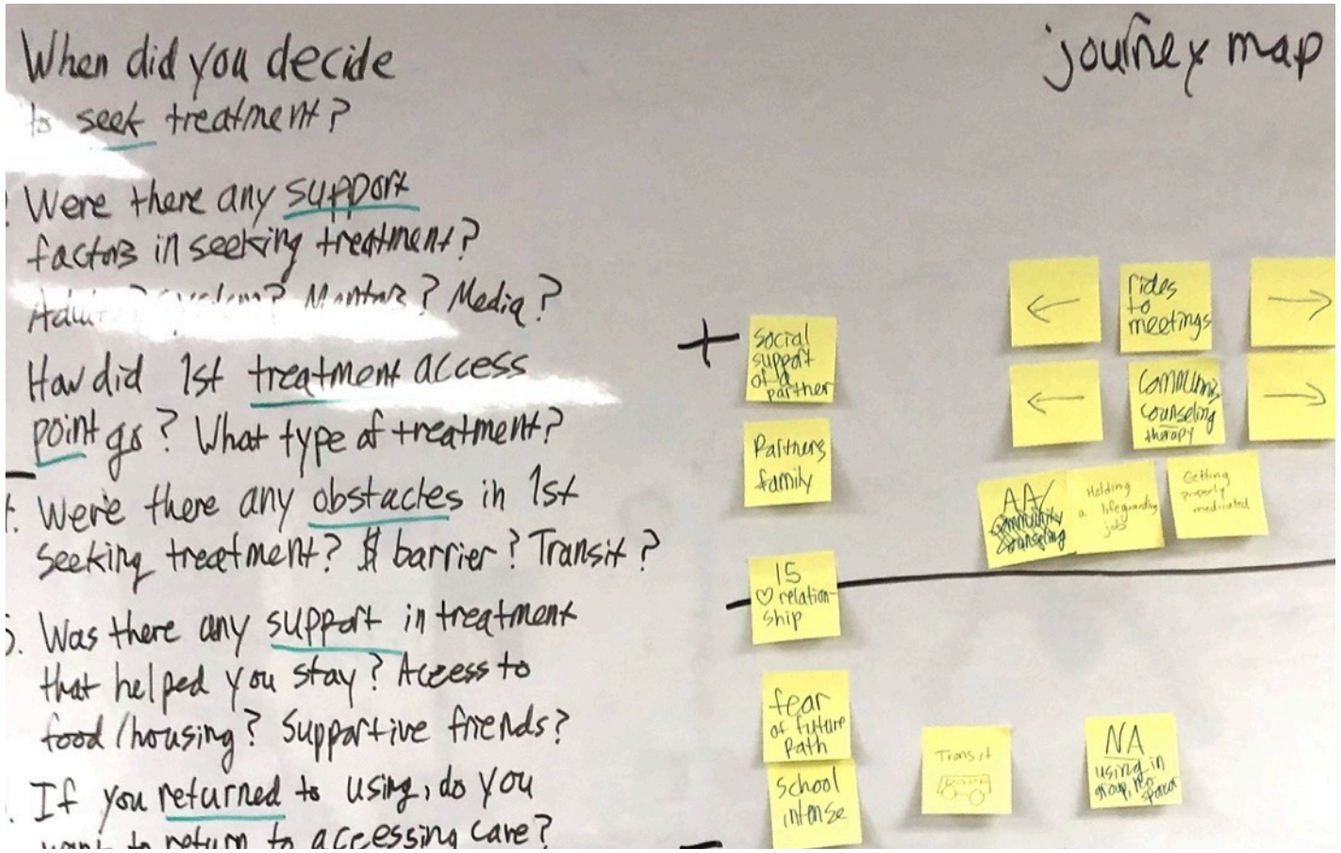
Our five (5) phase workshop series began in June with an opportunity for both youth and community partners to give input on the project, co-designing the process with us. At this and all co-design sessions, participants were offered a $75 participation stipend.

Youth Session: We conducted our first co-design session as a series of one-on-one phone interviews to begin the process while outreach was ongoing. From seven (7) young people we learned that it was important to offer one-on-one interviews going forward, which we did.

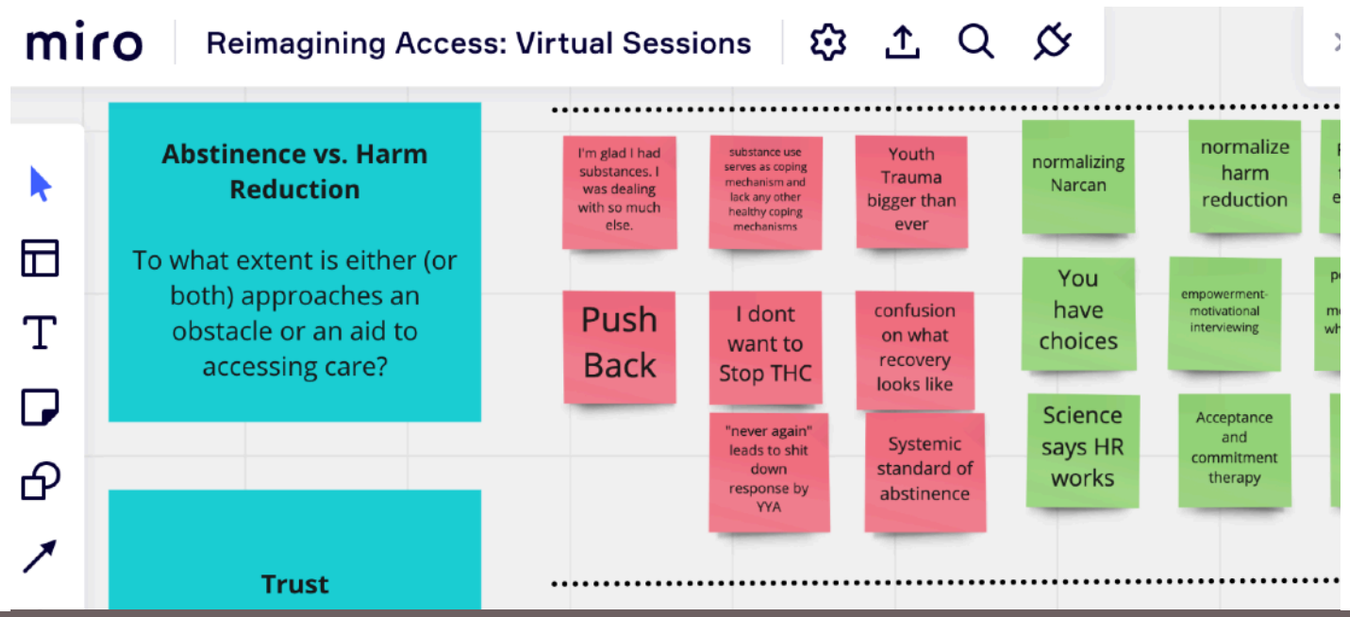
Community Session: At the first community session we shared the problem statement, goal and outputs of the project (see insets) and also did a brainstorm on youth outreach pathways, using using the digital whiteboard platform Miro (left), with the twelve (12) community members who attended.

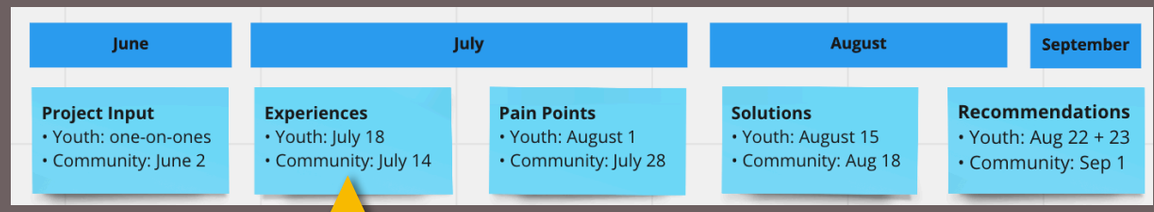
Session 2: Experiences

Youth Session: Longview



Community Session: Virtual





Grounding in Lived Experience

Co-design grounds all decisions in the lived experiences of those directly impacted by the problem. With that in mind, we used a diagram called a "journey map" (left) to diagram access experiences on a visual timeline.

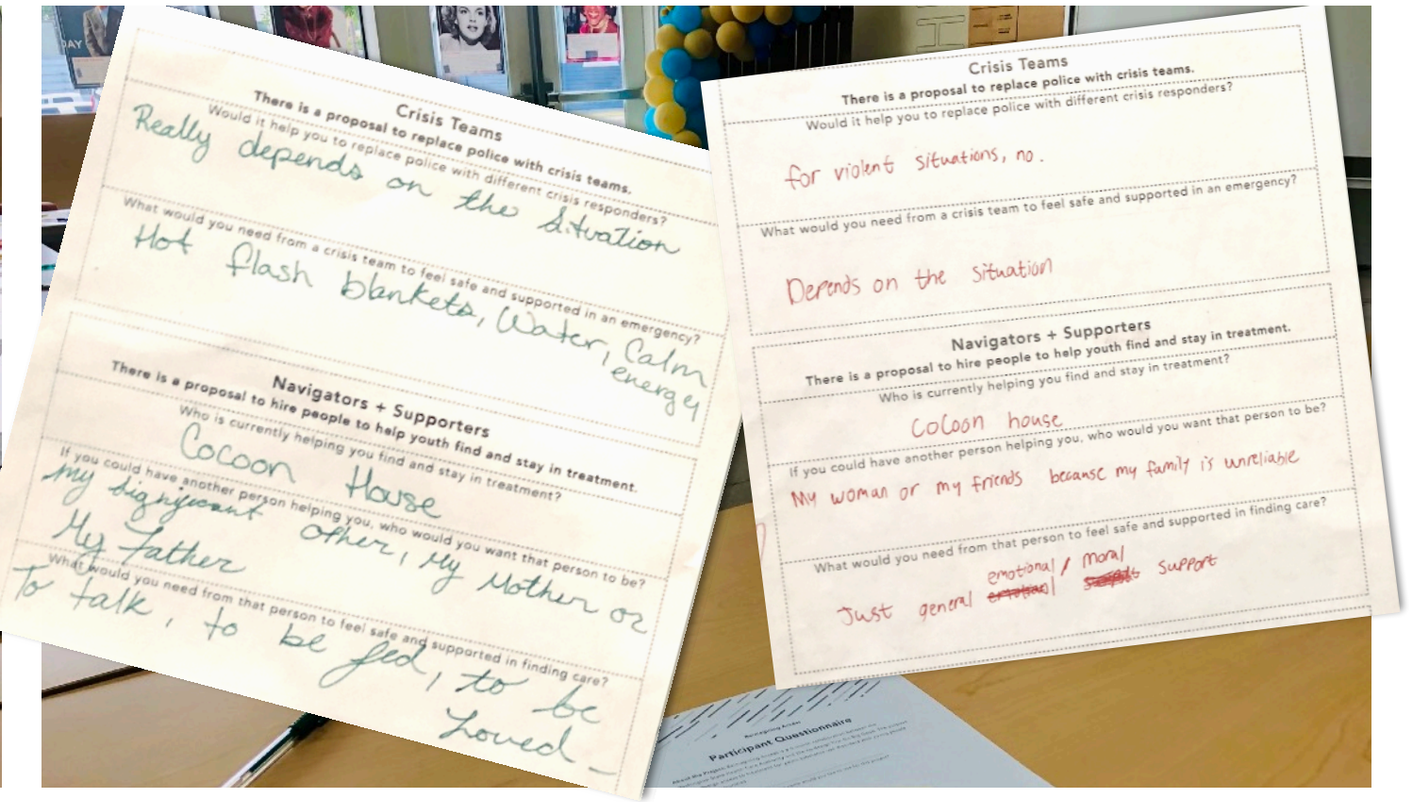
Youth Session: We presented our first in-person session in July to an intensive outpatient (IOP) group in Longview managed by the Cowlitz Tribe. There, we guided fourteen (14) teenage participants through a series of prompts (top left). The young people then drew journey maps of their treatment experiences (see example, p. 32).

Community Session: For adult allies, we first interviewed a representatives sample (categories on p. 12) of ten (10) community members about their experiences supporting youth in accessing treatment. At a follow-up virtual session we asked a group of thirteen (13) to reflect and add to the themes that emerged in the interviews (left).

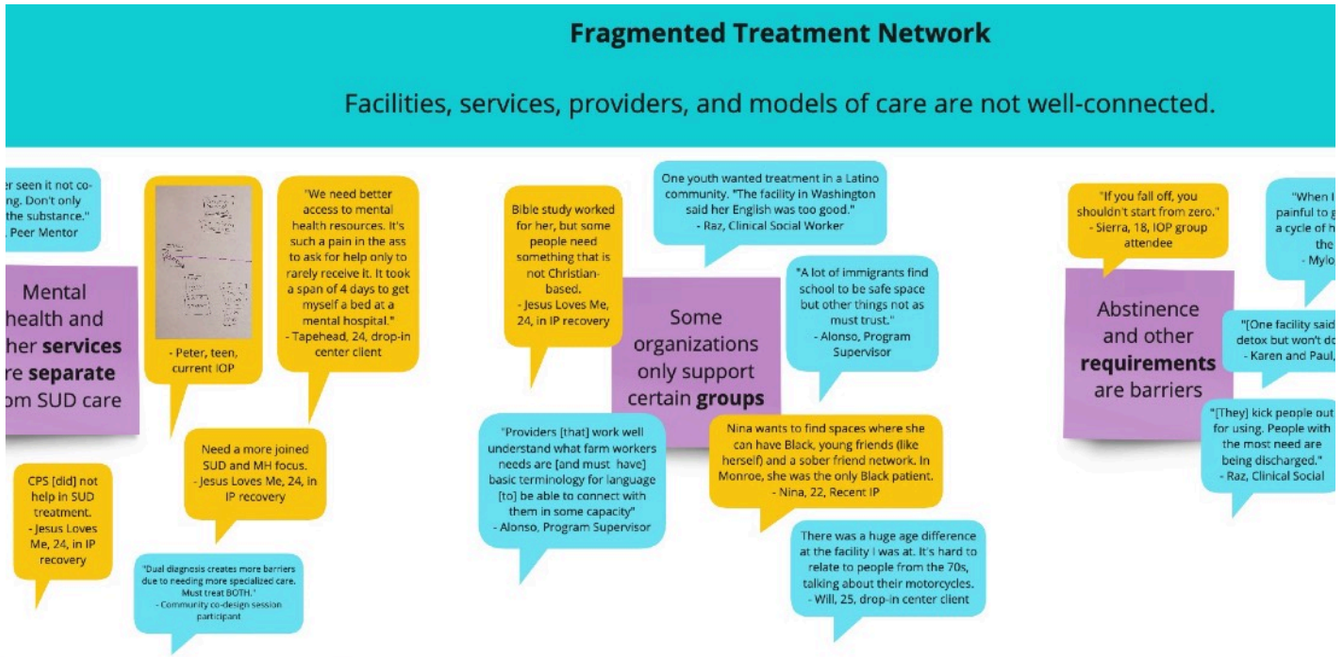
16 images: Do Big Good

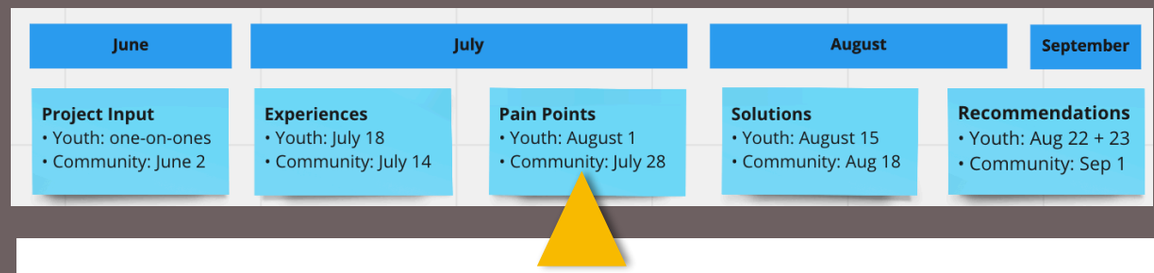
Session 3: Pain Points

Youth Session: Everett



Community Session: Virtual





Identifying Recurring Problems

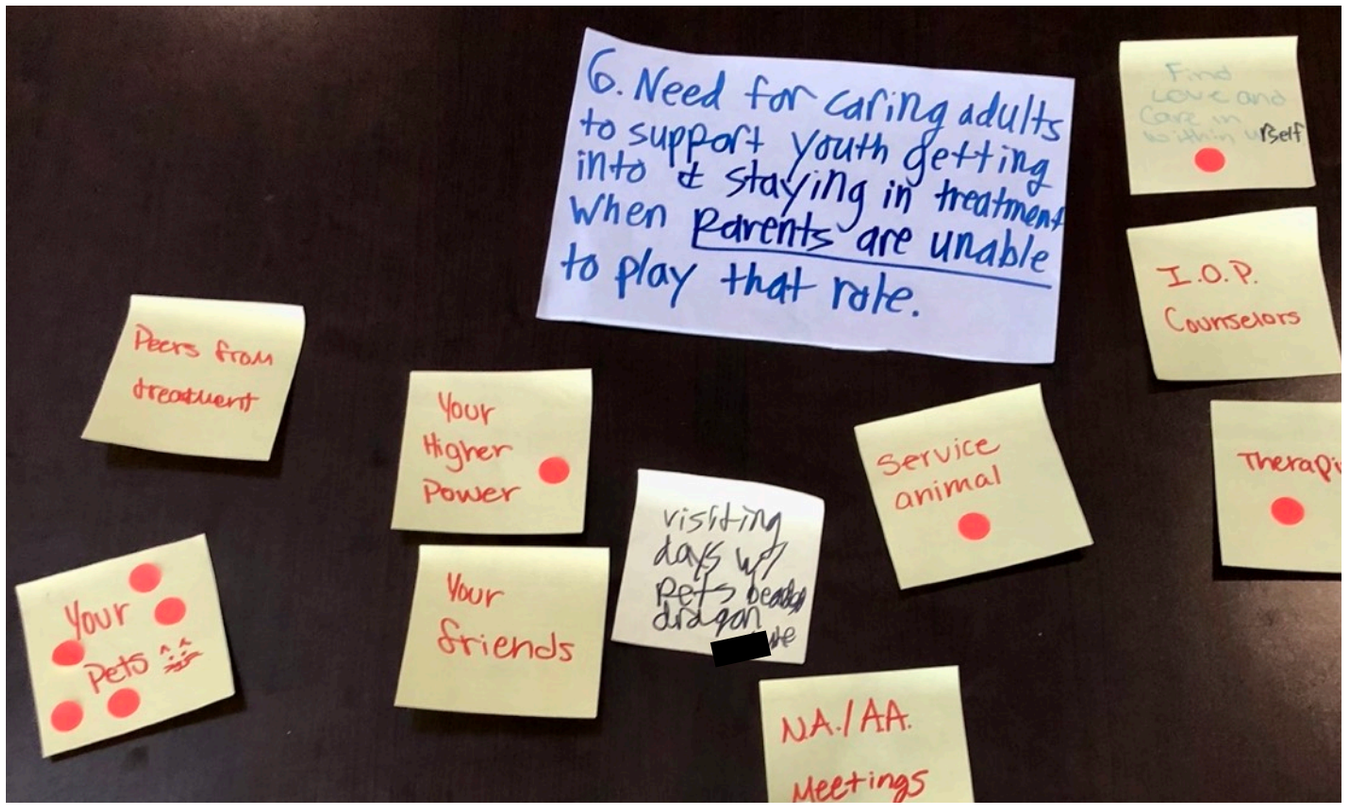
In a co-design process, "pain points" (recurring problems) emerge from experiences. Pain points indicate the source or cause of the central challenge identified in the problem statement. Resolving pain points is the means of solving that central challenge.

Youth Session: We went to Cocoon House, an organization serving homeless youth in Everett, and refined our understanding of community pain points with thirteen (13) clients through group discussion. We also used a worksheet (insets) to get feedback on crisis response teams and navigators, themes HCA asked us to probe.

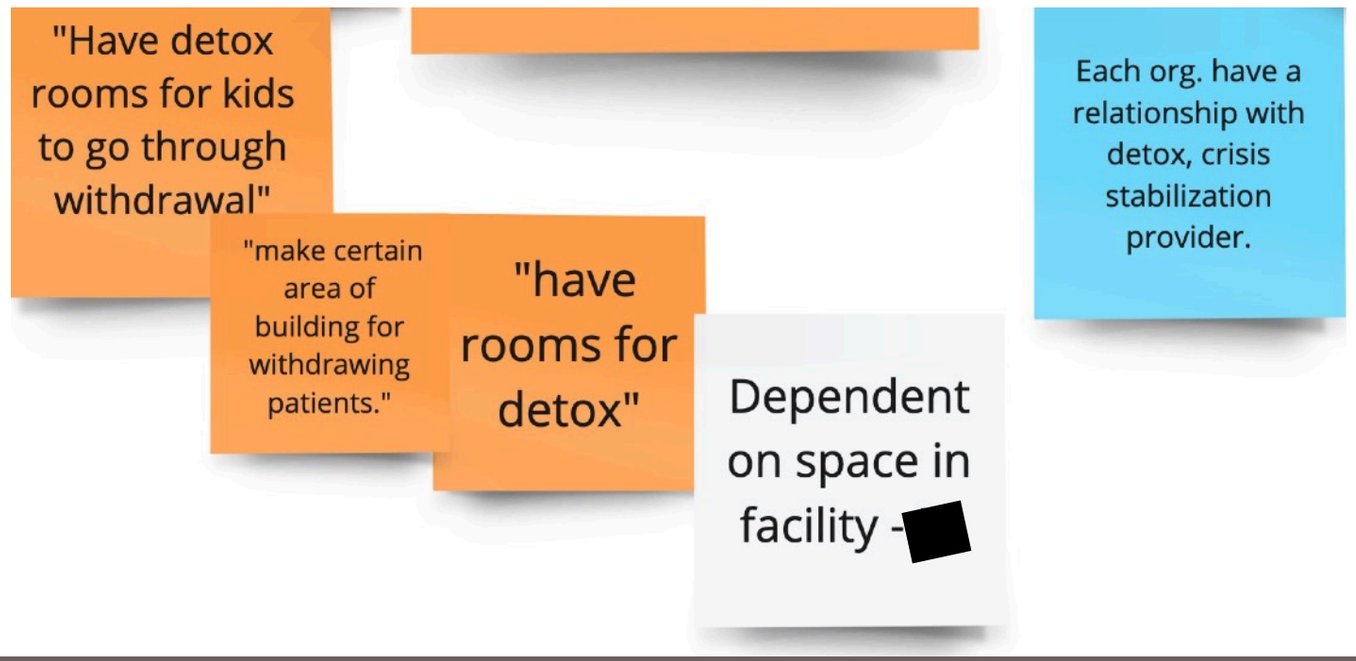
Community Session: For the virtual community session, we received feedback from nine (9) participants on updated themes (left) emerging from HCA and all youth and community workshops and interviews up to that point. We also starting brainstorming solutions.

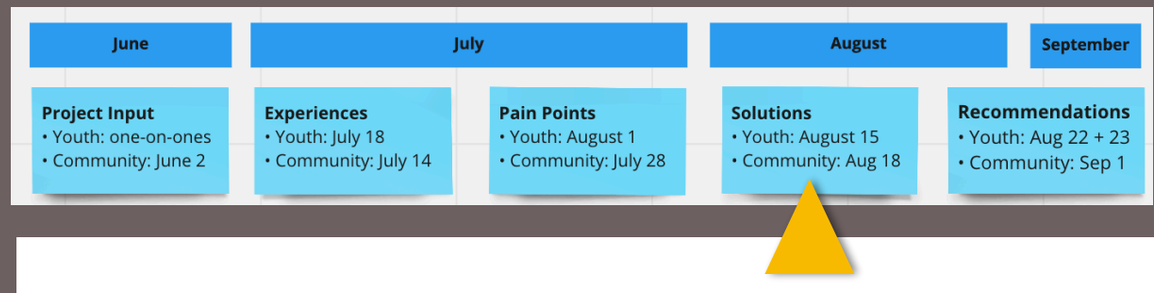
Session 4: Solutions

Youth Session: Bellingham



Community Session: Virtual





Youth-Led Ideas for Change

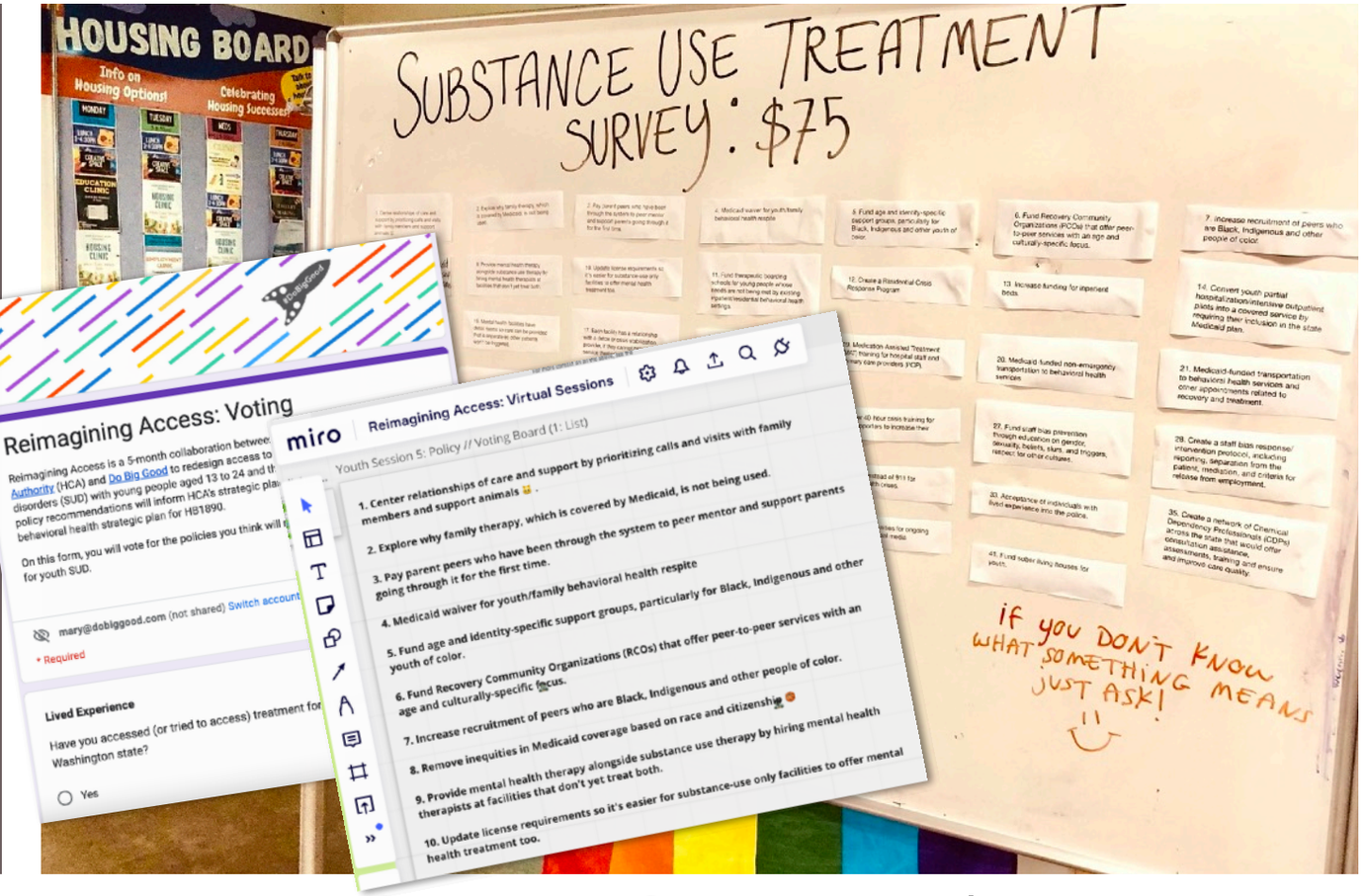
In co-design, solutions emerge out of pain points through open-ended brainstorming.

Youth Session: Our youth brainstorming sessions occurred at the Sea Mar Visions Youth Treatment Center in Bellingham, an all-female inpatient facility. Following a warmup brainstorm, we presented pain points with no solutions to twelve (12) femme, trans, and nonbinary patients. They generated solutions to the pain points and then voted with ● stickers for the solutions they most wanted to be implemented.

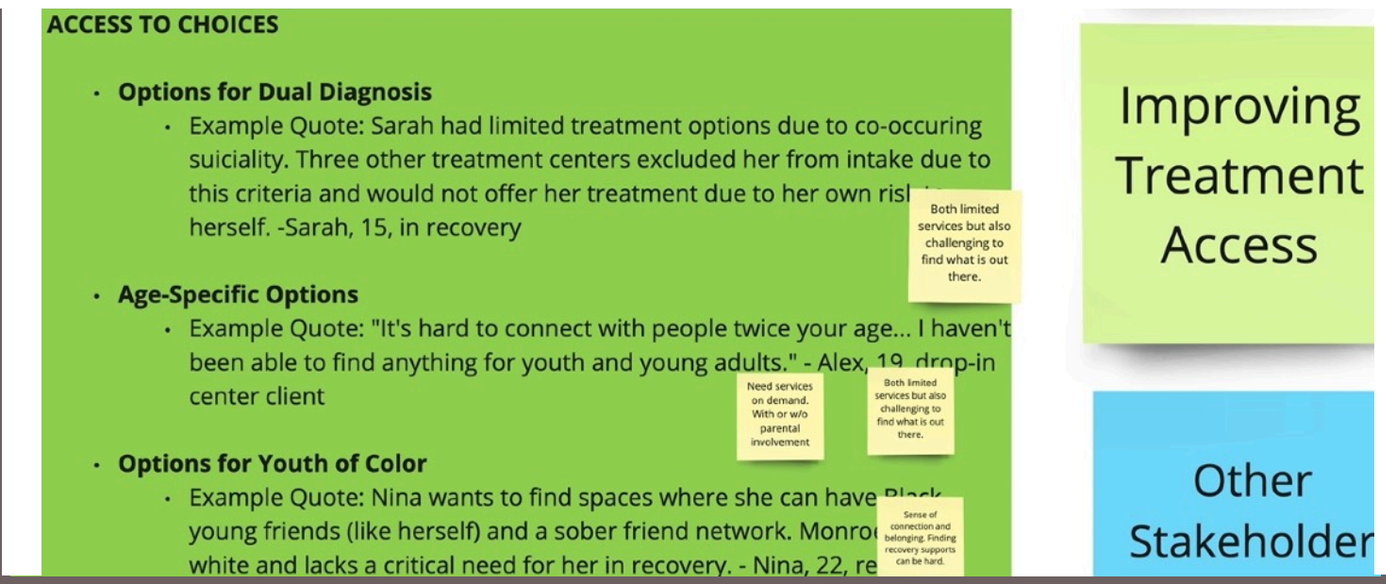
Community Session: For the virtual community session, we asked attendees to transform the solutions generated by youth into formal policy proposals (left). This session did not generate many proposals, however, perhaps because only six (6) people attended the mid-August session.

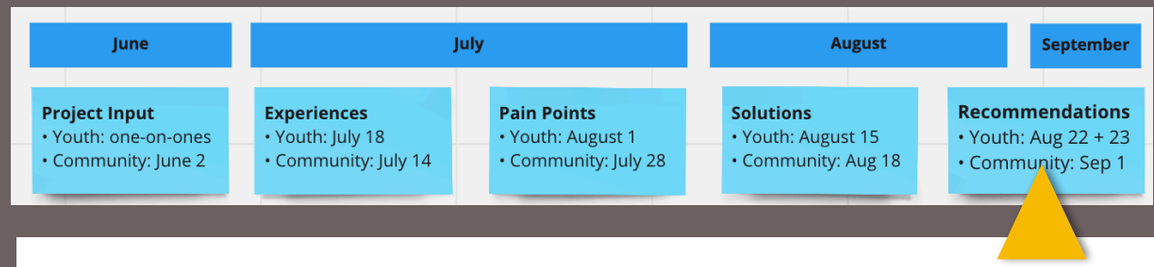
Session 5: Recommendations

Youth Session: Seattle and Virtual



Community Session: Virtual





Youth Voting and a Pivot

Youth Session: For the final youth session, we hosted an in-person session at New Horizons in Seattle, and a virtual session and online form (insets) for past participants. The purpose was to have young people dot-vote with ● stickers on the solutions and proposals developed during the previous sessions. Twenty-six (26) young people participated in the vote.

Community Session: Between the final youth and community sessions, we learned from the YYACC* subgroup that the broader solutions developed by the co-design process were not in line with the group's expectations. With this feedback, we pivoted our recommendations (next section) to a more focused interpretation of access and used our final community session to get feedback from community members on the new outline (left).

Pain Points

2. Need to be clean to get into treatment.

Clean 4 treatment
Make certain area of building for patients withdrawling.

detox area so not [redacted]

... and Solutions

IT SHOULDN'T DEPEND ON THEIR U.A. THOUGH BECAUSE DRUGS CAN [illegible] UP IN URINE [illegible] LONG.

Clean 4 treatment
change the policy & Give patient 2 to withdr-

People do not need to be clean to get into treatment, all People should have access to treatment no matter what.

Kids under the use When they come in. should be perate them selves from Peers until sober, or not high.

Shouldn't matter if you [illegible] or not.

go into detox then into ✱ treatment

Recommendations

Voices of Youth and Community

Youth-generated post-it from co-design session at Sea Mar Visions Youth Treatment Center in Bellingham (August 15, 2022)

Access to Information

Young people, their parents, and even providers lack information about what treatment is available. Navigation services and outreach would help.

 icon: Freepik

Navigators for Parents and Providers

Both parents and professionals need help finding treatment for youth they care for.

Analysis

The new Regional Youth Behavioral Health Navigation Teams and HCA's parent web portal should make a big dent in this problem, as would paying parent peers, like Pam* (right). Recovery Helpline could also add navigation capacity.

"[We] started looking at private pay. It might be 70 grand but we were running out of options. [C]ombing through insurance [and wondering] is this treatment covered?"

- Karen and Paul, parents

Voices

"Everyone is kind of winging it... I call around. It really matters who's on the other end of the line, if someone picks up, if my calls are returned."

- Jeremy, outreach counselor

Nina's mother tried calling every in-patient facility in WA state that had decent reviews and photos online. Nina was thankful her mother was there to support her through the process and advocate on her behalf. She had given up.

- Nina, 22, recent inpatient (IP)

"Other parents call me for help…. Some don't even make the call or email. They want me to do it…. I don't get paid"

- Pam*, parent

"We were looking up facilities on Google."

- Karen and Paul, parents

"[I recommend clients] call every day. Call multiple times a day."

- Raz, clinical social worker

Nina was told she would need 2 weeks for approval, then that she would have to pay out of pocket because her insurance was not on file.

- Nina**, 22, recent inpatient (IP)

"System navigators? King County might have some. Either [they're] good or not good…. Recovery Helpline is great, but they are volunteers. I wish there were professionals there. I wish they had better information."

- Jeremy, outreach counselor

 icon: Freepik // *Community pseudonyms are selected by Do Big Good. // ** Youth names and pseudonyms are self-selected.

Outreach and Informed Access

Youth wish they knew more about treatment options before and during entry into care.

Analysis

Youth we spoke to wanted more information about treatment, at the moment of accessing care and before. When entering treatment, they wish they knew which options were available to them. Fox* and Nina, both of whom accessed treatment through court-ordered diversion programs, were surprised to learn when they would enter treatment and how long it would take. Along with Lila Love and Sarah, they wished the referral process kept them better informed. Youth would also like to learn about treatment options in school and through community outreach.

"We need community partnerships to do outreach so youth know their options, like with schools and sports programs. It worked really well to educate on other health issues, like vaccination."

- Camila, youth network member

Voices

"Before someone enters treatment they need to talk to someone who loves them and make sure they're comfortable with treatment… see where they need help… at school, get a piece of paper. What do you need? Is there anything we can help you with?"

- Jesus Loves Me, 24, in shelter + recovery program

Sarah wants options and transparency about what she is walking into.

- Sarah, 15, in recovery school

"Teach about substance use treatment options in school assemblies or in class."

- Anonymous teen, current IP

"Sometimes places don't give you all the information."

-Lila Love, 20, drop-in center residential client

"Advertisement — damn, where was this housing program?"

- Fredo, 21, drop-in client

Nina didn't know she would be admitted the same day as her assessment. That was jarring.

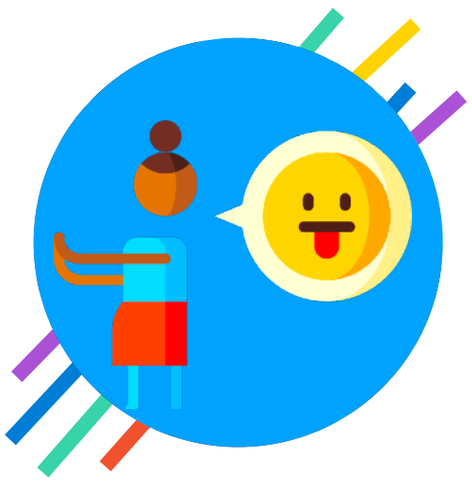
- Nina, 22, recent IP

Fox feared the "gnarly" 1.5 year diversion requirement would uproot his life.

-Fox, 22, in recovery

 icon: Freepik // * All youth names and pseudonyms in this report were selected by the young people themselves.

Countering Negative Expectations



Better outreach could counter negative perceptions of treatment.

Analysis

One pattern we came across in our co-design sessions and one-on-one interviews is that youth often had a better experience of treatment than they expected. Whether formed by the media (an Eminem video) or war stories from peers who had been through the system, young people, particularly those who entered treatment through court-ordered diversion, expected a bleak experience, something "like jail". Once they entered treatment, whether inpatient (IP) or intensive outpatient (IOP), they found it to be better than they expected.

While the legal process meant these young people went to treatment even though they had low expectation, youth who have the choice may also have these negative perceptions and may not be accessing treatment as a result.

Voices

"I got arrested and put on treatment as diversion because parents knew I had been smoking. [Treatment is] better than I expected."

-Anonymous teen, currently in an intensive outpatient program (IOP)

Low expectations of AA were formed by an Eminem video. Once she started, it was totally different and she was able to connect with people.

- Jesus Loves Me, 24, in shelter + recovery program

Nina had low expectations for SUD treatment overall. However her experience was not as bad as she anticipated. She anticipated treatment to "be like jail", but, in reality, it was not as tough.

- Nina, 22, recent IP

Expectations of ordered treatment were different than expected. Those expectations were largely influenced by peer descriptions of what they had been through after getting big charges and then recovery.

- Fox, 22, in recovery

Access to Social Support

Young people need supportive relationships to seek treatment. Peers and providers are valuable, but it's hard to overstate the central role of parents.

icon: Freepik

The Central Importance of Family

Family relationships are tremendously important to youth seeking treatment.

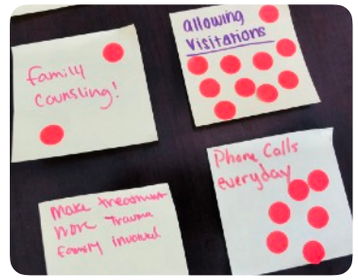
Analysis

It's hard to overstate how important family, particularly parents (and, even more specifically, mothers) are to youth seeking care for SUD. The possibility of staying in touch with family while in treatment, or -— even better — entering treatment with family, would be a huge incentive for youth to access care. Although parents are centrally important, siblings also play a role. They can lead youth into treatment, as Cat (right) experienced, or they can lead them out of treatment, as young people often use with their siblings.

Voices

"Have family treatments so not just an individual."

- Anonymous teen, current IP



"My Mommy... my cousins, cuz they're always there for me."

-Lila Love, 20, drop-in center residential client

"[I was] using with my sibling."

-Anonymous teen, current IOP

"I wish I could call my Mom to check on her. I worry about her."

- Sunny, 15, current IP

"My Mom, she always says she believes in me."

- Imani, 16, current IP

"I was able to give the young person a card to local treatment as diversion, but the parents were not a part of it."

- Evette, court administrator

"My family wanting me to quit 'cause they feel it makes me less successful [is motivating] along with court ordering it."

- Anonymous teen, current IOP

"I stopped drinking because I wanted a better relationship with my Mom and brothers…. [Y]ou gotta do better for the people you love…."

-D. Boy, 20, drop-in center client

"I followed my sister around. She got clean, but was on cocaine. I followed her to her counselor. I felt safe because she was there."

- Cat, 21, drop-in center client

 icon: Freepik / photo: Do Big Good LLC

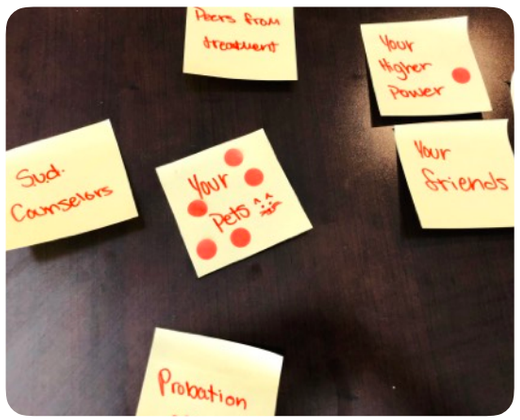
Parental Surrogates

Alternate navigators are needed when parents are unable to fill that role.

Analysis

Community members had seemingly strong suggestions of non-parental allies for youth, but young people didn't particularly like any of them. Fox's quote (right) on the challenge of identifying healthy support may explain why.

At the Bellingham youth co-design session, for example, the support option with the highest number of ● votes was "your pets" (image, right).



"A person using tends to not know what support is or healthy support."

- Fox, 22, in recovery

"[I'd like] help with calling hospitals, experience with learning disorders."

-Tapehead, 24, drop-in center client

"More supported (line where people can call for support)."

- Anthony, 23, drop-in center client

"[T]he brain isn't functioning normally and yet we're still… trying to access care with these brains."

- Fox, 22, in recovery

Voices

"A youth was in a remote mental health care program and their Mom didn't want to be involved. They assigned someone to check in with the youth, who needed to be in intensive care. The advocate made it happen."

- Evette, court administrator

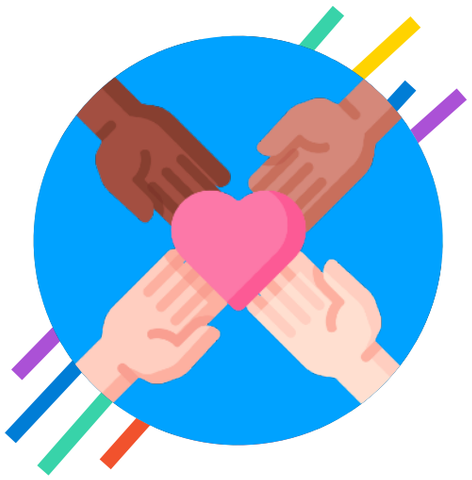
"If I had magic wand, no cost barriers, if a kid says no to a Mom, maybe get a department of health case manager, someone to work with that kid."

- Paul and Karen, parents

"You could add a paid peer navigator.… [P]eer navigators have been a missing element in a lot of processes in the social work field."

- Desmond, 21, in recovery

Multiple Messengers



Every invitation to access treatment matters.

Analysis

Young people often need to be invited to access treatment multiple times by multiple people. Every intervention helps, even if it is not immediately successful. This anonymous testimony from a teen diverted into an intensive outpatient program (IOP) is one example:

"[I] went to jury. Court made me do treatment for the first time because of MIP [minor in possession]. Court and family supported it. Didn't stop using, ran aware for four months 'til I got in a car crash and hospitalized. Started using again after car crash. Used more and different things. Started treatment my second time almost four months after the crash. Went four months clean, then relapsed. Got kicked out of treatment. New treatment is working with me to keep my sobriety. Used for a while longer and now starting treatment for my third time."

-Anonymous teen, current IOP

Voices

"It took 20 people to sit down and tell me essentially 'wtf' are you doing?... I didn't get sober until I actually wanted to….[Now I] love to help people seeking out recovery [to] get it."

- Fox, 22, in recovery

"Help people find their tribe, find their people."

- Fredo, 21, drop-in center client

A big moment in recovery was going to meetings and having a sponsor, attaining community and friends.

"Most people who make connections and support others make it out, peers helping peers."

- Sarah, 15, in recovery school

"[We need] good people-matching. A social worker from a rich city...DC, Boston… You can sympathize, but you can't empathize. I talked to a social worker from Cleveland. He was Black. He got me."

-Kay, 18, drop-in center client

Unplugging
Bottlenecks

There are referral bottlenecks in the courts and in ERs. Dual diagnosis prohibitions and "clean to treat" policies also block access, as does the lack of capacity.

Referral Bottlenecks in the ER

Overloaded hospitals struggle to refer youth to treatment.

Analysis

Hospital emergency rooms (ERs) are often not able to play the referral role that youth in crisis need. Youth who have fallen through the cracks of other referral pathways, such as school-based diversion or referral by a therapist or primary care provider (PCP), end up in the emergency room desperate to enter treatment. There they wait for hours and then, as in Nina's case (right), may meet with a dismissive doctor from whom they need to beg a referral. She was only able to keep pushing for the referral because her mother was there to advocate for her. Other youth may just give up. Overloaded social service agencies are also not playing the referral role youth wish they would, as Jesus Love's Me's experience with Child Protective Services (CPS) indicates (right).

Voices

Even with a court mandate, Nina needed a doctor's referral for inpatient care. She went to the ER with her mother to get that referral. At this time she was suicidal and had emotionally given up. After waiting for 8 hours, she was met by an ER doctor who, after hearing her binge drinking symptoms, dismissed them as "mild" and not that severe.

- Nina, 22, recent IP

"So many different buckets that are being looked at with the peer connection. Navigator type of position in an emergency room. Connect with the parent.. [a] bridger role…."

-Brenda, policy analyst, state agency

"CPS [did] not help in SUD treatment… [I] relapse[d], lost [my] son, yet still no CPS support!"

- Jesus Loves Me, 24, in shelter + recovery program

"I waited in the ER for six hours — no help."

--Tapehead, 24, drop-in center client

30 icon: Freepik

Referral Bottlenecks in the Courts

Diversion programs are blocked, but more research is needed to probe the obstacles.

Analysis

We received a few tantalizing details about obstacles in court-ordered diversion programs, and would like to dig deeper in the future. We would also like to speak with police officers, whom we did not get a chance to speak with during this process.

In our initial findings, Evette (right), a court administrator, and Bryan (right), the clinical supervisor of a detox facility, both agreed that there were a lot less treatment referrals coming from the courts, though neither could immediately identify the cause. We hope to explore court referral obstacles more deeply if this work is extended.

Voices

"When we lost courts pushing kids into treatment, we lost a big pool of patients. Without the enforcement of courts on our side it made it difficult for us to retain patients in our program."

- Bryan, clinical supervisor, detox facility

"There's a lot less referrals and there's less ability to provide support."

- Evette, court administrator

"[Students] keep re-offending because there is no accountability with police reports…. Probation shouldn't end until [treatment ends]."

- Julieta, school chemical dependency specialist

Fox wasn't able to access much help from counselors due to fears of police and further potential charges and more court-ordered treatment.

-Fox, 22, in recovery and sober

The Dual Diagnosis Obstacle

A mental health challenge should never be a reason to refuse treatment.

Analysis

Throughout our workshops and interviews, we found only one person who supported the idea of treating co-occurring disorders (COD) and substance use disorders (SUD) separately, and that was due to the difficulty in re-licensing his facility to be able to hire mental health counselors. Far more common was the argument (see Alonso's and Mylo's quotes here) that substance use *always* has a mental health component. Mental health care needs to be provided at the same time as substance use treatment. It certainly must never be a reason to refuse treatment, as Sarah experienced (upper right).

"Get a sponsor or SUD counselor if you [as a facility] only have mental health counselors. Same the other way around."

- Anonymous teen, current IP

"I've never seen it [SUD] not co-occurring. Don't only address the substance."

—Mylo, peer mentor

Voices

Sarah had limited treatment options due to co-occurring suicidality. Three treatment centers excluded her from intake due to this criterion and would not offer her treatment due to her own risk to herself.

-Sarah, 15, in recovery school

"I did so many things to cope during COVID."

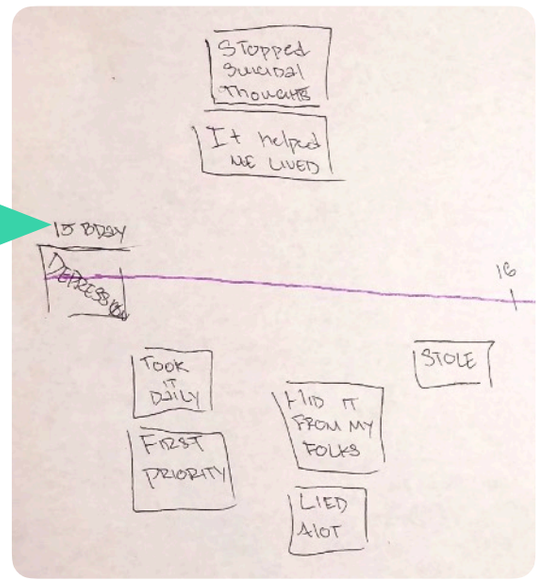
- Tamara, teen, current IOP

"When I do see substance abuse, I see a need for mental health. They're 100% linked."

- Alonso, program supervisor, state agency

Journey map (right) starts with depression on their 15th birthday. Using stopped their suicidal thoughts.

- Anonymous teen, current IOP



 icon: Flat Icons / photo: Do Big Good LLC

The “Clean to Treat” Paradox

Needing to be off substances to be treated for substances is cruel and illogical.

Analysis

Demanding that a young person be off substances to be treated for substances — a practice we call “clean to treat,” but which may have another name — is one of the cruelest and most Kafkaesque barriers to access we came across in Reimagining Access. This barrier affects not only initial access, but also relapse while in treatment. As Raz, a clinical social worker said succinctly, “people with the most need are the ones being discharged.” The stigma that results is a further barrier to re-entry (see Mylo’s quote). The preferred youth solution was unanimous (right): allow non-sober young people to enter treatment, but quarantine them while they go through withdrawal so as not to trigger other patients.

Voices

"If someone comes to treatment under the influence, they should still be admitted because they are at treatment for a reason and it's possible for them to change. But if they're drunk or high upon arrival they should be kept in a separate area from other clients and be monitored until they are no longer under the influence and be away from clients so clients don't feel triggered."

- Shy, 17, current IP

"[They] kick people out for using. People with the most need are the ones being discharged."

- Raz, clinical social worker

"[One facility said] they do detox but won’t do benzos."

- Karen and Paul, Parents

"If you fall off, you shouldn't start from zero."

- Anonymous, 18, current IOP

“There should be a detox area so people can enter the facility if they are not sober and other patients won’t be triggered.”

- Luke, 15, current IP

“Change the policy and give patients 2 weeks [for] withdrawal…. Make certain areas of the building for patients withdrawing.”

-Anonymous teen, current IP

"When I relapsed it was painful to go back. There was a cycle of hiding. It reinforced the addiction."

- Mylo, peer mentor

Wait Times and Capacity

Wait times due to lack of capacity was a recurring barrier.

Analysis

Though it will come as no surprise to the readers of this report, we felt the need to mention the recurring problem of wait times due to lack of capacity to meet youth treatment demand. Though most of the testimony we received on this topic (and most of the quotes on this page) concern inpatient treatment, the capacity problem is not limited to this type of care. According to Washington's Mental Health Referral Service for Children and Teens*, a 2-3 month wait to access community mental health agencies is not uncommon, and some waits are even longer.

"If a young person wants more time, they should have more time."

- Anonymous community member

Nina's mother tried calling every in-patient facility in WA… but none of these facilities had immediate availability. Because of this, they considered contacting SUD facilities outside of WA.

- Nina, 22, recent IP

Voices

"You know what's easy for me to do? Getting a Suboxone prescription. You know what's hard? Finding an inpatient bed."

- Jeremy, outreach counselor

"Once we put [my son] in a dementia-care ward because there were no SUD beds."

-Pam, parent

"Might be 90 days out before you can talk to someone , but you need support now. The time and crisis is now…. If you have a bed, don't leave it. It will take months to get another."

- Brenda, policy analyst, state agency

"Standard of Care needs to change: Inpatient Treatment needs to be longer than 30 days."

- Anonymous community member

"We need better access to mental health care. It's such a pain in the ass to ask for help only to rarely receive it. It took a span of 4 days to get myself a bed at a mental hospital."

- Tapehead, 24, drop-in center client

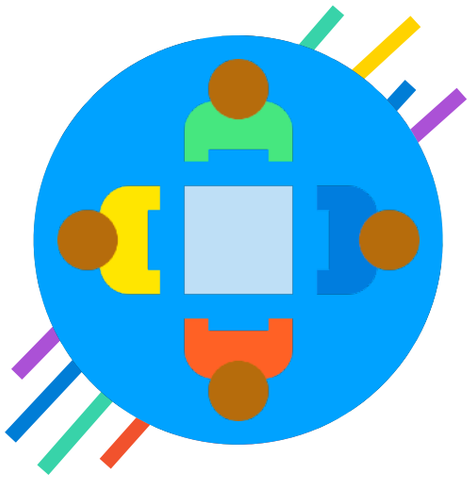
Connect

Marginalized Youth

Youth with marginalized identities would benefit from age and culturally-specific care.

 icon: Freepik

Age and Culturally-Specific Care



Youth want support with peers who share their identifies.

Analysis

To create a more effective peer support experience, young people want treatment options specific to their age and to their ethnic identity. This request applies to both inpatient and community-based care, such as Narcotics Anonymous (NA), Alcoholics Anonymous (AA), and other support groups.

"More treatment centers that are culturally-based."

- Jocelyn, 17, current IP

"This client went to the East Coast and paid out of pocket for… treatment with [other] Latinas."

- Raz, clinical social worker

"The point of this is to provide the client with more personalized, direct, and unconditional services that meet their specific needs their way."

- Desmond, 21, in recovery

Voices

Nina wants to find spaces where she can have Black, young friends (like herself) and a sober friend network. Monroe is very white and lacks a critical need for her in recovery.

- Nina, 22, recent IP

"There was a huge age difference at the facility I was at. It's hard to relate to people from the seventies, talking about their motorcycles. I want to be surrounded by people going through the same things."

- You, peer mentor

"There's no resources for younger people. It's hard to connect with people twice your age. I haven't been able to find anything for youth and young adults."

- Alex, 19, drop-in center client

"[I wish there were] meetings for [specific] ages."

- Cat, 21, drop-in center client

Pathways for Undocumented Youth

Undocumented and migrant youth need legal and linguistic support to access care.

Analysis

Among youth of color, undocumented youth, resident youth who entered the country illegally, DREAMers, and migrant youth experience especially high obstacles to care.

One clear and addressable barrier is the lack of Medicaid eligibility based on citizenship status. For many undocumented youth, the inability to access even state-funded care is catastrophic. As Camila (right) noted, “I was suicidal. I was only 17. I wanted to get my life in order and I couldn’t.”

Other barriers for youth newly arrived in the US are linguistic. For example, youth from Latin America may not be conversant in Spanish and may need to access services in an indigenous language.

Voices

"It's really heartbreaking. They want to get their life in order and they can't because of something as simple as how they came into the country. It happened to me. I was suicidal. I was only 17. I wanted to get my life in order and I couldn’t.”

- Camila, youth network member

“Youth that are undocumented have the ability to be become documented in treatment.”

- Jocelyn, 17, current IP

“Because [one client] spoke English they wanted the spots open for Spanish speakers… Would have been awesome at a treatment center with Latinx folks.”

- Raz, clinical social worker

"Providers [that] work well understand what farm workers’ needs are [and have] basic terminology and language to be able to connect with them in some capacity…. Depending on age and citizen status, [they're] not granted the same level of care. Medicaid eligibility needs to be addressed."

- Alonso, program supervisor, state agency

Improving Court-Ordered Diversion

Youth wish they had more choice within diversion.

Analysis

Though it may not be a representative sample, the young people we talked to who went through court-order diversion were grateful to access treatment, which surpassed their admittedly low expectations (see p. 24).

Still, they wish they had better options in diversion programs. Nina (right) wishes there had been an outpatient option that had taken less than 1.5 years. Fox (right) was able to negotiate for community-based care through an Alcoholics Anonymous (AA) group, but it ended up being insufficient, so he relapsed and was reincarcerated.

Absolute choice may be neither beneficial nor possible, but youth value their agency and increased options for court-ordered treatment would be appreciated.

Voices

Nina received a DUI, two felony assault charges, and a misdemeanor charge. Treatment was part of a court mandate, as well as her personal goals for getting support with her SUD. Initially, she attempted to receive support via an intensive outpatient program (IOP). She and her mother contacted an IOP located in Federal Way, but was told that the IOP process would be about 1.5 years.

- Nina, 22, recent IP

"The court and this program work well together."

- Anonymous teen, current IOP

"I wish we could have more privacy and choose who observes us when we do UAs (urinalysis), wish it could be once a week instead of twice."

- Anonymous, teen, current IOP

Fox was court-ordered into long-term treatment due to charges, but he feared the "gnarly" 1.5 year requirement would uproot his life…. He ended up in AA, which wasn't really enough, resulting in relapse and multiple incarceration for parole violations.

-Fox, 22, in recovery

Making Treatment Non-Punitive

Youth don't want legal repercussions for use. Some adult allies do.

Analysis

The role of legal repercussions for substance use is one of the few areas where youth and adult community members disagreed.

Youth want all treatment to be non-punitive, with urinalysis (UA) used only for diagnostic purposes and no risk of further charges based on what one might say in a counseling session.

Conversely, Julieta (right), a school chemical dependency specialist, appreciates the incentives that legal repercussions put on youth who have substance use disorders, but are resisting treatment. "They keep re-offending because there is no accountability with police reports," she laments.

Voices

"UAs (urinalysis) should only be done to show staff what care could be provided. UAs should be confidential and not shared with probation officers…."

-Shy, 17, current IP

"The court and this program work well together."

- Anonymous teen, current IOP

"We don't have cops in the [school] system. [Students] will say to me, 'If I get caught, I'll see [about treatment]." They keep re-offending because there is no accountability with police reports…. Probation shouldn't end until [treatment ends]."

- Julieta, school chemical dependency specialist

Fox wasn't able to access much help from counselors due to fears of police and further potential charges and more court-ordered treatment.

-Fox, 22, in recovery

Treatment Access in Public Schools

Youth want to access recovery services at school... and school services in recovery.

Analysis

Particularly for immigrants and other marginalized populations, public school is a safe and preferred space to receive services. Youth would like to receive care on campus and information about treatment options at assemblies or in class. Regarding in-school diversion, Kathy, a recovery coach and school-based recovery navigator, favors Teen Intervene, 3-5 sessions for students exhibiting experimentation or problem use. The program talks about motivation to change, how to deal with peer pressure, and how to say no and is designed for youth who have just started using. It also integrates well with peer support sessions. Recovery schools and the ability to take classes while in inpatient treatment were also favored. Julieta (right) describes the bottlenecks in school diversion. There is lots here to explore in future co-design work.

Voices

Sarah attends a recovery school. That's where she started to decide to turn her life around.

- Sarah, 15, in recovery school

"Visions was good. They provided classes."

-Lila Love, 20, drop-in center residential client

"It's about a continuation of care: recovery support on campus, information about recovery, care coordination, someone who identifies with what they're going through. [I'd like to see] peers in every school."

- Kathy, recovery coach and school-based recovery navigator

"A lot of immigrants find school to be a safe space, but other things not as must trust."

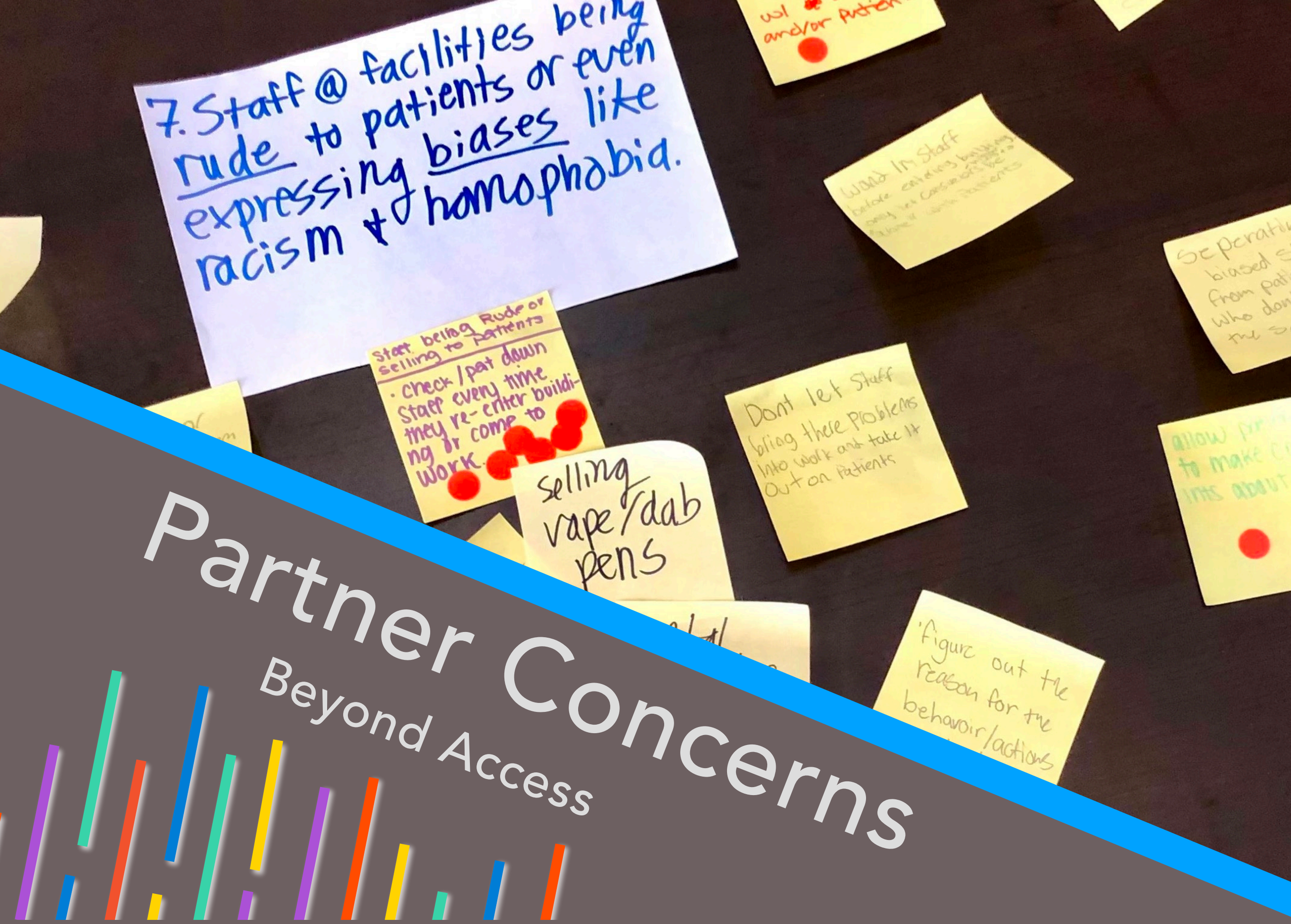
- Alonso, program supervisor, state agency

"I work at 3 schools all by myself, 2 middle schools and a high school, 120 kids in my case load…. They'll say to me, 'If I get caught, I'll see [about treatment]"…. From parents I'll hear, 'my 13-14 year old is not going.' I become ineffectual at that level."

- Julieta, school chemical dependency specialist

Partner Concerns

Beyond Access



41 Youth-generated post-its from co-design session at Sea Mar Visions Youth Treatment Center in Bellingham (August 15, 2022)

Do Big Good

Access to Physical and Emotional Safety

Youth asked for physical and emotional protections, both during first encounters and while in treatment.

 icon: created from Freepik elements

Protection from Bias in Treatment

Youth want a mediation-based response to staff bias.

Analysis

Youth are experiencing bias from staff while in treatment and requested that education and mediation-based protocols be put in place. The areas that youth would like staff to be trained in include “gender identity, sexuality, beliefs, slurs, and triggers”.

Youth also asked that staff be given mental health care themselves so as not to “bring their problems into work and take it out on the patients.”

Though all feedback we received was based on experiences in inpatient settings, we do not think that bias and emotionally insensitive care would necessarily be limited to those contexts.

Voices

"Racist...homophobic shit behind the door... clients can hear it."

- Raz, clinical social worker

“Separating staff from patients who don’t have the same beliefs.”

-Anonymous teen, current IP

“Give mental health to staff or patient, [such as] DBT, distraction, noise-cancelling headphones.”

-Anonymous teen, current IP

There was another staff member who “belittled” patients. She was rude, dismissive, and disrespectful.

- Nina, 22, recent IP

“Don’t let staff bring their problems into work and take it out on the patients.”

-Anonymous teen, current IP

“[Staff] education on gender identity, sexuality, beliefs, slurs and triggers”

-Anonymous teen, current IP

“If patient or staff has problem with each other, get a third party to mediate the situation.”

-Anonymous teen, current IP

“There should be mediation with staff present.”

-Anonymous teen, current IP

Protection from Physical Harm in Treatment

Youth feel physically unsafe in treatment and want staff pat-downs upon entry.

Analysis

One surprising finding of our co-design process was that youth in some inpatient settings feel so unsafe that they want staff to be patted down (or to go through a metal detector or the be wanded in) every time they entered the facility.

Their concerns seemed to be mostly based on contraband. For example, Luke (right) reported being in a facility where staff brought in dab rigs and vape pens "to keep patients calm". Another patient, Ari, expressed a concern about guns being brought into a facility. Another anonymous female teen patient did not want to be "alone" with staff, which was concerning. Patients also seemed not to be aware that they can report staff and/or do not know how to do so.

Voices

"One treatment center sold drugs to a client and had sex with clients."

- Raz, clinical social worker

"Don't prescribe patients controlling medication."

- Anonymous teen, current IP

Ari asked that metal detectors be added to the entrances of inpatient facilities to protect against staff entering with guns.

- Ari, 14, current IP

"Staff are selling vape and dab pens to keep patients calm."

- Luke, 15, current IP

"Allow patients to make complaints about staff."

-Anonymous teen, current IP

"Wand in staff before entering building. Only let counselors [and] higher-ups be 'alone' with patients."

-Anonymous teen, current IP

"Check/pat down staff every time they re-enter the building or come to work."

-Anonymous teen, current IP

 icons: Shmai, Dinosoft Labs

SUD Training for Police

Youth support Crisis Response Teams, but still want police to be better trained.

Analysis

On a check-in call in late July, HCA staff asked us to probe the question of Crisis Response Teams. We did so at our next youth co-design session at a drop-in center. While youth at that session — and others on this page — support alternate first responders, most still see a role for police. They just want them to be better trained in SUD care.

"I would say that our police department was very good about coming any time they were called and extremely skilled at de-escalating [my son]."

- Pam, parent

"Even police departments need to be better educated. [For example,] in that meeting a police chief said, 'we need Narcan for individuals on trank[uilizers].' I had to correct him: 'No, Narcan is not effective when on trank.'"

- Joseph, program manager, state agency

Voices

"I think both police and a crisis team would help."

-Tapehead, 24, drop-in center client

"How would we do that? Are police not trained? Would 911 be able to dispatch them properly? If I was high right now, how would I ask for a crisis team?"

- You, peer mentor

"Maybe it depends on the call.... It would help if police are trained different. It would help with the world."

- Anthony, 23, drop-in center client

"Depends on the situation... for violent situations, no."

- Brock, 22, drop-in center client

"PRIORITIZE SUD TRAINING FOR POLICE > CRISIS RESPONSE TEAM [and] COMMUNITY LED"

- Desmond, 21, in recovery

"[I want] patients' rights. Don't throw me in the back of a cop car."

- Kay, 18, drop-in center client

"Fear of calling the police."

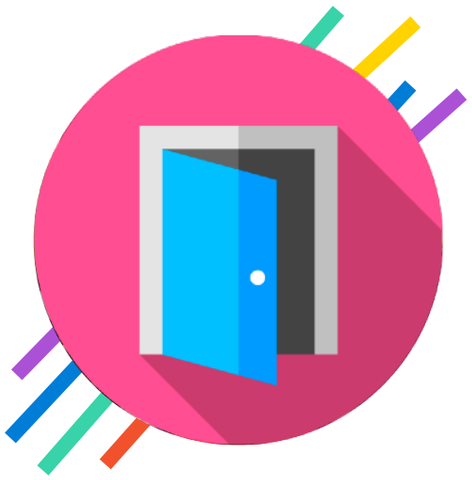
-Lila Love, 20, drop-in center residential client

Access During Recovery

Access to sober housing was a youth priority while providers and parents asked for better release planning.

icon: Flat Icons

Better Release Planning



Poor exit planning is seen as equally or more serious than access barriers.

Analysis

Although it falls on the opposite end of the continuum of care from access, so many young people and community members expressed concern about poor or absent release planning, that we felt we needed to include it. This was a particular problem for youth exiting inpatient treatment.

"Lack of communication + support when leaving [multi-month] treatment"

-Lila Love Love, 20, drop-in center resident

"Planning around getting out.... Cobbling together [a] release plan."

- Jeremy, outreach counselor

"They didn't help me with anything. Prison just threw me out there."

- Anthony, 23, drop-in center client

Voices

"We have spent a lot of time thinking about the front end. Still not good at it, but haven't even begun to think about the back end."

- Brenda, policy analyst, state agency

"What helped me get clean was IOP. I left with no resources from the psych ward. "

-Tapehead, 24, drop-in center client

"Maybe, assigning a peer mentor during the recovery process so that way they can build a bond for when the time comes for the client to get out."

- Desmond, 21, in recovery

"Failed transitions, no plan for afterwards."

-You, peer mentor

"[It's a] continuous journey. [I] still attend AA meetings and sponsor [and] work at AA.... The journey of treatment will be forever. There's no reason for stopping treatment."

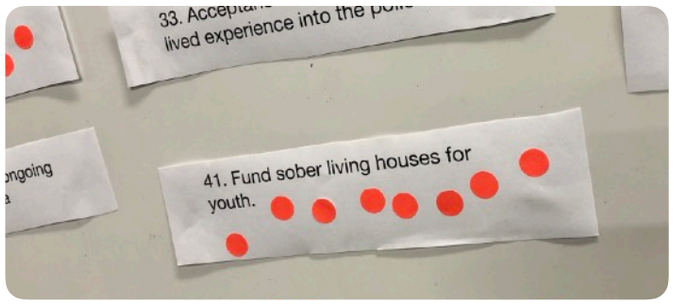
- Jesus Loves Me, 24, in shelter + recovery program

Sober Housing

The biggest post-treatment request is for housing.

Analysis

In solving the problem of transitions of care after release, the preferred solution was sober housing. This was the number one request emerging from youth voting (●) at New Horizons Ministries, a drop-in center in Seattle (photos right and on p. 3 and 19). Jeremy (right), an outreach counselor, envisioned a creative and therapeutic space, while Jesus Loves Me (right) appreciated the holistic approach of Comprehensive Life resources in Tacoma, which extended care far beyond her SUD and even helped her schedule an eye exam.



Voices

"After 30 days they kept me there 8 more times until my insurance stopped. My parents told them there was nowhere for me to come home to. I was dropped at the doorstep of [drop-in center] with no other info."

- Cat, 21, drop-in center client

"I don't want to return to my housing after this. Do you know any other options?"

- Luke, 15, current IP

People "support[ed] me with property to live on."

- Fox, 22, in recovery

"Clean and sober housing.. liv[ing] in [a] creative therapeutic environment before re-enter[ing] the home.... A lot don't have homes."

- Jeremy, outreach counselor

She went to Comprehensive Life Resources because of her own desire. It was not ordered.... The care was holistic, which she really appreciated. They even helped her schedule an eye exam.

- Jesus Loves Me, 24, in shelter + recovery program

Continuing the Work

By Amanda Lewis, HCA

49 Set-up for our third youth co-design session (Cocoon House, Everett, August 1, 2022)

Outline of Next Steps

As mentioned in the beginning of the report, the initial intent of this project was more narrow in scope. As the project progressed, the scope became more broad, learning from young adults that access can be defined and seen in many different ways.

Building on what we have learned in this project and adapting where needed, we must continue this important work, creating relationships and trust with youth and young adults and communities. Having this space of safety, trust and equal partnership that is meaningful, consistent, and innovative will be tremendously impactful. In order to have continuity in progress and partnerships, support from community leaders and participants is critical. This project appears to have resonated with participants, establishing rapport and a foundation for continued progress. We hope this initial project is just the beginning of reimagining access to treatment and supports with and for young people and their communities.

Continued Funding Beyond Federal Fiscal Year End (Sept. 30, 2022)

This project was fruitful, but very short in duration. It only scratched the surface. Participants felt very encouraged having space for open and honest dialogue, and for their voices to be heard. Community members also shared words of enthusiasm, being a liaison that supports youth and young adult engagement in such a unique and valuable way. We want to create change by centering and elevating young voices for years to come.

Proposed Outline for Next Steps:

We propose to facilitate community sessions and youth, young adult co-design sessions in six-month intervals with single topic areas, allowing us to take a deeper dive into specific access points and referral pathways. Having single areas of focus will allow us to be clearer and more direct in messaging materials to increase necessary partner involvement throughout each area and involve YYA who are engaged in each system.

Future Topics

Focusing on one area at a time will also help us to better understand barriers, gaps and needs, without diversion and competing topics. While sessions are being held during each six month period, continued outreach and messaging can be taking place in preparation for the next round. A report and summary would be produced annually as to the progress, outcomes and recommendations from sessions and continued work.

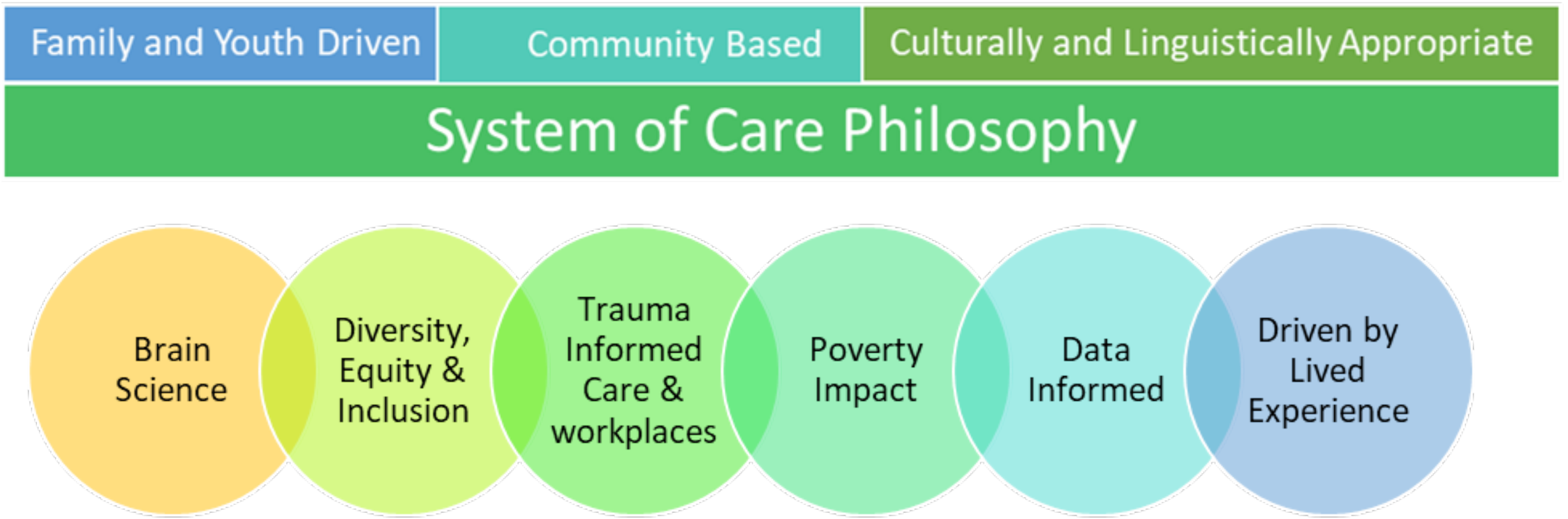
System, Pathway	Key Question	Youth Focus	Community Focus
Six-month intervals for each system pathway, including but not limited to the following groups:			
Education: Public Alternative Tribal schools Collegiate	What are the barriers for accessing behavioral health services for students?	School aged youth, students attending Tribal, alternative schools and college. Students with low attendance	Teachers, counselors, administrative staff, school based behavioral health professionals, Educational Service Districts (ESDs), security staff, ancillary supports such as housing, sports, clubs etc.
Juvenile Justice	What is working and not working in first encounters, diversion, and probation for YYA with SUD?	YYA who had a possession-related first encounter with law enforcement	Community detention, probation, law enforcement, Juvenile Rehabilitation, county courts

Future Topics...continued

System, Pathway	Key Question	Youth Focus	Community Focus
Six-month intervals for each system pathway, including but not limited to the following groups:			
Temporary Housing, Outreach	What are challenges for YYA receiving housing support in accessing behavioral health services?	Recipient of housing services	Short, long-term housing, drop-in centers, shelters
Health Care	What are the gaps in how YYA are identified and referred?	Have or have not received primary health care services during adolescence	Physicians, nurses, Health Care Authority, Managed Care Organizations, Office of the Insurance Commissioner (OIC)
Caring Adults, Friends, Self	What is missing so you or loved ones can effectively refer?	With or without social supports, have self-initiated	Friends, family, coaches, peers, supportive adults
Foster Care System	How effective is identification/ referral for youth in foster care?	Youth currently in foster care and young people who have aged out of foster care	Foster care parents, social workers, regional administrators, Dept. of Children, Youth and Families (DCYF)

Future Topics...continued

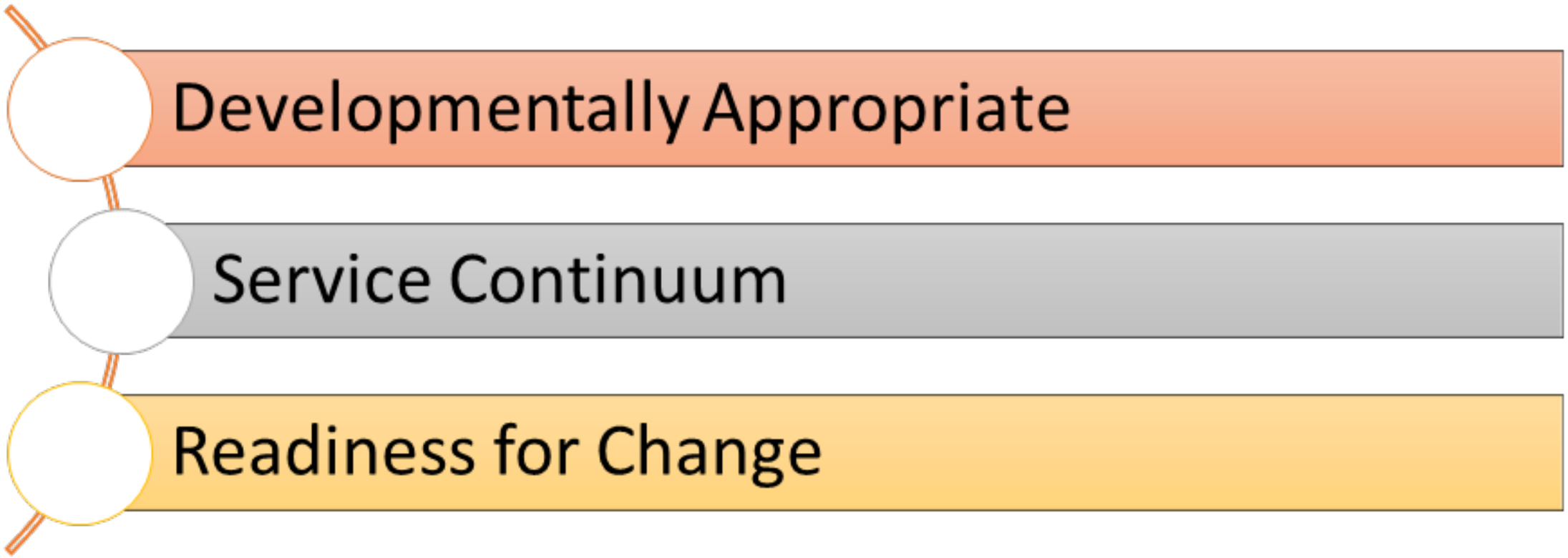
As we continue using a human-centered approach to system redesign we will ensure system of care values and philosophy are embedded throughout. We must also stay committed to improving and creating services and supports that have all the core elements needed to promote healthy lives.



We plan to have the Reimagining Access project and co-design with youth and young adults be a primary focus long-term means of improving substance use disorder access and treatment for young people and their families. Coordination and collaboration with workgroups such as the Children and Youth Behavioral Health Work Group (CYBHWG) and each of its subgroups is crucial in maintaining cohesion toward common goals and leveraging established cross-system efforts. We will also stay connected with other projects and programs within Health Care Authority that span from substance use disorder prevention and mental health promotion, across the Prenatal to 25 Behavioral Health Lifespan Section and Adult SUD section to encompass young adults.

Future Topics...continued

The effects of the COVID-19 pandemic have been felt throughout our lives, impacting our social, emotional and mental health, likely for years to come due to social and physical isolation, school closures, public health guidelines, limiting connection and access to care. It's more important than ever that we listen to YYA with lived experience and from diverse cultural backgrounds to reimagine access to care that is easily accessible, looks like help to a young person and meets their needs.



Thank You

Let’s continue our collaboration.

Project Team: Mer Joyce, Kayla Cody-Lushozi, Kathryn Shroyer, Elizabeth Berry, Jess Hernandez

Do Big Good

Do Big Good LLC is a co-design firm based in Seattle. We used human-centered design methods and social justice principles to help clients create transformative resources, policies, and strategies with their partners.

Contact // Mer Joyce // Founder and Principal // mer@dobiggood.com