Research Report

The Journey into Allegheny County's Substance Use Disorder Treatment System:

Using Human-Centered Design to Learn More About People's Experiences with Entering Treatment

November 2018

The Allegheny County
Department of Human Services
One Smithfield Street
Pittsburgh, Pennsylvania 15222

PHONE 412.350.5701
FAX 412.350.4004

www.alleghenycountyanalytics.us

TABLE OF CONTENTS

Introduction *2*

Background *2*

Project Goals *3*

How We Worked *3*

- Human-Centered Design *3*
- Phase 1: Inspiration *4*
- Phase 2: Ideation *5*

Key Insights *8*

- What We Learned: Consumer Insights *8*
- What We Learned: Provider Insights *11*

Next Steps *12*

APPENDIX A: Personas of People with Publicly Funded Substance Use Treatment System Experience *13*

INTRODUCTION

There are many reasons that a person may decide to take the first step to address unhealthy alcohol or drug use. Encouragement from family or friends, a recommendation from a health care professional, or a court referral can all motivate someone to access treatment. There are many challenges to taking the first step, however. National research suggests that lack of insurance, a shortage of available residential or outpatient treatment slots, anxiety about engaging in treatment, unfamiliarity with treatment options, or a fear that treatment will not work are barriers for many.[1] Additionally, social stigma, concerns about child care, and the perceived economic and time costs pose obstacles.[2]

The Allegheny County Department of Human Services (DHS) and its stakeholders wanted to learn more about the barriers that people face when trying to access publicly funded substance use disorder (SUD) treatment.[3] In the midst of the opioid overdose crisis, understanding ways to improve access to SUD treatment for people who might be at risk of an overdose is even more critical. To better understand the challenges people face, DHS used a human-centered design (HCD) approach in which interviews were conducted with a range of people, including those who had experience with the treatment system, family members and friends of people who had treatment experience, and staff who work in treatment programs. This report describes the process of gathering information about people's experiences, insights gained about the successes and challenges when accessing treatment, and next steps that DHS can take to respond to what we have learned.

BACKGROUND

In recent years, more than 14,000 people have encountered Allegheny County's publicly funded substance use disorder (SUD) treatment system for assessment, treatment and recovery supports.[4] Use of publicly funded SUD services has increased by approximately 15 percent since January 2015, when Medicaid was expanded in Pennsylvania and health insurance was made available to a larger number of citizens in the County.

1 Philip W. Appel, Ph.D., "Barriers to Enrollment in Drug Abuse Treatment and Suggestions for Reducing Them: Opinions of Drug Injecting Street Outreach Clients and Other System Stakeholders." *The American Journal of Drug and Alcohol Abuse*, Vol. 30, No. 1, pp. 147–152, 2004.

2 Jan Copeland, Ph.D., "A Qualitative Study of Barriers to Formal Treatment Among Women Who Self-Managed Change in Addictive Behaviours." *Journal of Substance Treatment*, Vol. 14, Issue 2, pp. 183-90, 1997.

3 This analysis focuses on the experiences of people receiving publicly funded SUD treatment only; people engaged in privately funded treatment services are outside the scope of this analysis.

4 These services are paid for by Community HealthChoices, i.e. Medicaid, or by DHS funds. Services are provided by contracted community providers.

Once a person decides to seek publicly funded SUD treatment, he or she is assessed by a licensed provider to determine what level of care (LOC) is needed. During the assessment, a set of guidelines called the Pennsylvania Client Placement Criteria (PCPC) is used to determine the need for treatment and the appropriate level of care for the person. The PCPC provides clinicians with a basis for determining the most appropriate care for people with SUDs while providing the best opportunity to efficiently utilize SUD treatment, intervention and other community resources.[5]

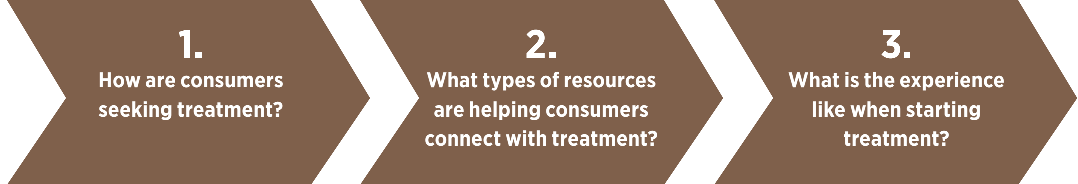
5 https://www.ddap.pa.gov/Manuals/PA%20Client%20Placement%20Criteria%20(PCPC)%20Edition%203%20Manual.pdf.

After the assessment has been completed, a person is referred for treatment, but not all people whose assessment recommends treatment ultimately enter into treatment.

PROJECT GOALS

The goal of this project was to describe how Allegheny County residents experience accessing and engaging with SUD treatment.

We concentrated our efforts to understand three specific components of treatment access and engagement:



HOW WE WORKED

Human-Centered Design

Human-centered design uses methods such as field interviews and observation to better understand behavioral, emotional and environmental contexts (depicted in the inspiration phase in **Figure 1**). Then, in the second phase, called ideation, the project team and/or stakeholders participate in synthesis sessions to translate these behavioral insights into concepts and then into prototypes, i.e., ideas are transformed into tangible things for further feedback. Finally, the prototypes become implemented into pilot initiatives in the third phase, implementation. This report describes how DHS used the first two phases of human-centered design (inspiration and ideation) to gather and summarize people's experiences with accessing substance use treatment.

FIGURE 1: Process phases in human-centered design

Phase 1: Inspiration

For this project, we undertook the initial phase in HCD, inspiration, by gaining insights about people's experiences with accessing SUD treatment. A team of DHS staff interviewed a total of 63 people, including 29 who were in treatment (also referred to here as consumers) or who were family members or friends of people who were in treatment, and 34 professionals (both administration staff and direct service staff). Respondents had a range of SUD system experience (e.g., no history, prior history, actively engaged in treatment), represented different geographic areas, and had varying demographics. Qualitative interviews were conducted by a team of at least two people in most cases. The interviews addressed topics such as challenges with seeking treatment, successes with seeking treatment, and suggestions and recommendations to improve the experience for people seeking treatment.

Examples of interview questions asked of people who had experience with SUD treatment personally or through a family member or friend:

- How did you learn about treatment?
- How did you get started with treatment for substance use?
- What was it like when you actually entered the treatment center or office?
- What will successful recovery look like for you?
- How might we make it easier for someone to access treatment?

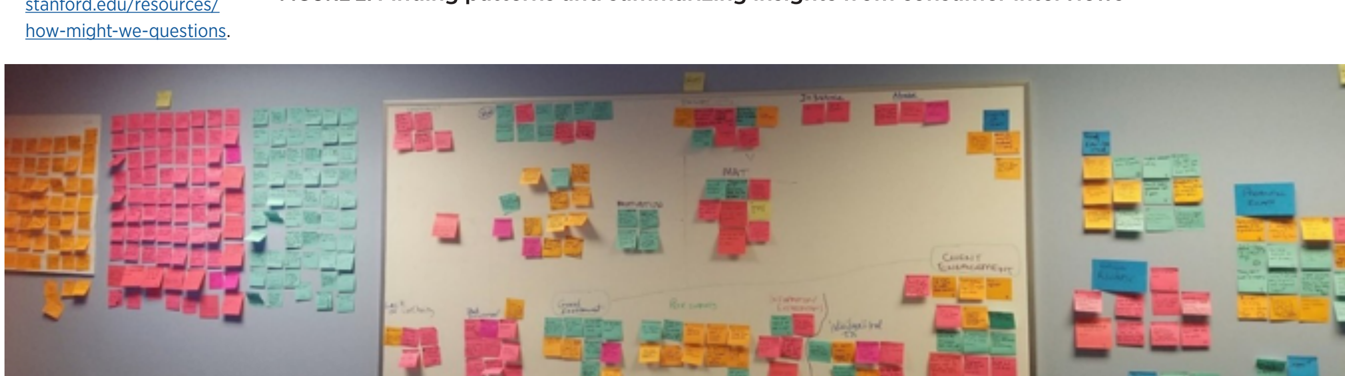
Examples of interview questions asked of people who had experience with SUD treatment as a professional:

- What types of services do you offer? What kind of information do you provide?
- Can you describe the typical steps in a treatment referral?
- What helps referrals be more effective? Do you see system gaps with referrals?
- What do you think could have the most impact for improving how people access substance use disorder treatment?

Phase 2: Ideation

After interviews were completed, we summarized our interview notes in synthesis sessions, reviewing what we learned[6] and capturing insights on Post-it notes. Then we looked for patterns and summarized the patterns into themes (see image below), insight statements, and "How-Might-We" questions.[7] In HCD, "How-Might-We" questions are then used in the implementation phase to brainstorm opportunities or potential solutions.

FIGURE 2: **Finding patterns and summarizing insights from consumer interviews**

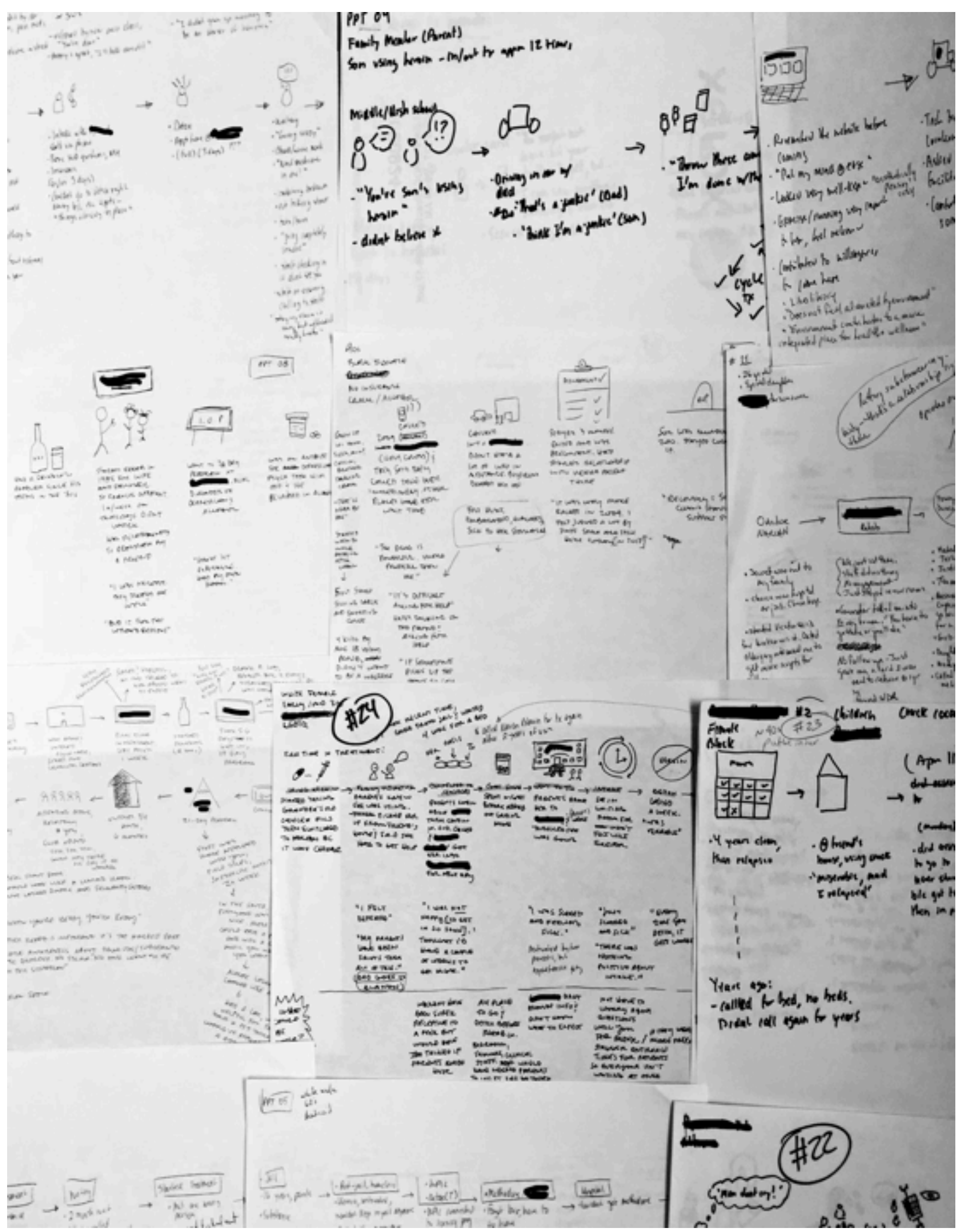


6 For more information on the Share and Learn process, see [this report], p. 23.

7 For more information on "How-Might-We" questions, see https://dschool.stanford.edu/resources/how-might-we-questions.

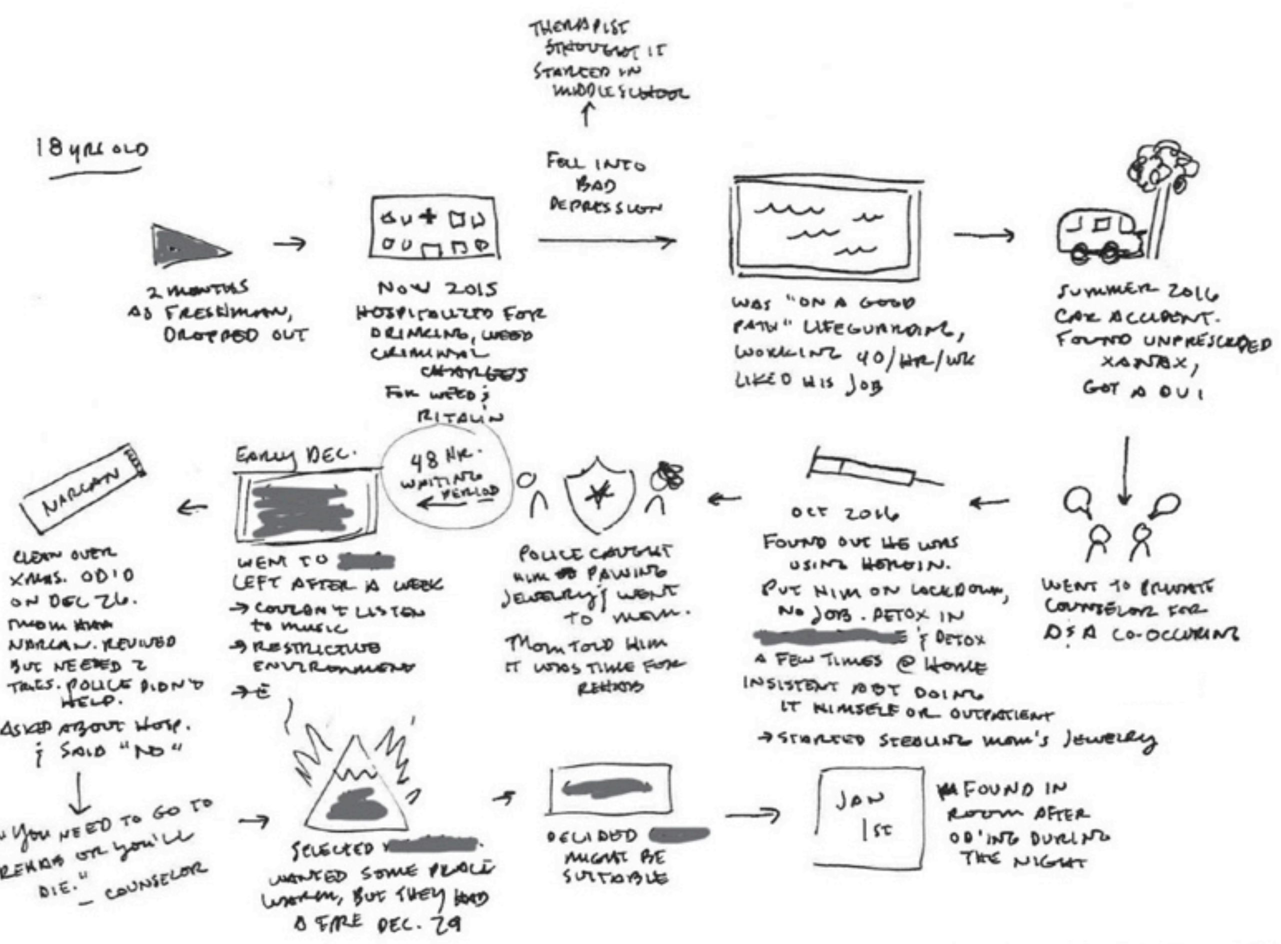
We then mapped 29 consumer experiences to understand what is working and what is not (**Figure 3**).

FIGURE 3: **Examples of consumer maps based on consumer interviews**



The following depicts one example of a journey map drawn by an interviewer. The 18-year-old subject declined into a dependence on opioids over a five-month period and passed away from a fatal opioid overdose, a few days before a planned second attempt at residential treatment.

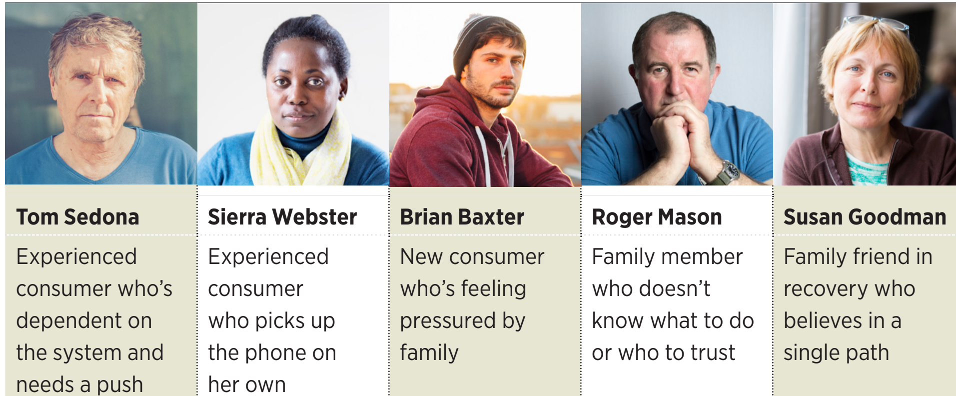
FIGURE 4: **One consumer's experience as depicted by an interviewer**



Insights gained from the synthesis sessions and experience maps were then used to create "personas,"[8] or aggregated representations of the people for whom we seek to design solutions, to help us understand the common pathways and barriers into publicly funded SUD treatment (**Figure 5**). Personas were created by compiling what we learned from interviews and observations in the field. These personas enable DHS and its partners to create different solutions for different kinds of people and to design for a specific somebody, rather than a generic everybody. See **Appendix A** for a full description of each of the five personas that were developed.

8 Note that personas do not represent individuals; rather, they use fictional names and are based on aggregated experiences gathered from interviews.

FIGURE 5: **Personas developed based on information gathered from interviews with consumers**



KEY INSIGHTS

Using observations from our interviews, synthesis sessions, experience maps and personas, we compiled our findings into insights from both consumers and providers and then used the insights to generate "**How-Might-We**" questions.

What We Learned: Consumer Insights

While we heard many joy points around seeking SUD services (caring staff that worked diligently to find services, families who worked to find resources, and superb providers who offered quick and quality SUD services), the insights below reflect opportunities to improve a system that is strained by additional demand due to the opioid crisis.

> **"I don't know who to trust."**
> — FAMILY MEMBER
>
> **"If he had cancer, I'd know what to do [for him]."**
> — FAMILY MEMBER

People "follow their hearts" to find treatment.

- Consumers and their families reach out to someone they trust in their personal and/or professional networks to get advice on where to seek treatment.
- They also seek out other resources by searching the internet, attending support groups, and relying on media representations.
- Information on SUD treatment is often hard to find, unreliable and biased.
- Informal and formal interventions by family and friends are frequent first touch points or referral sources into treatment.
- Friends and family members often seek advice from those more experienced on how to "hack" systems to get into treatment faster.

"HOW-MIGHT-WE" QUESTION(S):

How might we provide useful and trustworthy information to consumers and families as quickly and as simply as possible?

"I was afraid of getting sick, not knowing what to expect."
—CONSUMER

"[There is] a lack of willingness to go into treatment because of fear; [people] don't know what life will be like post-drugs."
—SUBJECT MATTER EXPERT

"I didn't know treatment would be so intense."
—CONSUMER

"I had no idea that 70% of people relapse after treatment."
—CONSUMER

First-time consumers don't know what to expect.

- Consumers have difficulty picturing a life of meaning or purpose without consuming drugs and alcohol.
- There is a lack of info and a lack of knowing what to expect.
- Treatment does not offer planning for success or failure.
- Consumers feel reluctant to have to start all over again when they get kicked out of treatment.
- Transitions to other levels of care are sometimes unplanned.

"HOW-MIGHT-WE" QUESTION(S):

How might we help consumers understand what the paths of recovery look like?

How might we increase education about treatment experiences among consumers?

"When you're an addict and go into treatment, it feels like you no longer have the right to make decisions."
—CONSUMER

"The ideal drop-in center should look like someone's living room."
—CONSUMER

"We need culturally appropriate and competent treatment that matches consumers with treatment that is right for that individual."
—SUBJECT MATTER EXPERT

Consumers want choices with their treatment.

- Consumers and providers both identify the need for more individualized treatment.
- There is a need for a better way to match consumer preferences with existing treatment options. Better matching leads to better initiation and engagement throughout treatment.
- Important treatment center attributes include geography, being family-friendly, having convenient hours, being gender- or LGBTQ-friendly, having a non-sterile environment, matching people of similar age, having physical exercise facilities, offering holistic care (e.g., yoga) and being pet-friendly.
- Balancing consumer treatment preference with timely placement is a challenge.
- Treatment plans should be individualized and more person-centered.

"HOW-MIGHT-WE" QUESTION(S):

How might we better connect consumers to a treatment setting that is personalized to their needs and preferences?

"Only mental health basics taught in Master-level programs, nothing on chronic or co-morbidity."
—SUBJECT MATTER EXPERT

"My doctor never knew about my substance use."
—CONSUMER

"If the screener identifies a problem, our people are not equipped to help."
—SUBJECT MATTER EXPERT

"Child welfare workers aren't trained to notice signs of drug use."
—SUBJECT MATTER EXPERT

"Now means now."
—CONSUMER

"I was going completely insane during [the] two-week waiting period."
—CONSUMER

"Make treatment on-demand, like an Uber call."
—CONSUMER

"Make people feel like they're getting help as soon as they call."
—CONSUMER

"Send materials, get started now."
—CONSUMER

Workforce development challenges create missed opportunities for assessing and referring people to substance use treatment.

- Missed opportunities are present across various health and human service settings such as jail, health care and child welfare.
- Limited staffing (medical, behavioral, addiction) is a barrier to providing integrated addiction care.
- Staff knowledge, attitudes and behaviors can negatively impact a consumer's engagement with treatment.

"HOW-MIGHT-WE" QUESTION(S):

How might we improve workforce development to reduce missed opportunities?

When consumers are seeking help, they are experiencing both physical and emotional pain, which may cause them to lose motivation to enter treatment.

- When consumers seek help, they want and need it immediately.
- Both consumers and family members received limited support and information during the waiting period.
- Treatment staff lose contact with consumers during the waiting period, and this results in high no-show rates.

"HOW-MIGHT-WE" QUESTION(S):

How might we reduce the hardships for consumers and families while waiting for treatment?

Staff engagement is critical early on and includes showing consumers and families empathy while providing helpful information.

- High staff turnover inhibits continuity of care and results in consumers having to retell their story again and again.
- Consumers want to be seen, heard and respected.
- Positive aspects of staff engagement include staff showing that they care or showing empathy, providing good information, and checking in with progress. Staff's genuine interest in consumers' recovery process enhances consumers' commitment to their treatment and recovery.

"HOW-MIGHT-WE" QUESTION(S):

How might we facilitate more person-centered care?

"We have compassion for other diseases, why not addiction?"
—FAMILY MEMBER

"I'm used to getting kicked. You kick, I'll kick you back… re-establish connection, respect, don't hurt, and treat like a human being."
—CONSUMER

"Love heals."
—SUBJECT MATTER EXPERT

"Successful engagement is 'Let's make this important to you.'"
—SUBJECT MATTER EXPERT

"Hope then hoops."
—SUBJECT MATTER EXPERT

"Sell a person on their goals and values, not their disease state."
—SUBJECT MATTER EXPERT

What We Learned: Provider Insights

In our conversations with system professionals, we discovered the following insights:

Staff training, licensure and turnover present challenges for effective treatment.

- Gaps in knowledge, attitudes and skills are present among health and human services providers. These gaps are barriers for getting people into SUD treatment efficiently and effectively.
- Maintaining a skilled workforce is a challenge for providers.
- The majority of consumers receiving substance use treatment have co-occurring mental health issues, and many providers want to treat both; however, issues around workforce and licensure are barriers.
- Providers are becoming more accepting of medication-assisted treatment (MAT) an option.
- Regulations on privacy are a barrier to organizations serving their consumers.

"HOW-MIGHT-WE" QUESTION(S):

How might we ensure that staff/providers are adequately prepared to provide effective treatment to consumers?

A provider's outreach, engagement and after-care plans can all affect people's willingness to begin and stay in treatment.

- Consumer readiness is a barrier to getting help.
- As people wait for treatment, they may lose motivation, or may binge, overdose or self-medicate using street drugs.
- Peer supports can build a "trust bridge" for consumers by helping address basic needs and facilitate consumer readiness for treatment.
- Discharge from detox or rehabilitation is often poorly planned and not person-centered.
- Connection to after-care resources (e.g., recovery housing, meetings, peers) is a critical aspect of SUD treatment.
- Providers want to take consumer preferences into account, but there is a delicate balance between expressed needs and clinical judgment.

"HOW-MIGHT-WE" QUESTION(S):

How might we improve provider interactions with consumers to encourage initiation and adherence to treatment?

Using these provider insights, we identified potential opportunities, including:

- The expansion of peer services (additional training, funding)
- Opportunities to increase staff trainings (including a workforce survey on skills and beliefs)
- Setting new standards for providers around co-occurring disorders, recovery-oriented systems of care and customer service
- Creating a coordinated process for users who are entering the SUD system
- Advocating for reduced licensure/policies around behavioral health privacy and co-occurring behavioral health needs
- Opportunities to increase awareness about SUD services availability and preferred pathway to access SUD services

NEXT STEPS

Our next step in advancing this critical work will be conducting community design workshops where consumers, families, treatment staff and administrators will convene to brainstorm and prototype solutions to some of the overarching issues we found in accessing treatment for substance use disorders in Allegheny County. We are hoping to collaborate with community stakeholders and conduct the workshop(s) later in the year to brainstorm potential design solutions, which may include creating concepts or prototypes to test out and get further feedback. The design workshops might focus on one of the "How-Might-We" questions above, such as "How might we improve information to friends and family members seeking substance use services?" or "How might we reduce the hardships for consumers and families while they are waiting for care?" As it plans for future workshops, DHS can also learn from and build on other human-centered design projects being conducted in the region, such as the design workshop around overdose prevention that was conducted by Smallify in conjunction with the Allegheny County Health Department, Pittsburgh City Police, DHS and community stakeholders.

CONTRIBUTORS
Emily Ianocone, Peter Jhon, Mike Mitchell, Alison Wolfson, Erin Dalton

REVIEWERS
Robert Burack, Kelley Kelley, Abby Wilson

APPENDIX A: PERSONAS OF PEOPLE WITH PUBLICLY FUNDED SUBSTANCE USE TREATMENT SYSTEM EXPERIENCE

Note: These personas use fictional names and aggregated information in order to provide typical experiences of people accessing treatment.

TOM SEDONA

Experienced Consumer Who's Dependent on the System and Needs a Push

Motivation

INTRINSIC: *Feeling miserable*

EXTRINSIC: *Family and friends, provider staff*

The first time I got treatment was because my wife pressured me into it. Most recently, I was encouraged to go back into treatment from a group of family and friends when they came together to talk to me about their concerns. After this meeting, I asked a friend of mine for a referral and followed up with that treatment provider.

Needs

- Help me get my mental health issues under control
- No one judging me
- Assistance with my basic needs, such as housing, health insurance, food assistance
- Some guidance about existing treatment options

Attitudes

- "I went first for my wife and kids, but that was a mistake."
- "All you get is the misery, none of the high."
- Having had multiple treatment experiences, he knows what he wants and what he needs and is eager for professional assistance.

Opportunities for DHS

- Integrated co-occurring care with medication and counseling from a psychiatrist
- Better screening and referral by human services providers for substance use disorders
- Resource guide about available treatment options

Appendix A
(continued)

SIERRA WEBSTER

Experienced Consumer Who Picks Up the Phone on Her Own

Motivation

INTRINSIC: *Being exhausted*

EXTRINSIC: *Losing a good job and benefits, her kids*

The first time I entered treatment, I initiated it on my own. I found out about treatment through a Google search. When I experienced a relapse, I called my previous treatment provider for guidance because I had a positive experience there last time.

Needs

- More education around relapse triggers and coping mechanisms
- To be able to receive treatment while working and caring for my kids
- Immediate action when I reach out for help

Attitudes

- "Asking for help is hard. If someone picks up the phone to call you, you need to treat it like a crisis."
- "I grew up watching everyone in my family use crack, and I said that would never be me."
- Not open about emotional needs and vulnerabilities

Opportunities for DHS

- Create a relapse plan with her treatment provider.
- Connect her to a treatment provider that can meet her needs related to location, work schedule and child care responsibilities.
- Find or provide a safe place for her to stay while she detoxes if treatment isn't immediately accessible.

Appendix A (continued)

BRIAN BAXTER

New Consumer Who's Feeling Pressured by Family

Motivation

INTRINSIC: *Having purpose*

EXTRINSIC: *Parents and getting a job / finishing school*

The first time I went to treatment, I was forced into it by my parents. They asked a friend of a friend for a treatment referral. Most recently, I went to treatment on my own after I got into some legal trouble. I did a Google search to find a place that looked like a good fit for me.

Needs

- Some information on what I can expect with treatment, recovery
- Treatment that is fitting for me — around people my own age and addiction experience
- For my family to better understand addiction and recovery

Attitudes

- "I can't picture a life for myself without drugs."
- "Those old guys at rehab got to have all the fun before they got clean."
- "Therapy isn't a cure for my addiction. My group is. I go on Friday nights because that used to be my big party night, and I want to have something to do with people my age during that time."

Opportunities for DHS

- Family resources for understanding substance use disorders and recovery
- Better mechanism to match him to a provider that can accommodate his personal preferences
- Road map setting expectations about multiple clinical paths to recovery
- Recruitment of younger peers

Appendix A
(continued)

ROGER MASON

Family Member Who Doesn't Know What to Do or Who to Trust

Motivation

INTRINSIC: *Seeking solutions*

EXTRINSIC: *Helping his daughter find recovery*

When my daughter was arrested with heroin in her possession, my wife and I felt overwhelmed and like failures as parents. We searched the internet for rehab facilities, but they wanted $50,000 for private pay. Luckily, I remembered my neighbor's kid went to rehab, and I got the name of a place we could afford. I've tried community support meetings, but they don't help much.

Needs

- Social resources to support Roger and his wife
- Professional guidance to understand addiction and recovery and available treatment options
- Engagement strategies for their daughter as well as good community education

Opportunities for DHS

- Connection to a support group for families with new consumers
- A single and comprehensive website tailored to multiple audiences including new users
- Family-specific resources about substance use disorders, including information about engagement, treatment and harm-reduction strategies

Appendix A (continued)

SUSAN GOODMAN

Family Friend in Recovery Who Believes in a Single Path

Motivation

INTRINSIC: *Her personal recovery experiences*

EXTRINSIC: *Role as a community convener*

In recovery for alcohol misuse, Susan has helped link many friends, family and community members to treatment facilities. While she can navigate and hack systems adeptly to help others access treatment, she tends to rely on the same path and same providers which, generally, do not include an option for medically assisted treatment (MAT). She is a strong community presence.

Needs

- A greater understanding of multiple treatment paths/options
- Better coordination from first responders, community leaders, families and treatment professionals
- Immediate resources after identifying a consumer in need of treatment

Opportunities for DHS

- More formal training around multiple paths/multiple providers, including a better understanding of MAT
- Can serve as convener of multiple stakeholders
- A place for first responders to call or take someone that isn't jail