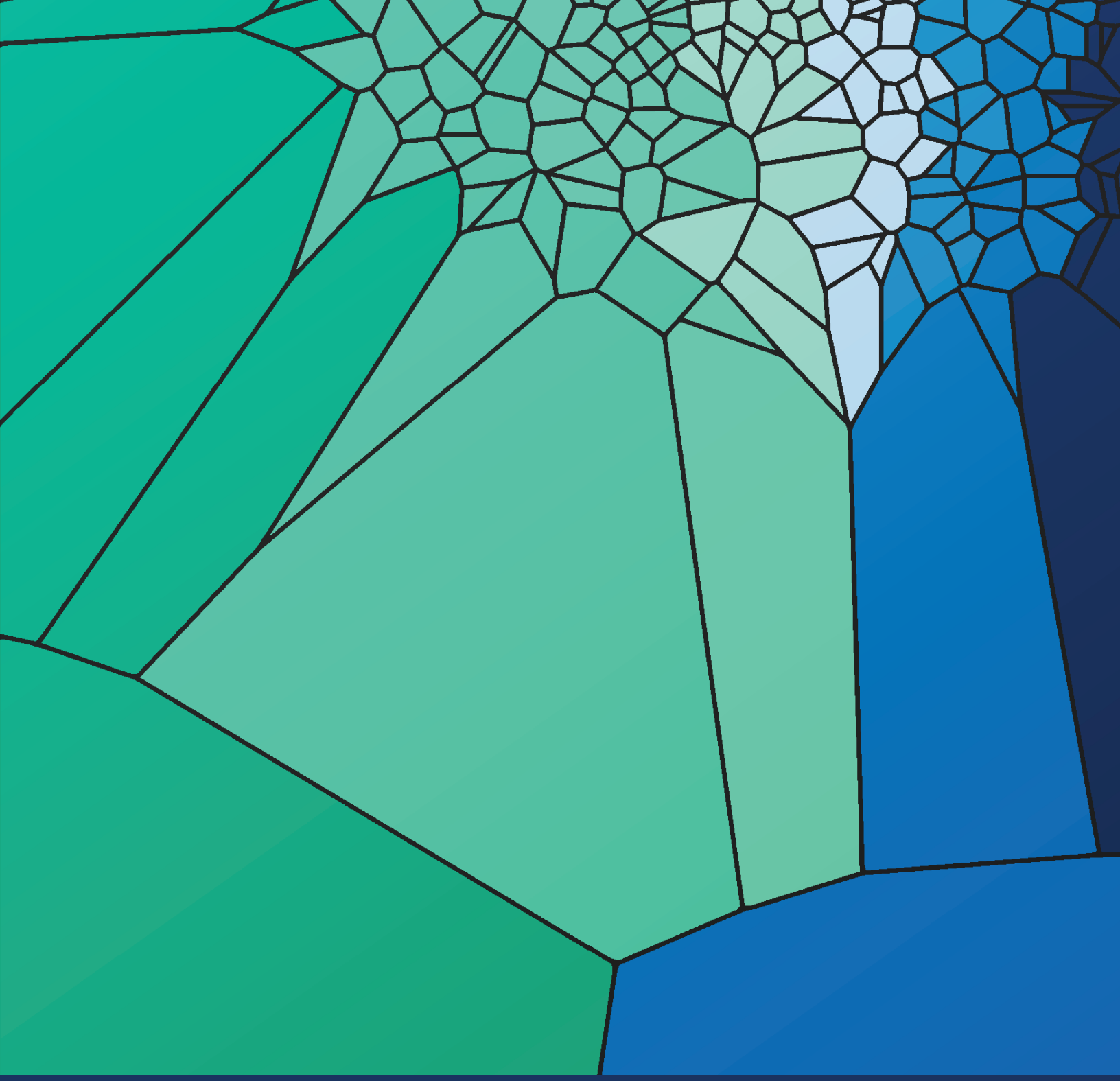

Understanding Barriers to SUD Treatment in Kentucky from the Consumer Perspective

College of Medicine
Department of Behavioral Science

Center on Drug and Alcohol Research

Acknowledgments

PREPARED BY:

Michele Staton, Martha Tillson, TK Logan, Jennifer Cole, & Allison Scrivner

University of Kentucky,
Center on Drug and Alcohol Research,
Department of Behavioral Science,
College of Medicine
333 Waller Avenue, Suite 480
Lexington, KY 40504
http://cdar.uky.edu/bhos

Corresponding Author:
Michele Staton, PhD, MSW
mstaton@uky.edu
(859) 312-8245

SUGGESTED CITATION:

Staton, M., Tillson, M., Logan, T., Cole, J.& Scrivner, A. (2023). *Understanding Barriers to SUD Treatment in Kentucky from the Consumer Perspective.* Lexington, KY: University of Kentucky, Center on Drug & Alcohol Research.

Acknowledgments: Special thank you to Casey Baker and Hope Tevis for their coordination of data collection activities for this project, and Martha Tillson for mixed methods data analysis. Also, a huge thank you to the interview team who assisted with study data collection: Madeline DeJesus, Misty Boyington, Mary Levi, Meghan Walker, Shawn Jamison, Jaxin Annett, Carrie Knight, Hope Sloan, and Martha Tillson. Also, a special thank you to the qualitative transcription team: Katrin Flores, Shawn Jamison, Jaxin Annett, Olivia Johnson, Martha Tillson, and Casey Baker.

Executive Summary

Background

Even though treatment for substance use disorders (SUD) can provide a number of benefits and advance recovery, there are many reasons people may not begin or stay in treatment once they start. The goal of the Consumer Survey Project is to learn more about the facilitating factors and barriers associated with entering substance use treatment from individuals who have either recently thought about treatment and decided not to go, or entered treatment and dropped out. The Consumer Survey Project included the following primary objectives: (1) understand the restrictions and barriers at the program level that discourage treatment entry and/or engagement from the perspectives of individuals with SUD; and (2) explore personal barriers to treatment related to SUD program entry or dropout. This project, the Consumer Survey Project (i.e., Project 3), was one of four research projects undertaken by UKCDAR in 2023 to document the barriers to SUD program entry and engagement.

Method

This mixed methods study used in-depth interviews consisting of both open-ended and close-ended responses with 62 diverse consumers who had thought about but did not enter a SUD program (41.9%) or consumers who had entered a SUD program and then dropped out (66.1%) in the past year to understand program and personal barriers to SUD treatment. Study measures, recruitment approaches, and overall procedures were informed by (1) The SUPRA Survivors Union of the Bluegrass, a community advisory board of individuals engaging in active use convened through the HEAL initiative, to provide feedback on community-based research projects, (2) a prior study of provider perceptions of barriers (Logan et al., 2018), and (3) the KTOS, RCOS, and CJKTOS studies. Study recruitment flyers were distributed broadly in Lexington, Kentucky and surrounding areas (e.g., Georgetown, Richmond), as well as statewide through existing project staff networks (including social media pages). Flyers were hung in public places (e.g., grocery stores, gas stations), as well as specifically targeted in recovery communities (e.g., Voices of Hope, self-help and SMART meeting areas). The study link was also highlighted in radio spot ads. The flyers included a QR code to access a website for interested individuals to get information about the study.

Individuals who accessed the website were able to complete an online screener to assess study eligibility, which was broadly defined as individuals in Kentucky (1) who self-report drug use and have recently considered treatment but not gone; or (2) who have recently dropped out of a SUD treatment program. Individuals who completed an online screener and were assessed to be eligible for the study were then scheduled for a phone interview. The study screener was active from March 1, 2023 to June 2, 2023. During this time, 263 completed an online screener, 135 were assessed as eligible following the validity screening check, and 62 completed the phone-based interview.

Results

Consumer Survey Project participants were mostly White (83.9%) and slightly more than half were women (56.5%). They were on average about 38 years old, half (56.1%) were employed in the past year, and the majority (88.7%) had a history of incarceration. The study sample was diverse with representation from participants who lived outside the metropolitan counties of Fayette and Jefferson (40.3%).

Consumer survey results are divided into four main sections including: (1) Substance use history; (2) SUD treatment utilization and entry barriers; (3) SUD treatment retention and barriers; and (4) SUD treatment-related needs.

Section 1 of this report describes participant need for treatment based on histories of substance use. Participants had extensive histories of substance use and reported regularly using alcohol for an average of 10.4 years and illicit drugs for 19.2 years. Self-reported drug use in the past year included marijuana (54.8%), methamphetamine (53.2%), and opioids (33.9%). About two-thirds (69.4%) of the sample reported past year symptoms consistent with a DSM-5 SUD diagnosis, with 59.7% of those falling in the "severe" SUD category of 6+ symptoms.

Section 2 describes participants utilization of treatment and recovery resources, and highlights noted barriers to ***treatment entry***. Consistent with the study recruitment plan, most participants had a history of inpatient/residential treatment (82.3%), with most of those individuals attending two or more times. Other treatment modalities commonly visited by study participants included outpatient or intensive outpatient programs (75.8%) and recovery housing or sober living programs (64.5%). Qualitative analysis of participant responses revealed four primary themes with regard to reasons for why individuals chose to enter SUD treatment: (1) being tired of the cycle of addiction; (2) losing everything; (3) having legal system involvement; and (4) attempting to preserve or reconcile relationships.

Findings also indicated that about 42% of respondents thought about entering treatment in the past year but ***decided not to***. The most common barriers to entering treatment included personal reasons (88.7%) such as having to take off work (59.7%) and shame/embarrassment (54.8%). Other barriers included program and resource barriers (87.1%). Examples of these types of barriers included the program being located too far away from where they lived or the requirements for entry being unreasonable (such as having to have a negative drug screen at treatment entry), as well as resource barriers such as being able to access safe and affordable housing. Concerns were also raised related to program quality (75.8%) such as fears of exploitation, limited structure, and limited diversity, as well as mention of programs not adapting to fit the needs of clients (67.7%). These barriers were consistent when clients were asked to share in their own words which barriers were most challenging to enter SUD treatment. Qualitative content analysis of responses indicated that participants believed the primary barriers to SUD treatment included: (1) limited personal resources such as lack of transportation; (2) responsibilities at home and work; (3) fear of losing or compromising relationships; (4) limited motivation or readiness to change; and (5) perceptions of program limitations to provide the help they need.

Section 3 discusses participants' perceptions on barriers associated with ***staying in treatment***. Nearly two-thirds (66.1%) reported dropping out of a treatment program in the past year. Similar to noted barriers for treatment entry, the majority of participants (90.3%) noted personal barriers to staying in treatment, with the most common barrier being having to take off work or endangering their employment (64.5%). Another commonly noted barrier to staying in treatment was that other participants did not take it seriously (59.7%). Other barriers were noted at the program level (75.8%) including requirements being hard to maintain or difficulty making appointments, as well as resource barriers (82.3%) such as access to safe and affordable housing and meeting basic needs. Other concerns were related to program quality (87.1%) and programs failing to adapt to meet client's needs (79.0%).

Qualitative data analysis helped to further explain these findings with participants noting key concerns such as perceptions of staff as unprofessional, having interpersonal issues with other clients in the programs, unreasonable treatment expectations, challenges associated with program logistics, being separated from family or loved ones, and a general lack of interest or commitment to treatment. Participants also described perceptions of program exploitation, which may be perceived as barriers to staying in treatment. These included feeling like they were exploited or taken advantage of (67.7%), programs keeping clients after they wanted to leave (62.5%), having to recruit other clients into the program (52.5%), and feeling like the program sacrificed treatment quality for financial gain (50.0%).

Section 4 describes other specific health and behavioral health needs discussed by participants that could have an impact on treatment entry or retention. About two-thirds of study participants reported having an ongoing chronic health condition (66.1%), and more than half (54.8%) reported taking medication on a regular basis for a physical health problem. In addition, the majority of study participants (75.8%) reported ongoing mental health issues like depression or anxiety, and more than half (56.5%) reported taking medication for mental health concerns. The majority (83.9%) also reported some form of maltreatment (abuse or neglect) before the age of 18.

Conclusions and Recommendations

Overall findings of this Consumer Survey Project highlight the significance of personal and program level barriers for individuals entering, engaging, and/or staying in SUD treatment programs. There is a lack of research on facilitating factors and barriers associated with treatment entry and retention for individuals who have thought about treatment and decided not to go or who have entered treatment and dropped out. This study addresses these gaps and contributes to a greater understanding of treatment barriers and experiences among individuals living in Kentucky.

Survey findings noted a number of barriers at the ***personal*** level for both entering and staying in SUD treatment. Commonly noted barriers included employment and feeling like their job would be threatened by taking the time off for treatment. Considering a number of individuals may have obligations to stay employed (e.g., probation &

parole, family needs), it is important for treatment programs to be flexible to accommodate work responsibilities. These responsibilities may also be significantly impacted by noted resource barriers such as being able to secure safe housing, meeting basic needs, transportation, and being able to feel safe. Other barriers included being able to maintain contact with family, friends, and children during the time they were in treatment. Since none of these noted barriers are likely to occur in isolation, it is likely that individuals feel a tremendous burden when considering entering treatment and still being able to meet their daily responsibilities. The obligations for single parents are even more challenging with having to delegate care of their children to someone else, or perhaps even being involved with Child Protective Services. Even though the consumers discussed generally having access to publicly-funded treatment, limits imposed by insurance and costs associated with treatment were mentioned as barriers.

Consumers also noted a number of barriers at the ***program*** level (such as maintaining strict regulations, program quality) and within the broader treatment system. Consumers noted specific concerns related to program quality and being able to adapt the program to fit the needs of specific clients. One example is individuals in the criminal justice system. While not a targeted recruitment criteria for the study, most (88.7%) reported lifetime history of incarceration, and 37.1% were incarcerated in the past year. Tailoring treatment to meet individuals' needs related to justice-system involvement is critical, particularly with regard to maintaining flexibility for meeting their responsibilities, as well as their unique treatment needs. In addition, a high percentage of clients reported mental health issues, history of abuse and neglect, and ongoing chronic health concerns, all of which may require certain specialized or unique forms of adaptations for treatment programs to consider. In addition, potential concerns were raised related to perceptions of program quality and program exploitation by treatment clients. Consumers in this study had very positive things to say about working with peer support specialists and recognized that they provide a unique understanding of the experience of addiction, as well as pathways toward recovery.

Since none of these noted barriers are likely to occur in isolation, it is likely that individuals feel a tremendous burden when considering entering treatment and still being able to meet their daily responsibilities.

A number of ***recommendations*** are forwarded in response to survey findings. Survey results shed light on the need to: (1) educate clients on what to expect regarding different treatment approaches including the time and expectations of continuing care, as well as any additional costs; (2) review state-level auditing procedures to ensure staff also have viable outlets to discuss any concerns related to exploitation, mistreatment, and misconduct; (3) increase program flexibility to respond to the individual needs of clients to potentially facilitate treatment engagement and reduce dropout; (4) increase program adaptation for special needs such as criminal justice involvement and mental health; (5) consider changes to SUD staff training, support, and supervision for program staff, as well as considering initiatives to incentivize expansion of SUD clinical

workforce; (6) support public campaigns aimed at reducing stigma, positive messaging about people in recovery, public education about recovery outcomes and pathways; and (7) expand peer support specialists' roles broadly in treatment venues including those focused on criminal justice and mental health issues with an eye to improving any potential concerns with treatment quality.

Table of Contents

List of Tables

Background

Although treatment for substance use disorders (SUD) can provide a number of benefits and advance recovery, there are many reasons an individual might not begin treatment or stay in treatment once they start. The goal of this Consumer Survey Project is to learn more about the facilitating factors and barriers associated with entering substance use treatment from individuals who have either recently thought about treatment and decided not to go, or entered treatment and dropped out. The survey included the following primary objectives: (1) understand the program level restrictions and barriers that discourage treatment entry and/or engagement from the perspectives of individuals with SUD; and (2) explore personal barriers to treatment related to SUD program entry or dropout. This project, the Consumer Survey Project (i.e., Project 3), was one of four research projects undertaken by UKCDAR in 2023 to document the barriers to SUD program entry and engagement.

Method

Study measures, recruitment approaches, and overall procedures were informed by the SUPRA Survivors Union of the Bluegrass, a community advisory board of individuals engaging in active use convened through the HEAL initiative, to provide feedback on community-based research projects. Procedures and measures were also informed by a prior study examining provider perceptions of barriers (Logan et al., 2018), and the KTOS, RCOS, and CJKTOS studies. Study recruitment flyers were distributed broadly in Lexington, Kentucky and surrounding areas (e.g., Georgetown, Richmond), as well as statewide through existing project staff networks using social media. Flyers were hung in public places (e.g., grocery stores, gas stations), as well as specifically targeted in recovery communities (e.g., Voices of Hope, self-help and SMART meeting areas). Flyers were also targeted to certain areas (e.g., Latino neighborhoods, college campuses) and facilities (e.g., health department syringe exchange programs, domestic violence shelters) in order to try to increase diversity of the sample. The flyers included a QR code linked to a website for interested individuals to get information about the study. The study link was also highlighted in radio spot ads that ran during the month of May (2023) on eight different radio stations.

Individuals who accessed the website or called in to the study phone line were able to complete an on-line screener to assess study eligibility. Initial screening data was downloaded each morning using LimeSurvey and assessed for initial eligibility which included: (1) being resident of Kentucky, (2) having recently dropped out of a treatment program OR reported a recent substance use problem and thought about entering treatment but did not; and (3) interested in being contacted and were assessed to be eligible for the study. Individuals who completed an on-line screener and assessed to be eligible were then scheduled for a phone interview. Study enrollment was open from March 1, 2023 to June 2, 2023. During this time, 263 completed an online screener, 135 individuals were eligible, and 127 were scheduled for the phone-based interview. As shown in Table 1, primary methods of study referrals included word of mouth, flyer distribution, and radio spot ads.

The primary reasons that individuals were not eligible after screening included not meeting the SUD treatment or treatment drop out criteria (62.5%) or not residing in Kentucky (16.4%). In order to increase validity of the online screening procedures, staff also administered an additional screening prior to conducting the interviews. An additional 12 people were excluded from phone-based data collection based on the validity screening (due to giving inconsistent responses from the original screening).

Of the remaining individuals who were eligible based on screening procedures, 47 were non-responsive to UK staff reaching out to schedule interviews (27 were not responsive at all, and 20 individuals were scheduled with repeated unsuccessful attempts to complete the interview). If no interviews were scheduled within 2 two weeks following at least three tracking efforts, the participant was considered non-responsive. In addition, 4 individuals refused participation following consent and 22 were not able to be scheduled in time before closing study enrollment.

TABLE 1. STUDY SCREENING AND REFERRALS

	N
Screeners submitted	263
Referral source	
Word of mouth	127
Flyer	73
Location (e.g., Voices of Hope)	23
Radio	22
Social media	17
Not Eligible	128
Not in KY	21
Not interested or no contact info given	8
Duplicate entry	7
Doesn't meet dropout or SUD treatment criteria	80
Failed validity screener	12
Eligible	135
Not scheduled/completed before close of data collection	22
Non-responsive	47
Refused	4
Completed interviews	62

During the three months of study data collection, 127 appointments were scheduled with potential study participants. The no-show/cancellation rate was 52.2%, which significantly impacted the number of completed interviews during this short window of data collection. Reminder calls or texts were sent either the evening before or the morning of the appointment. Phone-based interviews were conducted with 62 participants at the number they provided during screening. Participants were paid $50 for their time either through an Amazon gift card or check (depending on their preference).

Structured in-depth interviews with both open-ended (qualitative) and close-ended (quantitative) responses were conducted via phone using OpenPhone (a secure web-based phone system), and with the permission of the participants, interviews were recorded for transcription of qualitative responses. Quantitative data was entered into the secure University of Kentucky web-based REDCap portal, and downloaded into SPSS for analysis. Qualitative responses were transcribed by research staff, and downloaded into ATLAS.ti (v.9.1.7) for qualitative analysis.

Demographic Information

As shown in Table 2, the sample was mostly White (83.9%), and slightly more than half identified as women (56.5%). The sample did include representation from individuals living outside the major metropolitan areas with 40.3% reporting living in counties other than Fayette or Jefferson at the time of the interview. The majority of study participants reported lifetime incarceration (88.7%), and on average, their most recent incarceration occurred about 41.7 months ago. In addition, 37.1% reported being incarcerated in the past year, with an average of 21.4 nights incarcerated in the past year. This sample was overall fairly involved with the criminal legal system with an average of 13.9 times arrested and charged with a crime, and the longest incarceration period on average was 14.1 months.

TABLE 2. INTERVIEWS COMPLETED BY DEMOGRAPHICS

	Men (n=27)	Women (n=35)	Total (N=62)
Race			
White	23 (37.1%)	29 (46.8%)	52 (83.9%)
Black/African American	1 (1.6%)	5 (8.1%)	6 (9.7%)
Hispanic/Latinx	1 (1.6%)	0 (0%)	1 (1.6%)
Unknown	2 (3.2%)	1 (1.6%)	3 (4.8%)
Young adult (18-25)	0 (0%)	2 (3.2%)	2 (3.2%)
Identifies as LGBTQIA2S+	1 (1.6%)	7 (11.3%)	8 (12.9%)
Non-metro (vs. metro) residence*	12 (19.4%)	13 (21.0%)	25 (40.3%)
Ever incarcerated	25 (40.3%)	30 (48.4%)	55 (88.7%)
Incarcerated any nights in past ear	15 (24.2%)	8 (12.9%)	23 (37.1%)

**Note: "metro" defined as residence in Jefferson or Fayette counties.*

Participants were also 38.2 years old on average (range 20 – 55, median = 39), 43.5% were single (never married), 80.6% reported having children (66.1% had children under the age of 18 and 24.2% had children living with them in the past year), 79.0% reported at least a high school diploma or GED, and 51.6% reported being employed either full time or part time in the past year (with the majority working in the service industry). Additionally, 50.0% reported being homeless at some point during the past year and 33.9% reported living either on their own or with friends/family.

All participants (100%) reported having health insurance in the past year (88.7% Medicare/

Medicaid), but a high percentage (75.8%) reported difficulty meeting at least some basic living needs in the past year, and 44.3% reported difficulty meeting basic health care needs in the past 12 months.

Results

Consumer survey results are divided into four main sections including: (1) Substance use history; (2) SUD treatment utilization and entry barriers; (3) SUD treatment retention and barriers; and (4) SUD treatment-related needs.

Section 1. Substance Use History

As expected, study participants reported high prevalence of lifetime problem alcohol (e.g., use to intoxication and/or binge drinking; 75.8%) and illicit drug use (95.2%) in their lifetime (See Table 1.1). Participants reported initiating alcohol use on average at 13.2 years old, and using alcohol regularly for 10.4 years. In addition, they reported using illicit drugs for the first time at 14.3 years old, and using regularly for an average of 19.2 years.

TABLE 1.1. PERCENT REPORTING LIFETIME ALCOHOL AND ILLICIT DRUG USE

Used alcohol to intoxication or binge drank *(5 drinks for men, 4 drinks for women)*	75.8%
Used THC/marijuana such as smoking pot, edibles, etc.	96.8%
Used illicit drugs or prescription drugs for nonmedical reasons	95.2%
Injected any drugs	72.6%
	Mean
Age of first alcoholic drink *(more than a sip)*	13.2
Years of regular alcohol use	10.4
Age of first illicit drug use	14.3
Years of regular illicit drug use	19.2
Age of first injection drug use (n=45)	25.6

As shown in Table 1.2, in the past 12 months, 32.3% reported alcohol use to intoxication and 27.4% reported binge drinking. The most common illicit drugs used in the past year included marijuana (54.8%), methamphetamine (53.2%), and opioids (including prescription opioid misuse and heroin, 48.4%). Of those who reported drug use in the past year, the most common primary drug of choice was methamphetamine (36.4%) and heroin (18.2%). In addition, most participants reported cigarette use (88.7%) or use of e-cigarettes (72.6%) in the past month, and smoking or vaping on most days in the past 30 (28.1 days of cigarette use, 21.8 days of e-cigarette use).

TABLE 1.2. PERCENT SELF-REPORTING ALCOHOL AND ILLICIT (NOT PRESCRIBED) SUBSTANCE USE IN THE PAST 12 MONTHS

Smoked cigarettes or other tobacco products	88.7%
Used electronic nicotine delivery systems (e.g., e-cigarettes, vape)	72.6%
Marijuana (e.g., hashish/pot)	54.8%
Methamphetamine	53.2%
Any opioids	48.4%
Opiates/opioids, analgesics, pain killers not prescribed for you	33.9%
Heroin	33.9%
Subutex®/Suboxone® or buprenorphine that was not prescribed for you	16.1%
Alcohol	45.2%
Used alcohol to intoxication	32.3%
Problem alcohol use or binge drinking	27.4%
Cocaine/crack	27.4%
Gabapentin or Neurontin	22.6%
Sedatives, hypnotics, muscle relaxants, or tranquilizers not prescribed for you	17.7%
Stimulants not prescribed for you other than methamphetamine	17.7%
Hallucinogens/psychedelics	14.5%
Barbiturates not prescribed for you	8.1%

In addition to past-year alcohol and illicit substance use, a number of participants reported issues associated with their use which were consistent with DSM-5 criteria for a substance use disorder (SUD; see Table 1.3). About two-thirds (69.4%) met criteria consistent with DSM-5 SUD diagnosis by meeting at least 2 criteria (mean = 8.5 symptoms, median = 10.0, mode=11.0). Specifically, 6.5% met mild SUD criteria (2-3 symptoms), 3.2% met moderate SUD criteria (4-5 symptoms), and 59.7% met criteria consistent with severe SUD (6+ symptoms). Of all study participants who reported drug use in the past year (n=44), only one did not meet criteria of at least 2 symptoms.

TABLE 1.3. PERCENT REPORTING ISSUES CONSISTENT WITH DSM-5 SUD CRITERIA IN PAST 12 MONTHS

Felt craving or strong desire or urge to use drugs or alcohol	58.1%
Continued substance use in spite of physical or emotional problems related to drugs or alcohol	58.1%
Used drugs or alcohol in larger amounts or over a longer period of time than you planned	56.5%
Continued using drugs or alcohol even though you had ongoing social or personal problems related to your drug or alcohol use	53.2%
Repeatedly used drugs or alcohol in situations where it was physically dangerous	53.2%
Been unable to meet expectations in school or at home because of drug or alcohol use	51.6%
Given up social, educational, or recreational activities because of drug or alcohol use	51.6%
Had an ongoing desire or been unable to cut down or control drug or alcohol use	50.0%
Found you spent a great deal of time on activities necessary to obtain, use alcohol or drugs, or to recover from their effects	48.4%
Physical dependence, as evidenced by	59.7%
Had withdrawal effects when not using drugs or alcohol	58.1%
Used drugs or alcohol to relieve or avoid withdrawal effects	54.8%
Physical tolerance, as evidenced by	61.3%
Had a need for greater amounts of drugs or alcohol to get the same effect	48.4%
Had a weaker effect from continued use of the same amount of drug or alcohol use, like building up a tolerance	59.7%

In addition to issues consistent with SUD among study participants, 67.7% reported at least one lifetime non-fatal overdose that required intervention by someone to recover, and 27.4% reported overdosing in the past 12 months.

In addition to issues consistent with SUD among study participants, 67.7% reported at least one lifetime non-fatal overdose that required intervention by someone to recover, and 27.4% reported overdosing in the past 12 months.

Summary

Consumers interviewed for this study had a long history of substance use and the most common illicit drugs used in the past year included marijuana (54.8%), methamphetamine (53.2%), and opioids (including prescription opioid misuse and heroin, 48.4%). A majority of participants met criteria for SUD in the past year, and two thirds (67.7%) reported experiencing a non-fatal overdose in their lifetime.

Section 2. SUD Treatment Utilization and Entry Barriers

Considering substance use patterns among consumers in this survey, it is important to examine their utilization of formal and informal treatment and recovery resources. Treatment was conceptualized primarily as SUD treatment, but it is recognized that a number of participants engage in broader health service utilization, which may also provide venues to address substance use.

As shown in Table 2.1, consistent with other research, participants in this study reported high rates of lifetime emergency room utilization (95.2%), hospitalization (77.4%), and other doctor visits (88.7%). A surprisingly high number of participants also reported seeking out resources in their lifetime for substance use from other types of venues including mental health counselors, family/friends, self-help meetings, websites, and shelters. Among those who reported lifetime use of certain services or resources, use in the past 12 months was also relatively high.

TABLE 2.1. PERCENT SELF-REPORTING LIFETIME AND PAST 12 MONTHS UTILIZATION OF GENERAL TREATMENT AND RECOVERY RESOURCES

	Ever	Past 12 months
Emergency room	95.2%	62.9%
Hospitalization overnight	77.4%	19.4%
See a doctor but not through the ER or hospital	88.7%	72.6%
See a mental health provider/counselor	87.1%	75.8%
Stay in a homeless shelter	45.2%	14.5%
Stay in a domestic violence shelter	12.9%	4.8%
Talk to someone at a hotline/crisis line	33.9%	11.3%
Talk to a SUD program for information	74.2%	58.1%
Talk to a SUD counselor about your use of substances	85.5%	67.7%
Seek information about a SUD program on a website	46.8%	40.3%
Seek information about substance use recovery on a website	64.5%	51.6%
Talk to friends or family about your substance use	91.9%	87.1%
Talk to friends or family about going to SUD treatment or program	82.3%	71.0%
Talk to someone online about SUD programs/treatment	41.9%	30.6%
Talk to someone online about your use of substances or recovery	38.7%	33.9%
Talk to your clergy, pastor, someone from church about your use of substances	43.5%	25.8%
Talk to a coworker about your use of substances	46.8%	37.1%
Talk to a supervisor/boss about your use of substances	41.9%	32.3%
Go to self-help meetings such as AA, NA, SMART, MARA, or Celebrate Recovery	90.3%	85.5%
Talk with a sponsor such as through AA/NA	74.2%	61.3%
Used medication or other things to stop smoking	33.9%	25.8%

While study participants indicated reaching out to a number of general resources for SUD support, they also reported a fairly involved history of specific SUD treatment modalities, which was expected based on study inclusion criteria. As shown in Table 2.2, most participants had a history of inpatient/residential treatment (82.3%), with most of those individuals attending two or more times. Other treatment modalities commonly visited by study participants included outpatient or intensive outpatient programs (75.8%) and recovery housing or sober living programs (64.5%). Most participants who engaged in treatment reported initiating the treatment two or more times.

Most participants had a history of inpatient/residential treatment, with most of those individuals attending two or more times. Other treatment modalities included outpatient or intensive outpatient programs, and recovery housing or sober living programs.

TABLE 2.2. PERCENT REPORTING LIFETIME AND PAST 12 MONTHS SUD TREATMENT

SUD treatment utilization	Ever	Times (lifetime*)	Past 12 months
Inpatient/residential	82.3%	13.7% one time 86.3% 2+ times	51.6%
Outpatient or intensive outpatient (IOP)	75.8%	30.4% one time 69.6% 2+ times	58.0%
Recovery housing ("sober living")	64.5%	52.5% one time 47.5% 2+ times	58.1%
Medication for opioid use disorder	62.9%	28.2% one time 71.8% 2+ times	54.8%
Medical detox	58.1%	36.1% one time 63.9% 2+ times	35.5%
Prison or Jail Substance Abuse Program (SAP)	37.1%	47.8% one time 52.2% 2+ times	4.8%
Recovery program (e.g., Recovery Kentucky)	30.6%	52.6% one time 47.4% 2+ times	17.7%
Transitional housing	30.6%	73.7% one time 26.3% 2+ times	25.8%
Group home for adults who use substances	9.7%	50.0% one time 50.0% 2+ times	8.1%

** Note: number of times calculated for those who reported entering treatment*

Participants were asked to describe, in their own words, the primary reasons why people choose to go to substance use programs or treatment. Qualitative analysis of participant responses revealed four primary themes: (1) being **tired** of the cycle of addiction; (2) **losing everything**; (3) being involved in the **legal system**; and (4) attempting to preserve or reconcile **relationships**.

Many participants described feeling exhausted or **tired** with the endless effort required to sustain the cycle of addiction. Responses reflected that participants were:

- *"tired of the way I was living"*
- *"tired of living in their same repetitive lifestyle"*
- *"tired of running all the time"*
- *"tired of the monotony of addiction day-in and day-out struggles, trying to get high"*

Participants also recognized that, in addition to being tedious and draining, the work required to maintain active addiction had no positive long-term outcomes. As one participant stated:

- *"I didn't want to die, you know? I finally had enough."*

Other participants described **losing everything** as a strong motivation for entering substance use treatment, particularly when they had reached the point of homelessness. Participants stated:

- *"Sometimes it's [going to treatment] just to have a place to go."*
- *"Some people may go just for the benefits, because the drugs have strung them out to the point where they don't have anything, so they may pursue treatment based on a place to stay, food, housing, things for that reason."*

> ***"'Rock bottom,' of course, varies from person to person. In my case, being homeless and not being able to go back to family because I'd burned those relationships so many times."***
>
> - CONSUMER SURVEY PARTICIPANT

Meeting these types of basic needs may be a critical initial step before an individual can meaningfully engage in SUD treatment services.

Many participants believed that the most common motivation for entering SUD treatment was due to involvement with the **legal system**. One respondent indicated:

- *"[Some participants could be] forced to go; like a lot of people have to go, you know, for… CPS or for their probation."*

Other participants might request to be sent to treatment in the hopes that it would *"get the courts off their back"*, or if incarcerated, they could ask for treatment *"just to get out of jail, to be honest"*.

Several participants cited the legal/court system as *"the biggest reason"* individuals in Kentucky sought treatment, especially younger individuals, who may not yet have an extensive legal history or time in active addiction.

Lastly, several participants discussed **relationships** as another important motivator for SUD treatment initiation, stating:

- *"they do it for their loved ones"*
- *"to get their families back"*

Ties to family members can become damaged, strained, or severed during active addiction, and individuals may desire to repair those relationships. Illustrating this, one participant said:

- *"I just got tired of… having my family turn its back on me because I had done screwed them over so many times."*

Relationships with children and the desire to be active parents were mentioned by several participants:

- *"If they're not ready to do it for themselves, sometimes children give that extra push."*

> ***"I was tired of being down and I want better for myself. I want better for people that love me—drugs just always been there for me. And I could go to rehab and I could get out and there is drugs. If I go home there is drugs. If I go anywhere, to my friends, anywhere, there is drugs. So I've got to come to a decision in my life, to come to terms about me, and I need better for myself and the ones that really does love me."***
>
> - CONSUMER SURVEY PARTICIPANT

However, some respondents clarified that individuals who entered treatment solely to satisfy pressure from family would not ultimately be successful – that they had to also want it for themselves.

In general, participants felt like SUD treatment "worked" often (30.6%) or most of the time (22.6%). Participants were also asked some open-ended questions related to individual outcomes after treatment: how they might know if a treatment program has "worked," or if a person is "successful" after treatment, and whether they think SUD treatment "works" in general. As described below, findings indicated that success depends on an individual's commitment to change, as well as indicators of positive changes other than just sobriety.

Efficacy of SUD treatment depends on an individual's commitment to change. Rather than pointing to features of programs or services, participants overwhelmingly agreed (87%) that "success" after treatment rests on a person's desire to live a different life. Participants noted:

- *"It's up to the individual whether they want to stay clean. It'll work if they want it. I mean it – the program is one hundred percent, and it's guaranteed to work, but it's not going to work if the person's attitude ain't set for it."*

- *"They have to have willingness to do it, definitely. 'Cause they don't want to do it, they're not going to do it –and they actually have to want to be sober, because anywhere, you can go to any treatment center and be clean for 'X' amount of days and just get out and lose everything you learn."*

Success after treatment is most often defined by abstinence from drug and alcohol use, but also includes other dimensions of positive change. Almost all participants mentioned "sobriety" or "abstinence" when asked how they would know if an individual was successful after treatment. However, many participants also offered examples of other positive outcomes that indicated an individual had been "successful," such as employment or family relationships:

> ***"I would gauge it on their quality of life…abstinence being a key component to that, but not necessarily basing it on, like, perfection in sobriety… I think that anything is successful that you feel like you're in a better place than you were when you entered. I think any growth is better than no growth."***
>
> - CONSUMER SURVEY PARTICIPANT

- *"They usually have a job, and they have their family back; they have their family life, they're with their kids and wife or husband."*
- "*They're productive members of society… they contribute to their communities."*
- [They] *"help other addicts or alcoholics."*

Individuals may display positive physical changes, as well; one participant mentioned that:

- *"Sometimes you just see them you don't even recognize them because they look so healthy."*

Finally, participants noted a marked difference in mental health when individuals were *"successful"* after treatment. As one respondent said,

- *"You can just see how happy they are… you can see, like, this little light in them smiling… when before you didn't see that."*

While a number of participants had entered formal SUD treatment programs in the past year, 41.9% also indicated that they had thought about entering treatment in the past year, but decided not to. As shown in Table 2.3, the program most commonly considered was inpatient/residential treatment (17.7%), and overall percentages across programs were relatively low. In other words, there was no dominant program most individuals considered entering, instead they considered an array of types of programs.

TABLE 2.3. PERCENTAGE OF INDIVIDUALS IN THE PAST 12 MONTHS WHO THOUGHT ABOUT ENTERING ANY KIND OF TREATMENT PROGRAM BUT DID NOT ENROLL

Any treatment program	41.9%
Inpatient/residential	17.7%
Recovery housing ("sober living")	16.1%
Outpatient or intensive outpatient (IOP)	12.9%
Medication for opioid use disorder *(e.g. buprenorphine, methadone, naltrexone)*	11.3%
Medical detox	6.5%
Recovery program (Kentucky Recovery)	6.5%
Transitional housing	6.5%
Group home for adults who use substances	3.2%
Prison or Jail Substance Abuse Program (SAP)	1.6%

Participants reported a number of specific challenges related to entering SUD treatment programs. As shown in Table 2.4, the majority of participants (88.7%) noted personal barriers to entering treatment, with the most common barrier being having to take off work or endangering their employment (59.7%). More than half (54.8%) noted issues of embarrassment or shame, and 51.6% also noted that being with other clients in treatment who do not take it seriously is a barrier. Participants (87.1%) also noted a number of barriers to entering treatment related to both program barriers and resource barriers. Examples of these types of barriers included the program being located too far away from where they lived or the requirements for entry being unreasonable (such as having to have a negative drug screen at treatment entry) and resource barriers such as access to safe and affordable housing.

About three-quarters (75.8%) reported barriers related to program quality such as concerns about program exploitation, limited professionalism or knowledge among staff, and limited program structure. About two-thirds (67.7%) of participants reported barriers related to adaptability of programs such as matching the needs of clients to the program, limited options for trauma-informed care, and limited options for self-help beyond AA or NA. About half (53.2%) reported barriers to accessibility of treatment related to costs and insurance coverage.

TABLE 2.4. PERCENT OF INDIVIDUALS WHO NOTED THAT THE FOLLOWING WERE BARRIERS TO ENTERING TREATMENT

Personal barriers	**88.7%**
Employment; being able to leave work and go to treatment	59.7%
Embarrassment or shame	54.8%
Some clients in some programs are not serious *(e.g., they are mandated to be there or only there for the shelter part of some programs not the recovery part)*	51.6%
Stigma for seeking treatment	43.5%
Childcare—making sure children are cared for while in treatment	40.3%
Legal issues; or fear of legal issues	38.7%
Involvement with the criminal justice system	37.1%
Pet care	24.2%

TABLE 2.4. PERCENT OF INDIVIDUALS WHO NOTED THAT THE FOLLOWING WERE BARRIERS TO ENTERING TREATMENT (CONT.)

Program and Resource Barriers	**87.1%**
Program barriers	77.4%
Program or treatment is too far away from where you live	48.4%
Criteria for treatment *(for insurance purposes)* is too strict (*e.g., having to be at a certain point in withdrawal)*	48.4%
Requirements for entry or staying in the program were unreasonable	41.9%
Ability to see a therapist or counselor quickly	41.9%
Paperwork burden	32.3%
Difficulty making or getting an appointment	27.4%
Resource barriers	75.8%
Access to safe and affordable housing	61.3%
Difficulty meeting basic needs *(e.g., food, clothing)*	54.8%
Transportation to treatment	51.6%
Concern for personal safety; Not feeling safe in seeking or engaging in treatment	33.9%
Lack of options other than AA/NA	43.5%
No or limited support for SUD program/treatment or SUD recovery	41.9%
Finding specialized treatment for people with disability needs *(e.g., hearing impairment, other physical or mental disabilities)*	37.1%
Finding specialized treatment for marginalized individuals *(e.g., minorities, sexual orientation)*	35.5%
Lack of harm reduction treatment options *(e.g., needle exchange)*	32.3%
Accessibility barriers	**53.2%**
Limits imposed by insurance	48.4%
Cost of treatment	37.1%

As shown in Table 2.5, the average number of reported barriers to entering treatment differed slightly between individuals identifying as men or women. Specifically, while not statistically significant, women reported slightly higher rates of all noted barriers with the exception of program accessibility barriers which, were very similar.

TABLE 2.5. NUMBER OF BARRIERS TO ENTERING TREATMENT NOTED BY MEN AND WOMEN

	Men (n = 27)	Women (n = 35)	Total (N = 62)
Personal barrier	3.0	3.9	3.5 (range 0 – 8)
Program barrier	2.1	2.6	2.4 (range 0 – 6)
Resource barrier	1.7	2.3	2.0 (range 0 – 4)
Accessibility barrier	0.8	0.9	0.9 (range 0 – 2)
Program quality barrier	3.0	4.4	3.8 (range 0 – 8)
Adaptability barrier	2.2	3.4	2.9 (range 0 – 7)

Participants were asked to share, in their own words, what they thought were some of the reasons that an individual might think about treatment for substance use but never

actually go. Consistent with a number of the reasons noted in Table 2.4, qualitative content analysis of responses indicated that participants believed the primary barriers to SUD treatment included: (1) individual resources such as lack of transportation; (2) responsibilities at home and work; (3) fear of losing or compromising relationships; (4) limited motivation or readiness to change; and (5) perceptions of program limitations to provide the help they need.

Personal resources were mentioned as a significant barrier for many who may wish to enter SUD treatment. Several participants mentioned lack of transportation, most often needed to attend ongoing appointments through outpatient providers, but also to get to a residential or inpatient program. Other participants mentioned a lack of insurance or money for self-pay services, or individuals not having their own phones to call programs or receive call-backs. Without access to these types of resources, individuals may struggle to even make initial steps towards accessing treatment services. One participant explained:

- *"Transportation is usually – when people are on drugs, they don't have a way to get around; they probably don't have licensed transportation. They probably don't have a current residence to live… this is the basic necessity to get yourself back in order… they might not have health insurance, you know, or have a means to pay for it or any way to get started just trying to get in."*

However, individuals who may have those resources – housing, employment, insurance – may still face different barriers to SUD treatment: the **responsibilities** of maintaining rent or mortgage, car payments, other bills, and employment may be a strong deterrent against entering a treatment program. In addition to the fear of losing resources (e.g., house, car) as a consequence of entering treatment, the inability to support oneself while in treatment was described as a challenge. Participants noted:

- *"The treatment programs don't provide all of your needs… not just for hygiene, but also cigarettes and things like that, because most people that come into treatment are cigarette smokers… it is very stressful when you're forced to provide for yourself, but you're not able to work."*

- *"A lot of times, like the treatments I've been to… they don't let you go out to work. So then you leave treatment and you're in a financial hole. You're already in one when you go in anyways, but then you come out and you're usually in a bigger one than what you came in already in."*

Relationships were mentioned by a number of participants as a barrier to treatment entry. Discussions about relationships were complex enough to warrant analysis by additional subthemes.

Many participants mentioned family responsibilities as a major barrier to treatment entry, particularly children, but also included caretaking of parents or older family members. One participant explained:

- *"It's just so impractical. They're [the treatment programs are] so far away, your kids don't have care, maybe you have pets or you're caring for other family members… I can't just excuse myself from my life."*

Building on a previous theme, participants were not just concerned about losing resources for themselves, but also for others who depended on them.

Other participants described fear of isolation from family and friends as a barrier. Not only did they feel responsible for loved ones, but many respondents did not want to lose the supportive contact of their networks. Participants noted:

- [they feared] *"being cut off from like the whole outside world."*
- another was concerned that *"I was gonna miss out on something."*

These feelings of separation can be compounded by contact restrictions in early phases of some programs, as described by one participant:

- *"A lot of residential treatments, like when you first go in, you can't talk to your family… you can't have your personal cell phone. Those things are deterrents, too."*

> ***"There's nobody here to take my place, so if I go to treatment it's like a hole in my household, big hole in my household. And that goes on for as long as I'm gone."***
>
> - CONSUMER SURVEY PARTICIPANT

Some participants mentioned separation from a partner/spouse as being another relational barrier to treatment. Specific comments included:

- *"Some places don't accept couples… the number one or number two barrier to getting treatment is having a significant other that they're attached to and not wanting to leave behind."*
- *"Me having to go by myself is a big one [barrier]… my wife can't go with me… telling me that I'm not allowed to tell my wife 'I love you.'"*

Although not all romantic partnerships in active addiction may be healthy ones, the significance of these relationships to individuals considering treatment must be acknowledged.

Finally, an important aspect of relationships as a barrier to treatment is grounded in individuals' perceptions of stigma, shame, and embarrassment related to their drug use. Many participants had tried to hide their drug use in the past and had worried that others might think of them or treat them differently; as one participant said:

- *"The stigma of it, how people will judge you; 'oh, he's a drunk or she's a drunk or lush' or whatever term you want to use… you might have been able to hide that a little better sometimes, but if it gets out then they'll obviously have issues."*

Seeking treatment can have particularly serious consequences for parents, who may not only feel stigmatized for their struggles with SUD, but also face involvement with Child Protective Services (CPS). One participant noted:

- "*If you have kids and stuff, you don't want other people to know your addiction, you're still trying to hide it…You don't want to lose your kids or something, that's like a big fear.*"

Finally, although SUD is a chronic condition, some individuals may still feel shame at relapse as a "failure". One participant said:

- "*Well, when I when I relapsed, I went back to the rehab I just graduated from and it was a little you know…like, little embarrassing. Like, man, I don't want to do this over again, you know?*"

In addition, many participants discussed internal barriers to entering treatment, namely **motivation/readiness to change**. Some participants described that individuals often just were not ready; as one said:

- *"They don't want to; they don't want to stop using. I think that's the biggest barrier, is that they enjoy it."*

> ***"Now that I have three children, it is very daunting to think about – not only leaving them [to attend treatment], but also then being on the radar for CPS or DCS, just because you're struggling to cope… Your entire identity can end up wrapped up in that decision [to use drugs], when you know that it doesn't mean that you're a bad mom…I think that stigma is the biggest barrier."***
>
> - CONSUMER SURVEY PARTICIPANT

Some participants described feeling less motivated out of a sense of fatalism, that it would be impossible to stop using:

- *"Even if you went to treatment,"* one participant shared, *"and you did want to do something better, a lot of times you have to get out and go back to the environment that you came into and you came out of."*

However, many participants believed that lack of readiness for treatment was often grounded in fear:

- *"Fear of change – when you're so used to using drugs, it's…it's hard. It's a fear of change. It's not comfortable."*

Some respondents mentioned specific fears, such as experiencing withdrawals or fear of legal consequences (e.g., having warrants). For others, though, readiness could be hindered by not wanting to become someone different. One participant stated:

- *"For a lot of people with substance use disorder, I think that there's a fear of getting well too. Like, who would I be without this?"*

Program characteristics were mentioned by several participants as a reason that

individuals might not enter SUD treatment. Some participants mentioned negative things that they had heard or experienced about treatment as deterrents, such as programs *"scamming people"* or not calling individuals back for intakes (*"they not answering their phone calls… I'm leaving voicemails, and they don't return the voicemails"*). Poor perceptions of staff were also mentioned by a few participants, such as:

- *"They treat you in a way that like, you're less than them… like you're a bad person, basically."*

Participants also discussed that the type of services they wanted were not always available. Participants shared:

- *"They only had like one strict like program in the treatment center, like only AA-related stuff… and a lot of places won't give you Suboxone®."*
- *"All of them [SUD programs] being the same… having to be faith -- required to go to church to be there. Like, I believe in God, but I don't want to have to be made to go to church every Sunday or memorize bible verses and stuff like that."*

Although many individuals were speaking from personal experience, one participant indicated that people may have misconceptions about what treatment entails, and that education and outreach may be beneficial:

- *"Especially in this area, people… compare it to jail or a hospital because it's a controlled environment and… they're afraid because they don't know what it's like."*

Perceptions of program availability and accessibility are often noted barriers in the literature, so some additional measures were asked about time and travel specifically for SUD treatment. As shown in Table 2.6, respondents were able to identify and estimate a number of treatment programs in the area (average 27.4), which were fairly accessible with limited travel distance (7.7 miles) and time (20.1 minutes). These estimates were a bit longer when asked to assess distance (19.9 miles) and time (31.0 minutes) to travel to "good" treatment programs. In general, participants felt confident that they would either be able to make an appointment on the first call (64.9%) or the program would call them back (26.3%).

> ***"Fear of the unknown, of what's yet to happen or what's going to come…addicts are afraid of change … and you have addicts who are afraid of being a success…some addicts have always been considered a failure in their life…they don't know what success entails, what succeeding consists of, and that scares a lot of them."***
>
> - CONSUMER SURVEY PARTICIPANT

TABLE 2.6. PERCEPTIONS OF AVAILABILITY AND ACCESSIBILITY OF TREATMENT

Perceived average number of substance use disorder (SUD) treatment programs available in the community	27.4
Average miles and minutes people in your community typically have to travel to get to any treatment program	7.7 miles 20.1 minutes
Average miles and minutes people in your community typically have to travel to get to a **good** treatment program	19.9 miles 31.0 minutes
When calling a SUD program today to get an appointment, the expected outcome is...	
be able to make an intake appointment on the first phone call	64.9%
that the program would need to call you back before making an appointment	26.3%
some other outcome	8.8%

After reporting how long participants would expect to wait before receiving a call back from a new SUD service provider and to schedule an intake appointment, participants were asked *"What are your thoughts about this timeframe for starting services with a new treatment provider?"* Participants were divided: about half indicated that the timeframe was **acceptable**, with responses like:

> ***"I wish that there was more of a concern for the time sensitivity, because you can be ready in one moment and not ready in the next, and that can be the difference between life and death."***
>
> - CONSUMER SURVEY PARTICIPANT

- *"They're usually pretty good about getting it done as quick as possible."*
- *"I like that it's able to happen so quick; it reassures you that you can be somewhere if you need the help."*

However, the other half of participants believed the timeframe was **too long to wait** to begin treatment. Participants explained that:

- *"Once people make a decision to get clean, if we can't get in, we could relapse."*
- *"A person may want to go, but they may get discouraged if they have to keep calling back."*

Several mentioned the urgency inherent in SUD as a potentially fatal condition:

- *"If you call and tell someone you need help, you need help right then and there, not 2-3 days down the line. If they don't take you right then, you might decide to go out and do it one more, and that be the end of it, kill yourself or something."*

Recovery supports. While a number of participants noted barriers to treatment entry, most participants indicated that they had ever worked with a **peer support specialist** (75.8%), which may be considered a viable alternative or supplement to formal treatment modalities. This section describes the types of support provided by individuals working as peer support specialists, the benefits of working with peers, and any potential concerns

or drawbacks. Participants described two broad domains that peers provided support or assistance with, namely **resources/referrals** and **support**.

Resources, for many, included provision of basic material needs that participants required for day-to-day living, such as transportation, food, clothing, identification (e.g., birth certificates, social security cards), and shelter. When the peers themselves or their organizations did not provide these resources directly, participants described that peers would provide referrals to other resources.

These **referrals** could also include warm hand-offs and facilitating linkages to other services, when needed; as one participant described,

- "*If there's something that I need; say I needed parenting classes or domestic violence classes to get my kids back, she would get me set up for those classes… she goes above and beyond to find resources for every single one of her clients."*

> ***"[Peers] connect with you on your level. You know, you don't feel like 'less than.' So you're more comfortable talking about what's going on, you know, without being judged."***
>
> - CONSUMER SURVEY PARTICIPANT

Support was another critical domain that participants mentioned peers providing help with, including encouragement, compassion, guidance, and motivation. Participants indicated:

- [Their peer] *"helped me on the daily. They helped me stay put. They talked to me about what's going on in my life. They are very supportive of my decisions. They helped me do self-care. They helped me, like, get through my trauma; they helped me set boundaries. They did a lot, you know?"*

- [Their peer helped by] *"steering me in the right direction, just talking to me, being an ear for me, someone to talk to."*

Although less tangible than material resources, this type of emotional and recovery support was highly valued by many participants.

Participants described the primarily beneficial aspects of working with peers as related **shared lived experience** and **connection/friendship**. In contrast to other types of clinical professionals, peer recovery support specialists are required to have **shared lived experience** in addiction and recovery, which many participants described as a valuable part of this relationship. Participants shared:

- *"They've been where we – where I have been, so like, they know how we feel and they know what we're going through, and they've been in our shoes before, so they want to see the best for us."*

- *"They've been through what we've been through, you know, so they already know… like they could spot a relapse happening in my mind before it even happened… they call me*

out on my BS, you know what I'm saying? …Just because they been through it beforehand… they've been in my shoes so they know exactly what I'm coming through."

Relationships between peers and clients were also described with a strong sense of **connection/friendship**. Participants shared:

- *"My peer specialist, my favorite one, he has been a really good friend of mine for the past four years."*
- *"I have a good friend. I have good support. I have someone that's always there if I need them."*
- *"Nine times out of ten, you know, you - you become friends."*

Negative aspects of working with a peer were mentioned by few participants, but the majority indicated that they saw no downsides to the services peers provided (e.g., "they do nothing but help you"). Responses that mentioned drawbacks were not sufficient to constitute cohesive themes, but individual responses discussing negative aspects of peer support services included: (1) although all peers are in recovery, not all peers may have lived experiences that align closely with their clients; (2) peers can come from a different perspective or recovery pathway than participants; (3) peers' honesty can be difficult to accept; and (4) clients may not believe that peers are "qualified" to provide advice or guidance because of a lack of advanced professional training.

In addition to working with peer support specialists, a number of participants identified family, friends, and other supports for their recovery. In fact, 96.8% of participants indicated they had contact with family or friends who were supportive of their recovery in the past 30 days. As shown in Table 2.7, they were able to identify a fairly large network of supportive individuals (average 17.8). They also noted important components such as self-help groups, children, and employment as being helpful to maintain recovery. Additionally, participants noted important components such as self-help groups, children, and employment as being helpful to maintaining recovery.

TABLE 2.7. RECOVERY SUPPORTS

Average number of people counted on for recovery support when needed in the past 30 days	17.8 people (median – 5, mode – 5)
Self-reported chances of getting off or staying off drugs/alcohol based on what is known about yourself and your situation	1.6% = Moderately poor 3.2% = Uncertain 19.4% = Moderately good 75.8% = Very good
Things in life that would help getting or staying off illicit drugs or alcohol:	
Self-help (e.g., AA/NA)	30.6%
Children	21.0%
Employment	21.0%
Support from family	14.5%

TABLE 2.7. RECOVERY SUPPORTS (CONT.)

Will power	11.3%
Counseling	9.7%
Other people in recovery	8.1%
Support from a partner	6.5%
Staying busy	6.5%
Remembering the past	6.5%
Support from friends	3.2%
Change in environment	3.2%

Harm reduction. It is interesting to note that, of participants who had attended treatment in the past year, only 32.5% attended a program that offered any support for smoking cessation. This is particularly concerning when findings indicate that nearly 90% of participants reported using cigarettes in the past year, and they reported using almost every day in the last month. About half of participants (46.8%) indicated that SUD programs should focus on total abstinence, but participants also reported that a greater focus on harm reduction resources in their communities would be very helpful, as shown in Table 2.8. The majority of participants specifically indicated that distribution of naloxone kits and training (88.7%), sex education and STI testing (82.3%), fentanyl test strips (74.2%), and needle exchange (62.9%) would be very helpful as additional resources in their local communities.

TABLE 2.8. PERCEPTIONS OF HELPFULNESS OF HARM REDUCTION SERVICES IN LOCAL COMMUNITIES

	Not at all	A little/ Somewhat	Quite a bit/ Extremely
Naloxone kits and training	0.0%	8.1%	88.7%
Sex education, safe sex materials, STI testing and treatment	1.6%	16.1%	82.3%
Fentanyl test strips	6.5%	16.1%	74.2%
Free syringes/needles service	8.1%	27.4%	62.9%
Education about reducing the harm from substance use rather than abstinence-only	4.8%	30.6%	61.3%
Other free injection supplies (alcohol swabs, tourniquet, cooker and sterile water)	8.1%	32.3%	58.1%
Smoking cessation information and resources	9.7%	33.9%	56.5%
Pre-exposure prophylaxis (PrEP)	1.6%	9.7%	48.4%

Summary

Consumers noted utilization of a number of resources including health care facilities in their lifetime and in the past year, as well as informal resources for SUD such as family, friends, and self-help meetings. This is an important finding in that individuals may be

motivated to reach out about SUD issues and may be good candidates for treatment if they could find the right fit. Consistent with the study recruitment plan, most participants had a history of inpatient/residential treatment (82.3%), with most of those individuals attending two or more times. Other treatment modalities commonly visited by study participants included outpatient or intensive outpatient programs (75.8%) and recovery housing or sober living programs (64.5%). Qualitative analysis of participant responses revealed four primary themes with regard to reasons for why individuals chose to enter SUD treatment: (1) being tired of the cycle of addiction; (2) losing everything; (3) legal system involvement; and (4) relationships.

Findings also indicated that about 42% of respondents thought about entering treatment in the past year but decided not to. The most common barriers to entering treatment included personal reasons (88.7%) such as having to take off work (59.7%) and shame/embarrassment (54.8%). Other barriers included program and resource barriers (87.1%), concerns related to program quality (75.8%), and lack of program adaptation to fit client needs (67.7%). These barriers were consistent when clients were asked to share in their own words which barriers were most challenging to enter SUD treatment. Qualitative content analysis of responses indicated that participants believed the primary barriers to SUD treatment included: (1) limited personal resources such as lack of transportation; (2) responsibilities at home and work; (3) fear of losing or compromising relationships; (4) limited motivation or readiness to change; and (5) perceptions of program limitations to provide the help they need.

Section 3. SUD Treatment Retention and Barriers

Participants were recruited into the study based on their consideration of entering treatment, or if they dropped out of treatment in the past year. Nearly two-thirds of study participants (66.1%) reported dropping out of any treatment program in the past year. As shown in Table 3.1, about a quarter of respondents (27.4%) reported entering a MOUD program then dropping out, followed closely by inpatient/residential treatment (25.8%). It should be noted here that MOUD was treated as a broad category, and there may have been specific barriers to retention based on a specific type of medication. This should be explored in future research.

TABLE 3.1. PERCENTAGE OF INDIVIDUALS WHO REPORTED ENTERING THE FOLLOWING TYPES OF TREATMENT IN THE PAST 12 MONTHS, THEN DROPPING OUT

Any program	66.1%
Medication for opioid use disorder	27.4%
Inpatient/residential	25.8%
Recovery housing (“sober living”)	21.0%
Outpatient or intensive outpatient (IOP)	19.4%
Medical detox	8.1%
Transitional housing	8.1%
Recovery program (Kentucky Recovery)	6.5%
Prison or Jail Substance Abuse Program (SAP)	3.2%
Group home for adults who use substances	0%

Participants reported a number of specific challenges related to retention in SUD treatment programs. As shown in Table 3.2, the majority of participants (90.3%) noted personal barriers to staying in treatment, with the most common barrier being having to take off work or endangering their employment (64.5%). More than half (59.7%) noted concerns that being with other clients in treatment who do not take it seriously is a barrier.

Participants (88.7%) also noted a number of barriers to entering treatment related to both program barriers and resource barriers. Examples of endorsed program barriers included being located too far away from where they lived or the requirements for entry being unreasonable (such as having to have a negative drug screen at treatment entry). The majority (87.1%) reported barriers related to program quality such as concerns about program exploitation, limited professionalism or knowledge among staff, and limited program structure. Most (79.0%) of participants reported barriers related to adaptability of programs such as matching the needs of clients to the program, limited options for trauma-informed care, and limited options for self-help beyond AA or NA. About half (54.8%) reported barriers to accessibility of treatment related to costs and insurance coverage.

TABLE 3.2. PERCENT OF INDIVIDUALS WHO NOTED THAT THE FOLLOWING WERE BARRIERS TO STAYING IN TREATMENT

Personal barriers	**90.3%**
Employment; being able to leave work and go to treatment	64.5%
Some clients in some programs are not serious *(e.g., they are mandated to be there or only there for the shelter part of some programs not the recovery part)*	59.7%
Embarrassment or shame	43.5%
Legal issues; or fear of legal issues *(e.g., warrant out for your arrest)*	37.1%
Stigma for seeking treatment	37.1%
Involvement with the criminal justice system	35.5%
Childcare—making sure children are cared for while in treatment	33.9%
Pet care; making sure pets are taken care of while in treatment	24.2%
Program and Resource Barriers	**88.7%**
Program barriers	75.8%
Program or treatment is too far away from home	50.0%
Requirements for entry or staying in the program were unreasonable *(e.g., had to have a clean urine before entering the program)*	50.0%
Criteria for treatment (for insurance purposes) is too strict *(e.g., having to be at a certain point in withdrawal)*	48.4%
Ability to see a therapist or counselor quickly	40.3%
Paperwork burden	29.0%
Difficulty making or getting an appointment	21.0%
Resource barriers	82.3%
Access to safe and affordable housing	64.5%
Difficulty meeting basic needs *(e.g., food, clothing)*	59.7%
Transportation to treatment	40.3%
Concern for personal safety; Not feeling safe in seeking or engaging in treatment	33.9%

TABLE 3.2. PERCENT OF INDIVIDUALS WHO NOTED THAT THE FOLLOWING WERE BARRIERS TO STAYING IN TREATMENT (CONT.)

Program quality concerns	**87.1%**
Corruption or other organizational issues that make clients feel they are not the highest concern	66.1%
Program staff in some programs are not professional or knowledgeable	64.5%
Not enough structure in some programs	61.3%
Peer leaders are not helpful with treatment or with what clients need	58.1%
A staff person made you feel uncomfortable in some way *(e.g., wanted something more from you)*	54.8%
Lack of diversity among treatment or program staff	50.0%
Other clients engaged in harassment *(sexually or in some other way)*	43.5%
Concern about judgment from counselors	32.3%
Lack of program adaptation to client needs	**79.0%**
Person-treatment/program mismatch or not finding a good fit for you with regard to treatment or program	59.7%
Lack of trauma-informed or client-centered care	50.0%
Lack of options other than AA/NA	43.5%
No or limited support for SUD program/treatment or SUD recovery	43.5%
Finding specialized treatment for marginalized individuals *(e.g., minorities, sexual orientation)*	41.9%
Finding specialized treatment for people with disability needs (*e.g., hearing impairment, other physical or mental disabilities)*	40.3%
Lack of harm reduction treatment options *(e.g. needle exchange)*	30.6%
Accessibility barriers	**54.8%**
Cost of treatment	45.2%
Limits imposed by insurance	40.3%

As shown in Table 3.3, the number of reported barriers to treatment retention differed slightly between individuals identifying as men and women. Specifically, while not statistically significant, women reported slightly higher rates of all of noted barriers with the exception of program accessibility barriers which was very similar.

TABLE 3.3. NUMBER OF BARRIERS TO STAYING IN TREATMENT NOTED BY MEN AND WOMEN

	Men (n = 27)	Women (n = 35)	Total (N = 62)
Personal barrier	2.8	3.8	3.4 (range 0 –8)
Program barrier	2.3	2.5	2.4 (range 0 – 6)
Resource barrier	1.8	2.1	2.0 (range 0 – 4)
Accessibility barrier	0.8	0.9	0.9 (range 0 – 2)
Program quality barrier	3.4	5.0	4.3 (range 0 – 8)
Adaptability barrier	2.5	3.6	3.1 (range 0 – 7)

Participants were asked some additional open-ended questions to better assess barriers to treatment retention. Specific questions included:

1. For those people who do enter treatment/programs for their substance use, what do you think are the main reasons people drop out?

2. What are the three biggest reasons you have, or you would, drop out of SUD programs?

3. If participant reported having dropped out of a treatment program within the past 12 months: What were your main reasons for dropping out of that program?

Responses to these questions were combined for qualitative content analysis to examine reasons that clients who have entered SUD treatment may not complete programs:

Unprofessional staff were mentioned by the majority of participants as a critical factor that could cause individuals to exit treatment before completion. Responses include:

- [Staff who were] *"disrespectful and rude"*, *"scandalous"*, or *"unethical"*.

- *"Like they [were] judging, judging everybody and myself."*

- *"I just didn't feel comfortable being there… 'Cause stuff they were saying was like, well, 'you should have done this,' 'you should have done that,' 'you wasn't supposed to do this,' and it was like instead of helping, like motivation… just makes you feel bad about myself for doing the stuff."*

> ***"I've seen some places, staff don't handle their self to a higher level, you know, being a professional… I understand the type of work they do can get very stressful. But…maybe they could handle their self a little bit more professional and try to put the client first before their feelings."***
>
> - CONSUMER SURVEY PARTICIPANT

Even when staff also had lived experience related to SUD, this history did not automatically translate to empathy:

- *"Most of them [staff] go through recovery their self, so they were either addicts or alcoholics… but once they get a little bit authority underneath their belt, they kind of abuse it a little, you know what I'm saying? … If I'm not going to be cared for or supported, then why would I want to stay?"*

Finally, even when staff were not actively disrespectful to clients, a lack of care or compassion could still make clients feel unwelcome; as one participant shared about their experience at an outpatient MOUD clinic:

- *"It was like almost like… like a pill mill, like just there for patients in-and-out. That's basically just making money. That's what I felt like they were doing in the end. We were just a paycheck, they were seeing dollar signs."*

Participants also shared **interpersonal issues** with other clients as a reason that some individuals would drop out of treatment. Particularly in residential settings, participants

shared that:

- "*Other people's personalities don't mesh well all the time… Some people aren't there to recover, some people are there just because they need somewhere to go, you know, so they're not taking it serious.*"

- [Other clients did not] *"appreciate your boundaries"* or *"I couldn't get any privacy at all"*, on top of the fact that "*it is difficult living with complete strangers.*"

- *"So many different women, so many different personalities, people buddying up, kind of picking on you… people pointing a finger at you so that they don't look at themselves."*

These interpersonal challenges, combined with a lack of autonomy and personal space, could create significant tension for some clients.

Treatment expectations seemed unreasonable to several participants, who described feelings of being overwhelmed. For clients attending outpatient or MOUD programs, multiple weekly appointments could feel onerous, as one participant described:

- *"You had to have so many counseling sessions; you had to visit with your primary care every so often; you had a blood work drawn every so often… all that would keep a lot of people from meeting those requirements."*

> ***"Some of us have, you know, traumas that we have to deal with and they harbor these things for years, and they use alcohol and drugs to mask it, to numb … to keep from having to think about those things. So when you take away the alcohol and drugs and you're forced with the naked truth of why you use it, it becomes more than they can bear."***
>
> - CONSUMER SURVEY PARTICIPANT

In residential programs, rules and restrictions – although necessary – could be difficult, particularly in early phases of treatment:

- *"There's a lot of rules… you don't have control of your own life at first."*

One participant shared how this adjustment could be too challenging for some:

- *"All the requirements that you have to make is sometimes overwhelming to somebody who's coming off the streets and coming off of drugs, who's not used to having to do this… all these requirements of a normal life; when you lose the ability to have that normal life and you don't do that stuff daily. Going back into normal functioning style… is so overwhelming that some people just stop and walk away and go back out into the sickness because it's easier, because they understand and know it."*

These responses underline the critical importance of support for clients in early stages of treatment, as well as sensitivity to clients' acclimation to a (sometimes dramatically) new environment.

Program logistics (including transportation, insurance/cost, and schedules/work) were mentioned previously as a barrier to entering treatment programs, but once an individual was engaged in treatment, these factors could similarly present challenges for retention. For example, one participant shared that their IOP program:

- *"Conflicted with my work schedule, so… I dropped out of that program and then I had to join another program that was able to accommodate my work schedule."*

Another participant shared that they struggled with attending a MOUD clinic where:

- *"They was wanting me to come in once a week for my doctor's appointment for several hours, and then once a week for counseling services, and I had to sit there and wait for several hours to be seen… and it just, my boss wasn't going to let me be off work that many times that week, that many hours… they didn't offer no weekends or night hours available so I could do so."*

Another participant mentioned that their program was *"charging me extra money on top of my insurance"*, an issue mentioned by other respondents as well. Although clients may succeed in overcoming hurdles to initiate treatment, navigating ongoing logistical trouble may be a significant barrier to program retention.

Separation/isolation from loved ones was mentioned by several participants as a barrier to treatment entry; responses to the present questions confirmed that, once engaged in treatment, this continued to be a difficult issue to navigate for many clients. Participants noted:

- *"On lockdown, you couldn't use the phone to talk to your family, you couldn't write them."*
- *"Women are a big thing for guys… a lot of people I've seen in rehab… they, you know, get messed around in their head about they women and you take off."*

> ***"[Clients can be] too worried about what's going on outside of treatment…what their girlfriend's doing or what their family's doing or what their friends are doing. Because the world keeps moving, you know, even though while everything's standing still for you in there."***
>
> - CONSUMER SURVEY PARTICIPANT

Parenting participants were also often concerned about their children's' care, as one participant shared about why they dropped out of a residential program to enroll in outpatient treatment:

- *"I could take care of my kids… like, I didn't have to worry about who was going to be providing care for them. What are they going to eat tonight? Did anybody make sure my kid took a shower? Because she will not take a shower if you don't make her… I just had so many worries [while in residential] that it just made my treatment feel like it didn't matter at all."*

Feelings of isolation, disconnection, and powerlessness could make staying in treatment

difficult for many clients.

Lastly, participants described a **lack of desire/commitment** to treatment as a key contributing factor to drop-out, and can be related to the numerous resource and program level barriers. Participants noted:

- *"The desire to want the drugs overwhelms them"*, or they are *"jonesing to just get back out there and use again."*
- *"I knew then I wasn't ready to get clean, I still wanted to continue [to use]."*

Some participants shared that this lack of commitment was grounded in anxiety or fear – *"scared of doing something different"* – which was previously mentioned as a barrier to treatment entry as well. However, other participants left treatment prematurely because *"I thought I had it under control"*.

For individuals who leave programs prematurely, additional education about SUD and recovery as an ongoing, lifelong process may be beneficial. Although there are many commonalities in participant responses about retention challenges for different treatment modalities, **retention on MOUD** – specifically, buprenorphine (Suboxone®) or methadone – was described as a special case by several respondents. MOUD clients faced many of the same issues described previously, particularly related to program logistics and treatment expectations (e.g., waiting long hours to be seen by a clinic doctor).

However, many participants struggled with the principle of opioid agonist medications, which they perceived to be:

- *"a cycle… you're just trading one substance for another"*.
- *"It's just a tool to help me get off of the hard stuff. It's not something that I want to have a crutch for, for the rest of my life… it is a controlled substance. It'll still make you addicted to that."*
- *"It was just too much and made me sick, made me really unable to hold my head up."*
- *"I felt like it was making me drowsy and I didn't need it anymore… I just wanted to be abstinent… I didn't want any other drugs."*
- *"[My doctor] was trying to tell me that I can only take it for so long… I told her this may be a medication I need to be on my whole life, and she wasn't hearing that. She was telling me that she was going to put me on it for this certain amount of time, and then I was going to be tapered off when she saw fit, not when I thought I was ready."*

These opposing experiences reflect a need for increased education about MOUD as a recovery pathway, as well as for patients to feel empowered and heard in decisions about their treatment plans.

Other treatment characteristics that may affect retention. In addition to these personal and program level barriers to treatment retention, participants were also asked about their experiences in programs where clients may have been treated unfairly or exploited.

More than two-thirds (67.7%) of clients reported ever feeling like or hearing other clients feel like they were exploited, taken advantage of, or that a SUD program was corrupt. When asked to further explain, many participants shared that they believed some treatment programs were **driven by a profit motive** that contributed to compromised treatment quality:

> ***"So that's kind of how I felt with my original Suboxone clinic, with them not really wanting to taper me down … it just made me feel like they don't really care about your recovery. They just want you there to make their money."***
>
> - CONSUMER SURVEY PARTICIPANT

- *"They was just in it for the money, they didn't care whether you got better or not."*
- *"Most, they're there for the money – they take people food stamps, they checks, and so they just like leave them in the dirt."*

Beyond a lack of investment in clients' outcomes, several participants mentioned instances of **mistreatment** by program staff, including confidentiality violations, stealing donations meant for clients, and sexual misconduct. Participants responded:

- *"I've heard things, like some of the counselors having inappropriate contact with some of the, you know, the members of the program… sometimes they'd make you feel, I guess that kind of like you had to, to be able to stay in the program, or maybe they was scared to talk to somebody."*
- *"There was one [staff person]… she would sit there and tell us that the program was stupid and that most of us will end up back in there, that we didn't want to change, that we was just basically being made to do this."*

Overall, participants agreed that when staff engage in misconduct or mistreat clients, these behaviors undermine their trust in the program. Along these lines, 62.5% of participants indicated that they ever felt (or heard from others) that a SUD program wanted to keep clients involved in the program after clients wanted to leave or to become less involved. When asked to elaborate, some participant responses indicated that programs may change clients' treatment plans or try to **coerce clients into ongoing engagement**:

- *"A lot of them, after they [clients] graduate, they want them to go to like, aftercare and then a sober living," said one client – "or they want to do longer than they told them when they first went in there, like… oh, you're going to stay 30 days, ends up being 90 or whatever. So they lie to you a lot."*

- *"It's all about money; the more numbers they have, the more grants and funding they can get."*

- *"Some people come into treatment and they need that diploma for a judge or… probation officer, or something to that nature. And they [the programs] know that. So what they do is they say, 'hey, well, if you want your certificate, you're going to do 30 more days in IOP', and so they can get more money out of them."*

Some participants specifically mentioned programs providing medications for treatment of opioid use disorder (MOUD), particularly **buprenorphine (Suboxone®)**, as engaging in this behavior. As one participant said:

- *"I know that they very seldomly try to wean you off of the Suboxone or other [MOUD] treatment programs".* Another participant had a distrustful perspective of these programs, stating, *"if you're an opiate addict, they'll get you off of buying illegal drugs from the streets, and then they'll put you on Suboxone and they're getting your Medicaid money, and then… they're getting kickbacks from the people that are pushing the Suboxone to the rehab. So now you're just taking legal opiates."*

Reflecting a common misconception that MOUD is *"trading one drug for another,"* such responses suggest that additional education about MOUD may be needed.

Finally, some participants interpreted the question with a positive lens, and instead chose to speak about how programs **would not give up on clients** and were committed to their success. One participant believed that programs were just…

- *"Trying to keep people from leaving so they don't go back out and do drugs and die."*

Sometimes these efforts could seem extreme, as one participant shared:

- *"They wouldn't give me the paper to AMA [leave against medical advice], they wouldn't give me my belongings that were locked up, like they tried everything. Finally they gave me my things, but they tried everything in their power to make sure I didn't leave."* However, the client perceived of these actions as coming from a place of care for clients.

About half (52.5%) of participants reported ever having (or heard from others) a SUD program ask clients to recruit or get other people involved in the program. A large number of participants interpreted this question from a positive perspective: for programs that were high-quality and effective, they wanted to **share information about good resources** to other individuals who could benefit. One participant said:

- "*It's really more like word of mouth. Like… if I go to a self-help meeting, I'm going to tell anybody that I can about the program I'm in because it's helping me, and I want others to have what I have… So it's not a written rule or nothing like that."*

However, some other participants reported that they had experienced programs trying to **keep beds/slots filled**, even at the expense of treatment quality. As one participant shared:

- *"They seem very pushy and demanding about it, like we need people like we need to get these beds filled up… really on it, about getting more people in, even though we was at full capacity, and it just seems like it wasn't really for recovery purposes, it was more for financial gain."*

Several participants also shared stories about themselves or others being offered **vouchers/incentives** to refer others to treatment. Participants said:

- *"I was told that they [treatment center] have a referral program, and you can get gift cards for every person you referred, and then they can get gift cards for every person they refer;"*
- [Or that programs would] *"give you bonuses, or if you referred people they knock so much off your visit every month."*
- "*They'll take money off your rent if you get more clients to come."*

While opportunities to gain incentives may provide clients with an additional source of income (which may in turn increase recovery capital), programs must be cautious that incentive systems do not create compromises to treatment quality, or perceived negative effects on treatment quality.

In addition, half of participants (50%) indicated that they had been in a situation (or heard from others) where they felt that a SUD program was sacrificing treatment or treatment quality for financial reasons. Specific feedback included the following themes related to profit motivation, compromised services, and exploitation.

Participants once again discussed **profit motives** of some treatment programs, which they perceived as the reason why programs retained or dismissed clients at certain times. For example, one participant said:

- *"The state pays the most in the first 14 days, so what they'll do is… they'll get him in and around the 14 to 15 day, they'll find some reason to kick him out."*

Conversely, another participant discussed that some programs will keep clients enrolled even when they may need a higher level of care:

- *"They're just there for the money, pretty much… a lot of Suboxone clinics still let the patients, just still come in there and be dirty [have a positive drug screen] and get their Suboxone still. Them Suboxone clinics are just there for the money because that's not helping nobody."*

Other participants discussed how programs may have **changed or compromised services** to maximize insurance reimbursement or profit. One participant shared that a program they went to would:

- *"act like you can't do more than one thing on a day, which requires you to… be there almost every day because your insurance doesn't cover more… like if you go on a group*

day, you can't do your individual counseling or your parenting class on that day to keep you from having to be there every day of the week. And that takes time and having a ride. And sometimes that can get a little bit complicated."

- *"A lot of places say, 'well, we used to do that, but we don't have the funding for it anymore;' or 'we offer that, but your insurance doesn't cover it.'"*

Lastly, some participants mentioned perceived **exploitation** of clients, when programs would cut corners or reduce services for financial gain. Participants shared:

- *"I've seen these directors of some of these programs are living in multimillion-dollar houses, and then the centers look like they're run down and they're crappy, they don't have air conditioning… And it just it's like, hey, where's this where's this money going to here? …You got these guys [clients] out here busting their butts, making… stuff to sell at fundraisers. They don't get to see a dime of it."*

- *"Having that many people in the room is an issue… because you pack one more person in there, you figure the insurance is shelling out anywhere from $500 to $1000 a month, if not more… So for that one extra bed, it's 50% more income for the same room… At my facility I have to provide my own food, my own toilet paper, my own cleaning chemicals, my own mop, bucket, all this kind of stuff. They don't provide any off that. Toothbrush, toothpaste, shampoo, etcetera. So they're making out like a bandit."*

> ***"Everybody's really mentally and emotionally drained while they're on substances. And they don't need to feel exploited when they finally do reach out for help."***
>
> - CONSUMER SURVEY PARTICIPANT

Clients entering treatment, who often lack material resources and have a history of marginalization, may be particularly sensitive to these types of imbalances.

Summary

Nearly two-thirds (66.1%) of study participants reported dropping out of a treatment program in the past year. Similar to noted barriers for treatment entry, the majority of participants (90.3%) noted personal barriers to staying in treatment, with the most common barrier being having to take off work or endangering their employment (64.5%). Another commonly noted barrier to staying in treatment was that other participants did not take it seriously (59.7%). Other barriers were noted at the program level (75.8%), including requirements being hard to maintain or difficulty making appointments, as well as resource barriers (82.3%) such as access to safe and affordable housing and meeting basic needs. Other concerns related to program quality (87.1%) and programs failing to adapt to meet client's needs (79.0%).

Qualitative data analysis helped to further explain these findings with participants noting key concerns such as perceptions of staff as unprofessional, having interpersonal issues with other clients in the programs, unreasonable treatment expectations, challenges

associated with program logistics, being separated from family or loved ones, and a general lack of interest or commitment to treatment. Participants also described their experiences with program exploitation, which may be perceived as barriers to staying in treatment. Participants indicated either experiencing or seeing others experience feeling like they were exploited or taken advantage of (67.7%), keeping clients after they wanted to leave (62.5%), having to recruit other clients into the program (52.5%), and feeling like the program sacrificed treatment quality for financial gain (50.0%).

Section 4. SUD Treatment-related Needs

Participants were asked to describe any groups of people that might face unique difficulties in accessing SUD programs. As shown in Table 4.1, overall percentages of unique barriers were low, which may be attributed to the limited representation of some of these groups in the sampling frame. This should be considered more of a limitation to the study design rather than a lack of barriers for some of these marginalized groups of individuals.

TABLE 4.1. PERCEPTIONS OF UNIQUE BARRIERS FOR SUD TREATMENT FOR CERTAIN GROUPS OF PEOPLE

Individuals from racial groups other than White	16.1%
Individuals who identify as LGBTQIA2S+	16.1%
Individuals with mental health problems	11.3%
Individuals who live in poverty	6.5%
Individuals with physical disabilities	6.5%
Individuals with children	4.8%
Individuals with learning disabilities	4.8%
Individuals involved in the justice system	1.6%
Individuals who live in remote or rural areas	0.0%
Veterans	0.0%

Health and Mental Health

While this study focuses primarily on substance use and barriers and facilitators for treatment entry, it is also important to consider other factors which may affect decisions to enter or stay in treatment, such as health or mental health issues. As shown in Table 4.2, about two-thirds of study participants reported having an ongoing chronic health condition (66.1%), and more than half (54.8%) reported taking medication on a regular basis for a physical health problem. About a third (30.6%) reported serious chronic pain lasting at least 3 months in the past year. In addition, the majority of study participants (75.8%) reported ongoing mental health issues like depression or anxiety, and more than half (56.5%) reported taking medication for mental health concerns.

In addition, the majority of study participants (75.8%) reported ongoing mental health issues like depression or anxiety, and more than half (56.5%) reported taking medication for mental health concerns.

TABLE 4.2. PERCENT OF PARTICIPANTS REPORTING PHYSICAL AND MENTAL HEALTH CONCERNS

Description of general physical health	
Poor/Fair	29.0%
Good	40.3%
Very good/Excellent	30.6%
Reported any chronic health conditions	66.1%
Taking medications on a regular basis to treat a physical health problem	54.8%
During the past 30 days, average number of days described health as not good	3.9 days
Experienced any serious chronic pain lasting at least 3 months in the past 12 months?	30.6%
Average number of days in the past 30 days experiencing chronic pain	17.3 days
Reported any ongoing mental health concerns such as depression or anxiety that affect health	75.8%
Taking any medication for mental health concerns	56.5%
During the past 30 days, average number of days you would describe your mental health as not good	9.4 days

Considering the high prevalence of co-occurring mental health issues among individuals seeking SUD treatment, the PHQ-9 and GAD-7 were also administered, both of which are widely used, reliable, and valid screening tools (Kroenke et al., 2001; Spitzer et al., 2006). The PHQ-9 is typically used to assess DSM-5 criteria consistent with depression with overall scores ranging from 0 – 27. Participants in this sample scored an average of 9.0 (range from 0 – 27), which is suggestive of mild to moderate depression. The GAD-7 is used to assess DSM-5 criteria consistent with generalized anxiety disorder with overall scores ranging from 0 – 21. Participants in this sample scored an average of 7.1 (range 0 – 20), which is indicative of mild anxiety.

Participants were also asked about any experiences they may have had following stressful or traumatic experiences using a brief PTSD checklist. As shown in Table 4.3, most participants reported being bothered to some degree following a traumatic experience. The average score on the PTSD checklist was 6.7, with 24.2% meeting the cutoff for symptoms consistent with DSM-5 diagnosis of PTSD.

TABLE 4.3. RESPONSES TO STRESSFUL OR TRAUMATIC EVENTS

Bothered by repeated, disturbing, and unwanted memories of the stressful experience(s)	17.7% not at all 50.0% somewhat 32.0% a lot
Avoided external reminders of the stressful experience(s) (for example, people, places, conversations, activities, objects, or situations)	19.4% not at all 45.2% somewhat 33.9% a lot
Had strong negative beliefs about yourself, other people, or the world because of the stressful experience(s)	24.2% not at all 51.6% somewhat 22.6% a lot
Felt jumpy or easily startled	40.3% not at all 30.6% somewhat 27.4% a lot

Participants also reported using alcohol, prescription drugs, or illicit drugs sometimes (8.1%) or almost always (12.9%) in the past 30 days to reduce stress, anxiety, worry, sadness or fear associated with some of these mental health issues.

Mental health issues among adults are often associated with experiences of neglect, abuse, and other forms of maltreatment before the age of 18. These types of experiences were measured using the Adverse Childhood Experiences (ACEs) scale. Overall, participants reported an average of 5.8 experiences endorsed (range 0 – 10), with individuals identifying as women reporting slightly more than men (6.7 experiences vs. 4.6 experiences). The literature suggests that 4+ experiences can be associated with more distress and behavioral health problems (Friestad et al., 2014; Hughes et al., 2017; Merrick et al., 2017; Reavis et al., 2013). As shown in Table 4.4, the majority (83.9%) of study participants reported experiencing some form of maltreatment (neglect or abuse) before the age of 18. The most commonly reported maltreatment included emotional neglect (71.0%) and emotional abuse (59.7%), but about half (53.2%) also reported histories of sexual abuse or physical abuse. While percentages were slightly higher for women across maltreatment types, only sexual abuse was statistically significant for women compared to men. These findings may play a critical role in adults' severity of substance use and co-occurring mental health issues, and should be considered as part of assessment and treatment planning processes.

TABLE 4.4. PERCENTAGE REPORTING HURTFUL THINGS THAT OTHERS MAY HAVE DONE TO THEM BEFORE THE AGE OF 18

	Women n=35	Men n=27	Total N=62
Any type of maltreatment or abuse	91.4%	74.1%	83.9%
Experiencing emotional neglect in household	74.3%	66.7%	71.0%
Experiencing emotional abuse in household	65.7%	51.9%	59.7%
Experiencing sexual abuse by someone at least 5 years older in household**	71.4%	29.6%	53.2%
Experiencing physical abuse in household	60.0%	44.4%	53.2%
Experiencing physical neglect in household	57.1%	37.0%	48.4%
Witnessing IPV of mother or stepmother in household	51.4%	44.4%	48.4%

**X2 = 10.7, p<.01

Summary

Participants in the Consumer Survey reported a number of health and behavioral health needs that could have an impact on treatment entry or retention. About two-thirds of study participants reported having a chronic health condition (66.1%), and more than half (54.8%) reported taking medication on a regular basis for a physical health problem. In addition, the majority of study participants (75.8%) reported ongoing mental health issues like depression or anxiety, and more than half (56.5%) reported taking medication for mental health concerns. The majority (83.9%) also reported some form of maltreatment (abuse or neglect) before the age of 18.

Limitations

One limitation of this survey was that the small sample of 62 was relatively homogeneous with regard to diversity in race/ethnicity, sexual orientation, and age. It is anticipated that the barriers reflected here among individuals in this sample may be limited with regard to barriers faced by other diverse groups. Additional outreach efforts should be used in both research and treatment initiatives to better understand unique barriers by individuals representing other groups in order to make changes to treatment assessment and treatment planning.

Conclusions and Recommendations

Overall findings of this Consumer Survey Project highlight the significance of both personal and program level barriers for individuals entering, engaging, and/or staying in SUD treatment programs. There is a lack of research on facilitating factors and barriers associated with treatment entry and retention for individuals who have thought about treatment and decided not to go or who have entered treatment and dropped out. This study addresses these gaps and contributes to a greater understanding of treatment barriers and experiences among individuals living in Kentucky.

Survey findings noted a number of barriers at the **personal** level for both entering and staying in SUD treatment. Commonly noted barriers included employment and feeling like their job would be threatened by taking the time off for treatment. Considering a number of individuals may have obligations to stay employed (probation & parole, family needs), it is important for treatment programs to be flexible to accommodate work responsibilities. These responsibilities may also be related to noted resource barriers such as being able to secure safe housing, meeting basic needs, transportation, and being able to feel safe. Other barriers included being able to maintain contact with family, friends, and children during the time they were in treatment. Since none of these noted barriers are likely to occur in isolation, it is likely that individuals feel a tremendous burden when considering entering treatment and still being able to meet their daily responsibilities. The obligations for single parents are even more challenging with having to turn over care of their children to someone else, or perhaps even being involved with Child Protective Services. Even though the consumers discussed generally having access to publicly-funded treatment, limits imposed by insurance and costs associated with treatment were mentioned as barriers.

Consumers also noted a number of barriers at the **program** level (such as maintaining strict regulations, program quality) and within the broader treatment system. Consumers noted specific concerns related to program quality and being able to adapt the program to fit the needs of specific clients. One example is individuals in the criminal justice system. While not a targeted recruitment criteria for the study, most (88.7%) reported lifetime history of incarceration, and 37.1% were incarcerated in the past year. Tailoring treatment to meet individuals' needs related to their justice-system involvement is critical, particularly with regard to maintaining flexibility for meeting their responsibilities, as well as their unique treatment needs. In addition, a high percentage of clients reported mental health issues, history of abuse and neglect, and ongoing chronic health concerns,

all of which may require certain specialized or unique forms of adaptations for treatment programs to consider. In addition, potential concerns were raised related to perceptions of program quality and program exploitation of treatment clients. Consumers in this study had very positive things to say about working with peer support specialists and recognized that they provide a unique understanding of the experience of addiction, as well as the pathways toward recovery.

A number of **recommendations** are forwarded in response to survey findings. Survey results shed light on the need to educate clients on what to expect regarding different treatment approaches including the time and expectations of continuing care, as well as any potential additional costs. Programs should consider confidential ways for clients to express meaningful feedback on program concerns related to exploration or corruption in a way where they feel heard and validated. It is also important to review state-level auditing procedures to ensure staff also have viable outlets to discuss any concerns related to exploitation, mistreatment, and misconduct.

Considering a number of individuals may have obligations to stay employed (e.g., P&P, family needs), it is important for treatment programs to be flexible to accommodate work responsibilities. Treatment programs having greater flexibility to respond to the individual needs of clients may facilitate treatment engagement and reduce dropout. Treatment programs should consider expanding opportunities for individuals (such as telehealth and evening/weekend hours) in order for them to receive needed treatment while also meeting employment and family obligations. It should be noted, however, that additional research is needed to better understand potential differences in treatment outcomes for telehealth and in-person treatment. Nonetheless, these findings related to personal barriers suggest that treatment plans should involve consumers of treatment in order to better tailor or target options that best position them to be successful in treatment.

Research consistently shows that drug use and crime are highly related, and programs need to consider adaptation to meeting basic issues such as flexibility in programming time for supervision and ensuring that program clients are providing positive influences for each other. In addition, a high percentage of clients reported mental health issues, history of abuse and neglect, and ongoing chronic health concerns. Each of these should be considered in treatment planning in order to ensure success.

Oftentimes, issues such as criminal justice involvement and mental health may also contribute to perceptions of stigma and embarrassment in treatment. Treatment programs should consider changes to SUD staff training, support, and supervision for program staff, as well as considering initiatives to incentivize expansion of SUD clinical workforce. As many organizations struggle with staffing shortages, ensuring that staff members have appropriate training, supervision, and support is critical to providing quality services for clients. Other state-level initiatives should include supporting public campaigns that aim to reduce stigma, positive messaging about people in recovery, public education about recovery outcomes and pathways. In addition to general SUD treatment programs, these initiatives should include a focus on recovery pathways and MOUD education as ways to expand treatment opportunities.

Support from peers may also reduce certain stigmas associated with treatment retention,

particularly for high risk populations. Peer support specialist programs should be expanded broadly in treatment venues including those focused on criminal justice and mental health issues. Integration of peer specialists should also be done with an eye to improving any potential concerns with treatment quality.

References

Friestad, C., Åse-Bente, R., & Kjelsberg, E. (2014). Adverse childhood experiences among women prisoners: Relationships to suicide attempts and drug abuse. *International Journal of Social Psychiatry, 60*(1), 40–46. https://doi-org.ezproxy.uky.edu/10.1177/0020764012461235

Hughes, K., Bellis, M. A., Hardcastle, K. A., Sethi, D., Butchart, A., Mikton, C., Jones, L., & Dunne, M. P. (2017). The effect of multiple adverse childhood experiences on health: Asystematic review and meta-analysis. *The Lancet. Public Health, 2*(8), e356–e366. https://doi-org.ezproxy.uky.edu/10.1016/S2468-2667(17)30118-4

Kroenke, K., Spitzer, R.L., & Williams, J.B. (2001). Validity of a brief depression severity measure. *Journal of General Internal Medicine, 16*(9), 606-613

Logan, T., Scrivner, A., Cole, J., & Walker, R. (2018). *Voices from the trenches: Barriers and difficulties in working with substance abuse treatment clients.* Lexington: KY: University of Kentucky Center on Drug and Alcohol Research.

Merrick, M. T., Ports, K. A., Ford, D. C., Afifi, T. O., Gershoff, E. T., & Grogan-Kaylor, A. (2017). Unpacking the impact of adverse childhood experiences on adult mental health. *Child Abuse & Neglect, 69*,10–19. https://doi-org.ezproxy.uky.edu/10.1016/j.chiabu.2017.03.016

Reavis, J., Looman, J., Franco, K., & Rojas, B. (2013). Adverse childhood experiences and adult criminality: How long must we live before we possess our own lives? *The Permanente Journal, 17*(2), 44–48. https://doi-org.ezproxy.uky.edu/10.7812/TPP/12-072

Spitzer, R.L., Kroenke, K., Williams, J.B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine, 166*(10), 1092–1097. https://doi.org/10.1001/archinte.166.10.1092