# Vermont Baseline Needs Assessment

# **Qualitative Report:**

**Opioid Use Disorder Treatment Experiences in Rural Vermont** 



Prepared by the UVM Center on Rural Addiction Surveillance & Evaluation Core March 2023

## **Table of Contents**

| Background   | 3  |
|--|----|
| Abbreviations  | 3  |
| Methods  | 4  |
| Overview   | 4  |
| Recruitment and Eligibility  | 4  |
| Qualitative Interviews   | 5  |
| Data Analysis  | 6  |
| Thematic Areas   | 6  |
| Results  | 9  |
| Participant Demographics   | 9  |
| Contextual Factors   | 9  |
| A. Access to Treatment for Opioid Use Disorder   |    |
| A.1. Reasons for Initiating Treatment  | 10 |
| A.2. Access Experiences  | 12 |
| A.3. Facilitators and Barriers to Accessing Treatment                                  | 15 |
| A.4. Key Findings: Access  | 23 |
| B. Opioid Use Disorder Treatment Experiences   | 24 |
| B.1. Current Treatment Modalities and Settings   | 24 |
| B.2. Medication Treatment Experiences  | 25 |
| B.3. Other Treatment Modalities  |    |
| B.4. Facilitators and Barriers to Continuing Treatment                                 | 27 |
| B.5. Quality of Care   |    |
| B.6. Treatment Experiences During COVID-19   |    |
| B.7. Key Findings: Experience Continuing Treatment                                     |    |
| C. Recovery Success, Unmet Needs, and Recommendations for Improved Care                |    |
| C.1. Long-Term Recovery Success  |    |
| C.2. Unmet Needs and Recommendations for Improved Care                                 |    |
| C.3. What Care Providers Should Know about OUD and Treatment                           |    |
| C.4. Key Findings: Recovery Success, Unmet Needs and Recommendations for Improved Care |    |
| Takeaways  |    |
| Appendix A: Interview Questions  |    |
|  |    |

PAGE 2

This publication is supported by the Heath Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$17,032,587 with zero percentage financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, HRSA, HHS or the U.S. Government.

## Background

The mission of the University of Vermont Center on Rural Addiction (UVM CORA) is to expand addiction treatment capacity in rural counties by providing consultation, resources, training, and evidence-based technical assistance to health care practitioners and community organizations. With our Vermont baseline needs assessment, we aim to identify current and future substance use disorder treatment needs and barriers with direct input from practitioners, community partners, and people impacted by opioid use disorder (OUD).

In this qualitative phase of our Vermont baseline needs assessment, and in collaboration with our partners at University of Southern Maine Substance Use Research and Evaluation (USM SURE), we interviewed 16 people who were receiving medication for opioid use disorder (MOUD) while living in rural Vermont counties (i.e., counties designated as eligible for rural health grants by the Federal Office of Rural Health Policy and Health Resources and Services Administration (HRSA)). The following report summarizes qualitative interviews on topics related to participants' current OUD treatment plans, experiences accessing and continuing treatment for OUD, beliefs about OUD and treatment, quality of OUD care, unmet OUD treatment and recovery needs, and long-term recovery goals.

Visit **uvmcora.org** to find more information about our baseline needs assessments in Vermont, Maine, New Hampshire, and New York, as well as available resources and technical assistance on substance use treatment.

## **Abbreviations**

UVM CORA: University of Vermont Center on Rural Addiction
OUD: Opioid use disorder
USM SURE: University of Southern Maine Substance Use Research and Evaluation
MOUD: Medication for opioid use disorder
HRSA: Health Resources and Services Administration
MAT: Medication-assisted treatment

## **Methods**

## **Overview**

UVM CORA was founded in September 2019 with support from the HRSA Rural Communities Opioid Response Program-Rural Centers of Excellence on Substance Use Disorders (RCORP-RCOE) program, with the mission to increase substance use treatment access by providing consultation, training, resources, and evidence-based technical assistance to rural health care providers and community organizations. To this end, UVM CORA conducted a series of baseline needs assessments of health care practitioners and community stakeholders in Vermont, New Hampshire, and Maine to identify the substance use treatment needs, beliefs, and barriers in rural communities. In Vermont, UVM CORA conducted a qualitative phase of the needs assessment to gather the voices and stories of rural Vermonters receiving MOUD. The aim of this work was to further inform UVM CORA's efforts to increase OUD treatment access and capacity in rural areas of Vermont and throughout the country. This Qualitative Report: Opioid Use Disorder Treatment Experiences in Rural Vermont focuses on the qualitative phase of the baseline needs assessment project, which is considered a quality improvement project and thus met the UVM Institutional Review Board's criteria for exemption from review. In this comprehensive report, we share the diversity of experiences and perspectives of the people in treatment for OUD interviewed for this project. A summary of key themes can be found in our Qualitative Data Brief: Perspectives of Persons Receiving Medications for Opioid Use Disorder (MOUD) in Rural Vermont.

## **Recruitment and Eligibility**

Recruitment for the project occurred between August 2021 and December 2021 with initial email outreach to (a) contacts from our technical assistance activities, (b) rural practitioner respondents from our baseline needs assessment survey who reported currently treating patients with MOUD, and (c) a list of rural OUD treatment providers maintained by UVM CORA faculty. Our outreach to technical assistance contacts included practitioners working in rural areas of Vermont to whom we had previously provided support or resources. We also shared information about the project via email with professionals and community partners in the recovery center network throughout rural Vermont and recruited participants in person at rural syringe services program sites.

Our recruitment activities included provision of information about the project via digital recruitment materials, hard-copy materials, and/or verbal explanation of the project. We mailed flyers and postcards to contacts that requested hard copies and brought materials to the syringe services program sites. We periodically sent reminder emails to all recruitment contacts for continued engagement in project recruitment.

Individuals interested in participating in the project used a link available in the recruitment materials to complete an online screening survey to determine eligibility. Criteria for eligibility included living in a HRSA-designated rural Vermont county, age of 18 or older, and currently receiving MOUD. Sixty-eight individuals completed the online screener for the project between August and December 2021, 44 of whom reported living in a rural county and currently receiving MOUD. Of these, 16 completed interviews and are included in this analysis.

## **Qualitative Interviews**

We conducted semi-structured qualitative interviews using a guide with questions based on previous qualitative work done by our collaborative partners at USM SURE with similar populations, our quantitative Vermont Baseline Needs Assessment survey,<sup>1</sup> input from UVM CORA faculty, staff, and clinicians, and feedback from community partners. Interview questions (Appendix A) focused on interviewees' current OUD treatment plan, challenges related to accessing and receiving MOUD, and potential gaps in OUD treatment or recovery services within the community. All interviews were conducted between August and December 2021 via the Zoom virtual platform by an experienced qualitative interviewer from our partner group at USM SURE. The average interview length was 30 minutes (range: 11-59 minutes). Interviews were transcribed verbatim using a professional HIPAA-compliant transcription service and uploaded into NVivo 20<sup>©</sup> software<sup>2</sup> for analysis. Interviewees received a \$50 gift card for their time.

<sup>&</sup>lt;sup>1</sup> University of Vermont Center on Rural Addiction (2021). Vermont Baseline Needs Assessment: Rural Practitioners and Stakeholders. Retrieved from: www.uvmcora.org/resources.

<sup>&</sup>lt;sup>2</sup> NVivo 20<sup>©</sup> (QSR International) released March 2020, https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home.

## **Data Analysis**

We conducted thematic analysis using traditional qualitative data analytic techniques. Transcribed interviews were coded through an iterative process using a grounded theory approach, in which codes are drawn from the text, and coding involves frequent comparative analysis of the data.<sup>3</sup> While grounded theory is primarily inductive, moving from the specific to the general to explain phenomena in the qualitative theory-generating process, deductive approaches do have a role in building theory particularly if the study is guided by previous literature or data collection activities.<sup>3,4</sup> In this case, our study employed initial overarching analytical categories informed by survey data collected in the first phase of the Vermont Baseline Needs Assessment (deductive codes) as well as emergent themes (inductive codes) that emerged throughout the coding process.

Seven staff members experienced in qualitative data collection and analysis from USM SURE and UVM CORA coded transcripts in NVivo 20<sup>©</sup>. All transcripts were coded by a minimum of two members of the research team, and the coding team met weekly to discuss the coding process, compare codes, resolve coding discrepancies, and refine code definitions within the codebook. The final coding structure contained a hierarchy of broader topics or "parent" codes (e.g., treatment experience, barriers to treatment) as well as "child" codes (e.g., under treatment experience: initiation, current experience, past experience) to further organize content. We conducted queries of the data and continued to meet weekly to review findings and ensure that data were captured consistently in the analysis.

## **Thematic Areas**

We organized the data into three primary thematic areas based on the coding structure described above. First, **Access to Treatment for OUD (Section A)** describes interviewees' experiences accessing or initiating treatment. This includes reasons for initiating treatment, access experiences, and facilitators and barriers to treatment access.

<sup>&</sup>lt;sup>3</sup> Corbin, J., & Strauss, A. (2014). Basics of quality research: techniques and procedures for developing grounded theory. Thousand Oaks, CA: Sage Publications.

<sup>&</sup>lt;sup>4</sup> Charmaz K. Shifting the Grounds: Constructivist Grounded Theory Methods. In: Clarke A, editor; Morse JM, Stern PN, Corbin J, Bowers B, Charmaz K, editors. Developing Grounded Theory: The Second Generation. Walnut Creek, CA: Left Coast Press; 2009. pp. 127–55.

Second, **OUD Treatment Experiences (Section B)** describes interviewees' ongoing treatment experiences. This includes current treatment modalities and settings, MOUD treatment encounters, other nonpharmacologic treatment modalities, facilitators and barriers to continuing treatment, and quality of care. Some factors (e.g., transportation) described by interviewees as affecting both their experiences accessing treatment and their ongoing treatment experiences are discussed in both Section A and Section B. Third, **Recommendations (Section C)** describes interviewees' goals and visions for long term recovery success, views of unmet needs in the treatment and recovery system of care, and recommendations for patient-centered care improvements.

Interviewees shared about three additional key themes throughout the interviews. First, many shared personally-held **beliefs (i.e., value statements) about OUD and MOUD**, such as the belief that readiness or motivation are essential to treatment initiation, the belief that there are two types of people in treatment—those who are "genuine" or serious about treatment and abstain from substance use, and those who access treatment for harm reduction purposes while continuing to use illicit substances—and the belief that successful OUD recovery includes discontinuing MOUD. Descriptions of these beliefs are incorporated throughout the report and are highlighted in green call-out boxes.

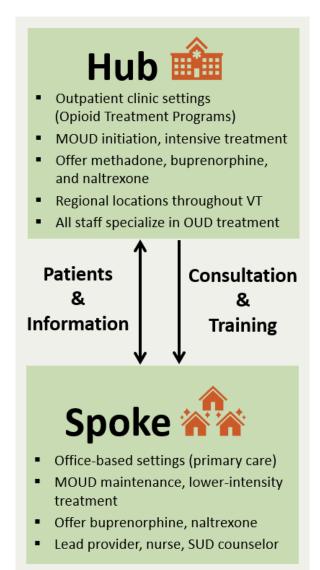
Second, interviewees shared broadly about the presence of **stigma among providers and in the community**, and its impacts on people seeking or engaging in treatment. Yellow call-out boxes highlight important themes related to stigma.

Throughout the report, we include quotations from interview participants, both embedded in the text in *italics* and in orange display quotes. These quotations include the original language<sup>5</sup> and terminology used by the interviewee, which does not always align with the language used and preferred by UVM CORA. For example, while MOUD is our preferred term for medication treatment, interviewees regularly used the term medication assisted treatment (MAT) to describe their medication, treatment team, or treatment program (e.g., "MAT team," "MAT program"). We have retained the term MAT in interviewee quotations but otherwise use MOUD throughout this report.

Some interviewee quotations in this report include language that is widely considered to be stigmatizing toward people experiencing and in treatment for OUD. We believe it is important to

<sup>&</sup>lt;sup>5</sup> Throughout the report, we removed pause words such as "um" from quotations, for clarity. We also removed potentially identifying information such as practice names/locations and replaced with general descriptive terms (noted in brackets). Otherwise, interviewees' original language is retained in the quotations we present.

share and respect the words chosen by our interviewees and have retained terms such as "addict" and "user" in quotations throughout the report. However, it is important to note that these terms should not be used in a clinical setting or by people without lived experience with OUD.



**Figure 1.** Vermont's Hub and Spoke system for medication for opioid use disorder (MOUD) treatment.

Vermont uses a Hub and Spoke system of care (Figure 1) to provide patients with MOUD treatment.

Regional Hubs (Opioid Treatment Programs) provide MOUD initiation and intensive OUD treatment services in an outpatient clinic setting. Interviewees most often referred to these Hub sites as *"clinic"* settings, which is the language we primarily use in this report.

Spokes provide less intensive MOUD treatment in office-based (e.g., primary care) settings in the community, primarily for patients who are established in their MOUD treatment plan. Interviewees most often referred to these Spoke sites as *"office"* or *"primary care"* sites; in this report we generally refer to Spoke sites as *"office-based."* 

For more information on Vermont's Hub and Spoke system, please visit *https://blueprintforhealth.vermont.gov/about-blueprint/hub-and-spoke*.

## Results

## **Participant Demographics**

Interviewees (n=16; **Table 1**) predominantly identified as white (94%), non-Hispanic (100%), and female (69%) with a mean age of 37 years (range 25-49 years). Interviewees lived in seven of the 13 rural Vermont counties.

| Age          | mean (SD)  |
|--------------|------------|
| Years        | 36.7 (5.2) |
| Gender       | n (%)      |
| Female       | 11 (68.7)  |
| Male         | 5 (31.3)   |
| Race         | n (%)      |
| White        | 15 (93.7)  |
| Other        | 1 (6.3)    |
| Ethnicity    | n (%)      |
| Hispanic     | 0 (0)      |
| Non-Hispanic | 16 (100)   |

#### Table 1. Demographic characteristics of interviewees (n=16).

## **Contextual Factors**

All interviewees (n=16) reported currently receiving MOUD, as this was required for project eligibility. Most were prescribed a medication containing buprenorphine while a few reported receiving methadone. Duration of current treatment course ranged from one month to almost 15 years, with a median duration of approximately 2 years. All participants reported participating in some form of counseling or regular check-in with an auxiliary practitioner related to their MOUD treatment. Treatment settings included outpatient treatment clinics (e.g., opioid treatment programs), health centers, primary care offices, rehabilitation facilities, and recovery centers. Thirteen interviewees reported being parents. Seven described experiencing legal issues associated with their substance use.

While we did not explicitly ask about other substance use, some interviewees discussed their past or recent use of other substances, including alcohol, cocaine, cannabis, benzodiazepines, and other psychoactive substances or "*club drugs*" (e.g., ecstasy, LSD). Of those who shared information about

other substance use, a few indicated greater concern about use of these other substances (i.e., alcohol, cocaine) than they did about return to illicit opioid use. Several interviewees reporting having acquired MOUD illicitly in the past, either as a means of self-treatment or to supplement an existing prescribed dose that did not sufficiently address breakthrough withdrawal symptoms.

## A. Access to Treatment for Opioid Use Disorder

Interviewees were asked to describe their most recent experience accessing treatment for OUD. They described their reasons and motivating factors for initiating treatment (Section A.1). They also detailed their access experiences, including pathways to treatment and whether their experience initiating treatment was easy or difficult (Section A.2), and described factors that made it easier (facilitators) or more challenging (barriers) to enter treatment (Section A.3). Additionally, broadening the responses beyond their own individual experiences, interviewees were asked for their perspective on why some people who are ready to begin treatment are able to access it while others are not. Key findings related to treatment access are outlined in Section A.4.

## A.1. Reasons for Initiating Treatment

Interviewees were asked the question, **What led to your most recent decision to start treatment?** In response, they described a variety of reasons for initiating treatment for OUD including external motivators (e.g., family, work) and internal motivators (e.g., readiness). Some interviewees noted more than one motivating factor.

#### External Motivators: Family, Work, Legal

Interviewees discussed how contextual factors including family, work, relationships, and legal concerns motivated their decision to seek treatment. Many interviewees attributed their decision to initiate treatment to their role as parents, expressing their

"I was really lucky to be alive and I couldn't keep doing what I was doing and expect to be there for my daughter."

concerns about overdose and the potential impacts on their children. As explained by this interviewee, "It was killing everybody, the fentanyl was, and I wasn't ready to die. I wanted to watch my kid grow up. I wanted to raise him."

Interviewees shared how multiple external motivating factors converged and led them to seek treatment. These included circumstances such as stressful life events, negative impacts on interpersonal relationships, and interactions with the criminal justice system.

"There were circumstances—a family situation and a relationship situation that really pushed me to make that final decision and make that call and get in there... And then I had some legal trouble that really just kind of pushed me over the edge and [I] said, 'This is it. Time to be serious.'"

Additionally, some interviewees indicated that people in their support network influenced their decision to enter treatment. For example, one interviewee described receiving encouragement from their service provider: *"My doctor actually is the one who kind of talked me into it."* 

#### **Internal Motivators**

Many interviewees described internal motivators as key factors, including feeling ready to initiate treatment and wanting to end their dependence on illicit opioids: "*I'm just so sick of the fact that I did it, but it's definitely time to change.*" One interviewee described turning to a health care provider

"I was done. I wanted to be home. I wanted to be with my kids. I needed to get my life back. It was just such a— I just needed normal. And I was ready." for treatment after struggling to taper off prescription pain medications on their own: "I moved into [family member's] house, and they helped me taper down, and then I was like, 'I can't do it.' So, I went back to the clinic." A few participants described how their decision to begin MOUD was influenced in part by the desire to manage chronic pain: "I have chronic back pain and it helps me curb my pain to make it a bit more tolerable."

Several interviewees described the desire to transition from illicit opioids to MOUD. Some described how illicitly obtained MOUD facilitated their treatment initiation: "I was buying Suboxone and being way out in [town], I didn't know anybody, but I still wanted to continue to take Suboxone, you know, because it made me not want to go look for anything else." Others described tiring of the stress of acquiring buprenorphine illicitly: "I said, 'I'm done. I'm done with the chase. I'm not chasing Suboxone. I'm not chasing anything anymore. I want sobriety, but I need help.'"

In addition to describing readiness as a personal motivator, many interviewees shared the belief that readiness was essential to initiating treatment. This theme emerged in response to the question, When thinking about people who are ready to get treatment, why do you think some people can access services and others cannot?

Belief: Readiness People with OUD need to be *"ready"* or *"motivated"* to initiate treatment.

Several interviewees shared value statements about the importance of intrinsically "wanting" or "desiring" services, while others described readiness stimulated by external factors: "If they're motivated by something—children, a job, going to jail—then people are motivated to do it."

"Some people just don't have the true desire to get clean. So, personal choice, I guess." Others described readiness as a personal decision or choice to stop illicit opioid use. Some interviewees expressed a view that a person's readiness for OUD treatment directly impacts the effort placed in locating treatment options which results in success accessing services if the person is motivated enough: "I just think it's all who wants it and who don't. Who tries to get it and who don't attempt to get it. I mean, if you want help, there's help out there for everybody."

## A.2. Access Experiences

Interviewees described diverse pathways for locating and accessing OUD treatment, as well as varied evaluations of the ease or difficulty of accessing treatment.

#### **Treatment Pathways**

Treatment pathways described by interviewees included initiating treatment through a clinic or treatment center, working with their current primary care provider, finding a new primary care provider, or initiating services via harm reduction or correctional settings. Some interviewees received support accessing treatment from family members or peers.

Most interviewees reported accessing services through either treatment clinics or primary care providers. Of those who accessed services through a clinic, some remained within this environment at the time of their interview while others had transitioned to a primary care setting after a period of stability receiving MOUD through the clinic: *"They graduated me, they're like, 'You're good, you can go see your doctor now.'"* 

"Through perseverance and a bit of luck, and after making more phone calls and doing more research, I found a private doctor in a town that's only twenty minutes away and was directly on the way to work at the time."

Some interviewees described working with their existing primary care providers to initiate treatment, such as one who described accessing treatment several years before the initiation of "*MAT teams*." Others described their experiences seeking out new providers to access treatment, including accessing convenient local providers and switching to new providers in their area: "*I had just switched to a doctor who was kind of new. It just really clicked with him right off.*"

"I just kind of settled in with my primary and went through it that way."

A few interviewees described initiating treatment through the correctional system, including referrals through the court system and initiating treatment while incarcerated: "I went to rehab a few times through [drug court], and I got in right away. They have some kind [of] connections, they get you in the next day or something." Finally, one interviewee described initiating treatment via a harm reduction setting and easily transitioning from harm reduction to MOUD treatment services: "I was going there for my supplies, and when it came time to stop, they had the resources, and it was just that easy."

#### Ease or Difficulty Accessing Treatment

Across these access points, interviewees reported a range of experiences from easy to difficult when trying to access treatment. Some described relatively straightforward experiences: "*I went through the Yellow Pages, picked a doctor, called them up, and they said, 'If you go into rehab, I will take you on as a patient,"* while others reported experiencing substantial challenges accessing treatment due to waitlists and other barriers (described in detail in **Section A.3**, below).

"I think it's pretty easy to get help if you need to get help at this point. Maybe not years ago, but now it is." Among those who described easy access to treatment, some expressed the view that it is easier to access treatment now than it was in the past. Others thought that the ease of access they experienced may no longer be typical, or that they were "*lucky*" to access the services they did.

"I was one of the last people, the [staff person] told me, to be able to just call from the street and say, 'Hey, I have issues and I need to be able to get in there.' Now you need to be coming in from the clinic, or coming in from a rehab center, and get referred into a doctor. I got lucky."

Some interviewees described difficult experiences with waitlists and other barriers when trying to access treatment, as well as associated negative consequences: *"The waiting list was really hard. Having to wait to get into treatment, knowing that I was still gonna have to buy off the street until I got into treatment. That sucked."* While waitlists were described in relation to diverse treatment settings (e.g., rehabilitation/residential facilities, primary care, clinics), discussion of clinic waitlists tended to be associated with initiation experiences from several years prior. Waitlists were most frequently reported for rehabilitation/residential facilities. Notably, those who experienced waitlists for these facilities did not always access other services in the meantime.

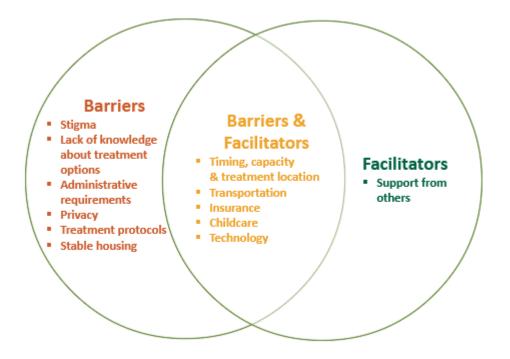
Interviewees frequently emphasized the importance of easy access to treatment, and the need for a streamlined treatment initiation process that would promote timely treatment onset and avert sustained use of illicit opioids. Interviewees' ease or difficulty accessing treatment was impacted by a variety of factors (facilitators and barriers), which are described in detail in **Section A.3**, below.

"With treatment, it's all about ease. It needs to be easy because somebody that is trying to get into [treatment] really probably doesn't have much willpower and resources left."

## A.3. Facilitators and Barriers to Accessing Treatment

Interviewees described a variety of factors that either helped or hindered their efforts to access treatment (**Figure 2**). A number of these factors, including the timing, capacity, and location of treatment, as well as transportation, insurance, childcare, and technology were variably reported as both facilitators and barriers depending on the degree to which they were experienced or not experienced (e.g., access to transportation as a facilitator, lack of reliable transportation as a barrier). These factors that can function as either facilitators or barriers are described first in the section below.

Interviewees described distinct barriers including lack of knowledge about treatment options, the time requirements of treatment, complex enrollment paperwork, and lack of stable housing. They identified support from family and peers as a distinct facilitator. Interviewees emphasized the importance of multiple factors aligning—both the absence of prohibitive barriers and the presence of facilitators—to successfully initiate treatment while living in a rural setting.



**Figure 2.** Factors reported by interviewees as barriers and facilitators to treatment access. Factors in yellow were described by some interviewees as barriers (e.g., not having a car) and by others as facilitators (e.g., having a car).

#### Factors Described as Both Facilitators and Barriers

#### **Timing, Capacity, and Location of Treatment**

The timing, capacity, and location of treatment resources were described by interviewees as key factors that could either help or hinder treatment initiation. Interviewees discussed a range of experiences with these factors, with some reporting prompt access to treatment, sufficient treatment resources, and convenient locations, and others reporting delays due to waitlists, insufficient capacity at treatment sites, or lack of treatment resources in their geographic area.

Among those who were able to access treatment quickly, benefits included transitioning smoothly from using illicit opioids to receiving MOUD, getting onto a stable dose quickly, and experiencing the relief of prompt treatment. As one interviewee described: *"I like the fact that you don't have to be sick—you can just go right from dope to methadone and stop doing dope."* 

"It was actually pretty quick getting into [the clinic]... To where I was starting the medication, and then it progressed from there pretty quickly to get to a stable dose."

"You've hit the lottery if you can find a private prescribing doctor. There's just not enough of them." Those who experienced challenges with these factors when trying to initiate treatment, or who witnessed others experiencing challenges, expressed concern about the overdose risk associated with treatment delays. They described lack of treatment options in rural areas, difficulty finding practitioners with availability (particularly at primary care sites), and long waits, particularly for residential or inpatient treatment): *"I was ready. I was ready at that point, and I couldn't do anything about it."* 

Several interviewees described long waitlists for residential or rehabilitation settings, including one who could not access inpatient care and eventually accessed treatment via the emergency room, and another who described waiting over a month for care on multiple occasions at two separate residential facilities: "Whether I go to [one facility] or whether I go to [another facility], it takes me at least a month to six weeks to get in there every single time."

Other interviewees described living in rural areas where there were no nearby treatment options, having to travel long distances or even out of state to access treatment. Some described the access difficulties of others attempting to initiate treatment, particularly within a primary care setting, due

"When we lived out in [rural town], there was nothing there. After we moved, it took me about a year to find a doctor that would take me, and it was nobody even around there." to the quantity of patients in need of treatment: "They're so overloaded with MAT patients. The trouble now is even finding a doctor that has room on their schedule."

#### **Transportation**

Interviewees recognized access to transportation as essential to initiating treatment in the rural areas where they live. Some described the importance of having their own car, such as the interviewee who stated, *"If I hadn't had my vehicle, I probably wouldn't have gone unless I could bum a ride with someone."* 

"If you don't have a car or something, how are you going to get to the methadone clinic every day?"

While transportation was not frequently reported as a personal barrier to initiating treatment, several shared the view that lack of transportation would be a significant problem for others attempting to seek treatment: "A lot of people don't have means of getting to and from places to receive treatment." Other interviewees identified not having a driver's license as an additional obstacle experienced by many people trying to access treatment.

"A lot of addicts don't have licenses, and even if they do, they don't have a vehicle to use. So, getting there is number one." Interviewees who were able to initiate treatment despite not having a driver's license or vehicle, and who reported relying on public transportation to travel to and from their appointments, described substantial barriers to continuing their treatment. These barriers, which include the considerable time required to get to appointments from rural areas via public transportation, are described in detail in Section B.

#### Insurance

Interviewees agreed that having health insurance or other financial means to cover the cost of treatment is a key factor for treatment access: *"Just not having insurance probably is the biggest [barrier]."* Interviewees described the importance of having insurance, the assistance or effort

"Once they get [you] in there and signed up, then they'll worry about insurance after, which is great. It really is [an] incentive for people to get the help. And then they have a specialist there that will help [you] get onto insurance, so that's a big leap over that barrier."

required to obtain insurance coverage through Medicaid, and the benefit of working with a treatment facility willing to start treatment while assisting with obtaining insurance coverage.

Those with sufficient insurance coverage expressed relief about not experiencing insurance as a barrier: *"I have Medicaid and Medicare, so I got lucky enough there to not have to deal with that or worry about that."* Interviewees who had private insurance coverage (most often through an employer), or who were transitioning off Medicaid coverage, reported additional barriers to maintaining steady access to MOUD treatment which are discussed in detail in Section B.

"I have kids and I'm a single mom, so it was my parents telling me, 'You need to go to rehab,' and 'Don't worry about the kids,' and 'We'll take care of it.' Because I wouldn't have wanted to just step away."

#### Childcare

Interviewees who were parents reported that reliable childcare was a necessity for treatment initiation, particularly when frequent appointments were required. They also noted the importance of childcare to enable engagement in counseling and other treatment or recovery services: "Having no childcare means not going to a meeting. I struggled with that a lot when my youngest was a baby because I didn't want to bring the baby with me to classes."

"I didn't even know that there were programs to help moms get daycare coverage. I guess it's kind of like a welfare program, but [a provider] guided me towards that program to help me get my oldest daughter into some daycare so that I could take part in some of the stuff going on at [the center]."

Some parents discussed childcare assistance they received from informal and formal mechanisms, including family assistance and state-supported programs, as instrumental in supporting their initial treatment engagement and ongoing participation in care, as they would not otherwise have had access to childcare.

#### Technology

A few interviewees reported that they were only able to access treatment because they were provided with technology needed for their treatment plan, such as a phone or tablet, which allowed for communication and participation in appointments: *"They made sure that I had a phone for my treatment, because this treatment requires a cell phone and I had lost mine at the time."* 

"My phone wouldn't let me do Zoom and one of the [staff people] that works at [the practice/clinic] gave me this lovely tablet. I thought I hit the jackpot! I've never had one like this. It comes in very handy. I do all my stuff over it because the phone still acts up.

#### Facilitators

In addition to the factors described above as both facilitators and barriers, interviewees discussed family and peer support as a distinct facilitator that helped them initiate treatment.

#### **Family and Peer Support**

Motivation and support from others helped some interviewees access treatment. This included encouragement, assistance identifying treatment locations, assistance with the initial steps of treatment enrollment, and help removing certain barriers to treatment access through transportation or child-care assistance.

"Luckily, I have an amazing family that rallied around me, and they supported me 100%. Basically, anything I needed they were there for, and they still are. I think that makes a big difference."

Some people relied on suggestions or guidance from peers or family members when initiating treatment: "I don't know if I would've done it if she wouldn't've done it for me, because I just wasn't in a good state of mind." Others shared that they first heard about treatment options through peers or friends who were actively using opioids or who were in treatment for OUD: "A friend of mine was part of the [local] treatment program so I just reached out and was put on a waiting list and then they called me, and I went in, and I've been with them since."

#### **Barriers**

In addition to the factors described as both barriers and facilitators above, interviewees discussed distinct factors that hindered their treatment initiation including stigma, lack of knowledge about treatment options, the administrative requirements for enrollment in treatment, time intensive treatment protocols, and lack of stable housing. Interviewees frequently cited multiple barriers and described how multiple barriers compounded the challenge of initiating treatment.

#### Stigma

Stigma was a recurring theme throughout the interviews, affecting experiences during treatment initiation and continuation, quality of care, and long-term recovery (each discussed in later sections of this report).

#### Theme: Stigma

Stigma deters people with OUD from initiating treatment due to fear about how they will be perceived or treated after disclosing their OUD. In addition to fear, interviewees described lived experiences of stigma.

Interviewees discussed how stigma deters those actively using opioids from initiating treatment due to fear about how they will be perceived after disclosing their use or its extent. Some also expressed concern that disclosing opioid use would prevent them from receiving prescription opioids for pain

management in the future. Interviewees described experiencing judgment or disapproval from community members and from the medical community, particularly those who lacked understanding of OUD or experience working with people with OUD. One person shared the view that stigma toward people with OUD was a barrier to the adoption of MOUD programs in certain areas: "[Town] doesn't have a MAT program, because all the snotty people in [town] don't want it in their backyard."

"There's a lot of people that I know who are still actively using that won't go seek help because of the stigma that comes along with it."

#### Lack of Knowledge About Treatment Options

Lack of knowledge about treatment resources was described as a barrier to treatment initiation: *"There are a lot of resources out there, and I know a lot of people don't know about them."* Some described difficulty figuring out how to access treatment and a sense of having to navigate the system

on their own: "I just keep going back to when I initially came to accept that I had a problem and needed help, and how frustrating it was trying to figure out how to do that."

"I only knew about [treatment] because I came to get clean needles. That shouldn't be the way that you find out, you know? I could have avoided all this by going [to treatment] before I relapsed. I would have made the switch if I'd have known the place existed."

#### **Administrative Requirements**

Once interviewees identified a treatment program or provider, some struggled with the paperwork and other administrative requirements for treatment initiation: *"It's so much paperwork [that] some people don't want to go through. I've been asked the same questions thousands of times."* 

#### **Privacy**

Lack of privacy, discussed in greater detail in Section B, was described as a barrier to treatment initiation in rural areas, especially when care options are limited: *"Everybody shows up between six and ten [o'clock], and everybody just gets a big old fat dose, and everybody knows your business."* Interviewees discussed that people seeking MOUD treatment likely do not want others with whom they regularly interact to be aware of their OUD.

"Addiction doesn't discriminate, and there's a lot of people who struggle with addiction that you and I wouldn't necessarily think would struggle with addiction. And they're certainly not going to go put themselves in a scenario where everybody in the town they've lived in for 40 years is going to know their business. I think private care is just not offered enough."

#### **Treatment Protocols**

Interviewees described treatment protocols, including the time commitment and frequency of appointments as well as limited MOUD clinic hours, as a barrier to treatment initiation: *"You have to go there every morning... And it was only open for three hours."* 

*"It was really just the rural distance and the impracticality of the daily dosing."* 

Some were discouraged by the prospect of long-term daily appointment requirements while others described the difficulty of daily appointments in the context of their rural location. Treatment protocols were described as especially difficult for those with co-occurring mental illness.

"Having to go in every single day for a single dose—That would be tolerable for maybe a week or so, but the way it was presented to me, it would be several months before I could get [treatment] without doing that. That was definitely off-putting."

"One of the things I struggled with was being homeless. I have nowhere to sweat it out for three days, even if I'm willing to, you know? I wouldn't be able to eat, drink fluids. Living just through the day takes a lot out of me, let alone trying to detox."

#### Lack of Stable Housing

Not having a safe, stable place to live was described by interviewees as an impediment to starting treatment. One person described the difficulty of facing withdrawal without a place to live, which prevented them from initiating MOUD more quickly. Other interviewees described significant housing challenges, including one who had spent time living in temporary motel housing and another who had unexpectedly lost their housing. While these examples were not discussed in direct relation to treatment initiation, they provide additional context regarding the challenging circumstances under which some interviewees accessed treatment.

#### **Multiple Barriers**

A common theme among interviewees was the need for circumstances to align across multiple factors to allow for treatment access (e.g., combinations of transportation, childcare, treatment requirements, stigma). Interviewees shared several simultaneous "They're requiring meetings or to go to the clinic five days a week with a mom who's got no car and no childcare."

barriers they encountered while initiating treatment: "The biggest obstacles were getting there, having someone to watch my daughter, and just following through with all the requirements." Interviewees' rural locations made some combinations of factors (e.g., distance to services, frequency of appointments, and lack of transportation) particularly challenging to overcome.

## A.4. Key Findings: Access

- Motivators for initiating treatment included family members (particularly children) and readiness to transition from illicit opioids to MOUD.
- Interviewees shared the belief that people with OUD need to be "*ready*" or "*motivated*" to initiate treatment.
- Some interviewees experienced quick and straightforward access, while others reported prolonged difficulty initiating treatment.
- Interviewees agreed on the importance of easy treatment access and a streamlined initiation process that would promote timely treatment and prevent the need for continued use of illicit opioids once an individual is ready to initiate treatment.
- Common barriers to treatment access included:
  - Inconvenient timing, limited patient capacity, and distant or inconvenient location of treatment services,
  - Lack of transportation, insurance, or childcare,
  - Stigma about OUD as well as MOUD,
  - Frequency of appointments, and
  - Lack of knowledge about available resources.
- Interviewees' rural locations made some combinations of factors (e.g., distance to services, frequency of appointments, and lack of transportation) particularly challenging to overcome.
- Facilitators to treatment access included:
  - Having a driver's license and vehicle,
  - $\circ~$  Having sufficient insurance coverage for treatment costs,
  - Access to childcare,
  - Access to technology,
  - Community awareness of OUD, and
  - Support from family members and peers.
- When a person is ready for treatment, multiple factors must align for treatment initiation to be successful.

## **B.** Opioid Use Disorder Treatment Experiences

In addition to their treatment access and initiation experiences, interviewees were asked to describe their ongoing experiences with OUD treatment, including their current treatment modalities and settings (Section B.1), MOUD treatment experiences (Section B.2), other nonpharmacologic treatment modalities they participate in (Section B.3), facilitators and barriers to continuing treatment (Section B.4), the quality of care they receive (Section B.5), and treatment experiences during COVID-19 (Section B.6). Key findings related to ongoing treatment experiences are outlined in Section B.7.

## **B.1.** Current Treatment Modalities and Settings

Interviewees were asked the question, **What types of treatment for substance use are you currently receiving?** All reported currently receiving MOUD, which was required for project eligibility. Most were prescribed a medication containing buprenorphine while a few reported receiving methadone. In addition to receiving MOUD, interviewees reported participating in other types of treatment or support including group and individual counseling, intensive outpatient programs, peer recovery, support groups such as Narcotics or Alcoholics Anonymous (NA or AA), and educational lectures (described in detail in B.3 below).

Responses to the question, **Around how long have you been on this treatment plan?** ranged from 1 month to almost 15 years, with a median duration of approximately 2 years. About one-third of interviewees reported that they had been on their current treatment plan for 5 or more years.

Interviewees were also asked about current treatment settings. Treatment settings included outpatient treatment clinics (e.g., Hub sites, opioid treatment programs), health centers, primary care offices (e.g., Spokes, office-based settings), rehabilitation facilities, and recovery centers. Some interviewees participated in concurrent services in more than one setting: *"I'm in a MAT program at a clinic here in [town]. I'm on the methadone program. I also attend a couple groups at [recovery center], and that's also here in [town], and I am part of a fellowship for NA."* Several interviewees reported accessing services at recovery centers in addition to primary care offices or outpatient treatment clinics.

## **B.2. Medication Treatment Experiences**

Interviewees were asked to describe their current experience receiving MOUD including their likes and dislikes related to MOUD treatment. They were also asked how their current MOUD treatment experience compared to any past MOUD treatment experiences, which for many included transitions between MOUDs (e.g., from methadone to buprenorphine) as well as improvements in their care experience.

### **Medication Treatment Likes and Dislikes**

Many interviewees, particularly those with longer duration on their current treatment regimen, described their current MOUD experience as a significant improvement over prior treatment experiences. This was attributed to factors such as greater treatment accessibility, improved patientprovider relationships, less frequent appointments, and receipt of take-home doses or prescriptions for MOUD: "What I like now is that I was able to graduate up to just having to get it from my primary, so it's a lot easier and I only have to go see them like once every two months right now."

"[Treatment] seems to be more present now— They have more of a presence in [town], and they [are] more online. Years ago, it felt kind of lonely... To try to find help was a really big struggle."

Other interviewees, primarily those with shorter duration on their current treatment regimen, shared less favorable aspects of their MOUD experience. These included frequent appointments and/or urinalysis (described in detail in Barriers below), removal of take-home privileges following return to use, dislike of their MOUD delivery modality, breakthrough withdrawal symptoms between doses, and MOUD side effects: *"[Sublingual buprenorphine] blisters underneath my tongue. If I put it on the roof of my mouth, it'll blister the roof of my mouth... And I hate the taste of it."* 

"Take-homes is a huge issue. I have been there almost a year and had one dirty urine since I began, and I got all my take-homes taken away for that. That was a harsh penalty for a small thing." "You do get some side effects. You have to keep moving, because if you sit down on methadone, you're going to fall asleep. And then it wears off, and then you're sick for the rest of the day."

#### **Medication Transitions**

Several interviewees reported having experience with more than one MOUD throughout their treatment history. Some reported transitioning from buprenorphine to methadone to help manage withdrawal symptoms, while some currently receiving buprenorphine treatment reported prior treatment with methadone. For a few, transitions coincided with involvement in the correctional system (e.g., drug court, incarceration): "I wanted to wean down, because [neighboring state] jails don't give you that type of medication."

Although transitioning from buprenorphine to methadone (rather than vice versa) was more commonly reported as a method of addressing withdrawal symptoms or cravings, one interviewee described transitioning from methadone to buprenorphine because "[methadone] didn't feel like it got me all the way through the day," which the interviewee thought may have been due to an insufficient dose. Finally, one participant currently receiving methadone reported prior treatment experience with extended-release naltrexone.

## **B.3. Other Treatment Modalities**

All participants reported currently receiving some form of non-MOUD treatment, such as counseling (weekly to monthly) or a regular check-in with an auxiliary practitioner or team member as part of

"We're required to either go to a group or see a counselor one-on-one at least once a month, or else we won't get dosed." their MOUD treatment protocol. Check-ins for some were coordinated around the timing of their appointment with their MOUD prescriber. Some interviewees who were receiving their MOUD within a clinic setting described counseling as mandatory. Counseling services, particularly those provided in a group format, were disrupted due to the COVID-19 pandemic (described further in Section 6).

A few interviewees reported receiving counseling for reasons other than OUD, including one whose counseling switched focus from opioid use to other substance use once their cravings for opioids had abated. Additionally, many interviewees mentioned receiving services through recovery centers or support groups, such as the interviewee who shared: "*I do attend one AA meeting, though NA is more of what my problems were.*" A few others described working with recovery coaches. Finally, many interviewees reported having received services through residential rehabilitation settings, sometimes multiple times: "*I went to rehab from the ER, and then I ended up relapsing, and then I went back to rehab again.*"

## **B.4.** Facilitators and Barriers to Continuing Treatment

Similar to the experiences described in Section A regarding treatment *access*, interviewees identified multiple factors that either facilitated or impeded their *ongoing* treatment and recovery. Several of these facilitators and barriers were the same as those identified during treatment initiation, including insurance, privacy, transportation, time requirements, and stigma. Some participants discussed factors relevant to their current treatment experience, while many shared factors relevant to prior treatment experiences.

#### Factors Described as Both Facilitators and Barriers

#### **Coordinated or Consolidated Care**

Interviewees commented on the helpfulness and convenience of consolidated or coordinated care, including receiving all health care services through one provider, meeting with MOUD treatment providers and counselors or other auxiliary providers backto-back, and providers from different settings coordinating with one another. This coordination resulted in saved time and energy for interviewees and strengthened the continuity of their care.

"I had my primary care, then I had my Suboxone doctor, then I had the behavioral health doctor. So, I was going to three different doctors and counselors and I'm like, 'That's too much, I feel like I'm crazy, bouncing here and there.' I said [to my Suboxone doctor], 'Can't you do all that?' After they said yes, they'd be my primary care, it's all worked wonderfully."

A few interviewees described how the continuity of care between the correctional system and providers in the community allowed them to continue treatment, such as an interviewee who described the benefit of receiving a prescription for MOUD upon release from incarceration to bridge the gap while transitioning to community treatment: *"The doctor at the institution I was at, they had written a prescription for a two-week supply, to have that transition time without having to go without and be able to get into the clinic and go from there."* 

In contrast, some interviewees discussed the challenges of having their health care managed by multiple providers in different locations, including one who reported that poor coordination slowed their treatment progression: *"I should be at tier one and I'm not because there's issues with the doctor and the clinicians and counselors getting along—in all of the places, actually, so it's not just one. There is a barrier."* 

#### Insurance

Similar to the importance of insurance coverage for treatment initiation described in Section A, interviewees discussed the importance of comprehensive insurance coverage for continuing treatment as well as challenges they had experienced related to insurance transitions. Several interviewees with Medicaid coverage reported that their insurance made their MOUD treatment affordable: "*I'm on Medicaid insurance. Yeah, that covers it pretty well.*" This sentiment was echoed by another participant with Medicaid coverage regarding the affordability of their MOUD prescription: "*I go to the pharmacy once a week, pay a dollar, and I get a week's worth.*"

Those with private insurance described varying experiences. Some interviewees described concerns about the cost-sharing required by private insurance plans, such as the cost of MOUD and other treatment services like urinalysis, or the stress associated with losing Medicaid coverage and facing unknown treatment costs with new employment.

"My insurance only covers maybe half of my appointment and... I have to do a [urinalysis] usually, too, so I have to pay for those."

"Now that I'm working full time, all that goes away—[the Medicaid] I was getting—So, I know that's going to change, and honestly [it] has caused a lot of stress and my security in being still actively recovering, because I'm scared to death that I'm not going to be able to afford my medicine."

Conversely, one person described benefiting from gaining employer-sponsored health insurance and accessing extended-release naltrexone without cost: *"I got a job and they paid for [extended-release naltrexone], and then there's a copay assistance thing from the medication, so I was paying nothing."* 

"Honestly, it's cheaper to pay out of pocket than it would be for me to have insurance, because the deductibles are so high." Some interviewees discussed receiving assistance with obtaining insurance or working with a provider's office to establish a payment plan for services: "My doctor's office is really good about setting up a payment arrangement. They take so much out of my account every month, and they just let my bill run up, and that's it." One uninsured interviewee explained that the cost of their care was less than paying private insurance premiums and costsharing.

#### **Privacy**

Interviewees discussed privacy as an important factor in continuing their treatment. Some shared concerns about lack of privacy while receiving MOUD in a clinic setting with other individuals receiving MOUD, including confidentiality of test results.

"When I had to go to the methadone clinic, I had relapsed and they had announced it, basically, to the whole group of people. They're like, 'Oh, your [urinalysis] is dirty for this,' and then they would only give you, like, half of your dose, too."

Other interviewees shared their preference for treatment within primary care offices or through telemedicine services rather than within outpatient clinic settings for greater privacy during appointments, as well as the privacy afforded by obtaining MOUD through a pharmacy: *"I prefer going to the pharmacy. Nobody knows what I'm picking up but the pharmacist."* 

#### **Transportation**

There was consensus among interviewees that reliable transportation is essential for both treatment access (described in Section A) and continuation. Many interviewees discussed the benefit of having their own car for attending treatment appointments. A few discussed the ability to arrange rides through treatment facilities: "Now it's like you make a phone call to the treatment center and they can hook you up with counseling or treatments, they can even give you rides."

Those who lacked a vehicle, either currently or in the past, discussed their experiences using public transportation to attend appointments. While one person shared that taking the bus to appointments works well when appointments are infrequent: *"If I don't have a lot of appointments, the bus works a lot. It's free,"* most interviewees who discussed public transportation reported substantial challenges due to limited bus routes and long wait times in rural areas, which add to the overall time spent receiving services on a given day.

"We have a bus that comes every hour and a half, but if you have back-to-back appointments like I normally do, it's hard waiting an hour and a half in between the bus."

"I used to take the bus out to [town] when I didn't have a car and my car was down and literally, I would leave and catch the first bus in the morning at 6 a.m. and not get back to my house until 5:30 at night." Some interviewees did not have a valid driver's license, and thus needed to rely on others for rides to appointments: "I was probably a half-hour away from where I had to go every day to get my medication and see my doctor. And at the time I didn't have a license, so I was relying on my partner or my mom, someone to give me a ride."

"I think the best way to do it is to go to [inpatient] treatment. It's just really, really hard to do it in your community around the people that you're using with, having access to a phone, being able to get texts from people still, go and get stuff, and still working you need to be removed from it, is my look on it."

#### **Social and Treatment Environment**

Several interviewees discussed their surrounding environments and peers within their communities and treatment settings as factors that affected their treatment continuation. Some talked about removing themselves from the presence of people in active use, or choosing to spend their time with friends who did not use opioids, as key factors in continuing their treatment and recovery: "People, places, and things— I know you hear that all the time, but it's so true, and I think if I hadn't gotten away from where I was living, [continuing recovery] would have been impossible for me."

Other interviewees described the difficulty of continued interactions with individuals with whom they had previously used opioids or others in active opioid use: *"I think cutting ties with a lot of people that were unhealthy, that was the hardest part. And now still running into those people is a big challenge for me."* 

Some interviewees discussed their perception that treatment settings where people in active substance use receive services are particularly challenging environments due to the potential availability of illicit opioids: *"Mixing in the people that abstain with the harm reduction people 1 think is a huge problem."* Of those, some made the distinction between what they perceived as two separate groups: people who are actively working toward, or *"genuine,"* in their recovery, and people who receive MOUD while continuing to use illicit opioids.

**Belief: "Genuine" Recovery** 

Interviewees shared the belief that there are two groups of people who receive treatment: those who are "genuine" or serious about treatment and who want to abstain from use, and those who continue to use substances or receive treatment for harm reduction. Other interviewees talked about exposure to illicit substances in housing environments, including shelters and recovery residences: "I have learned from other people going to [facility] and [facility] numerous times that there's sober houses and some of them are good and then others, people just go there, they live, and they do drugs."

"I refuse to stay in a shelter because there's literally people that will stand right outside the shelter and be waiting for you to sell you drugs."

While many interviewees shared about the challenges of continuing recovery in certain treatment settings, a few discussed the benefits of a supportive treatment environment where they could participate in activities or classes that allowed them to focus on health and recovery and connect with supportive peers: "I notice the busier I am with my appointments, the better off I feel. It just gets me closer—I'm around more people that I feel like actually care about what's going on with me."

One interviewee commented on the need for other reinforcing activities within the community to help occupy time: "It'd be nice to have more—even just like in my town, I don't know if there is even like sober community spaces... It'd be nice to see."

#### **Barriers**

#### Stigma

Many interviewees discussed stigma as a negative factor in their treatment experience. While some described increased community awareness compared to the past, interviewees expressed the collective view that stigma about OUD remains an issue: "I feel like it's gotten better over the past few years, but there's absolutely a stigma." Notably, several interviewees used stigmatizing language such as "addict" or "junkie" to describe themselves or to differentiate themselves from those in active use or from their own prior use: "I know I'll always be an addict, but I don't want to feel like a junkie, still. You want to feel proud. You want to feel like you've removed yourself from that lifestyle and situation."

Theme: Stigma People with OUD experience stigma, and also both use and express fear and frustration about stigmatizing labels associated with OUD: "user," "addict," "junkie."

"I hated joining the clinic, because everybody knows that I'm a drug addict now."

#### **Requirements of Treatment Programs**

As discussed in the Transportation section above as well as in Section A, interviewees described the time burden of OUD treatment in clinic settings, including daily appointments, random urinalyses, and the amount of time required for appointments on a given day: *"[Treatment is] three hours of your day, minimum. Then if you miss the bus, it's four and a half hours of your day."* One interviewee lamented not having lived *"years of my life… to the fullest"* due to the time spent initiating and continuing OUD treatment and recovery services. Difficulties with time and transportation often exacerbated one another, particularly for those relying on public transportation to get to their appointments.

"At [clinic], they would make you go to meetings twice a week, you have to see the doctor maybe once every two weeks, and then you'd have to get random UAs, so you'd have to drive over there whenever they called you to do your UA and stuff. I don't know; it's a lot of hoops to jump through."

"If I have to go there every day, it kind of would ruin—it wouldn't leave much of a day left for me to do everything I've got to do, that's all. So, with the doctor and doing the Suboxone, it gives me more of a life to do other things that I gotta do." Other interviewees described how receiving MOUD through private practitioners with less frequent appointments provides more time for other essential activities.

Some participants described rigorous or inflexible program expectations in certain treatment environments, such as requiring complete abstinence from opioids or other

substances (e.g., alcohol) to receive MOUD, and having their MOUD dose reduced or taken away for not meeting this requirement: "If I blew any numbers on an alcohol breath tester, I couldn't get my dose, or I'd get a split dose—half my dose or less. And so, I'm still being dope sick every so often, and sometimes really bad. When I'm in treatment and I haven't used for years, I shouldn't be laying in bed dope sick, sweating, with restless legs as if I just did heroin all weekend long."

## B.5. Quality of Care

Quality of care played a role in either facilitating or impeding interviewees' treatment engagement. Some interviewees described high-quality care that helped them remain engaged in treatment and focused on continued abstinence, while others described care experiences that negatively impacted their treatment engagement or progress.

### **High Quality Care**

Interviewees discussed various aspects of patientcentered care that positively affected their treatment experiences. Several commented on their involvement in decision-making about their MOUD dose, or discussions with their providers about managing cravings: *"Every time I go in, they ask me, 'Is this current dosing working for you, are you having cravings, do we need to adjust?' So, yeah, I feel I can talk to them."* 

"They've all been really caring and supportive and make it pretty easy to have my appointments and get my prescriptions. They stay on top of it, and it's been good. 'Cause I wouldn't do it otherwise."

Others discussed how having positive, caring, and supportive treatment teams and feeling respected by their providers helped them stay motivated to remain in treatment, as well as the reassurance that comes with "always [having] a team behind me." Interviewees described their treatment providers helping them problem-solve and remain engaged in treatment, including staying on track with their appointments and MOUD.

Several interviewees shared the concern that returns to use could lead to dismissal from a treatment program or withholding of MOUD doses. One interviewee described the comfort they felt upon learning that returns to use prompted a conversation with their treatment provider for the purpose of refocusing on treatment goals or MOUD dose adjustment, rather than penalties.

"If you do have any kind of slip, fall, whatever you want to call it—and as long as you are honest with them—yes, they will be let down, but they need you to not dwell on it and they need you to get back in your program, brush yourself off, don't beat yourself up and keep using, just get to where you were before that and, you know—they care about you there." Finally, some interviewees described providers who they felt went out of their way to deliver additional resources or assistance, such as finding food assistance, providing technology, or providing gas cards to help offset transportation expenses.

"They helped me [with] anything from resources, to finding food during the pandemic, getting gifts around Christmastime. They even at one point helped me find a gift card to get gas so I could go to my appointments and go to work."

#### **Negative Care Experiences**

Many participants also reported negative treatment experiences, some recent and many past, which affected their treatment or hindered their desired treatment outcomes. Some interviewees reported feeling stigmatized by members of the medical community who lacked understanding of OUD or experience working with people with OUD. Some described feeling labeled or judged while receiving services from emergency department or specialist providers, or while attending primary care

appointments: "I've been pregnant twice since I've been on a MAT program and there's a lot of stigma even from providers, especially providers who don't really understand Suboxone treatment. A lot of judgment but maybe not so much even interested in learning about it, just placing you in a category of a 'user.'"

#### **Theme: Stigma**

Interviewees described feeling judged or labeled by members of the medical community who lacked knowledge about or experience with treating OUD.

"I told them I was on the verge of relapse. I told them I was slipping. I told them that day that this is the end, like, this is it. That's three days in a row you took my dose from me for no reason. Like, I'm dope sick. I'm not going to go another day over nothing... So, I left and used." Some interviewees described experiences in which they did not have input regarding their treatment plan, did not feel that their provider listened when they requested an increase in their MOUD dose to relieve withdrawal symptoms, or had their MOUD stopped against their wishes. In some instances, these experiences resulted in the illicit purchase of MOUD to supplement a prescribed dose, or a return to illicit opioid use. One interviewee described supplementing their prescribed MOUD dose with additional illicitly acquired MOUD after frequent unsuccessful requests to their provider to increase their dose: "I have worked so hard and whatever I would buy on the street would end up being exactly 2mg, and that's all I had asked [my provider] was, 'Can we bump it up even 2mg, a milligram, something? 'Cause I'm not holding—I'm not in a good space. This isn't working.'" Interviewees noted a handful of other negative care experiences including staff turnover and inappropriate staff behavior at one treatment site, an uncomfortable unmedicated supervised withdrawal experience, and difficulty finding a recovery coach with sufficient availability.

## **B.6. Treatment Experiences During COVID-19**

Participants were interviewed between August and December 2021 and were asked how the COVID-19 pandemic affected their treatment and recovery experiences. The most commonly reported change was the transition from in-person appointments to online counseling or telehealth sessions. Some interviewees also noted cancellation of groups and fewer urinalyses. Interviewees reported additional challenges during COVID-19, but also some beneficial treatment changes. Some interviewees reported that COVID-19 had minimal or no impact on their OUD treatment.

### Negative Treatment Impacts During COVID-19

Several interviewees described how COVID-19-related changes to their treatment services had negatively affected their treatment progression or treatment experience: *"COVID really put a damper on the processes and the protocols, and, you know, the way that people progressed."* These changes resulted in pauses and delays for in-person appointments, canceled appointments, longer wait times for MOUD, and challenges finding counselors. For some, these COVID-19-related challenges compounded existing difficulties.

"The times became twice as long. I mean, there were days you had to literally wait in line for four hours. You could get there on time, and they couldn't get you in."

Some interviewees discussed the negative impact of canceled support group meetings, such as not getting to associate with one's peers in treatment or missed learning opportunities: "I like to go to meetings here and there—You know, when I have some free time, shoot to a meeting. You never know what you're going to hear, and you always meet some good people. That stopped."

"Having the social issues that I have, already having a hard time showing up to appointments, that whole COVID thing just—I regressed so bad."

While remote counseling or group sessions were sometimes available, some preferred the in-person to the remote experience: "I feel like it's kind of hard to connect with someone through a screen, and like read body language and stuff like that."

#### Positive Treatment Impacts During COVID-19

Some interviewees described positive changes that resulted from the transition from in-person to telehealth appointments, including the convenience of communicating with providers from home or work and not having to travel or take time off from work to attend appointments. One interviewee described how the availability of online services has allowed people in rural communities to increase their participation in meetings and groups: "I do think having things on Zoom now has helped a lot of folks who are rural, or... just way out in the middle of nowhere. I know having AA meetings on Zoom, NA on Zoom, we have groups on Zoom. That stuff, I think, has helped a lot for folks."

"I can email [a member of my treatment team] at any time and say, 'Hey, when you get a chance, can you give me a call?' And we'll either connect on the computer, or we talk on the phone. And that can happen almost at the snap of my fingers."

"For me it was just better, 'cause I didn't have to worry about going to the doctor every time, and especially if it was early in the morning, I could just get on the phone. Or if I'm at work I can just get on the phone. I don't have to take the time off."

#### No Treatment Impacts During COVID-19

Finally, a few interviewees reported that COVID-19 related changes did not disrupt their treatment experience, despite the larger effects of COVID-19 on care providers: *"At the health center, they were busier and more stressed and overworked at times, but it didn't affect me or my care in any way."* Some interviewees commented on the continuity of care from in-person to telehealth appointments and felt that their care experience was similar between the two.

## B.7. Key Findings: Experience Continuing Treatment

- All interviewees were receiving MOUD, with more receiving buprenorphine than methadone. Several described experiences with more than one MOUD during their treatment history.
- Interviewees who were more established with their current treatment providers and MOUD tended to describe more favorable current treatment experiences than those who had been on their current MOUD or with their current provider for less time.
- Receiving MOUD in a primary care setting was viewed more favorably than receiving MOUD at a clinic where frequent appointments are required and privacy is limited when waiting in line with others to receive treatment.
- Barriers to treatment continuation included:
  - o lack of insurance coverage for treatment costs and high out-of-pocket expenses,
  - o lack of privacy in clinic-based treatment settings,
  - continued exposure to others actively using opioids within social and treatment environments, and
  - reliance on public transportation, which increased the time requirements of treatment.
- A key theme that emerged was the belief that people in treatment differ by whether they are abstinent and thus *"genuine"* in their treatment or accessing treatment for harm reduction purposes or while continuing to use substances.
- Social and treatment environments with people in active use present were viewed as highrisk for return to use.
- Other factors that interfered with successful treatment outcomes included stigma, lack of input in treatment decisions, and not feeling heard by members of the care team.
- Facilitators to ongoing engagement in treatment included:
  - o coordinated care,
  - insurance coverage of treatment costs, and
  - o privacy and flexibility of treatment services within primary care vs. treatment clinics.
- Patient-centered care positively impacted interviewees' treatment experiences and included involvement in MOUD decisions, caring and supportive treatment providers, and respectful and nonjudgmental treatment.
- COVID-19 presented additional challenges to treatment continuation as well as some beneficial treatment changes.

# C. Recovery Success, Unmet Needs, and Recommendations for Improved Care

Interviewees were asked to describe how they envisioned their long-term recovery success (Section C.1). They were also asked for recommendations on how health care organizations and providers might improve the experience of care for people with OUD. This included how provider organizations could address interviewees' unmet treatment needs, enhance their engagement in treatment and recovery services as well as ensure their patients' involvement in and understanding of their OUD care (Section C.2). Finally, interviewees were asked what they wanted their providers to know about their experience with and treatment for OUD (Section C.3). Key findings are outlined in Section C.4.

## C.1. Long-Term Recovery Success

Interviewees were asked the question, **Thinking about the future**, **what does long-term recovery success look like for you?** In response, almost all interviewees expressed the desire to eventually discontinue methadone or buprenorphine, with many wanting to do so to be "*free of all addictions*," or due to concern about "*still getting an opiate*."

Two overlapping beliefs emerged from these views about longterm recovery success. The first is that use of MOUD represents an addiction or dependency. Some viewed moving beyond MOUD as

Belief: MOUD as an Addiction Receiving MOUD represents an addiction or dependency. Successful long-term recovery involves stopping all opioids, including MOUD.

a strength: "I'm sick of being addicted to stuff, and I know I'm finally ready to be able to be strong enough off of it." The second, related belief is that successful recovery from OUD involves ending "all addictions," including perceived dependency on MOUD. A few interviewees referred to MOUD as a "crutch," implying that it was heavily relied upon, had persisted longer than expected, or precluded what interviewees perceived as complete recovery from OUD.

"I don't like that I still have a crutch. I feel like it's—I don't know if I'm ever going to be able to get myself off of it completely, and that's scary to me. I feel that that's one piece that's linking me to my past." A few interviewees described the goal of transitioning from buprenorphine or methadone to extended-release naltrexone to be *"opioid free,"* or because they viewed naltrexone to be less addictive: *"Certainly being opioid free is the goal. I've talked several different times about transferring from Suboxone to—what's it called? Naltrexone, I guess."* 

Thus, while recognizing the benefits of MOUD in their treatment and recovery, many interviewees also expressed concern that long-term use of opioid agonists would perpetuate their dependency on opioids or continue to influence how they were perceived by others. While most interviewees expressed the desire to stop taking MOUD, only some discussed a timeframe or plan for tapering or discontinuing their MOUD. It was unclear whether most interviewees felt they had the resources and support to do so. Some expressed apprehension about the taper process, including concerns about experiencing withdrawal symptoms, overcoming the final taper dose, and maintaining abstinence from illicit opioids.

"I know my supports are there, and I know people who are kind of nudging me along. It's just that's a scary process. I've maintained, now, and I've—and this is the first time in my life, since before I started using, that I've been at this level, so it's just a personal choice, and, you know, it's scary."

Finally, many respondents shared long-term goals beyond their plan for MOUD, including acquiring stable housing, recovery from dependence on other substances, managing chronic pain, enjoying time with family, moving beyond worry about opioid cravings or withdrawal symptoms, and assisting others in their recovery.

"I have dreams of myself being sober and I can see myself helping other people. I've just got to make it first." "To eventually live a normal life where I'm not thinking about getting high and lead that lifestyle."

## C.2. Unmet Needs and Recommendations for Improved Care

Interviewees were asked, What could your current provider organizations(s) do better to meet your needs and help you remain engaged in treatment and recovery services? and, What could your current provider organizations(s) change to help you feel listened to, informed, and involved in your care? Overall, interviewees expressed satisfaction with their OUD treatment providers and with

the care they were receiving. However, some shared ways in which providers could better meet their treatment needs or improve their treatment engagement. These included increased contact time with providers, expanded service hours, provision of childcare, offering aftercare planning, holding patients accountable to their treatment plan, and improved integration or collaboration across providers and services. Satisfaction with current care as well as suggestions for improvement are described below.

## Satisfaction with Current Care

When asked about unmet needs and ways they could feel more involved in their OUD treatment, several interviewees expressed contentment with their current provider organizations, treatment course, and level of engagement in their care: "The nurse[s] that they have there are really good

"I think in some ways, sometimes they care more about me than I care about myself." ladies and they try to do whatever they can—They got a good group there, they really do. I'm not sure if they need to change anything right now." When asked about potential improvements, some made additional comments about their satisfaction: "I'm happy with the way things are going now." Many

also described feeling listened to, informed about their treatment plan, and involved in their care. When asked what their providers could change to increase their treatment involvement, one respondent shared that their providers' concern about their recovery exceeded their own, while others described feeling validated and included in treatment decisions: "I can't say anything about my provider now that I would want any different as far as hearing me out and me feeling heard and validated and understood."

## Suggestions for Improvement

## **Additional Contact Time With Providers**

While many interviewees expressed satisfaction with their level of treatment, some felt it would be beneficial to increase the amount of time they spent with their providers during appointments or through check-ins between appointments. This sentiment was more common among those who were well-established in treatment and therefore met less frequently with their treatment providers. "Every now and then I feel like I don't get enough time with the doctor because they're running between the hospital and... That leaves them short down at the office. So, just a little bit more time with them." "There's not a whole lot of flexibility for people who have families or who work full time to be able to get to meetings. So, if I could ask for something, it would probably be a more 24/7— or maybe not 24/7—but a more open treatment facility nearby that offered that kind of thing."

"If they were offering a group, I feel if they could have somebody—another therapist or somebody that could watch the children, I think that would be a huge step in the right direction. I think a lot more people could commit to that if they had somebody to watch their children."

## **Expanded Service Hours and Childcare**

Interviewees thought it would be helpful for providers to expand their service hours to give those who work full time or who have daytime childcare responsibilities the opportunity to attend appointments and meetings after work. A few expressed the desire to coordinate provider visits with other treatment services to decrease the amount of time spent traveling to and from appointments. One person recommended offering home visits: "Home health, essentially, but addiction-style. I think that would be such a great resource for people." Additionally, some parents discussed how on-site childcare would allow them to participate in additional services, such as meetings or counseling.

## **Aftercare Planning**

A few interviewees described the need for a greater emphasis on helping those transitioning from rehabilitation or residential treatment to outpatient MOUD feel better prepared for potential barriers to treatment and make connections with new providers and services. Interviewees described the potential benefit of discussions with treatment providers about anticipated living arrangements and employment plans as well as the desire for a more active role in the transition process.

"I think they need to do more for the aftercare plan. Instead of giving you group after group after group, have more one-on-ones and, you know, 'What are you going to do for employment? What are you going to do for housing? Is this safe for you? Is this a safe environment? Is this unsafe? Are these safe people to be around?""

## **Holding Patients Accountable**

A few respondents shared the view that providers should hold their patients more "accountable" during treatment, which contrasted with the prevailing desire for more flexible dosing and appointments. Examples included emphasizing the importance of regular appointment attendance and verifying abstinence from illicit opioids through observed urinalyses.

"[Provider] is very good at their job, but most recently, they'll say, 'Oh, that's okay. I understand that things are hard, and you couldn't make it here.' Just once say, 'Nope, I do not understand. There is no excuse. Get your ass in this office.'... And that's only for my personal—That's not 'cause they're not doing their job. That's just to motivate me to be better."

"There have been plenty of times where I felt like there could be much better communication between different health care providers and different venues for seeking help. Just some sort of—a better way of consolidation, basically, and having a more uniform approach throughout the state to figuring out how to get help."

## **Collaboration Across Providers**

Interviewees discussed their desire for better communication and integration between providers, both across and within agencies. Suggestions included improved communication between service providers and treatment settings to facilitate the transfer of services from one location to another, a consistent, respectful approach to patient engagement across the care team, and a uniform statewide approach to link people with treatment and services.

## **Greater Involvement and Input in Care and Decisions**

Interviewees expressed a desire to have greater involvement in decisions about their care, such as access to their medical records, and input on the timing and formulation (e.g., sublingual tablet vs. film) of their MOUD. A few interviewees also expressed apprehension about their treatment providers' perceptions of them. This apprehension at times precluded interviewees from actively seeking participation in their care (e.g., asking to view medical records, asking for a change in MOUD modality). Interviewees expressed a desire for reassurance from their providers that they are trusted and respected.

"You want to look at your chart because you want to know what's in there. You want to know if it says 'This person is doing great' or 'This person is just lying to me.' You don't know. I think accessing some of those documents might be helpful."

## **Residential Treatment**

Some interviewees commented on the desire to leave their own community for treatment, and the need for additional residential/rehabilitation treatment options within the state: *"There's not enough rehabs or recovery houses. There's just not enough here in Vermont."* In addition to describing challenges such as waitlists to enter existing facilities, a few people described the need for longer stays (i.e., longer than a few weeks) with more counseling and aftercare planning, or assistance with the costs associated with out-of-state residential treatment services.

"There's two—two maybe treatment facilities. I was talking to a buddy the other day that was struggling and telling him that he should probably go away, and he said, 'You know, I keep trying, it's there's a three-week waitlist.'" "You had maybe 30 days, and I kind of had to advocate to stay later—and the second time I went they only let me stay for two weeks before they were like, 'You don't need to be here anymore,' unless you had an alcohol addiction, then you could stay for 30 days... Their time was getting less and less, and they were just trying to open beds up for more people."

## C.3. What Care Providers Should Know about OUD and Treatment

Lastly, interviewees were asked the question, **What do you want the people providing your care to know about your experience with opioid use and treatment?** Interviewees shared different perspectives on what they would like their care providers to understand about their personal treatment experience. Their responses are grouped into two sections below. First, some interviewees wanted their care providers to better understand how barriers such as transportation and stigma affect the initiation and continuation of OUD and other health care treatment. Second, some interviewees wished that their providers were more understanding of the lived experience of people with OUD (e.g., experiencing cravings, return to use despite negative consequences).

## **Improve Understanding of Treatment Barriers**

Several interviewees described wanting their providers to know the ways in which treatment barriers such as lack of transportation, lack of support, and stigma can affect initiation and continuation of MOUD and other treatment services. Regarding stigma, interviewees wanted providers to know that seeking medical attention should not be judged as opioid-seeking behavior. Some wanted providers to know that not all people receiving MOUD want to do so indefinitely, and others wanted their providers to better understand their challenges in overcoming barriers to treatment: *"I think that if they knew and understood our barriers a little bit more as far as the beginning process, there'd be a little bit more understanding of why we come in hostile."* 

"A lot of them, they get shocked when they find out you don't have family to rely on. And they're like, 'Well, can't you get a ride here?' No, I literally don't have a friend with a car. Everywhere I go, I have to ride a bike or walk. 'You can't find somebody?' No, I really can't find somebody... I'm self-reliant. I only have me."

## **Theme: Stigma**

Interviewees wanted providers to understand that people in treatment need to access medical care, and that they should not assume that people in treatment are seeking opioids or automatically label them as opioid-seeking when they require medical attention.

"If we're coming in with a problem, it doesn't mean we're automatically seeking [opioids]. I feel like I've had that label kind of slapped on my back, not by my primary care or by people that know I'm receiving treatment through MAT, but by any doctor."

## **Improve Understanding of OUD**

Some interviewees wished that all care providers better understood aspects of OUD, such as what it feels like to experience opioid dependence, the effort involved in continuing recovery, and the fact that OUD is not a choice.

"When I first started [opioid use], I didn't know that it was going to lead me where it led me."

"I always wished that they, or anyone, could better understand what it's like to suffer with this... They definitely recognize that I'm serious about it and doing it for the right reasons. But yeah—I guess sometimes I wish they could know just how much I'm trying, even when it may seem I'm not."

Finally, interviewees discussed suggestions on how providers handle returns to use. One participant suggested that returns to use should be an anticipated part of the treatment and recovery process, and that they should not result in reduced dosing or discontinuation of treatment when they occur. Some participants spoke about how having OUD had resulted in continued use of opioids despite significant consequences.

"Relapses happen, and you can't reprimand someone or use their medication as a—
'Cause there are some doctors that, you mess up, and they take it right away, and then you're back and you're starting over, or the dose is cut in half...
You shouldn't do that. It's just showing them that, 'Hey, you might as well just go finish using and come back tomorrow and start your dose the right way.'"

# C.4. Key Findings: Recovery Success, Unmet Needs and Recommendations for Improved Care

- Almost all interviewees shared the view that long-term recovery success would involve discontinuing MOUD.
- Interviewees expressed the belief that use of MOUD, particularly buprenorphine and methadone, was similar to use of illicit opioids in that it involved *"addiction"* or dependency and continued opioid use. A few interviewees described MOUD as a *"crutch."*
- Beliefs surrounding MOUD as an "addiction" or "crutch" appeared to influence interviewee beliefs about successful recovery from OUD, specifically that long-term recovery success required ending "all addictions," including MOUD.
- Many interviewees were satisfied with their OUD treatment providers and with the care they were currently receiving.
- Ways in which providers could better meet interviewees' treatment needs or enhance their treatment involvement included:
  - o increased contact time with providers,
  - expanded service hours,
  - o on-site childcare,
  - o improved aftercare planning,
  - o better collaboration across providers and services,
  - $\circ~$  greater patient involvement in care and input on care decisions, and
  - expanded residential treatment options.
- Interviewees wanted their treatment providers to better understand how barriers (e.g., transportation, stigma) affect the initiation and continuation of OUD treatment.
- Interviewees wanted their health care providers to better understand OUD, including the
  effort involved in continuing recovery, that return to use should be anticipated as part of the
  recovery process, and that opioid dependence can lead to continued use despite significant
  negative consequences.

## **Takeaways**

Interviewees described several barriers to initiating and/or continuing treatment (e.g., the timing, capacity, and location of treatment; transportation; insurance; stigma) and the ways in which these obstacles interacted to affect treatment. For example, difficulties with time and transportation often compounded one another, particularly for rural patients relying on public transit to attend frequent treatment appointments. The treatment setting also often impacted the number of barriers experienced, with services through primary care offices often associated with reduced barriers to treatment continuation as compared to opioid treatment program settings (i.e., "hubs" or clinic settings).

Although opioid treatment program ("clinic") settings were described as the most available treatment option to people in the rural areas included in this project, they were often identified as the least favorable with the most barriers to continued treatment engagement. Interviewees who received MOUD in these clinic settings described long travel times due to large service areas, frequent appointments, rigid program requirements, privacy breaches, MOUD stoppages or reductions in response to substance use, and difficult interactions with other patients who were in active use. Interviewees also reported hearing negative things about these settings from their peers. As treatment sites continue to improve their practices and move toward patient-centered care, messaging must occur in the community to offset information from word-of-mouth or prior experiences that may not reflect current treatment practices.

Many of the challenges described by interviewees related to their rural location, including the need for reliable transportation, the time required for daily appointments, and limited treatment options in their immediate area. These rural barriers indicate the need for treatment protocols and resources that consider the specific needs of rural Vermonters and ensure that MOUD treatment and associated supports are easy to access.

Unsurprisingly, the COVID-19 pandemic disrupted OUD treatment by limiting contact with providers, increasing appointment wait times, and eliminating or reducing individual and group counseling sessions. For some, these disruptions resulted in perceived slowing of treatment progress. COVID-19 also brought positive treatment changes, with increased access to telehealth and online options for check-ins with MOUD providers, counseling sessions, and groups. For some interviewees, these options were convenient, timesaving, and gave people in rural areas the opportunity to access services that might not otherwise have been available due to time, distance, and transportation barriers.

Overall, many interviewees were satisfied with their OUD treatment providers and with the current care they were receiving in Vermont and hoped that this progress would continue. Nevertheless, several interviewees also shared suggestions for treatment improvement that aligned with many of the reported barriers to care, such as expanded service hours, on-site childcare, improved collaboration across providers or services, greater patient input and involvement in treatment decisions, increased contact time with providers, and better after-care planning when transitioning from residential to community services.

Three primary belief themes emerged during the interviews. The first belief was that people with OUD need to be "ready" or "motivated" to initiate treatment. The second was that there are two types of people receiving OUD treatment— those who are "genuine" or serious about treatment and who want to abstain from use, and those who continue to use substances or receive treatment for harm reduction—and that mixing these groups may present challenges to those abstaining from use.

The final widely-held belief among our interviewees was that use of MOUD itself constituted an "addiction" or dependency and that successful recovery from OUD would require stopping MOUD treatment. Given the well-established effectiveness of MOUD in preventing premature death and other consequences, as well as the significant risk of a return to illicit opioid use after stopping MOUD, this belief highlights the importance of continued efforts to address misunderstandings and stigma associated with MOUD. That is, given the role that stigma likely plays in the decision to end MOUD treatment (i.e., MOUD as replacing one addiction with another, MOUD as perpetuating one's label as an "addict"), these findings also suggest the need to evaluate MOUD stigma as part of the decision-making process.

Finally, interviewees described stigma in their communities and in health care settings and used labels such as "addict" and "junkie" to describe themselves (in the present or past) and others experiencing OUD. These labels, and the perception that one remains an "addict" until abstinent from all opioids, may explain in part why many interviewees defined successful recovery from OUD as ending MOUD treatment. Taken together, improved messaging within the medical and recovery communities, as well as in the community at large, about the effectiveness of MOUD and the differences between MOUD and illicit opioids are essential to changing this narrative.

## Acknowledgements

We would like to thank the Vermonters who shared their thoughts and experiences with us for this project. The information gathered will inform our programs and resources and help us in our efforts to support rural communities.

We would also like to thank our colleagues at the University of Southern Maine's Substance Use Research and Evaluation Unit who were instrumental in the completion of this project. UVM CORA faculty, staff, Clinician Advisory Board members, and partners in Maine and New Hampshire, provided helpful suggestions and guidance as we were developing the protocol for this project. We look forward to continued collaboration.

## Questions

Please contact us at cora@uvm.edu with any questions or for more information.

## **Suggested Reference**

University of Vermont Center on Rural Addiction (2023). *Vermont Baseline Needs Assessment Qualitative Report: Opioid Use Disorder Treatment Experiences in Rural Vermont.* Retrieved from: www.uvmcora.org/resources.



PAGE 49

This publication is supported by the Heath Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$17,032,587 with zero percentage financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, HRSA, HHS or the U.S. Government.

# **Appendix A: Interview Questions**

#### Section #1: General Context

These first questions will help us get to know your current situation and what types of treatment services you are utilizing.

## 1. What types of treatment for substance use are you <u>currently</u> receiving?

Probes:

- Medications for Opioid Use Disorder (MAT, MOUD; Suboxone, buprenorphine, methadone, naltrexone, other)
- Counseling services (individual, group, telehealth)
- Recovery center/recovery coach
- Support groups (AA, NA, etc.)
- Online or other tools (website, mobile app, books, other self-directed treatment)
- Detoxification/medically supervised withdrawal

## 2. Around how long have you been on this treatment plan?

Probe:

• Treatment setting (primary care, opioid-specific program, recovery center)

#### Section #2: Participant Background & Treatment Access

These next questions focus on the experience of finding and accessing treatment.

# 3. When thinking about people <u>who are ready</u> to get treatment, why do you think some people can access services and others cannot?

- Don't know about treatment options
- Stigma
- Point of access (geography, cost, transportation)
- Competing demands on time (childcare, employment)
- Other parenting concerns
- Costs of care (no insurance, high co-payments)
- Legal issues

## 4. What led to <u>your</u> most recent decision to start treatment?

Probes:

- What led you to choose medication/MAT/MOUD as part of your treatment plan?
  - Was MOUD your preference for treatment?
  - What other options were available to you?

If mentioned by interviewee, probe on:

- Issues related to parenting
- Legal issues/criminal justice system involvement/court order
- 5. What was your most recent experience like trying to find and access treatment for opioid use?

Probes:

- How did you learn about your treatment options?
- Do you have a doctor and did you discuss treatment options with them?
- How did living in a rural area affect your ability to find and access treatment?
- If induced in criminal justice system:
  - Did anyone help facilitate the transition to receiving treatment in the community? (caseworker, parole officer, etc.)
  - Were you able to find a provider in the community?
  - Was there a lapse in your medication treatment?

## 6. What were your greatest challenges to accessing treatment for opioid use?

- Financial, insurance, availability, transportation?
- Competing demands on time (childcare, job responsibilities)
- Other parental concerns
- Legal issues
- Any challenges related to living in a rural area?

## 7. How were you able to overcome some of these challenges?

Probes:

- What was helpful?
- What wasn't helpful?

Probe only if childcare/parental concerns are mentioned:

• Are there existing services that support your ability to care for your family while getting treatment? If so, what are these?

Section #3: Experience with MOUD

Now we would like to talk about your current experience receiving medications for opioid use disorder.

8. Tell me about your experience receiving medications for opioid use disorder treatment from your current provider(s).

Probes:

- What do you like about medication treatment?
- What don't you like about medication treatment?
- 9. (If not already known) Have you had any past experiences with treatment?

IF YES: Go to Q10 IF NO: Go to Q11

# **10. (IF YES TO Q9)** How has your current treatment experience been different from your past treatment experiences?

- Positives/negatives
- What led you to stop treatment in the past?
- Type of treatment: MAT/MOUD, residential treatment, partial hospitalization, etc.

# 11. (IF NO TO Q9) Once you started your current treatment program, what other challenges did you face?

Probes:

- Were there any services that you wanted or needed but did not get?
- Did you have difficulty meeting treatment/program requirements?

Probe if legal issues are mentioned:

• How did your legal issues affect your treatment?

Probe if childcare/ parental issues are mentioned:

• Are there existing services that support your ability to care for your family while getting treatment? If so, what are these?

#### 12. How has COVID-19 changed your treatment experience?

Probes:

- What changes did the organization or providers make to how you receive treatment or services?
- How have changes to treatment delivery during the pandemic affected your treatment and recovery experience? Positives / Negatives?
- Are there changes that you want to maintain after the pandemic is over (for example, telehealth)?

# 13. What do you want the people providing your care to know about your experience with opioid use and treatment?

- Is there anything you wish your providers knew when you started treatment, or now? (A provider can be your primary care physician, social services provider, behavioral health provider, MAT provider, etc.)
- Is there anything about your experience that you want your providers to understand, but you are not comfortable sharing with them? (IF YES, ask if comfortable sharing examples; reiterate this will be de-identified and will not be tied to their name)

## Section #4: Future Directions/Recommendations

Before we finish up today, I would like to ask if you have any recommendations on how health care organizations and providers might improve the experience of care for people with opioid use disorder.

# 14. What could your current provider organization(s) do better to meet your needs and help you remain engaged in treatment and recovery services?

Probes:

- Are there any services that you want or need that you are not currently receiving? If so, what?
- Some examples are:
  - Information on available services in your area
  - o Financial assistance
  - More or different treatment and program options
  - Assistance coordinating related needs (transportation, other community services)
- 15. What could your current provider organization(s) change to help you feel listened to, informed, and involved in your care?

## 16. Thinking about the future, what does long-term recovery success look like for you?

- What resources do you think you need to get there?
- In addition to provider/ behavioral health services: Housing, employment, skills training, transportation, childcare
- Do you have plans for how long you would like to continue taking MOUD?
- 17. Do you have any additional comments or thoughts you would like to share with us before we finish today's conversation?