

# Learning from Lived Experience

Understanding  
Barriers to Opioid  
Use Disorder  
Recovery

**MARCH 2022**





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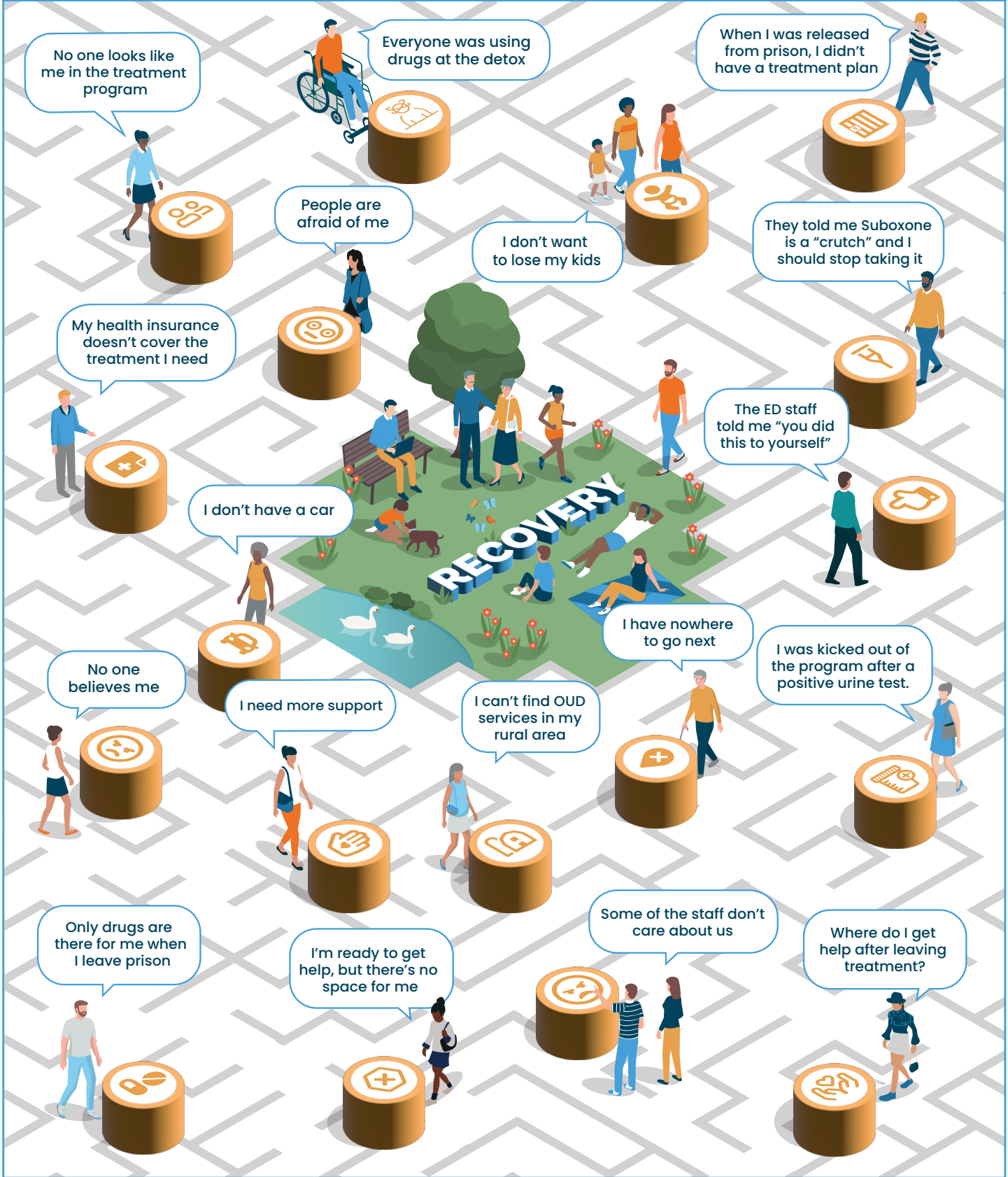
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## Learning from Lived Experience: **Understanding Barriers to Recovery**



## Introduction

After experiencing one of the highest opioid-related death rates in the country, the Commonwealth of Massachusetts has become a national leader in responding to the opioid overdose epidemic (National Institute on Drug Abuse, 2020). Across the state, there has been significant progress to save lives, including the expansion of Medicaid benefits for substance use disorder (SUD) care, increased access to naloxone, reduced opioid prescriptions, medications for opioid use disorder (MOUD) induction in emergency rooms, access to MOUD within the prison system, greater numbers of waived MOUD prescribers, improved medical school education, and other efforts to increase access to treatments and recovery supports (Bagley, 2018; Mace et al., 2020; Massachusetts Department of Public Health [DPH] MAT Commission, 2019a). Pandemic-era changes to federal guidelines have improved access to methadone and permitted opioid treatment programs to offer mobile services.

While concerted efforts across the state have removed several barriers to accessing treatment services for opioid use disorder (OUD), many persist and have been brought to the forefront by the COVID-19 pandemic, the continuing opioid epidemic, and increased awareness of disproportionate impact of both on Black, Indigenous, and people of color. The COVID-19 pandemic and its associated disruptions to daily life, isolation, financial and job losses, and other hardships have taken a significant human toll, with Americans reporting high levels of substance use, anxiety, depression, and suicidal ideation (Substance Abuse and Mental Health Services Administration, 2021).

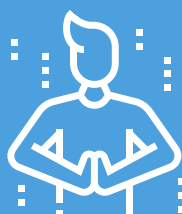
Nationally, drug overdose deaths increased by 31 percent from 2019 to 2020 (Hedegaard et al., 2021). In Massachusetts, opioid-related deaths rose by 5 percent in 2020 and 1 percent in 2021, respectively—increases that still break previous records (Massachusetts DPH, 2021a and 2021b).

Massachusetts communities of color are especially affected. Currently, Hispanic men experience the highest rates of opioid-related deaths and Black, non-Hispanic men experienced a 69 percent increase in opioid-related deaths between 2019 and 2020. At the same time, there has been a slight, but steady, decrease in opioid-related death rates among White, non-Hispanic residents (Massachusetts DPH, 2021c).

## Understanding the Lived Experience of Barriers to Opioid Use Disorder Care

A 2020 [National Academy of Medicine white paper](#) focused on addressing barriers to accessing evidence-based OUD treatment found that there is insufficient attention to understanding the perspectives of people who use drugs and what gets in the way of accessing treatment. Considering that approximately 70 percent of those who need OUD treatment do not receive it, the authors recommend that people who use drugs should be consulted to better understand their experiences and design services targeted to their needs (Madras, et al., 2020).

This paper seeks to address this gap by examining the barriers to OUD care from the perspective of the people most affected—those who have an OUD. Based on interviews with six Massachusetts residents who have sought help for their OUD during the past decade, this paper features their experiences with barriers to OUD care. It centers their perspectives, challenges, successes, and recommendations, in their own words. By sharing their nuanced and varied experiences, we hope to further expand and enhance understandings of barriers to OUD care and inspire more people to join the diverse stakeholders already working to advance evidence-based, person-centered care for OUD in Massachusetts, including policy makers, healthcare organizations, payers, unions, advocates, service providers, and others.



### What is Person-Centered Care?

Person-centered care is treatment, recovery planning, and decision making that is respectful of and responsive to a person's unique circumstances, wishes, values, and needs. It centers the goals of the person, not those of the service provider, program, or system. Person-centered care is rooted in compassion, empowerment, shared decision making, and the core belief that people can and do recover.



## Barriers to OUD Care

### People-level barriers

These are caused by lack of knowledge and skills or by attitude and beliefs among healthcare and other service providers, recovery community members, and members of the broader community. This category can also include barriers that are unique to an individual.

- ❑ Lack of education or training on evidence-based understanding of substance use disorder as a brain disease and the impact of opioids on the body and the brain
- ❑ Lack of evidence-based knowledge or information about multiple pathways to recovery
- ❑ Persistent myths and misinformation about MOUD treatment
- ❑ Stigma, especially toward people who use drugs and those taking MOUD as part of their recovery pathway
- ❑ Discrimination, racism, and other forms of prejudice

### Program or organizational-level barriers

These are created by policies, practices, procedures, or a lack of resources within programs or organizations.

- ❑ Stigmatizing practices, such as observed urine tests
- ❑ Failure-focused SUD treatment metrics
- ❑ Variable quality of care
- ❑ Limited treatment/recovery pathways offered or supported

- ❑ Services that are not fully person-centered, recovery-oriented, non-stigmatizing, and trauma-informed
- ❑ Limited offerings of individualized treatment and recovery supports
- ❑ Lack of discharge planning, warm handoffs, or continuity of care to provide support at key transitions: leaving inpatient treatment, post-overdose, leaving the hospital ER, leaving incarceration

### System-level barriers

These include barriers encountered at the level of service systems, resources, or related to coordination across systems.

- ❑ Limited availability of youth-driven substance use education, prevention, screening, and intervention for youth and young adults, especially those who are systemically and historically marginalized
- ❑ Lack of full implementation of standards of care that promote person-centered, recovery-oriented, trauma-informed care and environments
- ❑ Limited availability of individualized treatment, including family-centered, gender-specific, bilingual, and culturally responsive treatment services
- ❑ Limited availability of services in rural and historically marginalized communities
- ❑ Time limits on treatment services
- ❑ Limited access to justice diversion programs to receive treatment instead of incarceration
- ❑ Limited access to reentry supports to prevent homelessness and support recovery
- ❑ Challenges in accessing OUD treatment while incarcerated, especially long waiting lists for MOUD for those with lengthy sentences
- ❑ Substance use treated as a disciplinary issue, rather than a medical issue for those who are incarcerated
- ❑ Limited coverage for SUD treatment by private insurance

*Note: This list features the barriers encountered by the people interviewed for this paper and is not intended to be comprehensive.*



1

## Shannon

### Myths about Medications for Opioid Use Disorder

Medications for OUD (MOUD) are the evidence-based gold standard for OUD treatment, yet persistent and damaging misinformation about their proper use, value, and legitimacy stymies access to this life-saving treatment. When the sources of myths and misinformation are healthcare providers and members of the recovery community, it becomes a serious—and dangerous—barrier.

Shannon is a 38-year-old White woman who lives in Leominster and works as a recovery coach and harm reduction specialist, serving people in rural areas. Her journey to treatment for OUD began when she was prescribed MOUD.

*After about two years on Suboxone [buprenorphine and naloxone], I came off it. The only reason I came off is because everybody else told me I had to. I was hearing, 'it's a free high.' 'It's only supposed to help you get over that hump in early recovery. After that you're abusing it.' The people saying this to me were the counselor I was seeing at a community health clinic and the first doctor who prescribed Suboxone to me. They didn't have the Suboxone clinic like they do now. The doctors weren't trained in all of this then. They just had regular doctors giving prescriptions.*

Believing these myths and misconceptions, Shannon stopped taking MOUD and experienced recurrence of use. Later, she tried methadone treatment.

*I went on methadone, which was its own nightmare and a half. Methadone is not for me because you can just continuously go up [in dosage] as high as you want. As long as your EKG is fine, you can go up as much as you want. Every time my body would get comfortable with the dosing, I would go up because I was no longer feeling the effects. I was in mental relapse. Not one single person at the clinic asked me if I was okay.*

They told me Suboxone is a "crutch" and I should stop taking it



*I had a case manager that I met with once a month. You would only meet with your case manager if you were having positive swabs. I was doing good for a while but because I was already in a mental relapse, it wasn't too long until I physically picked up. I picked up because every single morning I went to the methadone clinic and my dealer was standing right outside the clinic. None of the security would make the dealers leave.*

*Every time I went to my case manager, it was literally two seconds. 'Hey, how you doing, everything good?' Yep. 'Okay. See you next month.' They never asked 'I see you've been going up quite a bit, what's going on? Is everything okay?' These questions mean a lot. Sometimes I do things just to see if people care enough to notice. After a year of being there, I was in full blown addiction. I lost my daughter. I lost my family, my fiancée, everything. Next thing you know I'm overnight in jail again after 10 years.*

While receiving methadone maintenance treatment, she did not receive the level of care or recovery supports necessary to find the right treatment pathway for her. She found her way to doctors who helped her find a better MOUD treatment option for her needs.

*I immediately got right back into recovery, and I went back on Suboxone this time. I've been on Suboxone for seven years . . . I found out that I metabolize opioids way faster than others, so I had to go on split dosing. I was told I was a liar, that I'm just trying to up my medicine because*

“ They’re still not listening, but I don’t give up. If I keep speaking up, maybe one day they’ll understand.

*I’m no longer feeling the effects. They wouldn’t take my word for it, that I was past the withdrawal point. That is my biology. It’s my medication for my disease, just like anybody else who takes their medicine on a regular basis. This is my medicine.*

Shannon returned to the community health clinic where she had experienced stigma and misinformation about MOUD. This time was different.

*[My doctors] are the two best MOUD providers I’ve ever had in my seven years of being on this journey. They care. They honestly care about me. Dr. G is always late because she’s spending that extra 15 minutes because she has someone crying in front of her and she wants to make sure they’re okay. When I had a couple false positives [urine tests] and freaked out, Dr. S honestly believed me. She tried figuring it out with me and together we were able to figure out why there were false positives. She didn’t jump to conclusions or say ‘once a liar, always a liar.’ She believed me. That was worth more than anything in the world to me, that somebody honestly believed me. She did that for me. I will forever be grateful for her.*

With the help of quality, person-centered, recovery-oriented health care and recovery supports, she was able to stabilize and enter recovery. She learned to trust herself and her own individualized pathway for treatment and recovery.

*What made the difference was to stop listening to everybody else and start listening to myself and what my recovery is. I grew up in AA, with an alcoholic father and an addict mother. The only thing I ever knew when it came to recovery was AA or NA. That’s what I thought recovery was: you go to detox and you go to meetings and that’s it. I never understood that recovery is so individualized and there’s so many different pathways. In order for me to find what works for me I have to try things and I have to stop letting others tell me what’s best for me because I know what’s best for me.*

*Being able to advocate for myself, learning where my voice is and when to use it, that was huge . . . Besides Suboxone, I go to a Dual Diagnosis Group, which helps with both my mental health recovery and my addiction recovery. We just started an All Recovery Meeting . . . it’s where everyone gets to heal together.*

After finding the right treatment and recovery supports, Shannon now works as a recovery coach to support others who have SUD. Informed by her own lived experience, she is an outspoken advocate for ending stigmatizing and traumatizing practices, such as observed urine testing for people who take MOUD and making trauma-informed care the standard.

*Once I got my life together and tried getting into recovery, I thought all the shame was gone. But then I go to a [community health clinic] that says they are going to help me, get me into counseling, help me work through everything and a nurse is following me into the bathroom and watching me pee into a cup. I understand that they want to make sure it’s legitimately your urine. But there are other ways they could do it. It is so very degrading. The only other time I’ve ever had to pull my pants down is when I was in jail. I’m already feeling shitty inside. I’ve already put myself down to the point of no return and feel like I’m never going to feel good about myself. I find this place that promises to lift me up again—and then they’re following me and watching me drop my pants. I don’t even think there is a word for how awful it makes me feel.*

*I still have to do it every month, for the last five years. Just this last Thursday, a nurse followed me into the bathroom and I had to pee in front of her. No matter how many times I voice my concern—about how it could trigger someone who has been raped, experienced domestic violence, or has just stopped prostituting. They’re still not listening, but I don’t give up. If I keep speaking up, maybe one day they’ll understand.*



*When it comes to addiction, we're all trying to numb something. Something that has happened to us. Every person who walks into a MOUD clinic has been through some type of trauma in their life. As a person who has survived domestic violence, I believe that every MOUD provider needs to be trained in how to deal with a trauma survivor. Sometimes not looking them in the eye or coming in the room flustered from another client can be triggering. Trauma needs to be taken into consideration when you're dealing with that person. They're not a number. They're not a statistic. They're a human being standing in front of you. You need to take more than five minutes to talk to them.*

Shannon's experiences show the damaging effects of myths and misconceptions about MOUD and the importance of shared decision making with healthcare providers to identify the right medication and dosage. Eradicating these myths and destigmatizing MOUD is critical. For example, MassHealth found that members who receive MOUD experience lower rates of overdoses and have lower cost of care (Massachusetts DPH MAT Commission, 2019b). The barriers that Shannon experienced help her to better advocate for the people she serves in the hopes that they will receive person-centered, recovery-oriented, and trauma-informed care.

### Shannon's barriers

- ❑ Misinformation about MOUD treatment
- ❑ Lack of full acceptance of multiple pathways to recovery, including MOUD
- ❑ Lack of accurate, evidence-based information about treatment options
- ❑ Lack of ongoing treatment monitoring and lack individualized treatment supports
- ❑ Stigma from within the recovery community toward people taking MOUD as part of their recovery pathway
- ❑ Stigmatizing and traumatizing observed urine tests

## 2

# Brian

## Quality of Care and Substance Use Treatment Workforce Challenges

Many members of the workforce who interact with people with OUD have not received in-depth training on understanding the neurobiology of opioids; their effects on the brain, body, and behavior; co-occurring mental and physical health conditions; the effect of stigma; and how to deliver culturally responsive, racially equitable, recovery-oriented, person-centered, trauma-informed care for people with OUD (Davidson et al., 2019). Further, many healthcare and behavioral healthcare workers are at risk of burnout, compassion fatigue, and vicarious trauma—especially during COVID-19 (Wagaman et al., 2015; Morse et al., 2012; Mauseth, 2021). These conditions may contribute to varying levels of care quality for people with OUD.

Brian spent seven years struggling with heroin and alcohol addiction and homelessness. He sought treatment services multiple times, experiencing different levels of quality of care. He is a 32-year-old White man from central Massachusetts.

*I was your classic White male story: car accident, painkillers, heroin. After getting home from the hospital [after his car accident], I took one of the painkillers they gave me and smoked a little weed. I remember saying to myself, 'I don't want to ever stop feeling like this.' I didn't know about addiction. My boss at the time said, 'Something's up with you. You need to do something.' I literally googled 'detox facility.' I was 20 years old.*

*They gave me methadone and it helped take the edge off. I was allowed to lay in bed if I felt like crap. I was able to go to groups. I remember being mortified by everything all around me. I was like, I never want to be like these people [other patients]. I never want to do this again. I was treated with respect. I had this eureka moment that I never wanted to go back there. I wanted to be normal.*

Brian entered recovery. On his own initiative, he obtained a prescription for MOUD after leaving treatment in 2010.



*I had heard about Suboxone and I wanted to try it. I found a psychiatrist who prescribed it. He wasn't covered by MassHealth. I had pay by check or cash: \$150 plus the cost of the prescription. Because MassHealth didn't cover the provider, the prescription wasn't covered either. It was almost a grand [\$1,000] every two weeks, \$300 – \$400 a week. It was a lot of money. I didn't know any better. I would go to his office, hand the secretary my check, he would turn on some Native American music and tell me to close my eyes and he'd say, 'You're not going to do heroin. You're not going to think of heroin. You're not going to do heroin.' I called him my Suboxone Shaman. I was so green. I was swallowing the Suboxone the first week. I didn't know you were supposed to take it under your tongue.*

*My boss at the time was like a father to me and he said, 'I'm glad that you're trying to help yourself, but I don't think this is the avenue.' I gave up on [Suboxone] and just started to drink and then drinking progressively turned into a problem. I turned 21, and as much as I hated alcohol, I also hated being sober. I grew up going to my grandfather's anniversary meetings at AA my whole life. He passed away with 37 years of sobriety.*

After he stopped taking MOUD, Brian entered a seven-year period of alcoholism, homelessness, and heroin use. He sought care multiple times at the same facility that had helped him when he was 20. He discovered that the quality of care had deteriorated significantly.

“*Basically, you weren’t treated like humans, no matter what you did. If you had the slightest bit of attitude, or just a bad day, it wasn’t understood.*”

*The only facility I ever went to for formal treatment is where 85 percent of my problems [barriers] took place. I’ve lived at shelters longer than I’ve owned or rented a house and I was treated better by people on the street than [by] some of the staff there. It was the only place I ever knew to go to [for substance use treatment].*

*I went there a total of seven times between ages 20 and 26. I got sober in September of 2017. I can make some generalizations. The staff was awful. The place had become disgusting. I had been sleeping in a tent with a couple that hadn’t showered in months and at the detox, I’m saying, ‘somebody get a mop.’*

*Basically, you weren’t treated like humans, no matter what you did. If you had the slightest bit of attitude, or just a bad day, it wasn’t understood. It was just immediately: ‘get your stuff, you’re out of here.’ A lot of the staff had issues with themselves and with the people there. They were just so mean, so brutal to people. We’re going through a horrifying chemical process [withdrawal] at this point. There’s nothing therapeutic about detox. There were 25 to 35 people on one floor, with one case manager. That doesn’t make sense. The level of drug use that was taking place inside the facility was bad.*

*In February of 2017, I was a man on a mission. I wanted to get clean. Every time I went back to detox, I learned more about the process [of treatment and recovery]. I never got to that next step, but I learned more. This time I was committed. I was going to go to a halfway house, do all the right things. I had a positive mental attitude, I was feeling good about myself, but everyone around me is getting high. It bothered me, but I kept my blinders on. I hadn’t touched heroin since the first detox.*

*I walked into the bathroom, and this kid is literally trying to shoot up [drugs] into his neck. I just snapped. I went to the director and said, ‘You need to do something about this. I can’t even use the*

*bathroom without it being filled with drugs, and this is supposed to be in safe place.’ Instead, I was written up for a bad attitude.*

*I go to group, and they tell everyone we have to take a drug test. At this point, I had already gone through detox and the CSS [clinical stabilization services] level. I’m upstairs at the TSS [transitional support services]. I take the drug test. Next thing I know, the director brings me out in the hall where there are two security guards. She says ‘you need to go with them. Your drug test failed for fentanyl.’*

*I was there for alcohol. I hadn’t done heroin in four years. I asked if I could get my sweater. It had been my great-grandfather’s and he had just died. She says, ‘one more question and they’re dragging you out.’*

*I went outside. I had \$6 and I knew there was a liquor store around the corner. I got a couple of nips. I bumped into the nurse who worked there, who I had grown to love. She’s amazing. She asks me ‘why are you out here?’ I tell her. She tells me to go to the hospital and get a blood test and bring the papers back. But I had already started to drink. And there’s no discharge plan—they just drop you on the street.*

Brian was falsely accused of using fentanyl and discharged from the program without any recourse or referral. The punitive approach of excluding people from treatment programs for a positive drug test creates a failure-focused pass/fail system that undermines people when they are at their most vulnerable, erodes trust, and ignores the reality that recurrence of use is part of recovery.

*After that, I went out and got drunk. I got drunk enough to use dope [heroin] again. I overdosed. I bought more dope. I overdosed again. In three months, I overdosed three times.*

*I had a seizure and ended up in the hospital. This guy [social worker] walked into my hospital room and asked me what I wanted. Did I want to start*

*medication? No one had ever asked me that question before. I was so desperate to just try anything different, anything new. He got me started on Suboxone, and he got me a treatment bed. Looking back at it now, the stars lined up for me.*

The social worker he met in the hospital emergency department asked him questions no one ever had: What do you want? Do you want to start medication? Brian started taking MOUD and connected with recovery supports. He has been in recovery since 2017 and now works as a recovery coach in the same hospital emergency room.

As a recovery coach, Brian now supports patients with SUD as well as hospital personnel who do not understand addiction nor how to provide person-centered, trauma-informed, recovery-oriented care to patients with SUD.

*I spend more time on calling out and have private discussions, chats, and meetings with hospital staff than I do with patients sometimes. Dealing with a patient is simple, it's the staff who usually need more attention. Some unintentionally treat patients wrong. They just don't know enough about it [addiction]. Then there are staff who are just absolutely demoralizing. It's just like, 'why would you do that?' Then there are staff who have such a fear of hurting a patient's feelings that they get walked all over. They're no better than the asshole doctor because there's no healthy boundaries. It's been an eye-opening experience being on the other side of the johnny.*

In his new role, he sees how lack of care coordination and resources become barriers for many people seeking help for OUD.

[The lack of care coordination between the hospital and SUD treatment program] is just devastating because when people want to get help, it's a flash in the pan. It's lightning that doesn't strike twice. When you actually have somebody who wants to help, we should be opening doors for those people.

*They're [SUD treatment program] in a building that is understaffed and doesn't have the resources or the capacity to offer any of the different pathways to recovery. They're not helping people understand what their real options are. At no point was I asked, 'Would you like to start medication? Would you like to stay on methadone? Would you like to start Suboxone? Do you think that Naltrexone is an option? Would you like to get the Vivitrol shot?'*

He continues to witness the barriers he encountered when seeking help for SUD.

*There was a kid who detoxed off alcohol at the hospital under my care. He was sent to the CSS [clinical stabilization services] on a Saturday morning. They tried to kick him out because he failed [urine test] for benzodiazepines. Of course, he's going to have them in his system when he comes straight from the hospital. We gave him those medications when he was detoxing. I wasn't there to advocate for him. He was getting in a cab and being sent back to the hospital, and everything was going to blow back up again.*

Brian's story vividly illustrates several barriers to OUD care, especially the highly damaging impact of receiving poor quality of care.

### Brian's barriers

- ❑ Misguided advice from support system, informed by misconceptions about MOUD
- ❑ Lack of insurance coverage for MOUD prescriber and medications
- ❑ Understaffed, overworked, and undertrained staff unable to provide person-centered, recovery-oriented, trauma-informed care and environments
- ❑ Poor quality of care
- ❑ Failure-focused SUD treatment
- ❑ Unprofessional retaliatory treatment
- ❑ Lack of discharge planning, warm handoffs, or continuity of care
- ❑ Lack of access to and knowledge of treatment and recovery pathways for OUD

3

## Joseph

### Racially Inequitable Cycle of Substance Use, Drug-Related Crime, Incarceration, and Homelessness

In Massachusetts, Black and Latinx people charged with drug offenses are more likely to face incarceration and longer sentences than those who are White (Criminal Justice Policy Program, Harvard Law School, 2020). These disparities persist after controlling for type of criminal charge and other factors. Massachusetts has high rates of racial and ethnic disparities for incarceration, imprisoning Black people at a rate 7.9 times that of White people and Latinx people at a rate 4.9 times that of White people (Massachusetts Sentencing Commission, 2016). Systemic racism, implicit bias, and over-policing communities of color contribute to these disparities.

Joseph is a 37-year-old Black man who lives in Boston. He was recently released from jail and is receiving MOUD treatment as he works to get back on his feet. His story illustrates the multiple, intersecting barriers that contribute to racially inequitable cycles of substance use, lack of access to treatment, drug-related crime, lack of justice diversion, incarceration, homelessness, and recidivism that have repeated for two decades, over half of his lifetime.

*I started using Percocet at an early age, say 16–17. As soon as I started using, I started going right to jail. I have spent half of my life in jail. I grew up with a lot of trauma. Every time I did Percocet, it made me not care about anything. I'd go through my whole day in a comfortable sleep, not feeling anything.*

*I've been homeless since I've been going to jail . . . When I leave jail, it's a fresh start, but it's not a fresh start because I have nobody to come out to. But drugs are always there. Percocet is always there. Weed is always there. You've got nowhere to go, no foundation, what are you going to do? When it gets cold and that jacket is not working [to keep you warm], what are you going to do? You're*

When I was released from prison, I didn't have a treatment plan

*going to grab a bottle or you're going to grab some Percs, and you're going to be numb.*

*You get a job and you stay clean, but after I get off my job where am I going to? How long can you keep a job if you don't have a home or somewhere to go that night? You can't work at a job and then come home to a tent.*

*Housing is what I need. If I had housing, I'd figure everything else out myself. I'm not dumb and I don't have a problem working. I've got kids—a 19-year-old, [a] 14-year-old, and one on the way. I'm just ready to be stable. I'm tired of this shit.*

Joseph is currently working, living with friends, and receiving outpatient care for OUD and mental health conditions. He works closely with a care coordination team that is supporting his reentry and recovery process by helping him access benefits, OUD treatment, mental health services, and health care; obtain identification documents; manage court dates; and navigate other supportive services.

*I'm on Suboxone right now . . . and it's been good because I haven't touched the Perc since. I met Sophia [care coordinator] when I was still in jail. She came to see me. I signed up for the program while I was in jail and she said, 'When you get out, we'll have something for you.' As soon as I got out of jail, I went straight to Sophia. She gave me a big backpack with a cell phone. She gave me some gloves and stuff like that.*



“Housing is what I need. If I had housing, I’d figure everything else out myself.”

*She is like my counselor. She does everything for me, I’m not even going to lie. She does stuff that she doesn’t even have to do. She helps me with all my paperwork, helped me with my housing and everything. She’s just been a big help. She reminds me of all my doctor’s appointments, dentist appointments. She reminds about everything. She helps me remember because I’ve got a bad memory. She just keeps me on point.*

*She helps me get jobs. She found this program [Suboxone] for me. I told her what I’m trying to do. I told her my vision and she’s on board. Every program she gets, I guarantee, I’m probably the first or second one she calls. We have that type of relationship. I don’t hold no punches. I be telling everything. She is real with me. We just have that kind of understanding. It’s a good working relationship. She’s part of a team. I’ve got a whole team over there . . . going to that clinic, that’s probably the best decision I’ve made.*

*Sophia understands my memory problems and all the things I’m going through. She understands and she doesn’t mind sending a text saying, ‘Make sure you call this one. Don’t forget your court date.’ She does stuff like that, ‘Don’t forget your court date. Did you talk to your lawyer?’ She helped me with my permit. She filled out all the paperwork for me to go get my permit. She does everything.*

Joseph speaks highly of the care coordination team that meets him where he is and helps him access OUD treatment and other supportive services during his reentry. In particular, he emphasizes the importance of having a care coordinator who understands him, what he has been through, and provides wraparound supports. Housing instability, however, is an ongoing challenge that affects all aspects of his life in recovery.

Joseph’s experiences show the missed opportunities and barriers to disrupting the cycle with youth interventions, justice diversion, access to SUD treatment, reentry supports, and homelessness prevention.

### Joseph’s barriers

- ❑ Lack of early substance use intervention or trauma services as a teenager
- ❑ Structural, institutional, and interpersonal racism
- ❑ No access to justice diversion programs where he could receive treatment instead of being incarcerated, thus disrupting the cycles of drug-related crime and incarceration
- ❑ No access to OUD treatment while incarcerated
- ❑ Limited access to reentry supports to prevent homelessness and support recovery
- ❑ Lack of access to affordable housing endangers efforts to sustain recovery, maintain employment, and avoid crime

# 4

## Kelly

### Need for Support at Key Transitions

Transitions between different levels of care bring challenges and opportunities during OUD recovery. Discharge planning, care coordination, warm handoffs, and reentry services are critical to help people navigate the challenges of transitions and connect with supports and services to strengthen the next phase of their recovery. When these services are unavailable or lacking, however, there are barriers to ongoing treatment and recovery.

Kelly is a 46-year-old White woman from rural Western Massachusetts. She struggled with opioid addiction for 17 years. She experienced what it was like to receive—and not receive—support at several transition points in her life.

*I had been in addiction treatment in my youth, but I didn't get into opioids until 2005. I started taking nonprescribed Oxycontin given to me by a partner. I was unaware of what I was doing to myself. I was getting a divorce and I had three small children. I thought it was a miracle drug that gave me energy. I got addicted pretty quickly. I called my mom who is a registered nurse and she took me to [an inpatient treatment program]. I was working for the state and I had good insurance, but two days into treatment they discharged me because there was a problem with my insurance.*

She returned home and went to the emergency room (ER) the next morning, where she received navigation and warm handoff support.

*The staff at the ER in 2006 worked very hard to get me into a detox program that accepted my insurance and even arranged for transportation. I went there and they did a methadone taper. My oldest daughter's father watched all three kids while I was in treatment. I am forever grateful for him. I was there about two weeks and they got me an extension, so I had to pay for a couple extra days that weren't covered by my insurance. I*

I can't find OUD services in my rural area

*remember saying 'I'm not feeling good.' Back then, I didn't understand much about my addiction. I didn't understand why I didn't feel good because the consensus was you did the methadone taper and you would be okay. But I had a raging habit and a high tolerance.*

*They sent me home and I was still not feeling good. There were no outside support services set up for me whatsoever. At the time, I registered as a well-rounded person. I still had my house and my job. It was an awful experience. I went home and I had a can of peas in the refrigerator for my kids. It was difficult finding day care. I ended up using again. I was set up for failure.*

Not being connected with recovery supports in the community or knowing how to find them was a missed opportunity. Kelly eventually found a prescriber and started MOUD, paying out of pocket. It helped her but it was challenging to get the right dosage. She was required to see a therapist, who helped her with trauma and boundaries. However, she worried that having a MOUD prescription would lead to losing custody of her children, so she began accessing MOUD through an abusive boyfriend, rather than a prescriber.

*I ended up losing my house, my job, and everything. I signed my two younger children over to my ex-husband so I could take my daughter to a shelter. Fast forward, I was off the Suboxone and started using heroin. I ended up having a really severe overdose in 2014 that resulted in a traumatic brain injury.*

*I was put on a ventilator. I don't remember a lot. I was dealing with a brain injury and I was also withdrawing. The nurses didn't want to deal with me and my treatment was definitely the worst that I've ever had. They saw it as a self-induced thing that I had done to myself. They were pissed that they had to deal with me. If my family members weren't there, I couldn't eat because I couldn't use my hands. Nobody would help me.*

*The hospital didn't know what to do with me. They didn't prescribe Suboxone. I think if things were handled a lot differently, I would've had a fighting chance then. I still talk about it with my daughter and her father, if they had just referred me to OUD treatment out of the hospital instead of shipping me home with a traumatic brain injury.*

After another missed opportunity during a transition point, Kelly started using again.

*In 2019 I had a really bad relapse and got involved in fentanyl. The ER staff were deplorable. The doctor was insulting. He was talking about me in front of other patients. My mom had brought me in. The nurses weren't supposed to, but they contacted a detox and found me a bed, if I could get there in the morning. My mom had to work the next morning, and as soon as she left, the doctor said, 'We can't hold you overnight.' They discharged me [and I had no transportation to the detox]. It was really embarrassing. I remember the doctor saying, 'The nurses aren't even supposed to be making these calls for you.' He was out in the hallway saying 'she is not even that sick.'*

Her 2019 experience contrasts vividly with the navigation, care coordination, and warm handoff support she received in the ER in 2006.

Over the past 17 years, Kelly has struggled to find

the right treatment pathway for her needs, especially living in a rural area. She participated in several treatment programs and services, both residential and outpatient. At the time of our interview, she was participating in a residential program in Boston that has helped to treat her ADHD (attention deficit hyperactivity disorder), brain injury, and OUD. She is taking naltrexone for the first time and working with a recovery coach. The drawback is that this treatment is far from her mother, daughters, and grandchildren in Western Massachusetts who are her support system.

*There is a huge lack of long-term treatment for women, especially if you have children with you. Most of us don't have custody of our kids. The most we get is six months in a halfway house. It's a lot to expect people to fix a lifetime of habit in a few short months. The staff who work here [halfway house for women in Boston] are overworked, underpaid, limited staffing and they don't do this job because they are making the big bucks. They do this job because they care about us.*

*With the right kind of care and right kind of people in your life, you can get better. I've had a really good support system and that's what's made the difference for me this time. But it shouldn't have taken decades. I've had a 17-year opioid addiction and it's been [me and my family] learning through trial and error. This time around, the support was different because I've educated my doctors and my family.*

Kelly's story highlights the missed opportunities when people don't receive support at key transition points. It also shows the difficulty of accessing individualized treatment tailored to people's specific needs. In Kelly's case, she needed treatment for ADHD and a brain injury; MOUD management; trauma therapy; support in her role as a mother as well as support for her children; and longer time limits for withdrawal management, treatment, and recovery housing.

## Kelly's barriers

- ❑ Lack of support at key transitions: leaving inpatient treatment, post-overdose, leaving the hospital ER
- ❑ Lack of family-centered, gender-specific treatment
- ❑ Lack of services in her community and region
- ❑ Limited coverage by private insurance
- ❑ Stigma and poor quality of care
- ❑ Time limits on treatment services
- ❑ Lack of trauma-informed treatment

5

## Christian

### Racially Inequitable Access to OUD Treatment in Correctional Institutions

In 2018, Massachusetts passed legislation that increased access to MOUD for people who are incarcerated. The law created a 4-year pilot program, allowing a limited number of jails and prisons to provide prisoners with access to all three FDA-approved medications (General Court of the Commonwealth of Massachusetts, 2018). The state later expanded the program to include all state and county facilities. Access to MOUD, however, remains uneven and excludes many, with a disproportionately adverse impact on incarcerated Black and Latinx people.

Christian, a 41-year-old Latinx man who has been incarcerated since age 27, is serving a life sentence for a drug-related crime. He entered the criminal justice system in active addiction 14 years ago and is still trying to access to OUD treatment.

*I came from a poor family and the only way to survive was to live the 'street life.' I started drinking alcohol in elementary school. I would steal it from my mother. My dad died when I was 13 years old and that's when my drug addiction started. I was lost and angry. Smoking marijuana and taking Xanax helped me cope. I tried crack for the first time when I was 14 years old. Then I moved on to PCP [phencyclidine]. By age 19, I was shooting up heroin.*

*My addiction has always been a major barrier in my life. I'm serving a life sentence in prison because of the choices I made while getting high. I could not get help in the streets for my addiction and now that I am in the system, it's still difficult for me to get help. This system isn't designed to help addicts who look like me. Especially those of us who are serving life, it's almost impossible to get services.*

To be eligible for MOUD in prison, prisoners must meet certain criteria. One category of eligibility



is having previously received OUD treatment in the community. This standard excludes people like Christian and fails to consider the cultural and structural barriers to accessing treatment. Unequal treatment is common in Black and Latinx communities, where access to treatment options have historically been more dependent on race, income, geography, and insurance status, rather than on individual preferences or medical and psychiatric indicators.

*When I was sentenced, correctional staff knew that I had a drug problem. My crime stemmed from my addiction, but they still classified me as low risk [for addiction]. Coming in, I wasn't offered any services—no detox, no programming, nothing. I asked if I could attend the programs for mental health, schooling, and addiction but they just kept giving me the run around. They would tell me I was on the waiting list, but my time never came. It's been 14 years and I'm still being told the same story.*

Like many, Christian continues using substances to self-medicate while he waits to get help. In correctional settings, substance use is considered a criminogenic risk factor, not a disease requiring medical treatment. As a result, prisoners who are close to release are prioritized for treatment to prevent overdose deaths and recidivism. Those with life or longer sentences, like Christian, can remain on the waiting list for an indefinite period without regard for the severity of their addiction.

“ *It’s hard to think about the childhood trauma I experienced. I want people to know that we are worth saving*

*Drugs are accessible in prisons the same way they are in the streets, if not more. When I first entered prison, I would do anything to get drugs. Drugs were the only thing that made me feel normal, like I was connected to home. It took me overdosing twice and almost losing my life before the prison acknowledged my addiction. The first time I overdosed, they punished me, they fined me, froze my [canteen] account, took away my phone calls and family visits, and threw me in solitary.*

*After I almost died the second time is when they upgraded me to high risk [for addiction]. I would talk to my caseworker about programs but they never enrolled me in anything. When I heard they were offering MAT [medication-assisted treatment] in here, I wanted to get the medication to help me quit using drugs illegally. I got a medical assessment and they told me I meet the requirements for MAT but now it’s the same thing, I’m just waiting. I am a lifer; I am not prioritized. My friend died from an overdose. He was also lifer and didn’t have access to programs.*

Those who use substances are frequently subject to punitive disciplinary actions instead of given access to treatment and recovery support. They may lose family visits, jobs, single-cell status, and phone access and be required to pay for urine testing as part of disciplinary measures. Some will engage in self-harming behavior because it moves people up on the waiting list for MOUD (L. Whiteside, personal communication, November 22, 2021).

*Everything in here is about punishment, not rehabilitation. The goal is not to help people with addiction but to make us suffer. All they [correctional staff] want to do is find the dirty urine, so they can take away things. Each time you have a positive test, they charge you \$144 and take away your property and family visits for six months. They take away the canteen [access], your phone privileges, and anything else they decide. Most of us being tested for urine are men of color. It feels like they take away your soul.*

*I say, ‘isn’t addiction self-harming in itself?’ But no one listens. I give up. No matter how many times I have asked help for addiction and mental health, I haven’t gotten any.*

*My mental health is damaged. I lost everything due to addiction. It’s hard to think about the childhood trauma I experienced. I want people to know that we are worth saving, even lifers.*

In expanding access to MOUD, the correctional system is prioritizing access for those with shorter sentences or who are close to release (L. Whiteside, personal communication, November 22, 2021). This is an important strategy, as risk for overdose death is elevated in the period after release (Merrall et al., 2010). Not providing OUD treatment to those with longer sentences, however, has multiple, damaging consequences. The barriers experienced by Christian are ones that disproportionately affect Black and Latinx men, the two groups with the highest rates of overdose deaths in Massachusetts (Massachusetts DPH, 2021c).

## Christian’s barriers

- ❑ Lack of early substance use intervention or trauma services as a teenager
- ❑ No access to OUD treatment in his community
- ❑ Inaccurate initial classification of substance use disorder
- ❑ Opioid use disorder diagnosis not recognized upon entry to prison system
- ❑ Long and undefined waiting list for MOUD for people with lengthy sentences
- ❑ Disciplinary consequences for substance use that adversely affect mental health



# 6

## Roberto

### Need for Individualized, Culturally Responsive Treatment Options

Many people with OUD have tried various types of treatment programs at different points. It can be a challenge to find treatment that is a good match for one's individual needs, especially when in crisis. The factors that lead to a good fit are individual, contextual, social, and not always obvious. Most people learn through trial and error. There are myriad reasons why a given program might not work for an individual, demonstrating the need for a range of different options and individualized treatment. Every person interviewed recounted experiences of trying different programs, with little support to navigate, assess, and determine the best treatment options for their individual needs and situation.

Roberto is a 45-year-old Puerto Rican man living in Worcester who became addicted to heroin as a teenager. He cycled in and out of prison from age 17 to 40, trying different treatment programs along the way.

*Heroin was the worst mistake of my life. I wanted to fit in with one of the guys. I was using and gave some to my girl. We became addicts. We had to steal radios from cars to feed my habit. That's how my desperation started. I'd go to jail for two years for stealing cars and then I would get out, and 90 days later, I'd be in jail for another two or three years more.*

*When I went to jail, you had to do one AA or NA group at night. I hear now they are giving methadone when you're in jail. Before, we got nothing to break the habit. They would take you to this little room and watch you, no meds or anything. You'd start crying from the pain and they would send you to the hole [solitary confinement].*

*One treatment program [in the community] I tried was too hard. It was an AA program and supposedly, you had a 50 percent chance you'd make it. It was all White people there and I was the black sheep. I ended up leaving.*



*I got HIV from a needle and I got hep C. That made me draw deeper into drugs. I thought I was worth nothing because I was so sick. I thought nobody cared about me.*

*The first time I came here [residential treatment program] was two years ago and I ended up relapsing. They gave me another chance and now I'm back here. I end up relapsing because I wasn't talking about my problems. That got me in trouble.*

*This program gives me hope. It's a nice slow program. They teach you little by little. They teach you how to be responsible. I got so deep into the life [of drugs and crime] that when I try to do the right thing, I don't have the right tools. My mind is not set up to do the right thing, but they teach us. They teach you how to go to the store, how to go downtown, how to get a job, how to make a resume. I just got a resume and I'm 45 years old. I got my GED here.*

*They give me stipend money and teach me how to work with food in their restaurant. The counselor here helped me get my birth certificate and Social Security card. I've got my ID now. I'm taking computer classes right now. You have to take it slow. When you're an addict, if you put too much stuff in your plate, you start exploding like a bomb.*

*We have three doctors here. There is one who prescribes Suboxone and other medications. Then we have the psych doctor. She comes to the house and she helps me with my psych meds. Then we have another doctor who treats HIV.*

“ I got so deep into the life [of drugs and crime] that when I try to do the right thing, I don’t have the right tools.

One of the doctors invited us to her house for Christmas. She treats us like a mom. We call her mom. A month ago, I was at the red light, asking people for money. I wanted to kill myself every day. I ended up in the hospital for attempting to take my life. But then God gave me another chance. If it wasn’t for my friend taking me here, I’d be still going back to jail or maybe dead.

When interviewed, Roberto was participating in a residential treatment program for Latinx men that provides integrated SUD treatment, recovery supports, and training and employment. Through their culturally responsive approach to OUD treatment, he was finding home, health, connection, and purpose.

### Roberto’s barriers

- No substance use intervention as a youth
- No access to justice diversion programs to receive treatment instead of incarceration and disrupt cycles of drug-related crime and incarceration
- Lack of reentry supports upon leaving incarceration
- No access to MOUD in prison
- Dearth of culturally responsive, Spanish-language treatment services
- Lack of access to mental health services



## Stigma

Woven throughout all of these stories are accounts of stigma against people who use drugs or experience addiction. This discrimination includes the negative associations and cultural and social beliefs attached to people in our society who use drugs and experience addiction. It results in blaming and shaming people for their illness, punitive tough love approaches, harsh disciplinary actions against those who are in state custody, lack of equitable funding for SUD treatment and recovery services, lack of prestige for addiction medicine, and lags in developing evidence-based SUD treatments as well as making them widely available. Stigma is borne of ignorance and fear. Being on the receiving end of stigmatizing treatment leads to feelings of deep shame, often internalized, becoming an even bigger barrier to asking for help. Stigma and shame lead to self-loathing and other forms of coping that often send people deeper into addiction, disconnection, and suffering.

The experiences featured in this paper show the damage of stigmatizing treatment from healthcare and treatment providers, first responders, correctional staff, and other professionals. Our interviewees also experienced stigma from those in the recovery community who hold damaging misconceptions about MOUD. The lack of information, understanding, and acceptance of multiple pathways to recovery is another manifestation of stigma. Lastly, people with OUD internalize the stigma shown to them, eroding their sense of self, agency, and self-efficacy.

“

*“You go to the hospital, and you are immediately black-balled. If you got a cut in your hand and knew you were going to be treated terribly, you wouldn’t bother going.”*

**—Kelly**

*“People look at us the wrong way and we just get deeper into addiction.”*

**—Roberto**

*“When people are in active addiction there are times when you wonder if anyone in the world even sees us, the real us, not the one that makes people clutch their purse. You wonder if anyone cares about the person inside of us who is dying.”*

**—Shannon**

”

## Conclusion

The perspectives shared by these courageous individuals offer a vivid snapshot of the varied challenges to getting help for OUD and sustaining treatment and recovery. Each person's story illuminates the many barriers that block pathways to treatment and recovery and erode trust and dignity. Yet, each narrative also includes the seeds of solutions (see below). By elevating the voices, experiences, and recommendations of people with OUD, we hope to deepen understandings of the barriers to OUD care and inspire more people to join the diverse stakeholders already working to dismantle barriers and re-envision a SUD treatment system that is truly accessible, equitable, person-centered, recovery-oriented, non-stigmatizing, and trauma-informed.

### Envisioning Solutions to Barriers to OUD Care

#### People-level solutions

- Train the workforce—such as healthcare providers, correctional and parole officers, SUD service providers, first responders—that interacts with people with SUD to understand the neurobiology of OUD and how to provide person-centered, recovery-oriented, racially equitable, culturally intelligent, non-stigmatizing, trauma-informed care
- Dismantle myths about MOUD
- Create multifaceted stigma eradication initiatives
- Address racism and discrimination

#### Program or organizational-level solutions

- Eliminate stigmatizing practices
- End failure-focused services
- Services that are fully person-centered, recovery-oriented, non-stigmatizing, trauma-informed
- Provide bilingual and culturally responsive services
- Acknowledge and address racism and discrimination
- Provide discharge planning, care coordination, and treatment navigation supports
- Implement anti-racist policies

#### System-level

- Provide strengths-based, youth-driven substance use education, prevention, screening, and intervention for youth and young adults, prioritizing those most at risk
- Offer wholistic wraparound care coordination across the continuum of care, especially at transition points, including harm reduction-focused and person-centered navigation services
- Expand justice diversion programs to offer SUD treatment instead of jail time, especially for juveniles
- Ensure equitable MOUD treatment access within all jails and prisons
- Offer recovery-oriented, person-centered post-incarceration reentry supports
- Infuse anti-racism policies and practices across the treatment system
- Develop low threshold, flexible housing options with generous time limits

*These recommended solutions derive from the interviews featured in this paper and are not intended to be comprehensive.*

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