Treatment Perspectives of Those Who have Experienced an Opioid Overdose and their Professional and Lay Caregivers

Begun Center for Violence Prevention Research and Education
Jack, Joseph and Morton Mandel School of Applied Social Sciences
Case Western Reserve University
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Glossary

Buprenorphine	A partial opioid agonist medication used for the treatment of opioid-use disorder and pain. It helps with cravings and withdrawal symptoms. It can be prescribed or dispensed in clinician offices and pharmacies.
Detoxification ("Detox")	The process of ridding the body of a toxic substance. The severity of this experience can be helped when done under medical care.
Fentanyl	Pharmaceutical fentanyl is a synthetic opioid, approved for treating severe pain, typically advanced cancer pain. It is 50 to 100 times more potent than morphine. It is prescribed in the form of transdermal patches or lozenges and can be diverted for use by someone for whom it was not prescribed. However, most recent cases of fentanyl-related harm, overdose, and death in the U.S. are linked to illegally made fentanyl. It is sold through illegal drug markets for its heroin-like effect. It is often mixed with heroin and/or other drugs (e.g., cocaine) as a combination product—with or without the user's knowledge—to increase its euphoric effects (see https://www.cdc.gov/opioids/basics/fentanyl.html).
Hispanic	A broad umbrella term used as a cultural identifier by some individuals who trace their roots to the US Territory of Puerto Rico, Mexico, Central America, parts of South America, Spain, and the Spanish-speaking nations of the Caribbean. Related identifiers include Latino and Latinx.
Intensive Outpatient Program (IOP)	Non-residential, direct-service substance use treatment programs designed to help clients build psychosocial supports and manage relapse via coping strategies.
Lay Caregivers	For present purposes, lay caregivers are friends and family members who cared for one who was at least 18 years old and experienced an opioid overdose.

Medication Assisted Treatment (MAT)	The use of medication in combination with counseling and other therapeutic techniques for treatment of substance use disorders. The Substance Abuse and Mental Health Services Administration (SAMHSA) recommends using "Medications for Opioid Use Disorder" or "MOUD" in place of MAT to reinforce that medication is its own form of treatment.
Methadone	A long-acting opioid agonist used in the treatment of pain and opioid use disorder. Requires an outpatient treatment program for opioid use disorder, which makes this treatment less accessible for many patients.
Naloxone/Narcan®/Kloxxado®	An opioid antagonist medication used for the treatment of a known or suspected opioid overdose emergency in which a person may have difficulty breathing, severe sleepiness or be unable to respond (see narcan.com).
Naltrexone	An opioid antagonist medication that blocks the euphoria provided by opioids that can aid in preventing relapse.
Opioids	A class of medications used in medicine to treat moderate to severe pain. They can have serious side effects including sleepiness, constipation, respiratory depression and death. They include oxycodone, hydrocodone, morphine, methadone, heroin and fentanyl. Buprenorphine is also an opioid, but it is a partial agonist.
Opioid Agonist	A molecule (or drug) that binds to a specific receptor on a cell and creates a response. Oxycodone, hydrocodone, morphine, heroin and fentanyl are examples of opioid agonists because when they bind to the opioid receptor, they **cause** pain relief, sedation, constipation, respiratory depression.
Opioid Antagonist	A molecule (or drug) that blocks a receptor on a cell and stops a response. Narcan® is an example of an opioid antagonist because when it blocks the opioid receptor, it can **reverse** pain relief, sedation, constipation, respiratory depression

Partial Agonist	A molecule (or drug) that binds partially on a cell and creates a partial response. Buprenorphine is an example of a partial agonist because when it binds to the opioid receptor, it causes relief of withdrawal symptoms and cravings without producing major respiratory depression and euphoria.
Peer Recovery Supporters	Persons in sustained recovery who have state certification to help others working toward sustained recovery.
Professional Caregivers	For present purposes, paraprofessional caregivers (e.g., unlicensed mentor/sponsor, certified peer recovery supporter) **and** professional caregivers (e.g., licensed treatment provider) are described as "professional caregivers" and are those who have provided opioid-related care (e.g., for chemical dependency, grief) for one at least 18 years old.
Suboxone®	A brand name for the partial agonist buprenorphine that also contains naloxone.
Subutex®	A brand name for the single product partial agonist buprenorphine. This formulation does not contain naloxone and is usually reserved for those with life-threatening allergy to naloxone.
Trauma	A broad term used to describe the effects within someone of a difficult or hurtful event. The resulting wound and how a person copes with it is often what "dictates much of our behavior, shapes our social habits, and informs our ways of thinking about the world."[1]
Vivitrol®	A brand name formulation for Naltrexone, an opioid antagonist, used in the treatment of both opioid use disorder and alcohol use disorder. This formulation is a long-acting injection given once a month in a physician's office.

[1] G. Mate, The Myth of Normal: Trauma, illness and healing in a toxic culture, (New York: Avery, 2022), 16.

Executive Summary

Five-thousand, one-hundred, forty-three (5,143) people died of an unintentional drug overdose (hereafter, "overdose") between 2014 and 2022 in Cuyahoga County, Ohio, a death rate that is among the highest in the US. Today these overdose incidents are driven by powerful synthetic medications originally marketed as pain-relieving opioids (e.g., fentanyl and its analogues). When used over time, **opioids alter a person's brain** so that it requires more of the drug to achieve the same pain-relieving effect. As a person takes more of an opioid, changes to their brain increase the severity of withdrawal symptoms if the person is delayed taking another dose or takes a smaller one. Today the opioid overdose epidemic is impacting Hispanic and non-Hispanic Black persons in the county, with Hispanic persons suffering the highest overdose death rate in recent years—almost double that of both the non-Hispanic Black and non-Hispanic white populations.

To learn more about how to ameliorate the devastating effects of the crisis, this study titled *Treatment Perspectives of those Who have Experienced an Opioid Overdose and their Professional and Lay Caregivers* was undertaken with **Woodruff Foundation** funding by researchers at the **Begun Center for Violence Prevention Research and Education** at Case Western Reserve University in Cleveland, Ohio. Begun Center researchers' work is based on the premise that communities should not be constrained in providing appropriately informed, evidence-based, strategically deliberated, and sustainable support to those in need due to lack of pertinent, sharable, and actionable data. In line with this guiding principle, the **goal** of the study was to collect data to inform approaches to reduce the impact of the opioid epidemic on persons who use opioids and others in the community. The **purpose** of this effort was to identify ways to quickly, effectively, and sustainably engage adults who have previously experienced an opioid overdose with substance use treatment (hereafter, "treatment"). This effort had three **objectives**:

1. to collect data on people's opioid-overdose experiences to inform treatment providers' efforts to quickly and effectively engage them with sustained treatment,

2. to collect data to inform the community's understanding of ways to connect and engage with adults who have experienced an opioid overdose, and

3. to support the dissemination of the opioid-overdose insights gained from the study to enhance opioid treatment, education, prevention and research.

The research team hypothesized that if it used mixed methods with an emphasis on qualitative data collection among a sample of people who have experienced an opioid overdose, and their professional and lay caregivers, lessons would surface on how to support more effectively people seeking opioid use treatment. Begun Center researchers recruited a total of 146 participants in Cuyahoga County comprised of **85 persons with lived experience of an opioid overdose** (hereafter, "persons with lived experience"), **59 professional caregivers**,

and **23 lay caregivers**. Data was collected via individual interviews and focus groups in February 2020 and from May 2022 through January 2023.

The research team learned that many **persons with lived experience share a broad array of self-reported characteristics.** For example, 98% reported polysubstance use, 93% previously had engaged in treatment, 91% had served time in a correctional facility, 87% said their incarceration was related to drugs, 73% had one or more co-occurring behavioral health diagnosis, 48% provided unsolicited accounts of traumatic experiences, and 32% started using opioids via a legal prescription.

It is evident that these characteristics fueled study participants' emphasis on **five interconnected and powerful impacts on persons engaged in opioid use**. All are recurring themes throughout this report:

- Personal motivation to use drugs
- Trauma
- Co-occurring behavioral health diagnoses
- Polysubstance use
- Criminal justice involvement

Because having experienced an overdose incident was an inclusion criterion for the study, the research team asked participants to **define 'overdose.'** Definitions ranged from "Someone is not responding" and "Sometimes you see them standing up doing nothing, just moving side to side" to "It just happens, you fall asleep," "You're just gone, just gone," and "Overdosing on heroin, you don't even realize it's coming like you do with coke, you'll do your heroin and the next thing is you wake up in the back of a medic unit."

The majority of participants with lived experience conveyed that they usually **remembered nothing about an overdose incident**. Participants commonly described an overdose incident as "falling out" and then "waking up," the latter of which most commonly was the result of Narcan® administration that immediately sent people into a state of opioid withdrawal characterized by body pain, headache, anxiety, distress, nausea, vomiting, diarrhea, and drug cravings. Most participants with lived experience said that they sought to resolve these withdrawal symptoms immediately, even if they were in an emergency department, by returning to opioid use.

Participants were prompted to discuss unintentional vs. intentional overdose. While there was broad agreement across participants that most overdose incidents were accidental, some participants detailed situations in which it was not. Participants also were prompted to discuss whether or not they always called 911 during someone else's overdose incident, with many acknowledging that they did not due to the widespread availability of Narcan® and fear of police response to what were stigmatized and often illegal activities.

Participants also were asked to offer their perspectives on **barriers to treatment with sustained recovery**, which were wide-ranging, interrelated, and situationally dependent. The research team divided the themes surfaced among three categories*: (a) neurological impacts of opioid use, (b) cultural diversity among professional caregivers, and (c) resources for individuals seeking treatment.* For example, one physiologic barrier was professionals' poor management of people's withdrawal symptoms early in treatment, which a majority of participants with lived experience cited as triggering their relapse. Professional caregiver participants highlighted the shortage of Spanish-speaking professional caregivers as a barrier to treatment for many Hispanic members of the community and emphasized that there are large treatment programs in the county that do not offer evidence-based care and resources.

Participants also discussed their **perspectives on pathways to treatment with sustained recovery** and the themes that emerged were categorized again as above. Participants discussed how existing treatment pathways could be improved via better management of withdrawal symptoms through longer treatment duration and expansion to other hospitals of an existing model in the county that mainstreams patients undergoing detox in general inpatient hospital settings. Participants also believed that more robust pathways could be built by developing a more culturally diverse and multilingual professional caregiver workforce that could more effectively communicate that opioid use is a treatable, chronic disease characterized by recovery and relapse. Others saw a transformative resource change that could limit fatal overdose incidents because federal law now permits more clinicians to prescribe buprenorphine for medication assisted treatment (MAT).

Data also were collected on **participants' dream treatment**. Themes surfaced under the topics of jail, detox, inpatient treatment, and outpatient treatment. Some participants expressed how the time and social isolation they experienced in jail was key to developing their motivation to enter treatment. Other participants zeroed-in on detox, if it could be of longer duration and included more comprehensive withdrawal management. Still other participants described their dream treatment as inpatient, comprised of among other criteria longer duration, alternative therapies (e.g., music, meditation, movement), and greater flexibility in class/group participation and scheduling. Finally, other participants' dream treatment was outpatient programs that were non-confining and centered around MAT.

Additional findings included perspectives on **how community members of all kinds can improve connections and engagement with persons using opioids.** Participants discussed (a) centering the wants and needs of those who use opioids in collaborative community-wide discussions, (b) harm reduction services, and (c) bereavement counseling as three ways in which community members can improve their connections and engagement with people who use opioids. The data collected from all types of participants tell the story **that there is no one-size-fits-all treatment modality, but locating people who use opioids and their wants and needs at the center of treatment planning** can foster community-wide connection and more effective collaboration. **Harm reduction services** function to mitigate the detrimental consequences of drug use based on people's needs,

including prevention of fatal overdose (e.g., Narcan® distribution) and transmission of disease (e.g., syringe exchange), through care that is free of stigma. Participants emphasized that these services allow harm reduction professionals to build trusting relationships with persons who use opioids so that when they are ready to engage with treatment they have an established connection to information, education, and referral. Some participants also had experienced themselves or observed the **ripple effect of overdose-death grief** felt by decedents' families and friends, many of whom use opioids themselves. Participants suggested engaging all of those experiencing grief, some of whom may desire referral to opioid-use treatment, through the systemic expansion of the existing 'prevention-intervention' public health model to a 'prevention-intervention-postvention' one.

The experiences, observations, knowledge, and opinions that shaped participants' expressed perspectives herein highlight that people face opioid use and overdose in many different ways. The challenges and barriers articulated by participants may seem imposing, but the insights surfaced from this project demonstrate that **the expansion of existing pathways and creation of new ones with the collaboration of persons who use opioids and their professional and lay caregivers** can guide positive steps in ameliorating the effects of this devastating epidemic.

The following recommendations emerged from the research findings:

1. The community would benefit from education efforts (e.g., media campaigns) highlighting that opioid users suffer from **a treatable, chronic disease that involves relapse**.

2. The increasing opioid use rates of often underrepresented individuals calls for **expanding prevention, intervention, and postvention efforts to include more diverse, culturally appropriate services** (e.g., Spanish-language professional trainings and treatment services; faith-based initiatives).

3. Providing **a menu of multiple treatment options, venues, and types** with increased understanding that an individual's recovery takes time, often includes set-backs, and evolves along a continuum of care is crucial to meeting the diverse wants and needs of persons using opioids.

4. **Treatment options need to include MAT and longer term supports** to promote recovery and prevent relapse.

5. **An individual's time in detox needs to be longer and provide pain-relief**, especially for the large percentage of those whose introduction to opioids began through their own legal pain-relief prescription.

6. Opioid users need:
    a. **better and more accessible notification systems to employ when they are ready to engage with treatment the first time and after relapse**, and
    b. **more immediate and supportive response mechanisms guiding their way to their desired treatment services**.

7. **An expansion of the role of certified peer supporters and trained patient navigators** is needed to strengthen opioid treatment engagement, recovery support, and relapse prevention.

8. **Increased stakeholder commitment to collecting, accessing, sharing, and disseminating opioid-related data** to better understand currently undocumented opioid use, non-fatal overdose and overdose death by suicide rates to inform prevention and treatment interventions.

It is the research team's hope that this report will be made publicly available to inform opioid education, treatment, and research in Cuyahoga County and similar settings. The research team also will use the research findings in funding requests to diverse funders for future, more in-depth, and longitudinal opioid-epidemic research.

1. Background

> *Perhaps they would not have thought that evil was a state so rare, so extraordinary, so disorienting, and to which it was so restful to emigrate, if they had been able to discern in themselves, as in everyone else, that* ***indifference to the sufferings of others one causes****—whatever other names one gives it—is the one true, terrible and lasting form of cruelty.*[2]

Opioids have impacted the lives of many people. Opioid use and overdose can be difficult and emotionally charged topics. Some of the discussion herein may be triggering, especially for those in recovery, those who have experienced an opioid overdose incident, those who have witnessed someone else's overdose, and/or those who have lost a loved one to an overdose incident. If you find yourself having difficulty reading this report, please set it aside and seek support from a loved one or trusted professional. You are not alone. Help is available in Cuyahoga County at the 24-hour Suicide Prevention, Mental Health /Addiction Crisis, Information and Referral Hotline operated by FrontLine Service at (216) 623-6888 or nationwide by dialing or SMS texting 988. Some of the language herein is colorful, sometimes profane, and may be offensive to some.

i. Perspectives on Opioid-Use Treatment with Sustained Recovery

Opioids are powerful pain-relief medications that impact the brain. When used over time, opioids can alter a person's brain so that it requires more of the drug to achieve the same pain-relieving effect. As a person takes more of an opioid, changes to their brain increase the severity of withdrawal symptoms if the person is delayed taking another dose or takes a smaller one. This cycle of opioid dependence can escalate until the person is drug seeking compulsively, experiencing distress, and having difficulty functioning socially.[3] Compulsively seeking drugs in spite of negative consequences, together with high rates of relapse post-recovery, are primary characteristics of addiction. This compulsivity cannot be attributed only to a person's habitual behavior. Instead many researchers hypothesize that it stems from an opioid-impaired brain's difficulty in applying "top-down cortical control over habitual actions."[4]

Conversely, for some persons opioid use may not create an escalating cycle of tolerance and dependence with associated social dysfunction. While it is clearly evident from the information gleaned from the participants in this study that opioid use is often not only devastating but deadly, it also is apparent that for certain participants—like others elsewhere—opioid use was purposeful and beneficial.[5]

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[2] M. Proust, The Guermantes Way, 233.
[3] Centers for Disease Control and Prevention (CDC), (2022), https://www.cdc.gov/dotw/opioid-use-disorder/index.html.
[4] R.J. Smith and L.S. Laiks, "Behavioral and Neural Mechanism Underlying Habitual and Compulsive Drug Seeking," *Progress in Neuropsychopharmacology and Biological Psychiatry,* 87 (2018) 11.
[5] A. Ivsins and K. Yake, "Looking Beyond Harm: Meaning and Purpose of Substance Use in the Lives of Marginalized People Who Use Drugs," *Drugs: Education, Prevention & Policy*, 27, no. 1 (2020): 27–36.

In any discussion about opioid-use treatment with sustained recovery (hereafter, "treatment"), it is important to acknowledge that not everyone shares the same perspective. Some people do not need and/or want treatment for their opioid use. Some individuals prefer to maintain their level of opioid use to address chronic pain and/or avoid the agony that can accompany stopping the cycle. It is possible for some individuals to maintain their opioid use allowing them to function in meaningful ways. For others who want to stop using, they may prefer to do so on their own and some of the participants in this study explained how they successfully did so.

From this inclusive view of people's opioid use and perspectives on treatment, the discussion that follows is more narrowly focused on learning the diverse treatment perspectives of persons in our community who are suffering from their opioid use.

ii. Opioid Use

The Centers for Disease Control and Prevention (CDC) recognize the treatable, chronic disease known as Opioid Use Disorder (OUD) as an illness that can affect anyone that is associated with opioid seeking, distress, and impaired social functioning.[6] While this disease does not discriminate, the names associated with substance use behavior (e.g., 'addict,' 'problem,' 'abuse,' 'risk,' 'disorder') often sound discriminatory, disparaging, and/or make it easy to classify those experiencing it as 'less than.' In line with the way participants in this study described their actions, the researchers use the simpler name 'opioid use.'

Opioid use and its physiological impacts can affect individuals in wide-ranging ways. When people use opioids, their overall health can be affected by not only the effects of the drug on their body and mind but also by associated injuries and infectious diseases.[7] One's initial opioid use may be compelled by the appeal of among other things emotional and/or physical pain management, euphoria, anxiety and/or stress relief. Yet as dependence increases, the symptoms of opioid withdrawal become more acute. Opioid withdrawal symptoms and their duration may range from early symptoms such as "drug craving, agitation, anxiety, muscle aches, [and] stomach cramps" to later one's including "tachycardia, hypertension ... chills, anorexia, nausea, diarrhoea and vomiting."[8] With greater opioid dependence, avoiding the resulting suffering of withdrawal often is the decisive driver of one's drug-seeking behavior.

An opioid dose beyond one's tolerance level can begin to shut down their bodily functions. At its most extreme an 'overdose'—as it is commonly referred to with a range a meanings as

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[6] CDC, (2022), https://www.cdc.gov/dotw/opioid-use-disorder/index.html.

[7] E.A. Evans et al. "A Qualitative Study of Big Data and the Opioid Epidemic: Recommendations for Data Governance," *BMC Med Ethics* 21, no. 101 (2020). https://doi.org/10.1186/s12910-020-00544-9

[8] Joseph V. Pergolizzi, Jr et al. "Opioid withdrawal symptoms, a consequence of chronic opioid use and opioid use disorder: Current understanding and approaches to management," *Journal of clinical pharmacy and therapeutics,* vol. 45,no. 5 (2020): 892-903. doi:10.1111/jcpt.13114; D.J. Flannery et al. "A Blueprint for Sharing Opioid Overdose Data; Action Research Lessons from Northeastern Ohio, 2018-22." (#2018-AR-BX-K033). [Grant], (2022) Bureau of Justice Assistance.

discussed further below—can drop one's blood pressure and even stop a person from breathing. Opioid use can be deadly.

iii. Opioid Overdose Incidents in Cuyahoga County, Ohio

The research forming the basis of this report took place in Cuyahoga County. The county is in the northern half of Ohio's most populous and urban community made up of 58 municipalities including Cleveland and its suburbs. Despite substantial healthcare resources, some internationally renowned, the county's population has stark differences in health outcomes, especially poor ones for non-Hispanic Black and Hispanic persons.[9] For example, 14% (*n* = 172,533) of its 1.2 million residents consists of 111,644 (65%) non-Hispanic Black and 16,476 (10%) Hispanic residents who live in census tracks rated "very low" for health and well-being on the Ohio Opportunity Index (2021).[10]

People began dying from prescription opioids in Cuyahoga County and elsewhere in the U.S. in 1999 during "Wave 1" of the opioid-overdose epidemic, with "Wave 2" marked by the rise in heroin overdose deaths in 2010, and "Wave 3" exhibited by an increase in synthetic opioid overdose deaths in 2013.[11]

The recent history of unintentional drug overdose (hereafter, "overdose")[12] demonstrates that death rates in Cuyahoga County are now among the highest in the nation as indicated by the following:

- The county medical examiner has ruled that from 2014 through 2022 at least 5,143 county residents suffered an overdose death.[13]

- Fentanyl and its analogues are the primary cause-of-death drugs in the county.[14]

[9] "2018 Cuyahoga County Community Health Assessment/2018 Community Health Needs Assessment," Adopted by University Hospitals on September 27, 2018.
[10] Ohio Opportunity Index, (2021), https://coronavirus.ohio.gov/dashboards/demographics/ohioopportunity-Index (2021); U.S. Census, (2022), Quick Facts. https://www.census. gov/quickfacts/fact/table/Cuyahogacountyohio, US/PST045219).
[11] CDC, (2023), https://www.cdc.gov/opioids/data/analysis-resources.html
[12] Both fatal and non-fatal overdose incidents can be defined in a variety of way. (See H. Palis et al. "Concurrent Use of Opioids and Stimulants and Risk of Fatal Overdose: A Cohort Study." *BMC Public Health*, 22, no. 1, (2022) 2084. https://doi.org/10.1186/s12889-022-14506-w;
[13] T.P Gilson, "Heroin/Fentanyl/Cocaine Related Deaths in Cuyahoga County (December 2022 Update Draft 1/12/23)." Cuyahoga County Medical Examiner's Office, (2023) https://cuyahogacounty.us/ docs/default-source/me-library/heroin-fentanyl-cocaine-deaths/2022/dec2022-heroinfentanyl.pdf?sfvrsn= b9408506_3
[14] T.P. Gilson, "Heroin/Fentanyl/Cocaine Related Deaths in Cuyahoga County (December 2021 Report)". Cuyahoga County Medical Examiner's Office, (2022), http://medicalexaminer.cuyahogacounty.us/ pdf_medical examiner /enUS/HeroinFentanylReports/ MAR2021-HeroinFentanylReport.pdf

- The Ohio Department of Health reported the county's overdose death rate for 2015 through 2020 was 37.7 per 100,000 population, which was higher than the Ohio rate of 37.4.[15]

- The CDC in 2020 ranked Ohio fourth among states for overdose deaths both by age-adjusted death rate (47.2 per 100,000) and total death count (5,204).[16]

- Cuyahoga County experienced 650 overdose deaths in 2022 with no signs entering 2023 of the numbers declining.[17]

While it is difficult to track non-fatal overdose incidents in Cuyahoga County, existing data sources make evident an ongoing and evolving threat to public health and safety. In 2017 county emergency departments (EDs) treated 6,761 patients experiencing an overdose, an average of 18+ patients per day with one-third of the cases opioid-related.[18] This rate remained largely unchanged in 2021 (n=6,367).[19] Recent Begun Center interviews with EMS personnel point to incidents in which increasing Narcan®[20] dosages are administered to the same persons experiencing a recurrent overdose who also refuse ED transport—possibly resulting in incident underreporting.[21] Interviewed Cleveland Division of Police Heroin-Involved Death Investigation detectives said they cannot respond to all non-fatal overdose incidents due to the sheer number.[22]

iv. Opioids and Other Drugs as Causes of Death in Cuyahoga County

The following drugs alone and in combination are driving deaths in the county:

[15] Ohio Department of Health. Violence Injury Prevention Program, (2021), https://odh.ohio.gov/wps/ portal/gov/odh/know-our-programs/violence-injury-prevention-program/media/ 2019% 20Ohio%20Drug%20Overdose%20Report)
[16] CDC, (2023), https://www.cdc.gov/nchs/pressroom/sosmap/ drug_poisoning_mortality/drug_poisoning.htm
[17] T. P. Gilson, "Heroin/Fentanyl/Cocaine Related Deaths in Cuyahoga County (December 2022 Update Draft 1/12/23)." Cuyahoga County Medical Examiner's Office, (2023), https://cuyahogacounty.us/docs/default-source/me-library/heroin-fentanyl-cocaine-deaths/2022/dec2022-heroinfentanyl.pdf?sfvrsn=b9408506_3
[18] Cuyahoga County Board of Health (CCBH), "Ohio EpiCenter Data," Cuyahoga County Board of Health, (2018).
[19] CCBH, "Overdose Data Dashboard," (2022a), https://www.ccbh.net/overdose-data-dashboard/
[20] Narcan® (naloxone) is a nasal spray is used for the treatment of a known or suspected opioid overdose emergency in which a person may exhibit difficulty breathing, severe sleepiness or an inability to respond (see narcan.com).
[21] D.J. Flannery et al. "Research Brief: Carfentanil—A Fourth Wave of Fatal Overdoses." *Police Chief Magazine* (2020) https://www.policechiefmagazine.org/rib-carfentanil-fourth-wave-fatal-overdoses/
[22] D.J. Flannery et al. "Cuyahoga County, Ohio Heroin and Crime Initiative: Informing the Investigation and Prosecution of Heroin-related Overdose. Final Research Overview Report," (Award number 2017-DN-BX-0168), (2022), Office of Justice Programs, US, Department of Justice, National Institutes of Justice. https://nij.ojp.gov/library/publications/cuyahoga-county-ohio-heroin-and-crime-initiative_Finalreport

- **Fentanyl** and fentanyl analogues emerged as factors in 2014 and by 2020 they were the cause-of-death drugs in 416 of 553 (75%) cases.[23]

- **Carfentanil** has played a more varied role and was found in 191 cases in 2017, 24 cases in 2018, 220 cases in 2019, 63 cases in 2020, 6 cases in 2021, and 1 case in 2022.[24]

- Deaths caused by **cocaine** and cocaine-opioid admixtures have grown to a record annual high of 301 in 2022 and the numbers are increasing in 2023.[25]

- **Methamphetamine** is another stimulant of concern. Overdose deaths involving methamphetamine have been trending upward from 5 in 2015 to 92 in 2021, most in-combination with fentanyl.[26]

v. Differential Impacts of Ethnicity on Opioid Overdose Deaths

Hispanic and **non-Hispanic Black** persons[27] in Cuyahoga County are experiencing overdose deaths at the highest rates, demonstrating tragic inequities.[28]

- Even though **Hispanic** persons comprise only 6.6% of the population, they suffered the highest overdose death rate in 2020 (60.4 per 100,000)—almost double that of both the **non-Hispanic Black** (34.7 per 100,000) and non-Hispanic white populations (32.7 per 100,000).[29]

- Another marginalized population are **non-Hispanic Black** persons (30.5% of the population) who are experiencing the second highest rate of overdose death.[30] This

[23] T.P. Gilson, "Heroin/Fentanyl/Cocaine Related Deaths in Cuyahoga County (December 2021 Report)". Cuyahoga County Medical Examiner's Office, (2021), http://medicalexaminer.cuyahogacounty.us /pdf_medicalexaminer/en-US/HeroinFentanylReports/MAR2021-HeroinFentanylReport.pdf.
[24] T.P. Gilson, "Heroin/Fentanyl/Cocaine Related Deaths in Cuyahoga County (April 2022 Report)". Cuyahoga County Medical Examiner's Office, (2022a), https://cuyahogacountyus/medical examiner/resources/overdose-statistics: T.P. Gilson, T. P. (2022b). "Heroin/Fentanyl/Cocaine Related Deaths in Cuyahoga County (May 2022 Report)". Cuyahoga County Medical Examiner's Office. https://Cuyahogacounty.us/ medicalexaminer/resources/overdose-statistics; Flannery et al. "Research Brief: Carfentanil; T.P. Gilson, Heroin/Fentanyl/Cocaine Related Deaths in Cuyahoga County 2023 January/February Update Draft." (2023), https://cuyahogacms.blob.core.windows.net/home/docs/default-source/me-library/heroin-fentanyl-cocaine-deaths/2023/jan-febheroinfentanyl.pdf?sfvrsn=dde51451_3.
[25] T.P. Gilson, T. P. "Heroin/Fentanyl/Cocaine Related Deaths in Cuyahoga County (2023 March Update Draft)". Cuyahoga County Medical Examiner's Office, (2023).
[26] T.P. Gilson, T. P. (2022b). "Heroin/Fentanyl/Cocaine Related Deaths in Cuyahoga County (May 2022 Report)
[27] Decedent ethnicity is provided to the Cuyahoga County Medical Examiner's Office by funeral homes based on next-of-kin reports.
[28] CCBH, (2022a), Overdose Data Dashboard; "2018 Cuyahoga County Community Health Assessment/2018 Community Health Needs Assessment,"
[29] CCBH, (2020). https://www.ccbh.net/wp-content/uploads/2021/04/2020-Cuyahoga-County-DOIEP.pdf; U.S. Census. (2022). Quick Facts.
[30] U.S. Census. (2022). Quick Facts.

may be a result of the greater presence of fentanyl in cocaine supplies as reflected in toxicology reports and cocaine being a common substance of choice among **non-Hispanic Black** persons.[31]

vi. Researching People's Perspectives on Treatment

The Woodruff Foundation awarded funding for a research project titled, *Treatment Perspectives of those Who have Experienced an Opioid Overdose and their Professional and Lay Caregivers*. The purpose of this research was to identify ways to quickly, effectively, and sustainably engage with opioid-treatment motivated adults who have experienced an opioid overdose. This project aligned with the Woodruff Foundation's mission to support behavioral health treatment research, promote the dissemination of research insights to enhance drug-use education and prevention, and drive coordination of resources in the community.

This study had three objectives:

1. to collect data on people's opioid-overdose experiences to inform treatment providers' efforts to quickly and effectively engage them with sustained treatment,

2. to collect data to inform the community's understanding of ways to connect and engage with adults who have experienced an opioid overdose, and

3. to support the dissemination of the opioid-overdose insights gained from the study to enhance opioid treatment, education, prevention and research.

The initial funding award was made in October 2019, but due to the COVID-19 pandemic the research was halted from March 2020 until May 2022. The research team was comprised of Principal Investigator and Senior Research Associate Karen Coen Flynn, Ph.D., Co-Principal Investigator and Senior Research Associate Michelle Riske-Morris, Ph.D., JD, and Research Associate Luma Masarweh-Zawahri, Ph.D., of the Begun Center for Violence Prevention Research and Education (Begun Center) in the Jack, Joseph and Morton Mandel School of Applied Social Sciences at Case Western Reserve University.

Begun Center researchers' efforts are based on the premise that communities should not be constrained in providing appropriately informed, evidence-based, strategically deliberated, and sustainable support to those in need due to lack of pertinent, sharable, and actionable data. In line with this guiding principle, the goal of the research team's work was to surface information to reduce the impact of opioid overdose on individuals who use opioids and inform the greater Cuyahoga County community. The following report presents the research findings.

[31] CCBH, "The 2020 Drug Overdose Integrated Epidemiologic Profile (DOIEP)." (2021). https://www.ccbh.net/overdosedata-dashboard/; T.P. Gilson, "Heroin/Fentanyl/Cocaine Related Deaths in Cuyahoga County (May 2022 Report) "2022b); K.C. Flynn and L. Hoffer, "Transitioning Illicit Drug Preferences and Identities in Ohio: The Proliferation of Methamphetamine use Among African-Americans." *Journal of Ethnicity in Substance Abuse*, July, (2018), 1-22.

2. Research Methods

i. Conceptual Framework

Based on insights gained via previous Begun Center research and evaluation activities, the research team hypothesized that if it used mixed methods—emphasizing qualitative data collection among people who have experienced an opioid overdose and their caregivers—then lessons would surface on how to better support people seeking opioid use treatment.[32]

ii. Participants

Both opportunistic and purposive sampling were employed to recruit participants at least 18 years of age with as much variety as possible in regard to ethnicity, gender, age, drug use history, and/or caregiving experience and/or professional caregiving.[33] Participants (n = 146) were initially recruited at one men's homeless shelter, one grief support center, one correctional facility, two harm reduction programs, and three treatment programs. Through snowball sampling recruitment spread to recovery housing and into the general community.

Participants had to meet at least one of the following participant definitions:

1. Those who were active or recovering opioid users with lived experience of an opioid overdose (hereafter, "with lived experience"), with active users experiencing their most recent opioid overdose within the last five years;
2. Lay caregivers who must have provided care for someone who was at least 18 years old and experienced an opioid overdose; or
3. Paraprofessional and professional caregivers (e.g., an unlicensed mentor/sponsor, certified peer recovery supporter or licensed treatment provider) (hereafter, "professional caregivers") who must have provided opioid-related care (e.g., for chemical dependency, grief) for someone who was at least 18 years old.

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[32] The Begun Center gains ongoing understanding of overdose incidents and community response via surveillance and outreach resources provided by the U.S. Attorney's Office of the Northern District of Ohio, Cuyahoga County Medical Examiner's Office, Cuyahoga County Board of Health (CCBH), and other partners. Begun Center federally funded research and evaluation efforts over the past five years also have contributed to development of its research team's insights. **National Institute of Justice** funding supported the ***Cuyahoga County Heroin and Crime Initiative*** **(NIJ-2017-DN-BX-0168**) research from 2018 to 2022. As evaluator, the Begun Center supported CCBH's **Centers for Disease Control and Prevention**-funded ***Cuyahoga County Overdose Data to Action Initiative*** **(CDC-RFA-CE19-1904)** from 2019 to 2023. Also, as evaluator the Begun Center supported the ADAMHS Board of Cuyahoga County's **Bureau of Justice Administration (BJA**)-funded ***Northern District of Ohio Opioid Data Sharing Action Plan*** **(#2018-AR-BX-K033)** from 2018 to 2022 and currently supports its **BJA**-funded ***Enhanced Data for Improved Substance Use Surveillance, Prevention, and Recovery on Re-entry in Cuyahoga County, Ohio*** **(15PBJA-22-GG-04436-COAP)** from 2022 to 2025.

[33] T. Sangaramoorthy and K.A. Kroenger, *Rapid Ethnographic Assessment: a practical approach and toolkit for collaborative community research* (Oxfordshire: Routledge, 2020), p. 50.

iii. Data Collection

Participants with lived experience were recruited in-person at syringe exchange programs or a men's homeless shelter and through subsequent snowball sampling some were recruited via telephone or teleconference. Licensed professional caregivers were recruited via email or teleconference. Unlicensed paraprofessional caregivers and lay caregivers were recruited via convenience sampling through email, teleconference, and in-person at syringe exchange programs or a men's homeless shelter and through subsequent snowball sampling via telephone or teleconference. The research team collected data via individual interviews and focus groups that took place in February 2020 and between May 2022 and January 2023.[34] Both quantitative (e.g., demographic) and qualitative data were collected from participants with lived experience. Qualitative data only was collected from participants who were professional or lay caregivers.

The interviewer (principal investigator) encouraged participants to share their personal knowledge, experiences, and perspectives, noting that there were no pre-determined correct answers, and asked probing follow-up questions to collect additional detail and/or further explanation.[35] The interviewer conducted confidential, semi-structured, individual interviews (*n* = 121) and focus groups (*n* = 5; 3 to 11 participants per group totaling 25 individuals) with a total of 146 participants. **If an individual met the inclusion criteria for two or more participant definitions, they were interviewed accordingly (*n* = 21). Data was collected from the 146 unique participants who met 167 participant definitions: those with lived experience (*n* = 85; 51%), professional caregivers (*n* = 59; 35%), and/or lay caregivers (*n* = 23; 14%).** Interviews lasted 7 to 66 minutes and focus groups lasted 34 to 48 minutes. Ninety-four (64%) were interviewed in-person, 37 (25%) were interviewed via teleconference, and 15 (10%) were interviewed via telephone. All interviews and focus groups were audio-recorded. Individuals with lived experience provided verbal informed consent. Professional and lay caregivers provided written informed consent. Individuals with lived experience, unlicensed professional caregivers, and lay caregivers were compensated with a $25 gift card. Licensed professional caregivers were not compensated. The Institutional Review Board for the Protection of Human Subjects at Case Western Reserve University approved this protocol.

iv. Analysis

All audio recordings were uploaded for transcription into Otterai®. Subsequently, each transcript was reviewed and cleaned by the research team. The quantitative data collected were extracted from the transcripts and analyzed in Excel®. The transcripts were analyzed

[34] This research was halted between March 2020 and April 2022 due to the COVID-19 pandemic.
[35] M. Hammersley and P. Atkinson, *Ethnography: Principals in practice (2nd ed.).* (New York, NY: Routledge, 1993); W. Hollway, W. and T. Jefferson, *Doing Qualitative Research Differently*. (London: Sage Publications, 2000).

via Dedoose® and Systematic Text Condensation.[36] The findings are presented in the participants' own words, with some edits for clarity and brevity. Participants are de-identified herein and referred to generally by their participant inclusion category and the gender-neutral and further anonymizing term "they" although gendered pronouns are used occasionally herein when a participant's self-identified gender is relevant to the topic under discussion.

[36] K. Malterud, "Systematic Text Condensation: A strategy for qualitative analysis," *Scandinavian Journal of Public Health*, 40 (2012): 795–805.

3. Characteristics of Participants with Lived Experience of an Opioid Overdose

i. Study Participants with Lived Experience of an Opioid Overdose

Eighty-five individuals with lived experience of an opioid overdose participated in this study. Forty-eight (56%) participants self-identified as male and 37 (44%) self-identified as female (see Figure 1).[37] Participants ranged in age from 26 to 73 years, with 64 (75%) falling between 30 and 49 years (see Figure 2). Fifty-seven participants (67%) self-identified as white, 10 (12%) as Hispanic or Puerto Rican, 8 (9%) as African American or Black, 3 (4%) as Native/Indigenous American, 6 (7%) as multiethnic, and 1 (1%) participant's ethnicity was not identified (see Figure 3).

Eighty-three (98%) participants reported polysubstance use (e.g., opioids, marijuana, cocaine, methamphetamine); 2 (2%) participants reported using only opioids (see Figure 4).

Seventy-nine (93%) participants said they previously had engaged in substance use treatment (see Figure 5) and 6 (7%) said they had not. Thirteen (15%) participants reported receiving treatment only once, 26 (31%) twice, 17 (20%) three times, and 16 (19%) four or more times. Seven participants (8%) reported receiving treatment an unspecified number of times.

Sixty-two (73%) participants had at least one self-reported, co-occurring behavioral health diagnosis in addition to their substance use: Twenty-six (31%) participants had only one co-occurring diagnosis, 36 (42%) had multiple ones, and 3 (4%) did not disclose (see Figure 6).

Seventy-seven (91%) participants said they had served time in a correctional facility, 5 (6%) said they had not, and 3 (4%) did not disclose (see Figure 7). Twenty-four (31%) had spent 6 to 30 years in a correctional facility; 35 (45%) served 5 years or less (see Figure 8).

Sixty-seven (87%) participants self-reported their incarceration was related to drugs and 10 (13%) said their incarceration was not drug-related (see Figure 9).

Forty-six (54%) participants started using opioids with "friends and family" (e.g., recreational use with friends (28, 61%), use with family who used opioids (8, 17%), sought opioids via friends to self-medicate for pain (5, 11%), opioid use forced by family (2, 4%), recreational use with family (2, 2%), use to endure abusive family (1, 2%)) (see Figure 10).

Twenty-seven (32%) started using opioids via a legal prescription (see Figure 10).

[37] See Figures 1 through 17 in the Appendix, p. 55

Forty-one (48%) participants mentioned their experiences with trauma (e.g., death/murder of loved one, human trafficking, sexual assault, sexual abuse as a child, severe chronic disease, gunshot wounds, gang-related violence, domestic violence) (see Figure 11). The highest level of education attained by participants was wide-ranging (see Figure 12). Twenty-six (31%) had completed some schooling between the 1st and 11th grades, 26 (31%) had been awarded a high-school diploma or GED, 18 (21%) attended some college, 2 (2%) had been awarded an Associate degree, and 6 (7%) a Bachelor's or advanced degree. The highest level of education attained by four (5%) participants was undisclosed.

Figure 13 portrays participant employment status, reflecting that 29 (34%) participants were employed full-time, 4 (5%) were part-time, 47 (55%) were unemployed (e.g., received disability benefits, were or were not searching for employment), and the employment status of 5 (6%) participants was undisclosed.

Forty-five (53%) participants were housed, 20 (24%) participants were experiencing homelessness, 8 (9%) were experiencing homelessness and lived in a homeless shelter, and 8 (9%) lived with family and friends. The housing status of 4 (5%) participants were undisclosed (see Figure 14).

The majority of participants (*n* = 42, 49%) were single, 13 (15%) were partnered, 3 (4%) were married, 6 (7%) were separated, 13 (15%) were divorced, 4 were (5%) were widowed, and the marital status of 4 (5%) was undisclosed (see Figure 15).

The majority of participants (*n* = 76, 88%) had health insurance, 44 (59%) of whom had Medicaid (see Figure 16). Four participants lacked health insurance and the health insurance status of 6 (7%) participants was undisclosed.

Four participants served in the military, 76 did not serve, and the service status of 5 (6%) was undisclosed.

ii. Five Interconnected and Powerful Potential Impacts on Persons Using Opioids

While reading this report, it may prove worthwhile to **keep in mind the following five impacts** raised by many individuals across participation categories:

1. Personal Motivation to Use Drugs. An individual's personal motivation to use drugs may be driven by the attractions of the lifestyle (e.g., use with family and friends, income generation). Other motivations stem from self-medication for a chronic emotional, mental health or physical health challenge. For example, *"I started this because of depression,* emphasized one with lived experience who continued by saying, *"This thing [divorce from] my wife and the kids, it really hit me."* These types of motivations to use opioids may or may not be mutually exclusive across one's trajectory of opioid use.

"I'm not really sure what would be the ideal treatment," remarked one participant with lived experience who continued, *"I have tried fancy/costly treatment centers, multiple MAT [Medication Assisted Treatment] programs, state-funded detox facilities, and 12-step programs. All of that and I ended up detoxing from methadone in a county jail and participating in a MAT program."* The participant described their motivation to use drugs as changing over time until it was compulsive and seemingly beyond of their control, which shifted only when *"I was actually tired, scared for my future and aging, and wanted to change. That is what I think is best. Once that is the mindset, the most important thing is engaging in a treatment pathway that fits."*

2. Trauma. As shown in Figure 11 (see Appendix), 48% of the participants with lived experience recounted difficult or traumatic past events. These were offered voluntarily; the interviewer did not provide prompts for participants to discuss traumatic incidents in their lives. For example, a professional/lay caregiver with lived experience of opioid use described drug addiction as a response to trauma. *"I think that most of the time, if you look at people who have addiction, they have some sort of trauma, and it may not be 'something serious,' like who am I [or others] to say that something is a trauma or traumatic to somebody?"* The caregiver continued by explaining:

> *[But] if you don't have a brain that knows how to process pain, and someone puts something in front of you regardless of what that something is and that takes the pain away immediately, why not? I was disciplined. My mom was an addict, but she always disciplined me. I knew the difference between right and wrong. I knew that drugs were bad, I did them anyways. No, I don't think it's a choice. I do think it's an illness. I'm willing to bet within time, we're going to see exactly in the brain where it's at and what's happening. I believe it's a disease of spiritual depletion. It's all of those things. If you look back at Michael Jackson, Elvis, Marilyn Monroe, Prince, if you break it down to the smallest component addiction is what killed all of them. Some form of addiction. Some form of wanting more. Some form of wanting to fill a hole inside of me with something that is never enough.*

Another participant explained their initiation to fentanyl use by saying, *"I didn't start doing it every day until last October, when I witnessed a murder. Then I started using it every day."* The participant explained fentanyl helped them avoid replaying the murder scene in their mind so they could sleep and for these reasons, *"I do meth during the day and fentanyl at night."*

3. Co-occurring Mental Health and Substance Use Diagnosis. Nearly three-quarters (73%) of participants with lived experience disclosed they had been diagnosed with a co-occurring behavioral health condition. For instance, one participant with lived experience recounted their challenges maintaining their treatment regimen at a time when they were not adhering to their mental health one:

I went to the clinic across the street for Suboxone® when I started wanting to get clean again. What my problem is, they just upped my dose. But I missed my [Suboxone®] doctor's appointment because of my mental health issues, like, I wasn't taking my meds. I was hearing voices and stuff again. So I was scared to leave the house and go to my appointment. I missed my Suboxone® and [went into withdrawal], so I started using [opioids] again.

4. Polysubstance Use. The vast majority (98%) of participants reported using more than one substance. *"You have to remember that I was not just detoxing off of opiates, I was detoxing [from] drinking a fifth a day,"* explained a professional/lay caregiver with experience of opioid use. They emphasized,

> *I had an alcohol habit. I was taking multiple benzodiazepines. I was taking Adderall every day to try to wake up to keep going. I was coming off about five or six different pharmaceutical drugs, in addition to the street drugs. So my detox was pretty brutal.*

A professional caregiver explained how intentional or unintentional polysubstance ingestion is observed among ED patients who have experienced an overdose:

> *It's kind of ongoing problem in the emergency department, where a patient may wake up and be arousable but they're not wide awake like they would be in the past. We can wake somebody up so that they're breathing on their own, but they're still really sort of out of it from other substances. And, you know, the xylazine that's out there doesn't respond to Narcan so that may be part of that. But everything is just poly substance now. We're hearing from the medical examiner that they see xylazine, they're also seeing benzodiazepines, and that illicit benzo that keeps showing up in the pressed pills. So now it's opioids, but maybe with a stimulant, and you got a little bit of a benzo, too. Some of it responds to Narcan, some of it doesn't. Most of the drugs will cause some sedation, but usually you can reverse the respiratory depression with the Narcan. But they still might be out of it a little bit.*

5. Criminal Justice Involvement. Ninety-one percent of the participants had served time in jail and/or prison and for many of them that experience impacted their views on different types of treatment. *"I would never do inpatient treatment ... again,"* emphasized an individual with lived experience and criminal justice involvement, *"because it is more like being confined."*

4. Perspectives on "Opioid Overdose" and Overdose Incidents

The CDC defines the general term "overdose" as a fatal or non-fatal poisoning resulting from taking a drug in excessive amounts.[38] Participants across all three categories offered their own definitions of an opioid overdose.

i. The meanings of "Opioid Overdose"

Participants with lived experience described an opioid overdose in the following ways:

"You don't know. It just happens. You fall asleep."

"It's terrible because you don't feel nothing. You're just gone. Just gone."

"I was put in the hospital and have no idea how I got there."

"You've done too much of something. Dying. It's shutting down. If no one's there to save you, you will die."

"I definitely took too much, blacked out or passed out or whatever and woke up on the floor with no idea how I got there. Had a hallucination when I woke up at least two or three times. I was unconscious. I would consider that an overdose because I wasn't expecting that to happen. And I wasn't aware of what was going on."

"I passed out when I shot up. I just passed out. One time I woke up, and I guess I tried to get up, but I fell into the coffee table because when I woke up I was laying on the coffee table. And my son's mom was laying in the chair with the needle still in her arm."

"The blue lips, they're not breathing. You have to Narcan® them to bring them back. To me that's an overdose."

"An overdose obviously is when they have that death gurgle or breathing and they're turning purple or gray and their lips are purple."

"Not breathing or barely breathing."

"Usually, what I would consider an overdose is when you go to get high and then you've done too much of any sort of substance and then you basically lose consciousness. And I know that I have overdosed on cocaine before, and I have fallen out and then I've woken back up, but I didn't have to be like resuscitated or anything. You end up coming to. Whereas overdosing on

[38] CDC, "Opioids: Commonly Used Terms," 2023, https://www.cdc.gov/opioids/basics/terms.html#:~:text=Opioid%20use%20disorder%20is%20preferred,can%20be%20fatal%20or%20nonfatal.

heroin, you don't even realize it's coming like you do with coke, you'll do your heroin and then the next thing is you wake up in the back of a medic unit."

Professional and lay caregivers described an opioid overdose in these terms:

"[When I was actively using opioids] I was always chasing the nod that, like my head dropping down, kind of that was the baseline of being an addict. And it was explained to me that that's your blood pressure dropping and that is the beginning stages of an overdose. So that was my state of being okay."

"As soon as they start losing consciousness. Sometimes you see them standing up doing nothing, just moving from side to side. For me, that's an overdose. [They're] not able to do anything."

"When someone is not responding. That's usually kind of the line because I've definitely been in that situation where I have it [Narcan®] out and I'm trying to assess ... breathing, dropped heart rate. Differentiating between nodding off and an overdose, I think that's usually it. Most of the time, they're still talking. Try to get them to keep talking!"

"I carry Narcan® on me. Sometimes it's just somebody passing out drunk. I actually have sniffing salts that I carry also. If I try that, and that don't work—if they're turning blue, clamminess, things like that, and are completely stopped breathing—I will Narcan® them, wait a couple of minutes and then do it again if they need it."

ii. What does it feel like to experience an Overdose?

Most participants with lived experience emphasized that there were neither overdose warning signs nor do they remember anything about their overdose experience.

"I don't remember nothing."

"I can't ever tell I'm about to overdose."

"I always knew when it was coming [with cocaine]. But with heroin, it's like, I remember getting the dope and stopping to do the dope, but then I remember nothing else from that point. Even if there is stuff that happens between when I did it and when I woke up ... I don't remember any of it any of the times."

A few participants described some signs that an overdose was imminent:

"You'll see pins and needles. Then it's just completely blacked out."

"Dope is like a creeper. You can feel the symptoms creeping up on you.... You start getting really high and then you can feel your breathing change. You can feel the drug rushing through your body and then it's black."

"I started feeling really hot and I can't breathe and panicky. That's like the sign. It's just been a few times where I got to experience that because every time I ODed I don't remember."

"I was driving in the car and I couldn't see with my eyes open. And I kept on telling myself, 'Pull over! Pull over!' But I didn't have the strength to do it because I kept on shutting down. And I think I hit a car."

iii. "Falling Out"

When discussing their own or others' overdose incidents, participants commonly use the term "falling out." For instance, one participant with lived experience who experienced an overdose at the same time with her nephew said, *"All I remember is snorting a tiny line and I fell out."* She continued, *"My daughter was downstairs and heard two thuds.... She came upstairs, both me and my nephew are lying there blue, foaming at the mouth, eyes rolled back into our heads, and she's Narcaning me and calling 911."*

Two other participants with lived experience explained what they meant when they described 'falling out:'

> *It means you did the shot and next thing you know you're turning blue and purple. You stop breathing. [Falling down] or standing up. I've seen people stand up and just hunch over for a minute and start turning blue and purple. Once you stop breathing and lose consciousness, you're falling out.*
>
> *You can't see anything or you're like in a deep state of unconsciousness. You're like dreaming. You can sometimes, it depends how strong the drug is, sometimes you can hear what's going on. And you can kind of like talk. But when you fall out, fall out means you don't know shit, like, you're just out of it. Damn near overdosed. That's how people like to be. That means the drug is good. That's what someone will tell you like, 'Damn this shit made me fall out. This shit is good as fuck.' Excuse my language, but that's just how people make reference to a drug being good. 'Did it make you fall out? Did you nod out?' 'Oh, yeah, that's a good-ass drug. Like it was fire.'*

A professional/lay caregiver in recovery described 'falling out' in this way:

> *I think 'fall out' came from when you use so much dope your blood pressure bottoms out and you actually start to overdose. You fall, you go down, and you start to turn blue. But I think with heroin you could come out of it before this. ... I believe fentanyl drops your blood pressure and your respirations so quick that without Narcan® you*

> *can't really come back from it. But I do believe with heroin you did have a little bit of a chance of like using some cold water and some ice to bring them out of this type of thing. Fall out would be typically when you find people overdosed, you find them in the tripod position, head down, because they'll be sitting down with their knees and their head on the floor. So you're not out so hard, so you are not all the way down. You are seeing the ataxia because they turn blue because there's no more oxygen.*

Participants with lived experience who also used other drugs noted that falling out on fentanyl was unique. One compared falling out on the drug Ecstasy to doing so on fentanyl. He began,

> *[On Ecstasy] it felt like I was having a heart attack. I knew it was happening. I was, like, just covered in sweat, felt like my heart was beating out of my chest. I couldn't breathe. I felt like I was having a panic attack mixed with a heart attack mixed with like a stroke. I guess would be the words because I couldn't feel half of my body.*

In response to the interview's question, "How is [a fentanyl overdose] different from the other overdose on Ecstasy?" the participant continued,

> *Because you just kind of blackout. You kind of just fall asleep, I guess. I was fully functioning in one moment. The only time that I knew I was overdosing, my girlfriend asked me, "Do you feel it?" because it was the first time we had tried this new stuff. And I was like, "Hell yeah! I feel it." And then I was like, "I think I did----" and that was last thing I remember. I was gonna tell her, "I think I did too much."*

iv. "Waking Up"

Many participants described emerging from an overdose incident as "waking up." For instance, when the interviewer asked a participant, "What do you remember about your overdose?" they said*, "Nothing. I was injecting, and then I woke up."*

a. Waking-up Without Intervention or With Intervention that Did Not Involve Narcan®.

Some participants with lived experience described waking up from some overdose incidents on their own, without anyone's intervention. Others described waking up after someone intervened in various ways. For instance, participants with lived experience and professional and lay caregivers described using CPR in an attempt to revive someone experiencing an overdose. One participant with lived experience spoke of learning CPR from YouTube®. Another participant with lived experience recounted reviving 30 friends or acquaintances with Narcan® and CPR. *"I've broken a lot of their sternums. A lot of ribs are broken,"* they said. When asked where they learned CPR, the participant said they took a CPR class for free at MetroHealth Medical Center 2015.

Participants also described reviving people experiencing an overdose by putting them in a cold shower, rubbing their sternums, and other means. One participant with decades of lived experience who is now a professional caregiver described the following historical scenario:

> *Coming back out of this, when you overdose, the most embarrassing thing is the body fluids. You lose control of everything.... Up in the shooting galleries when people fall out, we burned the bottom of their feet, we put ice down their pants, we did whatever it takes to get them back. You know, and sometimes it's not a pretty sight.*

b. Waking-up After Narcan® Administration

Many participants described waking up after the administration of Narcan® feeling the symptoms of withdrawal. *"Sweating, fatigue, headaches, diarrhea, everything,"* said one participant who continued listing the symptoms they experienced by adding, "the shakes. It's bad." Almost all participants with lived experience offered similar descriptions. For instance, *"You feel fucked up because it makes you want to throw up and all that because it automatically blocks it, said one person. They continued to explain, "You start throwing up right away. Your body starts getting cold and sweaty, same as if you were dope sick".* Another participant with lived experience described how they felt post-Narcan® and included some of the science behind it in the following way:

> *Awful. If you're addicted. I mean this is the science behind it. If you have a habit, if you are physically dependent on the stuff. Now naloxone is an antagonist on the MU receptor in the brain and throughout the body. It's an antagonist. Morphine is an agonist so it does the opposite effect. Morphine makes you feel good and gives euphoria. Naloxone doesn't. That's why it takes you out of it.*

Many of the participants with lived experience who reported being revived by Narcan® described going back to opioids soon thereafter. When the interviewer asked a participant with lived experience who said they had revived 30 people with CPR, "What did they do afterwards?" the participant said, *"Same thing. They got high."*

One participant with lived experience was asked, "After being Narcaned, did you go back to using the same amount?" one participant replied, *"More."* The participant continued, *"You have a blocker in you now. This little bit of drugs isn't going to help [with withdrawal]. You do more."* When the interviewer asked, "How long does the blocker last?" the participant explained, *"I don't know. I don't wait that long."* This response was very common because as participants explained they wanted to decrease the symptoms of withdrawal.

Only those with lived experience who had not yet developed a physiological dependence on fentanyl did not feel poorly after a Narcan® administration. One participant described the difference in response to the interviewer's question, "When you were Narcaned [a few days after being released from jail] it didn't make you dope sick?" *"No, not at all,"* said the

participant, *"but back when I was in active addiction, like fully dependent on it, and you get Narcanned you go from the highest you can possibly be to the most dope-sick that you could possibly be."*

c. Medical Treatment after Waking-Up

A professional caregiver emphasized that Narcan® saves lives by reversing respiratory depression, but there may be aftereffects of an overdose incident that may not be recognized if one does not seek medical care:

> *So you can vomit and swallow some of the secretions and you can have respiratory complications from that. Some people get what we call re-expansion pulmonary edema where they get fluid in their lungs. It's not totally clear whether if it's actually from the overdose or from the reversal of the overdose but can get fluid in the lungs. Some people probably get that to a lesser degree and don't need medical care, but, you know, if you're in respiratory distress you would need medical care.*

v. Unintentional vs. Intentional Overdose

a. Non-fatal overdose incidents

All participants in this research who responded to a prompt about intentional fatal overdose incidents explained that they believed the majority of overdose incidents were unintentional, but sometimes the lines between unintentional/intentional overdose and getting high/dying by suicide appeared to be blurred in the explanations of some participants. *"I wasn't trying to kill myself, well, I was always trying to get super high, but I wasn't trying to die,"* explained one person with lived experience who then continued by saying,

> *Yeah, well I remember the last time ... but this was in my 11 months on the run.... I OD'ed because I kind of stopped caring. I'm thinking, 'I'm going to do ten years [in prison].' I was just dumping it in there.*

b. Overdose Death by Suicide

Barring certain kinds of evidence (e.g., a witness, a note, an audio or video-recording) it often is difficult to determine if someone who died from an opioid overdose intended to do so. Yet a growing body of peer-reviewed literature and subject matter expert communications documents opioid-involved death by suicide.[39] For example, Braden et al. (2017) used National Vital Statistics data (1999-2014) to calculate age-adjusted rates of opioid-involved deaths by suicide per year and found that they had doubled from 1999 through 2014.[40]

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[39] M.A Oquendo and N.D. Volkow, "Suicide: A silent contributor to opioid-overdose deaths," *The New England Journal of Medicine,* 378, (2018), 1567-1569; N. Volkow and J. Gordon, "Suicide Deaths are a Major Component of the Opioid Crisis that Must Be Addressed," 2019, https://nida.nih.gov/about-nida/noras-blog/2019/09/suicide-deaths-are-major-component-opioid-crisis-must-be-addressed

[40] J. B. Braden et al., "Suicide Deaths With Opioid Poisoning in the United States: 1999-2014." *American Journal of Public Health,* vol. 107, no. 3 (2017) 421.

Another retrospective examination by Bahraini et al. (2023) found that 356,514 U.S. military service members between 18 and 64 years old had been diagnosed with mild traumatic brain injury between 1999 and 2019. Of this cohort, 886 (0.25%) died by drug overdose with one-third of those deaths attributed to opioids and 80 (9%) of those who died via drug overdose were ruled deaths by suicide.[41] Additionally, other researchers have highlighted what they view as a "perfect storm," associating persons with traumatic brain injury with a risk for fatal opioid overdose, both unintentional and intentional.[42]

Several participants in this study recounted instances in which: (a) they sensed someone was experiencing suicidal ideation and may attempt suicide, (b) they described someone else's opioid-involved suicide, or (c) they described their own opioid-involved attempted suicide (*n* = 4). For example, one professional caregiver recounted speaking with an approximately 40-year-old individual with lived experience who was not open to discussing any further treatment. According to the professional, the person kept repeating, "No, I have a plan. I've got a plan." *"It gave me the sense [that they were planning to die by suicide] because there's just the despair of what he was talking about in life,* said the caregiver. *"And I don't know for sure, but it gave me that sense of, 'I've got a way out.'"*

Other professional caregivers had clients recount for them their suicide attempts. *"I had a client,"* said one professional, *"He overdosed 13 times in one week and he would get mad every time they would Narcan® him because he wanted to die.* Another professional caregiver explained, *"I did speak with one of our clients and right after the assessment was done we had a conversation and he stated that he was done with his life several times and that the way he attempted to end it was by using as much as he could."* The professional caregiver continued*, "But there was a person around him at that time that had Narcan® and he was lucky enough to make it to the hospital in time."* An additional professional caregiver shared, *"I hear many times testimony of people that come off of drugs and they tell me how they tried to kill themselves by overdosing. What is surprising and amazing is that many times they do it because they are tired. They are tired of what they are doing and don't want the shame."*

A professional/lay caregiver described the circumstances around their estranged partner's death. The partner had a painful, chronic medical condition and used prescription opioids throughout life for pain management. According to the caregiver, *"I think he was passively suicidal, like he may not have made the decision that this is going to kill me."* The caregiver

[41] N. Bahraini et al., "Racial and Ethnic Differences in Deaths by Suicide, Drug Overdose, and Opioid-Related Overdose in a National Sample of Military Members With Mild Traumatic Brain Injury, 1999-2019." *Journal of Head Trauma Rehabilitation* 38, no. 2, (March/April 2023), 122

[42] R.S. Adams, "Traumatic Brain Injury and Opioid Use: Additional evidence supporting the "perfect storm" of cascading vulnerabilities. *J Head Trauma Rehabil.* 36, no. 5, (2021):303–309. doi:10.1097/HTR.0000000000000730; R.S. Adams et al., "Traumatic Brain Injury Classification Variability During the Afghanistan/Iraq Conflicts: Surveillance, clinical, research, and policy implications. *J Head Trauma Rehabil.* 2022 Sep 5. Epub ahead of print. doi: 10.1097/HTR.0000000000000775.

said the partner never used street drugs and would say, *"Don't use heroin because you never know what's in it—always use pharmaceuticals."* After the partner's death, the caregiver learned the partner was severely depressed and died using heroin. The caregiver believes the partner's state-of-mind at the time of death was, *"Kind of one of those things like if it does [kill me], I'm okay with it."*

Another lay caregiver described his brother-in-law's death by suicide in another state. *"He wrote a letter to it,"* said the participant.

> *He just got married. They just had a daughter and stuff. And he said, the letter said, 'Baby I'm sorry, but I can't do this no more. I'm trying to quit. I promised you I'd quit and this is the only way I know how to quit.' And he's just hung himself. And he had just recently got married and had a daughter.... Fentanyl and heroin. A whole ton of it. He did a whole shot of it, fell off and [hung and] broke his neck.*

An individual with lived experience said that they knew four people who had intentionally taken their lives via opioids. *"Some people just can't fight their demons anymore, you know?"* the participant said. They continued by saying,

> *And that's sad because most times I don't think people want to die. They just want the pain to stop. Most people don't want to die. They just don't know how to get rid of that aching that, 'why am I here?'*

Five participants with lived experience recounted stories much like this: *"My one friend, I know he has tried to [die by suicide]. He didn't die of an overdose, but he tried to kill himself ... but someone saved him."*

Four individuals with lived experience described their own opioid-related suicide attempt(s). One participant explained, *"I didn't really start messing with the harder stuff until I was almost 30 years old, and my daughter passed away.* They continued, *"I gave up on the world. I was selling drugs and I tried to overdose with them."* When asked if their intent was to die, the participant responded, *"Yeah, I tried to. I snorted a bunch of heroin."*

Another individual with lived experience explained their depression after their partner left by saying, *"I was really depressed and just didn't want to be here anymore."* To the interviewer's prompt about whether the participant's intent was to die by suicide, the participant replied, *"Yeah, I snorted a whole gram."* The participant was revived by a roommate.

A third participant recounted,

> *My life was just spiraling and I just nonchalantly—I knew it [the amount of fentanyl] was too much for me—and was just like, 'Hey, let me get a hold of that' and I did it ... then it started spinning. As soon as it started spinning, it went into nothing and then I woke up [in the hospital].... I was with somebody [when I took the drug] and I was just hoping they would let me fucking die.*

Finally, an individual with lived experience explained that one can go to a dealer and say one *"wants a special bag, a 'hot shot.'"* When the interviewer asked, "What's a 'hot shot'?" the participant replied, *"Enough to kill you. Nine times out of 10 it's carfentanil or fentanyl—just stronger."*

c. Overdose Death by Homicide

One participant with lived experience described a fatal overdose of someone who lived in the same house he did that he believed was a homicide. *"The girl [X] that died in February,"* said the participant, *"personally, I think it was murder."* The participant went on to say,

> *I think her boyfriend did it. A couple of people think that, too, but a lot of people think that it was suicide, too. She was really depressed. She just found out she was pregnant with her boyfriend's kid and her boyfriend is half her age. She was in her 40s. It would have been real life-changing.*

After the interviewer asked, "And why do people think that maybe he 'did her in?'" The participant continued,

> *Because when we tried Narcanning her, we couldn't find any of the Narcan® in the house at all. And then after she died, we were cleaning their bedroom, and we found all the Narcan® in a bowl under the dresser. And then some statements he made while she was overdosing, definitely, because he was [saying], "Why ain't that bitch dead yet?" So, they couldn't do nothing about it. But her toxicity levels were four times the normal overdose level.*

The interviewer follow-up by asking, "And she'd been a longtime user? She knew what she was doing?" *"I mean, she was a longtime user of meth,"* said the participant*, "but she just started doing heroin. She dabbled with it for the last five years, but not like full-blown every day."*

vi. Barrier to Gathering Information on Overdose Incidents to Inform Treatment System Response

a. Those Successfully Reviving an Individual May Not Call 911**.** Many individuals with lived experience explained that they often do not call 911 if they have revived someone successfully and the same goes for when someone revives them. When asked to respond to the prompt,

"The community knows how many overdose incidents there are because we know how many calls were made to 911," a participant responded, *"That's completely false."* They explained:

> *At the crack house I live in, we literally probably had from last October till now over 100. Probably over 100 overdoses and we called the ambulance one time. And we've only had one person die, sadly, in February. There was nothing I could do.*

In response to the question, "After your overdose did you end up at the ED?" a participant with lived experience answered, *"No."* They went on to recount,

> *I was with a girlfriend who Narcanned me every time [3 overdoses]. And every time I woke up, and she was crying. ... And I'm like, "Who died?" And she's like, "You, you fucking asshole," and I'm like, "Oh, no, I'm perfectly fine." And then I realize I'm covered in water and whatnot from her Narcanning me and pouring cold water on me and doing whatever she could to wake me up.*

Another participant said, *"People don't want to deal with the police, so if you have Narcan and they come back to life, we don't need to call them. That's what the Narcan is for."*

b. Those Unsuccessfully Reviving an Individual May Not Call 911. An individual with lived experience who is now in recovery and a professional caregiver explained historical instances in which persons experienced a fatal overdose and no one called 911:

> *Unfortunately some of them get rolled in the carpet and thrown in the dumpster. That's the funeral of a junkie. That's what they got to look forward to. Dying in the shooting gallery, getting rolled up in the carpet, and thrown in the dumpster. I've probably been a part of that scene over a dozen times.*

Participants with lived experience noted that at present if someone cannot be revived those around them may not call 911. One participant explained, *"We don't want to call the cops. ... I've heard of the Good Samaritan Law, but usually, I mean, if they die, they're usually looking into who they get it from.*[43]*"*

c. Those Unsuccessfully Reviving an Individual May Not Have Intended to Revive Them.
For an example of an overdose incident described by a witness in which it appeared that one experiencing an overdose incident may have been a victim of homicide, see page 22.

[43] The Good Samaritan law in Ohio (Ohio Revised Code 2305.23) states that "No person shall be liable in civil damages for administering emergency care or treatment at the scene of an emergency outside of a hospital, doctor's office, or other place having proper medical equipment, for acts performed at the scene of such emergency, unless such acts constitute willful or wanton misconduct."

d. Institutional Reporting. The ways in which some organizations track overdose incidents may not accurately capture an event. *"So, [in] our incident reports," one professional caregiver noted, "people often identify [an overdose incident] as a 'seizure.' Now they'll still use Narcan®, but it's identified as a 'seizure.' So I probably get like one-to-three of those incident reports a month. And I don't remember what year it was.... but one of the supervisors here administered Narcan® 35 separate times in one year, which was a lot and people responded to it. So, yeah, I don't know how many [overdose incidents] are missed.*

5. Perspectives on Barriers to Treatment with Sustained Recovery

This chapter outlines themes and sub-themes that emerged when participants discussed barriers limiting access to treatment and sustained recovery. While the discussion points are interrelated and situationally dependent, they have been divided for present purposes between three over-arching themes:

I. Neurological Impacts of Opioid Use
II. Cultural Diversity Among Professional Caregivers
III. Resources for Individuals Seeking Treatment

I. Neurological Impacts of Opioid Use

i. Motivation to Seek Treatment

a. As Perceived by Those with Lived Experience

An individual's belief that they would not benefit from treatment is a common barrier to seeking treatment.

"There were times that I would pray that God didn't let me wake up, but at the end of the day I knew that deep down I didn't mean it," a participant with lived experience shared. *"I was in that much pain and anguish and guilt and remorse from all of these decisions that I kept making and I just couldn't see that I was the problem, I was the source of all that turmoil."*

b. As Perceived by Others

An ED-based professional caregiver who works to engage with treatment persons who have experienced an overdose incident says that ED patients not ready to seek treatment often say the same thing, such as *"I just got a bad batch, I really don't even use drugs like that, I don't really even have a problem."*

c. As Dictated by Others: Varied Treatment Outcomes and Potential Risks

Persons sometimes engage with treatment to meet the demands of the criminal justice system or loved ones. *"The disease of addiction as a whole is probably the biggest barrier, because you can't force someone,"* one professional caregiver argued. *"If they don't want to,"* they continued, *"it's not going to be a good result.*

In response to the focus group prompt, "What do you think drives people to your treatment program's door?" one professional caregiver responded, *"For most of them, it is because the court or a family member asked them to do it. We have some men doing it on their own, but for most of them it is because the court or a family member asked them to do treatment. Maybe around 60% is court mandated and 40% is because they want to do it.* Another professional caregiver followed-up by explaining, *"When the client wants to do it, when they feel in the heart, "Okay, I'm stuck, I'm tired, I want to do it, I don't want to go back," they do it, and they get better, and they recover. But when its court mandated and they don't feel like they want to do it they just say, "Well, I'm here because I have to, I'm just going to do the*

program and when I finish, 'Okay, bye!'" We do the recommendations to continue to another program, [such as] IOP or OP. Some of them show up, the others truly don't care.... Some of them come forced so they usually don't stay longer."

Additionally, there can be significant risks involved in using coercion to engage with treatment someone using opioids. *"It's honestly dangerous to force or pressure people into treatment,"* recognized one professional caregiver,

> *because they could go and gain sobriety, [relapse] and end up overdosing. Whereas if they were to just continue their daily use, they wouldn't have. I know a lot of family and friends and professionals are more apprehensive to apply any pressure because they just wait till people are ready*.

Some professional caregivers pointed to fatal overdose incidents in the county, like elsewhere, occurring when someone leaves jail with decreased opioid tolerance and begins using again.[44] One caregivers stressed, *"It's dangerous.... They're being forced to go to jail and they have no intention of quitting."* An individual with lived experience expressed familiarity with this type of overdose event,

> *Last month when I got out of jail, I think I overdosed three times in the span of two days. ... I went through 35 days in jail so I guess at that point, I wasn't physically dependent on the drug anymore.*

ii. Compulsive Drug Seeking

Many participants with lived experience discussed the overwhelming power of compulsive drug seeking. *"Even when you are out there doing whatever and anything to get what you need, like to make the money or to get the money to get drugs, it's like you do it and you don't care, but you do care,"* one participant with lived experience shared,

> *It's not like you are having fun doing it. It's just the way you can live at the time or else you're going to be lying in a shelter and puking and shitting all over yourself. I prostituted and in the area everybody knew what I was doing.... They yelled stuff out the window of the car and it's humiliating. I still had to do it, at least at that time I did.*

A second participant with lived experience described their own and others' compulsive drug seeking after an overdose incident:

> *[I]t's so many overdoses. You know what's crazy about it? We just get high. We just keep getting high. Like when we're better [after an overdose incident], we go right back to using and we just use a little lighter. We act like it didn't even happen. Yeah,*

[44] O.K. Sugarman et al., "Interventions for Incarcerated Adults with Opioid Use Disorder in the United States: A systematic review with a focus on social determinants of health," PLOS ONE, (January 21, 2020): 1-14.

> *that's what we'll be doing anyway. Like, we're just kind of like in shock. That's just how we're dealing with all of our feelings and all of our problems—by just continuing to use.*

Compulsive drug-seeking can drive some people to seek-out known lethal batches. For example, in response to the question, "People aren't scared of dying?" a person with lived experience said, "No," and further explained the attraction,

> *Sometimes people will hear that a drug made somebody die. And they'll be like, "Where did you get it from? Where did you get it from?" And then they will go get it from the same dope dealer that the person got it from who died. And then they'll just try to cut it a little bit, like add something to it to make it not as strong and they'll do the same drug. Just trying to make it not quite as strong because that means it's really good.*

iii. Management of Opioid Withdrawal Symptoms

In ways similar to those described by people after Narcan® administration, a professional caregiver with previous lived experience of opioid use had difficulty describing the intensity of unmanaged withdrawal symptoms:

> *I can't even put it into words. It's like you want to crawl out of your skin. You feel miserable. You're nauseous. You're sweaty and you're cold. I always would get the twitches up in my arms and a lot of people get them in their legs. You can't control what comes out of you on either end. It is a disaster. When I say you can't help it, you cannot help it. It just like happens. It's your body that's just like, "We're gonna get all of this out in any way that we can." So when you're in jail that's the worst.... You get arrested and then when you go into jail you don't have dope anymore, so then you immediately start getting sick. I mean, it's just terrible and you can't sleep, which is all you want to do, but you just can't sleep. So, you're up feeling miserable. You can't turn it off. There's nothing you can take that's going to make you feel better other than the drugs.*

Unprompted, the professional caregiver weighed-in on their view of the significance of poor withdrawal symptom management's role as a primary obstacle for persons seeking treatment. "*So that part alone is, I feel, what makes most people keep using, even if they don't want to,*" they said, *"because it is just ... super bad."*

a. In the ED

Many participants with lived experience answered the question, "In the ED after an overdose, is it a good time to talk about treatment?" by saying it was not. Some said they left against medical advice and immediately used opioids to stop their withdrawal symptoms. *"No, no, no,"* said one individual with lived experienced of 14 overdoses, *"because your body is feeling funny because of the Narcan®. The IV helps. So, they come in but I don't want to talk. I*

feel terrible. Your mind, your eyes are just going around, spinning, spinning. You can't focus." Another person with lived experience summed-up many others' responses when they replied, *"No. Most of the time I wake up feeling bad and guilty."*

b. Waiting to Enter Treatment

Another professional caregiver with previous lived experience of opioid use explained their difficulty a few years ago navigating their own entrance into a residential treatment program. They recounted weeks of trying to lower the amount of opioids in their system while trying to remain functional enough during difficult withdrawal symptoms to move about town, self-advocate for treatment, and pass a treatment center's necessary drug screen:

> *I was in the waiting for residential group. So you would show up one day a week, and someone would call the facility that you're on a waitlist for. And then if they say you have a bed ... then they'll get all your paperwork and your drug test done and send it over so that when you go there to check in, they have all the stuff that they need. But since I was on opiates, my bed came and went at least four or five times, and the person who was running that group was just like, "Well, I mean, if you can't pass a drug test, you can't go." And I said, "Well, how am I supposed to pass this drug test if I have to keep using? Like, I don't understand?"*

A different professional caregiver with lived experience of opioid use explained how poor withdrawal symptom management can make entering MAT particularly difficult:

> *So they don't want [a lot] of opiates in your system. They can dose you while you still have opiates in your system with Suboxone®, you just have to be like sick when you go in, like when you're withdrawing, and then they start you out at a small dose, and they keep you there for like the entire day. And like, just keep upping your dose until you feel better so that they know that you're not being under-medicated and also not over-medicated. So it's like a whole day process to figure it out. But you have to go in sick, like, sick-sick, and it sucks.*

Building on the previous statement, the professional caregiver emphasized the contradictory messages they received repeatedly from a treatment professional during this difficult time. The person was fully committed to quitting opioid use but had to continue opioid use because *"the lady would always be like, 'Well, you're on the list for Suboxone®, but it's just not your turn yet so you're just gonna have to keep doing what you're doing until your name comes up.'"*

c. Treatment Programs

Physical pain is a recurring theme throughout this report and the opioid-use literature.[45] Continued pain management during detox was key for many people when describing their detox experiences. These participants recounted they had turned to illicit opioids after they had lost access to prescription pain medications for their chronic conditions and many participants discussed their physical pain as a barrier to maintaining a treatment regimen. For example, one person stressed, *"In detox where they flush your system out you got to be on some kind of pain medication that would help my body pain."*

Another professional caregiver explained:

> *A drug like buprenorphine, being a partial agonist, can cause withdrawal if it's administered [in too low a dose] because it will displace the full agonist that's bound to the receptor. However, given in high enough doses, and this is the key, it can displace many receptors and the likelihood of withdrawal is then lowered. One of the problems we experience is that although we administer buprenorphine to patients, we're giving it in doses that are too low, and that causes precipitated withdrawal. And so what we're learning right now, and the evidence shows, that in higher doses buprenorphine can be extremely beneficial, and patients are less likely to experience withdrawal and have a much more comfortable transition from illicit drug use.*

II. Cultural Diversity Among Professional Caregivers

A corrections-based professional caregiver articulated what other professional caregivers in this study observed about their profession:

> *The population of the jail is overwhelmingly Black compared to white. ... So, although the majority of the inmates are black, the majority of our clients [seeking referrals to treatment] are white. That's a challenge ... a lot of black inmates have a hard time trusting us. I'm a white male. Our staff is 99% white. You know, when I come to the table, looking how I look, and I say, "Hey, I can help you." They say, "No, you can't," even if they are eligible. We have a big hurdle.... We need more diversity in our profession.*

A lack of diverse language speakers among treatment providers also is a barrier, "*Specifically for people who are doing work in the community and in bilingual places,"* stressed a professional caregiver. *"And I would say not just Spanish,"* they continued, "*It's Arabic and it's many other languages. We're all facing that same challenge."* A professional caregiver working in a corrections facility disappointingly explained, *"We have an overwhelmingly white staff and no Spanish speakers, which is a problem."*

[45] K.R. Peck et al., "Impact of current pain status on low-barrier buprenorphine treatment response among patients with opioid use disorder," *Pain Medicine*, 22 no. 5, (2021): 1205–1212.

III. Resources for Individuals Seeking Treatment

i. Personal Resources

Most of the participants with lived experience lacked resources and many lacked access to basic needs (e.g., money, clean drinking water, food, clothing, transport, housing). People commonly mentioned their poverty when discussing their departure from in-patient treatment or jail/prison, or as a stressor fueling opioid use or relapses. One person explained,

> *Starting three or four years ago. Every year, like in the summer, I relapse. I don't know why. Stress, you know? The crying and stuff like that. Worrying about what I'm going to do to survive, to take care of the family, that we cannot even live.*

a. Housing/Safe Storage for Personal Possessions

One individual with lived experience—who at the time of the interview was experiencing homelessness and using prescription Suboxone® and illicit fentanyl—explained that they had been in treatment but had not stayed sober due to depression, stress and *"nowhere to go."* When asked if they would like to re-enter treatment, they said, *"Yes,"* but described how important secure storage and housing were to achieve this goal. They continued, *"If I can find a place where I can put my stuff and I know I would be secure once I got out, I'd probably go back through detox and probably a 30-day treatment or something like that."*

b. Transport

A professional caregiver at a homeless shelter explained the challenges of finding clients affordable, effective transport. *"Sending them on a bus?"* they said. *"They won't make it."* Transport problems also arise, a professional caregiver noted, *"When people have treatment set up somewhere but it's not in a place where they were required to see their probation officer or the judge."* They further explained,

> *I have a client who, if she's unable to get a ride that day because she doesn't have a license, can't pick up her [treatment] medication for the week. What does she do then? When she's a week without the medicine that's helping her stay sober? And they don't really see it as an issue because the judge wants what the judge wants.*

c. Childcare

Few of the people with lived experience that continued to actively use opioids disclosed that they had a child for whom they were responsible on a daily basis. The literature highlights particular challenges for women who are caring for a child/children and seeking treatment. These women often fear government intrusion resulting in loss of child custody, increased surveillance, and stigmatization.[46] A professional caregiver emphasized that for some people it is difficult for them to engage in many types of treatment because they cannot afford childcare and family and friends will not provide it. *"People,"* the caregiver observed, *"by the time they*

[46] M. Boeri et al., "Barriers and Motivators to Opioid Treatment Among Suburban Women Who Are Pregnant and Mothers in Caregiver Roles." *Front. Psychol.* 12, (2021).

come here for help, they've kind of exhausted all their resources and family members and friends are hands-off."

d. Re-entry Coordination

A professional caregiver discussed criminal-justice involved persons and highlighted their lack of basic resources on re-entry:

> *Especially with people coming out of jail or incarceration ... they get information while they're in there, but they don't really get directions on how to get to these places or acquire the resources. And a lot of people who end up coming out of jail, they have nothing. They will send them home with no money, the clothes on their back only, no food, they have nowhere to go. So it's like, "What? What do you expect people to do when you have them all locked up, and now you're just gonna kick them back out with absolutely nothing?" So I feel like that is a huge, huge issue. And it happens all of the time.*

e. Social Environments

One professional caregiver—like many participants in all categories—explained a primary challenge experienced by those who have recently entered recovery is returning to pre-existing social environments. *"I think it's hard for some of our clients to stop because their entire family and friends use, as well,"* said the professional.

> *To them, the day they're stopping means that they'll have no one, in their mind, especially when they're going through a whole detox and trying to go through the programs. In their mind they're like, "Well, I have no family or friends anymore." Obviously, when you go through rehab, you meet a lot of people, and you meet your sober friends. ... And I think it's hard in your mind when you're using to see that light at the end of the tunnel, that you'll you will have support systems.*

A story shared by an individual with lived experience underscored these difficulties. *"I had detox, like way before, and I stayed clean for a month and then went back on it,"* they shared. When asked, "Why did you go back on it?" the individual explained, *"Because, like I said, with my boyfriend and stuff, you know, all the times I tried to clean myself up I was with him. ... He's dead now. He ODed."*

A professional caregiver in a homeless shelter also explained how important one's social environment is to maintain one's trajectory of recovery. *"I've seen a lot of people here that you can tell by talking to them that they want help,"* they said.

> *But drugs are so prevalent in our facility and around our facility it's hard for somebody to actually get that help because if they go to treatment, they usually end up right back here until they get their housing. So they're back in the same situation and being in*

recovery myself, I know people, places, and things are pretty bad. I mean if it's shoved in your face, adopting the will is pretty hard to do.

ii. Treatment System Resources

a. Awareness

Many participants said they did not know where to find treatment or expressed confusion about which treatment programs offer what services, highlighting that the treatment system remains hidden or undifferentiated to many. *"A lot of people don't know the difference between what one facility does and what the other facility does,"* said a professional caregiver*, "and then they just get this idea that it's the same playing field across all facilities."*

b. Programs

Participants expressed concern about the systemwide availability of beds*. "It's harder to find detox beds than it used to be,"* a professional caregiver observed. They continued,

Maybe 10 years ago we weren't calling as often for detox services, but now we are and the beds are filled. So maybe 10 years ago it was more like cocaine and meth treatment that we were helping people with. So, there wasn't as much need for detox for those drugs, but there is need for detox for opiates.

"If somebody needs an inpatient level of care," another professional caregiver said*, "it's harder to find them beds now. Like there's now a month or so waiting lists now.... I've had someone on waiting lists for a month and a half."*

When prompted to discuss how professional caregivers deal with this shortage of beds, one responded*, "We hope for the best and that in that timeframe they're willing to engage in some other services."* When prompted to recount how many people denied an immediate inpatient bed engaged in other treatment services rather than continue to use opioids to avoid withdrawal, one professional caregiver explained, "Like a quarter."

Another major barrier in the system are programs that do not accept clients on MAT. One professional caregiver explained,

When I was at [X] I started as a counselor and I worked my way into intake. I had people calling all the time asking, "Do you take people on Suboxone®? People on methadone?" and we didn't. There weren't the proper things in place for us to take them on. We didn't know enough about it and ... the monitoring of it. I just felt awful for these people. One of my screening questions was, "Are you on MAT?" [and if the answer was] "I am," [my response was], "Sorry."

c. Modalities: Evidence-based Care and Too Much Focus on Drugs

Evidence-based care is comprised of practices that are supported by science and some participants were critical of some treatment practices in the county because of the lack of

scientific evidence behind them. *"I would say many of the programs are doing medications for opioid use disorder, probably more now than we're doing a couple of years ago,"* said a professional caregiver who expressed a caveat:

> *But there are several, well-known, local treatment programs that do not offer evidence-based care for addiction. And evidence-based care is a medication, either buprenorphine, naltrexone, or methadone to treat opioid use disorder. And going to detox and getting detoxified from illicit opioids can get rid of the physical withdrawal, but leads to relapse almost universally, you know, there's like a 90% relapse rate, if you don't transition to some form of MOUD [Medications for Opioid Use Disorder].*

Additionally, many participants explained that focusing on drugs in treatment, especially in group settings, fed their cravings for drugs. One explained, *"IOP [Intensive Outpatient Program] makes you think about drugs. You talk about drugs; you think about drugs. You think about drugs; you do drugs. So, I don't understand AA [Alcoholics Anonymous], NA [Narcotics Anonymous], IOP treatment. You might as well hand me fucking dope."*

d. Professionals: Stigmatizing Drug Users

One professional caregiver argued that there are many hurdles faced by persons who use opioids, *"But I think the most important is the fact that we treat people who use drugs like garbage,"* they said. The caregiver further explained,

> *We stigmatize them. We make them feel like they're 'less than.' We often don't listen to them. We don't address their needs, and they have significant needs! More so than many other disease conditions. We just kind of ignore it. We give them the least amount of care we can and then we send them on their way. And then we're done.*

Criminal justice involvement also may complicate people's treatment experiences. *"Our clients are overwhelmingly externally mandated from legal or other kind of means,"* observed a professional caregiver. *"And it's often difficult to balance laws for a therapeutic treatment modality with the stigma and acute punitive measures that they're facing in corrections or any legal things there involved with."*

Another professional caregiver said,

> *Talking about corrections or other organizations, the language that we use is so different because we are about like harm reduction and dual diagnosis and meeting people where they're at, and there are still some places that don't operate from that same treatment modality and viewing [opioid use] as a medical disease that can be treated. [Instead] it's like a problem with willpower or a three-strikes-and-you-are-out kind of thing.*

Those with co-occurring behavioral health diagnoses also suffer from stigma. *"I think stigma is just a big noose around addiction and mental health,* argued another professional caregiver. They continued,

> *I think that's gonna be a battle that we fight for a really, really, really long time. And I feel, especially for those who are dually diagnosed, they're like, "I already have this one issue, then I have this other issue. No one can help me." And that can be really hard. I work specifically for those in the criminal justice system. And it's really difficult. When you do have people who are external like, "Why can't you just fix this?" And I'm like, "It's not how this works." And that further complicates and compounds the issue of, "Okay, we're trying to work on this small thing, like right here, we'll worry about that other stuff next time." But I think that stigma doesn't just stop with the opioid epidemic. I think it's a whole big piece that we really live with every day with our clients."*

6. Perspectives on Pathways to Treatment with Sustained Recovery

This chapter outlines themes and sub-themes that emerged when participants discussed pathways increasing access to opioid-use treatment. While the discussion points are interrelated and situationally dependent, they have been divided between three over-arching themes:

I. Neurological Impacts of Opioid Use
II. Cultural Diversity Among Professional Caregivers
III. Resources for Individuals Seeking Treatment

Additionally, this chapter closes with the themes and subthemes that surfaced when participants with lived experience reflected on their 'dream' treatment.

I. Neurological Impacts of Opioid Use

i. Motivation to Seek Treatment

a. As Dictated by Others: Corrections-based Assessment and Referral

Professional caregiver participants recognized positive impacts of **corrections-based opioid-use assessment and referra**l. *"We do have a lot of folks [in jail] that are appreciative and thankful that we're there and even addressing the addiction concern,* recognized a jail-based professional caregiver. *"So, ultimately, we do have a number of folks that are willing to agree and do want to do some programming."*

ii. Management of Opioid Withdrawal Symptoms

a. Mainstream Detox

Many professional caregivers emphasized the need to **connect detox services** with more comprehensive counseling, education, and other community supports. One professional caregiver described a promising model that mainstreamed patients coming out of the ED into the hospital's general patient population. Once the patient was stable they were re-assessed to learn the patient's treatment wants and needs and then matched with an available treatment program. The professional caregiver said,

> *When I was working in an intake department, I had to do a lot of data management on referral sources coming into the agency. And I worked really heavily with BreakThru at Southwest [Hospital], which [admits and treats individuals within the general hospital population]. It's made for opioid users in the sense of a detox facility that could start [a patient] on any kind of medically assisted treatment. And then they usually would call me to refer [the patient] back to our team to get them assessed at-length for any kind of treatment. We need more of that! I don't know if other agencies ... have specific people making sure that those people get connected.*

b. Increased Duration of Opioid Treatment

Many participants with lived experience expressed that detox needs to be of **longer duration** and more integrated with other supports. *"Detox needs to be longer,"* they said, *"but then you don't need to live there because you want to be with your family, go to AA meetings and stuff like Casa Alma, be with people at HUMADAOP[47] and people at church."*

One professional caregiver's comments summarized what many others said about treatment programs, in general:

> *Care takes time. The problem is, we want to do it in a 30-day or 60-day program. If you want to start giving good care, make it 180 days.... If they're using out there 25 years, 365 days a year, do you think 30 days is going to turn that around? You can't even get them physically stable in that time.*

Another professional caregiver suggested year-long programs:

> *I would sequester people away for at least a year. I would say, "We're just gonna love you for a year. We're gonna love you for a year and we're gonna do everything we can to support you on this journey for a whole year."*

II. Cultural Diversity Among Professional Caregivers

Many professional caregivers recognized that Hispanic and non-Hispanic Black community members are experiencing fatal overdose incidents at the highest rates but these caregivers expressed frustration at their own inability to communicate with them or more easily train other professionals to serve them.

Spanish-language resources are key to professional development to serve the needs of many people in the county. *"We have to have funding, we have to have bilingual staff, we have to have trainings that are offered in Spanish,"* a professional caregiver underscored.

> *We have somebody who's ready to go through the peer [recovery] support training, and he's going to be great. The peer support training currently in Ohio is only offered in English, and we need someone to sit down and interpret for him for the full 40 hours of the training when he goes into the classes. And so for us, this is something that we do because the need is in our community. But we are not reimbursed for that. That is our staff taking time out of their schedule to do that, which means they're not doing the job that they were initially hired for. But they're doing it because we believe in this, we believe in the mission, we believe in the purpose, we believe in the cause. And so when I talk about funding, it can be things that appear to be invisible like that, like when we need to interpret for somebody.*

[47] Hispanic Urban Minority Alcoholism and Drug Abuse Outreach Program (HUMADAOP)

Another professional caregiver emphasized the importance of **cultural diversity among treatment professionals**:

> *We are fortunate here to have people that are Puerto Rican, Dominican, and Salvadoran. There are many more countries that we would like to see represented at our agency, because even within the broad scope of what Hispanic or Latinx is there are many cultures and then within those there are many sub-cultures. So a good example is we work with somebody from Guatemala. English is his third language. Before he spoke Spanish, he spoke his indigenous language. And so having someone who can represent different cultures is really, really important. And I also again want to stress how different subcultures within this umbrella can be. So when we talk about "Hispanics," it's just a huge word that covers many people like this and there's many differences among our cultures, too. And for that reason, again, this is an area that needs to be studied.*

A professional caregiver discussed ways in which harm reduction providers may take a more **inclusive approach**. *"As you know, the people who die from overdose lately have been disproportionately people of color,"* the caregiver said. They continued by explaining,

> *A lot of times, their drug of choice would be like cocaine or methamphetamines or different drugs, you know? ... So we were thinking about bringing in pipes and things like that to attract that population, because the majority of the people who use our [syringe exchange] are not people of color.*

III. Resources for Individuals Seeking Treatment

i. Personal Resources

a. Comprehensive Health Insurance Coverage for Opioid Use Treatment

In Ohio **presumptive Medicaid eligibility** gives uninsured persons access to receive immediate Medicaid-covered health care services if they are presumed to be eligible.[48] As one professional caregiver described it, *"[For those] with no insurance, we have something called presumptive Medicaid, where we can get them insurance right then and there."*

Other professional caregivers expressed concern about treatment costs and limitations of Medicaid coverage alone. Opioid use treatment with sustained recovery can take months or years, asserted some professional caregivers and *"who is paying for that?"* asked one. They continued, *"That's another issue. Most people don't have [enough] insurance; most people are in Medicaid."*

b. Transport

A professional caregiver observed, *"A lot of the newer treatment centers, they'll do a quick phone screening and come the **same day and pick up** these guys, which is lovely because our guys don't have transportation."*

[48] See https://medicaid.ohio.gov

c. Social Environments

Many participants emphasized the importance of **creating supportive environments** around those engaging in treatment and recovery. *They go through treatment, and then they return back ... to hell,"* observed a professional caregiver. *"They're not successful, so I don't think that's treatment,* they argued,

> *Treatment teaches them about the disease. It teaches them about what to expect. It teaches them about triggers and coping. It's what you do after you get out. You don't have those supports anymore. So you've got to have a tribe. You've got to have people [around you] who have success in this. And if you go back home and somebody there is using—even if it's alcohol or drugs of another kind—the chances of sobriety are very small.*

A different professional caregiver associated with a homeless shelter explained how they are seeing a more supportive community develop there.

> *A good support system and self-will is a big deal, too, you know, and just reaching out to people that they know they can talk to in sobriety and in sober communities. We've actually had a few guys that lived here get housing and actually start working here. A lot of our staff is in recovery. So we are familiar.*

ii. Treatment System Resources

a. Awareness

Many participants hoped to remove stigma by increasing community awareness that **opioid use is a treatable chronic disease characterized by recovery and relapse**. *"We need to normalize care for persons with substance use disorder, regardless of the substance,"* argued one professional caregiver while echoing many others. They asserted,

> *We have to treat them like we treat our diabetic [patients], our patients with hypertension. Because when you think about it, you have relapse in those diseases and all chronic diseases. So until we come to terms with treating patients with substance use disorders the same way that we treat our patients with these other chronic diseases, not much is going to change.*

Another professional caregiver discussed misconceptions that individuals who use opioids are 'bad' people engaging in 'bad' behavior, rather than suffering from a treatable disease:

> *I think for the Spanish community, the better thing is to get more money to have more [public] education go out, print flyers, print brochures, something that we could teach the people in churches, in schools, in different places. We can go and talk about it and let them know and let them know, "Hey, Casa Alma's here, we can help you," but we need something to go out. ... Because if we don't teach the people, if we don't let them know why these people are like that, they never learn about it. They only think*

they are bad people because I was [once] thinking that way. I was thinking that way, too.

b. Programs

More treatment programs are providing services observed participants. *"I can't even keep track of the amount of treatment programs that are available,"* observed a professional caregiver serving those experiencing homelessness.

Every week we have a community meeting here and we have different providers coming in to tell the residents about their programs and typically the same treatment centers will come in, but two or three times a month there's a new treatment center, which can be good or bad, you know, as far as quality, but we have outpatient providers, inpatient providers. There's a wonderful new MAT clinic that's pretty close and they offer Vivitrol®, Suboxone®, and methadone.

While the numbers of treatment programs are increasing, so are the numbers of **programs welcoming clients on MAT**. A professional caregiver observed that, *"More treatment centers are becoming more open to accepting people that use MAT."* Another professional caregiver saw this broadening pathway to treatment as vital to those working to diminish and eventually stop their opioid use. *"That's ultimately what we are trying to address, we're trying to keep them from being in withdrawal, because they can't tolerate that,"* stressed the caregiver. *"Get them stable on one of those forms of medication."*

Several professionals were proponents of creating **clinical safe use sites** in the county, which could act as among other things bridges to treatment for those continuing to use but in a holding pattern as they wait to enter a treatment program. One professional caregiver described a safe use site clinic as,

Kind of like a blood bank or any type of clinic where you can walk in. You can get all of your syringe supplies and whatnot right there. Most of the ones that I have experience with, it's a room full of cubicles that are up against the wall with mirrors, and you can look into the mirror and see everything that the person sitting at that mirror is doing. Some of them don't have mirrors, but they have everything they need. They have stuff to test their dope, they have all of the clean supplies and they will continue to get high in that cubicle, and the staff keep tabs on them, how long they've been there, you know, when do we need to check on this guy? And that's why it's called a safe site. It's just a safe place. A supervised site where you're probably going to have a nurse, maybe a doctor, a syringe worker, so on and so forth.

c. Modalities: Buprenorphine and Eye Movement Desensitization and Reprocessing (EMDR)

Recently the federal government removed a major restriction on **buprenorphine prescribing** practices and it can now be prescribed for MOUD by any clinician with an active

license that includes Drug Enforcement Administration Schedule III medications. A professional caregiver explained the potential beneficial ramifications of this action:

> *I think removal of the DEA waiver is potentially transformative because the more availability of buprenorphine, the much greater chance that people who want treatment at that moment can get it. You know, the pharmacology of buprenorphine is really unique and if you have you been buprenorphine in your system, you're really unlikely to have a fatal overdose just because it's binds so tightly to the receptors. So if that is universally available to people, I think we're going to see a significant reduction in overdose fatalities.*

Another professional/lay caregiver with a history of opioid use focused on the impact of trauma on opioid use and the potential benefits of **Eye Movement Desensitization and Reprocessing (EMDR)**:[49]

> *I believe [for some], their trauma and/or mental illness is so severe that the 12 steps by themselves will not work for them. And I think those people need to be in places where they can receive trauma counseling early on, like EMDR. It was originally developed for veterans. Trauma is stored in the limbic system of the brain and when you have that fight or flight or fawn or freeze response, EMDR actually neutralizes the triggering thought by utilizing bilateral brain stimulation. I've done EMDR.... And it's so much more effective than talking about your feelings and "What are you going to do different? How did that make you feel?" Because when you are coming off drugs, and you're not even knowing what the hell is going on, to sit there and [try to respond to the question], "Tell me how you feel?' with what? "I don't know. I just want to get high!" To have that proven method of trauma counseling early on, I believe in my soul, will probably be the game changer for many people recovering from addiction.*

IV. Participants' Perspectives on Their 'Dream' Treatment

Participants in all three participant categories with lived experience of opioid use were prompted to describe their ideal or 'dream' treatment. Themes and subthemes that surfaced are outlined in the following tables by the type of settings participants preferred for treatment (see **Jail** (Figure 18), **Detox** (Figure 19), **Inpatient Treatment** (Figure 20), and **Outpatient Treatment** (Figure 21)) with quotes provided to explain:

- why a particular setting was preferred, and
- the types of services with which participants would ideally engage.

[49] F. Shapiro, F. and M.S. Forrest. *EMDR: The breakthrough therapy for overcoming anxiety, stress, and trauma,* (New York, NY: Basic Books, 2004).

These figures below highlight that participants have diverse treatment desires.

Figure 18. Dream Treatment: Jail

Confinement	***Time***
1. I admit today that I definitely needed to be locked up like an animal. Some people might be able to do it in a nice [treatment] setting, but not me. I also needed everybody to turn their back on me because I needed to know that I had shot every angle and there was nothing left except this, because I was in so much emotional pain. *2. I'm considering maybe just putting myself in jail again. Go do something and then put myself in jail. It's easier to detox in jail. You can't leave. You are stuck there. I just have to be somewhere where I can't get to any drugs. If I have money or a way to get some, I'm probably going to get high.*	*1. I just got the time to detox.* *2. Jail gave me the time to think.*

Figure 19. Dream Treatment: Detox

Longer Duration	***With Improved Withdrawal Support***
1. For me, detox. [But] the detox needs to be at least 10 days because after the 6 days, when you come out, you still feel down. You don't want to move. Obviously, that's part of being sick, too, from the dope. They don't understand that. It sends me back to the streets. Get me another bag to feel better.	*1. Detox. You have to be on Suboxone® for 7 days, at least, so you can get on Sublocade because I want to do the shot again. I want to get back on the shot and go back to work.* *2. Detox ... [but] I don't trust myself to stay in there because I am feeling like crap.* *3. Detox ... [but] you could still want to leave because just the high, it's you know the mental thinking [drug cravings].*

Figure 20. Dream Treatment: Inpatient

Housing	Sedation	Increased Duration	Alternative Therapies	Voluntary Peers Only	Class/Group Flexibility
1. When I went to detox and tried to detox, there was no detoxing. As long as I had the choice to leave, I was gonna leave. *2. You gotta be locked down.* *3. I would like [to get treatment]. Well, I always had a place to live. Now I am out there. For the first time, not having a place to live.*	*1. I would love it if I could get put in a coma for two weeks. Maybe a little longer. A medically induced coma so I don't feel opiate withdrawals.* *2. To get put to sleep and just have everything pushed out of my system and wake up and be OK.*	*1. Probably six months because I don't have the structure or like the foundation to be sober. If only 30 days or 90 days, it's like, I don't have the grounding yet of sobriety in order for it to take root.* *2. The best treatments are at least two months or longer. The longer you stay in treatment the more chance you have of staying off the stuff.*	*1. In rehab, you sit around a lot.... They've been through rehab before.... Boredom for addicts is a trigger. My dream treatment, A lot of meditation and maybe some water therapy.* *2. I think alternative therapy such as music ... different things like yoga.* *3. Mind, body, spirit* *4. I want a gym.*	*1. It all depends on what kind of people are there. I mean, we're with a lot of people in there who are faking it to make it [e.g., criminal-justice involved individuals]. A lot of people don't even want to talk.*	*1. Depending on what program you were in, you went to different classes.* *2. Different meetings for different kinds of stuff. Different meetings every day.*

Figure 21. Dream Treatment: Outpatient

MAT	Non-confining	IOP	Support Groups	Peer Support
1. To get back on my meds and Suboxone® to get off of this [fentanyl]. *2. Now, since the last time I was there, they got different stuff that helps you and like the shot.*	*1. I like outpatient where I can come and go.* *2. If I could do it at home, like with a nurse being there and a doctor that comes and goes. But doing it at home around your family where you actually feel loved.* *3. Recovery housing. You live in a house. We have rules ... and we still have to give urine samples, but you feel the possibility more that you get your life back....*	*1. What I really needed was the disconnect from the routine that I had been in ... And it was that timeframe that put me in that [recovery] mindset. The information that I received the first time around in IOP, I liked it. I liked it a lot.* *2. Like you have your group [counseling] during the day and then your individual during the week.*	*1. I think what makes AA work for a lot of people is because it's so simple.... And the support you find in the rooms is nothing like you'll ever find. There's no one else that can better understand us than another ... addict.* *2. Doing groups.... Gay people, straight people, it shouldn't matter. If medication is prescribed by a doctor, you shouldn't get kicked-out.*	*1. Just like a counselor that gives you their number that you can talk to and that you can tell they give a fuck about you.*

7. Perspectives on How Community Members Can Improve Connections and Engagement with Adults Using Opioids

This chapter outlines three overarching themes and their sub-themes that emerged when participants discussed ways in which community members can better connect and engage with adults using opioids:

i. Wants and Needs: Centering Those with Lived Experience
ii. Harm Reduction: Building Trust by Supporting Opioid User's Health
iii. Moving Public Health Models Beyond Prevention and Intervention: Grief and Postvention
iv. Street Outreach

i. Wants and Needs: Centering Those with Lived Experience

The data collected from all types of participants tell the story that there is no one-size-fits-all treatment modality for the various wants and needs of people who use opioids. One professional caregiver offered the following perspective centered on community-wide connection, engagement, and action:

> *You know, for me, I always look at it from the standpoint if I can find an individual a sponsor, and they walked the metro parks and they sit underneath a tree and regroup and read poetry, if that keeps them sober then that keeps them sober. I think some complexities are out there, because we have so many people that are now pushing the button for MAT and so many [other] people that are like, "We're not doing it. We're strictly AA," so it's really hard to find that common ground. For me it's a difficult question to answer, because I want to help people where they are at and with what they need. And then I also, in the back of my mind, have to understand that some people are very open with their, "Hey, I'm not interested [in treatment]'" and then we have to deal with the fentanyl that's on the street. And you might have someone who's my age or older who went through AA and that worked for them and they're totally against MAT, because that's against their "higher power" and "substituting one drug for another," but ... the lethality that we see today on the streets was nowhere near that back then. So it goes back to being able to talk and collaborate.*

ii. Harm Reduction: Building Trust by Supporting Opioid User's Health

> Harm reduction is a public health approach that focuses on mitigating the harmful consequences of drug use, including transmission of infectious disease and prevention of overdose, through provision of care that is intended to be free of stigma and centered on the needs of people who use drugs.[50]

[50] Hawk, K.F., Vaca, F.E., & D'Onofrio, G. (2015). Reducing Fatal Opioid Overdose: Prevention, Treatment and Harm Reduction Strategies. *The Yale Journal of Biology and Medicine, 88* (3), 235–245.

Harm reduction service provides in Cuyahoga County offer among other free services: used-for-unused syringe exchange; Narcan®, fentanyl test strip, and condom distribution; opioid overdose and treatment education; HIV and Hepatitis C testing; and wound care, wound care materials, and wound-prevention education. Some harm-reduction services are provided in vans and other mobile units to increase client accessibility.

"Syringe exchange harm reduction has to be a catalyst to earn trust and relationships so they [opioid users] can come back to you when they're ready," said a professional caregiver who went on to emphasize, *"You can help them get into treatment and hopefully long-term recovery."*

"What I see to be helpful ... is harm reduction, and just being mindful that a lot of people will continue to use but not as much," described another professional caregiver who continued by saying:

> *We'll talk about fentanyl test strips and testing and making sure that if you're going to use, you're going to do it as safely as possible. And I think it makes people feel more comfortable and they don't feel judged, and it opens the door for conversation and for recovery.*

"I think [harm reduction] just boils down to unconditional positive regard, having someone really feel like they can still come even if they are chronic relapsers," noted another professional caregiver. They further explained that individuals with OUD need to know, *"'I still have options, I still have people who care about me and want to help me.'"*

Another professional caregiver explained how harm reduction practices allow those who do not use opioids to pay attention, listen respectfully, and build trust.

> *Listen, people are going to use drugs. ... The reason we [harm reduction professionals] are out there is not so we can supply them. Yes, fine, we give them needles.... We give them Narcan®. However, the main reason we're out there is to make connections with these patients. I don't know if you noticed how much the clients who use the [syringe exchange] love the people who work [there] and they respect them. ... They know that they can trust them. I've watched these relationships that were formed and I've watched the interaction between those [staff] people and the patient population they serve—and it is tight. So having this relationship, having that trust, is the first step to ensuring that these people have a place to go when they're ready and that is, I think, the number one reason why you would ever have a syringe exchange program. It's great to lower the rate of disease, it's great to provide them with safe injection supplies, but the main point is when I'm a user and I've seen [X's] face 85 times because I've come here 85 times to exchange my syringes and I'm done and I'm ready to do something, I know that she will do everything she can to help me out. And I*

> *think that's the best reason why the syringe exchange program is so important. It's the most important thing we can do for our patients right now.*

Even with its growing acceptance in the community, harm reduction services today are challenged more so than in the past by evolving drug supplies. The increasing supply of fentanyl in what was historically not only heroin's place but in combination with other drugs (e.g., cocaine, methamphetamine, illicit pills) is in many instances decreasing the time in which harm reduction services staff can establish trusting connections with individuals. As one professional caregiver said, *"The problem is with the fentanyl. You might have a conversation with one person one day and they can be dead in the next couple hours."*

iii. Moving Public Health Models Beyond Prevention and Intervention: Grief and Postvention

The impact of the opioid overdose epidemic has a ripple effect throughout families, circles of friends and acquaintances, and communities. Many participants described their reactions to losing family, friends, clients, acquaintances, and those who were previously unknown to them but whose death they witnessed, discovered or learned about through others. For instance, an individual with lived experience said they were trying to cut back their opioid use per day. When the interviewer asked, "Why?" the individual said, "Just seeing a lot of my friends dying, probably seven or eight." Participants descriptions of fear, horror, loss, and grief align with others' opioid epidemic-related traumatic experiences documented elsewhere.[51]

Highlighting these consequences, a professional caregiver at a bereavement center called for expansion of opioid-related, public-health funding and programming models from a *"prevention and intervention"* to a *"prevention, intervention, and postvention model."* The caregiver also highlighted some of the complexity of postvention support for survivors. In the caregiver's experience, survivors around an overdose death commonly can be divided into two groups: (a) those that had no idea the decedent was dependent on opioids because there was no history of substance use (e.g., someone prescribed post-surgical opioids), and (b) those that had awareness of a decedent's opioid use and/or other substance use and the decedent died from a fentanyl-laced batch of another drug (e.g., cocaine, methamphetamine). These groups process their loss differently *"because one is completely shocked and surprised. It came out of nowhere,"* explained the caregiver who continued by saying*, "And the other one is, 'No, we've been dealing with this for a long time.'"*

Survivors may have their own opioid use challenges and postvention efforts can be key to engaging survivors' with treatment. The caregiver continued,

> *What we're seeing with opioids is that many of the people that come into our support groups have opioid use issues themselves, because sometimes it runs in families. We have people coming to our group under the influence and we're having to figure out*

[51] A.V. Schlosser and L.D. Hoffer, "'I Don't Go To Funerals Anymore:' How people who use opioids grieve drug-related death in the US overdose epidemic." *Harm reduction journal* vol. 19 no. 1 (1 Oct. 2022).

*how to manage that.... But if we provide enough support, if they've had a loss, they see what it does to them, they see how it devastates the family in that they've lost this loved one. They don't want to continue doing that to their family. But **they** have to get the support. And so that's our [postvention] model.*

iv. Street Outreach

The simple origins of a successful street outreach project in Cuyahoga County developed out of one professional caregiver's grief and frustration after losing a family member to an opioid overdose in 2018 and attending funerals for many other friends the following year. As the professional caregiver with lived experience of opioid use recounted,

In 2019 there was a string of overdoses in this area, and funerals were pretty much our social activity for the summer. We had I think seven funerals in like a nine-week period for friends that had been in the [recovery] program and that we knew. So a couple of my friends and I were so frustrated at that time, because Cuyahoga had a decent amount of resources [and] there's no reason that somebody shouldn't have been getting help had they been willing to. We were just really frustrated.

The resulting program began with a simple idea:

We wanted to go out and remind people who we knew were using that there's resources out there, but we knew that confronting them and sitting down and talking with them doesn't always work. So we wanted to just subtly let them know, "Hey, somebody's thinking about you. Here are these resources." We wanted to go out and put some resources out so that they could access those in their daily routine. We made these cards, put the numbers for detoxes and a handwritten note on them, and hung them up on the streets. And we posted on social media what we were doing. More people started reaching out asking, "Can I help? Can I do that?"

With little start-up money but a deep understanding of opioid users' wants and needs, this participant and a few other community members have grown the street outreach program with county government financial support and so that it now provides harm reduction services and community education. *"We've evolved from just doing the cards to now handing out Narcan®, fentanyl test strips, and condoms,"* explained the participant, who further highlighted,

Through street outreach, we have a "Dispelling Stigma" gallery that we set up at local high schools ... We have a few displays for library branches on the calendar. It's been at John Carroll University. It's been at the Federal Reserve Bank of Cleveland."

The street outreach team also provides emotional support:

> *We also have these amazing stories from family members that we meet on the street who are just so closed-off from the rest of the world, because they don't know who to talk to. And they come to us and they're just dumping. And just being able, for [example], this mom who takes fentanyl test strips for her child ... and that relief that we're giving her ... is huge. That's my part of the work. That's what I absolutely love. That's why I do it.*

8. Recommendations and Next Steps

The experiences, observations, knowledge, and opinions that shaped participants' expressed perspectives herein highlight that people face opioid use and overdose in many different ways. The challenges and barriers articulated by participants may seem imposing, but the insights surfaced from this project demonstrate that **the expansion of existing pathways and creation of new ones with the collaboration of persons who use opioids and their professional and lay caregivers** can guide positive steps in ameliorating the effects of this devastating epidemic.

The following recommendations emerged from the research findings:

9. The community would benefit from education efforts (e.g., media campaigns) highlighting that opioid users suffer from **a treatable, chronic disease that involves relapse**.

10. The increasing opioid use rates of often underrepresented individuals calls for **expanding prevention, intervention, and postvention efforts to include more diverse, culturally appropriate services** (e.g., Spanish-language professional trainings and treatment services; faith-based initiatives).

11. Providing **a menu of multiple treatment options, venues, and types** with increased understanding that an individual's recovery takes time, often includes set-backs, and evolves along a continuum of care is crucial to meeting the diverse wants and needs of persons using opioids.

12. **Treatment options need to include MAT and longer term supports** to promote recovery and prevent relapse.

13. **An individual's time in detox needs to be longer and provide pain-relief**, especially for the large percentage of those whose introduction to opioids began through their own legal pain-relief prescription.

14. Opioid users need:
    a. **better and more accessible notification systems to employ when they are ready to engage with treatment the first time and after relapse**, and
    b. **more immediate and supportive response mechanisms guiding their way to their desired treatment services**.

15. **An expansion of the role of certified peer supporters and trained patient navigators** is needed to strengthen opioid treatment engagement, recovery support, and relapse prevention.

16. **Increased stakeholder commitment to collecting, accessing, sharing, and disseminating opioid-related data** to better understand currently undocumented opioid use, non-fatal overdose and overdose death by suicide rates to inform prevention and treatment interventions.

It is the research team's hope that this report will be made publicly available to inform opioid education, treatment, and research in Cuyahoga County and similar settings via the Begun Center website (https://case.edu/socialwork/begun/); in local, state, and national conference presentations and stakeholder meetings (e.g., U.S. Attorney's Office of the Northern District of Ohio Heroin and Opioid Task Force); and future publications (e.g., peer-reviewed articles, research briefs, infographics). The research team also will use research findings to design future, more in-depth, longitudinal opioid-epidemic research with requests for support made to diverse funders (e.g., Centers for Disease Control and Prevention (CDC), Justice Community Opioid Innovation Network (JCOIN), National Institutes of Health (NIH), Department of Justice (DOJ), Substance Abuse and Mental Health Services Administration (SAMHSA)).

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Appendix—Figures 1 through 17

FIGURE 1: GENDER

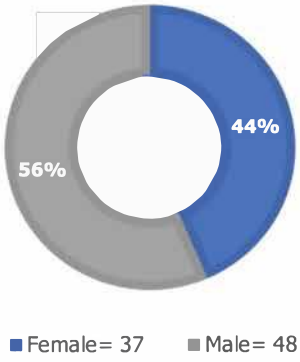


FIGURE 2: AGE

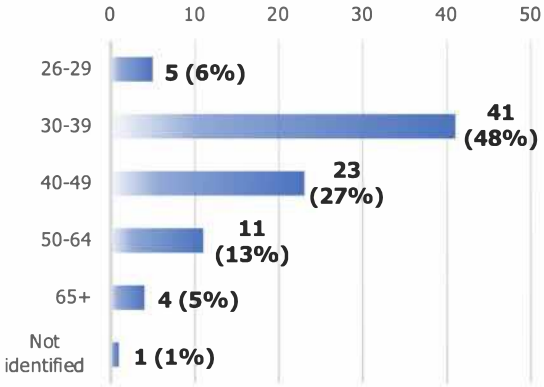


FIGURE 3: SELF-REPORTED ETHNICITY

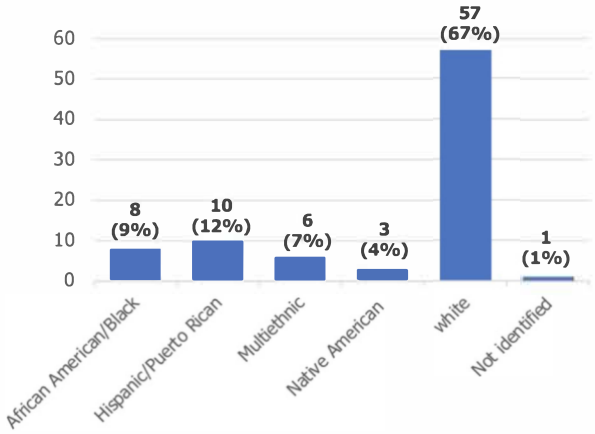


FIGURE 4: SUBSTANCE USE

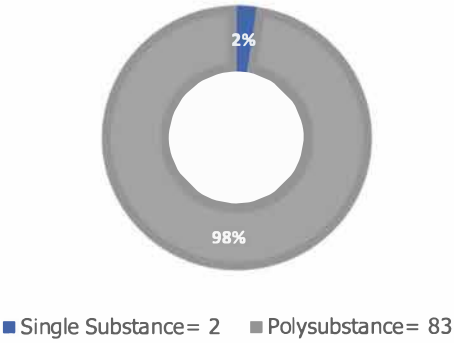


FIGURE 5: ENGAGED WITH SUBSTANCE USE TREATMENT (INNER CIRCLE)
NUMBER OF TREATMENT ENGAGEMENTS *(OUTER CIRCLE)*

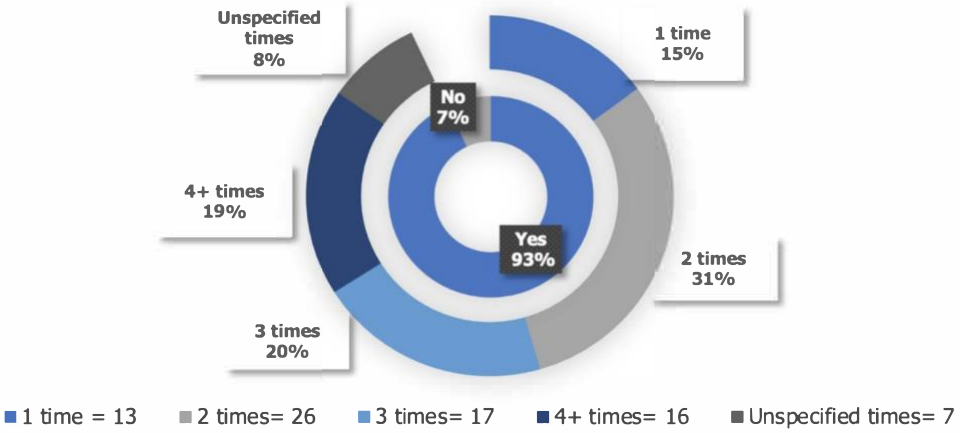


FIGURE 6: SELF-REPORTED BEHAVIORAL HEALTH DIAGNOSIS

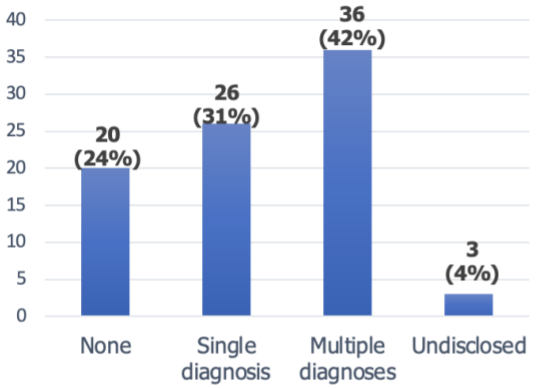


FIGURE 7: SERVED TIME IN A CORRECTIONAL FACILITY

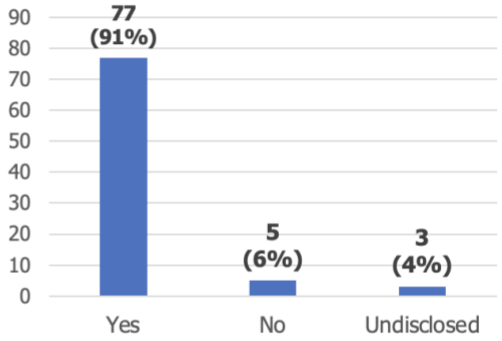


FIGURE 8: TOTAL TIME TO DATE SPENT IN A CORRECTIONAL FACILITY

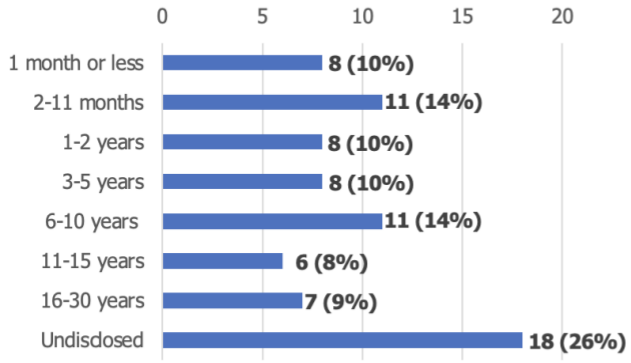


FIGURE 9: SELF-DESCRIBED DRUG-RELATED CHARGES

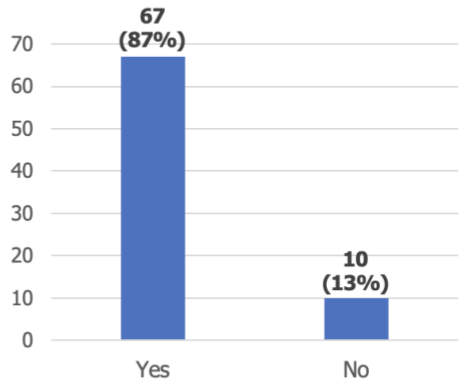


FIGURE 10: INITIATION OF OPIOID USE

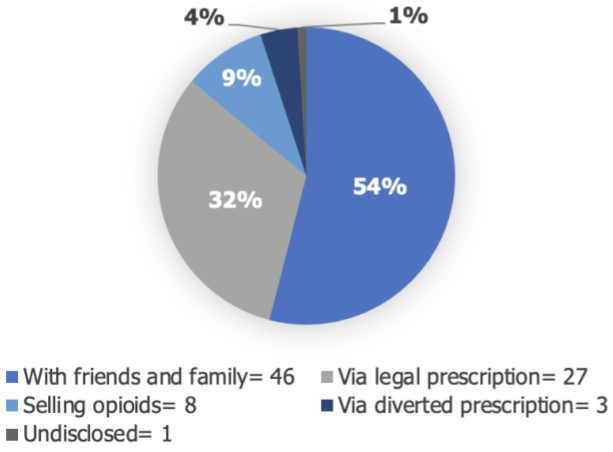


FIGURE 11: HISTORY OF TRAUMA

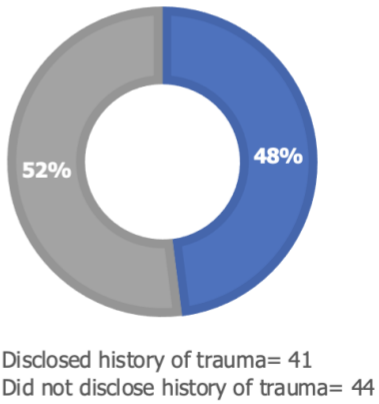


FIGURE 12: HIGHEST LEVEL OF EDUCATION COMPLETED

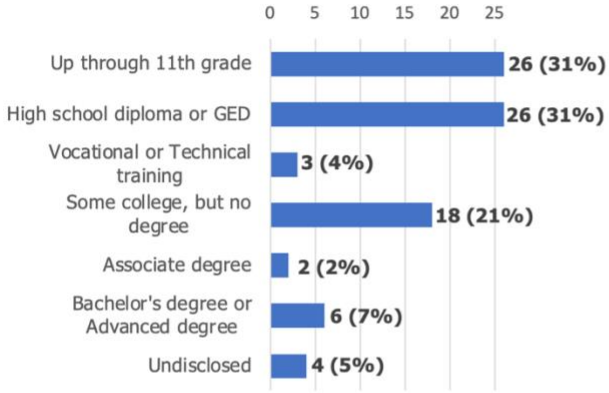


FIGURE 13: EMPLOYMENT STATUS

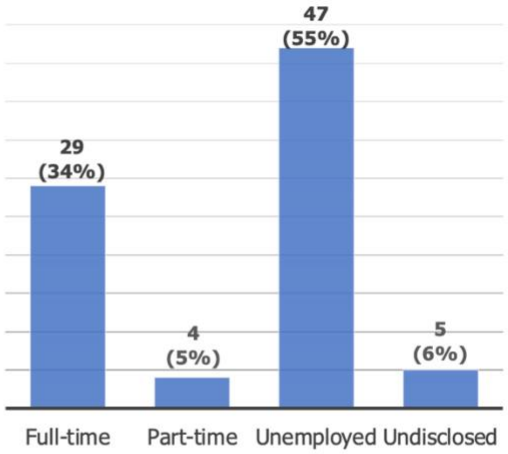


FIGURE 14: HOUSING STATUS

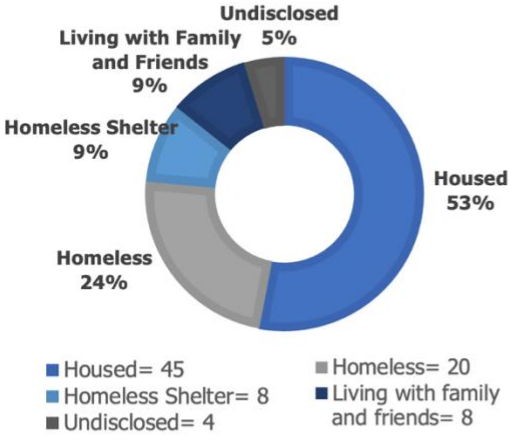


FIGURE 15: MARTIAL STATUS

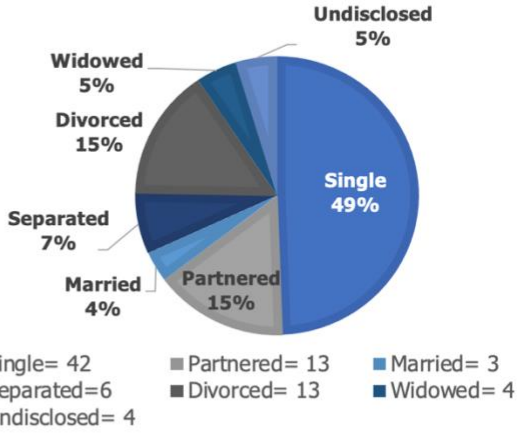
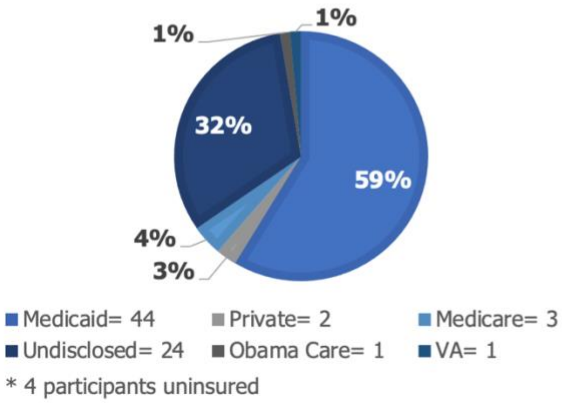


FIGURE 16: TYPES OF INSURANCE



* 4 participants uninsured

FIGURE 17: MILITARY SERVICE