NEBRASKA
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DEPT. OF HEALTH AND HUMAN SERVICES
DRUG OVERDOSE PREVENTION

UNIVERSITY OF NEBRASKA AT OMAHA
SUPPORT AND TRAINING FOR THE EVALUATION OF PROGRAMS

Drug Overdose Prevention: Lived Experiences Study

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"My past is my past, but my past is what has made me today. And I hope I can take everything and share it. And like I said, my goal is I want to save people, I want to save lives. I want to tell my story. Because I have a story to tell."

– Interview participant

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STEPs wishes to acknowledge and thank the following:
- The interview participants who were so generous in sharing their time, experiences, and perspectives,
- The many substance abuse treatment providers, treatment centers, the Grace Abbott School of Social Work, and the many other individuals who shared recruitment messaging, and
- NE DHHS DOP for their continued partnership and dedication to this vital work.

Key Findings

Drug Use Behaviors

- Drug use initiation began early in life and was often facilitated by family members.
- Substance use frequently served as a coping strategy for trauma, loss, and mental health concerns.
- Participants reported extensive drug use histories, often spanning several decades, with alcohol, marijuana, methamphetamines, and opioids being the most frequently used substances.
- The type of substances used by participants was primarily influenced by availability, and it was common for participants to change substances or use multiple substances.
- Participants experienced both intentional and accidental overdoses. Participants reported rarely receiving treatment referrals from medical providers after an overdose.

Substance Abuse Treatment

- Most participants reported some type of system involvement, which often served as a motivation for treatment or provided some financial access to treatment.
- Access to treatment was often facilitated by professionals, but financial barriers, waitlists, and struggles to find the right provider were common delays to timely treatment.
- Participants reported benefiting significantly from peer support and addiction and mental health education while in treatment, but some participants wanted more support developing robust and relevant coping skills.

Substance Use Prevention

- Participants were critical of the substance use prevention education they received growing up but believed that prevention education can be effective if it honors young people's autonomy and provides accurate and relevant information.
- Participants were skeptical of the criminalization of substance use as an effective deterrent. Instead, participants wanted systems to focus on substance abuse treatment as prevention.
- Participants supported the creation of a needle exchange program in Nebraska, which they believed would help mitigate health risks as well as create additional pathways to receiving treatment.
- Some participants speculated that having more positive opportunities as a child may have provided them with an escape from substance use in their home and, in turn, prevented their own substance use. This was especially true for participants who grew up in rural areas and identified limited community resources or programs for youth.

Evaluation Reflections

- Interviews with people who have lived experience misusing substances are a viable means of collecting data relevant to the information needs of the NE DHHS Drug Overdose Prevention Program.
- Data collected from people with lived experience misusing substances was highly granular and nuanced.

Recommendations

1. **Continue efforts to reduce the stigmatization of substance use disorders.** Participants reported experiencing significant stigma, often from medical, mental health, and criminal justice professionals, which sometimes delayed their readiness for or access to treatment.
2. **Advocate for timely access to treatment.** Missed referral opportunities, provider waitlists, and difficulties accessing funding can all delay treatment access. For some participants, these delays cut into the window of time that they were ready and willing to seek treatment and resulted in them forgoing treatment altogether.
3. **Recognize substance abuse treatment as overdose prevention.** Participants emphasized the powerful role of treatment in their lives, especially learning accurate information about their substance use and other mental health disorders.
4. **Increase access to mental health care.** Participants' substance use was often a means of coping with untreated mental health problems. Some participants reported that it was easier to access illicit substances than their prescribed mental health medications. Experiences of trauma or loss of a loved one often escalated their substance use to dangerous levels.
5. **Advocate for comprehensive substance use education and prevention programs in Nebraska.** Participants believed that accurate and empowering education could help prevent substance misuse. Participants specifically suggested partnerships between treatment centers and school districts as one means of facilitating effective prevention education.
6. **Prioritize and honor the role of families in treatment and prevention efforts.** Family disruptions and losses were common preludes to escalated substance use. Families were also frequent and compelling motivations for participants to seek treatment and maintain their sobriety.
7. **Continue to develop and advance the PDMP**. While not mentioned by name, participants noted opioid access has been reduced through prescription monitoring.

Evaluation Recommendations

8. Continue to seek out and listen to the perspectives of individuals with lived experiences misusing substances.
9. Focus groups, in addition to individual interviews, could be a viable means of generating more substantive overdose prevention ideas.
10. Secondary data analysis comparing the lived experiences data to previously collected data from substance use treatment providers could provide additional insights.

Methodology Summary

This section summarizes the methodology for the Lived Experiences component of the Drug Use Behavior project. The full methodology can be found in Appendix A.

The purpose of this qualitative component of the Drug Use Behaviors project was to better understand the experiences and needs of individuals who have misused substances to learn about drug use behaviors, treatment accessibility, and prevention opportunities.

Through 12 semi-structured interviews with individuals who have lived experiences involving substance misuse, STEPs sought to address primary questions (1-3) and a secondary question (4) :

1. How do participants describe their lived experiences involving substance misuse?
2. What interventions do participants believe may have served as effective primary prevention of substance misuse?
3. What systemic and personal barriers do participants report in accessing and utilizing substance abuse treatment?
4. Are interviews with people who have misused substances a viable means of collecting data relevant to the information needs of the NE DHHS Drug Overdose Prevention Program?

Recruitment

STEPs sent recruitment materials to substance abuse treatment centers and providers, NE DHHS DOP partners, previous interview participants, and the Grace Abbott School of Social Work. STEPs asked these partners to share the recruitment messaging with their networks. Utilizing snowball sampling, STEPs asked interview participants to refer others who may qualify for the study. Recruitment materials are located in Appendix B.

Data Collection

STEPs conducted 12 semi-structured interviews with individuals who have lived experiences involving substance misuse. Interviews took place over Zoom, an online video conferencing service, or by phone. STEPs audio recorded and transcribed each interview for analysis. The full consenting information is located in Appendix C. The interview protocol is located in Appendix D.

Data Analysis

STEPs analyzed the data using MAXQDA software. STEPs used methods of constructivist grounded theory, included initial coding, focused coding, and categorization. All data was initially coded independently by two STEPs staff members who collaboratively advanced the analysis to focused coding and categorization stages. STEPs staff engaged in memoing throughout the data analysis process.

Participant Profile

STEPs conducted semi-structured interviews with 12 participants. All participants self-identified as having engaged in serious substance misuse, which negatively impacted their home, work, or school life; their relationships; or their health. All participants had engaged in substance misuse or substance abuse treatment within the past 5 years.

In order to maximize participants' privacy and confidentiality, STEPs intentionally did not collect additional demographic information from participants. However, without being prompted, many participants shared relevant demographic information about themselves. Participants ranged in age from their mid-20s to their late 50s. The majority of participants were men, and about a third of participants were women. Nine of the 12 participants self-reported being a parent. Two participants self-identified as part of the LGBTQ+ community.

All participants resided in Nebraska at the time of their interview. While some participants spoke to out-of-state substance use and treatment experiences, the majority of their experiences took place in Nebraska. Participants identified experiences in both rural and urban parts of Nebraska. Seven participants were engaged in inpatient treatment within Region 5 at the time of the interview. As part of the snowball sampling strategy, three participants were referred to the study by previous participants.

Drug Use Behaviors

This section contains:

- **Type of Substance**
- **Drug Use Initiation, Sustained Use, and Escalated Use**
- **Experiencing Overdose**

"If they look in people's upbringings, if they see the history of what's gone on in somebody's life, maybe they would be more willing to help somebody. Because me going through the foster care system and getting adopted, and everything else, it had a big impact on everything I did."

– Interview participant with history in the foster care system

Type of Substance

"I started using drugs probably when I was 16. It started with the basics, you know, marijuana and alcohol. In my teen years I had a bunch of teeth problems, so I was constantly going to the dentist, and you know, at that point in time, they were so giving of narcotics, that that's when I first started those."

- Interview participant with aspirations of creating a needle exchange program

As part of the screening process, participants must have indicated misusing a substance other than, or in addition to, alcohol and marijuana. Most frequently, participants discussed misusing alcohol, methamphetamines, marijuana, and opioids. Participants also frequently discussed polysubstance use (the use of more than one drug at once) and changing substance use type over time. While many participants noted their substance use began with alcohol or marijuana, the type of substance used by participants in early life was largely dictated by availability.

Individuals with lived experiences involving substance misuse discussed the type of substance being used as highly fluid. Some participants, for example, discussed using substances strategically or to fill a need. One in particular discussed their methamphetamine use as a deliberate strategy to help them fulfill their multiple responsibilities as a single mother, stating:

> *I was a new mother of now three, and two little kids and the relationship kind of went separated. And then I think I started using it as a pick-me-up. You have to work, you have to be the mom, you have to do, do, do, do. And I just think it kept me going.*

Similarly, another participant discussed using alcohol as a method to ease their anxiety, stating, "*When I have like higher anxiety days, I'll try and drink to calm down.*" Many participants identified and linked their untreated mental health problems to their substance use.

Participants also discussed shifts in the type of substance being used based on their environment and social circle. While substance availability was a common explicit factor, some participants also appeared to be making implicit, strategic risk assessments in their substance type choices. One participant discussed stopping his opioid use once his social group no longer had access, explaining:

> *[I was] pretty much on [opioid] pills 'til the stoppage of them, really. They were just so hard to get. They were getting harder and harder to find. I wouldn't go too far out of my way, because I had to have a certain circle that I mess with again. Didn't want to ever go out that range, […] unless I knew them and been to my house, I'm not going to chase them.*

Type of Substance (cont'd)

Participants recognized the potential physical and legal risks of acquiring substances outside of their comfort zone. For example, another participant discussed a preference for K2, a synthetic cannabinoid, over marijuana, because they knew K2 would not show up on an employer urinary analysis and assessed it as a lower risk option.

Participants displayed extensive knowledge in substances and their interactions with each other and the effects they have on individuals. One participant discussed using Xanax while also participating in medication assisted treatment with methadone, which resulted in a non-fatal overdose. While this participant understood mixing these two substances was dangerous, they explained the methadone clinic did not intervene in their use, stating:

> *They did random UAs, but there was no consequence for it. You know, I was never thrown out of the program. I was never told that I had to wean off to quit. So I continued to take like, my Xanax that I shouldn't have been taking with the methadone, you know? And to me, that just wasn't very good. I don't think that they were set up properly to do what they do.*

Drug Use Initiation, Sustained Use, and Escalated Use

"Well, I grew up in a trap house, or in a house that was heavily involved with drugs. My uncle used to cook dope, my dad was really heavy into selling coke and weed when I was growing up. I took my first line of something white when I was 4."

– Interview participant with history of childhood abuse

Participants discussed multiple precipitating factors which influenced their substance use. These factors tended to be clustered by stages of substance use, with participants experiencing many similar factors during initial use, continued use, and escalated use.

Drug Use Initiation

Most participants' initiation into substance use involved peers or family members who were already engaged in it. For many participants, the motivation for initial use was primarily social. Participants described engaging in substance use in order to help them fit in, allow them to make friends or develop romantic relationships, or as a strategy to maintain existing relationships. Two participants' stories exemplified these social motivations:

> *When I met her, she was doing cocaine. […] I got into a relationship with her, and I didn't wanna change her, it wouldn't be fair, because I knew I met her that way. Then I started trying [cocaine] from her doing it. She started doing it more often and more often, and then, eventually I was like, 'Well, let me try it.'"*

> *It wasn't until I was 18 years old, when I met this girl out in [rural Nebraska] that I started using meth. And the only reason I did is because I kinda had the hots for her. And well, every day since I turned 18 years old, I've been using meth.*

Others attributed their initial substance use to curiosity combined with ready availability, often within the home, and a lack of appropriate adult supervision. One participant shared, *"I took my first line of something white when I was 4, I'm pretty sure it was coke, but I just know that my mom was caught up in conversation when the mirror was brought around her."* While 4 years old was the youngest initial substance use shared by the participants, most participants' initial substance use occurred in early adolescence and was with or facilitated by adults in their lives. One participant, for example, described their initiation into substance use around the age of 12 saying, *"The baseball coach took us to his house and turned us onto weed and alcohol. Kind of weird. It was a youth team, and I started from there."*

Additionally, many participants who discussed opioid use stated their initial use was non-recreational and resulted from being prescribed the medication after an accident or medical procedure. For example, one participant stated, "*In my teen years I had a bunch of teeth problems, so I was constantly going to the dentist and you know, at that point in time, they were so giving of narcotics, that that's when I first started those."*

Drug Use Initiation, Sustained Use, and Escalated Use (cont'd)

Sustained Use

After the initial use, participants discussed many factors which led to their continued use. Some participants discussed existing mental health diagnoses and stated their substance use eased the symptoms. One participant noted this shift in themself stating, *"I think a big part from going from, 'Oh this is just fun,' was to, 'Now I'm depressed, and this makes me feel better.' So definitely a mental health thing."* Many participants felt it was easier and more effective to access illicit substances than mental health medications. Many participants also noted their substance use stopped for periods of time when mental health medications were available to them or when illicit substances were less readily available.

Many participants also spoke of family or social environments that facilitated their continued substance use. In these environments, substance use was normalized and, in some cases, actively encouraged. One participant, whose substance use began when they were pursuing a romantic relationship, described a family environment that continued to enable their substance use even in the absence of their initial motivation:

> *When I turned 18, I moved back in with my biological father. And he was still in his active addiction [...and] I had no idea he was even using drugs—and told him that I did drugs, and I knew drugs are bad. He smiled at me and said, 'So, you wanna get high?' And it was just over from there, really."*

One participant also described the role of physical dependency on opioids, which they identified as a significant factor in their continued use, saying, *"And then with those, it just became, I mean I was so addicted to them, I had to have them just to get through the day because of my body. I mean, if I didn't have 'em, I'd be sick."*

While most participants identified that external factors influenced their continued substance use, a few participants explained that their continued use was because they enjoyed using drugs and how it made them feel. A participant who ascribed their continued use to enjoyment also speculated that their experience was likely not representative, saying, *"I think some people it's just they like to feel good, but I think a lot of people, I think it's they're dealing with something."*

Drug Use Initiation, Sustained Use, and Escalated Use (cont'd)

Escalated Use

For many participants, specific events triggered their substance use to escalate. Most frequently, participants discussed their substance use increased after the death of a loved one. Participants described their substance use as a way to cope with the intense emotions they were feeling. One participant stated:

> *Oh, it got bad. I lost my son 10 years ago. He was 6½ months old. And after I lost him, I completely lost control, I didn't care about anything anymore […] That was my downfall. When that happened, I really quit caring about anything, and I just wanted to mask how I felt. I was tired of hurting and not trusting anybody, so I dove headfirst into drugs and started selling drugs.*

Participants also discussed their interactions with law enforcement or NE DHHS Children and Family Services as a trigger which escalated their use. While participants frequently noted their children and families as motivations to enter treatment, which is discussed in "Motivations for Treatment," some also shared that their substance use escalated after losing parental rights because that motivational factor was no longer there. One participant explained, *"When they took my rights to my daughter, I really quit caring. I got the worst I'd ever been. Because there are some people out there that actually want their fucking kids and want to do better."*

Some participants also identified strained family relationships as triggers which escalated their substance use. Frequently, the participants' continued substance use caused family relationships to be strained. Once these familial relationships worsened, so did the substance use. One participant stated:

> *The alcohol got out of control when I was 28, extreme anger at some family members that—they basically excluded me from the family […] They told some lies about me. I was drinking a little too much. I'd been pulled over for a DUI [...] So he wrote me up anyway, and I made the newspaper, and my name was dirt in the family and everything fell apart. So I just started drinking every day rather than mostly on the weekends.*

While the circumstances varied, many participants shared similar stories where the stigma associated with their substance use led to a dramatic escalation in substance use.

Experiencing Overdose

> *"I never felt more shameful in my life. That's how [the hospital staff] made me feel. You know, it was like they just didn't care, that they had more important people to see. Because at that time, I really wanted help. I was really lost, and I didn't know even where to go to get it."*
>
> – Interview participant with history of accidental overdose

Some participants discussed their personal experiences with overdose. One participant discussed attempting to overdose as a suicide attempt after multiple psychiatric medications did not help with their bipolar disorder and severe depression. The participant stated:

> *I tried to overdose on alcohol and a bunch of pills 'cause I'd been on 8 or 10 different psych meds. And that didn't work, I just woke up like 22 hours later and wasn't dead. But I called for help, and they ended up taking me to a crisis center.*

While experiencing an overdose as a suicide attempt prompted mental health services to be provided for this participant, other participants who experienced accidental overdose had very different experiences.

One participant discussed experiencing multiple overdoses from alcohol and intra-veinous fentanyl use. This participant explained her state of mind during this period in her life by saying:

> *I lost the love of my life. He hung himself on my birthday back when in '07, and shortly after that, I was really at a low point, and I didn't care what drugs were being in my system. I just wanted to numb it; it hurt so bad.*

These overdose situations resulted in friends or emergency medical personnel resuscitating the participant and several overnight stays at an area hospital. This participant discussed being referred to outpatient treatment, but not following through at that time.

As mentioned in the "Type of Substance" section, one participant noted experiencing an overdose from the use of methadone and Xanax. This participant went on to describe experiences with medical staff and, despite being admitted for a drug overdose, not being referred to any type of substance abuse treatment. *"There was nothing about treatment brought up, there was nothing about nothing. In fact, I felt that I was looked down upon."*

Experiencing Overdose (cont'd)

Several participants reported similar experiences with medical professionals. One participant discussed being admitted to a hospital after fainting and shared:

> *I had marks going all the way up my arm. They knew I was an addict, I told them I was an addict, I told them the last time I did meth. Not one time did they offer any treatment, a phone number, a mental health clinic, nothing. My heart was doing funky things, they sent me home in a cab on a heart monitor thing and told me to bring it back in 2 weeks. That was it.*

These participants' experiences demonstrate the level of stigma experienced by individuals with substance use disorders, even among medical professionals.

Substance Abuse Treatment

This section contains:

- **Motivations for Treatment**
- **Access and Barriers to Treatment**
- **Treatment Experiences**

"I would say getting the correct therapists and getting the right doctor that works with you. It actually wasn't ideal. Because some of them just kind of preach it to you and then just like, throw you on a whole bunch of pills for your ailment and nothing else. And then you're still just kind of using. So finding the right doctors and like core support was really important."

– Interview participant wanting to end generational family substance misuse

Motivations for Treatment

"I was sick of what I was doing. I was sick of the life I was leading. I was losing friendships, and I was losing my kids, and I was losing my home. I mean, I came in here [treatment] with a car and my clothes. That's all I have right now. And I was sick of it, I was just sick of that life."

– Interview participant with a goal of starting their own sober living home

The majority of participants reported multiple substance abuse treatment attempts. Typically, participants' first attempt at treatment followed some level of system involvement, generally either with law enforcement or NE DHHS Children and Family Services. For example, some participants shared they first attended treatment following an arrest for DUI. In some cases, treatment was suggested by the participant's attorney while others were court ordered. For some participants, these initial treatment attempts were not motivated by a desire to end their substance use as much as a desire to avoid negative consequences. One participant shared:

> *At that point in time, I wasn't really looking to stop drinking or stop smoking. I was more so just like, 'Hmmm, I'll do [treatment] because I am young, and I don't wanna go to jail.' Like, that was the most terrifying thing at that point in time.*

Other individuals shared they participated in substance use treatment following interactions with NE DHHS Child and Family Services. Many participants stated losing custody of their children was their primary motivation for entering treatment. Participants also noted other familial bonds as motivating factors. One participant shared they were tired of their substance misuse causing emotional pain to their parents. Another stated:

> *I promised my auntie on my jail chair that I'm going to try to do things right. And she said that it was her biggest prayer for me and always has been, that I started doing things right, 'cause she started seeing me hurt. So it was kind of like my dying auntie's promise, a promise to my dying auntie.*

As noted in the "Escalated Use" section, system involvement played a decisively mixed role in many participants' substance use experiences. While system involvement sometimes served as a prompt for accessing treatment, participants also noted the fear and anxiety associated with the criminal court process, having children removed from their homes, and the uncertainty about their future triggering additional substance use. One participant observed the conflicting role of system involvement and shared:

> *Job insecurity is such a big thing, too, once you're an addict, and if you go through the legal system, it's even worse. If we had a way to help make sure that addicts had something to look forward to, a reason to get out of bed or a reason to not use, it would be so much better.*

Motivations for Treatment (cont'd)

While system involvement was a factor for most participants, many had other motivations for seeking substance abuse treatment. Participants often noted extrinsic factors such as their family or health as motivations for treatment. Several participants, for example, stated they wanted to be someone their children could look up to. One participant shared:

> *I love my kids, and I [will] shoot for any kind of trying to get help for to have a good family because I don't want to have my kids go down the same road that I did. You know what I mean? So I want to learn about what my illness is so I can tell them that I have an illness, and tell them that I'm okay, and not try to hide it. You know what I mean? To be open and more honest with my kids.*

Participants also noted intrinsic factors that motivated their treatment. Numerous participants stated they were tired of the lifestyle that came with their substance use. Others identified their overall happiness and quality of life are much better while sober. For many participants, a combination of extrinsic and intrinsic factors led them to seeking help. One participant explained*:*

> *My motivation to stop using was definitely, like once [substance use] got ruined for me, and it wasn't fun anymore, I definitely wanted to stop just to feel better about myself and to be able to move on with my life. I would probably say the biggest motivation though was fear, once again. Like, I didn't want to, once I got out of jail, go to prison because I got sanctioned on probation. I will say that those are the biggest motivators for me now, all three of those things, like mental, physical, and just not wanting to get in more trouble. But I've seen more of the benefits of [treatment], and I've started to realize that I'm more, I'm better off without [substances].*

Participants also noted the many positive characteristics they possessed which led them to enter substance abuse treatment. Participants recognized the bravery and determination that they needed to seek help. One participant encouraged others struggling with substance use to access their own determination, saying:

> *Remembering what you went through and where you can go back to if you don't use what you've learned [in treatment] to change your life and keep going on in a positive direction. And just to know that if you do fall back, to get up and keep going in the same direction where you felt good and where you were doing good, instead of the falling back into where you were.*

Access and Barriers to Treatment

"It's a bureaucratic nightmare, and without a caseworker it's almost impossible for just your average, you know, alcoholic or drug addict. It'd be very difficult for the average person who doesn't have a mental illness or doesn't have a drug or alcohol problem, you know, there's just a regular person to navigate through their aid program. People need a caseworker to try and get through all that. What is covered by DHHS? What's covered by [Behavioral Health] Region? What's covered by [treatment center]? What's covered by [mental health agency]? Where do you get what? And if you're a drunk half the day, it's impossible to figure out how to get help. You need a caseworker."

– Interview participant exploring non-addictive pain management

Accessing Treatment

When discussing access and barriers to treatment, it is important to note that nearly all the participants interviewed were in treatment or had treatment experiences within the last year. Many participants stated they did not face significant barriers when accessing treatment. These participants explained they accessed treatment through the courts, a probation officer, Region System caseworker, or social worker at a treatment center. Many participants believed that accessing treatment would have been much more difficult for them without the support and guidance of a professional, as demonstrated in the quote above. They also speculated that their experiences are different than those who do not have the same level of professional support. One participant shared:

> *My probation officer, I'm so lucky to have her. She doesn't ride my ass, but she's extremely supportive. Like, if I needed anything she would be there for me, I feel like. And I think that's something I don't think a lot of people have.*

In addition to professional support, participants frequently mentioned financial assistance, such as Medicaid, probation vouchers, and Region funding, as being essential to individuals trying to access substance abuse treatment. A couple participants expressed the following:

> *I would definitely say the best thing that's happened is opening up Medicaid. I'm not from this region. So I couldn't get region funding to come [to treatment] here. But luckily, I had Medicaid, and so that's just like another way that they can accept you into it.*

> *I've never had to pay to go to any of my treatments. The first two, I didn't have insurance, and it was a sliding scale or something, but I ended up not having to pay for it at [treatment center] either time. And then, for the third time, I had Medicaid since they opened it up, and I applied for that and got it. And it paid for my third time.*

Access and Barriers to Treatment (cont'd)

Barriers to Treatment

While all of the participants were able to access treatment, they did note barriers that had previously prevented or delayed their substance abuse treatment. For example, some participants discussed being placed on a waitlist for a few days to a few weeks. Participants stated that while this may not always be a large issue, there were instances when they changed their minds about going to inpatient treatment while on the waiting list. This dynamic shows the importance of timely access to treatment, as individuals may only experience short windows of time in which they are ready and willing to engage in treatment.

In one instance, a participant shared he was living in his vehicle during the wintertime while waiting to enter inpatient treatment. After 11 days, he initiated contact with law enforcement in order to receive quicker access to treatment. He stated:

> *Then one day it was so bitterly cold, like there's a police substation in between [intersection], and I walked up there and knocked on the door. They took me in and sent me to detox, and detox sent me upstairs to [treatment center].*

While this highlights the resourcefulness of individuals struggling with substance use, additional contacts with law enforcement can create additional concerns or risks for this population.

Other participants noted the importance of finding the right therapist, psychiatrist, or medical professional to be a part of the treatment team. One participant discussed an early and unsuccessful attempt at getting treatment by saying:

> *I had a therapist, so I was honestly just sitting there and getting nothing. And like he would try and talk but it's just like an uncomfortable time. And then like the psychiatrists, they won't put you on the right medicines because they're scared you're going to abuse it. But some of those people actually need that medicine at like lower doses to make them function.*

While participants were able to acquire financial supports for treatment, such as Medicaid, they often experienced significant difficulty accessing them. For example, one participant discussed a significant delay in accessing treatment, saying:

> *Well, I had troubles with getting Medicaid set up and my heart meds ran out. I couldn't go [to treatment] until I got a probation voucher, because I wasn't able to get on Medicaid since I was in a jail, so that held me back quite a bit.*

Access and Barriers to Treatment (cont'd)

Another participant explained that the financial supports available are often conditioned on criminal justice involvement:

> *I was never able to get the help, because treatment centers are expensive. And I couldn't afford it without getting in trouble. That's probably one of the only bad things I would have to say about the whole treatment thing, is that they are so expensive that when we're out there doing what we do, we don't have the money to put forth to get into treatment. It's like you have to get in trouble in order to get the help.*

While Medicaid made accessing substance abuse treatment possible for many participants, it did not remove all of the financial barriers they experienced. Several participants stated that certain medications are not covered by Medicaid and some mental health medications are too expensive for participants to afford. One participant discussed having access to needed medications while in treatment but losing that access once they left, which jeopardized the progress they made in treatment, saying, *"So, continue with the medication to the people who can't afford it after they get out of treatment. Otherwise, you're just wasting your money on treatment if they're just gonna fall off the system after they get out."*

Treatment Experiences

"[When] someone goes into treatment, I think that people should keep telling them they're doing a good job and that they're proud of them 'cause that makes them feel proud about themselves and makes him keep going. It's just acknowledgement that it's a good thing. You know what I mean? Like say that, 'Attaboy, that's good. Attagirl, keep doing it. You're doing good.' That really helps."

– Interview participant who regained custody of their children

Participants had much to say about what aspects of treatment were most beneficial. Most frequently, participants stated treatment was the first time anyone had explained substance use and other mental health disorders to them. This deeper understanding of their disorders allowed participants to feel better prepared to address them. One participant discussed being diagnosed with schizophrenia but receiving no information about the symptoms or treatments. They recounted learning about their disorder by watching YouTube videos and gaining a much better understanding of it through their experience in substance abuse treatment:

> *When I first heard I had schizophrenia I was like, "Great, this is really messed up and I'll be all like, go crazy on people, talking to myself." Like once you're on medicine, it's really manageable. And I didn't know that until I got on like the right medicine.*

Many participants also discussed peer support, sense of community, and structure of treatment as being helpful aspects. Participants reported connecting with individuals with similar experiences as one of their primary supports outside of treatment. One participant explained:

> *I don't do any of the 12 Steps or anything like that, but I do go for the comradery behind it and the support of actually getting to know the people and build the friendships and relationships with them. I would say that's been my biggest help outside of actual treatment kinda stuff.*

Participants also had ideas on what would enhance their experiences in treatment. Most frequently, participants stated they would like to learn more coping strategies and find hobbies while in treatment. Boredom was commonly noted as a factor contributing to substance use and participants felt developing hobbies would decrease this risk factor. One participant explained*:*

> *Because all your time is consumed by that [substance use]. And then once that big thing's gone, you don't know what to do. So I feel like finding hobbies, recommend things, do different things, go places. Something like that would definitely help.*

Treatment Experiences (cont'd)

Other participants noted the need for harm reduction education within treatment. Most participants had several treatment attempts with periods of substance use in-between. Learning how to reduce the risks of overdose while in treatment would have better prepared them to stay safe during a relapse period.

Another participant discussed that treatment takes place in a bubble. Clients build strong connections with each other, treatment center staff, and others in the recovery community in the city or town where they are receiving substance abuse treatment. However, participants routinely noted that they attended treatment hours away from their primary residence. One participant suggested treatment center staff should help clients make connections to the treatment community in the city or town they will be returning to after treatment. As many participants stated connection was a helpful aspect of treatment, this additional step would better support clients when returning home.

Substance Use Prevention

"There's this kind of like seething anger about the fact that we, we're in a pandemic for COVID-19, but we've also had a pandemic of use disorder for decades now, and it's—there's still is no change. And there's been people that have had—like what I'm saying is not anything new. There are people that have been saying that it's just the people that are in the positions to make these decisions to actually go that route or not.

– Interview participant completing their bachelor's degree

Substance Use Prevention

Once I decided I'm going to do it [use substances], I did it. 'Cause like all they're talking about is preventing it, don't do it. But like, maybe if you showed like some real facts and have like maybe like an addict come in and talk to them about what happened and just be real with them. I think that would work better.

– Interview participant with extensive family history of substance misuse

Participants held many views on what prevention efforts may have precluded or reduced their personal substance misuse and which may prevent others from drug use initiation. Most frequently, participants suggested implementing a comprehensive drug use education program in schools. One participant explained, *"Fifth and sixth graders, all the way on up—I think that's where you gotta start. That's your target audience where, if you want to prevent drugs or overdoses or whatever, you need to start there."*

Many participants stated the "Just Say No" and DARE campaigns were ineffective and compared them to scare tactics. One participant identified teenagers are more autonomous and in tune with the world than many adults may think. This participant continued by explaining this type of thinking is acting as a barrier to providing an effective drug education program. They explained:

> *So we have to say, you know, "Thou shalt not" versus "Thou shalt know." And I think as long as that's the approach, it's not ever going to change. Because good luck telling a 16 year old, "Hey, don't do this." They're going to go, "No, fuck you. I can make my own decisions," because that's like what they're trying to do. They're trying to enforce their own autonomy in some way.*

Many participants also indicated comprehensive education should contain individuals in recovery speaking directly to youth at schools about their experiences. Participants recounted learning drugs were bad in school but there were a lot they did not learn. One explained:

> *I didn't know that when I was like 14, that it was going to have this effect on my life for like 20 years. I didn't know that. I didn't know what that would look like. I didn't know that it would get my kids taken away, would put me in situations that it did. And it would—that even the friendships that you made along the way were mostly just some faulty encounters, you know?*

Participants felt hopeful that allowing individuals in recovery to share their stories with youth, many would decide against trying a substance to begin with.

Substance Use Prevention (cont'd)

Many participants felt that their home environment was the primary contributing factor to their subsequent substance use. However, their views on removing children from homes with significant substance use were very nuanced. Some participants had experienced the foster care system themselves and others had experienced the loss of custody of their own children. While they speculated that a different home environment may have prevented their substance use, they did not want to experience removal themselves or for their own children to be removed. Many participants spoke to the stigma they experienced while being involved with NE DHHS Children and Family Services. One participant stated:

> *I just felt like really judged [...] So it was really hard to connect with workers, especially you would have these workers that didn't even have kids. Or, you know, these workers that they have such a workload that they're not really doing much for you. And then you just didn't have the support where you felt like unjudged, you know, it's hard to trust people when you feel like you're being looked down upon.*

Instead, some participants highlighted the importance of having other safe environments that young people can engage in. Some participants speculated that having more positive opportunities as a child may have provided them with an escape from substance use in their home, and in turn, preventing their own substance use. This was especially true for individuals who grew up in rural areas who identified limited community resources or programs for youth. In addition, one participant identified even if these programs existed, transportation to and from can be a challenge for youth in rural areas.

A few participants identified needle exchange programs as a positive prevention technique which should be implemented in Nebraska. One participant noted this outreach would create a pathway for individuals misusing substances and professionals to build relationships, discuss resources, and provide connections to services. Another participant discussed how a needle exchange program would also serve as a harm-reduction strategy stating:

> *The person who uses the needle, they're gonna go use the needle whether it's a dirty needle or it's a clean needle. You know, that's just how it's gonna be. And I would rather give them that clean needle in hopes that they wouldn't go out and use somebody else's needle who had HIV or, you know, who had some disease that they could get from it.*

Substance Use Prevention (cont'd)

Participants also noted that substance use treatment is substance use prevention. Several participants identified that punishment is often the first response to substance use, rather than rehabilitation. Participants identified a number of changes to existing systems that would help people access care, including automatic treatment referrals for drug offenses and additional treatment opportunities without system involvement. One participant argued for a decriminalization approach, stating:

> *A healthy way to go about it would be to recognize this is a health issue and not a criminal issue, and to criminalize it is just going to continue all the deaths that are going to happen, all of the, you know, all of the violence that goes along with it because of the fact that people aren't getting like adequate like mental health help as well. Like the state needs to stop viewing users and people with use disorders as criminals and [see them as] people that are sick and need help.*

Evaluation Reflections and Recommendations

In the fall of 2020, DOP and STEPs entered a contract with the intent of conducting a pilot study interviewing individuals who have lived experiences misusing substances. In early spring of 2021, DOP amended the contract with STEPs to expand the project to a full qualitative study, though an assessment of feasibility remained a desired project outcome.

Overall, STEPs found that speaking directly with people who have lived experiences misusing substances was a practical method for gaining information relevant to NE DHHS DOP. Participants overwhelmingly reported they were motivated to share their experiences, insight, and ideas because it may help other people. One participant stated:

> *My past is my past, but my past is what has made me today. And I hope I can take everything and share it. And like I said, my goal is I want to save people, I want to save lives. I want to tell my story. Because I have a story to tell.*

While previous studies with substance abuse treatment providers have allowed STEPs and DOP to identify substance trends in aggregate, speaking directly to individuals with lived experiences provided a more granular and nuanced view into substance misuse. In particular, participants in the current study recounted detailed substance use histories, provided experiential accounts of their system involvement, and offered critical, consumer perspectives of substance abuse treatment programming in Nebraska. STEPs believes that this deeper context can be helpful for NE DHHS in preventing drug overdoses.

While the current study demonstrated the viability and value of hearing directly from individuals with lived experiences misusing substances, some goals of the study were not met. STEPs hoped to recruit participants who had not accessed substance abuse treatment in order to learn more about the individual and systemic barriers to treatment. In an attempt to reach these individuals, STEPs implemented a snowball sampling strategy in addition to recruitment through social service agencies. However, only three participants conducted an interview after being referred by a prior participant, and all participants had treatment experiences. Additional recruitment strategies and a longer recruitment and data collection phase may help address this gap in future studies.

While participants were passionate about substance use prevention and had a number of actionable insights and ideas to support prevention efforts, data addressing this area were generally less rich and detailed than in other areas. STEPs used an individual interview format in this study, which facilitated participant storytelling, but may have been less effective at eliciting idea generation. The addition of focus groups, which are commonly used to collect problem solving data, in future studies may elicit additional and richer substance use prevention strategies.

Limitations

1. While the sample size was well within the acceptable range for qualitative research, it may not have been fully saturated, and additional findings may have developed from additional data.
2. STEPs used purposeful, criterion sampling. While STEPs attempted to recruit a diverse sample of individuals with lived experiences misusing substances, the sample and resulting data should not be viewed as representative of all substance use experiences in Nebraska.
3. Most participants were currently accessing substance abuse treatment. Individuals with additional barriers to accessing treatment may not have been reached to participate in this study.
4. Many participants were recruited by the same substance abuse treatment program. Individuals participating in other treatment programs or other levels of care may have provided additional perspectives on substance abuse treatment.
5. STEPs conducted all interviews during the COVID-19 pandemic. It is not known how this affected the type or quality of data collected.
6. STEPs conducted all interviews via Zoom, an online videoconferencing platform, and phone. While researcher and participant satisfaction with qualitative data collection via Zoom has been documented, it is unknown if the use of these platforms affected the type or quality of data compared to in-person interviews.
7. Bias exists within all research. STEPs used two coders who engaged in initial coding independently and subsequent data analysis collaboratively in an effort to reduce the impact of bias.

Appendix A

Full Methodology

Drug Use Behaviors Background

Support and Training for the Evaluation of Programs (STEPs) at the University of Nebraska at Omaha is a leader in conducting evaluations of and needs assessments for social service programs and policies. The Nebraska Department of Health and Human Services (DHHS) Division of Public Health Drug Overdose Prevention Program (DOP) contracted with STEPs in the fall of 2020 to conduct a qualitative pilot study to determine the feasibility of collecting interview data directly from people who have misused substances.

In previous contracts with DOP, STEPs collected and analyzed data from professional populations with insights into the needs and experiences of people who have misused substances. STEPs had not yet purposefully collected data directly from people with lived experience misusing substances.

In early spring of 2021, DOP amended the contract with STEPs to expand the project to a full qualitative study, though an assessment of feasibility remained a desired project outcome.

Purpose

The purpose of this qualitative component of the Drug Use Behaviors project was to better understand the experiences and needs of individuals who have misused substances to learn about drug use behaviors, treatment accessibility, and prevention opportunities.

STEPs collected qualitative data from 12 individuals in Nebraska who have misused substances through semi-structured interviews and analyzed the data to identify information and themes relevant to the NE DHHS Drug Overdose Prevention Program.

The analysis sought to address primary (1-3) and secondary (4) questions:

1. How do participants describe their lived experiences involving substance misuse?
2. What interventions do participants believe may have served as effective primary prevention of substance misuse?
3. What systemic and personal barriers do participants report in accessing and utilizing substance abuse treatment?
4. Are interviews with people who have misused substances a viable means of collecting data relevant to the information needs of the NE DHHS Drug Overdose Prevention Program?

STEPs submitted information regarding the project for IRB review and received a determination that the project did not constitute human subject research, as the project was deemed program evaluation rather than research. As such, a full application for IRB review and approval was not required.

Appendix A (cont'd)

Inclusion and Exclusion Criteria

STEPs recruited participants who self-identified as having a history of serious substance misuse. Participants identified their substance misuse as having a negative impact on their home, work, or school life; their relationships; or their health. Participants had engaged in substance misuse or substance abuse treatment within the past 5 years. Participants must have been at least 19 years old and have resided in Nebraska while misusing substances or accessing treatment. Potential participants must have been willing to discuss their substance use history in a recorded interview.

STEPs excluded potential participants if their substance use history exclusively included alcohol or marijuana, which is outside the scope of DOP, unless combined with the use of other substances. STEPs screened for this criterion at initial contact. STEPs also excluded potential participants who were under the influence during an interview and were, therefore, unable to provide consent (Ryan, Smeltzer, & Sharts-Hopko, 2019). STEPs screened for this criterion prior to beginning an interview. All screening for inclusion and exclusion criteria was based on participant self-report.

Recruitment

STEPs emailed a recruitment message and recruitment materials (see Appendix B) to agencies and programs in Nebraska serving individuals with substance use disorders. STEPs asked agencies and programs to share, distribute, and/or post the recruitment materials to make clients, former clients, and community stakeholders aware of this opportunity. STEPs offered to mail or deliver physical fliers to Lincoln and Omaha agencies. STEPs also offered to mail physical fliers to be shared with others. STEPs asked that providers share the opportunity, but to not specifically ask clients to participate in any way that leads clients to perceive that treatment or services are dependent on or will be influenced by participation. NE DHHS DOP shared recruitment messaging with local health departments and the Drug Safety Advisory Group (DSAG). STEPs also emailed recruitment messaging to treatment providers who had recently participated in another component of the Drug Overdose Prevention project.

All participants were provided a $20 Amazon gift card as compensation for participating in the interview, which was sent to them after the interview. See Appendix E for compensation protocol.

STEPs also used snowball sampling to recruit participants, especially for those who were not currently connected to treatment. All potential participants were invited to refer other qualified individuals to STEPs in order to participate in the opportunity.

Appendix A (cont'd)

Participants were compensated $5 for each qualified participant (up to five) who they referred and who completed an interview. Compensation for successful referrals was sent to participants at the end of the data collection period.

Screening and Consenting

Recruitment materials directed potential participants to call or email STEPs to receive additional information and sign up for an interview. STEPs briefly screened the potential participant for inclusion and exclusion criteria and scheduled the potential participant for an interview (see Appendix F). Only one potential participant was screened out due to not having a substance misuse history beyond alcohol. Potential participants who contacted STEPs via email received full consenting information (see Appendix C) by email. Potential participants who contacted STEPs via phone were provided with the full consenting information by their choice of either emailing or texting them the link to a webpage. All participants were provided verbal consent prior to the start of the interview (see Appendix D).

Data Collection

STEPs staff collected data for this project through semi-structured interviews. Interviews were scheduled at a time that was convenient for participants and took place over Zoom, an online videoconferencing service. Both qualitative researchers and research participants have found Zoom to be a highly satisfactory method of conducting interviews, highlighting its convenience and user-friendliness (Archibald, Ambagtsheer, Casey, & Lawless, 2019). In instances where participants did not have access to Zoom, STEPs offered a phone interview option. Qualitative researchers found interviews conducted via telephone contained the same depth and detail as those completed in person and found telephone interviews to be a suitable method for hard-to-reach populations (Sturges & Hanrahan, 2004).

STEPs conducted 12 interviews. Interviews varied in length from 31 minutes to 68 minutes, with an average of 51 minutes. STEPs audio recorded each interview and developed transcriptions for analysis. STEPs developed and analyzed 160 single-spaced pages of transcripts. Interviews were guided by the interview protocol (see Appendix D), while allowing for flexible follow-up in order to elicit rich data and saturate emergent codes and themes.

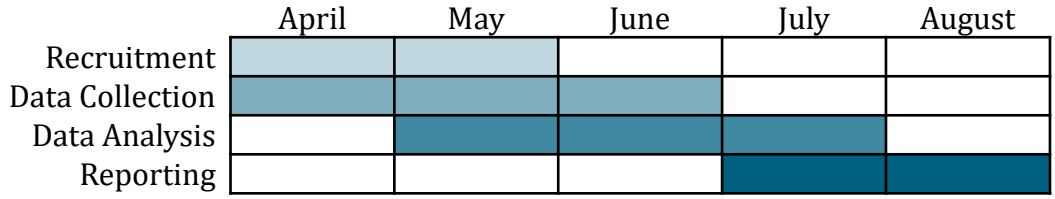
Data Analysis

Though the project is generally phenomenological in nature–attempting to better understand the lived experience of a phenomenon–a phenomenological analysis which attempts to reduce data to the essence of the experience was inappropriate for the purpose of this project. Instead, data collected for the project was analyzed using the methods of grounded theory (Charmaz, 2014), though the analysis did not progress to theory development.

Appendix A (cont'd)

Phases of initial coding, focused coding, and theme development provided structure and rigor to the data analysis process. Analysis was facilitated using MAXQDA software and performed by two coders.

Project Timeline



Participant recruitment began in April 2021 and continued until the end of May. A recruitment reminder was sent in May, and STEPs reevaluated recruitment methods and progress. At this stage, STEPs incorporated an additional recruitment strategy, emailing treatment providers who had participated in interviews with STEPs in the past. Recruitment and data collection continued through early July. STEPs engaged in some initial data analysis concurrent with data collection, a strategy used within the methods of constructivist grounded theory (Charmaz, 2014). Additional stages of data analysis took place in July after data collection was completed.

References

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Appendix B

Recruitment Email

Subject: Help recruiting participants

Hello _____,

We would like your help recruiting participants to an important study we are conducting on behalf of the Drug Overdose Prevention Program at the Nebraska Department of Health and Human Services (DHHS). DHHS has contracted with the University of Nebraska at Omaha's STEPs (Support and Training for the Evaluation of Programs) to **hear directly from individuals who have misused substances.** The purpose of this study is to better understand the experiences and needs of individuals who have misused substances to learn about drug use behaviors, treatment accessibility, and prevention opportunities.

We are asking for your help getting the word out to potential participants. We have attached several recruitment materials to this email:

- A flier to post in areas accessible to your clients (printed copies can also be mailed to you, reply to this email to let us know how many you need);
- Recruitment images and text to be shared on social media;
- A brief recruitment message for email distribution or inclusion in a newsletter.

Participation in the study will be kept confidential and **all participants will receive a $20 Amazon eGift Card as compensation.**

Please direct potential participants to contact Dan with STEPs at [phone number] or dkreuzberg-sw@unomaha.edu to learn more and schedule an interview.

If you have any questions or would like to receive a copy of the report, please contact Dan Kreuzberg at dkreuzberg-sw@unomaha.edu or Liam Heerten-Rodriguez at lheerten2@unomaha.edu.

Thank you for supporting this project,
[email signature]

Appendix B (cont'd)

Want to play a role in advancing substance abuse treatment?

Volunteer to participate in a study on substance use.

Nebraska DHHS Division of Public Health has partnered with UNO to learn more about the experiences of those who have misused substances and their experience with treatment.

You may qualify if you:

- Have a history of serious substance misuse or treatment in the past 5 years.
- Misused substances other than or in addition to alcohol or marijuana.
- Are 19+ years of age and lived in Nebraska during use or treatment.
- Are willing to discuss your experiences.

Participation involves:

- Participate in a brief screening.
- Participating in an approx. 60-minute remote interview.

Benefits of participation:

- A $20 gift card to compensate for your time.

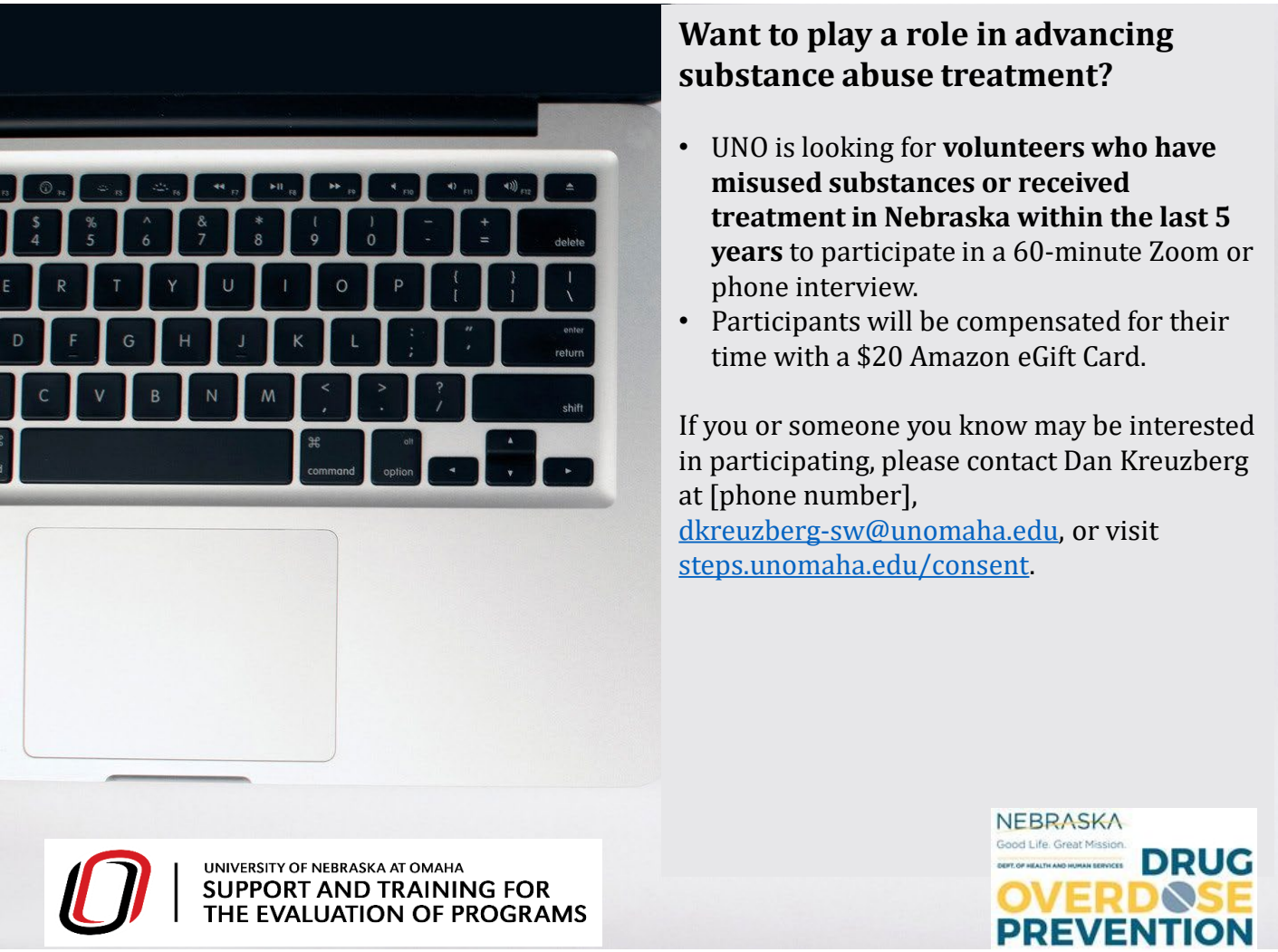
For more information or to sign up, contact Dan Kreuzberg at [phone number], dkreuzberg-sw@unomaha.edu, or visit steps.unomaha.edu/consent.

UNIVERSITY OF NEBRASKA AT OMAHA
SUPPORT AND TRAINING FOR THE EVALUATION OF PROGRAMS
6001 Dodge Street 223A CEC, Omaha NE 68182

NEBRASKA Good Life. Great Mission. DEPT. OF HEALTH AND HUMAN SERVICES
DRUG OVERDOSE PREVENTION

Appendix B (cont'd)

Social Media Image



Brief Recruitment Message

Want to play a role in advancing substance abuse treatment?

Nebraska DHHS Division of Public Health has partnered with UNO to learn more about the experiences of those who have misused substances and their experience with treatment. UNO is looking for volunteers who have misused substances or received treatment in Nebraska within the last 5 years to participate in a 60-minute interview. Participants will be compensated for their time with a $20 Amazon eGift Card. If you or someone you know may be interested in participating, please contact Dan Kreuzberg at [phone number], dkreuzberg-sw@unomaha.edu, or visit steps.unomaha.edu/consent.

Appendix C

Full Consenting Information

Thank you for your interest in participating in a lived experience interview. Interviews are being conducted through the Support and Training of the Evaluation of Programs (STEPs) at the University of Nebraska at Omaha. Nebraska Department of Health and Human Services (NE DHHS) Division of Public Health has contracted with STEPs to complete a needs assessment for the Drug Overdose Prevention (DOP) Program. The purpose of the DOP Drug Use Behaviors project is to equip NE DHHS with the information necessary to develop effective drug use prevention plans as well as provide relevant trainings and resources for treatment providers. Hearing directly from those who have misused substances is crucial to the development of those plans.

What will happen during the interview?

The interview will last approximately an hour. The interview will be scheduled at a time that is convenient for you and will take place over Zoom, an online videoconferencing service, or by phone. Zoom is user friendly and participants can connect over the internet or by phone, no software or camera required. The interview will consist of several open-ended questions regarding your personal experiences with substance use, prevention, and treatment. You can opt out of any question or opt out of the interview at any time. STEPs will record the interview in order to best capture your perspectives and to have a transcript of our conversation.

What will happen after the interview?

STEPs will analyze the transcript, along with the transcripts from other interviews, in order to develop a report. Your participation in the interview will be kept confidential and no personally identifying information will be included in the report. The report will be given to NE DHHS, who may distribute it to relevant stakeholders. With the permission of NE DHHS, a copy of the report can also be made available to you.

Limits to confidentiality

We will only tell someone your information and what you have said in the interview if you disclose child abuse or say that you, or someone else, is in danger. If this happens, we must tell the proper authorities to help keep everyone safe.

Why should I participate?

To compensate you for your time, STEPs will provide you with $20 Amazon eGift card. Additionally, by sharing your personal experiences and perspectives, you can ensure that your voice is heard by NE DHHS and other stakeholders as they develop plans relevant to your experiences. By including the voices of those who have misused substances, we hope to improve drug overdose prevention and treatment efforts in Nebraska.

Appendix C (cont'd)

Additional Supports

STEPs does not anticipate that participating in this interview will trigger substance use. However, here are resources available to provide you with additional support if you need it:

SAMHSA's National Helpline: 1-800-662-4357
Narcotics Anonymous Hotline: 1-818-773-9999
Alcoholics Anonymous Hotline: 1-800-839-1686

Appendix D

Interview Protocol

Verbal Consent

Today I am inviting you to participate in an interview, which should take about an hour. If you agree to participate, I will ask you a series of questions related to your drug use history, treatment history, and your perception of the substance abuse treatment system. If you consent, I would like to record our conversation so I can be sure to remember what you say. The recordings and transcription will be kept secured and will be destroyed once the project concludes.

The information you share today will help NE DHHS in understanding the experiences of individuals who have misused substances and inform decisions for future practices. Everything you say will be kept confidential. This means there will not be any names used in our report. We will only tell someone what you have said if you disclose child abuse or that you, or someone else, is in danger. If this happens, we must tell the proper authorities to keep everyone safe.

Please know that participating in this interview is optional, and you can stop participation at any time. Participants in this study will be compensated for their time by receiving $20 virtual Amazon gift card. The $20 compensation will be offered whether the interview is fully completed or not.

Do you have any questions before we begin?

Can you confirm that you are currently not under the influence of a substance?

Would you like to proceed with the interview?

Do I have your permission to record?

Interview Questions

1. Can you start by telling me about your drug use history?
    - What was your drug of choice?
    - When did you start using substances?
    - What motivated your substance use?
    - How would you describe the severity of your use?
- How common do you think your experiences are? Why?
- When we interviewed substance abuse treatment providers they shared that many of their clients struggle with trauma histories, family history of substance use, poor coping skills, and additional mental health diagnosis.
    - Do you think these are struggles that most people who have misused substances have in common?

Appendix D (cont'd)

    - Are there other struggles that you think most people who have misused substances have in common?
- Providers also discussed the strengths of their clients. The most frequently mentioned were determination, resourcefulness, intelligence, bravery, and supportive.
    - Do you think these are strengths that most people who have misused substances have in common?
    - Are there other strengths that you think most people who have misused substances have in common?
- Were you ever involved with the criminal justice system or NE DHHS while using substances?
    - What was that experience like?
    - What challenges did this cause?
    - What opportunities did this provide?

2. Can you tell us about your treatment history? This can include any attempts to stop or reduce use.
    - What motivated you to enter treatment?
    - What services did you use or access?
    - What personal challenges did you face?
    - What systemic challenges did you face? (insurance, funding, availability of services)
    - Were there additional supports you used which may not be typically thought of as "treatment"? (Peer support, spiritual counseling, self-help resources, etc.)
    - Did it work? Why?
    - What helps you maintain abstinence?

3. In your opinion, what are some things that may have prevented you from even starting to use substances?
    - How would this have prevented your substance use from beginning?
    - Does this approach exist?
    - If yes, what changes could be made to better reach (youth, adults, etc)?
    - If no, what do you believe is stopping this approach from being available?

4. What else would you like NE DHHS to know about your experiences?
    - Why do you want them to know that?
    - What do you want them to do differently because of that information?
    - How will you know that DHHS has gotten your message?

*The bulleted prompts listed after each question are meant to be flexible guides to help keep the conversation going and to dig deeper into what the participant is sharing. Not all prompts need to be asked. We may also need to ask prompts that are not listed here. The goal is always to dig deeper, and to elicit stories, examples, and meaning from the participant.

Appendix E

Compensation Protocol

In order to recruit qualified participants to this project, STEPs provided compensation for participation in a 1-hour interview and for successfully referring up to five other qualified participants to the project. The use of participant compensation was approved by the project funder, but NE DHHS DOP funds were not used for compensation.

Participant compensation was provided in the form of an Amazon eGift Card. A virtual gift card was necessary since all interactions with participants took place remotely. Amazon eGift Cards did not require a recipient name and were sent by email. These qualities helped preserve participant confidentiality while being easily accessible for most participants.

Compensation for interviews was sent to participants within the 7 days following their interview. Compensation for successful referrals was sent to participants at the conclusion of the data collection stage of the project.

STEPs staff members maintained a document for tracking participants, the compensation they earned, and the email or phone number where the eGift Card was be sent. Given the sensitive and stigmatized nature of the project and in order to maintain a high degree of participant confidentiality, STEPs only collected participants' first names.

STEPs evaluation staff provided the participant's email address and the compensation amount to STEPs director, Dr. Jeanette Harder, who managed the purchasing of the Amazon eGift Card. STEPs administrative staff documented that the eGift Card order had been placed and sent to the email address provided by the participant.

Documentation maintained by STEPs evaluation and administrative staff was kept in a password protected folder and was made available to other STEPs and UNO staff as necessary to ensure proper accounting.

Appendix F

Screening Script

Hello, my name is Daniel Kreuzberg, and I am an Assistant Program Evaluator with STEPs at the University of Nebraska at Omaha. STEPs has partnered with NE DHHS Drug Overdose Prevention Program to complete evaluation around the experiences of those in Nebraska who have misused substances. Do you have any questions about this study?

As part of this evaluation, we have certain inclusion and exclusion criteria. I need to ask you a few questions to determine your eligibility to participate in this study.

1. Are you currently under the influence of a substance? (No)
2. Are you at least 19 years of age? (Yes)
3. Have you misused substances or received substance use treatment within the last 5 years? (Yes)
4. Have you misused a substance other than or in addition to alcohol or marijuana? (Yes)
5. Were you living in Nebraska when you misused substances, or did you receive substance use treatment in Nebraska? (Yes)
6. Did your substance use have a negative impact on your home, work, or school life, your relationships, or your physical or mental health? (Yes)
7. Are you willing to discuss your drug use history? (Yes)