

Research Brief: An Ethnographic Assessment of Drug Use among Iowa Families

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Executive Summary

Project Overview

The purpose of this project was to strengthen the Iowa Department of Public Health's (IDPH) surveillance of substance use in Iowa, with particular attention to intergenerational impacts, through the deployment of an ethnographic assessment of active and former substance users. The goal of these activities is to help IDPH develop strategies to proactively identify and support children and families who have experienced harmful effects of substance use, either directly or indirectly. This report reflects the findings from the ethnographic research carried out by Iowa State University (ISU) between October 15, 2018-August 31, 2019. Four goals guided this work:

1. To better understand multi-generational impacts of substance use and family risk prediction.
2. To conduct a qualitative evaluation of substance use behavior, risk reduction, and socio-demographic and health characteristics in rural communities.
3. To better understand the dynamics of opioids and other substance use in Iowa, with special attention to substance use in rural areas.
4. To leverage ethnographic interviews to provide information that supports and enhances IDPH efforts to address substance use, with special attention to the two generational framework.

Summary of Key Research Findings

Research findings are based on in-depth interviews with 41 men and women from 18 Iowa counties that reflect the geographic and urban/rural mix of the state. Participants had a wide range of family backgrounds, education histories, political viewpoints, and experiences with different stages of the substance use cycle. Research teams conducted separate interviews, approximately 60-90 minutes in

length, with each individual and also conducted follow-up interviews with four individuals as couples. The interview protocol elicited rich insights into the social, economic, demographic and behavioral context in which substance use occurs among Iowa families. Our analysis of the data revealed six themes that provide IDPH an opportunity for small to large-scale programming and policy responses, as well as several methodological insights to inform future outreach. An overview of the themes is presented below. In a second phase of the project, to be carried out in September-November 2019, ISU researchers will collaborate with IDPH in two half-day facilitated workshops to identify potential avenues for translating these research findings into practice.

Theme 1: Social Isolation and Stigma

As a consequence of substance use, most of our study participants have experienced acute social isolation stemming from incarceration, job loss, frequent stays in treatment/rehabilitation centers, and the loss of friends and family. Our study participants describe lives characterized by chronic social isolation, in which their social support networks are stunted or non-existent due to the ongoing and cyclical effects of substance use. This includes the loss of old, ‘clean’ friends during and after use; loss of high-risk substance use friendships during remission; forced or voluntary moves to new communities; little contact with churches or civic associations; and the attendant stigma associated with substance use and its effects (e.g., gaining an identity of being a felon or ‘addict’). Participants described how their own social isolation fed loneliness, depression, and social anxiety, limited their access to social support, and harmed job prospects, each of which was a significant risk factor for use and relapse.

Theme 2: Economic Vulnerability

Many of the people we interviewed describe a dependence on substances that was interwoven with chronic resource deprivation, including extreme residential instability and homelessness (e.g.,

couch surfing, living out of cars and motels, or losing homes), reliance on theft and charity to make ends meet, transportation hardship (e.g., loss of driving privilege or vehicle), pawning personal possessions, limited labor market opportunities (e.g., due to felonies, low wages, few marketable skills or training), and state-imposed fines and fees. These economic stressors were often described as pathways into substance use and catalysts for relapse. This was particularly true in the weeks following release from treatment—a time of growing concern for policy makers as this is when drug-related mortality is on the rise. A common misperception is that the first days and weeks after a successful period in treatment will be the most hopeful time in the life of a person recovering from substance use. Instead, the people we spoke with describe this time as often the loneliest, most financially difficult, and hopeless period in their lives, providing a novel and important social and economic account for high mortality in the weeks and months following release from corrections and treatment facilities.

Theme 3: Substance Use Harms the Stability and Well-being of Iowa Families

Illicit substance use drove many of our participants to break ties with their nuclear and extended families (e.g., limit or have no contact with children, parents, and siblings; not attend family gatherings and events), limiting opportunities for family support and responsiveness. For many, familial breaks were the result of self-exile initiated by respondents who felt stigmatized by family members. Alternately, isolation was also enforced by families, especially when non-using family members thought of substance use as a ‘contagion’ that might infect others if the substance user was allowed to participate fully in family events and activities. While some of our respondents experienced modest, or even full, reunification with family members during extended periods of remission, most participants reported long-term estrangement and loss of intergenerational contact with nuclear and extended family members. Substance use also impacts the stability of people’s families of choice. Divorces were

frequently attributed to substance use, as were child separations, and histories of intimate partner violence. Taken together, these stories affirm that substance use not only negatively impacts the person who is actively using, but has ripple effects throughout the family system.

Theme 4: Trauma, Coping, Accountability, and Resilience

Trauma was prevalent in the childhoods and life experiences of our study participants. In most cases, traumatic events—death of loved ones, abuse, chronic residential mobility, incarceration, unemployment—were perceived as causes of a) initial substance use, b) chronic substance use, and c) relapses following periods of remission. Most participants describe licit and illicit substance use as coping strategies for dealing with life stressors. With few exceptions, study participants report high levels of personal responsibility and accountability for their substance use and the consequences of their usage, even in light of substantial personal hardships. Despite it all, the individuals we spoke with displayed an impressive sense of resilience, determination to take care of themselves and their children, and a desire to do good in the world.

Theme 5: Intergenerational Substance Use and Abstinence Parenting

Family history of substance use was endemic among our study participants and was seen as a personal risk factor driving participant's own use as well as the (mostly) anticipated substance use of their children. The vast majority of participants described a history of alcoholism in their family, and many reported having parents or close family members with other substance dependencies, ranging from marijuana to methamphetamine to heroin and opiates. Participants suggested that genetic factors likely predisposed them to their own substance dependence and this left many to worry that these same risks would have similar negative impacts on their children. Despite parent's belief that their children were

genetically predisposed to use or misuse drugs, there was scant evidence that any of the over three dozen parents in our study intended to advocate substance use abstinence to their children. On the contrary, there was a widespread belief among the parents in our study—all of whom currently use substances or have a history of substance dependence—that substance use in childhood and adolescence is common, even normal, and generally unavoidable. Most hoped that by being open with their children about the harmful effects of excess usage and by discouraging more than recreational/or experimental substance use, their children would not repeat their mistakes. Unfortunately, this approach does not seem to be working among Iowa families, as there was evidence of an emergent third generation of children using substances.

Theme 6: Competing Narratives: Choice or Disease?

Cultures are defined, in part, by narratives, and the culture surrounding substance use is no different. The entrenched narrative is that substance use and dependence are choices, while the emergent narrative is that they are a disease. We found evidence of both narratives among our participants, though the ‘choice narrative’ was the far stronger and taken-for-granted mindset of the two. We heard frequent reference to the need for people with substance dependence to hit rock-bottom or otherwise experience an extreme event so as to ‘decide’, ‘choose’, or ‘see the need’ for behavioral change. Hoping and waiting for individuals with substance dependence to hit rock-bottom is a high-risk strategy that leads to increased mortality incidence, child removals, incarcerations, unemployment, and homelessness, each of which is attended by high collateral damage to families and communities. To the extent that public health can replace rock-bottom or choice ideology with disease ideology, treatment services and interventions may come earlier and with greater effect than what we have seen to date. If substance

dependence is a disease, people should stop waiting or hoping for a ‘stage 4’ diagnosis before they are willing to act.

Methodological Insights

Before the ethnographic sample was selected, a rigorous quantitative assessment of the social, economic, and demographic context of substance use in Iowa was conducted. These results were used to identify communities at highest risk for substance use, develop an interview protocol to address the context of risk and resilience around substance use, and establish criteria for selecting respondents. As part of this work, three methodological findings of note emerged: First, in order to identify high risk counties from which to draw our sample, the ISU team developed and tested a county-level health risk indicator that produced a reliable measure of county health and shows strong similarity to the vulnerability index commissioned by the Bureau of HIV, STD, and Hepatitis (see Figure 1, p21). This ISU index provides additional support for valid items that might be included in a future IDPH surveillance system. Second, we found that multiple case-selection sampling strategies were needed to reach the diversity of vulnerable populations comprising the community of substance users in Iowa. Our use of a) state program participation registries, b) community action service provider networks and programs, and c) local, non-governmental organizational networks granted the ISU team access to a wide range of current and former substance users, especially in rural places. Finally, \$40 Walmart gift cards proved to be a highly effective incentive among the target population. New policies regarding the use of gift cards to access hard-to-reach populations could be key to ongoing surveillance of this group.

An Ethnographic Assessment of Drug Use among Iowa Families

NARRATIVE FINDINGS¹

Victoria is in her 30's and identifies as Latina and White. She sits across from our interviewer on her sectional couch in her small but tidy apartment in Council Bluffs. Throughout our interview, Victoria is open and engaged, telling a story that is unique because it belongs to her, but emblematic of many of the themes we found in the analysis of these interviews. Victoria wears a turtleneck sweater with two drawstrings at the neck, and throughout her story-telling, she involuntarily pulls at the strings.

Victoria was born in Illinois but moved to Iowa as a young girl. Her childhood was marked by family substance use, residential instability, and sexual abuse. Victoria knows little about her mother other than that she used illicit substances during her pregnancy with Victoria; Victoria and her three sisters lived with their grandmother until Victoria was five, when her father remarried. Her step-mother had six children, and the nine-child, two-adult, blended family moved into a two-bedroom trailer. The situation was bleak: Victoria experienced sexual abuse at the hands of her step-grandfather during her early years, her father was physically abusive, and her step-mother was verbally abusive. All the siblings spent some time in the foster care system. When she was at home with her family in her early- and mid-teens, Victoria had several sexual relationships with much older men who were frequently in and out of the trailer. The adults in her life encouraged her to drink early on.

Victoria met the father of her older two children—now seven and nine—and intentionally became pregnant to escape from her life with her family in the trailer:

¹ See Appendix A for an overview of documents and articles reviewed for this project. See Appendix B for a detailed breakdown of the demographic characteristics of our participants, and Appendix C for an overview of the interview protocol. A detailed description of our design and methods can be found in the next section and in Appendices D and E.

And then basically the only way I thought I can get out of that whole situation is by getting pregnant because I know [my stepmother] would kick me out if I did. So I got pregnant on purpose with my first daughter...

Victoria and her partner moved in with his mother, moving for a brief period to California. The relationship with the children's father quickly became abusive. She was regularly raped and beaten by this man, and turned to marijuana to help her cope:

So I was just kind of stuck there you know and I lived with him and his mom and I didn't want to go back to the trailer because I knew what would happen, you know with all that crap. So um, I started smoking weed because I noticed that that calmed me down a lot, like really, really calmed me down and I liked it.

At age 19, Victoria decided the situation was untenable and applied for housing assistance to move herself and her children into their own place. She told her partner's mother about her plan, and the mother "sabotaged" her:

So I went in there and I, I took one hit of weed and she was video camera-ing, had her phone out and was videotaping me the whole time doing this. And while she was doing that, I didn't know because I was already drunk, and then she showed Dee and then Dee showed the cops and then the CPS got involved.

Victoria was distraught. It was at this point in her life that she her substance use moved beyond alcohol and marijuana to a protracted period of methamphetamine usage. Victoria tells us story that echo's what we heard from numerous other study participants: Substance use escalates following traumatic events and is viewed as a way to cope with life's hardships:

I was nineteen. I quit both my jobs. I was homeless, I was just staying with a friend that lived in Oakland and I was smoking a lot of weed. I noticed that wasn't helping anymore, then I ran into my friend Dave, um, who was making methamphetamine. And he was basically like, "Well, I'm tired of watching you cry. This is fucking stupid." Sorry for me cussing, but that's what he said. And he's like, he's like, "Just try this," he's like, it's called, what he makes it's called Annie. So it's different from ice, what you call on the street, you know. So he's like, "Just try this and I swear to God you won't cry over anything, you won't have any more feelings." And I was like, "Well, how do you do it?" And he showed me how to do it, and I, I smoked it on foil and then he was right, I didn't, I didn't care about anything.

After moving back to Iowa, Victoria met a much older man—he was 46 and she was 19—and lived in a “drug house” with him for the next eight years. These years were defined by heavy meth use and fighting, stints at a domestic violence shelter, and heavy drinking. Finally, Victoria decided she’d had enough. She decided to become pregnant so she could “stop doing drugs”:

I [got] pregnant with Steve who I've known my whole life, since I was five years old. And I basically told him I wanted him to give me a baby so I could stop doing drugs because I don't want to do them anymore. So I did, he did.

Though she continued to drink after the birth of her second son by Steve, Victoria stopped using other substances. Then, after one “slip-up” with meth, CPS got involved, and her younger two children were taken away. Victoria continued to drink while her kids were in foster care. During this time, she met her current husband, and they married two months later. Together, they have quit drinking, and he has helped her purchase a car and get her kids back, four months after they were taken away.

We were together for two months and we got married this year, February, February fourth.

Yeah, uh, we quit drinking. We, well at first we were drinking really, really bad. And then when it was getting close to time to get my kids back I was like, "You know what? I don't want to drink anymore. I'm done. You know, I just feel like shit and I don't want my kids to see me like that. I just want to be healthy." So we stopped drinking together ...

Victoria recognizes that she didn't fight particularly hard for custody of her eldest children, and chalks it up to making the choice to party over making the choice to raise her kids. One of the things that makes Victoria proud these days is that she met and exceeded the DHS requirements to get her two youngest kids back.

So overall experience, I want to say definitely ten, versus my first [DHS experience] which was like a negative ten, because I didn't even try, I was so fucked up. This time I messed up one time and that's all it took, and you know, I got a second chance and I wasn't going to blow it, and I didn't. And normally cases like this happen, six, like six months or years, I mean years. ... I got my kids back, they took them in November, so December, January, February, March. Four months, I got my kids back, yeah. Because I worked my ass off, like I said, I mean I worked and worked and worked and did everything they told me to and I was open and honest and I would always go to my drug screens, all of my classes. I never missed a class, I went every Tuesday and every Thursday and I completed the sixteen weeks. And you have to do outpatient, uh, therapy there too and I never missed any of that either.

Victoria's current life is the most stable it has ever been, but it is still marked by some financial insecurities, some of which stem directly from her substance use: she doesn't have a license because of the years of DUIs, still owes quite a bit of back child support, and still has many fines to pay off for the state. This led to a lower tax return than she and her spouse had hoped for:

When we did taxes this year we didn't, we only got two thousand ninety dollars back because um, they took five thousand dollars from my student loans and I'm all caught up except for like one hundred and ninety dollars which I pay thirty bucks a week, or Mark pays, Mark makes me out a money order and I give it to them. So I only owe that much money left, thank God, and my child support is all caught up from all those years I was all messed up and I didn't pay. ... So next year hopefully will be better and I can, you know, think about better, or paying my fines off so I can, you know, get my license back.

Victoria is hopeful, though, that she'll be able to stay clean and get her family out of their current circumstances:

Hopefully out of here. [laughs] Hopefully out of here and I want, I want, I want a job, like I want a career. Like I just don't want to work at Subway because that's where I'm going after [the interview]. But I mean I don't see that as a career, but I mean I see, I want to be like a dental assistant.

Victoria's story speaks to the themes that we found in interviews with Iowans from all over the state who have had issues with—indeed, lives often built, demolished, and rebuilt around—substance use. In this report, we focus on six emergent themes: 1.) Social Isolation and Stigma; 2.) Economic Vulnerability; 3.) Substance Use Harms the Stability and Well-being of Iowa Families; 4.) Trauma, Coping, Accountability, Resilience; 5.) Intergenerational Substance Use and Abstinence Parenting; and 6.) Competing Substance Use Narratives: A Choice or a Disease?

Theme 1: Social Isolation and Stigma

Sam and Bill describe meeting at a “drug house” where they both use to buy drugs, and were together for five years while they were still using. During that time, they were literally “off the grid”: they had no running water or electricity, and were able to afford rent only because they lived in a house—just outside Des Moines—more or less gifted to them from Bill’s mother. Five years into their relationship and after the birth of their daughter, they stopped using, with a few “slip ups” since, as Bill describes:

...you've got to be ready and if you're not ready, you're not going to quit till you're really ready. Um, nobody does and I think that's really the key to it. If--if nobody--if you're not gonna be, you know, if you're not willing and ready, then you're not gonna--you're not gonna be successful.

One of the ways Sam and Bill have attempted to make their move from the world of substance use to abstinence successful was a residential move to get away from the people they were using with, including the environment in which they had been using. Now the couple lives in a small town in southern Iowa, where they are struggling with feelings of social isolation and stigma because of their past use. Sam acknowledges feelings of physical isolation, as well as social isolation, after their move:

That was a hard adjustment for me moving from a city to a small town like this not knowing. You know I mean I spent several years just back in the back bedroom. Didn't come out. ... You know, not everybody agrees with-with what I've done in my life, you know. No matter what my story is people aren't always--especially in a small town like this, people don't really to accept that [laughter] so, you know.

Bill cites the religiosity of the surrounding community as one of the reasons he feels judgement from his neighbors. The couple does take their daughter to church, and they talk about attending regularly, though Bill’s job in a meat packing plant is another reason they are socially isolated:

By the time you work six, six days a week you know the thing is this, ok uh like say two weekends a month they do, they do Saturday cut and kill. The two weekends a month they do Saturday cut and kill, I don't get no weekend I don't get no weekends off. I don't get no days off. Uh, because I'm already going in on Sunday morning and working four hours minimum.

Like Bill and Sam, many of our participants described acute social isolation (e.g., from incarceration, job loss, and frequent stays in treatment/rehabilitation centers) as a result of substance use. This isolation is particularly poignant when they transition back to the “real world” after treatment or when they stopped using substances. Though the observation of this isolation and judgement was outside the scope of our study, we take the respondents’ reports at face value that they perceive this judgement from their communities, and that they often self-isolate as a defense mechanism. This self-isolation defense may help them avoid relapse into substance use, but it leaves many of the people we talked to lonely and without much community. To the extent that they remain socially isolated, many will experience decrease mental health, including social anxiety and depression.

This is a problem perhaps specific to the geography of Iowa. For example, Lolly describes how treatment was a very positive experience, full of supportive people who had lived through substance use similar to her own, and who were able to support her in her recovery. When she returned to her hometown, however, she realized how isolated she had become from this support network, as they had spread out across the state. She felt judged by the people in town who knew about her struggles with illicit substance use:

I just felt guilty or like everyone...I felt like, because this town is so small, like, everyone thought I was a piece of shit or something, you know. Because of what was going on, or...I just felt like I had a bad name at that time.

Presently, Lolly's isolation is impacting her mental, emotional, and financial health as well:

I'm stuck here without a car. I don't have a job. I don't go to church. I'm going fucking crazy, honestly. I am. Like, I gotta do something. It's driving me nuts.

Many other study participants describe lives characterized by chronic social isolation, in which social networks are stunted or non-existent due to the effects of substance use. This includes the loss of old, 'clean' friends during and after use; loss of high-risk substance use friendships during remission; forced or voluntary moves to new; foreign communities, little contact with churches or civic associations; and the attendant stigma associated with substance use and its effects (e.g., gaining an identity of being a felon or 'addict'). Social isolation feeds loneliness, depression, social anxiety, limited social capital, weak support networks, poor job prospects, or just acute boredom, each of which is a risk factor for relapse.

Finally, many respondents described childhoods, adolescences, and early adulthoods feeling isolated, unrooted, or otherwise different in their communities. This often led to early experimentation with alcohol and marijuana to "fit it", as was the case for Kelli from West Des Moines:

I never really felt like I'd fit in anywhere, you know. And, um, I was pretty shy. Um, and I think that that had a lot to do with the way I reacted to different situations and scenarios and stuff in my life, and, um. So, I started, I started drinking at like a young age.[...] So, I was hanging out with people, uh, older people because they told me to like--Well I always used to hang out with older people. But they, I fit in better with them. I mean the kids my own age, um, or I was always, again, the one that was like shy or whatever. And I never, they would, I would get offered drugs a lot, but I never did it. Like I'd be like, "No, I, I don't think so." And then one day, um, I just decided like, okay, I'm gonna try it. And I remember it was, um, when my parents divorced, like when they separated. And, um, so I thought okay, I'm gonna try it and, and I liked it.

Indeed, many of our participants described experiences using alcohol or marijuana to be cool, fit-in, or otherwise facilitate socialization in rather “boring” Iowa adolescences; often, their first entrée into “harder” substances occurred when their inhibitions were lowered during use of alcohol or marijuana.

Elizabeth describes how this happened for her:

Me and [my partner] lived out in the country and some guy came over when we were drinkin' and he had [meth]. Which I didn't even know this guy did it. He just kinda pulled it out. Yeah. And I tried it. [Sniffing] I think the alcohol kinda helped me try it with that one.

The power of social isolation and stigma is present during the entirety of the substance use cycle, from entrée, to “rock bottom”, to recovery, to staving off another relapse.

Theme 2: Economic Vulnerability

Vincent and Elizabeth met when Vincent was 16 and she two years his elder during a party at his parent’s house; mutual friends and siblings connected them. Both had already experienced the shadow of economic vulnerability, and Vincent, at least, had experienced the correlate of substance use. Elizabeth grew up in a trailer park with her mother, three sisters, and stepdad, though she didn’t know he was not her biological father until she was 11 or 12. Vincent had what he described as a “normal” childhood until he was about 13, when both of his parents lost their jobs as a result of rapidly escalating substance use. While his older sister used her meagre wages to buy his school materials, Vincent started noticing things disappearing around the house; when his father went to jail for the first time, Vincent was 18, and learned that his parents were using—and selling off the family’s possessions to afford—illicit substances.

Elizabeth got a trailer and Vincent moved in with her around the time he graduated high school, after which he went to work for her dad. Vincent completed high school because Elizabeth encouraged him to stay the course even though many of his friends were skipping and dropping out. About a year after Vincent graduated, Elizabeth got pregnant: it was an unplanned pregnancy. Elizabeth stopped using substances for the pregnancy and up to a year after their daughter's birth, though Vincent continued to use. Both Elizabeth and Vincent had an incredibly close relationship with Vincent's mother. However, his mother passed away, and Vincent and Elizabeth both began to use heavily at that point (see section below about Trauma and Coping.) To deal with the grief of her death, they both began using even more, and they permanently moved into his mom's house because they could make relatively affordable payments.

The substance dependence took a huge toll on the couple's finances—Vincent's meth addiction led him to try opiates, which he found made the meth withdrawal easier. He then started using a needle to administer his opiates, as he found that he could get a better high for less money. However, this switch made it harder for him to keep a job, and this lack of funds led to criminal behavior.

Elizabeth and Vincent split up for some time, and during this time Elizabeth went to treatment at Hope House, taking her three children to the treatment center. The couple is now together, have both stopped using substances, and are trying to parent, though they are continually dealing with the literal financial costs of their past substance use. As Vincent says:

Like just cause when you're a recovering addict, you know you're going to have a lot of things from your past that follow you, you know, whether it be unpaid tickets, fines from things, um, fines from, you know, crimes that you've committed, any of those things. And if you don't pay 'em, they'll, they can take your license. They can take property. They can do things like that and when you're trying to get clean and build up your life, one small thing like that it can really, it can

really, you know, ruin your mood and your outlook towards recovery and just make you want to give up.

Though neither Elizabeth nor Vincent have “give[n] up,” their ability to improve their financial situation and take part in several of life’s significant milestones—namely marriage—is still hindered by past issues with substance use and their subsequent fines. They have agreed not to get married until they pay off their fines, get their licenses back, and “have things the way it’s supposed to be when you get married.” The financial hardships described by Vincent, and echoed in different ways by many of our study participants, represent significant risk factors for substance use relapse.

Illicit substance use and bad jobs—another source of economic vulnerability for Iowans—are also associated in stories our participants tell. In several instances, respondents describe substance use as an integral, and rational, strategy to meet their financial and familial responsibilities. Bill describes how meth use helped him to reconcile the competing demands of long hours at the local meat packing plant and his desire to be a supportive husband and active, engaged parent:

Seven years ago, I went to the shipping department out there and ah I was working. My first week, when I worked in shipping, I worked seventy-nine hours that week and it was like...On the average, I worked sixty-nine to seventy-five hours a week. I never got to see [my family]. I worked second shift. I never got to see them ever. So that was part of the reason I used then was because I could come home and stay up and visit with [my partner] all night. At least, at least get to see her and then baby would get up to go to school in the morning, and I'd be able to see her you know. [...]. But otherwise I'd fucking go in there and work twelve, thirteen hours, come home and go to bed and sleep right up until time to go. Get up to take a shower, get on my clothes and go to work. I missed everything.

Peter's work stories were similar to those we heard from Bill—both described a physically and emotionally challenging workplace, with long hours—but in Peter's case, he gave greater emphasis to the dangerous conditions and the ready availability of illicit substances in Iowa meat packing plants. Peter also reported that he and his coworkers often used drugs to get through the day, with he and coworkers from a variety of different communities spending meager factory wages on any number of illicit substances flowing in and out of the workplace:

I mean like we were working some days seven days a week. You know. I also started get like...I, I, ah, resin burns on my arms from workin' there. You know. So that's when the...I don't know, the whole pain pill thing hurt, you know. And then you wouldn't notice them or anything and if you're high on methamphetamines then you definitely didn't notice them. You know. But, yeah, I worked there about four years. ... That's where um [drugs] were so plentiful. Like you could find anything you wanted. You know. You had people workin' there that came from Marshalltown, that came from Newton, that came from Grinnell, came from Des Moines. You got so many different communities. Lot of drugs. Lot of drugs out there. Yep. And that's where, and that's where it really, yeah, it really took off. It, you know, especially methamphetamine stuff like that, you know, and the pills. That's, that's really where it took off.

Many of our participants—especially those who had frequent interactions with the criminal justice system—understood well the problem of working in jobs that were dangerous or difficult because they could not find stable, high quality employment because of their criminal record. Whereas jobs in the healthcare field are growing and relatively well-paid (and would promote economic security), felonies will preclude many of our respondents from this kind of employment. Emily, for example, wants to become a Parent Partner because it is one of the few jobs she perceives that her criminal justice history will allow her:

I want to go back to college but regardless if I go back to college or not, like my background is going to stop me from getting any job that I want. And that's what sucks. It sucks bad. Cuz regardless, I mean regardless my backgrounds. And I don't know if I can get certain things expunged off my record if they do a background check. Because that's usually how it goes whenever I get hired for a good job. My background is what stops me when they do a background check. So, that's why I always get stuck working shitty ass jobs.

Substance use is strongly entwined with economic vulnerability in the lives of our respondents as both a cause and effect. For example, many people we interviewed with a dependence on substances have experienced chronic resource deprivation, including extreme residential instability and homelessness (e.g., couch surfing, living out of cars and motels, losing homes), reliance on theft and charity to make ends meet, transportation hardship (e.g., loss of driving privilege or vehicle), pawning personal possessions, limited labor market opportunities (e.g., due to felonies, low wages, few marketable skills or training), and state-imposed fines and fees. These economic stressors increase risk of substance use and often catalyze relapse. As a result, successful substance use policies in Iowa will need to also address economic vulnerability to achieve a lasting change.

Further, the timing of those economic supports might be most effective when administered during periods of transition. In particular, those first days and weeks after a successful period in treatment should be the most hopeful time in the life of a person recovering from substance use. Instead, we find this is often the loneliest, most financially difficult, and hopeless period, providing a social and economic account for high mortality in the weeks and months following release from corrections and treatment facilities. As Vincent reminds us, when a person recovering from substance dependence must focus on paying fines and recouping financial losses, as opposed to the possibilities that life without substances poses, hope diminishes, or even burns out.

Theme 3: Substance Use Harms the Stability and Well-being of Iowa Families

Jessica, from Fort Dodge, grew up in a severely unstable family situation. Her father, who was 70-years-old when she was born, had been married six times previously, and Jessica was abused by one of her older stepbrothers. Jessica started using alcohol when she was 13-years-old, and by 17 was using crack cocaine. She had transitioned into methamphetamine by the age of 19. As she tells it, it was with her stepsiblings that Jessica first began experimenting with meth.

It was also around the age of 19 that Jessica entered into an abusive relationship with a fellow meth user. She became pregnant with their first child:

Um, during...during pregnancy was rough, um, a lot of abuse. Um, and the main...the main thing that I remember is being choked out, um so. Moving on from there um, the abuse just got worse and worse and worse and then I got pregnant with our...with our daughter in 2013. Um, so while I was pregnant with our daughter, um, I had been punched in the back around I was seven months pregnant and I'd...I'd had enough, I called the police and he was arrested.

When her partner was released from jail, Jessica took him back, but the intimate partner violence continued until he was eventually arrested on charges of child endangerment for throwing their young son across the room. Distraught, Jessica dove even deeper into substance use:

Um, so my methamphetamine use, it was spiraling, I was still using all in...during the time...I didn't use while I was pregnant with my son, um, I used a lot of methamphetamines while I was pregnant with our daughter. Um, so and she never tested positive for methamphetamines when I had her, they didn't take her so things just kept gettin' worse and worse and worse for me and I kept, um you know neglecting. As you're using methamphetamines, you're not a good mom. I wasn't a good mom while I was usin' drugs, that's just that. Um, in 2014, I, uh had a DHS call on

me of my methamphetamine use and I finally admitted to them that I had been using, um and that I needed help.

During the next few years, Jessica's children were in the foster care system while she was in treatment, during periods of substance use relapse, and while she sought treatment again. At the end of her final treatment at the YWCA in Fort Dodge, Jessica's children were allowed to join her in the inpatient program. Here, she was able to set up resources for herself and her family even after the treatment ended. Presently, the family is living with Jessica's mother, who helps out a lot now that Jessica is no longer using and has returned to school.

Other participants, like Melissa, have suffered the harmful effects of deep rifts with their families because of their illicit substance use. For many of our participants, an important part of the journey back from prolonged substance use is the attempt to repair damaged kin relationships. For others in our study, the journey required them to accept the loss of once close family members. Melissa started using alcohol and marijuana when she was about 14. At the beginning of her college years, Melissa's friend offered her meth, and she tried it. She went to bed and "woke up a full-blown addict." Melissa began using every day, and missed the death of her nephew to leukemia because she was cooking meth with her boyfriend. When her grandfather was dying of kidney cancer, she stole his pain pills and sold them to feed her substance dependence. Her family still feels resentment toward this time:

There's some family members that point fingers at me for stealing my grandpa's pills and you know, I've kind of forgiven myself for that and I just have to accept that. Yeah, I stole those pills and as soon as they ask me about it, just comes out honest and you know, I did the next brave thing after doing all the wrong things.

Melissa's substance use—and eight drug charges that followed—led to the removal of her young daughter from her care. DHS placed Melissa's daughter with her aunt, who ended up trying to adopt the

child without being upfront about this with Melissa. The removal of her daughter was a wake-up call for Melissa. She went into treatment. After three months at House of Mercy, she was able to bring her daughter to live with her there and regain custody. Melissa has not used substances for the last two years, but is still terrified of losing her daughter again, even though she has completely changed her lifestyle. Her aunt and uncle are still some of the only family sources of support in Melissa's life, due in no small part to the many burned bridges with other family members during her years of using.

Family-of-origin substance use sometimes set in motion the events of our participants' substance use histories, and the respondents' substance use drove many into self-exile from their families, both nuclear and extended. Abby describes her self-exile from her family that was fueled by—and in turn fueled—her substance use:

I never really got in trouble as a kid. I did get in trouble when I became an adult, though. That's when I started to really, kind of, I don't know, seclude myself from my family, you know. My mother got remarried, had another baby and I just didn't like it. I was, I don't know, I didn't... I wasn't happy. So, I was looking for something to make me happy or give me the attention that I, that I wanted. So, I got pretty into the drug scene for a while.

Largely owing to stigma, but also attributable to concerns over drugs being a 'contagion' that would infect other family members, many of our study participants have been banished from their families (e.g., eliminating contact with kids, parents, and siblings, or disinviting from family gatherings and events). Divorces were attributed to substance use as well, as were child separations, domestic abuse, and loss of intergenerational contact with nuclear and extended family members. Lolly, for example describes how her family has been hesitant to include her in their larger life, even after she sought treatment for substance dependence:

Even when I was in treatment, like, they were happy I was there, but got to go on a furlough, or whatever and I wanted to go to Christmas, because I hadn't been for the two years, and they were like that's good, you know, we'll see you there and like two days later they called me back and they were like "Oh we just think it's best if you don't come". So, I don't know, I've just kind of tried to stay away from them because I'm never good enough or whatever and they just keep bringing me down, so.

Often, the respondent's children are negatively impacted by the residential and family instability that stems from substance use. Sam describes this "spiral":

Um, so therefore, things just kind of spiraled out of control for me and then next thing I know, um, I don't have any rights to my daughter anymore and, um, when something like that happens, you continue to bury yourself in your use to forget about it and I think that's what I did for many years, um, many years and throughout periods of time of quitting and going back using and quitting and going back to using throughout my life.

There is much attention in the popular press and in government reports to the harmful effects of the substance use epidemic on communities and states. Additional attention is given to the many powerful stories of individuals all across the country who have been damaged or lost their lives as a direct consequence of the substance use epidemic. To date, far less attention has been devoted to the effects of substance use on American families. Data collected in our study reveals that families throughout Iowa have been devastated, even in cases where only a single family member struggled with substance use. Policies geared toward Iowa families would do well to have a clearer understanding of the myriad ways in which chronic substance use harms families throughout the state.

Theme 4: Trauma, Coping, Accountability, and Resilience

Lolly was born in Iowa, and her parents split up when she was four-years-old. She and her mom moved around a lot, and her mom eventually married one of the many men who came in and out of their lives. Lolly was sexually abused by her grandfather when she was a child, and she was estranged from her father because he was an off-again, on-again, ward of the state prison system during her childhood. Lolly describes herself as have been a “goody two shoes,” but eventually, all the moves and the trauma from her childhood built up:

Drinking. I didn't do anything until like, I was a goody two-shoes until my Mom moved me back here. I was like, tired of moving, starting over. I was a freshman, you know, trying to fit in.

Everyone was drinking, so I started drinking. And then, drinking led to everything else. Yeah.

Lolly tried other illicit substances during this time in high school. When she was 19, Lolly lost her mother to suicide, though she contends that her mother was actually murdered by her stepfather. That same year, Lolly gave birth to a son—her first—by her longtime boyfriend, who was three years older than her. When Lolly realized she was pregnant, her lifestyle changed and she stopped using substances during the pregnancy:

When I got pregnant with my son, like, I found out I was pregnant. We were all going to a party that night and I'm like, well, I'm done. Like, I quit everything, didn't do anything for ten or twelve years.

Though Lolly calls her children's father a “great dad,” she also calls him a “whore”: He regularly cheated on her throughout their 14-year relationship, even after the couple married around the time of Lolly's 23rd birthday. Though their lives were outwardly good, Lolly couldn't take the infidelity any more:

Like, I was an awesome Mom and we lived on his family farm, like it was all his family out there. It was awesome. Me and his Mom were best friends, his family was more of a family to me than my own family. You know. ... [But] I left him.

When Lolly left her husband, she also lost custody of her children. This, she says, was the beginning of a slide back into using alcohol and other substances:

Like, when I didn't have my kids, I started drinking, and you know, then it, then it just led back, over six years, it led back to other stuff.

Lolly has recently gotten out of treatment and feels isolated in her life, but is looking to get a job, a car, and enjoys spending time with her children, who are now 16 and 22.

Lolly's story is, unfortunately, not terribly unique in our sample of Iowans. Trauma was prevalent in the childhood and life experience of many of our study participants. In most cases, traumatic events—death of loved ones, abuse, chronic residential mobility, incarceration, unemployment—were perceived as causes of a) initial substance use, b) chronic substance use, and c) relapses following periods of remission. Most describe licit and illicit substance use as a coping strategy for dealing with life stressors, of which there were myriad.

Like Lolly, Bill lost his father during childhood. He found his father, to whom he was particularly close, dead when he was about 17-years-old. Bill, who occasionally used alcohol and meth recreationally, sank into chronic substance use:

I lost my father. I lost my fuckin mind. I didn't give a shit about nothing I didn't want to live or nothin. Day in day out from that point on for ten years was spent in the pursuit of methamphetamine. Anything, cocaine methamphetamine alcohol anything that would make it go away. Anything. I just could not deal with the grief. I didn't want to live or nothin. I didn't give

a fuck. [...] I felt grief no doubt about it. I just didn't have any way to deal with it. I needed the distraction. That's the only way I could make the fuckin pain go away is to distract myself

Other participants detailed stories of losing friends, losing parents, of sexual or physical abuse at the hands of friends and family, and other traumatic, impactful experiences during their childhood. Most of our respondents cite these experiences—as well as the dependence-creating nature of substances—as one of the main triggers for their substance use. In citing these events, our participants were rarely attempting to place blame or otherwise avoid responsibility. On the contrary, the Iowans we spoke with embodied core American values of personal responsibility and accountability for their actions.

With few exceptions, study participants report high levels of personal responsibility and accountability for their usage and the consequences of their usage, despite substantial hardships beyond their own control. Despite it all, the people we spoke with showed an impressive resilience, determination to take care of themselves and children, and a commitment to do good in the world. Bill describes this well:

And like I said you gotta grow up sometime. Something's got to be more important than that and then your wife and your family's got to be more important than drugs your drug and your drug than your vices. So that's why I made the decision I mean shit uh she had been fuckin clean for oh a long time and fuckin slipped up. It is what it is. You stumble and fall and you get back up and move on.

Bill's attitude, to just get back up and keep trying is emblematic of the attitude of many people with whom we spoke. Working hard, taking responsibility, and never giving up on the hope of substance use remission and reunification with family members is among the single most unifying attributes of the people we interviewed.

Theme 5: Intergenerational Substance Use and Abstinence Parenting

Amy has spent her whole life in Iowa. She lived with her mother and her three siblings until age nine, when the children were taken away because of their mother's illicit substance use and other reasons:

I was like nine and my mom's house got raided or whatever so we went to a foster care for a few months and then after that we went...my grandparents got custody of us. And I don't...I guess I was too young to be really involved in much, but, um, we just stayed with my grandparents after that for a while.

Around this time, Amy also started smoking marijuana, and had already started smoking cigarettes that were easy to access in her mother's house. By age 13 she was drinking, and by 15 she was smoking meth. Though Amy stopped all illicit substance use when she found out she was pregnant at age 16, she resumed after her second child was born. Recently, her youngest child (of five children) tested positive for meth and marijuana at birth, and Amy went to treatment. The treatment program eventually allowed the children to come live with Amy. Though Amy finds it hard to remain substance free because of her old networks and social isolation, she regularly attends NA meetings. Her mother, on the other hand, is still using.

Family history of substance use was endemic among our study participants, with more than three quarters of those we interviewed having described a history of substance use in their family. Most described a history of alcoholism in their family and many had parents or close family members who also had illicit substance dependence. Many saw these as personal risk factors for them and for their children. Participants suggested that genetic factors likely predisposed them to alcoholism or dependence and this left many to worry that these same risks would have similar negative impacts on their children.

Maria, for example, is Victoria's sister, and grew up under the same regime of instability, abuse, and access to substances. Maria's father was an alcoholic, and her sister Victoria introduced her to meth. By age 11, Maria was using marijuana and alcohol regularly. Maria had children early in her life and has since lost custody of them to their father, due to her substance use. Now, the two oldest live with their father and his new wife, and Maria describes how it is difficult to watch their childhood unfold much like hers did:

Like their home life? Oh because it's like me watching me all over again. [...]. Like you know but I can't literally help them or take them away. But um so yeah, it's just kind of shitty there. Just literally I just see my, them living my life like when I was little. It sucks.

Amy also sees some of the same issues that led to her substance use as systemic for her kids: there just isn't a lot to do in their small town, and alcohol and illicit substances are one way to find social connection or recreational activities:

Well, there's really nothing else to do when you're like fourteen to twenty-five there's really nothing to do. Once you hit twenty-one you can go to the two bars that we have in town, but there's no like skating rink. Like my kid right now, she's really rebellious, but she's kicked out of the library because they weren't studying like there's no place where they can just sit and hang out. They were...and they were just using the library for that and the library kicked em out cuz they weren't using the space appropriately. Well, there's nowhere for them to go so.

Though it was during supposedly innocuous usage of alcohol or marijuana that many of our participants' first tried meth, cocaine, or opiates, there was scant evidence that any of nearly 40 parents in our study intended to advocate for substance use abstinence to their children. On the contrary, there is a widespread belief among people with current or history of substance use or dependence we interviewed that alcohol and substance use in childhood and adolescence is common, even normal, and

generally unavoidable. Most hoped that by being open with their children about the harmful effects of excess usage and by discouraging more than recreational or experimental substance use, their children would not repeat their mistakes. Unfortunately, this approach doesn't seem to be working. Our data found evidence of an emergent third generation of substance use in Iowa families.

Rowan describes how her son started buying substances from the dealer she was using, even though one of her biggest fears was "my kids finding out I was using." She describes feeling helpless and "heartbroken" when her son admitted his substance use to her:

Yeah, he told me. Even when he first started using the pills and he'd come to me and he'd tell me he needed help, you know, and so I'd try to get him help, but then he'd change his mind. You know, and, um. Then he'd cry. You know, and I'd cry. And I really felt very helpless, you know. But once he first used meth and cried, and he cried, and he cried, and he cried, just. You know, I never wanted that for them. I don't think that, I don't think [my daughter] will ever have a problem with it. She, uh, I don't know. But I don't think so. But then again, I didn't think [my son] would either.

Theme 6: Competing Substance Use Narratives: A Choice or A Disease?

Vincent and Elizabeth both discuss moments of complete turns away from illicit substances, toward a life of family, sobriety, and growth. However, they use very different narratives to describe these moments. Elizabeth, who went to her first treatment after a DUI, eventually found sobriety during a second stint at Hope House, where she was able to live residentially with her children. Describing her experience of stopping to use, she says:

I wanted to be a better person. So I made the choice to try to stop using drugs and stuff.

Vincent describes his own removal from the culture of illicit substance use without the same kind of choice narrative. During the peak of his using, Vincent and his dad were using so frequently that Vincent was committing crimes to make enough money to keep them getting high. Though he had been in jail before, for a felony intimate partner violence charge, Vincent's stealing for money to access illicit substances finally caught up with him. He faced a choice between a long-term jail or long-term treatment. He did not choose to get off illicit substances, per se, but chose one of two options that both required this of him.

And it's crazy because you know the whole time I'm running, I don't want to get arrested. Once I finally get arrested and I get in that jail cell, I feel this huge relief over my shoulders knowing that I finally am you know I'm trapped. Like I can't go out and get high. I don't have to go commit crime no more. Even though I'm going to go through the withdrawal, it's still a relief cause I know I'm going to, I'm going to get off the drugs.

To Elizabeth, ending her substance use was a choice she personally made. Vincent, on the other hand, situates his end of substance use as forced. We see this different of narratives of substance use in many of our respondents.

Cultures are defined, in part, by narratives, and the culture surrounding substance use is no different. The culturally entrenched narrative is that substance use and dependence are choices, while the emergent public-health narrative is that they are a disease. We found evidence of both narratives among our participants, though 'choice narrative' was the far stronger and taken-for-granted of the two. We heard frequent reference to the need for users to hit rock-bottom or, like Vincent's time in jail, experience an extreme event so as to 'decide', 'choose', or 'see the need' for behavioral change. Bill describes rock-bottom like this:

Somewhere along the way everybody's got a rock bottom. Sometimes that rock bottom isn't their exact rock bottom. They have to do...it's got to be something you know. You know the more times that you get devastation through that I think...For me, you know I mean the more devastation I get over that drug, the easier it is for me to walk away from it. Um I don't know. I mean you've got to want a better life and if you don't, and if you don't have anything to live for or a better life to look at, look for...You know, if you don't have the ability to do so then, then you know...We know a lot of people that, that could have been so many things.

The rock-bottom narrative also comes out in stories of mothers who “choose” to stop substance use as soon as they realize they are pregnant. Many of our participants who are mothers described this process, particularly in their first pregnancies. Victoria, for example, actually asked a friend to get her pregnant with her third child so she could stop using. Likewise, Amy didn’t use until after her second child was born. This kind of ‘moment of enlightenment’ happens to many women when they first become pregnant. Participants who are parents often describe their rock-bottom as when the choice is between substance use and their children—at least in the short term, or the first time, they “choose” the children. As Ashley from Fort Dodge says, she stop substance use because:

My kids. Getting my kids back. Knowing that I had one last chance, um, with both of them basically.

However, subsequent pregnancies, and subsequent child removals, may very well create a lower rock-bottom. Many mothers describe using even through later pregnancies, and parents often do not have only one child removal in their past, even if it seemed like rock bottom at the time. Indeed, as Bill suggests, “sometimes that rock bottom isn’t their exact rock bottom.”

Hoping and waiting for individuals with substance dependence to hit rock-bottom is a high-risk strategy that leads to increased mortality incidence, child removals, incarcerations, unemployment, and

homelessness, each of which is attended by high collateral damage to families and communities. To the extent that public health can replace rock-bottom or choice ideology with disease ideology, treatment services and interventions may come earlier and with greater effect than what we have seen to date. If substance dependence is a disease, people and policy should stop waiting or hoping for a ‘stage 4’ diagnosis to drive change. Abby suggests thinking about substance dependence in terms of a disease to control, not completely overcome:

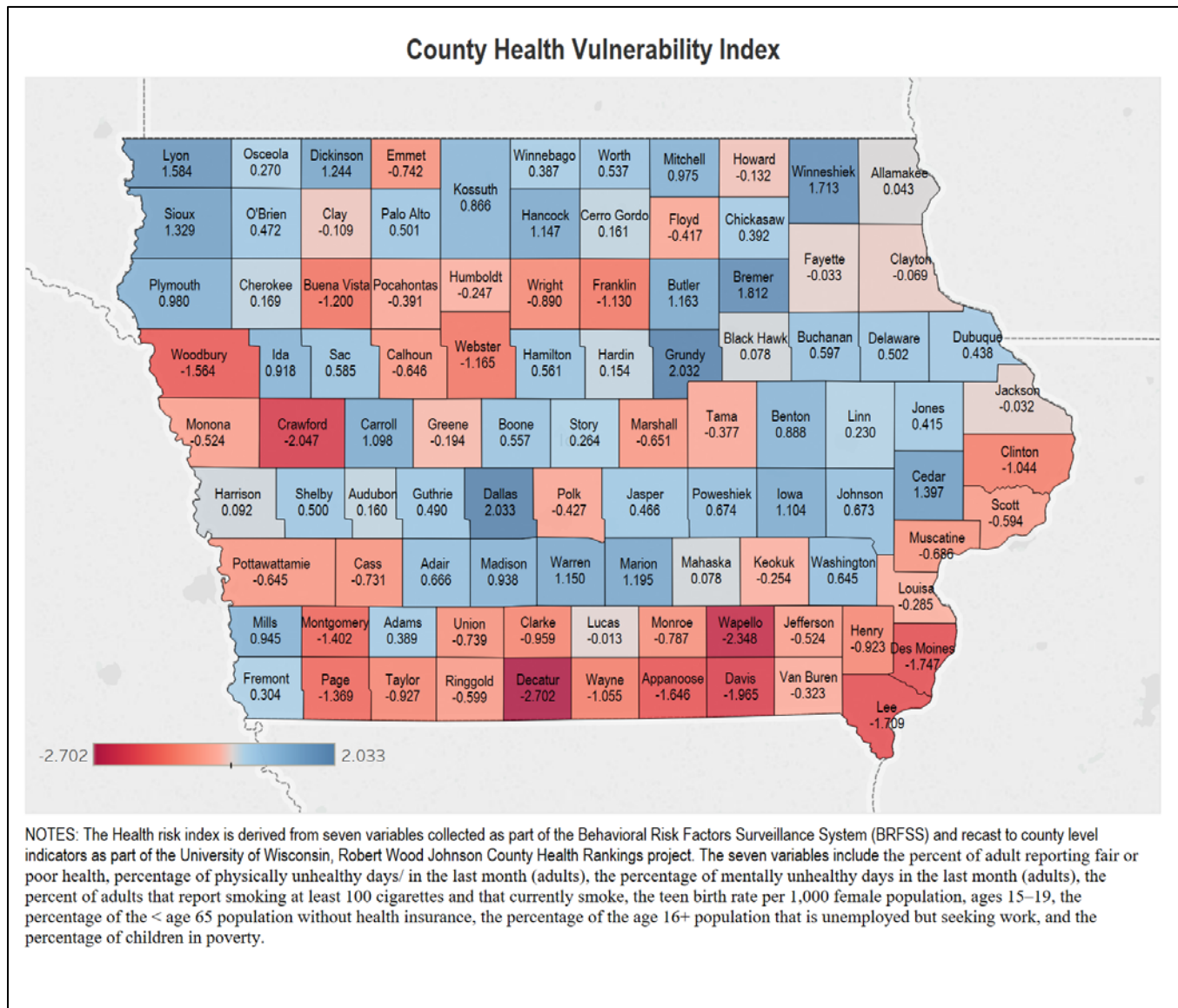
Cause the disease doesn't care if you're white, black, rich, poor, doesn't care where you came from. It affects everybody the same. I mean, for the most part, you know? Which, is sad, you know? I've seen many people die. I've had people in my family die from alcoholism. It's, it's a killing disease. It's kinda like dementia. You know? You can take your dementia drugs and it can control it to a certain extent and then, or diabetes even. You can take your insulin, but it's not gonna cure it. It's just gonna help maintain your life.

RESEARCH DESIGN

Conducting qualitative research among current and former substance users is notoriously difficult owing to the illicit nature of the behavior of interest. To aid in future research on hard-to-reach population such as substance users, our study deployed four distinct recruitment strategies and two incentives. We developed this strategy in part because the project budget did not allow for a state-representative sampling strategy, but also to test the feasibility of a multi-stage, geographically clustered recruitment design. This design was selected to meet our goal to target high-risk areas in which substance use prevalence was above average and in which both rural and urban areas were represented.

Prior to data collection, our team conducted an extensive national, regional, and state-based review of the substance use literature and data to understand historical and recent patterns of substance use, known risk factors, including both correlates and determinants of substance use, and documented effects of substance use on individuals, families, and communities (see Appendix A for a partial list of this document review). As part of this review, we collected a number of publicly available state and national datasets containing population-level measures of substance use, demographic events, social and economic risk factors, and health outcomes (e.g., BRFSS, RWJ county health rankings, CDC and Vital Statistics reports, and Monitoring the Future). We used these data to construct a **county-level health vulnerability index** (see Figure 1), which we paired with additional data to identify economically vulnerable counties. Collectively, these indexes and supporting quantitative data **revealed substance use ‘hot spots’ in Iowa where physical health, mental health, and socio-economic conditions were especially low relative to other parts of the state**. It was these areas of the state that we targeted in the sampling and case selection stage of our study.

Our data and literature review demonstrated that while Iowa has among the lowest opioid-related mortality rates and prescription rates in the country, it continues to have above average excess and binge drinking rates. The data also suggested that methamphetamine usage in Iowa poses a greater risk than opioids, at least in terms of usage rates noted in publicly available administrative data. The entire southern portion of the state was viewed as high-risk of endemic substance usage and disease outbreak. We also identified the Missouri river counties and the region centered on Webster County as high values areas for our study, given the high substance use prevalence rates and notable health vulnerabilities.

Figure 1. Iowa County Health Vulnerability Index

We focused our initial case selection on two representative areas of Iowa, one rural and one urban. The first is a rural micropolitan area that includes the southern corridor, comprising of the counties contiguous to Wapello (Keokuk, Jefferson, Van Buren, Davis, Appanoose, Monroe, Mahaska). These counties are characterized by below average education, above average poverty rates, and relatively high outmigration. The second area we targeted was the Des Moines metropolitan statistical area, which we expanded to also include the counties of Story and Marshall. This area is characterized

by rapid population growth from immigration throughout the state and the Midwest, high income and education, but also high health and income inequities.

In December 2018 and January 2019 our team held a series of meetings with administrators and staff working for a) the Bureau of Substance Abuse, b) three community action service providers that deliver substance use treatment services, and c) the FaDSS program within the Department of Human Rights. These discussions allowed us to informally survey expert opinions concerning the findings of our literature and data review and understand substance use in Iowa beyond what could be gleaned from government reports and data sets. Importantly, meetings with key stakeholders enabled those in attendance to contribute to the design of the study. We received valuable input in areas such as how to define the target population, how to identify, contact, and compensating participants, and in the development of the content of the interview protocol. Stakeholder discussions confirmed that methamphetamine usage has been a consistent problem in Iowa, especially in the southwest part of the state, and that alcoholism was a chronic issue in counties throughout the state. Stakeholders also identified trauma as one of the most significant upstream determinants of substance use in Iowa. Based on our discussions with IDPH administrators, it was resolved that a \$40 gift card to Walmart or Casey's gas station would be an appropriate compensation to our participants. (This exception to the general rule was approved by IDPH in December 2019). Our experience showed that Walmart cards were the more appealing option, with 33 out of 43 participants choosing the Walmart card. Future data collection with this population that uses these types of cards might obtain similar response rates with a somewhat smaller compensation (i.e., \$20-\$30).

INTERVIEW PROTOCOL

The ISU team designed and deployed a semi-structured interview protocol to help understand the social landscape of substance use in Iowa (see Appendix C for more details). Given our interest in substance use within a two-generational perspective, we also devoted a substantial portion of our interviewing to the ways in which families are affected by, and affect, substance use among our participants. With this approach, each interview began by asking respondents to tell the research team the story of their lives. We intentionally kept this aspect of the interview highly unstructured to ensure that participants were free to tell us about the key events, moments, and passage of their lives. Some respondents devoted little time to this question (around 2 minutes), while others responded to this question with little interruption or guidance from the interviewers for well over 30 minutes. In almost every instance, family members (including family-of-origin and family-of-choice), family life, and family events (e.g., births, marriages, and divorces) featured prominently in relation to substance use.

To the extent that participants hadn't already discussed them, we asked them to tell us about their family life, their community experiences and involvement, their job history and labor market experiences, their involvement with religious institutions, and the rhythm of life in a typical day for them. In no instance did our participants signal or state an unwillingness to discuss any of the topics contained in our protocol. Figure 2 provides a conceptual model of our interview protocol. The five topical areas of the interview protocol have strong cause or effect relationships with substance use, and collectively, attention to these areas gave us a broad and informed understanding of the social nature of substance use among Iowa families. During the interviews, we intentionally avoided in-depth discussion of their substance use. Instead, we focused the attention of our respondents on social and economic structures and life experiences *as they related to substance use*.

Figure 2. Conceptual Domains Comprising the Iowa Substance Use Interview Protocol

DATA COLLECTION

Field interviewing began on February 1, 2019 and continued through late August, during which time, a total of 44 interviews were completed (see Appendix B for a demographic description of participants and Figure 3 for an overview). Monthly interview totals included eight in February, 13 in March, seven in April, five in May, nine in July, and one in August. Many of the interviews conducted in February were obtained through visits by our research team to extended outpatient substance use treatment (EOP) sessions. In that approach, project leadership contacted administrators at treatment centers in three substance use provider regions and requested an opportunity to participate in EOP sessions. Where permission was granted, one or two members of our team attended EOP sessions as silent observers so as not to disrupt the normal flow of the sessions. We instructed our team members to listen for EOP

attendees who had history of substance use and ideally, had signaled or stated directly that they had minor children. After the sessions ended our team members approached select EOP attendees and invited them to participate in our study. From the EOP recruitment method, we completed five interviews via direct recruitment and an additional five interviews by way of referrals from EOP interviewees, for a total of 10 completed interviews through this approach. This recruitment strategy was important because it included many people in our study who had been remanded to treatment by the criminal justice system. This group included few current individuals who use substances, but nearly all had only recently entered a period of remission from substance use. From this method, we also obtained three ‘couples’ interviews. In the couple interviews, we developed a custom interview protocol designed to elicit the relationship history and the nature of substance use within the relationship, including its effects on their family life.

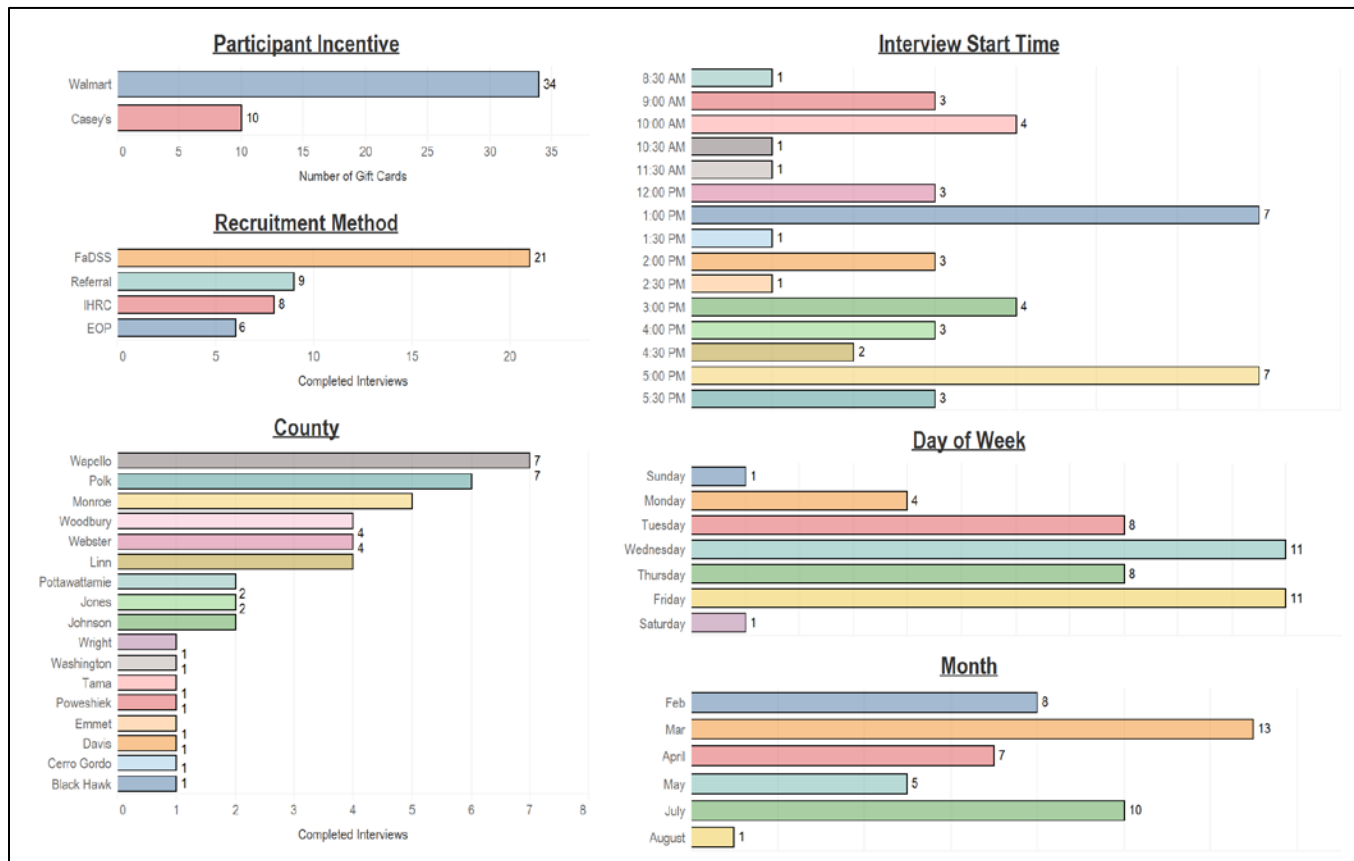
By late February, we began interviewing participants that were identified through our second recruitment method. In this approach, our team coordinated with the Iowa Family Development and Self-Sufficiency (FaDSS) program, housed in the Department of Human Rights (DHR), to recruit current and past program participants to our study. Delivery of the FaDSS program is divided into six service areas across the state. Each service area administrator provided a recruitment list including last known address and phone number. Former program participants with substantiated substance use were identified for recruitment into the present study. The lists also revealed whether program participants lived in a single or two-parent household, if there were others in the home, and the nature of their relation to the participant (e.g., child, other adult).

A FaDSS postdoctoral intern with an occupational history in community mental health services was hired to recruit participants by telephone. Recruitment occurred from February to May, 2019. The postdoctoral intern called each former FaDSS participant with a substantiated history of drug use

following the script co-created by the ISU and FaDSS teams. Recruits were asked if they would be interested in participating in a study about families and substance use. It was explained that an interview would be scheduled to take place in their home or in the community (at the discretion of the participant). The interview would last approximately 90 minutes and would include questions about their life story, and how substances have impacted them. Recruits were informed that all information collected during the interview would be kept confidential. Recruits were also informed that following completion of an interview, they would receive a \$40 gift card as remuneration for their expertise. When a recruit agreed to an interview, the postdoctoral intern matched the recruit with a pair of interviewers from the research team and scheduled a time, date, and location to conduct the interview. A confirmation text was then sent to the interviewers and recruit with the contact details, date, and time of the interview.

A total of $N = 250$ former FaDSS participants with substantiated substance use were identified from the DHR provided lists. Of those, 75 did not have a phone number listed, 35 phone numbers were disconnected, and 25 phone numbers were incorrect (e.g., the person who answered stated it was the wrong number). From the remaining 115 numbers, 23 agreed to participate in the study, two declined, and the remaining 90 numbers failed to yield a contact after repeated call-backs. In some cases, a voicemail box was full or was not setup ($n = 30$). Forty-two participants received voicemails, which yielded three returned calls. Eighteen participants' last known number was an inpatient treatment facility and were therefore unable to be reached. In total, 21 interviews were obtained via the FaDSS program. This method was especially valuable in recruiting parents of minor children to the study.

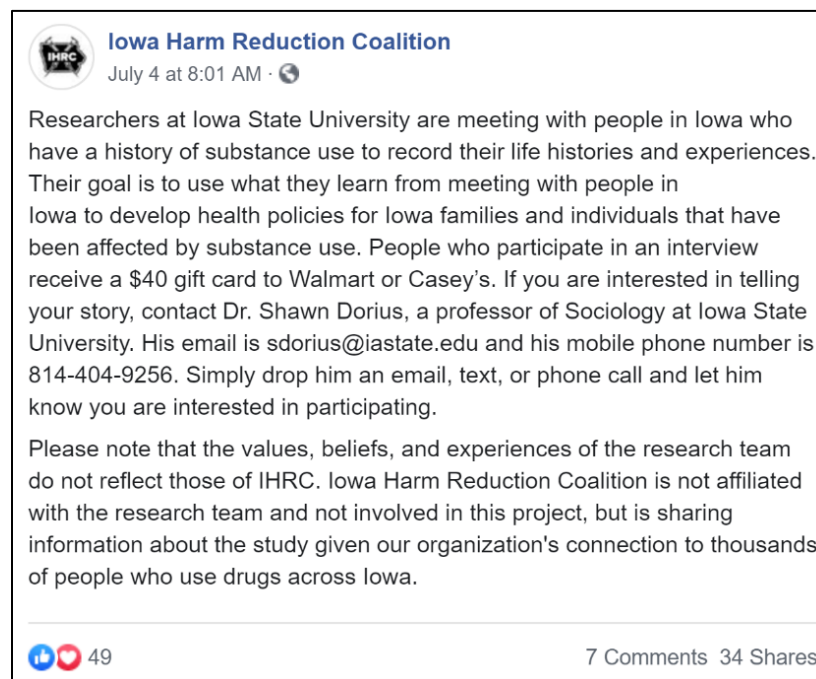
In our third recruitment strategy, we collaborated with the Iowa Harm Reduction Coalition (IHRC), a local non-profit organization that works directly with our target population in several high-density, populous urban centers. IHRC agreed to post an advertisement of our study to their Facebook page (see Figure 4). That post went out on July 4th and interviews from that approach began on July 11.

Figure 3. Completed Interviews by Place, Time, and Incentive

The post included the work email and personal phone number of Dr. Shawn Dorius, which respondents used to communicate interest in participating in our study. After several participants with a history of intravenous substance use posted positive stories about meeting with, and trusting, Dr. Dorius, a number of people contacted the team about setting up interviews. These respondents shared enthusiasm for the project goals and several stated that even though they were nervous about coming forward, they believed participating could help get their story told to the decision makers at IDPH and were therefore willing to engage. In total, we completed eight interviews via direct contacts with IHRC associates and an additional two interviews were completed by way of referrals from IHRC interviewees. The benefit of this strategy was that we were able to interview a number of actively using individuals, many of whom were in the higher risk population of intravenous substance use. These

interviews put us in contact with people at, or near, the rock-bottom stage of the substance use life cycle. This user group also provided rich insights into the nature of current intravenous substance supply networks and proximate risk factors among active users (e.g. current heroin supply in Iowa is contributing to high overdose rates).

Figure 4. Iowa Harm Reduction Coalition Recruitment Script

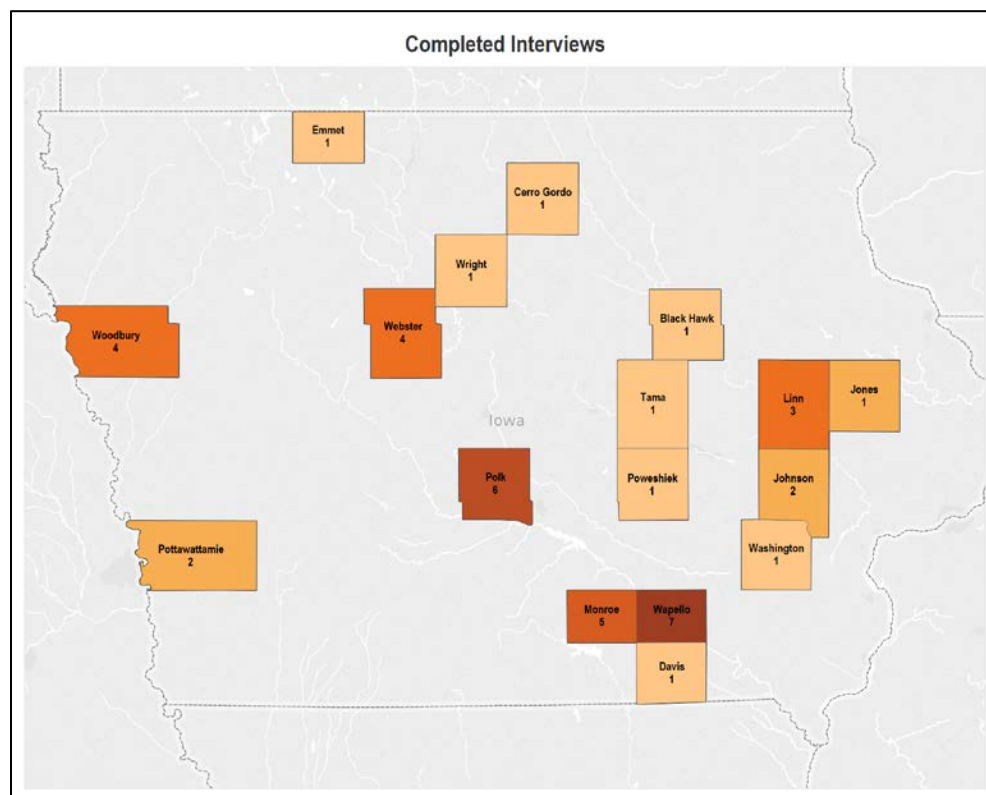


Most interviews were completed in the participant's own home, though a small number of interviews were also conducted in public libraries, fast food restaurants, treatment centers, and a public park. Interview start times ranged from 8:00 am to 5:00 pm, with the most common start times being 10:00 am, 1:00 pm, and 5:00 pm. Interviews were conducted on every day of the week, with the most common days being Wednesday (10) and Friday (12). Just six interviews were completed on a Saturday, Sunday, or Monday. A common explanation for selecting a particular day and time for the interview was

that parents did not want their children to be present when they were being interviewed, and so they selected times when their children would be in school or at child care.

Although our sampling strategy was not developed to geographically represent the entire state, our sample was fairly representative and included participants from 18 counties that reflect the major geographic regions of the state as well as several of the least and most populous counties in Iowa (see Figure 5). Wapello, Polk, Linn and Webster counties yielded the largest number of interviews at seven, six, and four completed interviews, respectively. Two regions of the state where future data collection is warranted include the southwest area and the Mississippi river counties. Both are high-risk areas for substance use and the state might benefit from collecting data from participants in these regions.

Figure 5. Number of Completed Interviews, by County of Residence



Demographic Characteristics of Study Participants

Having not used a self-report instrument to collect detailed demographic information on our participants, we relied on interviewer observations and information gleaned from the interviews to identify characteristics about our participants. For example, some participants explicitly stated their age, birth year, racial attributes (e.g. “I’m half Mexican”), education (e.g. “I didn’t finish HS”; “I started college, but never finished”), or union status (e.g. “My boyfriend lives with me”; “My wife divorced me last year”). From these statements, we constructed a dataset of demographic indicators, which are reported below and in Appendix B.

Roughly half of our study participants were in their thirties at the time of the interview. Four were less than 25 years of age at time of interview, seven were in their mid to late 20s, and 10 participants were 40 years of age or older. Thirty of our 43 participants were female. The gender skew in our study was largely attributable to our case selection strategy in which 18 of the 20 participants recruited from FADSS were female. Thirty-three participants were white, with another three describing themselves as mixed race that included a Caucasian parent. The study also included two African American women and four Latino’s, three of whom were female. Educational attainments of our study participants included three women who never graduated from high school, six with a highest attainment being a GED, and 13 with a highest attainment being a high school degree. An additional six participants went beyond the GED/high school degree to attain additional certifications, including nursing certifications, 12 were either in college or had completed some college in the past, and just one had earned a college degree. More than half of our participants were single at the time of the interview, with an additional nine participants reporting that there were currently dating someone. An additional five participants were married, two were cohabiting, and two were engaged at the time of the interview.

Contrasting the demographic profile of our study with the general population of Iowa, we over-sampled females, and under-sampled the highly educated, married individuals, and those over 50 years of age. That our study included a sizable number of women, all of whom are also mothers to one or more children, most of whom are not currently married, and few of whom have more than a high school diploma or GED, makes this an especially valuable source of information on one of the most vulnerable populations within the purview of IDPH.

Figure 6. Demographic Characteristics of Study Participants



COMPLICATING FACTORS

Weather was a complicating factor due to unusually low temperatures, numerous ice storms, and record snow in the month of February 2019. We had a number of cancelled interviews, poor attendance at EOP

sessions, and cancellations of EOP sessions as a direct result of the extreme winter weather. Often, these cancellations came at the last minute, such that team members were recalled from the field. If not for poor weather, it is likely that we would have recruited a larger number of participants from the EOP networks.

ANALYSIS PLAN

All interviews were recorded for accuracy and with the consent of study participants. We used a commercial transcription service to transcribe the recording into a text format suitable for qualitative data analysis. All interviews were coded in NVivo 12.0. As is common with research involving sensitive topics and vulnerable populations, we changed the names and locations of participants to protect their identities.

Analysis of the data was completed by a team of researchers who participated in study design and data collection. Two coders were assigned to each interview. Following training on common procedures, coders read through a subset of interviews and identified latent themes and concepts. Once all interviews were coded twice, we met as a team to discuss preliminary findings, define and refine themes, and integrate themes across coders and transcripts. This approach helped us to identify a number of important and often recurring themes across respondents with very different personal biographies and substance use experiences.

DISCUSSION & NEXT STEPS

During Phase Two of the grant (September-November 2019), the results from this analysis will be shared with IDPH leadership and staff in a facilitated ‘Design Thinking’ workshop. The goal of the workshop is to develop specific ideas for policy and program improvement related to drug use. The meeting will have three parts. Part 1 (45 minutes) will include a general overview of the research

findings to familiarize everyone with the CDC project. Part 2 (3 hours) will be a facilitated discussion of how you take facts and move them toward organizational specific goals related to programs and policies. Part 3 (15 minutes) is a wrap up where we vote on what people see as the most useful or reasonable program or policy changes that IDPH should consider to better support individuals and families with substantiated cases of drug use.

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Appendix A: Documents Reviewed

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Appendix B: Demographic Characteristics of Respondents

Pseudonym	Hometown	Recruit	Age	Race	Sex	Education	# children	Relationship status
Vincent	Ottumwa	EOP	25-29	White	M	High School	3	Engaged
Sam	Albia	EOP	40+	white	F	< HS	2	Cohabiting
Elizabeth	Ottumwa	Referral	25-29	White	F	High School	3	Engaged
Virginia	Ottumwa	FaDSS	30-39	African Am	F	GED	6	Single
Sam	Ottumwa	Referral	25-29	African Am	F	HS, Some college	2	Div, single
Carrie	Ottumwa	EOP	40+	White	F	High School	1	Single
Mindy	Ankeny	FaDSS	30-39	White	F	< HS	2	Married
Bill	Albia	Referral	40+	White	M	High School	1	Cohabiting
Lip	Albia	EOP	<25	African Am, White	M	HS, Some college	0	Single
Jeanette	Des Moines	FaDSS	<25	Latino	F	High School	1	Single
Emily	Otho	FaDSS	30-39	White	F	HS, Some college	4	Single
Ashley	Fort Dodge	FaDSS	25-29	White	F	High School	2	Single
Lolly	Clarion	FaDSS	30-39	White	F	HS, LPN	2	Div, dating
Jessica	Fort Dodge	FaDSS	30-39	White	F	GED, Some college	2	Single
Melissa	Des Moines	FaDSS	25-29	White	F	HS, Some college	1	Single
Michael	Ottumwa	FaDSS	40+	White	M	GED, Tech certificate	4	Div, single
Josh	Oelwein	Referral	30-39	White	M	HS, Some College	0	Married
Tony Stark	Fort Dodge	FaDSS	30-39	White	M	HS, Some college	1	Single
Jessica	Estherville	FaDSS	<25	White	F	< HS	2	Dating
Peter	Grinnell	Referral	30-39	White	M	College	2	Dating
Ashley	Bloomfield	FaDSS	30-39	White	F	HS, CNA	4	Div, dating
Diane	North Liberty	FaDSS	25-29	White	F	HS, Some college	4	Div, dating
Lucy	Oxford	FaDSS	30-39	White	F	High School	3	Married
Courtney	Waterloo	FaDSS	30-39	White	F	GED	6	Married
Veronica	Sioux City	FaDSS	30-39	Latino	F	GED, Some college	3	Single
Amy	Washington	FaDSS	30-39	White	F	HS, Some college	5	Div, dating
Ellie	Sioux City	FaDSS	30-39	White	F	GED	1	Single
Maria	Council Bluffs	FaDSS	25-29	Latino, White	F	High School	4	Single
Lexy	Sioux City	FaDSS	30-39	Latino	F	HS, Some college	1	Single
Abby Shuto	Sioux City	FaDSS	30-39	White	F	HS, LPN	2	Single
Victoria	Council Bluffs	Referral	30-39	Latino, White	F	High School	2	Married
Rowan	Cedar Rapids	IHRC	30-39	White	F	HS, Some college	2	Single
Cornelius	Cedar Rapids	IHRC	40+	White	M	High School	1	Dating
Nick	Mason City Rehab	IHRC	40+	White	M	HS, Some college	0	Single
Stephanie	Monticello	IHRC	30-39	White	F	HS, Some college	2	Dating
Jackson	Monticello	Referral	<25	White	M	High School	0	Dating
Tom	Cedar Rapids	IHRC	40+	Latino	M	GED	1	Single
Elaine	Cedar Rapids	IHRC	30-39	White	F	GED	4	Single
Michelle	Cedar Rapids	Referral	40+	White	F	High School	4	Single
Maria	Clutier	IHRC	40+	White	F	High School	2	Single
Kelli	W Des Moines	IHRC	40+	White	F	GED	3	Single

Appendix C: Interview Protocol

LIFE HISTORY:

- We'd like to begin with a big question: Tell me the story of your life?
- You know, take me back to when you were a child. Where did you grow up?

FAMILY:

- Sometimes family and friends are a source of support, and sometimes they may be a bit draining. How about for you?
- How has your family felt about your drug use? Can you tell me about some family that have been a support to you?
- Do you have family who have also used? *Would you feel comfortable telling me about it?*
- Have you had any experiences with DHS, such as a child removal? Can you tell me about that?

SUBSTANCE USE:

- How did you get into [substance use]? Tell me about the first time you used.
- Do you have a family history of substance use? Can you tell me a little about it?
- Did you ever have a DHS case? *Would you feel comfortable telling me about it?*
- Some people like to use with others, some people like to use alone. How about for you?
- How has substance use effected your life?
- Thinking about some of the last several times you were clean, what was life like then?

VOCATION:

- Tell me about your work life. How about your work history? What kinds of jobs have you had?
- What is your ideal job or career? How much would you like to make? How many hours would be reasonable to work for that? What's stopping you from having that career?
- What do you like to do when you're not working? What kinds of things to you like to do for fun?

COMMUNITY:

- Some people are really involved in their communities, and some people like to keep to themselves. How about for you?
- What kinds of activities did you participate in when you were in school?

CHURCH:

- Earlier you mentioned that God was really important to you. Can you tell me more about that?
- Some people say that religion or spirituality is important in their lives, for others not so much. How about for you?

STYLE OF LIFE:

- Now I would like to know more about what your life is like right now, day to day. What does a typical weekday look like? Tell me about what your day was like yesterday?
- How about your typical weekend? What does it look like?

OMNIBUS (Topics that don't have a home module):

- Transportation
- Social Isolation (Loneliness)
- Programs & Institutions

CLOSING UP:

- Where do you think you'll be five years from now? Ten years from now?
- What things give you hope in life? What are your sources of joy and happiness in life?

Appendix D: Human Subjects Protection Plan

A number of protocols were used to maintain the anonymity and wellbeing of the respondents. For example, each team member involved in collecting data on this project reviewed and signed a confidentiality agreement and completed CITI human subjects training prior to working on the team. During the recruitment process, participants were informed over the phone that all information collected during the interview would be kept confidential. Each interviewer was trained to verbally review informed consent with the participants prior to interviewing each participant and requested permission to record the interview. Interviews only continued if the participant provided verbal consent regarding their participation in the study and permission to record. Additionally, each team member connected to an IRB approved project completed the required human protections CITI training to maintain standards related to human subject's protection.

The lead investigator was responsible for protecting the identifying information of program participants by creating pseudonyms for each interviewee and only distributing contact information to team members on the day of the interview. To do this, the lead investigator created a file to link the actual names of participants to pseudonyms. In effort to minimize the number of people that have access to this data, the file was not shared with any of the team members, state agency staff, or any of the treatment center staff in effort to protect the confidentiality of the study participants. Additionally, the lead investigator was the only person with access to the entire data file that included identifying information of participants. The lead investigator shared the names, telephone numbers, and e-mails with the program manager and intern of the participants they were recruiting. Team members completing the interviews only had the first names and address of the meeting for people they planned to interview on a day-to-day basis. Additionally, the locations of participants were changed when inputted into the NVivo 12.0 software during the coding process to also protect the identities.

In effort to prevent participants from coercion regarding respondents' participation, the team utilized incentives of Walmart and Casey's store cards in the amount of \$40. The amount and store was identified as a result of consultation with IDPH administrators, and then approved by our IDPH partner in December 2019 as providing participants with store cards that allowed alcohol and tobacco purchase was an exception to the rule. This amount also reduced risk associated with participants losing benefits and the cards could not be used for the purchase of alcohol or tobacco. Team members completing interviews traveled in teams of two and carried a limited number of gift cards as a safety measure. Interviewees were asked to provide a signature for their store card with their pseudonym, rather than their real name, upon completion of their interview in effort to protect the confidentiality of their identifying information.

A final set of data files, including the transcripts, field notes, and individual profiles, will be sent to IDPH at the conclusion of this project with the pseudonyms only. Department of Human Rights (DHR) will not be provided a list of study participants. DHR was only provided the results from the data. As indicated in the agreement between ISU and IDPH, all audio recordings and transcriptions will be destroyed at the conclusion of the project.

Appendix E: Data Management Plan

A data management plan was established in effort to protect the confidentiality of participants, as well as the large amount of data collected through the team's interviews, notes, and observations. The team's data included digital files, handwritten notes, and audio recordings. Digital files, including digital files of the FaDSS administrative data, transcriptions, and audio recordings, were stored with encryption. Specifically, the results of the FaDSS administrative data recruitment, including the actual names of the study participants, was stored on an encrypted computer that was locked in the lead investigator's office. Digital files of transcriptions and audio recordings were securely stored in an encrypted folder on Iowa State's cloud storage system, CyBox. The digital files of the transcriptions and audio recordings did not include the real names of the participants, only the pseudonyms.

The team members had a variety of hand written notes taken throughout the project, as well as physical audio recordings of the interview. This data did not have the actual names of participants and was also stored in a locked file cabinet in a locked office.

Appendix F: Timeline

Project planning began in October of 2018 and project related activities will conclude in November 2019. The team began official work on the project in the Fall of 2018 with an extensive study of the drug-related literature and an analysis of substance use and health data at the local, state, and national level. This information contributed to a series of meetings with administrators from Iowa Department of Public Health in the targeted research areas. The meetings occurred in December of 2018 and January of 2019 and largely supported the team to develop protocols for the project, discuss data sharing agreements, and identify key informants and sample selection with key stakeholders. This time was also utilized to onboard team members with interviewer training and schedule preliminary interviews.

Preliminary interviews and transcription were held in February 2019. The preliminary sample was collected through silent observations of EOP sessions in the beginning of February. Participants were also recruited from the FaDSS program via telephone beginning in February 2019 during the second round of recruitment. At this time, a thematic coding system was also developed, and preliminary findings were disseminated to DHR and IDPH. Interviews continued to be scheduled, facilitated, and transcribed between February and June of 2019 and coding occurred throughout the spring and summer months. The team began a third round of recruitment and interviews starting in July by collaborating with Iowa Harm Reduction Coalition. These interviews occurred in July and August. The summer months of May, June, July, and August were utilized to follow-up with participants. The formal write-up and dissemination of the project's findings occurred in September of 2019.