

# INTERVIEWS WITH AMERICAN INDIAN AND ALASKA NATIVE PEOPLE WHO INJECT DRUGS

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*Abstract: This project gathered opinions, attitudes, and beliefs from American Indian and Alaska Native (AI/AN) people who inject drugs (PWID). The primary objective of this study was to build formative knowledge around AI/AN PWID to help define and develop health care services and strategies by better understanding existing services, barriers, and challenges to seeking care. A total of 32 semi-structured in-depth interviews were conducted. AI/AN PWID reported a number of structural, social, and geographical barriers when trying to access health care. PWID communities critically need integrative health care service strategies and improved education about injection drug use (IDU), outreach, and prevention programs and resources. More low-barrier and streamlined access to needles should be coupled with other health care services for PWID. PWID are a key resource to help health care providers and community members correct misconceptions and better understand IDU.*

## INTRODUCTION

American Indians and Alaska Natives (AI/AN)<sup>1</sup> experience disparities in access to health care and recovery services for substance use disorder, especially for persons who inject drugs (PWID).<sup>2</sup> Although there is vast variability with substance use patterns across tribes and between urban and rural context, overall AI/AN people have experienced the largest increases in drug and opioid-involved overdose mortality rates compared with other racial and ethnic groups. Misclassification of AI/AN race also oftentimes contributes to significant underestimates of AI/AN mortality rates. (Joshi, Weiser, & Warren-Mears, 2018). The rise in injection drug use (IDU) has

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<sup>1</sup> American Indian and Alaska Native (AI/AN) identity is used in this paper as a general term of identity for those participating in the project and does not capture the complex individual tribal histories and sociopolitical processes that have led to the multiple terms and levels of AI/AN identify, including Tribal, Pueblos and Nations affiliations.

<sup>2</sup> A list of frequently used acronyms can be found at the end of this article.

increased, placing AI/AN PWID at increased risk for HIV, hepatitis c virus (HCV), and other blood-borne infections (Centers for Disease Control and Prevention, 2014). In addition, IDU is associated with adverse health outcomes such as drug overdoses, drug-related suicidal behaviors, comorbid psychiatric disorders, and trauma (Roy, Arruda, Bruneau, & Jutras-Aswad, 2016). Morbidity and mortality rates due to substance use disorder (SUD), combined with barriers to access treatment and harm reduction services, are major public health issues in Indian Country (National Congress of American Indians, 2018; Fisher, Cahill, Broyles, Rorke, & Robinson, 2017). Particularly in the context of the current opioid epidemic, health care systems must do more to ensure stigma-free access to opioid and IDU treatment services, syringe services, and overdose prevention.

Acknowledging the interactions between individual and external factors that impede access to IDU treatment and harm reduction services is crucial in achieving health equity for AI/AN PWID. Further understanding these circumstances allows us to begin to address unmet health needs, such as delays in receiving appropriate care, inability to access harm reduction services, financial burdens, and associated preventable hospitalizations among AI/AN PWID. This project gathered knowledge, opinions, attitudes, and beliefs from AI/AN PWID, including persons who have injected drugs in the past. The primary objective of this study was to build formative knowledge around AI/AN PWID, which can be used to define and develop health care services and strategies for IDU. Barriers discussed included access to treatment for AI/AN PWID, lack of harm reduction services, barriers in accessing unused needles, and policy-level barriers. Moreover, this paper discusses PWID risk-taking behavior as a consequence of these barriers.

## **METHODOLOGY**

### **Theoretical Framework**

This project used the Community Involvement to Renew Commitment, Leadership, and Effectiveness (CIRCLE) framework for program design and community development. The model was based on three indigenous researchers' experience as Gathering of Native Americans (GONA) facilitators and developed during their time working at a tribal consortium in the Southwest. The CIRCLE framework is a four-step model (building relationships, building skills, working together, promoting commitment) that incorporates Western concepts of community capacity building (building the capacity to respond to health issues) and parallels the values of community-based participatory research (building mutual trust between researchers and communities without the

potential for exploitation or abuse of power). CIRCLE is uniquely indigenous in comparison to community capacity building and community-based participatory research in that it puts relationships – both professional and personal – at the center of program building. The creators of CIRCLE understood that relationship-building is an essential process in tribal communities and “one that is deeply embedded in history and context” (Chino & DeBruyn, 2006, pp. 598).

### **Target Population: American Indian/Alaska Native Tribes**

AI/AN communities were solicited to participate via the Nation-wide network of Tribal EpiCenters. The Northwest Tribal Epidemiology Center, as the project lead, sent emails to other Tribal EpiCenters to solicit Tribal communities in their region to participate in the project.

AI/AN communities that chose to join the project were located on or near reservations in the West, Northwest, and Midwest United States. The communities were selected based on the tribe’s and/or tribal organization’s expressed interest, their willingness to participate in planning meetings, and their diverse geographic location. Communities were located in areas designated rural to small urban (3,000 – 74,000 persons). Selected communities reflected the diverse barriers and opportunities for PWID who have attempted to access prevention, harm-reduction, clinical, or treatment services on or near tribal reservations.

Each tribe or tribal organization obtained agreements from the Tribal Health Director and/or Tribal Council to participate in this project. Letters of approval in the form of a memorandum of understanding, or other document as desired by the participating tribe, were submitted to the Portland Area Indian Health Service Institutional Review Board (IRB) upon receipt. All confidentiality requirements set by participating tribes were honored by the Northwest Tribal Epidemiology Center. Each tribe had the ability to decide how they would like to proceed with review and approval. Options included:

- (1) Accepting the Portland Area IRB review (letter stating such will be submitted to Portland Area IRB)
- (2) Proceeding with local IRB review (letter of approval will be submitted to Portland Area IRB)
- (3) Proceeding with local Tribal review (letter of approval will be submitted to Portland Area IRB)

Northwest Tribal Epidemiology Center project staff identified and collaborated with at least one local coordinator at each site during the development and design process to tailor the protocol to community needs. This co-ownership of research strategies and implementation

continued in each phase of the project. Monthly meetings were held with project staff across organizations and areas to discuss the project.

### **Participant Recruitment and Selection**

To be eligible, participants had to have previous or current engagement with IDU, live on or near one of the identified communities, and be between 18 and 40 years old. Due to the difficulty of reaching PWID with traditional sampling methods, a non-probability sampling, chain-referral sampling method was used. This method involved identification and recruitment of a small number of “seed” participants via word of mouth, who then provide contact information for other potential participants (Johnston, Whitehead, Simic-Lawson, & Kendall, 2010; Salvalaggio, McKim, Taylor, & Wild, 2013). Ideal seed participants had large social networks, were respected by members of the target population, are able to convince others to participate in the study, and had some interest in the study goals (Erickson, 1979). Each seed participant had up to three coded coupons to recruit peers from their social network. Positive experiences during the survey process promote further recruitment.

Additional recruitment strategies varied by community, since different communities required and/or permitted different outreach strategies. Some local coordinators recruited via signs and posters placed in local health clinics, behavioral health clinics, drug treatment facilities, prevention program venues, tribal buildings, or other areas deemed appropriate by local site coordinator(s). At other sites, local health and behavioral health clinic staff verbally told their patients of recruitment. Outreach was also conducted at local venues frequented by PWID for recruitment.

### **Data Collection**

The Northwest Tribal Epidemiology Center staff trained the local site coordinators to conduct interviews with participants. Local site coordinators who did not have experience conducting interviews for research received training via webinar and were coached from one of the project leads. Semi-structured in-depth interviews were conducted with participants in a private room. In-depth review of the methods and process of the project including details regarding staff training and interview guides has been previously published (Leston, Crisp, Lee, & Rink, 2019). Interview guide questions were written in collaboration between all project staff (including those working in the communities) and incorporated implementation science theory in order to

encourage the integration of research findings and evidence into policy and change. By mapping questions to the causal factors that influence implementation (innovation, personal, provider, organizational, and structural), study personnel were able to better conceptualize constructs affecting implementation of programs and services for PWID (Chaudoir, Dugan, & Barr, 2013).

Interviews lasted approximately 45-90 minutes. Participants received an information sheet and a verbal description of the study, along with residual points requiring clarification. Participants then signed an informed consent form to agree to participate in this study. Participants received a \$25 gift card as an incentive. Thirty-two ( $n = 32$ ) interviews were conducted with AI/AN and non-AI/AN PWID. Surveys were distributed to gather basic demographic information.

### **Data Analysis**

All interviews conducted during the study were audio recorded. Transcription occurred at an outside venue. Transcribed data were analyzed systematically using ATLAS.ti software. Content analyses were used to identify the presence, intensity, and frequency of topics and themes generated by groups and individuals. A data-driven approach was utilized, allowing themes to emerge from the data (Creswell, 2006). The codes created were used to identify and assign meaning to information gleaned from the study.

Interrater reliability was calculated during the coding process to establish consistency between reviewers. Initial interrater reliability was 77%, calculated by dividing the number of total agreements by the total number of agreements and disagreements. After the iterative process of building the codes, a final interrater reliability score of over 90% was achieved. Validation of the codes arose through the process of triangulation—in that the literature supported multiple findings of the study, multiple participants in different geographic regions reported similar findings garnered during the interviews, and multiple members of the research team analyzed the same data to establish validity and confirmed study findings.

## **RESULTS**

### **Participant Demographics**

Thirty-two ( $n = 32$ ) PWID were recruited. Seventeen participants (53%) identified as male and 15 (47%) identified as female. The average participant age was 32 years old. Many participants (69%) had finished high school and had some college or had completed a college degree. The

majority of participants (94%) identified as AI/AN. Over half of participants reported that they received their health care from IHS or the nearby tribal health services.

## Themes

Seven themes emerged from the interviews with PWID. These themes describe current structural, social, and geographical barriers to accessing services and treatment for PWID, as well as risk-taking behaviors that are a consequence of these barriers.

### **Theme 1: Stigma**

Social barriers, like stigma, feeling shame, guilt, and concerns about being judged, kept participants from accessing SUD resources, treatment services, and prevention programs. Health care providers (physicians, nurses, pharmacists, and pharmacist technicians) and community members were most frequently mentioned by participants as the main sources of judgment and stigma that PWID experienced in their everyday lives.

*You know you feel that guilt you think people know when you're going to buy those needles that they know you're a junkie...I think people are either very arrogant healthcare providers...or ignorant. They're either super anti-drug usage and have no compassion for it, or, you know. So it's like people reach out, and they don't really help, you know, like my own partner. (Participant A)*

*Like you're still being shamed, you know, people are still telling you that you're a shitty person because you did the things you did. (Participant D)*

*Once you get labelled an IV drug user, your name's just nothing. So I mean it... Because I remember whenever I wasn't one, you know. I remember whenever I didn't have that stigma. Doctors treated me so well, greeted me so nicely, you know. And now doctors look at me like, what's wrong with you? Nothing's wrong with you. (Participant W)*

### **Theme 2: Lack of access to Medication Assisted Treatment (MAT)**

Participant knowledge of medication assisted treatment (MAT) varied depending on where the participant was located geographically and if they had any prior experience with any of these

services. Most participants had no MAT in their area (including those living in small urban communities of up to 74,000 people) but had previously accessed them in large urban centers.

Participants that had experience using MAT advocated for its implementation in their area. One participant described having to travel to another neighboring state in order to obtain his medication:

*And a lot of doctors weren't even (prescribing MAT)...Most of them that I called weren't taking any new patients. And then I just kept calling and calling until I found one that would take me, you know? It's a four-hour drive once a month...I go to Cheyenne, Wyoming, once a month to do it, to get my prescription filled...I probably called at least 40 places within a five, within a four-hour radius from here. Most of them, you either had to be on pain management, they weren't taking street drug users, or you had to go through a lot of...You know, take in-patient treatment and do all these things before they would prescribe it to you. (Participant B)*

Another participant was located in an area that did not have many treatment options for PWID/Persons who have injected drugs and suggested that there should be more strides taken to alert members of the community that there are affordable treatment options available.

*Just if there could be a way to let the people of the community know, the people that use drugs, that there's treatment out there and that it's cheap. (Participant I)*

Participant D corroborates the statement made previously by another participant in that the availability of MAT services in their local area was nonexistent, and they knew of treatment options located in other areas that were not nearby geographically.

*My friend gets their Suboxone in Aberdeen. I know it's available, I've heard of it being available in Aberdeen and Sioux Falls and in Wyoming too, not sure where. And also I've heard of a lot of people going to Fort Collins, Colorado. But, I mean, as far as Suboxone in South Dakota, there's not a ton of options. And, I mean, Suboxone doctors can only take on so many patients. And so that's also pretty limiting, I think they put too much restrictions on it, you know. (Participant D)*

Another participant emphasized the benefits of MAT services in that it helped them in becoming sober previously.

*But the Suboxone and methadone clinic... Yeah, that's definitely the best things... Or that's the things that have helped me in the past. So. (Participant AC)*

**Theme 3: Lack of overall knowledge of and access to Harm Reduction Services**

Syringe service programs (SSPs) were often the only harm reduction services participants knew about. While most participants had positive attitudes and perceptions of SSP, a number of participants described scarcity of services and lack of health provider knowledge about local SSP as central barriers to access. Scarce services in this context refers to the lack of available SSP in participant areas. Many participants noted that the health providers they encountered did not know of any available SSP in their area and were unable to refer them to such services.

*Well first of all, they don't support them because they're not, like, offering clean needles...(Participant C)*

Most participants supported future harm reduction services, such as MAT and SSP, being established in their area to assist PWID and believed health care providers would be supportive of harm reduction services. However, there were some participants that weren't sure if health care providers would be supportive.

*Because like I said, me, myself, had lot of pride and it's tough to go in to get new needles. So here I am sitting around with the same old needle, sharing needles. When if there's opportunities like that [SSP], because I know in Colorado there are places like that where you could go and get a new needle every day. So if there's places like that here, that'd be fantastic. (Participant I)*

Participants also specifically described a variety of barriers which deter PWID from accessing unused needles, including prescription requirements, judgment by pharmacy staff, collection of personal information, and pharmacy store hours.

Giving out personal information made PWID uncomfortable. Most were afraid they would be reported to law enforcement. A number of participants stated that some pharmacies in their area required prescriptions for diabetic needles, which deterred many from attempting to purchase

unused needles. Diabetic needles were the most common type of needles used by PWID because they were available in most stores and pharmacies and could be bought in large quantities.

*Well, I guess pharmacies, they apparently have some regulations. I know I have bought syringes where they have actually made me write down my name, address and stuff, personal information. Most people that are using are not very open to that. Nobody wants to write their personal information down just to get these...It's on record or something. (Participant B)*

#### **Theme 4: Lack of access to SUD treatment and recovery resources (non-MAT)**

Participants discussed the available SUD resources, which were limited or non-existent. “Resources” were described by participants as any non-MAT behavioral or clinical-based treatment options for PWID. For the participants who were able to identify current facilities that were available to help PWID, many had negative interactions with health care providers and staff at these facilities, which discouraged them from accessing such resources. Participant examples of negative interactions included: feeling judged for their IDU, feeling stigmatized, experiencing health provider assumptions about their IV drug use, health providers being rude, and not taking them (PWID) seriously because of their addiction.

*They look at you like a bum, a junky, like with disgust. Like I don't know it's kind of like prejudice in a way, compared to how they look at somebody else that's, I don't know, but I see that, it's like it's ugly. That's why I don't even want to go to a hospital, I don't need nothing. (Participant H)*

*I think they feel like, I don't know, like they don't like us. Like we're not human, we're going to give them a disease if we touch them. I just think they just don't know how it is; they think it so easy. Why don't you just quit? You know, just...They just don't like us, I don't know. They treat us differently. (Participant Q)*

Further, many participants responded that they felt providers weren't compassionate enough towards individuals with addiction issues.

*I guess, for them (health care providers) to be educated, I guess, on drug addicts and what it really is about. You know, that they're just people and they're not trying*

*to hurt anybody, that they're just sick and stuck and don't know what they're doing. They're just desperate people really. (Participant B)*

Many stated that the SUD treatment they received was inadequate due to negative perceptions and attitudes about IDU and PWID from health care providers servicing PWID. Participants felt as though providers couldn't communicate effectively with them. They reported that providers needed to learn how to speak to them as people and not treat them as medical cases.

*I think they should be more, it seems like they're more of just there, mainly the counselors that do work at treatment, whatever treatment they're working at, is just work for them, another job, you know. Kind of lost their enthusiasm about what they're really, why they really wanted to be a counselor. (Participant G)*

Some participants felt that the resources (services and programs) for PWID were adequate, but this varied depending on geographic location. Most felt more resources should be allocated towards helping PWID. Participants had many ideas for future resources, including increasing the number of services, type of services, and duration of services.

*Just probably like some [inaudible] based treatment centers. And probably back to the equine therapy, because I know a lot of people that... Like one of my buddies was in equine therapy before and he liked it a lot. But I just think there needs to be more treatment centers in general (Participant C)*

*I would like to see more treatment centers. I'd like to see more outpatient treatment centers (Participant G)*

The experience of participants with treatment services varied depending on whether the respondent sought treatment voluntarily or because of a court order (involuntary treatment).

Participants flagged multiple issues with current treatment programs including: scarcity, limited services, and other barriers. It was very difficult for many participants to identify a voluntary program in their area they felt comfortable attending. Some participants described going through multiple treatment programs before “getting clean” (achieving sobriety). Many commented on the available programs being inefficient, limited, or staffed by people who were not interested in helping patients. Many participants commented that more compassion from

community members towards PWID would motivate them in accessing SUD treatment. Overall, participants did not believe that the treatment programs were effective in helping people with SUD.

*Well, they obviously get locked up and then they don't have access to that, so they get cleaned up. And then, you know, hopefully they're in there long enough and then they get their mind right and they realize they're better off without it. And then when they get out, that's when they have to make their choice, whether they're going to keep staying clean or whether they're going to go back to what they were doing and repeat that cycle. (Participant I)*

### **Theme 5: Risk-taking and protective behaviors**

Many participants described protective behaviors they undertook while using drugs, such as not sharing needles in order to avoid getting transmittable diseases such as HIV or HCV. One participant who had injected drugs in the past mentioned giving needles away to others.

*I know that there were several times that I would buy, just so it wasn't an issue and I wouldn't have to worry about it. I'd buy a whole box of a 100, which is ten packs of ten and that was \$13 and then it just wasn't an issue for me. And then I would freely give them out to my friends too, just so they wouldn't have to worry about it either. (Participant B)*

Participants also described risk-taking behaviors, including needle sharing, reusing needles, and unhygienic needle cleaning and injecting practices. Needle-sharing and reusing needles were most frequently mentioned.

The inability to access unused needles (Theme 3) contributed to risk-taking behaviors. Participant who lacked access to safe, unused syringes stated that they were more likely to reuse needles. A handful of participants discussed needle sharing among intimate partners, which is termed "fluid bonded." Engaging in such behavior was viewed by some participants as being less risky, because they shared needles with only their partner.

*Like my girlfriend and I, we share. We're what's called fluid bonded, we share needles all the time, but just us. We don't share outside of us, like I mean one time we accidentally used somebody else, but as far as reusing them yes, people are reusing them. (Participant F)*

Reusing and sharing needles contributed to participants engaging in unsafe and unhygienic injection practices, such as injecting repeatedly in the same area. A few participants used materials such as their own bodily fluids, water, beverages, bleach, and alcohol to clean and then subsequently reuse needles. Many participants knew that you could get an infection from a lack of injecting hygiene. Despite this knowledge, many had used unsafe or unhygienic injection methods while engaging in IDU.

*God knows what's on them. And it's a wonder that I don't have HIV or some other crazy disease. I mean, I got really lucky. And I know a lot of people that haven't got lucky, you know, and that are all messed up. And got nasty, funky diseases or, you know...Or abscesses, you know...Really bad abscesses. (Participant A)*

A few participants reported having been sold tainted drugs, which were laced with other drugs or other toxic chemicals that had extremely adverse impacts on their physical health. According to participants, this was done by drug dealers in order to get rid of products and make a profit or, at times, to harm certain individuals.

*I see people give people hot shots and stuff, they did it on purpose to give the person, to make them get sick just to do that harm, because they're bad one way or another or they don't like them, give it to them they're called hot shots. (Participant F)*

Although this concept didn't emerge as a major theme in the analysis, a few PWID commented that they knew of or heard about women trading or selling sexual favors for drugs or money to buy drugs.

*Oh, trade in, like, sex. I mean, they'll trade that for the fix or whatever. (Participant C)*

### **Theme 6. Motivation for treatment and recovery**

Many participants attested unless an individual was mentally ready to get treatment then they would not be successful in achieving recovery. Motivations for recovery included nearly overdosing, encouragement from people they knew, and self-realization that engaging in IDU was not contributing to their lives in a positive way. There were few to no successful cases of recovery from any behavioral or clinical treatments available in their area. Most participants believed most

PWID who entered into involuntary treatment were not mentally ready to recover and as a result would either leave treatment early, fail the program, or continue to use drugs while in treatment.

*It only works if you want it to work. And if you're just doing it because the court wants you to, more than likely, you're going to fall back to using again after treatment. (Respondent Y)*

Participants who had injected drugs in the past shared key physical, mental, and spiritual elements which contributed to a recovery. Physical constraints (i.e., being incarcerated, becoming exhausted or ill from the lifestyle of engaging in IDU) motivated some to seek recovery.

*Just crisis's in their life, where they realize that's not what they want anymore and they want to make a better life and something higher than themselves is giving them the strength to move forward and put that past them, become a better person and grow in all aspects of their life. (Participant I)*

Participants, particularly those who had injected drugs in the past, described emotional trials (i.e., having extreme feelings of low self-worth) and challenges (i.e., having children who required different emotional priorities) as motivators of recovery. Improved self-worth and recognition of personal potential was another driver towards recovery mentioned by a number of participants.

A handful of participants described spiritual awakenings and engaging in religious or Native American spiritual practices (e.g., praying or participating in sweat lodges) as motivators and maintainers of their recovery.

*Or they say, oh go pray, go pray this and that, but like we're from reservation, we have a strong medicine, a strong culture, but at the same time it's like most of us have no idea where to go sweat. They don't know that, I mean, so for us guys that do have that knowledge, we're the lucky ones. And I feel bad because it's like... (Participant H)*

Participants emphasized the importance of having strong social support networks (for example, family and friends) and engaging in treatment and behavioral health programs specifically tailored to their needs. This highlights the importance of SUD treatment programs which go beyond the “one size fits all” approach to treatment.

**Theme 7. Tribal Council policies and perceptions of PWID**

The level of support the tribal council provided for PWID varied with geographic location. Some participants felt that the tribes were providing adequate behavioral and clinical health services for PWID. Others perceived tribal policies which affect PWID as aggressive and strict because they resembled zero tolerance drug policies. Some participants believed that PWID were invisible to tribal councils and unacknowledged in the community, which made them feel isolated.

A number of participants wanted to see more tribal council support for PWID, including more collaborations across agencies and governments, more funding allocated towards SUD treatment and programs, and more awareness in tribal communities about the social issues that specifically impact PWID.

*I think the Tribal Council is trying to help people. I just think they're in the beginning process of it and I think like any process it takes time. (Participant A)*

**DISCUSSION**

The primary objective of this study was to build formative knowledge around the culture of AI/AN PWID and to help define and develop tribal health care services and strategies for PWID. AI/AN communities participating in this project have clearly identified barriers and opportunities for change in services and treatment programs for PWID. Yet, many of these same barriers are not much different from identified barriers and opportunities for non-AI/AN communities, and include lack of access to health services, lack of provider education, and social stigma (Wang et al., 2016; Lang et al., 2013). This would suggest that, regardless of specific AI/AN-cultural needs for intervention and competency, there are lessons all health care services should learn and implement to better reach PWID. This new knowledge should be used to improve health care systems for IDU, HCV, HIV, and other associated adverse health issues to eliminate disparities and access to health care and recovery services for persons who inject drugs (PWID).

Limited access to local MAT health care services contributes to disparities in nonfatal and fatal opioid overdose among AI/ANs and was a reoccurring theme from participants in this project. Opioid Use Disorder (OUD) is a chronic brain disease caused by reoccurring use of opioids (American Psychiatric Association, 2019). Like other chronic diseases, such as hypertension and diabetes, OUD can be treated with medication (MAT) and counseling or other behavioral therapy. Tribal reservations are often located far from urban centers where specialized health services for

OD treatment are available. In 2014, there were only eight documented tribal health facilities in the United States with MAT services and six tribal programs with MAT policies and procedures (Joseph, 2018). This treatment gap does not exist only in Indian Country. Only 23% of publicly funded treatment programs report offering any FDA-approved medications to treat SUD, and less than half of private-sector treatment programs reported that their physicians prescribed FDA-approved medication (Knudsen, Abraham, & Roman, 2011; Knudsen, Roman, & Oser, 2010). In some places, this lack of access is due to physicians not having or not using their DEA Waiver to use buprenorphine, one of the medications used for OUD treatment. Leadership, at all levels, need to continue to work together to ensure MAT treatment is available to all people with OUD.

Similarly, access to recovery services for people with SUD was an important theme repeated by participants. Recovery for PWID and with SUD should be broad and diverse, including but not limited to: MAT, culture-based prevention and recovery, evidence-based prevention and recovery, housing programs that do not discriminate against PWID (including those with felonies) and promote keeping families together during recovery, and training and professional development programs for PWID. From the Surgeon General's Report on Alcohol, Drugs, and Health, "Recovery from substance use disorders has had several definitions. Although specific elements of these definitions differ, all agree that recovery goes beyond the remission of symptoms to include a positive change in the whole person. In this regard, 'abstinence,' though often necessary, is not always sufficient to define recovery" (U.S. Department of Health and Human Services, n.d.).

Health systems should embrace varied recovery programs that meet the needs of individual PWID and should develop organizational approaches that lead to PWID achieving degrees of health and wellness, leading productive lives, and making valuable contributions to society (Substance Abuse and Mental Health Services Administration [SAMHSA], 2016). Most participants did not know what "harm reduction services" were and had not accessed these services. Education needs to be implemented among PWID as well as health care providers around harm reduction services. Harm reduction services integrates a large range of strategies from managed abstinence, to safer use of drugs, to meeting PWID at the space they are currently in, versus forcing them to be in a desired, prescribed state (Harm Reduction Coalition, 2010). Another important concept of harm reduction services, which was reflected in this project, is that there is no universal solution, definition, or formula that will work for all communities. Harm reduction services intervention and policies must be designed to fit individual and community needs by listening, respecting, and meeting PWID where they are at, instead of leaving them where they are

at. Though harm reduction is an old concept, implementation of harm reduction services is key to help PWID and includes traditional health promotion concepts, such as health fairs and education, decriminalization of drug use, lifting the ban on purchasing syringes with federal dollars, and removing punitive sanctions for people who use drugs while in treatment.

The complete absence of SSP in some tribal health facilities and limited access in other regions was one of the primary contributors to participants reusing and sharing needles. Engaging in protective behaviors such as buying non-prescription needles in bulk and distributing them to friends, being present when a friend was injecting, and sharing drugs was fairly common among PWID in this study. Studies have shown that SSP does not promote IDU (Sebelius, 2011). One study has demonstrated that PWID who accessed SSP had a higher likelihood of seeking treatment compared to those who never had accessed an SSP (Hagan et al., 2000). Therefore, increasing access to SSP will reduce blood borne disease transmission and other infections caused by risk-taking behaviors such as sharing and re-using needles (Sweeney et al., 2019).

Stigma surrounding SUD and PWID continues to adversely affect PWID. PWID often do not seek SUD treatment or harm reduction services because of fear of judgment, feeling shame, or guilt. Moreover, participants agreed that health care providers needed additional training about SUD and treating people with SUD. The stigma felt by every participant in this study, driven by general perceptions that SUD is a moral failing rather than a chronic disease, only exacerbates barriers to treatment and recovery. Whether real or perceived, negative perceptions and attitudes towards PWID from health care providers contribute to this stigma. Educational programs for health care professionals should emphasize communicating effectively with PWID and improving provider knowledge of local recovery services, MAT options, harm reduction services, and SSPs.

Recovery is possible for PWID, as demonstrated by interviews conducted with people who had injected drugs in the past. As noted by the participants of this study, people who had injected drugs in the past who were successful in recovery were mentally ready, had strong social support networks, and sought programs or treatment that worked best for them. Programming implemented in communities to reduce stigma towards PWID is likely to decrease feelings of social ostracization, increase the use of available SUD treatment centers among PWID, and increase the likelihood that PWID will access services to help them in recovery. Given their knowledge of the culture surrounding IDU and their lived experiences, PWID should be included in SUD program development.

## **Study Limitations**

As with any research, our study had limitations. It is important to consider that these results are not generalizable to all PWID in all of Indian Country given that the study was conducted with a small sample size and in only three geographic regions throughout the United States. Participants in the study were located in areas designated rural to small urban (3,000 – 74,000 persons), making their experiences different from one another and also very different from urban AI/ANs. These experiences are shaped by the context in which each person experiences their SUD, including distance to drive to access services (including those living in small urban areas but do not have access to treatment services where they live). Future studies should focus on the urban AI/AN experience as it relates to IDU and health services.

The recruitment to participate in the study was nonrandom at two levels. One, the Northwest Epidemiology Center recruited sites via other EpiCenters and Tribal Health Directors. There were pre-existing relationships between some EpiCenters and Tribal Health Directors, which biased recruitment of sites. Also, recruitment of participants largely relied on word-of-mouth and existing relationships, which may have limited the themes that emerged.

Another limitation recognized by the researchers was the lack of information gathered on cultural and uniquely indigenous contextual factors related to IDU. Although not discussed in great depth by the participants in this study, there are numerous pieces of literature that point towards healing of historical trauma, colonization, and growing interventions based in AI/AN culture (Walters et al., 2020; Croff, Rieckmann, & Spence, 2014; SAMHSA, 2018). Though questions were open-ended and left room for participants to discuss any and all factors related to health services, community, strengths, and needs for PWID, rarely did this come up. We believe that this had to do with the fact that we were particularly focused on improving health care services which operate almost exclusively in Western constructs. However, the lack of overlap could similarly be due to the disassociation and forced isolation of PWID from their traditional ancestral ways of knowing and community. Better understanding and future research should be challenged to understand PWID through an indigenous lens.

## **Study Strengths**

It is important to acknowledge the strengths of this study. This study was unique in that it obtained accounts of the lived experiences of AI/AN PWID, of which few studies in the United

States have done (Anastario et al., 2017). Additionally, the study was able to capture the behavioral patterns that PWID exhibited from how they obtained needles, the drugs themselves, and their actions leading to engaging in IDU. Furthermore, this study illuminated the social networks and culture that developed around IDU and PWID. Moreover, the study provides further empirical evidence about critical barriers that AI/AN PWID experience in accessing health care, such as limited services, negative health care provider perceptions and attitudes towards PWID, and judgment towards PWID from the community.

## CONCLUSION

Structural, social, and geographical factors influence access to SUD treatment and harm reduction services for AI/AN PWID. Greater access to MAT and other recovery and harm reduction services are needed for AI/AN communities. Changing social attitudes and beliefs about IDU, SUD, treatment and recovery services, and PWID will improve access to SUD treatment and harm reduction services for PWID. Education about SUD and local prevention and recovery programs and resources is critically needed in communities to 1) inform the community about SUD and behaviors, 2) decrease stigma and general misconceptions around PWID and SUD, and 3) increase access to comprehensive IDU services for AI/AN people.

## List of Acronyms

American Indians and Alaska Natives (AI/AN)

Persons who inject drugs (PWID)

Injection drug use (IDU)

Human immunodeficiency virus (HIV)

Hepatitis c virus (HCV)

Indian Health Service (IHS)

Institutional Review Board (IRB)

Medication assisted treatments (MAT)

Syringe service programs (SSP)

Opioid Use Disorder (OUD)

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## ACKNOWLEDGEMENTS

The authors acknowledge every single person involved in this project. In order to protect the anonymity of the Tribes we worked with, we are choosing not to name the organizations and people that were integral to making this project successful – but this project would not have happened without them. We also deeply indebted to the participants of this project who have helped develop our understanding with their knowledge.

### **FUNDING INFORMATION**

This project was funded by the Minority HIV/AIDS Fund and the Indian Health Service HIV/AIDS Program. The views, policies, and opinions expressed are those of the authors and do not necessarily reflect those of IHS or HHS.

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