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“You’re nobody without a piece of paper:” Visibility, the State, and Access to Services among Women Who Use Drugs in Ukraine

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Abstract

In Ukraine, women constitute a third of all new HIV infections, and injection drug use accounts for nearly half of HIV infections among women. Women who use drugs (WWUD) often have diminished access to drug, HIV, and other health and social services or underutilize women-specific services such as maternal health. While interpersonal and contextual factors diminish access to and utilization of services among WWUD, rules, processes, and bureaucratic structures also systematically exclude women from accessing services and resources. Institutions,

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Author Contributions

Jill Owczarzak: conceptualization, funding acquisition, methodology, formal analysis, writing – original draft preparation, **Asiya K. Kazi**: formal analysis, writing – original draft preparation; **Alyona Mazhnaya**: Investigation, data curation, formal analysis, writing – review & editing, project administration; **Polina Alpatova**: Investigation, data curation, formal analysis, writing – review & editing, project administration; **Tanya Zub**: Investigation, data curation, project administration; **Olga Filippova:** project administration, conceptualization; and **Sarah D. Phillips**: formal analysis, writing – original draft preparation

bureaucratic processes, and instruments of legibility such as documents regulate who can and cannot access services and raise questions about "deservingness." In this paper, we use the lens of bureaucracy to explore paperwork as a form of structural violence through its production of "legible" citizens, often through reinforcement of gender stereotypes and moral narratives of deservingness. Between December 2017 and October 2018, we interviewed 41 medical and social service providers and 37 WWUD in two Ukrainian cities. Our analysis revealed that requirements for internal passports and residency permits—the primary state apparatus through which rights to services are granted in Ukraine—compelled participants to continually render themselves visible to the state in order to receive services, despite financial, logistical and other challenges that undermined women's ability to obtain documents. These requirements exposed them to new forms of stigma and exclusion, such as reduced opportunities for employment and losing custody of children. Nongovernmental organizations, due to funding cuts, curtailed direct services such as support groups but became liaisons between clients and the state. They enforced new narratives of deservingness, such as the ability to define "good" behavior or reward social relationships with agency staff. Ukraine's current reforms to social safety net institutions present an opportunity to interrogate underlying assumptions about spheres of responsibility for the country's most marginalized and stigmatized groups.

Keywords

Women; Ukraine; Drug Use; Social Services; Health Care; Access; Documentation

Introduction

Since the collapse of the Soviet Union in the early 1990s, Ukraine has struggled with dual opioid drug use and HIV epidemics. The majority of HIV infections occur among people who inject drugs (PWID) and their sex partners (Booth et al., 2007, 2009; Vitek et al., 2014). In Ukraine, women currently account for around a third of all new HIV infections, and up to 35 percent of all people living with HIV (Ukraine Harmonized AIDS Response Progress Report, 2014). Estimates suggest an overall HIV prevalence among women who inject drugs between 14 and 40 percent (Des Jarlais et al., 2012). While only 18 percent of the total sample in one study of Ukrainian women living with HIV indicated injection drug use as the mode of transmission, these women represented nearly half of the women who presented with AIDS (Dethier et al., 2018).

Globally, studies have shown that women who inject drugs often have diminished access to drug use rehabilitation, HIV, and other health and social services in comparison with men (Des Jarlais et al., 2009, 2013), or underutilize women-specific services such as maternal health services (Ndimbii et al., 2018). Differences in service utilization can result in gendered health disparities, such as lower adherence rates to HIV treatment and poorer health outcomes (Ortego et al., 2012). Delays in care, lack of access to services, and poorer health outcomes are often rooted in gendered norms, expectations, and relationship dynamics (Barnard, 1993; El-Bassel et al., 2010, 2014; El-Bassel & Strathdee, 2015; Pinkham & Malinowska-Sempruch, 2008). In Ukraine, repressive drug policies, intimidation of people who use drugs, stigma, discrimination, and loss of confidentiality in the service delivery setting impact the ability of women who use drugs (WWUD) to receive essential services (Network 100 Percent Life, 2016, 2017; Spicer, Bogdan, et al., 2011; Tripathi et al., 2013).

The ability to access services is essential to improving health outcomes for vulnerable women, including women with histories of substance use and women with HIV (Ghose et al., 2019). While significant attention has been paid to the intra- and interpersonal factors that may diminish vulnerable women's access to and utilization of services (Boyd et al., 2018; El-Bassel et al., 2010; Pinkham & Malinowska-Sempruch, 2008), only recently has attention shifted to the rules, processes, and bureaucratic structures that systematically exclude or permit different women from accessing critical services and resources. For example, King and Maman (2013) documented that the lack of a residency permit or passport registration presents a significant barrier to services for female sex workers in Russia, and that in order to receive free services, women were required to register as HIV-positive, drug users, or syphilis patients. Knight (2015) explored the bureaucratic management of addicted women in the United States through complex "evidentiary documentation" that required them to prove serious mental illness in exception of substance use in order to receive any social security benefits. Similarly, Radcliffe (2011a, 2009) documented how women who use drugs in the UK employed compliance with bureaucratic demands such as keeping appointments, submitting to drug testing, and enrolling in drug treatment programs to manage their identities as mothers and access welfare resources.

Aretxaga (2003) argues that "the state—as a unified political subject or structure—does not exist," and refers to it as a "collective illusion" (Aretxaga, 2003; p. 400). However, institutions, bureaucratic processes, and "instruments of legibility or invisibility" such as state-sanctioned documents (Street, 2012; p. 2) instantiate the state with a social reality and material consequences. It is through documentation and regulation of who can and cannot access services that individuals and groups become "legible" or "illegible" in the eyes of the state (Scott, 1999; Seo, 2017). Documents, signatures, stamps and the like become proof of statuses and identities. As Frankfurter (2019) argues, documentation is a "productive agent" with the capacity to get things done through the power that is attributed to it (Frankfurter, 2019; 2). Documents are necessary in order to access resources, but they can either threaten or guarantee rights, such as by regulating one's ability to pass through a border checkpoint (Kelly, 2006; Pool, 2004) or inscribing a criminal or dangerous identity within the courts (Drybread, 2016). Documents can be viewed as "the material objects of law and governance" that, when placed in specific social relations and contexts, have material and experiential consequences (Navaro-Yashin, 2007; p. 81). At the same time, state entities often work in tandem with aid organizations, nongovernmental organizations (NGOs) and private entrepreneurs in the realm of health care (among other arenas) in collecting documentation and enacting bureaucratic processes (Aretxaga, 2003).

In the context of health and healthcare for people who use drugs, documentation and rules of participation also raise questions about "deservingness" (Willen, 2012). Rules about who can and cannot access services often reflect culturally and historically-based moral narratives of who deserves protection, aid, and resources (Netherland & Hansen, 2017). For example, sobriety requirements to access addiction treatment or residential services may deter care-seeking and are often grounded in moralistic rather than evidence-based understandings of addiction as a chronic, relapsing condition (Gerassi, 2018; Matejkowski & Draine, 2009; Salyers & Tsemberis, 2007; Tsemberis et al., 2004). Globally, women with histories of substance use and mothers and pregnant WWUD, in particular, are construed as deviant and dangerous for their failure to adhere to idealized norms of motherhood and womanhood, and for harming future generations (Kearney et al., 1994; Radcliffe, 2009, 2011a, 2011b; Sufrin, 2017). In Ukraine, women are similarly expected to adhere to stereotyped gender roles that cast them as responsible for the home and care of children and spouses, and willing to sacrifice their own needs and goals for those of their families (UNFPA, 2012, 2018; Yakushko, 2005; Стрельник, 2017).

In this paper, we use the lens of bureaucracy and documentation to explore paperwork as a form of structural violence (Drybread, 2016; King & Maman, 2013) through its production of “legible” citizens, often through reinforcement of gender stereotypes and moral narratives of deservingness. The framework of structural violence draws attention to the ways in which suffering and inequality are embedded in the taken-for granted practices of everyday life and asserts that these inequalities are the outcome of historical, economic, and political processes (Farmer et al., 1996). We also examine the relationship between the state and NGOs in the provision of services for WWUD in Ukraine and how they perpetuate inequalities by imposing new modalities of visibility that are required to receive services.

Methods

Data Collection

The aims of the broader study were to explore how WWUD in Ukraine access and receive services related to drug use, HIV prevention, mental health, social needs, and sexual health, including gender-specific vulnerabilities to HIV and gendered barriers to service. It also sought to assess the degree of gender responsiveness among service providers who work with WWUD and characterize the relationships between organizations that serve WWUD. Between December 2017 and October 2018, we interviewed service providers and WWUD from two Ukrainian cities, Poltava and Slovyansk. Poltava is a medium-sized city (population 289,000) located in central Ukraine. Slovyansk is small city (population 111,486) located in eastern Ukraine. These study sites were chosen to understand how contextual factors such as economic stability, population size, and number and diversity of service-providing organizations affected women’s access to programs and services.

Service providers included providers from governmental and nongovernmental medical clinics, homeless and domestic violence shelters, drug treatment facilities, and programs for family and youth. Providers included doctors, social workers from NGOs, representatives of prison services, representatives of religious organizations, drug treatment specialists, police officers, civil servants, and NGO directors. For WWUD, we sought a maximum variation sample in each city. All participants were 18 years of age or older and had a range of demographic characteristics and lived experiences, including education level, income level, partner status, whether they had children, and whether they were currently receiving services from any organization.

We interviewed 41 service providers and 37 WWUD across both cities. In Poltava, we interviewed 21 providers and 19 women; in Slovyansk, we interviewed 20 providers and 18 women. We used a combination of direct recruitment and snowball sampling. For interviews with WWUD, participants were recruited through direct contact from agencies that provided services to WWUD. Recruiters also used their own direct contacts to identify women who met inclusion criteria. Women who took part in the research also referred acquaintances to the study team for possible participation in the study. Table 1 contains an overview of the demographic, drug use, and health status of the WWUD who completed in-depth interviews.

For service providers, we worked with an NGO in each city to develop an initial list of organizations that provide services to WWUD. Study team members then contacted these organizations, explained the purpose of the study, and identified a person at each organization to interview. Study staff also asked interviewees to recommend other people to interview.

Interviews with WWUD explored employment and financial status; roles as mothers; interpersonal relationships with partners, parents, and other family members; and forms of socioeconomic aid. Provider interviews explored their experiences related to collaborations with other service providers; the perceived need for women-specific programs; and policy, social, and economic factors that contributed to their programs' successes and limitations. All interviewees provided oral informed consent. All interviews were conducted in Russian or Ukrainian based on the participant's preference by bilingual, native Russian and Ukrainian speakers. Interviewers were master's level sociologists with extensive experience collecting and analyzing qualitative data among service providers and marginalized populations in Ukraine, including people who use drugs and those living with HIV. Interviews were audio recorded. WWUD who completed the interview were compensated 300UAH (approximately 10USD). This study was reviewed and approved by the Institutional Review Board at the [AUTHORS' INSTITUTION] and the Sociological Association of Ukraine.

Analysis

Interviews were transcribed verbatim, translated from Russian or Ukrainian to English by 3rdparty professional translators and checked for accuracy by bilingual members of the research team who also conducted the interviews. Original and translated interviews were uploaded to MAXQDA for coding and analysis. Transcripts were coded and analyzed by the authors for emergent themes using principles of grounded theory analysis (Strauss & Corbin, 1990). The research team comprised of US-based researchers including two PhD-level anthropologists who have been conducting ethnographic and qualitative research in Eastern Europe for more than two decades, and a tri-lingual (Russian, Ukrainian, English) Ukraine-based group of researchers that included a PhD-level sociologist, two master's level sociologists, and a master's level epidemiologist. Qualitative analysis of the interviews proceeded through a multistep process that included open coding and axial coding (Carey et al., 1996; Ryan, 1999; Strauss & Corbin, 1990). In open coding, team members independently read the same transcript and identified preliminary *a priori* and inductive coding categories. For WWUD, *a priori* codes included types of services accessed, clients' relationships with family and health care providers, substance use, HIV and drug use disclosure, parenting and motherhood, and financial status. For providers, *a priori codes* included program development, funding, organizational goals, and collaborations and referral processes. *A priori* codes that cut across all interviews included attitudes about gender roles and people who use drugs and rules of program participation. Inductive codes that emerged from the data but not explicitly asked in the interview included situations with documents, “me versus them,” violence, and “being a goner.” Team members then individually coded the same transcript using the preliminary coding scheme. After discussion, the coding tree was revised, and a different transcript was coded using the revised coding tree. The process was repeated until all team members were satisfied with the final coding tree. Research team members then independently coded the remaining transcripts with the final coding tree, periodically checking for consistent use of codes.

During axial coding, categories and themes were explored in relation to each other, and broader themes that combined and transcended existing codes were identified. For example, the initial coding scheme included codes such as rules of participation in programs, referrals and service coordination, and financial access and paying. These were then organized into a broader theme of “access to programs and services.” Then, we used a complex coding query function to explore these coded segments in relation to other codes that included source of the service (governmental versus nongovernmental), parenting and motherhood, and situations with documents. Participants’ responses in these domains were summarized to understand the range of experiences, including typical and atypical experiences. Further analysis explored differences in perspectives on access to services between clients and providers, and between providers who worked at different types of organizations (e.g., NGO vs. government). All names used below are pseudonyms.

Results

Becoming Visible

To receive services, one must first become visible to the state, often in the form of official documentation. In Ukraine and other post-Soviet contexts, rights to benefits and resources have historically been linked to place. In the Soviet Union, an obligatory system of registration of permanent address—known as *propyska* [Ukr: Прописка, Ru: прописка)—authorized the holder to reside in a particular town at a specified address (Light, 2012) and served as the “precondition for all benefits and civil rights: jobs, housing, medical insurance, public assistance, ration cards, education, the right to vote, even access to public libraries” (Hojdestrand, 2009, p. 24). While this *propyska* system was abolished in contemporary Ukraine after the collapse of the Soviet Union, a system of formal residency registration continues in the form of a stamp (also called “propyska”) in the Ukrainian internal passport. The internal passport, which Ukrainians obtain when they turn 16, functions as a form of citizenship documentation. It serves all purposes of internal bureaucracy required to purchase a car or home including banking, voting, and financing. The *propyska* and present-day residency registration is a technique for documenting individual identity, which can be both emancipatory and repressive and can both stigmatize or secure a group’s rights (Abrahamson, 2004; Caplan & Torpey, 2001).

The internal passport and residency registration are the most essential pieces of documentation people need to receive state-funded services. Residency registration allows individuals to access a variety of services, including healthcare. It also governs the location of services that individuals are permitted to access. Without an internal passport, a person cannot access services provided by state-run entities, is forced to go through lengthy and expensive bureaucratic processes to obtain it, or must resort to procuring counterfeit documents. The situation that resulted from Russia's military aggression in Ukraine laid bare the problems that can arise when people in need do not have proper documentation, particularly residency registration or the internal passport itself. Slovyansk is in Donetsk Oblast, the location of the ongoing Ukraine-Russia military conflict. Given its proximity to battle, Slovyansk became the destination for people displaced by the war. Similarly, when Russia annexed the Autonomous Republic of Crimea in 2014, residents fled to avoid conflict or live in mainland Ukraine where they could access harm reduction and drug treatment services such as opioid substitution therapy (OST) (Carroll, 2014; Anonymous et al., 2014).

When people fled, many either left without their documents or never had them in the first place. In other circumstances, they had local versions of an internal passport, Soviet-era documents they never updated, or Russian-issued internal passports that were not legitimate forms of identity documentation from the perspective of the Ukrainian state. People may have lost their passports, had them stolen, or not recovered them when they left prisons. They also could have been released from prison to an address that was inconsistent with the formal place of residency indicated in the passport. Without these documents, people no longer had rights to the services of the state and lack of formal registration could be used as a reason to deny them services. A social worker in Slovyansk compared the situation to "gypsies wandering" with "neither a residence permit, nor documents." Yura, who directed programs for ex-inmates at an NGO in Poltava, described a former prisoner from Crimea as having lost all social and statutory ties to his home without a residence permit in Poltava. Yura described how the NGO stepped in to prepare documents, write letters of recommendation to state entities, attest that they would help their client with housing, clothing, and other social issues, and present the client's case to the court before his documents could be restored.

Residency-based rights can be especially problematic for women experiencing interpersonal violence. One staff member of a nongovernmental homeless shelter in Slovyansk recounted the experience of a client who was not registered in the town where she lived with her partner and their son. Even though her partner beat her, she felt that she could not leave him due to the consequences of not being registered:

> [Recounting the client's words] "We've lived as a family for 10 years. [We have] a 9-year-old boy, and [my partner] has been beating me for 10 years, and I live with him. I have nowhere to go. My parents live in Mayaki [a small village near the Ukrainian border with Moldova, approximately 700 kilometers away], and I live here in Slovyansk with him." And he is a cohabitant, I guess. [The] child is registered – he can claim an apartment. "And I live with him – I'm nobody at all. And how can I leave him? The child will be left without shelter, and nobody needs me."

The provider concluded that while someone might determine that this woman was “dependent” on her partner, it was the system of registration that created this dependency. She did not have official residency apart from that granted through her connection to a child in an apartment where *he* was officially registered, even though she had been living with her partner for years. She worried that if she took her son out of the apartment, both she and her child would lose rights to shelter and services due to lack of official registration. Without registration, this woman concluded that not only was she “nobody” but that she had no rights: her sense of personal agency was severely constrained.

Despite the benefits that official status can confer, both clients and providers criticized the system because it often excluded the very women who need the most help. Ida, a program manager for an NGO that worked with women, children, and other vulnerable groups in Poltava, explained that the Poltava region had a government-run maternal and child health center whose primary role was to prevent child abandonment. However, WWUD, alcohol-dependent women, and women with HIV could not receive services (including housing) from this organization. Even though the center had capacity for 15 women at a time, it was underutilized due to registration restrictions:

> If she has another [child], she will not get [served] there. Or if she has HIV, she won’t get services there either. The same is true for people addicted to drugs. In general, to get services there, you need to be quite a prosperous woman: to have a passport—a residence permit—because to be sent here … she must have a residence permit in Poltava region. If she does not have any registration, and the Center is financed from the regional budget, it has no right to … pay for her services. [Even if] she has lived here all her life … but she is not local [based on her registration status]. [Ida, program manager, Poltava]

In Ukraine, both women and men, people who use drugs and those who do not, are bound by residency-based access to services and the accompanying documentation it entails. While problems with documents can affect anyone, the consequences for WWUD can be more pronounced and detrimental. Paperwork is especially crucial for securing or retaining parental rights, and women in Ukraine are the most likely to care for children (UNFPA, 2012, 2018). For some women, the task of acquiring all the necessary documents and signatures seemed insurmountable and designed to make them fail. For example, changing registration is time-consuming and difficult and does not allow for flexibility or changing circumstances, as Alona from Poltava described. As a single mother, Alona received a governmental subsidy. To receive this subsidy, she needed to submit documentation that her ex-husband paid alimony. Unfortunately, he lived and worked in Kharkiv, a city about 200 kilometers and an expensive bus or train ride away:

Respondent: I have difficulties all the time … I have to go to Kharkiv constantly: get a certificate that I get alimony … every six months—registration. That’s it, of course … it takes a lot of time.

Interviewer: But can it be transferred to Poltava in some way?

Respondent: Unfortunately, it's impossible. He works there. He should pay from his place of work … For me, this is problematic. More expenses … They constantly make some mistake. Either the time period was printed incorrectly or something else. [Alona, 31 years old, 2 children]

Because benefits were tied to place—her ex-husband's workplace—Alona had to regularly travel from her current to her former home. She had to continually render herself visible to the state to receive services, illustrating that maintaining visibility—and therefore services—is an ongoing process in which people must "compel the state to see them" (Street, 2012; p. 2). The residency permit is a "relational technology" (Street, 2012, p. 15) that requires citizens to actively maintain a relationship to the state. However, the efforts that one must undertake to become "a human being" visible to the state revealed the precariousness in which marginalized populations often live and the tenuousness of visibility.

Managing and Regaining Parental Rights

Apart from the internal passport and residency registration, women in our study encountered myriad situations in which they needed to produce documentation to receive services or be granted certain rights. In the context of their efforts to maintain, retain, and otherwise manage their rights and roles as mothers, these documents often codified the conditions under which a woman was categorized as a "fit" mother. Women's demonstrations of caring for their children went unrecognized until they were formally documented.

The importance of having the correct documentation was summed up by Rina, a 28-year-old woman from Poltava who had voluntarily surrendered her parental rights at the behest of her husband. Her husband had convinced her that it would be easier to regain custody of their children if they placed them in an orphanage themselves, rather than wait for the state to take them. Her four-year-old daughter was living in the regional AIDS Center. Rina regularly visited her daughter because she wanted her daughter to be able to recognize her, although she was restricted to only seeing her through the window. Rina asserted that the staff tried to prevent her from seeing her daughter by claiming the daughter was under "quarantine," which she later learned was not true. She continued these visits, despite her perception that the staff at the Center "mocked" and "tortured" her. When she tried to retrieve her children, Rina encountered a series of prohibitive requirements, such as renovating her apartment, rules for visiting children that she could not follow, and the submission of a written application with references:

> To collect heaps of references to apply for help in these organizations. Formalities. Now when you have a piece of paper – then you're a human being. You do not need anything else. Go, get a piece of paper, and you're a person. You're nobody without a piece of paper. [Rina, 28 years old, 3 children]

Ultimately, Rina was unable to regain custody of her children. This need to document and make official one's worthiness as a "fit" mother was echoed by providers as well, who confirmed that in order to regain or retain custody of their children, women needed certificates that they had been in drug treatment for a certain amount of time, that they had a job, or that their housing was "adequate" for children.

Maya, a 36-year-old woman from Slovyansk recounted her experience trying to regain custody of her son who had Down Syndrome. On the advice of a social worker, she voluntarily placed him in an orphanage for children with disabilities soon after he was born, rather than have custody transferred to other family members, as had happened with her two older children. After two years, Maya was unable to get him out of the orphanage. She did not visit him very often in the orphanage—not because of lack of means or desire—but because she felt mistreated there and believed the staff were biased against her. Regarding documentation, she described two problems. First, getting the required documents in order to regain full custody of her son was impossible because the services providers did not help her: "The social services, guardianship agencies and everyone else do their best so that I don't get the papers that I need in order to take the child." Second, she thought that providers were more concerned with documents than caring for her child. She said that the only person who called her from the orphanage about her son was "some shitty lawyer who is responsible for the papers there, but not for the condition of my child." She described her son's condition when she finally got to see him:

> The "Antoshka" orphanage took my child … When they took him away from me, he could hold his head, he tried to sit, more or less. He was 7 months old. Now I have a child who does not even hold his head up and he is like a skeleton. There he was, spitting up, spitting up, constantly spitting up at them. And, when I was talking to the doctor in the hospital, the doctor said: "He's already recovered." I opened his diapers and there were just bones there. And now I understand who I am. A drug addict, a prostitute. [Maya, 36 years old, 3 children]

This mother encountered what she saw as neglect in her son's care, revealed in his undernourishment and backsliding on key developmental milestones. In her care, she believed, her son would have fared much better. Nevertheless, the state used her status as a person who uses drugs to disqualify her as a suitable parent. The lack of documentation materially instantiated this foregone conclusion.

Bureaucratic Failures and Nongovernmental Interventions

Women did not have documentation for many reasons, including paperwork that went missing in abrupt moves, lack of formal registration of place of residence, inability to pay for health screenings necessary to obtain paperwork, and reluctance to formalize an identity as a person who uses drugs. In addition, obtaining some official status with attendant documentation created a conundrum for WWUD. In Ukraine, to receive drug treatment services such as OST, a person must register with the local narcology clinic as a person who uses drugs. OST clients also need confirmation that they are employed to get some benefits at the drug treatment site such as flexible dispensing hours. However, they often feared asking their employers for such confirmation because they did not want to disclose that they used drugs and codify their drug use status:

> The site requires a certificate that you work. Well, how can I get this certificate that I work, in a situation where if they know that I am on OST, they will fire me? This is a problem. You cannot get this certificate. Will I come to my boss and say: "I'm a drug addict. Give me a certificate in order to have an opportunity to get drugs?" [Marianna, Slovyansk, 25 years old, 1 child]

Marianna worried that receiving this certificate would have caused her employer to see only one aspect of her identity, her drug use, conclude that her only motivation to work was to get money for drugs, and not hire her. A similar situation could arise regarding parental rights, given that in Ukraine, drug addiction itself is statutory grounds for termination of parental rights, even if a woman has entered treatment (Pinkham et al., 2012).

In addition, people on OST are connected to specific narcology centers where treatment is mostly administered in-person on a daily basis (Bojko et al., 2015; Mazhnaya et al., 2016). Radik, who worked as the head physician at a narcology center in Slovyansk, recalled the experience of a client who was registered to receive OST at his clinic, but had a child who needed to undergo a medical procedure in another city. Without appropriate permission and codification of this permission in the requisite documents, the mother could not be with her child for the operation:

> Her child was being operated on in another city, and she asked to give her medication on hand [that is, take a multi-day supply of OST with her to travel to the other city]. We could not do that without the documents from the treatment site where her child was, and they refused to give any confirming document, apart from an incomprehensible piece of paper with incomprehensible seals … We sat down with her and calmly discussed all the [options]. I explained to her: “I cannot give you the drug. I’ll give it to you today. Tomorrow you’ll come and I will not be here anymore. Criminal proceedings will be instituted against me for breaking the law. Do you want this?” “No, I do not want that.” “So, let’s find some comprise. It won’t benefit us, but it will be convenient for you.” [Radik, head physician at a narcology clinic, Slovyansk]

The provider decided to keep the narcology center open outside normal medication disbursement hours so that the client could get a single dose of her medication, go to the city where her child was being operated on and retrieve her, and then return to the narcology center to get her next dose. This example illustrates how place-based registration requirements often supersede other considerations and dynamic life circumstances, forcing women to choose between their own health and well-being and that of their children.

Many of the women we interviewed expressed deep gratitude for the help they received from various NGOs in their efforts to restore or obtain residency permits, passports, and other documents. Encounters with governmental bureaucracies often left participants frustrated and they attributed their inability to get services to their identities as people who use drugs. As one woman in Slovyansk concluded, “If a person looks like a drug user, nobody wants to help them” (Zinaida, 40 years old, no children). In contrast, participants saw NGOs as places where they could get help, as Veronika, a 46-year-old woman who lived in Poltava said: “They understand me better here. They support more and understand better than anywhere else—than in those polyclinics and everywhere. Like … they recoil [in other places].” Yulya, a 37-year-old woman from Slovyansk described the local NGO that served people with histories of substance use as willing to help her, no matter the circumstances or the condition: “I can phone any time. Or I’ll just crawl in here, no matter how I crawl in, dirty, smelly, high, drunk … I know that I will always be helped here.”

However, the scope of services an NGO could offer fluctuated, often in reflection of changing funding levels and priorities from regional, national, or international donor organizations (Harmer et al., 2013; Anonymous et al., 2017; Spicer et al., 2011b). The Ukrainian public health response to HIV, which includes services for people who use drugs, is strongly shaped by foreign donor organizations such as the Global Fund, the President's Emergency Plan for AIDS Relief (PEPFAR), and the United Nations Development Program (UNDP). The national response has been severely underfunded, with little funding for care and support for people living with HIV (PLHIV), medication procurement to treat sexually transmitted infections and Hepatitis C, and prevention activities for the most at-risk populations. Moreover, since 2004 two large Ukrainian NGOs—the Alliance for Public Health and the All-Ukrainian Network of People Living with HIV/AIDS—have been the country's Principal Recipients of Ukraine's Global Fund grant, due to perceived corruption and mismanagement of earlier grants given to the government (Doyle & Patel, 2008; Harmer et al., 2013). Local and regional NGOs rely on this international donor money to support their programs. When funding priorities change or grant money is reduced, the NGOs will cut their programs and services without an alternative source of funding.

Zinaida, a 40-year-old woman from Slovyansk, lamented the reduction in services at the local NGO:

> Well, they used to open at 9 in the morning and I could come and spend almost the whole day here. We watched TV, and we were given tea and biscuits, and we could get a haircut, and we could sew something. There was a playroom for children, so we could leave them here. And [they] conducted all sorts of trainings. I mean, we got together and discussed our problems. We had a lot to do every day. Right now, I can only come and get a syringe or something else … And right now, it's quite different. They almost have nothing. Nothing is left. [Zinaida, Slovyansk, 40 years old, 3 children]

Without funding to offer full services such as harm reduction programs, medical care, legal aid, and facilitation of document acquisition, liaising between clients and governmental institutions and finding solutions to bureaucratic hurdles became key functions for NGOs, as one client, Sveta from Slovyansk, explained:

> If I have a certain situation or some kind of conflict or misunderstanding … If I have problems with the police, well, with anyone, with the Social Security … If I cannot get any help, then I come here. And here they try to solve my problem … Where should I turn to with this problem in order to issue papers or to do something to solve this problem? I can get help. Well, not help, but a solution to this situation. [Sveta, Slovyansk, 37 years old, 4 children]

That is, the NGO staff helped clients problem-solve the issues they encountered with state-level institutions rather than rendering direct aid themselves. For clients, this often meant that they had to forge personal relationships with individual NGO staff to get the help they needed. Women characterized their relationships with NGO staff in familial or friendly terms. The drawback, however, was that some women felt a sense of embarrassment, shame, or fear of disappointing the NGO social workers they relied on for help. As Katerina, a 37-year-old from Poltava explained, although she often turned to a local NGO for help, she sometimes felt that she "did not live up to the expectations" of her social worker because she continued to use drugs. She worried that social workers would not help her as a result. Katerina recounted that a social worker actively punished her for not living up to expectations by ejecting her from housing and treating her in a demeaning and unkind manner. In this way, social workers' personal feelings and decisions had the power to exclude or restrict access to services, as well as shape the course of treatment. As individual social workers changed roles, advanced in their careers, or further professionalized, their clients felt they no longer had anyone they could turn to for help, as Violetta, a 47 year-old woman from Poltava lamented: "Sorry, [social worker] but I know for sure that you won't call me. I don't believe you, for the life of me. If it were ten years ago, you would have called me."

The frustrations with NGOs expressed by their current and former clients revealed two simultaneous problems. First, if so much of clients' ability to receive services did not pivot around documents and paperwork, NGOs could have spent precious time and resources providing women more crucial services. Second, the lack of funding severely limited what NGOs could do in terms of programs and direct services. Therefore, the women were forced to seek support from state institutions poorly equipped to support them.

Discussion

Analyzing "situations with documents" provides a window into the kinds of governance that states and NGOs enact. As Drybread (2016, p. 412) observes, prejudice and neglect are "embedded in even the most mundane bureaucratic procedures." Documentation requirements enact a form of structural violence on already marginalized women through the codification of marginalized, stigmatized, diseased, or disabled identities and prevent them from accessing the services and resources they need (Drybread, 2016; Gupta, 2012; Knight, 2020). As the tremendous bureaucratic hurdles to receiving support suggest, benefits are not given out automatically to WWUD. Further, when women are unable to get services, they are blamed for their own misfortune due to their inability to obtain the correct documents, befriend an advocate from an NGO, or navigate a complicated bureaucracy.

Legibility can be a double-edged sword, creating the opportunity for both access to and denial of services. The women in this study were overwhelmingly poor and struggled to meet their basic needs. Such women often interact with the state when they are their most vulnerable—in need of medical care, fleeing domestic violence, giving birth, or seeking shelter. When women complained about "problems with paperwork," they were calling attention to their subject positions as stigmatized women vis-à-vis health care and social service bureaucracies. Carroll (2019) documents a continued inequitable distribution of rights in contemporary Ukraine and shows how administrative tools can be used for "differential management of select portions of society" (Carroll, 2019, p. 185), with people who use drugs cast as the ultimate undeserving "other." Social and moral constructs are particularly salient in Ukraine, where, as Carroll suggests, "Ukrainian culture holds up willfulness and sober self-determination as the ideal manifestation of the social self" (2019, p. 27).

Ukraine and other post-Soviet states in Eastern Europe have been marked by now decades-long attempts at bureaucratic reform, reconfigurations of the role of the state in social service provision, and reimagining who constitutes a legitimate citizen of the state with full rights and privileges. As Petryna (2002) illustrated in her analysis of the Ukrainian response to the Chernobyl nuclear disaster in the context of concurrent democratization and the development of a market economy, existing forms of inequality were naturalized through selective social protection and access to health care and other social services. To receive government support, Ukrainians fashioned themselves into “biological citizens” in a process through which they could then access scarce state resources by claiming biological and bodily damage. Similarly, Haney (2002) showed that whereas women in socialist-era Hungary occupied a special position vis-à-vis the state and could draw on their identities as mothers to receive financial and social support from a variety of state and local agencies, with the introduction of neoliberal economic restructuring and the adoption of means-tested social welfare targeted at specific groups, women could no longer draw solely from their identities as mothers to receive social and economic support. Rather, state institutions “closed their doors to all but a few” (Haney 2002, p. 247), and those who were able to access welfare services were increasingly stigmatized as they needed to demonstrate greater states of mental, psychological, and physical deprivation in order to justify their need for assistance and support. Hansen et al (2014) refers to this system in which those seeking government aid must become a “permanently disabled pathological patient” as the “pathologization of poverty” (Hansen et al., 2014). Medicalizing poverty and blaming individuals for their disadvantage obscures structural vulnerabilities that emerge from reduced governmental support for the poor and marginalized.

Bourdieu (1999) argues that in contemporary neoliberal states, the “left hand of the state”--the sphere of government with responsibility for institutions of social welfare, such as housing, schools, and health care--is in conflict with the “right hand of the state,” or the technocratic and bureaucratic sphere concerned with regulatory and punitive functions such as justice, police, and corrections to control deviance (Bourdieu, 1999). Healthcare services mediate between patients and governments, and can act as agents of either the therapeutic or punitive forms of government (Berlin et al., 2019). For people who use drugs, it is the NGO sector, rather than traditional healthcare settings, that serves this mediating role. Rather than displacing state functions and practices (Trouillot, 2001), NGOs liaise between clients and the state. The state-NGO alliance is well-developed in Ukraine, in large part due to Ukraine’s status as a major recipient of international donor funding to combat its HIV and substance use epidemics (Harmer et al., 2013; McGill, 2016; Anonymous, 2017; Anonymous, 2014; Spicer et al., 2011b). NGOs in Ukraine simultaneously act as agents of the state and/or re-instantiate the conflict between the punitive and therapeutic modes of governance. As Katerina’s experience highlights, NGOs may not institute the same bureaucratic hurdles as the state that prevent people from accessing services, but they do enforce other narratives of deservingness, for example through the abilities to define “good” behavior and reward social relationships with agency staff.

Both the technocratic and punitive forms of government are infused with a moral logic, and strategic deployment of rules and requirements to grant or deny rights or services reveals and reinforces ideological and political debates about entitlements. Women in particular are subject to scrutiny because, as Campbell (2000) illustrated, “women embody a collision between normative expectations of how citizens should conduct themselves as citizens and how women should behave as women” (p. 4). According to Knight (2015), this “politics of recognition” requires social and economic inequalities to be made legible through a diagnosis such as mental illness to receive services. In Ukraine, bureaucratic practices of recognition through paperwork render WWUD visible to the state and influence their ability to receive housing and income assistance, maintain custody of their children, and access healthcare and welfare services.

Conclusion

In the tumult of socialism’s collapse in Eastern Europe in the 1990s, Gal and Kligman (2000; p.3) argued that a gendered perspective on social and institutional transformation can reveal “coded arguments that constitute new state-subject relations, moralize positions on diverse other issues, authorize new political mechanisms, and legitimate individual politicians” (Gal & Kligman, 2000, p. 34. Likewise, focusing on the experiences of marginalized women provides deeper analytic insight into who is and is not envisioned as a legitimate citizen and who can stake a claim of rights to resources. Ukraine continues to undergo rapid transformation of political, economic, and social safety net institutions. While the Ukrainian constitution guarantees the right to social protection through social insurance, social benefits (financial transfers), and social services, as the above data reveals, access to these benefits is neither guaranteed nor easy to secure, especially for an already marginalized group such as WWUD. In Ukraine, healthcare has been a primary site of continued reform, including recent moves to a single-payer system and elimination of residency-based service provision (Nitzan et al., 2018). With the Global Fund withdrawal, NGOs are essentially handing service provision “back” to the state. The questions arise, then, whether 1) NGO efforts and initiatives are being absorbed back into the state as financial support for NGO programs dwindles and 2) whether state institutions can facilitate more humane approaches to providing services for populations that have historically been subject to moral scrutiny.

Regardless, NGOs, government agencies, donors, and healthcare providers must collaborate in order to share resources and reduce obstacles to WWUD’s path to recovery from drug use disorders (Pinkham & Shapoval, 2010). Providers who work with WWUD, from both state and NGO sectors, should be trained in structural competency--the institutional and organizational processes that govern the division of social resources and sustain social roles and norms, including those surrounding WWUD (Knight 2020). Our results build upon other research that shows that when stigma against WWUD becomes legitimized and codified into law and organizational policies, WWUD and their children experience poorer health outcomes, partly because WWUD tend to avoid accessing care as a way to avoid punishment or further stigmatization (Faherty et al., 2019; Knight, 2015; Knight, 2020). Training in structural competency would allow providers to recognize the broader context within which WWUD seek care and follow medical recommendations, and account for structural barriers that WWUD experience in their interactions and treatment plans (Knight 2020). In addition, policy changes, such as reforming the drug user registry so that WWUD do not have their children removed as easily and can regain custody without as many bureaucratic obstacles when they demonstrate competency (Pinkham and Shapoval, 2010), are also critical.

These specific and programmatic reforms are necessary to improve access to services among WWUD and other marginalized and stigmatized populations. However, our findings suggest that widespread uptake and implementation of these reforms demands an interrogation of the fundamental assumptions of who can and should access services, where resources should be spent, and what values infuse the bureaucratic logic of the welfare state. It also requires reconfiguration of spheres of responsibility, given decreased funding for the NGO sector, where support for marginalized and stigmatized groups has historically been placed. Without a fundamental reimagining of who deserves aid and support, documents, bureaucratic processes, and compliance with norms of good behavior will continue as forms of structural violence against the most vulnerable.

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- Access to services is essential to improve health outcomes for women who use drugs
- Bureaucratic structures systematically exclude some women from accessing services
- The bureaucratic process of document procurement is a form of structural violence
- NGOs impose new forms of moral scrutiny on vulnerable populations

Table 1

Participant demographics.

	Slovyansk (n = 18)	Slovyansk Percent (%)	Poltava (n = 19)	Poltava Percent (%)	Total (n = 37)	Total Percent (%)
Average Age	35	N/A	33	N/A	35	N/A
Financial Situation						
"Below Living Wage"	10	55.6	6	31.6	16	43.2
"Can Afford only Essential Needs'	5	27.8	10	52.6	15	40.5
"Enough Resources to Meet Most Needs"	2	11.1	3	15.8	5	13.5
No Answer	1	5.6	0	0.0	1	2.7
Relationships						
Single	4	22.2	6	31.6	10	27.0
Live with Partner, Not Married	5	27.8	6	31.6	11	29.7
Married	1	5.6	7	36.8	8	21.6
Divorced	1	5.6	0	0.0	1	2.7
Widowed	4	22.2	0	0.0	4	10.8
Other	1	5.6	0	0.0	1	2.7
Don't Want to Answer	2	11.1	0	0.0	2	5.4
Ever Been Homeless						
Yes	9	50.0	8	42.1	17	45.9
No	6	33.3	10	52.6	16	43.2
Don't Want to Answer	3	16.7	1	5.3	4	10.8
HIV						
Yes	7	38.9	8	42.1	15	40.5
No	10	55.6	11	57.9	21	56.8
No Answer	1	5.6	0	0.0	1	2.7
HCV						
Yes	12	66.7	14	73.7	26	70.3
No	5	27.8	5	26.3	10	27.0
No Answer	1	5.6	0	0.0	1	2.7
Ever Incarcerated						
Yes	7	38.9	10	52.6	17	45.9
No	8	44.4	9	47.4	17	45.9
No Answer	3	16.7	0	0.0	3	8.1
Number of Children						
0	4	22.2	6	31.6	10	27.0
1 or 2	7	38.9	12	63.2	19	51.4
3+	6	33.3	1	5.3	7	18.9
No Answer	1	5.6	0	0.0	1	2.7