Women who use drugs and HIV

Joint briefing paper

Women and Harm Reduction International Network and International Community of Women Living with HIV

2023

This briefing paper was developed through collaboration on an internship between the Women and Harm Reduction International Network (WHRIN) and the International Community of Women Living with HIV (ICW). The purpose of the paper is to promote discussion, learning, consensus-building, and advocacy among people living with HIV/AIDS (PLHIV) networks, activists, service providers and other stakeholders to improve rights and health outcomes for women who live with the human immunodeficiency virus (HIV) and who use drugs.

This paper is based on a review of literature as well as a series of community interviews with women who use drugs who are living with HIV in different regions of the world as well as selected other stakeholders who work in the fields of HIV and harm reduction. The experience of women who use drugs and live with HIV along the HIV service continuum and factors that impact their health and rights are explored. The paper seeks to identify the key barriers faced and make recommendations on how to address them for improved health and rights outcomes.

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Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ARV	Anti-Retro Viral
ART	Anti Retro Viral Therapy
GBV	Gender-Based Violence
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV
IPV	Intimate Partner Violence
OAT	Opioid Agonist Therapy
PrEP	Pre-Exposure Prophylaxis
PLHIV	People Living with HIV/AIDS
SGBV	Sexual and Gender-Based Violence
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health and Rights
STI	Sexual Transmitted Infections
UNAIDS	The Joint United Nations Programme on HIV and AIDS
WHRIN	Women and Harm Reduction International Network

Background

It is a burden to be a woman in this patriarchal country, and even more of a burden if you are a woman who uses drugs living with HIV.

(Indonesia, community interview, Nov 2022)

Women who live with HIV and use drugs face significant barriers to realising their basic health, rights and safety due to stigma, discrimination, sexual and gender-based violence (SGBV), criminalisation, and imprisonment. Women who use drugs are especially at risk of HIV transmission while health and social services such as harm reduction services, HIV care continuum services, SHRH services, and others are rarely adapted to the unique needs and intersecting oppressions experienced by women living with HIV who use drugs.

Women who use drugs are at higher risk of acquiring HIV and viral hepatitis as well as sexually transmitted infections (STI) than the general population.[1] Women make up at least 20% of the estimated 11.3 million people who inject drugs,[2] yet calculations of the population size of women who use drugs are very likely underestimated given the lack of adequate services, pervasive marginalisation and related gaps in data available. People who inject drugs are 35 times more likely to contract HIV than those who do not,[3] and HIV prevalence among women who use drugs is higher than among their male counterparts.[4] One study showed that the pooled HIV prevalence among women who inject drugs was 13% (compared with 9% among men who inject drugs) based on data reported by 30 countries.[5] Numerous studies demonstrate that criminalisation, gender inequality, stigma and lack of services sensitive to their needs, all contribute to increased risk of HIV transmission among women who use drugs.[6,7,8,9] These factors are compounded for women who use drugs who also engage in sex work.[10]

Sexual and gender-based violence

As a woman who uses drugs living with HIV, I have experienced violence from my intimate partner. He said that "a junkie will always be junk". And law enforcement officers just use us - we have to provide sexual activities in order to get drugs.

(Indonesia, community interview, Nov 2022)

Women who use drugs[11] and women who live with HIV[12,13] experience higher rates of gender-based violence (GBV) than women in the general population. The criminalisation of HIV transmission, sex work and drug possession and/ or use leaves women at risk of violence at the hands of police and in closed settings. Women who use drugs are also particularly at risk of intimate partner violence (IPV), GBV and violence at the hands of medical staff including staff of unregulated 'treatment' centres.[14] Sexual and gender-based violence (SGBV) increases the risk of HIV infection among women[15] by increasing syringe sharing, reducing condom use, and increasing barriers to care services.[16] The experience of IPV is linked to reduced adherence to antiretroviral (ARV) medicines and decreased viral suppression in women living with HIV.[17]

A friend of mine who is also using drugs and living with HIV experienced violence from her husband. It happened when she told her husband that she was HIV positive - her husband beat her up and broke her leg. (Kenya, community interview, Nov 2022)

Women who use drugs and live with HIV face violence in medical settings. For example, physical examinations without informed consent or by force and other forms of obstetric violence including forced or coerced sterilisation deter women from seeking medical care.[18]

"They asked me to sign a paper and I didn't know what it was because I was under influence of anaesthesia (post-Caesarean section) - then I found out many years later that it was an approval paper to sterilise me"

(Indonesia, community interview, Nov 2022)

Stigma, discrimination, and criminalisation

Barriers and 'othering' happened to me more and more and I started to get used to discrimination, I almost felt that I deserved to be treated badly.

(Sex worker, using drugs and living with HIV, UK, Dec 2022)

Getting HIV made me realise that I needed to be taken seriously - but being female, and a junkie, - it was clear that I was at the bottom of the list, my life was in their hands but they discriminated against me.

(UK, community interview, Dec 2022)

Stigma and discrimination related to HIV status and to drug use (especially injecting drug use) is gendered and compounded among women who use drugs living with HIV and even further exacerbated if engaged in sex work.[19] Women who use drugs, particularly those living with HIV, face harsher stigma within families and communities and are often perceived as unfit mothers or as ill-equipped to manage their household.[20] Stigma, fear of stigma and self-stigma can deter women who use drugs and living with HIV from accessing health services. Discrimination in medical settings is a human rights violation and can leave women without access to needed services and commodities.

"I have experienced being rejected by the dentist, who complained that they would have to burn the medical instrument that was used to treat us.

(Indonesia, community interview, Nov 2022)

"*Young women who are living with HIV and use drugs are left out because of stigma. Our information is not confidential, and they treated us bad, saying that we are 'dirty'. This makes us not even want to come to the clinic for our medication."*

(Kenya, community interview, Nov 2022)

Women living with HIV and who use drugs in many countries are faced with criminalisation – sometimes even with overlapping criminalisation of HIV transmission, drug use or possession and/or sex work. Criminalisation, as mentioned above, adds to risk of violence and also deters women from accessing health and justice services.

The issue of criminalisation is critical because they are criminalised from both sides. They're criminalised because of the drug use and because of the HIV. And this double, sometimes multiple criminalisation because they are sex workers, leads to discrimination and human right violations.

(Ukraine, community interview, Dec 22)

There will be much less stigma if decriminalisation is applied, there will be a better, healthier approach to women who use drugs living with HIV.

(Indonesia, community interview, Nov 2022)

Inadequate health services

Many HIV responses are not sensitive to women - many interventions are gender-blind, and do not address gender-sensitive issues which are critical for women who use drugs and live with HIV.

(Ukraine community interview, Dec 2022)

Though excellent models for providing health services to women who live with HIV and use drugs exist, health services including harm reduction, HIV care continuum services and sexual and reproductive health services are often not designed with the involvement of women who use drugs and thus frequently fail to meet the actual needs of the women who utilise them.

Harm reduction services reduce negative health, social and legal impacts related to punitive drug policy and drug use. Harm reduction services do not require people who use drugs to abstain from drug use and they provide support to people without judgement, coercion, discrimination, in order to promote their access to health and justice. Harm reduction is well-evidenced and cost-effective in preventing the transmission of HIV, viral hepatitis and tuberculosis.[21] Examples of harm reduction services include the provision of sterile injecting equipment, opioid agonist therapy, and overdose prevention and management training. It is recommended that sexual and reproductive health and rights (SRHR) services and GBV services be integrated into harm reduction services.[22] Despite harm reduction's proven effectiveness in preventing HIV transmission among people who use drugs, these services are still not available in all countries and, where they do exist, they rarely address the specific needs of women.[23]

> *Sometimes the operational time of service providers do not match with our free time. They usually operate from morning until noon, meanwhile our morning is usually hectic with necessary errands. Even when we make it on time, we do not receive friendly services. They think that they are serving a 'junkie' and stigmatise us just because we are using drugs.*
>
> (Indonesia, community interview, Nov 2022)

The lack of childcare facilities in most services discourages access by women with children. Harm reduction services are frequently found in locations that are difficult to get to without transportation or where it is unsafe for a woman to travel alone. Limited opening hours make it challenging to attend for women who have work or domestic responsibilities. Many services lack outreach services that reach women. Services often lack woman employees and staff that are trained in issues specific to women service users, and there is also a lack of women-only spaces. Moreover, there is often gender insensitivity in program delivery.[24] Guidance from the Guttmacher Commission[25] and the WHO recommend that SRHR services be integrated into harm reduction services, but it is unfortunately not yet common practice.[26]

The involvement of women who use drugs and live with HIV in planning, implementation, monitoring and evaluating services can help to address unique needs. For example, Médecins du Monde in Myanmar enabled a group of women to form a committee to plan and implement services including special women's days, peer counsellors, and safe spaces which built trust and improved access to services.[27] Adjustments to harm reduction services to help address women's' needs vary by location but often address maternal and child health; services for women engaged in sex work; and childcare.

Many countries lack services focused specifically on addressing the treatment and care needs of women who use drugs. Women who use drugs faces particular challenges in starting and being adherent to ART regimens which negatively impacts health outcomes.[28] In Kazakhstan, for example, stigma, inconvenience, and unfriendly staff related to women's status as sex workers and/or as women who use drugs are all obstacles to HIV testing.[29] In medical settings, women who use drugs face discriminatory treatment that makes them reluctant to return for further care.

> *"I have to do blood tests and I have vein issues, so getting blood taken is a huge issue for me. My doctor is good and would let me get the blood myself. I need to get 20mils of blood and it is difficult, so it means organising a phlebotomist to get it if I can't do it. I've been going to my groin and even that is difficult. I need scans to check blood flow to my legs. They want me to go to a GP clinic. The GP knows about my HIV but not my drug use, so she doesn't understand. I have to go to the GP as the other service has been reduced. It is difficult for me with the GP for these reasons, so I have to manage the potential stigma from the GP. I have to ask her to put aside any judgmental, biases etc to ask her for tests. It would be good to be able to go somewhere without having to do this, where they are sensitive about women with my background. Without this, it becomes paralysing and we avoid services."*
>
> (UK, community interview, Nov 2022)

Sexual and reproductive health and rights

> *We have seen a lot of harm reduction services in the world that don't spend much time or aren't particularly comfortable talking about and are not knowledgeable about sexual and reproductive health beyond giving people a condom. Many are oriented and staffed to provide services to men. At the same time, we see services for women with HIV—reproductive health services, violence shelters and others—with no comfort or knowledge around drugs issues. Some even exclude women who are using drugs.*
> (Global Fund, stakeholder interview, Dec 2022).

Due to limited SRHR access, women who use drugs often experience a delay in pre-natal care and are sometimes diagnosed with HIV late in pregnancy or when already in labour.[30] Some countries allow compulsory HIV testing, compulsory abortions and termination of custody of women who use drugs or live with HIV.[31]

Misinformation, stigma and discrimination among health professionals can inhibit access to antenatal care by women living with HIV.

> *I have also experienced being rejected by the perinatal health care just because I am a woman living with HIV, I have to go across the town to find a doctor who will help my delivery process.*
> (Indonesia, community interview, Nov 2022)

Criminalisation, stigma and discrimination associated with illicit drug use during pregnancy leads many women to conceal their pregnancy and prevents them from accessing a range of services, such as antenatal care, harm reduction services including voluntary drug treatment programs, and interventions to prevent vertical transmission of HIV.[32] Vertical transmission rates for women who use drugs living with HIV are significantly higher than for other women living with HIV.[33] Laws that make drug use during pregnancy illegal further discourage women from seeking care and support.[34]

> *We still have a punitive article in Family Code, which is stated that we can lose our parental rights based on drug use. Many women are struggling because of this legal norm and social service can abuse because of this article.*
> (Ukraine, community interview, Dec 2022)

> *A women who uses drugs and is living with HIV can be forcibly separated from their children if anybody knows that you are a women who use drugs and living with HIV.*
> (Indonesia, community interview, Nov 2022)

Pregnant women who use drugs in some countries, such as Russia and Ukraine, are coerced by health providers to terminate their pregnancies or to voluntarily give up their children to the state.[35]

For women who use opioids, Opioid Agonist Therapy (OAT) has proven to be safe and effective during pregnancy[36] and is recommended by the WHO to be provided to women who use opioids during pregnancy.[37] However, is still not available in many countries and provided for women who are pregnant in even fewer.[38]

Globally, sexual and reproductive health (SRH) services tailored to the needs of women who use drugs are largely absent.[39] The Guttmacher-Lancet Commission on Sexual and Reproductive Health and Rights (SRHR) recommends the integration of SRHR services with harm reduction services and include: GBV; HIV/AIDS; STIs; contraception; perinatal health services; safe abortion and post-abortion care; infertility and other reproductive health services.[40] (For additional information, please see the WHRIN/Frontline AIDS guide: *advancing the sexual and reproductive health and rights of women who use drugs*[41] and the WHO *Consolidated Guidelines on the Sexual and Reproductive Rights of women living with HIV.*[42])

Incarceration

Punitive drug policy is a leading cause of imprisonment of women; over a third of women in prison are incarcerated for drug offenses (in comparison to one in five of incarcerated men).[43]The United Nations Rules Treatment of Women Prisoners and Non-custodial Measures for Women Offenders (the Bangkok Rules) signed by 193 countries in 2010[44], establishes standards to protect women in prison and promote non-custodial options for women involved with criminal justice systems. Although the countries agreed to find alternatives to incarceration for petty, non-violent offences, incarceration of women who use drugs continues to be accelerated by punitive drug policy. Access to harm reduction and evidence-based treatment in prison for women remains extremely limited.[45]

> *During detention, a woman who uses drugs living with HIV was not allowed to change her menstrual sanitation for 2 days; they did not feed her, let her take a shower and they didn't even give the ARV to her, even though there is an NGO to facilitate ARV access. (This sort of detention can last for around a week). Her condition measurably deteriorated as a result.*
>
> *If a woman who uses drugs living with HIV needs ARV, we have to find alternative ways to ensure treatment continuity. Sometimes their family can bring ARV for them, but more often an NGO must work on it, but then again it needs some amount of money to make it happen. Women that don't have money and so won't be treated.*
>
> (Indonesia, community interview, Nov 2022)

Inadequate surveillance and medical research

National and sub-national surveillance data on progress along the HIV care cascade is often not disaggregated by gender or by key population group[46] or, when that data that is available, is not used in planning. The majority of HIV treatment studies are not related to women who use drugs with associated viral load, mortality, and barriers to and facilitation of treatment uptake and adherence issues particularly poorly documented.[47] Understanding the ways in which GBV acts as a barrier to accessing HIV services, treatment, and care, such as ART or PrEP, should inform public health-oriented HIV response strategies while providing important insights into how to best meet individual women's HIV care needs.[48,49] The gaps in systematic surveillance and research make community-led monitoring (and meaningful engagement of communities in planning and evaluation) especially important.

> *Because they are stigmatised more than men, they are also among the affected populations that are least visible, this is why community-led monitoring and assessment is so important because again women who use drugs or women living with HIV who use drugs often know each other and are part of networks - but those women might not be visible to the people who are dropping into the country or dropping in from the capital or whatever to do the assessment survey.*
>
> (Global Fund, stakeholder interview, Dec 2022)

Women likewise continue to be under-represented in HIV pharmaceutical research.[50] Information on the effects of different drugs on women's SRH, particularly on menstruation regularity and pregnancy is lacking.

> *Research on drug interactions on women, the research is not happening nor is it a priority research gap. Medicinally, we lack research about our bodies, long term effects of the ARVs and drugs, menopause, aging. I get bone scans that show bone thinning, partly caused by aging, menopause and ARVs. Why can't there be a single service for women like me; there is rhetoric about holistic medicine! Doctors tend not to pay attention to our issues and as a result people get sick and die. I can feel these doctors thinking 'hmmm how much heroin does she have' - it is not nice thinking.*
>
> (UK, community interview, Nov 2022)

Exclusion from decision-making forums

Women living with HIV face gendered barriers to meaningful participation and are often marginalised within the broader feminist movements, while women who use drugs are often not included in forums to address women's rights or rights of people who live with HIV. Despite work within the feminist movement to advocate against 'victim blaming', women who use drugs living with HIV are still often held accountable within the movement for the marginalisation they experience. Gradually growing cooperation between groups of women using drugs and feminist groups is beginning to counter this tendency.[51]

The meaningful involvement of people affected by HIV is broadly acknowledged as essential to ensuring effective and rights-based programming but for women who use drugs and live with HIV there is still considerable progress to be made.

> *Women who use drugs and are living with HIV have to ask for their involvement in advocacy, the stake holders won't reach out to us, so we have to beg for our involvement; we are considered invisible for them.*
>
> (Indonesia, community interview, Nov 2022)

> *Women generally, and women who use drugs especially, are often not proportionally represented in strategic planning and funding allocation processes.*
>
> (Global Fund, stakeholder interview, Dec 2022).

> *We have to get involved in policy making, even when we have good participation from key populations in CCM, there is still no seat for women who use drugs in the CCM.*
>
> (PLHIV network, stakeholder interview, Dec 2022)

Around the world, human rights defenders, including those representing women who use drugs and who are living with HIV, are being limited by the effects of shrinking civil society space (*see for example the case of Natalya Zelenina*[52], *and the new report on the ASEAN region*[53]). Extremism and populism must be resisted and reversed to preserve the human rights of all citizens.

Practical steps must be taken to realise the meaningful involvement of women who use drugs and live with HIV within responses to HIV. Technical support, funding for advocacy work and core funding for women-led and community-led organisations is needed. Support should be provided to enable cooperation between groups of women living with HIV and women who use drugs.

> *It is very clear that women who use drugs have to be involved in discussion about their health and rights. It should be a community response and women's voices need to be the center of the response as well. Also, in community-led responses it is really important to have capacity building, but not many donors want to invest in capacity building. Advocacy cannot be done without financial back up.*
>
> (PLHIV network stakeholder interview, Dec 2022)

Women-led network and other networks of people living with HIV should reach out to women who use drugs and expand their involvement in their own decision-making and advocacy work.

> *My doctors don't want me, the HIV community don't want me!!! This is discrimination, it was so important to have that connection with the other women.*
>
> (UK, community interview, Dec 2022)

Conclusions

Countries' efforts to address HIV and viral hepatitis could be significantly delayed if women who use drugs are left behind.[54] Intersecting stigma, criminalisation, gender inequality, drug use, engagement in sex work and HIV status combine to leave women who use drugs with tremendous challenges to their health, rights and safety. However, there are opportunities to advocate for better responses to these challenges.

> *There will be much less stigma if decriminalisation is applied, there will be a better, healthier approach to women who use drugs and women living with HIV.*
> (Indonesia, community interview, Nov 2022)

> *Addressing gender related barriers and discrimination is a strategic priority for the Global Fund, so this can be a leverage point in the country dialogues that lead up to each funding request.*
> (Global Fund, stakeholder interview, Dec 2022).

Addressing SGBV through research, advocacy and providing services tailored to women who use drugs and who live with HIV will have positive impact on HIV transmission and HIV treatment outcomes as well as the realisation of rights and safety of groups of women who are severely affected by violence.

Decriminalisation and implementation of the Bangkok Rules would reduce the number of women in prison and expansion of harm reduction services in prison would improve the health outcomes of incarcerated women.

Integration of harm reduction, SRHR, GBV services and the HIV care continuum will make it easier for women to access services. The involvement of women who use drugs living with HIV in the planning, implementation and monitoring and evaluation of these services is essential to make them effective.

> *There has to be a place where provides services only for women who use drug and living with HIV, where the workers are have experience with drugs and HIV*
> (Kenya community interview, Nov 2022)

The needs of women who use drugs who are living with HIV are inadequately addressed in HIV surveillance programming and medical research. Support for community-led monitoring and related advocacy work by communities will be essential to overcome some of these gaps.

It is essential to ensure that the voices of women living with HIV who use drugs are heard in decision-making forums (including community-led fora) to advocate for sustainable scale up of evidence-based, client-centred services, tailored to need, is essential in order to improve health and rights outcomes. Building capacity and providing funding and support to scale up women-led responses and community-led advocacy and core funding of networks and organisations is essential.

> *Women who use drugs are at the center of many intersecting structural sources of risk and addressing these intersections can be an advocacy point for communities to engage on with the Country Coordinating Mechanism and with whoever the consultants or the UN agencies who often assist with the application process.*
> (Global Fund, stakeholder interview, Dec 2022).

Recommendations

In light of the realities for women living with HIV and who use drugs explored in this paper, ICW and WHRIN are issuing this set of recommendations as a call to action for increased focus and solidarity and collaboration to address the following urgent priorities:

Community-led groups and networks of people living with HIV and networks of women living with HIV

- networks of people living with HIV and networks of women living with HIV should make deliberate efforts to reach out to women who use drugs and enable their involvement in programming and decision-making processes and, likewise, groups of people who use drugs should deliberately seek to include women living with HIV in their decision-making processes;
- networks of people living with HIV and networks of women living with HIV should leverage their advocacy skills and their seats at decision-making tables to give voice to women who use drugs and live with HIV;
- networks of people living with HIV and networks of women living with HIV and people who use drugs should cooperate on advocacy work to:
  - end criminalisation of HIV transmission, drug possession and use and sex work;
  - promote implementation of the Bangkok rules; and
  - scale up sustainable HIV and SRHR services including especially harm reduction services designed with a gender lens.
- community groups should take advantage of the fact that the Global Fund has prioritised removing gender-related barriers to HIV services and advocate for inclusion of their priorities in funding requests. They should remind CCMs to factor gender including the needs and priorities of women living with HIV, women who use drugs and sex workers into country plans for action.

Providers of harm reduction, SRHR and HIV services should:

- recognise women who use drugs as experts in their own lives, and meaningfully engage women who use drugs and who are HIV positive in the design, implementation, monitoring, and evaluation of programmes and research affecting them and encourage women-led responses;
- work to increase access to information, communication, and education tools, particularly for HIV-positive women who use drugs. This should include increasing treatment literacy about ARVs, drug interactions between ARVs and opioid agonist therapies and other substances consumed by people who use drugs;
- integrate services to ease access by women who use drugs to multiple services needed and ensure that a gendered, person-centred care approach is taken;
- ensure that services for support, reporting, and prevention of SGBV are available for women who use drugs and who are living with HIV;
- ensure data is disaggregated by gender should be systematically gathered and used in decision-making and community-led research on the experiences of women who use drugs and live with HIV should be supported and used for planning and implementing improvements to services.

Government should:

- include women who use drugs meaningfully in consultation processes, as well as decision-making and policy-making, and ensure meaningful involvement at all levels of organisations that provide services to people who use drugs and people living with HIV and prioritise women-led and/ or community-led responses
- work towards decriminalisation of drug use and sex work and also to ensure implementation of the Bangkok Rules;
- remove any legislation that makes drug use a justification for removing children from their parent's custody or that aims to punish women for using drugs during pregnancy;
- ensure that SRHR services are attuned to the needs of, and available to women who use drugs living with HIV;

- work toward scaling up sustainable access to integrated harm reduction, SRHR, SGBV and HIV care continuum services that are available, inexpensive, evidence-based, and free of compulsion for women who use drugs and live with HIV;
- leverage the fact that the Global Fund has prioritised removing gender-related barriers to HIV services to seek funding to support research, advocacy and implementation of changes to address barriers; and,
- protect and expand civil society space that is inclusive of women who use drugs and who are living with HIV

Donors should

- enhance financial support for collaborative community-led efforts to address gaps in capacity building, services and advocacy for women who live with HIV and who use drugs, mindful of the need for research led by community groups, advocacy efforts by community groups and core funding to enable continuous meaningful involvement in decision-making processes;
- be wary of perpetuating harmful dynamics which deprioritise gender, and which pit women from key populations against each other for resources and focus; and,
- Ensure that systemic barriers and eligibility criteria and do not exclude proposals from networks of women who use drugs.

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