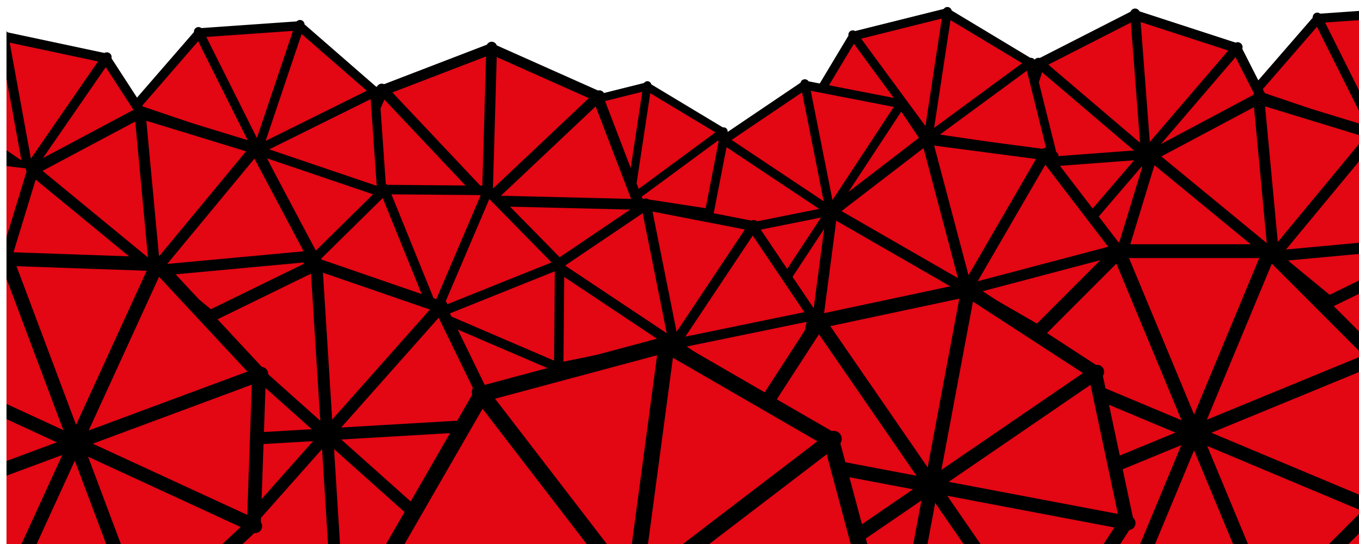
Global Network of Sex Work Projects
Promoting Health and Human Rights

BRIEFING PAPER

#06

The Voices and Demands of Positive Sex Workers



The Voices and Demands of Positive Sex Workers

Introduction

HIV prevention efforts are being scaled up globally, to target sex workers as a key affected population in the HIV response. The voices and experiences of sex workers living with HIV are too often rendered invisible: this means that the additional needs and rights of sex workers living with HIV are often overlooked in forums that support the rights of general populations of people living with HIV. NSWP – the global advocacy network for sex workers' rights – committed to address this invisibility as an annual priority in 2012. Accordingly, initial consultation was carried out during the 'Sex Worker Freedom Festival (SWFF): The Alternative IAC2012 Event For Sex Workers and Allies' in Kolkata, India, and was sustained throughout the year through face-to-face meetings, Skype conversations, and continued communication through setting up and maintaining a global advisory group of sex workers living with HIV. During the SWFF, a space was created for and by positive sex workers to meet every day and participate in group workshops on a range of topics that were selected due to their impact on sex workers living with HIV. During these sessions, the sense of frustration and anger among positive sex workers increased in relation to issues such as abusive testing practices; mandatory registration of sex workers living with HIV; the lack of safe, non-judgmental spaces for accessing care and support; inequitable access to treatment and required diagnostics; forced/coercive sterilisation and termination of pregnancies; increased stigma when HIV positive and continuing to work as a sex worker, and the number of preventable deaths of sex workers and others living with HIV due to the impact of trade-related matters and the growing monopoly of Intellectual Property Rights.[1]

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1 Intellectual Property Rights (IPR) refers to the rights given to the creators/inventors of a product that is seen to have scientific and/or creative value. There are three categories of intellectual property: copyright, trademarks and patents. For example, a song or a poem would be protected by copyright while the intellectual property rights concerning medicines are patents and trademarks.

During these sessions, positive sex workers came together in anger and solidarity to demand recognition of their voices and experiences in discussions, related policy, and programming, that directly impact upon their lives. These sessions comprised the beginning of NSWP+[2], a platform which brings together sex workers living with HIV with others campaigning for the rights of positive sex workers, to demand recognition that sex workers are *not the problem in terms of HIV but part of the solution!* The NSWP+ platform was launched with a list of demands made by positive sex workers. This document draws on the voices and experiences of sex workers living with HIV to explain these demands in more detail, and to make visible the needs and rights of positive sex workers globally.

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Positive Sex Workers – The Voices to be Heard

Sex work is perceived as a high-risk occupation. Because of this, positive sex workers are often wrongly labelled as drivers of the epidemic; this fuels the stigma faced by all sex workers, but it has a particularly negative impact on the lives of sex workers living with HIV. The legal recognition of sex work as work is vital to ensuring that sex workers are able to proactively manage their own health risks and behaviours, including gaining access to HIV prevention, treatment, care and support, all necessary components of reducing transmission. Evidence from places where sex work is decriminalised (such as New Zealand and New South Wales, Australia) reveals that granting labour rights to sex workers increases their access to HIV and sexual health services while encouraging very high condom use. Importantly, this practice has resulted in very low STI prevalence, and HIV transmission in the specific context of sex work is also understood to be extremely low or non-existent (UNDP, 2012[3]). In contrast, evidence from countries where sex work is criminalised or otherwise legally oppressed suggests that high numbers of sex workers are currently living with HIV. A recent review of all available data from 50 countries, which estimated that global HIV prevalence among female sex workers is 12%, found that female sex workers were 13.5 times[4] more likely to be living with HIV than other women. However, this number is likely to be underestimated: through experience, we know that sex workers are often forced to hide their work to healthcare providers and other professionals due to fear of stigma and discrimination.

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2 NSWP+ website: http://www.nswp.org/nswp-plus

3 United Nations Development Programme (2013) *Sex Work and the Law in Asia and the Pacific*

4 Baral, S., Beyrer, C., Muessig, K., Poteat, T., Wirtz, AL., Decker MR., 'Burden of HIV among female sex workers in low-income and middle-income countries: a systematic review and meta-analysis'. *Lancet Infect Dis* 2012, 12

Male and transgender sex workers are often included in other epidemiological studies such as studies on MSM, or more general studies of HIV prevalence. This has effectively made male and transgender sex workers particularly invisible in the HIV response, which has in turn created a lack of understanding and awareness of their specific needs across the spectrum of prevention, treatment, care, and support. NSWP argues that sex workers are not at increased risk of HIV primarily due to their work, but rather, from the criminalised and stigmatising legal and social environments in which sex workers are made to work. Furthermore, this paper highlights the numerous barriers that are faced by positive sex workers in accessing appropriate rights-based HIV treatment, care, and support. This situation must change to ensure that positive sex workers have self-determined agency over their own health and have access to the necessary prevention commodities required to protect both themselves and their clients.

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NSWP+ DEMANDS:

We demand the right to work in all sectors, including sex work, or any sector of the sex industry!

Stigma around working in the sex industry exists all over the world. Consequently, sex workers often state that stigma is the most harmful aspect of their lives. Stigma can exist in formal social structures, including but not limited to laws, policies, healthcare systems, education, religion, police, and other law enforcement agencies. But this stigma also impacts on sex workers everyday lives through more informal structures such as family, friends, partners, media, and other day-to-day relationships and outlets. Misunderstanding and ignorance around HIV can fuel the stigma targeted towards positive people, who are often assumed to have precarious lifestyles, and who are consequently often considered to be drivers of the epidemic. For example, the populations most affected by HIV (drug users, men who have sex with men, and sex workers) are all groups that face criminalisation and extreme stigma due to their choices, identities, or their work. Sex workers living with HIV share a sense of being marginalised in society: they often exist quietly at the sidelines through fear that their health or occupation status will be disclosed, or in fear that that their status will be used against them in instances of discrimination. This fear has been amplified at times of social or political anxiety around HIV; positive sex workers are often blamed and sometimes publically 'outed' as the problem. This has fuelled moral panics about sex workers and their perceived role in the transmission of HIV. The stigma of being a sex worker, combined with the associated stigma of living with HIV, clearly creates a 'dual burden' of stigma for positive sex workers.

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Criminalisation and other legal oppression of sex work impacts negatively on the lives of all sex workers. Coupled with laws around non-disclosure, exposure, and transmission, HIV-positive sex workers are placed at increased risk of prosecution. When a sex worker lives with HIV, their apprehension to report any violence or other human rights violations is typically heightened due to fear of additional criminal sanctions being used against them as a result of their occupation and also their health status. This climate of criminalisation can lead to greater exposure of HIV-positive sex workers, who may experience violence at the hands of law enforcement authorities and others who know that violence can be carried out with impunity. This creates a situation whereby sex workers living with HIV experience additional barriers to accessing justice, should they become victim to violence. Criminalisation can also impact on the use of health or other support services by positive sex workers; sex workers have shown that when working in supportive environments, their health and the health of their clients is a main priority. However, because laws and public attitudes continue to place the blame on the HIV-positive person, this imbalance must be addressed to ensure that responsibility for preventing the transmission of HIV lies with both (or all) people involved in the transaction.

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Positive Sex Workers Demand:

- To be able to choose employment as a sex worker or in the wider sex industry
- To be recognised as people with the ability to actively manage their own health
- To have full access to the prevention commodities required to protect their own and their clients health
- To be supported when challenging social stigma and the perception that positive sex workers are drivers of the epidemic (such as the moral panics fuelled by the media)
- To be able to work and live without fear of criminalisation or other legal oppression of sex work
- To be able to work and live without fear of criminalisation in the form of laws around non-disclosure, exposure, or transmission, which must be reviewed to reflect the shared responsibility for HIV transmission
- To have access to anti-discrimination protections in order to challenge discrimination on the grounds of sex work, HIV status, or both
- To have access to justice without fear of criminalisation or discrimination in cases of violence or other human rights violations

We demand not to be last in line for treatment or refused treatment because we are sex workers. This extends to our children and our families!

Sex workers worldwide have repeatedly described the negative attitudes they often encounter from health care providers, who are said to judge and morally condemn patients upon disclosure of their occupation. This judgement is heightened if the sex worker is also HIV positive, due to the perception that they are choosing to engage in a 'high-risk' occupation. This stigma is seen by positive sex workers as the main reason that sex workers are often made to feel 'last in line for treatment' or even refused treatment for HIV or other health-related issues. Sex workers often complain that health care providers view sex work as incompatible with adhering to treatment, or as incompatible with the ability to manage risks of transmission. As a result, these attitudes can prolong starting HIV treatment or necessary HIV-prevention commodities. In relation to sexual and reproductive health services, positive sex workers have highlighted stigma and misconceptions based on assumptions around sex work. For example, some female sex workers have experienced forced or coerced sterilisation and/or abortions based on the assumption that, as sex workers, they would not want to get pregnant. Female sex workers, like all women, are entitled to make their own decisions about pregnancy and contraception, and they should not be denied the chance to become a parent should they wish to. Female sex workers living with HIV have also noted experiences of being denied the appropriate treatment to ensure non-vertical transmission[5] of HIV. Recent consolidated WHO guidelines support the need for all positive mothers to receive PMTCT to prevent mother-to-child transmission: sex workers should not be excluded from this treatment.

Sex workers worldwide have repeatedly described the negative attitudes they often encounter from health care providers…

Positive Sex Workers Demand:

- To have access to all health services, but specifically HIV treatment, care, and support, without experiencing judgement or stigma from healthcare professionals
- To access HIV prevention commodities to reduce the risks of transmission associated with sex work
- To be recognised as having agency to actively choose their individual sexual and reproductive needs and desires. This recognition must also extend to intimate partnerships
- To choose termination of pregnancy and to have access to safe abortion services
- To choose pregnancy and parenthood and to have access to PMTCT

5 'Vertical transmission' means any infection transmitted between mother and child in the womb.

We demand that treatment is matched to the patient, not the patient matched to available drugs!

Positive sex workers in resource-limited settings noted that they often feel they are matched to available anti-retroviral treatment (ARVs) even in cases where these ARVs are known to cause negative side effects. For example, WHO now recommends that national treatment programmes phase out the use of d4T (Stavudine) in first-line treatment due to the frequency of negative side effects. The drug has however been the main antiretroviral treatment associated with the scale-up in resource-limited settings due to its low cost and its availability in cheap, generic fixed dose combinations. Upon phasing out d4T, treatment programmes are recommended to use Tenofovir or Zidovudine (AZT). This is problematic because both of these drugs are more expensive than d4T, and Tenofovir is only available as a three-drug fixed-dose combination with Efavirenz, which is also more expensive. Upon making the recommendation for phasing out d4T, WHO acknowledged that implementation is dependant on national circumstances, resources, and priorities. Given that national priorities determine the progress of phasing out d4T, sex workers, as a criminalised and stigmatised population, may be last in line for the recommended alternative treatment of AZT. Many sex workers remain on d4T despite complaints of serious side effects including peripheral neuropathy, nerve damage in the feet, legs and hands, which can cause numbness, tingling, or extreme pain. It must be recognised that sex workers have the right to the highest attainable standard of health: they must not be kept on treatment that is known to cause negative side effects on the basis that they are a criminalised and stigmatised population. Sex workers must also be given the opportunity to discuss viable alternatives should they not react well to the most available drugs.

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Positive Sex Workers Demand:

- The right to make informed choices and decisions about their HIV treatment
- Access to information regarding current research findings and global recommendations that recommend the use of alternative treatments rather than the mainstay drugs

We demand not to be used as guinea pigs in trials without our informed consent!

Sex workers, as a key affected population, are often targeted for participation in clinical trials to test out new technologies, vaccines, and medicines related to HIV. In particular, with the renewed focus on new prevention technologies including the initiation of early treatment (a technology that specifically targets PLHIV), sex workers are increasingly targeted as subjects of biomedical prevention trials. As previously stated, sex workers work mainly in criminalised legal environments, and even where direct criminalisation does not exist, sex workers still face extreme stigma and marginalisation. When designing and implementing clinical trials, ensuring that sex workers do not feel obliged to take part in trials due to their insecure legal and social status must therefore be made a priority. Trial sponsors and implementers, including investigators, research staff, pharmaceutical industry sponsors, foundations, government-supported research networks, non-governmental research sponsors, and all others involved in the designing, financing, and executing of HIV-related biomedical trials, must follow clear guidelines when working with criminalised and stigmatised populations in their investigations. Sex workers, sex worker-led organisations, and networks, must be engaged as partners in the design and implementation of these trials, to ensure that informed consent is always sought from participants, and to ensure that minimising harm for the participants is a priority of the investigation. Furthermore, sex worker-led organisations and networks must be supported to carry out consultation with sex workers prior to trials taking place, in order to ensure that any (even unintended) harm through participation is recognised and mitigated. Community engagement must be monitored as trials proceed: confidential evaluation and monitoring mechanisms must be put in place to allow community feedback and complaints to be taken seriously at any point in the trial's duration.

When designing and implementing clinical trials, ensuring that sex workers do not feel obliged to take part in trials due to their insecure legal and social status must therefore be made a priority.

Positive Sex Workers Demand:

- To be consulted prior to participation in clinical trials to ensure that any risks are known and consequently mitigated in the trial process
- All trial sponsors and implementers follow strict ethical guidelines that must be adhered to when carrying out trials with key affected populations
- To be able to give informed consent, based on truthful and unbiased factual knowledge about the treatment being trialled, including any side effects or possible development of drug resistance
- To participate as partners in the design and implementation of clinical trials
- To be given appropriate compensation for participation in trials

We demand that the drug companies in the West stop trying to kill us through their attacks on developing countries' rights to manufacture, export, and import generic ARVs!

Before the formation of the World Trade Organization (WTO), medicines were not widely subject to patents[6] in developing countries. This situation allowed local pharmaceutical manufacturers to develop generic[7] versions of drugs. However, with the formation of the WTO in 1994, any country that wanted to participate in global trade has since had to sign the Agreement on Trade-Related Intellectual Property Rights (TRIPS). TRIPS requires WTO member countries to give a patent for a minimum of 20 years to all medical produce and products, including medicines, vaccines, and technologies for HIV. It also requires the protection of 'originator data' against unfair commercial use, which means that local manufacturers cannot copy the medicines to distribute at a lower price. While those who defend TRIPS argue that the system is set up to encourage scientific innovation, the reality is that this system has led to what is referred to as a 'monopoly of patents' that protects the interests and huge profits of pharmaceutical companies in developed countries at the expense of access to essential medicines by people in developing countries.

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Before 2005, countries that manufactured and supplied generic drugs (mainly India which subsequently became known as 'the pharmacy of the world'), were not TRIPS compliant and as a direct result, over 9 million PLHIV now have access to ARVs. However, because India is now TRIPS compliant it is required to grant patents on newer medicines, meaning that it is unlikely that Indian companies will be able to manufacture and export new generic ARVs. Global commitments to further scaling-up of treatment and initiating earlier treatment means that millions more people are eligible to start treatment, and many PLHIV who have been on generic first-line ARVs for nearly 10 years now require access to second-line or third-line ARVs. This scaling up means that some countries may have to further prioritise access to treatment for PLHIV: due to this system, sex workers share a sense of fear that their work and HIV status may make them less likely to be able to access the necessary treatment.

6 Patents are the Intellectual Property Right given to the creators of medical products including drugs, vaccines, and medical technologies. Patents make medicines very expensive and as such are said to limit the access to ARVs by people in resource-poor settings where governments cannot afford to purchase the quantities of HIV-drugs needed.

7 Generic medicines are identical copies of the original product/medicine but are much less expensive to produce.

Bilateral and regional free trade agreements (FTAs) and economic partnership agreements (EPAs) also present huge threats to access to medicines. These agreements can be negotiated by countries signed up to the WTO, and have been used by developed countries to pressure developing countries to better protect Intellectual Property Rights, often at the expense of public health measures. These agreements have become known as 'TRIPS-plus' as they extend trade-related intellectual property measures even further, having an extremely dangerous impact on access to medicines. There is significant evidence that essential medicines are much more expensive in countries that have signed TRIPS-plus agreements. The main developed countries that are pushing for these agreements are the USA and the European Union[8].

Together, KAPs and treatment activists must ensure that within the climate of trade-related barriers and high pricing for patented medicines, governments take every possible measure to realise the rights to healthcare of the highest attainable standard.

Positive sex workers have expressed their desire to make their voices heard in the campaigns for treatment access. Mainstream civil society and other community groups must also recognise that stigma towards key affected populations often still occurs in community-led forums and spaces. Wider communities of PLHIV and treatment activists must work to ensure that space is given to the voices, needs, and rights of key affected populations (KAPs). Together, KAPs and treatment activists must ensure that within the climate of trade-related barriers and high pricing for patented medicines, governments take every possible measure to realise the rights to healthcare of the highest attainable standard.

Positive Sex Workers Demand:

- Inclusion in the campaign for universal access to treatment: this demand is in line with new guidelines that will increase the number of people eligible for treatment
- To be part of the growing movement against FTAs and EPAs and any other measure that creates further barriers to access to medicines

8 See NSWP Briefing Paper on 'Access to Medicines' (2013) for more information

We demand to be included in all official discussions about HIV policy and programming for sex workers!

Positive sex workers share a sense of frustration over the number of HIV services implemented without meaningful consultation with the community. This has led to services being offered that do not suit the needs and rights of positive sex workers, including services that require registration, tracking, and monitoring of sex workers, coercive and abusive testing and treatment practices, and services that do not ensure the confidentiality of test results and/or HIV status. The centres which provide these health services can implement barriers to sex worker engagement: positive sex workers have noted malpractice in instances when consultation has not taken place. For example, sex workers complain that upon accessing follow-up treatment, care, and support, or attending clinics for diagnostics, they are told to wait at one side of the room. This makes their status known to others visiting the clinic, which can be extremely detrimental for sex workers living with HIV due to the need to keep their status confidential, in order to maintain clients and resist further stigmatisation from their communities and/or criminal prosecution by authorities. Furthermore, sex workers are often unable to access health services regularly when they are not positioned in areas close to their home or their workplaces and/or when the clinics are not open at suitable times for the needs of sex workers. These factors can affect adherence to treatment regimes and can also prevent sex workers from accessing timely diagnostic services where they are available.

Positive sex workers share a sense of frustration over the number of HIV services implemented without meaningful consultation with the community.

When sex workers have input into the design and implementation of health and HIV services these are set up in accordance with community needs and preferences. This has led to the opening of several sex worker-friendly clinics around the world, and even some sex worker-led clinics where sex workers have been trained to test and treat positive sex workers. Services designed with input from sex workers are far more likely to ensure the needs and rights of positive sex workers are considered, for example, confidentiality, non-judgemental staff and attitudes, convenient opening hours, appropriate counselling, and support that is tailored to the additional needs a sex worker may have prior to, and upon, a positive diagnosis. Furthermore, these services can usually refer sex workers to support and empowerment groups; positive sex workers see these as a beneficial way to self-organise around and against the additional stigma and barriers that are faced by sex workers living with HIV.

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The voices of positive sex workers must be heard in all HIV policy and programming discussions to ensure that prior experiences of accessing testing and treatment services are used to inform future practice and service design. Consulting with general communities of PLHIV is not enough to ensure that the needs of positive sex workers are met. Positive sex workers highlight that stigma does not end at the level of community. They often feel their issues were not taken on board by other groups of PLHIV: for example, sex working mothers who were living with HIV often feel that they don't fit into general groups of mothers living with HIV due to judgement and stigma directed at their occupation as sex workers. Similarly, positive male sex workers felt that services tailored to men who have sex with men do not adequately reflect their needs as sex workers since they were designed with a different population in mind. Sex workers living with HIV must therefore be given their own space to mobilise and organise to ensure that their voices, experiences, and specialist needs are not rendered invisible in community forums or in national and international discussions.

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Positive Sex Workers Demand:

- To be included in community, national, and international discussions around HIV policy and programming for sex workers, and to have access to an inclusive environment within peer-based organisations
- To be meaningfully consulted on service provision, testing, and treatment policies
- To be meaningfully consulted on issues surrounding the everyday running of healthcare clinics that are set up to target sex workers
- To have appropriate channels open to feedback and the evaluation of services whereby sex workers are able to confidentially share their experiences of accessing services without repercussion
- To have access to sex worker-friendly or sex worker-led health care clinics and settings that promote confidentiality and non-judgmental attitudes towards sex work, and which also offer appropriate HIV pre-and-post counselling and support for sex workers who test positive
- To have positive sex worker-led spaces protected so that sex workers can collectively mobilise and organise to ensure that their voices are heard

Conclusion

Despite the legal settings and country-specific contexts in which sex workers work, our initial consultation with sex workers living with HIV highlighted that many issues are globally applicable. The demands in this document lay out the fundamental experiences, needs, and demands of positive sex workers in the attempt to make visible the plight of positive sex workers within the NSWP network. Positive sex workers identify with PLHIV on many levels and feel connected to the broader sex workers rights' movement. From the accounts of sex workers living with HIV, it was however clear that in the SWFF and following consultations there was widespread acknowledgement of dual stigma, which was felt to impact upon their lives in ways that were specific to positive sex workers. This dual stigma often occurred in community-level forums and spaces, and rendered the experiences of sex workers living with HIV invisible or ignored in other communities of PLHIV. In response, sex workers living with HIV make these demands as a starting point in the fight for the rights of positive sex workers. Activism and advocacy takes place at all levels to ensure that these voices are heard: NSWP+ will continue to provide a platform to communicate the experiences, needs, and demands of positive sex workers into all global forums and discussions.