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Global Network of Sex Work Projects
Promoting Health and Human Rights

GLOBAL BRIEFING PAPER:

**Sex workers' access
to HIV treatment
around the world**



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Sex workers' access to HIV treatment around the world



“We will not stay silent while they trade away our lives!”

SEX WORKERS AT THE SEX WORKER FREEDOM FESTIVAL, KOLKATA, 2012

Introduction

In 2009, 33 million people were living with HIV, 68% of them in Africa. Globally, female sex workers are 13.5% more likely to be living with HIV than the general population (UNAIDS 2013). However, in many places sex workers' rates of HIV are not known, whether due to insufficient research or due to sex workers' own reluctance to document it for fear that the response will be to treat them as 'vectors of disease', rather than to focus attention on the broader socio-legal context which informs their HIV risk.

Worldwide, only 65% of people living with HIV (PLHIV) have access to treatment. In the Caribbean, overall antiretroviral therapy (ART) coverage rose from 1% in 2004 to 51% in 2008; however, the majority of PLHIV in the Caribbean live in countries where national ART coverage is under 50%. ART is available to 58% of PLHIV in Haiti and Jamaica, versus more than 99% in Cuba. Only one third of PLHIV in the USA are on ART, with African Americans and young people least likely to be in receipt of ongoing care and effective treatment (CDC 2012a). In Myanmar, 40% of PLHIV already cannot access treatment, and this number is set to rise with the forthcoming patent law. In Eastern Europe and Central Asia, only 26% of people eligible for HIV treatment receive it (UNAIDS 2013, WHO 2013). In sub-Saharan Africa, treatment coverage is at 56%, reaching 6.2 million of the 11 million eligible.

The information in this report summarises the findings of five briefing papers on sex workers' access to HIV treatment in five regions: Africa; Asia Pacific; Europe; Latin America; and North America and the Caribbean. Research was carried out by regional consultants through online surveys and meetings with sex worker-led organisations and individuals, to identify the multiple barriers to ensuring access to appropriate health care for those living with HIV.

Stigma and discrimination are behind many of these barriers. Whorephobia, homophobia, transphobia, racism, and other prejudices, including prejudice against PLHIV, may be espoused by health care staff and backed up by legal measures against sex workers, LGBT people, migrants and HIV-positive people.

Furthermore, those who are unable to pay for private health care may be eligible only for limited treatment – or none at all. Access to life-saving HIV drugs is further complicated in many developing countries whose domestic supplies have been interfered with by international free trade regulations. The effects of these cannot be underestimated.

The following pages outline the multiple barriers faced by sex workers living with HIV in realising their right to health, before ending with recommendations for action to overcome them.

Barriers to effective HIV treatment for sex workers

MARGINALISATION

Those most affected by HIV are members of marginalised communities suffering from discrimination (sexism, homophobia, transphobia, whorephobia, racism, colonialism and xenophobia), socio-economic inequality (poverty, insecure housing, inaccessible health care), incarceration, criminalisation and drug dependency. They may be marginalised as newcomers and/or as undocumented immigrants, and they may face reduced access to services due to residence in remote or rural communities. A lack of cultural mediators to facilitate migrant sex workers' access to services is particularly noted in Europe. Members of easily identifiable ethnic groups, such as Roma in Bulgaria, Macedonia and Serbia, Uzbeks in Russia, and Latin Americans and Africans in France and the UK, are especially vulnerable to harassment, abuse and human rights violations. Homeless sex workers living with HIV, with nowhere to sleep or to store medication, as well as frequently needing to evade law enforcement, may have more immediate needs than accessing treatment. Discrimination is experienced not only by sex workers but by their families, including prejudice and peer pressure put on their children at school, as reported by sex workers from Cambodia.

Sex workers are liable to find themselves in a loop, from criminalisation of their work (and/or other aspects of their lives, such as sexual orientation, gender identity, drug use or HIV status) to incarceration, poverty and housing insecurity, alongside both an increased risk of contracting HIV and increased challenges in accessing and sustaining appropriate treatment for it.

Sex workers are variously seen as an offence to public morality and family values; as a serious threat to public health, welfare and safety; or, as in Sweden, as self-deceiving victims forced into the sex industry by male domination. This stigma is frequently perpetuated by the media, one notable example being the 2011 incident in Greece when the privacy and confidentiality of sex workers was violated through the publication of their identities, occupation and HIV status. Internalised stigma – fed by prejudice, criminalisation and negative media coverage – can lead to low self-esteem and diminished self-care, further contributing to sex workers' vulnerability to HIV.

Access to treatment is a human right, but denial of this right is tied to lack of recognition of sex work as work, an issue which must be recognised by national AIDS programmes.

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LEGAL RESTRICTIONS AND THEIR EFFECTS

The criminalisation of sex work and related activities leaves sex workers vulnerable, including in terms of health. This is the case whether the law targets sex workers themselves, their clients, or third parties such as managers and receptionists. Each of these approaches leads to policing which destabilises sex workers' working conditions, forcing them to operate clandestinely and leaving them more vulnerable to abuse and violence. It should be noted that implementation often exceeds the letter of the law, and police around the world abuse their power to engage in the extortion and harassment of sex workers. Anti-trafficking crackdowns lead to the detention of migrant sex workers, exposing them to physical and sexual abuse, and further deter sex workers in general from working openly.

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Even where sex work is not criminalised or penalised, if sex work is not treated as a legitimate occupation sex workers are not treated as full citizens under the law. They have no legal protection or labour rights, often necessary for inclusion in national public health care systems. As sex work is not recognised as part of the labour market or a form of (self-) employment in most of Europe, there is no framework for migrant sex workers to apply for residence or work permits.

The criminalisation of HIV non-disclosure, transmission and exposure serves to deter sex workers from getting tested for HIV, and sex workers living with HIV from accessing vital health care or from fully disclosing their circumstances if they do. Facing severe penalties, including criminal charges, if arrested for engaging in sex work, they have a disincentive to reveal their occupation to health and social services. In Canada, this criminalisation can lead to a conviction for aggravated sexual assault, placing them on a sex offenders' registry and threatening the immigration status of migrants. Such laws are also used to justify forced HIV testing during police raids, as in Eastern Europe and Central Asia. Furthermore, certain countries, such as Cyprus and Uzbekistan, place restrictions on residence and entry for PLHIV, and HIV-positive migrants are deported from Moldova, Russia, Kazakhstan and Turkmenistan.

The criminalisation of consensual sex between men further impacts male sex workers, while criminal offences such as 'crossdressing' are used against transgender and gender non-conforming people. These too serve to jeopardise sex workers' capacity to protect themselves from harm and to seek appropriate services.

Punitive drug laws, such as the criminalisation of drug use in Georgia, Russia, Kazakhstan and Ukraine, constitute an additional barrier for some sex workers living with HIV. Sex workers who use drugs are at increased risk of violence, coercion and abuse by police and others across Eastern Europe and Central Asia.

Laws criminalising sex workers, PLHIV, LGBT people and people who use drugs are not necessarily applied in equal measure across the board. It is noted that in the USA, police disproportionately target transgender sex workers and sex workers of colour. Street-based sex workers, being more visible, have less time available to negotiate with clients before committing to transactions, as they are forced to prioritise avoiding police attention over making risk assessments. This puts them at considerably greater risk of abuse and violence. Police in many countries seize condoms as evidence of engagement in sex work, deterring sex workers from carrying condoms and thereby increasing the risks faced by them, their clients and their partners.

Legal provisions in some countries enable the sharing of medical information with law enforcement and social services. Permanent documentation of sex work and/or HIV status may be used as evidence in court proceedings and as justification for forced testing. As a result, sex workers cannot have faith that confidentiality will be respected. An American sex worker noted, “Client/patient confidentiality only goes so far ... they will spill their guts to the cops.”

Those in prison may have reduced access to appropriate health care and services. Harm reduction measures such as safe sex supplies and equipment for safer drug use may not be available. The Centers for Disease Control and Prevention (2012b) recognise that current and former prisoners experience higher rates of health problems, including HIV. Stigma and discrimination impact prisoners living with HIV, and they may face challenges in initiating and maintaining treatment, including ART. A sex worker from Guyana told how two friends “died of denial” in prison: “they were serving a few years each and were afraid to accept treatment because of the stigma attached to it.” In the USA, there is no standardised care for prisoners living with HIV. Prison authorities may deny prisoners the right to take medication at prescribed times, confiscate it, and violate medical confidentiality.

Migrant sex workers the world over face barriers in accessing treatment due to lack of documentation, insufficient funds or simply linguistic barriers. Additionally, internal migrants in the vast majority of Eastern Europe and Central Asia, as well as some of the Balkans, cannot access local services if they are registered in a different part of their country – and identification documents necessary for obtaining residence permits are often confiscated by law enforcement officials during raids or imprisonment. In Canada, refugees’ access to treatment is restricted to public health concerns, meaning that although they are entitled to ART, they are denied other crucial treatment to maintain their health (HALCO 2012).

INTERACTIONS WITH HEALTH CARE SERVICES

Sex workers may avoid disclosing their occupation to health care staff due to fear of discriminatory and judgemental treatment; fear of intrusive and irrelevant questions motivated by general curiosity about sex work and ‘Othering’ of sex workers; and/or fear of being reported to the authorities because of their occupation, HIV status or immigration status. Anti-trafficking measures can also have an impact on this last point, with migrant sex workers often being assumed by default

to be victims of trafficking, and misguided and harmful interventions taking place because of this. Reluctance to fully disclose their occupation and health conditions undermines the ability for sex workers and health care providers to establish and maintain a constructive therapeutic relationship.

Negative experiences in the health care system reported by sex workers include discriminatory and paternalistic attitudes from staff; open hostility and reluctance to treat them; violations of their rights to privacy, confidentiality and informed consent; and refusals to prescribe antiretroviral (ARV) drugs and other treatment despite an absence of contraindications. Such deterrents can lead them to delay seeking treatment, interrupt treatment regimes, use traditional and alternative treatment instead of conventional health care, or avoid health services altogether.

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Further barriers to effective treatment include fragmentation of health care services, compelling sex workers to visit a range of different isolated and narrowly focused service providers which might variously handle, for example, ARVs, tuberculosis, viral hepatitis and other sexually transmitted infections (STIs), and (if even available) opiate substitution therapy. This has been reported particularly in Eastern Europe as being cumbersome, dysfunctional and inconvenient. PLHIV may also face a lack of information on where to go, what the procedures are, and how to access HIV treatment. In Mexico, for example, it is reported that the appropriate centres lack promotion and adequate mechanisms to connect with those who need them.

FUNDING

The funding environment remains largely hostile to sex worker-led interventions which could improve access to treatment. Already, funding for HIV and sex work comprises a minuscule portion of global HIV funding – one percent, as reported by UNAIDS in 2009. HIV programmes are seeing an overall decline in funding (2010 saw a 10% decline from donor governments), with shortages and dramatic cuts, leaving existing services highly vulnerable to withdrawal of support. Funders which have previously funded sex worker-led organisations and subsequently shifted priorities have not provided ‘bridge’ funding, leading to catastrophic consequences for their ability to continue operating.

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Eastern European and Central Asian countries are highly dependent on their largest donor, the Global Fund to Fight AIDS, Tuberculosis and Malaria, which is itself facing financial difficulties due to unfulfilled pledges by donor countries. In November 2011 it cancelled a funding round and suspended new grants. Its later introduction of the Transitional Funding Mechanism aimed to prevent disruption of services but does not allow for scaling up of treatment or provision of funding for community strengthening or advocacy work. In Mexico, its donations focus on HIV prevention strategies and do not cover access to ARVs.

The President’s Emergency Plan For AIDS Relief (PEPFAR) contributed 58% of global expenditure on HIV and AIDS programming in 2009. It is a significant donor in the Caribbean, Central Asia and Africa. While its anti-prostitution pledge, a condition imposed on recipients of funds, was ruled in 2013 to be unconstitutional for US-based organisations, the ruling did not change the requirements for foreign organisations. PEPFAR’s approach undermines best practices in HIV prevention, by making it difficult or impossible to promote sex worker leadership, recruit peer educators, affirm sex workers’ values as members of society, and combat stigma (Best Practices Policy Project 2011). As the leading funders, PEPFAR and the Global Fund have the power to ensure that sex workers are represented and included in HIV programming, but they have not harnessed this power.

Countries in the Caribbean, the Balkans and Eastern Europe are seeing changes to their eligibility for funding as they are reclassified as upper-middle-income (UNAIDS 2010, ACTION/TB Europe Coalition 2012, UNAIDS Reference Group on HIV and Human Rights 2012). Increasingly, their governments are left to take over HIV programming, but they will not necessarily prioritise an HIV response which targets the most vulnerable and marginalised populations, and may instead divert funding to the general population or low-risk individuals.

Many sex worker-led organisations in Africa fail to attract private funders from Europe and the USA. However, the Africa briefing paper suggests that they move to looking at human rights-based rather than HIV-specific funding, focusing their efforts beyond the HIV/AIDS paradigm and incorporating social, economic and civil rights in their funding applications. Private funders remain highly important to sex worker-led organisations given that national governments are frequently unlikely to lend financial support to organisations which may seek to challenge their laws as a matter of human rights. SHARP (2006) notes that “governmental funding for advocacy against governmental policies may be simply impossible or undesirable because of the inherent conflict.”

As the share of funding received by anti-trafficking organisations continues to increase, sex worker-led organisations, already struggling, are facing greater challenges in attracting funding for programmes not linked to anti-trafficking. National and international funding agreements often favour anti-trafficking initiatives by privileging ‘rescue and rehabilitation’ rather than rights-based approaches. The intentional conflation of sex work with trafficking undermines sex workers’ rights while bolstering the policing and incarceration of sex workers.

AVAILABILITY AND ACCESSIBILITY OF MEDICINES

Sex workers need first-line, non-toxic HIV medicines with little chance of harmful drug interactions, and treatment for HIV co-infections such as hepatitis C, drug-resistant tuberculosis, STIs and opportunistic infections. However, the high cost of treatment often leads governments to exclude HIV treatment from public health insurance or social security systems (Global Network of People Living with HIV et al. 2013). Access to effective treatment may also be impeded by poor procurement and distribution systems, shortages of supplies and late arrival of medicines. In Peru, for example, the required medicines may sometimes only be available for a week, which can lead to repeated changes in ARV drugs, causing negative repercussions for some patients. ARV drugs are not always available in rural, border and mining areas in Brazil, where services, if they exist at all, have little structure.

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Sex workers in the USA are less likely to have health coverage than the general population, and less than 20% of PLHIV have private insurance, while a third of PLHIV have no health coverage at all (AVERT n.d.). Although the Affordable Care Act and Ryan White HIV/AIDS Programme should go some way to helping them access treatment, migrants will be excluded. Additionally, even documented migrants have no access to Medicaid, a social health care programme for those on low incomes, for the first five years after immigrating.

EFFECTS OF INTERNATIONAL TRADE AGREEMENTS

National laws governing the approval of medicines for sale, how companies can market them, appropriate pricing and who has to pay for them are increasingly impacted by international trade agreements on intellectual property rights. A significant example is the Agreement on Trade Related Aspects of Intellectual Property Rights (TRIPS), implemented by the World Trade Organization (WTO) and affecting all of its member countries as well as those seeking to join. It applies to all products, whether luxury goods or life-saving medicines, and awards exclusive patent rights for a minimum of twenty years to the companies from which they originated. These companies have a monopoly on manufacturing and selling them, allowing them to raise their prices without pressure from competitors. Although some countries have laws which directly regulate the prices of medication, this does not apply across the board.

TRIPS signatories have the right to engage in ‘compulsory licensing’, allowing the manufacture of generic drugs without the patent holder’s consent, in exchange for ‘adequate remuneration’. This can limit monopolies and bring down prices. The manufacture and sale of generic drugs provides a lifeline for those who cannot afford to buy their branded counterparts. However, although the Doha Declaration, allowing for these flexibilities, was signed in November 2001, they have not

been widely and effectively implemented in most low- and middle-income countries in the European region, due to a lack of supportive and coherent legal frameworks, or an absence of technical and administrative resources to assess patents, negotiate with patent holders and make decisions on remuneration (El Said & Kapczynski 2011, ICO et al. 2013). Certain less developed countries, such as Haiti, are exempt from TRIPS rules in the case of pharmaceutical products until 2016, and most African

countries have an extension until 2021 to sign TRIPS, but have begun imposing intellectual property restrictions on medicines in line with WTO regulations. Brazil has managed to negotiate the North American Free Trade Agreement (NAFTA) in such a way that it continues to produce generic drugs, and Kenya and South Africa were the first countries in sub-Saharan Africa to introduce legislation permitting the import of generic drugs, expanding access to treatment. However, funding is inadequate for research and development on generic drugs (Correa 2004).

Brand-name pharmaceutical companies and certain developed countries, notably the USA and EU member countries, have attempted to impose even more stringent intellectual property rules through regional or bilateral trade agreements, gradually eroding TRIPS’ flexibilities. These have been labelled TRIPS-plus. They also require the adoption of measures such as the extension of patents’ terms on data exclusivity and enforcement, which hinders the production and distribution of generic drugs in many low- and middle-income countries. Developed countries put pressure on African countries to sign Economic Partnership Agreements (EPAs) and Free Trade Agreements (FTAs) which allow the developed countries to bypass compulsory licensing in exporting drugs to Africa (Baker 2011), and to sue African governments for passing pro-public health legislation which enables local firms to manufacture generic drugs. Further examples of TRIPS-plus include the forthcoming Trans-Pacific Partnership (TPP), to be signed by twelve countries bordering the Pacific; the Deep and Comprehensive Free Trade Agreement (DCFTA) signed recently by Georgia and Moldova (European Commission 2013); the Partnership and Cooperation Agreement between European Union and Central Asian countries (European Commission 2010); the European FTAs signed by Albania, Montenegro, Serbia and Turkey; and Trinidad and Tobago’s 1994 Memorandum of Understanding with the USA, limiting the scope for either country to adopt or create ‘limited exceptions’ to exclusive patent rights on medicine.

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The TPP could extend the definitions of ‘investments’ to intellectual property, and enable private corporations to sue governments if government regulations negatively affect their investments, including their potential for profit. This would undermine the autonomy of national governments and remove protection for local industries. Meanwhile, the EU is presently negotiating an EPA with key middle-income countries including India, Thailand, the Philippines and Indonesia. These countries are capable of producing generic drugs but the EPA will severely limit their production. Indian manufacturers, in particular, take a lead role in supplying generic ARVs to low- and middle-income countries worldwide, both through government sources of funding and donor-funded treatment provision, but this is likely to be jeopardised.

The Anti-Counterfeiting Trade Agreement (ACTA), led by the USA, has restricted access to generic medicines, and, although not explicitly called for in its text, has led to their seizure at some international borders. Activists have urged governments to stand firm against adopting anti-counterfeiting measures and instead strengthen their drug regulatory authorities to ensure quality.

High prices charged by pharmaceutical companies for patented medicines can force governments to make decisions on who to prioritise for treatment. Sex workers, already marginalised and stigmatised, are liable to be last in line, affecting not just them but their families too.

TRIPS-plus agreements are frequently negotiated in secret with insufficient information made available to the public. The public, including sex workers, needs to be informed on trade frameworks that impact the availability of medicine for PLHIV. Governments are making insufficient effort to include relevant stakeholders in decision making, as, for example, in Malaysia, where NGOs are not included in the process. Sex workers and other activists need skills to change these behaviours and overtake pressure groups which prioritise private profit over public health.

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Recommendations



LEGISLATION AND RIGHTS

Governments should repeal laws that criminalise sex work; HIV transmission, exposure or non-disclosure; same-sex activity; transgender identity and associated behaviours; and drug use; as well as civil and administrative offences used against sex workers such as public nuisance laws. Additionally, they should repeal or amend anti-trafficking laws that conflate sex work with trafficking or that are enforced to prohibit sex work.

Police harassment and violence against sex workers should end, allowing sex workers to operate in safer working conditions.

Sex workers' rights should be protected under employment standards and occupational health and safety legislation.

Anti-discrimination laws should be amended to expressly prohibit discrimination based on occupation, including sex work; health status, including actual or perceived HIV status; sexual orientation and gender identity.

Sex workers should be included in law reform in order to minimise the potential for harm, and funding should be made available to support such participation.

Sex workers, PLHIV and other marginalised communities should have access to adequate housing and other social and economic support.

Migrants should be guaranteed access to health care, including HIV treatment, without fear of their HIV or immigration status being disclosed to authorities.

FUNDING

A rights-based approach to funding should be adopted, together with the repeal of punitive conditions such as PEPFAR's anti-prostitution pledge.

All funded anti-trafficking initiatives should be evidence-based and grounded in human rights, and have involved meaningful consultation with sex workers.

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COMMUNITY EMPOWERMENT

Meaningful consultation should be carried out with sex workers to develop strategies to address the structural issues contributing to their vulnerability to HIV.

As per the World Health Organization's new guideline for sex workers, all sex worker programmes should be led by the affected community, fostering self-determination and empowerment.

Sex worker-led organisations should create partnerships with other NGOs in order to synergise human rights issues. Mainstream civil society and other community groups should recognise that stigma towards key affected populations occurs in community-led forums and spaces. Treatment activists should work together.

Support should be given to training led by sex workers to combat discrimination, stigma and judgemental approaches among service providers towards sex workers, MSM, transgender people, people who use drugs, and other marginalised communities.

Sex workers and their allies should hold governments accountable in protecting and promoting citizens' right to health.

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HARM REDUCTION AND HEALTH CARE PROVISION

Comprehensive, accessible and evidence-based HIV care and treatment; primary health care; and sexual and reproductive health care should be ensured through rights-based HIV programming.

People who use drugs should be provided with access to effective health services, including harm reduction services (encompassing needle and syringe exchange, opiate substitution therapy and supervised consumption services) and voluntary, evidence-based treatment for drug dependence.

The availability of HIV-related health care should be ensured in detention, including ART, nutritious food and supplements, as well as safe sex supplies and safer drug use equipment equivalent to that available in the community.

Increased human resources and expertise on HIV care and treatment should be put in place to enable the enrolment of increased numbers of patients, especially outside the main urban centres. A decentralised treatment model is needed, as currently sex workers and their families may face migrating to major cities for treatment.

Access to health care services must not be conditional on ceasing engagement in sex work.

INTERNATIONAL TRADE AGREEMENTS

Governments should refuse to accede prematurely to TRIPS requirements on intellectual property, reject TRIPS-plus standards in domestic legislation and international treaties, and refrain from pressuring other countries to adopt TRIPS-plus measures. Additionally, they should make full use of 'flexibilities' under TRIPS and similar agreements, and amend patent laws to permit the protection and promotion of the rights of those needing medicine to access it.

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