

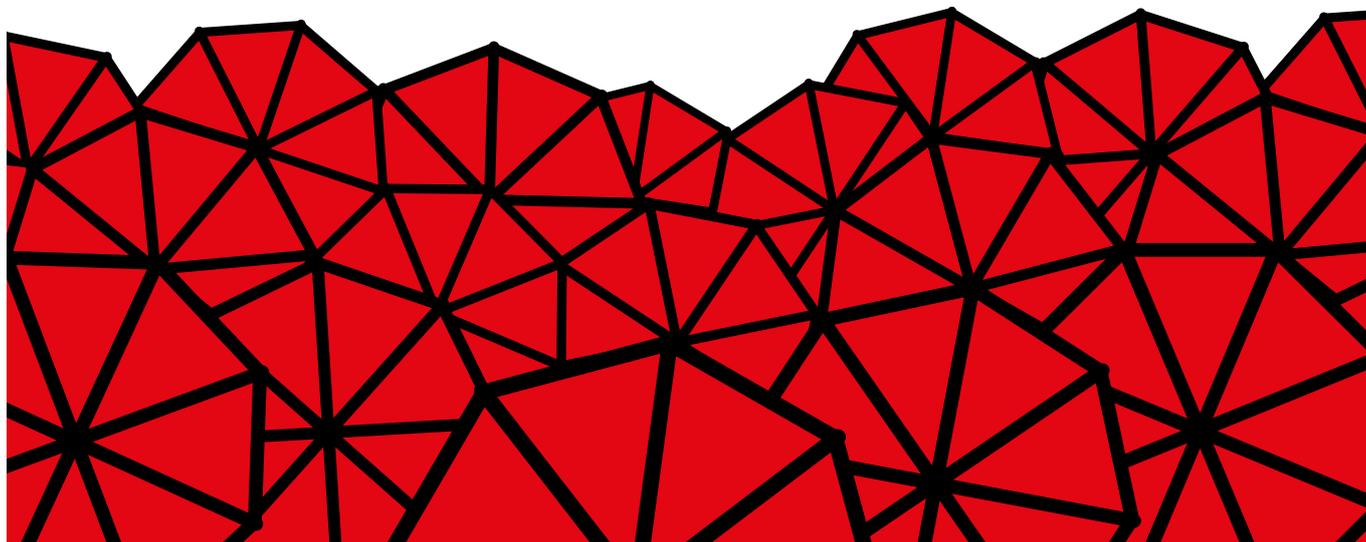


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Global Network of Sex Work Projects
Promoting Health and Human Rights

**BRIEFING
PAPER**

**The meaningful
involvement of
sex workers in
the development
of health services
aimed at them**



The meaningful involvement of sex workers in the development of health services aimed at them

Introduction

The ‘right to health’ was first codified in the 1946 Constitution of the World Health Organization (WHO), and then enshrined in the 1948 Universal Declaration of Human Rights. Article 12 of the 1966 International Covenant on Economic, Social and Cultural Rights declares that all people have the right to the highest attainable standard of physical and mental health. WHO has defined the universal right to health as a human right, inclusive of the right to freedoms and entitlements. That is, the right to control one’s own body and to be free from interference (e.g. non-consensual medical treatments and tests) and the right to “a system of health protection that gives everyone an equal opportunity to enjoy the highest attainable level of health”¹. Furthermore, everyone has the right to non-discriminatory services, as well as services, goods and facilities that are available, accessible, acceptable, and of good quality.²

Sex workers have the same entitlement to the right to health as everyone else.

Sex workers have the same entitlement to the right to health as everyone else. NSW’s Consensus Statement on Sex Work, Human Rights, and the Law affirms that “sex workers have the right to non-discriminatory, affordable, and culturally-specific access to universal, quality health services.”³ However, the field of

public health emphasises the health of the general population over the health of specific, marginalised populations. Sex workers are often stigmatised as ‘vectors of disease’; a negative impact on the health of the public. Public health programmes targeting sex workers for ‘high-risk behaviours’ attempt to manage the perceived danger that sex workers’ bodies present.⁴ This approach to health reinforces occupational stigma, a fundamental cause of health inequalities⁵ experienced by sex workers. A rights-based approach to health offers an alternative that does not treat sex workers as inherently separate from the general public, and offers an analysis in which sex workers’ vulnerability is more fully contextualised.

Stigma, displayed frequently in discriminatory attitudes and behaviours of healthcare providers, is a structural barrier to health for sex workers; it impacts their ability to access services. Health and support services aimed at sex workers that only cater to an ‘acceptable’ subset of sex workers (such as female sex workers who are citizens of the region in which they live and work) are not fully inclusive, excluding sex workers who are migrants, male or transgender. Health service providers can address stigma as a structural barrier to sex workers’ health by meaningfully involving sex workers in the development of health services aimed at them. Criminalisation of sex work is the main hurdle to upholding sex workers’ fundamental right to health.

1 “Health and Human Rights”, World Health Organization, last accessed 7 October, 2017 at <http://www.who.int/mediacentre/factsheets/fs323/en/>

2 Ibid.

3 Global Network of Sex Work Projects, 2013, “Consensus Statement: on Sex Work, Human Rights, and the Law”, available at <http://www.nswp.org/resource/nswp-consensus-statement-sex-work-human-rights-and-the-law> (last accessed 5 October, 2017)

4 Cyd Nova, “Vectors of Disease: Sex Workers as Bodies to be Managed”, QED: A Journal in GLBTQ Worldmaking 3.3, (2016): 196-200.

5 Mark L. Hatzenbuehler, Jo C. Phelan, and Bruce G. Link. “Stigma as a Fundamental Cause of Population Health Inequalities.” *American Journal of Public Health* 103.5, (2013): 813–821. PMC.

When sex workers are involved at all stages of health service provision, including planning, design, implementation, and monitoring and evaluation, health services are more comprehensive and holistic as well as better informed by sex workers' lived realities and unique needs. Delivery models consequently have the fewest access barriers for the greatest number of people as well as those who are most in need.

This briefing paper discusses the extent to which sex workers are currently meaningfully involved in the development of healthcare services that are aimed at them. This matter is examined on a global scale and in five regions: Africa, Asia Pacific, Europe, Latin America, and North America and the Caribbean. Within those regions, case studies were developed based on in-depth research conducted in ten countries: Belgium, Brazil, Cambodia, Ecuador, Ethiopia, Mauritius, Papua New Guinea, Trinidad and Tobago, Ukraine, and the U.S.A.

Background

Healthcare: service providers and service users

Discussions of healthcare service provision typically assume that an individual is either a 'service provider' or a 'service user'. The problematic nature of this dichotomy was addressed in the 2007 UNAIDS Policy Brief: *on the Greater Involvement of People Living with HIV*.⁶ The principle of Greater Involvement of People Living with HIV (GIPA) centres on "seek[ing] to ensure that people living with HIV are equal partners and break[ing] down simplistic (and false) assumptions of 'service providers' (as those living without HIV) and 'service receivers' (as those living with HIV)."⁷ Most governments, agencies and health providers assume sex workers are exclusively service users and cannot also be health service providers. When sex workers are not recognised as potential health service providers, their ability to develop health services is neither recognised nor encouraged. Consequently, they are not treated as equal partners.

The principle of Greater Involvement of People Living with HIV (GIPA) centres on "seeking to ensure that people living with HIV are equal partners and breaking down simplistic (and false) assumptions of 'service providers'...

Meaningful participation and meaningful involvement

In 2013, WHO, UNFPA, UNAIDS, NSWP, the World Bank, and UNDP collaborated on *Implementing Comprehensive HIV/STI Programmes with Sex Workers: Practical Approaches from Collaborative Interventions*, known as the 'Sex Worker Implementation Tool' (SWIT)⁸. It declares that meaningful participation of sex workers in the development of health services is an essential component of the development of health services, and a fundamental principle of sex worker-specific healthcare provision.⁹ Many authors and documents use the words 'consultation', 'participation', and 'involvement' interchangeably.

6 UNAIDS, 2007, "Policy Brief: The Greater Involvement of People Living with HIV (GIPA)" available at http://www.unaids.org/en/resources/documents/2007/20070410_jc1299-policybrief-gipa_en.pdf (last accessed 5 October 2017).

7 Ibid.

8 WHO, UNFPA, UNAIDS, NSWP, World Bank & UNDP, 2013, "Implementing Comprehensive HIV/STI Programmes with Sex Workers: Practical Approaches from Collaborative Interventions" available at http://www.who.int/hiv/pub/sti/sex_worker_implementation/en/ (last accessed 5 October, 2017).

9 Ibid.

The SWIT specifically identifies meaningful involvement and leadership of sex workers as an essential element of both condom programming¹⁰ and clinical and support services¹¹. The SWIT definition of community empowerment includes “meaningful participation of sex workers in all aspects of programme design, implementation, management, and evaluation”.

According to the SWIT, ‘meaningful participation’ means that sex workers:

- Choose how they are represented, and by whom.
- Choose how they are engaged in the process.
- Choose whether to participate.
- Have an equal voice with healthcare providers in how partnerships are managed.

Ashodaya Samithi, a sex worker-led organisation that involves sex workers at every level is described in the SWIT as a shining example of meaningful participation of sex workers in the development of health services. In Mysore, India, 12 sex workers have undergone formal training

in nursing and are now employed as nurses who are able to provide specialised, culturally appropriate health services to sex workers.¹²

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This briefing paper uses the term ‘meaningful participation’ to refer to sex workers taking part in a process of developing health services, whereas ‘meaningful involvement’ is used to refer to a health provider or other external stakeholder eliciting the meaningful participation of sex workers. The involvement of sex workers should not be limited to mere consultation, or to simply

informing them of health services that are aimed at them, both of which are token forms of involvement. Sex workers articulated an example of meaningful involvement in the consultation that informed this briefing paper. Sex workers from Cambodia who took part, stated that when they are included, for example, as members of committees, those committees must fully include their voices through action rather than only by listening to them:

Our members have been regularly invited to join monthly meetings at the healthcare, and Health Department to raise their concerns, however the concerns and issues are not addressed.

WOMEN’S NETWORK FOR UNITY (WNU), CAMBODIA.

Without full inclusion, sex workers’ involvement is cursory and token rather than meaningful. To fully include sex workers and thereby meaningfully involve them, providers and other stakeholders must not only actively seek sex workers’ feedback on current services but then also go on to integrate changes to services to better fulfil their needs based on that feedback. Processes and mechanisms to ensure the integration of this feedback into policy and practice must be put in place to ensure meaningful involvement and to uphold sex workers’ right to health.

¹⁰ Ibid., 78.

¹¹ Ibid., 121.

¹² Ibid., 121.

Meaningful involvement requires that constituency-led organisations are invited to represent the voices of sex workers...

Meaningful involvement requires that constituency-led organisations are invited to represent the voices of sex workers (and other key populations) rather than broader civil society being asked to represent them.

NSWP organised a global expert meeting to develop a community-led evaluation framework for the roll-out of the SWIT and for 'Defining Sex Worker-led Meaningful Involvement and Community Empowerment'. The following criteria were identified by sex worker-led

organisations and networks over a number of years and are included in this community-led evaluation framework to allow communities to determine the meaningful involvement of sex worker-led organisations and sex workers in the design, implementation, management and evaluation of programmes, policies and legislation across the full range of stakeholders:

- Sex worker-led organisations choose how they are represented and by whom.
- Sex worker-led organisations choose if and how they engage in any process (law reform, policy development or programming).
- There is a transparent and accountable process for consultation and decision making that allows time for genuine consultation within sex worker-led organisations in the country. Elements of the transparent and accountable process must include:
 - Information about processes and timeframes must be made available to all known sex worker-led organisations in a timely manner, including any requirements, criteria and deadlines.
 - Electronic or written communications that document the consultation with sex worker-led organisations and across a diverse range of sex workers.
 - Sufficient time to allow for genuine consultation (sex worker-led networks allow a minimum of 1 month for consulting members).
- In the event that sex worker-led organisations do not have the opportunity to choose how they are represented and by whom, a transparent and accountable mechanism for how 'their community representative' consults with and feeds back to sex worker-led organisations must be identified and shared with all known sex worker-led organisations.
- An appropriate national process has been agreed upon prior to the start of any selection process for community representatives, to ensure that the sex worker representative is genuinely endorsed by sex worker-led organisations.
- Sex worker representatives must represent the consensus position agreed upon across sex worker-led organisations, and not their personal opinions or own interests.

- Sex workers are not only beneficiaries of programmes, but are involved at all levels in the programme and partnerships including:
 - Board (legal-decision making).
 - Programme advisory committee.
 - Monitoring and evaluation committee.
- A diverse range of sex workers are engaged:
 - Female, male and transgender sex workers.
 - Sex workers with diverse sexual orientations and gender identities.
 - Sex workers living with HIV.
 - Sex workers who use drugs.
 - Sex workers with different education levels.
 - Sex workers who are young adults and aging sex workers.
 - Sex workers from various sex work settings.
 - Urban and rural sex workers.
 - Migrant and mobile sex workers, particularly undocumented sex workers.
- Translation and interpretation is provided to sex workers if required during events and activities.
- Sex workers choose to participate (or not) in the programme or process.

Sex workers' right to health

NSWP's 2013 *Consensus Statement* elaborates on sex workers' right to health, explicitly stating that sex workers have a right to non-

discriminatory, affordable, and culturally specific services that are universal and of high quality.¹³ It states that services must include: sexual and reproductive health services, drug harm-reduction and treatment services, primary health care, treatment of chronic illness, medical interventions and surgeries, and a continuum of HIV and STI prevention, diagnostics, and treatment.¹⁴

...sex workers have a right to non-discriminatory, affordable, and culturally specific services that are universal and of high quality.

According to the *Consensus Statement*, sex workers also have the right to:

- Be free from mandatory or forced STI and HIV testing and treatment, forced sterilisation, and compulsory drug treatment.
- Develop, run, and have access to sex worker-led health and HIV programmes.
- Access to commodities for safer sex and drug use.
- Work, and free choice of employment, including sex workers living with HIV.
- Be free from registration, including biometric tracking as a requirement to accessing healthcare services.

¹³ Global Network of Sex Work Projects, 2013, "Consensus Statement: on Sex Work, Human Rights, and the Law", 18.

¹⁴ Ibid.

In order for sex workers' fundamental human right to health to be realised and respected, NSWP demands that governments and responsible authorities involve sex workers of all genders, of all ages, and from all work sectors, including those living with HIV, in the planning, development, monitoring, evaluation, and implementation of health services.¹⁵ Furthermore, NSWP demands that governments and responsible authorities "invite and meaningfully consult sex workers to ensure that sex workers' expert opinions are included when sex workers' lives and work are discussed by government and other bodies."¹⁶

Aims and Objectives

This briefing paper aims to investigate the current extent of implementation of meaningful involvement of sex workers in the development of health services aimed at them.

It aims to explore the following topics by consulting sex workers and sex worker-led organisations in various countries and contexts across the globe:

- Whether sex workers are involved in the development of health services in any way;
- What, if any, health services are offered specifically to sex workers, rather than the general population, and if any of those health services are sex worker-led;
- Whether service providers have sought to meaningfully involve sex workers in the development of health services;
- What is and is not working well for sex worker health services;
- What sex workers need in order to become more meaningfully involved in the development of health services aimed at them.

Methods, Design and Demographics

This briefing paper is based on a qualitative study that was conducted among sex workers in 10 countries and a global e-consultation in various languages, conducted by NSWP amongst its membership. Across the 10

case-study countries, 166 individuals took part in focus group discussions and individual interviews. These participants included sex workers of all genders and diverse sexual orientations, with ages ranging from 18 to 50 and older. Their places of work included street or public place; indoors from their own home, hotels, or clients' residences; and managed establishments such as brothels/parlours/bars/indoor saunas. Some of

the participants were migrant sex workers, and some were sex workers' rights activists and leaders and did not necessarily identify as sex workers themselves.

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¹⁵ Ibid., 21.

¹⁶ Ibid., 3.

Analysis

Lack of health services that are aimed at sex workers

Only one e-consultation respondent specifically identified a health service provider that was sex worker-led: St. James Infirmary in San Francisco, U.S.A. Sex workers in the U.S.A. tend to rely on health services that cater to the general population or to LGBT communities, which do not provide services to sex workers in an informed and sensitive way. Health services for sex workers (where accessible) tend to be strictly limited to sexual and reproductive health services for female sex workers and do not encompass drug harm-reduction and treatment services, primary health care, treatment of chronic illness, medical interventions and surgeries, and a continuum of HIV and STI prevention, diagnostics, and treatment. Healthcare that is targeted at male and transgender sex workers was reported as non-existent.

Barriers to accessing health services

The consensus, based on the e-consultations, focus group discussions, and interviews was that sex workers are certainly not meaningfully involved in the development of health services that are aimed at them, although there may be some cursory involvement. Moreover, most sex worker participants experience major challenges and barriers to simply accessing any health services. For example, the cost of services and the cost of missing work were consistently identified as major issues regarding access (with varying levels of severity) throughout all regions. Sex workers in Cambodia reported prohibitive costs being charged for health services; state hospitals and clinics charge between USD\$1 and USD\$5 to access services. Many sex workers cannot afford these fees; sex workers earn between USD\$3.50 and USD\$10 per day.

Those able to access services often find services are of poor quality. Many participants stated that they avoided disclosing their occupation to healthcare providers because the quality of their care would

substantively deteriorate upon doing so. Access to healthcare was so poor that many participants focused on that issue during consultation rather than on meaningful involvement; they believe that sex workers' access to healthcare must come before their ability to be meaningfully involved in its development.

Across most regions and countries, sex workers do not have access to healthcare that is non-discriminatory, affordable, culturally specific, universal, and of high quality. Sex worker

participants in Belgium were the one exception; they expressed general satisfaction with their access to quality healthcare as sex workers. Due to the criminalisation of sex work and the criminalisation of engaging in sex work while living with HIV in other countries, many sex workers expressed fear of arrest and reprisal from state authorities if they disclosed their occupation to health authorities. Consequently, they have very little chance of receiving healthcare that is relevant and appropriate.

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Barriers to the meaningful involvement of sex workers in service development

Sex workers are not motivated to become meaningfully involved in the development of health services aimed at them when they cannot even access care, the care they are able to access is of very poor quality, or

Sex workers are not motivated to become meaningfully involved in the development of health services aimed at them when they cannot even access care...

because they are actively discriminated against by healthcare providers. For example, 90% of participants in Cambodia reported that health providers have discriminated against them, and some sex workers are denied access to health services when their profession is known. Some participants reported being denied access to services at state hospitals. Across all regions, lack of access to care and major challenges meeting basic survival needs were cited as barriers to sex

workers' meaningful involvement. A participant in the U.S.A. shared that health service providers do not remotely consider involving or consulting sex workers; stating sex workers are viewed as 'non-entities'. She also stated that she would not become meaningfully involved at a high level because she could not risk being outed as a sex worker. Another sex worker in the U.S.A. said:

...it doesn't feel like there's space for me in public health, and I know that other workers have tried to get involved and felt that there wasn't space for them. In the U.S., it feels like there's really no space at all for any of us to get involved - we just take care of each other within our community.

Lack of meaningful involvement of sex workers in service development

Health service providers are not making significant efforts to involve sex workers; engagement, if any, was described as token. For example, a sex worker-led organisation in the U.S.A. shared that as part of a public health project about PrEP, sex workers were hired to conduct interviews with other sex workers about PrEP, but these individuals were not involved in the development of enquiry frameworks, in the analysis, or in the drafting of reports. Sex workers who participated in focus group discussions noted that the analysis did not accurately reflect what took place during those discussions, and community feedback was manipulated to validate the pre-determined conclusion of that study.

The extent of such cursory levels of involvement in the development of health services varied across regions and between specific countries within those regions. No involvement or participation beyond simply informing sex workers of programmes was identified in the African region.

Women Network for Unity (WNU), a sex worker network in Cambodia, now has two representatives included on the National Coordinating Committee of the Global Fund, and they have consulted with government ministries such as the Ministry for Health, the Ministry for Women's Affairs, and the Ministry for Economics and Finance. WNU also attend monthly meetings at the Health Department. However, their representatives regularly raise concerns with the Coordinating Committee and during meetings at the Health Department, and these concerns are not addressed.

There were no reports of sex workers being able to choose *how* they were represented and by whom. Nor could they choose *how* they were engaged in the process, including whether they could choose to participate at all. There were no reports of sex workers having an equal voice with healthcare providers in how partnerships are managed or how projects and partnerships are carried out. An organisation in Ukraine stated that sex workers' participation was 'mediated' by the organisations that focus on providing them services.

The following are quotes from sex worker participants about the extent of their involvement and participation in health services:

They take decisions that affect us without considering our opinion. Everything is imposed [on] us and we have to comply with their policies without complaint or feedback. For example, when some services are de-localised we are not even informed.

SEX WORKER IN MAURITIUS

Feedback from Ukraine shows that sex worker involvement is token and even patronising:

When it comes to sex worker meaningful involvement into the provision of services the respondents pointed out that even if they are invited to participate in different events, working groups and round-tables they frequently see no meaning and purpose to [these] events. When sex workers bring their suggestions, those are mostly not taken into account under the pretext that they are not based on scientific data. At the same time, 'scientific data' gathered by the service providers do not reflect sex workers' needs.

SEX WORKER IN UKRAINE

When asked about the benefits and challenges of meaningful involvement, one gay, male sex worker in Ethiopia answered, in the context of criminalisation of sex work and homosexuality:

Please ask me this question when there is hope in Ethiopia. There is not. And do not call me cynical but I do not think there will be.

A sex worker in Ethiopia shared:

Sometimes healthcare providers come to Nikat [the local sex worker organisation] and ask us what information they need to include on fliers and training manuals in regards to health needs and services of sex workers. When we ask them about the next steps, they will say they will update us and leave. Most will disappear, but some will tell us that they have legal and/or financial constraints to proceed. That is why some of us choose not to participate in such useless activities. It is demoralizing and manipulative.

These structural problems not only act as barriers to accessing healthcare, but frequently also serve as barriers to the meaningful involvement of sex workers in the development of health services.

Sex workers who took part in the consultation consistently reported structural problems regarding health services and health service provision, e.g. the criminalisation of sex work, sexual orientation, and gender identity, and policy issues related to lack of funding and low levels of prioritisation of sex workers. These structural problems not only act as barriers to accessing healthcare, but frequently also serve as barriers to the meaningful involvement of sex workers in the development of health services.

Criminalisation of sex work, HIV, sexual orientation, and gender identity

The widespread criminalisation of sex work means that sex workers' right to health is not upheld in terms of freedoms or entitlements. For example, criminalisation makes it difficult for sex workers to carry

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condoms, and decreases the likelihood they will attend a clinic or healthcare centre. Sex workers may be reluctant to disclose their occupation to healthcare providers in case they are forced to take an HIV test (this was reported by sex workers in Ethiopia); in many countries, people who engage in sex work whilst living with HIV are further criminalised. In those contexts, if a sex worker is forced to take a test for HIV and the

test is positive, they will likely suffer further discrimination and even prosecution based on their occupation and HIV status. Sex workers risk being targeted by law enforcement if they participate in the process of being meaningfully involved in the development of health services, since it may require them to be more visible.

Homophobia and the criminalisation of same-sex sexual activity was identified as a major concern in Ethiopia, and barriers for transgender women were identified as major issues in Trinidad and Tobago and in Brazil. Severe levels of stigma are often accompanied by outright criminalisation of these groups. Sex workers in Trinidad and Tobago highlighted the challenges that transgender sex workers face in meeting their basic survival needs (food, shelter etc.), and the severe levels of discrimination they face when they try to seek healthcare and other types of assistance. Sex workers in Ecuador stated that health service providers should be more aware that not all sex workers are cisgender women, in order to meet the needs of all sex workers.

Criminalisation acutely limits the meaningful involvement of the most marginalised sex workers. A gay, male sex worker participating in the focus group discussion in Ethiopia stated:

Meaningful involvement is impossible and impractical in this country. Although legalization should come first; homophobia has been rooted in the religion, social and cultural lives of the Ethiopian society and the mere legalization act will only magnify the stigma and discrimination at family and community level.

People who identify themselves as sex workers to the authorities often risk the consequences of being outed; the meaningful involvement of sex workers becomes impossible in such contexts.

Stigma and structural discrimination

Sex workers face significant levels of stigma and discrimination from healthcare providers across all regions. Sex workers reported healthcare providers wearing double or triple layers of gloves when examining sex worker patients, and verbally abusing or otherwise demeaning patients they discovered were engaging in sex work. There is widespread, routine discrimination in the health system, by state bodies and by agencies such as the police. People who identify themselves as sex workers to the authorities often risk the consequences of being outed; the meaningful involvement of sex workers becomes impossible in such contexts. As a result of stigma, sex workers in Brazil who took part in the consultation did not want to be open about their occupation, which was seen as “affecting participation, access, political advocacy and full exercise of their rights.”

Denial of services and appropriate treatment

Outright denial of treatment and receipt of inappropriate treatment was also reported. In Mauritius, doctors often refuse to examine sex workers; they offer them irrelevant medicines such as non-prescription painkillers. One focus group participant in Cambodia reported having to deliver her baby in the back of a motor taxi after a hospital denied her service when she was in labour.

Lack of confidentiality

Participants frequently reported a lack of confidentiality, and that their fear of this was so great they stopped accessing healthcare altogether. In Mauritius, multiple patients reportedly share consultation rooms, and HIV status is regularly disclosed in public. Sex workers reported that health providers to whom they disclosed their occupation, sexual orientation and/or gender identity have shared that information with their colleagues and laughed at them when they attend the clinic again. Others reported that doctors speak amongst themselves in English to mock patients without consequence.

Financial and practical barriers

Sex workers reported difficulty accessing services due to cost, location and transport issues. Sex workers often cannot afford to take time off work to attend to their own healthcare needs at clinics, much less to take the amount of time away from work required to be meaningfully involved in the development of health services. Some sex workers also reported that they feared they would be punished by managers if they took time off work.

Sex workers in Belgium were more positive than others about their experiences of healthcare and health service provision, and reported the fewest barriers. They deemed the services in their country that target sex workers to be effective and acceptable, although the services for sex workers were not always provided at convenient times. However, no sex worker-led organisations are considered for funding to develop or run health services specifically for sex workers in Belgium.

Lack of primary/general healthcare

Where services aimed at sex workers were reported, it was noted that only sexual and reproductive services were made available. Sex workers struggle to access more general healthcare, such as a primary care physician. Even health providers in the U.S.A. that focus on sex workers and are sex-worker-led do not offer comprehensive care.

Policy and funding mechanisms are not aligned

Whilst sex workers are sometimes included in national plans (e.g. in the Democratic Republic of the Congo and Ukraine), there is often no funding mechanism in place to practically support their inclusion. In the U.S.A., sex workers are not even considered a key population, which severely restricts the funding of services that are aimed at them. When policy makers do not recognise sex workers as a key population, this serves as a barrier to meaningful involvement.

Capacity of individuals and community organisations

In areas and circumstances where sex workers have low levels of formal education, they often lack knowledge about their rights or about the benefits of seeking and receiving healthcare. Many sex workers are

Many sex workers are necessarily so focused on their basic survival that sex worker-led organisations are not able to build the capacity needed to allow sex workers to become involved on a more meaningful basis...

necessarily so focused on their basic survival that sex worker-led organisations are not able to build the capacity needed to allow sex workers to become involved on a more meaningful basis, for example, by increasing literacy levels (reported in both Ethiopia and the U.S.A.). Additional to the focus on individual survival, a sex worker organisation in Ukraine reported high levels of 'self-stigmatisation' among sex workers, and the respondents from Portugal reported high levels of distrust between sex workers. These factors limit community solidarity and the ability to self-organise to advocate for rights and involvement.

The majority of sex workers' rights organisations reportedly struggled with severe financial capacity issues.

Authorities do not prioritise capacity building

Sex workers reported that public health professionals do not have the time, patience, or energy required to engage in capacity building or community-system strengthening with sex workers. Worldwide, researchers and programme implementers merely pay lip service to involvement, prioritising the implementation of programmes in line with their own agenda rather than undertaking capacity building with sex workers, who often don't have a background in formal education, or formal experience in research, programme development and programme evaluation.

Requirements for identity documents and collection of biometric data

Sex workers struggle to access government healthcare if they do not have an identity card, and those most frequently unable to obtain an identity card are migrants. This is because many migrants, particularly migrants who are further marginalised by other factors, lack formal status or documentation in the area to which they migrated. This was highlighted in the case study from Ethiopia; one sex worker explained:

Since most [of] us are mobile, it is difficult to get ID card from local unit. In order to get a valid ID card we have to reside in one locality for six months and present three witnesses to verify that we did so. The witnesses should also have a valid ID from the locality. But this difficult for us, considering our mobility and social network.

It is unclear what the benefits of UICs and collection of biometric data are for sex workers, in comparison with the significant potential risk to their safety and livelihood associated with a breach in confidentiality.

Health providers often use Unique Identifier Codes (UICs) to record whether their clients are part of key populations, and the collection of biometric data (e.g. fingerprints) in association with UICs is routine. However, the use of biometrics can be dangerous for sex workers; it discourages individuals from accessing health services. It is unclear what the benefits of UICs and collection of biometric data are for sex workers, in comparison with the significant potential risk to their safety and livelihood associated with a breach in confidentiality.

Sex workers are barred from becoming licensed healthcare practitioners

Sex workers may be prevented from working as healthcare providers due to criminalisation, which limits their ability for meaningful involvement. For example, in the U.S.A., healthcare practitioners are barred from licensing if they have a criminal record relating to sex work. This severely limits sex workers' agency in meaningfully participating in healthcare services aimed at them, restricting their ability to become healthcare providers themselves.

Recommendations

Sex workers who took part in the consultation process articulated the following 12 recommendations for improving the meaningful involvement of sex workers in the development of health services.

For Governments, Policy Makers, and Health Service Programmers:

- **Decriminalise sex work, HIV transmission and same-sex sexual activity.** Criminalisation of sex work, HIV transmission and same-sex sexual activity contributes to bad practices among healthcare providers, increases stigma and discrimination, and causes fear among sex workers that prevents them from seeking the healthcare they need. Decriminalisation would significantly reduce the barriers to health for sex workers, in terms of both access to healthcare and meaningful involvement in the development of health services aimed at them.
- **Actively reduce widespread societal stigma against sex workers,** alongside decriminalisation. Suggested mechanisms include media campaigns aimed at the public, and professional development and training for police, health service providers, and all government employees.
- **Recognise sex work as work.** Governments should extend all legal protections and labour rights, to which all workers are entitled, to sex workers.
- **Align funding mechanisms and national policy priorities.** Including sex workers as a key population in national health strategies is essential. This must be funded by governments on a sustainable basis.
- **Reduce stigma in health service delivery.** This can be done in the following ways:
 - Sensitise all healthcare providers, at all levels.
 - Departments of Health should develop explicit policies to safeguard the equitable treatment of sex workers, and create mechanisms to ensure healthcare workers adhere to these policies.
 - Ensure that sex workers are not prohibited from becoming healthcare workers by law.
- **Provide comprehensive health services that are explicitly friendly to sex workers.** Governments should provide high-quality general health services that specifically include sex workers, or health services specifically aimed at sex workers, or (ideally) both. Health services for sex workers should not focus solely on sexual health but should instead take a more comprehensive approach.
- **Eliminate requirements for identity cards and collection of biometric information.** All governments should eliminate any laws that require people to have identity cards or to provide biometric information to receive healthcare. These laws actively prevent sex workers, who are often migrants and/or otherwise mobile, from receiving healthcare.
- **Support the formation of new sex worker-led organisations and increase the funding and capacity of existing sex worker-led organisations.** There is still a total lack of sex worker-led organisations in some countries. Sex workers first need to build a sense of solidarity and collective strength in order to advocate for their rights.

- **Healthcare providers should actively build trust and partnerships with sex workers and sex worker-led organisations.** Healthcare professionals should treat sex workers as experts on their own lives and their health needs, and as potential service providers, not just service users. They should actively work to build trust by reaching out to them, listening to their needs, and building effective partnerships with sex workers' rights organisations.
- **Provide equitable remuneration to sex workers who are meaningfully involved in the implementation and management of services.** Remunerating their efforts could significantly increase meaningful participation, thus improving health services aimed at them.

For sex workers' rights organisations:

- **Increase the capacity of sex workers so they are better equipped to become meaningfully involved.** This includes improving their financial capacity, literacy, basic education levels, and knowledge about their rights. Many sex worker organisations are already engaging in these efforts and simply lack the funding to bolster them.
- **Where possible, prioritise asserting sex workers' right to health.** This should be done with both government and non-government organisations. Sex worker-led organisations should try to actively collect data on the violations of their right to health and report and publicise these.

Conclusion

Sex workers' fundamental right to health is best upheld when sex workers are meaningfully involved in all stages of service provision development. This includes planning, design, implementation, and monitoring and evaluation. However, meaningful involvement is not possible in an environment rife with structural issues. The criminalisation of sex work, HIV status, same-sex sexual activity, and non-normative gender identities prevents meaningful involvement. Active discrimination by healthcare providers and state authorities (e.g. police) against sex workers is a major barrier to sex workers not only

identifying themselves for appropriate treatment, but also against collective organising. Without adequate funding, existing sex workers' rights organisations will not be able to actively advocate for the meaningful involvement of their members.

Building trust is essential for developing the effective and sustainable partnerships that are fundamental to upholding sex workers' right to health. Sex worker-led organisations cannot be expected to forge this path alone. Healthcare

providers must transform their view of sex workers as health service 'users', and instead view them as people who can also become health service providers and partners. Safeguards must be built into these partnerships to prevent retaliation against sex workers for organising and identifying themselves. Governments and health service providers should lead the way in this process by improving sex workers' basic access to healthcare, otherwise sex workers who would benefit most from meaningful involvement will not be motivated to do so.

Building trust is essential for developing the effective and sustainable partnerships that are fundamental to upholding sex workers' right to health.

The Global Network of Sex Work Projects uses a methodology that ensures the grassroots voices of sex workers and sex worker-led organisations are heard. The briefing papers document issues faced by sex workers at local, national, and regional levels while identifying global trends.

The NSWP Secretariat manages the production of briefing papers and conducts consultations among its members to document evidence. To do this, NSWP contracts:

- Global Consultants to undertake desk research, coordinate and collate inputs from Regional Consultants and draft the global briefing papers.
- Regional Consultants to coordinate inputs from National Key Informants and draft regional reports, including case studies.
- National Key Informants, identified by the regional networks, to gather information and document case studies.



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