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

The World Health Organization has defined the 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 to have the right to “a system of health protection that gives everyone an equal opportunity to enjoy the highest attainable level of health”. Everyone has the right to non-discriminatory health services, as well as health services, goods, and facilities that are available, accessible, acceptable, and of good quality. Sex workers have the same entitlement to the right to health as everyone else, yet they experience significant health inequalities.

Criminalisation, stigma and sex workers’ right to health

Worldwide, criminalisation and stigma against sex workers are major barriers to upholding their right to health and a fundamental cause of health inequalities. Severe societal stigma is demonstrated by discriminatory attitudes from healthcare providers and the outright criminalisation of sex workers, same-sex sexual activity, and gender-nonconforming people. These factors impact sex workers’ abilities to access services and to participate in the development of health services. Sex workers are often stigmatised as ‘vectors of disease’ who negatively impact the health of the public. A rights-based approach to health offers an alternative that does not treat sex workers as separate from the general population.

Meaningful involvement

Sex workers’ right to health is best upheld when healthcare providers acknowledge that sex workers not only receive health services but also potentially provide services, and can therefore meaningfully participate in all stages of service development. Health service providers can address stigma as a barrier to sex workers’ health by meaningfully involving sex workers, both as service receivers and providers, in the development of health services aimed at them. When sex workers are involved at all stages of development, including planning, design, implementation, and monitoring and evaluation, health services are better able to cater to sex workers’ needs. Meaningful participation occurs when sex workers take part in the development process in a substantial way and when stakeholders successfully seek out the meaningful participation of sex workers. When sex workers are not meaningfully involved, for example, when sex workers are merely informed about a programme before its launch, health service providers fail to uphold sex workers’ right to health.

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’. This framework is detailed in the Briefing Paper that this Community Guide accompanies.
Barriers to accessing healthcare and barriers to sex workers’ meaningful involvement in the development of health services

NSWP conducted a consultation about the current extent of the meaningful involvement of sex workers in health services aimed at them. This consultation included an e-consultation with NSWP’s member organisations, and in-depth focus group discussions and interviews with sex workers in ten countries. Sex workers reported they had not been meaningfully involved by health service providers in the development of health services that are aimed at them. Many concerns regarding the difficulty of accessing healthcare were reported. It became clear that sex workers are (understandably) not motivated to become meaningfully involved in the development of services when they cannot access care, the care they are able to access is of very poor quality, or because they are actively discriminated against by healthcare providers. This discrimination includes making judgmental comments, violating confidentiality, verbal abuse, asking inappropriate and invasive questions about their work, wearing multiple gloves during examinations, providing inappropriate treatment, and outright denial of treatment. Sex workers reported financial and practical barriers to accessing healthcare and becoming meaningfully involved in the development of health services. These barriers include the location and price of services and problems attending clinics due to transportation issues.

Where sex workers have low levels of formal education, they may lack adequate knowledge about their rights and knowledge of the benefits of seeking and receiving healthcare. Many sex workers are focused on meeting their basic needs (e.g. food and shelter), meaning sex worker-led organisations are unable to increase their capacity to engage with health providers and other stakeholders. High capacity and specific knowledge are typically required to communicate with health providers and funders (e.g. specific vocabulary). During the consultation, sex workers reported that public health professionals do not have the time, patience, or energy required to engage in capacity building with them. Researchers and programme implementers frequently only pay lip service to involvement. They prioritise the implementation of programmes in line with their own agenda rather than undertaking capacity building with sex workers who do not have a formal education background, or any formal experience in research, programme development and programme evaluation.

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Recommendations

For Governments, Policy Makers and Health Service Programmers:

• Decriminalise Sex Work, HIV Transmission and same-sex sexual activity.
• Actively reduce widespread societal stigma against sex workers.
• Recognise sex work as work, extending all legal protections and labour rights to sex workers.
• Align funding mechanisms and national policy priorities.
• Reduce stigma in health service delivery.
• Provide comprehensive health services that are explicitly friendly to sex workers.
• Eliminate requirements for identity cards and biometric information.
• Support the formation of new sex worker-led organisations and increase the funding and capacity of existing sex worker-led organisations.
• Healthcare providers should actively build trust and partnerships with sex workers and sex worker-led organisations.
• Provide equitable remuneration to sex workers who are meaningfully involved in the implementation and management of services.

For sex workers’ rights organisations:

• Increase the capacity of sex workers so they are better equipped to become meaningfully involved.
• Where possible, prioritise asserting sex workers’ right to health.

Healthcare providers should actively build trust and partnerships with sex workers and sex worker-led organisations.
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 by using Global and Regional Consultants as well as National Key Informants. Community Guides aim to provide simple summaries of NSWP’s Briefing Papers, further detail and references can be found in the accompanying Briefing Paper.