Community empowerment and access to sexual and reproductive health and rights services (including HIV) for sex workers in South Africa

Research report: a series of 6 research briefs

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Glossary

Sex worker	Sex workers are female, male and transgender adults (18 years of age and above) who receive money or goods in exchange for sexual services, either regularly or occasionally.
Decriminalisation of sex work	Decriminalisation of sex work is the removal of criminal penalties for sex work. In countries that decriminalize sex work, sex workers receive the same protection and recognition as workers in other industries.
SWIT	The Sex Worker Implementation Tool (SWIT) offers practical guidance on effective HIV and STI programming for sex workers. It provides evidence for the necessity of decriminalisation of sex work, the involvement of sex workers in developing policy, and the empowerment and self-determination of sex work communities as a fundamental part of the fight against HIV. SWIT is based on the WHO, UNFPA, UNAIDS and NSWP 2012 recommendations on HIV and Sex Work.
Community empowerment	According to the SWIT, community empowerment is an ownership process by sex workers to individually and collectively improve health and human rights. The SWIT defines community empowerment with eight elements: (1) working with communities of sex workers; (2) fostering sex worker-led outreach; (3) developing sex worker collectives; (4) adapting to local needs and contexts; (5) promoting a human-rights framework; (6) strengthening the collective; (7) shaping policy and creating enabling environments; and (8) sustain the movement.
Peer educators	Peer educators are representative members of a key population who serve as a link between the program and the key population. They manage the program on the ground through outreach and serve a population with whom they have a similar occupational, behavioural, social, or environmental experience and among whom they are trusted and serve as a role model. Peers typically work with 50–60 KPs to influence attitudes and provide support to change high-risk behaviours.
Meaningful participation	Meaningful participation requires that individuals are entitled to participate in the decisions that directly affect them, including in the design, implementation, and monitoring of health interventions. In practice, meaningful participation may take on a number of different forms, including informing people with balanced, objective information, consulting the community to gain feedback from the affected population, involving or working directly with communities, collaborating by partnering with affected communities in each aspect of decision making including the development of alternatives and identification of solutions, and empowering communities to retain ultimate control over the key decisions that affect their wellbeing.
Hotspot	A public or semi-public place where people gather in significant numbers for a particular behaviour (e.g., places where sex workers solicit clients, places where men commonly seek sex with other men, places where drug users gather to inject drugs together).

In-depth interview	In-depth interviewing is a qualitative research technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspectives on a particular idea, program, or situation.
Focus group discussion	Focus group discussion is a tool for qualitative market research where a group of people are selected and asked about their opinion or perceptions about a particular topic. The environment is interactive where the participants are free to discuss with each other.

List of abbreviations

AFAB	Assigned female at birth
ANC	African National Congress
AOR	Adjusted odds ratio
ART	Antiretroviral therapy
FGDs	Focus group discussions
GHJRU	Gender Health and Justice Research Unit
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
M4F	Mothers for the Future
MEC	Member of the Executive Council
MWC	Multi-party Women's Caucus
NACOSA	Networking HIV&AIDS Community of Southern Africa
NGO	Non-governmental Organizations
NHI	National Health Insurance
NSWP	Global Network of Sex Work Projects
ORWs	Outreach workers
PEP	Post-exposure prophylaxis
PrEP	Pre-exposure prophylaxis
SALRC	South African Law Reform Commission
SANAC	South African National AIDS Council
SAPS	South African Police Service
SLDC	SWEAT Legal Defence Centre
SRHHIV	Sexual and Reproductive Health (including HIV)
SRHR	Sexual and Reproductive Health and Rights
STI	Sexually Transmitted Infection
SWEAT	Sex Workers Education and Advocacy Taskforce
SWIT	Sex Worker Implementation Tool
UCT	University of Cape Town
UDHR	Universal Declaration of Human Rights
UNAIDS	United Nations Programme on HIV/AIDS
UNCHR	United Nations Centre for Human Rights
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
VCT	HIV voluntary counselling and testing
WBPHCOT	Ward-based primary healthcare outreach team
WHO	World Health Organization
WLC	Women's Legal Centre

Summary

This report documents a research study examining community empowerment and access to sexual and reproductive healthcare (including HIV) among South African sex workers. Sisonke, the Sex Worker Education and Advocacy Taskforce (SWEAT) and the Gender Health and Justice Research Unit at the University of Cape Town collaborated to design, implement and report on research documenting community empowerment and access to SRHHIV services for South African sex workers. The research team were led by the broad research question: what is the relationship state of community empowerment and access to SRHHIV services among South African sex workers? We further examined how community empowerment and access relate to each other through six theme, which we present here in six research briefs

To guide this research, the research team drew on the model of community empowerment documented in *Implementing Comprehensive HIV/STI Programmes with Sex Workers: Practical Approaches from Collaborative Interventions,* also known as the *Sex Worker Implementation Tool* (SWIT). The SWIT documents global best practice guidelines for community empowerment among sex workers and improved delivery of HIV/AIDS services. The SWIT defines community empowerment as an ownership process by sex workers to individually and collectively improve health and human rights, consisting of eight elements: (1) working with communities of sex workers; (2) fostering sex worker-led outreach; (3) developing sex worker collectives; (4) adapting to local needs and contexts; (5) promoting a human-rights framework; (6) strengthening the collective; (7) shaping policy and creating enabling environments; and (8) sustain the movement (WHO 2013). It further stipulates the importance of sex workers being involved in all aspects of sexual and reproductive health (including HIV) (SRHHIV) programming.

Despite ongoing efforts by sex worker activists and allies to amend laws for decriminalisation, the act of sex work is criminalised in South Africa by both the Sexual Offences Act (1957) and the Criminal Law (Sexual Offences and Related Matters) Amendment Act (2007). As a result, sex workers continue to experience discrimination from law enforcement, including little assistance for sex workers following sexual violence and instances of police confiscating condoms as evidence of sex work (Fick 2006; SHARP & LAHI 2006; Shields 2012; Peters 2015a; Peters 2015b; Women's Legal Centre & SWEAT n.d.). Research has also documented continued barriers to healthcare and discrimination against sex workers in South African government health services (Richter 2008; Scorgie et al 2013), and there is a great need to improve access to SRHHIV services. For example, the South African National AIDS Council (SANAC) has estimated that almost 60% of sex workers in South Africa are living with HIV (SANAC 2016). Also, due to the high risk of sexual violence, with little opportunity for recourse or law enforcement protection, as well as the occupational risk of sex with multiple concurrent partners, sex workers are at high risk for unplanned pregnancy and sexually transmitted infections (STIs).

To explore this topic, the research team completed: 15 interviews with NGO representatives, researchers and policymakers; 3 focus groups with sex workers (n=27); and a paper survey with a convenience sample of 298 sex workers in Gauteng (n=100), Limpopo (n=100) and the Western Cape (n=98), recruited using trained sex worker fieldworkers. Of those surveyed, 81% were cisgender women, 13% were transgender and 6% were cisgender men. We presented preliminary findings to a group of sex workers at a Cape Town Sisonke Creative Space meeting and incorporated their recommendations and feedback on the findings. All names reported in this brief are pseudonyms, to protect participants' privacy.

After reviewing the preliminary findings, the research team decided to report on the results in six research briefs:

1. Is community empowerment associated with access to SRHHIV services by sex workers? A description of SRHHIV access experiences in South Africa Ensuring access to sexual and reproductive health, including

HIV (SRHHIV) services for sex workers is paramount, due to sex workers having higher occupational risk for HIV and STIs as well as pregnancy (WHO 2013). In this brief, we first describe what healthcare services South African sex workers use, and their experiences in doing so, particularly related to discrimination. Next, we examine healthcare access for sex workers, drawing on McIntyre et al's 2009 framework, which conceptualises access through availability, affordability and acceptability (McIntyre, Thiede, & Birch, 2009). After describing access to healthcare, we will discuss our findings in relation to community empowerment.

2. Do sex workers meaningfully participate in SRHHIV services? Successes and challenges from South Africa The SWIT highlights that, in order to have effective community empowerment, participation must be meaningful. The SWIT describes meaningful participation as sex workers: (1) choosing how and by whom they are represented, (2) choosing how they engage, (3) choosing whether to participate, and (4) having an equal voice in managing partnerships. Government, NGOs and sex worker collectives (organisations run entirely by sex workers) must meaningfully work with communities of sex workers to ensure access to SRHHIV services (WHO 2013). We examine community empowerment and meaningful participation of sex workers in South African programmes for sexual and reproductive health (including HIV) (SRHHIV) and discuss how sex workers currently participate, as well as how participation could be improved.

3. Sex worker peer educator-led programmes in South Africa Sex worker-led outreach programmes are increasingly recognised as part of best practice for sexual and reproductive health, including HIV, (SRHHIV) programmes and community empowerment promotion. There are many ways in which sex-worker led outreach can be implemented, including employment of sex workers as educators and outreach workers. Peer educators are described as the "backbone" of the *National Sex Worker HIV Plan (2016-2019)* and are the central community empowerment mechanism therein. In this brief, we describe the structure and context of sex worker peer educator programmes in South Africa and examine successes of the current sex worker peer educator programmes, using the criteria from the National Sex Worker HIV Plan, which suggest that peer educators are highly utilised for connecting sex workers to health services.

4. Developing and strengthening sex worker collectives in South Africa According to the SWIT, sex worker collectives are groups that are entirely sex worker run and led. Sex workers themselves create collectives, and different collectives may have different goals. In this brief, we first describe the sex worker collectives we identified in South Africa. Then, using the national collective Sisonke as a case study, we describe how sex worker collectives contribute to individual and community empowerment. In the last section, we discuss opportunities for strengthening Sisonke and other collectives.

5. Promoting health and human rights for sex workers in South Africa Globally, human rights violations of sex workers, and the association of violations with increased vulnerability to HIV, have been documented, including homicide, physical and sexual violence, and forced HIV voluntary counselling and testing (VCT) (Decker et al 2015). These violations are exacerbated by the criminalisation and stigmatisation of sex work (Decker et al 2015; Wolffers & van Beelen 2003). Our study explored how health and community empowerment efforts with South African sex workers addressed human rights. We examine human rights violations of sex workers and mechanisms to address these violations, including education, complaints mechanisms, legal support and participation in public advocacy efforts for the general population. We further investigate whether and how community empowerment impacted sex workers' participation in these mechanisms.

6. The role of community empowerment in reducing sex work-related stigma and improving access to SRHHIV services in South Africa Evidence from across the globe has identified sex work-related stigma as a common and challenging barrier to healthcare access for sex workers (Ma et al 2017). We report on sex work-related stigma from our South African study, using three types of stigma – enacted, felt and project - to describe our findings, as well as to explain how they interact with community empowerment and access to healthcare among South African sex workers.

Community empowerment is a process. Our series of research briefs highlights numerous success stories of community empowerment of sex workers in South Africa, as well as ongoing barriers to empowerment and access to SRHHIV services. We summarise the most notable instances of each and reflect on how these findings contribute to existing literature about community empowerment among sex workers.

Success stories of community empowerment include:

- Extensive peer educator-led outreach
- Existence of sex worker collectives
- Dedicated legal services and human rights education for sex workers
- Recognition of sex workers in national policy

We also identified these main barriers to community empowerment:

- Sex work-related stigma and healthcare providers' attitudes
- Criminalisation of sex work and policing practices
- Need for transparency and *meaningful* participation at the government level

Our findings also document an apparent shift towards an institutionalisation of sex worker advocacy into national government policies and programmes. However, coordination by government—particularly while sex work remains criminalised—could hinder the goals of community empowerment, if government were to wield more decision-making power in policies and programmes that impact sex workers. In light of this, continued efforts to strengthen sex worker collectives and inclusion of sex workers in other roles in addition to peer educators are needed. Based on our findings, the model of community empowerment laid out in the SWIT is useful in the South African context. Paired with the voices of South African sex workers, the SWIT can offer continued guidance to government and NGOs alike.

Based on the findings from this project, this report closes with recommendations for government and policy makers, civil society organisations, SRHHIV funders and academics and researchers.

- Decriminalise sex work
- Improve the ways in which civil society, including sex workers, can participate in policy-making
- Increase the meaningful participation of sex workers in SRHHIV programme design
- Continue the implementation of peer outreach programmes
- Continued efforts for economic empowerment for South African sex workers
- Improve efforts to work with law enforcement to decrease human rights violations
- Expand human rights education and legal support for sex workers
- Prioritise interventions to reduce sex work-related discrimination:
- Provide pre-service and in-service sensitisation training for clinical and non-clinical healthcare providers
- Develop specific, measurable targets for sex worker collective strengthening
- Include community empowerment measures in research related to sex workers and SRHHIV
- Monitor community empowerment of South African sex workers over time:
- Expand the availability of comprehensive SRHHIV health services for sex workers, including gender affirming care
- Increase psychosocial support for sex workers

1 Introduction

This research project, *Community empowerment and access to sexual and reproductive health and rights services (including HIV) for sex workers in South Africa*, is a collaboration between the Sisonke National Sex Workers Movement in South Africa, the Sex Workers Education and Advocacy Taskforce (SWEAT) and the Gender Health and Justice Research Unit (GHJRU) at the University of Cape Town (UCT). Using the Sex Worker Implementation Tool (SWIT), which documents good practices for implementing sexual and reproductive health (including HIV) (SRHHIV) programmes with sex workers, as guidance, our series of research briefs examines the intersection of community empowerment and SRHHIV for sex workers in South Africa. To do this, we used a survey, focus groups with sex workers and interviews with service providers, researchers and government. Drawing on our evidence and available literature, we make recommendations for improving community empowerment and access to healthcare for sex workers.

In this report, we start with a brief overview of the literature related to sex workers, health and community empowerment in South Africa. Next, we describe our research methods. The heart of the research report is composed of six research briefs, which can also be used as stand-alone documents. We then conclude with an overview of what our findings mean and overall recommendations.

2 Contextual background

Sex workers, law and policy

Global climate of sex worker rights and laws

The sale and purchase of sex work, or organising by sex workers, is criminalised in most countries; globally, sex work is legal in 11 countries and in regions of 2 additional countries, and it is decriminalised in regions of 2 countries (Global Network of Sex Work Projects 2019). Globally, sex workers, including the Global Network of Sex Work Projects, a membership organisation of sex worker-led organisations around the world, have advocated for the decriminalisation of sex work for many years (see for example Global Network of Sex Work Projects n.d. and Sex Workers United Against Violence et al 2014).

International experts and advocates in the HIV/AIDS sector are increasingly supporting the removal of laws that criminalise sex work. Recognising the significance of the criminalisation of sex work on sex workers' health, the United Nations Development Programme (UNDP) established the Global Commission on HIV and the Law to investigate how laws increase or decrease deaths due to HIV. This independent body included world leaders, academics and legal specialists. The Commission's 2012 report documents that the criminalisation of sex work increases vulnerability of sex workers to HIV globally (Levine and The Global Commission on HIV and the Law 2012). The report details the lack of protections for sex workers, including no legal protection from discrimination on the basis of their occupation, harassment and violence from law enforcement, and, further, the high level of HIV infection among female sex workers.[1] In addition to more detailed recommendations, the Commission called for the repeal of laws that criminalise consenting adults who buy or sell sex, and encouraged meaningful efforts to reform policing practices (Levine and The Global Commission on HIV and the Law 2012). The release of the report was met with some controversy: a coalition led by NGO Equality Now released public statements and a letter writing campaign against the Commission's report, criticising the Commission for recommending decriminalisation of both those who buy and sell sex (El Feki et al 2014). However, in response, the Global Network of Sex Work Projects (NSWP) released a statement incorporating input from individual sex workers and sex worker organisations that rejected Equality Now's campaign, supporting the UN and the call for decriminalisation, while also calling out Equality Now for using 'morality, and evidence-free, punitive ideology' in their argument (NSWP 2013; El Feki et al 2014).

Current available research evidence supports the decriminalisation recommendation from the 2012 report. A recent global systematic review of both qualitative and quantitative research found that repressive policing—aimed at enforcing the criminalisation of sex work—is associated with increased sexual or physical violence experienced by sex workers, as well as higher HIV and STI prevalence among sex workers. Based on these findings, the authors called for the decriminalisation of sex work, in order to improve access to health services for sex workers (Platt et al. 2018).

In the next section, we explore the history of criminalisation of sex work in South Africa specifically.

South African context and legal framework on sex work

There are an estimated 132,000 to 182,000 sex workers in South Africa (Stacey et al 2013). Most sex workers are cisgender women, approximately 5% are cisgender men and 4% are transgender men or women and it is

[1] The report cites a 2012 systematic review by Baral et al examining HIV among female sex workers. This study does not provide a definition of female sex workers. It is unclear whether the study is inclusive of trans women sex workers.

estimated that sex workers make up about 1% of the population of South African cisgender women (Stacey et al 2013).

In South Africa, the act of sex work is criminalised. Both the Sexual Offences Act (1957) and the Criminal Law (Sexual Offences and Related Matters) Amendment Act (2007) criminalise sex work between people of any gender. Whether and how these laws should be changed has been the subject of advocacy efforts by sex workers for decades.

Over the last several years, the South African Law Reform Commission (SALRC) investigated whether these laws should be reformed. The mandate of the SALRC is to review legal topics through research and public consultation processes in order to make recommendations to the Minister of Justice regarding potential law reform. In 2009, the SALRC published a discussion paper, which put forth four options for legally addressing 'prostitution'[2]: (1) total criminalisation (as in the current law); (2) partial criminalisation, defined by the SALRC as mainly decriminalising selling sex and criminalising buying sex; (3) 'non-criminalisation', also known as decriminalisation; or (4) regulation. This discussion paper called for public comment, after which the SALRC would make a final recommendation in an additional report (Albertyn et al., 2009).

During the time between the SALRC's discussion paper and their final recommendation, many entities—in addition to sex worker NGOs and the sex worker collective Sisonke—came out in support of full decriminalisation of sex work. For example, the Commission on Gender Equality, which is responsible per the Constitution (1996) to 'monitor, investigate, research, educate, lobby, advise and report on issues concerning gender equality,' released a position paper in 2013 supporting decriminalisation of sex work (Commission on Gender Equality 2013). The Desmond Tutu HIV Foundation released an evidence-based report recommending decriminalisation of sex work as essential for achieving better health for sex workers, particularly related to HIV (Scheibe et al 2011).

In 2017, the SALRC released the long-awaited final report addressing 'adult prostitution' as a sexual offence. In this report, the SALRC recommended either (1) continuation of total criminalisation or (2) partial decriminalisation and included draft bills for both options. They did not put forth an option for full decriminalisation. Justifying their stance, the SALRC described sex work as 'inherently exploitative' and a form of violence against women. The SALRC report also made several non-legislative recommendations, including but not limited to: the development of a national strategy on 'prostitution; agreement that the Commission on Gender Equality and the Human Rights Commission investigate human rights violations of sex workers; that the South African Police Service (SAPS) should investigate the reported abuses of sex workers by law enforcement; and that instances of discrimination by healthcare workers should be dealt with through a complaints system, not criminal justice (South African Law Reform Commission 2015).

Following the release of the 2017 SALRC report, sex worker organisations released statements documenting the continued need for decriminalisation and news articles were published by others echoing these concerns. They highlighted: the lack of a strong evidence base in the SALRC report supporting the need for continued criminalisation; the high prevalence of violence against South African sex workers, including by law enforcement; the language of the report containing conservative ideology (painting sex work as 'inherently exploitative'); and concerns about barriers to HIV prevention (Asijiki 2017; SWEAT 2017; Furlong 2017; Richter 2017; Van Der Merwe 2017).

These statements were followed with renewed interest from the political arena. In December 2017, the African National Congress (ANC), a major political party in South Africa, announced its support for the decriminalisation of sex work (Rahlaga 2017). In March 2018, the Multi-party Women's Caucus (MWC) held a summit in response to the SALRC report on sex work. The MWC is an all-women committee of members of Parliament, coming from

[2] We acknowledge that the term 'prostitute' has negative connotations and therefore use the term sex work throughout this report. However, 'prostitution' is the term used in the SALRC reports. See the infosheet "Language Matters: Talking About Sex Work" by Stella for more context on langague, available here: https://www.nswp.org/sites/nswp.org/files/StellaInfoSheetLanguageMatters.pdf

different political parties. Written submissions were accepted from the public prior to the summit. The goal of the summit was to further engage with members of the public about whether sex work should be decriminalised before making their own recommendation. Although just over half of those present at the summit were in support of decriminalisation, the MWC decided that more extensive consultations, for example, in rural areas, would be needed before making a recommendation (Ngalo 2018).

At the time of writing this research report, no final decisions regarding law reform to criminalise or decriminalise sex worker in South Africa had been made or implemented at the legislative level.

South African law and policy framework on sex workers' SRHHIV

The South African constitution is among the most progressive constitutions in the world and offers a number of important legal protections and rights for sex workers. It is important to note that while doing sex work is criminalised in South Africa, being a sex worker is not illegal, and sex workers, like all South Africans, enjoy the same constitutional rights and protections. For one, Section 9 of the constitution prohibits discrimination based on, among other grounds, gender, sexual orientation and race and Section 22 states the right to choose one's employment.

The right to access healthcare, including sexual and reproductive healthcare, is firmly enshrined in Section 27 of the South African Constitution (1996). Several laws specify additional parameters for different types of sexual and reproductive health services (including HIV) (SRHHIV). The Choice on Termination of Pregnancy Act (1996) legalised abortion in many instances, including no restrictions on abortion in the first trimester of pregnancy. Although also upholding the criminalisation of sex work, the Criminal Law (Sexual Offences and Related Matters) Amendment Act (2007) outlines a definition of rape that is both gender neutral and inclusive of all types of non-consensual 'sexual penetration,' moving away from the previous narrow definition in which, legally, only people with vaginas could be raped. The law also gives rape survivors the right to access post-exposure prophylaxis (PEP) for HIV prevention (Artz & Roehrs 2009).

In addition to legislation, a number of South African policies have been created to improve access to SRHHIV services. Over the years, policy documents such as National Strategic Plans on HIV and STIs have been developed, with the goal of minimising the impacts of the HIV epidemic. These plans have put forth varying stances on sex work, with some addressing sex workers only minimally, and some with much detail. The previous *HIV & AIDS and STI Strategic Plan for South Africa 2007–2011* 'included robust provisions on sex work,' including a recommendation to decriminalise sex work (Department of Health 2007; Richter & Chakuvinga 2012). Yet, despite consistent efforts and engagements by sex worker organisations with the South African National AIDS Council (SANAC) to advocate for full implementation of the Plan's provisions on sex work, little to no progress was made for sex workers' rights during the period of implementation for the Plan (Richter & Chakuvinga 2012). Further, following advocacy efforts to ensure strong provisions on sex work in the next plan, the *National Strategic Plan on HIV, STIs and TB 2012–2016*, the draft plan's recommendation to decriminalise sex work—which had been included in the draft passed by the SANAC Plenary, following extensive civil society consultation—was pulled from the final document at the last moment (Richter & Chakuvinga 2012; SANAC 2011).

Currently in place are the *National Strategic Plan on HIV, STIs and TB 2017-2022* and the *National Sex Worker HIV Plan (2016-2019)* (SANAC 2016; SANAC 2017). The *National Strategic Plan on HIV, STIs and TB* names sex workers as a key population but does not specifically recommend decriminalisation of sex work. It does, however, refer to the *National Sex Worker HIV Plan* for guidance. The *National Sex Worker HIV Plan* was the result of a collaborative process between sex worker organisations, government departments, researchers and SANAC, and included a Sisonke member on the task team (SANAC 2017). This document calls clearly for law reform and the building of political will for the decriminalisation of sex work, citing the impact decriminalisation would have on decreasing HIV infections among sex workers and their clients. Further, the *National Sex Worker HIV Plan* created an expanded package for sex workers beyond HIV, including broader sexual and reproductive health services,

psychosocial services and access to justice, using sex worker peer educators as the 'backbone' for the implementation of the Plan.

The next iteration of the *National Sex Worker HIV Plan* has been drafted but was not publicly available at the time of writing this report.

In light of the legal and policy framework outlined above, we next briefly describe what is currently known about access to SRHHIV services for sex workers in South Africa.

Access to SRHHIV services for South African sex workers

Availability and use of SRHHIV services for sex workers

SANAC has estimated that almost 60% of sex workers in South Africa are living with HIV (SANAC 2016). Due to this high prevalence, most health services for sex workers in the past focused on HIV and sexually transmitted infection (STI) services rather than holistic sexual and reproductive health care (Dhana et al 2014). Nationwide research documenting the uptake of comprehensive SRHHIV services is limited, with most studies focusing on specific South African cities. Past research from Durban, KwaZulu Natal found that about three quarters of female sex workers had ever tested for HIV and about one third were currently using HIV care services, however, only 13% of participants reported that they used all of the health services they needed (Lafort et al 2016).

While HIV has been a priority issue, efforts have been made to expand the overall package of care for South African sex workers. The *National Sex Worker HIV Plan* calls for expanded services and defines sexual and reproductive health services as 'family planning, infertility services, prevention of unsafe abortion and post-abortion care, diagnosis and treatment of sexually transmitted infections, including HIV infection, reproductive tract infections, cervical cancer and other gynaecological morbidities, and the promotion of sexual health, including sexuality counselling.' The *National Sex Worker HIV Plan* also includes psychosocial services and addresses access to legal services. However, challenges in service provision remain. A recent study from Port Elizabeth, Eastern Cape documented gaps in HIV preventative care for pregnant and parenting sex workers, suggesting that more integration between HIV services and pregnancy care for sex workers is needed (Twahirwa Rwema et al 2019).

Despite the progressive Bill of Rights in the Constitution, and the inclusion of sex workers in key national policies both in development and in policy focus, these rights that exist on paper often do not translate into actual access to services for sex workers, as the following sections will show.

Discrimination in health services

Research has documented continued barriers to healthcare sex workers in South African government health services, such as sex work-related stigma, discrimination, criminalisation of sex work and the need for context-specific healthcare and integration of sexual and reproductive health services (Richter 2008; Scorgie et al 2013; Peters 2015a; Lafort et al 2016; Lafort et al 2017; Slabbert et al 2017). Sex-work related stigma and discrimination is discussed in most research articles about access to healthcare. For example, sex workers often experience discrimination based on their occupation, which ranges from judgmental attitudes by healthcare providers to being denied healthcare. Research suggests that cisgender men sex workers and transgender sex workers may be at the highest risk for discrimination in health facilities (Scorgie et al 2013). This might be because, according to a systematic review, most health programmes for sex workers focused on 'female sex workers' (Dhana et al 2014), thus side-lining cisgender male and transgender sex workers. Research has also documented the struggles of migrant sex workers and has highlighted increased discrimination and poorer access to healthcare among migrants as compared to non-migrant sex workers (Richter et al 2014).

Impact of criminalisation of sex work and policing

As sex work remains criminalised in South Africa, policing of sex workers continues to be a major issue. Because it is challenging to 'prove' whether someone is a sex worker, law enforcement has been known to use by-laws—such as arresting someone for loitering—in order to detain sex workers (Gould 2011). Law enforcement using condoms as evidence of sex work has been an ongoing problem that threatens the health and safety of sex workers (Shields 2012; Peters 2015a; Peters 2015b). Further, sexual violence against sex workers by law enforcement has been thoroughly documented, as well as law enforcement refusals to assist sex workers when they have experienced rape (Fick 2006; SHARP & LAHI 2006; Women's Legal Centre & SWEAT n.d.).

In the face of these human rights violations, it is crucial that sex workers know their rights, have organisational support and access to legal assistance, as well as access to recourse mechanisms. Community empowerment is an important aspect for achieving this, and the following sections will review the literature on community empowerment for sex workers globally, and in South African specifically.

3 Theoretical background

Community empowerment

Background

Community empowerment as a process for public health promotion goes back several decades. Fawcett and colleagues (1995) defined community empowerment as 'the process of gaining influence over conditions that matter to people who share neighbourhoods, workplaces, experiences, or concerns,' citing examples such as high school groups working to reduce drunk driving or community partnerships to reduce substance abuse risk. They then put forward a model of community empowerment that is based on personal factors, environmental factors and community capacity to influence outcomes, which are implemented through collaborative processes (Fawcett et al 1995). Notably, in 1997, the Centers for Disease Control released *Principles of Community Engagement*, which was one of the first practical guides for assessing and implementing community empowerment.

In supporting community empowerment initiatives, it is important to reflect on who the relevant community is comprised of, and reflect on who, if anyone, is excluded from that community. Due to the historical marginalisation of sex workers, it is important to consider community empowerment approaches that are contextualised to sex workers' needs. In the following section, we examine international best practices for community empowerment with sex workers.

The Sex Worker Implementation Tool (SWIT)

In 2012, the WHO released a document specifically contextualised for sex workers, *Prevention and treatment of HIV and other sexually transmitted infections for sex workers in low- and middle-income countries*, hereafter referred to as the "2012 Recommendations." This document outlined recommendations to promote sex workers' SRHHIV and human rights and was supported by the United Nations Population Fund (UNFPA), UNAIDS and the Global Network of Sex Work Projects (NSWP) (WHO 2012). To technically guide implementation of these recommendations, they later developed and released the resource *Implementing Comprehensive HIV/STI Programmes with Sex Workers: Practical Approaches from Collaborative Interventions*, also known as the *Sex Worker Implementation Tool (SWIT)* (WHO 2013). The SWIT is a tool developed between the WHO, UNFPA, UNAIDS, the Global Network of Sex Work Projects, the World Bank, and the input of sex workers from low- and middle-income countries around the world, who responded to a survey.

The SWIT centres community empowerment in its theoretical framework for HIV and STI programme implementation, and defines community empowerment with eight elements: (1) working with communities of sex workers; (2) fostering sex worker-led outreach; (3) developing sex worker collectives; (4) adapting to local needs and contexts; (5) promoting a human-rights framework; (6) strengthening the collective; (7) shaping policy and creating enabling environments; (8) sustaining the movement (WHO 2013). In this report, we use these elements of community empowerment to understand and present our findings. We used the SWIT to examine which elements of sex worker community empowerment are being successfully achieved in South Africa and to identify gaps in implementation. It is important to remember that the SWIT conceptualises community empowerment as a process, meaning that while an element may be implemented, it may continue to develop over time.

Next, we provide background information about community empowerment among sex workers in South Africa prior to the development of the SWIT, and the South African *National Sex Worker HIV Plan* (2016-2019) which followed it.

Key elements of community empowerment among sex workers
(WHO et al 2013)

Community empowerment and organising among South African sex workers

As early as the 1990s, researchers called for improved social mobilisation among South African sex workers in order to reduce HIV transmission (Karim et al 1995). However, these recommendations were not immediately heeded in interventions. Cornish and Campbell (2009) documented an early attempt at a sex worker peer educator programme that ran from 1998 to 2000 in Gauteng, which was unsuccessful in reducing prevalence of sexually transmitted infections. By comparing the South African programme with a relatively successful one in India, the researchers argued that it was the programme's approach which was problematic: rather than focusing on the sex workers and their needs, the programme's aim was to reduce STIs among their clients, therefore framing sex workers as 'vectors of disease' rather than people deserving of improved healthcare in their own right. As a result of this approach, the South African programme did not meaningfully involve sex workers in the decision-making aspects of the programme, whereas the successful Indian programme centred on sex workers' needs and therefore involved them in decision-making. Based on this, the researchers argued that community empowerment could 'partially compensate for very disempowering social conditions' in programme design and implementation (Cornish & Campbell 2009). This highlights the importance of community empowerment, meaningful involvement and centring the human rights of sex workers when it comes to health programming, which are also highlighted in the SWIT in the first key element of community empowerment, "Working with communities of sex workers."

In the early 1990s, the Sex Worker Education and Advocacy Taskforce (SWEAT) was co-founded by male sex worker Shane Petzer and clinical psychologist Ilse Pauw in the Western Cape (SWEAT 2016a). At that time, the emphasis of SWEAT was to provide sex education for sex workers. Over the years, SWEAT has grown its programming to include expanded health services designed to reach both street-based and venue-based sex

workers, but also to include advocacy. SWEAT officially created a programme to work for decriminalisation of sex work in 2000 (SWEAT 2016a). A few years later, in 2003, the sex worker collective, Sisonke, was established in the Western Cape, which later expanded to other provinces in south Africa to become a national movement (SWEAT 2016b). Sex workers working with SWEAT and Sisonke have achieved many important actions including, but not limited to: providing social mobilisation support to sex workers; participating in group litigation against the South African Police Service, which resulted in an interdict; and hosting the first African Sex Work Conference in 2008.

Following the development of the SWIT at a global level, and years of advocacy by South African sex workers, including those working with SWEAT and Sisonke, the South African *National Sex Worker HIV Plan (2016-2019)* was developed. The *National Sex Worker HIV Plan* acknowledges the importance of community empowerment in promoting sex workers' SRHHIV, echoing the eight community empowerment elements of the SWIT, and has laid out an ambitious plan for improving access to services. The *National Sex Worker HIV Plan* clearly drew on the SWIT's framework, echoing many of the same themes of community empowerment, such as adopting a peer educator programme, encouraging sex worker collective strengthening and involving sex workers in the development of the *National Sex Worker HIV Plan*. The working group tasked with designing the Plan was intersectoral, including those from government and civil society. A Sisonke member and sex worker served as a co-chair for this working group, signifying an important victory of advocacy to ensure sex workers had a voice at the table for policy that directly impacts their health and well-being.

In the research briefs in this report, we draw on the *National Sex Worker HIV Plan* in order to assess whether and how it has been implemented in South Africa. We also compare the recommendations of the SWIT with those of the National Sex Worker HIV Plan and identify conflicts where they exist.

The political climate in South Africa has been challenging for sex workers over the last several decades. Despite many hopeful moments and a broad global evidence base supporting the decriminalisation of sex work, amended legislation has yet to be realised.

Due to the relentless efforts of South African sex workers and fellow advocates, the *National Sex Worker HIV Plan* lays out a progressive and thorough programme for sexual workers' SRHHIV services and rights.

Despite this policy progress, South Africa's overall progressive constitutional rights, and the manifold advocacy efforts, current literature documents that sex workers experience discrimination based on their occupation in many public services, including healthcare and during interactions with law enforcement. Further, rigorous, peer-reviewed studies evaluating the effectiveness of community empowerment on sex workers' health remain limited, particularly in Southern African settings (Shahmanesh et al 2008; Kerrigan et al 2013). In this report, we use our data to describe the current reality of community empowerment and healthcare access for sex workers in South Africa. We compare this reality to the aspirations of the SWIT and National Sex Worker *HIV Plan*, in order to identity successes, challenges and recommendations for the future.

4 Research questions

The following research questions were used to guide the research project from start to finish. These questions were developed at the beginning of the project and guided the data collection and analysis.

Main research question

- How is community empowerment of sex work communities related to access to, and quality, of sexual and reproductive health and rights (SRHR) services (including HIV)?

- What are best practices in community empowerment of sex worker communities in policies, programming and services in South Africa?

Sub research questions

- In what ways are sex worker communities and organisations empowered or involved in policies, programming and services?

- What are the benefits of community empowerment of sex worker communities (including those living with HIV) in policies, programming and services, on access to SRHR services (including HIV)?

- What are most efficient and effective approaches in community empowerment and meaningful involvement of sex work communities?

- What are the core ingredients for success in community empowerment and meaningful involvement regarding increasing access and quality of SRHR (including HIV) services?

- How can community empowerment be further improved?

- To what extend has community empowerment led to sex worker communities holding the government to account and sex workers enjoying their human rights?

Methodology

Community empowered research

This research project was conducted in a partnership between Sisonke, SWEAT and the Gender Health and Justice Research Unit (GHJRU) at the University of Cape Town (UCT). We decided that all research partners should have shared decision-making power about the research design, implementation and dissemination. The project team consisted of two GHJRU researchers, the project manager from SWEAT and the project manager from Sisonke. All major decisions about design, implementation and dissemination were taken together as a project team.

Design

Based on the research objectives, literature review and an initial discussion among the project team, the GHJRU researchers drafted a survey instrument, an interview guide and a focus group discussion guide. The project team met to review these tools and amended them as necessary.

The project team met to plan the project and decide on each team member's role. Sisonke and SWEAT selected a small group of sex workers to be trained as fieldworkers to collect data for the survey. The GHJRU designed a training manual for the fieldworkers, based on the data collection instruments and input from SWEAT and Sisonke. The project team then worked together to train the fieldworkers over two days.

The project team decided that researchers from the GHJRU would be responsible for conducting the in-depth interviews and focus group discussions. Our Sisonke team member managed the recruitment for the focus groups and assisted with the facilitation of the groups. The GHJRU researchers were responsible for analysing the data.

Setting and population

We conducted a survey with sex workers on their use of, and access to, sexual and reproductive healthcare and levels of community empowerment in three provinces: Gauteng, Limpopo and the Western Cape. To be eligible to participate, one needed to be age 18 or older and have done sex work in the past thirty days.

Data collection

Survey data collection

Two trained fieldworkers, who were also sex workers, collected data in each province and used convenience sampling to survey approximately 50 participants each (approximately 100 participants per province). The fieldworkers conducted an informed consent process with each participant, including written informed consent for those who were eligible and agreed to complete the survey. All surveys were administered by the fieldworkers.

The survey was a convenience sample of people in Gauteng, Limpopo and the Western Cape who had done sex work in the last 30 days. Of the 298 survey participants, most participants were women (91%)—80% were cisgender (cis) women and 11% were transgender women. Six percent were cis men and 1% were trans men. One gender non-conforming person also participated (not pictured in pie chart). Participants spanned a wide age range and were 19 to 59 years old. The average participant age was 34.

Figure 2: Gender Identity

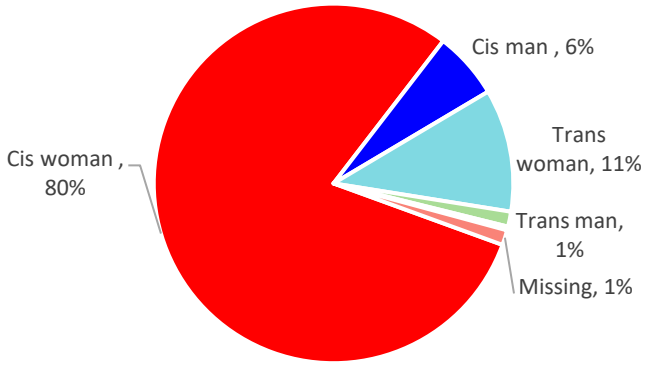
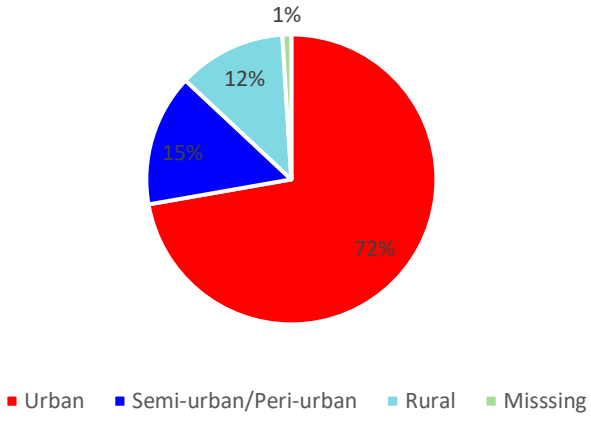


Figure 3: Area of living



About 1 in 5 survey participants were born outside South Africa (21%). Most participants (72%) currently lived in an urban area. About 1 in 9 participants (12%) lived in a rural area. Many were low-income: 72% had a monthly income of less than 5000 ZAR (approximately 300 Euro).

In-depth interview data collection

Interview participants were selected using purposive sampling. Based on the project team's experience and networks, a list of suitable individuals and organisations were compiled to be contacted. Additionally, we asked participants if they recommended anyone else for us to contact.

We spoke with 15 representatives from different types of organisations: sex worker collectives (created by and for sex workers), NGOs with sex worker programmes (of which the executive/administrative teams are not exclusively sex workers), NGOs that do not necessarily have sex worker programmes but otherwise work on improving health participation or access to healthcare, an academic researcher and a policymaker (see Table 1). Five additional organisations/individuals which we contacted to request an interview either declined to participate, were unavailable during the study period or were non-responsive.

Table 1: Table of participants

Type of organisation	Number of participants
Sex worker collective	2
NGO with specialised sex worker programmes	8
Health services	*4*
Justice services/Advocacy	*4*
Mainstream health organisation	1
Researcher	2
National civil society	1
Policymaker	1

Taking the survey findings into account, the project team developed an interview guide to explore the following topics:

- Opportunities for civil society, and sex workers in particular, to participate in healthcare
- Participants' experiences working on health policy or service provision with sex workers
- Training participants had received, or policies they were aware of, related to health of sex workers

Additional questions and topics were explored as relevant following probing with participants.

Focus group discussions data collection

We conducted three focus group discussions (FGDs) with 27 sex workers in total: one FGD in Cape Town (Western Cape province; n=5), one FGD in Johannesburg (Gauteng province; n=12) and one FGD in Polokwane (Limpopo province; n=10). Participants were purposively selected for participation by Sisonke. The participants represented a mix of genders and ages. Most, but not all, of the participants were Sisonke members.

We asked participants about the following topics:

- Whether they were members of a sex worker collective (Sisonke) and how they had made that decision;
- What they felt community empowerment and participation in healthcare were, and their experiences with each;
- Experiences of sex workers positively influencing health policy or service delivery.

Additional questions and topics were explored as relevant when they emerged during the group discussions.

Analyses

Research from the Global Network of Sex Work Projects documents that engagement with sex workers on research projects is lacking, and that the engagement that exists typically focuses on data collection only, but not on the interpretation and composition of results (NSWP 2017). In this project, all partners agreed at the inception meeting that the GHJRU would lead analysis and composition, and that SWEAT and Sisonke would be involved through reviewing the preliminary findings and providing input on study outputs. The project team met to review both the preliminary quantitative and qualitative findings, discuss their implications, and decide what the most useful format of the research output would be. Based on these discussions, the GHJRU researchers drafted the study outputs. SWEAT and Sisonke, as well as Aidsfonds and NSWP reviewed these outputs, and the GHJRU researchers finalised them based on their feedback.

Survey data analysis

The GHJRU team members entered, cleaned and analysed the survey data using descriptive statistics with Stata15 software. When necessary, we used chi squared tests and logistic regression models to examine relationships between variables.

Qualitative data analysis

The recordings from the interviews and FGDs were transcribed. The GHJRU researchers used Nvivo12 software to code the transcripts. We initially used the eight elements of community empowerment (Figure 1) from the SWIT to code the data, and added codes as needed when other themes emerged. Additionally, we coded text segments related to assess access to SRHHIV. After reviewing the coded text segments, the project team decided on the main six topics that emerged from the data, based on which we wrote the following six research briefs.

Community feedback

The project team met to discuss the analysis and decide on the method of dissemination. We then held a presentation of the preliminary research results at a Sisonke Creative Space meeting in Cape Town in February 2019. The sex workers who attended the meeting discussed the research findings in small groups and shared their feedback about the findings to the larger group. Based on their input, we finalised the data analysis and the findings shared in this document.

5 Results

Problem statement

The main purpose of this research was to study and document the relationship between community empowerment of sex worker communities in policies, programming, and service delivery, and access to SRHHIV services for sex workers in South Africa.

A series of six research briefs

We used the research questions to guide data collection and analysis. Based on the findings from the survey, in-depth interviews and focus group discussions, we then identified six topic areas related to community empowerment and access to healthcare to highlight in this document. These are presented in a series of six research briefs, which can stand alone and be used independently of the overall document:

1. Is community empowerment associated with access to SRHHIV services by sex workers? A description of SRHHIV access experiences in South Africa
2. Do sex workers meaningfully participate in SRHHIV services? Successes and challenges from South Africa
3. Sex worker peer educator-led programmes in South Africa
4. Developing and strengthening sex worker collectives in South Africa
5. Promoting health and human rights for sex workers in South Africa
6. The role of community empowerment in reducing sex work-related stigma and improving access to SRHHIV services in South Africa

Is community empowerment associated with access to SRHHIV services by sex workers? A description of SRHHIV access experiences in South Africa

Research brief 1 in a series of 6 from the project *Community empowerment and access to sexual and reproductive health and rights services (including HIV) for sex workers in South Africa;* a study completed in partnership between the GHJRU, Sisonke and the Sex Workers Education and Advocacy Taskforce (SWEAT)

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This brief describes research findings on access to and use of healthcare services as experienced by South African sex workers and examines community empowerment elements that might be related to improved access to healthcare. Community empowerment has been put forth as essential for sex workers' access to healthcare in the Sex Worker Implementation Tool (SWIT), which defines community empowerment as an ownership process by sex workers to individually and collectively improve health and human rights (WHO 2013). Community empowerment consists of eight elements according to SWIT 2013: (1) working with communities of sex workers; (2) fostering sex worker-led outreach; (3) developing sex worker collectives; (4) adapting to local needs and contexts; (5) promoting a human-rights framework; (6) strengthening the collective; (7) shaping policy and creating enabling environments; (8) sustaining the movement (WHO 2013). In South Africa, the *National Sex Worker HIV Plan* (2016-2019), which was developed in collaboration with sex workers, draws on many of these elements to outline a plan for improving access to comprehensive SRHHIV services. Based on the SWIT and the *National Sex Worker HIV Plan*, we examine the relationship between community empowerment and access to SRHHIV services in this brief. We completed: 15 interviews with NGO representatives, researchers and policymakers; 3 focus groups with sex workers (n=27); and a paper survey with a convenience sample of 298 sex workers in Gauteng (n=100), Limpopo (n=100) and the Western Cape (n=98), recruited using trained sex worker fieldworkers. Of those surveyed, 81% were cisgender women, 13% were transgender and 6% were cisgender men. We presented preliminary findings to a group of sex workers at a Cape Town Sisonke Creative Space meeting and incorporated their recommendations and feedback on the findings. All names reported in this brief are pseudonyms, to protect participants' privacy.

Sex work communities and access to healthcare

In this brief, we first describe what kind of healthcare services South African sex workers use, and their experiences in doing so, particularly related to discrimination. We also examine healthcare access for sex workers, drawing on McIntyre et al's 2009 framework, which conceptualises access through individual, community and system factors related to availability, affordability and acceptability (McIntyre, Thiede, & Birch, 2009). The emphasis of this project is to examine community empowerment from a sex worker perspective. After describing access to healthcare, we will discuss our findings in relation to community empowerment.

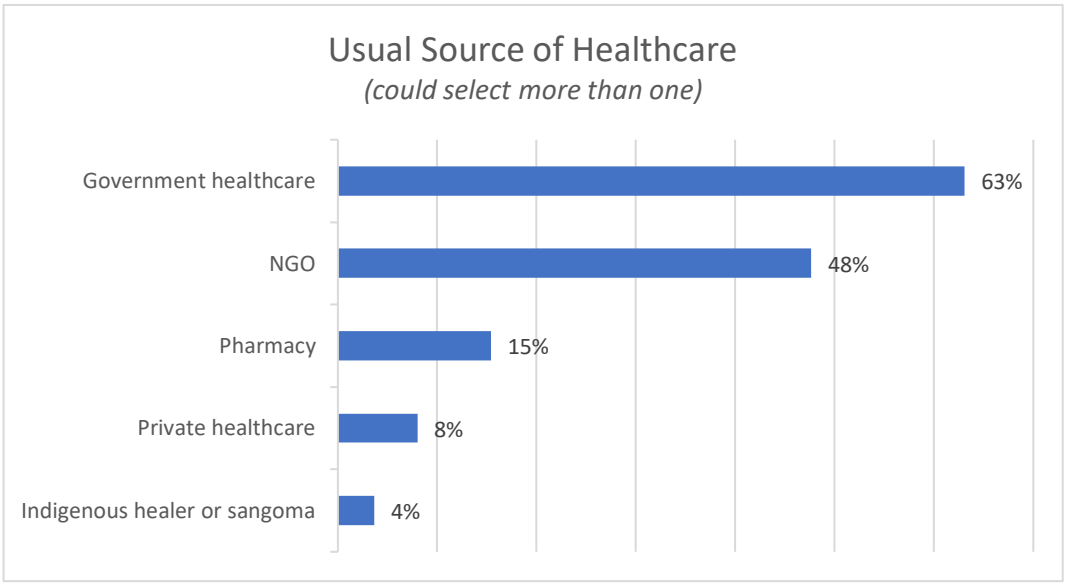
Ensuring access to sexual and reproductive health, including HIV (SRHHIV) services for sex workers is paramount, due to sex workers having higher occupational risk for HIV and STIs as well as pregnancy (WHO 2013). In South Africa, the Constitution (1996) explicitly states the right to healthcare, including access to sexual and reproductive healthcare. Despite this, challenges for sex workers remain. Criminalisation of sex work and the resulting vulnerability to violence remain a barrier for accessing SRHHIV services: past evidence documents that South African law enforcement regularly coerce or force sex with sex workers as bribes to prevent detention and refuse to assist sex

workers when attempting to report such incidents, or when reporting rape (Albertyn et al. 2009; Women's Legal Centre 2016; Fick 2006; SHARP & LAHI 2006; Women's Legal Centre & SWEAT n.d.). Due to this high risk for sexual violence, with little opportunity for recourse or law enforcement protection, as well as the occupational risk of sex with multiple concurrent partners, sex workers are at high risk for unplanned pregnancy, HIV infection and other sexually transmitted infections (STIs). The criminalisation of sex work exacerbates sex workers' vulnerability to HIV infection. For example, law enforcement agencies are known to use possession of condoms as evidence to arrest sex workers, resulting in confiscation of condoms or sex workers being less likely to carry condoms with them while working (Shields 2012). Further, sex workers living with HIV may struggle to access necessary health services due to negative healthcare provider attitudes and discrimination based on the stigma of their profession (Peters 2015; Scorgie et al 2013). In South Africa, migrant sex workers in particular have been documented to have increased difficulty accessing SRHHIV care due to discrimination and other factors (Richter et al 2014).

We report on findings from our survey with sex workers to describe where and why they access health services and their experiences with discrimination in health services. The survey findings also describe sex workers' self-empowerment and interactions with sex worker organisations as a way of examining community empowerment. We close the brief with an analysis of our qualitative research with sex workers, NGO workers, government and researchers to gain additional insight about access to healthcare, drawing on McIntyre et al's 2009 framework, and community empowerment, drawing on the SWIT.

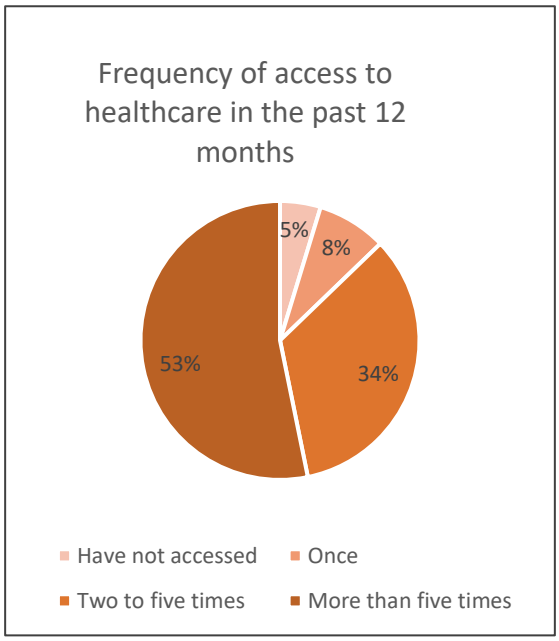
Health service use

We asked sex workers in our survey about where they regularly access healthcare and which services they used over the last year. Two thirds of sex worker in our survey regularly used government healthcare (63%), and almost half went to NGOs for health services (48%). Pharmacies were also used as a source of healthcare by about 1 in 7 participants (15%). About 1 in 12 participants (8%) used private healthcare or indigenous healers or *Sangomas* (4%). In the focus group discussions and interviews, a small number of participants also mentioned receiving healthcare by participating in research studies.

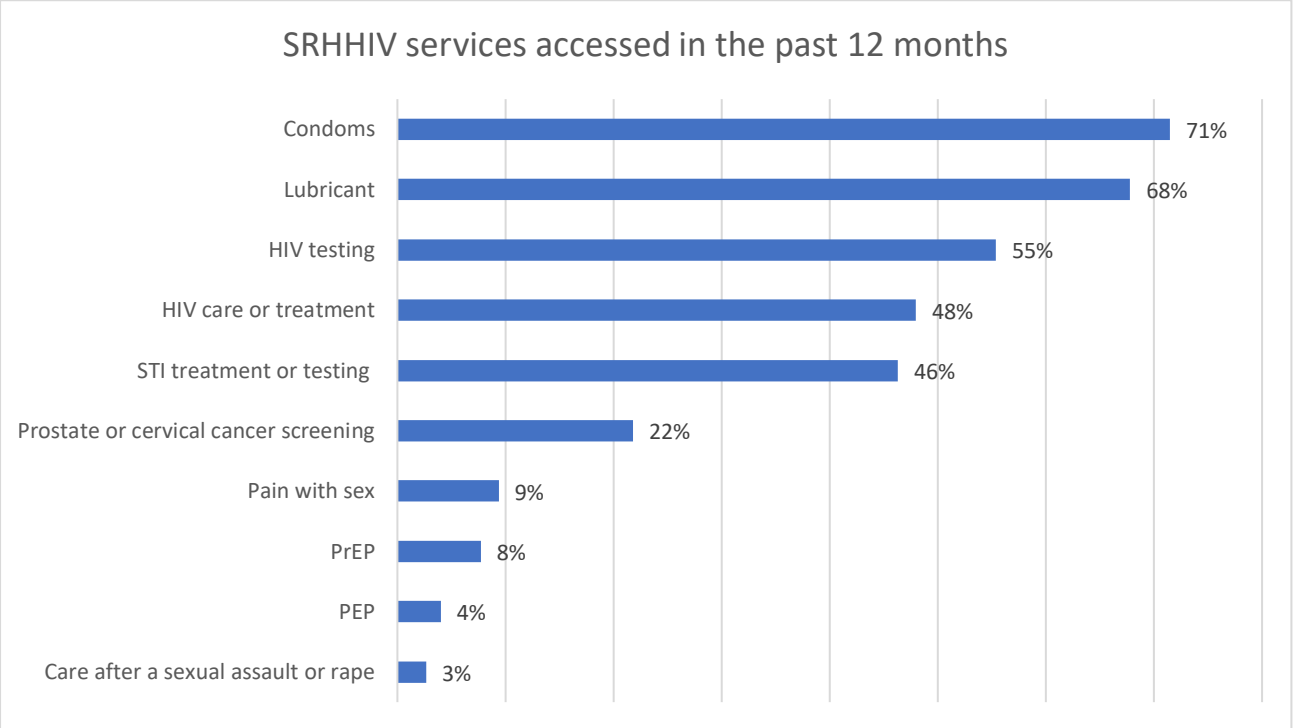


More than half the participants reported accessing healthcare over five times in the last year. Of those who had not accessed healthcare at all in the past year, most said it was because they had not felt sick or needed healthcare. Two participants said it was because they could not afford healthcare and one said it was because they were afraid of being discriminated against for doing sex work.

When asked about why health services were used in the last year, access to condoms and lubricant were the most common reason to access health services, by 71% and 68% of sex workers respectively. The least used type of service was care after a sexual assault or rape, which was accessed by only 3% of those in the survey. Due to what is known about the high levels of sexual violence in South Africa, and among sex workers in particular, this is likely due to underutilisation of services related to sexual assault rather than a low incidence of violence over the last year. In focus groups, a few sex workers spoke about the challenge of reporting sexual assault when the assault was related to doing sex work, due to fears related to sex work being criminalised.



"*As long as it is criminalised sex workers are still going to work underground and it's going to be a very difficult thing for sex workers adhere to like medication because they are scared to go to the clinics some of them because they are…it's criminalised and people are scared to go to the police station to say okay, I've been raped, I want to report a case*." (Natasha, Johannesburg focus group)



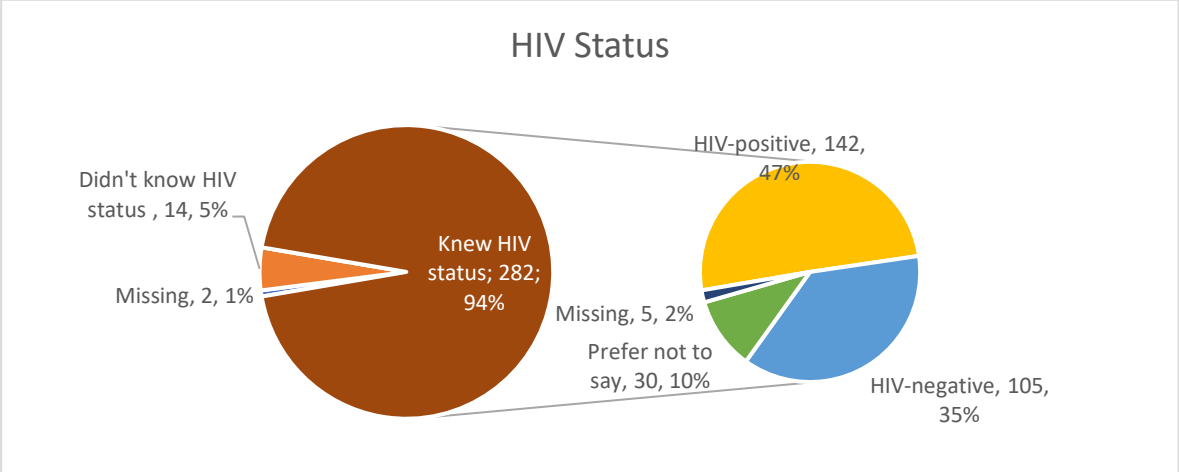
Sex workers' health

We asked the sex workers in the survey about specific health conditions and needs. About half of the sex workers we surveyed said they had a chronic health condition (48%). Fifty-seven percent said that they go for regular health check-ups.

Family planning and pregnancy

Among the sex workers we surveyed who were assigned female at birth (cisgender women and transgender men), only 1 in 5 (23%) had accessed hormonal contraception and 68% had accessed condoms in the past year. It seems likely that condoms were being used not only for HIV and STI prevention but also pregnancy prevention: In line with past research which documented condoms as the most preferred and used contraception by South African sex workers (Slabbert et al 2017; Lafort et al 2017).

One in 6 sex workers who were assigned female at birth had accessed pregnancy testing in the last year and one in 9 (13%) had been pregnant. Most participants (66% of those who were pregnant) said that they had continued their pregnancy. Three participants (10% of those who were pregnant) had terminated the pregnancy and 7 (23%) had a miscarriage.



HIV-related health services

HIV-related services were some of the most used services among the sex workers answering our survey. Over half had tested for HIV in the last year (55%) and the majority (95%) said they knew their HIV status. We gave participants the option of disclosing their HIV status and 56% said they were living with HIV. This level of HIV is much higher than the current statistic for the general South African population which is estimated to be 13% of all South Africans living with HIV, and 19% among those age 15 to 49 (Statistics South Africa 2018).

Among sex workers who were HIV negative, about 1 in 5 were using PrEP (19%). Among those who were living with HIV, 4 in 5 (82%) said that they had received HIV care or treatment in the last year.

Affordability of healthcare

The qualitative findings provide us with further information about barriers to access to services. Here, we first looked at affordability and availability of health services to understand why sex workers do not access services as much as they should.

According to McIntyre and colleagues, affordability of healthcare includes both price of healthcare at the point of service, as well as direct and indirect costs such as transportation to the health facility and time off from work to attend (McIntyre, Thiede, & Birch, 2009).

In South Africa, government clinics and hospitals provide free or low cost SRHHIV services. While sex workers can use government healthcare, many NGO-based programmes have been developed to address their specific needs and to provide a safe space free of discrimination based on sex work. NGO services are also provided at no or low cost. It is also important to consider the cost of transport to and from health services, as well as time away from work that results in loss of wages. In our survey, only two participants reported not using health services in the past year due to inability to afford care. However, in interviews and focus groups, participants spoke about loss of wages as a common concern for sex

workers who needed access to healthcare, suggesting that finances may still be a barrier to healthcare in some instances. One sex worker explained this was especially a problem for sex workers in brothels, as they are required to pay rent for their room daily, even if they do not work.

To facilitate access, it is common practice for NGOs to provide transport reimbursement to sex workers for some health services. We discuss this in more detail in our research brief on *Meaningful participation of sex workers in SRHHIV healthcare: success and challenges in South Africa.*

Unfortunately, the range of health services NGOs can offer are limited, as well as funding-dependent. While many NGOs were described as having strong HIV programmes, including testing, treatment and PrEP, some other services that make up SRHHIV were missing. Most programmes referred out for termination of pregnancy, maternity care and cancer treatment, although many did provide cervical cancer screening (pap smears). Some, but not all, programmes offered a full range of contraceptive methods. Building relationships between NGOs and government clinics was key to facilitating sex worker access to services that NGOs are not providing.

No sex workers spoke about private healthcare use during the focus group discussions.

Availability of healthcare

Availability of healthcare includes whether the location of health service provision is appropriate, as well as which services are offered. Availability addresses 'whether the appropriate healthcare providers or services are supplied in the right place and at the right time' (McIntyre, Thiede, & Birch, 2009).

According to those we interviewed, geographical location of health services was a barrier to access for some sex workers. In some situations, sex workers chose to use less 'friendly' clinics, because they are more accessible by public transport than NGO clinics or government clinics whose staff have been sensitised to provide services that are supportive to sex workers. Several NGO workers that we interviewed also explained the challenges of targeting services to sex workers, who may not have the same time availability as people with other occupations.

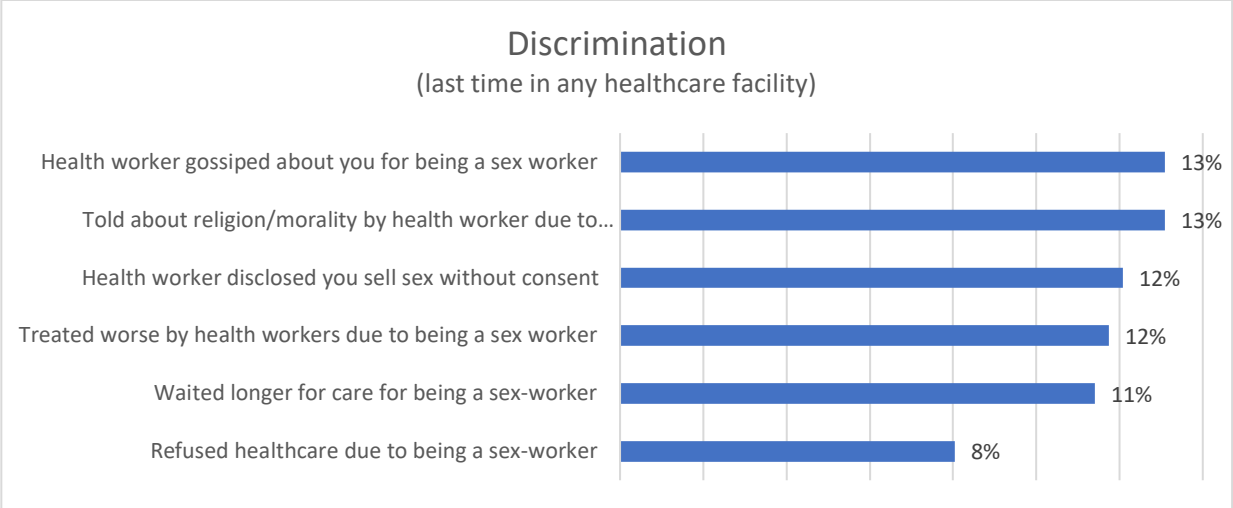
"*For me I think working with sex workers is not easy given the fact that most of the time when our peer educators or our health workers want to provide services, they [the sex workers] are busy. That is when they are also working…they will be busy most of the time as compared to the general community…with sex workers during the day is when most of them will be working. At night in the hotspots that they are also working, it is not safe for someone, maybe a [sex worker] peer educator going to them because of their issue of transport, there is the risk issue of safety also*." (NGO worker, health services, Limpopo)

Additionally, even when sex workers accessed a healthcare facility, some services that sex workers needed were unavailable. While most of the sex workers we surveyed said they received all of the services they needed at their last visit (86%), five sex workers (2%) said they experienced problems due to drug stock-outs or unavailability of necessary medical equipment. In interviews and focus groups, participants also highlighted safe termination of pregnancy as particularly challenging to access, despite the fact that abortion is legal in South Africa and should be accessible (Choice on Termination of Pregnancy Act 1996). In our survey, three sex workers said they had had a termination of pregnancy in the previous year; two had accessed safe termination at a facility and one had used an informal provider. Lastly, a transgender focus group participant also highlighted the lack of gender affirming healthcare for gender minority sex workers. This participant explained that this was not only about access to services such as hormones or surgery, but also that there was a lack of healthcare providers who understand transgender issues.

Sex worker-based discrimination in healthcare

In the survey, 1 in 4 sex workers (25%) had experienced some type of discrimination based on being a sex worker at their last visit to a healthcare facility. In our sample, the most common types of discrimination by a healthcare worker due to being a sex worker were: being gossiped about (13%), being told about religion or morality (13%) and disclosing they sold sex without asking their consent (12%).

In the raw data, we saw that those who were gender minorities were more likely to have experienced discrimination at their last healthcare visit. For example, the odds of gender minority sex workers experiencing gossip due to being a sex worker were 3 times that of cisgender sex workers, holding other



factors constant (adjusted odds ratio (AOR) 2.99 (1.11 – 8.05); p<0.05). Qualitatively, several sex workers and NGO workers highlighted both being a migrant and being a gender minority as creating additional barriers to care, due to increased stigma and discrimination based on these identities combined with being a sex worker.

One in 8 sex workers (14%) said they had delayed going to their last healthcare visit due to fear of discrimination. One sex worker (<1%) reported not using healthcare at all in the last 12 months due to fear of discrimination.

We further describe stigma and discrimination of sex work in the brief *Sex work stigma, community empowerment and access to SRHHIV services*.

Acceptability of healthcare

Against the background of the discriminatory experiences reported by sex workers in the survey, the qualitative interviews and focus group discussions aimed to elucidate more about the acceptability of healthcare for sex workers. Acceptability of healthcare 'is concerned with the fit between provider and patient attitudes towards and expectations of each other' (McIntyre, Thiede, & Birch, 2009). This includes factors such as age, gender or race, as well as how sex workers perceive healthcare providers and providers' reactions to sex workers.

On the whole, NGO-based health services designed specifically for sex workers were painted in a very positive light by those we interviewed and focus grouped. These health services were seen as accessible, supportive places to access care. Descriptions of healthcare access in government clinics were more varied than those of NGOs, and more sex workers spoke about discrimination.

Several participants described government clinics as being unfriendly places for sex workers. In some instances, sex workers experienced discrimination from clinic staff when trying to access SRHHIV services:

"*Most of the times from what we hear by the sex workers, is that sex workers are reluctant to go to the [government] clinic. One, the long queue that is there, the second one is the attitude towards them by the service providers*." (NGO worker, health services, Limpopo)

However, some sex workers described positive experiences with government clinics. These clinics had usually been through an engagement process with a sex worker organisation. In Gauteng and Limpopo, sex workers also shared that sex worker peer educators facilitated other sex workers' access to government clinics, particularly for sex workers who feared discrimination and would not have attended clinics on their own (see our brief *Sex worker peer educator-led programmes in South Africa*).

Relationship between access to healthcare and community empowerment

We now examine access to healthcare and the link to community empowerment using seven items, described in the table below.

We used four variables to represent access to healthcare: if the participant had used healthcare in the past year; if they knew their HIV status (as this would require having accessed an HIV test); if they felt they could access healthcare when they needed (a broad question we asked to assess their perception of access); and if they had delayed getting healthcare due to fear of discrimination based on doing sex work (which speaks to whether

safe and acceptable healthcare is available for sex workers).

We used three variables to represent community empowerment: collective agency (using items from the SWIT: if they had helped a fellow sex worker in five situations (problem with law enforcement, brothel owner, gang member, client, regular partner); if they received health information from sex work organisation outreach workers (sex worker-led outreach); and if they were a Sisonke Member (belonging to a sex worker collective).

Access to healthcare (n=298)	n	%
Used healthcare in the past year		
Did not access	14	4.70
Accessed	283	94.97
Missing	1	0.34
Knew HIV status		
Did not know status	14	4.70
Knew status	282	94.63
Missing	2	0.67
Felt they could access healthcare when they needed it		
Did not feel they could access	21	7.05
Felt they could access	268	89.93
Missing	9	3.02
Delayed attending last health visit based on fear of sex work-related discrimination		
Delayed	41	13.76
Did not delay	239	80.20
Missing/not applicable	18	6.04
Community empowerment		
Collective agency		
Had not helped fellow sex worker	13	4.36
Had helped in at least one situation	284	95.30
Missing	1	0.34
Received health information from a sex worker organisation outreach worker in the past year		
Did not receive information	50	16.78
Did receive information	243	81.54
Missing	5	1.68
Sisonke (sex worker collective) member		
Not a Sisonke member	200	67.11
Sisonke member	92	30.87
Missing	6	2.01

Based on the table, there were some indications that sex workers were successfully accessing healthcare. For example, 95% of participants had accessed healthcare in the past year and knew their HIV status. However, only 90% of participants felt they could access healthcare when they needed it and about one in seven participants (14%) delayed going to their last health facility visit due to fear of discrimination, highlighting that even though many sex workers are using healthcare, they are not always able to do so at the time they feel it is needed.

There were also some positive signs of community empowerment: the majority of sex workers (95%) had shown some type of collective agency by helping another sex worker with a problem. Four out of five (82%) of sex workers we surveyed had received health information from an outreach worker in the past year. Less than a third (31%) said they were a member of the national sex worker collective, Sisonke, although non-Sisonke members may still attend Sisonke activities such as Creative Spaces.

Using logistic regression, we examined the four variables describing access to healthcare and their relationship to the three variables describing community empowerment, also adjusting for gender, migrancy, province and income. Sex workers who had received health information from an outreach worker were more likely to know their HIV status and to have accessed healthcare in the past year. Every gender minority participant in the study knew their HIV status and all Sisonke members had accessed healthcare in the past year. We did not find any significant association between community empowerment and not delaying healthcare or feeling they could access healthcare when they needed it.

Contribution of community empowerment to access to SRHHIV services

The findings in this brief outline the health services used by sex workers who participated in our South African survey. We also present qualitative findings related to affordability, availability and acceptability of access to SRHHIV services. We now contextualise these findings within our project's larger goal of understanding community empowerment in relationship to SRHHIV access.

The SWIT is an important tool that links community empowerment of sex workers to improved SRHHIV services and rights (WHO 2013). Importantly, the SWIT was developed in global collaboration between sex workers, health professionals, government and researchers, and its recommendations come out of good practices from a variety of settings. However, rigorous, peer-reviewed studies evaluating the effectiveness of community empowerment on sex workers' health remain limited, particularly in Southern African settings (Shahmanesh et al 2008; Kerrigan et al 2013). While in our study knowledge of HIV status and health service use in the past year were already high at 95% of sex workers we surveyed, our findings suggest that educational interactions with peer educators ('outreach workers') were associated with increased knowledge of status and health service use. Also drawing on evidence from other studies, it also seems that sex worker community empowerment can decrease prevalence of HIV and STIs (Shahmanesh et al 2008).

In our study, we found a significant need for HIV-related services: 56% of the sex workers we were surveyed said they were living with HIV. This number is similar to the estimate of the South African National AIDS Council (SANAC), that almost 60% of sex workers in South Africa are living with HIV (SANAC 2016). Sex worker community empowerment interventions have been found to be effective in low- and middle-income settings to improve HIV related outcomes such as condom use with clients and other partners (Kerrigan et al 2013), suggesting that community empowerment efforts should continue to be prioritised in South Africa.

Qualitatively, we examined access to healthcare through affordability, availability and acceptability (McIntyre et al 2009). Few sex workers that we surveyed did not access healthcare at all in the last year due to not being able to afford care. However, it is possible that finances impacted their healthcare access in other ways, such as delaying care or not accessing healthcare as often as they needed. In interviews and focus groups, participants also spoke about the difficulty of lost wages on days when they needed to attend healthcare instead of working.

According to our qualitative data, the availability of SRHHIV services was a challenge due to sex workers not wanting to miss work during the day to attend clinics. The SWIT recommends expanded or flexible evening hours in order to make SRHHIV services more accessible for sex workers. We did not identify any facilities offering this in our study. Such expanded hours seem to be rare in African settings: a recent systematic review of 54 SRHHIV projects for sex workers on the continent found that only 4 offered night-time hours (Dhana et al 2014). It is unclear why expanded hours for sex workers and other populations requiring flexible access to SRHHIV services have not been more widely implemented, as this was a common concern cited by both sex workers and NGO workers in interviews and focus groups. However, a recent study from Johannesburg and Pretoria explored sex workers' experiences using SRHHIV services in four ways (clinic-based, mobile van, hotel-based and brothel-based) and found that service provision at sex workers' place of work resulted in increased SRHHIV service use. Further, the study found that offering alternatives to traditional clinic-based services—such as mobile vans—led to addressing vulnerabilities to violence or lack of housing (Slabbert et al 2017). These solutions may be useful to expand upon elsewhere in South Africa in order to increase SRHHIV service availability for sex workers.

Our study also highlights major challenges in acceptability of healthcare for sex workers, particularly related to discrimination (we explore sex work-related stigma and resulting discrimination in depth in our brief *Sex work stigma, community empowerment and access to SRHHIV services).* A quarter of participants in our study said that they experienced some type of sex work-related discrimination at their last visit to a health facility. Discrimination in healthcare is a violation of the human right to health and has been shown to impacts whether sex workers use health services or disclose their occupation to healthcare providers (Mtetwa et al 2013; Beckham et al 2015). Involving sex workers in sensitising healthcare providers on how to work with sex workers would be an important way to make SRHHIV services more acceptable to sex workers, as we found that NGO-based health services targeting sex workers (many of which who consulted with sex workers about their

needs, were received positively. Past South African research also found that NGO programmes developed specifically for sex workers were well-received by sex workers, which was also the case in the study (Scorgie et al 2013; Fobosi et al 2017). However, sex workers also need to have full access to government health facilities due to NGOs being unable to provide comprehensive SRHHIV services at this time. Sex workers raised in focus groups the need for improved access to broader SRHHIV services, particularly termination of pregnancy, antenatal care and cancer treatment. Abortion access is an ongoing problem, as in 2014, a systematic review of facility-based sexual and reproductive health services for sex workers in Africa found that no programmes addressed or offered termination of pregnancy services (Dhana et al 2014).

In the survey portion of this study, the fieldworkers responsible for collecting the data and recruiting participants were sex workers themselves. We used convenience sampling to identify participants and many fieldworkers used their personal networks to recruit. Because of this, the participants in this survey may be more likely to have achieved more community empowerment than sex workers who were not connected to other sex workers would be. This is a limitation of these findings.

Recommendations

Based on the findings presented in this brief, we recommend the following:

1) Expanded availability of comprehensive SRHHIV health services for sex workers, including gender affirming care: Participants explained that geographical location and hours of provision were barriers for some sex workers in accessing SRHHIV healthcare. We recommend that piloting of the expanded service provision at sex workers' places of work by Slabbert et al 2017 be done in other South African settings in order to identify the best ways to expand service delivery to sex workers. Additionally, we recommend that government prioritise ensuring availability of HIV-related services (including addressing stock outs), abortion services and gender affirming care.

2) Prioritisation of interventions to reduce sex work-related discrimination: As a quarter of sex workers in our survey reported experiencing sex work-related discrimination at their last visit to a health facility, we urge health facilities to implement sensitisation training and monitoring of sex workers' experiences.

3) Continued support for peer outreach programmes: We found that outreach by sex worker organisations is positively associated with increased knowledge of HIV status and use of healthcare. Although it is beyond the scope of this study to determine causality, this finding suggests that peer outreach programmes are linked to better access to healthcare. Additionally, sex worker-led programmes are considered good practice for SRHHIV services according to the SWIT as well as the qualitative input of our participants. We recommend these programmes receive continued support in South Africa.

4) Include community empowerment measures in research related to sex workers and SRHHIV: Both the SWIT and our findings suggest that community empowerment of sex workers is an important element in understanding and increasing access to SRHHIV services. We recommend that all future research with sex workers on the topic of SRHHIV considers measuring community empowerment as appropriate.

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Do sex workers meaningfully participate in SRHHIV services? Successes and challenges from South Africa

Research brief 2 in a series of 6 from the project entitled *Community empowerment and access to sexual and reproductive health and rights services (including HIV) for sex workers in South Africa;* a study completed in partnership between the GHJRU, Sisonke and the Sex Workers Education and Advocacy Taskforce (SWEAT)

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This brief examines meaningful participation as part of community empowerment of sex workers in South Africa. We describe the relation between meaningful participation and access to SRHHIV services. It also highlights some of the successes and challenges of achieving meaningful participation. This brief uses the *Sex Worker Implementation Tool (SWIT)* as a guiding framework. We completed: 15 interviews with NGO representatives, researchers and policymakers; 3 focus groups with sex workers (n=27); and a paper survey with a convenience sample of 298 sex workers in Gauteng (n=100), Limpopo (n=100) and the Western Cape (n=98), recruited using trained sex worker fieldworkers. Of those surveyed, 81% were cisgender women, 13% were transgender and 6% were cisgender men. We presented preliminary findings to a group of sex workers at a Cape Town Sisonke Creative Space meeting and incorporated their recommendations and feedback on the findings. All names reported in this brief are pseudonyms, to protect participants' privacy.

Background

In this brief, we examine community empowerment and meaningful participation of sex workers in South African programmes for sexual and reproductive health (including HIV) (SRHHIV). The Sex Worker Implementation Tool (SWIT) defines community empowerment as an ownership process by sex workers to individually and collectively improve health and human rights (WHO 2013). The tool highlights that in order to have effective community empowerment, participation must be *meaningful.* The SWIT describes meaningful participation as sex workers: (1) choosing how and by whom they are represented, (2) choosing how they engage, (3) choosing whether to participate, and (4) having an equal voice in managing partnerships. Government, NGOs and sex worker collectives (organisations run entirely by sex workers) must meaningfully work with communities of sex workers to ensure access to SRHHIV services (WHO 2013). The SWIT acknowledges that this type of partnership is built on trust.

Community participation in health care

'Community participation' in health care was introduced as a concept at the International Conference on Primary Health Care in 1978. At the conference, delegates composed the Declaration of Alma-Ata, which identified key tenets of primary health care and named 'individual and collective' participation in health care planning and implementation as a right (Anon 1978). Since that time, community participation has been expanded to address sustainability, evaluation and empowerment. For example, donors have increasingly recognised the importance of participation, yet at the same time evaluation methods are challenging: participation is difficult to define and operationalise, and its success is context specific (Morgan 2001). The SWIT is the result of international efforts to operationalise community empowerment in SRHHIV services among sex workers specifically and emphasises meaningful community participation (hereafter 'meaningful participation') as one of the essential aspects of community empowerment.

Peer-reviewed research that rigorously evaluates the impact of meaningful participation among *any* community interventions is limited. Available findings suggest that meaningful participation has a positive impact on intermediate health outcomes, such as improving access to, and use of, health services (Bath & Wakerman 2015). Beyond the positive impacts on health, meaningful participation has been shown to have other benefits for communities, such as promoting community building and ensuring community members' needs are met effectively in their local, cultural, social context (Sule 2005; Cyril et al. 2015).

While meaningful community participation has been an international tenet of primary health care for over four decades, few countries have achieved meaningful participation in healthcare for sex workers (Global Network of Sex Work Projects 2017). The Global Network of Sex Work Projects briefing paper on meaningful involvement documents that in a research project from 10 countries there were very few examples of meaningful participation being implemented; for example, the study identified only one sex worker-led health facility, based in the United States (Global Network of Sex Work Projects 2017).

In South Africa, opportunities for civil society to meaningfully participate in healthcare have been promoted through legislation and policy, though challenges in ensuring implementation of these practices persist (Cleary et al. 2015). Additionally, due to the marginalisation of sex workers, and the criminalisation of sex work, it may be that meaningful participation efforts targeting civil society implicitly or explicitly excludes sex workers and their needs.

In this brief, we examine meaningful participation of sex workers in SRHHIV practices related to services provided by government, NGOs and collectives. We identify successes and challenges and make recommendations for more meaningful participation of sex workers in these services.

Successful meaningful participation of sex workers

Meaningful participation and community empowerment more broadly are complex processes, and do not necessarily follow linear progressions (WHO 2013). We identified several successes in this process thus far:

- At national policy level, the development of the *National Sex Worker HIV Plan* by a partnership between government and civil society;
- At service provision level, the inclusion of sex workers' input into health programming at NGOs and the trust between sex workers and NGO service providers; and
- At individual level, the fact that sex workers were feeling prepared to engage with and through organisations that represent their interests.

Inclusion of sex workers in developing the National Sex Worker HIV Plan

The *National Sex Worker HIV Plan* (2016-2019) is a national policy by the South African Department of Health and provides policy guidance on SRHHIV service provision for sex workers, who are recognised as a key population at risk for HIV (South African National AIDS Council (SANAC) 2016; SANAC 2017). Similar to the National Strategic Plans on HIV and TB, the *National Sex Worker HIV Plan* was developed through civil society, government and SANAC collaboration. The *National Sex Worker HIV Plan* defines 'a minimum package of services' covering the areas of health, psychosocial services, human rights, social capital building and economic empowerment. The Plan uses a peer educator-led approach for health promotion. The development was led by a SANAC working group which included a Sisonke member as a co-chair. The document does not provide additional information as to how the technical working group was selected, however, the inclusion of a sex worker on in the group is a positive step towards sex workers having an equal voice to other stakeholders during decision-making processes.

Inclusion of sex workers' needs in NGO programming

Most NGO-led health programmes aimed specifically at sex workers had some type of consultation with sex workers that influenced their services. When we spoke with NGO workers from these programmes, they identified two main ways in which they engaged with sex workers in their programming: (1) employing sex workers as peer educators or other staff and (2) holding group meetings with sex workers to hear about their needs.

We have documented peer educator programmes thoroughly in research brief 3 in our series of research briefs, *Sex worker peer educator-led programmes in South Africa*. Peer educator programmes were the most common way in which sex workers were employed by SRHHIV service provision NGOs and were generally considered successful programmes. In addition to peer educators, some sex workers worked with NGOs in other capacities. One NGO representative described how having a board member who was a sex worker influenced their priorities as an organisation.

"Right from the start, Kazi has been a partner and has put sex work decriminalisation centrally on our table. And so, when there have been calls for solidarity…in policy documents that have come my way, I have certainly inserted sex work decriminalisation into that. So, for example, I looked at including the conditions of sex workers being able to access services, whether in the contraception policy, ensuring that it's in the sexual and reproductive health guidelines, just making sure that people note that the criminalization of sex work makes it harder for sex workers to access health services." (NGO worker, advocacy, national)

This example highlights how meaningful participation of sex workers—in this instance, selecting someone who did sex work to be an NGO board member—can transform organisational priorities to include sex workers' rights and needs, such as advocacy for the decriminalisation of sex work. Further, this impacted another NGO leader and built her capacity to advocate for sex workers in her spheres, despite not being a sex worker herself.

Several service provision NGOs explained that they held meetings with groups of sex workers not only to provide services, such as educational workshops, but to learn from sex workers about their needs and priorities. They sought to understand sex workers' lived experiences and use this information to influence their programming. For example, they might find out that many sex workers in their group had not tested for HIV and could arrange a testing day. Or, if there was a health topic that sex workers were unaware of, such as pap smears, they would arrange an educational talk as well as provision of pap smears. According to one NGO worker, this was a recent shift. She explained that a few years prior, the Networking HIV&AIDS Community of Southern Africa (NACOSA) had funded training for site coordinators to use this needs-based approach:

"*It was a three-day training wherein we now focusing on providing services based on sex workers' needs. Not to just go to a brothel and provide services that we think sex workers might need…we were taught to provide services according to the needs of the sex workers*." (NGO worker, health services, Limpopo)

Interestingly, sex workers in the focus groups did not seem to have an awareness that NGO programmers picked up on their needs or were directly influencing services in this way. No sex workers in the focus groups spoke about needs-based programming, although many did express being pleased with the services available to the through NGOs.

Trust exists between sex workers and NGO service providers

The SWIT highlights the importance of trust between programme partners as the foundation of developing meaningful participation. According to both sex workers and NGO workers, there was trust and respect between users and providers of NGO-based SRHHIV programming targeting sex workers.

The sex workers we spoke with were overall pleased with the services that these NGOs provided. Sex workers felt that NGO programmers cared about them, listened to them, and saw their points as valid. Many expressed gratitude for the non-judgmental sex worker-specific services and described them as safe places:

'The people that is [sic] in management of SWEAT, they really do care… you realise at the end of the day that you don't have to be shy. There's a place where you can run to. There's a place that I can find shelter in. Not shelter to go and sleep, I'm talking about shelter where you can express yourself. Where you can come and say, okay, this is my problem. At least somebody understands.' (Nosi, Cape Town focus group)

NGO workers who provided sex worker-specific services also spoke positively of their interactions with sex workers and felt that they had been successful in building relationships with their service users.

"Like in our case, as now it's long since we are working with sex workers. Now we've built that relationship in such a way that most of their problems they will come to the office and share." (NGO worker, health services, Limpopo)

NGOs also played a role in building relationships and trust between sex workers and specific government clinics. One of the effective ways of developing these relationships was through inviting government facility staff to attend a Creative Space, a model by the sex worker collective Sisonke to hold meetings with sex worker that are sex worker-led.

"So in those meetings, people from [district] Department of Health and people from the local clinics, they also tell us what kind of services they can give to sex workers and that if sex workers are having problems, they can go directly to who they can see when they can get to the clinic or if they need….From those who we have been inviting, they would end up understanding and saying oh no, we didn't know, we just thought sex work was dirty work…we also do dialogues, where we invite different people from different sectors, to come and we talk about this, so in the province, and in the districts we come from, we are well known, we are well established." (Sex worker collective employee, Limpopo)

Sex workers feel prepared to participate

Our survey findings suggest that many of the sex workers we spoke with are equipped and prepared for meaningful participation, and many are already engaging with meaningful participation at some level. Three out of four sex workers (78%) that we surveyed had attended an event with a sex worker organisation in the last year. The majority of sex workers were proud of being a sex worker (82%), suggesting they would be willing and able to advocate openly for sex workers' rights and needs. Additionally, three out of four sex workers (76%) said they were 'very confident' when giving fellow sex workers advice or speaking to crowds. These are strengths among the group of sex workers we surveyed, suggesting that they would welcome increased opportunities for meaningful participation.

We also identified the readiness of sex workers to expand their participation beyond the role of peer educators, for example. In interviews, participants described the positive outcomes of peer educator programmes (as described in the brief *Sex worker peer educator-led programmes in South Africa*) and that, to further grow community empowerment, it may be time for NGOs and government to expand roles for sex workers and facilitate career progression beyond the role of peer educator. One NGO participant described her determination to support sex workers' growth by facilitating promotions beyond the level of peer educator:

"We've empowered our staff with a lot of trainings and capacity building on different matters…I mean, I can just take Busi, my one senior team leader now, she's capable of being a project manager…She's amazing. She's really a star…if you have interactions with staff you realise, what is this person made up of and give them opportunities. So, if there's any opening position…I motivate staff to apply. I said, I want to see you grow…Apply for that job, let us update your CV…most of them have such a lot to offer and can grow so much." (NGO worker, health services, Gauteng/Limpopo)

This programmer's approach is essential to building community empowerment, as sex workers should be involved at higher levels to ensure programmes are increasingly community-led. The SWIT repeatedly emphasises the need for capacity building and meaningful participation of sex workers in all aspects of programming, which we describe in detail in the first brief in this series, *Meaningful participation of sex workers in SRHHIV healthcare*.

Challenges in promoting meaningful participation

While we identified several successes with meaningful participation of sex workers in SRHHIV services, particularly in the NGO sector, several challenges remain. Our findings suggest that sex workers: feel little ownership over SRHHIV programmes; often do not have opportunities to participate in government-based healthcare or policy development; and face socioeconomic barriers to meaningful participation.

Representation and engagement between sex workers and NGOs can be improved

While sex workers were pleased with the services provided to them by sex worker programmes within NGOs, the sex workers we spoke to did not seem to feel ownership or leadership of programmes. In general, both interview and focus group participants mostly described programmes being provided *to* sex workers, not *by* sex workers. This came out through the language most used to describe programmes in a positive light: sex workers expressed gratitude to NGOs for their services but did not speak about these services as if they were in a position of power to influence the types of services provided, or how provision would be implemented. In order to explore this further, we asked the group of sex

workers who attended the presentation of preliminary findings in Cape Town whether, in general, they felt SRHHIV services were provided *to* or *by* sex workers. Sex workers expressed that there was a difference between programming through sex worker collectives and programming by NGOs with programmes for sex workers. They agreed that they had opportunities to make decisions within Sisonke, for example, but that they did not have influence over programme design in non-collective NGOs, although further detail was not provided. Although our findings do document examples of sex workers influencing NGO programming (peer educators and needs-based programming), this suggests that sex workers may not perceive these as sufficient or that communication of how their input is used could be improved.

Variable involvement of sex workers with government-based healthcare

Overall, meaningful involvement of sex workers in government-based healthcare appeared to vary by facility. In the focus groups, many sex workers did not perceive government health centres to be a safe space for them. They anticipated discriminatory treatment from the facility staff, such as longer waiting times, refusals to serve them or negative comments about them based on being sex workers. However, in some instances, staff from NGO-based health services had built relationships with government facilities in order to refer sex workers to them for care. Sensitisation sessions such as the Creative Spaces example above (see Successes), was one of the only methods of meaningful participation of sex workers in government healthcare that we identified in this study. In the focus groups, most sex workers said they avoided government healthcare altogether due to past experiences of discrimination in government facilities. Although in the survey 63% of sex workers said they usually used public (government) healthcare, sex workers explained that they preferred to use NGOs over government clinics when possible.

Barriers to sex workers and civil society shaping policy in South Africa

We spoke with a government representative who explained the process for civil society, including sex workers, to give input on policy.

"*Whenever there is a need for any policy document to be developed, you identify stakeholders that will have influence in terms of doing that. You know, from conception. Government cannot do it alone… the method of communication would be, we would have a provincial person who is sitting at national. Provinces, after taking the information, they go to the district and they identify people, and sort of repeat the same process at that level.*" (Government representative, national)

She explained that government relies on a hierarchal chain of communication: from national, to provincial, to district, to sub-district, followed communication back up the chain. As such, even in terms of national policy, the most accessible opportunity to input on policy for most sex workers would be at the sub-district level; however, this would also rely on their input being properly communicated back up the chain to the national level. When we spoke with a representative of an NGO working to promote meaningful participation of all civil society in healthcare, he identified several barriers to meaningful participation in these policy development processes:

"*Recently we had the National Health Insurance (NHI) bill…it's in English, you are given only three months to comment on it…with other civils we drove a campaign to ask the Minister [of Health] to have it postponed until December so that people could read, digest and think through what they want to say to the Bill. The Minister said no, the deadline is a deadline, next year we need to implement the NHI…we rushed to make comments and so many comments were made. First of all, they don't acknowledge that they have received your comments. Secondly, after the comments have been made and they have read through them, the Bill still stays the same. No comments are being integrated into the Bill.*" (NGO worker, health and advocacy, no sex-worker specific programming, national)

The above demonstrates that even civil society organisations that do not experience the added layer of marginalisation due to the stigma and criminalisation of sex work struggle with meaningful participation in health policy in South Africa.

When prompted to discuss their influence on policy during the focus groups, almost no sex workers had input or felt this was available to them. A small number did share examples: a march in Johannesburg to promote sex workers' rights and a meeting with a Member of the Executive Council as examples of advocacy for improved policies and decriminalisation of sex work. However, the

majority of sex workers in the focus groups did not have any examples to share. To understand this further, we again asked this question to sex workers at the presentation of preliminary findings in Cape Town. The sex workers at this meeting felt participation in policy varied by sector. They noted clear efforts by government to involve sex workers in national policy, citing the *National Sex Worker HIV Plan* as an example of meaningful participation. However, they also felt that, while they appreciated NGO services, they had not influenced NGO policies.

An NGO worker from the Eastern Cape told us that in her province, sex workers were very engaged and influential in provincial government policy:

"*We called different stakeholders, the different departments of health, justice, the Eastern Cape AIDS Council…they came, and they listened, and they engaged in a way that was satisfactory, because that was led by sex workers, for sex workers...I am also interested to see what will follow…they are, you know, holding the council accountable. That, for me, is empowering and its inspirational on any day of the week*." (NGO worker, advocacy/health, Eastern Cape)

She linked this influence over policy to the meaningful participation of sex workers, highlighting that their advocacy efforts were 'led by sex workers, for sex workers.'

'Choosing' whether to participate: socioeconomic barriers to participation

Like many South Africans, most sex workers experience challenges due to having low-income and little access to education, particularly in light of the lasting impacts of apartheid policies which disadvantaged people of colour. Here we describe how these socioeconomic challenges can serve as a barrier to meaningful participation.

When asked about barriers to meaningful participation, NGO workers raised the issue of reimbursements for participation. In South Africa, it is common practice to provide cash to workshop attendees to cover transportation costs, as many would be otherwise unable to participate due to widespread inequality and poverty. This issue was not raised by sex workers in the focus group discussions, however, when we asked sex workers at the presentation of preliminary findings about reimbursements, the group response was loud and strong: considering the lived realities of most South African sex workers, some type of reimbursement must be offered, or many will be unable to choose to participate.

Some participants who were not sex workers shared concerns about the sustainability of requiring reimbursements for participation, suggesting this needs to be carefully budgeted for. There was a misunderstanding of the role of reimbursements among some of the people that we interviewed who were not sex workers. One NGO worker shared concern that reimbursements may influence whether and how sex workers participate.

"I find that with sex workers…if I come to a community meeting, it's not because it feeds my mind and feeds my soul. It's more about, you know, I'm going to get food that day, I'm going to get perhaps a transport reimbursement, which is really of great need especially if you're staying on the streets." (NGO worker, health, Western Cape)

Although this programmer expressed an understanding of sex workers' circumstances—and acknowledged that most South Africans who struggle financially would be motivated by reimbursements—the impact of incentives on community empowerment raised questions among NGO workers such as: should programmers respect when sex workers decide *not* to participate in a health promotion service that would improve their health? Do incentives for participation complicate the community empowerment process and serve as a barrier to 'meaningful' participation? These questions are at odds with the SWIT's principles of meaningful participation that sex workers should choose whether and how to participate. Further, they ignore the reality of socioeconomic inequality in South Africa, in which many sex workers would truly be unable to participate without reimbursements, for example. On the other hand, sex workers' decisions not to participate should be respected, regardless of NGO workers' perceived benefits of the programme. Respecting community empowerment and agency sometimes means accepting that sex workers may not make the choices that healthcare professionals deem 'best'—because sex workers have their own experiences and expertise with which to decide what they need.

One researcher we interviewed pointed out how the lack of financial stability and low socioeconomic status can hinder meaningful participation of sex workers:

"In clinical trials and epidemiology […] what we didn't know was how to create autonomy, how can we be engaged with the communities that are affected, better to understand the issues that they are facing and how better can those interventions get to those people…without facing discrimination, without facing issues around socioeconomic issues […] Because of the socioeconomic issues that are paired with a lack of education, which was manifested through apartheid […] So that discussion has been lacking in the community, so for them to be involved in decision making, has been a little bit slow, however… in the last few strategic plans we have made sure [to] include sex workers into this discussion…that is when the sex workers plan was made […] So what I can say is there has been a little bit of meaningful engagement with sex workers but I still feel, autonomy should be built more, because I am not a sex worker." (Researcher, health, national)

Discussion

In this brief, we identified successes and challenges in achieving meaningful participation of sex workers in SRHHIV services and policies in South Africa. While there has been some progress, our findings suggest that much more meaningful participation of sex workers is needed.

Meaningful participation in service delivery was varied. In NGOs, many worked directly with sex workers to understand their needs to design programming, though sex workers were not always aware that they had influenced the programmes. Meanwhile, in government facilities, many sex workers continued to experience discrimination. This challenge has also been identified in other settings: a recent project in ten countries by the Global Network of Sex Work Projects found that many sex workers were so concerned with poor access to healthcare that they were unable to focus on the promotion of meaningful participation; they felt that access and discrimination must be addressed first (Global Network of Sex Work Projects 2017). However, in some instances in this study, sex worker NGOs had built relationships with government healthcare facilities to improve their services for sex workers. This successful engagement between sex workers and their supporters with government shows the potential of meaningful participation of sex workers in improving SRHHIV access.

We identified a gap in sex worker input on policy development. Overall, civil society in South Africa face challenges in meaningful participation such as not receiving policy documents in local languages and having only short periods of time to engage and respond to policy. However, the existence of the *National Sex Worker HIV Plan*, and inclusion of sex workers in its development, is a success. Efforts in other settings to improve meaningful participation of sex workers have had little success, and often sex workers have been ignored by policymakers and programmers altogether (Global Network of Sex Work Projects 2017). Comparatively, having the South African government talking about and engaging with sex workers is a victory of sex workers' advocacy. The fact that a Sisonke member served as a technical working group member for the development of the *National Sex Worker HIV Plan* is a sign that meaningful participation of sex workers may be moving forward in South Africa.

Lastly, participants raised the socioeconomic status of sex workers as a potential disadvantage to meaningful participation. While sex workers at the preliminary presentation of findings were clear that reimbursements are needed for sex workers to participate in NGO programming, a few NGO workers had a misunderstanding about this and shared concerns about how and whether reimbursement programmes influenced sex workers' decisions whether or not to use SRHHIV services. Kabeer (1999) wrote: 'choice necessarily implies the possibility of alternatives' and that resources directly influence choice. It is important to consider whether reimbursing or incentivising programmes for arguably better health undermines efforts to build individual and community empowerment. However, in light of the extreme income inequality in South Africa, reimbursements are likely needed until economic justice is achieved. While programmers may have some discomfort with the use of reimbursements, sex workers' expertise about their needs must also be respected.

The *National Sex Worker HIV Plan* includes an 'economic empowerment package,' recognising the financial realities of South African sex workers: most are responsible for multiple dependents, do not have partners that provide financial support, and few employment and education opportunities make sex work a viable economic choice (Richter et al 2013; International Labour Organisation 2013). The economic empowerment package in the *National*

Sex Worker HIV Plan exists to make sex work safer and ensure the rights of sex workers are the same as those afforded to others in different occupations.

Recommendations

Based on the findings reported in this research brief, we recommend the following:

- **Lines of communication between national, provincial, district and sub-district levels of government should be improved, to ensure that sex workers can provide meaningful input to policy at all levels :** There were some examples of sex worker involvement in policy, however, many sex workers we spoke with did not feel they were involved themselves, suggesting there may be more engagement and communication needed between government and NGOs. Further, government should provide policy documents for review in all South African languages and work with civil society to ensure they receive enough time to meaningfully input. Use of their input should also be reported on in a transparent manner.
- **Increased meaningful participation of sex workers in SRHHIV programme and research design:** our findings documented two main ways in which sex workers were involved in health programming: peer educator programmes and needs-based programming. However, sex workers themselves did not seem to be aware of the needs-based programming as a method of involvement, suggesting that this should be more thoroughly explored and made explicit between sex workers and NGOs. Further, in this project we successfully designed and implemented the study as a team of sex workers and academics. Incorporating sex workers' knowledge and experience should be part of developing research that impacts them. We recommend that future research with sex workers meaningfully includes them in the entire process.
- **Continued efforts for economic empowerment with South African sex workers:** Efforts must continue to promote economic empowerment among South African sex workers. Decriminalisation of sex work would be an important step towards promoting sex workers' rights as workers' rights. Further, the issue of reimbursements for participation may warrant further exploration, particularly the question of how reimbursements may influence empowerment.

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Sex worker peer educator-led programmes in South Africa

Research brief 3 in a series of 6 from the project *Community Empowerment and access to sexual and reproductive health and rights services (including HIV) for sex workers in South Africa;* a study completed in partnership between the GHJRU, Sisonke and the Sex Workers Education and Advocacy Taskforce (SWEAT)

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This brief examines sex worker peer educator programmes in South Africa, which we identified as one of the main forms of sex worker led-outreach in use. In particular, we describe the ways in which sex worker peer educators appear to contribute to access to healthcare for sex workers. In this study, we completed: 15 interviews with NGO representatives, researchers and policymakers; 3 focus groups with sex workers (n=27); and a paper survey with a convenience sample of 298 sex workers in Gauteng (n=100), Limpopo (n=100) and the Western Cape (n=98), recruited using trained sex worker fieldworkers. Of those surveyed, 81% were cisgender women, 13% were transgender and 6% were cisgender men. We presented preliminary findings to a group of sex workers at a Cape Town Sisonke Creative Space meeting and incorporated their recommendations and feedback on the findings. All names reported in this brief are pseudonyms, to protect participants' privacy.

Community empowerment and sex-worker led outreach

Sex worker-led outreach programmes are increasingly recognised as part of best practice for sexual and reproductive health, including HIV, (SRHHIV) programmes and community empowerment promotion. The Sex Worker Implementation Tool (SWIT) was released by the World Health Organisation (WHO), the United Nations Population Fund (UNFPA), Joint United Nations Programme on HIV/AIDS (UNAIDS), the Global Network of Sex Work Projects (NSWP), the World Bank and the United Nations Development Programme (UNDP) as a set of implementation guidelines for sex worker SRHHIV programmes, and centres community empowerment in its implementation model. The SWIT defines community empowerment as an ownership process by sex workers to individually and collectively improve health and human rights. The SWIT defines community empowerment with eight elements: (1) working with communities of sex workers; (2) fostering sex worker-led outreach; (3) developing sex worker collectives; (4) adapting to local needs and contexts; (5) promoting a human-rights framework; (6) strengthening the collective; (7) shaping policy and creating enabling environments; and (8) sustain the movement. In this brief, we examine sex worker peer education programmes in the context of the second element of the SWIT, 'fostering sex worker-led outreach' (WHO 2013).

According to the SWIT, sex worker-led outreach is an essential method for scaling up community empowerment. The SWIT emphasises the need to shift from providing services *to* sex workers, to providing services *with* or *by* sex workers (WHO 2013). This frames and acknowledges sex workers as the experts on their needs and situates them as best placed to know how to protect their health and human rights. There are many ways in which sex-worker led outreach can be implemented, including using sex worker-identified needs as the basis of programme development; employment of sex workers as educators and outreach workers; and capacity building of sex workers to participate in implementation, management and governance of SRHHIV programming.

In our study on community empowerment and SRHHIV access, we found that the most common form of sex worker-led outreach in South Africa that participants spoke about was sex worker peer educator programmes. The sex worker peer

educator approach was first modelled by sex workers in India, where sex worker peer outreach was a major element of STI, HIV and violence prevention. These programmes demonstrated that peer educators can be an effective complement to clinical care, by supporting health promotion behaviours such as condom use (Steen & Dallabetta 2003). In one example, the sex worker collective Ashodaya Samithi organised their own programme for HIV and violence reduction, using a progressive model of engagement, involvement, ownership and ultimately sustaining the programme, which included sex worker peer outreach. Their programme was evaluated to reduce structural violence against sex workers, particularly by changing power dynamics between sex workers and institutions. This demonstrated that progression towards sustained community ownership of programming, including use of peer outreach, is an effective method of improving SRHHIV for sex workers (Reza-Paul et al 2012).

In South Africa, sex worker peer educator programmes have been scaling up through NGOs since 2010. The *National Sex Worker HIV Plan* (2016-2019) called for multi-sector commitment, including from the National Department of Health (NDOH), to expand sex worker peer educator programmes, with the target to reach 70,000 sex workers over three years. In fact, peer educators are described as the 'backbone' of the plan and are the central community empowerment mechanism therein. According to the *National Sex Worker HIV Plan*, peer educators are responsible for: (1) condoms and lubricants; (2) social and behavioural change communications; (3) HIV testing; (4) linkage to care; (5) social mobilisation; (6) psychosocial support; and (7) human rights support and access to justice.

In this brief, we describe the structure and context of sex worker peer educator programmes in South Africa. We then examine successes of the current sex worker peer educator programmes, using the criteria from the *National Sex Worker HIV Plan*, and also examine some remaining challenges in implementation.

Sex worker peer educator programme structure and South African context

In this section, we describe the history of 'community healthcare workers' in South Africa, to describe the broader context of peer education in which sex worker peer educators exist.

In our project, t organisational and funding structures of sex worker peer educator programmes in South Africa were described as complex by participants. According to interviews, the majority of the sex worker peer educator programmes were run by NGOs and funded by the Networking HIV & AIDS Community of Southern Africa (NACOSA), which served as the primary recipient of funds from the Global Fund. Sex worker peer educator programmes co-exist with many other community healthcare worker programmes that serve the general population across South Africa. Based on our interviews and literature review, it appears these programmes vary in size, scope and management by province and district. Historically, some of these programmes address specific health issues such as HIV or maternal health, and are usually led by NGOs, but funded by the National Department of Health (Colvin & Swartz 2015). However, there has been a renewed interest in community healthcare workers by the National Department of Health over the last several years as part of the re-engineering of South African primary healthcare and preparations for a new National Health Insurance (NHI). This includes rollout of ward-based primary healthcare outreach teams which will include community healthcare workers. The WBPHCOT model emphasises integration of health priorities for the general population with the aim to move away from models focusing on disease.

Meanwhile, participants also said the National Department of Health is implementing a national community healthcare worker programme as part of its High Transmission Areas (HTA) programme, which aims to reduce HIV, sexually transmitted infections (STIs) and tuberculosis (TB) among the general population. One NGO participant explained that High Transmission Areas community healthcare worker programmes function differently depending on where they are located in the country, but did not provide further detail. However, when we enquired as to whether and how the High Transmission Areas and ward-based primary healthcare outreach team programmes are related, participants were unable to provide a clear response, suggested there may be parallel programmes or lack of clarity about the future of programmes.

According to an NDOH employee and a national civil society employee who we interviewed, there is movement towards partnership between the High Transmission Areas community healthcare workers

and sex worker peer educators, with the hope of sex worker peer educator programmes becoming more sustainable and High Transmission Areas community healthcare workers being better equipped to assist sex workers as needed. The level of engagement between these two programme types does and will vary depending on local needs at sub-district level. For example, in some locations, sex worker peer educators may use High Transmission Areas peer educators as support for linkages to care. Further plans to decide on collaboration are still in progress, making it difficult to report definitively on future programme structure. There is planned movement towards sex worker peer educator programmes being divided by funders will either be NACOSA-funded, NGO-funded (through PEPFAR, the Global Fund or other donors) or government-funded through the National Department of Health. As these structural shifts take place, community empowerment processes may need to be revisited throughout implementation to ensure the model of sex worker-led outreach described in the SWIT continues to be strengthened.

The above is provided for context and to highlight considerations for future implementation of sex worker peer educator programmes in the South African context. The remainder of this brief focuses on current sex worker peer educator programmes.

Sex worker peer educator training

In this section, we describe the training provided to sex worker peer educators. We found that peer educators are trained by a range of different stakeholders, such as the Department of Health, NACOSA and individual NGOs overseeing individual peer educator programmes. Most peer educator training focused on HIV prevention efforts, and less took wider SRH concerns into account. According to the *National Sex Worker HIV Plan* and participants, all peer educators received basic training on condom and lubricant provision, social and behavioural change communications, linkage to care and basic psychosocial support. The basic psychosocial support covered how to be non-judgemental and build relationships with other sex workers as a peer educator. This created opportunities for strengthened social mobilisation in outreach. However, research participants did not mention social mobilisation being covered in training, despite being one of the main elements of the sex worker peer educator programme outlined in the *National Sex Worker HIV Plan*. One sex worker in the Cape Town focus group explained that before formal peer education programmes began, '*We do outreaches by ourselves in our pockets…we want to help those girls*,' suggesting that social mobilisation may be a core motivation of why sex workers become peer educators.

Some peer educators also received additional, specific training on HIV voluntary counselling and testing (VCT) (providing VCT themselves, rather than educating and linking to VCT at other facilities) and/or how to be a 'human rights defender.' Being a human rights defender entailed learning how to assist sex workers who experienced harassment by helping them open a police case or connecting them to medical or legal services following sexual violence.

Peer educator role and service provision

We now examine the role of South African sex worker peer educator programmes, drawing on the *National Sex Worker HIV Plan* and SWIT to describe the success of these programmes, as well as some implementation challenges.

A range of NGOs across the country told us that they housed a sex worker peer educator programme. These included a sex worker-led NGO, an NGO service provider serving only sex workers and several NGO service providers serving larger communities, but who also had sex worker peer educator programmes. We examine these peer educator programmes as a whole and sometimes comment on specific types of programmes as appropriate.

Within these programmes, sex worker peer educators played many roles, and qualitatively participants spoke about peer educators providing all seven responsibilities that are outlined in the *National Sex Worker HIV Plan*. Again, only peer educators who attended special training provided VCT and human rights support; however, peer educators could also provide linkage to care for VCT and human rights support. We now discuss successes and challenges related to these seven areas.

Successes

Most sex workers had contact with peer educators

In all peer education programmes that we analysed, peer educators were highly utilised and successfully assisted many sex workers to access healthcare and justice services. That these outreach services had a wide reach was evident in our survey findings: eighty-six percent of the sex workers we surveyed (n=257) had interacted with an outreach worker from a sex worker organisation in the last 12 months.

Support from NGOs and government for sex workers themselves to serve as peer educators

The necessity of sex worker-led peer education programmes was widely acknowledged among our interview participants. For example, one participant, from the NDOH, commented on the importance of having specific peer educators for sex workers in addition to the broader community healthcare worker programmes:

"*It should be a person who understands the industry...some of the community healthcare workers do the house to house [visits] and people do sex work, but they are still in the closet. So, if it is somebody who doesn't understand, they [can't] just get into a household where there are parents and children, and ask 'Are you a sex worker?' No-one is going to answer that. You understand?"* (Government worker, health services, national)

Here, the participant highlighted how the topic of sex work needs to be approached carefully, due to stigma in many communities. Because of this, asking about sex work in general outreach programmes, may not be effective in reaching sex workers and connecting them to resources. However, employing sex workers as peer educators draws on sex worker knowledge and expertise. As a result, participants described how these programmes have been effective in reaching many sex workers and creating a safe space for engagement.

Improved access to health services

A major benefit of the peer educator model was improved utilisation of healthcare by sex workers. Several participants explained that sex worker peer educators served as a bridge to services, particularly to 'mainstream' services for the general population that may not have a specific sex worker programme. This falls under the fourth element outlined in the *National Sex Worker HIV Plan*, 'linkage to care.' Sex workers felt this especially helped those who feared discrimination at health services, which happened often: a quarter of survey respondents said that they had experienced discrimination due to being a sex worker during their last visit to a health facility. In Limpopo, sex worker peer educators often physically escort sex workers in need of care to the necessary health facility in order to support them. This quote from a sex worker illustrated that linkage to care was effective:

"I was afraid to go alone to the clinic, but when I asked the Sisonke peer to accompany me to the clinic…I got help…now I can speak even for myself when I go to the clinic, which I could not do before." (Ann, Polokwane focus group)

In this way, sex worker peer educators were very successful in linking other sex workers to healthcare services they may not have otherwise accessed.

Peer education package coverage per the National Sex Worker HIV Plan

The *National Sex Worker HIV Plan* outlines seven areas that sex worker peer educators are responsible for: (1) condoms and lubricants; (2) social and behavioural change communications; (3) HIV testing; (4) linkage to care; (5) social mobilisation; (6) psychosocial support; and (7) human rights support and access to justice. In interviews and focus groups, NGO workers and sex workers' responses suggested that all seven components of the *National Sex Worker HIV Plan* peer education package are being implemented to some extent. Participants spoke more about some elements than others. Sex workers most commonly spoke about linkage to care, particularly in Limpopo (described in the previous section, '*Improved access to health services'*). Few sex workers described engaging with peer educators who provided VCT or paralegal services, although there was some service provision. This was likely due to only specific peer educators being trained to provide these services. Overall, the coverage and scope of the sex worker peer educator programmes successfully covered all seven areas laid out in the *National Sex Worker HIV Plan.*

Peer educator training fostered opportunities for education between sex workers

Some peer educators in the focus group discussions spoke about the importance of sharing their training with other sex workers.

"The peer educators…have the knowledge and get the training from the Department of Health…we can go to teach those who don't have the information, because when the researchers come up with the knowledge, they cannot give it to everyone. But the peer educators can go out and teach the others and the information goes like that." (Natasha, Johannesburg focus group)

In a resource constrained setting like South Africa, not every sex worker may have the opportunity to attend trainings or other types of educational events such as policy briefings or research dissemination sessions. However, peer educators who attended such events used their time with other sex workers to pass on the information and skills they learned. At the presentation of preliminary findings, this resonated with many of the sex workers present, who also asserted that peer educators should 'pay it forward' by sharing their knowledge with sex workers who did not have the opportunity to attend training. This may contribute to the social mobilisation goals of the peer education programme (element 5 in the *National Sex Worker HIV Plan*. Overall, the positive impact of peer educator training appeared to reach not only those who attended the training themselves, but their broader sex worker communities as well.

Challenges

Based on the above stories of sex worker peer educator programmes in South Africa, these programmes have been widely used, improved access to healthcare and educational opportunities for sex workers and are meeting the goals of the *National Sex Worker HIV Plan.* While very successful, we also identified a few challenges in implementation of these programmes.

Understanding outreach in rural areas

South Africa contains diverse urban and rural areas. Here we highlight the differing needs between them. While many survey participants said they had contact with an outreach worker in the last 12 months, our findings were different by province. Ninety-five percent of the sex workers who participated in Gauteng and the Western Cape had interacted with an outreach worker; however, only 69% of respondents from Limpopo had. In order to further understand why participants from Limpopo had fewer interactions, we also explored the difference between urban and rural participants. In Limpopo, urban participants were less likely to have contact with an outreach worker than rural participants (58% compared to 85%). This was surprising because participants suggested in interviews that rural sex workers may be the hardest to reach due to there being far distances between them.

"*These are people who do door to door by foot…if you are within an urban area, you can manage it, but then if you are in the rural where you have to go up the hills and… it is going to be difficult*." (NGO worker, 'mainstream' health, Western Cape/national)

The *National Sex Worker HIV Plan* uses a '3-tiered delivery approach' which varies the model of service delivery for sex workers based on the amount of sex workers in their district. The *National Sex Worker HIV Plan* states that low and moderate density areas (which are presumably more rural) will use outreach teams including peer educators, whereas the emphasis for high density areas (presumably more urban) are dedicated clinics for sex workers. Although this was not suggested by participants, it is possible that the different models of care between rural and urban areas could have led to the difference in outreach interactions. Further, due to being a more rural province overall, Limpopo programmes may have fewer resources than other provinces. The distinction between rural and urban areas may require further exploration in order to best address sex workers' needs.

Unavailability of safe abortion

While peer educators have been successful in connecting sex workers to SRHHIV services, structural barriers remain to some services. For example, multiple participants pointed to safe termination of pregnancy as a major challenge. Although abortion is legal in South Africa per the Choice on Termination of Act (1996), few facilities provide the service due to unequal budgets and management among government health facilities and poor regulation of conscientious objection (Amnesty International & Women's Health Research Unit 2017). Even when peer educators could

connect sex workers to a facility providing the abortion, waiting times sometimes delayed their access until their gestational age was beyond the legal limit of termination. This highlights not only the urgent need to improve access to abortion services, but also the opportunity to expand training for sex worker peer educators to include abortion-related care. Given the enormous challenges in accessing safe, legal abortion, sex worker peer educators could be trained to assist sex workers in navigating the health system to find the abortion care they need.

Condom confiscation by police

We also identified that police served as a barrier to healthcare, despite peer educators' ability to link sex workers to care. In interviews and focus groups, NGO workers and sex workers spoke about peer educators' role in condom distribution and demonstration, and this is one of the seven responsibilities of peer educators outlined in the *National Sex Worker HIV Plan.* Sex workers we spoke with appreciated and used peer educators to obtain condoms. However, participants also shared that law enforcement continue to use 'condoms as evidence' of sex work. If a sex worker is carrying condoms, law enforcement uses this as evidence that they are practicing sex work. They may arrest the sex worker and/or take their condoms. Previous research from South Africa has highlighted this police practice as a barrier to health promotion (Scheibe et al 2016), and our study found that condom confiscation continues, diminishing the ability of peer educators to improve condom usage among sex workers. Further, this practice is directly at odds with the condom provision focus area for peer educators in the *National Sex Worker HIV Plan.* This conflict means that sex worker peer educators who follow the Plan may be placing themselves at risk for arrest, making provision of this service an ongoing challenge.

Discussion

The peer educator programmes implemented throughout South Africa have clearly positively impacted sex workers' health. The majority of sex workers we surveyed had contact with peer educators. Most importantly, many participants felt that peer educators were not only well-established, but successfully connecting sex workers with a variety of SRHHIV services.

The history of community healthcare workers in South Africa is long and complex. While sex worker peer educators are relatively new, community healthcare programmes are not. Opportunities for collaboration between the two exist. While collaboration may be useful for sustainability of sex worker-led outreach, it is important to also note that currently a primary funder of the ward-based primary healthcare outreach teams, the up and coming national community healthcare worker programme, is the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) (PEPFAR 2018). PEPFAR funding comes with the requirement of adoption of the 'anti prostitution loyalty oath', which prevents funded organisations from using a harm reduction model with sex workers (NSWP 2015). This oath conflicts with the international and domestic best practices approaches outlined by both the SWIT and the *National Sex Worker HIV Plan*. Attempting to fully integrate ward-based teams and the current sex worker peer educator programmes in future could therefore be a challenge as long as the ward—based teams remain funded by PEPFAR. The South African government must adhere to its constitutional mandate and be prepared to advocate for sex workers' rights.

Overall, peer educators were very successful in linking sex workers to SRHHIV services. In particular, peer educators assisted sex workers by helping them navigate the healthcare system, especially when sex workers feared discrimination in health services. Despite these improvements in access to healthcare, we identified a specific challenge with peer educators' ability to provide linkage to care for all SRHHIV services: limited options for safe abortion. While barriers to safe abortion in South Africa have been thoroughly documented (Amnesty International & Women's Health Research Unit 2017), the recent United States' 'Global Gag Rule' restrictions in funding for programmes providing abortion information and services is also a cause for concern, as it has the potential to further restrict access (du Plessis et al 2019).

Sex worker peer education programmes have been shown to also have positive impacts on community empowerment and health in other settings (Benoit et al 2017). The approach to how such programmes are designed and implemented is essential. Previously research in South Africa documented a case study which demonstrated that sex worker peer educator programmes must not take a top-

down approach, but be part of a broader community empowerment framework to be effective (Cornish & Campbell 2009). It is essential that NGOs and the South African government continue to recognise sex workers as the people with the greatest expertise and knowledge to design and implement these programmes.

In addition to the success of peer educator programmes, sex workers should also have opportunities to grow and expand their community empowerment in other ways, including more ownership over the peer educator programmes. For example, the Ashodaya community-led initiative by sex workers in India yielded increased benefits when they shifted towards sex workers owning and setting the agenda of programming. These benefits included: reduction in structural violence, improved collective agency and less stigma and discrimination (Reza-Paul et al 2012). In another study from India, peer education programmes alone were not as effective in reducing sexually transmitted infections among sex workers as was a full package of what they called 'community mobilisation', which included building community among sex workers in order to advocate for their rights as a cohesive unit (Beattie et al 2014). Thus, an overemphasis on peer educator as the main role for sex workers to participate in the health system may be short-sighted and prevent the expansion of sex workers into other roles that can have a positive impact on health and community empowerment. With this in mind, it is important to note that the *National Sex Worker HIV Plan* only describes a 'peer educator-led approach' rather than a 'peer-led approach.' While peer educators are essential to programmatic success and have proven effective for improving health outcomes in multiple settings, community empowerment should not stop with sex workers serving as peer educators (see research brief 2: *Do sex workers meaningfully participate in SRHHIV?* for more information).

Recommendations

Based on the findings of this research brief, we recommend the following:

- **Continued use of sex workers as peer educators:** Based on the positive impacts of sex worker peer educator programmes on both access to services and community empowerment, we recommend that sex workers continue to be employed as peer educators and that these programmes should continue to be funded and implemented. In light of the movement by government to deploy a generalised community healthcare worker programme through ward-based primary healthcare outreach teams, we recommend continuation of specific programmes for sex workers. Our research showed the benefits of sex workers relating to each other in a safe space to discuss SRHHIV, which may not be achievable with non-sex worker community healthcare workers.
- **Expansion of sex workers' involvement beyond the peer educator role**: This brief documents the current success of sex worker peer educator programmes in South Africa. To further the community empowerment process, enabling environments should facilitate sex workers' involvement in programme development and design, as well as implementation. While the peer educator programmes have been successful, meaningful participation of sex workers beyond the educator role was limited. Peer educators should have opportunities for professional development and promotion, should they wish to grow within programmes.
- **Renewed commitment to ensuring a comprehensive SRHHIV service package within a framework of rights protection for sex workers:** Per the *National Sex Worker HIV Plan,* a health service package consisting of prevention care, HIV testing and TB screening and treatment and sexual reproductive health (SRH) services must be made available for sex workers. SRH services include STI testing and treatment, contraception, emergency contraception and the choice of termination of pregnancy. While our findings suggest that peer educators help sex workers access these services, barriers to any of these services must be addressed to ensure access. According to the *National Sex Worker HIV Plan*, sex worker peer educators are responsible for providing some basic services (such as condoms and lubricant) and providing linkage to care for clinical services. Through assessing peer education programmes, we identified gaps in comprehensive care, such as little access to safe abortion and the continuation of condom confiscation by law enforcement.

Government must show sustained commitment to comprehensive services, regardless of pressure from external funders.

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Sex worker collectives for community empowerment and sex worker representation: lessons learned from South Africa

Research brief 4 in a series of 6 from the project *Community Empowerment and access to sexual and reproductive health and rights services (including HIV) for sex workers in South Africa;* a study completed in partnership between the GHJRU, Sisonke and the Sex Workers Education and Advocacy Taskforce (SWEAT)

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This brief describes sex worker collectives in South Africa, primarily focusing on the large national collective, Sisonke. We explore how Sisonke has contributed to individual and community empowerment of sex workers and describe how strengthening the collective could impact the future. We completed: 15 interviews with NGO representatives, researchers and policymakers; 3 focus groups with sex workers (n=27); and a paper survey with a convenience sample of 298 sex workers in Gauteng (n=100), Limpopo (n=100) and the Western Cape (n=98), recruited using trained sex worker fieldworkers. Of those surveyed, 81% were cisgender women, 13% were transgender and 6% were cisgender men. We presented preliminary findings to a group of sex workers at a Cape Town Sisonke Creative Space meeting and incorporated their recommendations and feedback in the findings. All names reported in this brief are pseudonyms, to protect participants' privacy.

Sex worker collectives and community empowerment

In this brief, we explore sex the development and strengthening of sex worker collectives as part of sex worker community empowerment in South Africa.

The Sex Worker Implementation Tool (SWIT) is considered best practice on implementing sexual and reproductive health, including HIV, (SRHHIV) services for and by sex workers. The linchpin of the SWIT is sex worker community empowerment, defined in the tool as an ownership process by sex workers to individually and collectively improve health and human rights. The SWIT outlines eight elements of community empowerment: (1) working with communities of sex workers; (2) fostering sex worker-led outreach; (3) developing sex worker collectives; (4) adapting to local needs and contexts; (5) promoting a human-rights framework; (6) strengthening the collective; (7) shaping policy and creating enabling environments; (8) sustaining the movement (World Health Organization 2013). This research brief focuses on elements number 3 and 6 and examines both the development and strengthening of sex worker collectives in South Africa.

According to the SWIT, sex worker collectives are groups that are entirely sex worker run and led. It is important to distinguish sex worker collectives (hereafter 'collectives') from service provision NGOs which are not sex worker-led. In some instances, collectives may grow out of service provision NGOs. Service provision NGOs may engage with and employ sex workers but have leadership and administrative staff who are not sex workers. Conversely, sex workers themselves create collectives, and different collectives may have different goals: some collectives start as a "safe space" or "drop-in centre", a place where sex workers can spend time together and socialise. Other collectives may decide on specific issues they want to address, such as responding to police violence or improving conditions for migrant sex workers.

In this brief, we first describe the sex worker collectives we identified in South Africa. Then, using the national collective Sisonke as a case study, we

describe how sex worker collectives contribute to individual and community empowerment. In the last section, we discuss opportunities for strengthening Sisonke and other collectives.

Sex worker collectives in South Africa

We identified two sex worker collectives during the research: Sisonke, a national movement by and for sex workers, and Mothers for the Future, a small Cape Town-based initiative to support and address the needs of sex workers who are also mothers (this is not to say that there are no other collectives in South Africa; but these were the collectives discussed by participants in the interviews and focus groups in this study).

Sisonke

Sisonke was the collective most spoken about by participants, mostly likely because it is a large, national collective and Sisonke was instrumental in recruitment to participate in the focus groups in this study. Initiated by sex workers in 2003, Sisonke's mission is "to see a South Africa where sex work is recognised as work, and where sex workers' health and human rights are ensured" (SWEAT 2016). The collective is well known for its motto "Nothing about us, without us," which was often used as shorthand by sex workers when discussing community empowerment in the focus groups. The motto speaks to the need to involve sex workers in programmes and policies that impact them. While many of the sex workers participating in the focus group discussions were Sisonke members, most sex workers who completed survey were not Sisonke members: 31% of those who answered the survey were Sisonke members.

Sisonke has its own national peer educator programme and some focus group participants were also Sisonke peer educators. Many focus group discussion participants who were Sisonke members explained that they joined the collective as a result of outreach done by Sisonke. In this way, Sisonke used collective members in order to expand their membership.

Mothers for the Future

Mothers for the Future (M4F) is a Cape Town-based support group of about thirty members. Although M4F is housed with SWEAT, the initiative was founded and is led by a local sex worker (Aron 2017). M4F meets regularly to address different topics that impact them as mothers who also do sex work, as well as to encourage each other to do outreach with children and mothers in their communities (Aron 2017). M4F shows how collectives can be dynamic, and that there is diversity within sex worker communities. In this instance, the founder identified the need to bring together sex workers who are also mothers. Over time, new collectives may emerge as other specific needs are identified.

Unfortunately, leadership from M4F was unavailable to be interviewed at the time of our study; therefore, our discussion of this collective is limited to what has been previously documented about their work. Some of the participants in the Cape Town-based focus group stated that they were members of M4F but did not speak in detail about their experiences in the collective. One NGO worker we interviewed was familiar with the collective and provided some background and insight about M4F, describing it as an important initiative and one that is still in development.

Based on our data, we chose in this brief to use Sisonke as a case study of a successful sex worker collective and explore its future through collective strengthening. Sisonke came through as a powerful and far-reaching sex worker collective. However, we also wished to highlight M4F as an example of how collectives can differ in scale and purpose. M4F represents a smaller community with a specific set of needs. The emphasis of M4F goes beyond decriminalisation or human rights violations to broaden the approach to sex workers' needs—here, to focus on issues related to parenting. Sisonke, on the other hand, was a common portal for government to engage with sex workers and functions on a national scale.

Sisonke: success in individual empowerment through collectives

In this section, we document how membership with the national sex worker collective, Sisonke, strengthened individuals' empowerment.

Based on the survey results, approximately one third of participants said they were a Sisonke member. However, regardless of Sisonke membership specifically, 95% of sex workers had shown some type of collective agency by helping another sex worker with a problem with people such as brothel owners, clients or police. This suggests that whether in a formalised collective or not, sex workers are working in collective ways.

Through focus groups with sex workers, we identified several ways in which Sisonke membership built individual and community empowerment: for example, improved recourse with police, education about the right to access health services and the knowledge they had the support of other sex workers in facing their challenges.

Focus group participants shared that they felt empowered through their participation in a sex worker collective.

"For me to be a Sisonke member is because Sisonke is fighting for sex workers rights, so when we are united, we can fight for one thing and our voice can be heard." (Kefilwe, sex worker, Polokwane focus group)

Some sex workers in the Johannesburg focus group also reflected on the history of Sisonke, and how the collective's development improved their safety.

"When there was no Sisonke, all those years before, long time ago, we were abused by cops and when you go and report and open the case against them you were chased out of the cops station or getting 'klapped' [Afrikaans, meaning 'hit']…when I was introduced to Sisonke, it's where they're fighting for us and that's when we were more freely. (Sindi, sex worker, Johannesburg focus group)

The findings from our study show that sex workers continue to experience violence and poor policing practices in present day. However, the formation of Sisonke appears to have offered its members an added layer of protection, a feeling of community and support. Sex workers shared stories about how challenging and isolating it was to cope with human rights violations—such as violence from clients—prior to having a collective. These participants felt that being in Sisonke improved not only support for sex workers, but decreased violations of their rights overall due to advocacy efforts. Sisonke also helped to educate sex workers about their rights to access SRHHIV services (we discuss human rights education in more detail in research brief 4 of this series, *Promoting health and human rights for sex workers in South Africa*):

"By joining Sisonke it made me become aware of a lot of things that I didn't know, like I didn't know I have the right to get my medication at the clinics, I have the right, if I have STI, to go and explain at the clinic that I have STI, that is why I joined Sisonke because they don't judge sex workers, they are so helpful." (Natasha, sex worker, Johannesburg focus group)

Natasha went on to explain that once she learned about Sisonke, she knew that having a community of other sex workers to work for their rights was what she 'had been looking for.' *"There was a day that the police came to pick me up … he asked me to sleep with him, when I slept with him, he promised me that he was going to bring my money the next day, the next day came he didn't give me the money, two months down the line he came to arrest me again … so when I came to know about Sisonke, … what it does, I was like oh this is what I'm looking for, then the next day, I went to join Sisonke. (Natasha, sex worker, Johannesburg focus group)*

Natasha's story demonstrates how being a collective member not only develops community empowerment, but individual empowerment.

An NGO worker, who identified herself as someone who had done sex work in the past, highlighted why peer collectives are so essential in community empowerment:

"When you say empowerment, it creates the idea that some heterosexual, cisgender, probably a white man, in some air-conditioned office, came up with some programme that he thought was empowerment…and writes up the results and says he has empowered twenty transgender women…That is never ever the case. It is about me giving you my knowledge. That is my grapple with empowerment…What I call empowerment, for example, is our support group…when trans women or sex workers would come together, share our ideas and strategies peer to peer. That is empowerment, because that is something that came from us, with us, by us. It is not somebody who came and taught us something that they think is relevant to our lives, took our stories and then calls it empowerment." (NGO worker, advocacy/ health, Eastern Cape)

Interestingly, despite her scepticism about the concept of 'empowerment,' this participant's definition of the concept resonates with the definition of community empowerment put forward in the SWIT: that community empowerment must be rooted in the community at hand, with sex workers themselves building the empowerment individually and collectively. Her explanation touched on the history of SRHHIV programmes created for sex workers in the past that did not

engage with sex workers in a meaningful or rights-based way. This highlighted the need to acknowledge sex workers' input as integral to research processes—and how not doing so can deteriorate trust between researchers or programmers and sex worker communities. By forming collectives, sex workers learn from each other, support each other and build trust amongst each other.

The future of Sisonke: Collective strengthening

In addition to *developing* sex worker collectives, the SWIT also identifies the *strengthening* of collectives as one of the eight elements of community empowerment. Strengthening includes membership building, developing financial stability and growing their ability to address community issues of concern. The SWIT emphasises that all partners, from government to local and international NGOs, should not only support this process, but have a responsibility to ensure collectives' growth takes place.

In this brief, we next examine the future of South African sex worker collectives such as Sisonke. First, we summarise how the South African *National Sex Worker HIV Plan* (2016-2019) sets goals for collective strengthening. Next, we identify opportunities for collective strengthening based on our data.

Collective strengthening in the National Sex Worker HIV Plan

The *National Sex Worker HIV Plan* names its eighth and final objective as 'to support the strengthening of representative sex worker organisations such as Sisonke – the national sex workers movement' (the *National Sex Worker HIV Plan* appears to use several different terms for sex worker collectives interchangeably; here they use 'representative sex worker organisation'). The *National Sex Worker HIV Plan* repeatedly uses Sisonke as the example of a sex worker collective but refers to collectives in the plural implying that other collectives may need support now or in the future.

The *National Sex Worker HIV Plan* also contains a series of 'packages' to assist implementation of the Plan. The social capital building package strives to build a 'collective identity' among sex workers, which has been linked to decreased vulnerability to HIV. The *National Sex Worker HIV Plan* does not provide specific targets for this package, such as the number of collectives to be engaged, the amount of increased membership in collectives or specific allocation of resources.

Implementation of collective strengthening

In our study, in addition to focus groups with sex workers, we interviewed NGO workers based at both sex worker collectives (n=2) and NGOs that were not sex worker collectives (i.e. not entirely sex worker run and led, such as SWEAT) but had a dedicated sex worker programme(s) or worked with sex workers (n=8). Although interview participants universally called for continued, increased engagement with sex workers, there was almost no discussion about collective strengthening specifically. Most participants focused on strengthening programmes within NGOs not run by sex workers; understandable, as most participants we interviewed worked for such NGOs. However, a few such participants did highlight the need for strengthening collectives. This participant felt that, at this stage, both collectives and other NGOs are necessary to build sex workers' community empowerment:

"I don't think sex workers are standing up for their rights as much as they can or should, but there are reasons why. I think people feel disempowered, they feel that the system is too strong or too big for them to stand up against as individuals, and that is why it's so crucial for organisations like Sisonke to keep building that movement. So crucial for organisations like SWEAT to be there and to take sex workers' complaints seriously." (NGO worker, advocacy/justice, Western Cape)

This participant explained that in her experience, sex work-related stigma persisted as a major barrier to empowerment, which, at this time, necessitated involvement of non-collective NGOs. However, she called for interventions to reduce stigma, such as sensitisation training, in order to decrease this need.

In another example a different participant described how capacity building within collectives can be challenging, particularly when there is little access to organisational resources in early stages of the collective. Here the participant explained how a newer, small collective struggled with capacity, leaving responsibility of the collective on the shoulders of one member:

"I don't think there is a lot of capacity…it has never really been something that has been well funded or

supported…what has been difficult is that there is nobody else with capacity to sustain it as well…[NGOs] will be able to do the catering, but in terms of thinking strategically how to facilitate the space and work plan, I think that [the facilitator] is pretty much on her own…I think there needs to be funding and I think people need to work in partnerships, I think there needs to be facilitated time...building a common agenda." (NGO worker, health, Western Cape/national)

Based on our data relating to sex worker collectives, there appeared to be a divide between a smaller group of sex workers who drove the organising efforts of the collective and the other sex workers in their communities who were less capacitated and did or did not interact with collectives. While we found some sex workers were very engaged in policy and programming, this left a gap in community empowerment efforts, as many sex workers were not yet engaged at an ownership or leadership level. However, while not all collective members were at a leadership level, collective membership had other benefits for sex workers. Many appeared to benefit from participation in the collective through socialisation and support from other members:

"In the Creative Space, most of the time we talk about our stories…Sometimes I'm telling them that I'm HIV positive and I was on drugs for eight years. Then [the other sex workers] will start looking at me and say, seriously. As beautiful you are, you were on drugs and you are [HIV] positive. Then they'll start some exchange of [phone] numbers. Then we talk on WhatsApp. We meet. Then some are coming, you understand." (Ada, sex worker, Cape Town focus group)

However, the divide between the small group of sex workers leading the collective and 'everyday' sex workers did not yet challenge stereotypes about sex workers. Despite 'social capital building' being a main package in the *National Sex Worker HIV Plan*, the stereotype that all sex workers are disempowered seemed to persist among some policymakers. In one instance, a group of sex workers representing their collectives and NGOs were perceived as not being 'real' sex workers by policymakers, whose only understanding of sex workers was based on this victim stereotype:

"I think that we had some very good and powerful sex workers themselves, present at that meeting, presenting. But it's almost as if their voices were dismissed because they came wearing…the T-shirt of their organisation…they weren't 'real' sex workers…there was this continued reference to oh, well, [the policymakers] need to talk to 'real' sex workers, because they don't understand why women want to do this, right, like why would a woman want to sell herself…so I think for many of the sex workers who were there it was a very difficult day…because I think many of them felt like they had an opportunity to come here to raise their voices and to speak out, but that they were more or less being dismissed because the parliamentarians were so fixated on the picture that they had in their head of what a sex worker was." (NGO worker, advocacy/justice, Western Cape)

In this instance, the policymakers at the meeting had a preconceived notion of who a sex worker was and what a sex worker looked like, stereotyping all sex workers as victims of their circumstances. Sex workers who were activists and had strengthened their collectives in order to fight for their rights, were dismissed due to showing their agency. This highlights that de-stigmatising sex work and combatting negative stereotyping are necessary facets of collective strengthening. Ideally, as more and more sex workers move into leadership roles in their collectives and have the capacity to engage with people in power outside of the collective, those they engage with will come to understand sex workers as people with agency and the ability to influence policies and programmes impacting them—that is, the 'victim' stereotype will be challenged. Thus, there is a cycle between stigma and collective strengthening: expanded strengthening within the collective is needed to combat stereotypes, and reduction in stigma will facilitate increased community empowerment resulting from collective strengthening. We address stigma further in the research brief 5 of this series, *The role of community empowerment in reducing sex work-related stigma and improving access to SRHHIV services.*

Discussion

This brief examined sex worker collectives in South Africa, their relationship with individual and community empowerment, and opportunities to strengthen such collectives. We identified one large national sex worker collective, Sisonke, and a small local collective, M4F, in our research; it is possible that other small collectives also exist that we did not identify, as a thorough mapping of smaller sex

worker collectives was beyond the scope of this study. Emphasis across stakeholders appeared to focus on Sisonke—important, as Sisonke has been successful not only in unifying sex workers nationally, but in influencing policy and programming for sex workers.

We found few case studies in the literature documenting sex worker collectives and their impacts. However, Reza-Paul and colleagues (2012) documented that in India the Ashodaya Samithi collective has had increasing impact on its community in building community empowerment and reducing violence against sex workers. The collective developed through stages of engagement (most activities performed by non-sex worker project staff), to involvement (actions 'with' sex workers), to ownership (broader needs of the sex worker community addressed) (Reza-Paul et al 2012). Our findings suggest that the leadership of Sisonke have achieved ownership of the collective. That said, part of sustaining the collective will be continuing to leadership build capacity among newer collective members. Further, we identified several NGOs with sex worker programmes that operate in the engagement or involvement stage, without the ownership that collectives, like Sisonke, have.

Although the *National Sex Worker HIV Plan* calls for the development and strengthening of sex worker collectives, our findings suggest that the importance of strengthening collectives in South Africa is generally underestimated by NGO workers and government. We found that Sisonke was well known and respected as a sex worker collective; however, we found little evidence that outside organisations saw strengthening the collective as a priority. Further, there was almost no discussion about the possibility of other, smaller collectives who may wish to address issues specific to their local contexts and communities.

Sex worker collectives are crucial to achieve sex worker community empowerment. By definition, collectives are run by and for sex workers, ensuring that sex workers set the priorities for the organisation. Some participants we interviewed felt that non-collective NGOs are also needed to provide support to sex workers at this time, due to decriminalisation and stigma serving as barriers to other types of support. However, these participants agreed that collectives are essential to sex worker community empowerment. Collectives are undeniably needed for agenda setting and to protect sex workers' interests.

Recommendations

Based on the findings in this brief, we recommend the following:

- **Ongoing support for sex worker collectives**: Our findings demonstrate the importance of collectives, as outlined in the SWIT, in building community empowerment among sex workers. Collectives ensure that sex workers build their social communities, provide opportunities for leadership and learning and create a safe space for sex workers to address their needs. Continued support should be provided to collectives, while also respecting the collectives' autonomy.
- **Specific *National Sex Worker HIV Plan* targets for collective strengthening:** While the current (2016-2019) *National Sex Worker HIV Plan* includes collective strengthening as an objective of the Plan, it does not outline specific targets that support measurement of these efforts. We recommend that the next Plan contains concrete ways of evaluating support for collectives, in order to ensure adequate support is provided.
- **Need for continued capacity building within existing collectives**: Our findings show that some sex workers have taken up leadership of collectives, working to ensure sex workers have a seat at the table for policy and programmes planning. However, we also found that there are still many sex workers who do not have the capacity to play a leadership role. Increasing capacity among collective members would lead to meaningful involvement of a larger—and perhaps more diverse—group of sex workers. We recommend capacity building be a central objective within collective strengthening.

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Promoting health and human rights for sex workers in South Africa

Research brief 5 in a series of 6 from the project *Community empowerment and access to sexual and reproductive health and rights services (including HIV) for sex workers in South Africa;* a study completed in partnership between the GHJRU, Sisonke and the Sex Workers Education and Advocacy Taskforce (SWEAT)

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This brief focuses on the fifth of eight community empowerment elements in the SWIT: promoting a human rights framework. We begin the brief by reviewing the international human rights instruments related to sex workers' rights and sexual and reproductive health, including HIV (SRHHIV) and then describing South African law and policy, including the criminalisation of sex work. Then we examine, based on our data, South African sex workers experiences of human rights violations and opportunities for recourse. We completed: 15 interviews with NGO representatives, researchers and policymakers; 3 focus groups with sex workers (n=27); and a paper survey with a convenience sample of 298 sex workers in Gauteng (n=100), Limpopo (n=100) and the Western Cape (n=98), recruited using trained sex worker fieldworkers. Of those surveyed, 81% were cisgender women, 13% were transgender and 6% were cisgender men. We presented preliminary findings to a group of sex workers at a Cape Town Sisonke Creative Space meeting and incorporated their recommendations and feedback on the findings. All names reported in this brief are pseudonyms, to protect participants' privacy.

Background

International human rights instruments and recommendations for sex workers

The relationship between sexual and reproductive health, including HIV (SRHHIV) and human rights has been a subject of attention for several decades. In 1989, the United Nations Centre for Human Rights (UNCHR) and the World Health Organization (WHO) organized the first International Consultation on AIDS and Human Rights to develop guidelines for international human rights standards to be domesticated through law with the aim to help governments understand the context of human rights in the HIV/AIDS epidemic (Joint United Nations Programme on HIV/AIDS (UNAIDS) 2006). These were updated over the years, ensuring human rights remained linked to work to decrease the impact of HIV/AIDS. In 2012, the WHO, with support from the United Nations Population Fund (UNFPA), UNAIDS and the Global Network of Sex Work Projects (NSWP), released a document specifically contextualised for sex workers, Prevention and treatment of HIV and other sexually transmitted infections for sex workers in low- and middle-income countries, hereafter referred to as the "2012 Recommendations", which outlined recommendations to promote sex workers' SRHHIV and human rights (WHO 2012). To technically guide implementation of these recommendations, they later developed and released the Sex Worker Implementation Tool (SWIT), which serves as the guiding framework for our analysis (WHO 2013).

The international guidelines, 2012 Recommendations and the SWIT all emphasise the fundamental human rights of sex workers, as of all people, as specified in international human rights instruments. The Universal Declaration of Human Rights (UDHR), adopted by the United Nations, was the first instrument to set out rights for all human beings internationally, including, but not limited to, the rights to equality, non-discrimination, the right to life, freedom from arbitrary arrest or detention, right to a fair trial and the universality of rights (United Nations 1948). However, declarations are not legally binding. The UDHR was later followed by the International Covenant on Civil and Political Rights (ICCPR) (United Nations 1966a) and the

International Covenant on Economic, Social and Cultural Rights (ICESCR) (United Nations 1966b), which are only legally binding on countries that ratify them. The ICESCR includes the right to the 'highest attainable standard of physical and mental health.' In 2000, General Comment No. 14 provided a detailed interpretation of the right to health and clarifies that it includes socio-economic factors linked to health, as well as 'sexual and reproductive freedom' (Office of the High Commissioner for Human Rights 2000).

South African legal framework

On paper, South African law has met the requirements of domesticating international guidance on human rights, as recommended by the international guidelines, 2012 Recommendations and SWIT. South Africa ratified the ICESCR in 2015. The Bill of Rights in the South African Constitution (1996) outlines a strong legal framework for human rights. All South Africans, including sex workers, are entitled to rights including but not limited to: equality before the law (Section 9), dignity (Section 10), life (Section 11) and freedom and security of the person (Section 12; example: not to be detained without trial). Further, the Constitution states that all South Africans have the right to "choose their trade, occupation and profession." Section 27 of the Constitution guarantees the right to access to healthcare, including the right to access to reproductive health care.

Two laws in South Africa criminalise both the acts of selling sex and buying sex: the Sexual Offenses Act (1957) and the Criminal Law (Sexual Offences and Related Matters) Amendment Act) (2007). Although the rights outlined in the Constitution should apply to all, criminalisation of sex work creates difficulty for sex workers to benefit from these rights. Because of criminalisation, South African sex workers are vulnerable to abuse from clients and employers, with little course for redress due to fear of arrest. Despite the progressive South African Constitution, UN Women and the Open Society Initiative for South Africa have highlighted that criminalisation of sex work 'consistently leads to discrimination' against sex workers (Open Society Initiative for Southern Africa & UN Women 2013). The fight for decriminalisation of sex work in South Africa has been supported by a coalition of civil society organisations called Asijiki, as well as by the Commission on Gender Equality. Criminalisation of sex work directly criminalises sex workers' profession and their means to make a livelihood, violating Article 6 in ICESCR which recognises the right to work and to choose one's work (Peters 2015a; United Nations 1966b). Further, criminalisation contributes to discriminatory policing practices and human rights violations, including but not limited to: the belief by many law enforcement that sex workers cannot be raped, and resulting refusal to assist sex workers who report rape; fear of sex workers to report crimes to the law enforcement due to discrimination; wasted resources on arresting sex workers, often without recording a specific crime; the belief that condoms should be used as 'evidence' against sex workers (Peters 2015c).

The *National Sex Worker HIV Plan* (2016-2019) recommends decriminalisation of sex work. However, in 2017 the South African Law Reform commission (SARLC) released a report that recommended two options for continued criminalisation of sex work. They did not recommend decriminalisation (South African Law Commission, 2017).

Health, human rights and community empowerment

Globally, human rights violations of sex workers, and the association of violations with increased vulnerability to HIV, have been documented, including homicide, physical and sexual violence, and forced HIV voluntary counselling and testing (VCT) (Decker et al 2015). These violations are exacerbated by the criminalisation and stigmatisation of sex work (Decker et al 2015; Wolffers & van Beelen 2003). Research from Africa, including South Africa, reveals the pervasiveness of human rights violations such as gang rapes by law enforcement, brothel owners demanding sex, physical and verbal abuse within romantic partnerships, while also documenting sex workers' resilience (Scorgie et al 2013).

In the 2012 Recommendations, a key recommendation to strengthen the health and human rights of sex workers was sex workers' community empowerment, due to the need for a structural approach to improve health (WHO 2012). Community empowerment is the foundation of the SWIT and is defined as an ownership process by sex workers to individually and collectively improve health and human rights. The SWIT model shows eight elements of community empowerment: (1) working with communities of sex workers; (2)

fostering sex worker-led outreach; (3) developing sex worker collectives; (4) adapting to local needs and contexts; (5) promoting a human-rights framework; (6) strengthening the collective; (7) shaping policy and creating enabling environments; (8) sustaining the movement (WHO 2013). This research brief focuses on element number 5: Promoting a human rights framework.

Study findings on South African sex workers' human rights

Our study explored how health and community empowerment efforts with South African sex workers addressed human rights. We examined human rights violations of sex workers and mechanisms to address these violations, including education, complaints mechanisms, legal support and participation in public advocacy efforts for the general population. We further investigated whether and how community empowerment impacted sex workers' participation in these mechanisms.

Human rights violations of sex workers

Our findings show that human rights violations of sex workers are common in South Africa. In the survey, 1 in 4 sex workers said they had experienced some type of discrimination at their last visit to a healthcare facility. One in nine sex workers felt that they were treated worse than other people due to doing sex work and one in twelve said they had been refused healthcare due to being a sex worker. These results show clear violations of their constitutional right to access to healthcare.

Participants also described discriminatory treatment of sex workers by law enforcement — such as violence or arrests on petty charges—and attributed this, at least in part, to the criminalisation of sex work:

"*Criminalisation of sex work in itself causes many problems…if there's abusive process by law enforcement officials they also sometimes are hesitant to press the matter forward because they're fearful of repercussions of disclosing the fact that they're doing sex work…[The Community Policing Forum] would use almost these draconian and almost horrific violations of human rights, justify those violations by the fact that these people…are criminals… And in [Gauteng town] it was particularly bad because they would set dogs on the sex workers, yes. There's one incident reported where this guy would throw snakes at them.*" (NGO worker, Justice/Advocacy services, Western Cape)

In addition, participants spoke about law enforcement destroying or confiscating condoms as well as medications. If a sex worker was brought to jail for the night, the law enforcement would often not ensure that they had access to their medications. This is particularly problematic for sex workers who had to take chronic medication, for example, antiretroviral therapy against HIV.

Human rights education for sex workers

Due to the number of human rights violations that sex workers are experiencing, it is essential that sex workers have access to education about their rights and how to enforce them. Sisonke used Creative Spaces to provide education and training on human rights, by sex workers, for sex workers. Creative Spaces are gatherings of sex workers (who are not required to be Sisonke members), organised by sex workers themselves.

"When I started to know about Sisonke…I didn't even know about my rights, about the way I'm working in the street, I was just only thinking about like the way I'm making money, and the way I'm being treated by everyone, it's normal, not knowing that it's abuse already, so that's the reason why I'm saying Sisonke helped me." (Quinn, sex worker, Johannesburg focus group)

Focus group participants shared that Creative Spaces were often the first place they learned about human rights, including that sex workers should be treated as people first, the right to access healthcare, why decriminalisation is important and what they can or cannot be arrested for. Several also shared that they did not know that experiencing discrimination due to being a sex worker was a human rights violation, until they learned otherwise at a Creative Space.

Overall, most of the sex workers we spoke with in focus groups knew they had human rights. In general, they did not point back to where their human rights are documented, although one sex worker in the Cape Town focus group did reference the Constitution.

However, not all sex workers knew the extent of their human rights. In one example from the Cape Town focus group, participants explained that they knew of several sex workers who had lost custody of their babies following birth in a government

hospital. While the circumstances of the custody removal were unclear—whether the cause was the sex workers being perceived as 'criminals' to staff or due to other circumstances that might impact child safety—information for sex workers about their rights was lacking. Upon probing, the participants explained how criminalisation prevented sex workers from demanding to know more about their rights. Further, although important, knowledge of human rights is not sufficient, as the sex workers explicitly linked criminalisation to a loss of power or ability to advocate for their rights, even if they were known.

Accountability mechanisms in healthcare

Accountability mechanisms in healthcare play an important role in the protection and fulfilment of constitutional human rights, including the right to health and the right to non-discrimination. In the survey, about one in six sex workers (16%) said that they had previously made an official complaint about services they received at a clinic and four out of five (82%) said they would hypothetically file an official complaint if they were to receive bad service. These findings suggest that accountability mechanisms are one of the main ways that sex workers respond to challenges they face in the health system with bad service or discrimination. Our qualitative research examined two such mechanisms in government healthcare: health committees and complaints management at clinics.

Health committees

Public participation is a key tenet of the South African legal Framework. The National Health Act (2003) stated that each province is responsible for creating legislation to establish committees for clinics/community health centres as governance structures (hereafter: "health committees"). Therefore, the exact structure and duties of health committees differ by province. For example, the KwaZulu-Natal Health Act (2009) outlined health committees' duties as including: oversight of clinic/centre resources; biannual reports on clinic/centre "performance"; and facilitating collaboration between provincial and national stakeholders. Some health committees may consist of paid positions, while others are on a voluntary basis. In general, the health committee membership is meant to be representative and reflective of the communities that the clinic/centre services, though it is unclear if and how this is monitored. Health committees are a primary method of participation in healthcare for South African citizens.

Of the sex workers we surveyed, only one in three (36%) had heard of health committees. Among those who knew about health committees, few had a clear understanding of their role. Interview participants who were aware of health committees described their role as ad hoc and, at times, dysfunctional:

"*These health committees that are supposed to be representing the community, most of them are not even existing, most of them are actually malfunctioning, they are not working at all, some of them they are not being trained they don't know what their roles, their duties and so forth*." *(NGO worker, general population health, Western Cape/national)*

They alluded to the fact that health committees functioned differently depending on who comprised the committee and where they were located. A researcher we interviewed said that previously in the Western Cape some health committees were the main mechanism for complaint management; however, recent legislation in the Western Cape (Western Cape Health Facility Boards and Committees Act 2016) clarified that committees are no longer involved in resolving complaints. Instead, health committees can only link patients to the primary health clinic, whose staff are responsible for addressing the complaint. However, in other provinces, health committees may continue to serve in complaints management. Regardless of their role in complaints management, per provincial policies, health committees remain the main accountability mechanism connecting communities with health services.

No participants were aware of a sex worker being on a health committee. One participant shared that she heard a positive comment from a health committee member in the Western Cape, that sex workers' needs should be considered. However, the participant was not aware of any meaningful engagement with sex workers or other follow-up on this comment.

Complaints management at clinics

In instances of poor service at a health facility, such as experiencing discrimination, it is important that sex workers have the opportunity to file a complaint. When a sex worker attends a healthcare facility they

have the same option as any health service user to provide feedback directly to the clinic rather than going through a health committee. In the survey, sex workers were aware of this option, as half (51%) of those who said they would file an official complaint in the case of bad service said they would do so at the health facility. Like with health committees, options for reporting discriminatory treatment at government clinics were also variable. Participants felt there was little accountability with this system.

"You go to a hospital and experience discrimination…a sex worker is like any other person who is seeking the healthcare services…do you know who to report to, that's the first question, where do you lay grievances to? Who is the right person to talk to? … Is the person going to take you seriously? … because of fear you kind of give up and move to the next clinic and seek health services." (NGO worker, sex worker collective, Western Cape)

In the survey, of those who felt they would not make a complaint, the most common reason given (50%) was that they felt their complaint would not make a difference, showing a perceived lack of accountability at clinics. In interviews, participants elaborated on the reasons for not laying complaints. The most common reasons were unclear systems for reporting; poor follow-up by the facility with the complainant; sex work-related stigma and discrimination; and feelings of disempowerment among sex workers.

Lack of accountability and assistance from public authorities

Considering sex workers' safety beyond the healthcare sector, public authorities such as law enforcement or community policing groups rarely supported sex workers due to stigma. Sex workers' and NGO workers' experiences showed that law enforcement, as well as community policing groups made up of volunteers that patrol their communities for threats to community safety, perceive sex workers as a threat, rather than members of their community to be protected (see also our research brief 6 in our series of research briefs, *The role of community empowerment in reducing sex work-related stigma and improving access to SRHHIV services*).

Legal support for sex workers

We identified two types of legal services for sex workers: programmes designed specifically for sex workers and programmes designed for a broader population but with extensive experience in serving sex workers. The Sex Workers Education and Advocacy Taskforce (SWEAT) Legal Defence Centre (SLDC) is an example of legal services specifically designed for sex workers and was considered a welcome addition to sex worker services by sex workers and NGO workers alike (SWEAT 2017). The SLDC is physically located within SWEAT, an organisation that provides advocacy and services for sex workers in Cape Town. Headed by a lawyer, the SLDC assists sex workers with legal advice and litigation and employs sex workers as peer paralegals. Many of the cases brought to the SLDC are incidents of law enforcement abuse. Other Cape Town-based NGOs were aware of the SLDC and knew to refer sex workers who had experienced legal issues, including human rights violations to the SLDC.

The Women's Legal Centre (WLC), also based in the Western Cape, focuses on legal needs for all women using an intersectional approach, prioritising the most vulnerable communities of women, including black women, transgender women and women with low socioeconomic status. Due to this approach, the WLC chose not to run a sex worker-specific programme but to include sex workers in their general clientele so as not to single them out because of their occupation. The WLC's services include any legal issue with which a sex worker may need assistance, whether related to criminalisation of sex work or access to healthcare. With the addition of the SLDC, the WLC adjusted their services to complement them, and focused more on structural issues such as access to housing for women, while the SLDC focused on "day-to-day" legal issues such as unfair labour practices in brothels.

In the focus group discussions, sex workers referenced the above legal services; although no one shared about using these services personally, they were aware of their existence as a resource. Participants did not describe making use of other types of legal support that could be considered more 'mainstream' such as legal services that do not target a specific group like sex workers. Therefore, current legal support for sex workers appears to be closely linked with sex worker organisations, and in some cases, 'mainstream' organisations that have an existing relationship with sex worker organisations.

(logos)

Public advocacy by sex workers

To demand recognition of human rights, public advocacy can be used. This includes marches, demonstrations or campaigns to address rights violations or in some cases participating in public meetings with political or government bodies.

In general, few NGO participants had awareness about public advocacy by sex workers and few sex workers described participating in public advocacy. One participant shared about a march she participated in "*to be recognised and to be respected…to go to the clinic and get treatment as any human being*" (Ruth, Johannesburg focus group). Another in Johannesburg shared about attending a dialogue with a Member of the Executive Council (MEC) which was where she first learned about advocacy for decriminalisation of sex work. Most participants did not share about participating in these activities. This was surprising, as SWEAT and Sisonke have a long history of public advocacy campaigns.

While some sex workers may not be aware of opportunities for public advocacy, those that are may choose not to participate. Due to criminalisation and stigma around sex work in South Africa, sex workers may fear consequences from speaking publicly about their experiences:

"*If it's something that's going to be held in your community…it would be very difficult for someone to spontaneously decide 'I'm going to come to this public meeting and I'm going to stand there and I'm going to say I'm a sex worker and this is the difficulties that I'm having, this is the abuse that I'm suffering because of the work that I do.' I'm not completely convinced that the [Multi-party Women's] Caucus or Parliament understands the nature of them having to provide a safe space for women to come forward, to be able to participate in such an open public process*." (NGO worker, Justice/Advocacy services, Western Cape)

In this way, stigma and criminalisation are barriers to sex worker participation in public advocacy. Participants did not necessarily feel safe participating in public campaigns, while other participants (such as Ruth, who marched) found empowerment in the process despite the risk of further discrimination or violence when coming out publicly as a sex worker.

Discussion

Participants discussed human rights in almost every interview and focus group about community empowerment and access to healthcare for sex workers. There was a strong awareness that human rights are the driving reason behind campaigns to decriminalise sex work.

Overall, participants and documents (such as written policies or programmatic reports) suggested that a human rights framework was a central part of health programmes for sex workers. For example, one of three aims of the *National Sex Worker HIV Plan* (2016-2019) is to "reduce human rights violations experienced by sex workers," with the related aim of creating mechanisms to address human rights violations. However, based on our findings, there were varying degrees of implementation or prioritisation of services addressing human rights, and few such programmes explicitly catered to sex workers. While dedicated legal support and education on human rights under the South African Constitution reached sex workers, our research suggests that human rights violations of sex workers persist and remain common. Similar to previous reports from South Africa by Asijiki (Peters 2015a; Peters 2015c), we documented ongoing human rights violations among sex workers including discrimination in government health facilities and violence and medication/condom confiscation by law enforcement. These violations persist within the context of sex work criminalisation in South Africa, which limited sex workers' abilities to advocate for their rights due to fear of arrest, violence or discrimination.

We also identified that accountability' mechanisms for healthcare participation among the general population, such as health committees or complaints management at clinics, remain inaccessible for sex workers. Indeed, our findings suggest that this is in part due to poor management of these mechanisms, which impact not only sex workers but all South Africans. However, sex workers and NGO workers also highlighted how discrimination, criminalisation and stigma further create barriers for sex worker participation, despite community empowerment efforts. Past research has documented criminalisation in particular as a barrier to sex workers accessing health and legal services (Gable et al 2008).

(logos)

The SWIT emphasises that human rights must be at the centre of community empowerment for sex workers (WHO 2013). Other research from Africa suggests that collective action by sex workers, such as friendship and networking between sex workers, is as a key strategy for rights promotion and can, in turn, empower individual sex workers to 'take control of dangerous situations' (Scorgie et al 2013). While we have documented strengthened community empowerment in other areas, our findings suggest that much work is still needed to link community empowerment and rights promotion, particularly due to criminalisation of sex work in South Africa.

Recommendations

Based on the findings of this research brief, we recommend the following:

- **Decriminalisation of sex work**: Decriminalisation is needed for sex workers to realise their human rights and participate in healthcare fully. Government must take responsibility to ensure that sex workers are safe during their public engagements.
- **Continued support for human rights education and legal support for sex workers:** Our findings suggest that human rights education was useful to sex workers. Many sex workers were unaware of their constitutional rights before attending educational sessions. Additionally, NGO workers and sex workers were aware of legal services targeting sex workers and felt these were safe and useful resources. Such programmes should continue to receive funding in order to maintain their work and potentially expand it.
- **Improved efforts to work with law enforcement and healthcare staff to decrease human rights violations:** When surveyed, about a quarter of sex workers said that they experienced a violation to their right to non-discrimination when trying to access healthcare at their last visit. Many sex workers expressed fear of the law enforcement, rather than seeing the law enforcement as a safe source of assistance. This was due to human rights violations by the law enforcement themselves. Urgent measures must be taken to work with law enforcement and healthcare providers to ensure safe and respectful services are available.
- **Inclusion of sex workers in public accountability mechanisms:** We document health committees as one of the main mechanisms for South Africans to be involved in holding the health system accountable. While we identified challenges in the functioning of health committees, they remain an important opportunity for participation in healthcare. It is crucial that sex workers be included in public accountability and not be marginalised in these processes.

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The role of community empowerment in reducing sex work-related stigma and improving access to SRHHIV services

Research brief 6 in a series of 6 from the project *Community empowerment and access to sexual and reproductive health and rights services (including HIV) for sex workers in South Africa;* a study completed in partnership between the GHJRU, Sisonke and the Sex Workers Education and Advocacy Taskforce (SWEAT)

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This brief addresses one of the study's main objectives: to assess and describe levels of sex work-related stigma and discrimination in health facilities, which acts as a barrier to accessing sexual and reproductive health, including HIV, (SRHHIV) services. Stigma and discrimination were widely cited by NGO workers and sex workers in our study as barriers to community empowerment and access to SRHHIV services. Participants also described strategies to reduce stigma, comprising 'project' stigma We completed: 15 interviews with NGO representatives, researchers and policymakers; 3 focus groups with sex workers (n=27); and a paper survey with a convenience sample of 298 sex workers in Gauteng (n=100), Limpopo (n=100) and the Western Cape (n=98), recruited using trained sex worker fieldworkers. Of those surveyed, 81% were cisgender women, 13% were transgender and 6% were cisgender men. We presented preliminary findings to a group of sex workers at a Cape Town Sisonke Creative Space meeting and incorporated their recommendations and feedback on the findings. All names reported in this brief are pseudonyms, to protect participants' privacy.

Stigma and discrimination against sex workers

In this brief, we report on findings related to stigma from our South African study on community empowerment among sex workers and its relationship to SRHHIV access and rights, in line with the Sex Worker Implementation Tool (SWIT). The SWIT was developed to provide international guidance on implementation of SRHHIV programmes for sex workers and defines community empowerment as an ownership process by sex workers to individually and collectively improve health and human rights. Stigma and discrimination are addressed in the SWIT as key human rights challenges for sex workers (WHO 2013).

Evidence from across the globe has identified sex work-related stigma as a common and challenging barrier to healthcare access for sex workers (Ma et al 2017). A recent systematic overview of research in Southern Africa has also documented stigma against sex workers as a barrier to access to sexual and reproductive health (including HIV) (SRHHIV) services (Lancaster et al 2016). For example, in Zimbabwe, negative comments from healthcare providers towards sex workers were cited as a barrier to women's motivation to initiate antiretroviral therapy (ART) for HIV infection (Mtetwa et al 2013). Another study from Tanzania documented that pregnant sex workers attended antenatal care, but mostly chose not to disclose their occupation; they feared they would not be provided services in the same way as others because healthcare staff would assume that they require HIV services more than pregnancy care (Beckham et al 2015).

Stigma has been defined as "an attribute that is deeply discrediting" (Goffman 1968). According to Scrambler & Paoli (2008), sex work-related stigma may be described in three ways: (1) 'enacted' stigma, or discrimination by others against the stigmatised person; (2) 'felt' stigma, which is internalised by the stigmatised person, and can be manifested as a fear of discrimination; and (3) 'project' stigma, in which the stigmatised person responds without internalisation or fear, but with

strategies 'that acknowledge the risks of enacted stigma and deviance whilst trying to avoid the pitfalls of felt stigma' (Scrambler & Paoli 2008).

In this brief, we use these three types of stigma – enacted, felt and project - to describe our findings, as well as to explain how they interacted with community empowerment and access to healthcare among South African sex workers.

Enacted stigma in healthcare

We asked the sex workers we surveyed about discrimination at their last visit to a healthcare facility. One in four participants (25%) reported experiencing some type of discrimination. Examples of this are: 1 in 12 (8%) sex workers said they had been refused healthcare due to being a sex worker; 11% said they waited longer for care; 13% had been told about religion and morality due to their occupation.

The research showed that sex work-related stigma contributes to negative attitudes and stereotyping among healthcare providers. Approximately, 12% of surveyed participants reported that they had been treated worse by healthcare providers and one in eight (13%) was gossiped about by a health worker due to being a sex worker. Based on the qualitative findings, several participants felt that this is the result of a general community level of stigma, which in turn leads to negative attitudes among healthcare providers who are part of those communities, resulting in discrimination.

An NGO worker whose organisation promotes healthcare participation among the general population gave an example of negative attitudes from a training they conducted with community healthcare workers in the Eastern Cape. These community healthcare workers were part of the larger National Department of Health programme and were not sex worker peer educators (see research brief 3 *Sex worker peer educator-led programmes in South Africa* for more about this distinction). In a values clarification exercise, half of the group in training agreed with the statement that *'a rape of a sex worker is better than a rape of a virgin.'* In this instance, sex workers were seen as less valuable, and less worthy of protection from violence than other types of women, particularly virgin women (note that following the full exercise, the majority of the group did change their mind and understood the importance of sex workers' human rights). The NGO worker went on to explain how negative stereotyping impacted community perceptions of female sex workers in particular:

"There is a confusion of what a sex worker is. So, whoever [woman] goes to a club to drink and to have fun is also the body of a sex worker, right? …so, there is a need of training [community healthcare workers] ...the issue of stigma is not necessarily in them alone, but then also in normal community members." (NGO worker, 'mainstream' health, Western Cape/national)

Sex workers themselves were very aware of enacted stigma in their communities and it was discussed in each of the three provinces. Enacted stigma's impact on access to healthcare was particularly salient in the Western Cape focus group. Sex workers felt that most healthcare staff in government hospitals or clinics perceived sex workers in a negative way, resulting in discrimination.

"*If they know you are a sex worker, they put a stigma on you back and front…You are a carrier, you are spreading disease. Even in church we get a stigma."*

"For instance, in clinics. In clinics they are chasing us away, the sex workers." (Cape Town focus group participants)

In the Cape Town area specifically, about 1 in 6 (18%) sex workers we surveyed said they felt healthcare workers treated them worse than others for being a sex worker.

Throughout interviews and focus groups, NGO workers and sex workers also highlighted how intersectional issues may make sex workers more prone to stigmatisation. Participants raised immigration status, gender, race, socioeconomic status (including whether the participant was homeless) as important intersections that impacted the extent of enacted stigma.

Felt (internalised) stigma

While sex workers mostly spoke about enacted stigma, several NGO workers spoke about the impact of felt stigma on sex workers' use of SRHHIV services. Many NGO workers acknowledged the challenges sex workers experienced with self-worth due to stigma and discrimination, and how this in turn negatively impacted their use of SRHHIV services and safer sex practices. For example, this participant who identified as doing sex work in the past, spoke about the impact of felt stigma on using HIV services.

"First of all, we need to work from a place where we have to instil that trans people and sex workers […] should always operate from a place of self-love...because people do not value themselves, they do not take up HIV testing. They are not really concerned about accessing health care." (NGO worker, advocacy/health, Eastern Cape)

Many felt that poor self-worth, resulting from criminalisation and community stigma, caused sex workers not to seek healthcare, as they would feel they were not worthy of good health, or deserved to be sick or victims of violence.

Project stigma: strategies to cope with and reduce enacted and felt stigma

Project stigma

As explained above, enacted stigma was widely discussed by sex workers in the focus groups. Project stigma encompasses strategies to avoid or resist discrimination or enacted stigma, while preventing felt stigma from evoking fear (Scrambler & Paoli 2008). Although enacted stigma was well known as a barrier to SRHHIV services, particularly in some government clinics and with law enforcement, many sex workers persisted in accessing services.

Resilience within sex worker communities was apparent, suggesting an important link between community empowerment and felt stigma. Resistance to internalised (felt) stigma has been previously theorised as the 'power within' (Karnataka Health Promotion Trust 2012). While sex workers can internalise (felt stigma) societal beliefs based on negative stereotypes of sex workers (enacted stigma), the 'power within' leads to agency and taking action to challenge power imbalances in society. However, 'power within' is not sufficient to achieve this goal, requiring that community empowerment, in addition to individual empowerment, be developed ('power with') (Karnataka Health Promotion Trust 2012).

We now describe examples of project stigma, or strategies for coping with and reducing enacted felt stigma, that we identified in our research.

Social mobilisation of sex workers

In the Cape Town focus group, sex workers described the complexities of trying to achieve community (and individual) empowerment in the context of sex work being criminalised. They described how constant discrimination and violence, resulting from criminalisation, pushed them to develop 'power within' and 'power with', and join together as sex workers to fight for their rights:

"To raise our voice by joining Sisonke. We are sick and tired of harassment by the police, by the community, by our family members.

[ALL: yes]

They don't treat us like human beings. They treat us like dogs. Like we are not human, but we are the human." (Participants, Cape Town focus group)

Indeed, engagement with sex worker organisations ('power with') appeared to be positively associated with decreased felt stigma ('power within'): sex workers were more likely to feel proud of being a sex worker if they had been to an event at a sex worker organisation in the last 12 months (89% who attended an event were proud, as compared to 58% who did not attend an event).

In interviews, participants agreed that community engaged programming contributed to project stigma.

"*If you find somebody who has more activist knowledge, that has been exposed to human rights programming, health programming, would have a better capacity at getting healthcare that is free and fair, that is without discrimination, that is without prejudice, because they are able to stand up for themselves and they are able to advocate for themselves within that space."* (*NGO worker, advocacy/health, Eastern Cape*)

Inclusion of sex workers in broader activist spaces

One NGO worker explained that it is important to include sex workers within broader activist spaces, which may focus on general population issues or 'women's issues', to combat both enacted and felt stigma.

"*The idea of sex workers being included into a space where people didn't necessarily feel comfortable having them…because of the stigma attached to being a sex worker. One of the things that we tried to do, was to say, 'This is a meeting that is about access to land and housing, so you all have the same problem, you're all having the problem around accessing housing as Black women' and that's the issue that we should be focussing on." (NGO worker, advocacy/justice services, Western Cape)*

She went on to explain that in addition to creating inclusive activist spaces, there would be times that highlighting sex workers' specific vulnerabilities would be appropriate and important:

"It's about being inclusive but trying to maintain a uniqueness of the individual person."

Training for generalised service providers about how to work with sex workers

In both the survey and qualitative data, negative attitudes of healthcare providers and resulting discrimination in health facilities were a barrier to healthcare. Several sex workers in the focus groups recommended sensitisation training for healthcare workers in response to this:

"*I feel comfortable in our [NGO] clinic…and I would like to feel comfortable too in the government clinic. I think they must be taught and know about sex workers, so that I can be comfortable if I'm going to the government clinic, so they know, this is sex workers, let's treat her or him like other people in the community."* (Mpho, Johannesburg focus group)

While specialised clinics for sex workers were appreciated by participants, the need to use government healthcare remains, due to NGO clinics being unable to provide comprehensive health services. Further, maintaining specialised clinics may not be feasible in the long term due to funding constraints. Many participants called for training government health workers to reduce enacted stigma in clinics. Most participants agreed that basic sensitisation training affirming the humanity and lived realities of sex workers would be most necessary. Others also highlighted the need for including intersecting issues such as gender-affirming healthcare, serving clients who are migrants and providing assistance to those with housing insecurity. Involving sex workers in the production and implementation of such training may be one way to develop project stigma. A participant from the National Department of Health shared that an 'integrated training manual for key populations' (which include sex workers) was in development to be implemented for training healthcare workers nationally in future.

However, one NGO worker challenged the assumption that training healthcare providers would result in effective attitude changes, and highlighted the need for effective accountability mechanisms):

"The major thing for me when it comes to key populations and access to service, it is accountability. Because when you went and studied nursing you were trained to become a nurse. You were not trained to become a nurse for Christians, or a nurse for heterosexual people, or a nurse for people whom you think is 'normal,' right? So, for me when you talk sensitisation, how in God's name do you train a person how to treat another person?" (NGO worker, advocacy/health, Eastern Cape)

While healthcare provider training was broadly called for by participants, this NGO worker makes the point that training healthcare providers without broader community level change and mechanisms for accountability would likely be insufficient or unsustainable. We discuss accountability mechanisms in more detail in research brief 4 in this series, *Promoting health and human rights for sex workers in South Africa*.

Stigma and criminalisation

Sex work is both stigmatised and criminalised in South Africa. It is difficult to disentangle stigma from the criminalisation of sex work and determine whether one causes the other; it seems that stigma (partially) allows for sex work to remain criminalised, while the colonial roots of criminalisation were likely driven by stigma of sex work.

In our study, some participants shared examples of how criminalisation facilitated discrimination ('enacted' stigma) when sex workers interacted with law enforcement and healthcare providers. Many sex workers shared their concerns about interacting with law enforcement in particular. When asked about law enforcement treatment, only 1% of the sex workers we surveyed felt that sex workers were treated *as* fairly as everyone else, and 72% felt sex workers were *never* treated as fairly.

Despite the strides towards improved community empowerment by many NGOs, sex workers still felt limited in their ability to participate, be vocal and feel a part of their broader communities due to the criminalisation of their profession and resulting stigmatisation. As a result, sex workers were often afraid to advocate for themselves and their needs when accessing healthcare or facing challenges with the law enforcement. For example, a representative from a sex worker collective explained that he felt that decriminalisation would eliminate stigma from interactions with healthcare providers:

"*Decriminalisation of sex work is going to help sex workers to receive health services without experiencing stigma or discrimination in the health sector. It's going to take away that stigma and sex workers are going to be treated as any other citizen who is seeking health services…decriminalisation is the only way out… so that people can accept the sex work community to access those services*." (NGO worker, sex worker collective, Western Cape)

This made criminalisation a barrier to project stigma, or sex workers' ability to resist the effects of enacted and felt stigma.

Criminalisation kept some sex workers from using health and justice services that were available to their broader communities:

"*As long as it is criminalised, sex workers are still going to work underground and it's going to be a very difficult thing for sex workers adhere to…medication because they are scared to go to the clinics…people are scared to go to the police station to say okay, I've been raped, I want to report a case, but when it's decriminalised, sex workers can go to the police station and open cases." (Natasha, Johannesburg focus group)*

In this way, criminalisation directly contributed to both enacted and felt stigma: some healthcare workers discriminate against sex workers due to stigma and, as a result, sex workers do not wish to use health services. Criminalisation therefore separated sex workers from institutions meant to assist all community members. As the above participant put it, criminalisation drove sex workers 'underground.'

Discussion

Our study documented enacted and felt stigma as barriers to accessing SRHHIV services for sex workers. Enacted stigma was particularly challenging in government health services, where many sex workers felt that discrimination from healthcare providers was a common problem. This concern was recently also reported by other research from the South African provinces of the North West and Free State, which documented that internalised stigma as well as discrimination from healthcare workers made sex workers and other 'key population' groups fearful and reluctant to access HIV care (Duby et al 2018)

We also examined project stigma, or instances of sex workers showing resilience and resistance despite enacted and felt stigma. Importantly, we found that community empowerment in itself was an example of project stigma, as social cohesion and engagement with sex worker organisations seemed associated with decreased felt stigma among sex workers. Community empowerment for ending stigma has also been promoted in the SWIT and recommended by researchers as a strategy for ending sex work-related stigma (WHO 2013). A recent academic review of sex work-related stigma reduction found that sex worker activism can help decrease stigma, and that this is especially effective when they have sufficient resources and support from other sex workers and alliances from outside organisations (Weitzer 2017).

In addition to empowerment within the sex worker community, participants called for increased integration of sex workers within their broader communities, as well as additional sensitisation of healthcare providers. However, these interventions will only be effective if broader interventions to reduce stigma attached to sex work throughout South African communities are also implemented. Although there is little research available about the effectiveness of community level destigmatisation campaigns, one study from India about the Ashodaya project showed that acceptance of sex workers by the general community led to protection from violence. The authors recommended that programming for sex workers should not focus only on sex worker 'hotspots;' rather, integrating sex worker programmes with broader community structures would be more effective in reducing violence, sex worker marginalisation and HIV (Reza-Paul et al 2012). Other research has examined interventions to reduce HIV-related stigma at the broader community level. For example, a Thai action research project found that a community level intervention – which included integration with spiritual activities and training of youth volunteers to conduct web research on HIV, produce educational materials about HIV and create a special corner in their library with HIV resources – was significantly effective in reducing stigma and increasing knowledge about HIV (Apinundecha et al 2007). Drawing on this, facilitation of communication and education between sex workers and community members who are not sex workers could be an effective way of creating stigma reduction interventions in South Africa and other settings.

The majority of participants in our research recommended increased sensitisation training for SRHHIV providers working in government healthcare. A recent pilot of a 'low cost, integrated model for sex work programming' by the Sex Workers Education and Advocacy Taskforce (SWEAT) found that even a one-day sensitisation training of providers can be useful in reducing negative attitudes towards sex workers (SWEAT 2018). However, the report also recommended that training for providers be expanded beyond one day if possible.

Although we found several examples of project stigma, criminalisation of sex work facilitated enacted stigma and disrupted access to healthcare and justice services. Criminalisation also caused stigma by driving sex workers 'underground' and by reinforcing negative attitudes towards sex workers. Decriminalisation has been identified as the best legal model for reducing sex work-related stigma, as any type of regulation of sex work rests on stigma-based assumptions about morality and disease (Bruckert & Hannem 2013).

Lastly, we note that sex work-related stigma does not exist in a vacuum outside of other stigmatised identities. Our participants raised important issues such as stigma against sex workers due to being homeless and/or of a low socioeconomic status, transgender, a migrant or a person of colour. In addition to these intersections, other researchers have pointed to sex work type (for example, web-based, street-based, strippers) as important an important consideration when developing se work-related stigma reduction interventions (Sanders 2017).

Recommendations

Based on our findings related to stigma, community empowerment and access to SRHHIV services, we recommend the following:

- Decriminalisation of sex work:

The relationship between criminalisation and stigmatisation of sex work is complex. While decriminalisation will likely not be sufficient in ending sex work stigma, the current law is a contributor to both enacted and felt stigma and, as a result, creates barriers to SRHHIV service use.

- Pre-service and in-service sensitisation training of clinical and non-clinical healthcare providers:

While some sex workers described positive experiences at government clinics, many explained that they experience discrimination regularly. We also found that enacted stigma existed among non-clinical healthcare providers, such as community healthcare workers. In order to effectively reduce enacted stigma in healthcare, change in healthcare providers' perceptions of sex workers is needed. We recommend sex work sensitisation training for healthcare providers, including intersecting issues such as gender-affirming care and serving people who are homeless or have housing insecurity. In order to maximise the impact of sensitisation training on caring for sex workers, we recommend both pre-service (such as in nursing and medical schools) and in-service trainings for healthcare providers already in the field.

- Continued efforts to reduce enacted stigma at the general community level:

Focused training for healthcare providers is necessary, but likely insufficient to reduce stigma without also striving for broader community-level change. Interventions should be developed in partnership with broader communities and also address intersecting stigmas related to socioeconomic status, gender identity, race and immigration status.

- Evaluate interventions to reduce sex work-related stigma:

As a quarter of sex workers in our survey reported experiencing sex work-related discrimination at their last visit to a health facility. We recommend that future research examine interventions to reduce sex work-related stigma among healthcare providers, police and/or the broader community.

- Increased psychosocial support for sex workers:

In order to reduce felt stigma, psychosocial support for sex workers should be scaled up and affirm sex workers' autonomy and rights.

- On-going support for social mobilisation of sex workers:

Our study and past research suggests that social mobilisation and community empowerment of sex workers is an essential part of project stigma, or strategies to cope with enacted and felt stigma. Sex workers must be meaningfully involved in programming and policy decisions, and also be supported in their own organising efforts and collective formations. This generates resilience necessary to protect their health and safety even while enacted stigma exists.

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6 Conclusion

Community empowerment is a process. Our series of research brief highlights numerous success stories of community empowerment of sex workers in South Africa, as well as ongoing barriers to empowerment. In this conclusion, we summarise the most notable instances of each, and reflect on how these findings contribute to existing literature about community empowerment among sex workers.

Success stories of community empowerment

Extensive peer educator-led outreach

Sex worker peer educator programmes were one of the most widely cited examples of community empowerment in our study. We documented that sex worker peer educator programmes are implemented throughout South Africa and that sex workers view and use peer educators as an important resource for accessing health services and information. Peer educators also impacted on sex workers' SRHHIV: in this project's survey, sex workers who had received health information from an outreach worker were more likely to know their HIV status and to have accessed healthcare in the past year.

It is important to note the distinction between sex worker-led programmes and sex worker peer educator-led programmes. The *National Sex Worker HIV Plan 2016-2019* calls for a peer educator-led approach (SANAC 2016), which we have documented as successful in this report. However, meaningful participation of sex workers must involve sex workers at various levels and not pigeonhole sex workers as peer educators only. Our findings include some examples of sex workers working in different roles, such as being a board member of an NGO and being promoted within peer education programmes to positions that have increased responsibility *(see the brief Do sex workers meaningfully participate in SRHHIV services?)*.

Existence of sex worker collectives

Sisonke is a national sex worker collective, meaning that their organisation and all of their activities are completely run and led by sex workers. The existence of Sisonke as a well-coordinated organisation that has been successful in securing funding for their activities is a positive example of community empowerment of sex workers in South Africa. Further, every Sisonke member in this project's survey had accessed healthcare at least once in the previous year, suggesting that collective membership may also be associated with access to healthcare.

We also identified a small, Cape Town-based collective called Mothers for the Future (M4F), focusing on the needs of sex workers who are also parents. Although M4F is housed within the Sex Workers Education and Advocacy Taskforce (SWEAT), the initiative was driven by a sex worker who now runs M4F as a support group (Aron 2017). This is an example of how community empowerment is a process and can change over time based on sex workers' needs. M4F shows how an individual sex worker was able to mobilise others to develop a small collective based on their specific experiences as parents, which speaks to the diversity within the sex worker community. Overtime, new collectives may emerge as additional needs are identified.

Although the majority of survey respondents were not Sisonke members, many sex workers said they participated in social mobilisation activities such as Creative Spaces and engaging with outreach workers. Our findings suggest there is a link between social mobilisation and feeling pride in being a sex worker. This suggests that social mobilisation activities may be important for decreasing felt stigma, which participants described as a barrier to healthcare access.

Dedicated legal services and human rights education for sex workers

The Sex Workers Education and Advocacy Taskforce (SWEAT) Legal Defence Centre (SLDC) is an example of a successful programme for and by sex workers. Sex workers have been trained to provide paralegal services and a lawyer is employed by and physically located at SWEAT so that sex workers can easily access her. Our findings document that human rights education is currently prominent in sex worker-led outreach and that this education is having a positive impact on sex workers knowing their rights in South Africa.

Recognition of sex workers in national policy

Over the years, sex worker activists have worked to ensure that sex workers are recognised in South African policy. In the past, it has been challenging to have sex workers and their rights being recognised in national policy documents, most visible in the removal of a recommendation for the decriminalisation of sex work in the past *National Strategic Plan on HIV, STIs and TB 2012–2016*.

The development and implementation of the *National Sex Worker HIV Plan 2016-2019* is the result of sex worker advocacy. While sex workers in many other countries struggle to be recognised by their national governments (Global Network of Sex Work Projects 2017), the *National Sex Worker HIV Plan* recognises sex workers, emphasises the need to protect sex workers' human rights and promotes participation of sex workers in community empowered practices such as a national peer educator programme. Further, a Sisonke member served as a co-chair of the working group developing the policy document in the South African National AIDS Council, an intersectoral working group within the Department of Health. This demonstrates how advocacy by sex workers has been successful in creating government buy-in for the community empowerment of sex workers and their meaningful participation in policy and programming.

Barriers to community empowerment

Sex work-related stigma and healthcare providers' attitudes

This project identified sex work-related stigma as a major challenge for sex workers. A common form of enacted stigma is discrimination by healthcare providers, which remains common: a quarter of sex workers we surveyed experienced some type of discrimination at their last visit to a healthcare facility. As a result, sex workers also experienced felt stigma, which some participants felt negatively impacted their access to healthcare.

Criminalisation of sex work and policing practices

The criminalisation of sex work remains a major challenge as, despite ongoing advocacy by sex workers and others for decriminalisation, the South African Law Reform Commission (SALRC) did not recommend decriminalisation in its most recent 2017 report. As others have also documented (WHO 2013; Government of New Zealand 2008; Gable et al 2008), participants in this project widely called for decriminalisation of sex work in order to improve community empowerment and access to healthcare. This project showed how criminalisation of sex work is linked to stigma and can prevent sex workers from fully participating in healthcare. Further, we documented that poor law enforcement practices linked to criminalisation that have also been documented in previous research (Shields 2012; Peters 2015a; Peters 2015b), such as the confiscation of condoms and destruction of medication by law enforcement, persist.

Need for transparency and *meaningful* participation at the government level

Despite the success of the *National Sex Worker HIV Plan*, challenges for meaningful engagements between not only sex workers, but all civil society, and national government remain. Notably, accessibility and transparency remain an issue, because draft policy documents are often only produced in English and feedback is rarely

provided to civil society to explain how policymakers engaged with their input. Government has a responsibility to ensure that community empowerment of sex workers in policymaking is fully realised and supported.

Contribution to the literature

There have been numerous previous studies examining the healthcare experiences of South African sex workers, which have mainly focused on HIV/AIDS and/or human rights violations (Karim et al 1995; Richter 2008; Shields 2012; Peters 2015a; Peters 2015b). In this piece of research, the project team examined both human rights violations and HIV/AIDS, as well as broader sexual and reproductive health and rights issues. This project adds to the existing body of literature by using a community empowerment framework, specifically informed by the eight elements in the SWIT. Some previous work has also explored community empowerment among South African sex workers, such as the documentation of advocacy for sex worker inclusion and decriminalisation of sex work in the National Strategic Plans for HIV/AIDS and STIs by Richter and Chakuvinga (2012). By drawing on the SWIT (WHO 2013), we expand the understanding of sex worker community empowerment in the South African context by:

- Looking in depth at the extent to which meaningful participation of sex workers has been achieved;
- Sex worker-led programming, using the peer educator programmes as an example;
- Examining Sisonke as an effective national sex worker collective;
- Human rights education and services for sex workers;
- Sex work-related stigma and its impact on access to SRHHIV services; and
- The relationship between community empowerment and access to SRHHIV services.

Looking at each of these elements as a whole paints a broad picture of sex worker community empowerment in South Africa and highlights its ongoing importance for access to healthcare.

Our findings document an apparent shift towards an institutionalisation of sex worker advocacy into national government policies and programmes. The development of the current *National Sex Worker HIV Plan* shows commitment at the national level to improving access to SRHHIV services for sex workers, including methods that promote community empowerment such as strengthening collectives such as Sisonke and supporting a strong sex worker peer educator programme. Yet barriers to community empowerment of sex workers remain, including challenges with transparency at the national level of government. The current *National Sex Worker HIV Plan* is explicit in assigning responsibility to various stakeholders, including the Department of Health, the Department of Social Development, the SANAC Secretariat, NGOs and sex worker peer educators. Over time, it will be important to re-evaluate the role of sex workers in national policy and programming to ensure that sex workers continue to be meaningfully involved. While partnership with government is likely necessary in the South African context due to limited resources, vigilance will be required to (1) ensure ongoing prioritisation of SRHHIV services for sex workers and (2) expanded inclusion of sex workers in programming and policy development as these services expand.

For example, the future of sex worker peer educator programmes could be tenuous, in light of national plans to implement generalised ward-based primary healthcare outreach teams (WBPHCOTs), which may indicate a shift away from targeting specific population groups. It is unclear at this stage whether and how the community healthcare workers on the WBPHCOTs would be trained to work with sex workers, and whether sex worker peer educator programmes would be integrated with other existing community healthcare worker programmes. One government representative who was interviewed in this study stated that government was planning to employ specific sex worker peer educators, although this has not yet been written into policy. Government employment of sex worker peer educators would also signify another shift towards institutionalisation of sex worker community empowerment. In the context of resource-constrained South Africa, this institutionalisation could be the best way forward to ensure sustainability of sex worker (peer educator)-led programming. However, coordination by government—particularly while sex work remains criminalised—could hinder the goals of community empowerment, if government were to wield more decision-making power in policies and programmes that impact sex workers. In light of this, continued efforts to strengthen sex worker collectives and inclusion of sex workers in other roles in addition to peer educators are needed. Based on our findings, the model of community

empowerment laid out in the SWIT is useful in the South African context. Paired with the voices of South African sex workers, the SWIT can offer continued guidance to government and NGOs alike.

7 Recommendations

Based on the findings presented in the briefs making up this report, we summarise the following recommendations:

Recommendations for government and policy makers

- **Improve the ways in which civil society, including sex workers, can participate in policy-making:** There were some examples of sex worker involvement in policy, however, many sex workers we spoke with did not feel they were involved themselves, suggesting there may be more engagement and communication needed between government and NGOs. Lines of communication between national, provincial, district and sub-district levels of government should be improved, to ensure that sex workers can provide meaningful input to policy at all levels. Further, government should provide policy documents for review in all South African languages and work with civil society to ensure they receive enough time to meaningfully input. Use of their input should also be reported on in a transparent manner.
- **Decriminalise sex work**: Decriminalisation is needed for sex workers to realise their human rights and participate in healthcare fully. Government must take responsibility to ensure that sex workers are safe during the public policy engagements. Further, there is a cyclical relationship between criminalisation of sex worker and sex work-related stigma. While decriminalisation will likely not be sufficient in ending sex work stigma, the current law is a contributor to both enacted and felt stigma and, as a result, creates barriers to SRHHIV service use.
- **Provide pre-service and in-service sensitisation training for clinical and non-clinical healthcare providers**: While some sex workers described positive experiences at government clinics, many explained that they experience discrimination regularly. As a quarter of sex workers in our survey reported experiencing sex work-related discrimination at their last visit to a health facility, we urge health facilities to implement sensitisation training and monitoring of sex workers' experiences. In order to effectively reduce enacted stigma in healthcare, change in healthcare providers' perceptions of sex workers is needed. We recommend sex work sensitisation training for healthcare providers, including intersecting issues such as gender-affirming care, serving people who are homeless or have housing insecurity and access to healthcare for migrant sex workers. In order to maximise the impact of sensitisation training on caring for sex workers, we recommend both pre-service (such as in nursing and medical schools) and in-service trainings for healthcare providers already in the field.
- **Continued efforts for economic empowerment for South African sex workers:** Efforts must continue to promote economic empowerment among South African sex workers. Our research documented socioeconomic status as a challenge for some sex workers to access healthcare and meaningfully participate in policy and programme development.
- **Improve efforts to work with law enforcement to decrease human rights violations:** In our focus groups, many sex workers expressed fear of the police, rather than seeing the police as a safe source of assistance. This was due to human rights violations by the police themselves, including destruction of sex workers' medication. Urgent measures must be taken to work with police to ensure safe and respectful services are available.
- **Develop specific, measurable targets for sex worker collective strengthening:** While the current (2016-2019) *National Sex Worker HIV Plan* includes collective strengthening as an objective of the Plan, it does not outline specific targets that support measurement of these efforts. We recommend that the next *National Sex Worker HIV Plan* contain concrete ways of evaluating support for collectives, in order to ensure adequate support is provided.
- **Expand the availability of comprehensive SRHHIV health services for sex workers, including gender affirming care:** Participants explained that geographical location and hours of provision were barriers for some sex workers in accessing SRHHIV healthcare. We recommend that piloting of the expanded service provision at sex workers' places of work by Slabbert and colleagues (2017) be done in other South African settings in order to identify the best ways to expand service delivery to sex workers. Additionally, we recommend that government prioritise ensuring availability of HIV-related services (including addressing stock outs), abortion services and gender affirming care.

Recommendations for civil society organisations

- **Increase the meaningful participation of sex workers in SRHHIV programme design:** our findings documented two main ways in which sex workers were involved in health programming: peer educator programmes and needs-based programming. However, sex workers themselves did not seem to be aware of the needs-based programming as a method of involvement, suggesting that this should be more thoroughly explored and made explicit between sex workers and NGOs.
- **Expand human rights education and legal support for sex workers:** Our findings suggest that human rights education was useful to sex workers. Many sex workers were unaware of their constitutional rights before attending educational sessions. Additionally, NGO workers and sex workers were aware of legal services targeting sex workers and felt these were safe and useful resources. Such programmes should continue to receive funding in order to maintain their work and potentially expand it.
- **Support sex worker collective strengthening:** Our findings demonstrate the importance of collectives, as outlined in the SWIT, in building community empowerment among sex workers. Collectives ensure that sex workers build their social communities, provide opportunities for leadership and learning and create a safe space for sex workers to address their needs. Continued support should be provided to collectives, while also respecting the collectives' autonomy.
- **Continue the implementation of peer outreach programmes:** We found that outreach by sex worker organisations is positively associated with increased knowledge of HIV status and use of healthcare. Although it is beyond the scope of this study to determine causality, this finding suggests that peer outreach programmes are linked to better access to healthcare. Additionally, sex worker-led programmes are considered good practice for SRHHIV services according to the SWIT as well as the qualitative input of our participants. We recommend these programmes receive continued support in South Africa.
- **Expand the availability of comprehensive SRHHIV health services for sex workers:** Due to challenges with physically accessing healthcare, we recommend piloting of expanded service provision at sex workers' places of work (see Slabbert et al 2017) continue in order to identify the best ways to expand service delivery to sex workers in different South African settings. NGOs should also build relationship with local government clinics in order to facilitate sex workers' access to healthcare for services that NGOs are not equipped to provide.

Recommendations for SRHHIV funders

- **Increase the meaningful participation of sex workers in SRHHIV project design:** In our study, our project team included representatives from two sex worker organisations throughout implementation. We recommend that funders promote this approach and also include sex workers' input during the proposal development stage, to ensure that projects meet the needs of sex workers in objective and design.
- **Support the decriminalisation of sex work**: While projects related to sex workers may not focus on legal reform specifically, we recognise the power that funders have in determining local SRHHIV programming. We strongly recommend that funders support South African sex workers' advocacy efforts for the decriminalisation of sex work. In particular, funder requirements should be consistent with the South African constitutional framework, and not create barriers to decriminalisation advocacy, nor impose other ideology related to sex work.
- **Support sex worker collective strengthening:** Our findings demonstrate the importance of collectives, as outlined in the SWIT, in building community empowerment among sex workers. Collectives ensure that sex workers build their social communities, provide opportunities for leadership and learning and create a safe space for sex workers to address their needs. Continued support should be provided to collectives, while also respecting the collectives' autonomy.
- **Continue efforts for economic empowerment for South African sex workers:** Efforts must continue to promote economic empowerment among South African sex workers. Funders should also be aware of the economic reality in South Africa, in that sex workers will likely require reimbursements in order to participate in SRHHIV programming. We recommend that funders work with sex worker organisations to understand the amount of reimbursement required for programmes they fund.
- **Utilise a human rights approach:** Funders focused on SRHHIV services should acknowledge the impact of human rights violations on access to these services. For example, sex workers should have access to

education informing them of their rights should they encounter discriminatory treatment from healthcare providers and police.

- **Increase psychosocial support for sex workers:** In order to reduce felt stigma, psychosocial support for sex workers should be scaled up and affirm sex workers' autonomy and rights. We recommend psychosocial support be promoted and funded alongside SRHHIV services.
- **Prioritise interventions to reduce sex work-related discrimination**: As a quarter of sex workers in our survey reported experiencing sex work-related discrimination at their last visit to a health facility. Reduction of stigma and discrimination against sex workers should be prioritised as an intervention to improve sex workers' sexual and reproductive health and well-being.
- **Continue support for peer outreach programmes:** We found that outreach by sex worker organisations is positively associated with increased knowledge of HIV status and use of healthcare. Although it is beyond the scope of this study to determine causality, this finding suggests that peer outreach programmes are linked to better access to healthcare. Additionally, sex worker-led programmes are considered good practice for SRHHIV services according to the SWIT as well as the qualitative input of our participants. We recommend these programmes receive continued support in South Africa.
- **Expand availability of comprehensive SRHHIV health services for sex workers:** We recommend that funders support comprehensive SRHHIV services for sex workers, which include abortion services and gender affirming care. Funders should not stipulate which services are included under the SRHHIV umbrella but work with sex worker organisations and collectives to ensure provision of priority services. In our study, sex workers identified gaps in abortion service provision and gender-affirming care, suggesting that these areas need increased support from funders.

Recommendations for academics and researchers

- **Increase the meaningful participation of sex workers in SRHHIV research design:** In our study, our project team included representatives from two sex worker organisations throughout implementation. We recommend that funders promote this approach and also include sex workers' input during the proposal development stage, to ensure that projects meet the needs of sex workers in objective and design. Further, incorporating sex workers' knowledge and experience should be treated as an important aspect of evidence-based research with sex workers.
- **Include community empowerment measures in research related to sex workers and SRHHIV**: Both the SWIT and our findings suggest that community empowerment of sex workers is an important element in understanding access to SRHHIV services. We recommend that future research with sex workers on the topic of SRHHIV also consider measuring community empowerment as appropriate. Research focused on which aspects of community empowerment are most effective and impactful may be the most useful.
- **Evaluate interventions to reduce sex work-related stigma**: As a quarter of sex workers in our survey reported experiencing sex work-related discrimination at their last visit to a health facility. We recommend that future research examine interventions to reduce sex work-related stigma among healthcare providers, police and/or the broader community.
- **Monitor community empowerment of South African sex workers over time**: In the conclusion of this report, we consider whether government involvement with sex workers may be shifting towards an institutionalisation of community empowerment. While this may be the most sustainable way forward, it has the potential to reduce sex workers' power and influence on policy and programming. We recommend that community empowerment processes among sex workers continue to be documented and monitored, with an understanding of how these processes and their impacts change over time. A particular focus on case studies of sex worker collectives in South Africa and elsewhere could be a powerful addition to the literature, as we found little data assessing collective specifically.

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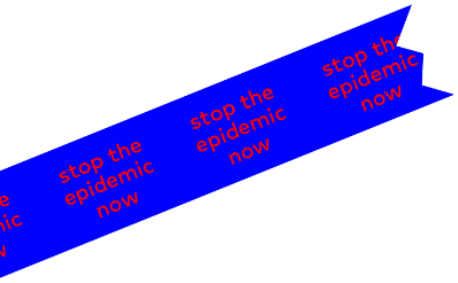
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