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STIGMA Foundation

Empowering Drug Users to Prevent HIV in Indonesia

Kai Spratt

A stone in the front yard of the STIGMA office.

The taxi twists and turns its way through progressively narrowing streets and alleys in South Jakarta. It finally arrives—after several stops to ask directions and a couple of wrong turns—in front a six-foot high, unmarked, solid metal green gate. From the outside, it looks just like any other residential compound in the lower middle class neighborhood where houses, laundries, beauty salons, small restaurants, and kiosks selling sundries and cell phones take up every square inch of space along the street. Beyond the anonymous gate lies a small garden where, among the grass and a few flowers, there is a large brown stone painted in bright yellow with the words "STIGMA Garden." Inside the compound is a small one-story yellow house; a bulletin board nailed onto one of the compound walls displays posters on the rights of people who inject drugs (PWID)—basic human rights and the right to HIV prevention services. Shoes, sandals, and flip-flops are lined up neatly at the front door, and from within, rock music beckons visitors.

Welcome to the STIGMA Foundation (SF). This nongovernmental organization (NGO), staffed by former injecting drug users and people living with HIV (PLHIV), focuses on helping PWID—both men and women—live safer, healthier, more productive lives through community organizing, advocacy, and networking. The foundation's staff and volunteer educators visit neighborhoods where male and female PWID congregate to offer information on preventing HIV and a needle and syringe exchange service, and to provide referrals for health care. STIGMA also works with local police and health care workers, and consults with government organizations, to ensure that PWID receive adequate services, participate in decisions that affect them, and are accorded their basic human rights.

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PEPFAR GENDER STRATEGIES ADDRESSED BY THE STIGMA FOUNDATION

- Increasing gender equity in HIV programs and services
- Reducing violence and coercion
- Increasing legal protection.

Background

While the overall national prevalence among adults 15 to 49 years of age remains quite low at 0.2 percent, the prevalence of HIV among most-at-risk populations, such as PWID, sex workers, transgender persons (*waria*), and men who have sex with men are disturbingly high (Joint U.N. Programme on HIV/AIDS [UNAIDS] 2009b). Of the estimated 333,200 PLHIV in Indonesia, 42.2 percent are PWID (Needle and Zhao 2010). According to a 2010 unpublished report by AusAID, HIV prevalence in Indonesia among all PWID (male and female) is 40 percent and 20 percent among female sex workers in Bali (Block 2010). One factor contributing to the high HIV prevalence among these vulnerable populations is inconsistent condom use among male PWID, especially with sex workers and with long-term partners. Because PWID often have multiple paid and unpaid sex partners, the potential for HIV transmission to spread rapidly within social and sexual networks of PWID is very high (Iskandar et al. 2010).

Indonesia's national response to HIV has focused on the most-at-risk populations. The government has scaled up programs to reach PWID to address the preponderance of HIV infections in this group. An important, though controversial, element of the national response is the harm reduction approach, which includes access to accurate information; distribution of clean needles, syringes, and male condoms; access to primary health care; and access to voluntary counseling and testing. By the end of 2009, harm reduction programs were available around the country in 120 sites including public health centers, correctional institutions, and NGOs. PWID who use heroin and want methadone maintenance therapy or other oral substation therapies such as buprenorphine alone or in combination with naloxone can receive services in designated health centers, hospitals, and prisons in each province (National AIDS Commission Republic of Indonesia 2009). However, new efforts are needed to include the intimate partners of high-risk individuals as partners represent a growing proportion of newly infected individuals (UNAIDS 2009a).

Gender Norms in Indonesia

The Indonesian Constitution gives equality to all citizens, and legislation protects women's civil liberty and freedom of movement. Local systems of *adat*, or traditional law, dictate gender-specific rights and obligations. In practice, gender norms in Indonesia vary by region,

location (urban or rural), religion, socioeconomic status, and ethnic group, as does the prevalence of early marriage, polygamy, female genital mutilation (though this was banned in 2006), and contract marriages (Jacubowski 2008).

During the Suharto "New Order" era (1965 to 1998) the state played a large role in defining the appropriate roles and responsibilities of men and women of all classes. The main elements of this gender ideology are "housewifization" which promoted women's "natural" roles as wives and mothers. "The *bapak* (father, man) is considered as the elementary source of power, whereas the *ibu* (wife) was one of the mediums of this power" (Jacubowski 2008, 90). A man is expected to be the primary breadwinner, providing financial support for his wife and children and making decisions in the interest of his family's welfare.

Indonesia has no national laws proscribing homosexuality, transgender behavior, or sex acts between adults of the same sex. However, discrimination against sexual minorities is pervasive and some local governments, citing religious doctrine, have instigated local laws (*perdahs*) that punish same-sex sexual relationships and sexual contact between unmarried persons (Blackwood 2007). A few local governments require that all women, Muslim or not, wear a jilbab (a long and loose-fit coat or garment) to receive the services of the village government. There are indications, however, that while piety and religiosity is increasing in Indonesia, a populist movement to formalize these religious laws within the legal system peaked around 2004 and is waning in appeal (Bush 2008).

Recent government investment in infrastructure has increased girls' access to education and women's participation in the political and public spheres, as well as in the economy, albeit in lower-paying and lower-status occupations than men. Tensions between traditional and religious interpretations of the laws, which seek to further restrict women's and men's roles, and the influences of rapid modernization and globalization, especially in the large urban areas, has sparked intense public debate on the role of the state in the areas of sexuality and morality (Blackwood 2007; Rinaldo 2008).

Indonesia's 2004 Domestic Violence Law (Law No. 23/2004) prohibits physical, sexual, or psychological violence and neglect or abandonment within a household occurring among legally married couples but does not protect cohabiting or unmarried couples. Domestic violence, though believed to be fairly common, is considered a private matter, and incidents are rarely reported.

The Policy Environment

Indonesia is a major route for drug trafficking in Asia, and drug use has increased steadily in Indonesia, especially in large urban areas like Jakarta and Bandung, and in West Java and Bali. Policies related to drug use in Indonesia have traditionally been framed as a war on drugs with a "zero tolerance" approach. Drug use is criminalized and in some cases punishable by death. Male and female drug users are subject to harassment by police and to arrest and imprisonment in extremely harsh conditions.

As a country dealing with a dual epidemic—HIV and drug abuse—Indonesian policymakers and program implementers have had to walk a fine line between undermining drug enforcement authorities, who view any support to drug users as criminal and encouraging drug use, and the public health community, which sees harm reduction as a strategy to slow the escalating HIV prevalence among PWID. In 2003, the government instituted the Harm Reduction Strategy, which seeks to

reduce transmission of HIV among PWID, and from PWID to the general public, by providing clean drug injecting equipment and access to health care and HIV testing and counseling. A law passed in 2009 sought to mitigate the risks of drug addiction and HIV by stipulating that identified drug users be sent to rehabilitation centers during the pretrial period, which can last for three to six months; if found guilty, the drug user may be sent to prison or remain in the center for a year or more for further rehabilitation (National AIDS Commission Republic of Indonesia 2009). However, the implementation of the Harm Reduction Strategy remains limited and PWID continue to be arrested and sometimes charged with trafficking; as for the 2009 law, there are no regulations, standards for treatment or care, or support programs for "rehabilitated" PWID when they return to their communities.

Reaching PWID with HIV programs remains a challenge as these individuals fear being arrested if they interact with NGO outreach workers.

Program Description

SF is a community-based organization located in Jakarta whose workers are former drug users and PLHIV. The main goal is to empower male and female drug users through community organizing, advocacy, and networking (Wulandari 2010). The foundation's ultimate vision is to empower drug users through 1) a dependable livelihood, 2) access to harm reduction resources and health services, 3) a critical awareness of human and legal rights for PWID, 4) participation in decision making at the community, district, and higher levels, and 5) providing input and influence on decisions at all government levels that affect PWID. To that end, SF conducts outreach, advocacy, networking, and educational

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Nongovernmental organization and public health staff doing joint work planning. Jakarta, July 2010.

activities, both among PWID and government and nongovernment stakeholders.

SF grew out of a support group for PWID living with or affected by HIV set up in 2001 at the Fatmawati Hospital in Jakarta. Initially, SF developed informational material about HIV and other health issues for use by support group members. In 2004, SF was officially recognized as an NGO and was funded by the Australian Agency for International Development to begin harm reduction activities in South Jakarta. In subsequent years, SF received funding from the Hivos Foundation (the Netherlands) and the U.S.-based Open Society Institute to expand outreach in HIV prevention and harm reduction.

SF began with a staff of six and a small number of member volunteers, working out of a small house that functioned as an office and drop-in center. Beginning in 2005, SF trained outreach workers to visit "hot spots," or places where PWID meet to obtain or use drugs, and provide information about HIV prevention, offer needle and syringe exchange programs (NSPs), and give referrals to

health services. By mid-2010, SF had 22 full-time staff members.

Over time, outreach on legal and human rights of PWID became an increasingly important component of SF's work. PWID endure widespread stigma, discrimination, harassment, and violence from communities, the police, and prison authorities. Most PWID know little about available legal protection or how to address and prevent violence. SF collaborates with the Community Legal Aid Organization in Jakarta, which provides lawyers and staff pro bono to help PWID who have been arrested and detained.

SF's advocacy activities include the following:

- Training and outreach to change community perceptions of PWID as criminals and increase understanding of the injustice that PWID experience

> ***The idea of human rights of drug users is not well accepted by some people in the communities where we work and live because they refuse to admit they have [PWID]. People in the community say "when [PWID] begin to behave in the community, then we can discuss human rights. Right now [we] don't talk about human rights; right now we have to worry about eating tomorrow."***
>
> ***–STIGMA Director***

- Intervention in cases where a person who injects drugs is harassed or harmed
- Routine meetings with health care workers and police staff to resolve instances of stigma, discrimination, or abuse in the clinic and in the community
- Advocacy when a person who injects drugs is arrested. When a person who injects drugs is detained, a network of former PWID contact SF. SF staff then contact the family of the person arrested to find out where the person is being detained and whether he or she is living with HIV and on antiretroviral therapy (ART). If so, SF will advocate with the police to ensure ART is available during the pretrial detention, which can last as long as six months.

Collaboration with government and international agencies: The Indonesian Government has invited SF to participate in consultations, including those on revising the 2009 Narcotics Law, which includes, among other provisions, an option for sentencing PWID to a rehabilitation center. However, SF staff feel that their participation in events with government, international agencies, and other NGOs is often not meaningful. One staff member said, "We are treated like dolls. We have no real control over decision making on issues related to our lives." SF's position is that PWID must demand their rights and demand greater involvement of people living with or affected by HIV. This rights-based approach is not always welcomed by government staff who are not accustomed to working in partnership with marginalized communities, or by other NGOs whose approach to government is less confrontational.

Networking: SF collaborates with other NGOs that provide programs and services for people at risk of exposure to or affected by

HIV. For example, SF works with the Ikatan Perempuan Positif Indonesia (IPPI; National Positive Women's Network) on policy advocacy for women, particularly women living with HIV. IPPI builds leadership skills among women advocates who are living with HIV to push for changes in policies that are detrimental to women. Such laws include the Law on Population, which allows only married women to obtain services for sexual and reproductive health, and the Law on Domestic Violence, which protects married women but not unmarried, cohabiting women. SF also has strong ties to the Community Legal Aid Organization, which provides legal services for arrested and incarcerated PWID. This assistance, which begins following arrest and continues throughout the trial, is an important collaboration because SF has no funds for providing legal services to its members.

Raising awareness: SF recognizes that drug users are mainly passive recipients of services provided by harm reduction organizations and are not expected to think critically or participate in discussion about the challenges they face or the services they receive. SF leads several workshops every month for PWID so as to introduce them to social analysis, including discussion on gender norms, Indonesia's narcotics policies, and human rights. SF staff also note that harm reduction programs are designed for men, who constitute the majority of PWID, but the program fails to address the concerns of women who inject drugs, such as family planning, gender-based violence (GBV), and reproductive health. SF is planning to invite other NGOs to discussion sessions about human rights and gender perspectives as a way to increase awareness of the needs of women who inject drugs.

Since 2005, SF has published a newsletter, *Lingua*, that is a forum for delivering information in simple language for the PWID community, as well as for health care centers and other NGOs on drug issues, HIV, laws, human rights, gender rights, and citizen's rights (SF n.d.).

Collaboration with health center staff: With decentralization, lower-level (provincial, district, and municipal) governments have taken more responsibility for budgeting, implementing, and managing health services. Rather than NGOs providing outreach, NSP, and harm reduction services, local health clinic staff are expected to take on these services. This means that government health workers must provide the majority of services for HIV prevention, care, and treatment.

In 2005, when SF began its NSP and harm reduction programs, the foundation worked with health care staff to increase their awareness of the

> ***I'm not sure if the law requires I tell a woman if her husband is HIV-positive. Men won't tell their wives or fiancées they are HIV-positive. Some [PWID] find it difficult to find a wife. It's hard because he is a drug user; if she knew he was HIV-positive she wouldn't agree to the marriage. So the families don't tell the brides. Being a [person who injects drugs] and being HIV-positive and not being married—it's a triple stigma men want to avoid.***
>
> ***–A doctor at a health care center***

health issues affecting PWID and the benefits of the NSP program. In 2010, SF began collaborating with a number of health centers as part of a pilot program to integrate NSP with methadone maintenance therapy. In the near future, NSP programs will operate mainly under the supervision of local health centers; the role of NGOs like SF will be to monitor the quality of these services and to continue referring or accompanying PWID who are seeking these services. SF currently collaborates very closely with health centers in its catchment area and meets regularly with center directors to coordinate referrals and activities identified in each year's workplan. This long experience with partnerships may ease SF's transition from an NGO that provides services to one that provides outreach, referrals, and monitoring.

Gender-Related Work

SF outreach workers realized very early that while their work mainly reached men who inject drugs, women who inject drugs also existed; many of the staff and volunteers were women. As of 2009, only 200 of the 3,000 PWID that SF had worked with were women and not all of these women were accessing harm reduction programs or health services. This was for a variety of reasons, many having to do with cultural norms that restrict women to the household-based roles of wife and mother. Women also have less education than men, and therefore less access to information about HIV and reproductive health, or about such services as NSP or methadone maintenance for PWID. Women's fear of stigma, family disapproval, or lack of confidentiality may also keep them from seeking services. Many women who inject drugs have experienced sexual harassment or violence from police and thus may not seek NGO services for fear that police will arrest both the NGO workers and their clients who inject drugs. Some PWID have heard stories about women having to agree to sterilization when they try to obtain ART, or that staff in programs for prevention of mother-to-child transmission (PMTCT) will tell women not to have any more children.

Recruiting women's participation: To increase recruitment of women who inject drugs, SF outreach workers spend one day per week looking only for these women, including waiting in networking spots to identify new or unknown women or girls. The workers ask male and female PWID to invite female friends who inject drugs to the SF outreach programs or office, and encourage men who inject drugs to send their partners to SF or other NGOs for support or referral to services. If a female partner is reluctant to seek services, an SF worker tries to visit her at home, sometimes talking with in-laws or family to persuade them to allow the woman to talk to an outreach worker or to allow someone from the SF team to accompany her to obtain services.

Conducting research: Research on women, especially those who inject drugs, is very limited in Indonesia. There is little information about the constraints that affect women's access to services for needle exchange, drug substitution therapy, or rehabilitation services—national data about use of these services are not disaggregated by gender. There is no information on GBV against women who inject drugs and little information on the physical effects associated with ART, the ability of women who inject drugs to pay for ART services, or ways to address negative perceptions against women who inject drugs among some health care providers. In 2009, SF began a small qualitative study to understand the health service and information needs of women who inject drugs. SF plans to use the study, which is still underway, to advocate with stakeholder and donor agencies on ways to incorporate a gender perspective within harm reduction programs.

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STIGMA Foundation office. July 2010.

SF has also started a new newsletter, *Angels*, that focuses on women who inject drugs and their concerns. In addition, SF produces leaflets on specific topics such as PMTCT, the impact of ART on women, legal rights during arrest and detention, and actions that women can take if they are facing or experiencing violence.

Institutionalizing gender considerations within the organization: SF is seeking to build gender equity into its organizational framework, but has yet to benefit from ongoing and focused technical assistance on this issue. Some staff participated in four training sessions on organizational capacity building, provided by an international consultant, that included a gender and rights component, but the training has not been repeated. SF's internal policies support equitable employment through maternity policies that specify the rights of pregnant women and their husbands, as well as recruitment of female staff.

Referring cases of violence: Women who inject drugs commonly experience GBV. Though GBV is illegal, communities where SF works see it as a "normal part of being a woman," and informants from SF felt that few people in the community would intervene to address violence. In cases of GBV, SF will refer women to one of several NGOs that provide services for them; the government does not provide services for survivors of violence, including those who face violence during detention.

SF is also concerned that women who inject drugs may be at risk of GBV when they are arrested. They may be frisked by male police and may be forced to have sex in prison, or during arrest, on the promise of being released from jail. Though informants suspected that GBV against women might be common, they added that women were reluctant to share their stories because of fear or shame, or because they worry about being victimized again if they press charges and the case is investigated. It is less well-known to what extent men who inject drugs experience GBV. SF informants reported that men had told them about severe physical abuse—even torture—while in detention or prison.

What Worked Well

Introducing the concept of human rights for PWID: SF's advocacy work is breaking new ground by promoting the basic rights of this marginalized group and developing approaches for helping PWID protect themselves and their sexual partners from HIV. SF is helping to bridge the "justice gap" by educating communities about PWID while building the capacity of PWID to advocate for themselves.

Recognizing the importance of gender equality: While the donors who support SF promote gender equality and equity, none have required that SF integrate gender equality into its work or provide ongoing capacity building to do so. SF learned from its experience in the community that harm reduction programs were too male-focused and the data collected by these programs were too general to provide insight into the reasons why female and male PWID were not accessing

services provided by NGOs or by the local health centers. With very few resources and little technical assistance, SF has recognized and is trying to meet some of the needs of women who inject drugs. Where many programs focusing on PWID are gender-blind, SF is "gender-aware" and is trying to integrate gender strategies such as equity and access to programs and services and increasing legal rights and protections of all PWID.

Challenges

Aligning funding with strategic planning: SF is eager to expand its programming beyond Jakarta and continue its organizational capacity building and staff development, but its limited funding base has hindered this growth. Most donors fund SF on a year-to-year basis. Longer funding cycles would make strategic planning and internal capacity building goals easier to implement and achieve. The challenge for SF (and many other NGOs) is to identify donors willing to commit to longer term funding.

Policy changes: The policy-related shift of services for PWID from NGOs to health centers may have a negative impact on SF's mission and funding. SF will evolve from a role as service provider for PWID to a focus on referring PWID to health centers for treatment, and monitoring the care PWID receive. It may be difficult to identify donors to support this new role. SF staff are considering strategies to generate their own funding, from launching business ventures to serving as expert consultants on the needs of PWID.

Limited partnerships: SF is committed to addressing the cultural and structural barriers that PWID face. Its primary roles are advocacy and activism on the issue of harm reduction far beyond a focus on distributing needles and syringes driven by the requirement to "hit targets—numbers not quality." SF expressed that other NGOs deliver what donors want, not based on the NGO's own vision, or what is needed by the community of PWID. SF staff members recognize that their advocacy on behalf of PWID has caused some friction with other NGOs working with PWID and with some in the government. Others think that SF "is too vocal." In addition, SF has few partnerships with non-HIV-related women's organizations because of stigma against PWID. As a result, SF's network of collaborating and partnering NGOs is limited.

Need for increased focus on gender: When SF staff discuss gender issues, they generally mean issues that affect women. That gender norms also influence the vulnerability of men who inject drugs to HIV infection was a new concept. SF's training in social and critical analysis on PWID and human rights does not specifically include gender analysis. Yet a gender analysis, which could examine how being male or female affects the experience of PWID, might be a way to further empower all PWID. For example, understanding how GBV influences service uptake by women who inject drugs might enhance the effectiveness of SF's outreach strategies and activities.

Limited research capacity: SF staff have little experience in either qualitative or quantitative research. Their initiative to conduct qualitative research with women who inject drugs is commendable, but there is a possibility that the results may not be of sufficient quality to significantly inform their program approaches.

Hard-to-reach groups: SF staff recognize that some groups of PWID remain beyond the reach of HIV prevention programs by SF, other NGOs, and health center staff. SF staff report that more men who have sex with men and sex workers are becoming injecting drug users. Positive prevention

programs to help people who inject drugs and are living with HIV prevent transmission to their sexual partners are almost non-existent. The foundation's limited funding makes it difficult to develop programs with these populations.

Recommendations

Seek organization capacity building assistance: SF would greatly benefit from technical assistance in organizational capacity building, gender integration, and business development; staff are very motivated and cohesive, and investing in SF may substantially strengthen the long-term prospects for the organization and the PWID to whom it is most profoundly committed. SF should consider support from groups such as the U.K.'s Voluntary Service Overseas, the Asia/U.S. Exchange Programs, or local universities for no-cost technical assistance in areas related to health, HIV, participation and governance, and secure livelihoods, or seek support directly from its donors for capacity building in areas beyond HIV-related harm reduction.

Strengthen advocacy and policy development skills: SF plays an important role in holding the government accountable for providing the services and protections included in policies and laws. However, SF would benefit from training and mentoring on how to more effectively challenge, and more effectively collaborate with, government and other NGOs.

Conduct dedicated gender capacity building: Despite stated commitments to gender equality and equity, it is surprising that none of the major funders and donors in Indonesia require their programs to integrate gender sensitivity or strategies into their HIV program approaches—beyond general support of "gender mainstreaming" and sex disaggregated data. Defined activities—supported by dedicated funding—to make gender integration meaningful and measureable are lacking. Gender technical assistance that builds the capacity of the donors and especially program implementers—and goes beyond a one-off "gender training"—is greatly needed. The senior leadership within SF is sensitive to gender norms and how access to services is impacted by those norms. The entire staff would benefit from gender sensitivity training and ongoing technical assistance to integrate gender throughout their program goals and activities.

Future Programming

In the last year, SF has initiated a series of organizational capacity building activities. Managers identified data collection as an area for improvement. SF's data collection systems, while fulfilling the requirements of its donors (essentially, the number of contacts, disaggregated by sex), are inadequate for documenting and monitoring the results of its activities. SF's strategic plan includes developing a monitoring and evaluation framework, and it has hired a staff person for this role. SF is also improving and expanding its communication products, such as improving and updating its website and newsletter, to increase SF's credibility and outreach to PWID and the larger community.

By developing strategies to reach women who inject drugs, conducting research to determine the health and information needs of these women in Jakarta, and trying to bring more awareness about gender issues into its work with PWID and its staff, SF is charting an important direction for programs for PWID in Indonesia and beyond. But SF has not yet made the connection between the human rights abuse of PWID and women's equality and equity more generally. GBV against PWID is so pervasive that integrating GBV strategies and training into staff and volunteer development and community

outreach programs would provide an opportunity to find common ground with the larger community. Introducing the link between human rights and gender norms to larger structural barriers, such as poverty, lack of economic opportunity, and lack of accountability by government, would benefit not only PWID but also the communities in which they live. ■

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