



STRATEGIES FOR CHANGE

# Breaking Barriers

TO HIV PREVENTION, TREATMENT, AND CARE FOR WOMEN



OPEN SOCIETY INSTITUTE  
Public Health Program



**STRATEGIES FOR CHANGE**

# **Breaking Barriers to HIV Prevention, Treatment, and Care for Women**

*Edited by*

MELANIE CROCE-GALIS

**PUBLIC HEALTH WATCH**



**OPEN SOCIETY INSTITUTE**  
Public Health Program

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# Contents

5	Foreword
7	Introduction
17	<b>Empowerment: For Women By Women</b>
	1. Watch Out!: Grandmothers on the Move
	2. Mobilizing Through Cyberspace: Sex Workers Unite to Advance Their Rights
	3. Out of the Shadows: Female Drug Users Building a Community
	4. Tending to Themselves: Who Cares for the Caregivers?
31	<b>From Paper to Practice: Taking Back the Law</b>
	1. Storming the Courts: Using Strategic Litigation to Secure Women's Rights
	2. Reclaiming Tradition: Cultural Practices and Women's Property Rights
	3. Tipping the Balance: Integrating Harm Reduction and Legal Services
	4. The Law: What Have You Done for Sex Workers Lately?
47	<b>It's Our Money: Making It, Tracking It, Spending It</b>
	1. From Small Loans to Big Impact: Combining Microfinance with HIV Prevention
	2. Uniting for a Common Goal: Securing Funds for Women and Girls
	3. On the Runway to Success: Using Fashion as an Economic and Advocacy Tool
	4. Following the Money: Ensuring Equitable Financing for All
63	<b>Patience No More: Advancing Health Care for Women</b>
	1. Bringing Up Baby: Linking HIV Programs and Motherhood Support
	2. Do No Harm: Providing Sex Worker-Friendly Health Services
	3. Getting Results: Studying an Enhanced Support Model for Pregnant Women
75	Notes





A South Africa initiative links HIV prevention with economic opportunity, providing loans to women, such as the food vendor above, to launch their businesses.

# Foreword

AIDS is increasingly taking a toll on women and girls. In 2007, women accounted for approximately half of all people living with HIV worldwide and for more than 60 percent of all infections in sub-Saharan Africa. Young women aged 15 to 24 in the region are more than three times as likely to be infected with HIV than young men.<sup>1</sup> In other areas, women still represent less than half of all people with HIV (26 percent in Eastern Europe and Central Asia, 29 percent in Asia, 43 percent in the Caribbean) but their proportion continues to grow.<sup>2</sup>

While much has been documented about the disproportionate impact of the AIDS pandemic on women and girls, less attention has been paid to supporting and scaling up efforts to address the underlying factors that contribute to this imbalance. There are many examples of initiatives that seek to prevent new infections among women and girls and to provide more comprehensive care and treatment, from creating employment opportunities for young women in South Africa to incorporating legal services as part of post-test counseling. With the increased availability of resources to address AIDS and commitments from bodies such as the Global Fund to Fight AIDS, Tuberculosis and Malaria to ensure that the needs of women and girls are addressed, it is critical that the initiatives that have been shown to be effective or promising in meeting the needs of women are widely shared, studied, and scaled up. Further, we must also advocate for the lessons learned from these initiatives to result in HIV policies and programs that reflect and meet the needs of women.

In an effort to share proven and promising initiatives that respond to the needs of women and girls, the Public Health Program of the Open Society Institute convened a symposium, “Strategies for Change: Breaking Barriers to

Prevention, Treatment and Care for Women,” prior to the 2008 International AIDS Conference in Mexico City. The initiatives were categorized into four broad strategies—empowerment, legal, economic, and health services—which OSI supports to ensure that women have equitable access to quality, comprehensive HIV services and information. The symposium, which featured speakers from many of the organizations described in this report, also explicitly sought to highlight efforts that address the needs of a diverse range of women, including those who are particularly marginalized and stigmatized, such as sex workers, drug users, and women living with HIV.

This report provides an overview of the strategies as well as the initiatives highlighted at the OSI symposium. It is our hope that this publication will be a resource and an inspiration for those engaged in efforts to promote a more “woman-friendly” response to HIV.

**Françoise Girard**  
**Director, Public Health Program**



# Introduction

## *Background*

Globally, women and girls are increasingly being infected and affected by HIV, particularly in sub-Saharan Africa. Women and girl's vulnerability to HIV and its impact are inextricably linked to gender inequality. In much of the developing world, women and girls have fewer opportunities for education or employment, often do not enjoy equality in sexual relationships or in marriage, and face the burden of caring for family and community members who are ill from AIDS-related causes.

In Africa and Asia, women whose partners become sick or die due to AIDS are likely to face discrimination, abandonment, and violence. Testing positive for HIV or losing a husband to AIDS have caused women to lose their homes, possessions, or even custody of their children. Such economic insecurity results in women resorting to survival strategies, such as engaging in transactional sex that may increase their risk of contracting HIV.<sup>3</sup>

There is growing recognition that violence against women and girls contribute to their vulnerability to HIV.<sup>4</sup> According to a multi-country study by the World Health Organization (WHO), the proportion of women who had experienced physical or sexual violence, or both, by an intimate partner in their lifetime ranged from 15 to 71 percent.<sup>5</sup> Numerous studies have shown strong associations between violence and women's HIV status, such as limiting women's ability to negotiate safer sex practices and access HIV services.<sup>6</sup>



Grandmothers who care for their orphaned grandchildren march to raise awareness about their contribution to Swaziland's AIDS response and their need for support.

Women, particularly in developing countries, also do not have access to comprehensive, evidence-based HIV and sexual and reproductive health services. In seeking services, women living with HIV endure discrimination, disparaging remarks, and substandard care—ranging from not receiving information about or access to prevention of mother-to-child transmission of HIV services,<sup>7</sup> to being sterilized as a condition for receiving ARV treatment. HIV-positive women report facing expectations that they should no longer be sexually active and being pressure not to have children. In some places, HIV-positive women avoid going to an STI clinic for fear of being labeled as a sex worker.<sup>8</sup> Evidence indicates that women living with HIV are more vulnerable to some sexual and reproductive health problems such as precancerous cervical cancer abnormalities, yet information about and access to pap smears is not widespread.

Prevention of mother-to-child-transmission (PMTCT) has been the primary entry point for women to access HIV services. Globally, about 33 percent of women living with HIV received treatment to prevent mother-to-child transmission in 2007, up from 26 percent in 2006. However, in sub-Saharan Africa, where nearly 90 percent of HIV-positive pregnant women in low- to middle-income countries live, only 11 percent of those women needing ARVs for their own treatment had access in 2007.<sup>9</sup> The PMTCT strategy defined by the WHO consists of four components: (1) prevention of HIV infection among women; (2) prevention of unintended pregnancies among HIV-positive women; (3) prevention of HIV from women to their infants; and (4) provision of treatment, care, and support to HIV-positive women and their families.<sup>10</sup> However, most PMTCT programs in practice focus on the third component of the strategy, the provision of ARVs to prevent HIV transmission from women to their infants. Moreover, many women in PMTCT programs receive only a single dose of the ARV drug nevirapine, despite a WHO recommendation for combination therapy with two anti-AIDS drugs.<sup>11</sup> Nevirapine used alone is less effective than a combination regimen in reducing transmission and has been shown to lead to drug resistance, potentially jeopardizing future treatment options for women.<sup>12</sup>

Women engaged in socially marginalized activities such as drug use and sex work are highly stigmatized and frequently encounter rights abuses, which further complicate and hinder their access to HIV and sexual and reproductive health services. Sex workers are subject to arbitrary arrest and detention, physical or sexual assault by law enforcement officials, and coercive tests for HIV and sexually transmitted infections (STIs).<sup>13</sup> Stigmatization and discrimination in health care settings present significant barriers to access to services for women in socially marginalized groups. As a result, some sex workers travel long dis-

tances to access treatment for STIs outside their communities where their status as a sex worker is not known, pay for services at private clinics, or self-medicate with drugs obtained at pharmacies.

There is little data available on women drug users, but a number of studies in European countries have shown up to 50 percent higher HIV prevalence rates among women who use drugs compared to their male counterparts.<sup>14</sup> Women who use drugs are highly vulnerable to HIV—they may have sex in exchange for drugs, protection, or food, are often unable to negotiate condom use, and are more likely than male drug users to share or borrow injection equipment.<sup>15</sup> Yet, there is inadequate attention paid to women drug users and their needs. There is a lack of integrated services that address the link between sexual and drug-related risk for women. Pregnant drug users are seldom offered the medical and social services they need, and are instead demonized and pressured to have an abortion or to give up custody of their babies. Women drug users are also underrepresented in drug treatment programs, in part because the programs do not provide for basic needs such as separate sleeping areas, women's bathrooms, or child care. Many women avoid drug treatment and other care because they fear losing custody of their children if they enter inpatient treatment or are identified as drug users.<sup>16</sup>

### *Promoting initiatives that are responsive to women*

The Public Health Program of the Open Society Institute (OSI) supports and promotes innovative initiatives that seek to more effectively address women's needs for rights-based and quality HIV and related services, with a particular emphasis on women who are socially marginalized. The initiatives can be classified into four broad strategies—empowerment, legal, economic, and health services—all with the goal of ensuring that women have equitable access to HIV services and information and are engaged in the development and implementation of policies and programs that impact their lives. These strategies go beyond a health sector response and address the direct and indirect factors that contribute to women's vulnerability to HIV, such as socioeconomic inequality and cultural practices like “property grabbing” and widow inheritance.

The 2008 International AIDS Conference in Mexico City provided an important opportunity to share initiatives that have been successful in responding to women's needs in the context of HIV and AIDS. OSI therefore convened a





Sex workers' rights advocates in Brazil use fashion for advocacy and fundraising.

symposium “Strategies for Change: Breaking Barriers to Prevention, Treatment and Care for Women” to highlight these innovative approaches so that other organizations can learn from these experiences and funders can be inspired to support women-friendly programs.

These and other initiatives around the world are responding to the diverse needs of women. The secret of their success is in putting women at the center of their programming; the initiatives are designed for, and in many cases, by the specific population of women whose needs are being addressed, whether they are grandmothers, sex workers, rural women, or women living with HIV. These are the kinds of programs that women have identified as important and have shown to be effective in meeting their needs. It is critical to engage women in program design and implementation processes and in making funding decisions so that more support can be given to solutions driven by women.

## *Overview of strategies*

Women’s empowerment is at the foundation of a more woman-friendly response to HIV and AIDS. Women must be empowered to speak out about their needs and to advocate for and participate in processes that lead to effective policies and programs. Strategies to build women’s leadership include initiatives that raise awareness about the human rights of women who use drugs or engage in sex work; establish gender-sensitive health facilities and harm reduction programs so women feel comfortable accessing services<sup>17</sup>; promote the use of technology such as mobile phones, blogs, podcasts, and digital photography among sex workers to use in advocacy; mobilize grandmothers caring for orphaned children to advocate for inclusion of their needs in national HIV/AIDS programming; and form watchdog groups among rural women to guard against property evictions and hold community leaders accountable on HIV and development issues.

Legal strategies can address gaps in the law and redress practices that drive women’s vulnerability to HIV. Examples of initiatives that employ legal strategies include using strategic litigation and constitutional challenges to secure women’s property rights; utilizing informal legal systems and cultural structures to address violations of widows’ rights, such as eviction from their homes



or loss of property; integrating harm reduction and legal services to address obstacles to accessing treatment and care; and advocating for legislative changes to protect the rights and health of socially marginalized women such as sex workers.

Poverty and lack of economic opportunities for women are key underlying factors that contribute to the disproportionate impact of HIV on women. Economic strategies outlined in this report include monitoring government budgets and financial allocation to ensure equitable distribution of resources to programs that benefit women; combining microfinance programs with HIV-prevention training to empower women, improve their economic well-being, and reduce the risk of intimate partner violence and vulnerability to HIV; supporting coalitions of women to secure funds from the Global Fund to Fight AIDS, Tuberculosis and Malaria for women-centered HIV interventions; and creating a fashion label designed and produced by sex workers to raise funds for HIV prevention activities and to reduce stigma surrounding sex work.

As indicated above, the current AIDS response has not adequately addressed women's need for comprehensive HIV and sexual and reproductive health services, particularly with regard to women in socially marginalized groups. Strategies to improve health services for women include providing comprehensive health and other support services to HIV-positive pregnant women and new mothers; establishing a medical center to provide care for STIs and HIV for sex workers, in an environment free of stigma and discrimination; and ensuring that pregnant women have access to comprehensive post-test support and a full range of services, including legal and sexual and reproductive health services.

### *Summary of recommendations*

The following are recommendations drawn from the initiatives highlighted in this publication. The recommendations offer insight into how best to ensure that HIV policies and programs can effectively address the needs of women.

**Mobilize women, particularly those in socially marginalized groups, to identify priority issues and empower them to advocate for change.** Women infected and affected by HIV have first-hand knowledge of the issues that im-



Grassroots women in Kenya mobilize to address the AIDS epidemic.

pact their lives. Bringing women together with shared experiences can help to identify their priority needs; giving women a voice and opportunities to articulate these needs can help to empower them to advocate for the changes that will have the greatest impact.

**Put women at the center of HIV programming to ensure their particular needs and challenges are addressed.** Women are more likely to access facilities, and therefore benefit from their services, where they feel comfortable and welcome. Listening to women so that health services are of high quality and tailored to women's experience and challenges, addressing stigma and discrimination in health care settings, educating providers about the specific needs of women and involving women and people living with HIV in implementation, where appropriate, can help to make sure that interventions truly meet women's needs.

**Provide comprehensive services that address a range of women's needs in order to achieve better participation rates and health outcomes, and to help to reduce their vulnerability.** It is important to provide a wide range of services beyond health interventions, such as social, economic, legal, and psychological support, in order to meet the diverse needs of women and to address the problems, such as poverty, gender inequality, and violence, that increase women's vulnerability to HIV.

**Enhance women's economic, social, and cultural rights.** Protecting women's property rights and providing economic security through livelihood support, social security or income generation opportunities can help to reduce factors that put women at risk for HIV.



# Empowerment: For Women by Women

Imagine 2,500 Swazi grandmothers marching for change with the little ones they are caring for by their sides . . . sex workers around the world mobilizing through the Internet . . . grassroots women in Kenya deciding to track resources for and fight corruption in the delivery of HIV services at the community level . . . and women drug users becoming leaders in Indonesia's fight against HIV. This chapter will explore how these strategies have empowered women to protect themselves from HIV infection, to organize and advocate for change, reduce stigma and discrimination, and to become leaders in their communities' response to HIV and AIDS.<sup>18</sup>

Power imbalances between men and women exist in varying degrees in most cultures. In the context of HIV/AIDS, these power imbalances result in women's increased vulnerability to HIV infection and a disproportionate burden for caring for family and community members living with HIV and AIDS. Consequently, in many countries women's and girls' lack of empowerment results in:

- inadequate access to information about sexuality and how to protect themselves, especially if they are young;
- a limited ability to negotiate condom use, especially where women are expected to be mothers or are financially dependent on their sexual partners;
- an increased risk of physical or sexual violence;
- inequitable access to health services and, in many cases, less ability to decide when and where to seek health care;

- the double burden of stigma and discrimination for women who are HIV-positive; and
- an increased likelihood that they will be the sole caregivers of those living with HIV, or orphaned because of it.

Empowering women and girls to be able to make decisions about their health, demand the protection of their human rights, and advocate for the structural changes necessary to protect their health and rights must be a critical part of the HIV response.

Geeta Rao Gupta of the International Center for Research on Women has outlined seven approaches for HIV interventions that empower women<sup>18</sup>. These strategies include:

- educating women about their health and sexuality;
- giving women the skills they need to use condoms and negotiate condom use;
- improving women's access to economic resources;
- ensuring women's access to health services and prevention technologies that they can control, such as female condoms;
- providing opportunities for social support for women, such as the opportunity to meet in groups and organize, and strengthening community-based women's organizations;
- moving discussion of violence against women from the private to the public sphere; and
- giving women a voice in decision-making, within the family, within the community, and at the national level.

The projects that are described in this chapter use many of these strategies to empower the women they are working with.

## IN THIS CHAPTER

Strategies that empower women can have a transformative impact. When women have the knowledge, skills and confidence to take action necessary to protect their health and assert their rights, they are more likely to be able to protect themselves from HIV infection, reduce their personal risk of violence, and access health services when they need them. They are also more likely to take



their place in a meaningful way at decision-making tables and work to reduce stigma and change laws and policies that discriminate against women, particularly women who are HIV-positive or otherwise socially marginalized. The four following projects are beginning to achieve these results.

Swaziland for Positive Living's mobilization of grandmothers provided opportunities for educating them about their health and rights, while giving them the space and skills to make their needs known to local and national government officials and advocate for meaningful policy change.

In Indonesia, the Stigma Foundation's outreach to women drug users and provision of harm reduction and health services in a safe space has increased their involvement in political activism and increased their sense of independence.

The Desiree Alliance in the United States is one of many sex worker organizations using information and communication technology to organize and increase communication between sex workers, raise awareness about sex workers' rights, and advocate for changes in discriminatory laws that criminalize or marginalize women in the sex industry.

And in Kenya, GROOTS Kenya demonstrates how grassroots women, overwhelmed with the burden of taking care of community and family members living with HIV and AIDS, organized themselves into a home-based care alliance that tracks resources for care, distributes resources equitably among caregivers, and reduces duplication, corruption, and waste at the community level.

# 1.

## Watch Out!: Grandmothers on the Move

AIDS has orphaned as many as 77,000 children in Swaziland—a country that, with one in four people infected, has the highest percentage of HIV-positive people in the world. Because the disease has struck young adults the hardest, grandmothers are often the only ones left to care for the orphans that their own children have left behind. Women, who at this stage in their lives were hoping to be taken care of themselves, are doing everything they can to ensure that their grandchildren are fed, clothed, educated, and cared for. Yet grandmothers are ill equipped with the necessary resources to provide for their grandchildren and their struggles have gone unnoticed for years.

### *Recognition*

Swaziland for Positive Living (SWAPOL), a nongovernmental organization dedicated to strengthening the AIDS response in rural communities by working closely with women living with HIV, orphans, and vulnerable children, has put a spotlight on the heroic efforts that grandmothers are making to rear yet another generation. Since its founding in 2001, SWAPOL has worked at the community level and recognizes that without the efforts of grandmothers, the HIV epidemic would be even more devastating for Swazi children. This year, SWAPOL conceived of an international women's day celebration focused on grandmothers as a way to highlight their struggles and show appreciation for the work that Swazi grandmothers (“Gogos”) do to sustain communities.

### *Grandmothers' campaign*

On March 7, 2008—the day before International Women's Day—SWAPOL, along with the Swaziland Group Against Abuse, the Lutheran Development Services, and the Council of Swaziland Churches, brought 685 grandmothers together for a one-day empowerment workshop. The workshop covered such topics as: meeting the needs of grandmothers in HIV/AIDS national programming; challenges faced by grandmothers as they care for orphans; prevention and care programs focusing on grandmothers; and social security for grandmothers. Grandmothers were divided into groups to discuss these topics in-depth and to identify additional areas where they, as women and grandmothers, would like further advocacy.

Key areas for advocacy identified by the grandmothers include the following:

- **The health system**, where advocacy is needed to support the inclusion of prevention, care, and support programs for grandmothers in current national policies. Grandmothers also want to advocate for grants for basic needs like food and travel to treatment sites for all people living with HIV who are taking ARVs.
- **The judicial system**, where advocacy is needed to ensure privacy in domestic violence cases, and to support legislation focused on protecting women, such as the Sexual and Offences Bill, the Marriage Act, and the Administration of Estate Act. Each of these pieces of legislation affects grandmothers as rural women who face rape, domestic violence, and property theft.
- **The Constitution**, where advocacy is needed to ensure women can own land and retain their property rights.
- **Access to resources** and a review of the resettlement policies so that grandmothers have proper water and sanitation services.
- **Access to education grants** for orphans under the Department of Social Welfare so that grandmothers can pay for their grandchildren's school fees.
- **Social security** benefits for grandmothers so that they have a monthly income with which to care for their families.

Following the workshop, SWAPOL launched the Grandmothers Campaign with a march from the Manzini Jubilee Park to the Mavuso Trade Centre. More than 2,500 grandmothers participated in the march and they were joined by the minister for health and social welfare, the Manzini regional secretary, the deputy prime minister for justice and constitutional affairs, the minister for home affairs, and a number of UN agency representatives.

### *Unique approach is successful*

Drawing the attention of the government and the broader public to the needs of grandmothers in this way has been a major achievement. The platform for grandmothers to demonstrate the power of their numbers has allowed their voices and their needs to be heard by those who can help. Many government officials are now conscious of grandmothers' needs and have committed to addressing their concerns within governmental programs. This event has also mobilized women to form a grandmothers committee to work with SWAPOL in continuing to advocate for their concerns.

The Grandmothers Campaign demonstrates how successful mobilization of marginalized women—especially those in the rural areas—can empower women to build a platform for real change.

**For more information about SWAPOL's Grandmothers Campaign, contact Siphiwe Hlophe, director, SWAPOL, [hlophess@hotmail.com](mailto:hlophess@hotmail.com) or [swapol@realnet.co.sz](mailto:swapol@realnet.co.sz) (T: +268 5057088, +268 5056172, Mobile: +268 6027324) or visit [www.swapol.net](http://www.swapol.net).**

## 2.

# Out of the Shadows: Female Drug Users Building a Community

Women who use drugs are a well-hidden group in plain sight. Female drug users, who tend to partner with male drug users, face an enormous amount of social pressure to hide their drug use. In Indonesia, where a majority of the population is Muslim and many patriarchal, conservative gender roles hold sway, women who use drugs face very high levels of stigma and shame for their drug use and are commonly subjected to violence, sexual harassment, and discrimination.

As a result, the Stigma Foundation, a Jakarta-based community organization made up of former drug users and people living with HIV and AIDS, had only seen 70 women at their harm reduction programs compared with more than 1,500 male drug users over the course of three years. Women drug users often tell outreach workers that they must get permission from their boyfriends or husbands to attend the harm reduction programs. Many others say they are too ashamed to admit to health care workers that they use drugs because of the heavy stigma attached to female drug users in Indonesia.

### *Women under the radar*

Because of their larger numbers, men are usually the focus of harm reduction programming; female drug users exist under the radar. The health care services

for women, for example, are woefully inadequate in handling the full range of female drug users' sexual and reproductive health needs, yet women are not empowered to demand better treatment and an end to discriminatory policies. Many drug treatment facilities don't even accept female clients, particularly those who might be pregnant or are living with HIV. With high HIV infection rates among injecting drug users in Indonesia (an estimated 60-90 percent), programs that can truly reach drug-using women are critically important.

The Stigma Foundation was founded in 2004 to reduce stigma and discrimination towards all drug users and people living with HIV and AIDS. The organization also seeks to educate drug users about their human rights and their rights to health services, empower drug users to advocate for their rights, and provide networking and self-help opportunities for those struggling with addiction. Notably, the Stigma Foundation is one of the first Indonesian organizations to address the special needs of female drug users. In 2007, the Stigma Foundation launched the FEMME project to specifically reach female drug users through gender-oriented harm reduction programs, education workshops, and trainings.

### *Understanding women's needs*

In late 2007, the Stigma Foundation's FEMME project carried out a needs assessment to learn more about the specific needs of female drug users in order to increase participation in harm reduction programming. As a community-based organization made up of former drug users and people living with HIV and AIDS, the Stigma Foundation was uniquely qualified to carry out this work.

The research project began with in-depth interviews with health care providers, harm reduction program managers and outreach workers, and in-depth interviews and focus group discussions with female and male drug users. Several themes emerged from the interviews, such as women who use drugs lack understanding about what harm reduction is and what their human and civil rights are; harm reduction programming often varies depending on requirements set by donor organizations; some health agencies view drug users as a "target" to be reached without recognizing the humanity behind the numbers; and above all, there is a lack of effective outreach models for female drug users. Additionally, most health care professionals are not trained to provide pregnant women with methadone or buprenorphine—medications that are proven to reduce opiate addiction—and some professionals encourage HIV-positive women to be sterilized.

### *Empowering female drug users*

The Stigma Foundation, through FEMME, is using this information to better guide programming to meet the needs of female IDUs and bring them into harm reduction programs in greater numbers. In addition to creating targeted information, education, and communications materials for women, FEMME is organizing peer workshops to build women's self-esteem and self-confidence. Essential leadership training for women is conducted to build a base of female activists who will advocate for policies and services that better address their needs. FEMME is building networks of female drug users in at least five Indonesian cities to provide support and solidarity for women. This work can be very challenging in a country with gender roles and expectations that do not encourage women—particularly marginalized ones—to be outspoken advocates or to take control of their own health.

### *Successfully reaching women*

Still in its initial stages, the FEMME project has shown some success in reaching women who use drugs. Women have described FEMME as a safe place for them to gather and learn how to take care of themselves. According to the Stigma Foundation, the key to FEMME's success is its inclusion of women who use or have used drugs in designing and implementing programs. The Stigma Foundation will continue to provide information and education materials that focus on women, and will work to raise awareness among women of their rights, and among health care workers about the particular needs of women who use drugs. A gendered perspective on treatment will help make rehabilitation facilities more woman-friendly so that women feel comfortable accessing support.

The Stigma Foundation also advocates for provision of vocational training to give drug-using women alternatives to sex work and calls for a review of all harm reduction interventions with a human rights and gender perspective. Such a perspective will help reduce disparities and increase the number of women taking advantage of available programming. Above all, efforts to empower female drug users and build a leadership network of confident, assertive women who can advocate for the rights of female drug users—and women in general—at all levels of Indonesian society will go a long way in bringing women out of the shadows to access harm reduction and HIV prevention programs that can save their lives.

**For more information about the Stigma Foundation, contact Sekar Wulan Sari at [our\\_stigma@yahoo.com](mailto:our_stigma@yahoo.com) or visit [www.stigmafoundation.blogspot.com](http://www.stigmafoundation.blogspot.com).**



### 3.

## Mobilizing Through Cyberspace: Sex Workers Unite to Advance Their Rights

*“We make the media before the media makes us.”*

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Information technology evolves at lightening speed, and it is no surprise that creative entrepreneurs immediately seize upon new developments to improve their work. Sex workers have demonstrated a flair for using technologies such as photographs, PowerPoint, videos, karaoke, and audio in innovative ways to communicate with each other as well as to advocate for themselves in regional and international forums.

The use of information and communication technologies (ICT) among sex workers has been growing steadily and is used primarily in four ways: to communicate with and mobilize sex workers, to increase sex worker participation in advocacy, for regional and international networking, and to support national advocacy campaigns. Sex worker advocacy campaigns typically focus on ending discrimination and stigmatization of sex workers, promoting labor rights, and including sex workers in policy and law reform.

### *ICT internationally*

Around the world, sex workers are using information and communication technology in a number of innovative and creative ways. Mobile phones, for instance, have revolutionized communication in under-resourced areas. RedTraSex, the Latin American and Caribbean Sex Worker Network in Argentina, uses mobile phones to mobilize members for political demonstrations. Empower, a sex worker organization of several thousand members based in Thailand, has also had great success in mobilizing sex workers for demonstrations through SMS text messaging.

Emails, listservs, and websites are immensely valuable tools for sex worker em-

powerment and advocacy, and have been used worldwide to share information about policy developments and upcoming events. The Asia Pacific Network of Sex Workers (APNSW) maintains a website ([www.apnsw.org](http://www.apnsw.org)) that brings together materials and documents from a variety of sources to support advocacy positions. Other websites such as Daspu ([www.daspu.org.ar](http://www.daspu.org.ar)), the fashion label designed and modeled by sex workers from the NGO Davida, show the vitality, creativity, and strength of sex workers around the world.

Videos posted on YouTube and Blip as well as audio podcasts are additional venues for sex worker advocacy. These strategies are less commonly used but have been effective in creating testimonies and oral histories and documenting advocacy activities. RedTraSex, for example, has been using digital photography to document their demonstrations. The Collective of Sex Workers and Supporters in Taiwan (COSWAS) has produced a video narrative about the plight of a sex worker in Taipei on YouTube (<http://www.youtube.com/watch?v=eBAZ4RxPxDM>) that's been viewed nearly 10,000 times. APNSW has produced a karaoke video featuring a protest song used to promote a global advocacy message. The video, set to the tune of U2's song "One" and challenging the United States and others to stop raids on sex workers, was used as a public education piece at the XVI International AIDS Conference in Toronto and is also available on YouTube and Blip at <http://www.blip.tv/file/199048/>.

### *Sex worker blogs*

The Desiree Alliance, a diverse, volunteer-based, sex worker-led network of organizations and individuals across the United States, has been at the forefront of this growing ICT movement and provides leadership and safe space for sex workers and supporters to come together for human, labor, and civil rights for all workers in the sex industry.

The Desiree Alliance launched the blog [BoundNotGagged.com](http://BoundNotGagged.com) in response to the scandal created when former U.S. Deputy Secretary of State Randall Tobias, architect of global antiprostitution policies, was revealed as a client of sex workers. Cofounded by Melissa Gira Grant and Stacey Swimme, this online forum provides a space for the voices of sex workers to be heard. BoundNotGagged is a place for sex workers to respond to the way they are portrayed in the media and to the sexist laws that are used to undermine sex workers' rights. The overwhelmingly positive response to the introduction of the blog demon-

strates that this mode of communication has a prominent place in sex worker empowerment:

*Thank you for creating a public voice for the hundreds of intelligent and successful women that have a secret life as a sex worker. (Jenn, 2007)*

*I'm so glad to see that you are doing something to open peoples eyes, its time people realize that this is a real profession with real people that need to be treated with respect. Thank You! (Cynthia, 2007)*

BoundNotGagged is currently written collaboratively by more than 20 sex workers. This medium continues to be a way for anyone interested or involved in the sex work industry to speak up, share their thoughts, and coordinate media response in real time. According to the site, “we make the media before the media makes us.”

## Challenges

While great strides have been made, information and communication technologies pose several difficulties for sex worker advocates. The primary challenge is privacy. Many sex workers who would like to make the most of new technologies fear that their privacy will be compromised. Some lack access to or awareness of digital protection services. The cost and language of hardware and software are additional challenges, as are adequate technical skills. Many of the sex workers who take advantage of new technologies are self-taught or are relying on friends or volunteers with some knowledge to help them with their ICT needs. Improving these skills and providing the necessary hardware and software will help sex workers continue to create innovative pieces like the ones mentioned above to mobilize and advocate for their rights.

## United through technology

The growth of information and communication technology reduces the crippling isolation that sex workers around the world have typically felt. Uniting—through mobile phones, email contact and websites—is empowering sex workers to raise their voices in solidarity and take collective action to advance their human rights. New technologies have the ability to produce more powerful communication by taking advantage of both sight and sound, and to be created collaboratively across the world. Sex workers, as intrepid entrepreneurs,

have been successfully capitalizing on this potential to promote the right to be respected as women, citizens and workers.

**For more information about sex workers' use of ICT, contact Melissa Gira Grant at [melissa@melissagira.com](mailto:melissa@melissagira.com) (T: +1 415 690 9651), or visit the Tactical Technology Collective at [www.tacticaltech.org](http://www.tacticaltech.org).**

## 4.

### Tending to Themselves: Who Cares About Caregivers?

As is true in many countries in sub-Saharan Africa, AIDS has become a major challenge that threatens to reverse the development gains made in Kenya over the last several decades. While HIV prevalence has notably decreased, UNAIDS data indicates that 1.3 million Kenyans are living with HIV and 1.1 million children have been orphaned due to AIDS. Poor communities in urban slums and in rural areas comprise a large portion of those affected by HIV, and within those areas women and girls disproportionately shoulder the burden of caring for the sick and the orphans. The women providing home-based care play a critical role in holding families and communities together in the face of an enormous crisis, yet the value of their efforts and their needs for financial support, education, and medication have been largely ignored.

#### *Community support needs*

In the late 1990s, many home-based caregivers organized into groups and approached GROOTS Kenya for support to improve their knowledge and access to resources that would enable their communities to deal with the impact of AIDS. GROOTS Kenya, a movement of women self-help groups and community-based organizations, was founded in 1995 and is a member of GROOTS International and the Huairou Commission. Its goal is to strengthen the role of grassroots women in community development by serving as a platform for

women and grassroots groups to come together, share experiences and best practices, network, and participate in the design and implementation of strategic programs that address their priorities and those of their communities. In response to the request from the home-based caregivers, GROOTS Kenya developed a comprehensive home-based care training program that has helped more than 5,000 grassroots community leaders develop HIV/AIDS care, support, prevention, and advocacy strategies.

During program implementation, GROOTS Kenya found that many agencies and institutions were dedicating money to grassroots communities that didn't reach the intended beneficiaries. At the same time, the home-based caregivers were too fragmented and had little capacity to hold governments and NGOs accountable for the management of resources aimed to help communities deal with the pandemic. With support from GROOTS Kenya, grassroots women in Kenya now have the ability to analyze the available resources. They began to map institutions working in their communities and started to engage them in dialogue. This process has been strengthened by the development of a home-based care alliance in Africa.

### *Home-Based Care Alliance in Africa*

The initiative brings caregivers together to effectively and collectively advocate for transparency and accountability in HIV/AIDS programming and resource allocation.

The Home-Based Care Alliance in Kenya has a threefold aim:

- to build the capacity of home-based caregivers to share experiences and speak with a collective voice;
- to establish home-based caregivers as monitors and evaluators of resources for HIV/AIDS services and responses; and
- to draw attention to the contributions of grassroots communities, particularly women home-based caregivers, in mitigation, management, and coping strategies for the HIV/AIDS pandemic.

The initiative includes community-led mapping of the caregivers, orphans, and people living with HIV/AIDS in a given region, followed by mapping of institutions and organizations implementing HIV programs in that region. Local dialogues among communities and institutions are then held, led by women caregivers. These discussions focus on analyzing the available resources and

resource allocation for the region and include community-led documentation of caregivers' contributions. They also provide a platform for community-led planning and priority setting to guide external partners on effective service delivery for that particular area. Throughout the process, grassroots women are continuously networking and improving their communications and advocacy skills through training, peer learning, and mentorship.

### *Real results*

This innovative process has not only empowered the women involved, it has also significantly contributed to the accurate tracking of resources related to HIV/AIDS and effective delivery of services to the communities involved in the initiative's pilot. As coordination has been improved through grassroots women's leadership, corruption and duplication of services have been reduced. The women involved in the project have continued their leadership roles in other areas within their communities. Importantly, many development agencies are increasingly appreciating the role of home-based caregivers as key partners. In fact, the National AIDS Control Council (NACC) is now including grassroots women caregivers in their consultative meetings at the local and national levels and some NACC officials are endorsing organized home-based caregivers as primary partners in local program implementation.

### *Important lessons*

One of the most critical lessons from this work and others like it is that the population most affected by AIDS must be a primary partner for decision-making, priority setting, and monitoring of effective delivery of services and information. Governance and accountability are key elements to ensure programs are effectively reaching their target populations. The women caring for the sick and the orphans are the first set of actors that deal with the HIV pandemic and yet they have been the last to be consulted on what to do about it. GROOTS Kenya and the Home-Based Care Alliance seek to change that pattern by ensuring that grassroots women are masters of their own development through their direct participation in decision-making processes. And it's working.

**For more information about GROOTS Kenya and the Home-Based Care Alliance, email [grootsk@grootskenya.org](mailto:grootsk@grootskenya.org), call + 254 20 3873186, + 254 20 2718977, or + 254 720 898222 or visit <http://www.groots.org/members/kenya.htm>.**



# From Paper to Practice: Taking Back the Law

*“Although we cannot count on law alone to change society, the law can and should play the role of a leader and an educator by showing people the way forward. In that sense, if the law is carefully studied, dynamically interpreted and imaginatively applied, it can provide a basis for social action and a political platform for change.”* — Bart Rwezaura, *Protecting the Rights of the Girl-Child in Commonwealth Jurisdictions*

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Of all the challenges facing women in the context of HIV, their legally inscribed inequality and subordination to men is one of the most acute and challenging to address. There is an urgent need for effective legal interventions to address human rights abuses that render women more susceptible to HIV and impede their access to testing and treatment. Human rights abuses fueling the AIDS epidemic include women's legal subordination, discrimination in access to property and resources, pervasive domestic violence, and exploitation of caregivers. The situation is especially dire for women who engage in sex work or use drugs, because they are often forced to the margins of society and away from HIV services.

In 1998, the International Guidelines on HIV/AIDS and Human Rights, jointly issued by UNAIDS and the Office of the High Commissioner for Human Rights, recognized that “discrimination against women . . . renders them disproportionately vulnerable to HIV/AIDS. Women’s subordination in the family and in public life is one of the root causes of the rapidly increasing rate of infection among women . . . [W]omen and girls are often unable to negotiate safer sex or to avoid HIV-related consequences of the sexual practices of their husbands or partners as a result of social and sexual subordination, economic dependence or a relationship and cultural attitudes.”

This description remains as true today. Gender inequality makes women more vulnerable to HIV, with women and girls now having the highest rates of infection in heavily affected countries. Discrimination, stigma, and violence are also daily realities for many women living with HIV and AIDS.

In many countries, national laws restrict women’s ability to own, inherit or dispose of property. Women suffer inequality in access to education, credit, employment, and divorce. Legal and social inequality renders women economically dependent on their husbands, leaving them little choice but to remain in relationships where they cannot refuse sex or insist on condom use. Women often sink into poverty upon the death of their husband or the dissolution of their marriage, finding themselves in lodging or work situations where they are exposed to sexual abuse or violence.

In settings of high HIV prevalence, advancing women’s legal rights is made more daunting by weak and corrupt justice systems that are legitimately perceived as not acting in the interests of women. Yet the case studies in this compilation illustrate the tenacity of women’s rights activists in pursuing a range of promising legal strategies: launching test case litigation and constitutional challenges, mobilizing the informal legal system and cultural structures, integrating health and legal services, and advocating for law reform.

## IN THIS CHAPTER

In an era where national legislation continues to violate recently adopted progressive constitutions and ratified international human rights conventions, there is a tremendous opening for test cases to give teeth to equality provisions and spur reform of disempowering legal frameworks. This chapter illustrates

successful use of such strategic litigation in South Africa by the Women's Legal Centre.

Laws and formal policies alone, however, are not adequate to ensure women's rights and protection from HIV vulnerability. The Kenya National Commission on Human Rights and the Kenya Legal and Ethical Network on HIV engaged with cultural leaders and informal legal structures to address women's disinheritance, thereby infusing greater equality into communities at the grassroots level and increasing widows' and children's access to health services and education.

Integrating legal services into health services already used by women is a particularly powerful tool for the protection of women's rights. It both enables the provision of comprehensive care and increases access to justice for underserved communities. For women who use drugs, police abuse, difficulty retaining or regaining custody of their children, lack of identity documents, and forfeiture of apartments following conviction are fundamental legal problems requiring resolution for good health and effective treatment. A number of harm reduction programs in Ukraine include legal assistance as a central component of their services for people who use drugs.

Both litigation and legal services feed into law reform efforts to change legal frameworks rendering women vulnerable to HIV infection and impeding their treatment and care, Argentina's Association of Women Prostitutes has worked to organize and mobilize sex workers to secure health services and successfully challenge discriminatory practices.

# 1.

## Storming the Courts: Using Strategic Litigation to Secure Women's Rights

Some of the most overt discrimination against women has been perfectly legal. Women's legal and human rights have been systematically violated through ingrained laws and policies around the world. To rectify this imbalance, several organizations—such as the International Centre for the Legal Protection of Human Rights (INTERIGHTS) in London and the Women's Legal Centre in South Africa—have begun implementing strategic litigation to reform discriminatory laws and secure women's rights.

### *Focus on law reform*

Strategic, or test, litigation is focused on law or policy reform. While the litigation is in the client's interest, strategic litigation often goes beyond the immediate interests of the client and is designed to have maximum impact with lasting effects that will extend beyond the individual case.

Organizations such as INTERIGHTS promote respect for human rights worldwide through the use of strategic litigation, bringing or supporting cases in critical areas where there is either potential for human rights standards to be developed or where existing standards are under threat. When successful, strategic litigation can establish important legal precedents or effect changes in legislation, policy or practice, in addition to influencing public opinion.

### *Ensuring women's property rights*

The Women's Legal Centre (WLC) in South Africa used strategic litigation in the Western Cape to challenge the implementation of primogeniture, the common law right of the firstborn son to inherit the entire estate. Two cases were brought to the Constitutional Court. One was brought on behalf of two young sisters who were unfairly discriminated against in inheriting their father's estate. The WLC argued that all three minor children had a right to the inheritance. A second case was brought on behalf of a woman who was prevented from inheriting her late brother's estate.

The cases were consolidated and heard in 2005 by the court as *Bhe and others v. Magistrate, Khayelitsha, and others*. The cases challenged the implementation of section 23 of the Black Administration Act that essentially codified the customary law of primogeniture. This not only discriminated against women, it also served to separate laws which applied to black people versus white people—thus violating the equal rights provisions in South Africa’s constitution.

The Constitutional Court agreed with the WLC, ruling that the African customary law of male primogeniture, as it has been applied in relation to the inheritance of property, discriminated unfairly against women and illegitimate children. The court declared the law unconstitutional and invalid, stating:

“In the light of its history and context, section 23 of the Black Administration Act is an anachronistic piece of legislation which ossified ‘official’ customary law and caused egregious violations of the rights of black African persons. The section created a parallel system of succession for black Africans, without sensitivity to their wishes and circumstances. Section 23 and its regulations are manifestly discriminatory and in breach of the rights to equality in section 9(3) and dignity in section 10 of our Constitution, and therefore must be struck down. The effect of this order is that not only are the substantive rules governing inheritance provided in the section held to be inconsistent with the Constitution, but also the procedures whereby the estates of black people are treated differently from the estates of white people are held to be inconsistent with the Constitution.”

This decision left a gap in the law, and the Constitutional Court put an interim regime in place, pending legislation dealing with succession in African customary law. The Law Reform Commission presented a draft bill in June 2008 to the parliamentary portfolio committee. The bill is based on the court’s findings in the case, and will finally regulate the position. The primogeniture rule has been replaced with a system of inheritance that does not discriminate against women.

### *More than just litigation*

Strategic litigation initiatives such as those brought by the Women’s Legal Centre and INTERIGHTS have the power to make strong statements about the legally ingrained discrimination toward women worldwide. But litigation alone is not enough. INTERIGHTS, for example, complements its litigation work with legal capacity building of local lawyers, judges, and NGOs, and by publish-

ing and disseminating legal information to keep the legal community abreast of developments in human rights laws.

By publicizing legal developments and improving the ability of attorneys worldwide to effectively advocate for women's rights, these organizations will ensure that greater attention will be paid to the culturally and legally embedded injustices that make women vulnerable to destitution and disease.

**For more information about strategic litigation and women's inheritance rights, contact Sibongile Ndashe at [sndashe@interights.org](mailto:sndashe@interights.org) or visit [www.interights.org](http://www.interights.org) or [www.wlce.co.za](http://www.wlce.co.za).**

## 2.

# Reclaiming Tradition: Cultural Practices and Women's Property Rights

*The culturally sanctioned sexual abuse of widows leaves them vulnerable to HIV, putting their survival and that of their children at risk.*

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Historically, property in much of Kenya has been passed to men through a patrilineal system. Each man would hold the land in trust for his family and, depending on the number of wives he had, the land would be divided so that each wife and her children had their own homestead on which to farm and make their livelihood. When a husband passed away, a younger male relative would step in to head the household, to be a father figure to the children and to represent the family at cultural meetings. At times, and depending on the age of the widow, a sexual relationship would develop and any children born to the couple would be considered children of the deceased husband. If the widow did not want a sexual relationship, there were other ways to show that she had

been inherited by a male relative (and thus ward off any bad omens): she could wear his coat at a public ceremony or alternatively, a piece of the roof on her home could be replaced with fresh grass to signify the inheritance and allow the woman to participate freely in community life. At no time could the inheritor take the land or move a widow from her homestead.

### *Cultural disintegration*

This cultural practice has been disrupted by the introduction of land title deeds that enable an individual to hold the land to the exclusion of others, thereby destroying the cultural practice of holding it in trust for the family. Today, the broader value of inheritance—to responsibly care for families in the community—has largely been lost, with many male relatives of deceased men using their culturally advantageous position to target women for property and sexual relations. There is rampant sexual abuse of women by male relatives who insist on forcibly having sex with them in the name of inheritance. If a woman resists, she is ostracized and forced to leave her home. Even if a woman is HIV-positive, she is still expected to undergo sexual “cleansing” before she or her children are allowed to mingle with the community.

This leaves Kenyan women today in a perilous situation when their husbands pass away. Women who have previously never needed to understand the procedures related to acquiring land titles are suddenly thrust into legal disputes when they are forced from their land by relatives claiming ownership. In the unusual circumstance that a woman can afford to fight the claim, disputes often take more than six years to resolve, during which time the woman is frequently ejected from the property and must find other ways to ensure the survival of her family. Further, the culturally sanctioned sexual abuse of widows leaves them vulnerable to HIV and other infections, putting their survival and that of their children at risk.

### *Reaching out to cultural leaders*

Because personal matters such as marriage, divorce, property rights, and dispute resolutions are governed by customary law in 42 ethnic communities in Kenya, the community of elders is a key decision-making body with the power to address the abuses of widowed women. Two women—Catherine Mumma and Angeline Siparo—recognized the need to work within these cultural structures and began a pilot project with the Kenya National Commission on Human Rights (KNCHR) to reach out to the Luo Council of Elders.



The pilot project in the Luo community—chosen for its high HIV prevalence and large number of widows’ rights violations—aimed to work directly with the council of elders as the custodians of the cultural practices. The project identified women whose rights had been violated and worked with them to overcome their fears and tell their stories. These emotional sessions were presented to the elders as part of a forum focusing on human rights and culture. After presentation of the widows’ cases and a facilitated discussion of the impact of cultural practices on the rights and welfare of the community, the elders then took on the mediation or arbitration of the individual cases. In most cases, the elders managed to restore justice and get the widows reinstated in their properties. Such a widow would still need support to resettle and to register the property in her name or joint names with her children for more permanent protection, but the judgment of the elders provides a powerful stamp of approval.

The Kenya Legal and Ethical Network on HIV (KELIN), a national network of legal experts, representatives of people living with HIV and AIDS, NGOs, community-based organizations, and human rights groups, is scaling up these cultural intervention activities in the Luo community and beginning similar projects in other communities across Kenya.

KELIN, working in collaboration with KNCHR, has had great success in reinstating properties to disinherited widows, and the positive publicity generated from the initial cases has fueled the community’s determination to continue to do so. Thus far, more than 20 widows have been reinstated and the Luo Council of Elders has resolved to document and disseminate the Luo culture of inheritance. Luo women are now feeling hopeful about receiving just treatment and are forming support groups to help other women; HIV-positive women are proactively seeking health services and living more positively; and their children have better opportunities for education and protection from abuse. Importantly, a demand has been created in other communities for similar programming and this model is being considered for use in other development issues where corruption of cultural practices has impeded human rights.

### *Valuing culture*

A critical component to this project is that the community culture is valued overall, even while addressing some of the negative aspects. Some of the important lessons learned from this approach are that:

- formal laws and policies alone may not be adequate to protect women’s rights;

- it is possible to positively engage with traditionally conservative cultural structures to infuse gender equality into communities at the grassroots level;
- enhancing women's economic, social, and cultural rights and the right to own and inherit property, in particular, is central to the reduction of women's and children's vulnerability to HIV; and
- those working in the field of HIV and gender must acknowledge the central role of culture in the economic and social lives of women and incorporate that knowledge into program designs.

**For more information about this project, contact Catherine Muyeka Mumma at [cathymumma@yahoo.com](mailto:cathymumma@yahoo.com) or [lawtechs@rachieradv.co.ke](mailto:lawtechs@rachieradv.co.ke); T: + 254 20 2210613 or +254 20 2212186, Mobile: +254 20 2247807.**

### 3.

## Tipping the Balance: Integrating Harm Reduction and Legal Services

*The link between legal protection and health promotion is intuitively clear.*

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Stigmatized groups such as drug users and sex workers are heavily impacted by the HIV epidemic. Harm reduction programs work to reduce the health and social risks related to drug use, but law enforcement practices often prevent drug users from accessing these lifesaving programs. In Ukraine, female drug users must overcome enormous barriers to access harm reduction and other health services, many of which require legal assistance. Apart from criminal sanctions, drug-using women face violence, persecution, and unlawful treatment at the hands of law enforcement. If the growing HIV epidemic in Ukraine is to be curbed, it will require close attention to the links between stigma, poor health outcomes, and human rights abuses.

## *Overcoming obstacles*

The obstacles that keep drug users in Ukraine from accessing harm reduction services include abuses by police (physical abuse, fabrication of evidence, and forced confessions); forfeiture of apartments following convictions; the requirement that those seeking treatment register with the state; denial of methadone or buprenorphine treatment, despite evidence that such treatment reduces illicit drug use; inability to regain identification documents lost or confiscated by the police; difficulties re-establishing housing, employment, and other social services after treatment or incarceration; and discrimination based on HIV status, criminal history, or prior drug use. Problems especially pressing for women include difficulty regaining custody of children following periods of time spent in drug treatment or incarceration; sexual abuse; domestic violence; and difficulty enrolling children into school after a mother's registration or public recognition as a drug user. Drug user registration, which can lead to further discrimination and stigmatization, is especially problematic for mothers, who are concerned not only about their own welfare but also about that of their children. Further, punitive drug policies make women drug users vulnerable to sexual abuse and exploitation by police, who may demand sexual services in exchange for freedom from prosecution.

Drug users rarely have access to the legal assistance needed to effectively deal with these problems and often wind up jailed for relatively minor infractions, unemployed because they don't have identification papers, or losing custody of their children after combating their addiction.

## *Integrating legal services into harm reduction programs*

NGOs in five Ukrainian cities supported by the Open Society Institute's Law and Health Initiative and International Harm Reduction Development Program developed creative ways of integrating legal services into harm reduction programs for drug users. Several models employed by these NGOs made effective use of limited resources and identified opportunities for systemic advocacy to improve drug users' social and health outcomes, drawing lessons for future funding and replications of the programs in other cities and countries.

## *Effective integration*

One very promising model for integrating harm reduction programs with legal services involved having one or more full-time lawyers on staff with the harm reduction program to provide services whenever clients from the program

approached them. This model worked best with harm reduction clients, particularly those who were still using drugs, because the lawyer was present all the time and developed a relationship of trust with the program participants. Clients could also reach out for legal services whenever they felt comfortable doing so, as they knew that a lawyer was available at any time. Other models consisted of a referral system whereby program staff would refer clients to a lawyer who came in at regular intervals to do “intake” assessments of clients’ legal needs and then scheduled appointments. Although valuable, this model was less accessible to clients because it required them to stick to a schedule, which can be particularly difficult for women with children.

Only one NGO had lawyers attend outreach services such as mobile syringe exchange in addition to the fixed centers. This outreach model, when combined with an easily accessible, private office where the client and the lawyer can arrange to have subsequent confidential meetings, may be a model that is most in line with a harm reduction philosophy.

### *Simple information needs*

Most of the time clients simply need information about their rights and how to go about solving minor problems. For example, legal professionals who can answer clients’ questions about the best way to proceed with a case or who can help draft appeals and documents on behalf of their clients to such entities as prosecution agencies, courts, public health and social protection institutions, and local authorities, appear to be the most useful to drug users seeking assistance. Between 2004 and 2006, lawyers associated with the five harm reduction programs in Ukraine provided consultations to more than 4,000 drug-using clients and people living with HIV.

Lawyers involved in harm reduction programs often help more than just the clients. In addition to providing direct client services, legal professionals can also assist the NGOs themselves with various legal issues such as representing social workers harassed by law enforcement while they were working or assisting with employment contracts and agreements.

### *Clear linkages*

Access to legal assistance in conjunction with harm reduction programming is invaluable for female drug users who experience particularly high levels of discrimination, stigma, and exploitation. For harm reduction and HIV treatment

programs in Ukraine, the link between legal protection and health promotion is intuitively clear. When clients have access to services to help them resolve some of their seemingly intractable problems, they are able to begin to focus on their health. In those programs that have been able to secure funding for legal services, staff have seen how the provision of legal services results in improved health outcomes.

In one case, an HIV-positive pregnant woman in Poltava was physically assaulted by police because she was a drug user, suffering kicks and punches to the head. Literally adding insult to injury, she was verbally taunted and discriminated against by the delivery room staff, including her own treating physician, because she was HIV-positive. They placed her on a cold concrete floor, refusing to provide her with a bed or blanket, saying that they would have to disinfect the bed and burn the blanket because she was diseased. Acting on her behalf, the Light of Hope harm reduction program scheduled a meeting with the head of the city health department, the head of the maternity ward, and the offending physician to address the situation. The doctor received a verbal reprimand, and the city promised that this abuse will not happen to any other HIV-positive pregnant women in the future. In this way, the program hoped to use one woman's case to bring about a larger change in the system.

For many current and former drug users, knowing that someone is willing and available to help them with their many legal and administrative hassles is empowering. For example, a client of a harm reduction program in Kherson decided to stop using drugs after the attorney associated with the program was able to secure a reduction in her criminal sentence. Clients of the harm reduction program in Lviv said that they were certain that the fact that they had access to legal assistance influenced the way that police treated them. Subject to frequent stops, searches, and arrests, these clients would simply show the police a card that they had been given with the lawyer's name and number, call the lawyer, and find her waiting at the station ready to fight for their rights. According to the lawyer, Mariya Kaminska, "If the client has the organization behind her, it shows the investigator that if he does things wrong, he'll have problems. If no one is protecting the client, the investigators will threaten her."

### *Win-win*

While there is not yet a perfect model for successfully integrating legal services into existing harm reduction and HIV prevention and treatment programs, much can be learned from the pilot programs that have designed their own

ways of providing services to clients. These programs have increased access to legal services by placing lawyers at sites where drug users access harm reduction services including needle exchange, counseling, and referrals to substance abuse treatment. Likewise, the programs have increased access to harm reduction by drawing in new users who come for the legal services and stay for the HIV prevention services.

Several recommendations emerge from these NGOs. For Ukraine, strengthening linkages between legal services and harm reduction programs will require:

- increasing funding for legal services within a harm reduction context;
- building the capacity of existing legal service providers by investing in professional development for individual lawyers so they can assist clients with their diverse legal needs;
- fostering communications and working relationships among professionals to share expertise;
- supporting publications and the strategic use of the media to both disseminate legal information to drug users and to educate the media about drug use to reduce stigma and sensationalism;
- investing in qualitative and quantitative evaluation and strategic planning; and
- using legal services as the basis for participatory policy advocacy.

Providers of legal services are in a position to document and analyze the most common forms of human rights abuses against drug-using clients. The experiences of clients, as told by their legal service providers, can help inform legal and policy reform at the regional, national, and international levels.

For NGOs, recommendations to maximize the scope and impact of their services include:

- establishing formal and informal networks between legal service providers to share best practices and materials;
- working towards empowering clients to advocate for their rights and represent themselves with administrative authorities; and
- engaging in evaluation efforts to review the demographics of clients served, legal problems addressed, outcomes, and client satisfaction.

Programs with a legal services component have seen drug users and sex workers who had previously been difficult to reach benefiting from HIV prevention

and treatment services as a result of their work with lawyers. The integration of these two services is a new concept that has demonstrated success and should continue in Ukraine and beyond.

**For more information about integrating harm reduction programs and legal services in Ukraine, contact Corinne Carey, consultant, Open Society Institute, at [corinne.carey@yahoo.com](mailto:corinne.carey@yahoo.com) (T: +917 517 6096) or read *Tipping the Balance: Why Legal Services are Essential to Health Care for Drug Users in Ukraine*, [www.soros.org/tippingthebalance](http://www.soros.org/tippingthebalance).**

## 4.

### The Law: What Have You Done for Sex Workers Lately?

Sex work is legal in Argentina but for years female sex workers have been arrested, extorted, and even assaulted by police, while brothel owners who operate illegally collude with the police to exploit women. Tired of the constant stream of violations against sex workers, Elena Reynaga decided enough was enough and coordinated AMMAR, the Asociación de Mujeres Meretrices de la Argentina (Association of Women Prostitutes of Argentina), to organize sex workers and challenge the laws that impede their equal rights.

#### *Organizing for recognition*

In addition to organizing sex workers, Reynaga established AMMAR nearly 14 years ago in 1994 to raise awareness of the discrimination and exploitation faced by sex workers, attain access to health services and education for sex workers, and promote skills-building initiatives to provide job alternatives to sex work for those who seek them.

One of the biggest successes for AMMAR was joining the Central de Trabajadores Argentinos (Argentine Workers Center – CTA) in 1995. Joining this union allowed recognition of sex workers as workers with basic rights.



Through their affiliation with CTA, AMMAR works with the national government to assist sex workers in obtaining identity papers and securing unemployment benefits. AMMAR also meets regularly with the Women's Commission in Parliament to discuss women's issues.

### *Challenging the law*

AMMAR operates across the country with a comprehensive set of programming that is designed to raise awareness among sex workers about their rights and their health, and raise public awareness about the rights of sex workers as equals under the law, subject to the same legal provisions as other workers.

AMMAR focuses its legislative work on two fronts: providing legal assistance to sex workers wherever possible to enable them to understand and stand up for their rights, and proposing direct legal challenges to repeal local ordinances that allow harassment of sex workers. One ongoing legal challenge is to repeal three articles of the code of misdemeanors and an article of the constitutional law of police which punish so-called “scandalous prostitution,” “offenses to modesty,” and transvestitism. The articles explicitly allow police intervention to ensure “good manners.” AMMAR has begun a national campaign to draw attention to these discriminatory articles as the first step in repealing them. In addition, AMMAR is reaching out to town councils directly, arguing that the articles are vague and allow the police to openly harass and abuse sex workers and others.

AMMAR has previously succeeded in striking down police decrees that have victimized sex workers in several provinces and has been working at a national level to change legislation that marginalizes sex workers by drawing attention to the discrimination that has been codified in the law. As part of the ongoing legislative efforts, AMMAR is challenging a regulation by the Argentine government that designates “red zones,” which limit where sex work is legal and render sex workers more vulnerable to abuse by brothels, pimps, and law enforcement.

### *A wide reach*

As part of a larger effort to educate and empower sex workers to exercise their rights, AMMAR staff also run peer education programs for more than 4,400 sex workers in 17 cities throughout nine provinces in Argentina. Using games like Bingo to make the information fun, peer educators focus on HIV and STI prevention strategies and condom negotiation skills to reduce unsafe sex practices. Condoms and lubricants are provided free of charge and referrals are made to local

health facilities for those who need them. Peer educators also ensure that women are aware of their rights to fair treatment both as women and as sex workers.

Nationally, AMMAR spends a great deal of time advocating for fair treatment of sex workers under the law and for provision of comprehensive health services that include testing and treatment for HIV and other STIs. Sex workers themselves who best understand the challenges faced by sex workers and who are best able to propose appropriate solutions undertake AMMAR's advocacy. AMMAR's activists have created a very public profile to bring attention to the plight of sex workers. They have organized protests demanding changes in the legal codes and are advocating for recognition as a Union of Sexual Workers. They've also created and disseminated legal and policy documents, held press conferences and distributed press releases analyzing the situation faced by sex workers.

### *National recognition*

AMMAR plays a leading role in the national recognition of sex workers as citizens. With a strong national secretariat and a decentralized system of volunteers across the country, AMMAR is a very visible presence among sex workers and government alike.

AMMAR recognizes that sex workers can better secure their human rights when they are united and continues to play a strong role at the national, provincial, and municipal level to coordinate health, education, human rights, and justice for female sex workers. An important lesson emerging from their work is that women must not feel they are alone. By working together, women are empowered to educate themselves, protect their health and families, and raise their unified voices for fair and equal treatment under the law. AMMAR's ability to coordinate sex workers on an individual level as well as to coordinate social services on a governmental level is the key to their profound and sustained development.

**For more information about AMMAR, contact Elena Eva Reynaga, secretary general, at [nacional@ammar.org.ar](mailto:nacional@ammar.org.ar) or [asesoria@ammar.org.ar](mailto:asesoria@ammar.org.ar) (T: +54 11 4342 0574) or visit [www.ammar.org.ar](http://www.ammar.org.ar).**

# It's Our Money: Making it, Tracking it, Spending it

Women bear a disproportionate burden of caring for the orphaned and the sick alongside their responsibilities to provide food and shelter for their own families. The double and sometimes triple duties of being the sole economic provider, houseworker, and caregiver exact a major and often unrecognized toll on women. Mounting evidence suggests that women's inheritance rights and economic independence enhances their empowerment and thus their ability to protect themselves from HIV.<sup>19</sup>

Economic empowerment strategies, therefore, represent one of the most important ways to tackle the epidemic among women. Poverty, dependence on men for financial security, lack of economic opportunities, gender inequality, and violence are all key underlying factors that contribute to the disproportionate impact of HIV on women. Property ownership, for example, provides women with security as well as a measure of status. Research in India shows that 49 percent of women who do not own property reported physical violence, compared with 7 percent of women who own property. Interventions that not only provide income, but also enable women to control and manage that income, will be critical in lifting women and girls out of poverty and reducing their vulnerability to HIV.

The strategies highlighted in these case studies all creatively support women's economic and financial means, both at a microeconomic and macroeconomic level. For example, microfinance lending programs can target women's broader

risk environment of gender inequality by assisting with basic income needs and addressing economic insecurity at the household level. At the global level, innovative funding mechanisms like the Global Fund to Fight AIDS, Tuberculosis and Malaria provide women with the opportunity to access resources for women-centered HIV support, treatment, and care programs. These two examples represent strategies that cut to the heart of gender inequality and empower women in practical ways that are crucial to fighting the feminization of the HIV epidemic.

The economic strategies highlighted in the following case studies convey three distinct themes. The first theme is that of women accessing and securing funds for and by themselves. The second theme addresses women—particularly stigmatized groups such as sex workers—steering, designing, and driving their own creative HIV peer prevention messages and interventions. The third theme relates to accountability and civil society’s watchdog role to ensure their government’s health budgets fairly and equitably reflect the priorities of women. All the organizations profiled here highlight innovative strategies pertaining to accessing the money, spending the money, and following the money. Most significantly, in each case, there is a fundamental women-centered approach that puts resources directly in the hands of women and enables them to shape funding to address their specific needs.

## IN THIS CHAPTER

Economic security at the household level is vital if women are to support their families and protect their health. Income generation opportunities also allow women a measure of autonomy and respect within their community. The IMAGE project demonstrates that combining small business loans with HIV and gender training programs can not only provide women with that economic security, it can also increase HIV-related communication and reduce intimate partner violence, thus improving women’s lives and reducing their HIV risk.

At the national level, countries must have a coordinated effort to address HIV prevention, treatment and care among women. NGOs working on women’s issues in Zambia created a coalition to prepare a joint proposal to the Global Fund to ensure that global monies flowed to groups addressing the needs of women and girls in an organized and effective manner. In doing so, members

of the Zambia Rainbow Coalition secured their own reputations as experts on what constitutes effective programming for women in Zambia.

Adequate funding for programming for women's needs is absolutely vital to stemming the HIV pandemic. After Brazil famously refused to sign the anti-prostitution pledge required by the United States in order to receive U.S. funds, sex workers at the NGO Davida established a sexy and sassy line of clothing to advocate for their rights and raise much needed funds for HIV programming. The Davida project is a great example demonstrating that when traditional funding sources are suddenly cut off, women are innovative in creating alternative sources.

Following the money is the most telling indicator of commitment to women's programming. Operating with the notion that what is budgeted is implemented, the Malawi Health Equity Network analyzes and publicizes the national health budget to ensure that adequate funding for women's HIV services is reaching those at the local level.

Today, we live in a world where more resources are available to fight AIDS among women and girls than ever before. But the existence of more funds for women does not necessarily translate into effective programs and strategies that reverse the feminization of the HIV epidemic. These savvy economic strategies have empowered women to advocate for themselves and ensure adequate resources are reaching the very women in need.

# 1.

## From Small Loans to Big Impact: Combining Microfinance with Gender and HIV Training

Gender inequalities in both relationships and communities can make women vulnerable to HIV infection because they do not have the power to protect themselves. Poverty, another driver of the HIV epidemic, forces many women to make survival choices that lead to poor health outcomes. In addition, millions of women around the world also face violence at the hands of their partners. These aspects combine to substantially increase women's vulnerability to HIV. Indeed, women now make up 61 percent of those living with HIV in sub-Saharan Africa. Identifying solutions that address each of these components is necessary to empower women and reduce their HIV risk.

The Intervention with Microfinance for AIDS and Gender Equity Project (IMAGE) is the first strongly evaluated intervention study to address the links between what UNAIDS calls the “triple threat” of poverty, gender inequalities, and HIV. Based in rural Sekhukhuneland, Limpopo Province, South Africa, IMAGE combined microfinance with a 10-part gender and HIV training program called “Sisters for Life” in order to test whether linking a microfinance program with participatory gender and HIV training could improve economic well-being, empower women, and lead to reductions in the risk of intimate partner violence and HIV.

### *Innovative combinations*

The project brought together two organizations: the Small Enterprise Foundation (SEF), a South African NGO that focuses on sustainable income generation, job creation, and social empowerment, and the Rural AIDS and Development Action Research (RADAR) Program—a collaboration between the School of Public Health, University of the Witwatersrand and the London School of Hygiene and Tropical Medicine that conducts clinical and social intervention research on HIV/AIDS and gender-based violence.

### *Reaching those in need*

Women living in the poorest households in villages were selected to participate

in the program. Using the Grameen Bank microfinance model, individual loans were given to solidarity groups of five women, who each served as guarantors for each other's loans. None could apply for further loans until all five had repaid their original loans. Women used the loans to support retail businesses, such as fruit and vegetable vendors, or second-hand clothing and tailoring businesses. Each group held fortnightly meetings to discuss loan repayments, share business strategies and provide support for each other. Over the course of the project, more than 1,750 loans with a total value of US\$290,000 were disbursed. Loan repayment rates were 99.7 percent.

Additionally, during the loan repayment meetings, RADAR's team of four trainers conducted one-hour participatory learning sessions that explored gender roles, culture, sexuality, communication, and relationships, as well as intimate partner violence and HIV. Following this training, participants elected "natural leaders" who then encouraged loan centers to mobilize their villages around these issues. IMAGE participants organized more than 40 village workshops and 16 meetings with leadership structures, five marches, two partnerships with local institutions, and formed two new village committees to address rape and crime in the community. Leading numerous HIV marches and the area's first "16 Days of Activism" march to end domestic violence, IMAGE women made headlines in their local newspaper.

## *Success*

The IMAGE study involved more than 850 women and 4,000 young people. Using a cluster-randomized design (which enables measurement of the overall effect of an intervention at the population level as well as the individual level) and both quantitative and qualitative methods, the project leaders assessed the impact of the interventions. They found that after two years, improvements in economic well-being and nine indicators of women's empowerment were observed among IMAGE participants, including self confidence; financial confidence; challenging gender norms; autonomy in decision making; perceived contribution to the household; communication within the household; relationship with partner; social group membership; and participation in collective action.

Furthermore, the risk of past year physical and sexual intimate partner violence was reduced by 55 percent. In relation to HIV risk, the greatest impacts were seen among those directly exposed to the intervention—young women participants reported higher levels of HIV-related communication, HIV testing, and greater condom use with non-spousal partners. The study also assessed indirect



impacts on 14-35 year-old males and females living within IMAGE households and villages. Although changes in sexual behavior were not observed among these groups within the two-to-three-year timeframe of the study, significant improvements in openness and communication about sex and HIV were documented among youth living in IMAGE households. The project has now expanded to reach an additional 4,000 women and will continue to scale up to reach 15,000 of the poorest households within 150 villages in rural South Africa.

### *Important lessons learned*

Several lessons emerge from this project that are relevant to stemming the tide of a growing HIV epidemic among women:

- Instead of focusing only on individual behavior change (for example, abstain, be faithful, use condoms), HIV interventions can and should target the broader environment that puts women at greater risk—including poverty, gender inequalities, and intimate partner violence.
- Although violence against women may appear culturally entrenched and resistant to change, it is possible to empower women and reduce intimate partner violence—and to do so within programmatic timeframes.
- Addressing basic needs (e.g. through income generation) can motivate vulnerable groups to maintain intensive contact with an HIV intervention over months to years—an opportunity rarely afforded most stand-alone health interventions.
- Building creative partnerships across sectors can generate practical, community-based approaches that are more likely to succeed. Microfinance is one vehicle. Other opportunities for integrating programs to reduce violence against women and HIV (e.g. job skills retraining, literacy, water and sanitation programs) should be explored.

**For more information about the IMAGE project, contact [eleannormacpherson@mac.com](mailto:eleannormacpherson@mac.com) or [pronyk@agincourt.ac.za](mailto:pronyk@agincourt.ac.za) or visit <http://web.wits.ac.za/academic/health/PublicHealth/Radar>.**

## 2.

# Uniting for a Common Goal: Securing Funds for Women and Girls

With one in seven residents infected with HIV, Zambia is experiencing the devastating personal, social, and economic impacts of a mature, generalized HIV epidemic. Life expectancy has fallen below age 40 and the number of orphans has increased dramatically. Women have disproportionately suffered the ravages of the HIV epidemic, but few programs are available that specifically target the needs of women and girls in Zambia.

### *Joining forces for a common goal*

The Zambia Rainbow Coalition on HIV/AIDS (ZRC) is a group of eight civil society organizations that came together in 2007, united by a common purpose: to secure funding for HIV prevention, treatment, and care interventions that meet the needs of women and girls in Zambia. The coalition formed to prepare a substantial proposal for women-centered HIV interventions to be included in Zambia's national application to the Global Fund to Fight AIDS, Tuberculosis and Malaria. In the end, the country did not participate in the Global Fund's 2007 application process so the ZRC has reconvened for the 2008 Round 8 funding cycle, in which Zambia will be participating.

The eight diverse ZRC organizations bring a unique perspective to the issue of HIV among women and girls and each are engaged in gender-specific HIV/AIDS activities. Together, their work covers all nine provinces in Zambia:

- **Family Health Trust**, established in 1987, is one of the oldest HIV and AIDS service organizations in Zambia. Its mission continues to be that of preventing and controlling the further spread of HIV and AIDS as well as to provide an integrated response to those infected and affected.
- The **Forum for African Women Educationists of Zambia** is one of the 33 national chapters of a network of leading African female education and research leaders strategically positioned to influence policy reform to be more responsive to the education needs of women and girls.
- The **Girl Guides Association of Zambia** runs programming to develop

girls' skill sets as well as their self-esteem in order to reduce gender inequalities.

- The **Network of ARV Users** is a network recently established to share experiences and challenges among ARV users, particularly women and girls.
- The **Society for Women and AIDS in Zambia** mobilizes traditional counselors and community-based volunteers to reduce women and girls' vulnerability to HIV and help those living with the virus to access treatment.
- The **Tasintha Programme** provides counseling and training for sex workers to protect themselves from HIV and other sexually transmitted infections.
- **Women and Law in Southern Africa** is part of a regional organization responding to the socio-legal needs of women, with a focus on rights-based approaches.
- The **Young Women's Christian Association** is dedicated to the empowerment of the community, especially women and children, and has mainstreamed HIV/AIDS into all women's human rights programming.

### *First things first*

The ZRC identified five critical areas in which to focus interventions for women: general prevention of HIV/AIDS among women and girls; women's access to treatment, care, and support; girls' education; marginalized and at-risk populations; and violence against women. Before developing interventions to address these issues, the ZRC needed to become a visible and recognizable authority on women and HIV in the eyes of the coordinating body that managed the country's Global Fund application process—the Country Coordinating Mechanism (CCM).

After establishing the ZRC Secretariat and guidelines to guide the interactions between member organizations, the ZRC held regular planning meetings to prepare the proposal of gender-specific HIV interventions and discuss how to ensure that the CCM included these interventions in the country's national proposal to the Global Fund.

### *A participatory process*

With financial and capacity-building support from UNAIDS, the Open Society Institute, and the Open Society Initiative for Southern Africa (OSISA), the ZRC sought widespread participation in the process of developing a strong gender-oriented proposal. Recurrent coalition member meetings as well as consultative meetings with organizations in six of the nine provinces were held to inform the gender proposal development group of the real needs of women and girls in Zambia. In addition, advocacy with the CCM members to include a strong gender-focused element to the country's national proposal was conducted regularly.

The results of these activities have been promising. The ZRC has been invited to review drafts of the national proposal and to be a member of the Technical Working Group on Gender—a subcommittee under the CCM responsible for ensuring that the national proposal adequately addresses gender issues. Further, Family Health Trust—the current chair organization of the ZRC—has been endorsed as a potential sub-recipient for Global Fund monies under the Zambia National AIDS Network.

### *Important lessons learned*

As of June 2008, the Global Fund Round 8 proposal process was not yet complete. However, the Zambia Rainbow Coalition's creation of a strong, unified voice for women and girls in Zambia has already demonstrated success in bringing gender-specific interventions to the forefront of a national effort to secure financial resources to fight HIV/AIDS. Key elements that have resulted in this successful process include:

- **On a coalition level**
  - > Spelling out clearly stated guidelines to guide the smooth interaction of coalition members
  - > Regular information sharing and planning meetings to help clarify the linkages between women's rights, gender-based violence, poverty and HIV/AIDS, thereby improving programming, the proposal content, and chances for successful funding
- **On a national level**
  - > Advocacy with key stakeholders, such as CCM members, to obtain endorsement of a gender-specific proposal

> Garnering support from other stakeholders, such as UNAIDS, OSI, and OSISA, which strengthened the process and provided international legitimacy

> Promoting consensus building through a consultative process, which helped to identify the real needs of Zambian women and build ownership of proposed project interventions

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### 3.

## On the Runway to Success: Using Fashion as an Economic and Advocacy Tool

*“Lost women are the most sought after.”*

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Stigma and shame often keep prostitutes<sup>20</sup> hidden from sight. Daspu puts them front and center. In fact, Daspu puts them on the catwalk demonstrating the latest fashion collection of t-shirts, skirts, trousers, dresses, and more. Conceived by retired prostitute Gabriela Leite in July 2005, the label was created as part of the nongovernmental organization Davida to strengthen the fight against discrimination of prostitutes and for better regulation of sex work in Rio de Janeiro. The provocative name is derived from “das putas” (“by whores”).

### *Innovative ideas*

Davida is one of the many organizations that have suffered financially since the United States instituted its “antiprostitution pledge” policy in 2003, which

requires HIV projects to sign a statement condemning prostitution in order to receive U.S. funds. Funds from Daspu sales go back into Davida to help support prostitutes and provide HIV prevention education. The mission of the Davida organization is to strengthen prostitutes' citizenship by helping them to organize as well as to defend and promote their civil and human rights.

Some of the very first clothes in the Daspu line were designed and produced by prostitutes from Davida, though several collections have now been completed with designer Sylvio de Oliveira. The collections are done in cooperation with various stylists and approved by the prostitutes.

The first fashion shows were held in December 2005 and January 2006, crowding the prostitution district in downtown Rio around Praça Tiradentes. The shows generated a great deal of excitement with significant local and international media coverage, divided between the Daspu show itself featuring Betty Lago, the ex-supermodel, actress, and activist, and the attendance of top model Gisele Bündchen who was in town to walk the catwalk for the traditional fashion event of the city—FashionRio.

### *Using humor to promote safer sex*

Daspu launched its first complete collection, Daspu On the Road BR-69, for Spring/Summer 2006-2007, at Circo Voador in Rio, with the pro-bono art direction of famous designer Gringo Cardia. Inspired by the world of truck drivers and highways, where prostitutes do business, the collection included a full range of skirts and dresses, blouses, tops, shorts, and bikinis. Several incorporated humorous phrases from bumper stickers, such as “Lost women are the most sought after.” The renowned movie director Neville de Almeida portrayed a truck driver on the catwalk. This same collection was later presented at the classic Glória Club, in São Paulo, featuring Miss Brazil 1996, Anuska.

The t-shirts that are part of the recent “Activism” collection focus on human rights and AIDS prevention and have been well-received by the public, mainly due to the ironic messages based on the issues affecting prostitutes: citizenship, freedom, sexuality, and AIDS prevention, among others. “We are bad, and we can be worse” and “Before the show, tune your instrument” are some of the messages that have made the t-shirts hot items.

By organizing fashion shows with prostitutes and supporters as models in red light areas, at AIDS conferences, and at art exhibitions, Daspu can publicize



safer sex messages and gain visibility for prostitutes in a lighthearted way to reduce the stigma surrounding sex work. In many ways, this approach has garnered greater visibility than traditional political tactics.

### *Reinvesting the income*

Raising money for sex work activism can be difficult. Daspu has enabled Davida to increase visibility for prostitutes through local, national, and international media by demonstrating that sex workers can be innovators in culture and art. Currently, income from Internet and store sales of the Daspu collections mainly funds the events needed to promote the line, but Davida plans to grow the business to produce and sell the clothes in large enough quantities for more stores to carry them or to open their own stores and combine the clothing with information on HIV prevention and sex workers' rights. By growing the business, more of the income from Daspu can be reinvested in Davida to continue advocating for the rights of prostitutes and helping them protect themselves from HIV and other sexually transmitted infections.

### *Fashion for change*

In July 2007, Daspu launched its Spring/Summer 2007-2008 Collection, CopaSicana (a play on the words Copacabana and *sicana*, meaning sexy), along with the book *As Meninas da Daspu* (The Daspu Girls), featuring interviews with nine prostitutes from Davida. This collection included the contribution of stylist Franklin Melo and his team. The Activism T-shirt line continued to be designed by Sylvio de Oliveira, and a literature and fashion event was held in a Rio bookstore for 300 people. Daspu was invited to the 2nd Edition of the Bienal Favela Festa at Circo Voador, where its models performed for leaders and artists from 60 poor communities in Rio.

For Gabriela Leite, who was a prostitute for 15 years and a pioneer of the activism movement in Brazil, Daspu is “turning prejudice upside down.” According to Ms. Leite, “When my prostitute friends walk so beautiful and proud, with no shame of being who they are, they are talking about their lives and becoming political revolutionaries. Daspu was a dream that came true. The road is open for the prostitute citizen. It’s *moda pra mudar* (fashion-to-change).”

**For more information about Daspu and Davida, contact Friederike Strack at [davida@davida.org.br](mailto:davida@davida.org.br) (Tel/Fax: +55 21 2224 3532 or +55 21 3298 5849) or visit: [www.daspu.com.br](http://www.daspu.com.br) or [www.davida.org.br](http://www.davida.org.br).**

## 4.

# Following the Money: Ensuring Equitable Financing for All

Severe poverty and ingrained gender disparities in Malawi have exacerbated the effect of HIV on women and children. Women now make up 60 percent of those living with HIV in the country and nearly 100,000 children are living with HIV, with roughly half a million orphaned children. The limited national health care budget—US\$14 per capita health expenditure in 2005—means that a large proportion of those affected by HIV are not being treated and cared for. With help from the World Health Organization and the Global Fund to Fight AIDS, Tuberculosis and Malaria, 81,000 of the nearly 200,000 people in need were receiving ARVs by the end of 2006. Even so, many more need treatment and care services that aren't receiving them.

### *Equitable financing*

The Malawi Health Equity Network (MHEN) serves as a watchdog of the national government's budget implementation and advocates for increased allocation for HIV and AIDS treatment. Since its formation in 2000 when the Health Advocacy Network and the Malawi EQUINET Chapter merged, MHEN has sought to influence health policies so that all people in Malawi have access to equitable, quality, and responsive health care services. Strategically located near the government offices in Malawi's capital city of Lilongwe, MHEN employs research, networking, monitoring, and advocacy strategies to ensure an equitable distribution of social services, including human resources, to ensure good health for all the people of Malawi.

### *Vigilant monitoring*

MHEN recognizes that the country's budget is the roadmap for putting Malawi's stated priorities into action. Keeping a close eye on what is budgeted is implemented and how much is allocated is the most effective way to ensure that policies and programs designed to reach vulnerable populations are enacted. MHEN closely monitors health financing with three key strategies:

- ***Training community monitors*** at the local level to survey available

services, to be sure that clinics are sufficiently stocked with necessary medications—including ARVs—and other supplies, and to ensure that district funds have made their way to the community level. These community monitors feed this information back to the district, regional, and national levels, thus serving as a “check” to hold each level accountable for their budget implementation.

- ***Advocating for equitable financing with national government.*** Through constant communication with community and district level monitors, the national coordinator of MHEN can convey what is happening on the ground to the National AIDS Commission and the ministries of finance and health. In the past year, MHEN successfully advocated for an increase in the overall health budget using local data to show that the current level of funding was insufficient to meet the country’s growing needs. The health sector budgetary allocation was increased from around 8 percent of the total 2006-2007 national budget to 14.5 percent of the 2007-2008 budget.
- ***Analyzing and publicizing the national budget.*** MHEN doggedly tracks down and analyzes drafts of the national budget before it is finalized and then publishes that analysis in the newspaper so that the public is aware of—and has the opportunity to weigh in on—how policies and programs are being funded.

MHEN also keeps a close eye on budget allocations by sitting on the Ministry of Health’s *Equity and Access Sub-Group*, a group of government, donors, and civil society organizations that are mandated to apprise the ministry and partners of relevant research related to health equity and wider poverty monitoring initiatives. The group is also charged with technically supporting the implementation of health interventions for the poor by reviewing the district allocation budgets and the distribution of resources between various levels of health care.

## ***Women and HIV***

MHEN is now beginning to turn its attention to the inequitable distribution of resources for women with HIV. It can be difficult to monitor these inequities because data is not often detailed by gender, but MHEN has begun by undertaking a desk study of the feminization of HIV and AIDS in Malawi and drafted

a presentation and several pieces of literature to draw attention to the needs of women in HIV prevention, treatment, and care. This material was presented at the Southern Africa Social Forum's HIV thematic group in October 2006.

In addition to the activities at the forum, MHEN has been integrating financial inequities in women's care with other HIV campaigns, including World AIDS Day and Health Day campaigns, as well as in their budget analysis reviews. Key to MHEN's successful campaigning has been the use of facts in their advocacy materials that come from the Ministry of Health and National AIDS Commission's own documents, thus making it difficult for the national agencies to disagree or dismiss the information. Another useful and powerful technique is the personalization of materials through the use of testimonials from women directly affected by HIV and AIDS.

MHEN's strategy to monitor and hold all levels of government accountable for the equitable allocation of crucial health care funding has been widely successful and can be a useful tactic to ensure that vulnerable women and children in Malawi receive the treatment and services they most desperately need.

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# Patience No More: Advancing Health Care for Women

The AIDS epidemic has heightened the need to ensure that women and girls have access to acceptable, available, and adequate health services. On World AIDS Day 2004, the World Health Organization called on countries to set national targets for treatment of women and girls and to take measures to ensure equitable access to AIDS prevention and treatment services.<sup>21</sup> To date, few national AIDS strategies have integrated interventions or allocated resources to ensure health services are tailored to the needs of women and girls. Marginalized women such as drug users and sex workers often find that health services are particularly inaccessible.

When working to provide access to health care, it is essential to consider external factors such as family obligations, domestic violence, material needs, travel requirements, and time constraints that may limit women's access. Ensuring equitable access to HIV and AIDS services requires innovative approaches that empower women to protect their own health. People with HIV, drug users, and sex workers have all called for the greater involvement of affected communities in health responses; only by involving these groups in service design and implementation can health programs respond effectively to their needs.

This chapter presents three case studies that demonstrate that it is, in fact, possible to provide women and girls with high-quality HIV and AIDS care if

proactive, realistic measures are taken to tailor services to their needs. Whether the project is working to provide health services to sex workers in Mexico City, HIV-positive drug users in Kyiv, or pregnant women in Durban, respect for human dignity and the right to health care is paramount. Model interventions include simple but critical adaptations such as reimbursing local transportation costs, expanding a waiting room to better accommodate families, or providing food and supplies to new mothers who are HIV positive.

## IN THIS CHAPTER

Adapting health services to the needs of women and girls requires a comprehensive care and support approach that addresses a full range of needs and minimizes the barriers encountered by women who want to access services. This is particularly true with underserved and marginalized populations. MAMA+ was established in Kyiv, Ukraine in response to the high rates of child abandonment among HIV-positive women and poor access to HIV testing and support to prevent perinatal transmission of HIV. MAMA+ acts as the entry point for a host of services for pregnant or parenting HIV-positive drug users, including child care, legal advice, a buprenorphine clinic, a drop-in center, an inpatient drug rehabilitation center, and counseling services. Women even receive home visits from staff, facilitating access for women unwilling or unable to travel to the center.

Health care services must respect women's rights and take their specific needs into account. In Mexico City, general public health clinics can often be hostile or abusive to sex workers, and fail to meet their specific health needs. To address this problem, the Asociación en Pro Apoyo a Servidores (Aproase) opened a medical center to provide sex worker-friendly health services and education. Although the center is open to the general public, it specifically addresses the needs of sex workers through sensitive service protocols and remaining open during hours convenient for sex workers.

In South Africa, disclosure of HIV status has been identified as a major barrier to PMTCT services because of the potential negative consequences, including violence, facing women who disclose their status. For this reason, the proportions of women accepting voluntary counseling and testing services and following through with antiretroviral medication when necessary is far lower than it should be. Researchers who initiated the South Africa HIV Antenatal Post-Test



Support Study believe that women who receive comprehensive post-test support will be more likely to disclose their status and access PMTCT services. The services include legal support for pregnant women's unique legal needs, facilitating other health behaviors including risk reduction, infant feeding, and disclosure.

In all three contexts, women and girls face high levels of discrimination and stigmatization in health care settings, reducing their willingness to seek services. In many contexts, there is double stigma and discrimination in health care settings and in communities: first because of gender and second because of socio-economic characteristics such as sex work, drug use, or poverty and lack of education. These case studies demonstrate that providing comprehensive services, adapted to the needs and realities of women, in a safe, respectful environment will increase use of health services for women and their families. Increased investment by donors and national governments in projects that support HIV prevention, treatment, and care approaches tailored to the needs of all women and girls is critical.

# 1.

## Bringing Up Baby: Linking HIV Programs and Motherhood Support

*The key to the project's success is partnership.*

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Ukraine has one of the fastest growing HIV epidemics in the world. Yet women who are pregnant and living with HIV have few resources to care for themselves and their infants. Since 1987, more than 18,000 children were born to HIV-positive women in Ukraine. The lack of support services and interventions have resulted in a 10 to 15 percent child abandonment rate. Linking HIV-positive pregnant women with the appropriate resources to help them take care of themselves and their infants is critical to providing hope in what seems like a hopeless situation.

MAMA+, also known as the Prevention of Abandonment of Children Born to HIV-Positive Mothers project, was launched by Doctors of the World-USA (DOW) in three cities of Ukraine—Kyiv, Donetsk, and Simferopol in July 2005 to provide such hope for women. Implemented in partnership with the All-Ukrainian Network of People Living with HIV and its regional representative offices, the project provides high-risk HIV-positive new mothers and pregnant women with services to empower them to keep their newborn children in the face of the many challenges ahead, including adjusting to their HIV status, social discrimination, lack of family support, and difficult economic or other life circumstances.

### *A comprehensive approach*

The critical first step in the MAMA+ approach is early identification and screening of pregnant women who are newly diagnosed with HIV. By identifying those most at risk and providing early support, MAMA+ staff can show

each expectant mother that she and her child can live a healthy life and help her access supportive resources available to her.

Women enrolled in the project receive a comprehensive set of services that meet their individual needs and improve the quality of life of both mother and child, including the following:

- Psychological counselling
- Social work support
- Material assistance
- Improved access to medical care, including ARVs and opiate substitution treatment
- Case management
- Regular home visits
- Counseling and workshops on topics such as parenting, health, harm reduction, self-esteem, safe sex, and relationships
- Employment training and job search coaching
- Peer support groups
- Mobile medical units for outreach to rural communities
- Family caregiver support

Such services have meant that 95-99 percent of MAMA+ clients have been able to care for their children in the family—an impressive achievement compared to baseline abandonment rates of up to 20 percent among HIV-positive mothers in some project sites.

### *Partnership: the key to success*

The key to the project's success is partnership. Each MAMA+ site has cooperated with an average of 16 governmental and NGO service providers. These relationships integrate women into the local health care systems. Partnerships for community-based MAMA+ implementation with maternity hospitals, women's clinics, children's infectious disease hospitals, AIDS centers, and NGOs ensure that women receive necessary support and also plant community roots for the project's long-term continuation. MAMA+ referral networks among service providers also remove barriers to client care and reduce stigma among providers. Not only does this model support HIV-positive pregnant women and new mothers, the MAMA+ project builds the capacity of service providers through training and partnership, thus increasing the potential of incorporating MAMA+ principles into local policies.

In just 30 months between 2005 and 2007, 150 representatives of state and non-governmental agencies were trained by DOW in the MAMA+ model on case management and early intervention techniques; 49 state institutions and NGOs participated in the MAMA+ project referral network and referred potential clients for services; 772 HIV-positive women were screened and received post-test counseling, referrals, and information about the project; and 230 new mothers were enrolled in MAMA+ support services. Of these, 228 children remained within their biological family environment and received project services (a 99 percent success rate); 11 infants born to HIV-positive mothers who were previously abandoned to state institutions were reunited with their biological or extended families.

### *Moving forward*

The MAMA+ referral network is a replicable model of social, medical, and psychological support for HIV-positive women with infants. DOW has documented and disseminated its best MAMA+ practices, including a publication of MAMA+ Case Management guidelines, a photo exhibit and photo album entitled “MAMA+: Helping HIV-Affected Families,” and a MAMA+ training movie and posters.

The MAMA+ project has been successful in enhancing prevention of mother-to-child transmission efforts and linking HIV-affected and injection drug-using young women into care. It also demonstrates that prevention of early abandonment of children born to HIV-positive mothers is an efficient and effective approach in preventing AIDS-related orphanhood. A key component to the success of MAMA+ has been the involvement of people living with HIV/AIDS as project implementers, ensuring that stigma and discrimination are reduced.

However, the sustainability of MAMA+ and other effective interventions is endangered in Ukraine due to the absence of stable state funding and the lack of a mechanism for the government to contract NGOs to provide social services to marginalized populations. Ukraine also still lacks a comprehensive social network of professional and peer support for HIV-affected women, children, and their families. A continuum of care and support has yet to be developed to provide MAMA+ graduates with a stable and sustainable future. Such support would include services for housing, vocational training and employment, day care, and education for children. This support is vital in order to continue the MAMA+ success of helping marginalized and disenfranchised mothers to gain

the confidence, knowledge, skills, and other assets needed to retain guardianship of their children.

**For more information on MAMA+, contact Erin Finnerty, program manager, DOW-USA at [Erin.Finnerty@dowusa.org](mailto:Erin.Finnerty@dowusa.org) (T: +1 212 226 9890) or Halyna Skipalska, acting country director, DOW-USA in Ukraine at [Halyna.Skipalska@dowusa.org](mailto:Halyna.Skipalska@dowusa.org) (T/F: +38 44 4254613 or +38 44 4923148; Mobile: +38 50 4115556), or visit [www.dowusa.org](http://www.dowusa.org) and [www.dowusa.org.ua](http://www.dowusa.org.ua).**

## 2.

# Do No Harm: Providing Sex Worker-Friendly Health Services

HIV is a concentrated epidemic in Mexico with much higher prevalence rates among men who have sex with men (12.6 percent), commercial sex workers (6.6 percent), and injecting drug users (1.2 percent) than among the general population (0.3 percent)<sup>22</sup>. Sex workers face a particular burden because they are stigmatized as disease carriers and consequently regulated by health control workers. Sex work is not illegal in Mexico (though it is illegal for a third party to profit from sex work) but sex workers are often subjected to mandatory HIV testing as a condition for working. This mandatory testing and its attendant costs—which are borne by the worker—is associated with rampant human rights violations, many of which are carried out by the very medical centers where women seek treatment. Sex workers have reported being subjected to discrimination, including receiving substandard medical care, and even physical violence during attempts to force them to take HIV tests.

### *Sex worker-friendly services*

The Asociación en Pro Apoyo a Servidores (Aproase) is a nongovernmental organization dedicated to providing health services and support to sex workers in Mexico. It began in 1985 as an association of women sex workers fighting for their human and labor rights and in 1997 it launched a medical center to provide health services and health education to sex workers. The medical center

operates according to sex workers' schedules and provides voluntary HIV testing and counseling according to their needs. Its aim is to provide STI and HIV services to sex workers without the stigma and discrimination often found in the public health services centers.

The medical center has since expanded to provide services to all women, regardless of their occupation or socioeconomic status. By broadening its client base, Aproase has been able to reduce the stigmatization attached to the center, which in turn has attracted sex workers who previously did not access the center for fear of being "outed" as sex workers.

### *Colposcopy=health=life*

In addition to its focus on HIV and STI services, the medical center offers complete medical consultations, including colposcopy to detect pre-cancerous lesions in the cervix. The center's COLSAVI initiative (Colposcopía = Salud = Vida) has become a popular program, reaching an average of 60 women per month with diagnosis and treatment services for human papillomavirus (HPV) and cervical cancer. Once there, these women also have access to comprehensive HIV services.

### *More than just health services*

Aproase takes a comprehensive approach to supporting sex workers' health in Mexico. In addition to respectful gynecological consultations and treatment and appropriate pre/post-test counseling for HIV, Aproase provides:

- **Peer education** covering HIV, HPV and other STIs as well as awareness about breast and cervical cancer. Sex workers are also coached in correct use of male and female condoms and negotiation techniques for using condoms with clients and partners. This approach has been successful because women feel more comfortable asking questions when the answers are coming from their peers, and the information is provided without judgment.
- **Advocacy** to defend the labor and health rights of sex workers. Aproase lobbies the public health service centers to reduce stigma and discrimination against sex workers and is advocating for a law to recognize sex work as an official job with basic rights.

- **Networking** for sex workers as Mexico's focal point for RedTraSex, the Latin American and Caribbean Sex Worker Network, which advocates for the universal human rights of sex workers.

### *Sex workers taking charge*

One of the most important lessons learned from Aproase's activities is that when training sessions, campaigns, and peer education programs are created by sex workers for sex workers, acceptability among women improves, stigma is reduced, and new challenges can be identified and immediately addressed. By raising awareness among sex workers about the importance of taking charge of their own health care and reducing the stigma associated with doing so, Aproase is providing a uniquely tailored service for sex workers in Mexico to prevent HIV and meet their other sexual and reproductive health needs.

**For more information about Aproase, email [aproase@yahoo.com](mailto:aproase@yahoo.com) or [cynthia\\_navarrete@msn.com](mailto:cynthia_navarrete@msn.com).**

## 3.

### Getting Results: Studying an Enhanced Support Model for Pregnant Women

The HIV epidemic has grown to such a level that AIDS is now the leading cause of death in South Africa. Women between the ages of 25 and 29 are the most severely affected, with HIV rates between 32-34 percent according to data from antenatal clinic (ANC) sentinel surveillance sites and population-based studies. Preventing mother-to-child transmission of HIV is of critical importance to halting the epidemic. However, in South Africa—a country where more than 85 percent of pregnant women deliver in a health facility and the average number of ANC visits per woman exceeds the national target—far fewer women than expected (only 23 percent) access voluntary counseling and testing services and only 56 percent of women who test HIV-positive receive ARVs to prevent perinatal transmission.



### *Fear about disclosure*

A review of the literature indicates that women who test in the context of antenatal care are the least likely to disclose their status and the most likely to suffer negative social consequences such as violence when they do disclose. For this reason, disclosure could be a barrier to the efficacy of services aimed at prevention of mother-to-child transmission of HIV (PMTCT). Enhancing the counseling services associated with PMTCT programs may address women's fears and increase uptake of testing, counseling, and ARVs, thereby reducing perinatal transmission.

### *A study of integrated services*

The South Africa HIV Antenatal Post-test Support Program (SAHAPS) is a randomized controlled trial that is designed to evaluate the impact of enhanced HIV post-test support, including legal support, for HIV-positive and HIV-negative pregnant women in Durban, South Africa. The study will help determine whether providing women with enhanced, integrated support following HIV testing will result in better outcomes, including higher rates of participation in PMTCT, greater risk reduction between partners, and better psychosocial conditions for women.

This is a collaborative research study being conducted by faculty at The University of North Carolina at Chapel Hill, School of Public Health and the University of KwaZulu-Natal, Nelson Mandela School of Medicine. Investigators from these institutions have combined their expertise in social and behavioral research related to HIV counseling and testing with biomedical research on prevention of mother-to-child transmission. Other partner institutions involved in the implementation of the study include the University of KwaZulu-Natal Faculty of Law, the University of Stellenbosch, Department of Psychology, and the Medical University of South Carolina Department of Psychiatry and Behavioral Sciences. Funding for the study comes from the National Institutes of Child Health and Human Development. Supplemental funding for the legal post-test support components comes from the Open Society Institute and the Elton John Foundation.

The study will enroll 1,495 women when they seek antenatal care at a public clinic in Umlazi, one of the poorest townships in Durban. Each woman who participates in the study will be followed for nine months after giving birth. Enrollment for this study began in May 2008 and follow-up is expected to continue until July 2010.

## *Enhanced support*

The enhanced post-test support model is being compared to the standard model of HIV counseling and testing that provides a pre- and post-test counseling session for women. The objectives of the enhanced post-test support model are:

- **To meet pregnant women's psychosocial needs during pregnancy.** Evidence suggests that women who test positive for HIV during pregnancy have ongoing psychosocial needs related to status disclosure, infant feeding, and family planning that are not being met by counseling protocols. Currently women receive one HIV pre-test and one HIV post-test counseling session with lay counselors. HIV counseling protocols have not been appropriately adapted for HIV testing during pregnancy.
- **To improve health outcomes of women, their partners, and their infants.** Addressing women's ongoing psychosocial needs through comprehensive post-test support may lead to better outcomes for women, their partners, and their infants. Greater awareness of HIV status among couples can lead to more informed choices about risk behaviors and family planning. Partner awareness of status has been shown to be the most significant predictor of women's infant feeding choices.
- **To integrate legal support into HIV post-test support services.** Comprehensive HIV post-test support for women represents an opportunity to address women's legal needs. Legal support organizations in South Africa report a large unmet need for legal services among women. Pregnant women have unique legal needs that may facilitate other health behaviors including risk reduction, infant feeding, and disclosure.

While there are models for providing free legal counsel to women in KwaZulu-Natal, there are no existing models of integrating legal support into HIV post-test support for women. The referral links between the legal and health service organizations are weak and there is little communication between the organizations that provide legal counsel and the organizations that provide medical care to women.

## *Study design*

Women at the Umlazi clinic who are randomly selected to be the control arm of the SAHAPS study receive standard WHO/CDC pre- and post-test HIV counseling and will have brief follow-up sessions with counselors six and ten weeks

after giving birth. Women who are selected at random for the intervention arm receive enhanced HIV counseling and testing services including:

- a standardized health education video before HIV pre-test counseling;
- HIV pre- and post-test counseling sessions that prepare women for decisions related to testing, serostatus disclosure, and ARV prophylaxis, and help women plan strategies for sexual risk behavior change;
- two additional post-test counseling sessions which coincide with six- and ten-week postpartum visits to the clinic for baby immunizations—the six-week visit focuses on legal education and referral; the ten-week visit focuses on family planning and reviews previous issues discussed;
- an active referral system to post-test support groups run by a staff psychologist; and,
- an active referral system to legal services provided one day a week at the clinic by University of KwaZulu-Natal Campus Law Clinic attorneys and students.

### *Helping women through enhanced support*

It is crucial that feasible strategies be identified to better integrate PMTCT, Voluntary Counseling and Testing (VCT), legal support, and reproductive health programs in order to slow the spread of HIV. The SAHAPS study is designed to comprehensively address the health, psychosocial, and legal issues that women face when they test HIV-positive.

**For more information about the SAHAPS Study, contact Dr. Suzanne Maman, The University of North Carolina at Chapel Hill, School of Public Health, Department of Health Behavior and Health Education, [maman@email.unc.edu](mailto:maman@email.unc.edu) or call +1 919 966 3901.**

# Notes

1. UNAIDS/UNFPA/UNIFEM. 2004. *Women and AIDS: Confronting the crisis*.
2. WHO/UNAIDS/UNICEF. 2008. *Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector*.
3. Nancy Luke and Kathleen Kurz. 2002. *Cross-generational and transactional sexual relations in sub-Saharan Africa: Prevalence of behavior and implications for negotiating safer sex practices*, International Center for Research on Women (ICRW) and Population Services International (PSI).
4. Global Coalition on Women and AIDS and WHO. 2004. *Violence against women and HIV/AIDS: Intimate partner violence and HIV/AIDS*. Information bulletin series, Number 1.
5. WHO. 2005. *Multi-country study on women's health and domestic violence against women: initial results on prevalence, health outcomes and women's responses*.
6. WHO. 2006. *Addressing violence against women in HIV testing and counseling: a meeting report*.
7. For instance, see Human Rights Watch, *Rhetoric and risk: human rights abuses impeding Ukraine's fight against HIV/AIDS*, March 2006.
8. Susan Paxton and Alice Welbourn. 2004. "Oh! This one is infected!": *Women, HIV & human rights in the Asia-Pacific region*.
9. WHO/UNAIDS/UNICEF. 2008. *Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector*.
10. WHO. 2006. *Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants: Towards universal access, recommendations for a public health approach*.
11. *ibid*.
12. Cynthia Eyakuze, Debra Jones, Ann Starrs, Naomi Sorkin. 2008. "From PMTCT to a more comprehensive AIDS response for women: a much-needed shift," *Developing World Bioethics* 8(1), 33-42.
13. Anna-Louise Crago. 2008. *Our lives matter: Sex workers unite for health and rights*. Sexual Health and Rights Program, Public Health Program, Open Society Institute.
14. Open Society Institute. 2007. *Women, harm reduction, and HIV*. International Harm Reduction Program, Public Health Program, Open Society Institute.
15. Sophie Pinkham and Kasia Malinowska-Sempruch. 2008. "Women, harm reduction and HIV," *Reproductive Health Matters*, 16(31): 168-181.
16. *ibid*.
17. Harm reduction is a pragmatic and humanistic approach to diminishing the individual and social harms associated with drug use, especially the risk of HIV infection.
18. Geeta Rao Gupta, "Approaches to Empowering Women in the HIV/AIDS Pandemic: A Gender Perspective," Expert Group Meeting on The HIV/AIDS Pandemic and its Gender Implications, 13-17 November 2000, Windhoek, Namibia.
19. Global Coalition on Women and AIDS: Economic Security for Women FIGHTS AIDS, Issue #3.
20. Davida requested that the terms "prostitute" and "prostitution" be used in this section of the report. OSI uses the term "sex worker" because it does not have negative cultural, historical, and linguistic meanings.
21. <http://www.who.int/mediacentre/news/releases/2004/pr86/en/>
22. CENSIDA 2006.

## **Open Society Institute**

The Open Society Institute (OSI), a private operating and grantmaking foundation, aims to shape public policy to promote democratic governance, human rights, and economic, legal, and social reform. On a local level, OSI implements a range of initiatives to support the rule of law, education, public health, and independent media. At the same time, OSI works to build alliances across borders and continents on issues such as combating corruption and rights abuses. Investor and philanthropist George Soros created OSI in 1993 to support his foundations in Central and Eastern Europe and the former Soviet Union. OSI has expanded the activities of the Soros foundations network to other areas of the world where the transition to democracy is of particular concern. Today, the Soros foundations network encompasses more than 60 countries, including the United States.

## **Public Health Program**

The Open Society Institute's Public Health Program aims to promote health policies based on social inclusion, human rights, justice, and scientific evidence. The program works with civil society organizations to promote the participation and interests of socially marginalized groups in public health policy and foster greater government accountability and transparency through civil society monitoring and advocacy, with a particular emphasis on HIV and AIDS. Program areas focus on addressing the human rights and health needs of marginalized persons and advocating for a strong civil society role in public health policy and practice.

## **Public Health Watch**

Public Health Watch is an initiative of OSI's Public Health Program that aims to strengthen meaningful and sustained engagement by infected and affected communities in the development, implementation, and monitoring of TB, HIV and TB/HIV policies, programs, and practices. Public Health Watch supports advocates to identify, document, and articulate priority human rights issues, and to press for accountability at the national, regional, and global levels. Specifically, Public Health Watch engages in and supports national, regional and global advocacy to press for TB and HIV policies that are informed by community perspectives and scientific evidence; and enhances and supports the capacity of community-based advocates to monitor and document TB and HIV responses, and push for action on their recommendations.

**[www.soros.org/health](http://www.soros.org/health)**



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The disproportionate impact of the AIDS pandemic on women and girls is clear. The additional barriers faced by women and girls in obtaining appropriate services and care—including stigma and discrimination, violence, lack of information, and poverty—have been well documented. Yet effective strategies to address these barriers and the underlying factors contributing to them have received less attention.

*Strategies for Change: Breaking Barriers to HIV Prevention, Treatment, and Care for Women* examines innovative empowerment, legal, economic, and health services strategies for a more “woman-friendly” response to HIV. This report highlights the efforts of HIV activists, women’s advocates, and health experts to address the needs of women who are often marginalized by society, including sex workers, drug users, and women living with HIV.

The programs described in this report vary widely in scope, targets, and implementation, but they all put women at the center. They were designed for, and in many cases, by the specific population of women whose needs are being addressed, whether they are rural grandmothers in Swaziland or sex workers in Rio de Janeiro.

It is our hope that this publication will be a resource and an inspiration for those engaged in the fight against HIV to support efforts that reflect and meet the diverse needs of women.

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