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# INTRODUCTION



Over the last decade, the interplay between sexual and reproductive health and rights and women's vulnerability to HIV has become increasingly recognized by activists from the grassroots up to the global policy arena. For women living with HIV, stigma and discrimination and gender-based violence acutely affect their access to comprehensive services and human rights. Within health services, they often face a lack of choice with regard to family planning; disapproval from service providers with regard to meeting sexuality and fertility desires; and violence in the form of coerced or forced abortion or sterilization. It is clear that advancing the health and rights of women in all their diversity is fundamental to the success of the HIV response, just as the HIV response is a critical avenue for achieving sexual and reproductive health and rights for women.

Building from and contributing to this increasing recognition, the ATHENA Network and UNAIDS have collaborated to identify key examples of community innovation to achieve sexual and reproductive health and rights through the HIV response, and vice-versa. As we move forward from the 2011 High Level Meeting on AIDS, and in light of the Millennium Development Goals, it is a watershed moment to learn from country experiences on how the promotion of gender equality, human rights and efforts to address HIV are all linked and benefit from joint action. Specifically, these must include the empowerment of women; improvements in maternal and child health; and attention to sexual health and sexual diversity.

This work has been undertaken in the context of the UNAIDS *Agenda for accelerated country action for women, girls, gender equality and HIV*<sup>1</sup> and the UNAIDS *Getting to zero: strategy 2011–2015*.<sup>2</sup> Creating an enabling environment for women in all their diversity – especially for women living with HIV – to access services and fulfil their human rights, is one of the central tenets of the UNAIDS Agenda for Women and Girls. Equally important is the support for leadership and meaningful participation by networks of women living with HIV, and other women's groups, in addressing gaps in services and barriers to achieving women's rights to sexual and reproductive health. Further, the UNAIDS Agenda highlights the importance of increased knowledge and understanding of the needs of women and girls in the context of HIV, and the use of such knowledge to create evidence-informed policy, programmes and practices.<sup>3</sup>

# EXECUTIVE SUMMARY

The case studies that follow, from across sub-Saharan Africa, South Asia, Europe and Central Asia, Latin America and North America, highlight the rich diversity of community initiatives that bridge sexual and reproductive health and rights and HIV. The report has a strategic emphasis on the innovation that is being led by women living with HIV and features pioneering endeavours that reflect community and key stakeholder interpretation and understanding of how this intersection is defined. It profiles initiatives that have emerged from within the HIV sector as it broadens out to encompass a sexual and reproductive health and rights approach, as well as initiatives that have emerged from within the women's health and rights sector as the latter has taken on HIV-related services and programmes; showing that both sectors are taking steps to integrate services and build synergies.

The strategies profiled cover and demonstrate a broad spectrum of the overlap between sexual and reproductive health and rights and HIV. The case studies in Chapters 1 and 4 address how gender-based violence, harmful gender norms and taboo issues affect women as causes and consequences of HIV. The importance of prioritizing women on the margins and engaging young people through comprehensive sexuality education is also investigated in Chapters 3 and 7. The case studies profiled in Chapter 5 demonstrate HIV-positive mothers in the United Kingdom and Uganda providing leadership and peer support around positive pregnancy. Elsewhere, the report examines how reproductive justice for women of colour, promoting the rights of sex workers and members of sexual minority communities and better integration across intersecting movements are being achieved.

The main lesson to draw from this broad range of strategies is the importance of community engagement and the key leadership role that women living with HIV have to play in tailoring the HIV response to their needs. When HIV and sexual and reproductive health and rights providers come together to empower affected communities to take the lead, enabling environments are created that help to open discussion, improve knowledge of the issues affecting women living with HIV, and ultimately improve access to comprehensive and holistic services that advance women's and girls' health and rights. Effective initiatives include training members of the community as advocates, providing safe arenas for open discussion and engaging men as co-drivers of social change.

Through documenting and expanding our understanding of and approaches to the intersection of sexual and reproductive health and rights and HIV, it is hoped that efforts toward integration of services will be strengthened in practice. This is a unique opportunity to give community innovation and leadership greater attention and thus help to champion gender equality and achieve health and human rights for all.

# 1. Breaking the silence on taboo issues



Ipas, ICW Malawi,  
Namibia Women's  
Health Network

## Women living with HIV in Malawi and Namibia: key advocates for sexual and reproductive health and rights

Women face unique obstacles and challenges to accessing and fulfilling their sexual and reproductive health rights, and as a result they are less able to access HIV prevention, care and support services. However, creating enabling environments within the community; empowering men and women within the community as standard bearers for gender equity; and forging better links between HIV and women's rights movements, can begin to tackle these problems.

In both Malawi and Namibia, gender inequality, illiteracy (especially among rural women), early sexual debut, early marriage, pregnancy-related complications and violence against women and girls all present barriers to women achieving sexual health or exercising independent sexual and reproductive choice. In particular, maternal mortality continues to be a priority for women's health activists. Unsafe abortion-related complications account for up to a third of maternal deaths in these countries, yet the issue is still shrouded in stigma and often neglected in advocacy. Additionally, a lack of access to, and accurate information about, timely and appropriate contraceptive options for women, including young women and women living with HIV, as well as gender inequality frequently expressed in high rates of violence against women and girls, mean that women and girls have less power to negotiate sexual and reproductive choice in relationships or health services.

However, networks of women living with HIV, together with relevant stakeholders, are coming together to tackle these problems and are taking the lead in breaking the silence around the taboo issues of unwanted pregnancies and abortion.<sup>45</sup>

### Malawi

In Malawi, Marie Khudzani Banda, together with the International Community of Women Living with HIV/AIDS (ICW) and with support of Ipas, mobilized ICW members around sexual and reproductive health and rights – particularly focusing on reproductive choice.

ICW members then carried out a series of community meetings with HIV-positive women focusing on the topics of contraception, early pregnancy, unwanted pregnancies, and unsafe and safe abortion, with the aim of breaking the taboo and reducing stigma associated with abortion.

**“It is obvious that we cannot achieve our MDG 5 target of 155 [maternal deaths] per 100,000 if abortion deaths alone are responsible for 200 deaths per 100,000 live births on our current maternal mortality rate of 807 per 100,000.”<sup>6</sup>**

David Mphande, Malawi's Health Minister

During community meetings, held in three districts of Malawi, women were invited to tell stories about experiences of unwanted pregnancy and abortion, if needed in a private encounter. This activity had a two-fold intent: to create a safe environment in which to give voice to women whose experiences are often silenced by stigma, and to collect stories for the production of a booklet that could be used

as an advocacy tool to raise awareness and mobilize around the issue of safe abortion. The resulting booklet, which includes eleven stories about abortions and three stories about women who decided to carry the unintended pregnancies to full term, is an important tool for awareness-raising and advocacy at local, national, regional and international levels. The process of collecting stories has helped to destigmatize unwanted pregnancy and abortion, and provided opportunities for women to share common experiences.

The community meetings also provided an opportunity to strengthen alliances and relationships with other organizations working on issues of abortion and sexual and reproductive health and rights. Ipas has also helped raise the visibility of the national ICW network in Malawi by including ICW members in meetings associated with a strategic assessment on unsafe abortion carried out by the World Health Organization (WHO) and the Ministry of Health also members of ICW have joined the National Coalition for the Prevention of Unsafe Abortion.

### Malawi

- Generalized HIV epidemic (prevalence at 11% in 2009).
- Women account for 59% of those living with HIV.
- Girls aged 15–17 account for 24% of maternal deaths.
- Abortions only permitted in order to save a woman's life; otherwise punishable by 14 years imprisonment.
- As a result, backstreet abortions are common.

Sources: [UNAIDS report on the global AIDS epidemic 2010](#). Geneva, UNAIDS, 2010.

De Bruyn M, Banda MK. [Expanding reproductive rights knowledge among HIV-positive women and girls. Tackling the problem of unsafe abortion in Malawi. Final project report](#). Chapel Hill, Ipas, 2010.

### Namibia

The Namibia Women's Health Network, a national organization by and for women living with HIV, is at the forefront of sexual and reproductive health and rights advocacy and agenda setting with new reach and new possibilities emerging each day. Its strategies, developed in collaboration with Ipas, include community workshops; training young people and women living with HIV as sexual and reproductive health and rights advocates, particularly around the issues of communication and decision-making; and local- and national-level advocacy on access to contraceptives. Additionally, the Network is pioneering litigation to address the coerced and/or forced sterilization of women living with HIV and forging alliances to expand their advocacy around unwanted pregnancies, "baby dumping" and safe abortion with partners such as the Namibia Planned Parenthood Association.<sup>[i]</sup>

### Namibia

- Generalized HIV epidemic (prevalence at 13% in 2009).
- Women account for 59% of those living with HIV.
- Maternal mortality in 2008: 449/100,000 births.
- Estimated third of maternal deaths due to complications following illegal, unsafe abortion.
- 59% of women who die due to illegal, unsafe abortions are under the age of 25.
- Unlikely to meet targets for MDG 5.

Sources: [UNAIDS report on the global AIDS epidemic 2010](#). Geneva, UNAIDS, 2010.

De Bruyn M, Mallet JG. [Expanding reproductive rights knowledge and advocacy with HIV-positive women and their allies in Namibia. An action-oriented initiative. Summary report](#). Chapel Hill, Ipas, 2010.

[i] The Network has also secured a seat on the Technical Working Group for the Removal of Discriminatory HIV/AIDS-related Laws, Regulations, Policies and Practices, led by the Ministry of Justice with the assistance of UNAIDS.



The training of people aged 17–35 as sexual and reproductive health and rights advocates, or “youth peer educators”, was organized in tandem with community dialogues, utilizing a series of ten knowledge- and skills-building workshops on sexual and reproductive health and rights, including abortion and related issues. The workshops resulted in more positive attitudes among participants to issues around HIV-positive women’s sexual and reproductive rights and abortion, and an increased enthusiasm to declare those positive attitudes openly in the community. Demand for additional workshops, from young people and adult community members, has occurred as a result of this enthusiasm.

The Network has also seen success in its advocacy for post-exposure prophylaxis (PEP) and emergency contraception. By utilizing radio, newspaper articles and other mass media, members of the Namibia Women’s Health Network working with youth mobilizers at local and national level, ensured access to PEP, emergency contraception and counselling for rape survivors at a local clinic in Dordabis. This success was the tipping point for access to PEP and emergency contraception in other clinics in the Katatura district of Windhoek.

### Looking forward

The initiatives in Malawi and Namibia demonstrate the importance of HIV-positive women’s leadership around sexual and reproductive health and rights issues. By placing HIV-positive women’s networks firmly at the forefront of knowledge and advocacy efforts around unwanted pregnancy, safe abortion and violence against women and girls, the initiatives have been able to mobilize dialogue and break long-held silences around taboo issues, at both community and policy levels. In conclusion, engagement of women and girls living with HIV is critical for initiatives around maternal and child health, including prevention of vertical transmission, requiring stepped-up investment in their capacity and leadership skills.



## Engagement of men and boys in South Africa: advancing social change around reproductive choices

Positive male attitudes towards abortion, and women exercising independent sexual and reproductive choice, are key to continuing progress towards gender equity. In order to enact social change in this regard, men and boys must be engaged through peer and community education in a variety of settings.

Engaging men and boys for social change, as supporters of women's rights and gender equality, is fundamental to halting violence against women and girls; advancing sexual and reproductive health and rights for women, men, girls and boys; transforming harmful masculinities; and addressing socio-cultural practices that are harmful to the health and rights of women and girls, men and boys. This is recognized by both the UNAIDS Agenda for Women and Girls, which calls for strengthened collaboration between women's organizations and networks and men's organizations<sup>7</sup>, and the UNAIDS Strategy 2011-2015, which "*emphasizes the importance of actively engaging men in addressing negative male behaviour and changing harmful gender norms such as early marriage, male domination of decision-making, inter-generational sex and widow inheritance*".<sup>8</sup>

A leading example of the work to engage men and boys for social change is the flagship One Man Can campaign of the Sonke Gender Justice Network. By encouraging men to adopt attitudes of greater responsibility, openness, support and respect with regard to choices and decision-making around sexual and reproductive health issues, this organization works to promote gender equality; prevent domestic and sexual violence; and to reduce the impact of HIV. Through this work, Sonke has found that family planning and termination of unwanted pregnancy sit at an intersection of complex gender roles and responsibilities in relation to sexual and reproductive health and rights. Men are generally seen as being in the driver's seat when it comes to sexual and reproductive decision-making, yet women are expected to take responsibility for family planning, including accessing contraception.

The above severely affects the utilization of safe abortion services, even in South Africa where, under the Choice of Termination of Pregnancy Act of 1997, women of any age are eligible to access an abortion up to thirteen weeks into the pregnancy, with no obligation to seek consent from a male partner or family member, or to disclose the termination. Nevertheless, many South African women continue to put their health and life at risk by seeking backstreet abortions for a variety of reasons. Knowledge relating to the legal status of abortions is uneven and often inaccurate. Even when women are aware of their right to terminate a pregnancy, they may still seek backstreet services due to the high stigma around termination of pregnancy or out of a fear that their partner will learn of the abortion through indiscretion by the service provider or other community members. Such disclosure may result in conflict with, or violence from, their partner, or even bring about the end of the relationship, when the termination of pregnancy is seen as an irreparable breach of trust.

Sonke's Khayelitsha Termination of Pregnancy Community Project, which ran from January 2009 to March 2010, aimed to educate and involve men in matters pertaining to their and their partners' sexual and reproductive health and rights, and to create safe and stigma-free access to abortions in the community. The project inspired a broader campaign across South Africa, to engage men and boys in halting domestic and sexual violence and to prevent the spread of HIV.

The Khayelitsha project trained twelve peer outreach workers using Sonke's One Man Can programme tools, and provided them with mentoring to identify and reach large numbers of men in the community. Men were reached through soccer clubs, drinking establishments, clinics, community-based organizations, parks and even in their homes. Community education techniques used to engage the men included door-to-door campaigns, "ambush theatre"<sup>[ii]</sup>, organized debates, soccer events, men's

[ii] Ambush theatre involves performing a skit or role play in a public place – such as a mall – to gather an audience of bystanders who believe they are witnessing an event such as an argument between a couple; at the end of the skit, the actors engage onlookers in dialogue around the issues.

dialogues and opportunistic engagement wherever the outreach educators came across groups of men “just sitting around”. Project Coordinator Zithulele Dlakavu estimates that the project directly engaged approximately 2,000 men over the course of a year, with many more being reached through radio slots.

One of the challenges of the project was to persuade men to talk about the issue of abortion at all, and then to deal with responses of anger that were sometimes expressed when the subject was raised. During door-to-door campaigns, some of the attitudes encountered among the inhabitants seemed prohibitive to further discussion (*“We don’t talk about such things at this house”*). Methods such as staged debates and skits, as mentioned on page 8, and presenting relevant statistics such as those relating to the abandonment of children in the area, helped facilitate dialogue.

A further challenge was to sustain the changes of attitude that these dialogues engendered. Some men reported finding that their beliefs in more equitable partnerships, responsibility and support were hard to uphold when confronted with negative attitudes towards abortion or women’s right to reproductive choice from other community members. As many of the case studies featured in this report have identified, sustained funding for social change is key – and resources to ensure that successful pilot endeavours continue and are scaled-up is one way of tapping into community-led innovation for population level change.

Evaluative focus groups from the project indicated that shared and mutually supportive sexual and reproductive health decision-making was emerging from the efforts to open dialogue around the taboo topic of abortion and to transform men’s attitudes. Focus groups documented that changes in attitude regarding abortion had occurred; participants were more understanding of why women may seek to terminate a pregnancy, and said they would refer them to a safe and legal abortion clinic. Overall, and further underscoring the importance of engaging men and boys at the intersection of sexual and reproductive health and rights and HIV, men presented a more committed attitude towards condom use and discussion with their partner around contraceptive use and family planning.



## 2. Coalition building across intersecting movements



Balance:  
Promoción para el  
desarrollo y  
juventud

### Coalition building between networks of women living with HIV and the women's rights movement in Latin America: advancing a unified sexual and reproductive health and rights agenda

Stigma and discrimination experienced by women living with HIV, within the community and in health service settings, is a major barrier to women accessing sexual and reproductive health services. Alliance building between the HIV and women's rights movements, and a more unified policy agenda, is key to advancing gender equity with relation to HIV and women's rights issues such as abortion and access to contraception.

Most Latin American countries have concentrated HIV epidemics, with prevalence mostly below 1% in the general population but higher among specific populations such as men who have sex with men, sex workers and people who inject drugs. Despite women accounting for approximately 35% of people living with HIV<sup>9</sup> there remain significant gaps in addressing women's sexual and reproductive health needs in relation to HIV. As analysis of national HIV plans across the region reveals, there are inadequate prevention strategies specific to women, and inadequate integration of sexual and reproductive health services for women living with HIV.

One of the reasons for these shortcomings in national HIV plans is that the power of civil society in influencing political will is being under-utilized. Both the HIV movement, generally dominated by men, and the women's rights movement have failed to advance a common sexual and reproductive health and rights agenda in relation to HIV. At the same time, there has been a lack of alliance building between the well-

established women's movement and growing activist networks of women living with HIV.

Stigma and discrimination remain high in the region, particularly as HIV tends to be associated with "high-risk" activities. The experiences of women living with HIV within the healthcare sector throughout Mexico and Central America suggest a lack of awareness and understanding among health service providers around the intersections between HIV and women's sexual and reproductive health options.<sup>10</sup> Women have reported, for example:

**// I am not sure if it is counselling or scolding, because what they say is that you can't get pregnant."**

Activist woman living with HIV, Guatemala

**// You can't talk about it with them because they think it is wrong, you're not allowed to get pregnant."**

Woman living with HIV of reproductive age, Mexico

**// They practise sterilization without the consent of women with HIV – there is only one contraceptive method offered to women with HIV."**

Activist woman living with HIV, Nicaragua<sup>11</sup>

Furthermore, policy-makers and feminist or women's rights activists in the region have shown a similar lack of awareness:<sup>12</sup>

**// If they know they are HIV [sic] and they get pregnant, I think there must be a psychiatric issue."**

Decision-maker, Mexico<sup>13</sup>

**“ In our own feminist organizations, we have not effectively incorporated the issue of HIV in the agenda – because of our assumption that it is an issue for gay groups.”**

Women’s rights activist, Central America<sup>14</sup>

The women’s movement has followed the general public view that HIV is an issue primarily affecting men who have sex with men, thereby reducing the issue of sexual and reproductive health and rights in relation to HIV to a simple matter of condom use. Even where a broader analysis has taken place, other barriers crop up: prevention of vertical transmission has proved divisive, seen by the women’s rights movement as positioning women as vectors of transmission and prioritizing the child’s rights over the mother’s; competition for resources has hindered an integrated rights-based approach; and class divisions have compounded the lack of dialogue between women’s rights advocates, often highly-educated professionals, and activists among women living with HIV, many of whom come from situations of social disadvantage and may not be conversant in the language of rights.<sup>15</sup>

The Mexican organization Balance, in collaboration with the Latin American chapter of the International Community of Women Living with HIV/AIDS (ICW Latina), has developed a two-pronged strategy that both engages with policy analysis and seeks to catalyse dialogue between the women’s rights and the HIV-positive women’s movements.

As part of this strategy, a nine-country situational analysis of services and policies was carried out, identifying glaring omissions in services to address the sexual and reproductive needs of women living with HIV in the areas of:

- HIV testing in antenatal clinics to prevent vertical transmission
- Family planning access for women living with HIV
- Assisted reproduction, or adoption, for couples where one or both partners are living with HIV
- Diagnosis of HPV/cervical cancer and other sexually transmitted infections
- Screening and care for survivors of gender-based violence in HIV clinics.

Follow-up workshops were held with ICW members in each country. The workshops were designed to address priorities identified by ICW leaders, to develop tools for conducting dialogues with the women’s rights movements, and to increase participants’ knowledge about sexual and reproductive health. The participants explored their sexual and reproductive health priorities as women living with HIV, and used

the evidence generated by the situational analysis to examine whether these needs were being addressed at the policy level, as well as to develop indicators for monitoring and evaluation around them.

Following the workshops, a two-way dialogue has been established between the HIV and women’s rights movements. Members of the women’s movement have provided training to HIV-positive women leaders around advocacy issues in which they are experts, such as legal termination of pregnancy, or violence against women, while local women’s organizations have come to a greater understanding of issues affecting women living with HIV and have incorporated these into their existing advocacy work – e.g. adopting indicators on HIV-related maternal mortality and promoting these indicators to legislators. Although these collaborations are still in their infancy both movements are demonstrating that the participation of women living with HIV and women’s movement is critical in better addressing the rights and needs of women and girls.



## Coalition building between people living with HIV and sexual minorities in India: towards human rights and gender equality

People living with HIV and sexual minority communities in India share a series of common challenges when it comes to fulfilling their sexual and reproductive health and rights needs. By presenting a united voice for these two communities; strengthening civil society's advocacy capacity through training; developing information and resource centres to improve access to sexual and reproductive rights; and tackling gender bias within both communities, the two communities are moving beyond potentially stigmatizing behaviour change approaches to HIV and initiating a positive cycle of change for human rights and gender equality.

Members of sexual minority communities, and people living with HIV, face considerable vulnerability in respect to rights violations, and greater challenges in their ability to access and make effective use of services. The stigma and discrimination experienced by these communities results in hostile attitudes from healthcare providers; a fear of exposure by accessing services; and a lack of a support from community and family members to access services. Members of sexual minority communities who are *also* living with HIV face a double burden of stigma.

To date, India's government-led HIV response has targeted perceived "high-risk" groups with behaviour change information and education communications. When not taking into consideration the human rights and social determinants of HIV, this approach may result in increased stigma towards sexual minority groups, people living with HIV and other key affected communities, thereby increasing their isolation within the community.

To better address the needs and rights of people living with HIV and sexual minorities, Solidarity and Action Against The HIV Infection in India (SAATHII), together with Interact Worldwide has developed the Coalition Based Advocacy Project. The project has

established two coalitions of organizations of, or for, people living with HIV and sexual minorities, in two East Indian states, West Bengal and Orissa<sup>[iii]</sup>. It thus aims to advance equality for people living with HIV<sup>[iv]</sup> and sexual minorities<sup>[v]</sup>, focusing specifically on sexual and reproductive health and rights and associated issues such as sexual abuse and harassment, crisis counselling and safe hormone therapy.

**// Government and civil society programmes have been struggling over the years to reach out to enough people, to change behaviours ... they are trying to put the cart before the horse. What they need to do is first look at structural issues, human rights issues, and sexual and reproductive health as issues within which HIV has a place – but HIV is not something that you can really successfully address in isolation."**

Pawan Dhall, Director of the SAATHII Kolkata office, West Bengal

The two coalitions – Sampark in Orissa, and the Coalition of Rights Based Groups in West Bengal – are undertaking activities in three areas:

- 1 Leadership training and coalition building to strengthen civil society's capacity, among sexual minority communities and communities of people living with HIV, to advocate for their rights, including equitable access to sexual and reproductive health and HIV services.
- 2 Advocacy campaigns at national and state levels to reduce stigma and discrimination, and to sensitize policy-makers, healthcare service providers, and the general public to the needs and rights of sexual minorities and people living with HIV.
- 3 Information and resource centres to improve access to, and uptake of, sexual and reproductive health and rights support services by sexual minorities and people living with HIV. This includes helplines and referrals to specialist sexual and

[iii] The project has received the support of of the UK Department for International Development (DfID) Civil Society Challenge Fund.

[iv] Refers to men, women and transgender people living with HIV.

[v] Refers to male-to-female transgender persons; gay, bisexual and other men who have sex with men; lesbians and bisexual women; female-to-male transgender persons.

reproductive health and HIV services, including legal aid, anti-retroviral provision, psycho-social support services and services for people who have experienced gender-based violence.

One of the main challenges of the early stages of the project has been bridging the two communities of HIV-positive networks and the sexual minorities' movement. Although they have often worked separately, the stigma and discrimination that these communities face stem from common underlying structural biases. For example, health services barriers may occur at different stages or settings within the healthcare system for members of each community, but both face a denial of their fundamental right to health, which stems from societal perceptions of heteronormativity and "deviance".

Gender biases also cut through the two communities, such that women living with HIV and women with minority sexual identities (lesbians, bisexual women and female-to-male transgender persons) tend to be under-represented at the network/organizational level. SAATHII continues to address these issues internally through training and capacity building with coalition member organizations. *"Our long-term plan is to encourage women leadership and transgender leadership in the groups themselves and therefore in the coalition,"* says Dhall.

After only one year, the coalitions are already seen as a strong united voice representing the two constituencies. They have successfully garnered the support of mental health professionals in advocacy efforts to reduce stigma and discrimination against people living with HIV and sexual minority groups at the policy level, as well as in health settings. The coalitions are also building relationships with champions of sexual and reproductive rights, including parliamentarians and other high profile media or health professionals who have spoken out on these and similar issues. One such person is the Commissioner for People with Disabilities who spoke out on issues of sexuality and disability at a recent Bhubaneswar film festival on sexual and reproductive health and rights and HIV issues.

This case study demonstrates that when working in tandem, marginalized communities can significantly contribute to a gender equitable and rights-based HIV response.



Members of the  
Huairou  
Commission<sup>[vi]</sup>

## HIV home-based care: engaging grassroots women to achieve sexual and reproductive health and rights

The strain on under-resourced health services, as well as the experience of stigma and discrimination within health service settings and subsequent demand for care at home, is a powerful argument for alternative models of care. Home-based care initiatives that are able to support marginalized populations and link women and girls to existing HIV and sexual and reproductive health services are a credible and relevant alternative model of care.

Grassroots caregivers are ideally placed to advance sexual and reproductive health and rights through the HIV response, as the following three examples demonstrate. They further show the critical role of home-based care initiatives in recognizing the linkages between issues faced by communities. To ensure optimal utilization of home-based care initiatives and appropriate management of the increasingly complex chronic care needs, home-based caregivers must be given the necessary tools and knowledge to capably provide these services, as well as to care for themselves. In addition, the increasing urgency to create demand for services tailored to the needs of local community, in support of the achievement of the Millennium Development Goals, requires that the long overdue issue of unpaid voluntarism be addressed at global policy level.



### GROOTS – Kenya

In Kenya, women living with HIV are at the forefront of offering home-based care and support to other family and community members affected by the HIV epidemic. However, many lack an enabling environment in which to fulfill their sexual and reproductive health rights and, as a result, unwanted pregnancies and sexually transmitted infections are common among caregivers, especially those living with HIV.

In addition to direct care and support for sexual and reproductive health issues, GROOTS has facilitated the formation of girls' clubs to empower youth caregivers with life skills, particularly in regard to sexual and reproductive health. The Mathare Girls' Club is one such club, bringing together youth caregivers and providing training on reproductive health, family planning and prevention of vertical transmission. The members, all HIV-positive mothers aged 12–17, have also formed "micro" peer groups of three to five girls to give one another support with issues such as disclosure and positive prevention.

It is anticipated that these support groups will assist members, in particular those living with HIV, to recognize and voice the underlying structural issues for improved access to sexual and reproductive health and rights services, with the support of GROOTS.

[vi] The Huairou Commission is a global membership coalition of women's networks, non-governmental and grassroots women's organizations in 54 countries.



### Swayam Shiksam Prayog – India

Swayam Shiksam Prayog (SSP) is a learning and development organization based in Mumbai that has helped to better link community needs with government health services through its innovative community empowerment initiative. In 2003, SSP began training women from self-help groups on how to increase access to existing health services, including HIV and sexual and reproductive health services. The women then went out in their communities, encouraging greater use of existing services and giving a voice to their community's needs.

Since then, local initiatives have further shaped this innovative community empowerment effort. Acting as liaison points between the community and the primary health centres, the women began to be recognized as community monitors. As such, some women have been trained as "health friends" to act as home-based health providers and many of them have become government sponsored Community Health Leaders, as part of an initiative of the National Rural Health Mission. A number of "health friends" have established Health Governance Groups – groups of 15 to 20 women – with a focus on linking women to basic government services (e.g. health, water and sanitation) and building accountability of service providers. Some members of self-help groups have also set up Health Mutual Funds, which are community-based and -managed insurance schemes. Linking up with the Health Mutual Funds, and working with childcare centres, Health Governance Groups have been able to secure access for pregnant women living with HIV to appropriate treatment, care and support services.

### Nuevo Amanecer – Honduras

The ethnic Garifuna community within Honduras, a country with a higher HIV prevalence (0.8% in 2009<sup>16</sup>) than its neighbours, has a HIV prevalence of 4.5% and experiences widespread poverty and poor access to health information and care. In addition, domestic violence is commonplace; of the 130 women living with HIV who participated in a 2008 study, 32% reported having experienced a form of domestic or intimate-partner violence.<sup>17</sup>

Nuevo Amanecer (New Dawn) was founded in 2001 by, and for, people living with HIV in the Trujillo community – an area with a significant Garifuna population. The mission of the organization is to empower people living with HIV to participate in decision-making around policies that directly affect them. The organization provides information and training on treatment literacy; supports clients and their relatives on adherence to anti-retroviral treatment, HIV prevention, and overall quality of life; and has secured representation in national meetings.

Nuevo Amanecer works with over 120 women and seventy men who receive services that include: home-based care; accompaniment to local health centres; and outreach to family, friends and community members through awareness raising around HIV. Nuevo Amanecer caregivers and clients meet every fifteen days to keep accurate and up-to-date records of clients' conditions, and to enable caregivers to communicate regularly with clinics to monitor clients' progress. In addition, the clients take part in support groups as well as workshops that specifically aim to provide information and training, as well as building their self-esteem.

The dedicated focus on women's rights and the comprehensive approach of Nuevo Amanecer, in terms of support groups, home visits, clinical accompaniment and raising awareness, enable women to access available care and better claim their rights.

### 3. Prioritizing women on the margins: bringing the margins to the centre



#### Women and girls of colour involved in sex work in Washington, DC: building a rights-based advocacy agenda

Women and girls of colour involved in sex work face a great number of challenges to accessing their sexual and reproductive health and rights, including harassment from law enforcement services due to the criminalization of sex work and discrimination at the hands of healthcare and social services professionals. By providing harm reduction services; empowering women and girls of colour involved in sex work to drive their own advocacy agenda; and strengthening existing advocacy efforts with better research, these challenges are being addressed.

Women, men, and transgender persons who engage in sex work have long been recognized as one of the populations most affected by the HIV epidemic. Yet criminalization of sex work in many societies continues to create challenges that have a negative impact on HIV prevention, treatment and care efforts, and which make it more difficult to meet the sexual and reproductive health needs of those engaged in sex work. Specifically, criminalization pushes those who engage in sex work underground, making them hard to identify and reach.<sup>[vii]</sup>

Washington, DC has the highest HIV rate in the United States, with HIV prevalence among the adult population at 128 per 100,000, compared to 60 per

100,000 for the United States as a whole.<sup>18,19</sup> African Americans are disproportionately affected, and, among women (who account for about 30% of people living with HIV in the DC area), heterosexual contact is by far the principal mode of HIV transmission at 61%, followed by injecting drug use (16%).<sup>20</sup>

Despite local and international acknowledgement of sex workers as a key affected population, funding for HIV-related projects that engage sex workers in the DC area has been deprioritized. In 2007, the number of projects receiving funding from the District HIV/AIDS Administration Offices dropped from two to one.<sup>21</sup>

Different Avenues is a non-profit Washington, DC-based outreach, training and advocacy organization that works to address sexual health issues, including the prevention of HIV, among women and girls of colour involved in the sex trade. The organization also provides harm reduction services, such as distribution of condoms, hygiene kits and information, needle exchange, and referrals. At the same time, Different Avenues works with individual women of colour engaged in sex work to build the leadership and capacity of this key population to set and carry out their own advocacy agenda towards building an enabling environment and fully accessing their rights.

One of the main issues faced by sex workers in the DC area and elsewhere, according to Different Avenues Executive Director Kelli Dorsey, is in accessing adequate sexual healthcare. Many sex workers experience discrimination at the hands of healthcare and social services professionals. Consequently, women and girls involved in sex work are frequently

[vii] All sex work in DC is illegal, though exotic massage, nude dancing and escorting (in venues where sex work may also happen) is legal under license.

reluctant to access these services. Some women may choose to access services outside of the area where they live and work for fear of identification, and many avoid accessing services at all unless in an emergency situation. Those who do access services, tend not to disclose that they are involved in sex work.

**// That's a huge, huge, huge issue ... Not being able to have an honest conversation with your healthcare providers is very scary – not being able to say 'I do sex work' or just exactly where you're at with your sexual health."**

Kelli Dorsey, Executive Director, Different Avenues

Another major challenge is the absence of data on sex work in the DC area, regarding the number of women and girls of colour engaged in sex work, HIV prevalence among sex workers, and data relating to their realities and needs. This critical missing data makes it difficult for Different Avenues to assess the impact of their work and formulate ways in which they could better address the needs of the population they aim to reach; it also hampers efforts to raise awareness and mobilize resources. *"It's hard to figure out how to work with sex workers well, if we do not have not have data on what the challenges women in sex work face and what they need,"* says Dorsey.

More recently, the organization's work has been affected by the 2006 Omnibus Public Safety Emergency Amendment Act, and the 2006 Nuisance Abatement Reform Amendment Act, which were designed to give the police "more tools to combat prostitution"<sup>22</sup> and effectively legitimized police harassment of, and discrimination against, people believed to be engaging in sex work. The new laws gave police the power to move people out of temporary Prostitution Free Zones (PFZs), as well as profile and arrest suspected sex workers.

The increased movement of street sex workers due to this new legislation has a number of implications for sex workers and other street users (including people who are homeless or use drugs), including their ability to access sexual health and HIV prevention services. Outreach workers are less able to find and reach sex worker populations who are more mobile or dispersed. Furthermore, sex workers may be identified as such by police if they are carrying three or more condoms or other harm reduction or safe sex supplies. These may be confiscated or destroyed, or can be used by police as grounds for arrest. Thus, prevention efforts based on encouraging sex workers to practise safer sex are diminished.

Recognizing the impact of the increased stringency of laws governing sex work in the DC area, Different Avenues decided to undertake research on police harassment of street sex workers<sup>23</sup> for advocacy purpose. Previous research<sup>24</sup>, carried out by Washington, DC-based organization Helping Individual Prostitutes Survive (HIPS), found that among 149 street-based sex workers surveyed, 90% had experienced violence. In focus groups and interviews with African American venue-based sex workers, Different Avenues found that fear of violence, by clients or members of the public, was the number one concern of up to 85% of the women with whom they spoke.<sup>25</sup> A related fear is that these experiences may not be treated with appropriate importance by the police and justice systems. For example, when PFZs are established, sex workers report being forced to move to areas where they feel less safe significantly more often than moving to areas where they feel more safe. However, resistance or refusal to move along, or returning to the PFZ within the duration of the zone may result in them being arrested and fined or jailed. Moreover, several of the research respondents shared that they had been asked to perform sex acts for the police, in order to avoid arrest.

On a broader scale, the worsening of relations between street sex workers and the police (caused by frequent humiliation, harassment, discrimination, and even violence experienced during interactions with police) may lead to sex workers being afraid to call the police for assistance and protection, leaving them at further risk of discrimination and violence.

Organizations like Different Avenues play a vital role in harnessing the knowledge, skills and experience of women and girls of colour involved in sex work. Successful campaigns such as the Move Along: Policing Prostitution in Washington, DC campaign are critical in understanding how local policies and programmes impinge on or uphold their sexual and reproductive health rights including their ability to address HIV-related vulnerabilities.



## Women who have sex with women, in all their diversity: putting their needs and rights on the HIV agenda

Women who have sex with women, in all their diversity, face stigma, discrimination and even sexual violence while also lacking access to HIV services and information due to neglect within the HIV policy and programming environment. This double burden is beginning to be addressed by new in-depth research on women who have sex with women, in all their diversity, and HIV, which will inform national, regional and global advocacy efforts to counter discrimination and gender-based violence.

Lesbians, bisexual women, transgendered people, and other women who have sex with women constitute a neglected and invisible minority in policy and programming around HIV and other areas of sexual and reproductive health and rights, despite evidence<sup>26</sup> that shows women who have sex with women are at risk.

In particular, HIV policy and programming often neglect the documented area of targeted gender-based and homophobic violence against women who identify as lesbians, including so-called “corrective” or “curative” rape. “Secondary victimization” at the hands of service providers can deter lesbian women from reporting rape, which hampers their access to time-sensitive medical treatment, including post-exposure-prophylaxis.

This neglect within HIV policy and programming is partly due to the perception that the risk of HIV transmission through women-to-women sex is low. Data on women-to-women HIV transmission is lacking as gender bias and heteronormativity have largely excluded women who have sex with women from research agendas and the data that do exist tend to be obfuscated by the research participants’ exposure to other transmission risks.<sup>27</sup> This gap in the research reinforces both assumptions of low HIV transmission risk among women who have sex with women communities and the continued sidelining of women who have sex with women in policy and research.

Furthermore, activists point to the fact that HIV- and sexual health-related research around women who have sex with women tends to associate estimates of risk with sexual identity or orientation, rather than with general high-risk activities and practices, which may include bisexual and lesbian-identified women who have sex with men *and* with women; sex work or transactional sex (including with male partners); drug use; and the use of sex toys.

Studies from different parts of the world, including South Africa and Canada, confirm that it is very difficult for women who have sex with women to access accurate, relevant information around STIs and HIV.<sup>28,29</sup> As a result, popular myths that women-to-women sex carries a low risk of STI and HIV transmission may result in greater likelihood that women who have sex with women will engage in unprotected sex (including with male partners) while simultaneously decreasing the likelihood that they will seek out HIV or STI testing. Despite all this, some studies show that STI incidence among women who have sex with women<sup>30</sup> is not significantly lower than among heterosexual women and anecdotal evidence from southern Africa suggests that women who have sex with women in South Africa and elsewhere are living with, and affected by, HIV.

**“ The issue is basically around understanding transmission – that’s the gap in terms of addressing this issue. We have been seeing in southern Africa increasing numbers of lesbian women who are HIV-positive. The question is: where is this coming from?”**

Steve Letsike, Chair of the South African National AIDS Council’s women and LGBT sectors

Although South Africa has a progressive constitution and legal framework regarding the rights of sexual minority people, this has not translated into policy and programming that target women who have sex with women communities, challenge institutionalized notions of patriarchy, tradition, and gender norms, and attempt to transform the practices of institutions such as the police and judiciary.

To begin to address these gaps, a groundbreaking multi-partner research programme has been launched<sup>[viii]</sup> in four southern African countries: Namibia, Botswana, Zimbabwe and South Africa.<sup>[ix]</sup> The programme is comprised of two components: in-depth qualitative research on the impact of HIV on women who have sex with women and transgender persons in southern Africa; and, an intensive evidence-informed advocacy campaign at the national, regional and global levels.

The research findings will inform advocacy for women who have sex with women by lesbian-led community-based organizations. Engagement in the research process will build the research capacity of these organizations, and increase the visibility of the constituencies they serve. The programme aims to result in the tailoring of health, social and legal services that address the needs of women who have sex with women, particularly those living with HIV, in the participating countries. Specifically, the programme will focus on HIV prevention and reduction of gender-based violence.

The research will thus assist in addressing the absence of women who have sex with women on the HIV and sexual and reproductive health and rights agenda, and reducing their vulnerability to the transmission and impact of HIV and other sexual and reproductive health issues, through tailored policy and programming. Obtaining evidence is a hugely important step in challenging the structural and institutionalized invisibility and marginalization of this population of women.

[viii] The programme, 'Women who have sex with women and HIV in southern Africa: a four country research project on HIV, health and community-building for advocacy' was initiated by the Open Society Initiative of South Africa (OSISA), and is supported by the United Nations Development Programme (UNDP), OSISA and the Open Society Institute (OSI) Sexual Health and Rights Project (SHARP). A research team from the Human Sciences Research Council in Pretoria is leading the project, supported by civil society partners working in the area of LGBT (lesbian, gay, bisexual and transgender) and women's rights in each country.

[ix] At the time of writing, the research tools for the first phase of the project were being finalised.



## Women and injecting drugs use: linking harm reduction and sexual and reproductive health

Women who inject drugs are particularly vulnerable to HIV transmission, and the overlap of different stigma from injecting drug use and related risk behaviours make it difficult for them to access their sexual reproductive health and rights. However, the use of situational analyses in Russia and Ukraine has enabled a better understanding of the services available to these women, and training-of-trainer programmes are helping empower women who inject drugs to fill the gaps identified by these analyses.

Eastern Europe and Central Asia are home to the world's fastest growing HIV epidemic, with prevalence in the regions having doubled in the last ten years. About two-thirds of HIV-positive people in the region live in Russia or Ukraine, where the prevalence rate in 2009 was approximately 1%.<sup>31</sup> Throughout the region, the epidemic has been concentrated among the overlapping communities of injecting drug users and sex workers, and their sexual partners. In Russia and Ukraine up to 25% of injecting drug users are women.<sup>32</sup>

Despite the fact that people who inject drugs have been recognized as vulnerable to HIV transmission since the early 1980s, the linkages between drug use and access to HIV prevention, treatment and care services for women, including sexual and reproductive health services, have been largely overlooked. Furthermore, the particular vulnerabilities, risks and needs of women who inject drugs often differ from those of men, and vary depending on cultural and social context. In addition to the stigma and discrimination related to injecting drug use in general, women are doubly stigmatized due to traditional gender norms and expectations. There is a substantial overlap between drug use; formal and informal (transactional) sex work; lower levels of condom use; and higher frequency of HIV and sexually transmitted infections (STIs). Women who inject drugs are more likely to have regular sexual partners who also inject drugs, to inject drugs with their partners, and to rely on their partners for drugs and supplies. These factors reduce their ability to control whether

sterile injecting equipment and condoms are used. Violence, and the threat of violence, in relationships, and the criminalization of drug use also add to the vulnerability of women who inject drugs in the intimate and public realms.

Despite recent recognition of these overlaps, gendered harm reduction programmes and mainstream HIV or sexual and reproductive health services that address the needs of women who inject drugs are in their infancy. Stigma and discrimination towards women who inject drugs among service providers remain commonplace, and accurate information regarding the sexual and reproductive health needs and options of women who inject drugs is lacking.

The UNAIDS Agenda for Women and Girls calls for increased knowledge and understanding of the needs of women and girls<sup>33</sup> to underpin the complex and nuanced intersections between HIV prevention, treatment and care, and sexual and reproductive health and rights for women who use drugs and their dependents. Women who inject drugs, and female partners of men who inject drugs, need to have access to integrated multi-sectoral services which include appropriate harm reduction strategies, and address violence against women.

Through research, advocacy, awareness raising, and training, the Eurasian Harm Reduction Network (EHRN) has begun to work towards realizing these aims over the last two years. The EHRN's 2010 Women and Drug Policy report gives a clear overview of the issues faced by women who use drugs in the areas of child custody, drug treatment during pregnancy, police abuse, domestic violence and imprisonment, and makes policy and programme recommendations.<sup>[x] 34</sup>

[x] These recommendations include the development of evidence-informed national guidelines and protocols on healthcare for pregnant women who use drugs; the training of obstetrician/gynaecologists, narcologists, HIV specialists, paediatricians and primary care providers accordingly; and guaranteeing accessibility and availability of opioid substitution therapy to people dependent on opiates, especially pregnant women.

EHRN and the Harm Reduction Knowledge Hub for Europe and Central Asia have also carried out situational analyses in Russia and Ukraine to map what services are available for women who inject drugs, and where the gaps lie. From these analyses and ongoing research, EHRN and the Knowledge Hub have developed a training course on creating harm reduction services for women, which is being rolled out through training-of-trainer workshops across Central Asia. The course makes comprehensive recommendations about adapting existing harm reduction services to make them more accessible and appropriate to women's HIV and sexual and reproductive health needs, as well as creating specific women-centred services to fill gaps.

Women who inject drugs are fully involved in the workshops, both as trainers and trainees, and in the development of materials, as writers and reviewers. Their engagement is critical for understanding the complexity of the issues faced by women who inject drugs, and for breaking down stigma and negative attitudes towards them. So far two workshops have taken place, engaging participants from Russia, Ukraine, Georgia, Belarus, Kyrgyzstan and Uzbekistan, with an additional training for service providers in Russia. Through the workshops, the project has begun to create a strong community of people who are trained to develop special services for women drug users, and the topic is being recognized at the national non-governmental organisation level.

**“ Two or three years ago we had no such services at all – we were not talking or thinking about such things at all in our region – we had only needle syringe exchange and some things for medical or drug treatment.”**

Kaleria Lavrova, former Coordinator of the Harm Reduction Knowledge Hub for Europe and Central Asia

Now service providers and donor agencies are beginning to talk about the need for “one-stop-shops” to provide drug treatment for women who are pregnant and to address other pregnancy-related needs for women who use drugs. Advocates and activists are also bringing attention to the deficit in knowledge around the interaction of street drugs and drug treatment for women on anti-retroviral therapy, as well as the need for drug treatment centres for women who have babies or young children. As a result, pilot services that address these issues are beginning to appear across the region.

## Looking forward

Comprehensive understanding of the experiences of women who inject drugs; gender sensitive awareness-raising among service providers; and a rights-based, rather than behaviour change or punitive, approach to injecting drug use are the first steps towards providing integrated, gender-sensitive HIV and sexual and reproductive health and rights services that incorporate harm reduction. Adjustments in service delivery could start with simple steps towards integration – for example provision of harm reduction information, services and/or referrals in family planning, maternal and child health, or abortion clinics. Likewise, child-care facilities in drug treatment centres would enable women with young children to access services without risking the loss of their children.



## 4. Addressing gender-based violence as a cause and consequence of HIV



Doctors to  
Children's MAMA+  
Project

### Addressing intimate partner violence against women living with HIV in St. Petersburg: creating safe spaces for women with children

Violence against women in Russia is endemic; there are few support services for survivors who have little opportunity for legal redress. This problem is exacerbated for women living with HIV, who are often separated from their children due to psychological problems, caused by discrimination and violence both inside and outside of the home. However, in St. Petersburg, the development of a day-care centre and a halfway house for women living with HIV is helping women escape violence. Through peer-mentorships and support in these settings, women living with HIV are being empowered to access their sexual and reproductive health and rights.

St. Petersburg is one of the cities with the highest prevalence of HIV in Russia; with, at the end of 2010, approximately 46,000 people living with HIV<sup>35</sup>, of whom over 30% are women.<sup>36</sup> Every year about 400–500 HIV-positive women living in St. Petersburg become mothers, and about one fifth of them abandon their children because of extreme psychological problems, due to discrimination and violence both inside and outside of their homes. The most common mode of HIV transmission in Russia is injecting drug use, and many women living with HIV have either injected drug themselves or have lived with one or more partners who inject drugs. This not only increases women's susceptibility to HIV, but also to intimate-partner violence, as well as instability within the relationship, and engagement in sex work to support their own or their partner's drug use.

Violence against women is a deeply entrenched, endemic issue in Russia. There is no official term for "domestic violence", there are few support services for survivors of violence and the legal framework for redress is weak. Research by Amnesty International reports that up to 70% of Russian women experience some form of sexual, physical or psychological violence, and between 9,000 and 16,000 women are killed each year by intimate partners.<sup>37</sup>

Women living with HIV may face an even higher risk of intimate-partner violence, as HIV itself can be a reason for worsening family relations. This is especially true in already unstable domestic circumstances, including poverty, unemployment, and often also either their own and/or their partner's alcohol or substance use. A sociological survey carried out by Doctors to Children and HealthRight International in 2008 suggested that women living with HIV in St. Petersburg show a lower than average awareness of support services for survivors of domestic violence and an above average tendency to deal with the problem alone, with only about 14% likely to seek professional assistance. For pregnant women or women with young children, who have greater need of partner support and a stable environment for their own and their children's security, the vulnerability to, and impacts of, domestic violence may be exacerbated. Violence or fear of violence resulting from disclosure can prevent women from accessing HIV services for themselves or their children, and may in turn lead them to abandon their children.

St. Petersburg-based non-governmental organisation Doctors to Children was set up in 2001 to protect the



rights of vulnerable children and provide children and families in need with quality social, medical and psychological support. Since 2004, Doctors to Children has been working with HealthRight International to implement MAMA+, a project to mitigate the effects of violence against women living with HIV. From 2004–2009 the rate of child abandonment by HIV-positive mothers in St. Petersburg dropped from 27% to 6%, which suggests that the project has had some success in this aim.

More broadly, the project aims to strengthen cooperation between government institutions and non-governmental organisations that provide services to women living in contexts of violence and their children through the development of an inter-agency protocol. A sociological survey has been conducted to explore the extent of, and responses to, intimate-partner violence among women living with HIV vis-à-vis HIV-negative women; and 200 members of staff of social welfare and healthcare institutions and law enforcement agencies have been trained around the issue of domestic violence, including how violence affects women living with HIV. In 2009, MAMA+ launched a web-portal for women living with HIV. The site received nearly two million hits in its first year.

The project includes a range of services for HIV-positive women who experience violence including a hotline service, which provides crisis counselling and information about support services, and received 650 calls in its first nine months of operation; and a day-care centre where counselling, referrals, peer support and information are available for women living with HIV. Women may also safely leave their children at the centre while attending other appointments. Partner involvement, however, is challenging as a result of a combination of drug and alcohol use, and a culture in which men tend not to seek assistance from others. Furthermore, men are often the principal or only household breadwinner, and so have little free time.

In 2008, MAMA+ initiated a pilot halfway house, or “social apartment”, with the aim of enabling HIV-positive mothers to remain with their children. The social apartment – to date the only one of its kind catering specifically to women living with HIV who have children – provides safe housing for periods of three months to one year for up to six women and their children. The presence of a full-time childminder and carer enables the mothers to go out to work or undertake further education until they are ready to settle independently.

Since 2004, MAMA+ has supported about 370 women to keep 453 children in family care. The project has also succeeded in increasing gender awareness

among professionals working on issues related to HIV and violence against women. In addition, women are more aware of support services and willing to use them, as shown by the increase in number of survivors of violence who have taken part in the programme. Furthermore, the twenty-six women who have sought shelter at the social apartment since its inception have gone on to start new relationships, marry, live alone or return to the parental home. Only one client has returned to a previously violent partner and both she and her partner continue to receive psycho-social support from MAMA+.

Through MAMA+, Doctors to Children and HealthRight International have adopted an effective multi-pronged strategy that addresses the dearth of services and resources dedicated to mitigating the impact of violence on HIV-positive women and their children in St. Petersburg. Based on the demonstrated results, the MAMA+ model has been integrated into the government services of three large districts in St. Petersburg, with former project staff heading up the departments and providing supervision to their government colleagues. The project provides a proven and tested model for scale-up and replication in Russia and elsewhere. HealthRight International has already begun implementing MAMA+ projects in Yekaterinburg (Russia), Ukraine and VietNam.



Coalition of  
Women Living with  
HIV/AIDS in Malawi,  
UA Now!

## Women living with HIV building community engagement in Malawi: challenging gender norms to address violence against women

Gender inequality, harmful cultural norms and practices, and taboos around sex and sexuality make it more difficult for women living with HIV to access their sexual and reproductive health and rights. However, the “Stepping Stones” approach is encouraging dialogue within communities in Malawi and reducing violence and HIV-related stigma and discrimination against women. Furthermore, the empowerment of women and men as advocates within their communities has cemented the sustainability and growth of these efforts.

Women in Malawi are disproportionately affected by HIV (see box) for a variety of reasons that are linked to gender inequality. Gender issues that women shoulder, such as blame, abandonment, and loss of property in cases of divorce or widowhood, heighten their vulnerability to HIV transmission. In addition, culturally accepted notions of men as the sole decision-makers in the household contribute to a male-centred environment of domination and control when it comes to the fulfilment of sexual and reproductive choices and desires. Notions of what it means to be a “good” woman or wife frequently suppress women’s ability to express their own sexual and reproductive needs and desires. Furthermore, harmful cultural practices, such as widow inheritance and “shaking the dust” initiation ceremonies<sup>[xi]</sup>; high levels of illiteracy in rural areas; lack of implementation of international legal and policy frameworks that protect women’s rights; and, conformity to cultural taboos around sex and sexuality, compromise women’s health and wellbeing.

The Coalition of Women Living with HIV/AIDS in Malawi (COWLHA) is leading efforts to better address the

[xi] “Shaking the dust” is a tradition commonly practiced in central and southern Malawi, whereby girls and young women are either ‘visited’ by older men or are encouraged to have sex with any boy after a week-long initiation, when the girls return to their village, to ‘seal’ the teaching they have received. (Source: ‘We will still live: confronting stigma and discrimination against women living with HIV/AIDS in Malawi’, Leitner Centre, New York, 2007)

### HIV in Malawi

- Prevalence rate of approximately 11% (in 2009).
- Women are disproportionately affected, accounting for 59% of all cases.
- Prevalence among young women aged 15–24 is more than twice that of men in the same age group (6.8% to 3.1% respectively).

Source: UNAIDS report on the global AIDS epidemic 2010. Geneva, UNAIDS, 2010.

needs of women and girls through the HIV response in Malawi. COWLHA is supported in its undertaking by UA Now!, a UNDP-led UNAIDS initiative, which started in 2009 and specifically aimed to accelerate universal access to HIV prevention, treatment, care and support, and the achievement of Millennium Development Goals for women and girls. As part of this initiative, COWLHA has documented incidents of gender-based violence against women with HIV, including HIV-related stigma and discrimination particularly affecting women and girls. In response to these findings, COWLHA has adopted the “Stepping Stones” methodology<sup>[xiii]</sup> to challenge gender inequality through effective communication and to catalyze a transition from a male-centred approach to decision-making in the intimate realm, to a couple-centred one in which the sexual and reproductive health needs and rights of both women and men are respected.

In addition, COWLHA has engaged senior traditional leaders, through a national workshop and follow-up community meetings, to foster a culture of dialogue between community leaders and women living with HIV. Subsequently, women living with HIV organized


[xiii] Stepping Stones is an approach that encourages participants to explore issues around intimate-partner violence, sex and sexuality, reproductive choice and decision-making, love, trust, intimacy, conflict and confrontation in relationships, in safe and gender-segregated groups. Women and men then come together in plenary sessions to report back on the key issues that arose during those discussions, and to jointly identify causes of those issues as well as develop solutions to the problems.

community dialogue meetings in collaboration with their community leaders in order to seek collective solutions to the stigma and discrimination faced by women living with HIV. Traditional leaders have taken a leading role in these meetings to denounce gender-based violence, and discourage practices that compromise women's sexual and reproductive health and rights and other human rights.

Based on the above, COWLHA has expanded the pilot project to eight districts across Malawi where members had reported high rates of violence against women, in the process developing a multi-stakeholder programme to build the capacity of police and social workers, women (and men) living with HIV, and other community members. Among the strengths of the undertaking are the engagement of men on issues of gender-based violence; the strengthening of linkages between community leaders and support groups; and the community dialogue approach to raise awareness on the harmful practices and entrenched gender norms which predispose women to HIV infection, sexual and reproductive health abuses, violence and stigma.

COWLHA has supported the gathering of success stories to track the changes that have taken place in people's lives, as an innovative way to monitor and evaluate the success of the programme. Monitoring findings reveal that as a result of the programme, participants have reported greater uptake of condoms; a reduction in instances of gender-based violence among participating couples; and a reduction in the number of men carrying out multiple concurrent relationships. Furthermore, community leaders' involvement has led to a reduction in HIV-related stigma and discrimination as evidenced by the increase in the number of people disclosing their HIV status publicly and the swelling of support group numbers. Finally, community dialogue meetings have emerged as a forum for challenging previously accepted gender norms.

Strengthening the leadership of women – in particular women living with HIV – and supporting initiatives to challenge gender norms and cultural factors that underpin unequal gender power relations, with the engagement of men, are crucial for social change for women.



Enita Jailosi is a member of Umodzi support group in Lilongwe district and whose husband abandoned her after she revealed to him that she was HIV-positive. When the support group members embraced the “Stepping Stones” approach, they invited Enita's husband to be part of the training.

**“ After being found HIV-positive, my husband left me. But after attending the Stepping Stones training, my husband decided to go for HIV testing and counselling, a thing that he vehemently refused to do in the past. His results revealed that he was HIV-positive. The training helped him to rediscover himself and he apologized for leaving me. My husband and I are now back together and happily married again with no incidents of violence because we are able to communicate better as a couple and respect each other's rights.”**

Enita and her husband now support other couples going through similar experiences.



## 5. Positive motherhood: peer to peer mentorship by women living with HIV



### HIV-positive mothers in the United Kingdom: providing peer support and leadership around positive pregnancy

Women living with HIV who are pregnant, or who may want to have children, can face additional stigma and stress due to the risk of vertical transmission. However, through one-to-one peer mentorship and workshops, women living with HIV are able to access the information and advice they need when pregnant or, when desiring to have children, in order to access high quality healthcare, improve their experience of pregnancy, and ensure their child is healthy. This project is illustrative of healthcare professionals and women living with HIV working in partnership to successfully ensure that reproductive choice is central to care and treatment provision in the United Kingdom.

Many women are tested for HIV during pregnancy as part of their antenatal care package. For women who test HIV-positive, this is an opportunity to ensure that timely access to treatment, information and advice reduces the risks of vertical transmission during pregnancy, birth and infant feeding. However, women who are faced with such a life-changing diagnosis may experience confusion, anxiety, depression and stress as they try to come to terms with the diagnosis; some choose not to continue with the pregnancy.

#### HIV in the United Kingdom

- In 2009, 85,000 people were living with HIV. Of this group, 26,000 were women.
- Nearly one in 500 women who give birth are HIV-positive.
- Approximately 1,200 infants are born to HIV-positive mothers each year.
- Vertical transmission is less than 1% for women diagnosed antenatally or prior to conception who receive anti-retroviral therapy.

Sources: UNAIDS report on the global AIDS epidemic 2010. Geneva, UNAIDS, 2010.

HIV in the United Kingdom: 2010 report. London, Health Protection Agency, 2010.

National study of HIV in pregnancy and childhood. [www.nshpc.ucl.ac.uk].

Positively UK (formerly Positively Women)<sup>[xiii]</sup> is a London-based charity that is piloting a UK-wide project to assist women living with HIV who are pregnant, or who may want to have children, through education, information, and emotional and practical one-to-one or group peer support.

[xiii] Positively Women changed its name to Positively UK in June 2010 following a strategy review and consultation, which resulted in the organisation expanding its services to include more work with men and young people living with HIV in the United Kingdom. It continues to support the growing national network of women living with HIV, PozFem, and produces the quarterly magazine Positively Women – the only magazine written by and for women living with HIV.

The project, From Pregnancy to Baby and Beyond (FPBB) is led by HIV-positive women, and guided by an advisory group made up of representatives of healthcare professionals from several London hospitals' centres of excellence. The project, funded by the MAC AIDS Fund <sup>[xiv]</sup>, focuses on women living with HIV from three groups: women diagnosed HIV-positive antenatally; women who are HIV-positive and pregnant; and, women who are HIV-positive and may consider getting pregnant in the future.

**// Positive women diagnosed antenatally need even more than your average person who's diagnosed HIV-positive – making decisions about keeping or not keeping the pregnancy, worrying about whether or not the baby will be infected, looking at disclosure to your partner and what repercussions that might have. You might already have other children that you then might need to test. Some of them might end up being positive and how do you deal with that? Then you have the issue around delivery – which mode of delivery to use, whether or not to breastfeed ... Even if you have all the information around the risks of transmission, you still have to make that decision and then that decision is on your head, whatever the outcomes.”**

Angelina Namiba, Coordinator FPBB project

While the United Kingdom generally charts good biomedical outcomes for HIV-positive women accessing treatment, the quality of services and the experiences of pregnancy differ depending on where women live and which health institutions they can access, as well as their access to other sources of support and information.

It is for this reason that FPBB strived to enable women to access the best standards of healthcare available through a peer mentorship programme. By creating a supportive, enabling environment, peer mentorship helps women make decisions about, and deal with, the consequences of disclosure, testing of other children, delivery and feeding options. Peer mentorship also aims to increase women's confidence around negotiating their sexual and reproductive health rights both in the intimate realm and within health services.

In 2010, its pilot year, FPBB aimed to reach 100 women, offering them tailored peer support to make the reproductive choices that are best for them. Seventeen workshops, made up of women living with HIV and their partners, were held to provide information around treatment, vertical prevention, and reducing the risk of co-infection in sero-positive couples, or HIV transmission in sero-discordant couples.

[xiv] The Fund was established in 1994 to support people who are living with HIV worldwide. [www.macaidsfund.org](http://www.macaidsfund.org)

Follow-up one-to-one support was also given to thirty-five women through a team of eight specially trained volunteer peer “Mentor Mothers” – women living with HIV who were either diagnosed in the antenatal setting, or who have had children since diagnosis. The one-to-one support addressed the specific needs, concerns, available treatments and care options that HIV-positive women may encounter at all stages of pregnancy: pre-conception, pregnancy, delivery and post-natal care for baby and mother.

### Lessons learned: sample feedback from workshop sessions

- An HIV-positive mother can still bond with her baby even if she didn't breastfeed.
- There is progress towards normalizing HIV-positive birthing because of research around breastfeeding.
- It is critical for the baby to get medication straight after birth.
- There are ways to protect the HIV-negative partner when trying to conceive, such as inter-uterine insemination and provision of PREP should a couple choose to have timed unprotected intercourse.
- By using tips and strategies it is possible to counter the stigma attached to caesarian-sections when explaining this to people you haven't disclosed to.

Creating an enabling environment for all women – including women and girls living with HIV – to exercise reproductive choice is a key element of the UNAIDS Agenda for Women and Girls.<sup>38</sup> Complimenting this, the UNAIDS Strategy 2011–2015 prioritizes the elimination of vertical transmission,<sup>39</sup> while upholding women's human rights, including their sexual and reproductive rights.

Responding to an urgent need of pregnant women when found to be HIV-positive, this project is illustrative of healthcare professionals and women living with HIV working in partnership to successfully ensure that reproductive choice is central to care and treatment provision in the United Kingdom. Acknowledging the need to harness and support HIV-positive women's particular areas of knowledge, experience, expertise, and leadership, the project also demonstrates that women living with HIV have an important watchdog role over reproductive choice within existing health service packages, thus contributing to an enabling environment for all women.



## Community-based HIV-positive mothers in Uganda: redefining the prevention of vertical transmission

A community-based, family-centred system of peer mentorship is proving effective in advancing access to the sexual and reproductive health and rights of women living with HIV who are pregnant, or who may want to have children. By drawing together the prevention of vertical transmission with the empowerment of women living with HIV this strategy works at the intersection of poverty, HIV-related stigma and gender equality.

Women living with HIV, young women in particular, face a range of specific challenges and needs when deciding whether or not to become mothers and during pregnancy itself. These challenges and needs include the burden of stigma and discrimination faced by HIV-positive mothers and access to the available information, support and services needed to enjoy a healthy pregnancy and welcome a baby born free of HIV. Women's experiences show that within prevention of vertical transmission programmes, which typically focus on the baby, the broader range of services, support and care that the pregnant woman needs can easily be overlooked.

It was for this reason that Mama's Club – a community-based organization led by women living with HIV in Uganda – was started in 2003 by Dr Lydia Mungherera, who at the time was working at The AIDS Service Organisation (TASO) in Uganda. Similar to the programme run by Positively UK, Mama's Club brings women together in response to the sense of isolation and concern experienced by newly diagnosed HIV-positive women facing pregnancy, through peer mentorship and support. However, while the Positively UK programme focuses on pregnant women, Mama's Club was envisioned as a community-based model of expanding prevention of vertical transmission services to a family-centred approach to meet the needs of the mothers, engage fathers and ensure the well-being of all the children in the family. It was through taking this family-centred approach that Mama's Club has emerged as a pioneer in drawing together

the prevention of vertical transmission with the empowerment of young women living with HIV.

Fifty women attended the first meeting, saying that they were very much in need of an environment in which they could share experiences with other women in similar circumstances and also gain support from each other.

**“ They talked about learning more about prevention of vertical transmission, about how to look after their children, about how to deal with early diagnosis, and about human rights and legal rights – so many of us have been in situations where we feel we've been abused and we don't know what to do.”**

Lydia Mungherera, founder and Director, Mama's Club

TASO provided a meeting room and a small annual stipend, which allowed the group to reimburse members' transport costs and to buy a sewing machine. A trainer was brought in to teach the women to sew, providing the women with skills that could be used for small income-generating projects. Other professionals gave talks on a range of topics including anti-retroviral therapy, legal rights and child development. The group was member-driven and informal, and continued to attract members through the referrals of TASO clinic staff. However, for reasons such as cost, distance and stigma, most women in Uganda – including women living with HIV – were not accessing clinic or hospital services for antenatal, delivery or postpartum care. So, Mama's Club worked with TASO staff to train the members as peer outreach workers to mentor women in their communities around the need for HIV testing, treatment and access to prevention of vertical transmission services.

Nowadays, the services that Mama's Club provides span from reducing HIV-related stigma through psycho-social peer-to-peer support, to training opportunities that include strengthening knowledge of HIV prevention, treatment and care, to income-generating skills. Even as a small community endeavour with an uncertain funding stream, Mama's Club demonstrates how structural drivers of the

epidemic such as stigma, discrimination and women's economic dependence on men can be addressed hand in hand with specific interventions to increase factual HIV prevention knowledge, treatment literacy and access to services.

Although the organization operates entirely independently of TASO, close links are maintained and TASO continues to provide much of the counselling and peer mentorship training. At present, there are twelve branches of Mama's Club across Uganda, supported by a secretariat comprised of six staff members. Branches operate autonomously according to the particular needs of the communities in which they are based. For example, in Gulu, in the conflict-affected north, women who are coming from internally displaced peoples' camps have different support needs from women living in their own homes.

Another evolution is the Real Man Project supported by the UN Joint Team on AIDS in Uganda. This project consists of approximately thirty-five men and aims to carry out community sensitization with other men to encourage men to use healthcare services and to be more involved in and supportive of their wives' and partners' reproductive health needs, as well as prevent gender-based violence.

In 2008, Mama's Club won the Red Ribbon Award for innovative, effective and sustainable community leadership. The initiative demonstrates how peer support and community innovation is fundamental to increasing access to, and uptake of, prevention of vertical transmission services – and how a family-centred approach can be a means of empowering women and engaging men. Even with the attention to income-generation, legal rights, treatment literacy and all the other strands of Mama's Club's work, founder Lydia Mungherera believes that the element of peer mentorship is the organization's key strength. *"If you talk about how things were for you as a positive mother... the peer support is very powerful."*

Despite international recognition, funding has been and continues to be the major challenge for Mama's Club, as is common for many community-based organizations working on a small-scale with a large reach. Mama's Club continues to survive on piecemeal funding. A key lesson from all of the community models of achieving sexual and reproductive health and rights through the HIV response is the need for accessible funding streams that can support, sustain and scale-up the success of these models. Many initiatives such as Mama's Club are too small to access large funding streams that require substantial administrative capacity and at the same time, too large to be sustained by small, one-off grants. Countries and development partners need to ensure access to funding that can support, sustain and scale-up the success of these models.



## 6. Advancing reproductive justice for women of colour



### Women of colour living with HIV in the United States: advancing reproductive justice

Women of colour living with HIV in the United States (US) face stigma and discrimination on several fronts. Through better education on HIV and sexual and reproductive health and rights, and peer-driven activities that reduce isolation, these women are being empowered to pursue and achieve their sexual and reproductive desires.

Communities of colour in the US are disproportionately affected by HIV (see box). The double burden of stigma and discrimination – in terms of HIV status and race – acts as a deeply rooted impediment to women of colour living with HIV accessing their sexual and reproductive rights. Despite US-based advocates adopting a framework of social justice and reproductive freedom – reproductive justice – women of colour still struggle to claim and access the full range of reproductive health services they need. Popular myths related to HIV and sexual and reproductive health and rights further exacerbate this problem.

**// It's almost like it could be a mistake if someone who is HIV-positive says they are having a child. It's like, 'Well how do you do that? Aren't you supposed to be using condoms?'**

Del'Rosa Winston-Harris, Prevention Outreach, Sister Love

These commonly held assumptions and beliefs reinforce internalized feelings of stigma, shame, guilt and fear. Additionally, messages from health services are inconsistent – in certain instances healthcare

#### HIV status and race in the US

- HIV prevalence is about 15 times higher among black women than white women.
- In Georgia (8th highest HIV prevalence in the US), African Americans constitute approximately 30% of the population but account for 78% of those living with HIV.

Sources: [CDC HIV/AIDS fact sheet: HIV/AIDS among women who have sex with women](#). Atlanta, Centre for Disease Control and Prevention, 2006.

[2008 Georgia data summary: HIV/AIDS surveillance](#). Atlanta, Georgia Department of Human Resources, Division of Public Health, 2008.

providers try to dissuade women living with HIV from pursuing their reproductive desires – and laws that criminalize HIV transmission further entrench feelings of guilt and fear around actions that are perceived – rightly or wrongly – to carry high-risks of transmission.

Sister Love, an Atlanta-based NGO, has built a movement to claim reproductive justice for women living with HIV by giving women the information and confidence to pursue and achieve their sexual and reproductive desires. To this end, the organization has adopted three approaches: education and factual information on HIV and sexual and reproductive health and rights; reducing HIV-positive women's isolation by linking them to other women and services; and a peer-driven activities programme that helps to break down barriers of stigma, shame, guilt and fear to enable utilization of services. In addition, Sister Love





*"HIV is a human immunodeficiency virus that's causing a fight inside my body, yet people have made it about lifestyle" says Elveth Bentley, 46, of Atlanta. As a result of that widespread perception, many women hide their HIV status, fearing that people will judge them for having sex or succumbing to an addiction. For Bentley, the road to disclosure (with the support of Sister Love) began as she noticed how damaging shame could be. "You lose your sense of identity when you begin to buy into the stigma," she says. "You let the disease define you." She also saw that self-defeating behaviours often accompanied shame, such as avoiding the doctor's office or HIV clinic because of a fear of being recognized.*

Del'Rosa Winston-Harris began the process of disclosure after watching a friend who'd kept her diagnosis a secret die alone. Realizing how isolating the stigma of HIV could be, she had an epiphany. *"The idea of dying alone is one thing, but living alone is another," she says. "I realized somebody had to speak up and let people know this is a disease that anyone can get. [With the help of Sister Love] I've learned how to communicate and socialize with any kind of person," says Winston-Harris.*

advocates and supports the linking of HIV and sexual and reproductive health and rights services, and has adopted different social media communication and leadership approaches to reach women and break the silence and isolation they experience.

Leveraging the mutually reinforcing nature of strategic partnerships, Sister Love has broadened the scope and reach of its own work by working together with organizations such as the Women of Color Reproductive Justice Collective and Sister Song. Other partnerships are with reproductive rights organizations. As a result of the latter, Sister Love has increased its outreach capacity to (primarily) African American women living with or affected by HIV who lack access to information and education around their reproductive options and rights. At the same time, the partner organizations, whose focus has traditionally been on reproductive rights, are also expanding their scope and understanding to take on board the *specific* reproductive needs and concerns of women living with HIV.



## Service providers in the United States: leading the integration of HIV into sexual and reproductive health and rights services

HIV and sexual and reproductive health and rights services have historically been separated in the United States. However, the potential for integrated services to help women living with HIV better access their sexual and reproductive health and rights is now being realized. Reproductive health providers are integrating HIV services into their activities, and also building trust for referrals through workshops and networking events.

Despite the obvious intersections between HIV and sexual and reproductive health and rights for women, stigma around issues like HIV and abortion, as well as federal funding mechanisms and policies that address both issues separately, have historically discouraged service providers from integrating sexual and reproductive health and HIV programming.

As one of the few abortion providers in a region characterized by strong anti-abortion sentiment, the Memphis Center for Reproductive Health (MCRH) in Memphis, Tennessee has a reach of approximately 200 miles, and attracts clients – 60% of whom are African American – from about fifty counties in Tennessee and neighbouring states. Like the majority of organizations focusing on reproductive health issues, the MCRH had not integrated HIV services into its programmes up until 2006.

However, since 2006, the MCRH has increasingly integrated HIV services<sup>[xv]</sup>, including HIV testing, prevention and risk counselling, and referrals to local HIV services, into its existing package of sexual and reproductive health services, which includes safe abortion care, assisted fertility programmes for all people including lesbian, gay and transgender couples, STI treatment and counselling and family planning.

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### African Americans and HIV

- African Americans constitute approximately 12% of the US population, but account for 46% of people living with HIV and 45% of new cases each year.
- The rate of new cases each year for African American men and women is six and fifteen times that of Caucasian men and women, respectively.

Source: *HIV in the United States*. Atlanta, Centers for Disease Control and Prevention, 2010.

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More recently, MCRH has started providing reproductive health services to women and men living with HIV.<sup>[xvi]</sup> These include testing and treatment for sexually transmitted infections; pap smears and treatment for abnormal smears; pregnancy planning counselling; pregnancy prevention counselling; and, menopause counselling.

In 2009, MCRH, concerned still with the lack of dialogue between reproductive health services and HIV services, initiated the Parallel Paths project with funding from the MAC AIDS Fund. The Parallel Paths project increases the capacity of MCRH to address the sexual and reproductive health and rights of women living with HIV through working with HIV service providers to integrate sexual and reproductive health and rights information, education, and related referrals, into their services. MCRH has also received grant support from the Mid-South AIDS Fund to expand the programme more specifically into the Memphis Latino population through the sister project Caminos Paralelos.

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[xv] With support from AIDS United, formerly the National AIDS Fund

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[xvi] In 2010 the MCRH was awarded Ryan White Part A funding to provide reproductive health services to men and women living with HIV. See [www.hivmemphis.org](http://www.hivmemphis.org) and [http://mcrh-tn.org/services\\_hiv\\_aids.asp](http://mcrh-tn.org/services_hiv_aids.asp) for more information.

**“When we first started doing it we found that one of the biggest barriers was the attitude that ‘HIV-positive people don’t need family planning services because they shouldn’t be having children and they shouldn’t be having unprotected sex so I don’t know why I need to talk to them about birth control.’”**

Jennifer Marshall, Assistant Director, MCRH

Attitudes among the different service providers were surprisingly recalcitrant; many HIV service providers, particularly in the social services sector – such as food pantries, transportation services and education on positive health, dignity and prevention for women living with HIV – assumed that women living with HIV would have all their sexual and reproductive needs taken care of by the use of a condom. Through training sessions, MCRH were able to highlight to HIV providers the need for sexual and reproductive health and rights and then educate these service providers around safe pregnancy and abortion options for HIV-positive women, and the ways in which women living with HIV need to be supported in making such decisions so they can receive the appropriate medical care.

**“People with HIV are living longer lives, and they don’t stop being sexual beings after diagnosis. Women’s desires for family or children may change after receiving an HIV diagnosis, but they don’t disappear.”**

Jennifer Marshall, Assistant Director, MCRH

The main challenges encountered by MCRH was first persuading HIV service providers of the need for an integrated approach, and then reassuring them that other service providers could be trusted to treat their HIV-positive clients in a non-stigmatizing and non-judgmental manner. Project leaders at MCRH are finding that once service providers are on board, they are excited about the ability to be able to offer expanded services to their clients through referrals to organizations like MCRH with a sexual and reproductive health and rights focus.

To address these issues, and to launch the programme, MCRH initiated a series of “Lunch and Learn” sessions, incorporating topics of relevance to providers working in both HIV and sexual reproductive health services, while also functioning as a networking event. Marshall explains: *“The very first topic we covered was about intra-uterine devices and other forms of reversible long-acting contraception.”* The popularity of the sessions have led MCRH to seek out larger venues, and pre- and post-training evaluations have shown that the “Lunch and Learn” sessions are effective in increasing providers’ knowledge and

confidence around addressing specific topic areas. As a result, providers are more comfortable making referrals within the network of sexual and reproductive health and rights providers that the programme has established. At MCRH between five and ten women living with HIV are referred to them each week for additional STI testing, family planning, assisted conception and other services.

The Parallel Paths project is also extending MCRH’s reach further out into the community. Friends For Life, a local HIV service provider, hosts a Wellness University that offers classes to people living with HIV on a number of topics. As part of this Wellness University, MCRH was invited to provide a weekly class for HIV-positive women covering sexual and reproductive health and rights issues over a course of twelve weeks. The women in the class are keen for MCRH to carry out the first ever needs assessment around the sexual and reproductive health and rights needs of HIV-positive women in the region. This is underway, with preliminary results expected to be published in the fall of 2011.



## 7. Engaging young people through comprehensive sexuality education



### Empowering young people in India: a “healthy adolescence” approach to overcoming stigma and achieving comprehensive sexuality education

Young people in India are woefully under-educated about sexuality and gender issues. This increases women’s and girls’ vulnerability to HIV and other sexually transmitted infections as they are less able to protect their sexual and reproductive health and rights. However, a scheme to provide comprehensive sexuality education, which allows students’ questions and concerns to guide the content, is winning support from teachers, administrators and parents in Bangalore.

Although India has a relatively low HIV prevalence, it is nevertheless home to about 2.4 million people living with HIV.<sup>40</sup> While the epidemic varies in terms of prevalence rates, transmission routes, and most affected populations from state to state, one of the consistently neglected groups is women and girls. Information and awareness around sexual and reproductive health is low country wide, and sexuality remains a strictly taboo subject in many regions. At the same time, myths and strategies to reduce, or at least attempt to contain, vulnerability to HIV infection abound. The result of this is that women’s and girls’ sexual health is pushed even further out of their reach.

International Services Association, INSA-India, a Bangalore-based community development organization, has been working throughout India on sexual and reproductive health, and HIV since the 1980s. The organization works through various community-based institutions such as self-help groups, village committees, non-governmental

organisations, schools and churches. Their work falls into three areas: empowerment building, networking and linking, and advocacy, with the principle aim of working towards a life of dignity for all.

According to INSA-India, a failure to provide comprehensive sexuality education leaves women and girls vulnerable to HIV and other sexually transmitted infections as they have limited power to negotiate when, how and where sex takes place. Silence and taboo around sex and sexuality are also seen to fuel India’s endemic rates of sexual abuse in children as young as five.<sup>[xvii]</sup> Questions about the reproductive system frequently remain unanswered even as children enter adolescence, as teachers are uncomfortable addressing such issues.

**“ Children are really, really, really vulnerable because no-one talks about sex, no-one talks about sexual abuse, no-one talks about parts that are covered by your panties. In fact, even the names of penis and vagina are missing in the kindergarten textbook when the child learns about parts of the body.”**

Edwina Pereira, Programme Director-training, INSA-India

In one community in North Karnataka, INSA-India found that girl children as young as five were being “married” to put them out of reach of men who

[xvii] A study on child abuse carried out by the Ministry of Women and Child Development in 2007 found that 53% of children reported having faced one or more forms of sexual abuse (<http://wcd.nic.in/childabuse.pdf>); the acronyms HIV and AIDS occur three times (each) in this 200-page report. UNAIDS estimates that 160,000 children are living with HIV in India.

believe having sex with a virgin will cure a sexually transmitted infection. In another community, daughters-in-law living in their husbands' households were expected to have sexual relations with their husband's younger brothers, a practice justified by their mothers-in-law, who say, *"We can't stop our boys from sleeping around; at least it's safer if they have sex with the daughter-in-law of the house"*.

One of INSA-India's programmes, the Jeevan Amulya (Life is Precious) programme for young people aged 12–15 in secondary schools, began in the early 1990s through one-off trainings in schools, with follow-up biannual newsletters and an annual debate. It is now run on a monthly basis in thirty participating schools in Bangalore. Teachers and school administration staff are given a three-day training on "the body and soul of HIV/AIDS prevention" prior to the programme's implementation, and the Block Education Office in the local authority has supported the programme and encouraged schools to sign up.

The programme focuses on healthy adolescence rather than sexuality education per se, and uses the pupils' experiences, attitudes and questions as an entry point to address issues around sexuality and gender. Pupils are invited to use "question boxes" to post questions, which are then analysed to discern priority topics to address in the next sessions and through the biannual newsletter. Commonly asked questions are about whether girls can get HIV through sex "before they reach maturity", and whether contraceptive pills will protect girls and boys from HIV transmission

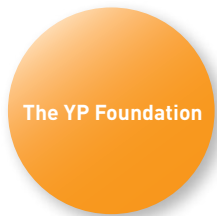
INSA-India's approach in school-based education programmes is to explore, unpack and de-link patterns of learning around gender, sexuality and HIV that create stigmatizing and disabling myths and associations. Examples of these include the religious communities' framing of sex as a sin that leads to HIV, or the commonly held belief that it is a women's role to control her sexuality and a man's role to enjoy his.

The Jeevan Amulya programme has received support from parents and teachers, who tacitly acknowledge the need for someone to address issues around sexuality and gender. As inter-generational dialogue around these areas is scarce, parents and teachers often feel under-equipped to address them head-on. INSA-India has been invited to take part in parent-teacher evenings as parents *"did not know whom to ask for such assistance and were clueless about why their child was no longer their 'listening docile child'"*.

Several schools have adjusted the programme to accommodate their local needs, which often involves de-compartmentalizing school, home and "outside" life on the part of school authorities. This has led to a more holistic and tailored approach to schoolchildren's well-being. One school requested assistance from INSA-India to raise funds for bus passes for thirty-two female students who would not otherwise be able to attend school. In another school, where many students come from poor or low-income families, children mostly live in one-room houses, and alcoholism and domestic violence are common. Girls are expected to supplement the income of the family after school hours. The school authorities felt INSA-India's weekly counselling services would help students manage these stressful situations constructively. Since uptake of the programme, individual participating schools have observed positive changes such as increased school attendance (including a decline in the number of girls under the age of 15 dropping out of school to get married); improved exam results; and greater assertiveness on the part of young people to take charge of their lives.

Through school-based HIV prevention work, INSA-India has successfully navigated a path for inter-generational dialogue around a range of issues affecting adolescents that address and challenge gender norms and attitudes around sex and sexuality, as well as HIV. INSA-India thus demonstrates that strategies developed as part of the national HIV response can be positive forces for wider societal change, and provide entry points for challenging traditionally taboo or culturally sensitive areas.





## Young people's leadership in India: know your body, know your rights

Comprehensive sexuality education is under-developed in India, but a youth-led initiative that empowers young people to create programmes and influence policy is helping ensure young women have access to their sexual and reproductive health and rights. As described below, young people are taking the lead in peer education and advocacy.

More than half of new HIV infections and 40% of sexually transmitted infections in India occur among young people aged 15–24. By the age of 18, around half of India's young women will be married, and over a quarter will already have borne one child.<sup>41</sup> In this context it is vital that young people are equipped with evidence-based knowledge, skills, and access to appropriate, youth-friendly services, and resources to enable them to make responsible choices about their social and sexual relationships. Access to comprehensive sexuality education is recognised in the UNAIDS Agenda for Women and Girls<sup>42</sup> and UNAIDS Strategy 2011–2015 as a key strategy for strengthening HIV prevention efforts.<sup>43</sup>

In a pan-India study carried out by the Population Council in 2006–2007, only 15% of respondents reported receiving information from parents or teachers on any form of sexuality education.<sup>44</sup> The implementation of the Adolescence Education Programme in the schooling system has been banned in seven Indian states, and may vary significantly in quality and content in others. There is a lack of inter-generational dialogue on sexual and reproductive health and rights issues and thus young people often find themselves without reliable sources to which they can turn.

The YP Foundation is a youth-led and -run organization that was established in 2002 to enable young people to create programmes and influence policies in the areas of education, health, governance and gender and sexuality. The organization is based in New Delhi, India, where it promotes, protects and advances young people's human rights by building capacity and leadership, connecting young people to information

and services, and strengthening youth-led initiatives and movements through partnership and technical assistance.

Through ensuring access to information and youth-friendly non-judgmental services, The YP Foundation aims to close the gap between young people and the decision-making process on issues that affect them. Part of this includes empowering young people with life skills to negotiate decision-making in all spheres in an informed and confident way. This is particularly important for young women and girls, whose access to their sexual and reproductive health and rights may be further hampered by high levels of violence and entrenched gender divisions, patriarchal roles and stereotypes that restrict women's choices.

Project 19: Know Your Body, Know Your Rights is a peer education programme in the New Delhi National Capital Region for young people aged 18–25. At the core of the programme is on-going advocacy for comprehensive sexuality education and youth-friendly sexual and reproductive health services, for empowered and informed decision-making by young people. Project 19 takes a holistic approach covering sexuality, gender, rights, relationships, health and HIV.

**“ At the heart of addressing HIV is addressing the body and human needs and desires.”**

Ishita Chaudhry, founder and CEO of The YP Foundation

Project 19 trains up to thirty young people per year as peer educators through a four to six month programme. During this time, participants are supported to design and execute research projects using creative media, which then feed back into the peer education training manual and advocacy campaign materials. Peer educators then run a series of “open workshops” that encourage frank and non-judgmental conversations, and provide correct information, about a range of sexual and reproductive health and gender issues.

## Responses to the Project 19 workshops

Responses from workshop participants have been overwhelmingly positive, confirming young people's need for greater access to education, information and services related to their sexual and reproductive health.

**“ It is important to know about this stuff at this age [16]. Young people should be given knowledge about sexuality, so that they know what's right and what's wrong.”**

**“ Such knowledge is extremely essential for our safety as well as to be able to have enjoyable and pleasurable relationships in life.”**

**“ Sex is so much of a taboo in our country that half the things that go wrong are because of lack of awareness.”**

**“ I believe that sex education is very much lacking in schools and sometimes even wrong messages are conveyed through media and other mediums.”**

**“ It's important to tackle issues of discrimination and harassment. Even 'educated' and 'liberally bought up' people have stereotypes and misconceptions.”<sup>45</sup>**

Chaudhry says, “It has been a challenge to convince policy-makers to let young people speak out directly and not second guess their needs”. However, The YP Foundation is making headway in both opening doors to decision-making fora and mobilizing young people across the country to feed into consultative processes.

The YP Foundation's Project 19 represents a unique example of youth participation and leadership to ensure that the sexual and reproductive health needs of young women and girls are accurately and appropriately represented. By addressing the need for comprehensive sexuality education at the grassroots level through peer education workshops; through national level campaigning and mobilization of youth; and advocacy at the policy level, the YP Foundation's Project 19 also makes an important contribution to HIV prevention.

The organization has engaged with concerned parents to clarify the need and perceived morality of talking openly about sexuality and sexual health and rights. *“It took us almost two years to be able to establish a consistent dialogue with parents and use the process of peer education to help them clarify their own concerns on sexuality and encourage them to trust young people, rather than judge them. We've also had parents who've come back to us and said 'thank you for talking about it, because we really didn't know how to',”* says Chaudhry. An important realization on the part of the organization has been that a lot of mothers – especially those who married and began child-rearing young – have never had access to sexuality education themselves and often lack the kind of information their children are now asking for. The YP Foundation now receives requests from parents asking for workshop sessions just for them. The project hasn't yet been extended to include adult-only sessions, but an annual national festival now brings components of the project to a wider multiple-stakeholder audience that includes parents, teachers, school administrators, policy-makers and the general public.



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## Participating entities, contacts and related links

### UNAIDS

[www.unaids.org](http://www.unaids.org)

### ATHENA Network

[www.athenanetwork.org](http://www.athenanetwork.org)

### Asia Pacific Network of Sex Workers (APNSW)

<http://apnswdollhouse.wordpress.com>

### Balance: Promoción para el desarrollo y juventud

[www.redbalance.org](http://www.redbalance.org)

### Coalition of Women Living with HIV/AIDS in Malawi (COWLHA)

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### Different Avenues

[www.differentavenues.org](http://www.differentavenues.org)

### Doctors to Children

[www.vd-spb.ru](http://www.vd-spb.ru)

### Eurasian Harm Reduction Network (EHRN) and Knowledge Hub

[www.harm-reduction.org](http://www.harm-reduction.org)

### Global Coalition on Women and AIDS (GCWA)

[www.womenandaids.net](http://www.womenandaids.net)

### Global Network of Sex Work Projects (NSWP)

[www.nswp.org](http://www.nswp.org)

### GROOTS International/GROOTS Kenya

[www.groots.org](http://www.groots.org)

### HealthRight International

[www.healthright.org](http://www.healthright.org)

### Huairou Commission/Home Based Care Alliance

[www.huairou.org](http://www.huairou.org)

### Human Sciences Research Council

[www.hsrc.ac.za](http://www.hsrc.ac.za)

### ICW Global: International Community of Women Living with HIV/AIDS

[www.icwglobal.org](http://www.icwglobal.org)

### INSA-India

[www.theinsaindia.org](http://www.theinsaindia.org)

### Ipas

[www.ipas.org](http://www.ipas.org)

### Mama's Club

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Email: [clubmamas@yahoo.com](mailto:clubmamas@yahoo.com)

### Memphis Center for Reproductive Health

[www.mcrh-tn.org](http://www.mcrh-tn.org)

### Namibia Women's Health Network

[www.nwhn.wordpress.com](http://www.nwhn.wordpress.com)

### Open Society Initiative for Southern Africa (OSISA)

[www.osisa.org](http://www.osisa.org)

### OUT

[www.out.org.za](http://www.out.org.za)

### Positively UK

[www.positivelyuk.org](http://www.positivelyuk.org)

### Sister Love

[www.sisterlove.org](http://www.sisterlove.org)

### Solidarity and Action Against the HIV Infection in India (SAATHII)

[www.saathii.org](http://www.saathii.org)

### Sonke Gender Justice Network

[www.genderjustice.org.za](http://www.genderjustice.org.za)

### Stepping Stones from Salamander Trust

[www.steppingstonesfeedback.org](http://www.steppingstonesfeedback.org)

[www.salamandertrust.net](http://www.salamandertrust.net)

### Universal Access for Women and Girls Now! (UA Now!)

[www.undp.org/HIV](http://www.undp.org/HIV)

### United Nation Development Programme (UNDP), Malawi

[www.undp.org.mw](http://www.undp.org.mw)

### Women of the Asia Pacific Network of People Living with HIV/AIDS (WAPN+)

[www.apnplus.org/WomenAPN%2B.asp](http://www.apnplus.org/WomenAPN%2B.asp)

### Women's College Research Institute

[www.womensresearch.ca](http://www.womensresearch.ca)

### The YP Foundation, India

[www.theypfoundation.org](http://www.theypfoundation.org)

## About ATHENA

The ATHENA Network was created to advance gender equity and human rights in the global response to HIV and AIDS. Because gender inequity fuels HIV and HIV fuels gender inequity, it is imperative that women and girls – particularly those living with HIV – speak out, set priorities for action and lead the response. The Barcelona Bill of Rights, promulgated by partners at the 2002 International AIDS Conference, is our framework for action.

ATHENA's mission is to:

- advance the recognition, protection and fulfilment of women's and girls' human rights, comprehensively and inclusively, as a fundamental component of the response to HIV and AIDS
- ensure gender equity in HIV-related research, prevention, diagnosis, treatment, care and the development of interventions based on a gendered analysis
- promote and facilitate the leadership of women and girls, especially those living with HIV, in all aspects of the response to HIV and AIDS
- bridge the communities around the world that are addressing gender, human rights, sexual and reproductive health and rights, and HIV.

