

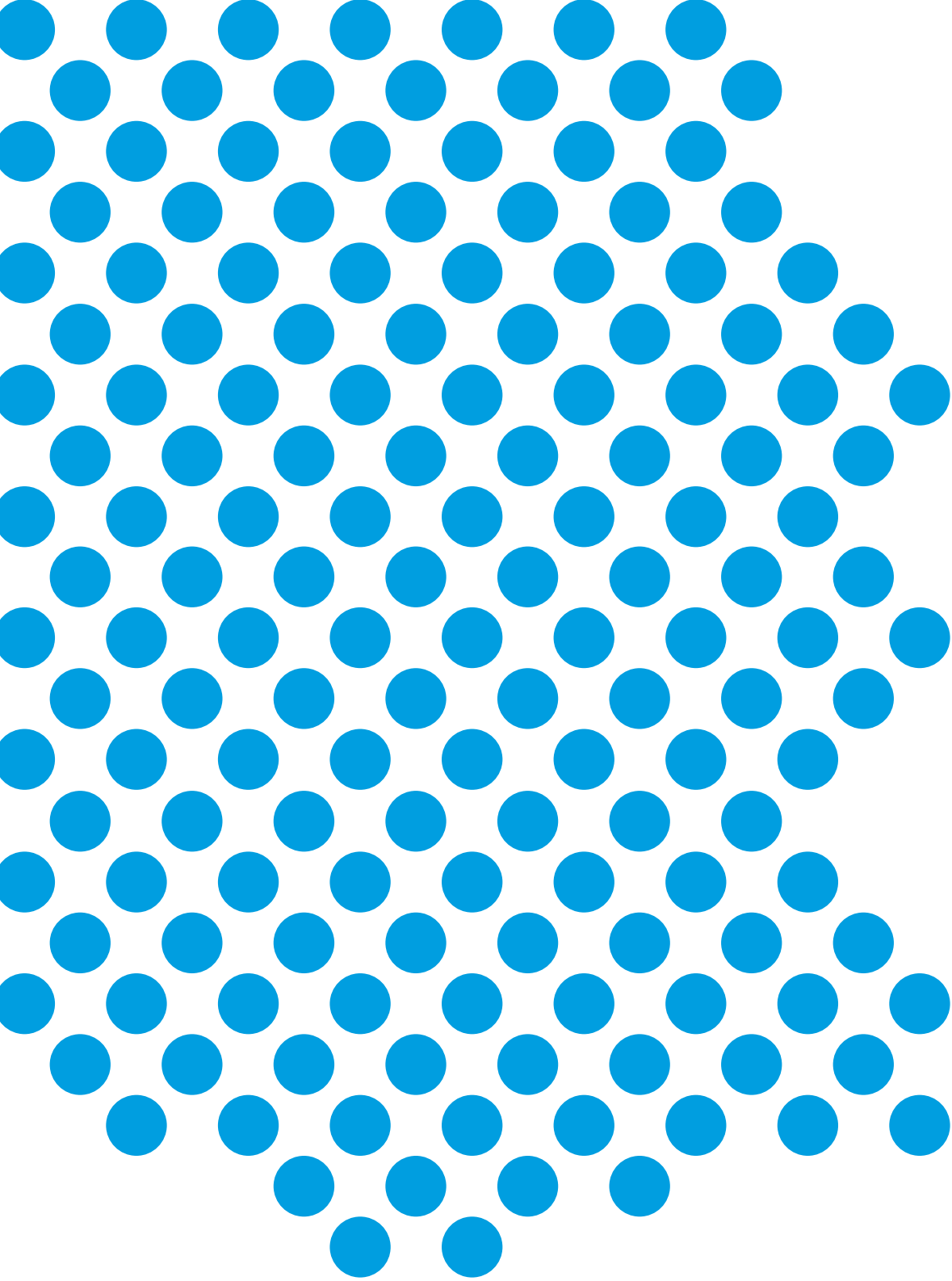


WOMEN OUT LOUD

HOW WOMEN LIVING WITH HIV
WILL HELP THE WORLD END AIDS



REACHING THE TEN TARGETS OF THE 2011
UNITED NATIONS GENERAL ASSEMBLY
POLITICAL DECLARATION ON HIV AND AIDS





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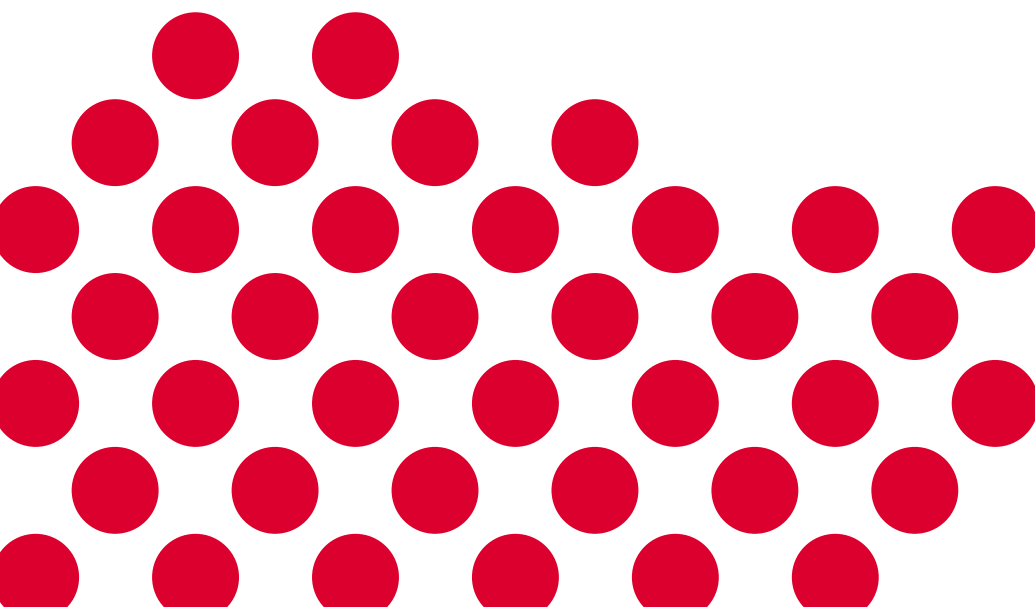
Women out loud: How women living with HIV will help the world end AIDS.

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FOREWORD

Women may make up half the world's population, but they do not share it equally. This is especially evident when it comes to HIV. Half of all people living with HIV are women, yet many are underserved or do not know their status. Despite the many successes we have seen, women still face inequalities that will keep the AIDS response from reaching its full potential.

Women out loud amplifies the voices of women living with HIV so that their knowledge is shared and acted upon. This is essential to achieve the 10 targets of the 2011 United Nations Political Declaration on HIV and AIDS.

Those who collaborated on this report present a snapshot of the diversity of women living with HIV. They are grandmothers, wives, mothers, transgender women, migrants and students. They include women who use drugs, women who have engaged in sex work, women who have been in prison and young women born with HIV. They are women working in grass-roots networks, international nongovernmental organizations, academia and the United Nations. They are leaders in their own right and living proof that women living with HIV can build better futures for themselves, their loved ones and their communities.

This report reinforces UNAIDS' efforts to strengthen the AIDS response's focus on women. We celebrate the fact that UN Women has joined UNAIDS as its 11th Cosponsor and hope that the newly created UNAIDS Women Living with HIV Dialogue Platform will bring the voices and influence of women living with HIV closer to the UN's day-to-day work.


It is our collective responsibility to push for the needed changes in laws, policies, programmes and practices and to end continuing human-rights violations and gender inequalities that enable HIV to spread. The full involvement of men, and securing their commitment to change, must be central to these efforts.

As this report testifies, women's leadership, resilience and good practices to transform societies are widespread. What is needed now is stronger support for women's full participation in the response to HIV, and better data to track progress as it relates to women. This requires a concerted effort to promote and protect the rights of women and of all people living with HIV. When women speak out, we must listen carefully, and act with solidarity and commitment to transform words into action.

Michelle Bachelet, Executive Director, UN Women

Jennifer Gatsi-Mallet, Executive Director, Namibian Women's Health Network

Michel Sidibé, Executive Director, UNAIDS



REDUCE
SEXUAL
TRANSMISSION!

1 MINUTE

Each minute, one young woman is infected by HIV.

49%

Women represent 49% of all adults living with HIV.

13.5×

Female sex workers are 13.5 times more likely to be living with HIV than other women.



TARGET 1

REDUCE SEXUAL TRANSMISSION OF HIV BY 50% BY 2015.

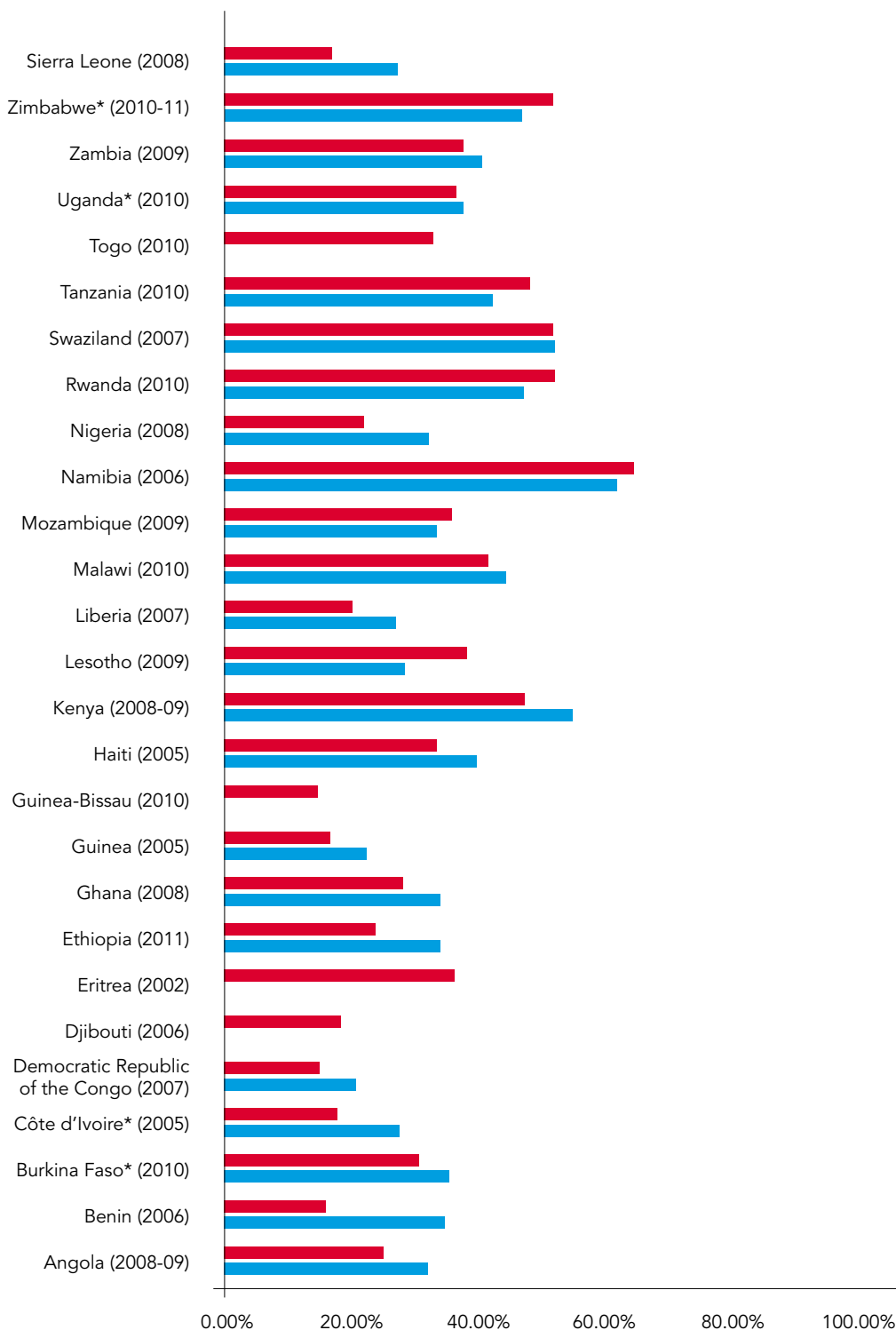
WOMEN REPRESENT 49% OF ALL ADULTS LIVING WITH HIV. IN MOST AFFECTED REGIONS, SUCH AS AFRICA AND THE CARIBBEAN, ABOUT 60% OF PEOPLE LIVING WITH HIV ARE WOMEN.

Introduction

Globally, young women aged 15–24 are most vulnerable to HIV, with infection rates twice as high as in young men, at 0.6%. This disparity is most pronounced in sub-Saharan Africa, where 3.1% of young women are living with HIV, versus 1.3% of young men. Each minute one young woman acquires HIV, accounting for 22% of all new HIV infections (1), with sexual transmission being the dominant mode of infection (2). Much remains to be done to ensure that young people are able to correctly identify ways of preventing the sexual transmission of HIV (Fig. 1.1).

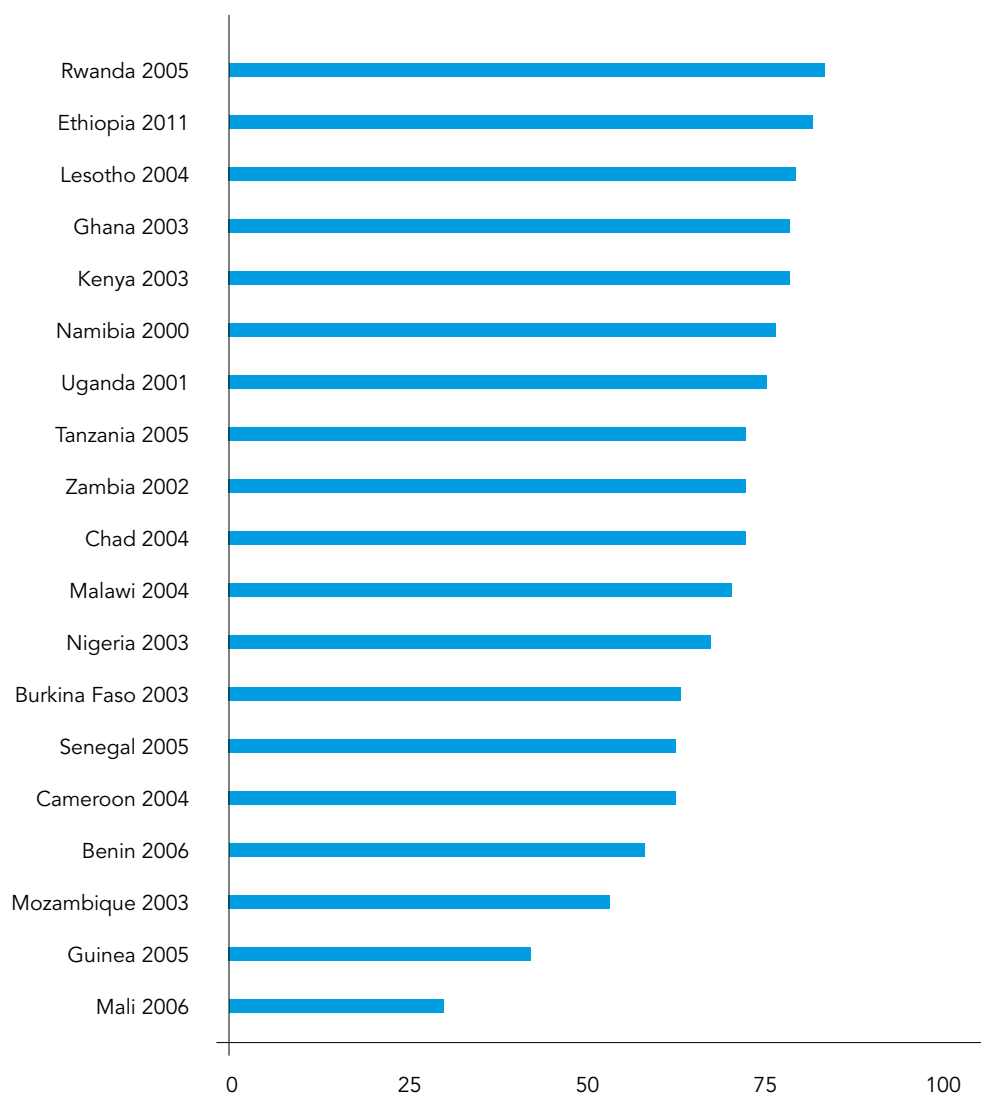
Even in cases where HIV knowledge exists, harmful gender norms can act as barriers for women to negotiate condom use and otherwise protect themselves from HIV (3, 4, 5, 6). Surveys show that in 12 of 19 countries with available data, less than 75% of women believe that a woman is justified in refusing to have sex with her husband when she knows he has sex with other women (Fig. 1.2). As a 2005 WHO multicountry study (7) showed, there is a close link with violence. The proportion of women physically forced into intercourse ranged from 4% to 46%, while 6% to 59% of the women reported sexual abuse by a partner. This high rate of forced sex is particularly alarming in the light of the AIDS epidemic and the difficulty that many women have in protecting themselves from HIV infection.

FIGURE 1.1. PERCENTAGE OF YOUNG WOMEN AND MEN AGED 15-24 WHO CORRECTLY IDENTIFY WAYS OF PREVENTING THE SEXUAL TRANSMISSION OF HIV AND WHO REJECT MAJOR MISCONCEPTIONS ABOUT HIV TRANSMISSION, GENERALIZED EPIDEMICS



Source: Demographic and Health Surveys and other population-based behavioural survey data.

FIGURE 1.2. PERCENTAGE OF WOMEN REPORTING THAT THEY AGREE WITH THE STATEMENT THAT A WIFE IS JUSTIFIED IN REFUSING SEX WITH HER HUSBAND IF SHE KNOWS HE HAS OTHER PARTNERS



Source: Demographic and Health Surveys, 2000–2011

Interestingly, women’s attitudes towards refusing sex barely change across the different age groups, pointing to persistent socially and culturally defined ideas about gender attitudes and behaviour.

Lack of economic empowerment also makes women more vulnerable to sexual transmission of HIV. Studies in low- and middle-income countries show that financially autonomous women find it easier to negotiate condom use with their husbands. Factors such as experience with an at-risk partner, the desire to maintain good social standing, fear of acquiring HIV and parental guidance and support influence women to reduce perceived HIV risk, despite constraining

gender norms and power imbalances in a marriage. Findings suggest that improving women's social and economic status can cut their risk of acquiring HIV by reducing dependence on male partners and enhancing their decision-making power (8). Studies on cash transfers among secondary school-aged young women in Malawi showed that such transfers not only encouraged women to reduce their risky sexual behaviour in the short term, but also resulted in a reduction in teenage pregnancy, as well as lower self-reported sexual activity (9, 10).

Female sex workers can also be particularly vulnerable to HIV (see Table 1.1), with country-reported prevalence among this key population in capital cities of more than 20% for some countries. Meanwhile, a recent review of data from 50 countries found that female sex workers were 13.5 times more likely to be living with HIV than were other women (11). Worldwide, the available evidence suggests that HIV prevalence rates reach as high as 68% in transgender communities (12). WHO defines transgender as an umbrella term for persons whose gender identity and expression does not conform to the norms and expectations traditionally associated with the sex assigned to them at birth. Incidence among transgender persons ranges from 3.4 to 7.8 per 100 person-years in some countries (12). In the United States of America, rates for newly identified infections among transgender women are threefold higher than for transgender men (13).

Empowering women

There has been growing recognition of how sociocultural factors driving gender inequalities critically influence the risk of HIV infection. This is particularly true of the role of gender norms and how they impact on HIV acquisition in women and affect women's access to services and social support. Women's particular vulnerability to HIV makes a better understanding of gender barriers to HIV transmission paramount.



**WE – WOMEN LIVING WITH HIV –
ARE KEY TO CREATING SAFE
ENVIRONMENTS AND EFFECTIVE
STRATEGIES TO REDUCE HIV.**

TABLE 1.1. COUNTRY-REPORTED PREVALENCE AMONG FEMALE SEX WORKERS IN CAPITAL CITIES

>20%	10-20%	5-10%	<5%
Chad	Ghana	El Salvador	Afghanistan
Latvia	Togo	Cape Verde	Bosnia and Herzegovina
Nigeria	Cambodia	Eritrea	Japan
Kenya	Djibouti	Estonia	Mongolia
United Republic of Tanzania	Burkina Faso	Algeria	Somalia
Mauritius	Guyana	Lithuania	South Sudan
Guinea	Senegal	Indonesia	Czech Republic
Côte d'Ivoire	Papua New Guinea	Angola	Germany
Uganda	Burundi	Mauritania	Sri Lanka
Niger		Portugal	Belgium
Guinea-Bissau		Haiti	Philippines
Zimbabwe		Ukraine	Madagascar
Rwanda		Myanmar	Bangladesh
Swaziland			Bulgaria
			China
			Cuba
			Spain
			Bolivia
			Pakistan
			Tunisia
			Mexico
			Serbia*
			Azerbaijan
			Belarus
			Lao People's Democratic Republic
			Romania
			Montenegro*
			Armenia
			Kazakhstan
			Timor-Leste
			Nepal
			Argentina
			Thailand
			Panama
			Georgia
			Nicaragua
			Morocco
			Paraguay
			Netherlands
			Uzbekistan
			Honduras
			Colombia
			Viet Nam
			Kyrgyzstan
			Iran
			Guatemala
			Suriname
			Tajikistan
			Jamaica

Source: 2012 Country progress reports (www.unaids.org/cpr)

Reducing sexual transmission by 50% by 2015 requires scaled-up access to comprehensive and nonjudgemental HIV services for women and girls throughout their lives. It will also be necessary to scale up access to comprehensive sexuality education in and out of school, and to expand youth-friendly services that empower young women to protect themselves (14, 15, 16). Recent evidence shows the cost effectiveness of delivering sexuality education programmes and services jointly at scale has the strongest impact (17).

Investing in research into female-controlled prevention technologies is also essential. These include microbicides, pre- and post-exposure prophylaxis and female condoms, as well as working with networks of women living with HIV and women's organizations to ensure access to these technologies for women and girls.

WOMEN OUT LOUD

JANE BRUNING, ELISHA (RINA) KOR, ANNAH SITHEMBINKOSI SANGO

Women and girls account for more than half of people living with HIV globally, and must be equal and valued partners in decision-making if sexual transmission of HIV is to be reduced by 50% by 2015. But, almost 30 years since the onset of the HIV epidemic, there has been a failure to meaningfully engage women living with HIV as leaders in prevention efforts.

A critical enabler to reaching the target of reducing sexual transmission of HIV by 50% by 2015 is ensuring that we women living with HIV are empowered, and that laws protect our right to choose with whom and how we have sex, and who we choose to marry, and when and whether or not we will have children. However, despite decades of advocacy and evidence, the voices of women and girls remain on the margins, and many young women still cannot or do not know how to protect themselves.

Our vulnerability to HIV in many cultures is due to our position in society, and those of us who are young are at an increased risk of contracting HIV. Cultural expectations of masculinity encourage men to assume the patriarchal attitude that wives, partners and daughters are the possessions of men, and most husbands expect or demand their conjugal 'rights'.

There is a strong link between gender-based violence and HIV. Violence, or the fear of violence, sometimes prevents women, transgender women and girls from negotiating safer sex, discussing fidelity with their partners or leaving risky relationships. No man should have the right to beat his wife, force her to have sex or throw her out of her home with nothing, simply because she is the first to be diagnosed with HIV, but this is happening.

Poverty is another driver of HIV transmission. Many women and girls turn to transactional sex as a means of sustaining their livelihoods and young girls are often coerced into sexual activities with older men.

Women who engage in sex work are vulnerable to violence, and consequently HIV, through police persecution and lack of agency when clients demand sex without condoms. Carrying condoms can risk a police search that may result in a prosecution for sex work. Transgender women (i.e. male-to-female transgender persons), who are often homeless and jobless, frequently suffer the double stigma of living with HIV and being transgender women. Many countries do not recognize transgender women, which leaves them with little or no choice but to turn to sex work as their only source of income.

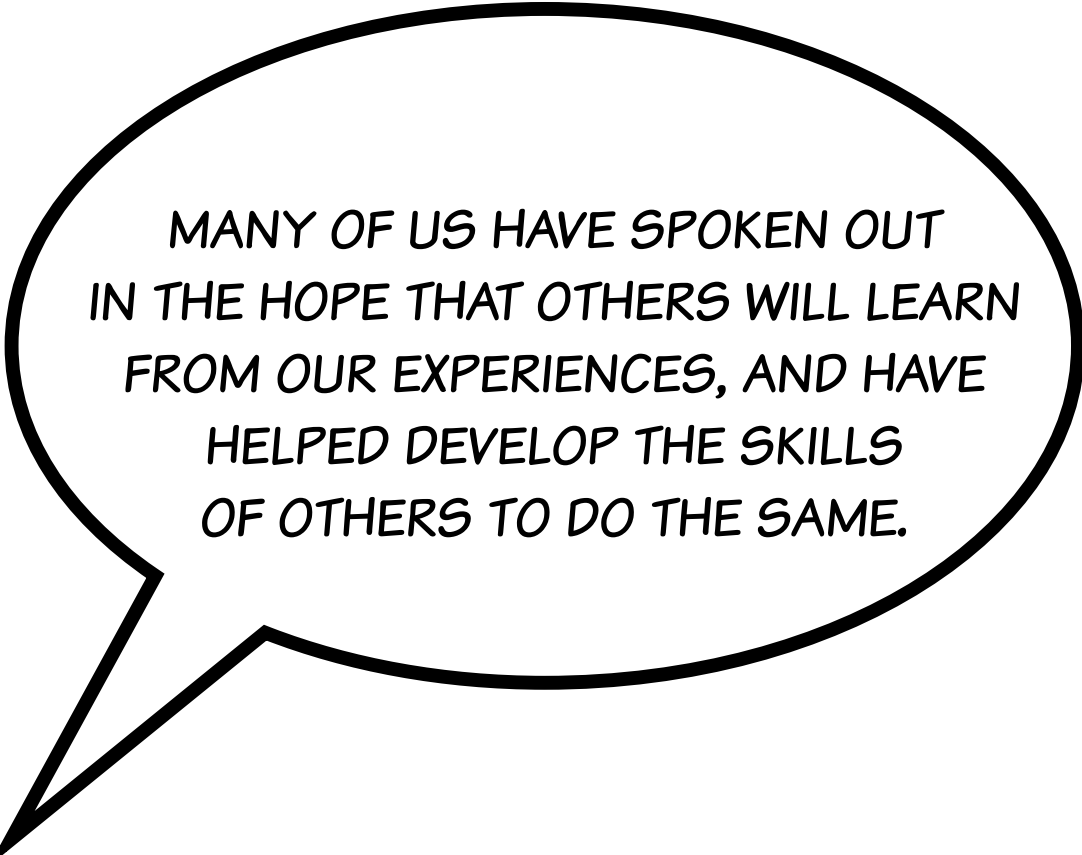
Similarly, women who use drugs are generally unable to access harm-reduction services and may engage in sex work to sustain their drug habits. All of this places women who use drugs at further risk of contracting HIV and possibly coinfection with hepatitis through sexual transmission.

Today, migrant women and girls experience harsh working conditions and are more at risk of contracting HIV by being separated from their families and communities. Migrants are often unable to access health-care services as these are not specifically designed to reach people on the move.

Thirty years into this epidemic, we are still arguing over what information young people are 'ready' for. Young people have sex for exactly the same reasons as adults: procreation, pleasure, income or to avoid being beaten. How will young women know to avoid harm if we are not talking to them about sex and how to negotiate safer sex?

We know what we need

In some countries, treatment as prevention is being seen as a silver bullet to address the epidemic. This is premature as systems are not able to sustain this approach and there are long-term side-effects and complications from taking antiretroviral medications. This is particularly pertinent for pregnant women who, in some countries, are being encouraged to use treatment to prevent the vertical transmission of HIV to their child and to subsequently stay on treatment irrespective of their CD4 count. This is known as Option B+. While treatment enables us to pose less of a risk to our unborn infants and also to our HIV-negative partners, we should be the ones making decisions about when and if we begin treatment. The choice to begin treatment is an individual one, which every woman should be empowered to make. If a woman chooses to begin treatment she should have access to consistent and reliable life-saving antiretroviral medications for her own well-being and not just because it is good for public health.



**MANY OF US HAVE SPOKEN OUT
IN THE HOPE THAT OTHERS WILL LEARN
FROM OUR EXPERIENCES, AND HAVE
HELPED DEVELOP THE SKILLS
OF OTHERS TO DO THE SAME.**

A successful rights-based response to HIV prevention requires the involvement of women living with HIV, especially young women, at all levels in the design and implementation of policies and programmes. Even though our perspectives are not often considered important in the HIV response, there are many strong and brave women living with HIV who have started community-based organizations, as well as regional and global networks.

We are raising awareness of HIV through our leadership role in positive health, dignity and prevention. This new approach to programming encompasses improving and maintaining the dignity of individuals living with HIV and supporting and enhancing their physical, mental, emotional and sexual health, resulting in an enabling environment that will reduce the likelihood of new HIV infections.

Women living with HIV have developed training tools on gender, communication and relationships for older and younger women and men to address their vulnerabilities and reduce gender violence. Due to patriarchy and many older people's repressive attitudes towards young women, these programmes are critical. One such example is 'Stepping Stones', currently implemented in 100 countries.

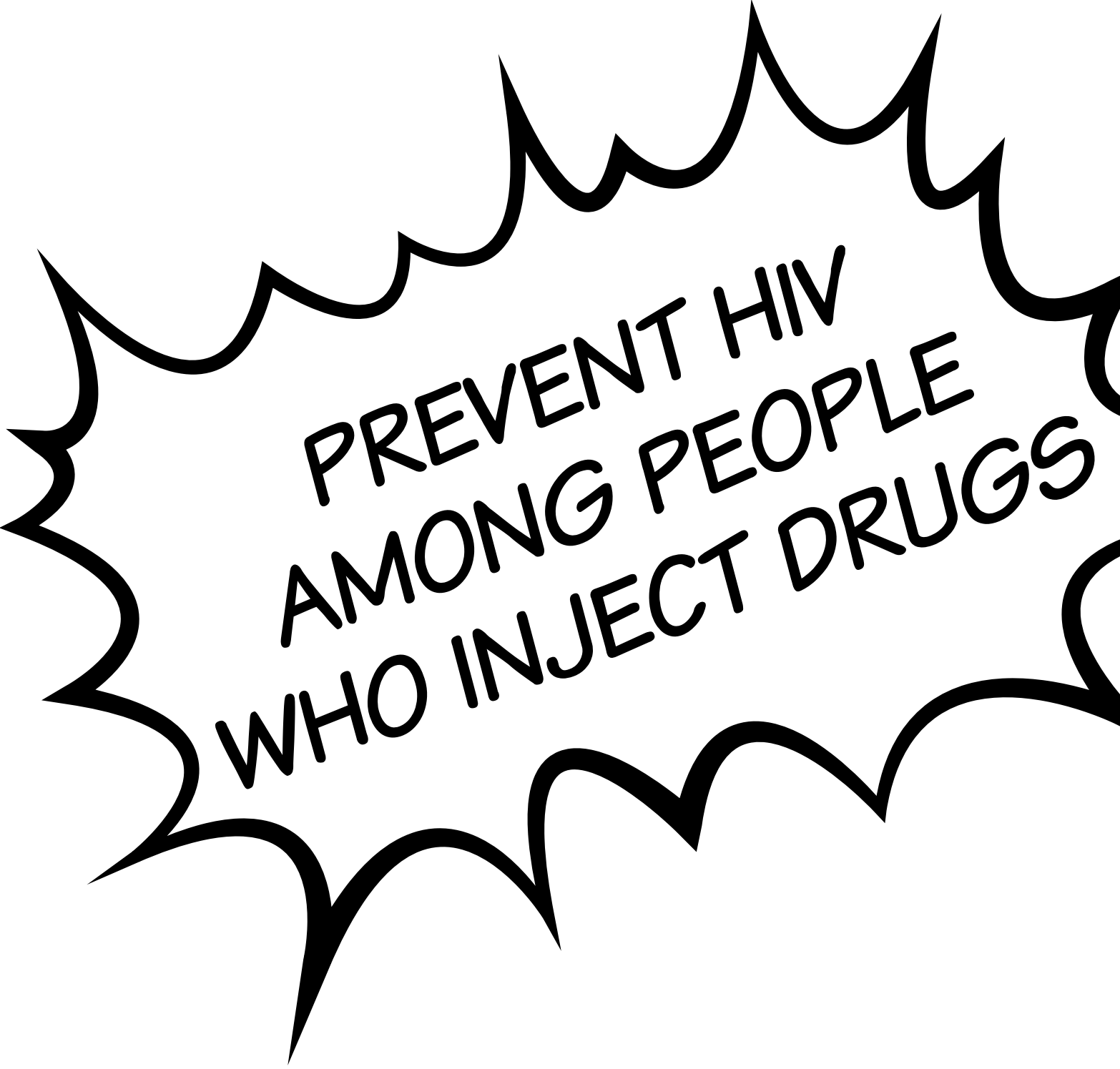
Many of us have spoken out in the hope that others will learn from our experiences, and have helped develop the skills of others to do the same. 'Lifting the burden of secrecy', one such training package, has been translated into eight languages.

Projects such as these are grassroots initiatives that have been successfully embraced on a global scale. They all address elements of HIV education and prevention. We, women living with HIV, know which programmes have failed us and why. We are key to creating safe environments and effective strategies to reduce HIV and provide high-quality services to all women, irrespective of where we live, our age, profession or lifestyle.

Jane Bruning is the National Coordinator, Positive Women Inc., New Zealand; Elisha (Rina) Kor is Programme Manager at the PT Foundation, Malaysia; and Annah Sithembinkosi Sango is a member of the International Community of Women Living with HIV/AIDS Southern Africa, Zimbabwe.

ACTION POINTS

- **Uphold our rights** and eliminate laws and policies that do not advance gender equality.
- **Resource our networks** as key partners in reducing new transmissions.
- **Organize strategic engagement** between us and government, civil society and religious agencies on HIV prevention.
- **Ensure access to comprehensive sexuality education and contraceptive options** for all women, especially young women.
- **Uphold sex workers' rights** to ensure safety at work.



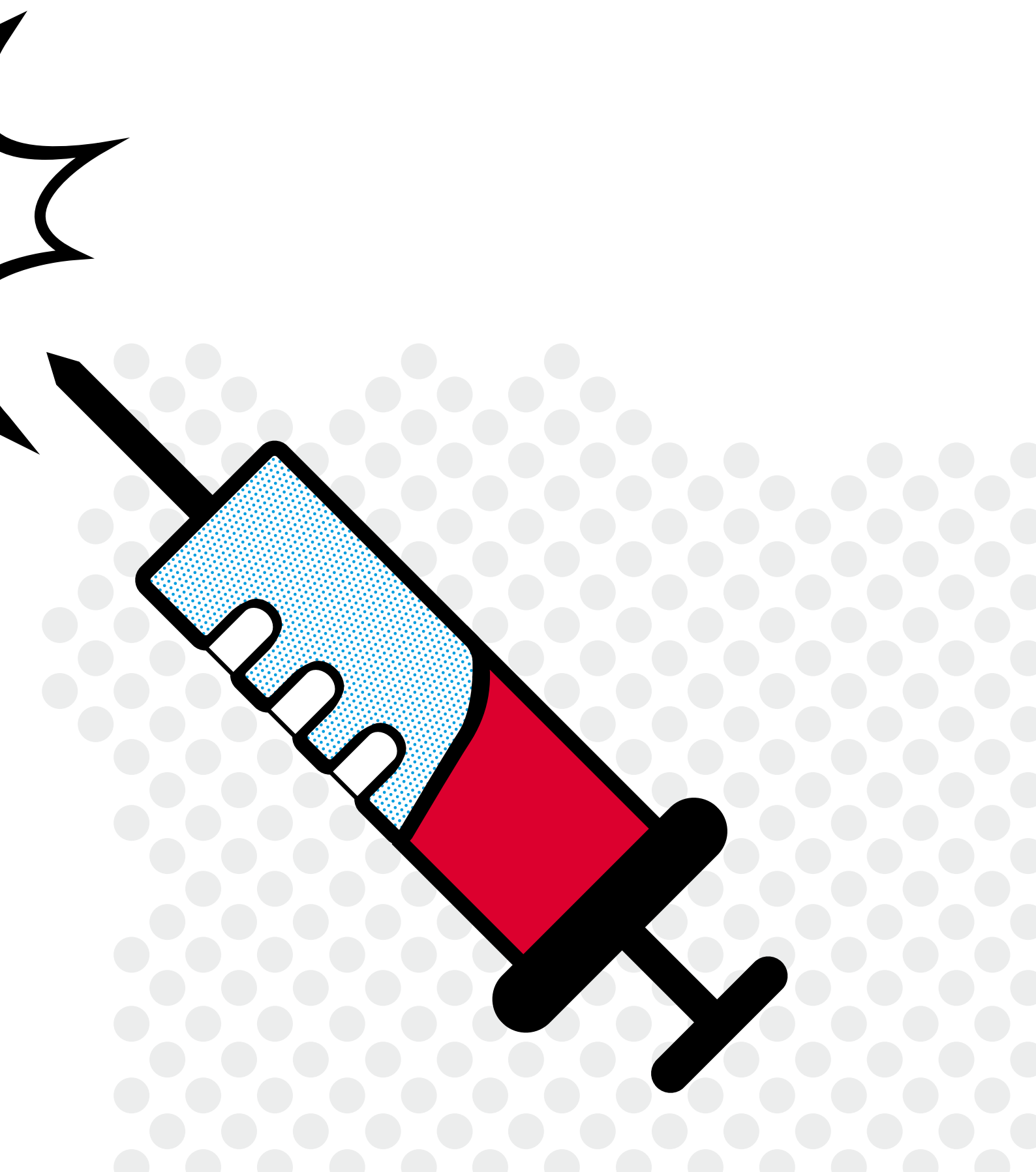
PREVENT HIV
AMONG PEOPLE
WHO INJECT DRUGS

50%

Women who inject drugs have a 50% higher prevalence of HIV than their male peers.

8%

Globally, 8% of people who inject drugs have access to needle and syringe programmes.



TARGET 2

REDUCE TRANSMISSION OF HIV AMONG PEOPLE WHO INJECT DRUGS BY 50% BY 2015.

WOMEN LIVING WITH HIV WHO USE OR HAVE USED DRUGS MAY ALSO BE EXPOSED TO BREACHES OF CONFIDENTIALITY, WHICH MAY THEN HEIGHTEN THE RISK OF VIOLENCE AND ABUSE (1).

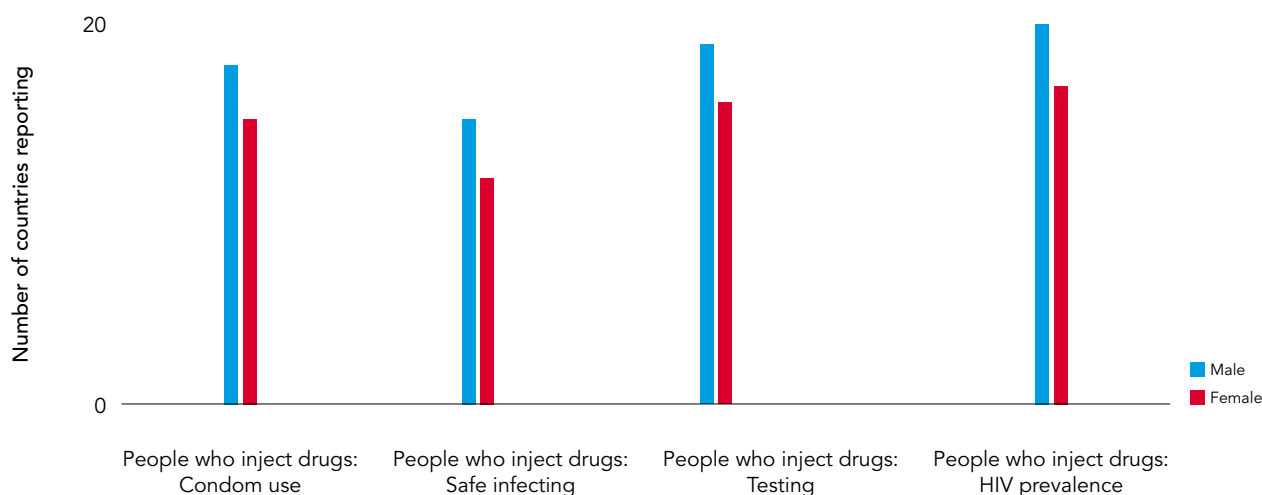
Introduction

Despite the fact that more countries than ever are reporting data on people who inject drugs, they remain the lowest reported key population. Moreover, data on females who inject drugs in concentrated epidemics is less reported than data on males for all indicators in the 2012 Global AIDS Response Progress Reporting submissions (see Figure 2.1).

Studies conducted in nine European Union countries have indicated on average a 50% higher prevalence of HIV among women who inject drugs than their male peers (2). In the Philippines, estimates suggest that almost 14% of people who inject drugs are living with HIV, yet prevalence among women who inject drugs is 27%, more than twice that of their male counterparts at 13% (3).

Country-reported data on levels of access to safe injecting equipment appears to be similar for both sexes, at close to 80%. However, this reporting most likely represents an overestimation of the coverage of needle and syringe programmes. A global review found that only 8% of people who inject drugs had access to needle and syringe programmes (estimate based on service coverage data from 102 countries). There are also substantial variations in regional and national coverage (4).

FIGURE 2.1. NUMBER OF COUNTRIES WITH CONCENTRATED EPIDEMICS REPORTING ON INDICATORS PERTAINING TO PEOPLE WHO INJECT DRUGS, BY SEX.



Source: 2012 country progress reports (www.unaids.org/cpr).

Even where harm-reduction programmes are in place, women who use drugs may face a range of gender-specific barriers to accessing HIV-related services (5). Recent studies indicate that women who inject drugs are more exposed to violence from intimate partners, police and sex-work clients (6). Added to this, homelessness and psychiatric illness can further increase exposure to HIV infection (7, 8). Women who use drugs are widely reported to experience disproportionate levels of stigma and discrimination, often compounded during pregnancy, and as mothers (9, 10, 11).

Studies have also shown infrequent use of condoms by women who use drugs with long-term and casual partners, and a correlation between inconsistent condom use and the sharing of injection equipment (12). Women who use drugs may be unable to negotiate condom use due to unequal relations with their partners. When sex is exchanged for drugs or other resources, women often exert little influence over a partner's condom use (10).

Pushing for policy change

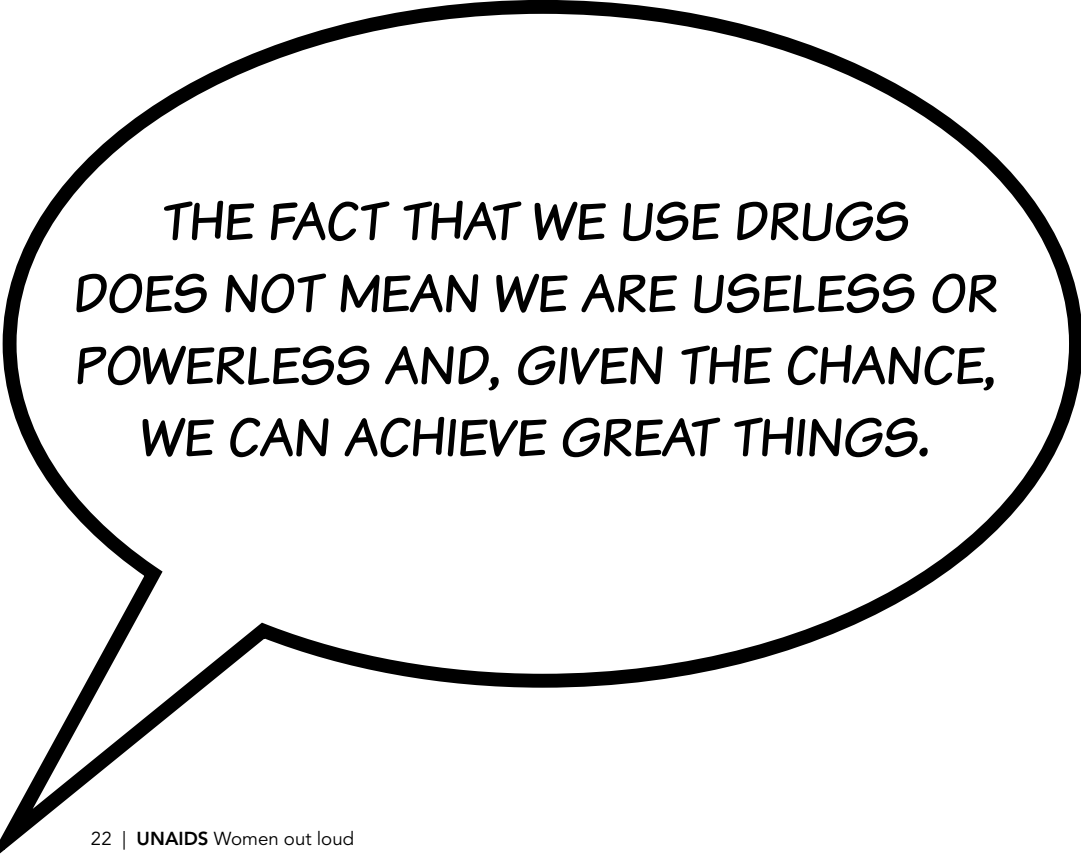
The commitment to reduce by 50% transmission of HIV among people who inject drugs by 2015 is an historic one, which recognizes the specific vulnerability of this population.

Stronger monitoring systems for people who inject drugs are needed to fulfil this commitment, as is gender-disaggregated data related to service uptake and accessibility. Scaling up evidence-based harm-reduction services, including those for opioid substitution therapy and needle and syringe programmes, will be critical. Women living with HIV who inject drugs must be meaningfully engaged in conceptualizing and delivering such services to ensure they are women-friendly and address their often multiple and complex needs.

Specific efforts must be made to integrate HIV, sexual and reproductive health and harm-reduction services, through, for example: training service staff to provide opportunities for couples counselling, empowering women to negotiate safer injecting and sexual practices within their relationships; providing services and support specific to women; and opening centres with child-care facilities for those women who are primary caretakers (5).

Women who inject drugs must have access to confidential and voluntary HIV counselling and testing. They also need reliable information and access to sexual and reproductive services for ending new infections in children and keeping mothers alive, as well as to protect their own health, free of stigma and discrimination.

Laws and policies that punish, stigmatize and discriminate against women living with HIV, as well as women who use drugs, create a significant barrier to women accessing both harm-reduction and HIV-related services. Greater strides must be taken to ensure all policies and initiatives are evidence-informed and uphold the rights and dignity of all women.



**THE FACT THAT WE USE DRUGS
DOES NOT MEAN WE ARE USELESS OR
POWERLESS AND, GIVEN THE CHANCE,
WE CAN ACHIEVE GREAT THINGS.**

WOMEN OUT LOUD

FRIKA ISKANDAR, FILIA JUNG, SILVIA PETRETTI

The target to reduce transmission of HIV among people who inject drugs by 50% by 2015 is critical, but it cannot be accomplished unless stigma, discrimination, criminalization and violence are addressed and we women living with HIV, who are or have been drug users, are engaged in developing and leading interventions.

Most literature on people who inject drugs does not differentiate between men and women, yet we have our own specific risks and needs. As women who inject drugs, we have significantly higher mortality rates, are more likely to face injection-related problems, have faster progression from first use to dependence, and engage in more risky injection and sexual-risk behaviours compared with men who use drugs (10).

We are disproportionately more likely to have HIV, and we have higher rates of other sexually transmitted infections, hepatitis B and C, and tuberculosis (10). Our vulnerability is compounded by gender, power and other structural dynamics and imbalances.

To reduce transmission of HIV among people who inject drugs by 50% by 2015 in an equitable way for women, it is paramount to first gain a better understanding of our lives. We face profound stigma, discrimination and violence, including from HIV, drug and other service providers. Because our rights are often violated, remaining invisible is often our best survival mechanism.

Drug use and sex work are criminalized in most countries, and sexual transmission of HIV is criminalized in an increasing number. Revealing our HIV status may not only mean that we will be ostracized, but can also put us in prison. When we are in prison, we have little to no access to opioid substitution, antiretroviral therapy and other medical treatment.

Reaching us can be a great challenge. Many of us want to stop injecting drugs but we have little access to appropriate opioid substitution and women-focused rehabilitation and detoxification services. It is difficult for women who use drugs to access appropriate, safe, skilled and respectful sexual reproductive health and maternal, natal and child-health services.

Often even within HIV support organizations, those of us who are pregnant are treated in a negative way, as if we cannot possibly be good mothers. But those of us who use drugs have the same desires and rights as all other women. In many countries, families will help men who use drugs, whereas women who inject are thrown out on the streets for 'disgracing' their family. Until recently, there were no drug treatment facilities for women in the Middle East and in most of Africa.

Health system failures

To deal with our own health and life can be complex and overwhelming. Not only do we use drugs and have to deal with HIV, we may also have hepatitis B and C, tuberculosis or multi-drug-resistant tuberculosis. It is essential that services for women living with HIV are not judgemental and are specialized to deal with the complexities around gender-based power and violence, drug use, HIV and hepatitis and tuberculosis coinfection. We have the right to and need for treatment, but often health workers will not give us medicine: they assume we will be 'non-compliant'. We experience discrimination and stigma when we try to get services, including antiretroviral therapy.

Our needs can easily fall through the cracks. While there is some evidence that lesbian and bisexual women are more likely to use drugs and alcohol compared with heterosexual women, there are few services for those of us who have sex with women, and the needs of us who are transgender, HIV positive and inject drugs are almost always ignored (13). Those of us who inject drugs and do sex work have different risks and vulnerabilities to other women who use drugs but do not engage in sex work, or who perform sex work and do not inject drugs.

We can lead

All that said, the fact that we use drugs does not mean we are useless or powerless. With the right structure, acceptance, recognition and support, drug users can achieve great things, and we know many examples of successful involvement and leadership among women living with HIV who use drugs. Many of us, when given the chance, have skilled up, and helped other women and men. We have set up new organizations and made a difference, taking the lead and making sure women's issues are voiced and addressed. Some of us have become professionals in this arena.



**BECAUSE OUR RIGHTS ARE OFTEN
VIOLATED, REMAINING INVISIBLE IS
OFTEN OUR BEST SURVIVAL
MECHANISM.**

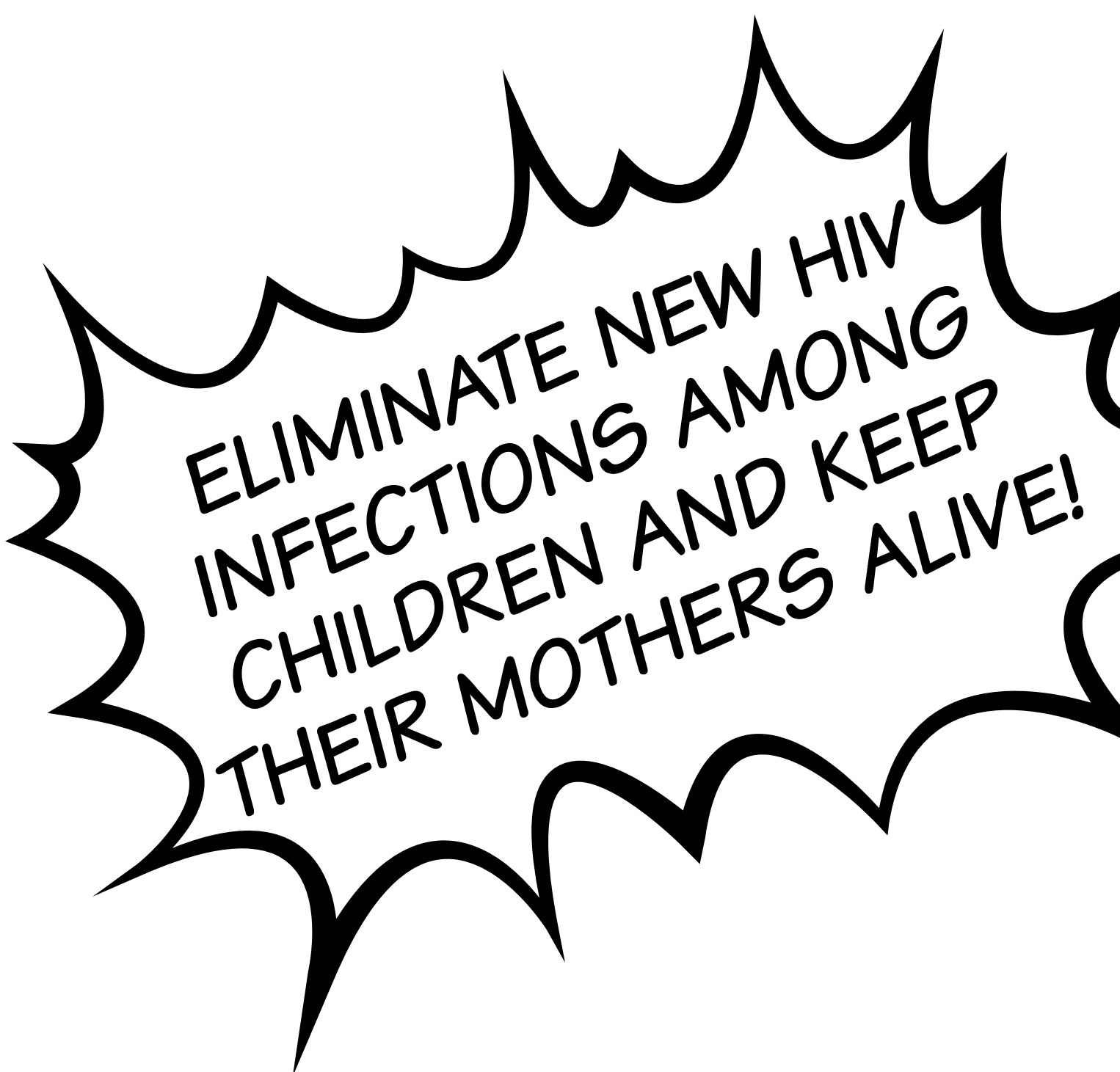
For example, the HIV network in Indonesia (Ikatan Perempuan Positif Indonesia) is led by a group of women living with HIV with an injecting drug-use background. Another example of good practice and the agency of women with HIV who use or have used drugs is the All-Ukrainian Network of People living with HIV. This organization has produced excellent documentation on how women living with HIV on opioid substitution can go on being good mothers, living satisfying lives.

However, there has been little other documentation of our successes. The importance and success of our leadership as women living with HIV who use drugs is rarely acknowledged. We need to further build our skills and capacities so we can take control of our lives and contribute to our communities. We need more appropriate space and resources to demonstrate how to better work with us and to provide evidence of our impact.

Frika Iskandar is a member of the women's working group, Asia Pacific Network of PLHIV, Indonesia; Filia Jung is a member of the International Community of Women Living with HIV/AIDS, United States of America; Silvia Petretti is Deputy CEO of Positively UK and Coordinator of PozFem UK, United Kingdom.

ACTION POINTS

- **Trust us to take care of ourselves** and be an integral part of policy-making and programming, including those of us who are still active drug users.
- **Fund us and invest in interventions** and policies specifically for women who inject drugs, including peer-developed and peer-implemented programmes, where we can be trained, supported and paid for our work.
- **Treat us holistically with more respect** via integrated services for HIV, hepatitis, tuberculosis, sexual and reproductive health and drug use, including opioid substitution therapy, overdose prevention and access to clean injecting equipment.
- **Make us and our lives visible**, with gender-specific monitoring indicators for interventions with people who inject drugs in order to show gaps and build evidence for increased attention to our needs and priorities.
- **Support us, especially when we are most marginalized.** We need access to services for lesbian, bisexual and transgender women who use drugs, who do sex work and/or are in prison.



ELIMINATE NEW HIV
INFECTIONS AMONG
CHILDREN AND KEEP
THEIR MOTHERS ALIVE!

2:3

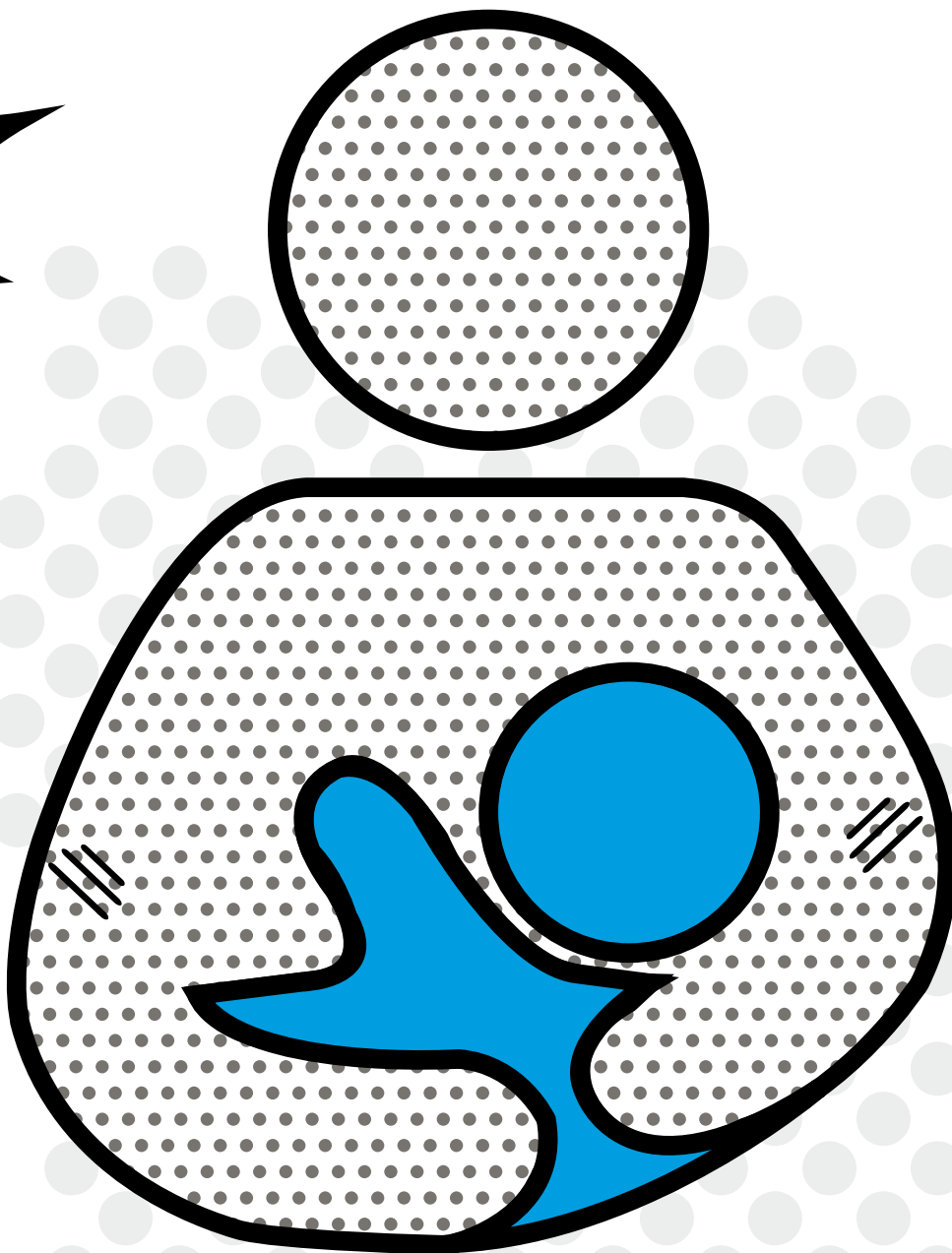
Nearly two of every three pregnant women in low- and middle-income countries do not know their HIV status.

57%

Among pregnant women living with HIV, 57% received prophylaxis to prevent transmission to their child.

48%

In 21 priority countries of the Global Plan in sub-Saharan Africa, 48% of pregnant women living with HIV and eligible for antiretroviral therapy for their own health received it in 2011.



TARGET 3

ELIMINATE NEW HIV INFECTIONS AMONG CHILDREN BY 2015 AND SUBSTANTIALLY REDUCE AIDS-RELATED MATERNAL DEATHS.

BY KEEPING MOTHERS ALIVE, RESPECTING THEIR RIGHTS AND VALUING THEIR LIVES, THE WELL-BEING OF THE ENTIRE FAMILY IS IMPROVED.

Introduction

HIV continues to be the leading cause of death of women of reproductive age (1). Ensuring access to treatment for women living with HIV benefits not only women themselves, but also their families, as studies indicate that children whose mothers die are also at increased risk of death.

In the 21 priority countries in sub-Saharan Africa under the Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive, the percentage of pregnant women living with HIV eligible for and receiving antiretroviral therapy for their own health increased from 16% in 2009 to 48% in 2011. While this constitutes a significant increase, it also means that approximately half the eligible mothers still do not receive this life-saving treatment, and not all women are receiving optimal antiretroviral regimens.

Nearly two thirds of pregnant women in low- and middle-income countries still do not know their HIV status, including many pregnant women living with HIV who could benefit from further health interventions, such as lifelong care and interventions to reduce mother-to-child transmission (2). Globally, 57% of pregnant women living with HIV received prophylaxis to prevent HIV transmission to their child. In 2011, this prevented approximately 180 000 new infections, averting the potential challenges of caring for a child who has been infected with HIV.

Pregnant women may be at increased risk of becoming HIV positive (3). HIV acquisition during pregnancy is increasingly being identified, and this increases the risk of onward transmission to infants since viral load is high after being newly exposed. The potential transmission of HIV to a child during pregnancy, childbirth and breastfeeding makes it especially crucial that pregnant women who are HIV negative can remain so.

It is also important for women living with HIV, as for all women, to have clear, accurate information on reproductive health and the links with HIV. They must also be able to access reproductive health and family planning services to support their fertility intentions, including preventing unintended pregnancies, if they choose. Studies suggest that women living with HIV have at least equal, if not more desire to limit childbearing compared with HIV-negative women (4). In addition, models suggest that reducing the unmet need for family planning among women living with HIV is critical for meeting the targets of reducing new child HIV infections by 90% (5).

Discrimination impedes access to services

Studies show that women living with HIV are often afraid to seek prenatal care because of possible condemnation from health professionals who disapprove of their pregnancy. A study conducted with 841 women living with HIV in Argentina found that women were discouraged by health professionals when they expressed a desire to become pregnant or were already pregnant (6). Additional studies have found similar findings, with stigma and discrimination sometimes manifested through forced or coerced sterilization (7). A peer-led study on access to reproductive and maternal health services of more than 750 women living with HIV in six Asian countries found that because of the discrimination women with HIV face from health-care workers, many women choose not to visit antenatal clinics and missed out on care for themselves and their baby (8). Those who do access services may experience stigma and discrimination in diverse forms. As one woman from the study related:

During the delivery the doctor wanted to put on two sets of gloves. He had put on one set but the baby was already coming out and the doctor tried to push it back in so he could put on another set. (Saru, Nepal)

Protect the right to stigma-free care

To reach the target of eliminating new child HIV infections and keeping their mothers alive, it is critical to protect the sexual and reproductive health and rights of all women living with HIV. These include their right to access voluntary and confidential HIV testing and counselling, accurate and nonjudgemental information, quality treatment and services, and to bear children in a safe environment, free of stigma, discrimination and violence.

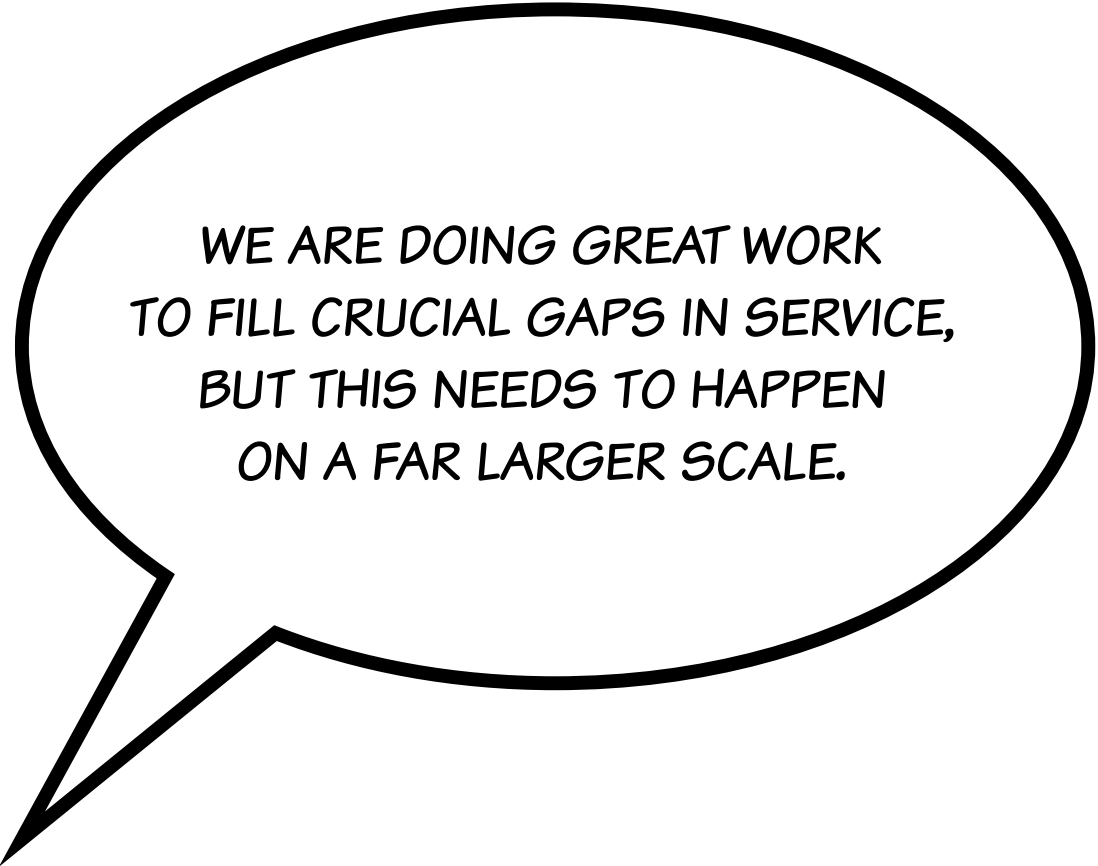
Greater commitment is needed to ensure that no woman has her rights violated, such as through mandatory HIV testing, forced abortion or coerced sterilization, or by promoting the view that only certain women, meeting certain criteria of social acceptability, can be mothers and receive adequate and appropriate treatment, care and support. Women living with HIV should be treated with dignity and respect and should be supported to know and demand their rights, including to be sexually active and have children. There is also a compelling public health argument for integration of HIV services

with sexual and reproductive services to ensure women living with HIV access the services they need. It is not enough for services to exist: the conditions that enable women to make use of them must be in place. Women and girls in humanitarian aid settings are among those most vulnerable, and may have difficulty accessing HIV services.

Respect women's autonomy

There are potential benefits to keeping women on the most effective prophylaxis from the time of diagnosis, throughout pregnancy, childbirth and breastfeeding, and then maintaining them on antiretroviral medicines even after they have stopped breastfeeding (known as Option B+). This regimen has many benefits, including reducing transmission rates in future births, reducing potential transmission to future partners, simplifying treatment and improving the mother's odds of survival (9). While these potential benefits appear promising, it is essential to ensure that women living with HIV decide for themselves what is best for them, and that the translation of evidence into concrete services and support is done in a rights-based manner.

While respecting women's rights to autonomy and confidentiality, health workers should promote the participation of supportive male partners in services to prevent transmission from mother to child. This may be particularly important during pregnancy, where there is increased risk of acquiring HIV due to physiological changes in the woman. Studies have shown that gender-sensitive interventions aimed at couples have encouraged uptake of antiretroviral treatment and HIV testing (10). Research in urban Zambia and Rwanda has shown that effective scale-up of programmes for voluntary and confidential counselling and testing of couples could reduce heterosexual HIV transmission by 35–80% (11).



**WE ARE DOING GREAT WORK
TO FILL CRUCIAL GAPS IN SERVICE,
BUT THIS NEEDS TO HAPPEN
ON A FAR LARGER SCALE.**

Encouraging men to participate in prevention services and strengthening couples counselling and testing provide a chance to address gender disparities that impede women's access to care, and provides an opportunity to reduce transmission risk (12). Moreover, any efforts to secure the involvement and support of men should never come at the cost of women's access to health care nor infringe on the rights and autonomy of women, especially in cases where no partner exists.

In working towards zero new HIV infections among children and keeping their mothers alive, women living with HIV are indispensable partners. They are best suited to lead the way and guide health-care planners and providers to deliver services that meet their needs. Engaging them in developing and delivering programmes ensures programmes contribute to reducing HIV-related discrimination throughout the health sector.

WOMEN OUT LOUD

**KRISTOFINA MWAONGELANGE MEAMENO, LILLIAN
KYOMUHANGI MWOREKO, ANGELINA NAMIBA**

Many of us women living with HIV, especially those of us born with HIV, never imagined that there would be a shift from preventing vertical transmission of HIV in some places to ending such transmission worldwide. Yet we are concerned that while approaches are intertwined with the sexual and reproductive health and rights of women living with HIV, too few global policy-makers grasp this connection or its implications.

Preventing vertical transmission is one of the most remarkable successes of the global AIDS response, yet globally AIDS responses have failed to provide women living with HIV with comprehensive and high-quality sexual and reproductive health information and services.

AIDS programmes have also failed to create environments that enable us to negotiate protection from other sexually transmitted infections, unplanned pregnancies and unwanted sex. There have been numerous reports of human rights violations of women living with HIV who want to exercise their sexual and reproductive rights (13). In addition, AIDS is the leading cause of death and disease for women of reproductive age.

The reality for many of us is that exercising that basic human right of having a baby, either by continuing with a pregnancy after an antenatal HIV diagnosis or choosing to become pregnant after an HIV diagnosis, brings with it a myriad of clinical, psychosocial and practical issues. These include coping with the diagnosis, decisions about testing other children, and uncertainties about access to and starting antiretroviral therapy. Disclosure to our families and partners has numerous implications, including the potential for both domestic and institutional violence. There have been reports from Chile, Papua New Guinea, Namibia, Kenya, Uganda and the United Republic of Tanzania of women living with HIV being coerced into sterilization (14, 15).

Treatment: our right, our choice

Every year an estimated 1.5 million of us living with HIV become pregnant, but only 57% have access to medication that reduces the chance of our babies being born HIV positive, and many services are not founded on human rights principles. For the millions of women living with HIV globally, the ability to exercise our sexual and reproductive rights is crucial. Unfortunately, power dynamics are often skewed against us and in favour of the service provider.

One example of such a skew is the strong programmatic push for countries to give pregnant women Option B+, a triple antiretroviral therapy from diagnosis and for life, regardless of CD4 cell count and their own health needs. While we appreciate the good intentions of Option B+, we should all be able to choose when we begin treatment. In addition, adherence and sustainability are major issues. Women should be able to have options and choose the treatment combinations that work for them and to make informed choices about how they deliver and feed their babies.

As is reflected in the Global Plan targets towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive, vertical transmission of HIV is preventable. Just how much this means to those of us who live with HIV and who wish to have children of our own is indescribable. We welcome the ambitious targets of the Global Plan and the declared need for women living with HIV to be at the centre of the response, but without the significant involvement of the community of women living with HIV the approach is flawed.



**FOR THE MILLIONS OF WOMEN LIVING
WITH HIV GLOBALLY, THE ABILITY
TO EXERCISE OUR SEXUAL AND
REPRODUCTIVE RIGHTS IS CRUCIAL.**

Helping ourselves

We have taken the lead in developing services and programmes that address these key issues of concern. There are several good examples of leadership from women living with HIV. In western Uganda, the Giramatsiko Post Test Club, an organization set up by women, has taken a leading role in implementing prevention of vertical transmission, training mentors to register and refer people to prevention, care, treatment and services.

In the UK, the From Pregnancy to Baby and Beyond programme run by Positively UK provides peer support for women living with HIV throughout their pregnancy, childbirth and into motherhood. Women receive information, education and practical support. This programme was designed, implemented and monitored independently by women living with HIV alongside clinicians and health-care providers, and has been a huge success.

However, community responses that have effectively worked to overcome structural barriers are chronically and severely lacking resources. We are doing great work to fill crucial gaps in service, but this needs to happen on a far larger scale. Until the major challenges, such as the criminalization of HIV, coerced abortions and sterilizations, gender-based violence perpetrated by health staff, stigma and discrimination and others, are overcome, the prospect of an HIV-free generation will remain distant.

On the journey towards ending new HIV transmissions to children by 2015 and substantially reducing AIDS-related maternal deaths, women living with HIV need to be meaningfully involved at all stages. We are – and want to continue to be – a part of the solution. We have the skills, expertise and experiences to make a difference.

Kristofina Mwaongelange Meameno is a member of the Namibia Women's Health Network, Namibia; Lillian Kyomuhangi Mworeko is Regional Coordinator for the International Community of Women Living with HIV&AIDS Eastern Africa, Uganda; and Angelina Namiba is a Project Manager at the From Pregnancy to Baby and Beyond programme run by Positively UK, Kenya and United Kingdom.

ACTION POINTS

- **Uphold our rights, including those of us born with HIV, to understand our sexual and reproductive rights.**
- **Make comprehensive services available to us, and provide them in a safe space.**
- **Enable us to expand the mentor model so we, women living with HIV, can counsel other women.**
- **Educate our health-care workers on human rights so that they can better support us to access services.**
- **Invest in our organizations to increase our involvement, not just as service recipients but also as service providers, and to play a part in policy and programme design, implementation and independent monitoring and evaluation.**



**15 MILLION
ACCESSING
TREATMENT!**

68%

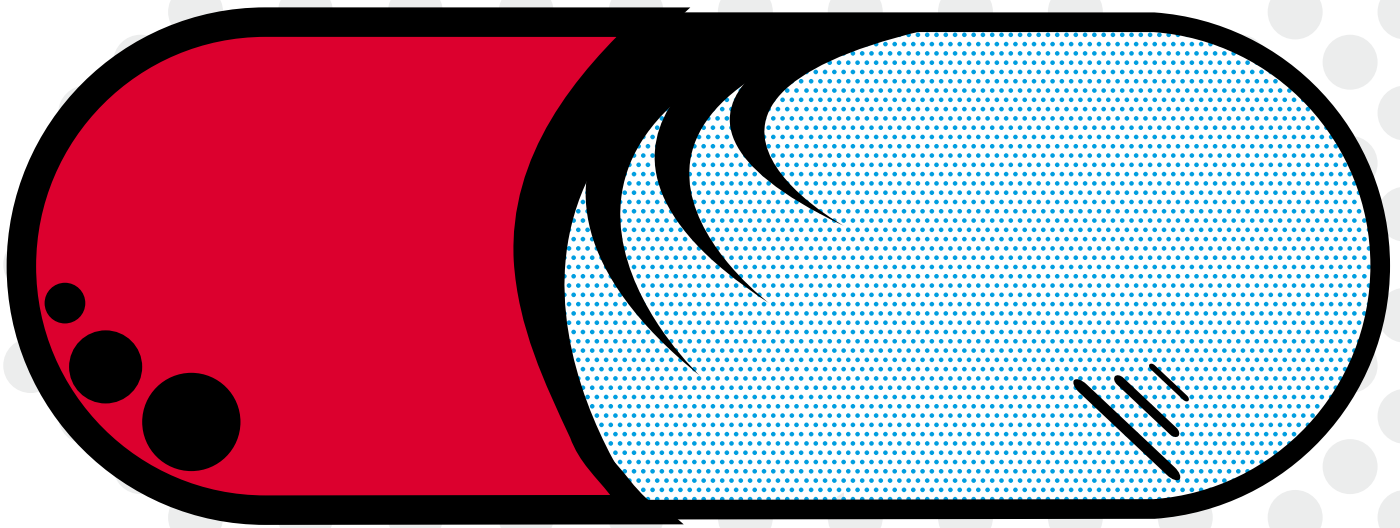
HIV treatment coverage for women is 68%, compared to 47% for men.

14 COUNTRIES

In 14 countries in sub-Saharan Africa, testing rates tend to be higher among women than men.

20.5%

In the USA, 20.5% of women reported experiencing physical harm since they were diagnosed with HIV.



TARGET 4

REACH 15 MILLION PEOPLE LIVING WITH HIV WITH LIFESAVING ANTIRETROVIRAL TREATMENT BY 2015.

WOMEN ACCESS ANTIRETROVIRAL THERAPY MORE FREQUENTLY THAN MEN, YET IN SOME SETTINGS THEY STILL FACE MAJOR BARRIERS TO DOING SO.

Introduction

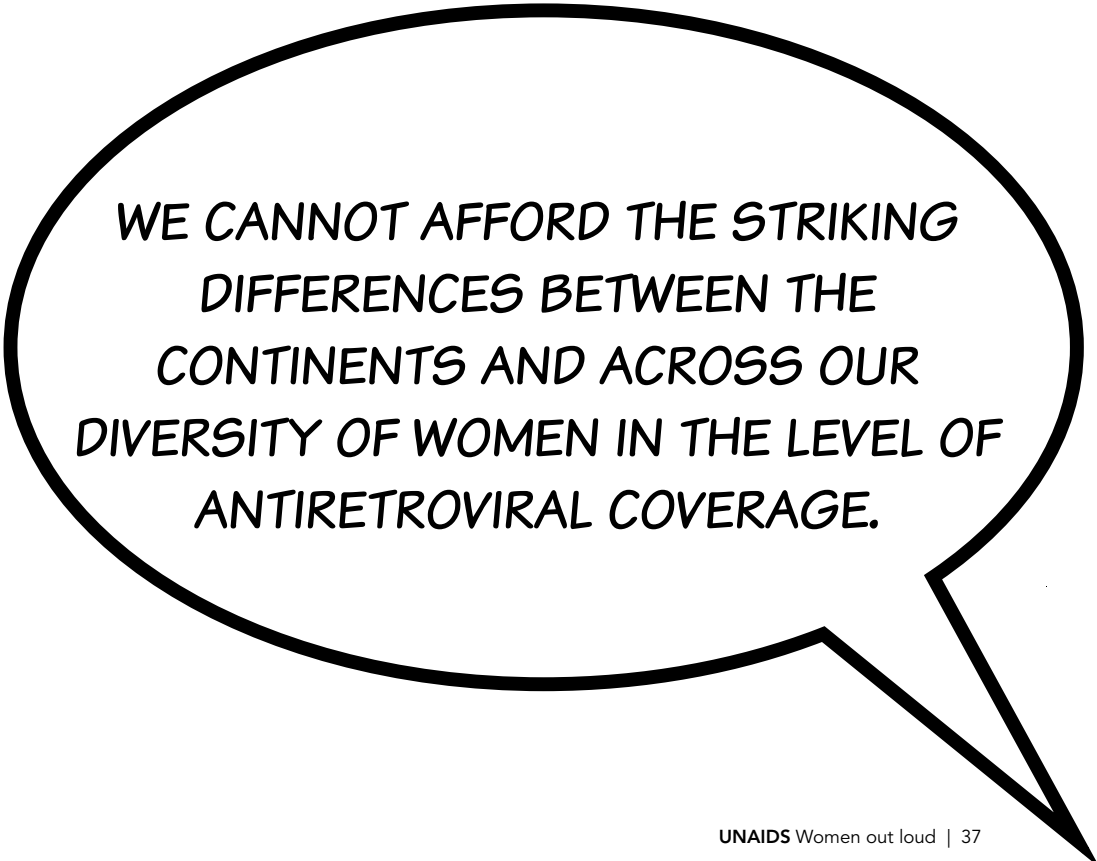
Women living with HIV who are eligible for antiretroviral treatment are more likely to access treatment services than their male peers (68% coverage compared with 47% for men) (1). Several studies have shown that women in resource-constrained settings are not necessarily disadvantaged in their access to antiretroviral treatment. This is partly because there are specific entry points for women, such as maternal and child health-care settings, to access HIV testing and treatment. In 14 countries in sub-Saharan Africa, testing rates are higher among women than among men, perhaps in part because of the increased availability of testing in those settings. However, this pattern is not universal for all women across all epidemics, key populations and age groups. This is confirmed by the fact that although antenatal care clinics serve as a key entry point to HIV services, only 30% of the eligible pregnant women receive antiretroviral treatment for their own health (2).

In some places women face various barriers in accessing HIV services. Women with low incomes frequently experience difficulty in accessing treatment and care. Women living with HIV in Chennai, India, for example, cited travel distance and/or transportation to services, and financial issues with child care (3). A study describing the association between adherence to antiretroviral therapy among women in the United States of America and child-care burden, household composition, and health-care utilization showed that greater child-care burden and the number of children aged 18 years or younger in the household were inversely associated with adherence. Assessing patients' difficulties in caring for children and household composition are important considerations when addressing adherence to treatment (4).

Criminalization of HIV exposure or transmission is another important barrier to utilization of HIV testing and treatment services. Criminalization affects both men and women's ability to choose whether or not, how, when and with whom to engage in sex. Furthermore, criminalization of vertical HIV transmission (5) marks women living with HIV as potential offenders, and further marginalizes women who are vulnerable as a consequence of poverty, lack of education, absence of health promotion and services, and gender inequality.

Gender inequality also affects women's ability to access and adhere to HIV treatment and care. A recent study in Ethiopia revealed that women who have fewer economic opportunities and are economically dependent on their partners are more likely to discontinue antiretroviral therapy for fear of revealing their HIV status to their husbands and suffering the potential negative consequences on their marriage, including divorce (6).

Research also shows that experiencing gender-based violence affects women's access and adherence to treatment (7). Violence, and the fear of future violence, can also play a major role in an individual's reluctance to know his or her HIV status, receive testing for HIV, seek HIV care, and subsequently receive appropriate treatment. In one study in the United States, 20.5% of women, 11.5% of men who reported having sex with men, and 7.5% of heterosexual men interviewed reported physical harm since diagnosis, and almost half reported HIV-seropositive status as a cause of violent episodes. In a study of HIV-positive women seeking care in Boston and Rhode Island, 68% had histories of physical or sexual abuse. Women who were victims of abuse were more likely than women who were not abused to consider their providers as judgemental, annoyed and disrespectful, and to find it difficult to discuss private and emotional issues with them; such perceptions among those who have faced abuse can also affect treatment outcomes (8). Another study found that women who face challenges in adhering to treatment may be mistreated by service providers when they explain that they have missed doses (8).



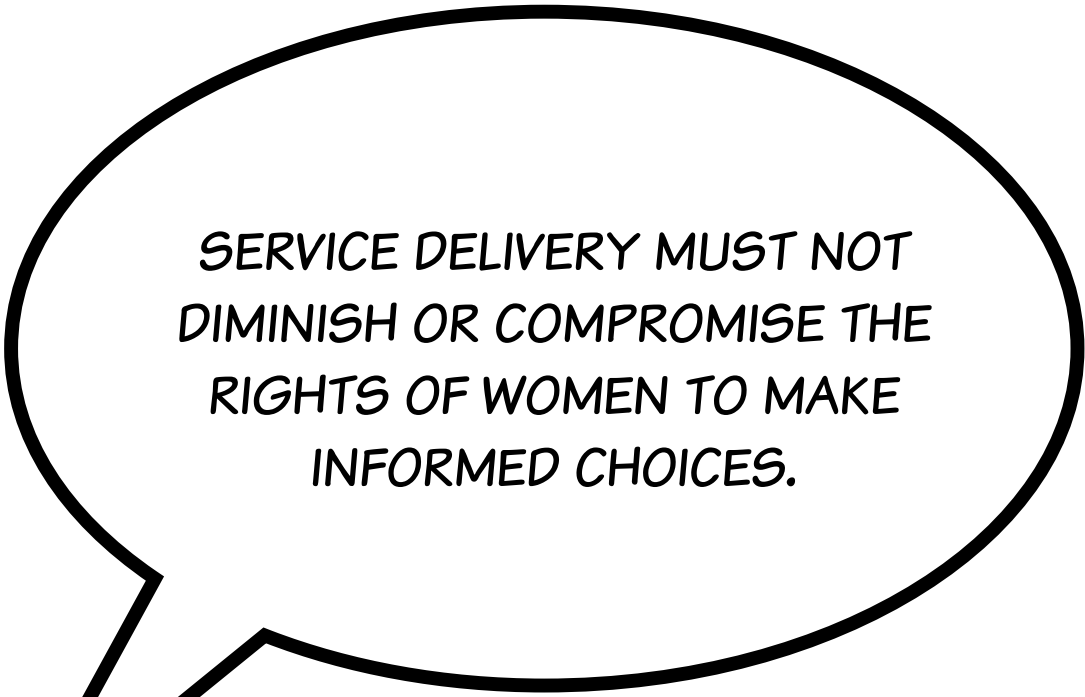
**WE CANNOT AFFORD THE STRIKING
DIFFERENCES BETWEEN THE
CONTINENTS AND ACROSS OUR
DIVERSITY OF WOMEN IN THE LEVEL OF
ANTIRETROVIRAL COVERAGE.**

Women from key populations, including sex workers, transgender women, women who inject drugs, women in prison, and displaced women, may experience barriers to treatment access and adherence due to stigma and discrimination, the threat of violence or arrest, fear of disclosure, or legal and policy barriers. For example, HIV-positive female drug users who are pregnant or have children may not seek antiretroviral therapy because they fear hostility from practitioners or having their children taken away. Many HIV prevention and care services around the world, including for drug dependence treatment, do not admit women clients, particularly if they are pregnant, HIV positive or have children. The reasons for restrictive admission policies include lack of sex-segregated accommodation and child-care facilities. Negative perceptions of women who use drugs by health professionals and community-based organizations create additional barriers to entering treatment (9).

Even in places with universal access to free HIV treatment and medical care, such as Canada, women who inject drugs are less likely to access and adhere to antiretroviral therapy, a finding that is independent of drug use and clinical characteristics (10).

It is clear that to reach 15 million people with HIV treatment by 2015, efforts must be intensified to ensure increased uptake of treatment among women, especially in populations without easy access to care. There is also a need to identify barriers that are stopping men from accessing care. In the context of serodiscordant couples, more attention must be paid to ensuring that men living with HIV are accessing treatment services. This will ensure that all people living with HIV have fair access to treatment programmes.

Meanwhile, women must be able to access treatment for their own health, both within and beyond antenatal settings. Ensuring that treatment services are accessible, gender-sensitive, non-discriminatory and uphold the rights and confidentiality of all women, regardless of age, sexual orientation, socioeconomic status, or occupation, will be key to meeting the target.



**SERVICE DELIVERY MUST NOT
DIMINISH OR COMPROMISE THE
RIGHTS OF WOMEN TO MAKE
INFORMED CHOICES.**

WOMEN OUT LOUD

DAWN AVERITT BRIDGE, LILLIAN KYOMUHANGI MWOREKO,
ANNA ZAKOWICZ

The goal of providing access to antiretroviral treatment to 15 million people is an essential next step, but it must be made with the health, the lives and the human rights of women at the forefront. As women living with HIV, we are an extraordinary resource for scale-up, design and implementation strategies that will succeed in reaching our communities.

In the past two years there have been dramatic scientific breakthroughs and programmatic expansions, delivering treatment and prevention modalities to more people and in more communities than ever before.

The experience of one of the coauthors, Lillian Mworeko, who has been on antiretroviral treatment for 10 years and has an undetectable viral load, is testament to the human cost of inequitable access to antiretroviral therapy:

In 1999 when I had been diagnosed with HIV we formed networks of people living with HIV in Uganda. Out of 10 trainers, one person was on antiretroviral therapy and the message was 'eat well to live longer'. In 2003, when finally our friends in the western world donated drugs they no longer needed, it was difficult for people living with HIV to select who to start on antiretroviral therapy and who to leave out. We had to set criteria and we agreed to start with those for whom it was obviously only a matter of time to succumb to the disease.

Services live on different continents and in different economic circumstances but we all must have equitable access to treatment. This is a human right. We cannot afford the striking differences between the continents and across our diversity of women in the level of antiretroviral coverage. Women who use drugs, sex workers, transgender women, women in prisons, migrant women, young women living with HIV, and women living with HIV and with disabilities should all have the same level of access to treatment.

As important as the services for the prevention of mother-to-child transmission are important for HIV testing and they link women to care and treatment initiation. Yet it is essential that treatment scale-up does not focus entirely on these settings; women have the right to access treatment outside maternal health settings and should be supported to access it for their own health. Moreover, service delivery must not diminish or compromise the rights of women to make informed choices about treatment, prevention strategies,

pregnancy and care. We have the right to be fully informed and consulted on new strategies that governments are considering, such as Option B+ whereby a pregnant woman starts antiretroviral therapy immediately upon diagnosis, regardless of her CD4 cell count.

We, women and girls living with HIV, are mothers, friends, wives and daughters. We are drivers of change in our communities. As well as HIV, we face other conditions, such as hepatitis C, tuberculosis and noncommunicable diseases, for which we also need access to treatment and to understand the corresponding drug interactions. For those of us who are transgender women, we struggle to access information on potential interactions between antiretroviral therapy and hormones.

Each day we get older living with HIV. We are subjected to violence and discrimination from partners, family members and even health-care providers, in the context of family planning and overall health care, as well as HIV-specific services. All of this can adversely affect our access to treatment and our adherence.

And yet, we have been delivering HIV testing, treatment and care, adherence support programmes, advocacy, monitoring and service delivery at all levels, as well as creating networks to share knowledge, support each other, and to mobilize and sensitize communities.

As women living with HIV, we have persistently engaged in supporting access to antiretroviral therapy. This engagement includes: bold advocacy actions against Trade-Related Aspects of Intellectual Property Rights agreements in India; monitoring treatment interruptions in Russia; providing care and love for orphaned children in Africa; interventions to ensure access to HIV treatment for African-American women in prisons; and HIV treatment literacy for transgender women in Brazil.

The expertise of women living with HIV and women from marginalized populations must be deployed to ensure that optimal diagnosis, treatment and care services are developed and delivered in a manner that supports women's human rights and reflects their real lives. The successes to date could have been even greater had women living with HIV been more meaningfully involved in the process. Such involvement continues to be conspicuously absent from many essential leadership, policy-making and programming positions. Similarly, the proportion of funding for the work of women living with HIV and the organizations that serve us is not proportional to our needs and contributions.

The commitment to deliver treatment offers the possibility of health and longevity to those who would otherwise lose their lives or those of their loved ones. In order for this to succeed we must move from measuring and reporting on numbers receiving treatment to quantifying the quality of services, and we must disaggregate data to take into consideration the diversity of groups.

When our daily challenges, successes and lessons learned are sufficiently documented and turned into operational guidelines, undoubtedly they can significantly enhance the lives of women living with HIV and ultimately improve treatment outcomes.

As women living with HIV, we applaud the scientific advances, such as treatment as prevention, but we urge that our right to decide when and if to start treatment must never be sacrificed in the name of public health. Ultimately, ensuring universal and comprehensive coverage, including diagnostics, viral-load monitoring and treatment of opportunistic infections, must all be provided within a human rights-based framework.

Dawn Averitt Bridge is Founder and Chair of The Well Project/Women's Research Initiative on HIV/AIDS (WRI), United States of America; Lillian Kyomuhangi Mworeko is the Regional Coordinator with the International Community of Women Living with HIV&AIDS Eastern Africa, Uganda; Anna Zakowicz is co-Chair of the Board in Poland for the Global Network of People Living with HIV.

ACTION POINTS

- **Increase continuous investment in The Global Fund to Fight AIDS, Tuberculosis and Malaria**, *focus efforts to reduce drug prices and scale up generic medicine availability through increased generic competition that is unhindered by free trade agreements, data exclusivity and monopoly protection.*
- **Strengthen the Medicines Patent Pool** *by developing meaningful indicators for women, and increase the pool's use by pharmaceutical companies.*
- **Bring down costs of new combinations of antiretroviral therapy**, *together with the universal expansion of accessible second-line regimens.*
- **Make antiretroviral therapy accessible to all women who need it** *in the most appropriate and easy-to-use pill burden.*
- **Increase investment in treatment literacy for all women living with HIV** *to ensure non-coerced treatment decisions and support adherence to antiretroviral therapy.*
- **Advocate for long-term, sustainable funding from high-income countries** *and require that African leaders live up to their Abuja Declaration commitments to devote 15% of public expenditure to health.*



**AVOID TB
DEATHS!**

10x

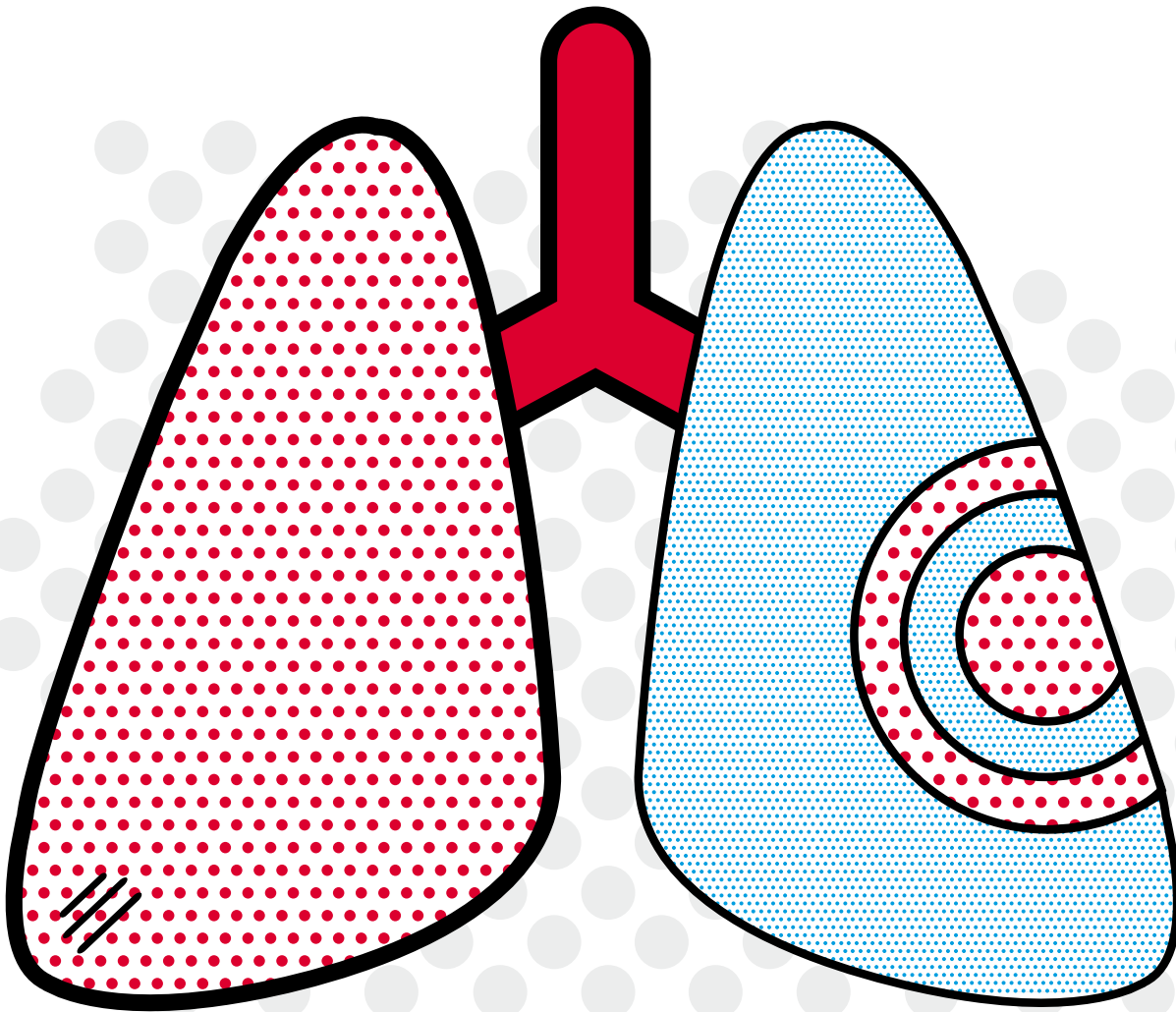
Pregnant women living with HIV have a 10-fold higher risk of developing active tuberculosis compared with HIV-negative pregnant women.

2.5x

Tuberculosis carries a 2.5-fold increased risk of new infections in children born to mothers living with HIV.

20%

In Africa, approximately 20% more tuberculosis-related deaths occur among women than among men.



TARGET 5

REDUCE TUBERCULOSIS DEATHS IN PEOPLE LIVING WITH HIV BY 50% BY 2015.

HIV IS THE STRONGEST KNOWN RISK FACTOR FOR TUBERCULOSIS, AND HIV-ASSOCIATED TUBERCULOSIS IS A LEADING KILLER AMONG PEOPLE LIVING WITH HIV, LEADING TO 200 000 HIV-ASSOCIATED DEATHS IN WOMEN EACH YEAR.

Introduction

Tuberculosis and HIV are closely interlinked. In 2011, some 1.1 million (13%) of the estimated 8.7 million people who developed tuberculosis worldwide were HIV-positive, with African countries accounting for almost 80% of coinfections (1).

Globally more tuberculosis cases are reported in men, but in high HIV prevalence settings the case and mortality rates appear to be higher among women (1,2). Although the ratio of HIV-associated tuberculosis deaths worldwide is relatively balanced between men and women, in the African region in 2011 there were approximately 20% more of these deaths among women than men. Among women living with HIV, tuberculosis is associated with more than double the risk of maternal mortality, and more than triple the risk of infant mortality, compared with both outcomes in HIV-negative women (3, 4).

Tuberculosis also kills more women than all causes of maternal mortality combined (5). Of an estimated 8.7 million cases of tuberculosis worldwide in 2011, it is estimated that nearly 2.9 million were among women (1). In 2011, there were an estimated 500 000 tuberculosis deaths among women globally, including approximately 200 000 (range 185 000–215 000) HIV-associated deaths (1).

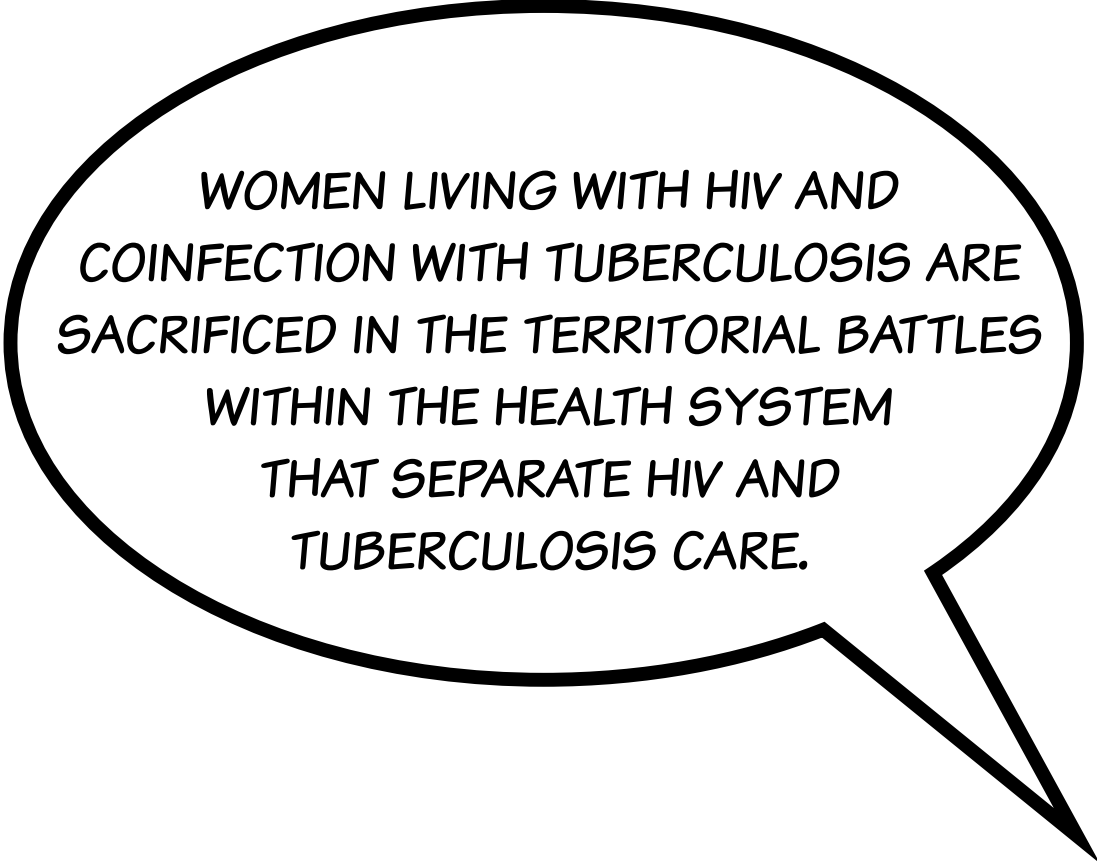
At the same time, there is an increasing trend of tuberculosis notifications among women in high HIV prevalence settings, particularly in southern Africa, reflecting the increased burden of tuberculosis among women there (2).

Undiagnosed active tuberculosis is common among pregnant women. HIV has been reported to be a significant trigger of tuberculosis during pregnancy (3), and pregnant women living with HIV have a 10-fold higher risk of developing active tuberculosis compared with HIV-negative pregnant women (6).

Tuberculosis is associated with a 2.5-fold increased risk of mother-to-child transmission of HIV (7). Antiretroviral therapy is critical to prevent tuberculosis among women. A recent meta-analysis (8) of studies in low- and middle-income countries found that antiretroviral therapy was associated with a 65% decrease in the risk of tuberculosis irrespective of the CD4 cell count. However, coverage of antiretroviral therapy is still at a low level; 68% of all women globally received treatment in 2011 while only 57% of pregnant women living with HIV in low- and middle-income countries received effective medicines to prevent transmission to their child (9).

Pushing for change

It is evident that socioeconomic barriers can impact on women's access to tuberculosis information and services, and these contribute to late or missed case detection. For example, in resource constrained settings where women are economically dependent on their partners, they may delay seeking medical care for themselves. Some studies have also shown that women wait up to twice as long as men to seek treatment for tuberculosis, which can increase the severity of their illness, decrease the success of treatment, and raise the risk that they will infect others (10). Women living with HIV, who are often subjected to stigma and discrimination, may be fearful of seeking information and care for HIV and tuberculosis (11).



**WOMEN LIVING WITH HIV AND
COINFECTION WITH TUBERCULOSIS ARE
SACRIFICED IN THE TERRITORIAL BATTLES
WITHIN THE HEALTH SYSTEM
THAT SEPARATE HIV AND
TUBERCULOSIS CARE.**


To achieve a reduction in tuberculosis deaths in people living with HIV by 50% by 2015 that is fully inclusive of women living with HIV, tuberculosis prevention, diagnosis and treatment should be included as key interventions at all stages of pregnancy, neonatal, postpartum and postnatal care, particularly in high-prevalence HIV settings. Specifically, women should be offered HIV testing and, if found to have HIV, considered for the so-called three I's for HIV/tuberculosis (intensified tuberculosis case finding, isoniazid preventative therapy and infection control for tuberculosis) as well as early initiation of antiretroviral therapy if eligible.

Better systems needed

Systems need to be in place to offer eligibility screening for antiretroviral therapy as well as tuberculosis screening, and new rapid diagnostics need to be available at HIV or sexual and reproductive health facilities where possible. Otherwise, an effective referral system must be in place to facilitate early diagnosis of tuberculosis for women living with HIV. In addition, early tuberculosis treatment and antiretroviral therapy should be provided for all women who are diagnosed with both diseases.

Furthermore, information on early HIV treatment and tuberculosis must be made available to women living with HIV, particularly those who are pregnant, so that they are able to access the necessary services for tuberculosis screening, diagnosis and treatment.

More research is needed focusing on tuberculosis and HIV among women living with HIV. Networks of women living with HIV must be mobilized and supported to build knowledge and demand for better integration and earlier access to tuberculosis and HIV interventions in mother and child health services.



**WOMEN ALL OVER THE WORLD ARE
LEADING TUBERCULOSIS CASE-FINDING
PROGRAMMES AND COMMUNITY-LED
PREVENTION PROGRAMMES
AMONG THEIR PEERS.**

WOMEN OUT LOUD

CAROL NAWINA NYIRENDA, GRACIA VIOLETA ROSS,
ALEXANDRA VOLGINA

As women living with HIV, we saw the epidemic change when grassroots communities all over the world claimed their power to lead in the AIDS response. This has yet to happen with tuberculosis.

We have seen many women living with HIV who have died because of tuberculosis. We too have experienced the potentially deadly effects of the stigma that surrounds both HIV and tuberculosis: life-threatening misdiagnosis, mistreatment in the health system and the dual burden of caring for others while sick.

Tuberculosis often goes undiagnosed, particularly the extrapulmonary infections that are associated with HIV. With the increase in HIV sexual transmission rates in some settings, such as Russia, both HIV and tuberculosis are starting to affect groups of people not usually referred to as most vulnerable, including the so-called 'socially integrated' women. Doctors rarely suspect tuberculosis or HIV in such patients, treating them for pneumonia instead of suggesting voluntary and confidential testing for HIV and tuberculosis. As a result, the disease is only identified at advanced stages.

Marginalized women, on the other hand, often have dependencies such as alcohol, drug use and smoking which, besides the obvious negative effects on health in general and on the tuberculosis treatment outcomes in particular, lead to severe depression. A diagnosis of tuberculosis can lead us to encounter a health system that is disempowering, where doctors use technical language that is difficult for us to understand and which diminishes human dignity, with such terms as 'tuberculosis suspect' and 'treatment defaulter'. Women who have become coinfecting through injecting drugs are treated as the dregs of society.

Once diagnosed, as women we usually carry the dual burden of having tuberculosis and needing to care for our family members and other loved ones. When a husband is sick, a wife is expected to take care of him, even when she is also sick. But when a wife is sick, in most cases, the husband will take her to her family so they can nurse her, and this home-based care is also given by a woman. If coinfecting with HIV and tuberculosis, this double stigma and dual burden is hard to bear for many women.

Treatment for tuberculosis can be gruelling, requiring many trips to health facilities or prolonged stays in hospital, isolated from our families and separated from our children. In some countries, stock-outs of life-saving medicines are common, exacerbating the growing problem of multidrug-resistant tuberculosis.

No grass-roots response

Women living with HIV and coinfection with tuberculosis are sacrificed in the territorial battles within the health system that separate HIV and tuberculosis care. There is so much talk about integration of treatment, but we do not see the action on the ground.

As women living with HIV, we are aware that much has been done to address HIV, even for women. We have global networks; many of us speak publicly about our HIV status and help make a difference. Not so much has been seen of women from the grass roots in the tuberculosis response. In fact, there is little sense of community among people living with tuberculosis.

Even in the HIV community, there has been scant discussion and in-depth analysis of coinfection among women. Despite numerous recommendations for activities to deepen the gender analysis and vulnerability of the HIV-tuberculosis epidemics, there has been little action. For us, this means a huge gap in the understanding of the gender dimensions of both epidemics.

How can we say that tuberculosis is the leading killer of people living with HIV (including women, of course) but not ensure that HIV and TB programmes work hand in hand? How can we save the lives of those living with HIV while at the same time neglecting efforts to end tuberculosis?

In the face of stigma it is hard for such patients to unite and openly fight for their rights. In this context, community organizations play a role that is hard to overestimate. Women all over the world are leading tuberculosis case-finding programmes and community-led prevention programmes among their peers, especially those in Africa. Some women are taking a leadership role in the Stop TB Partnership, and as part of the communities delegation of the Global Fund to Fight AIDS, Tuberculosis and Malaria and other international health bodies. But where are the other women? Where is the voice of the feminist movement globally? Where are the voices of advocates on maternal and child health?

We are speaking out

Those of us women living with HIV who have been diagnosed with tuberculosis and have been successfully treated can and do use this experience to speak out and to advocate for better services for tuberculosis and HIV, especially for women and children. We advocate for the inclusion of affected communities at all levels, especially decision-making, for more resources for tuberculosis and for the demystification of the disease.

The coordinated actions of civil society do matter. The case of multidrug-resistant tuberculosis drug stock-outs in St Petersburg shows that. The Equity. Verity. Advocacy. (E.V.A) network of women affected by HIV and other socially significant diseases kept in constant contact with the tuberculosis clinics, pharmaceutical companies and patients, while the initiative group Patients in Control chose a more strident advocacy, protesting in the streets, with wide coverage in the mass media.

We do not need to reinvent the wheel; the HIV world has good mechanisms that can help ease the burden of women with regards to tuberculosis.

Carol Nawina Nyirenda is Executive Director of the Community Initiative for TB, HIV/AIDS & Malaria in Zambia; Gracia Violeta Ross is National Chair of the Bolivian Network of People Living with HIV and AIDS; Alexandra Volgina is Executive Director of Equity. Verity. Advocacy. (E.V.A), Russia.

ACTION POINTS

- **Address how our gender is associated with both epidemics** *through common challenges such as poverty, disease, lack of access to health services and information, and stigma.*
- **Make our lives easier through triple integration of services** *for maternal and child health, HIV and tuberculosis.*
- **Respect us. Treat those of us with tuberculosis and/or HIV as partners** *and not only as patients.*
- **Empower us to address the tuberculosis and HIV epidemics** *in our communities. We are the best medium to use to get the right information where it is needed.*



**CLOSE THE
RESOURCE GAP!**

30 COUNTRIES

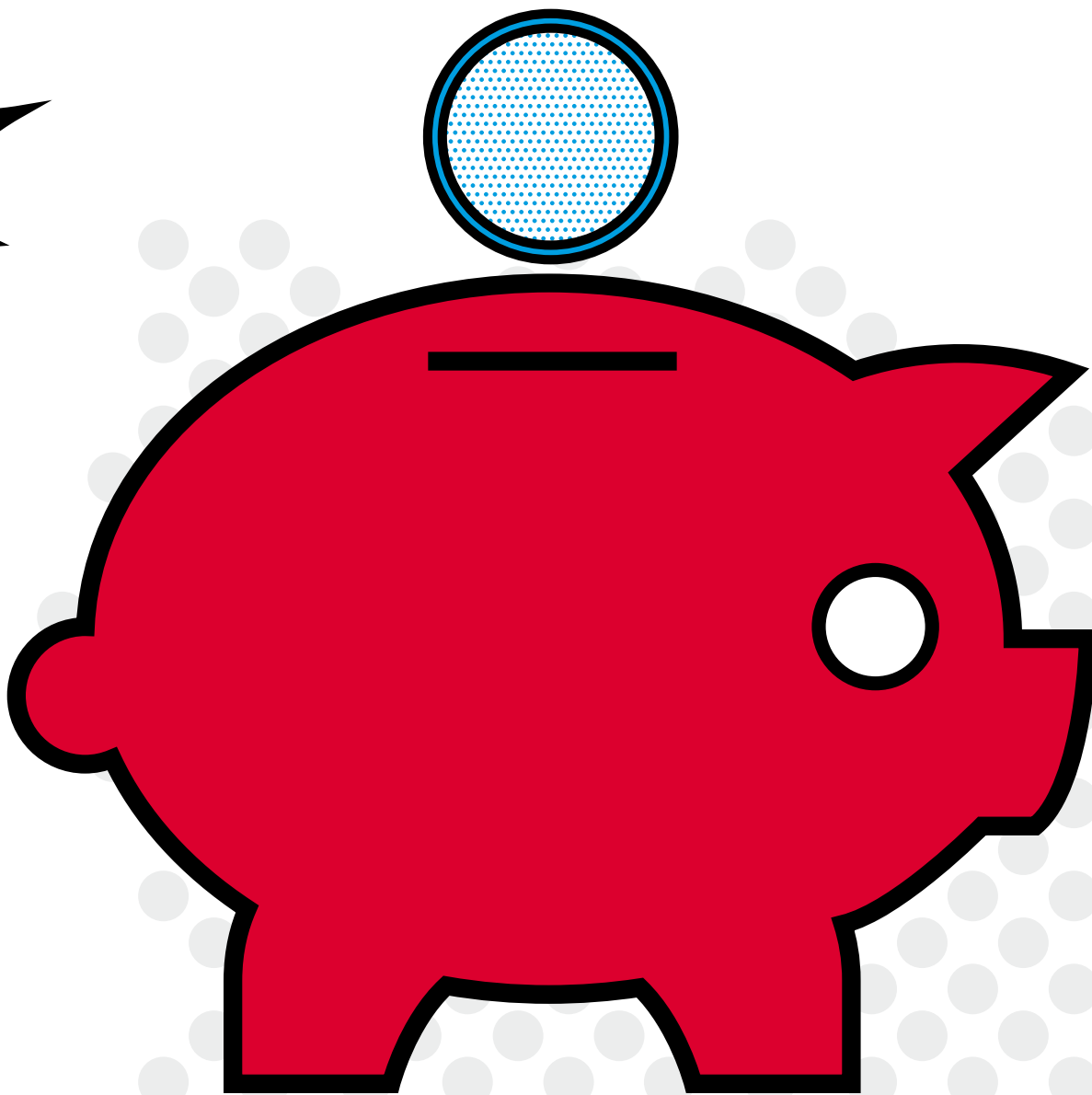
Thirty low- and middle-income countries have reported spending on programmes to reduce gender-based violence within the HIV response.

71%

Of HIV funding specific to women, 71% is allocated to preventing vertical transmission.

43%

Domestic sources provide 43% of HIV spending targeting women in low- and middle-income countries.



TARGET 6

CLOSE THE GLOBAL AIDS RESOURCE GAP BY 2015 AND REACH ANNUAL GLOBAL INVESTMENT OF US\$22-24 BILLION IN LOW- AND MIDDLE-INCOME COUNTRIES.

TOTAL GLOBAL HIV INVESTMENTS IN 2011 WERE US\$ 16.8 BILLION. THIS REPRESENTS AN 11% RISE IN SPENDING COMPARED WITH 2010, AND A 15% INCREASE IN DOMESTIC EXPENDITURE IN LOW- AND MIDDLE-INCOME COUNTRIES. IT IS THE FIRST TIME THAT NATIONAL RESOURCES FOR HIV HAVE SURPASSED EXTERNAL INVESTMENT WORLDWIDE.

Introduction

127 low- and middle-income countries provided reports in 2012 about their spending for HIV interventions targeting women (Table 6.1). Their reports included programmes to stop new infections in children and keep mothers alive, prevent HIV among sex workers and their clients and reduce gender-based violence, as well as AIDS-specific programmes focused on women. In all, 85 countries reported spending on the selected categories and the total national spending for interventions specifically targeting women was approximately US\$ 288 million. Of this, about 42.4% was from domestic resources.

However, gender-disaggregated spending data is not available for most interventions that target both women and men, such as antiretroviral treatment, or for interventions for which it is assumed the bulk of funding is aimed at women, such as family/home support or social protection through monetary or in-kind benefits and income-generation projects. Therefore, the total amount of HIV funding for women may be larger than it might seem when considering only the funding for gender-specific interventions.

TABLE 6.1. HIV SPENDING SPECIFIC TO WOMEN, BY INTERVENTION

INTERVENTION	NO. OF COUNTRIES REPORTING	TOTAL SPENDING TARGETING WOMEN	% FROM DOMESTIC RESOURCES	% OF TOTAL SPENDING
PROGRAMMES TO END NEW INFECTIONS IN CHILDREN AND KEEPING MOTHERS ALIVE	79	US\$ 203 million	47%	70%
PREVENTION PROGRAMMES FOR SEX WORKERS AND THEIR CLIENTS	73	US\$ 65 million	15%	23%
PROGRAMMES TO REDUCE GENDER-BASED VIOLENCE	30	US\$ 16 million	92%	6%
OTHER AIDS-SPECIFIC PROGRAMMES FOCUSED ON WOMEN	34	US\$ 4 million	5%	1%
TOTAL		US\$ 288 million	43%	100%

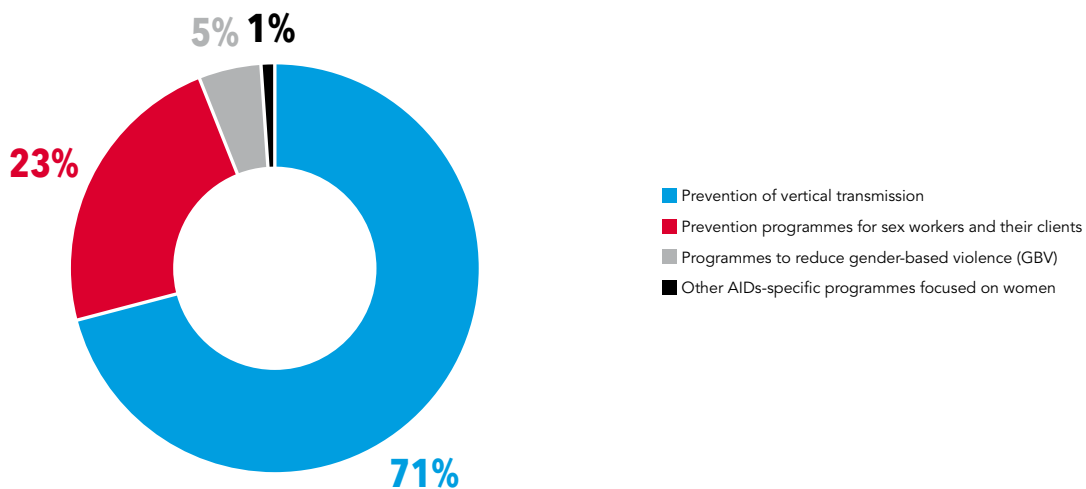
Source: 2012 country progress reports (www.unaids.org/cpr)

While these data are the best available about country-level gender-specific HIV spending, there are limitations in capturing the total HIV investment in women. For example, some high-burden countries (Malawi, Mozambique and Zambia, for example) did not submit reports, and many of the countries that did report on the selected interventions have low HIV prevalence. In addition, the completeness of reporting for the reviewed interventions varies; some countries did not include information on all interventions focusing on women. There is a dearth of guidance providing criteria for what is ideally included in women-focused interventions.

Also, prevention services (which include sex-worker interventions) and treatment programmes generally target persons of both sexes, but gender-disaggregated spending data are generally not reported in most countries. Prevention of new infections in children and keeping mothers alive accounts for a large proportion of gender-specific HIV interventions, and these services are given priority. These services do not always include continuing treatment of HIV for women or address their sexual and reproductive health needs, including primary prevention. (Fig. 6.1).

Data limitations aside, this analysis does provide evidence that significant investments are being made for HIV prevention, treatment and care services among women, using funding from both domestic and international sources. Approximately half of gender-specific spending occurs in sub-Saharan African countries, while, at the same time, upper-middle countries with higher incomes are investing a higher proportion of their domestic and overall funding in comparison with low-middle and low-income countries.

FIGURE 6.1. TOTAL HIV SPENDING SPECIFIC TO WOMEN, 2009–2011



Source: 2012 country progress reports (www.unaids.org/cpr).

The relevance of investing in gender equality is demonstrated by a landmark study from South Africa, which found that 13.9% of new HIV infections could be prevented if gender inequalities were eliminated (1). In addition to gender equality, the UNAIDS Agenda for Women and Girls and the UNAIDS Strategy 2011–2015 also recognize the importance of addressing violence against women and girls as an integral part of an effective the HIV response (2, 3). Yet the level of investment in gender-based violence within the response to HIV is limited, with only 30 low- and middle-income countries reported spending on programmes to reduce gender-based violence within the HIV response, constituting only 5% of the funds spent on interventions specifically targeting women. (Table 6.1)

Global Fund data on gender-specific interventions

It is estimated that 44% of Global Fund investments go to support the health of women and girls, contributing to Millennium Development Goal (MDG) four, to reduce child mortality, and MDG five, to improve maternal health (4, 5). Nevertheless, funding requests to the Global Fund indicate limited approaches to the HIV response for women and girls (6). For example, countries implementing programming to end new infections in children and

keep mothers alive have mainly requested funds for provision of antiretroviral drugs provided during pregnancy and/or labour. There is limited evidence of the other pillars of prevention of mother-to-child transmission being implemented: meeting the long-term treatment needs of women living with HIV, comprehensive reproductive health services and family planning.

In addition, evaluation of the gender-equality strategy of the Global Fund showed limited roll-out of the strategy and limited dedicated funding to gender equality within country grants. The Global Fund Strategy 2012–2016 encourages and supports countries to increase programming that will improve access to health services for affected communities and create an enabling social and policy environment that can be rolled out for any highly affected group, including women (7). However, the limitations of the Global Fund's previous approach raise concerns that gender inequality and gender-based violence will be inadequately prioritized in future funding.

Civil society organizations, including networks of women living with HIV, have expressed concerns about shrinking financial support for their operations, impeding their ability to effectively engage in the AIDS response (8). As the Global Fund moves forward with a new funding model and as countries develop new investment cases, it will be important to ensure civil society remains fully involved in the design and implementation of programmes. Appropriate levels of funding must reach their organizations for community systems strengthening and community led service delivery, including gender-related interventions. Dual Track Financing will continue to be a critical element in these efforts.

United States President's Emergency Plan for AIDS Relief data on gender-specific interventions

Among the major global AIDS donors, the United States Government has provided significant leadership and resources targeting women and girls. The President's Emergency Plan for AIDS Relief (PEPFAR) focuses on:

- Increasing gender equity in HIV/AIDS programmes and services, including access to reproductive health services;
- Reducing violence and coercion;
- Engaging men and boys to address norms and behaviours;
- Increasing women and girls' legal protection;
- Increasing women and girls' access to income and productive resources, including education.

PEPFAR has been a significant source of funding to address gender-based violence, which has been recognized as both a cause and a consequence of HIV. The United States has invested a total of US\$ 155 million over the past two years and has worked to mainstream efforts to address gender-based violence via existing HIV programmes (9). PEPFAR is addressing a niche in national HIV programming and making a strategic contribution to HIV responses that tackle harmful gender-related attitudes and behaviour. During 2010-2011,


PEPFAR invested approximately US\$ 8.5 billion to support AIDS responses in 34 countries and 3 regional programmes. Of this, US \$155 million was directly targeted at combatting gender-based violence.

Moving towards the 2015 targets

Closing the resource gap will rely on countries increasingly sharing responsibility to maximise responses by scaling up domestic resources and allocating investments through a focused and strategic approach. At the same time, AIDS remains a global development challenge and demands that all partners remain committed to ending the epidemic in the spirit of global solidarity.

As domestic expenditure and country ownership increase, countries must be responsible for ensuring that the AIDS response has a distinct focus on the rights of all women living with and affected by HIV, including their sexual and reproductive health and rights, beyond their potential role as mothers. As strategic investment cases are being utilized to focus efforts and optimize national AIDS responses, it is a crucial moment to position gender equality and gender-based violence at the core of the HIV response.

Development partners and national governments must invest in networks and organizations of women living with HIV, enabling them to develop and implement innovative strategies to meet women's needs. Resource allocation that is intended to meet gender-responsive performance indicators and gender-responsive budgeting measures are a key to smart spending and improved tracking of resources targeting women and girls. Countries must also be supported in improving their data collection on HIV expenditure that responds to the needs and priorities of women.



**WITH MULTILATERAL AND BILATERAL
AID WANING, THE NEED FOR A MORE
SUSTAINABLE FUNDING MODEL FOR HIV
THAT CAN MEET OUR NEEDS HAS
NEVER BEEN MORE URGENT.**

WOMEN OUT LOUD

MOROLAKE ODETOYINBO, RACHEL ONG, KIM NICHOLS

Women must reinforce the message in the halls of their national governments that country ownership is essential for sustaining prevention and treatment gains. Women living with HIV must be recognized as central to the call for mobilizing the US\$ 24 billion needed annually by 2015 to fill the global gap in universal access. When we are sitting at the table negotiating for the resources we need, we are a powerful force and a powerful voice, and we are there as equals.

At the final drafting of the UN Political Declaration negotiations in 2011, a meeting that was open only to country representatives, we women activists breached security and fielded information on the positions of various governments to colleagues outside the room. While the overall target to reach global investment of US\$ 22–24 billion in low- and middle-income countries was agreed, the Declaration strived to reach this target by increasing national ownership of AIDS responses, putting the onus on governments in the South to scale up investments in HIV. Some of us feel this marked the beginning of eroding resource commitment among the G8 countries.

The establishment of timetables by some donor countries to allocate 0.7% of Gross National Product for official development assistance by 2015 has increased available resources, but even though global contributions towards HIV have increased year-on-year, they have not matched the speed of scientific advances that have yielded newer and safer drugs. Scaled-up testing means that we are being diagnosed as HIV-positive at a much younger age, and those of us with access to antiretroviral therapy are dealing with the broader health implications of living longer.

With multilateral and bilateral aid waning, the need for a more sustainable funding model for HIV that can meet our needs has never been more urgent. As described in the new investment approach for the global HIV response, as well as relying on external support, countries need to invest in themselves, and have longer-term strategies in health service delivery and community systems strengthening (10).

The last decade has seen greater value for money as medicine patents have expired, compulsory and voluntary licences for essential antiretroviral drugs have been issued and generic manufacturers have begun to supply the bulk of HIV medications in low- and middle-income countries.

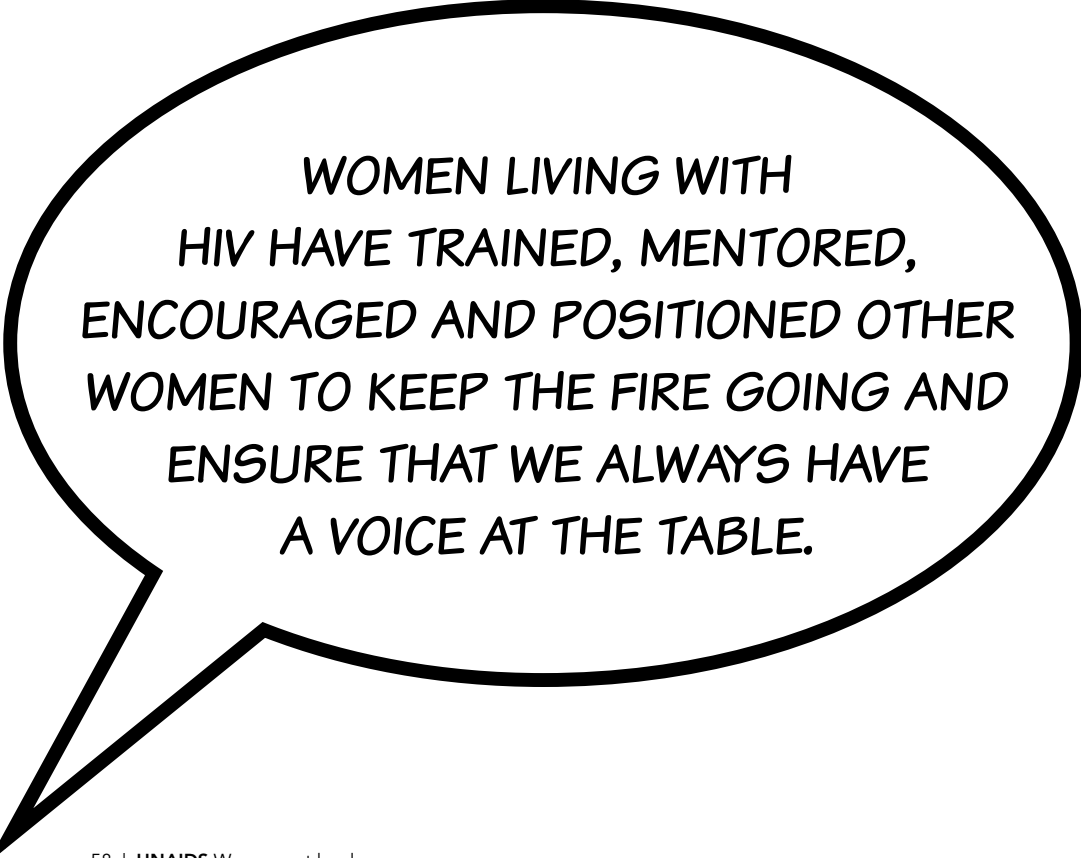
We expect that new and more equitable intellectual property arrangements, such as the Medicines Patent Pool, will put antiretroviral drugs into the hands of women and children who depend on them for survival. In order to reach universal treatment coverage and make zero new infections a reality in the

following decades, we also have to budget for second- and third-line HIV medicines that are double or triple the cost of current first-line regimens, until equitable patent licensing arrangements can be reached for low- and middle-income countries.

Despite impressive treatment advancements we still lack well-tested HIV prevention interventions, an efficacious and affordable microbicide for pre-exposure or an effective HIV vaccine. HIV prevention behavioural interventions for women fall perilously short of the effectiveness levels required for reducing sexual transmission by 50% by 2015.

As we work towards fewer infections we can no longer sweep under the rug issues of gender inequality, self-respect and dignity for all, and violence against women. As long as gender-based violence and survival sex make it impossible for women and girls to negotiate safer sex, preventing new HIV transmission will require more than just access to condoms and expanding virgin clubs for young women. In order to protect the health of women and girls, we need greater investment in research to develop women-owned biomedical HIV prevention methods.

When we talk about closing the resource gap, we cannot continue to pay lip service to the so-called four prongs of prevention of mother-to-child transmission (primary prevention of HIV in women of childbearing age; preventing unintended pregnancies in women living with HIV; safer infant feeding; and treatment) when, in reality, resources are mainly funnelled to vertical transmission services. The same effort and investments that have gone into providing antiretroviral therapy as pre- and post-exposure prophylaxis for women and babies should go into preventing unintended pregnancies among women living with HIV. It is shameful that the majority of women still cannot access family-planning services from HIV treatment sites.



**WOMEN LIVING WITH
HIV HAVE TRAINED, MENTORED,
ENCOURAGED AND POSITIONED OTHER
WOMEN TO KEEP THE FIRE GOING AND
ENSURE THAT WE ALWAYS HAVE
A VOICE AT THE TABLE.**

Women are still missing in leadership positions because they still bear the greater burden of care for the family. A sense of urgency for women's care in the AIDS response has never really surfaced at national leadership level, and we have had to fight for a place at the table for resources.

In Asia, women pioneered self-help groups addressing the unique challenges of women. African women have participated actively in lobbying efforts to mobilize resources for The Global Fund to Fight Aids, TB and Malaria. Women in Europe, North America and in Latin America and the Caribbean have taught us that lobbying with decision-makers is a sure way of getting them on our side and making advocates of politicians and bureaucrats. Globally, women living with HIV have trained, mentored, encouraged and positioned other women to keep the fire going and ensure that we always have a voice at the table.

We must be respected partners in developing country strategies, plans and budgets so that programmes address our needs and rights directly as women in all our diversity. To close the resource gap, our needs have to be acted upon.

Morolake Odetoyinbo is Executive Director of Positive Action for Treatment Access in Nigeria; Rachel Ong is Communications Focal Point for the communities delegation on the Board of The Global Fund to Fight AIDS, Tuberculosis and Malaria, based in Singapore; Kim Nichols is co-Executive Director of the African Services Committee, New York, United States of America.

ACTION POINTS

- **Meaningfully consult us as respected partners** *in the women's HIV research agenda, prevention, treatment, care, and support.*
- **Include us and fund us to do our work: we are a powerful influence** *on the boards of multilateral institutions.*
- **Involve us in pursuing innovative financing** *for health and in developing country- and community-level expenditure frameworks.*
- **Work with us to address barriers** *to generic and other low-cost medicines access.*
- **Use the common ground** *between the HIV response and efforts to achieve internationally agreed development goals.*
- **Provide national-level aggregated data** *that documents investments in different communities.*



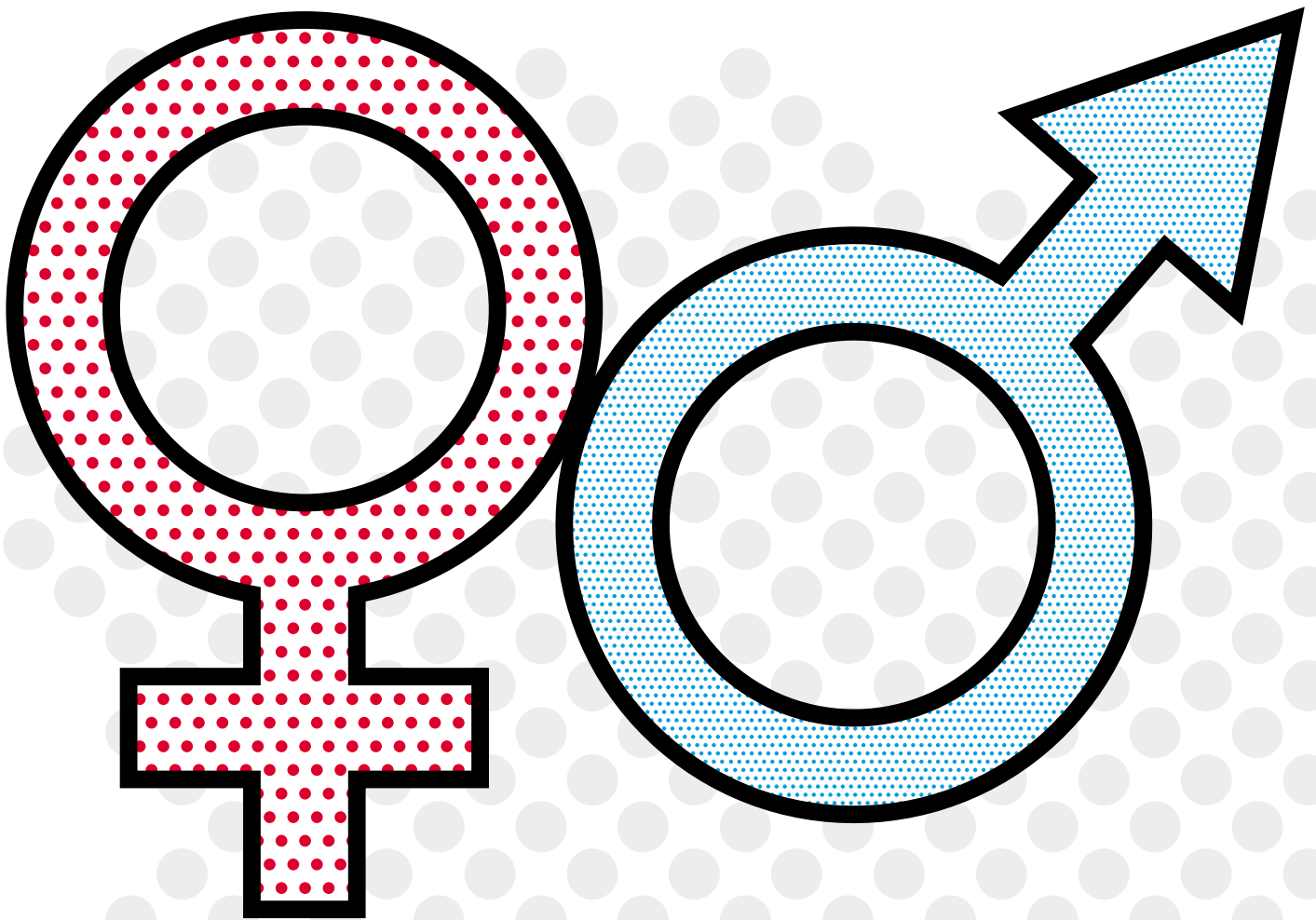
**ELIMINATE
GENDER
INEQUALITIES!**

29%

In Zimbabwe, rates of reported sexual or physical violence are 29% higher among women living with HIV than other women.

50 MILLION

In Asia, 50 million women are estimated to be at risk of HIV from their intimate partners.



TARGET 7

ELIMINATE GENDER INEQUALITIES AND GENDER-BASED ABUSE AND VIOLENCE AND INCREASE THE CAPACITY OF WOMEN AND GIRLS TO PROTECT THEMSELVES FROM HIV.

FOR WOMEN LIVING WITH HIV, THEIR SEROSTATUS, COMBINED WITH GENDER INEQUALITY, MAKES THEM PARTICULARLY MARGINALIZED, PHYSICALLY, SOCIALLY AND ECONOMICALLY (1).

Introduction

Nearly half of all people living with HIV are women. The impact of the HIV epidemic on women and girls is intensified by women's physiological susceptibility to HIV and unequal power relations between men and women. Widespread social and economic exclusion makes women more affected by the consequences of HIV in terms of stigma and discrimination, fear, violence and misconceptions about the disease.

In most cultures, this exclusion, combined with unequal access to education and resources, restricts the potential for women in all their diversity to access essential services and support (2). Many women and girls have limited capacity to protect their health and rights, in particular in relation to sexuality and reproduction due to gender inequalities.

Transgender women living with HIV face multiple layers of stigma. Many transgender women are forced to engage in high-risk activity such as sex work, due to exclusion from other economic opportunities. Data suggests that transgender female sex workers have rates of HIV infection four times higher than sex workers who were born female (3). In 2012, only 43% of countries reported that their national strategies address transgender people.

Gender-based violence

Gender-based violence is one of the most brutal manifestations of gender inequality. Women living with HIV may experience more violence because of their serostatus. Transgender women living with HIV are particularly vulnerable (4). Sexual, physical and emotional abuse of women living with HIV can take place within an intimate partnership, in the broader family or community, and even at points of medical care. Women living with HIV are particularly vulnerable to violence; in Zimbabwe, for example, rates of reported sexual or physical violence are 29% higher among women living with HIV than other women (5).

The experience of violence in addition to the direct damage to physical and emotional health also leads to longer-term problems. For example, it is associated with increased sexual risk behaviour in later years (6). Studies have also found that women and girls who have experienced violence often are unable to reveal what they have gone through due to shame and fear of abandonment or reprisals (7). Their enforced silence stops them accessing the services they need and perpetuates the cycle of violence against women living with HIV (8, 9). Furthermore, women living with HIV cite violence or the fear of violence as a significant barrier to accessing life-saving HIV prevention and treatment services (10).

Violence can also be associated with increased vulnerability to HIV. Research in South Africa indicates that 11.9% of new HIV infections could be avoided if women were not subjected to physical or sexual abuse by their partner (11). In India, a study of more than 28 000 married women found that those who had experienced both physical and sexual violence from intimate partners were more than three times more likely to be HIV-positive than those who had experienced no violence (12). In addition to human and social costs, the economic cost is estimated to be substantial (13).

Access to services and information

Traditional AIDS messaging, such as “abstain, be faithful, use condoms”, have failed to address the realities and needs of women living with HIV. Monogamous women who contracted HIV in marriage are a testament to this. Indeed, for many women marital sex is a high-risk activity. In Asia alone, 50 million women are estimated to be at risk of HIV from their intimate partners (14). Pregnant women may be at higher risk of seroconverting during pregnancy (15).

UNAIDS-led participatory assessments (16) of gender-related barriers to services to prevent new infections in infants and to keep mothers alive found that women living with HIV often lack decision-making power and access to resources. Fear of violence and abandonment, and cultural attitudes towards sex, pregnancy and HIV, were also found to be significant barriers.

Women and girls living with HIV face many barriers to treatment services. Lack of confidentiality and unsympathetic attitudes of health-care workers are known to discourage women from HIV testing and disclosure (17). When women do test for HIV and disclose their status they are often blamed for contracting HIV and face abuse and rights violations due to perceptions of immorality (18). Young women living with HIV in particular face stigmatizing attitudes when seeking services for their sexual health.

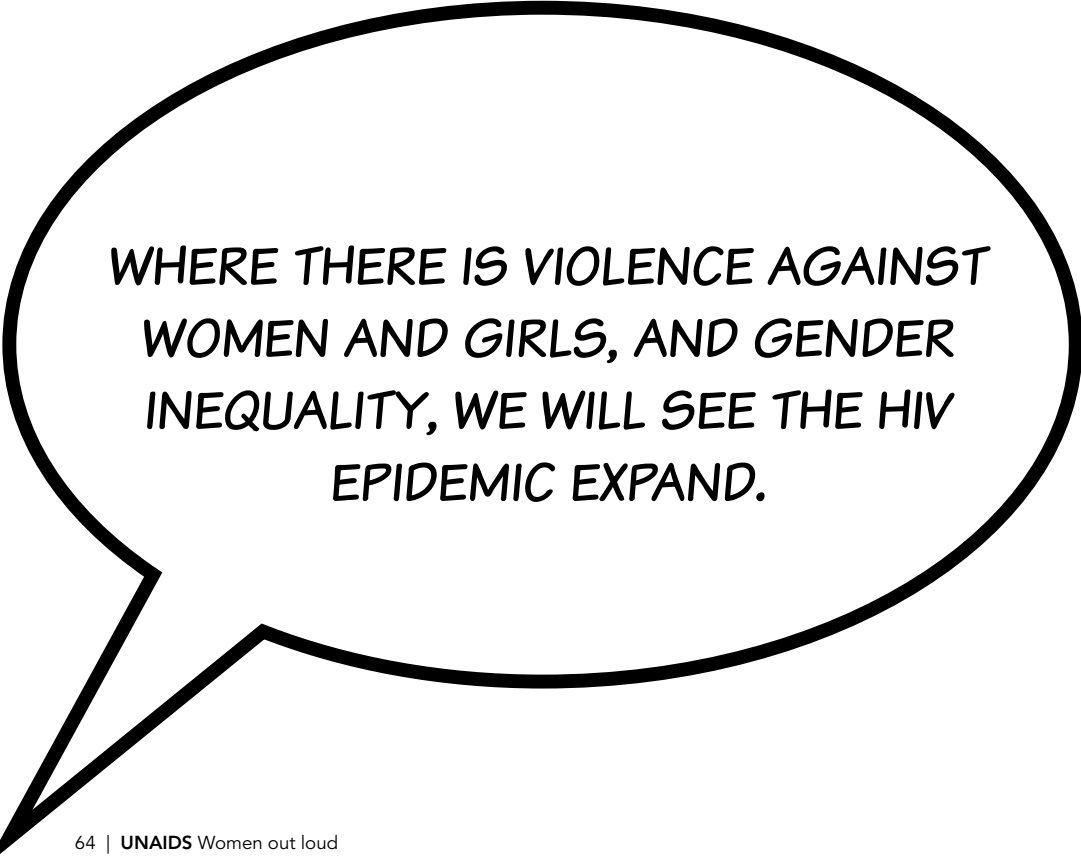
Cultural values and norms that discourage young women from knowing and understanding their bodies put their lives at risk. Evidence shows that the particular needs of girls and young women with regard to sexuality education are largely unmet (19). Comprehensive sexuality education is important for all young people and particularly so for girls and young women living with HIV who face specific challenges in relation to sexual and reproductive life and intimate relationships.

Transgender women encounter serious difficulties accessing HIV-related information and services as they often face ridicule and neglect at the hands of health-service providers and confusion over where they should access services structured for men or women (4). Research from the United States found that 28% of transgender persons postpone seeking health services when they are sick or injured due to stigma (20). In another study, 73% of the transgender women who tested HIV-positive had been unaware of their status (21).

Engage women living with HIV

Women living with HIV around the globe are already taking initiatives and are on the frontlines of the HIV response, bringing about change in their communities. The AIDS response should further engage women living with HIV at all levels and safeguard appropriate funding for their work to ensure that HIV services and actions are tailored to their needs.

The AIDS response should include integrating services to counter and manage gender-based violence into HIV services. Women living with HIV must be supported to lead social transformation for gender equality, sexual and reproductive health and rights, and zero tolerance for violence within their societies. Men and boys must be engaged in this movement to engender a supportive environment at family, community and national levels.



**WHERE THERE IS VIOLENCE AGAINST
WOMEN AND GIRLS, AND GENDER
INEQUALITY, WE WILL SEE THE HIV
EPIDEMIC EXPAND.**

Dedicated advocacy and awareness-raising is required to promote the greater accountability of service-providers, governments and other duty bearers to meet the needs and rights of women living with HIV in all their diversity, including those from key populations and transgender women. It is critical to address the HIV and sexual and reproductive health and education needs of the new generation of young women and girls who were either born with HIV or became HIV positive at an early age (22, 23). These young women are rightfully demanding their full sexual and reproductive health and rights (24).

Inclusion and engagement of women and girls living with and affected by HIV is essential to ensure the AIDS response is effective and sustainable.

WOMEN OUT LOUD

PRUDENCE MABELE, GRACIA VIOLETA ROSS QUIROGA, ANANDI YUVARAJ

Violence against women is often framed as ‘stigma and discrimination’. This is a trivialization and neutralization of experiences, which are clear manifestations of structural, cultural and direct violence against women living with HIV. From our experience the AIDS response has failed to adequately curb gender inequality and fully address the needs of women and girls.

Over the years, the terminology of HIV has evolved with the epidemic. Some have referred to the ‘feminization of the epidemic’; others argued it was overstated. In the midst of this ‘epi-war’ on who is and is not most at risk, our rights as women and individuals belonging to diverse groups and taking on multiple roles, have been compromised. Our identities have been narrowly defined as mothers under vertical transmission programmes, AIDS widows under care and support programmes, or sex workers within most-at-risk populations, while those of us who are transgender women have been almost invisible.

This approach to the epidemic is highly patriarchal. Everything that is offered to us is in relation to men and our relationship with men, not as women and girls on the basis of gender equity and equality. Understanding gender inequality in the HIV epidemic also means speaking about men and understanding men, not only as a group of perpetrators, but also as victims of the same gender system that forces men to behave in a certain way to prove their masculinity.

Where there is violence against women and girls and gender inequality, we will see the HIV epidemic expand. HIV prevention programmes need to address both our risk of and vulnerability to HIV. For example, risk factors are those that one person alone can sometimes control (such as deciding to use a condom) while vulnerability includes factors that cannot be controlled by changing our own behavior (such as walking down the road and being raped) and they require community change.

Vulnerability to HIV is contextual and in many settings it is culture, our social and economic status and the power dynamics between men and women that place us at special risk. In Latin America, as in many parts of the world, the dominant 'macho' culture and an ideal of passive women defines unequal relationships between women and men. While it is acceptable for men to be aggressive and sexually active, women are often socialized to be quiet and silent, sexually inactive and ignorant. This is just one of the many ways in which violence and gender inequality are perpetuated under cultural norms and beliefs.

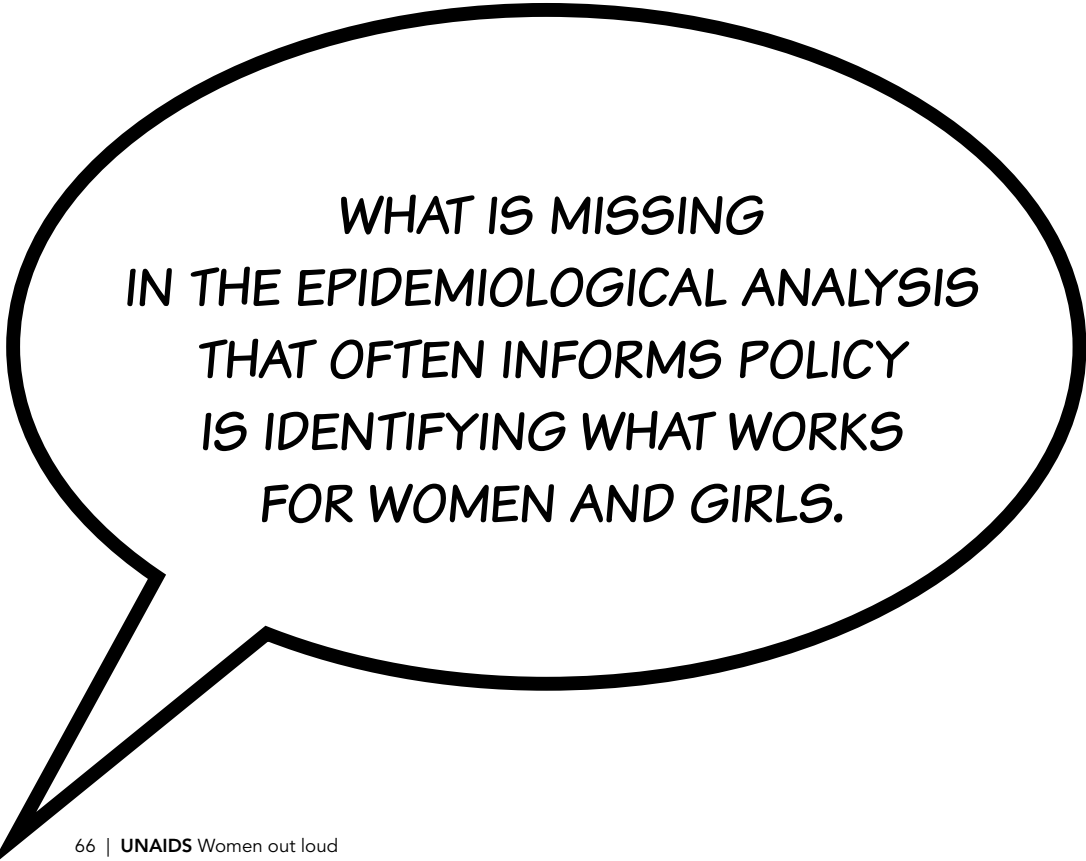
In South Africa, every day we see women young and old being raped and murdered. We ask: How did we get to this point, which does not resonate with our values and culture? Women ask: how have services failed to keep us safe? Our women need counselling and post-exposure prophylaxis, they need the police and authorities to listen and to bring the perpetrators to justice.

Similarly, young people face poverty issues, lack protective social networks and may experience homelessness while using drugs. Young women who are homeless may experience violence and abuse, and in some countries, women who use drugs are unable to access shelters for abused women.

Learn from us

Epidemiology has mapped various factors that increase our vulnerability to HIV. What is missing in the epidemiological analysis that often informs policy is identifying what works for women and girls, learning from our personal experiences as women in all our diversity.

In South Africa, for example, most times women and girls are not addressed as a key population even though we live in a region where more women than men live with HIV. Around the world, programmes that take a gender-transformative approach, (that is, those that seek to change harmful gender norms and inequality, and achieve equitable social norms, structures and relationships)



**WHAT IS MISSING
IN THE EPIDEMIOLOGICAL ANALYSIS
THAT OFTEN INFORMS POLICY
IS IDENTIFYING WHAT WORKS
FOR WOMEN AND GIRLS.**

are under-funded and not well integrated into national HIV responses. Many countries continue to use the 'abstinence, be faithful and condom use' approach to women and girls, ignoring our realities and the sociocultural and religious context we come from.

Interventions should be based on our own need and right to protect ourselves from HIV. The AIDS response should not box us into a category as we all hold multiple identities. A sex worker is also sometimes a wife, and while she uses condoms religiously with clients, she does not with her husband or partner. Equally, a married woman living with HIV may not disclose her HIV status to her (perhaps) HIV-negative husband because she fears losing him or being badly beaten. A young woman ignores the signals that she is at risk because all she feels is love for her partner. This is the social context that we live in and, therefore, we need to revisit all our prevention programmes through a gender and human rights lens and re-strategize.

We work in an environment led by men. We have pushed our way to the table and have taken up leadership positions in our national AIDS councils. We are working closely with ministers of gender and also being strategically linked with the ministries of health, making sure that gender equality is addressed and that more efforts are made to realize a gender-transformative national AIDS response.

We have been documenting our experiences, reviewing the existing research on gender equality and advocating for more action in national policies and plans. Women are taking leadership positions in all levels of civic work. Collectively, women are changing, but this could happen faster if this growth was celebrated and supported.

Prudence Mabele is Executive Director of the Positive Women's Network in South Africa; Gracia Violeta Ross is National Chair of the Bolivian Network of People Living with HIV Bolivia; Anandi Yuvraj is Regional Coordinator with the International Community of Women Living with HIV/AIDS Asia Pacific in India.

ACTION POINTS

- **Provide adequate resources** to scale up and implement gender-transformative programmes that work for us.
- **Advance research on gender inequality, discrimination, and harmful cultural practices** that affect HIV transmission, including the gender-based violence many of us have experienced.
- **Engage us to monitor and evaluate achievements** to gauge progress;
- **Invest in our empowerment through education, health, jobs and positions of leadership.**
- **Expand programmes for us beyond prevention of mother-to-child transmission** to comprehensive prevention and care programmes.
- **Invest in our communities with gender-transformative approaches** that address harmful gender norms and reach girls and boys in their formative years.



**ELIMINATE
STIGMA AND
DISCRIMINATION!**

80%

80% of governments report laws or regulations to protect women from discrimination.

22%

Up to 22% of women living with HIV report feeling suicidal.

37%

Up to 37% of women living with HIV report having been physically assaulted.



TARGET 8

ELIMINATE STIGMA AND DISCRIMINATION AGAINST PEOPLE LIVING WITH AND AFFECTED BY HIV THROUGH PROMOTION OF LAWS AND POLICIES THAT ENSURE THE FULL REALIZATION OF ALL HUMAN RIGHTS AND FUNDAMENTAL FREEDOMS.

WOMEN LIVING WITH HIV HAVE FACED LOSS OF LIVELIHOOD, FORCED EVICTION, RIDICULE, INSULTS, HARASSMENT, EXCLUSION, PHYSICAL THREATS, ASSAULT AND EVEN MURDER. YET IN THE FACE OF STIGMA AND DISCRIMINATION THEY HAVE ALSO BECOME A FORCE FOR CHANGE (1).

Introduction

Women have been found to often bear the strongest brunt of HIV stigma and discrimination, across different epidemics and settings, as they are frequently expected to uphold the moral traditions of their societies and HIV is regarded as evidence that they have failed to fulfil this important social function (2).

Women living with HIV continue to experience stigma, discrimination and other human rights violations on a daily basis within families and communities, in health-care settings, and in the context of legal and social services and the world of work. (Table 8.1).

Stigma and discrimination negatively impact on women's health-seeking behaviour and their ability to access services and support. Human rights violations against women living with HIV are common in health-care settings, including refusal to provide information or providing misinformation on sexual and reproductive health, family planning and HIV prevention and treatment. Women living with HIV have also reported that they experience denial of services, harsh and judgemental treatment, lack of confidentiality and lack of informed consent (1). A recent cross-sectional study in Kenya found that fear of HIV-related stigma and violence can be a barrier to acceptance of HIV testing by pregnant women (3).

TABLE 8.1. PEOPLE LIVING WITH HIV STIGMA INDEX, RESULTS BY COUNTRY

COUNTRY	% EXPERIENCING STIGMA IN FAMILY AND COMMUNITY				% EXPERIENCING VIOLENCE				% STIGMA AND DISCRIMINATION IN WORK PLACE				% INTERNALIZED STIGMA				ACCESS TO HEALTH CARE			
	Excluded from family events		Gossiped about		Verbally insulted		Physically assaulted		Employment opportunity refused		Loss of job or income		Feel ashamed		Feel suicidal		Denied health services including dental care		Denied sexual and reproductive health services	
	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women	Men	Women
CAMEROON	14.5	11	46.5	53.5	30.2	36.9	11.1	12.3	12.5	3.4	21.9	23.1	32.6	36.3	4.9	4.6	13.4	13.1	3.4	5.6
ELSALVADOR			21.5	37.4	7.3	17.4	2.3	4.6												
ESTONIA	*	*	57	72	35	44	23	23	*	*	*	*	39	47	7	15	*	*	*	*
ETHIOPIA	25.5	25.7	65.5	70.5	30.4	33.4	9.5	11.7	25.9	22.4	41.6	42.2	45.1	46.1	16.6	21.5	8.1	7	5.5	5.6
GUATEMALA	4.2	3.1	18.2	20.4	10	9.9	2.3	4.3	2.3	5.2	9.3	6	37.6	50	15.3	12.7	5.2	5.7	2.1	1.3
JAMAICA	*	*	53	56.6	25.7	33.2	5.9	9	*	*	10.6	15	*	*	13	24	7	5	*	*

Note: These countries represent a cross-regional snapshot of information collected through the People Living with HIV Stigma Index

Among the most egregious human rights violations against women living with HIV is the involuntary sterilization of HIV-positive women (4). A report published in 2012 by the African Gender and Media Initiative (5), found evidence that HIV-positive women are routinely sterilized without their consent in government hospitals in Kenya. Involuntary sterilizations of HIV-positive women have also been reported in Chile (6), Argentina (7), and Mexico (8), as well as in Asia (9) and southern Africa (10).

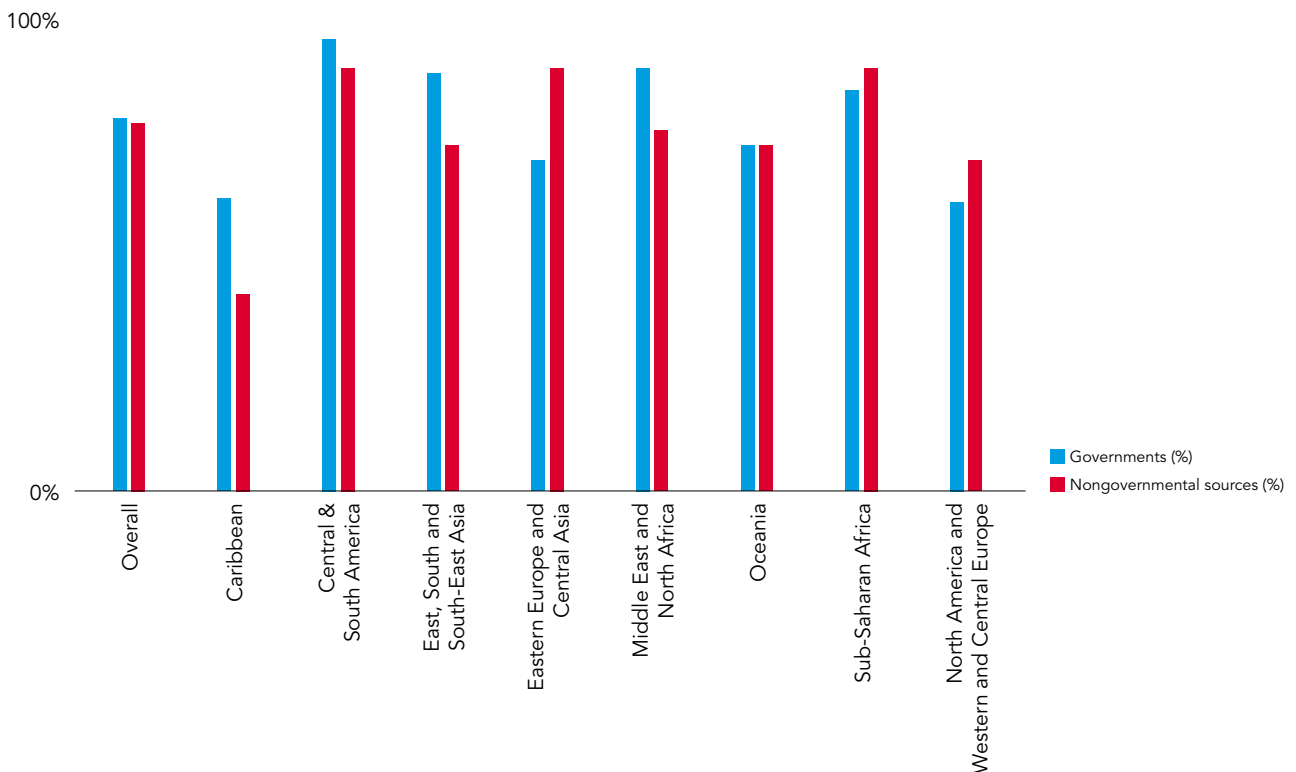
Another critical challenge faced by women living with HIV is the denial of their property and inheritance rights, often when their husbands have died as a result of AIDS. This can lead to forced eviction, loss of housing, livelihood, and abandonment by families and communities. In this context, affected women and their children may face heightened barriers in accessing treatment, care and support (11). As a study in Uganda and periurban areas in South Africa found, women who own property are significantly more capable of escaping abusive relationships and negotiating sexual relationships, including demanding condom use (12).

Women living with HIV who sell sex, use drugs or are lesbian or transgender face serious additional disadvantages especially where these conducts are criminalized. Criminal laws and abusive law enforcement (harassment, extortion, rape and violence) drive members of these populations away from HIV-related services, including treatment. Women living with HIV among these populations face multiple layers of stigma, discrimination and marginalization.

Legal progress

The 2012 Global AIDS Response Progress reports submitted by countries indicate some progress in addressing stigma, discrimination and punitive laws that affect women. Approximately 80% of governments report laws or regulations to protect women from discrimination although important differences exist between regions (Fig. 8.1). However, even where laws exist, legal remedies may be remote and prohibitively expensive for women living with HIV. In addition, women’s access to justice may be compromised if not supported by prevailing customary norms by district authorities and/or community/traditional leaders.

FIGURE 8.1. GOVERNMENTS AND NONGOVERNMENTAL SOURCES REPORTING WHETHER COUNTRY HAS LAWS OR REGULATIONS PROTECTING WOMEN, 2012.




Source: National Commitments and Policy Index

In a number of countries, women living with HIV and their advocates are challenging punitive laws and practices. In Malawi, women living with HIV worked closely with other women's groups to ensure parliament adopted a new Deceased Estates Act in 2011, recognizing a woman's right to inherit from the marital estate (13). The new act, adopted after 12 years of discussion, makes property dispossession a criminal offence (13).

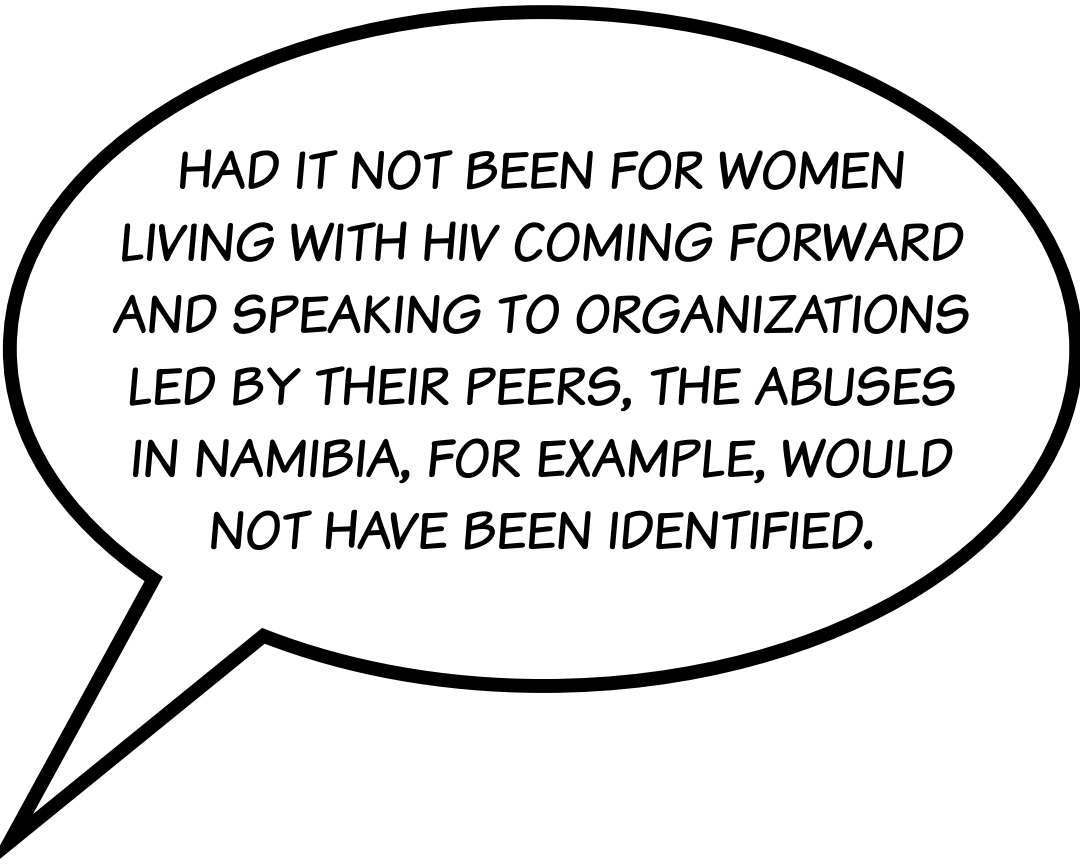
In India and Nepal, HIV-positive women who use drugs are working with local organizations to support their peers for access to HIV prevention and harm reduction services. They also work to sensitize the police against punitive law enforcement and violence towards people who use drugs and sex workers (14).

Recent successes led by women against stigma, discrimination and punitive laws show that negative legal and social environments can be addressed. This requires engaging women living with HIV and their advocates and ensuring that their experiences shape the response to the epidemic. These efforts must be in keeping with the Positive Health, Dignity and Prevention Framework, which focuses on improving and maintaining the health and well-being of people living with HIV in a holistic manner. This, in turn, contributes to the health and well-being of partners, families and communities (15).



**AS WOMEN LIVING WITH HIV,
WE FACE PARTICULAR DISCRIMINATION
IN THE AREA OF SEXUAL
AND REPRODUCTIVE RIGHTS.**

However, there is still insufficient support for networks of women living with HIV to meaningfully and sustainably engage in the AIDS response and end stigma, discrimination and violence against them. Resources must be made available to support women living with HIV through concrete programmes to challenge stigma, discrimination and punitive laws. Such programmes include law reform, human rights literacy, legal services, stigma and discrimination monitoring and reduction, training of police and health-care workers, and programmes to reduce or eliminate harmful gender norms and violence against women. Specific attention must be devoted to addressing the needs of women living with HIV who belong to key populations.



**HAD IT NOT BEEN FOR WOMEN
LIVING WITH HIV COMING FORWARD
AND SPEAKING TO ORGANIZATIONS
LED BY THEIR PEERS, THE ABUSES
IN NAMIBIA, FOR EXAMPLE, WOULD
NOT HAVE BEEN IDENTIFIED.**

WOMEN OUT LOUD

JENNIFER GATSI, SUSAN PAXTON, RITA WAHAB

It is increasingly clear that policies, laws and law enforcement have a significant impact on how we access HIV prevention, treatment, care and support. Women living with HIV acutely feel the impact of punitive and discriminatory laws, policies and practices. Stigma and discrimination constrain our ability to claim and enjoy our rights.

Although HIV has become manageable and those of us with access to treatment are living longer, we continue to face stigma and discrimination. As women living with HIV, we face particular discrimination in the area of sexual and reproductive rights. Around the world there are many examples of how we experience stigma and discrimination. We face criminalization, harassment, coercion and violence, including at the hands of the law enforcement authorities that are supposed to protect us. This pushes many women who fear being identified as HIV-positive out of the reach of essential HIV services.

More than 60 countries have passed legislation that criminalizes HIV transmission and more than 600 people living with HIV in 24 countries have been convicted under HIV-specific or general criminal laws. Similar laws have been enacted, or are pending, in parts of Asia, Latin America, and the Caribbean. Such laws do not increase safer sex practices. Instead, these laws discourage people from accessing services, for fear of being prosecuted (16). These laws increase women's risk of violence and abuse, and promote HIV-related stigma, undermining public health and women's rights. We also face structural and legal inequalities concerning property inheritance, child custody and maintenance rights, and stigma in the workplace.

There are restrictions on access to HIV prevention information, commodities and services, especially for young women, who instead are led to believe that they should 'know better' than to ask questions about sex and or sexuality. Young women living with HIV are often told that they should not be having sex and, therefore, are afraid to ask service providers about contraceptive choices that they can control.

Women face increasing discrimination due to government policies in many countries to test all pregnant women for HIV. There is also mandatory HIV testing in the context of migration and employment (including sex work), access to health-care services and for women in prisons. More than 20 countries in sub-Saharan Africa alone have passed legislation with clauses that include mandatory HIV testing and disclosure. Because of these policies, we often learn our HIV status without having consented to testing and without having received counselling or clear and accurate information on essential issues related to HIV.

Women are usually the first person in the family to be diagnosed with HIV and more often than not this happens when a pregnancy is confirmed. Many women face subsequent violence from their spouse or eviction from their homes by in-laws when their HIV status becomes known. Many women diagnosed with HIV during pregnancy also face discrimination by health-care workers, including coerced sterilization and refusal of care at time of delivery.

Most countries have signed international human rights treaties, and made many political commitments that are meant to safeguard our rights as women living with HIV to be treated equally, but often these commitments have not been translated into appropriate laws, policies, programmes and services.

Pushing for policy change

In some countries, women living with HIV have questioned the status quo and engendered policies that realize the equal rights of all women, regardless of our HIV status. Challenging government responsibilities through the judicial system is more difficult, yet we women living with HIV have begun to do so. In July 2012, the Namibian High Court issued its ruling against the Government of Namibia, finding in favour of three women living with HIV who claimed they were coerced into sterilization. The judge, however, denied the plaintiffs' contention that the coercive sterilization happened because of their HIV-positive status. Consequently, many challenges remain in addressing ongoing and widespread violations of the rights of women living with HIV.

Research by our networks in Asia and Africa indicates that women living with HIV are segregated and discriminated against throughout their pregnancy and during labour (17, 18). These practices send many women underground, so they avoid prenatal health-care services and, therefore, miss out on optimal care during pregnancy.

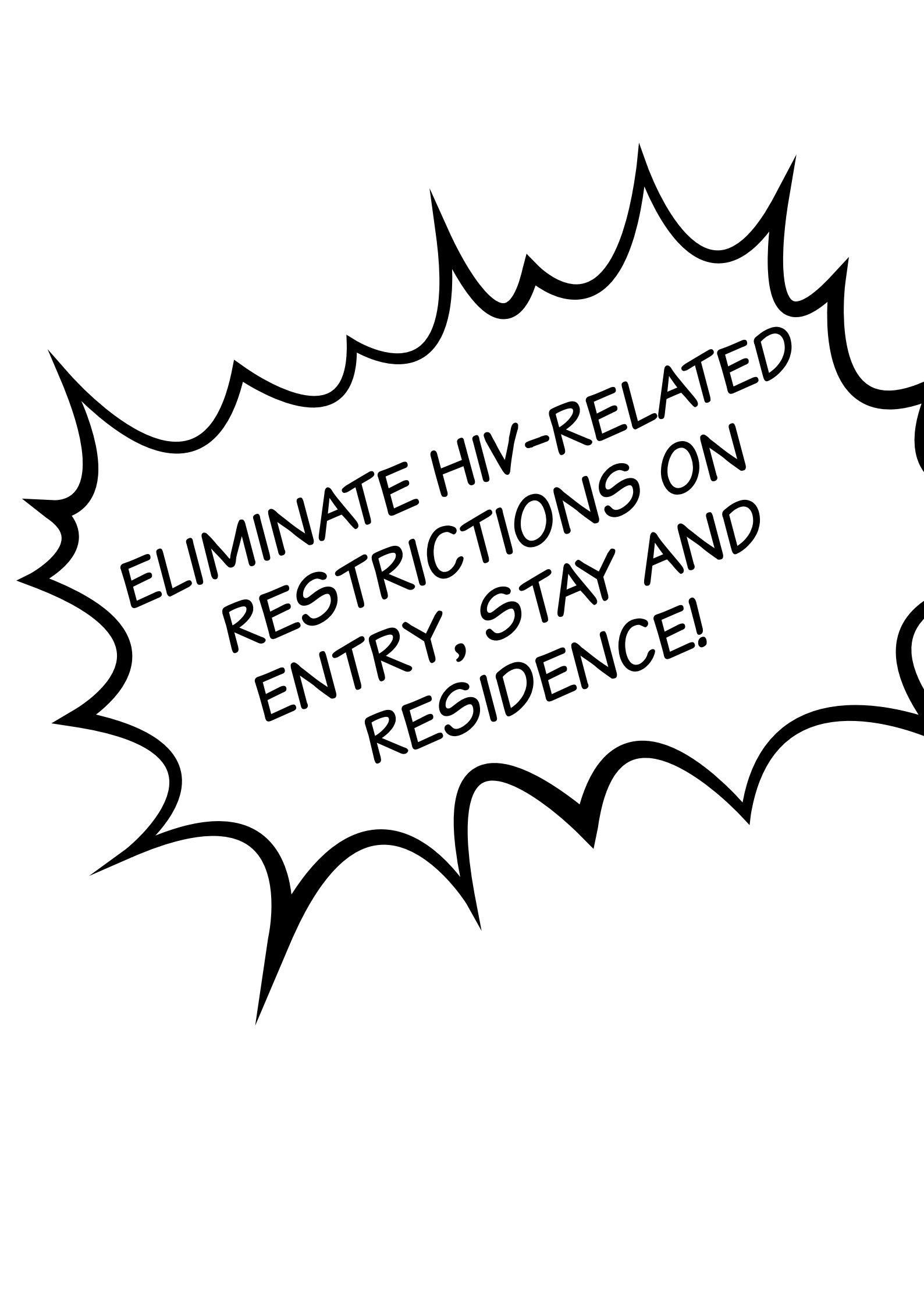
The rights violations faced by pregnant women who are HIV-positive arise out of a broader context of HIV-related discrimination. Until this is recognized by governments, any policies and programmes to eliminate HIV-related stigma and discrimination will fail.

There must also be meaningful involvement of women living with HIV. Had it not been for women living with HIV coming forward and speaking to organizations led by their peers, the abuses in Namibia, for example, would not have been identified. This speaks volumes about the importance of our networks as an integral constituent in addressing HIV-related stigma, discrimination and human rights violations.

Jennifer Gatsi is Director of the Namibia Women's Health Network; Susan Paxton is an Advisor to the Asia Pacific Network of People Living with HIV; Rita Wahab is Regional Coordinator of MENA-Rosa in Lebanon.

ACTION POINTS

- **Meaningfully involve us** in all HIV-related policy-making and programme design and implementation.
- **Protect us by acting immediately at the government level to stop forced and coerced sterilization**, issue clear guidelines to ensure informed consent prior to sexual or reproductive health-care tests, treatment or procedures, and provide us with a range of contraceptive options.
- **Respect our rights by enacting laws and policies that uphold the rights of all people with HIV** and consequently reduce HIV-related stigma.
- **Invest in our networks financially and provide technical support** so that we can actively advocate for and monitor legal, policy and programmatic reforms.
- **Provide us with donor and UN agency support to document HIV-related discrimination**, with a particular focus on violations of our sexual and reproductive health rights, and to challenge policies or laws when our rights are violated.



**ELIMINATE HIV-RELATED
RESTRICTIONS ON
ENTRY, STAY AND
RESIDENCE!**

45 COUNTRIES

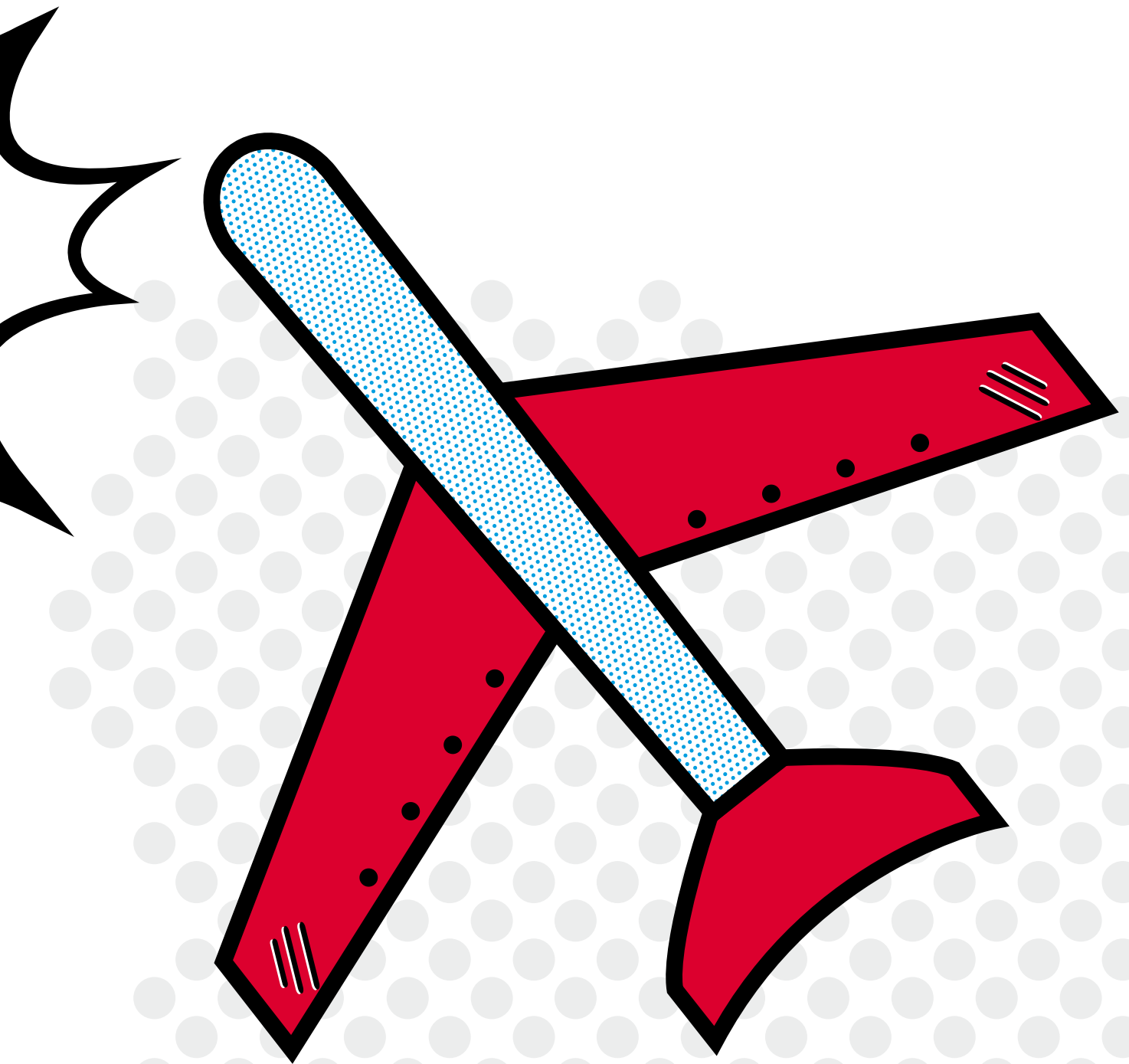
In July 2012, 45 countries had some type of HIV-related restrictions on entry, stay or residence.

214 MILLION

From 2005 to 2010, the number of international migrants rose from 191 million to 214 million.

50%

Women comprise almost 50% of those migrating for employment purposes.



TARGET 9

ELIMINATE HIV-RELATED RESTRICTIONS ON ENTRY, STAY AND RESIDENCE.

HIV-RELATED RESTRICTIONS ON ENTRY, STAY AND RESIDENCE ERRONEOUSLY ASSUME THAT PEOPLE LIVING WITH HIV POSE A THREAT TO NATIONAL HEALTH. INSTEAD, THEY ARE DISCRIMINATORY, PERPETUATE STIGMA AND THEY DO NOT PROTECT PUBLIC HEALTH.

Introduction

Progress to eliminate HIV-related restrictions on entry, stay and residence has accelerated: since 2010, Armenia, China, Fiji, Moldova, Namibia, South Korea, Ukraine and the United States of America have removed such restrictions. However, as of July 2012, 45 countries still had some type of such limitations in place.

There are no data available on how many people are affected by such restrictions. However, it is likely that migrant workers are the most affected as millions of them seek to enter, work and remain in key destination countries – primarily the Gulf States – that apply such restrictions. From 2005 to 2010, the number of international migrants rose from 191 million to 214 million. Women comprise almost 50% of those migrating for employment purposes (1).

HIV-related travel restrictions on entry, stay and residency also affect the human rights of asylum-seekers and refugees. A key strategy is to ensure that the HIV status of an asylum-seeker constitutes neither a barrier to accessing asylum procedures, nor grounds for returning them to their country of origin. Refugee women living with HIV may face these challenges.

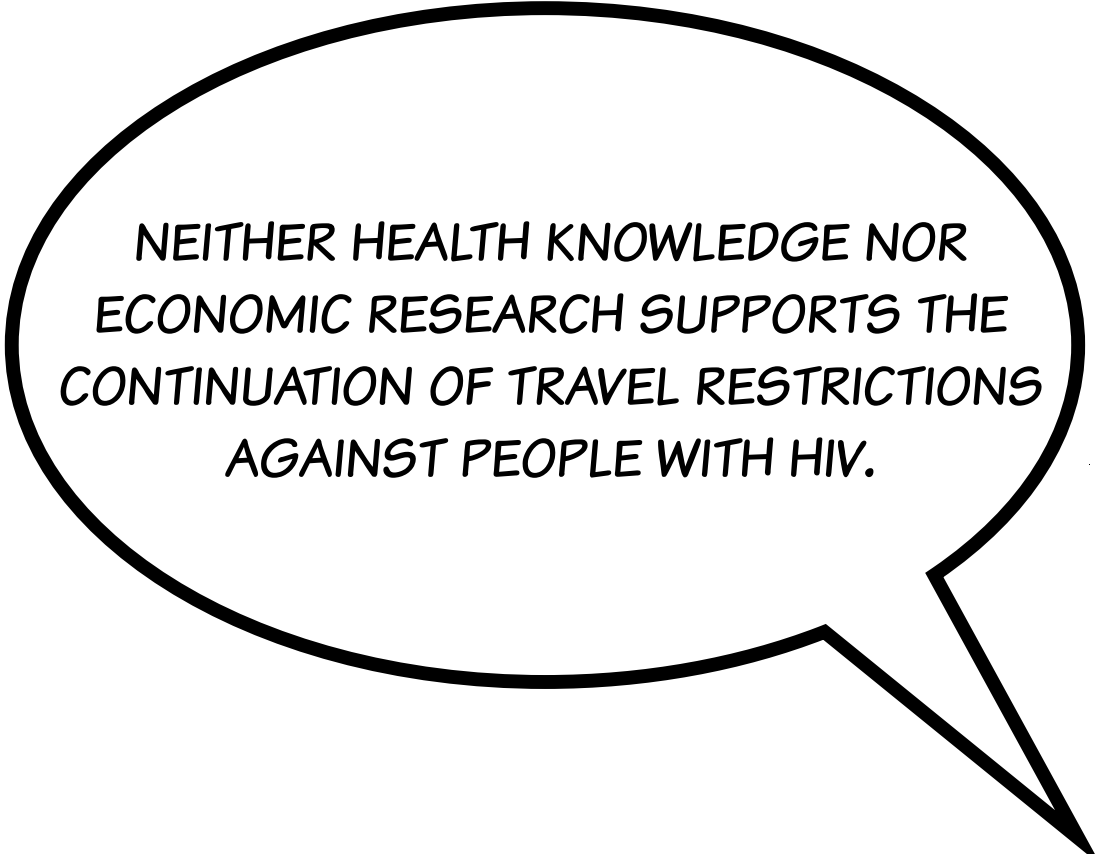
HIV-related restrictions on entry, stay and residence take various forms that can affect the rights and dignity of people living with HIV. Some countries require people to have a HIV test in order to obtain or renew a visa, whereas others require a medical certificate that indicates their HIV-negative status, or require declaration of HIV status on visa application forms. Some countries deport migrants already in the country if they become infected and their HIV-positive status is known. Such deportation often involves detention and occurs without due process of law and protection of confidentiality.

Women migrants face additional challenges, including HIV-related restrictions on entry, stay and residence. Women migrants are more vulnerable to physical, sexual and verbal abuse and more likely to be targeted for human trafficking (2).

Prevention and treatment for all

Research has found that migrant women who are domestic workers are more vulnerable to HIV infection due to the heightened risk of sexual exploitation and violence, and because they often lack legal protection (3). For migrant women living with HIV, restrictions on entry, stay and residence exacerbate the various types of stigma they may experience. This stigma may relate to their migrant status, gender, being a survivor of sexual violence and/or being HIV-positive.

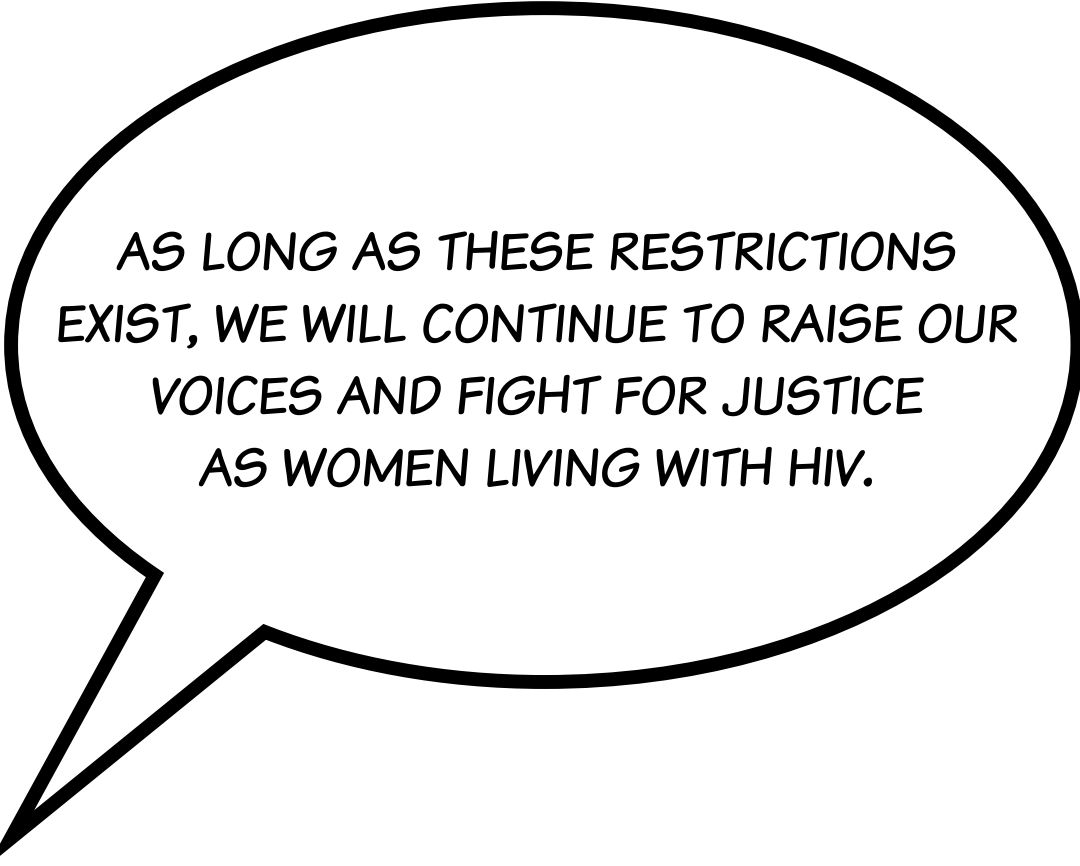
Deported migrant workers living with HIV may also be stigmatized and discriminated against by their families and communities upon return to their countries of origin (3). For female migrant workers who may already have limited employment choices and low socioeconomic status, such stigma and discrimination can be devastating.



**NEITHER HEALTH KNOWLEDGE NOR
ECONOMIC RESEARCH SUPPORTS THE
CONTINUATION OF TRAVEL RESTRICTIONS
AGAINST PEOPLE WITH HIV.**

The rational and effective way to protect public health in the context of HIV and mobility is to provide access to HIV prevention and treatment information and services to all those entering and leaving a country, citizens and noncitizens alike. Argentina and Brazil are good examples of countries offering universal access to HIV treatment, care and support. Both countries provide antiretroviral therapy, care and support to people from bordering countries regardless of their nationality or immigration status. England has also removed charges for HIV treatment and care for undocumented migrants and non-UK citizens.

In light of increasing migration and globalization, addressing the broader health and human rights issues of those on the move, including women migrants and those living with HIV, is key to global and national health. Successful efforts to remove restrictions on entry, stay and residence have often involved coalitions of people living with HIV, advocates for the rights of migrants, women's groups and human rights organizations working together. Countries whose citizens are subject to such restrictions should also take up the issue as a bilateral matter.



**AS LONG AS THESE RESTRICTIONS
EXIST, WE WILL CONTINUE TO RAISE OUR
VOICES AND FIGHT FOR JUSTICE
AS WOMEN LIVING WITH HIV.**

WOMEN OUT LOUD

LOUISE BINDER, MARÍA LORENA DI GIANO, BABY RIVONA

The freedom to move should be universal. Travel restrictions violate our basic human rights. They jeopardize our rights to education, to work, to intimacy and to the highest attainable standard of health. Surely, with nearly 30 years of knowledge, experience and research, we have learned that this epidemic at its core is a global, socioeconomic, human rights issue, not just a health issue.

While travel restrictions discriminate against all people living with HIV, as women we make up half of the epidemic globally and are the most adversely affected. With our knowledge of HIV and the advent of antiretroviral therapy reducing infectiousness by 96%, people living with HIV carry no inherent health risk. Neither health knowledge nor economic research supports the continuation of travel restrictions against people with HIV.

Yet we have personally experienced the impact of such travel restrictions. We have experienced loss of employment due to HIV status, with no referral to health care and subsequent deportation. We have been in the invidious position of having to interrupt antiretroviral treatment in order to take up study in a country with travel restrictions against people living with HIV.

More than tourism

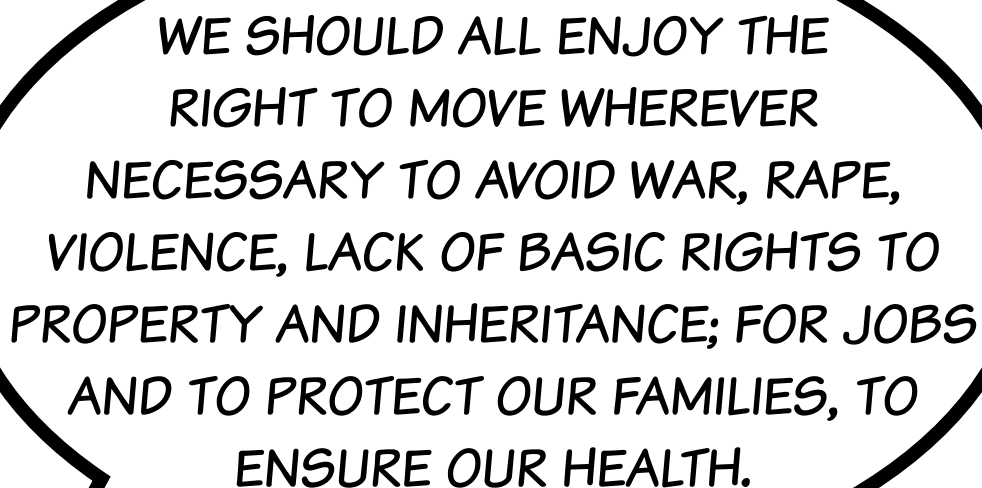
Travel is more than tourism. Many people from the developing world, especially women, travel seeking opportunities to generate income. In some countries only migrant workers are required to be tested for HIV, especially women, as they are perceived to be a source of HIV transmission. The reality is that, on the contrary, we women are often vulnerable to HIV once we enter a country. Women migrants are often subject to sexual abuse or exploitation while abroad. One study in Ontario, Canada, for example, showed that women from African-Caribbean countries who were diagnosed with HIV usually acquired HIV after entry, not before. Many women have little control over when and how they have sex, increasing vulnerability to HIV.

We should all enjoy the right to move wherever necessary to avoid war, rape, violence, lack of basic rights to property and inheritance; for jobs; to protect our families; and to ensure our health. Travel restrictions effectively prohibit our mobility. Worse, these restrictions can reinforce and entrench women's subordinate status. Women are often unable to find work, or instead get low-paying jobs with no benefits, and have no health insurance in their countries of origin. Women often enter countries as refugees. Pregnant women who require care are at extreme risk. Transgender women are so discriminated against, they often dare not try to enter a country with travel restrictions.

Each country with travel restrictions has its own rules, typically including mandatory, non-confidential HIV testing without pre- or post-test counselling, and without referral to HIV prevention and treatment services. Restrictions also include the requirement to disclose our HIV status on visa applications. The consequences of disclosure include detention and deportation of people living with HIV, refused work permits, and the inability to attend business meetings, to study abroad or to reunite with family and friends.

Why should people living with HIV face mandatory, non-confidential testing to emigrate or study abroad? The open testing requirement effectively stops women from applying to travel due to fear of rejection by their family and community and the threat of violence, ostracism and even death once their status is known. For those fortunate enough to travel, fear of detection may cause us to leave our HIV medications at home, making us more likely to become ill or build drug-related resistance, leading to potential problems in the future.

One argument is that people with HIV will cost a country more money if allowed to enter and will become a burden on the state, but this is invalid. There is no evidence that we are not fully contributing members to the economic and social fabric of our new homes. Providing people with treatment enables us to lead long, productive lives and contribute to the host country's economy.



**WE SHOULD ALL ENJOY THE
RIGHT TO MOVE WHEREVER
NECESSARY TO AVOID WAR, RAPE,
VIOLENCE, LACK OF BASIC RIGHTS TO
PROPERTY AND INHERITANCE; FOR JOBS
AND TO PROTECT OUR FAMILIES, TO
ENSURE OUR HEALTH.**

At the forefront of advocacy

Women living with HIV are involved in and leading many initiatives to end this discrimination. One example is the Committee for Accessible AIDS Treatment in Ontario Canada, an organization of legal, health, settlement and HIV sector members. In 2001, it conducted ground-breaking community-based research on improving treatment access for people living with HIV who are immigrants, refugees and without status, with the findings forming the basis of its public policy work. The Canadian HIV/AIDS Legal Network has also done excellent research on immigration policies used for public policy globally. The network's Law Project helps people such as Heidemarie F Kremer, a German doctor living with HIV, who was originally denied entry to the United States, to attend the 2012 International AIDS Conference in Washington.

The Argentinean Network of Women living with HIV is at the forefront of advocacy for the rights of migrants living with HIV, in coordination with women's migrants groups, particularly focusing on rights to access treatment and care. These are only a few of the many local and international organizations courageously fighting discrimination against people living with HIV.

As long as these restrictions exist, we will continue to raise our voices and fight for justice as women living with HIV.

Louise Binder is a member of the International Community of Women Living with HIV/AIDS, North America; María Lorena Di Giano is a member of the Argentinean Network of Women Living with HIV/AIDS; Baby Rivona is Cofounder of the Indonesian Positive Women Network.

ACTION POINTS

- **Advocate alongside us for governments to urgently repeal travel restrictions against people living with HIV.**
- **Protect those of us impacted by HIV-related restrictions on entry, stay and residence and make diplomatic efforts on our behalf to countries restricting our movement.**
- **Work with us to convince governments to adopt policies that guarantee our rights as migrants and refugees living with HIV to access health care.**
- **Respect our rights. HIV testing must be anonymous, voluntary and confidential, and must include pre- and post-test counselling.**
- **Provide those of us who are pregnant with full health care for ourselves and our child upon entry to a country as required.**
- **Meaningfully involve us as networks of people and women living with HIV in developing appropriate policies and laws.**
- **We, women living with HIV, must mobilize and build coalitions with AIDS service organizations, networks of people living with HIV and UNAIDS to ensure restrictions are eliminated in laws, regulations, policies and practices.**



STENGHTEN

HIV

INTEGRATION!

81%

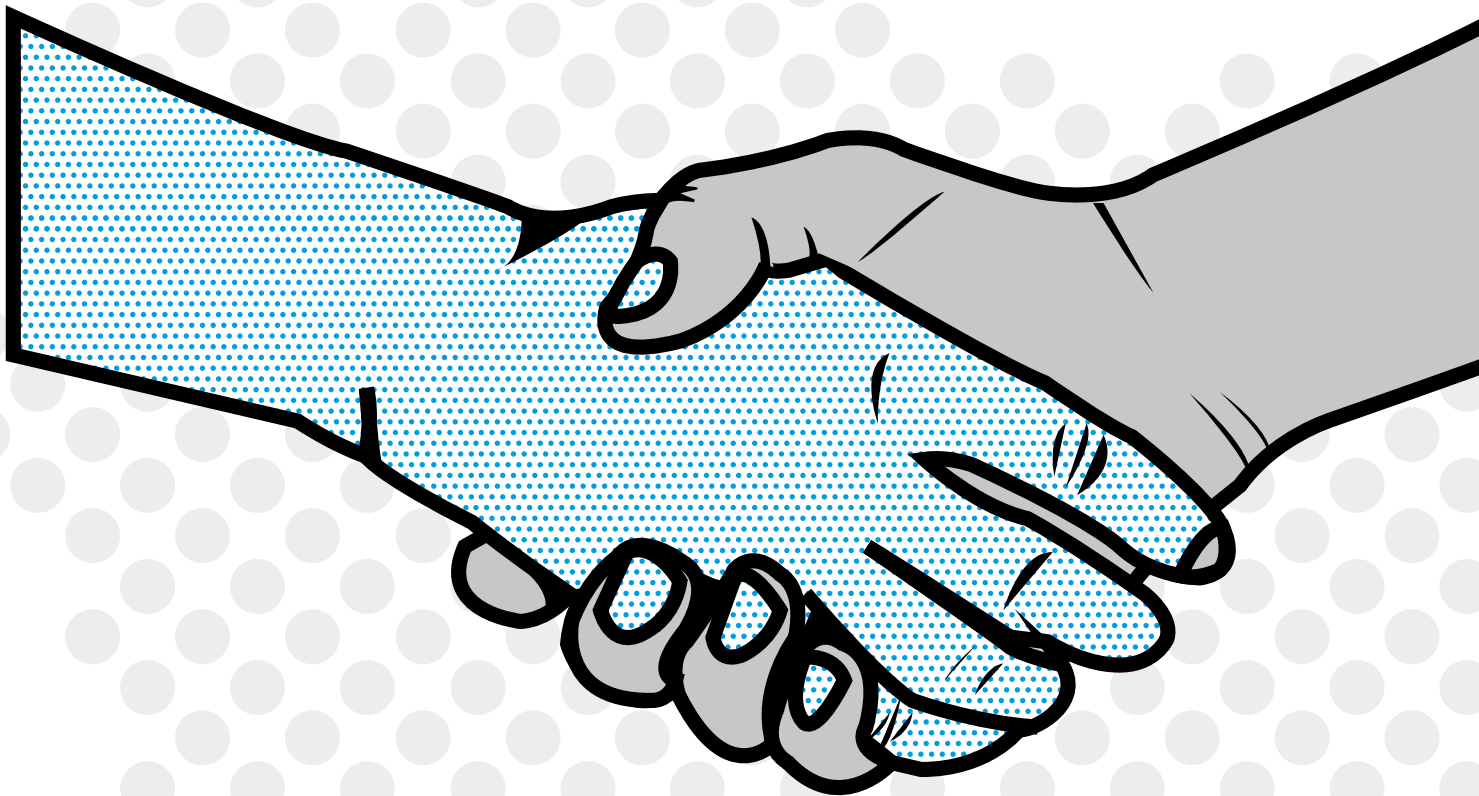
In 2012, 81% of countries reported including women as a specific component of multisectoral HIV strategies.

41%

Of countries that report including women as a specific component of multisectoral HIV strategies, 41% allocate a specific budget for women.

3 MILLION

An estimated 3 million people aged 50 and over are living with HIV in sub-Saharan Africa.



TARGET 10

ELIMINATE PARALLEL SYSTEMS FOR HIV-RELATED SERVICES TO STRENGTHEN INTEGRATION OF THE AIDS RESPONSE IN GLOBAL HEALTH AND DEVELOPMENT EFFORTS.

STRENGTHENING THE INTEGRATION OF HIV PROGRAMMES AND OTHER GLOBAL HEALTH AND DEVELOPMENT EFFORTS, PARTICULARLY SEXUAL AND REPRODUCTIVE HEALTH, FURTHERS THEIR REACH, ENHANCES THEIR LONG-TERM SUSTAINABILITY AND GENERATES BROADER HEALTH AND DEVELOPMENT GAINS, ESPECIALLY IN HUMAN RIGHTS (1).

Introduction


The mandate to integrate gender into HIV programmes has been underscored in various international agreements and declarations, including the Programme of Action of the 1994 International Conference on Population and Development and the Beijing Declaration and Platform for Action of the 1995 Fourth World Conference on Women (2), as well as the 2011 Political Declaration on HIV/AIDS.

Governments increasingly recognize the importance of gender equality in national HIV responses, including how the epidemic differentially impacts on women and girls. In 2012, 81% of countries reported that they included women as a specific component of their multisectoral HIV strategies. However, this means that almost one fifth of countries have no strategy that specifically includes women. Of those that do, only 41% allocated a specific budget for women (3).

In sub-Saharan Africa, the epicentre of the global epidemic, gender inequality continues to result in women and girls bearing a disproportionate burden of HIV, with women comprising an estimated 60% of prevalence in this region. Intimate partner violence and financial dependence on male partners, and poor educational attainment among girls, are linked to increased vulnerability to HIV infection (4). Given that gender-based violence has been shown to be both a cause and a consequence of HIV, linking the responses to both epidemics is crucial. Positive examples of such integration exist and can be scaled up (5).

Integrating HIV prevention, treatment, care and support with services for sexual and reproductive health can advance progress towards the Millennium Development Goals. One example is in Malawi, where the number of facilities providing integrated HIV and sexual and reproductive health services rose from zero in 2011 to 15 in 2012 (1). Such integration makes it easier for women to access the full range of services that they need. About 40 countries have used the Rapid Assessment Tool for Sexual and Reproductive Health and HIV Linkages to review how well their policies, health systems and service delivery link HIV and sexual and reproductive health, including the gender-equality dimensions, and make recommendations for strengthening laws, policies, coordination mechanisms, partnerships, joint planning, human resources and integrated services.

There is significant evidence supporting an association between behaviour change and education level. Studies have consistently found higher levels of reported condom use among those women with a higher education level (6). Studies from Zambia have shown that programmes to keep girls in school have demonstrated an association between school attendance and lower rates of HIV (7). Studies in South Africa are testing the utility of social protection tools and conditional cash transfers to promote school attendance with the goal of reducing HIV transmission (8).



**AS WOMEN LIVING WITH HIV,
WE ARE AS ENTITLED TO RECEIVE
THE HIGHEST STANDARDS
OF CARE FROM ALL SECTORS
AS EVERYONE ELSE.**

Meeting the needs of women throughout their lifespan

There is a growing number of people aged 50 and over living with HIV; an estimated 3 million in sub-Saharan Africa alone (9).

Despite this, HIV prevention efforts tend to overlook the fact that older women are sexually active and focus only on women of reproductive age (15–49). Data on sexuality at older ages indicates that women’s ability to negotiate sex is limited, thereby increasing their risk of HIV infection. Furthermore, access to prevention is lower than it is for younger women (10). Health services are ill-equipped to meet the specific needs of older women and reinforce a sense of shame that discourages them from disclosing their status or accessing services for treatment (11).

To improve the response to the needs of women living with HIV, integration efforts must address gender inequalities, combat gender-based violence, improve access to education for all girls and women, and address the sexual and reproductive health needs of women throughout their life-cycles.

In addition, it is of key importance to champion and invest in women’s leadership and participation for a more effective and integrated HIV response. It is important to invest in strengthening the capacity of women to organize and lead beyond the delivery of care and support services, and also to ensure the full participation of women and girls.

WOMEN OUT LOUD

ALEJANDRA TROSSERO, ALICE WELBOURN

A rights-based approach to HIV starts with people. It seeks to build health, community and social protection systems that respond to people’s needs, rather than expecting people to fit into them. In order to be effective, existing systems should be flexible and adaptive to respond to the complex realities of women living with HIV as we go through our life-cycles.

Responsive systems for HIV-related services are able to meet women living with HIV where we are and uphold our rights. When that response is well coordinated, and respect for our rights is upheld, integrating services is both possible and effective.

We applaud the good progress made in many parts of the world to integrate HIV with other health services such as those for sexual and reproductive health, maternal and child health and tuberculosis. This integration has reduced the frequency of clinic appointments and helped us to appreciate that there are other issues to consider, that our health status goes beyond being HIV positive.


A recent study conducted by the Asia Pacific Network of People Living with HIV/AIDS shows that some women living with HIV in India, Indonesia, Cambodia and Viet Nam are accessing HIV, reproductive, maternal and child-health services in the same health facility, as are many women in sub-Saharan Africa.

However, due to our HIV status, the presence of other disabilities, drug use, selling or exchanging sex for money or goods, having a different sexual or gender identity, or living in prison, or any combination of these, the services we receive do not always reflect our real needs. The elimination of parallel systems for HIV-related services is also far from being achieved.

Too many barriers

There are structural and institutional barriers that affect our ability to access health care. The quality of the care we receive is also questionable, particularly when accessing services that are not HIV-related. We are still being rejected, left last in the queue or turned away from receiving services for the simple fact of having an HIV-positive diagnosis.

One challenge is the existence of unequally supported parallel systems, a legacy of years of vertical programming that reflects donors' priorities. Staff training and supply-chain systems supporting the delivery of sexual and reproductive health services are not nearly as well-resourced as those for HIV. This is clearly illustrated by the frequent stock-outs of family planning methods seen in rural Kenya in the same facilities where antiretroviral treatment is provided without much disruption. Similarly, in Burkina Faso and Morocco, the ministries of health follow separate procedures for procuring and distributing sexual and reproductive health and HIV commodities.



**WOMEN LIVING WITH HIV HAVE
SHOWN HUGE INITIATIVE IN BECOMING
ACTIVE AGENTS FOR SHARING HEALTH
KNOWLEDGE AND SKILLS IN OUR
OWN COMMUNITIES.**


Another major obstacle for women and girls has been the focus of health-care systems on their sexual and reproductive health, ignoring women's holistic health-care needs. Girls aged 5–15, young women aged 15–25, women with no children and postmenopausal women are largely overlooked by health services. The major parallel, and closely connected, global pandemic of gender-based violence against women and girls is largely untouched by health-service providers.

As women living with HIV, we are often viewed as vectors of HIV and unfit to have babies, rather than as women with health-care issues in our own right. A rights-based approach would start with women's and girls' own range of physical, sexual, psychological and material health-care needs throughout the life-cycle.

Economic, food-related, legal, housing, education, social and other services all form a crucial part of our ability to manage our own health-care needs. Different sectors need to create linkages and ensure strong reciprocal links with communities. This also necessitates funding for our community-based work and to strengthen community systems. This is a critical sector to which resources are rarely allocated. Since more than HIV is so often at stake, this cross-sectoral collaboration is even more essential, often including the legal system, the police, magistrates and prisons.

We are active agents of change

Women living with HIV have shown huge initiative in becoming active agents for sharing health knowledge and skills in our own communities. For example, in Cambodia and Viet Nam, some women living with HIV who were determined to have a child educated themselves about HIV science and discovered supportive doctors within the public health system. Enlightened health-care systems have harnessed this agency to connect with networks of women with HIV in their communities and to promote and support women living openly with HIV as staff in their services.



**WE ARE NOT ONLY MOTHERS.
ESTABLISH INTEGRATED HEALTH
SYSTEMS THAT ADDRESS OUR
NEEDS THROUGHOUT OUR LIVES.**

The resilience of women in the face of widespread inequities continues once they have HIV. This has repeatedly been demonstrated over the past two decades through many social protection strategies created by women living with HIV to leverage income and support for their families and communities. Examples include widespread local microcredit initiatives in Kenya, and networks and informal associations among women with HIV to develop small business initiatives, such as exporting handmade crafts, textiles and fashion items in South Africa and Cambodia.

Cash and voucher programmes initiated by the state or nongovernmental organizations to cover costs for health and other services are also promising. These include maternal health vouchers in Cambodia supporting institutional delivery for poor women, and cash transfers to pay for transport costs to access medications in Kenya and Uganda. Yet there are no magic bullets and such initiatives need careful independent monitoring by women with HIV. For example, cash transfers to keep girls in school and HIV-free can backfire if the school itself does not offer a supportive environment.

All women's lives are complex, multifaceted and rich in what we offer our societies. As women living with HIV, we are as entitled to receive the highest standards of care from all sectors as everyone else, and if we are justly supported we can continue to offer society so much. We know the problems. We have the solutions. We are ready to act: are you?

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ACTION POINTS

- **Respect our rights by linking HIV and other health services** *through a rights-based holistic approach.*
- **We are not only mothers. Establish integrated health systems** *that address our health needs throughout our lives.*
- **Promote multisectoral responses to our care and support,** *including investments in our own community-led systems and initiatives.*
- **Work with us to foster better coordination in the response to HIV,** *ensuring our multiple contributions are recognized and valued.*
- **Uphold our rights by promoting an integrated response** *where we are equally treated, irrespective of our own lifestyles and choices.*

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