

# Impact

# 8

## Women and AIDS



Photograph Courtesy UNAIDS

The twentieth anniversary of the identification of HIV brings into focus the changes in scale and epidemiology of people affected by the virus.

HIV has a truly global face, with over 40 million people living with HIV at the close of 2003. Around half of new infections now occur among women. In December 2002 Kofi Annan stated "In Africa, AIDS has a woman's face" and it is true that women and girls are particularly vulnerable to HIV, not just because they are biologically more susceptible but also because many live in cultures where there is inadequate knowledge about HIV and AIDS as well as an inability to negotiate safer sex with their partner. This can be a very dangerous combination.

Here in the UK we are seeing increased levels of infection. Substantial numbers of these have been acquired abroad through heterosexual contact. The theme of the 2004 World AIDS Campaign is Women, Girls, HIV and AIDS and it is as relevant to the UK as anywhere else in the world.

In this issue of *Impact* we focus on many of the key issues around women, HIV and AIDS. We produce an edited version of Stephen Lewis' powerful speech to the Microbicides 2004 conference in which he eloquently highlights the complex gender inequality, which, in his words, "sustains and nurtures the virus". Anna Forbes of the Global Campaign for Microbicides argues that this new technology gives women more power to choose safer sex. Peter Piot, Executive Director of UNAIDS, Emma Thompson, the well-known actress, and Hazel Chinake of SIDA highlight the cultural changes needed in many countries if women are to be allowed to assume a greater role in dealing with the spread of HIV.

We also report on the newly established Global Coalition on Women and AIDS which takes as a guiding principle the recognition that women are leaders in the response to HIV and AIDS.

*Impact* also looks at women in the UK. Dr Delphine Valette, NAT Policy Officer considers the nature and impact of HIV-related stigma and discrimination on black African women in the UK. We also ask a number of prominent women involved with HIV for their views on the relevance of the 2004 World AIDS Campaign to the UK.

*Impact* welcomes any comments you may wish to make on this edition. The debate about women, HIV and AIDS is central. It must not stop at the end of this particular campaign.

**Deborah Jack**

Chief Executive  
National AIDS Trust

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# Women – Empowering the Unsung Heroes and Victims

THE FOLLOWING IS AN EDITED VERSION OF THE SPEECH MADE BY STEPHEN LEWIS, UN SPECIAL ENVOY ON HIV/AIDS IN AFRICA TO THE MICROBICIDES 2004 CONFERENCE IN LONDON.

I'm here because I think the work in which you're collectively engaged . . . the discovery and availability of microbicides . . . is one of the great causes of this era, and I want to be a part of it. It is in this room that morality and science will join together.

I've been in the Envoy job for nearly three years. If there is one constant throughout that time, a large part of which has been spent traversing the African continent, it is the thus-far irreversible vulnerability of women. It goes without saying that the virus has targeted women with a raging and twisted Darwinian ferocity. It goes equally without saying that gender inequality is what sustains and nurtures the virus, ultimately causing women to be infected in ever-greater disproportionate numbers.

The phenomenon of women's acute vulnerability did not happen overnight. It grew relentlessly over the twenty years of the pandemic. What should shock us all is how long it took to focus the world on what was happening. Why wasn't the trend identified so much earlier? Why, when it emerged in cold statistical print did not the emergency alarm bells ring out in the narrative text that accompanied the numbers? Why has it taken to 2004 — more than twenty years down the epidemiological road — to put in place a Global Coalition on Women and AIDS? Why was it only in 2003 that a UN Task Force on the plight of women in Southern Africa was appointed to do substantive work? Why have we allowed a continuing pattern of sexual carnage among young women so grave as to lose an entire generation of women and girls?

Ponder this set of figures if you will: in 2003, Botswana did a new sentinel site study to establish HIV prevalence, male and female, amongst all age groups. In urban areas, for young women and girls, ages 15 to 19, the prevalence rate was 15.4%. For young men and boys of the same age, it was 1.2%. For young

women between 20 and 24, the rate was 29.7%. For young men of that age it was 8.4%. For young women between the ages of 25 and 29, the rate was 54.1% (it boggles the mind); for young men of the same age, it was 29.7%.

This wanton attack on women is because it's women. The African countries themselves, the major external powers, the influential bilateral donors, even my beloved United Nations . . . no one shouted from the rhetorical rooftops, no one called an international conference and said what in God's name is going on, even though it felt in the 1990s that all we ever had time for were international conferences. It amounts to the ultimate vindication of the feminist analysis. When the rights of women are involved, the world goes into reverse.

For more than twenty years, the numbers of infected women grew exponentially, so that now virtually half the infections in the world are amongst women, and in Africa it stands at 58%, rising to 67% between the ages of 15 and 24. This is a cataclysm, plain and simple. We are depopulating parts of the continent of its women.

And while finally, after the doomsday clock has passed midnight, we're starting to be engaged and agitated, very little is changing. Please believe me: on the ground, where women live and die, very little is changing. Everything takes so excruciatingly long when we're responding to the needs and rights of women.

Between three and four years ago, I visited the well-known pre-natal health clinic in Kigali, Rwanda. I met with three women who had decided to take a course of nevirapine; they were excited and hopeful, but they asked a poignant question which haunts me to this day: they said "We'll do anything to save our babies, but what about us?" Back then, more than four years after anti-retrovirals were in widespread use in the west, we simply watched the mothers die.

Everything proceeds at glacial speed for women, if it proceeds at all, in the face of this global health emergency.

We deplore the patterns of sexual violence against women, violence that transmits the virus, but all you have to do is read the remarkable monographs by Human Rights Watch to know that for all the earnest blather, the same malevolent patterns continue. We lament the use of rape as an instrument of war, passing the virus, one hideous assault upon another, but in Eastern Congo and Western Sudan, possibly the worst episodes of sexual cruelty and mutilation are taking place on a daily basis as anywhere in the world, and the world is raising barely a finger. We have the women victims of Rwanda, now suffering full-blown AIDS, to show the ending of that story. We talk ad nauseam of amending property rights and introducing laws on inheritance rights, but I've yet to see marked progress. We speak of empowering women, and paying women for unacknowledged and uncompensated work, and ushering in a cornucopia of income generating activities . . . and in tiny pockets it's happening, especially where an indigenous local women's leadership is strong enough to take hold . . . but for the most part, in Churchill's phrase, it's all "Jaw, Jaw, Jaw".

For much of my adult life, I have felt that the struggle for gender equality is the toughest struggle of all, and never have I felt it more keenly than in the battle against HIV and AIDS. The women of Africa and beyond: they run the household, they grow the food, they assume virtually the entire burden of care, they look after the orphans, they do it all with an almost unimaginable stoicism, and as recompense for a life of almost supernatural hardship and devotion, they die agonizing deaths.

Undoubtedly with the sudden growing awareness internationally of what the virus hath wrought, we will all make increasing efforts to rally to the side of women. It's entirely possible that we will make more progress over the next five years than we have made in the past twenty. But I cannot emphasize strongly enough that the inertia and sexism which plague our response are incredibly, almost indelibly engrained, and in this desperate race against time we will continue to lose vast numbers of women. That is not to suggest for a moment that we shouldn't make every conceivable effort to turn the tide; it is only to acknowledge the terrible reality of what we're up against.

We have to work with the men. Of course we do. But please recognize that it's going to take generations to change predatory male sexual behaviour, and the women of Africa don't have generations. They're dying today, now, day in and day out. Something dramatic has to happen which turns the talk of generations into mere moments in the passage of time.

I'm not pretending that microbicides are a magic bullet. Microbicides aren't a vaccine. But when so many interventions have failed, when the landscape for women is so bleak, the prospect of a microbicide in five to ten years is positively intoxicating.

The idea that women will have a way of reasserting control over their own sexuality, the idea that they will be able to defend their bodily health, the idea that women will have a course of prevention to follow which results in saving their lives, the idea that women may have a microbicide which prevents infection but allows for conception, the idea that women can use microbicides without bowing to male dictates — indeed the idea that men will not even know the microbicide is in use . . . these are ideas whose time has come.

For me, while microbicides are not a salvation, they come as close to salvation as anything else I've heard about. I pray that everyone at this conference understands that the women of Africa and many other parts of the world are counting on you. It is impossible to overstate how vital is the discovery of a microbicide. If we were making progress on several other fronts, microbicides would pale. But we're not making progress, or we are making progress in such painfully minute instalments, that it feels as though we're moving from paralysis to immobility. The resources of the international community should flow, torrentially, into the hands of the scientists and researchers and advocates and activists assembled here who fight the good fight, because in those hands lies life. I don't have to tell anyone here about the science and the trials and the timetable and the resources. I ask only that you see microbicides, not merely as one of the great scientific pursuits of the age, but as a significant emancipation for women whose cultural and social and economic inheritance have put them so gravely at risk.

Never in human history have so many died for so little reason. You have a chance to alter the course of that history. Can there be any task more noble?

**Stephen Lewis**  
UN Special Envoy on HIV/AIDS in Africa

The full text of this speech is available at:  
[www.microbicides2004.org.uk](http://www.microbicides2004.org.uk)

# HIV efforts are failing women and girls

THIS IS TAKEN FROM THE SPEECH GIVEN BY PETER PIOT AND EMMA THOMPSON AT THE LAUNCH OF THE GLOBAL COALITION ON WOMEN AND AIDS ON WEDNESDAY 4 FEBRUARY 2004

Mrs Akinyi's husband died of AIDS in 1990. She believes her husband infected her with HIV — he had a history of extra-marital affairs. When he died, her in-laws denied her property inheritance: in her words, "Immediately after the burial I was chased away from home with my children."

Mrs Nyakumabor's husband died of AIDS in 1998 and left her HIV-positive with five children. Her in-laws grabbed household items and took over the house and land she had helped pay for. Soon after her husband's death, Mrs Nyakumabor's father-in-law called a family meeting, told her to choose an inheritor, and ordered her to be cleansed by having sex with a fisherman. Mrs Nyakumabor refused, causing an uproar. She now struggles to meet her family's needs, and her slum landlord has threatened to evict her because she cannot always pay rent on time.

These women's stories (their names have been changed) are two of the hundreds collected by Human Rights Watch and other organizations documenting the stripping of property rights in the wake of AIDS among some of the most vulnerable people on earth.

The global fight against AIDS has been endorsed by all the UN member states, and declared a high priority at countless summits. Resources are being mobilized — still short of what is needed, but a lot more than was available only a few years ago. At last, programmes to extend life-saving HIV treatment to the developing world are being mounted with the seriousness and urgency they require. And HIV prevention, which currently reaches fewer than one in five of those who need it, is also on the agenda.

But for as long as women and girls are unable to enjoy education, property rights, freedom from violence and economic security, progress on the AIDS front will pass them by. Women make up about half the global HIV pandemic, and where the pandemic is longer standing, in Africa, they are well over half.

The 'ABC' slogan — 'abstain, be faithful, use a condom' — is the mainstay of many HIV prevention programmes. But for too many women and girls, this message has no purchase. Where sexual violence is widespread, abstention or insisting on condom use is not a realistic option.

Across the world, between one-fifth and a half of all girls and young women report that their first sexual encounter was forced. Only 11% of women in Zambia believed they had the right to ask a husband to use a condom.

Nor does marriage provide the answer. The reality across the developing world is that the majority of women will be married by age 20, and have higher rates of HIV than their unmarried, sexually active peers.

At the same time, women bear a disproportionate share of the burden of AIDS care. In poor households, the presence of an AIDS patient can absorb a third of all household labour, most of it by women.

The knock-on effects of the plunge in household income caused by AIDS is often to pull children out of school — and girls are the first to go. Across Africa, formal school participation is declining.

The answers to reducing women's vulnerability to AIDS clearly lie deeper than

the use of slogans. To address AIDS effectively, we first have to understand how women are being treated and why. A comprehensive strategy is needed to boost girls' access to education — particularly secondary education — strengthen legal protection for women's property and inheritance rights, eradicate violence against women and girls, and ensure they have fair access to HIV care and prevention services.

Tackling these inequalities is not just a matter for women; men must be fully involved. For starters, they need to declare zero tolerance for violence against women, be committed to their daughters' education and help alleviate the burden of care.

Moves are under way, for example the global push to achieve education for all, or the campaign by the World Health Organization and UNAIDS to ensure that three million people in the developing world have access to HIV treatment by 2005, and that half are women. But more is needed, and more urgently.

The escalating global struggle against AIDS cannot afford to neglect women, and special efforts will be needed to ensure it is not allowed to. To that end, UNAIDS has pulled together a high profile group of men and women — the Global Coalition on Women and AIDS — which gathers activists, government representatives, celebrities, and community workers who are committed to improving the lives of women and girls.

The call to empower women is not new, but AIDS makes it more urgent. Millions of women around the world were already facing a lifetime of hard labour. AIDS has turned it into a death sentence.

The skills, knowledge and resources to relieve women of the devastating burden of AIDS already exist. What is needed now is the political will to see that they are applied.

**Dr Peter Piot, Executive Director of the Joint United Nations Programme on HIV/AIDS (UNAIDS)**

**Emma Thompson, Oscar-winning actress and a Steering Committee member of the Global Coalition on Women and AIDS**

The full text of this speech is available at: <http://womenandaids.unaids.org>



Photograph Courtesy: UNAIDS

# The Impact of HIV and AIDS on Women and Girls in Africa

*"We need to see a deep revolution that transforms relationships between women and men, so that women will be able to take greater control of their lives — financially as well as physically"*

**UN Secretary General's message on International Women's Day, 8 March 2004**

## INTRODUCTION

Women and girls throughout Africa bear the biggest brunt of the HIV and AIDS global burden, whether infected, affected or not yet infected. The epidemic has become increasingly prevalent and more profound in the sub-Saharan region of Africa. Gender norms continue to significantly influence individual and societal risks to HIV, as reflected by the profile of infections and affected groups throughout the continent. Women and girls find it impossible to negotiate sexual relations due to skewed power dynamics and notions of sexuality, which are inversely related to socio-economic status, age and authority.

Gender-based violence presents an insurmountable barrier to reducing HIV risk, and it is deeply entrenched in the lack of respect for women's rights. The argument for promoting sexual and reproductive rights through prevention tools that women can control has to take into account the reality that men have an equal responsibility in addressing the situation of women in African cultures affected by HIV and AIDS.

## REVISITING CULTURES

HIV and AIDS is the largest obstacle to achieving the Millennium Development Goals by the year 2015. The UNAIDS report<sup>1</sup> has estimated that 50% of the adults infected with HIV worldwide are women. Most of the countries in eastern and sub-Saharan Africa have been experiencing a generalised epidemic in the past three decades, with over 25 million adults and children currently living with HIV and AIDS today. Prevalence rates in southern

African countries are presently between 20 to 38% of the population. Characteristically, women are often infected at an earlier age than men, with young women aged 15 to 24 being 2.5 times more likely than young men their age.<sup>2</sup>

Countries in Africa, south-east Asia, the Caribbean and Latin America show common cultural trends as well as diversities linked to traditions, religious beliefs, sexual norms and behaviours that exacerbate women's and men's vulnerability to HIV and AIDS. We need a full appreciation of the multiplicity of social and cultural constructions of sexuality if we are to have more effective HIV prevention strategies.

Whilst western culture asserts itself, calling for attention to individual rights, 'traditional culture' in Africa focuses on the community and family. Definitions of 'culture' and 'customs' have largely been controlled by men who emphasise male rights as custodians of African culture at the expense of female rights.

This explains why the ideal feminine attributes are based on sexual innocence, the social rewards of their fecundity and the fulfilment of the 'good woman' role of a hardworking wife and caregiver, within most African cultures. For most women and men worldwide, the desire to have children outweighs the concern of HIV infection.

As a consequence, saying 'no' to sex or the slightest suggestion of condom use is usually perceived as absurd, particularly for 'decent women' who are expected to be passive in sexual interactions. To deny a man 'his conjugal rights' because you are simply 'not in the mood' or you are afraid of contracting HIV from a promiscuous partner is 'culturally' unacceptable. Marital rape is often legitimised through 'customary laws' that justify forced sex by calling it 'custom'. The risk is compounded for a woman who is economically dependent — she lacks a voice and choices. A study of 1458 childbearing women from Rwanda found an infection rate of more than 45% among women who were reportedly in

monogamous, marital relationships<sup>3</sup>. Another study in Zambia established that only 11% of women interviewed felt that they could negotiate condom use, even if there was proof of unfaithfulness and HIV<sup>4</sup>. Similarly, studies in the United States suggest that the majority of women infected by male partners did not know that the men had had multiple sex partners, sex with other men or that they were intravenous drug users<sup>5</sup>.

Ultimately, perceptions of African and Asian women as passive and controlled within patriarchal family systems have to be understood within their cultural contexts. Afro-Caribbean women, on the other hand, are perceived as dominating and run matriarchal households, and yet they are equally vulnerable to HIV risk and violence.

Multi-site research studies in Cameroon, the Caribbean, Peru and South Africa have attempted to substantiate these anecdotal assertions by revealing that between 20 to 48% of girls aged 10 to 25 reported that their first sexual encounter was forced<sup>6</sup>. Fear of violence has been reported as preventing girls and women from getting tested, disclosing their status and receiving treatment and counselling.

'Silence' and 'authority' thus play a coercive role in definitions of women's sexuality that put them at high risk of HIV infection in most African, Asian and Latin American contexts. Many other norms remain unchallenged, often reinforced by tradition, politics and religion.

#### UNPACKING GENDER RESPONSES TO HIV/AIDS

*"All too often, HIV prevention is failing women and girls"*

**Dr Peter Piot,  
Executive Director of UNAIDS**

Denial, blame, stigma and discrimination surrounding HIV have silenced candid discussions, derailed effective responses and compounded the burden of women in African cultures living with HIV and AIDS. Their situation has been worsened by extreme poverty and hunger as a result of drought and the effects of wars, often leading to a lack of funds to maintain good nutrition and access comprehensive treatment and care.

The International Community of Women Living with HIV/AIDS, an international network run for and by HIV-positive women, is an example of a gendered response to HIV-positive women's sexual and reproductive rights and well being through the Voices and Choices initiative. The project was developed in response to the lack of sensitive, relevant research into the experiences of HIV-positive women. The study found that risk perception

among married women in particular is very low. Information on discordance among couples is largely unknown<sup>7</sup>. For women infected with HIV, the cycle of physical and emotional violence continues. They are abandoned by their own families, and ostracised by the very communities they serve. In the case of widows and orphans, unequal property and inheritance rights fuel this predicament. Women with disabilities and affected by HIV are simply ignored.

In 1997, WHO, UNAIDS and UNICEF designed a new policy on infant feeding which advised HIV-positive women not to breastfeed. But for the majority of women in Africa, milk substitutes are loaded with another layer of stigma and discrimination as it may reflect one's HIV status, and lack of alternatives due to economic deprivation.

The risk to the infant of early death because of not breastfeeding at all is greater than the risk of HIV transmission and social pressure.

There is a desperate need for an approach to HIV prevention that is grounded in the realities of African women's lives and sexual experiences. The Musasa project in Zimbabwe is one such project that seeks to empower abused women. Musasa developed a culturally sensitive empowerment campaign on gender violence, HIV and AIDS, supported by Sida. This is currently being piloted in selected sites in the country. Through the project, women also receive support services through counselling, temporary shelter, and free legal assistance enabling them to obtain maintenance rulings in the courts, while victims of abuse have won restraining orders.

As a result of high mortality rates due to AIDS, the demand for anti-retroviral therapy in Africa has mounted, with pressure by activists on national governments to act urgently. This comes years after ART was first introduced in developed countries and priorities are therefore different as a result.

#### THE FINAL FRONTIER: SPOTLIGHTING MALE SEXUALITY AND HIV/AIDS

*"Broadly speaking, men are expected to be physically strong, emotionally robust, daring and virile. Some of these expectations translate into ways of thinking and behaving that endanger the health and well being of men and their sex-partners"*

**UNAIDS Report on 'Men and AIDS — A gendered approach'<sup>8</sup>**

The assertion that many HIV interventions have failed because they do not pay attention to the identity constructions that interact with women and girls at all levels is accurate. Unchallenged and deeply held cultural notions of masculinity often lead to risky behaviour for HIV infection among men and women. The pervasive silence also surrounding male sexuality is thus a common thread across African cultures.

Research and surveys within the sub-Saharan region point to socialisation as a reinforcing agent of masculinity as sexual prowess, dominance and superiority over women<sup>9</sup>. At the same time, men throughout Africa perceive their advantaged position in society to be threatened by socio-cultural changes in the continent. Such threats include rural and urban migration, changes in land tenure systems and 'western' culture which 'makes noise about women's rights' through various media and well-funded programmes. High unemployment levels and spiralling effects of poverty are inextricable links to men's vulnerability. The fact that men have traditionally had more control over whether or not to have safe sex is evidently self-defeating.

Padare, a Zimbabwe based men's group formed in 1993, seeks to tackle the issues of gender violence and HIV and AIDS from a male perspective, but admits there are problems in promoting a message of gender sensitivity in a society where men have traditionally held power. They conduct innovative outreach programmes to engage men in Zimbabwe's bastions of manliness — the beer halls. Some men are reported as believing that their manhood is being compromised, and that the oppression of women is God-ordained. Padare also targets adolescent boys through their programmes and has formed social networks within communities around the country. There is hope.

The culture of silence is beginning to crack with sexual taboos in other parts of Africa such as male rape and male-to-male sex taking the spotlight in HIV interventions. Sex is happening

between male prisoners, and so is male-rape and increased sexual violence against boys. In Malawi, Namibia, Kenya, South Africa and Zambia, researchers and development practitioners have begun to confront these realities through AIDS awareness, peer counselling and condoms in prisons as well as promoting home based care by men. A growing number of male caregivers are being recorded in Malawi, whilst on the other hand Namibian prisoners are not given condoms because of the fear of encouraging sodomy.

African culture does play a central role in shaping masculinity and femininity. What has also emerged is that culture is dynamic and can adapt or change to accommodate different constructions that are relevant to the contemporary situations that impact negatively on overall development.

## CONCLUSION

Global intervention efforts therefore have to be cognisant of the diversity of cultural factors that underpin sexual behaviour across continents, but specifically in the African context where the epidemic has reached alarming levels. The relationship between HIV, gender norms, poverty and other key variables, is a complex one. Perhaps a fusion of radical, culturally sensitive approaches with equitable access to prevention, care and treatment is critical in steering the social revolution for transforming the face of HIV and AIDS in Africa.

**Hazel Chinake**

**National Programme Officer responsible for HIV/AIDS and Gender Programmes — Sida, Zimbabwe**



*In Sida's policy Perspectives on Poverty, the importance of addressing HIV and AIDS is emphasised. In 1999, in collaboration with the Swedish Ministry for Foreign Affairs, Sida developed a strategy on HIV and AIDS entitled Investing for Future Generations—Sweden's International Response to HIV and AIDS. It is within the context of this international strategy that Sida in Zimbabwe are supporting multi-sectoral initiatives focusing on HIV prevention care and support as well as coping strategies.*

<sup>1</sup> [www.unaids.org.uk](http://www.unaids.org.uk)

<sup>2</sup> AF-AIDS eForum 2003: [af-aids@healthdev.net](mailto:af-aids@healthdev.net), [www.unaids.org.uk](http://www.unaids.org.uk)

<sup>3</sup> Anderson, R.M (1996) 'The Spread of HIV and Sexual Mixing Patterns', in J. Mann and D. Tarantola (eds.) AIDS in the World II (Oxford and New York: Oxford University Press); Barnett, T., and Whiteside, A. (2002) AIDS in the Twenty-First Century: Disease and Globalisation, Palgrave Macmillan, Hampshire; Kallings, L.O. and Vella, S. (2001) 'Access to HIV/AIDS Care and Treatment in the South of the World', AIDS 2001, 15: 1-3

<sup>4</sup> [www.equinet africa.org/policy.html](http://www.equinet africa.org/policy.html); [www.saf aids.org.zw](http://www.saf aids.org.zw)

<sup>5</sup> Anderson, R.M (1996) 'The Spread of HIV and Sexual Mixing Patterns', in J. Mann and D. Tarantola (eds.) AIDS in the World II (Oxford and New York: Oxford University Press); Gregorio, D.I., Walsh, S.J. and Parturzo, D. (1997) 'The Effects of Occupation-based Social Position on Mortality in a Large American Cohort', American Journal of Public Health, 87(9): 1, 472-5.

<sup>6</sup> Anderson, R.M (1996) 'The Spread of HIV and Sexual Mixing Patterns', in J. Mann and D. Tarantola (eds.) AIDS in the World II (Oxford and New York: Oxford University Press); Barnett, T., and Whiteside, A. (2002) AIDS in the Twenty-First Century: Disease and Globalisation, Palgrave Macmillan, Hampshire; Bassett, M. and Mhloyi, M (1991): 'Women and AIDS in Zimbabwe: The Making of an Epidemic', International Journal of Health Services, 21(1): 143-156; Burjra, J. (2000a) 'Masculinity in Africa'. Lecture in the series 'HIV/AIDS: The first Epidemic of Globalisation', School of Development Studies, University of East Anglia, Norwich, May; Schoepf, B.G. (1991) 'Women at Risk: Case Studies from Zaire', in G. Herdt and S. Lindenbaum(ed.) IN The Times of AIDS: Social Analysis, Theory and Method (Newbury Park, CA:Sage)

<sup>7</sup> [www.saf aids.org.zw](http://www.saf aids.org.zw)

<sup>8</sup> [www.unaids.org](http://www.unaids.org)

<sup>9</sup> Bassett, M. and Mhloyi, M (1991): 'Women and AIDS in Zimbabwe: The Making of an Epidemic', International Journal of Health Services, 21(1): 143-156; Burjra, J. (2000a) 'Masculinity in Africa'. Lecture in the series 'HIV/AIDS: The first Epidemic of Globalisation', School of Development Studies, University of East Anglia, Norwich, May; Caldwell, J.C., Caldwell, P. and Quiggin, P. (1989) 'The Social Context of AIDS in Sub-Saharan Africa', Population and Development Review, 15(2): 185-234; Kallings, L.O. and Vella, S. (2001) 'Access to HIV/AIDS Care and Treatment in the South of the World', AIDS 2001, 15: 1-3

# The Global Coalition on Women and AIDS

THIS ARTICLE IS AN AMENDED VERSION OF THE UNAIDS BACKGROUND NOTE ON THE COALITION. THE COALITION WAS LAUNCHED IN FEBRUARY 2004 BY PETER PIOT OF UNAIDS AND THE ACTRESS EMMA THOMPSON

The Global Coalition on Women and AIDS, which was launched in London on 2 February 2004, is a new initiative made up of activists, government representatives, community workers and celebrities, that seek to stimulate concrete action on the ground to improve the daily lives of women and girls.

The Coalition aims to advocate globally and nationally to highlight the effects of HIV and AIDS on women. Its main focus will be preventing new HIV infections, promoting equal access to treatment, addressing legal inequities and mitigating the impact of AIDS on women and girls.

## THE COALITION'S FIVE KEY AIMS

- **Address the increasing global impact of AIDS on women and girls**  
The latest epidemiological figures show that AIDS is having an ever-increasing impact on women and girls, highlighting the inadequacy of efforts to date.
- **Help meet a series of ambitious international targets**  
The UN Declaration of Commitment on HIV/AIDS, adopted by the General Assembly Special Session on HIV/AIDS in 2001, provides a series of progressive, measurable targets to tackle HIV and AIDS — many relate directly to women and girls. Most of these targets are set for 2005 and need extra effort and attention if they are to be met.
- **Support the wider global AIDS response**  
The epidemic has had a devastating impact on women and girls. Any progress will depend on what we do for women and girls today. They will be key to driving the response tomorrow.

- **Improve prevention for women and girls**

To be effective, prevention programmes must recognize the realities of many women's lives. Women and girls often have limited access to essential education and health care services and have little choice in sexual relations. They may be coerced into unprotected sex or infected by husbands in societies where it is accepted that men may have more than one partner.

- **Address severe societal and legal inequities which compound the impact of HIV and AIDS on women and girls**

Women and girls are disadvantaged by society in a number of ways that men are not. HIV and AIDS make these inequities worse and life threatening. Women face particular challenges in the areas of: access to property rights; limited access to education; limited access to care and treatment; and when violence against women is tolerated.

## THE COALITION'S APPROACH

The Global Coalition recognises that the vulnerability of women and girls to HIV infection and the impact of AIDS are linked to underlying gender inequalities and societal norms that need to be challenged. The Coalition is focussed on effecting changes in areas that have a direct and significant impact on the lives of women and girls — through strengthening their capacity and resilience, as well as their position in their families and societies.



The Global Coalition is guided by the following **key principles**:

- Women are not victims and their vulnerability does not stem from inherent physical or psychological weaknesses. The strong resilience of women to persevere in the face of hardship and difficulty is inspiring.
- Women are leaders in many areas of the AIDS response but too often interventions are not adapted to their realities leaving them at greater risk of HIV infection and at a disadvantage when it comes to coping with AIDS.
- Many women who are infected with HIV — or at great risk of becoming infected — do not practise high-risk behaviours. They are vulnerable largely because of the behaviour of others, through their limited autonomy and external factors, including social and economic inequities, beyond their control.
- Factors that make women and girls more vulnerable to HIV infection can be changed — given sufficient commitment, attention and resources.
- Women living with HIV and AIDS have a unique and valuable contribution to make in tackling the spread of HIV and fighting AIDS.
- Men, boys and wider communities are positive forces for change in improving the situation of women and girls. Efforts to foster more equitable and respectful gender relations are essential including the promotion of models of masculinity among young men that support this.

#### THE COALITION'S FOCUS

- **Preventing** HIV infection among girls and young women
- **Reducing** violence against women
- **Protecting** the property and inheritance rights of women and girls
- **Ensuring** equal access by women and girls to care and treatment
- **Supporting** improved community-based care, with a special focus on women and girls
- **Promoting** access to new prevention options for women, including microbicides
- **Supporting** on-going efforts towards universal education for girls

#### THE COALITION'S STRUCTURE

The coordination of the Coalition is light, dynamic and evolving alongside the needs of its partners. The overall direction and guidance of the Coalition is provided by a high-level Steering Committee which meets once a year and includes 20-25 leaders from a range of different constituencies including UN agencies, civil society, the public sector and academics. Leadership in each of the key areas identified for action is provided by expert partners, who will seek to convene broad partnerships for advocacy and action. Staff support for the Coalition is provided by the UNAIDS Secretariat.

#### FUNDING

The Coalition advocates for increased funding at global and national levels to help address the challenges facing women and girls. It also works with the implementing partners to assist in resource mobilization for activities in each of the focus areas.

**For more information about the Coalition, please go to <http://womenandaids.unaids.org>**

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# Microbicides for Women

Imagine for a moment that you had no way to protect yourself from HIV infection. And that this was not because of anything more complicated than your gender. Globally and here at home, women's number one risk factor for HIV infection is unprotected sex with a long-term partner. Although up to eight times more likely than men to contract HIV from a single unprotected act, women must still rely on male co-operation to protect themselves from HIV. This has led to rapidly escalating infection rates among women in many parts of the world.

- Globally, approximately half<sup>1</sup> of the 16,000 people<sup>2</sup> who become infected with HIV every day are women. In 2003, 58% of the 26.6 million people living with HIV and AIDS in sub-Saharan Africa were women<sup>3</sup>. Of those, the vast majority had only one mode of exposure to HIV — sex with their husbands<sup>4,5</sup>
- In Africa, young women (15–24) are 2.5 times more likely to have HIV than young men<sup>6</sup>. Among teenagers in some African and Caribbean countries, girls are 5 times more likely to be HIV-positive than their male peers<sup>7,8</sup>.
- In Russia and central Asia, where HIV rates are escalating, a third of all new infections are among women<sup>9</sup>.

More than two decades into the AIDS pandemic, women still lack an HIV prevention method under their control. Male and female condoms are highly effective and data confirm<sup>10,11</sup> that condom promotion programs can increase their use, especially among casual or paying partners. But study after study<sup>12,13</sup> shows low rates of consistent condom use in primary partnerships. Even after exposure to condom promotion, fewer

that 20-30% of long-term couples use condoms consistently.

The reasons for this are not difficult to understand if we switch, for a moment, from viewing the situation through a professional lens to considering our personal knowledge of how relationships work. Think about the “condom conversation” and what it raises for couples in stable relationships. It may occur between new lovers who have been using condoms for the first few months but now want the intimacy of skin-to-skin contact. Or it may occur among long-term couples when one suspects the other of being unfaithful. Either way, it raises complicated and potentially painful issues. How do you talk about fidelity, trust and control without scepticism and anger? Who wants to question a lover's honesty? Who wants to start a conversation that could lead to accusations, domestic violence and/or breaking up?

Not surprisingly, many couples simply avoid the “condom conversation”, allowing HIV risk to happen because it seems a distant and improbable threat — nowhere near as immediate as the threat of de-stabilizing the relationship.

For millions of women, even this choice is not available. Societies that permit women no role in sexual decision-making and condone male infidelity effectively put the possibility of requesting condoms (and, often, material access to condoms) beyond a woman's reach. Violence, coercion, economic dependency and stigma render millions of women of all ages unable either to “negotiate” condom use or to abandon partners who put them at risk.

Contraceptive impact raises yet another barrier to use. Since condoms prevent conception, women now have to choose

between childbearing and HIV prevention — an untenable dilemma for women who want to get pregnant for their own reasons and/or to achieve the status and security that, in many societies, they can only attain through motherhood.

For these reasons and more, those working in the field of HIV prevention and treatment have shown increasing interest in microbicides. Microbicides, products that can be applied vaginally or rectally before sex to reduce the risk of infection, would offer women something they could use on their own without partner co-operation. This is not wishful thinking — over 60 potential microbicides have been identified to date and, of these, 18 are already in human trials. Unlike vaginal spermicides, microbicides are being developed in both contraceptive and non-contraceptive forms.

Formulated as a gel, film, sponge, lubricant or time-released pessary, a successful microbicide could provide primary protection to women and couples who can't or don't use condoms. It would also serve as an important adjunct to condom use by offering added protection in case of condom failure. Most importantly, microbicides would put HIV and STI prevention within the reach of millions of women by offering protection that is under their direct control.

### **A SECRET FOR WOMEN TO HIDE FROM THEIR PARTNERS?**

Some women may choose to use a microbicide without any partner discussion. Initiating covert microbicide use in long-term partnerships could be somewhat challenging because several of the products now under development are likely to increase vaginal lubrication somewhat. Delivery systems are also under development, however, that may minimize this effect. A flexible, microbicide-loaded vaginal ring, for example, offers the possibility of time-released protection with minimal lubrication change, thus meeting the needs of women who can't or don't want to discuss the issue of protection with their male partners.

According to social scientists conducting acceptability research, many women say they probably would discuss their interest in using a microbicide with their husbands or boyfriends. With a woman-initiated method, however, this conversation could be a one-

time event occurring outside the context of the sex act. Instead of interrupting passion to ask the man to put on a condom or allow insertion of a female condom, a woman could initiate the conversation in a neutral setting, simply as information sharing. She wouldn't be asking him to change his behaviour in the bedroom to accommodate microbicide use. If necessary, she would have the option of claiming to use the product for contraception, hygiene or sexual enhancement rather than for disease prevention. The substantial market for "vaginal cosmetics" of all types, problematic as it is from a health standpoint, shows that such products are used in all parts of the world already and, hence, offer a ready excuse to the woman in need of a pretext for her microbicide use.

Gender activists are rightfully concerned that the pursuit of microbicides, as a "technological fix", should not distract from the over-arching need to correct the social and economic inequalities that fuel women's vulnerability. Transforming gender relations across the board is unarguably integral to lowering HIV and AIDS prevalence rates. In this context, microbicides are simply a material tool that can help level the playing field for women in the near future. Thus, they can serve as a component of the vital, on-going struggle to institutionalize women's rights to equality, dignity and sexual autonomy across the globe.

### **AN 'ACADEMIC BACKWATER'**

Lower tech than an AIDS vaccine, microbicides could be on the market in as little as five to seven years if their development were adequately funded. Despite its enormous scientific and public health potential, microbicide research has been severely underfunded and "academically seen as a backwater" according to Robin Shattock, a leading microbicides researcher based at St George's Hospital, London. Talking about microbicides necessarily requires talking about subjects that make some people uncomfortable — like vaginas, sexuality, power and gender. As drugs administered systemically by clinicians, vaccines and treatments have an aura of respectability that microbicides lack.

Large pharmaceutical companies — the normal engines of product development — have been reluctant to invest in microbicides because of concerns about the uncertain regulatory environment and competing opportunities to invest in products that are potentially more profitable. As a result, microbicide research and development (R&D)



Photograph Courtesy UNAIDS

has been conducted exclusively by non-profit entities, academic researchers, and small bio-pharmaceutical companies, all of which are dependent on government and foundation grants to pursue their research.

Microbicides are classic public health goods<sup>14</sup> — as are contraceptives and treatments for diseases associated with poverty. Unlike those areas of science where the motives of profit and professional ambition are sufficient to propel innovation, microbicides will only become a reality in the near future if sufficient political will exists to garner substantial investment on the part of governments and private foundations.

#### **HOW MUCH WILL IT COST?**

Unfortunately, the current government and philanthropic investment is insufficient to keep the microbicides research pipeline moving at an optimal rate. In 2002, a Pharmacoeconomics Working Group convened by the Rockefeller Foundation estimated the direct product-development costs of testing the existing pipeline of potential microbicide products at roughly \$775 million over five years.<sup>15</sup> Investment at that level, they predicted, would be likely to yield one or more safe, effective microbicides by 2010.

More recent estimates developed by the Alliance for Microbicide Development calculate that \$532 million was invested in microbicide research and development between 1997 and 2003, 80% of it by governments and 20% by the philanthropic sector. They further calculate that the average cost of taking one candidate

microbicide from pre-clinical development through registration (assuming its efficacy is proven) as \$35 million, but acknowledge that their estimates are based on the assumptions of HIV as the only primary trial endpoint and do not include the cost of developing and preparing new clinical trial sites.

The EU and UK governmental contributions toward closing this gap have been encouraging. In March 2004, the EU invested more than £7.4 million (12 million Euros) to the creation of the European Microbicides Project (EMPRO), an initiative that will engage the efforts of an international consortium of universities, research institutes and biotechnology companies, including several important British teams, in basic science research, pre-clinical and Phase 1 safety testing of candidate products. This funding came from the EU's current research framework which activists want to see increased in the next funding period.

The UK Department for International Development, meanwhile, has put £24 million into microbicides R&D to date, primarily to fund the Microbicides Development Programme (MDP), a five-year research collaboration administered by the Medical Research Council Clinical Trials Unit and Imperial College London and involving institutions in South Africa, Tanzania, Uganda, Cameroon, and Zambia. The MDP is currently mounting Phase 3 effectiveness trials of two candidate microbicides, Dextrin-2-Sulfate (Emmelle(tm), developed by ML Laboratories, a British biotech based in Liverpool) and PRO-2000/5(tm). These trials will enrol 12,000 women in the five African countries listed above and may produce results as soon as 2008. The MDP is also developing new products to enter safety studies in the UK and Africa.

Their big problem is a typical one in the microbicides R&D universe; the MDP still does not have sufficient money in the bank to guarantee completion of these trials. Like other products now entering Phase 3 effectiveness trials, they face the real possibility of seeing the trial interrupted in mid-course if funding runs out. This dilemma is one that will have to be resolved by the British government and the scientific community in the very near future.

Only a handful of other European nations have contributed to microbicide research, namely the Netherlands, Denmark, Ireland and Norway. Most have elected to contribute to the International Partnership for Microbicides, a public-private partnership set

up to accelerate microbicide research. Another excellent initiative to address the funding shortfall in HIV and AIDS-related clinical trials in general, the European and Developing Countries Clinical Trials Partnership (EDCTP), still lacks adequate support from European national governments and private sources. European governments, having welcomed and approved the creation of the EDCTP, now need to come through with the financial backing to make it work.

In May 2003, the Global HIV Prevention Working Group called for \$3.8 billion in additional annual spending by 2005 for existing prevention programmes. Specifically, the Working Group (a 40-member, international panel of leading public health experts, clinicians, biomedical and behavioural researchers, and people affected by HIV and AIDS) recommended additional public sector spending of \$1 billion for microbicides. Realistically, this may be the level of investment needed to optimize development of the first generation of microbicides. These first products, the Rockefeller Foundation study predicted, will create enough of a market to attract private investment. Market forces will then drive the development and refinement of second and third generation microbicides, which are hoped to have efficacy rates as high as 80–90%.

Governmental investment into microbicide research is, therefore, not going to be required indefinitely. Rather, it is an opportunity to kick-start a public health intervention that could save millions of lives in the near future — lives that will otherwise be lost because women lack the means to protect themselves from HIV infection.

No one strategy or technology will end the AIDS pandemic. We need all our existing prevention strategies – such as behaviour change, voluntary counselling and testing, STI diagnosis and treatment, broad access to male and female condoms, and anti-retroviral treatment — as well as new tools such as microbicides and vaccines. Once developed, these new technologies will meet specific areas of need, with microbicides putting prevention options directly in women’s hands.

For over two decades now, women confronted with a raging pandemic have been handed condoms. Knowing what we know about women’s lives, this is no longer enough. It’s time for microbicides.

**Anna Forbes, MSS**  
**Global North Programs Coordinator**  
**Global Campaign for Microbicides**



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- <sup>3</sup> Supra at 1.
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- <sup>5</sup> Irin PlusNews (a publication of the UN Office for the Coordination of Humanitarian Affairs), 21 May, 2004. “Introduction: A message from UN Secretary-General Kofi Annan: Women empowerment key to global response to HIV/AIDS”. (<http://www.plusnews.org/webspecial/womensday/default.asp>)
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- <sup>13</sup> Heise L. Topical Microbicides. Takoma Park, MD 20912: Center for Health and Gender Equity (CHANGE); 1999. <http://www.genderhealth.org/>. Site accessed: 6 Dec 2002.
- <sup>14</sup> The term “public health good” refers to products that yield a social or public health benefit but that fail to attract private capital.
- <sup>15</sup> This amount does not include discovery of additional leads, work on access and introduction, organizational overhead or advocacy efforts.

# Microbicides 2004

M2004 WAS HELD IN LONDON IN LATE MARCH OF 2004, AND ATTENDED BY 800 PEOPLE FROM 53 COUNTRIES. THE HIGHLIGHTS OF THE CONFERENCE ARE SUMMARISED BELOW

Microbicides are desperately needed because the AIDS pandemic continues to spread and girls and women lack options to protect themselves from HIV. In many African countries, girls and women are now the majority of those living with HIV and dying with AIDS. The “ABC” strategy — abstain (or delay sex), be faithful, or use a condom — is limited in its impact on HIV because women who marry have little or no control over their husbands’ past or future behaviour.

The main emphasis of current research is on experimental products, six of which are due to enter full-scale trials to test their effectiveness against HIV during 2004. These trials are costly and very complex undertakings. However, they are seen as vital to create confidence among pharmaceutical companies and others that such products can actually work, will have a real market, and are worthy of private investment. At present, almost all work in the microbicide field relies on public funding.



Photograph Courtesy: UNAIDS

Scientists working in the UK, with British government support, have pioneered HIV microbicide research and play a leading role in global efforts in this area, working closely with their counterparts overseas. The US and other governments, charitable foundations, and the European Union, are funding equally important work.

Within the UK, there is a need for more and better methods to prevent transmission of HIV among gay men. Rectal microbicides, to be applied before or during anal sex, may eventually be developed and may have value for the even larger number of heterosexuals who also engage in anal sex.

There is also a potential market in the UK and other western countries for a microbicide that could protect heterosexual women and men against other infections, especially genital herpes.

Planning for field trials was discussed at length during the meeting and there are disagreements about the need for, and value of, a “condom only” arm in clinical trials that will all compare possible microbicide gels with what are thought to be “inactive” placebo gels. The standard of care for trial participants has been very actively debated and there is clearly a need for access to better treatment both for HIV and other conditions than is generally provided in the countries where trials are to be held. However, this topic (standard of care) is not covered further in this report.

Of the six leading candidates, there were extensive reports of preliminary safety studies and laboratory tests on four of them (*Carraguard*, cellulose sulphate, *Emmelle*, *PRO 2000*). There were also extensive reports

of social research and feasibility studies for trials on four of the products (*BufferGel*, *Carraguard*, *Emmelle*, *PRO 2000*). The sixth product, *Savvy*, was not discussed although there are safety issues which may not favour its use in populations highly exposed to HIV.

There are several products at earlier stages of testing as microbicides which show some promise and one, cellulose acetate phthalate (CAP) is about to be entered in a safety trial recruiting 60 women volunteers in London.

An alternative route to a microbicide is being explored in India. This centres on testing existing medicines for their anti-HIV potential and has identified an antifungal cream that is already on the market in India, as a possible microbicide. Further testing is essential to evaluate the safety and efficacy of this or other such products.

Condoms are not the only barrier method of contraception, and it is possible that the diaphragm, a device inserted in the vagina to cover the cervix, could give limited protection against HIV in its own right and also serve as a delivery method for microbicides. Some research in this area was reported at the meeting.

Another approach is based on locally applied hormones that change the properties of the mucus and the vaginal wall to reduce the risk of infection and, incidentally, limit absorption of the drug. An oestrogen-based cream marketed for the control of menopausal symptoms has been shown to protect some monkeys against HIV-like viruses. Its short-term and long-term safety for women and babies and its effects during prolonged use in younger women are unknown. The priority for testing will be for women using Depo Provera as contraception, who are now known to be at increased risk of HIV and for whom the reproductive health concerns may be lower.

Microbicides for men, in the form of penile wipes to be used after sex, have been developed and may be of value against some infections. Unfortunately, the chemicals chosen for the first products of this kind to be described increase susceptibility to viral infection when mice are exposed to them and so cannot currently be recommended.



Photograph Courtesy UNAIDS

A number of anti-HIV drugs are being evaluated as potential microbicides and several are already in early stage clinical trials. One of these has been licensed free of charge to a not-for-profit organisation, the International Partnership for Microbicides, by the pharmaceutical company Tibotec (part of Johnson & Johnson). Johnson & Johnson retains the rights to license any successful product back from IPM for sale in wealthier markets and has thereby become the first major international company with any commercial stake in microbicide development.

Many other experimental approaches have been proposed, and some show promise in human cell and tissue cultures and in animal models for infection with HIV and other viruses. All of these are at early stages of development and have many hurdles to overcome before they could be adopted as methods of HIV prevention.

*References in this report relate to abstracts, which can be accessed online at [www.microbicides2004.org.uk](http://www.microbicides2004.org.uk)*

**Julian Meldrum**  
**Independent Consultant**

# Talking Heads

THE THEME OF THE WORLD AIDS CAMPAIGN THIS YEAR IS WOMEN. IS THIS RELEVANT TO THE UK AND HOW CAN WE MAKE IT WORK? NAT ASKED A NUMBER OF PROMINENT WOMEN INVOLVED WITH HIV FOR THEIR VIEWS



**Ceri Hutton**  
*Ceri worked in the HIV and AIDS field for 10 years, first as Head of Policy and PR at NAT, and then as Director at Immunity Legal Centre. For much of this time she*

*was Chair of the UK Forum on HIV and Human Rights. She now works as a freelance consultant and trainer.*

Of course HIV is still an issue for women in the UK. Firstly, there are more of us living with HIV than ever, with all the issues this brings up. Staying well, dealing with stigma, making treatment decisions, discussing our status with partners, running the gauntlet of the medical professions (often still all too ignorant of HIV once you get outside the specialist centres) — these are all continuing realities for many of us. Secondly, for those women who don't know their status, HIV continues to raise the issues it always raised — how to inform yourself and protect yourself when you have to negotiate with men.

And there's another dimension. Women experience a kind of 'double whammy' when infected by HIV. On top of the continuing stigma associated with HIV there is also a continued double standard in our society about the role and place of women in relation to sex. Our role as child bearers is celebrated, but not as conveyors of potential infection. Our bodies and sexuality are celebrated, but not if they 'hide' a lurking lergy. Our infection is, of course, a simple medical

condition except for the fact that 'nice girls' don't really (still) get HIV, do they?

To deal with any long-term medical condition, you need to be sure about yourself, the nature of the condition, and the social construct around the disease. If you don't have certainties about these things, you feel frightened — about who you are, what your diagnosis means to your identity, what you should do, who you should tell, how much you should trust medical information.

The other day I sat in a meeting with an HIV medical 'expert'. She not only assumed none of us there were HIV-positive, but also talked airily about the fact that we need to make sure that "microbicides didn't stop women with HIV being sensible and using condoms". There's still a long road to go before the complexity of living with HIV as a woman is understood, it seems.

## Elisabeth Crafer



*Elisabeth is Director of Positively Women, a multicultural organisation providing peer support to women living with HIV & their children.*

Us women generally have attachments; we come attached to families, friends and assorted dependents. No woman is an island.

Also attached to us are the labels of carers and 'good girls'. Even in the equality

conscious UK, the old constraints still persist. We may no longer be barefoot, pregnant and in the kitchen, we have Manolo Blahniks and contraception, but getting out of the kitchen has been harder. Women sure aren't the leaders in the power stakes. This makes HIV stigma a double whammy for women. Nice girls don't get HIV, and with no voice in the power games, women don't get the consideration in research, treatment or policy that they deserve.

This year's theme of women is relevant to the UK because a substantial part of the increase in HIV infections is in women from abroad. Not everyone has made the connection between a global economy and global migration, or that the rich West may have a responsibility to the global workforce whose cheap labour produces our goods. Do we have to wait until an economically active generation and its children is wiped out before we take equity of access to treatment seriously? I hope this WAC theme will give more women living with HIV the courage to act boldly and claim what is theirs.

#### Ruth Webb



*Ruth, 41, has known about her HIV infection since 1993. She worked with UK Coalition of People Living with HIV and was their Chairman for three years until 2002. She has been the*

*Chairman of the European Coalition of Positive People since it was set up, and works with ECPP in Eastern Europe and Africa.*

In recent years we have seen a continuing rise in the number of women infected with HIV in the UK, with more being infected within the UK. Most of these women are still of childbearing age, so there is the added risk of babies being infected through their mothers. Women make up by far the largest proportion of carers, looking after their loved ones often at the expense of their own health. HIV infection still carries a huge stigma that is not being addressed effectively at all — largely due to a lack of will. And finally we are seeing increasing sexual

exploitation and trafficking of women even to the UK for the sex trade.

These are things we should not be turning a blind eye to. We should be demanding effective and timely sex education for our children by properly trained people. We should be using a wide range of methods to educate our children about stigma and discrimination, so that they understand in their hearts as well as their minds what it really means. Sexual health should have the same priority that is given to heart disease. We need to stand up and campaign until everyone begins to understand that HIV is something that can happen to 'the girl next door'. Unless we have understanding and support now, we will not be able to help those living with HIV tomorrow.

#### Sandra Gidley MP



*Sandra was elected Member of Parliament for Romsey in 2000 and is now the Liberal Democrat Spokesperson for women and older people. She is an active member of the All Party parliamentary group on AIDS.*

Ask almost any member of the British public what sort of people are likely to be HIV-positive and they will probably give you the answer "gay men". The stereotypes persist and there is little awareness that the incidence of the disease among heterosexual women is rising rapidly. There is also little general knowledge that, on a global level, the face of HIV and AIDS is predominately female.

There appears to be a public reluctance to highlight the increased incidence in women. This is probably connected with the fact that the women involved are mainly ethnic minority women and the fear that this issue could be dominated by a racial aspect. Few seem to consider that the current situation of rising infection rates in women should alert us to the changing HIV and AIDS demography in the UK.

This campaign should be an opportunity to get the message across to UK women that

they too are vulnerable and need to be taking more notice of safer sex messages. Being politically correct about this issue will not help anyone and we need to inform people that the problem of HIV and AIDS is getting closer and closer to home.

We need to do all we can to highlight this issue among women because greater awareness will, ultimately, save lives.

### **Winnie Sseruma**



*Winnie is the Chair of the African HIV Policy Network and a new Trustee of the National AIDS Trust*

The profile of HIV and AIDS has dramatically changed in the last few years. In the early stages of the AIDS pandemic, it was seen as mainly affecting men. However, women are currently the fastest growing group of newly diagnosed people.

Globally, at least half of those newly infected are women. In sub-Saharan African more young women are being diagnosed HIV-positive than young men. In the US, AIDS is now the leading cause of death among ethnic minority women from the Hispanic and African American populations, between the ages of 25–44 years of age.

As the heterosexual AIDS pandemic takes hold in the UK, more and more women are being diagnosed. In the last few years, twice as many African women have been diagnosed with HIV than African men in the UK. The UK also has the highest rate of teenage pregnancy in Europe, and sexually transmitted diseases are on the rise especially among young people.

The focus on women and HIV in the World AIDS campaign this year is long overdue. We need to review how well the needs of women are being addressed in the UK. Very little discussion goes on about the specific needs of women, even though we remain biologically more vulnerable to HIV, and many of society's inequalities add to this risk.

Kofi Annan, the UN's Secretary-General, summed up the need to support and recognise women in his International Women's Day message this year —

"In most countries and communities I have visited around the world, it is women who have been most active and effective advocates and activists in the fight against AIDS. Everywhere that the epidemic is taking a severe toll, there are heroic women's groups and cooperatives doing remarkable work on prevention and care. Supporting these women, and encouraging others to follow their example, must be our strategy for the future. It is among them that the real heroes of this war are to be found. It is our job to finish them with strength, resources and hope."

# HIV-related stigma and discrimination:

## THE CASE OF BLACK AFRICAN WOMEN IN THE UK

### INTRODUCTION: HIV EPIDEMIOLOGY AMONGST WOMEN IN THE UK

Statistics issued by the Health Protection Agency in February 2004 showed that the number of HIV diagnoses in the UK has increased by 20% for a second consecutive year.<sup>1</sup> The number of new HIV heterosexual infections now exceeds the number of new diagnoses of gay and bisexual men.<sup>2</sup>

In 1992, women made up 12% of people living with HIV and AIDS in the UK. By 1998, the proportion had grown to 35%.<sup>3</sup> Women are now the fastest growing group of newly diagnosed people in the UK, with a significant percentage of them being from minority ethnic communities, mainly black Africans.<sup>4</sup>

The HPA's figures released for World AIDS Day 2003 showed that three quarters of heterosexually acquired HIV infections diagnosed in the UK in 2002 were probably acquired in Africa. Two thirds (1993 of 3153) of the heterosexually acquired HIV infections diagnosed in 2002 were in women, and three quarters of the total (2338) were probably acquired in Africa.<sup>5</sup> An overwhelming majority of those black African women (more than four fifths) have been infected from a male partner.

Domestic violence, rape and sexual assault are very much a reality in the UK and potentially expose women to HIV. A recent report by the Women and Equality Unit, *"Living without fear: An integrated approach to tackling violence against women"*,<sup>6</sup> highlights appalling statistics. In particular, the report states that one woman in four experiences domestic violence at some stage in her life. It is estimated that between one in eight and one in ten women has

experienced domestic violence in the past year. Finally, 70% of women aged 16-29 worry about rape, and reported rape has increased by 165% in the last 10 years.

Domestic violence affects all cultures and classes, but some communities such as black and minority ethnic communities are more visible to the public eye than others.

Because of their status in some African societies and the "transposition" of cultural practices in Europe, some African women are left without any means of protection against HIV transmission. Those who refuse to have sex with their husband or who want to use a condom are accused of having an affair. Women trying to access sex information are also likely to be seen as promiscuous. Most of the time they will also be refused contraceptives and information about risk reduction and safer sex.

Black Africans seeking asylum often arrive in the UK with no money or possessions and an uncertain immigration status. They are not likely to be aware of their HIV status. They may have been infected with HIV by their husbands or as a result of rape and live in a community with rules, cultural traditions and expectations about sexual behaviour and the role of women.

Sexual violence in intimate relationships occurs often in South Africa. A study by a South African university revealed that more than 60% of South African women are regularly battered by their boyfriends or husbands. It also reported that men beat their partners if they refuse to have sex.<sup>7</sup> African women may also have been infected in countries in conflict and civil wars where sexual violence and rape are used as a

weapon of war by militias and soldiers. In the early years, a majority of Africans coming to the UK were from Eastern Africa, in particular Rwanda where the Hutu militia groups and the Rwandan military used rape as a weapon of genocide (“genocidal rape”). Recently, most asylum seekers and refugees have come from south-eastern Africa, particularly Zimbabwe where the pro-government militia has also used rape as a political weapon. It is estimated that over 50% of women asylum seekers in the UK, whose majority comes from Africa, are fleeing rape, mostly by soldiers, police or other agents of the state.<sup>8</sup>

African women entering the country alone or with children are also facing poverty and may resort to prostitution for a living. These women often flee gender-based persecutions such as rape, sexual slavery or female genital mutilation (FGM).<sup>9</sup> They are sometimes lured to the West on the promise of a work permit and well-paid jobs but are sold into bondage. Some others do not see any other choice but to sell themselves to survive.

**HIV-RELATED STIGMA AND DISCRIMINATION**  
HIV and AIDS as a disease has been marked by stigma because it has been associated with lifestyles and behaviours already stigmatised or considered “deviant” (e.g. homosexuality, injecting drug use, sex work). It is also life threatening and people have misconceptions about the routes of HIV transmission.

Whilst the medical characteristics of the disease have made some degree of stigma inevitable, HIV has mainly been used as a catalyst for exacerbating or reviving existing prejudice and negative attitudes towards specific population groups (e.g. gay men, immigrants, injecting drug users) found to be the “ideal” scapegoats to the pandemic.

HIV stigma can be “felt” (i.e. shame associated with HIV and the fear of being discriminated against on the grounds of HIV) and “enacted” (i.e. actual experiences of discrimination, e.g. isolation, rejection, loss of job, housing, denial of health care).

Very often the fear of discrimination is as harmful and detrimental as actual discrimination. It very often leads an individual to conceal their HIV status in order to protect themselves from

discrimination.

HIV-related discrimination is complex because it affects people living with HIV and AIDS but also extends to people presumed to be HIV-positive because of their membership of a group (e.g. gay men, black Africans, injecting drug users) or their association with a seropositive person (e.g. carer, family members, a person working in the HIV sector).

Discrimination can be “institutional” and operates in spheres such as health care, employment, and housing, as well as “non-institutional” in families and communities. It can also be direct, where it is explicitly based on a characteristic or attribute of the affected individual (a black African woman is refused housing because of her race) or indirect, where a practice, rule or condition appears to be neutral but has the effect of discriminating against specific groups who cannot or are less able to comply with it (excluding job applicants who live in a certain area of a city, where that area is occupied by a higher proportion of ethnic minority people). Finally, discrimination may be the result of an omission, such as a failure to act to meet the special needs of particular groups.

#### **HIV-related stigma and gender**

The link or intersection between HIV-stigma and gender builds on existing economic, educational, cultural and social disadvantages.

HIV- and gender-related stigma mainly stems from discriminatory assumptions about a woman’s sexual and private life (i.e. an HIV-positive woman is presumed to have been infected as a result of having multiple partners or having engaged in prostitution). Women are judged as being “dirty” and “promiscuous” and are blamed for someone else’s behaviour and actions.

HIV-stigma can be directed at women who have been infected with HIV by their partner, husband or through blood transfusions. It also easily affects female sex workers often identified as “vectors” of HIV infection, the illegal status of prostitution heightening the perception of the women being responsible for HIV transmission. In fact, very often clients do not want to wear a

condom and the women are exposed to violence, either by the client or a pimp, if they refuse to have unprotected sex.

### **HIV- and race-related stigma**

In the UK, the HIV epidemiology and the existing context of racism potentially expose black Africans to stigma and discrimination because of their race and their presumed or actual HIV status.

Irresponsible associations between migration and HIV made by the media over the past year have heightened anti-immigrant sentiments and the perception of migrants, particularly Africans, as “infectious disease importers”.

The Government’s introduction of punitive asylum and immigration policies has perpetuated the association of migrants with “problems” (e.g. HIV, the public cost of treating migrants’ medical conditions). Prime Minister Tony Blair himself admitted that “[i]f they can’t support themselves, they will be put out of the country” and that the Government “will take whatever measures are necessary in order to make sure that the pull factor is closed off”.

Recent media coverage of the legal prosecution for sexual HIV transmission involving African men has also heightened prejudices and negative assumptions against immigrants depicted as “predators” knowingly transmitting HIV to women.

### **Gender- and race-related HIV stigma and discrimination**

The intersection of HIV with gender and race may expose black African women to multiple stigma and discrimination.

HIV is greatly stigmatised in black African communities. It is very often perceived as a curse that someone deserves for having done something wrong or is merely disregarded as an issue in the community:

*“Even now it is very hard to tell somebody I am sick, because like our community they take it as a curse, or like you misbehaved or went out with somebody, like they take you as a prostitute, it is an attitude which is very bad that we have” (woman from Zambia)<sup>10</sup>*

Because of the patriarchal nature of black African communities, women are more likely to experience stigma and discrimination from their own community, particularly because the gender factor contributes to discrimination that men would not face because of prevailing cultural attitudes in their country of origin.

Women might be exposed to harassment, vilification or be refused access to some of the local services or shops, or community activities. They might also end up being isolated, ostracised and shunned by husbands, friends and family:



Photograph Courtesy AHPN

*“Like people from back home, they can make you die when the time is not yet” (woman from Cameroon)<sup>11</sup>*

*“I was chucked out of the house. Well, we just differed, because she kept on — even the cup, she’d mark it, this is the cup you should use, she would just put them in a separate corner” (woman from Zambia)<sup>12</sup>*

Because of the fear of stigma and discrimination, black African women may decide not to disclose their HIV status. Very often, HIV stigma alone will lead to them hiding their medical condition.

For women involved in sex work, HIV will add further stigma to that of being associated with their activity. They are very likely to hide their HIV status for fear of being judged, blamed or even losing their job if their pimp “fires” them.

Societal racism, as well as racism within the sex business places black women in vulnerable situations. But the effects of prejudices are multiplied for those marginalised as women of colour and as prostitutes. As sex workers, black African women are both isolated from the mainstream of society and from their own community.

Stigma and discrimination also happen within society with black African women being discriminated against on grounds of sex, race and HIV — known or presumed — status (i.e. multiple discrimination).

In most areas, HIV stigma and discrimination adds to the existing societal discrimination faced by black African women on grounds of their race and gender.

A working paper published by the Equal Opportunities Commission (EOC)<sup>13</sup> revealed the extent of stereotypical, “racialised” and cultural assumptions about black and minority ethnic women in relation to access to health care. Many women were dismissed by professionals as a nuisance and hard to please. The women’s difference in terms of cultural practices, language and diet were also seen as a problem.

Because of their HIV status, HIV-positive black African women are exposed to

“gendered racialisation” of health and may not receive adequate and appropriate level of care and be most exposed to stigma from health professionals.

HIV-related discrimination against women may occur specifically in relation to pregnancy-related issues. In particular:

- Women might be tested for HIV without their consent;
- HIV-positive women might be coerced into having an abortion because they are not presented with any alternatives;
- They might be coerced into not having children; or
- They might be refused appropriate treatment and drugs to prevent antenatal HIV transmission.

HIV-positive black African women are also likely to suffer from systemic discrimination. In particular, because of their responsibilities as carers for a majority of them, HIV-positive African women’s needs are very much disregarded and they may not be able to access health care as men do. They may also lack economic resources and education, and do not always speak English. Because of those factors, they may not be given appropriate health care and support available to other HIV-positive people.<sup>14</sup>

Discrimination can also result from the failure of Government departments and agencies to address the specific needs of black African women. Some of the Government’s asylum and immigration policies indirectly discriminate against HIV-positive African women. For example, there is a national policy offering all pregnant women an HIV test via ante-natal screening, but it has been reported that some PCTs have failed to provide treatments to prevent onward transmission of HIV from mother to child because of the unclear immigration status of the mothers concerned. There have also been reports that the National Asylum Support Service sometimes penalises pregnant asylum seekers by not giving them milk tokens forcing some HIV-positive women to breast-feed their babies. Similarly, detention has a detrimental impact on pregnant asylum seekers, especially HIV-positive women, by depriving them of food and adequate pregnancy-related health care,

as well as exposing them to communicable diseases. The All Party-Parliamentary Group on AIDS' report on migration and HIV<sup>15</sup> mentions that in some cases, the effect of the dispersal policy on pregnant women has led to children being born HIV-positive.

### **Impact of HIV-related stigma and discrimination**

The impact of HIV-related stigma and discrimination, either felt or enacted, is far-reaching. It can have detrimental consequences on a person's ability to cope with HIV. In particular, the stress and secrecy about HIV status often lead to social isolation and has a negative impact on the person's psychological health.

HIV-related stigma and discrimination can also prevent women from coming forward for HIV-testing or accessing HIV treatment and pregnancy-related care and services. As a result, HIV-positive pregnant women might pass on the virus to their children during pregnancy or when breast-feeding. Women may also be deterred from seeking information, education and counselling or from asking their partners to use condoms and talking to them about HIV testing.

These consequences are not specific to black African women but their impact is likely to be greater on them because of pre-existing

gender- and race-related factors (e.g. economic, educational, cultural and social disadvantages) as well as cultural-based differences:

*'My husband didn't want me to get the information, he didn't want anything to do with HIV discussion. If there was a programme on the television he just wouldn't want to watch it or anything like that. There was a time where I just wanted to get out and go and have myself tested, but he discouraged me — "what is it going to help you if you go - what is the test going to do?"'. (woman from Uganda)<sup>16</sup>*

### **POSITIVE PERSPECTIVES**

NAT has commissioned Sigma to examine HIV-related stigma and discrimination faced by people living with HIV, in particular the link between HIV, racism, homophobia, and gender inequality. The research is based on focus groups and will provide invaluable data on the experiences of stigma and discrimination faced by black African women in the UK, particularly how it manifests itself and how it impacts on their lives.

**For more information, go to**  
[www.sigmaresearch.org.uk/projects28.html](http://www.sigmaresearch.org.uk/projects28.html)

**You can register for campaign news at**  
[www.areyouhivprejudiced.org](http://www.areyouhivprejudiced.org)

**Dr Delphine Valette**  
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**National AIDS Trust**

<sup>1</sup> HPA, 12th February 2004 (press release at [www.hpa.org.uk](http://www.hpa.org.uk))

<sup>2</sup> Ibid.

<sup>3</sup> Source: [http://ivillage.co.uk/health/whealth/stds/articles/0,180665\\_184157,00.html](http://ivillage.co.uk/health/whealth/stds/articles/0,180665_184157,00.html)

<sup>4</sup> HPA, "HIV and other Sexually Transmitted Infections in the United Kingdom in 2002" Annual Report, November 2003.

<sup>5</sup> Ibid.

<sup>6</sup> Report available at [http://www.womenandequalityunit.gov.uk/archive/living\\_without\\_fear/contents.html](http://www.womenandequalityunit.gov.uk/archive/living_without_fear/contents.html)

<sup>7</sup> L. Ackerman and G. W. de Klerk, "Social Factors that Make South African Women Vulnerable to HIV Infection", Health Care for Women International, 2002, Vol. 23, pp. 163–172. See also Human Rights Watch reports on sexual violence against women ([www.hrw.org](http://www.hrw.org))

<sup>8</sup> Source: Women against Rape ([www.womenagainstrape.net](http://www.womenagainstrape.net))

<sup>9</sup> See Human Rights Watch's web site ([www.hrw.org](http://www.hrw.org))

<sup>10</sup> Quoted in Prof. L. Doyal and Dr. J. Anderson, "My Heart is Loaded — African women with HIV surviving in London", THT, 2003.

<sup>11</sup> Ibid

<sup>12</sup> Ibid

<sup>13</sup> Source: [www.eoc.org.uk/cseng/research/multiple%20identify.pdf](http://www.eoc.org.uk/cseng/research/multiple%20identify.pdf)

<sup>14</sup> See "Migration and HIV: Improving Lives in Britain — An Inquiry into the Impact of the UK Nationality and Immigration System on People Living with HIV", APPGA, July 2003.

<sup>15</sup> Ibid

<sup>16</sup> THT's report, supra at 10.

## Criminalisation of HIV Transmission

Criminalisation of reckless HIV transmission has emerged as a key issue for the HIV sector in the UK. The first conviction for HIV transmission took place in Scotland in February 2001 and in the last few months there have been three convictions under English law, all of black African men (although the Court of Appeal has recently ordered a retrial of the first case). All three received extended custodial sentences.

The offence is 'grievous bodily harm' and the relevant statute is the Offences Against the Person Act 1861. These three cases are, however, the first time that this statute has been used successfully to prosecute for the transmission of a sexually transmitted disease.

NAT has produced a policy paper, available on the NAT website at [www.nat.org.uk](http://www.nat.org.uk), outlining the

reasons for concern at these developments. In summary, the complexities surrounding sexual relationships and disclosure of HIV status make the criminal law a very blunt instrument to deal with this issue, with the likelihood of unjust outcomes. Furthermore, there could well be a harmful impact on public health as fear of prosecution deters people both from testing and from candid discussion of sexual behaviour in counselling sessions.

NAT intends to work with partner organisations to develop further thinking within the HIV sector on criminalisation. A seminar to take place in late July 2004 will bring together HIV organisations, people living with HIV, lawyers and clinicians to discuss the implications of recent convictions and develop policy in this area.

## Joint Committee Report on Draft Disability Discrimination

On Wednesday 26 May, the Joint Committee on the Draft Disability Discrimination Bill published its Report.

The draft Disability Discrimination Bill was published in December 2003 following a 6-year process started in 1997 with the appointment of a task force. It sets out the Government's proposals for amending the Disability Discrimination Act 1995.

Whilst the draft bill proposed an extension of the definition of disability to include HIV (as well as cancer and multiple sclerosis) from the moment of diagnosis, it contained remaining and significant deficiencies which have been addressed by the Joint Committee, especially the lack of protection for those associated with disability or wrongly identified as disabled, and the failure to address systemic or group-based discrimination.

The Joint Committee's recommendations include the prohibition of discrimination against people associated with a disabled person — such as carer or family member — and those wrongly identified as being disabled, the removal of further exemptions, and additional powers to employment tribunals (i.e. power to order reinstatement or re-engagement of an employee and power to recommend changes to policies, procedures or practices that have been found to be discriminatory).

Finally, the Joint Committee makes a recommendation for consistency of the Bill with sex and race discrimination law.

It is hoped that the Government will respond positively to the recommendations of the Committee

and introduce a Bill that provides comprehensive protection from discrimination for disabled people, including those living with HIV.

The Joint Committee's Report is available at <http://www.publications.parliament.uk/pa/jt200304/jtselect/jtdisab/82/8202.htm>

### Biomedical Prevention of HIV: current status and future directions

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## **NAT**

THE NATIONAL AIDS TRUST (NAT) IS THE UK'S LEADING HIV AND AIDS POLICY DEVELOPMENT AND CAMPAIGNING ORGANISATION.

NAT WORKS IN THE UK AND INTERNATIONALLY TO DEVELOP AND CAMPAIGN FOR POLICIES THAT WILL PREVENT HIV TRANSMISSION, IMPROVE ACCESS TO TREATMENT, CHALLENGE HIV STIGMA AND DISCRIMINATION AND SECURE THE POLITICAL LEADERSHIP NEEDED TO EFFECTIVELY FIGHT AIDS.

## **IMPACT**

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