

# Mujeres Adelante

Daily newsletter on women's rights and HIV - Melbourne 2014

## In Focus...

Kate Griffiths-Dingani

### Is 'stepping up the pace' to non-discrimination enough?

We, the signatories and endorsers of this Declaration, affirm that non-discrimination is fundamental to an evidence-based, rights-based and gender transformative response to HIV and effective public health programmes. [Melbourne Declaration 2014]

The Melbourne Declaration for AIDS 2014 was released several weeks before the 20<sup>th</sup> annual international AIDS Conference. The document is patterned on previous manifestos produced by conferences in 2000 in Durban and 2010 in Vienna, which each tackled particular pressing problems facing the community of HIV and AIDS researchers, clinicians, and people living with and affected by HIV.

In Durban, the spotlight was South Africa's denialist HIV policy and lack of access to antiretroviral treatment; in Vienna it was on the issue of criminalisation of HIV and safe and accessible treatment for intravenous drug users and sex workers.

The Melbourne Declaration shows that most of these issues remain important problems for the international HIV community, four years later:

*We affirm that all women, men, transgender and intersex adults and children are entitled to equal rights and to equal access to HIV prevention, care and treatment information and services. The promotion of*



*gender equity is essential to HIV responses that truly meet the needs of those most affected. Additionally, people who sell or who have sold sex, and people who use, or who have used illicit drugs are entitled to the*

*same rights as everyone else, including non-discrimination and confidentiality in access to HIV care and treatment services.*

Since 2010, when the Vienna Conference adopted the slogan

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'rights here, rights now' a human rights-based framework has taken an increasingly prominent place in IAS conference themes and documents. It is clear that the long-standing advocacy for women living with HIV has helped to push 'gender equity', criminalisation and the rights of transgender people, drug users and sex workers into the mainstream agenda of IAS and AIDS 2014. But notably, while the Vienna Declaration commitment to 'rights here, rights now' promised an increased focus on the global status of women; the Melbourne declaration mentions women specifically only once.

Instead of centering women's rights as the basis for increased access and rights, 'Stepping UP' in Melbourne is framed as a matter of advancing non-discrimination for seemingly discrete categories of the most affected, conveniently ignoring that women as a marginalised global majority is a category that cuts across criminalised and discriminated groups of diverse lesbian, gay, bisexual, transgender, queer, questioning and intersex people, sex workers and injecting drug users. Without women at the centre, are we really *stepping up the pace* on rights and on treatment access? Or are we moving backward? Are women and girls getting left behind in Melbourne?

### 'Gender equity' or 'gender invisibility'...

The Melbourne Declaration points to the potential health consequences of over 80 countries with laws that criminalise lesbian, gay, bisexual, transgender, and intersex people, and demands that such laws be repealed, and be given no platform at International AIDS Society conferences and events. Likewise, the declaration targets agencies that refuse funding to agencies that work with and treat sex workers and drug users.

At the same time that new laws criminalising lesbian, gay, bisexual, transgender and intersex people have gone on the books in Uganda and several other countries, many more countries have dusted off and begun enforcing colonial-era anti-sodomy laws for much the same purpose. Meanwhile, Uganda's

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'anti-pornography' law, passed during the same parliamentary session as its anti-homosexuality bill, has gotten less attention in the international media, and goes unmentioned in the Melbourne Declaration, though its impact on the HIV epidemic may be even more dire. The law interprets pornography as:

...any representation through publication, exhibition, cinematography, indecent show, information technology or by whatever means, of a person engaged in real or stimulated explicit sexual activities or any representation of the sexual parts of a person for primary sexual excitement.

As a result, it has become a legal declaration of war against women, legitimising the public sexual assault of women, as they go about their daily business, and empowering any man to 'correct' any women he may find to be 'indecently' dressed or dressed for 'primary sexual excitement'. Reports of such assaults are numerous and growing. Such extreme legitimization of gender-based sexual violence cannot only by itself become a dangerous vector of HIV transmission, but will limit women's access to healthcare, and other necessities of life, by limiting their daily movements and normal social interaction.

### Rollback on reproductive rights

While lesbian, gay, bisexual, transgender, queer, questioning and intersex people's daily existence is being increasingly criminalised in many countries, particularly in sub-Saharan Africa and south Asia, the rollback of women's reproductive rights is a global phenomenon. Though recent Supreme Court rulings have put the spotlight on the erosion of reproductive rights in the USA in particular, the push back against women's health and autonomy goes beyond the right to contraception and abortion, and includes the right to access maternal healthcare and retain bodily autonomy against forced sterilisation.

Court rulings, new laws, inadequate austerity infrastructure, and denial of care to women in many places around the world, can only have a negative impact on recent gains in responding to HIV when women are denied access to reproductive healthcare; when women, and children are denied access to HIV testing and treatment. Amnesty International has called on five countries, including the United States to address the deteriorating state of their national maternal health.

It is encouraging that the Melbourne Declaration calls for the 'exclusion' from donor funding of agencies and organisations that discriminate on the basis of sexuality and gender; but does this include organisations that limit women's reproductive rights and autonomy?

### Criminalisation circumscribed...

Careful reading makes it clear that the 'criminalisation' referred to in the Melbourne declaration refers specifically to the 'criminalisation' of lesbian, gay, bisexual, transgender, queer, questioning and intersex peoples' lives, and calls for the decriminalisation of drug use and sex work, echoing 2010's Vienna document. For all people living with HIV, criminalisation of HIV exposure, transmission and non-disclosure remains an important barrier to care and driver of the epidemic; and for women, a law and

precedents that criminalise HIV exposure, transmission and non-disclosure can have an added negative impact.

For women living with HIV, criminalisation means increased vulnerability to domestic abuse, disincentive to treatment, disincentive to seek prenatal care, restricted access to reproductive healthcare, and increased likelihood of prosecution. It also puts children at greater risk of perinatal transmission and decreases access to care.

Awareness of the intersections of gender, socio-economic status and the criminalisation of HIV exposure, transmission and non-disclosure is gaining ground in the international HIV community, but the concern remains side-lined in the Melbourne Declaration.

**Beyond non-discrimination: Research for women's health and rights**

The HIV epidemic is taking place in a global landscape of increasing austerity in healthcare and a world-wide assault on

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women's economic status, legal rights and access. To go beyond 'tolerance' and 'non-discrimination' on the basis of sexuality and gender identity, more than exclusion of discriminatory providers is required. Instead, investment in research and programmes rooted in the lived experience of women, and particularly women living with HIV, can strengthen the social, legal and economic status not only of women, but of lesbian, gay, bisexual, transgender, queer, questioning and intersex people (including women), sex workers and people who use drugs, who still face intolerance, discrimination and increased criminalisation of their daily lives.

In just one salient example, a debate will take place in this conference and beyond as to the possibilities of universal PrEP for men who have sex with men; preliminary research shows PrEP protects women, too. Where is the scientific and policy debate about risk factors for women that might justify pre-emptive antiretroviral treatment?

*Stepping up the pace* to the right to care – not simply to be free from discrimination – means putting women at the centre, not on the side-lines.

*Kate is an anthropologist and writer, who lives in Brooklyn, NY, and frequently works in South Africa.*

## News from the Global Village...

### *From criminalisation to agency... A Women's Dialogue*

Women experience violations of their rights, particularly in the context of HIV and sexual and reproductive health. These include limited access to sexual and reproductive health services; stigma, discrimination, coercion and violence within services; gender-based and sexual violence at domestic, community and institutional levels; and denial of agency to make free, informed choices about their sexual and reproductive lives, including negotiating safer sex and deciding whether or not to have children.

This interactive dialogue among leading women's rights advocates and the audience will focus on strategies to transform women's criminalisation into women's agency, and *step up the pace* to advance women's rights in the context of and the response to HIV. In particular, this session will explore:

- Who is responsible for the various ways in which women are criminalised and denied agency?
- What works to transform rhetorical commitments into concrete action for the rights of women in all their diversity? What can be learned from other movements?

- Regionally and globally, what have we gained, and where are the gaps, in forging a strong, united advocacy voice for laws, policies and practices that respect and protect women's rights?

**Moderator:** *Johanna Kehler – AIDS Legal Network, South Africa*

**Presenters:**

*Jennifer Gatsi – Namibian Women's Health Network*

*Leigh Ann van der Merwe – S.H.E. Feminist Collective of Transgender and Intersex Women in Africa*

*Mabel Bianco – FEIM, Argentina*

**Come join us and participate in *stepping up the pace* on women's agency...Now More Than Ever**

**When:** *Tuesday, 22 July 2014, 13h00 to 14h30*

**Where:** *Human Rights Networking Zone*



# Special report:

## Become our own agents of change...

Leigh Ann van der Merwe

**Very often, the voices of those who really matter are silenced. Silenced by people speaking on our behalf; silenced by people who think our experiences and views do not matter; and silenced by people who think our challenges do not have enough legitimacy to be part of the discourse. But more importantly, the voices that matter the most, those at the grassroots level, are silenced when policy makers develop, implement and evaluate policies and programmes without consulting the very same people who are meant to benefit.**

**S**outh Africa subscribes to a number of human rights commitments, and locally the Batho Pele (People First) principles. Not taking the issue far from home, the Constitution of our country is explicit in its commitment to the full enjoyment of human rights by all people. At the same time, the Constitution also commits to the promotion of traditional and cultural leadership. Culture and harmful cultural practices have been cited in a number of articles on human rights violations in South Africa. Not only do harmful cultural practices undermine gender equality, it also contributes to the risks of HIV transmission. Siqwana Ndulo (2013)

makes reference to the disjuncture between rights (human rights) committed to at one level, and the promotion of cultural rights and leadership, on another.

Post 1994, in a new democratic state, the dream of a 'free' South Africa is bashed by the disparity between the political commitment to health rights and the lived realities of the people. In 2013, S.H.E. conducted a small study on cultural circumcision among transgender women. The study highlighted, among others, the challenges and intersectionalities between cultural identity, femininity and HIV. A research participant describes the realities:

*Whether we go for cultural circumcision or not, we are still targeted for violence in our communities. We are called very bad names when we walk down the road, and we are rejected by our families if we do not undergo cultural circumcision.*

The transgender population is recognised as a 'most at risk population' for contracting and also transmitting HIV. This is an established fact documented and cited in numerous studies on HIV in key populations. Recent reports paint a picture of despair with a meta-analysis indicating that transgender women are 49% more

likely to contract HIV, than any other key population, including men who have sex with men and sex workers. With these figures in mind, we should all be concerned that there is no particular HIV programme for transgender women in South Africa.

Pervasive violence, prejudice and discrimination are recognised barriers for transgender women to access HIV and other health services. In a recent case, a transgender woman from East London, South Africa, experienced violence at a taxi rank while commuting. Incidences like these are not uncommon and exhibit the risks of transgender women in accessing health services. This is also disconcerting, because in a province such as the Eastern Cape people have to travel long distances to access ARV drugs and other health services. Community violence is part of the 'norm' for transgender people in East London and elsewhere.

In a focus group discussion for transgender women living with HIV, participants stressed a need for multi-sectoral approaches when designing HIV programmes for transgender women. The same group cited unemployment, poverty and structural discrimination as factors increasing HIV risks and vulnerabilities among transgender women. Asked about their experiences of rape and sexual violence, almost all the participants raised their hands. A participant questioned.

*How can we take our ARV drugs and adhere to them when we don't even have food?*

There are multiple layers of complexity and intersecting oppressions manifesting in the lives of transgender women. Race, class and gender are all relevant factors in determining appropriate, quality and affordable healthcare

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for transgender populations. South Africa's ever maturing democracy has not transformed enough to bridge the disparity between the rich and the poor. Many vulnerable groups of people in South Africa remain at high risk of HIV exposure and transmission, because of the disproportionate way in which colonialism and racial segregation is affecting our existence. Health policies and affirmative action aimed at addressing these inequalities shaped by the past have not translated into real actions for some groups in South Africa.

Ethnographic studies must take into account all the factors that prevent transgender women from accessing adequate and quality HIV

and gender affirming care. There also has to be a recognition that we are vulnerable and at high risk, because of the likelihood of being a sex worker; and that we are driven into sex work, for the most part, because of structural inequalities; and that structural inequalities are driven by discrimination, stigma and prejudice; and that ignorance is one of the root causes of all discrimination and prejudice.

*Nothing about us without us* is a powerful approach in building the capacity of transgender women to address the challenges by ourselves and for ourselves. There must be efforts to build the capacity of groups functioning at the grassroots level, so as to ensure

that programmes and interventions are informed by and based on the voices and experiences of transgender women. We must drive the advocacy and become our own agents of change. We need to own both the challenges and solutions, because they shape our daily realities. Finally, there must be the recognition that we know our realities, risks and needs best and, therefore we are best positioned to champion our own rights, including the right to comprehensive sexual and reproductive health.

*Leigh Ann is with S.H.E., a Feminist Collective of Transgender and Intersex Women of Africa.*

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## Women living with HIV speak out...

### Experiences and actions towards ending violence against women

Over the last decade, the interplay between gender-based violence, sexual and reproductive health and rights and women's vulnerability to HIV has become increasingly recognised by activists from the grassroots up to the global policy arena. The goals of ending the AIDS epidemic and zero tolerance to violence against women go hand-in-hand, and both demand a place in the post-2015 sustainable development agenda.

In *'Women living with HIV speak out: Experiences and actions towards ending violence against women'* women from the community come together to give an honest account of the HIV epidemic and violence against women, and provide strategic recommendations to further action in these areas.

This session will bring together women living with and affected by HIV from across regions, to discuss how violence against women can and should be addressed as an essential component of the HIV response, thus facilitating the achievement of sexual and reproductive health and rights for all women, particularly women living with HIV, at every stage of their lives.

**Moderator: Ebony Johnson** – GCWA Member

**Keynote remarks: Rebecca Matheson** – GCWA Advisory Group member, ICW Asia Pacific and Australian woman openly living with HIV

**Panellists:**

**Annie Banda** – Coalition of Women living with HIV/AIDS in Malawi

**Khartini Slamah** – Pink Triangle and GCWA Advisory Group member

**Susan Paxton** – ICW Asia Pacific

**Svetlana Moroz** – Union of Women affected by HIV in Ukraine 'Positive Women'

**Luiz Loures** – UNAIDS, Deputy Executive Director of Programmes, UNAIDS

**When:** Monday, 22 July 2014, 10h00 to 11h30

**Where:** IAC Melbourne UNAIDS Meeting Room 1

## In my opinion...

Nelago Amadhila

# Hailed as a milestone in Africa...

**The African Commission on Human and Peoples' Rights (the African Commission) adopted a Resolution on Protection Against Violence and Other Human Rights Violations Against Persons on The Basis of Their Real or Imputed Sexual Orientation or Gender Identity (SOGI) at the 55<sup>th</sup> Ordinary session of the Commission held in Luanda, Angola from 28<sup>th</sup> April to 12 May 2014.**

The African Commission resolution is part of a steady development of international and regional human rights instruments re-affirming that all human beings enjoy equal rights, despite their sexual orientation or gender identity. In June 2014, the General Assembly of the Organisation of American States (OAS) adopted a Resolution which condemns violence and discrimination against lesbian, gay, bisexual, transgender and intersex people. In May 2014 the United Nations agencies issued an interagency statement on 'Eliminating forced, coercive and otherwise involuntary sterilisation', which supports the rights of transgender and intersex people not to be subjected to forced sterilisation in May 2014.

The adoption of the African Commission Resolution, which condemns the increasing violence and other human rights violations of persons on the basis of their

sexual orientation or gender identity, can be considered to be a significant achievement for SOGI rights on a continent rife with increasing incidents of violence, murder, rape assault, arbitrary imprisonment and other forms of persecution against lesbian, gay, bisexual, transgender and intersex people.

Despite the fact that the Resolution is not binding on African states, it expresses an acknowledgment and confirmation of Articles 2 and 4 of the African Charter on Human Rights that every human being shall be entitled to the enjoyment of the rights and freedoms recognised and guaranteed in the African Charter, such as sexual orientation and gender identity, and that each individual shall be entitled to respect of their life and the integrity of their person, despite their sexual orientation or gender identity. More specifically, the resolution re-iterates that the rights enshrined in the African Charter extend to lesbian, gay, bisexual, transgender and intersex people on the continent. It further expresses a position on incidences of violence and human rights violations and abuses by State and non-State actors targeting human rights civil society organisations, who work on sexual orientation and gender equality issues.

Although the Resolution can be hailed as a milestone in Africa, the legal environment continues to be riddled with barriers. States continue to consider and

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...the momentum and vigour which preceded the adoption of the resolution should not be diminished...

adopt legislation that specifically criminalises homosexuality, for example in Uganda and Nigeria, or apply existing criminal law, such as colonial sodomy laws, to persecute lesbian, gay, bisexual, transgender and intersex people as seen in Zambia and Malawi. Such legislation also extends to violating other rights, such as access to healthcare services and also impedes public health strategies, such as HIV prevention. Uganda's Anti-Homosexuality Act, for example, has proven to act as a barrier for lesbian, gay, bisexual, transgender and intersex people to access services because of fear of prosecution. It also makes it a criminal offence to provide services to lesbian, gay, bisexual, transgender, and intersex people, therefore healthcare workers are also less inclined to offer health services out of fear of prosecution.

Moving forward, the momentum and vigour which preceded the adoption of the resolution should not be diminished. It is imperative that civil society organisations now use this resolution as an advocacy tool to create a legally enabling environment for lesbian, gay, bisexual, transgender, and intersex people on the continent and work together with the African Commission to hold states accountable for their obligations under the African Charter.

*Nelago is with ARASA.*

## News from the *margins*...

### Queer Resistance...

A roundtable discussion on global LGBTI rights

This session will explore the many ways in which the increasing attacks on the rights of lesbian, gay, bisexual, transgender and intersex people are currently manifesting in various contexts. Participants and panellists will discuss challenges defending LGBTI rights, especially in hostile 'hot spots' around the world.

Key topics for the discussion will include:

**The provision of sexual and reproductive health services to LGBTI in these environments**

**How activists can use courts and human rights mechanisms to challenge anti-LGBTI laws**

**How to build international solidarity**

**Moderator:** Patrick Eba – UNAIDS

**Panellists:**

**Maurice Tomlinson** – LGBTI Aware Caribbean

**Syinat Sultanalieva** – Labrys Kyrgyzstan

**Mauro Cabral** – Global Action for Trans\* Equality

**Gennady Roshchupkin** – Eurasian Coalition on Male Health

**Geoffrey Ogwaro** – Civil Society Coalition on Human Rights and Constitutional Law (Uganda)

Come join us in this discussion.

**When:** Tuesday, 23 July 2014, 11h00 to 12h30

**Where:** Human Rights Networking Zone

## News from the Global Village...

### HIV and Human Rights in Southern and East Africa...

Is the law helping or hindering the response to HIV and AIDS? The AIDS & Rights Alliance for Southern Africa (ARASA) will be launching the latest report on HIV and human rights in Southern and East Africa at AIDS 2014.

The report examines the legal and regulatory frameworks for responding to HIV and AIDS in 18 countries in Southern and East Africa in order to determine whether:

1. Laws, regulations and policies protect and promote the rights of all people, including key populations in the context of HIV and AIDS; and
2. Populations are aware of their rights, are able to access justice and are able to enforce their rights in the context of HIV and AIDS.

The report identifies significant national and regional findings and developments in creating enabling legal and regulatory frameworks for key and emerging human rights issues; provides country snapshots for 18 countries with information on universal access and human rights, and makes recommendations for advancing human rights and achieving universal access (which are based largely on the recommendations of the Global Commission on HIV and the Law).

**The Honourable Michael Kirby, retired Australian High Court Judge, will deliver the keynote address.**

**Come join us for the launch of the report!**

**When:** Tuesday 23 July 2013, 15h00 to 15h30

**Where:** Human Rights Networking Zone

# In Focus...

## From Criminalisation to Agency... and other stories

Women in all of our diversity, especially women living with HIV, young women, women who do sex work, women who use drugs, and women in same sex relationships, have and continue to experience violations of our rights, particularly in the context of sexual and reproductive health.

Despite advances made in many areas, these continue to manifest, amongst other things, as: limited access to sexual and reproductive health services; stigma, discrimination, coercion and violence within services; gender-based and sexual violence at the domestic, community and institutional level; inability to negotiate safer sex, including condom use, and enact fertility intentions; and, exclusion from the spaces where decisions are made which affect our lives, especially in relation to our sexuality and our fertility. From the moment we are born, until the moment we die (and especially the closer we are to either end of the spectrum) decisions are being made 'for us', but without our informed and meaningful engagement. These rights violations are sustained by societal norms and values, which seek to control and 'contain' women's sexuality and limit women's agency; societal and political structures, which limit



women's access to and control of resources; and, laws and policies which explicitly criminalise women on the basis of their sero-status, sexual practices, work, and lifestyles.

Fundamental to bringing about a shift from criminalisation to agency is the need for spaces in which women in all of our diversity – and in particular aspects of our diversity – can meet, exchange experiences, and break the silence of isolation and the belief that 'bad things happen' – to us, as individuals – because we have done something wrong, transgressed, been 'other'. This transformation begins with the telling (and hearing) of stories, making sense of and finding patterns and meanings within events that may seem either chaotic and unconnected, or deliberate and targeted. The need to tell stories is universal; it's hard-wired into us as human beings, and everyone has stories to tell. All we need to release them is someone to listen.

*I will tell you something about stories ... They aren't just entertainment ... They are all*

*we have...to fight off illness and death. You don't have anything if you don't have the stories.*

[Leslie Marmon Silko, *Epigraph to Ceremony*, 1977]

The Women's Networking Zone has its roots at the 15<sup>th</sup> International AIDS Conference in Durban, in 2000. Here, there were no spaces for women from the local community to tell their stories amongst the high level speakers, the global policy makers, the technical bureaucrats, the programme implementers, the drugs manufacturers, the media, and the 'Aidserati' of the activist movements, who could afford, or leverage funding, to participate in the conference proper. The space created itself, in the form of a parallel community conference ... what would become the Global Village, and within that 'Women at Durban' sowed the seeds for the subsequent Women's Networking Zone, convened for the first time under this banner at Toronto, 2006.

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The Women's Networking Zone is essentially a story-telling space. It offers a platform to women whose stories are not or have not been heard on the main stage, or in the plenary sessions; who do not cut the ice in the selection of abstracts, because stories still do not constitute evidence in the eyes of the academics and researchers who sit on selection committees. But stories are sometimes all we have, and they provide a springboard to collective visions, joined-up actions, partnerships, innovations and change.



Stories have been the corner-stone of action to address one of the most egregious human rights violations affecting women living with HIV: the coerced or forced sterilisation of women living with HIV without their informed consent. The telling of stories in a dedicated women's space (the 'Young Women's Dialogue', a space created by ICW in Namibia in 2006), underpinned a lengthy process of investigation, documentation and advocacy which culminated in a court process in which it was recognised that the claimants' consent had not been appropriately obtained before they underwent sterilisation procedures. More than this, this process put the issue of coerced and forced sterilisation on the global policy agenda, and contributed to both a broader and more inclusive understanding of both violence against women living with HIV, and sexual and reproductive health and rights.

*Violence against positive women in any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.* [MariJo Vazquez & Fiona Hale, *Violence against women living with HIV/AIDS: A background paper*, 2011]

Storytelling, and the ability to hear one another's stories, is and *must be* at the heart of women's advocacy and leadership, yet the spaces for telling our stories are constantly under threat (and closing), due to lack of funding for women's networks, and spaces for dialogue, be they virtual or physical, though examples of the need for and ultimate 'success' of such spaces – in

## WNZ@AIDS2014: 'Stepping Up'

The WNZ programme will be arranged around the following daily themes:

- Monday:** Access to ART and Health Services
- Tuesday:** Sexual and Reproductive Health and Rights
- Wednesday:** Discrimination and Violence
- Thursday:** Criminalisation and Justice

A full programme of related sessions, will explore these themes, showcase the work spearheaded by women – including young women – living with HIV, and from key affected populations, and engage key stakeholders and thought leaders in critical dialogue.

A daily (11h00) Community Dialogue led by women living with HIV will kick-start the programme unpacking and debating the theme for each day, and an early evening session 'Let's talk about it at the Zone'\* led by ATHENA Network will provide a chance for debriefing, downloading and reflection over a cup of tea, at the end of the day's conferencing.

\* 'Let's Talk about it at the Zone' will take place on Monday, Wednesday and Thursday at 17h00.

harnessing energy and catalysing change – abound. Networks of women living with HIV, including the European Network (WECARE+), the UK Network (PozFem), and the Cameroonian Network of Women Living with HIV (CCAF+), are currently inactive due to lack of funding, to name but three. And those networks and spaces that remain universally rely on the voluntarism and personal commitment of their staff and members creating stress and burnout. But without funding to sustain our spaces, how are we to move towards agency?

*Funds for these programmes, whether women's rights, LGBTI rights, sex worker rights or rights for people who use drugs, are key to ending gender-based violence and HIV. Lack of funding is a gross human rights violation.* [Alice Welbourn, *The gender politics of funding women's human rights defenders*, openDemocracy, December 2012]

The Women's Networking Zone (WNZ) also provides an opportunity for the 'testimonies of ordinary women' to be heard by policy makers, technical agencies and donors, and for these actors to engage in critical, solution-oriented dialogues with women in all our diversity. One such critical dialogue taking place in the WNZ this week will be among women living with HIV, women's rights and gender advocates, and representatives of the senior leadership team of the Global Fund for AIDS, Tuberculosis and Malaria, regarding the implementation of the Global Fund's Gender and Sexual Orientation and Gender Identity Strategies.

Yet, the WNZ itself faces a greater challenge to raise adequate funding for its installation from conference to conference, and relies on the goodwill, energy, creativity and resources of more and more volunteers, despite a growing demand by an ever broader constituency for its use and continuation.<sup>1</sup>

But during AIDS 2014, the WNZ will provide an opportunity for storytelling, exchange, learning and dialogue; an opportunity to bring those frequently left on the margins to the centre; an opportunity to 'push the envelope' and move ourselves, sometimes in sweeping strides, sometimes inch by uncomfortable inch, from criminalisation to agency...

### Footnote:

1. The WNZ lives to see another conference thanks to the tireless efforts of the Australian coordinating team, Straight Arrows, Positive Women Victoria, Women from Asia-Pacific Plus, and ICW Global, and generous donations from the Global Coalition on Women and AIDS/UNAIDS, UNDP, UN Women and others.

*Luisa is an independent consultant and a women's rights advocate*

...without funding to sustain our spaces, how are we to move towards agency?...

## Women's Voices... On conference expectations...

### Emily Bass, USA

Every aspect of prevention is gendered – whether it is voluntary medical male circumcision, where women play a key role in decision-making, wound care, communicating and negotiation with partners; PrEP using oral Tenofovir-based drugs (the first potentially woman-initiated prevention strategy since the female condom;) or treatment as prevention, which can mean vastly different things in terms of the responsibility for prevention for men and women in sero-discordant relationships.

What I would love to see from Melbourne and from the global response in general, is that the gendered nature of these strategies and other possible additions, like microbicides, finally ends-up front and center. We can't keep talking about the beginning of the end of AIDS, without talking about what high impact prevention means for women. And of course, this means placing women at the center of the conversation – leading dialogues, designing strategies, delivering the messages.

### Kate Montecarlo Cordova, Philippines

I am very optimistic and positive that the AIDS 2014 Conference will open a wide path to understanding the different women's rights, health and needs. Women should not just be defined by what is between their legs.

I am hoping that health and HIV advocacy will open its doors to the concept that people have different sexual orientation, regardless of their assigned sex at birth or gender identity and expression and that, their bio-psychosocial health needs are essential to their well-being, so this should be treated separately.

Right interventions provided for people's respective health issues is a basic human right.

### Claudia Ahumada, Chile

My hope is that this International AIDS Conference will be a space for advocates to re-energise and come together, to show the world that we know how to do things differently to truly achieve change, to take forward and scale-up effective HIV responses, which are rights-based and gender transformative..

### Susana Fried, USA

Holding the meeting in Melbourne will be an opportunity to highlight HIV issues in Asia and the Pacific – especially the key issues of the gender dimensions of HIV in the region's predominantly concentrated epidemics.

One excellent outcome would be stronger communication and collaboration between networks of key HIV affected populations, networks of women affected by HIV, women's health and rights organisations, and organisations focusing on TB amongst marginalised groups.

Recognising that these are not mutually exclusive categories, could, perhaps, result in vastly stronger advocacy, vastly more effective HIV responses, and vastly decreased internal conflict for those who stand with feet in more than one affected community.

It could, indeed, help us to '*step up the pace*' toward a human rights and gender equality affirming HIV response.

## Regional Voices... On conference expectations...

### Jennifer Gatsi, Namibia

I hope that the 2014 AIDS Conference will provide a platform to share experiences and innovations not only from scholars of various fields, but also from community members and organisations who will be able to use this opportunity to also contribute their opinions to the global HIV and AIDS response. Above all, it is crucial to invest in the meaningful involvement of communities in dealing with the epidemic's impact on the grassroots levels, and I look forward to seeing this implemented within and beyond the conference walls.

While the importance of treating the social determinants of HIV and AIDS have been increasingly recognised, I also look forward to a scaling-up of support from civil society and national stakeholders in addressing gender equity, women's empowerment, food security, and rural areas as factors that impact, and are impacted by, the HIV and AIDS epidemics.

### Lillian Mworeko, Uganda

What we need, and what I expect from AIDS 2014 are *strategies to respond to governments that embrace harmful, human rights violating, and discriminatory laws and policies that directly undermine the response to HIV and impact on women*. The International Community of Women Living with HIV and AIDS Eastern Africa (ICWEA) has been battling with the Uganda's HIV and AIDS Prevention and Management Bill 2014, which has provisions for mandatory HIV testing, mandatory HIV status disclosure, attempted transmission and intentional transmission of HIV, which heavily impact on women, men, young people and children disproportionately, with the greatest impact on women and girls.

We need *strategies to facilitate access to justice, and the safety of frontline human rights activists*. The outrageous trial of the HIV positive nurse Rosemary Namubiru, accused of 'criminal negligence' in the workplace, when a patient in her care was accidentally exposed to her blood, and whose HIV positive status meant she never got a chance to a fair hearing or a presumption of innocence. She did not have a lawyer at the beginning, and even the life of frontline advocates was at risk.

### Mmapaseka Steve Letsike, South Africa

The AIDS Conference 2014 has to make sense!

The International AIDS Conference in Melbourne, AIDS 2014, is a biennial gathering for those working in the field of HIV, including policy makers, people living with and affected by HIV, and other individuals committed to ending the multiple pandemics. However, too many times, conferences like these speak about best practices, best models, guidelines and what needs to be done, while the message should be reaching the policy makers and implementers at a national and regional level.

We are nearing our 4<sup>th</sup> decade in the time of AIDS – and hence, we cannot still be talking about whether or not we should commit and/or take actions. Instead, fundamental criteria of our responses should be ensuring that *'no one is left behind'*.

The upcoming AIDS Conference should not only be seen as the re-union of those in the field, but should be seen as another chance to make it work. We have to get to *Zero* new infections, *Zero* AIDS-related deaths, *Zero* discrimination and *Zero* gender based violence. We need to end the *'struggles'*, and start ensuring that communities have access to competent and quality health services.

### Michaela Clayton, Namibia

The conference theme for AIDS 2014, *Stepping up the Pace*, reminds us that although substantial gains have been made in cure and vaccine research, and we are seeing growing numbers of people receiving antiretroviral treatment and falling rates of infection, progress in the AIDS response has not been universal. Widespread and often state-sponsored violations of the fundamental human rights to equality, dignity and freedom from discrimination have directly contributed to the fact that sex workers, LGBTI, people who inject drugs and many others are being left behind. This situation is being exacerbated by a lack of political will on the part of many governments to remove the repressive laws and policies that fuel these violations, which in turn present major barriers to access to prevention and treatment services for all who need them.

We hope that AIDS 2014 provides an opportunity to finally drive the message home to policy decision-makers around the world that what we need to leave behind is moral judgement and personal and religious prejudices – not people.

## Women's Voices...

Ebony Johnson

# Positive change is limitless...

*I will no longer be silent, and we together will no longer be neutral. We will no longer say we are doing enough. Our aim for post 2015 should be clear and uncompromising. Zero compromise for violence against women and zero tolerance for discrimination against women affected by HIV.*

[Michel Sidibe, UNAIDS Executive Director, CSW 2014]

Nor shall we be silent! With our fingers clasped together as we stand side by side unified and resolute on change. Together we have joined from many places across the globe connected by one spirit. A spirit of revolution... A spirit of justice and a spirit that knows that positive change is limitless. In these moments, we join now here in Melbourne, as we have joined in WNZ's across the globe hungry, tenacious and championing for the health, rights and full lives of women and girls. In many tongues we cry out, '*Todos los derechos de todas las mujeres*', '*Amandla Awethu*', '*Includere le donne nella ricerca*', and we are more than wives and mothers – we are women and girls and our lives matter!

The WNZ creates a safe, vibrant and energised advocacy space for women and girls from every spectrum to stand-up, speak-out

and create change. Birthed as a way to connect women to the International AIDS Conferences, the WNZ has grown into a global space for women's organising, empowerment and unity that is utilised by thousands of women world-wide.

Looking back to 2008 in Mexico, the WNZ gave a platform to a brave group of women living with HIV from Namibia. With courage, tenacity and resolve for change, they shared their accounts of being forcefully sterilised. They spoke of the atrocities and injustices reinforced by patriarchy, punitive laws and medical negligence that dared to rob them of their choice, strip them of their right to motherhood, and unravel the very fabric of their womanhood. As these brave few spoke, it was immediately clear that in the spirit of the WNZ, they had not spoken as victims, but rather to rally women to victory. This was the beginning of a ground-swell. Women world-wide heard their call and with a small seed planted, the women of Namibia and women world-wide, became united in a mission to ensure that all women living with HIV are informed and empowered about their options to have healthy HIV negative babies, holding the medical community accountable to follow science, about harmful cultural norms and

personal beliefs that oppose sound science, repeal inhumane and medically unjust laws and practices that have fuelled forced and coerced sterilisation and hold governments accountable to upholding the health and human rights of women living with HIV. From seeds planted by few to the outcry of many...from the WNZ to the Namibian High Court and the halls of the United Nations, change has taken root and forced and coerced sterilisation shall no longer be ignored or accepted.

*Sterilization should only be provided with the full, free and informed consent of the individual.*

[OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO Interagency Statement, May 2014]

*Women living with HIV demand our fundamental human rights and reclaim our right to motherhood and to make informed choices about our reproductive health.*

[ICW Global, CSW March 2014]

In 2010 in Vienna, women, mothers, leaders, advocates joined at the WNZ from every corner of the globe. Here we stood in thanksgiving as the CAPRISA Microbicide trial results were announced, the emergence of a revolutionary new prevention tool for women with unlimited possibility. Together in the WNZ, we advocated for medication for women living with HIV beyond prenatal care, we called for women to be included in the laws, policies and practices that impact on our lives, and spoke-out for sexual and reproductive health and rights for women who perform sex work, use drugs, and all those from communities who are too often underserving or simply forgotten. Through dialogues, roundtables and panel discussions

...atrocities  
and injustices  
reinforced by  
patriarchy, punitive  
laws and medical  
negligence...

we unpacked the issues core to advancing women's health, safety and rights. We took to the streets of Vienna moved by the sounds of Annie Lennox, fuelled by our determination for equality. So we marched...marching for change... marching for our lives!

*We know that equality for women means progress for all.*

**[Phumzile Mlambo-Ngcuka,  
UN Women Executive Director,  
CSW 2014]**

In 2011, the WNZ had taken flight beyond the confines of the International AIDS Conference destined to expand this dynamic forum with a mission to increase the visibility, advocacy and action to health and human rights of women and girls. With this came an invigorated focus on young women. First stop was the 6<sup>th</sup> IAS Conference on HIV Pathogenesis, Treatment and Prevention in Rome. HIV and sexual and reproductive health and rights advocates, researchers, political leaders and UN officials assembled daily in the WNZ to provide interactive dialogues, mentorship and trainings for emerging young leaders from across the globe. The WNZ became a virtual school without walls building the literacy and capacity of young women on everything from Microbicides and treatment as prevention to

informed decision-making to grassroots advocacy. In 2011, the next stop was Addis Ababa with again the WNZ being the place for creative ingenuity for advocacy and beaming bright eyed young women learning about their bodies over traditional tea ceremonies and calling for an end to violence.

*We believe that no one should be left behind, so we must deal with the challenges that women and girls face...If we go this way we will make more gains than ever before.*

**[Nana Oye Lithur, Ghana Minister of Gender, CSW 2014]**

In 2012, women and girls, mothers and daughters, advocates and activists made the WNZ come alive in Washington, D.C. at the IAC. The WNZ provided a multi-faceted conference within a conference. Presidents, HIV leaders, dignitaries made themselves at home alongside rising young leaders and seasoned change-makers; together calling for women's rights, an end to violence against women, inclusion of women in research, and education for girls. Innovative sessions highlighted best practices in sexual and reproductive health, and tools for organising and impact. New partnerships were formed and new pathways to advocacy were built continuing the legacy of the WNZ.

**...dynamic forum  
with a mission  
to increase the  
visibility, advocacy  
and action to  
health and human  
rights of women  
and girls...**

In 2013, the WNZ took regional focus at ICAAP in Bangkok and at ICASA in Cape Town. During ICAAP, the WNZ brought together women from across Asia and the Pacific. For many women this was one of the few treasured safe spaces to talk about the complexities of sex work, reproductive health, living with HIV, supporting women who use drugs, or even rights. In Cape Town, young women leaders took the helm at the WNZ with bold sessions addressing violence, lesbian health, education, leadership, organising

and HIV criminalisation. The WNZ at ICASA gave young women from across Africa a place to stand-up, speak-out and fuse together to vision new healthier realities for African women and girls.

*As a leader this was my first time in a conference and my first time to stand up and speak. It was great to speak on the issues of rape and discrimination for lesbians and our children. Lesbians are not safe in South Africa. I took a STAND! I felt so good...*

**[Young woman, South Africa, ICASA 2013]**

As the sun rises on the WNZ in Melbourne for IAC 2014, we will dare to be declarative, determined and united as women to build on our successes, be clear of our asks, and move toward a post-2015 agenda that puts the health and rights of women and girls front and centre. Be a part of creating change...

*Ebony is with the Athena Network.*

## UPCOMING EVENTS

### Sunday, 20 July

**09:00-11:00** *A health systems strengthening (HSS) approach towards elimination of new infections among children and keeping mothers alive: A Zimbabwe experience*  
Room 109-110 [Non-Commercial Satellite]

**11:15-13:15** *Gender and sexual and reproductive health and rights in the Post-2015 Framework*  
Room 203-204 [Non-Commercial Satellite]

*Stepping up to advance issues globally for sex workers and HIV*  
Room 101-102 [Non-Commercial Satellite]

**13:30-15:30** *Intersecting risks, strategies and barriers for key affected populations to prevent and treat HIV: How to step up the global gender pace*  
Clarendon Auditorium [Non-Commercial Satellite]

**18:50-20:30** *Plenary: Opening Session*  
Plenary 2

### Monday, 21 July

**07:00-08:00** *By women for women. Harm reduction among women who inject drugs*  
Room 203-204 [Non-Commercial Satellite]

**07:00-08:30** *The impact of HIV funding on Trans\* communities: Keeping human rights central to the HIV response*  
Room 101-102 [Non-Commercial Satellite]

**08:20-10:30** *Plenary: Where are we now?*  
Plenary 2

**11:00-12:00** *Community Dialogue: Access to ART and services*  
Women's Networking Zone, Global Village

**11:00-12:30** *Criminalisation of key populations: How to respond to HIV?*  
Melbourne Room 2 [Symposia Session]

*Upholding the rights of women and girls living with HIV in healthcare contexts*  
Room 103 [Community Skills Development Workshop]

**12:50-13:50** *Pushing the envelope: Gender, equality and rights – getting it right for key affected women*  
Women's Networking Zone, Global Village

**13:00-14:00** *No One Left Behind: Stepping up the pace on the removal of punitive laws to advance human rights and gender equality*  
Melbourne Room 1 [Special Session]

*Shedding light on social protection responses*  
Room 103 [Oral Poster Session]

*The social and cultural context of risk and prevention*  
Room 105-106 [Oral Poster Session]

*Antiretroviral therapy in pregnancy: A brighter future*  
Room 109-110 [Oral Poster Session]

**14:30-15:30** *Positively fabulous+ women's voices: Feature Documentary*  
Clarendon Room C, Global Village

**14:30-16:30** *Living, loving, working: HIV and sex work*  
Plenary 3 [Oral Abstract Session]

**14:30-17:30** *HIV, gender-based violence and sexual health – men, women and transgender: How to bring these intersecting and interlinked issues into the Post-2015 Agenda*  
Room 103 [Leadership & Accountability Development Workshop]

*Using the law to defend human rights in the HIV epidemic: Courts in action*  
Room 109-110 [Leadership & Accountability Development Workshop]

**16:30-18:00** *A roadmap for women's rights*  
Clarendon Auditorium [Symposia Session]

*Rape stories that rural community grassroots women never tell*  
Community Dialogue Room, Global Village

**18:30-20:30** *Women, HIV/AIDS and non-communicable diseases: A Call to Action in lower and middle income countries*  
Plenary 3 [Non-Commercial Satellite]

*The Second Robert Carr Memorial Lecture: Celebrating Robert Carr's legacy*  
Clarendon Room D&E [Non-Commercial Satellite]

*Validating the elimination of mother-to-child transmission has been achieved: Global criteria and current status*  
Room 101-102 [Non-Commercial Satellite]

### Tuesday, 22 July

**08:20-10:30** *Plenary: What's holding us back and how do we move faster?*  
Plenary 2

**11:00-12:00** *Community Dialogue: Sexual and reproductive health and rights*  
Women's Networking Zone, Global Village

**11:00-12:30** *Sexier than you think: HIV policy, regulation and legislation*  
Plenary 3 [Oral Abstract Session]

*Women drugs users: Our voices, our lives, our health*  
Clarendon Auditorium [Symposia Session]

*Criminalising condoms: Sex workers and HIV services at risk*  
Room 109-110 [Community Skills Development Workshop]

**12:00-12:45** *Rights, Camera, Action! The pregnancy journey when you are living with HIV*  
Women's Networking Zone, Global Village

**13:00-14:00** *Sex Workers: Gaps in prevention and care*  
Room 109-110 [Oral Poster Discussion Session]

*Public health and human rights: How to support both in the context of HIV, women and motherhood*  
Community Dialogue Space, Global Village

**13:35-15:00** *Strengthening partnerships for advancing the SRHR of women and girls living with HIV*  
Women's Networking Zone, Global Village

**14:30-16:00** *Critical justice: Human rights, legal issues and HIV*  
Plenary 2 [Oral Abstract Session]

*When science meets the bedroom: 50 shades of pleasure and prevention*  
Clarendon Auditorium [Bridging Session]

**14:30-17:30** *From within: Understanding and addressing self-stigma among people living with HIV*  
Room 104 [Community Skills Development Workshop]

**16:30-18:00** *Stigma: Contexts, intersections and responses*  
Plenary 2 [Oral Abstract Session]

*Improving advocacy for respectful maternity care and the reproductive rights of women with HIV*  
Clarendon Room D&E, Global Village [Workshop]

# Women's Realities...

Sally-Jean Shackleton

## Challenged to make real progress

**Sex workers will be at AIDS 2014 this year, in the hopes of shifting paper commitments to address sex workers as 'key populations' to real and tangible access to services, as well as a shift in legal contexts, which are a barrier to both service access and addressing stigma.**

In many cases, state-sanctioned violence against sex workers is systemic, and sex workers have no recourse if they are exploited or abused by clients, their partners or community members. In many cases, even where selling sex is not criminalised, law enforcement officials still arrest sex workers (Zimbabwe is an example). In other spaces, like Kenya, municipal authorities are considering further sanctions against sex work, in spite of progress in the health sector acknowledging sex workers as vulnerable.

Those in power, distracted by an ideological debate, forget their responsibilities in favour of endless discussions that often fail to involve sex workers (let alone, be led by them) and focus on stereotypical, essentialist and simplistic versions of what sex work is, and who sex workers are. Framing sex workers

as either victims OR agents fails to acknowledge the complex and fraught every-day decisions that women, transgender women and men make. Even in this framing, sex workers themselves are left out, invisibilised and marginalised – and rendered characters in a drama of extremes (Somaly Mam being a recent example.)

In reality, sex workers are on the front lines of battles where gender, poverty, sexual identities, race and class intersect. With most countries across the world preferring to deal with easy wins (South Africa's Women's Equality and Gender Equity Bill as an example) but neglecting to take a stand against the criminalisation of sex work, sex workers will continue to face enormous hurdles in accessing services and justice.

The World Health Organisation, in its soon-to-be launched (at AIDS 2014) *Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations*, recommend that countries across the world

*...work toward decriminalization of sex work and elimination of the unjust application of non-criminal laws and regulations against sex workers.*

**...left out, invisibilised and marginalised – and rendered characters in a drama of extremes...**

This is a noble goal, but few countries will take it up without significant advocacy at country level.

To achieve this, there needs to be strong sex worker led alliances, organisations and movements – and more investment in strengthening and supporting these often fledgling and threatened groups. The Red Umbrella Fund, a pioneering donor which involves sex workers directly in decision-making on grants, is a good example of progress in this regard.

We also need to diversify support – rather than supporting purely bio-medical interventions. Structural interventions that have the potential to address more holistically the challenges sex workers face, will have more rewards in the longer term than HIV testing/treatment initiatives alone. Very little of the funding available for HIV programme goes to support human rights initiatives, and fewer still, support sex workers' human rights protections.

So, as sex workers gather for a pre-conference, and create safe spaces for themselves in Melbourne, leaders, researchers, academics, institutions and policy makers will be challenged to make real progress and support change, and will be measured by their response.

*Sally is with SWEAT (Sex Worker Advocacy Task Team), South Africa.*

## In my opinion...

# Understanding the community

**A**t the international AIDS conference in Vienna in 2010, the South African research group, (CAPRISA), headed by Quarraisha and Salim Abdool Karim, presented evidence from their randomized control study, that a microbicide, based on the well-known anti-AIDS drug, Tenofovir, effectively prevented HIV infection among users. What a triumph!

After a decade of effort and disappointment, at last we had a microbicide: at last, we had a protective method for women!

### *Four years later, and what results do we have to report...?*

Unfortunately, since 2010, new research, also executed in Southern Africa, has documented the failure of a randomized control trial, directed by a US team with excellent credentials, to confirm the CAPRISA result. This finding has much delayed the roll-out of the microbicide.

We must ask whether this failure was due to the Tenofovir effect itself, or to the fact that the US researchers failed to set-up the conditions for many women to apply the microbicide?

We already knew from evidence-based adherence in the CAPRISA study that the beneficial effect achieved there depended on adequate numbers of women using the microbicide. Just as we know from comparable adherence measures in testing the preventive capability of oral use of Tenofovir that actual use determined the preventive power of Prep.

At this juncture, current observers

attribute the failed result of the US trial to a failure in appropriate usage. The US team, for instance, advised women to use a different frequency pattern for applying the microbicide, based, apparently, on an assumption that women would be more likely to remember to use the microbicide gel, if they had to do so every day. CAPRISA, on the other hand, responding to the known pattern of intercourse that was adapted to the vagaries of migrant work and other absences of partners, advised use only on the morning before intercourse and again afterwards. Were these differences in protocol responsible for differences in effect?

We would argue that this was only one part of a general failure of the researchers to facilitate responses by the women in the study. In fact, none of the expected results were shown in this trial. Prep, an oral form of Tenofovir, had been demonstrated to be an effective preventive two years later than the microbicide, and was certainly anticipated to reduce infection in this particular research. However, in this trial, oral Tenofovir also failed to have any effect.

### *Local-level community-based methods*

CAPRISA has in the meantime published carefully controlled evidence of the effects of a theory-based method of administration on microbicide usage, and, in turn, on results. Without study at the local level of the understanding and response of community women, preventive methods will fail.

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...a crucial  
reason why,  
shockingly, we  
still do not have  
a microbicide...

### *Community prevention*

If the health services are not themselves in touch and knowledgeable about the needs of local women; the trial results will be affected.

Perhaps, the success of the CAPRISA trial, in contrast with the second trial, was facilitated by the continuity of care and contact provided by many trialists in Vulindlela, the site of health and educational activities over more than a decade. Vulindlela women more often used the microbicide, and hence had better results in the trial than city women. Was this a sign of trust?

Repeated control trials, whether in similar or dissimilar sites, cannot be expected to provide a realistic model for comparison, unless the community is knowledgeable and carefully informed, the methods used with individual trialists are studied and tested, and there is familiarity and trust with investigators. Trials need to aim as far as possible to copy the original trial in these respects, which are not as easy to duplicate as is the pharmaceutical.

In this case, the failure to replicate the conditions of the original study may be a crucial reason why, shockingly, we still do not have a microbicide – four years after the original success.

*Ida is a professor of anthropology at CUNY, NY, and Zena is an epidemiologist of Columbia University.*

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