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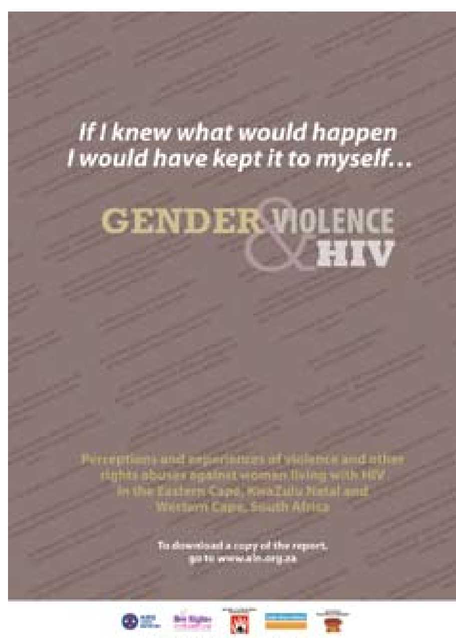
If I knew what would happen I would have kept it to myself...

Women's experiences of HIV status disclosure and its implications[1]

Johanna Kehler

With growing evidence on the effects of HIV-related violence on women's lives, the need to address the various links between gender violence and HIV has been the centre of both discourse and commitment for a long time. Yet, women's realities and risks in the context of HIV remain largely unchanged, as women continue to be most at risk of HIV exposure and transmission, as well as violence and abuse based on and in the context of HIV.



Recent findings from a new study conducted in 2012 by the AIDS Legal Network (ALN) and partners in three provinces confirmed that women are at high risk of violence and abuse as and when their HIV positive diagnosis becomes known – irrespective of their HIV disclosure being voluntary or involuntary. Nearly 2500 women and their communities from New Brighton (Eastern Cape), Illovo (KwaZulu Natal), and Tafelsig

Mujeres Adelante
A NEWSLETTER ON WOMEN'S RIGHTS AND HIV

Editorial...

Continuing the critical discourse on women's rights and HIV, this edition of the ***ALQ/Mujeres Adelante*** examines some of the persistent challenges and barriers women face in claiming their right (and agency) to '*taking control*' over their risks and vulnerabilities to HIV and violence.

The various articles in this edition explore the extent to which progress has been in the response to women's realities, risks and needs based on and in the context of HIV; and highlights some of the pervasive '*obstacles*' to women's access to and realisation of rights. Some of the issues discussed include the risks associated with women's HIV positive status disclosure in South Africa and its implications for the adequacy of the response to women, violence and HIV; the criminalisation of HIV non-disclosure and its failure to '*protect women*' in the Canadian context; the impact of violent language and narrow agendas on the realities of, and responses to, violence against women; the effectiveness of the AIDS response to '*key affected women*' in Southern Africa and Indian Ocean states; and the need for meaningful investment in women living with HIV. This edition also includes an opinion piece on categories of '*normality, respectability and value*' and the role of the '*movement*' in addressing violence against women, and violence based on sexual orientation and gender identity.

Gender violence as both a cause and consequence of HIV is well recognised. Based on latest research findings evidencing the multiple risks associated with women's HIV positive status disclosure, **Johanna Kehler** raises questions not only as to the effectiveness of the AIDS response in protecting women's human rights, but also as to the '*collective responsibility*' for the occurrence, perpetuation and

Continued on page 4

In this issue

1. **If I knew what would happen I would have kept it to myself...** **Page 1**
   Women's experiences of HIV status disclosure and its implications
   Johanna Kehler

2. **Editorial** **Page 2**

3. **No power, no protection...** **Page 14**
   The cautionary tale of the Supreme Court of Canada criminal cases involving HIV non-disclosure in the context of sexual encounters and its failure to protect women
   Louise Binder

4. **Violent language and narrow agendas...** **Page 22**
   The problem with 'corrective rape'
   Dipika Nath

5. **Silenced and forgotten...** **Page 31**
   HIV and AIDS agenda setting paper for women living with HIV, sex workers and lesbian, gay, bisexual, transgendered individuals in Southern Africa and Indian Ocean states
   OSISA

6. **Collateral damage...** **Page 45**
   On normativity, respectability, and value
   Lynn Darwich

7. **MIWA...** **Page 48**
   Meaningful **investment** *in women living with HIV and AIDS*
   Luisa Orza

8. **Campaign messages...** **Page 56**

and Beacon Valley in Mitchell's Plain (Western Cape) participated in the research.

Undoubtedly, women's experiences of HIV disclosure give evidence to the multiple forms and the continuum of abuse and violence in all aspects of their lives, perpetrated by partners, families, friends, communities and service providers alike. Violence and other rights abuses, as experienced by women living with HIV, ranged from interpersonal to structural to institutional, with women recalling incidences of being beaten, rejected, chased away from their homes, humiliated by healthcare workers for missing their clinic appointments, as well as ridiculed and further victimised when seeking redress.

…women's realities and risks in the context of HIV remain largely unchanged…

> *…although, I was ready to disclose my status, the community was not ready to accept me…*[2]

Reflecting on their experiences of violence and abuse upon HIV disclosure, including the effects of the continued violations on their health and overall well-being, some women underscored the need to be '*careful*' to whom and when to disclose one's HIV positive status, while others questioned the rightfulness of HIV disclosure given the associated risks or chose to not disclose their HIV status anymore after they moved to a different area.

> *…it is risky…you need to think carefully about disclosing and that's why I keep mine a secret…*[3]

ACCESS TO HEALTHCARE

The experiences of women living with HIV gave an account of the ill treatment, abuse and rights violations endured at clinics and hospitals, including healthcare providers' discriminatory attitudes and remarks. As such, women's accounts illustrates that accessing healthcare is but one of the elements in the continuum of abuse and rights violations against women living with HIV.

…women underscored the need to be *'careful'* to whom and when to disclose one's HIV positive status…

Women recalled numerous incidences of being shouted at and humiliated by healthcare staff for missing their appointment, without ascertaining the reasons as to why women did not come to the clinic – '*she didn't wait for an explanation, she was just rude*'[4]. However, even when women explained why

pervasiveness of abuse and violations of women living with HIV. Highlighting women's experiences of HIV disclosure as a continuum of violence by a continuum of perpetrators, and communities' lack of preparedness to '*accept*' women living with HIV '*as part of the community*', she argues that we need to '*shift*' from '*promoting HIV disclosure*' to '*promoting safe environments for HIV disclosure*' – so that women can make informed and free decisions as to whether or not, when and to whom to disclose their HIV positive status, without fear of stigma, discrimination and other forms of violence.

The adverse effects of laws criminalising HIV non-disclosure, as well as HIV exposure and transmission, especially on women, has been a key element of the human rights and HIV discourse for a long time. It is within this context that **Louise Binder** looks at the '*cautionary tale*' of the Supreme Court of Canada regarding criminal cases involving HIV non-disclosure in the context of non-disclosure and its failure to protect women. Introducing Canadian case law, she discusses the role and impact of the law on HIV-related stigma and discrimination against women, and argues that applying criminal law to prosecute HIV non-disclosure is not only '*bad public health policy*' and '*defying the logic of evidence-based science*', but also '*bad news for women*'.

The problem with the concept and understanding of '*corrective rape*' in the South African context is the focus of the article by **Dipika Nath**. Exploring the impact of '*violent language and narrow agendas*' on the occurrence and perpetuation of violence against women, as well as sexual violence against lesbians (and failure to '*respond to*' these occurrences), she argues that the language of '*corrective rape*' not only creates untenable (and unsustainable) hierarchies of various '*kinds of violence*' and their effects on survivors and victims of sexual violence and rape, and hierarchies between '*lesbian*' and '*heterosexual woman*' experiences of sexual violence and rape – but also prevents a clear understanding of the extent and foundation of '*gendered violence*'.

Despite the growing commitment at a global and regional level, '*key affected women*' in Southern Africa and Indian Ocean states continue to lack recognition, representation, participation and engagement in the AIDS response, thus manifesting their risks and vulnerabilities to HIV and subsequent rights abuses. Based on this premise, the contribution by the **Open Society Initiative for Southern Africa (OSISA)** introduces an HIV and AIDS agenda setting paper for women living with HIV, sex workers and lesbian, gay, bisexual and transgender people. The article highlights some of the persistent challenges and barriers for '*key affected women*' to access HIV and sexual and reproductive health services and rights, and argues that '*appropriate*' responses to '*key affected women*' and HIV are to be based on a wide range of '*quality evidence*', and '*mutual and meaningful partnerships*'.

Exploring some of the '*successes*' and '*setbacks*' of social justice movements in addressing gender violence (and violence based on sexual orientation and gender identity), **Lynn Darwich**

they did not honour their appointment, healthcare providers' attitudes often led to women being sent away without access to healthcare or treatment.

> *…I missed my appointment to collect my ARVs, because I had to go to work that day…when I went to the clinic three days later to get a new appointment, the nurse shouted at me to leave and come back when I don't have a job to go to…*[5]

Women's experiences of accessing healthcare also highlight the extent to which especially healthcare providers' attitudes and prejudices against women living with HIV not only limit women's access to quality healthcare free of fear, stigma and discrimination, but also deter women from accessing healthcare.

> *…you might be scared to go back to the clinic, because you are scared of what will happen to you…sometimes you end up defaulting…*[6]

The lack of assured confidentiality within healthcare provision, and risks of involuntary disclosure of women's HIV status, based on the infrastructural set-up of the clinics, as well as the separation of services – as '*that's how most people find out that you are HIV positive, when they see you at the clinic*'[7] – similarly deter women from accessing healthcare and treatment.

…dire need to re-evaluate not only the infrastructural set-up of HIV-related services, but also by whom and the manner in which these services are provided…

> *…by sitting there everyone knows that I am HIV positive…so, let me not go sit there…if they can mix us, then maybe also the death rate of people living with HIV and AIDS will be decreased…*[8]

Women's accounts point, among others, to the apparent inherent rights violations within service provision, due to the infrastructure of

raises the question as to the '*complicity*' of '*our movements*'. She discusses concepts of '*normativity, respectability and value*', the role of '*our movements*' in perpetuating and replicating '*violence*', and reasons that due to the failure to connect '*racialised, gendered and sexualised devaluations of human life*', social justice movements have, more often than not, not only '*failed to challenge systems of oppressions*', but also, to an extent, perpetuated and replicated '*violence*'.

Although the concepts of '*nothing about us without us*', and the meaningful involvement of women living with HIV (MIWA) in all aspects of the AIDS response have long been recognised, it seems that their translation into practice remains to be a '*significant challenge*'. Revisiting some of the '*spaces*' for women, and the involvement of women living with HIV, **Luisa Orza**, underscores the continuing lack of political spaces for meaningful participation and involvement of women living with HIV, and argues that women's meaningful engagement and leadership can only be realised by moving beyond '*securing a place at the table*' for women living with HIV to the '*serious and committed investment of resources*' – thus, the meaningful *investment* in women living with HIV.

The common '*thread*' in all articles seems to be that *violence* has been, still is, and will continue to be intrinsically linked to especially women's HIV realities, risks and needs – despite an ever-growing knowledge and evidence base, with an equally ever-growing commitment to recognise and address both the causes and effects of violence against women based on and in the context of HIV. At the same time, the common '*threat*' portrayed appears to be both the pervasiveness of societal contexts, '*nurturing*', '*perpetuating*' and '*condoning*' the violation of women and women's rights (and '*refusing*' women's agency), and the failure of the AIDS response to effectively respond to women and HIV, whilst ensuring the promotion, protection and advancement of women's rights based on and in the context of HIV.

Indeed given these recurring '*threats*', it seems high time to '*move*' beyond merely recognising women's realities, risks and needs to actually transforming the societal contexts defining the very same – through re-evaluating our '*concepts*' of and '*narrow approaches*' to women, violence and HIV, and to truly '*move*' from the theory of '*meaningful involvement*' of women in all aspects of the AIDS response to a practice of '*meaningful investment*' in women, so as to ensure that women are not only '*capacitated*' and '*resourced*' to meaningfully participate with, and engage in, processes affecting their lives, but also that women and women rights are at the centre of the AIDS response in '*commitment*', '*policy*', and '*practice*'. As failing to do so will continue the status quo of women's disproportionate risks and vulnerabilities to HIV exposure, transmission and related rights abuses…

JOHANNA KEHLER

healthcare centres, as well as healthcare workers' attitudes and prejudices against women living with HIV, arguably underscore the dire need to re-evaluate not only the infrastructural set-up of HIV-related services, but also by whom and the manner in which these services are provided. Moreover, as women experience access to healthcare as an element in the continuum of violence perpetrated against them, it seems pivotal to not only restructure service provision, but also to ensure that programmes and interventions, meant to '*benefit*' women living with HIV, are indeed based on and informed by their experiences of the multiple causes, forms and effects of HIV-related violence and other rights abuses in their lives.

…laden with humiliation and further abuse…

SEEKING REDRESS AND ACCESS TO JUSTICE

The research shows that women are well aware of their right to take legal actions against any person(s) for unlawful disclosure of their HIV status, and other forms of abuse, due to their HIV status. Yet, many women choose not to seek legal redress; instead they sought support from family and friends or advice from social workers and counsellors, for fear of further abuse, humiliation and HIV status disclosure, as well as reluctance to lay charges against family members.

> *…I was scared that he will beat me again…I was also scared that people will know about my HIV status…*[9]

Women who sought legal redress generally spoke about their disappointment ranging from lack of support received to inadequate investigations and insufficient sentences, as well as the risks of further HIV status disclosure and violations while pursuing legal actions. Similar to healthcare provision, women's experiences of accessing police and court services are

…inherent rights violations within service provision…

laden with humiliation and further abuse, as well as the risks of involuntary disclosure of their HIV status – the very same violations women seek justice for – as '*there is no privacy at the police station*'[10].

> *…we were told not to open a case… because she should just accept her HIV status…*[11]

…an indicator of the *'value'* of women and their safety subsequent to HIV acquisition…

Although mechanisms are in place to seek redress and access justice, women's experiences clearly highlight lack of access to the available structures and mechanisms; hence, leading to a lack of access to justice for women who have been violated and abused based on and in the context of HIV. Recognising the impact of taking legal actions on women, combined with the limited to no redress received, some women felt strongly that it might be better not to lay a charge, since '*at the end of the day, you do more harm to yourself*'[12].

> *…the community will keep on talking. What can you do? On the other hand you will just be stressed further. So you're going to report one person today, another one tomorrow and somebody else the next day. At the end of the month, how many people are you going to report?…*[13]

In order for redress mechanisms to become truly available and indeed a source of redress and justice, women called for training of police and court personnel, and stricter sentences, as and when cases do go to court.

> *…I think police must be more informed about the charges to be laid and how to deal with people like us when they come to the police station…if one or two cases are being made and the police takes on those cases, then, I believe, that more will fall out of the closets to lay charges…*[14]

WOMEN'S VISIONS FOR POSITIVE CHANGE

Based on their experiences of rejection, violence and abuse upon HIV status disclosure women also clearly articulated what they thought needs to be done to ensure the autonomy and safety of women living with HIV. Equal treatment and respect, especially within healthcare provision; the protection of women's rights in all aspects of their lives; access to quality and comprehensive services free of stigma, coercion and violence; and education for communities and service providers alike on HIV and women's rights, are but some of women's calls for change.

> *…I must not be seen as a woman who is HIV positive, but as a woman who is a human being…*[15]

Highlighting the pervasiveness of abuse and other rights violations within healthcare settings, as well as its impact on access to healthcare, women emphasised the dire need to not only train healthcare providers to ensure a professional attitude and access to quality services, but also to assure confidentiality within healthcare provision through, among others, integrated services.

> *…I think if government can mix the patients so that we cannot differ from other patients, because we are not different…we must not have special rooms, special nurses and special administration…*[16]

…becomes to be 'unethical'; hence, a form of violence in and of itself…

…the potential role of programmes and initiatives promoting HIV disclosure in the perpetuation of violence against women living with HIV…

Women also articulated the need for safe places for women living with HIV who experienced violence and abuse, as well as the need to come together as women living with HIV and to collectively claim their spaces within communities.

> *…we are tired of people looking down on us and discriminating against us…we are part of the community, you should accept us…*[17]

QUESTIONS TO BE RAISED…

Recognising the various risks associated with women's HIV disclosure, the data seems to raise the question as to the potential role that societal expectations of, and pressures on, women to disclose their HIV status play in the continuum

of abuse and violence women experience in all aspects of their lives, irrespective of whether or not women themselves decided the time of and the manner in which their HIV status became known.

The research shows that although communities are aware of the risks associated with women's HIV status disclosure, communities nonetheless feel strongly that women need to disclose their HIV positive status.[17] While this could be seen as an '*indicator of success*' in the efforts to promote HIV disclosure and its potential benefits, communities' expectations of and pressure on women to disclose their HIV status, despite the multiple risks, could also be seen as an indicator of the '*value*' of women and their safety subsequent to HIV acquisition. Considering the apparent disconnect between beliefs that women's HIV disclosure is essential and the awareness and knowledge of the risks for women who do disclose their HIV status, it appears then that for communities, women's HIV disclosure takes priority over women's safety – as communities' '*need to know*' women's HIV status seems to override the knowledge of women's risks of violence and abuse associated with their HIV positive status becoming known.

…'collective responsibility' for the occurrence, perpetuation and pervasiveness of abuse and violations against women living with HIV…

In light of women's experiences there also seems to be the need to further interrogate the potential role of programmes and initiatives promoting HIV disclosure in the perpetuation of violence against women living with HIV. Notwithstanding the potential benefits of HIV status disclosure, an argument could however be made that calling for HIV disclosure in a societal context which fosters not only HIV-related stigma, violence and other rights abuses, but also violence against women, comes to be '*unethical*'; hence, a form of violence in and of itself. In an environment in which claiming the right to autonomy and privacy are perceived as key to women's safety, the focus of attention should arguably not be on advocating for HIV status disclosure, but instead on transforming the '*unsafe*' societal context, so as to create an '*enabling*' and '*supportive*' environment for women to make informed and free decisions as to whether or not, when, and to whom to disclose their HIV positive diagnosis – without fear of discrimination, violence, coercion and other rights abuses.

Recognising the multiple risks of violence, abuse and other rights violations upon women's HIV status disclosure – whilst simultaneously promoting HIV status disclosure – arguably

also underscores, to an extent, the '*collective responsibility*' for the occurrence, perpetuation and pervasiveness of abuse and violations against women living with HIV. Moreover, within the gendered and normative context of society, advocating HIV status disclosure, with the knowledge of the risks associated with such disclosure, seems to further '*condone*' and '*justify*' HIV-related stigma, violence and other rights abuses against women. And finally, it also seems to imply that women's experiences of HIV disclosure are not as '*valuable*' as the potential benefits of HIV status disclosure, since the perceived '*collective*' need for women to disclose their HIV positive status supersedes as much women's realities as women's rights to autonomy and privacy.

It is within the same context of women's rights to autonomy and non-violence that the findings seem to raise questions as to the extent to which societal expectations of women's '*responsibility*' to care for and protect others limit, if not deny, women the right to freely decide whether or not, when and to whom to disclose their HIV status. Although communities are knowledgeable about the right to choose, they nevertheless believe that women are to be held accountable, including through legal actions, for not disclosing their HIV status as and when their partners subsequently acquire HIV.[19] Such beliefs not only perpetuate the '*misguided*' assumption that HIV prevention is largely a responsibility for women living with HIV, but also manifest, and to an extent justify, the subsequent blame of and abuse against women living with HIV. Furthermore, it seems to highlight that women's rights are only as realisable, as they are '*acceptable*' to communities' perceptions of the '*roles and responsibilities*' of women living with HIV – as women claiming their rights to autonomy and privacy, seem to (in most

…women's experiences of HIV disclosure are not as *'valuable'* as the potential benefits of HIV status disclosure…

instances) linearly lead to violence and other rights abuses.

Given both women's experiences of violence and abuse upon HIV disclosure and communities' perceptions that women claiming their right not to disclose their HIV positive diagnosis should be '*punished*' and held accountable, arguably afford rather limited (if at all any) possibilities for women living with HIV to be free from stigma, violence, coercion and abuse – irrespective of whether or not they disclose their HIV positive diagnosis.

...rights are only as realisable, as they are *'acceptable'* to communities' perceptions of the *'roles and responsibilities'* of women living with HIV...

In the context of women's experiences of accessing healthcare, the study also seems to highlight a need to re-visit the concept of providing '*integrated services*' (as in providing '*one-stop-centres*'), so as to ensure that women's '*visions*' of integrated services (as in '*no specialised services*') have the potential of being realised. Although acknowledging the resource implications of '*restructuring*' healthcare provision, failing to do so will arguably not only perpetuate the abuse and rights violations against women living with HIV, but also maintain service provision which is not based nor informed by women's realities and needs.

CALL FOR CAUTION...

Although women's experiences of HIV status disclosure as a continuum of violence and abuse perpetrated by a continuum of people could potentially be interpreted as a '*call for non-disclosure*', it could arguably also be seen as a '*call for caution*' to halt and

…a *'call for caution'* to place women's realities, risks and needs at the centre of the response to women, violence and HIV…

evaluate the impact of programmes and initiatives promoting HIV disclosure on women. Similarly, these findings should be seen as much as an indicator of the many (and presumably) '*unintended*' adverse consequences of HIV disclosure, as of the lack of communities' preparedness to '*accept*' women living with HIV '*as part of the community*'.

Since, as evidenced by women's experiences, the current societal context is neither conducive nor supportive nor safe for women living with HIV – irrespective of women's HIV status disclosure being voluntary or involuntary – it seems however crucial to shift the focus from the '*benefits*' of HIV disclosure to the '*benefits*' of HIV disclosure in safe and supporting environments, which are truly '*enabling*' and thus, affording women the (constitutionally guaranteed) autonomy and freedom to decide whether or not, when and to whom to disclose their HIV positive diagnosis without fear of violence and other rights abuses.

And finally, women's accounts of the multiple risks associated with HIV disclosure should arguably be a '*call for caution*' to place women's realities, risks and needs at the centre of the response to women, violence and HIV, as otherwise violence and other rights abuses against women living with HIV will prevail – whilst women continue to conclude that '*if I knew what would happen, I would have kept it to myself*'[20].

FOOTNOTES:

1. This article is based on the findings from the research report. See Kehler, J. et al. 2012. Gender Violence and HIV: Perceptions and experiences of violence and other rights abuses against women living with HIV in the Eastern Cape, KwaZulu Natal and Western Cape, South Africa. AIDS Legal Network. [www.aln.org.za/downloads/Gender%20Violence%20&%20HIV2.pdf]
2. Woman in Illovo, KwaZulu Natal, 29 August 2012.
3. Woman in Beacon Valley, Western Cape, 29 September 2012.
4. Woman in Beacon Valley, Western Cape, 18 August 2012.
5. Woman in New Brighton, Eastern Cape, 25 August 2012.
6. Woman in Illovo, KwaZulu Natal, 29 August 2012.
7. Woman in New Brighton, Eastern Cape, 23 August 2012.
8. Woman in New Brighton, Eastern Cape, 25 August 2012.
9. Woman in Illovo, KwaZulu Natal, 28 August 2012.
10. Woman in New Brighton, Eastern Cape, 29 August 2012.
11. Woman in New Brighton, Eastern Cape, 22 August 2012.
12. Woman in Beacon Valley, Western Cape, 16 August 2012.
13. Woman in New Brighton, Eastern Cape, 24 August 2012.
14. Woman in Tafelsig, Western Cape, 31 August 2012.
15. Woman in Illovo, KwaZulu Natal, 27 August 2012.
16. Woman in New Brighton, Eastern Cape, 24 August 2012.
17. Woman in New Brighton, Eastern Cape, 23 August 2012.
18. Of all participants, 78% believe that women need to disclose their HIV positive status.
19. Of all participants, 69% thought that women are to be held responsible.
20. Woman in Beacon Valley, Western Cape, 16 August 2012.

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No power, no protection...

The cautionary tale of the Supreme Court of Canada involving criminal cases of HIV non-disclosure in the context of sexual encounters and its failure to protect women

Since the beginning of the HIV epidemic, HIV has been synonymous with stigma and discrimination directed at people living with HIV, and those populations overrepresented in the epidemic.

Louise Binder

This has led to a culture of fear, shame, self-loathing and secrecy in these groups and in turn has kept them away from the traditional healthcare and public health environments, which have been as guilty as other members of society at perpetrating this disgraceful, immoral conduct.

GROWING KNOWLEDGE BASE

At the outset of the epidemic, the argument for isolating people with HIV was that we did not know its genesis and how it was transmitted, but that argument quickly rang hollow since those in the gay and lesbian communities who came forward to help did not acquire HIV from their contact with us. It became even more untenable once we knew how HIV was transmitted and it was clear that the general population was not at risk of acquiring this disease, unless they had unprotected sex with a person living with HIV; shared unclean needles with a person with HIV; received blood containing HIV; or acquired it as a baby in the breast milk of a mother living with HIV.

We also learned that HIV transmission did not occur every time there was contact in one of these ways. In fact, the transmissibility rate of HIV from a man living with HIV to a woman without HIV is on average only 1 in every 1250 sexual encounters or 0.08%, while the transmissibility rate from a woman living with HIV is even lower at an average of 1 in every 2500 sexual encounters or 0.04%.[1] The use of a condom further reduces this already low transmissibility rate by 80%. The fear of sexual encounters, not to mention social and work interactions with people living with HIV, should surely have lessened considerably, if not totally disappeared, at this point of increased knowledge, and yet it continued.

Stigma and discrimination should further have receded once highly active antiretroviral therapy became available. It had the impact of protecting our immune systems from decimation, regenerating our damaged immune systems to some extent, and reducing the amount of virus in our blood and secondary compartments to very low levels, often undetectable by blood tests. This was not a cure, but it definitely meant an improved quality of life and longevity – a miracle after the devastation reeked by the virus on relatively young, vibrant people prior to its advent.

Researchers discovered that the transmissibility rate during a sexual encounter with a person living with HIV who has a low or undetectable viral load in the blood (less than 40 copies per millilitre of blood) was between 0.0% and 0.14 per 100 person years.[2] At last, we thought, the stigma and discrimination against people living with HIV would be at an end, and their right to lead the same kinds of lives as others in society would finally be recognised. How wrong we were!

> ...HIV has been synonymous with stigma and discrimination directed at people living with HIV, and those populations overrepresented in the epidemic...

THE ROLE OF THE LAW

All evidence to the contrary, society, in the guises of the law enforcement and judicial systems, has done just the opposite. It has raised the spectre of people living with HIV as heartless criminals, intent on hiding their HIV status from sexual partners and infecting them, or at least putting them at significant risk of infection knowingly and intentionally at every turn. How did we come to this shocking and untenable conclusion after we have come so far in knowledge about transmissibility and about treatments?

...stigma and discrimination should further have receded once highly active antiretroviral therapy became available...

The impact of this misconception on endeavours to turn the tide of this epidemic, particularly in the most marginalised and vulnerable populations in the epidemic, will be perverse.

So what is the role of the criminal law in perpetuating this folly? Early in the epidemic in Canada, we relied on public health laws, policies and officials to manage the prevention issues that arose, including situations where a person knew his or her HIV status, but did not disclose it to a sexual partner. Due primarily to a serious misstep by public health in managing a case of serial HIV transmission by a person living with HIV, people began to rely on the criminal law for redress, when a sexual partner living with HIV did not disclose his or her HIV status in situations of unprotected sexual encounters.

Today, Canada has the dubious distinction of having charged and prosecuted more people living with HIV than any other country – over 140 such prosecutions – 11% of these are women living with HIV. Since Canada does not have a specific criminal law related to HIV, charges are laid under sections of the ***Criminal Code***, including assault, sexual assault, aggravated sexual assault, attempted murder and murder. Decisions by judges in various provinces in Canada led to a range of interpretations of these laws in the context of the facts put before the court.

Finally two cases reached the highest court, the Supreme Court of Canada, setting rules for lower courts and law enforcement to follow. The first, ***R v Cuerrier*** (1998) 2 S.C.R. 371, was an allegation of aggravated sexual assault. Mr. Cuerrier, a man living with HIV, had vaginal sex with several women who did not have HIV. None of them acquired HIV. The defence in law to this charge is consent. The Court interpreted the law of consent to be vitiated where the consent is obtained by fraud and found that failure to inform a sexual partner that one is living with HIV prior to the sexual encounter is fraud. This fraud put the partner

...the impact of this misconception on endeavours to turn the tide of this epidemic, particularly in the most marginalised and vulnerable populations in the epidemic, will be perverse...

who is HIV negative at significant risk of infection, which was an attempted sexual assault. The Court mused that vaginal sex with a condom might not create this significant risk.

Unfortunately, hopes that this would be the law were dashed by the ***R v Mabior***, ***R v DC*** decisions (2012) S.C.R. 47. The charges in those cases were aggravated sexual assault. The Court confirmed the interpretation of the law in ***Cuerrier***. It went on to determine that a person living with HIV had a responsibility to disclose his or her HIV status to a sexual partner prior to vaginal intercourse, unless he or she *both* used a condom and had a low (undefined) viral load.

… return to the use of public health as a mediating device to avoid criminal law interventions…

This was the worst of all possible outcomes, except perhaps saying that people living with HIV could not have sexual intercourse at all. People working in the HIV, LGBT, women against violence, sexual and reproductive health and rights, human rights, women's rights and related communities were

appalled. For me, the fact that the Court had women on it was doubly upsetting. The rarefied air of the Supreme Court chambers appears to have had an unfortunate influence on them, i.e. forgetting real world realities for many women. The decision reflected a lack of understanding of the science of transmission and the public health impact it would have on prevention. It also lacked any understanding of the lived experience of the populations overrepresented in the epidemic, including women.

THE IMPACT OF THE LAW

This decision has an adverse impact on many populations living with HIV. I submit, however, that the impact on women, particularly women in those populations already vulnerable and marginalised, will be compounded and will have a profound impact, not only on prevention but also on the criminalisation of women. The main reason for this is the concurrent epidemic of violence against women taking place globally. When one brings together the intersection of these two epidemics plus the societal discrimination against women, you leave women out in the cold on the issue of disclosure.

If a woman is in a violent relationship, whether physical, sexual, emotional, verbal or psychological, from which she cannot practically extricate herself for any number of reasons, her fear of harm will surely override her concern for the criminal law and she will not disclose that she is living with HIV. If her violent partner does know her HIV status, she will certainly be in no position to negotiate condom use or refuse sex, because she does not have an undetectable viral load. The same will be true of a woman who is dependent on her partner socio-economically for her own needs and those of her dependents, an all too common scenario. She will not disclose her status if it threatens the protection she requires from him. He will determine how, when, and where they have sex, not her.

> ...her fear of harm will surely override her concern for the criminal law and she will not disclose that she is living with HIV...

> ...forgetting real world realities for many women...

For these reasons she may also not be taking medications even if she fits the guidelines for treatment for HIV or has poor health.

The whole issue of demanding a low viral load in addition to condom use is also problematic. Highly active antiretroviral treatments, while generally quite effective in reducing viral load, are, after all, effectively chemotherapy for life. They have been discovered to cause serious diseases, including heart disease, liver and kidney damage, bone problems, certain cancers, as well as aging people with HIV up to ten years more than their chronological age. In addition they may cause daily side effects that reduce quality of life, including

nausea, diarrhoea, lipodystrophy and depression. Few would want to start these before it is absolutely necessary.

Even if one is prepared to start treatments, they are not necessarily available in all jurisdictions or may only be available if you pay for them. This may also be true of condoms.

Women may well also feel a false sense of security from this decision, believing that a man with whom they are having unprotected sex must not be living with HIV or he would disclose as required by the criminal law. Yet, there is no evidence that supports the belief that men are impacted by these legal decisions to behave in accordance with them.

…those who are sensitive to the court decisions are not necessarily moved to act as they direct, but rather to find ways to evade them…

Those who are sensitive to the court decisions are not necessarily moved to act as they direct, but rather to find ways to evade them. There is talk in some populations about '*no test, no arrest*', meaning that people who may consider themselves at risk of acquiring HIV and would otherwise have tested will not do so to avoid the impact of the court decisions. This is a recipe for increased acquisition of HIV among women and flies in the face of prevention strategies.

Simply put, these court decisions are bad law, bad public health policy, defying the logic of evidence-based science. They are definitely bad news for women.

Why is it that among all of the diseases that can be acquired by infection, HIV is the only one that has been deemed to create criminal consequences until recently? This is true even where no actual harm, i.e. transmission of HIV, has occurred. It is just another form of stigma and resultant discrimination dressed up in black robes for credibility.

My view of why stigma and discrimination exist against people living with HIV in North America, which is not the politically correct reason people have given in the past, or are trying to use to advance the criminalisation argument, is found in the epidemiology of this disease. In North America this epidemic was first discovered in the gay population, generally in large cities. While people may deny it, discrimination against this group in society still exists and in some places is virulent. Rhetoric at the time, and even more recently, about gays bringing this plague on themselves, because of their sinful conduct, and related homophobic comments

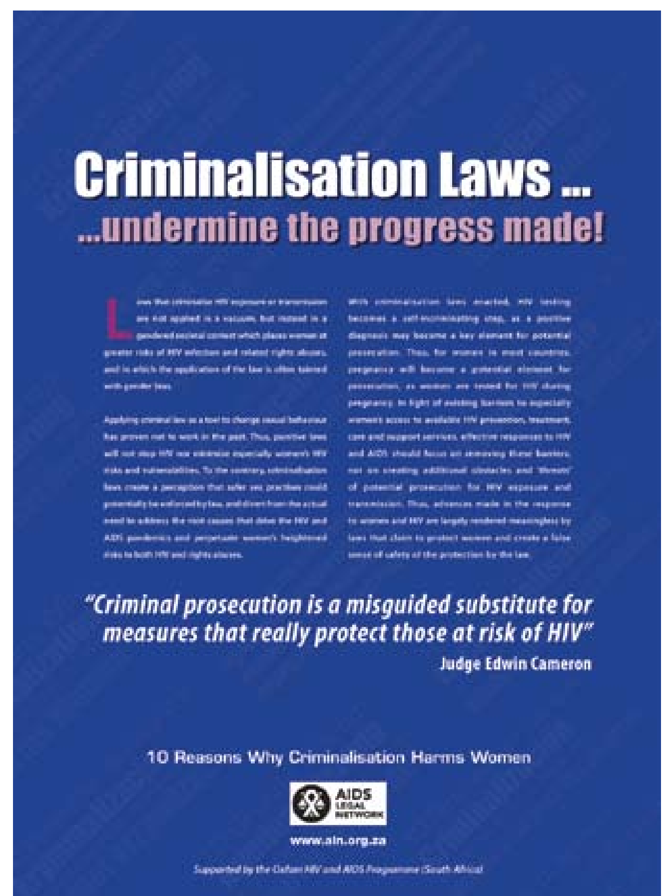
make the point. Since then, this epidemic has expanded its grasp into other populations generally found on the margins of the power base in society, people who use drugs, prisoners, the homeless, young people, women, immigrants, African-Americans, Hispanics, Aboriginal people and transgendered people, among others. These people are seen as disposable and unimportant no matter their number or their involvement in keeping the wheels of society in motion. In my opinion, and that of other far more erudite people, this is the crux of AIDS-phobia. We do not like the populations who acquire it; we do not consider them powerful or important; we do not frame our views of our society from a universal human rights lens. No power, no protection.

WHAT TO DO NEXT?

What can we do in the face of bad law? Avoid its use except where it is truly appropriate to the situation and work to change it?

In order to ensure that it is only used where the facts clearly demonstrate a clear intent to do harm to others without any regard for them, we must begin by educating those entering the legal and law enforcement fields about HIV, including the real risk of HIV acquisition, gender-based violence and socio-economic realities. We must get on school curricula.

We must also get on the curricula of medical school and schools educating healthcare providers in the same way. If they educate their patients or help them with their real world issues, we may keep people from being in harm's way of the criminal law.



We must reach law enforcement officers, prosecutors, defence lawyers and judges as well. My legal colleagues working in this field have strongly advocated for prosecutorial guidelines that will ensure that the criminal law is correctly used.

I would also like to see a return to the use of public health as a mediating device to avoid criminal law interventions. This requires appropriate resources and education for this group.

I feel strongly that issues that impact particular groups overrepresented in this epidemic, and the epidemic of gender-based violence, must be emphasised in all fora and forms of education.

…just another form of stigma and resultant discrimination dressed up in black robes for credibility…

NEEDING HELP, NOT PUNISHMENT

Recently I presented on this topic to a feminist legal studies conference at my *alma mater* Queen's Law School. I will end by telling you the story I told them. I was infected nearly 25 years ago by my late husband who was diagnosed while we were married. He did not tell me. After we divorced I was tested and found out my status. It was before the age of effective antiviral therapy so I was sent home with two years to live. I was homicidally angry. Fortunately I did not act on those feelings. Over time, with the help of a therapist, I came to realise that my husband was not a pathological liar and murderer, but a tragic figure with demons of his own. On his death bed I forgave him everything. I meant it.

I know that had I relied on the criminal law and sent this sick man to jail to die alone in some prison infirmary with no care and probably no pain medication I would be carrying around more guilt and stress than I could bear. Besides I need my emotional and physical energy to take care of my own health every day. Time heals – it is a cliché because it is true. It also provides perspective. Putting him in jail would not have changed my situation, but would have made it worse. He needed help, not punishment.

FOOTNOTES:

1. See www.catie.ca/en/pif/summer-2012.
2. See www.aidsmeds.com/articles/heterosexual_transmission_1667_23387.shtml.

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Violent language and narrow agendas...
The problem with 'corrective rape'

Dipika Nath

*When people in other parts of the world hear about lesbians in South Africa through the media, almost the only thing they are likely to learn is that butch, black, soccer-playing lesbians in townships are raped, and sometimes killed, by black men who wish to '**correct**' them; and that black lesbians may become pregnant and/or contract HIV as a result of sexual violence.*

In much of the coverage of the rape, torture, and murder of black lesbians in the only country on the continent whose constitution and laws offer lesbians and gay men protection from discrimination, there is little critical engagement with the fact that this violence takes place in a context of widespread state-sponsored and -condoned violence against various sections of society.[1] Students, labourers, workers, sex workers, the unemployed, the landless, single women, people living with HIV, migrants, people with disabilities, and, of course and disproportionately, all women, girls, and feminised people in and beyond these groups, are at the receiving end of state indifference on the one hand, and its corruption, inefficiency, and violent crackdown on the marginalised on the other, that together erode people's capacity for self-determination, their claim to bodily integrity, and their access to decent food, housing, healthcare, and livelihoods.

THE SOUTH AFRICAN CONTEXT

Almost two decades into the new South Africa, the poor are poorer than they were in 1994, when the African National Congress (ANC) took over the reins of government.[2] In a society with as high levels of inequality and all forms of crime and violence in South Africa[3], social prejudice is almost inevitably expressed in violent terms. The bodies of the socially and economically disempowered are permanently available for abuse – through the exploitation of workers[4] in the country's extractive industries[5], commercial farms[6], as volunteer caregivers[7], or as domestic workers[8]; through poor education[9] and high levels of unemployment[10]; unchecked sexual and physical violence, including murder[11]; infrastructural barriers to mobility[12]; through the absence or inadequacy of basic public services[13]; and through the marginalisation of certain bodies even within already disenfranchised communities, such as those of black, unemployed, HIV-positive women, who are almost completely excluded from the economic sphere, and of female and transgender sex workers.[14]

The privatisation of lucrative sectors of the economy (as well as of basic services)[15]; the continued lack of redress for the land grabs of the last three centuries that deprived millions of native and indigenous people of their ancestral land, as well as of sustainable sources of livelihood[16]; the historical and ongoing extraction of the country's natural resources by multinational corporations; the political economy of aid, whose conditionalities represent the modern face of old colonialism in the name of development[17]; and a dysfunctional education system that is unable to even deliver textbooks to certain parts of the country and whose failure at such a fundamental task goes unexamined by the country's elected leaders ensure that new generations of an uneducated and disenfranchised black workforce will continue to be available for exploitation in the country's businesses, whose profits serve to further increase the distance between poor and rich.

…little critical engagement with the fact that this violence takes place in a context of widespread state-sponsored and -condoned violence against various sections of society…

VIOLENCE AGAINST WOMEN

Unsurprisingly, violence against women, as both symptom and malaise, occurs with alarming impunity and amidst a deafening social and political silence on its scope, prevalence,

and consequences.[18] Female bodies are considered permanently available and easily disposable objects, and male and state entitlement over them remains a constant through all layers of social and private life. The militarised police force fails to both prevent crime and apprehend wrongdoers. As a manifestation of gender and sexual oppression, violence against lesbians has to be placed at the confluence of an anti-poor state, a fragmented socius, and codes of misogynist and predatory masculinity modelled by influential leaders and woven into the social fabric in the name of culture.[19]

A lesbian who flouts gendered codes of social and sexual behaviour disrupts the naturalised sexual order and social hierarchy, signalling her independence from male control, by simultaneously denying cisgender,[20] heterosexual men sexual access to her body and appearing to replace the male figure in the heterosexual dyad. The rejection of normative gender roles in combination with a seeming usurpation of masculine social and sexual power is often the expressed reason for why men attack, intimidate, rape, torture, and kill lesbians.

...with alarming impunity and amidst a deafening social and political silence on its scope, prevalence, and consequences...

Activists in the field of lesbian, gay, bisexual, and transgender (LGBT) rights have worked hard to capture the homophobic nature of violence against lesbians in order to visibilise lesbian experiences within a generally heteronormative society. They have re-worked language to assist in this effort and undertaken research, outreach, training, and consciousness building within and beyond lesbian, gay, bisexual, and transgender communities.[21]

...to visibilise lesbian experiences within a generally heteronormative society...

However, due to the increasing ascendance of identity politics and the dominant discourse of human rights (progressing hand in hand with globalisation and free-market capitalism), the desire to visibilise the nature of this violence has resulted in the isolation of (sexual) violence faced by lesbians (and other members of lesbian, gay, bisexual, and transgender communities) from other forms of gendered violence. The human rights paradigm – focusing on participatory rather than socio-economic and distributive aspects of democracy and on legal remedies for socio-economic problems – requires every

problem to be articulated as a rights claim; such a legalistic view of self-determination and agency necessarily trades in the discourse of victimisation and entitlement, a discourse that is unable to address structural causes of inequality and violence and which effectively disables alliance building and the formulation of multi-issue politics.[22]

In addition to the restriction of '*social justice*' to '*individualised human rights*' (which is only one way of thinking about social justice), the heteronormative approach of the South African state to gendered violence has augmented this silo-style thinking.[23] As a result, lesbians have been excluded from much of the discussion on women's rights, locally as well as internationally.[24] In turn, and in order to carve out space for issues specific to sexual orientation and gender identity, the lesbian, gay, bisexual, and transgender sector has, with only a few exceptions, also failed to co-articulate sexual orientation and broad concerns of gendered violence.

...such a legalistic view of self-determination and agency necessarily trades in the discourse of victimisation and entitlement...

SEXUAL VIOLENCE AGAINST LESBIANS

It is against this backdrop that the proliferation of a term such as '*corrective rape*' must be understood, as a term that (currently) obscures more than it (historically) illuminated. By assigning a unique value to some forms of violence experienced by some members of a presumably bounded community, the term creates various smokescreens and untenable hierarchies – among kinds of violence and their effects, among survivors and victims of violence, and among perpetrators.

First, it suggests that sexual violence faced by individuals presumed or known to be lesbian is worse than all other instances of sexual violence. One of the ways in which this presumed difference is articulated is in the sometimes explicit, often implicit, claim that the harm done to a raped lesbian is greater than the harm that follows the rape of a presumably heterosexual woman, particularly a sexually active one. Apart from reinforcing misogynist ideas about the unrapeability of sexually active heterosexual women, leave alone the issue of marital or relationship rape, such a claim also reinforces the myth that only strangers perpetrate real or '*serious*' rape. Such deductions are already found among police personnel and in the pronunciations of the judiciary. For example, in a 2005 case in which then High Court Judge Mogoeng Mogoeng, appointed by the president as the Chief Justice of the Constitutional

Court in 2011, reduced a convicted rapist's sentence on the grounds that the rapist was the rape survivor's boyfriend, and that the rape was, therefore, less '*serious*' than '*the rape of one stranger by another between whom consensual intercourse was almost unthinkable*'.[25]

The resulting hierarchy between '*lesbian*' and '*heterosexual woman*' results in a stereotyping of both categories, which, in turn, yields fictional ideas of what a '*real lesbian*' is – a stereotype that is used to police sexual desires, practices, and gender expression, including within lesbian communities. Thus, relatively feminine appearing lesbians, bisexual women, lesbian parents, and lesbians who may currently have or in the past have had sexual relationships with cisgender men may be treated with suspicion and disbelief when they say they have been raped; concomitantly, gender non-conforming lesbians and transgender men may be considered to have suffered greater harm through sexual violence. Through such normativising strategies, '*lesbian*' ceases to be a temporally specific and socio-politically constructed identity and becomes a biologically determined set of sexual and gender characteristics.

Second, the term's exclusive focus on sexual violence deprioritises and invisibilises other forms of violence faced by individuals presumed or known to be lesbian; all forms of verbal abuse, threat, intimidation, harassment, physical attack, and sexual violation that do not involve vaginal penetration are relegated to a lower status. The narrow focus on a normative understanding of rape, and its elevation above all other forms of violence, is also partly explained by the fact that mainstream human rights discourse – which is only now, and unevenly, recognising human rights abuses perpetrated by non-state actors – often fails to consider as rights violations much of the violence faced by women and members of lesbian, gay, bisexual, and transgender communities. Because the discourse of human rights is also notorious for calling for an end to (some forms of) violations without acknowledging the political, economic, and social contexts

…acknowledging the political, economic, and social contexts that create the enabling conditions for the violations…

…*'lesbian'* ceases to be a temporally specific and socio-politically constructed identity and becomes a biologically determined set of sexual and gender characteristics…

that create the enabling conditions for the violations,[26] a narrow focus on rape also fits neatly into the mainstream human rights framework.

UNSUSTAINABLE HIERARCHIES

The isolation of one kind of experience of violence through the language of '*corrective rape*' not only yields sensationalist and de-contextualised reportage, it also prevents a clear understanding of the extent and foundation of the problem of gendered violence. A closer inspection of the voluminous research on sexual violence in South Africa would immediately disrupt the exceptionalising discourse surrounding sexual violence directed at lesbians. It is by now well established that men rape women who reject their sexual advances, regardless of sexual orientation, age, or other characteristics. Study after study establishes the fact that in addition to being '*fun*', rape is the preferred mode of punishment of, or revenge against, women who turn down male suitors, and are perceived to be '*high-class*', or display '*inappropriate femininity*'.[27]

For example, popular forms of gang rape, such as the historical phenomenon of jackrolling, in which gangs abducted girls and women who were considered '*snobbish*', and the current one of streamlining, in which a woman is tricked or coerced into having sex with two or more men (a situation sometimes organised by the woman's boyfriend), are not considered to be rape by the men, who justify their actions by claiming that they wanted to teach the woman a lesson.[28] Moreover, arguments about tradition, used by attackers to justify their attacks on lesbians, are also used to justify rapes of other women, as well as other misogynist practices, such as '*virginity testing*', which is considered by its practitioners to be essential for maintaining cultural authenticity. Furthermore, restricting the concept of '*female masculinity*' or encroachments on male entitlements to only lesbians ignores the fact that even presumably heterosexual and gender conforming women

are seen to transgress gender roles when they assert their physical or sexual independence or earn more money than their male partners.

Finally, the discourse of '*corrective rape*' (and the allied discourse of '*hate crimes*') also creates categories of perpetrators – '*ordinary*' rapists and '*correctional rapists*', who rape only lesbians – when there is nothing to suggest that rapists in South Africa select specialised victim profiles. There is no reason to believe that the person who rapes a lesbian has not in the past, or will not in the future, also rape other women and female-born people. In fact, research establishes the high number of rapists in South Africa who rape more than once,[29] and lesbian survivors are raped by people who are not aware of their sexual orientation.[30] In creating a hierarchy among survivors and victims, this discourse, by extension, creates a hierarchy among rapists and among an individual rapist's different acts of rape. To take these hierarchies to their hypothetical conclusion, consider a situation in which a person rapes a lesbian and her heterosexual friend on the same occasion, inflicting the same degree of injury on both. Would we argue that the rapist should be awarded a higher sentence for the former rape than for the latter? Would we judge the harm done or intended on the basis of whether the perpetrator had known or guessed the two women's different sexual orientations? Would we argue for different sentences if the rapist had known, or guessed, their different sexual orientations and had used a homophobic slur when raping the lesbian and a misogynist slur when raping her heterosexual friend?

…prevents a clear understanding of the extent and foundation of the problem of gendered violence…

In exceptionalising the reasons for and consequences of sexual violence against lesbians, the term '*corrective rape*' implicitly reduces sexual non-submissiveness to only an effect of non-normative sexual orientation. A person who is not identified as a lesbian is thus deprived, however unintentionally, of her capacity to be sexually non-submissive. To the extent that the dominant discourse of lesbian, gay, bisexual, and transgender rights (and other individual rights discourses) exceptionalises lesbian, gay, and transgender experiences (they do not for the most part pay any attention to the concerns of bisexual people), this discourse misses the opportunity for creating common cause with other struggles and instead creates hierarchies of victimisation among various marginalised groups.

The result of such a critique cannot be a re-closeting of violence against lesbians and other challenges faced

…this discourse misses the opportunity for creating common cause with other struggles and instead creates hierarchies of victimisation among various marginalised groups…

by members of lesbian, gay, bisexual, and transgender communities; it was in direct response to the invisibilisation of these issues that specialist language was developed in the first place. Critiques of the term '*corrective rape*' only point to the fact that language is a living phenomenon, both serving the social and ideological context in which it evolves and shaping discourse and ideology. Perhaps the term served the important role of drawing attention to a hitherto masked phenomenon, but it may have outlived its utility, and it behoves us to rethink its use in the light of its incorporation into non-liberatory agendas.

FOOTNOTES:

1. For example, see http://pulitzercenter.org/reporting/south-africa-gender-inequality-womens-rights-sexual-acceptance; www.pinknews.co.uk/2012/11/12/south-africa-lesbian-dies-after-being-stabbed-with-spear/; www.gaystarnews.com/article/south-african-lesbian-soccer-player-brutally-murdered121112; espn.go.com/video/clip?id=5181871; www.bbc.co.uk/news/world-africa-13908662; www.cnn.com/2011/10/27/world/wus-sa-rapes.
2. Not only are the poor poorer, but the rich are richer; inequality in South Africa is significantly worse today than at the formal end of apartheid, and it is growing, with South Africa being by far the most unequal of the G20 countries. See 'Left Behind by the G20'. 157 Oxfam Briefing Paper, January 2012. [www.oxfam.org/en/policy/left-behind-by-g20]
3. See the latest government statistics at www.saps.gov.za/statistics/reports/crimestats/2012/downloads/crime_statistics_presentation.pdf.
4. For the minimum wage in various sectors, see www.mywage.co.za/main/salary/minimum-wages.
5. See www.bbc.co.uk/news/world-africa-13275704; www.iol.co.za/business/companies/lonmin-an-example-of-exploitation-1.1365221#.UStI8qU29SV.
6. See a Human Rights Watch report at www.hrw.org/reports/2011/08/23/ripe-abuse.
7. See http://mg.co.za/article/2009-08-11-cry-for-help-caregivers; Daniels, K., Clarke, M. & Ringsberg, K. 'Developing Lay Health Worker Policy in South Africa: A Qualitative Study'. [www.health-policy-systems.com/content/10/1/8]
8. See the International Labour Organization's 'Decent Work Country Profile for South Africa'. [www.ilo.org/wcmsp5/groups/public/---dgreports/---integration/documents/publication/wcms_180322.pdf]
9. Less than half the children who enroll in grade 1, finish schooling, and sexual abuse and pregnancy are a key reason that girls do not finish school. [http://learningenglish.voanews.com/content/high-dropout-rate-a-problem-for-south-africa-141919353/608451.html]
10. About a quarter of the country's population is unemployed according to the latest figures, and about half the population between the ages of 15 and 34 is unemployed. [www.statssa.gov.za/publications/P0211/P02114thQuarter2012.pdf]
11. South Africa Police Force's statistics already speak volumes (see note 3 above), but in the case of sexual violence, reported numbers are only the tip of the iceberg because of underreporting. The real numbers may be anything between eight and 25 times the reported numbers. See Jewkes, R. & Abrahams, N. 2002. 'The Epidemiology of Rape and Sexual Coercion in South Africa: An Overview'. In: *Social Science & Medicine*, vol. 55, no. 7, pp1231-44; and Gender Links. 'The War@Home: Findings of the GBV Prevalence Study in South Africa'. [www.genderlinks.org.za/article/the-warhome-findings-of-the-gbv-prevalence-study-in-south-africa-2012-11-25]
12. On the public transport system, see www.ipsnews.net/2012/10/reducing-poverty-in-south-africa-by-cutting-time-in-traffic/; http://sacsis.org.za/site/article/758.1.
13. For access to toilets, see http://mg.co.za/article/2012-11-19-access-to-adequate-toilets-hindered-by-blockages-in-the-system; for access to water, see www.irinnews.org/Report/82750/SOUTH-AFRICA-The-quiet-water-crisis; for access to healthcare, see www.southafrica.info/about/health/health.htm#.USdhwqU29SU.
14. See Kehler, J. et al. 2012. 'Gender Violence and HIV: Perceptions and experiences of violence and other rights abuses against women living with HIV in the Eastern Cape, KwaZulu Natal and Western Cape, South Africa' [www.aln.org.za/downloads/Gender%20Violence%20&%20HIV2.pdf]; One in Nine Campaign. 2012. ''We Were Never Meant to Survive': Violence in the lives of HIV positive women in South Africa' [www.oneinnine.org.za]; Amnesty International. 2008. ''I Am At the Lowest End of All': Rural women living with HIV face human rights abuses in South Africa' [www.amnesty.org]; [www.who.int/gender/documents/sexworkers.pdf Gould, C. 2008. *Selling Sex in Cape Town: Sex Work and Human Trafficking in a South African City.* Pretoria: Institute for Security Studies.
15. See http://apf.org.za/spip.php?article145.
16. Although land had been usurped for at least a century before, the Native Land Act of 1913 systematised land dispossession by allowing the white minority population to appropriate over 90 per cent of the country's land. The ANC government promised to restore 30 per cent of agricultural land by 2014; so far, it had restored about 8 per cent, and some of the reclaimed land is no longer viable agricultural land. See http://allafrica.com/stories/201211010750.html. Also see Yanou, M.A. 2009. *Dispossession and Access to Land in South Africa: An African Perspective.* Cameroon: Langaa RPCIG; and www.ldd.org.za/images/stories/Ready_for_publication/V8-2_right_access_land.pdf.

17. See, for example, Biccum, A. R. 2005. 'Development and the 'New' Imperialism: A reinvention of colonial discourse in DFID promotional literature'. In: Third World Quarterly, vol. 26, no. 6, pp1005-1020. Also see critiques of aid conditionality at www.sxpolitics.org/?p=7371 and http://staging.awid.org/eng/About-AWID/AWID-Initiatives/IDeA/Resources-on-Aid-Effectiveness/Conditionalities-Undermine-the-Right-to-Development.
18. Mathews, S. et al. 2004. 'Every Six Hours a Woman is Killed by Her Intimate Partner'. [www.mrc.ac.za/policybriefs/woman.pdf]; Kalichman, S. et al. 2005. 'Gender Attitudes, Sexual Violence, and HIV/AIDS Risks among Men and Women in Cape Town, South Africa'. In: *The Journal of Sex Research*, vol. 42, no. 4, pp299-305.
19. For example, in August 2012, the president, Jacob Zuma, said on national television, '*I wouldn't want to stay with daughters who are not getting married. Because that in itself is a problem in society. I know that people today think being single is nice. It's actually not right. That's a distortion. You've got to have kids. Kids are important to a woman because they actually give an extra training to a woman, to be a mother*'. [http://mg.co.za/article/2012-08-21-zuma-women-must-have-children]
20. The counterpart of *'transgender', 'cisgender'* refers to the gender identity of people whose birth gender (the gender they were declared to have upon birth) conforms to their lived gender and self-identity.
21. See Forum for the Empowerment of Women. 'The Rose Has Thorns: Stories of Hate Crimes Against Black Lesbians in South African Township' [https://khanyacollege.org.za/Documents%5CKJ3.pdf]; Mkhize, N. et al. 2010.' The Country We Want to Live In: Hate crimes and homophobia in the lives of Black Lesbian South Africans'. [www.hsrcpress.ac.za/product.php?productid=2282&cat=0&page=1&featured&freedownload=1]; Gay and Lesbian Network of Pietermaritzburg. 'An Exploration of Hate Crime and Homophobia in Pietermaritzburg, Kwa-Zulu Natal'. [www.gaylesbiankzn.org]
22. For a critique of the human rights model, see Kennedy, D. 2001. 'The International Human Rights Movement: Part of the Problem?'. In: *Harvard Human Rights Journal*, vol. 15, pp101-126. For a critique of undue reliance on the law in feminist struggles, see Menon, N. 2004. *Recovering Subversion: Feminist Politics Beyond the Law.* New Delhi: Permanent Black.
23. For example, in late 2010, change.org, '*the world's petition platform*', ran a petition asking the South African Department of Justice and Constitutional Development (DoJCD) to '*take action against corrective rape*'. DoJCD responded by setting up a task team in mid-2011 to '*attend to LGBTI issues and corrective rape*'. Several activists on the task team had to engage in a protracted discussion with government representatives on the inadvisability of not articulating links between violence against lesbians and gender based violence as a whole. [www.justice.gov.za/m_statements/2011/20110504_lbgti-taskteam.html]
24. For a striking example of such exclusion at the international level, see Human Rights Watch's 2012 *The Unfinished Revolution: Voices from the Global Fight for Women's Rights*. The volume contains two, non-substantive, mentions of the word *'lesbian'* (both by a non-staff person) and gives the impression that no lesbians and bisexual women have played any role in women's rights movements anywhere in the world.
25. *S v Moipolai* 2005 (1) SACR 580 (B). Among other cases in which Mogoeng wrote or concurred with decisions that reduced sentences of convicted rapists of children, in *S v Sebaeng* (CA 16/2007) [2007] ZANWHC 25 (22 June 2007), a case involving the rape of a 14-year-old girl, Mogoeng observed, '*One can safely assume that* [the accused] *must have been mindful of her tender age and thus so careful as not to injure her private parts, except accidentally, when he penetrated her. That would explain why the child was neither sad nor crying when she returned from the shop notwithstanding the rape. In addition to the tender approach* [sic] *that would explain the absence of serious injuries and the absence of serious bleeding, he bought her silence and cooperation with Simba chips and the R30.00*'.
26. A good example of the latter is the refusal of influential international human rights organisations, such as Human Rights Watch and Amnesty International, to support the decriminalisation of sex work. Obviously, this is not to say that the human rights framework contributes nothing to social justice; it often helps to shed light on hidden violations and helps generate social consensus on their wrongness.
27. See Hallman, K. 2005. 'Sexual Violence and Girls' Education in South Africa'. [http://paa2005.princeton.edu/download.aspx?submissionId=51448]; CSVR. 2008. 'A State of Sexual Tyranny: The prevalence, nature and causes of sexual violence in South Africa'. Johannesburg: CSVR; Moffett, H. 2006. "'These Women, They Force us to Rape them': Rape as narrative of social control in Post-Apartheid South Africa". In: *Journal of Southern African Studies*, vol. 32, no. 1, pp129-44.
28. See Mokoena, S. 1991. 'The Era of the Jackrollers: Contextualising the rise of youth gangs in Soweto, 1991'. [www.csvr.org.za/wits/papers/papmokw.htm]; and Wood, K. 2005. 'Contextualizing Group Rape in Post- Apartheid South Africa'. In: *Culture, Health & Sexuality*, vol. Q7, no. 4 (July-August 2005), pp303-317.
29. See Jewkes,R. et al. 2009. 'Understanding Men's Health and Use of Violence: Interface of rape and HIV in South Africa'. [www.mrc.ac.za/gender/violence_hiv.pdf]; and Abrahams, N. 2004. 'Sexual Violence against Women in South Africa'. In: *Sexuality in Africa Magazine*, vol. 1, No. 3 [www.arsrc.org/downloads/sia/sep04/sep04.pdf].
30. The other argument in favour of promoting hate crimes legislation is that a hate crime is a '*message crime*' that affects communities, not only individuals, and that the perpetrator was motivated by hate. While this is true of violence against members of lesbian, gay, bisexual, and transgender communities, it may be argued that it is no less true of all gendered violence. See Jacobs, J & Potter, K. 1998. *Hate Crimes: Criminal Law and Identity Politics*. New York: Oxford University Press.

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Silenced and forgotten...

HIV and AIDS agenda setting paper for women living with HIV, sex workers and lesbian, gay, bisexual, and transgender individuals in Southern Africa and Indian Ocean states[1]

OSISA[2]

In 2010, an estimated 68% of all people living with HIV resided in sub-Saharan Africa – a region with only 12% of the global population. AIDS has claimed at least one million lives annually in sub-Saharan Africa since 1998. Nearly half of all AIDS-related deaths in 2010 occurred in southern Africa. The region also continued to account for 70% of all new HIV infections globally.[3] Despite these statistics, women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals remain marginalised and excluded from HIV information, education and communication (IEC). They are also often left out of treatment, care and support programmes.

Most countries in Africa criminalise sex work activities and same sex practices in one form or another, either explicitly or latently. This consistently leads to discrimination against individuals who belong to these groups through poor access to justice, inappropriate healthcare services and stigmatisation – characterised by their being blamed for driving diseases such as HIV and other sexually transmitted infections (STIs). Furthermore, the unwillingness of state actors and stakeholders to engage in meaningful dialogue and research regarding sex work, gender roles and same sex practices erects barriers towards appropriate and effective policy formulation.

The lack of recognition, representation, participation and engagement of these groups further excludes them from important national health programming and campaigns. It also denies them their right to be accepted as part of the community for which policies or laws are formulated.

Women living with HIV

Women living with HIV in southern Africa and the Indian Ocean states continue to suffer grave violations of their human rights. Women living with HIV have had their right to reproductive choice taken away, by denying them the right to conceive and give birth.[4] Authorities in many countries in the region continue to pay lip service to cases of women living with HIV being coercively and, in some cases, forcibly sterilised. In Namibia and Swaziland, cases of women living with HIV being subjected to coerced sterilisation have been documented and litigated. In a recent landmark judgment, the High Court in Windhoek found that the Namibian government had coercively sterilised three women living with HIV in violation of their basic rights.[5]

At the end of 2010, it was estimated that out of the 34 million adults worldwide living with HIV and AIDS, half of them were women.[6] The AIDS epidemic has had a unique impact on women, which has been exacerbated by their role within society and their biological vulnerability to HIV infection. Generally, women are at a greater risk of heterosexual transmission of HIV. Biologically, women are twice as likely to become infected with HIV through unprotected heterosexual intercourse as men. In many countries, women are less likely to be able to negotiate condom use and are more likely to be subjected to non-consensual sex. Additionally, millions of women have been indirectly affected by the HIV and AIDS epidemic. Women's childbearing role means that they have to contend with issues such as mother-to-child transmission of HIV. The responsibility of caring for AIDS patients and orphans is also an issue that has a greater effect on women in southern Africa and the Indian Ocean states.

…most countries in Africa criminalise sex work activities and same sex practices in one form or another, either explicitly or latently…

Incidents of violence against women (VAW) – regarded as any '*act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private*

life'[7] – continue to escalate in southern Africa and the Indian Ocean states. In Zambia, Demographic Health Survey (DHS) data indicates that 27% of ever married women reported being beaten by their spouse/partner in the past year – a rate that rose to 33% for 15-19 year-olds and 35% for 20-24 year-olds. Fifty-nine percent of Zambian women reported having experienced violence after the age of 15.[8] In South Africa, 7% of 15-19 year-olds reported having been assaulted in the past year by a current or ex-partner, while 10% reported being forced or persuaded to have sex against their will[9].

Violence against women increases their vulnerability to HIV by limiting their ability to negotiate safer sex practices. Women may also be infected with HIV and other sexually transmitted infections through direct means of violence like rape. In South Africa and other neighbouring countries in the region, there has been a growing trend of violence towards lesbian and bisexual women by men who claim to be '*curing*' the women of their homosexual tendencies. The attacks also extend to transgender people and other gender non-conforming women. These attacks are very violent and many of them end up in death or permanent injury. This form of violence has continued to make lesbian and bisexual women and transgender people more vulnerable to HIV and has been a major barrier to them accessing sexual and reproductive health services.

...barriers towards appropriate and effective policy formulation...

Cervical cancer is one of the leading causes of cancer-related deaths among women in developing countries, including southern African and Indian Ocean states. Zambia, for example, has the world's second highest rate of cervical cancer and deaths each year. Women who are HIV-infected are 4-5 times more likely to develop cervical cancer than women who are not HIV-infected.[10]

Sex Workers and HIV & AIDS

Recent studies continue to confirm that in many southern African and Indian Ocean states sex workers experience higher rates of HIV infection than most other population groups.[11] For example, female sex workers have the highest prevalence of HIV in Malawi at 70.7%.[12] The Swaziland HIV Bio-Behavioural Surveillance Study and a Qualitative Study among Most At-Risk Populations, which was conducted by Population Services International in conjunction with Johns Hopkins University in the United States, showed that HIV prevalence among sex workers stood at 70.3%.[13]

Violence and discrimination against sex workers, police raids, incarceration, and a lack of accessible and relevant information, evidence-based prevention tools and treatment services compromise the ability of sex workers living with HIV to protect their health and receive adequate care, treatment, and support. Migrant sex workers who are living with HIV are particularly excluded from access to treatment and care due to xenophobia and other barriers. Transgender sex workers seeking transgender-specific healthcare and gay male sex workers seeking non-judgmental healthcare are similarly neglected in most of the region.[14]

...authorities in many countries in the region continue to pay lip service...

In cases where interventions targeted at sex workers do exist, these are often confined solely to female sex workers who have sex with male clients with none targeting male or transgender sex workers.

Lesbian, gay, bisexual, and transgender individuals and HIV & AIDS

For same sex practising people in southern Africa and the Indian Ocean states, like in other parts of the globe, HIV and AIDS research and programming has focused on men who have sex with men rendering other same sex practising individuals invisible in the HIV and AIDS picture.

The belief that women who have sex with women are at no or low risk of HIV infection has led to the exclusion of women who have sex with women from HIV prevention efforts, access to healthcare services, education, treatment and research[15]. Specific groups of women are more affected by this

exclusion than others, such as women who have sex with women and are living with HIV, including those who do not identify themselves as lesbian or bisexual[16]. This social exclusion is in many respects informed by gender inequities inherent in almost every country of the world. For this reason, any HIV prevention, treatment and care programme for women who have sex with women must work from the premise that access to knowledge and services on health is disproportionate for women and men in a context where gender inequities persist[17].[18]

...compromise the ability of sex workers living with HIV to protect their health and receive adequate care, treatment, and support...

represents a substantial number of people for whom no targeted HIV prevention, treatment or care services currently exist.[19]

Same sex practising women in southern Africa and the Indian Ocean states – and in South Africa in particular – continue to experience sexual violence in the form of rape, and this form of violence increases their vulnerability to HIV and AIDS and is an infringement of their sexual and human rights.

There is also a widespread misconception, characterised by exclusion from research or focus, by both women who engage in same sex relations and other stakeholders that women who have sex with women are not at risk of HIV and AIDS. In a 2002 study conducted by the Human Science Research Council (HSRC) in South Africa, 13% of lesbian women (aged 15–49) self-reported a positive HIV test result. While this rate is lower than seroprevalence rates for heterosexual South African women, it still

In southern Africa and the Indian Ocean states today, transgender people continue to remain at the margins of HIV and AIDS programming, their needs and issues are under researched and health programming for transgender people is usually integrated into programming for men who have sex with men. The marginalised position of transgender people can have serious effects on their quality of life. Overall, high HIV infection rates, inaccessibility of health services, high incidence of sexual violence and murder, and vulnerability to societal ills, such as substance abuse, can

...incidents of violence ...continue to escalate in southern Africa and the Indian Ocean states...

…social exclusion is in many respects informed by gender inequities inherent in almost every country of the world…

all potentially reduce the life expectancy of transgender people in Africa.[20]

In the context of the global AIDS epidemic, sex between men is significant and throughout the course of the global epidemic, consistently high levels of HIV infection have been found among men who have sex with men. However, in many southern African and Indian Ocean states, men who have sex with men are – like other same sex practicing people – less visible. Same sex relations are stigmatised, officially denied and criminalised in most of these states. Most governments and societies in the region continue to refuse to acknowledge the existence of same sex practising people in their countries, although research done in southern Africa, the Indian Ocean states and other parts of Africa proves otherwise. As a result, HIV prevention campaigns often only talk about the risks of heterosexual sex and there is little or no appropriate information available for lesbian, gay, bisexual, and transgender individuals. This gives a false impression that they are not at risk and serves to justify their exclusion from HIV and sexual and reproductive health services.

CHALLENGES AND BARRIERS TO ACCESSING HIV AND SEXUAL AND REPRODUCTIVE HEALTH SERVICES AND RIGHTS

During the workshops and consultative meetings conducted by OSISA, representatives from the women living with HIV, sex worker and lesbian, gay, bisexual, and transgender sectors came up with a list of barriers to accessing services and challenges to attaining a holistic and human rights based approach to HIV and AIDS programming in the region. The challenges below are a collective summation of the issues presented by the three groups. However, in some instances, where indicated, a particular group faces a specific challenge or set of challenges that may not necessarily affect members of the other groups.

Research and knowledge

- Lack of evidence-based and targeted research outlining the situational needs of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals.
- Research ethics boards not wanting to approve research on sex work, and lesbian, gay, bisexual, and transgender

individuals citing laws, culture, religion and morals for their rejection.

- Lack of recognition of lesbian women and transgender people as groups that are vulnerable to HIV and AIDS.
- National research is neither inclusive nor specific as evident in national demographic health surveys that exclude sex workers, and lesbian, gay, bisexual, and transgender individuals.
- Exclusion of women living with HIV, sex workers, and lesbian, bisexual and transgender individuals from vital research around microbicides, reproductive cancers, HPV vaccines and contraceptives.

Legal frameworks and access to justice

Most countries in the region have laws that criminalise same sex conduct and sex work activities. Even if such activities are not explicitly outlawed, penal codes based on so-called '*morality*', criminalise sexual relations that are regarded as '*immoral*', '*indecent*' or '*crimes against the laws of nature*' and so forth.

- Criminalisation of HIV transmission, sex work and same sex relations also occur in some countries – these laws are usually structured to target women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals who are wrongfully labelled as '*drivers*' of the epidemic.
- Poor access to justice – reports of violations of the rights of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals are often not investigated or taken seriously by both state and non-state parties.
- Lack of protective policies and their implementation – where policies exist to mitigate and address the HIV and AIDS epidemic, they often exclude women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals.
- Lack of freedom of association and expression – some groups, such as sex workers, and lesbian, gay, bisexual, and transgender groups, are often unable to register as legal entities and are therefore denied legal status, which deprives them of the liberty to collectively demand both

...the marginalised position of transgender people can have serious effects on their quality of life...

their rights and tailor-made sexual and reproductive health and HIV and AIDS services.

- Lack of legal recognition of gender identity – transgender people cannot access identity documents in their chosen name and identity, which negatively impacts on their access to services and justice.

…same sex relations are stigmatised, officially denied and criminalised in most of these states…

Access to health

Health service delivery systems do not recognise the diverse rights of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals. Health service providers also lack training and sensitivity to the specific HIV care, treatment and support, and sexual reproductive health needs and rights of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals – thereby making healthcare centres potential sites of exclusion, physical and emotional violence.

- Health service delivery systems discriminate against women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals and lack a human rights-based approach to service provision.
- Post-Exposure Prophylaxis (PEP) is not always accessible to women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals who have survived rape and other violence against women.
- Emergency contraceptives are not always accessible. Women living with HIV, female sex workers, lesbian and bisexual women, and transgender men who seek them are often blamed instead of being assisted by health professionals.
- Healthcare services often do not cater to the specific needs of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals.

Access to information and education

- Lack of tailored Information, Education and Communication (IEC) material for women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals.
- Lack of inclusive campaigns on sexual and reproductive health and rights affecting women living

with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals.

- Sex workers, lesbian, gay, bisexual, and transgender individuals and women living with HIV lack the space, representation and participation within the information and education arenas to give legitimate voice to their communities.
- The media is often discriminatory, non-objective and biased, evidenced in its lack of – or negative – coverage of issues related to women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals, which further fuels stigma, discrimination and prejudice against them; increases their vulnerability to HIV; and makes it even harder for them to access HIV and AIDS services.
- The media lacks the knowledge, sensitivity and skills needed for objective reporting on the sexual and reproductive health and rights of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals, which leads to these groups being denied access to the media as a critical tool for advocacy.
- The education system does not embrace a culture of diversity and is therefore not cognisant of the specific issues affecting women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals and has been used to perpetuate intolerance.

Movement building and strengthening

The prevailing legal, cultural, social and religious contexts are major obstacles to movement building and strengthening for women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals.

- Lack of recognition, representation and meaningful participation of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals and groups leads to exclusion from national health programming and campaigns.

- The marginalisation of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals and organisations by the broader human rights, health and social movements impedes movement building and strengthening.
- Lack of effective capacity building and organisational strengthening strategies leads to unsustainability and may lead to perpetual dependency on external support.

Resource allocation and mobilisation

- There is a lack of national government funding for women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender organisations with most of them not being included in country health programme budget allocations. In cases where funding does exist, the allocations are very minimal and insignificant.
- Limited availability of and access to funds for women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender groups and organisations.
- There is a lack of core support for women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals and organisations, which leads to organisations being understaffed and inadequately resourced with key staffing skills and this negatively impacts on the execution of programmatic interventions.
- Limitations are imposed on activities by having to fit in with a funding driven programmatic and strategic approach that may not respond to the needs of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals.

CONCLUSIONS

Development programmes work best when they reflect local realities and respond to both rights violations and lack of access to services. Basic and '*beyond basic*' needs programming should be planned together from intervention design, with a clear step-by-step process to move from one to the other. A rights-based approach to programming is crucial for the achievement of long term and sustainable empowerment of marginalised groups.

...not cognisant of the specific issues affecting women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals...

While the vulnerability of marginalised groups is widely acknowledged, the mechanisms that drive this vulnerability and the measures that will address them

…limitations are imposed on activities by having to fit in with a funding driven programmatic and strategic approach…

are not coherent. Most laws that increase their vulnerability are '*morality*'-based and not evidence or human rights-based. In this regard, policies need to be all-inclusive and laws – rather than being punitive, abusive or enabling of abuse and discrimination – should be protective of vulnerable people. Formulated laws and policies must also be complementary rather than contradictory.

There are a number of actions that can be undertaken in order to reduce the burden of the epidemic among women. These include promoting and protecting women's human rights, increasing education and awareness among women, and increasing access to preventative technologies, such as post-exposure prophylaxis and microbicides. Evidence and experience show that providing AIDS programmes and services to those who are most at risk can be hugely beneficial to a country's fight against HIV and AIDS. Yet, key affected groups in the global AIDS epidemic, such as women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals are all too often neglected by governments, broader civil society and international donors. Stigma and cultural intolerance of same-sex relations and sex work are largely to blame and until these issues are addressed it will be difficult to make headway in reducing HIV infection levels among these vulnerable groups. In turn, this will hinder the wider global fight against AIDS. Attacking stigma and discriminatory practices whether based in law or not, will serve to empower marginalised groups to more effectively inform themselves about HIV and facilitate access to testing, prevention, treatment, care and support.

To ensure the response to the HIV epidemic among marginalised groups is appropriate, it should be based on a wide range of quality evidence concerning, among other things, behavioural and epidemiological trends, human and legal rights, and programme monitoring and evaluation. Furthermore, such activities

…the mechanisms that drive this vulnerability and the measures that will address them are not coherent…

should involve a wide variety of people, including affected communities, governments, the private sector, nongovernmental organisations, and international partners and organisations.

RECOMMENDATIONS FOR KEY STAKEHOLDERS:

Governments should:

- Review and repeal all laws that implicitly or explicitly criminalise HIV transmission and sex work, and where applicable enforce protective laws that already exist to end the marginalisation and exclusion of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals
- Enact and implement laws and policies that create an enabling environment and ensure equal access to health and justice services
- Invest in restructuring and capacity strengthening of healthcare delivery systems to respond to the specific healthcare needs of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals
- Hold perpetrators of violence against women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals accountable for their crimes and enforce stiffer punishments

Civil Society should:

- Advocate for laws/clauses in constitutions and other legislation that prohibit discrimination of any kind based on an individual's sex, gender,sexual orientation, HIV status, choice of profession or any other status.
- Advocate for evidence-based health programming that reduces HIV transmission and protects the sexual and reproductive health and rights of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals
- Work with the media to respect and uphold the sexual and reproductive health and rights of sex workers, women living with HIV, and lesbian, gay, bisexual, and transgender individuals by objectively reporting on issues
- The media should uphold ethics and strictly adhere to codes of conduct as prescribed in various national, regional and international instruments

...attacking stigma and discriminatory practices whether based in law or not, will serve to empower marginalised groups...

- Ensure mutual and meaningful partnerships exist between all social movements, particularly with women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender movements

UN Women should:

- Urge governments to repeal punitive laws, like the criminalisation of HIV transmission, sex work and adult consensual same sex relations
- Ensure that programming on violence against women includes women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals

…ensure that programming on violence against women includes women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals…

Donors and International Partners should:

- Fund and support the transformation of the public health service so that it responds to the specific HIV treatment, care and support needs of women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender individuals
- Ensure that funding for vital research around microbicides, reproductive cancers, HPV vaccines and contraceptives includes women living with HIV, sex workers, lesbian and bisexual women, and transgender people
- Provide core support to women living with HIV, sex workers, and lesbian, gay, bisexual, and transgender organisations in order to enhance their development and strengthen movement building, and to ensure their equal and meaningful participations in programming and policy formulation

FOOTNOTES:

1. This article is an excerpt from the report 'Silenced and Forgotten: HIV and AIDS agenda setting paper for women living with HIV, sex workers and lesbian, gay, bisexual, and transgender individuals in southern Africa and Indian Ocean states' published by OSISA and UN Women in March 2013, reprinted with the permission of OSISA. [http://www.osisa.org/sites/default/files/open_policy_-_sileneced_and_forgotten.pdf]
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Collateral Damage…
On normativity, respectability, and value

Lynn Darwich

You're probably eager to hear the sad and heart-wrenching stories of queer women and trans persons back home, with an inspiring conclusion on strategies to overcome, but I will not be talking this. I will not be talking about tortures, killings, violence and discrimination based on sexual orientation and gender identity on this panel.

Instead, what I want to explore here is a status update written by one of my closest friends, Zainab, also known as Abdo, a few days ago. He said that we were more powerful when we were underground. I think what Zainab/Abdo was referring to, is our complicity, as growing movements, with the policing and preservation of the difference between those who can and want to conform to categories of normativity, respectability, and value, and those who are outside of these categories.

For over a decade now, social justice movements in Lebanon have been fighting for women's right to pass on the nationality to partners and children; for the protection of women and girls from family violence, and that includes marital rape; to abolish the sponsorship system for migrant workers, with a focus on female domestic workers in particular; to stop '*virginity tests*' for women and girls who report cases of sexual assault; to bring to an end the '*egg test*' that supposedly criminalises men

who have had anal sex; to legalise safe abortion; to include affirming comprehensive sexuality education programmes in school curriculums; to legalise civil marriage; to abolish the sectarian system that reproduces dangerous forms of cultural nationalisms. We have been fighting for these issues and many more, with very little progress in terms of policy change, if any at all. Most of the time, it looks as though we are actually regressing and losing ground. The question is why?

In our failure to connect racialised, gendered, and sexualised devaluations of human life, our movements have, more often than not, failed to challenge systems of oppression, and have instead sustained hierarchies that rely on neo-liberal forms of normativity. We cannot talk about gender-based violence, and violence based on sexual orientation and gender identity, without an analysis of the racialised, sexualised and gendered devaluation of human life, the world over. We cannot talk about any of this, without looking at today's normative standards that define the value and level of respectability that, in a given society, a human being supposedly deserves. In other words, for each of us to ask ourselves, '*what is it that makes me deserve to be a respected and valued human being*?'.

...our complicity, as growing movements, with the policing and preservation of the difference...

...our failure to connect racialised, gendered, and sexualised devaluations of human life...

In December 2011, Secretary of State Hillary Clinton declared to the world what is now possibly the most famous speech in LGBT history. She said,

> *...like being a woman, like being a racial religious tribal or ethnic minority, being LGBT does not make you less human. And that is why gay rights are human rights and human rights are gay rights.*

Like war drums, this statement reverberated across the world.

At home, the implications of such a speech are tremendous. With increasing drone attacks in Pakistan and Afghanistan, and with Israeli jets frequently hovering over my head and violating *my* airspace, at which point does '*the switch*' exactly happen? When am I a universally recognised and respected member

of the so-called global lesbian, gay, bisexual, and transgender community, and when am I collateral damage?

Audre Lorde says,

> *…there is no such thing as a single-issue struggle because we do not lead single-issue lives.*

And this is true more than ever. I will not sit here and congratulate governments that speak up on sexual and bodily rights on one hand, but who naturalise and instigate racialised violence and exploitation on the other. I refuse to let my body be used by regimes of power this way. I refuse to bargain with a government, my own, when at every corner, the basic rights of working class citizens, women, young people, migrants, and refugees are undermined to preserve and protect an imagined sectarian balance in the country.

…what we need right now, more than ever, is a paradigm shift…

In trying to organise against all of these conservative currents, all of us here have compromised well enough to sustain this world order, and to perpetuate and replicate its violence in our communities. Our superficial understandings of movement building and solidarity are violent. Our sense of entitlement is violent. Our entitlement to privileges that cannot contain and that will always compromise the rights of the working class, the gender nonconforming, the sex workers, the refugees and the migrants is violent. Our victimisation is violent. Our reliance on funding – one of the main development tools that standardise organising efforts turning them into 9 to 5 jobs – is violent. Our complicity with the military industrial complex and the institution of marriage is violent. Our victories are violent.

My critique is an acknowledgment of the tremendous efforts that are exerted in spaces like the CSW every year for progressive outcomes that can hopefully speak to people's realities back home. It is here as a reminder of the absurdity around some of the compromises we've had to make along the way for small wins. But it is also here as a reminder of the radical potential of our movements, that what we need right now, more than ever, is a paradigm shift.

FOOTNOTES:

1. This article is based on a paper presented at the Panel 'Killings and violence against women based on sexual orientation and gender identity' at the Commission on the Status on Women on 05 Mar 2013, in New York.

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MIWA...

Meaningful *investment* in women living with HIV and AIDS

The centrality and value of involving women living with HIV and other key affected women in all aspects of the HIV response has long been recognised, but it was not – and ***is*** *not – always thus.*

Luisa Orza

Twenty years ago, at the 1992 International AIDS Conference, held in Amsterdam, 55 women living with HIV stormed the conference stage in protest about the lack of recognition of issues affecting them, and their own lack of voice to platform those issues. This event marked the birth of the International Community of Women Living with HIV and AIDS (ICW).[1]

The principle of community engagement has been codified in various political commitments since then, going back to the coining of the principle of the Greater Involvement of People Living with HIV (GIPA) in the 1994 Paris Declaration[2], and reiterated in the 2001 UNGASS Declaration of Commitment[3], and the Political Declarations of 2006[4] and 2011[5].

While this principle represents one of the most *potentially* enduring – and truly transformative – characteristics of the HIV response, nevertheless, women living with HIV and other key affected women, continue to face significant challenges and barriers to accessing political spaces for meaningful participation and to realising their leadership. Moreover, these challenges remain largely unchanged over the last decade. Women and HIV activists have been talking about the same things for so long now, that GIPA (or better, *MIWA*: the meaningful involvement of women living with HIV) -fatigue must be setting in. Yet, take our eye off the ball, and the back-slide occurs in a flash.

At the International AIDS Conference in Washington DC in July 2012, the planning failed to include a woman living with HIV among plenary speakers. The *Make Women Count* movement was quick to respond and push back, resulting in Linda Scruggs' extraordinary and powerful plenary presentation, which acknowledged both MIWA-fatigue, and the on-going challenges faced and solutions sought by women, for women:

I'm not going to ask you for anything. I think women have been asking for the last two decades ... We've decided to stop asking, and maybe you just need the recipe. To turn the tide on behalf of women, we must do [the following]*: we must accurately count all women in all of our diversity into research ... We must meaningfully involve women at all levels, within our governments, within our local communities, within organizations ... We need to put women in a position of leadership and authority within the titles that they serve. We are not just asking for male-run organizations that will tolerate a women's program, we want women to have the tools to follow the research for us, by us, with us ... We need to be part of the solution; we need the support; resources that…give us the power to heal our sisters, to change our world.*

[Linda Scruggs, AIDS2012, Wednesday 25th July 2012]

MEANINGFUL INVOLVEMENT

The engagement of women living with HIV in the HIV response has both intrinsic and instrumental value. Intrinsically, participation is a human right. But this must not reduce women's involvement to a tick-box exercise. The *meaningful* involvement of women living with HIV in decision-making which effects their lives also ensures that other rights are protected.

…these challenges remain largely unchanged over the last decade…

Policy and programming around vertical transmission of HIV, such as the Global Plan to Eliminate New HIV Infections in Children by 2015 and Keeping Their Mothers Alive, and the introduction of '*Option B+*' appear to be strong from a bio-medical perspective. However, the Global Plan neglects to reinforce some of the most entrenched HIV-related rights, including confidentiality, voluntary testing, and informed consent. Similarly, Option B+ prioritises treatment as prevention over treatment for the primary purpose of improving the health and well-being of a woman living with HIV. The voices of women living with HIV need to be heard to ensure that fundamental rights, such as these, are upheld and protected, while we enjoy the fruits of bio-medical advances such as ARVs, PrEP and prevention of vertical transmission.

At the same time, the engagement of women living with HIV can RAISE[6] the effectiveness of the response, first by ensuring that policies and programmes are aligned with principles of Rights, Access, Investment, Security and Equity in the first place; second by alerting policy and programme makers to overlooked or emerging barriers and challenges affecting them; and third by acting as '*critical enablers*' in the response, by educating, sensitising, mobilising and providing services within communities around them. These efforts help to ensure (among other things) the uptake of existing services, that hard to reach populations are reached, and that quality of care is monitored. Networks of women living with HIV play a vital role in acting as a conduit between on-the-ground reality and high level decision-making. Increased effectiveness is vital at a time of global economic crisis and an overall '*shrinkage*' of resources available for the HIV response at the level of government, multi- and bi-lateral donors and civil society.

...a vital role in acting as a conduit between on-the-ground reality and high level decision-making...

SPACES FOR WOMEN

The Women's Networking Zone (WNZ) is a community-focused and -led forum running parallel to the International AIDS Conference since 2000. It provides an alternative free space for women to meet and share ideas alongside the main conference. A founding principle of the Women's Networking Zone has been to promote the leadership of women living with

HIV, and to showcase the ways in which women living with and affected by HIV are spearheading the HIV response. Core WNZ partners include networks and organisations of women living with HIV, such as ICW Global, Voices of Positive Women, the Blueprint Coalition, and Salamander Trust. And each successive WNZ to date has seen a greater representation of women living with HIV. At AIDS2012, 87% of the WNZ sessions were run by, in partnership with, or with the engagement of, women living with HIV as presenters and participants, and the MIWA principle was cross-cutting through nearly all sessions.[7]

> *It is crucial that women continue to carve out a space to address the nuanced concerns facing women, especially women living with HIV. If we do not continue to create these spaces, women's concerns will fall to the end of the agenda.*
>
> [Participant, WNZ@AIDS2012]

Yet, as funding for the HIV response flat-lines (or worse), the walls are beginning to close in on spaces like the Women's Networking Zone. Despite demand for the WNZ@AIDS2012 being the greatest to date, the financing of the Zone was nail-biting stuff; piecemeal, last-minute, and hugely labour-intensive in its achievement, administration and accountability.

One thing remains abundantly clear: outside of '*women's spaces*', and despite the proven gains of community engagement, we still

...increased effectiveness is vital...

…ensure that those with seats are truly representative of those without…

face great resistance to having people reserve us a seat at the table. What for some is a core principle remains for others a happy bonus: an extra, if resources suffice. And in times of global recession and the development community's de-prioritisation of funding for HIV as we begin to embark on a post2015 paradigm, that is a big, big '*if*'.

MEANINGFUL INVESTMENT

And the reservation of seats is not enough. Engagement is not a simple matter of turning up at a meeting. To transform that seat into a place of meaningful engagement and leadership requires a serious and committed *investment* of resources to ensure that those with seats are truly representative of those without.

Among others, issues that continue to stand in the way of HIV-positive women's meaningful involvement and leadership include: literacy – including rights literacy – language barriers, and lack of access to information; insecure livelihoods; stigma, discrimination and violence against women living with HIV at household, community, and institutional levels; voluntarism, the burden of care, burnout, and the lack of recognition for the contribution grassroots women have made to the HIV response, largely through the investment of their own resources; lack of specific skills to engage with policy, budgeting, monitoring and evaluation and accountability frameworks from a human rights and gender perspective; lack of funding to organise and engage;

patriarchal gender norms which result in a heavy burden of domestic and reproductive work, and underrate the potential and value of women's political representation and leadership.

Securing a (lasting) place at the table for women living with HIV is step one. Beyond this, governments and development partners must:[8]

1. Provide a range of accessible funding options, including core funding and seed grants for women's organisations and networks

2. Develop mechanisms, tools, and processes to ensure the meaningful participation of women living with HIV in the planning and budgeting processes of national AIDS strategies, operational plans, and accountability frameworks, as well as in monitoring expenditures and results

…securing a (lasting) place at the table for women living with HIV is step one…

3. Invest in training and capacity strengthening for women's organising and leadership beyond the delivery of care and support services, to enhance engagement in policy processes; and, promote social protection mechanisms to meet material needs, as well as empower women through skills development

4. Ensure women's access to information: invest in legal literacy and rights awareness among women, especially women living with HIV, including through translation of relevant legal and policy resources into local languages

5. Strengthen capacity among implementers and policy makers to effectively engage in two-way learning and dialogue with women living with and affected by HIV

6. Invest in women's HIV prevention, care and support programmes; documentation and sharing of good practice

7. Bridge the disconnect between national and local decision-making processes to ensure women's voices are carried through from local to national levels

8. Address cultural barriers, patriarchy and gender norms that prohibit women's engagement, including through
   a. addressing the gender division of labour, so as to create time and space in women's domestic labour, for women's effective engagement in the public sphere
   b. engaging men and boys to break down gender norms/ cycles, and promote gender equality, and
   c. sensitising men to the importance of women's political participation

9. Work with women's organisations and networks to define benchmarks and articulate indicators of success for women's meaningful participation

10. Transform signatures into action: implement existing normative frameworks that uphold women's rights, and promote women's political representation

...invest in legal literacy and rights awareness among women...

I HAVE A DREAM...

The hosting of AIDS2012 in Washington DC called to mind other social justice movements that have converged on this city. 2013 marks 50 years since Martin Luther King's immortal '*I have a dream*' speech; and in homage to that moment, the Salamander Trust[9] filmed a collection of

60-second '*dreams*' from women living with HIV. Here is one, which I think speaks for many.

I think my dream may be as follows: 'I have a dream that one day we women will no longer need to remind the powers that be in the world – that we exist. That in my lifetime all women and girls, including those of us who are living with HIV, are recognized as having the same human right to health, to participation in the world and to dignity as men and boys. That in my lifetime we will no longer have to strive to remind the world that without us it would collapse. I have a dream that one day, soon, all this – which is just a basic human right – will no longer be a dream, but a reality'.[10]

[Alice Welbourn, Founder and Director, Salamander Trust]

…articulate indicators of success for women's meaningful participation…

FOOTNOTES:

1. See www.icwglobal.org.
2. See http://data.unaids.org/pub/externaldocument/2007/theparisdeclaration_en.pdf.
3. See http://data.unaids.org/publications/irc-pub03/aidsdeclaration_en.pdf.
4. See http://data.unaids.org/pub/report/2006/20060615_hlm_politicaldeclaration_ares60262_en.pdf.
5. See http://daccess-dds-ny.un.org/doc/UNDOC/LTD/N11/367/84/PDF/N1136784.pdf?OpenElement.
6. See http://aidsconsortium.org.uk/wp-content/uploads/2012/06/Raise-the-Bar1.pdf.
7. See www.athenanetwork.org for more details and a full programme of events at AIDS2012.
8. These standards for meaningful participation are drawn from a satellite session at AIDS2012 on 'Women Leading, Organizing and Inspiring Change in the AIDS Response' hosted by UN Women in partnership with UNAIDS, ATHENA Network, Huairou Commission, and the Canadian International Development Agency.
9. See www.salamandertrust.net.
10. See also Welbourn, A. 'Is There a Future for Women Living with HIV?' [www.opendemocracy.net/5050/alice-welbourn/is-there-future-for-women-living-with-hiv]. This article is part of a series of articles commissioned for openDemocracy during AIDS2012, and edited by Alice Welbourn. To see the whole series, go to www.opendemocracy.net/5050/aids-2010-rights-here-right-now.

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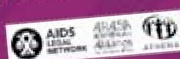
Campaign Messages...

Women say NO ...
...to criminalisation

10 Reasons Why Criminalisation Harms Women



Women say NO ...
...to criminalisation

We need supportive legislation... not criminalisation!

10 Reasons Why Criminalisation Harms Women

www.aln.org.za

We need supportive legislation...
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10 Reasons Why Criminalisation Harms Women

www.aln.org.za

Women need agency...
...not prosecution

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Women say NO...
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