



A PUBLICATION OF THE AIDS LEGAL NETWORK

Effective rights-based responses...?

The NSP response to gender violence

Johanna Kehler

Gender violence as both a cause and effect of HIV has long been recognised. Yet, thus far very few responses effectively address the links between gender violence and HIV, thus perpetuating especially women's heightened risks and vulnerabilities to HIV and to violence and abuse.



Similarly, addressing gender violence in its various forms is well-recognised as a key strategy for effective responses to HIV at a national and global level.

...violence needs to be dealt with as an integral part of multisectoral HIV responses...to better address structural determinants of violence and undertake socially transformative programmes that promote gender equality and respond to violence against women, including discouraging its perpetration.¹

CONTEXTUAL FRAMEWORK: AN OVERVIEW

It is also well-established that women are at greater risk

of and vulnerable to both HIV transmission and violence, including violence based on and in the context of HIV.²

Violence and the threat of violence can hamper women's ability to adequately protect themselves from HIV infection and/or assert healthy sexual decision-making. In addition, women living with HIV are likely to experience violence due to their HIV status.³

Data indicates that an estimated 5.63 million adults and children are living with HIV in South Africa, 3.3 million (59%) of whom are women. Furthermore, young women (aged 15 to 24 years) are four times more likely to be living with

Editorial...

This issue of the **ALQ** continues with the discourse on human rights challenges in the context of the HIV response, and highlights some of the contentious and seemingly persistent 'obstacles' to effective rights-based responses to HIV.

Moving forward with the 'new' National Strategic Plan on how to effectively address the multiplicity of HIV risks and vulnerabilities, the various articles raise questions as to how far we have come in not only recognising, but realising human rights as the core of responses to HIV realities and needs. Exploring the various links and causalities between HIV risks and gender violence, as well as the recognition of the dire need for effective rights-based responses to the 'twin pandemics' of HIV and gender violence, **Johanna Kehler** examines some of the 'new' NSP responses to gender violence. Although commending that gender violence is identified as one of the determinants of the HIV pandemic in South Africa, she argues that the somewhat 'narrow' understanding of and approach to gender violence based on and in the context of HIV will ultimately limit the effect of this 'new' response.

The need to move 'beyond commitments and oratory' and towards 'robust, radical actions and responses' to especially women's and girls' realities and needs is further highlighted by **Mmapaseka Steve Letsike** in her thoughts on the 'new' NSP. Pointing to the progress in both analysis and approach, she argues that an increase in the uptake of services can only be achieved as and when women and girls in all their diversities are truly at the centre of the national response to HIV.

Further elaborating as to whether or not women are indeed at the centre of HIV prevention efforts, particularly efforts to prevent the vertical transmission of HIV, **Gahsiena van der Schaff** introduces the views and opinions 'from the provinces'. Exploring current and newly emerging challenges across the provinces in preventing vertical transmission of HIV, limited access to and availability of quality services, persistent rights violations, and 'rude' service providers are but some of the recurring issues that were raised across the country. Moving towards accessible, user-friendly, women-centred, and rights-adhering service provision, the common theme clearly identified in all provinces is the dire need for a health plan that 'suits women,

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...the effects of gender violence
in its various forms are far-reaching...

HIV, as compared to their male counterparts of the same age, and HIV risks are further exacerbated for pregnant women and survivors of physical and/or intimate partner violence in this age group.⁴ In addition, the 2010 Antenatal Survey published by the Department of Health in 2011, calculated the national prevalence among antenatal women aged 15 to 49 years at 30.2%, with the highest recorded prevalence of 39.4% in KwaZulu Natal. According to latest data, the peak of HIV prevalence now occurs in women between the ages of 30 to 34 years, with a prevalence rate of 42.6% in this age group.⁵

The effects of gender violence in its various forms are far-reaching and well-documented. Violence and/or the fear of violence greatly impact not only on the extent to which women are in the position to claim their rights and to access and benefit from available HIV prevention, testing, treatment, care and support services⁶, but also on decisions as to whether or not, and when to access services, including HIV prevention and testing; and whether or not and to whom to disclose a positive HIV diagnosis. A study by Amnesty International⁷, involving rural women from KwaZulu Natal, concluded that women continue to live ‘in a general environment of high levels of sexual and other forms of gender-based violence’⁸. The study continues to highlight that women’s access to services is, amongst other things, impeded by both the impact of sexual and other forms of abuse on women who have been exposed to the risks of HIV through coercive and unprotected sex, and the impact of HIV-related stigma and discrimination on the extent to which women are in the position to make informed decisions whether or not to test for HIV without fear of violence and abuse.⁹

HIV-related stigma and discrimination further lead to

a situation in which especially women living with HIV are further subjected to violence and other rights abuses within their relationships, families, households, communities and service provision, as and when their positive HIV diagnosis becomes known. Within healthcare settings, women living with HIV are often exposed to discriminatory attitudes and practices from healthcare providers, and as a result experience limited, delayed and/or denied access to services, and are subject to coercive practices, especially in the context of sexual and reproductive healthcare, such as coerced termination of pregnancy and sterilisation without consent. Prevailing rights violations and abuse within service provision not only impact negatively on women’s access to services and information, but also seem counterproductive to effective responses to women and HIV.

Many women living with HIV are unable to access services because they fear stigma and discrimination if their HIV status is disclosed. Violence against women, which has been defined as a form of gender-based discrimination, also creates barriers for women living with HIV who may fear the consequences of accessing HIV testing and medication. They risk violence, abandonment and poverty if their HIV status is discovered by their partners and families.¹⁰

Especially within the context of HIV testing, including HIV testing during pregnancy, women and women’s rights are frequently compromised and violated, as women find themselves often coerced and/or forced to test for HIV as a pre-requisite for accessing antenatal care and other sexual and reproductive health services.¹¹ A recent study on

...counterproductive to effective
responses to women and HIV...

protects their rights, and caters for their needs.

The need for women, and particularly women living with HIV, to be at the centre of the response is a well-recognised core element of 'successful' prevention of vertical transmission interventions. Findings from a virtual consultation, facilitated by the **AIDS Legal Network and the Global Coalition on Women and AIDS**, with women in 22 countries reveal not only the common challenges and gender barriers to service access across countries, but also that women are 'eager and ready' to engage in all processes affecting their lives, and to have their voices 'listened to and acted upon'.

Women's sexual orientation and/or gender identity are additional factors greatly impacting on the extent to which women's voices are 'listened to and acted upon', and services are accessible to lesbian, bisexual and transgender women. Exploring the Namibian context, **Linda Baumann** argues that effective responses to the realities, risks and needs of women in all their diversities requires that lesbian, bisexual and transgender women are 'visible' in and part of the discourse of women and HIV.

While there seem to be many 'new' commitments, approaches and responses to HIV realities, risks, and needs, there also appears to be as many remaining 'threats' and 'compromises'

to human rights in the response to HIV. Intensifying the scale-up of HIV testing, including through HIV testing in schools, has long raised debates as to the 'inherent threat' to human rights posed by these interventions. The article by **Vivienne Mentor-Lalu and Kerry-Jane Coleman**, revisits the concept of HIV testing at schools, discusses the human rights implications of this approach, and asks 'have children been considered?'

The impact of criminalising HIV exposure and transmission on people and the effectiveness of the AIDS response seems to be a similarly 'old' and ever-recurring debate, with its most recent renaissance 'triggered' by Zille's 'populist' statements on HIV in November last year. Responding to Helen Zille and her views on HIV, **Gavin Silber and Nathan Geffen** argue that the Premier's views are not only 'misinformed and unscientific', but also 'irresponsible and wrong', as their implementation would cause 'terrible harm'. Introducing the law, **Pierre de Vos** further responds to Helen Zille arguing that criminal law cannot be used to punish individuals merely for not conforming to the 'moral standards' of sexual behaviour, as otherwise the law would then become an 'oppressive and authoritarian instrument of social control'.

One of the 'common threads' in all articles is the persistence of rights violations based on and in the context

of HIV, severely impacting not only on service access, but also on the extent to which especially women are in the position to take control of their own HIV risks. Thus, the 'loud and clear' call by many, including the 'new' NSP, is for redress mechanisms to be available and accessible to all in need. The 'pros and cons' of seeking redress for HIV-related discrimination at the Equality Court, as one avenue of accessing justice, are discussed by **Nonandi Diko**. Based on the premise that any form of unfair discrimination based on HIV status is unconstitutional and thus, unlawful, she argues that the Equality Court although 'in principle' affording redress also carries potential 'risks and negative consequences', as seeking redress may also cause further violations of rights. Thus, it seems to be the combination of changing social environments and increasing rights literacy, which will ultimately lead to increased access to 'safe' and 'effective' redress mechanisms.

Notwithstanding the 'visible' progress and increased commitments to ensuring rights protections in the response to HIV, the need for 'robust' discourse on the many 'contentious' and often 'invisible' issues and realities affecting both HIV risks and HIV responses remains. And so, the human rights debate continues...

JOHANNA KEHLER

women's experiences of HIV testing during pregnancy¹² conducted in the Western Cape and KwaZulu Natal, for instance, revealed that in reality there seems to be little to no option for pregnant women to voluntarily decide whether or not to test for HIV; to have access to adequate information and time to make such a decision; and to make an informed choice free of coercion and fear of repercussions. Women participating in the study also indicated that their right to confidentiality, both during the testing process and on receiving their test results, was severely compromised and violated. The majority of respondents spoke about being tested with others present, of doors left open, staff interruptions and open discussions about women's HIV test results, which in turn often lead to further violence and abuse by both healthcare workers and community members.¹³

...the dire need for effective rights-based responses to the 'twin pandemics' of HIV and gender violence...

Women's HIV risks and vulnerabilities are further exacerbated by high levels of sexual and gender violence.¹⁴ According to UNAIDS, experiencing violence increases the risk of HIV transmission by a factor of three¹⁵, and women are more likely to experience violence and abuse based on their positive HIV diagnosis¹⁶. In South Africa, cases of sexual assault and rape remain highly under-reported. An estimated 88% of incidences are not reported¹⁷, due to self-blame, fear of not being believed, trauma, and fear of secondary victimisation¹⁸. It is further estimated that every 17 seconds a woman is raped in South Africa.¹⁹ These pandemic



proportions of incidences of sexual violence perpetrated against women are yet but another indicator of women's greater risks and vulnerabilities to HIV, violence and other rights abuses.

The inadequate integration of services, as well as a lack of adequate access to justice for women who have been violated, often create a situation in which women experience multiple layers of violence and other rights abuses, ranging from interpersonal to structural and institutional violence. Recognising both the gendered nature of HIV risks and vulnerabilities, including related stigma, discrimination and other rights violations, as well as the pervasiveness of gender violence based on and in the context of HIV, arguably, highlight the dire need for effective rights-based responses to the 'twin pandemics' of HIV and gender violence, with women and women's rights, realities and needs at the centre of the response.

...there are arguably also some fundamental challenges within the conceptualisation of the NSP...

COMMITMENTS AND RESPONSES

Global commitments

Women's risks and vulnerabilities, as well as the need to adequately address women's realities through the protection and advancement of women's rights have been recognised in HIV-related declarations and commitments at a global, regional and national level. Furthermore, women's rights to equality, non-discrimination, and freedom from all forms of violence and gender-based discrimination are as much core elements of numerous human rights instruments, as they are fundamental principles to South Africa's constitutional, legislative and policy framework.

The 2011 Political Declaration on HIV/AIDS²⁰, for instance, recognises that women remain the most affected by the epidemic, and that

*...the ability of women and girls to protect themselves from HIV continue to be compromised by physiological factors, gender inequalities, including unequal legal, economic and social status, insufficient access to healthcare and services, including for sexual and reproductive health, and all forms of discrimination and violence, including sexual violence and exploitation against them.*²¹

Based on this recognition, head of states and governments 'pledge to eliminate gender inequalities and gender-based abuse', through among other, ensuring that

...women can exercise their right to have control over, and decide freely and responsibly on, matters related to their sexuality in order to increase their ability

*to protect themselves from HIV infection, including their sexual and reproductive health, free of coercion, discrimination and violence.*²²

Human rights obligations

The promotion of women's rights to equality and prohibition of all forms of gendered discrimination and violence are also primary objectives of the Convention on the Elimination of Discrimination Against Women (CEDAW), and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (African Women's Protocol).²³ In addition to explicitly protecting women's sexual and reproductive rights and health needs, the African Women's Protocol recognises 'harmful practices' as a factor significantly impacting on women's risks and vulnerabilities and, thus, urges state parties 'to condemn and prohibit all forms of harmful practices which negatively affect the human rights of women'²⁴, and to

...enact and effectively implement appropriate legislative or regulatory measures, including those



*prohibiting and curbing all forms of discrimination particularly those harmful practices which endanger the health and general well-being of women.*²⁵

In South Africa, the right to equality, non-discrimination, autonomy and consent, and to be free from all forms of violence are constitutionally guaranteed²⁶, with numerous laws and policies giving effect to these provisions. However, despite these commitments and the enabling legal environment, women and women's rights continue to be compromised and violated, especially in the context of HIV, as gendered inequalities and unequal power relations prevail, which determine and further manifest women's risks to HIV and to violence and abuse.

The national response to HIV

The 'new' National Strategic Plan on HIV, STIs and TB, 2012 – 2016, launched on 01 December 2011, provides 'the strategic guide for the national response', and aims to

*...inform national, provincial, district and community-level stakeholders on strategic directions to be taken into consideration when developing implementation plans.*²⁷

The 'new' NSP also reaffirms, among other, its commitment to a rights-based national response to HIV, STIs and TB, and as such identifies as one of its principles that

*...the NSP must be rooted firmly in the promotion and protection of human and legal rights, including prioritising gender equality and gender rights.*²⁸

The national response will be informed by four strategic objectives²⁹, namely to

- *Address social and structural barriers to HIV and TB prevention, care and treatment* – the primary objective is to address societal norms and behaviours through structural interventions to reduce vulnerability and to mitigate the impacts of HIV and TB

- *Prevent new HIV, STI and TB infections* – the primary objective is to ensure a multi-pronged approach to HIV, STIs and TB prevention, which includes all biomedical, behavioural, social and structural approaches in order to reduce new HIV, STI and TB infections
- *Sustain health and wellness* – the primary objective is to ensure access to quality treatment, care and support services for those with HIV, STIs and/or TB and to develop programmes to focus on wellness, inclusive of both physical and mental health
- *Ensure the protection of human rights and increase access to justice* – the primary objective is to address issues of stigma, discrimination, human rights violations and gender inequality

...narrow approach to addressing gender-based violence as one of the determinants of the HIV...

The national response to women and HIV, as outlined in the NSP, is undoubtedly informed by an analysis of the various risks and vulnerabilities of women to HIV transmission and related violence³⁰. Based on this analysis, the NSP highlights, among other, gender roles and norms, as well as sexual abuse and intimate partner violence, as structural determinants of South Africa's HIV epidemic. To respond to these factors fuelling the pandemic, the NSP recommends to

*...challenge the gender roles, norms and inequalities that increase women's vulnerability to HIV and compromise men's and women's health; address the position of women in society, particularly their economic standing; and engage with men on changing socialisation practices.*³¹



Furthermore, the NSP calls for *'interventions to prevent gender-based violence, as well as intimate partner violence, and educate men about women's rights'*³².

The NSP includes a number of *'social interventions'* aimed at changing cultural and social norms and practices that define and perpetuate risks and vulnerabilities to HIV transmission and related violence, ranging from addressing gender inequalities and gender-based violence (Objective 1.3) to social and behavioural change communication strategies (Objective 2.4) and providing training to prevent unfair discrimination within service provision (Objective 4.3.2). In addition, the NSP clearly recognises the negative effects of persistent HIV-related stigma, discrimination and other rights abuses on women's access to services, including the lack of access to redress mechanisms as and when women have been violated. Reaffirming the *'centrality of constitutional values and human rights'* in the national response to HIV, the NSP Objective 4 further emphasises that *'interventions be planned*

and implemented' in such a way that recognises both the specific needs of *'particular groups and key populations'* and *'the social, cultural, legal, economic and other possible barriers to accessing services'*.³³

While the NSP objectives and interventions seem to indicate a comprehensive approach to the multiple risks and vulnerabilities to HIV and violence in its various forms for women and other key populations at higher risk, there are arguably some fundamental challenges within the conceptualisation of the NSP. For instance, interventions aimed at addressing gender-based violence seem to largely focus on sexual and intimate partner violence (Objective 1.2 and 2.7), thus failing to adequately address gender violence in its various forms, including institutional and structural violence impacting on especially women's risks and vulnerabilities. Notwithstanding the dire need for these interventions, this seemingly narrow approach to addressing gender-based violence as one of the determinants of the HIV epidemic will impact on the overall effectiveness of the NSP to challenge and transform the societal context in which women's risks and vulnerabilities are defined and perpetuated.

Even though South Africa has a generalised HIV epidemic, the NSP recognises and defines *'key populations'* in need of *'targeted'* interventions. According to the NSP, key populations are *'those most likely to be exposed to, or to transmit, HIV'*, and include people

*...who lack access to services, and for whom the risk of HIV infection and TB infection is also driven by inadequate protection of human rights, and by prejudice.*³⁴

...the ultimate transformation of these norms and practices...

...it is greatly disturbing that women are not explicitly listed...

Key populations included in the NSP range from young women and people living in informal settlements to migrant populations and people with disabilities. It is also important to note that the NSP explicitly includes sex workers and their clients, men who have sex with men, and transgender persons as *'key populations'* in need of specific targeted interventions. Given this fairly broad and inclusive list of *'key populations'*, it is greatly disturbing that *women* are not explicitly listed, despite the recognition of women's greater risks and vulnerabilities highlighted throughout the NSP, as well as data indicating HIV prevalence rates of 42.6% among women (30 to 34 years), which is far beyond the national prevalence rates of 30.2%. This, arguably, raises the question as to the extent to which interventions will be in the position to adequately address women's realities and needs, including violence based on and in the context of HIV, if women are not seen as a *'key population'* in need of specific programmes and targeted interventions.

The national strategic plan does however place a certain amount of responsibility on provinces and districts calling for the assessment and identification of specific *'transmission hotspots and key populations'*, which must form part of provincial and sector implementation plans. One can only hope that *women* are explicitly included as a *'key population'* in provincial and district plans, especially since there is plenty evidence that women by virtue of birth (biological) and by virtue of the gendered societal context are *'most likely to be exposed to HIV'*, *'lack access to services'*, and are at heightened risks of rights abuses.

It is widely recognised that sex workers' criminalisation is one of the causes increasing the risks of both violence and

HIV transmission, as sex workers often remain unreached by programmes and access to services continues to be severely limited and/or denied, due to their criminalised status. The NSP recognises sex workers and their clients as one of the *'key populations'*, which is commendable. However, one of the major flaws of the *'new'* NSP is undoubtedly its failure to call for the decriminalisation of sex work, thus, acknowledging the effects of criminalisation on sex workers risks and vulnerabilities to both HIV transmission and to violence and abuse.

MOVING FORWARD...

While it is commendable that the NSP recognises the unequal gendered societal context as one of the determinants of the HIV epidemic, questions, however, should be raised as to whether or not the analytical framework and contextualisation of its analysis is sufficiently informed by the very same gendered inequalities, power relations, and patriarchal systems that define and manifest women's greater risks to HIV transmission and to violence based on and in the context of HIV; and whether or not the recognition of *'drivers'* of the epidemic has been adequately translated into interventions that indeed will change women's risks and vulnerabilities.

Challenging gender roles, norms and inequalities is a key element of addressing women's greater risks and vulnerabilities to HIV; although it is the ultimate

...the remaining shortfalls within its analysis and interventions will ultimately limit the effect of this *'new'* National Strategic Plan...

transformation of these norms and practices that will lead to an environment in which women are equally in the position to claim their rights, control their HIV risks, and access and benefit from available services.

As long as women in their own right and in all their diversities are not recognised as 'key populations', women's realities, risks and needs will remain on the 'margins' of the response to HIV. Similarly, as long as violence based on and in the context of HIV is not truly addressed in all its forms and in its gendered nature, the correlations between violence and HIV will continue to define and further manifest especially women's risks and vulnerabilities. Subsequently, responses to HIV, although recognising women's risks, the adverse effects of violence and gender roles, and calling for the protection of human rights in all aspects of developing and implementing programmes and interventions, will remain largely ineffective for women. Hence, notwithstanding the progress made in the document guiding the national response to HIV, the remaining shortfalls within its analysis and interventions will ultimately limit the effect of this 'new' National Strategic Plan.

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FOOTNOTES:

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Misinformed and unscientific... Premier Helen Zille's views on HIV¹

In November 2011, Western Cape Premier Helen Zille made various comments suggesting that the provision of healthcare to those who behave 'irresponsibly' should be reconsidered. Writing in her weekly newsletter², the Premier noted that over half of the Province's budget is spent on 'preventable illness', while the 'scraps' are given to unpreventable conditions. This, she claimed, 'has further widened the gap between "rights" and their "essential corollary – responsibility'.



Gavin Silber and Nathan Geffen

Specifically citing people who contract HIV through 'irresponsible' behaviour Zille rhetorically questioned why 'taxpayers must foot the bill without asking any politically incorrect questions – enough already!'. She later tweeted that 'if you duck responsibility, don't come running to the state when you need treatment'.

A few days later – at a provincial health summit – the Premier went further to say that people who knowingly infect others with HIV should be charged with attempted murder.

The premier's views are possibly popular across the political spectrum, but they are misinformed and unscientific. This debate is repeated periodically. Although there are existing rebuttals of the arguments the premier puts forward³, this article first addresses arguments about why the Premier's arguments on responsibility are wrong. We then deal with

criminalisation. Finally we deal with the Premier's concern that HIV treatment is taking resources away from unpreventable diseases.

WHY THE PREMIER'S ARGUMENTS ON RESPONSIBILITY ARE WRONG

The premier's proposal is unconstitutional

The Constitution says that everyone has the right to have access to healthcare services and that the state must, within its available resources, realise this right. The Constitutional Court has found that the state, because it has limited resources, can limit the provision of a health service using reasonable criteria, such as how well patients will respond to treatment. But it is unlikely that the court would consider the way an illness was contracted to be a reasonable criterion.

Provision of health-care based on 'responsibility' is impractical

It is impractical to provide antiretroviral treatment depending on how people contract HIV. Health workers cannot be expected to investigate how their patients became infected. Besides being an invasion of privacy, it is often impossible to determine this reliably. Also, on what criteria is a health worker supposed to decide if the particular behaviour that resulted in infection was irresponsible or not?

The consequences of the Premier's proposal are untenable

Consistently only providing medical care to people based on 'personal responsibility' leads to frightening consequences. It would mean cigarette smokers would not get treated for cancer. People who eat unhealthily would not get treated for type II diabetes or heart disease. The same for people who do not look after their teeth properly, or suntan too much and develop skin cancer, or sportsmen who over-train and injure themselves. There is no precedent for providing healthcare only to people who live a life of perfect responsibility.

Treatment based on 'responsibility' discriminates against the poor

People who can afford private healthcare would still be treated irrespective of how they contracted HIV, or for that matter any other ailments acquired through irresponsible behaviour. It is only poor people who use the public health system who would be affected by Zille's proposal.

...providing treatment as widely as possible is not only good for personal health, but is also a critical public health intervention...

Providing antiretroviral treatment is an effective way to reduce HIV transmission

Zille laments the large sums of money spent on AIDS treatment, as opposed to prevention. However, science shows that HIV positive people on treatment with an undetectable viral load are unlikely to transmit HIV. Studies in several cities around the world have shown a decline in new HIV cases, as antiretrovirals are scaled up. On balance, the evidence shows that the rate of new HIV infections is declining in South Africa. Antiretroviral

treatment is likely one of the factors contributing to this. Providing treatment as widely as possible is not only good for personal health, but is also a critical public health intervention.

...criminalisation will stigmatise the disease further and discourage people from getting tested and finding out their status...

Withholding antiretroviral treatment has huge costs

People on antiretroviral treatment have almost normal life expectancy. But people denied treatment will frequently get opportunistic infections and need to be hospitalised. Failing to provide treatment will cause poor families great emotional and economic hardship. Parents will be far more likely to die young and there will be more orphans.

WHY THE PREMIER'S ARGUMENTS ON CRIMINALISATION ARE WRONG***Preventing HIV transmission should be based on science, not morals***

Moral judgments about responsibility are easily made by people who never have to face the choices about sex that many poor people in this country constantly have to make. Reducing HIV transmission should be based on science, not moralising.

In a Cape Argus interview in November 2011, Zille claimed that countries in Europe that criminalised HIV transmission had 'beaten' the HIV epidemic. But no country in Western Europe, whether or not it has criminalised transmission, has had a large HIV epidemic. What does she mean by 'beaten'? If she means a reduction in HIV incidence, there

is no evidence that criminalisation is associated with reduced incidence.

On the contrary, criminalisation will stigmatise the disease further and discourage people from getting tested and finding out their status. The Premier's response to this is to make HIV testing 'mandatory'. Besides the appalling human rights consequences of this argument, the state does not have the capacity to do this.

On the other hand, the programme of voluntary counselling and testing introduced into the health system is resulting in millions of people getting tested. Why would Zille want to change an approach that is starting to produce results?

...reducing HIV transmission should be based on science, not moralising...

People are most infectious just after becoming infected

A challenge of HIV prevention is that people are most infectious just after becoming infected, when they do not know their HIV status and cannot yet determine it using standard tests. Neither criminalisation nor mandatory HIV testing can address this, but scaling-up antiretroviral treatment might.

Criminalisation removes responsibility from uninfected people

An important HIV prevention message is that people should take responsibility for their own HIV status. For an HIV negative person this means assuming that your sexual partner or partners are HIV positive and therefore, practising safer sex. Criminalising HIV positive people who have unprotected sex sends the message that their HIV negative partners do not have to take equal responsibility to practice safer sex.

Current laws sufficiently deal with intentional transmission of HIV

Very few people intentionally transmit HIV. Those that do can and should be prosecuted under assault laws. HIV is no longer a fatal disease, but a chronic condition, much like diabetes.

We know of no other sexually transmitted infection whose transmission is expressly criminalised

Human papilloma virus is a sexually transmitted infection and the cause of cervical cancer. Its transmission is not criminalised. Hepatitis is often transmitted sexually, and is frequently a lifelong chronic illness that can be fatal. Its transmission is not criminalised.

It would be inconsistent to demand the specific criminalisation of only one sexually transmitted infection, as well as impractical to criminalise the transmission of most or all sexually transmitted infections.

It is extremely hard to scientifically determine who infected whom

HIV mutates quickly and it is almost always impossible for genetic tests to determine routes of transmission to determine who infected whom.

SPENDING ON HIV VERSUS SPENDING ON THE DISABLED

The Premier argues that HIV treatment takes resources away from other health services, such as those for children with disability. In reference to children who are deaf, she claimed that 'there are protests outside my office every week on almost every conceivable issue. Why is no-one out there protesting for the rights of these children? Is it because people with disabilities are not regarded as fully human?'

The Premier has missed opportunities to provide care to the disabled

Both the Western Cape and national governments opposed

a court action on behalf of severely mentally disabled children requesting special provisions for their education.

Although the case was brought against the Western Cape government when the ANC was in power, it was only heard in 2010, a year into the DA's rule. The Premier had the opportunity not to oppose the plaintiff's demands. Instead the Western Cape government argued, shockingly, that *'for children who do not qualify for admission to special schools, no amount of education would be beneficial'*. The court found for the plaintiff.

...her views might be popular, but if they were implemented, they would cause terrible harm...

Zille's comments create competition for resources between people with HIV and people with disability for limited public health sector resources. A better strategy would be to look for ways to make the public health system less wasteful and to get the private sector to take responsibility for a greater share of the health burden.

Government can do more to reduce preventable illness

The Premier is right to be concerned about the large burden placed on the public health system by preventable illnesses. But there are far more productive ways for government, both nationally and provincially, to reduce disease. For one thing condoms should be available in all schools, along with sex education programmes. Many youths have sex. Pretending they do not is a recipe for increased HIV incidence and teen pregnancies.

One of the biggest causes of preventable childhood disease and infant mortality is diarrhoea, and in most cases

directly attributable to poor communal sanitation facilities in informal settlements. The provincial health department has an important role in monitoring environmental health and diarrhoea in these communities. While much has been done to improve treatment of diarrhoea, a lot more needs to be done to address the root cause. In August last year, a Western Cape Provincial Government presentation was released showing serious shortcomings with repairs of standpipes and toilets in informal settlements – most faults reported were never addressed. Working with municipalities to ensure that there is adequate monitoring to identify problem areas – and addressing them swiftly – would contribute enormously to reducing this easily preventable illness, which strains the public health system.

Premier Zille's prescriptions would violate the Constitution, discriminate against the poor, increase stigma, and ultimately be counter-productive. Her views might be popular, but if they were implemented, they would cause terrible harm.

FOOTNOTES:

1. This is an expanded version of an article that was published in The Cape Argus on 15 November 2011, available on Quackdown. info [www.quackdown.info/article/helen-zilles-views-hiv-are-unscientific/] and Politicsweb [www.politicsweb.co.za/politicsweb/view/politicsweb/en/page71619?oid=266888&sn=Detail&pid=71616].
2. See www.da.org.za/newsroom.htm?action=view-news-item&id=9971.
3. For instance, Doron Isaacs has written a succinct rebuttal of the criminalisation of HIV [See www.quackdown.info/article/five-quick-reasons-why-criminalisation-hiv-wrong/]; Scott Burris, Judge Edwin Cameron, and Michaela Clayton have written an in-depth explanation of why criminalisation of HIV is wrong [http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1189501]; Gavin Silber has previously argued against the Premier's position when she made similar arguments in 2009 [www.politicsweb.co.za/politicsweb/view/politicsweb/en/page71619?oid=141446&sn=Detail]; and Edwin Cameron and Nathan Geffen debated David Benatar on whether a person contracting HIV through his or her irresponsibility has a right to treatment [<http://witnessoaid.com/debates.html>].

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HIV testing in schools... Have children been considered?

Vivienne Mentor-Lalu and Kerry-Jane Coleman

Promoting HIV testing in South Africa has been a priority for the Department of Health (DOH) for reasons that are not difficult to understand.

South Africa currently faces a pandemic, where its HIV infected and affected population is rated amongst the highest in the world.¹ It is a well-established argument that early diagnosis will lead to early treatment and intervention, prolonging and increasing the quality of life for people living with HIV. In addition, people who test negative for HIV will be encouraged to adopt behaviours that will keep them negative. The president of South Africa thus launched an HIV Counselling and Testing (HCT) Campaign in April 2010. The HCT² campaign, as it is commonly known, had the ambitious target of testing 15 million people by April 2011.³

Many, therefore, welcomed the proclamation made by the Departments of Basic Education and Health of their intention to launch an HCT campaign that will specifically target high school learners in 2011. Although schools may provide easy and fast access to large numbers of children for the purposes of HIV testing, the very setting of these schools provides the potential context for the violation of children's rights many would argue should be intrinsic to the HCT campaign. Many children's rights, human rights

and AIDS organisations and activists have raised a range of concerns about HIV testing in schools with the state departments involved in this particular campaign.⁴ The key question has been whether or not schools are conducive spaces to protect the basic rights of learners, and many have argued that testing in schools is far more likely to compromise the basic standards required for an HCT campaign.

Minimum standards for HCT were developed for the Southern African Development Community region (SADC) by its Directorate for Social and Human Development and Special Programmes. This document identifies principles to guide HCT minimum standards. These principles include, amongst others, gender equity promotion; greater involvement of people living with HIV; contextual relevance of programmes; partnerships with civil society; protection of human rights; and environments that need to be conducive for HCT. The following minimum standards around HCT are proposed for member states⁵:

- HIV testing facilities are available and accessible free of charge
- Routine offer of testing in health facilities
- The age of consent for HIV testing is 12 years and above
- Standards for service provision need to include consent, confidentiality and counselling
- Capacity building for providers
- Accreditation of HCT sites must be done by a team of technical experts, and requirements for accreditation include staff, space, equipment and supplies
- Quality assurance of HCT services
- Appropriate referrals must be made to additional services as needed

- Comprehensive HCT approaches
- Involvement of men and people living with HIV

The main concerns regarding the HCT campaign in schools focus on the likelihood that key principles and minimum standards for HCT could be jeopardised.

INFORMED CONSENT AND COUNSELLING

Using schools as a base for HIV testing in order to reach large numbers of children poses a serious challenge to informed consent, which is a central requirement in HCT. Concerns have been raised about whether children will have enough time to absorb the information and ask questions regarding the process and possibly their HIV status. Questions have also been raised about whether schools can provide the logistical space required to conduct pre- and post-test counselling.

Tied closely to informed consent is the basic requirement that all HIV testing be voluntary. Concerns have been raised regarding the complex dynamics particularly facing teens, such as peer pressure, and how this may influence their ability to voluntarily consent to testing. The possibility exists that adolescents may feel coerced or pressured to test. Furthermore, there is an existing power dynamic between educators and learners, which could result in the mere presence of an educator making a learner feel compelled to take the test.

...the very setting of these schools provides the potential context for the violation of children's rights...

CONFIDENTIALITY

Testing at schools immediately restricts the right to confidentiality. This is particularly the case with the confidentiality of the results. Children's possible emotional reactions to the results, or refusal to participate, can easily be interpreted to mean that they have tested positive for HIV. There does not appear to be any plans for psychosocial education with educators and learners on the range of emotions that learners may experience, once they have tested. For example, a learner crying after testing could be interpreted to mean that the learner tested positive. However, it could also mean that the learner is relieved at testing negative. This demonstrates the need for an approach to HCT testing in schools, which includes awareness raising and information sharing with educators and learners before HIV testing is introduced.

STIGMA

An important aspect of living positively with HIV is support and acceptance. In the absence of proper engagement with educators and learners regarding HIV, there is a high probability that learners who test positive for HIV will face stigma and discrimination at school from the peers and educators who have not received enough, if any, capacity building to be able to provide support to learners who test positive. This will add to the isolation faced by the learner and have an impact on the learner's ability to access treatment. Bongani Mani, president of the Congress of South African Students (COSAS), raised concerns around stigma in an article published in the Sowetan:

The country has not dealt with the stigma attached. You cannot expect a learner to go for such a life-changing test and then go back to class as if nothing happened. Serious medical tests such as HIV and Aids should be done outside the school. Schools are for learning and should remain so.⁶

A common strategy to ensure support for adults living with HIV is the recommendation for that adult to disclose their HIV status to at least one supportive person. The DOH has suggested this strategy apply to children as well where a child can bring a 'buddy' with them through the testing process. The 'buddy' would also be required to keep this information confidential. This approach will place adult responsibility onto the 'buddy' to provide support should their friend test positive. It also merely transfers an approach designed for adults onto children.

PSYCHOSOCIAL SUPPORT AND TREATMENT

Psychosocial support and HIV treatment programmes specifically geared for children have not been established in anticipation of the HCT programme. Mental health problems are known to increase dramatically after adults have tested HIV positive, with people living with HIV being 36 times more likely than the general population to commit suicide. Assumptions have been made that since the figure of adolescent suicide is generally higher than that of the general population that one could predict higher figures of suicide among young people who test positive. This will result in children who test positive and their families being left unsupported or expected to fit into existing services already constrained and geared towards adults.

LEGAL RAMIFICATIONS OF DISCLOSURE OF CONSENSUAL SEX

Children's rights organisations and activists have long been critical of conflicting provisions in various pieces of legislation affecting children. The Children's Act of 2005 makes provision for children aged 12 and older to be able to consent to HIV testing, without the permission of a parent or guardian. The Amended Sexual Offences Act of 2007 in turn stipulates that children between the ages of 12 and 16, who engage in consensual sexual acts, are liable for

...a serious challenge to informed consent, which is a central requirement in HCT...

prosecution. The National Director of Public Prosecutions had demonstrated, with what has become known as the *Jules case*, their intentions to act on the provisions in the law with children engaging in consensual sexual activities.⁷ The Amended Sexual Offences Act further places a duty on adults, who are aware of children engaging in sexual activities, to report this to the relevant authorities. In the process of HIV testing, a child may disclose to the healthcare practitioner that they have been sexually active. This will then potentially incriminate the child and place a responsibility on the healthcare practitioner to report the child to the authorities.

CONCLUSION

In conclusion, South Africa listed the objectives of the broader HCT Campaign announced by President Zuma as follows:

- Mobilise people to know their status
- Provide key prevention messaging to encourage healthy lifestyle practices irrespective of HIV status
- Increase incidence of health-seeking behaviour
- Increase the access to treatment, care and support

The state's approach to this particular campaign to test children in schools seems only to focus on the first objective. Moreover, the campaign appears to be designed to meet government targets rather than to adhere to the initial holistic intentions and meet basic human rights whilst doing that. The state's promotion of HCT, laudable as it is, should not

overshadow the importance of protecting the rights of people being tested, and in this case the rights of children.

ADDENDUM

Due to increasing pressure from civil society the Department of Health agreed to suspend its HCT campaign in schools. In an article from The Times Live in May 2011 the Department of Health acknowledged that serious legal and ethical concerns needed to be addressed. The department, however, remained adamant that the campaign would still start in 2011.⁸

According to an article in the Mail & Guardian Online in December 2011, the Department of Basic Education stated that HIV testing of learners in school could not start in the first quarter of 2012, due to a number of unresolved issues.⁹ Currently there has been no indication of how the Department of Health intends to address the legal and ethical concerns

...the campaign appears to be designed to meet government targets rather than to adhere to the initial holistic intentions and meet basic human rights whilst doing that...

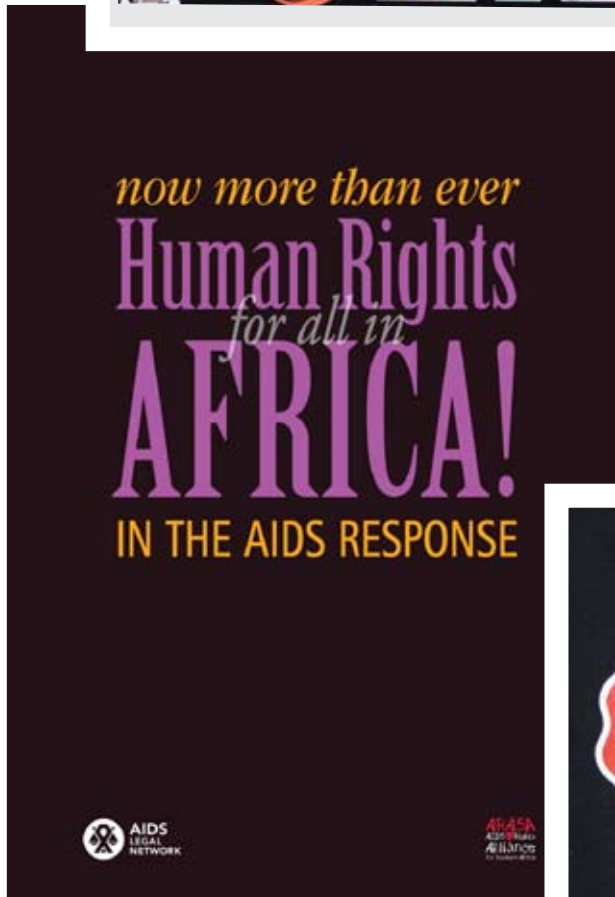
raised. A date for the implementation of the campaign has not been set. It is however, important to note that the new NSP includes HIV testing in schools as one of its strategies, although recognising that policies guiding HIV testing in schools need to be developed.¹⁰

FOOTNOTES:

1. According to the NSP, South Africa has an estimated 5.63 million people living with HIV. Of these, 5.3 million were adults aged 15 years and older, 3.3 million were females and 334,000 were children. The 2010 National Antenatal Survey, published in 2011, further estimates the national HIV prevalence among women (aged 15 to 49 years) attending antenatal services at 30.2%, showing a slight increase from 29.4% in 2009. KwaZulu Natal continues to have the highest recorded prevalence of 39.4%. Similarly, the 2010 Antenatal Survey confirms great disparities among the provinces ranging from a low of 18.4% in the Northern Cape to a high of 39.4% in KwaZulu Natal. While the HIV among young people (below age 20) slightly declined from 2008 (14.1%) to 2009 (13.7%), the prevalence in this age group slightly increased in 2010 to 14%.
2. The AidsBuzz website explains the difference between VCT and HCT as follows: With the introduction of new guidelines in February 2010 the government's policy on VCT has been expanded to include provider-initiated HCT. Previously, healthcare workers recommended testing only if HIV disease was suspected. Now regular HIV testing, while still voluntary, is to be routinely recommended to everyone as an important part of normal health-seeking behaviour. This is the main difference between VCT and HCT. [http://aidsbuzz.goodwebmarketing.com/index.php?option=com_content&view=article&id=231&Itemid=34]
3. See also Treatment Action Campaign [www.tac.org.za/community/node/2870]
4. RAPAN is a member of the Yezingane Network: a civil society network of networks whose membership includes organisations working to address the impact of HIV on children, families and communities. The Yezingane Network also represents the Children's Sector on SANAC. This network has actively campaigned, consulted and advocated on the issue of HCT in schools.
5. Taken from Regional Minimum Standards for Harmonised Guidance on HIV Testing and Counselling (HTC) in the SADC Region (August 2009).
6. 'Fury over HIV tests for pupils', 01 February 2011, Sowetan Online. [www.sowetanlive.co.za/news/2011/02/01/fury-over-hiv-tests-for-pupils]
7. RAPAN and the Teddy Bear Clinic have filed court papers with the North Gauteng High Court which challenge the constitutionality of the laws that criminalise children between 12 and 16 years of age who are consensually involved in sexual activity with each other. This is the law under which the National Director of Public Prosecutions has recently made a decision to prosecute the children involved in the Jules High School incident.
8. 'School HIV tests on hold', May 2011, The Times Live. [www.timeslive.co.za/local/article1063135.ece/School-HIV-tests-on-hold]
9. 'No date set for school HIV testing programme', 27 Dec 2011, The Mail & Guardian Online. [<http://mg.co.za/article/2011-12-27-no-date-set-for-school-hiv-testing-programme/>]
10. Objective 2.1 of the NSP.

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Messages from ICASA...



The need for robust, radical actions and responses...

Thoughts on the NSP from the women's sector

As South Africa finalised the development of the National Strategic Plan 2012-2016 that was launched on 01 December 2011 by the President of the Republic, Jacob Zuma, and South African National AIDS Council (SANAC) led by the chairperson Deputy President, Kgalema Motlanthe, I want to scream again and again that we need to move beyond the commitments and oratory to what I call robust, radical action and response. For many years, women have been advocating, requesting, demanding, negotiating and claiming their rights as patriots to centralise all women and girls in their diversity for interventions.

Mmapaseka Steve Letsike

Currently, South Africa has the new National Strategic Plan (NSP) for HIV, sexually transmitted infection (STI's) and tuberculosis (TB) (2012-2016), a framework to guide all partners whose work is relevant to HIV, STIs and TB in South Africa. The aim of the NSP is to focus the country on the most important interventions that SANAC believes will bring about significant change in the incidence and prevalence of HIV, STI and TB. While the NSP does not outline every intervention that must happen, mainly because it is not an operational plan, it does however expect provinces to develop operational plans in advance of the implementation target date 01 April 2012. The NSP has five goals, which the country aims to achieve by 2016. The NSP aims to:

- Halving the number of new infections
- Ensuring that at least 80% of people who are eligible for treatment for HIV are receiving it (at least 70% should be alive and still on treatment after five years)
- Halving the number of new TB infections and deaths from TB

- Ensuring that the rights of people living with HIV are protected
- Halving the stigma related to HIV and TB

The NSP has identified a number of strategic objectives that will help South Africa reach these goals. These are

- Addressing social and structural factors that drive these epidemics, influence their impact, and affect the way we care for affected people
- Prevent new HIV, STI and TB infections through a combination of interventions
- Sustain health and wellness primarily by reducing deaths and disability from HIV, AIDS and TB
- Protect the human rights of people living HIV and improve their access to justice

Through the above, the NSP is based on a 20-year vision for reversing the burden of disease to **ZERO** new HIV and TB infections, **ZERO** new infections, due to HIV transmission from mothers to child (MTCT), **ZERO** preventable deaths from HIV and TB, and **ZERO** discrimination associated with HIV, STIs and TB.

Thirty years into the HIV epidemic, HIV-related stigma and discrimination persist and continue to pose significant barriers to successful HIV responses. Women living with HIV experience particular forms of stigma and discrimination, especially in relation to our perceived or actual roles as mothers and carers; in accessing services, such as sexual and reproductive health; and in claiming our rights. Women belonging to key affected populations are often doubly stigmatised on the basis of gender and age, sexual orientation and gender identity, use of drugs, experience of prison, disability, migration status, and/or profession – including sex work. The HIV response requires great effort to eliminate the stigma and discrimination faced by women living with HIV and other key affected women, particularly within health services. Hoping that as we move towards the finalisation of Provincial Implementation Plans, these issues will be taken seriously, and the complexity of women's HIV risks and vulnerabilities, as well as the need to address fundamental determinants, are totally acknowledged and adequately addressed.

The fact that South Africa is being guided by an NSP, that is informed by Know Your Epidemic/Know Your Response (KYE-KYR) approach, which extracts and highlights key populations (which includes almost everyone), is not a bad

...we need to move beyond the commitments and oratory to what I call robust, radical action and response...

...HIV response requires great effort to eliminate the stigma and discrimination faced by women living with HIV and other key affected women, particularly within health services...

thing – but we just hope that implementation plans, will indeed extract clear interventions for groups, particularly women and girls, women and girls living with HIV, and marginalised women and girls.

Since 2001, attention to the gender dimensions of HIV has grown. The HIV epidemic has necessitated increased focus for advancing gender equality to ensure better and more successful HIV prevention, treatment, care, and support. What the implementation plans should do is forge stronger alliances between the HIV movement and the women's rights movement; reinforce advocacy for gender equality and disability equity, within the context of HIV; and enable all women to seek greater autonomy over our sexual and reproductive health and rights, as well as greater economic independence.

The discourse in the NSP highlights the increasing availability of approaches for linking services – in particular those that aim to address the sexual and reproductive health and rights of women living with HIV, and marginalised and key affected women, as well as broader key populations. However, comprehensive services remain an exception,



requiring accelerated action for an effective HIV response tailored to women and girls in all our diversity. Women identified an essential package of integrated HIV and sexual and reproductive health and rights-related services, including youth friendly services; a full range of contraceptive choices; the ability to decide responsibly and freely whether and when to have children; access to STI and cervical cancer prevention, screening, and treatment; access to post-exposure

...the discourse in the NSP highlights the increasing availability of approaches for linking services...

...rights violations undermine efforts to improve all maternal and child health...

prophylaxis and emergency contraception; harm reduction measures; and access to services to support safe conception, pregnancy, childbirth, and infant feeding.

While significant progress is being made to increase HIV-free delivery, women face major challenges in terms of securing their sexual and reproductive health and rights, and are at risk of being treated as 'vessels' and 'vectors' of sick babies and disease. While prevention of HIV transmission to babies has served as an important entry point for HIV prevention and treatment services for women and families, this approach alone is reductionist and inadequate, as it primarily focuses on children and fails to prioritise the rights and needs of women/mothers. Moreover, utilisation of antenatal clinics is often hampered by judgmental attitudes and ill-treatment by healthcare providers, particularly for marginalised women. These rights violations undermine efforts to improve all maternal and child health, as well as HIV care. Integrated sexual and reproductive health and HIV prevention, care, and treatment services must be available and accessible for all women and girls, within and beyond the antenatal settings, requiring accelerated operationalisation of the WHO-endorsed four-pronged strategy to prevent the vertical transmission of HIV.

The HIV prevention research field has equally yielded

promising results, with recent breakthroughs in women-centred prevention technologies. However, access to existing technologies continues to pose challenges as women globally cite an unmet demand and need for female condoms. While most notably the proof of concept for a microbicide has been achieved, much more investment needs to be directed to research in women-centred prevention technologies (such as microbicides and female condoms; pre- and post-exposure prophylaxis; microbicides for women with HIV), as well as ensuring availability of and access to these technologies for all women.

Whilst South Africa, and globally, increasingly recognises the need for comprehensive, rights-based, and evidence-informed sexuality education, consistent access to comprehensive gender-sensitive sexuality education within and outside schools, particularly for young women in all their diversity, is still inadequate or even lacking. Young women and girls require the necessary knowledge and skills to protect themselves from HIV, to uphold the rights of those who have HIV, and for all to lead healthy, productive lives.

Women leaders, who provide care in their communities, are becoming increasingly mobilised and visible – yet, they still lack adequate recognition, support, training, supplies, or remuneration for all their work. In addition, female health service providers living with HIV experience significant levels of stigma and silence, affecting their own health-seeking behaviour for effective treatment. Women and girls further seek to more equitably share caregiving with men and boys in their communities.

While we expect to get the Provincial Implementation Plans and M&E system we need, put in place, we should also take note and remember that women and girls from

...an increase in uptake of HIV services will only occur when services respond to the realities and needs of all women and girls...

every region of South Africa articulated a clear desire for an HIV response that engages and addresses women and girls in all our diversity, regardless of age, HIV status, sexual orientation, or socio-economic status. An increased uptake of HIV services will only occur when services respond to the realities and needs of all women and girls, including those of us living in rural and hard-to-reach areas, young women, women living with HIV, women with disabilities, women in conflict areas, transgender women, women who have sex with women, women involved in sex work, refugees, women who use drugs, and indigenous women – thus, our realities have to be at the centre of the national response to HIV.

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The Global Plan... Are women at the centre?

Feedback from provinces

Gahsiena van der Schaff

The 'Global Plan for Elimination of HIV infection in Children and Keeping Mothers Alive' provides an important framework to achieve the ambitious goal of Zero new HIV infections amongst children by 2015, as well as to keep 'mothers alive'. In achieving the goal set out in the Global Plan, it will be crucial to have women's realities and needs at the core of the response; to take into account the gendered barriers experienced by women in accessing services; and to move forward within a human rights framework. Although well designed, the Global Plan can arguably only be as effective as it is translated into national prevention of vertical transmission scale-up plans that are responsive to women's needs and are thus, truly in the position to facilitate women's enhanced access to effective, comprehensive and supportive programmes.

This particular series of provincial networking meetings facilitated by the AIDS Legal Network (ALN) took place from October to November 2011 in Mpumalanga, Eastern Cape, Northern Cape, Western Cape, North West, KwaZulu Natal, Limpopo and the Free State. Networking partners in the various provinces represented various sectors, such as gender, women, human rights, child rights, HIV, home-based care, faith-based sector, chapter nine institutions, local health

service providers, and HIV support groups, and the meetings are free spaces for debating, discussing, analysing challenges, and collectively identifying human rights advocacy strategies relevant to the areas in the provinces. Based on recognising the importance of the Global Plan for the prevention of vertical transmission of HIV, whilst acknowledging the need to equally ensure that women's realities and needs are taken into account, the meetings sought to explore current and newly emerging challenges to the prevention of vertical transmission of HIV; to analyse whether or not and the extent to which women's realities and needs are at the core of programme design and implementation; and to collectively identify and develop potential advocacy strategies to ensure national scale-up plans that ensure both Zero new infections in children, and Zero stigma and discrimination against women living with HIV.

Prior knowledge among participants about the Global Plan was extremely low. Two provinces (Eastern Cape and Mpumalanga) each had an individual who had heard of the Global Plan and Millennium Development Goals (MDGs) though were unable to provide details of the plan, while another province (KwaZulu Natal) had three individuals who were knowledgeable about the plan. As there was mostly consensus on the challenges around the national prevention of vertical transmission programme, most provinces came up with similar human rights strategies moving forward.

The topic for discussion at the meetings latched onto and extended the virtual consultation on the Global Plan, which was conducted as a partnership between ALN and GCWA (Global Coalition on Women and AIDS) in

October 2011, and which focused on collating women's experiences, voices and opinions on prevention of vertical transmission programmes in the 22 priority countries.¹ The article is based on the dialogue, debates and discussions from eight provincial meetings, and will introduce some of the challenges and concerns raised, provincial experiences and opinions, as well as the human rights advocacy strategies identified, by civil society partners participating in these meetings.²

THE GLOBAL PLAN PRINCIPLES FOR SUCCESS

The Global Plan provides a foundation for countries to move towards ending new HIV infections among children and keeping mothers alive. Though only launched a few months ago (June 2011), hardly anyone was aware of the Global Plan or of national scale-up plans to be developed in response to the Global Plan. This lack of knowledge and awareness begs the question as to how to hold government and ourselves, as civil society, to account for the implementation of a plan when we are unaware of it. Neither can it be expected that community members will actively participate in and benefit from a programme unknown to the majority. It is not surprising then that one of the strategies in all provinces

...necessitate that the plan is based on what women living with HIV think, feel and recommend...

is for both the national and global prevention of vertical transmission plans to be widely disseminated and discussed, most importantly in remote and rural areas.

The success of the Global Plan is based on four key principles: 1) Women living with HIV must be at the centre of development and implementation of national vertical transmission plans; 2) States must take ownership of the plan; 3) Leveraging synergies, linkages and integration for improved sustainability; and 4) Shared responsibility and specific accountability. Whilst debating the meaning and implications of these principles, participants highlighted key strategies for realising each principle.

Women living with HIV must be at the centre

Firstly, for government to make this principle a reality, positive women's voices, views and opinions based on their experiences must be widely and actively sought, taken seriously and adequately responded to. To achieve the goals of ending new HIV infections among children by 2015 and keeping mothers alive will necessitate that the plan is based on what women living with HIV think, feel and recommend, taking into account positive women's needs, challenges and realities and putting things in place to avoid adding to positive women's challenges, or 'put more stress on positive women', or worsen their risks and vulnerabilities.

Secondly, positive women must be trained, paid and posted at health centres in their areas to take up issues of complaints on behalf of women accessing the service, and to monitor antenatal service provision. Care givers must also be trained to identify and pass on information, including information of rights violations at a family and community level, to NGOs who can take up these issues. Regular feedback must be provided to the community and health centres about the progress made.

Thirdly, to enhance women's access to quality services, as well as to help and support, all stakeholders must be engaged and involved in, starting at grassroots level, educating the community about their rights, taking complaints and experiences of stigma and discrimination, and mitigating stigma and discrimination, so that women can feel free to seek help.

...a health plan that suits women,
protects their rights and caters for
their needs...

Fourthly, regular calls must be made to various community-based groups and structures, including support groups, community leaders, NGOs and the community at large, to ensure that the family and community take responsibility to support and provide adequately for positive mothers and their infants. Community radio stations must be approached to get involved and to develop programmes calling for support for positive women who are pregnant or have delivered their children, and discussing the continued challenges affecting their families and communities. To ensure greater support for women living with HIV and their families, forums could be established in every community for NGOs to engage with, and reach out to the community at grass roots level as well as the leaders, to call on their support and responsibility to ensure mothers live longer and infants are not newly infected with HIV post-delivery.

And lastly, give all women who test positive for HIV, regardless of their CD4 cell count or pregnancy, access to ARVs.

States must take ownership of the plan

To show that government is serious about reducing new infections among children and keeping mothers alive, government has to, as a matter of urgency, get all departments and all communities involved in taking responsibility to actively work towards this goal. It is, however, crucial that this is done within the legal framework of the country, and the protection of rights prioritised in all aspects of the programme. In order for government to take ownership of the national prevention of vertical transmission programme, participants felt strongly that government must:

- Consult with and ensure meaningful participation of all stakeholders, including the participation of civil society in AIDS Councils at provincial and district levels
- Ensure that planning processes, as well as M&E systems, are transparent and include clear mechanisms of accountability
- Monitor and evaluate the progress made towards implementation, and remove any barriers and challenges impacting on timely implementation of the plan
- Ensure that an effective programme is put in place, including adequate costing and budget, to actively reduce or eliminate stigma and discrimination as barriers to access to services
- Increase efforts to improve coverage in rural areas
- Develop a communication strategy promoting messages of support for positive women in general, and positive mothers and their families in particular, so as to increase women's access to and benefit from prevention of vertical transmission services
- Design and distribute easily accessible and user-friendly material providing comprehensive

information about the programme, including information as to where and when the services are available

provide spaces for women to share their experiences and challenges; and to increase women's levels of adherence to the programme.

...allows its users to make their own choices and where these choices are respected unconditionally and fully provided for...

Shared responsibility and specific accountability

Communities, service providers, government structures, the faith community and all other stakeholders must play their role in mobilising communities in supporting and taking responsibility for reducing new HIV infections among children and keeping mothers alive. To facilitate this, government must allocate adequate funding, including to civil society, must encourage everyone's involvement and participation in all aspects of programme design and implementation, and must call on all leaders in the community to actively discourage stigma, discrimination, violence and rejection at family and community level.

Improve sustainability through linkages and integration

To improve sustainability of the programme it is crucial for government to come up with and implement a health plan that suits women, protects their rights and caters for their needs. Although home-based care gives care for the sick, this 'care' could be expanded to include breastfeeding mothers and their infants, as this will decrease the chance of women 'falling through the cracks' after birth, due to the lack of follow-up. In addition, while protecting the right to privacy and avoiding family members asking questions about care worker's visits, it is important to get care workers to provide ongoing support to women who participated in the programme, and to also engage the family and church to support and assist all women who have babies.

There is also the need to develop programmes aimed at changing society to one less gendered and free of stigma and discrimination, so as to build communities that are supportive of women's participation in prevention of vertical transmission programmes. For these programmes to be successful, church leaders and faith-based communities have to show leadership in transforming discriminatory attitudes and practices preventing women from accessing and benefiting from these and other services.

It is essential to link NGOs working in the communities with various government departments, including the Department of Home Affairs, to speed-up and facilitate access to birth certificates for women and to have access to health and social services. At the same time it is important to set-up and/or strengthen support structures for women to decrease the risk of women defaulting on their treatment;

THE FOUR PRONG APPROACH TO PREVENTION OF VERTICAL TRANSMISSION

The Global Plan proposes a four-prong approach for the prevention of vertical transmission of HIV, namely to prevent HIV among women of reproductive age; to provide comprehensive reproductive health services to women living with HIV; to prevent HIV transmission to infants during

pregnancy, birth and breastfeeding; and to provide treatment care and support to the woman, infant and family members.

Recognising that national prevention of vertical transmission programmes are, in principle, based on this four-prong approach, participants discussed each of the prongs in more details as to the progress made towards the implementation of this approach.

...female condoms remain scarce in most clinics, whilst male condoms are available and accessible everywhere...

Do women of reproductive age have access to comprehensive reproductive health services?

Participants, although commending the progressiveness to impose the 'duty' on states to prevent HIV and pregnancy among women of reproductive age as an integral part of this programme, collectively agreed that women of reproductive age do not have access to comprehensive reproductive health services. The meetings identified *comprehensive reproductive health services* as services which are available where women live; which offer or afford easy access to a full range of reproductive health options to all women (including hormonal injection, diaphragm, pills, termination of pregnancy, female condoms, male condoms, and voluntary sterilisation); and which are of high quality and provided in a non-judgemental and non-discriminatory environment.

A health service can only be as accessible and comprehensive as it allows its users to make their own choices and where these choices are respected unconditionally and

are fully provided for. Besides the fact that the community is not a safe environment for women to make sexual and reproductive choices, reproductive programmes are not designed nor allow for most women to make informed choices about sex and reproduction. In addition, parents/guardians, teachers, faith communities and society in general, prescribe societal norms that are gendered, leading to a situation in which women are disadvantaged, policed and punished for making their own choices, thus seemingly justifying the violation of women's rights. This is further compounded by the taboo on 'sex talk' in general; teachers' inability to think and teach/discuss issues of sex and sexuality outside of the societal norms, thus failing to provide rights-based sex and sexuality education, and perpetuating negative connotations, as well as stigma, discrimination and other rights violations as and when women make their own choices regarding sex and reproduction. While many women do not know their rights, those who know and dare to exercise their sexual and reproductive rights are often silenced, judged, abused and rejected as a result.

...women's needs and realities are largely ignored, especially in the context of exclusive breastfeeding...

In addition to these societal norms and discriminatory practices impacting on women's sexual and reproductive decision-making, access to comprehensive reproductive healthcare for women is further limited due to poor conditions in healthcare settings, including lack of resources and health care workers' attitudes; long distances to health services,

especially in rural areas; and inadequate information and resources available to women of reproductive age. Participants also highlighted that while family planning in general mainly consists of injections and tablets, many clinics do not provide pills, only injections; information about termination of pregnancy is rarely provided, as nurses often assume women want to be pregnant, or refuse to provide this information due to their own religious beliefs; and that female condoms remain scarce in most clinics, whilst male condoms are available and accessible everywhere.

...the lack of interest in mothers after birth is evident in the lack of follow-ups and after care provided...

Do women living with HIV have access to comprehensive reproductive health services?

Participants again were united when responding to this question in that according to partners, there is lack of access to comprehensive reproductive health services for women living with HIV, partly based on the perception that women living with HIV are not to be sexually active, thus not in need of reproductive healthcare. In some instances, women living with HIV are even offered, under the guise that it is in their own, their families, and society's best interest, to be sterilised, with little to no access to information about the procedure and/or consequences of such procedure.

The attitude of nurses, especially towards women living with HIV, is 'off-putting' and insulting to the point of being

hostile at times, which further deters women from accessing services. The fear of stigma and discrimination, as well as the lack of confidentiality greatly impacts on positive women's 'choices' as to whether or not and when to access health services. The lack of integration of service poses an additional challenge, as 'services are not all in one place, and so one is sent from the one to the other section having to sit in queues for most of the day, or have to come on another day'.

Does the current programme adequately prevent HIV transmission to infants, during pregnancy and after birth?

Partners were divided in their responses to the question as to whether or not current programmes are doing enough to prevent transmission of HIV to infants. The ones who felt that 'enough' is being done, were however unanimous in that 'enough' is only being done to prevent HIV transmission during pregnancy, but not after birth. Although women participating in the programme are provided with Nevirapine and offered a caesarean birth to prevent the risk of HIV transmission to the infant, many partners disagreed that enough is done, based on the fact that even during pregnancy women's rights continue to be violated, in that women are often denied their choice to make informed decisions regarding HIV testing, and after childbirth women are seldom in the position to freely decide whether or not to breastfeed, given the pressures by healthcare providers and family members.

Partners also felt that women's needs and realities are largely ignored, especially in the context of exclusive breastfeeding, which is difficult for women who want to keep their HIV status private. Healthcare providers aggressively promote exclusive breastfeeding, at times to the point of not informing women of the option of formula milk feeding or of the possible risks attached to breastfeeding. In reality,

women who choose formula feeding over breast feeding find themselves watched, gossiped about, judged, discriminated against, rejected or isolated by family, community and healthcare providers alike. As some women are ‘scared to be found out’ to be HIV positive, they ‘choose’ breastfeeding, while working women who opt for breastfeeding will have difficulties, as workplaces, including civil society organisations, do not accommodate women and their infants at work, and also have no facilities for childcare.

Despite the challenges presented by both options, partners stressed that it should still be the woman who should freely and informed decide which option best suits her.

Is there sufficient support for women, infant and the family members after birth?

There is definitely not sufficient support provided to women, let alone her family, after birth. Participants also pointed to healthcare providers that are forthright about their quest to have babies born free of HIV; thus the focus on the mother is mainly during pregnancy, while the lack of interest in mothers after birth is evident in the lack of follow-ups and after care provided.

In addition to discrimination and stigma, the family of a positive mother generally lacks sufficient information to

respond and deal with this situation, and/or information on how to care for the mother and child when she gets sick. Women are also often sent home without the necessary information on adherence and the importance of regular check-up’s, whilst nurses too are seldom equipped to empower women on how to disclose to their families and establish much needed support systems.

IDENTIFIED BARRIERS AND CHALLENGES

According to partners, the way we address the challenge of reducing new HIV infections among children and keeping mothers alive is short-sighted; fraught with gross human rights violations against women in general, and positive women and pregnant women in particular; continuously fails to address, or respond to, women’s needs, realities and challenges, or the root causes of women’s heightened and disproportionate vulnerabilities and risks to HIV.

Barriers to women’s access to comprehensive prevention of vertical transmission programmes, as identified by partners, include health services and health facilities; the failure to respond to women’s realities and needs; violence and abuse; stigma and discrimination; socio-cultural and religious beliefs and practices; and the lack of human rights protections.

Health services and health facilities

A necessary component of a comprehensive sexual and reproductive service is access to quality healthcare, free of judgment and discrimination, close to where women live. Prevention of vertical transmission services are not equally accessible to all women for various reasons, including:

- Lack of access to healthcare and healthcare information for women in rural, farming and remote areas

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or respond to, women’s needs,
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risks to HIV...

...although these realities and fears are known, programmes and services fail to respond to these barriers – thus limiting women’s access to services...

- Distance to healthcare facilities and lack of resources to gain access to clinics, as well as long queues and waiting periods, with, at times, no service provision as women are asked to return the next day
- Health services in antenatal clinics and hospitals are ‘unprofessional’ and extremely hostile in many areas deterring women from accessing these services for fear of ill-treatment
- Lack of confidentiality and involuntary disclosure of women’s positive HIV status by healthcare workers and clinic structures, including ‘special rooms and staff’ known to only be for women living with HIV and clear identifications of HIV test results on patients’ folders
- Many healthcare providers are ‘very much rude, insulting and harsh’ to young women who are pregnant, and their attitudes towards positive women are ‘harsh and judgemental, and downright hostile’
- Neither the messages, nor counsellors or other service providers, sufficiently engage men in the prevention of vertical transmission, which not only perpetuates the perception that it is women’s responsibility, but also manifest the stigma of women as the ones who are to blame for bringing HIV into the homes

- Lack of adequate information and/or explanations to women on how to administer and adhere to medication, as nurses are ‘too much in a hurry’

Women’s realities and needs

Healthcare services are only as beneficial to women, as they are responsive to women’s realities and needs. However, women’s realities and needs are seldom at the centre of programme design and service provision, as the majority of healthcare providers do not see women as people in their own right and with their own needs (*‘away from being mothers’*). Hence, women’s needs, experiences and backgrounds are generally not considered when entering the programme.

Women have many fears linked to the participation in prevention of vertical transmission programmes, which most of the time are not responded to by healthcare providers. Women are afraid to tell partners they are HIV positive for fear of being rejected and abused, and are afraid of being labelled ‘loose’, as a result of their positive diagnosis. Women fear raising the issue or demanding condom use as it makes them uncomfortable to speak about sex, and because ‘they fear being accused of sleeping around’, and becoming ‘the object of suspicion and blame’. Women are scared of disclosure and breastfeeding, because of the fear of ‘being found out’. Women in abusive relationships do not speak-up, and are afraid to take medication for fear of partner’s reaction and violence; so women default. Women fear community making comments and asking questions, and to avoid this many women do not attend ANC; or deliberately present late to the clinic, while some only come when in labour. Partners felt strongly that although these realities and fears are known, programmes and services fail to respond to these barriers – thus limiting women’s access to services.

Violence and abuse

Gender violence increases women's HIV risks and vulnerabilities and women's HIV positive status increases the risk of violence or leads to more violence. The experience of violence and abuse is a barrier to accessing quality healthcare and living a quality life.

Most women find out about their HIV positive status when pregnant. To prevent having to experience abuse on

...despite all the efforts, HIV-related stigma and discrimination is very much alive and rife in all spheres of society...

disclosing their HIV status, some women opt for homebirths, while others participate in the programme, without disclosing their HIV status for fear of negative consequences. Women may also choose not to take ARVs, for fear of the partner discovering the medication.

Most healthcare providers do not screen for signs of abuse or ask a woman if she is in an abusive relationship. Many do not even ask how her positive status will be received by her partner. (*'Maybe they deliberately do not want to be informed that the woman is in an abusive relationship because then it adds more work for them'*). On the contrary, if healthcare workers know that a woman is in an abusive relationship, there is insufficient follow-up and support. Even if the woman has access to a shelter, there are limited resources available to shelters to sufficiently assist women during pregnancy and ensure successful participation in prevention of vertical

transmission programmes, as due to lack of funds shelters may not be in the position to provide formula milk.

Stigma and discrimination

Despite all the efforts, HIV-related stigma and discrimination is very much alive and rife in all spheres of society, and continue to be one of the main barriers for women's access to services. At the same time prevailing stigma and discrimination also greatly impact on the extent to which women can freely participate and benefit from programmes to prevent vertical transmission of HIV.

Lack of information

There is a general lack of correct and accessible information, as well as a lack of understanding, about prevention of vertical transmission programmes. Information available is often inaccessible due to language barriers, or information provided is unclear, value-based, moralistic, and lack sufficient facts about the benefits and risks associated with these programmes, as well as women's rights in the programme. Subsequently, women have inadequate and/or mixed information potentially impacting on their decisions as to whether or not and when to access services.

Culture, traditions, gender and religious beliefs

Socio-cultural and religious norms and beliefs greatly influence the extent to which women are in the position to make sexual and reproductive choices, and access services. The very same norms and beliefs define men as *'head of households'* and *'decision-makers'*, and women as *'house keepers'* and *'child bearers'*; cause men to refuse condom use (as *'men do not fight with their clothes on'*); and makes being pregnant and giving birth *'a matter of pride'* for women and their families. Practices of lobola and polygamy further entrench women's lesser power to make free and informed

...information provided is unclear, value-based, moralistic, and lack sufficient facts about the benefits and risks associated with these programmes, as well as women's rights in the programme...

choices about sex and reproduction, not only increasing women's risk to HIV, but also severely impacting on women's access to healthcare, as women are not *'in control'* of these decisions. In addition, cultural beliefs may favour homebirth, thus denying women access to healthcare and increasing the risk of vertical transmission of HIV, despite services being available.

Participants emphasised that as long as male domination, patriarchy, and the *'power of men'*, at the expense of women's ability to make their own choices regarding whether or not they want to be pregnant or have unprotected sex, prevail, these programmes will remain ineffective.

Lack of human rights protections

Although women's rights are constitutionally guaranteed and are at the core of legislative and policy provisions, women continue to experience gross human rights violations in all spheres of life, including within health services. Prevailing rights abuses increase women's risks to HIV, whilst living with HIV and accessing prevention of vertical transmission services increase women's risks of further rights abuses. The key to achieving the goals of eliminating new infections and keeping mothers alive is to ensure human rights are promoted and protected – in policy and practice. It also requires a

major shift in sexual and reproductive healthcare provision from the current situation of judgemental, discriminatory and directive service provision to one that is firmly based on rights protections in all aspects of service provision. To ensure the promotion, protection and advancement of women's rights in service provision it is as essential to enhance levels of knowledge about their rights, as it is necessary to ensure accessible redress mechanisms as and when their rights are violated.

PRIORITIES FOR ADVOCACY STRATEGIES

Recognising the challenges and barriers impacting on women's access to prevention of vertical transmission programmes, as well as on the effectiveness of these programmes, partners identified the following key priorities for change.

- Cultural, traditional, and religious beliefs, values and norms create, contribute and perpetuate women's risks and vulnerabilities to HIV, as well as cause barriers to women's access to HIV-related services – hence, an essential component of prevention of vertical transmission programmes must be a comprehensive plan to address and transform norms, values and beliefs that *'harm'* women

...key to achieving the goals of eliminating new infections and keeping mothers alive is to ensure human rights are promoted and protected – in policy and practice...

- As long as there is male dominance and patriarchal systems, giving the *‘power to men at the expense of women’*, programmes will not reach women and be ineffective – thus, prevention of vertical transmission programmes must include concrete plans to challenge and transform the gendered context of society
- Recognising the adverse impact on women, healthcare providers and the way sexual and reproductive health services are provided, must radically change so as to ensure that women have access to factual and rights-based information, and to services that are rights-affirming and truly responsive to women’s realities and needs
- Comprehensive and quality prevention of vertical transmission services must be equally accessible to all women
- The promotion and protection of human rights must be guaranteed in all aspects of programme implementation – hence, the need to roll-out rights-based information and education about programmes across all communities, as well as the provision of accessible redress mechanisms
- To ensure effective, supportive and comprehensive programmes for the prevention of vertical

...ensure that women have access to factual and rights-based information, and to services that are rights-affirming and truly responsive to women’s realities and needs...

transmission, all relevant stakeholders, including women and women living with HIV, must be meaningfully involved and participate in the design, implementation, and monitoring of the national prevention of vertical transmission scale-up plans

FOOTNOTES:

1. The virtual consultation report can be accessed on www.aln.org.za.
2. A total of 187 partners participated in the meetings.

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...it is as essential to enhance levels of knowledge about their rights, as it is necessary to ensure accessible redress mechanisms...

Active at ICASA...



We are everywhere...

The empowerment of lesbian, bisexual and transgender women in rural areas of Namibia¹

Linda RM Baumann

The foundation of one's economic justice and freedom to be who one is, as a woman in Africa, has faced far more discrimination over the years just because of one's physiology. The additional label of one's sexual orientation and gender identity has added even more layers of discrimination, which makes it much more difficult for lesbian, bisexual and transgender people to freely be themselves, and to access information, education, employment, and the list goes on.

Where I come from, there is a definite identification of what 'rural' is, due to the classification of local government boundaries. However, I would like to take this classification broader, as the element of urban townships and its demographics clearly manifest that the living conditions are to the standard of what people are facing in areas, commonly identified as rural.

Lesbian, bisexual and transgender people in the urban townships are much closer to resources, as compared to lesbian, bisexual and transgender people in the far rural areas. Whilst these resources and services are supposed to empower

them, their living conditions do not allow them to empower themselves, because of the high levels of homophobia – be it political, social, religious, and/or cultural.



As an organisation, we have strategically framed our work to be inclusive of all lesbian, bisexual and transgender women, irrespective of where they live, as we work across the country. The community facilitators who we work with on the ground are faced with horrible cases of what lesbian, bisexual and transgender people are going through on a daily basis, as there is no infrastructure to accommodate them, let alone

services that would be able to assist them with and through the experiences and challenges they are faced within their communities, such as forced marriages, sexual violence, denial of education, and being disowned by their families.

...the sensitisation of the women's movement to include lesbian, bisexual and transgender women's issues in their agendas...

Out-Right Namibia has now mainstreamed its programming through mainstream human rights and health organisations to ensure the inclusion of sexually diverse people. Upon reports received from the field, lesbian and bisexual women, and transgender people, are further at risk, due to the segmentation of our justice system, since the Namibian legislative framework provides for two judicial systems; the common law and customary law. And as for lesbian, bisexual and transgender people in rural areas, they are more faced with and confronted by the traditional authorities, because their behaviours and actions are perceived as cross-bordering the cultural values and norms, which not only lead to further violations of their rights, but also to more disempowerment of their aspirations.

It is within this context, that there is a great need to invest

in the skills and knowledge building of lesbian, bisexual and transgender women to ensure empowerment is taking place, and to have representation of these communities engaged in key issues affecting their lives. In order to achieve this, the use of information communication and engagement with support groups are crucial, as it will demystify the lack of confidence within the system, and also assist in identifying the actual needs of communities by communities, as compared to being designated what their needs are and what to do.

Another attainment that needs to be achieved is the sensitisation of the women's movement to include lesbian, bisexual and transgender women's issues in their agendas, by ensuring the visibility of our existence in and to the discourse of women, as well as the need to be included in agendas affecting our lives, including strategic economic empowerment agendas.

FOOTNOTES:

1. This contribution is based on a paper presented at a CSW 2012 Side Event, hosted by ILGA/RFSL, on 27 February 2012.

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Seeking redress...

The Equality Court and HIV-related discrimination

Although significant progress has been made in restructuring and transforming society and its institutions, structural and systemic inequalities and unfair discrimination remain deeply embedded in social structures, practices and attitudes, especially in the context of HIV, not only undermining the aspirations of our constitutional democracy, but also limiting the extent to which individuals are in the position to claim their rights and benefit from progressive legislation afforded by the South African constitutional and legislative framework. HIV not only poses an enormous health crisis, but also threatens human rights¹.

Nonandi Diko

LEGISLATIVE PROVISIONS

The principle of and right to equality and non-discrimination are firmly enshrined in the country's laws and policies. Section 9 of the Constitution provides for the right to equality and the right not to be discriminated against on many grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth, amongst other things². Whilst the Constitution does not equivocally list HIV as one of the grounds based on which a person may not be discriminated against, the interpretation and application of constitutional and legislative provisions clearly indicate that any form of unfair discrimination based on HIV status is unconstitutional and thus, unlawful.

The Promotion of Equality and Prevention of Unfair Discrimination Act (No 4 of 2000) (the Equality Act) was passed in February 2000. The legislation was introduced to

give effect to the constitutional injunction of the right to be treated equally and not to be discriminated against requiring that national legislation 'must be enacted to prevent or prohibit unfair discrimination'³ and to promote equality.

The objectives of the Equality Act are, among others, to enact legislation required by Section 9 of the Constitution to give effect to the letter and spirit of the Constitution, in particular, the equal enjoyment of all rights and freedoms by every person, and the promotion of equality; to provide remedies for victims of unfair discrimination, hate speech, harassment and persons whose right to equality has been infringed; and to fulfil South Africa's international obligations under binding treaties.

Among these obligations are those specified in the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (the African Women's Protocol)⁴. Article 2 of the African Women's Protocol requires from State Parties to address all forms of discrimination against women, including through the enactment and effective implementation

of legislative/regulatory measures. The African Women's Protocol also provides for the prohibition of harmful practices that endanger the health and well-being of women, and calls for modification of social and cultural practices with a view to eliminate discriminatory and harmful traditional practices. Furthermore, Article 2 of CEDAW obliges State Parties to eliminate discrimination and embody the principle of equality between men and women in laws and policies; and to take all appropriate measures to eliminate discrimination against women in the field of health care (Article 12)⁵.

...structural and systemic inequalities and unfair discrimination remain deeply embedded in social structures, practices and attitudes, especially in the context of HIV...

However, despite various provisions in national and international instruments intending to protect women from unfair discrimination and violence, women continue to be discriminated against and violated in all spheres of life, often exacerbated by their actual or perceived positive HIV status, with little access to redress mechanisms. The Equality Court affords a potential redress mechanism for HIV-related discrimination and other rights abuses experienced by women living with HIV.

The Constitutional Court, in a unanimous judgment prepared and delivered by Ngcobo J, in the matter of *Hoffman*

v South African Airways (Pty) Ltd 2001 (1) SA (CC) dealing with the right to equality and not to be discriminated against on the basis of HIV, took judicial notice of the fact that the Equality Act recognises HIV status as a serious ground of unfair discrimination and that the Act further stipulates this in the Schedule of illustrative practices that are or may be discriminatory, as well as incorporating a directive to the Minister to consider the inclusion of HIV and AIDS in the listed grounds.⁶

Although recommendations have also been made by the Equality Review Committee, established in terms of Section 32 of the Equality Act, that HIV and AIDS be added as a prohibited ground, especially as evidence suggests that people living with HIV face discrimination and stigmatisation, and that legal recourse is often not accessible, HIV status has, as of yet, not been included as a 'prohibited ground' in this legislation. However, Section 34 of the Equality Act includes a directive stating that

...in view of the overwhelming evidence of the importance, impact on society and link to systemic disadvantage and discrimination on the grounds of HIV/AIDS status, socio-economic status, nationality, family responsibility and family status –

- a) special consideration must be given to the inclusion of these grounds in paragraph (a) of the definition of 'prohibited grounds' by the Minister;*
- b) the Equality Review Committee must, within one year; investigate and make the necessary recommendations to the Minister.⁷*

The non-inclusion of HIV as a 'prohibited ground' is of great concern as it has adverse consequences, especially for

...often exacerbated by their actual or perceived positive HIV status, with little access to redress mechanisms...

women living with HIV who continue to be disproportionately infected and affected by HIV, and who constitute the majority of people living with HIV in South Africa. The failure to explicitly include HIV as a 'prohibited ground' further undermines the rights of women who continue to experience HIV-related stigma, discrimination and other rights violations in all spheres of life; as well as the progress made towards redressing the imbalances of the past and promoting equality and non-discrimination. The non-inclusion of HIV may also limit the accessibility to justice for individuals seeking redress in the Equality Court, and impact on the attractiveness of the use of an inexpensive, expeditious, easily navigated forum for complaints concerning issues of HIV-related discrimination.

Without access to the Equality Courts, people seeking redress for unfair discrimination would have to utilise

...any form of unfair discrimination based on HIV status is unconstitutional and thus, unlawful...

more costly and time-consuming solutions, such as the ordinary High Courts or Constitutional Court in order for the individuals to claim and benefit from their constitutional rights to equality and non-discrimination. In reality, however, the majority of individuals most affected by HIV-related discrimination do not have the necessary resources to do so, thus placing this vulnerable group in the position where they are denied their rights to access justice.

THE EQUALITY COURTS

The Equality Courts, established by Section 16 of the Equality Act, complement the Constitutional Court, by providing an alternative, more accessible, easily navigated venue for equality claims. The reasoning applied in the Equality Courts must follow the reasoning established by the Constitutional Court in the existing equality jurisprudence. The Constitutional Court has said that in order to prove a breach of the right to equality, one must show that there has been discrimination, that the discrimination is unfair, and that it is not a justified limitation of the right in terms of the limitation clause in Section 36 of the Constitution. The limitation clause further states that in assessing whether the limitation is justifiable or not, certain factors must be taken into account, including the nature of the right, the importance of the purpose of the limitation, the nature and extent of the limitation, the relation between the limitation and its purpose, and less restrictive means to achieve the purpose.

In the context of HIV, particularly when dealing with discrimination against a woman on the grounds of her

HIV status, it is unimaginable that the limitation of her right to dignity, equality and freedom could be seen as a justifiable limitation, especially taking into account the degrading, abusive manner and unequal treatment women living with HIV often encounter in their homes, communities and in many other sectors of society, including healthcare facilities, because of the woman's HIV status. Forced and/or coerced sterilisation of women living with HIV in South Africa by healthcare workers is but one example of gross human rights violations women experience within healthcare provision.

Procedures and key features of the Equality Court

A complainant who wishes to lodge a complaint in the Equality Court needs to complete an easy to understand, user-friendly form, making the Equality Court more accessible than other court mechanisms. Furthermore, the Equality Act only requires complainants to make a basic showing of discrimination, which means that on the face of the papers lodged by the complainant, there must be sufficient evidence/facts indicating that the complainant suffered unfair discrimination. For a woman living with HIV, this means that she would have to submit sufficient evidence indicating that the reason that she has been discriminated against is because

...the non-inclusion of HIV as a 'prohibited ground' is of great concern as it has adverse consequences...

...an inexpensive, expeditious, easily navigated forum for complaints concerning issues of HIV-related discrimination...

of her HIV positive status. It would also be advisable, and easier, if she had a witness who could attest and confirm that she was treated differently or discriminated against based on her HIV status.

If it appears that the complainant has suffered unfair discrimination, then the respondent bears the burden of proof and must show, on the balance of probabilities, that the discrimination did not take place or, conversely, that the discrimination was not unfair. This has the effect that the evidentiary burden on the complainant is substantially eased, as the onus is placed on the respondent to prove that the discrimination was fair or instead did not occur.⁸

One of the key features of the Equality Courts is that they are 'specialist courts' with unique procedures and personnel that are specifically trained to deal with equality issues. In addition, Equality Courts are especially designed for unrepresented litigants. This means that a woman who has been discriminated against on the basis of her HIV positive status would not have to procure the costly services of an attorney. If the woman is not familiar with the court system, or not in the position to employ the services of a legal representative to represent her, she has the benefit

of the trained clerks of these courts who can assist her in lodging her complaint.

The fact that a woman who has been discriminated against on the basis of her HIV status can have the benefit of a trained clerk representing her, arguably further facilitates access to justice, especially for people who may not be familiar with the court system. An additional feature and advantage of using the Equality Court is that the proceedings are usually conducted speedily and a complainant would not have to wait years before the matter is heard, which is often the case in other ordinary Magistrates and High Courts, due to backlog where sometimes parties have to wait as long as up to three years before the matter is heard. In terms of the rules for procedures in Equality Courts, a matter may be brought before a Magistrate for a Directions Hearing⁹, no later than 37 days after lodging the complaint. This ensures speedy justice for aggrieved parties and assists the movement for instilling confidence in the judiciary.¹⁰

The practice of forced and/or coerced sterilisation of women living with HIV, which is taking place in



some hospitals, would be one of the examples of unfair discrimination to be heard by the Equality Court¹¹. That would be an ideal case to bring to the Equality Court as the woman is discriminated against, firstly on the basis of being a woman, and secondly on the basis of her HIV status amongst other things.

An additional feature of the Equality Courts is that the hearings are informal, thus setting an inquisitorial and meditative as opposed to a formal and adversarial tone. Furthermore, fairness, the right to equality and the interests of justice prevail over mere technicalities. Whilst the Equality Courts still apply the same rules as in the ordinary High Courts and Magistrates' Courts, these rules are not applied as rigidly. As a result, cases heard at the Equality Court are less likely to be delayed and/or postponed due to technicalities. Furthermore, each party is responsible for their own costs as opposed to the losing party paying the winners' fees, which also lowers the financial risks of lodging a complaint at the court especially for indigent complainants¹². One of the things the complainant can ask for is an unconditional apology, as

...she also has the benefit of the trained clerks of these courts who can assist her in lodging her complaint...

...the hearings are informal, thus setting an inquisitorial and meditative as opposed to a formal and adversarial tone...

well as monetary compensations, for any damages a person may have suffered, such as emotional and psychological trauma, as a result of HIV-related discrimination.

GENDER EQUALITY CASES

The Equality Court system has been successfully used for gender equality in a high profile case, *Z. Mpanza v. Sibusiso Cele*, also referred to as the ‘*Umlazi T-Section case*’. In 2008, Ndunas (informal male leaders) in Umlazi, a township outside of Durban, issued an edict that prohibited women from wearing trousers in the community. The Ndunas argued it was not traditional for women to wear trousers, and that doing so contributed to moral degeneration and incidences of rape. Shortly thereafter, a resident of Umlazi, Zandile Mpanza, was chased by a mob of men who assaulted her, stripped her pants off, and made her walk home partially naked for violating the ‘code’ prohibiting women from wearing trousers. She was not the only woman who had been subjected to violence and harassment for wearing trousers in violation of the supposed code.

With legal representation provided by the Commission for Gender Equality, Mpanza took her complaint against the

men who instituted the ban to the Umlazi Equality Court. The magistrate overseeing the case ruled in favour of Mpanza, and ordered the removal and prohibition of the ban on women wearing trousers because it unfairly discriminated against women under the Equality Act. Two of the respondents, Thulani and Sibusiso Cele, were ordered to unconditionally apologise for implementing the ban. The four men who attacked Mpanza are currently facing criminal charges in the criminal courts for assault, malicious damage to property, intimidation, and indecent assault¹³.

HIV-RELATED CASES BROUGHT TO THE EQUALITY COURTS

Despite many incidences of HIV-related discrimination in all spheres of society, there is thus far a lack of cases of unfair discrimination based on a person’s HIV status, which have been brought to the Equality Court. A general lack of knowledge about this specific redress mechanism, as well as the fact that HIV status is not explicitly stated as a prohibited ground in the legislation, are arguably two of the reasons, why Equality Courts are seldom sought as recourse for HIV-related discrimination.

As already mentioned previously, there have been reports of doctors and healthcare workers forcibly sterilising women

...anyone who experiences HIV-related discrimination can go to the Equality Court and seek redress...

on the basis that they are living with HIV. However to date, no such cases of discrimination on the basis of HIV status have been brought to the Equality Courts. Perhaps one of the reasons could be the fact that if the women were to bring such cases to the courts, they would be subjected to further stigmatisation and discrimination, particularly since matters in the Equality Court are usually conducted in an *'open court'*, unless directed otherwise, meaning that any member of the public would be allowed to attend the court processes, and find out the HIV status of a person and this could have adverse repercussions for the woman, as her HIV status would be known by more people whom she would not necessarily have wanted to know. Furthermore, her right to privacy would be infringed over and above the discrimination and abusive treatment and stigma she would most likely have to endure in her home, community and in society.

...risks of further involuntary disclosure of one's HIV status could potentially deter women living with HIV from using this much-needed and easily navigated forum of redress...

THE IMPACT OF THE EQUALITY COURT

As already stated above, the Equality Act affords a remedy for people who have been discriminated against based on their HIV status. Thus, anyone who experiences HIV-related discrimination can go to the Equality Court and

seek redress, such as an unconditional apology and/or damages for the emotional and/or psychological trauma suffered as a result of such discrimination. Although a potential avenue for redress, it is crucial to also take into account the many potential adverse implications and consequences for people who choose to lay a complaint in the Equality Court.

Whilst the Equality Court is an attractive forum for many reasons, such as the low costs, the benefit of being represented by the clerk of the court in the event that the complainant is unrepresented, and the fact that the matter can be conducted expeditiously and that technicalities are overlooked in the interests of justice, the fact that the proceedings are conducted in an *'open court'*, carries potential risks of further stigma and discrimination for the complainant. Bearing in mind that matters brought to the Equality Court are often of a sensitive nature, such as discrimination on the basis that one is living with HIV, could mean that even if a complainant is successful in her case, people would still know that the woman lodged a claim on the basis of HIV-related discrimination, as anyone can access court documents. Such risks of further involuntary disclosure of one's HIV status could potentially deter women living with HIV from using this much-needed and easily navigated forum of redress, for fear of secondary discrimination and stigmatisation, which in turn impacts on the accessibility and effectiveness of redress mechanisms available for cases of HIV-related discrimination.

Perhaps a more appropriate approach in addressing discrimination and stigma against women living with HIV could be by way of conducting rights awareness campaigns which include promoting understanding among people living with HIV and their rights¹⁴, addressing broader inequalities

through participatory education, creating a supportive and confidential space for the discussion of sensitive topics, mobilising community leaders to encourage greater openness around sexuality and HIV-related issues within communities by building on positive social norms¹⁵, as well as addressing gendered inequalities; and creating an enabling and supportive environment in which rights and freedoms are fully protected and realisable for all.

...raising public awareness and challenging the attitudes of offenders have to become an integral part of orders and remedies...

CONCLUSION

The Equality Courts afford in principle recourse for women who have been discriminated against based on their HIV status. However, accessing redress also carries potential risks and negative consequences for women who choose to exercise their rights and lodge a claim of discrimination, as this may further expose women living with HIV to stigma, discrimination, violence and other rights abuses.

The Equality Courts also have the potential to both compensate victims of prejudice, and to challenge the attitudes of offenders; thus achieving both dimensions of the Act: to prevent discrimination and to promote equality. However, for the courts to have this dual impact, raising

public awareness and challenging the attitudes of offenders have to become an integral part of orders and remedies handed down by presiding officers in cases brought to the Equality Court.¹⁶

FOOTNOTES:

1. Ntlama, N. 2004. The Challenge for democracy: Doing justice for persons living with HIV/AIDS. [www.aifo.it/English/resources/online/books/other...ntlama.doc]
2. The Constitution of the Republic of South Africa, Act 108 of 1996
3. Liebenberg, S. & O'Sullivan, M. 2001. 'South Africa's new equality legislation A tool for advancing women's socio-economic equality'. In: *Acta Juridica*, p70.
4. See www.africa-union.org/root/au/Documents/Treaties/Text/Protocol%20on%20the%20Rights%20of%20Women.pdf
5. A guide to Using the Protocol on the Rights of Women in Africa for Legal Action. [www.equalitynow.org/sites/default/files/Manual%20on%20Protocol%20on%20Women%20Rights%20in%20Africa_EN.pdf]
6. Gutto, S. 2001. *Equality and Non-Discrimination in South Africa: The Political Economy of Law and Law Making*. New Africa Books, p228.
7. Section 34 of the Equality Act.
8. Lane, P. 2005. 'Transformative Human Rights Unit'. In: South Africa's Equality Courts: An Early Assessment. [www.csvr.org.za/wits/papers/paprctp5.htm]
9. A 'Directions Hearing' brings together the complainant, respondent, and the Presiding Officer. It is at this Hearing where the Presiding Officer will resolve all issues relating to the conduct of the proceedings and other administrative and procedural matters, such as when the parties can come to trial, whether anyone needs an interpreter and whether assessors should be used.
10. Hauser, B. 19 May 2011. 'The Equality Courts explained'. [www.polity.org.za/article/the-equality-court-explained-]
11. 'South Africa: HIV-positive women sterilised against their will'; City Press. 7th June 2010.
12. *Ibid.*
13. *Ibid.*
14. Aggleton, et al. 2005. 'HIV-Related Stigma, Discrimination and Human Rights Violations: Case studies of successful programmes'. In: Joint United Nations Programme on HIV/AIDS (UNAIDS), UNAIDS Best Practice Collection. [data.unaids.org/publications/irc-pub06/jc999-humrightsviol_en.pdf]
15. *Ibid*
16. Lane, P. 2005. 'Transformative Human Rights Unit'. In: South Africa's Equality Courts: An Early Assessment. [www.csvr.org.za/wits/papers/paprctp5.htm]

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Spreading the word at ICASA...



Ensure that women's voices are heard...¹

Building women's meaningful participation in the scale-up of prevention of vertical transmission programmes

AIDS Legal Network, The Global Coalition of Women and AIDS

Most HIV infections in children occur in low- and middle-income countries, and more than 90 percent are the result of vertical transmission.² Approximately 1,000 babies acquire HIV every day during pregnancy, birth, or breastfeeding.³ 52% of all pregnant women living with HIV in low and middle-income countries did not receive anti-retroviral medication to prevent vertical transmission of HIV in the year 2010.⁴ Many countries still do not have sufficient services to reach women who need them and even where services are available, access and adherence to prevention of vertical transmission services remain weak.⁵ Yet, vertical transmission of HIV is preventable and constitutes a key strategy in effective HIV responses.

SETTING THE SCENE

It is possible to virtually eliminate vertical transmission and, in doing so, the *Global Plan towards the Elimination of New*

*HIV Infections among Children by 2015 and Keeping Their Mothers Alive*⁶ (the Global Plan) is an important tool. The goal of the Global Plan is to reduce the numbers of new HIV infections among children by 90%, and to reduce the number of AIDS-related maternal death by 50% by 2015. Although covering all low and middle-income countries, the Global Plan prioritises the 22 countries⁷ estimated to have the highest number of women living with HIV. During the High Level Meeting on AIDS in June 2011, the goal of the Global Plan was taken to the highest level, with governments of the world committing to virtually eliminating vertical transmission and reducing maternal deaths.

The 2011 Political Declaration on HIV/AIDS, in conjunction with the Global Plan, provides an important framework towards ending new HIV infections among children by 2015, as well as toward the promotion and protection of the rights and health of women. The Global Plan does not seek to replace existing efforts, but rather to afford a framework which supports countries to assess their work, to cost what it would take to support pregnant women living with HIV and to stop new infections, to mobilise resources, to implement activities, and to monitor and evaluate these interventions.

Based on the recognition that current programme approaches have to be transformed, the Global Plan sets forth, as a first key principle for success, that women living

with HIV are to be at the centre of the response, and that HIV responses are guided by a human rights framework⁸. It will thus be crucial to recognise and respond to the gendered barriers, as experienced by women, in accessing prevention of vertical transmission programmes at a national level. At the same time, it is essential to listen and act upon the recommendations and interventions made by women to address these barriers.

In line with the above, the AIDS Legal Network (ALN), South Africa, in partnership with the Global Coalition on Women and AIDS (GCWA) undertook a virtual consultation on the Global Plan among women in the identified 22 priority countries in October 2011. The consultation was qualitative in nature, aiming to better understand women's realities and needs – as presented by women – with regards to prevention of vertical transmission initiatives. To facilitate participation of and engagement with women in the priority countries, women and their organisations from across the countries were actively involved in the virtual consultation, from the early stages of survey development, to gathering responses, analysing the data and collating the findings and key messages. In addition, a diversity of networks of women living with and affected by HIV, and women's rights advocates from the sexual and reproductive health and rights

...crucial to recognise and respond to the gendered barriers, as experienced by women, in accessing prevention of vertical transmission programmes...

movement, acted as focal points at a national and/or regional level throughout the process.⁹

Nearly 300 women participated in the consultation, with special efforts made to reach out to women who did not have access to the internet. Thus, in some of the countries, the survey was administered in-person and the responses later entered into the on-line system for analysis.¹⁰ Women who participated in the survey are between the ages of 18 and 50 years old. Almost half of the women participating also indicated that they personally have sought out or accessed prevention of vertical transmission services in their country.

This briefing paper presents the key gender barriers and related recommendations, which women themselves have identified and voiced throughout the consultation.

KEY BARRIERS TO WOMEN'S ACCESS TO PREVENTION OF VERTICAL TRANSMISSION PROGRAMMES

Guided by national policies, prevention of vertical transmission programmes are available in all the priority countries.¹¹ However, the identified gap between policy development and its implementation, challenging the effectiveness of national HIV responses is also applicable to prevention of vertical transmission of HIV.¹²

Although specific challenges for the adequate implementation of prevention of vertical transmission programmes may differ by country and context, many of the challenges appear to be similar across the priority countries.¹³ While the Global Plan refers to structural barriers, including a wide range of social, cultural and economic factors that impact on women's access to and adequacy of prevention of

vertical transmission services¹⁴, the gender-specific barriers to these services are not explored in detail. As such, it is relevant to consider women's views on and experiences with prevention of vertical transmission programmes, and identify the gender-related barriers that may affect their ability to make use of such services.

It is clear from the responses that the unequal context of society, where women and men are treated differently and have different opportunities, greatly impact on the extent to which women are in the position to make informed sexual and reproductive health choices; to access healthcare services; and to ultimately benefit from available HIV prevention, treatment, care and support programmes and interventions. Moreover, socio-cultural and religious values and norms are as much key to women's risks and vulnerabilities, as they are additional barriers for women's access to prevention of vertical transmission programmes.¹⁵ The following section outlines such barriers, following the themes that emerged from the findings of the virtual consultation.

STIGMA AND DISCRIMINATION

Stigma and discrimination of women living with HIV, by communities, healthcare workers and women's families, were highlighted by women as key barriers to service utilisation. In cases where women did not know their HIV status, they indicated that fear for stigma and discrimination led them to not want to get tested. Moreover, women openly living with HIV, reported experiencing stigma and discrimination in the form of judgements, because they were having children,

and because they were seen as carriers of HIV that would then spread.

...women are still not accorded their rightful status when approaching clinics, since they are judged and subjected to many unfriendly clinics and health workers... [Swaziland]

...it is essential to listen and act upon the recommendations and interventions made by women to address these barriers...

Women also reported that the fear that these judgements could be extended to legal sanctions in cases where criminalisation of HIV has been established by law, make them refrain from seeking services.¹⁶ In some cases, women noted that given the degree of stigma and discrimination they risked experiencing from healthcare providers, they turned instead to traditional birth attendants. Alternatively, women would chose to attend antenatal services without disclosing their HIV status, in order to not expose themselves to mistreatment, humiliation and discrimination.

In many instances, women living with HIV encountered ill-treatment by healthcare providers, in the form of derogatory communication and mockery.

As a woman from Botswana said:

...the discrimination and punishment of women living with HIV for having children make us then not to

want to use services, because the risk is too high...
[Botswana]

Even in situations where women have made use of prevention of vertical transmission programmes, some reported feeling pressured into breast-feeding their children, due to the high degree of stigma that would surround them, should they choose not to do so.

...women would choose to attend antenatal services without disclosing their HIV status, in order to not expose themselves to mistreatment, humiliation and discrimination...

ABANDONMENT, ABUSE AND VIOLENCE

A common theme throughout the reports was the fear of abandonment, abuse and violence, and/or their actual occurrence, serving as significant barriers to women's access to prevention of vertical transmission services. The reports specifically highlighted that women were often the first member of the household to discover their status, through antenatal testing, and that this could result in them being blamed for bringing HIV into the household. Alongside with this blame, women reported experiencing abandonment, abuse and violence by partners, family, friends and/or the community at large. As a

result, some women would abstain from accessing services and/or testing for HIV, or only do so at a late stage in their pregnancy.

Respondents also noted that violence often existed in the relationship prior to accessing the services and, as such, engaging with the services represented a risk of this augmenting. As a woman from South Africa said:

...if you are in an abusive relationship, the woman will be scared to access the services, because she is scared of her partner... [South Africa]

The consequences of accessing prevention of vertical transmission services could be severe. Women reported that they may be forced to leave their homes; shunned by their partners, families and/or communities; or be subjected to violence by their partners. As a woman from Botswana said, a key barrier to women's access to prevention of vertical transmission services is:

...the discrimination that we face and the judgement, sometimes violence from our families... [Botswana]

MALE INVOLVEMENT

Respondents also indicated that men may not support their partners to go to antenatal clinics and participate in prevention of vertical transmission programmes, because of societal norms and practices in particular those surrounding pregnancy and delivery. Women reported that - as part of the cultural norms - they were expected to be subservient and humble, because they were women. In cases where a woman's partner did not want her to take part of these

services, she was expected to conform. Also, male partners would sometimes see pregnancy and related healthcare as a 'woman's issue', and would thus refuse to be involved or participate in prevention services, or even stop their wives/partners accessing information and services.

While most partners were not willing to be engaged, some women highlighted that in some societies it would be seen as inappropriate to access services without their partner's involvement, thus limiting their access. This was exemplified by reports that healthcare workers would sometimes ask where the woman's husband was before providing treatment.

Family dynamics, in particular the opinion of the mother-in-law, would further compromise access to services. Without the support and engagement of their partners, respondents shared that they were unable to take part in prevention of vertical transmission programmes or that their involvement became more challenging, because of these family dynamics. Women also indicated that these prevention programmes neither tended to facilitate the engagement and support of their male partners, nor address hierarchies within families.

As a woman from Mozambique said:

...some women don't do it (access prevention of vertical transmission services) because they are afraid of their husband... [Mozambique]

...women are often experiencing levels of poverty that leave them with impossible choices: food or medication...

In line with this, a respondent from Uganda called for greater awareness raising efforts, stating that:

...(countries) should sensitise their fellow women and husbands and support them to take on the programme... [Uganda]

ECONOMIC DEPENDENCE

Poverty and economic dependence were highlighted as additional factors hindering access to services, further aggravating women's dependency on the approval from their partners and/or his relatives whether or not and when to access services. Provision of free services did not offer relief, as women still had to manage the costs related to travel, medication and formula, amongst others. Also, the time needed for accessing these services often involved negotiations with their partners, and thus added barriers to women's ability to access prevention of vertical transmission services.

In cases where the household money is controlled by the male partner, these challenges may be more intense, as women reported not being in the position to access the necessary funds, unless they could obtain it from their husbands. At the same time, even in cases where funds are not controlled by male partners or there is no partner present, women are often experiencing levels of poverty that leave them with impossible choices: food or medication. As a woman from Zimbabwe said:

...Competing priorities for use of limited funds in both urban and rural areas to cover associated antenatal costs and transport costs to health facilities. With

the economic meltdown and inequalities, women are left at a disadvantage. Many, especially those in female-headed households struggle to make ends meet... [Zimbabwe]

...women are not featuring enough as women in programmes and interventions...women as mothers are only seen as the bearers of children who have to prevent transmission to the child... [South Africa]

...women identified the lack of their meaningful involvement as a barrier to the effective implementation...

COMPREHENSIVE PREVENTION OF VERTICAL TRANSMISSION SERVICES

Women underlined the challenges of HIV and sexual and reproductive health services being located in different places, as this added to the burden of travelling to different locations and also increased the time and resources needed to access services. Moreover, women noted that prevention of vertical transmission services appeared to be only focusing on avoiding HIV transmission to the infant, without taking care of the women's HIV-related or overall health needs.

As such, there would not only be a lack of care and support for the woman during the delivery process, but also lack of support for the woman to care for their infants after child birth. Women particularly underscored challenges around continued access to treatment to sustain their health, as well as a limited ability to access formula to feed their infants. As a woman from South Africa said:

ACCESS IN RURAL AND REMOTE AREAS

Rural women highlighted the challenges faced in accessing services nearby their homes. They shared that it was difficult for women – time and money-wise – to undertake multiple trips to areas where services do exist, and that this obviously would affect the levels of service utilization.

Even in situations where prevention of vertical transmission services are available in rural and remote areas, women reported that healthcare workers were not in the position to adequately care for the significant number of women who needed these services, due to shortage of personnel. Women also underscored that many times available healthcare workers were not trained or sensitised to provide prevention of vertical transmission services without stigma and discrimination, thus adding to service utilisation barriers.

In addition, respondents pointed out that women residing in rural areas were hardly reached by HIV education and awareness programmes, and often not informed about the possibility to prevent their child from acquiring HIV.

As a woman from Lesotho said, prevention of vertical transmission programmes are not equally accessible as:

...I am staying in one of the rural areas of my country and not even once have I ever heard of people coming to launch any of these programmes... [Lesotho]

MEANINGFUL PARTICIPATION OF WOMEN LIVING WITH HIV

One of the four key principles for success of the Global Plan is that women living with HIV are to be at the centre of the response.¹⁷ Yet, women identified the lack of their meaningful involvement as a barrier to the effective implementation of prevention of vertical transmission programmes. This was noted at all levels, from the development of plans and programmes, to the implementation and monitoring and evaluation.

While some women reported having been asked to participate and asked for their recommendations, they noted that there remained a gap in terms of their recommendations being truly listened to and acted upon.

As a woman from Uganda said:

...I strongly believe that change can be effected, but there is the need to meaningfully involve those who have gone through/are going through the experience...

[Uganda]

...healthcare workers were not trained or sensitised to provide prevention of vertical transmission services without stigma and discrimination, thus adding to service utilisation barriers...

Recommendations for Action

Based on the above findings, seven key recommendations for action emerge:

1. Include anti-stigma and discrimination campaigns and awareness raising as an integral part of the roll-out of prevention of vertical transmission programmes
2. Strengthen social and legal systems to support women who fear or experience abandonment, abuse and/or violence
3. Ensure that prevention of vertical transmission programmes strive not only to avoid HIV transmission to infants, but also ensure optimal health of women, while upholding and protecting women's rights
4. Work with partners to address cultural barriers, including norms around masculinities and womanhood, so as to increase women's empowerment and strengthen male partners' support and engagement with prevention of vertical transmission programmes
5. Link prevention of vertical transmission programmes to women's economic empowerment initiatives
6. Evaluate the need for increased availability of prevention of vertical transmission services in rural and remote areas and determine ways to better enable women in these areas to access services
7. Reach out to and meaningfully engage women living with HIV at all levels of prevention of vertical transmission programmes

CONCLUSION

The findings of this virtual consultation reveal that there are serious gender barriers to women's access to comprehensive services to prevent vertical transmission of HIV. While virtually eliminating vertical transmission and saving mothers' lives is possible, doing so requires placing women living with HIV at the centre of the response and jointly taking action to overcome each of these gender barriers.

Women's voices and key messages gathered with this virtual consultation reaffirming that women are eager and ready to engage in all processes affecting their lives, to have their voices listened to and acted upon. Women seek to be consulted and asked about their realities and needs, to be meaningfully involved in all stages, and to be truly placed at the centre of the development and implementation of prevention of vertical transmission plans at the national and global level.

Effectively responding to the challenges which lie ahead require meaningfully involving women living with HIV at every level, from the community, to national, regional and global levels. It will require engagement by the state and civil society, but also by communities and families, which can have a tremendous influence on how women and girls, as well as men and boys, perceive themselves and each other in society. It will be key to take forward a shared message which clearly underscores that gender equality, just as services that prevent vertical transmission of HIV, benefits everyone.

Only in this way will it be possible to reach the goal and fulfil the commitment of virtually eliminating vertical transmission and decreasing maternal deaths.

FOOTNOTES:

1. Woman, South Africa, October 2011.
2. Retrieved from www.avert.org/pmtct-hiv.htm, 23 January 2011.
3. UNICEF (2010). *Preventing Mother-to-Child Transmission (PMTCT) of HIV* [www.unicef.org/aids/index_preventionyoung.html]
4. GLOBAL HIV/AIDS RESPONSE: Epidemic update and health sector progress towards Universal Access, Progress Report 2011 (WHO, UNICEF, UNAIDS), p.154.
5. Stringer et al (2008) found that only half (49%) of all women living with HIV that accessed ANC services adhered to the full course of vertical transmission treatment.
6. The Global Plan can be accessed on www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110609_JC2137_Global-Plan-Elimination-HIV-Children_en.pdf.
7. The 22 priority countries identified in the Global Plan are: Angola, Botswana, Burundi, Cameroon, Chad, Cote d'Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana, India, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Swaziland, Uganda, United Republic of Tanzania, Zambia and Zimbabwe.
8. Global Plan, p8.
9. This initiative would not have been possible without the collaboration, expertise, support and assistance from women and their organisations across the priority countries. We would like to acknowledge and express our thanks to ICW East Africa, ICW Southern Africa, ICW West & Central Africa, ICW Asia Pacific, Swaziland Positive Living (SWAPOL), Femme Plus A.S.B.L. (Democratic Republic of Congo), Kenya Network of Women with AIDS, National Network of Positive Women Ethiopians, Coalition of Women Living with HIV/AIDS (Malawi), Tanzania Network of Women Living with HIV, Society of Women and AIDS (Ghana), Muleide (Mozambique), Her Rights Initiative (South Africa), Namibian Women's Health Network, and AIDS & Rights Alliance for Southern Africa (ARASA).
10. These countries include Democratic Republic of Congo, Lesotho, Mozambique, Namibia, South Africa and Zimbabwe.
11. UNICEF. 2010. 'Preventing Mother-to-Child Transmission (PMTCT) of HIV: Fact sheets on the status on national PMTCT responses in the most affected countries'. [www.unicef.org/aids/index_preventionyoung.html]
12. UNAIDS. 2010 Report on the Global AIDS Epidemic.
13. Global Plan, p24.
14. Global Plan, p10.
15. Global Plan, p8. See also UNAIDS. 2010. UNAIDS Action Framework: Addressing women, girls, gender equality and HIV.
16. Of the 22 priority countries, Ghana, Namibia, Nigeria and South Africa are the only countries which do not have laws in place that criminalise HIV transmission or exposure, or are in the process of drafting such legislation. [www.gnplusplus.net/criminalisation/index.php?option=com_content&task=view&id=12&Itemid=34]
17. Global Plan, p8.

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The criminalisation debate continues...

The law response to Helen Zille, the HIV populist¹

Political leaders holding executive office (like the President and the nine Premiers) cannot be expected to know everything about every conceivable subject, which is why they employ advisors to assist and advise them. However, sometimes they think they know everything about everything (always a dangerous thing for a politician to think, as we know from experience with former President Thabo Mbeki), and sometimes their advisors fail to do their job properly.

Pierre de Vos

It is unclear whether Premier Helen Zille relied on advisors before making truly astonishing statements about the criminalisation of sex, or whether she came up with her hare-brained scheme all by herself.

Zille said in November 2011 that she was so worried about the spread of HIV and its cost to the government that she wants men who have multiple sexual partners and refuse to use condoms to be charged with attempted murder. Zille told a wellness summit hosted by the provincial health department in Newlands on 08 November 2011 that it was time the government shifted its exclusive focus from treating diseases to preventing them and promoting wellness.

If she was quoted correctly, her statement represents a frontal attack on the Rule of Law and the basic principles of criminal law applicable in any democratic society.

If she said that men who have multiple sexual partners and refused to use condoms should be charged with attempted murder regardless of whether they are HIV positive and regardless of whether they knew that they were HIV positive, she was advocating the criminalisation of conduct that no

civilised society based on the Rule of Law and a respect for human rights would criminalise.

A fundamental principle of the criminal law in a country that adheres to the rule of law is that one could only be charged and found guilty of a crime (or attempting to commit a crime) if one could be proven to have had the intention to commit the crime or (in exceptional cases) had the knowledge that his or her actions could have resulted in the commissioning of unlawful action and nevertheless negligently proceeded to act. In South Africa, culpable homicide is the unlawful and negligent killing of another. Attempted murder is committed where one intends to kill somebody else, but fails in doing so.

Merely potentially endangering the life of another can never be culpable homicide or attempted murder and one cannot be convicted of attempted culpable homicide. One can only be convicted of attempted murder if it can be proven that one had the intention to kill another but failed to do so. In *S v Naidoo*, the SCA set out the position quite clearly:

What the crimes of murder and culpable homicide have in common is a fatal outcome for a human being. Absent a death, absent the particular crime. What they

do not have in common is that absent a death, there may be a conviction of attempted murder, but not a conviction of attempted culpable homicide. The reason for the difference lies in the distinction between the two forms of mensrea, which are essential elements of the respective crimes of murder and culpable homicide.

The crime of murder cannot be said to have been committed unless the act or omission of act, which caused death, was intentionally committed or omitted and death was the desired result, or, if not the desired result, at least actually foreseen as a possible result the risk of occurrence of which the accused recklessly undertook and acquiesced in. In short, *dolus* in one or other of its manifestations (*directus, eventualis, indeterminatus, etc*) is the kind of *mensrea*, which must have existed. Where the act or omission is accompanied by such *dolus*, but death does not in fact ensue, it is easy to understand why the accused's conduct should be visited nonetheless with penal sanctions. A deliberate attempt to commit the crime of murder cannot be ignored and left unsanctioned simply because the perpetrator has failed to achieve his or her objective.

Where it can be proven that a person intentionally tried to kill another by infecting him or her with the HI virus (which would be very difficult to prove), a person could be charged with attempted murder. But where someone does not know his or her HIV status and has sex without a condom, it could never lead to a criminal conviction for attempted murder due to the absence of intention. If somebody negligently transmits HIV to another and that person actually dies, the person could theoretically be charged with culpable homicide, but proving

the causal link between the sexual act and the death of the person, as well as the negligence on the part of the accused, would be almost impossible to do.

...the criminal law cannot be used to punish individuals merely for not conforming to Judaeo-Christian moral standards regarding sexual behaviour...

Given the fact that antiretrovirals are now widely accessible, a person who responsibly gets tested and takes this medicine will in all probability live a long and productive life, which means that it would be almost impossible to prosecute someone for attempted murder as the state would not be able to show the causal link between the sexual act and the death.

In the age of ARVs, deliberately transmitting HIV to another should not be viewed as attempted murder, because one's action would not lead to the death of the other person. Where a person dies of an HIV-related illness, the accused charged with his or her murder or with culpable homicide would argue – that but for the failure of the deceased to take ARVs – death would never have occurred, and that there was hence no causal link between the sexual act and the death.

There are good reasons for this. In a constitutional democracy – as opposed to a theocratic state – the criminal law cannot be used to punish individuals merely for not conforming to Judaeo-Christian moral standards regarding sexual behaviour. If one criminalised all unprotected sex with

one or several partners, one would be punishing people for something that might never have happened (HIV infection, leading to death) or for something they might not have foreseen at all (as they might not have believed that they were HIV positive at all or might not be HIV positive). One would be punishing people for not behaving in a manner one believes is appropriate – regardless of the consequences or potential consequences.

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The criminal law then becomes an oppressive and authoritarian instrument of social control, turning large numbers of ‘ordinary citizens’ into ‘instant criminals’. Where the criminal law punishes behaviour not based on the consequences or potential consequences of said behaviour, but for its own sake and without taking into account the guilt of the accused, the Rule of Law is fundamentally undermined.

Perhaps Premier Zille was misquoted or she ‘misspoke’. Perhaps she meant to say that somebody who has multiple sexual partners and knows that he is HIV positive, but nevertheless fails to use a condom and then transmits HIV to a partner, who later dies from AIDS-related illnesses, should be charged with attempted murder.

Even so, this view is quite shockingly misinformed and would have disastrous consequences. It would create an incentive for some men not to get tested for HIV and hence not to take ARVs. Not only would the men then die needlessly, but those men would be also far more likely to transmit HIV to their sexual partners. This is because an HIV positive person on ARVs whose viral load becomes undetectable is far less likely to transmit HIV, than one who is not on ARVs and whose viral load is high.

Criminalising sexual behaviour in this way might therefore increase the rate of HIV transmission. It will certainly not decrease it.

FOOTNOTES:

1. An earlier of this article has been published on 10 November 2011 on the Constitutionally Speaking blog. [<http://constitutionallyspeaking.co.za>]

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Oslo Declaration on HIV Criminalisation¹

1. A growing body of evidence suggests that the criminalisation of HIV non-disclosure, potential exposure and non-intentional transmission is doing more harm than good in terms of its impact on public health and human rights.²
 2. A better alternative to the use of the criminal law are measures that create an environment that enables people to seek testing, support and timely treatment, and to safely disclose their HIV status.³
 3. Although there may be a limited role for criminal law in rare cases in which people transmit HIV with malicious intent, we prefer to see people living with HIV supported and empowered from the moment of diagnosis, so that even these rare cases may be prevented. This requires a non-punitive, non-criminal HIV prevention approach centred within communities, where expertise about, and understanding of, HIV issues is best found.⁴
 4. Existing HIV-specific criminal laws should be repealed, in accordance with UNAIDS recommendations.⁵ If, following a thorough evidence-informed national review, HIV-related prosecutions are still deemed to be necessary they should be based on principles of proportionality, foreseeability, intent, causality and non-discrimination; informed by the most-up-to-date HIV-related science and medical information; harm-based, rather than risk-of-harm based; and be consistent with both public health goals and international human rights obligations.⁶
 5. Where the general law can be, or is being, used for HIV-related prosecutions, the exact nature of the rights and responsibilities of people living with HIV under the law should be clarified, ideally through prosecutorial and police guidelines, produced in consultation with all key stakeholders, to ensure that police investigations are appropriate and to ensure that people with HIV have adequate access to justice.
- We respectfully ask Ministries of Health and Justice and other relevant policymakers and criminal justice system actors to also take into account the following in any consideration about whether or not to use criminal law in HIV-related cases:
6. HIV epidemics are driven by undiagnosed HIV infections, not by people who know their HIV-positive status.⁷ Unprotected sex includes risking many possible eventualities – positive and negative – including the risk of acquiring sexually transmitted infections such as HIV. Due to the high number of undiagnosed infections, relying on disclosure to protect oneself – and prosecuting people for non-disclosure – can and does lead to a false sense of security.
 7. HIV is just one of many sexually transmitted or communicable diseases that can cause long-term harm.⁸ Singling out HIV with specific laws or prosecutions further stigmatises people living with and affected by HIV. HIV-related stigma is the greatest barrier to testing, treatment uptake, disclosure and a country's success in *'getting to zero new infections, AIDS-related deaths and zero discrimination'*.⁹

8. Criminal laws do not change behaviour rooted in complex social issues, especially behaviour that is based on desire and impacted by HIV-related stigma.¹⁰ Such behaviour is changed by counselling and support for people living with HIV that aims to achieve health, dignity and empowerment.¹¹

...any new HIV prevention strategy requires carefully-developed context-specific messaging...

9. Neither the criminal justice system nor the media are currently well-equipped to deal with HIV-related criminal cases.¹² Relevant authorities should ensure adequate HIV-related training for police, prosecutors, defence lawyers, judges, juries and the media.

10. Once a person's HIV status has been involuntarily disclosed in the media, it will always be available through an internet search. People accused of HIV-related 'crimes' for which they are not (or should not be found) guilty have a right to privacy. There is no public health benefit in identifying such individuals in the media; if previous partners need to be informed for public health purposes, ethical and confidential partner notification protocols should be followed.¹³

FOOTNOTES:

1. This Declaration has been prepared by international civil society in Oslo, Norway on 13th February 2012.
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4. GNP+/UNAIDS. 2011. Positive Health Dignity and Prevention: A Policy Framework . Amsterdam/Geneva.
5. UNAIDS/UNDP. 2008. Policy Brief: Criminalization of HIV Transmission. Geneva, July 2008.
6. UNAIDS, 2012, op. cit.
7. Marks, G. et al. 2006. 'Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA'. In: *AIDS* 20(10):1447-50; Hall, HI et al. 2012. 'HIV transmissions from persons with HIV who are aware and unaware of their infection, United States'. In: *AIDS*, 26, online edition. DOI: 10.1097/QAD013e328351f73f, 2012.
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9. UNAIDS. 2010. Getting to Zero: 2011-2015 Strategy. Geneva, December 2010.
10. Bernard, EJ & Bennett-Carlson, R. 2011. Criminalisation of HIV Non-disclosure, Exposure and Transmission: Background and Current Landscape. UNAIDS, Geneva.
11. GNP+/UNAIDS, 2011, op. cit.
12. Bernard & Bennett-Carlson, 2012, op. cit.
13. UNAIDS. 2000. Opening up the HIV/AIDS epidemic: Guidance on encouraging beneficial disclosure, ethical partner counselling & appropriate use of HIV case-reporting. Geneva.

For more information and/or to sign the Declaration, please go to www.hivjustice.net/oslo/olso-declarartion.

Marching at ICASA...



Supported by the Oxfam HIV and AIDS Programme (South Africa)



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