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Patrick Eba

One size punishes all…

A critical appraisal of the criminalisation of HIV transmission

Lauded by lawmakers as an expression of their strong will to *'fight AIDS'*, HIV-specific laws have become a ubiquitous feature of the legal response to HIV in sub-Saharan Africa[1]

As of 1st December 2008, twenty countries in sub-Saharan Africa had adopted HIV-specific laws.[2] HIV-specific laws or '*omnibus HIV laws*', as they are sometimes ironically referred to, are legislative provisions that regulate, in a single document, several aspects of HIV and AIDS, including HIV-related education and communication; HIV testing, prevention treatment, care and support; HIV-related research; and the protection of people living with HIV. The emergence of HIV-specific laws in sub-Saharan Africa can be traced to the adoption of the Model Law on STI/HIV/AIDS for West and Central Africa in September 2004. Generally known as the N'Djamena Model Law, this document was adopted by the Forum of African and Arab Parliamentarians for Population and Development (FAAPPD) at a workshop organised on 8-11 September 2004 in N'Djamena (Chad) by Action for the West African Region on HIV/AIDS (AWARE-HIV/AIDS), in collaboration with the FAAPPD, the ECOWAS Parliament, the West African Health Organisation (WAHO), the Center for Studies and Research on Population for Development (CERPOD), the Network of Parliamentarians in Chad for Population and Development and the USAID West African Regional Programme.[3]

The stated objective of these HIV-specific laws, as provided under several of their preambulary provisions, is to

> *…ensure that every person living with HIV or presumed to be living with HIV enjoys the full protection of his or her human rights and freedoms*.[4]

In spite of these proclamations of intent by their drafters, the content of HIV-specific laws suggests a different and grimmer reality. Several HIV-specific laws adopted in sub-Saharan Africa restrict access to information and education for children;[5] provide for mandatory pre-marital HIV testing and for compulsory HIV testing for commercial sex workers;[6] introduce compulsory disclosure of HIV status;[7]

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Editorial...

Decriminalisation, not more criminalisation is what is needed. [Kirby, 2007]

It is within the context of this quote that this Double Edition of the *ALQ* is focussing on HIV criminalisation – exploring various aspects of legislative trends towards the criminalisation of HIV exposure and transmission; as well as the extent to which prevailing '*criminalisation*' realities, as experienced especially by positive women, lesbian women and sex workers, impact on HIV risks and vulnerabilities. The numerous articles in this edition examine the legislative trends towards criminalising HIV exposure and/or transmission as to their inefficiency and inability to halt the spread of HIV; explore various human rights and gender implications, particularly as to the extent to which HIV-specific laws will affect women, and especially positive women, will deter people from accessing HIV prevention, testing, treatment, care and support services, will increase, instead of decrease, existing HIV risks and vulnerabilities for already '*vulnerable and marginalised groups*', and will further HIV-related stigma, discrimination and the *'criminalisation'* of people living with HIV. Moreover, this edition questions the '*ability*' of the law to influence and transform behaviour, especially sexual behaviour; to halt new HIV infections, and to '*protect*' women from '*wilful*' HIV infections.

This edition also introduces the Namibian experience of coerced or forced sterilisation of young positive women; is '*making a comment*' on the meaningful involvement of women living with HIV at the 2008 Mexico conference; as well as a '*comment*' on the changes signalled for global responses and funding for HIV and AIDS through Obama's victory at the US election; and includes an introduction of the WC End Hate Campaign – a civil society response to numerous incidences of violent homophobic hate crimes against especially black lesbian women; and the '*provincial feedback*' on the implementation of the NSP. And finally, this edition introduces 10 reasons to oppose the criminalisation of HIV exposure or transmission.

In this edition, **Patrick Eba** provides an overview of the legislative trends towards the criminalisation of HIV transmission in sub-Saharan Africa. Analysing various provisions and their impact of HIV-specific laws in the region, he highlights the inefficiency of these laws by specifically focusing on the concepts of '*prohibited activities*', '*knowledge of infection*', condom use, and '*disclosure and consent*' as utilised in HIV-specific laws, and argues that the very language and content of these laws are '*problematic*', since structural responses to the spread of HIV, such as HIV-specific laws, are only raising more questions and concerns, than they are in the position to provide answers and thus, reduce the spread of HIV.

Based on the premise that '*criminalisation*' may have good intentions, but is bad policy, **Michaela Clayton**, **Edwin Cameron** and **Scott Burris** examine some of the negative impacts of laws criminalising HIV exposure and transmission on especially '*those vulnerable to becoming infected*'. Exploring the various implications of criminalisation, the article argues that since HIV is a tragedy and not a crime, laws criminalising HIV transmission is not the answer to halt new HIV infections – as the answer would lie in the review of the law so as to remove legal barriers to HIV prevention, treatment and care services.

Highlighting the extent to which legislative trends towards criminalisation of HIV transmission affect women and girls, **Alice Welbourn** analyses some of the realities, closely linked to the application of laws criminalising HIV transmission, including the fact that laws are not gender specific. Examining various realities as to the extent to which they impact on women's and girls' HIV risk, she argues that laws criminalising HIV transmission, irrespective of whether or not they may have had '*good intentions*', are in reality nothing more than practices that judge, penalise and ostracise HIV positive women.

Recognising the impact of existing criminalisation of sex work on, amongst others, sex workers heightened HIV risks and vulnerabilities, **Marlise Richter** stresses the need for decriminalisation of sex work, and advocates for the immediate implementation of one of the NSP recommendations calling for the decriminalisation of sex work. In her analysis, she argues that maintaining the '*status quo*' of criminalising sex work will not only continue the human rights abuses and violations sex workers are subjected to, but also ensure that available HIV prevention, testing, treatment, care and support services remain largely inaccessible to sex workers.

Looking specifically at the impact of criminalising HIV transmission within a patriarchal society, **Raphaela Madlala** discusses the extent to which laws criminalising HIV exposure and transmission will

and nineteen out of twenty criminalise HIV transmission or exposure[8,9].

The criminalisation of HIV transmission or exposure is generally invoked to epitomise the embrace of coercive measures in HIV-specific laws in sub-Saharan Africa.[10] Consequently, there is a growing number of advocacy initiatives and scholarly writings challenging the explosion of HIV-specific laws that criminalise HIV transmission and exposure in this region.[11] However, most of these efforts have, thus far, focused on highlighting the inefficiency of these laws in affecting behaviour change and their negative impact on people living with HIV, or public health interventions, without linking these arguments to a systematic and coherent analysis of the content of HIV-specific laws. This article argues that a strong case against the criminalisation of HIV transmission or exposure, through HIV-specific laws, lies in the very language and content of these laws.[12]

Navigating through the nebulous content of HIV-specific laws that criminalise HIV transmission or exposure, this article identifies several elements (as illustrated in Table 1) that disqualify them as ill-informed and potentially harmful to the response to HIV. Firstly, the activities prohibited under HIV-specific laws are overbroad and fail to distinguish between high and low risk activities, hence spreading misconceptions about HIV. Secondly, HIV-specific laws fail to integrate the use of condoms in the definition of the crime of HIV transmission or exposure, thus, undermining one of the most effective HIV prevention strategies. Thirdly, by requiring the knowledge of HIV infection, HIV-specific laws may discourage HIV testing. Finally, by failing to integrate disclosure and consent, HIV-specific laws disregard an important public health message and ignore the sexual and reproductive health rights of people living with HIV and their partners.

Prohibited activities

Proponents of the use of HIV-specific laws to criminalise HIV transmission or exposure argue that they provide clarity and ensure the protection of the right of the accused by defining in advance what acts are prohibited.[13] However, the analysis of HIV-specific laws adopted in sub-Saharan Africa provides very little evidence to support this affirmation. As illustrated in Table 1, all the HIV-specific laws reviewed include overbroad provisions related to the criminalisation of HIV transmission.[14] These provisions are considered overbroad, because they fail to identify what specific acts are targeted for criminal punishment. A typical example of overbroad provision is that of Mauritania, which defines HIV transmission as

> *…any attempt to a person's life by the inoculation of substances infected with HIV, regardless of how these substances were used or employed and independently of the consequences thereof.*[15]

This provision is extremely vague and may be used to target a wide range of activities. The provision prohibits any '*inoculation of substances infected with HIV*' regardless of whether or not the substance can lead to HIV infection. Arguably, this provision can be used to criminalise a person living with HIV who engages in a deep kiss or French kiss with another person as this may involve the transfer of saliva. Although the presence of HIV has been reported in saliva, deep kissing is considered an ineffective route of HIV transmission in the absence of open sores in the mouth, because of the very low concentration of HIV in saliva.[16]

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Due to the overbroad wording, all but one of the HIV-specific laws (Togo) could be used to punish mother-to-child transmission (Table 1). Several HIV-specific laws stipulate that the crime of transmission of HIV is considered to have been committed regardless of '*how the* [substances infected with HIV] *were used or*

increase women's risks and vulnerabilities – both to HIV infection and to be '*prosecuted*' for transmitting HIV. She explores the potential impact of these legislative trends on HIV testing, as well as HIV-related stigma and discrimination, and argues that with the introduction of these laws not knowing one's HIV status seems to be the '*safer*' option, as these laws will endorse the perception that people living with HIV are potential '*criminals*' with the '*desire, potential and intent to harm others*'.

Jennifer Gatsi introduces the Namibian reality of coerced or forced sterilisation of young positive women. Exploring the gross human rights abuses inherent to these practices, she shares experiences of advocacy responses demanding an immediate halt to coerced or forced sterilisation and justice for women who have been violated, and argues that, in order to stop this clear expression of denying positive women the right to reproduce, healthcare providers performing sterilisation without the consent of women, as well as government officials failing to adequately intervene, have to be held fully accountable.

Raising concerns as to the impact of criminalising HIV transmission on the occurrence of gender-based violence, **Jameyah Armien** examines the links between trends towards criminalisation and the reality of gender-based violence. Examining various factors influencing the extent to which gender violence is not only often '*justified*', but also reinforced by the normative and gendered societal context in which it occurs, she argues that laws criminalising HIV exposure and/or transmission will further augment the invisibility of gender violence, while at the same time '*enforce*' in the name of the '*law*' violence directed at people living with HIV.

Exploring some of the human rights implications intrinsically linked to the introduction of HIV-specific legislation, **Johanna Kehler** examines the likely effect of criminalising HIV exposure and/or transmission on the accessibility of available prevention, testing, treatment, support and care services, as well as on human rights gains made in the response to HIV and AIDS. She argues that human rights will be further compromised as the increased risk of human rights abuses seems to be as much inherent to HIV-specific legislation, as the heightened risk to HIV infection, to abuse, and to '*HIV-related prosecution*' for already '*vulnerable and marginalised groups*'.

Recognising women's full participation and active leadership in the response to HIV and AIDS as the key to ensuring a gendered response to women's realities and needs in the context of HIV and AIDS, **Tyler Crone** raises the question as to the adequacy of women's participation and leadership. Analysing data as to who is informing, and actively participating in, the design and implementation of HIV and AIDS responses at a national, regional and global level, she argues that as long as the participation and leadership of women are largely seen as a privilege, instead of a right, women's voices will continue to be silenced, as policies and programmes remain largely non-inclusive.

Gahsiena van der Schaff examines provincial experiences and challenges relating to the knowledge and implementation of the NSP. Exploring information and data received during various meetings at a provincial level, and discussing some of the recurrent challenges and obstacles raised, she argues that because the NSP remains largely unknown and since there are no effective partnerships in place, which are inclusive of civil society, to further the implementation of the NSP, the NSP remains to be but a document for a few, with little or no benefit to the people it is meant to benefit.

Discussing America's HIV and AIDS policy, as well as the extent to which HIV and AIDS featured during the 2008 election campaign, and the potential for change after the 2008 US election, **Nathaniel Meyer** is '*making a point*' about the fact that Obama's victory signals a new beginning, which also carries the potential of change in the global HIV and AIDS response and funding.

Analysing the meaningful involvement of women living with HIV (MIWA) at the 2008 Mexico conference based on collected data during the conference, **Luisa Orza** provides a critical assessment of the gains and continuing challenges of positive women's involvement at international decision-making structures, including international AIDS conferences. Exploring the positive impact of positive women's involvement in the processes leading up to, and during, the international AIDS conference, as well as the barriers to greater and more meaningful involvement of positive women, she is *'making a point'* that, despite progress made, gains continue to be hard-won, even though, '*they ought to, by now, be a given*'.

While the approach and focus may differ in analysing the various trends, realities and implications of HIV criminalisation, there seems to be common concerns raised in all the contributions ranging from a potential increase in stigma and discrimination to

administered'. Under these laws, a mother living with HIV who transmits HIV to her child during pregnancy, delivery or breastfeeding can be prosecuted for HIV transmission. Arguably, any woman living with HIV who becomes pregnant can be prosecuted for exposing her child to HIV as these laws do not require actual transmission of HIV. Similarly, the HIV laws of Tanzania, Burundi and Kenya that broadly criminalise the exposure or transmission of HIV, without defining the modes of transmission or exposure, may also be used to criminalise mother-to-child transmission.[17]

Unlike the other HIV-specific laws that may be interpreted to include mother-to-child transmission, that of Sierra Leone expressly criminalises mother-to-child transmission.[18] This provision is clearly intended at deterring women living with HIV from bearing children. It constitutes a violation of the sexual and reproductive health rights of women living with HIV, and may contribute to the stigmatisation of women as '*vectors of diseases*'.[19]

…constitutes a violation of the sexual and reproductive health rights of women living with HIV, and may contribute to the stigmatisation of women as 'vectors of diseases'...

Another feature of the criminalisation of HIV transmission or exposure through HIV-specific laws in sub-Saharan Africa is that several of them specifically target healthcare workers (Table 1). For instance, the HIV laws of Mauritania, Mali and Guinea Bissau punish medical practitioners who may be accomplices of HIV transmission or exposure.[20] The HIV law of Madagascar doubles the penalty for HIV transmission if the crime is committed by a healthcare provider.[21] These provisions seem to be a reaction to incidents similar to that of healthcare workers in Libya, who had allegedly infected children with HIV in a hospital setting.[22] It should be noted from the outset that the Libyan prosecutions were largely regarded as an attempt to deflect blame from the government's role in the infection of the children by failing to put adequate measures (such as blood safety) in place.[23] Targeting healthcare workers for criminalisation is based on a sensationalised view of the AIDS pandemic. It creates the wrong impression that HIV is spread through that route, and that it will somehow be curbed through these measures.[24] These provisions further stigmatise HIV and are merely deflecting the attention from the real causes of HIV infection.

The analysis of the prohibited activities under HIV-specific laws also unveils a peculiar characteristic of these laws that we describe as '*over-criminalisation*' (Table 1). '*Over-criminalisation*' refers to the fact that several provisions, in the same HIV-specific law, can be used to prosecute HIV transmission or exposure. A typical example of '*over-criminalisation*' can be found in the HIV law of Burkina Faso. This HIV law contains three separate provisions with different constitutive elements that may be applied to the criminalisation of HIV transmission or exposure namely, Article 20, which is expressly related to the sexual transmission of HIV; Article 22, which deals with the transfer of substances infected with HIV, and could also be used to criminalise the sexual transmission of HIV; and finally Article 26, which criminalises any person living with HIV, who does not take the necessary precautions to protect his or her partners, which again could be invoked to prosecute the sexual transmission of HIV.[25] This '*over-criminalisation*' is source of confusion on the nature of the prohibited acts, as vague and overbroad provisions often coexist in the same HIV laws with narrowly worded ones that specify the prohibited acts. The merits of the latter are invalidated by the former, because vague provisions can be invoked to prosecute a person who engaged in acts that are not specifically prohibited.

Although referred to as HIV transmission or

further deterring people from accessing HIV prevention, testing, treatment, care and support services, as well as the disproportionate negative impact HIV-specific laws will have on women, including increased risks and vulnerabilities to gender-based violence and to HIV infection. There also seems to be the common argument that criminalising HIV exposure or transmission is not only '*bad policy*', but will also, in its application, reverse many of the human rights gains made in the global response to HIV and AIDS – thus, the criminalisation of HIV exposure or transmission is in its very design a human rights violation.

Similarly, exploring the various realities and challenges of '*HIV criminalisation*' as experienced especially by '*vulnerable and marginalised groups*', such as by positive women, lesbian women and sex workers, clearly highlights that specific laws criminalising HIV exposure and transmission will further enhance, rather than decrease, existing risks and vulnerabilities – and thus, further jeopardise the extent to which especially '*vulnerable and marginalised*' groups are in the position to access and benefit from existing services and programmes. Most notably, prevailing rights abuses and violations based on a person's sex, gender, sexual orientation and/or HIV status will not only increase, but also be '*sanctioned*' by the law.

Notwithstanding the need to '*punish*' a person who '*intentionally*' exposes another person to HIV with the '*intent*' to infect the other person with HIV, it has to be recognised that existing legislation is more than adequate to prosecute cases of '*intentional*' HIV infection – raising the question as to why '*new*' legislation needs to be introduced to prosecute '*intentional*' HIV infection. Whatever the reasons may be – reducing HIV transmission or '*protecting*' the most vulnerable from the risk of '*wilful*' HIV infection – introducing HIV-specific legislation will not and cannot, by its very design, achieve either of these.

Amongst the many concerns is the fact that the '*punitive approach*' fails to take into account not only the societal context defining existing HIV risks and vulnerabilities, as well as prevailing realities of HIV-related stigma, discrimination and violation of rights, but more importantly the underlying factors fuelling the HIV and AIDS pandemics, such as gendered power relations maintained and strengthened by '*social values*', placing especially women at greater risk of HIV infection. Acknowledging women's greater risks and vulnerabilities, including women's lesser '*power*' to make informed sexual decisions, as well as the reality that women are '*first to know*' of their HIV status, also demands recognising the potential '*impact*' of 'new' legislation in that women are more likely to be '*prosecuted*' by the very same law, which may indeed be meant to '*protect*' women.

If we are to agree that human rights are to be at the centre of the response to HIV and AIDS, then we need to equally agree that criminalising HIV exposure and/or transmission is indeed '*bad policy*' – as this will further compromise human rights, instead of promoting the protection of human rights, in the response to HIV and AIDS. Moreover, if we are to agree that '*behavioural change*' is key to reducing the spread of HIV, than we need to agree that the '*punitive*' approach is most concerning – as this might create the perception that '*behavioural change*', and more importantly '*sexual behaviour change*', can be legislated. At the same time, it is equally impossible to challenge or transform, through legislative reform, deep-seated value and belief systems, '*condoning*' and '*justifying*' prevailing '*HIV-criminalisation*'.

As long as we fail to design HIV and AIDS responses, which are indeed addressing the underlying factors of the pandemics, we will not only continue to '*by-pass*' the needs and realities of '*vulnerable and marginalised groups*', especially women, but also heighten the risks and vulnerabilities of '*those*', who are meant to benefit. Similarly, as long as we look for legislation to impact on the spread of HIV, we will continue to fail in addressing the '*real*' issues furthering the spread of HIV. Thus, only as and when human rights are indeed at the centre of the response to HIV and AIDS, will we be in the position to design and implement '*responses*' that are both based on, and responsive to, HIV risks and vulnerabilities – and hence, '*beneficial*' to the ones most at risk of HIV infection. If we, however, '*allow*' legislative trends towards criminalising HIV exposure and/or transmission to continue, then we not only '*allow*' prevailing '*HIV criminalisation*' to continue, but we also, to an extent, '*legalise*' the criminalisation of HIV – and thus, the '*criminalisation*' of people living with HIV…

Johanna Kehler

Table 1: Assessment of HIV-specific laws criminalising HIV transmission or exposure in sub-Saharan Africa[37]

Country	Exposure	Transmission	Overbroad	Over-criminalisation	Targets medical practitioners	Applicable to MTCT	Disclosure	Informed consent	Condom	Knowledge of HIV infection
Angola		X	X		X	X				X(a)
Benin			X	X	X	X	X		X	X
Burkina Faso	X	X	X	X		X	X(a)		X(a)	X
Burundi		X	X			X				X
Cape Verde	X		X			X				
Central African Republic	X	X	X	X		X			X(a)	X(a)
Chad	X	X	X	X	X	X			X(a)	X(a)
Democratic Republic of Congo		X	X			X				X
Guinea	X	X	X	X	X	X			X(a)	
Guinea Bissau	X	X	X		X	X				
Kenya			X	X		X	X	X		X
Madagascar		X	X		X	X				
Mali	X	X	X		X	X				
Mauritania	X	X	X	X	X	X	X(a)		X(a)	X(a)
Niger	X		X	X	X	X				X(a)
Sierra Leone			X	X		X	X	X		X
Tanzania		X	X		X	X				X
Togo			X	X					X	X

X(a) means 'yes/no' and is related to cases in which an HIV-specific law contains several provisions related to the criminalisation of HIV transmission, some of which require a particular element of the crime and others not.

exposure laws, many of these laws do not require '*exposure*' or '*transmission*' of HIV (Table 1). For instance, the HIV laws of Kenya (Article 24(1)(b)) and Sierra Leone (Article 21(b)) compel any person who is HIV positive, and is aware of that fact, to '*inform, in advance, any sexual contact or person with whom needles are shared of that fact*.' The obligation to inform on the person living with HIV exists, regardless of whether or not he or she '*exposes*' or '*transmits*' HIV to another person. These provisions fail to understand that '*a sexual contact*' or '*a person with whom needles are shared*' is not by these facts alone at risk of contracting HIV from a person living with HIV. Indeed, a person living with HIV can engage in activities with a '*sexual contact*', or a '*person with whom needles are shared*', that do not expose them to HIV, or that are unlikely to lead to the transmission of HIV, such as talking to each other, sharing a cup of tea, having protected sex, or sharing sterilised needles. By opening the possibility of criminal prosecution in the absence of exposure or transmission of HIV, these provisions are likely to send confusing messages to the general public about the modes of HIV transmission and may undermine the efforts of public health campaigns that promote the acceptance of people living with HIV.

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Knowledge of infection

Knowledge of infection means that only those who know their HIV status can be subjected to criminal liability for HIV transmission or exposure. Of the eighteen countries surveyed, thirteen, either expressly or implicitly, require knowledge of HIV infection as an element of the crime (Table 1).

The requirement of knowledge of infection as an element of the crime of HIV transmission or exposure

illustrates how dangerous HIV-specific laws can be. Requiring knowledge of infection means that HIV testing, which is commonly used to determine a person's HIV status, is no longer the life-saving step, or '*entry door*' towards access to prevention, treatment, care and support services advocated by public health messages.[26] Instead, testing for HIV becomes a self-incriminating step that may provide the state with a key element for prosecution under HIV transmission or exposure laws. It may, therefore, appear wiser for the general public to avoid knowing their HIV status as a way to escape potential prosecution: '*the less you know the safer you are*'.

Another concern related to the provisions requiring knowledge of HIV infection is that they fail to define what knowledge actually means. Does knowledge only refer to an HIV test? Does knowledge include a clinical diagnosis of AIDS by a physician specialising in infectious diseases? Or does knowledge also refer to '*constructive knowledge*'? [27] By failing to define the notion of knowledge, many HIV-specific laws provide room for the application of the notion '*constructive knowledge*', which is likely to lead to unfair prosecutions and may discourage any knowledge related to HIV.

Use of condom

Condom use is a central element of HIV prevention efforts among sexually active individuals.[28] For people living with HIV, the consistent and correct use of latex condoms is recommended to protect themselves (against the risk of re-infection) and others (against the risk of transmission of HIV).[29] In spite of these public health messages emphasising the importance of condom use among people living with HIV, only the HIV-specific laws of Togo and Benin shield people living with HIV, who use a condom during sexual intercourse, from prosecution.

Chad, the Central African Republic, Mauritania, Guinea and Burkina Faso have provisions that prevent the prosecution of people living with HIV who '*engage in protected sex*' (which includes the use of condoms). However, these provisions are made irrelevant by the fact that these laws also contain provisions that may be used to prosecute people living with HIV, even in the event of use of condoms. The other countries surveyed do not incorporate the use of condoms in the definition of the crime of HIV transmission or exposure (Table 1). The fact that sixteen of the eighteen countries surveyed provide for the criminalisation of people living with HIV, even when they engage in protected sex, is a major concern, as it clearly contravenes the prevention efforts based on condom use and introduces a disincentive for protected sex, because it does not protect against the possibility of criminal prosecution.[30]

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Disclosure and consent

Of all the HIV-specific laws surveyed, only those of Kenya and Sierra Leone exclude criminal liability when the person living with HIV discloses his or her HIV status, and obtains informed consent from his or her partner to the sexual act.[31] The HIV law of Benin excludes criminal liability when the person living with HIV discloses his or her HIV status, without referring to the consent of that person to the sexual act.[32] This means that in the fifteen other countries under review, disclosure and informed consent do not shield the person living with HIV from criminal prosecution (Table 1). This situation is paradoxical, as all these HIV statutes either encourage disclosure of HIV status or make it compulsory.[33]

The failure to protect those who disclose their HIV status and obtain the informed consent of their partners to sexual acts further illustrate the conflict between HIV-specific laws and public health messages. Indeed, in spite of its many challenges,[34] the disclosure of HIV status to sexual partners is encouraged as a measure of HIV prevention, and

as an element that may foster support for the person living with HIV and help reduce stigma.[35] Furthermore, disclosure and informed consent to sexual acts are an important element of sexual and reproductive health rights of people living with HIV who may agree with their partners to have unprotected sex for several reasons, including procreation. The prosecution of people living with HIV, who informed their partners and obtained their consent, will clearly be unfair and is likely to have a detrimental effect on disclosure.

…the recourse to the criminal law as a structural response to the spread of HIV, like Pandora's Box, raises more questions and concerns than answers…

Conclusion

Conceived with the blinded ire of legislators, frustrated by the complexity of the AIDS pandemic and desperate to show results, HIV-specific laws criminalising HIV transmission or exposure contribute to reinforcing stigma; spread myths and misconceptions about HIV and its modes of transmission; and undermine effective public health efforts based on the use of condoms and encouraging disclosure.

Our analysis proves, yet again, that the recourse to the criminal law as a structural response to the spread of HIV, like Pandora's Box, raises more questions and concerns than answers. It reminds us that we should not allow frustration, fear and prejudice cloud our mind and drive us away from the responses that have proved successful in addressing HIV, including HIV-related information and education targeted at behavioural change for risk reduction, addressing the underlying causes of vulnerability to HIV, and increasing access to HIV-related prevention, treatment, care and support services.[36]

FOOTNOTES:

1. The expression '*sub-Saharan Africa*' in this article is a shorthand to refer to all the African countries in the exclusion of those situated in Northern Africa. The expression also covers the African countries located in the Indian Ocean.

2. These countries are **Angola** (Lei No 8/04 sobre o Virus da Immunodeficiência Humana (VIH) e a Síndroma de Immunodeficiência Adquirida (SIDA)), **Benin** (Loi No 2005-31 du 10 Avril 2006 portant prévention, prise en charge et contrôle du VIH/SIDA), **Burkina Faso** (Loi No 030-2008 du 26 Juin 2008 portant lutte contre le VIH/SIDA et protection des droits des personnes vivant avec le VIH/SIDA), **Burundi** (Loi No 1/018 du 12 Mai 2005 portant protection juridique des personnes infectées par le Virus de l'Immunodéficience Humaine et des personnes atteintes du Syndrome Immunodéficience Acquise), **Cape Verde** (Lei No 19/VII/2007), The Central African Republic (Loi de 2006 fixant les droits et obligations des personnes vivant avec le VIH/SIDA), **Chad** (Loi No 19/PR/2007 du 15 Novembre 2007 portant lutte contre VIH/SIDA/IST et protection des droits des personnes vivant avec le VIH/SIDA), **The Democratic Republic of Congo** (Loi de 2008 déterminant les principes fondamentaux relatifs à la protection des droits des personnes vivant avec le VIH/SIDA et des personnes affectées), **Guinea** (Loi No 25/2005 relative à la prevention, à la prise en charge et le contrôle du VIH/SIDA), **Guinea Bissau** (Lei No 5/2007 de prevençao, tratamento e controle do VIH/SIDA), **Guinea Equatorial** (Ley No 3/2005 sobre la prevención y la lucha contra las infecciones de transmisión sexual (ITS), el VIH/SIDA y la defensa de los derechos de las personas afectadas), **Kenya** (HIV Prevention and Control Act, No 14 of 2006), **Madagascar** (Loi No 2005-040 du 20 Février 2006 sur la lutte contre le VIH/SIDA et la protection des droits des personnes vivant avec le VIH/SIDA), **Mali** (Loi No 6-028 du 29 Juin 2006 fixant les règles relatives à la prevention, à la prise en charge et au contrôle du VIH/SIDA), **Mauritania** (Loi No 2007-042 relative à la prevention la prise en charge et le contrôle du VIH/SIDA), **Mauritius** (HIV and AIDS Act, No 31 of 2006), **Niger** (Loi No 2007-08 du 30 Avril 2007 relative à la prevention, la prise en charge et le contrôle du Virus de d'Immunodéficience Humaine (HIV), **Sierra Leone** (The Prevention and Control of HIV and AIDS Act, No 8 of 2007), **Tanzani**a (HIV and AIDS (Prevention and Contol) Act, No 28 of 2008), and **Togo** (Loi No 2005-012 portant protection des personnes en matière du VIH/SIDA).

3. For an overview of how the N'Djamena Model Law influenced national legislation in several sub-Saharan African countries, see Pearshouse, R. 2007. 'Legislation contagion: The spread of problematic new HIV laws in Western Africa'. In: *HIV/AIDS Policy and Law Review,* Vol 12, N 2/3, pp1-12.

4. Preamble of Lei No 5/2007 de prevençao, tratamento e controle do VIH/SIDA of Guinea Bissau [translation of the author]. Similar proclamations can be found, among others, under article 3 of the HIV Prevention and Control Act of Kenya, article 1 of Loi No 2005-040 du 20 Février 2006 sur la lutte contre le VIH/SIDA et la protection des droits des personnes vivant avec le VIH/SIDA of Madagascar and article 2 of Loi No 2005-012 portant protection des personnes en matière du VIH/SIDA of Togo.

5. Article 2 of Loi No 25/2005 relative à la prevention, à la prise en charge et le contrôle du VIH/SIDA of Guinea provides that: '*It is strictly forbidden to provide* [HIV related education] *to minors below the age of 13*' [translation of the author]. Similar restrictive provisions can also be found under Article 2 of Loi No 6-028 du 29 Juin 2006 fixant les règles relatives à la prevention, à la prise en charge et au contrôle du VIH/SIDA of Mali.

6. Article 50 of Loi No 2005-012 portant protection des personnes en matière du VIH/SIDA of Togo provides for regular compulsory testing for commercial sex workers, and Article 28 of Loi No 25/2005 relative à la prevention, à la prise en charge et le contrôle du VIH/SIDA of Guinea provides for compulsory pre-marital HIV testing.

7. For instance, the HIV laws of Cape Verde (Article 22), Mali (Article 27) and Niger (Article 15) provide that people living with HIV who know their status must inform their partner(s) or spouse within six weeks from the day they become aware of that HIV status.

8. Mauritius is the only sub-Saharan African country with an HIV-specific law that does not provide for the criminalisation of HIV transmission or exposure.

9. For a general analysis of several of these HIV-specific laws, see Canadian HIV/AIDS Legal Network. 2007. *A human rights analysis of the N'Djamena model legislation on AIDS and HIV-specific legislation in Benin, Guinea, Guinea-Bissau, Mali, Niger, Sierra Leone and Togo*.

10. While this approach is strategically useful to bring attention onto these coercive HIV laws, the criminalisation of HIV transmission or exposure should not overshadow the major concerns related to the other coercive provisions that are found in these laws.

11. For examples of recent publications and initiatives against the criminalisation of HIV transmission, see Burris, S. & Cameron, E. 2008. 'The case against the criminalisation of HIV transmission'. In: *Journal*

of the American Medical Association, Vol 300 No 5, pp578-581; Open Society Initiative, UNDP & ARASA. 2008. *Ten Reasons to oppose the criminalisation of HIV exposure of transmission;* and Stackpool-Moore, L. 2008. *Verdict on a virus: Public health, human rights and criminal law.* A further illustration of the increasing campaigns against the criminalisation of HIV transmission was to be found in the important number of sessions, presentations and satellite events dedicated to the issue at the XVth International Conference on AIDS and STI in Africa organised in Dakar (Senegal) on 3-7 December 2008. See XVth International Conference on AIDS and STI in Africa, 2008, *Programme Book*.

12. While focusing, for the purpose of this article, on HIV-specific laws, this author stresses that in many sub-Saharan African countries, provisions that specifically criminalise HIV transmission or exposure can be found in a variety of documents. In Lesotho, HIV exposure is criminalised as an unlawful sexual act under the Sexual Offences Act No 29 of 2003, and may be punishable by death. In Zimbabwe, the criminalisation of HIV transmission or exposure is provided under Article 79 of the Criminal Law (Codification and Reform) Act No 23 of 2004 http://www.chr.up.ac.za/undp/domestic/docs/legislation_20.pdf http://www.chr.up.ac.za/undp/domestic/docs/Zimbabwe_07.pdf. In countries, such as Mali (Article 15 of Loi n 02-044 du 22 Juin 2002 relative à la santé de la reproduction), Benin (Article 19 of Loi No 2003-04 relative à la santé sexuelle et de la reproduction), and Burkina Faso (Article 18 of Loi 49-2005 portant santé de la reproduction), the laws on reproductive health also provide for the criminalisation of HIV transmission or exposure.

13. Markus, M. 1998-1999. 'A treatment for the disease: Criminal HIV transmission/exposure laws'. In: *Nova Law Review,* 23, p867, and also Tierney, TW. 1992. 'Criminalizing the sexual transmission of HIV: An international Analysis'. In: *Hastings International & Comparative Law Review*, 15, pp511-512.

14. In the United States of America, constitutional challenges have been laid against HIV-specific statutes on the ground that they are vague and overbroad. See, for instance, *State v. Mahan,* 1998 WL 312752 (Mo. June 16, 1998), and *State v. Stark,* 832 P.2d 109 (Wash. Ct. App. 1992). Although in all these cases the challenges were rejected, they highlight the human rights concerns posed by the vague and overly broad provisions of HIV-specific laws. For a discussion on the issue, see Lisko, EA. 'Constitutional challenges brought against State statutes that criminalise HIV transmission' Available at: [http://www.law.uh.edu/healthlaw/perspectives/HIVAIDS/980717 Criminalization.html].

15. Article 1 of Loi No 2007-042 relative à la prevention la prise en charge et le contrôle du VIH/SIDA of Mauritania [translation of the author]. Identical provisions can be found, among others, in the HIV laws of Mali (Article 1), Guinea Bissau (Conceitos Básicos), and Guinée (Article 1). These provisions are directly copied from articles 1 and 36 of the N'Djamena Model Law.

16. Brett-Smith, H. & Friedland, G.H. 'Transmission and treatment'. In Burris, S. et al (ed). 1993. *AIDS law today: A new guide for the public,* pp17-18; and also Howe, J.M. & Jensen, P.C. 'An introduction to the medical aspects of HIV disease'. In Webber, D.W. (ed). 1997. *AIDS and the law* 3rd Edition, p25.

17. See Article 47 of the HIV and AIDS (Prevention and Control) Act of Tanzania, Article 42 of Loi No 1/018 du 12 Mai 2005 portant protection juridique des personnes infectées par le Virus de l'Immunodéficience Humaine et des personnes atteintes du Syndrome Immunodéficience Acquise of Burundi, and Article 24(2) of the of the HIV Prevention and Control Act of Kenya.

18. Article 21(2) of the Prevention and Control of HIV and AIDS Act of Sierra Leone provides that '*any person who is and is aware of being infected with HIV or is carrying and is aware of carrying HIV antibodies shall not knowingly or recklessly place another person, and in the case of a pregnant woman, the foetus, at risk of becoming infected with HIV, unless that other person knew that fact and voluntarily accepted the risk of being infected with HIV.*'

19. Increasing infringements to the sexual and reproductive health rights of women living with HIV have been recorded in sub-Saharan Africa over the past few years in the form of coercive laws and practices, such as the criminalisation of mother-to-child transmission, forced sterilisation and enforced abortion. See, for instance, Tjaronda, W. 2008. 'Namibia: women robbed of motherhood'. Available at [http://allafrica.com/stories/200802120307.html].

20. See respectively Article 23 of Loi No 2007-042 relative à la prevention la prise en charge et le contrôle du VIH/SIDA of Mauritania, Article 37 of Loi No 6-028 du 29 Juin 2006 fixant les règles relatives à la prevention, à la prise en charge et au contrôle du VIH/SIDA of Mali, and Article 37(1)(e) of Lei No 5/2007 de prevençao, tratamento e controle do VIH/SIDA of Guinea Bissau.

21. Article 67 of Loi No 2005-040 du 20 Février 2006 sur la lutte contre le VIH/SIDA et la protection des droits des personnes vivant avec le VIH/SIDA of Madagascar.

22. See Tsankov, N. & Kehayov, A. 2005. 'Crisis in Libya: Doctor and nurses under death sentence'. In: *Clinics in Dermatology*, Vol 23, Iss 5, pp527–527.

23. See Rosenthal, E. 2006. 'HIV injustice in Lybia – Scapegoating foreign medical professionals'. In: *The New England Medical Journal*, Vol 355, No 24, pp2505-2508; Tsankov, N. 2007. 'The Libyan AIDS crisis and a miscarriage of justice'. In: *Clinics in Dermatology*, Vol 25, Iss 1, pp146-146; and also Smith, A.D. 'Medics face death while Libya uses HIV children as diplomatic pawns', *The Observer*, Sunday 17 December 2006. Available at: [http://www.guardian.co.uk/world/2006/dec /17/libya.aids].

24. See Viljoen, F & Eba, P. 2008. 'A human rights assessment of the Draft Bill on Defending Human Rights and the Fight Against the Stigmatisation and Discrimination of People Living with HIV of Mozambique'. Available at: [http://www.chr.up.ac.za/centre_projects/ahrru/docs/Comments%20 Mozambique%20Draft%20HIV%20Bill.pdf]

25. See Article 20, 22 and 26 of Loi No 030-2008 du 26 Juin 2008 portant lutte contre le VIH/SIDA et protection des droits des personnes vivant avec le VIH/SIDA of Burkina Faso.

26. UNAIDS emphasises the importance of HIV testing as a gateway to a wide range of HIV-related services. See UNAIDS, *Report of the Consultative meeting on HIV testing and counselling in the Africa region*, Johannesburg South Africa, 15- 17 November 2004, p15.

27. The notion of '*constructive knowledge*' is based on the idea that the exercise of reasonable care would have revealed the HIV infection to a person living with HIV. Such an ambiguous concept is ill suited for HIV transmission or exposure statutes, due to its potential to lead to unfair judgements based on prejudice and public sentiments. See Eba, P.M. 2007. 'Pandora's box: The criminalisation of HIV transmission or exposure in SADC countries'. In Viljoen, F. & Precious, S. *Human rights under threat: Four perspectives on HIV, AIDS and the law in Southern Africa*, pp30-31.

28. UNAIDS, WHO & UNFPA. 'Position statement on condoms and HIV prevention'. July 2004, p1. Available at: [http://www.unfpa.org/upload/lib_pub_file/343_filename_Condom_statement.pdf].

29. When used consistently and correctly, latex condoms are considered to reduce significantly the risk of HIV transmission. See Howe, J.M. & Jensen, P.C. 'An introduction to the medical aspects of HIV disease'. In Webber, D.W. (ed). 1997. *AIDS and the law*. 3rd Edition, p18.

30. The failure to promote condom use is also identified as a major flaw in HIV-specific criminal laws adopted in the United States. See Galletly, C.L. & Pinkerton, S.D. 2006. 'Conflicting messages: How criminal HIV disclosure laws undermine public health efforts to control the spread of HIV'. In: *AIDS Behaviour*, 10, pp453-456.

31. See Article 24(2) of the HIV Prevention and Control Act of Kenya, and Article 21(2) of the Prevention and Control of HIV and AIDS Act of Sierra Leone.

32. Article 27 of Loi No 2005-31 du 10 Avril 2006 portant prévention, prise en charge et contrôle du VIH/SIDA of Benin.

33. See note 7 above.

34. There are several challenges associated with the promotion of disclosure, especially for women who have been reported to face negative reactions ranging from abandonment to violence. See A Medley, A. et al. 2004. 'Rates, barriers and outcomes of HIV status disclosure among women in developing countries: Implications for prevention of mother-to-child transmission programmes'. In: *Bulletin of the World Health Organisation.* Vol 82, No 4.

35. See, for instance, Chesney, M.A. & Smith, A.W. 1999. 'Critical delays in HIV testing and care: The potential role of stigma'. In: *The American Behavioural Scientist,* 42/7, pp1162-1174, and also Waddell, E.N. & Messeri, P.A. 2006. 'Social support, disclosure, and use of antiretroviral therapy'. In: *AIDS and Behaviour*, 10/3, pp263-272.

36. See Auerbach, J.D. & Coates, T.J. 2000. 'HIV prevention research: Accomplishments and challenges for the third decade of AIDS'. In: *American Journal of Public Health,* 90, p1029, and also UNAIDS. 2008. 'Policy brief on the criminalisation of HIV transmission'. p2.

37. This assessment includes all the countries in sub-Saharan Africa with HIV-specific laws that criminalise HIV transmission or exposure, except Equatorial Guinea. Although, this author was able to confirm that Equatorial Guinea has an HIV-specific law criminalising HIV transmission, all his effort to secure a copy of that law were unsuccessful.

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Michaela Clayton, Edwin Cameron, Scott Burris[1]

A tragedy, not a crime...

At the beginning of 2008, in Dallas, Texas, Willie Campbell was convicted of assault with a '***deadly weapon***' against police officers who were arresting him for being drunk and disorderly. He was sentenced to 35 years in prison. Too bad, you may say, but so what? Well, Campbell has HIV, and the '***deadly weapon***' was saliva, which he spat into the officers' faces. But saliva has never been shown to transmit HIV, so the '***deadly weapon***' Campbell wielded was no more lethal than a toy pistol – and it was not even loaded.

His sentence also reflected his criminal record, but there is no denying that Willie Campbell was punished not just for what he did, but for the virus he carried. He is not alone. Across the world, people with HIV are going to prison, even when they have not transmitted the virus, and never intended to.

Bermuda recently jailed a man with HIV for 10 years for engaging in unprotected sex with his girlfriend, even though she has tested negative. A Swiss man was sent to jail this year for infecting his girlfriend, even though he thought he was HIV-negative.

In Africa – which has about two-thirds of the world's HIV cases – a U.S.-financed '*model*' statute, that broadly criminalises HIV transmission and exposure, has been adopted by 15 countries, and others may do the same. The law requires people who know they have HIV to inform '*any sexual contact*' in advance – without defining '*sexual contact*'. (Does the definition, for example, include kissing?) Sierra Leone's version of the law expressly brings a pregnant mother within its terms. She can be jailed if she does not '*take all reasonable measures and precautions to prevent the transmission of HIV*' to her unborn baby. In Southern Africa similar laws have been adopted in Tanzania, Madagascar and the Democratic Republic of Congo and are being considered in Mozambique and Malawi.

IN SOUTHERN AFRICA:

Democratic Republic of Congo: Disclosure = immediate notification of spouse and sexual partners. **Transmission** = 10 yrs imprisonment and fine of 200 000 FC

United Republic of Tanzania: Immediate disclosure to spouse or sexual partner required. 'Wilful transmission' = the transmission of HIV from an infected to an uninfected person, most commonly through sexual intercourse, blood transfusion, sharing of intravenous needles, during pregnancy or breastfeeding 'Wilful transmission' = **Life imprisonment**

Mozambique: Bill currently before Parliament provides for: **Mandatory testing**: pregnant women, sex workers, persons charged with sexual offences **Transmission:** 'Any person who deliberately, recklessly or negligently does an act or omission that he knows or has reason to believe to be likely to infect another person with HIV commits an offence and shall be liable to imprisonment of 14 years'

Madagasscar: Transmission by recklessness, carelessness, inattentiveness, negligence = 6 months to 2 years and a fine of 100 000 to 400 000 ariary

So what is behind the drive to deal with HIV through criminal laws? It aims to stem the rising tide of HIV infections, to protect those vulnerable to becoming infected – especially women, who often fall prey to careless or unscrupulous men - and to encourage disclosure by people who know they have the virus.

…most of those who will be prosecuted… will be women…

Good intentions, but bad policy. Studies, and more than two decades of experience, show that making exposure to, and accidental transmission of, HIV into crimes does not change sexual behaviour or stem the spread of HIV. Criminalisation is a misguided substitute for measures that really protect those at risk of contracting HIV: effective prevention, protection against discrimination, efforts to reduce the stigma associated with AIDS, greater access to testing and, most importantly, treatment for people who are dying of the disease.

Far from protecting women, criminalisation endangers them. In Africa, most people who know their HIV status are female, because most HIV testing occurs at natal healthcare sites. The result is that most of those who will be prosecuted because they know – or ought to know – their HIV status, will be women. The material circumstances in which many women find themselves – especially in Africa – make it difficult for them to negotiate safer sex, or to discuss HIV at all. These circumstances include social subordination, economic dependence and traditional systems of property and inheritance that make women dependent on men. Criminalisation will make women more vulnerable to HIV, not less.

…criminalisation will make women more vulnerable to HIV, not less…

Moreover, criminalisation is often unfairly and selectively enforced. Prosecutions and laws single out already vulnerable groups – like sex workers, men who have sex with men and, in European countries, black males. Criminalisation also places blame on one person, instead of putting responsibility on two. Realistically, the risk of getting HIV (or any sexually transmitted infection) must now be seen as an inescapable facet of engaging in sex. We cannot pretend that the risk is introduced into an otherwise safe encounter by the person who knows, or should know, he or she has HIV. The practical responsibility for safer sex practices rests on everyone. These laws are difficult and degrading to apply. Where sex is between two consenting adults, the apparatus of proof and the necessary methodology of prosecution, degrade the parties and debase the law.

What is more, the legal concepts of negligence and even recklessness are incoherent in the realm of sexual behaviour. We know that the '*reasonable person*' often has unprotected sex with partners of unknown sexual history, in spite of the known risks – that is why we have an HIV epidemic, and that is why interventions to reduce unsafe sex are so important.

…the practical responsibility for safer sex practices rests on everyone…

Criminalisation increases stigma and may well deter HIV testing. Why would a woman in Sierra Leone or Malawi or Tanzania want to have an HIV test that will, if positive, put her at risk of a jail sentence, if she becomes pregnant, or the next time she has sex? The laws put diagnosis, treatment, help and support further out of her reach.

The prevention of HIV is not just a technical challenge for public health. It is a challenge to all humanity to create a world in which behaving safely is feasible for both sexual partners.

Criminalisation does the opposite. It is a harsh, punitive and unproven policy toward an epidemic that has consistently responded best to interventions that care for and support people doing their best to be healthy.

In an attempt to stem the tide of criminalisation of HIV transmission in the SADC region, the SADC Parliamentary Forum has developed a Draft Model Law on HIV in Southern Africa to provide a legal framework for the review and reform of national legislation related to HIV in conformity with international human rights law standards.[2]

Rather than criminalising HIV transmission, the Model Law seeks to address the root causes that drive the demand for criminalisation of HIV transmission in the first place. It places an emphasis on removing barriers to accessing prevention, treatment and care services, and specifically addresses the particular vulnerability of women to HIV in Southern Africa as a result of gender inequality and gender-based violence[3].

…to create a world in which behaving safely is feasible for both sexual partners…

The Model Law provides Members of Parliament, sitting to review laws, with a framework for placing their focus where it should be: on removing legal barriers to HIV prevention, treatment and care, and on effectively addressing the very factors that make women and other vulnerable groups, such as injecting drug users, men who have sex with men, and sex workers more vulnerable to HIV.

Criminalising HIV transmission does not stop new HIV infections. If we seek to use the law to address HIV transmission, then let us do so wisely. Let us focus on revising our laws to remove legal barriers to HIV prevention, treatment and care services and on using the law to fight discrimination and stigma, and to protect women and other vulnerable groups from HIV infection.

FOOTNOTES:

1. This article is based on an op-ed written by the same authors and published initially in the International Herald Tribune on 7 August 2008.
2. Article 1, Draft Model Law on HIV in Southern Africa. The Model Law has been passed at the end of 2008.
3. Article 27.

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ALQ | September/November 2008

Alice Welbourn

Into the firing line...

Placing young women and girls at greater risk[1]

Responding to legislative trends towards criminalisation of HIV transmission, this contribution is to highlight some of the aspects of criminalising HIV transmission, and to discuss especially the extent to which these trends are affecting – and will continue to affect – women and girls.

It has been almost 20 years since the Australian High Court Judge, Michael Kirby, warned of the spread of a dangerous kind of a virus, '*highly inefficient laws*'. Even then, Kirby identified '*variant strains*' of highly inefficient laws, such as laws providing for mandatory HIV testing of vulnerable groups, or restrictions on the freedom of movement of people living with HIV. He noted that

> *…the virus of which I speak is not detectable under the microscope. It is nonetheless a tangible development, which may be detected in a growing number of societies. In some ways, it is as frightening and dangerous as the AIDS virus itself. It attacks not the body of an individual, but the body politic.*[2]

Recognising both the contentious nature of responses to the debates as to whether or not to criminalise HIV transmission and the societal context in which HIV transmission occurs and potential prosecution will take place, it seems essential to analyse some of the realities intrinsically linked to these debates, including existing laws already available to prosecute such '*offences*'; lessons to be learned from history; and the fact that laws – whether or not existing or proposed – are not gender specific.

Wilful transmission of HIV

In the context of these debates about the criminalisation of HIV transmission, many people have highlighted the challenges and potential human rights abuses related to criminalising HIV transmission. As many have emphasised before, I have met many people, like myself, around the world who are living with HIV, and all report, as I do, that there are extremely few people who wilfully intend to transmit HIV to others around them. I certainly have not met one yet.

In most countries, there is already an existing law which covers '*wilful*' HIV transmission – in the UK we call it '*grievous bodily harm*'. Thus, there is no actual need to introduce a new, HIV-specific law to address such rare events.

Historical perspective

In relation to historical perspectives, it is not clear to me that any public health issue has ever been effectively addressed through punitive legislature. Look for instance at the time of '*prohibition*' in the US[3], which failed to stop the use of alcohol. Similarly, look at the way in which Typhoid Mary[4] was treated – interestingly, a woman, an immigrant, on low wages as a domestic employee. The arms of public health policy, the law and the media, combined effectively, meant that she felt ostracised and alienated by society. Many others actually transmitted typhoid to more people than she did, but she was the one who was hounded – and the treatment she received probably exacerbated the situation. When will we start to learn from history[5]?

Lack of gender-specific laws

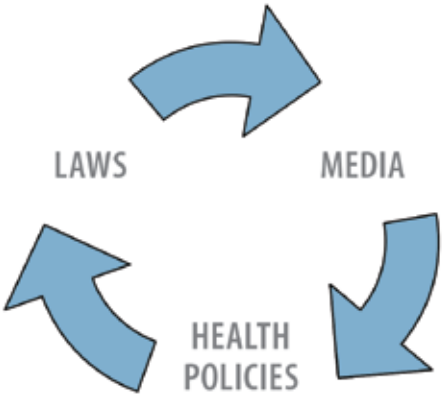
One point that has emerged very quickly in this debate is the fact that laws are not gender-specific. Indeed, I was talking to an ICW member who told me that:

> *…I didn't realise the implications of my recommendations until recently, when I talked to ICW.*

At the time of supporting criminalisation of HIV transmission, she had been sitting on a review panel, which was advising on the implementation of new HIV-specific punitive laws in her country. She was calling for maximum penalties, thinking that this would be a way of stopping men from transmitting HIV to their wives. She tells me that only when she made contact with ICW members from other countries did she realise that not only are these laws dangerous for women, but also that they are not the right way to go for *any*body. HIV-specific punitive laws will just not stop HIV.

Health policies, laws and media

The intrinsic links between health policies, laws and media coverage are a crucial element in the debate as to whether or not to criminalise '*wilful*' transmission of HIV.



We are addressing here a crisis on three fronts – health policies, the media and punitive HIV-specific laws. One feeds off the other two in an interactive process. Take for instance health policies. A recent study in Nigeria by Journalists Against AIDS[6] found that 70% of healthcare providers reported that their attitudes towards HIV, and people with HIV, were shaped by the media. Meanwhile, health policies and practices around the world increasingly focus on antenatal HIV testing. There are an increasing number of reports, including from ICW[7], from Amnesty International, from Physicians for Human Rights, and from Human Rights Watch, which consistently show that if women are not prepared to be tested for HIV when pregnant, or test positive for HIV, women are denied antenatal services, are treated judgmentally by health staff, and can experience violence and ostracism from partners and other community members.

…the more we can all do

to resist these laws, the better…

With only few exceptions, health workers in any community of the world are influential members of their societies. Their views count in their communities and in wider society. It is all too easy to see how policies, no matter how much they initially might have been intended to be of public health good, have quickly slipped into practices, which judge, penalise and ostracise HIV positive women. It is easy then for society to take this one step further and turn HIV transmission from women to their partners, or to their children, into a crime. So, in Sierra Leone, for instance, a woman who transmits HIV to her child can be fined or jailed up to seven years – or both[8]. Such legal judgments, as Reynolds[9] has clearly explained, fuel hysterical and discriminatory headlines in the media – continuing the vicious circle.

Vertical transmission of HIV

Therefore, looking more closely at what women are up against, we can understand more clearly why many women may indeed fear going anywhere near health services, especially if women believe that they may be HIV-positive. First there are the negative reactions of the ill-trained health staff to contend with[10]; the lack of assured confidentiality; and the resultant fear of violence from family and community members. This year, we have heard of three women in Uganda being killed by their husbands, allegedly because the men believed that the women had transmitted HIV to them.

Secondly, many women with HIV live either in resource-poor settings in high-prevalence countries, or in resource-poor settings in rich countries. They do not

have recourse to the defence of the law, which is expensive. Many women also are faced with situations where, even if they manage not to transmit HIV to their baby during the birth, have no social or practical option other than to breastfeed their baby. Lack of clean, safe drinking water; lack of access to formula feed; and lack of access to fuel to sterilise bottles, or other vessels, are still huge issues for millions of women around the world. Moreover, if a woman is seen not to breastfeed, by people around her in a community, where breastfeeding is still the norm, she is in immediate danger of ostracism on suspicion that she must be HIV positive. So what options does this leave a woman?

Thirdly, although ARVs are increasingly being rolled-out in resource-poor settings, there are still only a mere three million, out of the ten million people living with HIV who need ARVs *now*, who are in the position to access them. What does this mean for the seven million people, who cannot yet access ARVs? Without access to ARVs, the chances of transmitting HIV to a baby are far greater, than they are *with* ARVs. Questions need to be raised as to whether or not the laws allow for this reality; and where does states' commitment to *Universal Access* to treatment stand in relation to all of this?

One of ICW's members in Uganda shared experiences she faces in going to a clinic to access treatment:

> *…when he learnt that I went to the health centre for medication, he beats me saying that I am embarrassing him, that I am showing everybody that we are sick. Now I fear going for services*. [ICW Member, Uganda]

This is but one of the many challenges, which women living with HIV in particular are faced with on a daily basis. This arguably highlights one of the areas in which women are already '*criminalised*' and '*prosecuted*' – without a legislative framework. Criminalising HIV transmission is leading to, among other things, limited access to healthcare services.

Especially in the context of accessing PMTCT services, the question arises of what women are supposed to do. If a woman is following her partner's wishes and does not access treatment, it is more than likely that she will either be accused by her partner of passing HIV to him, or be accused by health workers of passing HIV to her baby.

Men's words against women's…

This moves us to the question of blame. It has been frequently proven by scientific evidence that it is extremely difficult to identify who has passed HIV to whom. However, popular views, the media, and the law are often less impartial.

…women to be found guilty of 'wilful HIV transmission' by a court of law, irrespective how difficult condom negotiation actually is…

Since the realisation that HIV exists in a family is often heralded by a positive HIV test result for a pregnant woman at antenatal clinic, the assumption is often made that the woman must have introduced HIV into the relationship. Irrespective of whether or not this assumption is accurate, a woman is often at the most vulnerable stage of her life, when she is pregnant. To have the often joyful news of pregnancy followed swiftly by the shocking news of an HIV diagnosis is not a pleasant experience – and I speak here from personal experience. Even if a woman is disappointed to learn of her pregnancy, why then should this be exacerbated by yet more bad news of a positive HIV diagnosis, especially when this latter news is likely to result in anger, violence and ostracism? Take-up of antenatal services around the world is already poor enough. Why diminish this further with the threat of violence[11] and a criminal prosecution?

As one of the poster abstracts, presented at the 2008 AIDS Conference illustrated, based on research conducted in South Africa by the Human Sciences Research Council and Oxford University, there are immense psychological issues experienced by women being tested for HIV during pregnancy[12]. The policy of '*routinely*' testing pregnant women for HIV really needs revising, until all pregnant

women, when testing positive, can be guaranteed all the love, care, respect, support and treatment, for themselves and their children, that is needed for their own safety and those of their children. In addition to the very real and valid fear of violence by women testing positive for HIV during pregnancy, a woman also may decide not to disclose her HIV positive status to her partner, for fear of this violence. What if he wishes to continue engaging in sex with her during the pregnancy – which is likely to be without any form of contraception, because she is already pregnant? Will this be tantamount to a criminal offence, once she has learnt of her positive HIV status, even though she may suspect that she has acquired the HIV from her partner in the first place and that he, therefore is also HIV positive?

…policies, no matter how much they initially might have been intended to be of public health good, have quickly slipped into practices, which judge, penalise and ostracise HIV positive women…

Lack of education and lack of income both make women, in general, less likely to be in the position to access legal defence mechanisms, than men around the world. So if a woman is accused by her partner, or others, of HIV transmission, there is an uneven playing field in terms of recourse to legal defence. And finally, the Model AIDS Law, which is being rolled-out through programmes in West Africa, proposes that health workers themselves should turn into police – in that six weeks after diagnosis, if someone with HIV has not yet disclosed to their partner, the health worker should make this disclosure instead. Is this what health workers are really there to do?

Challenges faced by health workers in Kenya clearly indicate that this new responsibility is clearly not what health workers envisaged as their role in relation to people in their care.

> *…last month one pregnant woman tested HIV positive in this antenatal clinic. This week she came back and told us that she has been thrown out of her husband's house, divorced, desperate and alone with no relative to turn to or any support for herself or her unborn child. We haven't been prepared or trained to deal with this…* [Healthcare nurse, Kenya][13]

Lack of access to condoms

Looking at condom access, it is necessary to acknowledge that we have condoms, that is still the one most likely, consistent and effective barrier method to prevent HIV transmission. Yet, when looking closer at condom access in relation to women, it becomes clear that women face numerous challenges. We know that most women, even if they would like to use condoms, face the realities of lack of access to money to buy condoms, and lack of negotiation skills with partners to use them.

If anyone would want to doubt that, let's ask ourselves how many of us last negotiated the use of a condom with a regular sexual partner. We often like to think that others '*should*' behave in certain ways, without connecting these issues to our own lives. But, if a woman cannot argue that she took '*reasonable precautions*' against passing HIV to her partner, such as using a condom after learning of her positive HIV status, then it is all too easy for women to be found guilty of '*wilful HIV transmission*' by a court of law, irrespective of how difficult condom negotiation actually is.

Family break-up

So, in the context of family life, what are the consequences for women of criminalisation of HIV transmission, to partners or to children? They are several. First of all, if a woman is fined or sent to jail, there will be immense physical, psychological and material effects on her children also, since mothers around the world are their children's primary carers.[14] There are vast amounts of documented information

testifying to the fact that if a woman is sick or absent, her children are deeply affected. More than this, we need to remember that children of a woman, who has somehow been shamed by society, are '*worse than orphans*'. Just as in the past, when children of sexual liaisons outside marriage were branded as '*bastards*', children of women penalised by society, will also bear the brunt of society's judgments on their mothers. Thirdly, the physical break-up of her family is an emotional disaster for any woman, especially for women in societies where a woman's role as wife and mother is all she has in terms of her social standing.

…HIV-specific punitive laws will just not stop HIV…

And fourthly, it seems hard to reconcile legal punitive measures regarding HIV transmission with the promotion of an '*AIDS-free generation*' through public health measures, especially when we learn from the UNAIDS[15] 2008 Global Report that food shortages particularly exacerbate women's and girls' vulnerabilities in relation to HIV. If a woman has to leave her household for jail, how and where will she find the means to feed her children, to continue to weed or harvest her crops, buy food, collect water or firewood, or cook for them? If a woman is fined, she often also has to take on more work to pay the fine, or repay the debt incurred to pay that fine – adding precious unaffordable hours to her existing workload. Neither option is a useful addition to a woman's basic practical child care roles.

Stigma will continue into the future

Indeed, on most occasions when women are legally penalised, whether financially or through incarceration, the likely result will be permanent break-up of the family unit. The stigma, which a woman faces through either of these options, will not only affect her children, as well as herself, but are also likely to affect her, and their, options for many years to come. A woman who has been fined or jailed for HIV transmission will carry this albatross around her neck, both physically and emotionally for the rest of her life. The chances of her being able to form a new relationship with someone in the community are remote.

Making bad situations worse

So far we have been talking about women who have otherwise been so-called '*ordinary*' members of society. We have not begun to think of how such punitive laws might additionally affect women who, in some way or another, have already experienced the brunt of societies' punitive attitudes.

People who have been marginalised by society in most countries are often also legally ostracised, such as people in the sex trade or people who use drugs. They already face huge problems with lack of access to health, social or legal services, and the introduction of punitive legal measures will make their situations even worse. Moreover, with the new UN-led drive to '*know your epidemic*', there will be increasing pressure of expectation on people already at the margins of society to '*know your status*'. This is because there is *still* a widely-held – but often erroneous – assumption that women with HIV must be sex workers, drug users, or other women who somehow or other are already ostracised by society. So if a woman who is HIV-positive falls into one of these ostracised categories, she will then especially be at risk of having been expected to '*reasonably*' know her HIV status, despite all the odds against her reasonably daring to doing so.

Girls

It has already been widely recognised in Mother and Child Health (MCH) circles, well before HIV came along, that girls are less well cared for when their mothers are sick or absent or have less education; and that girls are taken out of school first to replace their mothers when the latter are sick or absent. We also see now that girls are especially ostracised if they are HIV-positive since birth, when practically *all* education for young people assumes that young people are HIV-negative; and that this is because

girls around the world have a heavy mantle cast around their shoulders as the guardians of their society's morality.

...laws to protect the rights of everyone *with HIV are good; laws designed and introduced specifically to criminalise transmission of HIV are fundamentally a bad idea...*

Lessons Learnt…

In England, this is reflected in the two words: '*stags' and 'slags*'. If a boy has multiple female sexual partners, he is known as a bit of a '*stag*' – a proud adult male deer. If a girl has multiple male sexual partners, she is known as a '*slag*':

'…***slag***[3] **noun**, *derog. slang someone, especially a woman, who regularly has casual sex with many different people.*'

What is more…

What is more? There are many aspects of sexual and reproductive health and rights, as they relate to women and girls, which have either already attracted punitive legal measures, or which have not yet received the legal protection, which they deserve to receive. These include the fact that there are, in many countries, no adequate laws on domestic violence and/or sexual offences, such as rape; that there is a general lack of legislation protecting lesbian women, as well as sex workers, from violence and abuse; that there are property and inheritance laws, which are unfavourable and discriminatory towards women; that there are many countries upholding laws against access to emergency contraceptives and safe termination of pregnancy procedures; and that there continues to be a general lack of regulations – or, if regulations are in place, adequate and '*user-friendly*' regulations – pertaining to post-exposure prophylaxis, and emergency contraceptives, for survivors and victims of sexual assault and rape. In addition, laws prosecuting marital rape are especially non-existent, patchy or vague.

As for lessons learned, it seems fairly obvious, but there are two key points that we all need to take away from this: laws to **protect** the rights of ***everyone*** with HIV are good; laws designed and introduced specifically to criminalise transmission of HIV are fundamentally a bad idea.

We should all be aware of the pitfalls involved in the specific criminalisation of HIV transmission and the more we can all do to resist these new laws, the better. Once a new law is in place, it is extraordinarily difficult to repeal it and thus, we all need to do our utmost to avoid the introduction of these laws in the first place.

FOOTNOTES:

1. An earlier version of this article was presented at the 2008 International AIDS Conference in Mexico City, as part of the satellite session organised by IPPF on this subject. I would also like to acknowledge Aziza Ahmed of ICW and Maria de Bruyn of IPAS.
2. As quoted by Richards Pearshouse in 'Legislation contagion: The spread of problematic new HIV laws in Western Africa', *HIV/AIDS Policy and Law Review*, Canadian HIV/AIDS Legal Network, Vol. 12, No. 2/3 Dec 2007, p1.
3. See, for instance, [http://www.digitalhistory.uh.edu/database/article_display.cfm?HHID=441] for an interesting account of this.
4. See also [http://www.pbs.org/wgbh/nova/typhoid/mary.html].
5. See also [http://www.opendemocracy.net/blog/alice-welbourn/2008/11/30/a-message-for-world-aids-day-by-alice-welbourn].
6. Rolake Odetoyinbo, personal communication, 2008. See also [http://www.nigeria-aids.org/documents/EvaluationProject1.pdf].
7. See [http://www.icw.org/node/227, http://www.amnesty.org/en/library/info/AFR53/001/2008/en; http://physiciansforhumanrights.org/library/report-2007-05-25.html; http://www.hrw.org/reports/2003/uganda0803/5.htm].
8. See [www.icw.org/node/227; http://www.ippf.org/en/Resources/Guides-toolkits/Verdict+on+a+virus.htm].
9. 'Race and Immigration: Determinants of a sound policy'. IAS Mexico, IPPF Satellite session: [http://www.aids2008.org/Pag/PSession.aspx?s=475].
10. Listen, for instance, to [http://www.stratshope.org/d-audio-maura.htm].
11. Anecdotal evidence suggests that some women in South Africa begin to avoid local antenatal care at all for fear of the consequences of a positive HIV test. Johanna Kehler, ALN, personal communication, November 2008.
12. Rochat, T.J., Stein, A. & Richter, L. 2008. 'Women's feelings, attitudes, and experiences on learning their HIV status during pregnancy in rural South Africa.', Poster exhibit, THPE0923, IAS Mexico, 2008.
13. Heard in NE Kenya, May 2006.
14. In addition, sending a child's mother to jail also contravenes the rights of the child according to Article 9 of the CRC.
15. See [http://viewer.zmags.com/showmag.php?mid=wwfwrp#/page0/].

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Marlise Richter

Criminalisation of sex work...

Sex work, HIV and AIDS and the socio-legal context in South Africa[1]

Background

Since the advent of the AIDS epidemic, sex workers, as a group, have been at high risk of contracting HIV and STIs.[2] Factors such as the criminalisation of sex work, concurrent sexual relations, the difficulties in obtaining and using HIV prevention technology, on-going exposure to high levels of violence (in particular gender-based violence), stigma and the barriers to accessing healthcare services, compound and interlock to render sex workers particularly vulnerable to HIV and AIDS.

Sex work in South Africa – what are the research gaps?

South Africa has one of the largest STI epidemics in the world[3] and is the country with the most people living with HIV and AIDS.[4] It is, therefore, not surprising that HIV prevalence amongst sex workers in Hillbrow was found to be 45% in 1998,[5] while in the same year sex workers at a mining project in Carltonville had an HIV prevalence of 69%.[6] In the latter study, sex workers had an HIV prevalence rate that was more than three times higher than the 20% prevalence rate of that segment of the general population.

Regrettably, these studies are more than a decade old and significant gaps exist in our knowledge on sex workers. We do not know how many women work as sex workers in South Africa; from where they originate; the HIV and STI prevalence rates in this population; whether or not they are able to access general healthcare services; whether or not HIV prevention and treatment services are reaching sex workers; and the extent to which criminal laws contribute to their vulnerability to HIV. Other gaps in our knowledge include how the number of sex workers is affected by increasing unemployment, as well as cross-border migration to South Africa, where their various places of work are, and who their clients are.[7]

Sex work and the law

Sex work is illegal in South Africa.[8] The South African Law Reform Commission (SALRC) has been tasked to provide solutions to the legal problems attached to sex work. The SALRC released an Issue Paper in July 2002 and listed three options in relation to sex work and the law:

- Criminalise all aspects of adult prostitution as criminal offences;
- Legalise adult prostitution within certain narrowly circumscribed conditions;
- Decriminalise adult prostitution, which will involve the removal of laws that criminalise prostitution.

Ongoing criminalisation of sex work in South Africa would maintain the status quo, while decriminalisation of sex work would see all laws that criminalise sex work removed. Sex work would, thus, be like any other profession and would enjoy the protection of labour and occupational health laws. Legalisation would entail the decriminalisation of sex work within certain areas only (i.e., zoning of sex work), and sex workers would, for instance, have to register with authorities and submit themselves to mandatory health checks.

The SALRC is mandated to release a Discussion Paper after the Issue Paper, which will contain proposed legislation. The Discussion Paper will be open to public comment, after which the SALRC will submit a final report with recommendations to the Minister of Justice and Constitutional Development. Although, more than five years have passed since the publication of the Issue Paper, the SALRC has yet to publish its much-anticipated Discussion

Paper. Current predictions are that the Discussion Paper will be released in late January 2009.[9]

...significant gaps exist in our knowledge on sex workers...

Why is the decriminalisation of sex work necessary to mitigate HIV?

Sex workers' health is compromised by violence, stigma, the intrinsic nature and dangers of their work, economic hardship, and the lack of access to services and support. All of these factors are aggravated and entrenched by a legal system that criminalises the industry. The public health consequences of, and human rights abuses entailed by, criminalisation of sex work have been well documented in the literature. Arguments canvassed in a South African context highlight the following consequences of the on-going criminalisation of sex work:

- Increasing sex workers' vulnerability to violence from clients, partners and police;
- Creating and sustaining unsafe and oppressive working conditions;
- Increasing the stigmatisation of sex workers;
- Restricting access to health, social, police, legal and financial services;
- An adverse impact on safer sex practices; and
- Impacting on the ability to find other employment.[10]

All of these factors impact adversely on sex workers' ability to protect themselves from HIV, prevent HIV transmission to their sexual partners, and to access the necessary HIV-testing, treatment, support and care.

Sex work and the National Strategic Plan 2007-2011

South Africa's National Strategic Plan 2007-2011 (NSP) explicitly rejects discrimination against sex workers[11]; acknowledges the increased vulnerability of sex workers to HIV[12]; and recommends the rolling out of customised prevention packages for sex workers.[13] Significantly, the NSP recommends that sex work in South Africa is decriminalised.[14]

Yet, little progress has been made on any of these targets or recommendations.

Conclusion & Recommendations

A recent systematic review of the literature, on effective interventions to prevent HIV and other STIs amongst sex workers in resource-poor settings, found that combining sexual risk reduction, condom promotion, and improved access to STI treatment reduces the risk of HIV and STIs to sex workers involved in the intervention.[15] The importance of structural interventions, policy change, and the empowerment of sex workers in reducing HIV and STI prevalence was also emphasised. This research provides a strong rationale for the provision of sex worker-specific health and social services, dismantling the discriminatory legal environment, and safeguarding the human rights of sex workers – all elements that are contained in the NSP.

...sex workers' health is compromised...

The NSP provides a sound framework of principle, as well as a systematic plan of action in dealing with HIV and AIDS and sex workers, with the South African National AIDS Council (SANAC) as its custodian. SANAC has not yet prioritised sex workers as a vulnerable group within the South African AIDS epidemic, nor has it pushed for the decriminalisation of the industry in line with the NSP recommendations.

This can still be remedied and in light of this, the following recommendations are submitted:

Decriminalise sex work in South Africa

The Programme Implementation Committee (PIC) of

SANAC should focus its energies on the recommendations within the NSP to decriminalise sex work, and dismantle all forms of discrimination against sex workers. SANAC may legitimately seek ways of conveying, to the South African Law Reform Commission and the Minister of Justice and Constitutional Development responsible for it, the intense urgency surrounding the finalisation of the Discussion Paper. The build-up towards the FIFA World Cup, which has prompted calls to decriminalise the industry, provides a strategic opportunity for effecting changes to the legal framework on sex work.[16]

Upon the release of the Discussion Paper, the SALRC will request input and comments on the Paper. The PIC should put forward a submission, on behalf of SANAC, supporting the call for decriminalisation of sex work.

...aggravated and entrenched by a legal system that criminalises the industry...

Implement and fund sex work-specific programmes

The PIC should collaborate with government departments, civil society and service-based organisations to implement sex worker-specific social, health and economic programmes that target and strengthen the well-being and legal position of sex workers. These programmes should also include a focus on sex worker clients, and provide tailored education and health services to men. This is in line with the targets and recommendations of the NSP. It is vital that sex workers are consulted and are included in every phase of the planning and implementation of these programmes. The health model provided by the Reproductive Health & HIV Research Unit's Sex Worker Project should be replicated in other urban areas, and be adapted to rural and semi-urban areas.[17]

Strengthen research on sex workers

Research on sex work in South Africa and in the Southern African region should be expanded, and should include a focus on non-national migrant sex workers. Research is urgently needed on HIV prevalence rates amongst sex workers and their sex partners, the barriers that sex workers face in protecting themselves against exploitation, ill-health and HIV, as well as the difficulties they face in accessing HIV prevention, testing, treatment, support and care services. This research should inform appropriate, sensitive and context-specific interventions for sex workers.

FOOTNOTES:

1. This article is based on a Policy Brief, commissioned by the Reproductive Health & HIV Research Unity, University of Witswatersrand, 15 October 2008.
2. UNAIDS. 2002. Sex Work and HIV/AIDS. In UNAIDS (Ed.) *Technical Update.* Geneva; and Evans, C. 2005. Toolkit for targeted HIV/AIDS prevention and care in sex work settings. Geneva, WHO.
3. Johnson, L., Bradshaw, D. & Dorrington, R. 2007. 'The burden of disease attributable to sexually transmitted infections in South Africa in 2000'. In: *South African Medical Journal*; 97**,** pp658-62.
4. UNAIDS. 2008. Report on the global HIV/AIDS epidemic 2008.
5. Rees, H., Beksinska, M. E., Dickson-Tetteh, K., Ballard, R. C. & Htun, Y. E. 2000. 'Commercial sex workers in Johannesburg: risk behaviour and HIV status'. In: *South African Journal of Science*; 96**,** pp283-284.
6. Williams, B. G., Taljaard, D., Campbell, C. M., Gouws, E., Ndhlovu, L., van Dam, J., Carael, M. & Auvert, B. 2003. 'Changing patterns of knowledge, reported behaviour and sexually transmitted infections in a South African gold mining community'. [Miscellaneous]. In: *AIDS,* 17**,** pp2099-2107.
7. A recent study in Cape Town cast some light into sex work conditions in Cape Town, but did not focus on health and HIV. See: Gould, C. & Fick, N. 2008. *Selling sex in Cape Town: Sex work and human trafficking in a South African city.* Pretoria/Tshwane, Institute for Security Studies.
8. It is made a criminal offence under section 20(1A)(a) of the Sexual Offences Act, 23 of 1957.
9. Telephonic conversation with Cathi Albertyn (Commissioner: SALRC), 15 October 2008.
10. This is a summary of the arguments that were advanced in the Constitutional Court in Sex Worker Education & Advocacy Taskforce (SWEAT), the Centre for Applied Legal Studies (CALS) & the Reproductive Health & HIV Research Unit (RHRU) (2002) Amicus curiae submission in the case *Jordan v State*. Johannesburg.
11. Department of Health. 2007. HIV & AIDS Strategic Plan for South Africa 2007-2011 [National Strategic Plan]; pp60&96. [http://www.info.gov.za/otherdocs/2007/aidsplan2007/]
12. National Strategic Plan, pp32, 35-36.
13. National Strategic Plan, p86.
14. National Strategic Plan, p120.
15. Shahmanesh, M., Patel, V., Mabey, D. & Cowan, F. 2008. 'Effectiveness of interventions for the prevention of HIV and other sexually transmitted infections in female sex workers in resource poor setting: a systematic review'. In: *Tropical Medicine and International Health,* 13**,** pp659-79.
16. Germany legalised sex work in 2002 – four years before hosting the FIFA World Cup. See Groneberg, D. Molliné, M & Kusma, B. 2006. 'Sex work during the World Cup in Germany'. In: *The Lancet* , Volume 368 , Issue 9538 , pp840-841.
17. See, for example, Pleaner, M., Motloung, T. & Richter, M. 2008. 'Working with Sex Workers – A Resource Pack for Health Care Providers'. In: Reproductive Health & HIV Research Unit (Ed.) Johannesburg, Reproductive Health & HIV Research Unit.

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Raphaela Madlala

Perceived as potential criminals...

Thoughts on criminalisation of HIV transmission and its implications for women

The criminalisation of HIV transmission and its implications for women has been receiving a lot of attention – both from those who are infected and those who are affected – and numerous perspectives have emerged. Although consensus has been reached in both camps, the modus operandi, or rather terms and conditions, are quite contrary.

HIV is an illness – Facts and correlations

It is well documented that very few people can pinpoint for certain, and provide empirical proof, of by whom and when they were infected with HIV. It is also well recognised that the progression of the illness is influenced by numerous factors, including experiences of the self – in that every individual experiences the illness differently both physiologically and emotionally.

The risk of HIV infection is similarly linked to numerous factors – besides the biological make-up – and includes the occurrence of gender-based violence; the general lack of access to information; socio-economic factors and dependencies, impacting greatly on the risk of HIV transmission; cultural and religious beliefs, perpetuating especially women's risk to HIV; gender inequality, leading to women's lesser power to negotiate condom use; and high incidences of sexual abuse and rape. Moreover, HIV risks and vulnerabilities are maintained by HIV-related stigma and discrimination; by a general lack of political will to address the underlying factors of the pandemics; recurring misrepresentation of information about the risk of HIV transmission, leading to greater HIV risks for people with lesser power and resources to access information; and a general lack of access to preventative measures, especially women-initiated and controlled HIV prevention measures.

Implications of criminalisation

The criminalisation of HIV transmission is neither responding to, nor reducing, prevailing HIV risks and vulnerabilities. On the contrary, criminalising HIV transmission will reinforce existing risks of HIV transmission, and lead to the further criminalisation of people living with HIV.

Criminalisation will turn HIV into a '*weapon*', insinuating that all people infected with HIV have the desire, potential, and intent to use this '*weapon*' to harm others. Criminalisation will further endorse the oppression of women – as women are '*first to know*' and thus, women will be easy '*targets*' for prosecution. Criminalisation will also give momentum to the patriarchal system – as existing gendered power relations will be strengthened, instead of addressed. And finally, criminalisation will impact on the overall well-being of women infected with HIV – as women will have to endure the whole process of the '*law*', with little or no access to resources and redress.

The fear of being criminalised, and potentially prosecuted for transmitting HIV, is likely to lead to a reduction in HIV testing, as not knowing one's HIV status seems to be the '*safer*' option. Criminalisation will impact greatly on access to healthcare services, as people are likely to avoid accessing pivotal healthcare for fear of being tested for HIV, and/or discovered to be living with HIV.

As such, people living with HIV will be largely perceived as potential '*criminals*' waiting to be prosecuted – increasing stigma, discrimination and other violation of rights.

Challenges of proof

Prosecuting the '*crime*' of transmitting HIV to another person raises a number of questions in relation to empirical proof. While it is quite possible to prove whether or not the '*accused*' had knowledge of her or his HIV status, proving '*intent*' to transmit the virus to another seems impossible – especially considering that this would entail that the person had a thorough understanding of the nature and modus operandi of the virus holistically. Though faithfulness seems to be an obvious defence, proving faithfulness however, is logically impossible.

...criminalisation will also give momentum to the patriarchal system...

These are a few of the challenges relating to proof clearly indicating that the application of laws criminalising HIV transmission are questionable, as well as less than objective – and as such likely to be biased and not favourable to women, as women have lesser resources to engage with the court of law.

Conclusion and alternatives

Criminalisation of HIV transmission is counter-productive to the many efforts of ensuring greater access to HIV prevention, testing, treatment, support and care. Laws criminalising HIV transmission are also counter-productive to the progress made with regard to human rights protections in the response to HIV and AIDS.

Moreover, the criminalisation of HIV transmission promotes the discrimination against people living with HIV – further driving transmission of HIV, instead of reducing HIV transmission.

And finally, it has to be recognised that criminalisation of HIV will not only increase HIV-related stigma, but also that statues criminalising HIV transmission incites violence against women who are openly living with HIV, as positive women will be '*labelled*' as potential criminals.

...is likely to lead to reduction in HIV testing, as not knowing one's HIV status seems to be the 'safer' option...

Assuming that the goal is to reduce HIV transmission, to minimise the impact of HIV, and to promote and protect human rights in the context of the pandemics, then efforts and resources should be spent on the underlying factors driving the HIV and AIDS pandemics and not on legislation, which will erode and compromise many of the achievements made. Ensuring greater access to preventative measures; supporting and encouraging new preventative measures, such as microbicides should be areas of priorities. As for law reform processes, focussing on the decriminalisation of sex work, the decriminalisation of homosexuality, and the criminalisation of human trafficking seem more pertinent areas for law reform at this time of the pandemic.

And in re-evaluating the focus of new avenues to halt the pandemics, we might be in the position to truly develop measures that will achieve both the decline in prevalence and the protection of women.

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Marlow Valentine

Still forced to live on the margins of society… Western Cape End Hate Campaign[1]

In 2007, the Joint Working Group, a national forum for LGBTI-focused organisations, initiated the 070707 Campaign in response to the escalating violent crimes of hate against black lesbians living in townships and rural communities. This campaign was launched after the violent and brutal murders of Sizakele Sigasa and Salome Masooa in Meadowlands, Soweto on the 07th July 2007.

The Western Cape End Hate Campaign, under the banner of the National 070707 Campaign, was launched in Cape Town in February 2008 on the 2nd anniversary of the brutal murder of 19 year old Zoliswa Nkonyane, stoned and bashed to death on the 6th February 2006 by a mob of 20 heterosexual men in Khayelitsha.

These women, together with other victims of violent homophobic hate crimes, have one thing in common – they were killed, because they chose to live their lives as out gay, lesbian, bisexual, transgendered persons. They were victimised, violated, brutalised and targeted, because of their homosexual orientation.

Despite having one of the most liberal and celebrated constitutions; despite progressive legislation; despite a democratic system; and despite national campaigns, like the 16-days of activism, vulnerable people, like women, children and LGBT persons, still cannot access their constitutional rights – and are still forced to live on the margins of society.

Ignoring attitudes and negative mindsets are a huge challenge even in an age of information-overload – information regarding our rights; our health; HIV and AIDS; safer-sex messaging; substance and drug abuse; sexual diversity; etc-etc-etc. Fourteen years into democracy, and we have not been successful in shifting attitudes, altering stereotypes, reducing prejudice and discrimination, and breaking the silence of stigma and fear. Despite advocacy and human rights programmes, we are not winning '*the battle*' to change society, and to heal the divides of our political past.

We cannot deny the power that exists within stigma and prejudice. Even activists and human rights defenders are in denial about their own prejudices – we think that we are immune to the affects of our political past and we assume that just because we are in the field of human rights, we understand the issues.

Stigma and prejudice attached to HIV run deep and we are only prepared to challenge this when we are personally affected. When you are gay or lesbian, people assume you are promiscuous, that you engage in '*abnormal*' sexual conduct and that you live an amoral lifestyle. HIV and AIDS in many communities are still generally associated with gay sex or lesbian sex.

Because of the ignorance that exist with regards to sexual diversity and the issues facing LGBT persons; because of the rise of fundamentalism and the drive for ethnic cleansing; because of the escalation of hate speech and violent homophobic attacks, particularly in townships and rural communities, criminalisation of HIV will further

marginalise vulnerable groups, particularly black lesbian and bisexual women, and effeminate gay men.

The construction of gender, power and privilege, class, race, culture, religion and the social construction of heterosexuality in our hetero-normative society are fundamental to this discussion. Our masculine and patriarchal society is heavily influenced by the current political, cultural and religious climate:

- By being a woman in Africa or in our country, you are already marginalised and disadvantaged by the way in which gender identity and sexual identity has been constructed over time.
- If you are a black woman, you are further marginalised socially, politically, economically, intellectually – even in terms of culture, tradition, religion, marriage, etc.
- If you are a gay or bisexual woman, the odds are stacked even more against you as you are not only marginalised, discriminated or prejudiced by the broader society – you are ostracised by fellow women as well.

In the case of Zoliswa, the attack on her and her partner was initiated by a woman, who taunted them and called them '*tomboys*', and '*recruited*' the mob to attack them.

Through the End Hate Campaign, the alliance partners ask the following questions:

- Where do the sites of power lie? How do the SAPS, the judiciary, the healthcare system contribute to the increase of '*that*' power and control?
- In a country where there is no legislation around Hate Crimes, how can we ensure advocacy and lobbying for laws that protect the victim against violence borne out of hate and prejudice – and not further stigmatise or victimise the victim?
- How can we ensure that vulnerable persons within society – which include persons who present or express themselves in terms of their gender identity as butch women or effeminate men – know and understand their rights and have access to claiming their rights?
- How can we ensure that crimes of hate; gender-based violence within society and domestic relationships; sexual abuse and assault; rape – be it vaginal or anal – is reported and recorded by the relevant authorities?
- How can we ensure that lesbian and bisexual women caught-up or forced into heterosexual relationships receive the necessary emotional support, understanding and healthcare in safe environments, as they are usually victims of abuse – and are vulnerable to be infected by their heterosexual male partners, who have multiple sexual partners – and engage in risky, unsafe sex?

The WC End Hate Campaign has been active for the past nine months in the greater Cape Town area. We have been monitoring trials and reported cases and are appalled at the lack of political will by those, who make the laws of this country and those, who enforce the law.

...criminalisation of HIV will further marginalise vulnerable groups, particularly black lesbian and bisexual women, and effeminate gay men…

Two years later, there is still no justice for Zoliswa, her family and the witness. This case has been postponed 22 times in the Khayelitsha Regional Court – the trial has still not begun in earnest. We are further outraged that the spotlight of the 16-days will be turned off and the campaigns packed away for yet another year without any meaningful progress in the reduction of fear, stigma, prejudice and the effect gender-based violence has on us as a community.

Criminalisation is ineffective, if we fail to educate, change attitudes and alter behaviour.

FOOTNOTES:
1. This article is based on a paper presented at the 'HIV Criminilisation' Roundtable, 27 – 28 November 2008, Cape Town, South Africa.

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Jennifer Gatsi

Denying us the right to reproduce…

Forced and coerced sterilisation of HIV positive women[1]

The International Community of Women Living with HIV/AIDS (ICW), the Legal Assistance Centre (LAC), and the Southern Africa Litigation Centre (SALC) have provided documentation on thirteen cases of HIV positive women, who were subjected to coerced or forced sterilisation at public hospitals in Namibia, to the Deputy Minister of Health and Social Services, Petrina Haingura. The documented forced and coerced sterilisations occurred at Katatura State Hospital, Central State Hospital, and Oshakati State Hospital.

'Coerced sterilisation' is generally defined as the use of coercion in obtaining the necessary informed consent for the sterilisation procedure. *'Forced sterilisation'* refers to instances where the woman is unaware that she would be undergoing a sterilisation procedure at the time of the surgery, and only learned of the sterilisation after the fact.

Female sterilisation can occur either via a hysterectomy (the removal of the uterus), or through a tubal legation (restricting the Fallopian tubes such that a woman's egg does not reach her uterus). Both are serious surgical procedures and are considered permanent. Both often occur while a woman is undergoing a caesarean section.

Coercive or coerced sterilisation

The thirteen documented cases of forced and coerced sterilisation are only the tip of the iceberg. Of the 230 HIV positive women in education programmes facilitated by ICW, 40 have indicated that they were subjected to forced or coerced sterilisation. The ICW is continuing to work on providing documentation of additional cases.

At least two of the women subjected to coerced or forced sterilisation have filed cases before the High Court, alleging violations of their right to life, human dignity, equality, and the right to be free from cruel, inhuman and degrading treatment. The women are represented by the LAC.

In all thirteen of the cases documented, informed consent was not adequately obtained due to one or more of the following factors: consent was obtained under duress; consent was invalid, as the women were not informed of the contents of the documents they signed; and medical personnel failed to provide full and accurate information regarding the sterilisation procedure.

In at least six of the cases, consent was obtained by

medical personnel in situations of duress. In a number of cases, women were asked to sign consent forms while they were in labour, or on their way to the operating theatre. In other cases, women were told, or given the impression that they had to consent to sterilisation in order to obtain another medical procedure, such as an abortion or caesarean section.

Women were asked to sign a consent form for sterilisation, without being informed of the contents of the form, in at least six of the cases.

In all of the cases, the medical personnel failed to provide the women with a full description of the nature of the procedure, its effects, consequences, and risks. No medical personnel informed the women of the irreversible nature of the procedure, or provided information on alternative forms of birth control and family planning. In addition, no information was provided on the potential side effects of sterilisation.

In many cases, the women's continuing trauma of being subjected to coerced or forced sterilisations is compounded by the discriminatory treatment they experienced. In one of the cases documented, nurses at the Oshakati State Hospital refused to touch the patient and made disparaging remarks about her.

Namibia's constitutional guarantees and international human rights obligations

Forced or coerced sterilisation violate numerous rights guaranteed under the Namibian Constitution and Namibia's obligations under international and regional law, including the right to be free from cruel, inhuman and degrading treatment; the right to liberty and security of person; the right to health and family planning; the right to privacy; the right to equality and to be free from discrimination; and the right to life.

To ensure that the abovementioned rights are not violated, doctors are required to obtain the informed consent of patients before they undertake any sterilisation procedure, including a tubal legation or a hysterectomy. This requires that the patient be fully informed and that consent be obtained freely and without any coercion. This did not occur in the documented cases.

Namibia's neighbour, South Africa, has, through legislation, mandated that consent be obtained prior to any sterilisation and, further, that consent must be *'given freely and voluntarily,'* without any inducement. No such legislation exists in Namibia currently.

Advocacy responses

A submission by ICW to the Deputy Minister of Health on the 15th of July 2008 highlighted that forced or coerced sterilisation violated numerous rights guaranteed under the Namibian Constitution; Namibia's obligations under international law; Namibia's human rights obligations under the African Charter on Human and People's Rights; and the Protocol on the Rights of Women in Africa. Rights violated under these

agreements include the right to be free from cruel, inhuman and degrading treatment; the right to liberty and security of person; the right to health and family planning; the right to privacy; the right to bodily integrity; the right to equality and to be free from discrimination; and the right to life.

In addition to lobbying the Ministry of Health and other policy makers, ICW continues to engage in research and advocacy with partner organisations, in order to raise awareness of sterilisation in Namibia, and to end the forced and coerced sterilisation of women living with HIV.

ICW and the Women's Health Project tried to identify cases of coerced or forced sterilisation throughout Namibia, and provided information about rights violation in the context of coerced and forced sterilisation, as well as support to women who were subjected to sterilisation without consent.

Lessons learned

Findings from key informant interviews and media outreach show that coercive sterilisation of HIV positive women is regularly occurring, when HIV positive women access healthcare services during pregnancy, such as a caesarean section.

Next steps

Redressing and halting coerced and forced sterilisation is recognised as a cornerstone of efforts to advance the sexual and reproductive rights of HIV positive women. The International Community of Women Living with HIV and AIDS is partnering with regional and global entities to raise the visibility of these rights violations, and to work within the healthcare system and human rights accountability mechanisms to halt this practice.

As women and girls living with HIV and AIDS, our reproductive rights are being compromised by such practices within the healthcare system. It is very clear that forced or coerced sterilisation of HIV positive women is an expression of denying us the right to reproduce, and as it is women specific, it has the potential to create some controversy as an advocacy issue.

As such, we demand forced and coerced sterilisation to be put to an end, as it is a violation of women's fundamental rights and in so doing send a clear message to those entrusted to provide medical care that such unlawful behaviour will not be tolerated.

FOOTNOTES:

1. An earlier version of this paper was presented at the *HIV Criminalisation* National Roundtable Discussion, 27 – 28 November 2008, Cape Town, South Africa.

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ALQ | September/November 2008

Jameyah Armien

Invisibility of gender violence augmented…

Implications of HIV criminalisation

Introduction

Canada 2006 and Mexico 2008 respectively hosted the XVI and XVII International AIDS Conferences, where once again emphasis, apprehension and dissatisfaction were shown with countries, who have instituted laws criminalising HIV or countries in the process of investing in legislation to pass similar laws. This caused enormously vehement debates concerning the risk and '*benefits*' thereof, as these criminalisation laws have, thus far, been ineffectively implemented, creating further violation of people's rights[1]. Further to this, it does not aid in de-stigmatising HIV and AIDS but on the contrary, adds to discrediting persons living with HIV. As HIV and AIDS is still viewed as a female epidemic, a huge concern is the lack in reducing gender violence, as criminalisation adds to increasing gender violence aimed specifically at vulnerable groups.

South Africa's responsibility towards non-criminalisation of HIV

South Africa's constitutional environment[2], more specifically the Bill of Rights, promotes basic human rights which encompasses vulnerable, marginalised, and persons living with HIV and AIDS. This implies that the South African government can be held liable for any legislation promoting, inciting or instigating violence.

Criminalisation of HIV is one such possible legislation, where rights will be blatantly ignored. Since the HIV and AIDS epidemics were first diagnosed, consistent reports of stigma and discrimination have been received by people living with, or believed to be vulnerable to, the HI virus. These discriminations incessantly overlap demographical domains, such as age, social, political and more importantly, gender boundaries, which has simply embedded women's '*perceived role*' in the HIV pandemic – in predominantly heterosexual relationships – as being the '*carrier*' of the HI virus[3].

South Africa's *equality clause*[4] enforces the responsibility on all to ensure that equal treatment of all is practised, promoted, protected and respected. However, traditional gender norms and practices have historically been used to treat, especially marginalised groups – including women, children, lesbian and transgender women – unfairly. This reflected the inequality being experienced by vulnerable groups, and especially, seeing women as bearing the disproportionate burden of reproductive health problems, being primarily responsible for contraception and childcare, and to have less power to negotiate sexual relationships[5].

Implications of HIV criminalisation

Criminalisation frameworks will contribute to unequal norms by allowing a minority of people the power to decide on behalf of others. This becomes not just problematic, but also invasive, as decisions made on behalf of others could be met with disagreement, and abuse could be seen as a possible method of adherence to these laws. This method of adherence could be enforced through violence by partners and even communities wanting to take the law into their own hands, or looking for a '*legal*' way of dealing with HIV infected persons. Therefore, the mere consideration of criminalising HIV is unacceptable, as any kind of instigation of violence is dangerous to control, or to keep account of.

These lessons could also be learned from current criminalisation laws, where application of these laws are too broad, ineffective and open to various interpretations[6], which can lead to forced and degrading treatment of others. Consequently, the most alarming factor of HIV criminalisation is that the most vulnerable voices within communities will be further repressed through means of violence, and will be silenced to such an extent that they will not be heard, due to fear of intimidation, exploitation and ill-treatment. These minority voices will be overpowered by those who feel that they have the power, through legislation, to decide for and on behalf of others what is considered to be '*in their best interest*'. Verbal and psychological abuse is extremely intimidating and difficult to understand as it requires the ability of power to oppose. Within any relationship, the ability to overcome gender violence is complicated, and even more so, within relationships where gender violence has been aggravated by a positive HIV status.

Moreover, criminalisation of HIV transmission contradicts and compromises the right to privacy, as it implies that people living with HIV will have to disclose their HIV status. Disclosure will no longer be an informed and personal decision, but will be a decision made on behalf of people, who have been infected with, and affected by, HIV. These '*silent rules of disclosure*' will be unjustly executed, as people will find mechanisms to ensure that HIV positive persons' statuses are revealed. Communities would be constantly in conflict, as they would justify their attitudes and behaviours by what the law promulgates. In addition, there is also the risk that HIV criminalisation will lead to less community support and mobilisation programmes addressing stigma and discrimination[7].

Violence will be enforced in the name of the law as the judiciary and communities raise '*valid reasons*' for HIV infected people to disclose their HIV status, even though current legislation affords the right not to. This will ensure that vulnerable groups, such as women and children, will be discriminated against further, as their power to negotiate non-disclosure will be non existent. In addition to this, the responsibility of protection against HIV transmission, and other sexually transmitted diseases, will be one person's responsibility and not an individual or personal responsibility of each person[8]. This alleviates the responsibility of protection from one partner, as criminalisation will ensure safer sex is always the responsibility of the '*other*' person. Where then does it leave past and current conscientious behavioural change programmes around HIV transmission and safer sex? Criminalisation will promote blame, which may ultimately lead to violent reactions and behaviours, especially as protection, prevention and promotion of HIV will always be considered another person's responsibility.

…solely be responsible for augmenting gender violence…

Criminalisation of HIV legislation will ensure that stigma and discrimination is further ingrained into social norms, and that the right to non-disclosure becomes an irresponsible act towards others. We are already struggling with patriarchal rights, which are constantly evolving, how then do we foresee the conceptualisation of criminalising HIV to assist human rights in ensuring that equality is achieved? This criminal behaviour irresponsibly allows people to be treated unfairly and differently, instead of ensuring that each person's choice is respected. This criminalisation legislation will ensure that people, who treat others unfairly, are not held accountable for their actions, and that they determine the ethics of the next person's personal behaviour.

Gender violence will further be exacerbated when it comes to testing and treatment of HIV. Consequently, HIV testing for women is already considered challenging, as disclosure thereof to their partners may lead to physical or psychological harm. The non-disclosure clause allows a partner to make an informed decision to disclose once they are ready, thus, reducing the risk of violence. Criminalising HIV will, therefore, have a huge influence on HIV testing, as it will be a way of identifying persons, irrelevant of the status, who have been for HIV testing. It will be a persuading factor for people wanting to be voluntary tested, as vulnerable

groups will be fearful of additional stigmatisation, or bodily harm, by personal and social relationships.[9] The mere consideration of HIV criminalisation laws makes HIV testing daunting, as these laws are poorly drafted, unclear and open to interpretation.[10]

…to whose benefit and to what purpose will criminalisation of HIV be?...

A primary weakness of HIV criminalisation legislation is that it does not address the role of gender inequality relations, and how this plays a role in sexual and reproductive life, and/or HIV prevention, treatment and testing. The changing face of the epidemic over the past few decades has highlighted the gender and social inequalities that shape people's behaviours and limit their choices.[11] However, in view of these inequalities, the right to privacy will be further violated should HIV transmission be criminalised. A criminal legal framework to address the issue of HIV transmission further accentuates an unsupported perception that people living with HIV '*intentionally*' and '*recklessly*' transmit HIV to others. This feeds into the notion that invisible, marginalised groups will now be even further marginalised by having to undergo criminal prosecution, due to their health status[12]. Thus, a human rights approach based on informed consent, autonomy, confidentiality and non-discrimination are increasingly threatened[13], should criminalisation of HIV transmission be legislated, as HIV transmission will now be '*curbed*' through policies, instead of behavioural change.

Costing HIV criminalisation

Have we ever contemplated costing the impact criminalising of HIV within a gender violence context would have? Of course not, because if we did we could not even be considering debating legislation around this. The cost implication will not only be too massive, but also continuous, as it can be calculated on two parts 1) human costs and 2) legal costs.

The most important cost associated with criminalisation of HIV will be that of human fatality – taking into consideration that both gender violence and gender-based violence will escalate out of proportion, due to assumptions of people's HIV statuses. Statistics may not be readily available to reflect these cases, but health facilities may see an increase in abuse cases. In most cases, death, due to violence, may not be reported, as most people who are abused do not seek medical assistance; for a variety of reasons, including additional stigmatisation by the health and police sectors.

In addition to the above, the judiciary will see an increase in cases, particularly cases that involve rape, domestic abuse, and gender violence, which requires prosecution. The monetary value attached to this will escalate, especially as some of these cases will be trialled over years. Moreover, perpetrators may commit more than one act of violence, thus increasing social violence.

…HIV transmission will now be 'curbed' through policies, instead of behavioural change…

The second significant contributing factor will be the monetary implication. The fact is that government and civil society will have to spend extra money on reducing gender violence, on campaigns promoting behavioural change, and most importantly, on initiatives aimed to get people tested for HIV. The current voluntary HIV testing approach will not be an option for most people, as they will be too fearful of stigmatisation, and would, thus, be reluctant to even be tested for HIV and/or to access treatment.

Purpose of criminalisation of HIV in a gender violence context

To whose benefit, or to what purpose, will criminalisation of HIV transmission be? Is it a method of

controlling the spread of HIV? I think not! It seems more as if systemic institutions want to prescribe who people should sexually engage with; how people should be protecting themselves from HIV transmission; and the importance of informing others of one's HIV status. However, money and time should rather be spent on supplying people with unbiased information to make informed choices around sexual practices and behaviours. If these institutions are there to protect individuals' rights, then why should it be important for others to know whether or not a person tested for HIV, and the test result? So, the question remains to what, and to whose, benefit should there be legislation criminalising HIV transmission – and if there is none, countries that have implemented HIV-specific legislations should be held responsible for endorsing human rights violations.

…the gender and social inequalities…
shape people's behaviours
and limit their choices…

Conclusion

Currently, South Africa does not have legislation criminalising HIV transmission, but this does not exclude the possibility that the future may become daunting if we should. Thus, the criminalisation of HIV transmission will not just change social attitudes increasing discrimination and stigma, gender violence and human rights abuse; it will also ensure that at the heart of stigma lies the fear that people who are stigmatised should be seen as a threat to society[14]. Consequently, the act of HIV criminalisation has major consequences for people who are living with, or who have been affected by, HIV. Criminalisation of HIV transmission, as can be argued, will solely be responsible for augmenting gender violence and guarantee that various institutions violate basic human rights.

The question that should be continuously raised is who will benefit from the criminalisation of HIV transmission? Repealing basic human rights of privacy, non-disclosure and equality can be seen as just another way of making the invisible more invisible; and as negotiating people's rights without their permission. Is the criminalisation of HIV transmission really what we want, what we need, or is this something that just has no benefit for anybody?

Criminalisation of HIV transmission is, therefore, not about ensuring that people's rights are protected, but instead about who holds the power to decide for others, who holds the power to make decisions on behalf of marginalised and vulnerable groups.

FOOTNOTES:

1. Cameron, E., Burris, S. & Clayton, M. 2008. 'HIV is a virus, not a crime'. Paper presented at the 17th International AIDS Conference, Mexico City, Mexico.
2. The Constitution of South Africa, Act 109 of 1996.
3. Pan American Health Organisation, PAHO. 2003. Understanding and responding to HIV/AIDS-related stigma and discrimination in the health sector. [http://www.paho.org/English/AD/FCH/AI/stigma.htm].
4. Section 9 of the Constitution.
5. Holland-Muter, S. 2007. 'Sexual and reproductive health and rights of women living with HIV: A long road to travel…'. In: *ALQ*, March 2007, pp1-8.
6. Cameron, E. 2008. 'HIV is a virus, not a crime; Criminal statutes and crminal prosecutions'. Paper presented at The 17th International AIDS Conference, Mexico City, Mexico, August 2008.
7. Van der Schaff, G. 2007. 'People need to know their HIV status, but…'. In: *ALQ*, September 2007, pp17-23.
8. Cameron, E. 2008. 'HIV is a virus, not a crime; Criminal statutes and crminal prosecutions'. Paper presented at The 17th International AIDS Conference, Mexico City, Mexico, August 2008.
9. Pan American Health Organisation, PAHO. 2003. Understanding and responding to HIV/AIDS-related stigma and discrimination in the health sector. [http://www.paho.org/English/AD/FCH/AI/stigma.htm].
10. Cameron, E., Burris, S. & Clayton, M. 2008. 'HIV is a virus, not a crime'. Paper presented at the 17th International AIDS Conference, Mexico City, Mexico
11. United Nations Population Fund. 2004. The gender dimensions of the HIV/AIDS Epidemic. Population issues: Promoting gender equality: Gender and HIV/AIDS. [http://www.unfpa.org/gender/aids.htm]
12. Ahmed, A. 2008. 'The impact of criminalization of women and girls'. In: *Mujeres Adelante*.
13. Kehler, J. 2008. 'HIV testing practices'. Paper presented at the 2nd Wits HIV/AIDS in the Workplace Research Symposium. Johannesburg, 29 – 30 May 2008.
14. Pan American Health Organisation, PAHO. 2003. Understanding and responding to HIV/AIDS-related stigma and discrimination in the health sector. [http://www.paho.org/English/AD/FCH/AI/stigma.htm].

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ALQ | September/November 2008

Johanna Kehler

Increasing the risk of human rights abuses…

Effects of criminalisation of HIV transmission

> *It is stigma that I believe lies behind the enactment of these bad laws. Those laws seem attractive, but they are not prevention or treatment friendly. They are hostile to both. And this is simply because they increase stigma. They add fuel to the fires of stigma.* [Edwin Cameron, 2008]

It is in the context of acknowledging that human rights are to be at the centre of effective responses to HIV and AIDS; legislative trends to criminalise HIV transmission; and recognising a reality in which stigma, discrimination and other violation of rights, based on a person's sex, gender, sexual orientation and/or HIV status, prevail – that representatives from over 40 national, regional and international human rights, gender and HIV organisations came together in Cape Town on 27 and 28 November 2008 to dialogue and discuss, in depth, various trends, implications and realities of HIV criminalisation. The Roundtable Discussion was hosted and convened by the AIDS Legal Network (ALN), in partnership with SWEAT, the Triangle Project, and Leadership South.

Contextual framework

Recent global, as well as regional legislative trends indicate a strong call for criminalisation of HIV transmission as one of the measures to respond to the growing HIV and AIDS pandemics. While supporters of '*criminalisation*' reason that it is the only possible response to halt the HIV pandemic, since individuals' '*reckless*' behaviour need to be '*criminalised*'; opponents to these legislative changes are united in that any form of criminalising the transmission of HIV is a gross human rights violation. Moreover, there is also the common understanding that the criminalisation of HIV transmission will further deter individuals from accessing HIV testing services for fear of being '*criminalised*'; increase already prevailing HIV-related stigma, discrimination and violation of rights; and thus, heighten HIV risks and vulnerabilities, particularly of already '*vulnerable and marginalised groups*' – women, especially positive women and young women, as well as sex workers and lesbian women.[2] Also, calls for criminalisation of HIV transmission not only fail to recognise that existing legislative provisions are in place to prosecute '*wilful*' transmission of HIV[3], but also seem to ignore the gendered implications of criminalising HIV transmission[4].

At the same time, there is a growing global advocacy voice calling for the recognition that human rights are to be at the centre of all responses to HIV and AIDS. An integral component of the call for rights-based responses to the HIV and AIDS pandemics is the principled understanding that public health responses will only achieve their desired goals, if they are based on human rights approaches. Responding to growing global concerns about the implications of criminalising HIV transmission, a document, introducing 10 reasons why criminalisation of HIV exposure and transmission is bad public policy and threatens human rights gains, has been released toward the end of 2008.[5]

It is within the paradigm of public health needs and responses to the HIV and AIDS pandemics that human rights are increasingly threatened, and legislative trends of criminalising HIV transmission have flourished. Over the past 5 years, 20 African countries, including Tanzania, Mali, Kenya and Sierra Leone, have already adopted HIV-specific legislation, while other countries, such as Uganda, Malawi and Mozambique, are currently in the process of finalising HIV-specific legislation. While legislative provisions vary from country to country, common clauses include restrictions on access to education and information for children (in Guinea, for example, legislation prescribes that children under the age of 13 years are not to have any access to HIV and AIDS education); various conditions of mandatory and/or compulsory HIV testing (such as

pre-marital HIV testing in Guinea); provisions legislating HIV-disclosure and/or partner notification (in Mali, for instance, the law places a legal duty to disclose a positive HIV diagnosis to a spouse or regular sexual partner within a period of six weeks after diagnosis); and the criminalisation of HIV transmission (for example in Kenya). There are also examples, such as the HIV-specific legislation in Sierra Leone, which explicitly criminalises mother-to-child transmission of HIV.[6]

Recognising these legislative trends in the region, it is imperative to not only acknowledge that these legislative responses are primarily driven by public health needs, but also to critically assess and analyse the various human rights implications inherent to legislative trends toward criminalisation of HIV transmission. Moreover it is crucial to clearly identify the extent to which HIV-specific legislation, especially legislation criminalising HIV transmission, impact particularly on women.

Human rights and gender implications

The following provides an overview of some of the commonly raised human rights and gender implications highlighted in current debates about HIV-specific laws – many of which were also highlighted and affirmed during the 2-day meeting.[7]

…address prevailing HIV-related stigma, discrimination and other violation of rights – instead of increasing the risk of human rights abuses…

Based on the principled understanding that any form of HIV criminalisation is a gross human rights violation, participating organisations at the '*Criminalisation Roundtable Discussion*', including ARASA (AIDS Rights Alliance of Southern Africa) and ICW (International Community of Women living with HIV), felt very strongly that these legislative trends will not only further deter people from accessing HIV prevention, testing, treatment, support and care services, due to fear of being criminalised, but also increase HIV-related stigma and discrimination, as people living with HIV, or are perceived to be at '*high risk*' of HIV infection, will be further stigmatised as potential '*criminals*' and a '*threat*'.[8]

In the context of access to HIV testing, prevailing stigma, discrimination and other rights abuses, including the lack of assured confidentiality, are commonly recognised barriers – highlighted also by the continuing low uptake in HIV testing. Many of the arguments made against criminalising HIV transmission emphasise strongly that the fear of an HIV positive diagnosis, and the potential of a subsequent prosecution, will further deter people from accessing services, including HIV prevention and testing services.[9] Legislative and policy measures providing for mandatory HIV testing of pregnant women – a step often accompanied by debates to introduce legislation that criminalises HIV transmission – carry the risk that women may decide not to access antenatal healthcare, out of fear of being tested for HIV, as a positive HIV diagnosis may lead to a woman being prosecuted for transmitting HIV to either her child and/or sexual partner. Thus, women's right to access healthcare, including reproductive healthcare, will become severely compromised with the introduction of legislation that criminalises HIV transmission.

In the context of mandatory HIV testing of pregnant women, the meeting expressed great concerns as to the impact of mandatory HIV testing on the extent to which healthcare services, especially antenatal services, will be freely accessible. Considering already existing negative implications, based on the understanding, that pregnant women are to be tested for HIV, such as the risk of blame, shame, violence, abuse and destitution as and when women do test positive for HIV – the meeting felt strongly that legislating mandatory HIV testing will further increase women's risks.

It is also fair to assume that criminalising HIV transmission will undermine HIV prevention efforts, as a person accessing HIV prevention measures could be perceived to be living with HIV and thus, could be seen as a potential '*criminal*'. Moreover, HIV criminalisation will further limit access to prevention of mother-to-child transmission of HIV programmes, as women are easily identifiable as living with HIV, when participating in PMTCT programmes. And finally, criminalising HIV transmission will severely impact, and ultimately compromise, especially a positive woman's right to freely

decide whether or not to have children, as there will the risk of being prosecuted for infecting, and/or exposing her child, and/or partner, to HIV.

…creates a perception that 'safer sex practices' could potentially be enforced by the law…

> *Criminalisation acts increase stigma for women living with HIV and AIDS by blaming women for transmission of HIV, especially in the context of mother to foetus transmission. This serves to entrench the stigma against women as the vectors and transmitters of the epidemic, justifying violence against HIV-positive women, their expulsion from their homes, and denial of their right to inherit property.*[10]

Acknowledging women's specific risks and vulnerabilities in the context of HIV and AIDS, the two-day meeting also affirmed that legislative trends towards HIV criminalisation will, in its application, criminalise mostly women – as women are often '*the first to know*' of their positive HIV status, and thus, women are more likely to be prosecuted. Subsequently, legislation – often introduced as a means '*to protect women*' – will lead to the arrest and prosecution of women for infecting their partners and children with HIV.

It is commonly recognised that one of the underlying factors defining women's greater risks and vulnerability to HIV transmission is the patriarchal system placing women in a position of lesser power to make informed choices, including sexual choices. Thus, women are least in the position to negotiate conditions of sex, as well as to negotiate condom use. Yet, women, with the introduction of HIV-specific laws, will be liable for prosecution for '*wilful*' transmission of HIV.

> *The laws do not take into account existing social, economic or other existing inequalities or injustices in our societies. Therefore those most needing the protection of the law are in fact in most danger of having their human rights further eroded by these laws.*[11]
>
> *Not enough has been done to address the violence, inequality and human rights abuses that drive the epidemic – in other words, not enough has been done to address the real legal challenges.*[12]

Similarly, gender violence is widely recognised to be as much a cause as a consequence of HIV infection. Research findings[13] indicate that young HIV infected women are ten times more likely to have experienced violence, than women who are not infected with HIV. The fear of violence is an often cited barrier – especially for women – to disclosing their HIV positive status. Criminalising HIV transmission is likely to lead to more incidences of HIV-related violence, as the law prescribes people living with HIV as potential '*criminals*'.

HIV criminalisation may also potentially reverse some of the gains made in relation to sexual and reproductive health and rights, such as the right to make informed sexual and reproductive choices. In countries, such as Namibia, a country where there is no existing or proposed legislation criminalising HIV transmission in place, HIV infected women are coerced and forced into sterilisation – solely based on the ground of an HIV positive diagnosis, while many HIV infected women are, all over the region, subjected to coercive and forced '*abortions*'.[14] These are only two of the many examples clearly indicating the extent to which women living with HIV are already '*criminalised*' – irrespective of whether or not HIV-specific laws are in place. With the introduction of HIV criminalisation into the statutes, women's and especially positive women's, sexual and reproductive rights, including sexual and reproductive health rights, will be further limited, violated, and subsequently denied.

A similar argument can be made with regard to human rights gains in the response to HIV and AIDS. Achieved rights-based responses to HIV, such as access to HIV testing services, protecting the right to autonomy, informed choice, confidentiality and non-discrimination, as well as the right of access to HIV treatment, support and care, are severely compromised and threatened by legislative trends to criminalise HIV transmission.

> *This not only violates the most basic rights of people living with HIV, it also threatens public health, by making it dangerous for anyone to seek information about HIV prevention or treatment.*[15]

Concluding remarks

So, while an argument could be made that these legislative trends are founded in '*good intentions*' to halt the spread of HIV, the outcome, HIV-specific laws, are '*bad policy*' – reversing the progress made, as limited as it may be, in responding to HIV and AIDS realities and challenges from a human rights perspective. Furthermore, opponents to HIV criminalisation are united in the recognition that '*change in sexual behaviour'* – which is key to reducing the risk of HIV transmission – cannot be legislated, and adopting HIV-specific legislation that criminalises HIV transmission is not only an approach to the pandemic that violates, by its very definition, fundamental rights and freedoms of people infected with, and affected by HIV and AIDS, but also misleading, in that it creates a perception that '*safer sex practices*' could potentially be enforced by the law.

…achieved rights-based responses… are severely compromised and threatened…

Highlighting 10 reasons, why criminalisation is '*bad policy'*, Judge Cameron states that:

> *…criminal prosecutions are a misguided substitute for measures that really protect those at risk of contracting HIV*.[16]

Hence, efforts to halt the spread of HIV and to reduce especially women's risks and vulnerabilities to HIV infection are to focus on removing barriers to HIV prevention, testing, treatment, care and support – instead of creating additional barriers further deterring people from accessing much needed services and information; on effectively addressing the underlying factors of the HIV and AIDS pandemics, such as the patriarchal paradigm fostering women's lesser power to negotiate conditions of sex, and thus, enabling and perpetuating women's greater risk and vulnerabilities; and to effectively address prevailing HIV-related stigma, discrimination and other violation of rights – instead of increasing the risk of human rights abuses, through '*legalising*' criminalisation of HIV transmission and, in so doing, '*legalising*' the criminalisation of people living with HIV.

FOOTNOTES:

1. This contribution is based on the Roundtable Discussion, '*Criminalisation: Obstacle or key to effective HIV and AIDS response?*', held on 27 – 28 November 2008 in Cape Town, South Africa. A full copy of the report can be accessed from the AIDS Legal Network (ALN). [www.aln.org.za]
2. See, for example, Eba, P. 2008. 'HIV specific legislation in Africa: Are human rights concerns addressed?'. AIDS and Human Rights Research Unit, Centre for Human Rights & Centre for the Study of AIDS, University of Pretoria; Cameron, E. Burris, S. & Clayton, M. 2008. 'HIV is a virus, not a crime'. Paper presented at the 17th International AIDS Conference, Mexico City, Mexico; and IPPF, GNP+ & ICW. 2008. *HIV: Verdict on a virus – Public health, human rights and criminal law*. [http//:unaids.org/en/knowledgeCentre/Resources/Feature_Stories/archive/2008/20081114_verdict_on_virus_IPPF.asp].
3. Open Society Institute. 2008. *10 Reasons to Oppose the Criminalisation of HIV Exposure or Transmission*. [http://www.soros.org/health/10 reason].
4. See, for example, Clayton, M. 2008. 'Criminalising HIV transmission: Is this what women really need?'. Paper presented at the 17th International AIDS Conference, Mexico City, Mexico; and Welbourn, A. 2008. HIV/AIDS a war on women. Open Democracy. [http//:www.opendemocrcy.net/article/5050/international_womens_day/hiv_aids].
5. Open Society Institute. 2008. *10 Reasons to Oppose the Criminalisation of HIV Exposure or Transmission*. [http://www.soros.org/health/10 reason].
6. See also, for example, Ngonyama, L. 2008. 'Criminalisation of HIV Transmission: Legislative trends and implications'. Paper presented at the Criminalisation Roundtable Discussion, 27 – 28 November 2008, Cape Town.
7. See, for example, Open Society Institute. 2008. *10 Reasons to Oppose the Criminalisation of HIV Exposure or Transmission.*[http://www.soros.org/health/10 reason]; and IPPF, GNP+ & ICW. 2008. *HIV: Verdict on a virus – Public health, human rights and criminal law*. [http//:unaids.org/en/knowledgeCentre/Resources/Feature_Stories/archive/2008/20081114_verdict_on_virus_IPPF.asp].
8. See, for example, Ngonyama, L. 2008. 'Criminalisation of HIV Transmission: Legislative trends and implication'. Paper presented at the Criminalisation Roundtable Discussion, 27 – 28 Nov 2008, Cape Town; and Madlala, R. 2008. 'Criminalisation of HIV transmission and implications for women'. Paper presented at the Criminalisation Roundtable Discussion, 27 – 28 November 2008, Cape Town.
9. See, for example, IPPF, GNP+ & ICW. 2008. *HIV: Verdict on a virus – Public health, human rights and criminal law*. [http//:unaids.org/en/knowledgeCentre/Resources/Feature_Stories/archive/2008/20081114_verdict_on_virus_IPPF.asp].
10. Tzili Mor, Georgetown University Law Centre, and Aziza Ahmed, ICW, USA, 2008. As quoted in IPPF et al. 2008, p18.
11. Alice Welbourn, ICW, UK, 2008. As quoted in IPPF et al. 2008, p31.
12. Richard Pearshouse, Canadian HIV/AIDS Legal Network, 2008. As quoted in IPPF et al. 2008, p31.
13. See [http://www.unfpa.org/gender/docs/fact_sheets/gender_hiv.doc]
14. See, for example, Gatsi, J. 2008. 'Criminalisation of positive women: The Namibian experience'. Paper presented at the Criminalisation Roundtable Discussion, 27 – 28 November 2008, Cape Town; and Tjaronda, W. 2008. 'Namibia: women robbed of motherhood'. [http://allafrica.com/stories/200802120307.html].
15. Rebecca Schleifer, Human Rights Watch, 2008. As quoted in IPPF et al. 2008, p15.
16. IPPF, GNP+ & ICW. 2008. IPPF, GNP+ & ICW. 2008. *HIV: Verdict on a virus – Public health, human rights and criminal law*. pp36-37. [http//:unaids.org/en/knowledgeCentre/Resources/Feature_Stories/archive/2008/20081114_verdict_on_virus_IPPF.asp].

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Participation is seen as a privilege, not a right...
Women Leaders Speak[1]

The only way you will empower me is if we sit at the table together and share our power.
[MariJo Vazquez][2]

Clear calls for women's full participation in the AIDS response have been made at, and even before, the 1994 Paris AIDS Summit, whose Declaration pledged to

…support initiatives to reduce the vulnerability of women to HIV/AIDS by encouraging national and international efforts, aimed at the empowerment of women…by ensuring their participation in all the decision-making and implementation processes which concern them; and by establishing linkages and strengthening the networks that promote women's rights.

These calls have been repeated time and again, not only by the United Nations General Assembly in the 2001 Declaration of Commitment on HIV/AIDS, but also in numerous civil society statements and declarations, such as the 1992 Twelve Statements of ICW, the 2002 Barcelona Bill of Rights, the 2005 Compact to End HIV/AIDS, the 2006 Johannesburg Position on HIV/AIDS and Women's and Girls' Rights in Africa, the 2006 Panama Declaration, the 2006 Blueprint for Action on Women and Girls and HIV/AIDS, the Nairobi 2007 Call to Action and the 2008 Women Demand Action and Accountability Now statement.

Yet, despite the increased attention to, and resources allocated for HIV and AIDS, as well as heightened debate around the '*feminisation*' of the epidemic, women's full participation in the AIDS response has still not been realised. As the Honourable Charity Ngilu, former Kenyan Minister of Health, stated at the 2007 International Women's Summit:

My dear sisters, where policies are being made, our faces are not at those tables.[3]

This is particularly true for the women, who are the most affected by the epidemic, as for too long HIV-positive women are invited only after agendas have been set, or policy decisions have been taken. HIV-positive women leaders from Latin America have, therefore, boldly embraced the position of '*nothing for us without us*'.

Obtaining information on who is participating where in the AIDS response at the national, regional or global level is a frustrating endeavour of stitching together data sources and asking individual questions of key informants. There is no consistent monitoring of involvement by key stakeholders in the formal and informal AIDS response, and the deeper question of meaningful participation by people most impacted by the epidemic is even more difficult to assess.

However, after an extensive review of existing documentation and lengthy in-depth interviews with key stakeholders in Southern Africa, South Asia, Southeast Asia, Latin America and elsewhere, the evidence is clear. Although women are on the frontlines leading innovative initiatives that are central to the success of the AIDS response – as community-based caregivers, women's rights advocates and so on – they are not yet full participants in all levels of the response. For example, too few women have a seat on powerful mechanisms, such as the National AIDS Coordinating Authority or the Country Coordinating Mechanism of the Global Fund to Fight AIDS, Tuberculosis

and Malaria. According to October 2008 data from the Secretariat of the Global Fund to Fight AIDS, Tuberculosis and Malaria, women's participation on the Country Coordinating Mechanisms hovers at a 32% average[4]. Women's participation does not necessarily imply the participation by, or representation of networks of women living with HIV, women's rights organisations or grassroots women's groups. So, even when gender parity is met, critical stakeholder involvement may not be.

…why is so much of women's involvement invisible?...

At the opening of the International Women's Summit in Nairobi, Kenya in July 2007, Dr. Musimbi Kanyoro, speaking as the then World YWCA General Secretary, said that '*the leadership of positive women is not negotiable'*. If women are leading the response in important ways, and, if calls for women's full participation in the AIDS response have been made for over 15 years, why is so much of women's involvement invisible? And why are women, particularly the most affected women, still absent from formal and informal decision-making forums?

> *Positive women bring a unique experience, inside knowledge and a drive to survive. Positive women need to be involved. Even though the rhetoric is changing, where is this happening?*[5]

Situational Analysis

> *First, we need to raise awareness on human rights, and also create an environment where women can come and talk freely and openly about their needs and rights. At the same time, we need to set up a policy that supports the involvement and participation of women. Also, we need to sensitize policymakers about the issue of women.* [Mony Pen][6]

Even as women actively strive to lead, or even participate in civil society or governmental structures, significant barriers limit their capacity and reach. Central among these are the responsibilities women shoulder in their homes, as illustrated by the following quotes of women leaders:

Achieving the Power of Participation: Recommendations*

1) Recognise affected women, such as HIV-positive women, home-based caregivers and young women, as key stakeholders in the AIDS response, through creating formal places for real participation and leadership in decision-making bodies, as these mechanisms are places of power.
2) Ensure democratic processes for selecting civil society representation and enable true representation, through providing support for consultation and collaboration.
3) Ensure that national plans and programmes on HIV and AIDS prioritise women's needs and priorities as identified by women through consultation and engagement.
4) Invest in organisations and initiatives led by and with HIV-positive women.
5) Invest in developing a new cadre of women leaders, particularly HIV-positive women, at local and national levels.
6) Simplify funding mechanisms, so as to facilitate greater access to resources by women's organisations, especially community-based women's organisations, and target resources to these organisations.
7) Support programmes that address the immediate needs of women, including increased access to HIV prevention, treatment, care and support services.
8) Prioritise gender expertise in all aspects of the AIDS response, including in formal decision-making bodies and funding mechanisms.
9) Increase women's awareness and understanding of human rights, including the right to full and meaningful participation.
10) Promote the participation, empowerment and leadership of women at all levels of society.

**These recommendations build on those developed by the Huairou Commission, ICW, VSO and the World YWCA, among others, as well as from the numerous calls to action and statements developed by civil society on this topic. Number 10 is taken specifically from the 2007 Nairobi Call to Action.*

In households that are affected, everything is blamed on the women.[7]

At the household level, I think the main problem is that as much as men say they are breadwinners, women are the backbone. The housework is done by women and they are unable to do their own things. They have too much work.[8]

Building Young Women's Leadership in Namibia

The Namibia Women's Health Network is the first network of HIV positive women, founded with a majority of young women, in Namibia. The Namibia Women's Health Network builds upon the alliances forged through the Parliamentarian for Women's Health project with policy makers (Members of Parliament sitting in the Parliamentary Standing Committee on Human Resources, Social and Community Development), with civil society and community-based organisations, faith-based entities, and the private sector. The Ministry of Health and Social Services, Ministry of Gender Equality and Child Welfare, SADC Parliamentary Forum, and the UN family in Namibia are also key allies. Because of the Young Women's Dialogue led by ICW in Namibia to mobilise and create space for HIV positive young women, one of the young women participants has been nominated by the National Council at Parliament to sit in the HIV and AIDS committee of the National Council.

I think many of the challenges women in the U.S. face are probably quite similar to women around the world. According to the Kaiser Family Foundation July 2007 report, 76 per cent of HIV-positive women have children under 18 to take care of, many are heads of households and must work to support the family, living in poverty (64 per cent of HIV-positive women in the U.S. have incomes under $10,000 compared with 41 per cent of HIV-positive men) with limited transportation available and are faced with intense stigma in deciding whether or not to step forward.[9]

Similarly, the care giving role that many women undertake in the context of HIV and AIDS is not sufficiently recognised as a core component of the response:

…Until we get away from the concept that 'women's work' is voluntary or unpaid while men require payment, we will not enable a meaningful involvement of the people most disproportionately affected who also have the least resources.[10]

Compounding the barriers raised by women's socially defined roles are the barriers women face when attempting to engage with the AIDS movement as a whole:

The movement of HIV-positive women emerged in a male-controlled context. In the beginning of the pandemic, and even until now in some regions of the world, AIDS activism is dominated by men. Sometimes these leaders have formed elites, and it is very difficult for women to be part of the decision-making levels. The first battle for gender equality has been inside the AIDS movement.[11]

…the heterogeneity of women's lived experience is frequently overlooked and the critical alliances across movements do consistently exist…

There is an AIDS power structure in the U.S. that does not include many women. Many men in policy and advocacy work have been doing AIDS work since the epidemic hit gay men over 20 years ago. They are skilled and well versed on how to gain entry into decision-making arenas. Many women do not have the experience, confidence and technology literacy to gain access to this arena.[12]

Even when, for example, HIV-positive women are

invited to a meeting or hold a seat in a decision-making forum:

> *The main challenge to participation and leadership in the response to HIV/AIDS at the social level is that besides taking care of our daily tasks, we have to go over the social structures set up by people who hold on to knowledge and who exercise power. They build their own interest groups, and in order to participate we need to raise awareness and win their trust. We participate but we do so in a situation of inequity, implementing first the actions that other people, with their own interests, decide for us.*[13]

…the space afforded HIV-positive women in the AIDS movement has been contested…

> *Rarely, if ever, do those creating the policy, holding the meeting, developing the programme, ask: what are your priorities? Where do you think we should start? What are the biggest challenges facing you at home?*[14]

Lastly, even within the community of women advocates, researchers and decision-makers, the heterogeneity of women's lived experience is frequently overlooked and the critical alliances across movements do not consistently exist. For example, sex worker leaders commented after the 2006 International AIDS Conference that it was the first time they had been included in women's rights sessions. Despite the violence faced by lesbian women, in South Africa for example, in the context of HIV and AIDS, this issue is not consistently on the women and HIV agenda. Women who use drugs struggle to add a gender perspective to harm reduction, and their particular concerns are too frequently overlooked as well. The manner in which young women struggle to have a voice and be recognised in the women's sector is one more case in point. Further,

> *…it has been rare for women's organizations to stand by positive women's organizations…hard to get support by the women's movement.*[15]

These are only a few ways in which, even across overlapping and related movements, there are stronger alliances to be built and critical gaps to fill.

Challenges across continents

The challenges women face in order to participate, both in formal and informal structures in the AIDS response, are consistent across continents, even if variable in degree. Women's responsibilities within their homes limit their ability to travel for extended lengths of time to meetings or trainings. The space afforded HIV-positive women in the AIDS movement has been contested. A key informant from the National Movement of Positive Women Citizens in Brazil noted:

> *We still have many spaces to conquer. Recognition that we need to have specific spaces because we have specific requirements is still not a matter of consensus inside the AIDS movement.*[16]

Investment in building the strategic capacity of most affected women has been inconsistent. Projects and programmes to address women in the context of HIV and AIDS are too frequently focused on women as objects of services, not as agents of change.

> *They give us money but do not include us. They do not ask us what the issue is…I'm not sure they will support us long term. For women to be empowered, they need long-term support from donors.*[17]

Resources are donor-driven, and as such, organisational structures can lack attention to gender dynamics.

> *We are doing work supporting most at risk women, but programme staff for this are mostly men. It's similar to other organizations, both non-governmental and governmental…At high levels, there are more male staff than female; at grassroots levels, there are more women. It can appear as: Men are thinkers, decision makers, and women are doers.*[18]

Broader alliances between the women's rights movement and the HIV-positive women's movement have been slow to form. Women, particularly those most affected by HIV and AIDS, have had to struggle constantly for a voice in agenda-setting and policy-making. Transparent entry points frequently do not exist.

Mobilising Communities for Change in Uganda

Mobilising Communities for Change in Uganda
The Ugandan Mama's Club is a peer education, advocacy, and information resource for young HIV positive mothers to gain psycho-social support, knowledge, and training at the intersection of sexual and reproductive rights and health and HIV. Organised by, and comprised of, women living with HIV, the Mama's Club is a model for community-based support, mobilisation, and change that can work to ensure the health and welfare of HIV positive women, their families, and their communities. The Mama's Club has carried forward three key priorities to date: 1) male involvement in PMTCT programs (the prevention of perinatal transmission); 2) strides to positive parenthood; and 3) protect and support young mothers. The Mama's Club is a 2008 Red Ribbon Award recipient.
Through mobilising young mothers who are living with HIV, the Mama's Club has created an engine for advancing sexual and reproductive health and rights, as well as for facilitating local women's participation in the AIDS response.

> *We need the voice of women at the table, especially women living with HIV. But how do we do that? How do we get involved, say, at NIH* [National Institutes of Health]*?…No one answers me. I plan to go to* [Washington] *DC in April to speak to people about this – but how do I get involved and who do I speak to?*[19]

The pace of communication and decision-making at the global level far outstrips the ability of women with limited Internet access, or ability to converse easily in English, to keep up. Structural barriers go hand in hand with broader policy and practice that are not inclusive. HIV-positive women or their networks are invited late to meetings, after agendas are set, or into processes after guidance or policy has been formulated. Thus, positive women are constantly placed in the role of reaction, disappointment and complaint, rather than in a position of proactive, constructive and creative contribution. Similarly, women are invited to speak to '*women's issues*' only, and not to address the broader policy directives under consideration. Participation is seen as a privilege, rather than as a right, or as meaningful, sustained engagement.

…structural barriers go hand in hand with broader policy and practice that are not inclusive…

Roadmap for Action

So what is the roadmap for realising the meaningful involvement of women in all aspects of the AIDS response and for them to have full power of participation?

> *We will never see a reduction in new infections and deaths without investing in the strategic capacity of the most directly affected, HIV-positive women.*[20]

Advancing women's leadership and participation in the AIDS response requires concrete steps to address the obstacles they face, as well as longer term commitments to leadership development, training and resource allocation.

> *One* [strategy] *is to understand the need for affirmative action to ensure there are always two places at the table for persons living with HIV, one woman and one man. Many of the major organizations do not understand the need for women to be represented by themselves, but issues for women are often very different from those addressed by other constituencies…Secondly, we must ensure resources are put in the hands of positive*

women's networks and the vast army of women who provide the majority of treatment, care and support services without material support.[21]

…placed in the role of reaction, disappointment and complaint, rather than in a position of proactive constructive and creative contribution…

1) Monitor the *'full and active participation of people living with HIV, vulnerable groups, most affected communities'*[22] in the response, particularly as it pertains to women living with, and affected by HIV.
2) Collect sex and age disaggregated data on participation and implement an assessment of the extent to which women's participation is indeed meaningful and a part of leadership, to better guide policy development and resource allocation.
3) Develop definitions of, and standards for meaningful participation, through consultation with women, most importantly with HIV-positive women and their networks.
4) Strengthen the capacity of affected women, particularly HIV-positive women, to participate fully in the HIV and AIDS response, through leadership training, sustained technical support and mentorship.
5) Document and disseminate successful strategies and innovative initiatives to strengthen and promote the leadership and participation of HIV-positive women.
6) Identify strategic areas for advocacy and influence, such as increasing the participation of HIV-positive women and women's rights organisations in Country Coordinating Mechanisms of the Global Fund to Fight AIDS, Tuberculosis and Malaria.

FOOTNOTES:

1. This contribution is an excerpt from a Review of Women's Leadership and Participation in the AIDS Response by UNIFEM and the ATHENA Network; and has been drawn from an extensive year long global review of women's leadership and participation in the AIDS response.
2. MariJo is the past Chair of the International Community of Women Living with HIV/AIDS (ICW) and Chair of the ATHENA Network.
3. Speech at the International Women's Summit: Women's Leadership on HIV and AIDS, Nairobi, Kenya, July 2007.
4. Data received by email, October 2008.
5. Beri Hull, International Community of Women Living with HIV/AIDS (ICW), Interviewed 6 February 2008.
6. Mony Pen, Cambodian Community Network of Women Living with HIV/AIDS, Interviewed by ICRW and CEDPA 4 February 2008.
7. Asha Juma, Kenya, Interviewed by ICRW and CEDPA 1 February 2008.
8. Ignatia Jwara, Gender AIDS Forum, Interviewed by ICRW and CEPA 6 February 2008.
9. Maura Riordan, WORLD, Personal communication 11 February 2008.
10. Lynde Francis, The Centre, Personal communication April 2008.
11. Violeta Ross, 'A Bridge Needs Two Sides', presented at the Global Round Table, Countdown 2015 Sexual and Reproductive Rights for All, London, 2004.
12. Maura Riordan, WORLD, Personal communication 11 February 2008.
13. ICW Brazil, Personal communication 18 February 2008.
14. Luisa Orza and Jennifer Gatsi Mallet, 'Thinking Positive', 30 November 2007, Open Democracy, [http://www.opendemocracy.net/article/5050/16_days/hiv_aids_namibia].
15. Undisclosed informant, Interviewed 15 February 2008.
16. Alessandra Nilo, 'Case Study of Women's Leadership and Participation in the AIDS Response in Brazil' from full review.
17. Mony Pen, Cambodian Community Network of Women Living with HIV/AIDS, Interviewed by ICRW and CEDPA 4 February 2008.
18. Hoang Thi-Le An, Vietnam, Interviewed by ICRW and CEDPA 31 January 2008.
19. Shannon Behning, Women's Lighthouse Project, Interviewed by ICRW and CEDPA 5 February 2008.
20. Terry McGovern, Ford Foundation, Interviewed 18 March 2008.
21. Lynde Francis, The Centre, Personal communication April 2008.
22. United Nations General Assembly, 'Declaration of Commitment on HIV/AIDS', A/RES/S-26/2, 27 June 2001, [http://www.un.org/ga/aids/docs/aress262.pdf].

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Gahsiena van der Schaff

The NSP remains a document for a few…

Provincial feedback on the implementation of the NSP

The first round of provincial networking meetings facilitated by the AIDS Legal Network (ALN) in 2008, focussed on the implementation of the HIV and AIDS & STI National Strategic Plan, 2007 – 2011 (NSP).

One of the purposes of the meetings was to explore the challenges, experiences, lessons learned at a community/district level, as this is seen to be a key element in identifying the remaining gaps in the implementation of the NSP; but also to engage with civil society's role in the implementation of the NSP; as well as to examine community's level of awareness of the NSP and its desired goals, targets and interventions. Another purpose was to collectively identify remaining gaps and develop advocacy strategies to further enhance civil society's role and responsibility in the implementation of the national strategic plan at a community/district level.

Meetings were conducted in the following provinces: North West (08 May 2008), Free State (28 May 2008), Western Cape (05 June 2008), Eastern Cape (30 June 2008), KwaZulu Natal (28 August 2008), Northern Cape (03 September 2008) and Mpumalanga (03 October 2008). The various civil society sectors participating at the meetings, included home-based care; human rights advice offices, LGBTI, youth, gender violence, victim empowerment, orphans and vulnerable children, community members, traditional healers/leaders, sexual and reproductive health and rights, VCT counsellors, and the treatment sector. In some provinces representatives of Provincial and District AIDS Councils attended, while in others some of the Chapter 9 institutions participated in the meetings. In one of the provinces, one of the departments heard about the meeting and used the opportunity to respond to many of the questions raised around the implementation of particular interventions.

One of the guiding principles for the implementation of the NSP, namely **effective partnerships**, highlights that:

> *…all sectors of government and all stakeholders of civil society shall be involved in the AIDS response.*

One could argue that ideally all stakeholders and civil society shall be involved in the HIV and AIDS response. Ideally, stakeholders who are involved, outnumber those not involved in the implementation of the NSP; as ideally most communities are involved in the implementation of the NSP. But that is only the ideal. The reality, from what one could gather from the meetings, is that there is minimal involvement by civil society and community in the implementation of the NSP.

Fewer than 5% of social and networking partners and community members, participating in the meetings, had knowledge of the NSP. Also, fewer than 5% had ever attended a meeting on the NSP, or the Provincial Strategic Plan (PSP), or the District Strategic Plan (DSP). This, most certainly, raises the question as to the extent to which the guiding principle of '*effective partnerships*', and the involvement of all of civil society is applied. As one participant pointed out:

> *…It is one thing to know what the NSP is promising, but quite another to engage with government officials who are not forthcoming with information around accessing funds for programmes, and when meetings are going to be held and such.*

However, it is important to recognise that civil society organisations are, in fact, involved in implementing programmes and interventions of the NSP – through their own programmes and initiatives – many without being acknowledged by, or receiving funding from, the government. On the question as to what changes partners observed pre-NSP and now fourteen months into the NSP, partners indicated, amongst others, that HIV information '*is now more free flowing*' and that messages have changed '*somehow*'; that more people are treatment literate; and more and more people are seen testing for HIV.

However, concerns were also raised about things that,

according to partners, should change but where no change has been observed and/or experienced as yet, including that:

- Rural areas remain largely excluded from funding and initiatives
- Legal literacy is still missing
- Healthcare workers are still as '*invisible*' in some communities as before
- Lack of transparency is still a major concern
- Representatives of AIDS Councils are largely unknown to civil society and community
- Accessing information from municipalities remain a huge challenge
- NGOs remain fragmented and are still '*fighting over resources*' (e.g., HBCs receiving stipends and those who do not)

…identified 'solutions and strategies' to further the implementation of the NSP may be as 'ambitious', as some of the identified NSP interventions themselves…

One partner raised the issue of lack of access to follow-up support after people have tested for HIV, pointing out that organisations run campaigns to encourage people to test, but put nothing in place for '*after-care*'.

> *…no one cares what happens to me after I have tested. All they are concerned about is to report the number of people who have tested in that campaign.*

Furthermore, some of the participating organisations disagreed with the view that changes happening in the communities should be ascribed to government implementing the NSP, but rather due to the hard work of NGOs, who '*go the extra mile*'.

In all the meetings, questions were posed as to the '*lead agents*', who are responsible for the implementation of particular interventions and programmes.

The NSP outlines requirements for effective implementation of the NSP[1], stating that:

> *…It is recommended that Provinces duplicate appropriate national structures, such as SANAC, at provincial and local level. It is particularly important to establish appropriate structures at district level and it is recommended that District HIV and AIDS Committees be established. These district structures should include all role players within communities. Local government structures should mainstream HIV and AIDS, TB and STI activities to harmonise with local integrated development plans: issues such as access to transport and poverty alleviation are integral to HIV programmes.*

Yet, the majority of participants at the meetings expressed a common sentiment, best highlighted with the following statements: '*We do not know of the existence of either the PAC or LAC – who they are, is a mystery!*', and '*No meeting was called where we were present and where the PSP or LSP was discussed!*'.

The guiding principle on **financial sustainability** states that:

> *…No credible, evidence-based, costed HIV and AIDS and STI sector plan should go unfunded. There should be predictable and sustainable financial resources for the implementation of all interventions. Additional resources from development partners shall be harmonised to align with policies, priorities and fund programme and financial gaps.*

Yet, one of the challenges mentioned by the majority of partners throughout the provinces is the lack of financial resources to implement interventions and programmes relevant to their work. The NSP also confirms that clear and effective communication is an essential tool for the attainment of the aims of the plan. However, few of the well-established civil society organisations are informed of calls for funding; or of meetings of District AIDS Councils – which is of great concern.

The NSP also states that[2]:

> *…More can still be done by civil society to improve the manner in which they are organised for better efficiency.*

During the meetings, several provinces admitted to '*being fragmented*'; '*not organised*'; and '*fighting over resources*' – thus, indicating that there remains plenty of room for civil society to improve their level of efficiency.

Another concern is that for the attainment of the aims of the NSP, *'Individuals and communities need to take charge'*[3] The apparent lack of '*clear and ongoing*' communication does, however, raise the question as to how civil society, individuals, and communities would, in fact, know that they

are to not only '*take charge*', but also to, more importantly, participate – if to benefit from intended interventions and programmes. The responsibility of all is to make sure that communication is ongoing and clear, and that all are involved, as highlighted in some of the strategies identified during the meetings.

> *…It is important to take the process forward- raising awareness about the NSP in the communities, making sure implementation is taking place and that everyone understands their responsibility in implementing interventions and programmes, and to start a process of engagement between government and civil society.*

Overview of challenges

The NSP remains a document for a few, with little or no benefit to the people who are meant to benefit. Achieving the goals of the NSP is a national responsibility – *a responsibility of all*. Yet, very few have knowledge of the document, its content and implications, and thus, limited understanding of the responsibility. Effective partnerships cannot be achieved with the exclusion of civil society. Similarly, individual representation and/or single organisational representation at provincial or local AIDS Council level does not constitute '*partnership*' with civil society, as no single organisation can claim to represent all of civil society. And while this may highlight the challenges within civil society itself, it may also point to the ineffectiveness of provincial/district/local AIDS council structures engaging with individuals and/or individual organisations, which do not necessarily have a mandate to be on these structures.

There is also the continuous challenge of lack of access to information, as well as the challenge of '*representing*' the realities, concerns and needs of especially rural communities. Rural communities are often solely reliant on information dissemination and messaging from lovelife (who speaks primarily to young people, and remains a '*feeder*' of moral, instead of factual information), and from Khomanani (who does largely the same). Moreover, there is also the concern that very little human rights education is happening in rural areas.

The question of violations being reported to advice offices was also commonly raised. Yet, the advice offices often fail to educate people about their rights, especially the meaning of rights in the context of HIV and AIDS. It is, thus, not surprising that advice offices receive limited complaints regarding human rights violations in the context of HIV and AIDS. This could be based, arguably, on the fact that advice offices do not always fully understand the complexity of HIV-related rights violations – especially if the rights violation does not appear to be closely linked to abuses of a socio-economic nature. Often, advice offices also lack full understanding of their crucial role in the partnership, and the voice, which they could and should be playing in the NSP implementation process.

…'take responsibility'… form 'effective partnerships'…and ensure civil society's active involvement and meaningful participation in the implementation of the NSP…

A general lack of knowledge and understanding of human rights, as well as of prevailing rights abuses in the context of HIV and AIDS persists among the majority of participating organisations – often impacting not only on the effectiveness of organisational programmes and initiatives, but also on the '*quality*' of the services provided by organisations. Subsequently, organisation's effectiveness in addressing and challenging underlying factors, such as gender inequality, male dominance, and prevailing stigma, discrimination and violation of rights, remains limited.

Process

In each of the meetings, participants engaged by means of group work with various NSP objectives and interventions. The groups formed themselves based on sector, interest and/or experiences with particular issues; and were tasked to identify specific interventions to in-depth engage with; to raise questions/concerns, which were initiated through the engagement with a particular intervention; to highlight existing and foreseeable challenges for the implementation of the intervention; and to identify strategies of how to address these challenges.

As part of this process, participants opted to engage with

interventions in the NSP that specifically focused on the increased uptake of VCT[4]; workplace programmes[5]; young people[6]; home-based care[7]; ART promotion and treatment literacy programmes[8]; comprehensive sexual assault care[9]; public sector drug rehabilitation[10]; drug and alcohol abuse[11]; stigma and discrimination[12] infection control[13]; human rights and LGBTI[14]; human rights and access to justice[15]; women and human rights education[16]; gender-based violence[17]; victim empowerment[18]; and needs of women in abusive relationships[19].

…disagreed with the view that changes happening in the communities should be ascribed to government implementing the NSP, but rather to the hard work of NGOs, who 'go the extra mile'…

Provincial voices

While the identified challenges and responses varied by details between the provinces, the following provide an overview of recurring questions/concerns, challenges and responses, by identified intervention, highlighted by participants across provinces.[20]

INCREASE UPTAKE OF VCT

Objective 5.2.1

Increase the number of adults who have had an HIV test, with a focus on men

[Lead Agency: Department of Health; Target: 2007-25%; 2008-35%]

Questions/Concerns

- How can we best convince men to access VCT
- How many people in the community know where the VCT sites are, and what services are provided in the communities
- How is confidentiality handled/assured at the sites
- How credible/qualified are the people providing VCT services, in terms of necessary skills and information
- How can people, who work from six-to-six, access VCT services, as the opening times for VCT are not convenient for working community members
- Did an increase in VCT uptake happen, where did happen, and how is this measured
- How is civil society's participation in implementing this intervention ensured

Challenges

- Men refuse to go for an HIV test, and say that they have a right not to test, and women get accused, or create suspicion, of cheating and ill-will, when they introduce the matter of HIV testing
- Women get beaten up for raising the issue, and also for bringing the '*virus home*'
- Stigma and the fear of knowing deter people from accessing HIV testing services
- Lack of privacy at most facilities where VCT is offered, as structure of the facilities are set up in such way that people who test are clearly identifiable, due to the rows allocated for HIV testing
- People who would like to test privately cannot afford to do so, due to poverty and unemployment
- People still fear discrimination at the workplace
- No lists of non-medical sites, and after-hours facilities are available at community level
- Women especially mentioned that even if men test, they refuse to communicate their HIV status or to use condoms after testing, so how can a woman protect herself, when the husband works in the city and when he comes back home, he refuses to use condoms
- One participant felt that:

  …since the launch of the NSP, women are still the ones mostly accessing VCT, and 14 months after the launch of the NSP, a greater effort should have been made to increase men's access to VCT. Thus far, there seems to be no focus on men to get tested for HIV, but instead an increased focus on women, particularly in ante-natal settings is observed.

Challenges of HIV counsellors

- Accessibility to accredited training
- Attitudes of health professionals towards counsellors, including lack of recognition of lay counsellors as skilled people/professionals

- Stigma, discrimination and violation of rights are not clearly understood, while stigma and discrimination impact on counsellors' quality of work
- Lack of confidentiality, due to lack of resources and private spaces at sites for counselling
- Limited distribution of female condoms

The group of counsellors suggested that the institutions that train counsellors be expanded, so that more counsellors could be trained; femidoms be made available as soon and widely as possible; standardised procedures for mentoring of counsellors be implemented; health professionals be educated on confidentiality and laws/rights; and better marketing strategies are to be embarked on in all spheres.

Strategies

- Providing mobile services to especially service men
- Establishing men's forums, where a multitude of issues affecting men's health can be raised, and where VCT can be accessed
- Intensifying HIV and AIDS interventions and programmes in the workplace and transport sector industry
- Intensifying education and capacity enhancement of traditional healers and leaders
- Providing more education and awareness on values, or regeneration of morals, and focus on young men
- The Department of Health to release the numbers of men tested per clinic, to encourage more men to access VCT services

HOME-BASED CARE

Objective 8.2.1

Recruit and train new community caregivers, including community health workers, with emphasis on men

[Lead Agency: Department of Social Development; Target: 2007-10 000 (10% men); 2008-15 000 (10% men)]

Questions/Concerns

- How many and percentage of the people recruited and trained were men
- Are the home-based care positions advertised in all communities
- How many health care practitioners, community health workers, HBCs were trained thus far
- How much is budgeted for the implementation of the PSP, and how much of the available budget is allocated to NGOs
- What are the department's strategies of getting men interested in providing care

Challenges

- Cultural and traditional beliefs, which lead to men avoiding '*caring work*'
- Stipend too small to attract men, as men are not interested in volunteering
- Organisations do not have enough funding for HBC programmes; while more carers are required, there are no funds to increase the number of home-based carers
- Carers need advanced training; who is going to provide that, including the funding for the additional training
- Lack of professional nurses in HBC organisations
- Lack of commitment by officials to find solutions to the shortage of HBC
- Government campaigns not productive, as '*one day*' events have little to no impact
- Caregivers use some of their stipends to transport clients to clinic appointments – stipends are for the carer's benefit, and it should not be expected from caregivers to use this money to taxi clients to their appointments
- Lack of support and mentoring provided to caregivers
- Duplication of services and no coordinated effort and dialogues
- Patients, especially female patients, may be reluctant to be looked after by men carers

Strategies

- Dialogue with men to inform them of what their responsibilities are towards the communities where they live
- Apply for more funding and give home-based carers an increase in their stipends
- Ensure that HBC is not gender-based, because HIV and AIDS affect all
- Care giving organisations should establish contact and links with the Department of Social Development, and not wait for the department to contact organisations, as this may never happen
- NGOs should establish an effective network for

support and mentoring, as well as to strategise and speak as one voice, when approaching the department
- Support, debriefing and mentoring, meetings must be structured and include skilled supervisors (e.g., social workers and professional nurses)
- Caregivers and their clients are subjected to unacceptable treatment and attitudes from clinic staff and this should urgently be addressed

Opportunities

Cultural attitudes and myths could be changed if men partake in community home-based care. And if it is implemented successfully, then these attitudes and myths can be proven to be a waste of time, unnecessary, and counter-productive to community-based efforts and initiatives.

ART PROMOTION AND TREATMENT LITERACY PROGRAMMES

Objective 6.1.8

Develop and implement community-based ART promotion and treatment literacy programmes

[Lead Agency: Department of Health; Target: 2007-50% of sub-districts covered]

Questions/Concerns

- Were the programmes developed
- Were the programmes implemented and in which sub-districts
- The key priority for the design of these programmes is so that it can be implemented in the most vulnerable communities – when are these programmes going to reach the vulnerable communities who live very far from cities

Challenges

- NGOs working in rural areas seldom have infrastructure and/or resources/funding and municipalities face similar challenges
- Materials are mostly prepared in English, which makes it inaccessible to rural NGOs, and the communities served by NGOs
- Caregivers have to travel long distances to find clients and assist them to keep clinical and pharmacy appointments
- Shortage of staff at clinics leading to a down-referral system, contributing also to increased levels of non-adherence to Rx

Strategies

- Making enquiries at the local level about the programme itself and the levels of implementation

COMPREHENSIVE SEXUAL ASSAULT CARE & VICTIM EMPOWERMENT

Objective 2.9.3

Evaluate, improve and roll-out training programmes on the management of gender violence and rape for the police

[Lead Agency: Department of Social Development; Target: 2007-Training programme developed; 2008-30% of police trained]

Objective 2.9.4

Increase the number of districts with accessible social and mental health services to support child and adult victims of gender-based violence

[Lead Agency: Department of Social Development; Target: 2007-20% of districts covered; 2008-40% of districts covered)

Questions/Concerns

- Where is this programme, and what is contained in it, as we are not aware of the programme
- Who is involved in this programme, and where can one get a copy of the programme
- How many police were trained in 2007
- Did the police, who received the training, share the information with their colleagues and are they going to get follow up training

Challenges

- Training is mostly only provided to mostly senior management, whilst the lower level officers who deal with the cases are '*left in the dark*' about programme implementation, and also do not understand their role and responsibility toward effective implementation
- Lack of resources, including first aid kits, transport, basic infrastructure, and condoms for women
- Approach and attitude of SAPS and DOSD
- Lack of independence of VEP, which are largely dependent on SAPS
- Lack of human rights and legal rights education for members of VEP

Strategies

- All levels of police must attend these trainings to ensure effective implementation and maximum

benefit to both the police and sexually assaulted persons
- The communities should be participating in the programmes, because how else will they be aware what to expect regarding services and PEP, and also how to hold the police accountable

STIGMA AND DISCRIMINATION

Intervention 17.1.1

Develop a people living with HIV manual on human rights, including children and people with disabilities; distribute manual through health facilities, social development offices, and courts

[Lead Agency: Department of Health; Target: 2007-Manual developed; 2008-50% manuals distributed with training]

Questions/Concerns

- Where is this manual
- Who received training and when

Challenges

- People afraid to know their HIV status
- Lack of confidentiality in VCT sites/services
- High levels of illiteracy, which becomes a challenge in respect of access to information and messages
- People are not familiar with legislative framework regarding their human rights, and what to do when rights are violated

Strategies

- To organise a community general meeting and invite traditional leaders, health workers, municipality and councillors to address these challenges mentioned
- To establish a formal structure, such as a health forum, representing all sectors of the area, including community members

YOUNG PEOPLE

Objective 2.2.1

Identify and prioritise interventions in schools reporting high rates of teenage pregnancies per year through a gender-sensitive package that addresses sexual and reproductive health and rights, HIV, alcohol and substance abuse

[Lead Agency: Department of Education; Target: 2007-Create special map and database and start implementation in priority schools; 2008–Implementation in 50% of priority schools]

Questions/Concerns

- Was a special map and database created; and if so, which schools were identified and how many of these are in our district, since there are still high numbers of teenage pregnancy reported
- Did they start with implementation yet, and in which schools

Challenges

- There are high rates of teenage pregnancy at high schools and high levels of lack of education and information among young people at schools
- There is a general lack of knowledge among, particularly, young women

Strategies

- Engaging with both women and men on the benefits of condom use, and not just focusing on women, will make a big difference in reducing teenage pregnancy rates
- Make available, as a matter of urgency, femidoms and male condoms in places where young people can freely access them, and educate all young people on condom use
- Education and training should come from people, who will not judge young people's sexual behaviour

Objective 2.1.1

Introduce, evaluate and customise curricula and interventions for different target groups, including young people out of school, primary school children, secondary school children, higher education institutions, young women and pregnant women, older men and women, higher risk groups and vulnerable populations

[Lead Agency: Department of Education; Target: 2007-Evaluation, improvement & introduction; 2008-Ongoing]

Questions/Concerns

- How do we monitor progress
- Where does one access funding for this

Challenges

- The Department of Education is running on old policy, which is not linked to this strategic objective in the NSP
- Access to condoms at school is not allowed, and as such, condoms and condom distribution is not allowed

at schools

- Projects that are implemented by relevant stakeholders are mostly '*once-off*' and, thus, have no impact, because behaviour does not change based on once-off/ one day programmes
- The DOE and partners are not speaking the same language

Strategies

- Education and training, as well as intensified awareness raising on rights, and the meaning of these rights in a school environment
- All stakeholders must be involved in the planning sessions of projects and interventions
- Monitoring and evaluation must be continuous
- Dissemination of information need to be improved
- Resources must be accessible to everyone, without any form of discrimination in terms of race, gender, etc.

Objective 2.3.5

Increase and coordinate multi-media strategies aimed at youth that promote communication about HIV, including HIV prevention, gender and sexuality

[Lead Agency: Department of Health; Target: 2007-2011 Quarterly campaigns]

Questions/Concerns

- Who is the target for these quarterly campaigns
- Are these quarterly campaigns effective, and how is the effectiveness of the campaigns measured
- Are the campaigns sustainable

Challenges

- We have no funds to carry out these kind of activities
- There is a general lack of communication between local and provincial structures

Strategies

- Proper communication between all role players on local and provincial levels, and with civil society and community
- Identify ways to raise funds to carry out activities effectively
- One participant highlighted that:

  …since there are no funds for the activities, NGOs cannot implement activities mentioned in the NSP; and since there is no communication between role players (local and provincial), NGOs find themselves having to go the extra mile.

Objective 2.2.2

Implement legislation and policies and programmes aimed at keeping young people in schools, particularly orphaned and vulnerable children

[Lead Agency: Department of Education; Target: 2007-Identify & implement; 2008-Ongoing]

Questions/Concerns

- Have the priority schools been identified
- Were programmes implemented, and where were they implemented
- What is contained in the programmes
- What role does the department play in all of this
- How is funding accessed for this
- Where is the legislation for keeping orphaned and vulnerable children in schools

Challenges

- Schools do not accept children who do not/cannot pay their fees, and lack of information as to who the relevant people are in the Department of Education to approach about this
- Accessing funding for these interventions is problematic, and/or the funding allocated does not go to the right people
- Training of teachers, who are supposed to implement some of these interventions, is not taking place

Strategies

- Adequate communication between all role players
- The district strategic plan should be common knowledge, and must be made available to all role-players
- Funding to implement these programmes must be easy to access

HUMAN RIGHTS & LGBTI

Intervention 2.5.2

Incremental roll-out of comprehensive customised HIV prevention package for men who have sex with men, lesbians and transsexuals, including promotion of VCT and access to male and female condoms, and STI symptom recognition

[Lead Agency: Department of Health; Target: 2007-Programme developed with relevant groups; 2008-40% of groups covered]

Questions/Comments

- No interventions were introduced by DOH with the NGOs that work with LGBTI issues, and/or LGBTI communities
- Was this programme developed, and if so, who were the '*relevant*' groups that participated in the drafting of this programme
- Where was the programme implemented thus far

Challenges

- Stigma and discrimination based on a person's sexual orientation/identity
- Hate crimes and hate speech based on a person's sexual orientation/identity
- Coming out challenges, including being chased away from home, due to one's sexuality

Strategies

- Increase efforts on educating communities about LGBTI
- From DOH we need the following: access to treatment, femidoms and dental dams to be freely available
- Equal treatment and no discrimination

HUMAN RIGHTS AND ACCESS TO JUSTICE

Objective 16.3

Ensure a supportive legal environment for the provision of HIV and AIDS services to marginalised groups

[Lead Agency: Department of Health & South African Human Rights Commission; Target: 2007-Materials developed and approved; 2008-40% of organised groups covered]

Questions/Concerns

- Discrimination within households, and how is this addressed
- How is stigma being addressed

Challenges

- Lack of adequate resources, including financial resources, within DOH, DOSD, DOE, and human rights sector
- Developed policies and programme materials are not widely distributed

Strategies

- Approach, and engage with LAC, PAC and SANAC to present challenges
- Guidelines to be made available to relevant persons and/or organisations
- Material on education to be made available and distributed for special needs persons, including drug users, prisoners, orphaned and vulnerable children, and older persons
- Materials to be language accessible

WOMEN AND HUMAN RIGHTS EDUCATION

Objective 19.1

Improve access to human rights education and information for women in resource limited settings

[Lead Agency: Department of Health & Department of Social Development; Target: 2007-30% of identified nodes; 2008- 50%)

Questions/Comments

- Where and which nodes were identified
- Where do we get the 2007 report
- Are these lead agencies working with other stakeholders, including with civil society stakeholders
- From the civil society point of view, who is monitoring implementation

Challenges

- Lack of access and control of resources
- Gender equality not mainstreamed into other goals
- Limited access to people most in need of help
- When a lead agency is named, without mention of a specific lead person, it becomes difficult to get information, as one would be sent from pillar to post
- There should be open communication lines, so that one could engage with reports submitted on implemented objectives

Strategies

- Using the national gender framework to infuse gender in the NSP→PSP→LSP
- Involving more community leaders in the projects
- Inviting other organisations and departments, when discussing strategic plans, so as to get '*buy-ins*'

GENDER-BASED VIOLENCE

Objective1.2.2

Develop and implement a communication strategy, including leadership messages, to educate men and women, boys and girls, on women's rights and human rights

[Lead Agency: Presidency; Target: 2007-Communication strategy developed; 2008-quarterly campaigns]

Questions/Concerns

- Was the communication strategy developed, and where is the proof
- What kind of quarterly campaigns are in place
- Are there any national policies and legislation about improving the status of women, and if so, why don't we know about them

Challenges

- No real partnership with government to address human rights abuse issues
- Policies are in place within government structures, but there is lack of implementation
- Secondary victimisation lives unabated, and so too the delay of cases
- Lack of adequate counselling and ongoing counselling for rape survivors, and no adequate counselling skills among health workers

Strategies

- Officials need gender training, as many do the talk, but do not understand the meaning of gender
- Call meeting with relevant stakeholders, including SANAC and provincial and district AIDS Councils
- Materials must be inclusive, accessible, and speak to the realities of all people (not just, for example, speak to youth)

Objective1.3.1

Develop communication strategies, including leadership messages, which addresses the unacceptability of coercive sex, gender power stereotypes and the stigmatisation of rape survivors

[Lead Agency: National Prosecuting Authority; Target: 2007-Communication strategy developed; 2008-quarterly campaigns & ongoing]

Questions/Concerns

- Was the communication strategy developed, and, if so, where is it
- What kind of leadership messages are included in the communication strategy
- Were the quarterly campaigns launched, and if yes, what has been the impact
- How come we are not aware of your campaigns
- What is the strategy to deal with the stigma of rape survivors

Challenges

- Lack of information materials that are accessible to illiterate persons
- Lack of resources to implement programmes
- Lack of adequate implementation of legislation
- Lack of government assistance/resources
- NGOs are often excluded from government

Strategies

- Forming partnerships with CBOs, NGOs, FBOs to discuss issues that affect communities, including matters arising from the NSP
- Lobbying government, as a consortium, for adequate and timely implementation – it is the duty of NGOs to monitor the implementation of policies and
- Lobbying government to speed up the rape case process; to provide counselling to assessors; and to ensure that victims receive thorough counselling therapy

ADDRESS THE NEEDS OF WOMEN IN ABUSIVE RELATIONSHIPS

Objective 19.3

Distribute guidelines on SAPS and their responsibilities in terms of the National Sexual Assault Policy

[Lead Agency: Department of Justice; Target: 2007-40% of facilities covered; 2008-50%]

Questions/Concerns

- Where are the guidelines
- Which facilities have benefited from these guidelines thus far
- One participant, representing a rural-based organisation, highlighted:

  …as an organisation working in a rural area, and in the gender-based violence sector, there is still a big gap in how to help women in abusive relationships, so, it would be very helpful to us to have these guidelines.

Challenges

- Lack of funding to send people, who will return and can train others on the Guidelines, for training
- Lack of adequate knowledge amongst SAPS personnel – for example, loss of dockets; discrimination of women and girls from male

SAPS police officers; SAPS fails to provide proper explanations and follow up to victims of abuse

…SAPS fail to follow proper procedures, with the result that many women will come to our organisation to seek assistance.

Strategies

- Train SAPS officials on how to address needs of abused women, and let officials conduct workshops to communities.
- Police officers who received the training must workshop their colleagues, so they are also informed
- Distribute information flyers to the community so as to ensure community awareness

…that there is minimal involvement by civil society and community in the implementation of the NSP…

Conclusion & Way Forward

These meetings clearly highlighted that civil society is experiencing many challenges relating to both the implementation of interventions and programmes, as well as the effects of fragmented approaches within civil society. However, civil society organisations also offered '*solutions*' for the identified challenges. And while some of the identified '*solutions and strategies*' to further the implementation of the NSP may be as '*ambitious*', as some of the identified NSP interventions themselves, it clearly points to showing civil society's commitment to '*take responsibility*', to address and overcome challenges, to form '*effective partnerships*', and, in so doing, to facilitate and ensure civil society's active involvement and meaningful participation in the implementation of the NSP.

FOOTNOTES:

1. Chapter 12, p119.
2. NSP, Foreword, p4.
3. NSP, Foreword, p4.
4. Objective 5.2.1 of the NSP.
5. Objective 16.1.2 of the NSP.
6. Objectives 2.1.1, 2.2.1, and 2.3.5 of the NSP.
7. Objective 8.2.1 of the NSP.
8. Objective 6.1.8 of the NSP.
9. Objective 2.9.3 of the NSP.
10. Objective 2.8.4 of the NSP.
11. Objective 2.8.3 of the NSP.
12. Objective 17.1.1 of the NSP.
13. Objective 4.1 of the NSP.
14. Objective 2.5.2 of the NSP.
15. Objective 16.3 of the NSP.
16. Objective 19.1 of the NSP.
17. Objectives 1.2.2 and 1.3.1 of the NSP.
18. Objective 2.9.4 of the NSP.
19. Objective 19.3 of the NSP.
20. For the purpose of this article, only some of the interventions will be introduced. For a full report on all the interventions, please contact admin@aln.org.za.

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Nathaniel Meyer

The decision signals a new beginning...

The first documented case of AIDS in the United States was in 1981. These findings shocked the nation. While Americans were still learning what the disease was, what to call it, and how to respond, nearly two cases of AIDS were being diagnosed in the country every day. The disease was labelled as a '***gay cancer***' both in everyday language, and supposed scientific terminology such as GRID, (gay-related immune deficiency). Four years later, President Ronald Reagan publicly mentioned AIDS by name for the first time during a press conference, and the national discussion finally began.

It is argued that these four years where silence and denial replaced the need for confronting the disease and providing the American people with the information they so desperately needed, only fanned the flames of fear and hate. In speaking openly about HIV and AIDS, we are helping to reduce the stigma associated with the disease. We are lifting the cloak of fear and ignorance from where intolerance and indifference reside. We are all affected by AIDS, and how we address this issue is of paramount importance to respond to the disease, but to voice concern, and to act, are two vastly different and challenging tasks. A leader must not only make promises, but keep them as well. On November 4th the United States elected a new President, and it is critical that this person takes a stand to not only speak publicly and openly about the realities of HIV and AIDS, but to commit fully to stop the pandemic. At the time of the 2008 election campaign, both presidential candidates, John McCain and Barack Obama, had a distinctly different approach to the subject, which is worth analysing.

In 2007, there were an estimated 2 million people living with HIV in North America, Western and Central Europe combined. The United States accounted for 1.2 million of that total, the highest in the region. There were 31 000 AIDS related deaths in the United States in 2007, a number which has been steadily growing since 2004. HIV and AIDS is still a serious problem in the United States, and a strong domestic strategy for responding to the disease is essential to improving the general health of the population, and to encourage investment and immigration from abroad, a key source of income and cultural contribution to the country. As expected, the then two presidential candidates differed on several issues.

Senator McCain's domestic HIV and AIDS policy is one of stark contrasts. In 1993 Senator McCain voted to prevent permanent immigration to the United States if a person is living with HIV. This ban is still in existence, continuing to humiliate and discriminate against people living with HIV. He has also voted to imprison HIV-positive healthcare workers who perform surgery, and to involuntarily test patients for HIV, if they are

about to undergo surgery. In terms of domestic funding, John McCain assisted in passing one of the most important pieces of legislation in America's '*battle*' against AIDS. McCain was a co-sponsor of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990. The CARE Act was, and continues to be, the largest federally funded programme for people living with HIV. While Senator McCain chose not to co-sponsor the Act's 2000 re-authorisation, the vote passed, and the Act was re-authorised again in 2006, with an increase in funding to $2.1 billion until 2009.

…Obama is strictly opposed to federal funding for abstinence-only-until-marriage programmes…

President-Elect, Barack Obama, a Senator from Illinois, has taken a far different approach to the response to HIV and AIDS in the United States. Obama has created a national AIDS strategy, detailing both a domestic and global agenda. In the plan, he outlines his goals to lift the federal ban on funding for safe needle exchange programmes. Out of all new HIV diagnoses in the United States in 2005, 19% were attributed to infected needle injections. His running mate during the election campaign, Senator Joe Biden from Delaware, also believes in needle exchanges. Biden has been quoted as citing the benefits of such a programme in a report by the National Institute of Health that showed a 30% or higher reduction in HIV transmission rates among injection drug users who participate in needle exchange programmes.

Barack Obama has also been a primary sponsor of the Microbicide Development Act, which would promote research of microbicides to prevent HIV prevention, and has supported the JUSTICE Act, which would allow the distribution of condoms in federal prisons. Obama is strictly opposed to federal funding for abstinence-only-until-marriage programmes, and along with Senator Biden, is a co-sponsor of the Prevention First Act. The bill includes provisions to ensure that private health plans provide the same coverage for contraceptives as for prescription drugs and other services. The Prevention First Act also increases access to information and services such as emergency contraception in order to reduce the number of unintended pregnancies, abortions and sexually transmitted infections including HIV.

AIDS is a disease that crosses deserts, oceans and mountains, borders and battlefields. It is critical for there to be open international discussion and multilateral support in order to effectively respond to HIV and AIDS across the globe. The American President-Elect must be ready to respond to international calls for aid, and provide voluntary assistance to help effectively respond such a global epidemic. Previous U.S. Presidents have done much to help the nations of the world with respect to HIV and AIDS, some doing more than others. Barack Obama has, thus, an enormous responsibility to do more than the minimum, to increase funding, promote open discussion, and reduce the international stigma attached to the disease.

One of the most important topics with regards to HIV and AIDS funding and prevention, both in the United States and sub-Saharan Africa, was the requirement of abstinence-until-marriage programmes. Up until 2008, one third of all U.S. foreign aid to halt HIV was provided only to abstinence-until-marriage based programmes. McCain has argued the need for abstinence programmes, insisting that only if this strategy fails, will preventative measures, such as contraceptives, be provided. In following with this policy, John McCain publicly supports Republican Senator, Dr. Coburn, who advocated abstinence requirements in the recent

re-authorisation of the President's Emergency Plan for AIDS Relief (PEPFAR). This legislation was, and continues to be, the largest contribution to respond to a single disease, by a single nation, in history. John McCain and Dr. Coburn demand, however, that a significant portion of these funds are only released, if used for abstinence programmes in the host country.

Barack Obama has made several significant commitments to Africa and the rest of the world, including his pledge for support in the global response to HIV and AIDS, and other major diseases. In order to more effectively distribute aid, Obama believes that to engage in effective sex education, people must have all the information necessary – information on contraceptives, other science, and reality-based prevention methods, in addition to abstinence-only education. A restructuring of the fund distribution system of PEPFAR is also a cause Obama supports.

Barack and Biden are co-sponsors of the HIV Prevention Act, which no longer requires that one-third of overseas HIV prevention go to abstinence-only-until-marriage programmes, and would instead direct that funding to comprehensive prevention education. Though there was opposition, including Senator McCain and Dr. Coburn, when PEPFAR was re-authorised in 2008, abstinence-only requirements were lifted, thanks to support from policy makers like Obama and Biden. Reaching beyond sub-Saharan Africa, Obama also has supported an increase in funding for Southeast Asia, India, and Eastern Europe. These additional funds would be provided by PEPFAR and would constitute an increase of $1 billion over the next five years. Barack Obama has co-sponsored several pieces of legislation aimed to improve the world's capacity and response to HIV and AIDS. He co-sponsored the African Health Capacity Investment Act of 2007, which plans to improve the capacity of health systems in sub-Saharan Africa, and the International Cooperation to Meet the Millennium Development Goals Act of 2005, which urge the forgiveness of debt, in addition to, increased funding for the United States' international commitments to the responses to HIV and AIDS globally.

…made several significant commitments to Africa and the rest of the world…

President-Elect, Barack Obama, has been straightforward, and open about his policies to halt the global increase of the disease. He has given his share of inspiring, heartfelt speeches as well, but he has also backed them up with a national and international strategy based on the reality of the disease, passing legislation that has sought to increase the rights and protections of people living with HIV, and has pledged to double American foreign aid to $50 billion a year by 2012.

As an American, I had the privilege of voting in what has been described as the most important U.S. Presidential election in a generation, and the results will have far reaching consequences. I hope the decision signals a new beginning in American politics and foreign policy, and I am proud to be a part of the process. I am asking you, the international community, to help us achieve this. We all must demand action and remind our leaders what they promised to do, and what still needs to be done in order to effectively respond to the global HIV and AIDS epidemic – as we are all equal, we are all affected, and we are all positive.

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Luisa Orza

Gains continue to be hard-won…

Meaningful Involvement of Women Living with HIV (MIWA) at the IAC

The International Community of Women Living with HIV and AIDS (ICW), the only global network of HIV positive women, was founded in 1992. We have over 6000 members from 128 countries. For over a decade, ICW has been a co-organiser of the International AIDS Conferences (IAC). The principle aim of our role as co-organiser is to increase the meaningful involvement of HIV positive women, in both content and form, of the conference.

Introduction

In the build-up to the Mexico City Conference of 2008, ICW developed a simple meaningful involvement of women living with HIV (MIWA) report card for conference delegates, be they HIV positive women, general delegates, or members of the IAC to fill out. We felt the need to build up a proper dossier of experiences and thoughts about the meaningful involvement of HIV positive women in events like AIDS2008, and to examine the continuing challenges that need to be overcome to assure that MIWA happens.

The responses we received are summarised here, and from them we make recommendations for how the environment of International AIDS Conferences can be developed to protect and enhance positive women and men's involvement at Vienna 2010 and in the future. This report also contains views put forward through other evaluative methods, such as ICW conference reports (submitted by staff and members attending the conference), personal communications between conference delegates and the compilers of the report, the ATHENA network, and other email list-serves, such as SEA-AIDS.

Positive women's involvement in Mexico City AIDS2008

The 17th International AIDS Conference had probably the greatest (and most meaningful) involvement of women – and men – living with HIV of any of the international AIDS conferences to date. At least four openly positive women sat on the Conference Coordinating Committee (CCC), and at least one on each of the three programming committees: community, leadership and scientific (see below for more details). The conference itself, in the words of one ICW member, was '*vibrant with HIV positive people*', and HIV positive women were more visible then ever, speaking in the opening ceremony of the conference, a plenary session, and in myriad abstract-driven, skills building, satellite and global village sessions. Positive women were involved in the International AIDS Conference as delegates, speakers, volunteers, poster authors, advisors to other speakers, mentors, scholarship recipients, as organisers of the Global Village or involved in Global Village activities, particularly in the People Living with HIV Networking Zone or the Women's Networking Zone – 75% of whose sessions included positive women speakers. Positive women with committee involvement tended to have an unmanageable number of other commitments and responsibilities throughout the conference as well – one respondent who sat on the CCC was involved in '*over 50 different events*'. Many positive women were also involved in pre-conferences and in side-meetings and events not directly related to the conference itself. And for a great number of positive women attending the conference, networking with other positive women, exchanging ideas and

updating themselves on issues were the focus of their participation.

Increasingly, however, ICW feels that these gains continue to be hard-won, when in fact they ought to, by now, be a given; GIPA[1], MIPA[2], MIWA, however you initial it, is an accepted rule of AIDS and related organisations. And yet, these acronyms are not always even spelt out, let alone put into practice.

Although HIV positive women are increasingly leading, or being represented, in sessions that address human rights issues and positive women's experiences, they may not have been so visible in more '*general*' or scientific sessions. The separation of the Global Village (GV) – both physically and in terms of programming – from the main conference forum is adding fuel to what is increasingly being seen as a deliberate side-lining of the community.

> *There were HIV positive women presenting in all the sessions I attended. Perhaps this was because of the nature of the sessions I attended, which focused on human rights and access to HIV services.* [Mexico City Conference Delegate]

Though numbers of younger people attending the conference and sessions that address the interests of young people have risen steadily, the visibility of young HIV positive women continues to be markedly low. In particular, there is a significant absence of HIV positive youth (under 18) for whom even attending the conference presents an additional layer of financial and logistical barriers, as people under the age of 18 are not permitted to attend without a guardian or chaperone, nor are they eligible to apply for a scholarship. Furthermore, despite the increased visibility of HIV positive women speakers and delegates, often, it is the same few positive women speakers representing in several different sessions. There is a conspicuous need to create spaces for new and young HIV positive women leaders to come through.

> *We need to let new faces and more women onto the surface not the same faces every time.* [Mexico City Conference Delegate]

> *I would have liked to see more young positive women and if possible more married positive couples who had the chance to have children and their experiences with that challenge.* [Mexico City Conference Delegate]

…a few positive women appear in an overwhelming number of sessions and meetings, risking burn-out and illness by the end of the conference…

> *I think that in this conference there was a greater participation of women than in other conferences, and women's themes were more on the agenda than in other conferences. However, I think that we need greater participation of positive women in sessions.* [Mexico City Conference Delegate]

Civil society organisations (networks, NGOs, bilaterals, etc) play an important part in facilitating the involvement of HIV positive women in the IAC, through a variety of means: consultations with positive women prior to the conference; representation of positive women's issues in sessions, posters and materials; report backs; by attending sessions that had positive women speakers and participating in ICW events; through partnering with positive women's organisations and networks; fundraising for positive women to attend the conference; ensuring that, wherever possible, positive women are present as presenters in their sessions; mentoring and giving support to women to apply for abstracts through workshops and outreach.

> *Most of the people I work with are positive African women[3]. I spoke to them about the conference before I went to the conference and they advised me on sessions to attend and topics they wanted me to listen out for and report back to them (which I'll be doing on the 16th Sept). At the conference, I attended sessions where I heard from positive people – they challenged me, inspired me and motivated me in my work.* [Mexico City Conference Delegate]

> *We conducted a process of outreach and mentoring to support women with HIV to present their work as abstracts and to apply for scholarships.*

This involved a 'hands on' workshop on abstract writing and helping women to write up their abstracts, abstract review, translation, and help with inputting the data into the online IAS system. [Mexico City Conference Delegate]

Challenges in supporting the greater involvement of HIV positive women include communications – especially where women do not have regular access to the internet. Stigma and discrimination also constitute a challenge to involving positive women in places where fewer women feel able to disclose their status. Women living with HIV may simply not make themselves known for consultation.

We are ready to involve positive women in our work and in our association. It would be great pleasure and honour for our association but in our area there are not positive women. Usually in my country women keep their status in secret. [Mexico City Conference Delegate]

The impact of positive women's involvement at the IAC

The main impact of positive women's involvement at the IAC is the raising of positive women's visibility – including young HIV positive women, and therefore also raising awareness of positive women's issues with conference delegates, and in some instances, with specified target audiences (e.g., the WHO); influencing the programme to be more inclusive of positive women and positive women's perspectives and experiences.

...[my] *involvement in the CCC was to ensure the meaningful inclusion of positive women on all the committees and at least one positive woman to speak in plenary session.* [HIV positive woman, Mexico City Conference Delegate]

Positive women feel that their participation at the IAC has the effect of encouraging, motivating and inspiring other positive women (both at the conference and those that do not attend, through report-backs, newsletters, blogs and other internet-based forums during and immediately after the conference) in areas of disclosure, accessing appropriate treatment and care, positive living, and leadership; providing lasting resources that other positive women can use in their (advocacy) work; networking and establishing connections with other positive women and sharing experiences.

Positive women tend to feel that what they learn at the conference will be shared with others when they return home. However, the very small (relative) number of people living with HIV attending the conference remains problematic in terms of representation and ways for reaching, influencing and representing those who do not attend, need to continue to be explored and experimented. Research needs to be done on how, or whether or not, women living with HIV who did not attend the conference take an interest in, follow or learn from the conference at all and to what extent.

…women living with HIV may simply not make themselves known for consultation…

The IAC is a useful forum for forging new and strengthening old partnerships, which positive women feel will benefit their networks and organisations. For women, participating in global conferences for the first time, the issue of meeting other positive women and hearing how women all over the world have faced and dealt with similar challenges to their own, continues to be, for HIV positive women, one of the most powerful impacts of attending an International AIDS Conference.

I think that the most important thing when women participate in conferences like this for the first time is that they can find and share the experience with other positive women, that they feel that they are not alone, that they see that things are difficult but that it is possible to enjoy a good quality of life and that they have to learn how to get their rights valued. [HIV positive woman, Mexico City Conference Delegate]

However, the manner and shape of the involvement of positive women and men at the AIDS conferences reflect the ways in which people living with HIV, are

and are not, involved in responses to HIV and AIDS in general: prominent in some areas, but basically under-resourced and sidelined to certain activities.

> *It has made me see the global architecture as a whole and see more clearly the role that people living with HIV have and do not have. I see that the AIDS response is sometimes more of a business than a humanitarian effort and that people that are HIV + are incidental to the bottom line, that resources are often not going to where they should go or are needed most. The conference helps me to see this more clearly. It is a microcosm of the industry as a whole.* [HIV positive woman, Mexico City Conference Delegate]

The IAS

The International AIDS Society (IAS) is the custodian and principle organiser of the International AIDS Conference (IAC) and the Conference on AIDS Pathogenesis, prevention and treatment, both of which are held on an alternating biennial basis. As sole underwriter of the IAC, the IAS leads the Conference Coordinating Committee (CCC), made up of IAS members, international partners, regional/local partners, co-chairs of each of three Programme Committees (Leadership, Scientific and Community) and UNAIDS. The CCC is ultimately responsible for the theme, vision, policies and programme of the Conference; and the role of Programme or Track committee members is to plan and execute respective programming within the Conference and to advise on issues pertaining to each programme within other areas of the conference.

The IAS supports the involvement of the international partner* members of the CCC through provision of a conference package, consisting of a conference co-organiser fee (full fee = $50,000), a satellite session space, press conference space, booth, 20 free registrations, office space and press office space/media booth. For the first time, in 2008, the international partners were also eligible to apply for a pre-conference outreach package to enable consultation and capacity building among constituencies of the networks and organisations that make up the CCC. Further, the IAS carries out its own outreach specifically within the host community, and positive women are one of the targets of its local outreach programme.

In addition, the IAS provides scholarships. For the Mexico City conference, 9757 scholarship applications were received, and 854 scholarships were eventually awarded (8.8% of all applicants). Of these, 903 applicants self-identified as HIV-positive women, of whom 77 were offered a scholarship (8.5% of positive women scholarship applications and 9% of the total awarded scholarships). Of the scholarships awarded to HIV positive women, 47 were full scholarships (of a total of 369 full scholarships offered; 12.7%) It should be noted however, that not all applicants request a full scholarship and that disclosure of sero-status on the application form is entirely optional.

A further source of support is the provision of the People Living with HIV lounge during the conference. This is a space for which entry is restricted to HIV positive delegates, and where comfortable seating and free food is provided. Several of the respondents to the ICW MIWA report card said that they found this space a valuable resource, affording rest and respite while at the conference.

> *The positive lounge provided a most welcome respite from the hustle and bustle of the first ever IAC I was attending.* [HIV positive woman, Mexico City Conference Delegate]

*For Mexico City 2008, the international partners on the CCC were ICASO, World YWCA, Asian Harm Reduction Network, and ICW/GNP+. (ICW and GNP+ shared a seat)

Overwhelmingly, non-positive women respondents felt that hearing a positive women speak on issues affecting positive women was real, moving, inspiring, powerful and brought insights to the issues that otherwise would or could have been missed, including gender-specific insights. The challenge is to extend this beyond the walls of the conference proper.

> *It breaks the silence which too often affects women in every country, North and South. I appreciate the gender-specific insights that women bring to the discourse, and the naming of particular issues that affect women living with HIV which too often are overlooked when the speakers are male, or are presented second-hand by women or men speaking 'on behalf of' women living with HIV.* [Mexico City Conference Delegate]

> *It moves and inspires me. I think that positive women are the most appropriate to explain the complexities of their own lives, their priorities, and to present and validate good practices in the response.* [Mexico City Conference Delegate]

The presence of positive women also made delegates more determined to ensure that they start or continue to involve positive women more meaningfully in their own work, and also brought a new or different meaning and reflection to their work.

> *I think after hearing their views, seeing them in the discussion I am more inspired to work with HIV+ women in my own country.* [Mexico City Conference Delegate]

> *I was extremely happy to hear the issues affecting these women so I can review my ways of working with them so as to really address their issues properly.* [Mexico City Conference Delegate]

Barriers and Challenges to greater or more meaningful involvement

Nevertheless, many barriers still remain to a greater, more meaningful, and yet, more fruitful involvement of HIV positive women in the international events of this scope and scale. The main impediment to positive women's participation at the conference as delegates was lack of funds and financial support through scholarships. Some women also had abstracts rejected, and felt that they were not given the opportunity to contribute in meaningful ways, because spaces for doing so were not made available. It was felt that there was a need for more positive women in the programming committees, and also that more time, mechanisms and structures are necessary to ensure wider consultation with and between networks – so that those representing on committees would have ample opportunity to consult with broader networks of positive women, so that there could be greater dialogue and linkages between positive women and men representing on different committees and tracks. Also the conference organisers should work with the host government to ensure more involvement from, and engagement with, the host community and, particularly, that more positive members of the host community are able to attend the conference.

…the dearth of young HIV positive people was particularly noticed…

Conference attendance

For the vast majority of women living with HIV attending an International AIDS Conference is impossible. Language and technology barriers will prevent most HIV positive women from applying for a scholarship. The fact that abstract and scholarship submissions have to be made on-line and in English (or another official conference language depending on which country is hosting the conference) automatically excludes most HIV positive women. And even for those who are able to apply for and receive a full scholarship, financial barriers – opportunity costs, childcare and other logistical considerations – may prevent them from being able to take it up. Further, already marginalised groups of positive women, such as young positive women, positive women with other disabilities, or socially marginalised positive women, such as sex

workers, drug users, migrants and prisoners, are even less likely to have access to the necessary resources to enable attendance.

Further challenges, such as the difficulties obtaining a visa, and travel restrictions for people living with HIV, provide additional barriers to attendance. And once at the conference, language can continue to act as a barrier to meaningful participation, as well as the overwhelming size and nature of the conference itself for women who are not used to this kind of environment.

> *My case was not like the majority of women, but many of them had problems with visas, since the standard letter of invitation on the conference website often wasn't enough. As for the registration via Internet, there were a lot of difficulties getting on to the webpage and with how slow the webpage was. A lot of people are not used to filling in forms on the internet. These conferences are supposed to enable participation, not exclude them.* [HIV positive woman, Mexico City conference Delegate]

At the Mexico City conference, the dearth of young HIV positive people was particularly noticed, and especially the particular challenges facing under-18 youth, who are only permitted to attend with a chaperone. To apply for a scholarship the applicant must be 18 years old or above.

> *Now we need more young positive women – there was a huge gap here!* [HIV positive woman, Mexico City conference Delegate]

Participating as a presenter

Similar challenges face positive women who wish to participate in the conference as a speaker or presenter. Abstracts have to be written in English and submitted via the internet. Abstract-writing is a skill that many women will not be familiar with, and without knowledge of the process it is hard to guess what the abstract reviewers will be looking for. The fact that almost any involvement is done on a voluntary basis – i.e., may mean sacrificing other sources of income – can prove challenging.

Positive women are often approached to speak in sessions organised by other organisations or delegates, but often this is on the condition that they have already received funding from elsewhere, which partly accounts for the fact that a few positive women appear in an overwhelming number of sessions and meetings, risking burn-out and illness by the end of the conference. This situation is exacerbated by multitudes of last-minute requests for positive women speakers and input; conference and global village programmes are finalised as little as a month before the start of the conference, and individuals' and organisations' schedules tend to be subject to changes right up to the eleventh hour. This makes it very difficult to bring in extra speakers even when (as rarely happens) resources are available.

…barriers still remain to a greater, more meaningful, and yet, more fruitful involvement of HIV positive women…

Involvement in the conference coordinating and programming committees

Having positive women on the conference coordinating committee (CCC), track or programme committees (PCs) definitely serves to increase avenues of involvement and impact in other areas of the conference – through lobbying for positive women speakers and inclusion of certain issues and sessions. Women and men living with HIV participate in these committees on the same terms as other committee members (and in fact are not required to disclose their sero-status in the selection process or at any other time). However, this kind of involvement needs to be supported by local, regional and/or international civil society mechanisms, networks and constituencies, if not, it becomes both unsustainable for the individuals involved and meaningless for the wider constituency they represent. Furthermore, the work put into the conference committees is done on a voluntary basis, and – depending on how far committee members have to travel – can result in fatigue and burnout long before

ICW at the IAC

ICW has been a co-organiser of the International AIDS Conference since the conference was held in Durban in 2000. Our foremost aim has been to increase the participation and visibility of HIV positive women in this, the largest forum dedicated to issues around HIV and AIDS.

At the Mexico 2008 AIDS Conference, ICW highlighted the following issues:

- Violence Against Women – discussed at the ICW/ ATHENA satellite
- Using the law to protect HIV positive women's rights, including when they are coerced to be sterilised
- Exploring why MIPA does not always work for us
- Putting women back into the gender debate
- The impact of criminalisation on HIV positive women

Many of our members spoke on these areas and others such as ACTS and SRHR in the main conference and in the Global Village. In the latter arena we helped organise and run sessions in the People Living with HIV Networking Zone with GNP+, and the Women's Networking Zone (WNZ), with the ATHENA Network and other women's rights organisations. The ICW Booth, much larger this year than in previous years, in the Global Village gave a chance for ICW members to meet, stay in touch with what is happening of interest to HIV positive women at the conference, and collect new ICW materials.

ICW used our Satellite and Press Conference at the Mexico City to raise the profile of ICW's peace initiative – A campaign initiated by ICW Latina. Called *'2011 – A Year of Peace as a chance to stop AIDS'*, the campaign has been bolstered by ICW International Steering Committee member and long-time AIDS advocate, Patricia Perez's nomination for a Nobel Peace Prize.

At least 12 ICW members sat on the CCC and track/programming committees. Programme co-chairs are nominated and elected by members of CCC, and then form part of the CCC. Programme Committee members – some of whom kept in regular touch with other human rights and positive activists through organisations, such as the World YWCA and the ATHENA network, to ensure that they represented a diversity of views in their recommendations – are also nominated and elected by the CCC.

ICW was also a co-organiser of Living 2008, a two-day pre-conference for people living with HIV, which focused on four areas: criminalisation, sexual and reproductive health rights, access to care, treatment and support, and (positive) prevention, to develop and consolidate advocacy messages for delivery and the creation of a critical mass in the IAC. (Report now available.)

It is important to ICW, not only to encourage and support as many members as possible to apply to attend the conference, through abstract and scholarship application writing support, partnerships, and putting members' names forward as speakers and presenters; we also make every effort to ensure that the views of our members who do not attend the conference are adequately represented by those who do through pre-conference consultation, and that those who act as representatives remain accountable to the entire constituency through regular and accurate feedback of our conference activities. Funding provided by the IAS during the lead-up to the Mexico City conference was used to carry out out-reach, support and consultation with ICW members during the conference planning period. Other funds were used to support an e-consultation in preparation for Living 2008 and daily blogs through our e-forum back to non-attending members on a daily basis throughout the conference. An issue of our regular quarterly newsletter is dedicated to what ICW achieved at the 17th International AIDS Conference, thus, providing a snapshot of the conference experience to non-attending members as well as raising crucial issues for debate that were prominent conference discussions.

the conference takes place. In addition, participation in the actual conference is not guaranteed for organising committee members. One ICW member from Namibia who sat on the leadership programme committee for Mexico City, was so exhausted from the four trips she had taken over the course of the 18 months she sat on the committee – travelling for up to 40 hours (including transfer times and layovers) in each direction, that, even being awarded a full scholarship, she decided not to come. Her scholarship, however, was not transferable. She was unable to pass it on to another ICW member to come in her place and represent the work she had done, while others who had sat on track committees had to source their own funding support to enable them to attend the conference.

For a member of the CCC, 5-6 meetings take place during the two-year preparation period of the IAC, and for representatives sitting on programme or track committees 4. Individuals applying for these positions need to have the support of the organisation or network they work for, and for this work to be part considered of their remit. Even under these circumstances, positive women sitting on the committees have found themselves at sea among more experienced or '*in-the-know*' others, feeling isolated and voiceless. One ICW member who sat on the leadership committee reported that it was easy to feel '*overpowered*' by committee members with more experiences, and that women's issues tended to be the last to be considered**.**

Committee participants and chairs need to feel confident that they have the backing of their constituency behind them, yet broad consultation – especially at an international level – within positive people's networks can prove financially and logistically beyond the reach of the organisations or networks sending representatives to the table. Decisions are made on the spot and at high speed, and for those who are not ready with their constituents' needs and recommendations, the opportunity to influence programmes, sessions and key themes and messages is quickly lost.

> *Being on the committee for Track D meant that I was able to appoint various positive women to chair or present on various sessions; and even to create sessions (including two non-abstract driven sessions – one on social reproduction and one on conflict and HIV) which included positive women.* [HIV positive woman, Mexico City Conference Delegate]

...positive women sitting on the committees have found themselves at sea among more experienced or 'in-the-know' others, feeling isolated and voiceless...

> *There is always scope for improvement in the way we do things. Often our involvements in this mechanism are not well planned and do not reflect in our work plan or sometimes we underestimate our role and the time commitment involved. My impact could have been greater if I have had enough time to consult other Positive women to enhance the processes- often these meetings are held in rush and do not give us adequate time to consult others...this is frustrating at times...lack of adequate or appropriate mechanisms to consult is also an issue for us.* [HIV positive woman, Mexico City Conference Delegate]

In 2006, following the 16th IAC, held in Toronto, Canada, the structure of the CCC was changed so that, whereas in the past, the two main international networks of HIV positive people (GNP+ and ICW), and ICASO, an international network of AIDS service organisations had held a seat each on the CCC, from now on it was agreed that they would only hold two between them, of which the two positive people's networks would share one, to allow for more civil society participation from other organisations.

> *The decision that ICW and GNP+ should share a seat was taken…on March 6, 2006. That was after the Future Direction consultation where most stakeholders that had an opinion on the issue – especially NGOs and activists – thought*

> *that it shouldn't be the same three civil society partners for all conferences. The conclusion of that consultation, which all international partners agreed on, was to let two new Civil Society partners in as partners[4] and keep the three old ones on two seats.* [Member of the IAS]

...the community has unwittingly extracted itself from the conference proper, and is now becoming confined to the Global Village, where there is also a danger of its becoming 'ghettoised'...

Though this decision was approved by members of the CCC including ICW, the ICW representative states that to retain any involvement at co-organiser level '*there really was no choice in the matter*'. From 2006 to the Mexico City conference in 2008, ICW and GNP+ therefore shared a seat on the CCC whereas in previous years they had each occupied their own seat. The arrangement remains the same with one of the two civil society partners rotating on and off the CCC, every other conference, (the Caribbean Drug and Alcohol network replacing the Chiang Mai-based Asia Harm Reduction Network post Mexico City), and the two positive networks sharing the one seat from now until Vienna (2010). Thereafter, the future involvement of the international positive networks in the coordination of the IAC remains to be seen.

Many positive activists feel that this move undermines the GIPA principle and reduces rather than enables the participation of men and women living with HIV. For ICW, this decision has impacted on our ability to influence the conference in a number of ways. Primarily having only half a vote meant that ICW has needed to shout even louder than ever to be heard. This meant that ICW nominations or votes (e.g., for programming committee chairs/members) and priority areas for the conference agenda carried less weight. Next, the IAS awarded ICW half the amount of funding to bring members, staff and activists to the conference than we had received in previous years, with the result that ICW was only able to support six women to attend the Mexico City conference, and had fewer available resources to allocate to communications and materials development and distribution both prior to and during the conference.

> *ICW's lack of influence on the Conference Coordinating Committee and the apparent squeezing of positive people's organisations on that committee* [has meant that] *ICW did not have enough funds to get people to the conference.* [HIV positive woman, Mexico City Conference Delegate]

> *The IAS has limited PWAs involvement in the IAC at the top: on the CCC our vote was cut in half and resources that used to be shared with us are no longer shared.* [HIV positive woman, Mexico City Conference Delegate]

Conference or Global Village?

There is the beginning of a sense that the community is being side-lined, especially with the separation of the Global Village space, and a greater interest from the IAS in the scientific and leadership tracks. Since Durban in 2000, the creation and growth of the Global Village as a '*community*' space – both in the sense of its accessibility to the local community, and in the sense of a space for discussing issues pertaining to the people living with HIV community – has attracted rights activists and more controversial and rights-focused topics, than the main conference. Many NGOs, community-based organisations, networks and '*identity*' groups have found that the Global Village provides a more inclusive and accepting space in which to organise, and to give voice to the experiences, realities and aspirations of specific groups, where these have traditionally been missing from the main conference. To an increasing extent these organisations and activists have focused attention and energies on the Global Village, rather than the main

conference forum. However, it is beginning to be felt that the community has unwittingly extracted itself from the conference proper, and is now becoming confined to the Global Village, where there is also a danger of its becoming '*ghettoised*'.

> ...[t]*he GV is becoming more intentionally programmed, though this carries both benefits and drawbacks. On the one hand, it is a very vibrant and well-programmed space, but as it becomes that, it also runs the risk of functioning as a parallel conference – making it, perhaps, easier to direct some kinds of conversations to the GV, when those should be reaching the entire AIDS conference audience.* [Mexico City Conference Delegate]

...there is a need...to ensure that the Community, Leadership and Scientific programmes speak to each other and develop united rather than separate responses to emerging themes...

There is need to ensure greater interlinking, dialogue and reflection of issues between the different tracks and better communication between and among networks of people living with HIV and their supporters where they have members sitting on different track committees to ensure that the Community, Leadership and Scientific programmes speak to each other and develop united rather than separate responses to emerging themes and priorities. If the Community track continues to be – or be perceived to be – located within an increasingly separated-off Global Village area, there is a danger of community issues being (seen as) completely de-linked from those pertaining to the leadership and scientific tracks.

> *The IAC is a well-oiled machine. As the IAC is now run by the IAS, which is a professional organization for Researchers, Scientist and Doctors it is definitely biased to serve that constituency and has set up structures, systems, and processes to keep community at bay.* [HIV positive woman, Mexico City Conference Delegate]

> *There is no longer any tension between community and science – the cord has been cut between them.* [HIV positive woman, Mexico City Conference Delegate]

Related to this is the attitude and political will of the conference's host country government. Community members of the host country/city are eligible to take part in the conference on the same terms as everyone else – in other words they have to pay what is, for most people, a prohibitively high registration fee (of approximately $800 US). Entrance to the Global Village, however, is free. The Global Village plays an important role in bringing to the host community elements of the IAC, yet increasingly, rather than providing a reflection of the IAC as a whole, the Global Village constitutes only the '*Community*' programme and this is played out in competition with cultural and performance sessions meaning that the speakers taking part in global village dialogue sessions often have to fight with rock bands to be heard, while the '*serious*' sessions in the main conference are free to take place undisturbed.

> *From the evaluations that we collected, the most important problem was noise – we would suggest either programming 'quiet times' in the GV or exploring with hosts of zones and booths what they want to do, so that you can place groups who want to hold dialogues and people who want to have music all the time far away from each other. Another option would be to restrict sound equipment in the GV. At the very least some kind of noise guidelines should be provided to participants.* [Mexico City Conference Delegate]

> *Government' lack of commitment to ensuring the participation of more PLHIV* [is the main barrier to GIPA]. *Another barrier is the low number of scholarships that were awarded to the community sector and the lack of local participation, since in this case the local community had to pay*

their registration at the same price as other participants. I think this shows lack of strategic vision from the conference organizers and host country, since more people from the local community would have participated and this would have value added for the host country. [HIV positive woman, Mexico City Conference Delegate]

Recommendations for increasing the visibility, capacity and meaningful involvement of HIV positive women in the IAC

Outreach/pre-conference support

- The IAS can increase their support to ICW and other HIV positive women's networks, so they can work with HIV positive women at country level from an early stage in the conference preparations. This can ensure that HIV positive women are involved by adopting the following measures:

  They[5] should first work with women in the country. ICW representatives should do this work, with logistical and economic help.

...the real experiences and activities of positive women featured last – after all the other speakers. This could come across as tokenistic...

  There should be a one year campaign before the conference to motivate women and to apply and start fundraising early for attendance costs.

  - Identifying and preparing messages that they want to be heard at the conference;
  - Identifying and mobilising representatives of their networks to attend and are supported to participate in sessions, e.g., registering for the conference, writing abstracts, preparing speeches, linking with international NGOs.

  Maybe, ask within your network, if any women know any influential women living with HIV, so that these individual(s) can attend the next conference. People have a tendency to listen when they know the person or feel as though they know the person. We have to feel a personal connection with the speakers.

  - Helping networks consult with their members to ensure that their voices are fed into developing the conference content, feedback to their membership the important issues that were presented at the conference and to independently monitor MIWA.

  Resources need to be targeted to allow greater outreach to HIV positive women from the grassroots, from marginalised groups, such as young HIV positive women, injecting drug users and sex workers and from harder to reach places.

Conference attendance

- A greater number of scholarships must be offered to HIV positive women, especially HIV positive women from marginalised groups.
- The IAS could help to source alternative resources available to HIV positive women and men who do not receive a scholarship.
- The registration process needs to be simplified and expanded so that more than just internet technology can be used to register (e.g., SMS messaging; phone and written registration); and stagger abstract, scholarship and early registration dates so that applicants can find out earlier whether or not they have been accepted for scholarships – early enough to still meet early-bird registration deadlines or source alternative funding.
- The IAS, CCC members and other civil society organisations need to work with positive networks at international, regional and national levels to encourage positive women and men to register early.

Speakers/sessions/tracks

- The IAS can give greater support to ICW to identify and support HIV positive women speakers.

The World YWCA and ATHENA

Since 1855, the YWCA has been at the forefront of empowering women and girls who advocate for their rights and lead social, political, economic and civic change. Today the YWCA reaches more than 25 million women and girls in 125 countries, providing them with the space and skills to develop leadership for the benefit of entire communities. The YWCA's purpose is to develop the leadership of women and girls around the world to achieve human rights, health, security, dignity, freedom, justice and peace for all people. In the early 1990s, the World YWCA began responding to HIV and AIDS, recognising the potential to affect change as one of the largest organisations for women and girls worldwide. At the heart of the World YWCA's global strategy is to mobilise the leadership of women in local villages and communities in response to HIV and AIDS. With a membership and outreach of millions of women and girls, this is where the YWCA makes the greatest impact in responding to the needs of people infected and affected, and in halting infection rates.

The World YWCA began a fruitful partnership with ICW in 2003, which has brought an unprecedented scope to ICW's work, initiated through a series of internships at the World YWCA head office in Geneva and at ICW's International Support Office in London and the East Africa Regional Office in Kampala. In 2007, the World YWCA held a ground-breaking International Women's Summit on Women's Leadership on HIV and AIDS, including a one-day Positive Women's Forum in partnership and co-organised by ICW which was exclusively for HIV positive women, with the result that HIV positive women made up approximately a quarter of the total participants in the Summit. The World YWCA and ICW have continued to work in close partnership through their involvement in the CCC and programming committees for AIDS 2008, strengthening each other's ability to influence the conference programme and ensure that themes affecting women, young women and HIV positive women in particular were captured in the conference agenda.

ATHENA is a network of individuals and organisations including activists, people living with HIV networks, NGOs, CSOs, community based organisations, academics and others with an interest in promoting the sexual and reproductive health and rights of women (and men) living with HIV; linking the gender, human rights, SRHR, and HIV communities; and providing a platform for HIV positive women's voices. The network was born out of the *Mujeres Adelante* movement of positive women and their supporters at International AIDS Conferences, starting at Durban in 2000. Amongst other on-going work in raising and advocating around SRHR and HIV/AIDS issues, the IAC remains an important site of ATHENA activity and activism. Since the Toronto conference in 2006, much of this work has been brought together in the nexus of the Women's Networking Zone (WNZ). Located in the Global Village, the WNZ represents a flexible partnership of global and local women's organisations, some of whose participants come together for the specific event, while others form the corner stones of the ATHENA network and help to link one conference to another through, and in addition to, work that takes place in between. The WNZ creates a space for women, and in particular women living with HIV, to caucus and dialogue amongst themselves and with others, but in the knowledge that this is our space; to bring to light emerging issues, share cross regional dialogues, move forward discussions about contentious issues, and to apply an experiential and feminist/gender analysis to mainstream responses to the pandemic, the impact of which, on the lives of actual women, especially positive women, often go overlooked, due to their *'common sense'* public health appeal. The form and content of the WNZ is driven by HIV positive women through local and international networks, and priority is given in programming to sessions put forward by positive women's groups, or issues nominated or supported by positive women. In the 2008 WNZ

continued overleaf

75% of the sessions included at least one positive woman speaker.

This year for the first time ATHENA played a yet more influential role with regard to the organising and programming of the IAC. The World YWCA invited ATHENA to be part of their World YWCA Reference Group for AIDS 2008. The World YWCA was able to engage more substantively by having this reference group, which was made up of 6 different organisations .Through ICW and the World YWCA, and the co-chairs, ATHENA was able to provide a broader-based constituency to support the role of the CCC representatives, provide nominations for chairs of other track and programming committees to the World YWCA, and network to create alliances among other programme and track committee members. This was especially useful as the process of developing the agenda, choosing non-abstract-driven sessions and nominating chairs for abstract driven sessions unwound. The position of a CCC representative can be an isolating and disempowering one for women (and men) who lack the support of a broader constituency. At the same time, the reference groups allowed for greater accountability and transparency on the part of the individual sitting on the committee. This model also allowed positive women to move beyond identity politics towards an involvement based on their skills and knowledge, as well as that of other women, not necessarily living with HIV, by creating new alliances of strong women with specific areas of knowledge and expertise that includes the positive women's experience. Even with this successful model for collaboration, the need for the spaces positive women have carved out for themselves over the years remains critical and it is imperative to respect the history of these spaces, as well as their on-going use and value, and to ensure that they are not swallowed up by a more collaborative model of participation.

- Submissions by positive women and men, or positive people's networks, should be a criterion in abstract reviews.
- Make the involvement of HIV positive women (or men) speakers and/or facilitators a criterion for all plenary- and non-abstract-driven sessions.
- Make sure that positive women (or men) speak first in a session, not last.

  In some of the sessions I attended, the real experiences and activities of positive women featured last – after all the other speakers. This could come across as tokenistic. The same happened with Latin Americans – they were the last speakers. Conference organisers should ensure they are the FIRST speakers (while everyone is awake and alert)! Their contributions must be valued because after the conference, they are the ones heading back to support peers and lead in responding to the epidemic in their communities.
- Request that all keynote speakers are to apply a gender analysis to their presentation.

  If the issues they are addressing are different for women and men, this should be presented as standard.
- Have a (fourth) conference track dedicated to the life experiences of HIV positive people.
- Within the rubric of existing tracks, ensure dedicated inclusion of specific issues which are of particular relevance to the lives of HIV positive people (and positive people's perspectives on these areas), for example, the burden of care and criminalisation.

CCC and PCs

- More HIV positive women on non-community tracks and programmes (especially science) and better strategising between them and with HIV positive women's networks, starting earlier in the lead-up to each conference.
- Support for HIV positive women on all tracks and programmes, to develop a positive women's proposal addressing involvement and focus for each part of the conference.
- Support for HIV positive women on all tracks

and programmes via reference groups with strong positive network representation to ensure broader constituency participation

Additional measures to ensure that the conferences increase the visibility of HIV positive women and their issues

- A concerted effort needs to be made to increasing the links and create coherence between the global village and the main conference and different parts of the conference as a whole, both through ensuring that mechanisms exist for close dialogue between the different track committees, such that there is cohesion between the three programme tracks (Community, Leadership and Scientific), and that the coordinators of the Global Village are also more formally linked in to the programme tracks.

…a conspicuous need to create spaces for new and young HIV positive women leaders…

- Hold an HIV positive women's pre-conference or session, and ensure that information from such events is disseminated through to conference and to other delegates.

  I think that conference organisers could make one roundtable with positive women to express their hopes, sorrows or expressions of love; then to share these feelings with other participants.
- Provide HIV positive women only rest spaces.
- Profile HIV positive women and men in the conference newspaper, instead of focusing on the '*big names*'. The paper should also feature the work and views of HIV positive women's networks.

  In the newspaper that was distributed, the stories were of key figures at the conference or generic feedback from certain sessions. It would be great to profile stories of positive women in the magazine to hear about what is really happening on the ground (we'll probably learn that positive women are the most active in supporting their families and communities to respond to the epidemic).

Evaluation of the conference

- Include gender and positive involvement as indicators in the IAC evaluation. For example, all information about participation needs to be disaggregated, and, where possible, disaggregated by HIV status as well (number of scholarships, attendees, speakers/facilitators in sessions, positive women on CCCs)
- Conduct qualitative interviews with HIV positive women attendees (and positive women who tried and failed to attend) about their experiences of the IAC.
- Include gender and positive involvement as indicators in the IAC evaluation.

  Involve networks, such as ICW in key roles in organising the conference and monitoring the MIWA commitments.

FOOTNOTES:

1. Greater Involvement of People Living with HIV (GIPA).
2. Meaningful Involvement of People Living with HIV (MIPA).
3. The scholarship budget for Africa was 25% of the whole scholarship budget – a disproportionately low quota given the high prevalence of HIV in sub-Saharan Africa. ICW heard that African women were angry at how badly represented they were at this year's conference and at how their issues were represented by others speaking on their behalf (personal communications – ICW conference delegate)
4. ATHENA, International Women's Health Coalition, Women Wont Wait, Foundation for Studies and Research on Women, Ecumenical Advocacy Alliance, Youth Coalition.
5. In 2006. these were the World YWCA and the Asian Harm Reduction Network (AHRN). For the next two IACs, the Caribbean Drug and Alcohol Research Institute will take the place of the AHRN; the World YWCA will sit on the CCC for the second time in the lead up to Vienna 2010 in addition to the IAS, ICASO, and the shared GNP+/ ICW seat. After Vienna the World YWCA will be rotated off the committee.
6. Italics in this section indicate direct quotes from ICW's MIWA report card, distributed at and following the 2008 IAC in Mexico City

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We need supportive legislation, not criminalisation…

10 Reasons to oppose the criminalisation of HIV exposure or transmission

> *Responses to HIV should be based on evidence and human rights, not fear and stigma against people living with HIV*. [Craig McClure]

Responding to legislative trends towards the criminalisation of HIV transmission, a broad coalition of AIDS organisations have released the statement – **10 Reason to Oppose the Criminalisation of HIV Exposure or Transmission** – in December 2008. The *'10 Reasons'* emphasise various human rights and gender implications of criminalising the transmission of, and exposure to HIV, including deterring people from accessing HIV prevention, testing, treatment, care and support services; increasing HIV-related stigma, discrimination and violation of rights; as well as the fact that women are more likely to be prosecuted.

> *Criminalising HIV transmission will backfire and harm the very people it is intended to protect…the most vulnerable will surely be prosecuted, especially women who are routinely blamed for bringing HIV into sexual relationships*. [Jonathan Cohen, Open Society Institute]

> *Instead of oppressing women with criminal laws, governments should be passing laws that protect women from violence and theft of their property… women deserve real justice against gender-based violence and coerced sex, not criminal laws that will further victimise them*. [Michaela Clayton, ARASA]

The *'10 Reasons'* also highlight the potential losses for both public health and human rights gains, due to the passing and application of laws criminalising HIV exposure and transmission.

> *Criminalisation will impede our efforts to get HIV testing and treatment to those who need it most*. [Craig McClure, IAS]

The document also stresses the fact that there is no evidence that criminalising HIV exposure and transmission will, in fact, reduce new infections and/or decrease women's HIV risks and vulnerabilities – thus, it is less than likely that these legislative trends will have any significant impact on halting the HIV and AIDS pandemics.

The 10 reasons to oppose the criminalisation of HIV exposure or transmission are:

1. Criminalising HIV transmission is justified only when individuals purposely or maliciously transmit HIV with the intent to harm others. In these rare cases, existing laws can and should be used, rather than passing HIV-specific laws.
2. Applying criminal law to HIV exposure or transmission does not reduce the spread of HIV.
3. Applying criminal law to HIV exposure or transmission undermines HIV prevention efforts.
4. Applying criminal law to HIV exposure or transmission promotes fear and stigma.
5. Instead of providing justice to women, applying criminal law to HIV exposure or transmission endangers and further oppresses them.
6. Laws criminalising HIV exposure or transmission are drafted and applied too broadly, and often punish behaviour that is not blameworthy.
7. Laws criminalising HIV exposure and transmission are often applied unfairly, selectively and ineffectively.
8. Laws criminalising HIV exposure and transmission ignore the real challenges of HIV prevention.
9. Rather than introducing laws criminalising HIV exposure and transmission, legislators must reform laws that stand in the way of HIV prevention and treatment.
10. Human rights responses to HIV are most effective.

** The full document is available at www.aln.org/news or www.soros.org/health/10reasons.*

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