aLQ
AIDS LEGAL NETWORK

A Publication of the AIDS Legal Network **November 2006**

Felicity Harrison

HIV disclosure should be the norm…

Disclosing HIV Status: Prevention versus reality in South Africa

In many respects the approach to HIV and AIDS has been to repeat the same messages and promote the same strategies with the expectation of achieving different results. Given the extent of the infection rates and the impact on communities, it is clear that this approach has not worked and that new solutions are needed. One must, however, always be mindful of the consequences, especially the unintended consequences, which may arise from promoting alternative ways of dealing with the disease.

INTRODUCTION

One way to respond to the situation may be to place more emphasis on the need to disclose one's HIV status, as a means to educate and, thereby, prevent the further spread of the disease. There are many reasons that can be given to promote HIV disclosure, but it is also important to look at the realities of the South African situation.

In an ideal world, HIV would not exist and there would be no need to discuss these issues. In an ideal world, people would also have committed monogamous relationships, characterised by trust and communication. Given that we do not live in the ideal world and HIV is a reality, in a *'best case scenario'*, it would be *'the norm'* for everyone to know their HIV status and for people to be in the position to safely disclose their HIV status. Such openness would have a number of benefits, not least that knowledge of the disease and information could lead to prevention of the disease spreading.

Unfortunately, in South Africa we have neither the ideal, nor even the *'best case scenario'*. There are very real problems associated with living with HIV and disclosing one's HIV status.

ASSESSING THE SITUATION

When faced with such dilemmas, it is useful to remind ourselves of the principles that can be of assistance in coming up with solutions to the challenges facing South Africa. In responding to the situation, it is imperative that human dignity is preserved and respected at all times, while at the same time guaranteeing the rights of everyone.[1] It is important to remember that there is a human face to all of the statistics, and that people who are affected by the disease are infinitely valuable. Whatever solutions are explored, they need to be done in accordance with the recognition of the humanity and value of each person. At the same time, one also needs to bear in mind that people live in a community and that the common good also needs to be served. As so often is the case, one needs to look at balancing competing human rights, and the issue of HIV disclosure is no different. When considering whether or not to disclose one's HIV status, the right to

AIDS LEGAL NETWORK
Suite 6F, Waverley Business Park, Mowbray, 7700
PO Box 13834, Mowbray 7705, Cape Town, South Africa
Tel: +27 21 447-8435
Fax: +27 21 447-9946
E-mail: alncpt@aln.org.za
Website: www.aln.org.za

Editorial

…to be effective, HIV prevention programmes must address the context in which people live their lives… [UNAIDS 2005]

It is within the context of acknowledging the inadequacy of existing HIV prevention strategies, and recognising the need for effective HIV prevention strategies that this issue of the ***ALQ*** explores a variety of HIV prevention realities and challenges. The various articles in this edition examine a range of challenges to HIV prevention, as well as various realities in which HIV prevention occurs. Barriers to HIV prevention, such as stigma, culture, values and norms, the societal context, including the *'unsafe'* environment for HIV prevention and disclosure; the failure of HIV prevention strategies to cater for the needs of lesbian and gay people, *'the elderly'*, and people living with HIV; as well as the power of language are some of the issues explored in this issue. The integral features included in this edition of the ***ALQ*** look at HIV prevention challenges in Kabokweni, Mpumalanga; introduce various behavioural change communication strategies employed in the SADC region; and *'make a point'* about fertility desires of people living with HIV. This issue also includes a *'feedback'* on HIV prevention challenges, debates and insights from the provinces.

In this edition, **Felicity Harrison** examines the potential of HIV disclosure as one of the HIV prevention strategies. Exploring the pros and cons of promoting HIV disclosure, she argues that even though HIV disclosure should be the norm and *'best case scenario'* for effective HIV prevention, reality does not provide an environment in which people can *'safely'* disclose their HIV status.

Recognising the apparent failure of HIV prevention, **Johanna Kehler** raises the question as to whether or not HIV prevention strategies and messages coincide with the societal context in which prevention occurs. She examines various barriers to HIV prevention and argues that as long as HIV prevention strategies and messages fail to take into account people's lives and are not based within the context of behavioural change, stigma will continue to be the main barrier to HIV prevention.

The accessibility of HIV prevention for lesbian and gay people is discussed by **Fikile Vilakazi.** Analysing lesbian and gay people's prevention needs and experiences in accessing prevention methods, she argues that existing HIV prevention strategies not only exclude lesbian and gay people, due to the failure to encompass the diversity of sexual behaviour, but only ensure that lesbian and gay people remain to be the *'others'*, who are on the fringes and margins of society.

Acknowledging the *'power of language',* **Derrick Fine** examines how language, and being seen as *'different'*, impacts on attitudes and actions around HIV prevention and treatment. He analyses the change from the *'stigmatising stain of language'* and its influence on HIV and AIDS communication in South Africa to *'the power of positive language'* and argues that using positive, affirming language around HIV is not about political correctness, but about shifting attitudes, beliefs and policies.

In view of growing HIV infection rates amongst *'the elderly'*, **Emma Harvey** explores whether or not HIV prevention strategies are reaching people over 50. Looking at the considerations given to people over 50 in HIV prevention and exploring the existing stereotypes and myths about *'the elderly'*, she argues that people over 50 remain largely invisible and ignored in HIV prevention strategies, due to age-related stigma and discrimination.

The need for adequate and accessible prevention of mother-to-child transmission programmes is addressed by **Busisiwe Maqungo**. Reflecting on personal experiences with both the lack of, and the availability to, PMTCT programmes, she argues that PMTCT is an imperative for realising the constitutionally guaranteed right to life.

The need to address influences that taint HIV prevention messaging is highlighted by **Mduduzi Mthembu**. Looking at gender, gender violence, culture and norms, as well as stigma and prejudices as some of the factors influencing the *'success'* of HIV prevention messaging, he argues that effective HIV prevention strategies need to cater for everyone and promote values of unity, instead of diversity.

Suzanne Leclerc-Madlala analyses the sociological and gender context of HIV prevention in Southern Africa. Identifying various influences contributing to this context, she discusses custom and tradition, historic processes and modern trends; and argues that the sociological and gender work required to make a real impact on HIV and AIDS in the region is nothing short of substantial.

The challenges facing HIV prevention programmes in Kabokweni, Mpumalanga are introduced by **Sipho Fakude**. Discussing some of the realities and experiences

continued on page 4

privacy needs to be weighed up against the obligation not to harm others, nor to infringe on the rights of others.

DISCLOSING HIV STATUS

In a *'best case scenario'* there would be an enabling, supportive environment in which people with HIV could safely disclose their status. It is known that where such conditions exist, disclosing one's HIV status can be beneficial to both the person living with HIV, their families and the community at large. The operative words here are *'can be'*.

In the *'best case scenario'* it would be *'the norm'* for people to disclose their HIV status. But such a scenario presupposes a number of things. It assumes that a safe environment exists in which people can make such a disclosure. Following from this is the notion that there is a supportive family and social context within which a person would be in the position to get the medical, emotional, social and spiritual assistance needed in order to deal with the challenges of living with HIV. These things, however, are noticeably absent to many in South Africa, where inequalities, imbalances, stigma and discrimination exist and all impact on the decision of a person whether or not to disclose her or his HIV status.

Because of the complexities of the situation, it is important to look at individual circumstances when assessing if one should disclose one's HIV status or not. One needs to weigh up the positive benefits of disclosing against the possible negative consequences of doing so.

In the case for disclosing:

> *What Liziwe is saying is that her community knows that she [has] HIV, because she disclosed to them, but they don't believe. And they knew how she was before she was sick, but because she is well they don't believe any more. She doesn't understand why someone with HIV must have horns or … look different.*[2]

In a study[3] looking at the impact of HIV disclosure, one of the participants gave the following as a reason for disclosing her HIV status: *'I wanted him to be careful about HIV and get tested…'*[4]. Other participants indicated that they disclosed their HIV status when they became increasingly ill and family members, who are also their care-givers, needed to know about their status in order to care for them, and where appropriate, to take measures to prevent their risks of becoming infected with HIV. In other instances, people felt the need to disclose their HIV status, because the people around them did not know very much about the disease or they were misinformed about HIV and AIDS. There was a desire to educate the people around this issue.

In looking at HIV prevention strategies, it is important to look at the positive benefits that disclosing one's HIV status can have. If someone discloses to their household that they are infected with HIV, it expands awareness of the disease to others, who are then in the position to take the necessary measures to protect themselves from being infected. Information about the disease and knowledge are vital to HIV prevention. There is a conspiracy of silence in South Africa, where ignorance and lack of understanding are the source of much prejudice and discrimination. While disclosing one's HIV status is not the panacea for these maladies, it is an important step to assisting in finding their solutions.

FACING REALITIES

As was noted above, the situation in South Africa is far from the ideal. People who disclose their HIV status are opening themselves up for ridicule, rejection, ostracisation and alienation from their families and from their communities.

It is assumed by many that if someone is infected with HIV that that person is promiscuous and that somehow contracting HIV is a *'just punishment'* for their behaviour. Women in particular face moral judgement, which is coupled with gender and cultural perceptions that see women being blamed for not only contracting the disease, but also for spreading it to others. In addition, there are some people or communities, who blame people living with HIV for a host of other social misfortunes. In such a setting, it is understandable why people would choose not to disclose their HIV status.

...there is a conspiracy of silence in South Africa, where ignorance and lack of understanding are the source of much prejudice and discrimination...

This vulnerability has at times been compounded by the rejection and ostracisation of people within their families and households. Significant relationships have

continued from page 2

from a service provider's perspective, he argues that for HIV prevention to be successful, personal attitudes and behaviours need to change before HIV prevention strategies and programmes can be rolled-out into communities.

Behaviour change communication strategies, as a means to help young people *'avoid HIV and AIDS',* are introduced by **Kent Klindera**. Analysing the successes and obstacles of various strategies and programmes in the SADC region, aiming at behaviour change amongst young people, he argues that the *'key to success'* in effective youth specific behavioural change communication strategies lies in multi-faceted programmes with consistent messaging that involve young people.

Discussing fertility desires and sexual and reproductive health needs of people living with HIV, **Dorothy Odhiambo** is *'making a point'* about the lack of considerations given to these desires and needs at policy level, programme design and service provision. Exploring some of the obstacles experienced in accessing services, she argues that it is of utmost importance for policies to be explicit about, and inclusive of, sexual and reproductive health rights of people living with HIV, so as to prevent the violation of rights.

Irrespective of which one of the many HIV prevention realities and challenges have been examined, there seems to be the commonly raised question as to why HIV prevention does not seem to work, does not seem to prevent new HIV infections, and does not seem to protect people, who are vulnerable and at risk, of HIV infection. While the answers may vary in approaches and *'targets',* common is a call for *'change'* towards effective prevention strategies and programmes, which are, indeed, responding to people's prevention needs and which are applicable to the lives of people in need of HIV prevention.

Some may argue that HIV prevention messages need to *'change'*, so as to cater for the needs of a specific *'target group'* and/or that the *'target group'* need to *'change'* so that HIV prevention messages can work. Yet, others may argue that effective HIV prevention strategies and programmes are about *'change'* – not *'change'* in *'target'* and/or *'message',* but *'change'* in the environment, internal and external, in which HIV prevention occurs; *'change'* in attitudes and *'mindsets';* and *'change'* in behaviour. Whatever the preferred *'target of change'*, the common challenge seems to be the individual and collective *'reluctance and resistance to change'* – based on, justified by, and excused with, the well recognised 'barriers' of culture, religion, value, norm and belief systems and *'that's the way it is',* leading to stigma and its subsequent discrimination.

If we are to agree that there is a dire need for *'change'* towards effective HIV prevention, then there is a need to acknowledge that HIV prevention strategies and programmes can, and only will be, effective as and when *'targeted'* at people. Not, because people are of a certain age, profession, mobility and/or sexual orientation, but because people are sexual beings. Only as and when we understand the *'target group'* to be people, who are sexual beings, and who live lives filled with diverse contexts, desires and needs, will we be in the position to understand prevention needs and begin to develop and implement HIV prevention strategies and programmes that are responsive to the context in which prevention occurs.

So, if we are to *'remove the barriers'* to HIV prevention, so as to ensure that HIV prevention is accessible, available and beneficial to everyone, and that HIV prevention *'addresses the context in which people live their lives',* then there is a need to *'change'* and *'change'* then seems imperative to HIV prevention. A need to *'change'* existing concepts of *'prevention needs'* and perceptions of *'how people live their lives'*; a need to *'change'* understandings of *'risky behaviour'* and *'high risk groups';* and a need to *'change the unsafe environment'*, filled with stigma, marginalisation and exclusion of *'the other',* into an *'enabling environment'* of inclusion and respect of *'the other'.*

Besides a need to *'change the external environment',* there is an equally dire need to *'change the internal environment'*, the *'people'*, who sustain and maintain the *'external'*; a need to *'change us'*, as people who create *'the other'* and are part of *'the other'*; as people, who *'target high risk groups'* and *'address high risk behaviour',* while being at *'high risk'* through engaging in *'high risk behaviour'.*

Only as and when *'change happens'* at both levels, will HIV prevention strategies and programmes finally be in the position to offer *'real'* options of prevention. Thus, until we *'change the barriers'* preventing prevention, *'change people and people's lives'* upholding the very same *'barriers'*, and *'change us'*, HIV prevention efforts will continue to fail, remain *'meaningless'* and provide no real means of preventing the risk of HIV infections – neither for *'the other'*, nor for *'us'*…

JOHANNA KEHLER

been terminated as a result of disclosures made about HIV status, and this has resulted in some instances of people infected with HIV being kicked out of their homes. Others have experienced loss of emotional and financial support and/or verbal and physical abuse.

In addition to this is the fear of revealing one's HIV status for fear of the implications that this may have on one's job. Fears range from being overlooked for promotion to being fired: *'people fear that if they come out, they will be ostracised, overlooked for promotion and their jobs may be at threat' and 'when other workers see this happening it heightens their own fear'*.[5]

...people have the task of weighing up the consequences of disclosing against those of not disclosing – in some cases it amounts choosing the better of two bad situations...

Community and individual perceptions are often shaped by a host of misunderstandings coupled with gender, cultural and moral judgements, and a general lack of understanding of HIV and AIDS. In an environment, far from HIV disclosure leading to education about, and prevention of, the disease disclosing one's HIV status can place people in an even more vulnerable position than they already are.

LOOKING FOR A WAY FORWARD

In seeking solutions to preventing the spread of HIV and AIDS, promoting HIV disclosure should be *'the norm'*. In such a situation, disclosing one's HIV status would increase awareness of the disease, lead to support for the person with HIV, and lead others to take preventative measures so they themselves would not become infected.

The sad reality is that the experience of many people living with HIV is one of ostracisation, alienation and discrimination. What is needed is an enabling environment in which people feel as if they can come out with their HIV status, without increasing their vulnerability. In the present situation, when deciding whether or not to reveal one's HIV status, people have the task of weighing up the consequences of disclosing against those of not disclosing – in some cases it amounts choosing the better of two bad situations.

In the South African context, social realities and a host of complex issues serve to restrict the ability of many people to make decisions about disclosing their HIV status. While encouraging people to disclose their HIV status to their families and significant people in their lives, it is always important to take into account their circumstances and the possible consequences that may arise.

To change the situation, caregivers, counsellors, educators, healthcare professionals, churches and communities need to strive to create loving and supportive environments where people can feel safe and secure when they disclose their HIV status.

> *The genuineness of our convictions about supporting HIV positive people and creating a better society must be measured by our willingness to give the necessary support. Those who are in a position to help, and who do not, cannot escape their responsibility. No person should feel that they must face HIV alone.*[6]

FOOTNOTES:

1. United States Conference of Catholic Bishops. 1989. 'Called to Compassion and Responsibility: A Response to the HIV/AIDS Crisis', November 1989. (www.usccb.org/sdwp/international/ctoresp.htm)
2. Almeleh, C. 2006. 'A Qualitative Study into the Impact of HIV Disease Progression on Initial HIV-Serostatus Disclosure to Significant Others'. Paper presented at the 2006 International AIDS Conference, Toronto, Canada, 11 – 18 August 2006.
3. Ibid.
4. Ibid.
5. Dickenson, as quoted in 'Stigma keeps South Africans from AIDS drugs', BBC, 21 June 2002. (http://news.bbc.co.uk/2/hi/africa/2057835.stm)
6. Adapted from the Irish Bishops' Conference, 'Statement on Civil Law and the Right to Life', 21 July 1995.

Felicity Harrison is the Researcher at the Southern African Catholic Bishops' Conference Parliamentary Liaison Office. For more information and/or comments, please contact her on +27 21 461 1417 or at felicity@cplo.org.za.

Johanna Kehler

It is all about behaviour change...
Barriers to effective HIV prevention

HIV prevention is proclaimed to be one of the main strategic areas in the response to the HIV and AIDS pandemics. Yet, there are estimates of 1000 new infections per day.[1] Statistics[2] clearly indicate that the *'ABC'* prevention strategy is failing, especially in Sub-Saharan Africa. Yet, HIV prevention strategies and messages seem to continue to rely on the **A**bstain (until marriage), **B**e faithful (to one faithful and/or uninfected partner) and **C**ondomise (when engaging in risky behaviour) model of HIV prevention. Stigma and subsequent discrimination has been widely recognised as the barrier to HIV prevention efforts. Yet, very little has been done to adequately address stigma.

It is within this context that this article will explore the question as to whether or not current HIV prevention strategies and messages respond to the societal context in which people access and participate in HIV prevention.

HIV PREVENTION REALITY

The failure of the *'ABC message'* to prevent HIV infection is evident. Latest statistics indicate that despite numerous efforts to prevent new HIV infections, infection rates are on the increase. According to statistics[3], there are an estimated 6 million people in South Africa living with HIV and AIDS, with an estimated adult prevalence rate of 25%. In addition, the data highlights that women and girl children are the ones adversely impacted and affected by failing HIV prevention efforts. Of all people living with HIV, the majority are females; the prevalence rate amongst women attending antenatal clinics is 30.2%; and of all the ones caring for people living with HIV and AIDS, 75% are women and girl children.[4] Similarly, HIV prevention campaigns promoting condom use are failing to prevent HIV infections, as indicated by the rising numbers of people living with HIV and AIDS.

The various reasons for the failure of ABC-based HIV prevention messages are well documented. In addition to not taking into account the societal context in which HIV prevention occurs, including existing gendered inequalities and prevailing stigma, HIV prevention messages will continue to fail people at risk of HIV infection, namely people who are sexually active, because the messages relayed are, more often than not, prescriptive, judgemental, value-based and often confusing. Thus, instead of offering options for preventing HIV infections, current HIV prevention messages seem to *'prescribe'* who is at risk of HIV infection, and when HIV infection is likely to occur.

> *A woman who has remained abstinent until marriage and is faithful to her husband, for example, but whose husband is either HIV-infected or is sexually active outside the marriage, is in fact at high personal risk of HIV infection herself, notwithstanding her own monogamy.* [Cohen, 2004:12]

This is further evidenced in data[5] indicating that in Sub-Saharan Africa, the majority of new HIV infections are found in women within marriage and/or long-term relationships. There is plenty evidence that, as argued by [Sindig, 2005:38]:

> *…promoting abstinence or faithfulness as the only way to prevent HIV transmission will leave millions of people without the ability to protect themselves from infection.*

And yet, there are limited, if any, HIV prevention strategies and programmes, which promote an individual's right to make informed choices, including sexual choices; which provide *'factual'*, as compared to *'moral'* information on HIV prevention options; which coincide with the external and internal environment, the societal context, in which HIV prevention *'choices'* are made; and which are based within a human rights framework of equality, non-discrimination, human dignity and equal enjoyment of all rights and freedoms.

HIV PREVENTION CHALLENGES

> *To be effective, HIV prevention programmes must address the context in which people live their lives.* [UNAIDS, 2005:9]

The gendered societal context, gendered prescriptions of behaviour, including sexual behaviour, mostly value-based and judgemental messages, core beliefs and prevailing discriminatory attitudes and beliefs are but some of the underlying factors not only fuelling the HIV and AIDS pandemics, but also rendering most of the existing HIV prevention efforts meaningless.

The gendered prescription of behaviour, including sexual behaviour, largely defines *'who'*, in a relationship, has the *'power'* to make decisions about the conditions of sex, including whether or not

to prevent the risk of HIV transmission. More often than not, it is the very same societal context, and not the individual, who *'decides'* who is in the position to access, participate in and benefit from available HIV prevention methods. Thus, within the gendered context of society, women seem to be *'pre-defined'* as the ones least in the position to partake in any form of HIV prevention.

As mentioned above, HIV prevention messages will continue to fail, since most messaging is value-based and often judgemental in its approach. Since the ABC-based messaging is, arguably, founded within a societal accepted framework of *'right/wrong'* behaviour and *'good/bad'* choices, especially pertaining to sexual behaviour and choices, these messages not only convey limited and biased information, but also seem to justify the limitation and subsequent judgement of individual choices – especially if they are perceived to be outside the *'norm'* of what is *'accepted sexual behaviour'*. And since individual choices are in fact not part of HIV prevention messages, individual choices are often used to *'justify'* the violation of the individual, who made a choice.

It is within the context of HIV prevention efforts that the constitutional and human rights framework seems to have become a *'challenge',* in that provisions, based on equality, non-discrimination, dignity and freedom of choice, are in place, and yet, reality of HIV prevention remains to be mostly characterised by inequality, disrespect, denied and/or limited freedom to choose and the subsequent violation of rights. While there are various arguments as to why rights do not seem to coincide with the lived realities of most people, including a general lack of knowledge and/or understanding of rights, as well as a lack of knowledge, skills and often resources to address the violation of rights, it is ultimately the gendered context of society and the prevailing stigma that defines the extent to which rights can become a reality for everyone.

...messages relayed are, more often than not, prescriptive, judgemental, value-based and often confusing...

In addition, prevailing discriminatory attitudes, beliefs and practices are not only manifested in core beliefs and values, but also justified by the very same, leading, amongst other things, to *'society'* largely accepting and even condoning the occurrence of stigma and subsequent discrimination, especially based on one's sex, gender, sexual orientation and/or HIV status. While the persistence of stigma and subsequent discrimination denies and/or limits an individual's access to, control over, and benefit from all available resources, its impact seems to be compounded in the context of available HIV prevention information and services.

Recognising these consistent challenges to effective HIV prevention, the question could be raised as to whether or not existing prevention approaches, strategies and programmes do, indeed,

> *...take into account the growing linkages between AIDS and factors that put people at greater risk of HIV infection, such as poverty, gender inequality, and social marginalisation of specific populations.* [UNAIDS, 2005:7]

It could be argued that there are quite a number of programmes addressing poverty (by aiming at poverty alleviation and creating opportunities for income-generation); addressing gender equality (through *'the empowerment of women'*, as well as by re-visiting issues of *'masculinity'*); and programmes addressing not only the social marginalisation of specific social groups, but also catering for the specific needs of marginalised groups, such as sex workers, lesbian and gay people, and prisoners. And yet, the status quo seems to largely continue in that poverty and gender inequality place people, especially women and girl children, at greater risk of HIV infection, and that marginalised groups, such as sex workers, and lesbian and gay people, are further marginalised and often excluded from available HIV prevention information and services.

The failure to effectively address the underlying factors of the HIV and AIDS pandemics, including the core beliefs leading to stigma and subsequent discrimination based on, and in the context of HIV, is as much a factor for the limited impact of HIV prevention strategies and programmes, as the seemingly societal reluctance to change behavioural patterns and attitudes.

STIGMA AS THE BARRIER TO HIV PREVENTION

> *HIV stigma and the resulting actual or feared discrimination have proven to be perhaps the most difficult obstacles to effective HIV prevention.* [UNAIDS, 2005:10]

While stigma and subsequent discrimination based on, and in the context of, HIV and AIDS has been widely recognised *'as the single greatest challenge to slowing the spread of the disease'* [ICRW, 2002], very few responses have been developed and implemented to address HIV-related stigma. One of the reasons for this slow response, as argued by Ogden and Nyblade [2005:7] is that stigma is believed to be *'too cultural, too context-specific, and too sensitive to be addressed meaningfully'*.

HIV-related stigma is commonly defined as *'a complex concept that refers to prejudice, discounting, discrediting and discrimination'*[6] against people actually living with, or are

...stigma is expressed in various ways, including ... mandatory HIV testing of individuals perceived to be at *'high risk'*, without informed consent or assured confidentiality...

perceived to live with, HIV and AIDS, as well as against their partners, friends, and families. Research also highlights stigma as a social process producing and reproducing relations of power and control.[7]

Stigma is primarily based on core beliefs, values and norms often leading to, and justifying, moral judgements, as well as lack of knowledge, actual and/or perceived, leading to fear and misconceptions about the *'unknown'*. HIV-related stigma appears to be an integral part of the HIV and AIDS pandemics, in that it accompanies and fuels the pandemic at the same time.[8]

According to UNAIDS [2005:10], HIV-related stigma specifically

> *…stems from fear, as well as associations of AIDS with sex, disease and death, and with behaviours that may be illegal, forbidden or taboo, such as pre-and extramarital sex, sex work, sex between men, and injecting drug use…*[and] *also stems from lack of awareness and knowledge about HIV. Such stigma can fuel the urge to make scapegoats of, and blame and punish, certain people or groups.*

HIV-related stigma is expressed in various ways, including through ostracising, rejecting and avoiding people living with HIV or AIDS; discriminating against people living with, and/or perceived to live with, HIV; mandatory HIV testing of individuals perceived to be at *'high risk'*, without informed consent or assured confidentiality; and violence against people who are infected, actual and/or perceived, with HIV, or against people who are perceived to belong to a *'high risk group'* for HIV infection.[9]

While stigma '*taps into existing prejudices and patterns of exclusions and further marginalises people, who might already be more vulnerable to HIV infection',* it also *'prompts people to act in ways that directly harm others and deny them services or entitlements'* [UNAIDS, 2005:10]. Thus, stigma leads to actions, which are discriminatory, and often further marginalise and exclude already vulnerable and marginalised individuals and/or groups of individuals.

In reality, people's choices are limited, due to stigma and the fear of subsequent discrimination in that many people *'choose'* not to negotiate safer sex, not to access available prevention methods, not to test for HIV, not to disclose their HIV status, and not to seek available treatment, support and care – due to fear of negative consequences. This seems to indicate, amongst other things, that it is not the availability of information and services alone that determines whether or not information and services are accessed, but instead it is the level of prevailing stigma and fear of subsequent discrimination and violation of rights that defines people's *'choice'* not to access information and services, even when they are available.

Recognising stigma and the subsequent discrimination as the obstacle to HIV prevention efforts, the question arises as to how HIV prevention efforts can be scaled up effectively, so that people are *'empowered'* and in the position to make informed choices about HIV prevention.

EFFECTIVE HIV PREVENTION

Effective HIV prevention strategies and programmes require not only a holistic, multi-faceted and human-rights based approach to HIV prevention, but also

> *…requires a strong national policy framework that encourages safer behaviours, reduces vulnerability, maximises the accessibility and effectiveness of HIV prevention services, promoted gender equality and women's empowerment, and reduces stigma and discrimination.* [UNAIDS, 2006:145]

In order to be in the position to develop and implement effective HIV prevention strategies and programmes, the societal context, in which HIV prevention occurs, needs, arguably, to be challenged and transformed, so as to create an environment, which is *'safe'* and allows everyone to equally access, participate and benefit from HIV prevention information and services. Challenging and transforming the societal context includes not only challenging the underlying factors fuelling the pandemics, such as gendered inequalities, imbalances and injustices, as well as the discriminatory attitudes, beliefs and practices, but also challenging the core beliefs perpetuating the status quo and justifying actions, which stigmatise people and violate their fundamental human rights.

Effective HIV prevention strategies and programmes also imply that fundamental rights and freedoms become a reality for everyone, through enhanced knowledge and/or understanding of rights, as well as enhanced knowledge, skills and resources to address the violation of rights.

For HIV prevention strategies to be effective, as argued by Sindig [2005:40],

> *…we must recognise the complexity of sexual relations, which embrace every facet of our lives, including issues of culture,*

tradition, power and status. We must acknowledge the unequal power relationships between men and women…and we must design interventions that provide realistic choices. Above all, we must resist efforts to impose a particular morality on individuals. We must respect the individual and find ways of giving people realistic and effective options.

In addition, it is argued that there is a dire need to develop HIV prevention messages, which are non-prescriptive, non-judgemental, non-biased and non directive, as well as rights-based, so as to ensure that HIV prevention is based on an individual's *'ability'* to make an informed choice, to do so without fear of judgement, discrimination and/or abuse, as well as based on the protection, promotion and respect of an individual's right to make informed choices about HIV prevention, irrespective of one's sex, gender, sexuality and/or HIV status. This change in HIV prevention messaging is an integral part to addressing the stigma that hinders effective HIV prevention, since, as argued by Ogden & Nyblade [2005:39], the *'content of HIV and AIDS information, the style and delivery of messages also potentially creates and perpetuates stigma'*.

And finally, it is argued that the foundation for effective HIV prevention strategies and programmes lies within both individual change (internal environment) and structural change (external environment). Only as and when both the internal and external environments, which not only perpetuate stigma and the subsequent discrimination based on, and in the context of, HIV and AIDS, but also justify its perpetuation, are addressed, challenged and transformed, can HIV prevention strategies be effective, accessible and, thus, beneficial to people most vulnerable to HIV infection.

This argument is equally based on the acknowledgment that even though *'power relations that foster inequality are structural, they are perpetuated by individuals'* [Ogden & Nyblade, 2005:38], as it is on the recognition that

…stigma cannot be reduced without changing the behaviour of those stigmatising others. Preventing HIV transmission in healthcare settings cannot be accomplished without changing the behaviour of healthcare workers. Maternal-to-child transmission cannot be stopped without ensuring the compliance behaviour of mothers in taking the therapy in a timely manner. [AED, 2003]

Thus, effective HIV prevention must be based within the context of behavioural change at the individual level, as well as the societal level. It is as much about behavioural change that *'empowers'* the individual to make informed choices about HIV prevention, as it is about behavioural change so as for society to *'allow'* the individual to make informed choices about HIV prevention. And while behavioural change is not a *'quick intervention'*, but instead might take quite a long time, it is certainly *'high time'* to deliver and to begin developing and implementing HIV prevention strategies and programmes that carry the potential to prevent the risk of HIV infection for everyone equally, irrespective of one's sex, gender and/or sexual orientation.

...it is certainly *'high time'* to deliver ... programmes that carry the potential to prevent the risk of HIV infection for everyone equally...

REFERENCE

Academy for Educational Development (AED)2003. AIDS in Africa. (www.aed.org/HIVAIDS/International/upload/03-0821%20AIDS%20in%20Africa3.pdf).

Cohen, S. 2004. 'Promoting the 'B' in ABC: Its value and limitations in fostering reproductive health'. In: *The Guttmacher Report on Public Policy*, October 2004, pp11-13.

International Center for Research on Women (ICRW). 2002. *Addressing HIV-related Stigma and Resulting Discrimination in Africa: A three-country study in Ethiopia, Tanzania and Zambia.* ICRW Information Bulletin, March 2002. (www.icrw.org/docs/Stigma_Africa_InfoBulletin_302.pdf)

Ogden, J. & Nyblade, L. 2005. *Common at its core: HIV-related stigma across contexts.* International Center for Research on Women. Washington: USA.

Sindig, S. 2005. 'Does 'CNN' (Condoms, Needles and Negotiation) Work Better Than 'ABC" (Abstinence, Being Faithful and Condom Use) in Attacking the AIDS Epidemic?' In: *International Family Planning Perspectives,* Vol 31, No 1, pp38-40.

UNAIDS. 2005. AIDS Epidemic Update: December 2005.

UNAIDS. 2006. 2006 report on the Global AIDS Epidemic.

FOOTNOTES:

1. Actuarial Society of South Africa.
2. The State of the World Population Report 2005, Chapter Four.
3. UNAIDS. AIDS Epidemic Update: December 2005. Department of Health. 2005.
4. UNAIDS. AIDS Epidemic Update: December 2005. Department of Health. 2005 National HIV & Syphilis Antenatal Sero-Prevalence Survey in South Africa.
5. The State of the World Population Report 2005, Chapter Four.
6. Herek, G. 1999. 'AIDS and Stigma'. In: *American Behavioural Scientist,* 42:1102-1112. See also Patient, D. & Orr, N. 2005. 'Stigma: The extreme end of a discrimination continuum'. In: *ALQ*, June Edition, pp1-9.
7. Parker, R. & Aggleton, P. 2003. 'HIV and AIDS-related Stigma and Discrimination: A conceptual framework and implications for action'. In: *Social Science & Medicine*, 57(1), pp15-24.
8. See also Ogden & Nyblade 2005.
9. Herek, G. 1999. 'AIDS and Stigma'. In: *American Behavioural Scientist*, 42:1102-1112. See also Centre for AIDS Prevention Studies. 2006. How does stigma affect HIV prevention and treatment? (www.caps.ucsf.edu/pubs/FS/stigma.php)

Johanna Kehler is the National Director at the AIDS Legal Network (ALN). For further information and/or comments, please contact her on +27 21 447 8435 or at Johanna@aln.org.za.

Fikile Vilakazi

There is no mention of sexual minorities... HIV prevention challenges for lesbian and gay people in South Africa:

In December 2005, lesbian and gay people adopted an HIV and AIDS Declaration in Abuja, Nigeria that seeks to challenge heads of states and health ministries in different countries to address the HIV prevention needs of lesbian and gay people globally. One of the things the Declaration stated is that:

> *African countries are experiencing a high HIV seroprevalence and a high burden of STIs. As same gender loving people, MSM, and WSW, we are exposed to higher levels of stigma and discrimination and thus are more vulnerable to infections. We need qualitative and quantitative research into the factors that place us at risk to STIs and HIV.*
>
> *We need education and training for professionals in order to adequately attend to these. We are frustrated by the huge absence of appropriate STI and HIV transmission and prevention materials specifically geared toward us in our countries. We want to engage in respectful and loving safer sex practices and therefore demand adequate provision of appropriate prevention materials. We want target-specific pamphlets, dental dams, water-based lubricants, appropriate condoms and gloves. We demand access to STI and HIV treatment.*[1]

Current indicators suggest that, globally, less than 10% of men who have sex with men have access to the HIV prevention and AIDS care services they need. Many factors contribute to this situation, including, societal and community denial, stigma, discrimination and human rights abuses.[2] The situation is even worse for women who have sex with women, where risk factors are considered to be minimal and in some cases even absent. What aggravates the situation even further is the assumption that sexuality and sexual behaviour is exclusively heterosexual and transmission of HIV between people of the same sex is often obscured within these heterosexual patterns of viral transmission. This remains a global challenge in addressing HIV prevention for lesbian and gay people.

In South Africa, the Constitution[3] in Section 27(1) provides that everyone has the right to access to health care services. The term *'everyone'* in this section is read and understood to include lesbian and gay people in line with section 9(3) of the Constitution which states that:

> *The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.*

The challenge for South Africa is *'the right to access'*. When we talk about access, it is implied that the state has the responsibility to ensure progressive realisation of all rights enshrined in the Constitution, within its available resources, for all citizens of South Africa. *'All'* in this case means everyone, including lesbian and gay people. However, in dealing with the right to access to healthcare, specifically the right to access HIV and AIDS prevention programmes, the state continues to fail, marginalise and exclude lesbian and gay people. The state continues to introduce HIV prevention methods that are hostile and alienating to sexual behaviour between men who have sex with men (MSM), and women who have sex with women (WSW).

The HIV prevention methods and programmes that have been introduced thus far assume that the sexual population is exclusively heterosexual, by perpetually limiting HIV prevention to a safer penetration of a vagina by a penis. This is what a condom is aimed at achieving, protecting a penis from transmitting a virus into a vagina. As much as most people, who practice anal sex, also use a condom, the fact is that the idea behind the use of a condom is that of a heterosexual construction of sexual behaviour. It is this construction of sexual behaviour that is at the root of marginalisation and exclusion against lesbian and gay people. What remains a serious challenge is the supremacy of hetero-sexism. This is what needs to be uprooted. The state has a challenge to think beyond hetero-sexism. It is time to also think lesbian, gay, bisexual, transgender and intersex when designing HIV and AIDS and STI prevention programmes.

Prevention needs

Lesbian and gay people have specific needs for HIV and AIDS and STI prevention. This is not to suggest that there needs to be special treatment for men who have sex with men and women who have sex with women. On the contrary, men who have sex with men also need to use condoms similarly as men who have sex with women. In addition, women who have sex with women need to also use condoms

to prevent viral transmission, in an event that they share sex toys or have sex with men. The point suggested here is that the use of condoms alone is not adequate to address the needs of people from diverse sexual orientations. There is a need to provide accessible femidoms (female condoms), fingerdoms (finger condoms), dental dams (for viral prevention during oral sex), and water-based lubricants in addition to condoms.

Furthermore, it is crucial that safer sex and HIV prevention education programmes incorporate the diversity of sexual orientation, including education regarding women who have sex with women and men who have sex with men. Currently, the situation is such that safer sex and HIV and AIDS prevention education only talk about sex between people of the opposite sex, women and men. This is not only limiting, but also exposing lesbian and gay people, MSM and WSW, to dangers of lack of education around viral transmission in the way that they practice sex, and thus, making them vulnerable to, and at risk of, HIV transmission. This also marginalises, excludes and denies lesbian and gay people the right to access to information and education regarding their sexuality. This is a violation of basic human and constitutionally guaranteed rights. It remains a contradiction to the values and spirit of the Constitution and thus, requires to be challenged.

...the point ... is that the use of condoms alone is not adequate to address the needs of people from diverse sexual orientations...

HIV prevention strategies

The Khomanani Programmes introduced an HIV and AIDS prevention campaign late last year titled, *Let's Take Our Relationship To The Next Level.* This campaign was exclusively heterosexual in design. Even though a challenge was raised at a consultation where this campaign was launched, stating that it is important to build messages that also promote HIV and AIDS and STI prevention between men who have sex with men and women who have sex with women; this never happened. The campaign was all over the media, with no messages addressing the diversity of sexual behaviour in preventing HIV transmission. This remains a huge challenge.

One other challenge is the of lack of capacity of healthcare practitioners in dealing with issues of sexual orientation diversity and, specifically, the needs of lesbian and gay people in general. Most lesbian and gay people have been denied access to healthcare services on the basis that they were either lesbian or gay. Most lesbian women seeking post-exposure prophylaxis (PEP) after an incident of *'curative rape'* have experienced immense prejudice and homophobic attitudes from healthcare providers. As a result, some even decided to abandon treatment and run the risk of viral infection. The situation has been reported anecdotally by some lesbian women rape survivors, who fell pregnant as a result of hate-based rape, and, during pregnancy, discovered that they were infected with HIV. In seeking prevention methods for the child, using prevention of mother to child transmission (PMTCT) services, they also experienced extreme prejudice and homophobia from healthcare practitioners. This, arguably, indicates the importance that state and health ministries have, as part of its human resource development programme, to broaden the understanding of these issues and how they intersect with prevention of STI and HIV and AIDS.

National government introduced an HIV and AIDS prevention strategy between the years 2000 – 2005. The cornerstone of this strategy was the *'Abstain, Be Faithful and Condomise'* (ABC) programme. The ABC programme has been proven to be ineffective in South Africa. The rate of new HIV infections is on the increase, regardless of the proposed ABC programme. Most young people have alluded to the fact that abstinence and being faithful, as a strategy to prevent HIV transmission, is not realistic. Young people are sexual beings and they experiment with sex at a very young age. In fact, the idea of abstinence works for very few people, if any. It is a moralistic approach that can only be adhered to by few. This leaves the majority of youth at risk of viral infections and transmission. The situation is also similar for adult women in monogamous relationships. Their male partners often have more than one partner and do not disclose their sexual involvements. These women are mostly vulnerable to contracting HIV from their partners whilst in so-called *'faithful relationships'*.

Generally, in South Africa, there seems to be a serious lack of vision regarding the design and implementation of HIV and AIDS prevention programmes. The focus on lesbian and gay people is non-existent within mainstream agencies. Government policies and programmes, including prevention of mother to child transmission (PMTCT), post-exposure prophylaxis (PEP), and the ABC prevention programmes are inaccessible to lesbian and gay people, since they are not designed in such a manner that accommodate sexual behavioural diversity. In addition, the health practitioners are often not equipped to handle issues of sexual diversity in implementing HIV prevention programmes.

There are a number of lesbian women who are targeted for *'curative rape'* in South African townships and often require access to PEP and in some cases to the PMTCT programme as a result. The experience for most has been that the health practitioner will just assume that they are heterosexual. Health practitioners would ask questions like: *'Do you have a boyfriend? When was the last time you had sex with your boyfriend?'* The other extreme is pure homophobic treatment, where people are often asked why they are lesbians

...most lesbian women seeking post-exposure prophylaxis (PEP) after an incident of *'curative rape'* have experienced immense prejudice and homophobic attitudes from healthcare providers...

or gays in the first place. The treatment often diverts to people's sexual orientation, rather than addressing the issue at hand. Due to these factors, most lesbian and gay people eventually decide not to seek HIV prevention. It is estimated that about 6% of lesbian and gay people have been refused access to healthcare on the basis of their sexual orientation.[4] This is not only unacceptable, but also violates the right to access healthcare services, as guaranteed in the Constitution of South Africa. Everyone has the equal right to access to healthcare service.[5]

The experience is similar, and perhaps worse, in other countries where homosexuality is still considered a criminal offence. Many African states have laws that penalise homosexuality through imprisonment and death penalty. The situation varies from country to country. Most societies associate HIV and AIDS with homosexuality. It is often viewed as *'a homosexual disease'*. This phenomenon is common globally. This kind of perception creates a barrier for lesbian and gay people to access HIV and AIDS prevention programmes, due to fear of marginalisation and stigmatisation that may result in arrest, detention, assault and death for many. These abuses are also closely linked to the spread of HIV and AIDS. Sodomy laws, which violate human rights to privacy and non-discrimination, undermine HIV and AIDS outreach to men (and women) who have sex with people of the same sex. State failure to protect lesbian, gay, bisexual and transgender people from violence and abuse by police, healthcare practitioners and private citizens, marginalises and inhibits people from seeking prevention for HIV and other sexually transmitted diseases that increase the risk of HIV transmission.[6]

There is very little evidence of HIV prevalence in South Africa amongst men who have sex with men and women who have sex with women, such that there is lack of directed effort to design HIV prevention programmes that can target this group. The only available and accessible HIV prevention method is the use of a condom. This is useful to a certain extent for people of the same sex. Men who have sex with men and women who have sex with women do not always use condoms for protection and prevention of infections. Lesbian and gay people also require accessible dental dams, gloves and water-based lubricants and these forms of prevention are not available from state facilities. People needing them have to purchase them at very expensive costs. The challenge is that the majority of lesbian and gay people cannot afford to buy these products and resort to unsafe sex, or improvising with condoms and that is not always safe and adequate. This is a global experience for lesbian and gay people in different parts of the Africa and the world.

Conclusion

Lesbian and gay people in South Africa remain on the fringes and margins of society. In various mainstream programmes there is no mention of sexual minorities as a vulnerable group. Many programmes target women, children, youth, people with disabilities, displaced persons and refugees as vulnerable. Then there is a mention of *'other'* as a category. One would assume that *'other'* includes lesbian and gay people, but this is not necessarily implied, since it is always subject to the interpretation of the reader. This tendency is also very common with health programmes in South Africa, specifically with HIV and AIDS prevention programmes.

The state has, thus far, not attempted to address HIV prevention that encompasses the diversity of sexual behaviour present in South Africa. There is still a lot of work that needs to be done to lobby decision-makers and influence policy in this regard. It is important to have a joint collaboration between the state and civil society to address this social deficit impeding on HIV prevention efforts.

FOOTNOTES:

1. Abuja HIV Declaration for lesbian, gay, bisexual, transgender and intersex people, Nigeria, 2005
2. Men who have sex with men, HIV prevention and care: Report of a UNAIDS stakeholder consultation: Geneva, Nov 2005.
3. The Constitution of South Africa, Act No 108 of 1996.
4. Wells, H. 2003. *The Levels of Empowerment of Lesbian, Gay, Bisexual, Transgender and Intersex people in Gauteng*: OUT LGBT Wellbeing: Gauteng.
5. Section 27 of the Constitution.
6. HRW. 2004. 'Hated To Death: Homophobia, Violence and Jamaica HIV/AIDS Epidemic'. In: *Human Rights Watch*, November 2004, Vol. 16, No 6 (B).

Fikile Vilakazi is the Advocacy Officer at OUT LGBT Wellbeing, a non-profit making organisation aimed at reducing heterosexism and challenging homophobia in society. For further information and/or comments, please contact her on +27 12 344 5108 or at advocacy@out.org.za.

Derrick Fine

HIV prevention and treatment: **The power of positive language**

I have lost both my parents to cancer, yet I don't call myself a *'cancer orphan'*. Why then does our media write about *'AIDS orphans'* when referring to the many thousands of South African children who have been orphaned by HIV and AIDS?

I was diagnosed as living with HIV on 10 December 1999, International Human Rights Day. Why did negative media and a climate of fear around HIV/AIDS cause me to delay having an HIV test until 1999?

Today I live positively and healthily with HIV. The double stigma of being gay and living with HIV has made my journey a sometimes bumpy and eventful one. How does language and being seen as different impact on our attitudes and actions around HIV prevention and treatment?

The power of language

> *I was alive. I am alive. The most horrifying was the absolute lack of preparation of the doctor who gave me the news. Horror was exactly what I felt. I had in front of me a diagnostic machine, a dehumanised medical apparatus that could, suddenly, catch me in its gears and take me to something much more terrible than AIDS: the indignity of an empty death, hospitalised, death as a vital experience stolen from me. I left that consultation room unhinged.* [Herbert Daniel, 1989][1]

Language is powerful. It shapes our ideas and attitudes. It affects our behaviour – what we do, what we don't do, and what we would like to do, but avoid or put off until a rainy day.

Over the last 25 years since AIDS became a reality in our lives, the language of the mainstream media has played a leading role in casting the HIV/AIDS pandemic as a shadow soiling our world. This was the overt language of AIDS as a *'deadly disease', 'scourge', 'cancerous growth'* and *'gay plague'*. Or the covert language of indirectly referring to AIDS as a *'dreaded illness'* or *'that thing'*. Or simply saying nothing.

People living with HIV and AIDS were called *'AIDS sufferers'*, *'HIV victims'* and *'sick patients'*. We were defined by our HIV status as *'HIV positive'* or *'HIV-infected people'*, just as people living with disabilities used to be called *'disabled', 'handicapped'* or *'crippled people'*.

Negative labels and invisibility also clouded the language of the popular, spoken word:

- We heard hushed whispers at funerals of *'did you know?'*
- There was talk of *'tuberculosis (TB)'* or *'pneumonia'*, or the more comfortable shield of 'a long illness', rather than a link to an AIDS-related illness as cause of death.

Closer to home, the stigmatising stain of language was now a part of our indigenous languages too. HIV became *'amagama amathathu (the three words)'* and AIDS *'amagama amane (the four words)'*. Many people dared not speak the name, yet we conveyed the message that HIV was everywhere and affecting all of us – rich and poor, black and white, women and men, straight and gay, young and old. At least we began to admit that we were all affected, for example, saying *'isifo esikhoyo (the sickness that is among us)'*.

The language of power

The language of power has also influenced the South African HIV/AIDS landscape – for most of the over 5,5 million people living with HIV, in a negative and confusing way:

- President Mbeki openly questioned whether or not HIV is the cause of AIDS.
- Minister of Health Tshabalala-Msimang has repeatedly questioned the effectiveness of antiretrovirals (ARVs).
- Ex-Deputy President Zuma explained in his rape trial how he took a shower after unprotected sex to minimise the possibility of HIV transmission.

Denialist views, delays and confusion have characterised many government

programmes and messages. Why have so many of our people been misled into selecting between seemingly *'either-or choices'*, such as *'prevention or treatment'*, and '*ARVs or nutrition"*? Why has there been so little government urgency in only agreeing to an ARV rollout plan in November 2003 and in its delayed implementation of this plan, for example, through its very slow purchase and registration of medicines, and accreditation of ARV sites?

Government and leadership messages do not just float in the wind. People may not always understand these messages, but they do listen to them. The impact of negative, confusing messages is profound. Take the example of the years spent denying the existence of HIV, or at least seriously questioning the urgency of the HIV/AIDS pandemic as a challenge for all South Africans. In awareness workshops, participants would commonly ask in response: *'Why prevent something that doesn't exist? Why use a condom? Why take an HIV test if HIV doesn't cause AIDS? Why take ARVs if they are so bad for us?'*.

Similarly, messages that are not inclusive or messages that stigmatise affect our health-seeking and health-protecting behaviour:

- The Government's *ABC (Abstain, Be Faithful, Condomise)* campaign has failed to reach and change the behaviour of many young people, who are sexually active.
- Prevention messages and policies, such as the policy on donating blood, have sometimes labelled '*high-risk groups',* rather than identifying *'risky sexual acts'* that affect all people. This has, for example, led to stigmatising and marginalising sex workers, or men who have sex with men.

...language is powerful. It shapes our ideas and attitudes. It affects our behaviour...

The pain of losing close friends has sharply brought home to me the damage caused by fear and denial:

- In 2002, S died a lonely death from AIDS-related TB. His self-stigma meant that he could not disclose that he had been living with HIV for some time, and thus, did not have access to the support he deserved. Was he influenced by the political climate at the time – little hope and no access to ARVs in the public sector?
- In 2005, D died from a number of AIDS-related illnesses. She had been living openly with HIV for a few years, but her mother discouraged her from taking ARVs when she needed them. Her mom, a nurse, believed the Minister of Health's view that *'ARVs are toxic'*. D did not have the chance to live and discover that the benefits of ARVs far outweigh possible side effects.

How do we, in any language, explain the continued lack of urgency around treatment, when around 1 400 people die preventable deaths every day, and an estimated 400 000 people await ARV treatment?

Our visibility as people living with HIV and open, clear HIV/AIDS communication are vital in overcoming stigma and more unnecessary AIDS-related deaths. The key questions are:

- Can there be a real change of heart and pace in the way our country responds to and prioritises HIV prevention and treatment efforts?
- Can this change of emphasis happen without strong political will and leadership, and a move away from political denialism and double-speak on HIV/AIDS issues?[2]

Can we turn the tide?

OUT OF THE SHADOWS
Keeping up with news
Of infected suffering victims
Unfeeling, unwelcome, deadly names
Written by others that think they know
How it feels to be alive

Time to show
Our faces
Our voices
Our names
Telling tales of positive living
Letting them know
How it feels to be alive.
[My poem]

Can we adapt our HIV/AIDS communication and get through to many more people by moving away from meaningless *'either-or'* options, or from language that is insensitive, hurtful and patronising? Yes, we can! We can start by getting the basics right, such as ensuring that our *'HIV prevention and testing'* messages are tied to *'treatment literacy'* messages – in other words, knowing that effective treatment is available if needed, can help reduce the fear of knowing your HIV status.

People living with HIV and AIDS have come a long way since the early *'panic'* years of the pandemic when we seldom heard about *'living with AIDS'* and there was hardly a mention of *'HIV'*. The main message was *'AIDS = death'*. Following courageous international role models, a number of South African people living with HIV began to disclose publicly in the late 1980s and early 1990s, and organisations emerged to speak for and represent our interests. We were inspired by gender activists and the efforts of NGOs, like Rape Crisis, in changing *'victims'* into a *'survivor'* mentality.

Positive role models, who were strong, proud and living positively, helped to slowly change the public discourse around HIV/AIDS, with the growing support of parts of the media in talk shows, newspaper columns, magazines and videos:

- A wider circle of people disclosing and living positively gave HIV a human face and voice. As people living with HIV, we talked about our lives, hopes and dreams.
- In time, the media began to write more about *'HIV'* and *'living with HIV'*, and not just *'AIDS'* and *'dying of AIDS'*. We were whole people living with HIV as one part of our lives.
- The advocacy and pressure of communities and civil society organisations, like the Treatment Action Campaign, helped to bring the possibility of increasing access to the health care we needed, for example, through struggles to make lifesaving ARVs and treatments for opportunistic infections available.

...in awareness workshops, participants would commonly ask in response: *'Why prevent something that doesn't exist? Why use a condom? Why take an HIV test if HIV doesn't cause AIDS? Why take ARVs if they are so bad for us?'*....

The tide was slowly turning away from the negative language of doom and gloom to a more positive outlook of hope, options, partnerships, knowing your HIV status, disclosing where possible, and facing up to the challenge of HIV as an increasingly manageable condition. AIDS denialism, pseudo-science and moralistic opposition to prevention methods, such as condoms, were being gradually overtaken by advances in HIV science, for example, research into microbicides to enhance prevention, and developing ARV combinations with a lower profile of side effects and a reduced pill load.

Some positive language guidelines

I will remember that I don't help patients, I help people.
[Link Pharmacist's Oath]

The shift from silence to visibility created space for us to develop our own ways of talking about ourselves as people living with HIV. Openness was the key to help us turn negatives into positives, for example, to make young people feel that they could benefit from finding out their HIV status, and protecting themselves and others.

Using positive, affirming language around HIV is not about political correctness, but about shifting attitudes, beliefs and policies where these stand in the way of vital goals, like reinforcing HIV prevention and increasing access to HIV treatment. The links between openness and prevention are often overlooked. Short-sighted, limited HIV prevention efforts tend to focus only on people who are *not* already living with HIV:

- As close to 6 million people in South Africa are living with HIV, what about also reaching these people with focused messages about the possibility of re-infection or being infected with a different strain of HIV?
- Against a backdrop of an estimated 500 000 new HIV infections every year, what about all the people who do not know their HIV status? Or people who do know, but do not disclose, or do not practise safer sex, or do not seek access to ongoing health care.

Openly Positive[3] is a collective of people living with HIV that aims to help create a public climate that makes it easier for people living with HIV to disclose, and to participate in developing, implementing and evaluating programmes, policies and practices that affect us as people living with HIV. My colleague, Elaine Maane, and I developed a number of *'positive language guidelines'*[4] to encourage us all to use personal, precise, inclusive and sensitive language in our HIV/AIDS communication:

NEGATIVE LANGUAGE	→	POSITIVE LANGUAGE
GUIDELINE 1: Avoid labelling people or reducing ourselves to HIV *Example: HIV positive person or HIV-infected person*		Recognise HIV as one part of who we are *Example: Person living with HIV or person who has HIV*
GUIDELINE 2: Don't disempower *Example: AIDS victims*		Try to empower and give hope *Example: People facing the challenges of living with HIV and AIDS or people affected by HIV and AIDS*
GUIDELINE 3: Don't stigmatise or judge *Example: AIDS orphans*		Humanise *Example: Children orphaned by AIDS or children affected by AIDS*
GUIDELINE 4: Don't victimise or criminalise *Example: HIV sufferers*		Humanise *Example: People living with HIV*
GUIDELINE 5: Don't sensationalise *Example: Full-blown AIDS*		Contextualise, describe and inform *Example: AIDS (and explain HIV progression, as there is no half-blown AIDS)*
GUIDELINE 6: Don't depersonalise and create distance *Example: Patient*		Personalise and identify with people *Example: Person, Elaine, Derrick*
GUIDELINE 7: Don't generalise or be vague *Example: AIDS transmission or AIDS test*		Specify and be precise *Example: HIV transmission or HIV test*
GUIDELINE 8: Don't generalise with individual people *Example: She is living with HIV/AIDS*		When possible, individualise with people *Example: She is living with HIV (if factually correct and she has consented)*
GUIDELINE 9: Try not to disguise or avoid *Example: The virus*		Be as open and transparent as possible *Example: HIV*
GUIDELINE 10: Don't exclude *Example: AIDS conference or AIDS policy*		Be inclusive *Example: HIV/AIDS conference or HIV/AIDS policy*
GUIDELINE 11: Avoid unnecessary abbreviations *Example: PLHAs (in a speech)*		Use abbreviations selectively and sensitively *Example: People living with HIV and AIDS (more people-friendly, although an abbreviation may be better with repeated use in a long written document)*
GUIDELINE 12: Don't confuse or be inconsistent *Example: AIDS patients and people on ARV treatment*		Be clear and consistent in one document *Example: People on ARV treatment*

What can you do?

What can we all do, as individuals and community members, to implement these positive language guidelines, and help reduce stigma and unfair discrimination in other ways?

Start with yourself, and work through your own personal views and situation:

- Read, think, talk and share – try to *'step into the shoes'* of someone living with HIV, or facing another kind of stigma.
- Have an HIV test.
- If you test HIV negative, try to ensure that you stay HIV negative.
- Promote and practise safer sex.
- If you test HIV positive, make sure you get ongoing support.
- If you test HIV positive, disclose to yourself first and then to others at your own pace.
- Support other people living with and affected by HIV and AIDS.

..how do we, in any language, explain the continued lack of urgency around treatment, when around 1 400 people die preventable deaths every day...

When you are interacting with a person who is living with HIV, or someone who is HIV negative, or a person who does not know their HIV status:

- Treat everyone equally and with dignity.
- Promote diversity and non-discrimination.
- Be sensitive with your spoken and written language.
- Try to adapt and use the positive language guidelines in all our South African languages.
- Be sensitive about confidentiality around HIV status.
- Recognise the rights of all people, and especially people living with HIV, to make informed choices, for example, to have or to adopt children.
- Be sensitive in giving, or referrals, for emotional support, counselling, treatment and care.
- Consult and involve people living with, or affected by, HIV in HIV/AIDS policies, programmes and practices.

Sentenced to life with HIV!

Four years on ARVs have given me back my life and my health. I have been sentenced to life with HIV. Actually, it is not a sentence that hangs over me in any way. It is an opportunity. I have long stopped feeling sorry for myself. Instead, I am actively engaging in changing my own life and the lives of others.

For me, *'positive living'* means that today is the first day of a long and full life living with HIV, and facing all of life's other challenges and joys. I invite you to join me on a journey to help break down stigma, and, in the spirit of positive language, to build an environment where people living with HIV can live open, visible, healthy and fulfilling lives.

FOOTNOTES:

1. Herbert Daniel was an HIV activist in Brazil. Daniel H. 1989. *Vida antes da morte – Life before death.* Available at www.geocities.com/Athens/Acropolis/7051/exilio4in.html.
2. Recent statements by Deputy Minister of Health Madlala-Routledge have been a breath of fresh air, for example, saying clearly that good nutrition is not an alternative to ARV treatment.
3. *Openly Positive* believes that our openness and visibility as people living with HIV is our most important tool in breaking down stigma and prejudice around HIV/AIDS. To reach *Openly Positive*, please contact the author of the article.
4. The guidelines in this article have been further developed from an original longer version *Positive language in HIV/AIDS communication* presented at the 2005 South African AIDS Conference in Durban.

Derrick Fine is an independent HIV/AIDS writer, editor and trainer, who is also active in the Openly Positive collective promoting positive living and positive language around HIV/AIDS. For more information and/or comments, please contact him on +27 21 783 1699 or at derrickf@iafrica.com.

Emma Harvey

'Those' elderly people

HIV prevention messages miss people over 50

The goal must be to ensure that countries everywhere come as close as possible to achieving universal access to HIV prevention.
[AIDS Epidemic Update, 2005:5]

This article explores whether or not HIV prevention messages in South Africa are effectively *'targeting'* and/or reaching people over 50, and what kind of considerations are given to people over 50 in HIV prevention planning and messages, especially in the light of growing infection rates amongst the *'elderly'*. This article argues that people over 50 are largely invisible and ignored, both from a societal and HIV prevention perspective, primarily due to prevailing age-related stigma and discrimination.

Increasingly impacted by HIV infections and yet invisible

It is becoming increasingly clear that people over 50 are not only impacted by HIV and AIDS in terms of providing care and support, but are also, in fact, representing a greater percentage of the number of people infected with HIV. This is evidenced in the UNAIDS decision for the 2006 global epidemic report to shift the age bracket of people infected with HIV from '15 – 49 years old' to '15 years and over' stating that *'it is now evident that a substantial proportion of people living with HIV are 50 years and older'* [2006 Report on the Global AIDS Epidemic:9]. The report also states that the estimated number of people aged 50 years and older, living with HIV in 2005, is 2.8 million[1], approximately 7% of the total number of people living with HIV.

Yet, this *'group'* remains for the most part invisible in reporting. UNAIDS data sheets for South Africa reflect on numbers of people aged 15 and over, on women aged 15 and older, on children from 0 – 14, and nothing to indicate the prevalence of HIV amongst South Africans over 50 years old.[2] In fact, most research and information regarding people over 50, comes from US-based sources, where in 1998, over 10% of people infected with HIV were over 50 years old.[3] According to another report[4], the rate of infection has been climbing steadily ever since. Speculation around the infection rates in South Africa cannot be based on US estimates, due to the different circumstances and HIV prevalence rates in these countries, but one indication that the levels in South Africa might be as high as 20% for people over 50 comes from the 2005 AIDS Epidemic Update where data for Botswana indicate the current infection levels among people over 50 is at 21%.[5] The same report indicates in the same paragraph that Botswana's rates of infection are comparable to South Africa's, and thus, we can deduce that the number of people over 50 who have tested HIV positive in South Africa might be as high as 20%.

The invisibility of people over 50 in the HIV and AIDS discourse is further evidenced by Du Guerny (2002) writing about UNAIDS and its multi-sectoral response, which includes many specific *'at risk'* or *'focus groups'*, such as labour, substance abusers, children and youth, and yet, no organisation is directly representing *'the elderly'*.[6] Currently, UNAIDS is calling for the necessity of prevention strategies to *'tackle underlying factors'*, such as *'societal inequalities and injustices'*, and to appropriately address groups that are marginalised, stigmatised or otherwise at greater risk of HIV infection.[7] However, besides a paragraph detailing that people over 50 are increasingly infected by HIV and AIDS, there is little mention of people over 50 as a *'group'* who are at risk of HIV infection, or who need to be included in HIV prevention programmes.

This invisibility continues in most HIV prevention messages. A telling comment that indicates why the HIV infection rate in people over 50 is climbing comes from Engle [1998:1] who argues that

> *...looking at the majority of safer sex workshops and street outreach programs, one would get the impression that only the young are at risk of contracting HIV.*

This is certainly reflected in South Africa, where prevalent HIV prevention campaigns, such as LoveLife, target youth specifically. If

prevention messages geared towards preventing HIV infection through sexual intercourse do not reflect people over 50 as being at risk, then why would there be cause to think about prevention? And even if the prevalent assumption is that *'the elderly'* are caring for children orphaned by AIDS-related illnesses, there are still no HIV prevention messages for caregivers that focus on universal precautions. The question then remains why people over 50 are not included in HIV prevention messages. It could be argued that this is due to the prevalence of stigma and discrimination against people over 50, and perceptions of what kind of behaviour *'they are supposed to be engaging in'*.

Myths, stereotypes and misconceptions about people over 50 and HIV

One of the prevalent misconceptions around people over 50 and HIV is that people over 50 are, and can only be, considered as the caregivers to a generation of children whose parents have died of AIDS-related illnesses. Du Guerny did a survey of a UNGASS meeting with 123 paragraphs of resolutions. The *'elderly'* are only mentioned three times in this document, and only in relation to the fact that the impact on the *'youth'* is more severe, than the *'elderly'*;

...and even if the prevalent assumption is that *'the elderly'* are caring for children orphaned by AIDS-related illnesses, there are still no HIV prevention messages for caregivers that focus on universal precautions...

and that *'elderly women'* end up being caregivers. The only mention of the impact of HIV and AIDS on the *'elderly'* is grouped with other *'minorities'*, in the context of overburdened public healthcare systems which may further marginalise *'minorities'*.[8] Du Guerny [2002:2] states that:

> *In this inter-government consensus, the only role recognised for the elderly is that of caregiver and the association with the traditional role of women leads one to think that countries are mostly referring to elderly women and not men. It should also be stressed that certain roles are assigned to the elderly by others; they are treated as minors. The issue of HIV/AIDS is nowhere seen or presented from the perspective the elderly themselves.*

Though, even with this strong argument, Du Guerny himself fails to take into account that people over 50 may be increasingly infected with HIV. As mentioned above, if caregiving is *'the role'* of people over 50 in the AIDS pandemic, there is still a general lack of prevention messages, which would ensure that caregivers are aware of the risks of HIV infection through bodily fluids.

The *'caregiver only'* role ties in to what seems to be the primary misconception, which is simply that people over 50 are not at risk for HIV infection, because people over 50 are not sexually active, and *'shouldn't be'*, which, in turn, relates to many other myths and stereotypes around sex.

Engle (1998) identifies the myths around people over 50 and sex as:

> *Old people are no longer interested in sex; if they are interested, no one is interested in them; If they do have sex, it's within a monogamous, heterosexual relationship.*

Yet in reality, as argued by Djihemine et al (2004):

> *...it has been noticed that people classified as the elderly (more than 50 years old) are still sexually active, have frequent sexual relations with much more younger people and are reluctant to prevention methods such as the systematic use of condoms during sexual intercourse in general.*

The association of HIV with sexual behaviour, combined with the taboo on sexuality for people over 50 creates an environment in which stigma based on age and sexual activity preclude the possibility of doctors, service providers and prevention messages even raising the issue of sex with people over 50, let alone talking about HIV prevention.[9] This is especially true in a context where UNAIDS identifies a key area of prevention intervention through family planning clinics. If people over 50 are no longer accessing family planning clinics,[10] or engaging with health service

providers about sexual and reproductive health, there are no opportunities for engaging in conversations that might include information on HIV transmission and prevention.

This reality that people over 50 are still sexually active has another reality associated with it in that people over 50 have a higher risk of HIV transmission, due to lack of information, age-related biological reasons (especially for women, since the mucosal lining is not as active resulting in more tearing during sexual intercourse), and are, for the most part, not willing to use, or do not know about, condoms.

...people over 50 are not at risk for HIV infection, because people over 50 are not sexually active, and *'shouldn't be'*...

A US-based survey in 1994[11] indicated that people over 50 are only one sixth as likely to use condoms, than counterparts in their twenties; and only one fifth as likely to be tested for HIV. There is no data for a comparison to South Africa, but it could be argued that given the traditional and patriarchal social models of behaviour, and the tendency to keep sex as *'a hidden and unspoken of thing'*, it would not be surprising if the statistics in South Africa exceed those of the US in terms of *'older people'* being less likely to use condoms and be tested for HIV.

Only one project, in a limited search, showed evidence of a project in South Africa working with people over 50 around HIV prevention – the Community Information, Empowerment and Transparency Trust which is based in Amathole. The project is conducting HIV prevention workshops geared specifically towards *'elderly'* people; though these activities focus on people over 50 to be a role model or *'moral yardstick'* for youth. In essence, these programmes are still aimed at providing support services for younger people. However, a definite side effect is that people in the community, who are over 50, are becoming HIV prevention literate, and it would be interesting to ascertain whether or not this has an impact on HIV prevention amongst the *'elderly'*, but the source, unfortunately, does not indicate this. The following two quotes[12] illustrate the reluctance and level of taboo of talking about sex with people over 50:

> *The first few sessions are very quiet, but then they get used to all the new words and they start asking us all the questions that may have been bottled inside them for years.*
>
> *We keep the male and female elders separate, because they are shy even to talk in front of members of the opposite sex of their own age group.*

This reluctance to speak about sex and sexual practices, including HIV prevention, has, arguably, a deep impact on the level of HIV prevention that can be spoken about, or accessed, or used by people over 50. If a person is reluctant to speak to a service provider about sex, what is the likelihood of that person accessing HIV prevention information and methods?

Another common stigma relating to people over 50 and HIV relates to resource allocation. Ageism and prejudicial attitudes that consider it a *'waste'* to spend money on people over 50 may play a role in limiting *'elderly'* people in choices around access to HIV prevention and other necessary resources. This myth that it is a *'waste'* is fuelled by an attitude that people over 50 have already *'lived their lives'*, so it is not really important to spend money on HIV prevention messages focussing on people over 50.[13]

...if a person is reluctant to speak to a service provider about sex, what is the likelihood of that person accessing HIV prevention information and methods?...

All of these myths, stigmas and stereotypes represent, sometimes subtle and sometimes blatant, discrimination against people over 50 that has a direct impact on the extent to which HIV prevention messaging reaches people over 50, and how freely HIV prevention measures are accessible and used. *'Those pushed to the margins of society are at particular risk'* [AIDS Epidemic Update, 2005:11].

The very invisibility of people over 50 points to their marginalisation, and this combined with the rising HIV infection rates, creates a disabling environment for people over 50 to access prevention. Given this, it would be fair to argue that HIV prevention messages are failing people over 50 years old.

Solutions

It is evident that the combination of stigma and misconceptions about people over 50, along with the prevailing stigma and discrimination relating to HIV and AIDS, creates an environment in which people over 50 are not adequately provided for in terms of HIV prevention and prevention measures; not in respect of prevention of HIV transmission during care giving activities, and even less so in respect of sexual transmission of HIV. It is also clear that:

> *Stigma taps into existing prejudices and patterns of exclusion and further marginalizes people who might already be more vulnerable to HIV infection.* [AIDS Epidemic Update, 2005:10]

The imperative remains to determine what would be an appropriate solution. Should HIV prevention programmes and strategies provide specific messages for people over 50? Recognising that HIV and AIDS expose prevailing stigma, discrimination and marginalisation that occur in society, Du Guerny [2002:2] argues that:

> *One thing issues such as aging, gender or HIV/AIDS have in common is that they reveal the hidden face of societies, the areas of dysfunction since the reality of the situation usually clashes with the images every society likes to project of itself. One can then only wonder whether the more representative view of the elderly is not to be found in the HIV/AIDS statements rather than in those on aging?!*

Or should HIV prevention programmes and strategies provide universal messages and access to create an enabling environment for all to access prevention? This would require following some of the essential policy actions for HIV prevention according to UNAIDS, namely, ensuring that human rights of all people, including people over 50, are promoted, protected and respected, and that stigma and discrimination are addressed; and that information on modes of HIV transmission and prevention messages are widespread. It would also require recognising that people over 50 are sexually active, and have equal rights to sexual and reproductive healthcare.

In summary, this means: *'Prevention programme efforts must also address people of all ages to be fully effective'* [AIDS Epidemic Update, 2005:10].

...this myth that it is a *'waste'* is fuelled by an attitude that people over 50 have already *'lived their lives'*, so it is not really important...

REFERENCES

Djihemine, A. et al. 2004. 'The elderly and the prevention of HIV transmission: The case of centers for prevention and voluntary testing (CPVT) in Yaounde, Cameroon'. Paper presented at the International AIDS Conference. 2004, July 11-16.

Du Guerny, J. 2002. 'The elderly, HIV/AIDS and sustainable rural Development'. Paper presented at a seminar on Aging and Rural Development sponsored by the American Association of Retired Persons. January 2002.

Elderly take up Aids Challenge. 2 May 2006. (www.southafrica.info/ess_info/sa_glance/health/aids/ciet-amathole.htm)

Engle, L. 1998. *Old AIDS. Body Positive.* (http://thebody.com/bp/jan98/old_aids.html)

FOOTNOTES:

1. UNAIDS. 2006 Report on the Global Epidemic, p9.
2. UNAIDS. 2006 Report on the Global Epidemic, p455.
3. Engle, 1998.
4. HIV and older people.(www.health24.com/medical/Condition_centres/777-792-814-1768,22151.asp)
5. UNAIDS. 2005 AIDS Epidemic Update, p10.
6. Du Guerny, 2002:1.
7. UNAIDS. 2005 AIDS Epidemic Update, pp5,7,10,14.
8. Du Guerney, 2002:2.
9. This article focuses primarily on the sexual transmission of HIV, as research indicates that this is the primary mode of transmission.
10. AIDS Epidemic Update, 2005:13
11. Engle, 1998.
12. Elderly take up AIDS Challenge, 2 May 2006.
13. HIV and older people.(www.health24.com/medical/Condition_centres/777-792-814-1768,22151.asp)

Emma Harvey is the Trainer/Facilitator at the AIDS Legal Network (ALN). For further information and/or comments, please contact her on +27 21 447 8435 or at emma@aln.org.za.

Busisiwe Maqungo

I am happy now...

PMTCT in South Africa: A personal reflection

It's been more than 6 years now, since I lost my nine month old child to AIDS. She really didn't have to die. Something could have been done to save her life. Her death was so premature and unnecessary. Thousands of young children died during that time. They died, because their mothers didn't know about their HIV status. Mostly, because there was no prevention of mother to child transmission (PMTCT) programme in place.

They were never given a chance to save the lives of their children. Today, we are still unnecessarily losing about 600 babies to AIDS. Back then, it was the government denying children a right to life. Today, it is their mothers.

When I was pregnant with Nomazizi, everything was fine with me. I never looked like someone who has AIDS. Back then, we were looking at the physical being of a person. We were looking for symptoms. If one shows no symptoms, then one is ok. That is why, even I, could not be bothered to find out about my HIV status. On top of everything else, I didn't know much about HIV. Women today are more educated about HIV. There are PMTCT programmes in almost every government antenatal clinic. It is up to a woman now to use that opportunity. It breaks my heart to know, that there are still a number of children born with HIV.

She was born on the 9th of April 1999. A month later, she fell sick with Diarrhoea, flu with temperature and pneumonia. When I took her to the hospital, the doctors thought that it was unusual for a child her age to have all these things at the same time. They suggested that I give permission to run various tests. One of the tests was going to be an HIV test. I wanted to know what it is exactly that was wrong with my baby.

It was on a Friday when they took her blood sample. I had to come back for the results on the Monday. It was an Elisa test. The baby had to be hospitalized, because she was very sick and dehydrated. Because I never thought I was infected with HIV, I expected the test results to come back negative.

On this Monday morning, I got the shock of my life. The doctor told me the baby tested positive for HIV. I could not believe this! That meant I was positive myself. But it needed to be confirmed. I went for a test and I tested positive for HIV. I was sent to a hospital social worker for counselling. At the time, I was more worried about my child. I thought she never deserved that. I was the one who knew about the existence of HIV, but chose to be ignorant. She really didn't have to suffer. I asked the social worker, how long she has to live. She told me about six to nine months. At nine months my child passed on. For the whole nine months, she was always in and out of hospital. She never got better.

Her death put me where I am today. I became an activist. I knew my child died, because I didn't know much about HIV, so I became an educator. I knew she died, because our government didn't care, so I became an activist. I was bitter inside. I felt my baby had been robbed of her life. I wanted to fight for justice. I had no idea where to start. That is when a friend of mine introduced me to the Treatment Action Campaign.

Together with TAC, we took the government to court for denying women and children their basic right. The right to life! The Constitution guarantees everyone the right to life. I knew a lot of children were dying, while our government was busy with submarines and arms. They just didn't care. Someone had to do something. There was no way we were going to tolerate and endure pain after apartheid. We chose this government. It had to work for us. We live in a democratic society! It was in 2001 when we went to court. The case dragged on until 2003. One needs to bear in mind, that the court was our last resort, after so many attempts of trying to convince our government to do the right thing.

In July 2002, the Constitutional Court ruled in our favour. We had won the case. It was a victory! I was the happiest person in the whole world. My child's death was not going to be in vain.

The next battle now was to see to it that mothers are kept healthy to care for their children. We entered into negotiations again with our government; with no luck at all. There was no more time or lives to be wasted. We never wanted any more orphans. We felt treating

...her death put me where I am today. I became an activist. I knew my child died, because I didn't know much about HIV, so I became an educator. I knew she died, because our government didn't care, so I became an activist...

mothers was part of PMTCT. What is the point of saving children, when their mothers are not going to be there? We had to go back to court. We had again to force our own elected government to do the right thing. South Africa is a constitutional country. The judge ruled in our (the people's) favour. We had won again.

It was after the High Court ruling in December 2001 that I thought I could have another child. All was well. There was PMTCT in place and ARVs to guard me, if I fall sick with AIDS. I fell pregnant in 2002 and gave birth to a beautiful boy the same year in

...just before he was born, I took one Nevirapine. I gave birth within 12 hours of taking it. When he was 12 months old, I took him for a test and he tested HIV negative....

December. I didn't just do it. I went through the right channels. I had to make sure I was healthy enough to carry a healthy HIV free child. I spoke to my doctor, who did all the blood tests, and confirmed my healthy status.

Just before he was born, I took one Nevirapine. I gave birth within 12 hours of taking it. When he was 12 months old, I took him for a test and he tested HIV negative. He is today one of the most healthy children in South Africa. I am happy now!

Busisiwe Maqungo is a Researcher and Treatment Literacy Practitioner at the Community Health Media Trust. For more information and/or comments, please contact her on +27 21 788 3971 or at busi@beatit.co.za.

Provincial Activities

Gahsiena van der Schaff

Feedback...

Prevention is an individual responsibility…

…we all realised after the meeting, that what most of us took as facts, were actually myths… [Limpopo Participant]

The second round of provincial networking meetings facilitated by the AIDS Legal Network (ALN) explored realities and challenges of HIV prevention. The meetings took place in the Northern Cape (4 October 2006), KwaZulu Natal (12 October 2006), Mpumalanga (25 October 2006), Limpopo (30 October 2006), Western Cape (2 November 2006), North West (9 November 2006), and the Free State (17 November 2006). At time of print the meeting in the Eastern Cape (22 November 2006) has not yet taken place.

The meetings were based within the framework that HIV prevention is proclaimed to be one of the main strategic areas in the response to the HIV and AIDS pandemics, while, at the same time, there are estimates of 1000 new HIV infections per day in our country; and that acknowledging this contradiction demands raising the question as to the efficiency of current HIV prevention efforts and strategies and as to whether or not HIV prevention strategies are indeed addressing the context in which people live their lives and make choices, including sexual choices.

The meetings were aimed to analyse the adequacy of current HIV prevention strategies; to explore the various societal factors influencing the effectiveness of HIV prevention strategies; as well as to assess whether or not there is a need for a broader scope of HIV prevention strategies.

HIV prevention, as identified by participants, is essentially about two things: access to, including the availability of, prevention tools and services, and participation in HIV prevention. Providing access to factual information, based on which informed decisions can be made and the right to informed consent can become a reality; access to prevention tools, such as femidoms, condoms, VCT; as well as access to healthcare was identified as the responsibility of the state.

…prevention is about access and participation, and creating a conducive environment to ensure maximum participation… engage municipalities and AIDS councils… [Mpumalanga Participant]

…issues of the unavailability and lack of access to femidoms were interpreted as … women are not *'supposed to'* be the one's making decisions about sexual matters...

The identified challenges to access to HIV prevention included, amongst other things, one's age, sex, gender, marital status, geographic location, and sexual orientation. Access to HIV prevention is also limited depending on where the facilities are situated (inside or outside the community), who the healthcare professionals on duty are, and whether or not the healthcare professional is a known person in the community. In addition, prevailing discriminatory attitudes, beliefs and practices from healthcare practitioners, including counsellors, were raised as one of the barriers to the access to HIV prevention.

Issues of the unavailability and lack of access to femidoms were raised in most meetings and interpreted as a reflection of existing societal beliefs, norms and values in that women are not *'supposed to'* be the one's making decisions about sexual matters. It is within this

context that participants highlighted as the *'biggest challenge'* the fact that healthcare professionals are from the same societal context as the users and thus, married women, for instance, will experience difficulties in accessing femidoms, since *'married women are not supposed to use any form of prevention'.*

A general lack of assured confidentiality at the facility was commonly raised as one of the challenges. Participants shared experiences pertaining to the violation of the right to confidentiality, including incidences of forced disclosure, and of professionals, who perform the HIV test, giving the test results to the counsellor, who, in turn, informs the user of her or his HIV status. In addition, it became evident that *'shared confidentiality'* appears to be the practice in some of the provinces. While in some cases facilities *'persuade'* and/or *'coerce'* users to inform their partners of their HIV status, in other cases the counsellors have a duty to inform supervisors, who, in turn, inform management that user *'so-and–so'* refuses to inform their sex partner.

> *…I will remember not to force anybody to go for testing…*
>
> [Limpopo Participant]

Recognising that available HIV prevention services do not define the extent to which these services are accessible, an individual's *'ability'* to participate in HIV prevention was identified as a factor influencing the effectiveness of HIV prevention strategies and programmes. The expressed rationale for the debate was that everyone who engages in sexual activities must participate in HIV prevention through, for instance, adopting safer sexual practices and accessing VCT.

> *…men and women have to communicate about safer sex, even though they are married…*
>
> [North West Participant]
>
> *…prevention is an individual responsibility…keep organising such gatherings…they are eye opening…* [Mpumalanga Participant]

However, the meetings revealed that the lack of personal responsibility for HIV prevention might be understood on an intellectual level, but not in practice. This was illustrated by various debates, including debates on how one could alter the right to privacy so as to be *'legally'* in the position to force people to disclose their HIV status in order to protect the partners of people living with HIV; or how one could put pressure on communities to test for HIV. In some provinces, participants would argue that when it comes to *'my protection'*, the other person's right to privacy cannot be protected, since *'my partner owes it to me'* to disclose her or his HIV status. Another issue strongly defended in some provinces, was the argument that people must be forced to test for HIV and to disclose their HIV status, because, *'if everyone knows their HIV status, the spread of HIV will be reduced'.* There was also the displayed sentiment that it would be *'easier, less problematic and take less time and efforts'* to force people to test for HIV and to disclose their status, than it would take to change the status quo of persistent and continued violation of rights based on one's sex, gender, sexual orientation and/or HIV status.

...participants would argue that when it comes to *'my protection'*, the other person's right to privacy cannot be protected, since *'my partner owes it to me'* to disclose her or his HIV status...

Participants felt strongly that the societal context (external environment) is not conducive and/or enabling to make individual informed choices to protect oneself from the risk of HIV infection. Issues raised in this context included prevailing gender inequality, as well as persistent justifications and acceptance of the status quo. An individual's *'ability'* to participate in HIV prevention, including access to available services, is influenced by the internal – own values, beliefs and norms (*'a common sense of what is right or wrong'*); individual knowledge (*'am I empowered enough to act on the knowledge'*) – as much as the external environment – values, beliefs and norms existing in society (*'it is wrong to have sex before marriage'*), as well as society's reluctance to accept individual choices – in which HIV prevention takes place.

> *…very thought provoking…I will remember most*

to change the internal self, before going to the community… [Western Cape Participant]

The need to re-evaluate the *'target groups'* for HIV prevention programmes and messages were also raised as one of the factors influencing the prevention environment.

Participants also identified advocacy and lobbying strategies and activities aimed at addressing various HIV prevention challenges and, simultaneously, intensifying HIV prevention efforts. Strategies included that individuals must be empowered through knowledge of facts; understanding of rights; and the *'know how'* of where to report the violation of rights. This *'empowerment'* also includes the understanding of the individual responsibility to prevent HIV infection. In addition, participants identified the need to raise awareness of the societal context in which HIV prevention takes place, including patriarchy, prevailing value, norm and beliefs systems, and acceptance of continued violations based on gender, sex, sexuality, age and/or one's HIV status, and how this is directly linked to the extent to which individuals are in the position to access and participate in HIV prevention.

…government needs to be challenged and revisit prevention strategies that have been enforced for 10 to 15 years and have not yet yielded positive results…e.g., high new infection rates, high teenage pregnancy rates, and the 'insights' of the ABC that even high ranking officials are ignoring… [Northern Cape Participant]

Other identified strategies included:

- Increased networking and sharing of knowledge, ideas and strategies, so as to learn from each other's experiences
- Communication as the key to effective HIV prevention (through for instance, door-to-door campaigns), as well as between partners
- Availability of femidoms – femidoms must be readily available and women must be made aware of the use of femidoms (through, for instance, door to door campaigns)
- Marketing of femidoms – femidoms must become a *'fashionable'* commodity
- Developing HIV prevention messages which give *'clear'* (not myths) information
- Learning and understanding rights (and the law) – rights are *'not just for communities'*, but for everyone
- Increase understanding of individual responsibility to prevent HIV transmission
- Create a supportive and enabling environment (free from prejudice and inequality), where facts inform choices and everyone's choice is respected and not judged

...the ... sentiment that it would be *'easier, less problematic and take less time and effort'* to force people to ... disclose their status, than it would take to change the status quo...

…it is always good to discuss certain issues, but the actual work start now with the implementation within every individual…

[Northern Cape Participant]

According to Anand Grover (2006) *'all living organisms, including human beings, are in a dynamic relationship with their environment'*. Thus, if the internal environment changes to one of knowledge, empowerment, and assertiveness, one will be in the position to participate in HIV prevention. Similarly, if the external environment changes to one, which is free of stigma, discrimination and violations of rights, based on one's sex, gender, sexuality and/or HIV status, one will feel *'free'* to access and participate in HIV prevention.

…the issue of participation in prevention needs to be addressed by the majority of the population, not only 25 participants…that would be a real positive outcome…

[Western Cape Participant]

Gahsiena van der Schaff is the Networking and Campaign Coordinator of the AIDS Legal Network (ALN). For more information and/or comments, please contact her on +27 21 447 8435 or at campaign@aln.org.za.

Mduduzi Mthembu

Influences that taint HIV prevention messaging

Current statistics[1] reflect that approximately 16, 2%, of the 1000 to 1400 new HIV infections daily in South Africa, are amongst young people aged 15 to 24 years of age. This is an alarming figure by any degree of argument, and certainly a catalyst for effective campaigning to drastically reduce new HIV infections amongst youth.

But young people are not the only people at risk of infection and, therefore, we need to start to recognise other vulnerable groups in developing HIV prevention messaging, and most importantly, we need to address and be cautious of, social influences that promote stigma and discrimination. Otherwise no HIV prevention strategy, no matter how brilliant, can reach its desired result to drastically reduce the rate of new HIV infections.

DENIALISM REFLECTS STIGMA

The South African Government's Comprehensive HIV and AIDS Care, Management and Treatment Programme (YEAR) has been implemented with a number of *'denialist messaging'*. The initial insistence that poverty, and not HIV, causes AIDS; the failure to promote antiretroviral treatment (ARVs) as the only proven medicine to reduce the prevalence of HIV in the body; and nutrition, as an effective supplement, and not an alternative to ARVs, are the main examples of a denialist government that has further fuelled the stigma attached to people that are living with HIV and AIDS. This non-acceptance has played a pivotal role in failing to prevent new HIV infections.

Perhaps, the focus on solely young people in our HIV prevention campaigns is a signal of a deeper and more silent denial. If we were to assume that young people are a micro of the macro society, then do their behaviour patterns not mirror those of mainstream society? Do we not just focus on young people to evade our fears of the influence of socialisation? The denial of our behavioural patterns, influenced by norms, culture and social prejudice, is evident in the messaging that our prevention campaigns carry, or not carry. And, perhaps, not seriously taking these *'influences'* into account could be one of the reasons why HIV prevention campaigns have, thus far, been ineffective.

INFLUENCE OF GENDER, CULTURE AND 'NORMS'

Rape and gender violence

55% of South African rape survivors are most likely to be young women between 16 to 25 years of age; and as high as 34,6% of rapists are relatives or intimates of these rape survivors.[2] These statistics are only fractions of the real picture, since countless rapes go unreported in South Africa, because of the stigma women have to endure if they decide to speak out.[3] The *'victim'* becomes the *'perpetrator'*. These young women and girls are usually scorned, loose access to important economic resources and are often chased from their own homes for taking away the only breadwinner (if the perpetrator ever even gets arrested).

Service delivery is another reflection of our own attitudes and prejudices, post-exposure prophylaxis (PEP) is supposedly available at most state health institutions and, yet, very few service providers administer it. Law enforcers interrogate *'victims'* in a fashion that blames them for the rape, because of suggestive clothing etc. This patriarchy, including the cultural hierarchy, that places *'men on top'* continues to make women *'submissive third class citizens'*; is reflected in all our gender interactions. If ABC prevention messaging is to work, then these attitudes need to be addressed immediately, because if not, then young girls and women, will not only continue to be victimised by society, but

also not being able to negotiate safer sex practices.

Jewkes[4] argues in the context of gender violence that:

> *In South Africa you have a culture where men believe that they are sexually entitled to women. You don't get rape in a situation where you don't get massive gender inequalities. One of the key problems in this country is that people who commit rape don't think they are doing anything wrong.*

...55% of South African rape survivors are most likely to be young women between 16 to 25 years of age; and as high as 34,6% of rapists are relatives or intimates of these rape survivors...

Polygamy, and multiple partner relationships, are not only culturally accepted in South Africa, but are also the *'norm'* in many communities. This *'culture'*, which solely exists to *'prove a man's status'* and affirm his masculinity, transcends itself in many informal ways. It socialises boys and young men to believe that *'women are trophies'*, to satisfy their needs and *'proof of their manhood'*. Girls and young women are socialised to not only accept, but also respect this aspect; which leaves females vulnerable, because they believe that their self-worth, as socially prescribed, is dependent on their faithfulness to this relationship, leaving females submissive to the instructions, and sometimes abusive commands, of their male partners.

Practices, such as *'ukungenwa'* – a practice where a widowed woman is required to marry her late husband's brother to fulfil her duties as a *'bought wife'*, or alternatively having to have sexual intercourse with her infertile husband's brother to further the family blood line, further compromise a women's dignity and freedom of choice.

These, and many other, traditional practices, continue to draw the gender lines and socialise young women to be *'susceptive to abusive men'*. These gender inequalities also lead to a situation where women are often not in a position to make informed choices about HIV prevention.

Male circumcision

Although a study[5], recently conducted in Orange Farm (Gauteng), found a 60% reduction in new HIV infections amongst males, who had been circumcised; cultural circumcision remains a high risk practice for not only new HIV infections, but also HIV and AIDS deaths.

Government's failure to formalise this cultural practice, and traditionalist society's closed ideology to change or adapt, leads to more and more of 17 to 24 year old Xhosa and Tswana *'boys'* to be subjected to a violation of their constitutionally guaranteed right to dignity, freedoms of choice and expression.[6] Young men are socially expected to go through this ritual, as a right of passage to manhood, and are subjected to the stigma that people, who are not culturally circumcised, are not *'real man'*. This type of discrimination takes away the power from these young men to assess the risks posed by cultural circumcision to their health and the freedom to choose a practitioner that they trust.

...this *'culture'*, which solely exists to *'prove a man's status'* and affirm his masculinity, ... socialises boys and young men to believe that *'women are trophies'*, to satisfy their needs and *'proof of their manhood'*...

Virginity testing

Virginity testing continues to make girls and young women vulnerable to sexual violence and discriminatory practices. In a country, where a culture of violence is a dominant feature, and has spawned attitudes, which are tolerant of sexual violence, girls and young women are *'prey to myths'*, such as that *'sleeping with a virgin can cure HIV'*. Not only do girls and young women become clear targets of rape, as a means of fulfilling *'curable claims'*, but as proclaimed virgins they are epitomised and celebrated as virtuous and are appointed husbands, mostly not by choice, who prize women as *'submissive bought objects'*, whose primary role it is to bear children and take good care of the man. The same man is *'socially expected'* to have mistresses on the side, and sometimes, even has the option of multiple *'virtuous wives'* at his disposal.

Girls and young women, who do not subscribe to the practice of virginity testing, or who are *'found to be non-virgins'*, are ridiculed and often blamed for any sexual violence, which may happen to them. The practice also makes no recognition of girls and young women, who were previously sexually assaulted, or even physically active in sport. Furthermore, it defies their constitutionally guaranteed rights to equality, dignity, privacy, and to be free from all forms of violence.[7]

HIV prevention campaigns, such as Lovelife, claim to be *'lifestyle brands'* that promote options to propagate choice to young people, and yet, amidst their unclear messaging, they fail to address social realities, such as the *'burdens'* of circumcision and virginity testing, which affect millions of South African youth. These cultural practices are often enforced by parents, guardians and the larger community, by means of *'moral blackmail'*, and play on the need to socially belong and be accepted. *'Lifestyle branding'* needs to advocate for making life-defining practices, such as male circumcision and virginity testing, an actual choice, and not a predetermined reality, for young people.

INFLUENCE OF PREJUDICE AND DISCRIMINATION

Our arrogance, as human beings, leads us to judge and morally prosecute *'those'*, who are different from *'us'* and *'those'*, whom we do not understand. Prominent minority groups in South Africa, who are in dire need of specific HIV prevention messaging and service delivery, which equally recognises them as equal citizen, largely feel the impact of these discriminatory acts.

...cultural practices are often enforced by parents, guardians and the larger community, by means of *'moral blackmail'*, and play on the need to socially belong and be accepted...

Migrant labour

South Africa's culture of a migrant labour force has created a platform for another *'high-risk group'*. Miners, truck drivers and impoverished rural dwellers, who seek work in more urban areas, are known to solicit commercial sex workers, or to have *'a string of mistresses'*, in the absence of their life partners.[8] Often, because of persisting gender inequalities, neither the *'solicited woman'* nor the life partner back home are in a position to negotiate safer sex practices. In addition, women often do not make use of health services, because of the moral judgment placed on them.

Generic HIV and AIDS interventions seem to have little, if any, impact in migrant settings and situations of high mobility. Stigma attached to the mobile population, and related *'industries'*, needs to be challenged, and models of intervention that are sensitive to the circumstances of mobile people need to be developed.

Lesbian, Gay, Bisexual, Transgendered and Intersex (LGBTI)

The gay, lesbian, bisexual and

...people may be ignorant sometimes, but they are not stupid and therefore quickly pick up on insincerity. We need to live what we teach and send out a uniform message...

transgendered communities have faced much of the blame, discrimination and prejudice linked with HIV/AIDS.[9]

The discrimination against LGBTI people has led to greater risk of, and vulnerability to, HIV infection. Research presented at the first African Congress on Sexual Health and Rights[10], showed that HIV and AIDS prevention and support programmes left lesbians and gays at greater risk of contracting HIV, because HIV prevention focused solely on heterosexuals. This marginalisation compounds the stigma that LGBTI people already face. Many LGBTI people are afraid to, or cannot, use healthcare services that would either assist to reduce or deal with HIV infection. Open safer sex education does not take place, because of prejudice towards same-sex relationships; and this creates a distinct disadvantage for LGBTI people, who are un-open about their relationships, because of fear of social prejudices.

Despite evidence of rising HIV prevalence rates in the LGBTI community[11], South African homosexuals are still finding themselves excluded from HIV prevention campaigns and programmes.

CHARTING FORWARD

The existence of HIV and AIDS reminds us that no matter how different we are, ultimately we are made of the same matter. It forces us, as a society, to examine the injustices we bestow on our fellow human beings. For effective HIV and AIDS prevention and management to take place we need to start addressing socio-economic issues, within the framework of the values enshrined in our constitution, that flawed our society even before the emergence of this epidemic.

We can do this first by being genuine in our awareness and educational programmes. We need to bring credibility and testimony to what we say or teach. How many gender activists do you know that teach equal gender dynamics by day and live gender stereotypes by night? How many HIV and AIDS activists and service providers teach condom use and later are seen pregnant or on treatment for a sexually transmitted illness? People may be ignorant sometimes, but they are not stupid and therefore quickly pick up on insincerity. We need to live what we teach and send out a uniform message.

The success of preventing new HIV infections lies in our ability to look beyond ourselves and truly start to understand those who are different from us and those who are motivated by different socio-economic factors. We need to implement integrated HIV prevention messaging that caters for everyone and promotes the values of a unified nation as celebrated in our Constitution.

FOOTNOTES:

1. 'War on HIV/AIDS demands a combined assault'. In: Cape Times, Tuesday, October 31 2006.
2. 'HIV and AIDS and gender-based violence'. (www.unicef.org/southafrica/hiv_aids_729.html)
3. Dempster, C. 'Rape: silent war on SA women'. (www.news.bbc.co.uk/2/hi/Africa/1909220.stm)
4. Ibid.
5. 'HIV/AIDS: Things we should know'. (www.southafrica.info/public_services/citizens/health/aids-findings-101205.htm)
6. Constitution of South Africa, Act 108 of 1996, Section 10, 12, and ??.
7. Constitution of South Africa, Act 108 of 1996, Section 9, 10, 12, and 14.
8. Crush, C. 'Spaces of Vulnerability: Migration and HIV/AIDS in South Africa. (www.queensu.ca/samp/cam-presources/samppublications/policyseries/policy24.htm)
9. 'Know your rights – Gays, Lesbians, Transgendered People'. AIDS Law Project, South Africa. (www.alp.org.za)
10. Behind the Mask. 'Gays neglected in HIV/AIDS campaigns'. (www.mask.org.za)
11. Behind the Mask. 'Gays neglected in HIV/AIDS campaigns'. (www.mask.org.za)

Mduduzi Mthembu is the Assistant Editor at the AIDS Legal Network (ALN). For more information and/or comments, please contact him on +27 21 447 8435 or at thami@aln.org.za.

Suzanne Leclerc-Madlala

What Prevents Prevention?

An overview of the sociological and gender context of HIV prevention in Southern Africa[1]

An awareness of the linkages between poverty, gender inequality and vulnerability to HIV and AIDS has informed most public discourses on women and AIDS in Southern Africa. Acknowledging these linkages has often led policy makers and others, tasked with programming HIV prevention, to interpret the prevention challenge as an effort in behavioural change, more specifically as an effort to change women's behaviour in order that women may better defend themselves against the HI virus. The erstwhile belief has long been that if women could become sufficiently skilled at negotiating safer sex, more active in decision-making around sex, more confident in expressing their views, more direct with their feelings and desires, and more able to have their opinions heard and respected by their partners, then the rapid spread of HIV would be halted in its pace, if not altogether stopped. Sadly, we chose to ignore the context of women's lives in this part of the world, and hence, our HIV prevention efforts have largely failed.

The Southern African regional AIDS epidemic, now referred to as a *'hyper-epidemic',* is still the undisputed epicentre for HIV and AIDS in the world.[2] The high rates of HIV are currently being sustained by mostly normative, everyday sexual activities between *'ordinary people'*, who have traditionally been thought of as *'low risk'*. At present, the focus is on discordant couples, who represent one of the fastest growing pools of new HIV infections in the region.[3] While we might acknowledge that gender inequality plus poverty is *'a deadly combination'* anywhere in the world, there can be no doubt that its specific expression in Southern Africa contributes to a context that places severe constraints on women's and men's abilities to protect themselves against HIV and AIDS.

There is a need to work towards changing the *'lethal context'* in which HIV and AIDS so seamlessly reproduces itself, and one place to start would be to identify the various shaping influences that have contributed to the building of this context. There are several major social inheritances or *'confluences of influence'* that I believe are foundational shapers of the current context in which our HIV prevention interventions are failing. For the sake of discussion let us focus on three broad streams of influence, those being 1) custom and tradition, 2) historic processes, and 3) modern trends.

CUSTOM AND TRADITION

Most all societies throughout Southern Africa are traditionally ***patrilineal*** with descent and affiliation passing along male lines from father to son. These societies practiced ***patrilocal*** residence at marriage, whereby the wife was brought to her husband's father's home or '*kraal',* and marriage was made legal and socially-recognised, through the payment of ***bridewealth*** (or *lobola*) by the husband's family to the wife's family. Bridewealth was, and still is, essentially a transfer of wealth from one group of men to another in exchange for jural rights over a particular woman and her children. Compared to all other regions in Africa, the eastern and southern African societies contracted marriage with a substantially large bridewealth, in some cases up to 11 heads of cattle. In some west African matrilineal societies for example, the value of bridewealth was relatively low, with several bolts of cloth and bottles of expensive liquor, or even a few months of bride-service (where a man worked for his in-laws), being sufficient to legitimate a marriage. The patrilineal/patrilocal social arrangement provided a supportive environment for what is popularly termed *'patriarchy'*, the system of power imbalances that favour men. Such a system promoted social values that upheld ***male privilege*** and prescribed roles for women that emphasised loyalty, humility, silence and *'respect'*. In such societies, the marriage bond between husband and wife was expected to take second place to the primary bonds of affiliation between brothers, or what scholars term *'agnatic kin'*. Here, the man's family of orientation (that in which he was

born) rather than his family of procreation (that which he makes with his wife) was expected to be the family which held a man's main loyalties and allegiances.

With the transfer of the relatively large bridewealth a man and his family secured many rights over their wives and children.

...one could argue that the current pervasive sexual networking patterns of concurrent multiple partnerships for men represent a modern evolution of polygyny. ...

Brideweath, along with the custom of the *'levirate'* or ***wife-inheritance***, also functioned to give women and children a large degree of social security in traditional societies. While bridewealth transfer is still part-and-parcel of modern marriage rituals throughout the sub-region, to some extent it represents an additional yoke that contributes to women's vulnerability to HIV and AIDS. Today, reference to bridewealth is frequently made to justify men's control over women and children, and to justify unsafe, condomless sex in marriage. It is also not uncommon for both men and women to justify both domestic and sexual violence on the grounds that a man has paid bridewealth. I would suggest that the bridewealth tradition also provides cultural reference for ***transactional sex***, which, beyond being a means of survival for poor women, studies suggest that the exchange of gifts, favours or money for sex is a normative expectation in most non-married relationships throughout the region. The popular stereotypical *'sugar-daddy'* is not a role reserved for a few rich men. Less well-off men can and do impress and attract girlfriends with their offers of cool drink, biscuits, rides in a car, or simple make-up. In one study conducted in rural Tanzania, a small bar of soap or a packet of peanuts was enough to get a man one round of sex.[4]

Polygyny, when it could be afforded, was the ideal traditional marriage arrangement in all indigenous Southern African societies. One could argue that the current pervasive sexual networking patterns of concurrent multiple partnerships for men represent a modern evolution of polygyny. A common scenario in the region today is one that might be described as *'monogamy de juror, polygyny de facto'*. A man may be legally married to one wife, but that does not preclude the possibility of one or several concurrent partnerships outside of marriage. Men's infidelity is to a large extent accepted and expected. I would also suggest that the tradition of polygyny helps to lend legitimacy to another of today's common sexual partnering practices in the region, which is ***intergenerational sex***. Where a man was allowed to have as many wives as he could afford, the most common pattern of wife acquisition was to take progressively younger and younger wives. Throughout the region today where wealthy Kings continue to have multiple wives, it is not unusual that wife number four or five is a young woman from the King's granddaughter's generation. The tradition of polygyny provides for both a cultural reference for intergenerational sexual liaisons and helps to socially legitimise its practice.

HISTORIC PROCESSES

Colonialism and its later manifestation of ***apartheid*** in varying degrees throughout the Southern African region have profoundly affected the gender and social contexts of people's lives. The introduction of ***Christianity*** with its new prescriptions for *'good and evil'*, achieving salvation and life-after-death for example, created much discordance with traditional values and ideologies. For one thing, all forms of pre-marital sex were considered sinful, and traditional ways of regulating the sexual activities of youth (i.e. various practices of non-penetrative, intra-crural sex) were considered to be morally unacceptable and stigmatised. The whole institutionalised system of elder sisters, *'aunties'*, age-mates and elders, who guided youth in their development towards adulthood was undermined. Disruptions in sexual socialisation were part of a much wider disruption in the communal socialisation of children more generally. The breakdown of traditional nurturance structures have not been adequately replaced by more western approaches to child rearing and methods of intergenerational communication on sex. The ***very limited communication*** on issues of sexuality in most African homes, as revealed in studies throughout the Southern Africa region, is leaving our youth extremely vulnerable, very ill-informed and poorly equipped to successfully negotiate their sexual debuts and subsequent sexual relationships.

Christianity, together with the introduction of the ***cash economy,***

labour migration and mobility placed many new stresses on family and communal life. Some studies reveal how bridewealth became increasingly more expensive over time, with the result being that marriage rates started to decrease while the rates of casual sexual partnerships, *'informal'* wives and illegitimate children started to increase. Men's traditional role as '*heads of households'* was undermined, as men moved to the cities and women were left behind to manage almost everything. Men became increasingly marginal to household processes and increasingly dependent on women. The ***'dethronement' of men*** that some have argued to be a significant contributor to the current high rates of gender-based violence, child abuse and HIV and AIDS in the region, had its origins back in the colonial era.[5]

Colonialism has also played a big part in helping to establish and normalise the ***structural violence*** that is pervasive in our part of the world today. Sexual violence appears to be endemic in the region. One study estimated that about 30% of adults in Southern Africa have experienced forced-sex before the age of 18.[6] Perhaps more than anything else the ghost of our colonial heritage and its step-child, the apartheid system, affects the region's engagement with HIV and AIDS by placing fundamental ***constraints on our ability to think and act*** when it comes to changing sexual behaviour to protect ourselves against the virus. It is almost certain, in any public debate or national conversation on HIV and AIDS, that the spectre of colonial racist representations of African people, as diseased and hyper-sexed, will be raised. That *'ugly ghost'* still lingers, and it causes people to refrain from a close examination or discussion of issues related to sex that is vital to our response to HIV and AIDS. This alone presents a huge challenge to the crafting of contextually-specific and closely tailored programming on HIV prevention in the region.

...it is almost certain, in any public debate or national conversation on HIV and AIDS, that the spectre of colonial racist representations of African people, as diseased and hyper-sexed, will be raised...

MODERN TRENDS

While ***urbanisation*** has been underway since colonial times, urbanisation today is not so readily linked to employment. Increasingly people are coming to cities and towns and not finding jobs. This creates a situation where frustration, hunger and poverty fester. Throughout the region, it is not only men who move to cities, but it is also women, alone or with children, who come to seek a better life. Studies indicate that the gap between rich and poor is increasing in many places, and in many instances prosperity and poverty are existing in close proximity and both are highly visible. A person living in a shack need not hop onto a plane to observe the manner in which the rich live. Most need only to look across the road. There does not appear to be much that constrains poor women from using their bodies to obtain some of the trappings of wealth or to partake in some of the fruits of *'the good life'*. Unfortunately, there also doesn't seem to be much that constrains men with money from exploiting the situation, and in so doing create a near-perfect context for transactional and intergenerational sex.

The demise of apartheid in South Africa and the embracing of neo-liberal policies have opened the flood-gates for the promotion of ***consumer values***. With it has come the creation of new needs and wants that have far out-paced the creation of new means to meet those needs and wants. In many homes, the television is used much like the radio, on during most of the day, providing background conversation, drama, comedy and violence to accompany the routines of domestic life. ***Foreign media imagery***, with its portrayal of modern life as fast, easy, prosperous and glamorous, helps to propel young women into transactional or intergenerational liaisons where their abilities to negotiate safer sex, and the incentives to do so, are limited. I would argue that in some ways the media also contributes to a sense of resignation amongst parents. Studies reveal that many parents in the region feel they have lost authority over their children. The images that are being conveyed via the mass media are so new, so different and so advanced from anything that the older generation has known before, that it causes parents to feel irrelevant and inadequate as people who are supposed to guide and advise the youth. In the context of our burgeoning AIDS hyper-epidemic, we

simply cannot afford to have parents relinquishing their role as parents.

While the ***changing roles, rights and expectations of women*** are hallmarks of modernity everywhere in the world, the emerging gender regimes have to be reconciled at the local level. Modern legislation to promote gender equality is in place in most Southern African countries. The need to empower women in order that they might have greater control over their lives, financially and physically, is viewed as a matter of urgency in the context of our regional response to HIV and AIDS. Yet, we haven't given enough thought to the consequences of women's empowerment in a context in which men's authority in the household and in society has been progressively undermined over the course of several generations. I would posit that many, if not most, men in Southern Africa consider the promotion of gender equality and expectations of a *'new gender order'* to be a further continuance of their own *'dethronement'*. For men it is a simple equation: women's empowerment equals men's disempowerment. One can only wonder about how much of our excessively high rates of rape, sexual assault, child molestation and all other manner of violation against women and their children, is directly or indirectly related to some sort of collective psychic trauma suffered by men, who perceive the very essence of their manhood to be constantly and continually under siege.

...the cost of maintaining socio-cultural norms and expectations that give men a false sense of power and contribute to the incredible vulnerability of women is literally killing us all...

CONCLUSION

For HIV prevention to be effective in Southern Africa it needs to take better cognisance of the many influences that have informed, and continue to inform, the local gender and sociological contexts that give meaning to peoples' lives. The real challenge is to effectively address the lethal context in which poverty, socio-cultural norms and expectations, gender and HIV and AIDS intersect and interact to catalyse the spread of HIV. Policy and programmatic approaches that aim to challenge and transform norms and expectations are required for the creation of a less violent and more gender-equitable environment in which HIV prevention is possible. Ways need to be found that empower men to resist and challenge those social scripts that condone an aggressive masculinity that is uncaring, uncooperative, unfaithful and ultimately unchangeable. At the same time, these efforts need to affirm new constructions of manhood and assist men to at the least accept, if not embrace, a new gender order.

The sociological and gender work that is required to make a real impact on HIV and AIDS in the region is nothing short of substantial. It means replacing many old habits of thought and behaviour that have developed over long periods of time, and replacing them with new thoughts and behaviours that are often perceived as being counter to much of which is held sacred and dear in the name of culture or tradition. Yet, the cost of maintaining socio-cultural norms and expectations that give men a false sense of power and contribute to the incredible vulnerability of women is literally killing us all. High-risk notions of masculinity that propel the growth of HIV and AIDS must be put firmly on a social transformational agenda. If we are serious about preventing the future growth of HIV and AIDS in the region, we have little choice, but to try to change the way in which we currently conceive, construct and express our gendered social selves.

FOOTNOTES:

1. This article is based on a paper presented at the International AIDS Conference held in Toronto 2006.
2. Wilson, D. 2006. *HIV Epidemiology: A Review of Recent Trends and Lessons.* Paper presented at UNAIDS Special Meeting on Behavioural Change and HIV. Geneva, 13 September.
3. O'Reilley, K. 2006. *Counseling, Testing, Discordancy.* Paper presented at Expert Meeting on HIV Prevention in High-Prevalence Countries in Southern Africa. Maseru, 10-12 May.
4. Plummer, M. et al. 2004. 'A bit more truthful': The validity of adolescent sexual behaviour data collected in rural northern Tanzania using five methods. *Sexually Transmitted Infections*, 80:49-56.
5. For more discussion on men's historic dis-empowerment see Rebombo, D. 2006. 'Dethroned men' …an underlying factor fuelling the pandemic? In: *ALQ*, June 2006.
6. This estimated is based on a SADC regional study conducted by CIET*Africa* and presented in a paper entitled *Gender-Based Violence* by N. Andersson. Presented at Expert Meeting on HIV Prevention in High-Prevalence Countries in Southern Africa. Maseru, 10-12 May, 2006.

Suzanne Leclerc-Madlala is the Head of Anthropology at the Howard College Campus at the University of KwaZulu Natal. For more information and/or comments, please contact her on +27 31 260 2387 or at leclercmadlals@ukzn.ac.za.

Sipho Fakude

The challenges facing HIV prevention programmes

> *For almost a quarter of a century, we have experienced the collective and personal tragedy that is AIDS. 25 years of fear, 25 years of illness, 25 years of death and 25 years of courage.* [Richard Pratt, 2003]

What seemed as a simple disease, in our laboratories, when it started, has today plunged the world into a crisis. Children have been orphaned; grandparents are raising children for the second time, due to deaths and illness of their infected parents. The challenge to establish what should be done to turn the pandemic around remains. In our efforts to respond to the pandemic, various questions need to be raised, including whether or not we are doing enough to prevent further HIV infection; whether or not the HIV approaches and strategies in place are indeed effective – or are we wasting time?

The *'lion is in the house'*, and we need to do all what it takes to turn the tide against pandemic. And, right now, the greatest instrument at our disposal is *'prevention'*. But, how do we prevent HIV transmission; and when and why must we prevent the spread of HIV? We are losing our sisters and brothers to this pandemic, not because the pandemic is 'a warrior', as so many people depict it, but because we seem to give in to denial. We succumb to the disease, because of cultural and religious barriers, which perpetuate the spread of HIV. We succumb, due to our attitudes and behaviours. How can we effectively prevent HIV infection, if there are still people who think HIV is *'a disease for prostitutes'*, a *'curse from the creator'*? One night, attending a night vigil, I heard the preacher say to the congregants: *'people are dying like flies, due to ill behaviours, prostitution, and I won't go and preach, if asked to bury a person who died of AIDS, since it is an abomination against God'.*

If we continuously hear such remarks from public figures, where are we going as a nation in the response to the pandemic? A woman, delivering a testimony in church, talked about all the good things God did for her. In her closing remarks, she was talking about how young people are behaving, and the things young people do, which are abominations to God. She concluded by saying: *'AIDS would not get me. Why? Because HIV is fair and only people who choose to have sex before marriages are susceptible to the disease'.*

While it is good for young people not to rush into sexual intercourse, before attaining negotiation powers and being able to make informed decisions, we must be very cautious in passing these judgements. We seem to turn a blind eye on the real issue, which is that sex is sex, married or unmarried, young or old and that engaging in unprotected sex is the greatest risk of HIV infection.

The above issues highlight how reality exacerbates the challenges we are facing when dealing with HIV, and how our own attitudes and beliefs *'nurture'* the pandemic in our community. If we say people who are infected with the HI virus are *'those who choose to have it',* then what are we saying about children, who do not even know about sex, but who are raped every day on account of perpetrators believing that their HIV status will be cured. And what are we saying about the faithful woman, who is infected with HIV, since she could not negotiate conditions of sex, including condom use, in her marriage, due to culture and the patriarchal society we are living in? How can we progress in our HIV prevention efforts, when women have to *'prove*

their worthiness', through giving birth and expanding the family? And when questioning this, one is told that it is *'our culture'*.

One other factor that exacerbates the challenge is the economic dependency, with mostly women falling *'victims'* to this. Many women are exploited on account of man being the sole *'breadwinner'* and, subsequently, women are left with no power to negotiate. Most people involved in HIV and AIDS activities are mostly women, who are expected to instil their learning on their families and homes. Often this initiated *'process of change'* poses a serious challenge to women, since women become *'targets'* and are vulnerable. Klouda [as quoted by van der Vliet, 1992:797] argues that:

> *…the critical factors in controlling the epidemic do not lie among people who make choices, but rather among those who cannot – especially the poorest, least powerful, most vulnerable and most isolated.*

A family man once raped his child and when the mother discovered the rape, she laid a charge against the man. As a result, she became very *'unpopular'* in the family. Everyone said she should not have laid charges; rather have the family deal with the matter internally. With incidences like these, it is really challenging to prevent the spread of HIV and AIDS in our communities.

One also wonders how we assist girl children, who resort to *'prostitution',* due to unbearable living conditions, with HIV prevention. The fact that girl children have to use their bodies to get the next slice of bread, places them at very high risk of HIV infection. This is but one of the examples indicating that HIV prevention strategies should be diverse and also embrace socio-economic aspects, such as special needs of child-headed households and poverty alleviation programmes.

In a forum of young people from different sectors, looking at why there are still new HIV infections on a daily basis, even though there are information about HIV everywhere, participants stated that:

> *…people who are dangerous are the activists [HIV and AIDS], because they end up thinking they are immune to the virus. When I am involved in an affair for three months with the person, I begin to trust the person without knowing our HIV status and then, we forget to use a condom – this is ignorance.*

A female participant suggested that:

> *…men should advocate for a massive supply of female condoms, because it can be worn 8 hours prior to sexual intercourse, while the male condom needs a man to be erect, before it can fit, and some men get carried away and regret afterwards.*

While this may sound like a workable suggestion, one has to ask how likely is this to happen, considering the patriarchal society we live in?

We also need to look at the psychological impact of the writings and speeches we used to hear at the inception of the pandemic. This is not an attempt to justify, but instead a reminder to be mindful of the impact of sentences, such as *'beware AIDS kills'* (*'umashayabhuqe ubhubhane'*) presenting fear and stigma. And sitting on the bench waiting for one's turn in the counselling room, one remembers all the many times one heard of the message that *'AIDS kills'*. While some will leave, some will stay and get tested for HIV, but will not come back for the test results. We heard so many people saying *'it is better not to know, than to know, that I am infected'.*

Goldstein [1989:84] argues that *'many illnesses transform their victims into a stigmatised class, but AIDS is the first epidemic to take stigmatized classes and makes them victims'.*

We have to ask ourselves how many people we have driven to suicide, by not accepting their HIV status, rejecting them from their own land, family and friends. Stigma is a silent killer and an obstacle to HIV prevention. Why should people test for HIV, when we just want to *'gamble'* with their HIV status and not assisting them? An illustration of this is also the limited number of males in the HIV testing rows, since many men use *'proxy testing'* – *'my wife*

gave birth to a healthy child and, therefore, I know I am not infected'. Needless to say, this perception perpetuates the further spread of HIV in communities.

A further challenge is the HIV messages conveyed to the community, through billboards, pamphlets and newsletters. In some areas these billboards are not even written in the local language for people to understand and this is how we sometimes miss the point of HIV messages.

How are we going to prevent the spread of HIV and AIDS, when it is still difficult for people to test for HIV, due to the stigma that we have not addressed thus far? In many instances, people have been diagnosed with HIV and their confidentiality not observed by the service personnel.

In addition, there is a lack of a proper referral system from the hospital to the community carers. Pratt [2003] argues:

> *Many patients with late symptomatic disease (AIDS) will require community-nursing services at some point in their illness. Successful community nursing care is in part dependent upon good discharged planning procedures when patients are in hospital.*

The hospitals are often not aware of the environment, where the patient is going after being discharged from the hospital. The people who are close to this environment are the home-based carers. However, there is no adequate mechanism of referring the patient from one level of care to the other.

There is also the further burden, carried by home-based carers, who have to care for a patient without the necessary materials, such as gloves, linen, etc, to support and care for the patient and to minimise their own risk of HIV infection. The question is, who looks after, and is responsible for, the well-being of home-based carers? What is needed, is sufficient supply of material, as well as provision of ongoing support, including psychological support, so that home-based carers can improve and sustain the service. The reality is, however, that home-based carers help people and often use their own limited resources to do so.

These are some of the realities, which present serious challenges to the effectiveness of HIV prevention strategies. And, until we address these issues, HIV strategies and programmes will be stagnant. We have to embrace the set of diverse actors in responding to the HIV and AIDS pandemics. And more importantly, we need to acknowledge that our behaviours need to change, and that we first need to deal with our own attitudes, beliefs and behaviours, before we can go to the community and roll-out HIV prevention strategies and programmes.

REFERENCES

Goldstein, R. 1989. 'AIDS and the Social Contract'. In: Carter, E. & Watney, S. (Eds.) *Taking Liberties.* London: Serpent's Tail.

Pratt, J. 2003. *HIV and AIDS: A foundation for nursing and healthcare practice*. Fifth Edition. Edward Arnold.

Van der Vliet, V. 1996. *The politics of AIDS.* London: Bowerdean.

Sipho Fakude is the Project Coordinator at the Phaphamani Home-Based Care Centre. For further information and/or comments, please contact him on +27 13 796 1624 or at sipho@phaphamani.com.

Kent Klindera

Behaviour Change Communication Strategies

as a means to help young people avoid HIV and AIDS[1]

By nature, *'youth'* is a period in a person's life to explore. Young people begin developing their own identity and values, moving away from that of their parents and family. They often are influenced by their peers, the media and other outside experiences. Another aspect of this transition is puberty, the time when young peoples' bodies begin transforming into adults. This period in life is full of excitement and challenges. Unfortunately, very little guidance is offered by parents, families, community leaders, and other adults to assist youth through this transition, especially related to understanding their sexuality and reproduction. Too often, sexual exploration during this transition can place young people at risk of HIV infection. No where is this more evident than in Southern Africa, where currently, in some countries, roughly one-third of the 15-24 year olds are infected with HIV.

For years, programme planners and policy makers have been developing strategies to assist young people in adopting healthy behaviours related to HIV and AIDS. At stake are not only individual lives, but family and community structures, as well as entire national economies, as young people often make up the economic powerhouse of emerging economies – the workforce. In low socio-economic areas, youth often provide supplemental income to families. In some cases, they may be the primary breadwinners for households. Thus, powerful interventions are needed to slow the destruction of HIV and AIDS amongst young people.

Fortunately, youth have the capacity to overcome these challenges. With creativity and science, programme planners and policymakers can develop programmes that assist youth through this transition. The most successful interventions harness the energy and drive of youth and combine it with theoretical and science-based approaches to develop healthy behaviours. The following document is a summary of *theoretical approaches and effective strategies* for working with youth, specifically in Southern Africa.[2]

WHAT DOES THEORY SAY ABOUT ADOPTING HEALTHY BEHAVIOURS?

For many young people, as is true with most people, adopting healthy behaviours can prove difficult. For example, the very essence of a youthful identity is a feeling of inevitability – that youth have future lives ahead and nothing is going to stop them. Research suggests that for youth, the connection between decisions made today do not always translate into consequences in the future. Thus, effective programmes need to take this factor, among others, into consideration.

The adoption of healthy behaviours is not a simple process of providing information to people and then watching them change. Years of research has proven that knowledge alone will not assist young people in adopting the behaviours needed to prevent the spread of HIV and AIDS. Additional factors play a role in assisting the youth.

The following is a list of components that summarises what young people need to adopt healthy behaviours.[3]

- **Information** about the need to be healthy
- **Motivation** to be healthy
- **Skills** to initiate and sustain behaviour
- **Belief** that the change is possible and positive
- **Community Norms** that support the behaviour

- **Supportive Environment** to enable the behaviour
- **Policy Structures supporting the** behaviour

Programme planners and policy makers need to take this theoretical framework into consideration in developing programmes.

INFORMATION is vital for young people to make healthy decisions. Information about HIV and AIDS, other STIs and unwanted pregnancy is needed to get attention of youth of the need for safer behaviours. Research indicates that throughout Southern Africa, many young people lack basic information regarding HIV and AIDS. One study in Botswana showed that two thirds of students in their final year of secondary school could *'tell if someone had HIV'*.[4]

Unfortunately, for those programmes that *are* offering information, many fail to go beyond information strategies. These programmes inform youth and expect them to adopt healthy behaviours on their own.

Additionally, information related to sexual health can be difficult for some programmes to confront. Taboos around discussing issues of sex and sexuality make it difficult for programme implementers to bring up the subject. As well, some programmes do not provide adequate and full information (e.g. abstinence-only sexuality education). These programmes are based on the assumption that informing youth about sexual intercourse, including the use of condoms, will encourage youth to practice more sexual behaviour. Research throughout the world suggests, however, that providing youth with full accurate information related to sexual health, and allowing them to make their own decisions, is the most successful strategy. Sexual behaviour rates are not increased, however, safer sexual practices, such as condom use, are.[5]

Young people need MOTIVATION to want to be healthy. What motivates young people? For years, researchers have experimented with various strategies, identifying various successes in the process. By far, the most successful motivator is a bright future. Youth want to feel that their future will be positive, with economic attainment and a healthy family life, among other things. Thus, for this example, to motivate youth, programmes need to help young people begin thinking about ways in which their decisions today may affect that bright future. Messages should focus on how becoming infected with HIV, or to have an unwanted pregnancy, may disrupt a young person's plans of achieving their goals.

Additional motivators include:

- self reliance – being able to take care of oneself
- activism – being linked to a process of societal change
- feeling valued – linkage to adults that value the young person
- authenticity – living a life that seeks truths
- identity – formulating a unique identity

Young people need LIFE-SKILLS-BASED HIV AND AIDS EDUCATION. Ask any young person in Southern Africa and they will say how tired they are of hearing about HIV and AIDS, the transmission routes, the means to protect oneself. Many have the information, however, they often do not know what to do with this information.

In most projects, programme planners and policy makers identify a message, post it around, hand out information about HIV and AIDS and expect youth to comply. Researchers[6] have found, however, that life skills-based HIV and AIDS education is a key factor in assisting youth adopting healthy behaviours. Thus, programmes need to add a skills-building component – taking the information and motivation, and turning it into a concrete action young people can take to protect themselves. The researchers also indicate that these skills-building sessions need to be reinforced over time. A one-hour session is not enough – rather 10-20 hours is the norm.

For example, communication is a key skill needed to navigate the tricky world of romantic relationships. Young women and men can pressure each other into sex when one partner may not be ready. Young people need skills-building sessions, including role playing, that allow youth to explore the skills needed to communicate assertively, as well as developing good listening skills.[7]

Young people need to believe that they have the ability to change themselves – SELF EFFICACY. Many young people are raised in environments whereby they do not think they have *'the ability'* to perform certain functions. Various factors, such as sexism, racism, ageism, and xenophobia disempower youth, creating a basis by which youth do not feel confident that they can perform the function necessary to protect themselves from HIV.[8] For example, young women are culturally biased towards deferring to men in decision-making. When it comes to deciding if a couple should use a condom, if the man does not want to, a woman with low self-esteem can be hesitant to demand that a condom is used.

To address self-efficacy, programmes should adopt empowerment messages, helping young people recognise that they have the ability to adopt safer behaviours. Effective programmes also need to create an empowering environment to assist young people in recognising that they can control their actions and make changes.

COMMUNITY NORMS related to healthy behaviours is an important component of a theoretical approach. Young people are influenced greatly by their peers. Part of the process of adolescent development is youth creating their own identity – separate from their parents and family. Therefore, friends and other peers become extremely important in the values and behaviours young people adopt.

Research[9] indicates that if young people perceive their peers to be acting out certain behaviour, they will comply. It does not even have to be true, as long as youth *'perceive'* their peers to be doing so. Thus, peer education is an excellent strategy, because it helps build set community norms related to sexual health. For example, if a project is promoting abstinence and peer educators promote a message that abstinence is cool, it is much more likely to be adopted.

Young people need SUPPORTIVE ENVIRONMENTS for healthy behaviours. In addition to peers, other parts of a young person's environment need to be supportive. If a young person's environment is not supportive of healthy behaviours, it is much more difficult for them to adopt the behaviour.[10] For example, if a programme is promoting condom use, and, attitudes amongst teachers, faith leaders, health professionals and parents are against youth using condoms, it will be very difficult for young people to obtain condoms and feel comfortable using them.

This environment includes school, parents, family, faith community, health services and community in general. Thus, programmes should seek out ways to include the entire community in an intervention. One example may be to have a message that is targeted at young people, but also their parents/families and communities. A coordinated message, which is reinforced from various sectors of a young person's life, is a definite boost to success of a project.

POLICY STRUCTURES need to be in place to promote sexual health. From governments to organisations, policies are essential to assist young people in adopting healthy behaviours. Too often, well intentioned, but restrictive, policies exist that inhibit young people's sexual health. For example, if a young person needs their parents' consent to get tested for HIV, they may be much more unlikely to get tested, as many do not necessarily want to inform their parents of their sexual behaviour.

Programme planners need to work in coalition, to review policies related to young people's sexual heath and to ensure that these policies are not working against the goals and objectives of the project. If there are restrictive policies, programmes should include components to address such policies. Youth leaders and adult professionals must promote policies that respect the rights of both youth and parents, and promote sexual health.

WHAT ARE BEST PRACTICE INTERVENTIONS?

So, what works in reaching young people? The following is a list of evidence-based strategies that have proven successful in assisting young people in adapting healthy behaviours to minimise the risk of HIV infection. There are two basic components that are evident

throughout all successful programmes, followed by a list of specific strategies that can be used in conjunction with each other or by themselves.[11]

WHAT ARE THE BASIC COMPONENTS NEEDED FOR EVERY PROGRAMME?

Involve Youth: Effective programmes need to be based in realism; addressing the true needs of youth. Successful interventions have attained this realism by using a most basic strategy: involving the target audience. Indeed, many young people have the knowledge and skills to be a part of programme design, development, implementation and evaluation. Young people are not seeking to take over what adult professionals are doing, they do, however, seek to partner with adults to ensure a realistic intervention. Successful programmes begin with a sense of *'youth-adult partnership'*.

Involving youth is easier said than done. Various factors, such as traditional culture's view of the role of young people, can hamper such efforts. Basic things, such as logistics, can make youth-adult partnerships difficult. Too often, youth are not available during business hours (on account of school or other commitments) and adult professionals often have families to care for after hours. A simple action, such as finding time to hold a meeting between youth and adults can prove difficult.

Tailor Programmes for Specific Types of Youth: Youth populations are diverse. In any country there are rural and urban youth, male and female, rich and poor, in school and out of school, to name a few of the differences. Interventions for one population are not necessarily transferable to other populations. For example, messages for young women about communicating assertively with potential sexual partners will be received differently by young men. Thus, effective behaviour change communication strategies tailor programmes for the unique circumstances of differing young people. Comprehensive programmes may offer specific sub-projects for specific target groups. For example, a programme may have a gender empowerment project that works separately with young women and men to meet the specific needs of the differing genders.

These differences need to be examined during the planning, implementation and evaluation of programmes. Programme planners and policy makers need to recognise the specific needs of some young people that are in higher risk situations. Specifically, some youth are forced into commercial sex work and need specific interventions to assist them. Similarly, other groups of youth in higher risk situations include women/girls in general (based on gender norms that deny women their rights), out-of-school youth, homeless youth, migrating youth, and same-sex attracted youth (e.g. homosexual or bisexual), to name a few.

Address Gender Inequalities and Stigma: Data indicates that young women are adversely infected and affected by HIV, compared to young men. Thus, effective programmes need to address gender inequalities. For example, programmes need to engage in efforts to improve girls' and young women's opportunities to obtain education and skills training. In addition, boys and young men need to be engaged in processes to redefine *'masculinity'*. Along this same line, boys and young men need to be given skills to communicate more equally and openly with romantic partners, and taught that violence against women and coercive sexual behaviour is not a characteristic of *'real men'*.

In a similar light, stigma, related to people infected and affected by HIV and AIDS, increases the risk for youth. Research indicates the main causes of HIV-related stigma are incomplete knowledge, fears of death and disease, sexual norms and the lack of recognition of stigma.[12] Thus, programme planners need to continue to raise awareness about the reality of HIV and AIDS transmission, and correcting myths about how HIV can be spread (e.g. that HIV is not spread by sharing eating utensils). In addition, programmes need to encourage community-wide dialogues related to sensitive subjects, such as sexuality.

Promote Specific Messages about Small, Doable Actions: If youth are asked to adopt behaviour, the message

must be clear, realistic and concise. For example, *'Play it Safe'* is a clear message about what needs to be done; however, it needs to be followed up with clear directions. *'Abstain, Be Faithful, Condomise* (ABC)' is a clear message that reaches across a spectrum of youth, and is realistic. These messages need to be reinforced throughout the intervention using various forms of communication. Specific mediums include:

- Small print (e.g. posters, pamphlets, stickers, cards)
- Large print (e.g. billboards)
- Mass Media (e.g. newspapers, magazines, radio, television)

Link to Comprehensive HIV and AIDS Programmes: Effective HIV and AIDS related behavioural change communication programmes for youth are also linked to comprehensive programmes. Thus, programmes offer a continuum of care between HIV prevention, testing, treatment and care. For example, if a project is promoting condom use for sexually active youth, the programme should have linkages to clinical services, meeting the needs of young people who want to test for HIV and/or potentially receive treatment, if testing positive for the virus.

WHAT ARE SPECIFIC STRATEGIES THAT SHOULD BE COMBINED TO WORK?

Youth Development Approaches: Too often, youth-specific HIV and AIDS interventions focus on immediate aspects of HIV prevention (e.g. abstain, be faithful, condomise). However, young people have different needs related to their risks for HIV. Ask any group of youth what their needs are and most will say that it is economic attainment (e.g. good job) or healthy romantic relationships (e.g. boyfriend/girlfriend). Thus, successful programmes integrate *'youth development'* approaches that indirectly address HIV and AIDS issues, focusing on building the self-efficacy of the individual, as opposed to the direct HIV and AIDS messages. For example, many successful HIV and AIDS behaviour change programmes contain a *'livelihood'* component, offering youth a job skill, such as computer literacy. Thus, youth are drawn to the programme, because they will be offered skills that will assist in getting a job. While young people are getting important information, motivation and skills related to HIV and AIDS, they also are gaining skills to achieve economic attainment.

Life skills-based HIV and AIDS education is an extension of a *'youth development approach'*. This form of education assist young people in developing *'skills for life'* that have direct linkages to HIV prevention. These skills include value clarification, goal setting, communication, relationship-building, decision making, to name a few. Successful HIV and AIDS related behavioural change communication programmes typically employ such life skills approaches.

The main disadvantages of a *'youth development'* approach are costs, as livelihood initiatives, focusing on economic attainment, are expensive. Most NGOs promoting sexual health are not setup to offer non-health related services. This type of approach may require hiring staff with diverse expertise, as well as investing in capital expenditures. Youth development approaches can also shift an organisation's mission, as these approaches demand the offering of new types of services. To meet this need, organisations may consider partnering with other NGOs that are already offering such youth development approaches.

There are numerous types of *'youth development'* approaches to HIV and AIDS behaviour change interventions. Popular examples include, amongst others, mentoring (establishing meaningful one-on-one relationships between an adult and a youth); youth leadership programmes (offering skills-building and empowerment programmes for young people empowering young people to be leaders); and involving young people in advocacy efforts for social change.

Edutainment: Traditional discourse in African societies used drama as a tool to inform and involve communities in making decisions about the well-being of the community and individuals. In modern times, music and entertainment is still a powerful message bearer for HIV and AIDS interventions. Powered by an *'MTV generation',* young people are more likely

to tune into healthy behaviours, if the message is delivered in an entertaining way. Working through entertainers, such as local musicians, often can turn negative messages into positive ones; highlighting young people's desire to do well in the world. Thus, successful programmes have been able to engage music, drama, poetry, and the visual arts to entertain young people while being educated.

Disadvantages of Edutainment approaches include the costs of hiring performers, as well as costs involved in stages, lighting and sound systems. As well, Edutainment strategies can lack depth, as young people are more entertained, than they are educated. Successful programmes recognise that performance artists need to be trained to be HIV and AIDS educators, adding a new dimension to their talent as performers.

Mass Media: Related to Edutainment, mass media offers a means to reach a large number of young people at one time. Although, the message is not as deep as one on one conversation, sustaining community norms and creating enabling environments are enhanced with messages repeated through mass media, such as radio, television, billboards, and websites. In the modern age, young people are often far more technologically and media savvy, than their parents' generation, and, hence, reaching youth through mass media is appropriate.[13]

There are several disadvantages to this approach, however, primarily related to costs. For example, renting space on billboards, radio or television is extremely expensive, and that is after expenditure for production of the advertisements. In using mass media channels, programme implementers also need to be careful that they are using messages, which are coordinated or linked to local, national and international campaigns already occurring. The public can be confused when several mass media campaigns are operating at the same time. Finally, such visibility for a campaign can also alert and ignite opposition to efforts around sexual health and youth. Therefore, programme planners need to be prepared to handle potential criticism.

Peer Education: Often used as a strategy for young people, peer education is still one of the most effective ways to build motivation and create community norms related to HIV and AIDS interventions. Peer education embodies social learning theory about positive social norms. Thus, if the goal of the project is to delay the onset of sexual debut, to have younger adolescents talk to other younger adolescents about how they are abstaining is an effective strategy.

In addition to reaching a target audience, peer education programmes also have impact on the peer educators themselves. These young educators are trained to help others adopt healthy behaviours, which also can be applied to their own behaviour. Thus, programme implementers should look at outcomes at two levels, measuring the impact the peer education programme has on the audience, as well as the impact on the peer educators themselves.

There are several disadvantages to using peer educators. Firstly, heavy emphasis must be placed on training peer educators. This training often needs to be repeated on an annual basis, as young people are often in transition and not available from year to year. Volunteer peer education programmes also have to compete with various other opportunities for young people, especially when young people are in need of income, as they may need to provide economic resources for their household.

School-based Programmes: Working within school-based settings is an efficient way of reaching a large group of youth. Formal school settings offer a ready audience, as well as teaching structures to roll out a sustainable programme. For example, a life skills-based HIV and AIDS curriculum can be developed to be taught in a school setting. Teachers can be trained to implement the programme and it can be sustained for years.

To the contrary, school-based programmes can be limiting in reaching youth, especially those in higher risk situations. School-based approaches are best for reaching *'mainstream'* youth; however, they should be offered in parallel process with

programmes to reach out-of-school youth. In addition, school administrators and bureaucracies can limit the message of a campaign, as the school is often responsible to the community, who may be more conservative than programme planners.

Youth Friendly Health Services: Many behavioural change communication programmes for youth ask youth to seek out sexual and reproductive services (e.g. VCT, PMTCT, contraceptive services). Unfortunately, youth often have negative experiences, when interacting with adult service providers, based on attitudes. Namely, many adult service providers hold attitudes against pre-martial sex. Thus, for example, if a project is promoting HIV testing and a young person has a difficult experience at the testing site, or is denied a condom, how is the project really going to get the young person to listen again?

Training needs to be offered to reproductive and sexual health service providers on developing youth-friendly HIV and AIDS services. The training needs to focus on the delivery of quality services, and assisting the providers in changing their attitudes related to young people's sexuality, or at least holding their attitudes to themselves. In addition, many successful programmes that employ youth-friendly services ask youth to define *'youth friendly'* themselves, and then work with the providers to ensure such a setting is developed. In some cases, youth serve on advisory boards, are hired to work in the clinics, or peer education programmes are run out of the health facility.

Disadvantages to this approach include the fact that young people do not often feel the need to attend health service facilities, as they are invisible and never going to be sick. As well, health services facilities can often have limited resources, in terms of both human and financial. Asking health service providers to add additional activities to their workload may prove impossible.

CONCLUSION

These are numerous examples of effective HIV and AIDS-related youth-specific behavioural change communication interventions. Many are multi-faceted programmes, working to reach youth with a consistent message, through numerous ways and channels. While this overview is by no means a comprehensive list of programmes, it is, however, highlighting promising theory-based strategies and model programmes that have shown success. There is always potential for additional innovative programming to be developed and documented. In addition, with the energy and insight that young people themselves bring to such programme development and implementation, there will always be additional ground-breaking interventions created to lessen the impact of HIV and AIDS on individuals, families, communities, and countries in the SADC region.

FOOTNOTES:

1. This article is based on an Issue Brief prepared for the SADC/EU Cross Border Initiative on Youth and HIV/AIDS. The findings were drawn from a review of various behaviour change communication strategies and programmes in the SADC region, including Dzalobana Bosele Arts Festival (Botswana), Nchanda ni Nchanda (Malawi), Trendsetters (Zambia), and an initiative by the Zimbabwe National Family Planning Council promoting sexual responsibility amongst youth (Zimbabwe).
2. This document is designed for HIV and AIDS-related programme planners at non-governmental organisations (NGOs) and government agencies (both adult professional and youth leaders), as well as policymakers.
3. Green, L. & Kreuter, M. 1991. *Health Promotion and Planning: An Educational and Environmental Approach.* Mountain View, CA, USA: Mayfield Publishing.
4. UNAIDS. 2004. *At the Crossroads: Accelerating Youth Access to HIV/AIDS Interventions.* UNAIDS Interagency Task Team on Young People. See also: UNICEF. 2004. *Young People Speak Out. Meeting our Rights to HIV Prevention and Care: Access for All.* Prepared for the XV International AIDS Conference, Bangkok July 2004.
5. Alford, S., Cheetham, N. & Hauser, D. 2005. *Science and Success in Developing Countries: Holistic Programs that Work to Prevent Teen Pregnancy, HIV and Sexually Transmitted Infections.* Advocates for Youth, January 2005.
6. UNICEF. 2004. *Young People Speak Out. Meeting our Rights to HIV Prevention and Care: Access for All.* Prepared for the XV International AIDS Conference, Bangkok July 2004. See also: Green, L. & Kreuter, M. 1991. *Health Promotion and Planning: An Educational and Environmental Approach.* Mountain View, CA, USA: Mayfield Publishing.
7. UNICEF. 2004. *Young People Speak Out. Meeting our Rights to HIV Prevention and Care: Access for All.* Prepared for the XV International AIDS Conference, Bangkok July 2004.
8. Green, L. & Kreuter, M. 1991. *Health Promotion and Planning: An Educational and Environmental Approach.* Mountain View, CA, USA: Mayfield Publishing.
9. Ibid.
10. Ibid.
11. Speizer, I et al. 2003. 'The Effectiveness of Adolescent Reproductive Health Interventions in Developing Countries: A Review of the Evidence'. In: *Journal of Adolescent Health,* 33:324-348.
12. Academy for Educational Development (AED)/LINKAGES. 2003. *Behavior Change Communication.* Experience Linkages Results. See also: Academy for Educational Development (AED)/Change Project. 2003. *Understanding and Challenging HIV Stigma: Toolkit for Action.*
13. Palmer, A. 2002. *Reaching Youth Worldwide.* John Hopkins University Center for Communication Programs (JHU/CCP).

Kent Klindera is the Senior Technical Advisor on Gender and Youth at EngenderHealth. For more information and/or comments, please contact him on +27 72 709 1534 or at KKlindera@engenderhealth.org.

making a point

Dorothy Odhiambo

Do HIV and AIDS make us less human than others…?

Fertility desires and sexual and reproductive health needs of people living with HIV[1]

My input is going to take a slightly different approach in that I am going to use a story line to highlight the sexual and reproductive health needs of people living with HIV and AIDS. My story line is basically bent around the typical dilemma faced by people living with HIV and AIDS, concerning their fertility desires and sexual and reproductive health rights and needs. As persons living with HIV and AIDS, we need to strongly affirm that we are still alive and each living being has a right to some level of comfort, compassion, and love. Due to our HIV status, we have been 'condemned', more often than not, to a life in solitude and loneliness, which makes it very difficult for us to live healthy and comfortable lives with HIV or AIDS. Our fertility desires, including our sexual and reproductive health needs are always assumed, sometimes misconstrued or outright misinterpreted, depending on the context in which the conversation around these issues is taking place.

As persons living with HIV and AIDS, we do have sexual and reproductive health needs and rights. We do have fertility desires that should normally be taken into consideration, whether at policy level, in programme design, and in service provision, especially in those services that target, or claim to target, people living with HIV and AIDS. The interesting question that normally arises has always been – when people are HIV positive – what needs do they have and why do they have sexual and fertility desires if they are already living with the virus? If they have any needs, as I want to presume they have, and if one wants to believe that these needs are part and parcel of the rights of people living with HIV and AIDS, then these needs must be met, and in the comprehensive manner that fulfils the entire continuum of care and needs for people, both women and men, living with HIV. How and when we can demand these rights and services is a question that we must address, if we want to deliver adequate services.

Reports from people living with HIV and AIDS affirm that their sexual desires and needs are hardly taken into consideration by service providers. Sexual, reproductive health and HIV and AIDS programmes and services have often failed to take into consideration the unique needs and desires of people living with HIV and AIDS. A lot of focus has been previously placed, and is still being placed, on issues of maternal health, especially issues around the prevention of mother to child transmission, normally at the expense of the full range of sexual and reproductive health needs of people living with HIV and AIDS.

It is difficult for me, sometimes, to even access the most basic things – condoms. Access to condoms is normally construed that, I ought not to infect other people by continuing to have sex and, thus, condom education, which we need, is always put aside. Instead of condom education, and, instead of being provided with information, people living with HIV and AIDS are normally castigated and condemned. Much of the counselling is to ensure that people living with HIV stop being sexually active – the expectation that they are HIV positive and are not supposed to have sex, has always taken the front line thoughts.

The big question is: do HIV and AIDS make us less human than others? Besides access to treatment and to antiretroviral therapy and the drugs, we strongly believe that a positive mental outlook and enjoyment of life is an important factor in extending the lifespan of

a person living with the virus. When we seek a safe, satisfactory, responsible, and a healthy sexual life, is that asking for too much? Can that be delivered against a context that is considerate and compassionate to the needs of persons living with HIV and AIDS? In order to fulfil, or to express, our sexual desires, we need information; we need education on safe and protective methods of engaging in sex. Yet, service providers hardly think about such needs and they often concentrate their education either on abstinence or other methodologies, and, at best, education on condom use, which sometimes does not apply to women living with HIV in most part of the world.

This approach, as we all know, and as evidence is now showing, presents a dilemma to women, because women have very little control and they cannot even enforce when, how and with whom to have sex. Many sexually active people living with HIV and AIDS need dual protection, yet, service providers only think about the easiest way and that is condoms – and we know that condoms have had considerable failure rates in preventing pregnancy. Providers are likely to discuss contraceptives, but very little information is given on contraceptives that are appropriate and right for people living with HIV and AIDS.

We are all aware now that increased access to antiretrovirals has also led to improved quality of life of people living with HIV and AIDS, resulting in a positive shift in their sexuality and fertility desires. However, we have also noted that the majority of persons living with HIV and AIDS still have no access to antiretrovirals and even people, who have access, have to contend with antiretroviral or treatment services that are non-comprehensive and do not address fertility and sexual health needs of people on treatment. How can programmes be comprehensive enough to start thinking about related issues, especially those issues that touch on the sexual and reproductive health of persons living with HIV and AIDS? At what level should national treatment programmes consider sexual reproductive health needs of their clients? What are the benefits, if there are any at all, in bringing these services to a one-stop point? How and when do we insist, as people living with HIV and AIDS, that these services are made comprehensive enough for us not to shuttle from one point to another, looking for different services in 10 places on the same day. Because at the end of the day, I am only one person and yet, I am expected to go to these different places for different services so as to ensure that I get all the care I need.

Is this practical? We have seen programmes that make people living with HIV and AIDS, and especially women, go from service point to service point. At point A, I go and pick up my antiretrovirals. Then, I am expected to go another distance to point B to pick up my treatment for my opportunistic infections. At point C, I am supposed to go and talk to a family planning service provider to see if there are any services for me there. At point D, if I have a child, I have to look for services to ensure that my child is healthy – and all these must take place in the same day. Surely, are we being fair when we design programmes that make us shuttle like this?

Many of us are, at times, made to withdraw from sex. Not because of our diagnosis, but because of the loss of a partner, the loss of sexual desire, the fear of re-infection, or the feeling of guilt, due to the judgemental attitudes of service providers towards people living with HIV and AIDS. This makes it very difficult to pursue a safe and satisfactory sexual life.

Normally, due to the nature of the programmes, whether they are HIV and AIDS programmes or sexual and reproductive health programmes and services, sexually transmitted diseases often go undiagnosed, especially in people living with HIV and AIDS, because it is presumed that they are not supposed to have sex and, therefore, they are supposed to be free from most of these infections. Yet, more often than not, we are supposed to grapple with some of these infections, without much attention or much support.

Now, look at the possible fertility desires. We are always discouraged to have children after diagnosis, reasoned that we are likely to infect our children. This is totally in disregard to the fact that we have, at times, very little control over our fertility and decisions

whether or not to have children. In addition, this is also not based on other factors that come into play, for example, the community and family pressure to have children, despite one's HIV status.

When such pressure build up, women living with HIV and AIDS are often left alone to grapple with these dilemmas and to make decisions with no prior information on how to prevent the transmission of the virus from mother to child. Current statistics are now showing that only 10% of women, especially in Sub-Saharan Africa, are able to have the full knowledge of, and the access to treatment, so as to ensure that they prevent transmission of the virus to their children. Where prevention of mother to child transmission (PMTCT) programmes have taken off, the cost is always prohibitive, especially if there is no donor funding support, and this normally excludes many women, who have the desire to have children, who are free of HIV and AIDS. Many people living with HIV and AIDS have complained of inadequate information from service providers to enable them to make informed decisions about their fertility from service providers.

The question is who do we turn to, when service providers who are expected to address our needs and to provide the critical support that is needed by us, are judgemental and have negative attitudes towards women living with HIV and AIDS, who still desire to have children? Access to ARVs, in some countries in Sub-Saharan Africa, is pegged on whether or not the woman agrees to be sterilised. This is a violation of human rights of women living with HIV and AIDS. Who do we turn to – to help us address these issues? How do we deal with service providers, who insist that to access antiretrovirals, or to be put on treatment, women have to be sterilised? More often than not, we are coerced into decisions and left with no option, but to go with what service providers propose, and what they think is best for us.

On the other hand, termination of a planned pregnancy is considered illegal in so many countries. Access to safe and legal termination is still a big issue for women living with HIV and AIDS. Emergency contraceptives are still out of reach for these women and yet, sometimes women living with HIV and AIDS require such services. Access to HIV testing is another issue that we have to grapple with and, in so many contexts in Africa; women in their reproductive age have no access to HIV testing services. So, women get pregnant and then they learn during their pregnancy that they are already infected with HIV – and this presents a dilemma. Furthermore, women living with HIV and AIDS need information on safe contraceptives and information on how these contraceptives may react to other medications that they take, for example, antiretrovirals and other treatments for opportunistic infections.

Looking at policy issues, we need, urgently and as a priority, dialogue on how to develop and improve on policies at national level that are explicit on inclusion of sexual and reproductive health needs and rights of people living with HIV and AIDS. Meaningful engagement of people living with HIV and AIDS is critical for national programmes.

In conclusion, I would want to say that it is high time we start acting differently. We need committed leadership and ownership in facing the reality and adversity of our sexual and reproductive health needs. We need to close the gap between what we say and what we do. We need accountability and timelines, strict timelines, from stakeholders and organisations on how, when, and from whom we can demand and expect action on our sexual and reproductive health needs. And this action, if it comes to being at all, must include us, as people living with HIV and AIDS.

FOOTNOTES:

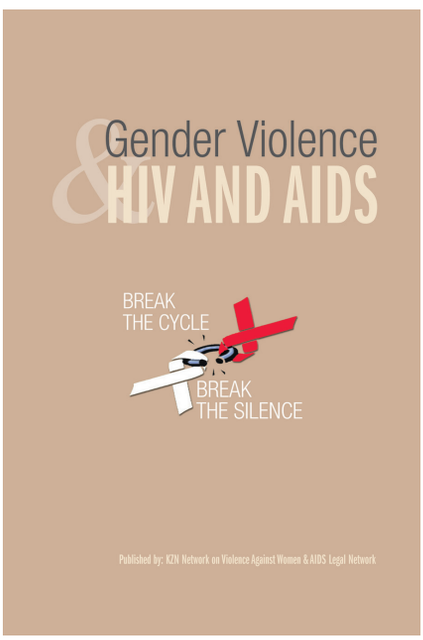
1. This article is based on a paper presented at the 2006 International AIDS Conference in Toronto, Canada.

Dorothy Odhiambo is the Senior Regional HIV/AIDS Partnership Officer at the International Federation of Red Cross and Red Crescent Societies, based in Nairobi. For more information and/or comments, please contact her on +254 2 2835000 or at dorothy.odhiambo@ifrc.org.

Gender Violence & HIV and AIDS

…prevailing discriminatory attitudes and beliefs create a situation in which women are at greater risk of violence and HIV infection…

Looking at an holistic approach in response to the links between gender violence and HIV and AIDS, the AIDS Legal Network (ALN) and the KZN Network on Violence Against Women combined knowledge and resources to develop, write and publish a resource and training manual on *Gender Violence and HIV & AIDS.*



A potpourri of concepts and realities of gender, gender violence and HIV, a gendered look at prevention, treatment, support and care (of both violence and HIV and AIDS); *'spiced up'* with relevant legislation (including fundamental rights and freedoms) – this is what trainers and *'wannabee trainers'*, can look forward to in this resource and training manual.

Ever wondered why there is little joy to be had for women while celebrating ten years of constitutional guarantees of dignity, equality, non-discrimination and freedom? Ever wondered why we don't seem to be *'able'* to enjoy our *'freedom'*? Free to equally and fully enjoy all rights and freedoms; free to make choices, to make informed decisions about one's own body; free to choose whether or not to have sex, with whom, when and where; free to choose whether or not to test for HIV and to disclose one's HIV status; free to enjoy respect and protection from all forms of violence, be it at home, the bedroom, the workplace, or the many places where we want to access services for our own protection. Ever wondered why some human beings are at the forefront of decision-making while others remain to be *'voiceless'*, vulnerable and violated? Ever wondered why *'some are more equal than others'* just seems to be the way it is…? What needs to be explored, done and challenged to create a society which is free of violence and free of HIV, is what this publication is all about.

The manual aims to give insights, and to provide valuable information and resources to everyone, including trainers, facilitators, educators, who feel compelled to *'stop wondering and do something'* about the linked pandemics of gender violence, HIV and AIDS and stigma and discrimination of the 'other'. The *'book'* is a tool; a tool to train and educate, to build and strengthen capacity of self and others, to give information and deepen knowledge, to promote an understanding of the links, and to contribute to change of the environments fostering the pandemics.

...ever wondered why some human beings are at the forefront of decision-making while others remain to be *'voiceless'*, vulnerable and violated? Ever wondered why *'some are more equal than others'* just seems to be the way it is...?

The resource and training manual will be officially launched during the 16 Days of Activism for no violence against women and children. For more information on the manual and/or how to get a copy, please contact us at campaign@aln.org.za.

This publication has been made possible through the assistance of the Joint Oxfam HIV/AIDS Programme (JOHAP) managed by Oxfam Australia

Oxfam Australia

DTP: MELISSA SMITH • PRINTED BY FA PRINT