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AIDS LEGAL NETWORK

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David Patient and Neil Orr

Stigma: The extreme end of a discrimination continuum[1]

Many people are calling urgently for laws and policies to curtail or prevent HIV and AIDS stigma. This is a call for changes in structures. It is also a useless exercise, until such time as we examine the roots of stigma, and understand its very nature. Then we can build structures to support the understandings and mechanisms that alleviate stigma.

DEFINING STIGMA

What exactly is stigma anyway? For the sake of this discussion, we will define stigma as a behaviour or law/policy that unfairly and negatively impacts upon the rights, life and opportunities of a person actually living with HIV or ill with AIDS; a person associated (affected) with someone living with HIV or AIDS (e.g., family and friends); a person, perceived to be infected with HIV or to have AIDS; or a person perceived to be at risk of HIV infection or AIDS illnesses.

To distinguish this form of discrimination from other types, such as gender or racial discrimination, it needs to be motivated primarily by the perpetuator (person or policy) of the stigma to have knowledge or a perception (true or false) that the other person is infected or affected by HIV or AIDS. HIV and AIDS stigma is thus, essentially discrimination based upon HIV status. In other words, it is not stigma if, for example, you lose your job, because you did not do your job properly. It is, however, stigma if you did your job properly, but got fired, because your boss discovered you are living with HIV.

Is HIV and AIDS stigma different from any other form of discrimination? This is a difficult question. Stigma is not exactly the same as discrimination, at least in terms of connotation. Stigma has an additional connotation to discrimination, namely that of strong emotional rejection, over and above structural inequality. We would hazard a guess that *'stigma'* is characterised by overt fear, whereas *'discrimination'* is not always overt. We, therefore, propose that stigma is the extreme end of a discrimination continuum.

Why does stigma exist?

Core questions we need to ask are: What causes people to behave in a stigmatising manner? What causes people not to change stigmatising behaviour, even when they have knowledge about this? Why are people treating their loved ones, colleagues, employees and friends in such inhumane ways? Why is stigma so widespread, regardless of social, educational or economic strata? How do the ones infected contribute to the perpetuation of stigma?

The answer is simple, at least conceptually. At the core of any behaviour one will find a belief (or a series of beliefs) that causes individuals or groups to behave in a specific manner. We need to strip away these beliefs to their core, before we can effectively counteract stigma.

The nature of unconscious beliefs

Important considerations include that

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Editorial

It is in light of the seemingly persistent violation of rights, marginalisation and exclusion of people and groups of people that this issue of the *ALQ* focuses on stigma and discrimination based on, and in the context of, HIV and AIDS. The various articles in this issue examine the meaning, causes and understanding of stigma and discrimination, as well as the various realities of stigma and discrimination as experienced by people living with HIV and AIDS, by young people, by lesbian and gay people, as well as by prisoners. This issue also introduces two new integral features to the *ALQ,* namely a *'regional view'* and a *'provincial view'*. The former introduces the HIV and AIDS realities and challenges of Namibia and the latter explores some of the experiences and challenges unique to the Limpopo province.

In this issue, David Patient and Neil Orr explore the theory and meaning, as well as the causes of stigma in the context of HIV and AIDS. Analysing core questions as to why stigma exists, how it manifests itself in beliefs and behaviours, and some of the fundamental beliefs leading to stigma and suggesting measures, as to challenge and counter these very same beliefs, the article argues that as long as the core beliefs, leading to, and justifying the occurrence of, stigma are not challenged, stigma cannot, and will not, be addressed and thus, will continue to prevail.

Acknowledging prevailing homophobia faced by lesbian and gay people, Nonhlanhla Mkhize looks at stigma and discrimination as experienced by LGBT people in various areas of their lives, as well as from various service providers, such as healthcare and police. She argues, that stigma and discrimination not only limit the extent to which information, resources and services can be accessed, but also that as long as these injustices are not addressed, human rights will remain but a dream for most LGBT people.

The extent to which stigma affects the behaviour of people living with HIV is looked at by Jason Wessenaar. He explores the effects of stigma and subsequent internalised stigma on behaviour, including sexual behaviour, and argues that as long as issues of self-image/worth are not an integral part of education and awareness programmes, many people will remain vulnerable to, and at risk of HIV infection.

Exploring the concept of *'everyone',* Johanna Kehler examines questions as to how discrimination on the basis of age leads to the violation of rights, to stigmatisation and to blaming young people for the extent to which they are at risk of, and are vulnerable to, HIV infection. She argues that without addressing, or even acknowledging, the status quo of stigma and discrimination based on age, young people who are vulnerable to not only HIV and AIDS, but also to the violation of their rights, will become an accepted and justifiable reality.

The extent to which HIV and AIDS exacerbates the situation of human rights violation within South African prisons is discussed by Umesh Raga. Examining various constitutional and legislative provisions, as well as various judgements of the courts affirming the rights of prisoners, he argues that while the legislation is in place, it is the inadequate application and implementation that perpetuate the violation of prisoners' rights.

Limpopo, with its two unique realities of *'beauty'*, the *'Garden of Eden'* and the *'beast'*, the lived HIV and AIDS realities, is introduced by Cecile Manhaeve. Exploring the various realities of Limpopo, she examines the challenges of accessing, and adhering to, ARVs and argues, that behaviour needs to change as much as people need to get

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(a) beliefs can be conscious or unconscious (e.g., socialised norms). Many beliefs are not conscious;

(b) there may be beliefs that conflict or contradict each other; and that

(c) the relative ‘*stress*’ of a situation influences the extent to which conscious beliefs are put aside, allowing unconscious beliefs to prevail (i.e., the strongest belief will win).

More often than not, beliefs, especially unconscious beliefs, are presented as facts. For example, a sexist statement such as ‘*men are stronger than women*’ is defended as an ‘*obvious fact*’. Defence of such beliefs include ‘*it’s normal*’, ‘*everybody knows this*’, ‘*we’ve always done it this way*’, ‘*it’s my culture*’, and ‘*the Bible says so*’. In other words, there is often little individualised thought or reasoning to support some types of belief; they are often merely accepted by the individual or group through socialisation processes. As a result, most people would not really be able to tell the real reasons as to why they are discriminating against someone, as they have not really consciously thought about it.

> **Just like any other apparently irrational behaviour, at the core of stigma is a set of beliefs, presented as facts, creating discriminatory behaviour.**

It is not possible for us to influence any long-term changes in discriminatory behaviour, unless we have the courage to challenge people’s core beliefs. It is neither a comfortable – nor popular – process. All too often, we are so busy worrying that we might offend a community’s sensibilities that we do communities a disservice, simply because we are too scared to take the risk of challenging these beliefs. If we do not challenge these core beliefs, we have failed in doing what needs to be done to serve our communities.

It is also important to keep in mind that many beliefs have never been discussed, even during socialisation, and are absorbed through modelling and behavioural processes. For example, a child may learn how to deal with anger through violence by observation, not through rational discussion of the pros and cons of such behaviour. Therefore, when we say ‘*challenging beliefs*’, we mean talking about them, bringing them into conscious awareness and giving them words, so that they can be expressed and examined.

This unconscious aspect of many deep-seated beliefs behind discrimination makes it problematic in terms of rational ‘*education and awareness*’ processes. Not only is the individual unconscious of some of these beliefs, she/he may also have no words to express these beliefs.

Stigma as a utilitarian survival strategy

There is also a category of beliefs concerning survival issues that are deeply entrenched. This concerns the functional reasons for discrimination. An example is how groups approach and respond to major threats to their survival. The unspoken belief is to do whatever is necessary, including the sacrifice of the weak, to ensure the survival of the group as a whole. This is the ‘*utilitarian*’ approach (i.e., that the greater good for the greater number of people sometimes requires sacrifice of a minority).

Studying social phenomena: The danger of bias

Human behaviour is not random. Instead, it has a structure and a reason, instigated and directed by beliefs of various degrees of strength and conscious awareness. Just as the medical fraternity believes that an accurate and in-depth knowledge of the virus and the immune system will allow us to effectively counter HIV through vaccines and anti-HIV treatments, so does a rational social scientist believes that an accurate and in-depth understanding of people’s beliefs will allow us to understand and modify behaviour so as to reduce vulnerability to infection, and to behave fairly towards the ones already infected with HIV.

The difference between a medical scientist and a social scientist is that a medical scientist studies something (e.g., a cell or a virus) that can be placed outside of her or himself, on a slide under a microscope. She or he studies something external. In contrast, a social scientist studies something of which she or he is part. This is the problem. A social scientist cannot separate her or himself from what is being studied. She or he has beliefs too, which may – and usually do – strongly determine not only where we look (and not look), but also how to view it, what is ‘*right*’ and ‘*wrong*’, and so forth.

Social scientists, whether they like it or not, are just as powerfully affected by their socialisation and survival-based beliefs, which create phenomena such as ‘blind spots’ (i.e., literally not seeing something, because it contradicts fundamental personal beliefs). Another common pitfall is the intellectual justification of something according to a specific pre-existing belief system (i.e., we try to fit the facts into what we would like to believe).

Stigma can neither be understood as a simple nor as a largely conscious behaviour. If we examine and seek to understand the beliefs behind stigma, we stand a chance of doing something about it. Just like any other apparently irrational behaviour, at the core of stigma is a set of beliefs, presented as facts, creating discriminatory behaviour.

So, let us examine some of the possible unconscious (or conscious) beliefs that could explain the stigmatisation of the ones infected with HIV.

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involved for the 'right' reasons, to ensure the adequate implementation, and maximum benefit of, treatment programmes.

Damoline Muruko introduces HIV and AIDS realities in Namibia. Looking at the interrelation of social, economic and cultural factors that largely define individual choices about sexual relationships, she argues that it is Namibia's gender inequality that forms the basis for women's greater vulnerability to HIV and AIDS and that only a *'gendered'* approach to HIV and AIDS education, awareness and prevention carries the potential to challenge and transform the power dynamics leading to women's greater vulnerability to HIV and AIDS.

Shamim Meer is *'making a point'* about *'mainstreaming'* and questioning whether or not the concept in its entirety has been understood. Analysing various confusions, misunderstandings, as well as resistance to, and fear of 'mainstreaming', she argues that it is the failure to address the underlying gender imbalances and women's subordination that leads to a situation in which 'mainstreaming' will continue to bypass its cause, which is to advance gender equality.

Exploring the meaning and various realities of stigma and discrimination in the context of HIV and AIDS, the recurring theme seems to be that stigma and discrimination manifest itself not only in attitudes and behaviours, but also in language; that stigmatising and discriminatory attitudes and behaviours are often determined by core beliefs and norms at a conscious and unconscious level; that stigmatising and discriminatory attitudes and behaviours are not only based on, and reinforced by, existing societal prejudices, as well as existing imbalances and injustices, but also support and reinforce the very same; that stigma and discrimination occur in all spheres of society; and that this reality prevails, despite constitutional and human rights provisions guaranteeing equality and human dignity for everyone. In addition, stigma and discrimination appear to have become largely societal acceptable and justifiable, since stigmatising and discriminating against the *'other'* seem to *'conform'* and *'adhere'* to the societal perceptions and core beliefs of what is, and what is not, *'acceptable'* and/or *'appropriate'* behaviour.

Recognising the need to address stigma and discrimination in its various forms and realities, the question as to the *how* seems to have various answers, ranging from information dissemination, education and training to improving one's self-image/worth and challenging the status quo. However, the one approach common to all, is the dire need to not only challenge, but change the very same core beliefs of *'us'* and *'them'* explaining and often justifying the occurrence of stigma and discrimination. And if we are to agree that *stigma is the extreme end of a discrimination continuum* and that stigma is fundamentally based on core beliefs and norms, then we will have to agree that without challenging the very same core beliefs and norms, as *'unchallengeable'* as they might seem, we will not be in the position to adequately address stigma and discrimination. In other words, if we are to accept core beliefs and norms to be the *'problem'*, then the *'problem'* of stigma and discrimination does not seem to be the one that needs addressing and/or challenging. Thus, recognising the need to address stigma and discrimination seems to be the *'easy'* part, as compared to the practical implementation of addressing and challenging the *'actual problem',* the core beliefs, people's core beliefs, everyone's core beliefs.

And while this might seem *'impossible'* to some, the fact remains that as long as we are not addressing and challenging the causes and 'roots' of stigma and discrimination, fundamental human rights and freedoms will remain but a dream for most of us…

JOHANNA KEHLER

BELIEFS THAT MOTIVATE STIGMA & COUNTER-ACTIVE MEASURES

Belief 1: *'If you have HIV you are going to die, so I will not invest time or resources in you'.*

This means withdrawal of support from the ones who are perceived as no longer able to contribute to the survival of the group. This is the simple outcome of a group survival strategy, which has been a survival strategy used throughout human history.

Many years ago, there were reports that clinics in certain parts of Zimbabwe were told not to provide any treatment for the ones infected with HIV, including the setting of a broken bone. The reason was that this would be a waste of scarce resources. Whether this report was true or a myth is irrelevant. What is relevant is that this report illustrates behaviour based upon a belief that is quite fundamental and widespread in situations where resources are limited. We have heard this belief expressed in different ways by a wide range of people, including business people, the devoutly religious, politicians, and general public. No doubt, this belief causes outrage, as it should. However, this outrage needs to be tempered with the recognition that the rejection of the ones infected is no different from other – more personal – behaviours. We have all done something similar at some point in our lives, based upon an assessment of whether or not the other person will contribute to our lives in the future.

For example, when a friend announces that she or he is leaving town, and moving to another city, many people start to withdraw immediately, prior to the actual departure. Emotional withdrawal, some say this happens to reduce the pain of loss, is common to all societies. However, when physical resources are limited, this effect is magnified, and expressed in more hostile rejecting behaviour too, such as expelling family members from the home. Is this any different, or is it a matter of degree?

There are two sub-beliefs in this behaviour, pertaining to HIV stigma:

- It is believed, based upon what has been said in media and otherwise, that *everyone who is infected with HIV is going to die*. In other words, she or he is going to leave.
- she or he is going to get sick at some point, which means that scarce resources are going to be used, with no *'cure'* to justify the use of these scarce resources.

How do we counter this? Well, for one thing, we need to start to be a little more careful of how we tell people about the dangers of HIV and AIDS. For two decades we have been drumming the same *'death and fear'* message into communities, and we are surprised at the stigma that emerges? We try to motivate through fear – terrifying all and sundry with HIV and AIDS – and we don't understand why people respond with *'irrational'* rejection to the ones infected?

So what do we do? How do we counter this basic (and functional, from a raw survival perspective) belief?

Counter-active measures

We suggest two strategies, both of which we have been applying with great success in Mozambique, in our Positive Living programme.

Measure 1: *Instead of using fear as the primary message and motivator, focus upon the effects of HIV and AIDS (or malaria, poverty, etc) on a desirable future, both by the individual and community*

What we mean by that is that few people have any sense of future beyond the immediate and short-term. For many people, dealing with the problems of today is infinitely more real and urgent than some unseen threat that apparently can kill you sometime in the distant future.

We utilise methods where people become aware of long-term future-related goals – which we call the Future Dream – that are then emotionally energised through a simple process. *Our view is that life is only protected – and respected – when it is valued.* Furthermore, life is only valued when my life is believed to be moving towards something desirable, pleasurable, fulfilling. We have found that when we do this process first, before HIV and AIDS education and awareness, prevention methods suddenly have relevance and genuine meaning to the individual. Then the ABC options/choices make sense to the individual, as HIV and AIDS literally stand in the way of the desired future.

> **Our view is that life is only protected – and respected – when it is valued. Furthermore, life is only valued when my life is believed to be moving towards something desirable, pleasurable, fulfilling.**

We utilise exactly the same process for people living with HIV, as they are no different from anyone else in believing that they have no future. If we are to teach the ones infected how to live with the virus successfully, we need to ensure that they also believe that they have a future, and that there are good things still to come, that it is still possible to live a good life.

It is often assumed that the ones infected will do anything to stay healthy, when in reality this is not true. Many just *'don't bother'*; because they believe there is no point. The same rationale applies to HIV testing: What do I stand to gain (except anxiety), if I get tested? Without a good reason (i.e., improved quality of life), what other sustainable reason is there?

Our belief is that the first thing to die, when a person is diagnosed with HIV, is their future. It dies in the doctor's office. The body follows a few years later, unless the future can be opened up again.

How often have we seen or heard an *'AIDS Sufferer'* speak to an audience, with nothing to say, except how miserable, and how hopeless-helpless they are? How many public *'AIDS Sufferers'* cannot answer the most basic questions about HIV and AIDS? There is an assumption that publicly declaring one's infection with the virus somehow translates into instantaneous expertise, or entitlement for public sympathy and support, when in fact it does not. In many ways, by virtue of the *'Victim Persona'* presented, the ones who disclose their status publicly perpetuate the belief that living with HIV and AIDS is *'helpless'* and *'hopeless'*, which in turn supports the unstated shared belief that people living with HIV and AIDS are simply an additional burden on a society with scarce resources.

It is imperative that public disclosure is encouraged, but it should only happen with full awareness of the impact of such a disclosure. The bottom line is that, in order to prevent victimisation through stigma, the person living with HIV needs to ensure that she or he does not utilise the *'victim'* image in the first place.

It is a tragic reality that *'victims'* get persecuted, once sympathy has run out (which is fairly soon). People living with HIV or AIDS (PLWHAs) have exactly the same responsibility as the ones who do not, in terms of making efforts to contribute to the future development of the community. In other words, PLWHAs need to pay attention to what is called *'secondary gain'* – the perception that *'victim'* status confers special privileges and attention, as well as exemption from community responsibilities. People don't like it, and won't support it – they have problems of their own. However, the situation changes, when a person (any person) is viewed as contributing to the future of the community. Therefore, the helpless-hopeless *'AIDS Sufferer'* image is counter-productive in the fight against stigma.

The essential recommendation of the above is that, regardless of HIV status, communities will reject and eject members who are considered a non-productive, non-contributing burden to that group. The exception is the elderly, who have already made their contribution, and very young children, who do not yet have the capacity to contribute. Therefore, one aspect of reducing stigma is for PLWHA's to earn the respect of others through engaging in a productive life, and not wallowing in *'sufferer'* or *'victim'* sympathy-seeking roles.

Measure 2: *Focus upon the possibility of living with HIV, versus dying from AIDS*

This sounds very similar to the previous item, namely focusing upon a desired future. However, there is a slight – but important – difference in emphasis. In the previous item, the focus was upon working towards a life that is desired, whether that life is five years or twenty years. In other words, its focus is the *quality of life*, regardless of the *quantity of life*. In the second item, the focus is upon quantity of life (i.e., what can you do to live longer?). This includes advocating for better medical treatment, changing diet towards immune-supporting nutrition, and attitudinal shifts that support longevity. The likelihood of a PLWHA in acting to increase the quantity of her or his life is not high, unless the first item – increasing the potential quality of life – is first addressed.

> **...the first thing to die, when a person is diagnosed with HIV, is their future. It dies in the doctor's office. The body follows a few years later...**

At a social and community level, it is critical that people hear and see that (a) it is possible to live well with HIV for many years, if certain actions are taken; and (b) that the infected person can – and will – add to the collective resource base for a long time, if she or he is supported in staying healthy. In other words, don't expect people to care about you, if you do not care about yourself.

Belief 3: *'HIV/AIDS is a punishment for sin'.*

Whether we like it or not, no matter how principled and objective we try to be, we cannot escape from the reality that the most fundamental components of our internal and external social interactions, laws and other infrastructures, are rooted in religious beliefs. Even the ones who claim to be agnostic or atheist, cannot escape from the socialisation of these beliefs through education systems, the very words we use to explain our reality (right/wrong, good/bad), laws, and so forth.

There is not a single society that does not have – either explicitly or implicitly – a value system based upon some dogma, whether religious or otherwise. This does not mean that the dogma is *'good'* or *'bad'* – it simply means that it exists, and needs to be taken into account.

One of our most basic social beliefs is that, when *'bad'* things happen, something caused it. Whether this is because we assume the power to cause these things to happen, or whether it is because of some mystical process (when it is called *'sin'*), we need to blame someone or something. Blame is a very powerful social force. From blame comes shame, and from shame comes the need to punish, to alleviate the shame.

When we tell people that if they do certain things they can get infected, it is automatically assumed – usually by all concerned – that it was their *'fault'* that they became infected. The word *'fault'* is used carefully here, not to mean the same as responsible.

Why do we use the word *'fault'* versus *'responsible'*? Because the word *'fault'* (or *'blame'*) more accurately describes the emotions and thoughts involved. The words *'fault'* and *'blame'* imply that something *'bad'*, *'sinful'*, *'wrong'* has happened, and that someone needs to be punished for it. In common usage, the words *'fault'* and *'blame'* are never used to describe *'good'* things or behaviours, only *'bad'*. In contrast, the word *'responsible'* is used to describe *'good'* things, as well as *'bad'* things, such as *'who is responsible for this lovely dinner?'*.

Many people living with HIV will probably agree with this, especially when it comes to explaining stigmatising behaviour originating from others. However, although this does indeed seem to explain some aspects of stigma, the ones living with HIV should keep in mind that they share in this belief. This is what is referred to as *'internalised stigma'*.

It is incredible that, with so many people living with HIV, that so few openly protest against stigma. We joked a few years back that, if we were to start a political party only for the ones infected with HIV, we could win the next election. That is not going to happen, simply because the overwhelming majority of the ones living with HIV feel that their infection is their *'fault'*, and that they are to *'blame'*, and that they need to be *'ashamed'*. The ones who refuse to accept the *'blame'* tend to try to blame someone else, which is probably the basis of *'revenge'* infections. Regardless, the behaviour is based upon blame/shame, which in turn is based upon the belief that *'bad'* things need to be punished.

We are not sure where this fault-blame-shame phenomena is strongest – society, or the ones infected. It is probably evenly spread, with the one sector merely feeding and supporting the other in a co-dependent symbiotic manner.

The bottom line is that most people accept this cause-effect (blame-shame-punishment) belief, including many of the ones who fight stigma or who care for the ones infected. In many stigma forums, the process merely involves the shifting of blame and shame, and consequently punishment, merely perpetuating the problem.

The issue of blame-shame-punishment is not unique to HIV and AIDS. Rape survivors have been blamed-shamed-punished by courts and the public for decades, because people seem to need an explanation of why things, that are controllable, happen to people. For example, there is a belief that if we can pinpoint that what a woman was wearing contributed to her being raped, then we can prevent rape by not wearing the same clothes. At the same time, this means that she was to blame. We feel *'safer'* when blame-shame-punishment has occurred. The fact that rape is an act of violence, that the motivation for rape has nothing to do with sex, age, or what someone wears, and has instead got to do with the need to express power and dominance, due to deep-seated inadequacy, is ignored in this blame-shame-punishment of the rape survivor.

So where do we begin in the process of eliminating blame-shame-punishment?

Counter-active measures

We would imagine that the first place to look is why we seem to need this process in terms of maintaining a sense of coherence in our worldview. In other words, we all need to be able to understand how things work in our world, in terms of cause-and-affect, so that we can do what needs to be done, and take responsibility for what we do. We simply cannot allow entropy (decline of order into chaos) to happen – it is in our nature to create greater order, not less. The exception is when a system is so dysfunctional that we need to destroy it, because it cannot be rehabilitated. However, even this destruction is viewed as a means to an end, with the end being a more ordered and functional system (defined according to some or other belief). This is how wars are justified.

Measure 1:. *Acknowledge that individuals have the power to choose to refrain from discrimination, as opposed to placing all power to socialisation, and, thus, removing individual responsibility.*

When we tell people that if they do certain things they can get infected, it is automatically assumed... that it was their *'fault'* that they became infected.

Measure 2:. *Encourage/challenge organised religion to not only examine their emphasis on blame-shame-punishment (versus compassion), but also to do so actively and publicly.*

It is probably a good time to introduce eligion at this point, as the various religions of the world have had a fundamental and profound influence in the understanding of *'blame'*, what causes *'bad'* things to happen, and how we should respond to this. However, when one adds religion to sex (and HIV is after all a sexually transmitted disease for most people in the developing world), one gets a rather heated debate that is rarely rational.

If we may summarise such a debate: Sex is *'bad'* and punishable unless sanctioned by the representative of the religion (i.e., marriage). Therefore, HIV and AIDS is somehow a punishment for some or other sexual *'sin'*. Therefore, HIV and AIDS is viewed as the physical proof of *'sinful'* sexual behaviour. So why should this matter? It matters because people want to go to Heaven. And guess who controls the security access codes to Heaven? Yes, the moral authorities – the same ones who say sex is a *'sin'*, and HIV and AIDS is proof of *'sin'*.[2]

The root of value-based blame-shame-punishment is fear – fear of being worthy enough to be accepted and loved. This applies not only to their relationship with God, but also to other people.

We cannot ignore the reality that the majority of the population in the developing world has a strong and enduring religious value system, whether this is Muslim, Christian, or traditional animist. We also cannot ignore the fact that these systems of belief have a powerful influence on stigmatisation, including the internal stigmatisation by the ones infected. To ignore this reality, we not only ignore probably one of the key areas to deal with stigma, but we also set aside one of the most widespread resource infrastructures in dealing with the consequences of HIV and AIDS, such as home-based care, caring for orphans, prevention and a myriad of other issues.

Measure 3: *Encourage/challenge politicians and other leaders to be conscious of how they reinforce stigma through their words and actions, which contradict non-discriminatory policies and principles.*

Another important area is within the political arena. Politicians need to spend less time reacting to each other, and spend more time creating a vision for a better world, and then earn their keep by making this a reality. It is perhaps time that we start asking ourselves why people do not resist death too strongly, and why people are so willing to accept *'blame'* and *'shame'* for merely having a virus in their blood. Leaders need to engage the task of addressing stigma directly, by simple actions, such as publicly embracing the ones living with HIV.

Belief 3: *'It's the way we do things' – Culture and tradition should not be questioned*

We were doing a talk a while ago and during the question and answer session a woman, who had taken a cell phone call while we were speaking earlier, raised her hand and said: *'It is not in my culture to discuss sex with my children'*. Our response was: *'It's also not in your culture to carry a cell phone, but you've adapted to that with great ease'*.

This story illustrates an important quality of culture. It is about convenience and increased survivability (functionality). At first, there is scepticism, but if it works, it soon becomes *'what we do'*.

Culture and traditions include a wide range of behaviours and activities, including language, dance and rituals, as well as how we deal with illness and death, and the regulation of relationships, gender roles and sexuality.

In recent years, there has been an enormous amount of energy directed at protecting *'culture'*. This is based upon the value of respecting diversity and differences. However, protecting a culture or tradition is a two-edged sword. On the one side, the unique qualities of a group of people are preserved and on the other side, such protection can reduce the flexibility of that group in the face of change, thus reducing their ability to survive.

Historically, there is no such thing as a culture or tradition that arrived spontaneously, and endured unchanged. This is simply because cultures and traditions were born out of specific situational necessities, and endure only as long as that necessity continues. At the very moment that the need changes, the tradition ceases to fulfil any survival function. However, this does not mean that the behaviour ceases. For example, even though, we often forget why we were doing it this way in the first place, we continue with it anyway.

It is also important to realise that every tradition serves specific groups more than others, and will be protected by the ones whom it serves most. It is at this point that self-interest interferes with the interests of the group as a whole. Gender roles are a case in point. Women stand to gain a great deal from equality in practical reality, while men perceive this as a real threat to their power. When resources are scarce, this becomes very difficult, as there is not a lot to share equally.

Politicians need to spend less time reacting to each other, and spend more time creating a vision for a better world, and then earn their keep by making this a reality.

Cultural traditions and norms are also comforting in that they provide a sense of identity and belonging. When situations become difficult, it is reassuring to know that you know *'what people like us do'* in such circumstances, even if the methods are no longer effective.

The harsh reality is that a culture or tradition cannot be effectively protected, since this is guaranteed to cause harm to the people it is supposed to serve, in the long term. The reason is simple. Change is the only guaranteed reality, and this requires adaptation and flexibility. Languages come and go, as do all other cultural behaviours and norms. The only way to allow some language or tradition to survive is to incorporate it into a newer tradition or language.

We have spent 20 years trying to fix everything, except what really needs to be fixed. We are addressing everything, except our core beliefs, and yet, it is these very beliefs that are creating the problem.

Counter-active measures

Measure 1: *Tell the truth*

One of the only forces that we can rely upon to encourage communities to adapt to the new realities of HIV and AIDS, is a full awareness of these realities. However, we are not referring to the bland intellectual type of awareness that most people associate with *'awareness'*. Awareness does not come from statistics or posters. Instead, we refer to direct awareness of the realities of HIV and AIDS, including all the gory details. Social change, unfortunately, is usually motivated by pain. For as long as society can hide the pain, change tends not to happen.

Communities will continue to stigmatise the ones infected until such time as communities can no longer function without the ones infected. In other words, until there are simply too many people to hide away, and until the ones infected – and others knowing that that they are infected – are filling important and valuable roles in society.

This is not a theoretical concept. In almost every country affected by HIV and AIDS, stigma has endured until there were simply too many people infected or ill to ignore. Then, when the realities are so huge, the society undergoes a *'stigma burnout'*, which is a process of giving up trying to deny what is really going on. One of the primary methods to accelerate *'stigma burnout'* is for people to see and know the truth about HIV and AIDS realities.

Once we have a more realistic view of HIV and AIDS (from a public perspective), we need to allow various cultures to adapt to these realities, as they have done in the past. Yes, there will be resistance, but overall, people will find solutions. None of this can happen if they do not know, see, hear and touch the realities that threaten their survival. People do not respond to abstracts, nor to statistics. They respond to real life reality, which affects them directly.

CONCLUSION

In conclusion, stigma is in essence one of two things The onset of a Dark Age of fear, pain and social fragmentation, or the opportunity for a Renaissance, a revival of a new social order, based upon greater compassion and understanding. The only way to head off this potential 21st Century Dark Age is the open questioning of what we hold to be true in our cultures.

In order for us to be effective, we *must* challenge people's core beliefs. We have spent 20 years trying to fix everything, except what really needs to be fixed. We are addressing everything, except our core beliefs, and yet, it is these very beliefs that are creating the problem.

There is only one solution, if we hope to make any difference at the social level. We must challenge people's beliefs. When we can do this, we can then make a real impact on stigma, discrimination, gender inequity and a range of other social issues. What are the values we want to share? How do we want to live? Unlike past generations, we cannot say: *'For my children I want …'*. If we wait and delay, it will be too late. This time, we need to start with *'For me, and my children, I want …'*.

It is small comfort to the ones infected, who have been stigmatised to know, that there is a larger social process which is occurring, and that at some point things change for the better. However, this is how it happens in every society. Therefore, continue to challenge the fear and ignorance, fight with understanding, knowing that you are helping to accelerate the larger process. However, always remember that the change starts with you – your beliefs about yourself. Question these beliefs, and then you have earned the right to challenge the beliefs of others.

FOOTNOTES:

1 This article is a shortened and edited version of the paper *'Stigma: Beliefs determine Behaviour'* published on www.empow.co.za.

2 We need to make it abundantly clear that we are fully aware of the incredible work and compassion displayed by many people from all religions, including in the area of HIV and AIDS. It has been our observation that they focus their values and beliefs upon love, compassion, forgiveness and that they do not place much energy on blame-shame-punishment. They are too busy making a difference to engage in dehumanising activities.

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New premises...

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Nonhlanhla Mkhize[2]

Homophobia is supposed to have no place

HIV and AIDS: An extra layer of stigma and discrimination for Lesbian and Gay people[1]

Veli Maya[3], the youngest of 5 sisters, was often referred to as her father's son, since she looked just like him. For her 21 stbirthday, she was thrown a party at which she was expected to introduce her boyfriend. In her speech, she jokingly said she did not like boys. That afternoon, local boys told her she needed to behave like a woman. A week later, they threatened to make her a woman. Her parents took it lightly. She ran to the police who laughed at her and told her 'maybe she needed to get a man'. She is currently unemployed and 5 months pregnant with a child whose father she will never know. She and her best friend were raped by local boys who suspected them to be in a lesbian relationship. Both are HIV positive and without social support.

Veli might not have been gay, but what happened to her and her best friend is a reality for many lesbian women in South Africa today. What then is the reality for individuals who are stigmatised and discriminated against because of their sexual orientation and their HIV status? Previously, we engaged in an article *'We need to challenge our prejudices'* (*ALQ*, Nov 2004) which briefly looked at how human rights, as enshrined in the Constitution, continue to be a dream for most lesbian, gay, bisexual and transgender (LGBT) people. Now, I would like us to engage on *'homophobia'* faced by LGBT people resulting, amongst other things, in their inability to access adequate services and resources.

Literally, *'homophobia'* refers to the *'hatred or fear of homosexuals'* (Branford, 2001). In reality, homophobia comprises the experience(s) of being discriminated against, rejected, stigmatised, marginalised and alienated, because of one's sexual orientation – the attraction to someone (of the same sex).

In South Africa, we come from an era where peace officers (police) had a right to arrest and detain men and women suspected to be homosexuals. Today, everyone is equal before the law and has the right to equal protection by, and benefit of, the law. We are in an era, where neither the state nor an individual may 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 (Section 9 of the Constitution)[4]. Homophobia is supposed to have no place in this era.

There has been little medical or behavioural research into developing a comprehensive LGBT well-being programme. Cultural, economic, racial, age-related, and sexual diversity within the LGBT community dictate a broad range of needs. Various factors further impact on LGBT people leading to inadequate physical and mental health care, including:

- Concealment of sexual orientation and gender identity from care provider
  - Delayed medical care or reluctance to seek preventive care
  - Disclosure of sexual orientation and gender identity
  - Depression, anxiety, suicide
  - Lack of support from family, school, church, government
- Societal prejudice, discrimination and intolerance
  - Sexism and heterosexism (oppression of non-heterosexual identities)
- Violence against LGBT community – physical, sexual and psychological violence in the public domain and, as well as in the private sphere[5]

A series of research in Durban by the KZN Coalition for Gay & Lesbian Equality, 1995-2000, revealed that there was no information and/or service catering for LGBT people, or that discussed the transmission of STIs among people of the same sex. This posed an urgent need to promote an awareness of health, HIV and AIDS issues as they affect LGBT people. Through the work of the Durban Community Centre, we learn that homophobia faced by LGBT people has been, and continues to be rife resulting as well in their inability to access adequate services, information and resources.

Discrimination experienced at home

At home, LGBT people are subjected to ridicule and rejection. Most families, upon finding out that a family member is a **L**esbian,

Gay, **B**isexual or **T**ransgender, take this as an insult. Depending on age, the person is either beaten, kicked-out of the home or both. Some families subject the person to harsh punishment with an aim to *'change'* her/him and others organise lovers of the opposite sex, arrange appointments with psychologists (who must *'treat'* the person), or send the person to a local religious leader or local traditional healer to help pray for, or heal the person.

LGBT youth above the age of 18, who have been kicked out have nowhere else to, but the streets for refuge, since the access to shelters in Durban is rather limited, due to capacity (shelters are full), age restrictions (refusal to take in youth above 18), and required fee (boarding fee per day has to be paid). Sadly, for LGBT youth who have access to shelters, life within shelters is often defined by degrading living standards, situations and treatment.

Discrimination experienced at school

The South African Constitution guarantees everyone the right to basic education. In addition, the South African Schools Act (No 84 of 1996) based on constitutional principles and values, guides schools, governing bodies and principals towards adhering to the law. Sadly, even with this in place, LGBT scholars continue to be subjected to discrimination and stigmatisation at schools. They are bullied, manipulated and ill-treated by others. Youth, who display lesbian and gay *'characteristics'* or *'behaviours'*, are subjected to punishment, detention and suspension. In a situation in which most of their teacher(s) allow their own prejudiced views to determine how they handle such matters; it is not surprising that there is an increase in bullying and suicide at schools.

In the incidences reported to the Community Centre, homophobia faced by LGBT youth in schools and the infringement of their human rights have hindered their access to information and resources.

1) Two girls found kissing at a convent school are expelled.[6]

2) A transgender girl who prefers to wear full boy's uniform is told to either obey the school rules (scholars are expected to wear full school uniform) or to leave school.[7]

3) A young man arrives for the school's matric dance with his boyfriend. His principal tells him that such behaviour is not acceptable and that he and his boyfriend must go home.[8]

Discrimination experienced at work

The Employment Equity Act (No 55 of 1998), including Equal Opportunities and Affirmative Action Policy, the Labour Relations Act (No 66 of 1995), the Basic Conditions of Employment Act (No 75 of 1997) and other labour legislation and policies are geared towards fair labour practices and equal benefits for all employees. Reality is that employees are not treated equally nor with dignity and respect, despite the legislation. Many LGBT people are not able to find employment, are fired from work, denied promotions and benefits (i.e. medical aid, insurances and maternity leave), because of their sexual orientation and gender identities.

LGBT people experience discrimination and ridicule at work from their work colleagues and even their employers. The experiences of LGBT people within the informal sector of employment are even worse, because one is also vulnerable to violence and abuse.

Discrimination experienced from religious institutions

Many LGBT people, who are brought up to regard their religious institutions as home, find themselves without this home once they are discovered to be L, G, B or T. They are refused entry to their places of worship and are denied access to other services that come with being a member of that religious institution or faith. In such cases, experiences of homophobia include being treated with utter disgust and humiliation by members of the religious institution and society. Subsequently, the family is no longer ashamed, but is embarrassed and despised.

Most families, upon finding out that a family member is a Lesbian, Gay, Bisexual or Transgender, take this as an insult.

Most people fail to understand that one does not have to be religious to be affected by what religious leaders say about LGBT people. But most religious leaders preach hate speech which results in LGBT people being hated and segregated by society, if not abused and even killed.[9]

Discrimination experienced by the legal system

While in 1999 the crime of sodomy was decriminalised[10], in 2002 two men were sentenced to 25 years in jail for the *crime of sodomy*. To their advantage, when media reported on the case, they received support, appealed the decision and walked home free. This is but one of many instances where the judiciary fails to adhere to South African laws and, in so doing, infringes on the rights of LGBT people and further hinders their access to legal protection that is unbiased and unprejudiced.

LGBT people may not have a legal right to marry yet, but many have gone ahead and married. The Durban Community Centre is aware of cases where same-sex couples have gone to courts to get married and/or to get divorced and were ridiculed by officials, instead of being provided with accurate information on how to address their matters.

Most people fail to understand that one does not have to be religious to be affected by what religious leaders say about LGBT people.

In civil matters, the legal practitioners often fail to assist LGBT people with regards to same-sex assault matters; domestic violence and sexual offences claims are not taken seriously. In 2001, officials in the Department of Home Affairs (DHA) laughed at a lesbian couple who wanted to apply for a birth certificate for their child.[11]

Discrimination experienced at the hands of police

On Thursday 24 March 2005, Charles (18 years) and friends (20 and 21 years) threw a party for their friend's 20th birthday. After 2 nights of no sleep, non-stop drinking and partying, more guys joined them. On the Saturday afternoon, about 15h00, as he went down to the garage to collect more drinks, Charles found himself surrounded by three men. After they each had their turn forcing themselves on him, he managed to escape to the nearest police station. The police asked him where home was and referred him to a police station next to his home. Here, the police told him that male rape cases were handled by the Regional Head Office (45 minutes away), and that no car was available to take him there. Around 19h18, he collapsed en route to the police station. At 21h00, he was found by a passing driver who drove him to a police station. Here, the police told Charles that he was drunk, did not know what he was saying and needed to return when he was sober. The driver took him to a local district surgeon who first argued that men cannot be raped. He later argued that he could not help him without a form from the Police. The district surgeon only attended to him around 00:45 after a local LGBT activist (who was called in) threatened to sue the hospital. Charles made a statement with the police at 01h15.[12]

The above clearly indicates that police require further training on how to do their job adequately. Police need to understand the urgency in accessing health care after rape (i.e. of any kind). Numerous cases of male/female rape go unreported, because of the very same prejudice, ridicule and discrimination that individuals are subjected to at the hands of the police.

Discrimination experienced within the health profession

Increased risk for certain diseases, combined with inadequate healthcare, places LGBT people at a disadvantage and jeopardises their health. Sadly, within the health profession are many people who discriminate against LGBT people, resulting in the violation of their rights, including the right to have access to healthcare services and reproductive healthcare, as guaranteed in Section 27(1)(a) of the Constitution.[13]

Findings of research on the sexual practices that render LGBT people vulnerable to STIs and HIV[14] revealed that most LGBT people do not undergo medical examinations every six months as required and delay seeing a doctor. In most cases, the reason is not lack of money, but homophobia, discrimination and stigmatisation experienced while accessing the services.

Some health professionals have admitted that they are treating LGBT people because they must, but if they had a choice would not. Subsequently, LGBT people receive compromised health care services and treatment. Similar to Charles' case, Mdu went to a doctor for an STI check-up in his anus and the doctor refused to treat him. Instead, he asked his secretary to find him a doctor, who is prepared to treat a homosexual.[15] To ensure that LGBT people have access to health care, VCT, STI/HIV testing, treatment, and so on, the Durban Community Centre has had to compile a list of LGBT, and LGBT friendly, service providers, including health

Some health professionals have admitted that they are treating LGBT people because they must, but if they had a choice would not.

professionals and institutions in Durban and KZN. This has also been the case in Gauteng, Eastern Cape and Western Cape.

LGBT people are at risk of STIs. While safer sex means learning and practising behaviours that decrease the chance of contracting or transmitting diseases sexually, this still needs to be negotiated and planned. Prevention is possible, but only if one understands STIs and how they are transmitted.[16] Section 27 of the Constitution affords us the right to have access to reproductive healthcare which includes prevention measures. The reality for the Durban Community Centre is that there are not enough male condoms to distribute to all areas in and around the city. Currently, condoms are limited to 6000 male and 100 female condoms a month. In addition, there are no gloves, no dental dams or even anal sex condoms for LGBT people to use for safer sex.

...to realise just how heavy the extra layer of marginalisation, stigmatisation and discrimination that HIV adds to the lives of LGBT people.

The 2003 Oral Sex Survey by the Durban Community Centre revealed that the majority of people engaging in oral sex did so without protection. Most believed that oral sex was safe sex.[17] These findings were reported months after the former Deputy President Jacob Zuma, during a LoveLife media campaign aimed at encouraging people to talk openly about sex, was quoted, arguing during question time in Parliament, that oral sex was *'wrong'* and *'unnatural'*, and that he could not *'answer on wrong things that people do'* (Mail & Guardian, 21-27 June 2002).

While it is also important to have access to accurate and up-to-date information, it is crucial that the information received is applicable to the individual. It does, therefore, not help me, as a lesbian, to be consulted on sexual and reproductive health and health care that is based on heterosexual biases. It is of utmost importance that health professionals realise that not every person attending a family planning clinic and/or consulting on reproductive health issues is in a heterosexual relationship, further stigmatising the very existence of LGBT people.

CONCLUDING COMMENTS

Engaging with these few examples of how homophobia experienced by LGBT people impacts on their lives and often results in their inability to access adequate services, information, resources and so on, it is my hope that you, the reader, begin to realise just how heavy the extra layer of marginalisation, stigmatisation and discrimination that HIV adds to the lives of LGBT people. It is, therefore, important that these experiences are recognised and addressed at home, at work, in communities, within government, in business, by policy makers, service providers and by society. Until such time that these injustices are attended to and are effectively addressed, human rights will remain a dream for most LGBT people.

REFERENCE:

Branford, W. 2001. *The South African Pocket Oxford Dictionary of Current English*. Oxford University Press.

FOOTNOTES:

1. The article is in part based on research conducted by the Durban Lesbian & Gay Community & Health Centre.
2. The article was prepared and written by Nonhlanhla Mkhize with input from Nomvuyo Dlamini (Programmes Manager) and Mduduzi Mthembu (Centre Volunteer).
3. Veli Maya (not her real name) is a former client of the Durban Community Centre.
4. The Constitution of South Africa, Act 108 of 1996.
5. Mkhize N. September 2003. *LGBT Sexual Health*. Paper presented the Behind the Mask Lesbian Workshop. See also *Sex and Secrecy Conference*, 22 – 25 June 2003, South Africa. (http://wiserweb.wits.ac.za/conf2003/)
6. A case of two girls found kissing at a Convent High School, Durban, 2003.
7. The person is from a school in Lusikisiki, Eastern Cape, and a client of the Durban Community Centre.
8. An experience related to a group of youth during an Amnesty International Human Rights Seminar in March 2005 in Durban, South Africa.
9. Reference is made to Mathew Sheperd, who was beaten to death as a result of homophobic comments of local leaders; and the violence, rape and murder LGBT people face (as reported by the Forum for the Empowerment of Women and a 2002 Felicia Mabuza-Suttle Show on hate crimes).
10. National Coalition for Gay & Lesbian Equality v Minister of Justice 1999 (1) SA 6 (CC).
11. The matter was brought to court. See J & B v Director General of Home Affairs (1906/2002 DCLD).
12. An experience previously (2004) lived by one of the Durban Community Centre's clients.
13. Mkhize N. September 2003. *LGBT Sexual Health*. Paper presented the Behind the Mask Lesbian Workshop.
14. Research conducted in 2004/2005 by the Durban Lesbian & Gay Community & Health Centre.
15. An experience shared with the Durban Community Centre by a former volunteer.
16. Mkhize N. September 2003. *LGBT Sexual Health*. Paper presented the Behind the Mask Lesbian Workshop. See also *Sex and Secrecy Conference*, 22 – 25 June 2003, South Africa. (http://wiserweb.wits.ac.za/conf2003/).
17. See also Mail & Guardian, 19 – 31 December 2003.

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Jason Wessenaar

I am not defined by HIV

People living with HIV are at risk of high levels of stress, caused by living in a society that does not easily accept people, as they are, or for who they are. The same stress could be caused by the denial, rejection and discrimination by partners and society, as well as by internalised stigma of the person living with HIV her/himself. Being HIV positive increases the risk of stress related to daily challenges, including hearing references and words like *'AIDS victim'*, *'guilty'* and *'AIDS sufferers'*. It also makes one more susceptible to harmful behaviour, like the wilful infection of HIV to one's partner, not disclosing one's HIV status, as well as the self-destruction through alcohol and drug abuse and/or overcompensation.

Most of us have coping strategies to deal with the stress of living with HIV encountered in our daily lives. These can range from finding someone to talk to, going for counselling, praying, attending support groups, writing journals, taking some time out, meditation, to just accepting things as they are. But, for a lot of other people living with HIV, who have not disclosed their HIV status, these kinds of support can be very difficult to access. As a result, many people living with HIV, who are constantly confronted by the negative attitudes of the ones around them, internalise these experiences and come to believe that some of the negative messages they receive about being HIV infected are true. These attitudes are related to words and images portrayed in the media (print and audio), words used by colleagues, friends and the society at large. These internalised negative attitudes can lead many people living with HIV to have self-image/worth problems; ranging from lack of self-confidence to actually hating themselves.

Clearly, this is not good, but how does it affect our sexual relations and our behaviour at large?

For most people living with HIV in relationships, to have protected sex depends on several factors, including knowledge, negotiation skills, assertiveness and/or fear of rejection and isolation. Practicing safer sex is not easy, if one has never done it before. It is not easy for women to negotiate safer sex with their husbands and partners. It is also not easy for men who have sex with men. The lack of skills to negotiate safer sex plays a crucial role in how HIV is spread. In addition, most people living with HIV, who have constantly faced rejection, stigma and discrimination, find it difficult to negotiate safer sex with their partners. Damage to their self-image may lead to a lack of self-value, which might mean that engaging in *'flesh to flesh'* sex weighs more heavily, than the benefit of protecting themselves from re-infection and protecting their partners from infection. The other side of the coin is that they are, arguably, wilfully infecting others.

Persuading people living with HIV to start practising safer sex depends more on improving their self-image and self-worth, as well as on addressing issues of internalised stigma. There are no programmes focusing on building the self-image/worth of people living with HIV. Prevention programmes tend to focus on people preventing themselves from HIV and not on people living with HIV. The fact of the matter is that as a person living with HIV, I am more likely to infect someone with HIV, than someone who does not know her/his HIV status. People living with HIV learn from each other, rather than from available programmes, about positive living. While this is good for some, it is not enough and not even an option for the ones, who are not open about their HIV status.

Damage to one's self-image and the *'shame'* associated with being infected with HIV, may further aggravate this dynamic and can lead to difficulties in discussing safer sex and/or sexual satisfaction. This places a lot of people at risk of infection. And women are the ones who bare the brunt in most cases, as they have no power to negotiate safer sex practices with their partners, while their partners fear rejection and being accused of infidelity, as and when they disclose their HIV status.

Working on one's self-image/worth is a difficult task, but I believe that it should be integrated in the counselling sessions, be part of education and support groups, as well as disclosure campaigns aiming at de-stigmatising HIV and, therefore, mitigating discrimination. People living openly with HIV should be encouraged and supported in their leadership, as well as support role.

Rebuilding my self-image and confidence was not an easy journey for me. But, I must say, it was worth it. I constantly have to maintain my self-worth and confidence, without being over compensating. The following steps worked very well for me.

Disclosing my HIV status to myself played a big role in how I looked at myself and, therefore, affected how others looked at me. I am not defined by HIV and, therefore, I introduce and view myself as a person living with HIV and not as *'I am HIV positive'*. I am, first and foremost, Jason.

Going through a process of self-introspection meant that I looked at the childhood stuff in my life and how I viewed myself then, because I believed that how I looked at myself now, as an adult, had a lot to do with how I viewed myself then, as a child. I realised that there were a lot of similarities. I never was a self-confident person, I was insecure about many things and I hated my life and the environment I grew up in. I grew up wishing that I could have a different life to the one I had.

During this period, I realised, I had so much work to do and that all the things I had believed about myself, had very little to do with what was done to me, but had a lot to do, with how I treated myself because of it. I had to first forgive myself for all the negative things I have ever said and believed about myself. And the journey continues…

> **The fact of the matter is that as a person living with HIV, I am more likely to infect someone with HIV, than someone who does not know her/his HIV status.**

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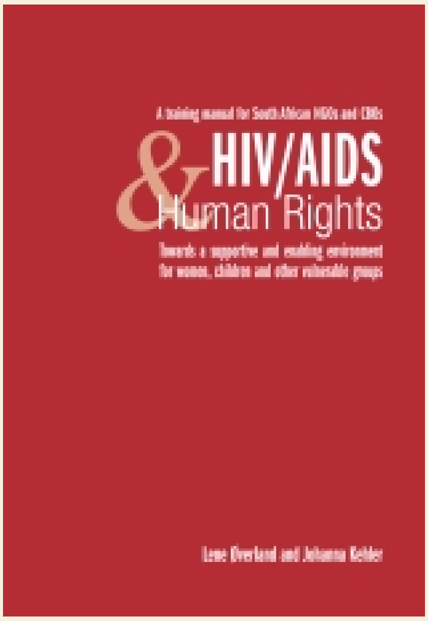
News on resources...

Another new publication, that has been developed, prepared and published by the AIDS Legal Network in 2005, is the *'HIV/AIDS and Human Rights: Towards a supportive and enabling environment for women, children and other vulnerable groups'* training manual. The training manual, conceptualised and compiled by Lene Øverland and Johanna Kehler, focuses specifically on Guideline 8 of the International Guidelines on HIV/AIDS and Human Rights and targets trainers within civil society and is prepared for a facilitation approach based on interaction, participation, information sharing and skills development.



The manual includes four modules pertaining to defining and understanding core concepts, to the meaning and implication of Guideline 8, to South Africa's response to the principles outlined in Guideline 8 and to practical advocacy steps aimed at enhancing the access to, and implementation of, legislative and policy measures. While these modules are prepared to be facilitated concurrently, it is also possible to utilise any one of the modules as a stand alone module for a education and training session. Thus, the manual provides as much a resource for human rights education and training on the Guideline 8, as it allows for sessions that specifically deal with one of the issues, such as gender and gender legislation, the legislative and policy framework as it pertains to HIV and AIDS realities and challenges, as well as meaning and practical steps of advocacy.

A copy of this ALN publication can be obtained by contacting Sandy Okkers at the ALN office at +27 21 447 8435 or on Sandy@aln.org.za.

Johanna Kehler

Has age-related stigma and discrimination become acceptable and justifiable?

Young people and the vicious cycle of discrimination, vulnerability and blame[1]

Equality, dignity and freedom form the cornerstone of our Constitution[2], guaranteeing EVERYONE the right to not only equal entitlement, but equal enjoyment of all rights and freedoms. However, while the concept of EVERYONE is one of the fundamentals constitutionally guaranteed rights are based on, the reality is marked by exclusion, prejudice, marginalisation, stigmatisation, inequality, discrimination and vulnerability of people belonging to particular social groups, such as young people, women, people living with, and affected by, HIV and AIDS. Subsequently, social groups, due to certain characteristics, such as their sex, gender, age and/or HIV status, seem to not only become excluded from the concept of EVERYONE, but the extent to which the various social groups are in the position to equally enjoy their rights and freedoms remain limited in accordance with these very same characteristics. Thus, and despite the constitutional commitment, society, arguably, fails to provide an enabling society in which the fundamental principles of equality, dignity and freedom can become a reality for EVERYONE and instead seems to nurture an environment, not only perpetuating, but justifying the discrimination, marginalisation and stigmatisation of the *'other'*.

Acknowledging the gap between the concept of *'everyone'* and the reality of *'us'* and *'them'*, this article aims to explore some of the reasons as to why especially young people (15 to 24 years) are at greater risk of HIV infection; examine the correlations between discrimination, vulnerability, lack of responsibility and blame; and argue that it is the very same correlation that determines the extent to which young people are, and will remain to be, discriminated against, vulnerable and at risk.

REALITY AND FACTS

The fact is that while the right to equality and non-discrimination (Constitution, Section 9), the right to have one's human dignity respected and protected (Constitution, Section 10), the right to life (Constitution, Section 11), the right to be free from all forms of violence (Constitution, Section 12), the right to privacy (Constitution, Section 14) and the right to have access to healthcare services (Constitution, Section 27) are constitutionally guaranteed to EVERYONE, young people continue to encounter numerous obstacles and experience discrimination in claiming their fundamental rights and freedoms.

It is also a fact that young people are discriminated against, vulnerable and at risk, even more so in a societal context in which HIV and AIDS has reached pandemic proportions. While an estimated 5.6 million South Africans are living with HIV, young people between the ages of 15 to 24 are the ones mostly at risk of HIV infection. The prevalence rate amongst young people is 10.2%.[3]

Acknowledging the fact that young people are vulnerable to, and at risk of, HIV infection, often leads to the seemingly recurring question as to WHY. The recurring answer seems to be that it is because of young people's lack of responsibility, because of young people's reckless behaviour, because of young people engaging in sexual activities and/or because young people do not *'want to listen'*.

But is this really explaining young people's vulnerability? Does this really explain why young people are discriminated against and have their rights violated? Should the question not be what role we, as society, have played in creating an environment in which young people are discriminated against and are vulnerable, and where we, as society, may have failed our young people? The question should not be whether or not young people are engaging in sexual activities, but rather why young people (or anyone else for that matter) are engaging in unprotected sexual activities. The question should not be whether or not young people *'do not want to listen'*, but *what* young people *'do not want to listen'* to. The question should not be whether or not young people lack responsibility leading to vulnerability, but rather who needs to take responsibility for young people's vulnerability.

It is a fact that a large amount of time, resources and efforts have been dedicated to educate young people about various factors of HIV and AIDS, as well as to educate young people about their rights and responsibilities. But maybe we need to ask ourselves, whether or not our HIV and AIDS education and awareness has reached the ones who were meant to benefit, the ones who are most at risk of HIV infection. Looking at the harsh realities of seemingly ever increasing numbers of young people living with, and affected by, HIV and AIDS, the answer seems to be no, we failed the ones who were meant to benefit the most. That seems to raise the question as to whether or not the information disseminated, and the message portrayed, in all the education and awareness programmes are the correct one, the *'truth'* reflecting the facts.

> **The question should not be whether or not young people are engaging in sexual activities, but rather why young people (or anyone else for that matter) are engaging in unprotected sexual activities.**

It is also a fact that women, including young women, are disproportionately infected with, and affected by, HIV and AIDS. This raises the question as to whether or not our young people are adequately educated about gender and gender equality, about sexual rights and sexual behaviour, and/or about making responsible and informed decisions about sexual activities and sexuality.

And finally, it is a fact that we live in a society in which discriminatory beliefs, attitudes and practices seem to prevail, as well as a society who seems to be not only reluctant, but also resistant to change. A society, in which the entitlement and enjoyment of rights seem to be much more based on one's gender, age and/or HIV status, than on the concept of equality and human dignity. A society, in which young people's discrimination and, thus, vulnerability is as much determined by their age, as it is by their HIV status. Thus, while young people are, for various reasons, vulnerable to, and at risk of, HIV infection, they are, similarly, vulnerable to, and at risk of, discrimination, stigmatisation and violation of their rights and freedoms, as and when they become young people living with HIV.

> **And while we *'educate them'*, while we *'tell them'* what is *'good for them'*, while we *'guide'* them, we often seem to forget to equip *'them'* with the necessary skills and knowledge to make responsible decisions**

There are undoubtedly numerous reasons explaining, as well as justifying, young people's vulnerability. Lack of education, high levels of unemployment and poverty, lack of adequate healthcare services, lack of recreational facilities – are but a few of the reasons used to explain and/or justify young people's vulnerability. There are also factors, such as socialisation, as well as social, cultural and religious values and belief systems and the extent to which they are adhered to or not, that are often used to explain young people's vulnerability to HIV infection. While the former seems like the one we cannot challenge or change, the latter seems to be, and should be the one, we, as society, have to take responsibility in challenging. It is, arguably, the status quo of young people's vulnerability, as well as its causes that has to be challenged so as to create an environment in which young people's vulnerability to HIV infection can be adequately addressed.

Young people's right to choose cannot, and should not, be limited to *our* understanding ... of what might be *'appropriate'*, *'acceptable'* and the *'right choice'* for a young person.

But what is the status quo? The status quo is a society, in which young people are often not seen and/or treated as equal to people; a society, in which young people's rights are limited and violated in accordance with their age; a society, in which morals and belief systems seem to justify the limitations placed upon young people's entitlement to rights; a society, in which young people are subsequently discriminated against, marginalised, excluded and, thus, vulnerable.

And this status quo manifests itself despite the constitutional guarantees provided for EVERYONE. While everyone has the right to be treated equally and not to be discriminated against, young people, based on their age, seem to be not as equal. Young people are often excluded from decisions concerning their lives; young people are often *'talked to'* and *'talked about'*, instead of *'talked with'*; young people are often told what to do and what is best for *'them'*, instead of asked, what they may want to do or perceive to be best for them. Young people's lives seem more often lived by parents, families, communities and the ever so strong *'need'* to conform to societal expectations so as to not become subjected to stigma, discrimination and marginalisation, than by young people themselves. It seems to be acceptable to treat young people different, because they are young, because they don't know, because they have to be guided. And while we *'educate them'*, while we *'tell them'* what is *'good for them'*, while we *'guide'* them, we often seem to forget to equip *'them'* with the necessary skills and knowledge to make responsible decisions; we often seem to be challenged by the concept that they are people, who have to have their rights as respected, as we expect our rights to be respected. And part of these rights is the right to choose, which seems to be one of the most difficult ones. Young people's right to choose cannot, and should not, be limited to our understanding, to society's understanding, of what might be *'appropriate'*, *'acceptable'* and the *'right choice'* for a young person. The right to choose has to be based on information and facts, including the pros and cons that enable one to make a choice, to make an informed and responsible choice.

The fact is that everyone has the right to privacy and the right to be free from all forms of violence. However, in the context of our homes and families, we seem to be able to justify that young people have only as much privacy as we, as *'head of the household/family'*, are prepared to give, whereas our privacy seems to be *'absolute'*. So, it seems to be justifiable for us to *'check'* in young people's belongings, whereas it might be *'punishable'* or at least it would be *'reprimanded'*, if a young person would *'check'* in our belongings. Similarly, *'disciplining'* young people seems, despite their right to be free from all form of violence and abuse, to be justifiable in the context of our homes and families, whereas the moment someone else *'disciplines'* a young person, or ourselves, then it becomes a crime, a violation of rights. Once again, the challenge seems to be the concept of EVERYONE, who is entitled to have their rights respected and protected, as well as EVERYONE, who is vulnerable and who is at risk to be discriminated against and to have their rights violated.

Everyone is entitled to have access to healthcare, including reproductive healthcare. And yet, young people's access to healthcare, especially reproductive healthcare, seems to be limited by not only their age, but by societal perceptions of *'appropriate'* and *'acceptable'* age and/or marital status to access reproductive healthcare. If, however, young people are expected to make responsible and informed decisions about their lives, including their sexual lives, then young people need to have access to the information based on which they are expected to make responsible choices. And considering young people's vulnerability to HIV infection, shouldn't they rather be encouraged to access as much information and services, including prevention methods, as possible, instead of being judged and *'scolded'*, because they are too young. Healthcare services, facilities and providers can, arguably, only be an adequate source of information to young people as and when provided healthcare services are non-judgemental, non-discriminatory and confidential. Especially in the context of HIV and AIDS, it is of utmost importance that the services, including prevention, testing, treatment and care, are offered in an environment, which is free of judgement, discrimination and prejudices, so as to facilitate responsible decision making for everyone, including young people.

CONCLUSION

The above seems to indicate that as long as young people are not perceived to be equal members of our families, our communities, our society, the discrimination and violation of their rights and their subsequent greater vulnerability to HIV infection will continue. Similarly, as long as we expect young people to respect us, while we are seemingly not quite as prepared to give the same amount of respect to young people, we will continue to strengthen a societal context in which young people are least in the position to make informed responsible decisions about their lives. Only if we begin *'talking with'*, as compared to *'talking to'* and *'talking at'*, our young people about their needs, their desires and their hopes and fears of being young, blamed and vulnerable, can we engage in a process that carries the potential of adequately addressing and responding to young people's discrimination, marginalisation and, thus, vulnerability.

> **...it is our responsibility to treat young people, as we would want to be treated, and to ensure that young people are equally in the position to make responsible informed decisions that are primarily based on facts and realities and least on morals and belief systems.**

While the fact that young people are vulnerable and at risk remains, the challenge seems to be taking responsibility and thus, addressing the causes of their vulnerability. If we agree, that it is *'us'*, as society, and not *'them'*, as young people, who could be as much blamed for the status quo of young people's vulnerability, than it is *'us'* and not *'them'*, who have to take responsibility for not only challenging, but also changing the status quo.

And finally, if we agree that EVERYONE is, and should be, equally entitled to have their rights and freedoms protected and respected, than we will have to agree that young people are part of EVERYONE and that it is our responsibility to treat young people, as we would want to be treated, and to ensure that young people are equally in the position to make responsible informed decisions that are primarily based on facts and realities and least on morals and belief systems. If young people are the ones who need to be *'guided'* and *'protected'* by *'us'*, than it should be part of our *'guidance'* and *'protection'* to create an environment in which young people are not discriminated against, marginalised and judged based on their age, and thus, are less vulnerable and more positive.

FOOTNOTES:

1. An earlier version of this article has been presented at the AIDS Legal Network Public Debate *'Youth: Blamed and Vulnerable'* on 15 June 2005 in Cape Town.
2. The Constitution of South Africa, Act 108 of 1996.
3. UNAIDS. 2004. Report on the Global AIDS Epidemic: July 2004.

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Umesh Raga

Prisoners have rights too...

Prisons, as microcosms of society, are part of the HIV and AIDS pandemic

South Africa's transition to democratic rule has brought with it many challenges. Our people's need for housing, jobs and basic necessities makes the Minister of Finance's task daunting – a classic case of limited means with unlimited needs.

R23,5 million per day is spent on our prisons or R9,2 billion for the financial year 2005/6.[1]

At first glance, the temptation, when confronted with this astronomical expenditure, would be to accuse government of unnecessary expenditure on a category of South Africans, who deserve very little, if anything at all. It would be popular to proclaim that prisoners, who after all, have broken the rules, should not be concerned about. Reality, however, requires that we do exactly the opposite.

It is argued, that one judges a nation by how it treats its prisoners. A nation that addresses the needs of the poor, the marginalised, the unemployed and the weak, is a nation that does not deny its responsibility to afford assistance to the ones in need, a nation that recognises that prisoners require assistance; assistance, not in the form of a hand-out without responsibility, but by means of tools and opportunities to improve. The South African Constitution recognises our past and enjoins us to establish a society based on democratic values, social justice and fundamental human rights.[2]

When the average prisoner is a Black African male between the ages of 19 to 35, unemployed, with little or no primary education and little prospect of that changing on his release, this category, *'a captive audience'*, provides our society with the ideal opportunity to produce an individual who can rejoin society educated, skilled, healthy and corrected.[3]

THE COMMON LAW AND CONSTITUTIONAL RIGHTS

Section 35(2)(e) of the Constitution proclaims that:

> *Everyone who is detained, including every sentenced prisoner, has the right to conditions of detention that are consistent with human dignity, including at least exercise and the provision, at state expense, of adequate accommodation, nutrition, reading material and medical treatment.*[4]

Various judgments of our courts have affirmed the rights of prisoners, including with the often quoted passage by Judge Corbett in 1979 stating:

> *It seems to me that fundamentally a convicted and sentenced prisoner retains all his basic rights and liberties…of an ordinary citizen* ***except*** (emphasis by author) *those necessarily inconsistent with the circumstances in which he, as a prisoner is placed…There is a substantial residuum of basic rights which he cannot be denied; and if he is denied them, then he is entitled, in my view, to legal redress.*[5]

More recently, in the post constitutional (interim and final) era, the residuum principle was again invoked, for example, when prisoners challenged the fact that their access to ARVs was denied. Judge Brand stated in the judgement of this case that:

> *There are prisoners, like the first applicant, who may well be able, upon their release, to earn an income which will enable them to afford anti-retroviral treatment…Since such inroad cannot be described as* ***a necessary consequence of incarceration*** (emphasis by author), *I do not believe that the refusal to provide these prisoners with anti-retroviral medication is consistent with the principles of our common law.* [6]

Prisoner's have been, and are, theoretically at least, protected by our law. Besides their deprivation of liberty and free movement, they retain all of the fundamental rights and freedoms, as free persons, including the right not to be unfairly discriminated against.[7]

PRISONERS AND HIV AND AIDS

Prisons are microcosms of the broader society. As with our communities, in general the ones likely to contract the HI virus and/or AIDS are young, unemployed, poor, and are un-or under-educated Black South Africans. Similar socio-economic conditions that afflict broader communities, affect prisoners. The prison population is not static. Approximately 26 000 prisoners are released from prisons each month. A similar number enter the prisons each month.[8] It has to be recognised, that people carry their health status, including transmissible diseases, such as TB, HIV and AIDS, in and out of prisons.

Inside prisons, high risk behaviours for HIV transmission include unprotected sex, intravenous (IV) drug use and the use of contaminated cutting instruments. Coupled with the inhumane conditions, such as overcrowding (in some instances in the region of 200 to 300%), as well as stress and related problems, our prisons are, arguably, havens for diseases to run rampant. A study, pertaining to the rate of natural deaths in prisons, shows that it increased exponentially from 211 in 1996 to 1683 in 2003.[9] These deaths are largely attributed to the HIV and AIDS pandemic and the lack of constitutionally guaranteed access to adequate health care.[10]

A study, pertaining to the rate of natural deaths in prisons, shows that it increased exponentially from 211 in 1996 to 1683 in 2003.

Judge Van Zyl, in a case in which a terminally ill prisoner (cancer) was released by order of the Court, was scathing, stating that:

> *The facts set forth in the most recent annual report of the Judicial Inspectorate of Prisons indicate a shocking state of affairs. Despite the huge increase in the prevalence of HIV/AIDS and other terminal diseases in our prisons, only the tiniest percentage of prisoners suffering from such diseases were released on medical grounds during 2002.*[11]

He further stated that if more prisoners were not so released, *'the alternative is grotesque: untold numbers of prisoners dying in prisons in the most inhumane and undignified way'*.[12]

In recent years, several cases brought to the courts have confirmed and reinforced prisoners' rights, including their right to equality, to human dignity and the right to adequate healthcare. For instance, in the cases of Van Biljon[13] and Cloete[14], both dealt with prisoners who live with HIV and AIDS; the Court in the former ordered the Department of Correctional Services to provide anti-retroviral medication and in the latter held that the prisoner, who contracted the HI virus in prison, be eligible for reconsideration of his sentence. In addition, in the case of C v Minister of Correctional Services[15], the Court held that prisoners cannot be tested for the HI virus without their consent and thus, have the right to informed consent. The prisoner in this case was successful in his application.

THE CORRECTIONAL SERVICES ACT (NO 111 OF 1998)

The Act contains no provision for the separation and/or segregation of prisoners solely on the basis of their health status. It does provide, however, for the segregation as prescribed by a medical practitioner[16]. The intention in this instance is for the sole purposes of the safety, and the prevention, of transmissible diseases amongst prisoners. The Department of Correctional Services in its recent *White Paper on Corrections in South Africa*, outlining the strategy for the future, only mentions HIV and AIDS in a passing and peripheral way, which is, arguably, a major cause for concern. The White Paper [2005:82] states that:

> *HIV/AIDS and other communicable diseases such as TB and sexually transmitted infections (STIs) will be addressed as integral to provision (sic) of comprehensive health care services and health care education to inmates. The Department should focus on programmes to reduce the impact of HIV/AIDS and other communicable diseases to allow people under correction to leave thesystem as healthy as possible.*

CHALLENGES AND WAY FORWARD

In conclusion, the following recommendations are but some of the steps and measures carrying the potential to ensure that the rights of prisoners are not violated based on their HIV status:

- Whilst the legislative and policy framework is in place prohibiting the discrimination of prisoners living with HIV and AIDS, NGO's and civil society must lobby for a detailed policy and action plan to supplement the White Paper and to ensure adequate implementation.
- Legislation, providing for early release of prisoners who are terminally ill and/or where prison healthcare facilities are inadequate, must be adequately applied and implemented .
- Conditions and procedures violating prisoners' right to privacy, in that prisoners' HIV status can be easily identified when queuing for food (special diets) and at medical parades must be addressed as a matter of urgency.
- It is the responsibility of the Department of Correctional Services to ensure that prisoners can not only engage in private and consensual sex, but also in private and consensual safer sex.
- The feasibility of conjugal visits in prison must be addressed, as one of the possible mechanisms to respond to prisoners' emotional and sexual needs.

REFERENCES:

DCS. 2005. *White Paper on Corrections in South Africa.* Department of Correctional Services.

FOOTNOTES:

1. 2005 estimates of National Expenditure, Vote 10, Department of Correctional Services Budget.
2. The Constitution of South Africa, Act 108 of 1996, Preamble.
3. Department of Correctional Services' stated core function.
4. The various other fundamental rights are equally applicable subject to limitations as per Section 36 of the Constitution.
5. Goldberg and others v Minister of Prisons and others 1979 (1) SA 14 (A).
6. Van Biljon and others v Minister of Correctional Services and others 1997 (4) SA 441.
7. See Section 9 of the Constitution, as well as Promotion of Equality and Prevention of Unfair Discrimination Act (No 4 of 2000).
8. Judicial Inspectorate of Prisons Annual Report 2003/2004, p. 18.
9. Op cit, page 16/17.
10. Section 35(2)(e) of the Constitution.
11. Stanfield v Minister of Correctional Services 2003 (4) All SA 282 (C).
12. [Stanfield v Minister of Correctional Services 2003 (4) All SA 282 (C). This case is equally important in the context of prisoners' right to dignity.
13. Van Biljon v Minister of Correctional Services 1997 (4) SA 441.
14. S v Cloete 1995 (1) SACR 367 (W).
15. 1996 (4) SA 292 (T).
16. Section 30(1)(c) of the Correctional Services Act.
17. Section 79 of the Correctional Services Act, as well as Section 276A(3) of the Criminal Procedure Act (No 51 of 1977).
18. The Judicial Inspectorate of Prisons has noted that some prisoners have complained that these are not conducted confidentially.

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Limpopo, the Home of Peace, the Garden of Eden...

Cecile Manhaeve

For many people hearing and talking about Limpopo is thinking about nature and people drenched in extremely hot and dry weather… When driving to Limpopo from Gauteng one is ushered in by a big billboard saying: *'Limpopo, the Home of Peace, the Garden of Eden'*. And truly, this is what living in Limpopo reflects. But, I guess, there is more to it too.

Limpopo is a province with high unemployment rates, low literacy levels, severe poverty and lack of access to basic services, such as water and electricity, in many of the almost forgotten villages and communities. Sparingly distributed and far apart, there are some towns and larger communities with better access to jobs, health, education and many other necessities needed to prosper in life, but these remain few.

Many people are trekking from the one place to the other in the hope of improving the living conditions for loved ones. At month end, when salaries and wages are paid, one can witness *'the great trek North'* bringing the hard earned cash home to assist the ones who stayed behind. On Sunday afternoon, and early Monday morning, the reverse happens. Families are torn apart by the drive for survival, and this becomes a breeding ground for HIV, silently taking hold of many people in vulnerable life situations. Indeed, for many, life is not easy in Limpopo.

Statistically, Limpopo does not feature amongst the highest HIV infection rates on the list of South African provinces, but this could be a misgiving. It needs to be taken into account that many residents and communities are situated far from health facilities. In several instances, clinics and hospitals might be available, but they lack the skilled staff to deal with this situation and to provide Voluntary Counselling and Testing (VCT), as well as other services. A high turnover in employment of healthcare workers gives rise to loss in confidence in the system. Many people find a way out, by seeking help from traditional healers and practices, which might not always be the appropriate approach to deal with AIDS related illnesses and diseases. The need for HIV and AIDS education is high.

No wonder that stigma and discrimination are rife. It is much easier, and takes less effort, to deny that one is infected with HIV, than to accept and learn to live with the disease. When HIV enters a family, through an infected family member, it turns the situation around for all. Scarce family resources are re-directed to keep the loved ones alive. Many go to great lengths and are willing to pop out high amounts of money in an attempt to turn the HIV 'verdict' away, because it might lead to loosing one's *'sense of belonging'*.

Through joint efforts, local communities try to meet the needs experienced in their communities; community-based organisations (CBOs) are mushrooming. Many people join and become volunteers in the hope of finding a job and/or getting the assistance one hopes for.

The ARV roll-out is taking off slowly, very slowly in some areas. A lot of misinformation is spread about ARV medication. Many challenges are ahead to bring the life-saving pills to the people infected. Internal, as well as external stigma needs to be overcome, to venture out into the open and to face the reality of one's life living with HIV. In some areas, huge travelling distances are part of the 'deal' to get to health facilities involved in the roll-out, a strain and extra challenge, especially when the family is stripped of cash.

For the ones able to access the medication, additional challenges might be a lack of nutrition, difficulties to provide long-term food security and a lack of support from family and/or community, as well as poor access to Disability Grants and the removal of the grants, when the health condition improves. All these might lead to patients dropping out of the system, followed by a fast deteriorating health condition, which creates in turn more disbelief in the medication and warrants for more misinformation about ARVs. The vicious cycle is complete.

Healthcare workers and NGOs, involved in the roll-out, are challenged too. Because of the few accredited facilities, as well as the restriction in number of patients to go on the drugs, it is a constant dilemma to select candidates. Criteria have to be stringently adhered to. How can one make sure that a client will adhere? Whom to select? Whom not to select? Do patients not have equal rights to obtain the medication? What are we missing in our adherence training programmes? Where does all the misinformation come from? Which information should be given to communities? Who should distribute the information?

Once a patient drops out of the system and wants to return, it takes an enormous amount of effort and time to re-establish the trust of the patient and her/his family in the medication and the system. Investigations for possible resistance are to be done and it may be difficult for the patient to understand why it *'takes so long'* to get back on the drugs. And although, it might be easier for the patient to understand why all these investigations need to happen, it may be even more difficult for the relatives, especially when they are weary of the working of, and the need for, the drugs. In such instances, family counselling might assist in dealing with the matter, but resistance from the people involved may be hard to deal with, skills might be missing, feeling discriminated against might be enhanced.

Active involvement in programmes of people living with HIV and AIDS helps to ease the burden. Many of the people are strongly motivated and go to great lengths to ease the burden of the disease on individuals and families. Support groups for people living with HIV and AIDS, as well as for people on ARVs are successful strategies, which can help to bring down the stigma and discrimination, and to assist clients with adherence. Why do we find so few of these? Networking with experienced organisations and individuals could help us forward.

HIV and AIDS, are, and remain to be, complex issues to deal with. Approaches, knowledge and education develop fast and seem to remain ahead of us all. More people need to get involved for the *'right'* reasons. Behaviours need to change. Windows and doors need to be opened wide, so that a wind of change and commitment can flow freely.

Beloved reader, what have you done so far? Do you really care?

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Learners are Positive

Young people are the ones who are vulnerable and at risk. While this applies to any society, young people are even more vulnerable and more at risk in a societal context in which HIV and AIDS has reached pandemic proportions. According to statistics, an estimated 5.6 million people in South Africa are living with HIV and AIDS and young people between the ages of 15 and 24 years are the ones mostly at risk of HIV infection, with a prevalence rate of 10.2%.

Acknowledging that young people are vulnerable to, and at risk of, HIV infection, often leads to a discourse, in which young people are often blamed; blamed for a lack of responsibility, blamed for reckless behaviour, blamed for engaging in sexual activities, as well as blamed for living with HIV and AIDS. Another possible discourse could be, and should be, to question society's responsibility for young people's greater vulnerability to HIV and AIDS. We, as society, need to ask ourselves whether or not our HIV and AIDS education and awareness programmes are reaching the ones most at risk of HIV infection. Since women, including young women, are the ones disproportionately infected and affected, it also raises the question as to how far we have come in educating our young people about gender and gender equality, about sexual rights and sexual behaviour, about making responsible and informed decisions about sexual activities and sexuality. But then again, acknowledging the large amount of time, resources and efforts that have been dedicated to various factors of the HIV and AIDS pandemic, it seems 'easier' to not question the efficacy of these efforts, but to blame young people.

It is within that discourse that the AIDS Legal Network (ALN) asked questions as to young people's views, opinions and beliefs to HIV and AIDS realities and challenges experienced by young people themselves. So, as part of the ongoing *'We are all equal…aren't we?'* campaign, an ongoing campaign launched by the AIDS Legal Network in October 2004, we embarked on a nationwide School Survey, inviting Secondary School learners to respond to the ALN slogan and to write an essay exploring the extent to which we are all equal, we are all affected and we are all positive.

The aim has been to facilitate a forum in which young people can be heard and raise their voices to issues affecting their lives and future. The response has been overwhelming; both in the sense of numbers and in the many creative ways young people expressed themselves. Initiated by the enormous response from young people, what began as a 'survey' to collect some data, grew into a published 'booklet', filled with numerous, interesting, inspiring and thought provoking stories, experiences, views and opinions written by 142 learners from 20 Secondary Schools from 8 provinces in South Africa.

Learners are positive – is what we, the AIDS Legal Network, had to conclude after reading the responses and what we hope, the reader, will discover while engaging with young people and their views and experiences. And, hopefully, it will initiate debates and discussion amongst all of us as to the reason for young people's vulnerability and maybe even question the rightfulness, or even necessity to blame…

A copy of this ALN publication can be obtained by contacting Sandy Okkers at the ALN office at +27 21 447 8435 or on Sandy@aln.org.za.

Damoline Muruko

Gender Inequality and HIV and AIDS:
The Namibian experience

Based on research on issues of HIV and AIDS and gender, conducted in Namibia,[1] it can be concluded that sexuality and fertility are not simply matters of rational individual choices, but are embedded in a complex set of social, economic and cultural relationships.

The strategies to prevent the spread of HIV have focused on the promotion of condom use, reduction of numbers of sexual partners and the treatment of sexually transmitted diseases (STDs). Many of these responses have, however, failed to address social, economic and power relations between, and amongst, women and men. These relationships together with physiological differences, determine to a great extent women's and men's risk of infection, their ability to protect themselves and their respective share of the burden of the epidemic.

Gender Inequality: The Basis for women's vulnerability to HIV and AIDS

In the Namibian society, gender inequality is one of the social structural factors significantly contributing to the spread of HIV. As well as other social challenges, unequal power relations between women and men place women at greater risk of HIV infection.[2] Kaundjua (2000:18)[3] argues that unequal power relations between women and men in Namibia make women more vulnerable to ill health, which includes HIV infection. The consequences of gender inequality, such as gender-based violence, women's poverty and women's lack of access to social and economic resources, further determine that women are at particular risk of HIV infection.

According to statistics,[4] in 1999 women accounted for 54% of all new cases of HIV infection in Namibia. In addition, women are also diagnosed at a younger age, given that the median age of HIV diagnosis is 30 years old for women and 35 years old for men. While young women between the ages of 15 to 24 have an overall infection rate of 18.8% to 20.8%, the corresponding estimates for young men is 7.9% to 10.4%. In Namibia, the percentage of young women living with HIV is 29%, as compared to only 8% for young men. Given the age/gender differential in HIV infection rates, it is not surprising that women are less likely to live beyond the age of 40 and that women have a life expectancy at birth that has dropped from age 55.4 in 1999 to age 45.6 in 2000.

Although, it is a fact that women are physically more vulnerable to HIV infection, because of biological factors, biology alone does not account for the significant gender differential in the abovementioned statistics. Women and young girls are disproportionately vulnerable to HIV, because of social structural factors. In 2002, Steven Lewis, the Secretary General to the UN Envoy on HIV/AIDS in Africa, stated:

> *That the pandemic is now, conclusively and irreversibly, a ferocious assault on women and girls ... The toll on women and girls is beyond human imagining; it presents Africa and the world with a practical and moral challenge which places gender at the centre of the human condition.*[5]

Girls, due to a number of social structural factors, are particularly at greater risk of HIV infection. Their exposure to the disease is usually by older men, who exploit the low socio-economic status of girls and have sexual intercourse in exchange for small gifts or money.[6] In addition, many of the girls are exposed to HIV infection from their male cohorts, who consider sexual intercourse a necessary part of dating, and the girls fearing rejection, give in to the boys' demands.

Recently, a 19 year-old girl from northern Namibia publicly announced her HIV positive status in an effort to warn other young people that HIV and AIDS is a real threat. In an interview, she mentioned that she not only had full knowledge about HIV and AIDS, as well as preventative measures, but also that she had previously been an HIV and AIDS awareness campaigner. When asked how, with all the knowledge she had about HIV and AIDS, she could let herself become infected, she explains

[The Namibian, DATE, 2002:1-4]:

> *It is true that I have the knowledge and the information but I did not have the courage or the power to tell my partner to use a condom each time we had sex. I had the fear of telling the guy please let's use a condom. I was shy. I kept thinking, what this guy would say.*

In Namibia, women are more likely to live in impoverished circumstances and their economic, as well as social, marginalisation places women in HIV risk-taking situations. A UNAIDS report [UNAIDS, 1998:28] stated that *'The high incidence of HIV among Namibian women is the result of the complex interaction of poverty, lack of power over sexual decision-making, and infidelity of men'*. As much as girls in Namibia are at risk, due to transactional sexual exchanges, so are many older women in Namibia forced, by economic circumstances, to engage in sexual relationships in exchange for *'gifts'* of food, clothing and support for their children. Many of the men, who participate in these exchanges, have several women whom they have sex with in exchange for gifts, as well as a wife with whom they have a formal relationship.[7]

For many women, their economic dependency and lack of decision-making power means that they do not have the 'right' to refuse high risk sexual behaviour or to enforce condom use, even if they know their sexual partners have been unfaithful. Furthermore, many women in sexual unions are perceived not to have the right to refuse their partners' sexual advances without condom use; wives especially do not have the right to refuse sexual intercourse with their husbands, who feel they have the right of control over their wives' bodies.[8]

Many women in Namibia live in abusive relationships, which frequently lead to high risk sexual behaviour. Domestic violence is in many situations accompanied by sexual violence.[9] Sexual violence places women at greater risk of contracting HIV, because condoms are usually not used during forced sexual intercourse. Marital and date rape take place within many sexual relationships. As previously stated, many men do not believe that marital rape is possible, given that sexual intercourse with a wife is seen as a right, not a privilege. LeBeau et al. (1999:88) found that:

> *From an early age, coercion and violence may be part of many women's experience of a sexual relationship. Some women have no reference point for a sexual relationship outside of violence, since they have been exposed to violence throughout their entire relationship history.*

Sexual violence within a dating relationship also exposes girls to HIV infection.[10] Very often, young men who take young women out and pay for drinks and food expect that the girls will have sex with them, while other young men feel that girls do not really mean *'no'* when they say *'no'* and they feel *'you must force her'*.[11]

In addition to marital and date rape, rape by a stranger has increased dramatically and thus, women are at increased risk of HIV infection. However, while the number of rape incidences have increased dramatically over the last few years, Namibia has neither the infrastructure nor the finances to provide PEP to survivors of rape, thereby significantly increasing their chances of HIV infection.[12]

Further to the challenges women face, due to social structural factors, many women in Namibia face the additional challenge of negotiating sexual relations in a social environment that fosters high risk sexual behaviour. Subsequently, young women are at significantly greater risk of HIV infection than young men; women in Namibia are forced, due to the economic circumstances, into relationships of sexual exchange for economic benefit; women in relationships often do not have condom use enforcement rights; and many women's lives are dominated by gender-based violence.

Given the primarily sexual dimension of infection, HIV and AIDS is closely linked to reproductive and sexual rights, since the social and cultural dimensions of sexual and reproductive activities promote and entrench gender inequality, as well as increase women's vulnerability to HIV infection. [13]

Reproductive rights take on another dimension in relation to HIV and AIDS, as hard-fought battles of the feminist movement are being eroded. Examples include the control often exerted by healthcare workers over the reproductive choices of women living with HIV and AIDS, in that women living with HIV requesting termination of pregnancy are *'forced'* into sterilisation;[14] women living with HIV and AIDS are often not given accurate information regarding pregnancy and breastfeeding;[15] women often face difficult decisions regarding breastfeeding as a culturally preferred option in that a decision to not breast feed can lead to a *'forced'* disclosure of a woman's HIV status;[16] and women are faced with judgmental and hostile attitudes from service providers, including testing without consent and refusal of services.[17]

CONCLUSION

The analysis of the HIV and AIDS pandemic, including the driving forces and huge impact on individuals (women, men and children), households and communities, clearly shows that gender inequality is at the centre of the epidemic and that a human-rights approach is an important lens through which to view HIV and AIDS.

The main focus of any approach should incorporate a careful analysis of gender power relations and the particular context in which women and men live, and a deeper understanding of women's position within society and the HIV and AIDS pandemic.

While initially a *'gendered'* approach meant working with only women, for example, on educating women on condom use, a stronger recognition of the factors constraining women's ability to negotiate safer sex, allowed a shift in focus from women to working with women and men, or with a focus solely on working with men.

This is certainly true in the context of HIV and AIDS, where the focus of many programmes and campaigns is now on involving men. This is not a problem in itself, but when programmes targeting men are at the expense of programmes for women, or when programmes target men, but do not challenge gender inequality, such programmes become problematic and should be challenged.

A *'gendered'* approach should, therefore, not be at the expense of a feminist agenda, which gives a high priority to help women change or transform power dynamics. Baden and Goetz (1998)[18] caution that in some policy applications, gender has lost its feminist political content. Thus, gender becomes descriptive, focusing on the different roles and responsibilities of women and men, instead of challenging the power imbalances.

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Annual General Meeting...

The AIDS Legal Network (ALN) held its Annual General Meeting on 19 February 2005 in Cape Town. As part of the AGM, a new Board of Directors was nominated and duly elected. The ALN Board of Directors comprises of Pierre de Vos (Chairperson), Isabella Mabengeza (Vice Chairperson), Beverley Franks, Printha Sewdass (Treasurer), Umesh Raga, Wendy Isaack and Johanna Kehler (Secretary).

making a point

Shamim Meer

Mainstreaming: Understood or Misunderstood?

Mainstreaming is not an end – it is a strategy

The problem with mainstreaming is that it is seen as an end in itself. We ask have we successfully mainstreamed. Is mainstreaming working? Is mainstreaming misunderstood? And as we ask such questions, we get more and more lost in the dark. And as we fumble about, we get more distant from the goal mainstreaming was meant to address in the first place – the goal of gender equality.

Mainstreaming is an approach, an overall strategy, advanced by women's rights and feminist activists in development, to make sure that women's concerns would come into the centre of things – into the mainstream. It came from the thinking that everything is gendered; that access to economic institutions and/or political office, to one's experience of harassment when standing at a bus stop are all gendered, in that a person will experience all of these differently, depending on whether you are a woman or a man. These women's rights and feminist activists realised that the unequal gender relations between women and men – their unequal access to resources, to power and authority shapes all experiences. That the way women and men experience poverty, or their place in a community project, will be affected by women's lesser access to resources, power and authority. And that within a class, race or ethnic group, which might suffer discrimination, it is the women who will have less than the men, the women who will be subordinate.

Women's rights and feminist activists realised that in order to ensure women's interests were met, it was important to find ways ensuring that development thought and practice took on board the difference being a woman or a man made to every area of life. And so, the approach of mainstreaming came into being. It was an approach meant to work for a society where women will no longer be subordinate, where women and men will share workloads, decision making and resources, where women will no longer be the victims of violence and rape, where women will have control over their bodies. Where being a woman will not make one more vulnerable to HIV or to poverty.

What mainstreaming, as an approach, was trying to get away from was marginalised projects for women, where women in a community would, for example, be tinkering away on the margins – baking bread or making baskets – while the men of that same community discussed politics and made decisions on land reform. Or, at a national level, where a marginalised under resourced government ministry of women's affairs, low down in the hierarchy, dealt with women's welfare problems, while the more powerful departments of government, such as finance and treasury, neither included women as participants nor took into account women's concerns. A mainstreaming approach intended that, in addition to separate women's projects development practitioners, women participated as equals to men in discussions and plans on all matters, including such concerns as land reform or economic development, so that they would bring their needs and interests to these discussions and, thereby, shape policies and resource allocations together with men. The women's rights activists, who advanced mainstreaming, thus, saw in it the potential to bring women and their concerns to economic and political discussion and planning, and to challenge male power and male dominance in all areas of life.

Since the 4th International Conference of Women in Beijing, mainstreaming has been adopted by most governments and development organisations as a strategy by which to achieve gender equality. But, as mainstreaming got taken up in practice by governments, development organisations, policy makers, project planners and implementers, it seems to have resulted in a number of confusions – at times even being derailed deliberately by the ones who were terrified at the very thought of women's equality.

Confusions, misunderstandings, resistance and fear

The first confusion, it seems, is about what it is that we are mainstreaming. Most often people talk about mainstreaming gender. What they really mean to be saying, since unequal gender relations are everywhere and in everything, (in ways that make women subordinate) is that we are mainstreaming *gender equality.*

Secondly, there is often confusion over what it is that we are mainstreaming into? Is it simply a matter of ensuring gender equality in all and every agenda without discerning whether that agenda is in women's interests? Or as some have put it, have we checked to see if the stream is a dirty stream that we want to even enter? In other words, to take an extreme example, were apartheid policies to return to South and Southern Africa, will we be clamouring to mainstream gender equality into this agenda or would we be looking for ways to eliminate this agenda? Definitely, our aim would be to eradicate this agenda, but in this process of struggle we would be making sure that women and their interests are a part of the challenge to unwanted and sinister social policies. Or, to take our current economic context, would we want to mainstream gender equality into current economic and trade policies, which result in job losses and increasing costs for the poor, or would we be attempting to challenge such policies, at the same time bringing concerns for women's rights to such challenges? In other words, our mainstreaming agenda should not simply be about uncritically integrating gender equality into everything and anything, but it should be about transforming harmful agendas in the interests of the majority, so as to end gender, race, class and other forms of exploitation and oppression.

Thirdly, and this point is linked to point two above, the stream, women's rights activists are mainstreaming into in development, is a rational economic framework, which only admitted the technical and did not admit the political (Mukhopadhyay, 2004).[2] This framework failed to recognise the conflict and power which lie at the root of unequal gender relations. It assumed consensus. It assumed that all problems are technical. Agencies got caught up in their own logic and so, even when they tried to uncover why they were not moving closer to gender equality, they identified the blockages as being technical – as related to inadequate planning and the solution as more adequate procedures.

So, instead of dealing with unequal relations of power, tools and checklists were devised and the approach was to *'number crunch'*, to count the number of women on projects. From the point of view of existing development practice, it was easier to address procedures and operations, and to count numbers, without tackling deeper structural change (Jahan, 1995).[3] Not surprisingly, these technical solutions have proven inadequate in redressing unequal relations of power. Mainstreaming gender equality in these contexts was like trying to fit a square peg into a round hole.

Mainstreaming attempts worked

with what was already there and did not challenge this overall framework. Gender equality was thus, grafted on to existing planning methods and procedures (such as log frames) without questioning whether or not these were capable of addressing goals of social equality.

For their part, the women's rights activists, who were advancing mainstreaming, were concerned with speaking the language of development practitioners in order to get them to take on gender equality and so they were to an extent complicit in developing tools, checklists and other technical means to plan, implement and monitor projects. More recently, there has been considerable reflection on this and an awareness that the strategies we use to advance equality need to be constantly reviewed; as these could act against the very issues we are trying to change.

Fourthly, mainstreaming came on the back of a shift in development – a shift away from a focus on women to a focus on gender. The focus on women had some difficulties – the main difficulty being that women tended to be seen as the problem. What the focus on gender was trying to clear up was that it was not women, but the *system* of gender oppression that was the problem. Like systems of class and race oppression there was this gender system that subordinated women and gave men power. In the same way as black and working class people were not the problem, but rather the systems of racial and class domination that were the problem and that had to be addressed. However, this was misinterpreted and the intent of this distinction between women and a system of oppression was taken to mean that women's projects were out, because mainstreaming was in. Separate women's projects were seen as backward and the more progressive move was seen as doing away with women's projects.

The architects of mainstreaming – the feminist and women's rights activists – never intended that we do away with separate projects for women. In fact, they saw separate projects for women as critical for women's empowerment and key for attaining women's rights. But, the shift to gender and to mainstreaming was taken by many NGOs, international development agencies, and national states to mean a shift from a focus on women to projects for women and men. This shift is harmful to women and harmful to goals of gender equality. This is not to say that men should not be involved in the struggle for women's rights, but this struggle has to be led by women as agents and men must support this struggle on women's terms (Win, 2005).[4] In much the same way as any oppressed group, black people, indigenous people, workers, the landless must be the leaders in their struggles even though others may act in solidarity with them.

This brings me to my fifth point, which is not so much about confusion as about resistance – resistance to gender equality and to the language of politics. Why would there be such resistance? Resistance is born out of prejudice and self-interest. Gender relations affect each and every one of us in very deep and personal ways. Men and some women also, are threatened by gender equality, by women being full citizens, being people in their own right, instead of being under male control as daughters, wives, and mothers. To eradicate male power over resources and power, including power over women, goes against men's gender interests, and against the interests of the women who help to bolster the existing gender system. Eradicating male power is threatening to development institutions, to communities and families all of which are organised on the premise of male superiority and women's subordination. To end women's subordination is to attack the very fabric of society.

Many of the individual development actors across institutions, such as NGOs, nternational donor agencies, national governments, each have their own gender interests and often, unless one is a feminist or women's rights activist, these interests are about keeping existing unequal gender relations of power intact. In other words, policies, such as mainstreaming, do not fall into a vacuum. They enter institutions which are already gendered in particular ways – usually in ways that subordinate women and their interests – and, as they get taken up by individuals in these institutions, who might have their own interests in keeping the existing gender order intact. Mainstreaming policies thus, get manipulated and reshaped in accordance with institutional agendas and the agendas of the individuals in these institutions. Out of the hand of gender activists and into the hands of people, who have no real interest in advancing women's equality, these strategies take on different meanings and can end up working counter to the intent of their architects, and entrench existing power imbalances.

Often, the resistance to gender equality is not overt. Most often resistance hides behind a symbolic acceptance of mainstreaming gender equality. The evidence of resistance is in the watering down of gender equality to mean nothing more than more women – the *'number crunching approach',* which takes increasing numbers of women to equal mainstreaming, while in the meanwhile the culture, the rules and procedures of institutions women enter, such as parliament, remain unchanged. We see evidence of resistance in responses, such as public awareness campaigns and income generation projects, to address women's vulnerabilities in relation to HIV and AIDS, without addressing the power relations which lead to women's vulnerability in the first place.

So, what is to be done?

Much of the current experiences of mainstreaming seem to be marked by the confusions above about what it is that we are mainstreaming, not critically examining whether the stream is one we want to enter in the first place, about how to transform the mainstream and not reflecting sufficiently on how we should go about mainstreaming gender equality.

We need to be asking whether we are moving closer to gender equality. And more particularly, are all women across class and across race caught up in this move towards gender equality? And, if we are not moving to gender equality, we need to ask what is it that we should be doing. And it is not simply equality of opportunity we are talking about (ensuring women have the same opportunities as men), but rather substantive equality, which ensures that women are able to take up the opportunities available through, for example, measures to level the playing field.

In development at the present, a rights-based approach is being advanced in struggles against poverty and for gender equality. Approaching development questions as rights, has the potential to shift us away from a welfare approach to an approach which sees poor women and men as citizens who have rights, who are agents who can organise together to determine their destiny. But, we need to make sure that a rights approach is informed by gender equality concerns and includes women rights as human rights – for often rights frameworks work from a notion of a de-gendered, de-raced, de- classed human being and, in so doing, does not address gender, race and class inequalities. We also need to guard against rights approaches being little more than the latest fad (Wheeler & Pettit, 2005)[5], which entails new language to cover up the reality of resistance to change, the reality that systems of class, race and gender privileges, that give some people power over others, remain unchallenged and untransformed.

Women's organisation for women's rights and empowerment is the key

We need to search in an ongoing way for strategies to achieve substantive equality and women's rights. An overarching proven strategy is the organisation of women to address women's subordinate position in the family, community, state and market. But, we need to keep in mind that in addition to being a strategy, and a means to an end, women's organisation is a right in itself and of value in itself.

At community level, women's projects run by women can be a starting point in enabling women to develop the confidence and skills needed to be agents in control of their destiny at local, national and international levels. But, we also need to realise that not every women's project is about empowerment – women can be organised in ways that reinforce their subordinate status or in ways that do not question the status quo. And, unless gender equality goals and goals of women's rights and empowerment are consciously made a part of project and programme planning, women's subordinate position in relation to men will not be automatically addressed.

We need to reclaim our language around women's rights and women's empowerment, recognising that while the term gender has its uses at an analytical level; it has resulted in no end of confusion at the level of practice. It has enabled the ones resistant to women's liberation from relations of subordination to argue that our concern is women and men and has led to a shift to projects for men in the past decade or so.

We need to reverse the trend where donor organisations believe that a gender mainstreaming approach means that they stop supporting women's projects and instead put their money into projects, which include women and men, because gender means women and men, and because men are also disempowered. Such thinking ignores that gender is about a *system of power* relations between women and men. We need to accelerate strategies for women's empowerment and we need to develop *analytical* and *strategic* skills to take on the political battle for women's rights and full equality.

We need to get back to basics to understand that what we are fighting is a system of social arrangements and cultural rules, which provide men greater capacity than women to mobilise cultural rules and material resources in pursuit of their own interests, and that power relations between women and men are at the levels of ideas and practice and, therefore, we need to challenge both ideas and practice (Kabeer, 1992).[6] We need to also take into account that this system, which privileges men, operates simultaneously with systems of racial and class domination resulting in power imbalances of poverty within nations and across nations, and in power relations among women.

We need to rescue mainstreaming. It can still be a very powerful tool to advance gender equality goals, even within current rights-based approaches to development. Perhaps, in the end it is not so much whether mainstreaming is understood or misunderstood, but about how it has been manipulated to do different things by different people. An approach, a tool, a strategy, is at the end of the day only as good as its user. If each one of us is sincerely and seriously concerned about ending women's subordination, about advancing gender equality, we will find ways of going about this, and we will advance women's organisation to this end. But, if we are getting something out of the existing gender order as men, who do not want to give up our power over women, or as women, who benefit from the subordination of other women (for example the ones who cook, clean and care for our children), then, we may not be so keen to end this situation, which denies human rights to one half of humanity, so that the more powerful may benefit. The core question for all of us is how afraid are we of change?

FOOTNOTES:

1. An earlier version of this paper has been presented at the SAfAIDS Conference on Gender Mainstreaming in Swaziland, April 2005. Thanks to Everjoice J. Win and Penny Plowman for valuable comments to an earlier draft.
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Feedback...

As part of our ongoing activities at a provincial level, the AIDS Legal Network (ALN) facilitated provincial networking meetings focussing on *stigma and discrimination in the context of HIV and AIDS* with various social and networking partners in 7 provinces, namely Northern Cape, Free State, Limpopo, Mpumalanga, Eastern Cape, KwaZulu Natal and Western Cape during April and May 2005. The aim of these meetings was to identify the realities, as well as causes of stigma and discrimination; discussing and analysing the extent to which fundamental rights and freedoms are implemented and applied; and to collectively identify potential advocacy and lobbying strategies to address and respond to prevailing stigma and discrimination.

A young participant at a recent workshop was spotted in deep contemplation...

The responses to, and feedback from, the various provinces varied in accordance with provincial realities and challenges. However, there were a number of commonly raised issues and concerns amongst all provinces, including:

- Lack of in-depth understanding of core concepts, such as stigma and discrimination
- Lack of understanding of differentiation between vulnerable and marginalised groups
- Lack of knowledge and/or understanding of the legislative and policy framework pertaining to equality and non-discrimination, including Section 9 (‘Equality Clause’) of the Constitution and the Promotion of Equality and Prohibition of Unfair Discrimination Act (‘Equality Act’)
- High levels of stigma and discrimination, including amongst service providers
- Need for strengthening provincial networks to address and respond to issues collectively

The meetings clearly indicated not only a general lack of in-depth knowledge and understanding of the causes and realities of stigma and discrimination, as well as the meaning of fundamental human rights and freedoms, but also a lack of information and knowledge about available legislative measures to address the occurrence of stigma and discrimination in the context of HIV and AIDS.

…I learned a lot and now I know that every person has rights…thank you… [Western Cape Participant]

…the major issue I learned was about rights and what we, as NGOs, can do for our communities… [Northern Cape Participant]

…I’ll remember how we take it for granted that we are aware of concepts…but when we break it down, we learn so much more… [KwaZulu Natal Participant]

…I learned that the community/society has started stigmatisation, discrimination and marginalisation and the very same society must end it… [Mpumalanga Participant]

…the exercise on discrimination versus stigma was a real brain teaser and educational…you are doing a great job…keep it up!... [Free State Participant]

…I gained a lot of information about the rights of all people… [Eastern Cape Participant]

…I learned that it is so easy to violate people’s rights, if one does not fully embrace terms like equality, dignity and freedom as applying to ALL… [KwaZulu Natal Participant]

…the workshop was excellent and it was extremely interesting to unpack the meaning of so many concepts…well done!... [Western Cape Participant]

…I learned a lot about discrimination and can tell people about it…people who are still discriminating… [Limpopo Participant]

…I will remember that I can make a difference…the ALN is doing an excellent job… [Eastern Cape Participant]

In addition, we learnt in these meetings that there is still a dire need for further basic human rights education and training and information on how to access rights and freedoms. Participants also clearly identified a need for follow up sessions, as well as a need for education and training specifically on issues of stigma and discrimination amongst service providers.

…service providers still need to be empowered on basic HIV and AIDS education, before we can even consider additional information… [Limpopo Participant]

…these workshops are needed most in disadvantaged communities where discrimination and human rights violations are not reported… [Eastern Cape Participant]

…we will invite you frequently to educate our communities so that there will be less abuse… [Mpumalanga Participant]

…we should have more workshops on human rights and on the rights of women… [Western Cape Participant]

…I particularly enjoyed your facilitation and humour and the way in which you allowed participation and respected people’s views, but challenged them at the same time… [KZN Participant]

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