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Stigma is complex, but an integrated approach can work…

HIV-related stigma and discrimination – what can we do?

Introduction

Stigma is an extremely complex phenomenon and because of this, interventions to address it are difficult to develop and even harder to measure. How do we know we have made a difference about stigma if we are not sure what it is? Is it a feeling, an attitude, an action, a response? Does stigma always lead to negative consequences? In this article I will attempt to set out an understanding of stigma which we at the Centre for the Study of AIDS (CSA) at the University of Pretoria have reached, based not only on our reading of the literature, but also based on our experience of trying to develop interventions to make an impact on stigma. I will also set out some ideas for interventions – based on our view that a multi-pronged, multi-level approach is needed. There is no '*quick fix solution*' or one that will always work – stigma evolves and shifts and so the interventions need to evolve and shift.

Stigma and its related concepts

Stigma is a negative attitude to people who are seen to possess an attribute or quality which is discrediting. So if someone is known or suspected to be HIV positive, they may be seen negatively. Stigma allows people living with HIV or AIDS (PLHA) to be treated differently from others. When negative attitudes turn into negative behaviours, actual measurable acts, we call this discrimination. Discrimination is often called external (or enacted) stigma. Examples of external stigma are: family or community members avoiding people living with HIV or AIDS; not wanting to share bathrooms and kitchens; name calling; physically hurting or killing someone for being infected with HIV; preventing people living with HIV or AIDS from worshipping in a religious space with other people; being rude and aggressive in a clinic setting; refusing a child living with HIV permission to attend a school; – thus, violating their basic human rights.

In this issue

Editorial…

> *…stigma and discrimination simultaneously reduce the effectiveness of efforts to control the global epidemic and create an ideal climate for its further growth…stigma prompts people to act in ways that directly harm others and deny them services or entitlements…stigma prevents many people from negotiating safer sex, taking an HIV test, disclosing their status to their partners or seeking treatment, even when services are made available…* [UNAIDS 2005]

Stigma and discrimination are recognised barriers to HIV prevention, testing, treatment, support and care and so are the correlations between stigma and '*HIV risk*', in that stigma and discrimination leads to a heightened risk of HIV infection, while actual or perceived HIV infection leads to a heightened risk of stigma and discrimination. However, despite acknowledging that stigma and discrimination are as much reducing '*the effectiveness of efforts*', as they '*further*' the HIV and AIDS pandemics, there seems to have been, thus far, very few '*real*' efforts, and/or very little impact made with efforts, to mitigate stigma and discrimination.

It is within this context that this edition of the ALQ is focusing on stigma mitigating efforts, and exploring experiences and challenges of a wide range of '*anti-stigma*' strategies, programmes and interventions. The need for not only an integrated approach, but an '*evolving and shifting*' approach to '*anti-stigma*' work; a rights-based workshop approach challenging the stigma '*within us*' and '*around us*'; a '*zero tolerance*' approach in rural Limpopo; as well as strategies for free, informed and confidential HIV testing are some of the issues discussed in this edition.

This issue is also introducing experiences and challenges from a project in Lethabong, North West, aimed at enhancing rural communities' access to information; examining HIV-related stigma and discrimination in healthcare facilities in Nigeria; and '*making a point*' about HIV-related law and policy reform in the SADC region.

In this edition, **Pierre Brouard** explores various causes and forms of HIV-related stigma. Examining stigma, its related concepts and dynamics; its various psychological and social functions; and its impact on individuals, communities and society, he discusses potential interventions to mitigate HIV-related stigma and discrimination and argues that even though there is no '*quick fix solution*', an integrated approach can work. Thus, for any anti-stigma intervention to be adequate and effective, they need to evolve and shift, as stigma evolves and shifts constantly.

Experiences of challenging stigma and discrimination are introduced by **Johanna Arendse** and **Johanna Kehler**. Discussing a workshop approach aimed at not only addressing the various causes and forms of HIV-related stigma and discrimination, but also challenging underlying beliefs, values and norms leading to both the stigma '*within us*' and the stigma '*around us'*; and exploring the '*ups*' and '*downs*' of this process, the article argues that while change is difficult, there are '*opportunities*' for change – provided the need for, as the '*barriers*' to, change are recognised.

Recognising the lack of impact of existing advocacy strategies, **Fiona Nicholson** introduces the concept of the '*Zero Tolerance Village Alliance*' as a potential strategy for behavioural change. Discussing the goals, objectives and methodology of the '*zero tolerance*' behavioural change concept, as '*tried and tested*' in Thohoyandou, Limpopo, she argues that even though there are no '*blue prints*' for this concept, there is hope – provided the programme succeeds in creating an enabling environment for people to feel safe and supported enough to '*speak out*' and '*stand up*' for their rights.

Gahsiena van der Schaff provides the '*provincial feedback*' and explores stigma and discrimination as the barriers to HIV testing. Analysing provincial views and responses on the '*why*', '*who*' and '*when*' to test for HIV; and HIV testing barriers, such as fear, prevailing stigma and discrimination, lack of knowledge, and conditions of, and within, healthcare provision; and introducing provincial strategies for free, informed and confidential HIV testing, she argues that an uptake in HIV testing services can only be achieved as and when the environment of both people's lives and healthcare facilities are challenged and transformed.

Various programme activities focussing on young people and aiming at behavioural change through access to information and skills are introduced by **Sizwe Hlatshwayo**. Discussing experiences and challenges of the various Amanzimtoti YMCA programme activities, which are primarily aimed at enhancing young people's skills to cope with, and

Stigma by association

Sometimes people who work in the field of HIV and AIDS, or individuals who associate with people living with HIV or AIDS, such as family members, are stigmatised because of this association – this is called '*courtesy stigma*'. Secondary stigma would be stigma attached to things which are associated with HIV and AIDS, for example to have TB or not to breastfeed are often viewed as reasons to decide people must be HIV positive.

Internal stigma

Internal stigma refers to the process of internalising the shame, blame and fear associated with living with HIV or AIDS. Examples of internal stigma are: people living with HIV or AIDS not wanting to access services or not applying for work, because they are afraid of being exposed as living with HIV (sometimes this is called perceived or expected stigma); people living with HIV or AIDS have low self-esteem as a result of their HIV positive status; people living with HIV or AIDS withdrawing from social and intimate contact or relationships, because they feel unacceptable; or people living with HIV or AIDS believing that they have to contribute more than other people to prove themselves (these last examples are sometimes called '*self-stigma*'). External and internal stigma often lead to people living with HIV or AIDS being unwilling to disclose their HIV status, because they are afraid of the consequences. What is interesting about this is that a person living with HIV may not have experienced discrimination, but can still be afraid of it – so, even the fear of discrimination or blame may have an effect, thus making stigma very complicated to address.

Stigma is dynamic

Stigma is not unique to HIV and AIDS and has been seen in history in relation to other diseases, such as TB, syphilis and leprosy, which are associated with '*going against social norms*'. There is no one explanation for stigma. It would seem that a number of different strands come together to explain why HIV and AIDS have been stigmatised: firstly, because it can be fatal and thus, causes fear; secondly, because it is often associated with stigmatised behaviours, such as sex work and homosexuality; thirdly, because infection with HIV is seen as the result of choices made by an individual and so they are to blame for being HIV positive; fourthly, because it is believed that people living with HIV or AIDS have broken society's moral codes and they must be punished for their '*deviant*' behaviour; and lastly, in some communities people living with HIV or AIDS are seen as a drain on limited resources and so we try and exclude them.

Stigma develops over time in communities and does not occur in a vacuum. The process may occur as follows: differences (such as HIV status) are noted and labelled; these differences are then given a negative attribute; a distinction is made between '*us*', who do not have this negative attribute, and '*them*', who do; the person with this negative attribute is seen to have a lower status; and finally, this person is discriminated against. So stigma is socially created – this is a process shaped by individuals, institutions and the media over time.

> *...stigma often lead[s] to people living with HIV or AIDS being unwilling to disclose their HIV status, because they are afraid of the consequences...*

In some cases, stigma linked to HIV and AIDS may be layered onto other forms of stigma and discrimination around class, race, gender, age and sexual orientation. So, a gay man or lesbian woman with HIV may be stigmatised for being gay and for being HIV positive. Sometimes the poor are blamed less for their HIV infection than the rich, yet, the poor face greater stigma, because they have fewer resources to hide an HIV-positive status. Youth are often blamed for spreading HIV through what is perceived as their '*highly risky sexual behaviour*' yet, an older person living with HIV might be judged because '*they should have known better*'. While both women and men are stigmatised for breaking sexual norms, gender-based judgments result respond to, life's challenges, including risk of HIV infection and HIV-related stigma, he argues that despite the many obstacles, there is hope, since young people are as committed to the programme, as they are committed to behavioural change.

Recognising the protective constitutional and legislative framework, **Erica Kessie** raises the question as to whether or not workers are indeed protected against HIV-related stigma and discrimination at the workplace. Looking at a particular incident, she argues that as long as '*management*' fails to support and be actively involved in HIV awareness and education at the workplace, constitutionally guaranteed rights to equality, non-discrimination, dignity and fair labour practices are no more than *'paper rights'* providing very little protection to workers living with HIV or AIDS.

The dire need for access to information for rural communities in the North West Province is highlighted by **John Moerane**. Introducing experiences of facilitating human rights and HIV education and training in various areas in and around Lethabong, he argues that despite all challenges, information is the '*key to change*', since rights-based information and messages are taken forward and thus, contribute towards behavioural change.

The impact of HIV-related stigma and discrimination on healthcare services in Nigeria are explored by **Busari Olusegun**. Discussing various causes of HIV-related stigma and discrimination; various forms of how it exhibits itself in healthcare services; and Nigerian approaches to, and experiences with, addressing HIV-related stigma and discrimination, he argues that stigma and discrimination will remain the greatest barrier to progress in the response to HIV and AIDS, unless a human rights-based solution to this all important aspect of these pandemics is found and implemented.

Looking at various legislation and policy provisions, **Eric Axelrod** is '*making a point*' about the effectiveness of HIV-related law and policy reform within countries of the SADC region. Exploring the development pertaining to labour legislation, mandatory HIV testing in the military, public health law, and criminal law; and recognising the progress made, he argues that laws are only as effective as they are adhered to and '*enforced*', since without a '*culture of legal accountability*' legislation will remain '*empty*' and provide little '*real*' protection to people living with HIV or AIDS in the SADC region.

While the strategies addressing HIV-related stigma and discrimination may vary in their programme design and '*target group*', there seems to be the common understanding that '*change*', and particularly behavioural change, is the key to any effective '*anti-stigma strategy*'; as there is the common acknowledgement that without the much needed '*change*' in both the external and internal environment, stigma and discrimination will remain to be the barriers to HIV prevention, testing, treatment, support and care efforts. The extent to which stigma mitigating interventions, programmes and activities are adequate and effective appears thus not to be defined by the utilised approach – irrespective of whether or not it is a '*zero tolerance*', rights-based, multi-prong, innovative, integrated and/or holistic approach – but instead by the extent to which any chosen approach does indeed create '*opportunities for change*'.

If we are to agree that there is a need for '*change*' as there is for creating '*opportunities for change*', then we are to acknowledge that the societal context in which '*change*' is to occur, is the very same societal context which seems largely reluctant and resistant to '*change*' – thus, '*threatening*' the very concept of '*change*'. Similarly, if we are to agree that the '*tried and tested*' approaches thus far failed to mitigate HIV-related stigma and discrimination, then we are to equally agree that it is imperative to '*try and test*' new approaches to stigma mitigation – approaches that indeed carry the potential to not only address, but challenge and transform the very foundation of the stigma '*within us*' and '*around us*'.

Thus, any effort '*capable*' of mitigating HIV-related stigma and discrimination has to , arguably, be '*capable*' of creating '*real*' opportunities to 'change' the very same foundations for stigma and discrimination – '*us*' and the societal context in which we live and '*stigmatise*'. Only as and when stigma mitigating interventions are aimed to address, challenge and transform both the stigma '*within us*' and '*around us*' will these interventions carry the potential to '*remove the barriers*' and to '*break the cycle*' of stigma and discrimination as a cause for, and consequence to, HIV infection. As long as stigma and discrimination not only prevail, but are seemingly largely justified and condoned by '*society*', stigma and discrimination will continue to be as much the reasons for our '*efforts*', as the reasons for our '*failure*' – and thus, the cycle continues as do stigma and discrimination…

Johanna Kehler

in women being blamed more easily. At the same time, the consequences of HIV infection, disclosure, stigma and the burden of care are higher for women than for men.

Functions of stigma

Stigma serves various psychological and social functions. At a psychological level, stigma enables us to distance ourselves from individuals seen to be '*dangerous*' or '*infectious*' and it allows us to falsely deny our own risk of HIV infection, as a form of self or community protection. At a social level, stigma tries to control human behaviour by excluding individuals who are seen as morally undesirable; allows society to punish individuals who it believes could have avoided HIV infection; and helps people to have power over people living with HIV or AIDS, and keep resources for themselves.

> *...anti-stigma programmes should also address all forms of stigma – internal, external, courtesy, secondary – and ...other prejudices, such as racism, homophobia and xenophobia...*

The effect of stigma

Stigma has a profound impact on individuals, communities and society – it results in a range of excluding behaviours towards people thought to be infected with HIV; it isolates, divides and breaks down communities; it undermines equal human rights; and it results in the internalisation of blame and shame. HIV testing, disclosure, prevention, as well as care and support for people with HIV are promoted, but are challenged by stigma. Preventive methods, such as condom use or discussing safer sex options, are considered indications of HIV infection or immoral behaviours and are thus, stigmatised. Available care and support services may be accompanied by judgmental attitudes and isolating behaviour, which can result in people with HIV delaying care until absolutely necessary.

People living with HIV or AIDS and their families develop various strategies to cope with stigma. Decisions around disclosure depend on whether or not disclosing one's HIV status would help to cope (through accessing care) or make the situation worse (through added stigma). Some cope by participating in networks of people living with HIV and actively working in the field of HIV or by confronting stigma in their communities. Others look for alternative explanations for HIV, besides sexual transmission, and seek comfort, often turning to religion to do so.

So what can we do?

Since HIV and AIDS stigma serves psychological and social functions, simply focusing on education about the routes of HIV transmission and the negative impact of stigma (awareness raising) is insufficient to address HIV and AIDS-related stigma. Nevertheless these are important components of any anti-stigma work.[1]

Take an integrated approach

Anti-stigma work should challenge individual attitudes and beliefs, but should also address the social processes which perpetuate stigma. To do this a multi-level, multi-sectoral and holistic approach needs to be adopted. Based on good evidence and research, programmes should empower individuals and communities to sustain any stigma-reduction strategy, utilise a gender focus, and be rights based. Anti-stigma programmes should also address all forms of stigma – internal, external, courtesy, secondary – and should also address other prejudices, such as racism, homophobia and xenophobia. Tackling HIV and AIDS-related stigma is everyone's responsibility and an integrated effort from all role players and stakeholders in society is essential. This can build greater cohesion in society and communities – sometimes this is called social capital, i.e. positive and affirming connections in communities – and this could be an important by-product of anti-stigma work.

...schools and tertiary education institutions need to address stigma in what they teach about, and how they act towards, people living with HIV or AIDS and those close to them...

Offer leadership

The government has a crucial role as it is in a position to offer leadership and resources on stigma mitigation. Since 2002, the Chief Directorate on HIV and AIDS and TB at the National Department of Health has been working with the Health Policy Initiative-funded Siyam'kela Project of the CSA to develop tools to better understand and mitigate HIV and AIDS stigma. With technical assistance from the Siyam'kela Project, government hosted a National Consultative Workshop on HIV and AIDS-related Stigma in September 2005. A draft national anti-stigma strategy was developed at this workshop. Task teams then conducted sector-based consultation to refine the strategy, which was presented to the sectors for final approval in November 2006. This strategy is now being reviewed for harmonisation with the National Strategic Plan for 2007 – 2011.

The strategy aims to provide clear and legitimate information on HIV and AIDS to all South Africans; to mobilise key stakeholders; to ensure that laws and policies are non-discriminatory; to involve civil society in raising awareness of stigma and challenging attitudes and beliefs; to involve people living with HIV or AIDS in these initiatives, both as partners in stigma mitigation and as recipients of supportive services; and to research stigma, because it is dynamic and ever-changing. The strategy will be monitored and evaluated to assess its impact and acts as a framework for other, more local, interventions.[2]

Leadership should also come from other sectors of society and within every organisation leaders should ensure that stigma awareness programmes are implemented.

Protect rights

The government should ensure that laws and policies exist to protect the rights of people living with HIV or AIDS – much progress has been made in this area and while these rights are still being violated, there are opportunities to bring justice. However, more work needs to be done to improve access to justice.

Provide good information to address myths and fears

The government, and all involved in providing information on HIV and AIDS, should provide consistent, coherent, accurate and legitimate information about HIV and AIDS to challenge fear, misinformation and myths.

Make health and other government services HIV friendly

Healthcare institutions can train both new and experienced providers on stigma, while at the same time, risks faced by providers need to be acknowledged and addressed. This is particularly important in HIV testing and treatment services where a non-discriminatory approach is critical. Service providers in all other government sectors, such as the Department of Social Development, which deals with the administration of social grants, need training on stigma and its effects.

Address stigma in schools and universities

Schools and tertiary education institutions need to address stigma in what they teach about, and how they act towards, people living with HIV or AIDS and those close to them. Schools in many communities are feeling the effects of HIV and AIDS through learners and educators, who are infected with, or affected by, HIV and AIDS. School governing bodies are made up of influential parents in the community and if they can be persuaded to address stigma then much good work can be done. This stigma work could include making sure that messages of acceptance go out to learners and that educators, who are HIV infected are retained as employees. In addition, schools can be used for community meetings, support group meetings and so on.

Work with civil society

- Social and cultural movements need to explore what they say about HIV and AIDS and provide positive messages of acceptance.
- NGOs and other community-based organisations can train their own staff to recognise and deal with stigma, incorporate ways to reduce stigma in all activities, and critically examine their communication methods and materials.
- Faith-based organisations can be supportive of people living with HIV or AIDS in their role as religious leaders and can incorporate ways to reduce stigma in their community service activities.

> *...media professionals can...limit misperceptions and incorrect information about HIV...and examine the possible impact of the headlines and stories they run...*

Use media constructively

Media professionals can examine and modify their language to be non-stigmatising, provide accurate, up-to-date information on HIV, limit misperceptions and incorrect information about HIV and people living with HIV or AIDS, and examine the possible impact of the headlines and stories they run. Positive success stories, for example about the value of ARV treatment, can make a difference. It is also critical to challenge stereotypes and images of people living with HIV or AIDS by promoting HIV disclosure from all races and genders.

Address stigma in the workplace

Public and private workplaces need to address stigma in all their HIV and AIDS interventions and in their employment policies and practices. These need to go beyond the board rooms into all aspects of how an organisation functions.

Offer workshops to challenge attitudes

All institutions working with stigma should provide experiential workshops to clarify and challenge attitudes around HIV and AIDS. These workshops should also make people aware of stigma and discrimination and its effects; educate about all aspects of HIV and HIV transmission; provide safe spaces to talk about values and beliefs about sex, morality and death; and find a common language to talk about stigma.

Build support for families and people living with HIV or AIDS

Families caring for people living with HIV or AIDS should be offered support. Support groups for people living with HIV or AIDS can provide a powerfully healing experience to address external and internal stigma and can build their social capital. Personal empowerment and counselling for people living with HIV or AIDS is critical so that they can challenge stigma, both external and internal. Good and accurate information help people living with HIV or AIDS to be positive and advocate for healthy living.

Use the GIPA principle (Greater Involvement of People living with HIV or AIDS)

The voices of people living with HIV or AIDS and organisations of people living with HIV or AIDS need to be heard and acknowledged in all stigma interventions and in the planning of HIV and AIDS work in general.

Address poverty

The upliftment of poor communities can address the impact of poverty on stigma by making people living with HIV or AIDS more self-reliant and less of a drain on their families. It is also critical to examine the role of social grants, so that they do not unintentionally increase stigma.

Work at community level

Some examples of community work include:[2]

- Giving **talks** at meetings in churches, mosques, temples, schools, hospitals, women's groups, youth groups, sports groups and union meetings – these can cover stigma and discrimination, clear information on HIV and AIDS, and can be strengthened through a presentation by a person living with HIV or AIDS.

- Setting up **community meetings** is an excellent way of bringing together a group of people to get across a message of acceptance and tolerance towards people living with HIV or AIDS, their family and friends.

> *...many South Africans visit traditional healers (each healer has an average of 2000 visits a year from people seeking healthcare), even if they use western medicine at the same time...*

- Running **door-to-door campaigns** where community volunteers come together to plan and implement door-to-door visits during which homes are visited, information is handed out, discussions are held, and openness to HIV and AIDS and people living with HIV or AIDS is promoted. In South Africa the government's Khomanani campaign is training and working with volunteers country-wide to do this kind of work. These kinds of personal encounters can be very useful and they allow for a more intense and challenging dynamic to be set up.
- Setting up **support groups** for people affected by stigma. In many communities there are organisations, such as the National Association of People Living with HIV/AIDS (NAPWA) or the Treatment Action Campaign (TAC), already setting up and running support groups for people living with HIV or AIDS and their families. These support groups offer safe spaces for people living with HIV or AIDS, and people affected by HIV and AIDS, to get support from each other and challenge internal and external stigma.[3]
- Working with **traditional healers**. Many South Africans visit traditional healers (each healer has an average of 2000 visits a year from people seeking healthcare), even if they use western medicine at the same time. This is also true of people living with HIV or AIDS. These healers are very important sources of support and acceptance of people living with HIV or AIDS and can play a role in challenging negative attitudes.
- **Community theatre** is used all over the world to present issues to communities to raise awareness, challenge ideas and provide entertainment. Theatre attracts people, is a break from everyday activities, and also reflects real issues which the community is facing.
- Using **local media**, including radio. Local newspapers and magazines can run stories about people living with HIV or AIDS, which help people in a community understand the daily reality of people living with HIV or AIDS, and promote acceptance. These stories also remind people living with HIV or AIDS that they are not alone, and that they are visible and recognised. Similarly, community radio stations can have interviews with experts and people living with HIV or AIDS on various topics to challenge fears and promote acceptance. All media can have regular columns to keep HIV and AIDS issues topical and foremost in the minds of the community.

A case study of a faith-based organisation

The Church of the Province of South Africa (the Anglican Church) has a highly visible role in South Africa in terms of HIV and AIDS; has assumed a national advocacy role in HIV and AIDS; and has been allocated large amounts of funding for HIV and AIDS-related stigma reduction. The Anglican Church has taken a bold stand in attempting to reduce stigma by advocating nationally that '*HIV/AIDS is not a punishment from God*'.

The Church has clearly come to have an important influence on other faith-based organisations. The Anglican Church's interventions have been at two levels: theological reflection and practice. Theological reflection about HIV and AIDS has involved academic study about the implications of the HIV and AIDS pandemics for the church, conducting training with clergy and reflecting about the meaning of responsible sexuality. Practical interventions have involved home-based care, counselling, education, orphan care, training of caregivers, challenging gender inequality, and wellness management. The Anglican leadership has also played a role in challenging government and giving voice to the concerns of the poor and voiceless.

> *...the Anglican Church has taken a bold stand in attempting to reduce stigma by advocating nationally that* 'HIV/AIDS is not a punishment from God'...

Strategies to reduce stigma adopted by the Anglican Church include:

- Adopting an inclusive approach, seeing HIV and AIDS as the responsibility of the entire religious community
- Rethinking sexuality, seeing sex as '*a gift from God*' and not as something negative
- Addressing judgemental attitudes, especially through emphasising compassion and inclusion, not punishment and sin
- Visibly involving people living with HIV or AIDS at every level of the church
- Using resources thoughtfully, for example by providing home-based care and orphan support, and by providing spiritual and emotional support to people
- Working in partnership, with mainstream Christian denominations initially, but also with smaller and traditional African churches, as well as groups representing other faiths

Stigma is complex, but an integrated approach can work, not only to assist in the challenges presented by HIV and AIDS, but also to contribute to a national process of building a South Africa where, in the words of the late Oliver Tambo, all citizens '*are freed and united in diversity*'.

FOOTNOTES:

1. The Stigma Resource Pack. An information, intervention and training resource on HIV/AIDS-related stigma. 2005. [www.csa.za.org]; Guidelines and promising practice documents on stigma mitigation in workplaces, faith-based organisations and media houses. 2003. [www.csa.za.org]; Campbell, C. et al. 2005. *Understanding and challenging HIV/AIDS stigma*. HIVAN; Clay, S. et al. 2007. *Understanding and challenging HIV stigma*. A toolkit for action. Change Project.
2. For more information on the anti-stigma strategy, please contact the author.
3. Information on running support groups can be obtained from HIVSA at the Chris Hani Baragwanath Hospital (www.hivsa.co.za) in Soweto.

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Johanna Arendse, Johanna Kehler

It will be very difficult to change…

Challenging stigma and discrimination: A facilitator's view

Stigma and discrimination are well documented and recognised as the main barriers to HIV prevention, testing, treatment, support and care services. Challenging prevailing stigma and discrimination within both service provision and amongst service providers is but one of the many means to address HIV-related stigma and discrimination. While this is an approach with many facets, the key to challenging discriminatory attitudes, beliefs and practices is a three-day process, as facilitated by the AIDS Legal Network (ALN), focusing primarily on healthcare service providers. This process is as much aimed at deepening the understanding and knowledge of the various causes and forms of stigma and discrimination, as it intend to highlight the impact of stigma and discrimination '*within us*' and '*around us*' on the quality and accessibility of available HIV prevention, testing, treatment, support and care services.

These three days are a process of many challenges and '*heated debates*'; a process of many challenges for both the participants and the facilitator. Three days of '*walking into people's lives*' questioning views, perceptions, and the status quo of '*how*' things are done, as well as challenging the very foundation of '*caring*' and '*providing*' for '*others*'.

It is a common assumption that '*providers*' care about their clients and '*want to help*'. However, various beliefs and values often strengthened and maintained by culture and religion, seem, at times, to interfere with people's '*ability*' to offer help and provide care that is non-judgemental and respecting clients' rights and needs.

Day One: The denial phase

Day one continues to be the most challenging. As service providers, we perceive ourselves as individuals '*caring for our community*', and helping and supporting '*people in need*'. Thus, it is difficult to '*pause*', sit back and look closely at the ways and mechanisms in which services are provided, at '*who*' has access to these services, and at whether or not the intended outcome of the available services has indeed been achieved. It is the time of examining not only the kind of services provided, but also at the structure and quality of the services.

It is also the time to reflect on '*us*', our beliefs, values and norms, and '*search*' for the stigma '*within us*'. And responses, such as '*I don't discriminate*', and '*I only do what is in the best interest of my client*', are only two examples of the initial '*resistance*' to realising and acknowledging that there is '*stigma*' within each and every one of us.

While there is '*knowledge*' of fundamental rights and principles, such as informed consent, autonomy, equality and non-discrimination, dignity, respect and confidentiality, there seems to be a general lack of '*understanding*' of the meaning of fundamental rights and freedoms. Although, there is the '*knowledge*' that no one can be '*forced*' to test for HIV, '*directive counselling*' and '*strongly suggesting*' that a client is in need of an HIV test is not '*understood*' as a violation of a client's right to make an informed choice as to whether or not to test for HIV. Similarly, there is the '*knowledge*' that everyone has the right to have their medical information, including HIV test results, kept confidential, a rather common practice of '*sharing*' this information with someone is not necessarily '*understood*' as a violation of a client's right to confidentiality. There is also the full '*knowledge*' that everyone has the right to be treated equally and not be discriminated against, and yet, '*judging*' and subsequently '*excluding*' people, such as sex workers, lesbians, and gays, from '*our*' homes, services and communities – because '*our*' culture and/or religion say this is '*wrong*' – is not really '*understood*' as violating people's rights.

As the day progresses, the debates become more and more emotional; the arguments seem to be recurring around the '*but*', trying to explain and/or justify the realities of ourselves, as people and as service providers, perpetuating '*stigma*'; the realisation process begins that, even though, perhaps '*unknowingly*' and '*subconsciously*', '*I do discriminate*' and '*I thought I knew what is in the best interest of my client, but I don't*'; and finally, there is a sense of total '*exhaustion*'.

Day Two: The phase of hope

With the dawn of day two there is a sense of '*honesty*' and trust that realising and acknowledging the '*stigma within us*' is presenting '*hope*' for the future of service provision, which truly respect the rights and needs of clients.

The interactions of day two are very different. While still realising the various facets and ways in which services and service providers violate clients, the debates are much more rights-based and focused on finding ways of improving the services and the way in which services are offered. Plenty of space seems to have evolved to look at challenges more '*realistically*' and to try and collectively identify ways of responding to these challenges. Ideas are '*tossed around*' and questions arising as to the extent to which these '*new*' ideas are indeed '*in the best interest of the client*' – in that it is the client defining what is '*in the best interest*', as compared to the service provider's perception of what is '*in the best interest of the client*'.

> *...various beliefs and values ...seem, at times, to interfere with people's* 'ability' *to offer help and provide care that is non-judgemental and respecting clients' rights and needs...*

At the end of day two there seems to be not only an '*understanding*' of stigma and discrimination in its various forms and facets, but also a '*realisation*' of its impact on service provision. Most notably, there is a common sense of '*realising*' how our own beliefs, values and '*understanding*' of what is '*right*' and what is '*wrong*' greatly impact on our interaction with the next person, including our clients accessing services; and how the very same '*beliefs*' often become the '*source*' for violating a client's rights. There is also a great sense of '*hope*' that, even though it will be '*very difficult*' to change behavioural patterns, there is the sense of realising the '*need for change*' – so as to offer services that are responding to clients' needs, and thus, are truly '*in the best interest of the client*'. Part of this process is the further realisation that '*change starts with me, as a person*' and both '*stigma within us*' and '*stigma around us*' can only be addressed and challenged if perceived as an individual responsibility of everyone.

Day Three: The phase of a new beginning

The start of day three is filled with excitement and positive energy to '*change*' and to put in place mechanisms facilitating the desired '*change*'. This is the day to re-evaluate the challenges and '*barriers*' identified thus far and to collectively find solutions of how to address and '*change*' existing '*barriers*' to become '*opportunities*' – bearing in mind that respecting and protecting clients' rights to equality and non-discrimination, dignity, autonomy, informed consent and privacy are paramount to the '*new beginning*'.

While the particular challenges differ between groups and geographic location, there are some recurrent '*fundamental*' challenges experienced in all the interactions, including:

- Lack of ongoing training and support for service providers – leading to '*burnout*' and lack of quality service provision
- Inadequate provision of protective equipment, such as gloves – creating a situation in which clients' identified HIV status becomes a means of '*risk management*'
- Visibility of service providers and services – resulting in '*indirect*' disclosure of clients' HIV status which in turn impacts on the '*uptake*' of services
- Lack of adequate understanding of clients' needs – leading to a situation whereby service providers '*decide*' what is in the best interest of the client
- Distances '*travelled*' to provide and/or access services – impacting on access to available services

- Lack of '*privacy*' in service provision structures – leading to '*indirect*' disclosure of clients' information and subsequently resulting in a lack of '*uptake*' in available services
- Attitudes of service providers – feeding into existing '*fear*' and impacting on '*uptake*' in available services

> ...'excluding' *people, such as sex workers, lesbians, and gays, from* 'our' *homes, services and communities – because* 'our' *culture and/or religion say this is* 'wrong' *– is not really* 'understood' *as violating people's rights...*

Some of the '*opportunities*' envisaged by the various groups for the '*new beginning*' leading to service provision that is non-judgemental, non-discriminatory and free of stigma, include:

- Engage with management so as to identify mechanisms for ongoing support and training for service providers, most notably ongoing '*legal literacy*' information
- Provide '*legal literacy*' training to communities at large so as to ensure knowledge and understanding of rights
- Provide inclusive and factual information to clients so as to facilitate informed decision-making
- Assess clients' needs without judgement and pre-conceptions of clients' needs
- Accept clients' needs and provide services accordingly
- Visit every house in the street so as to remove the '*stigma*' from the house visited by service providers
- Visit clients at times which are suitable for, and/or are requested by clients, so as to enhance quality of care
- Remove all '*identifiers*' distinguishing clients by their HIV status
- Integrate HIV prevention, testing, treatment, care and support services into healthcare services so as to remove the '*stigma*' from '*specialised*' services

At the end of day three there is a beginning of '*the new beginning*' with identified plans and actions. There is also an enormous '*commitment*' by everyone to '*change*'; to '*make things right*', to continue to challenge stigma '*within us*' and '*around us*'; and to provide services that are '*in the best interest of the client*'.

However, this is also the time of leaving the '*safe*' space created during the three day process, and of realising that the '*real challenge*' starts after the three days have come to an end and everyone has to individually continue the process. While the three days are very intense and seem like '*for ever*', the time spent together can only be the beginning of a '*process*' leading to change and creating an environment in which available HIV prevention, testing, treatment, support and care services are indeed freely '*accessible*'.

Thus, the process of challenging stigma and discrimination '*within us*' and '*around us*' is about creating '*opportunities*' for change – recognising both the need for and the '*barriers*' to change.

FOOTNOTES:

1. The authors have extensive experiences in facilitating the process of challenging stigma and discrimination.

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Fiona Nicholson

We are hopeful…

The Zero Tolerance Village Alliance: A Strategy for Behavioural Change?

> *…even well-informed rural people are unlikely to exercise their rights, unless the environment in which they live, is conducive to such change in behaviour.*[1]

Setting the scene

For the geographically-challenged, to find Thohoyandou, head North and just before you reach Zimbabwe, turn East. We, the Thohoyandou Victim Empowerment Programme (TVEP), are situated in Thulamela, Limpopo, which lies between the N1 and the Kruger National Park.

In Thohoyandou, social relations are patriarchal and systems, such as polygamy and lobola, are commonly practised. People are secretive by nature, and despite the popularity of Evangelism, traditional laws are strong and the '*dark side of witchcraft*' is still practiced. Women and children are generally extremely marginalised and subservient – some say there is an attempt to breed confidence and self-esteem out of girl children from birth. There is a strong belief in family privacy and many aspects of gender and child violence are commonly – but incorrectly – attributed to '*culture*'. Illiteracy and unemployment rates are high, and sexual abuse and domestic violence are frequently trivialised, even by the victims themselves.

The TVEP trauma centres see an average of 45 rape victims per month, of which 60% are minors, and 34% pre-teen. All clients have access to post-exposure prophylaxis (PEP) – if they meet the eligibility criteria. We assist around 1,600 domestic violence cases annually, and our district is alleged to be very high on the femicide check list.

For three years, '*TVEP Campaigners*' systematically moved through the Thulamela community informing people of all ages of their rights and responsibilities pertaining to TVEP core topics of sexual assault, domestic violence, child abuse, HIV, and access to ART without stigma. This campaign focused on learners from pre-school to grade 12, as well as educators, school governing bodies, grannies, clubs, women's societies, community leaders and traditional authorities. Despite this concerted effort, behavioural change remained minimal.

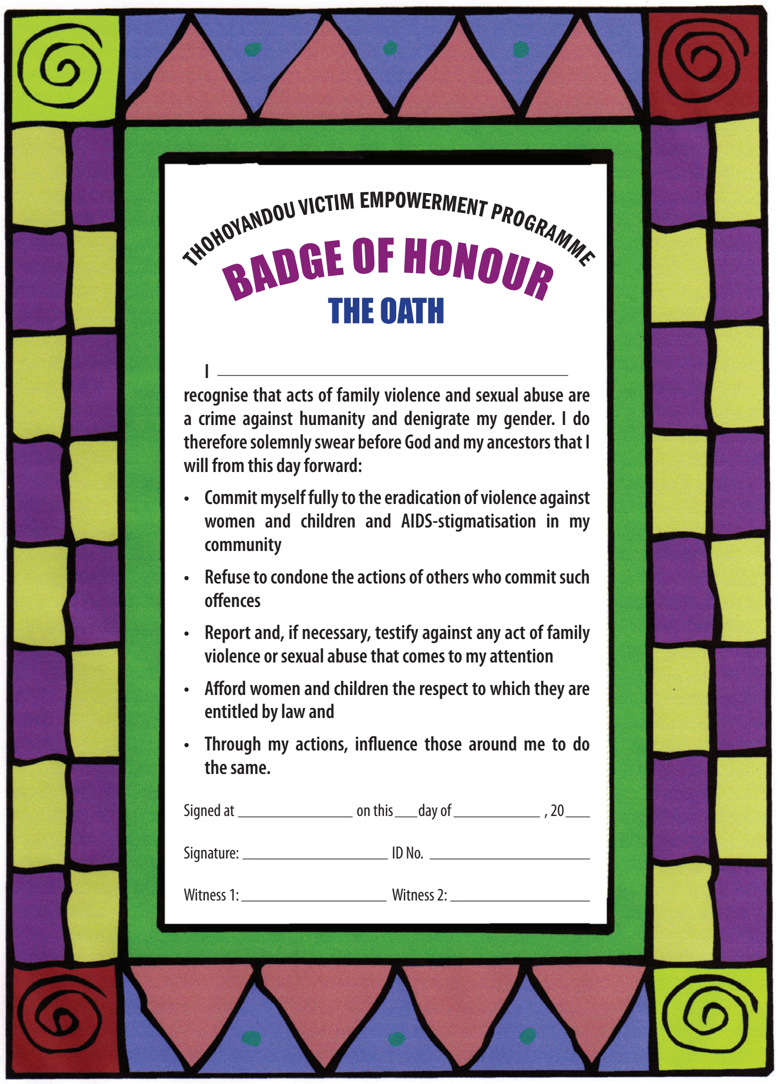
In 2005, following an evaluation of the impact of our '*Break the Silence*' campaigns, we were rudely awakened to the fact that truly speaking, the '*spray & pray*' approach does *not* work – referring to the common and popular technique of '*spraying*' a crowd with information, and '*praying*' that at least some of the information will stick!

Zero Tolerance Village Alliance Objectives

- Holistically empower targeted communities as to their rights and responsibilities pertaining to sexual assault, domestic violence, child abuse and HIV and AIDS, and ensure that these communities know how to act against infringements of such rights
- Encourage community leaders to publicly commit themselves to the eradication of violence against women and children, and HIV and AIDS discrimination
- Enable and encourage the community to exercise their rights and resist and report abuses, by creating a secure and empowered environment in which they feel safe to do so
- Increase the capacity of targeted communities to provide care and support to victims of domestic/gender based violence, sexual abuse, child abuse, and HIV and AIDS
- Restore the culture of Ubuntu

Some radical brainstorming followed, during which we listed every conceivable reason we could think of, and *then* some. The predominant contributing factors on which we all agreed was that people were still not willing to speak out and exercise their rights through fear of recrimination and/or ridicule, and the lack of '*faith in the system*'. Clearly then, one strategy to encourage behavioural changes would be to create an enabling environment, in which women and children would feel secure and supported enough to '*speak out*', and '*stand up*' for their rights. This enabling environment however, would also have to hold everyone accountable for their actions, including service providers for the services they are meant to be providing.

And so the concept of the '*Zero Tolerance Village Alliance*' was born. Simply put, it is an alliance of villages that have been thoroughly informed on the Thohoyandou Victim Empowerment Programme (TVEP) core topics of sexual assault, domestic violence, child abuse, and HIV-related stigma. Villages must have accepted ownership of abuse-related problems in their communities, and have publicly declared themselves willing to meet the challenge of '*combating such ills*'. Certain criteria have to be met, which include that police and clinic staff are well capacitated on victim's rights, access to post-exposure prophylaxis (PEP), antiretroviral treatment (ART), voluntary counselling and testing (VCT) for HIV, prevention of mother-to-child transmission of HIV (PMTCT) and so forth. There also has to be an operational support group (particularly difficult, given the level of stigma), a home-based care group, a safe house, people looking out for orphaned and vulnerable children (OVC), a consistent supply of femidoms – and so the list goes on. And of course, the intervention must be sustainable…



THOHOYANDOU VICTIM EMPOWERMENT PROGRAMME

BADGE OF HONOUR

THE OATH

I ____

recognise that acts of family violence and sexual abuse are a crime against humanity and denigrate my gender. I do therefore solemnly swear before God and my ancestors that I will from this day forward:

- Commit myself fully to the eradication of violence against women and children and AIDS-stigmatisation in my community
- Refuse to condone the actions of others who commit such offences
- Report and, if necessary, testify against any act of family violence or sexual abuse that comes to my attention
- Afford women and children the respect to which they are entitled by law and
- Through my actions, influence those around me to do the same.

Signed at ______________ on this ___day of ___________ , 20___

Signature: __________________ ID No. ________________

Witness 1: __________________ Witness 2: ________________

Methodology

We have been piloting this concept for two years or more now in eight villages, sometimes with funds and sometimes without. Fingers have been burned, toes stubbed, nerves strung-out with stress and frustration (lots of pain in this learning curve!) and of course, just as we think we have our '*ducks in a row*', community dynamics indicate otherwise. So this is basically where we are at now:

- Identify a village with a high rate of gender and child violence – HIV-related stigma is everywhere and thus, the common denominator. We are fortunate to be able to identify '*hot spots*' through our organisational database, into which all reported cases of sexual assault and domestic violence are entered.

- Allocate an '*Advocacy Officer*' to the village – a TVEP volunteer trained in all TVEP topics, as well as workshop facilitation

> *...the* 'spray & pray' *approach does not work...popular technique of* 'spraying' *a crowd with information, and* 'praying' *that at least some of the information will stick!..*

- '*Break ground*' – at meetings with community leaders (traditional, civic, church, business, educators etc) discuss the crime figures for the area, and encourage everyone to participate in a discussion as to the causes and possible solutions for such. Introduce people to the '*Zero Tolerance Village Alliance*' (ZTVA) concept, and invite everyone to enrol. Explain the list of criteria that must be met in order for the village to be awarded ZTVA status. Encourage participants to voice their concerns in relation to the TVEP core themes, and to give inputs on how these concerns could be addressed. Once the community have bought into the process, they are asked to form a small '*Steering Committee*' and appoint a '*Community Liaison Officer*' (CLO), who will be TVEP's contact person. The CLO should be literate, unemployed, and preferably '*mature*'[2]. While the CLO will primarily assist the TVEP Advocacy Officer in all her/his activities in the village, the CLO will also attend training sessions in the process and thus, be further capacitated.
- Over the next few weeks, both the Advocacy Officer and the Community Liaison Officer undertake community mapping, and prepare a very detailed list of all potential '*targets*' for empowerment, such as schools, crèches, churches, farms, clubs, societies, businesses, civic and traditional structures. This mapping process must also identify any other CBOs operating in the area, with whom partnerships can be formed, to avoid any duplication of services.
- A time-line is developed according to this list, taking into account the general understanding that workshops should never involve more than 40 participants. In the schools, for example, the Advocacy Officer and Community Liaison Officer may only workshop one class at a time, preferably using the '*life orientation*' period so as to minimise disruption. The churches are an exception in that if there are no specific church groups, the congregation has to be campaigned en masse.
- In the meantime, to enable us to assess impact levels, a baseline study is conducted to determine current levels of knowledge of TVEP's core topics.
- The Advocacy Officer and the Community Liaison Officer are responsible for ensuring that all the Zero Tolerance Village Alliance criteria are met, with the support and assistance of the Village Committee and TVEP Empowerment Team to whom they are accountable. As part of this process, they must:
    - Embark on a series of campaigns and workshops, aimed at ensuring that every sector of the community is fully empowered on the TVEP core topics as per the '*target list*' drawn up during the community mapping process. This will include workshops for grannies, community leaders, men and boys, learners, educators, and school governing bodies.
    - Ensure that all staff from the nearest clinic and police station are adequately empowered, and that healthcare workers have been trained on ART, VCT and PEP services. (This training is facilitated by the TVEP Victim Support Centre). Femidoms must be promoted from the clinic, and there must be a reliable supply.
    - Ensure that a temporary '*Safe House*' for women and children subjected to violence and abuse is identified, equipped, made available and marketed in the community.
    - Ensure that a home-based care group is active

in the community, as well as a support group for people living with HIV or AIDS, and a group monitoring and caring for orphaned and vulnerable children. (If these groups are not already in existence, TVEP can facilitate their establishment, provided that the community owns these services and programmes).

> *...hopefully, significant improvement will be found (we have yet to decide what to do if it is not found!)...*

- Once all the criteria have been met, an '*endline survey*' will be conducted, for comparison against the baseline. Hopefully, significant improvement will be found (we have yet to decide what to do if it is not found!) and the village will be awarded membership to the Zero Tolerance Village Alliance at a public ceremony to which '*high-profile people*' and the media are invited. At that ceremony, the men of the community will be invited to take a public oath and sign a '*Role of Honour*' committing themselves to the eradication of child and gender violence, and the de-stigmatisation of HIV and AIDS. The Role of Honour, in the form of a ledger, will be kept at a public structure, such as the Civic or Traditional Authority offices or Police Station. If a man, who has taken the oath, subsequently violates it, the Village Committee can remove his name from the role, as a '*name & shame*' tactic.
- As a member of the Zero Tolerance Village Alliance, the village will be given a large sign post declaring their status and name of the village. A small allowance[3] will also be made available to the village to use in a way that will help build a sense of community, such as road signs or a community notice board.

Sustainability

We are hopeful that, with the assistance of good media coverage, community pride generated by the Zero Tolerance Village Alliance will spread and create a demand for membership to the Alliance. The Community Liaison Officer is expected to continue with the empowerment of her/his community in all TVEP core topics, and to promote the reporting of abuses. The partnership with TVEP will be retained, and bi-annual meetings between members of the Alliance will be facilitated so as to have a platform for sharing experiences, successes and challenges.

Learning as we go along

As there are no '*blue prints*' for this strategy, we are learning as we go along, and as noted earlier, some of the lessons have been hard. '*Buy-ins*' by community leaders is undoubtedly the key, as is their willingness to play an active role. This way, if someone lacks cooperating, the '*big guns*' can be rolled in.

As much as possible, the workshops must be fun (despite the topics), and the Advocacy Officer must, of course, be highly skilled and knowledgeable. More and more we are using edudrama to illustrate our topics. For us, access to schools has been an issue in some areas – so the '*buy-in*' of the Department of Education is another one of the remaining challenges.

FOOTNOTES:

1. The authors have extensive experiences in facilitating the process of challenging stigma and discrimination.
2. The overriding principle of the Zero Tolerance Village Alliance.
3. '*Mature*' is primarily defined by age.
4. The allowance amounts to R5000.

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Gahsiena van der Schaff

People need to know their HIV status, but…

Provincial strategies for free, informed and confidential HIV testing

The first round of provincial networking meetings facilitated by the AIDS Legal Network (ALN) in 2007 aimed not only at analysing various HIV testing models and realities, but also at exploring the various societal factors which form barriers to HIV testing.

The purpose of the meetings was also to collectively identify potential advocacy and lobbying strategies and activities, at a provincial and national level, intended to create an enabling environment for free, informed and confidential HIV testing and, thus, for increased uptake of HIV testing services. Meetings took place in the Northern Cape (24 May 2007), KwaZulu Natal (28 May 2007), Limpopo (14 June 2007), North West (21 June 2007), Free State (26 June 2007), Eastern Cape (12 July 2007), Mpumalanga (26 July 2007) and Western Cape (7 August 2007).

The global call to scale-up HIV testing, as well as the introduction of '*provider-initiated opt-out routine HIV testing*', as the means to achieve this, has led to many debates about the need to promote and protect human rights in the context of HIV testing, and the simultaneous need to scale-up HIV testing – and these needs are often seen to be contradictory. Fundamental to these debates is the acknowledgement that while human rights abuses seem to be imminent to the model of '*opt-out routine HIV testing*', human rights abuses, including stigma and discrimination, are also some of the recognised reasons as to why the model of '*voluntary counselling and testing*' for HIV, the human rights model, has failed to achieve its goal – considering statistics indicating that more than 80% of people living with HIV are unaware of their HIV status[1].

Notwithstanding the need to scale-up HIV testing, the question remains as to whether or not this need does indeed justify, or can potentially be used to justify, sacrificing fundamental human rights principles of informed consent, security of a person, confidentiality and non-discrimination. The human rights-based answer would be that human rights principles are to be the foundation of any HIV testing model, especially considering the societal context in which HIV testing takes place – a societal context which is as much characterised by gendered inequalities, imbalances and injustices, as it is defined by prevailing stigma, discrimination and violation of rights based on, and in the context of, HIV and AIDS.

The ALN facilitated provincial networking meetings were thus, based in the context of the need to scale up HIV testing, while promoting and protecting human rights principles, so as to facilitate free, informed and confidential testing for HIV.[2]

The goal, the reality and the 'dilemma'

Considering the challenge of an estimated 80% or more people who currently live with HIV and are not aware of it, and the NSP goal[3] of increasing the uptake of voluntary counselling and testing for HIV (VCT) through an increase in the number of adults (aged 15 – 49 years) who have ever had an HIV test to 70% by 2011, seems to raise the question as to '*how*' to get people '*voluntarily*' to test for HIV.

Networking partners[4] in all provinces agreed in principle that as long as the gendered societal context – sustained and maintained by cultural, religious and societal norms and beliefs, which in turn create an environment of inequality, disrespect for human dignity and people's choices, prejudices and '*justifications*' for the violation of rights – is not addressed or transformed, it would be rather difficult, if not impossible, to get 70% of adults to test for HIV, '*voluntarily*', in the next five years. It seems, this *'target'* could indeed only be reached through further violation of fundamental rights of users, family and community members – which have not been challenged and/or reported in both the community and healthcare environments – in spite of constitutionally guaranteed principles of equality, non-discrimination, dignity, security and autonomy of the person, privacy, informed consent, access to information and healthcare among others.

HIV testing – why, who and when

None of the participants in any of the provinces disagreed with the fact that there is a dire need to scale up HIV testing and that people, in their numbers, '*should test for HIV*', and '*need to know their HIV status*'. Participants not only provided numerous reasons as to '*why*' people should test for HIV, but also clearly expressed '*who*' should test for HIV and '*when*' HIV testing should ideally take place.

> *...stigma and discrimination, are... recognised reasons...why...*'voluntary counselling and testing'*... has failed to achieve its goal...*

Reasons commonly expressed as to '*why*' people should test for HIV, included:

- **Personal health and well-being** – testing for HIV is '*for one's own sake*' ; '*to take better care of one's immune system*'; '*to know one's health status, make choices about one's health and to understand about one's own well-being*'; '*to know where we stand*'; '*to open our eyes*'; '*to plan for the future*'; '*to take necessary precautions*'; '*to take better care of yourself, by eating the right food*'; and '*if one knows, one has power*'
- **To access treatment and prolong one's life** – HIV testing is important because '*if one is sure of one's HIV status, one can get treatment*'; '*one can access treatment early and live longer*'; and '*so there can be less deaths*'
- **To prevent the further spread of HIV** – knowing one's HIV status is important in order '*not to transmit the disease to the next person*'; '*not to pass on the virus*'; '*to decrease the infection rate*'; and '*to make informed decisions about reproduction*'
- **To access relevant information** – HIV testing is key to '*get proper counselling*'; '*get correct treatment information*'; and '*to get counselling and information on how to use condoms*'
- **To change one's (sexual) behaviour** – HIV testing is necessary so as '*to change one's lifestyle*'; '*to change behaviour*'; '*to use condoms, if positive*'; '*when positive, to stay faithful to one partner*'; and '*if one knows one's status, one will stop judging other people*'
- **For the sake of '*others*'** – HIV testing is important '*so government can spend money on other things*'; '*to plan for and protect the family for the future*'; '*to encourage communities to test*', '*to alleviate fears of the disease and fears of the unknown*', and '*an increase of the number of people tested, can inform intervention strategies*'

However, participants in some provinces felt very strongly that people should test for HIV, '*but not be forced to test*', since *'people should be ready and aware of the possible impact of a positive test result*'. Participants also pointed to other conditions impacting on HIV testing, such as '*a person must consider if it is safe for one to do so and whether one is ready to do so*'; people must take into account '*what's going to happen after the test*'; '*what are others going to say*'; and '*one must also be mindful of discrimination*'. While participants strongly agreed on the need for HIV testing, they felt equally strong that HIV testing '*must be an informed decision*'; and should only take place '*after receiving all the facts that will inform* *one's decision*'. There was also a strong sentiment that organisations should '*create awareness*' about HIV testing, '*but let people make their own decisions*' of whether or not to test for HIV – '*and we all know this does not always happen, particularly with women*'.

> *...many concerns were raised during the debates on the healthcare facilities environment...[where] healthcare providers 'recommend' HIV testing... with seemingly no option of free, informed and confidential HIV testing...*

Some participants felt that especially '*young people*' and '*pregnant women*' **must** test for HIV, while some felt that people should go for '*regular*' HIV testing. Participants felt, however, strongly that young couples have to go for HIV testing, especially if they intend to '*take the relationship to the next level*' or '*get married*', since '*nowadays, we have to know our partner's sexual history*'. There was also a strong belief that women have to get tested for HIV – '*as soon as she knows she is pregnant*' – so as to '*protect her baby*'. Concerns were raised as to why it is that women always are the ones testing for HIV, while men are conspicuously absent from VCT sites and healthcare facilities.

In the context of the '*right time*' for an HIV test, participants felt that one should get tested **when intending to engage in sexual activities,** when **planning a family**, and/or when **getting married** – '*preferably both partners*' should get tested for HIV '*after introduction to a new sex partner*'; '*before making love to a husband*'; '*before having unprotected sex*'; and '*before or when pregnant*'; when one's **health is deteriorating** – it is '*time*' to test for HIV '*if one becomes sick often*'; when one has **suspicion of partner infidelity** – '*if I do not trust my partner*' and/or there is '*suspicion of unfaithfulness*'; after a **partner's disclosure** – '*my partner informs me of her/his positive status*'; or **death** – '*after one partner dies of an AIDS-related illness*'. In addition, the need for an HIV test after **rape** and after **exposure to blood** was highlighted.

Whilst some felt that one could go for HIV testing at '*anytime one feels to go for a test*', one healthcare provider participant felt very strongly that people should get tested for HIV '*as soon as possible*'.

Despite debates and discussions about the '*right time*' for HIV testing, there was an overall strong sentiment across provinces that it is an individual choice as to when to go for an HIV test – '*when I decide to do so*'; '*when I am prepared to do so*'; '*when my mind and heart tells me to do so*'; '*when mentally ready to do so in order to handle a positive test result*'; '*when I feel the time is right*'; and '*when confidentiality is respected*'; '*when pre and post-test counselling is provided*'; and '*when one is assured of ongoing support*'.

HIV testing barriers

Exploring the various reasons as to why people in communities do not come forward for HIV testing led to lively, heated, and at times emotional, debates around the challenges and realities facing people in communities and at HIV testing sites.

A primary barrier, raised by participants across provinces, preventing people from voluntarily accessing VCT is **fear**. While the degree of fear and experiences at HIV testing sites may vary between provinces, people in the more rural provinces generally expressed greater degrees of fear, as well as higher occurrence of violations at healthcare facilities providing HIV testing.

In summary, the **community environment** is an environment filled with fear – fear of being stigmatised; called names; rejected by family, friends, community and colleagues and/or divorced by partners; fear that people will find out and being gossiped about; fear of discrimination, isolation, blame and shame; fear of violence and abuse…and the list seems endless. A common challenge highlighted in all provinces is the fear of '*how the family/partner is going to react*' and '*what's going to happen to my children and to my family, if I test positive*'.

This environment is also marked with a reluctance to support and accept family and community members who test positive for HIV, as '*communities are not ready to support people who test positive*'. Subsequent to the lack of community support, people's concerns and worries of '*how am I going to cope*' with a positive HIV test result, further prevents people from testing for HIV.

The existence of **stigma and discrimination** in communities remains a major barrier, despite all the efforts of raising awareness about HIV and AIDS. HIV infection is still largely associated with '*promiscuity*' and '*sinful*' sexual behaviour. People testing positive for HIV are an '*embarrassment and are seen to have committed a sin*'.

> *...participants also expressed the sentiment that there seems to be* 'comfort in not knowing'*; a strong sense of* 'don't want to know' *and it is* 'better not to know'...

Other barriers raised included **lack of knowledge/ information** about HIV and AIDS. Concerns ranged from lack of information as in '*not knowing the testing procedure*' to '*lack of accurate information about prevention*' to lack of knowledge about '*human and legal rights*'. Participants felt strongly that existing awareness and education campaigns have, thus far, failed to reduce HIV infection rates, to provide HIV prevention options, and to increase the uptake of HIV testing services. Furthermore, women not only remain to be more at risk of HIV infection, but also more at risk of blame, shame, violence and abuse as and when their HIV positive status becomes known.

In most provinces the concern was expressed that existing **cultural and religious beliefs, values and norms** seem to contradict and not coincide with existing HIV and AIDS education and awareness programmes. While '*manhood*' and '*social status*' are often linked culturally to multiple sexual partners, HIV awareness and education messages focus on '*faithfulness*' to '*one partner*'. Similarly, a positive HIV test result is often associated with '*sinful behaviour*' and/or perceived as a '*weakness*'. In addition, there is a strong sense that if '*I believe in traditional meds and not western meds, why would I access western clinics for medicines, HIV testing and/or treatment*'; as there is a growing misconception that '*since I am circumcised, I am safe, and so, there is no need for testing*'.

Provinces not only agreed on the occurrence of **violation of rights** in the context of HIV testing, in that there is a general '*lack of confidentiality*' and/or '*compromised confidentiality*'; but also on the existence of **access barriers to healthcare facilities,** as well as violations occurring within healthcare facilities. Some of the barriers mentioned that prevent people from accessing healthcare facilities included that '*health centres are not friendly to users*'; that '*no proper counselling is given*'; and the '*attitude of healthcare workers*'. In addition, many of the healthcare settings '*lack confidentiality*'; fail to provide '*privacy in counselling rooms*'; and the infrastructure of '*dedicated rooms*' often leads to '*indirect disclosure*'.

Many concerns were raised during the debates on the healthcare facilities environment. Across provinces, participants felt that in many facilities, the '*client-initiated*' VCT model of HIV testing has in reality long become a '*provider initiated counselling and voluntary HIV testing*' approach, in that healthcare providers '*recommend*' HIV testing and counselling, especially to women, with seemingly no option of free, informed and confidential HIV testing. It is not only in the context of antenatal care services that women are '*forced*' to test for HIV – '*if you fall pregnant, you are asking for being tested for HIV*' – but many women are also '*coerced*' and/or '*forced*' into HIV testing, so as to have access to other medical services – as participants shared experiences of being told to first bring the HIV test result, before being treated for not only an STI, but also for suffering from constant headaches.

Furthermore, concerns were raised in all provinces as to whether or not counsellor services are effective; and questions were asked as to who monitors the counsellors, who is responsible for providing ongoing support, and whether or not counsellors are informed of all the legal aspects as part of their training. Another concern raised is how to ensure that people understand the information provided during counselling, so as to '*enable*' people to indeed give informed consent – '*they give you this information without checking if you understand this information*'; and '*after they send you home, you have to face your family on your own; there is no support, and also no counselling offered for the affected family*'.

...the absolute minimum requirement...would include assured confidentiality...and access... to...accurate information... about HIV testing...

Many of the participants also felt strongly that HIV testing services are **gender-biased** and seem to focus particularly on women, without taking into account women's realities – '*they tell you to use condoms; now how can a woman go home and tell the husband that he must use condoms*'; '*they don't think of these things that women have to go through; all they care about is that you must test*'.

Considering all the above, participants also expressed the sentiment that there seems to be '*comfort in not knowing*'; a strong sense of '*don't want to know*' and it is '*better not to know*'; and common **ignorance** that '*HIV and AIDS do not concern me*', since '*I am not at risk*'.

The **lack of protection** as and when violations occur is another challenge highlighted in many provinces. It was commonly agreed that this is primarily due to a lack of knowledge and understanding of rights, as well as the lack of information as to where to report violations. While many participants shared experiences of serious violations of the right to dignity, confidentiality, and consent – leading to '*forced*' HIV testing and/or HIV testing without consent, to unlawful disclosure of a person's HIV status, which in turn often subject people to discrimination, violence and abuse – only a few of the participants had knowledge of existing legislative provisions meant to provide protection and redress to people who have been violated in the context of HIV testing.

Strategies for free, informed and confidential HIV testing

It has been the principled understanding across provinces that any strategy aimed at facilitating free, informed and confidential HIV-testing has to have at its core the creation of an enabling and supportive environment – an environment in which everyone's fundamental rights and freedoms are respected and protected, irrespective of sex, gender, sexual orientation, age, and/or HIV status; in which people who stigmatise, discriminate and violate '*others*' are reported, and the '*stigmatised*' are supported, rather than rejected or isolated; and an environment in which healthcare services provided are non-judgmental, non-discriminatory, and access to services is based on informed consent. The absolute minimum requirement for an enabling and supportive environment for HIV testing would include assured confidentiality in all healthcare facilities (and amongst members of communities); access to inclusive and accurate information (benefits, risks, implications, consequences) about HIV testing so as to facilitate free and informed decision making as to whether or not to test for HIV without fear and/or '*force*'.

Numerous strategies and mechanisms, aimed at increasing the uptake in HIV testing services through providing free, informed and confidential HIV testing services, have been identified in all provinces. Some of the identified strategies include:

Community empowerment

- Increase access to standard information, in an understandable language, on HIV testing and disclosure, which is accurate, inclusive of advantages and disadvantages; and includes information on rights and legal issues, as well as where to report violations as and when they occur
- Inform community about the right to make an informed choice about HIV testing, the right to say ‘*yes*’ or ‘*no*’ to HIV testing
- Empower community with human rights knowledge and understanding – everyone must read and live the Constitution
- Provide *‘legal literacy’* and encourage people to enforce the law

> *...scaling up of HIV testing is needed, but not at the cost of...fundamental rights...*

Addressing stigma, discrimination and fear

- Change people’s external environment through promoting and adopting a caring and respecting attitude
- Involve people living with HIV or AIDS in programmes and campaigns addressing HIV-related stigma and discrimination
- Encourage open communication between members of families on issues of sex, sexuality and HIV
- Unpack the concept of stigma and challenge perceptions and beliefs leading to stigma, including concepts, such as AIDS = promiscuity
- Watch our language – use non-stigmatising language
- Take anti-stigma messages to schools, churches, social gatherings and taverns

Community support and mobilisation

- Create a culture of ‘*us*’ to accept and one another for who we are
- Change people’s mindsets
- Mobilise and network with everyone, including churches, youth groups, social groups, and encourage communities to support and take care of its members
- Provide referrals to NGO service providers, if needed, such as lifeline and advice offices
- Give information to people in waiting halls at hospitals and clinics
- Call community meetings where everyone can share their experiences
- Mobilise communities to take up ethical and legal issues

Community-provided *‘aftercare’*

- Establish what programmes and support are offered to people after the HIV test
- Encourage mentoring of people tested for HIV and/or intending to test for HIV
- Do not just give information, ensure that people understand the information
- Encourage people to join, build and assist support groups
- Encourage *‘mini dramas’* on radio and other media, as well as in communities, in languages people understand

Addressing gender bias

- Encourage men to become home-based carers, as well as counsellors
- Address gender stereotypes
- Encourage men’s groups, and get males involved in workshops and training
- Provide male friendly HIV testing sites, offer HIV testing also around pubs and places of social gatherings

...only...when the focus is on transforming the environment... will there be...more and more people 'wanting' to know their HIV status...

NGOs service providers

- Talk regularly to one another – service providers amongst themselves and with community
- Monitor the quality of services and act upon violations of rights
- Assist people who want to make a complaint
- Monitor and evaluate if there is change

Health facilities and healthcare personnel

- Change attitude of healthcare workers, and of users
- Create user-friendly health facilities
- Strengthen capacity of healthcare workers, provide adequate and ongoing training on legal issues

Counsellors and counselling services

- Provide counsellors of all ages, to cater for age specific groups
- Ensure that counselling is effective- that follow-up and ongoing counselling is provided to infected and affected persons
- Address counsellors' lack of protection – NAPWA in partnership with participants will make submission nationally to SANAC
- Build capacity of counsellors, provide adequate and ongoing training, including legal training

Addressing violations in healthcare facilities

- Address risks of indirect disclosure, including issues of '*dedicated rooms*', and nurses' '*gossip*'
- Remove '*identifiers*', such as markers on containers and folders
- Change '*climate of stigma*', including language

Conclusion

Scaling up of HIV testing is needed, but not at the cost of disregarding individual's fundamental rights to freedom of choice, dignity, security of the person, privacy, equality and non discrimination, and/or access to information. Thus, it is imperative to create

> *…a culture of self-knowledge regarding status that is firmly situated within a human rights commitment to the rights to privacy and non-discrimination*'.[5]

In summary, as networking partners in all provinces conceded, only as and when the focus is on transforming both the environment in which people live their lives, as well as at the healthcare facilities, which allow for, and seemingly justify, violation of rights to occur, will there be free, informed and confidential HIV testing leading to more and more people '*wanting*' to know their HIV status.

'*Stigma is killing our brothers and sisters!*' [Western Cape participant]

FOOTNOTES:

1. Kalichman, S. & Simbayi, L. 2003. 'HIV testing attitudes, AIDS stigma and voluntary HIV counselling and testing in a black township in Cape Town, South Africa'. In: *Sexually Transmitted Infections*, No 79:442.
2. See also *ALQ* September 2006 on HIV testing strategies.
3. Objective 5.2. of the HIV & AIDS and STI National Strategic Plan for South Africa (NSP) 2007 – 2011.
4. Networking partners participating in these debates are primarily civil society service providers working in the areas of HIV and AIDS, gender violence and human rights.
5. SANAC Law and Human Rights Sector Working Group Press Statement, 2 May 2007.

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Sizwe Hlatshwayo

Hope beyond visible obstacles…

Amanzimtoti YMCA addressing HIV-related stigma

The Amanzimtoti Young Men Christian Association (YMCA), known as 'Toti Y' to partners, is an organisation founded on Christian values and principles with the aim of developing young people and the community at large. As much as the organisation is Christian-based, we are non-denominational and thus, we do not service people on the basis of their Christian faith, but all members of society, regardless of whether or not they go to church.

Introduction

The organisation was founded in 1973 for the purpose of rehabilitating drug abusers, and helping matriculants, who were affected by the political up-rising in the province, through a supplementary education initiative. In the year 2000, we did a baseline study in our area of operation and the findings indicated that young people are at high risk of contracting HIV and AIDS; that people living with HIV and AIDS did not have adequate information and necessary skills to live with the disease; and that people living with HIV and AIDS experience a lot of stigma and discrimination from families and the community in general.

The organisation then developed and implemented programmes focussing on various issues, including HIV and AIDS, youth unemployment, poverty, gender-based violence, theology and democracy, lobbying and advocacy, providing a home for young offenders, life skills training, brokering of employment opportunities, technical skills training, restorative justice, as well as the integration of young offenders and street children, or young people at risk of offending, back into society.

Amanzimtoti YMCA is currently implementing its programmes within the South Operational Entity of the Ethekwini Municipality, KwaZulu Natal, servicing the following communities: Folweni, KwaMakhutha, Adams Mission, Lovu, Umgababa, Nsimbini and Ezimbokodweni. While these are the official project sites, our initiatives go beyond these communities, through our working relationship with various partners in the province and beyond.

Our Approach

The organisation works in the six communities through youth committees and lay leaders that reside in the area of operation. The youth committees and lay leaders are the representatives of different structures in the community to inform the organisation of the real and immediate needs of the community, and thus, ensuring that the services we deliver, are relevant for the communities.

During the initial needs assessment, as well as during the planning, implementation and evaluation of programmes, the organisation makes sure that all affected and interested parties are part of these processes. The organisation is implementing HIV and AIDS awareness and prevention programmes, working with young people and people living with HIV and AIDS as primary beneficiaries. The following are the different programme activities:

Edutainment

Edutainment group participants are young people, in and out of school, who are interested in dance, music and life skills. The aim is to ensure that young people are kept active through various activities, and are also equipped with necessary skills to minimise the risks of HIV infection. Amanzimtoti YMCA is working with young people by organising events around the theme of HIV and AIDS awareness and prevention, or any other social ill, that need immediate attention in the community. When we are addressing HIV and AIDS realities and challenges at a community level, we ensure that all underlying factors are addressed in a holistic and integrated manner.

Young people participating in the programme have also been involved in focus group discussions, assessing the level of HIV-related stigma and discrimination, and participated in the campaign '*say no to HIV, AIDS or any other discrimination that is taking place in the community*'. These young people have not only consistently displayed commitment to the programme, but are also committed to behavioural change.

> *...many churches are still discriminating against people living with HIV and AIDS; and...perceive community development as a political issue and not ...a responsibility of the church...*

Drama

The drama group is composed of more '*senior youth*', as compared to the edutainment group. The participants use drama as a tool to address and reduce HIV-related stigma and discrimination, gender-based violence, and other social ills. The drama group has performed at different churches, schools, community and other gatherings, spreading messages of '*no to unprotected sex*', '*knowing your HIV status*', and of '*positive living*'. The drama group is also providing information on where to go and what to do when one is HIV positive, or when one has been violated.

The involvement of these young people in the response to HIV and AIDS has made a world of difference in the lives of many people. This has been visible with the amount of young people, and community members in general, who have approached Amanzimtoti YMCA for assistance after interacting with the young people during performances.

These drama performances have also marketed the various other programme activities facilitated by the organisation. As a result of intensive capacity building focussing on church leaders and the drama performance in various churches, two church leaders forums have been formed, and HIV and AIDS peer educators from more than 15 churches are currently trained.

Church Leaders Forums

Through working with churches, Amanzimtoti YMCA came to the realisation that many churches are still discriminating against people living with HIV and AIDS; and that churches perceive community development as a political issue and not necessarily as a responsibility of the church.

Church leaders participating in the forum are '*sharpened*' in the area of theology and democracy, HIV and AIDS, traditional and western religions, as well as planning, implementation, monitoring and evaluation of programmes responding to various needs in the community. In addition, church leaders have not only been equipped with a lot of skills to respond to the needs of people living with HIV and AIDS, and to address HIV-related stigma and discrimination, but have also been linked to resourceful partners, such as the University of KwaZulu Natal, Theology School, the National Association of People living with HIV and AIDS (NAPWA), the Treatment Action Campaign (TAC), and other organisations in and outside the area of operation, so as to ensure that church programmes are sustainable beyond the YMCA involvement.

Lobbying and advocacy

Lobbying and advocacy activities are done for, by and with beneficiaries in order to ensure that communities have access to basic social services; through capacity building of various stakeholders participating in our programmes. While Amanzimtoti YMCA does not claim to be ‘*experts*’ in lobbying and advocacy, we are in the position to enhance capacity amongst community stakeholders, through our JOHAP (Joint Oxfam HIV and AIDS Project), APAC (Australian Partnership with African Communities) and other partners.

The involvement of networking partners in our work has enabled us to reach goals and targets, which we could have not achieved alone, because of limited resources. Networking partners’ involvement in programmes has affirmed the organisation’s credibility and stretched our limited resources to achieve more than we anticipated. Networking partners, not only from KwaZulu Natal but also beyond, have brought different perspectives and lessons enhancing the capacity of both the beneficiaries and the organisation.

As an organisation, we have similar beliefs as the Youth Development Network (YDN), in that young people in the community, or any other person benefiting from the interventions, should not be seen as a mere beneficiary, but as an active participant in his or her own development. We also believe that programme sustainability will only be achieved if communities participate in each and every stage of their own development and are continually equipped with necessary skills, so that programmes can continue when we are no longer there.

Support group facilitation

Support groups are facilitated on a weekly basis as a platform for people infected and affected by HIV and AIDS to come together, to share experiences and challenges, and to assist one another with coping skills. It is the responsibility of Amanzimtoti YMCA to ensure that project beneficiaries in support groups are equipped with income-generating skills and life skills, as well as lobbying and advocacy skills.

> *...while Amanzimtoti YMCA does not claim to be ‘experts’ in lobbying and advocacy, we are in the position to enhance capacity amongst community stakeholders...*

Support group members are also equipped with necessary skills to respond to HIV-related stigma and discrimination, and skills to address gender-based violence, amongst other things. These areas are a special area of focus, since a majority of people participating in support groups are women, who report incidences of both HIV and AIDS and gender-based discrimination.

Amanzimtoti YMCA is currently working on formalising support groups as community-based organisations (CBOs) in order to facilitate sustainability. This will also assist in facilitating beneficiaries’ involvement in income-generation and other activities contributing to their own sustainability. The initiative came about as a result of decreasing numbers of people attending support groups, once participants received all the information they needed.

Life skills training

Life skills training sessions are facilitated with all project beneficiaries, in and out of school, with the aim of assisting young people in finding themselves, in valueing themselves, and to be equipped with the necessary skills to cope with, and respond to, all of life’s challenges, primarily focussing on HIV and AIDS. In working with project beneficiaries in and out of school, it became clear that if people lack self-worth, they are more likely to expose themselves to all kinds of danger; facilitating life skills sessions became an important part of our programme activities.

Life skills sessions are, thus, assisting young people, and project beneficiaries in general, to find the meaning of life, and to take life's challenges as stepping-stones.

Entrepreneurship

The unemployment rate in our area of operation is over 40%, mostly affecting young people, who have either dropped out of school or have passed matric. The entrepreneurship training is purposed to equip participants with necessary skills to alleviate and bring about hope. Hunger and desperation have caused people to involve themselves in dangerous situations and risky behaviour, exposing young people, and people in general, to the life of crime and to risky social activities, as well as to HIV and AIDS.

> *...if organisations would stop competing...and...start sharing resources....so much more could be achieved.*

As part of the entrepreneurship training, life skills and HIV and AIDS awareness are facilitated and links are made between business and various social ills in the community. Young people first resisted participating in entrepreneurship, since they believed that in order '*to make it in life*' one has to be employed, but after witnessing other people '*making it in business*' and realising that job opportunities are scarce, young people are now participating in the programme.

While young people participating in these programmes are discriminated against by financial service providers for being '*young*', people living with HIV and AIDS are discriminated against, based on their HIV status. The programme strives to instil hope beyond these visible obstacles.

Networking

As an organisation we strongly believe that if organisations would stop competing over beneficiaries and resources and would start sharing resources, skills and expertise, so much more could be achieved. Amanzimtoti YMCA has built strong networks with partners in and out of the area of operation. While these partners add value to our work, we add value to their work – thus, benefiting all project beneficiaries.

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Erica Kessie

No other option than to resign…

HIV-related stigma and discrimination at the workplace

Despite a constitutional and legislative framework, including labour legislation, guaranteeing everyone the right to be treated equally and not to be discriminated against, people living with HIV or AIDS are still stigmatised and discriminated against at the workplace. Women workers are particularly vulnerable, due to their position in society.

Legislative provisions

The Constitution of South Africa[1] guarantees everyone the right to equality and non-discrimination (Section 9), which includes the right not to be discriminated against based on a person's HIV status; the right to have one's dignity protected and respected (Section 10), which includes that no one has the right to disrespect, insult, undermine a person's dignity and worth because of her or his HIV status; and the right to privacy (Section 14), which includes that no one has the right to '*force*' another person to disclose her or his HIV status. The Constitution also guarantees everyone the right to freedom of trade, occupation and profession (Section 22), which includes that no one can be denied the opportunity of employment because of a person's HIV status; and the right to fair labour practices (Section 23), which includes the right of any worker not to be discriminated against at the workplace because of a worker's HIV status.

Labour legislation, giving effect to constitutional provisions of equality, dignity and non-discrimination, further regulate the implications of these fundamental rights and freedoms in the work environment. In the context of HIV and AIDS at the workplace, various pieces of legislation clearly outline what is considered an '*unfair*', and thus '*illegal*' act and/or behaviour at the workplace. The Employment Equity Act (No 55 of 1998), the Labour Relations Act (No 66 of 1995), the Basic Conditions of Employment Act (No 5 of 1997), and the Occupational Health and Safety Act (No 85 of 1993) are some of the laws affording protective measures to all workers, including workers living with HIV or AIDS.

While the Employment Equity Act[2] clearly stipulates that no one applying for employment may be refused a position, because of a person's HIV status, and that no one can be subjected to pre-employment HIV testing; the Labour Relations Act[3] clearly stipulates that the dismissal of any worker based on her or his HIV status is '*unfair*' and thus, '*illegal*'. A worker can only be dismissed as and when a person is too ill to perform the tasks required by the job – thus, the worker's health conditions are such that the worker may be considered '*incapacitated*', due to ill health, to continue the employment. However, it is the responsibility of the employer to find a suitable position for the worker, taking her or his health condition into account.

The Occupational Health and Safety Act[4] legally obligates the employer to provide a working environment that is safe and free of any hazards to the health and well-being of workers – thus, a working environment in which adequate measures are put in place to minimise the risks of occupational exposure to HIV, including access to treatment and care as and when an occupational exposure to HIV does occur.

However, despite all the constitutional guarantees and legislative protective measures, workplace reality remains to be marked by stigma, discrimination and violation of workers due to their actual and/or perceived HIV positive status.

Workplace reality

At the workplace, employees are often treated like '*outcasts*' when their HIV-positive status becomes known to fellow workers and management – as the following example illustrates[5]. Kathy[6] chose to disclose her HIV positive status to management, expecting that she would get the support and understanding from her employer and fellow workers. In reality, however, colleagues often treat people living with HIV as if they do not have the right to be at the workplace. '*You must go to the boss and tell him to fire Kathy, because she can infect the rest of us*' – one worker said to the shop steward. '*Make sure that Kathy washes her own eating utensils and separately from the rest of ours*' – was another comment made by a colleague, Kathy expected to get support from.

> *...the majority of companies, especially small companies, have no HIV workplace policy in place and thus, often no redress for workers who have been violated based on their actual and/or perceived HIV positive status...*

Situations like these are not uncommon – despite all the HIV awareness and education campaigns at workplaces. This seems to raise the question as to why these situations and human rights violations continue in the working environment. Is it because of ignorance, or is this a blatant act of stigma and discrimination?

In this particular case, the perceptions about HIV and about people living with HIV expressed by the workers were not addressed. Thus, the company failed to address human rights violations at the workplace; failed to provide '*protection*' to Kathy who has been violated; and thus, arguably, condoned, through the lack of action, the existing discriminatory attitudes beliefs, and practices against people living with HIV. The words and actions of fellow workers remained '*unpunished*' and subsequently, Kathy had no other '*option*', than to resign.

While this is but one example, it is indicative of many workplaces which fail to create a '*safe*' environment for people living with HIV to disclose their HIV status. The majority of companies, especially small companies, have no HIV workplace policy in place and thus, often no redress for workers who have been violated based on their actual and/or perceived HIV positive status. Even though there are peer educators employed in many of the companies, the lack of adequate support from management often leads to a situation in which HIV awareness and education are reduced to 15 minute talks during the workers' lunch time. Needless to say, these conditions are neither conducive, nor is the time sufficient, to provide adequate information about HIV, its transmission, and about people living with HIV. As a result, existing discriminatory perceptions and beliefs about HIV and about people living with HIV or AIDS are not addressed as part of HIV awareness and education provided at the workplace; and Kathy's experience will potentially repeat itself with other workers who choose to disclose their HIV-positive status in the working environment.

This seems to indicate that as long as '*management*' fails to not only support, but become actively involved in HIV awareness and education at the workplace, the constitutionally guaranteed right to fair labour practices remains but a '*right on paper*' with little to no impact on the reality of workers living with HIV or AIDS.

FOOTNOTES:

1. The Constitution of South Africa, Act 108 of 1996.
2. Sections 6 and 7 of the Employment Equity Act.
3. Sections 187 and 188 of the Labour Relations Act.
4. Section 8 of the Occupational Health and Safety Act.
5. This particular incident occurred in 2006 in a small factory in the Western Cape.
6. Not her real name.

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John Moerane

Taken seriously and taken forward…

Human rights education and training in Lethabong

Lethabong Legal Advice Centre is a non-profit organisation committed to serving in different communities around Lethabong in the North West Province by addressing various issues, such as HIV and AIDS and human rights; by providing free legal advice; and by empowering communities and disseminating information to especially marginalised communities. We are facilitating workshops around these issues in various rural and marginalised communities; together with our networking partners, who assist us in research, facilitation process and information dissemination.

Challenges in Lethabong and the surrounding areas

There are many challenges facing rural communities; a shortage of healthcare facilities and qualified healthcare workers; a shortage of ambulances; and the violation of patients' rights by healthcare providers are but a few of the challenges. Illiteracy and high levels of poverty and unemployment are further contributing to the vulnerabilities of rural communities. People in these rural areas have to travel long distances to access healthcare facilities, as some of the villages have no clinics. There is also a general lack of healthcare facilities operating 24 hours, as there is a lack of healthcare facilities providing HIV testing services. In addition, there is a lack of *'crisis centres',* providing treatment, support and care to people who have been abused and/or raped. Finally, there are no mechanisms in place to monitor the quality of healthcare provided to people in rural communities, and most facilities have no provisions for the indigenous payment system.

In the Bojanla district, there are more than 300 rural villages. In most of these villages, there is a general lack of human rights knowledge and understanding, as well as a strong male dominance in all spheres of life leading to a situation in which men are perceived to be the *'head of the house and village',* and to have *'control over women'* and thus, women are least in the position to access available resources and opportunities, including information.

Access to information as key to change

In July 2006, our organisation was introduced to the *'philosophy'* and *'unique'* facilitation style of the AIDS Legal Network (ALN), who facilitated a three-day workshop in Lethabong. For many people in our community it was the first time to be exposed to human rights and HIV and AIDS education and training. This programme was an eye-opener to the people in our community, since the lack of understanding of human rights in the context of HIV and AIDS not only led to ignorance, but also to high prevalence of HIV-related stigma and discrimination in our communities.

Realising that this information is much needed in communities in and around Lethabong, we came up with a strategy of identifying relevant stakeholders in schools, churches, community-based organisations, non-governmental organisations and rural community structures. We then invited various stakeholders to participate in a three-day training session on different aspects of HIV-related stigma and discrimination, and its impact on various HIV prevention efforts. It was during the course of this training that educators, services providers and community leaders started to realise the limited impact of HIV prevention messages and programmes on behavioural change, due to a lack of accurate information provided on issues of HIV prevention and informed choice.

Participants responded very positively to the workshop and have since taken the acquired knowledge and information back to their workplaces and communities. Strategies are in place to address issues of cultural practices increasing the risks of HIV infection; to respond to *'cultural stigmatisation',* as well as to address and respond to HIV-related stigma and discrimination. There are also follow-up mechanisms in place so as to enhance access to accurate information and resources about HIV and human rights within healthcare facilities and amongst healthcare providers. And finally, we have managed to *'bring men on board'* – men are participating in most of the activities and are more and more empowered with information and understanding of human rights, including women's right to make informed choices about how and when to sexually engage with men.

We have since facilitated more than 20 workshops in different rural communities who lacked access to information. These activities have facilitated not only the knowledge of human rights and HIV and AIDS, but also empowered community members to access and realise their rights, including the right to make informed sexual choices.

Together with our partners, we have made impact and contributed towards behavioural change. The provided rights-based information and messages are taken seriously and taken forward by people and organisations and are now reaching many more beneficiaries. As a result, more and more vulnerable and marginalised communities are empowered with knowledge and tools to claim and enjoy their fundamental rights and freedoms; and with enhanced access to factual and rights-based information about HIV and AIDS. Thus, communities are in the position to make informed choices leading to an increased number of people accessing HIV testing services, and more patients adhering to treatment regiments.

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Busari Olusegun

Turning *'difference'* into *'inequality'*...

HIV-related stigma and discrimination in Nigeria

Inroduction

HIV-related stigma and discrimination is a pervasive problem worldwide, and Nigeria is not an exception. As far back as 1987, the late Jonathan Mann, then director of the WHO Global Programme on AIDS, identified three phases of the HIV and AIDS epidemic: the epidemic of HIV, the epidemic of AIDS, and the epidemic of stigma, discrimination and denial. He noted that the third phase is *'as central to the global AIDS challenge as the disease itself'*[1].

HIV-related stigma and discrimination occurs in a variety of contexts, including household, community, workplace, and healthcare setting. It remains an enormous challenge against effective control of the pandemics as it constitutes a major barrier to HIV testing, treatment, support and care services. The fear of stigma and discrimination keeps people from HIV testing, and if tested positive for HIV, from disclosing their HIV status to others, and from accessing healthcare services. The psychological burden it imposes on an infected individual is a potential cause of rapid decline in health status. With a population of about 140 million people and a prevalence rate of 4.4%, Nigeria is home to one of the largest number of people living with HIV or AIDS. Thus, Nigeria occupies a critical status in any issue on HIV and AIDS.

Definition of stigma and discrimination

Stigma is a complex social phenomenon that involves interplay between socio-economic factors in the environment and psychosocial issues of affected individuals. It is a process that turns *'difference'* into *'inequality'*, and as a derogatory tool used by dominant groups to produce, legitimise and perpetuate social control through exclusion of stigmatised groups, thus limiting the latter's *'ability'* to resist or *'fight back'*. HIV-related stigma can be described as a *'process of devaluation'* of people either living with, or being associated with, HIV and AIDS. It usually stems from the underlying stigmatisation of sex and intravenous drug use, the two primary routes of HIV infection worldwide.

Discrimination is defined as the negative practices that stem from stigma. It occurs when a distinction is made against a person that results in being treated unfairly and unjustly on the basis of belonging, or being perceived to belong, to a particular group. Thus, HIV-related discrimination is the unfair and unjust treatment based on an individual's actual and/or perceived HIV status.[2]

Causes of HIV-related stigma and discrimination

Stigma and discrimination are associated with social stigma manifested in blame, value judgments and shame, and with fear of infection through casual contact. The moral dimension of stigma in the context of HIV and AIDS is linked to the so-called *'social evils',* namely sex work and drug use, in people's minds, in policy and in programmes. Sex work is regarded in Nigeria as a *'sinful'* behaviour that deviates from traditional and religious morals, norms and values. It is a generally held view that *'prostitution is rewarded with AIDS'* and that *'those'* with AIDS contracted the disease through this *'perverted'* way of life.[3]

The fear of HIV and AIDS is another major cause of stigma and discrimination against people living with HIV or AIDS in the healthcare settings. There is also the deep-seated disbelief that the presently known modes of transmission are the only ways the virus can be contracted. This fear is increased by the prevalence of unfavourable and unsafe hospital working environments and the absence of social securities for healthcare workers. This fear persists despite the fact that most people have some information about HIV transmission. The issue of general welfare and safety of healthcare workers is central to HIV-related stigma and discrimination and can, thus, not be overemphasised. A poorly motivated healthcare worker is an *'angry'* service provider, who is more likely to displace her or his anger on the stigmatised group of patients.

Forms of stigma in the healthcare settings

There are many forms and shades of HIV-related stigma and discrimination in healthcare settings. Some are very subtle and may pass unnoticed to an undiscerning mind, but a critical look at them often reveals their true colour. Some forms of HIV-related stigma and discrimination in healthcare settings are discussed below.

Attitudes of healthcare workers

Judgemental feelings and prejudiced attitudes often characterise the ways and manners in which healthcare workers relate to patients living with HIV or AIDS. This is pervasive and very obvious at every point of healthcare contact with the patients: from the consultation room to the laboratory.

Denial of care

This is a form of *'man's inhumanity to man'.* The denial of care to patients living with HIV or AIDS ranges from a delay in, or a refusal of, physical examination to an outright rejection or ejection from a healthcare facility. Some healthcare workers only *'prescribe'* for patients living with HIV or AIDS, without any physical examination; while some facilities do not even admit the patients at all. Once an HIV test is positive, which is often done without adequate counselling, the patient is either neglected, discharged home, or transferred to another hospital. Some of the patients are refused parenteral medications, even when they are needed for survival.

Isolation of patients because of their HIV serostatus remains a common practice. Although the issue of an *'isolation ward for HIV patients'* is no longer a major problem, the reservation of a corner in an admission ward for *'camping these people'* is also not ideal. Patients living with HIV or AIDS are often clumped together in a corner of a ward – that is, they are ostracised when they should be given love and care.

HIV counselling and testing procedure

In many places, the word *'consent'* has different interpretations. In HIV testing, it often exists on paper only. Without adequate and appropriate counselling, there cannot be *'informed consent'*. What happens many times during the so-called counselling process is that the patients are informed about the test the healthcare worker has made up her or his mind to perform. *'Mandatory HIV testing'* remains a common human right's problem in many hospitals.

Disclosure of HIV test results and patient confidentiality and privacy

More often than not, the disclosure of HIV test results is not done with adequate and appropriate post-test counselling. This is more common with negative HIV test results, where there is no counselling on protection from future risk of HIV infection. There are many shades of breaches of patient confidentiality. The use of coded phrases or terminologies to describe HIV and AIDS, and the sharing of a patient's HIV status with non-treating staff are unhealthy practices and habits that go on unabated in the healthcare facilities.

Use of universal precautions by healthcare workers

It is common for health care workers to take inadequate precautions with the general patient population but excessive precautions with patients infected with HIV or AIDS. This *'special'* treatment usually leads to a disclosure of patient identity and HIV status.

Nigerian approaches and experiences

In Nigeria, the National Action Committee on AIDS and the Federal Ministry of Health have taken some steps to address the issues of HIV-related stigma and discrimination in healthcare settings. These include public campaign and awareness programmes; provision of free HIV testing and other ancillary investigations; free antiretroviral treatment and drugs used for opportunistic infections; and training of healthcare workers to improve case management and HIV counselling and testing practices. However, there are still gross lacunae in the overall efforts to eliminate or reduce HIV-related stigma and discrimination, and what is on ground now is very far from the minimum ideal.

HIV education and awareness campaigns

Although some progress has been made on general HIV education and awareness campaigns, not much has been achieved specifically as it relates to reduction of HIV-related stigma and discrimination. In fact, in many instances, the situation appears to be further exacerbated by some campaign programmes to respond to HIV and AIDS, which capitalise on the notion of *'social evils'* to encourage people to give up these practices. Government AIDS campaigns on *'social evils'* have achieved much in terms of raising awareness, but this achievement needs to be assessed together with the unintended perpetuation of HIV-related stigma and discrimination.

An appropriate campaign intervention should focus on fear reduction, improved awareness, and universal precautions. Healthcare workers should have access to up-to-date information on HIV and AIDS so as to keep abreast of new research and developments. But for now, in Nigeria, access to global research information is expensive and outside the reach of most healthcare workers.

Legal approach

The Constitution of the Federal Republic of Nigeria[4] guarantees the fundamental human rights of every citizen. In addition, Nigeria has ratified some international and regional human rights instruments relating to HIV and AIDS. However, there is currently no specific legislation on HIV and AIDS in place in Nigeria.

Human rights violations are widespread, ranging from common place non-consensual HIV testing to the extreme issues like the arrest and containment by quarantine of AIDS patients by the military administrator of a state, or the ruling of a High Court judge to a plaintiff who had tested HIV positive, that she not be allowed to give evidence, unless a medical expert satisfied the court that her presence would not endanger the lives of other people in the courtroom. But it is important to add that these gross human rights abuses have improved significantly in the last decade. However, there is an urgent need for government, at all levels, to formulate and implement specific policies and enact legislation that adequately address HIV and AIDS human rights related issues.[5]

Voluntary HIV counselling and testing

One major way to reduce HIV-related stigma and discrimination is, arguably, to encourage people to know their HIV serostatus, through VCT. There is no doubt about the proliferation of free voluntary counselling and testing for HIV (VCT) services in the past few years, but not without *'hiccups',* some of which are related to the *'voluntariness'* of these services, particularly within the healthcare setting. As I have discussed above, *'mandatory HIV testing'* is still rampant in many hospitals, and is part and parcel of HIV-related stigma and discrimination. It is obvious that any approach to HIV testing that tramples on an individual's basic right to personal choice and free-will would make any response to HIV-related stigma and discrimination a lost hope.

Provision of free highly active antiretroviral treatment

This is one interventional approach in HIV and AIDS control that has increased significantly the patronage of VCT services throughout the country. The National Anti-retroviral Access programme was initiated in 2001, with service delivery commencing in 25 tertiary institutions across the country by February 2002. Since then the programme has scaled up to more than 200 public and private institutions in all states in Nigeria.[6] For now, this is somewhat a success story.

The free access to antiretroviral drugs can be regarded as the most important factor that has impacted positively on HIV-related stigma and discrimination in the country in that HIV and AIDS are beginning to disappear from people's minds as a *'death sentence',* as some people living with HIV or AIDS on HAART have *'passed from death unto life'*.

Hospital policies on reduction of HIV-related stigma and discrimination

There are no effective local hospital policies seriously focussing on reducing HIV-related stigma and discrimination. But this is not to say that there are no policy statements at government level on this issue. One of the major challenges in the management of HIV and AIDS in Nigeria is the coordination of various activities, services, agencies and organisations that are involved. For instance, it has been reported that the absence of an effective practical policy on post-exposure prophylaxis (PEP) for healthcare workers in many hospitals is a major factor for HIV-related stigma and discrimination in healthcare settings. Till today, most healthcare facilities do not have PEP on a stand-by basis for their staff in case of accidental injuries or exposure.

Conclusion and recommendations

The greatest barrier to progress in the response to HIV and AIDS in our world today is stigma and discrimination. Where I practice, Nigeria, HIV-related stigma and discrimination are palpably real, and not much is being done to tackle the problem. There is the need for a comprehensive package of human rights-based solutions to this all important aspect of the AIDS epidemic.

It would be inappropriate to conclude this article without making the following general recommendations: there is a need for legislation that covers the totality of human rights abuses associated with HIV-related stigma and discrimination; people living with HIV or AIDS should be encouraged to be more open about their serostatus; there should be more constructive and positive HIV campaign policies that specifically address the issues of HIV-related stigma and discrimination; there is a need for sustained political commitment by government; and expanded collaboration with NGOs that focus on counselling and reduction of HIV-related stigma and discrimination.

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Eric Axelrod

A need for laws to be adhered to…

Law and policy reform in the SADC region

Introduction

It has been eleven years since UNAIDS first developed the *International Guidelines on HIV/AIDS and Human Rights*. The goals which the guidelines put forth were clear: to help governments' response to HIV and AIDS, whilst protecting inalienable human rights of people living with HIV or AIDS. But how have these guidelines since translated into laws and policies of countries within the SADC region? Based on the *HIV/AIDS and Human Rights in SADC* report[1], published in 2006 by the AIDS and Rights Alliance for Southern Africa (ARASA), this article will examine this question and will also ask whether or not these laws and policies, passed in various countries of the SADC region, have been effective.

When the virus was first discovered, government responses to HIV were often of a highly oppressive nature. Forced HIV testing, forced disclosure of a person's HIV status, and '*the placing of HIV-positive persons in quarantine*' were common practices. [Strode et al, 2006:7] The legal response initially concentrated on responding to the disease at the expense of human rights. But, at least in principle, that is no longer a sacrifice the SADC region is willing to make. Several international protocols have been passed over recent years, such as *The Code on HIV/AIDS & Employment* (1997) protecting workers rights, and *The Declaration of HIV/AIDS* (2003) promoting multi-sectoral cooperation in a human rights-minded fashion.[2]

On the national level, the recent ARASA report has found that human rights organisations working in the context of HIV and AIDS from 13 out of 14 SADC countries reported that their governments were politically committed to addressing HIV and AIDS[3] – indicating, at the very least, some sort of political effort in the region has been made. Aside from the Democratic Republic of Congo, a nation in the midst of a regional war since the late 1990's, every SADC country has passed laws or enacted codes of conduct according to the requirements stipulated in the *International Guidelines on HIV/AIDS and Human Rights*. At the opposite end of the legal spectrum from the DRC, Angola has passed the most specific laws protecting the human rights of people living with HIV or AIDS.

The Angolan *Law on HIV and AIDS* (2004) protects workers' rights, prohibiting mandatory HIV testing before and during employment; sets out national prevention, control and treatment plans; sets goals for HIV education and research; and protects the confidentiality of people's HIV status. [4]Unfortunately, as with many HIV-related laws and codes of conducts the impact and reach of these laws needs to be questioned. In Angola's case, for instance, although the '*HIV Law*' does protect the confidentiality of people's HIV status, the Angolan constitution does not protect citizens' right to privacy. If the privacy of the entire population is not constitutionally protected, it seems fair to ask as to how the privacy of a specific group of the population could possibly be effectively protected. It is these inconsistency between laws, between laws and practice, and between politicians' promises and actions, that have been the biggest obstacles facing the human rights-minded efforts to respond to the realities and challenges of HIV and AIDS in the SADC region.

...inconsistency...between laws and practice, and...politicians' promises...have been the biggest obstacles facing the human rights-minded efforts...

Employment laws

While only five of the SADC countries (Angola, Lesotho, Mauritius, Namibia and South Africa) have laws specifically protecting the rights of people living with HIV or AIDS in the workplace, all but one of the SADC countries (DRC) have laws in place protecting the human rights of all workers, including workers living with HIV or AIDS. Angola has the most specific of all HIV-related workers rights laws in the SADC region. *The Law on HIV and AIDS* (2004) prohibits '*unfair discrimination in the workplace*', requires employers to educate their workers on HIV and AIDS, and '*threatens*' all violations with a fine, of which 50% must be paid to the National Programme to Fight AIDS. [Strode et al, 2006:39] Although the effectiveness of Angola's Law on HIV and AIDS may be questionable, at least a '*system of punishment*' is in place to show employers that the government is '*serious*' about protecting workers rights, including the rights of workers living with HIV or AIDS.

In the case of Malawi and Botswana, there are codes of conduct suggesting that employers '*should not*' discriminate against workers, based on their actual and/or potential HIV status. Botswana's *Public Service Code of Conduct on HIV/AIDS and the Workplace* (2001) '*discourages*' pre-employment HIV testing.[5] Since '*codes of conduct*' are limited in their impact, as they lack legally enforceability, the question arises as to whether or not such codes are indeed useful. These codes are, at the least, indicating some government consciousness and commitment to the importance of protecting and promoting human rights in the context of HIV and AIDS; and if followed, can significantly improve the lives of people living with HIV or AIDS. It could also be argued that if the government does not see a potential in adequately implementing a law, then, instead of passing an '*empty law*', with no impact on people's lives, developing a '*code of conduct*' could be seen as the more adequate line of action. But, whatever the argument, in the end what is crucial is that government's inability to ensure the protection of workers' human rights needs to be changed, not accepted.

The recent ARASA report found that the number one complaint from SADC human rights organisations about their governments' efforts is that there is no commitment to adequate implementation of laws pertaining to HIV and AIDS – reiterating the sentiment that laws are only as effective, as their translation into practice.

> *...although the effectiveness of Angola's Law on HIV and AIDS may be questionable, at least a* 'system of punishment' *is in place to show employers that the government is* 'serious'*...*

In Mauritius, PILS[6] has noted that:

> *...the discrimination* [in the workplace] *is not openly on the basis of HIV status, the employer just says that they are not doing well or fires them for another reason. People also don't come forward to raise such abuses, because of stigma*'. [Strode et al, 2006:42]

This quote raises an important issue, in that even if a country does have specific legislation protecting the rights of people living with HIV or AIDS at the workplace, like South Africa and Mauritius, individuals, whose rights have been violated, must still report unfair treatment and/or dismissal in order for the law to be effective. In reality, many people would rather be quietly persecuted, than take an employer to court, and risk public ridicule for living with HIV or AIDS. But stigma is not the only barrier preventing individuals from legally challenging discrimination at the workplace. In order to have the impetus and '*know-how*' to report a human rights violation, people must be knowledgeable on how to go about making such a complaint. Thus, people must not only be aware of their rights, but also of the mechanisms of what to do if their rights have been violated. However, this seems to be a huge challenge, since many people infected with HIV are often amongst the poorest and least legally educated members of society, leading to a situation where people often lack the necessary funds or courage to pursue legal actions.

It is, hence, imperative that governments must not only pass laws, but also work towards creating a '*culture of legal accountability*', because if people do not know how to protect their rights, then laws become as futile as unenforceable '*codes of conduct*'.

Mandatory HIV testing and the military

In the ARASA report it is confirmed that in seven SADC countries, namely Lesotho, Mauritius, Namibia, South Africa, Swaziland, Tanzania and Zambia, people applying to enter the military must first take an HIV test.[7] This occurs despite the suggestion by the *International Guidelines on HIV/AIDS and Human Rights* that governments should pass legislation prohibiting mandatory HIV testing in the military.[8] In an additional three SADC countries (Botswana, DRC, Mozambique), the report could not establish whether or not there is mandatory HIV testing in the military, but none of these countries have legislation in place prohibiting mandatory HIV testing. In Mauritius, Namibia, and South Africa, while mandatory pre-employment testing for HIV is against the law, through passing of specific legislation, pre-employment testing for HIV is, however, permitted in the military.[9]

...in reality, many people would rather be quietly persecuted, than take an employer to court, and risk public ridicule...

Militaries often argue that people living with HIV or AIDS are '*not fit*' for military service, because they are not in peak physical condition, and the disease may prevent them from performing their duties. This was the case in Zambia in 2002, when the military was called before a parliamentary committee and asked why they were testing recruits, despite the fact that the Zambian law clearly prohibits mandatory HIV testing.[10] Despite orders by the committee, that the military are to stop the practice of mandatory HIV testing, NGOs report that the military still continues with this practice.

The problem with the '*poor physical health*' argument for denying a person living with HIV access to the military service is that, if it were true, then the same argument could be used for denying a person living with HIV work at any job which required physical labour. Working in a factory, for example, is often just as physically demanding, as the '*life of a soldier*'. Yet, all human rights organisations would agree that it would be a violation of fundamental human rights to deny someone work at a factory simply because of their HIV positive status.

In Namibia, the *Labour Amendment Bill* (2002) overrides legislation prohibiting pre-employment testing for HIV in the case of the military. Despite this fact, Namibian courts have found that an HIV status alone can not be used to determine whether or not someone is eligible for the military. In the case *Hiandongo Nghipohamba Nanditume v Minister of Defense*, Nanditume argued that he was barred from joining the military, because of the results of an HIV test. While the court upheld the military's right to conduct pre-employment mandatory HIV testing, the court also found that '*an HIV test on its own could not establish whether a recruit was physically fit*' [Strode et al, 2006:50]. The court decided that additional medical testing must be done to determine a recruit's eligibility, and after such testing, the court concluded that Nanditume was in fact '*physically fit*' to join the military. This case is important in that, despite upholding the right for pre-employment HIV testing in the military, it arguably sets a legal precedent for challenging discrimination against people living with HIV trying to join the military.

...in Mauritius...there are 'numerous reports of patients being refused treatment and admission at the public hospitals, because they have HIV'...

Public health laws

In every SADC country, except the DRC, '*there has been some sort of law or policy reform in regard to HIV as a human rights issue*' [Strode et al, 2006:42]. Some laws are HIV-specific, such as the *HIV and AIDS Preventative Measures Bill* (2006) from Mauritius[11], while other laws are not HIV-specific, but are broad enough to include HIV-related discrimination, such as South Africa's *Promotion of Equality and Prevention of Unfair Discrimination Act* (2000)[12]. Even though these pieces of legislation are clearly very well intended, there are reports of wide-ranging discrimination from many of the SADC countries.

> *...in South Africa it seems to have become common practice for healthcare providers to administer* ‘mandatory’ *HIV testing, before any other kind of treatment... will be provided...*

In Mauritius, as has been reported by PILS, there are ‘*numerous reports of patients being refused treatment and admission at the public hospitals, because they have HIV*’ [Strode et al, 2006:41]. Similarly, in South Africa it seems to have become common practice for healthcare providers to administer ‘*mandatory*’ HIV testing, before any other kind of treatment, such as STI treatment or antenatal care, will be provided – despite legislation prohibiting mandatory HIV testing.[13] The *Malawi Human Rights Report* (2003-2004)[14], compiled by the Malawi AIDS Network, has found that ‘*health workers around the country were demanding sexual, monetary and other favours from people living with AIDS to get proper treatment*’ [Strode et al, 2006:41], which is undoubtedly a gross human rights violation.

Seven of the SADC countries – Botswana, Madagascar, Malawi, Mauritius, Namibia, South African and Swaziland – have either a law or a policy protecting the confidentiality of people's HIV status. However, NGOs from Botswana, Mauritius, Namibia, South Africa and Swaziland have reported that healthcare workers are disclosing people's HIV status, without their consent. It is unclear whether or not these unlawful disclosures have been challenged in court, but either way it paints an ‘*ugly picture*’ for the state of confidentiality of a person's HIV status in Southern Africa.[15]

Angola has provisions in public health law stating that people living with HIV or AIDS have the legal duty to ‘*adopt habits that limit the possibility of infecting others and disclose their HIV status to sexual partners*’ [Strode et al, 2006:33]. While it is commendable that the Angolan government is showing interest in addressing HIV with public health law and not criminal law, it could be argued that such approach, even if well intended, is discriminatory as it ‘*targets*’ a specific group of the population, and legally prescribes ‘*code of conduct*’ only applicable to this specific group. Taking into account that women who disclose a positive HIV test result to their male partners are often physically abused and/or thrown out of the house, legal provisions requiring people to disclose their HIV positive status to their partners, seem to totally disregard the reality and potentially lead to more abuse and further discrimination against people on the basis of their HIV status. Notwithstanding the need for government and counsellors to promote HIV disclosure, a legal obligation to disclose one's HIV status, as introduced in Angola, arguably constitutes a violation of an individual's human rights, including the right to privacy.

...any politician seems capable of raising a voice and proclaiming 'all those who spread this disease will be punished!'...

Criminal laws

In four of the SADC countries, Lesotho, Madagascar, Swaziland, and Zimbabwe, there are specific criminal law provisions stating that it is a crime to wilfully infect someone with HIV. Also, in both Namibia and Zambia, there have been calls for such legislation to be passed.[16] Before specific legislation was passed by any of the SADC countries allowing the government to prosecute people who wilfully transmitted HIV, pre-existing common law or penal codes in each of the countries could have already been applied to such offences.

So, what then is the purpose of this new legislation? For one, it seems easier to pass criminal law, than to enact public health law. Faced with overwhelming pressure to take action addressing HIV, it could be argued that politicians would often rather pass a '*quick fix*' law (criminal), than a law, which takes much more planning and further requires the cooperation of various branches and levels of government (public health). Any politician seems capable of raising a voice and proclaiming '*all those who spread this disease will be punished!*'. It seems, however, far more difficult, even though far more effective, to create and implement a legal plan preventing '*wilful transmission of HIV*'. Thus, as argued, criminal law pertaining to HIV only attempts to treat the effect of the disease, as opposed to public health law which tends to deal more with the causes of the disease.

As of late 2006, there has not been anyone charged with wilful transmission of HIV in any of the four countries, where specific laws have been passed.[17] This is in part due to the difficulty to prove in a court of law, that someone has wilfully transmitted HIV to another, as it requires proof that an accused knew they were HIV positive at the time of sexual intercourse, and further requires proof that the '*victim*' could not have contracted the virus from anyone else. With only evidence of personal accounts, it is rather difficult to prove that a '*crime*' occurred.

The lack of litigation pertaining to these HIV-specific criminal laws is, arguably, one indication that criminal law tends to be ineffective, compared to public health law, in addressing issues of human rights and HIV.

Legal and political obstacles

There has been much legal progress in the SADC countries on the issue of HIV and human rights, but still some legal and political obstacles remain. In addition to laws permitting HIV testing upon enrolment into the military, there are still laws in some SADC countries, which are '*blatantly discriminatory*'. In Tanzania, for example, there is the *Expulsion and Exclusion of Pupils for Schools Regulation* (2002), permitting schools to deny a student's admission if the student is in '*undesirable*' physical health, clearly aimed at specifically rejecting students with HIV or AIDS, and thus, a clear human rights violation.[18]

...as of late 2006, there has not been anyone charged with wilful transmission of HIV in any of the four countries, where specific laws have been passed...

There are also legal and political obstacles hindering progress in countries like Zimbabwe, where the freedom to speak out against any government policy has regularly been met with arrests, disappearances and beatings. In February 2007, Zimbabwean President Robert Mugabe, went as far as introducing a national three months ban on protesting.[19] In a country with one of the highest HIV prevalence rates in the SADC region, how can any changes come about, if the government will not even allow peaceful protest, as such an environment also undermines any progress to be made towards protecting the rights of people living with HIV or AIDS.

> *...one of the biggest obstacles...is the lack of litigation that has been taken place ...six of the 14 SADC countries... have never had any HIV-related litigation...*

One of the steps that every SADC country, except the DRC, has taken is creating a multi-sectoral body, such as South Africa's National AIDS Council (SANAC). Unfortunately, the ARASA report concluded that the '*national AIDS councils were not found to be playing a significant role in law reform*' [Strode et al, 2006:26]. If national AIDS councils do not influence decision-making bodies on matters of HIV, then the question arises, who is? NGOs complain that it is difficult enough for people living with HIV or AIDS to influence the policy-making process, even if National AIDS Councils are effective. But when National AIDS Councils fail to play an active role in law reform, people living with HIV or AIDS seem to be effectively excluded from law reform processes.

One of the biggest obstacles facing the development of a strong legal system addressing human rights abuses in the context of HIV and AIDS is the lack of litigation that has been taken place in the SADC countries. According to the ARASA report, six of the 14 SADC countries, namely Angola, DRC, Lesotho, Madagascar, Zambia and Zimbabwe, have never had any HIV-related litigation.[20] Astonishingly, Angola, which has the most HIV-specific laws protecting the rights of people living with HIV or AIDS, is one of these six countries never to have had HIV-related litigation, while South Africa has had cases in all five areas of HIV-related litigation, namely employment cases, criminal cases/sentencing, discrimination cases, access to treatment cases, and children's rights cases.[21]

Any progress that the SADC countries have made pertaining to HIV-related litigation has to be commended, especially considering that in most of the countries these legal systems are relatively new. But unless laws are tested in a court of law, and legal precedent is set in relation to HIV and human rights, an effective foundation of legal protection will not be built for SADC citizens; and laws, although passed by parliament, will remain largely ineffective.

Conclusion

The SADC region has certainly made progress in the promotion and protection of the rights of people living HIV or AIDS, through legislation and policy reform. Thus, a legal foundation has been set on which a structure of legal protection can continue to be built. However, this structure has a long way to go before it can adequately and practically protect the rights of people living with HIV or AIDS in the region.

While the most progress has been made in the area of employment law, there seems to be a dire need for more public health law – but, more importantly there is a need for laws to be adhered to and translated into practice. It emerges that '*codes of conduct*', while providing important guidelines for how human rights should be protected, are far less effective than legislation, due to the unenforceability of these policy documents. However, even legislation can only be effective as and when people, whose rights have been violated, '*speak out*' and claim their rights.

> *...unless laws are tested in a court of law, and legal precedent is set... effective...legal protection will not be built...and laws...will remain largely ineffective...*

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